An Inclusive Design Perspective on Communication Barriers in Healthcare for Ethnic Minority Consumers

by

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ABSTRACT

This thesis contributes original knowledge through an inclusive design approach to lowering language and communication barriers in healthcare and suggests shifting the discussion from culture to context to lower intra-cultural hindrances towards learning English amongst some ethnic minorities. It offers an adaptable, scalable concept for gathering data on ethnic minorities (considering both different generations and religions) and employs a framework based analysis in design. Over the course of three studies grounded on theoretical insights from literature, primary research lead to the development and testing of innovative aids for communication, including educative and motivational elements.

This research began by seeking to understand ethnic minority consumers' (EMCs) perceptions of any barriers hindering their take-up of products or services in the UK, and their preferences. This is particularly significant as the UK's EMC population is predicted to double by 2051 and to diversify further, presenting challenges for social cohesion and planning future community goals. EMCs also represent a significant market for service and product providers. The research focussed on EMCs from the Indian Subcontinent based on religions and generations. It highlighted that first generation females lacking English and/or literacy (across religions and age groups) faced problems with services and issues around 'empowerment'. The importance of improved access to healthcare was a strong theme.

On investigating NHS staffs' perceptions, five barriers were identified (Language barriers; Low-literacy; a Lack of understanding; Attitudes, gender and health beliefs; and Information retention) and that a female subgroup was particularly affected. This study sets out staffs' perceptions of the aids currently employed and suggestions of what would help. It identified a (currently) low use of visual communication aids in adult-patient care and that pharmacist-patient communication in pharmacies was low. Ideally, staff would like patients to learn English and to use more low-cost visual communication aids. These findings lead to the development of innovative visual communication aids through inclusive and user-centred approaches and participatory design and brainstorming methods. This enabled the development of aids by considering the needs of NHS staff, EMCs lacking English and/or literacy and indigenous elderly people to promote better patient-staff communication including a take-away educational element for learning English at home.

Key words: ethnic minorities, language barriers, cultural factors, healthcare, elderly people, visual communication, inclusive design, user centred design.

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- **Acculturation** is employed as meaning the adaptation of cultural minorities to a host culture.
- **BME**: Black and Minority Ethnic is an acronym commonly employed in the UK's Public Sector to denote ethnic minority groups.
- **Culture**: is defined as the: *"Distinctive ideas, customs, social behaviour, products, or way of life of a particular society or people" (OED 2009)*
- **Context**: is defined as *"the conditions and circumstances that are relevant to an event, fact, etc."* (Collins English Dictionary 2012) or: the user, task, equipment and the physical and social environments in which a product (or service) is used (ISO9241-11 1998).
- **Current Affairs:** refers to UK government department reports, news reports, charities, summits or market reports.
- **EMCs**: Ethnic Minority Consumers is the preferred acronym used in this thesis.
- **HCI:** Human-Computer Interactions
- **ICT:** Information and Communication Technologies
- **Industry or Providers**: are used interchangeably and refer to the producers of product and services, i.e. designers, manufacturers, service providers or retailers.
- **Jouissance**: 'Joy' (French) used by the theorists Zizek and Lacan is taken to be synonymous with 'pleasure' i.e. pleasure in design (Jordan 2004).
- **NHS** National Health Service, UK
- **REC** NHS Research Ethics Committees
- **UCD**: User-centred design
- **User and Consumer** are used interchangeably.
- **USP-DI** US United States Pharmacopeia Dispensing Information

1. Introduction

This chapter introduces this thesis and research. It describes the background to the research, sets out the overall research aims, research questions and objectives, summarises the chapters and sets out the scope and limitations of the study. The terms used are clarified in the glossary above.

1.1. Background

This inclusive design research project commenced in 2009, with a focus on ethnic minorities in the UK for the reasons set out below. At this point, the global financial crisis had begun to impact on both the public and private sectors in the UK leading to cost cutting. UK businesses faced difficulties from the slow-down in consumer spending, increased competition from imports and some, also, from the growth of internet shopping with offerings from around the world. Demographic trends also indicated that the UK's ethnic minority population was rising in numbers and represented a significant market segment for UK businesses..

Ethnic minorities in the UK are accepted as being a heterogeneous group segmented by disparate cultures, religions and languages. The UK's ethnic population mix is significantly influenced by international migration and is predicted to rise to 20% by 2051 with wide implications for planning public services, social cohesion and for British culture (Rees *et al* 2011). For countries with extensive public sector services, the scale of the social issues and costs is potentially great, particularly in lean economic times.

Cultural differences are significant because different cultures influence peoples' thinking and perceptions differently and therefore their behaviour also, which can lead to difficulties when using or accessing services and products (Jylha 2007; Rau e*t al* 2008). This can be particularly true when services and products are designed or delivered by people from other cultures (Schifferstein and Hekkert eds. 2008) and differences in interpretation matter particularly where safety is involved (Crilly *et al* 2008).

Peoples' daily activities depend on interacting successfully with a range of products and services whether at work, leisure, travel, healthcare or

shopping, and the success of these interactions can influence their quality of life and wellbeing. Sophisticated technologies and processes are frequently used in the design and delivery of services and products nowadays, especially in 'developed' countries, at a pace of innovation unprecedented in history. Research has established that technological complexity challenges and marginalises users resulting in a loss of interest or under-utilisation of services and products (Clarkson 2008, adapted).

From a business perspective, EMCs represent a growing market. Their spending power was predicted to reach a substantial £300bn by 2010 (BITC 2007) when they were estimated at only 7% of the UK's population in 2007 (Laing and Kirkup 2009 citing ONS). Earning and spending capability in this market segment will rise also as a result of improved qualifications (Edinburgh University 2009) and greater numbers. Marketing experts believe that, to realise the full potential of these trends, a better understanding is required of how cultural variables like religion, generation and acculturation influenced EMC's behaviour (Burton 2002). Acculturation is broadly defined in this research as the integration of a smaller group into a larger one (Verkuyten and de Wolf 2002). These factors, in combination, suggested that researching how ethnic minority consumers (EMCs) were faring in the UK marketplace and whether they faced barriers in the take-up of products or services offered an interesting opportunity for study.

Over recent years (and in the foreseeable future) economic, social and political factors have challenged global perspectives as indicated by the communiqué for the G20 Toronto Summit Declaration (2010:p.3) which attested to the determination of economically advanced economies to halve their deficits over 3 years: the implications are far reaching. This background challenges product and service providers to find ever more efficient and effective ways of capturing a detailed understanding of their diverse consumers in order to facilitate take-up of their services or products.

1.2. Scope of this Thesis

This research project was conducted in the UK and EMCs from the Indian Subcontinent were selected as the study group, in part, from natural interest (this is the author's background) and also because her language skills (Hindi, Punjabi and Urdu) could help in interpretation and engaging with participants whilst knowledge of the culture could help to understand any problems cited. Henceforth, EMCs (Indian Subcontinent) refers to UK residents originating from Pakistan, Bangladesh, India, Sri Lanka or Nepal. (The reason for using the term 'Indian Subcontinent' will be explained in literature review 1.)

Several themes are present throughout this research. The underlying disciplines are user-centred and inclusive design approaches to better understanding EMCs' difficulties and preferences with products and services through a consideration of cultural and contextual influences. However, understanding the difficulties of both users and providers and designing inclusively required a cross-cultural, multidisciplinary view and a range of theoretical perspectives. As the research unfolded, theoretical insights were sought from literature in social sciences, design, marketing, healthcare and current affairs to lay the foundation for each study. The literature review is organised in three sections to maintain the integrity of the narrative.

There is a vast body of literature in all these topics, and this research project limited itself to the theoretical concepts that consider how some key variables, like inter-cultural dimensions and intra-cultural factors, influence peoples' thinking, perceptions and therefore their behaviours and motivation. Likewise, the topics in design and marketing are concerned with attracting and motivating consumers and creating positive user experiences to lower barriers in the take-up of services and products.

The early part of the thesis considered the theoretical perspectives of culture, how people make and use culture and its relationship with services and products. This led to a consideration of contextual factors which influence the success, or otherwise, of users' interactions with products and services (Thomas and Bevan 1995) and to not mistaken ascribe differences in users' objectives or psychological variables to culture (Rau *et al* 2008). Whilst culture has been described as a contextual factor (Thomas and Bevan 1995),

for the purposes of this research, culture and context are approached as two variables that affect all people. It considers the 'space' between these variables as a creative platform to consider the nature of difficulties and, thereby, to consider how solutions may be developed. These themes of culture and context are carried forward throughout the research in the synthesis of results to better understand the nature of difficulties. The themes of generations and religions, raised by marketing scholars (Burton 2002) in an effort to better understand EMCs' motivations, are also present throughout to better understand where problems lay.

Searches were carried out amongst design literature to identify difficulties that EMCs (Indian Subcontinent) encountered with products and services in the UK. Resources searched included CSA Illumina; *Inclusive Design: Design for the whole population* (Clarkson *et al* eds. 2003), Design and Applied Arts Index; Conference Papers Index, Business index, Mintel reports, Google Scholar, ABI, journals (*International Journal of Consumer Studies, Interactions, The Ergonomist, Ergonomics in Design*, etc.). Design literature revealed a rich body of research on ethnographic studies in 'home' countries, the cultural aspects of HCI and on design difficulties, designers, design education and the design process. However, there was little in design literature on EMCs in the UK, rather there was rich literature in other disciplines such as social sciences, marketing and medical/ healthcare research. For marketing scholars seeking to reach EMCs in the UK, the significance lay in the influence of acculturation (Burton 2002) which was not a consideration for research in home countries.

Thus, the first challenge for this design research was to narrow the research focus down to a specific service or product provider. A decision was taken to commence research with a user-centred study to investigate whether EMCs (Indian Subcontinent) felt any difficulties hindered their take-up of services or products in the UK. This was interesting in the context of internet-based product and service offerings from across the world, which over the past decade, has greatly expanded consumer choice. If EMCs cited difficulties, a specific service or product provider would be selected to further investigate the problem. This decision influenced the aims, research questions and

objectives of this research project. (Some EMCs' cited particular difficulties in using healthcare services in the first study and, as a result, the research focus narrowed upon the National Health Service, NHS.)

1.3. Research Aims

The overall aims of this research were:

1. To explore the nature of, and the individuals affected by, barriers perceived by EMCs (Indian Subcontinent) relating to their uptake of services and products in the UK, to identify a particular service or product for detailed investigation.
2. To explore the service/product providers' (staffs') perceptions of barriers and the aids used to overcome difficulties and to compare these with EMCs' perceptions.
3. To develop and test an inclusively designed aid to contribute to the lowering of a barrier and, hopefully, improving the uptake of a service/product by EMCs.

These aims were addressed by answering the following research questions through 3 user-studies.

1.4. Research Questions

Table 1.1 sets out the research questions: RQ1 addressed Aim 1, RQ2 and RQ3 addressed Aim 2 and RQ4 addressed Aim 3.

Table 1.1 The overall research questions, the 3 studies which addressed them and the study groups.

RQ1	Did EMCs (Indian Subcontinent) perceive that any barriers hindered their take-up of products or services in the UK? If present, what was the nature of the barriers and who did these affect?	**Study 1: Investigative** EMCs (Indian Subcontinent) (Chapter 4 - Aim 1)
RQ2	Having identified communication barriers in healthcare: What were healthcare staffs' perceptions of barriers and what aids were used to overcome difficulties?	**Study 2: Investigative** Service Provider NHS staff (Chapter 6 – Aim 2)
RQ3	What were the similarities or differences in views between EMCs and the NHS staff and what were the implications for inclusive design?	
RQ4	How might inclusive design contribute to lowering communication barriers for EMCs and NHS staff?	**Study 3: Generative** Inclusive, User Centred Design • EMCs lacking English and/or literacy • NHS Staff • Indigenous participants (Chapter 8 – Aim 3)

Answers to these research questions were sought through the following objectives.

1.5. Objectives

The objectives are grouped under the research questions (RQs) they addressed and the chapters in which they are set out.

Aim 1 and RQ 1 was addressed through objectives 1,2 and 4. Objective 3 informed the research approach throughout and RQ4 in particular.

Obj:1 To better understand the nature of ethnicity and cultural factors that influence individuals; how culture relates to products and services; and EMC demographic trends in the UK and the implications thereof.

Obj:2 To better understand the nature of services and products and how these are promoted to consumers; human motivation; and how the take-up of services and products is influenced by users' experiences with them.

Obj:3 To better understand how positive user experiences can be created through a consideration of human factors in design, such as user-centred design, inclusive design and the concepts of usability and context of use.

Obj:4 To commence research with an investigative study to ascertain and understand EMCs' perceptions of any barriers they experience in accessing or using services or products in the UK, and their preferences. From these results, to narrow the research focus to a particular service or product provider.

Aim 2 and RQs 2 and 3 were addressed through objectives 5, 6 and 7.

Obj:5 To review the literature as research progressed to lay the theoretical foundation for subsequent studies.

Obj:6 To undertake a 2nd investigative, formative user-study with the provider's staff to better understand their perceptions of any difficulties encountered and their needs and preferences.

Obj:7 To compare the results of studies 1 and 2 to determine whether inclusive design might play a role in lowering a barrier and accommodate the needs of both users and providers.

Aim 3 and RQ 4 were addressed through objectives 3 and 8

Obj:8 To undertake a generative study to design and develop an aid that might help to lower a selected barrier using user-centered design and inclusive design philosophy with iterative alpha-beta design testing and evaluation techniques, to benefit EMCs, providers and indigenous participants.

Figure 1.1 illustrates this research concept.

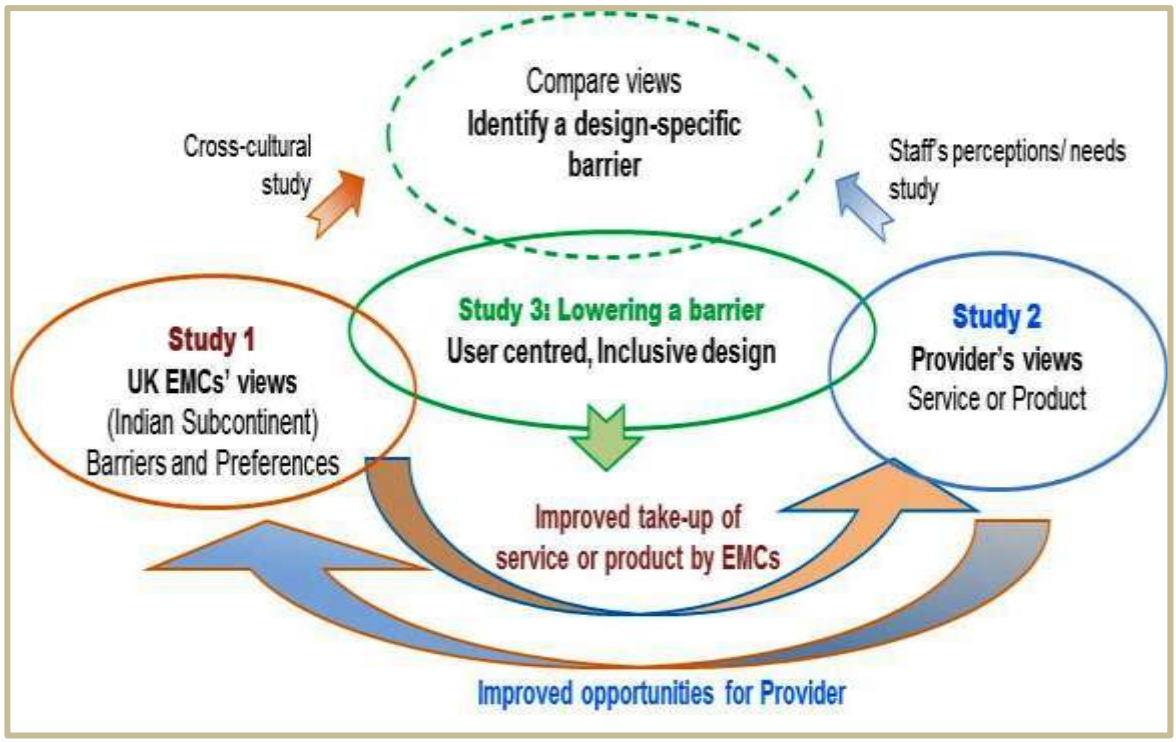

Figure 1.1 The overall research concept

1.6. Outline of Thesis

This thesis has 9 chapters which are summarised below. These include 3 user-studies and 3 literature reviews - one preceding each user-study. Each chapter summary, below, identifies the overall research questions (RQs) and the research objectives addressed in that chapter. Within each specific user-study chapter, the insights that informed the next stage of the research are set out at its end.

Creating positive user experiences through inclusive (universal) design and user-centred design formed the framework for the entire research project. These design approaches were first explored in Literature review-1 and their to context of patient experiences, in Literature review-2. How design elements in visual communication need to be manipulated to create favourable patient/ user experiences, was the focus of Literature review-3. In combination, the literature reviews and the findings from studies 1 and 2 informed the final study.

CHAPTER 2: Literature Review-1 (Objectives 1-3)

The first literature review laid the theoretical foundation that took this research forward and reviewed topics in three categories. It sought to better understand the theoretical concepts of cultural factors, inter-cultural dimensions and acculturalisation that influence EMCs' perceptions and motivations and how culture related to services and products. It considered EMC demographic trends in the UK and their implications. From a provider perspective, it sought to understand how products and services are designed and promoted to create positive user experiences to attract consumers. It considered key models used by marketeers and designers to better understand human motivation; design approaches like inclusive design and user-centred design; and human factors like usability and context of use.

CHAPTER 3: **Research Methodology**

This chapter describes the literature that informed the overall research strategy, conceptual framework, sampling and the methods used. It considers validity, reliability and reflexivity. This guidance informed the research throughout and specific details of methodology for each user-study are described in the study chapter.

CHAPTER 4: Study-1, EMCs (Indian Subcontinent)

(Research Aims1, RQ1, Objective 4)

Study-1 explored EMCs' perceptions of any barriers experienced in using or accessing products and services in the UK, and their preferences. This investigative study used purposive sampling and defined subgroups as religions and generations inspired by the

literature (Burton 2002). Open questions, probes and visual prompts were used to gather rich data from family focus groups and some semi-structured individual interviews. The findings indicated that a predominantly female subgroup lacking English and/or literacy faced particular difficulties in using and accessing healthcare services. This focussed study 2 on the National Health Service.

CHAPTER 5: Literature Review-2 (Objective 5)

Literature review 2 extended the theoretical framework of the research to lay the foundation for a study with NHS staff. It considered diversity initiatives in the NHS and the concept of positive user experiences (Literature review-1) from the perspective patient experiences. It reviewed the significance of positive patient experiences and the factors that affect it in the EMC context, such as language barriers in healthcare, interpreter and translation services, multilingual healthcare information and pictorial aids used in healthcare.

CHAPTER 6: Study-2. Front-line NHS staff

(Research Aim 2, RQ2-3, Objectives 5-7)

Study-2 investigated staffs' perceptions of barriers encountered whilst caring for EMCs lacking English and/or literacy, the impact on care, the aids employed and their suggestions of what would help to improve service delivery. Purposive sampling and semi-structured individual interviews were used to gather rich data. These findings identified a gap in adult patient care: the low use of visual communication aids in lowering language and comprehension barriers in the NHS. The views of staff and EMCs (study 1) were compared to determine similarities and differences in views. The findings focussed study 3 on developing visual communication aids to help lower communication barriers in adult patient care, EMCs in particular.

CHAPTER 7: **Literature Review 3** (Objective 5)

The final literature review expanded on the topics from literature review 2 in preparation for a generative study. It considered pictorial aids in the context of the significance of visual communication in people's everyday living. It considered guidelines on how design elements such as

images, colour-associations, typography, etc. should be used and the difficulties involved with learning pictorial languages. I explored the transliteration and phonetics, literature on cognition and learning and how the different facets of user experience can be meaningfully brought together through the concept of convergence design.

CHAPTER 8*:* Study-3 (Research Aim 4, RQ4, Objectives 3 and10)

The final, generative study focussed on visual communication in design (images, symbols, text, numbers), adding an innovative element to the communication tools. These tools aimed to facilitate more direct staff-patient communication for EMCs (Indian Subcontinent) lacking English and/or literacy and to include other patient groups following an inclusive design philosophy. This chapter describes how the literature and brainstorming informed the design rationale. It sets out how several aids were developed using use- centred design approaches with participatory techniques (Literature review-1) using convergence design and a combination of design elements (Literature review-2) to design the prototypes and develop them through alpha-beta iterative testing and evaluation. Sampling was purposive and included NHS staff, EMCs lacking English and/or literacy, adult indigenous and elderly indigenous people.

CHAPTER 9: Reflection, Conclusions, Future Research (Objective 11)

This final chapter critically reflects on the research: the three studies, the aims and objectives, appropriateness of methods, sampling, literature reviews, the applicability of research findings, scheduling and strengths and weaknesses. It sets out the conclusions, contribution to knowledge, the papers published and suggestions for future research.

A glossary of the terms used in this research is inserted before this introduction.

2. Literature Review 1

This chapter sets out the background and context of this research. It describes the literature and theoretical insights which laid the foundation for taking the research forward. Through a discussion of the concepts and themes drawn from this literature, it describes how the research was informed and inspired including the sampling strategy in study 1 with EMCs (Chapter 4). This chapter addressed the overall Objectives 1-3.

Obj:1 To better understand the nature of ethnicity and cultural factors that influence individuals; how culture relates to products and services; and EMC demographic trends in the UK and the implications thereof.

Obj:2 To better understand the nature of services and products and how these are promoted to consumers; human motivation; and how the take-up of services and products is influenced by users' experiences with them.

Obj:3 To better understand how positive user experiences can be created through a consideration of human factors in design, such as user-centred design, inclusive design and the concepts of usability and context of use.

2.1. Introduction

As discussed in chapter 1, the UK's EMC population is expanding and diversifying presenting both opportunities and challenges for service and product providers. This topic revealed a multi-faceted identity when unpacked and to design literature was added insights from social sciences, marketing and current affairs. The topics in this literature review are in three main categories followed by a discussion and conclusions.

- Culture
- Demographic trends and Implications
- Designing and Promoting Services and Products

Figure 2.1 depicts this literature review concept and the topics it explored.

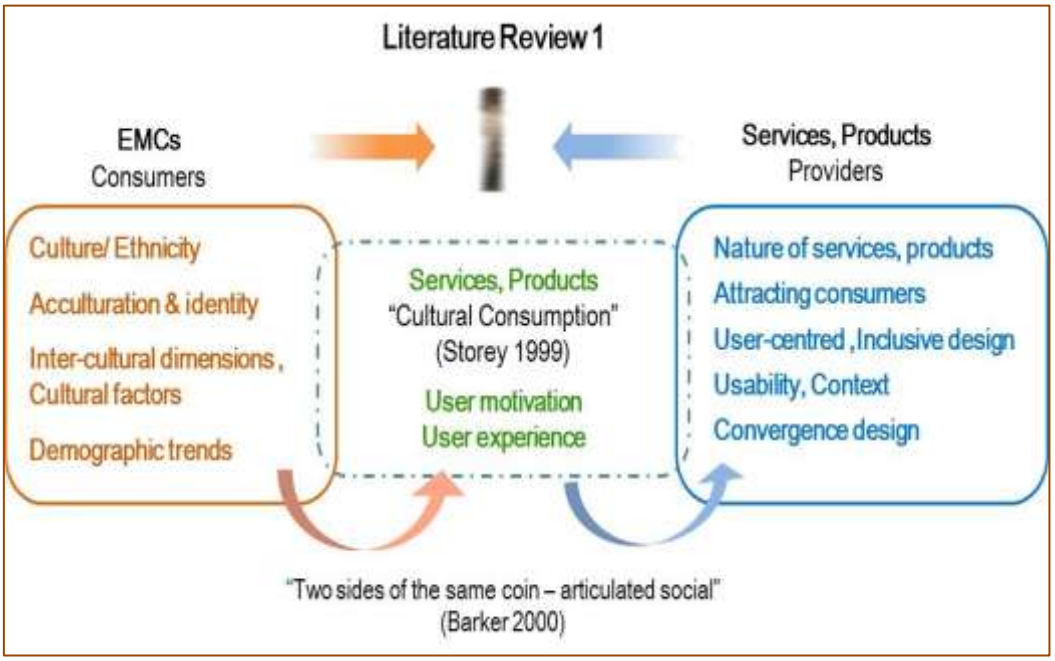

Figure 2.1 Literature review 1: topics influencing EMCs, providers and the take-up of products and services

2.2. Culture

This section explores the nature of culture and ethnicity, the relationship between culture and services and products, cultural dimensions and factors that influence people's perceptions and thinking and, thus, considers their interactions with services and products.

2.2.1. Culture and Ethnicity: Definitions

Culture is a ubiquitous word and used in many disciplines, however, in this thesis, culture pertains to ethnicity and race. Culture is defined here as the:

> *"Distinctive ideas, customs, social behaviour, products, or way of life of a particular society or people" (OED 2009)*

The cultural-context is:

> *"All aspects of life, the totality of meanings, ideas and beliefs shared by individuals within a group of people. Culture is learned, it includes language, values, norms, customs" (NAB 2000).*

For Thomas and Bevan (1995), culture is a contextual factor, that of social environment. The author accepts these definitions, however, as discussed in chapter 1, in this research culture and context are approached as two variable entities that influence users and context will be discussed further in

Although culture is often associated with countries, scholars argue culture cannot be defined by country 'rankings' (Jylha 2007; Boztepe 2007) as political boundaries alter and cultures overlap boundaries.

Ethnic pertains to the 'distinctive ways of living' of a people of common *"racial, cultural, religious or linguistic characteristics within a larger system"* (OED 1989; Princeton University 2009). Thus, culture can be considered part of the definition of ethnicity as Sekhon and Szmigin's (2005) observation suggests:

> *"As individuals or groups of individuals move from one country to another and re-settle, ethnicity is being re-created, re-defined and re-invented over time."*

For the UK's National Statistics Office, there is no clear definition of 'ethnic' rather ethnicity is a combination of categories including skin colour (NSO 2003). Williams and Johnson (2010:pp.1-9) agree that there is no simple, single or enduring way of using language to describe groups and no consensus on the use of words like *culture*, *race* and *ethnicity* as language, like 'culture', is constantly changing. *Culture* can be infinitely variable: the word denotes shared meanings: a peoples' ideals, values, patterns of behaviour and ways of living and (citing anthropologist Edward Burnett Taylor 1871), this 'complex whole' includes their knowledge, belief, art, morals, laws, customs, habits and capabilities. These attributes can be adopted through choice; people can be/choose to be members of several cultures and, (citing Hofstede 2001), these variables affect how people and groups respond, behave and how they are organised.

Citing scientists at the UN Experts Committee on Race and Race Prejudice (1967), they point out that *race* had no scientific justification, although the term was used to make explicit, to codify assumptions or to classify people based on a visual (phenotypical) description and, (citing Rex 1969) such differences were used as explanations to justify discrimination or conflict.

Agreeing with Sekhon and Szmigin (2005), William and Johnson (2010) state that *ethnicity* refers directly to people's identity, that people can have multiple identities and some adopted 'ethnic group' labels to make a political statement or to campaign. They set out the roots of these terms as follows:

	Primary characteristics	Origin	Associated perceptions
Race	Inherent, physical, nature/natural	Genetic - descent	Permanent, with sequelae (i.e. causative)
Culture	Behavioural expression of preferred lifestyle	Upbringing - learned	Capable of being changed
Ethnicity/Ethnic group	Indentity, multi-facted. 'political'	Socially constructed – internale or external – or legal	Situational, negotiated

For Johnson, ethnicity or identity is situational, hierarchical and nested and the identity alters depending on location; e.g. the region a person hails from in their home country, the particular group in that region, or when abroad, or indeed, if 'travelling in space' (homo sapien). Admittedly, these are complex discussions and the use of these terms will be further scrutinised by scholars as language alters.

In this thesis, the term *race* is not employed, and *ethnic* is taken to mean the racial origins of individuals: an unalterable genetic fact regardless of the geographic location of one's birth. *Ethnicity* remains the same whilst all the other characteristics such as languages, customs, identity, socially constructed behaviour, products, services, etc. (all of which can alter) are taken to form a part of *culture* and that people can choose to adopt norms of more than one culture. Storey (1999) offers interesting insights into the nature of culture, its relationship to services and products and cultural theories.

2.2.2. Making and Using Culture

In his book 'Cultural Consumption as Communication', Storey (1999:pp.xi-xii,75) explains culture as a two-way, dynamic every-day practice: an active combination of the produce of industry and consuming products or services. 'Cultural consumption' produces culture and can serve to say who we are or would like to be. Through cultural consumption we articulate our freedom to make culture and fulfil a range of social activities and personal purposes. We produce particular lifestyles, provide symbolic means to celebrate success or mark our achievements and to mark or maintain differences. Storey

highlights Marx's observation, that culture is real people engaging in everyday life through using services and commodities: culture does nothing, it is a social activity of making and becoming affected by context, not a series of objects. Jylha (2007) citing Hall, states that culture influences the thoughts and behaviours of people, which leads to continuous modification and reconstruction of groups. Thus, different cultures influence people differently and cultural theorists differ on how people use culture for their purposes.

Culturally-orientated products can be used to demarcate groups (Featherstone 1995). In Storey's (1999:pp.37-44) "critical assessment of a range of theoretical approaches to the study of cultural consumption", he notes Bourdieu (like Featherstone) states that cultural consumption can be used to mark and maintain social distinction: it is a heated debate between people. Simmel proposes it is one of differentiation, expressing individuality, a trickle down influence in society whereas, for McCracken, the dynamic is upwards (i.e. status/social mobility). Veblen's cultural model is that of social emulation whereas, for Douglas and Isherwood, services and products are a symbolic means of communication with fellow consumers, a 'live information system', a 'neutral language' (Storey 1999:pp.37-44).

Echoing Storey, Barker (2000:pp.82-83), citing Laclau and Mouffe (1987), observed that different groups in society become a unity under certain conditions. They are connected through breakable linkages in a temporary stabilisation of meaning (*articulated social)*. In this sense, consumers and producers may be considered to be the two sides of the same coin, two groups who come together in common purpose through mutual need.

In a study with Pakeha (white, Europeans) in New Zealand, Potter and Wetherell (1995:pp.89-90) noted that people have two, broadly different, ways of constructing culture. *Culture-as-Heritage* includes a set of traditions, rituals and values passed down the generations and a heritage to be preserved, treasured and protected from modernity. *Culture-as-Therapy* is a desire to rediscover cultural roots and is constructed as a psychological need, when and if people become estranged.

These discussions offer interesting insights that link culture, products and

services and social integration. We may conclude that culture:

- cannot be defined by national boundaries;
- is a dynamic social activity constantly modified by context and is also referred to as the cultural-context;
- is inextricably linked to using and producing services and products;
- and through culture and cultural consumption, people choose to emulate, demarcate or differentiate themselves in society.

2.2.3. Culture: Significance, Influencing Factors

2.2.3.1. Culture: Significance and Cultural Dimensions

In *Designing the customer experience*, Carroll (2009) states that cultural differences matter significantly in user experiences: what matters to one culture may not to another. Different cultures influence people's thinking and perceptions differently which, in turn, influences their behaviour: problems can arise whilst using or accessing services and products (Jylha 2007; Rau e*t al* 2008) particularly when these are designed and delivered by people from other cultures (Schifferstein and Hekkert eds. 2008). Whilst differences may be celebrated Krippendorff cautions that differences in interpretation matter where safety is involved (Crilly *et al* 2008).

People's daily activities from work to leisure, travel, healthcare to shopping depend on interacting successfully with a range of products and services. Cultural variables like perceptions, uncertainty/ anxiety avoidance (Hofstede and McCrae 2004, Rau *et al* 2008), cognitive ability (comprehension) or low literacy (Ngoh 2009) can all affect the success of these interactions which, in turn, influences their quality of life and wellbeing.

Hofstede identified four cultural dimensions that influence society (Hofstede and McCrae 2004) and affect people's behaviours.

- **Power distance** is the acceptance of an unequal distribution of power within families, between groups or organisations. Power distance in a society is represented through socialising children towards obedience or initiative and levels of inequality are endorsed by the followers and by the leaders.
- **Uncertainty avoidance** vs. **acceptance** is the level of tolerance

(comfort or discomfort) for unstructured situations, i.e. novel, unknown, surprising or unusual. Uncertainty-avoiding cultures try to minimise such possibilities by strict laws, rules, and safety and security measures. People are more emotional and motivated by inner nervous energy. Uncertainty avoidance is also related to anxiety. Uncertainty-accepting cultures are more tolerant of different opinions, try to have as few rules as possible, allow more philosophical and religious norms to co-exist, are more contemplative and are not expected by their environment to express emotions.

- **Individualism** vs. **collectivism.** Ties between individuals are loose in individualist societies and individuals are expected to look after themselves and their immediate family. In collectivist societies people are integrated from birth onward into strong, cohesive groups often in extended families whom they protect in exchange for unquestioning loyalty.
- **Masculinity** vs. **femininity**. Women's emotional values (modest/ caring) differed less between societies than men's. In 'feminine' countries, women and men have similar modest, caring emotional values, whereas, in 'masculine' countries men are more/ very assertive, whilst women may be assertive (Hofstede and McCrae 2004).

Another interesting inter-cultural factor is that information and knowledge are communicated differently in different cultures. Hall and Hall (1976) describe societies as: low-context and high-context. In *low-context* cultures (Northern Europe), information is problem-oriented, explicit, direct, analytical, abstract and functional, whereas in *high-context* cultures (like China) information is more implicit and experience-based (Hall and Hall 1976) as also the Indian Subcontinent where people prefer thematic arrangements (Rau *et al* 2008).

We may extrapolate that these dimensions potentially can influence how services and products might be obtained and used. Also, that consideration is required of the differences in how people communicate or absorb knowledge and information.

Peoples' behaviours and motivations are also influenced by variables like degree of acculturation and inter-cultural factors (in the EMC context), in expressing individual identity and choice, and through ICT.

2.2.3.2. Acculturation and Influencing Factors

The significance of acculturation lies in whether EMCs should be (or wish to be) approached differently to the indigenous population during marketing (Burton 2002). These comments apply equally to public-sector services and businesses as, for both, the challenge is to better understand and positively engage with disparate user groups.

Ngo (2008) citing Zane and Mak (2005), observed that theorists use socio-psychological factors to measure acculturation: language use and preference, social affiliation, daily living habits, cultural traditions, communication styles, identity and pride, perceived prejudice and discrimination, generational status, family socialisation and cultural values. When counseling multi-cultural clients in the US, Erwin *et al* (2006) assessed acculturation by asking the language they spoke, place of birth, where they were raised, food preferences, etc.

Research on acculturation suggests some EMC groups are adapting well and individuals are expressing their identity through personal choice. 'Visible minorities' (in Canada) are choosing whether or not to live in ethnically homogenous neighbourhoods based on personal preference (Balakrishan *et al* 2005). In the UK, 2nd generation cosmopolitan Punjabis, keen to integrate, were choosing elements from different cultures, although inter-cultural differences influenced consumption, family honour influenced decision-making and inter-cultural variables created family tensions (Sekhon and Szmigin 2005, 2011).

Verkuyten and de Wolf (2002) identified that people acculturate in four ways: assimilation/ one-sided adaptation (without preserving one's heritage); separation (focus only on their own culture); integration (favour own cultural maintenance and inter-cultural contacts); or marginalisation (the rejection of both cultures).

Integration appears to describe societal attitudes in the UK, i.e. uncertainty

acceptance (Hofstede and McCrae 2004) and public sector initiatives to include marginalised groups. However, there are also concerns over multiculturalism leading to fragmentation rather than integration (Castells 2000).

Peoples' acculturation attitudes are also influenced by intergroup and intragroup contexts (Verkuyten and de Wolf 2002). For Berry (1991, 1997) attitudes are influenced by two factors: the extent to which EMCs value and desire to maintain their heritage and the extent to which contacts and relationships with the majority group are considered important. Integration can only be freely chosen and successfully pursued by minority groups when the dominant society is open and inclusive in its orientation towards cultural diversity. Integration requires *mutual accommodation* and acceptance by both groups. These influences also raise a consideration of motivational factors (see 2.3.3) which suggests that people's attitudes and motivations can be influenced provided they perceive that they will benefit.

Berry (1997) discusses several influencing factors from literature that impact on acculturation (e.g. for 1st generation EMCs in particular).

- **Gender attitudes.** Depending on the relative status and treatment of females in the two cultures, females may be more at risk from censorship than males. Conflict with their heritage culture places them at risk.
- **Education** is consistently associated with positive adaptations: higher education results in lower stress.
- **Loss of economic status** and low mobility (i.e. people remain in ethnic minority neighbourhoods).
- **Cultural distance.** For some groups, the greater the cultural differences (language, religion) with the society in which they live, the less positive the integration.
- **Personal factors.** An individual's personality, including control and introversion/extraversion.

We may therefore consider from the above that low-literacy results in higher stress, language barriers create cultural distance, poor economic status and low mobility reduces choice and results in cultural clusters which, in turn,

emphasise language barriers leading to poor acculturation.

Acculturation is also affected by individual identities which affect people's choices, preferences, sense of belonging or alienation, sense of status and relationship to society (NAB 2000).

2.2.3.3. Individual Identity and the impact of ICT

In our pluralistic, interconnected world, one individual may reflect complex diverse cultural influences and have multiple identities which are sometimes contradictory, dynamic, constantly shifting and in process (Barker 2000:pp.135; NAB 2000). Culture is inseparable from an individual's identity, because identities are social constructions which exist within cultural representations of social practices, popular culture, language and power which pervade social relationship or order (Barker 2000:pp.10-12,165). Sekhon and Szmigin (2011) agree, balancing inter-cultural differences with the importance of family honour affects choices, creating familial tensions.

Cultural identities are influenced by majority culture, sub-cultures and counter-cultures: by main values, beliefs and customs of culture that can be enhanced and transmitted, or dominated by one or a combination of cultures or subcultures (NAB 2000). The site of power lies in people's minds, in the cultural codes of information and images around which they build their lives and decide behaviour but this can be diffused, difficult to seize and in a constant swirl (Castells 2000:p.359).

In *The Network Society* Castells (2000:pp.1-2,27) observed that cultures are mediated and enacted through communication and our multi-cultural, inter-dependent world can be understood only from the plural perspective of cultural-identity and global networking.

Patmore and Mahoney (2003) noted that Haase of MIT Media celebrated this as a unique moment in human history because global, pervasive and intimate technologies were extending individuals and communities. Castells (2000:pp.1-2, 27, 354-358,368) agrees, these new forms and channels of communication are shaping life, impacting on individuals and society. However, he adds, they are also creating social segmentation and fragmentation by challenging patriarchalism and disturbing the sequence of

transmitting cultural codes down the generations. Castells predicts our cultures will change forever as our codes will become fundamentally transformed as technological systems develop.

We may conclude that peoples' choices are influenced by cultural factors, inter-cultural variables and their pace of the acculturation is influenced by individual identity and ICT. Identities and culture are dynamic, thus, acculturation may be occurring more rapidly than evident in some groups through choice. The dynamic nature of culture also offers pathways for motivating people if they can perceive the benefits. This is particularly important in the context of the UK's EMC population which is growing and becoming more diverse.

2.3. Demographic Trends and Implications

Recent news reports (Daily Mail 2011:p.1,7; Gavaghan 2012) cite research indicating that Labour's immigration policies changed the face of Britain faster than any major country except Italy. Whether or not one agrees, there is little doubt that EMC numbers in the UK have risen and will continue rising bringing both challenges and opportunities.

2.3.1. Demographic Trends

In the UK, people are classified by 16 ethnic groups and asked to indicate to which they feel they belong (POST 2007). The decennial census (every 10 years) conducted on 27 March 2011 in England and Wales revealed the population was 62.6m, a rise of 7.1% (3.7m) from 52.4m in 2001, the largest rise in 10 years since 1801. The UK's population is projected to reach 72m in 2032 and 81m by 2060 (ONS 2012:pp.1-2). Data detailing ethnic groups, religions, health and families, identity, etc. will be released over the next 18 months (ONS 2012:p.34). In the period between censuses, the population is estimated (Appendix-A1).

By 2007, EMCs were estimated to account for 73% of the growth in population due to higher fertility rates and some inward migration and EMCs were concentrated in urban, particularly deprived, areas where they made up a much bigger share of the population (POST 2007). However, that distribution was changing and EMCs were becoming less geographically

segregated (POST 2007). The ONS predicted that two-thirds of the growth of the UK's population (70m by 2029) would be accounted for by immigrants or babies born to them (Laing and Kirkup 2009). In 2009, almost 25% of babies were born to foreign-born mothers (Hickley 2009).

Population experts Rees *et al* (2011:pp.9,150) predict the UK's EMC population will become ever more diverse, will rise to 20% by 2051 and is significantly affected by international migration. This will have wide implications for planning future goals: social, community (services, goods, schools) and economic and for social cohesion and the nature of British culture. The estimated annual population growth between 2001-2009 was highest from China, the African Commonwealth (Zimbabwe, Somalia, Eritrea, Republic of Congo), A8 Countries (Czech Republic, Latvia, Estonia, Hungary, Lithuania, Poland, Slovakia, Slovenia) and the Indian Subcontinent (Rees *et al* 2011:p.2). This includes many countries within and outside the EU, where English is not the first language and some in which education is not free nor mandatory.

Decisions of other EU governments also affect the UK as, once admitted, people are free to travel across national boundaries. For instance, successive Italian governments legalised more than 200,000 illegal workers during 1990-1998 and a fresh offer in 2002 generated almost 700,000 applications (Anonymous 2003:p.25, The Economist). Spencer (2003) noted that the large movements of people of different cultures across the EU is challenging social cohesion.

The BBC reported that EMC pupils had increased by 57% in a decade and in some areas EMCs were the new majority (Anonymous 2011). Schools were criticised as being 'too crude for super-diverse UK' and some EMC groups struggled in education and 'lagged behind' resulting in economic disadvantage (Burns 2012). However, extra English language help for minority pupils could face time limit of 3-5 years (Aujla 2011) whilst free language classes for immigrants was curtailed (Morrison 2011:p.30).

The scale of social issues and costs are potentially great for public-sector services facing lean economic times. Diversity initiatives testify to efforts to

understand and address the needs of EMCs, such as equality and diversity managers and training in healthcare and universities; a handbook on cultural differences for (Cleveland) police to understand communities (BBC *Home*, 2004); improvements in healthcare (Lakhani 2008); an EMC community awareness campaign by emergency services in 2004; interpreters and translated materials; pooling legal expertise and citizens advice (Scottish CAB Service 2006 and EMC Law Centre); etc.

EMCs are also of interest to marketing scholars keen to understand and to realise the potential of this significant market segment.

2.3.2. The 'Business' Case

EMCs represent an attractive market for businesses and it is extremely important that companies understand the market, the potential barriers and the strategies by which those barriers might be overcome (Considine 2003). When estimated at only 7% of the population in 2007 (Laing and Kirkup 2009, citing ONS), EMC's spending power in the UK was predicted to reach a substantial £300bn by 2010 (BITC 2007). This spending capability will expand with rising numbers and from improved earning potential. For example, EMCs are predicted to comprise 50% of the graduates in the working-age population by 2020 (University of Edinburgh 2009).

However, different cultures produce different motivations and consumption (Kinra 1983) and industry questioned whether it was missing opportunities (Emslie *et al* 2007) because not enough was understood about how EMC consumer behaviour was influenced by variations like religion, inter-generational effects and the acculturation of younger generations (Burton 2002). Anderson points out that the internet has the capability to successfully accommodate diverse consumer needs.

Anderson (2004) coined the term 'the Long Tail*'* (the customer demographic who purchase hard-to-find, non-hit items) and pointed out that even low-demand and low-sales products of hard-to-find items sold to many customers collectively comprised a market-share rivalling or exceeding the few bestsellers. Citing the business strategy of companies like Amazon and Nettfix, Brynjolfsson *et al* (2006, adapted) add that, where the long tail

worked, the preferences of the minority became available, individuals had wider choice, opportunities for diversification were presented and products and services in niche categories could be introduced to satisfy a wider variety of customer demands.

Over the last decade, consumer choice in the UK market has expanded and diversified extensively with the advent of internet shopping and offerings from all over the world, presenting challenges for competing UK businesses.

2.4. Designing and Promoting Services and Products

This section explores the nature of products and services, how designers and marketeers seek to attract consumers and to understand consumer motivation. It reviews human factors in design like user-centred design, inclusive/ universal design, usability, context and user-experience.

2.4.1. Definitions: Design, Products and Services

There are many definitions of design but all agree that design is a creative process and results in putting ideas into forms that consumers may use.

> *"Design is the purposive application of creativity to all the activities necessary to bring ideas into use either as product (service) or process innovations" (Besant et al 2005)*
>
> *"Design is... to form or conceive in the mind, invent ..." (OED 2005)*
>
> *"Design is a structured creative process ... All products and services are, in effect, 'designed', even if not by a professional designer." (Department of Trade and Industry 2005)*
>
> *"Design is the process of converting an idea or market need into the detailed information from which a product or system can be made" (Royal Academy of Engineering 2005)*

For marketing experts Masterson and Pickton (2004:p.202), services and products are a 'bundle of attributes' which lie at the heart of organisations and a means by which people satisfy their needs. The principle is that a need satisfied by someone else deserves to have a value and the only real debate is how consumers value that transaction (echoing Barker's observations of the 'articulated social', see 2.2.2). They suggest that products and services

should be treated similarly because services are also products that need pricing and promoting and that there are no service industries only industries whose service components are greater or less than others. However, promoting services presents challenges because services are intangible at their core and service providers are a part of the service.

The Marketing Association of Australia and New Zealand (MAANZ 2005) agree, adding, services are a package or "bundle of different services, tangibles and intangibles" comprised of two main categories: the core/substantive service and peripheral services.

2.4.2. The nature of Design

For Krippendorff (2010), design is an inherent social activity affecting others' lives. Designers are innovators in the domain of (material) culture who intervene in on-going social practices by encouraging novel interfaces with technology and, by this definition, undo what is predictable. Design is inherently innovative because it concerns itself with changing something that would not come about naturally and which cannot be predicted from past observations, i.e. it brings forth something that cannot be predicted without reference to the human actions that realise it.

For Mat Hunter (2010), Chief Design Officer (UK Design Council) the purpose of design is to tackle some of the big issues in the world: security, health, the environment, etc. and he concedes this includes cultural aspects.

Krippendorff (2010) highlights that designers have to compellingly justify a design proposal or suggestion to stakeholders and are interested in information that understands the stakeholders of a design and whether they are willing to commit themselves to realise a design or to use it in the process of affecting others. To do so they need to independently examine past successes and failures to draw lessons, although these may be debatable. Boztepe (2007) concurs but also highlights the conflict between data available from research and design process and Mitchell's *Applicability Gap,* that research data are not used by designers and the challenge is to translate rich data into actionable form for designers.

*S*trickfaden *et al* (2006) add that although designers' own sociocultural

capital is at their disposal without research, sociocultural insights inspire design aids communication, understanding and meaningful experiences by enhancing a sense of culture and creativity.

2.4.3. Promoting Services and Products, Human Motivation

There is close relationship between design and marketing because both aim to attract consumers. Storey (1999:p.75) noted that products become real products only by being consumed. The greater the consumer interest and consumption, the greater the production and success of an organisation. Thus, consumer perceptions are integral to an organisation's success.

Developing attributes to be attractive and valued by consumers plus the marketing elements is generally termed '*The Total Product* concept' (Appendix-A2) which is used to map 'everything consumers receive'. *Core benefit* is the essential need; *basic* is the form/packaging or service environment; *augmented* provides additional benefits; and *perceived* are the intangible associations like brand (Masterson and Pickton 2004:pp.192-5). Finally, there is *potential product* or service (Waterhouse 2008); what it could be.

Figure 2.2 illustrates the 'total product concept' adapted with attributes for services and products, and what it (the service/product) could be.

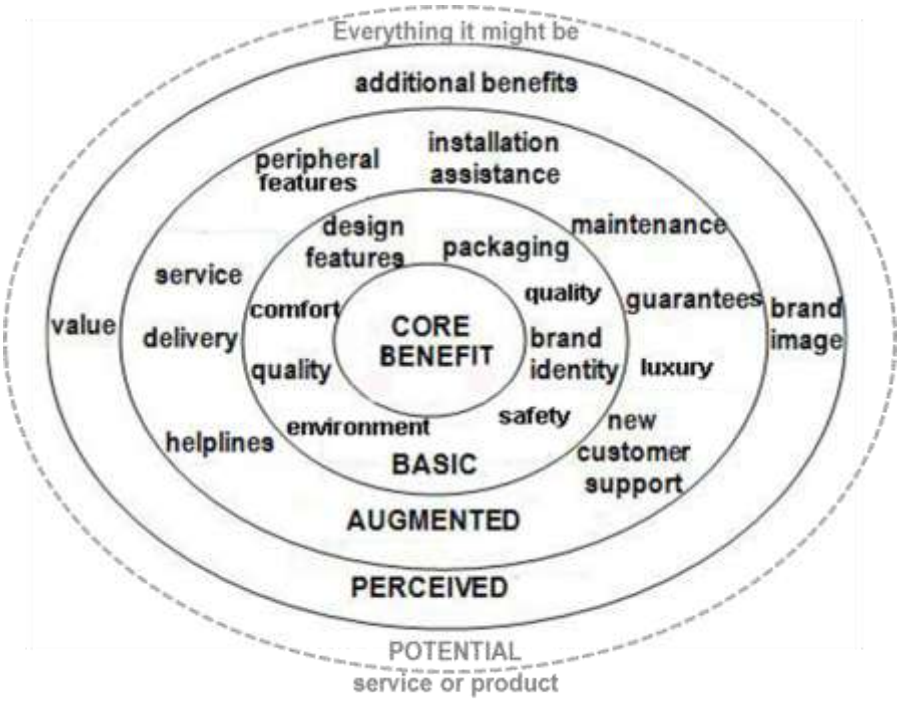

Figure 2.2 'The total product' concept' (Masterson and Pickton 2004, adapted)

MAANZ (2005) propose a similar conceptual model called 'Augmented Service Offering' (Figure 2.3), for describing the elements and intangible characteristics of services and Perceived Quality. It considers:

> *"How customers perceive the process itself (the functional quality) as well as the additional effects on perceived quality of the corporate and local image of the organisation."*

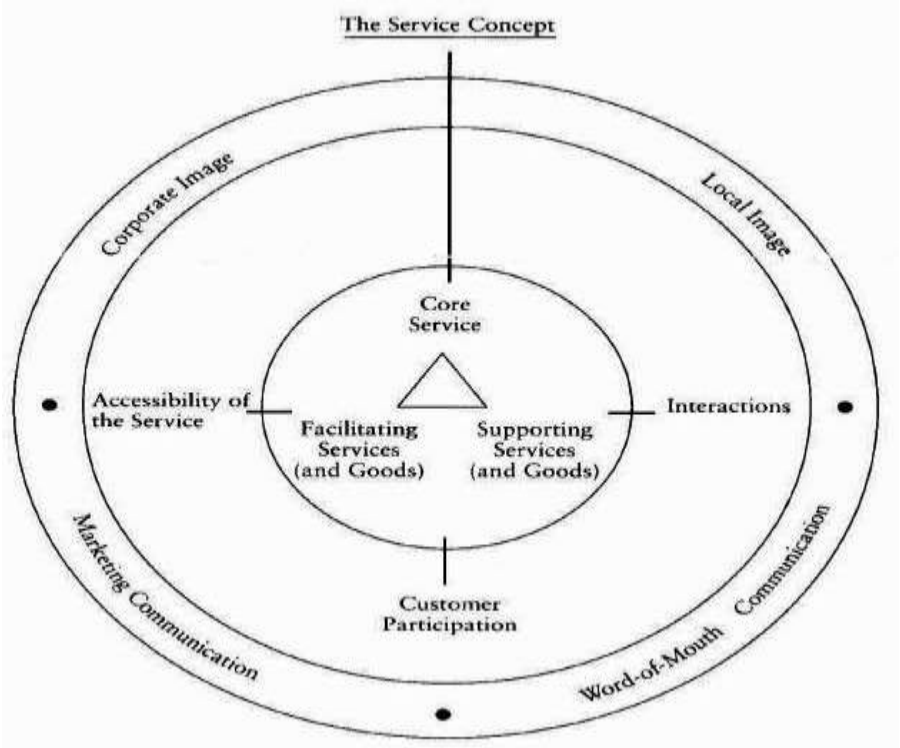

Figure 2.3 'Augmented service offering' (MAANZ 2005)

Burton (2002) lamented the paucity and fragmentation of information on the EMC market segment for preparing effective marketing strategies and pointed out the significant spending power of this market and its value to businesses. She predicted the lack of data would significantly affect businesses for many years to come as there was insufficient previous data against which existing, and future, consumer behaviour and marketing strategies could be compared and measured. Dusenberry (2006) of BBDO the worldwide advertising agency network, highlighted the importance of insights: in a business world bedevilled with the problems of differentiating oneself, insights (of user's motivations) are essential because one insight can fuel a thousand ideas.

Motivation is a complex relationship between needs, drives and goals: a motive is a need sufficiently important to seek satisfaction (Masterson and Pickton 2004). For Ryan and Deci (2000), 'motivate' means to be moved to do something and motivations differ based on different reasons or goals that give rise to an action. Motivation can be described in two basic ways: *intrinsic motivation* refers to doing something because it is inherently interesting or enjoyable and *extrinsic motivation* refers to doing something because it leads to a separable outcome. The quality of user-experience can vary considerably between behaviours arising from these motivations. Extrinsic motivation can lead to resentment and disinterest (feeling externally propelled into action) or to accepting the value or utility of a task (the goal is self-endorsed and adopted with a sense of volition) (Ryan and Deci 2000).

In his paper *A Theory of Human Motivation,* Maslow (1943) famously proposed the *Hierarchy of Needs* model (Figure.2.4) depicting human needs in a 5-level pyramid. The most critical levels form the base (*Physiological* survival and *Safety)* and *self-actualisation* its peak, with each level between becoming less critical: the higher the level, the greater a person's satisfaction. Three levels have since been added: *transcendence*, helping others self-actualise; *aesthetic,* beauty, balance, form; and c*ognitive*, knowledge, meaning and self-awareness (Thorson 2004).

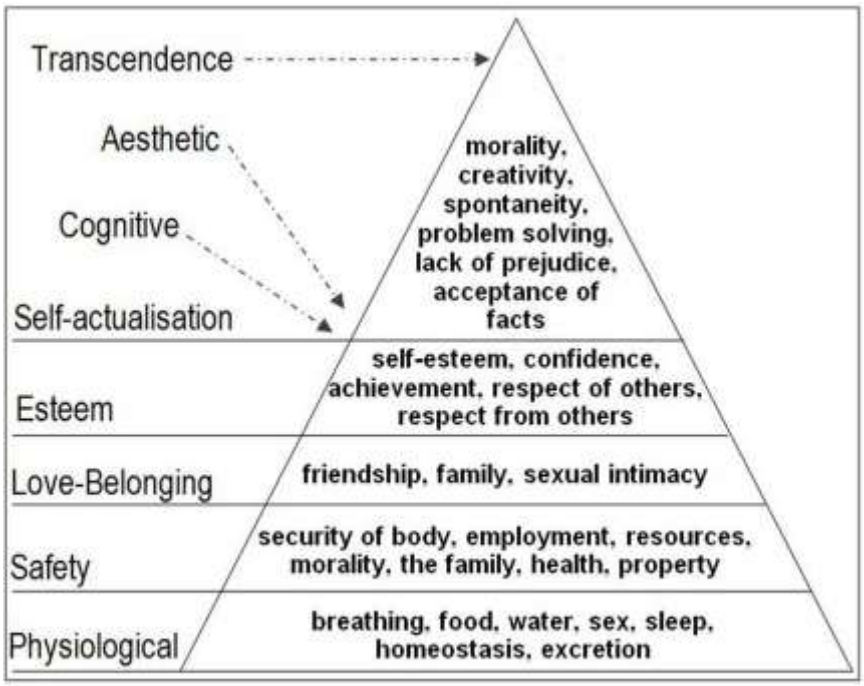

Figure 2.4 Maslow's Hierarchy of Needs model (Thorson 2006) with new layers

For Thorson (2006), the highly regarded marketing professional, success lies in mapping services and products to Maslow's hierarchy and powerful brands usually related to the pyramid somehow. It was often about image, reproduction or belonging (levels 3-4) and the more services or products resonated with Maslow's pyramid, the stronger was their brand potential and more users they attracted. He suggests this 'brand assessment tool' worked when one considered that *YouTube* supported all the top five levels from friendship to creativity.

Importantly, Maslow's insights are applicable across cultures and the simple depiction makes it popular with designers and marketeers across a myriad industries and disciplines. e.g. Haque (2009) discussing customer services (Figure 2.5).

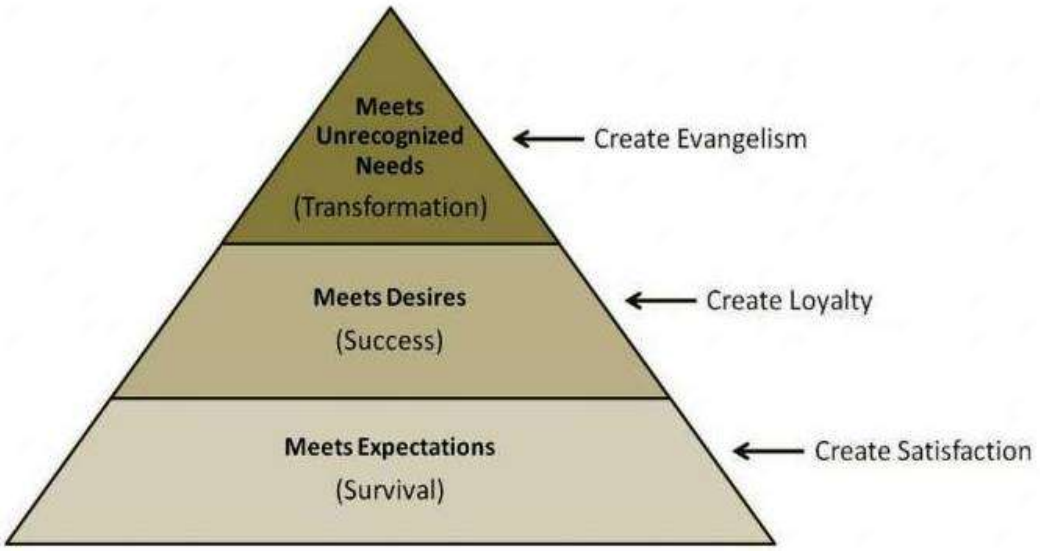

Figure 2.5 Maslow's pyramid in customer services strategy (Haque 2009)

Rait's (2008) depiction in product design and how Maslow's model is used to search for answers to consumers' needs, who will buy/ use, why, is the risk acceptable (Figure.2.6) and in the *Total Product Concept* (Figure 2.7).

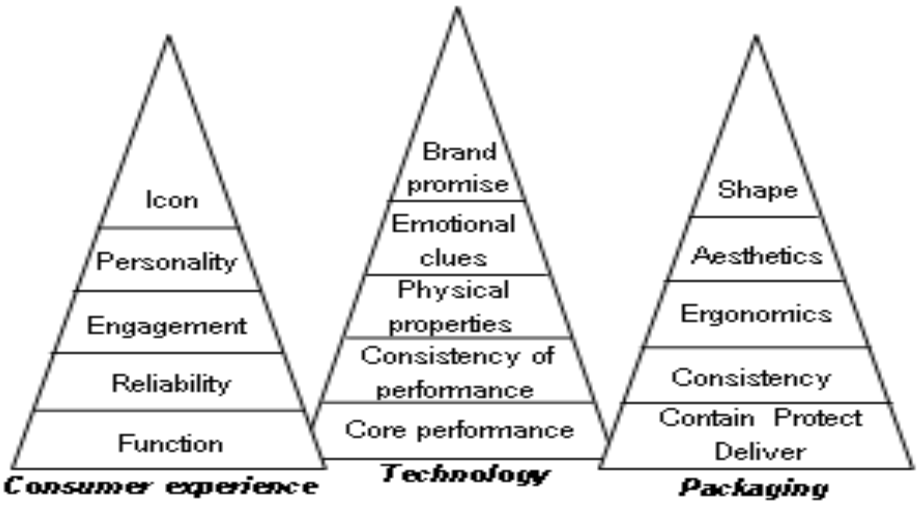

Figure 2.6 Maslow's *Hierarchy of Needs model* in product strategy (Rait 2008)

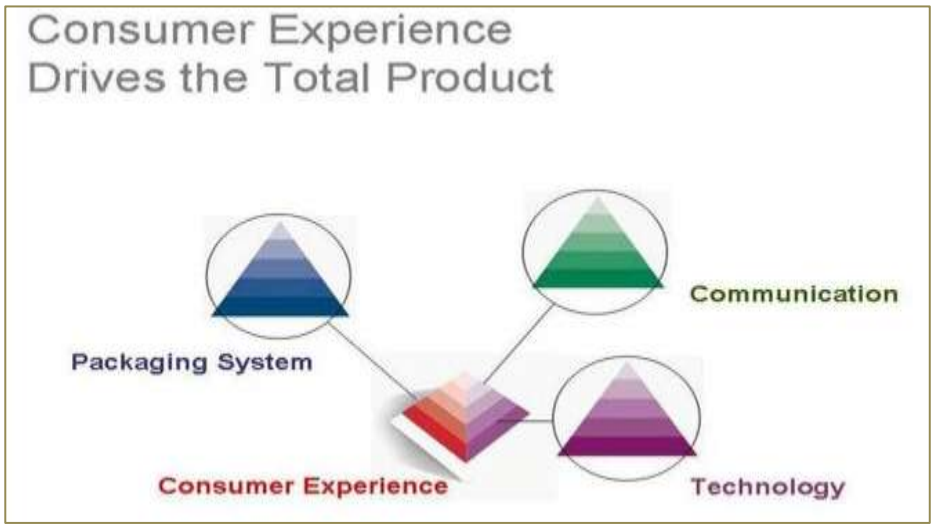

Figure 2.7 Maslow's model used in 'the total product concept' (Rait 2008)

In *Beyond Maslow's Hierarchy of Needs: What do people strive for?* Rouse (2004) discusses alternative models and questions Maslow's process and applicability.

For instance, Ford proposed 24 non-hierarchical human goals in 6 categories divided in two groups (Appendix-A3):

Desired Within-Person Consequences:

- *Affective* (happiness, tranquillity, joy/satisfaction, physical wellbeing)
- *Cognitive* (exploration, understanding)
- *Subjective* (spirituality, transcendence)

Desired Person-Environment Consequences:

- *Self-assertive relationship* goals (individuality, self-determination)
- *Integrative relationship* (belongingness, social responsibility)
- *Task* goals (mastery, management, material gain, safety) (Rouse 2004 citing Ford 1992)

Other scholars agree that affective attributes engage and motivate people: Jordan (2004) emphasises the importance of joy and pleasure in design; for Zizek and Lacan joy holds communities together (Dean 2002) and Evans *et al* (2002) propose the 'delighter attribute', i.e. offering users a significantly better understanding of their needs.

As noted, the simplicity of Maslow's depiction makes it popular in considering how positive user experiences may be designed to attract consumers and in

incorporating human factors research in design, which are explored next.

2.4.4. User Experience

Design has recently attempted to embrace 'designing the user experience' and to demystify how one may do so and how the services or products achieve specific user experience goals (Forlizzi and Ford 2000).

User Experience (UX) covers all the aspects of how people use a product or service: the way it feels, how well they understand how it works, how they feel about it while they are using it, how well it serves their purposes, how well it fits into the context in which they are using it and how well it contributes to the quality of their lives (User Intelligence 2011).

In *New Methods for Designing User Experiences,* Shedroff (2004) highlights the complexities of user experience (Figure 2.8) in the variety of perspectives involved and concludes: *"Experience Design, then, is an approach that integrates all of this."*

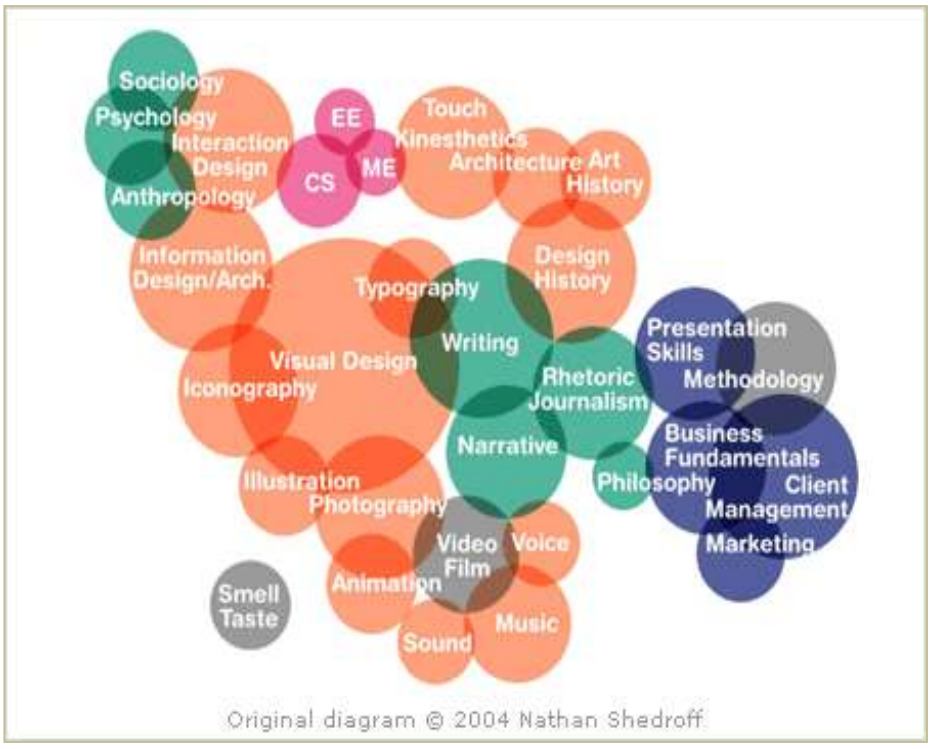

Figure 2.8 The complexity of user experience (©Shedroff 2004)

Forlizzi and Ford (2000) proposed an initial framework for understanding user experience and the influences on experience and qualities of experience. Figure 2.9, depicts their model adapted to include services.

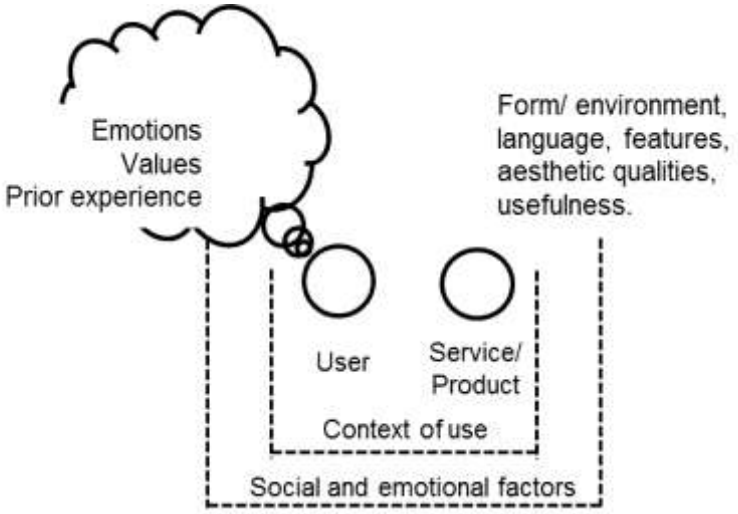

Figure 2.9 Influences on users' experiences (Forlizzi and Ford 2000, adapted)

For Kankainen, UX is "the result of a motivated action in a certain context" (Figure 2.10) where 'context' refers to people, place and things surrounding the user in the interaction; 'motivation' is understood as the need driving the user to the action; and 'action' is the means of the interaction, *"how the user is doing what he/she is doing"* (User Intelligence 2011).

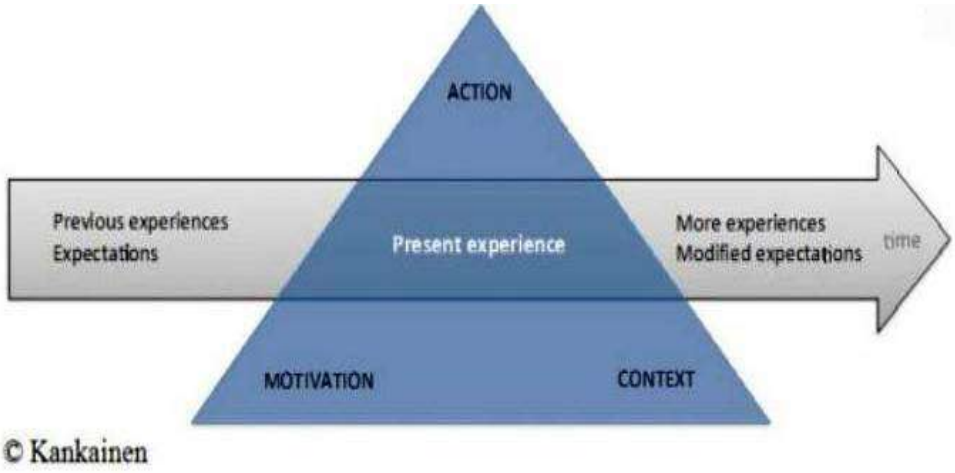

Figure 2.10 Action, motivation and context affect users' experiences (©Kankainen 2002 cite by User Intelligence 2011)

Thus, user motivation leads to a user's experience with services and products, which is influenced by context of use. The following section explores how designers try to create positive user experiences by considering how humans interact with services and products, adopting design approaches that place users' needs at their centre and considerations of usability (ease of use) and context of use.

2.4.5. Human Factors

The International Ergonomics Association (2010) defines human factors (or ergonomics) as "understanding of the interactions among humans and other elements of a system" and applying "theoretical principles, data and methods to design in order to optimize human well-being and overall system." Its focus is human-centred or user-centred design.

Promoting human factors in design gained popularity with Drefus's *The Measure of Man* prompting discussions of embedding human factors in design, 'humanising' technology, designing for disability, older users, avoiding design exclusion (Clarkson *et al* 2003), in identifying cultural and usability issues (Nielsen 2006; Rau e*t al* 2008) and, more recently, designing for pleasure/emotion (Jordan 2004). In services like healthcare: *"The impact of human factors is enormous. Awareness of and attention to the negative aspects of clinical human factors improves patient care"* (Cook 2011).

Jordan (2004) is critical that human factors research targets people as physical and cognitive processes and fails to connect with them emotionally. He suggests design is also about pleasure and understanding people's life-styles is critical to understanding consumer behaviour. He discusses Maslow's model's first three levels: Functionality, Usability (practical aspect) and Pleasure (something nice, positive or good). Designing for pleasure is an approach to user-experience design that created happiness by taking something 'bad' away or giving something 'good' (Jordan 2004).

Two design approaches are discussed next: user-centred design and inclusive design.

2.4.5.1. User-Centred Design

User-centred design (UCD) or human-centred design (HCD) is a philosophy and process which places people at the centre of design (Clarkson *et al* 2003:p.601) rather than things. Figure 2.11, depicts Burns *et al's* (2006) view. UCD is a multi-disciplinary activity that incorporates human factors to enhance effectiveness and productivity, improve human working conditions and to counteract possible adverse effects on human health, safety and performance (UsabilityNet 2006).

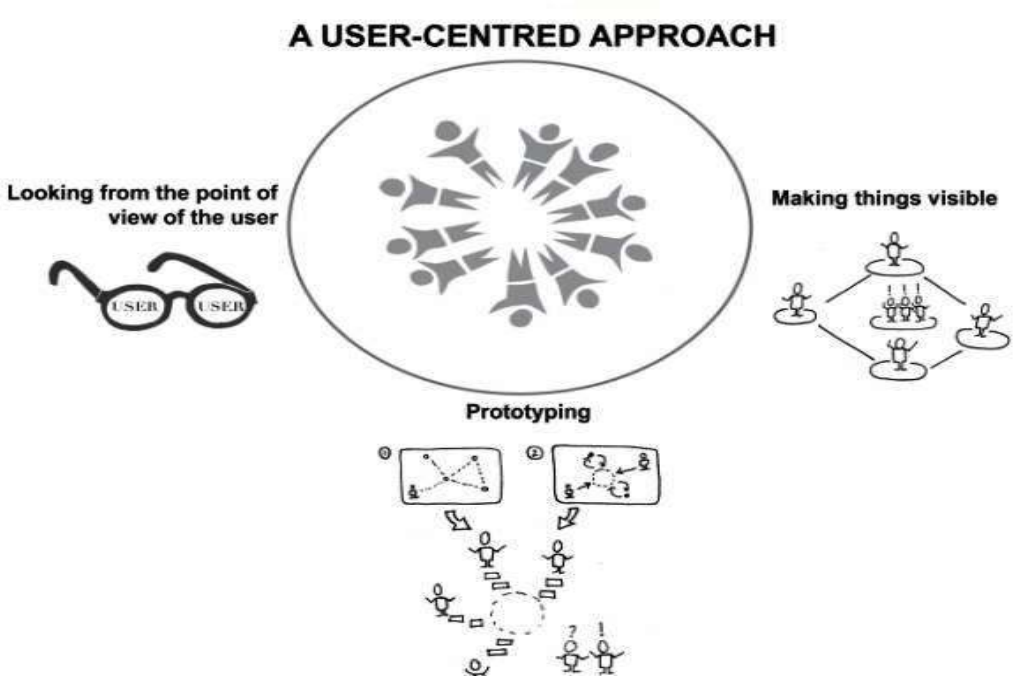

Figure 2.11 A user-centred approach to design (Burns *et al* 2006)

UCD focuses on cognitive factors (perception, memory, learning, problem-solving) and benefits organisations because it cuts costs, increases user-satisfaction and productivity (Katz-Haas 1998). It considers the needs of people within the population who have a range of different capabilities and skills, past experiences, wants and opinions. Organisations could gain valuable insights at little additional cost if they undertook research at the right time, with the right focus and within an appropriate design framework (Clarkson *et al* 2007).

For Black (2008), UCD inspires and focusses design, generates greater insights than aggregated market reports because what users *do* may not tally with what they *tell* market researchers. Good designs understand users' needs and are not about designers just relying on market-research or their own experience. Boztepe (2007) agrees, although critical to business success, user-related adaptation did not have sufficient design research priority: such user-related focus can provide a competitive edge, making competition irrelevant.

Boztepe (2007) comments that UCD in global markets creates different, cultural user-value but design across cultural-boundaries did not anticipate localisation in advance. Rau *et al* (2008) agree, commenting on internet

services, they observed that studies on cultural dimensions, presentation and cognition had not yet succeeded in making a very usable environment for different cultural backgrounds. They highlight that cultural behaviour and thinking influenced people's interactions with services and products which, in turn, influenced people's behaviour. However, whilst cultures change differences in thinking can remain. Moalosi *et al* (2007) add that cultural-design topics were limited to aesthetic stereotypes like national shape and colour and proposed a culture-orientated design model involving four socio-cultural categories (material, social, emotional, technological) for designers (Botswana) to create designs in a local cultural context. This emphasis on one culture, however, could conflict with accommodating multi-cultural diversity inclusively.

The International organisation for Standardisation (2010:p.2) ISO 9241-210, identifies four interdependent activities for UCD that use outputs from the other:

- Understand and specify the context of use.
- Specify the user requirements.
- Produce design solutions to meet these requirements.
- Evaluate the designs against requirements.

Although referring to interactive systems, this appears applicable across other services and products.

Preece *et al* (2002, adapted) propose 5 guidelines to focus on users and tasks:

- Users are consulted from earliest to the latest phases and their input is seriously considered;
- User's tasks and goals should drive the development;
- User-behaviour and context of use are considered and the process is designed to support them;
- Designers should capture users' characteristics and design for them;
- Design decisions are taken within the context of the users, their needs and environment.

For Norman (2005), an activity-centred design approach to design is superior because it includes UCD and can include ergonomics and engineering. UCD

does not guarantee good products although it can improve bad ones, avoid failures by ensuring everything works and people can use the service or product. However, *"too much listening to users"* can lead to over complications resulting a loss of understanding with each revision. Instead, user suggestions need to be evaluated by the designer from an activity-centred perspective and discarded if necessary to produce a cohesive well-articulated design model. *"This is the goal towards cohesion and understandability."*

One may conclude that UCD offers many benefits, however, there is a need to balance the inherent creativity of design and UCD because users may not always know what they want. An activity-centred approach is superior because it includes UCD but also facilitates cohesion and understandability.

2.4.5.2. Inclusive (Universal) Design

Mace (2008) coining the term *universal design* stated the intent was to simplify life by making services and products more usable by as many people as possible at little or no extra cost, benefitting all ages and abilities Inclusive or universal design is a design approach defined as:

> *"The design of mainstream products (and services) that are accessible to, and usable by, as many people as reasonably possible ... without the need for special adaptation or specialised design" (BSI 7000-6:2005).*

Clarkson *et al* (2003) add that inclusive design promotes user-satisfaction in a specified context of use and takes cultural differences and cognition into consideration. Maximising usability, simplicity and user-satisfaction requires knowledge of users' cognitive capabilities (Clarkson 2008) and their perceptions, which can differ in different cultures (Jylha 2007; Rau e*t al* 2008). Cognition is:

> *"The mental act or process by which knowledge is acquired, including perception, intuition and reasoning and the knowledge that results from such an act or process"* (Collins 2012).

Cognition is important to how messages are understood (Crilly *et al* 2008:p.443) and an inclusive design philosophy extends the UCD approach

to the widest range of users.

For Clarkson *et al* (2007), inclusive design is simply better design. It is user-centred, population aware and business focussed and ensures groups of people or views are not excluded thereby raising profitability. It applies an understanding of customer diversity to design, better satisfies the needs of more people, meets the needs of users who are excluded, reaches a wider market, improves product or service experience and satisfaction across a broader range of users and drives business success. It is not a stage that designers can simply add to the design process, or confuse with a product being easy to use, or design for a particular capability loss, or imply that it is always possible (or appropriate) to design one product that meets the needs of the entire population. Inclusive design should be embedded within the design and development process, resulting in better designed mainstream products that are functional, usable, desirable, satisfying and viable (Clarkson *et al* 2007).

Figures 2.12 and 2.13 depict the iterative processes used to designing inclusively and map the key activities.

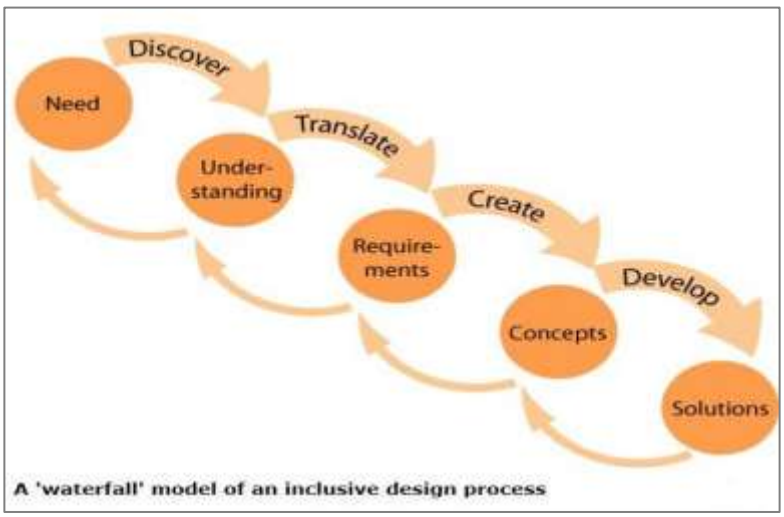

Figure 2.12 'Waterfall' model of inclusive design (EMMTII 2009)

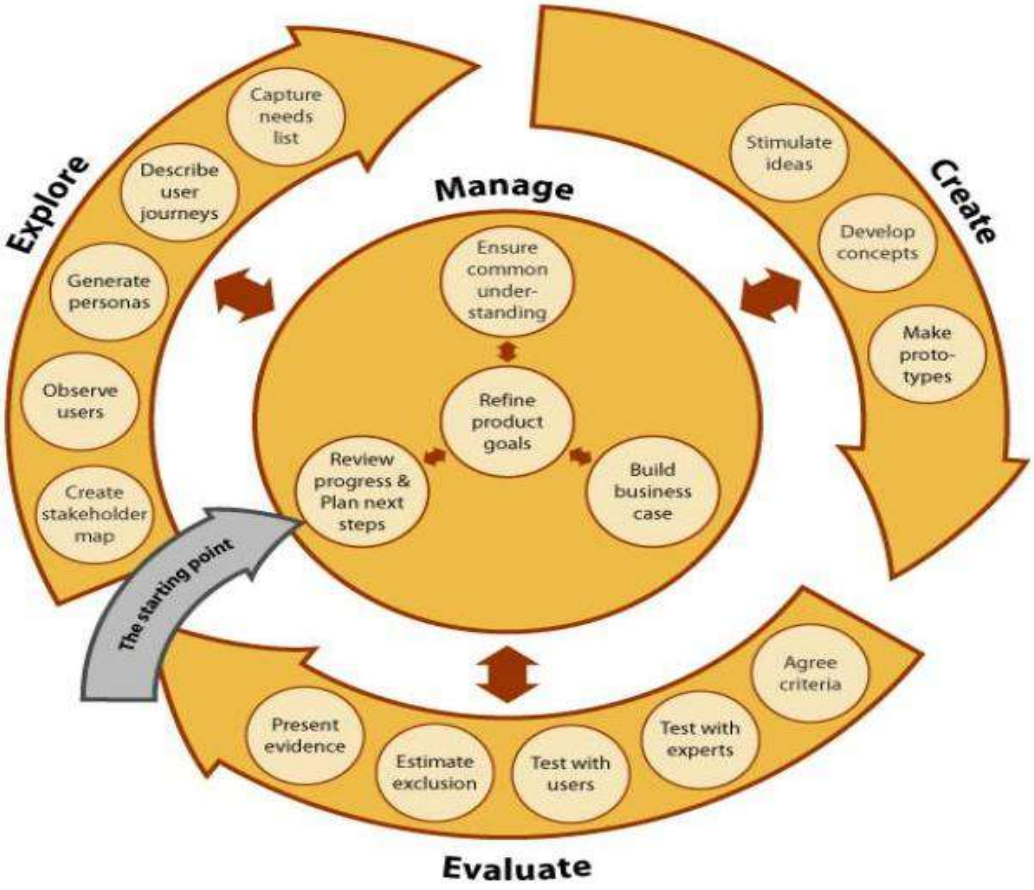

Figure 2.13 The inclusive design toolkit (Clarkson *et al* 2007)

Connell *et al* (1997) from The Centre for Universal Design propose seven principles for designing inclusively across a wide range of design disciplines:

- **Equitable use**: The design is useful and marketable to people with diverse abilities.
- **Flexibility:** The design accommodates a wide range of individual preferences and abilities.
- **Simple and Intuitive**: Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
- **Perceptible information:** The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
- **Tolerance for error:** The design minimizes hazards and the

adverse consequences of accidental or unintended actions.

- **Low physical effort:** The design can be used efficiently and comfortably and with a minimum of fatigue.
- **Size and Space for approach and use:** Appropriate size and space is provided for approach, reach, manipulation and use regardless of user's body size, posture or mobility.

They add that designers must also incorporate other considerations in their design processes, like economic, cultural, gender and environmental concerns, engineering. However, the principles offer guidance to better integrate features that meet the needs of as many users as possible (Connell *et al* 1997). (In Chapter 5, we shall review the

2.4.5.3. Usability

Usability, ease-of-use, is defined as:

> *The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use. (ISO9241-11 1998)*

Research has established that complex technologies (or processes) used in the design and delivery of products or services marginalises users with less experience resulting in usability problems, loss of interest and under-utilisation of facilities (Goodman *et al* 2003, Nielsen 2006, Clarkson 2008). Thus, usability is an important to generate positive user experiences.

Nielsen (2006), championing usability, states that people face three barriers, 'divides', that prevent them achieving the modern world's full benefits: usability, empowerment and economic. He urges industry to overcome the first two whilst addressing the third to attract more consumers. The usability barrier is a concern because many people cannot use some products (such as computers) whilst others find services too difficult to understand, especially those with low-literacy (Nielsen 2006). Usability is a simple concept but not always easy or intuitive to implement and designers need to consider: Visibility, Memory load, Feedback and Accessibility (Katz-Haas 1998).

UsabilityNet (2006) states that usability means making products, services

and systems easier to use and matching them more closely to user needs and requirements. Usability is about:

- *effectiveness* that users are able to complete tasks and achieve goals, i.e. do what they want to do;
- *efficiency* the effort required for the task or goal to be completed (often measured in time); and
- *satisfaction*, what users think about the products ease of use.

This requires an understanding of:

- Who the users will be (highly trained/ experienced or novices);
- Their goals (what they are trying to achieve; does the product or service facilitate this)
- The situation or 'context of use'

> *Usability should not be confused with 'functionality' […] the functions and features of the product and has no bearing on whether users are able to use them or not. Increased functionality does not mean improved usability (UsabilityNet 2006).*

The 'Quality-in-Use' model (Figure 2.14) for HCI product development is similar to ISO 92411-11 (UsabilityNet 2006) could apply to other products and services. For Bevan (1999) Quality-in-Use has cultural implications, linking human factors and UCD.

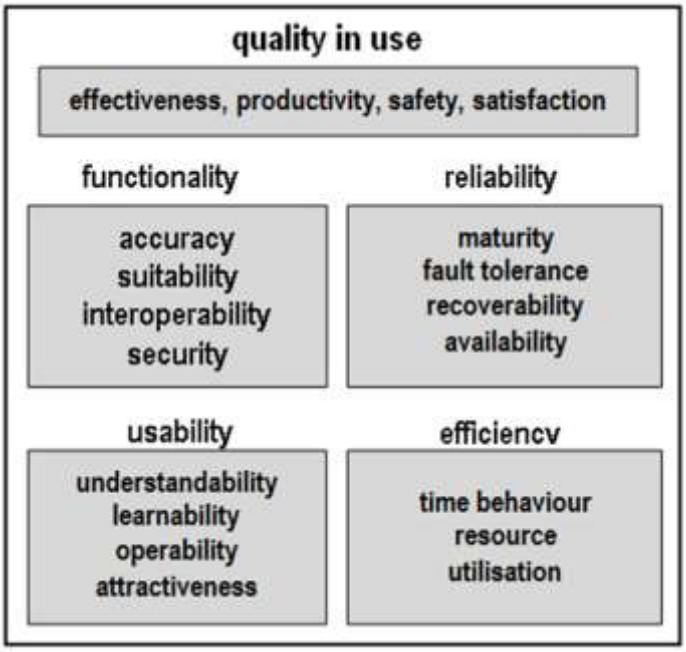

Figure 2.14 ISO/IEC FDIS 9126-1 Software Engineering Product Quality-Part 1: Quality model (2000) similar to ISO 92411-11

Rees (2009) identified *The 10 most common reasons for poor Usability*:

- Too much focus on technology and features;
- Working without user-contact;
- Designers use own experience as a guide ("scratch their own itch");
- Immersion in detail causing failure to 'step back' and ask reasons for design decisions;
- Too many project stakeholders;
- Poorly defined objectives;
- No incentives for good usability, and
- A lack of awareness of poor usability

2.4.5.4. Usability and Context

Context is defined as *"the conditions and circumstances that are relevant to an event, fact, etc."* (Collins English Dictionary 2012) or: the user, task, equipment and the physical and social environments in which a product (or service) is used (ISO9241-11 1998).

In their study on usability, Thomas and Bevan (1995, adapted) stated the awareness of contextual factors is important to develop products or services which are usable and appropriate for the intended users. They identified key context characteristics which are relevant to a user's satisfaction (summarised in Table.2.1 and adapted to this research).

Table 2.1 Context characteristics and their associated factors (Thomas and Bevan 1995, adapted).

Context		Associated factors
Users	Intended user groups	Personal attributes, physical attributes (age, gender), motor and sensory capabilities (vision, dexterity).
Skills and Knowledge	Background	Education, training, experience, linguistic capability, background knowledge.
Mental attributes		Intellect, motivation, attitudes, **cultural perceptions.**
Task	Actions required to	Frequency, procedure/ process, physical and mental demands, duration, flexibility,

	achieve the desired goal.	sub-tasks.
Equipment or service	Product(s)/ service process and the media used.	What is used, accessing it/ the location, choice.
Social environment	**Culture**, circumstances and people surrounding the user.	Location, assistance, group working, customs and surrounding people.
Physical environment	External conditions and surroundings.	Visual conditions, temperature, auditory conditions, vibration, the built environment.

Evaluation can help to assess the usability of a service/ product, however, meaningful results need evaluation to be carried out in conditions representative of those in which the service/ product will actually be used (Thomas and Bevan 1995, adapted).

Clarkson *et al* (2007) identified seven user capabilities which typically influence how successfully users interact with a product/ service: vision, thinking, communication, hearing, reach and stretch, locomotion, and dexterity. The characteristics of a product or service determine the demands placed on each capability and the task being accomplished, e.g. reading a paper pamphlet or accessing information on a website make different demands. In *The Inclusive Design Toolkit* (Clarkson *et al* 2007), the contextual characteristics that affect these seven user capabilities are identified, e.g. vision is affected by lighting quality and intensity. The *Demand Assessment Grid* tool assesses vision, hearing, thinking, mobility and dexterity demands associated with each of the steps required when interacting with a product. However, the vast majority of products make demands on the visual and dexterous (arm, hand and finger) capabilities of the user (Elton and Nicolle 2010).

The key concepts and themes from this literature review, which informed study 1 and the research journey, are discussed below. Drawing from the literature, the potential inter-cultural influences that 1st generation EMCs (Indian Subcontinent) might experience in the UK, are considered.

2.5. Discussion, Conclusions

There is an elegant synergy between the theories of culture, identity, acculturation and human motivation, their influence on users and providers. In multi-cultural societies like the UK, Hofstede's 4 cultural dimensions and Hall's contexts co-exist amongst different ethnic groups. Applying these to UK society and EMCs (Indian Subcontinent) suggests, broadly speaking, their approaches are dimensionally different. UK society broadly conforms to children are raised towards initiative, uncertainty acceptance, individualism, masculinity and low-context. Whereas, in EMC (Indian Subcontinent) society, particularly the 1st generation: children are raised towards obedience, uncertainty avoidance, masculinity and high-context, gender segregation and arranged marriages could be grouped under 'power distance' and extended families denote the collectivist approach

In preparation for user study 1, it was useful to compare potential inter-societal differences between the UK and Indian Subcontinent that might be experienced by 1st generation EMCs in particular. Table 2.2 draws from the literature and Table 2.3 draws from the authors experience and knowledge[1]. These are broad indicators of norms amongst the wider population of EMCs (Indian Subcontinent) although the specifics can vary greatly as explained below.

Table 2.2 Some key societal differences between the UK and Indian Subcontinent.

Indian Sub-continent	U.K.	Drawing from the Literature
17+ major languages, different scripts.	1 major language and script.	Five Government websites (Indian Subcontinent).
5 major religions, strong influence.	1 'Established Church' in a multi-faith society, moderate influence.	
Communicating Information: *High-context* society, more implicit, experienced-based,	*Low-context* society, more explicit, analytic, functional, abstract.	Hall and Hall (1976), Rau *et al* (2008)

[1]Multi-cultural/ religious background, raised and educated in India, extensive experience of living and working in the UK and India.

prefer thematic arrangements.		
Decision-making: *Collectivism;* family/ joint family; elders prefer family support.	*Individualism*; elders like to maintain independence.	Hofstede and McCrae (2004)
Uncertainty avoidance, more emotional.	Uncertainty acceptance, emotion expressed infrequently.	
Power distance: Gender segregation; arranged marriages widespread; females mainly pressured.	Negligible segregation; marriage by individual choice.	

Table 2.3 Everyday living societal differences between the UK and Indian Subcontinent (authors experience/ observation).

Indian Sub-continent	**U.K.**
Children's education: paid for, not mandatory; females sometimes excluded; learn by repetition.	Children's education: free at the point of delivery; mandatory for all; learn by application.
Healthcare: Paid for on demand. Little or no social services, family reliance.	Health and Social care: Free at the point of delivery; services are rationed.
Cheap labour for tasks: servants at home look after cleaning, cooking, elders, children.	Expensive labour, DIY society and social services support.
Communication: Unspoken word/ body language unfamiliar concepts (1st generation); sentences repeated for emphasis.	Unspoken word, body language significant; information repeated only on request.
Respect often ascribed to position and wealth (status) and elders.	Respect usually ascribed to each individual.
Cultural taboos: Discussing sex, mortality of elders, marrying into another religion, public shows of affection.	Few taboo subjects or limitations on marriage choices, public shows of affection.
Social courtesy: males rarely give females priority; use of *please*/ *thank you* often absent; personal space not understood.	Males (all ages) often give priority to females; *please* and *thank you* used frequently; personal space important.

This data suggests EMCs (Indian Subcontinent) are accustomed to living in multi-faith societies and, as literature confirms, the challenges would arise from other cultural variables like collective (family) vs. individual perspectives, cultural expectations, differences in communication and their degree of

acculturation. However, nothing is a simple rule in the Indian Subcontinent: expectations, influences and behaviours vary widely between urban and rural areas, between religions, from family to family depending on how traditional/liberal their views are.

In commencing this research the author subscribed to Masterson and Pickton's view that both services and products are a bundle of attributes and should be treated the same because both need to be priced and promoted to users although services have more intangibles and the service provider is part of the service. Also, that that there are no 'service' organisations but organisations which have a greater or lesser degree of service provision. Thus, service provision includes products and product providers offer the product with services surrounding the product. For instance, internet services offer a hotel booking, a trip, a CD, contact with friends, etc. and is based on software (a product). Likewise, our healthcare system is heavily dependent on products.

The key themes from this literature that were carried forward throughout the research are summarised below.

- Cultures are continuously changing, influenced by motivation, acculturation and choice. This dynamic nature of culture offers pathways for positive change.
- Cultures cannot be defined by national boundaries.
- Not enough is known amongst marketing scholars about how variables like religion, inter-generational factors and acculturation influence EMCs' choices and perceptions.
- Insights on inter-cultural dimensions and cultural variables help to improve understandings of phenomena.
- Demographic trends indicate fresh consideration needs to be given to the problems and preferences of EMCs by both business and public sector services.
- Design is an inherently creative activity and guidelines for inclusivity, user-centred design and usability anchor design in good practice that

achieve the successful take-up of products and services.

- Inclusive design includes users who might be excluded, is simply good design and benefits both users and the organisation
- Context of use, including cultural aspects, is an important consideration for the success of designs.
- An activity-centred approach to design includes UCD and can facilitate design cohesion and understandability particularly in a multi-cultural context where perceptions differ.
- To motivate consumers, maximally motivating opportunities can be created by making it possible to accomplish more than one goal simultaneously.
- Extrinsic motivation influences attitudes and is particularly interesting from the perspective of motivating users towards new ways of doing things or thinking.

These themes informed the design phase of the research (Chapter 8). However, for study 1, there also appeared to be a fine tension between the results of cultural studies which suggested cultural variables can give rise to difficulties and research on acculturation (Sekhon and Szmigin 2005; Balakrishnan *et al* 2005), which suggested many EMCs were adapting well in home countries.

For this research project, the questions were: Were all EMCs groups adapting equally well and, if not, who might not be and why? Where did they perceive the most difficulty lay: with services, products or both? In a highly diverse multicultural society as in the UK, how could inclusive design accommodate numerous cultural variables? This combination of literature generated the overall aims and research question.

The next chapter sought guidance from the literature on research methods and best practice to implement this research project.

3. Research Methodology

This chapter describes the methodology that enabled this research project to attain its aims and objectives. Through the literature and discussion, it sets out the research strategy used, the conceptual framework, sampling, and the methods and guideline followed in data gathering, design and analysis.

3.1. Preparing and Planning Research

Research is a process of gathering and analysing information from the world we live in and the purpose is to contribute new knowledge (Robson 2002).

Research can be carried out in 'open systems' in situations which are relatively poorly controlled and "messy" known as Social or Real World Research, or in 'closed systems' which control external factors, like laboratories (Robson 2002:p.4). This research project was concerned with an 'open system' and included 5 features which characterise successful research (Robson 2000:p.56):

Activity involved (frequent contacts in the field and with colleagues)
Convergence (bringing together 2 or more activities or interests, like an idea and method, interest or a problem);
Intuition (feeling the work is important, or timely)
Theoretical understanding;
Real-world value (leading to tangible/ useful ideas)

The three studies all involved field activity and consultation with colleagues. Research commenced from the author's idea and interest, combined with theoretical understanding and a review of current affairs which developed into intuition that the timing was right. Finally, it contributed some relief to a real-world problem.

Research projects require careful planning and designing a research framework involves 5 inter-related components that need to be balanced (Robson 2002:pp.81-81, Figure 3.1).

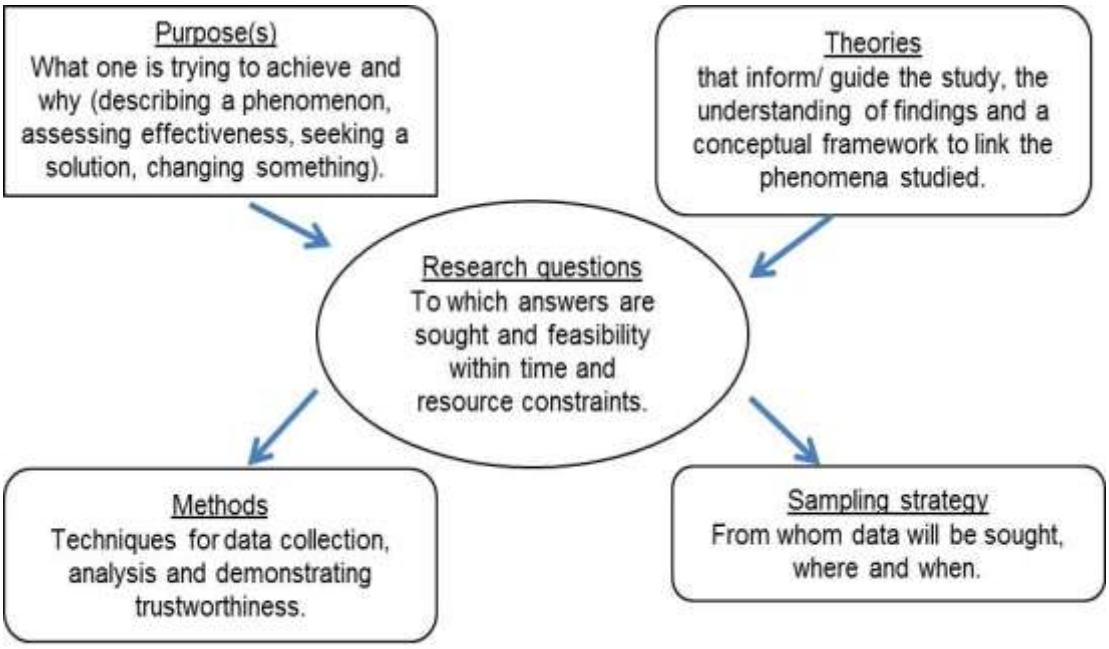

Figure 3.1 Framework for designing research (Robson 2002)

Different methodologies can be used which are determined by the research discipline, its area and focus: the research questions particularly determine the data techniques to be used. Good research questions need to be clear, specific, answerable, interconnected and substantively relevant (worthwhile) and researchers should (Robson 2000:pp.56-60):

Acquire knowledge of the area ('go public' through presentations or publishing a paper)

Widen the base of their experience (consider other fields that may offer useful insights into problems)

Consider creativity enhancing techniques (like brainstorming, Delphi techniques, and focus groups)

Avoid allowing the method/ technique to determine the question

Consider feasibility: the number of questions (develop a hierarchy with sub-questions nested under main questions), and

Clarify the research purpose (distinguish between 4 classifications, which can help resolve the research questions).

Table 3.1 sets out the purposes ('flexible' are qualitative studies and 'fixed' are quantitative, discussed in 3.2).

Table 3.1 Research Purposes (Robson 2002:pp.59-60)

Exploratory	Descriptive	Explanatory	Emancipatory
Find out what is happening, particularly in little-understood situations. Seek new insights. Ask questions. Assess phenomena in a new light. Generate ideas and hypothesis for future research. Almost exclusively of flexible design.	Portray an accurate profile of persons, events and situations. Requires extensive previous knowledge of the situation, etc. to be researched or described, so that you know appropriate aspects on which to gather information. May be of flexible and/or fixed design.	Seeks an explanation of a situation or a problem, traditionally but not necessarily in the form of causal relationships. Explain patterns relating to the phenomenon being researched. Identifies the relationships between aspects of the phenomenon. May be of flexible and/or fixed design.	To create opportunities and the will to engage in social action. Almost exclusively of flexible design.

However:

> *"A particular study may be concerned with more than one purpose, possibly all four, but often one will predominate. The purpose may also change as the study proceeds" (Robson 2000:p.58).*

Applying these guidelines to this research, studies 1 and 2 were informed by literature from marketing, social sciences and current affairs and study 3 by literature from healthcare and design. Focus groups were used in study 1 and brainstorming in study 3.

In considering the research purposes, 'exploratory' best frames the purpose of studies 1 and 2 (Chapters 4 and 6) which sought new insights into an existing problem, assessed phenomena in a new light and generated ideas for future research. They also had elements of 'descriptive' (to portray an accurate profile of persons and situations) and 'explanatory' (sought an explanation of phenomena). The design phase (Chapter 8) would be best framed under 'emancipatory' as it sought to create an opportunity, to motivate and empower individuals and thereby to improve wellbeing and contribute to social integration.

3.2. Research Type

Robson (2002) identifies 3 types of research designs: flexible (qualitative), fixed (quantitative) and mixed-methods. All are valid provided they are conducted systematically and the research explicitly identifies the nature and circumstances in which it was carried out, that ideas are subjected to scrutiny to avoid bias and the intention is to seek the truth about the subject of the research.

Flexible designs are qualitative studies where research findings are not arrived at by statistical or other means of quantification (although some researchers gather data by qualitative methods but code it in a manner that allows data to be statistically analysed). There is less pre-specification and the design evolves, 'unfolds', as research progresses (Robson 2002:p.5). The pre-requisites of qualitative research are a critical analysis of situations, recognising and avoiding bias, obtaining valid and reliable data and thinking abstractly (Strauss and Corbin 1990:pp.17-18). Research is more likely to be an inductive process.

Fixed designs are theory driven and the results are usually numerical and statistical generalisations. Fixed design is followed when a substantial amount of pre-specification exists about what will be done and how before starting the research (Robson 2002:p.4). Information is usually obtained from previous theories, tests, pilot studies, experiments etc. and research is more likely to be a deductive process.

The two types can be combined and used effectively in the same research (Strauss and Corbin 1990:pp.18) and there is considerable advantage in using mixed-methods (Robson 2002:p.5).

A flexible design research approach was the most appropriate for this research project although mixed methods were used in study 3 (see 3.8.3).

3.3. Research Strategy

The research strategy was implemented in the 4 stages described below. It was decided from the outset that both users and providers would be investigated to gain a holistic and inclusive understanding of any problems identified in study 1. Therefore, a user-centred design approach, with

particular focus on inclusive design, was used throughout. Specific details of methods for each user-study are described in the appropriate chapter.

3.3.1. Stage 1: Laying the foundation

This identified and selected research directions and opportunities to fashion the research (from literature and own motivation):

1. Understand theories on culture, how culture relates to products and services, cultural variables that impact on individuals, acculturation, ethnic minority demographic trends in the UK and the business case.
2. Understand the nature of products and services, human motivation and attracting consumers, user-centred design, inclusive design, usability and context of use.
3. Explore methodology through literature, training and lectures.
4. Undertake further literature reviews for the user-studies as the research focus is narrowed and progresses. Keep the literature up-to-date for the duration of the research.

3.3.2. Stage 2: Research Design

This stage involved the following.

5. Select the research approach and methodology and define the research concept for at least 3 user studies.
6. Identify relevant ethical clearance processes for each study in a timely manner.
7. Prepare a research schedule and write-up the research as it progresses.

3.3.3. Stage 3: Research Implementation

This was guided by the 4 steps proposed by Rohrer (2008; see 3.6.3):

8. **Define the problem:** Commence with a user-centred study to investigate the perceptions of any barriers with EMCs (Indian Subcontinent).
9. **Narrow the research focus:** Based on the findings of study 1 select a product or service provider and investigate their perspectives of the problem (Study 2), to define and understand the problem holistically.
10. **Optimise:** From the combined results of the 2 studies, identify an

opportunity for inclusive design to play a role.

11. **Design and Assess:** In a 3rd study employ generative design methods to inform and optimise a design concept, reduce risk and improve usability in an inclusive approach involving EMCs (Indian Subcontinent), the product/ service provider and an indigenous group. Prepare the prototypes and follow A/B iterative design user-testing and evaluation to user-select the preferred solutions.

3.3.4. Stage 4: Reflection and Conclusions (Assessing)

12. Reflect critically on different aspects of the research project.
13. Generate conclusions, contributions to knowledge and recommendations for future research.

3.4. Research Approach

This research took the *interpretive* epistemological position of *critical realism* and *social constructivism,* i.e. that people's experiences and perceptions are influenced by their cultures, history, language and other factors which set the contexts. People therefore perceive or understand, and thus describe, the same event in different ways - neither of which are necessarily wrong (Willig 2008). This was selected as appropriate due to:

- The cross-cultural nature of the research accepted that cultural variables influenced the perceptions of participants differently.
- That findings of EMC's (Indian Subcontinent) perceptions were compared to those of (mainly indigenous) healthcare professionals to generate improved understandings of the nature of difficulties.
- Findings considered inter- and intra-cultural differences.

The research adopted an empathic and inductive approach for the reasons set out below. These were combined with user-centred, inclusive design approaches (chapter 2) and employed participatory design techniques.

3.4.1. An Empathic Approach

Evans *et al*'s (2002:p.5) empathic approach guided the research. A highly sensitive approach was required as some EMC participants would be unaccustomed to research, be very elderly and some also non-literate and, later, would extend to research with indigenous elderly people. Whilst the

term inclusive design is not used, the researcher found their approach embodied these principles through its sensitivity towards the feelings and needs of consumers.

Evans *et al* (2002:p.5) proposed ten guidelines of which the following were adopted:

- Don't assume (ask the question)
- Delight your customers (move beyond usability to delighting stakeholders)
- Design with others (encourage stakeholders to participate in the design)
- Develop your own tools.

A continuous process for 'capturing the customer's murmur' (Figure 3.2 adapted) urges moving beyond satisfying users towards delighting them by offering significantly better understanding of their motivations and needs.

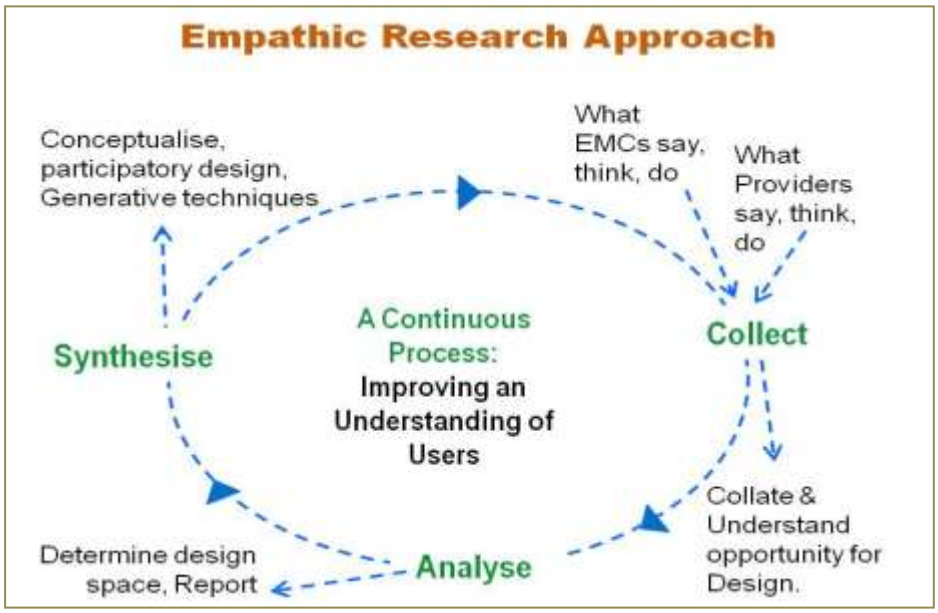

Figure 3.2 "Capturing the *murmur of consumers"* (Evans *et al* 2002; adapted)

(NB. This research was influenced by the empathic approach and does not claim to follow *empathic design methodology*, which involves observation studies, which were not used.)

3.4.2. Inductive Research

According to Mouly, people attempt to understand phenomena in their environments through *reasoning*, *experience* and *research*, which overlap and complement each other when seeking solutions to complex problems (Cohen *et al* 2001:pp.4-5). Reasoning can be *inductive, deductive* or a combination thereof. In an inductive approach, sufficient data are collected, without preconceived notions to objectively reveal the general case. It enables new research to contribute fresh insights to existing knowledge to counter *deductive reasoning,* the existing standard approach which commenced with a hypothesis and set out to prove it (Cohen *et al* 2001).

Inductive research accommodates qualitative, quantitative and combination data and *purposive sampling* (see 3.5) is frequently used. Willig (2008:p.38) states data can be about processes, experiences, structures, cognitions and various data-gathering methods are compatible (interviews, focus groups, audio-recording, diary studies, observation, etc.).

Guidance from inductive research was selected for its flexibility, to gain insights without preconceived notions, and also influenced sampling (3.5), the methods used (3.6) and data analysis (3.7).

3.5. Sampling

Careful preparation and planning are necessary: whom to interview and why, what questions to ask, how to recruit, record and transcribe data (Willig 2008:p.23) and Willig describes participants as:

- *homogenous* (share key features) or *heterogeneous*;
- *pre-existing* (friends/colleagues) or *new*; and
- *concerned* (stake-holders) or *naive* (uncommitted).

Sampling was purposive throughout the research to explore issues with particular participant groups. Purposive or non-probability sampling deliberately excludes a section of the wider population and is commonly used in flexible design studies (Robson 2002;p.265). Cohen *et al* (2001:pp.103-4, 138) describe it as selecting participants on the basis of their typicality for a specific purpose. One criticism can be that, as it is deliberately selective and biased, it does not represent the wider population, but it does enable the full

scope of issues to be explored. However, Robson (2002:p.177) concedes that data can provide theoretical insights and sufficient generalisation or universality "to allow projection to other contexts or situations".

Willig (2008:p.17) agrees: the *representativeness* of a sample is important in generalising research findings to the general population (or other groups within the population) and the relatively small numbers of participants involved in qualitative studies raises the question of whether or not these are representative samples. This depends on the research question and the method selected, e.g. representativeness is not a problem in case studies whereas, if the phenomenon is relevant to more people than are actually involved in the study, there is a likelihood of wanting to generalise the implications. Strictly speaking, this is not possible from a small-scale qualitative study; however, this issue can be addressed.

It can be argued if a *"given experience is possible, it is also subject to universalisation"* because we know the experience identified it is available within a culture or society even if the numbers of people sharing it are unknown. Thus, if participants' experiences are at least 'partially socially constituted' then we can also agree that 'each individual mode of appropriation of the social...is potentially generalisable' (Willig 2008:p.17).

As the research objective was to explore issues with particular segments of the population, it was accepted that the participants would not represent the wider population but could provide insights into particular issues and answer the research questions.

Sampling generally aimed for at least 40 participants, but was sometimes less (studies 1 and 2, due to recruitment difficulties and time-constraints) or more (study 3, due to the nature of the study). Participants were heterogeneous (both genders), stakeholders, and some were known to each other (families, acquaintances).

3.6. Data Gathering Methods and Techniques

Research is designed to answer questions and generate understandings of human experience that will be useful. There are no 'right' or 'wrong' methods for collecting data, rather some are more or less appropriate to a research

question and the main decision is about collecting the sort of data that can answer that research question and how the answer may be extracted from that data (Willig 2008:p.22). Human language provides a virtually unique window on what lies behind our actions and research is concerned with facts, behaviour and beliefs or attitudes (Robson 2002). Data gathering involves a set of items (usually questions), possibly sub-questions depending on the response, probes and prompts and a sequence for the questions (Robson 2002:p274). The interaction between the researcher and participant produces the data (Charmaz 1995:p35).

In good qualitative research design the research question, data collection technique and method of data analysis are inter-dependent and not considered separately or chosen independently from one another. Data collection generates data appropriate to the method of analysis (Willig 2008:p.22). Sometimes, two or more research (qualitative and quantitative) methods are appropriate, *mixed methods design*, within the study. Willig states that researchers share a common purpose and belief that knowledge is fallible, that they need to carry out research rigorously, conscientiously, be self-critical and to disseminate the findings.

Qualitative data can generate rich knowledge of the experiences and perceptions of participants to gain insights and an improved understanding of any problems. Black (2008), writing for the Design Council, urges that data should be gathered from the widest range of users to ensure the full potential for design responses is understood. Evans *et al* (2002) concur, including as many stakeholders as possible promotes a holistic view of issues.

3.6.1. Selecting Methods

Research has established that capturing a good understanding of users can be complicated as people have needs and desires they may not able to voice, are unaware of, find difficult to articulate or are unwilling to divulge and, thus, different methods are required to acquire different levels of knowledge (Evans *et al* 2002; Sleeswijck-Visser 2005). Evans *et al* (2002) propose ten research and design methods (*tools*) which are detailed for implementing an empathic approach, however, researchers are urged to be creative and innovative in developing their own tools

Figure 3.3 depicts some of the methods used in implementing this research and the levels of understanding they provide.

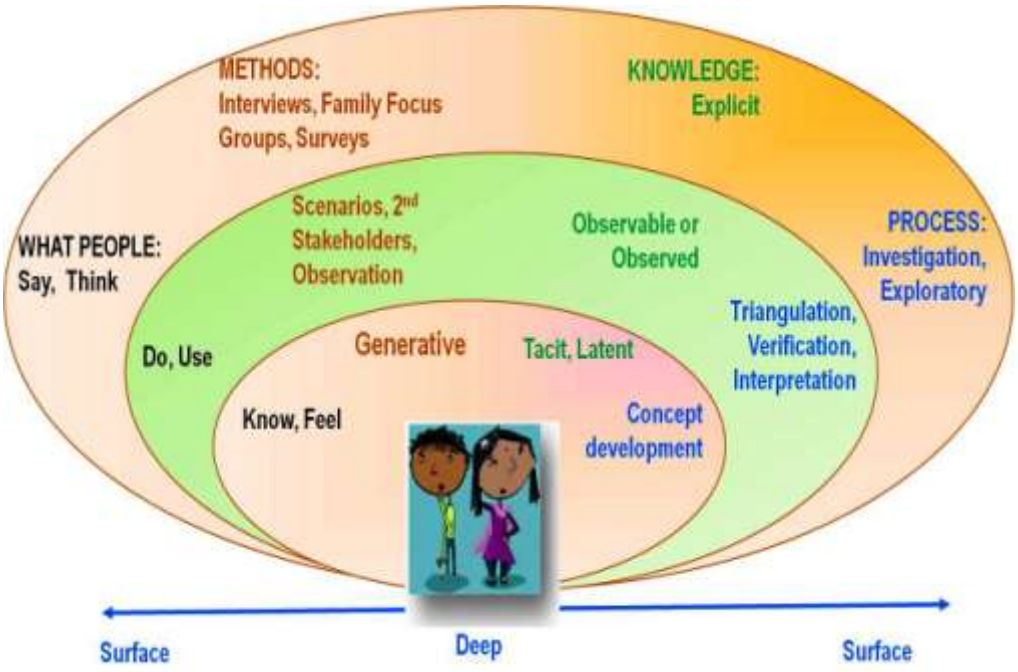

Figure 3.3 Understanding users: Levels of knowledge accessed by different methods (Evans *et al* 2002; Sleeswijck-Visser 2005; adapted)

Discussing *When to use which user experience research methods,* Rohrer (2008) states that user experience research differs along 3 *dimensions,* and suggests some research methods to accomplish research goals in these dimensions.

Table 3.2 summaries the dimensions and their application in this research project.

Table 3.2 Dimensions described by Rohrer (2008) and where some were used in this research.

Dimensions	Used in this research
1. Attitudinal vs. Behavioural: Understanding *What people say vs. What they do*	Studies 1, 2 (attitudinal) Study 3 (behavioural)
2. Qualitative vs. Quantitative: Determining *Why and how to fix* vs. *How many and how much*	Qualitative mainly, with some quantitative.
3. Context of use: How and whether participants are using a product or service. Studies can approach this in 4 ways:	
Natural minimises interference and is as close as possible to reality;	Studies 1, 2, 3
Scripted are used to focus insights in specific ways and the degree of scripting can vary considerably;	Studies 1, 2, 3
Not using helps to examine issues beyond use or usability, like studying a brand or cultural behaviours	Study 1
Hybrid methods use creative methods, like participatory design, to allow users to interact with and re-arrange design elements and to discuss their choices.	Study 3

Rohrer depicts the first two dimensions in 2 diagrams, along the X and Y axis, together with methods (Figure 3.4). The methods can move along one or more dimensions to satisfy multiple goals, e.g. interviews can focus on what people *say* and what they *do* (attitudinal and behavioural) or participatory studies can be both qualitative and quantitative.

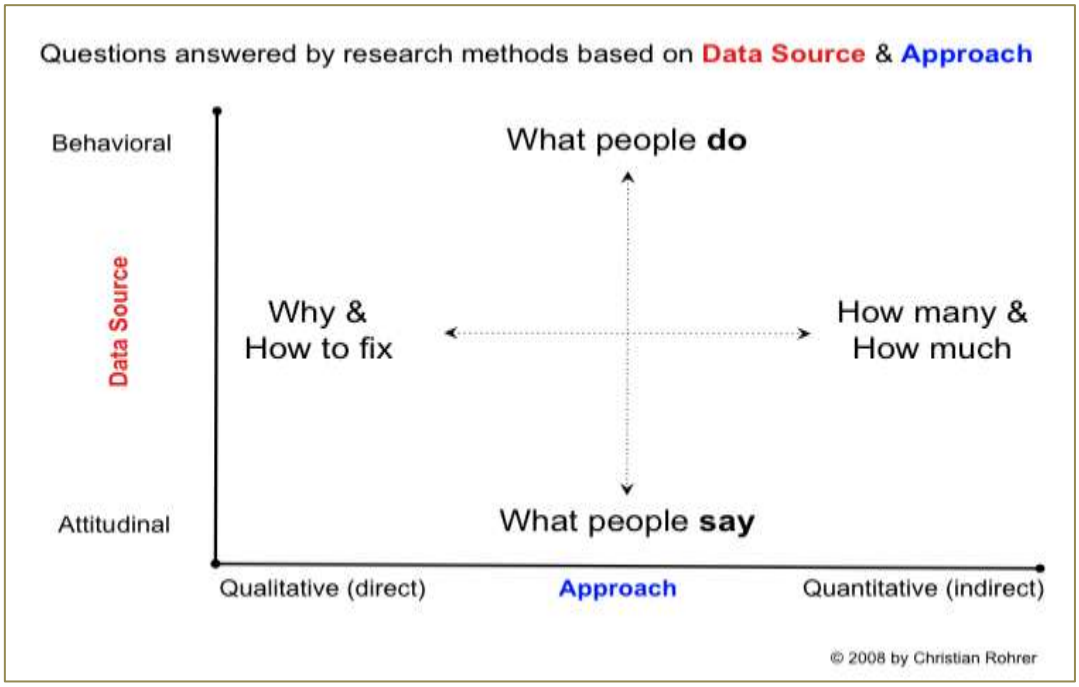

Figure 3.4 ©Rohrer's (2008) dimensions: Attitudinal-Behavioral & Qualitative-Quantitative.

Rohrer's guidance was applied in designing the stages of the research and different methods were used to gather attitudinal and behavioural data (Table 3.3).

Table 3.3 The three studies in this research project and the methods used

Study	Participants	Methods	Type of data	Knowledge
1	EMCs	Family focus groups and Individual interviews	Qualitative	Attitudinal-Behavioural
2	NHS staff	Individual interviews	Qualitative	Attitudinal
3	EMCs NHS staff Indigenous elderly	Individual interviews and participatory design - hybrid contextual techniques	Qualitative, Quantitative	Attitudinal-Behavioural
		A/B testing (Alpha/Beta)	Quantitative	Attitudinal, Behavioural

Time is Rohrer's (2008) 4th dimension. Time needs consideration when selecting research methods depending the *phase* of the research, i.e.

- **Strategising**: considers new ideas and opportunities for the future; methods can vary greatly.
- **Optimising**: when a decision is made about what is/ is not

possible and why and the design direction chosen must be improved. In this phase, research is mainly formative and helps to reduce risk.

- **Assessing**: is the last stage, when the product or service (or prototype) will be available for use, where a measure of success can be gauged.

These are general guidelines to help researchers select the best choice at the right time and the success of the research is determined by how much impact it has on improving user experience. Table 3.4 tabulates the time dimension, the goals, typical research approaches and methods associated with each and the studies in which they were used.

Table 3.4 Rohrer's (2008) 3 *Time* dimension and 3 phases, adapted.

	Product or Service Development Phases		
	Strategise	**Optimise**	**Assess**
Goal	Inspire, explore and choose new directions and opportunities	Inform and optimise designs to reduce risk and improve usability	Measure performance
Approach	~~Quantitative~~ Qualitative	Mainly Qualitative (formative)	Mainly Quantitative (summative)
Typical methods	Interviews, family focus groups, possibly other methods	Participatory design, paper prototype, usability studies, desirability studies, customer emails	A/B testing, Quantitative evaluation with open questions.
How used	Studies 1, 2 and 3	Study 2 and 3	Study 3

In qualitative studies the data needs to be *naturalistic,* i.e. not reduced at the point of collection but a comprehensive record of participants' words and actions, to minimise what is lost in translation (Willig 2008:pp.15-16). However, one difficulty is such data volume can be difficult to manage and researchers have to wait whilst the data are reduced and be careful of what is left out, which is particularly important in the issue of *validity,* e.g.

measuring *familiarity* vs. *conformity* (see 3.9.2).

This advice guided the study design in different stages of the research and different methods used to gather attitudinal and behavioural data from different stakeholders to optimise the design concept. The first 2 Studies were used to strategise and defined the problem area; the 3rd combined the 3 phases using interviews and participatory techniques to refine elements refine and assess elements of the design concept.

Qualitative data gathering was used throughout the research with some quantitative data in study 3. Three methods were selected as most appropriate to the research:

- family focus groups (study 1, EMCs),
- individual semi-structured interviews (all the studies)
- structured interviews (study 3, beta-testing phase) with open questions and a few survey-type questions (evaluation, NHS staff).

These methods were selected based on the milieu of participant groups, to obtain appropriate data following the guidelines above and to follow an empathic approach. The characteristics of each method are described below: their advantages, disadvantages, guidelines and advice and the study in which these were applied.

3.6.2. Focus Groups

Focus groups are group interviews focussing on a particular topic and are time-efficient for qualitative data gathering (Robson 2002).

- **Advantages**: Focus groups are excellent for investigating a topic to generate new ideas, for using knowledgeable participants and obtaining data based on personal experience (Wood 1992). The data has higher *ecological validity* (less artificial setting) than interviews (Willig 2008). Robson (2002) agrees: there are many advantages - natural quality control by checks and balances of participants views on each-other's statements; group dynamics help focus and stimulate views; assessing shared views is quite easy; participants are empowered to comment and enjoy it; it is relatively cost-effective, flexible and inclusive of non-

literate persons or those with impediments and less-inhibited members help start responses on taboo subjects.

- **Disadvantages**: Although they offer insights, focus groups can be "notoriously unreliable and incomplete" relying on self-reports of attitudes or practices (Wasson 2000). Robson (2002:pp.284-285) adds: possibly fewer questions may be asked; skill is required to facilitate the process, to encourage quiet participants and avoid domination by a few, and to manage conflicts/power-struggles. Confidentiality may be a problem, the researcher may place unwarranted faith in findings, the results cannot be followed up or generalised as they cannot be regarded as representative of the wider-population. However, Robson (2002:p.177) concedes, citing Sim (1998), that data can provide theoretical insights and sufficient generalisation or universality "to allow projection to other contexts or situations".
- **The process**: Willig (2008) describes the process: researchers moderate, introduce members, provide guidance, questions, stimuli (photo, object), encourage all to participate, steer participants to discuss points raised, identify agreements/disagreements and set a time-limit. Focus groups mobilise participants by responding to each-others statements and help to address ways in which attitudes may be formed. Disclosure is not necessarily enhanced and questions need careful consideration to avoid distorted data. Six participants is the ideal group-size.

Family focus groups were selected for study 1 for the reasons described above and because the family environment nurtured more confidence for participants lacking English/ literacy or those unfamiliar with research. Group size varied from 3-6, confidentiality was not an issue, and responses were cross-referenced with those of other participants during analysis to minimise problems from taking data at face value and to consider generalisability.

3.6.3. Semi-structured Interviews

Semi-structured interviews are used widely in flexible qualitative research designs and have the potential of providing rich and illuminating data and one of the occasions of use is when exploratory work is required (Robson

2002:pp.271,273).

- **Advantages**: They allow researchers to gain a detailed view of participants' beliefs about, or perceptions or accounts of, a particular topic and to explore interesting avenues of information emerging from the interview to allow a better understanding of the picture (Smith 1995:pp.9-10,14). This method is particularly suited to topics which are complex, involve process, may be controversial or personal. It facilitates empathy and rapport, provides greater flexibility, is a means for exploring novel areas and can produce rich information.

  Robson (2002:pp.271-273) concurs, adding: a line of enquiry can be modified and interesting responses and motives investigated. They are compatible with several methods for data analysis and there are fewer logistical difficulties in organising them (Willig 2008:pp.23-24).
- **Disadvantages** include they can be time-consuming, non-verbal cues require considerable skill to be of profitable use, a lack of standardisation can raise questions about reliability and biases may occur (Robson 2002:pp.271-273). Less than 30-minute sessions are unlikely to be valuable, but participants may be reluctant to commit to more which can reduce the numbers willing to participate.

  Researchers can have a reduced control over the situation, the schedule can take longer and the data are more difficult to analyse (Smith 1995:p.15).
- **Guidelines:** Avoid over-running the stated time; good closure skills are important to gracefully disengage with over-eager participants; and as the researcher expects to gain something from the interview, it is not unreasonable for participants to also expect to gain something from the researcher (Robson 2002:pp.271-273). Smith (1995:pp.13-14) adds: the questions of interest to the researcher should be open, guided, but not dictated by a schedule and start with a general question. The researcher should attempt to enter into the participant's world by:
  - Building a rapport;
  - Asking neutral questions in a logical but sensitive and less rigid order;

- Probing interesting areas which emerge and exploring the participant's interests or concerns;
- Encouraging responses with minimal prompting;

Willig (2008:pp.24-25) agrees, adding:

- Maintain a balance between steering the interview to obtain the data required to answer the research question and allowing the participant to speak freely, openly and to redefine the topic to generate novel insights.
- Maximise understanding of what is being communicated by considering the effects of their own social identities (like gender, ethnicity, social class, nationality, age) on the participant.
- Familiarise with a participant's milieu (cultural environment, state of life and social surroundings), e.g. formal interviews may be appropriate for a professional rather than a teenager.
- Understand what the interview means to the participant to fully understand their contribution.
- Be aware of linguistic variability: try to understand the meaning, what the participant means to convey rather than how they said it.
- Be aware of the context of the words: 'a long time' may mean 20 minutes for a bus or months/years to buy a house.

Willig (2008:pp.24-25) adds that much depends on researcher-participant rapport which can be established quickly but disrupted easily when the interviewer's role becomes salient (such as changing a battery), or if the participant feels they revealed much about themselves. Thus, a sensitive ethical approach is required that does not abuse the informal ambience to encourage participants to reveal more than they feel comfortable with after the event.

Smith (1995:pp.10-12) adopts a theoretical stance midway between two extremes of participant responses, i.e.: factual information that may be verified independently and those governed by the participant wishing to perform a certain function like pleasing the interviewer or using jargon or phrases to appear an expert. The midway stance assumes that, whilst the

responses may not be transparent, they do have significance and a reality for the participant beyond the framework of the interview. Also, they do reflect a part of the participant's life experience, the' world outside', and their psychological constructs, the 'world inside', like beliefs, attitudes. It is also accepted that the meanings are negotiated within a social context.

Smith's (1995:pp.10-14) mid-way stance was adopted in this research. This guidance was put to good effect and semi-structured interviews were used extensively in all 3 studies to gather rich information: in study 1 to include single and widowed individuals and in studies 2 and 3 with NHS staff.

3.6.4. Structured Interviews and Questionnaires

Structured interviews have pre-determined questions, which are pre-specified with standardised wording, a few open-questions recorded to capture word-for-word responses and data are often pre-categorised for analysis (Robson 2002:pp.251,270).

Smith (1995:p11) states in order to enhance reliability the interviewer follows the interview schedule closely and behaves similarly in all interviews. The interviewer:

- Uses short specific questions
- Reads the questions exactly as on the schedule
- Asks the questions in the identical order
- Ideally, has pre-coded response categories enabling the questioner to match what the participant says against one of the categories

Interviews were more structured during beta-testing in study 3 (chapter 8) to maximise feedback in the time and to systematically cover the design elements to determine participant's preferences. The questions were very short, simple, neutral – but open. Participants' responses were captured on a survey type response capture form.

3.6.5. Encouraging Participant Responses

Prompts

Prompts are suggestions to participants and may be a list that is read out, or a prompt card which can be displayed, however, these must be used consistently with different participants and form part of the interview record

(Robson 2002:p.276).

Visual prompts were displayed in study 1 to help participants recollect, to add enjoyment (Dean 2002, Jordan 2004) and to lower language and literacy barriers. In study 3 visual-communication played a major role in the prototype design, these were displayed with alternative design choices.

Probes

Probes were used throughout the research project. Probes are a device to encourage participants to expand on a response, these may be short specific questions (like Anything more? What is your view on?), might involve tactics like a period of silence, an enquiring glance, saying 'mmmhmmm…', repeating back part of what had been said (Robson 2002:pp.76,275-276).

Willig (2008:p.25) agrees: employing participant's comments and incorporate these into further questions demonstrates to the participant that the researcher is listening, provides the researcher with an opportunity to check it was correctly understood, whilst also serving to maintain coherence and continuity throughout the interview.

3.6.6. Participatory Design

Participatory design is a research technique which involves end-users in the development of a service or product. Such research often focuses on user groups who are disenfranchised by conventional organisational and market research approaches, such as ethnic minorities, people who are economically disadvantaged, etc. (University of Cambridge, undated).

Participatory design is a task-centred, iterative design process which involves users throughout the process in a series of stages. Design is a "complex phenomenon which involves generating ideas, testing them, revising ideas, testing these, etc." and the designer should take the attitude that the users understand elements of the task best and the designer's job is to learn from them (Umiker-Sebeok and Gregson 1999). This is of fundamental importance: clients are equal partners and the designer must see end-users as the "knowledgeable people even if they are unable to articulate precisely what is required". They emphasise: Don't assume that you know, a researcher's competence lies in eliciting from users the insights needed to

design a usable product or service. They identify a series of important steps the design researcher follows:

- Considering the setting/ environment of the task
- How stakeholders would interact with the product/task and whether completing the interaction required any additional resources
- How stakeholders would be involved in the iterative process and whether 'top-down approach' (to assure the task will be in keeping with the goals) would be used and/or a 'bottoms-up approach' (users generate the ideas)
- Considering a name for the product/task, why it might be important to users and how/where it will be located, stored, accessed, etc.
- What constituted a successful outcome and how would stakeholders evaluate the effectiveness.
- Usability considerations include whether the task/product helps the users to achieve their objective; accuracy and ease of maintenance; how pleasing it would be to use (i.e. user experiences should be positive) and how would usability be measured (ease of learning, ease of use, error handling) (Umiker-Sebeok and Gregson 1999, adapted).

3.6.7. Designing inclusively: User capability and Culture

Discussing different design approaches aimed at improving user accessibility, Keates *et al* (2000) observed that these approaches were commonly divided into the design method used, e.g. *Rehabilitation design, Design by story-telling, Transgenerational design, Universal design, User pyramid design*. *Universal design* was a laudable approach; however, they questioned "how inclusive 'universal' really is" due to the great diversity of people and their capabilities and whether it was likely that a single product could be accessible by everyone. The *user pyramid design approach* (proposed by Benktzon 1993) reflected a wide range of user capabilities in 3 broad categories: able-bodied/fully capable (base of the pyramid); reduced strength/mobility (middle layer); and the severely impaired (the peak). It claimed that products designed to be accessible by people in a particular layer would also be accessible by those in other layers, i.e. that products can

reach across boundaries of capability. This prompted a re-think of inclusive design although some of the filtered-down designs could be sub-optimal for more capable users. Keates *et al* (2000) suggested that complete population coverage could be achieved through a methodological design approach to implementing inclusive design and described a model, the Inclusive Design Cube (IDC), that illustrated how the different approaches are complementary.

This methodology required a strongly user-centred design approach, with iterative improvements and usability evaluations which, typically, involved measurement against known performance criteria of users' perceptions, cognition and motor actions (sensory, cognitive and motor capabilities). The solution development phase (stage 2 of 3) of the design process was expanded to include these 3 levels and Figures 3.5-3.7 illustrate the IDC approach and the difference in population coverage when applying the expanded 5-level approach.

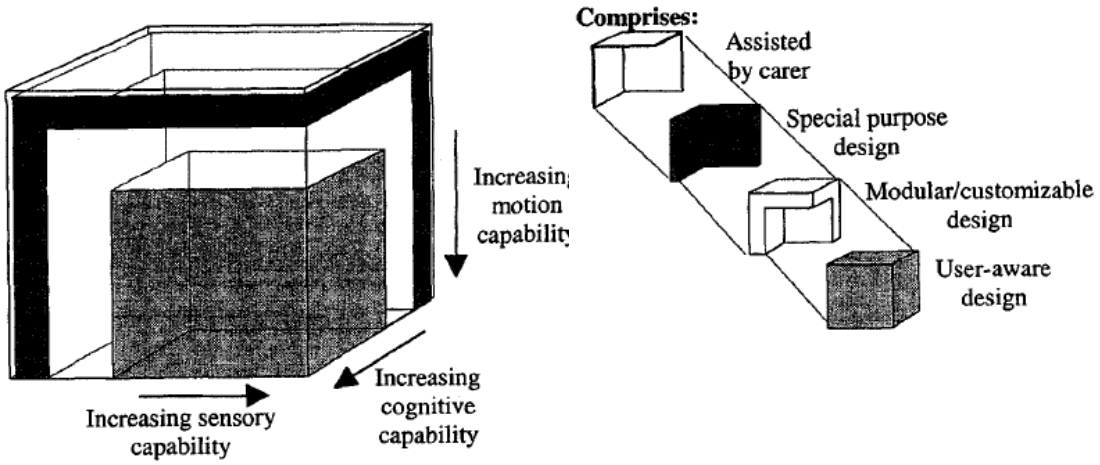

Figure 3.5 The IDC brings the different design approaches together (Keates *et al* 2000)

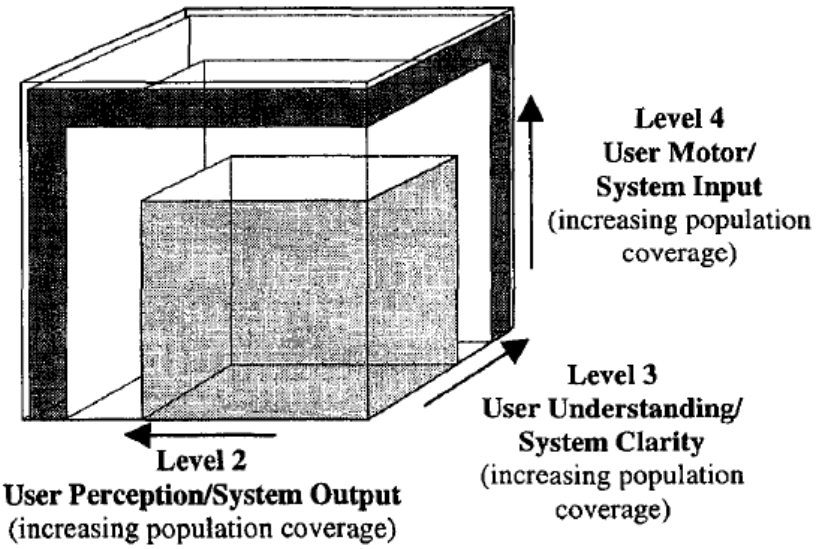

Figure 3.6 The IDC illustrating a greater population coverage through the 5-level approach (Keates *et al* 2000)

Reaching the widest range of users by combining:

- Three Sensory factors: Visual symbolic feedback (shapes, colours, icons and sign language); Visual textual feedback(written text) and Audio feedback
- Cognition (understanding and interpretation)
- User input comfort/Usability

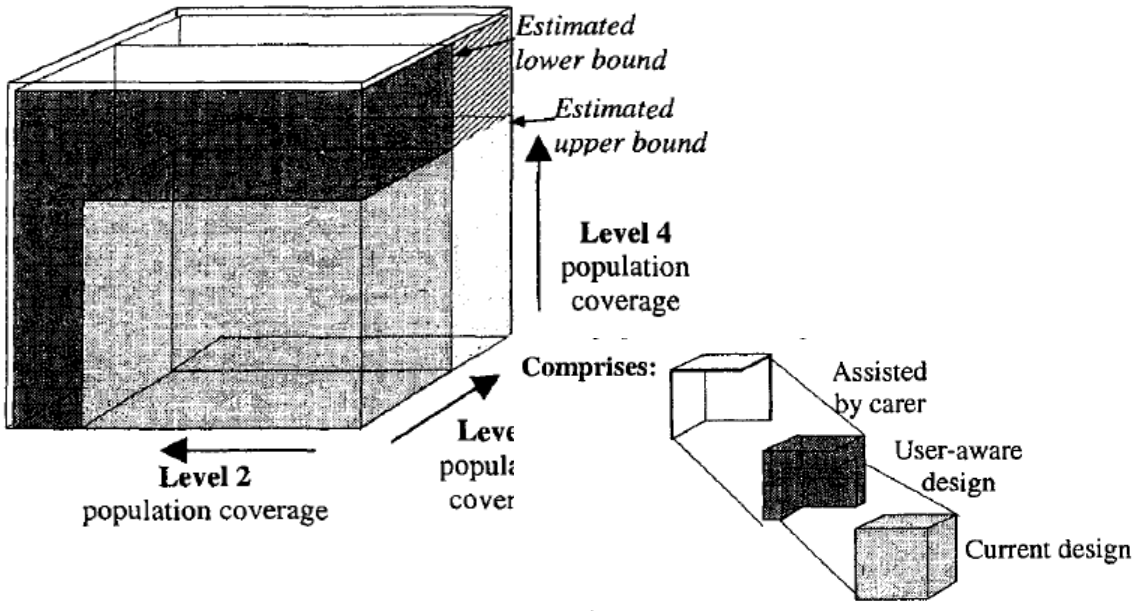

Figure 3.7 The IDC illustrating how a current design was extended to increase the population coverage (Keates *et al* 2000)

In considering products designed for elderly people in Thailand, Israsena and Boonvong (2009) extended the IDC model to the Inclusive *Incapability-Culture-Economy* (I.C.E.) model which incorporates users' cultural specificity and economic limitations (Figure 3.8).

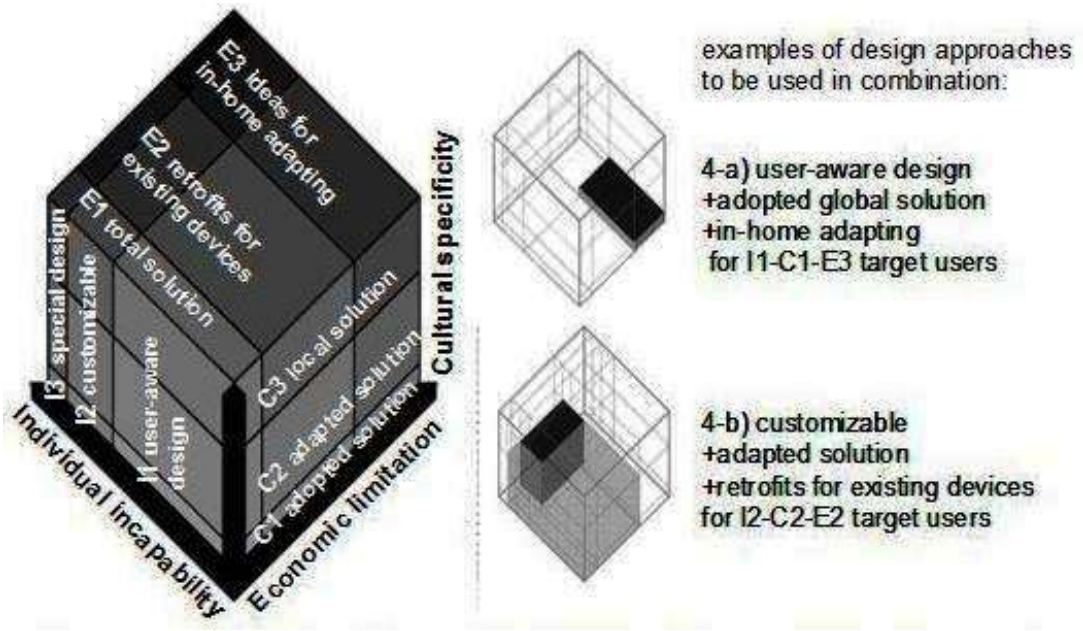

Figure 3.8 The ICE model extended the IDC model: cultural adaptations and economic limitations (Israsena and Boonvong 2009)

The *economic axis* represented 3 levels of users' purchasing power (E1 high, E2 to low, and E3 to none). Products that were designed creatively for users with low purchasing power, enabled them to adapt household items or environments themselves to different purposes without a financial barrier. For users with higher purchasing power, low-cost retrofits designed for existing devices could provide greater value from a smaller investment and extend the life of existing equipment. These design solutions, whilst essential for low-income users, were received well by users with higher incomes. Finally, total design solutions (redesigning or creating a new product class), or more efficient solutions, suited users with even higher purchasing power (Israsena and Boonvong 2009).

The *cultural axis* represented users' "lifestyle practice, customs, preference, information processing, and environmental arrangement" at 3 levels of cultural specificity: global culture (C1, whole population), blended culture

(C2), local culture (C3). Designs for local culture focussed on specific cultural practice/customs to suit specific needs and were not suited for the whole global population whereas adapted solutions enabled a product (or service) concept to accommodate a wider range of users *within* different cultures. A global product concept would produce solutions which appealed to a wide range of users in the global culture.

Israsena and Boonvong (2009) stated that optimising design inclusion required design approaches in the three dimensions of the I.C.E. to be used in combination. They noted that design solutions/approaches for users with reduced capability were also liked by fully capable users; designs for users in blended culture were also acceptable in global culture and those for low-income users were applicable for high-income users as well. When design solutions for no-income users were well executed, these could be preferred by higher income users, also. However, solutions/approaches for disabled users or for local culture were so specific that they were usually not applicable for other user groups.

These guidelines on data gathering, participatory design and designing more inclusively were very helpful in planning study 3. It was possible to design more inclusively for users' capabilities through considering a 5-level methodological approach to include users' sensory, cognitive and motor capabilities (Keates *et al* 2000) and cultural specificity and economic limitations (Israsena and Boonvong 2009).

However, for EMCs resident in host countries the context of 'local culture' altered from that in home countries: i.e. local culture was the host culture (opposite to home countries). In this context, perhaps the term 'cultural specificity' became appropriate and, rather than being too local and not applicable to other user groups, designing around EMC cultural specificity in host countries (e.g. sampling cuisines, attending a dance performance, purchasing an artefact, etc.) offered interesting and desirable experiences to many amongst the indigenous public (host culture).

Guidelines for data collation, coding, and analysis was reviewed next.

3.7. Data Coding and Analysis

3.7.1. Data capture

Willig (2008) states full data-analysis requires recording and transcription and notes are no substitutes, interfering with eye contact and communication, however, Robson (2002:pp.273-4) disagrees and suggests that note-taking and transcription are both valid. Careful preparation, allowing time for transcription (multiply recorded time by a factor of 10 for transcription time) and subsequent analysis were crucial for success in real-world enquiries.

Data were recorded in studies 2 and 3 and note-taking employed in study 1 as initial recordings of family focus groups proved jumbled and distorted due to participants' unfamiliarity with research, the intervention of children, use of different languages etc. (This will be explained further in chapter 4).

3.7.2. Data Transcription

Strauss and Corbin (1990:pp.30-31) discussing 'Is it necessary to transcribe all of your field interviews or fieldnotes?' state the general rule is to transcribe only as much as is needed, albeit, that is not an easy decision and cannot be made sensibly until one is well into the study. This does not imply only transcribing the first few interviews, rather to transcribing selectively. Generally, the first interviews should be entirely transcribed, before the next interviews, and this early coding will provide guidance to the next interviews. As interviews progress interview recordings or notes may be transcribed selectively – those sentences, passages, or paragraphs that relate to the evolving theory. They conclude by advising that all the recordings are listened to, for a full and varied analysis, and 'better more than less'. Robson (2002:p.171) agrees that it is not necessary to transcribe all the data.

This research did not aim to build a theory and all the data was transcribed from recordings and field notes to ensure different emerging themes could be captured to gain a holistic understanding. Data were subjected to thematic analysis in study 1 (EMCs, Indian Subcontinent) and a thematic framework based analysis in study 2 (NHS Staff).

3.7.3. Thematic Analysis

Thematic analysis is a flexible method for organising and describing data in

rich detail and is beneficial for reporting the experiences and the reality of participants (Braun and Clarke 2006). Aronson (1994) concurs adding that ideas that emerge from interviews or other methods can be better understood because through identifiable themes and patterns. He defines *themes* as units derived from conversation topics, vocabulary, recurring activities, meanings, feelings, etc. which are created by gathering the components or fragments of ideas or experiences which can be meaningless when viewed alone. The

> *"Coherence of ideas rests with the analyst who has rigorously studied how different ideas or components fit together in a meaningful way when linked together" (Aronson 1994)*

Thematic analysis can be undertaken manually or using software programs like *Nvivo.*

Thematic analysis requires the researcher to become familiar with the data in a recursive process by repeatedly moving back and forth across the data throughout data collation and analysis to understand and identify repeated patterns of meanings (Braun and Clarke 2006).

Data are typically analysed in 3 main steps: reduction, display and drawing conclusions and verification (Miles and Huberman 1994). *Data reduction* is achieved through *coding,* and *display* re-organises codes to form *categories.* Borrowing guidance from grounded theory:

- *Coding:* Collated data (events, process, occurrences) are marked with a series of *codes* (*labels*, words, phrases) which are *descriptive* in the early stages and words or phrases used by the participants should be used, i.e. *in vivo* (Willig 2008:pp.35-37):
- *Categories*: Data which share central features are grouped together to form *categories* which can function as *descriptive labels* or *concepts,* (Strauss and Corbin 1990:p.61), e.g. stress, anger, anxiety can be grouped as *emotion.*

Significantly, Dey (1999:p.93) suggests that both *descriptive* and *analytic* categories are based on relations of similarity and difference and *data can be allocated to more than one category.*

Table 3.5 sets out the process borrowed from an inductive approach in study 1, Chapter 4 and following guidance from Charmaz (1995:p37) data were coded line by line to build the analysis from ground up.

Table 3.5 Thematic analysis process followed study 1.

	(In Word 2007)
Familiarisation	Data were transcribed, collated and reviewed recursively to identify and understand patterns, meanings and relationships. Data gathering continued until nothing new was learned, i.e. data were *saturated.*
Analysis **Open coding**	As research progressed, collated data were marked with *descriptive codes* (words or phrases) often those used by the participants, i.e. *in vivo*. These were broad in these early stages to avoid making assumptions too early in the process.
Refining Coding:	Coding was refined recursively and analytic and interpretive coding added.
Categories and concepts	Codes were gathered, codes sharing central features were grouped into *categories* and sub-categories which functioned as *descriptive labels* or *concepts.*
	(In Excel 2007)
Themes	Codes were clustered and re-organised to identify patterns and emerging themes.
Review	Themes were reviewed, any negative case identified and the themes checked against coded extracts to refine, combine, separate or discard.
Interpretation	Emerging themes were interpreted in the context of the research questions; examined in the light of the findings in the literature to identify similarities or differences; the possible reasons for differences, variations and new data were considered.
Results and Conclusions	How the themes may inform the next stage of the research was determined and literature review 2 was undertaken.

Willig (2008:p.46) points out that whatever emerges from analysis is guided by the questions asked by the researcher and it is debatable whether categories emerge from the data, citing Dey, that the categories we discover depend on what we are looking for.

