Author(s): Szczepura A, Johnson M, Gumber A, Jones K, Clay D, Shaw A.
Article Title: An Overview of the Research Evidence on Ethnicity and Communication in Health
Year of publication: 2005
Link to published version:
http://www2.warwick.ac.uk/fac/med/research/csri/ethnicityhealth/research/communicationsrevi
Publisher statement: none

An Overview of the Research Evidence on Ethnicity and Communication in Healthcare

Final Report

October 2005

Address for correspondence:
Professor Ala Szczepura
Clinical Sciences Division
Warwick Medical School
University of Warwick
Coventry CV4 7AL
Telephone No: 024 7652 2958
Fax No: 024 7652 4963
E-mail:Ala.Szczepura@warwick.ac.uk

AN OVERVIEW OF THE RESEARCH EVIDENCE ON ETHNICITY AND COMMUNICATION IN HEALTHCARE

Project Team:

Professor Ala Szczepura[1]
Professor Mark Johnson[3]
Dr Anil Gumber[1]
Dr Kip Jones[2]
Diane Clay[1]
Anne Shaw[1]

October 2005

Commissioned by the Department of Health

All communication to:

Professor Ala Szczepura
Clinical Sciences Division
Warwick Medical School
University of Warwick
Coventry CV4V 7AL
Tel: 02476 – 522958 Fax: 02476 – 524963
E-mail: Ala.Szczepura@warwick.ac.uk

ISBN 0 9535430 4 8

1. Clinical Sciences Research Institute, Warwick Medical School / Centre for Evidence in Ethnicity, Health and Diversity (CEEHD) University of Warwick
2. Mary Seacole Research Centre (MSRC) / Centre for Evidence in Ethnicity, Health and Diversity (CEEHD)

Acknowledgements

The evaluation team would like to acknowledge the co-operation and support of a number of individuals. In particular, we have relied on the support of our librarians in both Warwick and De Montfort for ordering materials. We have also been given many suggestions on sources of information from community-based groups, and members of the minority-ethnic-health@jiscmail.ac.uk discussion list. Our contacts at the Department of Health and in other Government departments, and partners in other research projects, have been very understanding, and allowed us to combine activities in order to avoid duplication of work. Finally, thanks to Wendy Brown and Caroline Conneely at Warwick for their administrative support, and response to struggles with deadlines, printing, and photocopying, and maintaining communications between the team members.

This work was undertaken by the UK Centre for Evidence in Ethnicity, Health and Diversity (CEEHD), Warwick University, who received funding from the Department of Health's Policy Research Programme. The views expressed in the publication are those of the authors and not necessarily those of the Department of Health.

CONTENTS

Executive Summary

- This report was commissioned by the Department of Health following a number of earlier reviews of issues relating to ethnicity and health carried out jointly by the University of Warwick and De Montfort University (Johnson *et al* 1999, Szczepura *et al* 1999, Atkinson *et al* 2001).

- The study complements the work programme developed by the Centre for Evidence in Ethnicity Health & Diversity (CEEHD), funded by the ESRC at the two universities, and builds upon earlier work undertaken for the Department of Health and NHS Executive, to extend knowledge of the relevance of linguistic diversity in the context of the NHS.

- The aim of the present study was to identify and review the available research evidence on 'ethnicity and communication' in areas relevant to ensuring effective provision of mainstream services (e.g. via interpreter, advocacy and translation services); provision of services targeted on communication (e.g. speech and language therapy, counselling, psychotherapy); consensual/ participatory activities (e.g. consent to interventions), and; procedures for managing and planning for linguistic diversity.

- Since April 2001, following the implementation of the Race Relations Amendment Act 2000, there has been a statutory duty laid upon all UK health service agencies to ‘have due regard to the need to eliminate unlawful discrimination’, and to make explicit consideration of the implications for racial equality of every action or policy. This literature overview should therefore be viewed in the light of this major new requirement.

- The literature indicates strong linkages between population diversity (in particular ethnic diversity) and variations in service uptake, outcomes and involvement in decision-making, much of this mediated by issues of ‘communication’.

- Defining ‘ethnicity’ and ‘ethnic groups’ is not a simple matter. In essence, the concept of ‘ethnicity’ recognises that people identify themselves with a social grouping on cultural grounds including not only language, but also lifestyle, religion, food and origins (**see Annex 1**). Furthermore, in a world of migration and mixing, it is essential to recognise that these cultures and societies are dynamic rather than fixed.

- The total UK black and minority ethnic (BME) population is relatively large and rising. In the 2001 Census it was 4.6 million, or 7.9%, having risen from a figure of 5.5% in 1991 and 4.2% in 1981. In England, the proportion of minority ethnic origin rises to 9.1%, of whom just over half (4.6% of the population) are of south Asian origins while people of Caribbean and African origin make up 2.3% of the English population. The minority ethnic population has a more youthful age structure than the white population, so population growth will remain rapid over the coming years.

- The black and minority ethnic population is not evenly distributed but is largely concentrated in Greater London, West Midlands Metropolitan County, West Yorkshire, and Greater Manchester. Relatively few live in rural areas. Some specific ethnic groups are even more localised.

- Recent estimates suggest over three hundred languages are used as 'mother tongues' in London. Speaking a language does not necessarily imply literacy.

- The majority of studies on the language capability and literacy of minority ethnic groups in the UK have explored the 'preferred' or 'home' language of South Asian populations. Estimates of language capacity and literacy are available from different sources for both adults and children for different population groups (see **Annex 2**). For the three main resident South Asian ethnic groups (Indian, Pakistani, Bangladeshi), ability to speak English declines with increasing age, is lesser for women than men, and is much less for those born outside the UK. At the same time, those who have acquired English as a second language do get older, and often lose this 'learned' ability.

- Many *asylum seekers and refugees* will have poor levels of literacy in the English language, but no information on their language needs is available. *Seasonal or migrant workers* form another group of increasing significance, but it is difficult to gather information on these groups.

- Thus, the NHS faces a constantly changing picture of language needs with the migration of new groups, including refugees, combined with the language learning process undergone by settlers.

- Several approaches have been identified within the NHS for overcoming language barriers where verbal communication is required as part of the delivery of services (see **Annex 3**). Apart from the provision of interpreter or advocacy services for situations in which verbal communication is required, translation of written or taped (including video) material may also be required.

- This review has revealed a considerable and expanding literature in the field of ethnicity and health and issues directly, or indirectly, related to communication. Our searches produced over 3,000 potential papers for review.

- Extensive evidence is emerging from countries and regions that experience population diversity (including the USA, Australia, Canada and the United Kingdom) on the requirement for **cultural competence** as well as linguistic competence in health care organisations (see **Annex 2**).

- As part of the review process we have examined all this literature and identified key findings for the UK under the following 7 specific headings which can be related to practice areas and policy directions.

1. *Meeting language needs (interpreter/ advocacy services):* Despite substantial evidence in favour of providing proper language support, and demonstration of adverse effects linked to its absence, there is a lack of consistent, universal provision or adequate resourcing of such services in the UK. Indeed, there is little research into cost-effectiveness internationally, or into the direct clinical implications of introducing adequate services. Training is needed, for both users and providers of health care services, in overcoming language barriers. Similar problems are faced in all societies, and do not appear to be time-limited. The growth of globalisation may lead to increasing need, but offers possibilities (e.g. by international telephone linkages) of international solutions. More needs assessment may be required, but should be tied to guaranteed resourcing and evaluation, and adequate time and resources allocated to ensure that initiatives are fully worked through.

2. *Health promotion materials:* In health promotion there are various ‘models that work’ and an array of approaches and procedures for successful health promotion at the very local level. The issue for centralised programmes and policies of health promotion planning is to begin to encourage multiplicities of approach as the rule, rather than the exception to a 'one-size-fits-all' model of health information promotion.

3. *'Tele-consultation' services (e.g. NHS Direct, telemedicine, etc):* The use of existing media, new media and an expanding arsenal of technological advancements for the dissemination of health information is in its infancy. More study is needed to ascertain the effectiveness of these technologies, particularly at the interface of information provision and minority ethnic groups. A single technological approach may prove ineffective, particularly in reaching diverse groups with varying language skills and competencies and/or differing cultural expectations of health information and service provision.

4. *Procedures for managing and planning for linguistic diversity:* The provision of language and cultural support services is still in a developmental phase, but the current situation has been arrived at in an *ad hoc* fashion. Internationally, many ways of managing services have been tried, but there is a lack of systematic evaluation to explore how such services might relate to the stakeholders and structures existing in the UK. A degree of consensus exists around the importance of working with communities locally, integrating cultural awareness and training for staff, and understanding the roles and abilities of different levels of language intermediary. Needs analysis is also seen as an essential element, but similarly, guidance on accepted best practice has yet to emerge. It seems likely that local solutions have been developed in the UK, but are not formally reported or evaluated.

5. *Provision of services which diagnose and treat speech/language conditions:* Bilingual children and older people need to be assessed and treated in their mother tongue by therapists who are both bilingual and culturally sensitive. Training should develop therapists' cultural competencies and sensitivities in order to understand that language and communication disorders are culturally constructed within the often stressful environment of an adopted culture.

6. *Provision of 'talking' therapies (i.e. counselling, psychotherapy):* Empowerment is central to the expressed needs of carers and service users through their demands for information about available services, repeated over and over again in the literature. Individualised service provision that is sensitive to and expressive of cultural needs is highly valued by mental healthcare consumers and their families. Theoretical models need to be explored that will incorporate the multiplicity and diversity of service users, their beliefs and family values. Although interpretation and translation are important services, they do not represent an overall strategy for a proactive mental health system.

7. *Other aspects of ethnicity and communication:* For processes which require consent or participation of the patient effective communication is essential. A 'case study' issue was explored, by focusing on issues relating to organ and/or human tissue donation and transplantation, as illustrating the core issues of informed consent and providing evidence of effective interventions. Language differences and literacy or access to differing media are not the only considerations in this area; instead awareness of cultural issues other than language has particular significance in effective communication.

   We were unable to locate literature on informed consent in the context of research participation, and service planning consultation where the effectiveness of different approaches was discussed - other than papers stating that it had been an issue of concern, or that non-English speakers were excluded because of such concerns.

- At the end of the review process, we were able to identify a number of underlying issues that underpin the literature in all the above areas, and to make a number of recommendations in order to improve linguistic and cultural competence in the NHS.

- **Overview:** Communication requires attention to context, and the needs of the person seeking to transmit information, as well as the characteristics (language, literacy, culture) of the intended recipient. The messenger may be as importance as the message, and some health care workers may not feel comfortable in that role, with particular 'audiences'. Messages must be specifically tailored to their audience, taking religious and other beliefs and practices into account. Information from official sources may be of less impact unless fortified by personal experience and information from intra-community networks which establish a higher level of salience or 'emotional connectedness' with the issues being communicated. UK research and development is so far largely confined to descriptive, clinical, and exploratory work and does not yet include significant evaluation of interventions.

Key Recommendations

Overall key messages:

- Effective communication is central to safeguarding the quality of health care, especially in respect of the needs of members of cultural and linguistic or migrant minorities. Use of 'informal interpreters' in health care settings is dangerous and must be actively discouraged

- In the longer term, consideration needs to be given to moving from an approach based on the model of interpretation, translation, advocacy or language support service (ITALS), towards delivery of 'Culturally and Linguistically Appropriate Services' (CLASS).

- Ethnic monitoring requires the identification of individuals as belonging to groups defined in terms of their culture and origin - this should include language (and religion) and should be enforced.

- Health should develop language support policy and practice with other Government departments, perhaps through an inter-departmental working group: good practice already exists in legal services

- Organisations should have in place policies, structures, practices, procedures, and dedicated resources to support linguistic competence (e.g. those defined by the US National Center for Cultural Competence)

Messages for service planners, commissioners and providers:

- There needs to be support for a national telephone interpreter service to match the requirements of 24 hour emergency health care provision.

- There is a need to raise the awareness of health professionals on the advantages of having access to trained interpreters and on the limits of using relatives as translators.

- Needs assessment is required at national, regional and local levels tied to guaranteed resourcing and evaluation, and adequate time and resource allocated to ensure that initiatives are fully worked through.

- Health promotion activity should be alert to the need to move away from printed materials and passive dissemination towards audio-visual presentation and active engagement with minority communities.

- More consideration can be given to the use of pictorial representation and pictograms, which are also useful for communication with people who have learning difficulties, as well as use of video materials

- NHS Direct Online will require the development of quality assurance procedures for translated patient information materials, and also better dissemination and action to raise awareness of such resources

- When considering 'communication', it must be recognised that there is a difference between 'general awareness' and levels of 'detailed knowledge' and that there are different kinds of information field.

- Translating material into other languages can send out an important signal to minority communities about intentions to be inclusive.

- Interpreters trained 'generically' or for work in legal and commercial settings will require specific training to be effective in working with health specific knowledge

- There is a strong argument for recruitment procedures to seek to develop a more diverse work force in all clinical (and related) professions and settings

- Planners, Commissioners and Providers should work in partnership with black and minority ethnic communities to develop progressive community-based health care.

- There is scope for the development (and evaluation) of training programmes in
  - use of interpreters (for health care workers)
  - managing language support (and language competent) services

- There needs to be an active programme of social marketing to overcome possible reluctance of people to request proper language support.

- ***UK research is needed into:***

  - issues related to management and quality of these services (including quality standards for leaflets/translated materials);

  - pathways to care as key processes subject to different cultural contexts;

  - the clinical implications of not providing interpreter, advocacy and translation services;

  - collection of baseline data on the cultural and linguistic diversity of local areas;

- language learning process undergone by settlers, and language loss associated with ageing;

- effective training of interpreters/ advocates;

- training in the use of interpreters, and training in the management and delivery of ITALS services;

- effectiveness of alternative models of managing language support services;

- the process and outcome of psychotherapy for different groups;

- speech/language conditions, in children, older people or disabling conditions (e.g. stroke);

- cost and clinical-effectiveness studies in UK settings;

- levels of effective internet access among UK populations, and research into 'new technology' use in health

- care provision, explicitly including issues of diversity.

1 INTRODUCTION

1.1 Background

This report was commissioned by the Department of Health to provide an overview of the available research evidence on 'ethnicity and communication'. Literature exists in a number of different areas that suggests strong linkages between population diversity (in particular ethnic diversity) and variations in service uptake, outcomes and involvement in decision-making, much of this mediated by issues of ‘intercultural communication’ (Myhill 2003; Ulrey and Amason 2001; Kramsch 2002). Although communication is an essential component of the physician’s role, it is often the aspect of care with which patients are least satisfied (Stewart *et al* 1999) and therefore there have been developments in recent years in health services to meet the needs of black and minority ethnic groups which have been encouraged by good practice guidelines and local initiatives (Mander 2003; Chase-Ziokek 1999; Lodge 2001). Together with research into epidemiology and ethnic monitoring of services, these have enlarged understanding of the impact of diversity, in particular health care needs that result from the different demographics of minority communities (including their mobility and the arrival of new groups in the form of refugee populations).

Following the implementation of the Race Relations Amendment Act 2000, since April 2001 there has been a statutory duty laid upon all UK health service agencies to ‘have due regard to the need to eliminate unlawful discrimination’, and to make explicit consideration of the implications for racial equality of every action or policy.

There is therefore a policy imperative to ensure that the requirements of black and minority ethnic (BME) groups – including refugees and asylum seekers - are adequately included in initiatives to reduce health inequalities, and that their specific health care needs are met. It is evident that effective communication will be an important factor in achieving this objective because of the evidence that access and use of services is compromised for ethnic minority populations by language and cultural factors (Audit Commission 1994, Szczepura *et al* 1999). In some cases, ensuring effective communication in healthcare may entail provision of *interfaces to mainstream services*, requiring use of interpreters, bilingual workers, advocates and translated materials (written, taped, video, and increasingly web-based information); in other cases it may involve ensuring appropriate provision of *services targeted on communication* e.g. speech and language therapy, psychotherapy services. The present literature overview covers research on 'ethnicity and communication' in terms of both interfaces to mainstream services and services targeted on communication.

In order to produce a readable overview document, we have drawn selectively upon the now rather extensive literature in seeking evidence that is relevant to the specific question at issue, which is the extent to which it can be said that ‘communication’ impacts on access to, or provision of, services to specific minority ethnic groups. In particular, where possible we have identified and assessed any research evidence on:

- issues related to management and quality of these services (including quality standards for leaflets / translated materials);
- any evidence of the clinical implications of not providing interpreter, advocacy and translation services;
- effective training of interpreters / advocates, including training in the use of interpreters.

The current move towards a broader focus on health inequalities and disadvantaged populations should accentuate, rather than reduce, the significance of the findings of this literature overview.

1.2 Ethnicity and ethnic group

The increasing population growth of racial and ethnic communities and linguistic groups, each with its own cultural traits and health profiles, presents a major challenge to health care systems throughout the world.

1.2.1 Defining ethnicity

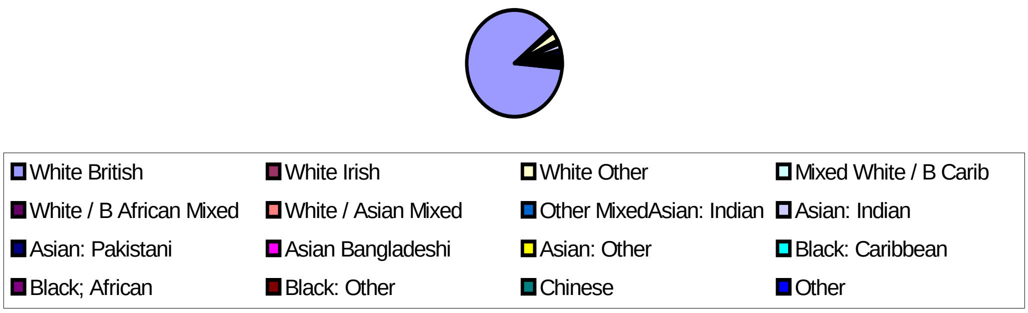
Defining ‘ethnicity’ and ‘ethnic groups’ is not a simple matter. In essence, the concept of ‘ethnicity’ recognises that people identify themselves with a social grouping on cultural grounds including language, lifestyle, religion, food and origins (see **Annex 1**). The basis of ‘ethnicity’ is thus often a tradition of common descent or intermarriage and shared culture or history. Furthermore, in a world of migration and mixing, it is essential to recognise that these cultures and societies are dynamic rather than fixed.

We were aware that there was likely to be substantial variation in the definitions of ‘ethnicity’ used in the articles retrieved. The study began therefore by considering what definitions would be used in describing ethnic groups in relevant literature. For this purpose we chose to use the Thesaurus of ethnic minority terms devised by the Centre for Research in Ethnic Relations, Warwick (Presley and Shaw 1995). This was able to accommodate literature which uses crude level categories such as ‘ethnic minority’, ‘black’, ‘migrant’ as well as that which provides more detailed information on ethnicity (including language and religious categories). Also included are key categories such as Roma or travellers, refugees and asylum seekers.

1.2.2 Multi-ethnic population in the UK

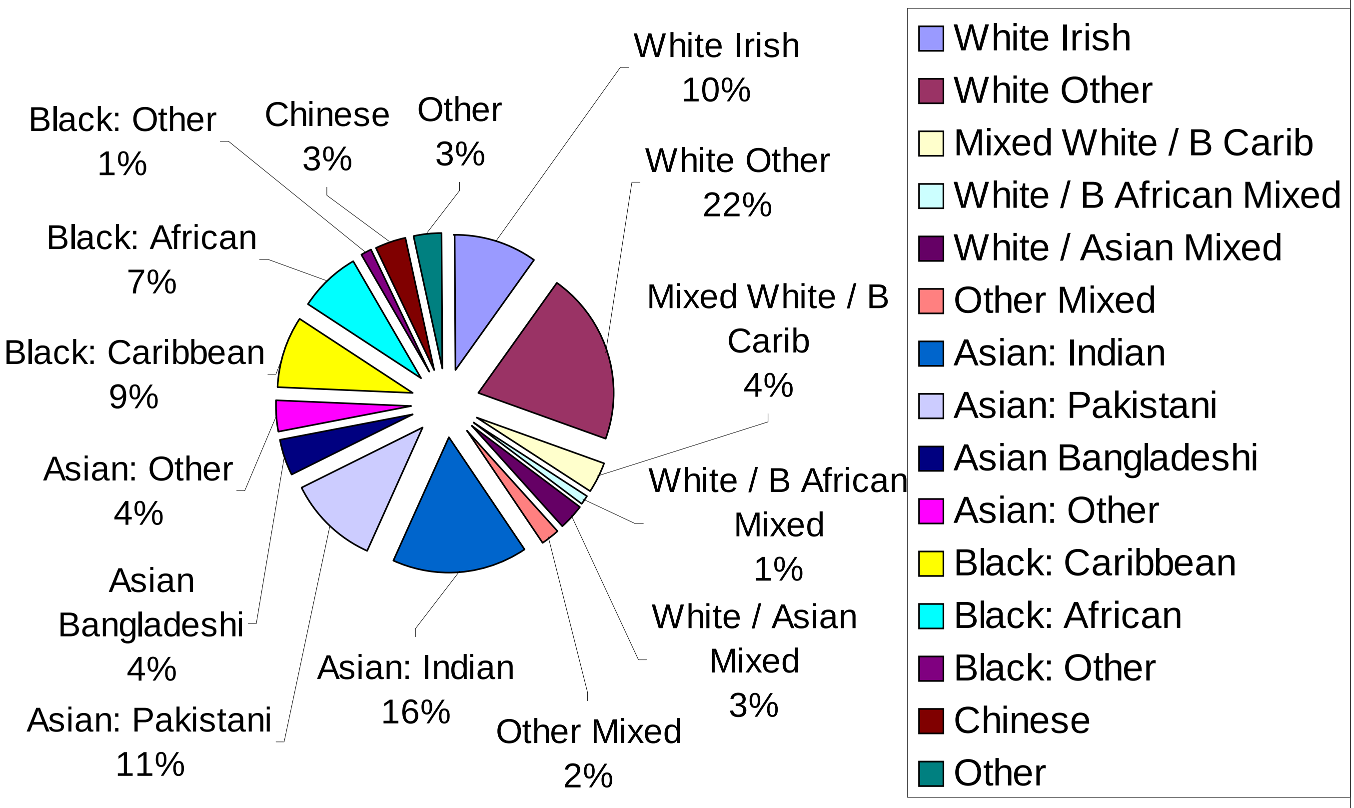
The total UK black and minority ethnic (BME) population is relatively large (see Figure 1 for breakdown of non-White British population) and rising. In the 2001 Census it was 4.6 million, or 7.9%, having risen from a figure of 5.5% in 1991 and 4.2% in 1981.