For critically judging the applicability of emerging themes to the phenomenon

guidance was borrowed from Strauss and Corbin (1990:p.23) and adapted to the research, i.e. *themes* were used in place of *theory*. They suggest using four criteria to judge the applicability:

1. **Fit:** The themes should be faithful to the everyday reality of the chosen area and carefully extracted from diverse data, then themes should *fit* that area (reality);
2. **Understanding**: Themes should make sense to the persons in that study as well as those practising in the area;
3. **Generality:** the data on which the results are based should be sufficiently comprehensive and the interpretations conceptual and broad to enable themes to be abstract enough with sufficient variation to make these applicable in a variety of contexts (this is discussed further in 3.12).
4. **Control:** Themes and results should provide control in the context of the next action towards the phenomenon.

These techniques were designed to stop researchers rushing past valuable data and encourages thinking to be steered outside of literature, experience and standard ways of thinking about phenomena so that thinking about the data are stimulated, allows clarifications, discards assumptions, considers meanings, asks questions, considers provisional answers and engenders productive (although provisional) labelling and discoveries of dimensions or properties (Strauss and Corbin 1990:p.23).

3.7.4. Framework based Analysis

Framework based analysis was used in study 2 with NHS staff. It is a hierarchical thematic framework that is used to classify and organise data according to key themes, concepts and emergent categories using charts to examine the data for patterns and connections (QDA 2011). Framework analysis was developed by two qualitative researchers, Jane Ritchie and Liz Spencer in 1994, from the UK's Social and Community Planning Research Institute in London.

It is quite similar to grounded theory approach, however, it differs in that it is better adapted to research that has specific questions, a limited time frame, a pre-designed sample (e.g. professional participants) and *a priori* issues (e.g. organisational or integration issues) that need to be addressed (Srivastava

and Thomson 2009). Framework analysis has also been used in a multitude of settings, including healthcare. The prime concern is to describe and interpret what is happening in a particular setting. (Applied policy) Research attempts to address 4 objectives:

- Contextual: Identify the form and nature of what exists
- Diagnostic: Examine the reasons for, or causes of, what exists
- Evaluative: Appraise the effectiveness of what exists
- Strategic: Identify new actions (or theories, policies or plans)

(Srivastava and Thomson 2009)

Barnard (2010) of the National Centre for Social Research describes framework analysis as a data management tool which aims to organise the data to facilitate interpretation. Interpretation is not dependent on the framework but some interpretation is facilitated by it. It can be used within a study or between studies. The primary objective is to bring together bits of data gathered during a 'fractured discourse' like discussions or semi- or unstructured interviews, i.e. data that are at the beginning, middle or the end of a transcript but all relating to a single subject, also to 'chunk' things by grouping data into small pieces to allow it to be handled better. The secondary aim is to reduce and prioritise data and to create a 'map' of the data so when you do your interpretation you know where to find the data relevant to that interpretation. In a theme-based approach, data are categorised into emerging themes.

Srivastava and Thomson (2009) identify 5 steps to the process:

- **Familiarisation**: the researcher becomes immersed in the data
- **Identifying a thematic framework**: This is based on using themes emerging from the data (which may include an *a priori* theme, however, data must not be forced into any *a priori* theme). Devising and refining a thematic framework involves logical and intuitive thinking, making judgments about meaning, relevance, importance of issues, implicit connections between ideas. Also, that the original research questions are being addressed.
- **Indexing** is charting the important bits of data (this can be a numerical system).

- **Charting** involves arranging the specific pieces of data that were indexed in the previous stage in charts of the themes. This means that the data are extracted from their original textual context and placed in charts under appropriate themes or sub-themes drawn from the thematic framework. Importantly, although the data are lifted from its original context it is clearly identifiable as to where it came from.
- **Mapping and interpretation**: involves the analysis of the key characteristics as laid out in the charts. It is at this point that the researcher is cognisant of the objectives of qualitative analysis: to define concepts, map range and nature of phenomena, create typologies, find associations, providing explanations and developing strategies (citing Ritchie and Spencer 1994).

The key differences between a thematic and framework based analyses lie in coding. In thematic analysis, transcribed data are coded, the codes are refined and grouped under themes (study 1). In framework based analyses, data are grouped (chunked) under themes from the outset (during transcription) and data are extracted and organised under themes in formats like spreadsheets (study 2), i.e. codes are not added.

Framework analysis was used in study 2: with NHS staff (a pre-designed sample) because it offered a robust approach within a limited time-frame, the questions were pre-determined and the study wished to investigate whether language or other barriers hindered healthcare delivery to patients lacking English. (Communication difficulties were cited by EMC participants in study 1). Whilst there was no focus on policy or strategy, the 4 objectives and how to inform the next study and to consider explanations for phenomena, resonated well with aims of study 2.

3.8. Research Validity and Transferability

It is important for researchers to demonstrate objectivity and rigour in the research process and this requires theoretical sensitivity and a consideration of reliability, validity and reflexivity which are described below using the terms used in the literature cited. Willig (2008:pp.23-24) emphasises the importance of reflecting on the meaning and experience and not assuming

participant's words are 'simple and direct reflections of their thoughts'.

However, Robson (2002:p.170) notes that Lincoln and Guba avoid terms like reliability and validity and prefer to use *credibility, transferability, dependability and confirmability.* An alternative tack is to focus on the credibility or trustworthiness of the research.

Theoretical sensitivity is the ability to recognise what is important in data and to give it meaning and this depends on the personal qualities which sensitise the researcher to subtleties of meaning (Strauss and Corbin 1990:pp.41-47). Sensitivity can be developed through reading the literature, previous professional experience (practise in a field), personal experience and during the research process through the analytic process.

"Good science is produced through this interplay of creativeness and the skills acquired through training."

Strauss and Corbin (1990:pp.41-47) urge researchers to maintain a balance between creativity and science:

- Periodically step back and ask: What is going on here? Whether what one thinks fits the reality of the data because the data themselves do not lie;
- Maintain an attitude of scepticism: all theoretical explanations or categories whether from comparisons, the literature or experience need to be checked against the data;
- Follow research procedures to give rigour to the study, to help break through biases and to re-examine any assumptions.
- Remember that (citing Rapport and Wright 1964)

  "Chance is never the predominant factor in discovery […] Pasteur's famous statement [was] that chance favors only the prepared mind" (Strauss and Corbin 1990:p.46).

Reflexivity: Because researchers influence and shape the research process in qualitative research, both as individuals and as a theorist/thinker, *reflexivity* ensures the entire research process is scrutinised to review their own role in the research to discourage "impositions of meaning by

the researcher" and to promote validity (Willig 2008:pp.16,18).

Thus, *personal* and *epistemological reflexivity* consider the ways in which the researcher influences the research and its findings which invites a reflection of one's personal biases and how one's reactions to the research context and findings make possible the insights and understandings gained. Although there is no set format, reflexive considerations can be integrated into the report context wherever relevant (Willig 2008:pp.16,18). Reflexivity was integrated in each study at its conclusion.

Validity can be defined as "the extent to which our research describes, measures or explains what it aims to describe, measure or explain" (Willig 2008:p16). Is the data collection and analysis addressing the question to which an answer is sought? The ways of addressing this concern in qualitative data collection include:

- Participants are free to challenge or correct the assumptions of researchers or the 'meaning and reliance of concepts and categories'. Feedback of participants' views of the study's findings can be sought, *participation validation,* which if in accord must provide some validity.
- Data gathering takes place in real-life settings, providing *ecological validity,* i.e. the real world.
- By addressing *reflexivity* (Willig 2008:p16).

Robson (2002:p.171-172) identifies 3 main threats to validity.

- Description: Whether the description is accurate and complete (which requires audio-recording or good quality note-taking).
- Interpretation: Imposing a framework on what is happening rather than this emerging from the data.
- Theory*:* Not considering alternative explanations.

Willing (2008:pp.23-24) is critical that data are taken at face-value and many contextual features did not receive adequate attention.

Reliability. For Willig (2008:p.17), reliability is less important in qualitative research which aims to explores a (possibly unique) phenomenon/ experience in detail (than in quantitative research). However,

appropriate and rigorous application of qualitative methods ought to generate results that are reliable and other researchers using the same method ought to be able to generate the same findings. However, there is disagreement on this point amongst qualitative researchers. Robson (2002:p.170) notes that Morse (1999) forcefully denies that reliability is less pertinent to qualitative research, but agrees that rigour in research leads to reliability and validity.

Generalisability refers to the extent to which findings are more generally applicable in other contexts, situations, times, or other persons than those directly involved (Robson 2002:p.100).

This refers us to sampling (see 3.5): Robson (2002:p.177) concedes that data can provide theoretical insights and sufficient generalisation or universality " to allow projection to other contexts or situations" (also see 3.6.2. Disadvantages). Also, Willig (2008:p.17) states: it can be argued if a *"given experience is possible, it is also subject to universalisation"* because we know the experience identified it is available within a culture or society even if the numbers of people sharing it are unknown. Thus, if participants' experiences are at least 'partially socially constituted' then 'each individual mode of appropriation of the social...is potentially generalisable'.

It was not possible to achieve validity through the participants' reading transcripts as participants lacked time. However, findings from study 1 were used to successfully recruit EMCs participants for study 3. Findings from study 2 were compared with literature which informed the selection of topics in study 3 and helped to recruit NHS staff. Findings were discussed with and presented to colleagues and all the data were transcribed and analysed thematically (themes being added as they emerged). Reliability was addressed by closely following methods guided by literature. At the end of each study chapter, the researcher reflected on validity, reliability and reflexivity. Ethical process was the final, important aspect of conducting this research, with EMCs, NHS staff and indigenous elderly.

3.9. Ethics

Ethics are the moral principles or rules of conduct (OED 1976) within which an activity is framed and applies to the treatment of research participants, protecting participants from any harm, loss, indignity and preserving their psychological wellbeing (Willig 2008:p.19). Procedures include:

- Informed consent prior to data collection
- No deception
- Right to withdraw without fear or penalisation
- Debriefing: participants are informed about the aim of the study after data collection and, ideally, have access to publications arising from the study.
- Confidentiality: should be maintained about information acquired about participants (Willig 2008:p.19).

Some maintain that ethics in qualitative research is much wider: Van Dijk proposed that when critical science starts from a prevailing social problem and examines the perspectives of those suffering, then researchers should aim to deliver positive benefits to participants (Willig 2008:p.19-20). Ethics is more than following rules or solving concerns once as ethical dilemmas can arise throughout a study. Willig advises researchers to develop an 'ethical research behaviour' and develop the 'ability to sense, judge and act in an ethically committed manner'.

Other issues can arise with participants: expectations or feelings the researcher is not equipped to deal with, or research reports offering interpretations of the interview that does not accord with the participant's own understanding and researchers must take care to avoid 'faking friendship' in order to gain information (Willig 2008:p.20). The researcher may discover serious cases of illegality or concern for the wellbeing of other persons in the data revealed by the participant, in which cases the requirement to report over-rides any confidentiality agreements (Robson 2002:pp.70-71).

Stringent ethical procedures were followed throughout the research and additional NHS procedures were followed during studies 2 and 3.

3.10. Discussion

The advice and guidance from this literature provided an invaluable framework for conducting this research project and highlighting the considerations and responsibilities of design researchers.

Research followed a broadly qualitative, inductive approach to gather rich data followed by (manual) thematic analysis throughout. Although some *Nvivo* training was undertaken, it was not possible to use it due to a combination of difficulties (distance from campus, pressures on accessing computers running *Nvivo,* the dedicated time required for data loading and analysis and family responsibilities).

Study-1 was an investigative study which used family focus groups and individual interviews to elicit data from EMC participants and the methodology used is described in the next chapter.

All the interviews and family focus groups were conducted in naturalistic settings and participants were always assured that there were no right/ wrong answers and data would be anonymised to encourage them to speak freely and to minimise bias towards sounding 'good'.

Literature reviews were undertaken prior to studies following to inform and extend the theoretical framework for each study.

The author played different roles as research progressed. '**Investigator'** dominated the first 2 studies and was an iterative one in study 3.That of '**facilitator'** dominated study 3 and also involved comparing findings from the first 2 studies with the literature, selecting and researching the topics (pain and medication) for study 3 and collating the content due to time constraints (staff and the author) and a lack of domain knowledge (EMCs, indigenous participants). '**Designer'** involved designing the research framework and the studies but dominated study 3 in collating views, developing the prototypes and following iterative design testing and evaluation. The author played the role of '**critic'** throughout the research in reflecting on validity and reflexivity and dominated chapter 9, in critically reviewing the entire research project.

3.11. Overall Methodology and Scheduling

Figure 3.9 depicts the stages of the research project and the scheduling. This project commenced in October 2008 and, together with this thesis was completed by September 2012. This included two phases for gaining NHS Research Ethical approvals and permissions which required applications, a research proposal and reports for the NHS.

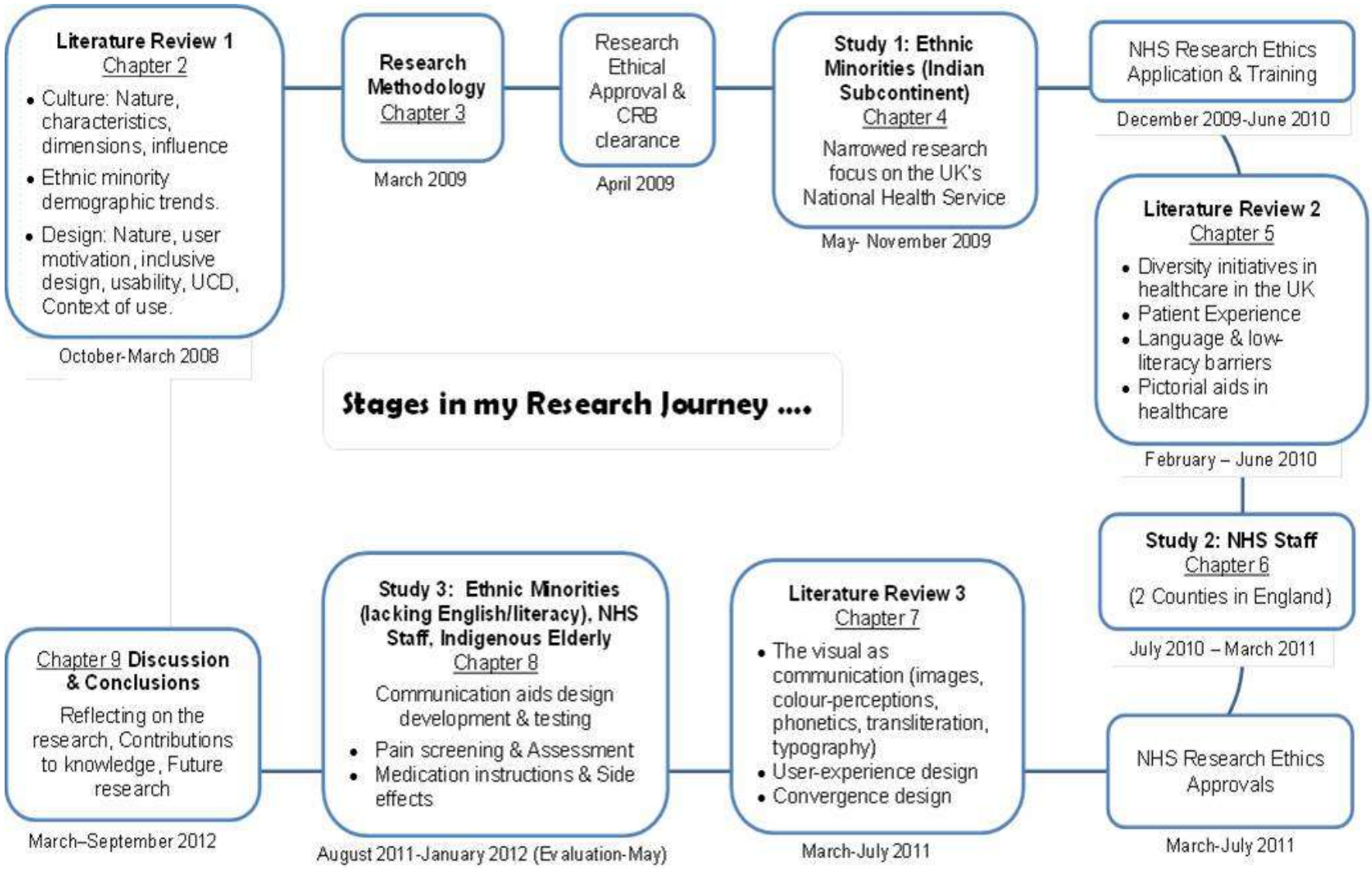

Figure 3.9 Overall research methodology and scheduling

4. The UK's Services and Products: EMCs' Perceptions

This chapter describes the first user study with EMCs from the Indian Subcontinent (Figure 4.1) which addressed the overall research objective 4 that enabled research question 1 to be answered. It sets out the methodology used, the findings that narrowed the research focus to the UK's National Health Service and a discussion of the findings.

RQ1	Did EMCs (Indian Subcontinent) perceive that any barriers hindered their take-up of products or services in the UK? If present, what was the nature of the barriers and who did these affect?	**Study 1: Investigative** EMCs (Indian Subcontinent) (Chapter 4 - Aim 1)
Obj:4	To commence research with an investigative study to ascertain and understand EMCs' perceptions of any barriers they experience in accessing or using services or products in the UK, and their preferences. From these results, to narrow the research focus to a particular service or product provider.	

Figure 4.1 identifies the first user study with EMCs.

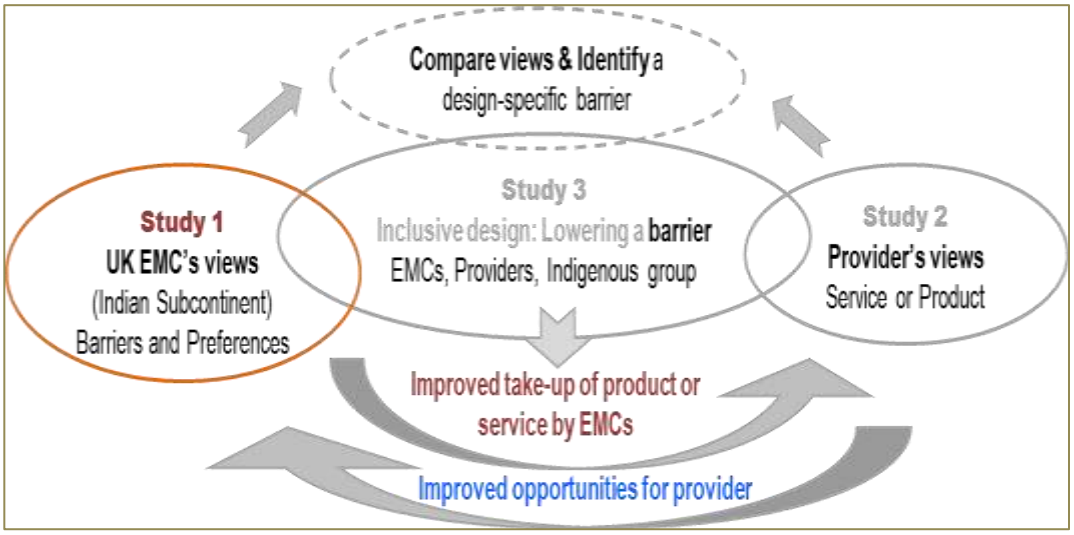

Figure 4.1 User-study 1

4.1. Introduction

Literature review 1 provided the theoretical concepts that laid the foundation for this study and the research project and a pathway to better understanding the phenomena researched in this project. They defined culture for the purpose of this research, explored its ever-evolving nature and the characteristics and dimensions that influence people and communities. They set out the relationship between cultural consumption and services and products and how the success (or otherwise) of these interactions governs peoples' everyday activities and, thus, their wellbeing.

UK residents with origins in the Indian Sub-continent (i.e. Pakistan, India, Bangladesh, Sri Lanka or Nepal, Figure 4.2) were selected as the study group. A region was selected rather than a country based on literature which rejects using country as a definition for culture (Jylha 2007, Boztepe 2007) and sampling was fashioned around the region where people have much in common by way of religions, culture, languages and history.

Figure 4.2 Indian Subcontinent (Freemap 2009, edited)

4.2. Aims and Research Questions

This study had two aims:

1. To investigate whether EMCs (Indian Subcontinent) felt any barriers, particularly cultural, hindered their take-up of products or services in the UK, and what their preferences were.
2. If there were any barriers, to narrow research down to a service or product provider to investigate the problem from the providers' perspective.

These aims were addressed by finding answers to the following research questions:

RQ.1. How were EMCs (Indian subcontinent) fairing in the current consumer market? Did they feel they faced barriers in the take-up of services or products in the UK that needed investigating?

RQ.2. If barriers existed, what was their nature and whom did they affect?

RQ.3. How acculturated were participants? Was there a need to approach them differently to promote services or products?

RQ.4. Upon which service or product should the research focus be narrowed to investigate the problem to gain an improved understanding of problems?

The service or product selected for further investigation would be selected from the difficulties cited by participants.

4.3. Methodology

An inductive, qualitative approach was used to gather rich data about participant's perceptions and experiences (Robson 2002, Willig 2008) from family focus groups and some individual interviews to include widowed and single persons.

Subgroups were defined as *religions* and *generations* (Burton 2002) to determine the differences and similarities of views. As wide a range of users as possible were approached to gain a holistic understanding (Evans *et al* 2002, Black 2008). Observing potential participants in public places and places of worship, suggested that the study could include people with a wide

range of skills and knowledge and that some elderly people lacked English and possibly literacy.

4.3.1. Methods

Family focus groups were selected as an inclusive, empathic method to capture the *murmur of customers* (Evans *et al* 2002) to reassure elderly people, participants who might lack English and/or literacy and those unfamiliar with research as well as aiding translation. Figure 4.3 depicts the flexible, scalable data-gathering concept used

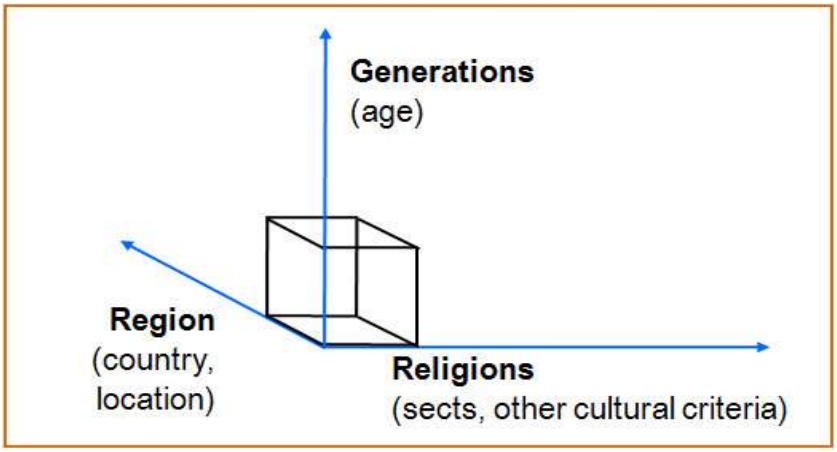

Figure 4.3 A flexible, scalable concept used for data-gathering.

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4.3.2. Sampling strategy

Sampling was purposive and aimed for 40 people from five major religions identified from the national websites on the Indian Subcontinent: Christianity, Sikhism, Hinduism, Islam and Buddhism. Sampling was also guided by the fact that EMCs (Indian Sub-continent) had settled in the UK since the 1960's which enabled a comparison of inter-generational views and acculturation. The author's background (raised in India, spoke Hindi, Punjabi and Urdu) could contribute to establishing rapport, aid with translations and in data interpretation.

4.3.3. Ethical Considerations

Loughborough University's research ethical approval was gained and a Criminal Records Bureau police clearance to visit participants' homes if invited and to work with vulnerable participants (elderly people and teenagers

in family focus groups). Ethics documents (Combined Letter of Invitation and Participant Information and Informed Consent, Appendix-E1-E2) set out the purpose and conduct of the study and confirmed participation was voluntary, there were no right/ wrong answers and no preparation was required. Participants were assured of anonymity, confidentiality and freedom to withdraw from the study at any time. There was little potential for harm or distress as they either spoke English or were with family and were offered comfort breaks and refreshments.

4.3.4. Tools

Four tools were prepared and Table 4.1 sets out the tools to help gather data, their purpose, sources of inspiration and the order in which they were used.

Table 4.1 The order in which the tools were used in study 1

Tools, Description	Purpose	Compilation/ Inspiration
Handed out with Participant information		
1. Services and Product Attributes lists	The 3 most/ least important attributes (self-selection, multiple choice)	Total Product (Masterson and Pickton 2004); Quality-in-Use (Usability 2006), Maslow's hierarchy (Thorson 2006)
Family Focus Groups and Interviews		
2. Discussion Questions Products Services	Identify difficulties and Preferences	Brainstorming Burton (2002), Capturing 'the murmur' of consumers (Evans *et al* 2002), Emslie *et al* (2007), Rohrer (2008)
3. **Visual Prompts** Service/ Product categories	Memory aid, focus, 'delighter' attribute	Empathic process (Evans *et al* 2002)
4. **Background** Questionnaire	Context, Background, Acculturation	Thomas and Bevan (1995); Robson (2002); Kunievsky (2003); Ngo (2008)

4.3.4.1. Attributes Lists

Two open lists of service and product attributes were compiled based on literature (Table 4.1, Appendix-B1). Participants were asked to select the 3

most and 3 least important attributes that influenced their choices when deciding to use a service or purchase a product.

4.3.4.2. Discussion Questions

These questions were simple and avoided any jargon (e.g. white goods) to be easily understood and easily translatable (Appendix-B2). Questions were open with some closed questions in the questionnaire to capture background, context and to reveal commonalities of use (Robson 2002; Kunievsky 2003:p.160-63; Willig 2008).

Questions for services and products were almost identical and arranged in two sections: Difficulties and Preferences. Participants' were asked about their experiences over the past 3 years in the UK and 'back home'. The first two questions under 'Difficulties' were consecutively to allow for some 3rd generation participants who might have little/ no experience of services or products 'back home' (which became evident as the research progressed).

Difficulties

- Easier 'back home'
- Difficulties in the UK
- Unavailable/ Missing in the UK
- Never used categories (Rohrer 2008)
- Culturally important

Preferences

- Favourite
- Most useful
- Most enjoyable
- Made them feel 'special' (status)
- Aspirations

Probes were used (Figure 4.4) and 2 questions were added as data gathering progressed, prompted by participants' responses:

- How did a family member who lacked English manage daily activities like needing medical attention, shopping, understanding instructions on packages and appliances, etc.?
- Did participants feel images might aid those with poor English or literacy skills?

What was/ is the problem?
Was it purchased or a gift?
Who purchased it/ gave it to you?
What was the occasion?
From where was it purchased?
How often do you use it?
Was the problem solved? *Yes*: How? *No*: What would you have liked done about it?

Figure 4.4 Probes

4.3.4.3. Prompts: Visual aids

Visual prompts (Appendix-B3) were used with the questions to focus the discussions and as memory aids. Images were grouped in service and product categories based every-day living areas. The categories were arrived at through brainstorming and consultation with colleagues.

Images were collated in Adobe Photoshop from web research and brainstorming to include a well-balanced range. Each category was designed in non-leading mosaics and care was taken to avoid brand identity aside from vehicle recovery firms. Cartoons were added for enjoyment (Jordan 2004; Dean 2002). These designs were printed in A4 formats using Word 2007.

Services were organised in 3 categories with a general list with further suggestions:

- **Government services**: Social services, Police, Hospitals, GPs, Dentists, Mobility centres, Education, Job centres, etc. (Figure 4.5).
- **Shopping**: Traditional and Local stores, Supermarkets, Online (internet) shopping, Catalogues, Designer stores and Market stalls.
- **Travel**: Hotels, airlines, buses, trains, ferries, vehicle recovery.
- **Open list**: Banking Services, Health and Fitness, Events, etc.

Figure 4.5 Services visual prompt: Government Services (non-leading mosaics).

Products (Figure 4.6) were compiled in 9 categories followed by a list which offered more suggestions:

1. Kitchen and Domestic equipment
2. Computers, software and accessories
3. Cameras, phones and personal media
4. Home entertainment systems
5. Car, accessories/ appliances
6. DIY tools/ equipment
7. Gardening tools/ equipment
8. Medical/ Health appliances/equipment

(Food and apparel were excluded to avoid distorting the research focus due to well-known differences.)

Figure 4.6 Product categories visual prompts: Computers; Cameras and personal media; Kitchen and domestic appliances.

4.3.4.4. Background questionnaire

A self-fill questionnaire (Appendix-B4) was designed to capture participants' background and context. Questions were mainly open, some were closed with one Likert 5-point scale and covered the following aspects: country of birth, education, community of origin, English and other language skills, preferred modes of purchasing, festivals celebrated, driving, age range, occupation, the best and the least liked aspects of living in the UK, etc.

A 'Festivals List' (Appendix-B4.42) was compiled as a memory aid. It included the main religious festivals of the five faiths, UK's religious and social festivals and those of other faiths (researched from the 5 national official Country websites and websites from the UK).

Figure 4.7 depicts how the tools were used in the study design.

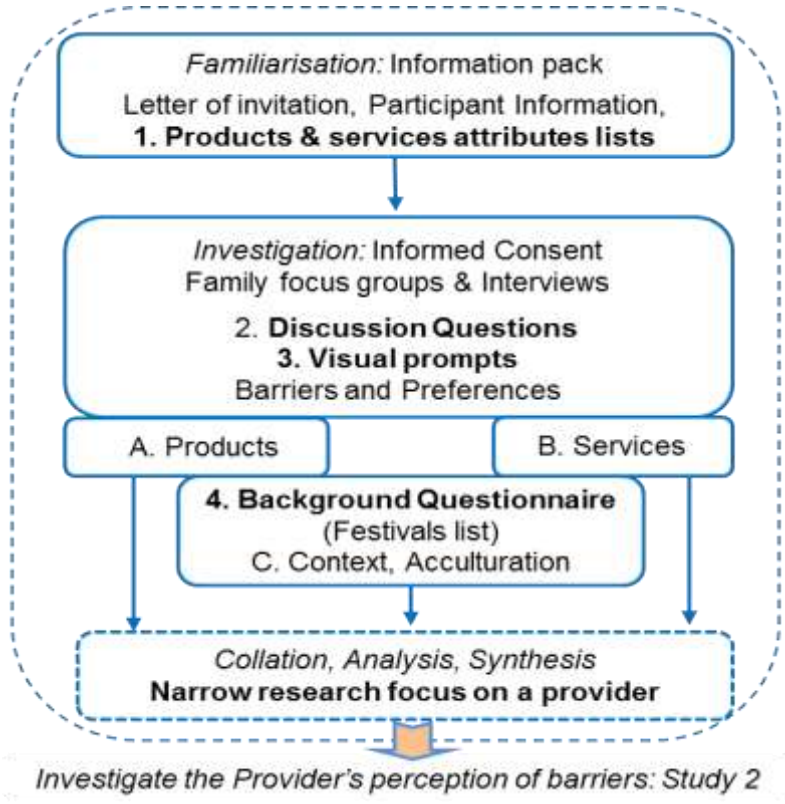


Figure 4.7 Study 1 tools and how the tools were used.

The family focus groups and interviews were designed to last up to 60 minutes.

4.3.5. Piloting

A family focus group and an expert interview with a 2nd generation EMC

ergonomist were used to pilot the questions and process. Some adjustments were made, like 'a PhD study' was removed (a participant felt inhibited). The questions were said to be simple, clear, the scheduling was to time and that peoples' preferences were also being elicited was appreciated.

4.4. Implementation

Participants were recruited directly from places of worship, small businesses, libraries and from amongst work colleagues. Potential participants were provided with study information to gain the consent of their families and to arrange a mutually convenient date/ time. The researcher travelled to each venue.

4.4.1. Family focus groups and Interviews

Seven family focus groups of between 3-6 persons were conducted in participant's homes, one took place at a place of worship and 5 interviews were conducted in homes and libraries (naturalistic settings, ecological validity, Willig 2008). Care was taken to confirm any participants lacking English were aware of the purpose of the study and happy to participate. Informed consent was gained, that there were no right/ wrong answers and the data would be anonymised was re-emphasised, then the recorder was switched on. Visual prompts on service or product categories were displayed for the appropriate questions and a list of festivals when the questionnaires were handed out at the end.

Participants relaxed quickly although few had participated in a research study previously. Translation was undertaken by the researcher (Hindi, Punjabi) or by family members (Malayalam). Questionnaires were translated by family or the researcher and filled for those lacking English. A choice of large chocolate bars were offered to each participant and were a popular token of thanks; a message of thanks was also sent subsequently.

Interviews took about 40-45 minutes and family focus groups lasted 60-75 minutes. Time overran on 3 occasions: when participants had not read the information; when translations were required or when children disrupted the process. For instance, one family focus group of 4 proved to be particularly challenging. It included a visually impaired male with fluent English and three

females who lacked English and literacy (with whom researcher conversed in Urdu). Proceedings were interrupted as a participant's 10-year old autistic son was present and required constant attention and, unexpectedly, several female family members visited unannounced with children to view proceedings and offered to participate.

4.4.2. Data Capture

Family focus groups were initially recorded, and note taking was also used (Robson 2002). Although video recording was a preferred option participants were reluctant to be photographed: some for religious reasons (Muslims) others were shy or wary. On replay, the recordings presented a problem in identifying who the speaker was. More confusion and incoherence arose from discussions between participants, the use of different languages, comments interspersed, to young children needing care, participants leaving/ returning, unexpected family visitors.

A decision was made that note-taking was the best option under these circumstances (guided by Robson 2002) which did interrupt the narrative a little and made the role of researcher explicit (Willig 2008). However, note-taking made it far easier to allow for interruptions amongst participants, for conversations to be picked up, for questions to be put again to those returning, avoided data clutter and made clear who was responding. Bias was minimised through identical questions for services and products, emphasising to participants that there were no right/ wrong answers and because there was no *a priori* theme.

4.4.3. Data Analysis

Data were transcribed using MS Word 2007 and subjected to manual thematic analysis (set out in 3.11.1) between interviews and focus groups. Questionnaires and attributes were analysed in Excel 2007.

Step1. Transcribed data were coded in a column with open descriptive codes (e.g. 'satisfaction,' 'confidence') to avoid inaccuracies or identifying themes too early in the process (Miles and Huberman 1994; Willig 2008). A second column was added for 'context-source', an alpha-numeric code which identified the participant's gender, generation

and faith (F1M = Female 1st generation Muslim). (This retained context when the codes were later extracted, grouped and clustered later.) The background of each participant was tabulated in each transcription (Figure 4.8).

Family focus group 7, Muslim					
Refs	Gender	Generation	English skills	Literacy	Comment
30 – Maj	M	2	Fluent	Fluent	Graduate; visually impaired
31 – Aunty1	F	1	Very little	Very little	Learning in college
32 – Aunty2	F	1	None	None	Gave up learning
33 - Nan	F	1	None	None	Never learned (few words: 100%, bus number)

Figure 4.8 Example of participants' backgrounds identified in transcripts

Figure 4.9 depicts an extract of a transcription, context-source and open coding of 'Services: Difficulties' from a family focus group.

Questions	RESPONSES	Context-Source	Codes
Concepts	SERVICES - Difficulties		
B1.1 B1.2	*For 1st / 2nd gen:* ***Are there any services you use in the UK, which you find were easier to use 'back home' (own country) than they are here?*** *Or 2nd/3rd Generation:* ***Can you tell me about any difficulties you may have faced with services you have used in the UK?***		
B1.1	Aunty2= services are better in the UK *[All agree.]*	All x4	Better-UK
	Nan *waves her arm and repeats several times, in English* = 100 percent! 100 percent! *[i.e. things are better in the UK than back home.]*	33-F1M-Nan	Satisfaction, confidence
B1.2 Problems	Aunty 2 = **Hospital** [now] **is no trouble**, but when my son was born a doctor, **2 midwives, 4 nurses attended – the room was full, I didn't know what was happening,** **...there was no sound**, they pulled the child, he couldn't breathe, later the midwife told me. I lost a lot of blood. **They didn't ask if they should take him for treatment** *[they just did it]*.They pulled him.... For **18 days he was on life support, I couldn't see my child I was so scared**. Once they told me *[in all that waiting time what was happening]*. **I thought I would lose him; Allah gave me back my son.** But **there has been no trouble since** then. **We always speak to an Indian doctor.** Our GP hasn't changed. **They did a scan but didn't operate on the child quickly enough.**	32-F1M-Aun2	Problem- Health service satisfaction, Previously good services but lack of information, fear, lack of empowerment, Problem - Health service lack of empowerment, lack of Information, fear, distress, faith. Confidence-NHS & Indian GP, critical-NHS
	Nan [M]= **We never speak to English doctors**, for the whole family **we go to an Indian doctor he speaks Urdu – we don't go to a Pakistani doctor – we trust the Indian doctor more, the service is better.**	33-F1M-Nan	Confidence-Indian GP, no translation, Poorer service - Pakistani GP
	Maj= **We changed to English doctors** *[the participant and his wife]* – the **Asian doctors asked stupid questions and receptionist (Pakistani) was asking personal questions on the phone** ... and **they ask for money for sick notes.**	30-M2M-Maj	Changed to English GP - Confidence, satisfaction, Critical-Asian doctors, stupid questions, Asian receptionists ask personal questions on phone, Critical-ask money for sick notes

Figure 4.9 Transcript with context and source and open descriptive coding

Participants' responses were compared recursively and the codes were refined. Emerging patterns were reflected upon and unproductive lines of enquiry critically identified and adjusted. Female participants' responses were colour-coded in maroon.

Step 2: The context-source and codes were extracted and grouped in worksheets to summarise participants' views by 'religion' (Figure 4.10).

MUSLIMS	
All Khan x4	Better-UK
33-F1M-Nan	100% Satisfaction, confidence
32-F1M-Aun2	Health service satisfaction, Problem-Previously good services but lack of information, fear, lack of empowerment, Problem-Health service lack of empowerment, lack of Information, fear, distress, faith. Confidence-NHS indigenous staff, Indian GP
33-F1M-Nan	Confidence-Indian GP, no translation, Poorer service GP
30-M2M-Maj	Changed to English GP -Confidence, satisfaction, Critical-Asian docs stupid questions & receptionists ask personal questions on phone, Critical-ask money for sick notes Pakistani receptionists –ask too many confidential questions-English ones only to protocol, Lack of confidence
30-M2M-Maj	Preference-Internet shopping service comprehensive audio descriptions
30-M2M-Maj	Problem-trains & public transport, usability-complex, lack of empowerment, lack of confidence, Preference-car control & comfort,
32-F1M-Aun2	Benefits office-2generation Asian staff communication problem, critical-bad attitude & excuses, English staff more helpful, satisfaction. Job centre Asian staff - critical of attitude & excuses, disbelief, frustration, lack of service,
32-F1M-Aun2 31-F1M-Aun1	Poor attitude-some Asians staff to own, lack of respect, lack of service 'come tomorrow', frustration, dissatisfaction. Pakistani's help own people less, Preference-Indian shopkeeper explains written instructions, satisfaction
30-M2M-Maj	Critical-attitude, Asians towards visually impaired persons, hesitant to too helpful, frustration, embarrassment, attitude-English or educated is a balance, appreciation, Critical-attitude, Pakistanis think they are more superior
32-F1M-Aun2 31-F1M-Aun1	Never use-trains lack of confidence, communication barriers, Preference-bus, confidence

Figure 4.10 Context-sources and open codes grouped by religion

Step3: Matrices were prepared for clustering codes (MS Word 2007, A3 format). Three categories: Products, Services and Acculturalisation were prepared with two columns for 'gender' under each 'religion' along the x-axis. The concepts like usability, not available/missing, were arranged along the y-axis corresponding to the questions asked (Figure 4.11.

CATEGORY SERVICES – S01 ANALYSIS Clustering Codes

FAITHS >	CHRISTIANS		SIKHS		HINDUS		MUSLIMS	
Concepts	Males	Females	Males	Females	Males	Females	Males	Females
UK Services General comments								
Problems UK Usability or Never used								
Problems Back-home								
Not Available or Missing								
Like (Favourite)								
Useful								
Special/ status								
Aspirations								
Cultural/ Religiously Important								
Attributes								
Attitude & Acculturation Relocate								

Figure 4.11 Services matrix ready for clustering codes in step 3 (Word 2007 A3)

The codes were copied into the columns and re-organised under gender in each religion and concept. An extract from the Services analysis matrix (Figure 4.12, Appendix-B5) depicts the codes grouped by faith and colour-coded by gender, and under usability problems and never used services.

CATEGORY: SERVICES - Study 1 Analysis – Clustering codes

Faiths >	SIKHS	
CONCEPTS	MALES	FEMALES
Problems UK Usability or Never used	**Call centre sales,** avoid, rudeness-2gen **Public transport -** No Interest- bus waiting times too long, especially in winter, dissatisfaction-1gen GrandPa **Public transport train** cleanliness, critical, quality of service important-2gen **Never use**- Citizens Advice/ mobility centres,no need-2&3 gen **Govt services slow**- bureaucratic, Critical, too many outsourcing service errors -2gen	**Health** - language barrier, communicating with doctors, respect from English doctors, appreciation, frustration, wasted visit -1gen GrandMa1 **Health** - Interpreter problems, lack of service, inter-faith disinterest, LoRespect, lack of empowerment. -1gen GrandMa1 **Health**– usability-cannot get to physiotherapist non-driver, language barrier, LoConfidence, feels doctors feel doing all they can but participant is too old now, resignation, disappointment-1gen GrandMa1 **Health** - lack of doctors continuity, repetition, inefficient, LoTime (working mum), dissatisfaction - 2gen **x3** **Language barrier -** Support of family, constant translation, instructions & usability, 1gen-GrandMa2 (No English skills) **Never Use-** Any services without family, language barrier, total reliance on GrandPa & family - 1gen GrandMa2 **Attitude-** Mother-in-Law lacks English-will not try to learn, language barrier, no contact outside community, constant interpretation, pressure on family -1&2gen
(Legend: Lo = Lack of, gen = generation)		

Figure 4.12 Extract from codes clustered in the matrix under religion, gender and concept

Step 4: The codes were refined further. Frequently occurring codes were taken as meaningful constructs from which themes were identified (Robson 2002; Willig 2008).

Themes were considered in the context of literature to identify similarities and meaningful understanding of the implications, e.g. to consider the absence of data or 'never used' (Rohrer 2008) in order to develop the story. Highlights

from the findings are set out below.

4.5. Findings

The findings are organised in the following sections:

4.5.1 Participants: Generations and Religions

4.5.2 Services: Difficulties, Preferences

4.5.3 Products: Difficulties, Preferences

4.5.4 Acculturation

4.5.1. Participants: Generations and Religions

The thirty-three participants were heterogeneous (15 males and 18 females, of different religions, aged between 13 to over 75 years), both pre-existing (family) and new (individuals). Four religions were represented: Christianity, Sikhism, Hinduism and Islam. Figure. 4.13 depicts the participants by religion as a proportion of the sample.

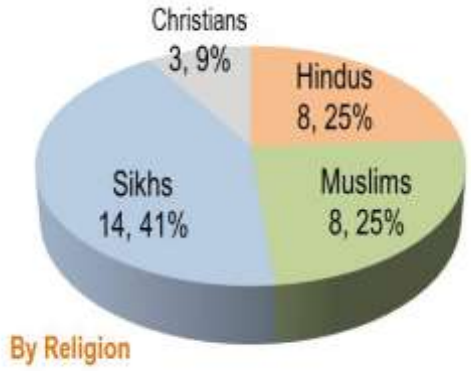


Figure 4.13 Participants by religion as a percentage of the sample (n=33)

An exact balance of numbers by religion proved challenging to achieve within the period due to variations in family sizes. Buddhists could not be included due to recruitment difficulties (low numbers, geographically scattered). Those approached were well-educated, fluent English-speaking couples or monks.

This did not represent the adjusted sampling because, as the study progressed and particular problems were identified amongst the1st generation who lacked English, more families were sought to include this subgroup. Recruiting Christian families proved difficult; many declined to participate feeling they had nothing to contribute (no difficulties and were happy with products and services in the UK). Recruitment was stopped at 33 when themes began to be repeated.

The data indicated that 3 generations from the Indian Subcontinent were now settled in the UK and Figure 4.14 sets out the number of participants in each generation.

Table 4.2 sets out how the generations were defined in this study and their age ranges. Some elderly participants did not know their age (birth was sometimes not recorded in rural areas).

This data highlighted the 3rd generation have reached marriageable age (a cultural factor) and that the UK is on the brink of a fourth generation.

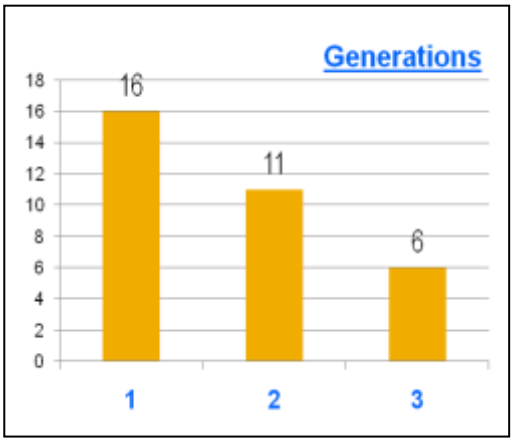


Figure 4.14 Number of participants by generation (y-axis) (*n*=33)

Table 4.2 Ages of the generations as revealed from the data

Generation	Defined as	Age range
1st	New arrivals to people settled in the UK for over 30 years; a subgroup has no English or no literacy.	Late 20's-75+ years
2nd	Included those who went to school but were not born in the UK.	Up to 40-49 years
3rd	Born and educated in the UK.	13- 25 years

Figure 4.15 depicts an analysis of participants' English literacy skills. Those with little or no English comprised almost 24% of the sample.

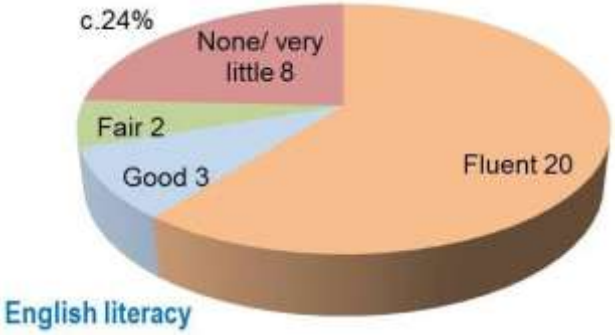


Figure 4.15 Analysis of participant's English literacy skills (n=33)

Figure 4.16 depicts participants by generation, age range and the subgroup with very little English and/or literacy. This subgroup were predominantly females of all religions, across a wide age range (late 20's to 75+ years) including recent arrivals resident under 3 years (young married females, arranged marriages) and UK residents of over 30 years. Low-literacy was present amongst older females aged 30's to 75+ years.

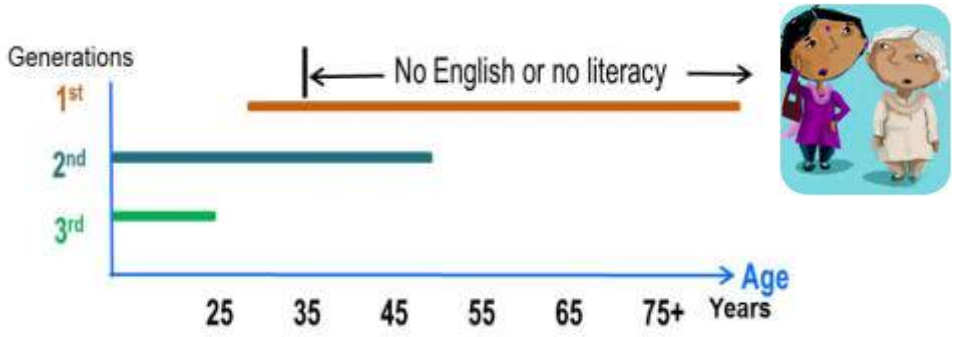


Figure 4.16 The generations by age and the female subgroup lacking English and/or literacy.

4.5.2. Services

This section is organised by generation (sometimes the 3rd generation did not comment, e.g. difficulties in public sector services) in two sections: Difficulties and preferences.

4.5.2.1. Difficulties

The four main themes overlapped and are summarised under:

- Communication Difficulties: Public services
- Lack of respect
- Language barriers: Everyday living
- Lack of trust

Table 4.3 identifies these emerging themes (colour-coded) under religion, gender and generation. The numbers following each theme indicate the number of times the problem was cited. Healthcare and language are the same colour depicting the language barriers in healthcare. The first three themes (above) overlapped in healthcare and included intra-cultural attitudes. Language barriers also resulted in difficulties in everyday living, whilst a lack of trust was mainly associated with internet services. These barriers are described under themes by generation.

Table 4.3 Services difficulties (themes): note healthcare and language difficulties.

Generation	SERVICES Difficulties							
	Christians		Sikhs		Hindus		Muslims	
	M	F	M	F*	M	F	M*	F*
1st	Healthcare Education standard LoTrust internet	Healthcare 2 Language (latent) Education standard LoTrust internet		Healthcare 5 Language 5 Lo Respect* LoConfidence LoEmpowerment		Public transport	Healthcare 6 Lo Respect 5* LoTrust 2	Healthcare 6 Language 9 Lo Respect 3* Social Services LoConfidence LoEmpowerment 4
2nd			Lo Respect* Lo Respect 3*back home Govt. bureaucracy	Lo Respect 3* Lo Respect 3* back home	LoTrust 3 internet Local Govt.	Healthcare LoTrust 3 internet Education standard 2	Healthcare 2 Lo Respect 2 LoConfidence 2 LoTrust internet	LoTrust internet (11)
3rd					Language Asian shops			

(Legend Lo = Lack of) *LoRespect: Negative attitudes from some Asian staff: Healthcare, Job Centre, Benefits Office staff.

A. **Communication Difficulties: Public services**

Difficulties in services were cited across religions and genders amongst the 1st and 2nd generations. Healthcare was a strong theme (cited 12 times) and was associated with language barriers 14 times (1st generation) and difficulties with process by the 1st and 2nd generations. English staff were viewed with affection but there were problems with some Asian staff.

1ST GENERATION

An inability to communicate with healthcare staff was a particular source of distress for females with minimal English and literacy. Similar problems were cited in social and job centre services. A Muslim mother (aged 30-39, resident 10+ years) with an autistic son aged 10 years and daughter aged 12, stated:

> *"I had to call the ambulance for my son but I couldn't tell them what was wrong, I had to ask my daughter to explain..."*

Although very scared during and after the birth of her son (given too little information, was not consulted) the participant confirmed that now the *"hospital is no trouble"* and *"there has been no trouble since then".* A Sikh grandmother with several health problems (widow, aged 75+, resident 30+ years) often visited her surgery in pain:

> *"I like the English doctors, they are very kind [but] I have difficulty understanding the doctors and explaining my problem."* Also*:*
>
> *"Hospital appointments are a problem. I tried to explain to the doctors, they are very kind but we could not understand each other. It [the appointment] was of no benefit."*

Her hospital interpreter arrived too late for one appointment and did not show up for another: *"She didn't come... later she said [to me] 'I have many others to look after'*." She looked frustrated and helpless: *"I think the doctors don't trouble about me too much now. They think they are doing their best: they think 'she is old and ill'. It was no use my going."* The participant also did not keep her physiotherapy appointments: *"I couldn't go to physio, [I could not] take a taxi"* - her grandson was away in India so she could not explain to the

driver.

A Muslim female (aged 30-39 years) also cited interpreter problems: “She doesn’t tell the doctor the same things I’ve said; I understand a little [English] so I know.”

A Muslim grandmother (aged 70+, resident 30+ years) stated: “*We never speak to English doctors. We go to an Indian doctor; he speaks Urdu.”*

2nd GENERATION

Being asked to repeat her son’s problem to doctors on 3 separate visits frustrated and alarmed a busy working Sikh mother.

A Muslim male (graduate, severely visually impaired) stated he and his wife changed to English doctors because:

> *“Asian doctors asked stupid questions and the [Pakistani] receptionist was asking personal questions on the phone: and they ask for money for sick notes.”*

He added:

> *“There is a lack of electronic applications for all kinds and sorts of services, the NHS, Jobs, etc. I like to do it myself and I am constantly relying on sighted people. There is a lack of empowerment.”*

B. **Lack of Respect**

Both 1st and 2nd generation were highly sensitive to inter-cultural and intra-cultural attitudes and negative attitudes which they associated with a lack of respect. Indigenous staff (‘white’ and ‘black’) were unanimously viewed with respect and affection for their kindness, politeness, helpfulness and ‘humanity’. In contrast, negative intra-cultural attitudes were cited 15 times from in their own community: some regarding 1st generation healthcare staff and some were about 2nd generation social and job centre services staff. Also, a further 6 comments related to experiences during visits ‘back home’.

1ST GENERATION

A Sikh grandmother (widow, aged 75+, resident 30+ years, minimal English, no literacy) speaking of her Muslim interpreter who said she had others to

look after concluded: *"She is a Musalmaan so I think she doesn't care about me."*

A Muslim mother (aged 30's, resident 10+ years, minimal English and literacy), speaking of attitudes in the social services office and job centre, associated the lack of help with a lack of willingness and, thereby, a lack of respect*:*

> *"Asians don't help Asian much. Not all, but some young Asians give no respect. If the person speaks a little [Urdu] he says 'come tomorrow'!"*
>
> She added: *"The Asians give excuses for not understanding; the English are more helpful. People should do their jobs. Even in the Job Centre, they say they can understand but can't speak. How can they can understand but not speak?"*

Two Muslim females agreed *"Pakistani people help one less, the Indian shopkeeper explains to me what is written."*

A Muslim male post-graduate (aged 30's, fluent English) echoed these views and was deeply unhappy with 'Asian' (1st generation, Indian Subcontinent) healthcare staff citing three negative experiences. He associated these attitudes with a lack of respect for him. He took a friend who was ill to the hospital and asked an "Asian at reception in blue clothes" for a doctor. He recounted how this individual claimed to be a doctor and "checked the veins and said my friend was OK". But "I told him he did not look like a doctor" and located a doctor:

> *"[…] who told the first guy to do this, and this. He was ashamed to be found out; he kept apologising. He misguided me: it hurt me a lot. Human life is important. He didn't need to be a liar! If I could, I would fire him. He is getting a hell of a lot of money and doing nothing [for it]."*

Three visits to his local GP to be registered as a patient elicited three requests to *"Come back tomorrow"* from Asian female receptionists: "*Like they do 'back home' in government jobs."* He finally refused to go back and told them to register him and post him the papers:

> *"I was fed up with this kind of staff. They are not looking after me*

properly. Asian people don't care about Asian people, they care more about white. They act superior; differentiate on account of skin colour: no respect."

Falling ill with chicken pox, he went to the hospital and:

"Unfortunately [I] saw an Asian doctor […] I showed her the problem. A male nurse from an African country was present: he behaved with very good manners but the Asian lady [doctor] did not even recommend Ibuprofen or allergic medicine or lotion. She said 'It's going to be OK with the passage of time'. What did she mean? If it were something serious, I could be dead! I felt not looked after."

In contrast was his experience with an English doctor. He rebooked the appointment: *"She checked me properly, thoroughly, wrote down the medicine and asked me to use the medicine and come again. She again checked progress and asked me to return in a week, and I was fine."* He concluded that:

"NHS Asian staff are horrible, they always escape from their duties. I prefer not to use Asian doctors, they are a nightmare. They are behaving as badly as back home as in government hospital: they treat you like rubbish."

2ND GENERATION

A Sikh father of two (aged 40) felt badly treated by a bank and airline ticket offices in India and the embassy in the UK:

"In the bank [India] they are not interested; it's who you know to get a level of service and respect. In ticket offices and banks [grimaces and shakes his head disapprovingly] the junior staff were very disrespectful, when the senior officials were respectful the underlings became respectful!"

He added: *"I feel it very strongly. There is no inherent respect and service. In official positions, people are that way but the common person is fine. The job holders want the status, they become really arrogant because 'amongst thousands we got the job'."* Also, *"Indian Embassy staff are exactly the same: so rude - no service mentality."*

His Sikh wife agreed. She added she had to intervene quietly between a secretary in the office (UK) and an Indian lawyer doing a Masters:

> *"He wouldn't understand: the secretary was trying to tell him and he said* ***"I*** *tell you what's right or wrong", that is, she was only a secretary so it wasn't her place to tell him. He was so totally rude she was almost in tears."* The participant apologised to the secretary: "*I told her he didn't understand, he didn't mean it".* She concluded:
>
> *"People in government jobs think they are above the ordinary person. He told me 'Why don't you come to […] people would be kissing your feet in the […] Supreme Court!"*

C. **Language barriers: Everyday living**

Language barriers impacted on all three generations in everyday living and were compounded by low literacy. Participants lacking English relied heavily on 2nd and 3rd generation to interpret information for a range of services as appointments at the doctors, benefits office, job centres, etc. were during the day when the family were working. Sometimes the 1st generation could not accomplish their tasks unless they lived in an ethnic minority neighbourhood. Activities like shopping, driving, taking buses understanding news or instructions were curtailed particularly when living in an indigenous neighbourhood. Loneliness was cited by those alone all day.

1ST GENERATION

A Christian widow (aged 60-69, literate in Malayalam) cared for her 2-year-old grandson alone all day. Asked how her mother managed if she needed shopping or a doctor, her daughter (resident 3-5 years) responded: *"No, she can't speak to anyone or go shopping; she only goes with us."*

Her mother needed translation to understand any instructions or when going shopping: *"She relies on the family, it's impossible without, she doesn't understand products, only sees fresh foods. She has no understanding of frozen or other packets.*" Her mother felt lonely because she could not talk to anyone.

A Muslim female (aged 30-39, resident 10+ years) lamented: "I can't

communicate with them [Benefits office staff] or understand..." and "I cannot go shopping or other things alone, as I cannot read" [or speak English]. I would like to learn." Her sister in law agreed. They explained their daily routines were governed by the need for interpretation:

> *"I use Asian shops only for translation, my daughter helps me by translating. We [females] go together then we help each other. I use Asian taxis, on the bus I go with friends and family and know some routes. Family interpret. We speak to an Indian doctor and at chemists the Asians explain it to you."*

A Sikh grandmother with several health conditions and painful legs from old injuries lived largely alone with a grandson who was often absent. She managed by taking food in empty food cartons from the place of worship.

> *"I rely on my grandson or ask a friend or eat at the Gurudwara. I cannot shop because I can't stand too long. The supermarkets and markets are difficult, I used to go but I understand only what I can see [or the pictures]."*

Repetition was used to aid memory and counter language barriers, e.g. a bus number. A Muslim grandson explained his grandmother (who started chanting prayers) had learned them through repetition:

> *"Nan doesn't understand what she is saying: we don't speak or understand Arabic. Nan […] thinks its good luck: she memorised them."*

A positive case. One Sikh grandmother spoke and understood English quite well although she did not write and read little. These skills were sufficient to give her confidence to drive cars (top brands belonging to husband, son and grandson), shop on her own (Sainsbury, Asda) and to maintain an enthusiastic keep-fit routine, awakening her husband at 6 am every morning to go with her to the gym.

An interesting factor was the participants lacking English and/or literacy were predominantly females. Whilst some 1st generation males had poor English they managed to make themselves understood (confidence), which enabled them to conduct everyday activities.

2ND GENERATION

A Sikh female speaking of her mother-in-law, (grandmother, aged 70's, resident for over 30 years) expressed frustration and dismay:

"*She relies on Father for everything. She prefers it if someone buys food, clothes, etc. – does everything for her!"*

A Sikh father (aged 40-49) was anxious about his widowed mother (UK resident for over 30 years) who remains alone at home whilst he and his wife are at work all day. His mother proudly said her son and daughter helped her but he commented quietly:

"I don't know if we'll have the patience to help her when the children have gone to college. I don't know how she will manage."

3rd GENERATION

The 3rd generation are routinely asked to interpret from English for parents/ grandparents, however, this could present difficulties as language barriers also occurred in the reverse. Some 3rd generation were losing reading and writing skills in their community language and some, also, spoken fluency. A young teenager (Sikh male) avoided Asian shops (he could not understand what was being said), however, parents appeared more concerned over community language skills than the 3rd generation.

D. **Lack of Trust**

Participants were making intra-cultural choices. A Muslim grandmother (aged 70+, resident 30+ years) stated*: "We don't go to a Pakistani doctor; we trust the Indian doctor more, the service is better."*

This included internet offers and TV demonstrations and was a problem for 2nd and 3rd generations of both genders. It was raised 11 times (and negative experiences of parents and siblings not present, were cited a further 11 times). The problems appeared to be similar to those amongst the general population: criticisms of service delivery (like purchases that did not arrive), bank accounts used without consent.

A 2nd generation Sikh couple were anxious about giving children access the internet and did not trust facebook (an issue that is true of most families).

Asked about culturally important services 2 Muslim females (with minimal English and literacy) agreed they did not attend their mosque because they did not trust its approach:

"I don't go to the mosque, I don't like to go, I pray at home. All has changed. I don't like what they [in the mosque] do and I don't want to send the children; it's all negative. Some mosques are good and others have spoiled the name of Islam."

4.5.2.2. Preferences

Participant's preferences are summarised under: 1) Favoured/ Useful and 2) Services that 'make one feel special' and Aspirational. Table 4.4 sets out the favoured and useful services cited by gender and faith group.

The themes are colour-coded in similar groups (e.g. government services, council services, police) and followed by a number which groups the number of times participants highlighted the theme.

Note the frequency of government services in general (including healthcare), healthcare separately, council services across the religions for the 1st and 2nd generation.

Table 4.4 Favoured or most useful services (themes).

Generation	SERVICES Like/ Favourite and Useful							
	Christians		Sikhs		Hindus		Muslims	
	M	F	M	F	M	F	M	F
1st	Government services* Police *Internet-travel*	Government services* TV 2 *Internet-travel*	Government services* 4 Healthcare super surgery Public transport 6 Respect UK staff, equality Online banking Keep-fit 2 swimming, gym PoWorship 4	Healthcare 2 super surgery Respect English healthcare staff Police Public transport 4 Keep-fit 3 swimming, gym Supermarket 3 PoWorship	Government services* Bank 2 *Internet* Pizza home	Sky TV Bank *Internet*	Healthcare 5 Respect 2 English healthcare staff Transport bus services *Education* Banks 3 and online Keep-fit gym	Healthcare 4 Respect 5 English Govt. staff TV Library *Adult education 2* Bank Post office Supermarkets 3
2nd			Healthcare emergency services, relief	Healthcare emergency services, relief	Council services* Sky TV Bank trust *Internet & communication media* 2 Pizza home delivery 3	Council services 2* Banks 2 trust Vehicle recovery Utilities Pizza home delivery 2	Healthcare 3 English staff *Internet shopping* (visimp)	TV 8 Travel 3 *Education/ University* Supermarkets Social services 2 Keep-fit 9 swimming, gym
3rd					*Internet & communication media* 2 *Education* 2	Shopping		

(Legend: Po = Place of, Visimp =Visually impaired participant) *Government/ Council services includes healthcare.

A. Favoured/ Useful

Participants regarded UK services very favourably compared to those 'back home' including the NHS, the UK's cleanliness, roads, public transport, availability of utilities and British banks were cited: *'Everything is available'*.

Government services (including healthcare) and the helpfulness of British staff in government jobs were highly appreciated across religions, genders and generations. Healthcare services were cited specifically a further 14 times by the 1st and 2nd generations for their excellence, care and respect. Social services were perceived as having improved accessibility and information.

Education facilities were cited by 1st generation Muslim males and females, and the 3rd generation (the Education Maintenance Allowance and Student Loan Service were mentioned as very helpful and motivational).

ATTRIBUTES

The most important service attributes were:

> Display of information, Incentive schemes/special offers, 77%
> Clarity of information, Staff attitude, price/ value-for-money, 69%
> Brand, convenience, availability, accessibility, c.62%
> Cleanliness, efficiency, 54%

Although not mentioned here, the discussions revealed that luxury and spaciousness of services and facilities were important in making participants feel good and under 'aspirations'.

1ST GENERATION

Gurudwara for prayers and socialising "It is a very good social network, a very nice group…and bad, political". (Elderly Sikh couple)

> *"The Ambulance service is very good. They came promptly. They were English people"* (Muslim female lacking English, 30-39 years).

Her nephew added*: "The bank and Post Office service help her if she forgets something."*

> *"Government services are very polite and helpful. The Police are very*

polite and look after us well. One day I made a mistake and an officer made me stop and told me very politely what I did wrong. She was very nice." (Christian couple, resident 3-5 years)

"We are very pleased with GP Super-surgery." (Sikh Grandmother and 2nd generation son)

The 1st and 2nd generations cited leisure activities including an elderly Sikh couple and a Muslim family with 5 daughters who, the female participant explained, swam regularly and she jogged with her father (acculturation).

Customer service areas of public transport were approved of and the transport services were considered clean (although two people did not consider daily bus services were usable due to very long waiting times.)

Mothers lacking English and literacy were very grateful the British government insisted all children (including females) were educated.

2ND GENERATION

For a visually impaired 2nd generation Muslim male, internet shopping was critically important, also, the attitudes of the education services and banks:

"The education services are fantastic. I couldn't express myself: I couldn't have done it [graduation] back home."

"The banks are very good: fantastic, great support. They treat you nicely and give great service."

Supermarkets, online banking and home delivery food were favoured for convenience and saving time by the 2nd generation and whilst home delivered pizza was popular with all generations. (This is likely to relevant for other population segments of a similar age group.)

Banks were trusted and considered helpful including by a visually impaired participant who was also commenting on behalf of his Aunt (who lacked English and literacy). Gym, bars, sports (boxing, football, cricket) were cited by a Sikh father.

Both genders of all religions rated government services very highly (including healthcare), the courtesy of indigenous staff in particular and mentioned healthcare services a further 17 times.

"At the back of your mind you know" the emergency services, doctors and 999 were available and it was a big relief (Sikh couple)

3RD GENERATION

Social networks, take-away pizzas, unlimited internet access anywhere in the world to talk to relatives and the Student Loan Service were popular with 4 Hindu teenagers (1 female and 3 males) which would be the case for indigenous groups .

B. Services that 'Make one feel special' and Aspirational

Almost unanimously, across religions and generations, memories of exotic holidays generated the most enthusiasm. Exotic holidays were also, almost unanimously, participant's aspirations, if cost were no problem (Tables 4.5-4.6).

Table 4.5 Services that make us feel special: themes.

Generation	SERVICES Make us feel special (status)							
	Christians		Sikhs		Hindus		Muslims	
	M	F	M	F	M	F	M	F
1st	Nothing mentioned		Travel 2 - nice hotels, holidays abroad Images engage Internet booking travel -trust PoWorship, socialising GPa	Travel -nice hotels, holidays abroad Images engage Internet 4 booking travel, trust, UK no interest PoWorship, socialising GMa	Travel – exotic holidays		Treating others well Helping others, pleasure, Cancer Research volunteer, satisfaction	Keep-fit gym, enjoyment, achievement,, acculturalisation Home delivery- beauty products, good quality, happy, bargains, time saving
2nd			Travel 3- Nice hotels, holidays abroad Luxury [services], convenience, space, confidence no question Images engage Internet booking travel –trust	Luxury, convenience, space, no question, confidence	Travel 3 - Luxury hotels, 5 star services, exotic holidays, driver	Travel 4 – exotic holidays, driver, luxury 5 star hotels, service	Nothing (visimp)	Nothing Leisure clubbing, socialising, sisters against it, pressure -family unaware Beauty treatment 4 Sisters
3rd			Travel 3 - nice hotels, holidays abroad, Images of holidays engage 3 Internet booking travel –trust		Travel 7 – exotic holidays, luxury hotels, 5 star luxury services	Nothing		
(Legend: Po = Place of, Visimp =Visually impaired participant)								

Table 4.6 Aspirational Services (themes).

Generation	SERVICES Aspirations (if cost was not a consideration)							
	Christians		Sikhs		Hindus		Muslims	
	M	F	M	F	M	F	M	F
1st	Nothing cited		Travel 2 -1st class air travel, anywhere, comfort, service	Charity work, nothing 2 satisfaction Walk-in shower instead of bath GMa *Learn English GMa*	Travel – exotic holidays		Nothing	Travel -1st class with children (no English) **Private healthcare**, *Learn English*
2nd			Travel 1st class air travel wheelchairs escort, luxury, space, entertainment None **No interest** private healthcare	Travel 3 -1st class air travel, 5 star hotels, Orient Express wheelchairs escort, luxury, space, entertainment **Private healthcare**	Travel 2 - 1st class always, regularly, exotic holidays, luxury hotel, luxurious services, cruises,	Travel 2 – always 1st class, regularly, exotic holidays, luxury hotels, services, cruises	Travel -1st class air, rail (visimp) **Private healthcare** (visimp)	Travel 3 -exotic holidays with 5 children, 1st class air travel, spa luxury hotel beauty treatments *Mum-Education* takes advantage of all offers
3rd					Travel 3 -exotic holiday, luxury hotel, luxurious services			

(Legend: Visimp =Visually impaired participant)

Comments included:

"Luxury, convenience, spaciousness: no question" (2nd generation Sikh)
"Orient Express, 5 star hotels, 1st class trains and air travel", "1st class […] has room, luxury, service and entertainment" (2nd generation Muslim mother)

"We got treated like kings, real luxury. There was always a waiter present, they pulled chairs out, placed napkins on our laps, they constantly made food, you could order/eat as much as you wanted." (Hindu family, 2nd and 3rd generations)

Although a lack of trust of the internet was cited, the internet was also a favourite service for booking holidays. Images of holidays abroad and 5-star luxury attracted participants. Aspirations took holidays to the next level: exotic holidays, regularly, with children, 1st class on aircraft, trains, cruises, 5-star hotels for luxuriousness and spaciousness. Although the Christian family did not comment, they always booked travel (to India) on the internet but said they did not trust the internet for much else.

However, a few participants across the generation also said there was nothing they desired, they were satisfied with life, would like to do charity work or preferred their prayers. Learning English was cited by 2 females unprompted and a further 4 (i.e. 6 of 9) when asked about learning English.

4.5.3. Products

Participants unanimously favoured UK products to those 'back home' for their design, technical features and beauty: '*nothing is missing'* or *'everything is available'* either in the stores, via the internet, even in small towns. Interest, choice and affordability guided take-up of products. The findings are organised in two sections: Difficulties and preferences.

4.5.3.1. Difficulties

The difficulties are organised by generation as many of the difficulties identified, like usability problems, were broadly similar findings amongst the general population. For instance, product complexity (cited across religions

and generations) and difficulties in learning and using a multitude of features on computers/IT, mobile phones, TVs (touchscreen).

Tables 4.7-4.8 set out the difficulties by generation and religions and the colour coding e.g. maroon, groups the difficulties associated with products, like a lack of time and instructions.

1ST GENERATION

Educated 1st generation attitudes were similar to the 2nd generation. Some 1st generation (even with good English skills) gave up trying to learning how to use the products, particularly the elderly, and simply relied on the 2nd and 3rd generation. There was trouble following instructions: complaints were too little instruction, small font sizes, poor contrast, or instruction were too complex for those with less English. There were particular problems for the elderly and compounded language barriers for some.

Participants lacking English relied heavily on 2nd and 3rd generation to interpret how to use products (like TVs, mobiles, appliances) and instructions on food and other packaging. The elderly and those lacking English learned one or two settings (on TVs, mobile phones, washing machines) by repetition, but frequently could not remember how to work phones and needed help.

A Sikh grandmother described herself as 'adventurous', always ready to learn new technologies (to her son's amusement). However, language and literacy barriers resulted in this subgroup's inability to follow written instructions on medication, packaging, appliances, frozen foods, etc. and necessitated continuous guidance and interpretation. They relied a lot on memory.

Frozen food was rejected by recent 1st generation arrivals and (mis)perceived as not '*fresh'*. Some females preferred Indian products that worked better (medicines, cooking griddles).

Table 4.7 Products: problems, 1st generation EMC views

PRODUCTS Usability Problems (1st generation)							
Christians		Sikhs		Hindus		Muslims	
M	F	M	F	M	F	M	F
Never use frozen food -2, not fresh [misconception] **Memorise-repetition-** GrandMa only 1 setting.		**Instructions** -2-too short, font too small, too complex if English not fluent **Need 3gen support** 2 GrandPas **LoTrust TV demonstrations,** frustration, buy & send back **Electrical products** poor durability GPa	**Instructions** -3- too short or complex, font too small, mobile phone, TV, remote control, too difficult, gave up **Need 3gen support or others - 8,** including 2 GrandMas & participants with no English **LoEmpowerment 4** (no English) **Memorise-repetition- 2** only 1 setting, washing machine & appliances **LoTrust TV demonstrations** -poor usability, frustration **Never use IT, mobile phone** no need	Parents - **Never use IT** products		**Affordability** UK expensive high mark-up on outsourced products **Never use** DIY or gardening, no need	**Memorise-repetition- 3,** only 1 setting, washing machine & appliances **Expectation, disappointed** Skin products didn't work, expensive brand **Indian products** medicine worked, Spice mix better (GMa), Roti griddles more, durable
(Legend: Lo = Lack of, 3gen = 3rd generation)							

Table 4.8 Products: problems 2nd and 3rd generation EMC views

PRODUCTS Difficulties (2nd generation)				
Sikhs		Hindus		Muslims
M	F	M	F	F
Complexity 4 computers, mobiles, fear, not user friendly, frustration **Instructions complex 2**, frustration **LoTime, 3gen support 4** to read, learn, work pressure **LoConfidence 4** frustration **LoTrust**, TV demos products, buy & send back poor qual	**Complexity 4** computers, mobiles, too much choice *[features]* **Instructions complex 2, LoTime, 3gen support 4** - to learn, frustration LoKnowledge **LoEmpowerment 4** not user friendly	**Complexity 7** touch screen TV no contrast for controls, too many channels/ functions, brand pride, frustration. Computer/ IT too much choice *[features]* **Instructions complex 5** **LoTime 5** to learn **Instructions -more images**, definitely helpful, save time **LoTime, 3gen support 7** **LoTrust 2 -** TV demos, anticipation, disappointment **LoTrust 4 -** grill, oven, washer dryer, fiddly, nightmare, 'ripped off' **Never uses** Dad: mobile phones	**Complexity 2** IT, Mobile phone touch screen too sensitive, TV touch screen brand pride, anticipation, frustrated, disappointed **Instructions poor 3** camera, disappointing **Instructions -more images 3**, definitely helpful, save time **LoTime 2, 3gen support -** to learn, read instructions **LoEmpowerment 2** **LoTrust 3-** Internet/TV demos, now only browse, anticipation, disappointment **LoTrust 4** grill, oven, washer dryer, fiddly, nightmare **Never use** -DIY products	**Complexity 2** Mobile phones, technical products set up difficulty, LoUnderstanding. **Instructions** unhelpful **Instructions - more images** make it easier **Never use 2** gardening appliances, DIY Poor quality 2-land phones, poor ring
(3rd generation)				
LoTrust 4- TV demos & products, buy & send back poor quality, frustration		**Complexity 6** TV, too many channels, functions, brand pride **Technical gap 3** 2nd/3rd gen **Instructions more images 3**, definitely helpful, save time **3gen expectations 3** - to learn/ teach 1st, 2nd gen **Never use** DIY products 3	**LoTrust 2 -** internet, shopping mall demos, usability poor, disappointed	
(Legend: Lo = Lack of)				

2ND GENERATION

Both the 2nd and 3rd generations agreed that a technological gap had developed between them.

2nd generation participants cited frustration, a lack of empowerment, a lack of confidence, even fear (getting it wrong) and a poor utilisation of products (TVs, mobile phones, computers, etc.). Anticipation culminated in disappointment. Products had too many features, TVs too many channels, there was too much choice. Simple things like insufficient contrast of the controls (e.g. touchscreen TV) lead to embarrassment (how to switch it on). Product complexity was cited 19 times and was also associated with poor instructions.

Like the 1st generation, the 2nd generation were dissatisfied with instructions (too little, too complex, too much text). One of the greatest impediments in learning new technologies was a lack of time from balancing daily socio-economic responsibilities. This was cited by 2nd generation 13 times.

More images in instructions (i.e. images and text) were favoured by both 2nd and 3rd generation to more easily and rapidly follow instructions and save time: the 2nd generation added, and empower themselves. Images could help people lacking English, if they were understood.

Functionality of products was a problem cited by the 2nd and 3rd generation. There was a lack of trust in products demonstrated on TV. The demonstrations suggested the products were easy to use but were found to not operate properly resulting in disappointment. Families used stores to view products and, if satisfied, located a better-priced internet offer of the same item, or simply bought in the store against a refund, if required.

Some products (self-cleaning ovens), were bought and did not work, brand dissatisfaction led to feelings of being 'ripped off'.

3RD GENERATION

Three male participants agreed that *"Things are getting very complicated"* and they had to learn the technologies to support parents and grandparents. They agreed with the 2nd generation that there were too many choices (features), insufficient clarity in instructions and more images would help

including for people lacking English.

A 3rd generation female teenager cited the effect of *Mr Bean* on her peers (visual communication). Everyone understood and laughed at the visual story (unspoken) even if their English skills were not very good.

4.5.3.2. Preferences

Participant's preferences are summarised under: 1) Favoured/ Useful products and 2) Aspirational products. Many views were unanimous (across the generations and religions) therefore, these findings have been organised and grouped in four themes: Audio-visual and ICT products; Cars; DIY products and appliances; and Sports, keep fit and the gym.

Individual preference, rather than religion, appeared to guide choice.

ATTRIBUTES

Participants were asked which attributes most influenced their purchasing decisions and these are ranked with the highest representing those cited most often.

Value-for-money: 93%
Appearance, design, beauty: 85%
Colour: décor or colour in all or certain products: 79%
Enjoyment, satisfaction, comfort, safety: 71%
Warranties: 64%
Trust, brand/designer-label, quality: 57%
Clear instructions, special offers/ add-ons, usefulness: 50%.

Although clear instructions scored only 50% under 'attributes' the discussions in 'Difficulties' (above) revealed the importance of instructions across the generations.

Favourite products (Tables 4.9-4.10) included a wide variety (latest technologies to leisure) and 'most useful' and 'enjoyable' products followed the norm (cars, computers, iPods, CDs, DIY gadgets).

Table 4.9 Products: Favourites (note popularity of audio-visual technologies)

PRODUCTS: Favourite (1st generation)							
Christians		Sikhs		Hindus		Muslims	
M	F	M	F	M	F	M	F
TV -oSny brand & portability Car, Satnav, Roads pleasure, satisfaction confidence DIY, tools, drill	TV 4-Sony brand portability & quality MP3 2 Kitchen/ domestic appliances 3	TV 3 -faith channels-Sky DIY products, gadgets 2 Gpa	TV 6 important (no English) faith channels-Sky CDs, MP3 2 - 'God send', simple usability, enjoyment, faith prayers GMa Car, Mobile phone GMa Kitchen/ domestic appliances 2 washing machine, slow cooker GMas	DIY Books		TV addicted English programmes DVDs Friday family entertainment Computer- education, immediacy, convenience, enjoyment Cars – BMW, Mercedes, brands, safety Satnav- Dad-Tom Tom, confidence, convenience DIY equip & tools 2 Keep-fit 2– home gym, Nintendo Wii Sweets mithai, chocolate No interest designer items	TV addicted- English programmes DVDs 3- Friday family entertainment Kitchen appliances, equipment 2 Keep-fit 2 -Nintendo Wii, home gym acculturation (6)

Table 4.10 Products: Favourites (note popularity of audio-visual and communications technologies)

PRODUCTS: Favourite (2nd generation)					
Sikhs		Hindus		Muslims	
M	F	M	F	M	F
TV 2 iPod -running, enjoyment, confidence, achievement Mobile phones Car DIY tools, Gadgets 3 home automation, appliances Sports	TV 2 - Samsung brand, shopping channel demos 2 Car- Volkswagen car brand	TV, DVDs 3 – plasma TV, big screen, 42" Samsung touch screen, joy, 'home cinema', pride, brands, achievement Status, prestige 3 iPhone enjoyment, features Car BMW 530, brand, status, Luxury, comfort, achievement, Empowerment, Affordability DIY & gadgets, empowerment, satisfaction, achievement	TV- 42" Samsung touch screen excellent, brand, pride, achievement DVDs Car BMW 530, brand, luxury, comfort, status, empowerment, affordability Washing machine- Zanussi brand Fashion-Shopping-clothes-shoes, enjoyment, appearance, confidence	Computer, Audio technology critical (vismp)	TV 2- addicted English programmes DVDs 5- Friday night family entertainment iPod Nano, pride, features, entertainment Nintendo Wii 2-keep fit, family socialising, gift Rado watch brand, luxury, diamonds, appearance, pride International brands trust Fashion 3 - Cheap chic, accessories, make-up, cultural pressure (change after leaving home) Keep-fit 6 home gym
(3rd generation)					
TV 3 Computers, IT 8- laptops, reliable, affordable, satisfaction Mobile phones 2 Car 2	HD box	TV 3- 42" Samsung touch screen, brand, pride Status prestige-3 iPod, Audio books, iPhone 3G 2 –brands, music Car-BMW 530, brand, Status Luxury, comfort 3 Xbox360 fun sharing www, socialising Piano & sax 3 play jazz/ blues, classical Fashion-Clothes No Interest reading	TV - Plasma home 'cinema experience', disco Computers, IT 2- love Mobile phone		

1) Favourite products

Favourite products included a wide variety from the latest technologies to leisure and designer products like Hugo Boss watch, Swarovski jewellery (sister's passion), i-phone 3G were cited by many as status symbols (makes them feel special). Whilst the 2nd and 3rd generations demonstrated a marked enthusiasm for top brands (particularly the 3rd) some commented "things don't matter", likewise, some educated 1st generation.

Enthusiasm was governed by the beauty of designs and the status. The 1st generation elderly cited fewer products, but were not averse to top brands. Two couples, Sikh grandparents, were proud of their Mercedes cars, one was a gift from an elder son.

For a visually impaired 2nd generation Muslim male computer and audio technologies were critical. Interest, choice and opportunity guided the take-up of products. Participants cited that religion affected product choice always to moderately for 63% mainly of food and clothes – but not other products. Special and ritual-foods were a big theme for festivals (all celebrated their own religious festivals and 69% also celebrated UK festivals).

Images were unanimously cited as being helpful for following instructions across all generations and religions. For the 2nd generation images with instructions helped them more easily follow domain knowledge, save precious time, improve the usability of products (e.g. computers, digital cameras) and empowered them.

2) Aspirational products

An interesting difference between favourite and aspirational products was a shift from audio-visual and ICT technologies to top-of-the-range cars (33 citations), jewellery and home improvements (Tables 4.11-4.12) across the genders and generations. Reasons included status/ prestige (brand), appearance and luxury. This change suggests the economic factor: all the aspirational items are very expensive. Several participants also cited 'nothing' and no interest in material things (cultural attitudes), however, this appeared to reflect their satisfaction.

Table 4.11 Products: Status and Aspirations (note the popularity of cars between the religions and genders)

PRODUCTS: Status and Aspirations (1st generation)							
Christians		Sikhs		Hindus		Muslims	
M	F	M	F	M	F	M	F
Car- Honda CRV, brand, status Farm- fresh food	Farm-fresh food	Cars 5 Mercedes, brand, status, prestige (Grandpa given a gift by son) Nothing 2 - satisfaction, contentment (family love expensive clothes)	Cars 2- Lexus, Mercedes VW brand, status GrandMa TV Samsung Nothing 3 - interested in faith, 3gen buy them everything, content- GrandMas Jewellery diamond ring, status, enjoyment	Cars 2 - BMW 530, brand prestige, pleasure, luxury appearance iPhone 3GS- brand, convenience, confidence, status	Car- BMW 530, prestige, pleasure, luxury	Cars 2- Mercedes, BMW black, brand, status, appearance Thing's don't give one status *[NB.likes Mercedes & BMW 'for safety']*	Cars 2- Mercedes, brand, appearance, status Nothing much Jewellery -gold ring, bangles, necklaces (cultural) Perfumes- lots, brands, Nina Ricci, Homme la Coste Big house really big, status

Table 4.12 Products: Status and Aspirations (note the popularity of cars and jewelry)

PRODUCTS: Status and Aspirations (2nd generation)					
Sikhs		Hindus		Muslims	
M	F	M	F	M	F
Car -Mercedes **Computer**- confidence **Nothing -4** Not interested in material goods (family love expensive clothes) *BUT* **Home extension**, space	**Car**- Volkswagen 1.4 hatchback, design, brand **TV** necessity **Nothing particular**, satisfaction, achievement **Keep-fit** home gym, heated pool, sauna, acculturation	**Cars -2** Porsche 911-(diesel); Ferrari, brand, luxury, status, enjoyment 2 **Not designer labels** (prefer holidays)	**Car** Peugeot 307 convertible, brand, hood down & sun out, enjoyment, appearance, confidence **Home extensions 2** - luxury, new kitchen, bathroom, conservatory, house cleaning robot (like Japan), enjoyment, save time **Designer labels** – like Gucci **Domestic gas dryer** - laundrette quality - **Not designer labels** (prefer holidays)		**Cars- 4** Toyota Yaris silver, Mercedes, Jaguar, Lexus bright yellow, alloy wheels, tinted windows, in car entertainment-big base, brands, status, pride appearance **iPods & media, big systems, big TV 4** - sisters, brand **Stereo system**- lilac & silver, colour, features, gift (Dad, Eid) enjoyment, love music UK, Indian **Fashion** brand names- Gucci Prada Gstar,classy, fit, quality, durability **Jewellery** -Swarovski, Rado watch diamonds 1K, luxury, pride, brand, status, expensive,
(3rd generation)					
Cars -4 - Love own, want VW Golf latest model, driving top brands-brand, enjoyment, status		**Cars -3** BMW 530, Bugatti Veyron. brands, luxury, status prestige, pleasure, luxury **Motorbike** -Ducatti, brand, luxury, status **Watch** - Hugo Boss designer watch, self-bought brand, status, achievement **Fashion**-Dog tags, design, cool **Nothing** particular	**Walk-in electric wardrobe**- space, luxury, status 3gen very aware of labels (2 gen) **Fashion**- River Island hand bag, brand, appearance, enjoyment, self-bought, achievement		

Audio-visual and ICT products like TVs, CDs, DVDs, home cinemas, personal media, iPods were unanimously popular across the generations. For the 3rd generation this included laptop computers. The majority of participants had a mobile phone, some elderly people forgot how to use them, and a 2nd generation Hindu father refused to use his from personal choice (did not like to be constantly accessible).

Audio-visual products were cited as critical to those lacking English and/ or literacy for their prayers and entertainment (particularly the widowed, elderly) and described as a 'God send' (2nd generation Sikh male). Through interpretation and repetition they familiarised themselves with one or two settings on appliances (symbols and text were meaningless).

Cars (cited 16 times) were popular with all generations, including elderly males, all of whom drove brand cars: Mercedes E Class, Lexus, top of the range Volkswagen, BMW 530's *("it's luxuriousness"),* yellow Peugeot (*"with top rolled down and breeze blowing through my hair: makes me feel good"*). Aspirations also include leading brands: Mercedes, Lexus, Jaguar, Porche 911, Honda CRV, Bugatti Veyron.

DIY products and appliances were a passion amongst males, however a 2nd generation Muslim female noted: *"Dad is more conscious of status back home than in the UK"* (he would not do DIY but hire labour, cultural factor, status and because labour was more affordable).

Sports, keep fit and the gym equipment were popular with both males and females according to preference: a Sikh couple (grandparents), Sikh father, a Muslim family with 5 female children (home gym, swam, jogged), and others aspired to have a home gym (acculturation, a 'Western' concept growing in popularity). Wii fitness was popular for family entertainment and cost effectiveness, as were DVDs (cultural).

4.5.4. Acculturation

Participants were asked what they liked best and the least about life in the UK compared to 'back home', whether they knew English and, if not, would like to learn.

4.5.4.1. Life in the UK

The unanimous view was life in the UK was very good ("*100%, 100%"* emphasised a Muslim grandmother, aged 75+, who lacked English and literacy). Reasons cited were satisfaction with the availability of products, the availability and access to essential services, great opportunities to progress, the standard of living, access to education - and affection for British people, their courtesy, politeness and good manners. This appreciation of the respect shown to them by the indigenous people was cited often.

Asked what they liked least about the UK, the majority stated 'nothing' although two 1st generation participants commented racism needed addressing and unsocial or *yob* behaviour. In combination, these indicated that participants, in general, were satisfied and content. Two thirds spoke reasonable to fluent English (75%). The generations appeared to be acculturating to differing degrees through choice. Elders were living either in a joint-family system or near the family, although a Sikh grandmother's family had scattered leading to difficulties: she saw her grandson intermittently and relied on the Gurudwara for help and companionship.

31 participants cited British culture as influencing their way of life, notably even 1st generation lacking English and literacy (grandmothers). Two 1st generation Sikh females (grandmother and daughter-in-law) did not comment. However, their other responses suggested a good degree of acculturation (running their own business, driving, speaking/understanding English, attending a gym, swimming). The reason may lie in an unwillingness to admit the influence of British culture as two 2nd generation Muslim participants confirmed. A married visually impaired male vehemently stated:

> *"In our community they put pressure on you. If I wear British clothes they ask me 'why are you wearing those clothes?' They don't like my British identity. But I am British, I love being British, I was born and raised here, I could not have achieved what I have back home. I have an identity crisis."*

A single female admitted: *"My father would be very angry if I said British also"* and her (younger) sisters would disapprove if they knew she socialised by

'clubbing' or used the train service to visit a boyfriend. The Hindu religion was cited by 2 teenage males as influencing their thinking (although this appeared to be, in part at least, to please their mother who was anxious for them to have more religious education). However, for one family (2nd-3rd generation), religion was not important.

Unanimously, participants celebrated one or more of UK's social (New Years Day, Valentines) and religious (Christmas) festivals to some extent. Some elderly people did so for their children. Unsurprisingly, the 3rd generation celebrated the most UK festivals plus all those their parents celebrated (like Diwali or Ramadan). Ritual foods and food (what to buy/avoid) were important as were purchasing gifts throughout the year for festivals, birthdays and anniversaries. Religion was expressed in material restraint but aspirations for a "good standard of living" remains unhampered.

The 3rd generation were learning other European languages (German and French) whilst losing fluency in community languages, i.e. good understanding, spoken less well, whilst writing and reading skills had largely faded. As a result, some younger 3rd generation avoided Asian stores because they did not understand what was being said. This trend was also apparent amongst the 2nd generation 4 of whom lamented their lack of reading skills. They were keen to pass religious guidance to the 3rd generation but the literature was in community languages.

The 3rd generation played Western musical instruments (classical piano, saxophone, one home had these instruments) and enjoyed both Western and Indian genres of music (R&B, Bhangra). A 2nd generation Hindu father had a room installed as an cinema-type home entertainment room.

As noted, the 2nd and 3rd generations were keenly conscious of *respect* inter- and intra-culturally (attitudes differ considerably between the UK and the Indian Subcontinent, see 2.4), however, this was not mentioned by the 3rd generation.

In general, the trend towards a higher percentage of English and European friends increased with the generations, with some 3rd generation citing 60% of their friends are in this group, although this was true also of a 1st

generation Muslim male aged 30's. At the other extreme a 1st generation subgroup lacking English had no English friends albeit they had been UK residents for 10-30 years. They were, however, highly aware of and appreciated the kindness and respect shown them by indigenous people.

4.5.4.2. Learning English

A majority of participants (6 of 9) aged late 20's to 75+ expressed a desire to learn English. Some did not how to do so and some faced intra-cultural attitudes that led to a lack of confidence. Some were realising late the importance of English, but did not know how to go about learning, others gave up due to intra-cultural attitudes.

- *"I would like to learn [English] but I have no help"* (to be able to talk to the doctors) (Sikh grandmother, 75+, resident 30+ years, no literacy).
- *"I would like to learn [English], but the girls in our own community make fun of me and make me feel bad*. *I needed English very much at the doctors. I don't go to class now, I gave my name then I withdrew. She [her sister-in-law] can write her name"* (Muslim mother, aged 30-39, with autistic son).
- *"I am enjoying it [English], speaking and learning. I am going to […] College Adult Education but our companions laugh at her [sister-in-law] because she is slower to pick it up: her pronunciations…"* (Muslim female, aged 40-49, resident 10+ years).
- *"My wife wants to move out of the area to learn and practice English better and not to have the pressure from them [Muslim males in the community] about why she wishes to speak English. I want her to learn."* (2nd generation Muslim, 24-29, severely visually impaired speaking of his wife, a resident under 3 years.)
- *"She is not interested in learning English, she is now too old…..but if she was going to live here she would learn."* (Christian female speaking of her widowed mother, aged 60-69, literate in Malayalam, resident under 3 years.)

Some felt there is no need to learn English and for several reasons: they were now too old, because they were confident of family support (cultural).

The 2nd generation cite frustration and anxiety:

- *"Mother will not do anything or try to even learn [English]! She has no desire whatsoever. Even at work she didn't need to learn English."* (2nd generation Sikh female of her mother-in-law aged 70-79, resident 30+ years).

- *"No, she [mother] is not interested [she says] it's too late to learn."* (Sikh male, 2nd generation).

These findings are discussed next in three categories: Services, Products and Acculturation.

4.6. Discussion

These findings are discussed by gender, generation and religion in the three categories and Table 4.13 summarises findings by generation and gender.

The findings suggested that participants were happy and satisfied with life, government services, other services (e.g. internet, stores) and products in the UK compared to 'back home'. This was true across generations and religions regardless of English or literacy skills. Nothing was missing, not available or particularly culturally important that they could not access. The generations appeared to be making intra-cultural choices based on individual preferences in accordance with literature (NAB 2000; Sekhon and Szmigin 2005, 2011; Balakrishnan *et al* 2005).

However, a predominantly female subgroup lacking English and/or literacy were adapting less well. This included females aged late-20's to over 75 years, recent arrivals to long-term residents (over 30 years). Elderly people (both genders) and this subgroup relied highly on family support.

Most product and service preferences had little to do with religion (except ritual food and clothes) although some cited more interest in spiritual matters than 'things'. The majority of participants did not perceive that cultural barriers hindered their take-up of products or services. However, some faced pressures from inter-cultural dimensions (Hofstede and McCrae 2004) and cultural factors (gender attitudes, Berry 1997), which they were trying to resist. Muslims mainly cited gender attitudes: a participant's wife faced negative attitudes over learning English from other Muslim males in the

community (although he wanted her to learn); he and a female participant (2nd generation) cited censorship about admitting British culture influenced them (power distance).

4.6.1. Services

Contrary to literature, although designed and delivered by people from another culture (Schifferstein and Hekkert eds.2008) these findings suggested that participants were satisfied with services in the UK in general with particular emphasis on the respectful and helpful attitudes of indigenous staff and the public.

Difficulties: Healthcare was a strong theme for the 1st and 2nd generations regardless of participants' gender or literacy. This was not surprising as health lies near the base of Maslow's model (Thorson 2006) and the desire for good health is ubiquitously important regardless of culture. The NHS and indigenous staff were viewed with affection but difficulties were cited from language barriers and/or a lack of respect (some staff from the Indian Subcontinent), and some difficulties were due to process. Younger 1st generation females also cited language and lack of respect from Asian staff in social and job centre services. Negative attitudes from some Indian Subcontinent staff generated frustration and anger due to a lack of care. This was perceived as disrespect (i.e. participants were not important, lack of status).There was a perception these attitudes reflected those of some staff 'back home' who were cited as quicker to provide care for those perceived to be important (status). Individuals and families were making inter- and intra-cultural decisions based on these factors.

Services, more than products, challenged the female subgroup lacking English and/or literacy. As literature confirms, services have more intangibles associated with them and staff are a part of the service (Masterson and Pickton 2004) and difficulties can arise when services or products are designed or delivered by people from other cultures (Schifferstein and Hekkert eds.2008). The family were working when services were accessed during the day and made them reliant on 'Asian' stores, services and staff. Unsuccessful interactions resulted in frustration, disempowerment and anger.

Favoured: Government services, healthcare, police, the banks were all viewed positively. Opportunities to travel were particularly enjoyed (Zizek and Lacan's "*jouissance*" or joy, Dean 2002) and brand was associated with luxuriousness and 5-star services. Education for females was appreciated for some who lacked literacy.

The internet was another strong theme both favoured by English-speaking 1st and 2nd generation (particularly for holiday promotions) but also a viewed with distrust. Overcoming this barrier merits the consideration of organisations relying heavily on internet-based promotion as this group usually make purchasing decisions. The 3rd generation cited few problems with services, enjoyed the internet for social networking and trusted it more.

4.6.2. Products

Participants were enjoying the designs (beauty, appearance) of products reflecting Zizek and Lacan's "*jouissance*" or joy (Dean 2002) and pleasure in design (Jordan 2004). Purchasing for social and festive occasions was strong year-round. Difficulties conformed to those amongst the general population in literature, like complex processes or technologies and under-utilisation of facilities (Goodman *et al* 2003, Nielsen 2006, Clarkson 2008).

Difficulties: Both the 2nd and 3rd generation cited product complexity, too many features and choices. Ease of use (usability) and more attention to instructions are important considerations for organisations aiming to reach this market segment. The 2nd made many purchasing decisions and presently feel frustrated and disempowered due to the generational technology gap. More images to balance the text in instructions needs consideration to save time and to empower people: more, understandable images, could also help the 1st generation.

Favoured: Audio-visual technologies (TVs, CDs, DVDs) were a 'God send' for those facing language barriers and together with personal media were unanimously popular. The enthusiasm and aspirations for top brands was noteworthy amongst the 2nd and 3rd generation. Although some 1st and 2nd generation cited material restraint this did not necessarily imply lowered aspirations as evidenced by two Sikh couples, grandparents, who drove

Mercedes cars(one a recent gift from his son).

Females lacking English and/or literacy placed less emphasis on problems with products than services, possibly because at home familial help was at hand (social environment, context, Thomas and Bevan 1995). An explanation may lie in Nielsen's (2002) three divides: that usability issues are superseded by pride in ownership (affordability, economic) and thus, empowerment, as these products may be less affordable to many were they 'back home'.

4.6.3. Acculturation

The generations appeared to be acculturating to differing degrees and educated, 1st generation English-speaker's acculturation could be compared to that of 2nd and 3rd generations. Language barriers impeded the acculturation of females lacking English who faced obstacles to learning English. Some appeared to arise from personal choice (lack of confidence, being too old) or from intra-cultural hindrances (Muslim community). The remarkable difference to quality of life that speaking English and reading a little made to a Sikh grandmother was noteworthy.

Participant's perceptions of a lack of respect from some Indian staff suggested acculturation of to the UK's norms: respect is ascribed to each individual regardless of status (Table 2.3).

A notable inter-cultural difference between elderly EMCs (Indian Subcontinent) and indigenous elderly appeared to conform to collective vs. individual attitudes (Hofstede and McCrae 2004). Whilst valuing family and friends, indigenous elderly try to maintain their activities and independence for as long as possible through technology and support services. However, elderly EMCs (Indian Subcontinent) expected to depend on the family sometimes to an extreme (when refusing to learn English). All the participants (except 1 family) were noted to be living near or in a joint-family with a married son (usually the eldest). Constant interpretation created pressure for the 2nd and 3rd generations although the 1st generation appeared unaware of it. The 2nd generation experienced anxiety (from leaving family who lacked English at home alone, particularly the elderly). Aside from the GrandMa who had learned English, none of the female participants who

lacked English and/or literacy were able to drive.

The place of worship for social contacts was also important for elderly 1st generation particularly those who lacked English and signified a shift from the material towards religion (cultural norm).

The impact of language barriers on the female subgroup are considered from three perspectives: *individual*, *social* and *societal* which are commonly used in literature (e.g. Castells 2000, Sekhon and Smizigen 2005) to better understand phenomena. The data also prompted using these perspectives: participants spoke of themselves (individual), their families and communities (social) and their interactions with service providers (societal).

- **Individual level:** A high reliance on interpretation made this subgroup potentially vulnerable to misinterpretation, a lack of information and stress (no interpretation). Daily living was confined to the EMC community and providers when family were absent. Although cultural cul-de-sacs offered a comfort zone, difficulties were repeated when support was needed from indigenous staff. They also experienced negative attitudes from some ethnic minority staff. There were on-going health and safety implications (cannot follow written instructions, relied on memory), potential for isolation and loneliness (if the family scattered rather than maintained a joint-family or lived in an indigenous neighbourhood). Interpretation added to time pressures for the 2nd generation. Benefitting from an 'information age' required materials to be interpreted or in audio-visual formats. Potentially, this lead to low empowerment, low confidence and almost static mental models.
- **Social level.** This subgroup were confined to companionship within their own community. They were potentially vulnerable to vested interests, poorer job prospects, exploitation in the job market and the attendant economic consequences. The needs of aging were rarely discussed (cultural factor) topics touching on the mortality or longevity of elders (being widowed) made it difficult for the 2nd generations to explain the need for English to

prepare parents for the future. Encouragingly, two-thirds of the female subgroup had realised the need to learn (even belatedly aged 75+) whilst some faced impediments.

- **Societally,** there was low interaction with this subgroup. Their economic contribution was low, they were less able to guide new generations in the host culture and, without a degree of communication, could not acculturate even when they wished to.

In order to better understand why a female subgroup (Indian Subcontinent) have not learned English, some contributory factors that potentially influence them were tabulated and their nature considered (Table 4.13).

Table 4.13 Some factors that potentially influenced 1st generation EMC females (Indian Subcontinent) and a poor motivation for learning English.

Potential contributory factors	Result/ Implication	Type of factor
Familial support is expected	Someone will translate.	Cultural
Gender segregation	Minimises contact with indigenous public. Possible shyness, a lack of confidence.	Cultural
Personal choice (particularly females unaccustomed to education)	It is too difficult.	Cultural or Contextual
Personal choice (living in a DIY society.	I am too busy.	Contextual
Lack of understanding: the wide benefits of English	Lack awareness; poor motivation.	Contextual
Lack of understanding: needs of aging (some issues are taboo)	Lack of understanding: the need for English.	Contextual and cultural
Feeling better off than 'back home'.	Contentment. 'Free' medical care, education for children and like benefits	Contextual
Negative male attitudes towards acculturation of females.	There is no need to learn/ learning is hindered.	Intra-cultural
Living in ethnic minority neighbourhoods.	There is no need to learn.	Contextual

It is noteworthy that contextual factors dominate these influences. That life in the UK compared favourably with that 'back home' perhaps inadvertently added to a lack of understanding/ motivation, some cultural factors added to shyness, a lack of confidence and some faced hindrance from males.

Table 4.14 broadly summarises participants' difficulties and preferences by generation.

Table 4.14 A summary of difficulties cited by EMCs by generation and gender

Generation	Age	Males	Females
1st	Older (40 and over)	English skills ranged from little to fluent but they managed. Have to support females of same generation lacking English. Audio-visual products very popular. Main difficulties: Instructions (too much or too little text, small fonts, poor contrast). Prefer more images in instructions.	Audio-visual products very important. Most difficulties arose from a lack of English (one exception). Highly reliant on family to communicate with local services and in following instructions. Main difficulties: Services cited more than products, particularly healthcare. Lack confidence and empowerment. Very sensitive to attitudes of respect. Memorise everything: learn through repetition or only use ethnic minority services. Leave purchasing decisions to 2nd generation.
	Younger (up to 40's)	English skills ranged from good to fluent. Audio-visual products were very popular. Very sensitive to attitudes of respect. Have to support females lacking English. Main difficulties: Healthcare (feeling they received a lack of respect and empowerment). Instructions (as above).	A sub-group lacked English, some face intra-cultural impediments and attitudes to learning English but have higher expectations of learning English and communicating on behalf of family. Also keen on education. Main difficulties: Similar to older 1st generation. Also cited difficulties with social and job centre services.
2nd	Older 30's-40's	Education in the UK has helped to overcome barriers. Likely to be well integrated. Keen to teach 3rd generation religious norms. Very sensitive to attitudes of receiving respect. Have high aspirations. Fluent English; community language mainly spoken. Audio-visual technologies very popular, ICT, cars and exotic holidays.	

		Main difficulties: More difficulties with products than services; however product difficulties are similar to the indigenous populace. Some problems with healthcare (process). Lack time from socio-economic responsibilities combined with constant interpreting for family members. Lack time to learn new ICT features and functions (too many, too complex). Instructions have too much text; prefer more images. Feel frustrated and dis-empowered. Like, but do not trust, internet services.
	Younger 20's and under	Likely to be as well integrated into Western lifestyle and education as the 3rd generation: have similar technological knowledge and preferences. Audio-visual technologies, ICT, cars and exotic holidays very popular. Less sensitive to attitudes of receiving respect. Have high aspirations. Fluent English; community language mainly spoken. Feel more British but some are unable to admit it. Have to support 1st generation with interpretation or instructions. Main difficulties: Cited more problems with products and a few using services. If family are religious, are likely to face greater intra-cultural pressures to conform and to learn prayers, females more than males.
3rd	Likely to be more integrated than the younger 2nd generation. Difficulties and preferences appear aligned with the indigenous population. Have very high aspirations and brand awareness. Are keen on audio-visual and ICT technologies and like to travel. Agree there is a generational technology gap and are called upon for interpretation and technological support. Favoured more images in instructions and education as a route to a good future. Fluent English; community language mainly spoken (the youngest were losing the skills). Feel more British but retain sense of ethnic identity. Main difficulties: Some difficulties with products but none with services. Otherwise, appear similar to the younger 2nd generation.	

4.7. Conclusions

Many participants appeared to be adapting well but a 1st generation female subgroup continue to face particular difficulties in communicating needs particularly to healthcare staff, including long-term residents. Of the difficulties identified, healthcare services were selected for the second study and negative attitudes from some staff (Indian Subcontinent) were felt to be best addressed through staff training.

In considering the research questions and the literature, we may conclude

that some cultural factors and inter-cultural dimensions do impact on the take-up of products and services for EMCs although this varies considerably between families.

Depending on one's point of view, language barriers may be considered a cultural factor or contextual factor. It is suggested that, although 'language' is an attribute of culture, 'language barriers' are a contextual factor, that of living in a different country often through choice and several contextual factors appear to have contributed to this problem. Democratic societies like the UK's place few barriers to people maintaining their cultural heritage, thus, it is suggested that fresh approaches like acculturation (e.g. promoting the wide benefits of English) need consideration alongside diversity initiatives to empower this female subgroup and thereby, their wellbeing and social integration.

This would take time and sensitive planning but concords with the dynamic nature of cultures (Storey 1999). Not viewing culture as a static phenomenon opens pathways to nurture positive change and to motivate people particularly when they better understand what those benefits might be as indicated by the positive case.

Three themes were carried forward:

- From services, the difficulties in communicating with indigenous staff, the anxiety and emphasis on healthcare, and the difference knowing English made (positive case).
- From products, arose the importance of audio-visual products for all generations; that images in instructions (visual communication) were preferred to empower individuals, improve usability and save time and those facing language barriers learned through repetition.
- From acculturation, we noted a desire for English-learning by the 1st generation and anxiety and time pressures faced by the 2nd generation.

The second literature review that laid the theoretical framework for the 2nd study is described in the next chapter.

4.8. Validity and Reliability

The validity and reliability rested in following the methodology: ecological validity, neutral and open questions, open descriptive coding and building the themes, avoiding generating meanings too early in the process. The themes were generated by the data. Also, there were no right or wrong answers, findings were interpreted in accordance with insights from literature to gain better understanding of phenomena and considered repetition of themes and constant comparisons between participants' views.

Generalisability of these data rests with the concept that, if a phenomena exists amongst a smaller sample of participants it is likely to feature among a larger sample (Robson 2002).

4.9. Reflexivity

The researcher accepts that, to some degree, the questions and categories guided what was being investigated (see 3.9.1.) and related specifically to services and products and any difficulties or preferences thereof. Thus, services and products were the main categories and the concepts were those explored like ease of use (usability), availability, difficulties, etc. Healthcare was selected to be explored further because it was a strong theme and because of its importance generally and the particular distress cited by participants. Finally, the researcher had an interest in this area as it is ubiquitously important.

5. Literature Review (2)

This short chapter sets out a literature review which extended the theoretical framework to lay the foundation for the second study with healthcare staff. It explores diversity initiatives and views within the NHS, the significance of patient experience and the factors that impact upon it, discusses interpreter and translation services, pictorial aids in healthcare and concludes with a discussion. This chapter addressed overall research objective 5.

Obj:5	To review the literature as research progressed to lay the theoretical foundation for subsequent studies.

5.1. Introduction

The following topics were reviewed to inform user study 2 with healthcare staff:

- Diversity initiatives in the NHS
- Patient experience from healthcare and design disciplines
- Factors impacting on patient experience
- Interpreter/ translation services
- Pictorial aids

Across UK's public sector, including healthcare, EMCs are commonly called BMEs (black and minority ethnic). BME is defined as people: "who do not define themselves as being White using the 2001 Census definitions" (The Electoral Commission 2005). User and patient are used interchangeably in this review.

5.2. Diversity Initiatives: Views from the NHS

In his report *High quality care for all,* Lord Darzi (2008) highlighted the importance of the entire patient experience within the NHS, which led to the development of the *NHS Constitution* which service providers and commissioners have a legal obligation to take into account in all their decisions and actions. Lakhani (2008) reported 'dysfunctional communication with BME people and proposed *personalisation* as the key. By March 2010,

the *Inclusion Health* project was lauded for making much progress, but more sophisticated and flexible responses were required to continue improving access and quality of services for socially excluded groups (Cabinet Office 2010). The NHS has made considerable efforts to improve patient experiences, including the website *NHS Choices* (to provide comprehensive information to help people to manage and to have choice about their healthcare) and the patient advice and liaison services (PALS), and on-going diversity initiatives over the past decade (National Institute for Health and Care Excellence, NICE 2012).

However, early in 2011, Paul Streets (2011:pp.11-17), Director of Public and Patient Experience and Engagement, UK Department of Health, concluded that further refinement and development were needed to fill gaps in care because patients' experiences closely related to, and influenced, clinical effectiveness and safety (Figure 5.1). Later that year Imison *et al's* (2011:p.1) report *Transforming our health care system: Ten priorities for commissioners* emphasised Corrigan's view, that one of the greatest untapped resources within the NHS was the empowerment of patients. Proactively engaging with patients was a common theme in the 10 priorities they identified for commissioners transforming UK's primary healthcare services.

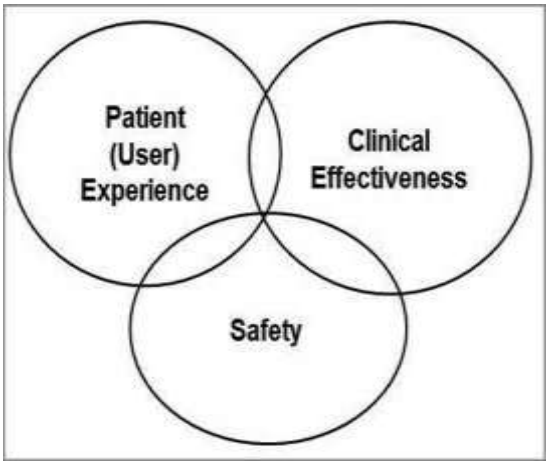


Figure 5.1 The importance of good patient experience (Streets 2011, adapted)

To improve clinical effectiveness, the NHS uses a plan-do-study-act (PDSA) model which is similar to the inclusive design waterfall model (Figure 2.1): the PDSA model's 4 stages involve (Figure 5.2):

- Plan - the change to be tested or implemented
- Do - carry out the test or change
- Study - data before and after the change and reflect on what was learned
- Act - plan the next change cycle or full implementation.

Changes to service processes should be initially tested on a smaller scale before being implemented widely as, sometimes, the changes do not produce the expected results. The cycle is repeated as often as required and it is possible to run several PDSA cycles sequentially, or when the changes are more complex or involve several departments, to run simultaneous cycles (Figures 5.3-5.4) (NHS Institute for innovation and improvement 2008).

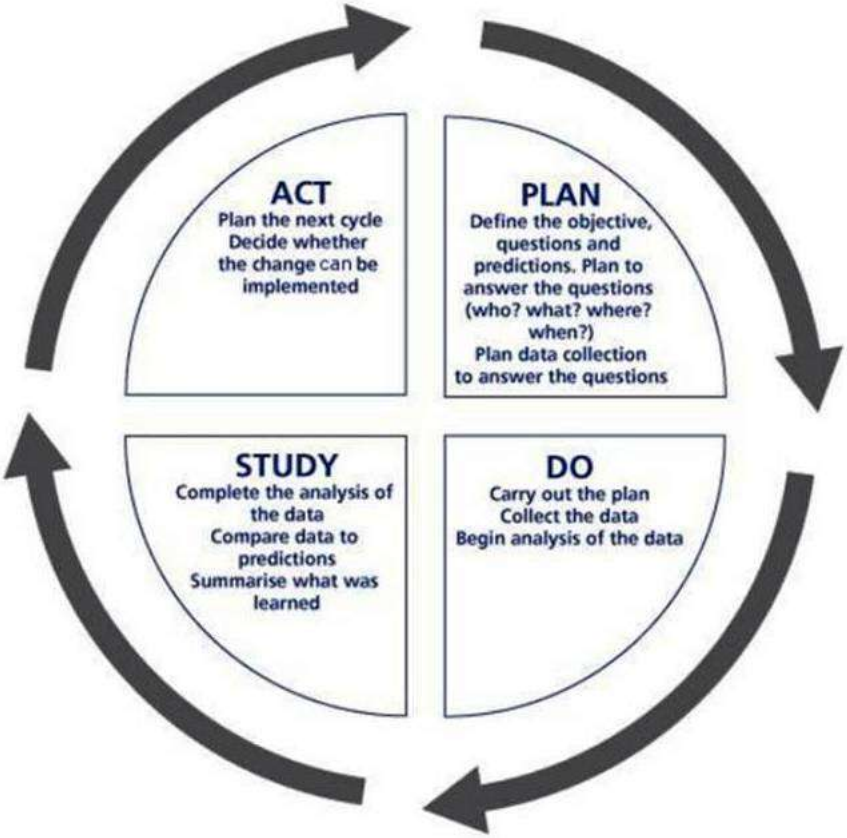


Figure 5.2 The PDSA model (NHS Institute for innovation and improvement 2008)

Figure 5.3 The PDSA model used sequentially (NHS Institute for innovation and improvement 2008)

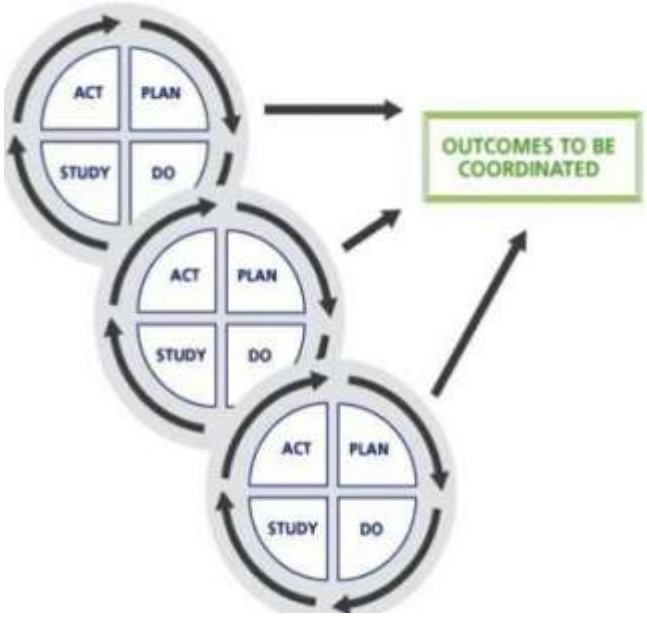


Figure 5.4 The PDSA model used simultaneously (NHS Institute for innovation and improvement 2008)

The model is based in scientific methodology and its purpose is to moderate the impulse for immediate action with the wisdom of careful study. The PDSA cycles form part of the improvement guide, which provides a framework for developing, testing and implementing changes leading to improvement. This framework poses 3 key questions and a process for testing change ideas: What are we trying to accomplish? How will we know if a change is an improvement? What changes can we make that will result in improvement?

The PDSA model supports the NICE (2002) 'audit cycle' (Figure 5.5) in its Quality, Innovation, Productivity and Prevention programme (eQIPP) to map, introduce, test, evaluate and effect change to facilitate improvements in care. The eQIPP programme is an online, national Department of Health strategy involving all NHS staff, patients, clinicians and the voluntary sector with the aim of improving the quality and delivery of NHS care while reducing costs to make £20bn efficiency savings by 2014/15 which, it is proposed, will be reinvested to support the front line (eQIPP undated).

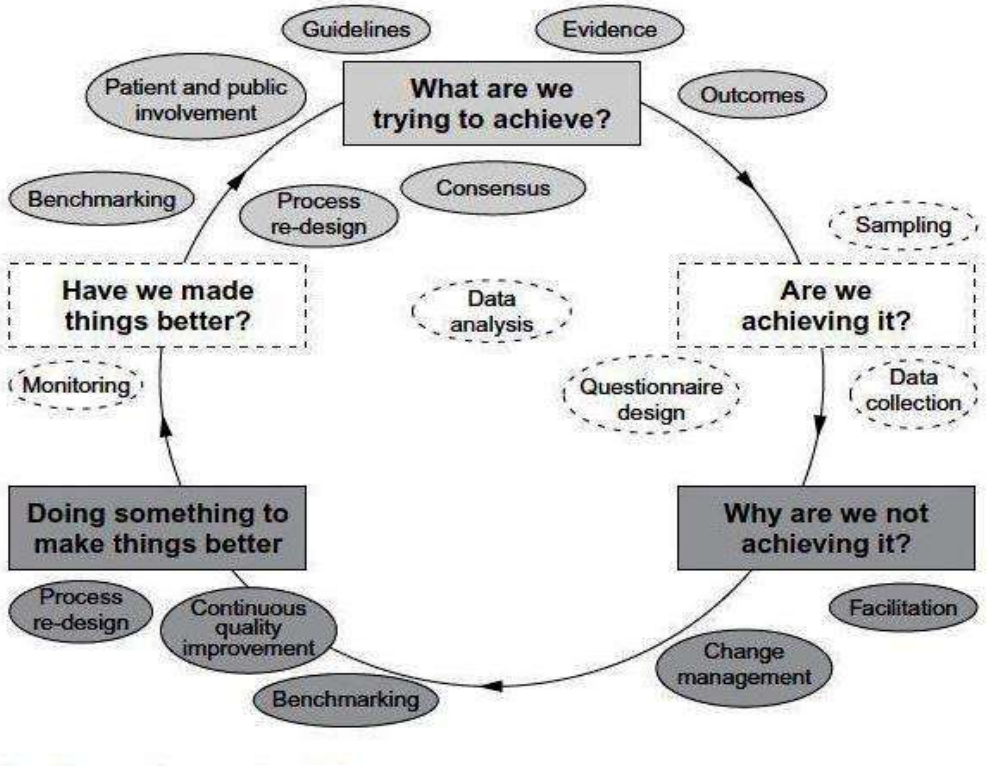


Figure 5.5 The clinical audit cycle (NICE 2002)

5.3. The Significance of Patient Experience

Streets (2011) emphasised that a patient-centred approach produced better clinical outcomes. Improved doctor-patient communication resulted in improved medication adherence and enabled greater self-management for people with long-term chronic conditions. It reduced individuals' anxiety and fear which could delay healing and the outcomes of surveys indicated more needed to be done to involve patients in decisions about their care/ treatment, to provide information to patients about treatment and conditions and to inform patients of medication side effects and the danger signals to look out for (Streets 2011). Johnson (2004), Professor of Diversity in Health and Social Care, concurs: good communication is critical to diagnosis, patient safety, compliance and health promotion, and NICE (2009) agrees.

Wensveen (1999, adapted) suggests that, to truly improve patient experiences, it is not sufficient to design services that function well. We need to design services and products which will provide positive user experiences (citing Sanders 1999) for both the user and the service provider, or to design

contexts for positive experiences (citing Overbeeke *et al* 1999). Doing so requires new methods to access and capture the experiences of users and this information can be an inspiration for design (Wensveen 1999).

However, Sanders and Dandavate (1999:pp.87-8) observe, it is difficult to 'design experience', because experiencing is a constructive activity. The experience of communication is constructed in equal measure of what the 'communicator' and 'communicatee' bring to the interaction. To design for experiencing requires us to have access to both parts: what is being communicated and what experiences are influencing the recipient. Boisaubin and Winkler (2000) add that a greater awareness is required of the complex nature of human beings whilst communicating.

5.4. Factors Impacting on Patient Experiences

How people communicate can depend on many factors. To summarise what we noted in the literature (see 2.2.3.1), cultural differences affect peoples' perceptions, thinking and behaviour differently, and their interpretations matter particularly in safety critical environments. It is also pertinent that people from high-context societies prefer thematic arrangements when information is being communicated whilst different approaches like individualism vs. collectivism can affect user decision-making and interaction. However, Rau *et al* (2008) highlighted the importance of avoiding mistakenly ascribing differences in users' goals, tasks and psychological variables to culture.

In healthcare, language barriers and low-literacy attenuate outcomes, result in poorer quality of medical decision-making, patient understanding and accessing healthcare and medication adherence (Johnson 2004; Safeer and Keenan 2005; Katz *et al* 2006; Amalraj *et al* 2009; Ngoh 2009; Salazar 2010). Although doctors speak slowly, limit information and use simple words, patients were more likely to be hospitalised whilst needs grew with aging (Safeer and Keenan 2005). Pharmacist-patient counselling improved medication adherence, but is deterred in busy pharmacies with heavy workloads of high volumes of prescription dispensing (Raynor 1992, American Pharmacists Association 2004).

The use of language is critical to the processes of caring for and encouraging patients, for patients to communicate their needs whilst hospitalised, to explain they are not eating due to religious fasting and in understanding medication instructions (Johnson 2004). Inherent meanings can differ even when using a common language and *"when dealing with ethnic and religious diversity, language differences are multiplied".* For instance, patients might describe their symptoms using terms or metaphors that are alien to the clinician. Communication cannot be effective without a shared language and this is a source of stress and, potentially, of confusion or conflict and it is doubtful that interpreters can fully resolve these difficulties as communication can be part of a therapy, like psychotherapy (Johnson 2004).

Speaking of internet services, usability expert, Nielsen (2006), highlighted 3 barriers (divides) which impact upon and alienate users from taking full advantage of facilities*:* economic, usability and empowerment. These seem pertinent to all services. Fortunately, for patients in the NHS the *economic* divide is, largely, not an issue. Nielsen ascribed usability and accessibility barriers to low-literacy and felt the empowerment barrier was the most difficult to overcome, resulting in 'participation inequality'. Some people did not participate *"because they lack the initiative and skill to take matters into their own hands"* and, thus, might be *"at the mercy"* of other people's decisions (Nielsen 2006).

Low-literacy is a barrier to health literacy*,* the basic literacy skills that enable patients to understand the healthcare environment and most patients are unwilling to admit to low-literacy (Safeer and Keenan 2005). Older patients can be particularly affected as their reading and comprehension abilities are influenced by their cognition, vision and hearing. In the USA, difficulty in accessing healthcare, following instructions or medication adherence result from healthcare materials written at a 10th-grade level whilst 20% of the population were at, or below, 5th-grade. Patient information needed to be at simpler reading levels, *preferably including pictures and illustrations* (Safeer and Keenan 2005).

Difficulties with hard-to-read materials were highlighted as far back as 1994 (Plimpton and Root 1994) and healthcare providers were unaware that

patients misunderstood oral instructions resulting in non-compliance and increased costs. All people preferred easy-to-read materials, whether or not they needed them. Wilson ***et al's*** (2001) study (NHS Centre for Reviews and Dissemination, University of York), aimed at developing patient information leaflets, highlighted that patients felt the leaflets were useful but that nurses should go over the information with them when their conditions were newly diagnosed. However, they found no evidence that the leaflets helped patients to *initiate* discussions with their health professionals. Charvet-Berard *et al* (2008) concluded that substantial efforts were required to improve the quality of patient information leaflets and suggested using a tool, such as the expanded EQIP scale (ensuring quality information for patients), of which several criteria coincided with the British Medical Association's patient information appraisal.

For, Kountz (2009) there remained a need for collaboration between healthcare providers to overcome barriers to health literacy to enhance quality of care, despite the advances in strategies to improve patient comprehension (as identified above), and the use of pictures and confirmation of patient comprehension *"via the 'show-me' or 'teach-back' method*". The international Cochrane Collaboration (2012), feels that collaboration needs to be wider: creating effective healthcare required equal partnerships between researchers, providers, practitioners and patients – and, one might add, families or friends.

In a study with Latinos with low-literacy or poor English in the US and a review of healthcare information on websites, Salazar (2010) identified a previously unknown group, *promotoras,* who voluntarily helped patients by translating healthcare information from websites. Salazar made several suggestions: healthcare websites should also be in Spanish to enable toggling between pages in Spanish and English; information needed to 'repurposed' for such groups and tiered on websites; communication of information should consider respect based on family, status etc., the use of plain language and the helpfulness of visual communication. She also proposed that respect (a 'cultural value') was an important design principle and need:

> *"Appropriate deferential behaviour towards other based on age, sex, social position, economic status, and authority."*

Accessing information also bedevils professionals. Professor Hedges (2011, Cornell University), stated that US health information systems were still predominantly localised and the lack of access to medical histories across States hindered medical care when residents of one State needed attention whilst in another. Recognising the problems, President Obama allocated $20bn, for the development of the Health Information Technology (HIT) system infrastructure, but this was complicated by differing inter-State IT laws (Hedges 2011). Fortunately, differing laws are not a consideration across the UK's counties.

Considering the impact of health literacy, culture and language on transcultural nursing, Singleton and Krause (2009) stated that nurses needed to practise cultural self-awareness to *"recognise their own cultural and linguistic assumptions and biases*", and "*to recognise [a patient's] health literacy assumptions and biases"*. Nursing practice had not included provider self-assessment in health literacy, and *"cultural competence self-assessment tools that incorporate health literacy"* were required for assessing patients' linguistic skills, cultural norms and health literacy for the patient's plan of care. However, they observe that

> *"The challenges related to this integrative process are daunting considering all the other challenges nurses face in providing daily care to their patients."*

They concluded that In the coming years, quality care would require the integration of all three in ways practical for nursing and to make a difference in the patient experience, and

> *"Nurses are in an ideal position to facilitate the interconnections between patient culture, language, and health literacy in order to improve health outcomes for culturally diverse patients."*

In the UK, the NHS purchases interpreter and translation services to communicate with patients lacking English.

5.5. Interpreter and Translation Services

Providing the best healthcare to every patient is a cornerstone of the UK's National Health Service (NHS) and, for patients lacking English, the NHS purchases interpreter-translation services. In recent years, the reported costs of such services have prompted growing public concern heightened by a lack of accurate figures (Bendoris 2008, Martin 2008, Holden 2009, Connell 2011, Wilson 2011). Costs to the NHS were 'conservatively estimated' at varying between £23m-£55m annually during 2006-2011 and covered 120 languages (Easton 2006, Chapman 2012) when ethnic minorities were estimated at only 7-9% of the population. Khan (2011) ascribes costs to services as being 'ad-hoc' per Trust, adding that the figures are much higher, possibly tenfold. Recently, NHS Portsmouth, a primary care Trust, made interpreters in 30 languages available to 110 healthcare services (GP practices, dental and orthodontic premises, pharmacies and opticians), for patients lacking English to ensure "fair and easy access to all health services for all residents remains a priority for the NHS" (The News 2012).

Despite these initiatives and the costs incurred, EMCs (Indian Subcontinent) cited difficulties in using healthcare services (study 1). Khan (2011) maintains that the NHS is still failing ethnic minority patients; that more needs to be done like streamlining services. For Khan (2011), the facilities for patients lacking English are no more than those required by patients with special needs - whilst it might be debatable, such support remains necessary in an era of international travel, particularly in countries providing healthcare free at the point of delivery.

In a review of translated materials in Asian languages produced for UK's Arthritis Research Council, experts Johnson *et al* (2006:pp.21-22,33) lauded the good work, but noted problems with translations included complex words which were not understood; English words were transliterated (not translated) because they lacked equivalents; people had difficulty understanding audio translations due to regional variations in pronunciations in the same language; listening to audio-translations could be boring and leaflets rather dull. In the same study with 120 multi-lingual BMEs (Indian Subcontinent), 86% of the respondents agreed translated materials were needed for BME

groups and only 3% felt it was not necessary of whom one felt BMEs should learn English (Johnson *et al* 2006:p.27).

Interestingly, the view of that respondent concurred with that of a Bangladeshi human rights lawyer. A BBC report (Easton 2006) quoted Zia Haider Rahman's view that his community was putting off learning English due to translation services:

> *"They are doing harm because they are reinforcing the language barrier which separates this community from the rest of Britain. They are de-incentivising Bangladeshis from learning English."*

The reporter was introduced to a Muslim female in her early 40s, a UK resident of 22 years who did not speak any English and feared to speak openly. Her view was that interpretation and translation support, albeit well-meaning, had "ruined her life":

> *"When you are trying to help us, you are actually harming us. All we have to do is say hello and they are here with their interpreters. We just sit here doing nothing and we don't need to speak in English at all."*

She explained that many men brought girls from Bangladesh as wives and deterred them from integrating [i.e. learning English] 'effectively enslaving' them because: "*the husband fears they will be corrupted, that she will gain courage and she will learn how to operate in this country."* She urged:

> *"There should be a law that requires these newcomers to learn English and that stops their families from preventing them learning English" (Easton 2006).*

These views have a direct bearing on NICE (2009) guidelines, which state that for good staff-patient communication, it is necessary to involve patients in decisions about medicines and to support medication adherence. NICE set out 32 guidelines for staff under 4 categories: Communication; Increasing patient involvement in decision-making; Understanding the patient's knowledge, beliefs and concerns; and Providing information. There are a further 17 suggestions under Supporting adherence, Reviewing medicines and Communication between healthcare professionals. These guidelines include establishing the most effective way of communicating; making information accessible and understandable (e.g. using pictures, symbols,

large print, different languages, an interpreter, a patient advocate); encouraging patients to ask questions; asking open-ended questions to uncover patients' concerns; acknowledging patients' views about their condition and treatment; providing information about medicine before prescribing it. Questions such as: what the medicine was for and the likely benefits; any likely/significant adverse effects and the actions to take if these occurred; how medicine should be taken and what to do if a dose was missed; whether further courses of medicine would be needed and how to get supplies; the risks if the patient stopped, or decided not to take, the medicine (NICE 2009); and so forth.

Improving patient comprehension through visual representations or pictorial aids is a topic around which there has been much research in healthcare and in design including information technology, icons on products and signs or information for services.

5.6. Pictorial Aids: The benefits and challenges

Pictorial aids are often assumed to be a self-explanatory universal language but viewers interpretations can differ due to unfamiliarity or from socio-cultural factors, like low-literacy, language or cultural differences (Dowse and Ehlers 2004; Pappachan and Ziefle 2008). Accurate interpretation depends on a viewer's degree of visual literacy, i.e. understanding for thinking and learning (Dowse and Ehlers 2004). Also, on users' mental models influenced by prior technical or domain knowledge (Pappachan and Ziefle 2008) and semantic distance and familiarity (Isherwood *et al* 2007). Differences in interpretation may be important for a service or product but particularly so in safety critical environments (Crilly *et al* 2008). Mis-interpretation may result in difficulties in accessing or using facilities to their full potential (*usability divide,* Nielsen 2006).

A great body of social and healthcare literature addresses how materials should be prepared to overcome low-literacy barriers (Mangan 1978; Plimpton and Root 1994; Doak *et al* 1996; Dowse and Ehlers 2004; Johnson *et al* 2006; Weiss 2007; NIH 2012). Boisaubin and Winkler (2000) affirm that although medicine has been a visual science since early times from the

drawings of anatomists to current high-speed scanners, images of anatomical parts do not necessarily help patients better understand their problems. They propose that *images in various media should be used.*

In a study in South Africa on the comprehensibility of medication instructions with people of different communities, languages, education and literacy, Dowse and Ehlers (2004), highlight Doak *et al's* (1996*)* observation that people with low-literacy required healthcare information materials in their first language accompanied by pictorial aids because these were recalled more effectively than aural or text messages. Although the US Pharmacopeia Dispensing Information (USP) offers 91 standard pictograms for taking medication, many of these designs are for a more sophisticated audience. Their study highlighted the importance of designing and evaluating pictograms in co-operation with the target population because these 'local' pictograms were better interpreted than their USP counterparts. Johnson *et al* (2006:p.35) concur and presented *A Model for assuring Culturally Competent Health Information in Community Languages* which proposes a 4-phase process of evaluating, validating, translating and disseminating information.

Research on the comprehensibility of icons on mobile phones, with participants in Kerala (India) and Germany, concluded that icons could be 'designed for all' and would be interpreted correctly the more detailed and 'concrete' (transparent) the icons were (Papachan and Ziefle 2008). Users could recognise a picture but not always understand its meaning and, importantly, recognition rates rose with familiarity. Domain knowledge, technical or familiarity were critical determinants for accurate understanding and varied amongst groups, and designers needed to pay attention to cultural differences that resulted in incomprehensibility. For instance, a 'slashed musical note' denoting that the phone was silent was not understood by Indian participants unfamiliar with the symbol for musical notes.

5.7. Discussion

This literature review provided a foundation for understanding the complexities and the debate around the barriers patients face in accessing,

understanding and using healthcare services and materials. Some studies have focussed on a top-down approach (on healthcare staff), whilst others have focussed on a bottoms-up approach (involving public with low-literacy or those lacking the country's language). The author noted that Equality and Diversity Managers in Trusts promoted inclusion in healthcare through regular staff training.

News reports of males preventing females from learning English indicate added complications from intra-cultural gender-attitudes and, unfortunately, English-learning is mistakenly confused by some males with 'corruption'. This phenomenon appears to be more consistent within Muslim subgroups (as in Study 1), resulting in a lack of empowerment of some females or, in some cases active disempowerment. Other problems arise from process (lack of information), mis-understanding or lack of awareness on the part of healthcare staff as much as patients.

The results of Salazar's (2010) study differed on several points with the outcomes from Study 1:

- In Study 1, the female subgroup lacking English and literacy did not use computers or access websites (*usability divide;* Nielsen's 2006). Tiering information on healthcare websites would certainly be helpful, but rather than 'repurpose', to consider simplification (Safeer and Keenan 2005), Johnson ***et al's*** (2006) model for preparing culturally competent information and to consider thematic arrangements (Rau *et al* 2008). The multiplicity of languages (Chapman 2012) in the UK and diverse medical conditions does, however, make this a daunting prospect.
- EMC participants did not mention members of their community offering similar help as *promotoras.* On the contrary, they felt 'Asians help Asians less' and indigenous staff were more helpful.
- Constant interpretation resulted in familial frustration (Study 1).
- Study 1 concluded that encouraging English-learning could result in long-term and wider benefits to quality of life. EMC participants did not ask for more translations, rather to learn English to communicate with healthcare staff, which was not reported of Latino participants.

- EMC participants did not cite a need for *respect* from indigenous healthcare staff or difficulty with how information was communicated. Indigenous staff's respectful attitude towards each individual regardless of other factors was appreciated. However, a lack of respect was cited from some 1st generation staff (Indian Subcontinent).
- Unlike the Latino populace, *gender segregation* impacted on female EMCs (cultural factor), entrenched a lack of English and, thereby, accentuated language barriers. Males managed much better and provided the main interface with the 'the world'.
- Some EMCs (Indian Subcontinent) faced hindrances from community males over English-learning or acculturation.

Literature on pictorial aids offered insights into the challenges and possibilities for pictorial aids, the transcultural issues of note and guidance on how to prepare 'culturally competent' materials. Depending on the size of the image, it might be debatable whether more detail is more helpful.

It is clear that topics like language, low-literacy and cultural factors permeate discussions of patient wellbeing in healthcare. What is particularly notable, and laudable, is the great effort of staff make in understanding, self-assessment and training to grapple with the complexities of these problems. However, this forms only part of staff-patient communication experience whilst the other part, the contribution of patients lacking English is low (Sanders and Dandavate 1999:pp.87-8) and an untapped resource to greater patient empowerment (Imison *et al* 20111). With 120 languages (Chapman 2012) and myriad cultures added to the responsibilities of healthcare delivery, the challenges are daunting although nurses are in an ideal position to facilitate interconnections with patients (Singleton and Krause 2009).

5.8. Conclusion

This literature review provided valuable insights into the social, cultural and contextual factors that impede healthcare delivery, accessibility and/or usability for several patient groups, particularly those facing language and low-literacy barriers. Notably, pro-actively engaging with patients is

highlighted as an important resource in improving patient engagement and wellbeing.

Although, the NHS has made much progress in improving access and quality of services for socially excluded groups, more sophisticated and flexible responses are still required and demographic trends suggest costs for interpreter-translation services in healthcare will continue to rise, lending urgency to considering the problems afresh. For example at its simplest, the cost per hour of an interpreter vs. that for a TEFL teacher.

Patient information needed to be 'culturally competent', arranged thematically for EMCs and to include pictorial aids, although it might be debatable whether or not smaller images ought to be more, or less, detailed. Respect from indigenous staff did not appear to be an issue. Greater collaboration was required not only between healthcare providers, but more widely to also include patients and researchers.

Two questions were raised for this research. Given the interpreter-translation facilities and recent diversity initiatives, whether staff felt language or other barriers impeded their delivery of healthcare. If this was minimal, it would suggest that communication problems were more confined to EMC subgroups and design considerations would focus primarily on an EMC group. If staff did feel language barriers hindered them despite the facilities in place, then subsequent design approaches would need to consider the needs of both EMCs and NHS staff. To design inclusively, the needs of other patient groups would also need consideration. The second question was to determine whether the barriers identified presented an opportunity in which inclusive design might contribute to lowering a barrier.

The next chapter describes Study-2 with NHS staff, which sought the answers to these questions. It was an investigative study and used individual interviews to elicit data from staff in different disciplines and healthcare organisations, and the methodology used is set out next in the next chapter.

6. Study 2. NHS Staffs' Perceptions of Barriers and Aids in Healthcare for EMCs lacking English

This chapter describes the 2nd study with NHS staff that sought to better understand the problems cited by EMC participants in Study 1. It describes the methodology used, the findings and discusses these followed by a comparison of the views of staff with those of EMCs from study 1. This study addressed objectives 6 and 7 of this research project which enabled research questions 2 and 3 to be answered.

RQ2	What were healthcare staffs' perceptions of barriers and what aids were used to overcome difficulties?	**Study 2: Investigative** Service Provider NHS staff (Chapter 6 – Aim 2)
RQ3	What were the similarities or differences in views between EMCs and the NHS staff and what were the implications for inclusive design?	
Obj:6	To undertake a 2nd investigative, formative user-study with the provider's staff to better understand their perceptions of any difficulties encountered and their needs and preferences.	
Obj:7	To compare the results of studies 1 and 2 to determine whether inclusive design might play a role in lowering a barrier and accommodate the needs of both users and providers.	

6.1. Introduction

This was the first of two studies with the NHS and research was conceived and designed in 2 phases to reduce the time involved in gaining NHS ethical approvals.

Patients from the Indian Subcontinent were the focus and other patient groups who might share similar difficulties and benefit from fresh approaches were also considered in accordance with inclusive design philosophy.

It was announced by the coalition government in 2010 that the primary care trusts (PCTs), who were responsible for community healthcare services and supplier contracts and who would be involved in this study, were to be

abolished. Their responsibilities were being transferred to General Practitioner consortia over 2 years. These changes impacted on recruitment but, for the duration of both studies, recruitment for some participants remained through the PCTs who were also the relevant authority for ethical approvals.

6.2. Aim and Research Questions

This study had two aims:

1. To investigate participants' perceptions of barriers encountered whilst caring for EMCs lacking English, the aids employed, the impact on care and what would help further.
2. To determine whether there was an opportunity to design inclusively to lower a barrier identified, thereby, to benefit patients and staff.

These aims were addressed by answering the following research questions:

RQ.1. What were participants' perceptions of any barriers encountered whilst caring for adult EMCs lacking English, particularly EMCs (Indian Subcontinent)?

RQ.2. If present, what was the nature of the barriers and whom did they affect? Did other patient groups share similar difficulties?

RQ.3. What aids were used to overcome obstacles, including visual and audio communication? What were their strengths and weaknesses and were there any gaps?

RQ.4. Did participants in areas of higher EMC density adopt different aids or strategies to those in areas of lower EMC density?

RQ.5. What was the impact on healthcare delivery?

RQ.6. What did participants feel would help them further to overcome difficulties?

These findings would be compared with those of Study 1 to determine an opportunity for inclusive design. Figure 6.1 illustrates the study concept.

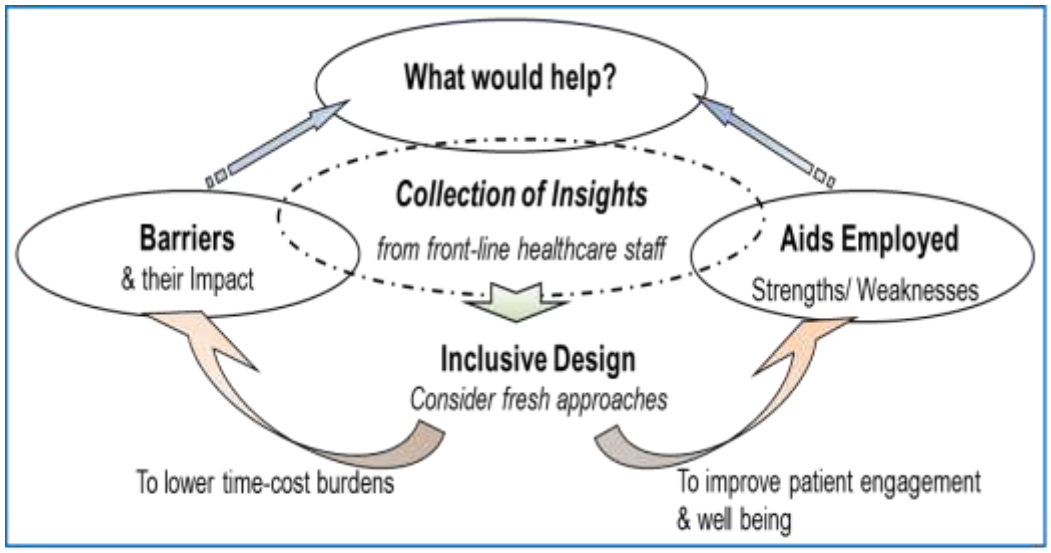


Figure 6.1 Research concept: Investigating NHS staffs' perceptions of barriers and aids whilst caring for adults lacking English

6.3. Methodology

6.3.1. Approach

An investigative, qualitative approach was selected guided by literature (see 3.6) to capture sufficient data to build a rich picture of current problems and the aids employed.

Research was guided by Evans *et al's* (2002:p.5, see 3.4.1) empathic approach which proposes holistically understanding problems by involving as many stakeholders as possible and urges '*Don't Assume: Ask the question'.* Also by Black (2008), who advises considering the widest range of users to ensure the full potential for design responses is understood (see 3.6) and the dynamic nature of culture (Storey 1999) which suggested pathways for positive change were possible.

6.3.2. Sampling and Recruitment

Purposive sampling focussed on front-line staff from 6 roles: paramedics, doctors, nurses, physiotherapists, pharmacists and receptionists. These were recruited from 5 Trusts in 2 English counties with differing demographics in the UK Midlands: 2 acute care trusts (ACTs), 2 primary care trusts (PCTs) and regional ambulance service. The inclusion criteria specified indigenous staff with experience of caring for adults with whom they did not share a

common language, particularly but not exclusively, patients from the Indian Subcontinent. The aim was to gain 40 participants. No patients were involved in the study. One ACT and PCT were located in a county where the EMCs (Indian Subcontinent) were estimated at 70%+ (majority population), and the other ACT and PCT were located in a county with an estimated 10% of EMCs (Indian Subcontinent). The ambulance service worked across the counties. The purpose was to determine whether the aids or strategies NHS staff used differed between the two.

The NHS, a coalition of Trusts and independent contractors, required different Trusts to be approached because staff were employed by different Trusts e.g. outpatients physiotherapists could be employed by an ACT or a PCT (Figure 6.2). Trusts were also sensitive to giving up staff time as the NHS was under much pressure from change.

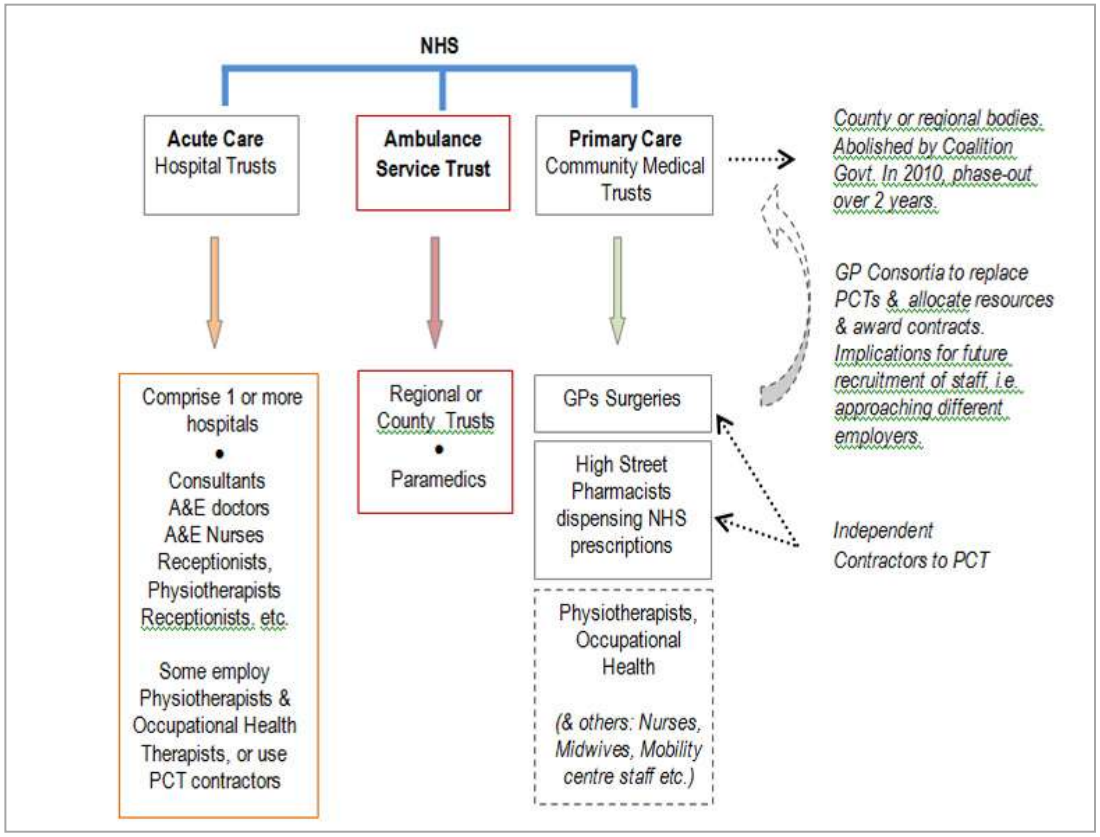


Figure 6.2 Where NHS staff were recruited from

6.3.3. Ethical Considerations

Ethical approvals were gained from Nottingham NHS Research Ethics Committee 1 (REC) and the 5 Research and Development (R&D) departments using the online IRAS (2010) system (Appendix-E3). *Consent Training* and *Good Clinical Practice* certificates were gained from the lead host. A Research Passport (for site visits) was compiled through Loughborough University's Research Office:

> University authorisation, Occupational Health clearance, Employer and Professional indemnity Insurance certificates, a CRB certificate

plus 5 Letters of Access from the Trusts. The Research Protocol submitted to the REC explained the research concept and rational (Figure 6.3) and how Study 1 led to research with the NHS which would be followed by phase 2 and would involving EMC participants and NHS Staff

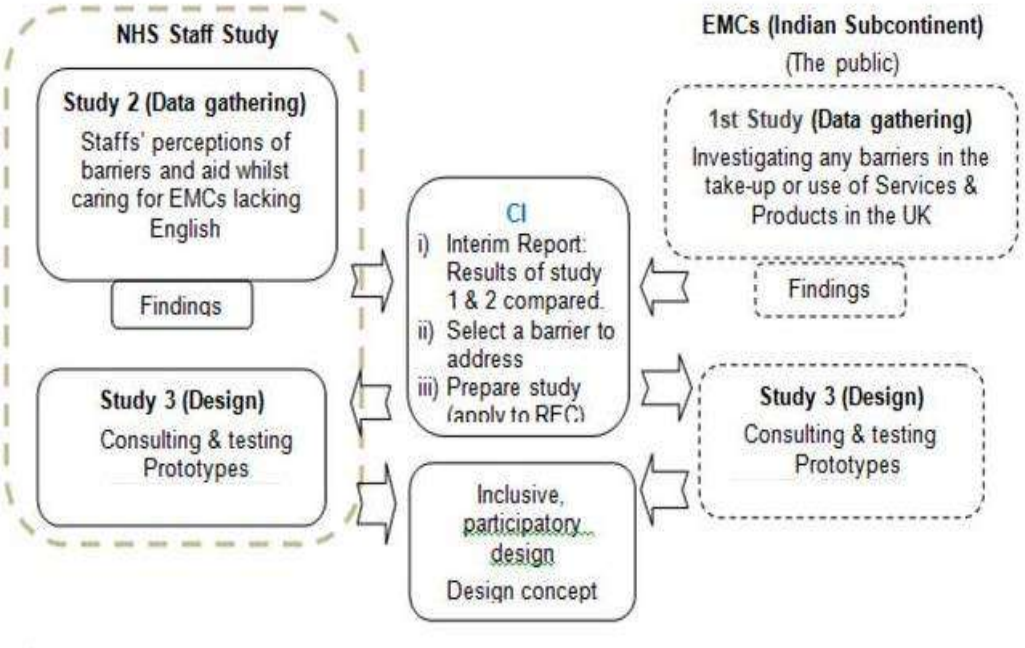


Figure 6.3 Research concept submitted to the NHS REC

The researcher answered questions before the REC's review panel of 12+ lay and professional members and, similarly, a Trust Governance Panel. They felt recruitment would be challenging and that a poster should be prepared.

There was minimal risk to participants who were fluent in English and were assured data would be securely maintained, anonymised and participants would be identified by reference and role to provide context. Vigilance was carried out by 5 Site Liaisons and 2 Academic Supervisors.

The majority of participants were sent Letters of Invitation and Information Sheets prior to the interview. However, those who volunteered on the day were given the information and 10 minutes were set aside for them to review the information and to ask questions: when they were happy to proceed, Informed Consent was obtained. A similar procedure was followed prior to each interview if participants who were sent the information had not reviewed it. These interview times were reduced by 10 minutes. Comfort stops were offered to avoid fatigue.

6.4. Methods and Tools

The study was designed to be time efficient to encourage participation as gaining volunteers was anticipated to be problem due to much proposed change and potential stress in the NHS. Semi-structured individual interviews, with open questions and probes were designed to gather rich data and to last no more than 1 hour. Participant information emphasised there were no *right/wrong* answers, no preparation was required, participation was voluntary and data would be anonymised and compiled for a 'bigger picture'.

The tools (Appendix-E4-E8) comprised:

- An A4 poster to attract participants (suggested by the REC)
- Letter of Invitation and a similar letter to Managers explaining the purpose of the study
- Participant Information and Informed Consent
- Interview questions (Appendix-C1)
- Interview questions explored any barriers staff experienced including language (if it was not mentioned), what aids were used to resolve difficulties, what were their strengths and weaknesses, the impact on care, what staff felt would help further and anything else they might wish to add that we had not covered.

Staff-patient interactions in the absence of an interpreter were of particular

interest. Participants were asked to estimate the percentage of EMC (Indian Subcontinent) patients they cared for in their department (to provide context) and the interview concluded with any other issues participants' wished to discuss. Questions irrelevant to certain roles were not asked, like follow-up appointments for paramedics or A&E participants.

Whilst the study focussed on participants' experiences with patients from the Indian Subcontinent, following an inclusive approach, questions were posed throughout of other EMC or indigenous patient groups who shared similar difficulties. This was to put difficulties into context and inform further stages of the research and to include as many patients as possible, who might also benefit from future recommendations and/ or design concepts. A choice of large chocolate bars was offered as a small token of thanks. The first interview was used to pilot the study.

6.5. Implementation

The study took place during a severe winter which further impacted on the availability of participants. Weather aside, it became clear the difficulty was *time* as many participants worked 12-hour shifts.

6.5.1. Recruitment

Participants were recruited from the roles mentioned (6.3.2 above). Recruitment was challenging, thus a rolling programme of contact-and-follow-up over several months was devised and an Excel spreadsheet designed to manage the process. Approximately 60 Department Managers, senior staff and PAs were contacted and information packs distributed to gain permission to approach staff. Guidance was gained from a Site Liaison to help overcome recruitment difficulties during a time of much proposed change for the NHS. Letters were also sent to the Trusts' CEOs to thank them for their Trust's participation and that of particular departments. The CEO's responses to the author were disseminated to departments (internally) and helped to secure further support.

Time was allowed for Managers to review the information as none were aware of the study. An additional 7 managers/ senior staff decided to participate. Recruiting ACT pharmacists proved the most difficult, almost

impossible. A shortage of wall space (generally) left little space for the poster to be displayed. It was handed out initially with information packs and then could not be used as the study progressed.

Some participants volunteered directly, others were suggested by Departments Managers/ Supervisors and, some volunteered on the day the researcher was on site. It became evident that availability was managed around workflow. The most successful means of recruitment proved to be to contact the Department Manager, provide information of an 'authorised study', agree a date/ quietest time for interviews; the Department Manager advised the Shift Manager who asked for volunteers according to the sampling criteria. If agreeable participants came forward and the ethics process described below was followed.

6.5.2. Interviews

The researcher travelled to meet participants and interviews were conducted in a room on-site (with management permission) or in a participant's home (ecological validity, Willig 2008). Interviews were carried out between 7 am to 10 pm to accommodate participants' shifts (before/ after, weekends, when children were abed, at quieter periods in departments). Anonymised interview schedules were emailed to academic supervisors in advance and periodic updates emailed to Site Liaisons. As requested, the numbers of interviews per month were logged on the host Trust research web-database. Where departments were busy, the researcher limited the interview to 40 minutes..

Participants were assured that there were no *right* or *wrong* answers, data would be anonymised, permission to record gained and the recorder switched on. If the department became busy, the interview was resumed the following day. Participants were offered chocolate bars and thanked by email or text later, as were the Managers when interviews in their department were completed.

In the pilot interview, the flow of questions flow worked well and to schedule. Following an inductive approach, one question was added under difficulties experienced: Do you receive irrelevant calls from EMCs or cases that are not emergencies?

6.5.3. Data Analysis

Data were transcribed, anonymised and subjected to thematic framework based analysis (Srivastava and Thomson 2009; see 3.7.4) in Word 2007 and Excel 2007. Data were organised in 4 categories: Difficulties experienced; Aids employed; Impact on workflow; and What would help further. Key texts in the transcribed data were emboldened and copied into the spreadsheet under the participant and themes in the relevant category (Appendix-C2-C5): new themes were added as they emerged. Data were simplified in a recursive process. Excel 2007 was used to analyse participants per role, years of experience.

6.6. Findings

The findings are set out as follows:

- The Participants
- Difficulties experienced
- Aids Employed
- Impact on Workflow
- What would help further

6.6.1. The Participants

The 34 participants included 20 females and 14 males (aged mid-20 to 60 years) who sometimes knew each other. 31 participants were indigenous, 1 was an Iranian immigrant and 2 volunteers were EMCs (Indian Subcontinent) who met the inclusion criteria and were included to provide a broader perspective. Participants by role included 7 doctors, 11 nurses, 4 paramedics, 5 receptionists, 3 pharmacists and 4 physiotherapists. Table 6.1 summarises the participants as a proportion of the sample and the years of experience in the NHS. Participants' combined experience represented 522 years (excluding training), averaging c.15.4 years, with 61.8% over 10 years.

Departments included Accident and Emergency (A&E), Assessment Unit, Orthopaedic Outpatients, Stroke and Elderly Care, Gynaecology, Oncology, Pharmacies (acute and primary care), Fracture Clinics, Receptions (Main/ Departmental/ Ward) and other Outpatients.

Table 6.1 Participants by role (*n*=34) and years of NHS experience

Role	% age of sample	Years of experience in the NHS (excluding training)		
		Lowest	Highest	Mean
Nurses/ Ward sisters	32.4	5	43	24
Doctors, Consultants, GP	20.6	2	31	16
Receptionists/ Managers	14.7	9	26	17.5
Pharmacists/ Managers	8.8	1	32	16
Paramedics/ Managers	11.8	5	24	15.5
Physiotherapists	11.8	2	26	14

6.6.2. Difficulties Experienced

The findings focus on EMCs (Indian Subcontinent) lacking English and/or literacy and their families, except where other patient groups are specified. Five overlapping difficulties were identified and are described below:

- Language barriers
- Low-literacy
- Lack of understanding
- Attitudes, Gender and Health beliefs
- Information retention

EMCs (Indian Subcontinent) cared for in different departments varied between 5-65% even where they comprised 65-70% of the population (majority). Other EMC groups and some indigenous patients shared some similar difficulties like communication barriers or anxiety. Indigenous patient groups were cited for different reasons like low-literacy, dyslexia, infirmity, or various degrees of visual or hearing impairments. EMCs groups who faced language barriers included: Eastern Europeans, Russians, French, Italians, Chinese, Somali, Africans, Afro-Caribbean, Middle Eastern, etc.

Participants' views[2] of difficulties and their impact varied considerably

[2]Legend: Staff are identified by alpha-numeric references as follows: R=Receptionist, PH=Pharmacist, PT=Physiotherapist, PM=Paramedic, N=Nurse, D=Doctor.

between departments. To provide clarity and context, participants were asked to state the generation of the patients or family cited (e.g. 1st or 2nd generation males might display gender attitudes but only some 1st-generation face language barriers).

6.6.2.1. Language Barriers

Participants prided themselves on resolving problems, however, 26 participants felt language barriers were the main obstacle and cited eliciting medical history, explaining and gaining accurate pain scores, communicating reasons for patient transport delays, arranging appointments by telephone, explaining medication and side effects or diagnosing and communicating problems. Physiotherapy for patients on elderly care wards was delayed until visiting times for family to interpret (PT2). A ward sister summed up the problem for nurses: *"Communication is 99% of our job"*(N5). Senior Nurses and a paramedic manager observed that older and younger 1st-generation females were particularly affected, along with some males:

> *"I don't know why I haven't thought of this before; we're also talking about the younger generations, because people come [to the UK] for marriage reasons and all sorts [of reasons] who have language barriers" (PM2).*

Sympathy for patients struggling to express their needs mingled with puzzlement over why even long-term residents had not learned English when it was so important to their wellbeing and, assuming it was a cultural issue, said nothing to avoid offence. A doctor commented:

> *"Even common conditions like constipation [require] drawing the shape of stools. The problem is no one has pushed them to learn [English] - without English they don't know to [whom to] ask or what's happening around them" (D5).*

Only 10% of one doctor's patients in acute care were ethnic minorities (although her colleague in the department cited 60%) in an area of ethnic minority density of 65-70% because she usually "passes them (patients with language barriers) on" to other colleagues. The difficulty for her was:

> *"Some patients can look confused all the time and it is unclear whether this is because they do not follow the medical problem or the language" (D7).*

Nurses in outpatients cited difficulties when doctor-patient conversations were not conducted in English. If a patient had not comprehended the doctor, nurses had to ask them to repeat the diagnosis in English and then find someone to explain to the patient (N9, N10). In contrast, a consultant noted that a few ethnic minority mothers had learned English over 4-5 years and were *"able to ask intelligent questions about future care proposed"* for their child (D3).

Eight participants cited they had no problems or only occasional problems because tasks were relatively simple (N3, N4), the process too quick (N11), few ethnic patients seen (5% in orthopaedics, D3, D4) or communication with patients was absent/minimal (in pharmacies PH1, PH2, PH3). When working in oncology, the pharmacist explained medication and checked progress with patients through interpreters or family (PH2); however, conversation with patients was minimised in pharmacies due to time constraints and heavy workloads. Pharmacists assumed patients knew how to take medication because repeat prescriptions were frequently dispensed or that their doctor had told them or they had help at home.

> *"There is no conversation at the moment, to say either they've got a problem or I'd like to help you find a solution. One hopes that information has gone into the patient and what we put on the label is a simple reminder because otherwise they're just remembering - but that could be dangerous" (PH3).*

All medication was dispensed labelled in English and language/literacy problems were not taken into considerations Asked whether labels should be in other languages, a pharmacy manager disagreed: English was critical to ensure he knew what he dispensed. Dosette boxes helped: *"Visually, it looks much easier than popping something out of a blister, opening a bottle and taking something out and reading a label* (PH3)", but patients still got confused (PH2, PH3). Pre-prepared dosette boxes (available for a fee) also presented problems and selling boxes to patients to self-fill was viewed with anxiety:

> *"We can't take everybody on, there's a capacity problem. They [patients] can get them [medicines] all mixed up, very, very easily (PH3)."*

Only one person was optimistic that language barriers were a passing phase

because people coming to the UK would speak English or learn it (D3).

6.6.2.2. Low-literacy

Ten participants cited low-literacy as a problem amongst some Asian patients and a further 7 felt it was a cross-cultural problem including Asian patients. However, 17 participants felt low-literacy was not a problem because they relied on family although one commented that the problem was in the *"long term, how to take medication, or read literature on the procedures"* (D7). A doctor in primary care felt patients were unable to articulate problems accurately and more time was required to explain: *"Just the important bit of the message*" (D5) was repeated 4-5 times, and there was concern for patient wellbeing:

> *"They don't know their rights - that they could ask the [Local] Council for assistance, if they are ill or old, or help from Social Services for a care worker" (d5).*

He also observed low-literacy resulted in a lack of confidence across cultures and included ethnic minorities lacking English, some indigenous elderly and teenage patients who preferred the doctor to select their treatment. A physiotherapist on the elderly care ward echoed the doctors concerns: that some ethnic minority families waited until crisis point before seeking help and observed that there was a growing number of elderly 1st-generation females from the Indian Subcontinent who lacked English, lived alone and had difficulties coping [PT2]. However, determining low-literacy needs based purely on appearance could be offensive and people were embarrassed to explain in front of strangers.

> *"What I would really benefit from is someone saying clearly, and with authority, what those patient's needs are. That's what I need to get to; that's where I need to get to" (PH3).*

Outpatient receptionists commented that some patients made excuses about filling forms in clinics and nurses had to help. Several reasons were cited: a lack of English, possibly low-literacy, poor vision, dyslexia, arthritis, or other frailties. Forms were not mailed to patients before appointments and, when asked if this would help, they agreed that it could give patients more time. Participants from main reception noted fear and anxiety amongst these

patient groups over navigating to departments particularly those outside the main building although maps and directions were provided. Patients were taken in wheelchairs to departments by porters but porters were not insured to go outside the building.

6.6.2.3. Lack of Understanding

This was a cross-cultural problem cited by 15 participants and a further 13 cited Asians patients in particular. Some 1st-generation females (from the Indian Subcontinent) did not understand the role of professional interpreters who were sometimes consulted over treatment: "What would you do?" or asked to hold their hand during therapy. Many females equated physiotherapy to a massage at hospital and the notion of exercise needed explaining before therapy could begin but a colleague observed the problem disappeared when physiotherapy was related to *yoga* (an ancient system of exercise in India). A 2nd-generation ethnic minority reception manager worried that some families cancelled their appointment without realising it could mean waiting for several weeks for another appointment. They also did not understand the purpose of ward procedures:

> *"They don't grasp why the hospital has condemned this [crowding around a patient's bed], the infection reasons, the restriction reasons. Why they say 'no' to [bringing] children. Why is the patient in the side room? Why have you got a gown on? Why it's not suitable for them to keep bringing things in" (R3).*

Paramedics felt 1st-generation ethnic minorities did not understand their role and there was general agreement amongst participants that the public, across cultures, did not understand healthcare services: *"the NHS looks complex from the outside"* (PH3). People used A&E inappropriately and 30-35% of paramedic call-outs were not related to emergencies but to *"jump the queue"* which was more common amongst the indigenous public. People did not realise they would have to wait as A&E operated a triage. Nurses in A&E faced difficulties over cleaning wounds from remedies like turmeric on wounds or toothpaste or oil on burns used by some ethnic minority patients.

For pharmacists, the implications of medication non-adherence were not understood: patients took medicine at the wrong time of day or stopped medication without consulting a doctor/ pharmacist if they were unhappy with

side effects. 'Percentage of risk' was not understood but research had found that when 'smiley faces' were grouped to depict percentages comprehension improved (PH3).

6.6.2.4. Attitudes, Gender and Health Beliefs

Fourteen participants cited problems with gender attitudes from males from the Indian Subcontinent resulting in interpretation problems, wasted appointments/time and uncertainty over informed consent. If staff-gender preferences were not known in advance appointments were wasted in small outpatient clinics if male family members (particularly Muslims) refused to allow a female patient to be examined by male doctors although a nurse was present. Who was objecting was unclear - the patient or family? This was less problematic in hospitals where more doctors were available. A 1st-generation husband tried to refuse paramedics entry to the house (his wife made the call) and a 2nd–generation son refused to discuss his mother's condition with a female ward sister and insisted on speaking to the (male) consultant.

Females were more likely than males to get physiotherapy exercises right because they asked and repeated exercises several times whilst over-confident males could hinder the process by reinterpreting or misinterpreting the physiotherapist's instructions during translation (PT3). Physiotherapy treatment could be halted when some males and females who were interpreting refused to view a family member of the opposite gender partially undressed (PT1).

For a 2nd-generation ethnic minority participant, some in her community were *'more demanding of services'* and less helpful than they might be:

> *"Even if they've got families at home who can help to translate, they will say they've got nobody" and some "just take it [the NHS] for granted. It doesn't matter, they'll sort it out" (R3).*

Patients and families needed to *"meet us half way: we're trying to make their life easy, but if they give us all the obstacles: we need a translator, we need this, we need that, then we're actually going through a lot of hurdles"*(R3).

Thirteen participants cited other cultural factors including religion and fear of

offending. Paramedics were expected to take off their shoes at a place of worship in emergencies by some ethnic minorities and found it confusing whom to address first: a female patient or male family member. Some problems were "*beyond language"* (D5) and correct diagnosis depended on understanding a patient's comments in the context of their culture and health beliefs. This affected how they perceived their problem and presented the symptoms which could be very different in other cultures (D5). A doctor commented that a patient attributed his illness to 'a bad spirit' which could have resulted in a misdiagnosis: *"If we hadn't found someone from the same culture, he could have been sent to psychiatry"*(D7).

6.6.2.5. Information Retention

Retention was a cross-cultural problem cited by 15 participants but 21 said it was not a problem (including some who acknowledge the problem) because they simply relied on the family to ensure that patients remembered. A consultant commented that people under stress recalled as little as 15% to, at best, 40% of what they were told (D3).

Sometimes even English-literate patients did not properly read information. A main receptionist recalled a patient lacking English was occasionally left at the reception of the wrong hospital (R1). Whether families were experiencing information overload was a concern for a ward sister (N5). Hospitals re-admissions resulting from not remembering medication was a big problem (PH1) although patients could be '*cute'* about medication: *"She knows she has to take the pink one at night"* (PH3). Some patients took another dose if unable to recall taking the first (even from a dosette box), some took a muddled pile of medicines to hospitals or pharmacies and, in an extreme case, a patient emptied all her medicines into a large sweet jar and *"Simply went every morning and randomly took one"* [gestured a handful] (PH3). In a new initiative to reduce re-admissions one hospital had begun telephoning oncology patients at home to determine how they were faring with medication (PH1).

6.6.3. Aids Employed

The aids and strategies employed by participants appeared to be broadly similar across Trusts but their use varied greatly between departments. They

appeared to be generally similar between areas of higher and lower density of EMCs (Indian Subcontinent, e.g. 70% or 10%).

Table 6.2 summaries these aids and the findings set out participant's views under 4 themes:

- Interpreters
- Translated information
- Visual-audio aids
- Other initiatives and strategies

Table 6.2 Aids and strategies employed by NHS staff caring for patients lacking English

	Aids/ Strategies		Type of aid (Use varied considerably between departments.)
1	**Interpreters**		• Familial/ Friend; Staff; Professional services; Colleagues. • Other: Bystander aid, Health visitors, Community volunteers.
	Other strategies		Simple words & limited information. Repetition. Patients asked to repeat information back. Speaking to other than intended recipient within their hearing. Google translation.
2	**Translated information**		• Leaflets/ booklets. • Multilingual phrasebook (paramedics)
3	**Audio-Visual aids**	**Visual**	• Widely: Self-demonstrations. • Few departments: drawing, models, illustrated leaflets, menu book, maps. • Some use: Communication Aid for Patients multilingual book, colour-coded corridors, picture cards.
		Audio	Language database
4	**Other Initiatives**		Public education: *In Case of Emergency* (ICE), *When is an Emergency not an Emergency*.

6.6.3.1. Interpreters

Participants took pride in competently resolving problems, *"We find a solution one way or another"* [R1]. The preferred order of interpreters was professional service, colleague and then family/friend. However, in practise this frequently worked in reverse to meet service delivery targets and to save time and cost [D7].

Family/ Friends: 31 participants used familial interpretation although it posed problems and the desirability of so doing varied considerably across departments.

"There is uncertainty of truly getting informed consent or whether responses

reflected a 'just fix it' approach. A husband may quickly speak to his wife and respond, but it was unclear whether all the complications were being communicated or the patient's needs/ wishes considered and communicated" [D3].

For instance, a husband (who understood a little English) instructed an interpreter to tell the doctor to remove his wife's entire breast, without consulting his wife (who lacked English), because he could not be bothered 'coming back again and again'. Ignoring this, the interpreter consulted his (tearful) wife directly, who chose to remove only the tumour. Confidentiality and signs of domestic violence (across cultures) were additional concerns for all participants. Familial participation was refused in gynaecology [N1], proactively encouraged in elderly care/stroke [N5] and outpatient physiotherapy [PT1], but a colleague in primary care felt family hindered the process [PT4].

Friend-interpreters were cited by 16 participants and one observed, 'a new trend':

"They build it into a social interaction, like a social outing; they sit outside chit-chatting, have coffee and go into town afterwards" [PT1].

For 10 participants, inappropriate interpreters made accurate interpreting impossible: a child, someone with poor English or the opposite gender/younger generation who declined to view the patient partially undressed. To ensure instructions were accurately conveyed and understood patients were asked to repeat these back to staff.

Colleagues were favoured for objective, accurate information and cited by 18 participants. Staff were recruited from different ethnic backgrounds also for their language skills, and were called for by phone or over loud-speakers from a register of volunteers maintained by the acute care Trust.

Face-to-face interpreters were cited by 12 participants and cited as particularly helpful because the body language of both interpreter and patient could be observed. The facility was available to most departments, except receptions and primary care pharmacies, neither of whom felt a need: the former found a solution 'one way or another' whilst the latter minimised

conversation. Logistics and the impact on service delivery targets could be deterrents *"especially if it's the middle of the night; I've never seen an interpreter brought into the [A&E] department" [D7].*

Telephonic Service*s*: The *Language Line* service was cited by 13 participants. 'In theory' a 3-way handset could set up a conversation, but single handsets were in use, resulting in a 'clumsy' process and confused conversation [D2]. Typically, a question was put to the patient and a pause ensued for the interpreter to transmit it. A long pause could cause uncertainty that the message had been understood by the interpreter, so the question would be repeated just as the interpreter began speaking [D2]. Some never/rarely used the service: it took too much time to set up; the patient's response was condensed by the interpreter so one could not *"gain a lot of things from what a patient says around what they've said"* [D7].

Doctors agreed that the inability to view the interpreter was a definite drawback: the implications of a patient's expressions whilst responding to an interpreter were lost; there was uncertainty the interpreter was *"telling you all of it"* or there was *"something else they [the patient] want to say but are not sure how to say it";* and a lack of privacy for patients when a phone was located in the main staff areas. One participant used the service only in conjunction with family/ friend:

> *"Using somebody who doesn't have any professional training for doing interpretation, most of the time we get a better outcome than using Language Line" [D5].*

Other support included bystander-aid (paramedics), health visitors and hospital volunteers (receptionists).

6.6.3.2. Translated Information

Websites. Individual Trusts, *NHS Direct* and *NHS Choices* offered abundant patient information. NHS Choices had translated materials in 12 languages (excluding Hindi) but on a limited number of topics (diabetes, cancer, pregnancy/ birth) which differed under the languages. NHS Direct offered interpreter services (in English). The bulk of information was in English.

Printed Information: Four participants routinely used translated materials, 6

had some translated materials but 22 had information only in English. A website with translated materials was available in one acute care Trust [D7] but was sometimes difficult to find the correct translation so information was handed out in English.

The *Emergency Multilingual Phrasebook* (Appendix-C6-C7) offered paramedics 62 English questions translated in 36 languages. They pointed out questions for family to read and to respond or asked a bystander, failing which telephonic interpretation was used. Although said to be very helpful, no copy of the phrasebook was available in the departments or ambulances contacted; paramedics admitted never using it (as did paramedics who were non-participants) and all said they had not seen it for years. Difficulties included size (too large to carry), going back for it and finding text in time-critical situations.

Food menus were translated, gynaecology patients were given leaflets but the manager felt more could be done; primary care pharmacists described themselves as "*only a conduit for information"* from the Trust [PH2, PH3] and nearly all the leaflets at the pharmacies and doctors surgeries were in English (Appendix-C8). Interpretation facilities were used in oncology, however, the tabulated list of medication and instructions for patients was in English [PH1]. All letters of appointment were in English as were TV and in-store advertising (Figure 6.4) to improve medication adherence (a primary care pharmacy chain). A general concern amongst senior participants was that textual information was not as effective as illustrations.

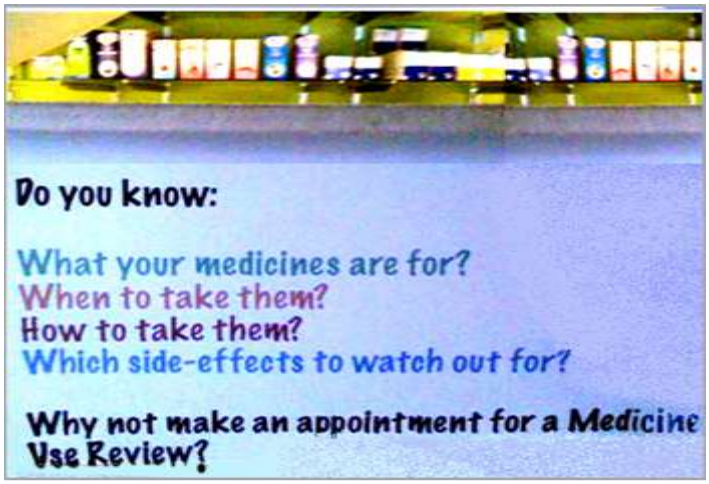


Figure 6.4 Primary care pharmacy advertisement offering to help patients with medication.

6.6.3.3. Audio-Visual Aids

25 participants did not have/ use visual aids whilst 31 did not have/use audio

aids. Participants who used visual aids in current or previous jobs were positive about them. The simplest forms of visual communication like self-demonstrations and gestures were cited by half the participants (17), across departments, whilst some said 'smiling widely' was official policy to welcome and reassure anxious patients [R1,R2].

Used Routinely. Eight participants used visual materials routinely and were content with facilities (orthopaedic consultants and physiotherapists). Both had 3-D models and physiotherapists printed illustrated exercises with English instructions from an online database (*PhysioTools*, Figure 6.5, Appendix-C9) for patients to take home. Some notices on ward notice boards were pictorially illustrated (Appendix-C10).

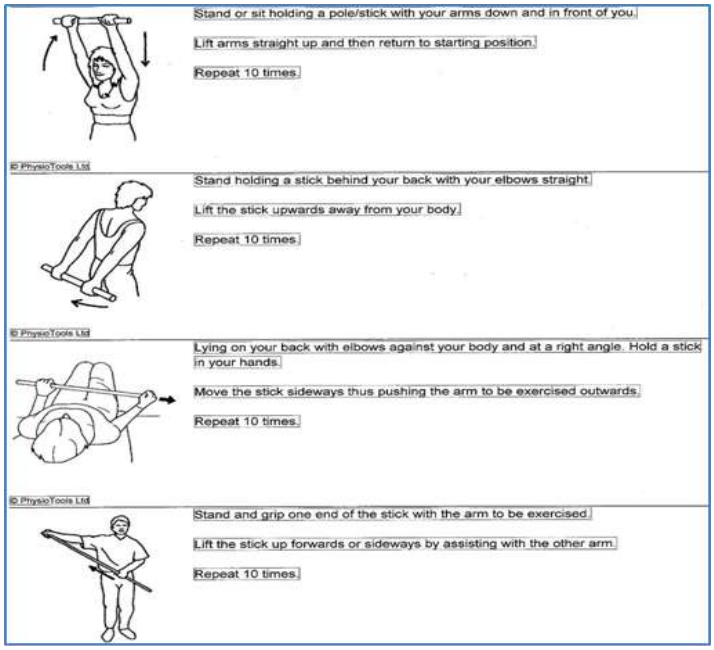


Figure 6.5 Illustrated physiotherapy leaflet in English ©*Physiotools*

Consultants drew extensively to explain to patients and retained drawings as evidence. Other participants had limited or few aids. Drawing was used to explain medication:

> *"We try to show to them what we mean; I draw stick diagrams, like this [short, vertical, parallel lines on a label] for how many tablets to take; then they understand [D5]".*

However, a colleague added

> *"Unless you can explain what you've drawn, it doesn't necessarily make any sense" [D7].*

Gynaecology used a chart and some illustrations; some hospital colour-coded corridors with English directions (Figure 6.6); images of items like toilet, food, etc. were used in elderly care. Maps were used but were said to be too complex (Appendix-C11-12) for patients some EMCs lacking English and/or literacy and for some indigenous

Figure 6.6 Colour-coded English directions in a waiting room.

Used Sometimes. A receptionist enthused about a '*fabulous'* book with wonderful illustrations about "*all manner of things in hospitals*" translated into different languages, but only ever saw one copy, once, concluding it must have been very expensive to produce [R1]. A single copy of *A Communication Aid for Patients in Hospital* (Figure 6.7) was located by the author in the A&E Major Injuries Unit. It was populated with images, each accompanied by text in 15 language scripts. A doctor felt it was helpful in communicating with mothers lacking English ("*good phrases, simple phrases")* and for 1st level information. The relevant script was pointed to for

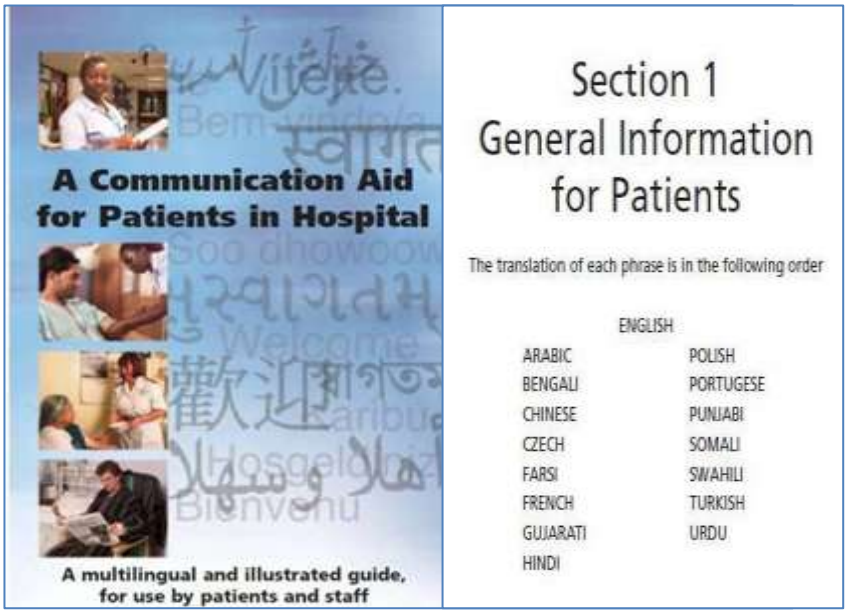


Figure 6.7 *A Communication Aid for Patients* and language scripts (©Participating Trust and Women's Royal Voluntary Service)

the patient to read (if literate in the script) and respond (Appendix-C13). However, the participant did not use it much because finding subsequent 2nd level information was difficult under time constraints and understanding patients' responses was a problem.

Low Use. Single participants mentioned different aids. DVDs were not cited as used although a cardiac department had DVDs [N5]; autism picture cards were being trialled (a new initiative in conjunction with the police) and a *'religion and beliefs handbook'* was helpful to understand the community being approached [PM2].

Audio aids were generally in low use. A gynaecology department refused familial interpretation and used a web-based database, *Babycentre Midwives,* on which medical terms were translated into several languages. Words and phrases could be played to hear the pronunciation which was clearly audible and said to be helpful. A participant felt more audio aids would be helpful: *"sometimes that's a bit more important for someone to understand the meaning".*

Would more AV Aids Help? Four participants responded negatively to more aids in different media and formats (some physiotherapists; orthopaedic consultants). They were content with facilities or felt issues were too complex and needed patient-specific responses. However, 28 favoured more visual aids. In previous jobs (in other Trusts), a DVD on birthing was recalled enthusiastically [N1] and video-links to communicate across northern Scotland [D2]. Comments ranged from cautious optimism : *"I'm probably guilty of not lifting the lid to peer inside that to see what you need to do, because it might just be the biggest thing you ever take on" [Pharmacy manager, PH3] to* "*Worth a try; definitely" [A&E doctor, D1]* and enthusiasm: *"Fantastic! I want it now" [Ward Sister, N5], "If we could, that would be great!" [A&E doctor, D2], "Absolutely; definitely helpful" [General practitioner, D5].*

The majority felt such aids could help several patient groups: EMCs lacking English; patients with low-literacy or dyslexia and hearing or visual or speech impairments. Elderly patients had been observed to *"draw a picture of* the *sun or the moon or something like that on the tablets or pot themselves as an*

aid memoire" [PH1]. In elderly care, a physiotherapist felt such aids could provide flexibility and a means to progress therapy rather than await interpretation during family visiting hours [PT2]. For paramedics, format and design were important otherwise deployment became difficult and the aid would not be used [PM3,PM4]. However, enthusiasm was tempered by concern over access and cost.

AV aids accessible on the web were considered helpful by 19 participants "*Yes, Definitely"* and *"worth a try",* particularly easily printable information, 11 had no view, 1 was unsure and 3 felt AV aids were not relevant to their needs.

6.6.3.4. Other Initiatives and Strategies

A consultant observed that, to improve patient retention, the best way to get the message across was to talk to another person within the hearing of the intended recipient (e.g. a mother whilst the child was listening or vice versa) because people absorbed far more when listening to somebody else's conversation [D3].

Google translation was used by some but was time consuming; the *Pacesetters* summit (2004) which sought to help EMCs' better understand the role of paramedics' during emergencies was successful (but time and budgets were limited to spread the message). The *In Case of Emergency* initiative urged EMCs to identify an interpreter under *ICE* on their mobile phone for paramedics to access in emergencies. One Trust distributed a colour-coded page *"When is an emergency a real emergency"* to promote appropriate use of health services amongst the public (Figure 6.8, Appendix-C14).

Figure 6.8 *When is an emergency a REAL emergency? a* public initiative for more appropriate use of healthcare services.

6.6.4. Impact on Workflow

Participants felt these barriers impacted the most upon time (25 participants), which was more than double that cited workflow/ volume (12) and on patient stress and anxiety (11). Nine senior participants cited cost but 4 felt there was little impact.

Doctors and physiotherapists agreed that language barriers resulted in double the time required to explain or carry out therapy, sometimes increased waiting times for other patients and affected target response times. Gender attitudes led to wasted appointments Interpreters were expensive (£48-55/hour) and had to be paid for even if patients cancelled appointments [R3]. A doctor agreed, adding that the more funds used for interpreters the less was left for healthcare [D5]. There was growing awareness that asking colleagues to translate was not necessarily cost-effective use of their time. However, ensuring that all patients accurately understood information took precedence over cost for all participants. Approving translations of information was time consuming; as healthcare progressed materials could be wasted or become redundant.

6.6.5. What would help further

The 6 key suggestions from participants are summarised below:

1. **Patients should learn English** was cited explicitly by 19 participants (55.9%), including making English-learning mandatory and was implicit in the problems identified by 11 more.
   "If I was going to plough my money into anything it would be to make it as nigh on compulsory as possible that everyone learns English because to be able to speak and write in English makes everything different [D3 Orthopaedic consultant]."
2. **Improved knowledge of patients' needs:** Prior, authorised data available to healthcare staff identifying language barriers, poor literacy, staff-gender preferences and any other factors like poor vision, etc., across cultures. Better understanding/ more feedback of EMCs' perceptions of health services: *"Positive feedback is nice, but negative feedback really helps to improve services*" [D3].
3. **More low-cost visual aids** were favoured by 28 participants (82.4%) and

web-based audio-visual aids by 19 participants (55.9%).

4. **More EMC community volunteer efforts:** *Expert patients* to share their experiences of treatments with patients lacking English and a register of translators and standardised arrangements for accompanying patients were suggested by doctors.
5. **Educating the public** was suggested by 28 participants (82.4%).
6. **Viewing telephonic interpreters and privacy** was important to doctors.

6.7. Discussion

This discussion focusses on EMCs (Indian Subcontinent) lacking English and/or literacy and their families, unless otherwise specified and NHS participants are referred to as 'staff'. Difficulties are considered from cultural and contextual perspectives as identified in the literature to better understand phenomena and to avoid ascribing differences in EMCs' goals and motivations to culture (Rau *et al* 2008).

The nature of difficulties cited appeared to be generally consistent across the Trusts but varied considerably between departments. As the interviews progressed, it became clear that the degree of difficulty cited related to the number of EMCs (Indian Subcontinent) cared for in that department and not the demographics of the area. Thus, even where EMCs (Indian Subcontinent) were a majority (65%+) estimates of the numbers cared for by departments varied from 60% to 5%. Where the percentage was low few or no problems were cited. Language barriers were common to other EMC groups and some difficulties were shared by indigenous patients for different reasons.

NHS Staffs' comments and approaches suggested they took problems in their stride because their focus was to deliver care effectively and safely to all patients. In this sense, problems posed by EMCs (Indian Subcontinent) lacking English did not supersede problems posed by other patient groups.

6.7.1. Difficulties

Some difficulties highlighted inter-cultural differences (Hofstede and McCrae 2004): staff focussed on each patient's preference (individualistic approach) whilst EMCs (Indian Subcontinent) relied on family or tried to consult the

interpreter (a *collective* approach).

Language barriers were noted to predominantly affect female EMCs (Indian Subcontinent), including long-term residents (as in study 1) and altering attitudes amongst some families will require positive intervention. The associated problems and countering strategies, like limiting and repeating information, concorded with healthcare literature (Safeer and Keenan 2005, Katz *et al* 2006, Amalraj *et al* 2009, Ngoh 2009, Salazar 2010). Also, that pharmacist-patient communication appeared to be minimal or absent in busy primary care pharmacies (Raynor 1992, American Pharmacists Association 2004). Ways of addressing this communication gap merits consideration to help address concerns cited over medication adherence, patient wellbeing and hospital readmissions, to maximise benefits from treatments and cost of medication to the NHS.

Although staff found solutions, language barriers presented on-going obstacles that had to be addressed repeatedly across healthcare services throughout patients' lifespans. Whilst family were relied upon, language barriers were noted to adversely affect patients (they did not know what was happening around them), disempowered them (they do not know whom to ask for help) and entrenched the need for interpretation. It was observed that the number of elderly females (Indian Subcontinent) who were living alone, lacked English and faced difficulties coping, was rising. In marked contrast was the difference learning English made to mothers motivated to participate in care for their child.

Staff were unclear why patients had not learned English when it was so important to their wellbeing and staff ascribed it to culture. However, in study 1, it was noted that many contextual factors appeared to influence some EMCs' lack of motivation. As Sanders and Dandavate (1999, adapted) pointed out, the experience of communication required an equal contribution by patients. This can be achieved by a combination of one or more of three options: society accepted the on-going (possibly rising) interpreter and translation costs across a myriad languages;

familial involvement was increased (which had some associated problems, whilst individuals still faced language barriers in daily living); or by promoting English. Of these, promoting English suggested the most beneficial, sustainable, cost-effective and holistic option for patients, families and healthcare services alike.

Low literacy was perceived by staff as less problematic in acute care, which was contrary to the literature (Johnson 2004; Safeer and Keenan 2005; Katz *et al* 2006; Amalraj *et al* 2009) although in primary care a doctor's frustrations and coping strategies, a pharmacist's observation of patient embarrassment to admitting it and concerns over patient safety conformed with the literature. Low-literacy and language barriers were observed to cause stress and anxiety amongst patients (navigating hospital corridors, filling forms). A pharmacy manager's suggestion that prior electronic information of patient's needs (see 6.6.2) be made available to authorised staff, including pharmacists, merits consideration and is relatively straightforward in this digital age. Prior knowledge would help staff to efficiently address potential difficulties and to improve patient experiences and outcomes. Forms mailed to patients prior to appointments might also help to give patients more time to get help.

A Lack of Understanding was noted on several topics and some were particular to EMCs (Indian Subcontinent): the notion of physiotherapy (yoga), the role of paramedics, procedures on wards, how to interpret appropriately. Other topics were cross-cultural: reasons for delays in clinics or patient transport, using paramedics or A&E appropriately. Albeit well meaning, some males (Indian Subcontinent) inadvertently hindered healthcare delivery through 'taking charge', re-interpreting or misinterpreting information. Implicit in these comments was that people need educating across cultures and that appointment information sent to patients and families might need some re-consideration on content and organisation of information (themes) to proactively engage with families and to lower barriers (aggression towards receptionists, anxiety amongst patients). Staff would also like to have more information on

EMCs' perceptions of services.

Attitudes, Gender and Health beliefs. The difficulties cited suggest many arise from a lack of understanding (context) and, sometimes, from cultural differences. Some male gender-attitudes and the 'just fix it approach' suggested a mix, power-distance (Hofstede and McCrae 2004) and contextual factors (frustration from constant interpreting, knowing the limits of a family member's comprehension, own difficulty translating). The significance of accurately conveying responses to staff needed to be raised amongst EMC families. Unhelpful attitudes of some EMC (Indian Subcontinent) families over translation support suggested a need for public education (and echoed findings in study 1), although taking the NHS for granted may be inadvertent through viewing interpretation as a part of the healthcare process. Erroneous health beliefs suggest a cultural factor but might be from a lack of education.

Retention is a cross-cultural problem and, when stressed, even people with English skills had difficulty with recalling information, whilst language barriers exacerbated the problem. That staff relied heavily on families to ensure healthcare adherence at home for those lacking English, impacted on a patient's privacy especially on sensitive medical issues (and added time pressure to the 2nd generation from interpretation).

Impact on Care. The impact on cost was cited only half as often as time. Double the time with patients was required to address language barriers, thus, fewer patients could be seen. It appears optimistic to consider language barriers a passing phase for several reasons. Costs already high, have risen over the years (Easton 2006, Khan 2011, Chapman 2012); needs rise with aging (Safeer and Keenan 2005) and as existing residents lacking English age they will require constant interpretation support; it is difficult to predict how many newcomers will know or learn English as EMC numbers rise.

6.7.2. The Aids

The NHS has made considerable efforts to address diversity; some aids were used consistently across Trusts whilst others varied considerably between Trusts and departments.

Interpreters: Familial interpretation and support at home was relied on heavily although it could present problems for informed consent and was refused by some departments (gynaecology). There appeared to be confusion between ethnic families and healthcare services over interpretation and that opposing cultural factors influenced staff-patient-family interactions, about which families need guidance. For instance, that accuracy was essential to diagnosis; the individual's choices were critical to wellbeing (*individualistic* approach in the UK, Hofstede and McCrae 2004); whom not to bring as interpreters; professional interpreters were not medical staff and to avoid engaging them in decision-making (ethnic *collective* cultural factor, Hofstede and McCrae 2004). That some EMC females asked interpreters to hold their hand suggested a lack of confidence.

Whilst translation by colleagues was favoured, there are indirect costs associated with time factors. Face-to-face interpreters were generally satisfactory but costly (also confirmed by literature, Easton 2006; Khan 2011; Chapman 2012), difficult to arrange at night and their use is minimised (due to cost). Difficulties repeatedly emphasised over telephonic interpretation highlighted the improvements required to functionality (observe interpreters, 2 or 3-way handsets) and in-house privacy arrangements. It was interesting that neither reception nor primary care pharmacies felt a need for interpreter services, although pharmacy-patient counselling is desirable to improve clinical outcomes (Johnson 2006; Katz *et al* 2006; Ngoh 2009) and an objective of healthcare reforms (Streets 2011) whilst Reception is seen as the gateway to care. The pharmacy chain advertising to help patients understand medication were taking positive steps, although it was unclear how time, language and low-literacy barriers would be overcome.

It is suggested that, like language barriers, interpretation support is a *contextual* factor: the need would rarely arise 'back home' except, perhaps, whilst travelling across the Indian Subcontinent. When the need arose, interestingly, English could be used to bridge language

barriers. Interpretation resolved the immediate difficulty but also resulted in continued dependence and tended to disempower individuals in the long-term (Easton 2012).

Whilst interpretation-translation facilities in the public sector are necessary in an era of international travel, the law of unintended consequences suggests these have inadvertently, adversely contributed to entrenching language barriers. Language barriers separate EMC subgroups from the indigenous population, particularly disempowering EMC females. Without empowerment and better understanding society in the UK, females cannot guide younger generations in societal norms and, in some EMC groups, young females bore the consequences of a lack of choice. Learning the language of a country is merely the first step on the journey to integration as, admittedly, people can still be 'divided by a common language'. However, it remains the first, important step

Translated materials: were helpful but did not appear to be produced in quantities due to cost and time required for approving them. The *Emergency Multilingual Phrasebook* and *A Communication Aid for Patients in Hospital* appeared to be helpful but required a degree of literacy. The former appeared to be not in use by paramedics (due to size, going back to get it from the ambulance) and only one copy of the was found in one A&E department. A review of translation Hindi section on the website *BabyCenter Midwives* (2011; Appendix-C15) displayed problems confirmed by Johnson *et al* (2006): some words were transliterated not translated, complex terms and mistranslations. Transliteration was also noted in *A Communication Aid for Patients,* e.g. 'doctor' was in Hindi, Punjabi and Polish. On a positive note, transliteration suggests that EMCs are familiarising with English words. That the bulk of patient information is in English, of necessity, re-emphasises the need for constant interpretation for patient's lacking English.

Visual and audio aids: Aside from simple visual communication used by the majority of staff (e.g. body language, gestures, self-demonstrations),

with a few exceptions (physiotherapy, orthopaedic, some food menus), a gap in adult-patient care appeared to be a low, patchy use of AV aids by participants, particularly in caring for EMCs lacking English and/or literacy. This is contrary to research citing its benefits for patient comprehension (Amalraj *et al* 2009; Katz *et al* 2006; Ngoh 2009). Encouragingly, staff using AV aids in different media (illustrations, models) were content with their facilities, those who had used AV aids previously were enthusiastic and the majority without aids were in favour (which concorded EMCs' preferences for more images, study 1). Making data appropriate, proportionate, accessible and available in differing formats/media (Boisaubin and Winkler 2000; Johnson 2004; Salazar 2010) merits consideration and in more thematic styles (Rau *et al* 2008) although some EMC groups hail from high-context cultures like Northern Europe (Hall and Hall 1976).

What would help? Staff's suggestions were noteworthy: that patients should learn English (even making it mandatory) was contrary to literature proposing more translations (Salazar 2010; Khan 2011) but concorded with the desire of EMCs to learn English (Easton 2006, study 1). Ethnic 'expert patients' and volunteer translators, could undoubtedly help to save time and cost, and allay anxiety, by playing a role similar to *promotoras* in the US (Salazar 2010), if the community proved willing. Some impediments might be that families who were disinclined to help patients may be more disinclined to volunteer to help strangers and patients could face intra-cultural negative attitudes (study 1) or EMCs could cite time barriers. If such difficulties could be overcome EMC volunteer support could be helpful, however, this would not resolve the empowerment of individuals for the long term.

Prior information of patient's needs available to authorised staff across healthcare services could save time and improve patient experiences, and is relatively straightforward to achieve in this digital age. The overall response to visual aids was favourable, provided cost and accessibility were addressed, and with literature (Amalraj *et al* 2009; Boisaubin and Winkler 2000; Katz *et al* 2006). Patient education initiatives across cultures were

favoured to nurture improved understandings amongst the public. For EMC families additional topics included the role of paramedics, promoting *ICE,* reasons for rules in wards, whilst other topics were cross-cultural.

6.8. Comparing the Findings of Studies 1 and 2

These findings were compared with those of study 1 to consider differences and similarities in views between EMCs (Indian Subcontinent) and NHS staff and their views appeared to agree on four themes: Language barriers, audio-visual aids, time constraints and English learning.

From these findings, we may add 2 further contextual factors that might have entrenched language barriers (Table 4.13): Interpreters are provided 'free' (this will continue, so there is no need to learn English) and a lack of understanding (the growing needs of aging, Safeer and Keenan 2005). This has implications for public sector services seeking to support this EMCs lacking English, particularly with a growing EMC population (Rees *et al* 2011).

Language barriers were confirmed by both studies as an obstacle in healthcare, despite the facilities in place.

English-learning: A majority of staff felt patients should learn English and the majority of EMC females wished to do so to be able to communicate with healthcare staff (and social services, job centres) and to alleviate loneliness. This female subgroup requires help to overcome intra-cultural impediments and misconceptions about English by educating families into the wide benefits. .

More audio-visual aids were received with optimism by a majority of staff, provided cost and printing were addressed. AV products were highly popular by EMCs (across generations, religions, genders) and more images in instructions were favoured unanimously, provided they were understandable. A greater use of AV media could contribute patient communication and healthcare initiatives (patient empowerment, comprehension, wellbeing).

Time barriers were cited by staff and 2nd generation EMCs who would, perhaps, welcome help to promote English-learning.

The combined results of the studies and literature suggests that *now* is an opportune time to promote English-learning and the long-term, lasting benefits to patients, families, public services and social integration are too great to ignore.

6.9. Conclusions

In an era of international travel, any one of us can be an 'ethnic minority' facing language barriers and interpretation services will remain important. However, demographic trends suggest wide implications in the UK for planning future economic, community and social goals (Rees et al 2011). It is suggested that a commonality of approach needs consideration (like English learning) alongside diversity initiatives to gain sustainable time and cost savings in healthcare whilst improving patient wellbeing.

For historical and socio-economic reasons English is an 'international' language and many words and phrases have become familiar to people globally, not least also through the globalisation of products and services (including healthcare). To sustainably empower patients (Imison *et al* 2011), improve patient experience and engagement (Streets 2011) and reduce participation inequality (Nielsen 2006) requires raising the contribution of patients lacking English to the communication experience (Sanders and Dandavate 1999). The literature, current affairs and the findings of studies 1 and 2 suggest that: 'all roads lead to learning English', to paraphrase an old saying.

It is suggested that the discussion on language barriers and the associated problems needs to be shifted from the domain of culture to that of context and be addressed as such. This, together with bridging the lack of understanding about the benefits of English amongst some EMC communities could help to counter and reduce potential intra-cultural hindrances, help to raise motivation for learning English and, thereby, to lower language barriers and associated difficulties and to empower females. Perhaps it will ultimately help EMCs access all the medical information available on-line as indigenous patients are doing more and more, and to participate more in their own and their family's care (as mothers who learned

English were doing).

The desire for good health is ubiquitous and healthcare is the singular pivot common to all individuals. This and the affection they are held in places, healthcare staff in a unique position, one of *respect* amongst EMCs: a prime position to promote English-learning. However, this will take time.

The next step was to determine how inclusive design might support such an initiative in the interim and the longer-term. Based on the insights gathered, it was determined to focus study 3 on visual communication in design. It considered whether (and how) visual communication aids might be developed to facilitate more direct staff-patient communication, to design inclusively to include as many patient groups as possible and how an educative element could be incorporated to promote English-learning.

6.10. Recommendations

An Interim Report with the main recommendations was put forward to the REC and Trusts as required. It accepted that some might already be 'in the pipeline' and suggested a consideration of what staff felt would help (see 6.6.2), more pharmacist-patient communication in primary care pharmacies and more visual communication aids in adult-patient care for patients lacking English.

6.11. Validity/ Reliability

The validity and reliability was achieved by close attention to guidance in literature methodology, following ethical processes laid down by the NHS, a research proposal and study tools that were approved in advance and the outcomes and recommendations disseminated in an anonymised *Interim Report* to the REC, 5 Trust R&D Departments and Site Liaisons, with an invitation to provide critical feedback.

The original sample size of 40, proved difficult to achieve due to recruitment difficulties, a bitter winter and the *time dimension* (Rohrer 2008, see 3.6.1). although gaining permission from managers took time to achieve, their prompting proved critical in gaining volunteers. Data gathering ceased when data began to repeat itself and due to time constraints.

Although the sample was small, collectively it offered much professional experience, participants were encouraged to speak freely by reminding them prior to interview that there were no right/ wrong answers and all data would be anonymised. Data were gathered in naturalistic surroundings (*ecological validity, W*illig 2008) for which encouraged participants to relax. Open questions and probes provided rich and improved understanding, whilst confirming the generation of patients or family cited provided improved contexts and accuracy for interpretation. One or 2 staff (e.g. reception) appeared to demonstrate occasional signs of desiring to 'look good' in resolving problems, like finding an interpreter. Second-generation EMC participants added further cultural insights.

The data analysis procedure followed provided a clear audit trail for the source of the data, the themes are familiar ones in healthcare and, in examining the data, a reassuring factor was that themes were repeated by staff in different roles. There were no extremes in variation, differences in views were noted across similar roles in acute and primary care and across departments. Discussions with academic supervisors throughout the study provided critical feedback at every stage. The discussion considered other viewpoints from literature and clearly lays out how interpretation was achieved (Robson 2002;p.171-5) and the results triangulated between previous literature and studies 1 and 2.

6.12. Reflexivity

The important factor was to understand the meanings of the themes in combination. Participants' gender did not appear to affect the data but older participants were more aware of some issues (like interpreter/ translation costs) and differences in ethnicity did influence views. For instance, indigenous participants were unclear why residents had not learned English, and the 2nd-generation ethnic participant was able to offer insights that others could not (unhelpful attitudes amongst the EMC community to helping with interpretation).

Whilst it is difficult to entirely rule out subjectivity, maintaining objectivity and balance and minimising researcher bias in data interpretation, was achieved

by a combination of factors. A knowledge of languages helped the author to review Hindi translation aids, which indigenous participants could not do not do and was, in turn, confirmed by the literature (Johnson *et al* 2006), and in contemplating the implications thereof.

Participants did not appear to hesitate in expressing their views, the questions did not probe controversial issues and, in this sense, participants did not feel the need to conform to any particular view, which added to objectivity in data collection. Participants' views sometimes confirmed and at other time diverged from their colleagues' views, and considered in combination, these helped to achieve better understandings of the current situation and potentially where the gaps lay. Objectivity was also gained through examining the data and themes and some critical feedback was sought from R&D departments and staff, to support objectivity.

The next chapter sets out the theoretical framework for study 3.

7. Literature Review (3)

This short chapter extended the theoretical framework and concepts to lay the foundation for study 3, the generative phase of this research. It discusses the difficulties and consequences of poor adherence to treatment, a range of pictorial aids in healthcare, visual communication and how users' perceptions of images and colour influence interpretation and emotion and convergence design. It concludes with a review of phonetics. Literature review 3 addressed the overall objective 5 of this research project.

Obj:5 To review the literature as research progressed to lay the theoretical foundation for subsequent studies.

7.1. Introduction

Preparation for the design phase of this research involved literature in two broad categories: healthcare and pictorial aids. The literature which provided the content for the prototypes on pain and medication, is identified in chapter 8 (8.4.2). Pictorial aids were discussed in 5.6 and this chapter reviews visual communication in healthcare, design and information technology. In the literature on visual communication, visualisations, products and visual communication are taken to mean images in all media. The terms designers and artists are used interchangeably as are viewers, consumers and users.

Context was the important theme in study 3, i.e. the extreme variations in the skills and abilities, mental models and education of users (Thomas and Bevan 1995) who were to be participants. Although all were treated as experts in their domains, on the one hand, staff were experts in healthcare, EMCs would lack English and/or literacy and indigenous elderly would probably display a range of physical impairments, as might elderly EMC participants.

7.2. Medication Adherence

"Good health is essential to human welfare and to sustained economic and social development" and people rate health as one of their highest priorities,

behind only economic concerns (The World Health Organisation, WHO 2012) and non-adherence to prescribed treatment is one of the greatest impediments to good health. Adherence can be defined as the extent to which patients follow the instructions they are given for prescribed treatments (Haynes *et al* 2005).

Medication non-adherence is a cross-cultural, global problem and results in a failure of therapy and advice, inadequate health outcomes and greater costs to healthcare (Nichols-English and Poirier 2000:pp.475-485; WHO 2003). Poor adherence occurs because patients experience difficulties in following treatment recommendations: non-adherence averaged 50% in developed countries and was even lower in developing countries. This severely compromises the effectiveness of treatment in longer-term therapies and is a critical issue for, both, patients' quality of life and for health economics. Interventions aimed at improving adherence provide a significant positive return on investment through preventing risk factors, adverse health outcomes, enhances patients' safety and improves effectiveness of treatment (WHO 2003). Indeed,

> *"Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" (Haynes 2001)*

WHO (2003) observed that patients needed support as they could face several barriers: social and economic factors, medical condition-related factors, therapy-related factors and patient behaviours. The American College of Preventive Medicine (2011) depict these barriers (Figure 7.1) and tabulated the contributor factors for each barrier (Appendix-D-LR1) which included limited English proficiency and low-literacy, complicated medication regimens, disparity in health beliefs, physical impairments, etc.

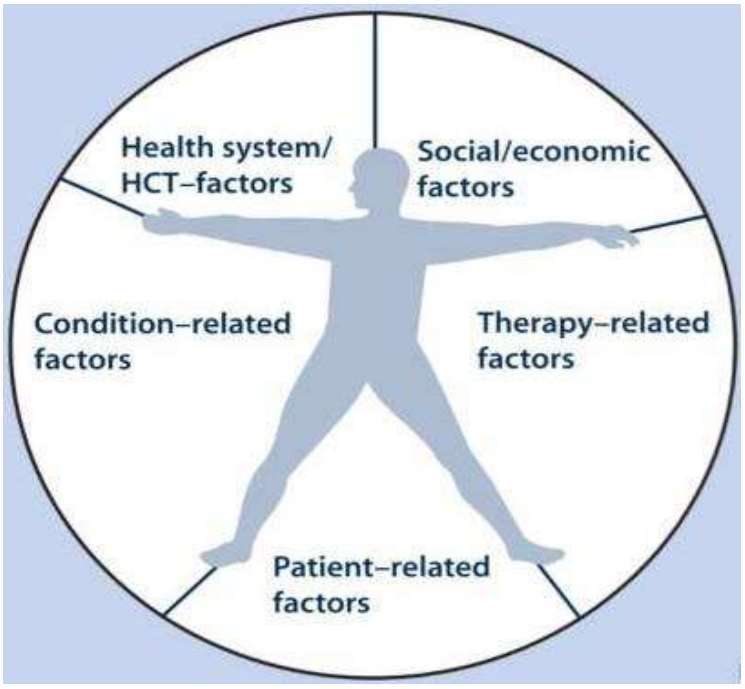


Figure 7.1 *Five Interacting Dimensions of Adherence* (HCT, Healthcare team, American College of Preventive Medicine 2011)

The WHO (2003) stated these barriers required patient-tailored interventions, an understanding of a patient's readiness for adherence to treatment and support from their family/ community. Progress in this area required a multidisciplinary approach including **"**coordinated action from health professionals, researchers, health planners and policy-makers". Haynes *et al* (2005) observe that further innovation is required and re-emphasised their conclusion that:

> *"Effective ways to help people follow medical treatments could have far larger effects on health than any treatment itself."*

American College of Preventive Medicine (2011) also offers a 'Time Tool' to aid adherence to treatment, and stated that healthcare providers are an:

> *"Integral part of the five interacting dimensions of medication adherence […] for improving medication adherence are the responsibility of all involved, but the focus of this is on the provider's role in medication adherence".*

Auerbach (2009:pp.77-84) synthesised 14 literature reviews of studies published between 1991-2007 on interventions that targeted the patient-physician relationship. He concluded that although interventions aimed at

healthcare providers consistently produced positive effects on provider communication behaviours and interpersonal skills, these had only moderately positive effects on patient satisfaction and limited impact on patient behaviours like adherence to treatment and appointments or resource use. There were minimal effects on primary medical outcomes although some positive effects on secondary outcomes like quality of life. However, patient-targeted interventions showed consistently positive effects on patient-physician communication in addition to enhanced patient participation in decision-making.

Speaking of patient interventions like pictograms, Dowse and Ehlers (2004) reported that designing and evaluating pictograms with the target population overwhelmingly improved results of participant's interpretation (from 2 to 42%) of instructions. Participants in their study in South Africa had a high incidence of poor literacy and visual skills, different health beliefs, cultural values, habits and lifestyles. Understanding or decoding pictorial information can be difficult especially for those with poor literacy.

7.3. Visual Communication

"Without image, thinking is impossible" (Aristotle).

Humankind has communicated through images from the early days of cave paintings (Prosser 1998). Cherry (1978:p.7) broadly defines 'communication' as the sharing and exchange of information or experiences in a way that relates one party to another. It is the relationship set up by the transmission of stimuli and the evocation of responses including languages, communicative signs, codes or sign systems. 'Visual communication' is a way of conveying ideas and information through vision and images that offer a potential method for people to understand (Sless 1981:pp.180,187).

Images have the power to inform, warn, impel, educate and persuade people. Visual representations are images in one or more dimensions from a single line to illustrations, typography, numbers, icons, signs, symbols, models, maps, tables, graphs, objects and colour. Visual resources include a myriad of media (photographs, electronic, paper, chalk on board, paint, multi-media like videos, CDs/DVDs) and artefacts (ceramics, stone, plaster, etc.).

They permeate everyday lives worldwide from signage in hospitals, airports, train stations (Figure 7.2) to directions for drivers, from icons on products to information, art and advertising.

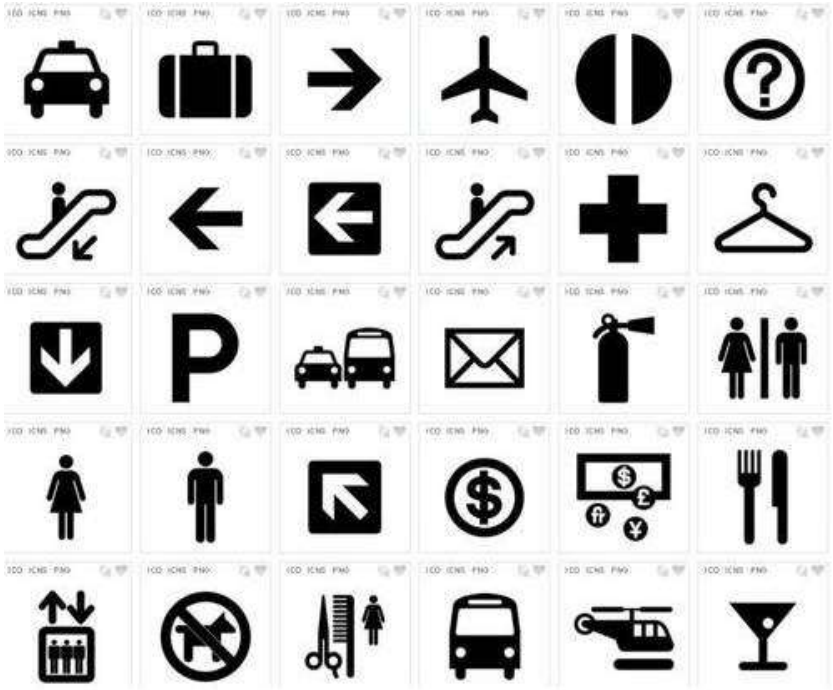


Figure 7.2 Pictograms for public spaces (Smashing Magazine 2012, free)

At a basic level users' interpretations are based on form and functionality, whilst more complex responses assess the values embodied and judgements on cultural associations evoked (Crilly *et al* 2008:p.425). Images accompanied by narrative, explanation or text, generate powerful multi-modal forms of expression, offering richness and variations of expression (Hull and Nelson 2005). Scholars differ on the purpose of visual communication. For Frascara (2004), the value of good visual communication design is in measuring the comprehension of the recipient, rather than the aesthetics about which views can vary considerably. Berlo (1960:p.16) states that the purpose is to elicit a response whilst Anderson and Meyer (1988:pp 19-20) consider it as the intent to achieve meaning. Creative disciplines attempt to structure communicative elements in ways that express the artist's purpose, have the most effect or intended meaning for the recipient (Berlo 1960:p.59), or control the behaviour or psychological effects of design decisions (Zeisel 1984:p34).

In *Design as communication,* Crilly *et al* (2008:p.425) maintained that the interpretation that designers intended, related to viewers' interpretations of the intended message, although this could differ to varying degrees or in unanticipated ways to that intention. Thus, design principles connect visualisations to the viewer's perceptions and cognition of the information (Agrawala *et al* 2011). Frascara's (2004) view of good visual communication design concords with Kazmierczak's (2003) view of the effectiveness of a design, which is the degree to which the intentions of designers and the interpretations of consumers correspond. The more strategically successful a design, the more accurately and consistently did similar thoughts influence different users to respond in a certain way, and this defined its effectiveness (Kazmierczak 2003:p.48). A user's perceptions influenced their ability to use visualisations as intended by the designer.

Consumers actively constructed meanings as they engaged with a product or service within a given context (Siu 2003:p.66, adapted) which may be culturally or geographically different to that in which the design was conceived (Brown and Duguid 1994:pp 5-6). Once released into the marketplace, the process of communicating meaning became a monologue as designs existed independently beyond the control of the designer and consumers could not consult the designer to confirm meanings (Draper 1994:p.63, adapted). This could result in interpretations and uses that were unanticipated with a significance or functionality that had not been intended (Crilly *et al* 2008). New interpretations could suggest useful feature changes or product categories and these differences should be celebrated and exploited (von Hippel 2005) and Krippendorff (2006:pp.87,231) concurs, provided safety or commercial integrity were not compromised.

Clarity and effectiveness were particularly critical in a healthcare environment. From the safety perspective, *how* designs might be interpreted is more important than intention because interpretation determines its use (Crilly *et al* 2008:p.438). Designers need to actively attempt to avoid potential problems from unintended interpretations by anticipating the ways in which designs might be interpreted and make reasonable efforts to constrain those within safe bounds (Crilly *et al* 2008:pp.439-440). Agrawala *et al* (2011,

adapted) suggest that optimising visual resources requires designers to identify and formulate good design principles, i.e. examine the best visualisations and the literature on perception and cognition of visualisations, to investigate user's perceptions and cognition through testing and to combine these results. Designers must

> *"Anticipate possible misunderstandings and contrive a communication that will be correctly decoded without feedback by a range of recipients who differ both from the designer and from each other" (Draper, 1994:p.63)*

Other factors that influenced users were how services or products were promoted, any official marks they carried and any instructions or warnings that were associated with them (Howells 2000).

Krippendorff and Butter's (1984:p.6) design-specific communication model (Figure 7.3) adapted to this research depicts the cultural and contextual factors that influence users' perceptions. This model has been adapted below to mirror these influences on a designer to reflect the factors that can influence differences in a designer's intended meaning.

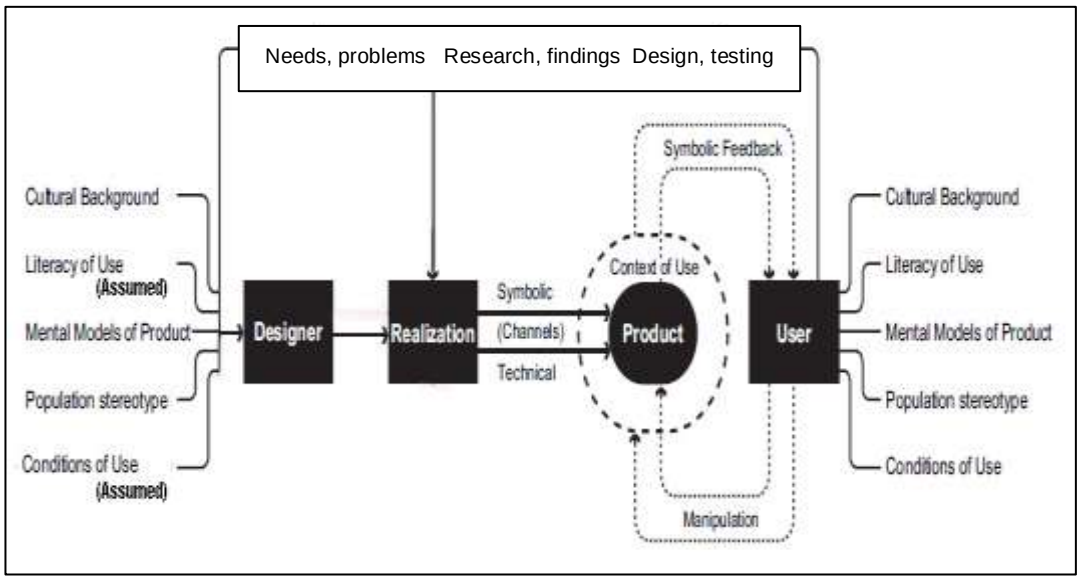


Figure 7.3 A design-specific communication model (Krippendorff and Butter 1984) adapted. ©Innovation Journal - Industrial Designers Society of America

Images and colour perceptions are two of the key elements of visual communication that influence user's perceptions alongside form.

7.3.1. Images and User Perceptions

The proliferation of icons is much researched and discussed nowadays with the rapid advance of HCI. *Icons* or *symbols* are small images that leap literacy barriers and their purpose is to remind people of what they already know (Macbeth *et al* 2006:pp.14-18, adapted). Pagels observed that humans are unique among the species in their symbolic ability to control existence by using symbols or images to represent and simulate reality and use them to service human purposes (Rheingold 1992:p.386). However, understanding images can be difficult and requires mental models and domain knowledge (Pappachan and Ziefle 2008).

Huxley (1974:p.50) agreed that what people perceived from what they saw depended on the *"amount, the kind and the availability of past experiences"* which existed only in memory and, therefore, perception depended upon memory. People saw familiar things more clearly than those for which they had no stock of memories and, when under emotional stress, imagination became more active and interpretation depended on imagination rather than manifestations actually present in the external world.

Lester (2006) highlighted that users' responses to images could be influenced by 6 perspectives which, in turn, influenced users' reactions and, therefore, the acceptability of designs:

- **Personal** reflected the individual's thoughts and values which could conflict with cultural values.
- **Cultural or semiotic**: The symbolism used here was important as were the words used with the image.
- **Ethical** prompted a moral stance.
- **Critical:** Criticisms were made in the interests of society rather than a personal perspective.
- **Technical** was a consideration of factors that improved the view of the image (right use of light, position, presentation).
- **Historical**: arose from the media used (a computer-edited image

differed to that made/edited by craft).

Alongside different imagery, designers needed to consider colour-combinations which are important considerations whilst designing for different markets or cultures (Feisner 2006:pp.133; Carroll 2009) and, Feisner adds, negative and positive connotations needed consideration in environments like hospitals, restaurants, etc.

7.3.2. Colour-Attributes

Colours are elemental tools for design communication, together with signs, typography and shapes (Hinz 2009). The significance of colours lies in their ability to provide visual and psychological information which artists and designers use to impart messages to viewers (Feisner 2006:pp.2-4). From *De Coloribus,* the first known book on colour by Greek philosopher Aristotle, colour has fascinated philosophers, artists, scientists, physicists, entomologist, engravers, physiologists, psychologists and chemists (Feisner 2006.pp.13-22). Colour is the physiological sensation which occurs when light is reflected off objects and transmitted through our eyes to our brain and helps us to interpret and describe the world around us, e.g. it is difficult to describe the sky without referring to colour. More than any other design element, colour makes us aware of what we see. Colour defines our world, it is seen before the details of an image, first on entering a room and deeply influences people's emotions, the symbolism of daily life and language (Feisner 2006).

The influence of colours on emotions is important in services like healthcare for, as Streets (2011) observed, emotion and anxiety play a role in clinical effectiveness. It is, therefore, critical that designers control their message according to what viewers perceive (Feisner 2006:pp.ix,2-4). Colour-perceptions are also important because these can influence people's capability or desire to use products (or visual media or service environments). People associate colours with different meanings and their reactions are influenced by cultural background, memories and experiences (Feisner 2006:p.5). Birren (1961:p.169) adds that people's colour-perceptions are defined by their language, the objects or forms, personality and senses, e.g. red stimulates the autonomic nervous system whilst blue (or colours at

similar energy levels) tend to relax it. Colour can create opposing reactions: those that attracted one demographic can sometimes repel another for reasons that are not yet fully understood (Guthrie 2003; Feisner 2006:p.133; Carroll 2009). Guthrie (2003) identified opposing word pairs used to test user-perceptions in studies of colour-associations (Figure 7.4).

Light/ dark	Clean/ cloudy
Masculine/ feminine	Deep/ pale
Cool/ warm	Heavy/ light
Calm/ agitating	Bright/ dull
Appealing/ retreating	Strong/ weak
Distinct/ indistinct	Vivid/ plain
Dynamic/ passive	Exciting/ dull
Transparent/ turbid	Soft/ hard

Figure 7.4 Word-pairs used in studies of colour-association (Guthrie 2003)

For Hinz (2009), the use of colour in global markets places too much emphasis on emotion and fashion-trends and more consideration of the differences in cultures, ages, levels of education and genders is required. In a study with German and Egyptian design students, Hinz found their colour-associations were similar for children, differed for adults and differed widely for older adults aged 60+ years. German students perceived (all) German adults as active, dynamic, outgoing and attractive and associated them with muted and natural colours (brown, black, beige), a few active colours (red, orange, yellow) and females with strong colours or light pastel shades. Egyptian students associated Egyptian adults (30-50+ years) with intense, colourful combinations and red and blue, however, elders (60+ years) were associated with black, dark brown or blue because they were perceived as *"inactive, mostly ill, inefficient and unproductive, fainthearted, generally rather sad and often even as unattractive or ugly".*

Peoples' reaction to colour also altered with age, according to Birren (1961:p.176): blue and red remained popular throughout life with adults but not yellow which was well-liked by children. Older adults preferred blue, green and purple, over red, orange, and yellow. Hallock's (2003) study in the USA confirmed Birren's observations and that green was popular with younger respondents. Feisner (2006;pp.42, 120-127) highlights the positive-negative cultural context of colour-associations, which are summarised in Appendix-D-LR2 under 'Western Christian culture' (as in the UK) and

compared to religious colour-associations of EMCs (Indian Subcontinent). Feisner did not include Sikhism, a study group in this research and the asterisks denote additions from the researcher's EMC background and knowledge. From this data, we can draw some broad conclusions of the similarities/ differences of perceptions:

SIMILARITIES: **White** has positive connotations of truth and purity (although all-white dress also symbolises death and mourning for Hindus and Sikhs). **Black** has negative connotations (fear, mourning). **Blue** symbolises truth and tranquillity for indigenous people and concords with the blue NHS healthcare logo whilst deep blue has religious symbolism for Hindus and Sikhs. **Red** is a festive (happy) colour or good luck but signifies danger.

DIFFERENCES: **Pink** has positive connotations for indigenous people and signifies feminine qualities (baby girls); however, except as a festive colour, the author notes that pink does not have a feminine connotation in the Indian Subcontinent. **Saffron** (orange-yellow) is not mentioned but is a powerful spiritual symbol for both Hindus and Sikhs (and some Buddhists, as Feisner noted). **Blue** does not have the negative associations for EMCs as Feisner describes, nor does it signify masculine qualities (baby boys). **Green** is an important symbol in Islam but not for Hindus or Sikhs.

These associations are put to practical use in everyday living and Feisner (2006:p.130) details some important uses of colour.

7.3.2.1. Everyday uses of Colour attributes

The order in which humans perceive colour is: yellow, orange, white, red, green and blue. Yellow is seen before any other colour (even in dim light) especially against black and is used as a warning combination in nature (stinging bumble-bees) and by organisations in safety measures (Jordan 2004; Feisner 2006) because yellow on a black background is seen with greater force than a black-and-white combination. Blue can be perceived clearly, even in poor light, but is not see first if yellow is present. Thus, yellow-and-black are used as hazard warnings by industry and on school

buses due to the high visibility of yellow, whilst orange can be seen better at sea (Feisner 2006).

Red should not be used in danger/ warning signs in support of people with colour-blindness, but as a combination with other colours to show greatest contrast. Therefore, red should not be used for danger signs (Fiesner 2006:pp.133,130). Green relieves glare, is the most restful colour, reduces stress and is associated with tranquillity (Fiesner 2006).

Elderly people saw colour differently as vision declined with age. Blues looked darker; there was difficulty distinguishing between blue combinations, dimmer blues appeared black and yellow could appear browner. It was best to use bright colours and brightness contrast should be especially high (Feisner 2006:p.133). Cost is always a factor: fewer colours make for more economy and designers needed to combine colours for maximum impact (Feisner 2006:p.127). Maguire (2012) identifies how some colour-associations are used in HCI (Table 7.1) and these may vary in different cultures.

Table 7.1 Colour -associations used in Human Computer Interactions (HCI) design (Maguire 2012).

Colour	Associations
Red	Stop, Fire, Hot, Danger, Error
Yellow	Caution, Slow, Test
Green	Go, OK, Clear, Safety
Blue	Cold, Water, Calm, Neutrality
Grey	Neutrality, background, borders etc.
White	Neutrality, used for text, highlighting boxes
Warm Colours – Red, Orange, Yellow	Action, response required, spatial closeness
Cool Colours - Green, Blue, Violet, Purple	Status, Background information

Guthrie (2003) observed that colour-language associations (Figure 7.4, above) are well developed in different markets like health, fashion, language, religious ceremonials, cultural and ethnic matters and colour-combinations

can be used to motivate.

Scholars identify several other factors that govern people's colour-perceptions and reactions that designers need to consider.

7.3.2.2. Contexts that influence Colour-perceptions

People's colour-perceptions are also influenced by different contexts, like the use of contrast, lighting, size and shape or surroundings, physical impairments, etc.

Contrast creates emphasis and produces clarity precision, objectivity and firmness, the greatest being black and white (Feisner 2006:p.127).

Lighting levels have a noticeable effect on visual acuity (Elton and Nicolle 2009) and how colours are perceived: the same colour can look different on a bright or dark day (Feisner 2006).

Shape, **space and surroundings** need consideration (Guthrie 2003; Feisner 2006:pp.5-6,88). The size of the 'colour patch' is important (painting a whole wall or a small dot) because this influences viewers' moods, but this can vary greatly even amongst people from similar social backgrounds (Patera and Draper 2007).

Impaired vision (partial sight, aging, colour blindness) reduces the effectiveness of certain colours. Colour blindness results in difficulties in distinguishing one or more of three colours: red, green and blue (Hoffman 1999; Feisner 2006:p.133). The visual effectiveness of certain colour combinations like red-green makes them difficult to discern rather than the individual colours themselves. Colour blindness affects approximately 19 million people in the US (males twenty times more than females). Therefore, red should not be used for danger signs (Fiesner 2006:p133,130) unless used in contrast. Figure 7.5 depicts the difference in clarity between

Figure 7.5 Impact of colour combinations (Arditi (2005) ©Lighthouse International).

black-white and red-green combinations.

Temperature: Warm colours suggest heat, cheerfulness, sunlight, aggression and emphasise an object or design whilst cool colours suggest distance and quiet (Feisner 2006:p.127).

Dark or light compositions: Dark compositions generate feelings of night, darkness and fear, whilst light compositions impart feelings of illumination, clarity and optimism (Feisner 2006:p.42).

7.3.3. Text

Print (text) is the medium for visual reading and the size of print can determine the design requirements for legibility, the layout of print on a page or screen, and the economics of document production and also determine visual acuity (Legge and Bigelow 2011).

Bailey (2005), writing about improving usability of printed and on-line materials for older users on the US Usability.gov website, notes that with an aging population information usability is increasingly important. On the use of text he suggests:

- Use few colours and avoid blue and green tones.
- Use 12-14 point sans serif (Helvetica, Arial), black text on a white background.
- The text should be left justified and have increased spacing (leading) between lines.
- The main body of the text should be in sentence case, rather than all capital letters.
- The text should have appropriate, large headings in 14-16 sans serif font (Bailey 2005).

Similar guidelines are offered by the UK's Government Communication Network (2011) and by Loughborough University for preparing theses. These guidelines were important both in the context of designing for older staff and older users and were followed during prototype development.

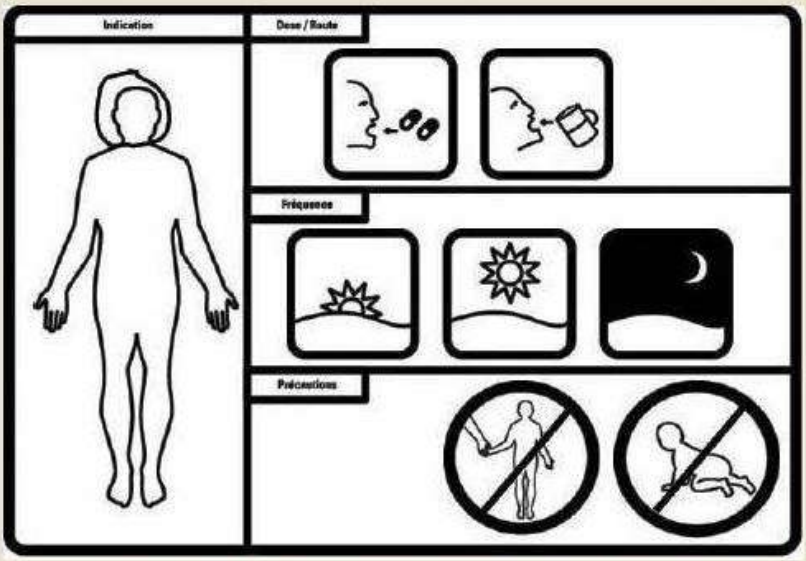
The next section considers pictorial aids that have been designed by different organisations and designers

7.4. Pictorial aids

In section 5.7, the improved patient outcome provided by pictorial aids was discussed and how some images were better understood than others. In 7.2.1, the challenges for designers in correctly co-relating intention with user interpretation, was noted. In this section, a selection of pictorial aids are considered for their clarity, what participants preferred and how the design elements were arranged.

In a study to design and evaluate pictographic instructions for medication counselling for a medical mission in Gabon, Sorfleet *et al* (2009) concluded that cultural sensitivity was required when there were language differences. A pictographic storyboard (Figure 7.6) was valuable; however, it also moderately increased the workload of healthcare providers. The storyboard offered low-literacy patients a less demanding and more suitable visual format to complement their medication counselling because low-literacy adults, much like children, do not scan visual information systematically but in small visual steps. (Note the use of a single line to denote 'do not').

FIGURE 1 Example of a storyboard pictogram for medication



This storyboard contains an outline of the human body where a health care provider can depict the indication by circling the appropriate location. The medication instructions are as follows: Take 2 capsules with water, 3 times a day. Keep out of reach of babies and children.

Figure 7.6 A storyboard for medication (Sorfleet *et al* 2009)

Figures 7.7-7.8 depict pictograms tested by Dowse and Ehlers (2001, 2004) with participants of low literacy and different language groups in South Africa.

They evaluated pictograms recommended by the US Pharmacopeia Dispensing Information (USP-DI) and developed local pictograms that were better understood. (Note the preference for a 'cross' to indicate 'do not'.) They suggested that images should not be used as the sole communication source as they produced a low recall of information and did not convey the level of information required for proper comprehension. In this context, visuals were a memory aid rather than a primary source of information. However, they were a highly effective means of stimulating recall of spoken information in people with poor literacy skills (Dowse and Ehlers 2004). They found patients unanimously felt pictograms on their medication were a good idea and would help them to remember their medication instructions.

In Figure 7.7, note the images for instructions for taking medicine are sequential (20) and participants preferred to see the context of the whole head rather than an enlarged specific part (22,23)

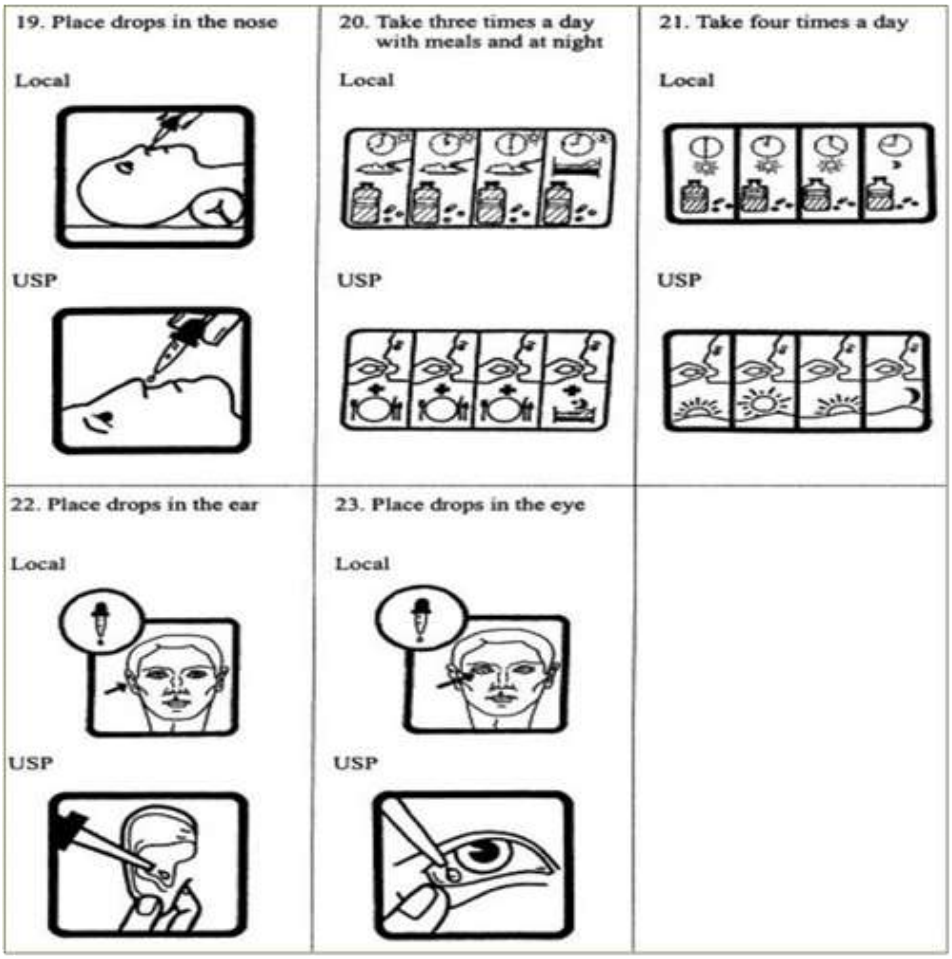


Figure 7.7 US Pharmacopeia Dispensing Information pictograms tested by Dowse and Ehlers (2001) and the local designs preferred.

Dowse and Ehlers (2001) concluded that low-literate patients were a population segment with special needs due to a higher risk of experiencing poor health. Pictograms could be successful in communicating information particularly if developed in collaboration with the target community and cultural influences were considered. Pictograms were also most successful in the recall of medication information if healthcare providers took time to explain the meaning.

In Figure 7.8, note the preference of an 'X' to denote 'do not' for taking medicine, and the arrangement of different elements of each picture to tell the story. Also, the USP pictograms are more sophisticated, e.g. in communicating a meal, but less well understood.

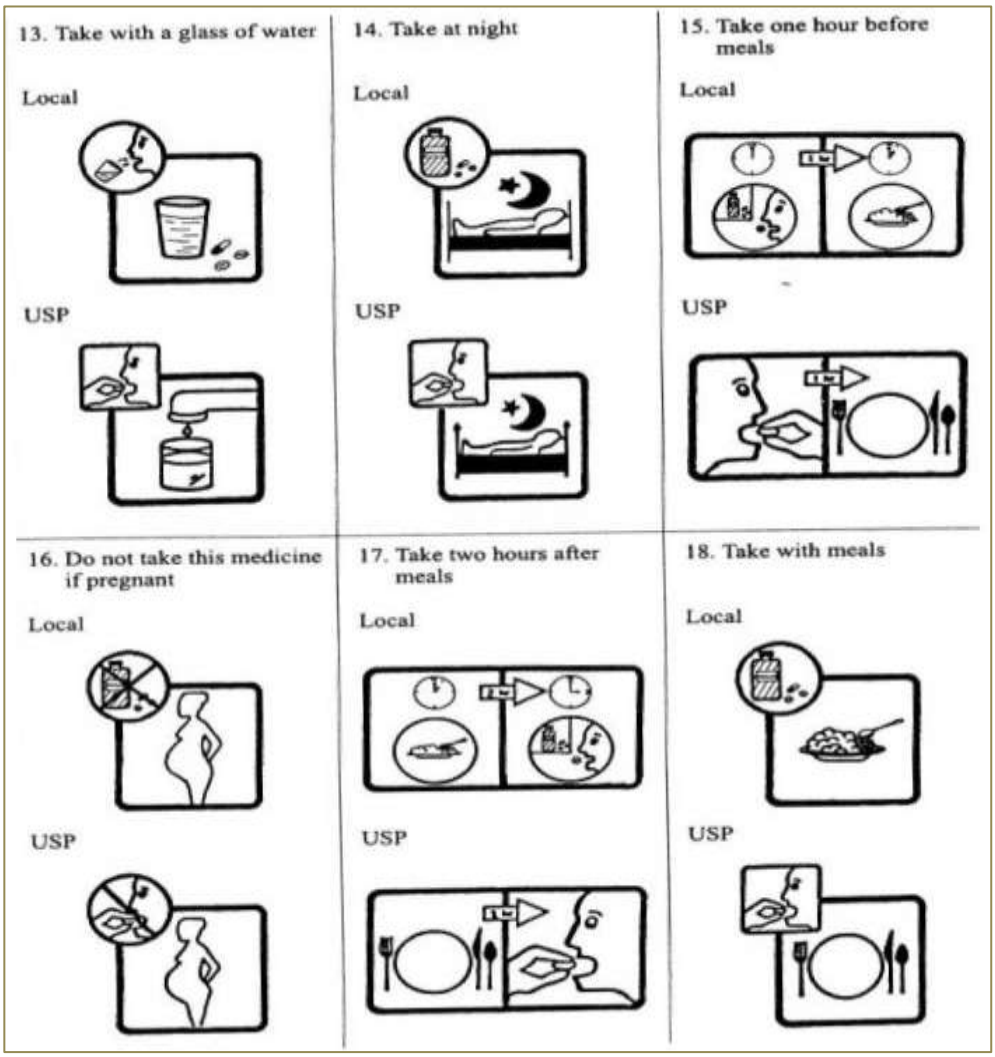


Figure 7.8 USP pictograms tested by Dowse and Ehlers (2001, 2004) and the local designs preferred.

A limited number of studies have also shown the positive influence on patient education and compliance, the challenge lying ahead was to:

> *"Influence and convince healthcare staff authorities of the need for this type of intervention, introduce pictograms into routine practice and monitor the outcomes of such an initiative" (Dowse and Ehlers 2001).*

Figures 7.9 and 7.10 depicts a selection of free autism picture cards from DoToLearn (2011) and from Use Visual Strategies (2012) to meet the communication needs of patients with Autism, Asperger's, etc.

In figure 7.9, note the simple clear representations of pain in different areas and of happy and sad. These were used in alpha-testing EMCs (Indian Subcontinent) lacking English (see Figure 8.22), and were generally, easily understood.

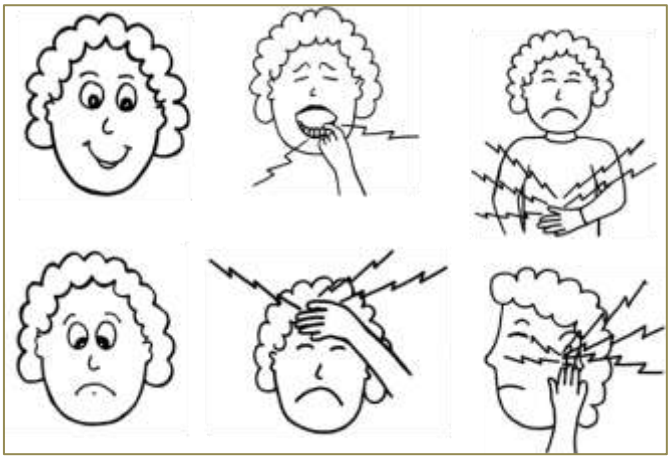


Figure 7.9 Free autism picture cards depicting pain and emotion (DoToLearn 2011)

In figure 7.10, words like 'Yuck' and 'don't' and symbol ? might prove unclear across cultures.

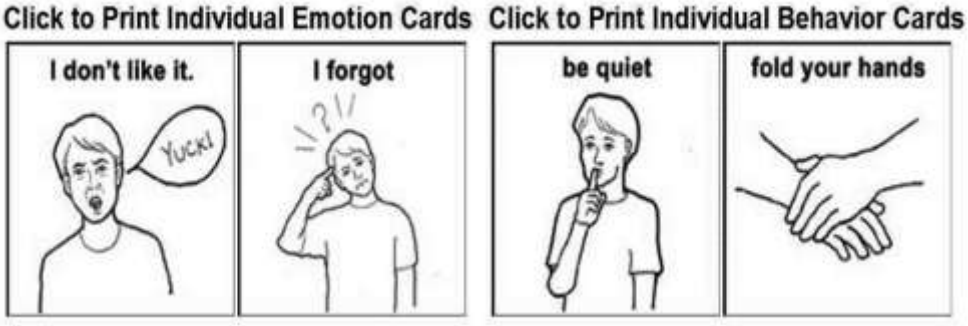


Figure 7.10 Picture cards for patients (Use Visual Strategies 2012)

Figure 7.11 depicts pictograms for medication adherence with text in a language script (Kannada) in a study by Anil (2007) in South India, who concluded that pictograms were very helpful in the local context. However, in the context of diverse EMC groups, the question is how many languages can be accommodated?

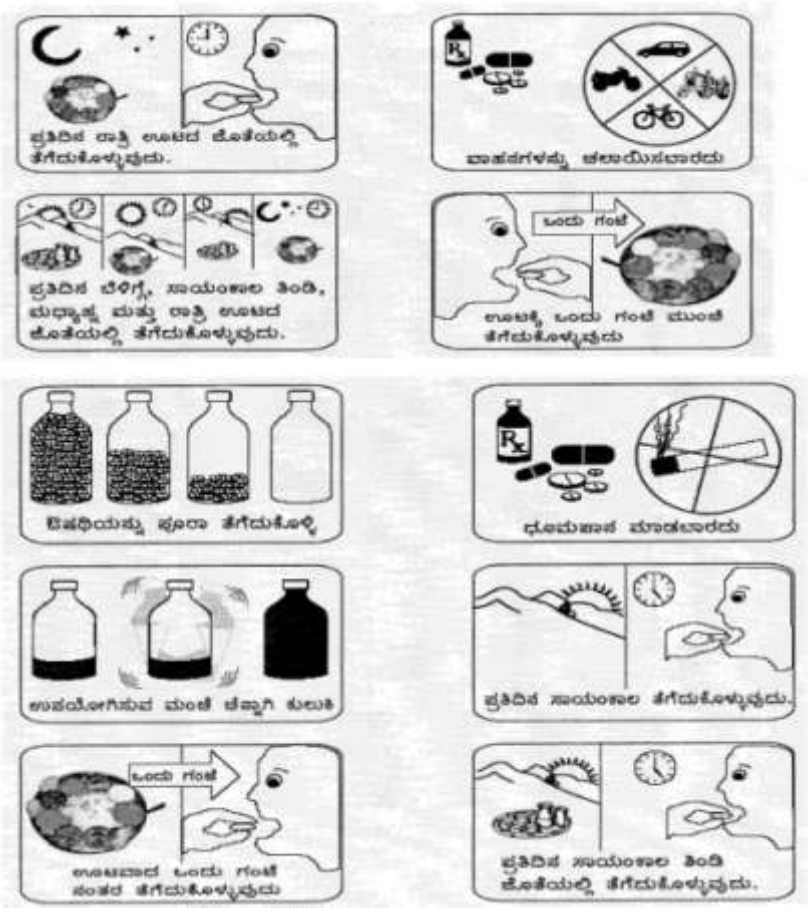


Figure 7.11 Pictograms for medication adherence from a study in South India (Anil 2007)

The following icons (Figures 7.12-7.14), display the great degree of sophistication amongst the designs and various degrees of clarity, with and without text. These more sophisticated designs suggest that patients with low-literacy and limited English may have difficulties with them. This may be particularly true of EMCs from developing countries.

Figure 7.12 Medicine icons (Vector logo 2011)

Figure 7.13 Healthcare pictograms (©Shutterstock 2012)

Finally, pictograms have been designed as apps for mobile applications and the web. Apple offers iPhone apps from 'Universal Doctor Speaker'. Universaldoctor.com was set up by Jordi Cerrano Pons. On Apple, pictograms front audio files (Figure 7.14) with *"hundreds of medical questions & explanations in several languages to ease communication between patients and healthcare professionals."* This audio application in multiple languages combined with new 4G technologies may become very attractive.

Figure 7.14 Apple iPhone apps from Universal Doctor (2012) offering audio files in multiple languages.

However, for people lacking literacy to choose what to ask based on text and technology is known to be difficult. Also, too much text is not favoured and people want more images. As Nielson says, often only the cognoscenti get to use the new technologies which can be sophisticated. Also, there is no educational element and this would be an important aspect in this research for developing future prototypes around people with poor literacy, no English and some physical impairments. In some instances, good old fashion paper options need to be available and images with text.

In considering how to select text for users, it was useful to understand the use of transliteration and phonetics.

7.5. Transliteration vs. Phonetics

This section was researched after the design decision was reached in 8.3.5. (see 10) but has been placed here to provide coherence.

Phonetics may be defined as the “science of speech and of pronunciation” (MediLexicon 2006) or as representing the sounds and other phenomena of speech. Phonetics constitute an “alteration of ordinary spelling that better represents the spoken language” that employs only characters of the regular alphabet and is used in a context of conventional spelling (Merriam-Webster 2012).

Transliteration, on the other hand, is defined as “to represent or spell in the characters of another alphabet”. Figures 7.15-7.16 depict a compilation of transliterated information extracted from two sources and the phonetic scheme used in dictionaries (OED 1964). Figure 7.15 is Punjabi transliterated into English. Figure 7.16 depicts a selection of words from McGregor’s (1972) Hindi grammar.

ਗਉੜੀ ਸੁਖਮਨੀ ਮਃ ੫ ॥
GAURĪ SUKHMANĪ MAHALĀ 5 (PAṆJVĀṆ)

ੴ ਸਤਿ ਗੁਰ ਪ੍ਰਸਾਦਿ ॥
Ik Oṅkār Sat(i) gur prasād(i).

ਸਲੋਕੁ ॥ SALOK(U)

ਆਦਿ ਗੁਰਏ ਨਮਹ ॥ ਜੁਗਾਦਿ ਗੁਰਏ ਨਮਹ ॥
Ād(i) Gur-e namah. Jugād(i) gur-e namah.

ਸਤਿਗੁਰਏ ਨਮਹ ॥ ਸ੍ਰੀ ਗੁਰਦੇਵਏ ਨਮਹ ॥੧॥
Sat(i)gur-e namah. Srī Gurdev-e namah. (1)

ਅਸਟਪਦੀ ॥ AṢṬPADĪ

ਸਿਮਰਉ ਸਿਮਰਿ ਸਿਮਰਿ ਸੁਖੁ ਪਾਵਉ ॥ ਕਲਿ ਕਲੇਸ ਤਨ ਮਾਹਿ ਮਿਟਾਵਉ ॥
Simrau simar(i) simar(i) sukh(u) pāvau.
Kal(i) kales tan māh(i) miṭāvau.

ਸਿਮਰਉ ਜਾਸੁ ਬਿਸੁੰਭਰ ਏਕੈ ॥ ਨਾਮੁ ਜਪਤ ਅਗਨਤ ਅਨੇਕੈ ॥
Simrau jās(u) bisuṅbhar ekai.
Nām(u) japat aganat anekai.

ਬੇਦ ਪੁਰਾਨ ਸਿੰਮ੍ਰਿਤਿ ਸੁਧਾਖ੍ਯਰ ॥ ਕੀਨੇ ਰਾਮ ਨਾਮ ਇਕ ਆਖ੍ਯਰ ॥
Bed purān siṅmrit(i) sudhākhyar.
Kīne Rām Nām ik ākhyar.

Figure 7.15 Transliteration from a Sikh prayer (Doabia 2000)

Notably, transliterations use symbols to guide pronunciation and one might consider this a difference with the definition of phonetics. (Figure 7.16 was used in beta-testing NHS staff offering ‘Alternative choices’ of guidance for correct pronunciation.)

Key Emphasis: ā ē ū ī Small accent: ụ ṇ ḍ ọ ị			*Sacred Sukhmani* (Doabia 1979)
name *(p.10)* sad *(p.12)*	nām dụkhi	naam du-khi	
yes *(pp.xxviii-xxxiii)*	hāṃ	haa (sound is haaṇ)	*Outline of Hindi Grammar with exercises.* (McGregor 1972: pp.xxviii-xxxiii,5,15,54)
sad/miserable	duḥkh	du-khi	
meaning *(p.54)*	matlab	muth-lab	
greeting *(p.15)*	namaste	namas-thay	
no *(p.5)*	nahīṁ	nahi	
where	kahāṁ	ka-ha	
two	do	dho	
three	tīn	teen	
water	pānī	pa-ni	
hour	ghaṇṭā	ghanta	
week	haftā	haf-tha	
today	āj	aaj	
Phonetic Scheme (English dictionary) ā ē ī ō ū ōō ă ĕ ĭ ŏ ŭ ār ēr īr ōr ūr âr êr e.g. cā'rrў lōc'al cōō'lў **Accent**: main accent is ' at the end of a stressed syllable but positioning is arbitrary depending on the required pronunciation			Pronunciation (English) (OED 1964:pp.xii-xiii)

Figure 7.16 Symbols that guide pronunciations (alpha-tested with NHS staff, study 3)

In considering how design elements of a communication aid could be combined to include an educational element, the basic concepts of cognition and how people learn were reviewed. This was particularly important in the context of patients with low-literacy and for supporting patients for the longer-term.

7.6. Cognition and Learning

“The more you see, the more you know.

The more you know, the more you see” (Aldous Huxley 1974).

Cognition is the “mental act or process by which knowledge is acquired, including perception, intuition, and reasoning and the knowledge that results

from such an act or process" (Collins English Dictionary 2012). For Bruner (1985:p.183), the process of learning needs a structure to help bridge the gap between a person's existing knowledge and new knowledge and there are many ways of doing so*:*

> "'*Learning' is, most often, figuring out how to use what you already know in order to go beyond what you currently think. Some [ways] are more intuitive [..] but they all depend on something 'structural' [...and] how to put it together."*

Chapter 2 discussed that in high-context cultures, like in the Indian Subcontinent, information communication is more experienced based and implicit (Hall and Hall 1976) and people preferred thematic arrangements of information (Rau *et al* 2008). Also, in chapter 5 and the foregoing literature, it was noted that pictorial aids bridge communication and comprehension barriers particularly for people with low-literacy. Scholars suggest that 'scaffolding' offers a positive strategy for learning.

'Scaffolding' is a concept built on Vygotsky's 'zone of proximal development' which refers to a higher level of learning achieved by people collaborating with someone more knowledgeable (Cole 1985:pp.154-5) or perhaps supported by an aid. This requires some form and structure which features action and response, judgment and assistance (Lackovic 2010). Bruner outlined three distinct modes of representing the world: actions (*enactive*), pictures (*iconic*) and words and numbers (*symbolic*) and believed people think through these modes because they are used in everyday living and tasks (UEA 2012). Language was the most important cultural tool in cognitive growth and the process of learning and social environment and interaction with other people was also important (UEA 2012).

Cole (1985:pp.154-155) concurs and supports a culturally based concept of cognition: individuals actively assimilate through existing cognitive processes and these cannot be meaningfully separated: culture and cognition create each other. The objective is to appropriately position images and other visual resources in teaching and learning (Barlex and Carre, 1985, p.21) to help those lacking the language of the country they are living in or have poor literacy.

7.7. Convergence Design

Given the complexities of designing for usability, context of use and user experience (see 2.4.4.) and incorporating all these design guidelines, creating positive user experiences is a daunting prospect and one may well ask: *How might one go about achieving these objectives*? Considering the different elements that needed to be brought together to create positive user experiences, the concept of *convergence design* appeared pertinent.

Wroblewski (2004; adapted to services) states that *convergence design* helps us to resolve human-centric problems by considering the connections and commonalities between services and the products used, areas of specialisation and processes. This includes how design can bring different elements together to streamline developments to make them "usable, useful, AND enjoyable" and c*onvergence zones* can be paths to innovation, but doing so requires an awareness of these connections.

Morville (2004) depicts user experience in a *honeycomb* (Figure 7.17) which represents the facets required to create a good user experience and, as Wroblewski (2004) succinctly puts it, "The "honey" responsible for "sticking" user experience principles together is convergence." Although developed for website design, this *honeycomb* appears relevant to other services and was borrowed to guide study 3.

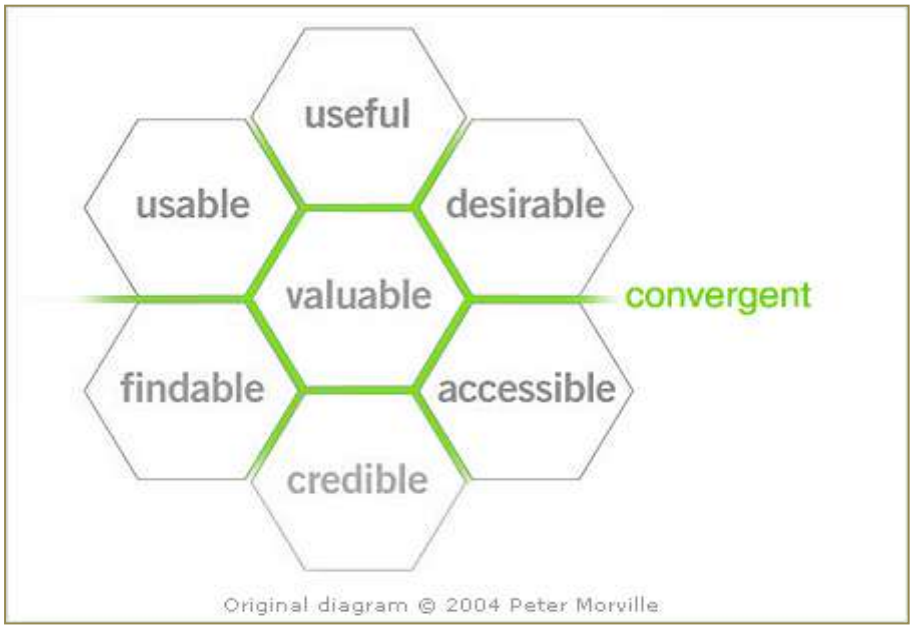


Figure 7.17 *User Experience Honeycomb* (Morville© 2004) adapted by Wroblewski (2004) to illustrate convergent design

According to Morville (2004) this is a tried and tested approach that works well, and he explains the purpose of these 7 facets:

1. **Useful:** Requires courage and creativity to ask whether the products or systems are useful and to apply ones knowledge of craft and medium to define innovative solutions that are more useful.
2. **Usable**: Ease of use remains vital and necessary, but usability is not sufficient.
3. **Desirable**: Appreciating the power and value of image, identity, brand, and other elements of emotional design.
4. **Accessible**: Particularly for people with disabilities.
5. **Valuable**: Deliver value to our sponsors, advance the mission, help the bottom line and improve customer satisfaction.
6. **Findable**: We must strive to design locatable objects, so users can find what they need.
7. **Credible:** Understanding the design elements that influence whether users trust and believe what we tell them.

Morville (2004) suggests the *honeycomb* serves several purposes simultaneously. It can transform how we see what we do by posing to ourselves *'Is it..?'* questions, i.e. *Is it useful? It is desirable?* etc.; it extends conversations beyond usability; supports a modular approach and enables us to explore beyond conventional boundaries. He concludes that:

> *"User experience design is a dynamic, multi-dimensional space where there's still plenty of room to build new boxes and draw new arrows, at least for the next ten years."*

Thus, asking the questions prompts a holistic consideration of the task. In the context of this research Items 1, 2 and 5 are implicit in the aims and objectives. To 3 we may add 'joy' or 'enjoyment' because shared enjoyment holds communities together (Dean 2002, citing Zizek and Lacan) and joy helps to motivate people (Jordan 2004). To 4 one may add people facing barriers due to variables like language, low-literacy, poor memory, acculturalation or impairments (that are not addressed by the Equality Act). Study 3 endeavoured to contribute elements to the first 5 facets using guidance from inclusive design, UCD and usability.

Convergence design and participatory techniques (3.6.6) are both user-centred and have much in common but they also contribute different elements to the design process. Convergence design brings a designer's creativity into focus whereas the participatory process set out above, identifies the steps and important questions designers need to consider in preparation and during implementation. It balances user-centred design with an activity-centred approach and highlights that designers usually have to justify the designs to stakeholders and/or management.

7.7.1. The etic and emic perspectives

Referencing the socio-cultural in design and discussing the design process milieu, *S*trickfaden *et al* (2006:p.5) suggest that designers need to consider the *local* and *universal*, *emic* (inside) and *etic* (outside) contexts. They state that "research into design has involved emic (inside) approaches […], e.g., design processes, problem solving, the design school and studio" and propose looking "outside of the designer, i.e. social and cultural forces that enter into the design process".

Akane (2011) explains that sociocultural research often involves studying at least two different cultures and the human behaviour within social world and the emic context refers to everything emanating from within a culture (belief, behaviour, values of an individual) and understands a single culture on its own terms. Harvard University (2008) agrees, (citing Letts 1990), adding that emic is also referred to as the insider, inductive or bottom-up approach and is the perspectives and words of research participants.

Whereas, the etic context is a description of a behaviour/belief by a social or scientific observer, that considers previously constructed theories to determine whether it applies to the new setting, i.e. it is applicable across cultures and attempts to be 'culturally neutral'. It is about discovering "the universal properties of cultures", which includes emotional, cognitive and perceptual structures (Akane (2011). Harvard University (2008) agrees, (citing Letts 1990), adding that an etic is also referred to as outsider, deductive, or top-down approach.

Whilst designing positive user experiences can be complicated, these

discussions reveal that the means do exist to continuously assess and bring together various elements through both convergence and iterative design in order to generate continuous improvements.

7.8. Discussion and Conclusions

These discussions highlight the importance of colour-associations and icons/images for communication in design. We may conclude that whilst all designs communicate a message, designs that are the most effective are interpreted consistently by different users. Where safety is involved, possible misinterpretation needs to be reduced through testing and evaluating users' perceptions with different groups, which accords well with an iterative, inclusive approach and good design principles.

The selection of images for developing the pictorial communication aids needed to consider the familiar (what people know already, which connects to what they understand), storyboards and the acceptability of images (whether the designs would be used). Images needed to be combined with text for clarity and colour schemes to consider emotions and cost. The author observed that colour-language associations ('green with envy', 'black moods') do not exist in the Indian Subcontinent although people would associate a red visage with rage or upset. Aside from particular negative associations with red, white and black, colours were generally viewed positively by EMCs (Indian Subcontinent) which enables harmonisation with the positive colour-associations of indigenous people. How colour was perceived by elderly people and people with visual impairments was an important consideration, for contrast and clarity.

The author noted that phonetics and transliteration into English have been employed in the Indian Subcontinent to bridge language barriers, e.g. Hindi to English phonetics on Bollywood film hoardings, Gurumukhi to English transliteration of Sikh prayers. In this thesis, 'phonetics' rather than transliteration has been used to describe one of the design elements of the communication aid because spellings were manipulated to focus on English pronunciation and avoided the symbols employed in transliteration.

Approaching the educational element as a scaffold (Vygotsky's concept, Cole

1985) could help patients to learn English beyond specific healthcare experiences in everyday living, i.e. the knowledge condensed in the pictorial aids could continue to act as a bridge to learning English and healthcare terms to empower and help patients in the longer-term, particularly including females. Improved understandings were also nurtured through better understand the etic contexts of the healthcare interactions and the emic contexts affecting EMC patients (Indian Subcontinent).

These themes were carried forward in the design of Study-3 which was guided by insights from this literature in the development of pictorial communication aids to facilitate more direct staff-patient for patients lacking English and/or literacy and other patient groups.

Study-3 used a generative approach, with individual interviews and participatory techniques to elicit data from three groups of participants and to iteratively develop and test the prototypes designed. The methodology used is described in the next chapter.

8. Study 3. An Inclusive Design Perspective on Communication Barriers in Healthcare

This chapter describes the generative phase of this research project. It sets out the development of the design rationale, the study design, the communication aid concept and the iterative design methodology used; the findings and concludes with a discussion. This study addressed overall research objective 8 which enabled the final research question to be answered.

RQ4	How might inclusive design contribute to lowering communication barriers for EMCs and NHS staff?	**Study 3: Generative** Inclusive, User Centred Design • EMCs lacking English and/or literacy • NHS Staff • Indigenous participants (Chapter 8 – Aim 3)
Obj:8	To undertake a generative study to design and develop an aid that might help to lower a selected barrier using user-centered design and inclusive design philosophy with iterative alpha-beta design testing and evaluation techniques, to benefit EMCs, providers and	

8.1. Introduction

"The way we see things is affected by what we know and what we believe. The relation between what we see and what we know is never settled."

John Berger (1972) In: *Ways of Seeing*.

Following the iterative models of inclusive design (see 2.4.5.2., Figures 2.12, 2.13) this study sought to translate the understandings gained from literature and studies 1 and 2, into user requirements to inform a design concept for a communication aid for staff and patients. An inclusive design approach with participatory design techniques were used to engage four groups of users creatively and to infuse the designs with their views and preferences.

8.2. Aim and Research Questions

This study had three aims:

1. To help lower communication barriers between staff and EMCs (Indian Subcontinent) lacking English and/or literacy, and other EMC and indigenous patient groups who shared communication difficulties, by inclusively designing visual communication aids using participatory design techniques.
2. To incorporate an educative element to encourage and motivate patients to learn English at home, particularly words commonly used in healthcare. Thereby,
3. To engage and empower patients and to contribute to positive healthcare experiences whilst reducing time pressures in the medium term and interpretation costs in healthcare in the longer term.

These aims were addressed by the following research questions:

RQ.1. How might visual communication be manipulated to design and develop aids to facilitate more direct staff-patient communication for EMCs lacking English and to help lower language/ literacy barriers?

RQ.2. How might the aids be designed to be inclusive of the needs of staff, EMCs lacking English and indigenous patient groups who share communication difficulties?

RQ.3. How might an educative element be designed to motivate and facilitate English-learning beyond specific healthcare experiences?

RQ.4. How might such aid(s) be designed to be useful and relevant across different healthcare departments and services?

8.3. Methodology

8.3.1. Approach

This study borrowed from several approaches to inform the different stages of the research and the researcher played the roles of investigator, facilitator and designer.

- **Translating and generating user requirements:** Insights were gathered from literature and the results of studies 1 & 2 (see 8.3.3).

- **Study design/ implementation*:*** followed a user-centred and inclusive design approach to understand users' difficulties and to capture the widest range of user preferences.
- **Concept design** was guided by Wrobleski's (2004) theory of *convergence design* and Morville's (2004) facets of user experience (see 7.7) to consider how the aids may be made *useful, usable, desirable, accessible, valuable* and *findable*.
- **Design development**: Participatory techniques and A/B iterative testing (Rohrer 2008, see 3.6.1.) testing used hybrid techniques to generate and capture preferences.

8.3.2. The Study Design

Table.8.1 summarises four considerations that influenced the study design how these were addressed (bullet points).

1. Maximising the time available (Rohrer's 2008, 4th dimension, see 3.6.1): Staff time was limited and retaining their interest and participation in an iterative process would need careful use of time.
   - To save time, generic topics on which the prototypes were based were selected and researched in advance. Thus, alpha testing elicited feedback on usefulness, structure and relevance, rather than commencing from determining its content (people find it easier to critique something than start from scratch, Nielsen 2006).
2. Gaining Trust: EMC participants lacking English and/or literacy may not be familiar or comfortable with research; gaining trust and motivating them was critical to an iterative process.
   - Trust was gained during recruitment by citing findings from studies 1 and 2 to potential participants, i.e. their difficulties and desire to directly communicate with healthcare staff were repeated to them and that staff would like them to learn English was added. Also, knowing English would profit them at work and as their needs grew with aging (Safeer and Keenan 2005).
3. Selecting the 3rd study group: indigenous participant (RQ.3).
   - Indigenous elderly were selected as the 3rd study group from the findings of Study 2 (see 6.6.3.3. Would more AV aids help) and the

literature.

4. Determining the order of iterative testing with participants.
    - Due to the safety critical nature of healthcare, alpha testing commenced with staff followed by EMC participant testing. The order was reversed in beta testing: EMCs, indigenous elderly people, indigenous participants then staff. Final testing and evaluation was carried out by staff.

8.3.3. Sampling Strategy

Sampling was purposive throughout to generate specific data from the different participant groups. The same staff and EMC participants were approached for beta-testing to save time re-familiarising participants with the research.

- **NHS staff:** 6 staff were selected from different front-line roles in different departments as 'experts' (see rationale 8.3.5., Table 8.1, 7): senior physiotherapist, A&E registrar, ward sister (elderly care and stroke), paramedic, General Practitioner and senior pharmacy technician.
- **EMC adults**: 10 participants with poor English and/or literacy who spoke either Punjabi, Hindi or Urdu for whom the researcher could translate.
- **Indigenous elderly**: 10 English-speakers aged 60+ years.
- **Indigenous adults:** 3 adults were added inductively as the research progressed.

Sampling numbers were influenced by time required for iterative testing and monitoring when data repeated itself. Patients were not involved by the researcher, but by Staff during final testing.

8.3.4. Ethical Considerations

- **Staff**: A Substantial Amendment application was submitted online to Nottingham NHS REC-1 through IRAS (2010) for a 'Favourable opinion' to recruit NHS Staff and continue research with the NHS. Updated ethics documents were also submitted: Letter of invitation, Participant Information Sheet, Informed

Consent, interview questions and the amended Research Protocol detailing the study rationale and conduct. These documents were disseminated to the 5 Trust R&D departments and Loughborough University's Research Office. The REC's Favourable opinion was disseminated and copies of the Research Passport updated to extend Letters of Access. Vigilance was carried out by 5 Site Liaisons.

- **EMCs**: Permission to approach the congregation in the Gurudwara (Sikh place of worship) was gained from the Committee. Ten minutes were set aside before each interview to review the study information.
- **Indigenous elderly:** The study information was emailed to a care home manager and permission gained to approach residents; the warden was fully informed and introduced the researcher to participants.
- **Indigenous participants** (included inductively).

Letters of invitation, Information sheets and consent forms were prepared for each participant group (Appendix-E9-17) and given to participants before the interview. Informed consent was gained from each individual before interview. That there were no right or wrong answers and data would be anonymised was reconfirmed before the recorder was switched on with permission and the interview commenced. All interviews were recorded for accuracy.

Staff and indigenous participants were fluent in English and the researcher translated the study information for EMCs and invited their family to review the information and Informed Consent. Refreshment and comfort breaks were offered where appropriate. At the end of every interview, participants were thanked and provided a choice of large chocolate bars as a small token of appreciation.

8.3.5. Design Concept Rationale

Whilst waiting ethical approval, brainstorming and insights from literature were used to address the challenges for developing the prototypes. The 12

considerations that influenced the design concept and the rationale for the design decisions are summarised in Table.8.1.

Table 8.1 Considerations and rationale that influenced the design concept

1.	On which topics should the design concept be based to make it relevant and useful across several departments? Two generic topics were selected from literature (Nichols-English and Poirier 2000; WHO 2003; Johnson *et al* 2006; see Chapter 7.2) and findings from study 2 (difficulties in pain screening and gaining a pain score; the Pain Screening and Assessment Medication instructions and Side effects
2.	Disparity in skills and knowledge (context of use, Thomas and Bevan 1995): There was wide disparity in the English skills and healthcare terminology between participants. Staff had a good knowledge, indigenous participants would be relatively familiar and EMCs lacking English had little/none. How could these needs be accommodated and complexities and duplications in the design be reduced? The needs of staff and patients converged in a desire for direct communication but diverged in the practical communication process. A 'twinned aid' concept was decided upon: questions-based for staff and, for patients, co-related rich pictures with carefully selected English text to accompany each image for clarity (Dowse and Ehlers 2004; Safeer and Keenan 2005; Studies 1 and 2).. Questions to patients would be kept short and simple.
3.	How could sub-levels of questions be developed for staff to determine patients' problems and convey treatment? The main questions were selected from researching medical literature and conversation-type sub-questions were developed using literature and brainstorming (like a greeting, results of study 2) and would be modified by staff during testing.
4.	How could the images selected facilitate communication and comprehension, but avoid a need for learning a pictorial language to avoid retention problems and a reliance on memory? (Findings, study 2.) Images were selected from everyday living guided by literature (see 7.4) and by using/testing different types of images to include an element of joy (Jordan 2004) or interest.
5.	What form might an educative element take to facilitate English-learning at home and improve medication adherence? What insights would help? A take-away pictorial leaflet with English text (and phonetics) was conceived of, for patients to take home to continue learning English. A printed format would make it useful, usable and accessible to those unfamiliar with computers (Moreville 2004; Nielson 2006; also see 8) and facilitate learning through repetition (Safeer and Keenan 2005; studies 1 and 2).

6.	How might the aids contribute to lowering cost and saving time in healthcare?
7.	How might the aids enhance patient experience, making it more cohesive across healthcare services? Both questions were addressed by harmonising the aids across departments and Trusts to reduce cost (usable, valuable, Moreville 2004) and would facilitate learning through repetition. Thus, in sampling, staff were recruited as 'experts' from different departments.
8.	What media should be used? The seven user capabilities which influence how successfully a product is used, particularly vision, thinking, communication, hearing, and accessibility (Clarkson *et al* 2007, see 2.3.3.1) of the different user groups was the main consideration. (see also 5 above) Paper-based prototypes were produced for testing with participants and staff were asked about the usefulness of web-based designs for access, printing and to reduce cost, possibly as 'apps'.
9.	What design elements would be included? The elements were images, colour, English text, a 'missing element' to bridge the language gap between text and images (see 10). From literature it was concluded that whilst thoughtfully designed pictorial aids with text improved cognition, these were unlikely to meet the need for sub-levels of questions and validating responses (study 2, doctors). Learning a pictorial language would add to barriers.
10.	What 'missing element' might help to bridge the gap between visual communication and English to facilitate sub-levels of communication? This proved a difficult challenge. Brainstorming helped to identify a cultural insight: *phonetics* was selected to be deployed as the 'missing' element.
11.	What language should the initial designs be in?
12.	How might patient's responses to questions be more easily understood and verified by staff? Hindi was selected and Hindi phonetics-English 'response checkers' were designed to validate responses.

Phonetics was the 'glue' (Wroblewski 2004), the innovative element in the concept, a potential bridge that spanned the gap between English and visual communication and facilitated at least simple conversations. Although transliteration was considered, the review of transliterated materials noted it employed symbols normally employed in dictionaries to product the right pronunciation (see 7.5). This would require staff to memorise the meanings of these symbols adding to their workload, which could hinder/complicate use

of the aid and deter staff. As research progressed it became clear that the disparity in English and Hindi alphabets and their pronunciations was a potential problem to accurate pronunciation by staff and, therefore, to a patient's comprehension. The focus therefore was very much on sound and how English words are normally pronounced was used to generate the correct sounds. Thus, phonetics became the 4th design element alongside images, English text and colour, to enable staff to put questions and sub-questions in a different language.

8.3.6. Methods: Overview

The tools and the design of questions emanated from the research and are described in each specific stage of testing. They were as simple as possible due to time constraints and because some participants would be unfamiliar with research.

8.3.6.1. Interviews

Semi-structured, individual interviews were selected as the most appropriate method to gather data for all participant groups to focus participant's attention, to encourage them to speak freely and to give each individual full attention to maximise feedback within the given time. The alpha-testing interviews with staff were semi-structured and all following interviews (with all participants) were more structured. The first interview in each stage was used to pilot and adjust questions.

All interviews were conducted in naturalistic settings. Informed consent was gained, notes were made by the author and the interviews were recorded. Responses were also captured on paper (prototypes, response forms and/or a notepad).

8.3.6.2. Questions

Questions were designed for each stage of testing and for different participant groups. The questions were mainly open questions (qualitative) with probes, some closed questions and 1-5 qualitative Likert scales. Iterative A/B user-testing and evaluation was used to validate and generate design improvements, using inclusive, participatory techniques. Some suggestions by participants were added inductively and tested at succeeding interviews.

The questions for user-testing are described under each stage as they emanated from the designs prepared.

8.3.6.3. Order of Testing

The questions tested each design element of the prototypes and the concept and tools were prepared for each stage of testing and are described in each stage.

Figure 8.1 depicts the order in which user-testing was organised and the purpose of testing. Due to the safety-critical nature of healthcare, alpha testing commenced with staff and pictorial prototypes were developed after receiving their feedback, whereas beta-testing commenced with EMCs. Beta-testing staff was interspersed with testing indigenous elderly people and indigenous participants.

A brief overview of implementation follows and details of participants, interviews and procedures are described in appropriate sections.

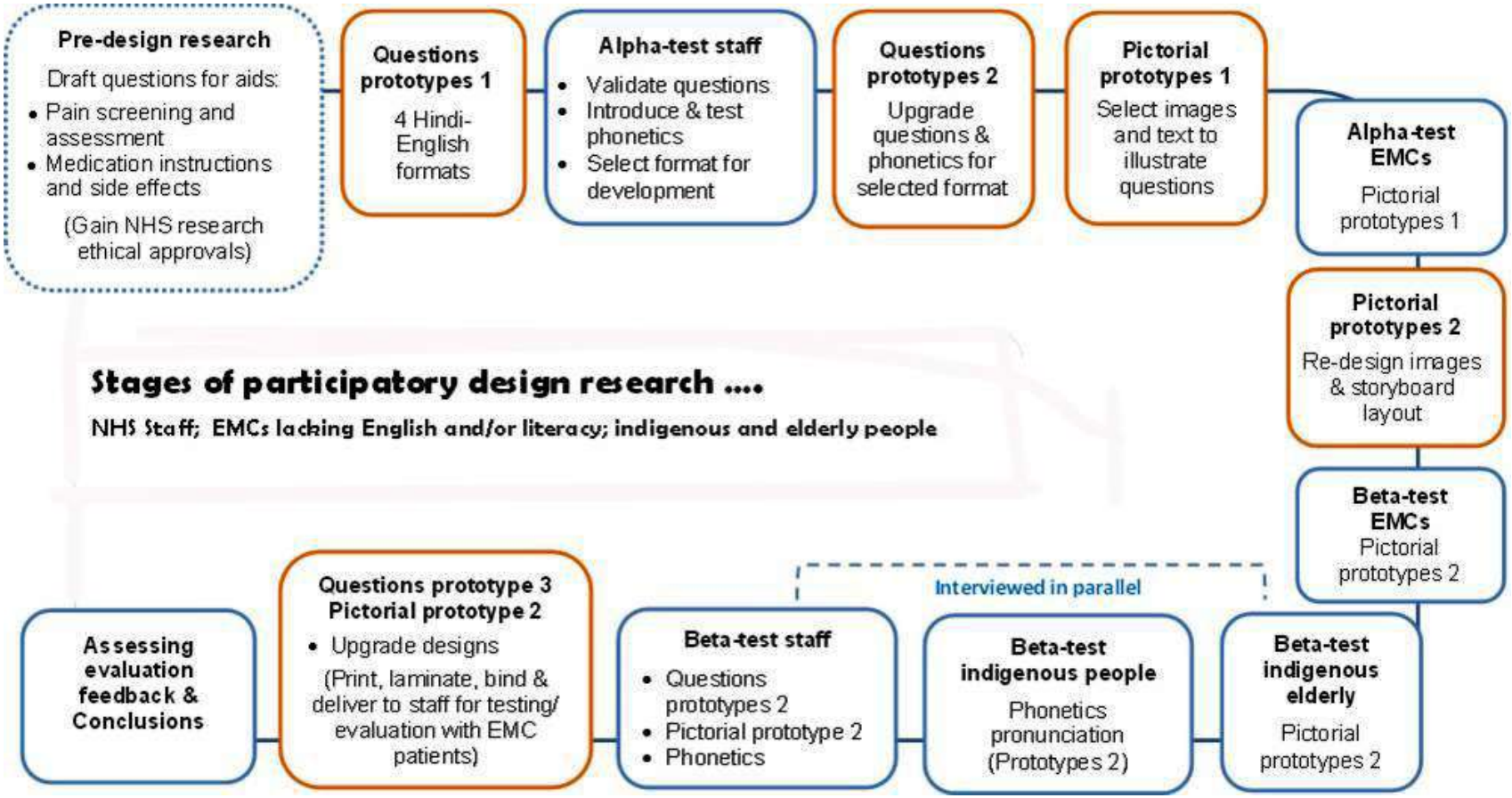


Figure 8.1 Participatory iterative design methodology and order of testing in study 3

8.4. Iterative Design Process Implementation

The study was conducted in 2 English Counties in the Midlands. Altogether, 34 adults participated from the 4 study groups. Table 8.4 sets out participants by group and gender.

Table 8.2 Participants by gender *(n*=34)

Participants	Males	Females
NHS Staff	6	1
EMCs lacking English (Sikhs)	3	10
Indigenous elderly	5	5
Indigenous	2	2
Total	16	18

Fifty-eight individual interviews were conducted. Table 8.3 sets out the order in which participants were tested.

Table 8.3 Individual interviews at each stage of iterative testing. *n*=58 Interviews

Participant testing	NHS staff	EMCs lacking English	Indigenous Elderly	Indigenous adults	Sub-total
Alpha-testing	6	13			**19**
Beta-testing	7	11	10	4	**32**
Final test & evaluation*	7				**7**
Sub-total	**20**	**24**	**10**	**4**	**58**

Ethics procedures were followed (see 8.3.4.) and, following naturalistic enquiry (ecological validity), the interviews were conducted at locations familiar to participants:

- NHS staff: Place of work or residence
- EMCs: Gurudwara or residence
- Indigenous elderly: residence
- Indigenous adults: Place of work or residence

Participants reviewed all the sections and design elements of the aids relevant to that stage of testing. As research progressed and feedback from different groups was collated and shared between participants and between participant groups (what EMCs said with staff and vice versa). This is reflected in the preparation of interview questions throughout, e.g. explaining to staff how the phonetics were designed (Appendix-D2), or in 'Setting the

scene' for EMCs explaining the context of using the images, i.e. they were unwell and wished to explain their problem to a doctor (Appendix-D4);

The testing process is described in the sequence undertaken as each step informed the next design upgrade, although during in beta-testing, staff testing was interspersed with testing indigenous elderly people and indigenous participants.

The findings are described and discussed in each testing stage. Data are organised as follows:

- Design Concept:
  - A Communication aid: Purpose
  - Preparatory research (compiling the questions)
- Alpha-testing staff
- Alpha-testing EMCs
- Beta-testing EMCs
- Beta-testing indigenous elderly people
- Beta-testing staff and indigenous people
- Prototypes-3 upgrades
- Final-testing: NHS staff

8.4.1. Design Concept

The design concept for pictorial content and questions drew on insights from literature (see 7.8 and 8.3.5) and from the results of studies 1 and 2. This section describes the iterative design and testing process followed to develop the communication aids for:

- pain screening and assessment and
- medication adherence and side effects

i.e. questions-prototypes and pictorial-prototypes, in accordance with the design rationale (8.3.5),

8.4.1.1. A Communication Aid: Purpose

The questions-prototypes sought to help staff to:

- Engage more directly with EMC patients lacking English
- Reassure patients to lower anxiety
- Guide patients to provide short answers to allow easier correlation to the phonetics,

- Encourage patients to speak in English by including commonly understood words (yes, no, small, big)
- Use repetition to validate a patient's response, i.e. repeating a patient's response in phonetics as a question or statement for accuracy (in the same way staff ask patients to repeat an instruction).
- Combine the foregoing with staffs' routine practice of observing patients' body language.

The pictorial-prototypes illustrated the questions-prototypes to help EMC patients lacking English and/or literacy explain their problems and to encourage English-learning. By prompting patients to use simple English words whilst responding, it was hoped patients would be motivated to do precisely that. Thus, each time individuals needed care, they would have added to their vocabulary and, over time, learned English (as observed by a consultant, study 2).

In the following narrative *prototypes* refers to both topics: *pain* and *medication*, unless otherwise specified and, for clarity, participants are specifically identified as staff, EMCs, indigenous elderly or indigenous adults, as appropriate.

8.4.1.2. Pre-testing research

Draft questions in English were researched and collated to lay the foundation for the communication aids as follows (see questions in 8.4.3.2A):

Pain Screening & Assessment

- *Working to improve nursing home care: Pain Screening* (Borun Center 2009)
- *The management of pain* (Watson *et al* 2005)
- *The Emergency Multilingual Phrasebook* (British Red Cross 2004)

Medication Instructions and Side Effects:

- *The Emergency Multilingual Phrasebook* (British Red Cross 2004)
- *NHS Choices* website (2011)
- Findings of study 2 (e.g. greeting patients)

8.4.2. Alpha-testing: NHS Staff

This section describes the interview with staff, the findings and the following design upgrades. Alpha-testing was carried out in two stages: questions-prototypes with staff and pictorial-prototypes with EMCs with an intervening design stage.

8.4.2.1. Participants

Staff were recruited from amongst those who had expressed an interest in participating further during study 2. They were from different departments, heterogeneous (1 female, 5 males) and new (unknown to each other):

Primary care: GP and paramedic

Acute care: Senior Pharmacy Technician; Ward Sister (Stroke and Elderly Care); Senior Physiotherapist (Elderly Care); A&E Senior Registrar (adult care).

8.4.2.2. Tools

Three tools were prepared for alpha-testing staff: Draft questions on pain and medication (English), Hindi-English questions prototypes (5) and interview questions. Table 8.4 sets out the tools, the purpose of testing and feedback sought.

Table 8.4 Alpha-testing staff: the tools and purpose

Tools	Purpose	Critical feedback
A. Alpha-testing staff		
Interview questions Draft Englishquestions 5 English-Hindi prototypes	Validate questions, sequence Introduce phonetics & test Determine formats/ size(s)	Accuracy, usefulness, relevance, gaps, preferences. Familiarisation. Select prototype for development.

A. **Draft Questions: Laying the Foundation**

Draft questions in English were prepared in the first person, as might be put to a patient in the order indicated by literature (see 8.4.2) and with a greeting and preamble on page 1 (study 2 results).

Pain: Fourteen questions were arranged in the following order (Figure 8.2)

1. The presence of pain
2. Severity/ pain score
3. Whether it was constant/ periodic
4. Pain pattern each day
5. Kind of pain
6. Pain pattern during the past week
7. Pain on moving
8. On eating
9. Going to the toilet
10. Any temperature
11. What relieved the pain
12. What treatment/ medication was being taken
13. Efficacy of treatment/ medication in the past week
14. Length of time before pain returned.

Figure 8.2 Draft questions on pain

Medication: Fifteen questions were divided into 2 main sections: 10 questions and 5 under 'Special Instructions' (Figure 8.3).

Current medication

1. Allergy to medication
2. Medicines the patient was presently taking.
3. Other medication taken, like natural/ herbal remedies.
4. Current dosage.
5. **What to take:** I am giving you these tablets/ this medicine
6. **How much to take:** Take.....tablets or..... small spoons or....big spoons.
7. **When to take:** Take it ....times in the morning/ afternoon/ evening/ night.
8. **How to take:** With water...before food.....after food.
9. **What to avoid:** Whilst you take these, don't drink alcohol/ coffee...
10. Don't take it too late before sleeping...(you will not sleep well)

Special Instructions

11. Do not stop taking the medicine. Finish the medicine... Take it for...days/weeks/months
12. Do not wet the area
13. Afterwards come and see me/ your doctor. I am making an appointment with your doctor. THIS month, this date. NEXT month, this date.

Possible Side Effects

14. Smaller affects
15. Bad effects and action to take

Figure 8.3 Draft questions on medication

Figures 8.4-8.5 depict the first pages of the drafts (see Appendix-D1.1-1.3). The highlighted text raised questions on content to put to staff.

PHASE 2 – DESIGN

DRAFT QUESTIONS FOR NHS STAFF TO EDIT

Greeting: My name is ___ ____ I am the nurse/ doctor.

Your name? _____ Date: _____

We are going to examine you, to see what the trouble or illness is, OK? Do not worry. We will ask you questions in Hindi, please respond Yes or OK, or No. Alright? If you know a few English words speak them please.

PAIN SCREENING & ASSESSMENT *(a Response Checker will be included)*

1. Have you pain? Yes? No? Show me where
   When did it start: Instead of calendar and clock: Today? 1-2 days? 1-2 week?
2. How **bad** is the pain?
   Possibly: Small? Medium? Big? Very big?

2b. Gaining a Pain Score:

If we count from 1 to 10, *(show on hands)*

1 means no pain, 10 means the worst pain you ever had (unbearable), what number is your pain?

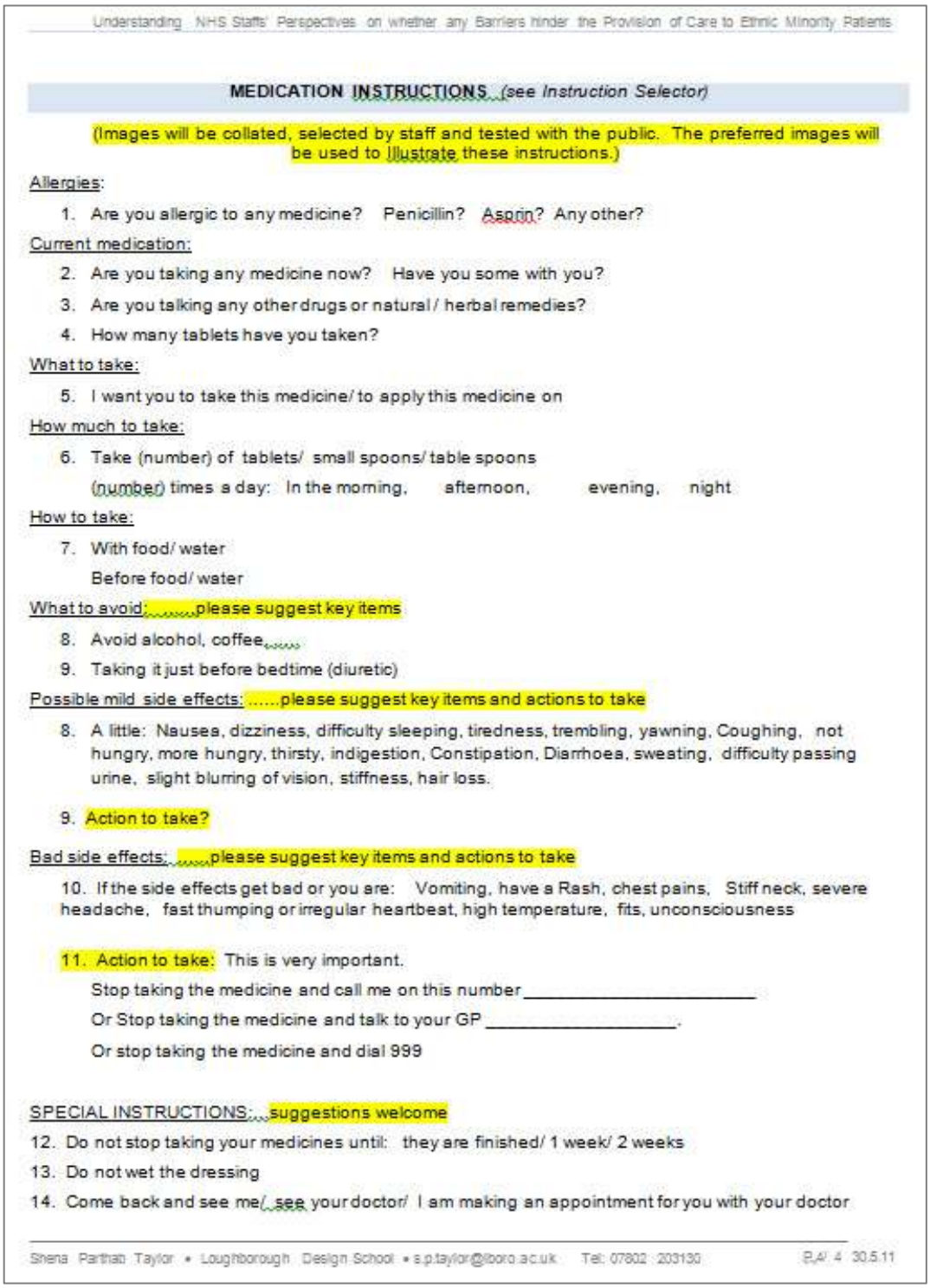
0 1 2 3 4 5 6 7 8 9 10

none worst pain

3. Is the pain constant/ always present, or does it come and go?
4. Do you have pain every day/ always?
5. If you move about, does it pain? Can you up sit up straight? Stand? Walk? (moved up)
6. I wish to know from you what kind of pain you have. I will ask some questions, please reply Yes or No
   Is the pain:

Aching	(is it like a headache or toothache pain)	Shooting	(appears suddenly then goes)
Throbbing	(comes-goes quickly all the time)	Tiring	
Pricking		Exhausting	Duplicate to tiring?
Burning		Penetrating	(deep)
Gnawing		Nagging	Duplicate to throbbing?
Sharp		Numb	(if touched one doesn't know)
Stabbing	(sharp pain, comes-goes)	Miserable	
Tender	(painful to touch)	Unbearable	

Figure 8.4 Pain draft questions (p.1)



Understanding NHS Staffs' Perspectives on whether any Barriers hinder the Provision of Care to Ethnic Minority Patients

MEDICATION INSTRUCTIONS *(see Instruction Selector)*

(Images will be collated, selected by staff and tested with the public. The preferred images will be used to Illustrate these instructions.)

Allergies:

1. Are you allergic to any medicine? Penicillin? Asprin? Any other?

Current medication:

2. Are you taking any medicine now? Have you some with you?
3. Are you talking any other drugs or natural / herbal remedies?
4. How many tablets have you taken?

What to take:

5. I want you to take this medicine/ to apply this medicine on

How much to take:

6. Take (number) of tablets/ small spoons/ table spoons
   (number) times a day: In the morning, afternoon, evening, night

How to take:

7. With food/ water
   Before food/ water

What to avoid: .....please suggest key items

8. Avoid alcohol, coffee,.....
9. Taking it just before bedtime (diuretic)

Possible mild side effects: .....please suggest key items and actions to take

8. A little: Nausea, dizziness, difficulty sleeping, tiredness, trembling, yawning, Coughing, not hungry, more hungry, thirsty, indigestion, Constipation, Diarrhoea, sweating, difficulty passing urine, slight blurring of vision, stiffness, hair loss.

9. Action to take?

Bad side effects: .....please suggest key items and actions to take

10. If the side effects get bad or you are: Vomiting, have a Rash, chest pains, Stiff neck, severe headache, fast thumping or irregular heartbeat, high temperature, fits, unconsciousness

11. Action to take: This is very important.
    Stop taking the medicine and call me on this number _____
    Or Stop taking the medicine and talk to your GP _____.
    Or stop taking the medicine and dial 999

SPECIAL INSTRUCTIONS:...suggestions welcome

12. Do not stop taking your medicines until: they are finished/ 1 week/ 2 weeks
13. Do not wet the dressing
14. Come back and see me/ see your doctor/ I am making an appointment for you with your doctor

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Figure 8.5 Medication draft questions

The drafts were emailed to staff with a letter confirming the research sources to establish the validity of data and critical feedback was invited prior to alpha-testing. However, anticipating this might not be received before the interview (due to time pressures on staff), to avoid further delay it was decided to gain feedback during the interview. Thus questions-prototypes-1 in English-Hindi phonetics were prepared to alpha-test with staff and to gauge reactions to the concept of using phonetics as a communicating tool.

B. **English-Hindi questions-prototypes-1: Features and Benefits**

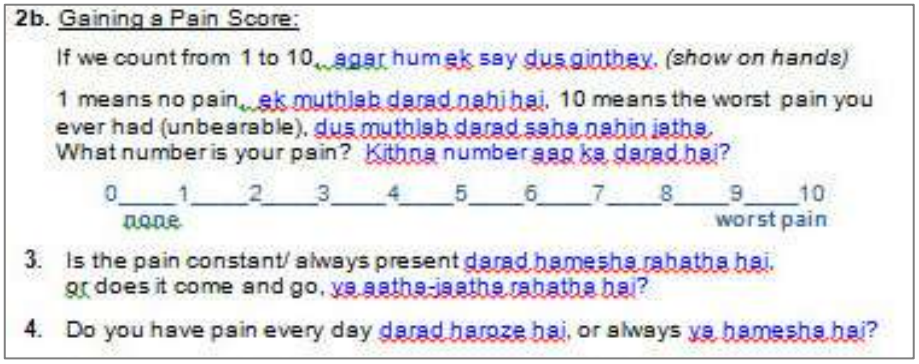
Five English-Hindi prototypes were designed based on the draft questions: 4 for pain and 1 for medication (see B2; Appendix-D2.1-2.5) for staff to select their preferred design elements. Medication would be developed further guided by feedback received on pain. Each of the following design elements was tested.

B1. Size and Fonts: Data was arranged to fit on 2 sides of an A4 page for simplicity. Arial sans serif font (Bailey 2005) was used: 11 point in v.1A bodytext, and medication (10.5 in the response checkers); and 10 pitch in v.1B-D. Although 10 is less user-friendly one of the design challenges was to accommodate all the information whilst avoiding congestion. The text was justified left.

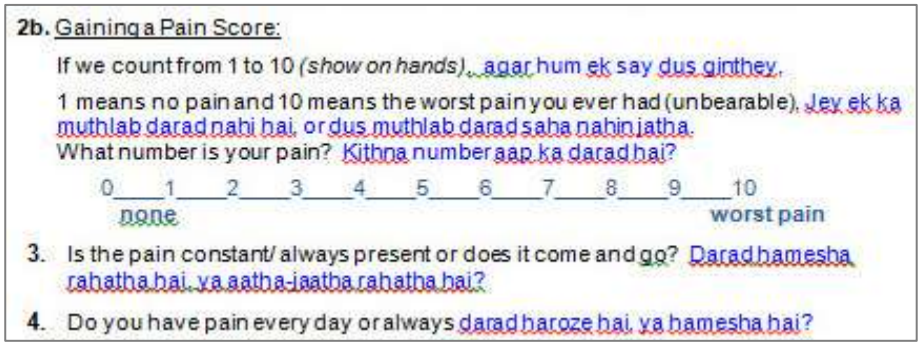
B2. Formats: The 5 questions-prototypes designs varied as follows:

Prototypes	**Layout of Hindi phonetics**	**Orientation**
Pain-1A	Interspersed closely with English words/phrases	Portrait
Pain-1B	Placed at the end of a sentence	
Pain-1C	Separated into a different column	
Pain-1D	Separated into a different column	Landscape
Medication-1A	As in Pain-1A	Portrait

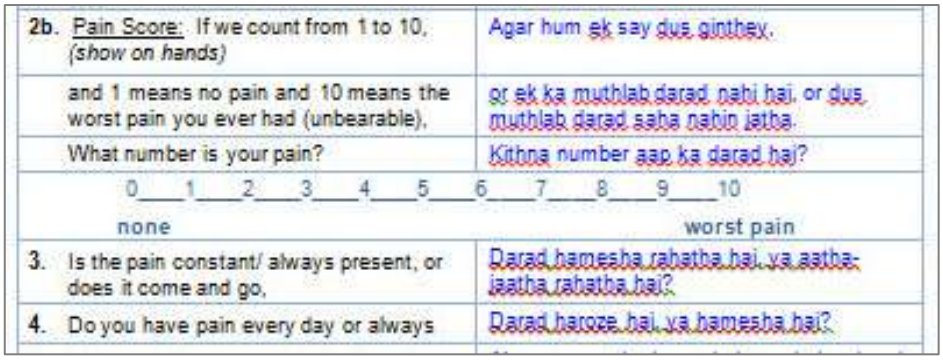
B3. Colours: The text was colour-coded: English text in black (contrast) and the related Hindi phonetics in deep blue (can be seen in dim light) to identify the 'speaking' sections which included a few simple English words that are commonly understood (yes, no, small, big). Figure 8.6 depict extracts from the four pain prototypes (see Appendix-D2.1-2.4).



Pain-prototype-1A Hindi phonetics interspersed with English.