Figure 1: Ethnicity in the Census - England and Wales 2001



Source: Office of National Statistics - Census 2001 National Report - (CD-ROM)

Breakdown of the 12.5% 'Non-White-British' Minority



Crown Copyright acknowledged: reproduced with permission

The south Asian group accounts for 2 million people. There are 1.15 million 'Black' people; nearly half a million are 'Black Africans', and nearly 0.6 million are from the more established 'Black-Caribbean' population. When confined to the population of England, the proportion of minority ethnic origin rises to 9.1% (one in eleven), of whom just over half (4.6% of the population) are of south Asian (Indian, Pakistani, Bangladeshi, and 'other') origins while people of Caribbean and African origin ('Black') make up 2.3% of the English population: the remainder are of various origins including Chinese, 'mixed' backgrounds, and others including Arabs. The minority ethnic population is more youthful in age structure than the white population. This means that population growth will remain rapid over the coming years.

(i) Geographical distribution

The black and minority ethnic population is principally located in England (83.6 per cent). The four main areas of high ethnic concentration are Greater London, the West Midlands Metropolitan County, West Yorkshire, and Greater Manchester. Relatively few live in rural areas. According to the 2001 Census, 45% (nearly half) of the 'minority ethnic' population lives in the Greater London area, where they form 29% of the population overall. A further 13% of the BME population is resident in the West Midlands. At the same time, they form only about 2% of the population of the North-East and South-West regions, where language support services may be least likely to be attuned to their needs. Other major urban areas show the proportion of people of minority origin to be roughly comparable with the national average. Certain minorities are even more concentrated in London - 78% of the population giving their origin as 'Black African' live in London (largely in four boroughs south of the river Thames) while nearly two thirds of the Caribbean origin population (61%) is also located in London.

Some towns or metropolitan boroughs also have local concentrations of people from particular ethnic origins. More than half the UK population of Bangladeshi origin live in the ‘East End’ of London, mostly in Tower Hamlets. The Vietnamese population, many of whom were refugees in the 1960s and 1970s, have mostly moved to live in London, with smaller numbers in towns such as Nottingham and Derby. Similarly, Leicester was the place of resettlement of Asian people (many of them Gujerati speakers) seeking asylum from events in east Africa in the 1970s, and the 2001 census shows that over a quarter of the population is now of 'Asian-Indian' origin. Birmingham has large populations of Punjabi, Pakistani (and / or Kashmiri) background, as well as a significant population of Caribbean background. The largest number of people of west African background are found in south-east London. The majority of people of south Asian origin in the northern towns of Yorkshire and Lancashire are of Pakistani origin, many deriving from the Mirpur area of Kashmir.

(ii) Religion

The 2001 Census was the first modern one to ask a question about religion in England, Wales and Scotland; 37.3 million in England and Wales stated that their religion was Christian, but 3.1% of the population in England were Muslims, and a further 1.1% were Hindu, 0.7% Sikh, 0.5% Jewish, and 0.3

Buddhist. Numbers of Muslims in Britain have been estimated variously at 1 million and two million, compared to the Census estimate of 1.54 million: many of these, however, may not be members of minority ethnic groups. About half of the 'Indian' group interviewed in a national survey said they were Sikhs, while a further third were Hindu (Modood *et al* 1997).

Although the terms used in the 2001 Census provide a suitable baseline, additional information on language and literacy, and migration history may be required for clinical and health service delivery planning and monitoring.

1.2.3 Monitoring ‘ethnicity’ in UK health care

Since April 1996, the NHS has expected that all hospital trusts will record, and provide as part of the ‘contract minimum data set’ to health commissioners, data relating to the ethnic origin of all ‘admitted patients’, including day cases. Ethnic monitoring requires the identification of individuals as belonging to one or more groups, defined in terms of their culture and origin (Gerrish 2000). Information on ethnicity can be collected in a number of ways. Although there has been a steady growth in the collection of ethnic monitoring data in hospital trusts, there have been relatively few indications of its use.

One of the least threatening and most commonly used identifiers for front-level staff to ask is that of *language* i.e. ‘mother tongue’ or ‘language most commonly used in the home’ - which can be seen to relate directly to the needs of the client. Unless language is asked about, and recorded, providers may have no idea of the need for interpreting and translation services. However, data on the size of language needs in relation to different NHS activities is not well documented. Furthermore, effective communication in health care may also require awareness of other aspects of culture, apart from language (see **Annex 1**).

1.3 Language needs and cultural / linguistic competence

1.3.1 UK ethnic groups and language needs / literacy levels

Data on UK minority ethnic population size is not necessarily a good indicator of the facility in English language of these local populations. This is because people from some minority ethnic groups (e.g. Black-Caribbean people) overwhelmingly have English as their first language, while a number of surveys (such as those carried out by the Health Education Authority) have shown that people from other minority ethnic groups born in the UK are mostly quite competent in the English language (and often report English as the language they understand best).

The majority of studies on the language capability and literacy of minority ethnic groups in the UK have explored the ‘preferred’ or ‘home’ language of South Asian populations, or relied on school-based data to estimate the number of languages spoken (and the size of child populations speaking another language at home) without being able to project from these back to true population estimates. Recent estimates suggest over three hundred languages are used as ‘mother tongues’ in London. Speaking a language, however, does not always imply literacy in it, nor lack of English. Levels of skills in English also vary, both between people speaking different languages, and also from town to town between people who appear to be of similar ethnic origin.

Three major national surveys have collected data in recent years which provide the opportunity to make some detailed estimates of adult language capacity and literacy (Rudat 1994; Johnson *et al* 2000; Modood *et al* 1997). A number of patterns consistently emerge; with most evidence available for south Asian population groups (see **Annex 2**). For the three main resident South Asian ethnic groups (Indian, Pakistani, Bangladeshi), ability to speak English declines with increasing age, is lesser for women than men, and is much less for those born outside the UK. However, there are also variations between ethnic groups. Thus, on current data, (Asian) minority ethnic women especially in Muslim cultural groups are the least likely to speak or read English: they may also not be literate in their ‘mother tongue’. Some languages, notably the Sylheti dialect of Bangladesh, do not have an agreed written form. Those who can speak Punjabi or a dialect variety of it, including Kashmiri forms such as Pahari and Mirpuri, may not be able to read it, or only to read in either Urdu or the ‘Gurmukhi’ (Devanagri) script. Older people of Bangladeshi origin in particular have a limited ability either to understand (spoken) English or to read (any language). Even in the early ‘middle-age’ group (30-49), there are significant numbers of Bangladeshi and Pakistani women who will be essentially illiterate in any language, and who also do not speak English. At the same time, those who have acquired English as a second language do get older, and often lose this ‘learned’ ability.

Another important source of information on cultural and linguistic diversity is the data from Local Education Authorities. This includes censuses of ethnicity of schoolchildren and surveys of first languages spoken. In London schools more than 300 languages are spoken by children, and for more than a third of pupils English is not the language used at home. School-based data have also been used to estimate the total number of people in London speaking specific languages (Storkey 2000).

Finally, net international migration to the UK has been at extremely high levels during the 1990s, an important part of this being made up of *asylum seekers and refugees*. Many such people will have poor levels of literacy in the English language, and therefore any consideration of the magnitude of language needs should take this factor into account, especially for Health Authorities in London. The Office for National Statistics does include estimates of the number of asylum-seekers, but no information on their language needs is available. Migrant workers form another group which may be of increasing significance, although one of political sensitivity. Nevertheless, in rural areas also there are significant numbers of NESB European workers, but because most data sources focus on more 'easy to reach' minority ethnic groups, it is also difficult to gather information on groups such as *seasonal or migrant workers*, who will have communication and language needs that will have to be met by the NHS.

Thus, the NHS faces a constantly changing picture of language needs with the migration of new groups, including refugees, and the learning process undergone by settlers.

Attempts have been made to estimate language need by geographical location taking these factors into account. The results of one such exercise (Szczepura *et al* 1999), using population data from the 1991 Census, English language ability data (Research Services Limited Social Research 1995; King *et al* 1996), and information on asylum seekers and refugees are shown in **Annex 2**.

1.3.2 Approaches to overcoming language barriers

Verbal communication: Interpreters and patient advocates

Several approaches have been identified within the NHS for overcoming language barriers where verbal communication is required as part of the delivery of services in primary and secondary care (Szczepura *et al* 1999). These include: patient selection of GPs (Ahmad *et al* 1989); use of bilingual health care workers (Phelan and Parkman 1995); use of full-time professional interpreters or experienced sessional interpreters (Ntshona 1997); use of tele-interpreter services and other forms of new technology such as touch-screen kiosks (Jackson and Peters 2003; Hornberger *et al* 1996; Leman 1997); and planned roll-out of language support services in the NHS-Direct programme (Cooke and Margerison, 2003); use of patient advocates (Chiu 1991; Parsons and Day 1992); use of volunteer and ad hoc interpreters (Phelan and Parkman 1995); and use of English speaking family members and friends as an interpreter (Ahmad *et al* 1989; Poss and Rangel 1995). Distorted communication and confidentiality are especially problematic in cases involving issues such as sexuality and child abuse (see **Annex 3**).

Non-verbal communication: Translated materials

Apart from the provision of interpreter and advocacy services for situations in which verbal communication is required as part of health care delivery, translation of written or taped (including video) material may also be required within the NHS. This can involve anything from the provision of menus in other languages, to the provision of leaflets and reports which are accessible to those who cannot read or speak English, or the adaptation of signs in hospitals and clinic locations. Some attention has been given to the use of pictorial representation and pictograms, which are also useful for communication with people who have learning difficulties (Nicoll 1998; Miller and Lewis 1999).

1.3.3 Organisational linguistic and cultural competence

Extensive evidence is emerging from countries and regions that have experience of population diversity (especially the USA, Australia, Canada and also the United Kingdom) on the requirement for linguistic and cultural competence in health care organisations (see **Annex 2**).

Linguistic Competence

Linguistic competence in health care, mental health and other service delivery systems refers to the capacity of an organisation and its personnel to communicate effectively, and convey information in a manner that is easily understood by diverse audiences including persons of limited English proficiency, those who have low literacy skills or are not literate, and individuals with disabilities. For ethnic minority communities this might include, but not be limited to, the use of: bilingual / bicultural staff; cultural brokers; foreign language interpretation services including distance technologies; materials developed and tested for specific cultural, ethnic and linguistic groups; translation services including those of: (i) legally binding documents (e.g. consent forms, confidentiality and patient rights statements, release of information, applications), (ii) signage, (iii) health education materials, (iv) public awareness materials and campaigns; and ethnic media in languages other than English (e.g. television, radio, Internet, newspapers, periodicals).

In order to demonstrate linguistic competence, it has been suggested that organisations should have in place policies, structures, practices, procedures, and dedicated resources to support such linguistic competence capacity (US National Center for Cultural Competence).

Cultural Competence

Although language barriers to delivery of health care may be important, it is also well documented in the literature that various aspects of culture may similarly influence successful health care delivery. These are likely to be more persistent than language needs, and include:

- patients' health, healing, and wellness belief systems;
- how illness, disease, and their causes are perceived;
- the behaviour of patients / consumers seeking health care, and their attitudes toward health care providers;
- the views and values of those delivering health care, which can compromise access for patients from other cultures.

Thus, an organisation that is culturally competent is one that recognises that the provider and the patient each bring their individual learned patterns of language and culture to the health care experience (US National Center for Cultural Competence). Health care service responsiveness to the health beliefs and practices, and cultural needs of diverse patient populations is necessary in order to achieve equity in access and quality health care. Cultural competence is a developmental process that evolves over an extended period in an organisation.

In order to demonstrate cultural competence, it has been suggested that organisations should, among other things, have a defined set of policies and structures that enable them to work effectively cross-culturally; have the capacity to acquire and institutionalise cultural knowledge; adapt to diversity and the cultural contexts of communities they serve; and incorporate these elements into all aspects of policy making, administration, practice / service delivery and systematically involve consumers / families.

2 STUDY OUTLINE

2.1 Aims and objectives

The main aim of the research was to identify and collate:

- available research evidence on issues associated with minority ethnic groups and communication in a range of healthcare contexts.

This would build upon our earlier reviews, especially that undertaken for the NHS Executive London on 'ethnicity and health service access' (Atkinson *et al* 2001). The present study would address three main questions:

- What is the overview of the available literature (academic papers and 'grey' literature) and research in progress in the following four broad areas?
    - provision of mainstream services;
    - provision of services targeted on communication;
    - consensual / participatory activities; and
    - procedures for managing and planning for linguistic diversity.

- What evidence does this overview provide to produce an informed commentary relating the findings to different contexts that will most effectively enable use by policy makers and practitioners?

- What are the gaps in the available research evidence and what recommendations do these gaps suggest for future research?

The project was directed by a Review Management Group consisting of Professor Ala Szczepura, Professor Mark Johnson, Dr Anil Gumber (reviewer), Dr Kip Jones (reviewer), Diane Clay (Librarian, Health Literature Specialist), and Anne Shaw (Librarian, Ethnic Literature Specialist). The Review Management Group was supported by Wendy Brown and Caroline Conneely (Clerical). The Review Management Group met at regular intervals throughout the course of the review.

2.2 Review process

The purpose of the review was to provide a succinct, research-based overview of the field which could inform policy and practice; to identify findings that might help ensure that the health needs of individuals from a range of ethnic minority backgrounds are met; and to support the introduction of changes to achieve this latter objective. It was recognised from the outset, that it would not be possible to produce detailed, systematic reviews of each area within the planned timeframe of the study (12 months), or within the budget available. Also, although our overview might identify specific questions which could subsequently be addressed by a Cochrane-type systematic review of the available trial evidence (e.g. are interpreters effective in improving outcomes for ethic minority patients?), or by a Campbell-type review of the available qualitative research evidence (e.g. what type of interpreter support do ethnic minority patients require?), these questions could not in themselves be addressed in our overview of the literature.

Thus, although our overall approach was modelled on that adopted by the Cochrane Collaboration on Effective Professional Practice for systematic reviews of the clinical, scientific literature (Sheldon and Chalmers 1994), this essentially ‘scientific’ approach was adapted to allow for the methodological diversity inherent in the research literature we accessed. The methodological issues associated with reviews of qualitative studies and overviews such as the present one are now being considered by the developing Campbell Collaboration for social sciences research (Campbell Collaboration 2005). The review might therefore best be considered to be systematic in the approach which we adopted, rather than a systematic review in the Cochrane sense. The approach used largely mirrored those used in our earlier reviews (Szczepura *et al* 1999, Johnson *et al* 1999; Atkinson *et al* 2001).

As the first stage, a review framework was developed for use in the study. This focused on a number of different aspects of ethnicity and health and was designed to enable the research-based evidence gathered from the literature to be recorded, compared and integrated into a final review. The Review Management Group met at the outset of the study to develop the framework, and to draw up a series of outline literature search protocol which could be used to approach the overall research question of communication in health services with members of minority ethnic groups. The framework was thus one which reflected the key comparisons to be made in the review itself, as well as directing the systematic review process.

It was recognised that this initial framework would need to be refined as the study progressed, using articles identified in the initial literature search to test its appropriateness. The preliminary framework was discussed at subsequent meetings a final version agreed which reflected the key comparisons to be made in the review itself, the availability of research evidence, and the perceived importance of the area. **Seven main topic areas** were identified, which were then incorporated into separate review processes:

(i) meeting language needs (interpreter / advocacy services)
(ii) health promotion materials (including specialist materials and web-based materials);
(iii) 'tele-consultation' services (e.g. NHS Direct, telemedicine, e-mail consultations etc).
(iv) procedures for managing and planning for linguistic diversity
(v) speech and language therapy (provision of services which diagnose and treat speech / language conditions);
(vi) 'talking' therapies (i.e. provision of counselling, psychotherapy etc)
(vii) other aspects of ethnicity and communication e.g. consensual / participatory activities

The review process for each consisted of three stages: a literature search and selection of suitable articles; assessment of article content, quality and relevance; and data extraction and synthesis. Literature searches were conducted by a trained information scientist using systematic search strategies. Abstracts and papers were reviewed by independent reviewers.

2.3 Strategies for identifying relevant research evidence

2.3.1 Database searches (published articles)

A number of preliminary search strategies were tested, looking at the question of 'communication' using the MeSH terms available, and 'ethnicity', using MeSH terms and a combination of other key words. It was found that 'exploding' these higher-level MeSH keywords could, with the addition of text-word searches, cover virtually all articles which dealt with racial or ethnic minority groups, even if the precise keyword had not been used. The seven main topic areas, in terms of the aspect of 'communication' covered, were then explored separately in greater depth. Following the preliminary scoping searches, we examined the effects of expanding the search terms, and a number of test searches were explored where a more detailed and sophisticated search strategy could be developed. The Review Management Group discussed the findings of these searches, and then considered a number of additional possible search terms. The review group also sought to expand the search terms used by referring to issues of equity or inequality and barriers to access.

Since the relevant literature crosses several disciplinary boundaries, systematic literature searches were then undertaken, and repeated in a range of general as well as specialist databases (see **Annex 4**). Articles were restricted to English language publications. A publication date of January 1st 1998 was used as the date filter for papers entered into the final review. Searches were updated during the period of the review.

2.3.2 Bibliographies and hand searching

Database searches were supplemented by a variety of strategies, including ‘hand-searching’ of more recent issues of journals, and ‘cascade-searching’ (c.f. Davies *et al* 2000). Follow up of other leads such as current research, citations in reviews, and editorials in major scientific journals, were also used. By searching the bibliographies of retrieved articles, further relevant papers were identified. Bibliographies can be good additional sources of articles for diffuse topics such as the present one (Atkinson *et al* 2001). Finally, hand-searching was also conducted on the very extensive personal collections of offprints developed by CEEHD.

It has to be noted that while the classic methods of electronic searching generated very significant numbers of citations, they certainly appeared to miss some which were obtained by other means.

2.3.3 Identification of 'grey' printed and electronic literature

An important element of most systematic reviews of ethnicity is the inclusion of material available only as 'grey literature' e.g. reports, electronic materials etc. Previous studies in this field have demonstrated the significance of these sources for evidence relating to minority ethnic groups.

We therefore searched two grey literature electronic databases: HMIC (Health Management Information Consortium) which is a strong source of semi-published literature and reports and the British Library Catalogue for other references. An extensive internet search was also carried out using Google. A number of sites were checked for useful material including the CRE, Runnymede Trust and ERCOMER (European Research Centre on Migration and Ethnic Relations - a site in the Netherlands), HDA, HARP, UNHCR, Royal College of Speech and Language Therapists, National Centre for Cultural Competence (USA). Additional materials were added from the CEEHD's own internal collections and other reviews or studies undertaken at CEEHD, providing that they met the universal criteria of the review.

Together, these various search methods produced a total of 2,972 publication hits which could be entered into the review process. Details of the searches carried out and the number of resultant hits are shown in **Annex 4**.

2.3.4 Identification of research in progress

Information was also collected on research in progress in a systematic manner via use of existing databases (e.g. NHS Research Findings Register (ReFeR), National Research Register (NRR)), and through contacting key bodies and networks (including e-mail groups). In some instances, the knowledge and expertise of academics, community organisations and others who specialise in aspects included in the review (e.g. NHS Direct and the Institute of Linguists / National Register of Public Service Interpreters) was obtained via telephone / email / face-to-face interview.

2.4 Strategies for selection of papers for review

Once the literature search had identified possible items for review, inclusion criteria for selecting materials to be reviewed and decision rules for operationalising these had to be defined and applied. Searches of the electronic databases identified 4,842 publications (see Tables 4.1 and 4.2 Annex 4), and examination of bibliographies, hand searching of selected journals, and contacting of key researchers in the field produced a final total of nearly 5,000 papers. Once repeat hits in different databases had been excluded, and papers that were clearly not relevant excluded (see Annex 4), there were in excess of 3,000 potential papers for review. Clearly, it would not be feasible to review all full-text articles within the planned timeframe of the study. This meant that a pragmatic approach had to be developed for selection of papers for review. A two stage process was developed.

2.4.1 First stage of process for selecting papers for entry into review

Based on an initial examination of a selection of abstracts, the following three main inclusion criteria were identified. Articles were considered for inclusion in the review (in all seven topic areas of the review) if they:

1. provided an *abstract* (so that a decision could be made on content) unless the full article was available in our resource centres or private collections or the title unambiguously demonstrated relevance;

AND

2. specifically mentioned one of the *pre-defined aspects of communication* in health care and specified ethnic minority groups, even if ethnicity was defined at a crude level in terms of our Thesaurus (Presley and Shaw 1995);

OR

3. were a *review article* of the literature in the area of interest.

A printout of the abstracts of those articles which passed this initial test was then made, for scrutiny by the review team.

In addition, for most topic areas a publication date of January 1st 1998 was used as the date filter for the final review (although some searches did go back to 1990 – see **Annex 4**). Earlier papers were only included if more than one member of the research team identified a particular article as 'seminal' i.e. a well cited article which contributed substantively to the review.

2.4.2 Second stage of process for selecting papers for entry into review

The following three step approach was adopted for filtering the published papers identified above.

Step 1: Inclusion (applied to abstract)

It was decided to read all the abstracts and to retrieve all articles which met set inclusion criteria. Various selection criteria were tested on the abstracts, but the most effective proved to be the simplest. An article was included if the abstract met further particular conditions, **depending on the review topic area** as follows:

Topic area 1: Meeting language needs (interpreter / advocacy services)

Papers were considered for inclusion in the review if, in addition to main criteria 1-3 above, they also:

- reported research that specifically focused on communication or interpreter / language needs in the context of a defined aspect of health care, excluding non-linguistic communication (e.g. body language);

- **either** presented UK based findings **or** findings relevant to UK ethnic minority groups **or** generic findings relevant to UK Health Service practice (e.g. excluding articles where the service provider does not speak the majority language).

Topic area 2: Health promotion materials (including specialist materials & web-based materials);

Papers were considered for inclusion in the review if, in addition to criteria 1-3 above, they also:

- reported research that specifically focused on translated materials, including representation of ethnic minorities, in the context of a defined aspect of health promotion in a health care context, but excluding non-health care settings (e.g. workplace, religious centre), service users' experience, or theoretical background material;

- **either** presented UK based findings **or** findings relevant to UK ethnic minority groups **or** generic findings relevant to UK Health Service practice **or** pilot projects with potential merit for further consideration and testing

Topic area 3: Tele-consultation' services (e.g. NHS Direct, telemedicine, e-mail consultations etc).