Pain-prototype-1B English sentence precedes Hindi phonetics



Pain-prototype-1C English and Hindi phonetics separated (tabulation)

Pain-prototype-1D as in1C but in A4 landscape

Figure 8.6 Depicting differences in four pain questions-prototypes-1

B4. Information arrangement. Information was arranged in distinct sections, each with a different purpose, to enable staff to:

- follow a logical order familiar to them (easy navigation)
- skip back-and-forth amongst questions to re-state questions if required
- verify/ validate the responses received by consulting the response checker
- repeat patients' responses back to them in phonetics for verification
- pick out Hindi key words/phrases that related to English

A greeting and introduction preceded the questions (top of page 1) in line with staffs' comments (study 2). Likewise, a **preamble** was inserted to reassure patients to explain what was happening (findings in studies 1 and 2), and requested patients for short answers to allow staff to relate responses to the response checker.

The main questions were numbered sequentially 1-14 and sub-questions added based on training staff received on capturing the nature of pain and other symptoms, and was developed through brainstorming to simulate a staff-patient 'conversation'. Thus, *What kind of pain is it?* typically has a list of physiological and emotional possibilities.

For instance the types of physiological pain (aching, burning, pins and needles) formed a section of the aid (and would be later illustrated) and were validated by staff including the accuracy of the simpler English phrases as research progressed. e.g. A literal translation of *pins and needles* (under 'Kind of pain' Q.5) would fail to accurately convey the meaning and be confused with a *pricking pain*. Thus, the symptom that produced pins and needles was substituted:

Pins and Needles goes to sleep followed by phonetics

Because pins and needles resulted from a part of the body 'going to sleep' participants were more likely to understand 'goes to sleep' was placed in phonetics (later tested successfully with EMCs).

B5. The Phonetics: The key factors guiding the phonetics development were as follows.

- Different possibilities for translating each question into Hindi whilst meaning the same. e.g. *Do you have any pain?* translated equally well into Hindi as *Have you pain*? due to differences in grammar. Thus, the latter was set out in English.
- To convey the meanings of complex English words in simpler everyday vernacular Hindi, simpler English phrases/ words were written alongside complex English words to maintain integrity, and the simpler English phrases were put in phonetics.
- Phonetics were written around how normal English words are pronounced to make producing the right sounds easier, e.g. they in English was used in *theyna,* to give.
- Questions were kept as short as possible to maximise staffs' control over the process and to provide time to match the response with the response checker.
- Simple Hindi and meanings were considered, e.g. medicine can be written phonetically as *goli (*Johnson *et al* 2006;p.21), something round, i.e. tablets. However, this does not include other medication, like syrup or powder or ointment (pointed out by a nurse). This was substituted with *davai* (pron. *dava-ee*) to include all medication, and later simplified to *dava.*

B6. Accuracy: To aid accuracy and control of questions, matching English-Hindi key words and phrases were underlined, e.g. pain and bad were underlined to co-relate to darad and bura, respectively.

B7. Response checkers contained potential responses from patients (Yes/No, number of days, hours, everyday/ yesterday etc.) arranged in logical categories. They were placed to the right of the questions and were initially the same on both sides of the page and for both prototypes. Figures 8.7 and 8.8 depict the arrangement of sections in the English-Hindi Questions-prototype-v.1A.

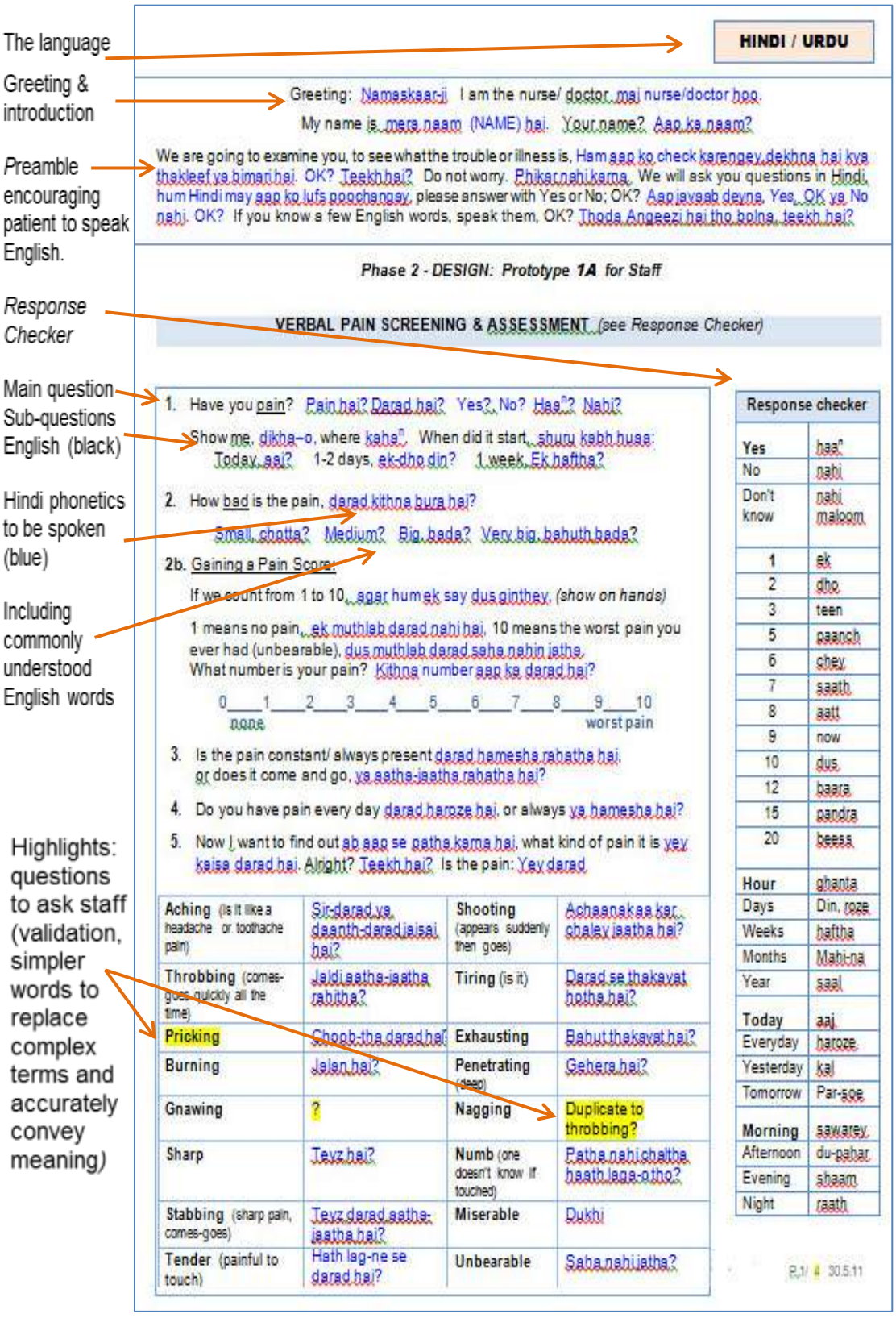
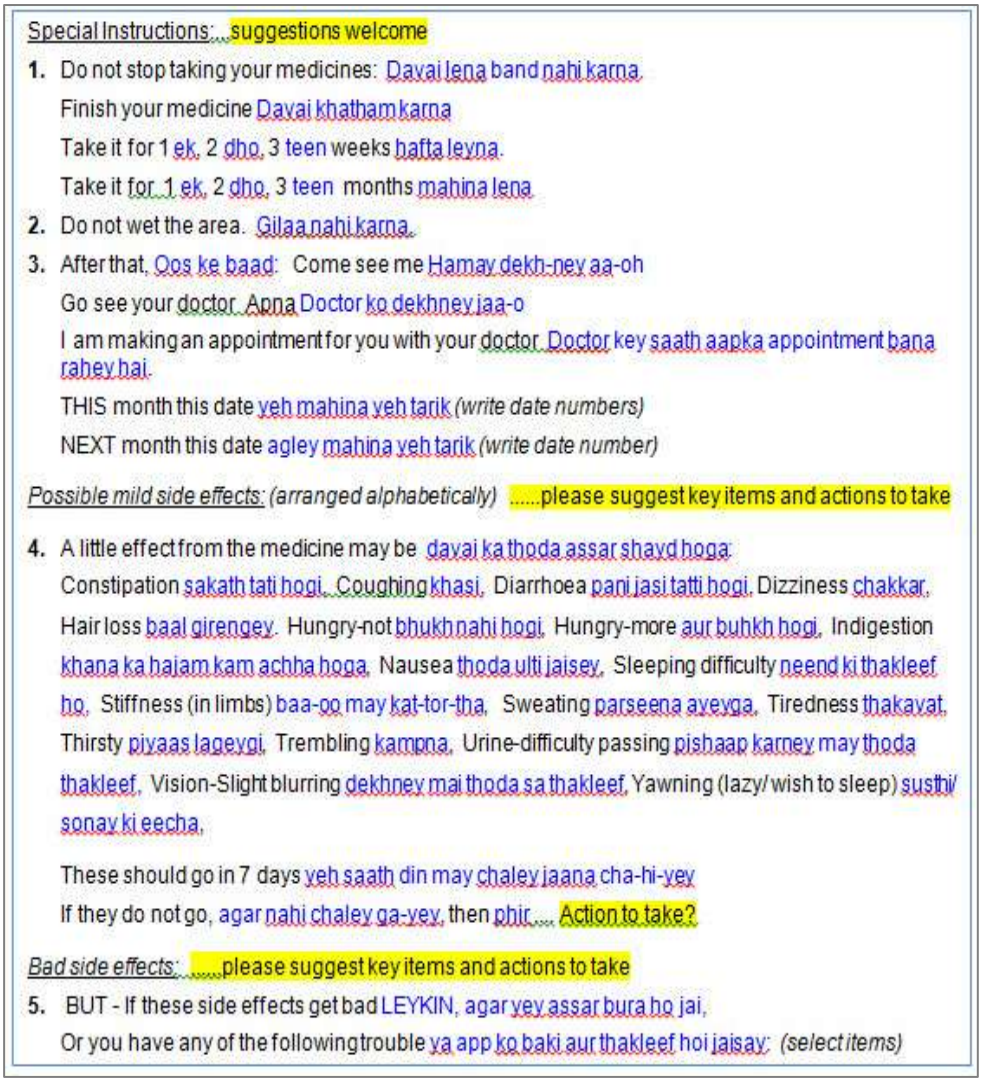


Figure 8.7 Pain-prototype-1A (p.1) depicting the arrangement of information.



Special Instructions: ...suggestions welcome

1. Do not stop taking your medicines: Davai lena band nahi karna.
   Finish your medicine Davai khatham karna
   Take it for 1 ek, 2 dho, 3 teen weeks hafta leyna.
   Take it for 1 ek, 2 dho, 3 teen months mahina lena
2. Do not wet the area. Gilaa nahi karna.
3. After that, Oos ke baad: Come see me Hamay dekh-ney aa-oh
   Go see your doctor Apna Doctor ko dekhney jaa-o
   I am making an appointment for you with your doctor Doctor key saath aapka appointment bana rahey hai.
   THIS month this date yeh mahina yeh tarik *(write date numbers)*
   NEXT month this date agley mahina yeh tarik *(write date number)*

Possible mild side effects: (arranged alphabetically) .....please suggest key items and actions to take

4. A little effect from the medicine may be davai ka thoda assar shayd hoga:
   Constipation sakath tati hogi, Coughing khasi, Diarrhoea pani jasi tatti hogi, Dizziness chakkar, Hair loss baal girengey, Hungry-not bhukh nahi hogi, Hungry-more aur buhkh hogi, Indigestion khana ka hajam kam achha hoga, Nausea thoda ulti jaisey, Sleeping difficulty neend ki thakleef ho, Stiffness (in limbs) baa-oo may kat-tor-tha, Sweating parseena ayevga, Tiredness thakavat, Thirsty piyaas lagevgi, Trembling kampna, Urine-difficulty passing pishaap karney may thoda thakleef, Vision-Slight blurring dekhney mai thoda sa thakleef, Yawning (lazy/wish to sleep) susthi/ sonay ki eecha,

   These should go in 7 days yeh saath din may chaley jaana cha-hi-yey
   If they do not go, agar nahi chaley ga-yey, then phir .... Action to take?

Bad side effects: .....please suggest key items and actions to take

5. BUT - If these side effects get bad LEYKIN, agar yey assar bura ho jai,
   Or you have any of the following trouble ya app ko baki aur thakleef hoi jaisay: *(select items)*

Figure 8.8 Medication-prototype-1A (p.2) The paragraph arrangement was later altered.

B.8. Benefits: The prototypes aimed to facilitate more direct, simple, staff-patient communication and to save time (waiting for interpreters, family) to help improve target response times. Also, the aids would focus patients' attention on the importance of learning English and to motivate them by observing the efforts staff were making to communicate with them.

C. **Interview Questions**

Open questions (Appendix-D3, approved by the NHS REC) elicited feedback on the draft questions and prototypes:

- Relevance, flow, determining whether staff-patient conversations in practise conformed to initial drafts, adjustments required
- Using phonetics as a communication tool

- Whether illustrations for the questions were already used
- Preferences for :
- illustrations: cartoons or real life
- Twinned aids: English and phonetics (verbal communication) for staff, and images and key English words for patients (more cost-effective for printing only the section desired.)
- A combined aid (text and images)
- Using the pictorial section as an educative element for patients to take home
- Dimensions
- Scenarios they may use it in
- Whether the material should be placed on a website and use of other new media (like video or audio files)
- Any other suggestions or preferences

8.4.2.3. Procedure

Semi-structured interviews lasted 30-40 minutes. The draft questions were reviewed first, the concept of phonetics as a communicating tool was introduced and the 5 Hindi-English questions-prototypes-v1 reviewed, i.e. the interview questions were put to participants.

Staff were asked to read the phonetics on page 1 of the pain prototype to gain familiarity. They were guided to speak the words as they would normally pronounce English, but with equal emphasis on all syllables as they were pronouncing phonetics and all the syllables needed to be heard. Views were then elicited on every design element including the phonetics. Feedback was recoded on paper copies of the draft questions and on the prototypes.

8.4.2.4. Data Analysis

The data were transcribed and analysed in Word 2007 (Appendix-D4-D5) for samples of feedback and analysis). Data were first transcribed by participant, then re-grouped by staff roles under each concept, e.g. relevance, using phonetics, etc., following the sequence of questions. Due to a small number of expert participants, further formatting or coding was not required.

8.4.2.5. Findings

The feedback received is combined and set out below in the sequence of the questions. It was used to adjust the main questions, sub-questions and to re-organise the data in the desired order to create the foundation for questions-prototypes-v2. The findings were as follows.

1a. Relevance of questions

The draft questions were relevant and reflected conversations with patients. Underlining keywords in English and the equivalents in Hindi was very helpful for clarity and tight control (so this was propagated in prototype-2). The greeting and preamble were helpful. However, a paragraph format made it difficult to select comments from the preamble, and repeat these (later renames 'Setting the scene' and paragraphs inserted). A doctor pointed out that questions for type of pain *"basic words to ask patients whether the pain is sharp or dull"* were right, but:

> *"I tell you that, a typical patient will say that its [the pain] very big, it's the worst pain, and "You know Doctor, I don't know what is the difference between throbbing, or aching or burning"* [1D].

For taking medication it was more important to emphasise actually taking the medicine: *"it does not matter* [about with or after food] *just take your medication"* [6PM].

Staff cited training received in pain assessment (SOCRATES), and how to assess a situation (SAMPLER) and Table 8.5 identifies the modifications incorporated to upgrade questions-prototypes-2.

Table 8.5 Alpha-testing staff: feedback used to upgrade questions-prototype-2

S O C R A T E S (pain assessment)	**Existing and new questions for questions-prototypes 2**
Site of pain: can you point?	Q1
Onset of pain (start)	Q1 sub-questions
Character: type of pain	Q6
Radiation: does the pain radiate anywhere	(Added to Q1 in prototype-3 as: do you have pain anywhere else?)
Associated signs, symptoms	Q8. Side effects section was expanded with the feedback below
Timing: does the pain come and go?	Q3
Exacerbating/ Alleviating factors (making the pain better or worse)	Added as Q6 alleviating factor. Q4 was expanded to include exacerbating factors
Severity: pain score 1	Q2
S A M P L E R (assessing the situation)	**Medication**
Signs, symptoms	The same as in pain 5, above.
Allergies, reactions	Q1.
Medication currently used	Q2, 3, 7
Past pertinent history	Added in Q7: exploring what alleviated the problem.
Last oral intake	Q4
Events leading up to the injury/ illness	Not included (potential complexity of conversation levels)
Recent hospitalisation	

Table 8.6 sets out the modifications requested to the questions and how these were incorporated in questions-prototypes-2

Table 8.6 Alpha-testing staff: modifications to questions

Feedback received	Design modifications
Preamble	
Added: Did the patient understand Hindi/Urdu.	Adjusted
Pain	
Added: Tight/ crushing pain, dull pain, nagging was duplicate to throbbing	Added to Q.5 'What kind of pain is it?'
Do you have pain at night whilst in bed? When you move? Sit? Stand? Whilst walking? Does pain awaken you from sleep?	Q.4 expanded as 'Occurrence of pain'
Do you have loose stools, blood in stools? Is it loose or watery? Have you seen any blood?	Added to Q.8 'Symptoms and side effects'.
Look left, right, up, down. Breathe in/ take a deep breath, breathe out.	Added to pictorial prototype: 'Requests of Patients and Needs'

Squeeze hand/ make a fist, open hands, stretch your fingers. Pull me, push against me.	
Moved Q 9 to after Q.4. Do you have pain on passing urine/ stools? Can you sit up straight? Do you have pain every day/ always?	Combined with Q.4; expanded into 'Occurrence of pain'
We use pain score 3-scale (see Appendix-D6) for older patients (1 mild, 2 moderate, 3 severe); 10-scale is fine.	Pain-score 10 selected based on literature Q.2b
Medication	
Include itching, vomiting, difficulty breathing Side effects were (were the same as in pain assessment)	Added to Q.8 'Symptoms and side effects' in pain and copied.
Tabulate medication side effects; easy to get lost with a paragraph	List, ordered alphabetically in English
Side effects All the drugs are available in the British National Formulary (2011); it's the 'bible' updated by the plain English Society twice a year. BNF warnings on what to avoid special instructions what to do if you miss a dose (see Appendix-D7).	A separate page was prepared to illustrate as many of the instructions as possible.

1b. Phonetics as a communicating tool

Comments included: '*That's a very good idea'* [1D] or a very interesting one. The concept was new to all the staff, none of whom had used it or heard of it used. Underlining English-Hindi words of similar meaning was unanimously approved because it gave staff tight control over communication.

During phonetics reading, it became apparent that, aside from the words sounding strange to their own ears, there were 4 complications as common norms of (English) pronunciation were being transferred to the phonetics:

- words were said rapidly and all the syllables were not pronounced
- 'r' was frequently silent
- A double alphabet was viewed as unusual by some: e.g. *aap* 'you' (later modified to *ah*-p and then to ahp iteratively)
- 'g' was pronounced as 'j' in 'gin' (beverage), thus 'to count', gin (as in go) was pronounced as *jin* (beverage) which is meaningless in Hindi.

Two staff explicitly and implicitly commented indicated they did not like to be laughed at, they were the professionals and had to be in charge of the situation.

All desired guidance on clear pronunciation and two suggested training or a training video. To reassure staff the researcher recounted a comment by a colleague in study 2: that elderly women in physiotherapy giggled, but it was in happy surprise that the physiotherapist knew words in Gujarati. Patients would probably be very encouraged to hear words in their own language even in a small way. Sampling was adjusted to extend phonetics testing.

2. Existing illustrations

Except for the ward sister who had a few illustrations (tea, coffee, water, toilet) in elderly care and stroke ward, staff did not have illustrated materials. The ward sister provided a form they used to capture pain assessment (Appendix-D6) which she was pleased to have helped design. This depicted an outline of the body for patients to point to where they had pain, a pain score numbered 1-3 which was easier for elderly patients, and a descriptive list for pain: physiological emotional state, non-verbal. The paramedic displayed a 3-scale pain score illustrated with emoticons used for children.

2a. Illustrations desired

Participants were happy with the questions and agreed as many of the conditions should be illustrated, as was possible. For the GP, time of day and numbers to indicate duration of pain were important and all agreed it was important to include needs like tea/coffee, water, toilet, food, and illustrate the pain score and type of pain. A 10 scale pain score was agreed as acceptable as it followed medical literature.

From a nursing perspective, in medication, the most important factor was allergies (eggs, food, medicines) and illustrations of dosage information (spoon, dispersed, chew, swallow). Illustrations of the British National Formulary guidelines would be helpful, the pharmacist added, *"We really need this sort of thing. We were just discussing it in a meeting today"* [6PM].

2b. Type of aid

Twinned-aids were a unanimous choice and particularly favoured was the

possibility of giving patients a section to take home to learn English.

2c. Formats

- Staff either liked the phonetics closely interspersed or completely separated. Preferences amongst the prototypes were as follows:

Version	Number of staff	Reason
1A	3	They knew exactly which bit of the phonetics related to English.
	1	2nd choice for another who suggested adding lines to 1A for greater clarity (similar to 1C, later rejected)
1B	0	
1C	1	Clarity (similar to 2nd choice above)
1D	1	You can just read off the phonetics

Although 1A was selected for further development, comments on 1C and 1D on usability (tabulation, simply read off the phonetics) were noted and discrete lines were introduced between sections. This appeared to also suggest that not all staff were interested in other languages, just doing the job as quickly and efficiently as possible to meet target response times. The author confirmed different preferences could be accommodated in future.

- The 2-colour text combination was approved of unanimously as it was clear and easy to pick out the spoken sections.
- **Size.** A4 size was favoured by all except the paramedic who wanted a foldable pocket-sized aid (maximum: 18.5 cm x 9.8 x 1.5cm thickest). This was critical otherwise the aid would not be used. Lamination was unanimously requested (staff section), font (Arial 10.5 and 11) were approved. A GP was happiest with the smallest possible formats (there was not much wall space for hanging things).

2d. A possible scenario the aid might be used? All responded with yes and described a typical context (e.g. the physiotherapist would not delay therapy until family visiting hours for interpretation support).

2e. Availability on a website (eventually). This was favoured by all as

helpful. Two staff were particularly keen: the A&E doctor commented that all the consultants had iPhones and the aid would be more likely to be used as a web-based app (application).

2f. Use of other new media too (eventually) like videos, was unanimously favoured.

2g. Any other comments. Staff liked the question: "Very good questions" [1D]; "Good questions, professional" [2PT; 3D]; "*The basic questions are good"* [1PM] and a doctor asked: "*Can I give copy to colleagues to test? But they might copy and distribute it*" [1D] and "*Can you do it in Polish and Arabic?"* [1D].

The unanimous view was to keep the aid simple. Pain and medication prototypes-1A were selected for further development and modified to 2A prototypes-2 for beta-testing with staff (see 8.4.7.2).

8.4.2.6. Discussion

The feedback was encouraging from several perspectives: the concept of phonetics was accepted as helpful and potentially as a good idea to help in communicating main questions and sub-questions. Likewise, the pictorial aid to help adult patients to respond and, particularly, as an educative aid to take home for English-learning.

To alleviate concerns about pronunciation, a small group of 4 indigenous adults were added to raise to 10 the numbers testing phonetics during beta-testing. Underlining and italics relating English-Hindi words were propagated throughout prototypes-2, hyphenated phonetics was introduced to aid a more even pronunciation and, finally, a simple guide to pronunciation was prepared.

In accordance with literature, a 10-scale pain score was used for the pictorial aid although smaller scales would be tested. From a design perspective, a 10-scale score offered more space for designs that could help to refine participant's responses to gain an accurate pain score.

8.4.2.7. Questions-prototype-v2: Design upgrade

This feedback was used to prepare questions-protototype-v2. The main sections were reduced from 14 to 8 (in pain) and 2 new response checkers

redesigned for page 2, as lists in alphabetic order by phonetics with English meanings. Figures 8.9-8.11 depict the design upgrades, which were beta-tested with staff, after the pictorial-protypes-v1 and v2 had been developed and tested with EMCs. (See Appendix-D8-D9 for larger figures.)

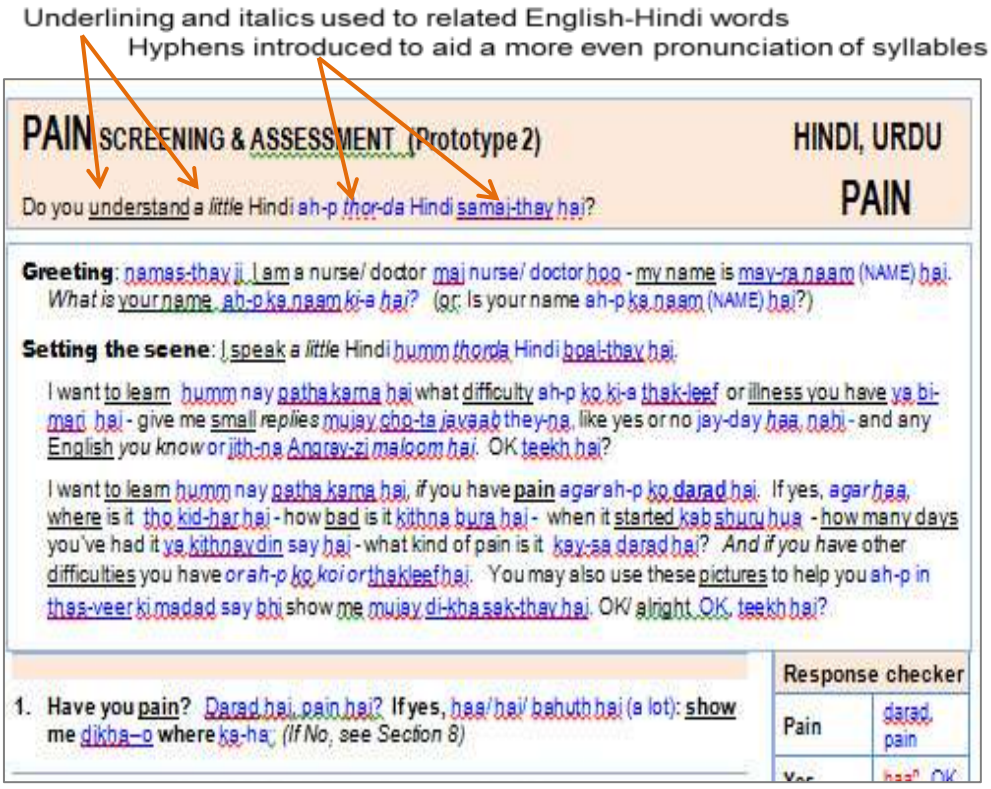


Figure 8.9 A section of pain questions-prototype-v2 depicting adjustments to phonetics

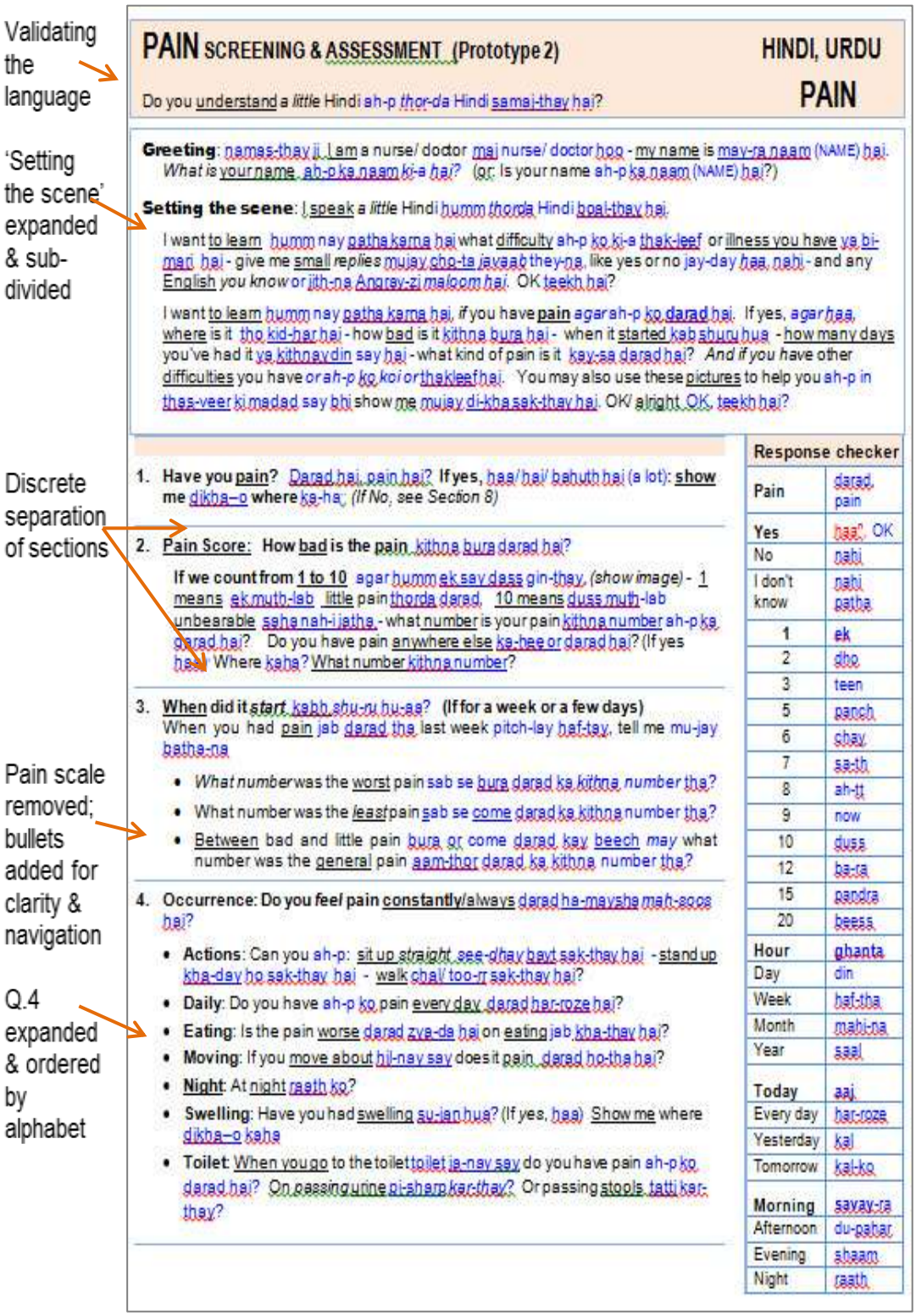


Figure 8.10 Questions-prototype-2 Pain (p.1) adjustments

Figure 8.11 Questions-prototype-2-Pain (p.2) new features

(The upgrades would be re-tested during beta-testing with staff.) Based on the modified questions in 8 sections, images were collated for alpha-testing with EMCs.

8.4.3. Alpha-testing: EMCs

The images for pictorial-prototypes-1 co-related to the questions to help patients respond to questions and to engage patients to use the pictorial-aid proactively to point out a need or problem and to encourage English-learning.

8.4.3.1. Participants

Punjabi Sikhs (Indian Subcontinent) who lacked English and/or literacy were recruited from a Gurudwara and local community in the East Midlands. The research aim and that it was voluntary was explained to several groups of ladies after prayer ceremonies and people were approached during lunch (*langar)* and word-of-mouth gained additional volunteers; both genders were invited. A visiting card was given to each individual who agreed to participate, their details noted and they were telephoned the following week to arrange an interview date. For most participants the motivational factor was learning English. To avoid excluding members of families the original sampling of 10 was exceeded.

The 13 participants were heterogeneous (10 females, 3 males, aged: mid-20's to over 75 years). Some were known to each other, all were 1st generation: 46% were over 50 years old; 77% were married and 23% widowed. The majority, 61%, had been resident in the UK for over 10 years (Figure 8.12).

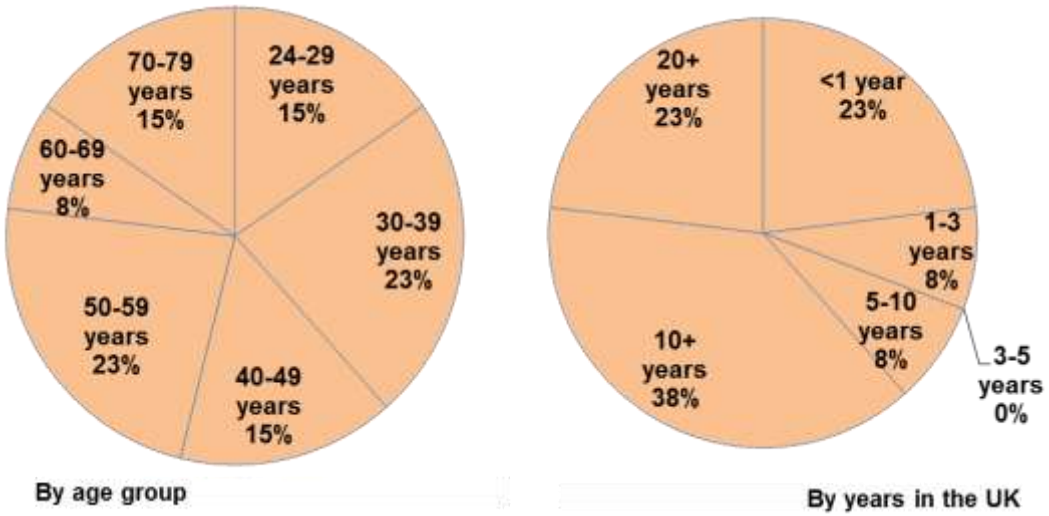


Figure 8.12 EMC participants by age group and years living in the UK (*n*=13)

8.4.3.2. Tools

Three tools were prepared: a pictorial section, interview questions and a response capture form. Table 8.7 sets out the tools, the purpose of testing and feedback sought.

Table 8.7 Alpha-testing EMCs: the tools and purpose

Tools	Purpose	Critical feedback
	B. Beta-testing EMCs	
Interview questions Pictorial prototype-2 Response form	Simple English words & numbers Re-tested images	Cognition, clarity, usefulness, preferences. Using images to explain.

A. **Pictorial-prototype-1: Ideas & Sketches Development**

Eighty-two images were compiled to prepare and test the concept and prepare the initial prototype to test participants' preferences and cognition. Five types of images were used: 14 emoticons, 42 illustrations, 19 photographs, 7 symbols and numbers in English. Some images were combined into composites to 'tell a story', e.g. 1 day, 1 week, sit, stand. Although it was difficult to include 'joy' in design in potentially stressful circumstances, variety was used to engage participants. The illustrations were in landscape format on 7 A4 pages, and related to the 8 sections of questions-prototype-2 for pain and medication (Figures 8.13-8.20), i.e. Do you have pain and where; how long have you had pain, etc.

The images designs sought to convey meaning in 3 ways:

- **Directly:** rising sun, glass of water, toilet, numbers;
- **In composites:** requesting an action, e.g. taking medication combined a 24-hour linear timeline, images of 4 main periods of day, tablets, bottle of medicine, numbers, food and water. *Sit* or *stand* combined a person, arrow and chair; and
- **By association**: *pain* score combined emoticons, numbers; *dizzy* combined a lady holding her head and swirls in the background; figure on a toilet with a pile of stones (constipation).

It was not possible to design the stools in accordance with the Bristol Stool Chart (NHS 2011, Appendix-D9) as the descriptive ‘sausage’ might be unfamiliar to vegetarians and possibly offensive Muslim patients. Moreover, patients were unlikely to use finer descriptives, like ‘fluffy’ stools, which were more physician-orientated.

Images for medication and pain were tested together during alpha-testing. Images were designed using pencil sketches, Crayola drawings, Adobe Photoshop, photographs and/or selected from the internet and free autism picture cards to capture user-preferences and cognition in preparation for illustrating the pictorial prototypes. Selection was based on guidance from literature on real-life images, clarity, density, and on acculturation. Also, on the globalisation of products and services which have propagated many images, English words and phrases world-wide. Text would accompany all images in prototype-v.2

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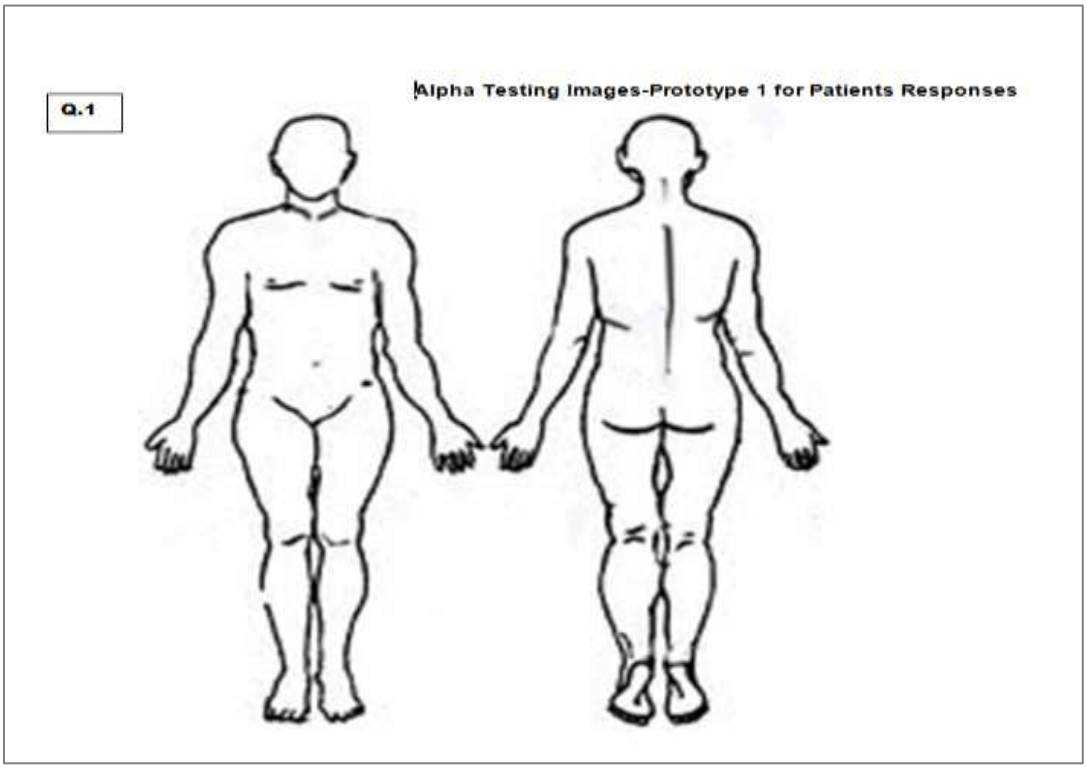


Figure 8.13 Illustrating question 1: Do you have pain? Where?

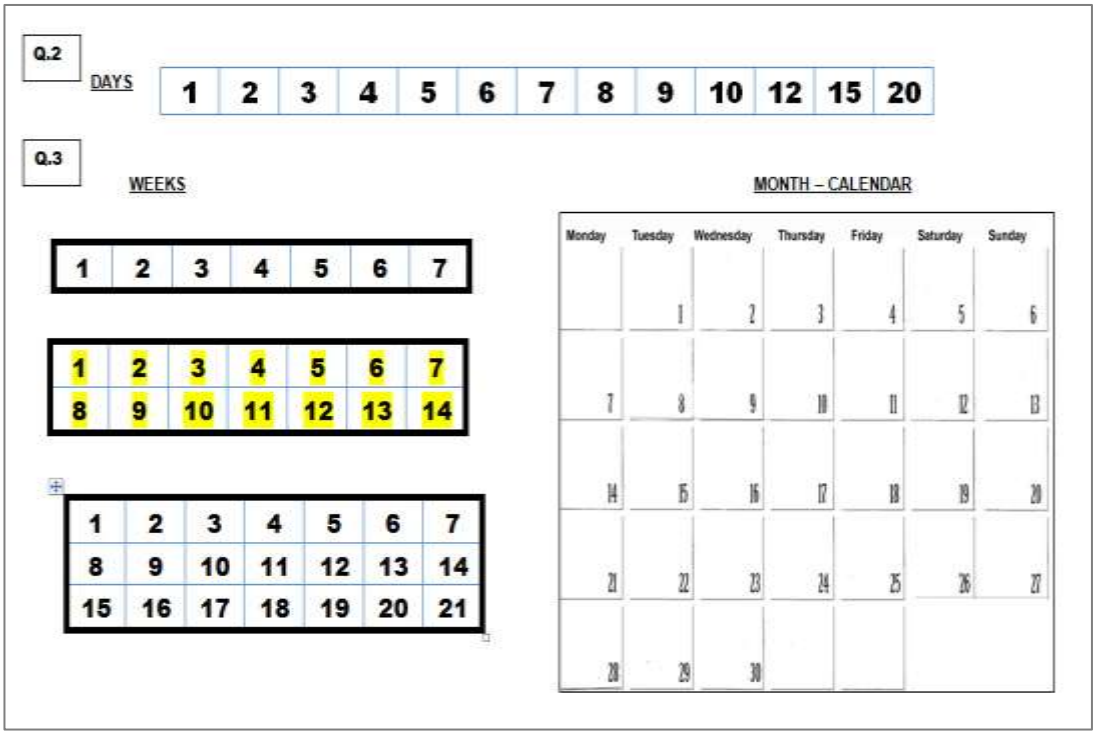


Figure 8.14 How long have you had pain? (Days, weeks or month; questions 2-3)

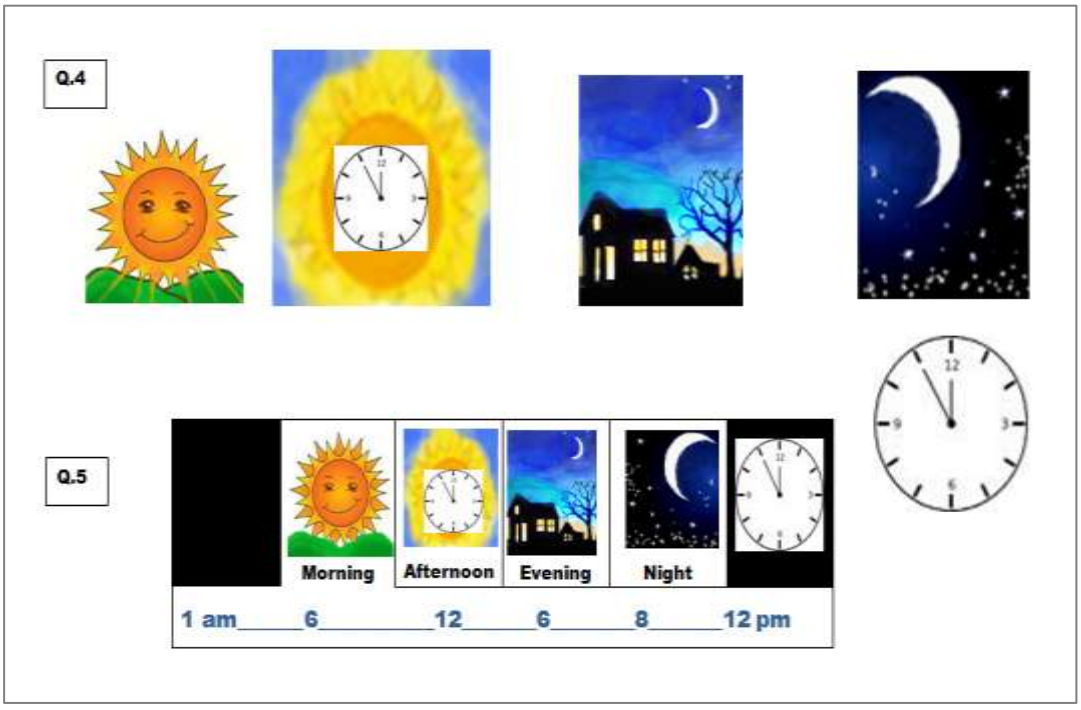


Figure 8.15 When did the pain start? (Questions 4-5). Images are repeated to nurture familiarity. Images depicting 1 day are reinforced by a clock

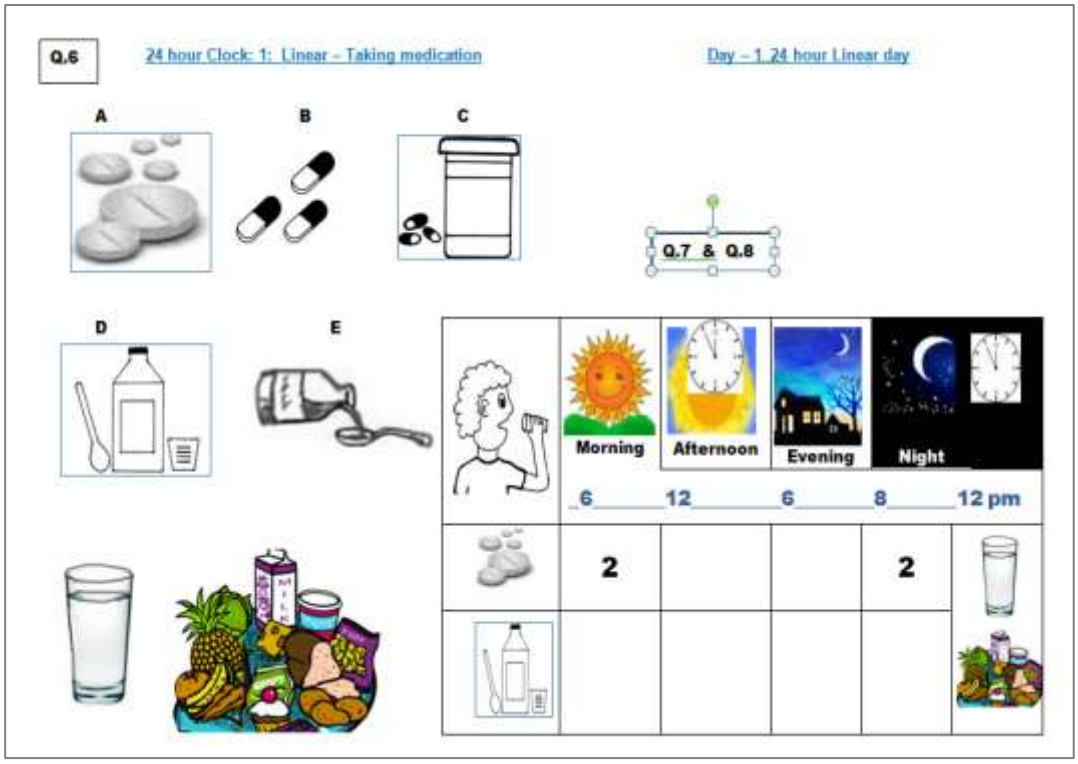


Figure 8.17 How to take medication (Questions 6- 8)

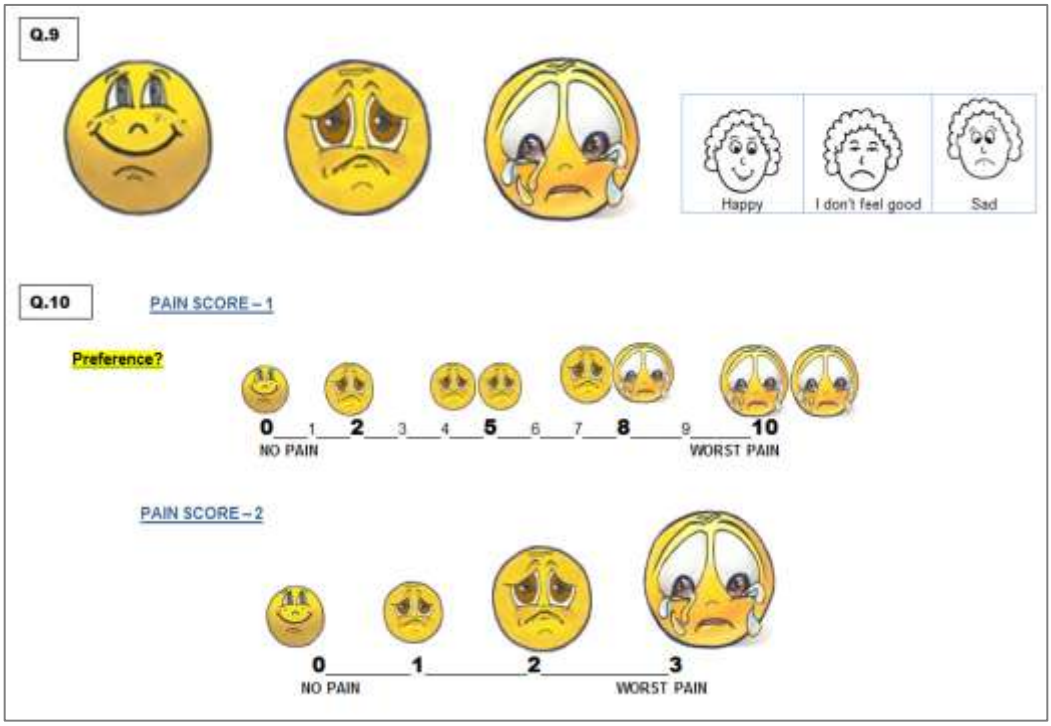


Figure 8.16 Illustrating the pain score: emotions (happy, sad, crying) and the 10 and 4 scale pain scores (Questions 9-10)

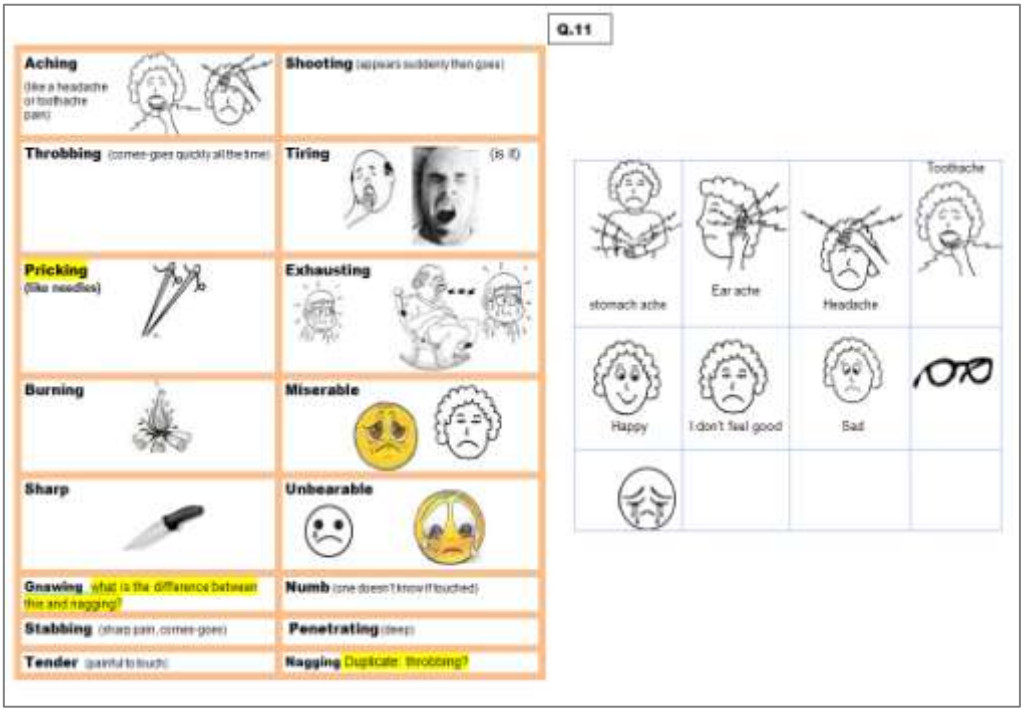


Figure 8.18 Kinds of pain (Question 11) and testing free autism picture card images

Figure 8.18 depicts pain associations used to convey different types of pain (burning with a fire, pricking with needles) and some autism picture cards that were tested. Figure 8.19 depicts symbols that would be combined with other images to 'tell a story' (e.g. sit up) and requests for simple needs, or movements from staff. Note the images and symbol for 'I don't know'

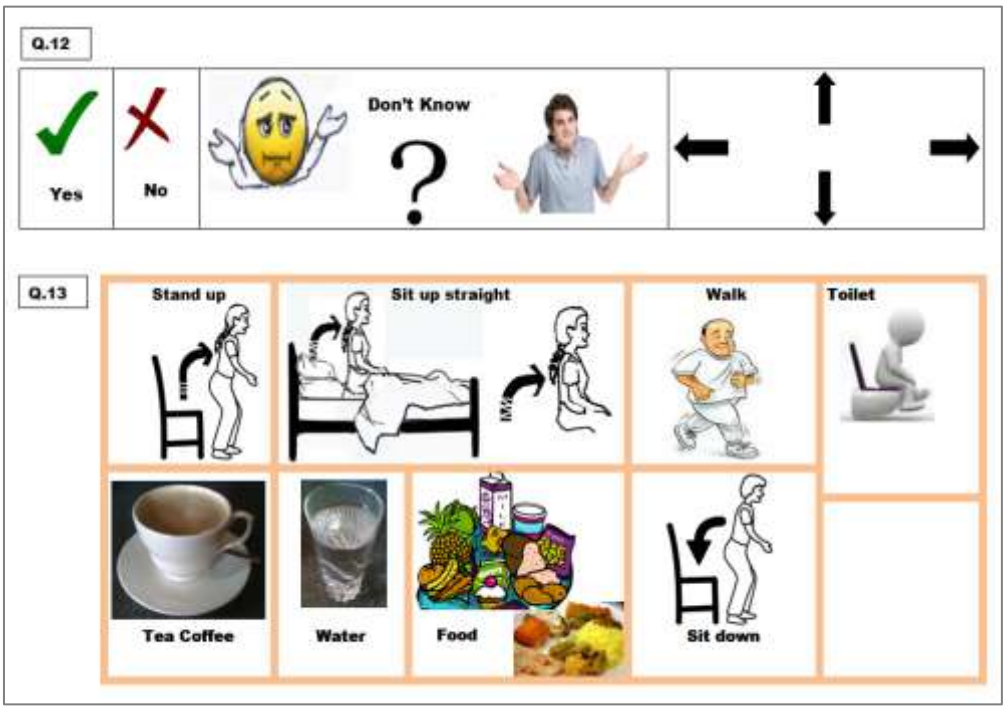


Figure 8.19 Yes, no, I don't know, simple needs and requests for actions by staff (Questions 12, 13)

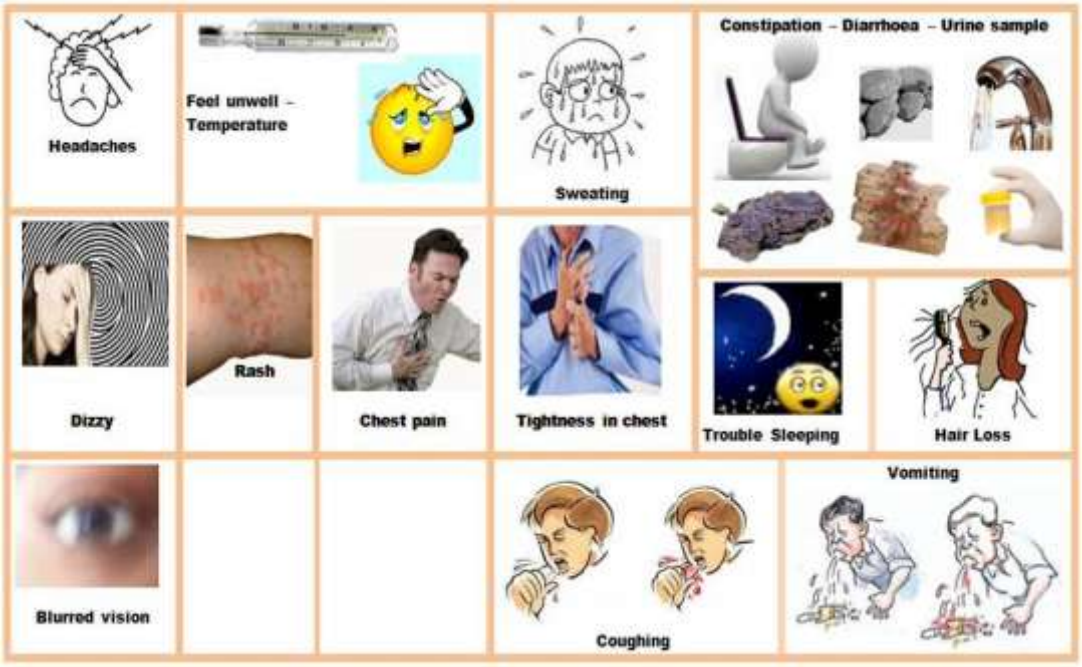


Figure 8.20 Illustrating more symptoms and side effects (Question 14)

B. **Interview Questions**

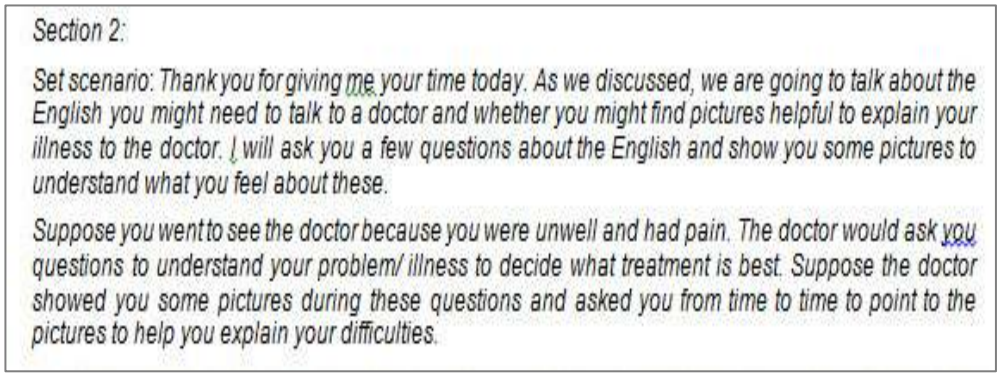
Open questions were designed for a structured individual interview and divided into 2 sections. (Appendix-D10): 7 questions in section 1 elicited background: gender, age, numbers of years lived in the UK, knowledge of English and other languages, whether their doctor was English, and then tested their knowledge of simple English words extracted from the questions prototype to determine whether they would be useful in the aid (Figure 8.21).

7. I will say some English words, please tell me in Hindi, Urdu or Punjabi what these mean to you: *(tick for right response, cross if not recognised)*

yes		evening		up		good		Monday	
no		night		down		not good		Tuesday	
I don't know		today		left		bad		Wednesday	
please		tomorrow		right		happy		Thursday	
thank you		week		sit		sad		Friday	
pain		month		stand		crying		Saturday	
doctor		next week		walk		big		Sunday	
nurse		next month		here		very big			
morning		now		there		small			
afternoon		after		OK		allergies			

Figure 8.21 Alpha-testing EMCs: simple English words to determine their knowledge

'Section 2' tested participants' interpretation of images and sought to gain suggestions for improvements. The context for using the images was explained (they were unwell and had gone to the doctor and the doctor would ask questions to understand their problem (Figure 8.22). Eighteen simple questions enquired: *What do these pictures mean to you?* or *Can you point out…?*



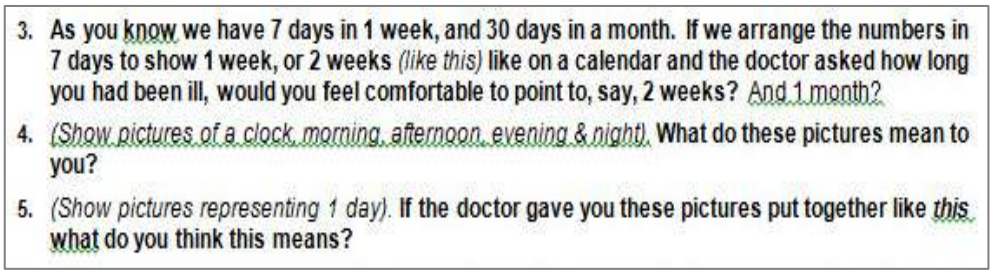
Section 2:

Set scenario: Thank you for giving me your time today. As we discussed, we are going to talk about the English you might need to talk to a doctor and whether you might find pictures helpful to explain your illness to the doctor. I will ask you a few questions about the English and show you some pictures to understand what you feel about these.

Suppose you went to see the doctor because you were unwell and had pain. The doctor would ask you questions to understand your problem/ illness to decide what treatment is best. Suppose the doctor showed you some pictures during these questions and asked you from time to time to point to the pictures to help you explain your difficulties.

Figure 8.22 Alpha-testing EMCs: setting the context of use

The interviews were designed to last 40-45 minutes preceded by 10 minutes to re-explain the study information and Informed Consent. Both were in English and family members were invited to review these. The questions were designed to gently encourage EMCs as they were not familiar with research. Wherever possible, images were repeated to nurture confidence and familiarity, e.g. the image for 'morning' was used in '1 day' and a medication label (Figures 8.16-8.17), or the image for headache was repeated (Figures 8.19, 8.21), Simple explanations were sometimes offered (Figure 8.23, Q.3).



3. **As you know we have 7 days in 1 week, and 30 days in a month. If we arrange the numbers in 7 days to show 1 week, or 2 weeks** *(like this)* **like on a calendar and the doctor asked how long you had been ill, would you feel comfortable to point to, say, 2 weeks?** And 1 month?
4. *(Show pictures of a clock, morning, afternoon, evening & night).* **What do these pictures mean to you?**
5. *(Show pictures representing 1 day).* **If the doctor gave you these pictures put together like** *this* **what do you think this means?**

Figure 8.23 Question 3-4 explaining the numbers and eliciting responses

Where images were interpreted incorrectly, or were not understood, the meaning they meant to convey was explained and suggestions for

improvements invited. Ease of understanding was important to pro-actively engage patients to point out images that conveyed their needs and problems.

Questions explored images for pointing out pain, knowledge of numbers 1-10 in English and days, weeks, months, years on a calendar, recognising: a clock, periods of the day, kinds of pain, the pain score, symptoms and side effects, simple actions and needs like tea/coffee. The 1st interview was used to pilot the study and adjust questions.

Some of the questions asked participants to use the images to explain how long they had been ill e.g. 2 or 6 weeks or 1 month.

B. **User-response Form**

A form was designed to record responses (Appendix-D11) as simply as possible, using some Likert 5-scale responses, i.e. very easy, to very hard, and words that represented the images relevant to each question. The interviews were also recorded for accuracy.

8.4.3.3. Procedure

The interviews lased 20-50 minutes and were conducted in the Gurudwara or participant's residences. To focus attention, images not relevant to a question were covered by a blank page and participants were asked the meaning of each image.

A step-by-step approach used the theme of repetition (from studies 1 and 2) to nurture familiarity and build confidence so that participants recognised the images when they appeared in composites. e.g. separate images of morning, afternoon, etc. were followed combined to represent 1 day with a 24-hour linear clock. Separate images for taking medication (tablets, pouring medication, drinking, glass of water and food), were combined with the composite of 1 day with '2' under morning and under night to represent a medication label and instruction (Figure 8.17). Arrows for direction were later used with a person in bed for 'Sit up straight' (Figure 8.20; Q.13).

For image composites, questions were rephrased to: *'What story does the picture tell you?'* to encourage participants to consider all the images together. As story telling is a ubiquitous concept, the use of 'story' (*kahani*)

appeared to help participants better grasp meanings, e.g. in dizzy. The flow of questions and images worked smoothly; 2 questions were added after the 1st interview:

- Which other languages do you speak, read and write? (To determine familiarity with education/ learning environments)
- Would English labels of body parts be helpful? (Requested by participant 1)

*'*Allergies' was added to the list of English words.

Participants felt comfortable and all asked the meaning of words or images they did not understand. Responses were recorded on the Response Form (Appendix-D12 depict extracts from a filled form).

8.4.3.4. Data analysis

Excel 2007 spreadsheets were used to record the data for each image . This data was analysed to identify the difficulties. Participant's comments were collated in Word 2007 and then grouped by participant reference under the relevant questions in preparation for upgrading the images (Appendix-D13-D15.6)..

8.4.3.5. Findings

Participants' comments, critiques, suggestions and preferences were combined and are summarised below in the sequence of questions 1-18 relating to the relevant images (Figures 8.13-20). All the images that were incorrectly interpreted were adjusted for pictorial-prototypes-v.2, according to participants' suggestions (i.e. Reference and F/M=female/male) as below.

Individual interviews (rather than group) were appreciated by participants ("very good") because *"In a group some people might not like to say what they don't know or that they disagree with others"* [1F].

Section 1: English. Participants of working age wanted to work but a lack of English was a hindrance. Some visited the doctor a lot and had to change to a doctor (Gujarati) who could speak a little Hindi. The study was viewed as *"very good"* to help participants learn English, *"it would be a great help".* A participant who could speak English *"not too bad""*

[13M] needed practice for work and although another he went to college for English lessons for 2 years he still could not could not read or write (Appendix-D14). Figure 8.24 depicts basic words not understood 31-46% of the time.

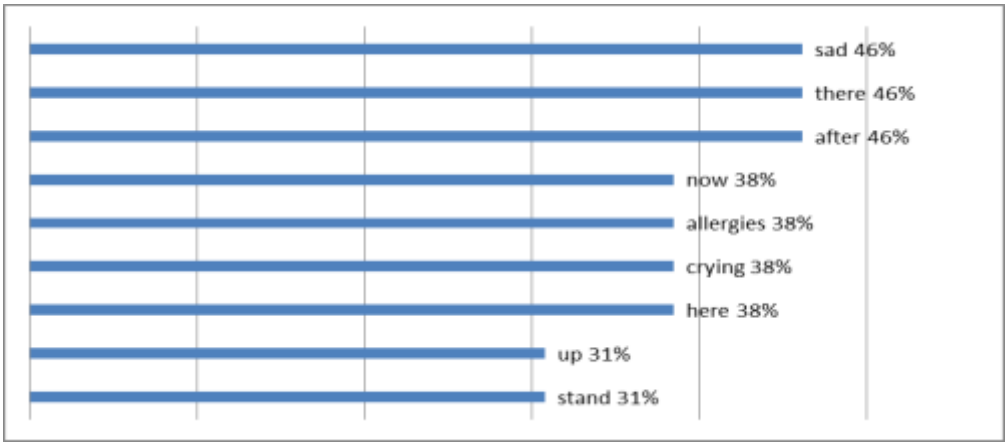


Figure 8.24 Common English words incorrectly interpreted by 31-46% of EMCs

Figure 8.25 depicts other basic words not understood a further 15-23%. *'No good'* and *'Sit down'* were better understood than *'not good'* and 'sit'. The lack of English included one male and female residents of 1-3 years (recent arrivals) and 3 long-term female residents (10-30+ years).

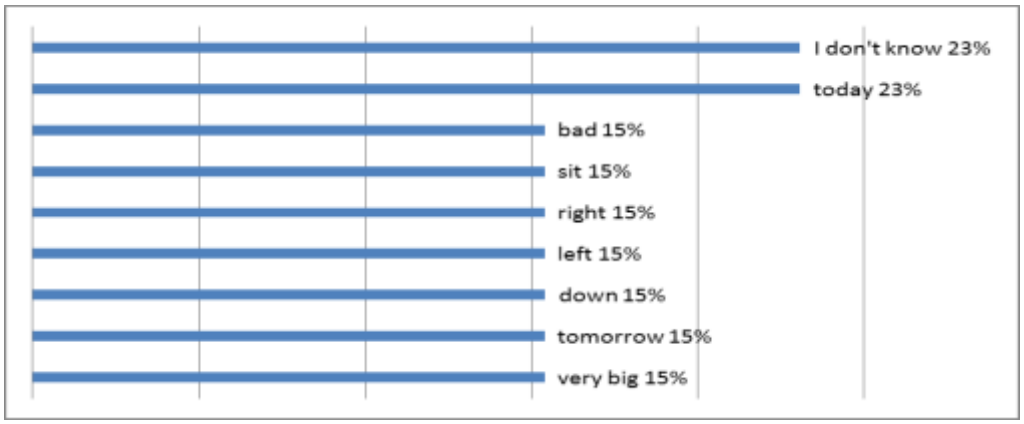


Figure 8.25 Common English words incorrectly interpreted by 15-23% of EMCs

Q.1: Where is the pain? (Figure.8.13) Participants unanimously wanted arrows and English labels to body parts (front and back) to help them learn the English (as they already knew it in their language); those who knew some English sometimes forgot. It was less helpful to have the image simple and clean. More suggestions were to show the face on the figure (for clarity, a real-life image) and to show the heart. Asked about using symbols for inside the body, like the heart, participants agreed that

would be fine.

Qs.2-3: Using numbers: How long have you had pain? (Figure 8.14) 100% could count, read numbers to 1-12; 77% could count over 11. Two big influences from everyday living that had motivated learning was the need to remember one's address, telephone number and date of birth, and telling the time. One elderly female (aged 75+, resident 30+ years) kept consulting her wall clock and then managed to count from 10 to 12. 92% recognised a calendar and could explain 2 weeks, 85% recognised 1 month and could explain 6 weeks.

Qs.4-5: When did the pain start? (Figure 8.15) 85% recognised the images for morning, afternoon and evening; 92% for night and 77% for 1 day. For 'evening', they preferred to replace the moon with a setting sun.

Qs.6-8: Pictorial medication instructions (Figure 8.16) were a new concept for a third of participants but, 77% recognised the composite for medication instructions and the meaning of '2' under images of *morning* and *night*, (take 2 tablets with water in the morning and 2 at night) and a further 23% understood it after explanation. 100% recognised everyday items like tablets, medicine bottle with a spoon, food and the linear clock, (clock, 24-hour time-line and images of morning, afternoon, etc.). Although 85% recognised the *crying* emoticon, 15% were unsure what was happening. Images for tablets and bottle/ spoon were selected by majority preference.

Qs.9-10: Recognising emotions and pointing out pain score (Figure 8.17). Figure 8.26 depicts the results of testing emoticons and cartoons. None of the participants were familiar with emoticons, but quickly

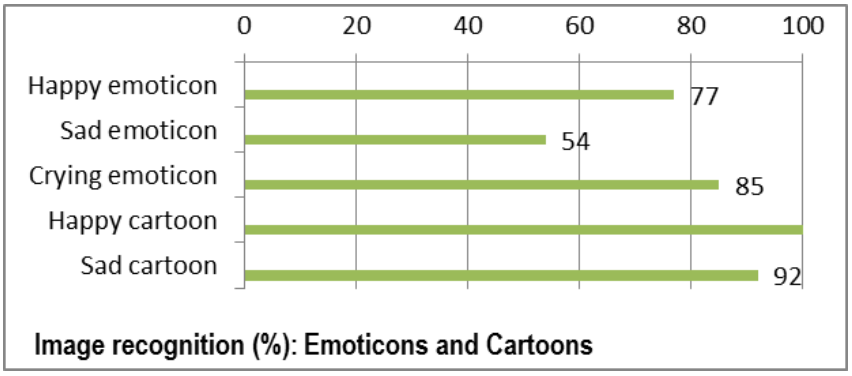


Figure 8.26 Comparing correct image interpretation (%): emoticons with cartoons.

understood when it was explained they represented how we feel. 54% interpreted *sad* correctly the others were unsure or thought it was *angry.* The autism pictures for emotions were recognised easily because, participants said, they had hair (real-life). They did not want to replace the emoticons with cartoons, rather, to remove the yellow colour (confused them with the sun) and to add some hair. 'Unhappy' emoticon was sometimes interpreted as confused or angry. 100% felt images made it easy/very easy to explain pain but, even so, 8% were unable to use the score (2 elder/y females). 92% correctly pointed out the correct pain score and emoticons for medium or very bad pain and 85% for very little pain (Figure 8.27).

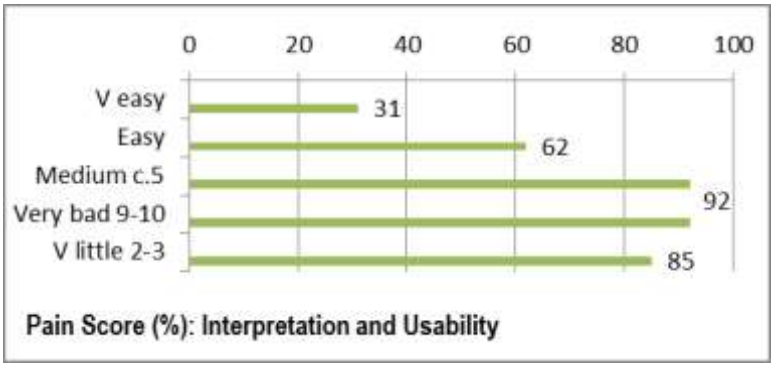


Figure 8.27 Pain Score responses (%): usability (easy, very easy) and correct interpretation

62% preferred design 2 (the images were larger, clearer) and a further 15% felt both designs were fine and the 10-scale pain score was fine. 93% found explaining pain using the pain score very easy or easy: having text (little, the worst) with the images provided clarity and choice.

Q.11: Types of pain. Associating the images with the type of pain needed a little explanation. The best understood images were headache, toothache, stomach ache and ear ache; the autism pictures with zig-zag radiations (Figure 8.18) were particularly clear. The least understood images were: exhausting (interpreted as sleeping) and sweating (understood by only 15%); pricking and tiring (understood by 54%). (Appendix-D15.6). Suggestions from one or more participants were as follows [square brackets indicate the author's comments]:

- **Exhausting:** make it clearer, perhaps person lying in a chair (possibly looking sad), lying on bed would be better

- **Pins & needles**: *so jatha hai* (goes to sleep)
- **Pricking**: understood after some explanation [remove thread from needles?]
- **Sad**: was sometimes interpreted as angry; remove yellow, make lines darker, add hair (realistic)
- **Tiring** (yawning picture): remove hand from mouth;
- **Throbbing heart**: *dil jaldi daraktha* important
- [Add very cold/shivering opposite of sweating]

Qs.12-13: Symbols, movements and needs. 92% understood a 'tick' as right and a cross 'x' as wrong or 'cut' from either school-days, children's school work or filling forms and cancelling sections that were not applicable (making applications, 'filling the paper', is a feature of everyday living in India).

'I don't know' and the arrows as directions were understood by 92% and '?' was not well understood. Placing 3 images of I don't know emphasised the meaning (Figure 8.19) but 69% preferred the man shrugging (true to life) and imitated his actions; 23% liked the images all together. Images of tea, water, food and toilet were understood by all: interestingly, the word 'toilet' was always used and not 'bathroom' which is commonly used in the Indian Sub-continent (highlighting acculturation). Between 69-85% understood images composites of sit down, walk etc.

- **Sit** was better understood as 'sit down'
- **Walking** was interpreted as running: suggested hands should be down

Q.14. Symptoms and side effects. (Figure 8.20) The least understood images were as follows: tightness in chest and trouble sleeping by only 23%; sweating by 54%; giving a urine sample, constipation 'like stones', loose stools, etc. and dizziness (Appendix-D15.7) were understood between 69-85%. The figure on the toilet was understood by all, as was, headache, temperature and chest pain. Interpretation and suggestions for improvements included:

- **Blurred vision**: understood as problem with eyes, *motia* ('white pearls', cataracts, reason for blurring); making eye red make problem clearer.
- **Coughing** understood after explanation; [make image larger]. coughing blood more easily recognised due to red drops.
- **Dizzy**: sometimes interpreted as head pain; not clear enough.
- **Falling hair:** make it clearer; place comb near hair not in front of face; put more hair on left; put a bald patch on head, less hair.
- **Sweating**: unclear, understood as crying; the drops are all over head and confusing; remove drops from above head and under eyes, make more below; show only the top of body.
- **Temperature**: make thermometer larger
- **Tightness in chest:** make it clearer; put a belt squeezing the chest; show figure's face.
- **Trouble sleeping:** sad face is better; cumulatively, the suggestion was: have someone sitting in a bed, awake with sad sleepy face unhappy, a window showing night.
- **Toilet 'story':** Move toilet to middle of the pictures; Constipation: *kabaz,* add more stones to the pile. English labels 'like water' not interpreted as 'watery'; would like a picture for can't pee, or peeing too much [possibly separate into 2 sections].

Qs.14-18: Helpfulness of images and preferences. Participants agreed unanimously that pictures helped, they felt they could explain much better using the pictures: *'No one has ever taught me like this before'* [7F, Grandmother]. The mix of images was unanimously favoured: *"all good in their place"* and the use of colour: *"It makes them clearer, black and white is less clear, like black and white TV"* [4F]. 77% liked all the images, 100% liked emoticons and 92% liked cartoons.

8.4.3.6. Discussion

From the feedback received it was clear that having a pictorial aid helped participants to respond and to explain themselves. It was clear that 'x' is associated with something wrong, and contradicts current requests on forms in the UK for people to insert a 'x' to indicate the right response. That '?' is not understood is important for future learning so people understand a question is being posed, particularly on information.

Some words like bad, very bad, big and very big were better understood than 'the worst' or the largest. The author notes that other useful English words like 'loose', 'tight' (from having clothes tailored back home) and 'medium' (there is no Hindi/Urdu/Punjabi equivalent) are also commonly understood.

These findings also confirmed the outcomes of study 1, that EMC females with poor English skills include recent arrivals to long-term UK residents.

The theme of proactively encouraging EMCs to use the aid to express needs or problems, rather than to only respond, was developed further during beta-testing. The development of the prototypes-2 is described next.

8.4.4. Beta-testing: EMCs

Beta-testing commenced with EMCs to determine whether the adjusted designs improved participant's understandings and confidence in using such an aid, prior to testing the aid with indigenous elderly and introducing it to staff, who would see the twinned-aid for the first time. The aim of the aid was to support patients to learn English and to gain confidence to use the aid as a communicating tool.

8.4.4.1. Participants

Eleven EMCs from alpha-testing participated (2 males and 9 females); 2 females declined. A grandmother living in a joint-family cited no interest in learning English and relied on her 2 daughter-in-laws who spoke a little English. A young female insisted the research could not benefit her unless the author provided English lessons at her residence on days convenient to her.

8.4.4.2. Tools

Five tools were prepared for testing as set out in Table 8.8 which sets out the purpose of testing and feedback sought.

Table 8.8 Beta-testing EMCs: the tools and purpose

Tools	Purpose	Critical feedback
	B. Beta-testing EMCs	
Pictorial prototype-2 Alternative Illustrations	Simple English words & numbers	Cognition, clarity, usefulness, preferences.
Medication prototype-2	Re-tested images	Using images to explain.
Interview questions		
Response form		

A. **Pictorial-prototype-v2**

The pictorial aid for pain screening was modified according to feedback from EMCs. Images were re-designed (Adobe Photoshop, Crayola, sketching), new photographs taken and the images re-organised in sections in the sequence of the sections in questions-prototype-2, as explained below. All the images were labelled for clarity and to facilitate English-learning. The section on symptoms and side effects was common to medication questions-prototype-2. Figures 8.28-8.31 depict pictorial-prototypes-2.

The images were laid out in A4 landscape, on 4 sides, with section labels (Arial black), labels on or for figures Arial narrow (12 pitch), that could be duplex-printed on two A4 pages or an A3 folded leaflet for patients (and families) as an educative take-away tool to familiarise themselves with English and use it in different healthcare services.

B. **Alternative Illustrations**

3 pages of alternative images were designed to offer more choice (Figure 8.32). Page 1 depicted 3 and 5-scale pain scores; trouble sleeping and images for ‘exhausted’. Pages 2 and 3 depicted emoticons with and without colour: happy (no pain) to sad/ miserable, crying, and sweating.

C. **Medication prototype-2**

A page was designed depicting a medication label (Figures 8.33) and images were repeated to depict for a medication list (findings of study 2) to capture medication instructions and to help patient understand and remember (how much to take, when, before or after food, with water).

Improved design features (p.1):
Large head added with a face; front and rear views of the body; English labels identifying body parts (2 colours and arrows for clarity); sections of the body in bolder fonts

Body details were kept simple to make the images acceptable to males and females alike (to avoid offence or embarrassment)

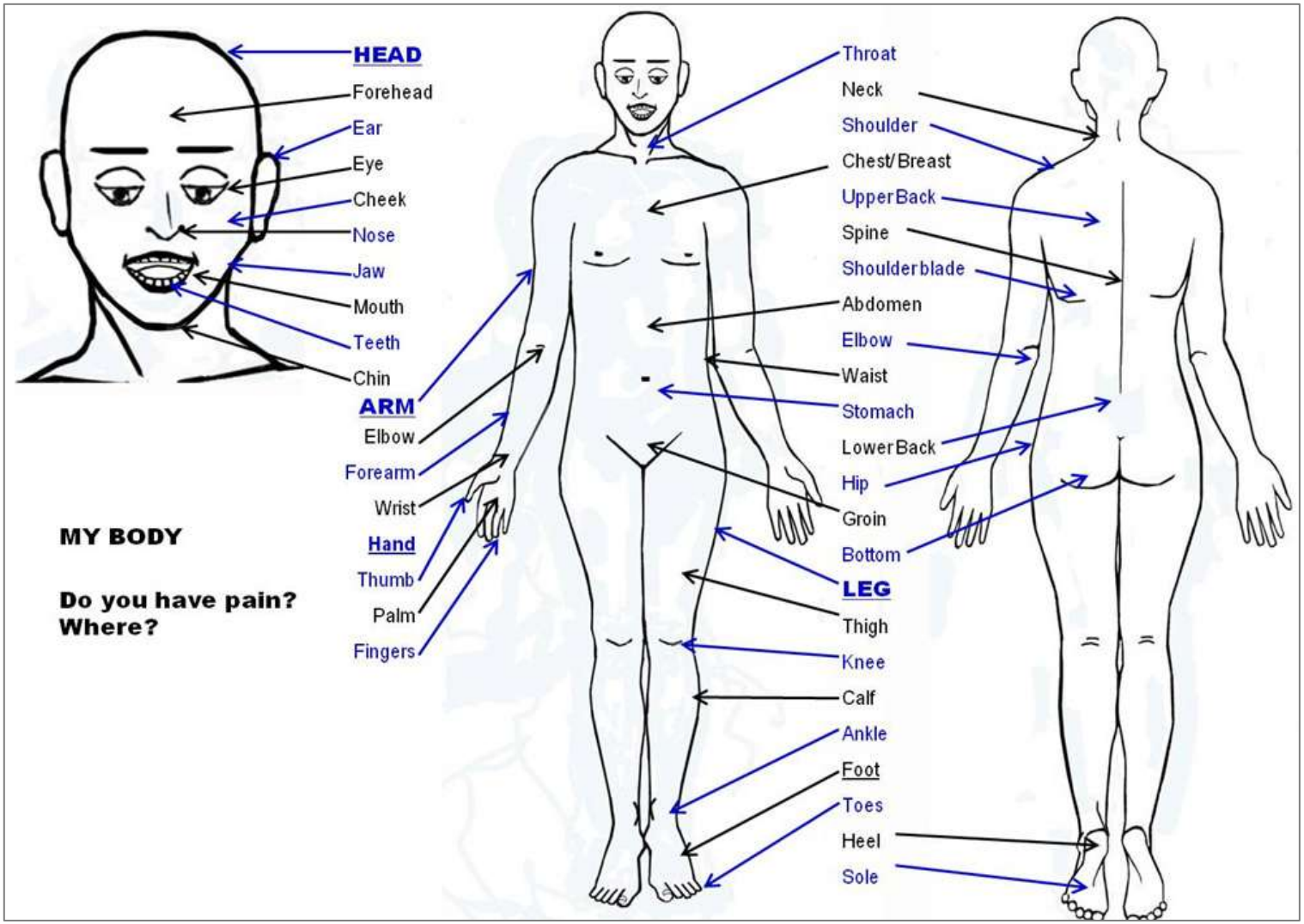


Figure 8.28 Pain pictorial-prototype-2 (p.1): Where is the pain?

Improved design features (p.2):
Pain score: Yellow colour removed from the emoticons, hair added; clearer, larger and more images express 'no pain' to 'unbearable'. Simple English words generally understood by EMCs lacking English were added to numbers to facilitate greater accuracy of responses.

Morning sun lowered to clearly depict sunrise; afternoon sun raised high; evening altered to sunset. A 'smiling' sun used to encourage patients and was repeated on medication instructions.

'I don't know' man redrawn, placed between 'yes', 'no'.

Numbers: simplified to commonly used under days, 2 weeks, a calendar-month.

Note the colour-perception testing of symbols (blue/ green=peaceful, right; red=danger, wrong).

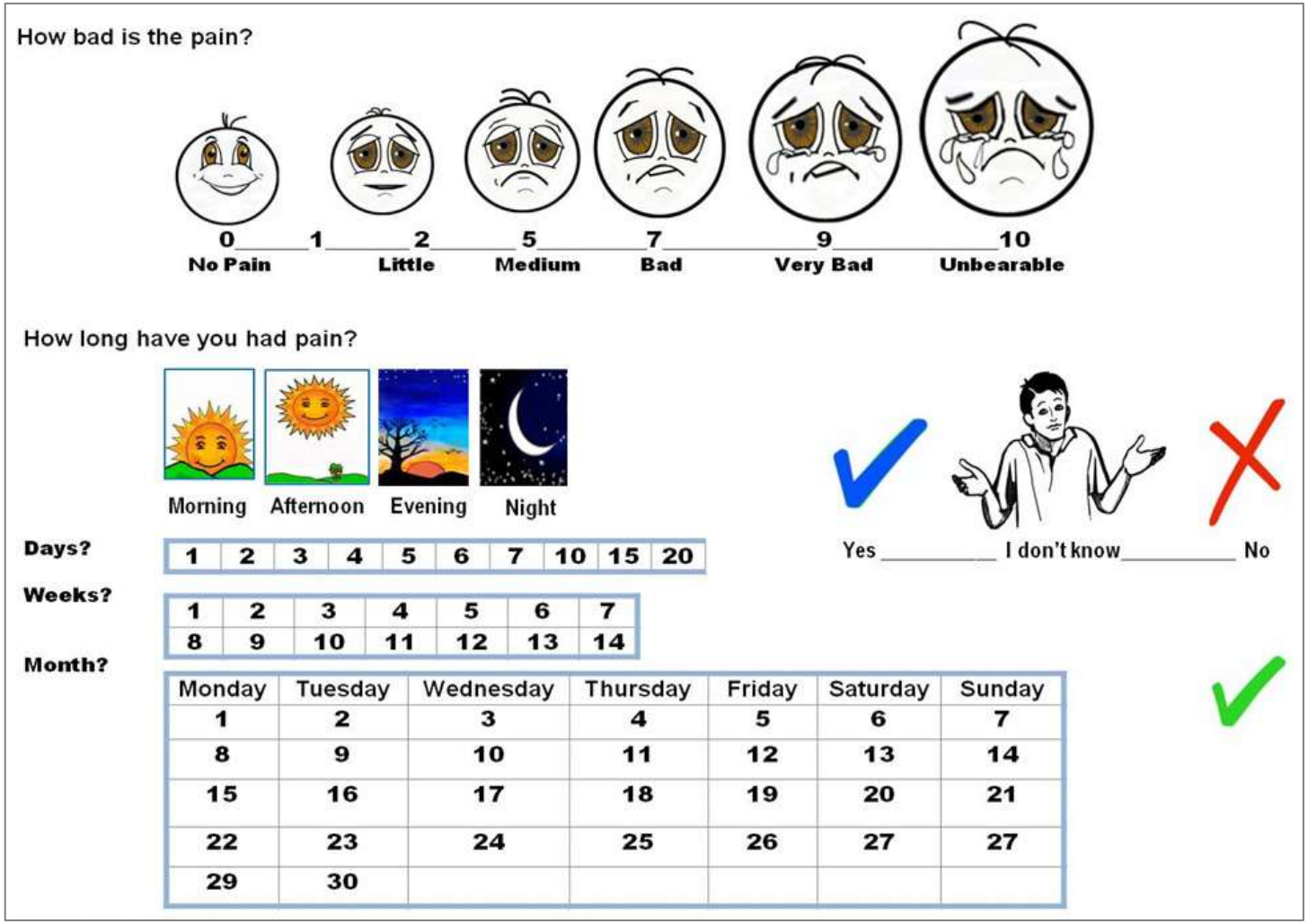


Figure 8.29 Pain pictorial-prototype-2 (p.2): pain score and 'How long have you had pain?'

Improved design features (p.3):

Images reorganised in English alphabetic order, in sections mirroring questions.

New photographs: aching (headache), crushing, chest pain, tight chest.

Redesigns: burning, pricking, knife, coughing, dizzy, hair loss, constipation, sweating.

Coughing: enlarged, blood drops made prominent.

Sweating: only the upper body, drops removed beneath the eyes and above the head.

'Breathless' was a question (red) .

New image: Exhausting.

Constipation/ Diarrhoea: stones re-emphasised (very hard). New images: bloody stools, watery stools, difficulty peeing (depicted by association, poor flow). Phonetics labels added.

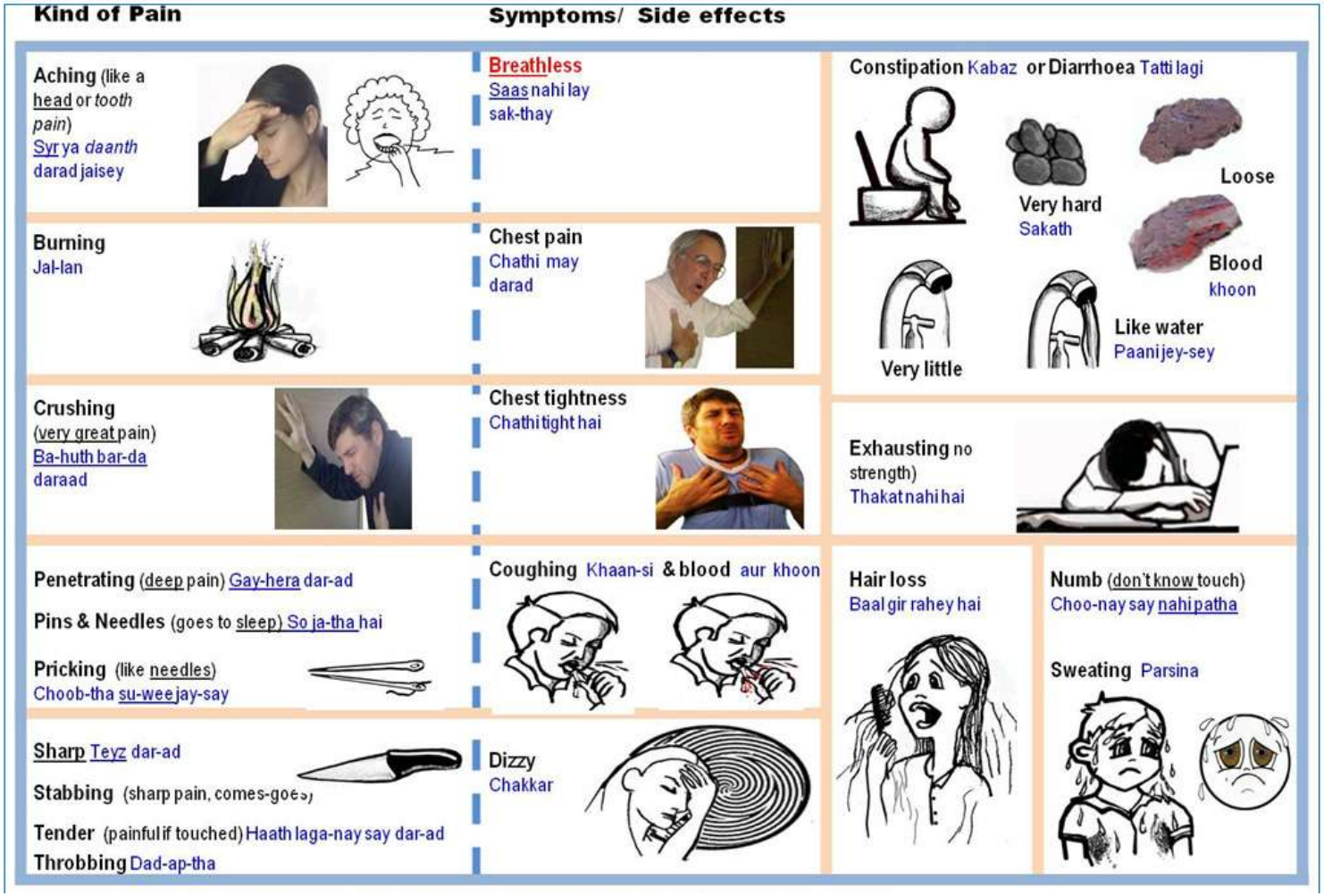


Figure 8.30 Pain pictorial-prototype-2 (p.3): 'Kinds of pain' and part 1 'Symptoms and side effects'

Improved design features (p.4):

English alphabetic order of images continued.

New photographs: tiring, blurred vision (by association, one eye is clear), cup of tea, water, food and walking.

New images: walk shivering, push and pull. Section added: need likes medicine, toilet.

Redesigns: temperature and thermometer made larger. Vomiting and blood made more prominent.

Note the inclusion of phonetic labels.

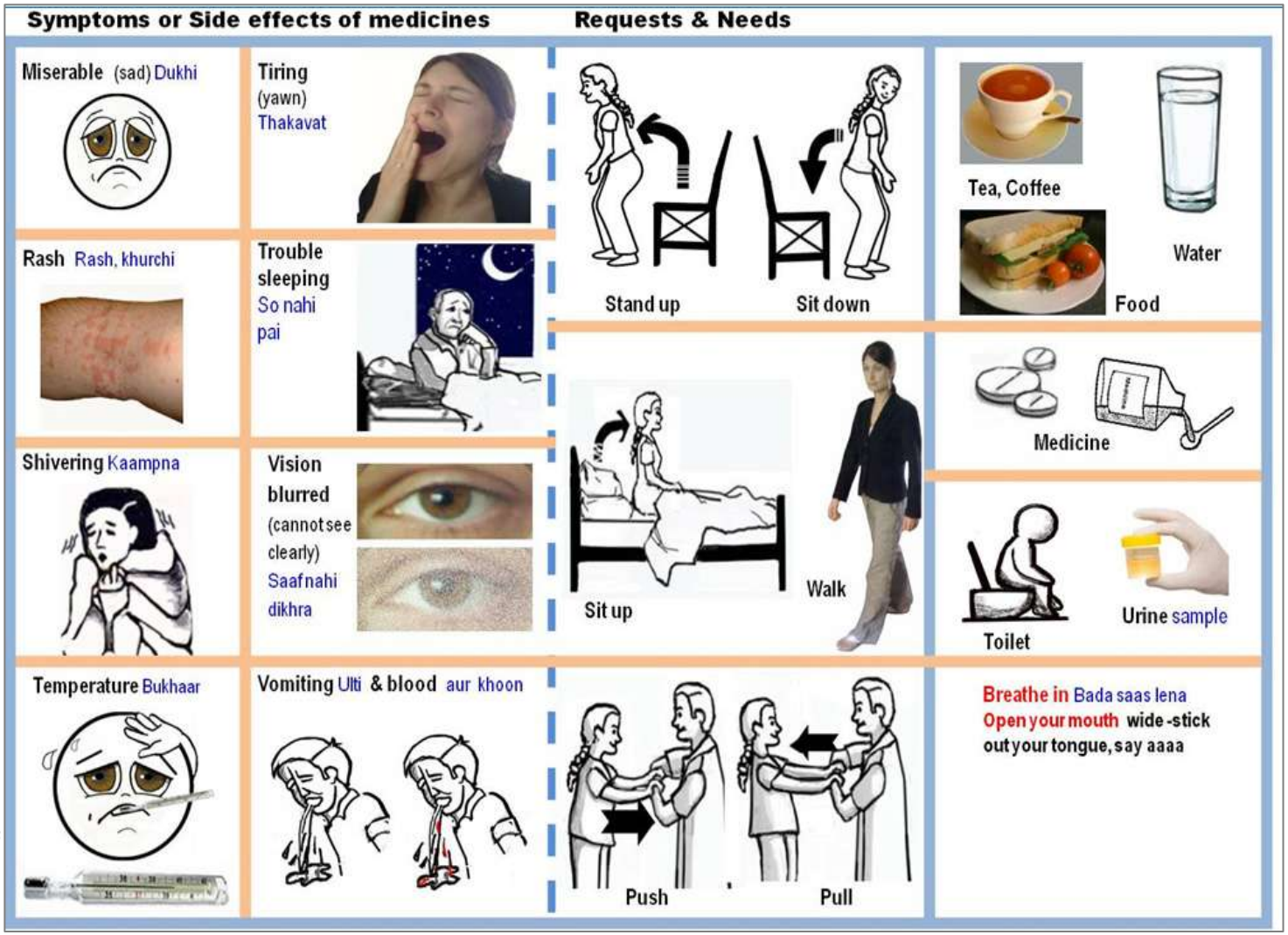
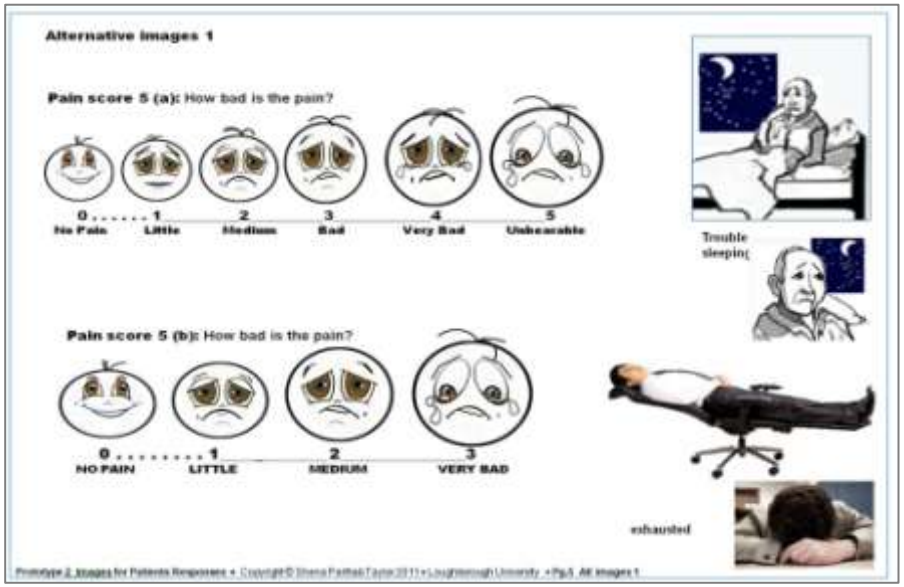
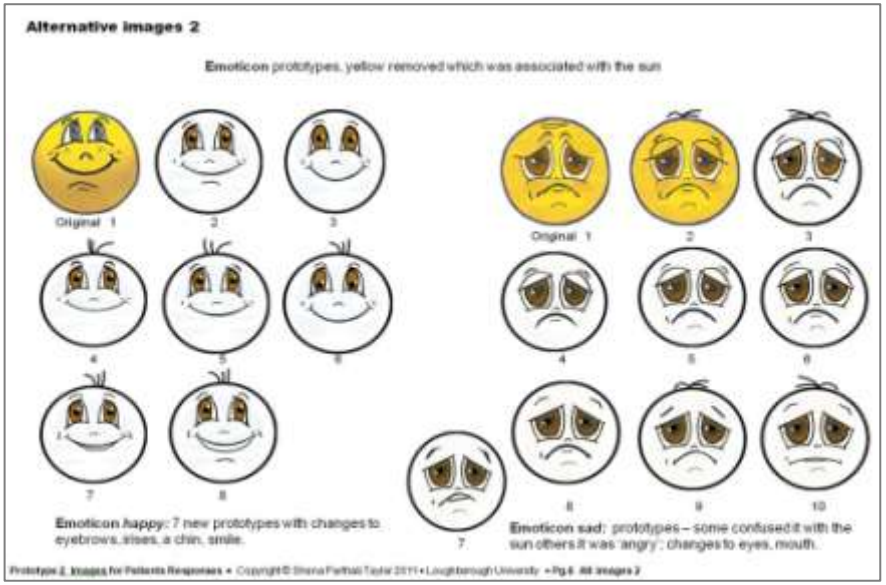


Figure 8.31 Pain pictorial-prototype-2 (p.4): 'Symptoms and side effects' continued, Requests and needs.





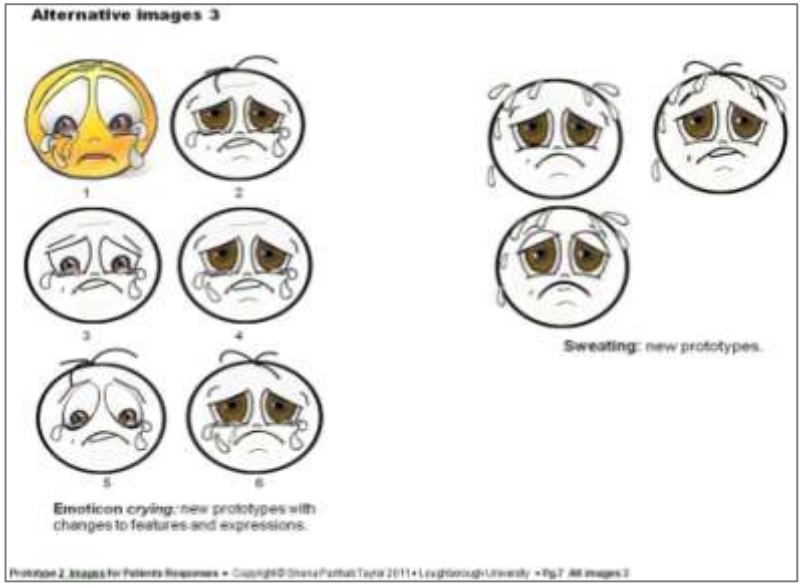


Figure 8.32 Three pages of alternative images offering more design choices

Medication prototype-2: Themes of times of day (when did the pain start) were repeated on a medication label and a list of medication.

The instructions try to guide patients on how much medicine to take, when, before or after food, or with water.

The tick and X symbols indicated what to do and avoid. X associated with a car X implied 'avoid driving when taking the medicine'.

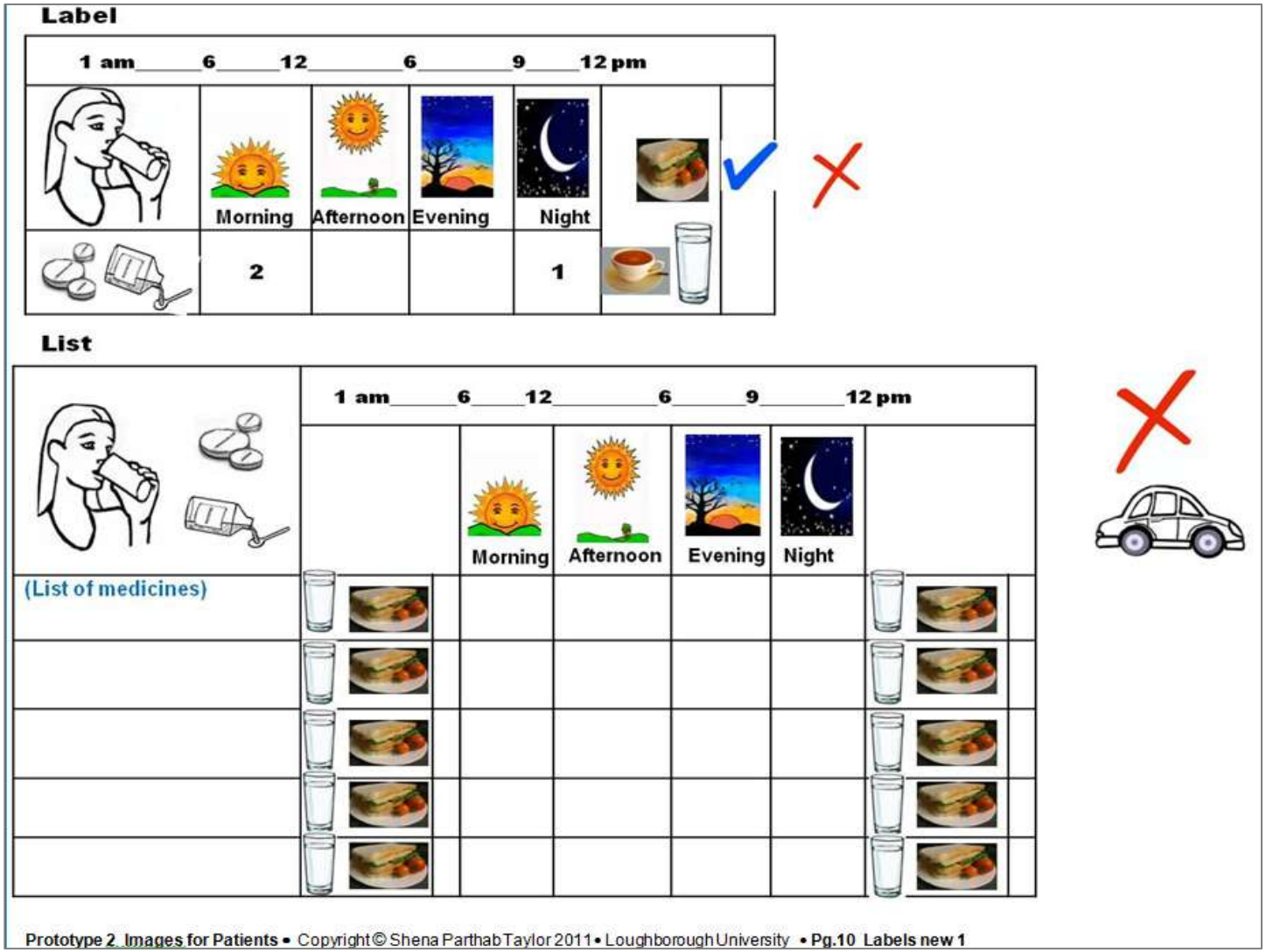


Figure 8.33 Medication pictorial-prototype-2: a medication label and list

The four pages for pain (Figures 8.28-31) were stuck together to represent a folded leaflet of A4 size. (Figure 8.34).

Figure 8.34 Pain pictorial-prototype-v2 formatted as 4-sided leaflet.

D. **Interview Questions**

The beta-testing questions were structured and open and sought to encourage participants to proactively use the prototype to explain their problem as well as answer questions (Appendix-D16).

All aspects of the designs were retested to determine whether interpretation had improved and whether the feedback implemented from alpha-testing proved to be what participants wanted in practice (see 8.6.3.1. B1).

Preferences of images were re-tested, e.g. cartoons or emoticons in pain score (Q2) and knowledge of English words. The latter question was reversed: the researcher spoke in Punjabi and participants were asked to speak the English equivalent (e.g.1 week, 6 weeks, last week; Q3).

The 11 questions and sub-questions explored:

- Views of labels on the body and of only English labels
- Using the pain score; preference between emoticons/ cartoons
- Using more than 1 image to explain when they became ill, e.g. I was dizzy last night (by selecting ‘dizzy’ and ‘night’ images) or other symptoms picked out in random order (Q7)

- Indicating ‘I don’t know’ and the difference with ‘I don’t understand’; indicating ‘yes’ for understanding; responding negatively to a question (e.g. Do you get pins and needles?)
- Picking out different types of pain or symptoms to explain to the doctor
- Instructions on medication labels and clarity of image arrangement on taking food before or after medicines (Q10)

E. **Response form**

A response form was designed as previously to capture feedback (Appendix-D17).

8.4.4.3. Procedure

Interviews lasted 20-50 minutes and were recorded on the form and digitally. The images were displayed and questions posed in sequence and the alternative images (Figure 8.32) displayed at appropriate points. Data was analysed using Excel 2007 and comments were collated in Word 2007. (Appendix-D18-D19).

8.4.4.4. Findings

Participant’s comments, critiques, suggestions and preferences were combined. Findings are reported as follows:

- Likes and interpretations (Table 8.9)
- Analysis of responses (Figures 8.35-8.36)
- Comments in question order and Difficulties
- Suggestions for improvement

A grandmother of 75 years, a UK resident of 30 years, with no literacy managed to answer a number of questions, but where she struggled, the questions were not asked, which is reflected in the figures below. However, she was keen to learn, but learned slowly, she explained.

Table 8.9 Beta-testing EMCs: pictorial-aids-2 (*n*=11)

Question/ topic		EMC responses: liked, understood
1	Labels on body and labels in English (Figure 8.28)	• Unanimously: easy or very easy
2	Pain Score with labels (Figure 8.29)	• Unanimously: easy or very easy • Emoticons preferred to cartoons • 10 scale pain score preferred for different levels of pain (91%)
3	Periods of day and numbers	• Unanimously: images (morning to night) clear • Some responded to questions with English words and could write days in English
4	Yes, No, I don't know (Figure 8.30)	• Unanimously: recognised 'I don't know ' • 91% understood the tick representing yes/understand and x was no/I don't understand and were able to say the words in English • Both blue and green 'ticks' for 'yes' were fine
5	Types of pain (Figure 8.30)	• Unanimously: liked labels on the image • 100% able to point out and explain different levels of pain (but 2 chose 7 for medium pain) • 'Goes to sleep' for pins and needles readily understood (symptom)
6-7	Symptoms and side effects (Figures 8.30-8.31)	• Most images were understood by 91-100% • 'Sweating': 73% preferred the image of the boy to the emoticon.
8	Labels: on all the images	• Unanimously *"better than without labels"* • Hindi phonetic labels "very good" (however, see Q8 below)
9	Requests for action and needs (Figure8.31)	• Unanimously: understood toilet, tea/coffee, water, medicines • Actions understood by 91% (asked in sequence and then randomly) • 'Sit up straight' scored slightly lower at 82% (straight not clear)
10	Medication images: (Figure 8.33)	• Unanimously: the label was easy or very easy to follow. Red was associated with 'No' or danger. • 91% correctly interpreted '2' under morning and night (take 2 tablets); understood the tick meant yes/ do this; the meaning of the arrow • 82% recognised the cross x meant no/ do not,
11	Other comments:	• See Q11 below

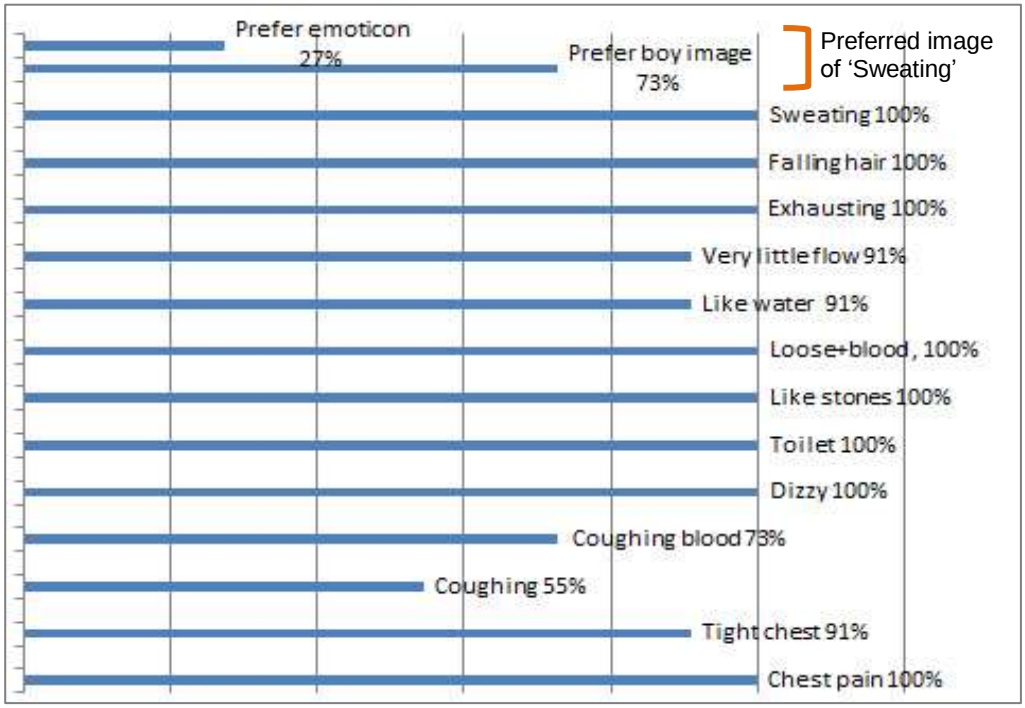


Figure 8.35 Beta-testing EMCs: percentage who understood images of symptoms and side effects; 73% preferred the boy's image in 'sweating'. (p.1)

Figure 8.36 depicts the results when participants were questioned on the meaning of images in order (blue) and then randomly (orange): rash and shivering were the least understood initially. However, participants asked the purported meaning, their suggestions for improvement were elicited and

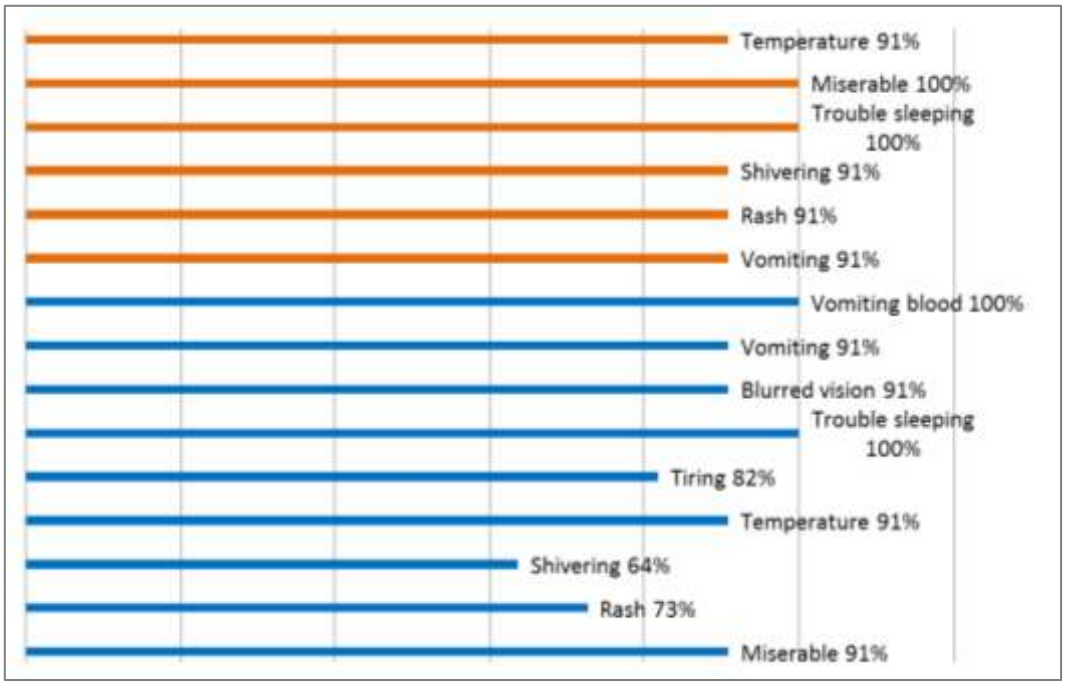


Figure 8.36 Beta-testing EMCs: percentage who understood images of symptoms and side effects (blue=in sequence, orange=random) (p.2)

during random questioning their recognition had improved (they were learning during testing) although a grandmother (75+ years) tended to forget.

Comments in question order and Difficulties

The comments below are representative of the majority responses unless otherwise indicated.

- **Q1. Labels on body and labels in English**

"Arrows show and help more; everyone will understand/learn what the name is in English" [1F]. *We can read and say what we don't know [i.e. find the word/ picture needed]"* [3M, 5F, 10M, 13M].

"[This is] Fine, mostly we need to learn English. We already know the parts in Punjabi and Hind" [1F, 6F].

"English is good" [2F, 3M, et al]. *"I don't know written Punjabi anyway" [6F].*

- **Q2a. Pain Score with labels**

"Very good; words and numbers of pain to unbearable" [1F].

"English labels are good" and *"Labels are helpful"* [6F, 7F,9F, 10M, 13M].

"It is clear and is written, so it's clear to see" [6F, Grandmother not literate].

- **Q3: Periods of day and numbers**

"It's best like this [images and labels] for those who don't know English" [1F].

Difficulties: Some confused 'day' and 'today'. Recent arrivals (male and female) were still learning and could not express week, next week, or year in English.

- **Q5: Types of pain/ symptoms**

"It [pins and needles] is very common in the leg or arm for people when they go to the Gurudwara. They always have this problem [sitting on the ground]. We need a leg or arm with little dots on them, like insects, ants crawling, to show people who cannot read English" [1F].

"They [the doctors] don't look at me" [6F, Grandmother aged 75+, fretted),

- **Q4. Understanding 'I don't know'**

18% confused 'I don't understand' with 'I don't know'.

- **Q5: Types of pain**

Burning: 64% understood it the first time, and 91% the second time

Crushing was not understood by 18% (interpreted as pain)

- **Q6-7: Symptoms and side effects**

The least understood images were: coughing 55%; coughing blood 73% (Figure 8.35) the latter was better understood because of red drops of blood; shivering 64%; and rash 73% (Figure 8.36).

- **Q8. Labels on all the images**

A female participant felt Hindi phonetics were not needed (the purpose was to learn English), another female was unable as she had no literacy.

- **Q10. Medication images**. Unanimously,

"Good; very nice; helpful to understand" [3M] and "*Both labels are good"* [7F].

- **Q11. Other comments**

"No has taught me like this before!" [7F, Grandmother, not-literate].

"I want to learn difficult words like constipation, pins and needles: I was concerned how to explain pins and needles. It happens to many in the Gurudwara; it's a common problem" [1F, widow].

"My husband goes with me but sits quietly on purpose [to make me speak], and the lady doctor tells me to explain my problem. Then I have to explain, but I don't understand her response" [8F, Grandmother].

"I would like a copy to learn, to remember" [F1].

"If we have it we can learn and those who don't know any English can show the pictures." (1F)

"Very good [aid], it will help me" [10M] *"I would like a copy of it"* [10M, 13M, 1F, and unanimously].

A grandmother [8F] commented that her daughter interpreted a bit differently to what she was trying to tell the doctor and experienced interpreters were a problem because they interpreted differently but she did not understand what they had said to the doctor.

Suggestions for improvement

The suggestions are combined, arranged in alphabetical order by image and all except the last point (to be done) were implemented.

- **Coughing**: put hand closer to face/mouth, make drops smaller.

- **Falling hair**: move hand holding the comb back a little.
- **Medication label** *"Put food and water before the medication then people will know to take it after water or food"* [1F, 2F, 10M].
- **Rash**: lighten it, it is difficult to see.
- **Shivering**: make image a bit clearer; give colour to the blanket, blue or red, hands out holding it; make blanket darker, and around head - a hat.
- **Sweating**: Preferred the boy image to the emoticon (73%): make it clearer, bigger.
- **Temperature:** make the thermometer larger and below emoticon.
- **Tightness in chest:** Have the belt above the hands; have hands at the side, shirt in red and a black belt (contrast).
- **Tiring** (**yawning**): picture of the man yawning preferred; make it clearer; show hand in front of mouth.
- **Trouble sleeping**: was now OK, use alternative image 2: larger face, clearer expression (Figure 8.32).
- **Walk:** lighten it
- [Add: 'I don't understand', "Please repeat" phrases]

8.4.4.5. Discussion

Beta-testing revealed an improved level of understanding for most of the designs, an indicator that participants were willing to learn if they had some tools. An important aspect was the ability to have the aid at home, so that it was easily accessible (e.g. paper based), that they could refer to as often as they pleased and ask the family.

The designs were updated after testing with indigenous elderly whose suggestions were combined with those of EMCs in pictorial-prototypes-v.3. This is described next.

8.4.5. Beta-testing: Indigenous elderly

Testing with indigenous elderly was kept very simple in order to avoid fatigue and to include as many participants as possible. The aim was to validate the images and English labels to ensure the designs were inclusive to help indigenous patients who unable to communicate easily (e.g. after an operation). Participants were advised their feedback was sought to help people when they were ill in hospital and finding it difficult to communicate (i.e. as staff described in study 2).

8.4.5.1. Participants

Ten indigenous elderly were recruited from a care home. Participants were heterogeneous (5 females and 5 males, aged between 65 and 92 years) and known to each other. All were retired and some suffered from impairments like profound deafness, frailty and impaired vision. Figure 8.37 depicts an analysis by age. Some agreed to participate to have someone to talk to, others felt they were helping the research or doing some good.

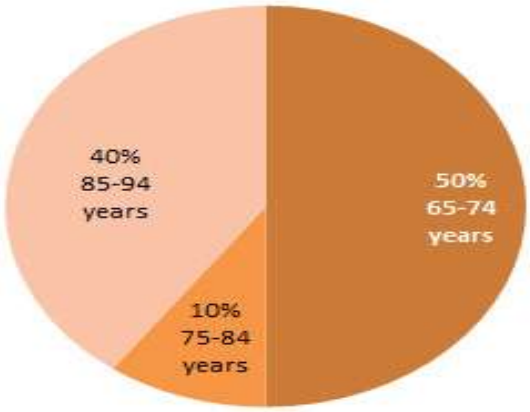


Figure 8.37 Indigenous elderly participants as a percentage by age (*n*=10)

8.4.5.2. Tools

The same tools were used as were used for beta-testing EMCs, i.e. pictorial protytpes-2 for pain and medication and alternative images and interview questions (see A-D 8.4.5.2 and Figures 8.28-8.33) and a notepad (not a response form).

The 11 open questions sought to explore participant's views of the clarity, difficulty and usefulness of the images and to elicited their preferences and suggestions, and to compare their views with those of EMCs.

8.4.5.3. Procedure

Largely structured, 30-40 minute interviews were conducted at participants' residences. Participants were reassured of anonymity, that there were no right or wrong answers and only their views were required. Data were transcribed and grouped by question in the order of participants' preferences and then reduced using Word and Excel 2007 (Appendix-D20-D21) in preparation for design adjustments. Figures 8.38-8.39 depict extracts of data grouped by question and ordered by reference, and then reduced.

Q5: Types of pain: using list, clarity

1: Images are clear – I like the words written like that, I could go down and say I need this done, if I had this.
2: Miserable (laughed at the expression).
3: Clear, yes. "This could help, I forget how to describe it."
4: Image are clear, good.
5,7: Yes, clear
6: Pefers the toothache in the autism picture card – dead easy, simple and clear. Change headache to be like it. The zig-zags are meaningful.
8: I can understand it, quite good, especially the burning one with the fire. It's all clear.
9: Helpful. Very helpful.
10: Very good, can understand, very helpful descriptions of pain.

Q6: Symptoms and side effects

1: Breathless/ Asthma [include]. *Chest tight:* make the belt bigger, couldn't see it, and shirt lighter – good idea. *Dizzy* I like that. *Toilet* is very helpful: *like water,* change [image] to very very loose. *Rash* make it lighter – very light. *Vomiting* make it stand out more and the blood.
2: Pictures are clear.
4: Breathless is very helpful. Toilet: Jolly good, very good.
5: Chest pain: looks breathless. Chest tight: make it bigger, emphasise the belt, a buckle, clear image. Constipation need diarrhoea and urination: taps with peeing,
6: Tight chest: Belt needs a buckle. Breathlessness – similar to chest tightness (change). Loose: cannot see red. Make the loose stools dark yellow with darkness (can associate darkness with red). Rash: lighten arm and darken the spots.
7: Yes, breathlessness is needed. For loose stools: Image indicate 'loose' loose + blood: more colour red would be understood may be more drop of blood than a solid block. Sweating: looks like crying, perhaps have him wiping brow. Rash on arm should be in red or different colour. Blurred vision: more mistiness over the eye.
8: They would be understood alright. I can understand them. Need breathlessness.
9: Breathlessness, yes. All are clear. Water = bladder issue. Sweating: wiping forehead.
10: No change, I think that's very good. Nice to have breathlessness. If you can come up with a nice image for breathlessness – head in arms, and **gasps for breath**

Figure 8.38 Testing indigenous elderly people: data grouped by question, ordered by reference

Q2. Pain Score: clarity, difficulty, pain scale (PS) preferred.

90% agreed the pain score was understandable and there was no difficulty, emoticons were good and the images covered all aspects of the amounts of pain. Comments included: "Easy to use", "Easy and clear", "Labels are satisfactory, perfectly explanatory", "I can pick it out perfectly alright", "Very good clarity", I really do find it clear."' One summed it up as: *"Very handy to use. I have been in unbearable pain. The words are very good; you haven't missed anything."* However, one profoundly hearing impaired female participant didn't understand the purpose too well because her family would tell the doctor.

There was unanimous agreement about the need to alter the image for 'unbearable': "I agree with the doctor" that unbearable was screaming/ shouting with pain. Suggestions also included: 7 should be 'fairly bad' not bad, bad= 8. For another: Bad (7) looked worried, and he suggested swapping image 9 to 7, and current image 10 to 9, and change 10 to a square mouth.

60% were happy with pain scale 10 (1 with any), 30% opted for 5, 10% scale 3.

Q3: Periods of day and numbers to explain when one became ill:

Unanimously the images for times of day were all clear: *"The images are clear; no change, that's OK."* For one participant felt *"I wouldn't use afternoon, there is no need for afternoon"*, another liked 'morning', another although 2 had opposing views of inserting a cockerill in 'morning'.

The duration of illness required only one set of numbers and the unanimous view was a calendar with clear numbers: "everybody relates to a calendar." A suggestion for **'Year' was to include the months 1 to 12, January to December**

Figure 8.39 Testing indigenous elderly people: data reduced by question

8.4.5.4. Findings

Participant's comments, critiques, suggestions and preferences were combined. Findings are reported in the order of questions as follows:

- Likes and interpretations (Table 8.10)
- Comments and Difficulties
- Suggestions for improvement

Table 8.10 Beta-testing indigenous elderly people: pictorial-aids-2 (*n*=10)

Question/ topic		Liked and Understood
1	**Pointing out pain on figures** (Figure 8.28)	• Unanimously: perfectly clear, easy, straightforward and understood
2	Pain Score with labels (Figure 8.29)	• 90% felt it was understandable: no difficulty. • Emoticons favoured over cartoons; the images covered all aspects of the amounts of pain • 10-scale pain score preferred by 60% (1 with any), 30% opted for 5-scale, 10% for 3-scale.
3	**Duration of illness:** periods of day and numbers	• Unanimously: images (morning to night) were clear. 'Morning' was liked (smiling sun). • Unanimously: only need one set of numbers; a calendar with clear numbers favoured
4	**Yes, No, I don't know** (Figure 8.30)	• Unanimously: clear, useful, good. • Both blue and green 'ticks' for 'yes' were fine.
5	**Types of pain** (Figure 8.30)	• Unanimously: images and labels favoured. • Easy, good ideas for describing pain, helpful if they forgot.
6	**Symptoms and side effects** (Figures 8.30-8.31)	• Majority: clear, no change was required. • Unanimously: 'Breathlessness' needed to be included.
7	**Requests for action and needs** (Figure8.31)	• Unanimously: clear, no change was required. • Actions understood by all.
8	**Medication images; a page for instructions** (Figure 8.33)	• Unanimously: very clear, very helpful; the list was liked. • Unanimously: page for medication instructions was a very good idea.
9	**Did pictures help**	• Majority: Yes, one felt some more than others.
10	**Preference amongst images**	• Unanimously: all the images were liked,
11	Other comments:	• See Q11 below.

Several participants had hearing impairments, one profoundly so. Another could not distinguish brown from red, and had difficulty with green.

Comments in question order and Difficulties

The comments represent the majority view except where specified [participants by reference and gender].

Q1. Pointing out pain on figures "

"Shows everything. Very easy" [1M], *Very clear, straightforward"* [5F].

"Need something in the heart area – symbol of the heart" [9F, similar to EMC participant's response!].

However, although a profoundly hearing-impaired female felt the designs were*: "Perfectly clear. No difficulty (using it)"* she then added, *"No, they're not helpful, the doctor knows about it - the doctor <u>should</u> know about it"* [8F].

Q2. Pain Score

"Easy to use" [7M], *"I really do find it clear; no difficulty"* [9F], *"Very good clarity"* [10M].

"Labels are satisfactory, perfectly explanatory" [6M].

"I can pick it out perfectly alright" [8F].

"Very good clarity, I really do find it clear" [9F].

"Very handy to use. I have been in unbearable pain. The words are very good; you haven't missed anything" [1M].

However, the profoundly hearing-impaired female did not understand the purpose too well, repeating that her family would tell the doctor.

Q3: Periods of day and numbers

Unanimously *"All the images are clear"* [e.g. 3M, 4F, 8F, 10M].

"The images are clear; no change, that's OK. I wouldn't use afternoon; there is no need for afternoon" [1M].

Q4. Yes, No, I don't know.

Unanimously *"Very useful, clear"* and *"Yes, that is very useful. 'I don't know' is clear"* [e.g. 1M].

Q5: Types of pain (images and labels)

"Very good, I can understand. Very helpful descriptions of pain" [10M].

"I like the words written like that, I could go down and say I need this done, if I had this" [1M].

"This could help; I forget how to describe it" [3M].

"I can understand it; quite good, especially the burning one with the fire. It's all clear" [8F]. *"Image are clear, good", " Yes, clear"* [4F, 5F].

One liked 'miserable' and laughed at the expression, another preferred toothache in the autism picture card: "*Dead easy, simple and clear. Change headache to be like it. The zig-zags are meaningful"* [6M].

Q6: Symptoms and side effects

"Jolly good, very good" [4F].

"They would be understood alright. I can understand them" [8F].

Breathlessness was important*: "Try and find a solution for breathlessness."*

"If you can, come up with a nice image, head in arms and gasps for breath" [10M]. "Perhaps a person blowing out wind image from the mouth" [9F].

Images were picked out randomly for comment: *"I like that"* [dizzy]; *toilet is very helpful"* [1M].

Q7. Needs and Requests for action.

"Nothing to add, pictures are clear" [2F, 10M and unanimously].

"Actions are clear. All done very well, 10 out of 10" [4F].

Q8. Medication label and list and a page for instructions

"Very clear", "Clear" and *"Really clear and helpful"* and recognised unanimously.

Pictorial medication instructions were *a "Really good idea"* [5F] for the majority although one was not sure.

"Did I take it or didn't I?" [5F] was a problem: a friend had to take a lot of medication and it was difficult to help her: *"Some every 2 hours, some 3 hours, it was complicated; different pills at different times"* [5F]. (See 'suggestions', below, on medication.)

One female felt doctors needed to check their computer more often to see what tablets a patient was on because their neighbour was 'overprescribed' and her sister was prescribed *"Tablets on top of tablets.*

It's very dangerous; you'd have been dead within the last 5 years" [10M] A new doctor stopped the medication and she was fine.

Q9: Did pictures helped in explaining?

All felt: *"Oh yes", "Yes, very helpful"* although for one *"Some parts, more than others"* [1M].

Q10. Preference amongst images: the mix was favoured and there was no preference amongst emoticons, cartoons or photographs.

Q11. Other comments: 40% said they would like a copy. Comments included:

"We need something like this not only for people who speak other languages but for old people who get forgetful. I will help you test them" [5F].

"I think the 'dos' and 'don'ts' for medication would be helpful" [9F].

Suggestions for improvement

The suggestions are combined, arranged alphabetically by image and the green text indicates all the suggestions that were implemented.

Blurred vision: **more mistiness was required** over the eye.

Breathlessness: Unanimously important: ***"Try and find a solution for breathlessness"*** [10M].

Chest pain: looks breathless (moved).

Calendar (periods of day and duration of illness) required **only one set of numbers: a calendar with clear numbers:** *"Everybody relates to a calendar"* [6M].

For '**Year' include the months 1 to 12, January to December.** A participant suggested a cockerel in 'morning' the others disagreed.

Headache: "Change headache to be like it [autism picture]. The zig-zags are meaningful."*

Medication instructions: **A page for medication do's and don'ts was a "Really good idea"** [5F]. Include no anti-inflammatory tablets like ibuprofen; allergies to tetanus, penicillin; **no alcohol.**

The medication list was favoured: "*Have a chart with a tick to help memory"* and to understand what it's for (the medicine), e.g. heart, cholesterol, high blood pressure [5F].

Pain*, pointing on figures: "Need a bit of hair" (on the head, 6M) and **"need something in the heart area, a symbol of the heart"** [9F].

Pain Score: Unanimously, participants felt the words were very good but agreed with the doctor that the **image for 10 'unbearable' pain need altering to screaming/ shouting with pain and a square mouth** [4F, 5F, 1M, 6M]. Also, **7 should be 'fairly bad' not 'bad' and 8 changed to 'bad'; c**urrently, 'bad' (7) looked worried [1M, 5F]**. Move the current image for 10 to 9, image 9 to 7 and alter 10 to a square mouth** [5F].

Rash*: was unclear to several: "lighten the arm and darken the spots" [6M] and the "rash on arm should be in red or different colour" [7M].

Stools constipation include **diarrhoea**

Stools loose: **change (image)** to "very very loose"

Stools loose/ blood: "M*ore colour red would be understood may be more drop of blood than a* solid block" [7M]. However, a male who could not distinguish red suggested "*Make the loose stools dark yellow with darkness*" [6M] because he could associate darkness with something different like blood, or red.

Sweating*: "looks like crying"; two participants suggested wiping the forehead (adjusted).

Tightness in chest*: Could not see it "***Make the belt bigger; shirt lighter, good idea"*** [M1] and a **"emphasise the belt, a buckle"** [5F, 6M].

Vomiting: ***"Make it stand out more and the blood"*** [1M].

(*=Similar to EMCs' reactions.)

8.4.5.5. Discussion

This valuable feedback confirmed literature (see 7.4) that the labels on the images enhanced clarity and could help even indigenous people find words to express themselves, e.g. kinds of pain. Several images that were not understood and the resulting comments and suggestions were similar to those of EMCs. The zig-zags used in autism picture cards proved clear for EMCs and indigenous people.

One of the most helpful aspects of iterative testing was the opportunity to test small modifications and to inductively add probes (testing the doctor's criticism of 'unbearable pain', did morning need a cockerel?). Suggestions also highlighted the similarities of thinking across cultures and most were accommodated in prototype-3 upgrades (except for the last 2 staff as the

prototypes were laminated and handed to them for final testing at the same interview). The design upgrades are described next.

8.4.6. Beta-testing: NHS Staff and Indigenous Adults

As NHS staff cited concern over correctly pronouncing the phonetics, indigenous adults were recruited to raise to 10 the number testing phonetics. It was emphasised throughout to staff that all elements of the designs could be altered to suit their needs and there were no right or wrong answers.

8.4.6.1. Participants

- **NHS Staff:** Seven staff participated: 5 from alpha-testing and 2 new A&E doctors (indigenous and German) were recruited with the help of department management to replace the original A&E doctor who changed jobs to a Trust outside the ethical permissions. Participants were heterogeneous (1 female, 6 males) and unknown to each other. The resulting delay for recruitment required an adjustment to the study design (see 8.5.6.3).
- **Indigenous adults:** The 3 participants were heterogeneous (2 females, 1 male), non-stakeholders and not known to each other.

8.4.6.2. Tools

Seven tools were used for testing NHS staff and, of these, E and F were used to test indigenous adults. Table 8.11 sets out some tools, the purpose of testing and feedback sought.

Table 8.11 Beta-testing Staff and indigenous people: Some tools and purpose

Tools	Purpose	Critical feedback
B. Beta-testing indigenous adults and staff		
Indigenous adults		
Questions-prototype Notepad	Testing phonetics	Clarity of pronunciations.
Staff		
Interview questions Pictorial prototype-2 Questions prototypes-2 Response form	Review and critique full aid (images and questions); concept of educational leaflet; testing phonetics; usefulness of web-based aids.	Validity, accuracy, missing, usefulness, relevance, preferences, accessibility. Clarity of pronunciation; confidence building.

A. **Questions**

The fourteen questions were prepared for a largely structured interview. Questions were open with prompts or simple explanations (Appendix-D22) and divided into 3 sections to explore the topics below.

Section-1: Pain & Medication questions-prototype-2

(7 questions, questions-prototypes-2 were displayed)

- **Phonetics pronunciation:** To test the phonetics and elicit suggestions for improvements.
- **Phonetics design.** Preference for current arrangement vs. symbols used in dictionaries.
- **Using underlining and *italics***. To relate English and Hindi keywords. Re-tested to determine whether the favourable opinions from alpha-testing would be repeated when the design was implemented.
- **'Setting the scene'.** Views on relevance of sub-sections; any gaps.
- **Overall format** used a Likert scale 5-point for views on the 8 sections, clarity, flow, navigation, response checkers and new designs. The red text indicated requests for clarification.
- **Anything missing,** unclear, irrelevant

Section-2: Fonts

(3 questions, alternative designs were displayed)

- **Use of 2 colour.** Current colours, context of lighting conditions, usability, results of photocopying (cost)
- **Use of bold** throughout the prototype
- **Font size.** Current Arial 10.5 pitch vs. a range of others
- **Arrangement of data** paragraph vs. list; using bold.

Section-3: Pictorial-prototype-v2 images

(4 questions**,** pictorial-prototype-v2 was displayed**)**

- **Labels on body** image, and only in English.
- **Pain score**: use of 10-scale (EMC preference)

- **Co-relating** the questions and images
- **Arrangement of information**: list vs. paragraph, using bold and colour.

B. **Response form**

A form was designed to capture 5-scale Likert type responses and responses to open questions (Appendix-D23).

C. **Alternative designs**

Designs were prepared to illustrate the options for Section-2, above, (Appendix-D24).

D. **Pictorial-prototype-v2**

The same as were used for beta-testing EMCs (Figures 8.28-8.33).

E. **Questions-prototypes-v2**

Those upgraded after alpha-testing were used (8.4.3.7, Appendix-D8). A tabulated version of one page was designed for staff who had selected more tabulation to test their views once their suggestion had been implemented

F. **A notepad**

The phonetic words that were incorrectly pronounced were listed on the pad for suggestions for improvement (Appendix-D25).

G. **Phonetics guidance**

A page of guidance on pronunciations was prepared based on observations of pronunciations during alpha-testing:

- Pronounce words evenly (all the syllables needed to be heard)
- The intonation of questions is identical to posing questions in English (i.e. voice rises at the end).
- - A dash denotes a minute pause
- aa Double alphabets denote an extension of sound
- r is pronounced as in *car*
- g is pronounced as in *begin* (not as 'j' as in *gin, gym*)
- th is pronounced as in *thump, thing, thigh* (not lightly as *this, thus*)

Of the tools, above, F and G were used in testing indigenous adults in 20-30

structured interviews. However once these were tested with them, the guidance to staff was modified a little over the dash.

8.4.6.3. Procedure and Adjustment to study design

Beta-testing interviews with staff took several weeks to complete, possibly due to time-pressures for staff. This time was used productively by interspersing staff interviews with interviewing indigenous adults and indigenous elderly people. Participants' comments were, thus, shared between groups and between participants.

- **Staff**: Thirty-minute structured interviews were conducted with 7 staff at work or in residences. Questions were open and staff were reassured that 10 colleagues and indigenous adults were being tested on the phonetics to generate improvements in pronunciations. They were asked to read the phonetics on both pages of the pain prototype and guided to treat hyphenated words (– the dash) as one word without a pause.

Staff were reassured that there were no right/wrong answers, the author would note any phonetics pronounced incorrectly and then review these with them to ain their suggestions for improved spellings to produce a more accurate sound. The pictorial aids were critiqued first and then the phonetics testing carried out. Data was recorded and captured on paper.

- **Indigenous adults:** Thirty-minute structured interviews using open questions to test phonetics (only) were conducted with 3 participants near their work or in residences. The same procedure used with staff was used here.

The questions and pictorial-prototypes were upgraded based on feedback received from the majority of participants, whilst waiting to recruit/ interview the new doctors, in order to meet the ethical timeframe permitted by the Trusts. For the new doctors, beta-testing and handing over the prototypes for testing were rolled together into a 1-hour interview in order to explain concept and carry out beta-testing. Indigenous adult numbers were reduced from 4 to 3 to bring to 10, with staff, the numbers testing phonetics.

8.4.6.4. Data analysis

Response forms were transcribed and analysed in Word and Excel 2007 and phonetics in Excel 2007 (Appendix-D26.1-26.4).

Phonetics were analysed after each interview and participants' suggestions were shown to the succeeding interviewee (inductive methodology). In the phonetics analysis (Figure 8.40, an extract), Hindi phonetics and their English meanings were listed alphabetically (x-axis) and the 10 participants' suggestions for improving spelling to produce the correct sound (y-axis) were added as interviews progressed.

		Brit	Iran	Brit	Brit	Brit	Brit	Brit	Brit	Germar	Brit
Phonetics	Refs:	10	1	2	6	8	9	5	4	3	7
Hindi Original	English		Least troubl								
aap	you	ah-p		ahp							
agar	if				ug-gar					ugh-gar	
ar-aam	rest			ar-raam							
aur	and	or									
bayt	sit										bait
bolna	speak						bowl-na				
bukh-aar	temperature/f						bukh-arr	book-haarr			
bura	bad	-		bu-ra							
chaley	goes	cha-lay									
choonay	touch	choon-nay									
cumm	less	come		cumm		come	come				
dadaptha	throb/ thumping			da-daptha		dadap-tha					
dheeray	slowly					**dheeray**					

Figure 8.40 Phonetics analysis extract: iterative testing

Questions-prototypes-2 were also adjusted 5 times (November 1st, 5th; December 1st,19th 2011; January 13th 2012) and tested iteratively. Data on the questions and pictorial prototypes were grouped by question and ordered by participants' references, then reduced and colour coded in preparation for design modifications (Figures 8.41-8.42).

Blue= author's comments, self-reminders, errors spotted

Green= design adjustments

Red= modifications to be made/considered.

The last 2 staff modifications could not be accommodated prior to printing/ laminating due to the delay in interviewing.

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Additional comments/preferences grouped by Question number & ordered by staff reference.

(**Legend**. References: 1 = GP, 2= Senior physio, 3=A&E doc, 4= Ward sister Stroke & Elderly care, 5= Paramedic, 6= Snr Pharmacy technician, 7= A&E doctor. Blue text=researchers comment; staff were pointing to images.)

Section-1. Qs on Pain & Medication----------

S1-Q2. Preferred phonetics presentation:
1: **Put in bullets.**
2: What you've done already makes it easy to read and will make it easy to pronounce, as it is; dictionary terms are not user-friendly.
5: **Keep to current method,** not the dictionary method.
7: (Current method, not dictionary) Prefer no hyphens or minimise hyphens.

S1-Q3. Underlining/ italics assoc. English & Hindi words:
2: Want these (; need a legend/key explaining the underling or italics.
6: Really helpful.

S1-Q4a. Preamble
1: Alter to: 'I don't know much Hindi, I am going to use this paper to help us'; emphasise very little [Hindi]. Make a larger space for preamble, last para – remove – use full stops and sentence case. (moved from S1-Q5.1a)
2: It's a nice way of making a person understand, but some words are not correctly pronounced.
4: Happy with preamble, do not particularly require bullet points.
5: Good.
7: Helpful. But shorten it to: I am speaking slowly, OK *teekh hai?*, Do you understand *samaj aya*? Speak as much English as you know. Learn English.

S1-Q4b. Anything missing:
2: No, I think that's very self-explanatory. Definitely the only other thing is layout – you may use a picture to help.
4: No
6: **Shooting pain: the important thing is it's a moving pain. Throbbing is a pulsing pain.**
7: Section 6 Pain: Medication: to Which medication? *konsi dava* add paracetamol?

S1-Q5 View of sections:

S1-Q5.1a. Clarity:
2: Covers all the points and easy to ask and clear to go through; a logical flow.
3: Everything is straightforward (answered same to all of aid)
4: It is clear to me

Figure 8.41 Staffs' comments grouped by question

S1-Q4a. Preamble: Good. Helpful. Happy with preamble, do not particularly require bullet points.
"It's a nice way of making a person understand. I think that's very self-explanatory. The only other thing is layout: **Add bullets** and put "you may use these pictures to help" in **the next paragraph** (so it stands out).
Alter to: 'I don't know much Hindi, I am going to use this paper to help us'; **emphasise very little [Hindi]. Make a larger space for preamble, use full stops and sentence case.**
NFIP: After OK **add 'Do you understand?'**

S1-Q4b. Anything missing: To communicate shooting pain: **"the important thing is it's a moving pain"** and **"throbbing is a pulsing pain".**
NFIP (pain): Q5: Shooting pain: suddenly appears and disappears. Stabbing pain **adjust to a VERY sharp pain. Add 'palpitations'.** Q6 the new responses (effect of medication) needs to stand out more (agreed **a box** would be fine). Q7 Urination: modify to **'very' little pee.** Q8 **add 'allergy'.**

S1-Q5.1a. Clarity: Covers all the points and easy to ask and clear to go through; a logical flow. Everything is straightforward (answered same to all of aid). It is clear to me
NFIP: (Add display images prompt to Qs.3,5,6)

S1-Q5.1b. Flow: "Links together well"
NFIP: **Move: 'Is there pain anywhere else' from Q2 pain assessment to Q1.**

S1-Q5.1c. Navigation: "Yes, definitely (very easy, selected 5), clear headings, and sections are separated by dividing lines. The start is concise and to the point." Comfortable.

Figure 8.42 Staffs' comments grouped by question and reduced for further analysis

Figures 8.43-8.44 depict the analysis of staff's responses. Unanimously, staff felt they did not need a form to capture patients' responses (their existing forms sufficed); there was no missing information in the questions and nothing was unclear - clarity was said to be either helpful (71%) or very helpful (29%). They also unanimously favoured the phonetics style adopted (and did not want the symbols usually used in dictionaries – which some commented they did not understand) and cited the following as helpful (43%) or very helpful (57%):

- the simpler English phrases (alongside the complex terms) which were translated into phonetics which they could assess and alter, if required (with associated adjustments to the phonetics);
- increasing the number of participants for testing the phonetics;
- the phonetics response checkers that helped to identify a patient's response to a question and enabled staff to validate the response by repeating the phonetics back to the patient (the reverse of the patient repeating back the instruction; study 2);
- Navigation and flow.

Unanimously, but in differing ratio's the following were favoured:

- The preamble was very helpful (57%) or helpful (47%); and
- Underlining and italics to associate phonetics and English words was helpful (57%) or very helpful (47%);

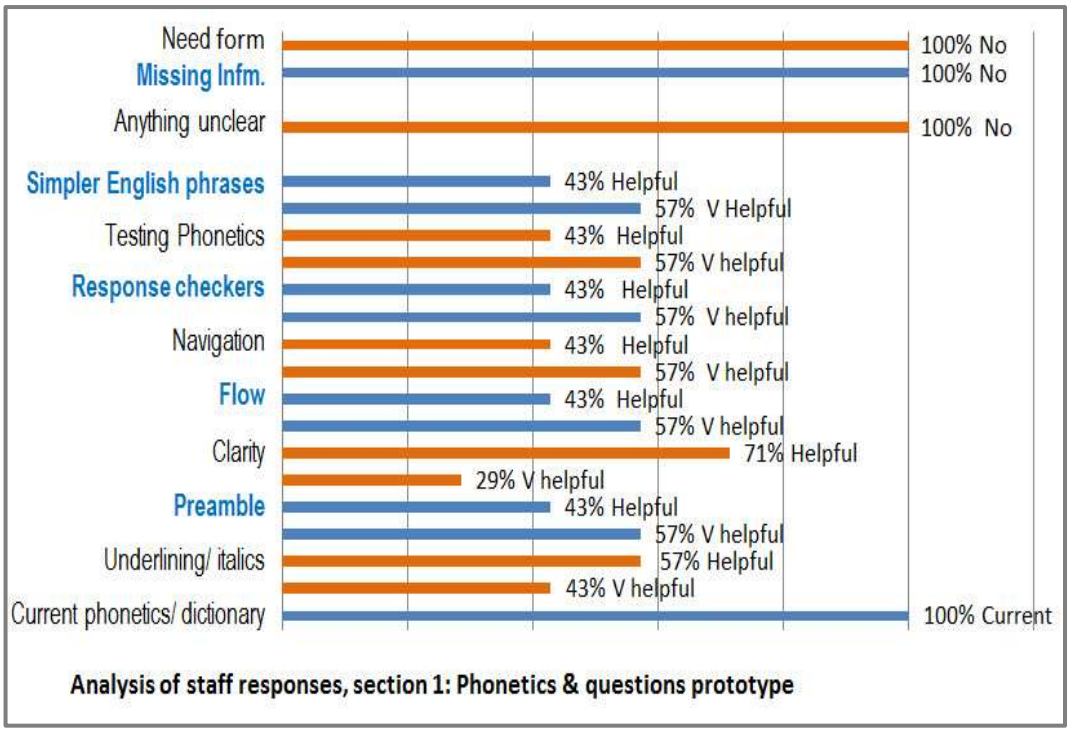

Figure 8.43 Analysis of staff's responses during beta-testing.

Staff unanimously favoured a 10-score pain scale (Figure 8.44; although a 3-score scale was commonly used for simplicity in elderly care and for children). Adding phonetics (Hindi) to the scale was favoured by 14%, however, 86% were not in favour (as the aim was to encourage English-learning). Unanimously, staff approved labels that identified parts of the body, data in list formats (rather than paragraphs) and the balanced use of emboldened text although 14% also favoured the phonetics might be emboldened (i.e. the 'speaking' sections).

The font and size (Arial 10.5) and the font colour scheme in use (deep blue and black) were favoured by 86% as clear whilst 14% preferred Arial 11 (to which the text was altered) and a black and emboldened black (English text and phonetics, respectively).

The views of the majority were accommodated in the design upgrades except for an increase in font size to Arial 11 to aid clarity. The latter provided challenges to retaining a 2-page A4 layout whilst reformatting the staff's section of the aid. In order to accommodate any overflow of data, the author asked whether it was acceptable to use an A3 format folded into A4 and this was fine with all the staff.

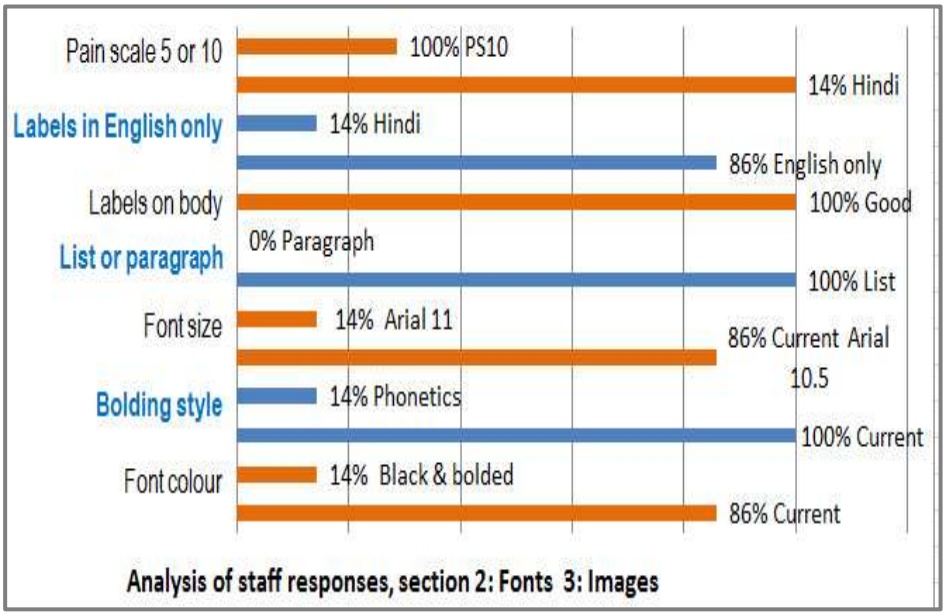

Figure 8.44 Analysis of staff's responses during beta-testing.

8.4.6.5. Findings

The findings combine the views of staff and the section on phonetics includes 3 indigenous adults. Most of the design elements were considered favourably and are summarised in the order of the questions.

Comments and Suggestions

Participants' comments[3] are combined and summarised: their suggestions are in bullet points. The findings were reviewed systematically for design adjustments: green denotes the modification effected; blue the researcher's comments (reminders or reasoning). Suggestions made at the late interviews (red) remain to be done.

Section-1: QUESTIONS-PROTOTYPES

1. Phonetics

As testing and analysis progressed, fewer words sounded incorrect (Appendix-D26.1). By the last interviews, new staff pronunciation progressed quite smoothly, although the concept was new and the sounds strange. One, a German doctor, added an interesting dimension as English pronunciations differ between nations, but he did not feel daunted: it was "*quite straightforward*" [3D] and he preferred no hyphens or minimising hyphens. The GP's pronunciations (Iranian origin) were clearest, possibly due to overlapping words and accents with the Indian Subcontinent.

An nurse commented: *"I think twice seeing aa"* and *"I ignore superscript" [4N].* One doctor commented on the potential for the aid (as did a colleague during alpha-testing): *"This is brilliant. I was thinking of doing an apps business and this would be ideal for it"* [7D].

2. Phonetics presentation

Unanimously: ***"Keep to the current method"*** [5PM, 7D] (not the transliteration method) and ***"Keep it simple"*** [3D].

"What you've done already makes it easy to read and will make it easy to pronounce as it is; dictionary terms are not user-friendly" [2PT].

[3] Legend: D=doctor, PT=physiotherapist, N=nurse, PM=paramedic, PH=pharmacist

- Minimise hyphens [7D].

3. Underlining, italics (relating English-Hindi words)

"Really helpful" [6PH], "*We want these"* [2PT].

- A legend/key explaining the underling and italics was needed.

4. a. Setting the Scene

Unanimously*: "Good" [5PM], "Helpful" [7D], "Happy with the preamble*" [4N].

"It's a nice way of making a person understand. I think that's very self-explanator." [2PT].

- "**Add bullets** and put 'you may use these pictures to help' in **the next paragraph"**.
- *"Make a **larger space, use full stops and sentence case*** [1D] (to separate thoughts so that sentences to be repeated can be easily selected).
- Alter '*I speak a little Hindi' to: **"I don't know much Hindi, I am going to use this paper to help us**". **"Emphasise very little"** (Hindi) so patients understand to speak slowly* [1D].
- *After 'OK?' to add **'Do you understand?'*** [7D].

b. Anything missing

Majority view: "Very little"

- Shooting pain: *"the important thing is **it's a moving pain"*** [6PH]
- Throbbing is a ***"a pulsing pain"*** [6PH]
- Stabbing pain adjust to a **"VERY sharp pain"**
- Add 'palpitations'
- Medication effect: Make the new response checker stand out more (agreed **a box** would be fine).
- Urination: modify to '**very' little pee**
- Add '**allergy'**.

5. a. Clarity

"Everything is straightforward" [3D], *"It is clear to me"* [4N]

"[It] Covers all the points and is easy to ask and clear to go through; a logical flow" [2PT].

b. Flow

"Links together well" [2PT]

- Move 'Is there pain anywhere else' to Q1 from Q2.

c. Navigation

"*Comfortable*" [7D]

"Yes, definitely (very easy, selected 5), clear headings, and sections are separated by dividing lines. The start is concise and to the point" [2PT].

d. Response checkers

Majority view: 'fine', however, one felt there was "No need" [7D] for these.

"Page 2 is organised really well. Excellent" [2PT].

e. Testing phonetics with staff and more indigenous people

This was received positively: *"Good idea"* [1D], *"Fine"* [4N]

"That's great; it's the only way to know for sure (pronunciation is correct); it gives more confidence, definitely, and people (staff) will like feedback" [2PT].

f. Simpler English explanations (for complex terms)

Generally viewed favourably: *"Helpful to some extent"* [1D]

"That's good for clarity, clarity of information back; yes" [2PT]

g. Removing duplications (in 'Kind of pain')

Views varied on removing 'crushing'*: "Can be helpful"* [1D] *to*

"Not important; these (current list) *are the ones used most often"* [4N]

- Crushing is **"like a heavy weight on the chest"** [5PM] (this explanation was adopted).
- Nagging could be 'irritating', a constant unremitting pain

6. Anything unclear

Majority view: No. A very helpful insight in medication instructions was provided by the pharmacist:

"All tablets have to be with a drink, you don't need the drink (image). It's the food (that's important): ***with or after food, a long time after, like 2 hours after,*** *on an empty stomach. That's hard to explain even to English speaking patients. Empty stomach=2 hours before food, whereas after food=with food"* [6PH].

Medication labels and instructions were modified with this advice.

7. Anything missing

Majority view: No (but this was tested again in section 3.Q4b)

8. Anything extraneous:

Majority view: No, although *"Some points are not used by physio's practice, like prescribing. But we can pick and choose; it's easy to choose"* [2PT].

9. **Form for department (for patients response)** Unanimously: Not required.

Section-2: FONTS

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10. Font colours

Majority view: *"Blue and black works"* [5PM]

"Prefer the colour, it looks good, particularly if some words are the same" [2PT]

Black only was preferred by one staff [6PH]. The implication was the phonetics would have to emboldened throughout the text to differentiate the spoken parts. This opposed the majority view on using bold, thus, this was not altered.

11. Use of bold

- Use ***"Less bold"*** [1D].

Bold was reduced, the 'Kinds of pain' and 'Symptoms and side effects ' were ordered alphabetically. Bold was confined to sections headings except for 'Occurrence of pain'. These modifications met with favourable responses:

"Bold little headers are helpful and the eyes are drawn immediately to them" [2PT].

"Good to navigate" [4N].

"Bold heading as current is good" [5PM].

One participant's 1st choice was 21b (blue emboldened phonetics, were *"definitely helpful")* and his 2nd preference was 21a (the current blue but unbolded) [6PH]. (Bolding one word in lists was iteratively re-tested later; the feedback was: "*Fine as it is, not needed.")*

12. Font type/ size (Current Arial 10.5)

Majority view: Current Arial 10.5 was *"clear with lines and spacing"* [2PT] however, one participant felt the smaller the better like Arial 10 [D1]. A colleague also liked Calibri 10 line spacing "*It's easy to read 10.5 or 11"*. However, for 1 participant **Arial 11 was preferred,** *"My eyes give me trouble"* [4N].

The designs were upgraded to Arial 11. A balance had to be maintained

between content, spacing, information arrangements and fitting content on to 2 sides of an A4 page (desired by all staff, Calibri spacing could not accommodate all these needs).

13. Information arrangement (paragraph vs. list)

Unanimously: The list was best. *"100% quicker, easier to read, in a paragraph there is delay and mistakes possible"* [2PT] between one line and the next.

One A4 sheet, *"Keep on 2 sides"* [6D], but A3 folded was fine.

Section-3: IMAGES

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14. a. Labels on body. Unanimously liked: "Fine", "Good"

"Yes, good size picture, arrows clearly point to key parts, wording is easy, alternate colours good" [2PT].

b. Labels in English only

Majority view: *"Very helpful, should be only in English"* [1D]

"Labels in another language are not necessary, but not a problem. If pictures are obvious, shouldn't need other language labels" [5PM].

However, one participant suggested including Hindi phonetics.

15. Pain score 10 with words

Majority view: Pain score 10 was fine or preferred. *"I love 'happy'"* [4N].

- A doctor critiqued the image for score 10: *"Should be **crazy** with pain, **screaming**, **make a square mouth"*** [1D].
- Tidy pain score questions (separated into listed sentences.)

16. Relating patients responses to response checker (p.1)

Unanimously: "*Yes, I like that, it's quite easy to navigate"* [4N], *"No trouble"* [5PM].

[**Add '4' to** response checker p.1]

a. Relating images and questions. Unanimously: It was fine; *"No trouble".*

b. Anything missing (like breathlessness?)

Generally: Little was missing

- Include breathlessness [1D, 3D, 4N, 6D]
- Add breathe in/out [2PT]

c. Usefulness of labels (to patients): Unanimous view: Yes

17. Other comments and suggestions

"I want to use it" [4N], *"Well designed, in every area"* [5PM]. "*This would be brilliant in apps"* [7D]

- *"Show stools like a puddle"* [1D].
- *"Add Sit/ stand up in Hindi"* [2PT].
- *"Keep it as simple as possible"* [3D].
- Include Vomiting, Diarrhoea, cough, temperature [3D]..
- In images-prototypes: *"Put translation on pain score"* [6PH] and the (tap) *"drips and flow should be in the same direction"* [7D]

Sections 6 and 7 of the pain prototype were merged (what reduced the pain and current medication), so overall, the sections were reduced to 7.

Future Design Adjustments

Due to the delays, the following suggestions have yet to be implemented and tested:

- Shorten the preamble to: "I am speaking slowly, OK teekh hai? **Do you understand samaj aya?** Learn English" [7D].
- Minimise hyphens in phonetics.
- Q2. Children's pain score: review Wong and Baker chart.
- Q4. Add Do you have pain when you breathe
- Q6: Add paracetamol to 'Which medication are you taking'? and whether patient is compliant with medication.
- Q7. Insert 'Dizzy' in symptoms list (author's error).
- Add cold, runny nose (possibly images).
- Add Hindi phonetics for Breathe in/out?
- Images: Note the remaining requests from Q17.
- Overall: Integrate pictorial images and text for staff copy, *"it would be more intuitive"* [7D], e.g. *Bahuth pathla* watery stools (Symptoms/side effects: toilet). Keep patient version the same.
- In future would like a paediatric specific aid [7D].
- Aid in Arabic and Polish [1D]

8.4.6.6. Discussion

Participants' views were very valuable and, encouragingly, generally favourable. Where staffs; views differed, the majority's views were accommodated (Norman 2005). However, the minority preference for Arial 11

was implemented for ergonomic reasons (Bailey (2005). The larger pitch required a careful readjustment of information to keep to '2 sides' of an A4 sheet. Figure 8.45 depicts extracts of iterative upgrades. One of upgrades to be implemented (integrating phonetics and questions for the staff copy) will resolve other requests like adding Hindi labels.

Figure 8.45 Pain questions-prototype-2 (p1 & 2, extracts): beta-testing adjusted iteratively

The upgrades to prototype-3 are described next.

8.4.7. Prototypes-3 design upgrades

The feedback from the iterative testing was collated and worked through systematically to create new designs or modify existing ones (Adobe Photoshop and photography). A new design medication 'do's and don'ts' was created based on guidance in the BNF and feedback from indigenous elderly people (8.4.5.4) and comments by the pharmacist (drawing on labels, study 2). Prototype-3 design upgrades are depicted in Figures 8.46-58 (for larger images see Appendix-D27).

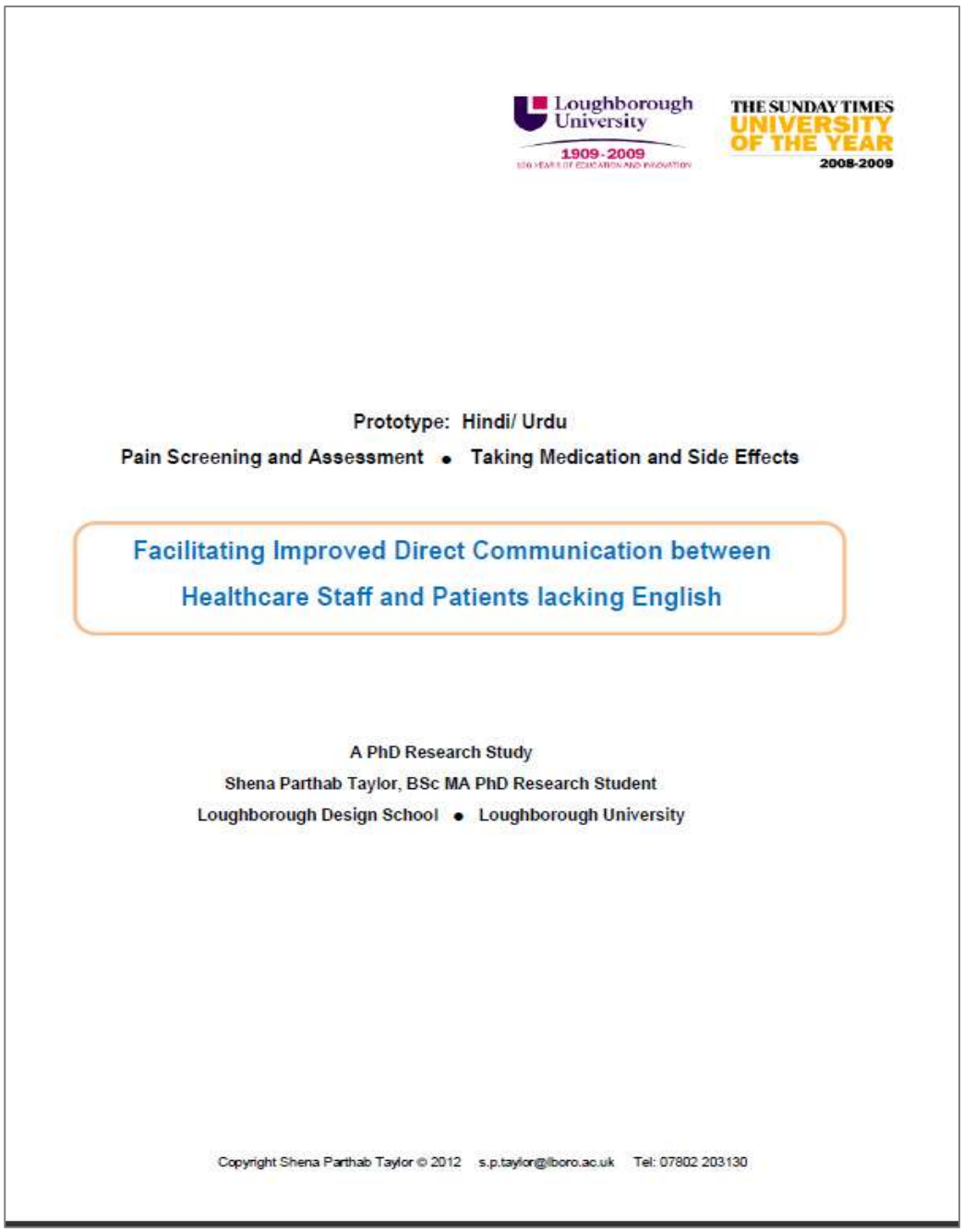


Figure 8.46 Cover sheet identifying the study

A SIMPLE GUIDE

Pain Screening and Assessment • Taking Medication and Side Effects

HINDI / URDU

This aid seeks to facilitate a greater degree of direct communication between Healthcare Staff and 1st generation patients lacking English, by encouraging patients to directly engage in communicating their difficulties and to speak as much English as they know. The aim is to motivate patients to learn English for the future and to save time in the delivery of care.

There are 2 sections which complement each other: Text for Staff to ask questions; and Images for Patients to help them point out their difficulties. The images have been tested twice with people from the Indian Subcontinent lacking English and/or literacy, with Indigenous Elderly and with NHS Staff. To help staff in pronunciation, the phonetics have been tested with NHS Staff and Indigenous English persons 10 times and adjusted.

Hearing our voices pronounce words in a new language sounds strange initially, but this should ease after a few times especially as the message is increasingly understood by the patient. You might get a smile in surprise that you are communicating in their language! Likewise, patients lacking English often feel shy hearing themselves pronounce unaccustomed English words. Research reveals they often know a range of basic English words, and encouraging them to use English and to engage directly with yourself will help to build their confidence in learning more English, with future benefits to themselves and for healthcare.

Pronouncing the phonetics

Naturally, you will ask whether the patient speaks English. If little or none, begin with *"Do you understand a little Hindi/ Urdu?*

- **Speak the words in blue only** which express the questions in English. Meanings of key words are denoted by matching underlining or *italics*.
- **Pronounce words evenly and normally** as you would in English - no part of the word is 'silent'. The - dash is to help you achieve an even pronunciation.
- Intonation of questions is identical to English.
- aa double alphabets extend the sound a little
- r is emphasised lightly as in *bring* or *car*
- g pronounce as in *begin* or *go* (not as 'j' in *gin* or *gym*)
- u pronounce normally as in *hum, ugh* (not as 'you' in *humour*)
- [ ] or ( ) brackets provide guidance or options, e.g. *display images*, *if 'no' go to section 7, etc.*
- *Response Checkers* on the right on each page provide a quick guide on replies likely to be received, and words you might like to use or to emphasise, e.g. every day. *Research reveals that people lacking English often know many basic English words.*

  On page 1 *Response Checkers* words are organised in simple categories (numbers, times of day, etc.), and on page 2 they are arranged alphabetically *phonetically* by keyword so the reply heard can be co-related to the question for verification, e.g. Page 2, *Other Difficulties:* pi-sharp urination >> urination question.

Figure 8.47 Inside cover sheet: the purpose of the aid and a guide to phonetics (requested by staff)

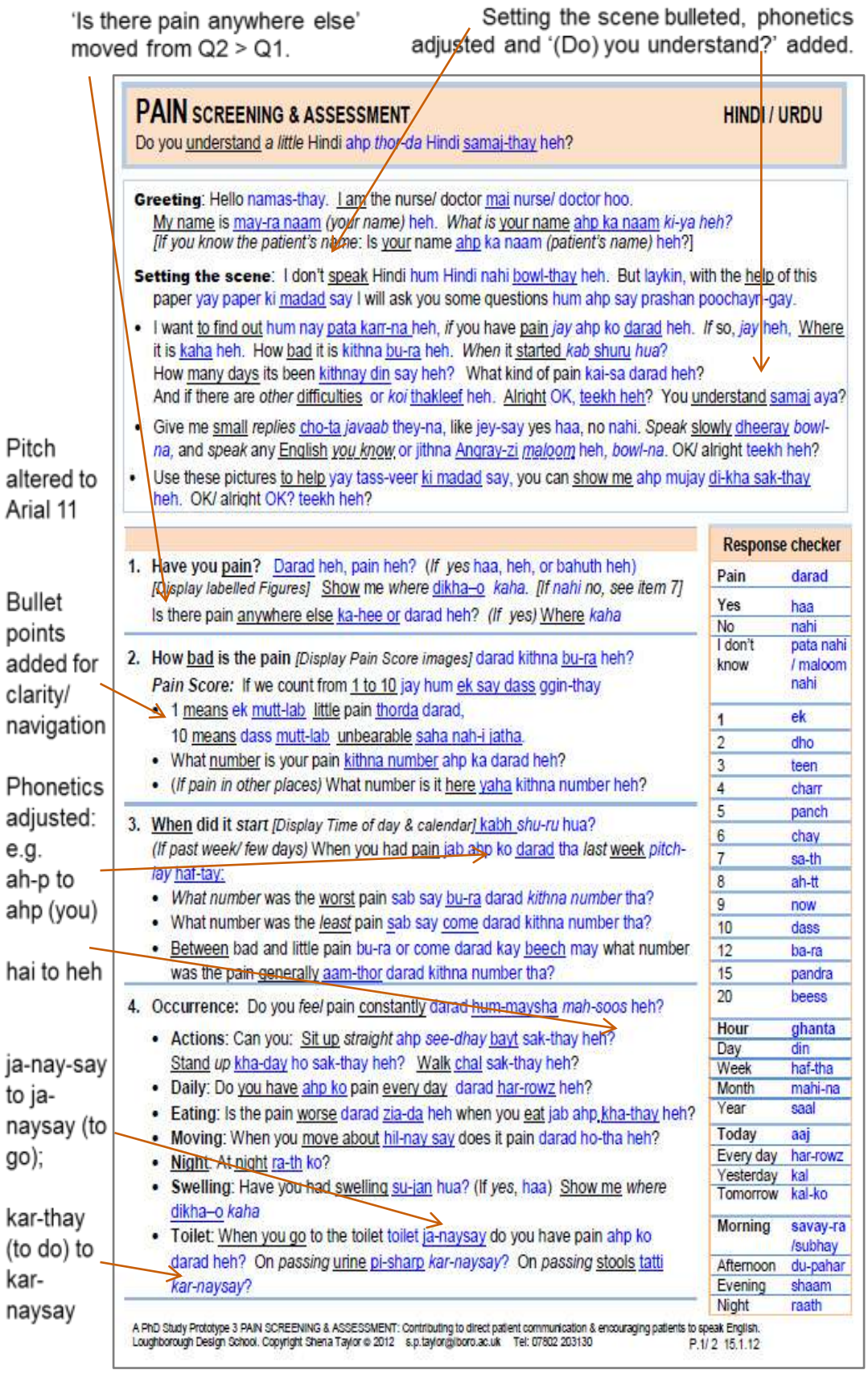


Figure 8.48 Pain questions English-Hindi-prototype-3 (p.1) upgrades.

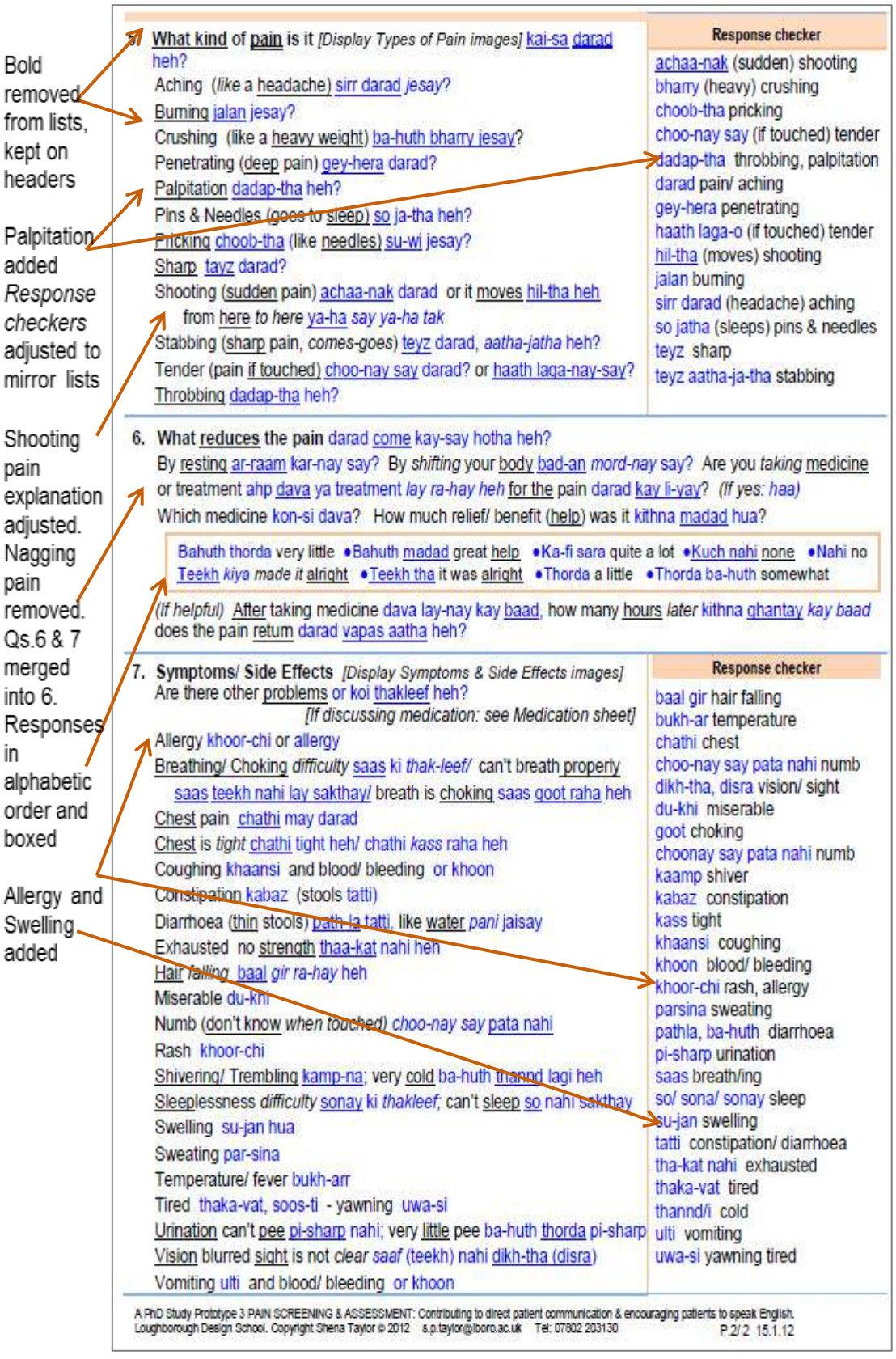


Figure 8.49 Pain English-Hindi questions-prototype-3 (p.2)

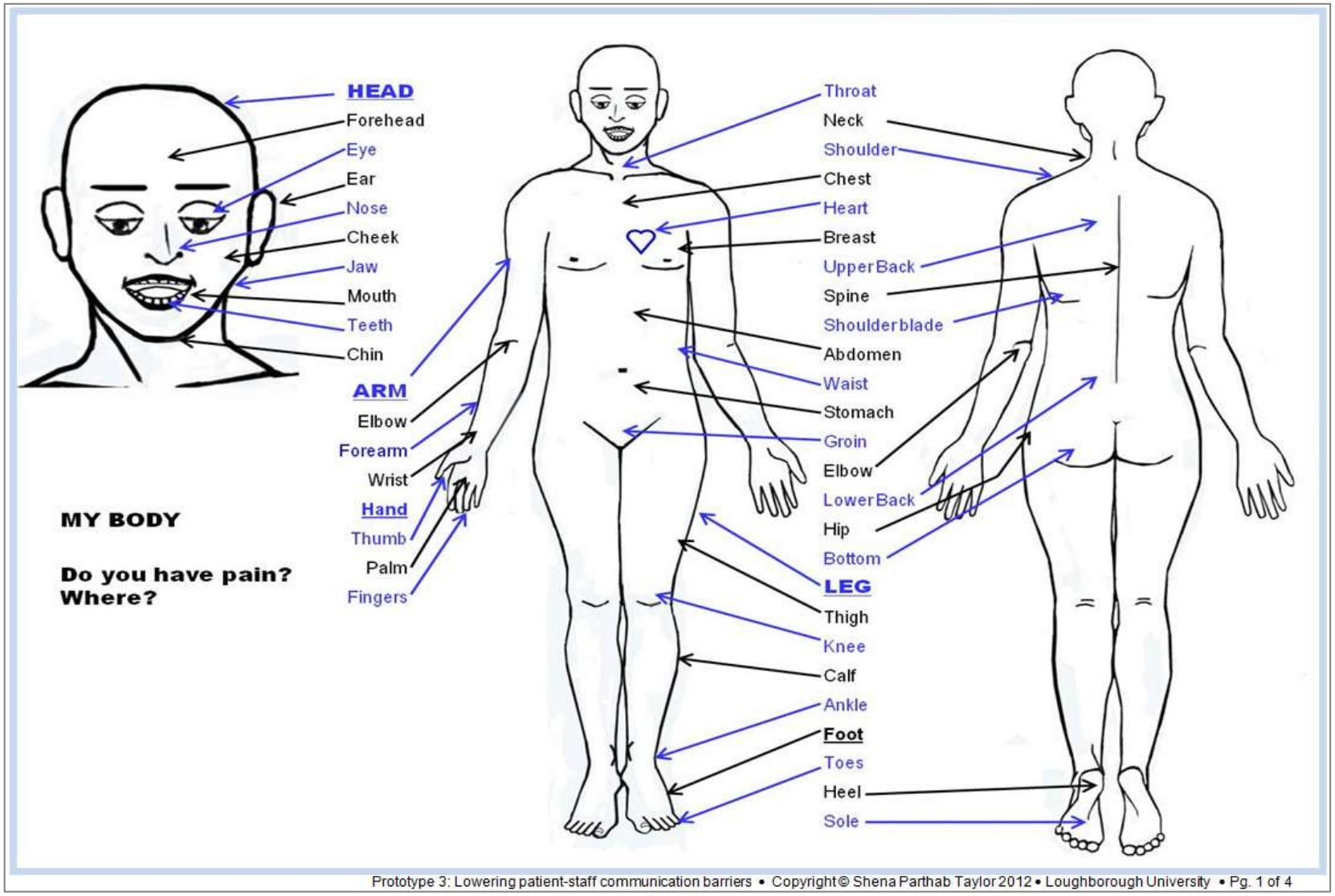


Figure 8.50 Pain pictorial-prototype-3 (p.1). Heart symbol and label added

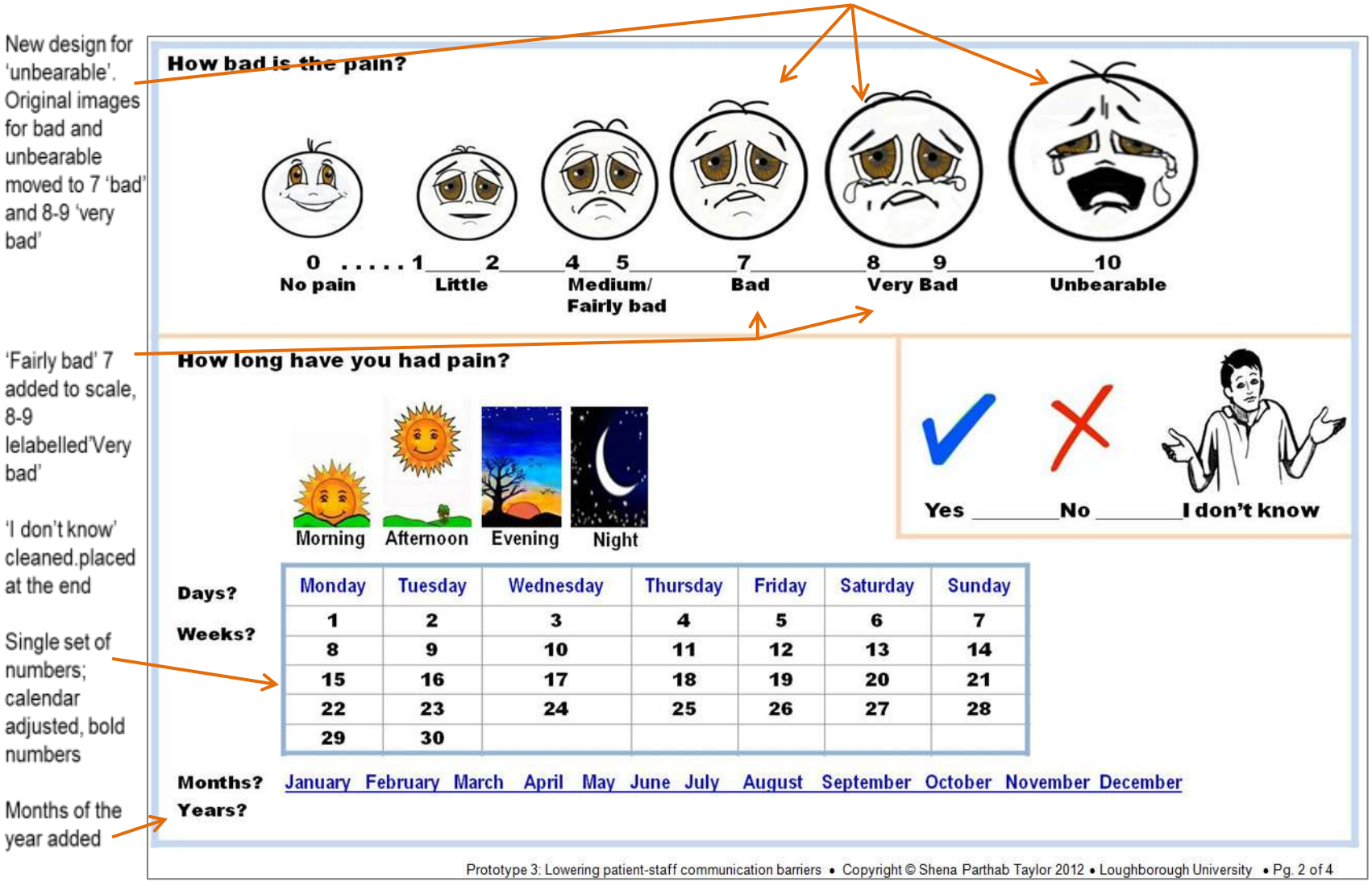


Figure 8.51 Pain pictorial-prototype-3 (p.2). Note alterations to Pain score.

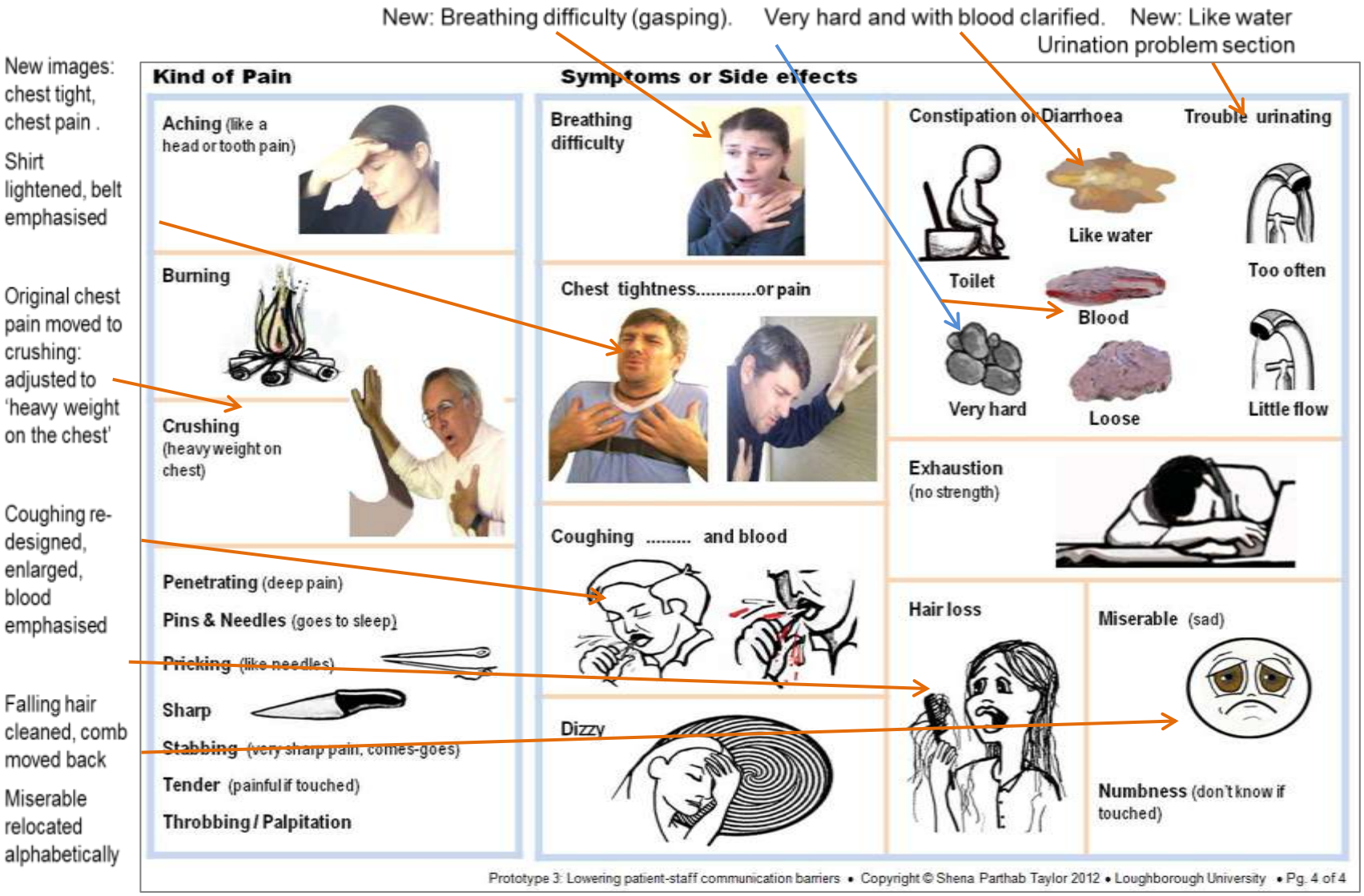


Figure 8.52 Pain pictorial-prototype-v3 (p.3). Kind of pain and Symptoms: images were cleaned, enlarged, re-designed and

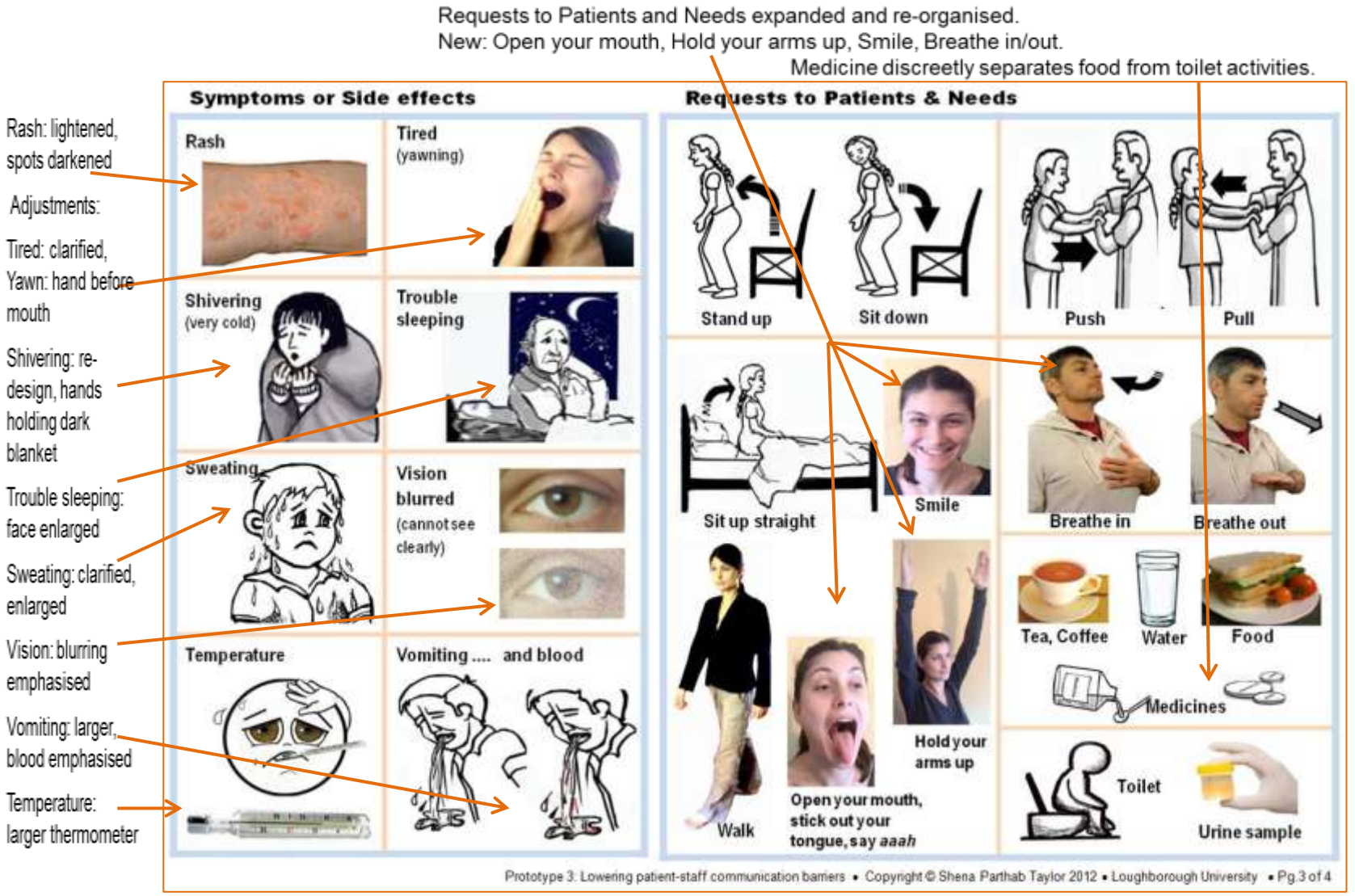


Figure 8.53 Pain pictorial-prototype-v3 (p.4). Sections re-organised and expanded.

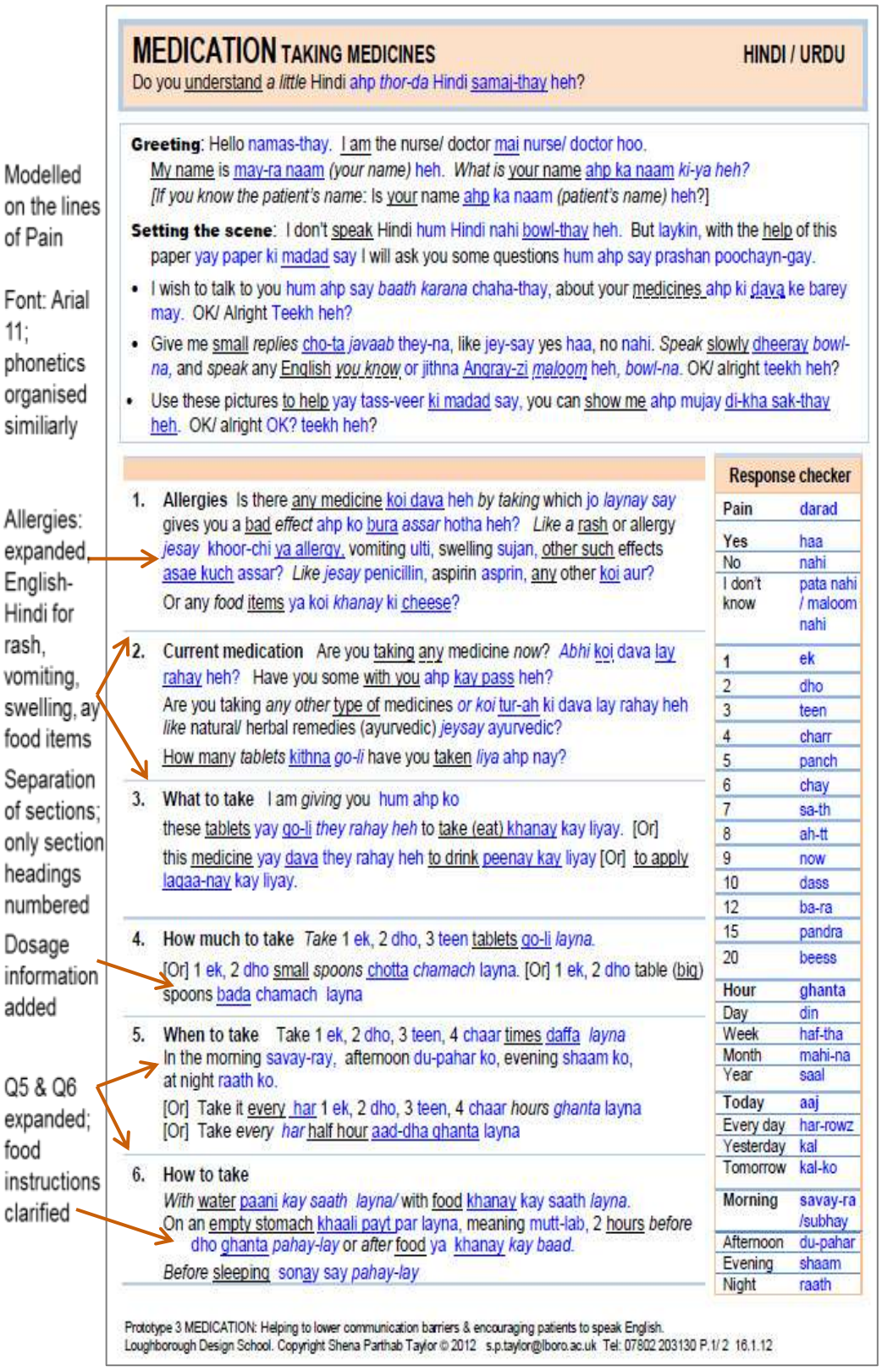


Figure 8.54 Medication English-Hindi questions-prototype-3 (p.1)

Page 2 re-designed completely

Clearer sectioning.

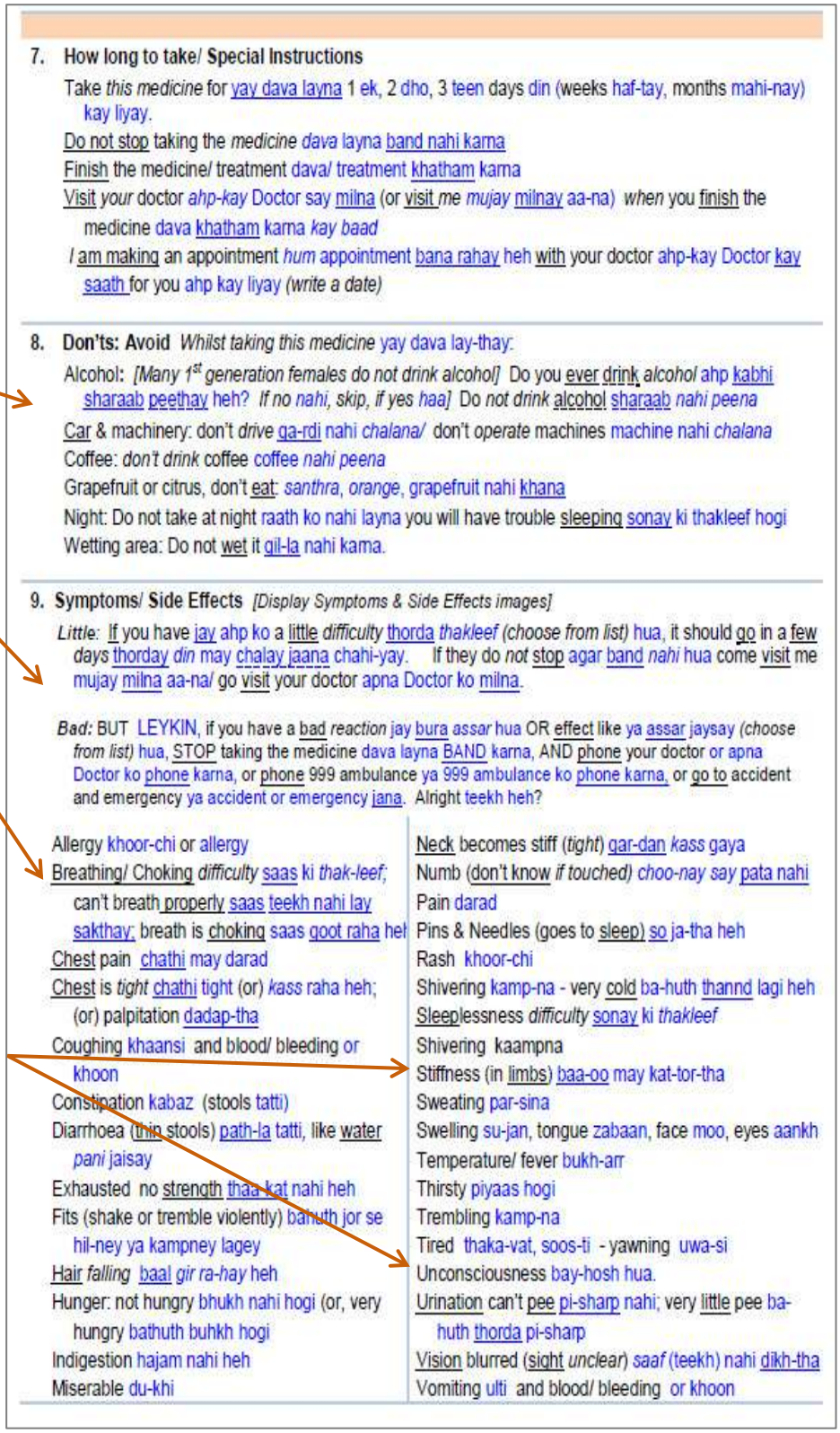
Q.8 expanded

Q9. New format:

Instructions for little & bad side effects

List in alphabetic order, as response checker in pain

New: Fits, hunger, Indigestion, stiff neck, stiffness, thirsty, unconscious



7. How long to take/ Special Instructions

Take *this medicine* for yay dava layna 1 ek, 2 dho, 3 teen days din (weeks haf-tay, months mahi-nay) kay liyay.

Do not stop taking the *medicine dava layna* band nahi karna

Finish the medicine/ treatment dava/ treatment khatham karna

Visit *your* doctor *ahp-kay* Doctor say milna (or visit *me mujay* milnay aa-na) *when* you finish the medicine dava khatham karna *kay baad*

I am making an appointment *hum* appointment bana rahay heh with your doctor ahp-kay Doctor kay saath for you ahp kay liyay *(write a date)*

8. Don'ts: Avoid *Whilst taking this medicine* yay dava lay-thay:

Alcohol: *[Many 1st generation females do not drink alcohol]* Do you ever drink *alcohol* ahp kabhi sharaab peethay heh? *If no nahi, skip, if yes haa]* Do *not drink* alcohol sharaab *nahi peena*

Car & machinery: don't *drive* ga-rdi nahi *chalana/* don't *operate* machines machine nahi *chalana*

Coffee: *don't drink* coffee coffee *nahi peena*

Grapefruit or citrus, don't eat: *santhra, orange*, grapefruit nahi khana

Night: Do not take at night raath ko nahi layna you will have trouble sleeping sonay ki thakleef hogi

Wetting area: Do not wet it gil-la nahi karna.

9. Symptoms/ Side Effects *[Display Symptoms & Side Effects images]*

Little: If you have jay ahp ko a little *difficulty* thorda *thakleef (choose from list)* hua, it should go in a few *days* thorday *din* may chalay jaana chahi-yay. If they do *not* stop agar band *nahi* hua come visit me mujay milna aa-na/ go visit your doctor apna Doctor ko milna.

Bad: BUT LEYKIN, if you have a bad *reaction* jay bura *assar* hua OR effect like ya assar jaysay *(choose from list)* hua, STOP taking the medicine dava layna BAND karna, AND phone your doctor or apna Doctor ko phone karna, or phone 999 ambulance ya 999 ambulance ko phone karna, or go to accident and emergency ya accident or emergency jana. Alright teekh heh?

Allergy khoor-chi or allergy
Breathing/ Choking *difficulty* saas ki *thak-leef;* can't breath properly saas teekh nahi lay sakthay; breath is choking saas goot raha heh
Chest pain chathi may darad
Chest is *tight* chathi tight (or) *kass* raha heh; (or) palpitation dadap-tha
Coughing khaansi and blood/ bleeding or khoon
Constipation kabaz (stools tatti)
Diarrhoea (thin stools) path-la tatti, like water *pani* jaisay
Exhausted no strength thaa-kat nahi heh
Fits (shake or tremble violently) bahuth jor se hil-ney ya kampney lagey
Hair *falling* baal *gir ra-hay* heh
Hunger: not hungry bhukh nahi hogi (or, very hungry bathuth buhkh hogi
Indigestion hajam nahi heh
Miserable du-khi
Neck becomes stiff *(tight)* gar-dan *kass* gaya
Numb (don't know *if touched) choo-nay say* pata nahi
Pain darad
Pins & Needles (goes to sleep) so ja-tha heh
Rash khoor-chi
Shivering kamp-na - very cold ba-huth thannd lagi heh
Sleeplessness *difficulty* sonay ki *thakleef*
Shivering kaampna
Stiffness (in limbs) baa-oo may kat-tor-tha
Sweating par-sina
Swelling su-jan, tongue zabaan, face moo, eyes aankh
Temperature/ fever bukh-arr
Thirsty piyaas hogi
Trembling kamp-na
Tired thaka-vat, soos-ti - yawning uwa-si
Unconsciousness bay-hosh hua.
Urination can't pee pi-sharp nahi; very little pee ba-huth thorda pi-sharp
Vision blurred (sight *unclear) saaf* (teekh) nahi dikh-tha
Vomiting ulti and blood/ bleeding or khoon

Figure 8.55 Medication English-Hindi questions-prototype-v3 (p.2)

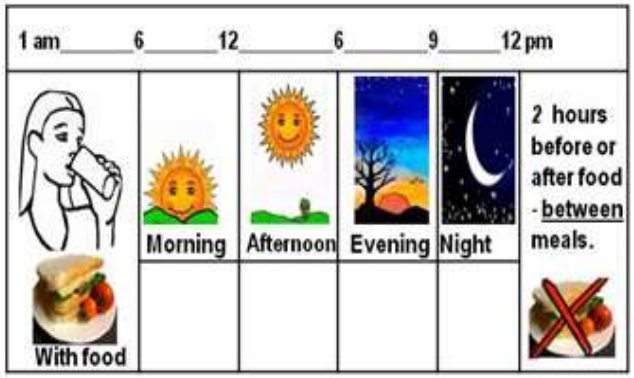


Figure 8.56 Medicine label-3 redesigned: glass of water removed, with/ without food emphasised

The cheerful sun was used to add joy to the design to motivate patients to take their medication. Image from labels were repeated on the list to nurture familiarity.

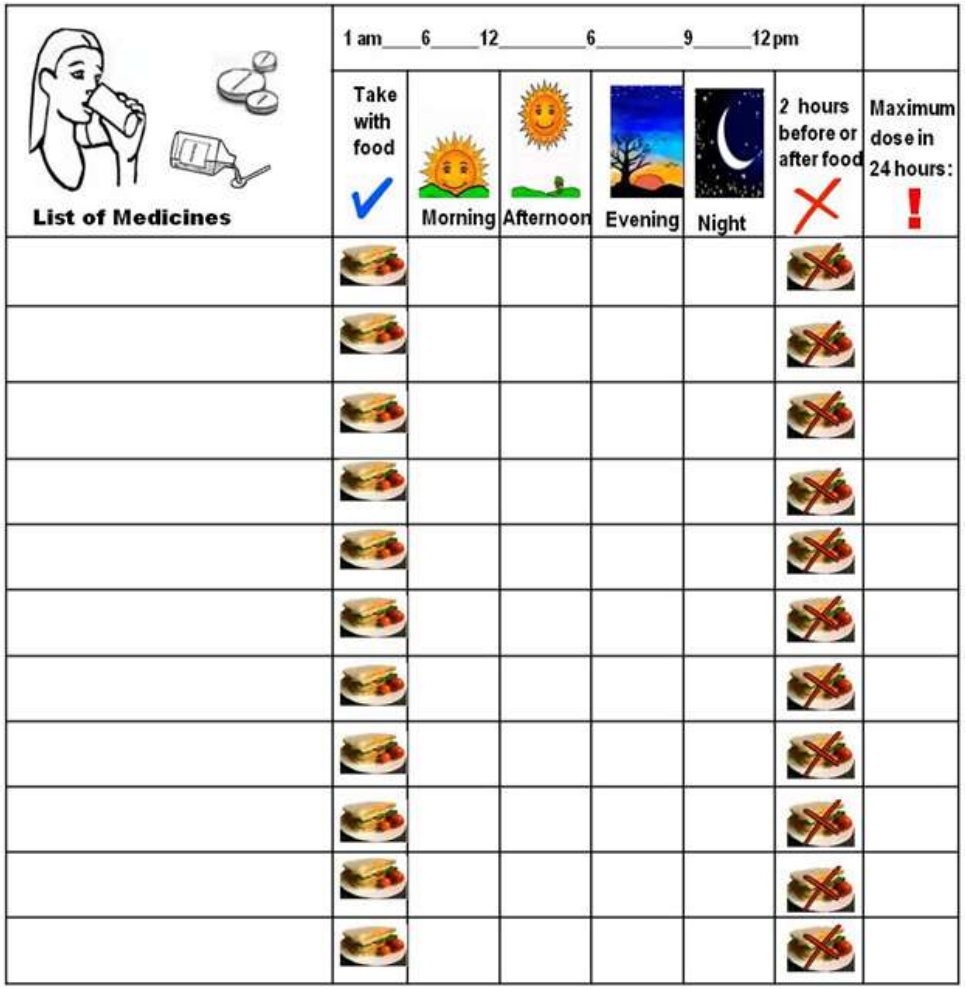


Figure 8.57 Medication list-3: images repeated for familiarity. Food instructions emphasized, maximum dosage added

Red used to symbolise warning/ danger emphasised by a X also associated with 'wrong'

Labels emphasise and add clarity

Blue used as a peaceful colour & echoes the NHS logo colour; red emphasises 'danger'.

Food instructions are emphasised.

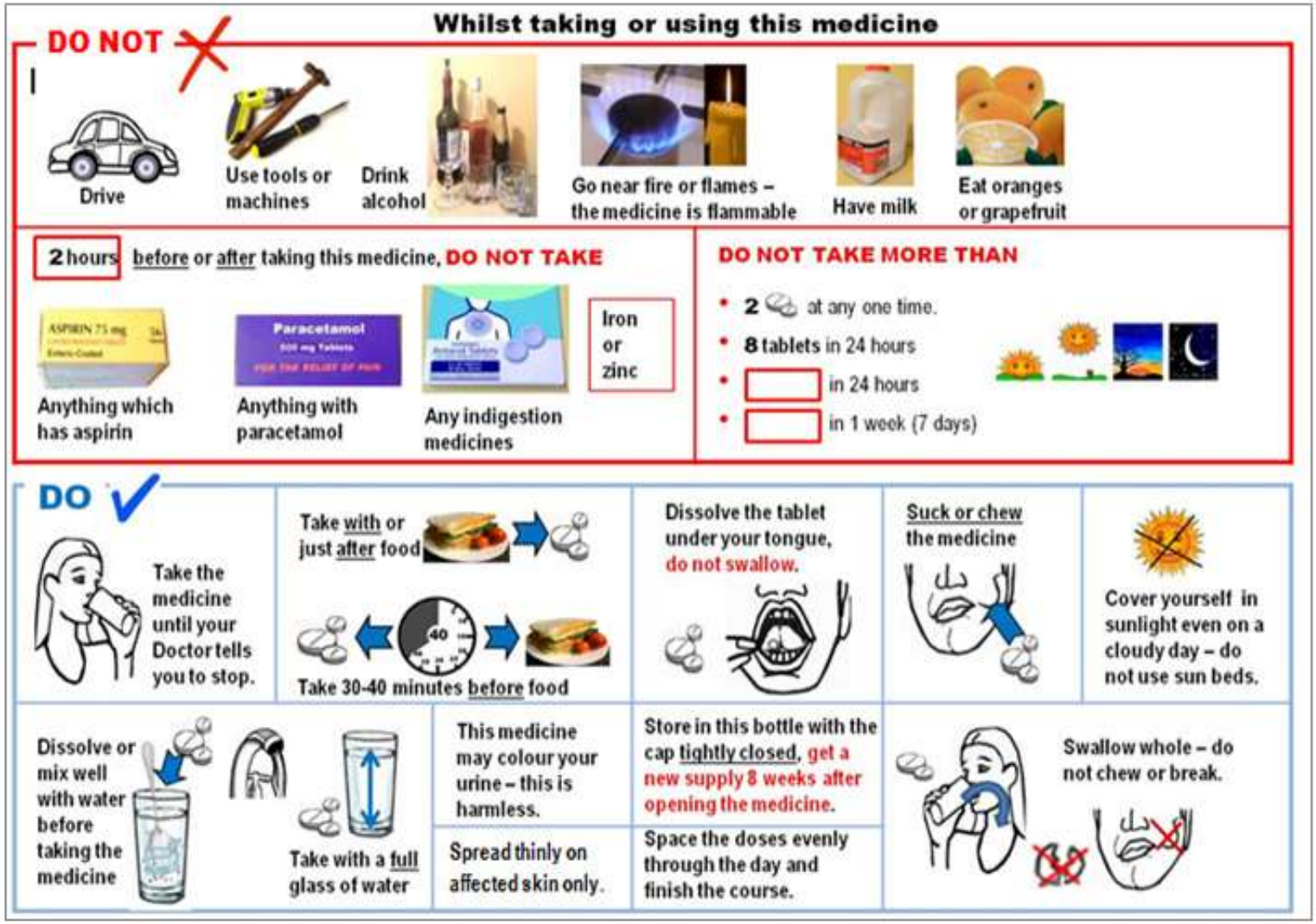


Figure 8.58 Medication guidance: New page; note images are repeated and the colour coding.

8.4.8. Final-testing: NHS Staff

This stage of the testing was to gain real-time feedback and to note what staff actually did. There was no interview but an evaluation form accompanied the prototypes.

8.4.8.1. Participants

The same 7 staff from beta-testing participated.

8.4.8.2. Tools

The study tools included the prototypes identified above and a self-fill evaluation form.

Tools	Purpose	Critical feedback
C. Final test Staff 8-12 weeks		
Pictorial prototypes Questions prototypes Evaluation form (Medication labels/ list and instructions: some staff)	Testing with patients in real-time	Evalutation of usefulness, usability, navigation of information, preferences any other critique.

Following the design upgrades the prototypes were printed on A4 formats and laminated as staff requested and spiral bound (Appendix-D28) to prevent their separation during testing in busy departments. They were, in fact, stand-alone and would be used independently in future. Patient leaflets were printed on A3 satin-finish sheets and folded to A4 size.

Table.8.12 identifies the prototypes, their formats and distribution. Staffs' requirements varied and were accommodated as follows:

- Paramedic: No need for medication questions (Q6 under pain sufficed).

English-Hindi Pain questions were re-scaled to pocket-size and folded as an insert into the laminated pocket-size pictorial-prototype (Appendix-D28.1-D28.3).

- Doctor, Pharmacy technician: Medication labels were scaled to fit widely used simvastatin and aspirin packets which were found to be smaller

than many others; or to be stuck to a bottle.

- Pharmacy technician: Pages for medication instructions were also given.

Table 8.12 Prototypes-3 and tools used in final testing with staff

Prototypes-3	Topics	Format	Copies
Laminated & bound			
Cover sheet	Research topic	A4	6 + 1 pocket-size (paramedic
Guidance (inside cover)	Research purpose, Phonetics		6
Pain questions English-Hindi	Pain screening and assessment	A4 and 9.8x 18.5x 1.5 cm	6 + 1 pocket-size (paramedic)
Pictorial	Pain & medication questions illustrated		
Medication questions English-Hindi	Medication and side effects	A4	6 (not required by paramedic)
Patient leaflets	Pain & medication questions illustrated	A3 folded satin finish	6 inserts
Medication instructions BNF	Pictorial 'dos and don'ts'	A4 (pharmacist)	3 colour, 3 B&W
Medication labels (sticky)	Pictorial	7.2 x 3.7 mm (pharmacist, GP)	2 pages, cut to size
Medication lists	Pictorial list similar to labels	A4 (pharmacist)	6

- **Cover letter** (Appendix-D29)
- **Pictorial and Questions-prototypes-3:** The prototype were given to all staff and to the last 2 staff after beta-testing on the same day.
- **Questionnaire/ Evaluation forms** (Appendix-D30): had 5-scale Likert questions and some multiple choice, all with open comments, and elicited feedback on aesthetics, editorial feedback, usefulness, inclusivity and general comments.

8.4.8.3. Procedure

The author travelled to each work location and gave staff the prototypes to retain for 8-12 weeks to allow time to meet EMC patients (Indian Subcontinent) who lacked English and to test it with appropriate elderly patients. A doctor requested to retain the prototypes for another month. Thereafter, the forms and prototypes were

gathered, the data grouped under the appropriate questions in Word 2007.

8.4.8.4. Implementation

Some staff were able to contribute more than others for reasons of workload, time, access to EMCs, etc. For instance, one did not have appropriate EMCs patients admitted to her ward (stroke and elderly care) and an A&E doctor did not do much testing. Data was collated and analysed in Word and Excel 2007.

8.4.8.5. Findings

As mentioned, each member of staff was approached as an 'expert' in their role, and although there were problems and that new participants joined very late, the results of final testing were mixed and also encouraging. The feedback from 5 staff is set out, 3 of whom followed the research and 2 were new, one of whom was very keen on web applications.

1. AESTHETICALLY

- **Overall impression:** Unanimously, the aids were considered helpful, some thought the images interesting and attractive.
- **Font size** was appropriate, unanimously.
- **Images** were clear/ very clear for 80%, or fine.
- **Consistency of design and style** was considered consistent/ very consistent by 80%
- **Colours** were liked/ liked a lot by 80%. *"Very clear. Contrast is perfect"* [2PT] (Figure 8.59).

However, 20% selected '3' from a scale of 5, i.e. a neutral stance: the colours were neither liked nor disliked; the designs were neither consistent nor inconsistent; and images were neither clear nor unclear. This group represented those who said they did not have an opportunity to test the tools.

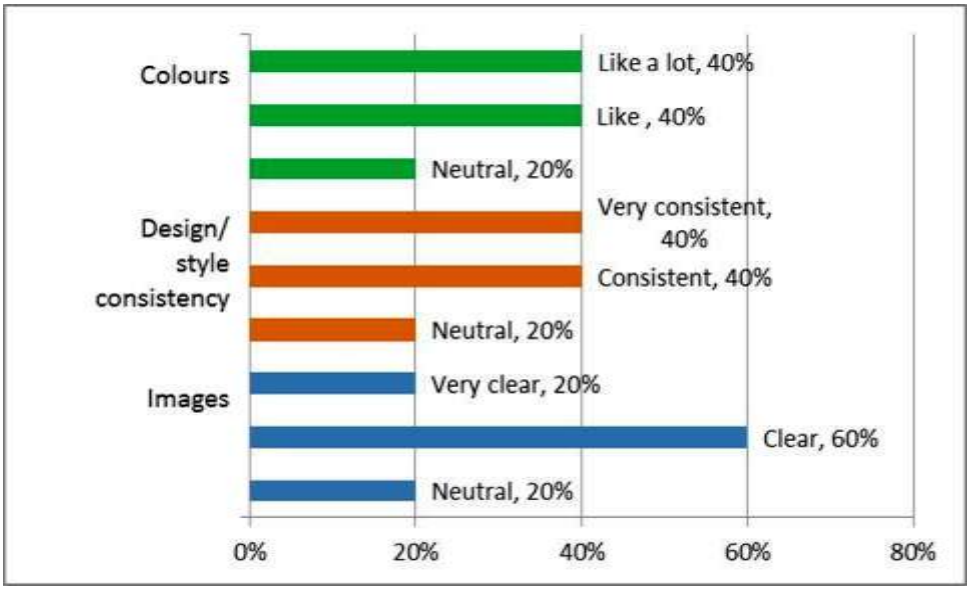


Figure 8.59 Aesthetic feedback from staff (final testing).

2. EDITORIAL FEEDBACK

80% of staff indicated that the image labelling was quite or very clear and appropriate; likewise the balance of images and data, "*Good*"; and th**e** mix of images:

"Illustrates the points well" [2PT]

"I would like the Hindi/Urdu translation on the picture as well" [7D].

3. USABILITY and INCLUSIVITY

60% of staff indicated that locating information was straightforward but was a little confusing for 40% (new participants, a lack of familiarisation).

- **Quality** and **usefulness** was good or very good (80%)
- **How EMC patients found the information.** Responses varied between fine (60%) and helpful (20%), and no response (20%). A GP commented it was:

  "Most useful in groups with no English, sometimes it was more confusing for groups who had some English" [7D] (a lack of familiarisation).

- **How indigenous patients found the information.** Responses varied between fine 40%, helpful 40% and no response 20%.
- **Website for access/printing:** Unanimously favoured as very helpful because it *"Would allow greater access but also cost savings as you would only print what you needed"* [2PT].

- **Other formats.** 80% wanted leaflets to give patients, 40% wanted a chart and pocket-sized cards.
- **Saving time.** 60% felt the aid saved time, 20% felt moderately so, 20% said not but this *"Would improve with future use"* [7D], (new participant).
- **Lowering anxiety** 80% responded moderately so, and 20% mostly, yes, one explained *"It was difficult to tell as patients weren't very anxious"* [2PT] (elderly care ward).

4. IN GENERAL

- **Staff's experience of participating in developing the designs:** Unanimously the response was enjoyable or **v**ery enjoyable: *"Was great. Thank you"* [2PT].
- **Whether more designs would be helpful.** 80% felt yes or very helpful, 20% were not sure (possibly). *"Obviously increasing the topic range would increase usage in the NHS"* [2PT]
- **Would more audio communication help** (in explaining the designs, study 2). 60% felt possibly, 20% yes, and 20% no. A comment was "*We do have a language line"* [2PT].
- **Usefulness.** Unanimously: the aids were useful to help them and patients.
- **Helpfulness if aids were provided to patients to improve English.** Unanimously the response was yes or definitely: *"Giving individuals the knowledge will better empower them and so may reduce inequalities"* [2PT].
- **What the aids helped to reduce.** Unanimously, they helped overcome poor English skills (language barriers), 60% also cited they reduced barriers for poor literacy, anxiety and frustration, 40% added poor hearing and 20% dyslexia**.**

5. OTHER COMMENTS

> *"The aid really helped during consultations with patients, who had very limited knowledge of English, like elderly patients from ethnic minority groups, specially Asian patients"* [1D] (GP).

On meeting, one doctor [3D] commented that he had shown the aid to nurses and they felt it would be very helpful.

A pharmacy clinical safety supervisor commented (not a participant):

> *"The medicines card was good but found the 'with food and 2 hours before and after food' confusing. The stickers are a nice option for tablet bottles etc."*

8.4.8.6. Discussion

Overall, the feedback was positive and encouraging, although there is much scope for improvement. Testing according to Morville's (2004) concept of convergence design and Wroblewski's (2004) facets of user-experience helped to produce very interesting feedback throughout the research. Using mixed hybrid techniques (Rohrer 2008l) like participatory A/B testing with open questions and some semi-structured interviews, highlighted what staff said and what staff did. They also highlighted the similarities between what EMCs and indigenous people did and did not understand, with an emphasis on similarity.

The results were consistent with those of study 2: empowering patients is the preferred option, in this instance, by encouraging them to improve their English. This was also true of responses from EMCs (Indian Subcontinent) who wanted a copy of the aid and the author to teach them English.

That one participant wanted Hindi/Urdu phonetics on the pictorial-aid indicated a design roll-back to prototype-v2 (Fig.8.36), and he also requested the staff questions and images be merged to be used more intuitively. Interestingly, the pharmacy supervisor appeared to agree. That the images were generally well-received concords with literature (see 7.4) and that there is a need for such aids in the NHS including the medication labels. The medication list emphasised by indigenous elderly people was not commented upon by staff. It might be possible that it is complicated, and/ or staff are not aware of this user perspective.

The A/B testing addressed the importance of correct interpretations. All staff agreed the aids could help lower language barriers and help a wider group of patients. Some comments made by staff during testing (they did not like to be laughed at) and the doctor who talked to nursing colleagues suggests that future research that used new concepts, like phonetics, amongst colleagues who are not participants, would find it helpful to gain more management involvement for widening the comfort zone amongst staff. It would have been useful to fill the gaps in the final testing with new participants, but this was not possible due to time constraints. More consideration needs to be given to merging information and more intuitive use. The pharmacist's inability to test the aid highlighted the difficulty in study 2: of engaging pharmacists in research.

There appeared to be a general lack of awareness of potential problems from changing demographics and high costs of interpretation, with the resulting impact on healthcare and social integration. Applications for funding medication appear to be disassociated from costs for interpreters (a different budget) which suggests insufficient lateral thinking amongst some senior staff. The methodology was scalable to include larger participant groups and participants from other EMC groups.

In considering the research questions, i.e.

RQ1	How might visual communication be manipulated to design and develop aids to facilitate more direct staff-patient communication for EMCs lacking English and to help lower language/ literacy barriers?
RQ3	How might the aids be designed to be inclusive of the needs of staff, EMCs lacking English and indigenous patient groups who share communication difficulties?
RQ4	How might an educative element be designed to motivate and facilitate English-learning beyond specific healthcare experiences?
RQ5	How might such aid(s) be designed to be useful and relevant across different healthcare departments and services?

the results suggested that:

RQ.1. Visual communication was the most effective when images were combined with text following the literature (Hull and Nelson 2005) and fonts were carefully selected (Bailey 2005). This provided clarity and suggested choices for patients to select words to express themselves (like types of pain). Also, the different types of images (emoticons, cartoons) were favoured by all groups and new concepts, like emoticons or image associations, were quickly picked up by EMCs who lacked English and/or literacy.

Phonetics was a new, innovative addition, the 'glue' that bonded visual communication and text to facilitate more 'direct' staff-patient communication whilst avoiding retention overload for staff and EMCs lacking English and/or literacy. Written phonetics facilitated and validated the spoken phonetics sub-levels of conversation. Importantly, it offered the possibility for lowering problems like memorising a pictorial language, reassured patients and could help to save time.

However, as a new design element it required familiarisation and staff who were familiar with the tool were also more comfortable with selecting

questions for their purposes. Training videos and demonstrations will undoubtedly nurture more confidence. Importantly, efforts by staff can to communicate with patients could act as a pivot for motivating patients to learn English.

RQ.2. It was possible to design aids to include the needs of staff, patients lacking English and indigenous patient groups and the findings highlighted much commonality of approach and of interpretation of images amongst participant groups and between departments. The use of different images was approved of by all participant groups which reflected the concept of 'joy' in design (Jordan 2004). It was interesting that, whilst staff did not need images, some requested their questions be merged with the images and, as a result, these could be used more intuitively (usability). That staff liked to use images concorded with the preferences of 2nd and 3rd generation EMCs (study 1).

RQ.3. The takeaway leaflets with English labels were unanimously favoured to help educate, motivate and facilitate English-learning beyond a patient's specific healthcare experiences by both staff and EMCs. However, staff wanted phonetic labels for images whilst EMCs did not think this was necessary, although it was well received by some. This needs consideration for patient leaflets too, but a problem might be the implications of incorporating diverse languages once again. Whether adding phonetics or EMCs is better or not, will need further testing.

RQ.4. Usefulness and relevance across different healthcare departments and services was achieved by basing the sequence of information on literature and then adjusting it to different staff requirements. Whilst the images represented possible conditions staff would look out for, which equated to responses from patients, the development process demonstrated that it was possible to harmonise inter-departmental needs (at least in some key areas like pain and medication) to nurture familiarisation amongst patients who lacked English.

8.5. Conclusions

This study highlighted that there was more in common amongst people's interpretation of images if these were selected according to everyday living than is perhaps suspected. Both groups' responses showed much similarity to what they

liked or what was unclear. The main difference between EMCs and indigenous elderly people was that EMCs focussed on understanding images and words and using them to communicate their needs (i.e. lower a language barrier). Although indigenous elderly people could face communication difficulties for different reasons, their focus was upon finding (remembering) words to better express their problem (e.g. kinds of pain) and remembering their medication.

It was also clear that using images to learn was a new concept for EMCs, particularly emoticons, but they quickly picked up the concept and this illustrated the willingness to learn to empower themselves. They felt they could learn with some support and encouragement (Vygotsky's scaffolding concept; Cole 1985), like having paper-based aids rather than computer based (none used computers). There were also the needs of indigenous elderly people that required further consideration, like some facility (list/ chart) to recollect medication taken or not taken.

Some comments made by staff during testing (they did not like to be laughed at) and the doctor who talked to nursing colleagues suggests that future research that used new concepts (such as phonetics) amongst colleagues who were not participants would benefit from gaining more management involvement to widen the comfort zone amongst participating staff. It would have been useful to fill the gaps in the final testing with new participants but this was not possible due to time constraints. More consideration needs to be given in future to merging information and more intuitive use. The pharmacist's inability to test the aid highlighted the difficulty in study 2 of engaging pharmacists in research.

There appeared to be a general lack of awareness amongst staff of potential problems from changing demographics, and the resulting impact on healthcare, which may need addressing to help motivate staff to be willing to motivate EMCs lacking English. We may conclude that the views of EMCs and staff were in concord over English-learning and that the results from this study were consistent with those of studies 1 and 2. This included the desire of EMCs to learn English, the need to empower EMCs and wider patient groups, the need for more visual aids in adult patient care, and that new approaches and inclusively designed aids can help to lower barriers although this will take time, training and patience to motivate staff as much as EMCs.

This study suggested that such aids, given some support, can help to save time and lower costs (in areas of major expenditure and critical need). Also, that motivating both staff and EMCs lacking English requires education to help raise awareness of the nature of future problems and the potential benefits, albeit from different perspectives.

Within the time-frame, this study was as inclusive as possible: it harnessed outcomes from studies 1 and 2 and included indigenous staff (and doctors raised in Germany and Iran) who had fluent English and immense domain knowledge. It included indigenous elderly people across a wide age-range (65+ to 90+ years), some with visual and hearing impairments, and EMCs lacking English and literacy, also across a wide age range (late 20's to 75+ years). It also shared knowledge between participants and helped to harness their creativity and interest following inclusive, user-centred design philosophy.

8.6. Validity/ Reliability

Once again, validity and reliability in this design research rested upon close adherence to guidance in methodology literature, following ethical processes laid down by the NHS and that study tools were approved in advance. Also, the tools emerged from each stage whose findings were infused in the prototypes and re-tested, which was consistent with participatory techniques which offer opportunities for further testing and continuous improvement.

Fifty-eight individual interviews provided rich information and there were no right or wrong answers. Each group were approached as 'experts' although for final testing purposes having more staff would have perhaps helped. Many themes were repeated, within each group and between participants groups. There were no extremes in variation and many similarities in views between EMC and indigenous participants as well as between staff in different departments (in acute and primary care). Themes like favouring pictorial aids are familiar in healthcare literature.

The data analysis procedure set out a clear audit trail for the source of the data and modifications. Discussions with academic supervisors throughout the study provided critical feedback at every stage. The discussion considered other viewpoints from literature and clearly lays out how interpretation was achieved (Robson 2002;po.171-175) and the results triangulated between previous literature and studies 1 and 2.

8.7. Reflexivity

The author acted as facilitator, investigator and designer but the emerging data was all about what participants felt and did not appear reticent in expressing their views. Rather, most appeared to enter into the spirit and provided valuable feedback that carried the research forward.

Whilst it is always difficult to entirely rule out subjectivity, objectivity and minimising researcher bias in data interpretation were achieved by sharing information and views between participants and between groups with a wide range of skills, knowledge and abilities. Knowledge of languages helped the author but the individual interviews provided a space for people to express their views without embarrassment or concern for others' opinions (like in focus groups). Participants did not appear to hesitate and the questions did not raise controversial issues, which aided objectivity.

The next, and final, chapter reflects upon and discusses this research project.

9. Reflections, Discussion and Conclusions

This chapter concludes this thesis. It reflects on this research journey through discussing the theoretical framework, the findings from the 3 user-studies, how the objectives undertaken answered the overall research questions which achieved the overall aims of the research project. It considers the appropriateness of methods and sampling, the problems encountered in time management, the generalisability of findings and the strengths and limitations of the research. It concludes with considering the main contributions to knowledge, the papers published and identifies opportunities for future research.

9.1. Introduction

> *"An 'educated man' is distinguished not as much by what he does as by what he 'sees' or 'grasps'. For being educated involves 'knowing that' as well as 'knowing how'"* (Nigel Cross citing the educationist Peters, 1982).

This citation by Professor Cross, the highly regarded design teacher, researcher and thinker, succinctly sums up this research journey: a journey of learning 'that' as well as 'how' from the wealth of scholarly literature and advice the author was privileged to access. It was also a journey of 'seeing' and 'grasping' through the doing. In concluding this thesis, one looks back also and considers how the research project might have been further optimised.

The domain of cultural studies is multi-dimensional, wide, deep and cross-disciplinary and exploring the influences on EMCs in a modern day context was a challenge. Research was guided by theoretical insights and advice from literature across a range of disciplines: design, marketing, healthcare, current affairs and social sciences. This laid the foundation that informed and inspired the life cycle of each study - from its aims to data gathering, from extracting and understanding meanings of phenomena to considering the next stage of research. However, understanding the difficulties of both users and providers and designing inclusively required a cross-cultural, multidisciplinary view and a range of theoretical perspectives.

9.2. The theoretical framework

Literature review-1 laid the foundation for the entire research project and influenced the thinking throughout; each subsequent literature review extended and deepened the key theoretical concepts in the preceding review to lay the foundation for the following study. As mentioned in chapter 1, inclusive and user-centred design were the underlying themes and disciplines throughout this research project together with the theories on culture and contexts. The final, generative study was underpinned by the scaffolding concept based on Vygotsky's 'zone of proximal development' (that people can achieve a higher level of learning by collaborating with someone more knowledgeable, Cole 1985) and Bruner's three modes of representing the world (actions *enactive,* pictures *iconic,* and words and numbers *symbolic*) because people think through these modes and they are used in everyday living (UEA 2012).

Other key themes present throughout were the significance of user experience (UX) and good communication. First explored in literature review-1, these were extended in Literature review-2 to the context of good patient experiences in healthcare and how language barriers adversely affected patient comprehension and treatment adherence, whilst needs grew with aging (Johnson 2004; Safeer and Keenan 2005; Katz *et al* 2006; Amalraj *et al* 2009; Ngoh 2009; Salazar 2010; Streets 2011). Poor patient participation within some EMC subgroups, as a result of barriers, also affected users' empowerment. Nielsen (2006) highlights that empowerment barriers were the most difficult to overcome: some people could be "at the mercy" of others' decisions because they lacked the initiative or skill to take matters into their own hands. This observation together with the scaffolding concept later led to a design concept to lower language barriers with the participation of all stakeholders: staff, patients and families.

Theories on the usefulness of pictorial aids (images) in healthcare in improving patient comprehension were explored first in Literature review-2. However, this theme was first identified in the findings of Study-1 in the desire of 2nd and 3rd generation EMCs for including more images in instructions and the popularity of AV products for all generations. Pictorial aids and the challenges they presented were later reviewed in greater depth in Literature review-3: the significance of visual communication in everyday living; the importance of consistency in users' interpretations in safety-critical environments; guidelines on design elements that

produced good visual communication and, finally, the ways in which users perceived images. These factors were applied to designing the prototypes, such as the images and text of the body, were chosen to ensure the designs met the usability guidelines and were gender-free and, therefore, sensitive and acceptable to patients across cultures, genders and generations.

Also important at each stage of the research, was the concept that it is joy that holds communities together (‘*jouissance’* Dean 2002 citing Zizek and Lacan) and ‘pleasure in design’: of taking away something bad or giving something good (Jordan 2004). In its widest sense, this concept was considered particularly important to social integration and harmony, particularly where the aim was to extrinsically motivate people into modes of interaction/behaviour (using the tools) that could benefit all stakeholders. We noted that positive patient experiences in healthcare are important to clinical effectiveness (Streets 2011) and one might reasonably argue that joy/enjoyment create positive UX.

However, this also raised the question of whether it was appropriate to include joy in an environment such as healthcare, which is known to generate anxiety amongst patients. The author suggests that, perhaps, lowering anxiety is the very reason it should be considered with a focus upon an empathic approach to context and detail, i.e. how much (degree), whom, where, when and how. Interestingly, some staff, but not all, also appeared sensitive to any hint that patients might laugh ‘at them’, if they tried speaking their language, whereas colleagues who tried words in Gujarati perceived it as laughing ‘with them’ and enjoyed watching old ladies ‘giggle’ (Study-2).

Jouissance was important for two reasons. If, as Zizek and Lacan suggest, joy is what holds a community together, and if we define ‘community’ as people united by a common interest, then joy is a factor that might motivate patients, family and healthcare staff to come together to jointly engage as a community in lowering language/ comprehension barriers and empowering patients. ‘Joy in design’ was also important in creating aids to encourage/motivate patients to continue learning English at home, beyond specific healthcare experiences, and to help them to remember information. Thus, although each study investigated participants’ difficulties together with their preferences and what would help them further, their preferences ‘waited in the wings’, so to speak, until they could play a role in the generative phase (Study-3) and, in this way, embed patient-empowerment in my

research approach. However, gathering this data from the outset was critical to formulating a potential pathway for a design concept in the later stages. 'Jouissance' was expressed discreetly in the variety and diversity of images used (and it was noted that emoticons were a new concept to EMCs lacking English and/or literacy, but they learned rapidly as research progressed).

Gaining a holistic understanding was guided by Evans *et al* (2002) whose empathic approach was very harmonious with the principles of inclusive design and of joy. We noted they urged designers to follow a continuous process for 'capturing the customer's murmur' (see Figure 3.2, adapted) and to move beyond user satisfaction to delighting users by offering a significantly better understanding of their motivations and needs. They urged research not to assume but to ask the question of participants; to delight users by moving beyond usability; to design with others (participatory design techniques encouraged gathered views from all participants); and to develop one's own tools for research – and, no doubt for the design concept as appropriate.

Figure 9.1 depicts an overview of some key highlights from the literature.

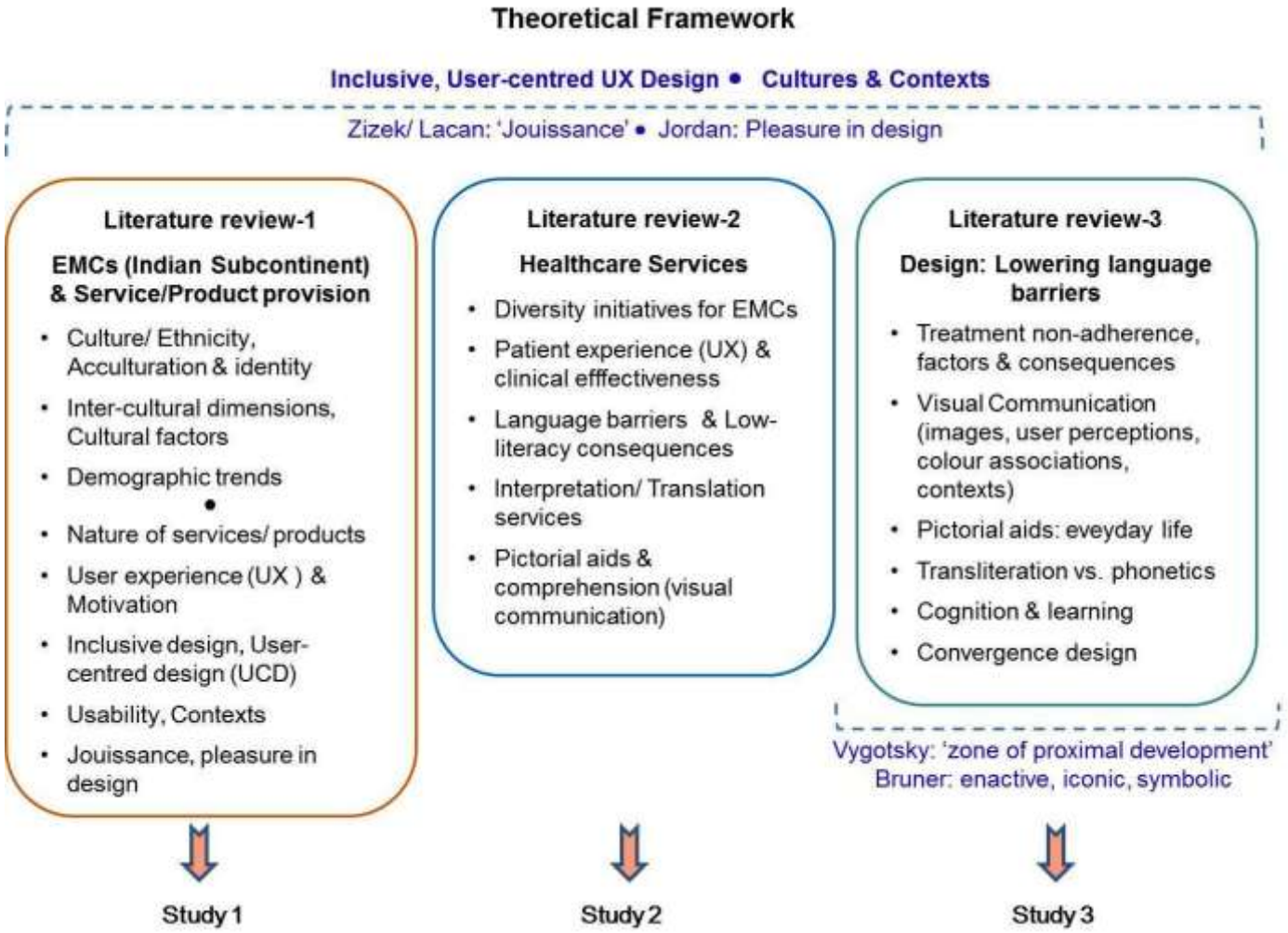


Figure 9.1 Depicting the theoretical framework as it was extended in each literature review.

Inclusive and UCD were key themes throughout the research project (particularly in Study-3) together with the theories of cultures and contexts. Study-3 was also underpinned by Vygotsky's and Bruner's theories.

The research challenges addressed in this project were placed in the context of 2 key factors. The first factor relates to the high cost of interpretation/translation services to the NHS (£23-55m/annum between 2006-2011) and fears that the costs were much higher (Easton 2006; Bendoris 2008; Martin 2008; Holden 2009; Connell 2011; Khan 2011;Wilson 2011; Chapman 2012). The second factor is that the UK's EMC population is predicted to double by 2051, to become ever more diverse because it is influenced significantly by international migration. This will have wide implications for planning public services, community goals and the nature of British culture (Rees *et al* 2011).

In considering the challenges of extrinsic motivation and a 'hearts and minds campaign' on potential users (patient, family and staff) to come together to use the tools, another motivating factor, good health, was posed as a fundamental issue.

9.3. Does everyone wish to enjoy good health?

Maslow's model (1943) as depicted by Thorson (2006) would lead one to conclude that the answer would be a resounding ubiquitous 'Yes!' regardless of culture - for individuals and, also, for their loved ones. Perhaps people would look askance at the very nature of the question. However, it is well established that, for many people, in the pursuit of socio-economic goals and the rush of everyday living, psychological, socio-economic or cultural variables can impede the achievement of this fundamental goal, e.g. poor diet, too much alcohol, too little exercise, etc. In effect, despite saying 'yes' to wanting good health other 'choices' are made that run counter to this goal which is fundamental and personal. For some 1st generation EMC females (Indian Subcontinent) this is made manifest by a failure to learn English which, we found, could arise from several cultural factors. However, a majority of contextual factors that impacted on this group do so at the individual, social and societal levels (using healthcare services, poorer job prospects, poor social integration). Therefore, in actuality, these challenges impact on everybody – families, healthcare staff and society.

A generally benign approach to multiculturalism in the UK's pluralistic society

appears to have had unintended consequences: the need across healthcare services to address on-going problems that have their root causations in language barriers, including for long-term residents. How can newcomers share *jouissance* with their new communities if they are unable to communicate and understand its customs, culture, literature and norms, including healthcare? It is suggested that patients and families need a better understanding of the negative effects of language/comprehension barriers upon the wellbeing of their relatives now and in the longer term as identified in the literature (Nicholls-English and Poirier 2000; Haynes 2001; WHO 2003; Johnson 2004; Katz *et al* 2006; Safeer and Keenan 2005; Amalraj et al 2009; Streets 2011). Given that understanding, it is possible that there would then be a greater acceptance of the need for English and more effort made to learn. We noted that the need also for improved health literacy is a cross-cultural problem which is exacerbated by language barriers. Although tools (visual media, translations) and facilities (such as interpretation) have been developed to improve staff-patient communication and adherence to treatment, problems persist. Admittedly, in some departments, such as orthopaedics, conditions are very patient specific and explanations using models/illustrations are necessary. However, if pictorial aids always have to be explained by staff it adds additional burdens to healthcare delivery (Dowse and Ehlers 2004) whilst familial interpretation does little to alleviate patient problems for the longer term. Meanwhile, the costs of interpreter/ translation services in different languages to the NHS have risen – one, imperfect, indicator that this population segment has increased together with the aging of long-term residents who still do not know the language.

The UK government recently stipulated that immigrants must have English language skills, and one healthcare consultant was optimistic that those coming to the UK would know/learn English (Study-2) whilst another felt if he had to put his money into something, it would be to get patients to learn English. Changes to the law do little to remedy the situation for existing residents who have not learned English or people arriving from EU countries or non-EU residents who have gained entry to the EU. Interpreters/ translations can help to resolve an immediate problem and will remain

necessary in this era of international travel, but do not offer a sustainable solution to the greater empowerment of patients (a mission of the NHS; Streets 2011) in the longer-term.

This research revealed a willingness in staff and patients to work together and to use aids if they were available and were produced, using a holistic approach to help to lower barriers sustainably and in the longer term.

9.4. Will the tools be used?

"Increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" Haynes (2001).

This is an interesting question: several user groups could use the tools and the testing phase suggested that users were positive about the tools, which led to a consideration of how each group could benefit and how more users could be motivated to use them. Understanding motivation was important because motivation can be intrinsic (inherently interesting/ enjoyable) or extrinsic (which leads to a separable outcome) (Ryan and Deci 2000). Extrinsic motivation can lead to resentment and disinterest (feeling externally propelled into action) or to accepting the value or utility of a task (the goal then became self-endorsed and adopted with a sense of volition) (Ryan and Deci 2000). Thus, behaviours arising from these motivations could vary considerably and affect the quality of UX, which applied equally to patients, families and staff.

Peoples' motivations differed according to different reasons/goals (context) and cultural variables. UX resulted from a "motivated action in a certain context" (User Intelligence 2011 citing Kankainen) and was a complex relationship between needs, drives and goals: a need was a goal that was sufficiently important to seek satisfaction (Masterson and Pickton 2004). Scholars had mapped a variety of human 'needs' but differed on whether these could/should be organised hierarchically (Maslow 1943; Ford 1942 cited by Rouse 2004). We noted that Maslow's model, depicted as a 5-level hierarchical pyramid, was/is popular with designers and marketeers attempting to create positive UX. They mapped their product/service

attributes to each level to create ‘maximally motivating' UX because highly regarded marketeers maintained that the greater the resonance with Maslow’s model, the greater would be the success in the marketplace (Thorson 2006). Thorson’s advice was employed in considering the ‘needs’ to create maximal motivation to use the tools amongst patients, families and staff (as discussed below).

To be successful, services need to be more than good functionally, they needed to create positive UX (for both the users and staff): accessing and capturing this information could be a source for inspiration (Wensveen 1999 adapted, and, citing Sanders 1999). Good communication was integral to service delivery and required that each recipient to contribute in equal measure and understand what was being communicated and what experiences might be influencing the other (Sanders and Dandavate 1995), i.e. cultural and/or contextual. Good communication required a shared language, without which patients became stressed and it could, potentially, result in confusion or conflict (Johnson 2004).

Therefore, the tools were designed to encourage patients to respond to short questions, to use as much English as they knew and, with a little familiarisation and to explain their needs/preferences. Similarly, for healthcare staff to reassure a patient, to put simple questions, understand/validate a patient’s responses and to put sublevels of questions to aid diagnosis. More collaboration between healthcare providers is still required to overcome barriers and to enhance quality of care despite the new strategies - the use of pictures and confirmation of patient comprehension using the ‘show-me’ or ‘teach-back’ method (Kountz 2009). To empower patients and improve patient experience in order to improve clinical effectiveness (Streets 2001; Imison *et al* 2011) required, it is suggested, moving patients from being ‘recipients’ to proactive ‘participants’. Study-1 and 2 both confirmed that interpreter services had not resulted in English learning amongst a resident female subgroup and an unintended consequence was interpretation being used as an intra-cultural barrier to some EMCs wishing to learn English (Easton 2006).

Primary research identified three positive factors that could help to nurture a

joint effort to lower language barriers. Firstly, the majority of staff relied on families to interpret (excluding some, such as a gynaecology ward); more did so to overcome low-literacy barriers; the majority already used actions (Bruner's *enactive*), simple English phrases ("check your blood pressure") to communicate a procedure they wished to carry out and observed body language to "gain meanings around what patients had said" (Study-2). Secondly, 2nd and 3rd-generation EMCs cited stress and time pressures from constant interpreting and anxiety from leaving relatives at home, particularly the elderly (Study-1). Thirdly, Singleton and Krause (2009) highlighted that:

> *"Nurses are in an ideal position to facilitate the interconnections between patient culture, language, and health literacy in order to improve health outcomes for culturally diverse patients"*

This also accorded with Wroblewski's (2004; adapted to services) statement that convergence design helped to resolve human-centric problems by considering the connections and commonalities between services, the products used and areas of specialisation. Despite the impressions that might be given by current affairs, nurses are generally perceived as 'trustworthy' and kind.

These factors were used (Study-3) to develop the design concept for a tool for patients and families to help them to prioritise which English words and phrases family members lacking English should begin learning (scaffolding). The tools were harmonised across healthcare services to nurture familiarity and to facilitate learning through repetition for patients with low-literacy (and to lower cost). The staff section with added phonetics and simple English facilitated more direct communication with patients (Study-2) and to encourage/ motivate patients to speak English (scaffolding, joy). Thus, each user-group could benefit as follows.

9.4.1. Usefulness, Valuable, Desirable

The benefits to participants were considered in the context of Maslow's hierarchy of human motivation.

- **EMCs lacking English/literacy** could more easily respond directly to questions from healthcare staff and point out their problems; learn English at home at a pace they were comfortable with; starting with

healthcare English, continue to extend their English language skills; be able, over time (some female subgroups, in particular) to initiate discussion; better understand the healthcare environment and indigenous society; be able to communicate a child's/ husband's health needs to staff (e.g. particularly in an emergency); and enjoy a wider choice of jobs.

- **The family/ friends** could encourage and help those lacking English to learn/ practise at home through repetition to, over time, reduce time pressures from constant interpretation; reduce anxiety about leaving them alone at home, particularly elderly people; the needs of children could be better communicated in healthcare, at school, etc. Self-interest would also be promoted: if a husband became ill then he would benefit from his wife being better able to explain his needs (particularly intimate needs), to ask for help, engage with the indigenous staff over arrangements; the family economics could benefit from members who now had a wider choice of work.
- **Healthcare staff (including emergency staff such as paramedics, A&E)** would be using tools that facilitated more direct communication with patients lacking English (which they preferred), and they did not have to await help from family/interpreters or be concerned whether the patient's needs were being communicated. Their *enactive* mode of communication would be aided by everyday images, numbers and symbols (*iconic* and *symbolic*). They could save time, cost and lower patient anxiety by being able to reassure patients (the preamble in the tools). They would be able, with a little familiarity, to locate/understand patients' responses and repeat these back in their language to validate them (tell-me-what-I-said method in reverse, Study-2) and rapidly find and ask sub-level questions. They could give patients' tools (in the form of a pictorial aid) and encourage them to use and learn English. They could screen for pain and symptoms and determine medication and provide guidance (without waiting for interpretation).
- **Indigenous elderly,** indeed all elderly people**,** could benefit if unwell (stroke, poorer vision, poor literacy, etc.) through using images to

communicate needs, finding or remembering words to better explain their difficulties.

- **Healthcare organisations** could save direct and indirect costs, improve target response times, create positive brand awareness amongst EMC communities, save money and time sustainably for the longer term by staff encouraging patients to learn English, and facilitate/harness patient empowerment (an NHS mission) to improve clinical effectiveness through a joint effort with patients and their families.
- **Society** would gain greater engagement and harmony with subgroups currently marginalised by language barriers, females in particular.

Importantly, there would be minimal cognitive load on the users, familiarity for patients (particularly with low-literacy) in tools harmonised across departments and healthcare services and a spirit of *jouissance* that holds communities together. It was crucial to ensure the designs were as simple and intuitive as possible to keep the cognitive burden on users low as Study-3 identified that there were some challenges to overcome. Some staff were sensitive about being laughed at (over sounding different) and consulted colleagues on the tools (most of whom who reacted positively), whilst other staff were not troubled, which suggested support from the department manager and perhaps having some colleagues participate would create an ideal environment to practise and gain familiarity. Getting more intrepid staff to use the tools would provide a good example to encourage more timid staff and also highlighting to staff that patients, like themselves, would also be using an unfamiliar language (English), could produce a joint staff-patient effort for positive results.

Addressing the gap in understanding amongst EMCs who lacked English and their families by highlighting the contextual factors that were influencing them, and the adverse long-term implications thereof, could help to shift discussions from ‘culture’ to ‘context’ and, thereby, to lower intra-cultural impediments/ misconceptions and improve social integration (Study-1). To gain wider acceptance, it would be important to highlight also the positive

cases by placing emphasis on the helpful difference understanding and reading some English made to the lifestyle and activities of a grandmother (Study-1) and the benefits for EMC mothers who were able to question the consultant about future treatment proposed for their child (Study-2). Finally, demonstrating how English would benefit everyday living and self-interest could be highly motivational, e.g. a middle-aged female was learning to drive (in Urdu) because her husband could not drive due to illness. Without English, how could mothers privately explain their intimate medical problems to healthcare staff? Or their children's problems to emergency staff? Or a wife convey a husband's needs/preferences if he was unable to do so?

Alongside these considerations, the harmonious factors between user groups were important to the inclusive design approach in Study-3.

9.4.2. Points of Harmony

Plain English: Encouragingly, Study-1 highlighted the positive attitude of the majority of females towards learning English (to be able to speak directly to the 'doctor') which accorded well with staff favouring English-learning (Study-2). Staff highlighted the problems associated with familial and interpretation facilities (Study-2) and it was interesting that some EMCs with poor English faced some difficulties or sensed the interpretation was not quite what they said. However, admittedly, another underlying cultural factor might be that EMCs (Indian Subcontinent) are unaccustomed to and, therefore, uncomfortable with, divulging confidential/ intimate matters to people beyond their immediate family (e.g. a stranger/interpreter), including people from their community.

The author is aware that EMC females (Indian Subcontinent) customarily gave birth to children soon after marriage. Females who lacked English remained homebound and could not acculturate rapidly, or make informed choices for themselves or teach the children English in their early years, which later affected their schooling. In a wider context, engaging with EMCs was important to encourage English learning to counter the possibility that a lack of information from British society was being replaced by media from other cultures that might be

contrary to desired societal norms in the UK. It is important for harmony to remedy a lack of understanding which is perhaps otherwise imbibed through partial information, possibly, misinformation (e.g. from a variety of TV channels, a popular source of information and entertainment), or biases from familial, community or religious sources.

Staffs' suggestions, such as EMC interpreter volunteers and expert patients could be helpful in the interim, if intra-community impediments (e.g. a lack of helpfulness) could be overcome. However, these arrangements did not resolve the problem of language barriers sustainably for the longer-term and did not empower patients holistically including in everyday living. Learning English was the most favoured option – the author's conclusion also. The Plain English Campaign's (2011) efforts to simplify information is also favoured by the NHS for all patient groups: its importance was emphasised in the literature (Johnson *et al* 2006) and The Plain English Campaign prepared the medication instructions for patients in the British National Formulary (2011) and guided Study-3.

Religion: We noted that EMCs stated that religion affected their choices of services/ products very little (except for attire and ritual foods at festivals) (Study-1) which appears generally true of the indigenous population. Thus, individual choice appears to be the guide.

Education: The higher/better education and less cultural distance (emphasised by language barriers) resulted in more positive adaptations/integration in the EMC context (Berry 1997). We noted that a good education was important to all participants (Study-1) and the positive adaptations by fluent English speakers of all generations and that social integration was the highest by the 3rd generation. Participants lacking English and/or literacy had adapted as much as they could and the majority were eager to learn English. A Muslim mother (aged 30's, non-literate) expressed relief/satisfaction that the government insisted that her daughter would be educated as also her son, the implication being this had overcome intra-cultural impediments. This is important point because, whilst the dynamic nature of culture

offered pathways for change, Rau *et al* (2008) pointed out that differences in thinking can remain the same– unless positive motivational interventions were employed.

Respect: Contrary to suggestions by scholars in the US proposing "Appropriate deferential behaviour towards others based on age, sex, social position, economic status, and authority" (Salazar 2010), Study-1 findings highlighted that respect was not a consideration in the UK as a result of the egalitarian attitudes on respect/status that are prevalent in this society. (It is an interesting cross-cultural difference, which appears at odds with the so called 'freedom from deference' of American culture.) This was reflected in the affection unanimously cited by EMCs towards indigenous people/staff in contrast to their extreme dissatisfaction with some EMC staff with origins in the Indian Subcontinent. Thus, attitudes of respect in the UK were, in general, a point of harmony.

Quality of life: That the quality of life in the UK was unanimously favoured to that 'back home', including by 1st generation lacking English, reflected the inter-societal differences and the benefits of life in the UK. EMC participants were unanimously happy across religions, generations from fluent English-speakers to those without literacy (Study-1). This included the availability of utilities to education, healthcare, road systems, social care, cleanliness, etc. The implication being that participants were happy with life in the UK because they benefitted in ways they would not 'back home': another potentially motivating factor to encourage/ assist English-learning and integration.

Visual communication: Another valuable point of harmony was the popularity of audio-visual (AV) products/ tools, which staff (Study-2) and EMCs of all generations and religions enjoyed using, thus staff and patients would view low-cost and accessible aids favourably. Although the literature (Chapter 7) established the benefits of AV (pictorial media) for patients'/users' comprehension, the use of AV aids in adult patient care was low and patchy amongst the staff interviewed (Study-2) excepting in physiotherapy and orthopaedics (both used English text

and interpreters). Many staff did not have illustrated materials/media or translations. Existing illustrated materials were of high quality (and expensive) and helped with level-1 (main) questions but understanding patients' responses, finding sublevels of questions and requiring patient-literacy to read their language scripts were impediments.

Another interesting point of harmony was acquired from the literature on inter-cultural colour associations (Fiesner 2006). There were found to be many points of harmony (red=danger, white=pure/clean, black=fear) and few impediments to harmonising colour associations in patient information. Contrary to this literature, EMCs' languages (Indian Subcontinent) did not include colour-associations (e.g. green with envy).

Gender: Reviewing the findings in Study-3, no noticeable differences were observed between the genders in cognition or preferences, either amongst EMCs or indigenous elderly people although the majority of EMC participants were female. For both EMC and indigenous elderly people, gender sensitivity was displayed by excluding any display of genitalia on the body images and the eyes pointed downwards depicting modesty. The images were received well by participants regardless of gender, culture or age and also by family.

In these complex relationships lie hidden opportunities for improvements. It is critical to building a harmonious society that indigenous people consider ways of engaging with EMC subgroups that lack English to encourage them to learn the language and to integrate as some cannot do so on their own. Some people lacked the skills or initiative to take matters into their own hands and/or find themselves at the mercy of other peoples' decisions (Nielsen 2006, Study-1). Note the husband who wanted the doctor to remove his wife's breast because he could not keep coming back with her (Study-2) or the wife who felt her husband was deliberately preventing her from learning English and her perception of his motivations (Easton 2006; Chapter 5). Learning the *lingua franca* is an important first step to helping people better understand "what was going on around them" in healthcare and, gradually, in the wider context of society in the UK (Study-2).

How, then, could we design inclusively for a multi-cultural society?

9.5. Inclusively designed UX for a multicultural society

Multicultural societies offer particular challenges for designing positive UX, particularly in services, which have more intangibles than products, where staff are a part of the service (Masterson and Pickton 2004) and where good communication is critical to service delivery, as in healthcare (Johnson 2004). We noted that inclusive design, UCD principles and human factors in design offered ways for designers and marketeers to create positive UX to motivate customers to buy/use their services/products. This research embedded an inclusive design approach from the outset and the design concept drew on insights of participants' difficulties and preferences from all the three studies.

The first stage of the design process was the 'discovering' and 'understanding' phases of the inclusive design waterfall model or the planning stage of the NHS PDSA model (Figures 2.1, 5.1). This required defining the objectives, understanding the several variables, such as etic/emic contexts of service delivery, contextual, cultural and inter-cultural dimensions potentially influencing stakeholders, before the study could be designed, the potential requirements captured or a design concept envisioned. In this section we discuss the inclusive design and how these variables were considered and brought together in the design process.

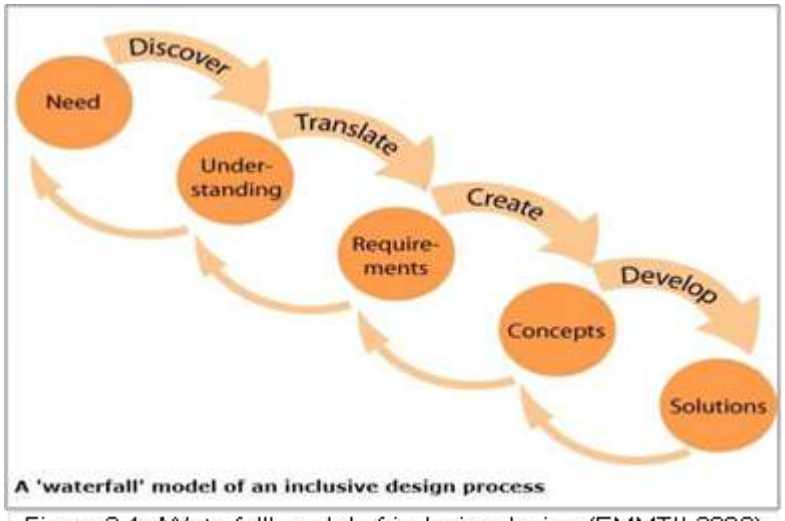


Figure 2.1 'Waterfall' model of inclusive design (EMMTII 2009)

Figure 5.1 The PDSA model (NHS Institute for innovation and improvement 2008)

The literature suggested that an inclusive design approach could harmonise multicultural users' needs, which suggests it can also contribute to greater social integration through shared experiences. However, because UX was affected by users' capability, context of use, economic considerations as well as cultural variables, this also raised some interesting questions:

- To what range of capability can the inclusive (universal) design envelop be pushed by designers: 80% of the population? 90%? 100%?
- In multicultural societies, such as in the UK, is 'good design' culturally competent by definition and, if so, what multi-cultural variables do we need to consider and how?

There also appeared to be some differences in scholarly views over designing inclusively. For Clarkson *et al* (2007, adapted) inclusive design was simply good design that was user-centred and population aware and ensured groups of people/views were not excluded and thus reached a wider market and improved success/profitability. Inclusive design was not a stage to be added to the design process, nor to be confused with usability or

considered as addressing a particular capability loss, nor did it imply that it was always possible/appropriate to design one product (or process) that met the needs of the entire population. Inclusive design principles needed to be embedded within the design and development process, in order to apply an understanding of customer diversity (Clarkson *et al* 2007) by taking cultural differences and cognition into consideration (Clarkson *et al* 2003) and to include as many people as possible at little or no extra cost (Mace 2008). The BSI 7000-6:2005 definition also stated "without the need for special adaptation or specialised design".

Others suggested that inclusive design should benefit people of all ages and abilities (Mace 2008), including people with reduced abilities or disabilities (Keates *et al* 2000; Israsena & Boonvong 2009) which was important because needs grew with aging (Safeer and Keenan 2005). Designing for reduced capability is encompassed in the inclusive design definition but not the special adaptations required when designing for disability. However, Keates *et al* (2000) offered a way to achieve *complete population coverage* through a methodological design approach to implementing inclusive design described in their model, the *Inclusive Design Cube* (IDC), illustrating how different design approaches were complementary. Indeed, some of the most successful designs have been those adapted for problems such as arthritis (e.g. 'good grip' kitchen products). Thus, the IDC methodological design approach offered designers an opportunity to include the full range of user capability and to cover the whole population. Indeed, designs that were created to be user-adaptable to different purposes reached a wider range of people by including those with few/ no economic resources (Israsena & Boonvong 2009).

We learned that cultural/societal differences influenced what mattered to people which could differ between cultures (Carroll 2009), which influenced peoples' perceptions and thinking differently, and governed their behaviours, which, in turn, could affect their degree of success when using services/products (Jylha 2007; Rau *et al* 2008; highlighted in Study-1 and Study-2). This also required a consideration of users' cognitive capabilities (Clarkson 2008) because culture and cognition created each other (Cole

1995) which was important to how designs were interpreted (Crilly et al 2008:p.443) particularly in safety-critical environments (Johnson 2004; Krippendorff 2006) such as healthcare. However, as Rau *et al* (2008) also cautioned, cultural differences were not to be mistakenly confused with differences in users' goals or psychological variables (i.e. contextual factors). These observations prompted the author to view 'context' and 'culture' as separate entities that affected all people and to the 'space' created to better understand problems and for innovating potential solutions.

We noted that Israsena & Boonvong (2009) proposed a consideration of *cultural specificity* in designing (for home countries such as Thailand) in three categories: local culture, blended culture and global culture (whole population). This suggests that, in this multi-media information age, people were acculturating (from choice) to other cultures even whilst in home countries, and appeared to be similar to designing for EMCs acculturating within host countries. Did EMCs who customarily sat together on the floor/ carpet/ at very low tables for their meals 'back home' adapt to using a dining table/chairs in, or whilst entertaining others, in the UK? Observation suggested that many EMCs in host countries used table/chairs at home but largely adhered to cultural customs in places of worship (e.g. sitting down, gender segregation, females frequently wore traditional attire) although tables/chairs were also present. Notably, this also appears true of EMC adaptations in 'home countries'.

When considering culture and capability for both, designing in the EMC context and for overseas markets, some designs require a focus on 'local culture', e.g. reducing an illness prevalent amongst a particular group; accommodating different customs/lifestyles; reaching niche markets or adding interest. However, for EMCs in host countries, 'local culture' was the 'host culture', i.e. the context of home/ host country becomes important when using the term *local culture*. In a multi-cultural and diverse society such as in the UK, *blended culture* is perhaps similar to multi-cultural inclusivity where, to a greater or lesser extent, EMCs adopt norms from the host culture, i.e. 'integrate', and vice versa. Verkuyten and de Woolf (2002) pointed out that integration could only be freely chosen and successfully pursued when the

dominant society was open and inclusive in its orientation towards cultural diversity as integration required mutual accommodation and acceptance by both groups. On the other hand, *global culture*, in this era of globalised products/services, generally refers to a greater coverage than the national population, i.e.to internationalisation.

Study-3 focussed on *harmonisation* - to test cross-cultural cognition and use of English in order to reduce cultural differences. It was also able to include the needs of people with poor vision and colour blindness but the special knowledge required for special adaptations was outside the scope of this study. Would it be useful to add a stage to the inclusive design waterfall model to embed the IDC model or does the 'solutions' stage prompt or include special adaptations? Would a specific stage prompt greater consideration of special adaptations as scholars/ designers of IT products/services and adaptations to the built environment have demonstrated?

Thus, designing good multicultural UX inclusively was complex and included a consideration of anthropology and sociology (cultural/social factors) and psychology, as Shedroff (2004) depicts (Figure 2.8). A consideration of the etic and emic influences helped nurture sensitivity whilst designing and proved valuable in avoiding embarrassment during testing.

9.5.1. The 'etic' and 'emic' perspectives

The 'understanding' phase of Study-3 considered the tools for staff-patient communication in the context of the emic (local) and etic (outside) contexts (Strickfaden *et al* 2006; Harvard University 2008; Akane 2011, see 7.7.1). In this research, *emic* influences on patients included cultural, contextual and socio-economic factors, i.e. when patients were at home away from the healthcare environment, and the *etic* influences were when patients were in the healthcare environment and interacting with indigenous staff. The period at home was for adhering to treatment and a time, potentially, in which patients could use the tools to learn some English to help them to participate more in their next 'communication experience' in healthcare and to reduce anxiety by better understanding what was going on around them. In the etic context, during a healthcare interaction, a member of staff and an EMC

patient were engaged in communication via a 3rdparty (family, friend or interpreter). This staff-patient communication involved individuals from different cultures, which required the two recipients involved in the experience to understand the intended meanings and the responses of the other. Throughout, staff observed the patient's body language to try to ascertain whether there were indications of any unexpressed factors in the responses being communicated (e.g. emotions, feeling, doubts, fears, cultural factors, familial situations, was the patient holding anything back, was the interpreter accurately and clearly communicating all the information; Study-2). Likewise, the EMC patient could be following a similar, but possibly less complex, process (subtle body language is not a well-developed concept in many countries) focussed on gaining understanding, sympathy, help and a remedy from the healthcare professional. When family were absent, the patient could be subject to anxiety and/or loneliness in both the emic and etic contexts (or, perhaps, relief if the familial environment were stressful, such as pressures from a mother-in-law).

In the emic (inside) context, the socio-familial-cultural influences upon the EMC patient and healthcare professional would be quite different, with an emphasis on 'cultural' in the context of EMCs lacking English. For EMCs (Indian Subcontinent), as noted, if English was not used in daily living, whether from intra-cultural factors/ impediments or for contextual reasons, their ability to communicate with healthcare professionals would remain static requiring the intervention of an interpreter.

Neither emic nor etic contexts for indigenous elderly people included cultural differences or language barriers. Their etic context focussed on comprehending the healthcare environment, difficulties with filling forms, comprehension, expression of needs, etc. This could be affected by poor memory/recall of words, poor vision, anxiety, frailty, difficulty communicating from the effects of a stroke, etc. and patients with dyslexia: in short, a wider group that could benefit by illustrated tools (as staff mentioned in Study-2).

9.5.2. Context

Separating the potential factors that influenced phenomena, such as reasons for a low motivation for learning English, into cultural/acculturation or

contextual factors, provided greater clarity of the nature and range of problems. As mentioned, this created the 'space' for brainstorming potential solutions and how impediments might be addressed or users positively motivated (some extrinsically) to adjust their thinking/ behaviours to their mutual benefit. This was important because understanding users was complicated: people were sometimes unable to voice their needs/desires or were unaware of them, or found them difficult to articulate, or were unwilling to divulge them (Evans *et al* 2002; Sleeswijck-Visser 2005).

Thomas and Bevan's (1995) context characteristics (Table 9.1; extract from Table 2.1) were found to have several aspects in harmony with Umiker-Sebeok and Gregson's (1999, adapted) advice on participatory design techniques (setting/environment, user interaction, involvement, access, usability). Following their advice the author learned from users, treated them as 'equal partners' and "knowledgeable people" accepting that they might not be able to articulate precisely what was required and, in accordance with Evans *et al's* (2003) empathic approach, the author did not assume that she knew, but asked the question. Finally, Umiker-Sebeok and Gregson (1999) added: consider whether the iterative design process should use a 'top-down approach' and/or a 'bottoms-up approach' (where users generate the ideas).

Table 9.1 An extract of Context of use characteristics: Usability (Thomas and Bevan 1995)

Users / target audience (includes physical capabilities)
Skills and Knowledge
Mental attributes
Task
Equipment/ service
Social environment
Physical environment

Following inclusive design, both approaches were employed in Study-3 to develop and test the relevant section of the aids (staff were consulted, and EMCs lacking English and/or literacy and indigenous elderly people) as the users' skills, knowledge, mental attributes, etc. varied considerably.

The next sections describes how the author set out to test how to infuse

cultural competence into the inclusive design process and how a framework was created bringing together cultural factors and design thinking which was used to good effect in Study-3.

9.5.3. Bringing cultural attributes into the design process

Cultural sensitivity is known to be a complex domain, for instance, it may not be apparent to healthcare staff that the person dressed in a *dhoti* or *kurta-pyjama* is a visiting priest with *parsad* (blest food) (Johnson 2012), however, it is also possible to 'over design'. The author noted that attention to equality and diversity had led to curious cross-cultural adaptations such as the NHS employing 'chaplains' for Sikh, Hindu and Muslim patients. In Christianity, the hierarchy, appointment and relationship between priest and congregation are completely different to these religions. Whilst an EMC committee in a place of worship may appoint a priest, or a priest manoeuvre to be appointed (they are frequently male), their ties with the congregation vary from fairly close to non-existent, particularly with females. In societies where gender segregation is often the norm, patients (particularly females) would not expect a priest to attend at their hospital bed and observe them in a state of partial dress (the author would be embarrassed).

To bring 'culture' into the design process, the author created a 'framework' by collating and harmonising theoretical concepts in three categories: cultural attributes, acculturation and inter-cultural dimensions (Chapter 2) used to interpret the findings in Study-1 and Study-2. This framework informed the 'understanding 'and 'evaluating' phase of design. Insights were drawn from findings in all the 3 studies, i.e. the differences/similarities of views between EMCs (by generations, religions, those lacking English and literacy), healthcare staff and indigenous elderly people to consider how to inclusively meet their needs and to motivate them to use the tools in the etic/emic contexts of service delivery. This was set in the context of the literature on visual communication, pictorial aids, clinical effectiveness, etc. (Chapters 5 and 7).

For instance, we noted that service delivery to some EMC patients was affected by the ways some 1st generation males dominated females (sometimes trying to help, sometimes negatively) or displayed negative

attitudes towards learning English/acculturation (particularly cited by 1st and 2nd generations Muslims females and males) or collectivist vs. individualistic approaches. We learned that the majority of females wished to learn English (Study-1; Easton 2006) and 2nd generation EMCs cited time pressures from constant interpreting. The author therefore innovated for a patient-centred intervention to empower EMC females and for staff to encourage learning English to help lower negative intra-cultural pressures, in order to help people who appeared unable themselves (for different reasons). We noted that pictorial aids could be helpful to indigenous elderly (Study-2 and literature) and the findings evidenced that many educated 2nd/3rd generation could be (covertly) pleased to have support to motivate relatives to learn English (Study-1).

The author suggests this theoretical framework devised offers a potential 'template' for design to consider cultural factors during the design process and raises interesting questions:

- Did designing for cultural specificity imply designing for multicultural diversity in the EMC context?
- Would designing for 'global culture or 'blended culture' equate to designing for inclusivity and acculturation of EMCs?

Answers to these questions may differ, however, the theories that were employed in this research (set out below) were nested and harmonised to provide specific points for consideration and this cultural framework was balanced with context (above).

9.5.3.1. Cultural attributes

Whilst considering cultural/inter-societal differences between the UK and Indian Subcontinent (Table 2.3), the author highlighted the difference in the numbers of languages, scripts, religions and in societal attitudes to marriage, education, labour, taboo topics, gender segregation, social courtesy which influenced the social milieu of participants in Study-1 and therefore, their attitudes and behaviours. Thus, 'Customs' has been expanded in the attributes list below and the author has proposed further cultural attributes for consideration (Table 9.2).

Table 9.2 Cultural attributes: a compilation

Religion(s) Language(s) Script(s)/ Text Cuisine(s) Customs (*including Taboos, Courtesy, Gender segregation/attitudes, Marriage) Family/ Lifestyle* (joint family or nuclear family) Shared history Experiences of racism/ exclusion Respect/ Status Communication of information Art, Products/ Artefacts. *Colour-associations Music, Dance*	Hall and Hall (1976) NAB (2000) OED (2009) Johnson (2010) Salazar (2010) and *Author
Health beliefs Attire Education Social care Laws/ legal framework Geo-Political environment/factors Economics (Utilities)/ Finance	Author: Additional factors affecting social milieus

9.5.3.2. Inter-cultural dimensions

This was important in considering etic influences cross-culturally (e.g. affected patient's decision-making) that needing factoring in or countering to achieve the desired results(Table 9.3).

Table 9.3 Inter-cultural dimensions expanded theoretically

1) Power-distance	The unequal distribution of power within families/groups/ organisations; affects females and children	Hofstede and McCrae (2004)
2) Uncertainty avoidance vs. acceptance	The level of comfort/discomfort for unstructured situations; it is linked to anxiety and greater expressions of emotion	
3) Individualist vs. collectivist approaches	Individual choices vs. group loyalty	
4) Masculinity vs. femininity	The relative assertiveness of males and females	
5) High-context vs. low-context societies	Knowledge is communicated/ presented differently: thematic, implicit vs. abstract, explicit information	Hall and Hall (1976) Rau *et al* (2008) Dowse and Ehlers (2004)

9.5.3.3. Acculturation

We noted that acculturation was an important consideration in promoting services/products (Burton 2002) and acculturations attitudes (Table 9.4) affected peoples' choices; better-educated EMCs displayed greater positive adaptation, also from choice. (*These were viewed as 'contextual factors' during data interpretation.)

Table 9.4 Acculturation attitudes expanded theoretically

1) Inter-group and intra-group contexts*	Intra-cultural and inter-cultural perceptions of groups in society	Verkuyten and de Wolf (2002)
2) 4 Ways of Acculturating*	1. Assimilation (one-sided adaptation), 2. Separation 3. Integration, 4. Marginalisation	
3) Gender attitudes	The status and treatment of females	Berry (1997)
4) Cultural distance	Greater the cultural differences (language, religion) ≡ less positive the integration for some groups	
5) Education*	Positive adaptation to culture (higher education ≡ lower stress)	
6) Loss of economic status/ low mobility*	Unable to choose; people remain in ethnic minority neighbourhoods	
7) Personal factors*	Personality, including control, introversion/extraversion	
8) Individual identity	Influenced choice/preference*, sense of belonging/ alienation, sense of status, relationship to society	NAB (2000)

A consideration of these theories together with context, highlighted that contextual factors were the majority influence for the continuing presence of language barriers (Study-1), that indigenous healthcare staff (mistakenly) ascribed language barriers to culture, and the cultural and contextual factors that appeared to underlay difficulties in healthcare delivery (Study-2). These understandings were used to shape the design thinking and process.

9.5.4. Convergence design: a cultural dimension

Convergence design guided the problem of addressing the human-centric problem of language and communication barriers to help the author to become more aware of the 'connections and commonalities' between healthcare services and the products used, areas of specialisation and processes and to consider how 'convergence zones' could be paths to innovation (Wroblewski 2004 adapted to services). In accordance with the author's conclusion on the importance of healthcare staff participating in the process to encourage English learning, nurses Singleton and Krause (2009) stated that nurses were in an ideal position to facilitate the interconnections between patient culture, language and health literacy in order to improve health outcomes for culturally diverse patients. Thus, elements from the three

studies and the literature were brought together to streamline developments in the design phase to make the tools usable, useful and enjoyable.

Wroblewski (2004), depicting Morville's model of UX, suggested that the "honey" responsible for "sticking" UX principles together was *convergence*. Morville suggests this modular approach was tried, tested and worked well and could take conversations and exploration beyond usability and conventional boundaries. Interestingly UX like culture is a dynamic domain:

> *"A multi-dimensional space where there's still plenty of room to build new boxes and draw new arrows, at least for the next ten years"* Morville (2004).

These 7 facets of UX and their purpose (Morville 2004) are set out with suggestions on how insights from other scholars cited in this research (Table 9.5) could be nested under the 7 facets. Opinions may differ on how some factors overlap, e.g. some of Thomas and Bevan's (1995) 'Context of use: Usability' characteristics include culture. Also, their characteristics could be nested under 'usable': however, as they highlighted many factors for consideration, an additional, new facet 'Context' is suggested next to 'usable' to ensure all the questions are posed.

Under 'Accessible' we might nest a consideration of different groups' economic barriers (Nielsen 2006) or purchasing power (high, low or none) and capability (full capability, reduced, disability; Benktzon 1993).

Under 'Valuable', could be a consideration of needs as depicted in Maslow's model with 3 additional levels (Thorson 2006).

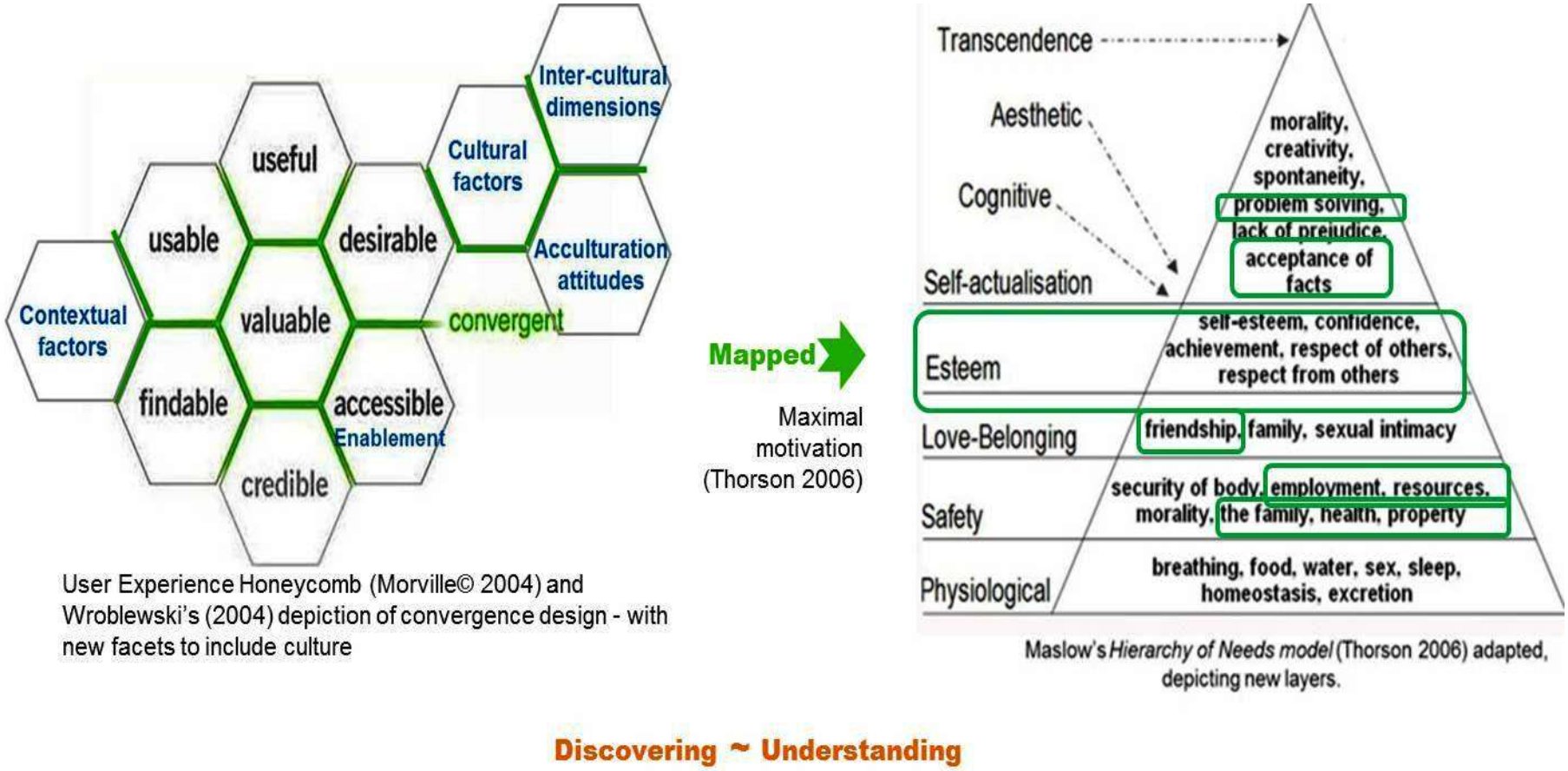
Under 'Cultural factors' we could nest 'Cultural specificity' (whether to design for local, blended or global culture, (Israsena & Boonvong 2009) and 'Cultural attributes' (Table 9.2). 'Acculturation' relates to Table 9.3 and 'Inter-cultural dimensions' to Table 9.4 (above).

Table 9.5 Morville's (2004) 7 facets of UX, with other scholarly insights nested under the facets and suggestions for 4 facets to emphasise context and highlight cultural factors

The 7 UX facets (Morville 2004)	Some suggestions of nesting insights from other scholars
1. Useful: Required courage/ creativity to define innovative solutions.	
2. Usable: vital and necessary, but not sufficient.	Context of use: usability (Thomas and Bevan 1995) Usability (Nielsen 2006)
3. Desirable: Appreciating the power/value of image, identity, brand and elements of emotional design.	*Jouissance* (Zizek and Lacan cited by Dean 2002); Delighter attribute (Evans *et al* 2002) Pleasure in design (Jordan 2004)
4. Accessible: Particularly for people with disabilities.	*Inclusive Design Cube* (IDC) (Keates *et al* 2000) Individual capability/ economic limitations (Israsena and Boonvong 2009); Economic barrier (Nielsen 2006)
5. Valuable: for sponsors (the bottom line) and customer satisfaction.	Maslow's *Hierarchy of needs model* extended (Thorson 2006)
6. Findable	Context of use: environment (Thomas and Bevan 1995) Empowerment barrier (Nielsen 2006)
7. Credible: The elements that influence whether users trust/believe.	(**Trust** was an important consideration throughout the research.)
	8. Context of use characteristics Thomas and Bevan (1995)
	9. Cultural Attributes Cultural specificity (Israsena and Boonvong 2009) Hall and Hall (1976) Johnson (2004) Salazar (2010); and Author
	10. Inter-cultural dimensions Hofstede and McCrae (2004) Hall and Hall (1976) Rau *et al* (2008)
	11. Acculturation Berry(1997) NAB (2000) Verkuyten and de Wolf (2002)

Figure 9.2 depicts the author's suggestion for extending the convergence design model to highlight and include both context and culture for a more inclusive approach to 'understanding' and 'discovering' whilst designing for a multicultural society, such as in the UK. These facets could prove useful also whilst designing for market segments in other cultures abroad to determine whether to design for blended culture/ inclusivity/ commonality or for diversity/ cultural specificity resulting in the inclusion of a greater cultural awareness and, perhaps, reaching more user groups in home countries and abroad.

The motivations for using the tools were then mapped to Maslow's model to consider how to maximally motivate users.



User Experience Honeycomb (Morville© 2004) and Wroblewski's (2004) depiction of convergence design - with new facets to include culture

Maslow's *Hierarchy of Needs model* (Thorson 2006) adapted, depicting new layers.

Figure 9.2 During the 'discovering/understanding' phases of the inclusive design process, new contextual and cultural facets are suggested for Morville's (2004) UX convergence design model; and how potential benefits for patients, family and staff were mapped to Maslow's model to consider maximal motivation to use the tools.

9.5.5. The design process

These considerations were then translated into requirements to create an inclusive design concept. The perceptions of a wide range of users from all three studies informed the designs (see 9.5.3.1). Participatory design techniques were allied to inductive research (which added questions and shared information between the groups) and social constructivism (that people perceived/understood and, therefore, described the same event in different ways, neither of which was necessarily wrong; Willig 2008). We noted that staff were a part of the service and the image of an organisation depended on how users perceived the process itself (Masterson and Pickton 2004; MAANZ 2005). Thus, it is suggested that the 'potential service', what it could be (Waterhouse 2008), offers opportunities for improving patients' perceptions of the healthcare organisation and also for the organisation to send positive messages to patients to counter particular difficulties (such as language barriers or a lack of understanding or, more recently, a lack of trust).

Although inclusive design and UCD principles, a Vygotskian bridge, 'scaffolding' (Cole 1985) and visual communication guidelines (Chapter 7) laid the foundation for the tools, these were not, on their own, able to address communication barriers. This was because the literature identified particular cognitive and comprehension challenges presented in designing and using pictorial aids, particularly for people with low-literacy (Dowse and Ehlers 2001, 2004; Johnson *et al* 2006; Sorfleet *et al* 2009) which affected safety. Thus, a further 5 theoretical 'ingredients' were added to the creative crucible:

- **To ensure the right questions were being addressed**. Convergence design for UX (Wroblewski 2004; Moreville 2004) was used to understand the connections and commonalities between healthcare environment/staff and the social milieus of EMCs lacking English and/or literacy (Indian Subcontinent) and indigenous elderly people. It was used also to establish how the tools could be made useful, usable and enjoyable and also credible, accessible, findable.
- **Motivation**. Users' potential aims were mapped to several levels of Maslow's pyramid to create 'maximally motivating' user responses

(Thorson 2006) and satisfaction, loyalty, even evangelism (Haque 2009) by better understanding users' needs – the delighter attribute (Evans *et al* 2002; Jordan 2004).

- **Topical research**. Culturally competent and accessible patient information required current knowledge on the topic to be collected, collated, reviewed and assessed with a range of staff and the community (evaluating and validating, Johnson *et al* 2006;p.35). Thus, pain screening and medication were researched, the information was collated, insights from Study-2 added (staff liked to greet/reassure patients) and organised into a 'conversation' and validated with staff (the experts) to adjust the questions. This provided the foundation, but was not assessed with the public who would subsequently assess the illustrated section (twinned tools).
- **Brainstorming** (Robson 2002) inspired the author to use phonetics as the 'honey' that 'glued' UX facets (Wroblewski 2004) and to develop this into a conversation format. Inspiration came from the difficulties Sikh generations face in reading and enunciating *Gurmukhi* script (the compositions of the Sikh Gurus in the *Guru Granth Sahib*) written centuries ago. The early Punjabi language, Sanskrit, Arabic and Persian is often transliterated into English inserted alongside the script in *gutkas* (small volumes of prayer) to help devotees to pronounce the words. However the English spellings incorporate dictionary symbols and, in many places, require prior knowledge of how to pronounce the Punjabi script. This problem was addressed by altering the emphasis to how English is pronounced.
- ***Jouissance***, pleasure, the delighter attribute (Dean 2002 citing Zizek and Lacan; Jordan 2004; Evans *et al* 2002) was introduced through variety.

Topical research generated the questions staff asked patients and these were validated with staff (not patients). Questions were illustrated for patients in accordance with NICE (2009) guidelines which suggested making information accessible and understandable by using pictures, symbols, large

print and different languages (however, language scripts were not used and were replaced with phonetics). It was noted that people with low-literacy could find standard pictograms too sophisticated (e.g. US Pharmacopeia Dispensing Information) and needed to be designed with the target population so that images were better interpreted and patient information was culturally competent (Dowse and Ehlers 2004; Johnson *et al* 2006). It was important that images should not be the sole source of communication; images alone did not convey the level of information required for proper comprehension although they stimulated recall of spoken information and patients unanimously felt pictograms on their medication were a good idea and would help them to remember their medication instructions (Dowse and Ehlers 2004). Images were therefore combined with text in thematic/ storyboard arrangements; the simplest English and Hindi/Urdu words were used; appropriate fonts and colours included users with poor vision or colour-blindness; and colour-associations considered the emotional effect on patients (Boisaubin and Winkler 2000; Johnson 2004; Safeer and Keenan 2005; Dowse and Ehlers 2001, 2004; Fiesner 2006; Sorfleet *et al* 2009; Plain English Campaign 2011).

With some departmental exceptions, we noted that the majority of staff relied on English-speaking EMC familial support to overcome literacy barriers and, often, to resolve language barriers and to monitor treatment adherence at home. Staff and familial roles in the communication experience were stronger in the cases of patients lacking English/literacy. Thus, the questions for designing were: How could such patients become more empowered? How could the designs be harmonised with the needs of indigenous elderly patients? How could the tools address users with knowledge ranging from expert to no-literacy? To address these questions, 7 factors were 'converged' to facilitate a 'community' bound by a common interest; healthcare:

- Staff had 'ownership' of the on-going process (i.e. expert lead, as normal), whilst each group was treated as 'experts' on their own needs.
- EMC patients lacking English/literacy could be greeted and encouraged to respond using simple words and as much English as

they knew.

- The tools created a meaningful ‘bridge’ between separate healthcare experiences and professionals for patients lacking English; were infused with the information needed by staff (on the topics selected) and provided an aid for learning English at their own pace/time.
- Familiarity with the tools (staff and patients) and a feeling of ‘community’ was generated through simplicity and following normal routines, the tools supported enactive methods used by staff and were harmonised across 6 departments to save money and nurture familiarity.
- The language and cognitive preferences of indigenous elderly people were harmonised in the tools through testing.
- The cognitive load (staff and patients) was minimised through phonetics.
- Family were engaged to support patient learning using the ‘take-away’ educational element.

The designs focussed on minimising burdens (cognitive, time), generating trust (credibility, accuracy), adding joy/interest, on identifying and incorporating as many points of harmony/commonality between the users and reducing potential differences. They accommodated different users’ existing cognitive processes (because culture and cognition created each other, Cole 1995) and the images and text were positioned appropriately to facilitate teaching and learning (Barlex and Carre 1985) and to nurture familiarity and ease-of-use.

Taboos were taken into account for EMCs (e.g. explicit images of naked bodies) as the tools were designed for a familial environment and to be sensitive to indigenous elderly of a different generation. Recognisable images of globalised products/services in everyday living were used, however, some new and diverse images and symbols were added to generate interest (emoticons, yes/no/I don’t know) because joy is what holds a community together. This was important to motivate users, although how joy was included in healthcare needed careful consideration, an environment

where patients became stressed.

The meanings users ascribed to the images were more important than aesthetics. Iterative testing and user suggestions ensured effectiveness of interpretation and that the different users' thoughts produced consistency/ accuracy as the designer intended (Draper 1994; Kazmierczak 2003; Frascara 2004; Crilly *et al* 2008). The knowledge infused in the tools was taken as representing Vygotsky's 'knowledgeable user' to nurture a virtual 'collaboration' between staff and patients (EMCs lacking English/ literacy, indigenous elderly).

Testing autism picture cards (relevant to healthcare) found them to be readily understood by a majority of EMCs lacking English (the hair on the head was favoured) and elderly indigenous participants and both groups liked the zig-zag representations of pain. The variety of images were unanimously favoured, the accompanying text was helpful to users for clarity, learning and for memory recall. No noticeable gender differences were observed in cognition or preferences amongst EMCs and indigenous elderly (although only 2 EMC participants were male). The images were received well by participants across genders, cultures or age groups, and by family.

As noted in Study-3, staff favoured the arrangement of information which was easy to navigate for most and the response checkers. Although they did not need images it was suggested by one doctor to include these in the staff tool.

In combination, these factors and the design process answered the questions posed. Could culturally inclusive tools be designed to motivate EMCs to learn English gradually (to reduce problems originating from language barriers)? How such patients could be empowered to harness patient-engagement (Corrigan cited by Imison *et al* 2011; Streets 2011) and to encourage more females lacking English to participate in the 'communication experience'. Could intra-cultural impediments be reduced through addressing misconceptions (that English is corrupting; Easton 2006) or negative gender attitudes (power distance; Hofstede and McCrae 2004)? Would staff, such as nurses who "are in an ideal position to facilitate the interconnections between patient […] and health literacy" (Singleton and Krause 2009) be willing to

reach out and use the tools developed? Ultimately, would they be prepared to put a simple message to patients to encourage learning English?

These questions were answered by considering the common drivers that could be harnessed to bring about a combined effort to lower language/ comprehension barriers, to lower costs in healthcare delivery whilst simultaneously nurturing social integration, and by mapping the attributes of the designs to Maslow's model (Figure 9.2). Research on pictorial aids in healthcare has wrestled with the problems of cognitive overload, patient comprehension and additional burdens placed on staff on explaining to patients, particularly for patients with low-literacy. As mentioned above, these burdens were reduced in this research by the use of innovative ways to bridge cognitive overload and sustain longer-term learning through harnessing the patient's potential.

9.6. Overall Aims, Objectives and Research Questions

In combination, the primary research in the three user studies (chapters 4,6,8) and the secondary research (chapters 2, 3, 5 and 7) successfully addressed the 3 overall aims of this research project:

1. To explore the nature of, and the individuals affected by, barriers perceived by EMCs (Indian Subcontinent) relating to their uptake of services and products in the UK, to identify a particular service or product for detailed investigation.
2. To explore the service/product providers' (staffs') perceptions of barriers and the aids used to overcome difficulties and to compare these with EMCs' perceptions.
3. To develop and test an inclusively designed aid to contribute to the lowering of a barrier and, hopefully, improving the uptake of a service/product by EMCs.

and helped to answer the four research questions that were integral to the overall objectives as discussed below.

Objectives 1-3 were addressed through the first literature review (chapter 2) to gain the theoretical understandings that informed the research journey.

Obj:1	To better understand the nature of ethnicity and cultural factors that influence individuals; how culture relates to products and services; and EMC demographic trends in the UK and the implications thereof.
Obj:2	To better understand the nature of services and products and how these are promoted to consumers; human motivation; and how the take-up of services and products is influenced by users' experiences with them.
Obj:3	To better understand how positive user experiences can be created through a consideration of human factors in design, such as user-centred design, inclusive design and the concepts of usability and context of use.

Objective 3 particularly underpinned the design phase and the key highlights of this literature are set out in 2.5.

Objective 4 was addressed by the 1st user-centred study (chapter 4) with EMCs (Indian Subcontinent) which answered Research Question 1 and fulfilled the overall Aim 1.

RQ1	Did EMCs (Indian Subcontinent) perceive that any barriers hindered their take-up of products or services in the UK? If present, what was the nature of the barriers and who did these affect?	**Study 1: Investigative** EMCs (Indian Subcontinent) (Chapter 4 - Aim 1)
Obj:4	To commence research with an investigative study to ascertain and understand EMCs' perceptions of any barriers they experience in accessing or using services or products in the UK, and their preferences. From these results, to narrow the research focus to a particular service or product provider.	

The key highlights of these findings, discussed in 4.6, narrowed the research focus to healthcare and the NHS. EMCs' preferences were also compared with the preferences of staff (Chapter 6) which informed the generative phase of the research (Chapter 8). Strong themes with the majority of both groups of participants was that they favoured English learning, attitudes of respect

were no hindrance, and that visual communication was popular (AV products/services, body language, visual media).

Objective 5 was addressed in two chapters:

Obj:5	To review the literature as research progressed to lay the theoretical foundation for subsequent studies.

Chapter 5 (Literature review-2) extended the theoretical foundation of the research in preparation for the study with NHS staff, whilst Chapter 7 (Literature review-3) prepared the detailed foundation for the generative phase (Chapter 8). This literature is discussed and summarised in 5.7 and in 7.8, respectively.

Objectives 6 and 7 were addressed by study 2 (chapter 6) which investigated front-line NHS staff perceptions of problems whilst caring for EMCs (Indian Subcontinent). This study answered **Research Questions 2 and 3** and fulfilled the overall **Aim 2**.

RQ2	What were healthcare staffs' perceptions of barriers and what aids were used to overcome difficulties?	**Study 2: Investigative** Service Provider NHS staff (Chapter 6 – Aim 2)
RQ3	What were the similarities or differences in views between EMCs and the NHS staff and what were the implications for inclusive design?	
Obj:6	To undertake a 2nd investigative, formative user-study with the provider's staff to better understand their perceptions of any difficulties encountered and their needs and preferences.	
Obj:7	To compare the results of studies 1 and 2 to determine whether inclusive design might play a role in lowering a barrier and accommodate the needs of both users and providers.	

These findings are discussed in 6.7 and the views of EMCs and staff are compared in 6.8.

Objective 8 (**together with Objective 3)** helped to implement the final generative study (Chapter 8); to answer **Research Question 4;** and to fulfil the last, overall, **Aim 4** of this project**.** The findings from this study are discussed in 8.5.

RQ4	How might inclusive design contribute to lowering communication barriers for EMCs and NHS staff?	**Study 3: Generative** Inclusive, User Centred Design • EMCs lacking English and/or literacy • NHS Staff • Indigenous participants (Chapter 8 – Aim 3)

Obj:8 To undertake a generative study to design and develop an aid that might help to lower a selected barrier using user-centered design and inclusive design philosophy with iterative alpha-beta design testing and evaluation techniques, to benefit EMCs, providers and indigenous participants.

9.7. Discussion of Methods

Research commenced with EMCs, 'the public', rather than a provider as being most appropriate to this user group and a user-centred approach. Participants were directly approached to minimise any potential bias from vested interests (Bent 2009).