All papers meeting criteria 1 - 3 above were read because of the limited amount of literature identified

Topic area 4: Procedures for managing and planning for linguistic diversity

All papers meeting criteria 1 - 3 above were read because of the limited amount of literature identified

Topic area 5: Provision of services which diagnose and treat speech / language conditions

All papers meeting criteria 1- 3 above were included, and because of the limited amount of literature identified it was decided to include the majority of the literature identified in this section.

Topic area 6: Provision of 'talking' therapies (i.e. counselling, psychotherapy)

Papers were considered for inclusion in the review if, in addition to criteria 1-3 above, they also:

- reported research that specifically focused on provision of talking therapies, including counselling, psychotherapy including specific consideration of ethnic minorities, service users' experience or theoretical background material;

- **either** presented UK based findings **or** findings relevant to UK ethnic minority groups **or** generic findings relevant to UK Health Service practice **or** pilot projects with potential merit for further consideration and testing

Topic area 7: Other aspects of ethnicity and communication e.g. consensual / participatory activities

Papers were considered for inclusion in the review if, in addition to criteria 1-3 above, they also:

- reported research that specifically focused on available evidence on the effectiveness or cost-effectiveness of different approaches designed to improve consent / participation for ethnic minority groups i.e. consent to treatment and other procedures (e.g. organ donation), compliance or concordance in treatment / medication, involvement of ethnic minorities in trials, or consent to use and disclosure of medical data;

- **either** presented UK based findings **or** findings relevant to UK ethnic minority groups **or** generic findings relevant to UK Health Service practice **or** pilot projects with potential merit for further consideration and testing

At this stage, one of two independent reviewers checked all the abstract or text to ensure that these major inclusion criteria were satisfied. This early screening enabled the exclusion of many items, including some items which on closer examination of the abstract proved not to be relevant to the UK setting.

Step 2: Exclusion (applied to full article)

On obtaining the full article, it was possible to examine whether the criteria used above had been met properly, or whether the abstract gave a misleading impression. This was often the case, when key words appeared but the full text showed that there was less detailed analysis or data than expected. The following exclusion criteria were applied by two independent readers to all articles selected at step 1 above:

- excluded if ethnic minorities or ethnicity ‘mentioned in passing’ and not a significant focus
- excluded if no mention of access and / or (differential) uptake of services
- excluded if not generalisable / appropriate to UK (settings or groups examined)

When examining whether ‘ethnic groups’ were discussed, papers which used the essentially ‘racialised’ notion of ‘non-white’ were, almost without exception, ignored as grouping together populations whose cultural, genetic and other characteristics rendered any form of generalisation (other than that they were ‘different’ from the ‘majority’) meaningless.

All items successful at this stage were entered into a central consolidated Research Bibliography.

Step 3: Identification of papers for full review

A final filter stage was used to select papers in terms of their quality and content for inclusion in the review. Because most of the studies were of a qualitative nature, qualitative principles were used to conceptualise and conduct the review systematically at this stage (Jones 2004). Such studies were not judged on formulaic criteria or exclusionary frameworks; the watchwords for inclusion were: *Purpose, Appropriateness* and *Fit.* Articles were selected for their capacity to contribute in a meaningful way to (i) *The research question* and (ii) *The target area of study under consideration by the individual investigator* and were read in full.

Although the pragmatic decisions above might be viewed as a departure from a *systematic review* of the literature, they were carefully monitored and driven largely by the type of research material uncovered. Furthermore, although the concept of a systematic review is well known and accepted for assessing evidence on the effectiveness of health care interventions, it is far less well developed or pertinent when providing an overview of a broad field of largely qualitative literature on ethnicity and communication in health care.

A total 141 articles and papers were finally identified for review. In addition, it was judged to be of value to retain a 'master bibliography' of all materials identified as of relevance to the topic areas of the review. The final master bibliography contained 363 published articles and grey literature papers. This included papers that were later excluded but might be of interest in a bibliography. New material was continually coming to our attention through various sources. Such items were included in the master bibliography if located up until the end of February 2004.

2.5 Strategies for data extraction and synthesis of papers

An annotated bibliography was first produced for each research area based on the papers selected in step 3 above. These annotated bibliographies, which we have developed in previous reviews, are useful in providing an overview and enable valuable information to be retained that would otherwise be lost. The annotated bibliographies also allowed us to build up more detailed profiles of the evidence in particular areas, including the quality of the research available and any research gaps.

The final stage involved synthesis of the available evidence in each area. The literature for each area was read in full and synthesised using an analytical approach of emergent themes (Jones 2004), using a method of 'Signal and Noise' (Edwards, Russell and Stott 1998; Edwards, Elwyn, Hood and Rollnick 2000; Booth and Fry-Smith 2001; Higginson, Finlay, I. *et al* 2002) to balance methodological rigor against the strength of the message itself for each paper. Thus, the qualitative meta-synthesis used was based on themes, interventions and results, but without attempting to combine the data into one variable. As reading progressed, a growing sense of both contexts and themes emerging from the existing literature on communication and race / ethnicity / diversity, and key themes and findings developed.

For each of the seven topic areas our syntheses not only included consideration of the main conclusions that could be drawn from the literature, but also the implications for policy makers and practitioners, and the relevance of the findings for decision-makers. Each topic area's *Discussion* was based in the read papers resulting in *Key Findings* which, in turn, produced the *Main Conclusions* for each topic under review. By adopting a similar structure, points raised in the *Discussion*, *Key Findings* and *Main Conclusions* could be compared and contrasted with other selected topic areas. This approach is particularly necessary in reviews of qualitative studies where synthesis is attempted rather than a simple reduction and / or distillation of results such as is the case with traditional randomised control trials or more quantitative reviews. In this way, policy and practice developers are given information that positions them to be able to identify positive policy and practice initiatives.

Thus synthesis was achieved by the use of an inductive analytic method of case study - building the knowledge base, case by case. Research in the field of ‘race and ethnicity’ is peculiarly subject to contested definitions and flexible, not to say moving uses of terms. There is certainly not “a high degree of consensus on the definition of problems and methods, where there are accepted means of defining these operationally which lead to a standard use of keywords and where the results come in forms that can be treated as equivalent. We have, therefore, had to adopt a more eclectic approach, while seeking to ensure a degree of systematic analysis, and an inclusive albeit rigorous paradigm for both searching out and accepting materials for consideration in this review.

3 RESULTS

3.1 Overview of the literature reviewed

The literature overview has revealed an extensive and expanding literature in the field of ethnicity and health and issues directly, or indirectly, related to communication. Our initial searches produced over 3,000 potential papers for review. As part of the review process we examined this literature and identified key findings under specific headings which can be related to practice areas and policy directions. The sub-sections which follow present our analyses of materials in each of these areas. Details of the key publications specifically mentioned in each area sub-section are provided in section 5. A more extensive, consolidated master Bibliography is also presented in **Annex 6**, including a selection of some of the relevant websites discovered. An **Annotated Bibliography** is available at ethnic-health.org.uk.

At the end of the review process, we were able to identify a number of underlying issues that underpin the literature in all these areas, and to make a number of recommendations. These are presented in section 4. It is hoped that the overview presented below will support an evidence-based approach to meeting the requirement for linguistic and cultural competence in the NHS.

3.2 Meeting language needs (interpreter / advocacy services)

The literature overview of this area builds on our earlier literature reviews of interpretation, translation, advocacy or language support (ITALS) services (Szczepura *et al* 1999, Johnson *et al* 1999), and our more recent review of ethnicity and access (Atkinson *et al* 2001). The former review also addressed the cost of different forms of ITALS service provision. The current study updated the findings from all these reviews (which are summarised in **Annex 5**). In addition, where possible we identified and assessed any research evidence on: issues related to management and quality of services in the UK; any evidence of the clinical implications of not providing ITALS services; and research on effective training of interpreters / advocates, including training in the use of interpreters. Our original reviews were limited to spoken and written language services, but the current review also examined the evidence on web-based and electronic means of communication; this is considered in section 3.4.

Several approaches have been identified within the NHS for overcoming language barriers where verbal communication is required as part of the delivery of services. These will vary in their effectiveness or ‘adequacy’, costs, and generalisability to different locations. The main models in use in the UK for provision of interpreting / advocacy services are described in **Annex 3**. National good practice guidelines for culturally and linguistically competent health care from the USA (that cover Language access services;

Culturally competent care; and Organisational supports for cultural competence) are described in **Annex 2** (section 2.5).

3.2.1 UK literature on language barriers to access and need for interpreter services

There continues to be evidence of the language and cultural barriers faced by ethnic minorities in the UK when accessing health services. Several studies have shown poor knowledge or understanding of English amongst particular groups of black or ethnic minorities, especially women and older people. The issues which arise where service providers and patients do not share the same language and culture have been widely regarded as a key barrier to access to health and other welfare services for these groups. Policy recommendations by the Department of Health in the recent past have focussed on the need to overcome the language and cultural barriers in both primary and secondary health care through methods such as the provision of appropriate interpreting services, employment of staff who speak a range of languages, and the appointment of link-workers or facilitators. Some of the more recent UK literature available on these aspects is presented below.

Language and communication continue to be reported as principal barriers in the UK to accessing health services by ethnic minorities for serious neurological disorders (Baxter and Baxter 2000); for coronary heart disease amongst South Asians in Leicester (Farooqi *et al*. 2000); and for utilisation of primary health care services by Bangladeshis in Cardiff (Hawthorne *et al* 2003). There is a larger literature on south Asians and the influence of language barriers on access to other forms of care, particularly in relation to maternal and child health. Certain linguistic communities, notably the Chinese, Bangladeshi and some other refugee-origin groups (e.g. Vietnamese) have been more intensively studied than others.

There is a recent research literature on the Chinese population in the UK. Sproston *et al* (2001) found that Chinese people in England were less likely than people from other minority ethnic groups to consult their GP, even after their relative health status was taken into consideration. Use of general practitioners by Chinese people was associated with a number of factors, of which the strongest predictor was the ability to speak English. Chinese who speak English were more likely than those who did not, to consult their general practitioner. Kwan and Williams (1998) identified language barriers for obtaining dental care services by Chinese people in the north east of England. Green *et al* (2002) while evaluating mental health services for Chinese women in South-East England found that a lack of communication resulted in delayed diagnoses, misunderstood treatment regimens, and deterred women from (re-) presenting to the NHS. These problems were more acute for those women who were most marginalised from English-language culture. Li *et al* (1999) describe various barriers encountered by Chinese people with mental health needs in England. The main barriers observed were language, interviewees' perceptions of symptoms as somatic rather than psychiatric in origin, lack of knowledge about statutory services, and lack of access to bilingual health professionals.

Hayes (1995) has provided a review of some of the issues surrounding barriers to access in maternity care for Asian women. This points out that these women may have a poor command of spoken English, and that Asian women who register with a GP with skill in their own language (one of the models for provision of interpreting in the UK*)* who is not on the local obstetric list have a 2 fold increased risk of having a perinatal death, compared to those registered with a listed GP. Fewer than half of district health authorities were found to have an interpreter / linkworker service; instead women were advised to bring someone with them for the purposes of interpretation.

More recently, Bulma and McCourt (2002) in west London have found that several Somali refugee women did not gain equal access to maternity services due to inadequate provision of interpreting services, stereotyping and racism from health service staff, and a lack of understanding from staff of cultural differences. A further issue found to affect the Somali women was poor management of female genital mutilation in pregnancy and labour. Similar views on dissatisfaction with maternity care by Bangladeshi women have been reported by Duff *et al* (2001). Davies and Bath (2001) explored the maternity information concerns of a group of Somali women in a Northern English city and investigated the relationships of these women with maternity health professionals. The study indicated that poor communication between the non-English speaking Somali women and health workers was perceived as an underlying problem in seeking information. Fears about misinterpretation and confidentiality also limited the usefulness of interpreters. The Somali women perceived that they were denied information due to punitive attitudes and prejudiced views among health professionals.

Uptake of immunisation for their children has also been reported to be low among South Asian and Chinese women. Larcher *et al* (2001) studied the barriers in uptake of hepatitis B immunisation among children of ethnic minorities in Hackney, London. The study concludes that in an area with high prevalence of hepatitis B carriage, mobility, and diverse ethnicity, a dedicated centralised immunisation service can be highly effective, provided that adequate support services (translation, counselling, and parental referral) are available.

Lack of awareness about availability of language support services also affects equity in access. Free *et al* (1999) examined the influence of communication difficulties, lack of knowledge of services, and the appropriateness of services in accessing out-of-hours health services by Vietnamese community in South London. Participants did not know about GPs' out-of-hours arrangements and their access to the range of services normally available was limited. They were unable to communicate with health care professionals or answering services and were also unaware of out-of-hours interpreting arrangements. Generally, participants were dependent on other people in gaining access to services. Some participants had used 999 services despite communication problems. Participants' experienced delays in seeking health care services and confusion regarding the medicines and advice given. Madhok *et al* (1998) while describing satisfaction level with health services among the

Pakistani population in Middlesborough found that only 5 per cent of hospital in- or out-patients were informed of the availability of a professional interpreter, and none used the service. One quarter of patients said that they would have used the interpreting service if they had known about it. The study also observed that the policies on culturally sensitive meals, as well as interpretation services, were not properly implemented.

Box (1998) has reported low cervical cancer screening levels among ethnic minority groups due to lack of general awareness. Health advocates revealed that they did not advertise their availability for such consultations because they feared they might be swamped with excess demand for their services. Advocates also suggested that the quality of their relationships with medical professionals was sometimes not what they would wish. It was concluded that there was a need for improved staff training for those involved in cervical screening so that interpreters and advocates are used as appropriate, and so that patients who consent can give informed consent. Thomas *et al* (2000) aimed to establish the efficacy of introducing trained bilingual health advocates for non-English speaking cancer patients. Male and female Bengali advocates received appropriate training. They were then given a group of patients to manage, while a control group received no such intervention. Outcomes were determined at the baseline and after three months. An interim analysis shows that the advocates had only recruited half of the expected number of Bengali cancer patients. Focus groups showed, however, that healthcare professionals felt that their training was inadequate to overcome language and cultural barriers, and many were distressed that they were not meeting the needs of minority ethnic patients. The authors anticipate that this study would reinforce research in other health sectors where bilingual health advocacy has been beneficial, and that future care would be better informed as a result. An interim conclusion, which we may draw from this and other studies, is that the introduction of such systems requires more time and planning than has been typically allowed for - and that more projects should report their evaluation findings, even when (as here) they are less than successful on early expectations.

3.2.2 Use of professional interpreter services or bilingual providers

Effective communication is central to safeguarding the quality of health care. Communicating with patients / clients that do not speak English as their preferred language brings an added dimension to communication that demands additional skills and knowledge on behalf of the health professional. There are several options for improving communication available to health professionals (see **Annex 3**). It may seem both convenient and reassuring for the client to use members of their family as an interpreter. This practice is fraught with difficulties, however, in that someone close to the client may find it difficult to stop their own views about the situation colouring their translation; family members may wish to protect someone from bad news or to conceal sensitive issues such as domestic violence or abuse. Furthermore, confidentiality is lost and the client themselves may be reluctant to discuss certain issues. Thus, the perceived benefits of using family and friends are out weighed by the pitfalls. Often, informal lists of staff or volunteers prepared to interpret are available and although this arrangement can be helpful at times it is not recommended, as volunteers are generally untrained and may have poor knowledge of health issues and professional communication. The ideal solution would be bilingual health workers who can carry out clinical work in the clients preferred language. However, bilingual health workers are few in numbers. The other best option is the use of trained interpreters or advocates who are able to maintain confidentiality and are skilled in interpreting.

(i) General Services

Jacobs *et al* (2001) examined whether professional interpreter services in the USA increased the delivery of health care to limited-English-proficient patients through a two-year retrospective cohort study. Preventive and clinical service information was extracted from computerised medical records from a large HMO in New England. Clinical service use and receipt of preventive services increased in both groups from year one to year two, and the study indicated that provision of professional interpreter services increased delivery of health care to limited-English-speaking patients. Heaney and Moreham (2002) found under-utilisation of professional interpreters and an over-reliance on informal interpreters in a metropolitan healthcare system in Australia. A lack of knowledge about interpreter services was related to a lack of formal interpreter use and an increased use of informal interpreters. In another study Tobin *et al* (2000) discussed the utilisation of bilingual counsellors within a public sector mental health service in Australia. An internal review of their own bilingual counsellor programme found that the counsellors' roles needed to be better defined; that mainstream staff needed to have more access to their expertise as cultural consultants; and that their function as an area team, rather than as service-based staff, needed to be encouraged.

Gerrish (2001) describes the nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients in the UK. It was found that over half of South Asian patients had little or no understanding of spoken English; and women and older people were the least likely to speak English. Although the community trust provided professional interpreting services in the main South Asian languages spoken by local communities, the district nurses rarely utilised them. This was partly because nurses were unaware of the levels of language competence among their patients, and also because the interpreter service was regarded as inadequate because of under-funding and difficult to access. Stolk *et al* (1998) investigated the effectiveness of a training and policy strategy to improve communication opportunities in an acute inpatient unit for patients of non-English-speaking background (NESB) with low English proficiency. Compared to the ESB population, a higher proportion of NESB patients rated low on proficiency. Following the intervention, interpreter bookings and booking duration increased significantly. The study concluded that a standard training package and a policy promoting interpreter use improved communication opportunities in an acute setting where language needs are typically poorly met. Failure to ensure effective communication raises risks of misdiagnosis and inappropriate treatment. By measuring patients' proficiency directly, this study identified a higher level of need for interpreter services than estimated by past reports.

One of the very few studies to examine cost issues was conducted in South Africa. Drennan (1996) concludes that staff trained in psychiatry are clearly preferred as interpreters. A significant proportion of patients were being assessed through the use of family members, cleaners and other inappropriate people. The financial burden to the hospitals of not providing an interpreter service was small, but the impact on improved working conditions and service to patients was considerable. Fagan *et al* (2003) discuss how interpretation affects the process of health care, including patients' visit length. One study found that limited English proficiency (LEP) patients using interpreters had visits that were longer than visits for English-speaking patients by 7 to 12 minutes (Kravitz *et al* 2000). This study also found that patients using a personal interpreter (family member) did not have significantly longer visits than English-speaking patients. Fagan *et al* (2003) also compared visit lengths of patients using 3 methods of interpretation (in-hospital facility, patient-supplied, and telephone interpreters). It was found that telephone and patient-supplied interpreters were associated with longer visit times, but full-time hospital interpreters were not.

(ii) Accident and Emergency Department

Enguidanos and Rosen (1997) have evaluated language (English vs. Spanish) as a variable in compliance with follow-up appointments from emergency department (ED) referrals and compared it with four other socio-economic variables. The study found that language was not a significant variable influencing follow-up compliance. Having a primary medical doctor prior to the ED visit was positively correlated with follow-up compliance and was the only significant socio-economic variable irrespective of language ability. There was no significant correlation between English speaking and any of the socio-economic variables. Among Spanish speakers, having a primary medical doctor and having some form of medical insurance were significantly correlated to compliance with referrals. In another study it was found that the use of ED services was lower for non-English speaking than English speaking patients. The use of trained interpreters was associated with increased intensity of ED services, reduce ED return rate, and increased clinic utilisation (Bernstein *et al* 2002).

Another American study, Sarver and Baker (2000) has explored whether patients who encounter language barriers during an emergency department visit are less likely to be referred for a follow-up appointment and less likely to complete a recommended appointment. The proportion of patients who received a follow-up appointment was 83% for those without language barriers, 75% for those who communicated through an interpreter, and 76% for those who said an interpreter should have been used but was not. Appointment compliance rates were similar for all 3 patients groups. The study concluded that the language barriers may decrease the likelihood that a patient is given a follow-up appointment after an emergency department visit. However, patients who experienced language barriers were equally likely to comply with any follow-up appointment.

Studies that have examined the use and effect of interpreters reveal that patients with LEP often believe that interpreters should be used more than they currently are. Baker *et al* (1996) observed while dealing with Spanish-speaking patients in a US emergency department that nurses and physicians interpreted most frequently (49%), and professional interpreters were used for only 12% of patients. The study concluded that interpreters are often not used despite a perceived need by patients, and that the interpreters who are used usually lack formal training in this skill. Language concordance and interpreter use greatly affected patients' perceived understanding of their disease, but a high proportion of patients in all groups had poor knowledge of their diagnosis and recommended treatment.

Lawrenson *et al* (1998) undertook a study to find what data on ethnicity are collected in North Thames Accident & Emergency (A&E) Departments. A range of staff working in A&E departments were interviewed. It was found that ethnic origin was recorded in all units but not on every patient. Only one unit had actively recruited staff from an ethnic minority. None of the units had formal training in place for staff to gain an appreciation of issues facing patients from ethnic minorities. Interpreters and written material in appropriate languages were available in all units.

Leman and Williams (1999) studied the support for a national telephone interpreter service for accident and emergency (A&E) departments across the UK, and the factors that might influence the level of support. Seventy-nine of 180 (43%) A&E departments had used some form of interpreter in the seven days preceding completion of the survey. Seventy-six of 86 (88%) of those departments using face-to-face interpreters had experienced difficulty obtaining an interpreter out of hours. The study demonstrated widespread need and support for a national telephone interpreter service that would match the requirements of 24 hour emergency health care provision. Those departments in favour were no more likely to have required an interpreter in the last seven days, be in the inner city, have predominantly local population needs compared with tourist needs, or be current users of a telephone interpreter service.

(iii) Primary Care / Outpatient Clinics

Bischoff *et al* (1999a) examined the languages spoken in medical consultations during a one-month period in an outpatient clinic in Geneva, and the ways health professionals use to communicate with their patients, in particular by using interpreters. In only 14% of consultations without interpreters, was the patient's and doctor's ability to speak a common language rated as good. Even if proxy solutions (informal interpreters) played an important role, access to an interpreter service was still widely used. The authors call for systematic and regular interpreter use; planning interpreting needs in a timely manner; and that training in working with interpreters should become an integral part of introductory sessions for junior physicians assigned to the outpatient clinic. Another study undertaken by Bischoff *et al* (1999b) examined how Swiss medical services address the problem of language barriers in health care and how they respond to the high number of patients with language needs. The study was based on two descriptive, quantitative cross-sectional surveys covering all internal medicine and psychiatric services. Qualified interpreters were less frequently used in internal medicine than in psychiatry. Once again, the authors conclude that there is a need to raise awareness among health professionals of the advantages of having access to trained interpreters, and of the limitations of using relatives as interpreters.