9.7.1. Appropriateness of Methods

The literature was invaluable in selecting the methods, which were appropriate to each stage of the research and generated the data that answered the research questions: sometimes, rich data of participants' experiences and views, at other times evaluative and critical responses. The inductive approach facilitated one or two questions to be added as research progressed and worked very well. Data was analysed between interviews to adjust the sampling.

The research approach of interpretive, critical realism and social

constructivism accepted that peoples' experiences and perceptions are influenced by their cultures, history, language and other factors which set the contexts. People therefore perceived or understood, and thus described, the same event in different ways, and all these might be valid (Willig 2008). This concorded well with an empathic, sensitive approach to participants' views (Evans *et al* 2002).

In studies 1 and 2, open, semi-structured questions and probes generated data of participants' views, experiences, processes and desires, enabling a more holistic understanding of the phenomena.

Study 1. Family focus groups provided reassurance to EMC participants, most of whom were unfamiliar with research. Naturalistic settings (ecological validity, Willig 2008) were empathic to the context of participants' variations in skills, knowledge and mental attributes (Thomas and Bevan 1995) which included extremes of literacy and English skills. It helped that the subject area was non-controversial and participants appeared to relax and to readily express their views. Semi-structured interviews included widows and single people in study 1, and used probes to elicit data. Visual prompts aided recall and helped to focus the discussions. Questions were mainly open but with some closed questions to elicit background data for context (age group, English skills, etc.)

Study 2. NHS staff appeared to freely express their views and a framework based analysis worked well in a limited time frame with a pre-designed sample (Srivastava and Thomson (2009).

Study 3 followed a user-centred, inclusive design approach and participatory, convergence design techniques in iterative design testing and evaluation process (Moreville 2004; Rohrer 2008; EMMTII 2009). The widest range of users possible within the timeframe were involved (Black 2008). Mixed-hybrid techniques generated rich data and helped to implement the stages of design development: semi-structured interviews were employed during alpha-testing with staff to help validate and modify the core base of questions; a more structured format with other participants for the remainder of the study produced good critical feedback. EMCs expressed satisfaction

that individual interviews enabled them to express their views freely.

Participatory design techniques (Umiker-Sebeok and Gregson 1999) enhanced creativity, provided accuracy and consistency of design interpretation (Frascara 2004; Kazmierczak2003). The evaluation form elicited critical feedback in the context of design characteristics for the visual aid proposed following guidelines from convergence design (Morville 2004). These methods worked well and enabled data gathering that was important in upgrading the prototypes in each stage.

Participatory design was also the most appropriate method, as participants either did not have the time or the skills to gather the data required; none had knowledge of design process. The author shared information between the groups, which promoted a learning process, particularly for EMCs lacking English/literacy. Also, participants did not 'know what they wanted' or how to go about developing the aids.

The design rationale closely followed the findings from primary and secondary research and content was either validated or modified as appropriate in an inductive iterative process. Thus, all aspects of the designs and the concept were user-tested and the process worked well as did the tools used (text, images, fonts, layouts).

9.7.2. Sampling

Purposive sampling was appropriate to this research project as it enabled the research to focus on particular groups and to explore particular issues, thereby, to achieve its aims and to answer the research questions (Robson 2002; Willig 2008). Involving as many stakeholders as possible provided a more holistic understanding of difficulties as did gathering a wide range of user responses.

Basing subgroups on religions and generations was revealing (inspired by Burton 2002) and using a region rather than a country (Jylha 2007, Boztepe 2007) worked well. Within the given time constraints and the project framework, this sampling approach provided the insight needed to design inclusively.

Sampling numbers worked well as themes were repeated, however, there

were areas in which improvements were desirable to raise numbers amongst particular subgroups.

Study 1. The main difficulty lay in recruiting Christian families who had come to the UK who felt they had no difficulties and therefore nothing to contribute. This appeared to be because the cultural distance was little – the family had learned English, followed Christian belief and had integrated well.

Study 2. In addition to the overall climate of change in the NHS which was challenging, there were two recruitment difficulties: a lack of response from pharmacists in acute care pharmacies and from GPs in primary care. There was no clear indicator as to why this was as no reasons were given. It would have been helpful to have more participants to confirm the themes; however, the rich qualitative data can be considered indicative of findings that could be attained from a larger sample.

Study 3. An inclusive approach was fostered by involving as many different groups as possible: NHS staff, EMCs lacking English and/or literacy and indigenous elderly people. This worked well and each participant group generated insights that helped to develop the prototypes according to individuals' preferences and to address any difficulties. Using a small number of NHS staff as 'experts' in different departments worked well during the iterative design process, but the small sample did not allow for the fact that some staff might not get the opportunity to test/ evaluate the prototypes which reduced the feedback gained. This possibility should have been anticipated and the staff sample numbers raised early on, particularly as the phonetics element part of the design concept was unfamiliar to them. Inclusivity will be enhanced with the inclusion of more EMC groups in future research.

9.7.3. Time management

Time impacted considerably on this research project. As Rohrer (2008) and Robson (2002) stated, time is a critical dimension in making decisions on sampling and methodology. Although recruiting participants was generally challenging, considerable time was required to gain NHS ethical approvals, much more than was anticipated.

Study 1: This study proceeded quite well and in a timely manner although some time was taken up in unsuccessfully trying to generate more Christian participants.

Study 2: Although researching with NHS staff was a time-consuming process, it was a necessary and rewarding aspect of the research. Time was mainly taken up in gaining regional NHS REC approval (7 months) and then in managing individual site R&D formalities and gaining permission from department managers to approach staff. However, this research project, could not have unfolded as it did without the insights provided by NHS staff, as each study emerged from its predecessor(s). The author's interest and curiosity were also caught by a combination of factors. The NHS had facilities in place to help deal with language barriers which are well-known problems in healthcare. Thus, it might have followed that perhaps NHS staff did not face difficulties (because these were resolved), or did they? If yes, what did they feel would help them further? Could some fresh approach be devised that might help?

In combination, several factors from the literature and current affairs suggested causes for concern and an opportunity for research. The annual cost of interpreters/ translations in the NHS is high; the UK's EMC population is predicted to double by 2051 and is significantly influence by international migration (Rees *et al* 2011) including from countries where English is not the first language; existing residents, particularly EMC females (Indian Subcontinent), did not know English (recent arrivals to long-term residents, Study-1); some females faced hindrance from males in their attempts to learn English (Easton 2006; Study-1); and the lean economic times. Finally, although facilities were provided in the NHS, still, a female subgroup in Study-1 cited problems in using healthcare (and other) services.

Data from the 2011 census on main language skills in England and Wales, released since the examination and completion of this thesis, provided further evidence for the necessity of addressing this issue.

- In 1m households (4%) no one spoke English as a main language;
- in 182,000 households (1%) one child spoke English; and
- in 868,000 households (4%) at least one adult spoke English as a

main language (ONS 2012;p.18).

Study 3: The initial NHS ethics application set out the research proposal as research in '2 phases' (i.e. studies 2 and 3) and, as a result, enabling study 3 to be approved through the shorter 'Substantial Amendment' process. However, time was required thereafter for site R&D approvals. The iterative design phases were also time-consuming and challenging but enjoyable including the final evaluation when the prototypes were left with staff to test.

9.8. Strengths and Limitations

Limitations

It could be argued that the limitations in the research project lay in the small sample sizes and the research focussed largely on factors influencing one EMC group, or a limited number of NHS staff and departments. However, the aim of each study was to investigate and better understand phenomena amongst a given group and, as discussed in 9.3.2 above, these findings can be extrapolated to the general population (Robson 2002; Willig 2008). Although a few more 1st generation Christian participants (Study-1), pharmacists (acute care) and general practitioners (Study-2) and more staff in evaluation (Study-3) would have been ideal, rich data was collected from all the participants and their views were cross-referenced between participants and with the literature.

Strengths

The strengths of this research project lay in a combination of factors: its close adherence to guidance from the literature; diligent primary research; careful analysis; that themes were compared and interpretation considered between studies 1, 2 and the literature; and that themes were repeated. Naturalistic surroundings and emphasising that there were no *right* or *wrong* answers and that the data would be anonymised, resulted in participants relaxing and expressing their views freely and key themes were repeated. Data gathering ceased when themes began to be repeated and emerging themes were compared recursively moving between the data.

In study 1, defining subgroups as religions and generational (based on literature) might be considered a strength because it provided a framework

for understanding differences and similarities in views and also in gaining context by comparing acculturation and background between generations, religions and genders. Tabulating the emerging themes aided comparison.

In study 2, the participants were professionals with substantial experience in the NHS and problems were considered in balance with the aids used, their strengths and weaknesses, any gaps and what staff felt might help further. Data were put into context by considering other patient groups who shared similar difficulties (staff cited other EMC groups and indigenous elderly people, albeit for different reasons). Findings set out the context of staffs' roles and underlying demographic factors.

Likewise, the strengths of study 3 lay in strict adherence to a user-centred approach and participatory and convergence design process, on basing the content of the aids on healthcare literature, and in user-testing every design element and sharing information between the participant groups. Within the given timeframe, the study adhered to the philosophy of inclusive design through considering the needs of a wide range of users of varying abilities and different cultural backgrounds to find common themes.

9.9. Contributions to Knowledge

It is suggested that the research findings may be applied across a range of topics in healthcare and in other disciplines also. This author subscribes to Robson's (2002:p.177) view that the data can provide insights and sufficient generalisation or universality "to allow projection to other contexts or situations". Also, if the *"given experience is possible, it is also subject to universalisation"* and, because we know the experience identified, it is available within a culture or society even if the numbers of people sharing it are unknown (Willig 2008:p.17).

The contributions to knowledge from this research project are suggested as follows:

Study 1:

- Provides an adaptable, scalable concept for gathering rich knowledge of EMCs' experiences by comparing differences/similarities of views between generations, religions and

genders. The concept incorporates larger or smaller geographic regions, religions or sects, or generations or age groups.

- Comparing and contrasting good versus bad experiences contributed to understanding of EMCs' perceptions and preferences, to provide contexts for designers and providers.
- Some socio-cultural insights were demonstrated (such as reasons for a poor motivation for English learning amongst long-term residents, particularly females).
- Improved the understanding of EMC communities that cultures are not static but keep evolving and shifting the discussion of learning English from culture to context, whilst explaining its wide benefits including the needs of aging, could help to reduce intra-cultural male hindrances and motivate existing residents to learn English. This would mutually benefit EMCs, families and healthcare providers whilst aiding social integration.

Study 2:

- Pharmacist-patient communication in pharmacies appeared to be low in the UK which, the literature confirms, adversely impacts on medication adherence and language and literacy barriers are not considerations.
- A gap in adult-patient care in the NHS was a generally low use of visual communication aids, contrary to the literature.
- Suggestions from NHS staff on what would help them further.
- Using framework based analysis in a design study (borrowed from social sciences and healthcare literature).

Study 3:

- An inclusive design approach involved NHS staff in different departments, EMCs lacking English and/or literacy and indigenous elderly people to harmonise aids, save cost and time across departments and healthcare services, and facilitate learning through repetition.
- The use of phonetics as a communication tool to bridge the gap between images and text; to improve patient comprehension; and to

facilitate direct staff-patient communication whilst avoiding memory overload,

- Incorporating a 'take-away' educational element in the communication aid and proposing healthcare as a motivational pivot to encourage more English learning, as a route to sustainably lowering language barriers for EMCs and future costs in healthcare delivery, whilst also aiding social integration.

Discussion:

- Suggestions for how cultural theories (cultural factors, inter-cultural dimensions, acculturation), context and inclusive design can be tabulated to pose questions and to embed cultural factors in the discovery/ understanding phases of the inclusive design waterfall model; and combined with the convergence design model and mapped to Maslow's model to create maximal user motivation.
- A suggestion to extend the facets of the convergence design model to include cultural factors, inter-cultural dimensions, acculturation and contextual factors (i.e. context of use characteristics expands on 'usable').

Papers

Three papers have been published on this research project, thus far:

- Taylor SP, Nicolle CA, Maguire MC (2010) *Preliminary Study of the Cultural Barriers which may affect Universal Access.* In: Proceedings of 5th Cambridge Workshop on Universal Access and Assistive Technology, CWUAAT 2010, Fitzwilliam College 22-26 March;pp.3-14. Clarkson PJ, Langdon P, Robinson P eds. Cambridge University Press. Available: https://dspace.lboro.ac.uk/dspace-jspui/handle/2134/6357
- Taylor SP, Nicolle CA, Maguire MC (2011) *Cultures and Contexts: An Empathic Study of the Needs of Ethnic Consumers in the UK*. In: Research into Design: Supporting Sustainable Product Development; pp.133-142. Chakrabarti A, ed. Singapore: Research Publishing. Proceedings of International Conference of Research into Design

(ICoRD11), Indian Institute of Science, Bengaluru, Jan.10-12, 2011. Available: https://dspace.lboro.ac.uk/dspace-jspui/handle/2134/7015

- Taylor SP, *et al* (2013) Cross-cultural communication barriers in health care. *Nursing Standard.* Vol.27(31):pp.35-43.

9.10. Suggestions for Future Work

Researchers might like to consider extending the studies in several ways: such as, increasing sample size in any of the studies and using generations and religions in combination to compare different study groups.

Study 1: Researching different EMC groups in the UK, or in a different region of the UK or a different country; exploring the difficulties cited with some staff from the Indian Subcontinent in healthcare, social services or job centre services in the UK; using difficulties and preferences to explore EMC perceptions in services like travel (airlines, trains, etc.) or product groups.

Study 2: Involving NHS staff in other departments; considering the problem of low pharmacist-patient interactions in the context of cost and time (i.e. alternatives that will not raise interpreter costs); researching different geographic areas, counties in the UK or other countries; considering problems in healthcare for different EMC groups; exploring perceptions of healthcare services in different EMC communities.

Study 3: Researching other healthcare topics to produce low-cost visual communication aids to lower language barriers; including other languages and ethnic minority groups.

The author proposes to take the development of the visual aids forward in a post-doctoral collaborative design-research project involving a University, NHS organisations and staff, the public and other stakeholders in a proposed social enterprise that will be capable of becoming self-funding. There is much work to be done to iteratively improve the prototypes and staff requested the tools be web-enabled and other languages and uses included. It is anticipated that the educational element will remain an integral part of the aids which will be based on rigorous research.

9.11. Conclusions

The main conclusions of this thesis are that, to lower the adverse impact of language barriers in healthcare and to improve patient experience for patients lacking English, commonality of approaches such as promoting English learning, merit consideration alongside multicultural diversity initiatives. Although interpretation will remain necessary in an era of international travel, demographic trends suggest time-cost burdens will rise unless fresh approaches are considered. In some spheres of healthcare, cost and time benefits can accrue from inclusive, user-centred design approaches.

Some marginalised EMC subgroups (like some females from the Indian Subcontinent) need inter-cultural support because they lack the knowledge of how to help themselves, or are unable to do so as a result of intra-cultural hindrances, possibly face pressure in joint-family arrangements and some are far from their families with whom they grew up. Moving the discussion of learning English from culture to context could help to lower intra-cultural hindrances and negative attitudes and serve to empower females in 1st generation EMC families, particularly if the family better understand the wide economic and health benefits and needs that grow with aging.

"If not now, when?"

(Hillel, the famous Jewish religious leader, d.10AD)

Promoting English will require sensitive handling and *now* appears to be an opportune time to do so for a combination of historical and socio-economic reasons. English is an 'international' language and words, phrases and numbers associated with daily living have proliferated amongst people worldwide with the globalisation of services and products, from remembering addresses and telephone numbers, from words transliterated in healthcare and the flow of information across the internet. Also, there appears to be a growing awareness of the need for English amongst those on both sides of language barriers. The desire for good health is ubiquitous, culture is not a barrier, rather, better understanding its nature offers pathways for positive change. As suggested in the literature, perhaps mapping the benefits of English to Maslow's model could help to motivate individuals and families.

These factors and the affection for indigenous healthcare staff amongst EMCs places frontline healthcare staff in a unique position for promoting the message, as nurses have also pointed out. It is possible that 2nd generation family members will appreciate such support, for whom it will lower time pressures and anxiety. Thus, there exists the possibility of a series of local health-based communities in which the common interests of professionals, patients and families become the means by which change may be driven. A sense of shared participation and joy can become the 'honey' that binds the communities together. In the context of language barriers amongst UK residents, engaging patients and their families would generate a combined effort to address difficulties and, in turn, offer the potential for mutual benefits to patients, families, staff and healthcare services – and, in the process, also aid social integration, harmony and well-being.

10. REFERENCES

ARDITI A (2005) *Effective Color Contrast - Exaggerate lightness differences between foreground and background color.* ©Lighthouse International. Available*:* www.lighthouse.org/accessibility/design/accessible-print-design/effective-color-contrast [Accessed: 15.03.2011]

AKANE I (2011) *Using one or more examples, explain "emic" and "etic" concepts – Akane.* SIS IB Psychology. Available: http://psychology.geckos.sis.org.cn/2011/10/using-one-or-more-examples-explain-emic-and-etic-concepts-akane/ [Accessed: 6.12.2011]

AGRAWALA M, LI W, BERTHOUZOZ F (2011) Design Principles for Visual Communication. *Communications of the ACM*; Vol.54(4):pp.60-69. Association for Computing Machinery. Copyright © 2011 ACM, Inc. Available: http://cacm.acm.org/magazines/2011/4/106586-design-principles-for-visual-communication/fulltext [Accessed: 26.8.2011]

AMERICAN COLLEGE OF PREVENTIVE MEDICINE (2011) *Medication adherence time tool: improving health outcomes*. Available: www.acpm.org/?medadhertt_clinref [accessed: 5.3.2011]

AMERICAN PHARMACISTS ASSOCIATION (2004) *Enhancing Patient Adherence.* In: Proceedings of the Pinnacle Roundtable Discussion, Washington, DC, June 16, 2004. Highlights Newsletter October 2004; Vol.7(4) Available: www.pharmacist.com/AM/Template.cfm?Section=Home2&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=11174 [Accessed: 15.11.2011]

AMALRAJ S, STARKWEATHER C, NGUYEN C, NAEIM A (2009) Health literacy, communication and treatment decision-making in older cancer patient*. Oncology* (Williston Park), April 15, 2009; Vol.23(4):pp.369-375

ANDERSON C (2004) *Long Tail.* Available: www.wired.com/wired/archive/12.10/tail.html [Accessed 15.7.2008]

ANDERSON JA, MEYER TP (1988) *Mediated communication: a social action perspective.* Newbury Park, CA: Sage

ANIL TM (2007) *The role of pictograms in patient medication adherence.* MA Dissertation, Department of Pharmacy, Visweswarapura Institute of Pharmaceutical Sciences, Bangalore, India

ANONYMOUS (2003) *Special Report: Europe's minorities. Forget asylum-seekers: it's the people inside who count.* The Economist, May 10th 2003; Vol.367(8232):p.25

ANONYMOUS BBC News in England. Available: http://news.bbc.co.uk/

(2004) *Cleveland police handbook.* [Accessed: 11.5.10]

(2005) *Mobiles 999 Contact Idea Spreads.* [Accessed: 21.2.11]

(2011) *Ethnic minority pupils increase by 57% in a decade.* [Accessed: 15.1.2012]

ANONYMOUS (2012) *Patients to get face-to-face interpreters, 27 October 2011.* The News Available: www.portsmouth.co.uk/news/health/local-health/patients-to-get-face-to-face-interpreters-1-3182024 [Accessed: 20.2.2012]

ARONSON J (1994) A pragmatic view of thematic analysis. *The Qualitative Report;* Vol.2(1) Spring. Available: www.nova.edu/ssss/QR/BackIssues/QR2-1/aronson.html [Accessed: 15.5.2010]

AUERBACH SM (2009) The Impact on Patient Health Outcomes of Interventions Targeting the Patient-Physician Relationship. *Springer, Adis The Patient: Patient-Centered*

Outcomes Research: 1 June 2009; Vol.2(2)

AUJLA G (2011) *English language help for minority pupils could face time limit*. BBC News: Education. Available: www.bbc.co.uk/news/education-16251714 [Accessed: 15.1.2012]

BABYCENTRE MIDWIVES (2011) *Keywords in Hindi*. Available: www.babycentre.co.uk/midwives/translated_keywords/hindi# [Accessed: 23.2.2011]

BAILEY B (2005) *Age-Related Research-Based Usability.* Usability.gov Available: www.usability.gov/articles/newsletter/pubs/112005news.html [Accessed: 11.6.2011]

BALAKRISHNAN TR, MAXIM P, JURDI R (2005) Social Class versus Cultural Identity as Factors in the Residential Segregation of Ethnic Groups in Toronto, Montreal and Vancouver for 2001. *Canadian Studies in Population* 2005*;* Vol.32(2):pp.203-227

BARKER C (2000). Culture, Meaning, Knowledge. In *Cultural Studies: Theory and Practice.* London: Sage Publications

BARLEX D, CARRÉ C (1985) *Visual communication in science*. Cambridge: Cambridge University Press

BARNARD M (2010) *Talk 2: Matt Barnard on Framework Analysis.* Online QDA Available: http://onlineqda.hud.ac.uk/movies/ESRC_RMF_2010/index.php [Accessed 3.3.2011]

BENDORIS M (2008) *Scandal of NHS interpreter costs*. The Scottish Sun18 Sep 2008. Available: www.thescottishsun.co.uk/scotsol/homepage/news/article1702733.ece#ixzz1YbBURtqH [Accessed: 10.03.2010]

BENKTZON M (1993) Designing for our Future Selves: the Swedish experience*. Applied Ergonomics;* Vol 24(1)pp.19-27

BERGER JOHN (1972) *Ways of Seeing*. Penguin, UK

BERLO D (1960) *The process of communication.* New York: Holt, Reinhart and Winston

BERRY JW (1997) Immigration, acculturation and adaptation. *Applied Psychology:* An International Review, Vol.46;pp.5–34. Available: www.unige.ch/international/etudageneve/gisp/prog/Readings/Akkari_Berry.pdf [Accessed: 12.02.2009]

BESSANT J, WHYTE J, NEELY A (2005) *Management of creativity and design within the firm*. Advanced Institute for Management and Imperial College, UK

BIRREN F (1961) *Color Psychology and Color Therapy.* New Hyde Park, New York: University Books Inc.

BITC (2007) *Facts and Stats: BME Spending Power.* Business in the Community. Study commissioned by Multi-Cultural Communications (MCC), Weber Shandwick 2007. Available: www.bitc.org.uk/workplace/diversity_and_inclusion/race/facts_and_stats.html#bme_spending_power [Accessed:9.12.2008]

BLACK A (2008) *Representing the full range of user need.* Design Council Available: www.designcouncil.org.uk/en/About-Design/Design-Techniques/User-centred-design-/ [Accessed: 12.02.2009]

BLACK A (2008) *The basics of user-centred design*. Design Council Available: www.designcouncil.org.uk/en/About-Design/Design-Techniques/User-centred-design-/ [Accessed: 12.02.2009]

BNF JOINT FORMULARY COMMITTEE (2011) *Recommended wording of cautionary and*

advisory labels. British National Formulary BNF No 61 March 2011 ed. British Medical Association and Royal Pharmaceutical Society. London: Pharmaceutical Press

BOISAUBIN EV, WINKLER MG (2000) Seeing Patients and Life Contexts: The Visual Arts in Medical Education. *American Journal of the Medical Sciences,* May 2000; Vol.319(5): pp.292-296

BORUN CENTER (2008) *Working to improve nursing home care: Modules - Pain Screening* GeroNet: Health and Aging Resources, UCLA. Available: www.geronet.med.ucla.edu/centers/borun/modules/Pain_Screening/faqs.htm [Accessed: 15.5.2011]

BOZTEPE S (2007) Toward a Framework of Product Development for Global Markets: A User-Based Approach. *Design Studies,* Sep.2007; Vol.28(5):pp.513-533. Science Direct. Available: www.sciencedirect.com/science?_ob=ArticleListURL&_method=list&_ArticleListID=848886805&view=c&_acct=C000010119&_version=1&_urlVersion=0&_userid=7419480&md5=50d5258f7d8580b327af5c5477a38086&zone=raall [Accessed: 14.11.2008]

BRAUN V, CLARKE V (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*; Vol.3;pp.77-101

BRYNJOLFSSON E, HU YJ, SMITH MD (2006) From Niches to Riches: Anatomy of the Long Tail *MIT Sloan Management Review* Summer 2006;Vol.47(4) Available: www.viewswire.com/report_dl.asp?mode=fi&fi=1740754759.PDF&rf=0 [Accessed 15.10.2008]

BRITISH RED CROSS SOCIETY (2004) *Emergency Multilingual Phrasebook 2004.* Available: http://shop.redcross.org.uk/shop/product.asp?id=90429 [Accessed 17.2.2011]

BROWN JS, DUGUID P (1994) Borderline Issues: Social and material aspects of design. *Human-Computer Interactions*; Vol. 9(1):pp.3-36

BRUNER J (1985) Vygotsky: A historical and conceptual perspective. In *Culture, communication, and cognition: Vygotskian perspectives,* WERTSCH J ed. Cambridge: Cambridge University Press

BSI7000-6 (2005) *About Inclusive Design: Definition British Standards Institute 7000-6, 2005.* Helen Hamlyn Centre. Available: www.hhc.rca.ac.uk/research/id/index.html [Accessed 15.6.2009]

BS9241-11 (1998) *Ergonomic requirements for office work with visual display terminals (VDT's).* Part 11- guidelines for specifying and measuring usability. British Standards Institute, London.

BURNS C, COTTAM H, VANSTONE C, WINHALL J (2006) *Transformation Design*, Available: www.designcouncil.info/RED/transformationdesign/REDPAPER02TransformationDesign.pdf [Accessed 10.3.2010]

BURNS J (2012) *School records 'too crude for super-diverse UK'* BBC News: Education. Available: www.bbc.co.uk/news/education-18118114 [Accessed: 15.6.2012]

BURTON D, ed. (2002) *Incorporating ethnicity into marketing intelligence and planning.* Available: www.emeraldinsight.com [Accessed: 3.11.2008]

CABINET OFFICE (2010) *Inclusion Health.* Was available: www.cabinetoffice.gov.uk/social_exclusion_task_force/short_studies/health-care.aspx [Accessed 15.4.10]

CARROLL M (2009) *Designing the customer experience: Barack Obama"s inauguration*

speech 28 January 2009. Foviance, Usability News. Available: www.usabilitynews.com/news/article5378.asp [Accessed: 06.02.2009]

CASTELLS M (2000) *The Rise of the Network Society: The Power of Identity.* 2nd edn. Oxford: Blackwell Publishing Ltd.

CHAPMAN J (2012) *NHS Spends £23million a year on translators: Costs rise as hospitals cater for 120 languages, 6 February 2012.* Daily Mail; p.19

CHARMAZ K (1995) SMITH JA (1995) Grounded theory. In: *Rethinking methods in Psychology.* SMITH JA, HARRE R, VAN LANGEHOVE L eds. London: Sage.

CHERRY C (1978) *On human communication: a review, a survey, and a criticism*. 3rd edn. Cambridge, MA, US: MIT Press

CHARVET-BERARD AI, CHOPARD P, PERNEGER TV (2008) Measuring quality of patient information documents with an expanded EQIP scale. *Patient Education and Counselling* 2008, Vol. 70: pp.407–411. Elsevier Available: http://qualite.hug-ge.ch/_library/pdf/Article_Evaluation_Brochure_Information_Patient.pdf [Accessed: 15.9.2010]

CLARKSON PJ, COLEMAN R, KEATES S, LEBBON C eds. (2003) *Inclusive Design: Design for the whole population.* London: Springer-Verlag

CLARKSON PJ, COLEMAN R, HOSKING I, WALLER S (2007) *Inclusive Design Toolkit.* Engineering Design Centre, University of Cambridge. Available: www.inclusivedesigntoolkit.com/betterdesign2/contents/idesign_publication.pdf [Accessed: 15.10.2010]

CLARKSON PJ (2008) Human Capability and Product design. In: *Product Experience* 1st edn. pp.165-166. SCHIFFERSTEIN HNJ, HEKKERT P eds. London: Elsevier

COCHRANE COLLABORATION (2012 *About us.* Available: www.cochrane.org/about-us. [Accessed 20.7.2011]

COHEN L, MANION L, MORRISON K (2001) *Research Methods in Education*. Oxon: Routledge

COLE M (1985) The zone of proximal development: where culture and cognition create each other. In *Culture, Communication, and Cognition: Vygotskian Perspectives.* WERTSCH JV, ed. Cambridge University Press, UK.

COLLINS ENGLISH DICTIONARY (2012) *Acculturation; Cognition; Culture.* Available: www.collinsdictionary.com/dictionary/english/ [Accessed 20.7.2011]

CONNELL J (2011) *Why does the NHS spend so much on translators?* Worcester News 25 July 2011. Available: www.worcesternews.co.uk/news/9156314.Why_does_the_NHS_spend_so_much_on_translators_/ [Accessed: 19.8.2011]

CONNELL BR, JONES M, MACE R *et al* (1997) T*he Principles Of Universal Design Version 2.0, 4/1/97* Center For Universal Design, North Carolina State University, USA. Available: www.design.ncsu.edu/cud/about_ud/udprinciplestext.htm [Accessed: 12.02.2009]

COOK T (2011) *Towards a working definition of human factors in healthcare.* Clinical Human Factors Group. Available: www.chfg.org/news-blog/towards-a-working-definition-of-human-factors-in-healthcare. [Accessed: 15.5.2011]

CONSIDINE P (2003) *Ethnic Diversity: Understanding ethnic media.* Campaign *26 September 2003*. Available: www.campaignlive.co.uk/news/191176/ [Accessed 9.1.2009]

CRILLY N, GOOD D, MATRAVERS D, CLARKSON PJ (2008) Design as communication: exploring the validity and utility of relating intention to interpretation. *Design Studies* September 2008*;* Vol.29(5):pp.425-457 Available: www.sciencedirect.com [Accessed 9.1.2009]

CROSS N (1982) Designerly ways of knowing *Design Studies* October 1982; Vol.3 (4): pp.221-227. BIRD Board of International Research in Design. Basel, Boston, Berlin: Birkhauser

DARZI LORD (2008) *High quality care for all.* Department of Health, June 2008, Available: http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_085828.pdf [Accessed 17.6.10]

DEAN J (2002) *Zizek's Politics.* Oxford: Routledge, Taylor and Francis

DEPARTMENT OF TRADE AND INDUSTRY (2005) *Economics paper 15: Creativity, design and business performance.* Available: www.dti.gov.uk [Accessed: 3.3.2009]

DEY I (1999) *Grounding Grounded Theory: Guidelines for Qualitative Inquiry*. London: Academic Press

DO2LEARN (2001) *Emotions/ Health/ People* Available: www.dotolearn.com/picturecards/printcards/social_emotionshealthpeople.htm and www.dotolearn.com/picturecards/printcards/2inch/imagegridswords/bodyparts.htm [Accessed: 15.4.11]

DOABIA HS (1998) *Sacred Sukhmani.* 17th ed. Amritsar India: Singh Brothers

DOWSE R, EHLERS MS (2001) *The evaluation of pharmaceutical pictograms in a low-literate South African population.* Elsevier: Patient Education and Counseling 45 (2001):pp.98-99. Available: http://*eprints.ru.*ac.*za/614/01/pharmaceutical*-pictograms.pdf [Accessed: 15.3.2011]

DOWSE R, EHLERS MS (2004) Pictograms for conveying medicine instructions: comprehension in various South African language groups. *South African Journal of Science* November-December 2004; Vol.100 Available: http://eprints.ru.ac.za/137/1/sajsci_v100_n11_a35[1].pdf [Accessed: 15.3.2011]

DRAPER SW (1994) Design as communication. *Human-Computer Interaction 2004*; Vol.9(1):pp.61-66

DUSENBERRY P (2006) *One Great Insight is Worth a Thousand Great Ideas* Slideshare. Available: www.slideshare.net/BrandAutopsy/ [Accessed: 15.07.2009]

EASTON M (2006) *Cost in translation.* BBC News 2006. Available: http://news.bbc.co.uk/1/hi/uk/6172805.stm [Accessed: 19.8.2011]

THE ELECTORAL COMMISSION (2005) *Black and Minority Ethnic Survey.* Available: http://www.electoralcommission.org.uk/__data/assets/pdf_file/0019/47260/ECBMEReportFINAL2_18810-13883__E__N__S__W__.pdf [Accessed: 2.2.2011]

ELTON E, NICOLLE CA (2009). *Now you see it, now you don't.* INCLUDE 2009, International Conference on Inclusive Design, Royal College of Art, London, UK, 5-8 April. Available: http://hdl.handle.net/2134/4619. [Accessed: 10.11.2010]

ELTON E, NICOLLE CA (2010). *The importance of context in inclusive design.* Available: http://hdl.handle.net/2134/5595 [Accessed: 10.11.2010]

EMMTII (2009) *Decision Making Explorer - Design Approach and Application.* Experiential Media Methodology and Theory II. University of Arizona. Available:

http://emmtii.wikispaces.asu.edu/Decision+Making+Explorer [Accessed: 15.3.2009]

EMLSIE L, BENT R, SEAMAN C (2007) Missed Opportunities? Reaching the ethnic Consumer Market. *International Journal of Consumer Studies;* Vol.31:pp.168-173. Blackwell Publishing Ltd.

ERWIN DR, ASAI C, DURHAM J, *et al* (2006) *Benefiting Multicultural Clients by Considering Acculturation.* North Dakota Counseling Conference, Bismark, North Dakota, February 6, 2006. Available: http://www2.edutech.nodak.edu/ndca/conference/2006/files.htm [Accessed 2.6.2009]

EVANS S, BURNS A, BARRETT R (2002) *Empathic Design Tutor.* Lofthouse V ed. Cranfield, UK: Cranfield University.

FEATHERSTONE J (1995) *Undoing Culture: Globalization, Postmodernism and Identity*. London: Sage Publications

FIESNER EA (2006) *Colour: How to use colour in art and design.* 2nd edn. London: Laurence King Publishing.

FORLIZZI J, FORD S (2000) *The Building Blocks of Experience: An Early Framework for Interaction Designers.* New York: ACM

FRASCARA J (2004) *User-centred graphic design: mass communication and social change*. London: Taylor & Francis

FREEMAP (2009) *Indian Subcontinent* Available: http://english.freemap.jp/index.html Used with permission under a Creative Commons Attribution 3.0 license.

G-20 Toronto Summit Declaration (2010) June 26- 27, 2010. Available: www.g20.org/Documents/201004_communique_WashingtonDC.pdf [Accessed 27.6.2010]

GAVAGHAN J (2012) *Immigration boom under Labour changed face of Britain faster than any major country except Italy, Oxford experts reveal*. Mailonline: News 19.4.2012 Available: www.dailymail.co.uk/news/article-2132012/Immigration-boom-Labour-changed-face-Britain-faster-major-country-Italy-Oxford-experts-reveal.html [Accessed: 15.6.2012]

GOODMAN J, SYME A, EISMA R (2003) *Older adjusts' use of computers: a curvey*. In: Proceedings of HCI 2003, Bath, UK

GOVERNMENT COMMUNICATION NETWORK (2011) Delivering *inclusive websites* Available: http://coi.gov.uk/guidance.php?page=137#section8a [Accessed: 11.6.2011]

GUTHRIE JT (2003) *Psychology and perception of colour and shape* Surface Coatings International Part B: Coatings Transactions March 2003; 35 Vol.86, B1:pp.1–90, Based on a paper at: The Third European Additives and Colour Conference, Antwerpen, Belgium, February 2003. Organised by the Society of Plastics Engineers (European Region)

HALL ET, HALL MR (1976) *Understanding Cultural Differences: Germans, French and Americans* Yarmouth, US: Intercultural Press, London: Nicholas Brealey Publishing

HALLOCK J (2003) *Colour Assignment* Available: http://joehallock.com/edu/COM498/index.html [Accessed: 17.10.2008]

HAQUE N (2009) *Maslow's Hierarchy of Customer Service.* Wikinomics. Available: www.wikinomics.com/blog/index.php/2009/02/27/maslows-hierarchy-of-customer-service/ [Accessed: 9.9.2009]

HARVARD UNIVERSITY (2008) *Emic and Etic Approaches.* Foundation of Qualitative

Research in Education. President and Fellows Harvard University. Available: http://isites.harvard.edu/icb/icb.do?keyword=qualitative&pageid=icb.page340911 [Accessed: 5.10.2010]

HAYNES RB (2001*). Interventions for helping patients to follow prescriptions for medications*. Cochrane Database of Systematic Reviews, 2001, Issue 1

HAYNES RB, MCDONALD H, GARG AX, MONTAGUE P (2005) *Interventions for helping patients to follow prescriptions for medications.* Wiley: The Cochrane Database of Systematic Reviews 2005, Issue 3. Available: http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD000011/pdf [Accessed: 17.5.2011]

HEDGES A (2011) *The State of Healthcare and Healthcare Information Technology use In the US.* Lecture10.5.2011, Loughborough School of Design, Loughborough University, UK.

HICKLEY M (2009) *The migrant baby boom: Foreign mothers help push Britain's population past 61m. Daily Mail.* Available: www.dailymail.co.uk/news/ [Accessed: 31.08.2009]

HINZ K (2009) Color Codes in the Times of Globalization. *Design for All Institute of India* July 2009; Vol.4(7):pp.52-59

HOFSTEDE G, MCRAE RR (2004) Personality and Culture Revisited: Linking Traits and Dimensions of Culture*. Cross-Cultural Research* 2004; Vol.38(52):pp.52-68. Available: http://ccr.sagepub.com/cgi/content/abstract/38/1/52 [Accessed 14.2.2010]

HOLDEN T (2009) *This is Nottingham: Demand for interpreters in NHS rockets10 April 2009.* Nottingham Evening Post. Available: www.thisisnottingham.co.uk/Demand-interpreters-NHS-rockets/story-12176080-detail/story.html [Accessed: 14.9.2010]

HOWELLS GG (2000) Strict liability. In: *Chapter 4: The law of product liability*. GRUBB A, HOWELLS GG eds. London: Butterworths.

HULL GA, NELSON MA (2005) Locating the semiotic power of multimodality. *Written Communication* 2005; VOL.22(2):PP.224-261. Available: http://uclinks.org/reference/research/Hull_nelson.pdf [Accessed: 10.3.2011]

HUNTER M (2010) *What design is and why it matters: Triple bottom line.* Design Council. Available: www.designcouncil.org.uk/about-design/What-design-is-and-why-it-matters/ [Accessed: 15.6.2010]

IMISON C, NAYLOR C, GOODWIN N, *et al* (2011) *Articles: Transforming our health care system: Ten priorities for commissioners 12.05.11* The Kings Fund. Available: www.kingsfund.org.uk/publications/articles/transforming_our.html [Accessed: 8.6.2011]

INCLUSIVE DESIGN TOOLKIT (Undated) *Map of key activities.* Available: www.inclusivedesigntoolkit.com/betterdesign2/gettingstarted/gettingstarted.html [Accessed: 15.6.2010]

ISRASENA P, BOONVONG N (2009) *The Inclusive I.C.E. Cube: Lessons learned from Thai elder care design.* Proceedings of the include09 Conference, Royal College of Art, London, 5-9 April 2009. Available: http://include09.kinetixevents.co.uk/4dcgi/prog?operation=detail&paper_id=26 [Accessed: 20.4.2009]

I-DESIGN PROJECT (2006) *Extending Active Living through More Effective Inclusive Design.* Available: www-edc.eng.cam.ac.uk/idesign3/ [Accessed: 15.7.2009]

INTERNATIONAL ERGONOMICS ASSOCIATION (2010) *Definition of Ergonomics: Approved in 2000.* Available: www.iea.cc/ [Accessed: 20.8.2010]

ISO, INTERNATIONAL ORGANISATION FOR STANDARDISATION Geneva

ISO 9241-210:2010 (2010) *Ergonomics of human-system interaction-Part 210: Human-centred design process for interactive systems.*

ISO9241-11 (1998) *Guidance on usability. Ergonomics of human-system interaction.*

IRAS (2009) *Integrated Research Application System.* NHS National Patient Safety Agency. Available: www.myresearchproject.org.uk/SignIn.aspx [Accessed: 2009-2011]

ISHERWOOD SJ, MCDOUGALL SJ, CURRY MB (2007) Icon identification in context: the changing role of icon characteristics with user experience. *Human Factors* 2007 June; Vol.49(3):pp-465-476

JOHNSON MRD (2004) Cross-Cultural Communication in Health*. Clinical Cornerstone-Diversity in Medicine* 2004; Vol.6(1):pp.50-52 © 2004 Excerpta Medica Inc.

JOHNSON MRD, SAMANTA A, HUDSON N, *et al* (2006) *Evaluation of Patient Information Resources on Osteomalacia in Asian Languages*. Mary Seacole Research Centre Paper 5. Leicester, UK: De Montfort University

JOHNSON MRD (2012) Discussion at the Mary Seacole Research Centre, Leicester, UK: De Montfort University

JOINT FORMULARY COMMITTEE (2011) Recommended wording of cautionary and advisory labels. In: *British National Formulary BNF No 61, March 2011 ed.* British Medical Association and Royal Pharmaceutical Society. London: Pharmaceutical Press

JORDAN P (2004) *How we can Move Design from Usable to Pleasurable*. 22.07.2004. KEVAL,H. ed. London: UK Usability Professionals Association

JYLHA M (2007) Comparisons, Cultures, Contexts. *European Journal of Ageing*, June 2007; Vol.4(2):pp.101-102. Germany: Springer-Verlag. Available: www.springerlink.com/content/p87h47883164/?p=8333091eaafa44299fc7fee4c3c2e08b&pi=6 [Accessed: 5.11.2008]

KANG RY (2003) *User Experience: Beyond Usability* Available: www.idemployee.id.tue.nl/g.w.m.rauterberg/conferences/CD_doNotOpen/ADC/final_paper/293.pdf [Accessed: 12.6.2009]

KANKAINEN A (2002) *Thinking model and tools for understanding user experience related to information appliance product concepts.* PhD Thesis: Helsinki University of Technology. Available: http://lib.tkk.fi/Diss/2002/isbn9512263076/isbn9512263076.pdf Accessed*:* 5.11.2008]

KATZ MG, KRIPALANI S, WEISS BD (2006) Use of pictorial aids in medication instructions: A review of the literature. *American Society of Health-System Pharmacists,* December 1, 2006; Vol.63

KATZ-HAAS R (1998) *Ten Guidelines for User-Centred Web Design.* Usability Techniques: User-Centered Design and Web Development. Originally publ. *Usability Interface* July 1998*;* Vol.5(1). Available: www.stcsig.org/usability/newsletter/9807-webguide.html [Accessed: 19.9.2009]

KAZMIERCZAK ET (2003) Design as meaning making: from making things to the design of thinking. *Design Issues*; Vol.19(2):pp.45-59

KEATES S, CLARKSON PJ, HARRISON LJ, et al (2000) *Towards a Practical Inclusive Design Approach.* Proceedings of the 1st ACM Conference on Universal Usability (CUU 2000), Arlington, VA:pp.45-52 Available: http://web.mit.edu/16.459/Keates.pdf. [Accessed 23.7.2010]

KHAN M (2011) Providing a quality service to patients without English as a first language - 21 April 2011. *Health Service Journal,* EMAP Ltd. Available: www.hsj.co.uk/resource-centre/best-practice/providing-a-quailty-service-to-patients-without-english-as-a-first-language/5027992.article [Accessed: 5.7.2011]

KINRA N (1983) *Ethnic Groups as Market Segments': Implications of the Demand Structure*. PhD Thesis; p.496. Birmingham, UK: Aston University

KOUNTZ DS (2009) *Strategies for improving low health literacy.* US National Library of Medicine, National Institutes of Health Postgrad Medicine 2009 September; Vol.121(5):pp.171-177. Available: www.ncbi.nlm.nih.gov/pubmed/19820287 [Accessed: 19.5.2011]

KRIPPENDORFF K, BUTTER R (1984) Product semantics: exploring the symbolic qualities of form. *Innovation*: *The Journal of the Industrial Designers Society of America;* Vol.3(2):pp.4-9

KRIPPENDORFF K (2006) *The semantic turn.* Boca Raton, FL, US: CRC Press

KRIPPENDORFF K (2010) Types of Design Research. *PhD-Design Digest,* 9-10 Aug 2010 (#2010-173) Available: listserv@jiscmail.ac.uk [Accessed: 12.8.2010]

KUNIAVSKY M (2003) *Observing the User Experience: a Practitioner's Guide to User Research*. San Francisco, US: Morgan Kaufmann (Elsevier)

LACKOVIC N (2010) *Creating and Reading Images: Towards a Communication Framework for Higher Education.* Learning International Journal of Media, Technology and Lifelong learning. 2010, Vol.6(1). Available: http://seminar.net/index.php/volume-6-issue-1-2010/134-creating-and-reading-images-towards-a-communication-framework-for-higher-education-learning [Accessed: 11.1.2011]

LAING A, KIRKUP J (2009) *Immigration will push British population to 70 million.* The Telegraph. Available: www.telegraph.co.uk/news/newstopics [Accessed 24.10.09]

LAKHANI M (2008) *No Patient Left Behind: how can we ensure world class primary care for black and minority ethnic people?* UK Department of Health. Available: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084971 [Accessed 17.6.10]

LEAN K (2008) *Urdu language package.* NHS Institute for Innovation and Improvement. www.institute.nhs.uk/index.php?option=com_mtree&task=viewlink&link_id=3833&Itemid=4930 [Accessed: 3.3.2011]

LEGGE GE, BIGELOW CA (2011) *Does print size matter for reading? A review of findings from vision science and typography.* Journal of Vision, August 9, 2011, 11(5), Article 8. Available: http://w.journalofvision.org/content/11/5/8.full [Accessed: 5.10.2011]

LESTER PM (2006) *Visual* Communication*: Images with Messages*. Belmont, CA: Thomson Wadsworth, 2006

MACBETH, SA, MORONEY WF, BIERS DW (2006) Developing Icons and Symbols: A Comparison of Two Methods*. Ergonomics in Design*: *The Quarterly of Human Factors Applications;* Vol.14 (4):pp.14-18. Human Factors and Ergonomics Society

MACE, Ron (2008) *About UD: Universal Design Principles.* The Centre for Universal Design Available: www.design.ncsu.edu/cud/about_ud/about_ud.htm [Accessed 12.02.2009]

MAGUIRE M (2012) *Colour associations used in human computer interactions.* Lecture notes: Loughborough Design School, Loughborough University

MANGAN J (1978) Cultural conventions of pictorial representation: iconic literacy and

education. *Edu. Commun. Tech.J.;* Vol.26:pp.245-267

MARKETING ASSOCIATION OF AUSTRALIA AND NEW ZEALAND (2005) *Managing the Service Product: The Augmented Service Offering* Available: www.marketing.org.au/images/cimages/servmark.pdf [Accessed: 12.8.2009]

MARTIN D (2008) *£250,000 lost in translation by NHS for providing interpreters.* Mail Online 18th October 2008. Available: www.dailymail.co.uk/news/article-1078677/250-000-lost-translation-NHS-providing-interpreters.html#ixzz1Yb7Yaov5 [Accessed: 10.03.2010]

MASLOW AH (1943) Theory of Human Motivation. *Psychological Review* 1943; Vol.50: pp.370-396

MASTERSON R, PICKTON D (2004) *Marketing: An Introduction.* Maidenhead: McGraw-Hill Education

McGREGOR RS (1972) *Outline of Hindi Grammar with exercises*. 2nd ed. England: Oxford University Press

MEDILEXICON (2006) *Phonetics* Available: www.medilexicon.com/medicaldictionary.php?t=68351 [Accessed 15.6.2011]

MERRIAM-WEBSTER (2011) *Phonetics* Available: www.merriam-webster.com/dictionary/phonetic [Accessed 15.6.2011]

MILES MB, HUBERMAN AM (1994) *Qualitative Data Analysis: An Expanded Sourcebook*. 2nd ed. California: Sage

MOALOSI R, POPOVIC V, HICKLING-HUDSON AR (2007) *Culture-orientated Product Design*. In: Proceedings IASDR07: International Association of Societies of Design Research 2007, Emerging Trends in Design Research, Hong Kong. Available: http://eprints.qut/edu.au/14432/1/14432a.pdf [Accessed: 15.6.2009]

MORRISON S (2011) *End to free language classes for immigrants.* The Independent on Sunday, 31 July 2011.

MORVILLE P (2004) *User Experience Design.* Semantic Studios. Available: http://semanticstudios.com/publications/semantics/000029.php [Accessed 15.3.2010]

MORVILLE P (2007) *User Experience Strategy.* Semantic Studios. Available: http://semanticstudios.com/publications/semantics/000179.php [Accessed 15.3.2010]

NAB (2000) *Cultural Context: Culture and the Individual Definition.* Department of Art & Design, Iowa State University. Available: www.design.iastate.edu/NAB/about/thinkingskills/cultural_context/cultural_individual.html [Accessed: 10.3.2009]

NICE (2002) *Principles for Best Practice in Clinical Audit*. National Institute for Health and Care Excellence,p.3. Abingdon, UK: Radcliffe Medical Press Ltd. Available: www.nice.org.uk/niceMedia/pdf/BestPracticeClinicalAudit.pdf [Accessed 15.6.2010]

NICE (2009) *CG76: Medicines adherence: Involving patients in decisions about prescribed medicines and supporting adherence. 1.1.3. Communication* National Institute for Health and Care Excellence. Available: http://publications.nice.org.uk/medicines-adherence-cg76/guidance [Accessed: 2.7.2011]

NICE (2012) *QS15: Quality standard for patient experience in adult NHS services.* National Institute for Health and Care Excellence. Available: http://publications.nice.org.uk/quality-standard-for-patient-experience-in-adult-nhs-services-qs15 [Accessed:10.5.2012]

NICHOLS-ENGLISH G, POIRIER S (2000) Optimizing Adherence to Pharmaceutical Care

Plans. *J Am Pharm Assoc* 2000; Vol.40(4):pp.475-485, ©2000 American Pharmaceutical Association. Available: www.ub.edu/farmaciaclinica/projectes/webquest/WQ1/docs/nichols.pdf [Accessed: 3.3.2011]

NIELSEN J (2006) *Digital Divide: The Three Stages*. Available: www.useit.com/alertbox/digital-divide.html [Accessed: 27.11.2008]

NGO VH (2008) A critical examination of acculturation. *Critical Social Work* 2008; Vol.9(1) Available: www.uwindsor.ca/criticalsocialwork/a-critical-examination-of-acculturation-theories [Accessed: 20.4.2009]

NGOH LM (2009) *Health literacy: A barrier to pharmacist–patient communication and medication Adherence.* Journal of the American Pharmacists Assoc. 2009; Vol.49:pp. e132–49. [Accessed: 10.11.2010]

NHS CHOICES (2011) *Upper back pain in adults.* Available: www.selfhelpguide.nhs.uk/Help/BodyKey/Questions/Index.aspx?nodes=xYHsD83zBYw%3D [Accessed: 20.5.2011]

NHS CHOICES (2011) *Symptom Checkers.* Available: www.nhs.uk/nhsdirect/pages/symptoms.aspx [Accessed: 31.5.2011-2012]

NHS IMPROVEMENT (UNDATED) *eQIPP Delivering quality efficiently*. Available: www.improvement.nhs.uk/Default.aspx?alias=www.improvement.nhs.uk/qipp [Accessed: 1.5.2010]

NHS INSTITUTE FOR INNOVATION AND IMPROVEMENT (2008) *Quality and service improvement tools: PDSA model.* Available: http://www.institute.nhs.uk/quality_and_service_improvement_tools/quality_and_service_improvement_tools/plan_do_study_act.html [Accessed: 15.6.2010]

NHS INSTITUTE FOR INNOVATION AND IMPROVEMENT (2012) *Engagement Experience.* Available: www.institute.nhs.uk/building_capability/general/engagement_and_experience.html [Accessed: 15.3.2010-2012]

NHS NATIONAL PATIENT SAFETY AGENCY (2010) *National Research Ethics Service* Available: www.nres.npsa.nhs.uk/applications/ and www.nres.npsa.nhs.uk/applications/approval-requirements/nhs-rd-approval/ [Accessed: 2009-2011]

NHS RESEARCH AND DEVELOPMENT FORUM (2010) NHS R&D Links Available: www.rdforum.nhs.uk/070.asp?otype=TRUST [Accessed: 2009-2010]

NIH (2012) *Clear communication: a NIH health literacy initiative.* National Institutes of Health US Dept. of Health. Available: www.nih.gov/clearcommunication/healthliteracy.htm [Accessed: 11.3.2011]

NORMAN DA (2005) Human-centered design considered harmful. *Interactions* July-August 2005:pp.14-19

NATIONAL STATISTICS OFFICE (2003) *How do you define ethnicity?* Available: www.statistics.gov.uk/about/ethnic_group_statistics/how_define/default.asp [Accessed 31.3.2009]

OED (2009-2011) *Culture; Design; Ethnic; Ethics; Pronunciation;* Oxford English Dictionary. Available: http://dictionary.oed.com/ [Accessed 30.04.2009-2011]

ONS (2011) *Census: Welcome to the 2011 Census for England and Wales.* Office for National Statistics. Available: www.ons.gov.uk/ons/guide-method/census/2011/index.html

[Accessed: 15.5.2012]

ONS (2012) *2011 Censu:- Population and Household Estimates for England and Wales, March 2011.* Office for National Statistics. Available: www.ons.gov.uk/ons/dcp171778_270487.pdf [Accessed: 17.7.2012]

ONS (2012) *2011 Census: Key Statistics for England and Wales, March 2011: Household language.* Office for National Statistics, December 2012. Available: www.ons.gov.uk/ons/dcp171778_290685.pdf [Accessed: 15.04.2013]

PAPPACHAN P, ZIEFLE M (2008) Cultural influences on the comprehensibility of icons in mobile-computer interaction. *Behaviour and Information Technology* July-August 2008; Vol.27(4):pp.331-337

PATERA M, DRAPER SW (2007) *Colour & Interior Design: Using Virtual Reality Technology to Study the Effects of Scale.* Available: www.designsonelearning.net/conferences/face_to_face/sept2007/2007_papers/ps2_papers/patera_draper.pdf [Accessed 30.10.2008*]*

PATMORE J, MAHONEY L (2003) Chapter 14: Internet usability. In *Inclusive Design: Design for the whole Population.* Clarkson *et al* eds. London: Springer-Verlag London Ltd.

PLAIN ENGLISH CAMPAIGN (2011) *The Crystal Mark standard* Available: http://www.plainenglish.co.uk/crystal-mark/about-the-crystal-mark/the-crystal-mark-standard.html [Accessed: 2.7.2011]

PLIMPTON S, ROOT J (1994) *Materials and Strategies That Work in Low Literacy Health Communication* US National Library of Medicine, National Institutes of Health *Public Health Rep.* January-February 1994; Vol.109(1):pp.86–92. Available: www.ncbi.nlm.nih.gov/pmc/articles/PMC1402246/pdf/pubhealthrep00062-0088.pdf [Accessed: 20.5.2011]

PONS JC (2012) *Universal Doctor* (2012) Available: www.universaldoctor.com/ [Accessed: 23.1.2012]

POST (2007) *Ethnicity and health.* Parliamentary Office of Science and Technology. Available: www.parliament.uk/documents/post/postpn276.pdf [Accessed: 15.6.2010]

POTTER J, WETHERELL M (1995) Discourse analysis. In: *Rethinking methods in Psychology.* SMITH JA, HARRE R, VAN LANGEHOVE L, eds. London: Sage

POTTIE K (2007) Misinterpretation: Language proficiency, recent immigrants, and global health disparities. *Canadian Family Physician*, November 2007; Vol.53. Available: www.cfp.ca/content/53/11/1899.full.pdf+html [Accessed: 22.10.2009]

PREECE J, ROGERS Y, SHARP H (2002) *Interaction design: Beyond human-computer interaction*. NEW YORK: WILEY

PRINCETON UNIVERSITY (2009) *Wordnetweb: Context, Ethnic Group, Ethnicity* Available: http://wordnetweb.princeton.edu/ [Accessed: 2.10.2009]

PROSSER J (1998) *Image-based Research: A Source Book for Qualitative Researchers*. London: Falmer Press

QDA (2011) *Framework Analysis.* School of Human & Health Sciences, University of Huddersfield. Available: http://onlineqda.hud.ac.uk/methodologies.php [Accessed: 11.1.2011]

RAIT J (2008) *Design Pyramid.* Design_at_the_edge Available: http://ic-pod.typepad.com/design_at_the_edge/design_pyramid/ [Accessed:15.3.2009]

RAU PL, GAO QA, LIANG SFM (2008) *Good Computing Systems for Everyone - how on*

Earth? Cultural Aspects. Behaviour and Information Technology, 24.07.08. Vol.27, (4) pp.287-292. London: Taylor & Francis. Available: www.informaworld.com/smpp/content~db=all?content=10.1080/01449290701761250 [Accessed: 15.11.2008]

RAYNOR DK (1992) Patient compliance: the pharmacist's role. *International Journal of Pharmacy Practice* 1992; Vol.1:pp.126–135

REES D (2009) *The 10 most common reasons for poor Usability Part 1 and part 2*. Usabilitynews.com and Experience Solutions. Available: www.usabilitynews.com/news/article5531.asp www.usabilitynews.com/news/article5532.asp and www.experiencesolutions.co.uk/blog/2009/03/03/top-10-reasons-for-poor-usability-%E2%80%93-part-2 / [Accessed 3.6.2009]

REES P, WOHLAND P, NORMAN P, *et al* (2011) A local analysis of ethnic group population trends and projections for the UK. *Journal of Population Research* 2011; Vol.28:pp.149–183

RHEINGOLD H (1992) *Virtual Reality.* London: Mandarin Paperbacks

ROBSON C (2002) *Real World Research 2nd edn.* Oxford, UK: Blackwell Publishing

ROHRER C (2008) *When to Use Which User Experience Research Methods.* Jakob Nielsen's Alertbox, October 6, 2008 Available: http://www.nngroup.com/articles/which-ux-research-methods/ [Accessed: 14.3.2009]

ROUSE KAG (2004) Beyond Maslow's Hierarchy of Needs: What do people strive for? *Performance Improvement*, November-December 2004; Vol.43(10):p.27 ProQuest Educational Journals. Available: www.cit.gu.edu.au/teaching/6118CIT/2623ICT/readings/maslow.pdf [Accessed: 24.6.2009]

ROYAL ACADEMY OF ENGINEERING (2005) *Educating engineers in design*. Available: wwww.raeng.org.uk [Accessed: 14.3.2009]

RUDY LJ (2011) *Top 9 Best Sites for Free, Low-Cost Communication Pictures.* About.com Autism Spectrum Disorders. Available: http://autism.about.com/od/autismproductsguide/tp/bestpix.htm [Accessed: 2.2.11]

RYAN RM, DECI EL (2000) Intrinsic and Extrinsic Motivations: Classic Definitions and New Directions. *Contemporary Educational Psychology* 2000; Vol.25:pp.54–67 ©2000 Academic Press. Available: http://mmrg.pbworks.com/f/Ryan,%2BDeci%2B00.pdf [Accessed: 7.2.2009]

SAFEER RS, KEENAN J (2005) Health literacy: the gap between physicians and patients. *American Family Physician*. 2005 August 1; Vol.72(3):pp.387-378

SALAZAR SI (2010) Language Barriers in Healthcare Information: Communicating with Bilingual Users. *User Experience,* 4th Quarter 2010; Vol.9(4):pp.22-24. Illinois, US: Usability Professionals Assoc.

SANDERS EBN, DANDAVATE U (1999) *Design for experiencing: New Tools*. In: Proceedings of the 1st International Conference on Design and Emotion, University of Technology. Delft, 1999. OVERBEEKE CJ, HEKKERT P, eds. Available: www.designandemotion.org [Accessed: 1.3.2011]

SCHIFFERSTEIN HNJ, HEKKERT P eds. (2008) *Product Experience* 1st edn. London: Elsevier

SCOTTISH CAB SERVICE (2006) *Advice Partnership Will Target Lanarkshire's Minority Communities.* Citizens Advice Bureaux Scotland. Available:

www.cas.org.uk/pressrelease2232006.aspx [Accessed:17.6.2009]

SEKHON YK, SZMIGIN I (2005) Conceptualizing Ethnicity and Acculturation of Second Generation Asian Indians in Britain. *Academy of Marketing Science Review* 2005; Vol.3 Available: www.amsreview.org/articles/sekhon03-2005.pdf [Accessed:7.6.2009].

SEKHON YK, SZMIGIN I (2011) Acculturation and identity: Insights from second-generation Indian Punjabis. *Consumption, Markets and Culture*; Vol.14(1):pp.79-98

SIU KWM (2003) Users' creative responses and designers' roles. *Design Issues*; Vol.19(2): pp.64-73

SHEDROFF N (2004) *User experience*. Available: www.lukew.com/ff/entry.asp?102 [Accessed 15.03.2010]

SHUTTERSTOCK (2012) *Healthcare Doctor Nurse Icon Symbol Sign Pictogram.* Available: www.shutterstock.com/pic-95278438/stock-photo-hospital-clinic-medical-healthcare-doctor-nurse-icon-symbol-sign-pictogram.html [Accessed 11.5.2011]

SINGLETON K, KRAUSE E (2009) Understanding Cultural and Linguistic Barriers to Health Literacy 30.9.2009 *OJIN:The Online Journal of Issues in Nursing;* Vol.14(3): Manuscript 4. Available: http://nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol142009/No3Sept09/Cultural-and-Linguistic-Barriers-.aspx [Accessed: 23.9.2010]

SLEESWIJCK VISSER F(2009) *Bringing the everyday life of people into design.* Thesis, TU Delft, Delft University of Technology. Available: http://repository.tudelft.nl/view/ir/uuid%3A3360bfaa-dc94-496b-b6f0-6c87b333246c/ [Accessed: 15.3.2010]

SLESS D (1981) *Learning and visual communication*. London: Taylor & Francis

SMITH JA (1995) The Search for Meanings: Semi-structured interviewing and Qualitative Analysis. In: *Rethinking methods in Psychology.* SMITH JA, HARRE R, VAN LANGEHOVE L eds. London: Sage.

SMASHING MAGAZINE (2012) *DOT Pictograms.* Available: www.smashingmagazine.com/2010/04/01/50-new-free-high-quality-icon-sets/ [Accessed: 15.7.2011]

SORFLEET C, GROVES S, DAWSON J (2009) Design, development and evaluation of pictographic instructions for medications used during humanitarian missions. *Canadian Pharmacists Journal,* March 2009; Vol.142(2):pp.82-88. Available: www.cpjournal.ca/doi/abs/10.3821/1913-701X-142.2.82 [Accessed: 10.5.2011]

SPENCER S (2003) *The Challenges of Integration for the EU.* Migration Information source. Available: www.migrationinformation.org [Accessed: 15.05.09]

SRIVASTAVA A, THOMSON SB (2009) Framework Analysis: A Qualitative Methodology for Applied Policy Research. *JOAAG* 2009; Vol.4(2):pp.72-79

STOREY J (1999) 3. Cultural Consumption as Communication. In: *Cultural Consumption and Everyday Life*. STOREY J, TURNER G, eds. pp.36-54 London: Arnold; New York distributors: Oxford University Press Inc.

STRAUSS A, CORBIN J (1990) *Basics of qualitative research: Grounded theory procedures and techniques.* London: Sage Publications.

STREETS P (2011) *Developing High Impact Actions for Improving Patient Experience, 8 Feb 2011.* In: Presentations of the Day, UK Department of Health. Available:

www.institute.nhs.uk/share_and_network/pen/welcome.html [Accessed 16.3.11]

STRICKFADEN MK, RODGERS P, LANGDON P (2006) *Referencing the sociocultural during designing.* WonderGround 2006. In: Proceedings of the Design Research Society International Conference. Lisbon: IADE

THOMAS C, BEVAN N (1995) *Usability Context Analysis: A Practical Guide, Version 4* Teddington, UK: National Physical Laboratory. Available: https://dspace.lboro.ac.uk/dspace-jspui/bitstream/2134/2652/1/PUB492.pdf [Accessed: 15.6.2010]

THORSON D (2006*) YouTube, Maslow and Dancing Monkeys.* Available: http://donthorson.typepad.com/don_thorson/2006/10/youtube_maslow_.html [Accessed 1.7.2008]

UEA, UNIVERSITY OF EAST ANGLIA (2012) *Jerome Bruner (1915-Present).* Available: www.uea.ac.uk/menu/acad_depts/edu/learn/morphett/bruner.htm [Accessed: 15.5.2011]

UMIKER-SEBEOK J, GREGSON K (1999) *User Needs and Behavior in Theory and Practice: The Participatory Design Process.* School of Library and Information Science, Indiana University, USA. Available: www.slis.indiana.edu/faculty/umikerse/L503/L503iub/design.html [Accessed: 23.3.2011]

UNHCR (2009) *Asylum Claims in Industrialized Countries.* UN High Commission for Refugees. Available: www.unhcr.org/news/NEWS/ [Accessed:18.02.2009]

UNIVERSITY OF CAMBRIDGE (undated) *Collaborative and Participatory Design* Available: https://camtools.cam.ac.uk/wiki/site/e30faf26-bc0c-4533-acbc-cff4f9234e1b/collaborative%20and%20participatory%20design.html [Accessed: 15.3.2011]

UNIVERSITY OF EDINBURGH (2009) *Careers Service: Ethnic Minority Students: Positive about Diversity.* Available: www.careers.ed.ac.uk/STUDENTS/Specific_Information/ethnics.HTM [Accessed:17.6.2009]

USABILITYNET (2006) *What is usability?* Available: www.usabilitynet.org/management/b_what.htm [Accessed: 11.04.2009]

USABILITYNET (2006) *International Standards for HCI and Usability (Quality in Use: ISO/ IEC FDIS 9126-1: Software Engineering - Product quality - Part 1: Quality model (2000)* Available: www.usabilitynet.org/tools/r_international.htm#9241-11 [Accessed: 11.04.2009]

USE VISUAL STRATEGIES (2012) *Visual Strategies for Improving Communication.* QuirkRoberts Publishing © 1998-2012 Available: www.usevisualstrategies.com/AutismVisualPrintablePictures.aspx [Accessed: 21.2.2011]

USER INTELLIGENCE (2011) *The Meaning of User Experience* UX. Alliance July 6, 2011. Available: www.uxalliance.com/ideas/publications/meaning-user-experience [Accessed: 30.9.2011]

VECTOR LOGO (2011) *Medicine Icons Vector.* All Free Logo Available: www.allfreelogo.com/rf-vector/8458436-medicine-icons-vector.html [Accessed: 3.5.2011]

VERKUYTEN M, DE WOLF A (2002) Ethnic minority identity and group context: Self-descriptions, acculturation attitudes and group evaluations in an intra- and intergroup situation. *European Journal of Social Psychology* 2002; Vol.32:pp.781–800 Wiley InterScience. Available: www.interscience.wiley.com [Accessed: 7.6.2009]

VON HIPPEL E (2005) *Democratizing innovation.* Cambridge, MA, US: The MIT Press

WASSON C (2000) Ethnography in the Field of Design. *Human Organization,* Winter 2000; Vol.59(4):pp.377-388. Washington: © Society of Applied Anthropology. Available: http://proquest.umi.com/pqdweb?did=66258058&Fmt=3&clientId=5238&RQT=309&VName=PQD [Accessed: 23.10.08]

WATERHOUSE P (2008) *The Product* UK. *Equerry On-Line:* Available: www.equerry.co.uk/?page_id=388 [Accessed: 06.0609]

WATSON M, LUCAS C, HOY A, BACK I (2005) Chapter 6A: The management of pain In: *Oxford Handbook of Palliative Care,* pp.172-177. Oxford: Oxford University Press. Available: www.123doc.com/fizix/uploads/76.pdf [Accessed: 15.5.2011]

WEISS BD (2007) *Health literacy and patient safety: Help patients understand*. Manual for clinicians 2nd ed. American Medical Association Foundation Available: www.ama-assn.org/ama1/pub/upload/mm/367/healthlitclinicians.pd [Accessed: 12.4.2011]

WENSVEEN SAG (1999) *Probing experiences*. In: Proceedings of the 1st International Conference on Design and Emotion, University of Technology. Delft, 1999. OVERBEEKE CJ and HEKKERT P eds. Available: www.designandemotion.org/society/knowledge_base/?root=24 [Accessed: 1.3.2011]

WILLIAMS C, JOHNSON MRD (2010) *Characteristics of key differences.* Race and ethnicity in a welfare society (p.9). Maidenhead, UK: McGraw Hill/ Open University Press

WILLIG C (2008) *Introducing Qualitative Research in Psychology 2nd ed*. Reading: Open University Press.

WILSON C (2011) *Patients with 'no English' face phone translations.* Evening Times,16 May 2011, Scotland. Available: www.eveningtimes.co.uk/news/news-editors-picks/patients-with-no-english-face-phone-translations.13703124 [Accessed: 30.6.2011]

WILSON P, SOWDEN AJ, WATT I, *et al* (2001) *Involving patients in effective health care: assessing the feasibility of the use of a patient information leaflet in routine clinical practice.* NHS Centre for Reviews and Dissemination, University of York. Available: www.york.ac.uk/inst/crd/Posters/Involving%20patients%20in%20effective%20healthcare.%20Assessing%20the%20feasibility%20of%20the%20use%20of%20a%20patient%20information%20leaflet%20in%20routine%20clinical%20practice.pdf [Accessed: 3.6.2010]

WOOD ML (1992) Focus group interview in family practice research. *Canadian Family Plysician* December 1992; Vol.38:pp.2821-2827

WHO, WORLD HEALTH ORGANISATION [Accessed: 11.5.2011]

(2003) *Adherence to long-term therapies: Evidence for Action.* Available: www.who.int/chp/knowledge/publications/adherence_full_report.pdf

(2011) *The World Health Report.* Available. www.who.int/whr/2010/en/index.html

WROBLEWSKI L (2004) *User Experience Diagrams.* Available: www.lukew.com/ff/entry.asp?156 [Accessed 15.03.2010]

ZEISEL J (1984) *Inquiry by design: tools for environment-behaviour research*. Cambridge UK: Cambridge University Press

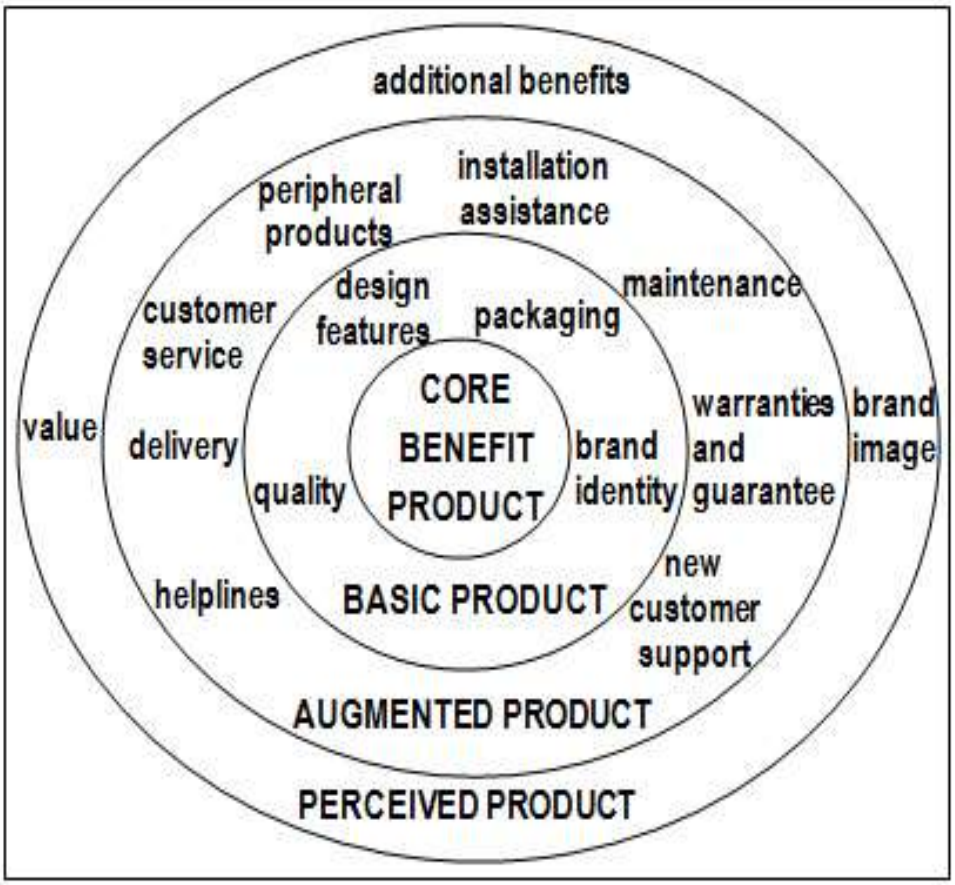
APPENDIX-A

Appendix A1. The UK's population breakdown: 2001 census (POST 2007)

White (includes non-British White minorities Irish)	92%
Asian or Asian British	4%
Black or Black British	2%
Mixed	1.5%

Appendix A2. The Total Product concept

The concept, 'Levitt's rings' was developed from Levitt's (2004) articles in Harvard Business Review: *Marketing Myopia* and *The differentiation of almost anything* (Equerry no-date).



Everything consumers receive (Masterson and Pickton (2004:pp.192-195)

Appendix A3. Ford and Nicholls Taxonomy of Human Goals

Adapted by Rouse (2004, from Ford 1992): 24 non-hierarchical human goals

DESIRED WITHIN-PERSON CONSEQUENCES	
Affective Goals	
Entertainment	Experiencing excitement or heightened arousal; avoiding boredom or stressful inactivity
Tranquility	Feeling relaxed and at ease; avoiding stressful over-arousal
Happiness	Experiencing feelings of joy, satisfaction, or well-being; avoiding feelings of emotional distress or dissatisfaction
Bodily sensations	Experiencing pleasure associated with physical sensations, physical movement, or bodily contact; avoiding unpleasant or uncomfortable bodily sensations
Physical well-being	Feeling healthy, energetic, or physically robust; avoiding feelings of lethargy, weakness, or ill health
Cognitive Goals	
Exploration	Satisfying one's curiosity about personally meaningful events; avoiding a sense of being uninformed or not knowing what's going on
Understanding	Gaining knowledge or making sense out of something; avoiding misconceptions, erroneous beliefs, or feelings of confusion
Intellectual creativity	Engaging in activities involving original thinking or novel or interesting ideas; avoiding mindless or familiar ways of thinking
Positive self-evaluation	Maintaining a sense of self-confidence, pride, or self-worth; avoiding feelings of failure, guilt, or incompetence
Subjective Organization Goals	
Unity	Experiencing a profound or spiritual sense of connectedness, harmony, or oneness with people, nature or a greater power; avoiding feelings of psychological disunity or disorganization
Transcendence	Experiencing optimal or extraordinary states of functioning; avoiding feeling trapped within boundaries of ordinary experience
DESIRED PERSON-ENVIRONMENT CONSEQUENCES	
Self-Assertive Social Relationship Goals	
Individuality	Feeling unique, special, or different; avoiding conformity with others
Self-determination	Experiencing a sense of freedom to act or make choices; avoiding the feeling of being pressured, constrained, or coerced
Superiority	Comparing favorably to others in terms of winning status, or success; avoiding unfavorable comparisons with others
Resource acquisition	Obtaining approval, support, assistance, advice, or validation from others; avoiding social disapproval or rejection
Integrative Social Relationship Goals	
Belongingness	Building or maintaining attachments, friendships, intimacy, or a sense of community; avoiding feelings of social isolation or separateness
Social responsibility	Keeping interpersonal commitments, meetings social role obligations, and conforming to social and moral rules; avoiding social transgressions and unethical or illegal conduct
Equity	Promoting fairness, justice, reciprocity, or equality; avoiding unfair or unjust actions
Resource provision	Giving approval, support, assistance, advice, or validation to others; avoiding selfish or uncaring behavior
Task Goals	
Mastery	Meeting a challenging standard of achievement or improvement; avoiding incompetence, mediocrity, or decrements in performance
Task creativity	Engaging in activities involving artistic expression or creativity; avoiding tasks that do not provide opportunities for creative action
Management	Maintaining order, organization, or productivity in daily life tasks; avoiding sloppiness, inefficiency, or disorganization
Material gain	Increasing the amount of money or tangible goods one has; avoiding the loss of money or material possessions
Safety	Being unharmed, physically secure, and free from risk; avoiding threatening, depriving, or harmful circumstances

APPENDIX-B: Study 1 Investigating EMCs' Perceptions

(Chapter 4)

Appendix B1. Study 1. Attributes lists

B1.1: Products attributes list (self-fill)

Ref. No: _____ ( )

A. When you are buying a PRODUCT, what is important to you?

Some examples of product features are listed below but you may like to think of anything else not mentioned here. Please:

PLEASE TICK (√) 3 features that are IMPORTANT and CROSS **(X)** 3 that are LEAST IMPORTANT - leaving the others blank.

Brand name/ Designer label		Colour, Contrast or Choices	
Appearance: Design / Beauty		Material used or Texture	
Size of Display & Buttons		Packaging design and unpacking	
Clear Displays (Information, Lighting)		Usefulness	
Clear Instructions or Menu		Speed, Efficiency, Accuracy	
Clear Symbols, images		Quality – Reliability/ Durability	
Clear explanation of technical words/Jargon		Energy Economy	
Ease of use: Navigation, Functionality, Remote Control		Long-battery life	
Finding Help information		Safety	
Personalising Choices in menu		Maintainability	
Ease of Assembly/ set up		Delivery service	
Connectivity, integration, stackability		Comfort	
Position of controls, sockets, switches, buttons		After-sales Service & support	
Size of handles, straps, locks, buttons, fasteners		Price/ Value for money	
Movability - wheels/handles/grips for moving		Credit or Instalment plan	
Portability - ability to take it with you		Warranty	
Dimensions - Height, Size, Fit		Special offers or add-ons	
Weight - or weight when full		Able to share it with friends/ family	
Provision & length of wiring, leads		Friend's Recommendation	
Sound quality & ease of recording/playback		Trust in supplier	
		Enjoyment/ Satisfaction	
Any Other:			

B1.2: Services attributes List (self-fill)

B. When you are using a SERVICE, what is important to you?

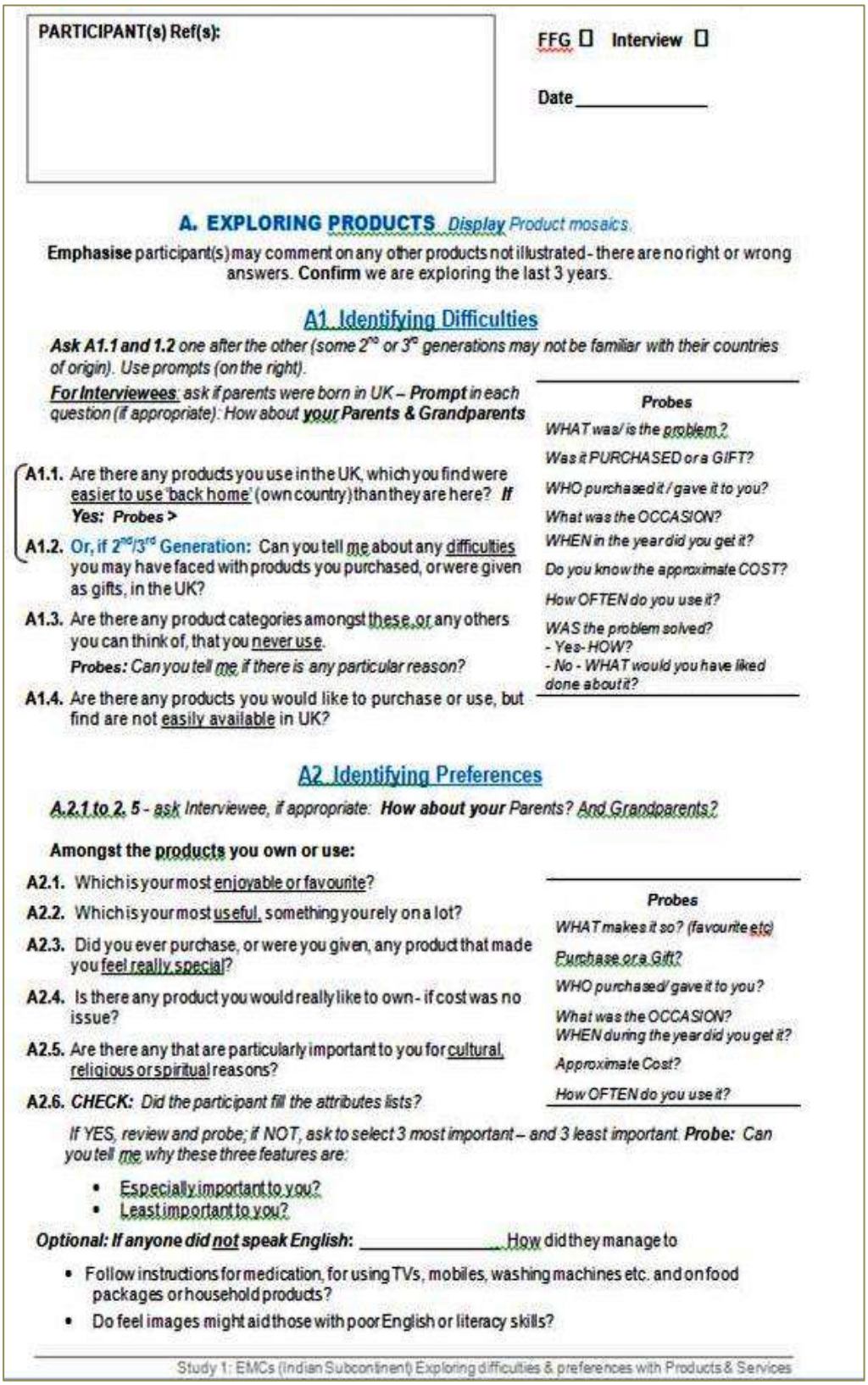
Some examples of service features are listed below but you may like to think of anything else not mentioned here. Please

PLEASE TICK (√) 3 features that are IMPORTANT and CROSS **(X)** 3 that are LEAST IMPORTANT leaving the others blank.

Usefulness		Colour /Decor	
Convenience		Clarity of images	
Availability, accessibility		Sound levels	
Staff attitude, approach		Speed, Efficiency	
Brand name, Designer label		Home delivery	
Variety of facilities, options		Incentive scheme, special offers	
Clarity of Menu, Instructions		Price, value for money	
Menu variety and choice		Credit facility, Instalment plan	
Display of Information		Free add-ons or special offers	
Safety		Children's facilities or play area	
Cleanliness		Facilities for disabled	
Spaciousness		Able to share it with friends/ family	
Luxuriousness		Enjoyment, satisfaction	
Parking facilities		Prestige, status	
Open non-office hours		Friend's recommendation	
Quality of service		Comfort	
Ease of locating different services/ facilities in a building or complex		Availability of service in other locations in UK	
Any Other:			

Appendix B2. Study 1. Semi-structured Interview Questions

B2.1: Questions on Products



PARTICIPANT(s) Ref(s):

FFG ☐ Interview ☐

Date _____

A. EXPLORING PRODUCTS *Display Product mosaics*

Emphasise participant(s) may comment on any other products not illustrated - there are no right or wrong answers. **Confirm** we are exploring the last 3 years.

A1. Identifying Difficulties

Ask A1.1 and 1.2 *one after the other (some 2nd or 3rd generations may not be familiar with their countries of origin). Use prompts (on the right).*

For Interviewees*: ask if parents were born in UK –* ***Prompt*** *in each question (if appropriate): How about* ***your Parents & Grandparents***

A1.1. Are there any products you use in the UK, which you find were easier to use 'back home' (own country) than they are here? ***If Yes: Probes >***

A1.2. Or, if 2nd/3rd Generation: Can you tell me about any difficulties you may have faced with products you purchased, or were given as gifts, in the UK?

A1.3. Are there any product categories amongst these, or any others you can think of, that you never use.

Probes: *Can you tell me if there is any particular reason?*

A1.4. Are there any products you would like to purchase or use, but find are not easily available in UK?

Probes

WHAT was/ is the problem?

Was it PURCHASED or a GIFT?

WHO purchased it / gave it to you?

What was the OCCASION?

WHEN in the year did you get it?

Do you know the approximate COST?

How OFTEN do you use it?

WAS the problem solved?
- Yes- HOW?
- No - WHAT would you have liked done about it?

A2. Identifying Preferences

A.2.1 to 2. 5 *- ask Interviewee, if appropriate:* ***How about your*** *Parents? And Grandparents?*

Amongst the products you own or use:

A2.1. Which is your most enjoyable or favourite?

A2.2. Which is your most useful, something you rely on a lot?

A2.3. Did you ever purchase, or were you given, any product that made you feel really special?

A2.4. Is there any product you would really like to own - if cost was no issue?

A2.5. Are there any that are particularly important to you for cultural, religious or spiritual reasons?

A2.6. ***CHECK:*** *Did the participant fill the attributes lists?*

Probes

WHAT makes it so? (favourite etc)

Purchase or a Gift?

WHO purchased/ gave it to you?

What was the OCCASION?
WHEN during the year did you get it?

Approximate Cost?

How OFTEN do you use it?

If YES, review and probe; if NOT, ask to select 3 most important – and 3 least important. ***Probe:*** *Can you tell me why these three features are:*

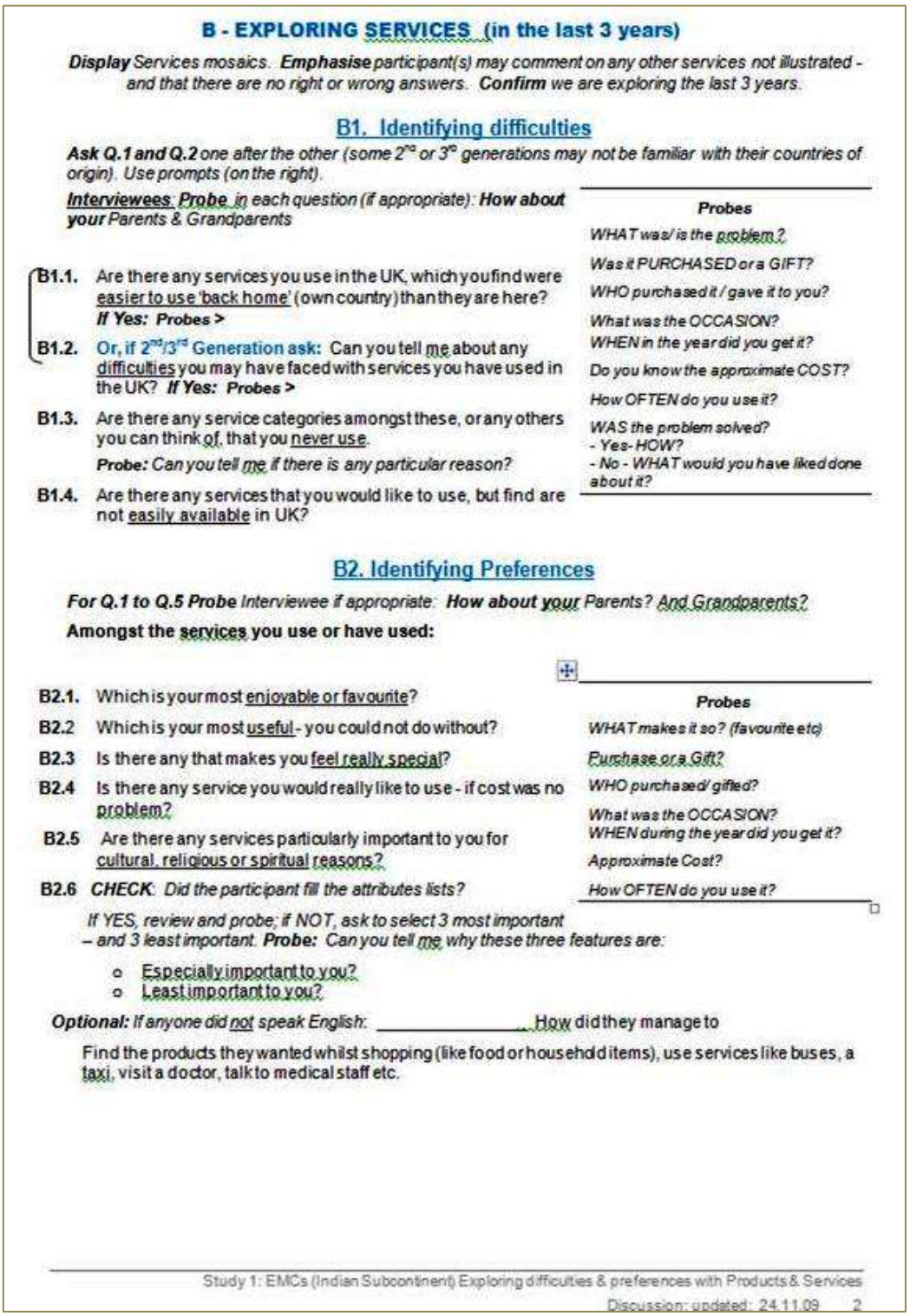
- Especially important to you?
- Least important to you?

Optional: If anyone did not speak English: _____ How did they manage to

- Follow instructions for medication, for using TVs, mobiles, washing machines etc. and on food packages or household products?
- Do feel images might aid those with poor English or literacy skills?

Study 1: EMCs (Indian Subcontinent) Exploring difficulties & preferences with Products & Services

B2.2: Questions on Services



B - EXPLORING SERVICES (in the last 3 years)

Display *Services mosaics.* ***Emphasise*** *participant(s) may comment on any other services not illustrated - and that there are no right or wrong answers.* ***Confirm*** *we are exploring the last 3 years.*

B1. Identifying difficulties

Ask Q.1 and Q.2 *one after the other (some 2nd or 3rd generations may not be familiar with their countries of origin). Use prompts (on the right).*

Interviewees: Probe *in each question (if appropriate):* ***How about your*** *Parents & Grandparents*

Probes

WHAT was/ is the problem?
Was it PURCHASED or a GIFT?
WHO purchased it / gave it to you?
What was the OCCASION?
WHEN in the year did you get it?
Do you know the approximate COST?
How OFTEN do you use it?
WAS the problem solved?
- Yes- HOW?
- No - WHAT would you have liked done about it?

B1.1. Are there any services you use in the UK, which you find were easier to use 'back home' (own country) than they are here?
If Yes: ***Probes >***

B1.2. **Or, if 2nd/3rd Generation ask:** Can you tell me about any difficulties you may have faced with services you have used in the UK? ***If Yes:*** ***Probes >***

B1.3. Are there any service categories amongst these, or any others you can think of, that you never use.
Probe: *Can you tell me if there is any particular reason?*

B1.4. Are there any services that you would like to use, but find are not easily available in UK?

B2. Identifying Preferences

For Q.1 to Q.5 Probe *Interviewee if appropriate:* ***How about your*** *Parents? And Grandparents?*

Amongst the services you use or have used:

Probes

WHAT makes it so? (favourite etc)
Purchase or a Gift?
WHO purchased/ gifted?
What was the OCCASION?
WHEN during the year did you get it?
Approximate Cost?
How OFTEN do you use it?

B2.1. Which is your most enjoyable or favourite?

B2.2 Which is your most useful - you could not do without?

B2.3 Is there any that makes you feel really special?

B2.4 Is there any service you would really like to use - if cost was no problem?

B2.5 Are there any services particularly important to you for cultural, religious or spiritual reasons?

B2.6 ***CHECK****: Did the participant fill the attributes lists?*

If YES, review and probe; if NOT, ask to select 3 most important – and 3 least important. ***Probe:*** *Can you tell me why these three features are:*

- Especially important to you?
- Least important to you?

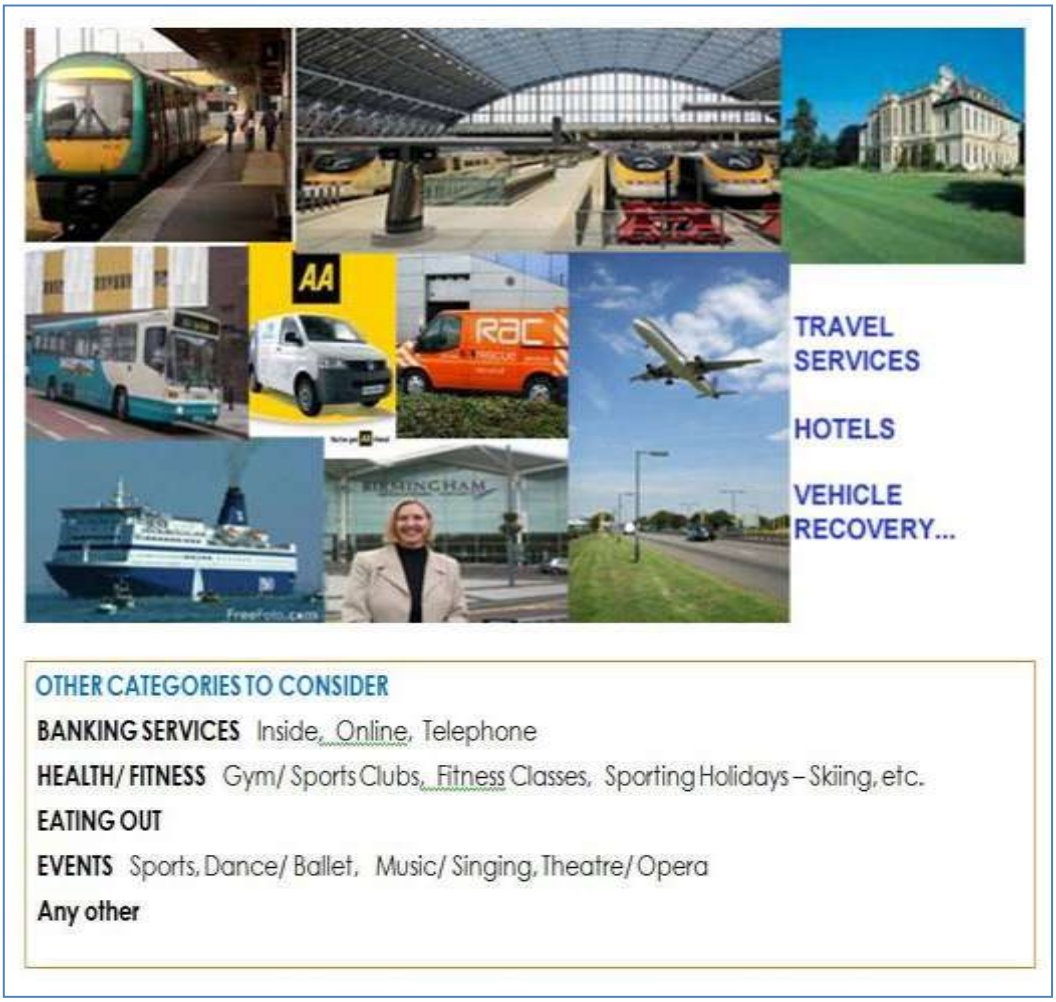
Optional: *If anyone did not speak English:* _____ How did they manage to

Find the products they wanted whilst shopping (like food or household items), use services like buses, a taxi, visit a doctor, talk to medical staff etc.

Appendix B3. Visual aids

B3.1: Services mosaics: Government & Shopping (A4 formats)

B3.2: Services mosaic: Travel & Other categories (A4)



B3.3: Products mosaics: Computing & Personal media (A4)

COMPUTERS, SOFTWARE or ACCESSORIES

CAMERAS, PHONES & PERSONAL MEDIA

B3.4: Products mosaics: Kitchen & Domestic (A4)

- **KITCHEN & DOMESTIC EQUIPMENT**

B3.5: Products mosaics: Home entertainment & Car (A4)

- **HOME ENTERTAINMENT SYSTEMS**

- **CAR & APPLIANCES**

B3.6: Products mosaics: DIY tools & Gardening (A4)

- **D.I.Y. TOOLS & EQUIPMENT**

- **GARDENING**

B3.7: Products mosaic: Medical & Health and Other Categories (A4)

- **MEDICAL AND HEALTH APPLIANCES/ EQUIPMENT**

- **OTHER CATEGORIES TO CONSIDER**

Jewellery & Watches

Medical or Health Appliances

Sport/Leisure equipment

Newspapers/ Magazines

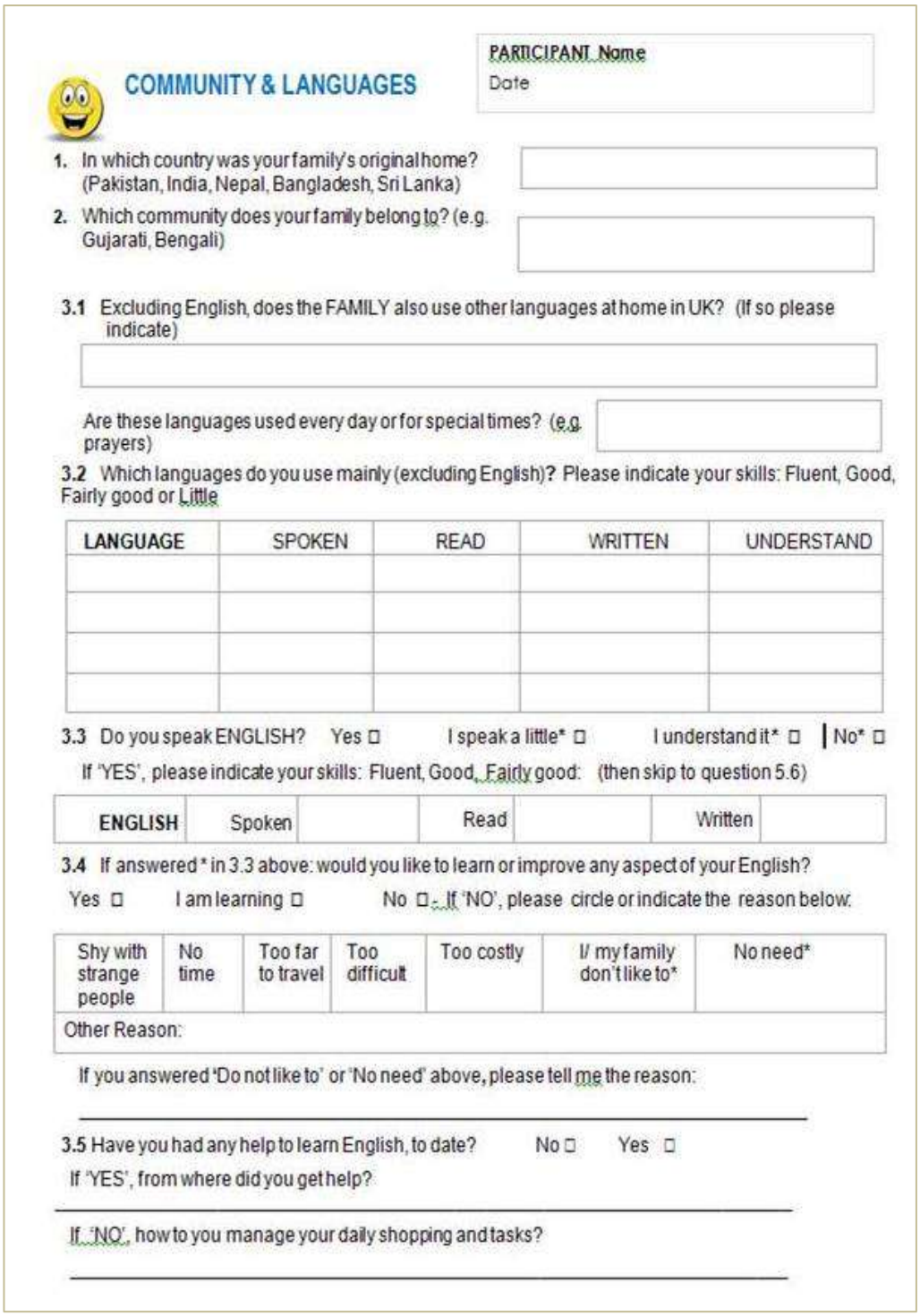
Clothes, Shoes, Cosmetics

Furniture & Fabrics (curtains, cushions, duvets)

Any other

Appendix B4. Questionnaire (Self fill)

B4.1: Community and Languages (p.1)



PARTICIPANT Name

Date

COMMUNITY & LANGUAGES

1. In which country was your family's original home? (Pakistan, India, Nepal, Bangladesh, Sri Lanka)
2. Which community does your family belong to? (e.g. Gujarati, Bengali)

3.1 Excluding English, does the FAMILY also use other languages at home in UK? (If so please indicate)

Are these languages used every day or for special times? (e.g. prayers)

3.2 Which languages do you use mainly (excluding English)? Please indicate your skills: Fluent, Good, Fairly good or Little

LANGUAGE	SPOKEN	READ	WRITTEN	UNDERSTAND

3.3 Do you speak ENGLISH? Yes ☐ I speak a little* ☐ I understand it* ☐ No* ☐

If 'YES', please indicate your skills: Fluent, Good, Fairly good: (then skip to question 5.6)

ENGLISH	Spoken		Read		Written	

3.4 If answered * in 3.3 above: would you like to learn or improve any aspect of your English?

Yes ☐ I am learning ☐ No ☐. If 'NO', please circle or indicate the reason below:

Shy with strange people	No time	Too far to travel	Too difficult	Too costly	I/ my family don't like to*	No need*
Other Reason:						

If you answered 'Do not like to' or 'No need' above, please tell me the reason:

_____

3.5 Have you had any help to learn English, to date? No ☐ Yes ☐

If 'YES', from where did you get help?

_____

If 'NO', how to you manage your daily shopping and tasks?

_____

3.6 **If you speak other European languages, please** indicate: Spoken, Read, Written

Language	Fluent	Good	Moderate	Conversational	A little

FAITH GROUP & FESTIVALS

4 Do you follow a particular Faith? (Please circle)

Hindu	Christian	Sikh	Muslim	Buddhist

5. How much would you say your faith affects your choice in purchasing products or using services:

Always	Often	Moderately	Sometimes	Not at all

6 Do you celebrate religious and other festivals - in UK?

Always	Often	Moderately	Sometimes	Not at all

7 Which RELIGIOUS & SOCIAL FESTIVALS do you like to celebrate?

LIVING in UK & BACKGROUND

(Please circle)

8 Were you born in UK? Yes ☐ No ☐

9 How many years have you lived here? Under 1 year ☐ 1- 3 ☐ 3- 5 ☐ 5-10 ☐ 10+ ☐

10 Did you attend school or college here? Yes ☐ No ☐

If 'yes', for how many years? Under 1 year ☐ 1- 3 ☐ 3- 5 ☐ 5-10 ☐ 10+ ☐

11 In order of importance, which cultures do you feel influence your lifestyle? Please put the most important first.

12 A) What do you like best about living in UK? :

B) What do you like least - and what would like to change?

13. Your Age group: 18-23□ 24-29□ 30-39□ 40-49□ 50-59□ 60-69□ 70-79□ 80+□

14. Your Gender: Male□ Female□

15. Current/recent employment status: (Please tick)

1.□ High School	2.□ College / University	3.□ Parent/ Home work	4.□ Full-time employed	5.□ Part-time Employed	6. □ Self-Employed	7. □ Retired	8.□ Charity / Volunteer
9.□ Other (please specify)							

16. Current/recent occupation:

17. Do you drive? Yes□ Provisional □ No □

If 'NO', did you drive before? Yes □ No □ - If 'NO', please indicate the reason:

18. Please add any other suggestions or comments you would like to:

Signature: _____

A warm 'Thank you' for your support & interest! Shena

B4.2: Festivals list

Festivals Examples

BUDDHIST			
☐ Buddha Purnima	☐ Hemis Gumpa	☐ Losar	
☐ Poya	☐ Ullambana	☐	
ISLAM			
☐ Id-ul-Fitr	☐ Id-ul-Zuha (Bakr-Id)	☐ Bangla Naba Barsha	
☐ Ashura	☐ Giaravahin Sharif	☐ Shab-e-Bharat	
☐ Ramzan	☐ Prophets birthday	☐ Muharram	
CHRISTIAN & GENERAL			
☐ New Year (Jan 1)	☐ Good Friday / Easter	☐ Thanks giving	
☐ Valentine's Day	☐ Christmas	☐ Father's Day	
☐ St Patricks Day	☐ Mother's Day	☐ Halloween	
HINDU			
☐ Diwali	☐ Ramnavami	☐ Rakshabandhan	☐ Teej
☐ Dussehra	☐ Ganesh Chathurthi	☐ Janmashtami	☐ Holi
☐ Durga Puja	☐ Karwa Chauth	☐ Shivratri	☐ Pongal
☐ Onam	☐ Mahavir Jayanti	☐ Paryushan Parva	
SIKH			
☐ Lohri	☐ Guru Nanak Jayanti	☐ Bandi Chorrh Diwas (Diwali)	☐ Maghi
☐ Baisakhi	☐ Gurupurab	☐ Hola Mohalla	

Appendix B5. Extract from codes clustered in the matrix under religion, gender and concept.

CATEGORY: SERVICES: *Study 1 Analysis – Clustering codes*

Faiths >	CHRISTIANS		SIKHS	
Categories	MALES	FEMALES	MALES	FEMALES
Problems UK **Usability or Never used**	**Health service**- Doctors appointment waiting time too long, worried -1gen **Education** standard anxiety, poss send son back home- 1gen *[latent problem: son's future acculturation]* **Internet-** shop for travel only, caution	**Health service**- Doctors appointment waiting time too long, worry 1gen **Health service**- expensive, cost conscious, medical technology too expensive, critical, nursing better in India-more nurses available, 1gen **Education std** anxiety, poss send son back home - 1gen *[latent problem: son's future acculturalisation]* **Language barrier** – can't follow Instructions, shop or speak to anyone, safety, health, more images helpful 1gen No English **Internet-** shop for travel only, caution	**Call centre sales,** avoiding rudeness 2gen **Public transport -** NI bus-too long waiting times, esp winter dissatisfaction 1gen GPa **Public transport train** cleanliness, critical, quality of service important 2gen **Never use**- Citizens Advice /mobility Centres-no need 2&3 gen **Govt services slow**, bureaucratic, Critical, too many outsourcing service errors 2gen	**Health** - language barrier, communicating with doctors, respect from English doctors, appreciation, frustration, wasted visit 1gen GMa **Health** - Interpreter problems, lack of service, inter-faith disinterest, LoRespect, lack of empowerment 1gen GMa **Health** – usability-cannot get to physiotherapist non-driver, language barrier, LoConfidence, doctors feel doing all they can but participant is too old now, resignation, disappointment 1gen GMa **Health** - lack of doctors continuity, repetition, inefficient, LoTime (working mum), dissatisfaction 2gen **x3** **Language barrier** - Support of family, constant translation, instructions & usability, 1gen-GMa NEL **Never Use**- Any services without family, language barrier, total reliance on GPa & family, 1gen GMa **Attitude**- MinLaw Lacks English-will not try to learn, language barrier, no contact outside community, constant interpretation, pressure on family 1&2gen, 1gen GMa NEL

APPENDIX-C: Study 2 Investigating NHS Staffs' Perceptions

Appendix C1.Interview questions

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

A PhD Study – Phase 1 Semi structured interview questions

Investigating NHS Staff's perspectives of any barriers that hinder the provision of healthcare to ethnic minority patients.

Participant Ref: _____( ) Date_____

Role:

Department/ Service & Location:

Introduction: Thank you for talking to me. I greatly value that that you are contributing to this research. I would like to confirm that there are no right/wrong answers and data provided by participants will be anonymised, as will the names of Trusts. I simply wish to explore your views on any barriers you might experience whilst caring for patients lacking English, particularly people from the Indian sub-continent, but also to know if other patients share similar difficulties. If barriers are present, I would like to understand their nature, and the aids you use to overcome these.

Q1. **Broadly speaking, of the patients you see, what percentage would you estimate are from ethnic minority backgrounds?**

Q2. *(If relevant to the role. e.g. the doctor)* **When a patient returns for a follow-up appointment, would they normally see the same doctor/** staff **as on the previous appointment?** Or
(Or for Paramedics and A&E staff). **Do you receive irrelevant calls from EMCs for cases that are not emergencies?**

Q3. **Have you faced any difficulties or are you aware of any difficulties faced by any of your colleagues whilst providing services to ethnic minority patients?**

If YES - Would you please describe the problem? How frequently does it occur? What do you do to overcome the difficulty? Are there other difficulties, too? (Explore as many difficulties as participant wishes to mention.)
Are there particular challenges relating to particular communities that you can remember? Can you recall any cases that caused particular difficulties

Q4. *(If not mentioned)* **Do spoken language barriers with patients affect your work?** e.g. patients lacking English skills
If YES - How frequently does this happen? What do you do to overcome the problem? *If NOT* - How do you manage to communicate with non-English speaking patients?

Q5. *(If not mentioned)* **Do you use Interpreters and, if so, how would they be brought in for a particular consultation?**
If YES - How easily can they be obtained and how much notice must be given?
How well do you think what the patient is saying to you and vice versa is communicated? Have you noted any difficulties when using interpreters?

Q6. **If patients from ethnic minority communities have low reading or writing skills, does this cause problems in your work?** e.g. reading medication instructions or a printout from the doctor

Q7. **When communicating medical conditions to ethnic minority patients, do you face any comprehension difficulties?**
If YES - How do you overcome this? Is this a satisfactory solution?

Q8. **Do you have any tools or hand-outs for ethnic minority patients that help you communicate with them or provide guidance to overcome the problem(s) we spoke of?**
If YES - What are these tools? Is it possible to see a copy? Where did they come from/ who developed them? How successful do you find them in achieving your objectives? If they are successful, how do you know or measure that? What do you feel about more of these tools? Is there scope for improvement?
If NO – What do you feel would help you? How do you manage to overcome this difficulty?

Q9. *(if relevant to role)* **In your experience, how well do the patients remember the guidance they have been provided once they have gone home?**
i.e. Do you find they return to you and have not followed the guidance for any reason? If so, how frequently does this happen? Do you notice this problem more with any particular group of patients or medical conditions?

Q10. **How do the difficulties we have discussed most affect your work?**
E.g. is it time, scheduling, you are unsure the patient has understood the guidance, or patients have to be re-treated for the same condition, etc. ***If you thought about helping to improve care for ethnic minority patients what would help you most?***

Q11. **Do you get feedback about what ethnic minority patients are happy about or are unhappy about?**
IF YES – please comment briefly on this
IF NO – do you think having feedback would help?

Q12. **If you thought about helping to improve care for EMCs, what would help you most?**

Q13. **Are there issues we have not discussed that you would like to talk about?**

Thank you very much for your time.

Would you like to have a copy of the outcome of these interviews?

Would you like to know what the future plans are for Phase-2 of the study?

Appendix C2.Extracts of transcribed data (Word 2007)

Data was 'chunked' following framework based analysis, i.e. grouped from different parts of the transcript under appropriate questions, and [time] denotes the point at which comments were made. Highlighted text was copied into a format in Excel and then reduced.

S02-INTV 32 - DR S, 3.3.2011, GP, Male

Legend: EMPs= ethnic minority patients, Black= Participant, Blue= researcher, Orange text= code or comment

The participant had not read the Participant Information: a copy of the PInS and Letter of Invitation were again given to the participant, we reviewed the information, gained Informed Consent - a photocopy of which was also given to the participant at his request.

How many years have you been with the NHS as a GP? Since 1997. I finished medical university, I was working as a GP, I started working with NHS in 2006, I did my GP training from 2006-2009, from 2009 I've been graduated GP. So you've been a doctor since 19..? 1996 And when you were a doctor were you working here in the UK? Before 2006 I was working back home in Iran, I was working as a GP there. What I did, I repeated my training in UK after obtaining my British passport. And have you spent that time here mainly? No, mainly in XXXXX. From July last year [2010] I started working as a salaried doctor for this new company. OK? So my experience of working as a GP is divided into XXX and here.

Q1. Broadly speaking, of the patients you see, what percentage would you estimate are from ethnic minority backgrounds?

Here in this surgery you mean? Or in general? In general – here and Birmingham. OK. Here of course its mainly, we have a very good portion of people from ethnic minority – from Asia mainly. In *this* surgery its less. It might be because we're in the town centre. The other surgery, over 90% of my patients are from ethnic minority. Mainly they're from Pakistan and India. [2.46] And over here you're working with a very low percentage? It's not a very low percentage, but compared to other surgeries in Leicester our percentage is less. How much would you say at the present time? I would – I don't have the demographic, I tried actually to obtain that for you [3.09]. Just a rough idea of whom you tend to see – would you say 20% from ethnic minorities, or 15%? Let's just look at today and yesterday, how many of my patients from ethnic minorities..errr...I say I get about *maybe* something about **15-20%** of my patients, umm.. the rest mainly are British. [3.33]

Q2. *(if appropriate)* **When a patient returns for a follow-up appointment, would they normally see the same doctor as on the previous appointment?**
Usually, sometimes a different doctor.

Q3. Have you faced any difficulties, or are you aware of any difficulties faced by any of your colleagues, whilst providing services to EMPs?

Yes I think there are 2 important problems, one can be language barrier, OK? **The other problem can be *beyond* language.** I think it maybe **cultural gaps and different health beliefs. Every culture has its own health beliefs** and its very important that you gradually acquire those skills, that to be able to understand people with different culture. For example *I have headache* or *I cannot swallow* or *I cannot eat* means different in different cultures. Perhaps *I cannot swallow* in one culture means, *Doctor I'm not able to put anything down*, you know. In another culture it means, *its difficult or it hurts but I still can swallow.* **So, basically, health belief and perception of people of their symptoms is very different in different cultures. That's the other barrier apart from language.** [4.45]

The other thing that you mentioned can be low literacy, obviously. **Because with low literacy the way they describe their symptoms, the way that they can help the doctor to figure out what is the reason for their problem, is different. And that's another challenge.** [5.04 contd Q5 problems with interpreting.] Note: Language barriers and comprehension mentioned, see Q6

Contd from Q6. 10.1] [10.16] Are there any other problems that you can think of that also affect your work? You mean about ethnic minorities? Yes. **As I mentioned to you its really important that we know there culture and their health beliefs.** Does this have to do with religion or so you think its to do with the other sides of culture? I think its more culture rather than religion. I mean that's what ...I mean why ...I don't mean like in particular religions they have rules and they have to follow. I'm not talking about that, **I'm more talking about their interpretation of what symptom they have and what it can be**. [10.58]

If I make an example for you. Yes. An Asian lady, who is, like, 70 comes to you with multiple pains. You definitely need to look into their mood, you need to look into other causes, this person might have pneumonia and be complaining about multiple pain, this person might be depressed and be complaining about multiple pain, or they might have really multiple pain, all over their body basically. **So its very important, and its very typical of *this* culture that they usually come with *this* presentation. So for a GP, its very important to understand the culture and say: complaining of pain in many parts of the body, what can it mean basically in *that* culture.** OK? [11.48] You don't get that for example, *this* type of presentation you don't get it with British patients. They're more particular. I mean they come and tell you that *I'm depressed* OK. [12.00]

So you feel that some people, like the elderly Asian lady, are not able to articulate the fact that she might be depressed? **Yes, it's difficult.** Because conditions like depression are perhaps not understood very widely in the culture? Yes. It *might* be, because you know what are ...The way I accept this is that it's a part of the culture in this culture, that's how depression presents, that's how the brain was trained from childhood. OK? Now it's becoming different: you see that the new generation, the 2nd generation over here, the way they describe their symptoms is very different. So *maybe* its because *pain* is very ...its one of the most important symptoms when it comes, to *this* particular culture. In another culture, pain might not be *as* important, although pain is always for every patient it *is* important, they don't look at it the way in other cultures. [13.07]

I'm just trying to say that the *way* people *look* at their problem is very different and its important for a GP to know every culture. Otherwise he's going to be very confused when he sees a patient, complaining of pain and tenderness all over the body: *Oh my God! What should I do? Should I get this patient admitted?* [13.26]

(advised Doctor previous study was based around generations and religions) As you say if you have somebody who comes from a rural background it *(conditions like depression)* may not be something they pick up on? **Exactly**. They may be suffering from it, but they could not articulate it? **[Nods] So they present in different ways**. But that then comes back to your earlier point that it's not just language it's that they do not know enough to be able to say, *I think...* **[Nods] What is the problem.** [14.56] contd Q.6 [14.56]

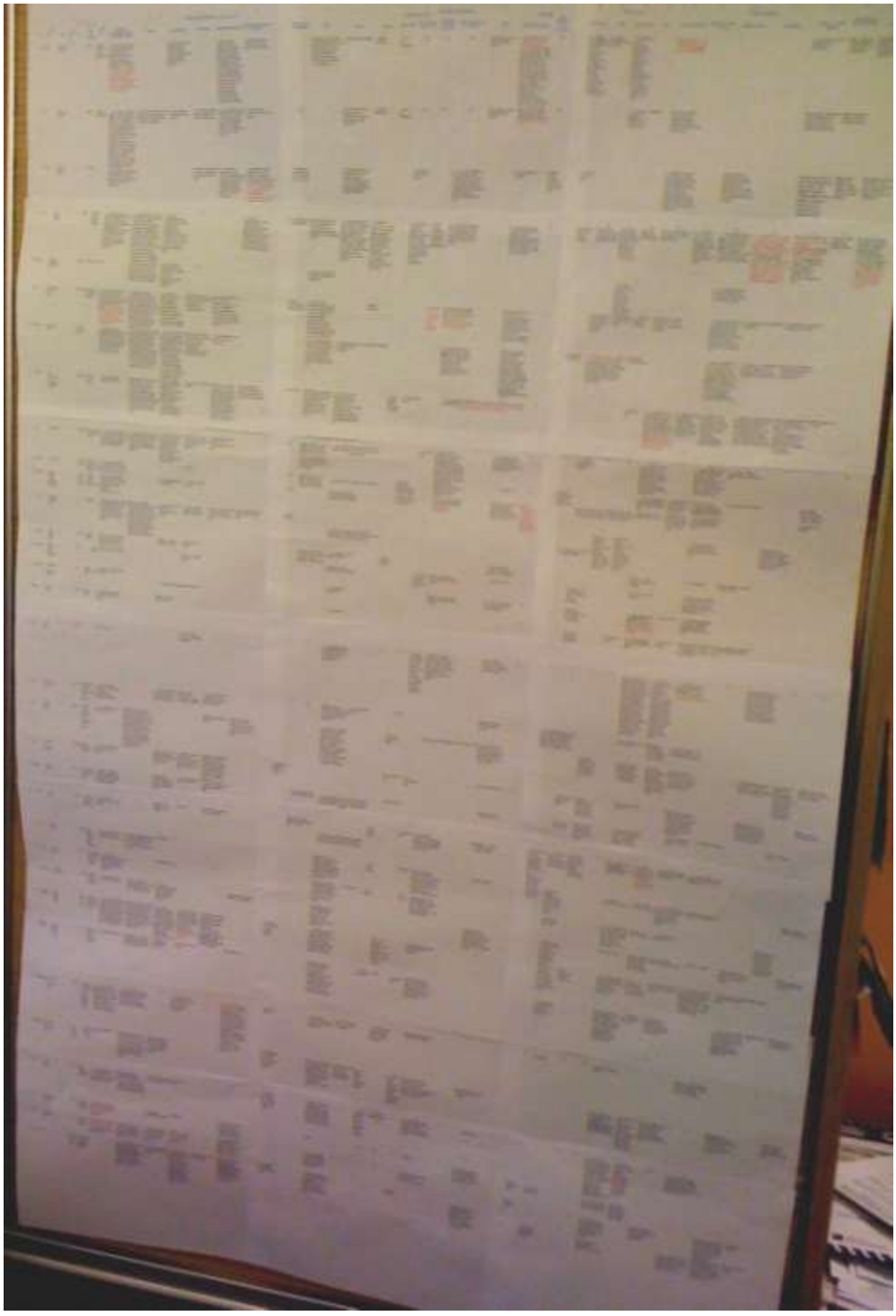
Q4. Do spoken language barriers with patients affect your work? covered in Q3

Q5. Do you use Interpreters - how would they be brought in for a particular consultation? Also see Q3

[Contd from Q3. 5.04] How do you manage to overcome some of these difficulties at present? OK. We use different techniques basically. **We use *Language Line*** – thats one way, using interpreters in person - which is becoming more difficult now in NHS. So **we have to ask patients to bring somebody who they trust with them so we can use them as interpreter.** Is the interpreter from the NHS difficult because of the cost. or don't you know? I don't...I am not aware. **What the NHS basically recommends is to use *Language Line*, which we do but as you know its not the best way. *Language Line* might not be really helpful – there are *many* times that we spend about 30, 35 *minutes* on the phone with *Language Line* trying to pass a message to a patient and we still cant.** [6.01] Now, as I mentioned to you, it might be because of the fact the person on the line does not *know* this patient so all he can do is translate word by word. **Alternatively, if we have a friend, who knows this patient, this patient trusts, who knows what sort of person he's interpreting for then he can be more helpful. [6.27] especially if he is more educated than the patient. So we found that's more helpful than *Language Line*.** [6.35]

Appendix C3.Following a framework analysis method.

Text was copied from transcriptions and formatted in Excel 2007 sheet under 4 *categories.* Themes were added as they emerged and the text was then reduced. The pages were collated and displayed for comparison (extracts from the data follow overleaf).



Appendix C4.Extract from the initial analysis in Excel 2007: *Difficuties experienced (and patient groups affected)*
Some themes: Language/communication barrier, cultural, lack of understanding/comprehension, low literacy, patient stress/anxiety, retention.

Ref.	Role	In role: Gender F	In role: Gender M	In role: Aprox % EMCs	Cultures	DIFFICULTIES EXPERIENCED (& patient groups): Language/ communication barrier (non-English speakers)	Cultural	Lack of Understanding/ Comprehension	Low literacy	Patient Stress/ Anxiety	Remembering guidance/ Retention
2	Reception, Main	1		60%	Asians, E Europeans	Y - more often x-cultural elderly - occasional Asian EMPs; some families leave EMPs with no English at main reception instead of the dept; explaining things - if dropped off at wrong hospital, directions to dept. some are down long corridors, some units in hospital grounds; scared of being lost - finding depts in hospital & grounds (breast screening, diabetes, disabled services); patients are already anxious due to illness, being in hospital;	Some elderly Asians on wards dont know to say 'please' & 'thank you', culturally, when asking for something.	Y -maps, locating departments esp. In grounds	Y - recognising English signs as department names, reading maps,	Y - people get lost - Asian EMPs withouth English worry more, are more scared, body language scared; E European EMCs more confident & find places; elderly scared;	Y - people get lost, confuse left & right, return for help;
3	Pharma, Cancer Unit		1	10-20%		Y - very hard to communicate, totally relying on interpreter; esp when patient goes home, trying to talk to them about the medicines;		x-cultural - treatment continues at home;	Uncertain - patients may be able to match word on tablet with word on table;	N- x-culturally in treatment unit (like cancer) patients grateful for help; Y - Pharmacy, if A&E patient: poorly, waiting in A&E & for medicines, asking for money; cumulative experience;	Dosette boxes- DDA patients only - not low literacy, no English or elderly; lots of people dont take medicines correctly, one of the biggest causes of re-admission across NHS **[?get info]**; remembering is important- treatment continues at home;
4	Snr Physio, OutP	1		30%	Ind Sub, Polish, French, Italians	Y - explaining exercises therapy happens at home; if a phone call about an appointment, non-Enlgish speakers cannot comprehend & not turn up; communication gap is huge; have a lot of questions & response-specific sub-questions; translated,	Y - gender issue, x-cultural requesting F therapist; many non-Western EMC Fs unfamiliar with exercise as part of life. Inappropriate interpreters - daughters look away when father dresses down, not ideal; son walks out of cubicle when mother dresses down, impossible to do job. Gender divide: Fs stay at home, rely on Ms for information, Ms might filter information, Fs 'scuppered' if M passes away. x-culturally now families at work & elders on own;	Y - lack of understanding what physiotherapy is about; confuse role of therapist with massage; also x-cultural; what exercise is about esp. Fs; where muscles ache is a good thing not bad; why exercise needs to be done			Y - x-cultural misinterpretation: what people *hear* is not necessarily what you've said; can do it when family are present; rely on repetition; people dont read appointment letter properly - forget to flag up an interpreter is required;

Appendix C5.Expanded extract: category *Difficuties experienced (and patient groups affected)* **(Excel 2007)**

Ref.	Role	Gender F	Gender M	In role: Aprox % EMCs	Cultures	DIFFICULTIES EXPERIENC: Language/ communication barrier (non-English speakers)	Cultural	Lack of Understanding/ Comprehension	Low literacy
2	Reception, Main	1		60%	Asians, E Europeans	Y - more often x-cultural elderly - occasional Asian EMPs; some families leave EMPs with no English at main reception instead of the dept; explaining things - if dropped off at wrong hospital, directions to dept. some are down long corridors, some units in hospital grounds; scared of being lost - finding depts in hospital & grounds (breast screening, diabetes, disabled services); patients are already anxious due to illness, being in hospital;	Some elderly Asians on wards dont know to say 'please' & 'thank you', culturally, when asking for something.	Y -maps, locating departments esp. In grounds	Y - recognising English signs as department names, reading maps,
3	Pharma, Cancer Unit		1	10-20%		Y - very hard to communicate, totally relying on interpreter; esp when patient goes home, trying to talk to them about the medicines;		x-cultural - treatment continues at home;	Uncertain - patients may be able to match word on tablet with word on table;
4	Snr Physio, OutP	1		30%	Ind Sub, Polish, French, Italians	Y - explaining exercises therapy happens at home; if a phone call about an appointment, non-Enlgish speakers cannot comprehend & not turn up; communication gap is huge; have a lot of questions & response-specific sub-questions; translated,	Y - gender issue, x-cultural requesting F therapist; many non-Western EMC Fs unfamiliar with exercise as part of life. Inappropriate interpreters - daughters look away when father dresses down, not ideal; son walks out of cubicle when mother dresses down, impossible to do job. Gender divide: Fs stay at home, rely on Ms for information, Ms might filter information, Fs 'scuppered' if M passes away. x-culturally now families at work & elders on own;	Y - lack of understanding what physiotherapy is about; confuse role of therapist with massage; also x-cultural; what exercise is about esp. Fs; where muscles ache is a good thing not bad; why exercise needs to be done	

Appendix C6.Emergency Multilingual Phrasebook: English

31 of the 62 questions (© British Red Cross Society 2004)

	ENGLISH
1	Yes. No. Don't know. I don't understand.
2	What is your name? Can you write it in English?
3	Please write your address.
4	How old are you?
5	Can you give us the name and telephone number or address of someone to be contacted?
6	You will be examined soon by a [1]doctor. [2]nurse.
7	Have you had an accident? When? (show on calendar and clock)
8	Did you lose consciousness?
9	When did you become ill? (show on calendar and clock)
10	Have you any pain? Point where. When did it start? (show on calendar and clock)
11	What is your level of pain? 1 (not in pain) 2 3 4 5 6 7 8 9 10 (chronic pain)
12	The pain, is it constant? Or does it come and go?
13	Have you any bleeding? Point where.
14	Do you have a cough? Do you cough anything up? What colour? white? yellow-green? red? brown?
15	Are you short of breath?
16	Have you vomited? Have you vomited blood?
17	Have you any diarrhoea?
18	Are you constipated?
19	Have you passed black stools?
20	Do your ankles swell?
21	Have you lost weight?
22	Have you difficulty [1]seeing? [2]hearing? [3]swallowing? [4]walking?
23	Have you ever had an operation? Point where.
24	When did your last menstrual period begin? (show on calendar) Are you pregnant? How many months pregnant are you? Could you possibly be pregnant? Can we do a pregnancy test?
25	Do you smoke? How many cigarettes a day?
26	Do you have [1]sugar diabetes? [2]epilepsy? [3]asthma?
27	Have you ever had [1]heart problems? [2]angina? [3]high blood pressure? [4]heart attack? [5]stroke? [6]jaundice? [7]hepatitis?
28	Are you allergic to any medicine? Penicillin? Aspirin? Any other medicine?
29	Are you taking any medicine now? Have you some with you? Are you taking any other drugs or natural remedies?
30	How many tablets have you taken?
31	Are you up to date with tetanus immunisation?

Appendix C7.Emergency Multilingual Phrasebook questions: Hindi

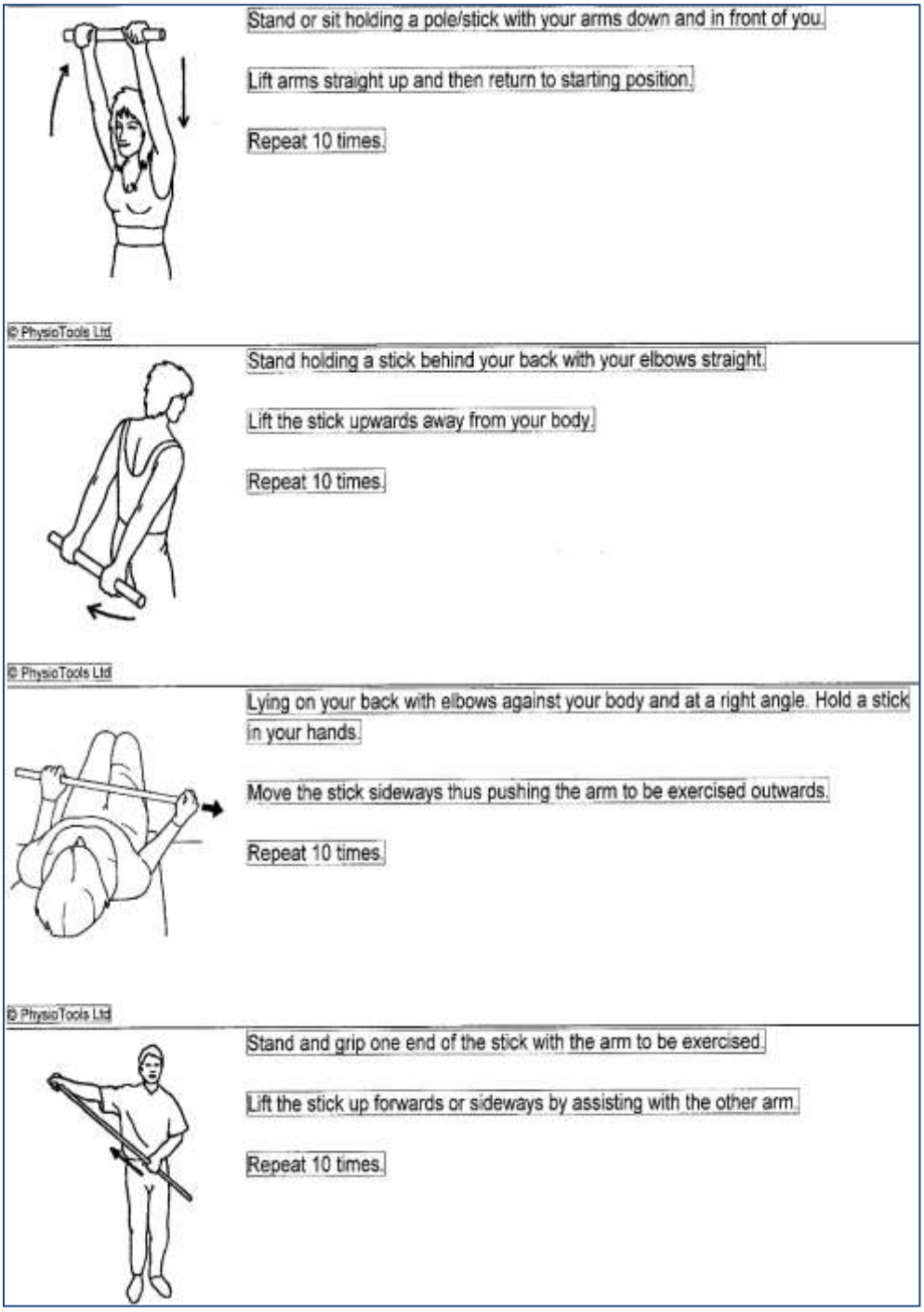
31 of the 62 questions (© British Red Cross Society 2004)

HINDI	25	हिन्दी
1	हाँ। नहीं। पता नहीं। मैं नहीं समझी।	
2	आपका नाम क्या है? क्या आप अपना नाम अंग्रेज़ी में लिख सकते/सकती हैं?	
3	कृपया अपना पता लिखें।	
4	आपकी उम्र कितनी है?	
5	क्या आप किसी ऐसे व्यक्ति का नाम व टेलीफोन नम्बर या पता दे सकते हैं जिससे हम सम्पर्क कर सकें।	
6	शीघ्र ही आप की जाँच की जाएगी ¹डॉक्टर द्वारा। ²नर्स द्वारा।	
7	क्या आपका कभी एक्सीडेंट हुआ है? कब? (कैलेण्डर व घड़ी में दिखाएं)	
8	क्या आप बेहोश हो गये थे/गई थीं?	
9	आप बीमार कब हुए/हुईं? (कैलेण्डर व घड़ी में दिखाएं)	
10	क्या आपको दर्द है? हाथ लगाकर बताएं। ये कब शुरू हुआ। (कैलेण्डर व घड़ी में दिखाएं)	
11	आपकी तकलीफ (पीड़ा) की सीमा क्या है? 1 (पीड़ा रहित) 2 3 4 5 6 7 8 9 10 (दीर्घकालिक पीड़ा)	
12	क्या आपको लगातार दर्द होता रहता है या रूक–रूक कर होता है?	
13	आपका कहीं खून तो नहीं बहा? इशारा करके बताएं।	
14	क्या आपको खाँसी है? क्या खाँसी के साथ बलगम निकलता है? किस रंग का? सफ़ेद? पीला–हरा? लाल? भूरा?	
15	क्या आपको साँस लेने में तक्लीफ़ होती है?	
16	क्या आपको उल्टी आई है? क्या आप ने खून की उल्टी की है?	
17	क्या आपको दस्त तो नहीं लगे?	
18	क्या आपको कब्ज़ है?	
19	क्या आपको काला पाखाना हुआ है?	
20	क्या आपके टखनों में सूजन है?	
21	क्या आपका भार कम हुआ है?	
22	क्या आपको मुश्किल होती है ¹देखने में? ²सुनने में? ³निगलने में? ⁴चलने में?	
23	क्या आपका कभी कोई ऑपरेशन हुआ है? इशारा करके बताएँ।	
24	पिछली बार आपकी माहवारी कब शुरू हुई थी? (कैलैण्डर में दिखाएं) क्या आप गर्भवती हैं? आप कितने महीने से गर्भवती हैं? क्या आप संभावित रूप से गर्भवती हो सकती हैं? क्या हम गर्भ की जाँच कर सकते हैं?	
25	क्या आप धूम्रपान करते/करती हैं? रोज़ाना कितनी सिग्रेट पीते/पीती हैं?	
26	क्या आपको इनमें से कोई बीमारी है ¹शुगर मधुमेह? ²मिर्गी? ³दमा?	
27	क्या आप आपको कभी ¹दिल की बीमारी? ²एंजाइना (कण्ठदाह)? ³उच्च रक्तचाप? ⁴दिल का दौरा? ⁵घात? ⁶पीलिया? ⁷हैपेटाइटिस?	
28	क्या आप किसी दवाई से एलर्जिक हैं? पैनिसिलिन? एस्प्रिन? और कोई दवाई?	
29	क्या अब आप कोई दवाई खाते/खाती हैं? क्या आपके पास वो दवाई है? क्या आप काई अन्य औषधि ले रहे/रही हैं या प्राकृतिक उपचार करा रहे/रही हैं?	
30	आपने कितनी गोलियां ली है?	
31	क्या आप को ताजा–ताजा टेटनस की टीका लगा है?	

Appendix C8.The bulk of patient information remains in English

Appendix C9.Physiotherapy leaflet for patients

Family help is particularly helpful for those lacking English, literacy and who are unfamiliar with exercises. Linking exercises to *yoga* helps people from the Indian Subcontinent put physiotherapy into the right context. (Photograph, original © Physiotools 2011).

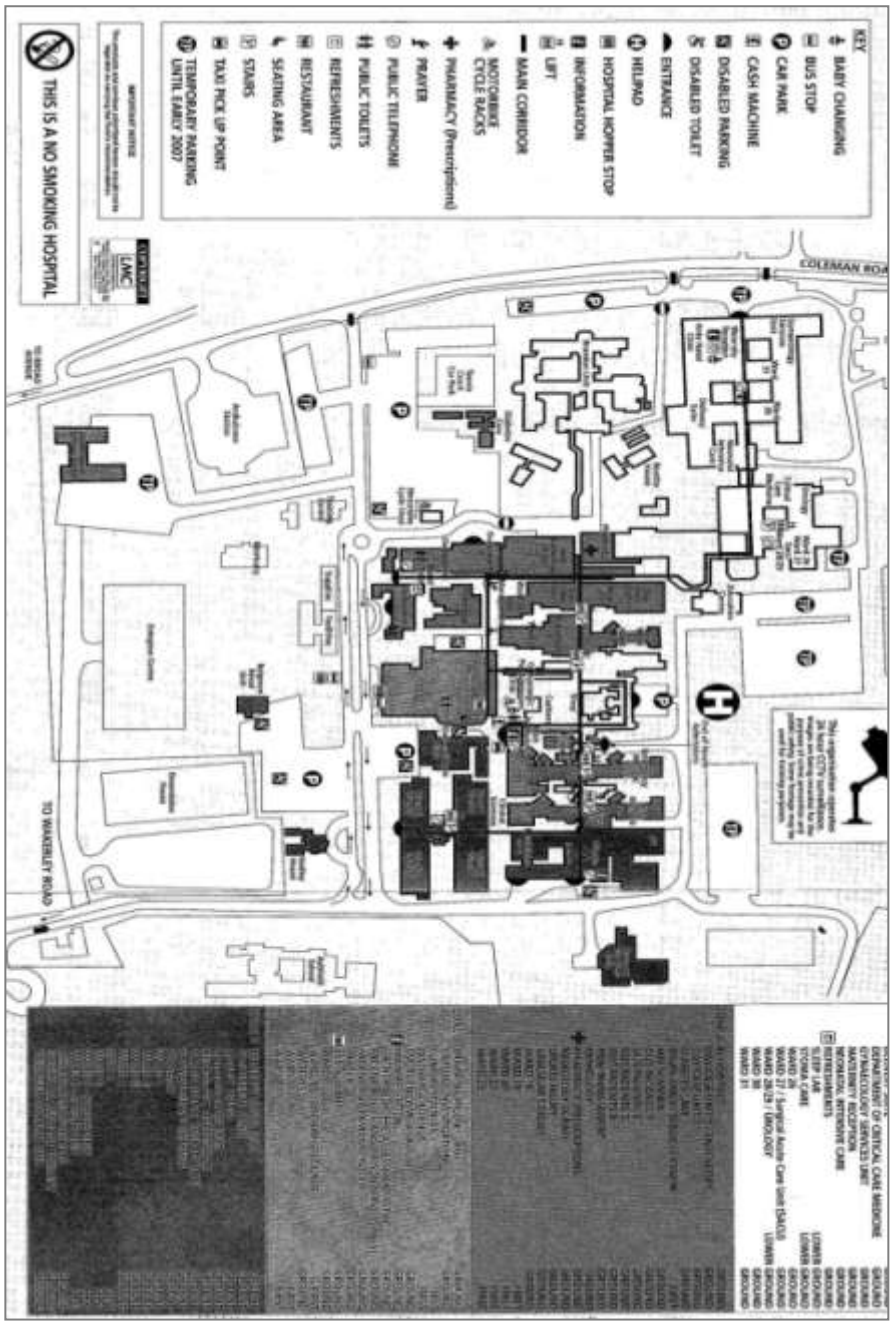


Appendix C10.Getting the message across:Visual communication on some notice boards.

Smileys/ emoticons were later tested in Study 3 with ethnic minorities lacking English for cognition and comprehension.

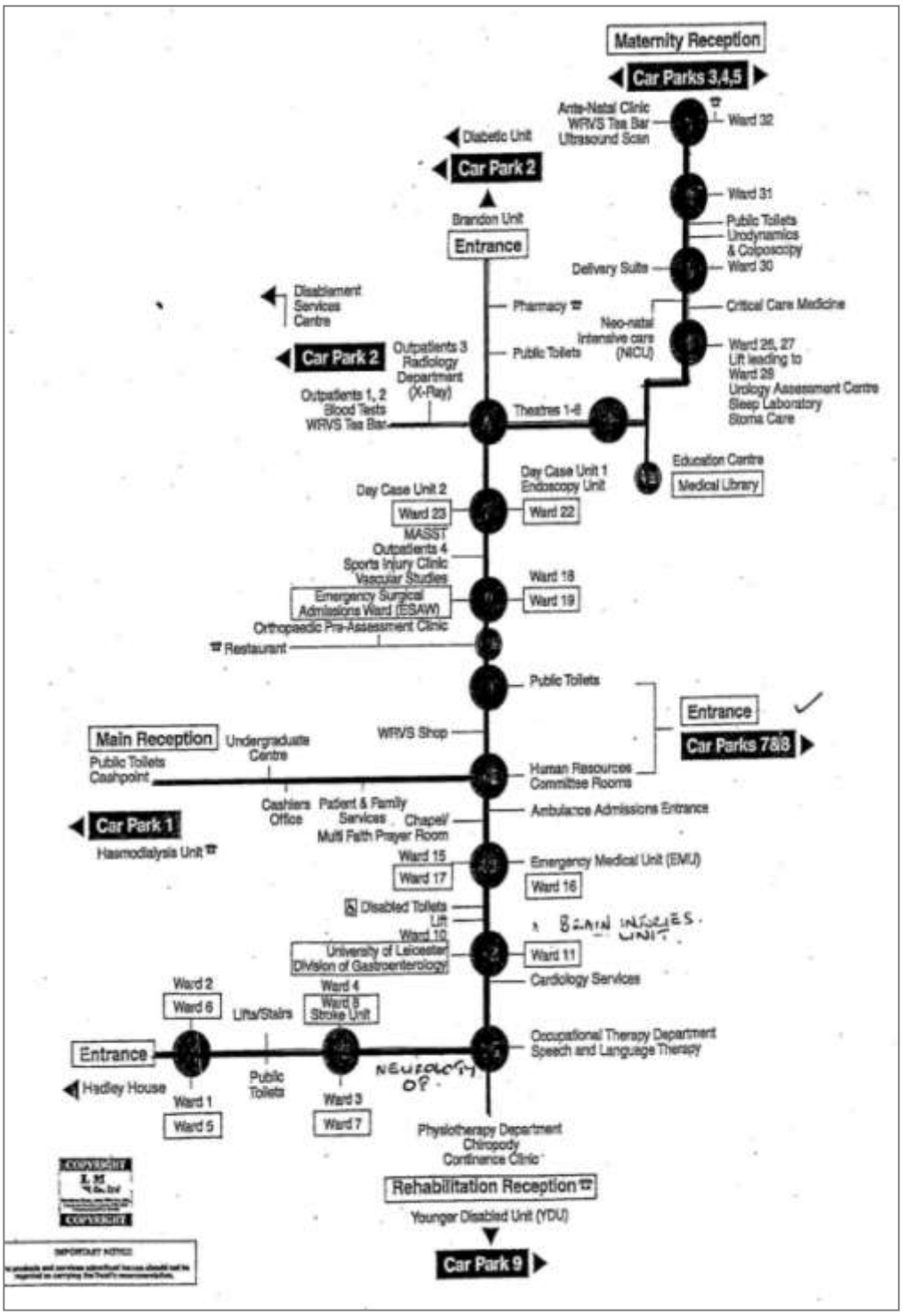
Appendix C11.Example of a map of hospital premises (exterior)

The map posed difficulties for people lacking English, those with low-literacy, poor vision or dyslexia. The dark areas denote colour schemes with less contrast; the fonts are small and colour overwhelms the text making some unreadable.



Appendix C12.Example of a map of hospital interior.

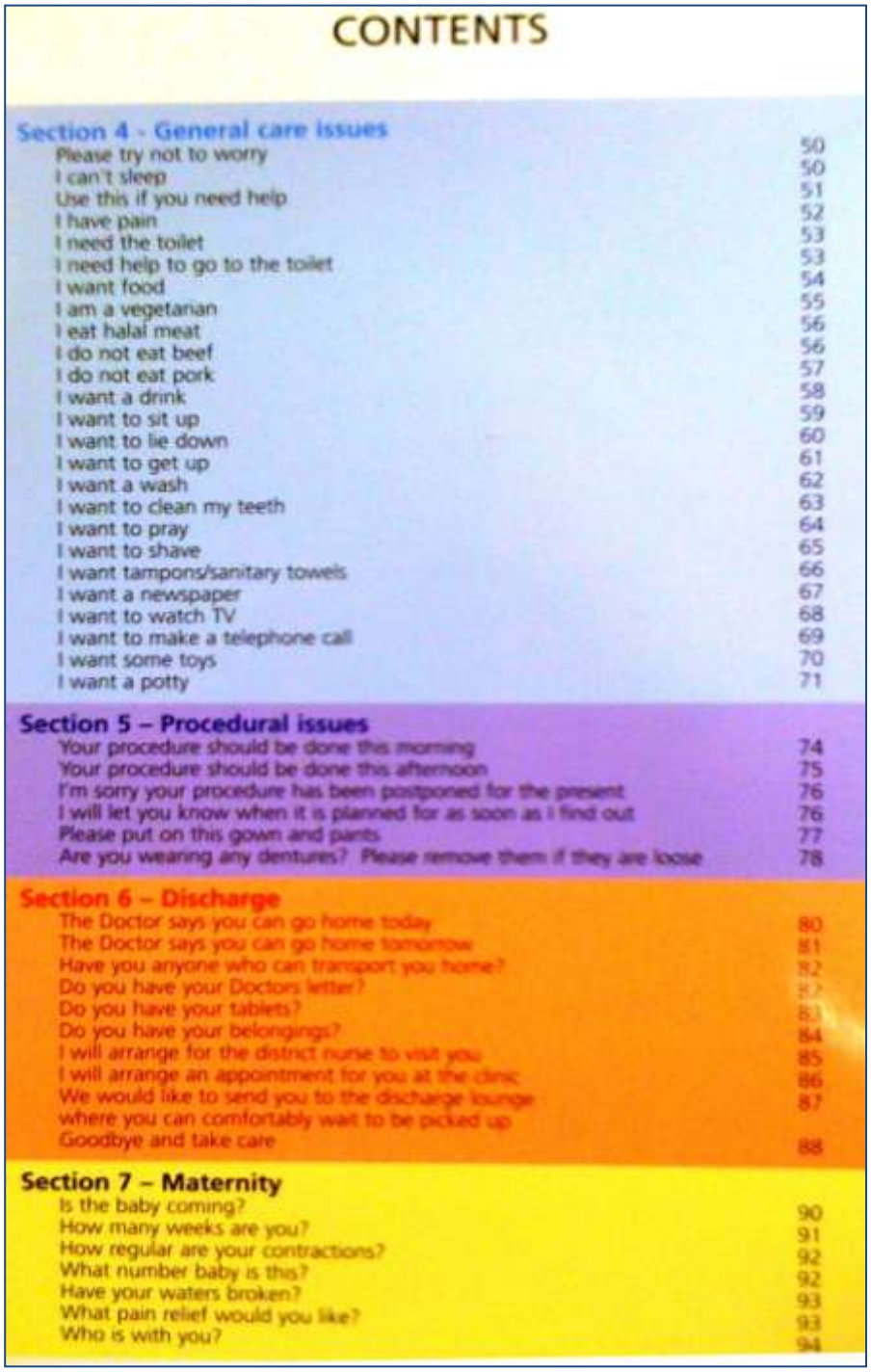
A simpler illustration: the dark areas were numbered but patients got confused so the numbers were removed.