Fuller (1995) addresses issues related to effective utilisation of ethnic health workers in primary health care in Australia. Ethnic health workers were employed to improve the access of communities of non-English-speaking background to health services, but their role has remained unclear in a national health system that has been criticised for being slow to respond to the needs of these communities. There were also pressures on ethnic health workers: clients from non-English-speaking backgrounds expected assistance with a wide range of problems, and mainstream staff lacked competence in meeting these needs. Ethnic health workers' involvement in needs assessment and health agency change was limited by these pressures; by ethnic health workers' separation from the work of mainstream staff; and because systematic planning of services to non-English-speaking communities was lacking. The author suggests that the appropriate role for an ethnic health worker is as an access provider, with a greater emphasis on needs assessment and agency change. Furthermore, agencies need to develop culturally appropriate service plans and training so that ethnic health workers and mainstream staff are better able to work together.

In primary care, the main source of help with communication for GPs and nurses remains the patient's family. In spite of heavy reliance on families, considerable dissatisfaction with family members as interpreters is reported. Inaccurate translation and embarrassment are problems for both white and Asian GPs. GPs resort at times to using children as interpreters, mime and other non-verbal methods of communication. Some practice team members may be an important source of interpreting help and some of them are recruited specifically for this purpose. However, the use of formal interpreting services of any kind remains very low. As a result, many of the methods used to overcome communication problems in primary health care involve a compromise in standards of privacy, confidentiality, accuracy and thoroughness, especially for elderly people.

3.2.3 Quality of interpreter services (use of informal and professional)

Several studies have been critical of the heavy reliance by health professionals on family members or relatives to interpret (Pharoah 1995; Robinson 1998; Chamba and Ahmad 2000; Gerrish 2001). The underlying reasons (as pointed out above) are quality of interpretation, privacy and dignity. Researchers are even more critical when professionals rely on children or minors to interpret (Cameron *et al* 1989, Pharoah 1995; Robinson 1998; Cohen *et al* 1999). It is not only considered inappropriate to place such a burden on a child who may not have the necessary understanding to interpret accurately or to cope with emotional aspects of the disclosure, it can also cause tension in the relationship between the child and adult, especially where a child and parent or grand-parent are involved (Ahmad 1996). Cohen *et al* (1999) argue that the operational constraints that GPs face because of the limited availability of professional interpreters or bilingual health advocates create situations where children are accepted in this role by GPs, subject to specific limitations. The perception of children's acceptability as informal interpreters is shown to be related primarily to the nature of the medical consultation in terms of whether it is likely to be straightforward, complex or sensitive. At the same time GPs expressed an ideological opposition to the appropriateness of this task for children generally.

Training of interpreters and health care professionals is an important consideration in terms of the quality of interpreting. In another study dealing with experiences of nursing care of Pakistani communities, Cortis (2000) observed that nurses have a poor understanding of ethnic needs, portray ethnocentric attitudes and behaviour. Some primary care nurses lacked skills in using interpreters appropriately in health care interactions, with the result that the skills of interpreters were not necessarily used most effectively. Similarly, interpreters generally regarded their training to have been inadequate on health specific knowledge. It has also been observed that interpreters and advocates might not be equally fluent in both languages and as a result may fail to translate, mistranslate, or edit questions and replies (Pfeffer and Moynihan 1996).

The literature also contains serious concerns about the quality of interpretations when dealing with *refugees and asylum seekers*. Tribe (1999) comments on some of the dilemmas inherent in the task of using interpreters / bicultural workers when working with refugee clients who have fled to Europe, many of whom have been tortured. A high proportion of these refugees may not speak European languages or share explanatory health beliefs. The author argues that these differences should not act as barriers to obtaining health and counselling services and that employing interpreters / bicultural workers may help to bridge these gaps and improve service provision and delivery. Graz *et al* (2002) discussed the opinions of physicians on interpreting and translation materials for refugees and migrants. According to a questionnaire sent to all of physicians who were members of a health care network for asylum seekers in the Swiss canton of Vaud (n = 169), it appears that 45% of practitioners would find a telephone interpreter service to be a practical solution, and 58% would like medical glossaries with phonetic pronunciation and visual illustrations made available. With a response rate of 91%, it is estimated that these two types of services would be used as often as qualified interpreters, if they were made available.

Jones and Gill (1998) discuss difficulties for these populations in accessing interpreter services in the NHS due to wide dispersal of refugees and asylum seekers in UK. The situation is exacerbated where appropriate interpreter services have not been developed and where there are no local communities of people of the same ethnic origin as the asylum seekers. The development of a national telephone interpreting service in a range of languages is a priority. The authors recommend that a separate capitation payment for refugee patients, together with a new item of service payment linked to the duration of each professionally interpreted consultation, should be introduced.

3.2.4 Translated brochures, telephone interpreting services, and other outreach activities

Translation of written materials can also have an empowering role if it provides the right information in the right way, at the right time, to ethnic minority groups. One factor which sometimes reduces the impact of translation is that in order to be effective patients must either be able to read translated material, or they will require access to someone who can explain it or read it to them. This may pose a problem because some minority groups may not be able to read the written version of their first language (see **Annex 2**). Moreover for some language groups a written version of the language is not available (e.g. Mirpuri and Sylhetti, the two most commonly reported dialects in the Pakistani and Bangladeshi populations).

Nevertheless translation of key material can fulfil an important role for minority communities. It can be used to increase patient awareness of health care provision availability. It is also potentially useful in order to convey health promotion information, and to empower minority communities by making them aware of complaints procedures etc. Translation of material into other languages may also be worthwhile if it makes service provision appear more culturally sensitive.

Conversely, failure to translate key leaflets or reports into other languages may have the effect of making patients feel marginalised. Thus, translating material into other languages can send out an important signal to ethnic minority communities about the extent to which those providing health services aim to be inclusive. The Audit Commission (1994) also implicitly acknowledged that translated material can play an important role in terms of alerting service users to the availability of interpreter provision, and pointing them in the direction of provision as required. The use of video material may also be particularly useful in order to convey information verbally and visually. This may be especially useful were individuals cannot read the written form of their language.

Zhu *et al* (2000) describe the experiences of using a centralised telephone service for tobacco cessation in the US. The programme was promoted state-wide by media campaigns, health care providers, local tobacco control programmes, and the public school system. The Helpline was centrally operated through the University of California, San Diego and provided services state-wide via telephone. Two randomised trials have demonstrated the efficacy of the Helpline's counselling protocol. The authors suggest that a similar centralised helpline operation should be included in any large scale, comprehensive tobacco control programme.

3.2.5 Doctor-patient communication: bridging the gap

A generation ago, the experience of practising medicine across cultural boundaries was far less common than it is today. The population is now much more diverse in race, culture, language, religion, and ethnicity and physicians must develop the knowledge and the skills to engage patients from different cultures and to understand the beliefs and the values of those cultures. If physicians focus only on a narrowly defined biomedical approach to the treatment of disease, they will often misunderstand their patients, miss valuable diagnostic cues, and experience higher rates of patient non-compliance with therapies. Such miscommunication will not only result in lower utilisation but in poor quality of care and greater patient dissatisfaction. Evidence also reveals how critical the physician's knowledge of culture and language is in delivering bad news to patients (Lee *et al* 2002).

Literature on outpatient settings in the US has shown that language discordance results in lower uptake, poor quality of care, worse outcomes and decreased satisfaction. Derose and Baker (2000) found that Latinos with fair and poor English proficiency reported 22 per cent fewer physician visits than non-Latinos whose native language was English, even after adjusting for other determinants of physician visits. Sarver and Baker (2000) have identified that language barriers decrease the likelihood that a patient is given a follow-up appointment after an emergency department visit. Carrasquillo *et al* (1999) indicate that Non-English speaking patients are less satisfied with their care in the emergency department (ED), less willing to return to the same ED if they have a problem they feel requires emergency care, and report more problems with emergency care. Strategies to improve satisfaction among this group of patients may include appropriate use of professional interpreters and increasing the language concordance between patients and providers. Another study describes that physicians believe that they are spending more time with non-English-speaking patients because of the challenges of language and cultural barriers (Tocher and Larsen 1999). An important limitation of this study is that the authors were unable to measure quality of care provided or patients' satisfaction with their care. A study of clinicians in three academic outpatient settings by Karliner *et al* (2004) shows that the clinicians encountered difficulties eliciting exact symptoms, explaining treatments, and identifying treatment preferences. Clinicians perceived that the lack of knowledge of a patient's culture hindered their ability to provide quality medical care and some felt they were unable to establish trust or rapport. Previous training in interpreter use was associated with increased use of professional interpreters and increased satisfaction with medical care provided.

A Canadian study dealing with the effect of language discordance on health outcomes for inpatients reveals that patients with limited English proficiency have longer hospital stays for 7 of 23 medical and surgical conditions (John-Baptiste *et al* 2004). However, the limited English proficiency patients were not at increased risk of in-hospital mortality. The study further suggests that the effect of communication barriers on outcomes of care in the inpatient setting requires further exploration, particularly for selected conditions in which length of stay is significantly prolonged.

To consolidate evidence further, Ferguson and Candib (2002) undertook a systematic review of the literature to determine how differences between physicians and patients in race, ethnicity and language influence the quality of the physician-patient relationship. The study brought out consistent evidence that race, ethnicity and language have a substantial influence on the quality of the doctor-patient relationship. Minority patients, especially those not proficient in English, were less likely to engender empathic response from physicians, establish rapport with physicians, receive sufficient information, or be encouraged to participate in medical decision making. The evidence calls for a more diverse physician work force since minority patients are more likely to choose minority physicians, to be more satisfied by language-concordant relationships, and to feel more connected and involved in decision making with racially concordant physicians. The literature also upholds the recommendation for professional interpreters to bridge the gaps in access experienced by non-English speaking physicians. Further evidence supports the admonition that 'majority' physicians need to be more effective in developing relationships and in their communication with ethnic and racial minority patients.

A few studies from Australia and the US highlight client-clinician ethnic matching in improving delivery of culturally competent health care. This has been found to be very effective in psychiatric care (Ferguson and Candib 2002; Ziguras *et al* 2003). Furthermore, although Cooper *et al* (2003) report that race-concordant visits are longer they suggest that they are characterised by a more patient positive effect. Previous studies have linked similar communication findings to continuity of care. The association between race concordance and higher patient ratings of care is independent of patient-centred communication, suggesting that other factors, such as patient and physician attitudes, may mediate the relationship. Until more evidence is available regarding the mechanisms of this relationship and the effectiveness of intercultural communication skills programmes, the authors suggest that increasing ethnic diversity among physicians may be the most direct strategy to improve health care experiences for members of ethnic minority groups. However, Sensky (1996) cautions that, even when physician and patient share the same ethnicity, it cannot be presumed that they share the same beliefs.

A number of papers identify the need for cultural competence training for physicians. Rothschild (1998) discusses cross-cultural issues in primary care medicine in the US aimed at bridging the communication gap between the doctor and LEP patients. This article reviews the role of culture in primary care medicine and the effect of health beliefs on decisions to seek care. Other influences, including the patient's family, language, and socio-economic status, are examined. The possible effects of the physician's own culture are looked at as well. Methods of eliciting the patient's explanatory model are reviewed, and guidance is given on strategies to avoid miscommunication or misunderstandings. Additionally, the physician is given guidance on how to draw on the patient's beliefs and values as resources in health promotion and in the treatment of disease. Specifically, the use of interpreters to overcome language barriers is reviewed, and behaviours are identified to maximise the accuracy of communication when interpreters are needed. Robinson and Gilmartin (2002) have reviewed the main barriers to effective communication between practitioners and ethnic minority service users not fluent in English. Barriers are reviewed at an interpersonal level, concerning differences in attitudes and beliefs, and communication skills. Consideration is given to the impact of organisational factors on practitioner-client communication, focusing on provision of bilingual health workers. A key argument is that education should enhance the ability of health professionals to reflect on both the individual and organisational aspects of transcultural communication competence. Another study reports that although primary care residents and faculty defined culturally competent communication in terms of both generic and culture-specific elements, they were sceptical of sensitivity and communication skills training, and worried that didactic presentations would result in cultural stereotyping (Shapiro *et al* 2002).

Key Findings:

- Repeated studies, internationally, demonstrate a link between language and cultural difference and health inequalities.
- Internationally, similar findings emerge consistently, although because of other models of health care provision alternative intervening effects and variables may appear to explain some effects (e.g. insurance status).
- Poor communication has an impact on all aspects of health care provision, from prevention through screening, acute, chronic and emergency care, and at all ages.
- Not all language communities have been equally well assessed, reinforcing inequalities between them.
- There is a poor level of information about levels of need associated with ageing, or the effects of demographic change on specific groups.
- Increasing attention is being paid to the possibility of telephone or new-technology based systems of language support, which has been shown to be effective in non-UK settings.
- Despite relatively substantial levels of research into language needs in maternal and child care, there has been little evidence of effective intervention to address such needs, other than locally.
- Services are provided inconsistently across areas, and a 'post-code lottery' exists in respect of language support.
- Non-English-speaking-background patients often have low expectations and seldom insist on interpreter support. By being willing to use 'bring-your-own' support, they may harm their own health, but are rarely aware of this.
- Training is needed for health care professionals in the use of language support.
- Creating, using and evaluating language support services requires more time and resources than are often allowed for.

Main Conclusions:

Despite a substantial evidence base in favour of providing proper language support, and demonstration of adverse effects linked to its absence, there is a lack of consistent, universal provision or adequate resourcing of such services in the UK. Indeed, there is a low level of research into cost-effectiveness internationally, or into the direct clinical implications of introducing adequate services. It would appear that training is needed, both for users and providers of health care services, in the proper ways of overcoming language barriers, and in raising expectations among non-English speakers. Similar problems are faced in all societies, and do not appear to be time-limited: the growth of globalised communities may instead be leading to increasing need, but also offering possibilities (e.g. by international telephone linkages) of international solutions. More needs assessment may be required, but should be tied to guaranteed resourcing and evaluation, and adequate time and resources allocated to ensure that initiatives are fully worked through.

3.3 Health promotion materials (including specialist materials and web-based materials)

Increasingly, the focus of the NHS has moved from treatment of disease towards health promotion, primary prevention and promoting healthy behaviours (formerly known as health education). Communication is fundamental to this activity, and there has been a considerable literature on health education materials and minority ethnic groups. Much of the earlier literature concentrated on the content, and criticised materials for their focus (ignoring 'common' health problems and criticising cherished cultural values). A common theme of all studies has been an assertion of the need to move away from printed materials and passive dissemination towards audio-visual presentation and active engagement with minority communities. Studies find minority groups eager for health promotion advice, but having poor uptake and recall, and (when examined) a low rate of impact on behaviour. A few studies have noted that translation alone, or provision of information in tape formats without active outreach and support, show little improvement over written materials. A 'social marketing' approach is thought to be the most likely strategy to have effect: (Barrett 2001; Shire 2002). There is a severe lack of evaluative intervention studies in UK (Johnson 1999, Robinson 2002). There have not been many recent studies, apart from reports of interventions described or proposed, and discussion papers repeating previous conclusions.

‘There are several explanations for the strong correlation between literacy and morbidity. The most obvious is that illiteracy prevents a person from reading, understanding, and following health instructions’ (Shire 2002). Schaafsma, Raynor and de Jong-van den Berg (2003) found that a combination of methods (verbal, written, multi-media) is more effective, since the advantages of the different methods can be combined. Choice of medium alone is insufficient to guarantee effectiveness: Kakai *et al* (2003) emphasise the critical role that cultural values and beliefs play in shaping cancer patients' health information seeking behaviours. In Hawaii, Caucasian (White) patients preferred information obtained through medical journals, and the internet. Japanese patients relied on media and commercial sources. Non-Japanese Asians relied on person-to-person communication with their physicians, social groups, and other cancer patients. This latter pattern appears to resemble the preferences of UK South Asian groups, as does the importance of the minority community individual in the person or group providing the health information, which must also be seen as 'culturally competent'. This approach:

- recognises the family and community as primary systems of support and intervention;
- assures that its efforts exist in concert with natural and informal health care support systems; and
- assures meaningful involvement of community members and key stakeholders (National Center for Cultural Competence 2003)

It also requires detailed prior assessment of contextually based qualitative data to provide insights, including use of qualitative methods (Goldman *et al* 2003) to understand how behaviours are situated in the person's life and identify salient themes and issues. An alternative recommended approach is through community development models (Smart, Titterton and Clark 2003). This cannot be developed as a model, however, without partnerships and alliances between statutory services and community groups and their representatives. Similar conclusions arise from considering research into women-centred health-promotion (Kar *et al* 1999), including the finding that health promotion programmes must go beyond health and begin with other community priorities.

Key findings:

- For patients who do not speak English (often older immigrants), communication is a problem as is access to interpreters / translations.
- There exists a strong association between illiteracy and poverty, both influencing health outcomes.
- "Social Marketing" as a solution needs to be funded.
- Combinations of verbal, written and multimedia messages prove more effective.
- Disparities exist between ethnic / racial groups in prevention behaviour which reflect social contextual factors, including communication factors.
- Effects of patients' ethnicity override their education level in shaping their choices of health information.
- The "cultural competence" model promotes health promotion within a community–level focus, with recognition of context, family and community, informal health care support systems, and meaningful involvement of community.

- Community development approaches tackle social exclusion of marginalised groups, targeting expressed community needs first, followed by health promotion efforts.
- The valuable contribution of the voluntary sector to community approaches to health promotion should be strengthened with financial support from central government departments.
- Empowering women and mothers for social action and health promotion movements has been shown as a way forward in tackling interethnic community differences by rallying women and mothers around common community priorities.
- Meaning-centred, contextually based qualitative data needs to be collected.

Main Conclusions:

In order to develop a national policy on health promotion that is inclusive of and translatable to all marginalised groups and to make headway on eliminating disparities, ‘you have to do it community by community’ (Barrett 2001). In health promotion efforts, there are various ‘models that work’ and an array of approaches and procedures for successful health promotion at the very local level of specific minority ethnic communities. There can be, therefore, as many models of good practice as there are communities. Within any approach that champions cultural and linguistic competency is an underlying acceptance of cultural and linguistic plurality and diversity at the macro planning level. The issue for centralised programmes and policies of health promotion planning is to begin to encourage multiplicities of approach as the rule, rather than the exceptions to a one-size-fits-all overarching model of health information promotion.

3.4 'Tele-consultation' services (NHS Direct, telemedicine, websites etc)

Modern methods of communication increasingly depend on telecommunication strategies, both personal (i.e. telephone) and using 'virtual' means, notably the internet or world-wide-web (Web) through computer terminals. Technology, including digital TV, is developing rapidly and offers many possibilities. The NHS Plan anticipates that future provision of 'out-of-hours' service, and much triage and advice work to be provided using telephone consultations. It also promises that NHS Direct will offer national availability and delivery of language support (interpreting between patient or carer and clinical professionals) through this means. At the same time, NHS Direct Online has begun to develop a resource of translated materials for patient information in diverse languages. However, there is as yet very little (non-USA) research evidence or evaluation of these services available in the professional literature, and even basic background information, insofar as it relates to minority groups, is sparse. It does however appear that minorities may not identify strongly with 'mainstream' national media and often turn to satellite TV from their countries of origin, if they do not see themselves represented locally (Georgiou 2001; Georgiou and Silverstone 2001).

It has to be assumed that household telephone ownership is nearly total in modern Britain (Ring and Jones 2004), and use of mobile phones is also growing rapidly, but American evidence on accessibility to the internet (Mandl *et al* 2000; U.S. Dept. of Commerce 2000) notes that there are significant social inequalities in access to the Web. Only half the homes surveyed had a computer, and only four fifths of these had access to the internet. Black and Hispanic groups were about half as likely as white or Asian American families to be so enabled. While these figures are now out of date, and there are no comparable data available for UK or Europe, there is little reason to doubt that similar gradients may affect disadvantaged communities in Britain (Anthony 2000). Inner city areas may be more likely to have 'broadband' telephone services and cable TV provision, but this will not offset established income and educational gradients in ownership and use of computer technology. Research will be required into the levels of effective internet access among UK populations.

Research into the effectiveness of telephone consultation and information giving and seeking has begun, but as yet we have not located any major studies of ethnic or linguistic differences in these, and there do not appear to be any studies recorded in the NHS National Research Register (issue 2004,1) that consider issues of ethnicity and inequality, either in respect of the use and experience of telephone consultation or web-based materials. Neither were we able to identify any studies in UK or USA which compared 'remote' interpreting and face-to-face provision or effectively evaluated the introduction of remote systems. One paper (Ring and Jones 2004) reports a small survey of the use of NHS Direct, showing lower than expected usage by ethnic minorities. The UK Department for Work and Pensions has also examined benefit take-up and the use of telephone services by minority ethnic elders: an early disappointing experience reduces their propensity to follow-up information sources (Barnard and Pettigrew 2003). A limited number of other papers and initiatives were located relevant to a discussion of 'new technology' in health care provision.

One new technology which has potential for personal access to information is the use of 'talking signs', which are being developed to provide guidance in minority ethnic languages: these clearly have relevance to health promotion and also in assisting visitors to health care facilities with local information and 'how to get to ' guidance: at present there appear to be no evaluations or research, and most development appears to be undertaken within transport settings (such as 'talking bus-shelters': Department for Transport 2003). A similar use of technology, however, is being developed in health-care settings using 'touch screens' (Phul *et al* 2003; Jackson and Peters 2003). This has the advantage of not requiring either previous experience of using a computer, or even literacy in any written script, and appears (from early results) to have potential, although Jones' (2002) monitoring of kiosk use (which had no ethnicity information) suggested low use by the majority population. Touch-screens may locally complement the proposed national use of digital TV by

NHS Direct Online. Future research will need to take explicit account of the use made by minority groups, unlike Cooke's (2003) rapid review of NHS Direct and its impact on emergency care.

While there are apparently no research-based studies or evaluations of internet health initiatives, there is a growing number of websites which offer information relevant to the health of ethnic minority groups. These may be categorised into four main groups, according to the target readership group and the sponsoring agency. One key group consists of research centres and academic bodies providing early or extended reports of research into ethnicity and health. These are not intended, usually, to be of immediate value to health service users as patients, nor are they usually aimed at being directly useful to clinicians and service providers. Secondly, there is a group of sites which are intended to provide rapid access to information and resources (including patient-information leaflets and forms in minority languages), some of which serve a dual readership of practitioners and 'users'. A third, and rapidly growing, sector consists of sites sponsored by community groups which fulfil a dual role of providing information about their community's culture and needs to 'majority' or 'generic' agencies and users, including health care professionals, and also provide 'validated' and authenticated health promotion materials to members of their own community. Finally, there are a number of sites within the NHS framework which are established to support health staff with tailor-made, and quality assured, information on meeting the health care needs of minority ethnic groups, much as the specialist libraries (SLs) of the National Library for Health (NLH) do in respect of emergency care, diabetes, cardiovascular disease, or other aspects of evidence based medicine and practice. At the time, there was no official NLH specialist library for ethnicity, but a significant amount of epidemiological and cultural information had been provided on the sites of some Public Health Observatories or by local initiative, and NHS Direct Online was beginning to accumulate a collection of translated materials for patient use. There remains, however, no agreed protocol or best practice on the validation of these documents, and no experience of evaluating their usefulness. Equally, there are few guidelines or quality assurance evaluations of other internet health information providers.

Key findings:

- Ethnic groups in the UK may develop competence within two cultures without losing a cultural identity or choosing one over the other.
- Digitalisation is opening up more channels of communication, increasing the possibilities for ethnic-specific information distribution.
- How language barriers and illiteracy are tackled greatly affects older people’s attitude to having further contact with government services.
- Service providers recommend language-specific helplines; and the use of community-specific media.
- Video and verbal presentations are considered the most effective formats for information dissemination by Asian people.
- Touchscreens can be developed to provide health information both aurally and visually. They simplify the process and make it interactive.

- NHS kiosks for health information, are currently very limited. Further study is needed, particularly around issues of minority ethnic use.
- NHS Direct patient satisfaction is high although studying the impact and effectiveness on minority groups is needed.

Main Conclusions:

The use of media, new media and an expanding arsenal of technological advancements for the dissemination of health information is in its infancy. More study is needed to ascertain the effectiveness of new technologies, particularly at the interface of information provision and minority ethnic groups. Media use should be seen as complementary to programmatic efforts, not a substitute. A danger lies in technology becoming a barrier to more effective person-to-person communication and the development of communication skills by providers of services. A one-size-fits-all technological approach may prove ineffective, particularly in reaching diverse groups with varying language skills and competencies and / or differing cultural expectations of health information and service provision.

3.5 Procedures for managing and planning for linguistic diversity

In addition to the aspects of ethnicity and communication outlined in other sections, there are also questions relating to the most effective ways of *managing and planning* for linguistic diversity. Pertinent research in this area would include evidence on different approaches to recording language needs (spoken and written), and methods which can improve their success. Also, any research evidence on the accuracy and strengths / weaknesses of different approaches to quantifying (estimating) UK population-based language needs, and mechanisms for translating population-based language needs data to service planning for multiple languages. However, these are hard to find.

It is agreed, almost universally, that health services should be committed to providing a quality service to all communities whether or not they speak English. The clinical governance agenda requires all organisations to continually review and improve services. Several NHS Trusts have developed their own interpreting services, or secured contracts with private interpreting companies, in order to meet the needs of their local community (Pennington 2001). Where this service is not available it may be appropriate to perform a needs analysis prior to making a bid for support from an interpreting service. There are, however, no agreed models of best practice or comparative studies of how these should be conducted.

A grey literature report from Leicestershire, Powell (1999) questions whether there is a need to improve communication, interpreting services, and literature for Asians needing to access cancer and palliative care services. Various actions were identified to improve access including: developing links with community leaders; establishing a central point of contact for information, translation services, and interpretation; having details of ethnic origin collated within medical records, and details of the patient's preferred language. It suggested that translated material needs to be reviewed and that a two-tier interpreting service should be developed involving a top tier of dedicated professional interpreters, and a secondary tier of bilingual and multilingual health care professionals. The use of link-workers was also advocated to provide advice and support to clients in their own language. The author suggests that healthcare staff ought to be given mandatory cultural awareness training, and that training should be provided in schools within the city. In addition, a multi-faith worker is suggested, inter-agency cooperation, and a joint strategy. It recommended that the health authority should prioritise ethnic minority health, and local authorities should create a 12 point check list similar to one adopted by a local community health council. A conference to be held in summer 2004 will seek to bring together these and other recommendations and create local consensus and an action plan (Eastern Leicester PCT pers. comm).

3.5.1 UK studies

Some procedures have been developed to address language diversity and improve health care services for ethnic minority patients with language needs in the practice area. Generally, these strategies rely on good planning and are designed with the goal of reducing communication barriers that may lead to improper diagnoses and care, higher health care costs, and poor patient compliance. In addition, anticipating the needs for language assistance can substantially decrease the cost of care.

A first requirement in terms of planning is needs assessment at local authority (or PCT) level. There is a need to collect useful, accurate and meaningful baseline data relating to ethnicity, culture, diet, religion, language and dialect. This information should be considered the first building block, fundamental to the provision of culturally appropriate care and the initial stage in assessing linguistic need. Familiarity with the numbers and origins of new immigrants in the community or service area and their language needs is necessary for the planning process in order to anticipate need.

Secondly, it is essential that there is a process of maintaining patient profile data that includes language needs at PCT and practice level. This might be achieved (but has not yet been reported as a routine activity), by updating information on language needs in patient records both in primary and secondary care. Access to information on language needs and forward planning should reduce the cost of language services particularly when an interpreter is required at short notice. Profiling has been piloted and found feasible in Liverpool (Mitchell & Jones 2002; Public Health Sector Group 2000).

The Commission for Health Improvement has emphasised assessment and account of language needs of population at PCT level and also at the service level. The Commission has further stressed that knowing the language would help encourage the patient's involvement in care. For example, the Paterson Centre for Mental Health in Central and North West London has produced an excellent resource pack with information about the social and language needs of people from a wide range of cultural and religious backgrounds (Commission for Health Improvement, 2002). This includes advice to staff about people’s needs and information about how to access support services provided by the trust and other local organisations. The trust also involves service users in the appointment of consultant psychiatrists, senior managers and directors. Service user panels have interviewed candidates, with planned questions to identify key experiences, attitudes and skills. Bekaert (2000) similarly discusses integration of ethnic minorities in rural healthcare provision in Oxfordshire as an example of good practice. Progress was assessed through audit forms filled out by staff, informal visits to wards, and random questioning of staff. The research revealed several areas of improvement in meeting the needs of ethnic minorities. With an interpreter on hand and targeted health care, there had been a shift of clients from a clinic set up specifically for Asian women into 'mainstream' services, increasing efficiency in service provision.

Several NHS Trusts have prepared information packages for staff that reflect the culture, beliefs and customs of local Black and minority ethnic communities.

3.5.2 International studies

A number of international studies from multilingual countries discuss efforts made in assessing the need for interpreter services on the basis of extent of language diversity in local populations. Tang (1999) considers the need for interpreter services in Canada, which is made up of people from diverse ethnocultural and linguistic backgrounds. As well as examining the complexity of allocation decisions and policy implementation, the author provides policy recommendations for an integrated system of interpreter services to be set up by healthcare agencies based on cost-effective and equitable use of finite resources and partnership between agencies. Murphy and Clark (1993) report a study from the UK that found that interpreting services and dietary facilities available for ethnic-minority clients were inadequate and they suggest the need to review these facilities within hospitals.

(i) Bilingual health staff

The presence of diverse language skills within the health care staff body provides opportunities to better meet the needs of a multicultural population. Bilingual staffs are a valuable resource for the organisation and the presence of a similar proportion of bilingual and bicultural staff may engender tolerance and adaptability in providing care to a diverse population. However, supply does not directly match community demand. This mismatch is likely to continue unless recruitment is focused towards identified language groups. Johnson *et al* (1998) have assessed the provision of culturally competent health care in terms of language use of bilingual staff in Australia. Only one third (37%) of bilingual staff used their language skills at least weekly, predominantly in situations of simple conversation and giving directions. The high proportion of such staff who appear to rarely use their language skills may be due to lack of opportunity or limited need. The authors suggest that further research is needed to examine service models that locate bilingual workers close to client need.

Ziguras *et al* (2003) discuss ethnic matching of clients and clinicians and the use of mental health services by ethnic minority clients in Australia. Research in the USA had indicated that matching clients from a minority group with clinicians from the same ethnic background increases use of community mental health services and reduces use of emergency services. The Australian study found that, compared with ethnic minority clients who were not matched with a bilingual clinician, those who were matched generally had a longer duration and greater frequency of contact with community care teams and a shorter duration and lower frequency of contact with crisis teams. The authors conclude that benefits of matching clients with psychiatric case managers on the basis of ethnic background include a lower level of need for crisis intervention and, for clients from some ethnic groups, fewer inpatient interventions.

(ii) Bilingual community workers

Kim *et al* (2002) focus on the primary health care needs of Korean immigrants in the USA. A model of service is reported which paired a bilingual advanced practice nurse, a certified family nurse practitioner, with a bilingual community advocate to conduct a programme emphasising community outreach and health promotion and prevention. A bilingual physician provided consultation for the nurse and attended to patients in need of medical care. The project aimed for the service development to be assimilated into the regular programming of the Chicago Department of Public Health, a goal that was achieved.

(iii) Cultural / shared brokering

A paper by Labun (1999) explores issues related to 'shared brokering' with a view to developing nurse-interpreter partnerships in the USA. The concept is used to provide complex, effective, and efficient care for clients who speak Vietnamese and live within the Vietnamese cultural worldview. Various criteria necessary for the development of a shared brokering relationship are described. Development of cultural brokering systems is also highlighted by Shaw-Taylor and Benesch (1998). Their review offers a framework for cultural competency in healthcare delivery based on the relationship between patient and provider, and the community and health system. For this relationship to be successful, the authors argue that health systems should foster providers that can also be cultural brokers. The cultural broker role is seen as core to achieving cultural competency.

(iv) Interpreters / cultural brokers for immigrants / refugees

Garrett *et al* (1998) raise the issue of barriers to health care for immigrants to the USA. Both immigrant and non-immigrant groups experience many of the same logistical barriers, including inadequate insurance coverage, transportation, mental stress, time constraints, and distance to their health care facilities. However, they authors identify language barriers and the need for trained interpreters as barriers for immigrants only. They identify 16 of 18 health services as more available to non-immigrants than immigrants, and emergency and obstetric services as equally available to both groups. Tribe (1999) also argues that employing interpreters / bicultural workers can help to improve service provision and delivery when working with refugee clients.

Kennedy *et al* (1999) present a comprehensive review of the refugee health screening and assessment programme in the USA. Key features of the programme include a single point of access for all family members, full availability of appropriate interpreting services, comprehensive health assessments that include a thorough mental health screening, data collection and evaluation, and education of health care providers to deliver culturally responsive care.

Wimmer and Ipsiroglu (2001) discuss communication barriers in the management of immigrants and their children in Vienna. Based on experience gained, and in agreement with developments in other European countries, the authors report that use of professional interpreters who combine their role as linguistic intermediaries with the cultural features of foreign-language patients (community interpreters) should be encouraged. The research further supports the use of specifically trained internal hospital staff and the development of centralised interpreter services.

(v) Quality of care

Ngo-Metzger *et al* (2003) have examined factors contributing to quality of care from the perspective of Chinese- and Vietnamese-American patients with limited English language skills. In addition to the dimensions of quality commonly expressed by English-speaking patients, Asian-American patients with limited English proficiency wanted to discuss the use of non-western medical practices with their providers, but encountered significant barriers. They viewed providers' knowledge, inquiry, and non-judgemental acceptance of traditional Asian medical beliefs and practices as part of quality care. Patients also considered the quality of interpreter services to be very important. They expressed a preference for using professional interpreters rather than family members, and also for gender-concordant translators. The authors conclude that cultural and linguistically appropriate health care services will improve health care quality for Asian-American patients with limited English proficiency. Important aspects of quality include providers' respect for traditional health beliefs and practices, access to professional interpreters, and assistance in obtaining social services. Timmins (2002) while analysing evidence from research studies undertaken on Latino population in the US has also suggested that language barriers adversely affect quality of care.

Mihalopoulos *et al* (1999) have examined the provision of mental health shared care for people of non-English-speaking backgrounds in Australia. Mental health shared care initiatives show much potential in terms of meeting the needs of people of non-English speakers.

Key findings:

- Health care agencies require adequate 'needs analysis' for language support services; this is a complex process, and there are no agreed models of best practice.
- There are many models for service provision in operation, but as yet no agreed best practice or evaluation of the cost-effectiveness of different models.
- Services should be developed in consultation with local community leaders and community groups.
- An adequate process of ethnic monitoring or 'patient profiling' is essential.
- Services are best managed by a single central point of contact providing an integrated service and with responsibility for quality assurance, including translation and all aspects of language support - including cultural competence.
- Staff require training and a handbook, which will include attention to issues of cultural competence as well as language.
- Service introduction should be accompanied by monitoring or audit of the impact on uptake of other services and clinical outcomes.
- Ethnic monitoring of staff may help establish the availability of in-house skills, while recognising that such bilingual workers may be more useful as cultural brokers, and may not be trained in the formal skills of interpreting and translation (and should not be exploited beyond their appropriate grades).
- Interpreters may be required to work across services outside the formal health care setting, especially in respect of community and social care services, which also has implications for finances and organisational management.

Main Conclusions:

The provision of language and cultural support services is still in a developmental phase, but the current situation has been arrived at in an *ad hoc* fashion. Internationally, there are many ways of managing services that have been tried, but there is a lack of systematic evaluation of the relationship between such services and the stakeholders and structures existing in the UK. A degree of consensus does exist, including the importance of working with communities locally, integrating cultural awareness and training for staff, and understanding the roles and abilities of different levels of language intermediary. Needs analysis is also seen as an essential element, but similarly, guidance on accepted best practice has yet to emerge. It seems likely that local solutions have been developed, but are not formally reported or evaluated.

3.6 Provision of services which diagnose and treat speech / language conditions

A number of services exist which target communication i.e. are communication-based. These include services which diagnose and treat speech / language conditions in children. Language is a function of culture. The two are related in a complex and inseparable manner. The culture of people is anchored within tradition, beliefs, attitudes and value systems. Speech and language therapists (SALTs) need to recognise the fact that the patient is a family member of systems which operate in a series of networks. Recognition of these factors is an important step in helping the child to progress (Semela 2001).

Competence 'bilingually and biculturally' (Isaac 2001) is central to communication and minority ethnic health. Bilingual clients frequently feature on speech and language therapists' caseloads and yet they are rarely assessed and treated in their mother tongue. Winter (1999) noted a lack of information about bilingual children but estimated the prevalence in caseloads (in London) at 43% and asked if therapists were equipped with the relevant knowledge and skills. Pert and Stow (2001) found 59% of paediatric speech and language therapists had at least one bilingual client in Rochdale. They found low representation of therapists from ethnic minority backgrounds. 'The fact that most therapists who work with children work with bilinguals (many with too few of them to make their most effective assessment and therapy a priority) and the fact that there are only a very few therapists who have a specialised bilingual caseload must be taken seriously when considering the priority given to initial and further training' (Winter 1999).

In a study of West African children and their families living in the UK, Law (1999) found that data on referral patterns to pre-school facilities for speech-and-language-delayed children suggests that West African children are over represented relative to other ethnic / language groups. Parents had generally been advised by health professionals to use English rather than their own language with their child if the child appeared to be experiencing difficulties learning language. On reflection, a number of parents said that they wished they had not followed this advice. The study concludes that West African families experience high levels of stress combined with high expectations of their children's development and relatively low levels of social support. Implications include the importance of cultural literacy for those who come into contact with West African children and the need to validate bilingualism and cultural practices by professionals. Similarly, Semela (2001) insists that language is a function of culture. A Dutch study found that the growing number of multilingual children makes the application of specific measures at a population level unworkable (Maas 2000). Bilingual or multilingual children deserve more attention, in terms of early detection of speech and language delays because of the lack of screening instruments and the diversity of the group.

While Speech and Language Therapy work is not confined to work with children, and is of particular importance in treating patients with stroke or oral (maxillo-facial) cancers, both conditions which are found at high prevalences among specific UK minority populations, we were unable to find research which explicitly considered the issue of SLT therapies in these groups, except indirectly (Rudd *et al* 1997; Forster and Young 1996; Sanderson and Ironside 2002). This is clearly an area requiring future research.

Key findings:

- There is a lack of information about bilingual children.
- There is an over-representation of bilingual children in speech and language therapy.
- There has been almost no research on speech therapy for older minority ethnic clients
- Bilingual clients are rarely assessed or treated in their mother tongue.
- Large proportions of paediatric speech and language therapists (SALTs) have at least one bilingual client.
- When the minority ethnic population is more than 7%, there are always 70% or more of SALTs working with bilingual children.
- West African children in the UK are over represented in speech and language therapy relative to other ethnic / language groups.
- Stressors in the family may contribute to children's speech and language development.
- Language is a function of culture; there is a close tie between culture and the understanding of language and communication disorders.
- Specific measures at population level are unworkable due to the diversity and growing numbers of multilingual children.
- There is a lack of screening instruments for use with multilingual children.
- Priority needs to be given to initial and further training of SALTs in working with multilingual children and the recruitment of staff from minority origins.

Main Conclusions:

Bilingual children and older people need to be assessed and treated in their mother tongue by therapists who are both bilingual and culturally sensitive. SALT training is needed that includes developing therapists' cultural competencies and sensitivities in order to understand that language and communication disorders are culturally constructed within the often stressful environment of an adopted culture.

3.7 Provision of 'talking' therapies (i.e. counselling, psychotherapy)

There are three key recommendations from the report, *Inside Outside: Improving Mental Health Services for Black and Minority Ethnic Communities in England* (Sashidharan / NIMHE 2003):

- To reduce and eliminate ethnic inequalities in mental health service experience and outcome.
- To develop the cultural capability of mental health services.
- To engage the community and build capacity through community development workers.

The consultation document, ‘Delivering Race Equality: A Framework for Action’ (Department of Health [DoH] 2003) states that a ‘tick box’ approach is not acceptable under the monitoring arrangements of the Race Relations (Amendment) Act and that it ‘seeks to drive up standards and create organisations that are pro-active rather than solely responding to complaints and acting defensively out of ignorance and fear’. The consultation makes its case for action based upon twelve consultations that took place within minority ethnic communities. The DoH’s synthesis of these consultations, which included the evidence set out in *Inside Outside* (Sashidharan / NIMHE 2003) and other research such as that undertaken by the University of Central Lancashire (Patel *et al* 2003), the Sainsbury Centre for Mental Health (SCMH 2002), and the Mental Health Act Commission, has shown the Black and minority ethnic people are more likely to experience many disadvantages, including:

- Problems in accessing services;
- Lower satisfaction with services;
- Cultural and language barriers in assessments;
- Inadequate community-based crisis care;
- Lower involvement of service users, family and carers;
- Lower satisfaction with hospital care;
- Lower effectiveness of hospital treatment;
- Less likelihood of having social care / psychological needs addressed within care planning / treatments processes;
- More severe and coercive treatments; lower access to talking treatments.

The three building blocks fundamental to successful delivery of improved outcomes and experiences are:

- Better quality and more intelligently used information.
- More appropriate and responsive services.
- Increased community engagement.

Thus the conclusions reached in the DoH review indicate high needs for communication skills and cultural competency (which includes communication skills themselves since culture and language are intertwined). Communication issues are directly or indirectly at the centre of policy efforts to produce positive change. In community engagement, issues of language, language interpretation and / or translation, understanding of cultures and cultural beliefs and practices all become part of the building blocks to successful service planning and delivery. *Inside Outside* concludes by calling on relevant agencies to work in partnership with Black and minority ethnic communities to produce progressively community-based mental health at the centre of service development and delivery (Sashidharan / NIMHE 2003)

The problems experienced by Britain's black and ethnic minorities within the mental health system have been the subject of exhaustive social inquiry (Pierre 2002). Nevertheless, there is a lack of research in the process and outcome of psychotherapy for different groups (Burman *et al* 2003). At the same time, health workers are clearly afraid to talk openly about issues concerned with race and culture that affect their practice (Sainsbury Centre for Mental Health 2002). Lack of information about services is an enduring issue among service users, a fact that could also apply to GPs who tend to refer to the services they know (Pierre 2002; Bowes and Wilkinson 2003).

Because of the complexities of race, ethnicity, diversity, language and communication, discussions in specific service provisions such as mental health can become mired down in group by group similarities, differences and the politics of access to scarce resources. Reviews of the research tend to be characterised by a medical epidemiological framework, while the potential insights offered by sociological and anthropological research are ignored. Even in a paper asking for 'Less Sensitivity, More Statistics' (Hayes-Bautista 2003), the call is for 'good, hard-nosed, science-based research into the *relationships* among culture, behaviour, and health outcomes'. Moving beyond enumerating differences, however, *pathways to care* need to be studied as social processes subject to a wide range of influences, including cultural context (Morgan *et al* 2004). Some tension appears to exist in the literature between the emic, or culturally specific, and etic, or universal, approaches to working with culturally different people (Fischer *et al* 1998).

The long intellectual tradition in the West of mind-body dualism is found to be counterintuitive to many minority ethnic groups of Eastern origin. Thakker *et al* (1999) conclude: 'The mere existence of culture-bound syndromes suggests the important influence of sociocultural variables in the manifestation of mental disorder. …It is reasonable to conclude that there appears to be a significant and dynamic interplay between the experience and manifestation of mental disorder and the many diverse and complex factors which comprise the sociocultural environment'. Such understanding is gained through language, communication and cultural sensitivity.

No single model can resolve the issue of providing appropriate psychological therapies to people from minority groups. We must abandon the hope for a unitary, simplistic answer in favour of recognising the diversity of intersecting identities and needs that people from minority ethnic groups present. Looking to other cultures for models of thinking and practice (such as India and Japan) holds promise (Burman *et al* 2003).