Appendix C13. *A Communication Aid for Patients in Hospital*

(Photographs, originals ©Participating Trust and Women's Royal Voluntary Service, WRVS)

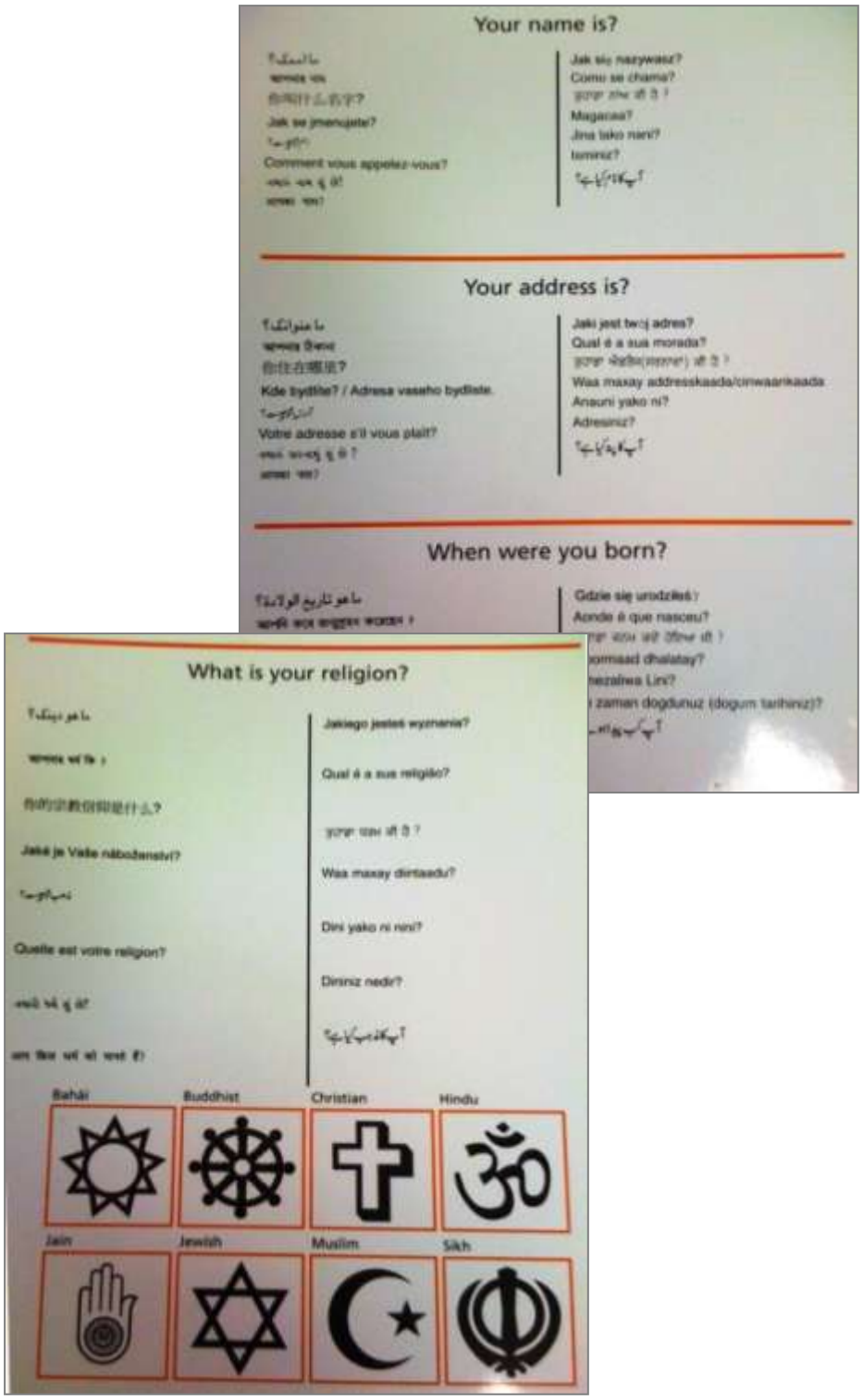
C13.1. A section of colour coded Contents.



CONTENTS

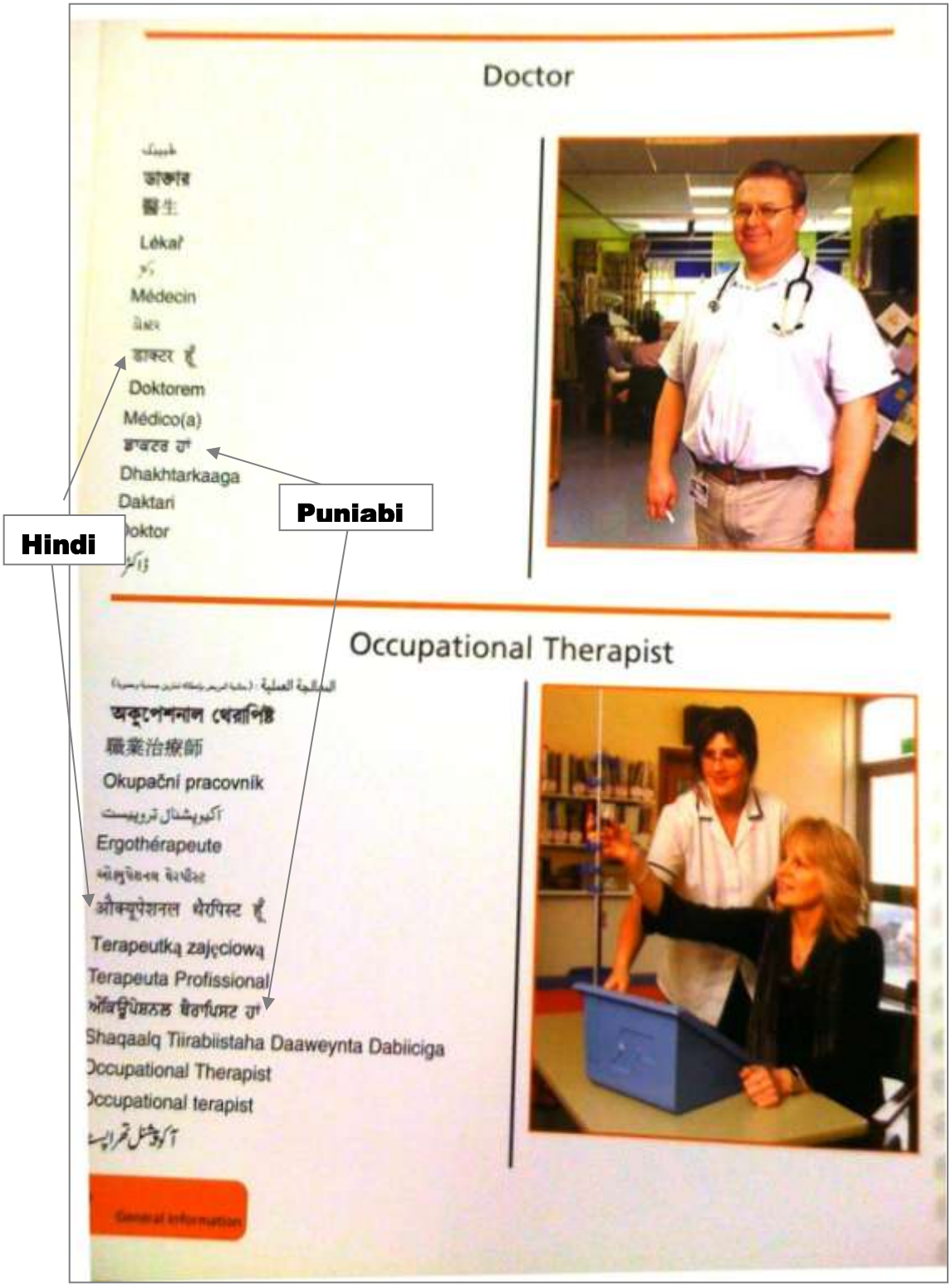
C13.2. Obtaining personal information

A Communication Aid for Patients in Hospital: patients are asked to read the script in their language (if they can) and to respond. For staff the problem is understanding responses and finding secondary information.



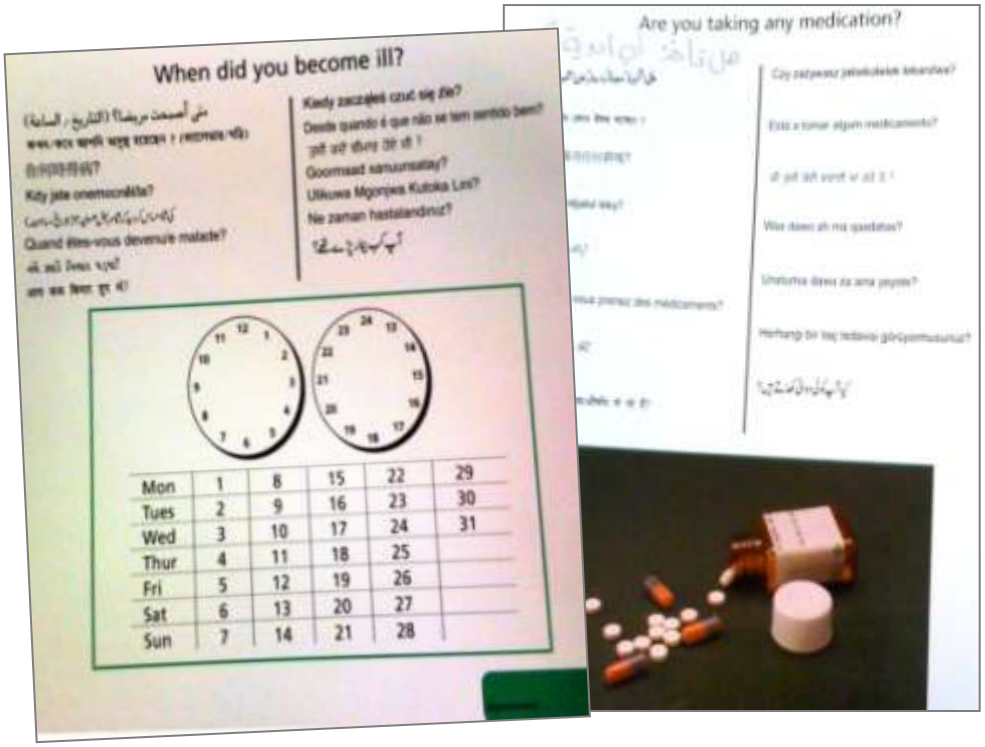
C13.3: ‘Doctor’ and ‘occupational therapist’ transliterated not translated.

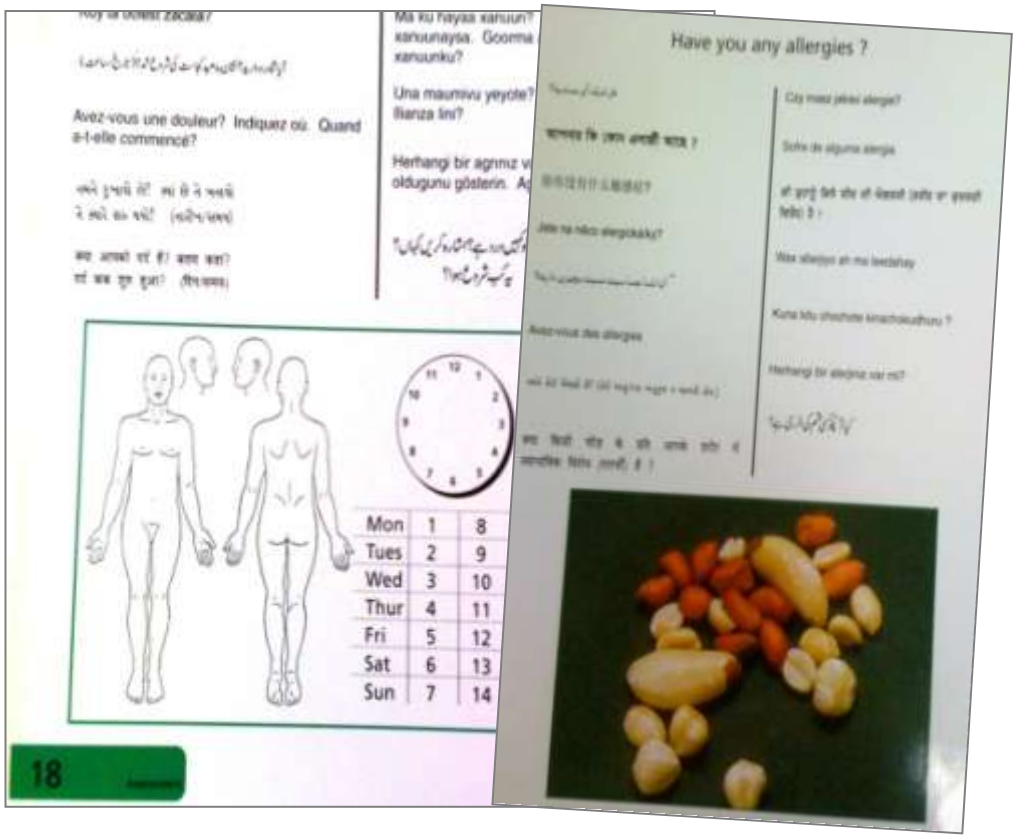
A Communication Aid for Patients in Hospital depicting scripts in Hindi and Punjabi. ‘Doctor’ is well understood, ‘occupational therapist’ is too complex: although not of translated, transliteration is familiarising patients with English.



C13.4: *Assessing the patient*

A Communication Aid for Patients in Hospital: Helpful pictorial aids, if the patient understands the images and is literate.





C13.5: Gaining consent and requesting action.

A Communication Aid for Patients in Hospital: Helpful if the patient understands the images and is *literate*. Would patients understand the 'forbidden' sign over jewellery?

C13.6: Explaining and eliciting ‘pain score’ on a scale of 1 to 10.

1=No Pain, 10= Bad pain *(A Communication Aid for Patients in Hospital).* Simple?

Ethnic patients lacking English or literacy, often responded with a 9 or 10, although they are advised 10 is the worst pain they have ever had in their life, say some paramedics.

Appendix C14. *"When is an emergency a real emergency"* public information.

Promoting the appropriate use of healthcare services. Note the importance given to colour, however, it overwhelms the text and font sizes are small (Photograph of the original ©NHSNorthamptonshire 2011)

Appendix C15.A section of Hindi translation from *Babycentre Midwives* (2011)

An analysis of translation confirming problems in literature: the use of complex words (Johnson *et al* 2006) and transliteration.

An review of a segment of Hindi translations on *BabyCenter Midwives* (2011) highlighting the complex terms used, the preferred colloquial terms and the implications.

	Current translation & preferred	Implication
1. Some medical terms are merely transliterated from English.	**Allergies** एलर्जीज़, **alcohol** अल्कोहल; **caesarean section** सिज़ेरियन सेक्शन, **caffeine** कैफीन, **catheter** कैथिटर	Patients are not receiving a translation; however, they are familiarising with English. (NB: In *A Communication Aid for Patients in Hospital*, 'doctor' is written in Hindi, Punjabi & Polish.)
2. Some terms are in complex rather than colloquial Hindi.	**Baby** is *shishu* शिशु (*bachha* or *baby* are common) **Blood** is often *rakth* रक्त , as in blood group रक्त समूह, bleeding, blood pressure, etc. which is rarely used and only sometimes *khoon* खून as in blood test खून की जांच – which is colloquial. **Breastfeed** is *sthanpaan kama* स्तनपान कराना, rather than *doodh pilaana* दूध पिलाना feed milk, as in bottle-feeding *bothal sey doodh pilaana* बोतल से दूध पिलाना. **Doctor** is *chikisthak* चिकित्सक - rather than *doctor*.	Probably require re-explanation (time factor)
3. Some terms are mis-translated:	**Anaemia** is *khoon ki kami* खून की कमी less blood. A closer approximation in *meaning* (avoiding complexities like red blood platelets, iron and oxygen) could be *khoon kamzor hai* your blood is weak, or *khoon may thakath nahi hai* your blood does not have strength. **Bath** is *bathtub* बाथ टब, whereas *nahana* (to bathe*) would be clearer.	(* Adults in the Indian Subcontinent generally use buckets of water to bathe, not bathtubs.)

APPENDIX-D Study 3. Design Concept Development

APPENDIX D: Alpha-testing

Appendix D-LR1: A summary of contributory factors that affect medication adherence
As reported by WHO (2003) and tabulated by the American College of Preventive Medicine (2011)

1. SOCIAL AND ECONOMIC DIMENSION
Limited English language proficiency
Low health literacy
Lack of family or social support network
Unstable living conditions; homelessness
Burdensome schedule
Limited access to health care facilities
Lack of health care insurance
Inability or difficulty accessing pharmacy
Medication cost
Cultural and lay beliefs about illness and treatment
Elder abuse

2. HEALTH CARE SYSTEM DIMENSION
Provider-patient relationship
Provider communication skills (contributing to lack of patient knowledge or understanding of the treatment regimen)
Disparity between the health beliefs of the health care provider and those of the patient
Lack of positive reinforcement from the health care provider
Weak capacity of the system to educate patients and provide follow-up
Lack of knowledge on adherence and of effective interventions for improving it
Patient information materials written at too high literacy level
Restricted formularies; changing medications covered on formularies
High drug costs, copayments, or both
Poor access or missed appointments
Long wait times
Lack of continuity of care

3. CONDITION-RELATED DIMENSION
Chronic conditions
Lack of symptoms
Severity of symptoms
Depression
Psychotic disorders
Mental retardation/developmental disability

4. THERAPY-RELATED DIMENSION
Complexity of medication regimen (number of daily doses; number of concurrent medications)
Treatment requires mastery of certain techniques (injections, inhalers)
Duration of therapy
Frequent changes in medication regimen
Lack of immediate benefit of therapy
Medications with social stigma attached to use
Actual or perceived unpleasant side effects
Treatment interferes with lifestyle or requires significant behavioral changes

5. PATIENT-RELATED DIMENSION
Physical Factors
Visual impairment
Hearing impairment
Cognitive impairment
Impaired mobility or dexterity
Swallowing problems
Psychological/Behavioral Factors
Knowledge about disease
Perceived risk/susceptibility to disease
Understanding reason medication is needed
Expectations or attitudes toward treatment
Perceived benefit of treatment
Confidence in ability to follow treatment regimen
Motivation
Fear of possible adverse effects
Fear of dependence
Feeling stigmatized by the disease
Frustration with health care providers
Psychosocial stress, anxiety, anger
Alcohol or substance abuse

Appendix D-LR2: Positive and negative colour-perceptions that impact on people.

Comparing Western Christian cultures and perceptions in other cultures (Feisner 2006: pp.42,120-127, extract).

*Meanings added from cultural knowledge of researcher relevant to this research (not included by Feisner)

Colours	Western Christian cultures		
	Positive	Negative	Ethnic Minority symbolism
Black	Sophistication, power, luxury. Being in credit, respect.	Death, depression, foreboding, bad luck, night, disapproval, fear.	Hinduism: Darkness Muslim: Grave, Death, Mourning
White	Purity, innocence, peace, cleanliness, sterility, empowerment	Surrender (flag), Cowardly (feather), cover-up (wash), pervert justice.	Hinduism: Truth, calmness, *Widowhood Purity: Islam, Buddhism,
Black & white	Combination: authority, truth (written in black and white), clarity, contrast.		
Grey	Neither positive or negative: Age, intelligence (grey matter), confusion (grey area), technology, shadows.		
Red	Red is seen first in a rainbow and has the greatest emotional impact.		*Auspicious Hinduism *Good luck Chinese
	Love, festivity, passion, compassion (Red Cross), power, courage.	War, danger, fire, bureaucracy, devil.	
Pink	Mostly positive: good health, pretty, sweet, babyish.		
Orange	Fruitfulness, warmth, cheerfulness, brightness.	Danger in some organisations.	Buddhism (avoid primary colours)
Saffron	(Yellow orange)		*Important in Sikhism, Hinduism
Yellow	Seen before other colours especially against black. A warning combination in nature (bees). Used by organisations to signal hazard.		
	Cheerfulness, hope, optimism, happiness, warmth, sun, vitality	Caution (traffic light), betrayal, cowardice, age.	
Brown	Comfort, security, earth, wood.	Gloom, melancholy, boredom.	Buddhism
Green	Spring, growth, freshness, nature, peace, calm, cool, refreshing.	Poison, envy, inexperience, immaturity, rawness, jealousy.	Islam: Colour of Prophet Muhammad, fertility, foliage.
Blue	Symbolises spirituality in many cultures: China, Judaism, Hinduism.		*Deep blue: Important in Sikhism Hinduism: Deity Krishna
	Royalty, heaven, truth, tranquillity, security, water distance.	Sadness, depression, introversion, cold.	
Purple	Royalty, bravery, spirituality, mystery, luxury.	Conceit, mourning, death, rage.	

Appendix D1.Study 3 Alpha-testing Staff: Letter and Draft questions in English for editing.

D1.1**:** Letter emphasising the questions were researched.

It also highlighted the author's suggestions for simpler text to be used in the phonetics in place of complex equivalents, and clarified the research process. (Phase 2=Study 3)

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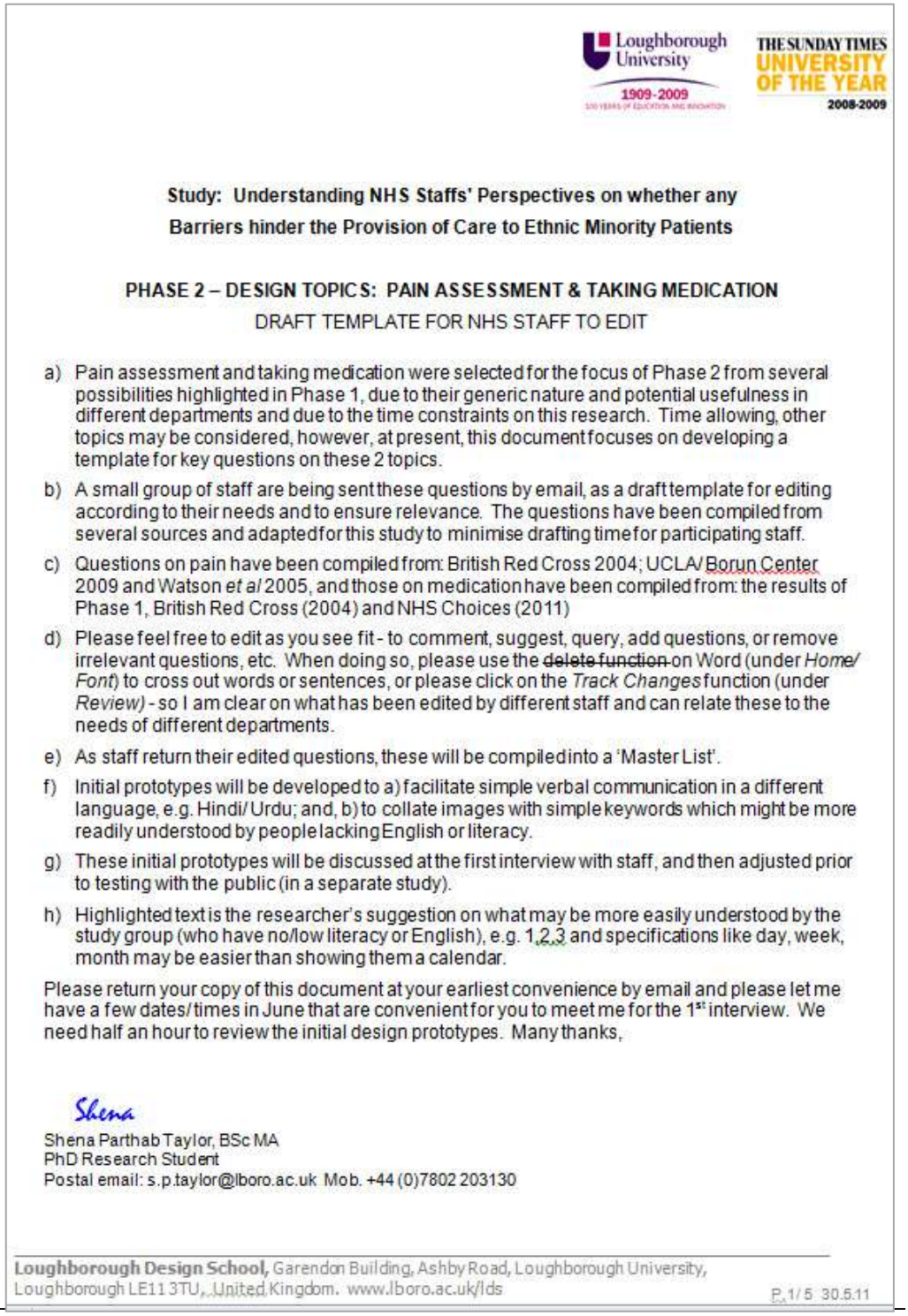

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

Study: Understanding NHS Staffs' Perspectives on whether any Barriers hinder the Provision of Care to Ethnic Minority Patients

PHASE 2 – DESIGN TOPICS: PAIN ASSESSMENT & TAKING MEDICATION

DRAFT TEMPLATE FOR NHS STAFF TO EDIT

a) Pain assessment and taking medication were selected for the focus of Phase 2 from several possibilities highlighted in Phase 1, due to their generic nature and potential usefulness in different departments and due to the time constraints on this research. Time allowing, other topics may be considered, however, at present, this document focuses on developing a template for key questions on these 2 topics.

b) A small group of staff are being sent these questions by email, as a draft template for editing according to their needs and to ensure relevance. The questions have been compiled from several sources and adapted for this study to minimise drafting time for participating staff.

c) Questions on pain have been compiled from: British Red Cross 2004; UCLA/ Borun Center 2009 and Watson *et al* 2005, and those on medication have been compiled from: the results of Phase 1, British Red Cross (2004) and NHS Choices (2011)

d) Please feel free to edit as you see fit - to comment, suggest, query, add questions, or remove irrelevant questions, etc. When doing so, please use the ~~delete function~~ on Word (under *Home/ Font*) to cross out words or sentences, or please click on the *Track Changes* function (under *Review)* - so I am clear on what has been edited by different staff and can relate these to the needs of different departments.

e) As staff return their edited questions, these will be compiled into a 'Master List'.

f) Initial prototypes will be developed to a) facilitate simple verbal communication in a different language, e.g. Hindi/ Urdu; and, b) to collate images with simple keywords which might be more readily understood by people lacking English or literacy.

g) These initial prototypes will be discussed at the first interview with staff, and then adjusted prior to testing with the public (in a separate study).

h) Highlighted text is the researcher's suggestion on what may be more easily understood by the study group (who have no/low literacy or English), e.g. 1,2,3 and specifications like day, week, month may be easier than showing them a calendar.

Please return your copy of this document at your earliest convenience by email and please let me have a few dates/ times in June that are convenient for you to meet me for the 1st interview. We need half an hour to review the initial design prototypes. Many thanks,

Shena

Shena Parthab Taylor, BSc MA
PhD Research Student
Postal email: s.p.taylor@lboro.ac.uk Mob. +44 (0)7802 203130

Loughborough Design School, Garendon Building, Ashby Road, Loughborough University, Loughborough LE11 3TU, United Kingdom. www.lboro.ac.uk/lds

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D1.2: Study 3 Draft questions in English: Pain (p.1/2) The questions were for NHS staff to review and edit: highlights indicate the author eliciting guidance.

PHASE 2 – DESIGN

DRAFT QUESTIONS FOR NHS STAFF TO EDIT

Greeting: My name is ___ ____ I am the nurse/ doctor.

Your name? _____ Date: _____

We are going to examine you, to see what the trouble or illness is, OK? Do not worry. We will ask you questions in Hindi, please respond Yes *or* OK, or No. Alright? If you know a few English words speak them please.

PAIN SCREENING & ASSESSMENT *(a Response Checker will be included)*

1. Have you pain? Yes? No? Show me where

   When did it start: Instead of calendar and clock: Today? 1-2 days? 1-2 week?

2. How bad is the pain?

   Possibly: Small? Medium? Big? Very big?

2b. Gaining a Pain Score:

If we count from 1 to 10, *(show on hands)*

1 means no pain, 10 means the worst pain you ever had (unbearable), what number is your pain?

0___1___2___3___4___5___6___7___8___9___10

none worst pain

3. Is the pain constant/ always present, or does it come and go?
4. Do you have pain every day/ always?
5. If you move about, does it pain? Can you up sit up straight? Stand? Walk? (moved up)
6. I wish to know from you what kind of pain you have. I will ask some questions, please reply Yes or No Is the pain:

Aching	(is it like a headache or toothache pain)	Shooting	(appears suddenly then goes)
Throbbing	(comes-goes quickly all the time)	Tiring	
Pricking		Exhausting	Duplicate to tiring?
Burning		Penetrating	(deep)
Gnawing		Nagging	Duplicate to throbbing?
Sharp		Numb	(if touched one doesn't know)
Stabbing	(sharp pain, comes-goes)	Miserable	
Tender	(painful to touch)	Unbearable	

Shena Parthab Taylor • Loughborough Design School • s.p.taylor@lboro.ac.uk Tel: 07802 203130 P.2/ 4 30.5.11

D1.2: Study 3 Draft questions in English: Pain (p.2/2)

Last week: from number 1 to 10,

- What number was the *worst* pain?
- what number was the *least pain*?
- what number was the *average* or general pain?

7. Is the pain worse on eating
8. When you go to the bathroom do you have pain? Passing urine? Or passing stools?
9. With the pain did you have temperature? Yes, No? Or swelling? Yes, No? (If yes) Show me where
10. What relieves the pain? Resting? Shifting your body? Taking medicine?
11. What treatments or medications are you receiving for your pain? (this is a difficult one to understand the responses!)
12. During last week: how much relief/ benefit has the treatment or medicine provided,?

0%____10____20____30____40____50____60____70____80____90____100%
No relief Little? Medium? A lot? Complete relief

16. If medicine was taken, how many hours afterwards does it take before the pain returns?

None? 1-2 hours? Over 12 hours?

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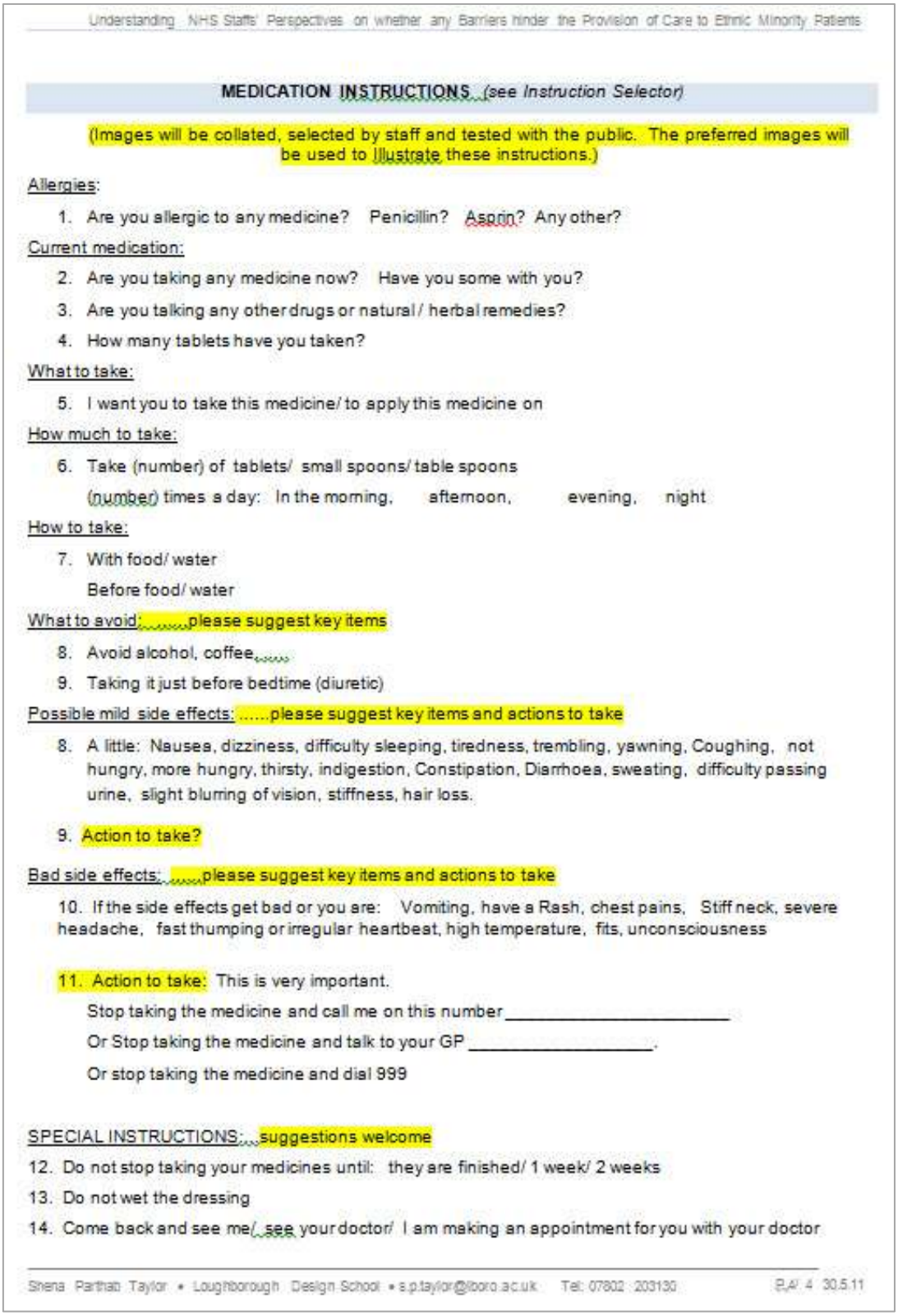
D1.3: Study 3 Medication draft questions in English

(p.1/1) The questions were for NHS staff to review and edit: highlights indicate the author eliciting guidance.



Understanding NHS Staffs' Perspectives on whether any Barriers hinder the Provision of Care to Ethnic Minority Patients

MEDICATION INSTRUCTIONS *(see Instruction Selector)*

(Images will be collated, selected by staff and tested with the public. The preferred images will be used to illustrate these instructions.)

Allergies:

1. Are you allergic to any medicine? Penicillin? Asprin? Any other?

Current medication:

2. Are you taking any medicine now? Have you some with you?
3. Are you talking any other drugs or natural / herbal remedies?
4. How many tablets have you taken?

What to take:

5. I want you to take this medicine/ to apply this medicine on

How much to take:

6. Take (number) of tablets/ small spoons/ table spoons
   (number) times a day: In the morning, afternoon, evening, night

How to take:

7. With food/ water
   Before food/ water

What to avoid:.....please suggest key items

8. Avoid alcohol, coffee,.....
9. Taking it just before bedtime (diuretic)

Possible mild side effects: .....please suggest key items and actions to take

8. A little: Nausea, dizziness, difficulty sleeping, tiredness, trembling, yawning, Coughing, not hungry, more hungry, thirsty, indigestion, Constipation, Diarrhoea, sweating, difficulty passing urine, slight blurring of vision, stiffness, hair loss.

9. Action to take?

Bad side effects: .....please suggest key items and actions to take

10. If the side effects get bad or you are: Vomiting, have a Rash, chest pains, Stiff neck, severe headache, fast thumping or irregular heartbeat, high temperature, fits, unconsciousness

11. Action to take: This is very important.
    Stop taking the medicine and call me on this number _____
    Or Stop taking the medicine and talk to your GP _____.
    Or stop taking the medicine and dial 999

SPECIAL INSTRUCTIONS:...suggestions welcome

12. Do not stop taking your medicines until: they are finished/ 1 week/ 2 weeks
13. Do not wet the dressing
14. Come back and see me/ see your doctor/ I am making an appointment for you with your doctor

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Appendix D2.Study 3 Alpha-testing staff: 5 versions of the English-Hindi Questions-prototypes.

D2.1: Pain-prototype-1A

(p.1/2) The phonetics are interspersed amongst English sentences/ phrases. In questions 1 and 2, pain and bad were underlined to co-relate to the Hindi phonetics darad and bura, respectively. Staffresponsed positively during testing, this was propagated throughout prototype-2. (There is much similarity between spoken Hindi and Urdu).

HINDI / URDU

Greeting: Namaskaar-ji I am the nurse/ doctor, maj nurse/doctor hoo.

My name is mera naam (NAME) hai. Your name? Aap ka naam?

We are going to examine you, to see what the trouble or illness is, Ham aap ko check karengey,dekhna hai kya thakleef ya bimari hai. OK? Teekh hai? Do not worry. Phikar nahi karna. We will ask you questions in Hindi, hum Hindi may aap ko lufs poochengey, please answer with Yes or No; OK? Aap javaab devna, Yes, OK ya No nahi. OK? If you know a few English words, speak them, OK? Thoda Angeezi hai tho bolna, teekh hai?

Phase 2 - DESIGN: Prototype 1A for Staff

VERBAL PAIN SCREENING & ASSESSMENT *(see Response Checker)*

1. Have you pain? Pain hai? Darad hai? Yes?, No? Haa"? Nahi?

   Show me, dikha--o, where kaha"? When did it start, shuru kabh huaa: Today, aaj? 1-2 days, ek-dho din? 1 week, Ek haftha?

2. How bad is the pain, darad kithna bura hai?

   Small, chotta? Medium? Big, bada? Very big, bahuth bada?

2b. Gaining a Pain Score:

If we count from 1 to 10, agar hum ek say dus ginthey, *(show on hands)*

1 means no pain, ek muthlab darad nahi hai, 10 means the worst pain you ever had (unbearable), dus muthlab darad saha nahin jatha.
What number is your pain? Kithna number aap ka darad hai?

0 1 2 3 4 5 6 7 8 9 10
none worst pain

3. Is the pain constant/ always present darad hamesha rahatha hai, or does it come and go, ya astha-jastha rahatha hai?
4. Do you have pain every day darad haroze hai, or always ya hamesha hai?
5. Now I want to find out ab aap se patha karna hai, what kind of pain it is yey kaisa darad hai. Alright? Teekh hai? Is the pain: Yey darad

Aching (is it like a headache or toothache pain)	Sir-darad ya daanth-darad jaisai hai?	**Shooting** (appears suddenly then goes)	Achaanak aa kar chaley jastha hai?
Throbbing (comes-goes quickly all the time)	Jaldi astha-jastha rahitha?	**Tiring** (is it)	Darad se thakavat hotha hai?
Pricking	Choob-tha darad hai?	**Exhausting**	Bahut thakavat hai?
Burning	Jalan hai?	**Penetrating** (deep)	Gehera hai?
Gnawing	?	**Nagging**	Duplicate to throbbing?
Sharp	Tevz hai?	**Numb** (one doesn't know if touched)	Patha nahi chaltha haath laga-o tho?
Stabbing (sharp pain, comes-goes)	Tevz darad astha-jastha hai?	**Miserable**	Dukhi
Tender (painful to touch)	Hath lag-ne se darad hai?	**Unbearable**	Saha nahi jatha?

Response checker	
Yes	haa"
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath

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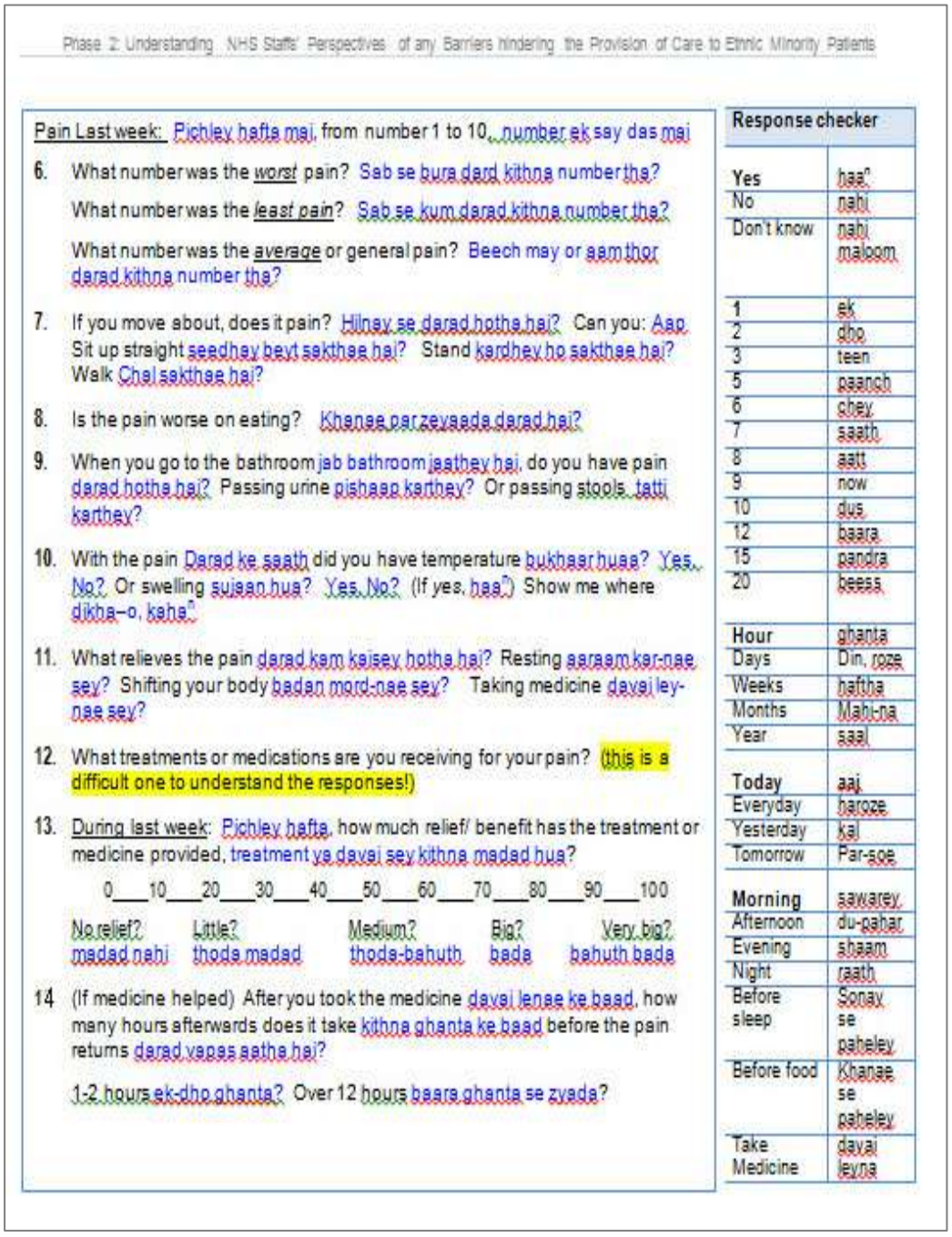
Pain-prototype-1A (p.2)

The phonetics are interspersed amongst English sentences/ phrases and the response checker was the same as on page 1; this was altered in prototype 2.



Phase 2: Understanding NHS Staffs' Perspectives of any Barriers hindering the Provision of Care to Ethnic Minority Patients

Pain Last week: Pichley hafta mai, from number 1 to 10, number ek say das mai

6. What number was the *worst* pain? Sab se bura dard kithna number tha?
   What number was the *least pain*? Sab se kum darad kithna number tha?
   What number was the *average* or general pain? Beech may or aam thor darad kithna number tha?
7. If you move about, does it pain? Hilney se darad hotha hai? Can you: Aap Sit up straight seedhay bayt sakthee hai? Stand kardhey ho sakthee hai? Walk Chal sakthee hai?
8. Is the pain worse on eating? Khanee par zeyaada darad hai?
9. When you go to the bathroom jab bathroom jaathey hai, do you have pain darad hotha hai? Passing urine pishaap karthey? Or passing stools, tatti karthey?
10. With the pain Darad ke saath did you have temperature bukhaar huaa? Yes, No? Or swelling sujaan hua? Yes, No? (If yes, haa") Show me where dikha–o, kaha"
11. What relieves the pain darad kam kaisey hotha hai? Resting aaraam kar-nae sey? Shifting your body badan mord-nae sey? Taking medicine dayai ley-nae sey?
12. What treatments or medications are you receiving for your pain? (this is a difficult one to understand the responses!)
13. During last week: Pichley hafta, how much relief/ benefit has the treatment or medicine provided, treatment ya dayai sey kithna madad hua?

    0___10___20___30___40___50___60___70___80___90___100

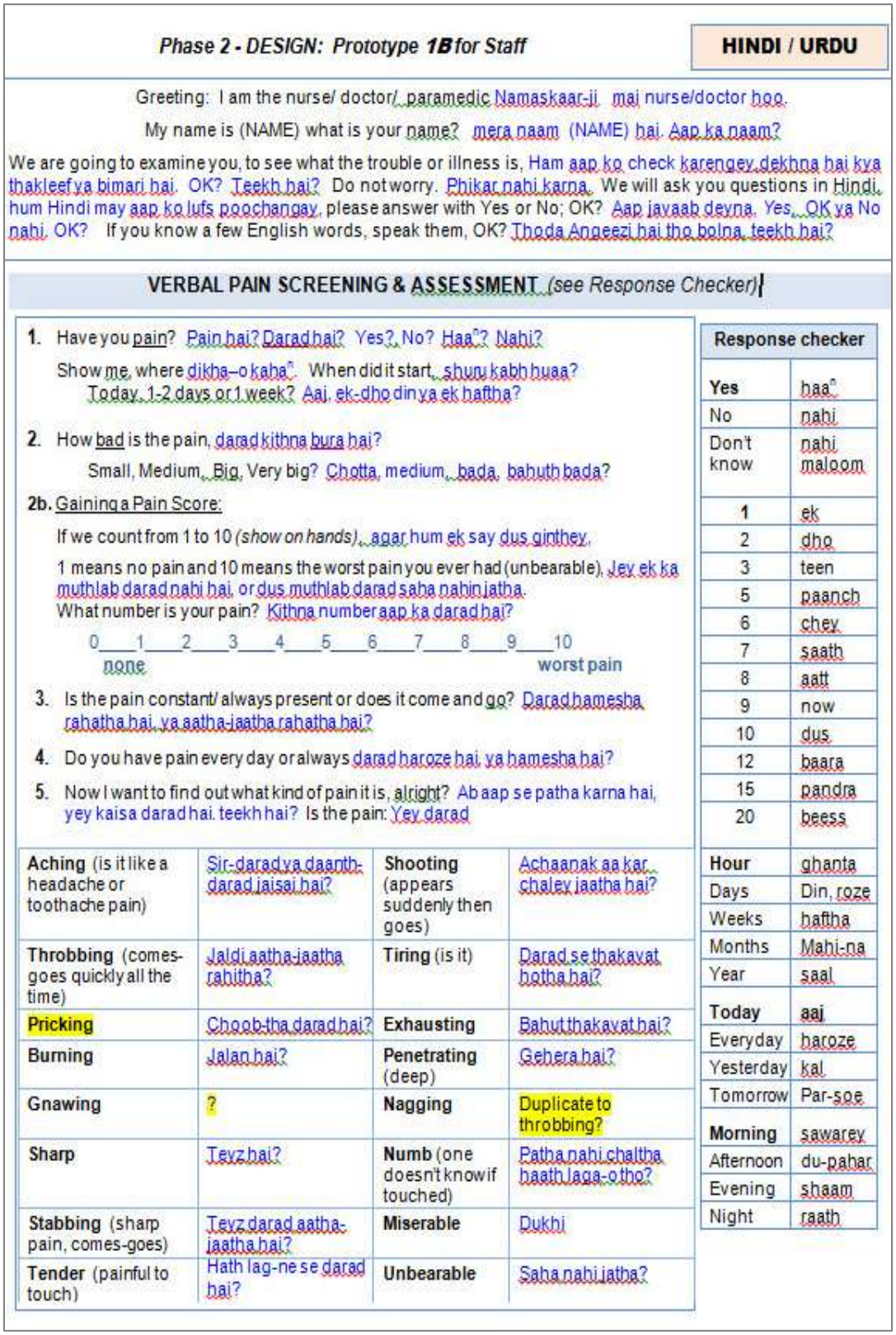
    No relief? madad nahi | Little? thoda madad | Medium? thoda-bahuth | Big? bada | Very big? bahuth bada
14. (If medicine helped) After you took the medicine dayai lenae ke baad, how many hours afterwards does it take kithna ghanta ke baad before the pain returns darad vapas aatha hai?

    1-2 hours ek-dho ghanta? Over 12 hours baara ghanta se zyada?

Response checker	
Yes	haa"
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath
Before sleep	Sonay se paheley
Before food	Khanae se paheley
Take Medicine	dayai leyna

D2.2: Study 3 Pain-prototype-1B

(p.1) Note the phonetics are placed at the end of the English sentence/ phrase.



Phase 2 - DESIGN: Prototype 1B for Staff **HINDI / URDU**

Greeting: I am the nurse/ doctor/ paramedic Namaskaar-ji mai nurse/doctor hoo.

My name is (NAME) what is your name? mera naam (NAME) hai. Aap ka naam?

We are going to examine you, to see what the trouble or illness is. Ham aap ko check karengey dekhna hai kya thakleef ya bimari hai. OK? Teekh hai? Do not worry. Phikar nahi karna. We will ask you questions in Hindi. hum Hindi may aap ko lufs poochangay, please answer with Yes or No; OK? Aap javaab devna. Yes, OK ya No nahi. OK? If you know a few English words, speak them, OK? Thoda Angeezi hai tho bolna, teekh hai?

VERBAL PAIN SCREENING & ASSESSMENT *(see Response Checker)*

1. Have you pain? Pain hai? Darad hai? Yes?, No? Haa°? Nahi?

   Show me, where dikha–o kaha°. When did it start, shuru kabh huaa?
   Today, 1-2 days or 1 week? Aaj, ek-dho din ya ek haftha?

2. How bad is the pain, darad kithna bura hai?

   Small, Medium, Big, Very big? Chotta, medium, bada, bahuth bada?

2b. Gaining a Pain Score:

If we count from 1 to 10 *(show on hands)*, agar hum ek say dus ginthey,

1 means no pain and 10 means the worst pain you ever had (unbearable). Jey ek ka muthlab darad nahi hai, or dus muthlab darad saha nahin jatha.
What number is your pain? Kithna number aap ka darad hai?

0 1 2 3 4 5 6 7 8 9 10
none worst pain

3. Is the pain constant/ always present or does it come and go? Darad hamesha rahatha hai, ya aatha-jaatha rahatha hai?
4. Do you have pain every day or always darad haroze hai, ya hamesha hai?
5. Now I want to find out what kind of pain it is, alright? Ab aap se patha karna hai, yey kaisa darad hai. teekh hai? Is the pain: Yey darad

Aching (is it like a headache or toothache pain)	Sir-darad ya daanth-darad jaisai hai?	**Shooting** (appears suddenly then goes)	Achaanak aa kar chaley jaatha hai?
Throbbing (comes-goes quickly all the time)	Jaldi aatha-jaatha rahitha?	**Tiring** (is it)	Darad se thakavat hotha hai?
Pricking	Choob-tha darad hai?	**Exhausting**	Bahut thakavat hai?
Burning	Jalan hai?	**Penetrating** (deep)	Gehera hai?
Gnawing	?	**Nagging**	Duplicate to throbbing?
Sharp	Tevz hai?	**Numb** (one doesn't know if touched)	Patha nahi chaltha haath laga-o tho?
Stabbing (sharp pain, comes-goes)	Tevz darad aatha-jaatha hai?	**Miserable**	Dukhi
Tender (painful to touch)	Hath lag-ne se darad hai?	**Unbearable**	Saha nahi jatha?

Response checker	
Yes	haa°
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath

D2.3: Study 3 Pain-prototype-1C

(p.1/2) The tabulation seperates the phonetics from English more completely.

HINDI / URDU

Greeting: I am the nurse/ doctor/ paramedic Namaskaar-ji mai nurse/doctor hoo.

My name is (NAME) what is your name? mera naam (NAME) hai. Aap ka naam?

We are going to examine you, to see what the trouble or illness is, Ham aap ko check karengey,dekhna hai kya thakleef ya bimari hai. OK? Teekh hai? Do not worry. Phikar nahi karna. We will ask you questions in Hindi, hum Hindi may aap ko lufs poochangey, please answer with Yes or No; OK? Aap javaab devna. Yes, OK ya No nahi. OK? If you know a few English words, speak them, OK? Thoda Angeezi hai tho bolna, teekh hai?

Phase 2 - DESIGN: Prototype 1C for Staff

VERBAL PAIN SCREENING & ASSESSMENT *(see Response Checker)*

1. Have you pain? Yes? No?	Pain hai? Darad hai? Haa"? Nahi?
Show me, where	Dikha-o kaha".
When did it start: Today? 1-2 days? 1 week?	Shuru kabh huaa: aaj hua? ek-dho din? Ek haftha?
2. How bad is the pain: Small, Medium,.. Big, Very big?	darad kithna bura hai? Chotta, medium,.. bada, bahuth bada?
2b. Pain Score: If we count from 1 to 10, *(show on hands)*	Agar hum ek say dus ginthey,
and 1 means no pain and 10 means the worst pain you ever had (unbearable),	or ek ka muthlab darad nahi hai, or dus muthlab darad saha nahin jatha.
What number is your pain?	Kithna number aap ka darad hai?
0 1 2 3 4 5 6 7 8 9 10 none worst pain	
3. Is the pain constant/ always present, or does it come and go,	Darad hamesha rahatha hai, ya aatha-jaatha rahatha hai?
4. Do you have pain every day or always	Darad haroze hai, ya hamesha hai?
5. Now I want to find out what kind of pain it is, alright? Is the pain:	Ab aap se patha karna hai, yey kaisa darad hai. teekh hai? Yey darad

Aching (is it like a headache or toothache pain)	Sir-darad, ya daanth-darad jaisai hai?	**Shooting** (appears suddenly then goes)	Achaanak aa kar, chaley jaatha hai?
Throbbing (comes-goes quickly all the time)	Jaldi aatha-jaatha, rahitha?	**Tiring** (is it)	Darad se thakavat hotha hai?
Pricking	Choob-tha darad hai?	**Exhausting**	Bahut thakavat hai?
Burning	Jalan hai?	**Penetrating** (deep)	Gehera hai?
Gnawing	?	**Nagging**	Duplicate to throbbing?
Sharp	Teyz hai?	**Numb** (one doesn't know if touched)	Patha nahi chaltha haath laga-o tho?
Stabbing (sharp pain, comes-goes)	Teyz darad aatha-jaatha hai?	**Miserable**	Dukhi
Tender (painful to touch)	Hath lag-ne se darad hai?	**Unbearable**	Saha nahi jatha?

Response checker	
Yes	haa"
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath

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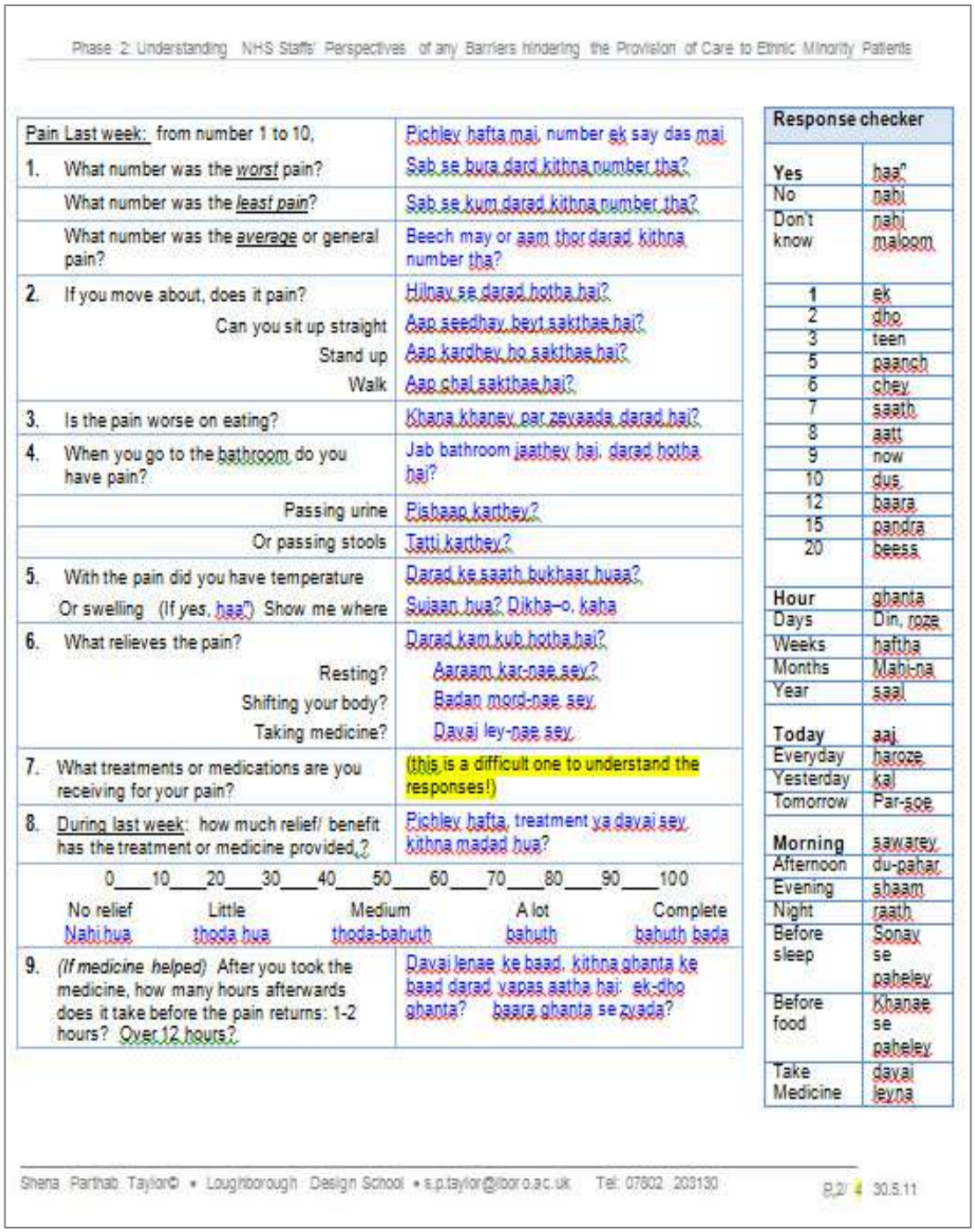
Pain-prototype-1C (p.2.



Phase 2: Understanding NHS Staffs' Perspectives of any Barriers hindering the Provision of Care to Ethnic Minority Patients

Pain Last week: from number 1 to 10,	Pichley hafta mai, number ek say das mai
1. What number was the *worst* pain?	Sab se bura dard kithna number tha?
What number was the *least pain*?	Sab se kum darad kithna number tha?
What number was the *average* or general pain?	Beech may or aam thor darad kithna number tha?
2. If you move about, does it pain?	Hilnay se darad hotha hai?
Can you sit up straight	Aap seedhay beyt sakthae hai?
Stand up	Aap kardhey ho sakthae hai?
Walk	Aap chal sakthae hai?
3. Is the pain worse on eating?	Khana khanay par zeyaada darad hai?
4. When you go to the bathroom do you have pain?	Jab bathroom jaathey hai, darad hotha hai?
Passing urine	Pishaap karthey?
Or passing stools	Tatti karthey?
5. With the pain did you have temperature	Darad ke saath bukhaar huaa?
Or swelling (If yes, haa') Show me where	Sujaan hua? Dikha–o, kaha
6. What relieves the pain?	Darad kam kub hotha hai?
Resting?	Aaraam kar-nae sey?
Shifting your body?	Badan mord-nae sey
Taking medicine?	Davai ley-nae sey
7. What treatments or medications are you receiving for your pain?	(this is a difficult one to understand the responses!)
8. During last week: how much relief/ benefit has the treatment or medicine provided..?	Pichley hafta, treatment ya davai sey kithna madad hua?
0___10___20___30___40___50___60___70___80___90___100	
No relief Nahi hua / Little thoda hua / Medium thoda-bahuth / A lot bahuth / Complete bahuth bada	
9. *(If medicine helped)* After you took the medicine, how many hours afterwards does it take before the pain returns: 1-2 hours? Over 12 hours?	Davai lenae ke baad, kithna ghanta ke baad darad vapas aatha hai: ek-dho ghanta? baara ghanta se zyada?

Response checker	
Yes	haa'
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath
Before sleep	Sonay se paheley
Before food	Khanae se paheley
Take Medicine	davai leyna

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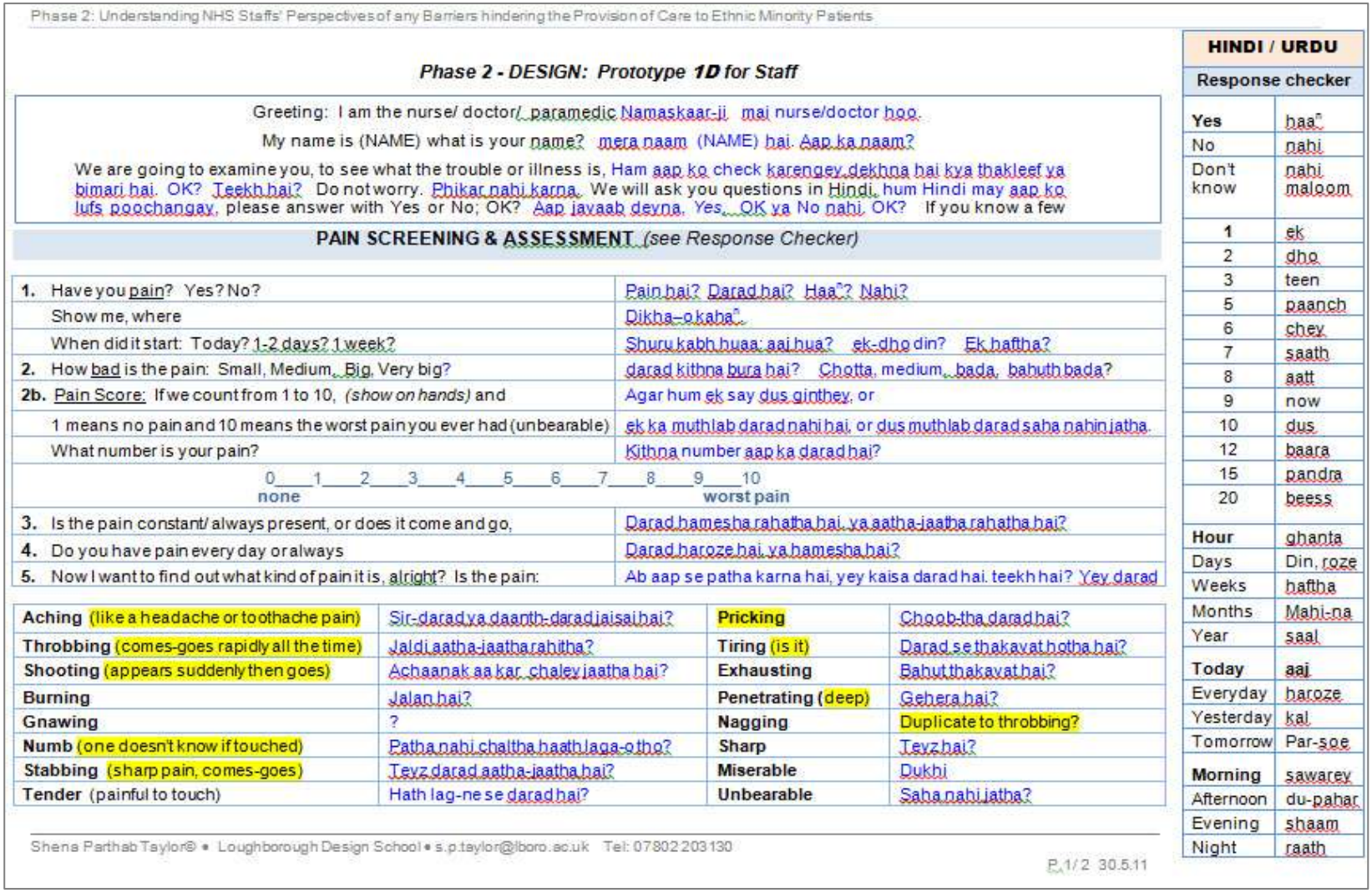
D2.4: Study 3 Pain-prototype-1D

(p.1) A4 landscape similar to 1C. This was viewed favourably by one participant.



Phase 2: Understanding NHS Staffs' Perspectives of any Barriers hindering the Provision of Care to Ethnic Minority Patients

Phase 2 - DESIGN: Prototype 1D for Staff

Greeting: I am the nurse/ doctor/ paramedic Namaskaar-ji mai nurse/doctor hoo.

My name is (NAME) what is your name? mera naam (NAME) hai. Aap ka naam?

We are going to examine you, to see what the trouble or illness is, Ham aap ko check karengey,dekhna hai kya thakleef ya bimari hai. OK? Teekh hai? Do not worry. Phikar nahi karna. We will ask you questions in Hindi, hum Hindi may aap ko lufs poochangay, please answer with Yes or No; OK? Aap javaab devna. Yes, OK ya No nahi, OK? If you know a few

PAIN SCREENING & ASSESSMENT *(see Response Checker)*

1. Have you pain? Yes? No?	Pain hai? Darad hai? Haa"? Nahi?
Show me, where	Dikha–o kaha".
When did it start: Today? 1-2 days? 1 week?	Shuru kabh huaa: aaj hua? ek-dho din? Ek haftha?
2. How bad is the pain: Small, Medium, Big, Very big?	darad kithna bura hai? Chotta, medium, bada, bahuth bada?
2b. Pain Score: If we count from 1 to 10, *(show on hands)* and	Agar hum ek say dus ginthey, or
1 means no pain and 10 means the worst pain you ever had (unbearable)	ek ka muthlab darad nahi hai, or dus muthlab darad saha nahin jatha.
What number is your pain?	Kithna number aap ka darad hai?
0 1 2 3 4 5 6 7 8 9 10 (none … worst pain)	
3. Is the pain constant/ always present, or does it come and go,	Darad hamesha rahatha hai, ya aatha-jaatha rahatha hai?
4. Do you have pain every day or always	Darad haroze hai, ya hamesha hai?
5. Now I want to find out what kind of pain it is, alright? Is the pain:	Ab aap se patha karna hai, yey kaisa darad hai. teekh hai? Yey darad

Aching (like a headache or toothache pain)	Sir-darad ya daanth-darad jaisai hai?	**Pricking**	Choob-tha darad hai?
Throbbing (comes-goes rapidly all the time)	Jaldi aatha-jaatha rahitha?	**Tiring** (is it)	Darad se thakavat hotha hai?
Shooting (appears suddenly then goes)	Achaanak aa kar, chaley jaatha hai?	**Exhausting**	Bahut thakavat hai?
Burning	Jalan hai?	**Penetrating** (deep)	Gehera hai?
Gnawing	?	**Nagging**	Duplicate to throbbing?
Numb (one doesn't know if touched)	Patha nahi chaltha haath laga-o tho?	**Sharp**	Tevz hai?
Stabbing (sharp pain, comes-goes)	Tevz darad aatha-jaatha hai?	**Miserable**	Dukhi
Tender (painful to touch)	Hath lag-ne se darad hai?	**Unbearable**	Saha nahi jatha?

HINDI / URDU	
Response checker	
Yes	haa"
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath

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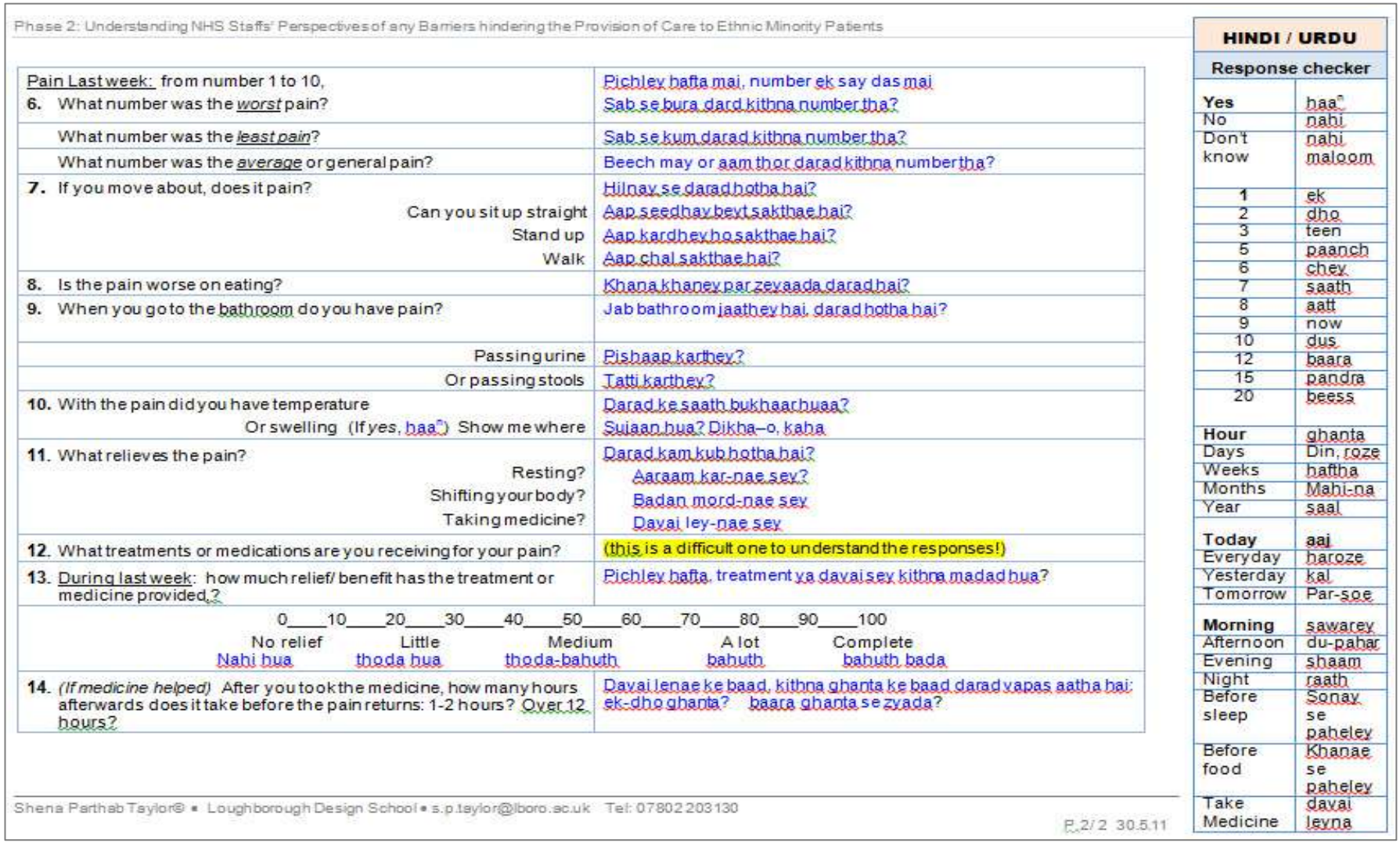
Pain- prototype-1D (p.2): The pain relief score in 13 was removed in prototype 2.



Phase 2: Understanding NHS Staffs' Perspectives of any Barriers hindering the Provision of Care to Ethnic Minority Patients

Pain Last week: from number 1 to 10,	Pichley hafta mai, number ek say das mai
6. What number was the *worst* pain?	Sab se bura dard kithna number tha?
What number was the *least pain*?	Sab se kum darad kithna number tha?
What number was the *average* or general pain?	Beech may or aam thor darad kithna number tha?
7. If you move about, does it pain?	Hilnay se darad hotha hai?
Can you sit up straight	Aap seedhay bey-t sakthae hai?
Stand up	Aap kardhey ho sakthae hai?
Walk	Aap chal sakthae hai?
8. Is the pain worse on eating?	Khana khaney par zeyaada darad hai?
9. When you go to the bathroom do you have pain?	Jab bathroom jaathey hai, darad hotha hai?
Passing urine	Pishaap karthey?
Or passing stools	Tatti karthey?
10. With the pain did you have temperature	Darad ke saath bukhaar huaa?
Or swelling (If *yes*, haa") Show me where	Sujaan hua? Dikha–o, kaha
11. What relieves the pain?	Darad kam kub hotha hai?
Resting?	Aaraam kar-nae sey?
Shifting your body?	Badan mord-nae sey
Taking medicine?	Davai ley-nae sey
12. What treatments or medications are you receiving for your pain?	(this is a difficult one to understand the responses!)
13. During last week: how much relief/ benefit has the treatment or medicine provided?	Pichley hafta, treatment ya davai sey kithna madad hua?
0 10 20 30 40 50 60 70 80 90 100	
No relief (Nahi hua) Little (thoda hua) Medium (thoda-bahuth) A lot (bahuth) Complete (bahuth bada)	
14. *(If medicine helped)* After you took the medicine, how many hours afterwards does it take before the pain returns: 1-2 hours? Over 12 hours?	Davai lenae ke baad, kithna ghanta ke baad darad vapas aatha hai: ek-dho ghanta? baara ghanta se zyada?

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HINDI / URDU

Response checker

Yes	haa"
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawarey
Afternoon	du-pahar
Evening	shaam
Night	raath
Before sleep	Sonay se paheley
Before food	Khanae se paheley
Take Medicine	davai leyna

D2.5: Medication-prototype-1A

(p.1/2) Similar to Pain-prototype-1A, the arrangement of phonetics was interspersed with the English.

PHASE 2 – DESIGN: Prototype 1B for NHS Staff

HINDI / URDU

Greeting: Namaskaar-ji I am the nurse/ doctor mai nurse/doctor hoo. .

My name is mera naam (NAME) hai. Your name? Aap ka naam? _____

We are going to talk about your medicines, ham aap ki davai ke barey may baath karangey. OK? Teekh hai?
We will ask you questions in Hindi, hum Hindi may aap ko lufs poochangay, please reply yes or not aap *Yes ya* OK bolna, ya No nahi, bolna. OK? Teekh hai? If you know a few English words speak them thoda Angeezi hai tho bolna. Teekh hai? OK?

TAKING MEDICATION VERBAL INSTRUCTIONS *(see Response Checker)*

Allergies:

1. Are you allergic to any medicine? Koi davai hai, jo leney se aap ko thakleef hotha hai, kurchna, ulti, asae kuch? Jaisae Penicillin? Asprin? Any other? Koi aur?

Current medication:

2. Are you taking any medicine now? Abhi koi davai leh rahi ho? Have you some with you? Aap ke pas hai?
3. Are you talking any other medicines or natural / herbal remedies (other type of)? Aur koi davai, ya kisi aur thura ke davai leh rahe ho?
4. How many tablets have you taken? Kithna goli liya aap ne?

What to take:

5. I am giving you these tablets, Hum app ko yeh go-li deh rahey hai, to take (swallow) leyney ke liyay.

I am giving you this medicine Hum app ko yeh davai deh rahey hai, to apply lagaaney ke liyay.

How much to take:

6. Take 1/2/3 tablets ek/ dho/ teen leyna; or 1/2 small spoons ek/ dho chotta chamach leyna; or 1/2 table (big) spoons ek/ dho bada chamach leyna

When to take it: take it 1/2/3/4 times ek/ dho/ teen/ chaar daffa leyna

7. In the morning, sawayrey afternoon, du-pahar evening, shaam night, raath

How to take:

8. With water paani ke saath before food, Khanae se paheley
After food, Khanae ke baad

What to avoid: .....please suggest key items

9. Whilst you take these, Yey davi leh rahi hai, don't drink alcohol, sharaab nahi peena dont drink coffee, coffee nahi peena
10. Don't take it too late, before sleeping sonay se pahaley nahi leyna (you will not sleep well) neend achha nahi hoga

Instructions/ Response checker	
Yes	haa"
No	nahi
Don't know	nahi maloom
1	ek
2	dho
3	teen
5	paanch
6	chey
7	saath
8	aatt
9	now
10	dus
12	baara
15	pandra
20	beess
Hour	ghanta
Days	Din, roze
Weeks	haftha
Months	Mahi-na
Year	saal
Today	aaj
Everyday	haroze
Yesterday	kal
Tomorrow	Par-soe
Morning	sawayrey
Afternoon	du-pahar
Evening	shaam
Night	raath
Before sleep	Sonay se paheley
Before food	Khanae se paheley

Medication- prototype-1A (p.2):The highlighted text invited feedback from staff.

Special Instructions: ...suggestions welcome

1. Do not stop taking your medicines: Davai lena band nahi karna.
   Finish your medicine Davai khatham karna
   Take it for 1 ek, 2 dho, 3 teen weeks hafta leyna.
   Take it for 1 ek, 2 dho, 3 teen months mahina lena
2. Do not wet the area. Gilaa nahi karna.
3. After that, Oos ke baad: Come see me Hamay dekh-ney aa-oh
   Go see your doctor Apna Doctor ko dekhney jaa-o
   I am making an appointment for you with your doctor Doctor key saath aapka appointment bana rahey hai.
   THIS month this date yeh mahina yeh tarik *(write date numbers)*
   NEXT month this date agley mahina yeh tarik *(write date number)*

Possible mild side effects: (arranged alphabetically) .....please suggest key items and actions to take

4. A little effect from the medicine may be davai ka thoda assar shayd hoga:
   Constipation sakath tati hogi, Coughing khasi, Diarrhoea pani jasi tatti hogi, Dizziness chakkar, Hair loss baal girengey, Hungry-not bhukh nahi hogi, Hungry-more aur buhkh hogi, Indigestion khana ka hajam kam achha hoga, Nausea thoda ulti jaisey, Sleeping difficulty neend ki thakleef ho, Stiffness (in limbs) baa-oo may kat-tor-tha, Sweating parseena aveyga, Tiredness thakavat, Thirsty piyaas lageygi, Trembling kampna, Urine-difficulty passing pishaap karney may thoda thakleef, Vision-Slight blurring dekhney mai thoda sa thakleef, Yawning (lazy/ wish to sleep) susthi/ sonay ki eecha,

   These should go in 7 days yeh saath din may chaley jaana cha-hi-yey
   If they do not go, agar nahi chaley ga-yey, then phir.... Action to take?

Bad side effects: .....please suggest key items and actions to take

5. BUT - If these side effects get bad LEYKIN, agar yey assar bura ho jai,
   Or you have any of the following trouble ya app ko baki aur thakleef hoi jaisay: *(select items)*

Appendix D3.Study 3 Alpha-testing staff: Interview questions on English-Hindi prototypes.

The questions were approved by the NHS REC (note the version number and date in the footer).

Study: **Investigating NHS Staff's perspectives: Whether any barriers hinder the provision of services to ethnic minority consumers**

Phase 2: Design concept &/or recommendations Development

Questions refer to patients who either lack English, have no/low literacy, as well as to other patient groups, e.g. the Elderly, have dyslexia or some visual or hearing impairment

Interview 1

Preparing a Design Concept: Create a shortlist for illustrations
(Semi-structured, open questions; record comments)

1. **Review the draft questions on: Pain Screening & Assessment and Medication instructions.**
   Which processes or procedures do you frequently need to communicate to patients for consent?
   a) Do these draft questions reflect your conversations with patients, in practise? What adjustments would you like? *(Identify whether key elements are missing e.g. are patients asked to point where the pain is and if behind the body is a figure needed for them to point to?)*
   b) What is your view of using phonetics as a means of communicating?
2. What would you like illustrated? Do you have illustrations for these already? *(Prompt: If so, may I have a sample? How would you like to add or change this?)*
3. How would you name these items (to be illustrated) – using the simplest English keywords possible?
4. Would you prefer
   a) cartoons or real-life illustrations? Please explain your preference.
   b) twinned aids - phonetic (audio) for staff and images + key English text for patients; or
   c) whether these (b) should be rolled together as one aid.

   NB. Explain that a) could be more cost effective and efficient, and the page on images can be handouts to help patients familiarise themselves with healthcare processes and English and for the Elderly, dyslexia, etc.
5. a) which of these initial phonetic prototype formats do you prefer?
   b) What sizes would you like to see the designs collated initially? *(Prompts: A4, chart, fold over leaflets, Pocket sized cards, Leaflets to give patients)*
6. Can you describe a scenario with a patient where you might use this aid? *(Prompt: Take to a patient's bed, show patient on the wall, give to patient.)*
7. Would you find it helpful, eventually, if the aids created are available via a website?
8. Would you find it helpful to use other new media too? *Like video and audio files*
9. Do you have any other suggestions, preferences or things you do not like?

Appendix D4.Study 3 Alpha-testing staff: sample of transcribed data

Study 03-Interview 1 – Dr S, GP (7.7.2011 11am Leics)

Investigating NHS Staff's perspectives: Phase 2: Design concept &/or recommendations Development

(Bold is participant's response.)

Interview 1

Participant said he was calling community services for patients who did not speak English well, because if he did not they did not.

Participant had not read information, brought up-to-date on outcomes of Phase 1 language and literacy barriers and poor patient participation, and focus of P.2.

1. **Review the draft questions on: Pain Screening & Assessment and Medication instructions.**
   Which processes or procedures do you frequently need to communicate to patients for consent?

   The 2 topics chosen are *Pain Screening & Assessment and Medication instructions.*
   Good good good.

a) Do these draft questions reflect your conversations with patients, in practise? What adjustments would you like?

[Briefly reviewed English draft questions with participant] **OK, yes. Can I mention something to you? This does only work for a very educated patient** *(points to basic English-based questions for patients)* **This ... basic words to ask patients whether the pain is sharp or dull or ...Yes. But I tell you that, you know a typical patient will say that its very big, its the worst pain, and "You know Doctor, I dont know what is the difference between throbbing, or aching or burning."**

I realise that there is a communication gap here. **Mmm.** But the first starting point i thought was are these the kind of questions you ask? **Yes.**

These are. And then you might ask what number was the pain? *[Q6 Pain Assessment]* **Mm** [nods]

[Q7] If you move does it pain – **Get worse** - If you sit up, stand, walk - **yes, thats good. Thats it. That's a good question.**

[Q8] **Yes**

[Q9] **Mm, Mm.** [nods]

[Q10, 11] **OK** [nods]

[Q12] This is a difficult one I highlighted a few areas to say that we need to develop these and we can change anything we like - **Yes.**

[Q13] -**Mm** [nods]

I sent you these so you can have another look and think about anything else you'd like to ask - **Yes. Do you have pain at nights? While in bed? Does the pain wake you up from sleep?** Thank you. Now I've done the same for medication instructions.

[Briefly went over questions on Medication][Q6] Yes and what time [Q10] Yes. *[Q4 side effects]* Yes....it'll go. I got these from NHS websites for different conditions, and how they describe it - these are generic things that happen. **Yes. Action to take,** *what I did with this was I created some prototypes. [Explained the prototypes]...this [the questions] are a basis for visual communication, but visual communication is not enough* - **you have to have something with it** - *verbal. Yes?*

Appendix D5.Study 3 Alpha-testing staff: Findings collated by question and ordered by staff's reference.

(Extract 1) This advice was nearly all incorporated in the questions prior to illustrating them.

S03 –RESPONSES ANALYSIS, NHS staff August 2011

(Legend: 1-GP = participant reference and role)

Unanimous: Questions are relevant. Underlining English and Hindi words that are the equivalent favoured.

1a. Do Qs reflect conversations with patients? Yes Unanimous

Flow of questions: 5-Paramed & A&E Specialist Registrar: We are taught:

S O C R A T E S *(taught how to assess pain):*

1. Site of pain:– can you point?
2. Onset: what time did the pain start
3. Character: Can you describe the pain
4. Radiation: does the pain radiate anywhere
5. Associated signs & symptoms / Aggravating factors
6. Timing: does the pain come and go?
7. Exacerbating/ Alleviating factors: Is there anything that you do that makes the pain better or worse?
8. Severity: pain score 1-10

S A M P L E R *(how to assess situation)*

1. Signs & symptoms (as 5 above)
2. Allergies: What is the reaction? A stomach ache or anaphylaxis!
3. Medication: prescribed, over the counter, somebody elses. Conforming?
4. Past pertinent history
5. Last oral intake
6. Events leading up to the injury/ illness
7. Recent hospitalisation

Adjustments required to questions and illustrations

1-GP

Do you have pain at night whilst in bed ?
Does pain wake you up from sleeping?
Do you have pain whilst walking?
Do you have pain whilst going to the bathroom?
Loose stools
Blood in stools

2-Snr Physio

Move Q 9: If you move about does it pain ? Can you sit up straight? Passing urine? Or passing stools? to Q4 as one would normally ask after: Do you have pain every day/ always?

Medication: itching, vomiting

3-Specialist A&E Doc

Can you breathe in - take a deep breath (breathe out)
Look left, look right, up, down
Squeeze hand/ make a fist, open hands, stretch your fingers, pull me, push against me. Tightness around the chest.
S O C R A T E S (taught how to assess pain)
Medication side effects, TABULATE, paragraph is less helpful, easy to get

(Extract 2) Study 3 Alpha-testing staff: Findings collated by question and ordered by staff's reference.

Add difficulty breathing, vomiting; this is also common to Pain. Bleeding, Blood in stools.

All this is also part of their assessment tool.

4-Ward sister, Elderly care & Stroke

They use pain score 1-3 easier for older patients (10 is fine) (1 mild, 2 moderate, 3 severe)

Medication, allergies are most important from a nursing perspective, add Itching, Vomiting

5-Paramed

- SOCRATES
- Tight/ Crushing pain
- Dull pain
- Nagging is duplicate to throbbing

6-Pharmacy Tech

- Medication, all the drugs are available in the British National Formulary, it's the 'Bible' updated by the plain English Society every twice a year. [*SEE BELOW]
- BNF warnings on what to avoid and special instructions (see Appendix:D4.3)
- What to do if you miss a dose

1b. What is you view of using phonetics?

- Very good idea. 1-GP
- Good idea..... TBA . Need guidance about clear pronunciation. 2-Snr Physio, 3-Specialist A&E Doc, 5-Paramed
- We don't like to be laughed at. We are the professionals we have to be in charge (of the situation). 5-Paramed

? 4- Ward sister

Training and a training video would be helpful.

2. Do you have illustrations for these already?

- No -1-GP, 3-Specialist A&E Doc, 5-Paramed (not for adults, displayed a children's version of 3-scale illustrated pain score).
- No, only some like tea/coffee, water, toilet, food. 2-Snr Physio, meaning unclear re-check., 4-Ward sister

3. What would you like illustrated?

The foregoing and:

- Happy with suggestions for responses; numbers and time of day and duration are important. 1-GP
- tea/coffee, water, toilet, food, pain score; types of pain. 2-Snr Physio, unclear re-check. 3-Specialist A&E Doc, -5-Paramed, 4-Ward sister
- Participant provided form (see D4.4) used to capture pain assessment and descriptive list for pain: physiological emotional state, non-verbal. Medication: Allergies are the most important from a nursing perspective, to eggs, foods and medicines. Dosage information: spoon, dispersed, chew or swallow. 4-Ward sister

4. Type of aid preferred: Twinned aids: All

5. Formats preferred:

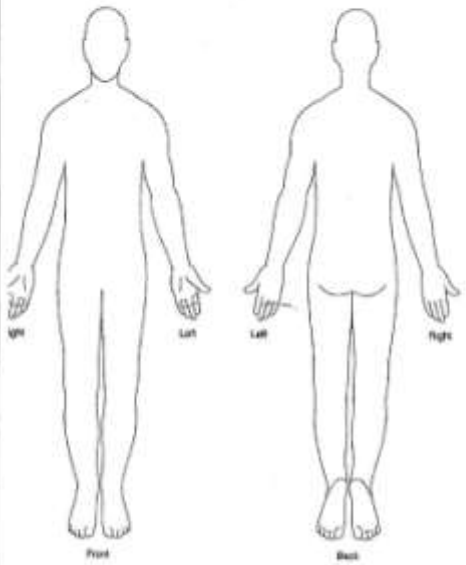
1. **Prototype:**

Appendix D6.Study 3 Alpha-testing staff: Document staff use for pain assessment in the Elderly Care Unit in one Trust.

Note the 3-scale pain score is preferred by the department for elderly patients and the descriptive words some of which were used to illustrate pictorial-prototype-2.

PAIN ASSESSMENT & EVALUATION

Patient identification label



Where is the pain ?

Descriptive words/presenting signs (please tick)

Physiological	**Emotional**	**Non-verbal**
Change in Vital signs	Aggression	Grimacing
Aching	Annoying	Wincing
Blinding	Crying	Rigid
Clammy	Frightful	Refusing to move
Crushing	Miserable	Creasing forehead
Cutting	Moaning	
Dull	Screaming	
Gnawing	Tiring	
Hurting	Unbearable	
Intense	Upset	
Nagging	Verbal/Physical	
Nauseating	Yelling	
Penetrating		
Piercing		
Radiating		
Searing		
Sharp		
Shooting		
Smarting		
Splitting		
Spreading		
Stabbing		
Stinging		
Tender		
Throbbing		
Vicious		

Other - please specify

Numeric/Verbal Scale

3 Severe Pain

2 Moderate Pain

1 Mild Pain

Tell me how bad the pain is?

Pain made better by:

Pain made worse by:

Please record score and assessment overleaf

Standard: Minimum 12 hourly review or at appropriate interval following intervention

Appendix D7.Study 3 Alpha-testing staff: British National Formulary plain English cautionary and advisory guidance.

This was used to inform the medication questions prototype and the pictorial aids.

(Suggested by a pharmacist, this list was written by the Plain English Society).

Joint Formulary Committee (2011). Recommended wording of cautionary and advisory labels In: *British National Formulary BNF No 61 March 2011 ed.* British Medical Association and Royal Pharmaceutical Society. London: Pharmaceutical Press

- Sleepy
- Do not drive, use tools, machines, drink alcohol
- Do not drive, use tools, machines
- Do not drink alcohol
- Do not take indigestion remedies - 2 hours before or after taking this medicine
- Do not take indigestion remedies, or iron or zinc - 2 hours before or after taking this medicine
- Do not take milk, indigestion remedies 2 hours before or after taking this medicine
- Do not stop taking this medicine until the doctor tells you to stop
- Spaces the does evenly through the day and finish the course
- Protect your skin from sunlight even on a cloudy day – do not use sun beds
- Do not take anything containing aspirin while taking this medicine
- Dissolve or mix well with water before taking the medicine
- This medicine may colour your urine – this is harmless
- This medicine is flammable – keep your body away from fire or flames when you have put on the medicine
- Dissolve the tablet under your tongue, do not swallow. Store in this bottle with the cap tightly closed, get a new supply 8 weeks after opening the medicine.
- Do not take more than .....in 24 hours
- Do not take more than .....in 24 hours or more than ...in one week
- Take with or just after food
- Take 30 -40 minutes before food
- Suck or chew the medicine
- Swallow whole – do not chew or break
- Take with a full glass of water
- Spread thinly on affected skin only
- Do not take more than 2 at any one time. Do not take more than 8 in 24 hours.
- Contains paracetamol, do not take anything else with paracetamol whilst taking this.
- Contains aspirin, do not take anything else with aspirin whilst taking this.

Appendix D8.Study 3 Apha-testing staff: English-Hindi questions-prototype-1 design upgrades to prototype-2

Pain screening(p.1/2) : information reorderd according to staff's suggestions

PAIN SCREENING & ASSESSMENT (Prototype 2)

HINDI, URDU

PAIN

Do you understand a *little* Hindi ah-p *thor-da* Hindi samaj-thay hai?

Greeting: namas-thay ji. I am a nurse/ doctor maj nurse/ doctor hoo - my name is may-ra naam (NAME) hai. *What is* your name ah-p ka naam ki-a *hai?* (or: Is your name ah-p ka naam (NAME) hai?)

Setting the scene: I speak a *little* Hindi humm *thorda* Hindi bool-thay hai.

I want to learn humm nay patha karna hai what difficulty ah-p ko ki-a thak-leef or illness you have ya bi-mari hai - give me small *replies* mujay cho-ta *javaab* they-na, like yes or no jay-day *haa, nahi* - and any English *you know* or jith-na Angrey-zi *maloom hai*. OK teekh hai?

I want to learn humm nay patha karna hai, *if* you have **pain** *agar* ah-p ko **darad** hai. If yes, *agar haa*, where is it tho kid-har hai - how bad is it kithna bura hai - when it started kab shuru hua - how many days you've had it ya kithnay din say hai - what kind of pain is it kay-sa darad hai? *And if you have* other difficulties you have *or ah-p ko koi or* thakleef hai. You may also use these pictures to help you ah-p in thas-veer ki madad say bhi show me mujay di-kha sak-thay hai. OK/ alright OK, teekh hai?

1. **Have you pain?** Darad hai, pain hai? **If yes,** haa/ hai/ bahuth hai (a lot): **show me** dikha–o **where** ka-ha *(If No, see Section 8)*

2. **Pain Score: How bad is the pain** kithna bura darad hai?

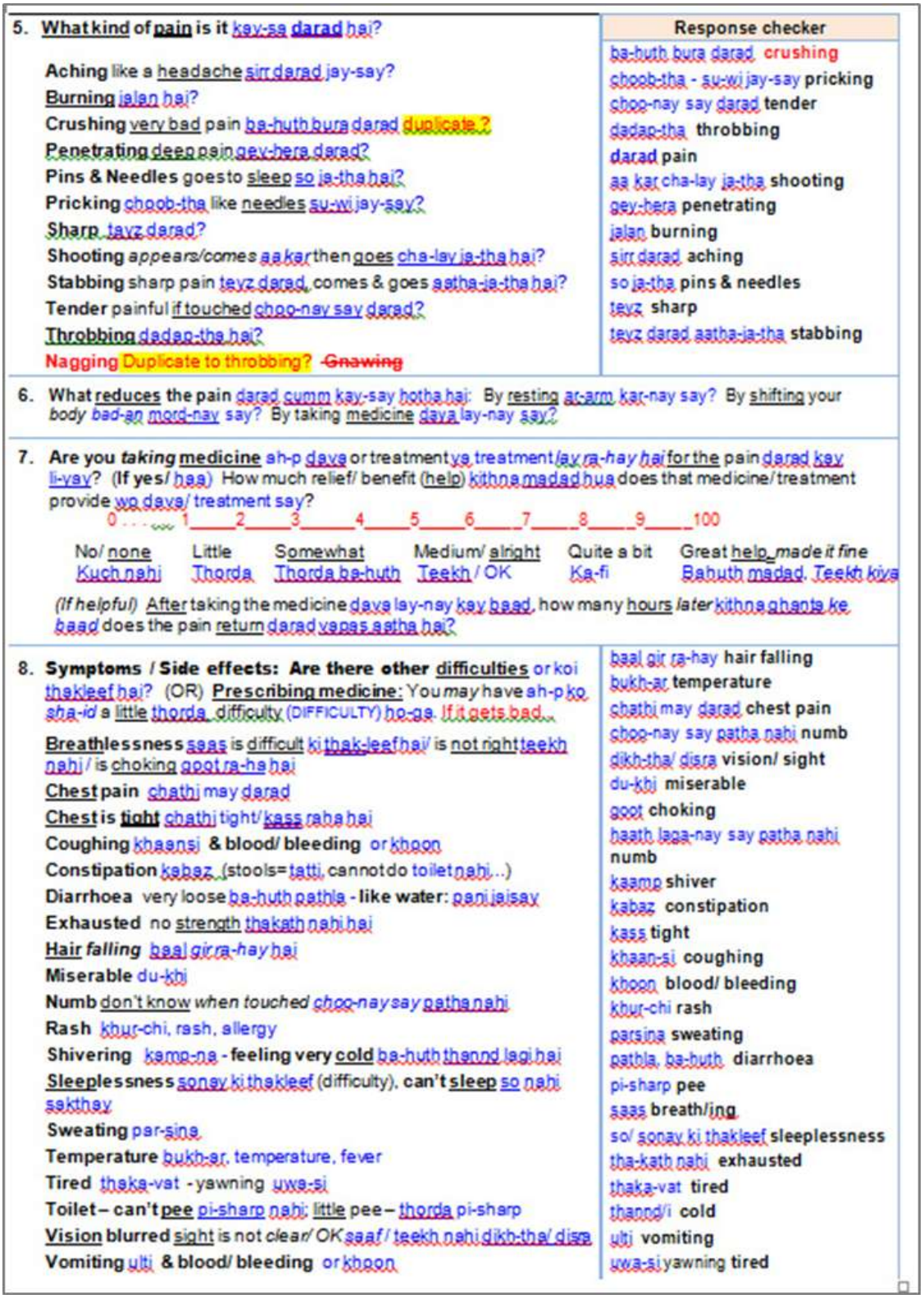
   If we count from 1 to 10 agar humm ek say dass gin-thay, *(show image)* - 1 means ek muth-lab little pain thorda darad, 10 means duss muth-lab unbearable saha nah-i jatha - what number is your pain kithna number ah-p ka darad hai? Do you have pain anywhere else ka-hee or darad hai? (If yes haa) Where kaha? What number kithna number?

3. **When did it *start*** kabh *shu-ru* hu-aa? **(If for a week or a few days)**
   When you had pain jab darad tha last week pitch-lay haf-tay, tell me mu-jay batha-na
   - *What number* was the worst pain sab se bura darad ka *kithna number* tha?
   - What number was the *least* pain sab se come darad ka kithna number tha?
   - Between bad and little pain bura or come darad kay beech *may* what number was the general pain aam-thor darad ka kithna number tha?

4. **Occurrence: Do you *feel* pain constantly/**always darad ha-maysha *mah-soos* hai?
   - **Actions**: Can you ah-p: sit up *straight* see-dhay bayt sak-thay hai - stand up kha-day ho sak-thay hai - walk chal/ too-rr sak-thay hai?
   - **Daily**: Do you have ah-p ko pain every day darad har-roze hai?
   - **Eating**: Is the pain worse darad zya-da hai on eating jab kha-thay hai?
   - **Moving**: If you move about hil-nay say does it pain darad ho-tha hai?
   - **Night**: At night raath ko?
   - **Swelling**: Have you had swelling su-jan hua? (If yes, haa) Show me where dikha–o kaha
   - **Toilet**: When you go to the toilet toilet ja-nay say do you have pain ah-p ko darad hai? On passing urine pi-shaab kar-thay? Or passing stools tatti kar-thay?

Response checker	
Pain	darad, pain
Yes	haa', OK
No	nahi
I don't know	nahi patha
1	ek
2	dho
3	teen
5	panch
6	chay
7	sa-th
8	ah-tt
9	now
10	duss
12	ba-ra
15	pandra
20	beess
Hour	ghanta
Day	din
Week	haf-tha
Month	mahi-na
Year	saal
Today	aaj
Every day	har-roze
Yesterday	kal
Tomorrow	kal-ko
Morning	savay-ra
Afternoon	du-pahar
Evening	shaam
Night	raath

Pain screening (p.2/2) : new response checkers.



5. What kind of pain is it kay-sa darad hai?

Aching like a headache sirr darad jay-say?
Burning jalan hai?
Crushing very bad pain ba-huth bura darad duplicate ?
Penetrating deep pain gey-hera darad?
Pins & Needles goes to sleep so ja-tha hai?
Pricking choob-tha like needles su-wi jay-say?
Sharp tayz darad?
Shooting *appears/comes* aa kar then goes cha-lay ja-tha hai?
Stabbing sharp pain tayz darad, comes & goes aatha-ja-tha hai?
Tender painful if touched choo-nay say darad?
Throbbing dadap-tha hai?
Nagging Duplicate to throbbing? ~~Gnawing~~

Response checker

ba-huth bura darad crushing
choob-tha - su-wi jay-say pricking
choo-nay say darad tender
dadap-tha throbbing
darad pain
aa kar cha-lay ja-tha shooting
gey-hera penetrating
jalan burning
sirr darad aching
so ja-tha pins & needles
tayz sharp
tayz darad aatha-ja-tha stabbing

6. What reduces the pain darad cumm kay-say hotha hai: By resting ar-arm kar-nay say? By shifting your *body bad-an mord-nay* say? By taking medicine dava lay-nay say?

7. Are you *taking* medicine ah-p dava or treatment ya treatment *lay ra-hay hai* for the pain darad kay li-yay? (If yes/ haa) How much relief/ benefit (help) kithna madad hua does that medicine/ treatment provide wo dava/ treatment say?

0 . . . 1 2 3 4 5 6 7 8 9 100

No/ none	Little	Somewhat	Medium/ alright	Quite a bit	Great help *made it fine*
Kuch nahi	Thorda	Thorda ba-huth	Teekh / OK	Ka-fi	Bahuth madad. *Teekh kiya*

(If helpful) After taking the medicine dava lay-nay kay baad, how many hours *later* kithna ghanta *ke baad* does the pain return darad vapas aatha hai?

8. **Symptoms / Side effects: Are there other difficulties** or koi thakleef hai? (OR) **Prescribing medicine:** You *may* have ah-p ko *sha-id* a little thorda difficulty (DIFFICULTY) ho-ga. If it gets bad..

Breathlessness saas is difficult ki thak-leef hai/ is not right teekh nahi / is choking goot ra-ha hai
Chest pain chathi may darad
Chest is tight chathi tight/ kass raha hai
Coughing khaansi **& blood/ bleeding** or khoon
Constipation kabaz (stools= tatti, cannot do toilet nahi..)
Diarrhoea very loose ba-huth pathla **- like water:** pani jaisay
Exhausted no strength thakath nahi hai
Hair *falling* baal *gir ra-hay* hai
Miserable du-khi
Numb don't know *when touched* choo-nay say patha nahi
Rash khur-chi, rash, allergy
Shivering kamp-na **- feeling very cold** ba-huth thannd lagi hai
Sleeplessness sonay ki thakleef (difficulty), **can't sleep** so nahi sakthay
Sweating par-sina
Temperature bukh-ar, temperature, fever
Tired thaka-vat - yawning uwa-si
Toilet – can't pee pi-sharp nahi; little pee – thorda pi-sharp
Vision blurred sight is not *clear/ OK* saaf / teekh nahi dikh-tha/ disra
Vomiting ulti **& blood/ bleeding** or khoon

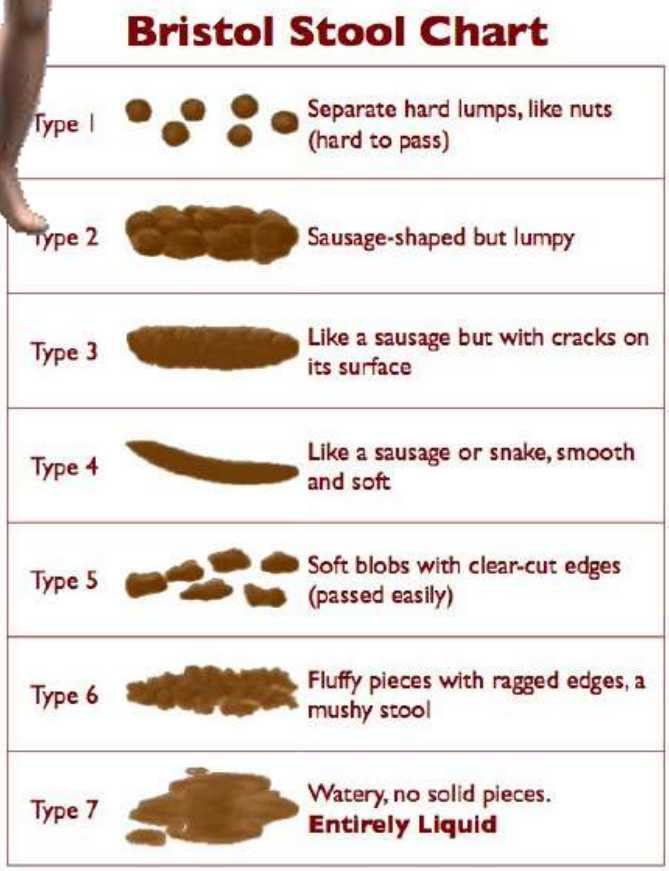
baal gir ra-hay hair falling
bukh-ar temperature
chathi may darad chest pain
choo-nay say patha nahi numb
dikh-tha/ disra vision/ sight
du-khi miserable
goot choking
haath laga-nay say patha nahi numb
kaamp shiver
kabaz constipation
kass tight
khaan-si coughing
khoon blood/ bleeding
khur-chi rash
parsina sweating
pathla, ba-huth diarrhoea
pi-sharp pee
saas breath/ing
so/ sonay ki thakleef sleeplessness
tha-kath nahi exhausted
thaka-vat tired
thannd/i cold
ulti vomiting
uwa-si yawning tired

Appendix D9.Study 3 alpha-testing EMCs: Images not used in the pictorial aid and reasons why.

Lester (2006) discusses 6 user perspectives of images (see 7.3.1.). These were not used for various reasons.

Male and female figures: potentially too explicit
http://www.nhs.uk/conditions/Pages/hub.aspx

'Stop' or 'no': potentially too sophisticated.



Bristol stool chart: Descriptives like 'sausage' would be potentially unfamiliar to vegetarians or offensive to non-pork eaters. 'Soft blobs' and 'fluffy' were unlikely to be used by patients. http://www.sthk.nhs.uk/library/documents/stoolchart.pdf

Appendix D10.Study 3 alpha-testing EMCs: Interview questions.

Section 1/2: Background and English words.

Study 3 - Alpha Testing Images Prototype 1: Response Recording Form - EMC Participants **AUGUST 2011**

Participant Ref: _____ **Date:** _____

SECTION 1 *Re-assure participants there are no right or wrong answers. Ask permission to record for accuracy, Put the recorder on. Thank you for giving me your time today__(Name)__*

Set the scenario: *As we discussed, I am first going to ask you about some English words you will need when talking to a doctor or nurse and, after this, show you some pictures to understand what you feel about these, and whether you feel they could help you in explaining your illness.*

1. **Gender** *(circle response):* Male Female
2. **What is your age group, please?** < 23 24-29 30-39 40-49 50-59 60-69 70-79 80+
3. **How many years have you lived in the UK?** < 1 year 1- 3 3-5 5-10 10+ Other:
4. **Do you know some English?** *(enter below as None, Little, Some, Good, V good)*

If yes	Spoken		Read		Written	

5. **Do you read and write other languages?**

If yes	Spoken		Read		Written	

6. **Is your Doctor English?** Yes No *If yes,* **Surgery** _____

7. **I will say some English words, please tell me in Hindi, Urdu or Punjabi what these mean to you:** *(tick for right response, cross if not recognised)*

yes		evening		up		good		Monday	
no		night		down		not good		Tuesday	
I don't know		today		left		bad		Wednesday	
please		tomorrow		right		happy		Thursday	
thank you		week		sit		sad		Friday	
pain		month		stand		crying		Saturday	
doctor		next week		walk		big		Sunday	
nurse		next month		here		very big			
morning		now		there		small			
afternoon		after		OK		allergies			

Study 3 alpha-testing EMCs: Interview questions

Section 2 (p.1/2): Recognising images.

I

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

Study 3: Development of the design concept &/or recommendations

Alpha testing the images (visual communication) section of the Initial Prototype.

Questions for participants from the Indian Subcontinent lacking English and/or literacy to determine how meaningful the images are and how much English they know already.

Semi-structured Interview: open questions, data recorded.

Assure participants there are no right or wrong answers, request permission to take photographs of them, and/ or of their answers.

Section 2:

Set scenario: Thank you for giving me your time today. As we discussed, we are going to talk about the English you might need to talk to a doctor and whether you might find pictures helpful to explain your illness to the doctor. I will ask you a few questions about the English and show you some pictures to understand what you feel about these.

Suppose you went to see the doctor because you were unwell and had pain. The doctor would ask you questions to understand your problem/ illness to decide what treatment is best. Suppose the doctor showed you some pictures during these questions and asked you from time to time to point to the pictures to help you explain your difficulties.

1. **a) If the doctor asked you to point to where you had pain and showed you this picture, how easy would it be for you to point to where the pain is on this picture?** e.g. suppose you have pain in your back, show me where you would point? *If not easy,* what is the problem?

   b) What do you feel about having labels in English to show the different parts of the body?

2. **a) Do you know numbers like 0 to 10 in English?** E.g. your house number and your mobile phone number. *(If no: skip to 3)*

   b) *If yes*: If these numbers are written down are you comfortable to recognise these? Are there any you do not recognise?

   c) *If yes*: Suppose you have been ill for 10 days and the doctor asked you how long you have been ill, what would you choose? For 20 days? 6 days?

3. **As you know we have 7 days in 1 week, and 30 days in a month. If we arrange the numbers in 7 days to show 1 week, or 2 weeks** *(like this)* **like on a calendar and the doctor asked how long you had been ill, would you feel comfortable to point to, say, 2 weeks?** And 1 month?

4. *(Show pictures of a clock, morning, afternoon, evening & night).* **What do these pictures mean to you?**

5. *(Show pictures representing 1 day).* **If the doctor gave you these pictures put together like *this* what do you think this means?**

6. *(Show pictures of tablets, pouring syrup, drinking, glass of water, plate of food)* **What do these pictures mean to you?**

7. *(Show picture of medication instructions).* **If we put these pictures together, what does this mean to you?**

8. **If the doctor was to write in here say, 2, what would that mean to you?**

9. *(Show emoticons of happy, unwell, more unwell, crying)* **What do these pictures mean to you?**

10. **If the doctor asked you how bad your pain was, and said to choose from 1 to 10, where 1 is no pain and 10 is unbearable pain, could you point this out on this picture by choosing a number, example for medium pain? Or very bad pain? Little pain?**

QUESTIONS & PROCEDURE – STUDY 3: EMCs Shena Parthab Taylor, PhD Student, Loughborough Design School, Loughborough University

Pg 1/2 v.1b – 30.7.2011

Section 2 (p.2): Recognising images.

11. **If you had pain and the doctor asked you what kind of pain was it, like a headache or toothache what would you point to?** What about a burning pain? Or a sharp pain? Pricking?
12. *(Show symbols of right, wrong, I don't know, arrows).* **What do these pictures mean to you?**
13. *(Show pictures of cup of tea, glass of water, food, toilet, etc)* a) **What do these pictures mean to you?** *If identified correctly:* b) **Do you feel you could use these to point if you wanted to ask for tea, water or the toilet?**
14. *(Show pictures of temperature, dizziness, pain in chest, etc)* **What do some of these pictures mean to you, like this one?** *Point to dizzy, rash, falling hair, chest pain, vomiting, constipation*
15. **Would you find it helpful to have pictures like these to help you explain your problem to the doctor?**
16. **Are there pictures you felt were not clear or you did not understand?** *Please explain the problem.*
17. **Do you like different types of pictures:** *(point out)* **emoticons? Cartoon? Real life images?** *(ask the reason for choice)*
18. **If you were unwell which favourite picture would you like to see near you?** e.g. Guruji, Saints, your family, or scenery like mountains or the sea, flowers, animals, birds.

Thank you very much for your time.

Appendix D11.Study 3 alpha-testing EMCs: Response form

(p.1/2) The author translated the questions and filled in participants' responses

Study 3 - Alpha Testing Images Prototype 1: Response Recording Form - EMC Participants AUGUST 2011

Participant Ref: _____ Date: _____

SECTION 2 *Set the scenario*: See *Questionnaire (circle response, or tick correct and cross incorrect responses)*

Questions	Responses & comments				
1. Point to where the pain is: (back shoulder)	Very easy	Easy	Alright	Hard	Very hard
Comment:					
2. a. Knows English numbers 0 to 10:	Yes	No	20, 30 etc		
b. Recognises written numbers	Yes	No	Unsure		
Not recognised:					
c. Can point to numbers of days ill:	3 days	9 days	20 days	Unsure	
3. Recognises numbers grouped by:	Calendar	Month	2 weeks	Can explain 6 weeks	
Not recognised:					
4. Recognises pictures of	Clock	Morning	Afternoon	Evening	Night
Not recognised:					
5. Recognises grouped pictures = 1 day	Yes	No	Unsure		
Not recognised:					
6. Recognises pictures of	Tablets	Pouring syrup	Drinking	Water	Food
Not recognised:					
7. Recognises composite for *medication instructions*	Yes	No	Unsure		
Not recognised:					
8. Recognises meaning of 2 on *medication instructions*	Yes	No	Unsure		
Not recognised:					
9. Recognises emoticons	Happy	Unwell	Crying		
Not recognised/ difficulty:					
9. Recognises pictures for type of pain	Headache	Toothache	Pricking	Burning	Sharp
	Tiring	Exhausting	Sad/miserable	Crying	Stomach ache
	Ear ache				
Not recognised:					
10. a. Pain score: choosing from 1 to 10	Very easy	Easy	Alright	Hard	Very hard
b. Can choose:	Medium pain	Very bad	Very little		

Study 3 alpha-testing EMCs: Response form (p.2)

Difficulty:			
c. Image preferred	1 Many emoticons 2 Large emoticons		
11. Recognises meaning of symbols	Right Wrong I don't know Arrows: Up Down Right Left		
Clearest image of 'I don't know'	Symbol ?	Man	Emoticon
Not recognised/ difficulty:			
13. a. Recognises pictures	Stand up Sit up Walk Toilet/ Bathroom Cup of tea Water Food Sit down		
b. Can ask using pictures?	Yes	No	Unsure
Comment:			
14. Recognises pictures	Headaches Temperature Sweating Dizzy Rash Chest pain Tightness in chest Trouble sleeping Falling hair Blurred vision Coughing Coughing blood Vomiting Vomiting blood Toilet: like stones loose like water with blood urine sample		
Not recognised/ difficulty:			
15. Are pictures helpful in explaining?	Yes	No	Unsure
Any comment:			
16. Any pictures unclear or not understood that were not discussed?			
17. Do you like:	Emoticons	cartoons	Real-life pictures
Any comment:			
18. If unwell, any favourite picture(s) nearby	Spiritual Family Scenic Animals Birds Not important		
19. Any other comment?			

Appendix D12.Study 3 alpha-testing EMCs: Sample of data capture Response form (p.1/2) on background and testing English words.

Study 3 - Alpha Testing Prototype 3 Images: Responses of EMC Participants AUGUST 2011

(2) Participant Ref: Mrs H[redacted] Kaur Date: 17.8.2011

SECTION 1

1. **Gender** *(circle response):* Male (Female)
2. **What is your age group, please?** <23 24-29 30-39 (40-49) 50-59 60-69 70-79 80+
3. **How many years have you lived in the UK?** <1 year (1-3) 3-5 5-10 10+ Other:
4. **Do you know some English?** *(enter below as None, Little, Some, Good, V good)* v. v. little.

If yes	Spoken	little.	Read	v. little	Written	X

5. **Do you read and write other languages?**

If yes	Spoken	Punjabi	Read	✓Good	Written	✓Good.

6. **Is your Doctor English?** (Yes) No *If yes,* **Surgery** Peter.

7. **I will say some English words, please tell me in Hindi, Urdu or Punjabi what these mean to you:** *(tick for right response, cross if not recognised)*

yes	✓	today	X	sit down	✓	big	✓
no	✓	tomorrow	✓	stand	✓	very big	✓
I don't know	X	week	✓	walk	✓	small	✓
please	✓	month	✓	here	✓	Monday	✓ Somv
thank you	✓	next week	✓	there	✓	Tuesday	✓ Mang
pain	✓	next month	✓	OK	✓	Wednesday	✓ Budh
doctor	✓	now	X	good	✓	Thursday	✓ Virvar
nurse	✓	after	X	not good	✓	Friday	✓ Shukarvar
morning	✓	up	X	bad	✓	Saturday	✓ Shanitar
afternoon	✓	down	X	happy	✓	Sunday	✓ Ithvar
evening	✓	left	✓	sad	✓	allergies	✓
night	✓	right	✓	crying	✓		

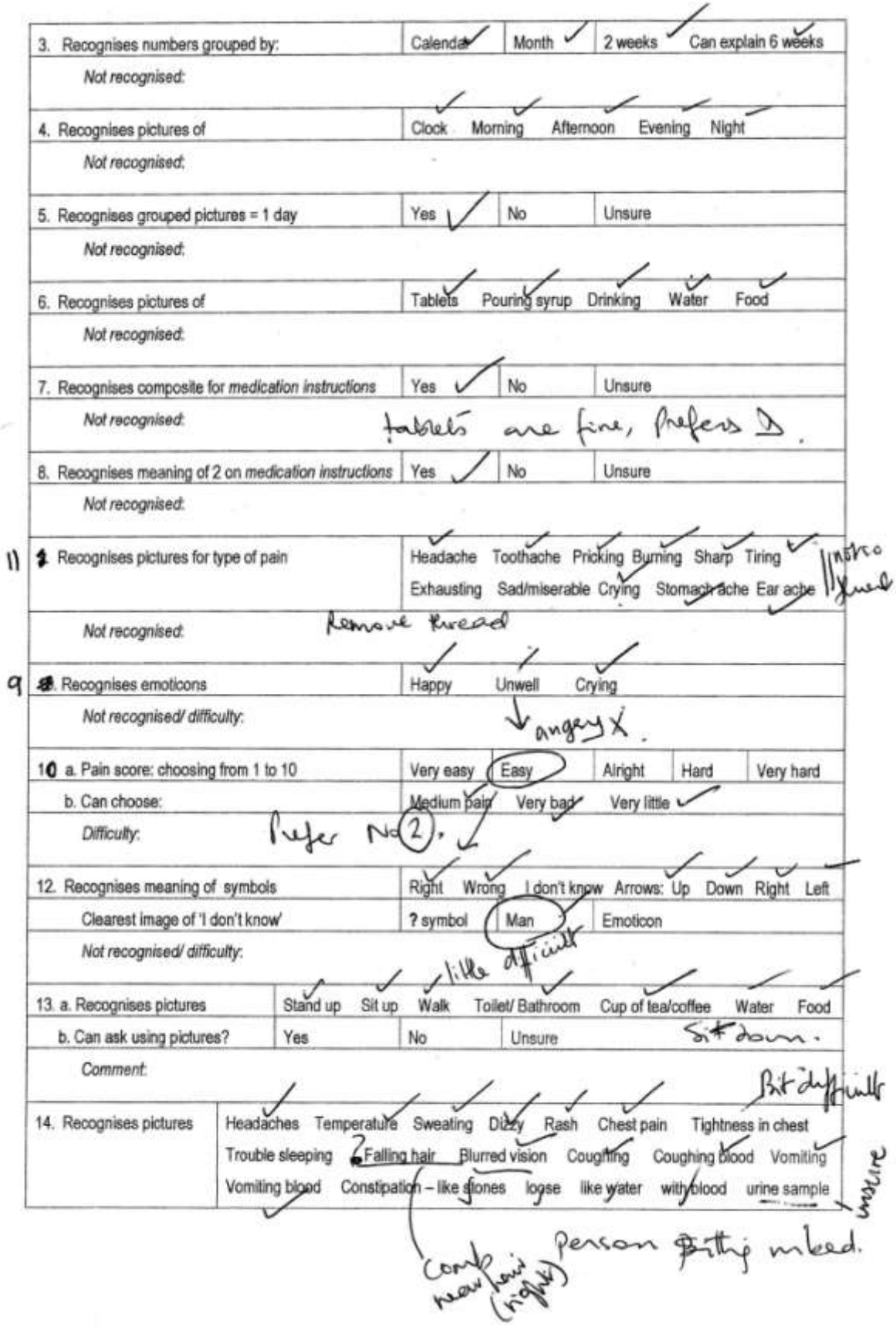
SECTION 2 *(circle response, or tick correct and cross incorrect responses)*

Questions	Responses & comments				
1. Point to where the pain is: (back shoulder)	Very easy	(Easy)	Alright	Hard	Very hard
Comment: draw face on figure for clarity. want labels on body parts.					11
2. a. Knows English numbers 0 to 10:	(Yes)	No	20, 30 etc	Some practice above 11 →	
b. Recognises written numbers	(Yes)	No	Unsure		30
Not recognised: above 11.					
c. Can point to numbers of days ill:	3 days ✓	9 days ✓	20 days	Unsure	

← Some practice.

(p.2) Study 3 alpha-testing EMCs: Sample of data on recognising images.

Note participants' suggestions to improve images, unwell appears angry (Q.9) and preferences.



Appendix D13. Study 3 alpha-testing EMCs: Extract of data analysis in excel 2007 of images recognition.

Section 2, Question 14: an analysis of responses to images in 'symptoms and side effects' and question 15: whether images aid understanding.

Study 3 Ethnic Participant Responses
Section 2 Qs 14-18: Recognising pictures and numbers

Re	Name	14: Pictures of																																		15: Do pics help?		
		Headache		Temperature		Sweating		Dizzy		Rash		Chest pain		Chest tight		Trouble sleeping		Falling hair		Blurred vision		Coughing		Coughing blood		Vomiting		Vomiting blood		**Toilet**		Like stones (Contipation)		Loose + blood		Like water		Loose		Urine sample				
		Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Y	N	Unsur
1	KamalK	1		1		1		1		1		1		1		1		1		1		1		1		1		1		1		1		1		1		1		
2	HarpK	1		1			1	1		1		1			1		1		1		1		1		1		1		1		1		1		1			1	1		
3	HarbS	1		1		1		1		1		1			1	1		1		1		1		1		1		1		1		1			1	1			1	1		
4	HarkK	1		1		1		1		1		1			1			1		1		1		1		1		1		1		1		1		1			1		
5	DaljK	1		1			1	1		1		1			1		1	1			1	1		1		1		1			1		1		1			1	1		
6	HarbK	1		1		1			1	1		1			1	1		1			1	1		1		1		1			1		1		1			1	1		
7	CharK	1		1			1	1		1		1			1		1	1		1		1		1		1		1		1		1		1		1			1		
8	ReshK	1		1			1		1		1	1		1			1		1	1			1		1		1	1		1		1		1		1			1		
9	ManinK	1		1			1	1		1		1			1		1	1		1		1		1		1		1		1		1		1		1			1		
10	GurmS	1		1		1		1		1		1			1		1	1		1		1		1		1		1		1		1		1		1			1		
11	BalwK	1		1		1		1		1		1		1			1	1		1		1		1		1		1		1		1		1		1			1		
12	PrakK	1		1		1		1		1		1			1			1		1			1	1		1		1		1		1		1		1			1		
13	KulvS	1		1			1	1		1		1			1		1	1		1		1		1		1		1		1		1		1		1			1		
		13	0	13	0	7	6	11	2	12	1	13	0	3	10	3	8	11	2	11	2	11	2	12	1	12	1	12	1	13	0	10	3	11	2	10	3	11	2	9	4	13		
		100%		100%		54%	46%	85%		92%		100%		23%	77%	23%	62%	85%		85%		85%		92%		92%		92%		100%		77%	23%	85%		77%	23%	85%		69%	31%	100%		

S1-Q1-4 | S1-Q5-6 | S1-Q7 | S2-Q1-5 | S2-Q6-10 | S2-Q11-13 | **S2-Q14-18** | Images used

Appendix D14. Study 3 alpha-testing EMCs: Extract of data analysis in excel 2007

Residents lacking English: recent arrivals and long term residents/ visitors.

Study 3 Ethnic Participant Responses
Section 1 Q7: Recognising English words

Years in UK		< 3 years				20+ years	Visitor-10 yrs	20+ years		< 1 year		10+ years			NE= No English
Gender	F	F	M	F	F	F NL	F NL	F NL	F	M	F	F NE	M		NL= No literacy
Refs:	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**		
(1=yes X=not understood)															
yes	1	1	1	1	1	1	1	1	1	1	1	1	1	13	100%
no	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
doctor	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
nurse	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
thank you	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
please	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
good	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
not/ *no*	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
happy	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
morning	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
evening	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
night	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
next week	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
Monday	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
Friday	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
Saturday	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
Sunday	1	1	1	1	1	1	1	1	1	1	1	1	1	13	
afternoon	1	1	1	1	1	X	1	1	1	1	1	1	1	12	92%
pain	1	1	1	1	1	X	1	1	1	1	1	1	1	12	
OK	1	1	1	1	1	1	1	1	1	1	1	X	1	12	
walk	1	X	1	1	1	1	1	1	1	1	1	1	1	12	
week	1	1	1	1	1	X	1	1	1	1	1	1	1	12	
month	1	1	1	1	1	1	X	1	1	1	1	1	1	12	
next month	1	1	1	1	1	1	1	1	1	X	1	1	1	12	
Tuesday	1	1	1	1	1	X	1	1	1	1	1	1	1	12	
Wednesday	1	1	1	1	1	X	1	1	1	1	1	1	1	12	
Thursday	1	1	1	1	1	X	1	1	1	1	1	1	1	12	
big	1	1	1	1	1	1	X	1	1	1	1	1	1	12	
small	1	1	1	1	1	1	X	1	1	1	1	1	1	12	
very big	1	1	1	1	1	X	X	1	1	1	1	1	1	11	85%
tomorrow	1	1	1	1	1	1	X	1	1	X	1	1	1	11	
down	1	X	1	1	1	1	1	1	1	X	1	1	1	11	
left	1	1	1	1	1	X	1	1	1	1	1	X	1	11	
right	1	1	1	1	1	X	1	1	1	1	1	X	1	11	
sit *down*	1	1	1	1	1	X	1	1	1	X	1	1	1	11	
bad	1	X	1	1	1	1	X	1	1	1	1	1	1	11	
today	1	X	1	1	1	1	X	1	1	X	1	1	1	10	
I don't know	1	X	1	1	1	X	1	1	1	1	1	X	1	10	
up	1	X	1	1	1	1	X	1	1	X	1	X	1	9	69%
stand	1	X	1	1	1	X	1	1	1	X	1	X	1	9	
here	1	X	1	1	1	X	X	1	1	X	1	X	1	8	
crying	1	X	1	1	1	X	X	1	1	X	1	X	1	8	
allergies	1	X	1	1	1	1	1	X	1	X	1	X	X	8	
now	1	X	1	1	1	X	X	1	1	X	1	X	1	8	
after	1	X	1	1	1	X	X	1	X	X	1	X	1	7	
there	1	X	X	1	1	X	X	1	1	X	1	X	1	7	
sad	1	X	X	1	1	X	X	1	1	X	1	X	1	7	
	47	**33**	**45**	**47**	**47**	**29**	**33**	**46**	**46**	**33**	**47**	**34**	**46**		
	100%	70%	96%	100%	100%	62%	70%	98%	98%	70%	100%	72%	98%		

Ref	**Comment**
1	re. Allergies: Cited causes *penicillin, food*
7	*here* understood as *hear;* understood *not good* good but not *not good*
8	Understands *ache, I think so, numbers 1-100, body parts (sometimes forgets), alphabets*

Appendix D15. Study 3 alpha-testing EMCs: Collating data

D15.1 Data collation by questions and participant's references.

Ref Comment S1: Q1-4

1 Doing individual interviews very good because in a group some people might not like to say what they don't know or that they disagree with others.

2 Would like to work but has no English.

4 Q4 English read *[SP: actually quite good]* but do not understand words. Worked 18 years, first as a machine operator, then packing. Couldn't work after shoulder operation the company refused. See the doctor a lot; changed to a doctor who could speak a little Hindi as appointments were during the middle of day.

8 The study is very good to help them learn English, it will be a great help.

13 Can speak English 'not too bad' but needs practice. Went to Tresham College for English lessons for 2 years but still cannot read or write.

(Ref Comments S1: Q5-6 None)

Ref Comments S1: Q7

1 re. Allergies: Cited causes *penicillin, food*

7 *here* understood as *hear;* understood *no good* but not *not good*

8 Understands *ache, I think so, numbers 1-100, body parts* (sometimes forgets), *alphabets*

Ref Comments S2: Q1-5

1 Q1: Would like arrows pointing to body parts with labels so they can learn the parts - perhaps also in Punjabi

2 Q1: Draw face on figure for clarity; labels on body parts

3 Q1: Would like arrows pointing to body parts with labels so they can learn the parts

4 Q1: Would like labels forgets parts of body in English. Asked about symbols for inside the body - like the heart – Yes, that would help.

6 Q2: Learned numbers 1 up to 12 from the clock *[no more than 12; kept looking at the clock].* Qs 4&5: needed explanation

7 Q2: Knows numbers over 11 and 20,30 etc in Punjabi not English. Q3: Easy. Q5: Easy

8 Q1: labels are good forgets sometimes. Q4 & 5: understood Morn, Afternoon, Evening & Day after explanation. Linear clock fine.

11 Q4 Evening - remove moon & add setting sun

12 Q1: Knows parts of body in English. Q3 Can explain in English

100% felt pointing to parts of the body where they had pain, was easy or very easy and all wanted the body parts labelled in English to help them learn (1 suggested in Punjabi).

All could count from 1 to 12.

Ref Comment S2: Q6-10

1 Q7 & 8: easy

2 Q6: all tablets pics are fine. Food interpreted as 'fruit' *[adjust pic].* Q9: interpreted Unhappy as Angry

3 Q9: interpreted Unhappy as confused. Q10 chose 5 for 'little pain'

4 Q6: all tablets pics are fine, prefers D for pouring medicine. Food interpreted as 'fruit' *(adjust pic).* Q10: likes larger face (image is clearer), likes emoticons.

6 Q6 Drinking needed explanation. Q9: liked cartoons more than emoticons, recognised smiling girl

5 Q9 likes happy cartoon and crying emoticon

Ref Comment S2: Q14-18

Q.14 symptoms

Blurred vision described as 'moti' (white pearls i.e. Cataracts, reason for blurring). 'blurred vision' make eye red Blurred vision: OK, could be clearer, blurred vision understood as problem with eyes

Coughing & vomiting understood after explanation. Coughing not understood, after explanation, able to recognise coughing blood, vomiting, vomiting blood

Dizzy interpreted as head pain. Not clear pics & to improve: Dizzy as headache - understood after explanation

Falling hair place comb near hair not in front of face. 'Falling hair' just put more hair on left. Falling hair put a bald patch on head and less hair. Falling hair -make clearer.

Sweating - drops are all over head and confusing. Sweating unclear, Sweating needed little explanation. Not clear pics & to improve: Sweating understood as crying, Sweating -remove drops from above head & under eyes, make more below. Sweating - remove drops on top of head & under eyes, show top of body. Sweating: confused with crying due to drops under eyes, remove drops under the eyes Sweating understood after some explanation;

'temperature: Make thermometer larger

tightness in chest less clear. tightness in chest less clear; Tightness in chest: please make clearer, tightness in chest understood but make clearer. Tightness in chest - put a belt squeezing the chest. Tightness in chest - not too clear. Tightness in chest make clearer; Tightness in chest unclear-show figure's face tightness in chest - not clear

Trouble sleeping: sad face is better. Trouble sleeping show bed and sad person. Trouble sleeping prefers 'b'. Trouble sleeping: add bed + person sitting in it, 'Trouble sleeping' b is better and a bed with person awake & unhappy. , Trouble sleeping both pics OK, Trouble sleeping prefers b & a bed would be clearer. Trouble sleeping prefers b, put a figure sitting in bed; Trouble sleeping put bet & window showing night & sad sleepy face. Trouble sleeping add bed & person. Trouble sleeping- some explanation, add bed, figure cannot sleep. Trouble sleeping need bed & person. Trouble sleeping - both designs are OK.

Move toilet to middle of those pics. . Move toilet to middle of those pics. Constipation etc put toilet in the middle,,

Constipation: kabaz, addmore stones in a pile. [*Move toilet to middle.*] *Labels in English on 'constipation' picture.* Constipation set not understood

'Urine sample' understood once explained.

'Like water; not recognised as 'watery' - would like a pic for can't pee, or peeing too much *(separate into 2 toilet pics?)*. 'Urine sample' understood once explained.

Q15: Very nice, like all pictures.

Q17 All are good. all are good in their place. Likes emoticons, likes photos best; remove yellow from emoticons.

Q18: Pictures near hospital bed: Guruji and Flowers. G Nanakji., G Nanakji. Likes colour in pictures - makes them clearer, B&W less clear like B&W TV. G Nanakji Guruji will make me better G Nanakji or GGobindji

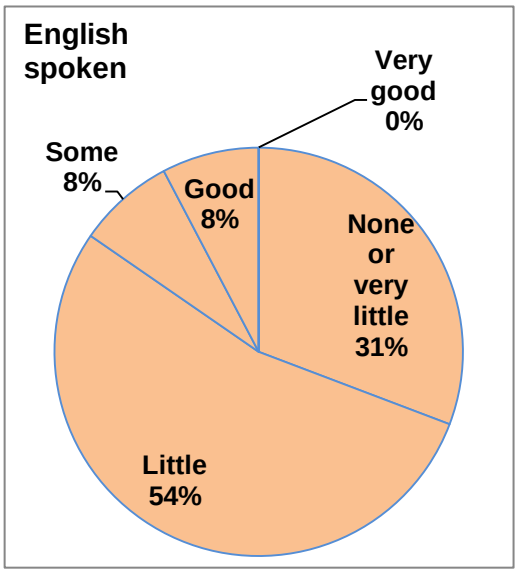
Main thing is to see the family.

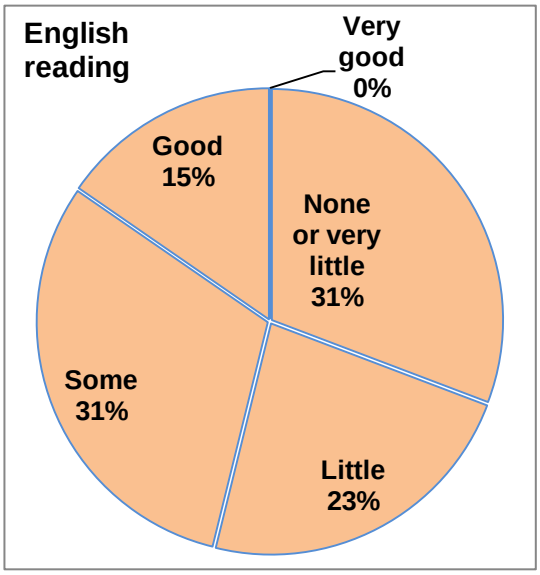
100% of the participants liked the emoticons, 77% illustrations and 92% liked photographs.

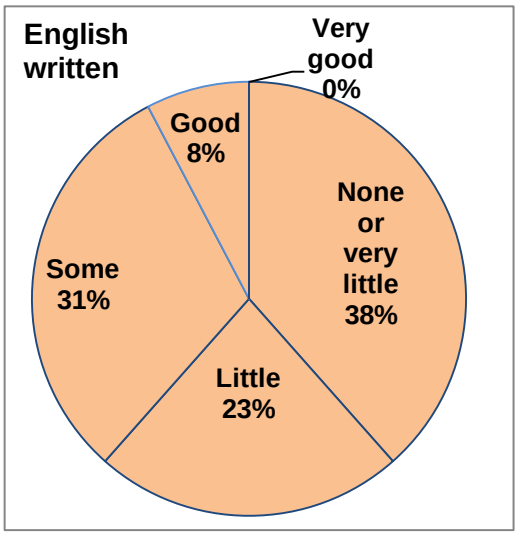
Overall, 77% felt all the images were good and helpful each in its own place. Participants were encouraged to put forward suggestions to improve images they did not understand. Emoticons were a new concept, but quickly picked up; the yellow confused many as they associated that with the sun. Photographs or illustrations closer to real life were understood more easily and favoured– one participant suggested putting hair on the emoticons!

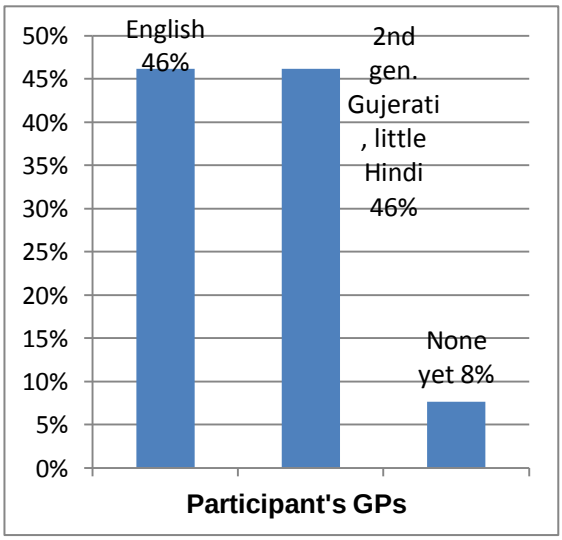
D15.3: Literacy skills (self-estimations) and GPs

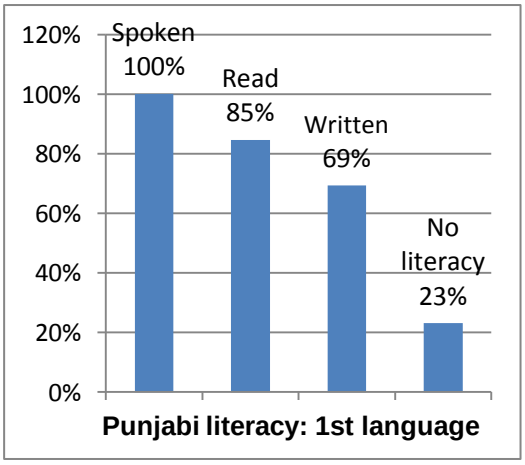
Section 1 Qs.4-6: A few were able to read and write English but did not understand the meaning. Those who estimated their English as 'good' could understand English but found it difficult to respond. Half had changed to a Guajarati GP who understood a little Hindi. The majority were keen to learn English.

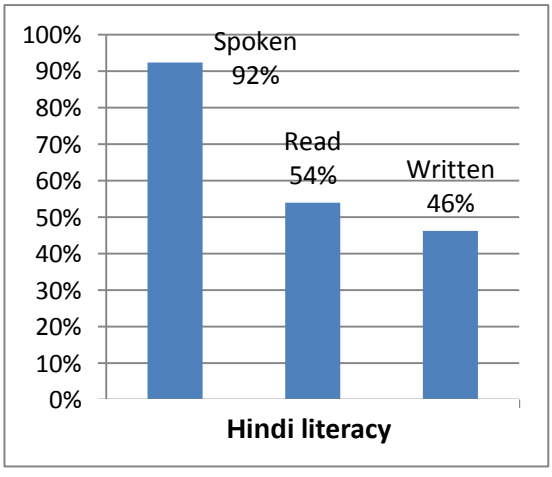






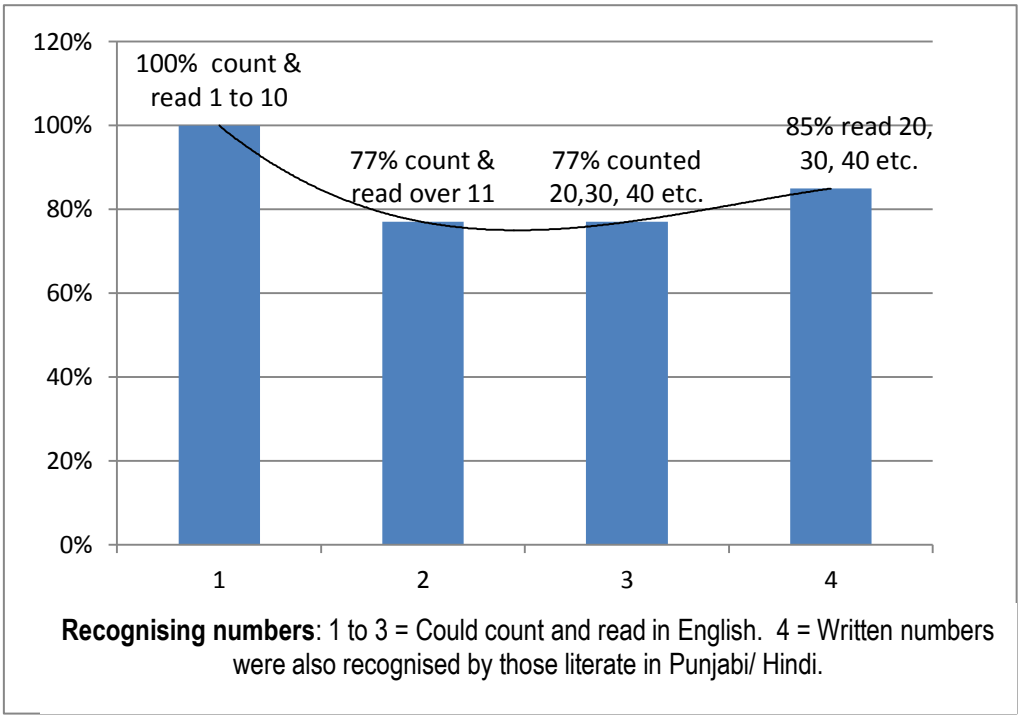




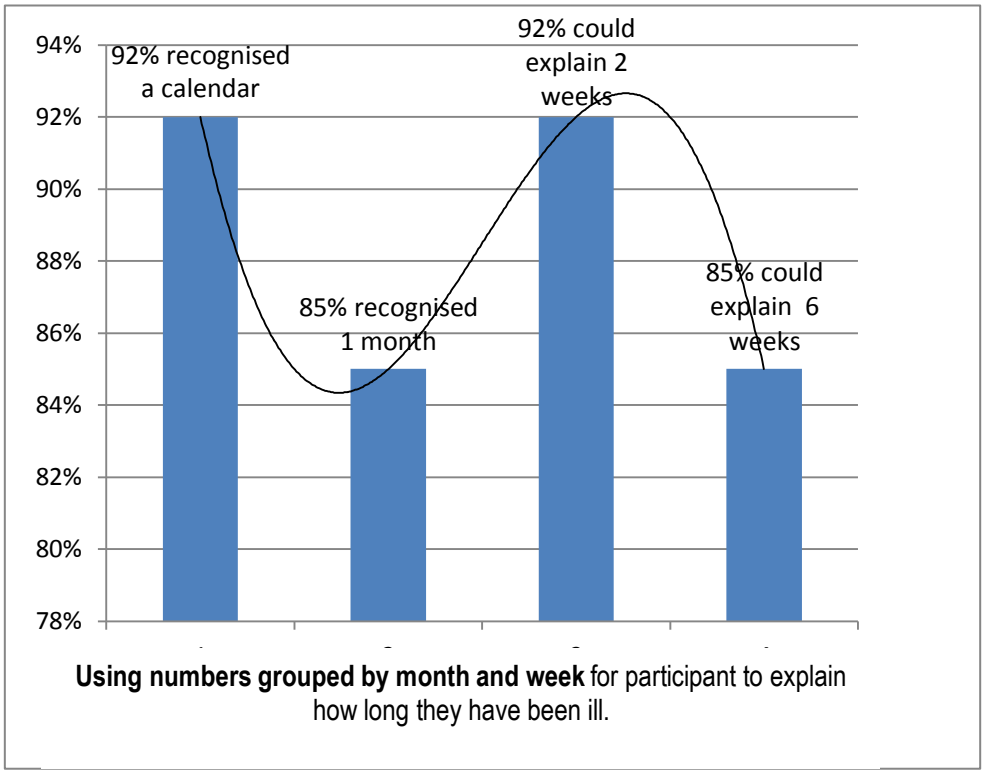


D15.4: Study 3 alpha-testing EMCs: Recognising numbers

and using them to explain days, weeks (Section 2 Qs 1-5). 23% could not count beyond 10.



Recognising numbers: 1 to 3 = Could count and read in English. 4 = Written numbers were also recognised by those literate in Punjabi/ Hindi.



Using numbers grouped by month and week for participant to explain how long they have been ill.

D15.5: Study 3 alpha-testing EMCS: Recognising medication instructions, pain score, emotion.

Section 2: Qs 6-10. Note the high responses in recognistion of 'real-life' cartoons (autism picture cards). Pictorial aids were a new concept and participants were adjusting rapily. Eventually the majority selected emoticons (a new concept for all of them)

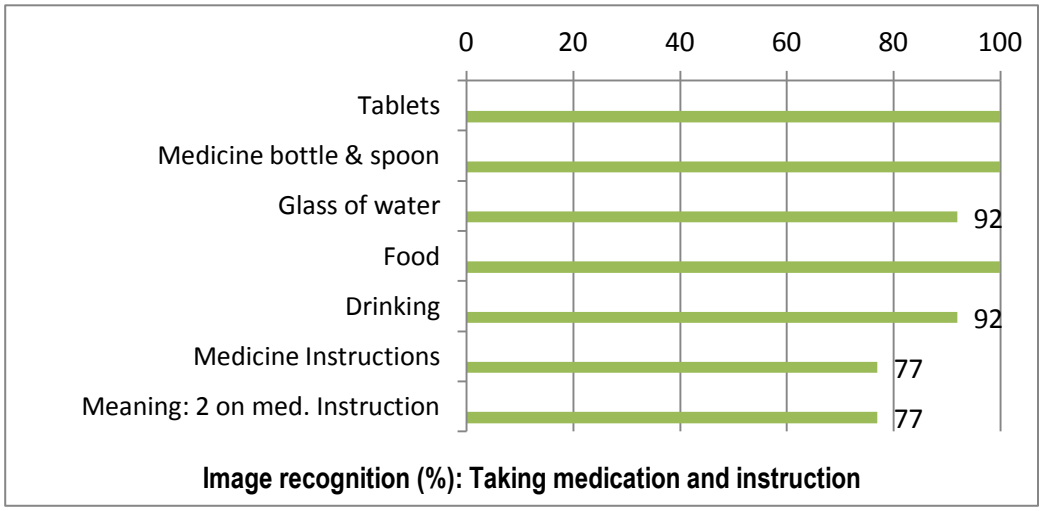
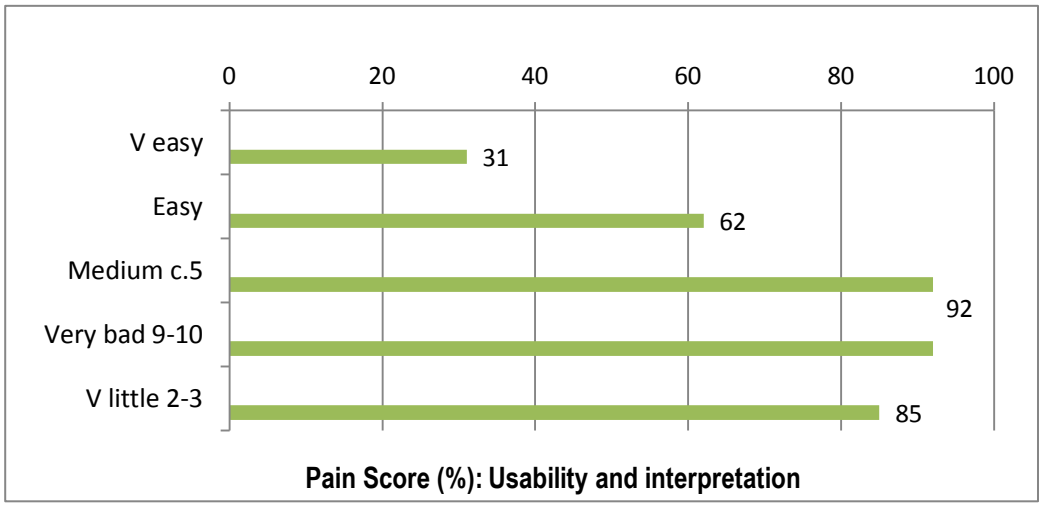


Image recognition (%): Taking medication and instruction



Pain Score (%): Usability and interpretation

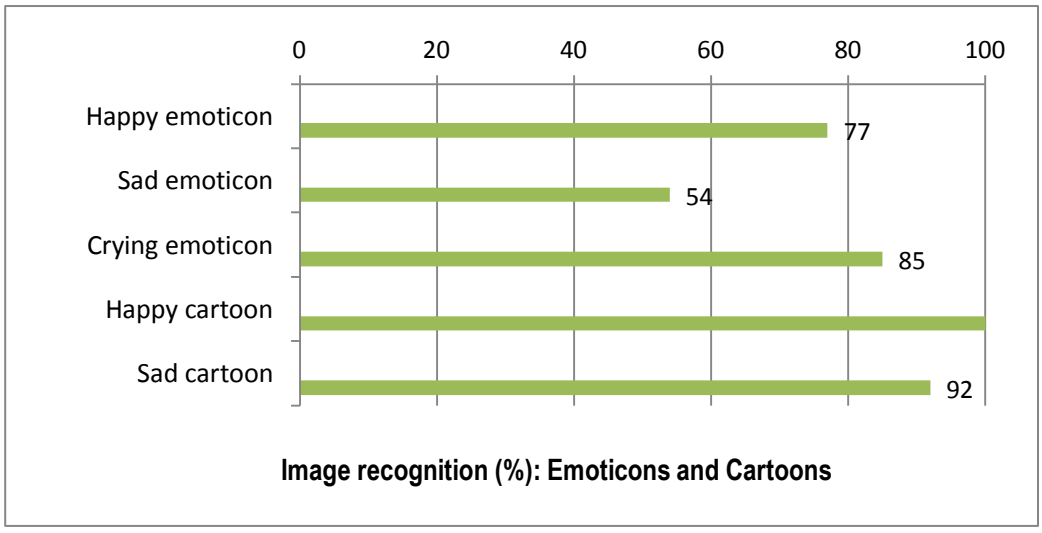


Image recognition (%): Emoticons and Cartoons

D15.6: Study 3 alpha-testing EMCS: Recognising images for pain, needs or a request for an action.