Key findings:

The reviewed evidence suggests that:

- Understanding is gained through language, communication and cultural sensitivity.
- Barriers to communication exist as a result of cultural differences, rather than just language differences.
- The need for communication skills and cultural competency are at the centre of positive change.
- Language, language interpretation and / or translation, and understanding cultures are part of the building blocks to successful planning and service delivery.
- Health workers are afraid to discuss race and culture.
- Carers (and service users) consistently demand better information about services across the studies reviewed.
- Carers fear that their demands for information will have negative consequences.
- A culture is needed where race and mental health issues can be discussed openly.
- Participation and partnership are vital means to generate inclusion.
- One in five patients does not have English as a first language.
- Interpretation is needed beyond the clinical encounter to include befriending and advocacy services.
- An interpreter can either provide comfort or discomfort in the therapeutic encounter.
- Most literature concentrates on the African-Caribbean community and it has been the subject of exhaustive inquiry.
- Indirect and implicit expression is common among Eastern cultures.
- Muslim families are reluctant to seek help from mental health professionals.
- Discussion of personal problems with someone outside of kinship networks is not valued by Muslims and can bring shame.
- Therapy should be directed towards finding a new order within the cultural system rather than threatening it.
- Pathways to care need to be studied as social processes.
- Partnerships need to be created with Black and minority ethnic communities to produce progressively community-based mental health at the centre of service development and delivery.
- There have been few attempts to develop or utilise theoretical models.
- Kleinman’s (1980) model of Health Care Systems is mentioned frequently in the literature.
- Models of care from other cultures need to be explored.

Main Conclusions:

Empowerment is central to the expressed needs of carers and service users through their demands for information about available services. This request for information, repeated over and over again in the literature, indicates an information vacuum. This suggests a population seeking knowledge for empowerment in order to begin to become proactive in the politics of mental health. Individualised service provision that is sensitive to and expressive of cultural needs is highly valued by mental healthcare consumers and their families. Theoretical models need to be explored that will incorporate the multiplicity and diversity of service users, their beliefs and family values. Although interpretation and translation are important services, they do not represent an overall strategy for a proactive mental health system.

3.8 Other aspects of communication e.g. consensual / participatory activities

There are a number of processes (clinical and non-clinical) which require consent or participation of the patient for which effective communication is integral. These include consent to treatment and other procedures (e.g. organ donation), compliance or concordance in treatment / medication, involvement of ethnic minorities in trials, and consent to use and disclosure of medical data. It was stipulated that the review would focus solely on available evidence on the effectiveness and cost-effectiveness of different approaches designed to improve consent / participation for ethnic minority groups. Evidence to support best practice was, in particular, to be identified.

As this was potentially an infinitely large sector, we defined it for the purposes of this review by focusing on issues relating to organ and / or human tissue donation and transplantation, as illustrating the core issues of informed consent and providing evidence of effective interventions. We had intended also to include discussion of informed consent in the context of research participation, and service planning consultation, but were unable to locate literature where the effectiveness of different approaches was discussed - other than papers stating that it had been an issue of concern, or that non-English speakers were excluded because of such concerns. All papers relating to human tissue donation were reviewed, and those relevant to effective 'communication' included; no papers on cost-effectiveness were identified. Language differences and questions of literacy or access to differing media are not the only considerations in this area; instead awareness of issues other than language has a particular significance in effective communication.

It is well established that minority ethnic groups show different patterns of tissue and blood type from the general (white) population, and that tissue-typing (i.e. matching of donor and recipient in terms of genetic markers) is fundamental to ensuring better outcomes (Ready *et al* 1997; Ready 1998). Equally, it is increasingly a matter of concern that relatively few members of minority ethnic groups - both in UK and elsewhere - are registering as donors, or agreeing for organs to be used after death, especially since these groups are showing much higher than average incidence of diabetes and related end-organ damage, notably, a very high level of need for end-stage renal failure care, which has a significant impact on health costs, and is best treated by donated organs (Roderick 1998). A number of initiatives have been developed in UK and elsewhere, and there is a small evidence-base for better practice.

A key element of strategy in UK has been a perception that there is a low level of awareness of the process of organ / tissue donation among minorities (as with other services) and that there may be religious or cultural barriers to cadaveric donation (Jeffrey *et al* 2002), requiring educational interventions to raise awareness about the religious acceptability of this practice. Relevant professionals did obtain a fatwa (religious ruling, for Muslims) on the issue (Carlisle 1995), but this was poorly known in the community (Randhawa 1998): Exley and colleagues (1996) cast doubt on the value of educational strategies in affecting attitudes in the Sikh religious community. Baines *et al* (2002) describe a regional forum using local business leaders to discuss the issue, and note that while there was high 'general' awareness, there were very low levels of detailed knowledge. An Australian study of blood donation (Kirsty 1998) demonstrates that there are different kinds of information field, and that 'localised' knowledge and intra-group communication - that is, between friends and within communities, are of critical importance in overcoming reluctance to act. Another major factor was a perception that individuals had not been (personally) asked to donate. Education about the regeneration of blood - for societies where 'balance' of humours in the body is seen as important, may also be required, requiring communication to be based on understanding of the cultural norms of the minority. As Baines *et al* (2002) observe, a complex mixture of messages is required to establish 'emotional connectedness' between the message and the target audience.

American studies have likewise laid stress on the importance of the education and knowledge, and the characteristics of the individuals, who seek consent to donate. Multiple interventions may be required, after which assertive outreach strategies may raise willingness to participate, having raised levels of trust among the community (Callender *et al* 2001). As Verble and Worth (2003) have noted (also demonstrated by Gentry and LeVert 2003), ethnic matching or at the least, having transplant co-ordinators and 'Special Requestors' who are at ease in the cultural milieu of the potential donors, has considerable impact in establishing that trust and emotional connectedness. Otherwise, the result demonstrated by other studies in America, of exclusion by default when staff do not feel culturally competent or at ease to work with members of minority groups leads to a self-denying failure to act and indirectly, to a discriminatory outcome (Guadagnoli *et al* 1999; Mitchell and Sedlacek 1996; Yuen and Burton 1998). Communication requires not only the comfort and attention of the recipient of the message, and an appropriate channel, but also the active involvement of the agency responsible for sending the message or initiating the transaction. The Acodap (African-Caribbean Organ Donation Awareness Project) at King's College Hospital London has attempted to follow these principles in UK, and if funding is continued, will be able to provide a local evaluation of these principles. However, this and other UK projects such as the generation by UK Transplant of ethnically and culturally sensitive targeted leaflets containing visual material, religion-specific information and messages from appropriate community leaders (Howitt 2003 - see www.uktransplant.org.uk), have yet to be supported for long enough to be evaluated.

Key findings:

- Effective communication is integral to processes (clinical and non-clinical) which require informed consent or participation , including research trials, and disclosure of medical data.
- Language differences and questions of literacy or access to differing media are not the only considerations: awareness of cultural issues is part of effective communication.
- Working through religious leaders and organisations may raise acceptability of information.
- There is a difference between 'general' awareness and detailed knowledge or willingness to act.
- A complex mixture of messages is required to establish 'emotional connectedness' between the message and the target audience.
- If staff do not feel culturally competent or at ease to work with members of minority groups there may be a self-denying failure to act and indirectly, to a discriminatory outcome
- Communication requires not only the comfort and attention of the recipient of the message, and an appropriate channel, but also the active involvement of the agency responsible for sending the message or initiating the transaction.
- Culturally sensitive targeted leaflets containing visual material, religion-specific information and messages from appropriate community leaders have not yet been properly evaluated in UK.

Main Conclusions:

Communication requires attention to context, and the needs of the person beginning a conversation or seeking to transmit information, as well as the characteristics (language, literacy, culture) of the intended recipient. The messenger may be as importance as the message, and some potential messengers may not feel comfortable in that role, with particular 'audiences'. Messages must be specifically tailored to their audience, taking religious and other beliefs and practices into account. Information from official sources may be of less impact unless fortified by personal experience and information from intra-community networks which establish a higher level of salience or 'emotional connectedness' with the issues being communicated.

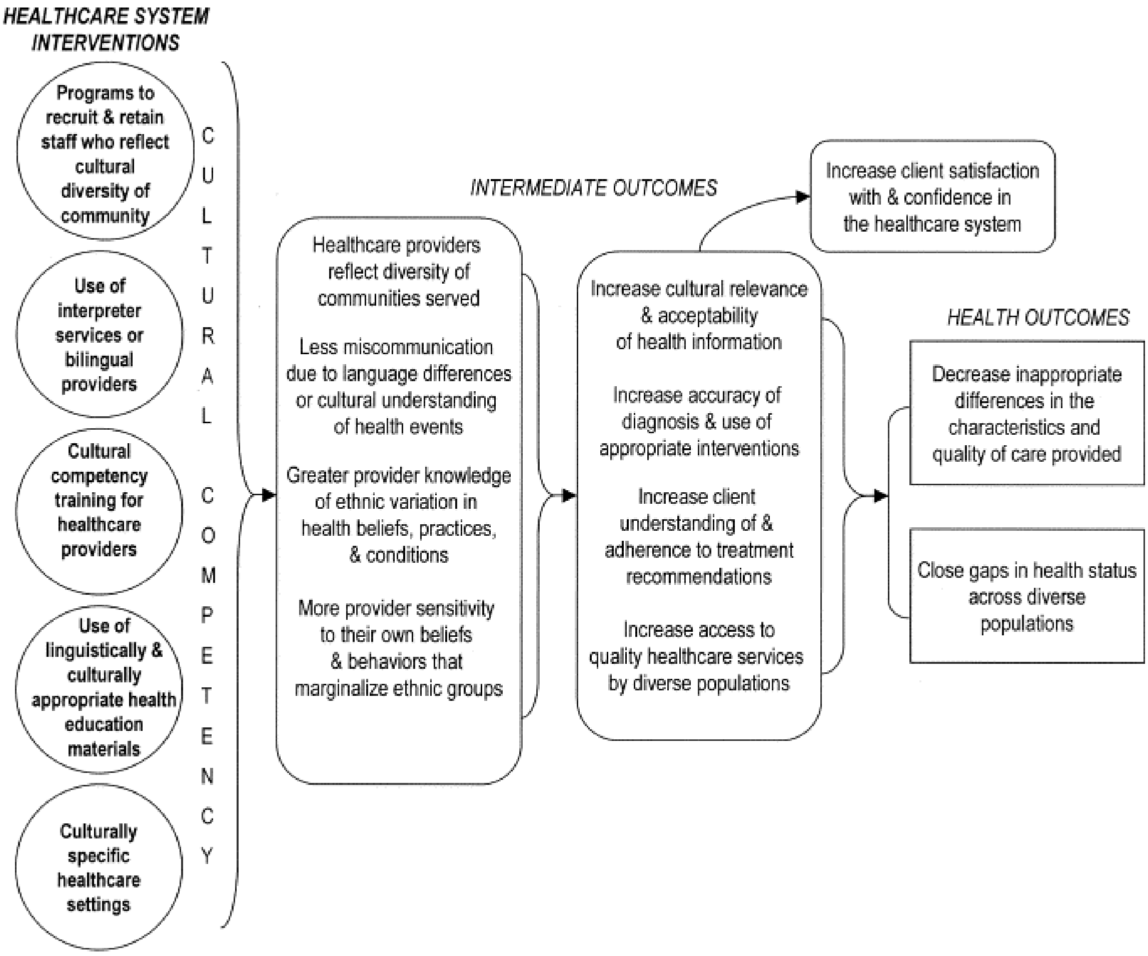
UK research and development is so far largely confined to descriptive, clinical, and exploratory work and does not yet include significant evaluation of interventions.

4 CONCLUSIONS AND RECOMMENDATIONS

4.1 Overview of research evidence base

Over the last couple of decades there has been a huge expansion in the literature on the need and provision of the culturally competent care in health services. Extensive evidence has emerged from countries and regions experiencing increased population diversity, including the United States of America, Australia, Canada and the UK. At the same time, addressing the needs of ethnic communities and linguistic groups, each with its own cultural traits and health profiles, presents a major challenge to health care delivery systems. Various models have been put forward to make medicine more responsive to cultural differences and, as the example shown in Figure 2 shows, this requires system-wide changes because the provider and the patient each bring their individual learned patterns of language and culture to the health care experience.

Figure 2: Analytic framework used to evaluate the effectiveness of healthcare system interventions to increase cultural competence



(*Source: Anderson et al. 2003:72)*

Culturally competent healthcare systems - those that provide culturally and linguistically appropriate services - have the potential to reduce racial and ethnic health disparities. When patients do not understand what their healthcare providers are telling them, and providers either do not speak the patient's language or are insensitive to cultural differences, the quality of health care can be compromised. This can lead to lower patient satisfaction with care, fewer improvements in health status, and inappropriate racial or ethnic differences in use of health services or in received and recommended treatment.

4.2 Final conclusions and recommendations

From this review of the literature, it is possible to extract a number of key conclusions and recommendations for policy makers and practitioners.

4.2.1 Overall key messages:

- Effective communication is central to safeguarding the quality of health care, especially in respect of the needs of members of cultural and linguistic or migrant minorities.

- The use of 'informal interpreters' using friends, family, partners or children in health care settings, is dangerous and must be actively discouraged

- Attention to 'language needs' should not focus exclusively on 'black and minority ethnic groups but also on groups such as seasonal or migrant workers

- The provision of interpretation, translation, advocacy and language support services (ITALS) may be cost effective and is essential to reduce health inequalities

- In the longer term, consideration needs to be given to moving from an 'ITALS' based approach, towards delivery of 'Culturally and Linguistically Appropriate Services' (CLASS).

- Since April 1996, the NHS has expected that all hospital trusts will record, and provide as part of the ‘contract minimum data set’ to health commissioners, data relating to the ethnic origin of all ‘admitted patients’, including day cases. Ethnic monitoring requires the identification of individuals as belonging to one or more groups, defined in terms of their culture and origin - this should include language (and religion) and should be enforced.

- The issue of language need and support services is not exclusive to health care: there is much good practice already developed in the field of legal services, and there are other interested groups including other Government departments, who should co-operate, perhaps through an inter-departmental working group to address these issues

- In order to demonstrate linguistic competence, it has been suggested that organisations should have in place policies, structures, practices, procedures, and dedicated resources to support such linguistic competence capacity following the model laid out by the US National Center for Cultural Competence

4.2.2 Messages for service planners, commissioners and providers

- All UK health service agencies must 'have due regard to the need to eliminate unlawful discrimination', and to make explicit consideration of the implications for racial equality of every action or policy (Race Relations Amendment Act 2000). This renders the provision of interpretation, translation, advocacy and language support services (ITALS) an essential element of policy and practice

- There needs to be support for a national telephone interpreter service to match the requirements of 24 hour emergency health care provision.

- There is a need to raise the awareness of health professionals on the advantages of having access to trained interpreters and on the limits of using relatives as translators.

- Critical consideration should be given to the possibilities of international solutions to ITALS needs (e.g. by use of international telephone or other information technology media)

- More needs assessment is required at national, regional and local levels but this should be tied to guaranteed resourcing and evaluation, and adequate time and resource allocated to ensure that initiatives are fully worked through

- Health promotion activity should be alert to the need to move away from printed materials and passive dissemination towards audio-visual presentation and active engagement with minority communities.

- More consideration can be given to the use of pictorial representation and pictograms, which are also useful for communication with people who have learning difficulties

- Service planners, commissioners and providers should recognise that there can be as many models of good practice as there are communities, and that specific communities may require highly specific solutions

- There is a lack of language screening instruments for use with multilingual children.

- Priority needs to be given to initial and further training of Speech and Language therapists in working with multilingual children and the recruitment of staff from minority origins

- The use of video material may also be particularly useful in order to convey material verbally and visually. This may be especially useful where individuals cannot read the written form of their language

- NHS Direct Online has begun to develop a resource of translated materials for patient information: this will require the development of quality assurance procedures, but also better dissemination and action to raise awareness of such a resource

- Models of care from other cultures need to be explored.

- When considering 'communication, it must be recognised that there is a difference between 'general awareness' and levels of 'detailed knowledge' and that there are different kinds of information field. 'Localised' knowledge and intra-group communication within communities are critical in overcoming reluctance to act.

- Translating material into other languages can send out an important signal to minority communities about intentions to be inclusive.

- Messages must be specifically tailored to their audience, taking religious and other beliefs and practices into account

- Interpreters trained 'generically' or for work in legal and commercial settings will require specific training to be effective in working with health specific knowledge

- There is a strong argument for recruitment procedures to seek to develop a more diverse work force in all clinical (and related) professions and settings

- Planners, Commissioners and Providers should work in partnership with black and minority ethnic communities to produce progressive community-based mental health care (as recommended also by NIMHE) - and in other community services

- There is scope for the development (and evaluation) of training programmes in
  - use of interpreters (for health care workers)
  - managing language support (and language competent) services

- There needs to be an active programme of social marketing to overcome reluctance of people to request proper language support.

4.2.3 Research needs

Further UK research is needed into:

- issues related to management and quality of these services (including quality standards for leaflets / translated materials);
- the clinical implications of not providing interpreter, advocacy and translation services;
- effective training of interpreters / advocates;
- training in the use of interpreters;
- training in the management and delivery of ITALS services;
- alternative models of managing language support services;
- the process and outcome of psychotherapy for different groups.

More generally,

- Pathways to care need to be studied as social processes subject to a wide range of influences, including cultural context.

- There is a need for more research or audit which will enable collection of baseline data on the cultural and linguistic diversity of local areas.

- This research needs to be complemented by research into the language learning process undergone by settlers, and also issues of language loss associated with ageing.

- There is scope for wider development of research into 'new technology' in health care provision, which should explicitly and overtly include attention to issues of diversity.

- Research will be required into the levels of effective internet access among UK populations.

- Research is needed into linguistic diversity in services which diagnose and treat speech / language conditions, both relating to children and older people or those with disabling conditions (e.g. stroke).

- There is a need for more cost and clinical-effectiveness studies in UK settings

5 KEY PUBLISHED & GREY LITERATURE – BY SECTION HEADING

Section 1: INTRODUCTION & Section 2: STUDY OUTLINE

1. Ahmad, W. Kernohan, E. & Baker M. (1989). Patients' choice of general practitioner: influence of patients' fluency in English and the ethnicity and sex of the doctor, *Journal of the Royal College of General Practitioners,* vol. 39, pp. 153-155.

2. Atkinson M, Clark M, Clay D, Johnson M, Szczepura A (2001). *Systematic review of ethnicity and health service access for London*. Centre for Health Services Studies, University of Warwick, Coventry, UK. February 2001. ISBN 0-9535-4300-6.

3. Audit Commission (1994). *What seems to be the matter: Communication between hospitals and patients*. Audit Commission report. HMSO.

4. Campbell Collaboration (2005). http://www.campbellcollaboration.org/FraAbout.html (accessed 3/10/05)

5. Chase-Ziolek, M. (1999). "The meaning and experience of health ministry within the culture of a congregation with a parish nurse." *Journal of Transcultural Nursing* 10(1): 46-55.

6. Chui, L. (1991). "Advocacy; the Leeds experience", *Community Dental Health.*, vol. 8, pp. 253-256.

7. Cooke, M., Margerison, C. (2003). NHS Direct –impact and effectiveness: available at: http://www.nelh-ec.warwick.ac.uk/ECL_Toolkit/source%20files/NHS%20Direct%20Rapid%20Review%20feb2003.pdf

8. Davies, S. C., Cronin, E., Gill, M., Greengross, P., Hickman, M., & Normand, C. (2000). "Screening for sickle cell disease and thalassaemia: a systematic review with supplementary research.", *Health Technol Assess*, vol. 4, no. 3, pp. 1-150.

9. Gerrish K (2000). Researching ethnic diversity in the British NHS: methodological and practical concerns. *J Adv Nurs*. 2000 Apr;31(4):918-25.

10. Hornberger, Gibson CD Jr, Wood W, Dequeldre C, Corso I, Palla B, Bloch DA. (1996). Eliminating language barriers for non-English speaking patients. *Med-Care*. Aug 1996; 34(8): 845-856.

11. Johnson MRD, Clark MD, Owens D, Szczepura A (1999). *The Unavoidable Costs of Ethnicity: A review of evidence on health costs*. Centre for Health Services Studies, University of Warwick, Coventry, UK. June 1999. ISBN 0953 5430 05.

12. Johnson MRD, Owen D, Blackburn C, Rehman H, Nazroo J (2000) *Black and Minority Ethnic Groups in England: The second health & lifestyles survey* London: Health Education Authority

13. Jones, K. (2004) Mission Drift in Qualitative Research, or Moving Toward a Systematic Review of Qualitative Studies, Moving Back to a More Systematic Narrative Review. The Qualitative Report Volume 9 Number 1 March 2004 95-112. Available at: http://www.nova.edu/ssss/QR/QR9-1/jones.pdf

14. King, S. and Murray, K. (1996) ‘Family and Working Lives Survey: preliminary results’, *Labour Market Trends*, March 1996, pp. 115-119.

15. Kramsch, C. (2002). "In search of the intercultural Review of FE Jandt. Intercultural Communication: An Introduction. 3rd edition; Young Yun Kim. Becoming Intercultural: An Integrative Theory of Communication and Cross-Cultural Adaptation.; Tony Schirato & Susan Yell. Communication and Culture: An Introduction.; Ron Scollon & Suzanne Wong Scollon. Intercultural Communication: A Discourse Approach. 2nd edition." *Journal of Sociolinguistics* 6(2): 275-285.

16. Leman, P (1997). "Interpreter use in an inner city accident and emergency department", *J.Accid.Emerg.Med.*, vol. 14:98-100, pp. 98-100.

17. Lodge, N. (2001). "The identified needs of ethnic minority groups with cancer within the community: a review of the literature." *European Journal of Cancer Care (England)* 10(4): 234-44.

18. Mander, G. (2003). "The Women's Therapy Centre Language Project: Evaluation." *British Journal of Psychotherapy* 20(1): 97-102.

19. Miller C, Lewis D (1999) *Wayfinding: Guidance for HealthCare Facilities* London: Stationery Office

20. Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon S. (1997). *Ethnic Minorities in Britain: Diversity and Disadvantage* London: Policy Studies Institute

21. Myhill, J. (2003). "The native speaker, identity, and the authenticity hierarchy." *Language Sciences* 25(1): 77-97.

22. Nicoll S (1998). Patients & Visitors. Wayfinding Study Report London: Royal London Hospital

23. Ntshona MS (1997). Are professional interpreters needed in the South African health care services. *S-Afr-Med-J*. Sep 1997; 87(9): 1143.

24. Parsons, L. & Day, S. (1992). "Improving obstetric outcomes in ethnic minorities: an evaluation of health advocacy in Hackney", *Journal of Public Health Medicine.*, vol. 14, no. 2, pp. 183-191.

25. Phelan, M. & Parkman, S. (1995). "How to do it: Work with an interpreter", *BMJ.*, vol. 311, 26 Aug, 555-557.

26. Poss, J. & Rangel, R. (1995). "Working Effectively with Interpreters in the Primary Care Setting", *Nurse Practitioner.*, vol. 20, no. 12, pp. 43-47.

27. Presley F; Shaw A. (1995). *Race and health: an information sources guide*. SHARE, King's Fund Centre, London. 1995.

28. Research Services Limited, Social Research (1995) *Family and Working Lives: technical report*, Harrow, RSL Social Research.

29. Rudat K, (1994). *Black and Minority Ethnic Groups in England: Health & Lifestyles* London: Health Education Authority

30. Sheldon T, Chalmers I (1994). ‘The UK Cochrane Centre and the NHS Centre for Reviews and Dissemination: Respective Roles Within the Information Systems Strategy of the NHS R&D Programme, Coordination and Principles Underlying Collaboration’ Health Economics 3: 201-203.

31. Stewart, A. L. N.-S., A. Perez-Stable, E. J. Posner, S. F. Bindman, A. B. Pinderhughes, H. L. Washington, A. E. (1999). "Interpersonal Processes of Care in Diverse Populations." *Milbank Quarterly* 77(3): 305-340.

32. Storkey M. (2000) Using the schools’ language data to estimate the total number of speaker of London’s top 40 languages. In Baker P & Eversley J (Eds) Multilingual Capital – The languages of London schoolchildren and their relevance to economic, social and educational policies. London: Battlebridge.

33. Szczepura A, Clark MD, Johnson MRD, Owen D (1999). *‘Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services*’ Centre for Health Services Studies, University of Warwick, Coventry. September 1999. ISSN 0964-7902.

34. Ulrey, K. L., Amason, P. (2001). "Intercultural communication between patients and health care providers: An exploration of intercultural communication effectiveness, cultural sensitivity, stress, and anxiety." *Health Communication* 13(4).

35. US National Center for Cultural Competence. http://www.omhrc.gov/omh/programs/2pgprograms/finalreport.pdf.

Section 3: RESULTS

3.2 Meeting language needs (interpreter/ advocacy services)

1. Ahmad W.I.U. (1996). Family obligations and social change among Asian communities. In Ahmad W.I.U and Atkin K. (ed.). *Race and Community Care*. Buckingham: Open University.

2. Atkinson M., Clark M., Clay D., Johnson M. and Szczepura A. (2001). *Systematic review of ethnicity and health service access for London*. Centre for Health Services Studies, University of Warwick, Coventry, UK. February. ISBN 0-9535-4300-6.

3. Audit Commission. (1994). *What seems to be the matter: Communication between hospitals and patients*. Audit Commission report. London: HMSO.

4. Baker D.W., Parker R.M., Williams M.V., Coates W.C. and Pitkin K. (1996). Use and effectiveness of interpreters in an emergency department. *JAMA*. 275(10): 783-8.

5. Baxter C. and Baxter D. (2000). Serious neurological disorders and minority ethnic people: A problem service, access needs immediate attention*. Public Health Medicine.* 2(2): 74 - 79.

6. Bernstein J., Bernstein E., Dave A., Hardt E., James T., Linden J., Mitchell P., Oishi T., and Safi C. (2002). Trained Medical Interpreters in the Emergency Department: Effects on Services, Subsequent Charges, and Follow-up. *Journal of Immigrant Health*. 4(4): 171-176.

7. Bischoff A., Tonnerre C., Loutan L., and Stalder H. (1999a). Language difficulties in an outpatient clinic in Switzerland. *Sozial- und Praventivmedizin*. 44(6): 283 - 287.

8. Bischoff A., Tonnerre C., Eytan A., Bernstein M., and Loutan L. (1999b). Addressing language barriers to health care, a survey of medical services in Switzerland. *Sozial- und Praventivmedizin*. 44(6): 248 - 256.

9. Box V. (1998), Cervical screening: the knowledge and opinions of black and minority ethnic women and of health advocates in East London. *Health Education Journal*. 57(3): 3-15.

10. Bulma K. H. and McCourt C. (2002). Somali refugee women's experiences of maternity care in west London: A case study*. Critical Public Health.* 12(4): 365 - 380.

11. Cameron E., Badger F. and Evers H. (1989). District nursing, the disabled and the elderly: who are the black patients? *J Adv Nurs*. 14(5): 376-82.

12. Carrasquillo O., Orav E.J., Brennan T.A., Burstin H.R. (1999). Impact of language barriers on patient satisfaction in an emergency department. *J Gen Intern Med*. 14(2): 82-7.

13. Chamba R. and Ahmad W.I.U. (2000). Language, communication and information: the needs of parents caring for a severely disabled child. In Ahmad W.I.U. (ed.). *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University.

14. Cohen S., Moran-Ellis J. and Smaje C. (1999). Children as informal interpreters in GP consultations: pragmatics and ideology. *Sociology of Health & Illness*. 21(2): 163 - 186.

15. Cooper L.A, Roter D.L., Johnson R.L., Ford D.E., Steinwachs D.M. and Powe N.R. (2003). Patient-Centered Communication, Ratings of Care, and Concordance of Patient and Physician Race. *Annals of Internal Medicine*. 139: 907-915.

16. Cortis J. D. (2000). Perceptions and experiences with nursing care: a study of Pakistani (Urdu) communities in the United Kingdom. *Journal of Transcultural Nursing*. 11(2):111-118.

17. Davies M.M. and Bath P.A. (2001). The maternity information concerns of Somali women in the United Kingdom. *Journal of Advanced Nursing* 36(2): 237-45.

18. Derose K.P. and Baker D.W. (2000). Limited English proficiency and Latinos' use of physician services. *Med Care Res Rev*. 57(1): 76-91.)

19. Drennan G. (1996). Counting the cost of language services in psychiatry. *S Afr Med J*. 86(4): 343-5.

20. Duff L. A., Lamping D. L., and Ahmed L. B. (2001). Evaluating satisfaction with maternity care in women from minority ethnic communities: development and validation of a Sylheti questionnaire. *International Journal for Quality in Health Care*. 13(3): 215 - 230.

21. Enguidanos E. R. and Rosen P. (1997). Language as a factor affecting follow-up compliance from the emergency department. *J Emerg Med*. 15(1): 9-12.

22. Fagan M.J., Diaz J.A., Reinert S.E., Sciamanna C.N. and Fagan D.M. (2003). Impact of interpretation method on clinic visit length. *J Gen Intern Med*. 18(8): 634-8.

23. Farooqi A., Nagra D., Edgar T., and Khunti K. (2000). Attitudes to lifestyle risk factors for coronary heart disease amongst South Asians in Leicester: a focus group study. *Family Practice*. 17(4): 293 - 297.

24. Ferguson, W. J. and Candib, L. M. (2002). Culture, language, and the doctor-patient relationship. *Fam. Med*. 34 (5): 353 - 361.

25. Free C., White P., Shipman C., and Dale J. (1999). Access to and use of out-of-hours services by members of Vietnamese community groups in South London: a focus group study. *Family Practice*. 16 (4): 369 - 374.

26. Fuller J. (1995). Challenging old notions of professionalism: how can nurses work with paraprofessional ethnic health workers? *J Adv Nurs*. 22(3): 465-72.

27. Gerrish K. (2001). The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers. *Journal of Advanced Nursing*. 33(5): 566-74.

28. Graz B., Vader J.P. and Raynault M.F. (2002). Refugees, migrants, language barrier: opinion of physicians on translation aids [Article in French]. *Sante Publique.* 14(1): 75-81.

29. Green G., Bradby H., Chan A., Lee M., and Eldridge K. (2002). Is the English National Health Service meeting the needs of mentally distressed Chinese women? *Journal of Health Services & Research Policy*. 7(4): 216 - 221.

30. Hawthorne K., Rahman J. and Pill R. (2003). Working with Bangladeshi patients in Britain: perspectives from Primary Health Care. *Family Practice*. 20(2): 185 - 191.

31. Hayes L. (1995). Unequal access to midwifery care: a continuing problem? *Journal of Advanced Nursing*. 21(4): 702-707.

32. Heaney C. and Moreham S. (2002). Use of interpreter services in a metropolitan healthcare system. *Aust.Health Rev*. 25(3): 38 - 45.

33. Jacobs E. A., Lauderdale D. S., Meltzer D., Shorey J. M., Levinson W., and Thisted R. A. (2001). Impact of interpreter services on delivery of health care to limited-English-proficient patients. *Journal of General Internal Medicine*. 16(7): 468 - 474.

34. John-Baptiste A., Naglie G., Tomlinson G., Alibhai S.M., Etchells E., Cheung A., Kapral M., Gold W.L., Abrams H., Bacchus M., and Krahn M. (2004). The Effect of English Language Proficiency on Length of Stay and In-hospital Mortality. *J Gen Intern Med*. 19(3): 221-8.

35. Johnson M.R.D., Clark M.D., Owens D. and Szczepura A. (1999). *The Unavoidable Costs of Ethnicity: A review of evidence on health costs*. Centre for Health Services Studies, University of Warwick, Coventry, UK. June. ISBN 0953 5430 05.

36. Jones D. and Gill P. (1998). Breaking down language barriers: The NHS needs to provide accessible interpreting services for all. *BMJ*. 316:1476-1480.

37. Karliner L.S., Perez-Stable E.J., and Gildengorin G. (2004). The language divide. The importance of training in the use of interpreters for outpatient practice. *J Gen Intern Med*. 19(2): 175-83.

38. Kravitz R.L., Helms L.J., Azari R., Antonius D., and Melnikow J. (2000). Comparing the use of physician time and health care resources among patients speaking English, Spanish, and Russian. *Med Care*. 38(7): 728-38.

39. Kwan S. Y. and Williams S. A. (1998). Attitudes of Chinese people toward obtaining dental care in the UK. *British Dental Journal*. 185(4): 188 - 191.

40. Larcher V. F., Bourne J., Aitken C., Jeffries D., Hodes D., Sloan D., Ramsay M., Goldberg D. and Bramley C. (2001). Overcoming barriers to hepatitis B immunisation by a dedicated hepatitis B immunisation service. *Archives of Disease in Childhood.* 84(2): 114 - 119.

41. Lawrenson R., Leydon G., Freeman G., Fuller J., Ballard J., and Ineichen B. (1998). Are we providing for ethnic diversity in accident & emergency (A&E) departments? *Ethnicity & Health*. 3(1-2): 117 - 123.

42. Lee S.J., Back A.L., Block S.D. and Stewart S.K. (2002). Enhancing Physician-Patient Communication. *Hematology.* 1: 464-83.

43. Leman P. and Williams D.J. (1999). Questionnaire survey of interpreter use in accident and emergency departments in the UK. *J Accid Emerg Med*. 16(4): 271-4.

44. Li P. L., Logan S., Yee L. and Ng S. (1999). Barriers to meeting the mental health needs of the Chinese community*. Journal of Public Health Medicine*. 21(1): 74 - 80.

45. Madhok R., Hameed A. and Bhopal R. (1998). Satisfaction with health services among the Pakistani population in Middlesbrough, England*.* *Journal of Public Health Medicine*. 20(3): 295 - 301.

46. Pfeffer N. and Moynihan C. (1996). Ethnicity and health beliefs with respect to cancer: a critical review of methodology. *Br J Cancer*. Suppl.29: S66-72.

47. Pharoah C. (1995). *Primary Health Care for Elderly People from Black & Minority Ethnic Communities*. London: HMSO.

48. Robinson, M. and Gilmartin, J. (2002). Barriers to communication between health practitioners and service users who are not fluent in English. *Nurse Educ.Today*. 22(6): 457 - 65.

49. Robinson L. (1998). *'Race', Communication and the Caring Professions*. Buckingham: Open University.

50. Rothschild, S. K. (1998). Cross-cultural issues in primary care medicine. *Dis. Mon*. 44(7): 293 - 319.

51. Sarver, J. and Baker D. W. (2000). Effect of language barriers on follow-up appointments after an emergency department visit. *J Gen Intern Med*. 15(4): 256-64.

52. Sensky T. (1996). Eliciting lay beliefs across cultures: principles and methodology. *Br J Cancer*. Suppl.29:S63-5.

53. Shapiro J., Hollingshead J. and Morrison E. H. (2002). Primary care resident, faculty, and patient views of barriers to cultural competence, and the skills needed to overcome them. *Med.Educ*. 36(8): 749 - 759.

54. Sproston K. A., Pitson L. B. and Walker E. (2001). The use of primary care services by the Chinese population living in England: examining inequalities*. Ethnicity & Health*. 6(3-4): 189 - 196.

55. Stolk Y., Ziguras S., Saunders T., Garlick R., Stuart G. and Coffey G. (1998). Lowering the language barrier in an acute psychiatric setting. *Aust.N.Z.J.Psychiatry*. 32(3): 434 - 440.

56. Szczepura A., Clark M.D., Johnson M.R.D. and Owen D. (1999). *'Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services*' Centre for Health Services Studies, University of Warwick, Coventry. September. ISSN 0964-7902.

57. Thomas V., Richardson A., Saleem T., Baylav A., Hall A., Richards M., Gallagher C., Patel M. and Ramirez A. (2000). The efficacy of bilingual health advocacy in ethnic minority patients with cancer. *Nurs Stand*. 14(26): 32-3.

58. Tobin M., Chen L., Edwards J. L., and Chan S. (2000). Improving the utilisation of bilingual counsellors within a public sector mental health service. *Australian Health Review*. 23(2): 190 - 196.

59. Tocher T.M. and Larson E.B. (1999). Do physicians spend more time with non-English-speaking patients? *J Gen Intern Med*. 14(5): 303-9.

60. Tribe R. (1999). Bridging the gap or damming the flow? Some observations on using interpreters / bi-cultural workers when working with refugee clients, many of whom have been tortured. *British Journal of Medical Psychiatry.* 72(4): 567 – 576.

61. Zhu S. H., Anderson C. M., Johnson C. E., Tedeschi G. and Roeseler, A. (2000). A centralised telephone service for tobacco cessation: the California experience". *Tobacco Control*. 9: Suppl - 55.

62. Ziguras S., Klimidis S., Lewis J., and Stuart, G. (2003). Ethnic matching of clients and clinicians and use of mental health services by ethnic minority clients. *Psychiatr.Serv*. 54(4): 535 - 541.

3.3 Health promotion materials (including specialist materials & web-based materials)

1. Barrett, S. (2001). Improving Access and Quality for Ethic Minority Women. *Women’s Health Issues* 11, 4: 345-348).

2. Goldman, R., Hunt, M. K., Allen, J. D., Hauser, S., Emmons, K., Maeda, M., Sorensen, G. (2003). The life history interview method: applications to intervention development. *Health Education Behavior* 30, 5: 564-81.

3. Johnson MRD (1999) Communication in health care: a review of some key issues. *Nursing Times Research* 4,1 :18-30

4. Kakai H, Maskarinec G, Shumay DM, Tatsamura Y, Tasaki K (2003) Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: An exploratory study using correspondance analysis S*ocial Science and Medicine* 56,4 :851-862

5. Kar, S. B., Pascual, C. A., Chickering, K. L. (1999). Empowerment of women for health promotion: a meta-analysis. *Social Science & Medicine* 49, 11: 1431-60.

6. National Center for Cultural Competence (2003). *A Guide to Choosing and Adapting Culturally and Linguistically Competent Health Promotion Materials*. Georgetown University Center for Child and Human Development University Center for Excellence in Developmental Disabilities. (Available at: http://gucchd.georgetown.edu/nccc/documents/Materials_Guide.pdf)

7. Robinson M (2002)*Communication and Health in a Multi-Ethnic Society* Bristol: The Policy Press

8. Schaafsma, E. S. R., Raynor T. D. , de Jong-van den Berg, L. T. (2003). Accessing medication information by ethnic minorities: barriers and possible solutions. *Pharmacy World Science* 25, 5: 185-90.

9. Shire, N. (2002). Effects of race, ethnicity, gender, culture, literacy, and social marketing on public health. *Journal of Gender Specific Medicine* 5, 2: 48-54.

10. Smart, H., Titterton, M., Clark, C. (2003). A literature review of the health of gypsy/traveller families in Scotland: the challenges for health promotion. *Health Education* 103, 3: 156-165.

3.4 'Tele-consultation' services (NHS Direct, telemedicine, websites etc)

1. Anthony D. (2000). Are nurses excluded from the Web? *Current Perspectives in Healthcare Computing Conference*, Harrogate

2. Barnard, H., Pettigrew, N. (2003). *Delivering benefits and services for black and minority ethnic older people*. Department for Work and Pensions. Research Summary. Available at: http://www.dwp.gov.uk/asd/asd5/summ2003-2004/201summ.pdf.

3. Cooke M, Margerison C. (2003). *NHS Direct –impact and effectiveness*: available at: http://www.nelh-ec.warwick.ac.uk/ECL_Toolkit/source%20files/NHS%20Direct%20Rapid%20Review%20feb2003.pdf

4. Department for Transport (2003). *Public Transport Needs of Minority Ethnic and Faith Communities Guidance Pack* Report by Social Research Associates (accessed online at www.info4local.gov.uk March 2004)

5. Georgiou M., Silverstone, R. (2001). *Diasporic Minorities and their Media in the EU: a Mapping*. Available at EMTEL II Research: http://www.lse.ac.uk/collections/EMTEL/Minorities/project_home.html.

6. Georgiou, M. (2001). *Mapping minorities and their Media: The National Context – The UK*. Working paper available at: http://www.lse.ac.uk/collections/EMTEL/Minorities/papers/ukreport.doc.

7. Jackson M, Peters J (2003). Introducing touchscreens to black and ethnic minority groups - a report of processes and issues in the Three Cities project. *Health Information and Libraries Journal* 20 :143-149

8. Jones, R. (2002). *Evaluation of NHS Direct Kiosks*. Seminar archive, University of Plymouth. Abstract available at: http://www.plym.ac.uk/assets/HSC/abstract%202002%20-%20Jan%2016%20evaluation%20of%20NHS%20Direct%20kiosks.pdf.

9. Mandl KD, Feit S, Pena BM, Kohane IS (2000). Growth and determinants of access in patient e-mail and Internet use *Archives Pediatric Adolescent Medicine* 154,5 :508-511

10. Phul, A, Bath, P.A., Jackson, M. G. (2003). The provision of information by health promotion units to people of Asian origin living in the UK. *Health Informatics Journal*, 9, 1: 39-56.

11. Ring F, Jones M. (2004). NHS Direct usage in a GP population of children under 5 years: is NHS Direct used by people with the greatest health need? *British Journal of General Practice* 54 :211-213

12. U.S. Department of Commerce (2000). *Falling Through the Net: Toward Digital Inclusion* http://www.ntia.doc.gov/ntiahome/fttn00/contents00.html

3.5 Procedures for managing and planning for linguistic diversity

1. Bekaert S. (2000). Minority integration in rural healthcare provision: an example of good practice. *Nursing Standard*. 14(45): 43-5.

2. Commission for Health Improvement. (2002). Brent, Kensington, Chelsea & Westminster Mental Health NHS Trust: Clinical Governance Review Report -Executive summary. August 2002. http://www.chi.nhs.uk/eng/organisations/london/brent/2002/exec_sum.shtml

3. Garrett C. R., Treichel C. J., and Ohmans P. (1998). Barriers to health care for immigrants and nonimmigrants: a comparative study. *Minnesota Medicine*. 81 (4): 52 - 55.

4. Johnson M., Noble C., Matthews C. and Aguilar N. (1998). Towards culturally competent health care: language use of bilingual staff. *Aust.Health Rev*. 21(3): 49 - 66.

5. Kennedy J., Seymour D. J., and Hummel B. J. (1999). A comprehensive refugee health screening program. *Public Health Reports*. 114 (5) : 469 - 477.

6. Kim M. J., Cho H. I., Cheon-Klessig Y. S., Gerace L. M., and Camilleri D. D. (2002). Primary health care for Korean immigrants: sustaining a culturally sensitive model. *Public Health Nursing*. 19(3): 191 - 200.

7. Labun E. (1999). Shared brokering: the development of a nurse-interpreter partnership. *Journal of Immigrant Health.* 1(4): 215-22.

8. Mihalopoulos C., Pivkis J., Dunt D. and Naccarella L. (1999). Shared mental health care and people of non-English-speaking backgrounds: A qualitative study of key informants' views. *Primary Care Psychiatry*. 5 (1): 19 - 24.

9. Mitchell P. and Jones B. (2002). *Patient Profiling in Primary Care: Report to Liverpool PCT.* Liverpool: Primary Care Trust

10. Murphy K. and Clark J. M. (1993). Nurses' experiences of caring for ethnic-minority clients*. Journal of Advanced Nursing*. 18(3): 442-50.

11. Ngo-Metzger Q., Massagli M. P., Clarridge B. R., Manocchia M., Davis R. B., Iezzoni L. I. and Phillips R. S. (2003). Linguistic and cultural barriers to care. *J.Gen.Intern.Med*. 18 (1): 44 - 52.

12. Pennington S. (2001). Language matters. *Nursing Times*. 97(6): 28–29.

13. Powell B. (1999). *Improving Assessibility and information services for Asian communities, relating to cancer and palliative care*. Leicester: Cancer Care - Ethnic Minorities Group.

14. Public Health Sector Group (2000) *Ethnicity Profiling in Primary Care: The Princes Park Health Centre Model* Liverpool: Public Health Sector Group, School of Health & Human Sciences, Liverpool John Moores University

15. Shaw-Taylor Y. and Benesch B. (1998). Workforce diversity and cultural competence in healthcare. *J.Cult.Divers*. 5(4): 138 - 146.

16. Tang S. Y. (1999). Interpreter services in healthcare. Policy recommendations for healthcare agencies*. J.Nurs.Adm*. 29(6): 23 - 29.

17. Timmins C. L. (2002). The impact of language barriers on the health care of Latinos in the United States: a review of the literature and guidelines for practice. *J.Midwifery Womens Health*. 47(2): 80 - 96.

18. Tribe R. (1999). Bridging the gap or damming the flow? Some observations on using interpreters/ bicultural workers when working with refugee clients, many of whom have been tortured*. British Journal of Medical Psychology*. 72 (Pt 4): 567 - 576.

19. Wimmer B. and Ipsiroglu O. S. (2001). Communication barriers in the management of immigrants and their children. An analysis and possible solutions based on case reports. [Article in German]. *Wien.Klin.Wochenschr*. 113(15-16): 616 - 621.

20. Ziguras S., Klimidis S., Lewis J. and Stuart G. (2003). Ethnic matching of clients and clinicians and use of mental health services by ethnic minority clients. *Psychiatr.Serv*. 54(4): 535 - 541.