Section 2 Qs 11-13

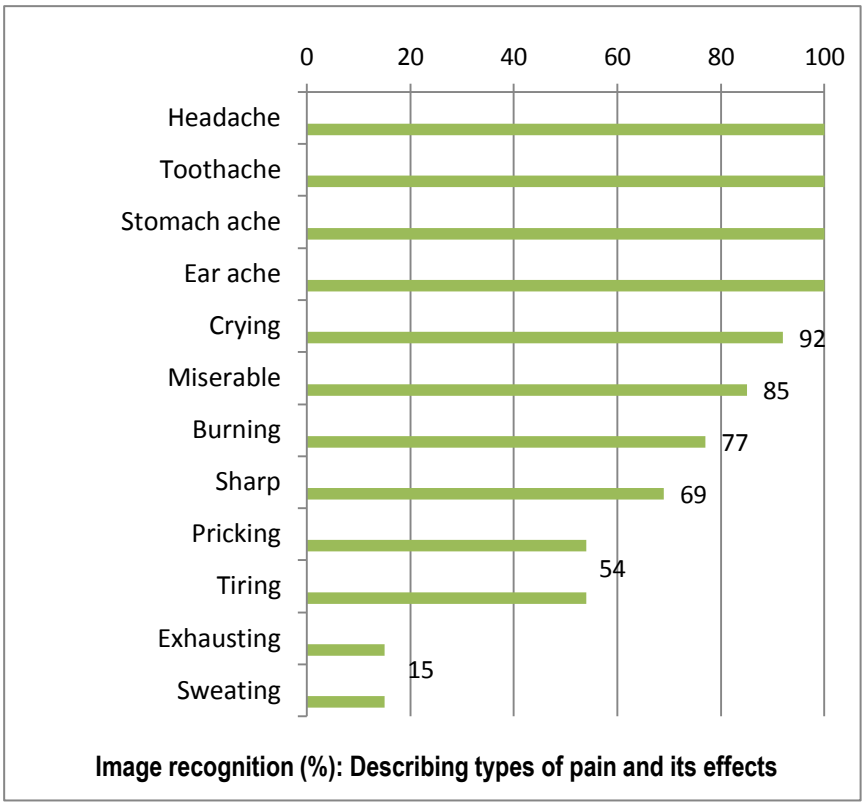


Image recognition (%): Describing types of pain and its effects

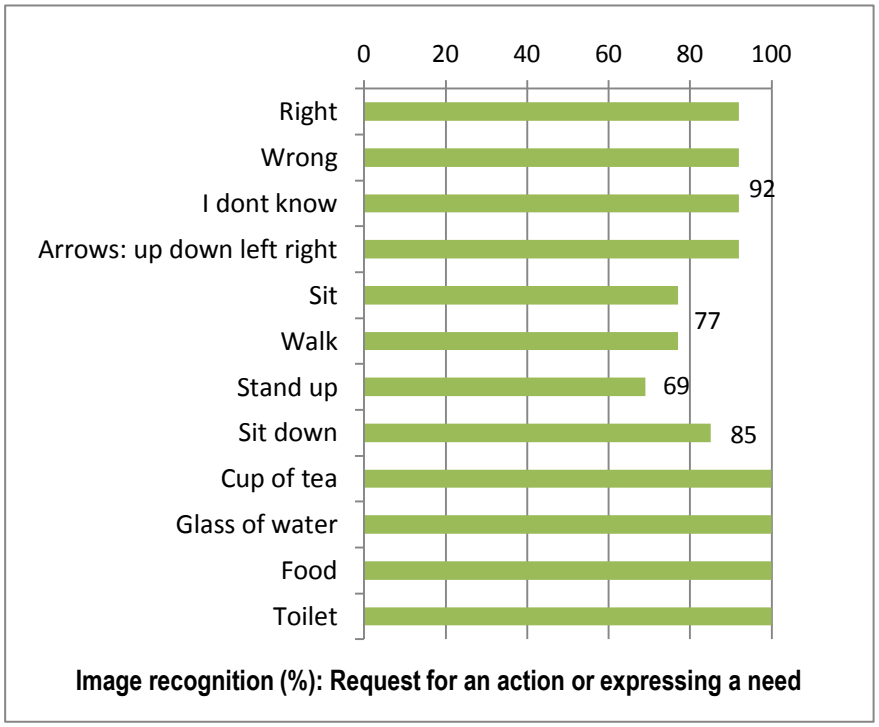


Image recognition (%): Request for an action or expressing a need

D15.7: Study 3 alpha-testing EMCs: Recognising symptoms and side effects

Section 2 Qs 14-18: Also, helpfulness of images and other preferences. Chest tight, trouble sleeping, sweating, rash and many others were all readjusted for greater clarity.

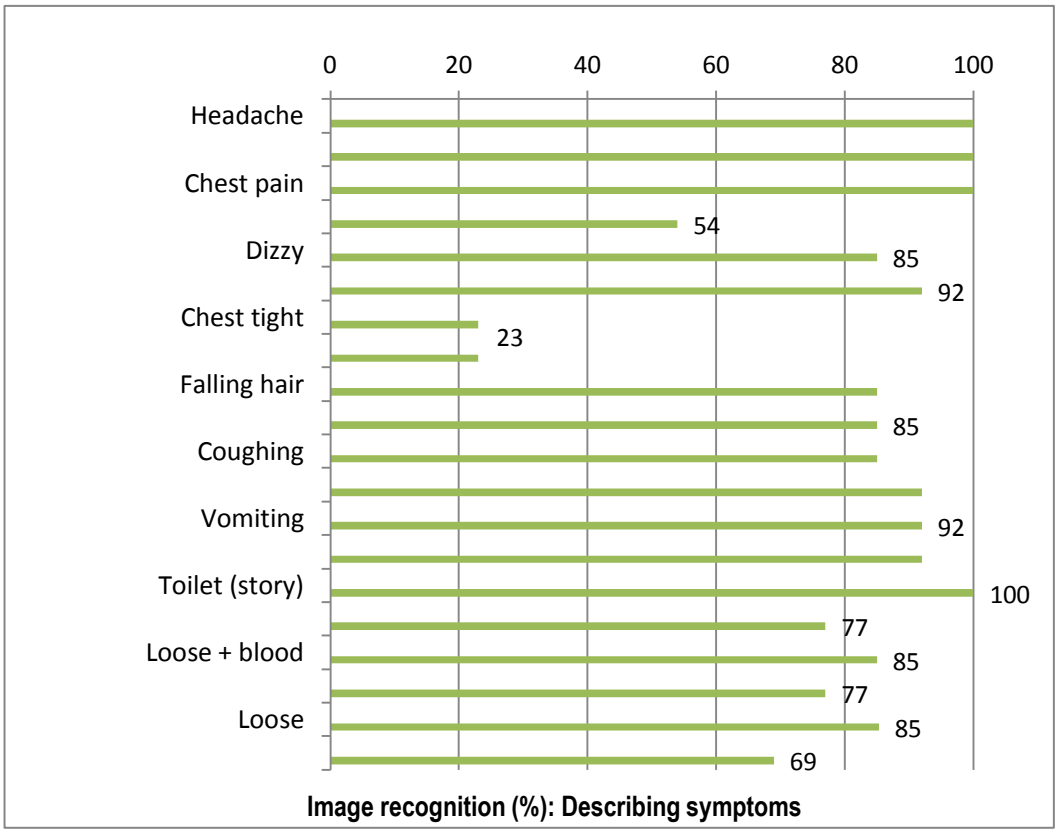
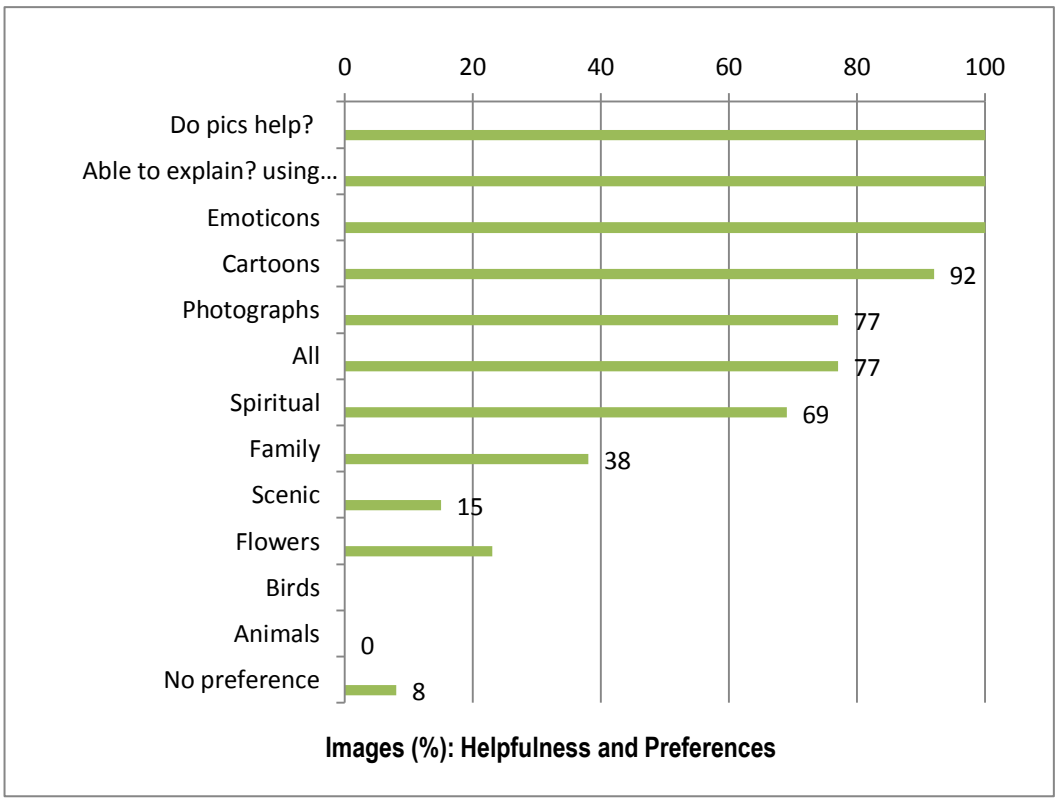


Image recognition (%): Describing symptoms



Images (%): Helpfulness and Preferences

APPENDIX D: Study 3. Beta-testing

Appendix D16.Study 3 Beta-testing EMCs: Pain-pictorial-aid-2.

D11.1: Interview questions (p.1/2)

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

October 2011

STUDY 3: Beta Testing Questions for EMC

(Semi-structured interview in Punjabi/ Hindi: open questions, data recorded.)

Purpose: Testing Prototype 2 Images, to determine how meaningful and clear the re-designed images are, what kind of labels are helpful, and whether participants feel they could use the images and the English words they know to explain themselves to a doctor/ nurse.

Participants: 1st generation from the Indian Subcontinent who participated in alpha testing and lack English and/or literacy.

Thank you again for seeing me __(NAME)___ We are again going to talk about a visit to the doctor, and look at some pictures as we did last time. These have been re-designed according to what people asked for. I would like your views of these designs and, if you do not like or understand anything, please tell me what you would prefer. There are no right or wrong answers.

(Set the scenario, emphasise underlined words). *Suppose you go to see the doctor because you are unwell and have pain. The doctor would ask questions to understand your problem/ illness to decide what treatment is best. The doctor would want to know where you had pain, how bad the pain is, how long you have had it, what kind of pain it is and what other difficulties you are facing. Suppose the doctor showed you pictures and asked you to use these to help you explain your difficulties.*

1. *(Show body with labels)* **Suppose you wish to show the doctor where you have pain on these pictures which now have labels in English for parts of the body:**
   a) **What do you feel about having labels - are they very helpful, helpful, OK, not helpful or a hindrance?**
   b) **What do you feel about having labels in English?**
2. *(Show pain score 10 using emoticons)* **When the doctor asks you how bad your pain is, and asks you to choose from 0 to 10, where 0 means no pain and 10 means unbearable pain,**
   a) **What would you choose on this picture, to show medium pain? Or very bad pain? Little pain?**
   b) **Do these new faces express your feelings about how much pain?**
   c) *(If not)* **What do you not find clear?** *(show alternative emoticon images for pain score)*
   d) *(Show alternative pictures)* **Do you prefer any of these other pictures?**
   e) *(Show autism pictures)* **Do you have any preference between using emoticons or cartoons?**
      Please explain the reason:
   f) *(Show pain score 5)* **Which design do you find clearer? Please explain the reason:**
3. *(Show images from morning to night, numbers arranged in weeks and month. Ask questions in Punjabi and prompt participant to respond with simple English words, if possible.)* **Suppose you wish to tell the doctor how long you have been ill. Please show me how you would use these pictures, numbers and any English words you know to explain to the doctor. For example,**
   a) **How would you show you became ill last night? In the afternoon? How would you say 'today' in English?**
   b) **How would you show you were ill for 2 days? How would you say 'days' in English?** *(If able to)* **What about 10 days? 15 days?**
      (If unable to) **What do you find difficult? What would be clearer for you?**
   c) **How would you show you were ill for 1 week? How would you say 'one week' in English? 6 weeks? Last week?**
   d) **How would you show you were ill for 1 month? How would you say 'month' in English? 1 year?**
4. *(Show symbols of 'yes', 'no' and 'I don't know' image – and exploring these responses and communicating understanding.)*
   a) **What do these pictures mean to you? Do you know the English words for Yes, No, I don't know?**

b) Sometimes the doctor asks a question, but we do not know the answer – how would you show you don't know?

c) Sometimes the doctor says something we do not understand (not the same as don't know) – how would you explain you do not understand?

d) Suppose the doctor says something and you do understand – how would you explain you do understand?

5. *(Show pictures of 'What kind of pain').* a) What do these pictures mean to you?

b) What would you point to, to explain you have a headache? If you already showed the doctor the pain was in your arm, but wanted to explain the kind of pain. Which would you choose for a ache? A burning pain? A sharp pain? Pricking?

c) If the doctor asked you, 'do you get pins and needles in your arm', and you did not, how would you answer?

6. *(Show pictures of 'symptoms or side effects 1– chest pain to sweating')* a) What do these pictures mean to you? *(Point to each one in turn.)*

b) How would you show you feel dizzy? What about coughing blood? Constipation? Sweating? Chest pain? Very tired/ exhausted? How about you were dizzy in the night?

7. *(Show pictures of 'symptoms or side effects 2 – miserable to vomiting')* a) What do these pictures mean to you? *(Point to each one in turn)*

b) What would you point to, to show you have temperature? Vomiting? Rash? Shivering? Trouble sleeping? Miserable?

8. a) All these pictures have labels in English to help you learn the English words – what do you feel about this?

b) *(ask if literate)* Some pictures also have Hindi words written in English next to the English words - what do you feel about this?

9. *(Show pictures of 'Requests and needs').* a) What do these pictures mean to you?

b) If the doctor asked you to hold his arm and 'push' *(in Punjabi)* and pointed to this picture what would you do? And 'pull'? Stand what would you do? Sit up straight?

c) *(ask underlined words in English)* What would you do if the doctor asked you to stand but you could not because you were dizzy - could you choose a picture to show this?

10. *(Show picture of medication instructions).* a) What story do these pictures tell you?

b) If the doctor was to write in here say, 2, and in here 1, what would that mean to you?

c) *(Show a Yes tick on food image)* If the doctor made this mark – what would that mean to you? *(Show a Yes tick on glass of water)* And this? *(Show a Yes tick on food)*

d) *(Show X with food and 1 day)* What story does this tell you? (Show a car and x) And this?

11. Is there anything else you would like say about what you have seen today, or like or do not like?

Thank you very much for your time.

Appendix D17. Study 3 Beta-testing EMCs: Image recognition Response form (p.1/3) Re-testing interpretation of modified images.

RESPONSE RECORDING FORM: Prototype 2-Images, October 2011
(Semi-structured interview in Punjabi/ Hindi: open questions, data recorded.)

Study 3: Development of the design concept - EMC Participants (from Alpha Testing phase)
1st generation from the Indian Subcontinent who lack English and/or literacy, and who participated in alpha testing.

Purpose: BETA TESTING To determine how meaningful and clear the re-designed images are.

Participant_____ **Ref:** _____ **Date:** _____

(Circle response, or tick correct and cross incorrect responses) See Questionnaire

Questions	Responses & comments				
1. a. Labels on figures	Very helpful	Helpful	Alright	Not helpful	A hindrance
Comments:					
b. Labels in English: *Comment*					
2. a. Pain Score 10 - choice	Medium	Very bad pain		Little pain	
b. Do faces express feelings about pain	Yes	No		Unsure	
c. Not recognised & reasons:					
d. Alternative emoticons preferred	Happy: **1 2 3 4 5 6 7 8**			Crying: **1 2 3 4 5 6**	
	Sad: **1 2 3 4 5 6 7 8 9 10**				
e. Preference	Emoticons	Cartoons		Either	
Reason:					
f. Pain Score preference:	PS 5	PS 10		Either	
Reason:					
3. a. How long ill	Last night	Afternoon		*Today* in English	
b. Days	2 days	10 days	15 days	*Days* in English	
Difficulties/ preferences:					
c. Weeks	1 week	6 weeks	Last week	*Week* in English	
d. Month/ Year	1 month	1 year	*Month* in English	*Year* in English	
4. a. Recognises pictures of	Yes	No	I don't know		
And knows English words	**In English**: Yes	No	I don't know		
b. Don't know the answer choice c. Don't understand image choice: d. I do understand image choice					
5. a. Recognises images : Kind of pain	Headache	Toothache	Burning	Crushing	Pricking (like needles) Sharp

Study 3 Beta-testing EMCs: Image recognition

Response form (p.2).

Not recognised, problem:					
b. Can indicate pain	Headache Associate arm pain with ache Burning Sharp Pricking (like needles)				
Not recognised, problem:					
c. Can indicate 'No' to pins & needles					
6. a. Recognises pictures: Symptoms/Side effects	Chest pain Tightness in chest Coughing Coughing blood Dizzy Toilet: like stones loose with blood like water very little. Exhausting Falling hair Sweating				
Not recognised/ difficulty: Sweating image preference:					
b. Able to pick out & use images	Dizzy Coughing blood Constipation Sweating Chest pain Exhausting Dizzy at night				
Not recognised/ difficulty:					
7. Recognises pictures: Symptoms/ Side effects	Miserable Rash Shivering Temperature Tiring Trouble sleeping Blurred vision Vomiting Vomiting blood				
Not recognised/ difficulty:					
b. Able to pick out	Vomiting Rash Shivering Trouble sleeping Miserable				
Not recognised/ difficulty:					
8. a. Picture with labels in English	Very helpful	Helpful	Alright	Not helpful	A hindrance
b. Picture with labels in Hindi	Very helpful	Helpful	Alright	Not helpful	A hindrance
Comment					
9. a. Recognises pictures	Stand up Sit down Sit up Walk Push Pull Cup of tea Water Food Medicines Toilet Urine sample				
b. Can do action if shown picture – or show cannot	Push	Pull	Stand	Sit up straight	
c. Cannot stand because dizzy *Any difficulty:*					
10 a. Recognises medication	Very easy	Easy	Alright	Hard	Very hard
b. Meaning of 2 and 1 instructions	Yes	No	Unsure		
Not recognised:					

Study 3 Beta-testing EMCs: Image recognition Response form (p.3).

c. Recognises yes tick on tea/water	Yes	No	Unsure
Difficulty:			
d. Recognises arrow above good	Yes	No	Unsure
Difficulty:			
e. Recognises cross against car	Yes	No	Unsure
11. Any other comments? Any other images preferred over those not understood – see Alt pics pages			

Thank you very much for your time.

Appendix D18. Study 3 Beta-testing EMCs: Responses collated by question and participant's reference (step 1).

BETA TESTING EMCS – IMAGES, October 2011

COLLATION OF COMMENTS

QUESTIONS 1-3

Ref Comment

1 **Q1a**. Labels on figures: arrows show/ help more. Everyone will understand/learn what is the name in English. **Q1b**. Labels in English: Fine, mostly we need to learn English. We already know the parts in Punjabi and Hindi. **Q2b**. Clear. **Q2g**. Very good - words and numbers of pain to unbearable. **Q3a&b**: Best like this for those who dont know English.

2 Q1b: Labels in English is good. Q2f: Pain at 1 or 2 is bearable. *(Q6: week, last week, year: unable to say in English, still learning.)*

3 Q2b. English is good. Q2c. Easy to understand (new pain score). Q3a. Used English, images were clear.

4 Q1b: Labels in English: Fine to learn English

5 Q1a. We can read and say what we don't know [i.e. find the word/ picture needed]. Q1b. Labels in English are ok for those who know English - but perhaps Punjabi - ok its best for learning English. Q1c. Pain: labels are helpful. Cartoons are less clear.

6 Q1b. English is good, don't know written Punjabi anyway. [Participant is not literate.] 2e. It is clear and is written, so its clear to see. 3b. They [doctors] don't look at me.

7 Q1b. English labels: Good. Q2e. Emoticons preferred, clear. PS10 fine. Q3a. Today: showed morning. Days; learned a little English, write days in English.

8 Q1b: should be used in English to practice. Q2a. Chose 7 for medium. Q2c. All good images. Q2f. PS10 good.

9 Q1b: Helpful to learn English. Q2a. Chose 7 for medium Pain. "f: good, clear.

10 Q1b. This is fine [English labels]. Q3. not familiar with next week, or year in English.

11 Q1b. Labels in English: Good. 2b. Emoticons express feelings: Good. 3b. Good images.

QUESTIONS 4-5

Ref Comment

1 **Q5a**: Pins & Needles: Very common in leg or arm for people when they go to the Gurudwara. They always have this problem (*sitting on the ground*). Need a leg or arm with little dots on them -like insects, like ants crawling to show people who cannot read English.

3 Q5b. Likes the labels

4 Q5b: said headache in English

5 Q4. both blue and green ticks are fine. For I don't understand said: Please repeat.

6 Q4.a- struggled, needed an explanation b-d not asked as a result. Q5a. Burning pain: understood with explanation, Sharp: knife, crushing/ Pricking not understood. [Associations a bit new to participant]. Struggled (not literate, 75+) not asked 5b. or c.

7 Q4c. I don't understand: not known. Q8b. Burning: Was able to point out after understanding in Q8a.,

8 Q4d. I do understand: no need for image.

9 Q.4d. I don't understand: put label near under picture.

10 Q4d. I do understand: with explanation. Q5a. Burning: flame [did not understand association first time, did so 2nd time]. Crushing: interpreted as pain.

QUESTION 6

1 Q6a: Tightness in chest: Have the belt above the hands. Q6b: Dizzy at night: image & night in English

2 Q6b: Dizzy at night: with a little help

3 4 Q6a: falling hair - move comb further from the face. Q6b: Dizzy at night: able to say in English

5 Q6a: sweating- needs to be clearer - make it bigger.

Study 3 Beta-testing EMCs: Responses re-grouped by question (step 2).

BETA TESTING EMCS – IMAGES, October 2011

COMMENTS REGROUPED BY QUESTIONS

Q1a. Labels on figures: arrows show/ help more. Everyone will understand/learn what the name is in English.
Q1a. We can read and say what we don't know [i.e. find the word/ picture needed].
Q1b. Labels in English: Fine, mostly we need to learn English. We already know the parts in Punjabi and Hindi. labels in English is good. Q1b: Labels in English: Fine to learn English. Q1b. Labels in English are ok for those who know English - but perhaps Punjabi - ok its best for learning English. Q1b. English is good, don't know written Punjabi anyway. [Participant is not literate.] Q1b. English labels: Good. Q1b: should be used in English to practice. Q1b: Helpful to learn English. Q1b. This is fine [English labels]. Q1b. Labels in English: Good.
Q1c. Pain: labels are helpful. Cartoons are less clear.

Q2a. Chose 7 for medium. Q2a. Chose 7 for medium Pain.

Q2b. Clear. Q2g. Very good - words and numbers of pain to unbearable.
Q2b. English is good. Q2b. Emoticons express feeling s: Good.
Q2c. Easy to understand (new pain score). Q2c. All good image
Q2e. It is clear and is written, so its clear to see. Q2e. Emoticons preferred, clear. PS10 fine.
Q2f: Pain at 1 or 2 is bearable. Q2f. PS10 good. Q2f: good, clear.

Q3a: Best like this for those who don't know English. Q3a. Used English, images were clear. Q3a. Today: showed morning. Days; learned a little English, write days in English.
Q3. not familiar with next week, or year in English.
Q3b. They [doctors] don't look at me. 3b. Good images.

Q4a. both blue and green ticks are fine. For I don't understand said: Please repeat. Q4.a- struggled, needed an explanation b-d not asked as a result.
Q4c. *I don't understand*: not comprehended difference with I don't know.
Q4d. I do understand: no need for image. Q 4d. I don't understand: put label near under picture. Q4d. I do understand: with explanation.

Q5a: Pins & Needles: Very common in leg or arm for people when they go to the Gurudwara. They always have this problem (*sitting on the ground*). Need a leg or arm with little dots on them -like insects, like ants crawling to show people who cannot read English. Q5a. Burning pain: understood with explanation, Sharp: knife, crushing/ Pricking not understood. [Associations a bit new to participant]. Struggled (not literate, 75+) not asked 5b. or c.
Q5a. Burning: flame [did not understand association first time, did so 2nd time]. Crushing: interpreted as pain.
Q5b. Likes the labels. Q5b: said headache in English. Q5b. Burning: Was able to point out after understanding in Q5a.

Q6a: Tightness in chest: Have the belt above the hands. Prefers the boy image. Q6a: falling hair - move comb further from the face. Q6a: sweating- needs to be clearer - make it bigger. Q6a. coughing/coughing blood, Stools like water or very little: recognised with explanation. Says she learns slowly. Sweating: prefers boy. Q6a.

Study 3 Beta-testing EMCs: Responses refined (step 3) ready for updating images.

BETA TESTING EMCS – IMAGES, October 2011

COMMENTS REDUCED BY QUESTIONS

(Elderly grandma struggled, needed an explanation; some questions were not asked as a result.)

Q1. Labels on figures and labels in English:

"Arrows show/ help more. Everyone will understand/learn what the name is in English. We can read and say what we don't know [i.e. find the word/ picture needed]."

"Fine, mostly we need to learn English. We already know the parts in Punjabi and Hindi."

"Labels in English is good."

"Fine to learn English."

"Labels in English are ok for those who know English, but perhaps Punjabi – ok, its best for learning English.
"English is good, don't know written Punjabi anyway. [Participant is not literate.]

"[Labels] Should be used in English to practice."

"Helpful to learn English." "This is fine." "Good." "Good".

Q2a. Pain Score with labels: Emoticons were preferred as clear and a 10-scale pain score was approved of as fine, good and clear. The emoticons expressed feelings clearly and "all good images" was the general view.

"Very good, words and numbers of pain to unbearable."

"English labels are good." and "Easy to understand" (new pain score) although 2 chose 7 for medium pain.
"Labels are helpful, [preferred emoticons] cartoons are less clear."
"It is clear and is written, so it's clear to see."

Q3a: Periods of day and numbers to explain when one became ill:

"Its best like this for those who don't know English." Some spoke in, images were clear. Today: showed morning. Days; learned a little English, write days in English. Recent arrivals (male and female) were still learning and could not express week, next week, or year in English. A grandma (75+ years) was unhappy: *They [doctors] don't look at me.* The images were viewed as "good".

Q4a. Yes, No, I don't know: Both blue and green 'ticks' for 'yes' were fine. For I don't understand said: *Please repeat.*
I don't understand: not comprehended difference with I don't know.
I do understand: no need for image. I do understand: understood with explanation.
Suggestion: I don't understand: put label near under picture.

Q5: Types of pain: Participants liked the labels on the images.

Burning pain: understood with explanation. Did not understand association first time, but was able to point out the second time.

Crushing pain was interpreted as pain.

Pins & Needles: "Very common in leg or arm for people when they go to the Gurudwara. They always have this problem (*sitting on the ground*). Need a leg or arm with little dots on them -like insects, like ants crawling to show people who cannot read English."

Sharp pain: knife, crushing/ Pricking not understood. [Associations a bit new to participant].

Grandma struggled not asked 5b. or c.

Q6-7: Symptoms and side effects

Coughing/coughing blood, Stools like water or very little: recognised with explanation. Says she learns slowly.
Sweating: prefers boy. Unable to say if labels are helpful - no literacy.

Blurred vision: understood after explanation.

Appendix D19.Study 3 Beta-testing EMCs: Sample of responses analysed in Excel 2007.

Study 3 Ethnic Participant Responses

Recognising pictures and responding in English

Recognising pictures and responding in English

Ref	1a: Labels of body in English						2: Pain Score																						3: How long ill: Recognising images & using English words																			
						1b: Labels in English*	2a. Choose pain				2b. Faces express feelings			2c.	2d.		2e			2f. Pain score preferred				Ease of use					3a. Time of day: English & image					3b. Days				3c. Weeks in English				3d. Month/Year in English			
	V helpful	Helpful	Alright	Not helpful	A hindrance		Medium 5	V bad 9, 10	V little 1, 2	Unbearable	Yes	No	Unsure	Not clear	As shown	Alt preferred	Emoticons	Cartoons	Either	PS 10	PS 5	PS 3	Uable to say	v easy	Easy	Alright	Hard	V hard	Last night	Afternoon	*Today*	Clear	Unclear	2	10	15	*Days*	1	6	Last week	*Week*	1 month	1year	*Month*	*Year*
1	1					See Comments	1	1	1	1	1			See Comments	1		1			1				1					1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
2		1					1	1	1	1	1				1		1			1					1				1	1	1			1	1	1	1	1			1	1		1		
3	1						1	1	1	1	1				1		1			1				1					1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
4		1					1	1	1	1	1				1		1				1				1				1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
5	1						1	1	1	1	1				1		1			1				1					1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
6		1					1	1	1	1	1				1		1			1	1				1				1	1	x	1		1	1		1	1	1	1	1	1			
7	1						1	1	1	1	1				1		1			1				1					1	1	x	1		1	1	1	1	1	1	1	1	1		1	x
8		1					1	1	1	1	1				1		1			1					1				1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
9		1					1	1	1	1	1				1		1			1				1					1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
10	1						1	1	1	1	1				1		1			1		1		1					1	1	1	1		1	1	1	1	1	1	x	1	1	x	1	x
13		1					1	1	1	1	1				1		1			1				1					1	1	1	1		1	1	1	1	1	1	1	1	1	1	1	1
	5	6					11	11	11		11				11		11			10	2	1		7	4				11	11	9	10		11	11	10	11	11	10	9	11	11	8	10	7
	45%	55%					100%	100%	100%		100%				100%		100%			91%	18%	9%		64%	36%				100%	100%	82%	91%		100%	100%	91%	100%	100%	91%	82%	100%	100%	73%	91%	64%

Appendix D20. Study 3 Beta-testing indigenous elderly people: Questionnaire for testing images

(p.1)

Study 3 - Beta Testing Images: Semi-structured Interview Questions: Elderly English Participants December 2011

Set the scenario: As we discussed, these pictures are for *Pain Screening and assessment and Medication Instructions and symptoms*, to help patients and healthcare staff who might have difficulty communicating for different reasons.

I would like to understand whether you find these images and labels clear and helpful and, if not, what we might do to improve them and whether anything is missing that you might wish to add. There are no right or wrong answers. *(Take a picture if consented, and again reassure participant names will not be used and the picture will form part of a group picture.)*

Put the recorder on. Thank you very much for giving me some time today__(Name)__.

Make notes to accompany recording: **Gender:** M F **Ask age group:** 55-64 65-74 75–84 85-94 95+

1. *(Display 'Where is the pain')* Staff want to first know if we have pain. These images of the body are labelled in English to help patients point out where they have pain. **Please give me your views on the following.**

   A) How clear do you find these images and labels? B) Is there any difficulty in using them to point out where the pain is? C) Is anything missing? D) Whether or not these might be helpful?

   If any problem: What might we do to improve them? (Any other Comment)

2. *(Display 'Pain Score 10')* Staff then wish to know how bad the pain is. *(Are you familiar with this type of image? If not, explain these are emoticons and used to express feelings.)* These emoticons try to show different levels of pain on a scale of 1 to 10, where zero is 'no pain', 1 is a little pain and 10 is unbearable pain.

   A) How clearly do these images express these levels of pain? *If any problem: What might we do to improve them?* ***A doctor pointed out 'unbearable' needs improving – what do you think?***

   B) Would you have any difficulty using this?

   C) *(Display 'Pain Score 5' and 'Pain Score 3' alongside 'Pain Score 10')* **We have the same design presented on scales of 5 and 3; please tell me which design you prefer and the reason for your choice?** *(Any comment)*

3. *(Display 'How long have you had pain')*

   A) *(Point to images of morning, afternoon, evening, night)* **What do feel about these images to help point to the time of day the problem occurred?** (Prompt: Are they clear? If not: What would you like to alter?)

   B) *(Point to numbers for days weeks month etc)* These numbers show days, weeks and a month. **Do you feel all these numbers are needed, considering there are duplications here?** (If not: **What would you suggest?)**

4. **What do you feel about these images for *Right*, *Wrong* and *I don't know*?**

Beta-testing indigenous elderly: Questionnaire (p.2)

5. *(Display 'Types of pain')* **a)** This lists the types of pain patients can have.

   A) Please tell me what you feel about using such a list?

   B) These images illustrate some types of pain. **What do you feel about these images – are any of them unclear?** *(If yes)* **How can I improve this?** *Is anything missing?*

6. *(Display 'Symptoms')* These images represent symptoms patients might suffer from and are alphabetically arranged. They are to help patients point out their trouble. **Do you find any images are unclear?** *(If yes: What do you suggest?)* **What do you feel about adding** *Breathlessness***?** *Is anything else missing?*

7. *(Display 'Actions & Needs')* These images represent actions the staff might request of patients and also some things patients might ask for, like medicine or help to get to the toilet. **Do you find any images are unclear?** *(If yes: What do you suggest?* **What do you feel about adding** *Take a deep breath & breathe out slowly* **and** *Put your tongue out and say ahhh***?** *Is anything missing?*

8. *(Display Medication label and list)* This label and list are to help people remember to take their medication correctly.

   A) How clear do you find this image – the 2 and the cross (label)**?** (Does participant recognise '2' under *morning* and 'cross' under *night*. **And the list?** *(Any Comment)*

   B) This cross and this car mean don't drive whilst taking this medication. **Would you find a page showing things to avoid might be helpful?**

9. **Do you feel pictures are helpful in explaining?**

10. We have looked at 3 kinds of images today: emoticons, cartoons and photographs. **Do you have any preferences, likes or dislikes ?**

11. **Is there anything else you would like to comment on?** **Thank you very much for your time.**

Appendix D21.Study 3 beta-testing indigenous elderly: sample of data analysis

Responses are grouped by question and ordered by participant's reference

Appendix D22.

BETA TESTING CLARITY OF IMAGES - INDIGENOUS ELDERLY, December 2011

RESPONSES GROUPED BY QUESTIONS, by participant's reference.

(Participants 1, 2,3 hearing impaired, 2 profoundly so.
6 could not tell brown from red, and had difficulty with green.)

Q1. Labels on figures: clarity, difficulty, missing, helpfulness

1: "Shows everything. Very easy; very helpful. What I can see here it's all clear."
2: It's alright. Yes (it's clear)
3: Yes helpful.
4: Clear and easy
5: Very clear, straightforward, chest, breast.
6: That's good - a bit of hair (on the head)
7: Understand them. Yes, the can point out, reasonably helpful.
8: Perfectly clear. No difficulty (using it). Can't think off-hand (anything missing). No, they're not helpful, the doctor knows about it – the doctor should know about it.
9: Very clear. No difficulty, nothing missing. Yes (they would be helpful). Need something in the heart area – symbol of the heart (similar to EMC participant's response!)
10: Very clear, No difficulty or anything missing. I think so (helpfulness)

Q2. Pain Score: clarity, difficulty, PS preference

1: "Very handy to use. I have been in unbearable pain. I agree with the doctor, unbearable (is screaming) the words are very good – you haven't missed anything." 7 should be 'fairly bad' not bad, bad= 8. PS5 is easier need a marker for fairly bad.
2: Alright, can use it, likes PS5 (didn't understand too well, felt her family would tell the doctor)
3: Has a 'job walking'. Pain score is easy and clear. Prefers PS5, Covers more than PS10 (?).
4: Emoticons are good – agree with doctor 10 should be shouting with pain. The images covered all aspects of the amounts of pain. PS10 or any of them, PS5 fine, and PS3 helpful.
5: Unbearable 10, yes , mouth open square. Bad (7) looks worried, swap image 9 to 7 and current image 10 to 9, and change 10 to square mouth. Like PS3.
6: PS10 labels are satisfactory, perfectly explanatory. 10 is not really unbearable. Prefer PS10 – repetition from medicinal programmes.
7: Easy to use. I would have thought so. Like PS10 to explain.
8: Yes, understand. Pick it out perfectly alright. PS10 is fine.
9: Really do find it clear, No difficulty, Happy with PS10.
10: Very good clarity. No difficulty, I think PS10.

Q3: Periods of day and numbers to explain when one became ill:

1: *"I wouldn't use afternoon, there is no need for afternoon. The images are clear; no change, that's OK."* morning is fine. Images are clear – no change, that's OK. Numbers: 'Days' is sufficiently clear [i.e. one set of numbers]
2: Liked morning (related figures to her routines in the morning).
3,4,8: All the images were clear.
5: Month is sufficient, need numbers rather than and day of the week.
6: Better with a calendar, everybody relates to a calendar.
7: I understand and the Calendar is fine, bigger print is easier to read on the calendar.

Study 3 Beta-testing NHS Staff: Interview questions (p.1)

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November-December 2011

STUDY 3: Beta Testing Questions for NHS Staff

Purpose: To test the phonetics element of Prototype 2: the flow of questions/ sections of Pain & Medication Questions used by Staff in conjunction with the images for patients. i.e. fonts (types, colours, sizes), paragraph and section layouts and the labelling of images. Also, to convey some of the research results from the EMC alpha and beta testing to help build confidence in preparation for testing the 3rd prototype.

Participants: 6 English-speaking NHS Staff from different departments, roles and Trusts who do not speak Hindi, Urdu or Punjabi. (Structured interview, open and closed questions, data recorded.)

Introduction: Thank you very much for seeing me __*(NAME)*_ You will recollect that the purpose of my study is how we might facilitate a greater degree of direct communication between staff and patients who have no or little English and/or literacy – and also how we might encourage such patients to begin learning English. I have focused on people from the Indian Subcontinent and selected Hindi because many of people who speak Punjabi, Gujarati or Urdu often understand or speak Hindi.

The 2nd Prototypes on Pain Assessment and Medication have been adjusted to include the views of staff from the 1st interviews. The 2nd Prototypes of the related images for patients, have been organised to follow the questions and have been twice tested with male and female participants and re-designed.

The phonetics for staff are being tested with 6 staff and a small group of indigenous English participants who do not speak Hindi, to refine pronunciations in order to alleviate concerns raised by some staff on this point. I would like to test the phonetics with you today and to review the 2nd prototype content, your preferences on fonts, etc and how the images for patients compliments the questions.

SECTION 1: Questions on Pain & Medication *(Display the questions on Pain)*

1. **a) Would you please read aloud the phonetics – there are no right or wrong answers – I will note any words that need further refining.** *(Make a list of those words that do not sound correct.)*

   b) I would like to work down this list, tell you how each word should sound and have your suggestions on how these might be spelled in English to make the sound more appropriate. *(Go down the list, write out suggestions, circle the one decided upon.)*

2. *(Display 'Section 1 Alternatives')* The phonetics used at present have been simplified to use a dash (-) to denote a minor pause *(point out)* and a double letter to denote emphasis, however, dictionaries use these other characters for differing emphasis. **What do you feel should be used?**

3. **Key words in English and associated meanings in Hindi are either underlined or in italics to denote they are similar in meaning – what do you feel about this?**

4. **The pre-amble is structured in 3 parts** *(point out section)*:

   - Ascertains whether the patient understands Hindi and, if so, a greeting;
   - Sets the scene: that you do not know Hindi, will use this paper to ask some questions and would like small replies and for them to use whatever English they know;
   - Explains what you wish to find out: Whether they have pain etc. or any other difficulties and to encourage them to use the images to help explain to you.

   4a) What do you feel about this? **4b) Is anything missing?**

Beta-testing NHS Staff: Interview questions (p.2)

5. **5.1) The questions on Pain are in 8 sections, what do you feel about the following on a scale of 1 to 5 where 1 = very unhelpful and 5 = very helpful** *(Prompts: Please explain the reason for your response. What would you prefer?):*
   a. **Clarity?**
   b. **Flow of questions?**
   c. **Navigation?**
   d. **Response checkers?** *(Point out: On page 1 these are arranged in logical categories - on page 2 they are arranged alphabetically in Hindi phonetics to more easily identify the response received.)*
   e. **Complex English terms** have simpler English text alongside which have been used in the phonetics because sometimes there are no direct equivalents. **Do you feel any require altering?**

   5.2) These terms in red *(point out)* **appear to be duplicate in meaning or quite esoteric with no ready equivalent in colloquial Hindi – do you feel these can be removed?**
6. **Is anything else unclear?**
7. **Is anything else missing?**
8. **Is anything extraneous?**

SECTION 2: Fonts *(Display 'Section 2 Alternatives' appropriate to each question.)*

1. Black has been used for English and this blue for Hindi – these are other alternatives or you may make a suggestion. **What would you prefer taking into account: reading in different lighting conditions, some colours do not copy well and red denotes danger by the EMC study group.**
2. This is the current bold/ not bold format employed, other formats could be these or any other suggestions. **What would you prefer?** *(Prompt: Reason for response)*
9. Arial 10.5 is the current font type and size, please view this table of other fonts. **What would you prefer taking into account different lighting conditions for staff, tiredness and our vision alters with aging?** *(Prompt: Reason for response)*
3. The types of pain and difficulties are in list format, but could by arranged like this, (show 4.1-4.3). **What would you prefer?**

SECTION 3: Images *(Display 'Prototype 2 Images' appropriate to each question.)*

1. *(Show body with labels)* **Ethnic participants asked for labels in English for parts of the body:**

a) What do you feel about this taking into account we wish to be inclusive of other patient groups (e.g. those with poor vision, suffering from stroke, the elderly)**?**

b) What do you feel about having labels only in English?

2. *(Show pain score 10 using emoticons)* Ethnic participants indicated the pain score of 10 was fine compared to that of 5 or 3 – they particularly found the words below the numbers meaningful, understandable and helpful. **What do you feel about this?**

3. These images and numbers helped ethnic participants to indicate when they became ill and for how long they have had a problem. Because they know their address (i.e. house number) and to read a clock all can count from 1 to 10-12; and many, more than this. **You have the Hindi equivalent for days, weeks, month and year on your response checker: what do you feel about co-relating this?**

4. *(Review symbols of yes-no-I don't know, images of Kind of pain, Symptoms/ Side effects and Requests and needs).* **a) What do you feel about co-relating these with the information you need to elicit?**

b) Is anything missing, e.g. would you need breathlessness? Thank you very much for your time.

Appendix D23. Study 3 Beta-testing NHS Staff: Response capture form (p.1)

Study 3: Design concept development

RESPONSE FORM: Prototype 2 - Pain, Medication & Images
Beta Testing NHS Participants, November 2011 (Semi-structured, data recorded.)

Participant_____ Ref: _____ Date:_____

SECTION 1 - Questions on Pain and Medication *1. a & b: Create separate list of words*

Questions	Responses & comments				
2. Preferred phonetics presentation	1 (current)	2	3	4	
Comment					
3. Key words in English & Hindi underlined & italics	Very helpful	Helpful	Alright	Not helpful	A hindrance
Comment					
4. a) View of preamble in 3 parts	Very helpful	Helpful	Alright	Not helpful	A hindrance
Comment					
b) Is anything missing?					
5. View of Questions in 8 parts:	5 V helpful	4 Helpful	3 Alright	2 Not helpful	1 A hindrance
5.1 a) Clarity	5	4	3	2	1
Comment					
5.11b) Flow	5	4	3	2	1
Comment					
1c) Navigation	5	4	3	2	1
Comment					
1d) Response checkers	5	4	3	2	1
Comment					
1e) Testing phonetics with staff and other English participants	5	4	3	2	1
Comment					
1f) Simpler English explanations	5	4	3	2	1
Any require altering					
5.2 a) Duplications to remove?	Crushing	Nagging	Gnawing		
Comment					

Study 3 Beta-testing NHS Staff: Response capture form (p.2)

6. Anything unclear?
7. Anything missing?
8. Anything extraneous?
9. Form for department to record patient's responses?

SECTION 2 - Fonts *(Display 'Section 2 Alternatives' appropriate to each question.)*

1. Font colour preferred: Black +	1.1 Current	1.2 Blue2	1.3 Blue3	1.4 a	1.4b	1.4c
Other:						
2. Bold format preferred	2.1a Current	2.1b	2.1c Reverse	2.2	2.3	2.4a	2.4b
2.5 Other preference/ suggestions:						
3. Font type & size preferred: *(Current: Arial 10.5)*						
4. Information arrangement preferred		List	Paragraph			
Comment/ Other:						

SECTION 3 - Images *(Display "Prototype 2 Images' appropriate to each question.)*

1a. Body parts labelled:
1b. Labels in English ONLY
2. Pain Score 10 with words (and any comment on PS 5 and PS 3 designs)
3. Co-relating response of days/ weeks/ month/ year with response checker Hindi
4a). Co-relating images with response checkers *(yes-no-I don't know, images of Kind of pain, Symptoms/ Side effects and Requests and needs)*
4b). Anything missing? e.g. would you need breathlessness? 4c). Would the labels come useful for your patients?
5 Any other comment on, critique or suggest that we have not discussed? Thank you very much for your time.

Appendix D24. Beta-testing Staff: English-Hindi Pain-prototype-2 alternative design elements

(p.1/4): Phonetics

PROTOTYPE 2: NHS Staff

Alternative colours and font preferences

To facilitate ease of reading under different lighting conditions.

SECTION 1

2. **Phonetics representation examples:** The phonetics design has been simplified to utilise only a dash (-) to denote a minor pause *(point out)*. Dictionaries use other scripts such as apostrophe ('), underline (_), grave (è), superscripts, etc. for differing emphasis. **What do you feel should be used?**

1 Current	**Dash** (– used to denote a minor pause for an even pronunciation of syllables). Double vowel to indicate emphasis. Incorporates how English words are generally pronounced. e.g. Can you *sit* up straight aap see-dhay *bayt* sak-thay hai? Can you stand khar-day ho sak-thay hai? Can you walk chal/ *thoo-rr* sak-thay hai? Do you aap ko have pain every day darad har-roze hai? Does the pain become worse darad zya-da hotha hai when you eat *food* jab aap *khana* kha-thay hai?		
2. Doabia HS (1979). Sacred *Sukhmani*. 17th ed. Amritsar, India: Singh Bros	**Key** Emphasis: ā ē ūī Small accent: ụ ṇ ḍ ọ į		
	name (p.10)	nām	naam
	sad (p.12)	dukhi	du-khi
3 McGregor RS (1972). *Outline of Hindi Grammar with exercises*. 2nd ed. Oxford University Press (pp.xxviii-xxxiii,5,15,54)	yes *(pp.xxviii-xxxiii)*	hām	haa (sound is haa°)
	sad/miserable	duhkh	du-khi
	meaning *(p.54)*	matlab	muth-lab
	greeting *(p.15)*	namaste	namas-thay
	no *(p.5)*	nahīm	nahi
	where	kahām	ka-ha
	two	do	dho
	three	tīn	teen
	water	pānī	pa-ni
	hour	ghantā	ghanta
	week	haftā	haf-tha
	today	āj	aaj
4 Fowler HW; Fowler FG eds. (1964) Pronunciation. In: *The Concise Oxford Dictionary of Current English* 5th ed. Oxford: Clarendon Press. (*pp.xii-xiii*)	**Phonetic Scheme** ā ē ī ō ū ōō ă ĕ ĭ ŏ ŭ ār ēr īr ōr ūr âr êr e.g. cā 'rrẎ lōc'al cōō'lẎ **Accent**: main accent is ' at the end of a stressed syllable but positioning is arbitrary depending on the required pronunciation		

(MS Word 2007, Symbols, Tahoma subsets)

Beta-testing Staff: English-Hindi Pain-prototype-2 Alternative design elements

(p.2): Font colours and bold formats (beta-testing staff)

SECTION 2

1. FONT COLOURS *(Explain: Red denotes danger for ethnic participants; If photocopying: Red, orange, green, yellow can photocopy poorly in B&W; different blues copy as pale grey, hard to read.)*

1.1 Current	black and blue1
1.2 Blue2	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai - how bad is it kithna bura hai - when it started kab shuru hua - how many days you've had it ya kithnay din say hai?
1.3 Blue3	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai - how bad is it kithna bura hai - when it started kab shuru hua - how many days you've had it ya kithnay din say hai?
1.4 Other preferences/ suggestions? (Some examples)	1.4a: I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai? 1.4b: I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai? 1.4c: I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai? 1.4d. Black only – **See 2.4**

2. BOLD FORMATS

2.1a Current	Questions and phonetics normal	**Headings** and **key, section questions** are in bold. I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai?
2.1b Blue1	Phonetics bold	I wish to learn **hum nay patha karna hai**, if you have pain **agar aap ko darad hai**. If yes, where is it ***agar haa*, tho kidhar hai?**
2.1c Reverse	Questions bold	**I wish to learn** hum nay patha karna hai, **if you have pain** agar aap ko darad hai. **If yes, where is it** *agar haa*, tho kidhar hai **- how bad is it** kithna bura hai?
2.2 Blue2	Phonetics bold	I wish to learn **hum nay patha karna hai**, if you have pain agar **aap ko darad hai**. If yes, where is it ***agar haa*, tho kidhar hai** - how bad is it **kithna bura hai?**
2.3 Blue3	Phonetics bold	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it *agar haa*, tho kidhar hai?
2.4a Black	Phonetics bold	I wish to learn **hum nay patha karna hai**, if you have pain **agar aap ko darad hai**. If yes, where is it ***agar haa*, tho kidhar hai?**
2.4b Black	Questions bold	**I wish to learn** hum nay patha karna hai, **if you have pain** agar aap ko darad hai. **If yes, where is it** *agar haa*, tho kidhar hai **- how bad is it** kithna bura hai?
2.5 Other preferences/ suggestions?		

Beta-testing Staff: English-Hindi Pain-prototype-2, alternative design elements

(p.3) Font types/sizes (beta-testing staff)

3. FONT TYPE and SIZE

	10	11	12	FONT
3.1	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Arial 10.5 Currently
3.2	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Arial Narrow
3.3	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Trebuchet
3.4	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Verdana
3.5	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Calibri
3.6	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Comic sans
3.7	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	I wish to learn hum nay patha karna hai, if you have pain agar aap ko darad hai. If yes, where is it agar haa, tho kidhar hai?	Tahoma
3.8	Other preference/ suggestions			

Beta-testing Staff: English-Hindi Pain-prototype-2 Alternative design elements (p.4): arrangement of information (beta-testing staff)

4. ARRANGEMENT OF INFORMATION

4.1 Current: List

Aching like a headache sirr darad jay-say?
Burning jalan hai?
Crushing great pain ba-huth bura darad
Penetrating deep pain geyhera darad?
Pins & Needles goes to sleep so jaatha hai?
Pricking - choob-tha like needles su-wi jay-say?
Sharp tayz darad?
Shooting appears then goes aa kar chaley jaatha hai?
Stabbing sharp pain, comes-goes teyz darad aatha-jaatha hai?
Tender painful if touched haath laga-nay say darad?
Throbbing comes-goes rapidly all the time dadap-tha rahitha?

4.2 Paragraph

Aching like a headache sirr darad jay-say **Burning** - jalan hai? **Crushing -** great pain ba-huth bura darad **Penetrating -** deep pain geyhera darad? **Pins & Needles -** goes to sleep so jaatha hai? **Pricking -** choob-tha like needles su-wi jay-say? **Sharp** - tayz darad? **Shooting** - appears then goes aa kar haley jaatha hai? **Stabbing -** sharp pain, comes-goes teyz darad aatha-jaatha hai? **Tender** - painful if touched haath laga-nay say darad? **Throbbing -** comes-goes rapidly all the time dadap-tha rahitha?

4.3: Any other preference/ suggestions

Appendix D25. Beta-testing Staff and Indigenous adults: Sample of data capture on correcting phonetics

Phonetics were listed in and the correct sound discussed with alternative spellings, the circles denote participants preferences.

Appendix D26. Study 3 Beta-testing Staff and indigenous adults: Dasta analysis

D26.1: Phonetics testing analysis (p1)

The questions-prototype was iteratively updated with the new suggestions between interviews and tested, and fewer words were pronounced incorrectly as research progressed.

Study 3 Beta Testing Prototype 2-v1 Pain screening & assessement - NHS Staff and Indigenous Participants

Alternative to phonetics spellings suggested by participants

	Background	Lay	GP	Physio	Pharma	Lay	Lay	Param	WardSis	A&E docs	
	Gender	F	M	M	M	M	F	M	F	M	M
		Brit	Iran	Brit	Brit	Brit	Brit	Brit	Brit	German	Brit
Phonetics	Refs:	10	1	2	6	8	9	5	4	3	7
Hindi Original	**English**		Least trouble								
aap	you	ah-p		ahp							
agar	if				ug-gar					ugh-gar	
ar-aam	rest			ar-raam							
aur	and	or									
bayt	sit										bait
bolna	speak						bowl-na				
bukh-aar	temperature/fever						bukh-arr	book-haarr			
bura	bad	-		bu-ra							
chaley	goes	cha-lay									
choonay	touch	choon-nay									
cumm	less	come		cumm		come	come				
dadaptha	throb/ thumping			da-daptha		dadap-tha					
dheeray	slowly					**dheeray**					
dikha-o	show							**dikha-o**			
dukhi	miserable, sad	duk-khi							dukhee		
dus	ten	duss (dass)									
gey-hara	deep										ge-hara
ghanta	hour			**ghanta**							
gin	count			(tough)							
gir	fall/falling	ghir							girr		
haa^{n} ^	yes	haa									
hai	is	-		ha-i		heh	heh			heh	
ha-maysha	always			hum-maysha							
hua	happen						**hua**				
hum	me, I	humm		**hum**		**hum**	**hum**				humm
kahi	where			ka-hee							
karnay	doing (this)	-		karr-nay				karr-nay			
karthey	do	kar-thay				(kar-nay)					
ke (saath)	with					kay					
khana	food	khan-na									
kha-thay	eating				**kha-thay**	**kha-thay**					

Study 3 Beta-testing staff and indigenous adults: Phonetics testing analysis (p2)

		Cathy	Dr S	Adam	Scott	Martin	Zoe	Michael	Joy	Haik	Dam
kha-thay	eating				**kha-thay**	**kha-thay**					
khur-chi	rash/ scratching				khurr-chi	khoor-chi	khoor-chi	khoorr-chi	khoor-chee		
kidhar *(replaced by kahi)*		*kid-har*									
kya	what	ki-a					ki-ya				
jaatha	goes	ha-tha									
muthlab	means			mutt-lab	mutt-lab						
nah-i	no								**nah-i**		
pani	water								panee		
patha	know			pata				pat-a			
pathla	thin			path-la							
pi-sharp	pee/ urinate								pee-sharp		
poo-chayn-gay	will ask						pu-chayn-gay				
raath	night			ra-th							raath
rahey	continous	ra-hay									
rahitha	continuously	rahi-tha									
roze	daily						rowz				rows
saath	with					**saath**					
sakthey	can you	sak-thay									
soos-ti	tiredness/lassitude										soos-thi
su-jan	swelling										sujan
thakath	strength			thaa-kat			tha-kat	taa-kat			
thaka-vat	exhaustion							thakaa-vat			
thak-leef	difficulty					tak-leef					
thasveer	pictures				tas-veer						
thoor	walk	too-rr		too-rr				toor			
ulti	yomiting				ool-ti						
zyada	a lot						zia-da				

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Additional comments/preferences grouped by Question number & ordered by staff reference.

(**Legend**. References: 1 = GP, 2= Senior physio, 3=A&E doc, 4= Ward sister Stroke & Elderly care, 5= Paramedic, 6= Snr Pharmacy technician, 7= A&E doctor. Blue text=researchers comment; staff were pointing to images.)

Section-1. Qs on Pain & Medication----------

S1-Q2. Preferred phonetics presentation:

1: **Put in bullets.**

2: What you've done already makes it easy to read and will make it easy to pronounce, as it is; dictionary terms are not user-friendly.

5: **Keep to current method**, not the dictionary method.

7: (Current method, not dictionary) Prefer no hyphens or minimise hyphens.

S1-Q3. Underlining/ italics assoc. English & Hindi words:

2: Want these (; need a legend/key explaining the underling or italics.

6: Really helpful.

S1-Q4a. Preamble

1: Alter to: 'I don't know much Hindi, I am going to use this paper to help us'; emphasise very little [Hindi]. Make a larger space for preamble, last para – remove – use full stops and sentence case. (moved from S1-Q5.1a)

2: It's a nice way of making a person understand, but some words are not correctly pronounced.

4: Happy with preamble, do not particularly require bullet points.

5: Good.

7: Helpful. But shorten it to: I am speaking slowly, OK *teekh hai*?. Do you understand *samaj aya*? Speak as much English as you know. Learn English.

S1-Q4b. Anything missing:

2: No, I think that's very self-explanatory. Definitely the only other thing is layout – you may use a picture to help.

4: No

6: **Shooting pain: the importantthing is it's a moving pain. Throbbing is a pulsing pain.**

7: Section 6 Pain: Medication: to Which medication? *konsi dava* add paracetamol?

S1-Q5 View of sections:

S1-Q5.1a. Clarity:

2: Covers all the points and easy to ask and clear to go through; a logical flow.

3: Everything is straightforward (answered same to all of aid)

4: It is clear to me

S1-Q5.1b. Flow:

2: Links together well

S1-Q5.1c. Navigation:

2: Yes, definitely (very easy, selected 5), clear headings, and sections are separated by dividing lines. The start is concise and to the point.

7: Comfortable.

S1-Q5.1d. Response checkers:

1, 3, 4, 5: Fine

2: Page 2 is organised really well.

6: Excellent

7: No need

S1-Q5.1e.Testing phonetics with staff and indigenous people:

1: Good idea

2: That's great; the only way to know for sure (pronunciation is correct); (gives) more confidence. Definitely, and people [staff] will like feedback

D26.3: Study 3 Beta-testing staff: Sample of data reduced by question, step 2

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Additional comments/preferences reduced by question (Step 2).

(**Legend**. Blue text=researchers comments. **Pink= adjustments made**. NFIP= Notes From Iterative Prototypes which were edited on paper.)

Section-1. Qs on Pain & Medication

S1-Q2. Preferred phonetics presentation: Unanimous view **"Keep to current method"** and not the dictionary method. *"What you've done already makes it easy to read and will make it easy to pronounce, as it is; dictionary terms are not user-friendly."* (Alter se to say and ah-p to ahp and se to say)

S1-Q3. Underlining/ italics assoc. English & Hindi words: "Really helpful" but need a legend/key explaining the underling or italics.

S1-Q4a. Preamble: Good. Helpful. Happy with preamble, do not particularly require bullet points.
"It's a nice way of making a person understand. I think that's very self-explanatory. The only other thing is layout: **Add bullets** and put "you may use these pictures to help" in **the next paragraph** (so it stands out).
Alter to: 'I don't know much Hindi, I am going to use this paper to help us'; **emphasise very little [Hindi]. Make a larger space for preamble, use full stops and sentence case.**
NFIP: After OK **add 'Do you understand?'**

S1-Q4b. Anything missing: To communicate shooting pain: **"the important thing is it's a moving pain"** and **"throbbing is a pulsing pain"**.
NFIP (pain): Q5: Shooting pain: suddenly appears and disappears. Stabbing pain **adjust to a VERY sharp pain. Add 'palpitations'**. Q6 the new responses (effect of medication) needs to stand out more (agreed **a box** would be fine). Q7 Urination: modify to **'very' little pee**. Q8 **add 'allergy'**.

S1-Q5.1a. Clarity: Covers all the points and easy to ask and clear to go through; a logical flow. Everything is straightforward (answered same to all of aid). It is clear to me
NFIP: (Add display images prompt to Qs.3,5,6)

S1-Q5.1b. Flow: "Links together well"
NFIP: **Move: 'Is there pain anywhere else' from Q2 pain assessment to Q1.**

S1-Q5.1c. Navigation: "Yes, definitely (very easy, selected 5), clear headings, and sections are separated by dividing lines. The start is concise and to the point." Comfortable.

S1-Q5.1d. Response checkers: Majority: Fine. Page 2 is organised really well. Excellent. No need.

S1-Q5.1e. Testing phonetics with staff and indigenous people:
Good idea. Fine. That's great; the only way to know for sure (pronunciation is correct); (gives) more confidence. Definitely, and people [staff] will like feedback.

S1-Q5.1f. Simpler English explanations: Helpful to some extent. That's good for clarity, clarity of information back. Yes.

S1-Q5.2a. Removing duplications : Crushing: can be helpful. Not important; these [current list] are the ones used most often. **Crushing is like a heavy weight on the chest.** Nagging could be 'irritating', a constant unremitting pain (in Kind of pain list Q5).

S1-Q6. Anything unclear? Majority: No. Medication instructions: **All tablets have to be with a drink, you don't need the drink (image). It's the food (that's important): with or after food, a long time after, like 2 hours after, on an empty stomach. That's hard to explain even to English speaking patients: empty stomach = 2 hours before food; whereas after food= with food.** Picture of toilet too often. (explained reason

D26.4: Study 3 Beta-testing staff: Questionaire Sections anlaysis

Responsses to phonetics and design elements.

Analysis of staff responses: Beta-testing

Section 1 (Legend: 5=V helpful, 4=Helpful)

Ref		Q2 Phonetcs	Q3 Underl-Italics		Q4 Preamble		Q5a Clarity		5b Flow		5c Nav		5d Response Ch		5e PhonTest		5f simple English		6 unclear		7. Missing		8.Form
		1-current	5	4	5	4	5	4	5	4	5	4	5	4	5	4	5	4	Y	N	Y	N	N
1	Sol	1		1		1		1		1		1	1		1			1		1		1	1
2	Ad	1	1		1			1	1		1			1	1		1			1		1	1
3	Hai	1		1		1		1		1		1		1		1		1		1		1	1
4	Jo	1		1	1		1		1		1		1		1		1			1		1	1
5	Ia	1	1		1		1		1		1		1		1		1			1		1	1
6	Sco	1	1		1			1	1		1		1			1		1		1		1	1
7	Dam	1		1		1		1		1		1		1		1	1			1		1	1
		7	3	4	4	3	2	5	4	3	4	3	4	3	4	3	4	3	7		7		7
		100%	43%	57%	57%	43%	29%	71%	57%	43%	57%	43%	57%	43%	57%	43%	57%	43%	100%		100%		100%

Analysis of staff responses: Beta-testing

		Section 2								**Section 3**					
Ref		1.Font col		2.Bold		3. Font size		4.InfoArrange		1a. Body labels		1b.Eng only		2.PS10	PS5
		1	4a	a.current	b	Current	11	List	Para	Y	N	5	4		
1	Sol	1		1		1		1		1		1		1	
2	Ad	1		1	1	1		1		1		1		1	
3	Hai	1		1		1		1		1		1		1	
4	Jo	1		1			1	1		1		1		1	1
5	Ia	1		1		1		1		1		1		1	
6	Sco		1	1		1		1			1			1	1
7	Dam	1		1		1		1		1		1		1	
		6	1	7	1	6	1	7		6	1	6		7	2
		86%	14%	100%	14%	86%	14%	100%		86%	14%	86%		100%	29%

Appendix D27. Study 3 Design upgrade: pain-prototype-3

(p.1/2) Note use of bullets and seperation of key questions.

PAIN & SYMPTOMS

Hindi, Urdu

Do you understand *a little* Hindi ahp thor-da Hindi samai-thay heh?

Greeting: Hello namas-thay, I am a nurse/ doctor mai nurse/ doctor hoo. My name is may-ra naam (NAME) heh. *What is* your name ahp ka naam ki-ya heh? (Or: Is your name ahp ka naam (NAME) heh?)

Setting the scene: I don't speak Hindi hum Hindi nahi bowl-thay heh, however laykin, with the help of this paper yay paper ki madad say I will ask you some questions hum ahp say prashan pu-chayn-gay.

- Give me small *replies* mujay cho-ta *javaab* they-na; like yes, jey-say haa no, nahi.
- Speak any English *you know* jithna Angray-zi *maloom* heh, bowl-na. OK/ alright teekh heh?
- I want to find out hum nay pata karr-na heh, *if* you have pain ug-*gar* ahp ko darad heh. *If* so, *agar* heh: Where is it kaha heh? How bad is it kithna bu-ra heh? When it started kab shuru hua? How many days its been kithnay din say heh? What kind of pain is it kai-sa darad heh? *And if there are* other difficulties *or koi or* thakleef heh.
- Give small *replies* cho-ta *javaab* they-na , - and speak slowly or dheeray bowl-na. OK teekh heh?
- Use these pictures to help in tas-veer ki madad say you show me ahp mujay di-kha sak-thay heh. OK?

1. **Have you pain?** Darad heh, pain heh? *(If No: nahi, see Section 7)*
   (If yes: haa or heh or bahuth heh a lot) Show me *where* dikha–o *kaha*.

2. **How bad is the pain** darad kithna bu-ra heh?

   Pain Score: If we count from 1 to 10 ug-garr hum ek say dass gin-thay *(show image)*
   - 1 means ek mutt-lab little pain thorda darad, 10 means dass mutt-lab unbearable saha nah-i jatha.
   - What number is your pain kithna number ah-p ka darad heh?
   - Is there pain anywhere else ka-hee or darad heh? *(If yes haa)* Where kaha? What number kithna number?

3. **When did it *start*** kabh *shu-ru* hua? *(If for a week or a few days)* When you had pain jab darad tha last week pitch-lay haf-tay.
   - *What number* was the worst pain sab say bu-ra darad *kithna number* tha?
   - What number was the *least* pain sab say come darad kithna number tha?
   - Between bad and little pain bu-ra or come darad kay beech *may* what number was the general pain aam-thor darad kithna number tha?

4. **Occurrence:** Do you feel pain constantly darad hum-maysha *mah-soos* heh?
   - **Actions**: Can you: Sit up *straight* ahp *see-dhay* bayt sak-thay heh? *Stand up* kha-day ho sak-thay heh? *Walk* chal/ too-rr sak-thay heh?
   - **Daily**: Do you have ah-p ko pain every day darad har-rowz heh?
   - **Eating**: Is the pain worse darad zia-da heh when you eat jab ahp kha-thay heh?
   - **Moving**: If you move about hil-nay say does it pain darad ho-tha heh?
   - **Night**: At night ra-th ko?
   - **Swelling**: Have you had swelling su-jan hua? (If yes, haa) Show me where dikha–o kaha
   - **Toilet**: When you go to the toilet toilet ja-naysay do you have pain ahp ko darad heh. On *passing* urine pi-sharp *kar-naysay*? On passing stools tatti *kar-naysay*?

Response checker	
Pain	**darad**
Yes	haa
No	nahi
I don't know	pata nahi / maloom nahi
1	**ek**
2	dho
3	teen
4	charr
5	panch
6	chay
7	sa-th
8	ah-tt
9	now
10	dass
12	ba-ra
15	pandra
20	beess
Hour	**ghanta**
Day	din
Week	haf-tha
Month	mahi-na
Year	saal
Today	**aaj**
Every day	har-rowz
Yesterday	kal
Tomorrow	kal-ko
Morning	**savay-ra /subhay**
Afternoon	du-pahar
Evening	shaam
Night	raath

Phase 2: Design. Helping to lower language barriers & encouraging patients to speak English. Prototype 2
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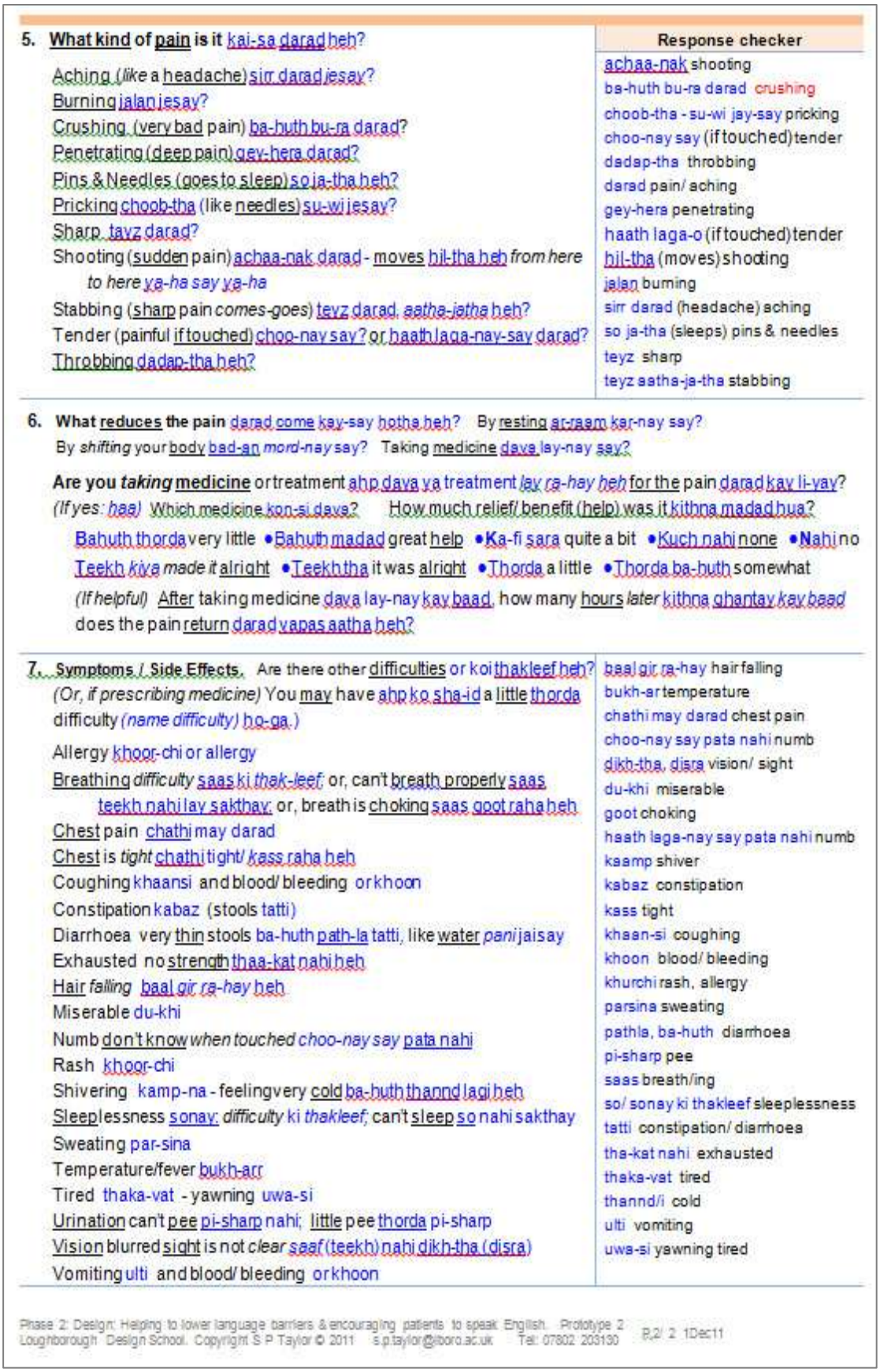
Study 3 Design upgrade: pain-prototype-2 (p.2)

Sections reduced to 7 (6 and 7 were merged for checking medication. Bolding removed except for small headings.



5. What kind of pain is it kai-sa darad heh?

Aching (*like* a headache) sirr darad *jesay*?
Burning jalan jesay?
Crushing (very bad pain) ba-huth bu-ra darad?
Penetrating (deep pain) gey-hera darad?
Pins & Needles (goes to sleep) so ja-tha heh?
Pricking choob-tha (like needles) su-wi jesay?
Sharp tayz darad?
Shooting (sudden pain) achaa-nak darad - moves hil-tha heh *from here to here* ya-ha say ya-ha
Stabbing (sharp pain *comes-goes*) teyz darad, *aatha-jatha* heh?
Tender (painful if touched) choo-nay say? or haath laga-nay-say darad?
Throbbing dadap-tha heh?

Response checker

achaa-nak shooting
ba-huth bu-ra darad crushing
choob-tha - su-wi jay-say pricking
choo-nay say (if touched) tender
dadap-tha throbbing
darad pain/ aching
gey-hera penetrating
haath laga-o (if touched) tender
hil-tha (moves) shooting
jalan burning
sirr darad (headache) aching
so ja-tha (sleeps) pins & needles
teyz sharp
teyz aatha-ja-tha stabbing

6. What reduces the pain darad come kay-say hotha heh? By resting ar-raam kar-nay say?
By *shifting* your body bad-an *mord-nay* say? Taking medicine dava lay-nay say?

Are you *taking* medicine or treatment ahp dava ya treatment *lay ra-hay heh* for the pain darad kay li-yay?
(If yes: haa) Which medicine kon-si dava? How much relief/ benefit (help) was it kithna madad hua?

Bahuth thorda very little • Bahuth madad great help • Ka-fi sara quite a bit • Kuch nahi none • Nahi no
Teekh *kiya made it* alright • Teekh tha it was alright • Thorda a little • Thorda ba-huth somewhat
(If helpful) After taking medicine dava lay-nay kay baad, how many hours *later* kithna ghantay *kay baad* does the pain return darad vapas aatha heh?

7. Symptoms / Side Effects. Are there other difficulties or koi thakleef heh?
(Or, if prescribing medicine) You may have ahp ko sha-id a little thorda difficulty *(name difficulty)* ho-ga.)

Allergy khoor-chi or allergy
Breathing *difficulty* saas ki *thak-leef;* or, can't breath properly saas teekh nahi lay sakthay; or, breath is choking saas goot raha heh
Chest pain chathi may darad
Chest is *tight* chathi tight/ *kass raha heh*
Coughing khaansi and blood/ bleeding or khoon
Constipation kabaz (stools tatti)
Diarrhoea very thin stools ba-huth path-la tatti, like water *pani* jaisay
Exhausted no strength thaa-kat nahi heh
Hair *falling* baal *gir ra-hay* heh
Miserable du-khi
Numb don't know *when touched choo-nay say* pata nahi
Rash khoor-chi
Shivering kamp-na - feeling very cold ba-huth thannd lagi heh
Sleeplessness sonay; *difficulty* ki *thakleef;* can't sleep so nahi sakthay
Sweating par-sina
Temperature/fever bukh-arr
Tired thaka-vat - yawning uwa-si
Urination can't pee pi-sharp nahi; little pee thorda pi-sharp
Vision blurred sight is not *clear* saaf (teekh) nahi dikh-tha (disra)
Vomiting ulti and blood/ bleeding or khoon

baal gir ra-hay hair falling
bukh-ar temperature
chathi may darad chest pain
choo-nay say pata nahi numb
dikh-tha, disra vision/ sight
du-khi miserable
goot choking
haath laga-nay say pata nahi numb
kaamp shiver
kabaz constipation
kass tight
khaan-si coughing
khoon blood/ bleeding
khurchi rash, allergy
parsina sweating
pathla, ba-huth diarrhoea
pi-sharp pee
saas breath/ing
so/ sonay ki thakleef sleeplessness
tatti constipation/ diarrhoea
tha-kat nahi exhausted
thaka-vat tired
thannd/i cold
ulti vomiting
uwa-si yawning tired

Phase 2: Design: Helping to lower language barriers & encouraging patients to speak English. Prototype 2
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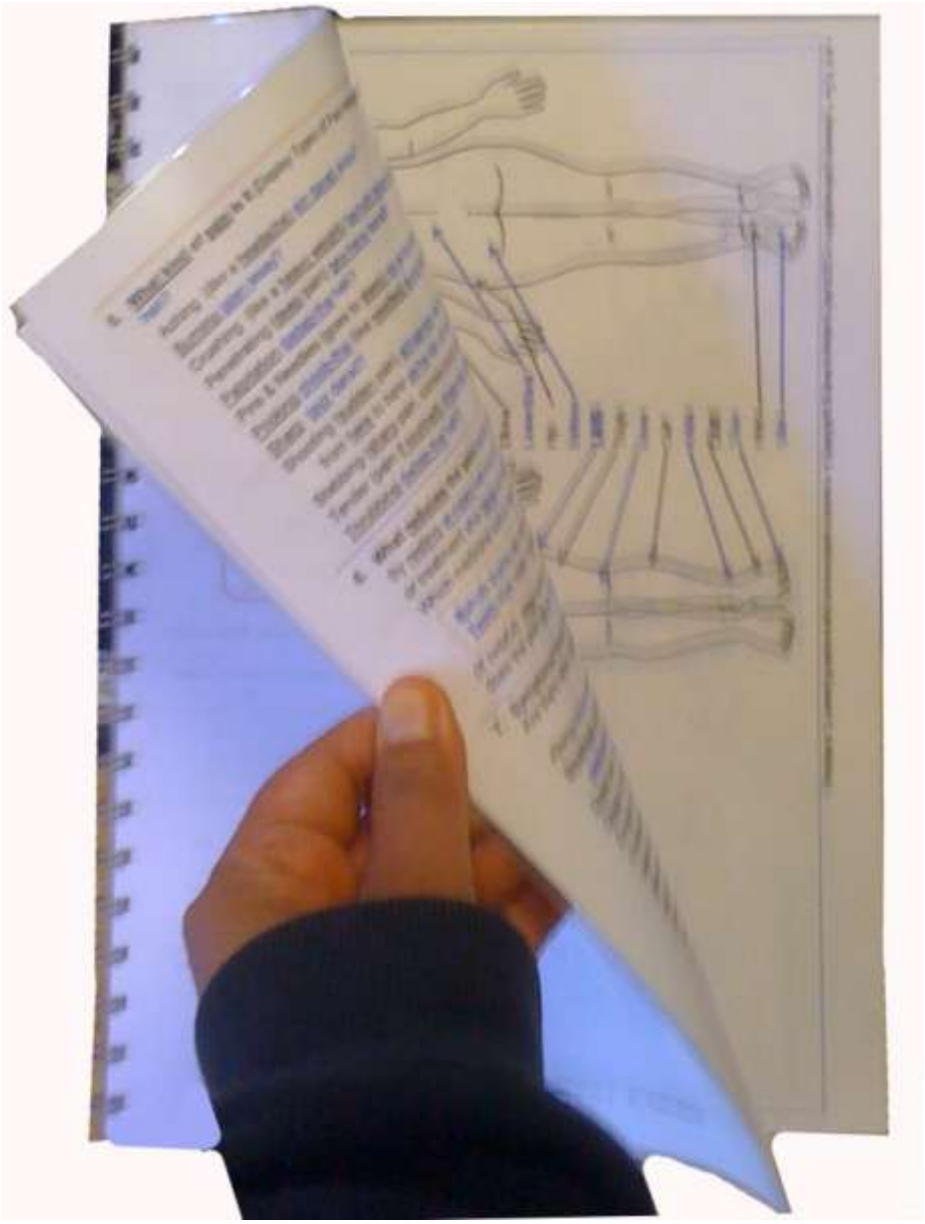
APPENDIX D: Study 3: Final-testing

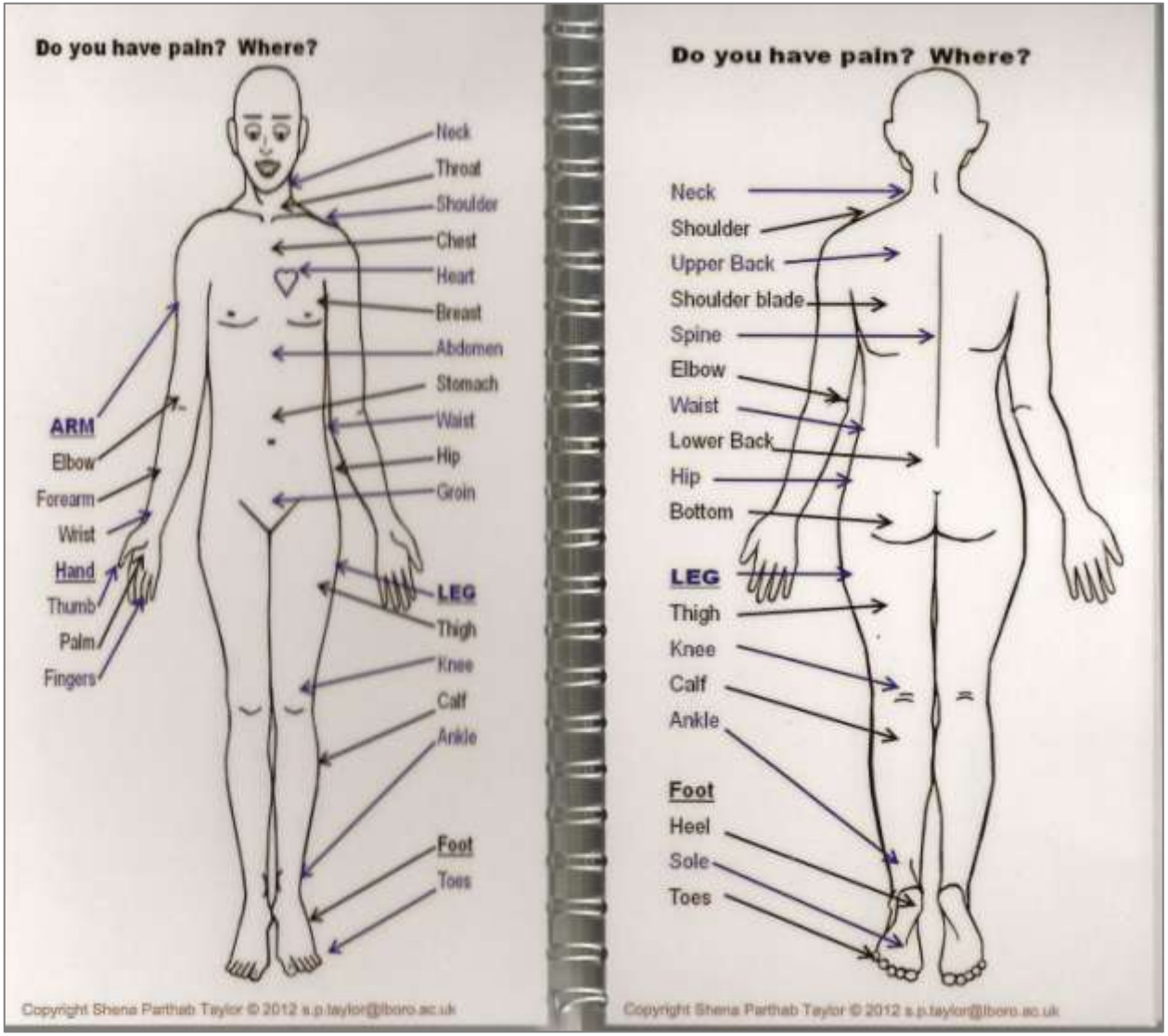
Appendix D28.Final testing: Pictorial-prototypes-v3

D28.1: Bound in A4 for testing



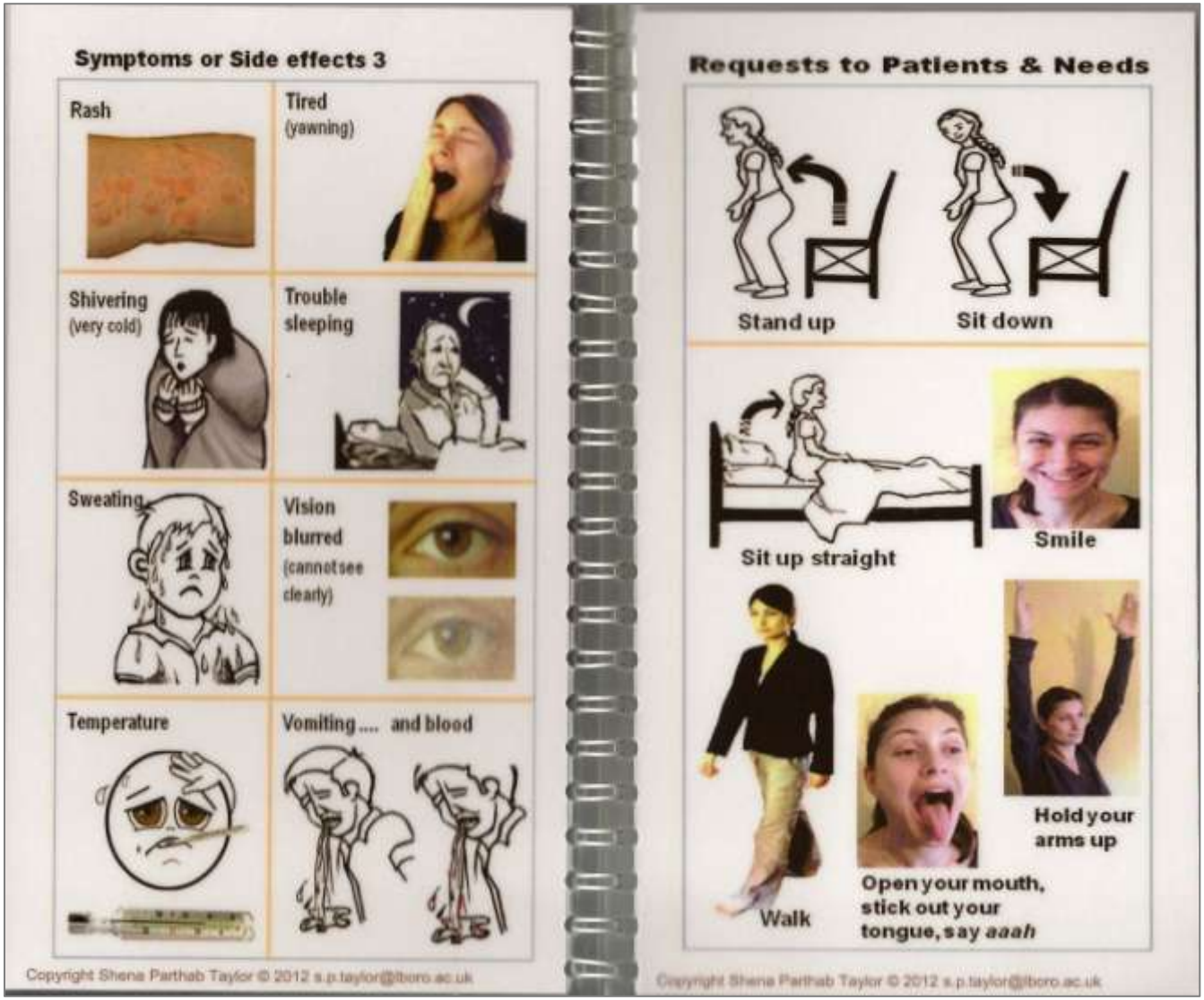
D28.2: Final testing: Pain pictorial-prototype-3 reformatted to pocket-size

For paramedics: Where is the pain?



D28.3: Final testing: pictorial-prototype-3 reformatted to pocket-size

Sample 2 – Symptoms, Requests to patients and Needs.



Appendix D29.Final testing staff: Cover letter to acompanying prototypes-3

Letter p.1

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

January 24th, 2012

Dear

Testing & Evaluating Design Prototype – Hindi/ Urdu
Facilitating more Direct Communication with Adult Ethnic Patients lacking English.

A warm 'thank you' for your enthusiasm, views and time contributed throughout this research. My study has focussed on whether, and how, visual and/or audio communication might be used to help lower language, literacy and comprehension barriers in adult patient care. The aim was to facilitate a greater degree of direct communication between staff and patients lacking English. Also, to encourage such patients to speak a little English as a means of motivating them to learn in the longer term and, thereby, to contribute to saving precious time and cost in healthcare delivery. The method chosen was 'inclusive design' so as to help other patient groups who find it harder to communicate through difficulties like stroke, dyslexia, poor vision, etc.

The study group was 1st generation patients from the Indian Subcontinent who lack English and the language selected was Hindi/ Urdu because it is spoken by many in that region and is understood by many who speak Punjabi and Gujarati.

Over several months, all aspects of the designs have been tested with several participants groups: NHS staff across departments and Trusts; 1st generation ethnic minority lacking English and/or literacy; elderly indigenous participants aged 68 to 91 years, and other indigenous participants.

The culmination of all our effort is a set of designs - a copy of which I am pleased to enclose for you to test in real-time and also a simple evaluation form. The page attached briefly outlines the designs. These will be left with you for 2-3 weeks to allow time for suitable patients in your workflow. When you have completed your testing please call or email me to collect the prototypes and evaluation forms, so the designs can be adjusted again. **During the testing, I will be on stand-by - please call my direct number if anything is not clear or you need help with any pronunciations or responses.**

Yours sincerely

Shena

Mrs Shena Parthab Taylor, BSc MA
PhD Research Student
s.p.taylor@lboro.ac.uk Direct: 07802 203130

This prototype is designed in two parts that complement each other.

A section for staff use: A4, laminated and spiral bound, this comprises:

- A section *Simple Guidance* on pronunciation,
- 1 page on *Pain Screening and Side Effects* (English and Hindi) with 'response checkers',
- 2 pages of images related to this, and
- 1 page on *Medication and Side Effects* (English and Hindi).

A section for patients use: A4 folded leaflet
Images and English words complementing the sections on *Pain Screening and Side Effects* for staff. This is proposed as a universal aid to help all patients point out responses to questions and to use it proactively to 'tell their story'.

Additionally: A4 hand-out - illustrating the *'Do's and Don'ts whilst taking this Medication'*

Stick-on labels for when and how much medication to take.

An evaluation form:

There are no right or wrong answers. Please feel free to comment as you see fit - the views of all the staff will be combined again to make the required alterations.

Appendix D30. Final testing staff: Evaluation form for staff to comment

(p.1/3) Aesthetics, editorial and usability feedback.

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

Study: **Investigating NHS Staff's perspectives: Whether any barriers hinder the provision of services to ethnic minority consumers**

Phase 2: Development of the design concept &/or recommendations: Testing & Evaluation of Prototype for further adjustments. *Self-fill, multiple-choice Questionnaire for Staff to report on testing prototype with patients,*

Name (CAPITALS please): _____ Date: _____2012

Please CIRCLE your closest preference, unless otherwise indicated.

1. AESTHETICALLY		**Any other comments?**
1.1. What is your overall impression about the aid at the first glance? (*Circle as many as you wish.*) Confusing Boring Unclear Helpful Interesting Attractive Difficult Fun		
1.2. What is your view of the font sizes? *1 = Too small... 5=Too large*	1 2 3 4 5	
1.3. What is your view of the images? *1 = Very confusing ... 5 = Very clear*	1 2 3 4 5	
1.4. Are the overall designs or styles consistent? *1 = Inconsistent... 5 = Very consistent*	1 2 3 4 5	
1.5. What do you feel about the colours used? *1 = Dislike a lot ... 5 = Like a lot*	1 2 3 4 5	
2. EDITORIAL FEEDBACK		**Any other comments?**
2.1. Is each item named appropriately? *1 = Often inappropriate... 5 = Clear & appropriate*	1 2 3 4 5	
2.2. What is your view of the balance of information (data and images)? *1 = Often inappropriate... 5 = Clear & appropriate*	1 2 3 4 5	
2.3. How to you view a use of a mix of images (cartoons, emoticons, photographs)? *1 = Dislike a lot ... 5 = Like a lot*	1 2 3 4 5	
3. USABILITY & INCLUSIVITY		**Any other comment?**
3.1. How did you find locating the information you needed in your workflow? (*Circle one, please.*) Confusing A little confusing Adequate Straightforward Efficient/ Easy		

Final testing staff: Usability & Inclusivity continued, General comments. (p.2)

		Any comments?
3.2. What do you feel about the Quality and Usefulness of the information? **a) Quality:** *1 = Very poor ... 5 = Very good*	1 2 3 4 5	
b) Usefulness: *1 = Not useful ...5 = Very useful*	1 2 3 4 5	
3.3. How did adult ethnic minority patients find the information? *1 = Very unhelpful ... 5 = Very helpful*	1 2 3 4 5	
3.4. How did indigenous and other patients find the information? *1 = Very unhelpful ... 5 = Very helpful*	1 2 3 4 5	
3.5. If this information was made available to you on a website for accessing or printing, would that help you? *1 = Very unhelpful ... 5 = Very helpful*	1 2 3 4 5	
3.6. In what other formats would you like to see these designs collated? *(Select as many options as you wish.)* Several per sheet On a chart Fold over leaflets Pocket sized cards Leaflets to give patients		
3.7. Did the aid help you to save time? *1 = Not at all ... 5 = Always, yes*	1 2 3 4 5	
3.8. In your view, did the designs help to lower patient anxiety? *1 = Not at all ... 5 = Always, yes*	1 2 3 4 5	
4. IN GENERAL		
4.1 How do you rate your experience of participating in developing the designs? *1 = Disliked a lot ... 5 = Very enjoyable*	1 2 3 4 5	
4.2 Would you find it helpful to have more designs prepared for your use? *1 = Very unhelpful ... 5 = Very helpful*	1 2 3 4 5	
4.3. Do you feel using more audio communication to explain the images might help patients? *1 = Definitely not ... 5 = Definitely, yes*	1 2 3 4 5	
4.4 Do you feel the aids were useful for you and patients? For neither of us For me only For patients only For us and patients		
4.5. Would you find it helpful if these aids were provided to patients lacking English or literacy, to help them familiarise with healthcare terms and processes? *1 = Definitely not ... 5 = Definitely*	1 2 3 4 5	

Final testing staff: General comments contd. (p.3).

4.6 In your view, do the aids, in combination, help to reduce any of the following difficulties for patients? *(Choose as many as you wish)* Poor English Poor Literacy Poor memory Poor vision Poor hearing Anxiety Frustration Dyslexia None of these	Any other:
5. Are there other issues that you would like to mention?	

Thank you very much for your time.

APPENDIX E: Ethics documents from all the studies

Appendix E1.Study 1 EMCs: Letter of invitation and participant information (p.1) Note the use of emoticons to add interest and engage participants.

Loughborough University 1909-2009

THE SUNDAY TIMES UNIVERSITY OF THE YEAR 2008-2009

Participant Information 2010

A Study with UK residents from the Indian Subcontinent

Investigating any difficulties with Services & Products in the UK

Dear

I am a student at Loughborough University with a background in design management. I am interviewing UK residents from the Indian Subcontinent aged 18 to 75+ years to better understand which products and services in the UK they:

1. May have any **difficulty** with, **dislike**, feel are **missing** or  are **unavailable,** and
2. those they like and **their preferences.** 

I will combine all participants' views to build a bigger picture to consider what might be done to **improve** a service or product to better suit peoples' needs.

There are no 'right' or 'wrong' answers, no names are required, the data will be anonymised and participation is voluntarily. You may also withdraw at any point. Answers to frequently asked questions follow. If you have further questions or need to contact me, I can be reached by email and phone. Thank you for reading this letter: I hope you will participate and enjoy our discussion.

Yours sincerely

Shena

Mrs Shena Parthab Taylor BSc, MA, PhD Student
Ergonomics & Safety Research Institute, Loughborough University
email: s.p.taylor@lboro.ac.uk Telephone: 07719 638 231

Frequently Asked Questions

Once I take part, can I change my mind?
Yes! After you have read this information and have asked any questions you may have, I will ask you to complete a *Consent Form*. If at any time, before, during or after our discussion you wish to withdraw from the study please just contact me and let me know. You can withdraw at any time, for any reason and you will not be asked to explain your reasons for withdrawing.

Will I be required to attend somewhere and where would that be? No, there is no need. I will meet you at an agreed place and at a time convenient to you. This may be in a library or other public place or at home near your family.

Study 1, EMCs: Letter of invitation and participant information (p.2)

How long will it take? The discussion part should take roughly an hour, depending on what your interests are. However, where some participants do not speak English, then translation is required and this wouldtake longer.

Is there anything I need to do or to bring with me? No. You may like to think about products and services you particularly like - and those that you do not like or have posed you with problems.

What type of clothing should I wear? Your normal wear is fine.

What will I be asked to do? I will ask you to answer some questions, so you just need to give me your views and opinions, look at some pictures I will bring for you to make a selection.

Are there any risks in participating? None at all; if you have any concerns, please let me know.

What personal information will be required from me? Information of a very broad nature, e.g. your community, languages, age group, etc. and your views on products and services. This will be combined with the views of all the other participants to create a picture of the community's needs.

Will my taking part in this study be kept confidential? Completely in the strictest confidence: all interview data will be identified by references, maintained anonymously, confidentially and used for the purpose described above. No data will be tracked back to you – there is no need. Data from all my studies will be kept for a period of 3-4 years for my PhD and stored on a secure computer at the university.

What will happen to the results of the study? The results of the study will be anonymised, analysed and prepared for my PhD thesis and reported in conference or journal papers to help providers of products or services to better understand the needs and preferences of the Asian Community. You may also have a summary of the findings if you wish.

From these findings, if there are difficulties, I will select a service or product provider and further explore problems with them to then consider what might be done to make improvements to reduce the difficulty in the future.

What do I get for participating? I will bring a choice of chocolate bars or laddoos. You may be sure that your views and opinions will help to build a picture that will contribute to improving product and service providers understanding of the needs of people from the Indian Subcontinent even, perhaps, help to identify and overcome difficulties with a. Also, I hope, you will simply enjoy our discussion.

If I have more questions whom should I contact? You are welcome to contact me.

What if I am not happy with how the research was conducted?
You may contact me to advise me if I am doing anything that is causing you concern, so I can take immediate steps to correct any errors. Or you may contact my Supervisors if you like and explain your concern (contact details below). You may also look at the University website on the University's policy on *"Research Misconduct and Whistle Blowing"* which is available online at: www.lboro.ac.uk/admin/committees/ethical/Whistleblowing(2).htm

SUPERVISORS. My Supervisors are fully informed of this interview and about my research. Their details are:

Mrs C Nicolle BSc, MSc, FErgS, Principal Researcher - c.a.nicolle@lboro.ac.uk
Direct: +44 (0)1509 226973.
Dr M Maguire, PhD, Principal Researcher - m.c.maguire@lboro.ac.uk.

Ergonomics and Safety Research Institute (ESRI)
Loughborough University, Ashby Road, Loughborough, Leicestershire LE11 3TU

Appendix E2.Study 1 EMCs: Informed Consent

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INFORMED CONSENT FORM

(Please complete *after* you have read the Participant Information Sheet.)

A Study of the preferences in Products & Services Of UK Asian Community members

Participant: **S01-2010-01-**_____ ( )

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the Loughborough University Ethical Advisory Committee.

☐ I have read and understood the information sheet and this consent form and have had an opportunity to ask questions about my participation.

☐ I understand that I am under no obligation to take part in the study, that I have the right to withdraw at any stage for any reason, and I will not be required to explain my reasons.

☐ I give my permission for photographs, tape recording or video to be taken as part of the research.

☐ I understand that the information I provide will be treated in strict confidence and will be kept anonymous and confidential to the researchers.

☐ I agree to participate in this study.

Name in CAPITALS: Mr, Mrs, Ms, Miss, Dr _____

Signature _____

Investigator's Signature _____

Date January 2010

I would be happy to participate in the next stage of the study, you may contact me on:

eMail: _____ **Phone:** _____

Recruiting NHS staff required Letters of Access from each NHS Trust for permission to work on their sites. This required a Favourable Opinion of the research from a NHS Regional Ethics Committee (REC).

An ethics application, i.e. documents A, B and C was prepared online on the NHS Integrated Research Application System (IRAS) (2010), with 12 supporting documents.

		Submitted to
A.	REC Application Form (IRAS Parts A-D) (signed/authorised)	REC
B.	Research & Development Forms	5 Trust R&D offices
C.	Site Specific Applications	

1. **The REC Application**

This required an application to be filled, a research proposal and 12 accompanying documents (listed below) in prescribed formats, each dated with a version number; the names and addresses of a *Site Liaison* (Manager) in each Trust; signatures from Loughborough University's Research Office Director (*the Sponsor),* Academic Supervisor and Researcher. Site Liaisons were identified with the assistance of each Trusts' R&D Officers (who were identified from the NHS website). The application included the study tools for prior approval.

1.	Project proposal (4 copies) (*the Protocol*)
2.	Summary CV of Chief Investigator (the researcher, in NHS format,signed)
3.	Summary CV of Academic Supervisor (signed)
4.	Participant Information Sheet (PInS)
5.	Letter to Department Managers
6.	Letter of Invitation to Participants (staff)
7.	Letter to GPs & Pharmacists
8.	Informed Consent Form
9.	Letter from Sponsor (signed/authorised)
10.	2 x Statements of indemnity, Loughborough University
11.	Validated questionnaire – Phase 1 (Study 2)
12.	Un-validated questionnaire: Phase 2 (Study 3, for submission via a *Substantial Amendment.*
13.	(Recruitment poster, submitted later)

The application was submitted following prescribed procedure: Nottinghamshire REC-1 was selected from the online NHS National Patient Safety Agency (2010) website; a telephone call was made to their office for a research reference number and to book a date for reviewing the application; this reference was entered on the covering letter, and the Application and 12 documents were emailed and posted to the REC office.

B and C Research & Development (R&D)

Applications were submitted to each Trust's R&D Department with copies of documents 1-12.

The author and Academic Supervisor attended the REC's review meeting, by invitation, to answer questions by a panel of 12+ professional and lay persons. The REC's initial Provisional Opinion requested some clarifications, an adjustment to the participant recruitment process and offered recommendations. Documents were modified, versions and dates updated (a critical point), item 13 (above) was designed and included, item 1 was revised according to helpful suggestions from a member of a Trust's governance panel.

The revised documents were resubmitted and copies with the REC's Provisional Opinion were disseminated to the all R&D departments and Loughborough University's Research office. This on-going distribution of correspondence had to be adhered to throughout the research.

The REC's Favourable Opinion was forwarded to the R&D offices and, to complete their ethics procedures and to issue Letters of Access, the Research Passport documents in original or pdf formats were emailed or posted recorded delivery. The Letters of Access completed the Research Passport file which was carried on all site visits and Loughborough University's student identity tag was worn as prescribed. The initial procedure took 9 months to complete.

The department managers were then identified by the researcher (sometimes with the assistance of Site Liaisons, PAs or secretaries and the study information distributed to inform managers of the study and for their permission to recruit participants for the research.

Managers were provided the study information, documents to be used with staff and the interview questions approved by the NHS REC.

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LETTER TO THE DEPARTMENT MANAGER

Name
Job Title
Department
Organisation

Date -2010

Dear

Permission to interview staff

Study Title: Investigating NHS Staff's perspectives: Whether any barriers hinder the provision of services to ethnic minority consumers

I am a PhD research student undertaking a study with NHS staff in front-line roles in 2 hospitals, 2 Primary Care Trusts and East Midlands Ambulance Services Trust. I am trying to determine whether, or not, staff face any barriers in providing care to ethnic minority consumers (EMCs, the public). If barriers are present, the aim is to determine whether inclusive design principles can be employed to help to lower (or begin to help lower) a barrier by developing solutions for the mutual benefit of service providers and EMC's.

To achieve this I would like to interview 2 staff in your department who have experience of providing services to EMCs *with whom they do not share a common language*. Ideally, the staff experiences will include people from the Indian sub-continent (Pakistan, India, Bangladesh or Nepal). The research is in 2 phases: Phase 1 will explore staffs' perceptions of any barriers that hinder care for EMCs lacking English. From these findings, in Phase 2 one barrier will be selected to consider whether a design approach might contribute to lowering it. In Phase 1, I will interview participants who volunteer using semi-structured open questions and, in Phase 2, I will conduct further interviews and use participatory design techniques based on the findings from Phase 1. I have NHS Research Ethics Committee approval for Phase-1, and will obtain ethical approval for Phase 2 once the 'barriers' have been identified and I can determine the right data-gathering tools required for Phase-2. I will forward this information in due course.

The initial interviews in Phase 1 will at the maximum last 1 hour and I would ask your permission if it is possible to conduct them during working hours? I understand if you feel that this may not be possible and I will inform any staff willing to participate that the interviews will be in their own time. The attached documents briefly outline my study and provide answers to FAQs: a *Letter of Invitation, Participant Information Sheet, Consent Form* (to confirm their voluntary agreement) and a copy of my proposed *Discussion Questions* which will be used in Phase-1. If you feel able to support this study, I would supply a number of study packs to yourself and ask that they be distributed to any staff interested in taking part in the study or, at your option, I can distribute them.

I have study authorisation from the REC, you R&D department and hold a Research Passport and CRB clearance. My Site Liaison will be _____. If you have any further questions or suggestions please do not hesitate to contact me. Thank you for considering this request and I look forward to hearing from you soon.

Yours sincerely

Mrs. Shena Parthab Taylor, BSc, MA, PhD Student

Office: Ergonomics and Safety Research Institute (ESRI), Garendon Building, Holywell Park, Loughborough, Leicestershire LE11 3TU. s.p.taylor@lboro.ac.uk. Tel: 01509 226900

Appendix E5.Study 2 NHS staff: recruitment poster

Working Effectively with Ethnic Minorities

Can you help? Do you have views & suggestions to contribute?

Investigating NHS Staff's perspectives: Whether any barriers hinder the provision of services to ethnic minority consumers

In March 2010, the Government recognised that much progress had been made in the *Inclusion Health* project, which has focussed on improving access and quality of services for socially excluded groups. However, there still remains a need for more sophisticated and flexible responses.

(www.cabinetoffice.gov.uk/social_exclusion_task_force/short_studies/health-care.aspx 2010).

Data-gathering; Understanding

A role for *Inclusive Design*?

Collating; Participatory design techniques

Inclusion Health: Improving usability & accessibility

Improved user-provider interactions

More is explained in the Information Sheet for Participants.

Investigator: Shena Parthab Taylor
Contact: s.p.taylor@lboro.ac.uk Mobile: 07802 203130

Loughborough Design School

Loughborough University

v.2.1.30.9.10

LETTER TO GPS AND PHARMACISTS
Name,
& Address

Date -2010

Dear

Re: Investigating NHS Staffs' perspectives on whether any barriers hinder the provision of services to ethnic minority consumers

Thank you for taking my call. I am undertaking a PhD research study with staff in front line roles in 2 NHS hospitals, and with GPs and Pharmacists, to investigate whether they face, or are aware of, any difficulties or barriers that affect the provision of services to ethnic minority consumers. _____ is my Site Liaison and is fully aware of this study.

If any barriers are present, I wish to understand their nature and whether, and how, a solution may be designed to help lower them. The aim of my research is to bring benefits to both staff as well as ethnic minority consumers. If you have experience of providing services to ethnic minority consumers (ideally including those from Pakistan, India, Bangladesh, Nepal) I would be very interested to interview you, please. I am interested in your interactions with patients with whom you do not share a common language. (No patients are required in this study.)

The questions I will ask relate to your experiences, any difficulties, how you overcome them and any tools you use in this, etc. There are no special requirements, no 'right' or 'wrong' answers, the data you provide will be strictly confidential and not related to you personally and I will combine it with other participants' views to build a 'bigger picture'. I can be flexible on dates/ times and will travel to meet you in a quiet area at work, cafe or local library etc. where we may talk relatively undisturbed. I will take notes and a recording, if you give your consent, to help me avoid errors when I collate the data.

The study starts in April and will be in two phases. Phase 1 will seek to identify any difficulties and to understand their nature. Phase 2 is when the solution will be designed. I will ask you to sign a 'Consent Form' before I interview you the first time. If you are happy to participate in Phase-2 in principle, you can tick this box on the Consent Form and give me your contact details so that I can advise you when the study starts. At the end of Phase 2 I may ask you to fill in multiple choice questions to evaluate the solution's efficiency, relevance, clarity, etc.

I have attached a 'Participant Information Sheet' to explain my research further and to provide answers to frequently asked questions. I would be happy to answer any other questions you may have and would be delighted if you would agree to participate. Please email (or phone) me as soon as convenient to let me know your decision - and thank you for taking the time to read this letter and the information.

Kind regards

Mrs. Shena Parthab Taylor, BSc, MA, PhD Student
eMail: s.p.taylor@lboro.ac.uk Direct: 07719 638231
(Please leave your name, a message, number or email for me to contact you.)

Information Sheet for Participants

Investigating NHS Staffs' perceptions of barriers hindering the provision of services to ethnic minority consumers who lack English.

Invitation

I invite you to participate in my research if you feel you have the experience I am seeking. If you do not, please pass this information to a colleague whom you feel might be interested.

I am researching the views of NHS Staff who have had experience in providing care to ethnic minority consumers (EMCs, the public) with whom they have not shared a common language and in situations when an interpreter has been absent. My particular focus are patients from the Indian Subcontinent (Pakistan, India, Nepal or Bangladesh). I am investigating whether, or not, staff feel they face, or may be aware of, any difficulties whilst providing care to EMCs lacking English. If so, I would like to better understand the nature of difficulties, the aids that are presently used to overcome problems, their strengths and weakness, whether there are any gaps and what staff feel might help them to further lower a barrier.

Part 1 of this *Information Sheet* explains my reasons for carrying out this research and Part 2 explains what this study would involve for Participants (i.e. more details about the conduct of the study in the form of 'Frequently Asked Questions'). When you have read this information, if you have further questions or wish to clarify any points, please do not hesitate to contact me by email or phone. You may also talk to others about my study if you wish e.g. my Site Liaison in your NHS Trust (I can give you the contact details) or my Academic Supervisors (details are provided in Part 2).

Part 1

Background & Purpose of this Research

Research into culture has identified that different cultures influence the thoughts of people differently. This affects how they perceive, understand or interpret information which affects their actions and behaviour in every-day living. Cultural differences can contribute to difficulties when using services or products which are designed by people from other cultures. Thus users' experiences can vary considerably. Considering the impact of culture and cognition on the design and delivery of services and products is part of a concept called *inclusive design*. This encourages designers and providers to meet the needs of the widest range of consumers with the widest range of abilities (short of assistive technology).

I recently undertook a study to investigate whether, or not, EMCs from the Indian sub-continent (the public) faced any barriers in the take-up of products and services in the UK. The results suggest that there may be scope for assisting some EMC sub-groups improve

their usability and take-up of services and as the NHS is a key service provider, it was a natural part of these discussions.

The outcome led me to previous research in healthcare which confirms that differences in culture, low literacy and several other factors can affect the provision of health services and their take-up or usability by EMCs - and also other user groups who are affected by similar factors. This prompted me to seek the views of NHS staff, who are important stake-holders, so that I might better understand any issues in order to build a holistic picture.

Your contribution could help to make a real difference. I wish to understand:

- Whether, or not, NHS staff face any barriers whilst delivering services to EMCs and, if so, the nature of the barriers.
- What tools might be in place to help overcome barriers and whether these could be improved or extended into the EMC community.
- How different NHS Trusts approach the problems.
- Whether sharing knowledge and using design could help, or begin to help, to lower a barrier and, how this can be accomplished?
- What might be the implications for inclusive design and what solutions may be developed.

The combined view of 40 Participants will help me to build a 'bigger picture' and to understand difficulties holistically. The aim is to bring mutual benefits to EMCs and to staff/ the Trusts as well as the wider groups of patients, through a better understanding of any issues and harnessing the expertise of Staff in any proposed designs and recommendations by using Inclusive Design principles.

There are no special requirements, no patients are involved and there are no right or wrong answers. Staff may feel that there are no, or few, difficulties; or issues are similar to, or different from, those identified by some EMCs sub-groups; possibly, even, other problems or factors which need addressing that EMCs are unaware of.

Mrs Shena Parthab Taylor, BSc, MA, PhD Student
eMail: s.p.taylor@lboro.ac.uk Direct: 07719 638231
(Please leave your name, a message, number or email for me to contact you)

Loughborough Design School
Garendon Building, Loughborough University, Leicestershire LE11 3TU

Part 2

FREQUENTLY ASKED QUESTIONS

Why have I been invited? You have been invited because you may have experience of providing services to EMCs with whom you did not share a common language. I would like t hear about these experiences particularly if any barriers were apparent during any service provision activity.

Do I have to take part and, once I do, can I change my mind? Your participation is entirely voluntary and, even after agreeing, you can still withdraw at any stage during the study if you wish to, without explanation; please just let me know.

What will I have to do if I participate in Phase-1? I will ask you to have one interview wit me. Before we start, I will request you to complete a *Consent Form* for Phase-1, which confirms you are happy to participate. Then I will ask you some questions to explore your views; this should take no longer than 45-60 minutes, depending on what you wish to discus I will take notes and, with your consent, also record our conversation (for data accuracy). If required, I *may* email this data back to you to ensure clarity. From the data in Phase-1, a barrier will be selected for the focus of Phase-2, in which in which design can play a role in a proposed solution. You can indicate on your *Consent Form* your interest to be advised abou Phase-2. (See below for more information.)

Where will the interview take place? The interview will be arranged at a mutually convenient place/time near your place of work or residence, e.g. a quiet cafe, or local library room, where we may talk relatively undisturbed. Although I have asked permission, it is possible your Manager/ Trust may prefer that we talk when you are off-duty due to the importance of your role and the pressures on staff time. I am prepared to be as flexible as possible to fit in with your timings e.g. a lunch-break, after your shift is over if not too late, one evening or at weekends.

Is there anything I need to do or to bring with me? Please think about any barriers or difficulties you may have experienced, or may be aware of, whilst providing care for EMCs. If possible, perhaps bring a sample of any tool you use to help you overcome any barriers, e.g. for communicating if an interpreter is absent.

Are there any risks in participating? No. If you have any concerns, please let me know.

What personal information will be required from me? Only information of a very broad nature, e.g. your role, your department's services, the range of ethnic minority patients you take care of, your views, preferences, etc.

Will my taking part in this study be kept confidential? Yes, strictly confidential; the data from this study will not refer to any participants or organisations. It will be stored anonymously under a reference number on secure university computers.

What do I get for participating? Some chocolate as a small token to thank you and, I hope, some personal satisfaction that your views will help to identify or clarify any issues an build the 'bigger picture'. This could lead to lowering a barrier in Phase-2 of the study and the potential benefits for your Trust could include savings in time and/or cost through a joining in proposing and advising on a proposed solution that people will enjoy interacting with. It could lead to improved interactions with EMCs, a greater appreciation within the community which would enhance your Trust's reputation as a place of excellence which promotes improved usability and accessibility.

(p.4) Study 3 NHS Staff: Participant information, frequently asked questions

Note that staff were advised of study 3 (phase 2) to try to generate advance interest future participation.

What will happen to the results of Phase-1 of the study? I will combine and analyse the data and prepare a report at the end of Phase-1 and you are welcome to a summary of this if you wish. If the findings highlight difficulties, one will be selected upon which to focus Phase-2 of the research, i.e. the design phase of this research, to determine whether design might help to lower a barrier.

What will be required of participants in Phase-2? Whilst this will depend on the results of Phase-1, I anticipate the activities will include three 30-minute interviews over a 2-3 month period (i.e. spread up to March-April 2011) which will invite your participation in the form of your expert advice, your views on the initial designs and/or recommendations and, finally, your views on the final designs proposed. If your experience is relevant to Phase-2 and you have indicated an interest in it, I will send you the details of the conduct of this phase and when it is due to start which, I anticipate, will be end-January/February 2011.

What will finally happen to the results of the study? I will prepare the results in the form of a proposed design concept &/or recommendations for helping to lower a barrier and a final report. These will be shared with participating Trusts and all interested Participants. I will also prepare papers for publishing in journals and at conferences (an essential requirement of my PhD) and the studies will be reported in my thesis for other researchers to review for their own research.

If I have more questions whom should I contact? You are welcome to contact me, my Site Liaison at your Research Office (I can give you the details) or my Academic Supervisors who are fully informed about my research and of all interview schedules in advance.

What if I am not happy with how the research was conducted? Please contact me to advise me if I am doing anything that is causing you concern, so I can take immediate steps to correct any errors. Or you may contact my Supervisors: Mrs C Nicolle BSc, MSc, FErgS, Research Fellow. c.a.nicolle@lboro.ac.uk Direct: 01509 226973. Dr M Maguire, PhD, Research Fellow. **m.c.maguire@lboro.ac.uk**

What do I do now? Please email me (s.p.taylor@lboro.ac.uk), or phone or text me (07802 203130) so that we can arrange an appointment to meet for the interview.

Thank you for taking the time to read this information.

John Donne, the English poet, wrote: "No man is an Island, entire of itself; every man is a piece of the continent, a part of the main..." *(Meditations XVII,* 1624*).*

Donne was observing that human beings depend upon one another to accomplish all things.

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s.p.taylor@lboro.ac.uk Mobile: 07719 638231 www.esri.org.uk

Appendix E8.Study 2 NHS staff: Informed Consent highlighting amendments (red)

Note how amendments were submitted for REC approval and to the Trusts. Item 9 elicited participants' potential interest in Phase 2, to help save recruitment time.

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INFORMED CONSENT FORM

Investigating NHS Staff's perspectives: Whether any barriers hinder the provision of services to ethnic minority consumers

(Please complete this *after* you have read the Participant Information Sheet. **Thank you.**)

Participant Ref. S02: _____ [ ]

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the NHS Research Ethics Committee, our organisation's Research Office and Loughborough University Ethical Advisory Committee. (Please initial the boxes below)

☐	1. I confirm that I have read and understood the Participant Information Sheet (dated 10.05.2010, version 5.2) and this consent form. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily.
☐	2. I understand that I am under no obligation to take part in the study and am free to withdraw at any stage without giving any reason, without my legal rights being affected.
☐	3. I understand that the information I provide will be treated in strict confidence and will be kept anonymous.
☐	4. I understand that relevant sections of my research notes and data collected during the study will be looked at by individuals from Loughborough University and may be looked at by regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
☐	5. I give my permission for audio recording to be made at interviews to support note-taking and, if relevant, for photographs of my choices (not of me) to be taken during the research.
☐	6. I agree to participate in Phase 1 (the exploratory phase) of this study.
☐	7. I would be happy to check the accuracy of the text from our discussion, if required.
☐	8. I would like to know the outcome of this study.
☐	9. I am interested in Phase 2, the development of the design concept &/or recommendations. Please contact me and tell me more about it in due course. My email: Phone:

Name (in capitals please): Dr, Professor, Mr, Mrs, Ms, Miss		
Department:		
Role:		
Signature:		**Date:**
Investigator's Signature:	Investigator: Mrs Shena Parthab Taylor	**Date:**

Office: Ergonomics and Safety Research Institute (ESRI)
Garendon Building, Ashby Road, Loughborough, Leicestershire LE11 3TU
eMail: s.p.taylor@lboro.ac.uk Mobile: 07719 638231 www.esri.org.uk

V2.3-15042010

Appendix E9.Study 3 NHS REC: Letter for Substantial Amendment application

Note the 7 documents that needed to be prepared for extending NHS research ethical approvals. These documents were deseminated to the Trusts and Loughborough University Research Student Office (RSO). Two uptodate insurance documents from the RSO were also obtained and copied to the Trusts. The process took 3 months with the REC and a futher 4-8 weeks to have the Research Passport updated and the extended Letters of Access from the Trusts.

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..... Co-ordinator
Nottingham Research Ethics Committee 1
Room 2.09, Level 2
1 Standard Court
4 Park Row
Nottingham
NG1 6GN

March 30th, 2011

Dear .....

REC Application Ref: 10/H0403/19 – Substantial Amendment Application – Phase 2 - Design

A PhD research study: Investigating Service Providers' perspectives on whether any barriers hinder the provision of services to ethnic minority consumers

Please find attached my application duly filled for your consideration.
The documents enclosed are:

1. Notice_of_Substantial_Amendment_(non-CTIMPs) (signed)
2. Amended Protocol
3. Participant Information Sheet – Phase 2 (PInS)
4. Informed Consent Form – Phase 2
5. Letter to Department Managers – Phase 2
6. Letter of invitation to Staff - Phase 2
7. Validated questionnaire – Phase 2 (Semi-structured interview & final design assessment i.e. self fill, multiple choice questions).

I would like to draw your attention to the non-risk nature of my study.

Thanking you,

Kind regards

Shena

Mrs Shena Parthab Taylor, BSc, MA
PhD Research Student

s.p.taylor@lboro.ac.uk, Direct: 07802 203130

Loughborough Design School
Garendon Building, Ashby Road, Loughborough University, Loughborough, Leicestershire LE11 3TU
Tel: 01509 226900, Fax: 226960 www.lboro.ac.uk

Information Sheet for NHS Staff - Study 3

Aim of Study:

Helping to lower Communication and Comprehension Barriers for adults lacking English or literacy to help Improve Patients' healthcare experience

Researcher:
Mrs Shena Parthab Taylor
Loughborough Design School
s.p.taylor@lboro.ac.uk

This design-oriented study follows earlier research which established that patients and staff face some barriers and, if these could be addressed, it could help both patients and staff, whilst potentially helping efficacy of care (see below). This next phase is considering whether, and how, a greater use of visual, and/or audio, communication aids can be combined with healthcare words in *English* to help lower communication and comprehension barriers for some adult ethnic patient subgroups from the Indian Subcontinent– as well as other ethnic and indigenous patients who might share similar difficulties.

The study will look into further developing or extending existing aids, or creating additional ones that patients can take home with them to help them and their families become more familiar with, and better understand, healthcare processes and requirements. The aim is to help lower language and literacy barriers in order to gain consent, reduce anxiety, save time, improve patients' experiences and bring mutual benefits to staff and patients. I am seeking to involve a small group of NHS subject matter experts, who are also interested in creativity.

An interesting aspect of this research is that, from a wider perspective, all of us have the potential of becoming 'ethnic minorities' when we travel to other countries, where we might well face similar barriers if we do not know the language or cultural norms. Thus, this study takes an inclusive design approach and will consider designs to assist the widest patient groups possible.

Part 1 of this *Information Sheet* outlines the reasons for doing this research and Part 2 answers 'Frequently Asked Questions' and explains how the study will be conducted. When you have read this information, please do not hesitate to contact me if you have further questions. You may also talk to your Trust's Liaison for this study (named in the letter) or my Academic Supervisors at Loughborough University (details on last page) who are sponsoring this research with the NHS.

I would be delighted if you think you might like to participate – there are no right or wrong answers and no preparation is required aside from your views and opinions as a professional.

Part 1 - BACKGROUND

Why do cultural differences matter?

Previous research into *culture* has identified that different cultures influence the thoughts of people differently which, in turn, affects how we perceive, understand or interpret information and this, therefore, affects how we behave. Cultural differences can contribute to difficulties whilst using products or accessing services, especially when these have been designed by people from other cultures. Today, our everyday experiences - whether work, healthcare, travel, education, access to information or leisure - depend on a myriad of products and services. These are increasingly designed and delivered using sophisticated technologies and processes, which can add to well known difficulties caused by complexity. Thus, cultural differences can compound these difficulties.

What led to this Research with the NHS?

In a previous study, this research, investigated whether, or not, ethnic minorities from the Indian sub-continent (Pakistan, India, Nepal or Bangladesh - the public) who are settled in the UK, faced any barriers in the take-up of products or services nowadays. The study explored differences and similarities of views based on *generations* and *religions*.

The results highlighted that a 1st generation subgroup, particularly females with no English and/or no literacy, across religions, cited anxiety and distress about their poor interactions with healthcare and some social services staff. However, they also expressed great affection particularly for indigenous NHS staff, in particular, whom they feel treat them with respect and kindness and a desire to learn English so as to be able to communicate better with staff. That healthcare was a strong theme is not surprising for healthcare is important to each one of us, irrespective of culture or age. A review of previous healthcare research also confirms that cultural differences, literacy and language barriers do impact on ethnic minority patients and other patients who might have similar problems, e.g. low literacy.

Other interesting results emerged from this study. The 1st generation subgroup that follows an oral tradition, are very fond of audio-visual products upon which they rely greatly for their entertainment and prayers. The 2nd generation also favour a balance of images with text to follow instructions, and to save time, e.g. when using/ understanding new technologies. The 3rd generation agree with the 2nd, that images could aid comprehension for the 1st generation subgroup with no English or literacy – *if the images were understood*.

These results suggested there may be scope for assisting this ethnic subgroup to improve their usability or take-up of health services through visual and/or audio communication. However, as substantial efforts have been made by the NHS in recent years to help overcome inclusion barriers, the first task was to understand the views of NHS staff about the presence of any barriers. Secondly, to understand, whether and how widely visual and/or audio communication might be in use for adult patients.

What did you learn from NHS Staff?

Phase 1 of this study explored the views of 32 staff in 5 Trusts to understand their perceptions, i.e. doctors/ consultants, physiotherapists, nurses, receptionists, paramedics, pharmacists, GPs. The study gave staff the opportunity to focus on any barriers that hinder the provision of care to ethnic minority patients from the Indian sub-continent – whilst exploring also whether other patient groups shared similar problems. We discussed what works well, any difficulties encountered, what aids are presently used to overcome difficulties and, finally, what staff feel might help them further.

The results indicate that the delivery of care and patients' experiences can still be hampered by language, literacy and comprehension barriers although staff have a wide range of aids to assist them, e.g. *Language Line*, professional interpreters, staff and family interpreters, *Multi-lingual phrasebook* (offering text translations in 36 languages although no copy was available), models or images in a few departments. NHS staff clearly take pride in competently resolving difficulties; however, they are aware also that the barriers remain and do impact on care. Although many enjoy learning words in different languages, there are a multitude of languages, and the level of communication achieved through a few words is not satisfactory. Other difficulties include a lack of understanding of the role of an interpreter; patients bringing inappropriate interpreters e.g. too young, poor English; gender and cultural barriers resulting in wasted appointments, inadequate interpretation or low empowerment (usually for females); and taking NHS services for granted.

These problems can impact on time - it takes longer to deliver care, which can place pressure on staff due to other waiting patients and delaying ward or clinic processes. Some are unable to participate fully in their care or to properly articulate their problems. However, other adult ethnic minorities and indigenous patients also share some of these difficulties, i.e. anxiety, poor comprehension, retention, compliance, information overload, including the elderly (mentioned frequently with compassion), those with poor literacy or no English, poor memory, visual or hearing impairments, dyslexia, etc. Inappropriate use of some services (e.g. ambulances, A&E) is cross-culturally common. Thus staff feel it is very important to educate the public.

The use of visual and audio communication aids for adult patients appears to be either patchy or absent - with a few exceptions like Physiotherapy (models and *Physiotools*), in orthopaedics (too patient specific to lend itself to such aids) or for patients with particular disabilities. Some staff cited occasional instances of the use of audio-visual aids in their current or in previous jobs, in other Trusts, with enthusiasm because they proved to be helpful. The majority views ranged from positive to enthusiastic about developing visual and audio communication aids.

Another conclusion of the study was that the patients' experience of healthcare services in the NHS can be a fragmented one. Some staff felt that some of the different services and processes might be confusing to those 'on the outside'.

Staff also stated that a major aspect of their roles is about *communication*. Previous literature identifies that an experience like *communication* is constructed from what the *communicator* provides as well as what "the *communicatee* brings to the interaction" in equal parts. Communication actually occurs in the area in which these two overlap, thus, to design for experiencing communication requires us to have access to both parts - what is being communicated and what experiences are influencing the recipient (Sanders and Dandavate 1999:pp.87-8).

Combining the results of the study with ethnic minorities and Phase 1, this phase will consider communication from the perspectives of both staff and patients, using several elements of visual and audio communication, i.e. illustrations, photographs, English text, perhaps audio clips. It will also consider how a patient might experience a more cohesive journey through healthcare with a set of aids that would see them, and their families, along the journey. The objective, therefore, is to add to or to create inter-departmental, inter-Trust resources, perhaps web-based, to help patients and staff alike.

Study 3 NHS staff: Participant information, Frequently asked questions (p.4/5)

Part 2 - FREQUENTLY ASKED QUESTIONS

Why have I been invited? It could be for a number of reasons: you have experience of caring for ethnic minorities with whom you do not share a common language; you indicated an interest during Phase 1; because you are creative and would like to contribute.

Do I have to take part and, once I do, can I change my mind? Your participation is entirely voluntary and, even after agreeing, you can still withdraw at any stage during the study if you wish to, without explanation - please just let me know.

What will I have to do if I participate in the study? I will ask you to agree that I may interview you times, just for 30 minutes each time, over the space of 2-3 months, to contribute your views and preferences. At the first interview, I will ask you to complete a *Consent Form*, to confirm you are happy to participate in Phase 2 of this research. With your consent, I will record our discussions to help with data accuracy when typing up, I will take notes and take photographs of your preferred choices (not of you). The interviews will be as follows:

- 1 – Identify the design focus: To learn what you have to frequently convey to patients and would most like illustrated, i.e. the products you use in your role or activities you carry out, and in what format you would like to see the designs. (I will then prepare the design concept.)
- 2 - Testing Stage 1: To critique initial design prototypes, and suggest and select your preferred prototype to take forward; and to help me to understand your preferences. (The designs will be adjusted by me.)
- 3: Testing Stage 2: To review and critique the adjusted designs. (The designs will be adjusted by me.)

I will give you copies of the final designs to test with suitable patients and a Design Evaluation Questionnaire with multiple-choice answers to record your views. I will then collect the designs and Questionnaires to combine your views with those of other participating staff. If required, further adjustments will be made.

NB. A parallel design process will be undertaken by me with ethnic minority persons (the public) to test the illustrations and texts.

Where will the interview take place? These will be arranged at a mutually convenient date and place, either near your place of work or residence. Somewhere we may talk relatively undisturbed - a quiet room, cafe or local library room. I am prepared to be as flexible as possible to fit in with your requirements e.g. at lunch-break, before or after your shifts, at the quietest time of your shift if your Manager permits, evenings or at weekends.

Is there anything I need to do or to bring with me? Please think about any of the products you use in your role or activities you carry out, that you would like illustrated and in what format you would like to see the designs. If you have an existing aid you would like modified or extended, perhaps you could bring a sample with you.

Are there any risks in participating? None at all - if you have any concerns, please let me know.

What personal information will be required from me? Only information of a very broad nature, e.g. your role, your department's services, the procedures you wish to convey to patients, etc.

Will my taking part in this study be kept confidential? Yes, strictly confidential; the data from this study will not refer to any participants or organisations. It will be stored anonymously, without names, under a reference number on secure university computers. The Final Report will be completely anonymous.

What do I get for participating? A large chocolate bar as a small token of thanks and, I hope, personal satisfaction that you are helping to create aids that may help patients lower literacy, comprehension and anxiety barriers. These aids might then be prepared for patients and families to take away and familiarise themselves with. This could lead to savings in time and/or cost for your Trust, contribute to improved patient experiences and staff-patient interactions. Thus a greater appreciation amongst the ethnic community and other patient groups could enhance your Trust's reputation as a place of excellence which continuously promotes inclusivity, usability and accessibility.

What will happen to the results of the study? The results will be prepared as a *Final Report* including outcomes, recommendations and designs and given to Management at the 5 participating Trusts. You are welcome to a summary of this, if you wish. If it is deemed useful, the research might be taken forward at a future date. The results will also be prepared as papers for publishing in journals and at conferences (which is an essential requirement for my studies), possibly on the National Health Research database, at Loughborough University's Library Repository and in my thesis.

If I have further questions, whom should I contact? You are welcome to contact me at any time. Or, if you wish, my Site Liaison at your Trust (named in the letter) or my Academic Supervisors (details below), who are all fully informed about my research.

What if I am not happy with how the research was conducted? Please contact me to advise me if I am doing anything that is causing you concern so that I may take immediate steps to correct any errors. Or you may contact my Supervisors:

Mrs C Nicolle BSc MSc FIEHF, Research Fellow: c.a.nicolle@lboro.ac.uk, 01509 226973
Dr M Maguire MSc PhD MIEHF, Research Fellow: m.c.maguire@lboro.ac.uk

Thank you for reading this information.

What do I do now?

Please, email me at **s.p.taylor@lboro.ac.uk** or

phone or text me on 07802 203130, so that we can arrange to meet.

Appendix E11.Study 3 NHS Staff: Informed consent

Note the amendment as information from researching EMCs and indigenous elderly was being shared with staff.

INFORMED CONSENT

Study Title: Investigating Service Providers' perspectives: Whether any barriers hinder the provision of services to ethnic minority consumers.

Phase 2 - Development of the design concept &/or recommendations

(Please complete this *after* you have read the Participant Information Sheet.)

S02 Participant Ref. *(Office use)*: _____ [ ]

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by the NHS Research Ethics Committee, our Trust's Research Office and Loughborough University's Ethical Advisory Committee. (Please **initial** the boxes below)	
	1. I confirm that I have read and understood the *Participant Information Sheet* dated 23.3.2011 v1 and this Consent form. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily.
	2. I understand that I am under no obligation to take part in the study and am free to withdraw at any stage without giving any reason, without my legal rights being affected.
	3. I understand that the information I provide will be treated in strict confidence and will be kept anonymous.
	4. I understand that relevant sections of my research notes and data collected during the study will be looked at by individuals from Loughborough University and may be looked at by regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.
	5. I understand that information provided to me by the researcher is strictly confidential and will not be divulged to third parties.
	6. I give my permission for audio recording to be made at interviews to support note-taking and for photographs of my choices (not of me) to be taken during the research.
	7. I would like to know the outcome of this study (Optional).
	8. I am interested in further stages of this research. Please contact me and tell me more about it in due course (Optional). My email: Phone:

Name (CAPITALS): Dr, Professor, Mr, Mrs, Ms, Miss		
Department:		
Role:		
Signature:		**Date:**
Investigator's Signature:		

Loughborough Design School, Loughborough University, Loughborough, Leicestershire LE11 3TU.
V2-18.10.2011

Appendix E12. Study 3 EMCs: Letter of Invitation

The letter and participant information was presented to English-speaking family members.

August 29th, 2011

A Letter of Invitation – Phase 2: Design

[Verbally communicated to potential participants in Hindi and Punjabi during recruitment and verbally translated prior to interview.]

Dear .....

Helping to lower Language & Literacy barriers to improve Communication and Comprehension for Adult Patients - and thus help improve Patient Experiences.

Thank you for your agreement to participate in my research study which is considering how, and whether, visual and/or audio communication aids might be used to ease communication problems with healthcare staff, and to help patients and their families familiarise themselves with healthcare processes and requirements.

This study is also working with NHS and the 2 topics selected for work are *Pain Screening & Assessment* and *Taking Medication and Side Effects*, because these are useful to all people.

Your views will be combined with other participants to develop aids that could help you and other patients communicate with staff. The process is very simple and, hopefully, enjoyable, involving only 2 interviews over 2 months. There are no *right* or *wrong* answers, no preparation will be required and I will meet you at a convenient place and time. The *Participant Information Sheet* provides more information about the background and conduct of this study.

Your participation could contribute to creating aids that can bring benefits to both Patients and Staff.

Thank you,

Yours sincerely

Shena

Mrs Shena Parthab Taylor, BSc MA
PhD Research Student
s.p.taylor@lboro.ac.uk Direct: 07802 203130

Appendix E13. Study 3 EMCs: Participant information (p.1/2)

The information was explained in Punjabi to participants and the key points highlighted again before the interview. To recruit participants, the information cited the EMCs difficulties in healthcare (in study 1) and the need to learn English.

Information Sheet for Participants Study 3

Aim: To understand how best to prepare an aid to help people lacking English or literacy to better communicate their needs to healthcare staff, to better understand the needs of healthcare services and to improve their English.

Researcher: Mrs Shena Parthab Taylor
Loughborough Design School
s.p.taylor@lboro.ac.uk Mobile 07802 201130

Some patients and healthcare staff in the UK face difficulties when trying to communicate with each other and, if this problem could be addressed, it would help both patients and staff. This research is considering whether, and how, a greater use of visual, and/or audio, communication can be combined with healthcare words in English to help people lacking English to better communicate and understand doctors and nurses, and to help other patients who might share similar difficulties. The study will focus on developing aids that patients can use to express their needs and take home to help them become more familiar with information that may be communicated to them and, thereby help them to give consent, directly communicate their needs, be less anxious and save time. Part 1 of this *Information Sheet* outlines the background to this research and Part 2 answers 'Frequently Asked Questions' and explains how the study will be conducted.

Part 1 - BACKGROUND

Why do cultural differences matter?

Previous research has identified that different cultures influence the thoughts of people differently which, in turn, affects how they perceive, understand or interpret information. These differences can give rise to difficulties when people use products or access services, especially when they are designed by people from other cultures, particularly for people living outside their countries of origin.

What did your earlier research find?

In an earlier study investigated whether, or not, people from the Indian Sub-continent (Pakistan, India, Nepal or Bangladesh) who are settled in the UK, faced any barriers nowadays in the take-up of products or services. The results highlighted that a 1st generation subgroup, particularly females with no English and/or no literacy, across religions, are anxious and distressed because they cannot communicate their needs to doctors and nurses. People also expressed great affection for indigenous NHS staff because they treat them with respect and kindness and many wished to learn English to be able to communicate better with them. This is not surprising because healthcare is important to all people, regardless of culture or age. The research also found that people who do not have English or cannot read or write well, follow an oral tradition and are very fond of products like TVs and CDs for their entertainment and prayers and their children and grandchildren felt images could help those lacking English or literacy *if the images were understood*. This led to research with the NHS.

What did your research with the NHS find?

This study with staff found that although the NHS helps people who do not know English by providing translation services, the problem for people is repeated next time because they still do not know English. Also, there are people with many different languages in the UK and it is very difficult for staff to learn all these languages, so it is important for people to learn English to help them to communicate their needs directly to doctors and nurses, and will become even more important as

people become old as they will need more care, and English will also help people in other areas of their daily lives and at work. These problems also affect how long it takes to treat patients because it takes twice as long to help them. So, this research is considering how to help patients to better communicate their problems to doctors and nurses and understand the treatment, by beginning to learn or improve their English.

Part 2 - FREQUENTLY ASKED QUESTIONS

Why have I been invited? You have been invited because you do not yet know English well and have difficulty communicating your needs, especially with the doctor. We need the views of yourself and other people to understand how we might be able to help you to learn English.

Do I have to take part and, once I do, can I change my mind? Your agreement is entirely voluntary and, even after agreeing, you can change your mind if you wish to, and withdraw at any stage during the study without explanation - please just let me know.

What will I have to do if I participate in the study? I will ask you to agree that I may interview you twice, first for 1 hour, then for 30 minutes, over 2 months, to contribute your views and preferences. A the first interview, I will ask you to complete a *Consent Form*, to confirm you are happy to talk to me. I would like to understand how much English you know already and what images you find clearest and helpful in responding to questions. In your 2nd interview I will show you the new design to test how helpful and easy you find it.

I will record our discussions with your consent, to help me have an accurate copy to back up my notes might take photographs of your preferred choices (not of you). I am also interviewing NHS staff to see bring together what they need and what you need.

Where will the interview take place? These can be at a mutually convenient date and quiet place near your place of work, worship or your residence where we may talk. I am flexible, including evenings or weekends.

Is there anything I need to do or to bring with me? No, nothing is required.

Are there any risks in participating? None at all; if you have any concerns, please let me know.

What personal information will be required from me? Only information of a very broad nature, e.g. how long you have been in England, your age group, how you rate your English.

Will my taking part in this study be kept confidential? Yes, strictly confidential; the data will not name any people and will be stored on secure university computers.

What do I get for participating? A large chocolate bar as a small token of thanks, and that you are helping to create an aid that will help you to communicate better with healthcare staff and to learn mon English. The aid will be prepared for you to take a copy home, and to familiarise yourself with English so you can communicate your needs and save time when you visit the doctor. English will also help yc in other areas of your life and work.

What will happen to the results of the study? The results will be prepared for the Management at the hospitals and published in my thesis to pass my studies, possibly on the National Health Research database, at Loughborough University's Library Repository and journals.

If I have further questions, whom should I contact? You are welcome to contact me at any time. Or, if you wish, my Academic Supervisors (details below), who are all fully informed about my research.

What if I am not happy with how the research was conducted? Please contact me to advise me if I am doing anything that is causing you concern so that I may take immediate steps to correct any errors. Or you may contact my Supervisors: Mrs C Nicolle BSc MSc FIEHF, Research Fellow: c.a.nicolle@lboro.ac.uk, 01509 226973. Dr M Maguire MSc PhD MIEHF, Research Fellow: m.c.maguire@lboro.ac.uk

Thank you for reading this information.

What do I do now? Please, contactt me on 07802 203130, or I will phone to to arrange a meeting.

Sponsor: Loughborough University
Loughborough Design School, Garendon Building, Loughborough University, Leicestershire LE11 3TU.
www.lboro.ac.uk/lds

P.1/34, v1-10.8.2011

Appendix E14.Study 3 indigenous elderly people: Participant information (p.1/2)

The letter of invitation and study information was sent to an elderly care home manager and given to the warden to gain permission to approach elderly residents.

Information Sheet for Participants

Mrs Shena Parthab Taylor
Loughborough Design School
Mobile 07802 203130

Aim: To understand how a visual communication aid may be prepared to help several groups of patients to more easily communicate their needs to healthcare staff, including people who lack English, have poor literacy, poor vision, dyslexia or other difficulties. Part 1 of this *Information Sheet* outlines the reasons for doing this research and Part 2 answers 'Frequently Asked Questions' and explains how the study will be conducted.

Part 1 - Reasons for doing this Research

Some patients and healthcare staff face problems when communicating with each other, and some patients find it difficult to read textual information, for different reasons. For example, people suffering from an illness, like a stroke, who cannot speak easily, those with difficulty reading text due to poor vision or dyslexia, those who are infirm, people with poor literacy, or those who lack English, and so on. This can result in delays and difficulties when patients need to give consent for treatment or to express their needs, causing greater anxiety and delays in carrying out treatment. People can also find it difficult to read medication instructions and to remember how to take their medicines correctly, adding to their daily difficulties.

This research hopes to help some of these different groups of patients through a greater use of images combined with English, with a focus on 2 topics: Pain screening and assessment, and Taking medication correctly and possible side effects.

I have been testing images that patients can use to more easily communicate their needs or difficulties to healthcare staff. I wish to understand whether the images which help people lacking English might also be meaningful and helpful to older English-speaking adults (whether or not they have difficulties) and whether there are things missing that older people may want to communicate.

Part 2 - FREQUENTLY ASKED QUESTIONS

Why have I been invited? You have been invited because you are an older English-speaking citizen who might be willing to help me find answers to my research.

Do I have to take part and, once I do, can I change my mind? Your agreement is entirely voluntary and, even after agreeing, you can change your mind if you wish to, and withdraw at any stage during the study without explanation - please just let me know.

What will I have to do if I participate in the study? I will ask you to agree that I may interview you once for about 45 minutes. I will ask you to sign a *Consent Form*, to confirm you are happy to talk to me. I will show you images to find out whether these are meaningful and clear to you and, if not, what you might prefer and whether anything is missing that you would like to add.

Study 3 indigenous elderly people: Participant information (p.2/2)

The study was explained to each participant in person the week before a interview was arranged with the help of the warden.

I will record our discussions with your consent, to help me have an accurate copy for my notes I am also interviewing NHS staff to bring together what they need and what you need.

Where will the interview take place? These can be at your residence or a quiet place where we may talk and I may record, at a date and time to suit you. I am flexible, including evenings or weekends.

Is there anything I need to do or to bring with me? No, nothing is required.

Are there any risks in participating? None at all; if you have any concerns, please let me know.

What personal information will be required from me? Only information of a very broad nature, e.g. your age group, whether you might find images more helpful than text and the reason, etc.

Will my taking part in this study be kept confidential? Yes, strictly confidential; the data will not name any people and will be stored on secure university computers.

What do I get for participating? A large chocolate bar as a small token of thanks, and that you are helping to create an aid that might help our Elderly and those lacking English or literacy.

What will happen to the results of the study? The results will be prepared for the Management at the hospitals and published in my thesis to pass my studies, possibly on the National Health Research database, at Loughborough University's Library Repository and journals.

If I have further questions, whom should I contact? You are welcome to contact me at any time, or, if you wish, my Academic Supervisors (details below), who are all fully informed about my research.

What if I am not happy with how the research was conducted? Please contact me to advise me if I am doing anything that is causing you concern so that I may take immediate steps to correct any errors. Or you may contact my Supervisors:

Mrs C Nicolle BSc MSc FIEHF, Research Fellow: c.a.nicolle@lboro.ac.uk, 01509 226973.

Dr M Maguire MSc PhD MIEHF, Research Fellow: m.c.maguire@lboro.ac.uk

Thank you for reading this information.

What do I do now? Please, phone me on 07802 203130, so that we can arrange to meet.

Sponsor: Loughborough Design School, Loughborough University, LE11 3TU. www.lboro.ac.uk/lds

P.1/2, v1-15.11.2011

INFORMED CONSENT

Study: Lowering communication barriers in healthcare.

(Please complete this *after* you have read the Participant Information Sheet.)

S03 Participant Ref. *(Office use)*: _____ [ ]

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by Loughborough University's Ethical Advisory Committee. *(Please tick the boxes below)*

	1. I confirm that I have read and understood the *Participant Information Sheet* dated 15.11.2011 v1 and this Consent form. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily
	2. I understand that I am under no obligation to take part in the study and am free to withdraw at any stage without giving any reason, without my legal rights being affected.
	3. I understand that the information I provide will be treated in strict confidence and will be kept anonymous and the information provided to me is in strict confidence.
	4. I understand that relevant sections of my research notes and data collected during the study will be shared with supervisors from Loughborough University and give permission for them to have access to my responses.
	5. I give my permission for audio recording to be made at my interview to support note-taking.
	6. I give my permission for my picture to be taken.
	7. I am interested in further stages of this research. Please contact me and tell me more about it in due course.

Name in CAPITALS:		
Role:		
Signature:		**Date:**
Investigator's Signature:		

Information Sheet for Participants

Mrs Shena Parthab Taylor
Loughborough Design School
Mobile 07802 203130

Aim: To understand how a visual communication aid may be prepared to help several groups of patients to more easily communicate their needs to healthcare staff, including people who lack English, have poor literacy, poor vision, dyslexia or other difficulties. Part 1 of this *Information Sheet* outlines the reasons for doing this research and Part 2 answers 'Frequently Asked Questions' and explains how the study will be conducted.

Part 1 - Reasons for doing this Research

Some patients and healthcare staff face problems when communicating with each other, and some patients find it difficult to read textual information, for different reasons. For example, people suffering from an illness, like a stroke, who cannot speak easily, those with difficulty reading text due to poor vision or dyslexia, those who are infirm, people with poor literacy, or those who lack English, and so on. This can result in delays and difficulties when patients need to give consent for treatment or to express their needs, causing greater anxiety and delays in carrying out treatment. People can also find it difficult to read medication instructions and to remember how to take their medicines correctly, adding to their daily difficulties.

This research hopes to help some of these different groups of patients through a greater use of images combined with English, with a focus on 2 topics: Pain screening and assessment, and Taking medication correctly and possible side effects.

I have been testing Hindi phonetics with indigenous healthcare staff to help facilitate a greater degree of direct communication with patients from the Indian Subcontinent who lack English. The purpose is to create an aid with images to help people lacking English to respond to staff in the absence of an interpreter.

Part 2 - FREQUENTLY ASKED QUESTIONS

Why have I been invited? You have been invited because you are an adult with an indigenous background from the UK. I would like you help me test phonetics pronunciations in a language you do not know, i.e. Hindi to help me to improve the sounds. This testing will help staff to make clearer sounds so patients will understand them.

Do I have to take part and, once I do, can I change my mind? Your agreement is entirely voluntary and, even after agreeing, you can change your mind if you wish to, and withdraw at any stage during the study without explanation - please just let me know.

What will I have to do if I participate in the study? I will ask you to agree that I may interview you once for about 20-30 minutes and to sign a *Consent Form*, to confirm you are happy to talk to me. I will ask you to read some phonetics and I will note any words where the sound was not clear. When you have finished reading I would like to have your suggestions on

how the words could be written to be pronounced more clearly. There are no right or wrong answers and the emphasis is on how English is normally pronounced. I will record our discussions with your consent, to help me have an accurate copy for my notes.

Where will the interview take place? These can be at your residence or a quiet place where we may talk and I may record, at a date and time to suit you. I am flexible, including evenings weekends.

Is there anything I need to do or to bring with me? No, nothing is required.

Are there any risks in participating? None at all; if you have any concerns, please let me know.

What personal information will be required from me? There is no information required aside from reading the phonetics.

Will my taking part in this study be kept confidential? Yes, strictly confidential; the data will not name any people and will be stored on secure university computers.

What do I get for participating? A large chocolate bar as a small token of thanks, and that you are helping to create an aid that might help ethnic minorities lacking lacking English or literacy.

What will happen to the results of the study? The findings will be prepared for my thesis to pass my studies, and possibly to prepare journal articles.

If I have further questions, whom should I contact? You are welcome to contact me at any time, or, if you wish, my Academic Supervisors (details below), who are all fully informed about my research.

What if I am not happy with how the research was conducted? Please contact me to advise me if I am doing anything that is causing you concern so that I may take immediate steps to correct any errors. Or you may contact my Supervisors:

Mrs C Nicolle BSc MSc FIEHF, Research Fellow: c.a.nicolle@lboro.ac.uk, 01509 226973.

Dr M Maguire MSc PhD MIEHF, Research Fellow: m.c.maguire@lboro.ac.uk

Thank you for reading this information.

What do I do now? Please, phone me on 07802 203130, so that we can arrange to meet.

Sponsor: Loughborough Design School, Loughborough University, LE11 3TU. www.lboro.ac.uk/lds

INFORMED CONSENT

Study: Lowering communication barriers in healthcare.

(Please complete this *after* you have read the Participant Information Sheet.)

S03 Participant Ref. *(Office use)*: _____ [ ]

The purpose and details of this study have been explained to me. I understand that this study is designed to further scientific knowledge and that all procedures have been approved by Loughborough University's Ethical Advisory Committee. *(Please tick the boxes below)*

	1. I confirm that I have read and understood the *Participant Information Sheet* dated 15.11.2011 v1 and this Consent form. I have had an opportunity to consider the information, ask questions and have had these answered satisfactorily	
	2. I understand that I am under no obligation to take part in the study and am free to withdraw at any stage without giving any reason, without my legal rights being affected.	
	3. I understand that the information I provide will be treated in strict confidence and will be kept anonymous and the information provided to me is in strict confidence.	
	4. I understand that relevant sections of my research notes and data collected during the study will be shared with supervisors from Loughborough University and give permission for them to have access to my responses.	
	5. I give my permission for audio recording to be made at my interview to support note-taking.	
Name in CAPITALS:		
Role:		
Signature:		**Date:**
Investigator's Signature:		