3.6 Provision of services which diagnose and treat speech / language conditions

1. Forster A, Young J (1996) Specialist nurse support for patients with stroke in the community: a randomised controlled trial *British Medical Journal* 312 :1642-1646

2. Isaac, K. (2001). What about linguistic diversity? A different look at multicultural health care. *Communication Disorders Quarterly* 22, 2: 110-113.

3. Law, J. (2000). Factors affecting language development in West African children: a pilot study using a qualitative methodology. *Child: Care, Health and Development* 26, 4: 289-308.

4. Maas, W. (2000). Early detection of speech and language delays in the Netherlands. The case for integrating primary and secondary prevention. *Child Care Health and Development* 26, 2: 150-162.

5. Pert, S., Stow, C. (2001). Language remediation in mother tongue: a paediatric multilingual picture resource. *International Journal of Language Communication Disorders* 36 Suppl: 303-8.

6. Rudd AG, Wolfe CDA, Tilling K, Beech R (1997) Randomised controlled trial to evaluate early discharge scheme for patients with stroke. *British Medical Journal* 315 :1039-1044

7. Sanderson RJ, Ironside JAD (2002) Squamous cell carcinomas of the head and neck *British Medical Journal* 325 :822-827

8. Semela, J. J. (2001). Significance of cultural variables in assessment and therapy. *Folia Phoniatrica et Logopaedica* 53, 3: 128-34.

9. Winter, K. (1999). Speech and language therapy provision for bilingual children: aspects of the current service. *International Journal of Language Communication Disorders* 34, 1: 85-98.

3.7 Provision of 'talking' therapies (i.e. counselling, psychotherapy)

1. Bowes, A., Wilkinson,H. (2003). ‘We didn’t know it would get that bad’: South Asian experiences of dementia and the service response. *Health and Social Care in the Community* 11(5): 387-396.

2. Burman, E., Gowrisunkur, J., Walker, K. (2003). Sanjhe Rang/Shared colours, shared lives: a multicultural approach to mental health practice. *Journal of Social Work Practice* 17(1): 63-76.

3. Department of Health (DoH)/Mental Health Policy & Performance. (2003). *Delivering Race Equality: A Framework for Action*. London: Department of Health.

4. Fischer, A. R., Jome, L. M., Atkinson,D. R. (1998). Reconceptualizing multicultural counseling: Universal healing conditions in a culturally specific context. *Counseling-Psychologist* 26(4): 525-588.

5. Hayes-Bautista, D. E. (2003). Research on culturally competent healthcare systems. Less sensitivity, more statistics. *American Journal of Preventative Medicine* 24(3 Suppl): 8-9.

6. Kleinman, A. (1998). *Rethinking Psychiatry: From cultural category to personal experience.* New York: Free Press.

7. Morgan, C., Mallett, R., Hutchinson, G., Leff, J. (2004). Negative pathways to psychiatric care and ethnicity: the bridge between social science and psychiatry. *Social Science and Medicine* 58(4): 739-752.

8. Patel, K., Winters, M., Bashford, J., Bingley, W. (2003). *Engaging and Changing Developing effective policy for the care and treatment of Black and minority ethnic detained patients.* National Institute for Mental Health in England (NIMHE) and University of Central Lancashire. London: Department of Health.

9. Pierre, S. A. (2002). Legal, social, cultural and political developments in mental health care in the UK: the Liverpool black mental health service users' perspective. *Journal of Psychiatric Mental Health Nursing* 9(1): 103-10.

10. Sainsbury Centre for Mental Health (SCMH). (2002). *Breaking the Circles of Fear*. London: Sainsbury Centre for Mental health (SCMH).

11. Sashidharan, S., National Institute for Mental Health (NIMHE). (2003). *Inside Outside Improving Mental Health Services for Black and Minority Ethnic Communities in England.* London: Department of Health.

12. Thakker, J., Ward, T.,Strongman, K. T. (1999). Mental disorder and cross-cultural psychology - Where did it come from and where should it go? II: Empirical studies, innovations and recommendations. *Clinical Psychology Review* 19(7): 843-874.

3.8 Other aspects of ethnicity and communication e.g. consensual/ participatory activities.

1. Baines LS, Joseph JT, Jindal RM (2002) A public forum to promote organ donation amongst Asians: the Scottish initiative *Transplant International* 15(2-3) :124-131

2. Callender CO, Hall MB, Branch D (2001) An assessment of the effectiveness of the Mottep model for increasing donation rates and preventing the need for transplantation - adult findings: program years 1998 and 1999 *Seminars in Nephrology* 21,4 :419-28

3. Carlisle D (1995) Life-Giving Fatwa *Nursing Times* 91,29 :14-15

4. Exley C, Sim J, Reid N, Jackson S, West N (1996) Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study. *Social Science and Medicine* 43,1 :23-28

5. Gentry D, LaVert T (2003) Meeting the Challenges of Organ Donation and Transplantation. *Ethnicity and Renal Failure: Disparity or Diversity* London: South West Thames Institute for Renal Research and Renal and Transplantation Unit (National Symposium report, British Library, London, 9 May 2003) :12-13

6. Guadagnoli E, McNamara P, Evanisko MJ, Beasley C, Callender CO, Poretsky A (1999) The influence of Race on approaching families for organ donation. *American Journal of Public Health* 89,2 :244-247

7. Howitt R (2003) Religious perspectives on organ donation. *UK Transplant Bulletin* 43 :13-15

8. Jeffrey RF, Woodrow G, Mahler J, Johnson R, Newstead CG (2002) Indo-Asian experience of renal transplantation in Yorkshire: results of a 10-year survey. *Transplantation* 73(10):1652-7

9. Kirsty S (1998) Toward understanding Vietnamese attitudes, beliefs and practices regarding blood donation. *Social Sciences in Health* 4,3 :154-162

10. Mitchell AA, Sedlacek WE (1996). Ethnically sensitive messengers. *Journal National Medical Association* 88,6 :349-352

11. Randhawa G (1998). An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton UK. *Nephrology Dialysis Transplantation* 13 :1949-1954

12. Ready AR (1998) Transplanting an ethnic community: approaches to the crisis. *Nephrol. Dial. Transplant* 13 :2490-2493

13. Ready AR, Trafford J, Hooker A, Briggs D (1997). Impact of a large non-indigenous population on the Renal Transplant waiting list. *Transplantation proceedings* 29 :3724-3725

14. Roderick P, Clements S, Diamond I, Storkey M, Raleigh VS (1998). Estimating demand for renal replacement therapy in Greater London:

the impact of demographic trends in ethnic minority populations. *Health Trends* 30,2 :46-50

15. Verble M, Worth J (2003). Cultural sensitivity in the donation discussion. *Progress in Transplantation* 13(1):33-7

16. Yuen CC, Burton W, Chiraseveenuprapund P, Elmore E, Wong S, Ozuah P, Mulvihill M. (1998). Attitudes and Beliefs about organ donation. *Journal National Medical Association* 90,1 :13-18

4 CONCLUSIONS AND RECOMMENDATIONS

4.1 Overview of research evidence base

1. Anderson, L. M., Scrimshaw, S. C., Fullilove, M. T., Fielding, J. E., and Normand, J. (2003). Culturally competent healthcare systems. A systematic review. Am.J.Prev.Med. 24; (3 Suppl) : 68 - 79.

Annex 1: Defining Ethnicity and Ethnic Group

1.1 The concept of ethnicity

There are many ways of defining an ‘ethnic minority’ (Pringle et al 1997). Indeed, several papers discuss this issue, and there has been considerable debate and controversy about the categories in use within the NHS (Bhopal 1991, Ahmad & Sheldon 1996, Sheldon & Parker 1992, Aspinall 1995, McKenzie and Crowcroft 1994). The crucial point made by many authors is that the categorisation used must be 'fit for purpose' i.e. it must be relevant to the delivery of the service being considered and to the recognition of client need. Unfortunately, there remains a huge diversity of terms in use, and considerable confusion between their meanings and conceptual bases - even in well-regarded journals such as the American Journal of Epidemiology or the American Journal of Public Health (Comstock et al 2004), and many proxy measures are used.

> The trouble with using nationality, birthplace, ethnic origin or language spoken at home as indicators of ethnic categories is that this implicitly assumes that such criteria all refer to the same clear-cut entities .... It is more effective to use different criteria to pursue different policy objectives ...
> (Vermeulen 1997)

In approaching the issue of ethnicity and diversity we need also to be aware of a complex and contentious history in the evolution of ideas and terminology. Traditional anthropology defined four major human ‘races’, usually described as ‘Caucasian’ (‘white’ or European), ‘Negroid’ (Black or African), ‘Mongoloid’ (Asian, Chinese or Indic), and ‘Australoid’ (that is, the group of people described as ‘Aboriginal’ to Australia). These groups assumed that race was a bio-scientific concept explaining significant biological differences between populations. This concept of race is now firmly discredited by modern genetics. Over 99% of the genetic make up of human beings is common to all ethnic groups. Those differences that do exist between people and populations are minor and largely reflect superficial physical characteristics (‘phenotypes’) such as facial features, hair or skin colour. In this sense the division of people into ‘races’ reflects social decisions rather than having any real scientific justification, being based on fallacious genetic/biological associations rather than cultural ones. Culture is, however, a complex social phenomenon and its definition problematic. It consists of the shared beliefs, values and attitudes that guide the behaviour of group members. The concept of ‘ethnicity’ is even more complex, but recognises that people identify themselves with a social grouping on cultural grounds including language, lifestyle, religion, food and origins. The basis of ‘ethnicity’ is thus often a tradition of common descent or intermarriage and shared culture or history. It is essential to recognise that, in a world of migration and mixing, cultures and societies are dynamic rather than fixed. The Table below compares the concepts of race, culture and ethnicity.

Table 1.1: Comparison of ‘race’, culture and ethnicity

Concept	**Primary Characteristics**	**Origin**	**Associated perceptions**
‘Race’	Inherent, Biological, Physical, Nature/ Natural	Genetic – Descent	Permanent
Culture	Behavioural Expression of preferred lifestyle	Upbringing – Learned	Capable of being changed, Optional
Ethnicity/ Ethnic Group	Identity, Multi-faceted, ‘Political’	Socially constructed – Internal or external – or legal	Situational, Negotiated

1.2 Ethnic monitoring in the NHS

The UK Race Relations Act 1976 defined a ‘racial group’ as ‘a group of persons defined by reference to colour, race, nationality or ethnic or national origins...’ ‘Ethnicity’ and ‘ethnic group’ became more formally defined in UK law by a House of Lords decision (Mandla v Lee 1983) as relating to those with ‘a long shared history and a distinct culture’. Other ‘relevant’ characteristics were ‘a common geographic origin or descent from a small number of common ancestors; a common language; a common literature; a common religion and being a minority within a larger community'.

Since April 1996, the NHS has expected that all hospital trusts will record, and provide as part of the 'contract minimum data set' to health commissioners, data relating to the ethnic origin of all 'admitted patients'. This includes day cases as well those admitted to hospital for any form of treatment. The circular authorising this data collection (EL(94)77) was the product of extensive discussion and prior testing, and led to considerable controversy at the time of its introduction (Johnson & Gill 1995, Ranger 1994).

Ethnic monitoring requires the identification of individuals as belonging to one or more groups, defined in terms of their culture and origin (Gerrish 2000). Were it nothing more than this, it might be the sort of casual categorisation that could lead to discrimination and harm based on stereotype (Ahmad 1999). To be effective and useful, ethnic monitoring in the NHS and elsewhere should rely upon the individual concerned being given the opportunity to define their identity in terms that are meaningful to them - and hence, which reveal something about them which is of value to the care-giver. This may mean looking for differences where they are not expected - including among the 'white majority' population - and that cannot be inferred from skin colour and appearance.

There has been a steady growth in the collection of ethnic monitoring data in hospital trusts since 1996, although rather fewer indications of its use. The NHS has also supported the development of ethnic monitoring procedures in primary care (Pringle and Rothera 1996) with several 'pilot sites' in West London (Brent & Harrow), the West Midlands, and Liverpool participating in this process. NHSCCC (Loughborough) generated a set of READ codes for use in primary care (general practice) systems, which related to the 1991 Census ethnic groups. They have also created codes for 22 'main spoken languages' (as well as English), although at present these are not widely used or standardised - nor do they cover all languages likely to be required in settings such as London, having been initially created for a Liverpool-based project. In January 2004 a new set in the Read code series 9i… compatible with the 2001 census was released to support monitoring 'to verify whether obligations under the Race Relations Amendment Act 2000 were being complied with' (London Health Observatory guidance). There remain problems in converting between category sets, but there is increasing recognition that Patient Profiling' is now desirable, and possibly a necessary activity under the new legislation.

The most common indicator of difference, or the size of 'minority' populations, in census data and other official records, has been *birthplace*. This information is recorded on most identity documents, and is used to analyse data such as that collected on death certificates. Unfortunately, it provides a poor indicator of cultural or 'ethnic' origin. At the time of the 1991 Census, over half the population in the 'Black' categories (54% Black Caribbean, 84% Black Other, and 36% Black African) were UK-born, as were half of those giving their ethnic group as Pakistani, 42% of 'Indians' and 37% of 'Bangladeshis'. It is now estimated that less than 40% of the black and minority ethnic population can be identified by birthplace, and increasingly few by the birthplace of their parents. In terms of ethnic health, birthplace data may therefore be of little or no value, even if still used in some epidemiological studies.

Information on ethnicity can be collected in a number of ways. One of the least threatening and most commonly used identifiers for front-level staff to ask is that of *language* i.e. 'mother tongue' or 'language most commonly used in the home' - which can be seen to relate directly to the needs of the client. Unless language is asked about, and recorded, providers may have no idea of the need for interpreting and translation services. Increasing numbers of refugees, and older people who settled in Britain after the war (from India, Italy or Poland, amongst other places), need such help.

Religion can also play an important part in providing care, especially for people in distress, and most hospital records do have a space for religion, although it is not always completed.

Nationality is probably one of the most problematic categories. Too often the notion of ethnic 'origin' is described as nationality. In ethnic monitoring, it is essential not to confuse the idea of identity with the question of the rights of the citizen to state-funded services. The official guidelines (Department of Health Manual of Guidance on the NHS Treatment of Overseas Visitors) make this quite clear.

1.3 Ethnic group categories

Data on ethnic groups can be aggregated at various levels. However, publication of research reports such as the Fourth National Study of the Policy Studies Institute (Modood 1997) has emphasised the considerable differences that exist even within the meta-category (broad level of aggregation) of ‘South Asian’. This and other studies (e.g. Johnson *et al* 2000) have shown that there are considerable differences in health status, as well as in expectations and priorities, between the recognisable sub-categories, such as ‘Indian’ (which in Britain may include Sikh Punjabis, Muslim Gujeratis and Hindus of various linguistic origin as well as other smaller groups), and the predominantly Muslim Bengali or Bangladeshi group whose health status is almost invariably shown to be less advantaged. Modood (1997) also makes a strong plea for the retention of the distinction of East African origin, as being associated with greater financial success and better health, although it is not clear that this will carry over to the ‘second generation’. Some, but not all, research reports do observe these distinctions, and are as a result more likely to be generalisable at least within the sub-category identified, even if there may remain geographical, ‘cohort’, and social class differences between communities and individuals reporting any identity.

For the most part, however, research to date has been confined to levels of analysis which are related not to the theoretical ideal, but to categories in use for administrative purposes, and linked to data (mostly meaning here the Census) against which some baseline for comparison can be established. Therefore, for research purposes and for ethnic monitoring, in general, the ‘ethnic group’ categories used to date have been those developed for use in the 1991 census.

1.4 Census categories

The ethnic groups identified by the Office of National Statistics in the decennial UK Census are shown below. Table 1.2 presents the categories used in the 1991 census and those utilised in the Census in 2001.

Table 1.2: Categories of ethnic group recorded in the UK Censuses of 1991 and 2001

1991	2001
White	White – British
	White – Irish
	White – Any other White background (please write in)
(Other...)	Mixed – White/Black Caribbean
	Mixed – White/Black African
	Mixed – White/Asian
	Any other mixed background (please write in)
Black- Caribbean	Black or Black British: Caribbean
Black- African	Black or Black British: African
Black- Other (Please describe)	Black or Black British: Any other background (please write in)
Indian	Asian or Asian British: Indian
Pakistani	Asian or Asian British: Pakistani
Bangladeshi	Asian or Asian British: Bangladeshi
Asian- Other (Please describe)	Asian or Asian British: Any other background (please write in)
Chinese	Chinese or Other Ethnic group Chinese
Any Other Ethnic Group (Please describe).	Chinese or Other Ethnic group Any other: (please write in)

(Adapted from ONS forms: reproduced with permission)

It may be that the ‘ethnic group’ labels used in the UK 1991 Census - ‘Black-Caribbean’, ‘Asian-Pakistani’ etc - are sufficient to identify the existence of discrimination on broad, racialised grounds.

On the other hand, for planning services and allocating resources more detailed information is needed. The Office of National Statistics therefore agreed that the 2001 Census would ask for more detailed information on ethnic group. The most recent census questions therefore reflect changes such as a tendency for some people of African-Caribbean origins born in Britain to determine their own identity as 'Black British'. Also, while the 2001 Census used the term 'Ethnic Group', it made it clear that this is seen as a matter of 'cultural background'.

The 2001 Census also asked people about their religion (see Figure 1.1), although this question was not compulsory.

Figure 1.1: Question 10 of the 2001 census

10: What is your religion?
♦ This question is voluntary
♦ (Tick) one box only

☐ None
☐ Christian (including Church of England, Catholic, Protestant and all other Christian denominations)
☐ Buddhist
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Any other religion (please write in)

(Cm 4253, 1999) and Census 2001 England Household Form page 6

Certain other groups which need to be considered in any discussion of ethnicity and health service communication are not recorded in any sense, either in the census data or in any other database providing a denominator for epidemiological studies or a basis for estimation of needs. These include, in particular, 'gypsies' (Roma or travellers - McKee 1997) regarding whose health there is already a considerable lack of knowledge but growing interest (Feder et al 1993). The second, larger and more problematic but less easily defined, is the growing population of refugees and asylum seekers (Johnson & Akinwolere 1997). Both groups place particular demands on the health service, including a necessity of specialist knowledge and peripatetic service provision, as well as having distinctive language and cultural needs and creating problems for administrative record keeping when they have no long-term fixed residential address.

1.5 Classifications in the literature

Medical journals are slowly moving towards a consensus on classification, but have to wrestle with the issue of international comparability and relevance. For example, the process of searching for references using Medline and other computerised databases elicits a number of idiosyncratic categories identified by MeSH terms such as 'Caucasoid-race' and 'Negroid-race'.

The British Medical Journal has published a series of articles discussing the question of terminology and good practice (British Medical Journal 1996), including some initial guidelines as follows:

> 'Authors should describe in their methods section the logic behind their 'ethnic' groupings. Terms used should be as descriptive as possible and reflect how the groups were demarcated. ... if it is unknown which ... is the most important influence then an attempt should be made to measure all of them. A range of information is best collected:
>
> - Genetic differences
> - Self assigned ethnicity using nationally agreed guidelines
> - Observer assigned ethnicity using ... national census categories
> - Country or area of birth ...
> - Years in country of residence
> - Religion'

The journal ‘Ethnicity and Health’ has also published a review of editorial policies, although avoiding a definitive ruling (Bhopal, Kohli and Rankin 1997). The authors conclude that there is at present much confusion and that the issue requires further debate.

1.6 References

Ahmad, W. (1999), "Ethnic Statistics: Better than Nothing or Worse than Nothing? Standard categories of ethnicity are often not appropriate", *Arnold., London*, vol. 124-131, p. -131.

Ahmad WIU, Sheldon T, Stuart O (1996) Reviews of ethnicity and health York: NHS Centre for Reviews and Dissemination

Aspinall P (1995) Department of Health’s requirement for mandatory collection of data on ethnic group of inpatients British Medical Journal 311: 1006-1009

Bhopal RS, Kohli H, Rankin J (1997) ‘Editors Practice and Views on terminology in Ethnicity and Health research’ Ethnicity and Health 2,3 :223-227

Bhopal RS, Phillimore P, Kohli HS (1991) ‘Inappropriate use of the term Asian - an obstacle to ethnicity and health research’ Journal of Public Health Medicine 13,4 :244-246

British Medical Journal (1996) ‘Ethnicity, race and culture: Guidelines for research, audit and publication’ BMJ 312 :1094

Comstock RD, Castillo EM, Lindsay SP (2004) 'Four year review of the use of race and ethnicity in epidemiologic and public health research' American Journal of Epidemiology 159,6 :611-619

Feder, G.S., Vaclavik, T. and Streetly, A. (1993) 'Traveller Gypsies and Childhood Immunization: a study in East London', British Journal of General Practice, 43(372): 281-84.

Gerrish K, (Apr 2000) Researching ethnic diversity in the British NHS: methodological and practical concerns. J Adv Nurs.;31(4):918-25.

Johnson M, Owen D, Blackburn C, Nazroo J (2000) *Black and Minority Ethnic Communities - Health & Lifestyles* London: Health Education Authority 2000

Johnson MRD, Akinwolere A. (1997) *Refugees and Access to Primary Health Care in the Midlands,-* A Review of Evidence from Literature and Professional Opinions Midlands Refugee Council & Sandwell Health, Coventry: CRER Research Paper 25, 1997

Johnson MRD, Gill P (1995) Ethnic monitoring and equity: Collecting data is just the beginning (editorial) British Medical Journal 8.4.1995 310 :890.

McKee M (1997) ‘The health of Gypsies’ BMJ 315 :1172-1173

McKenzie K, Crowcroft NS (1994) ‘Race ethnicity culture and science’ BMJ 309 :286

Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon. (1997) *Ethnic Minorities in Britain: Diversity and Disadvantage* London: Policy Studies Institute

Pringle M, Rothera I (1996) ‘Comment on practicality of general practice based ethnic monitoring’ BMJ 312 :1054

Pringle M, Rothera I, McNichol K, Boot D (1997) *Ethnic Group Data Collection in Primary Care* Nottingham University: Department of General Practice Monograph 3 Nottingham

Ranger C (1994) King’s Evidence Health Service Journal 104: 22-23 (7th April)

Sheldon T, Parker H (1992) ‘The use of ethnicity and race in health research: a cautionary note’ in Ahmad WIU (Ed) *‘Race’ and Health in Contemporary Britain* Buckingham: Open University Press

Vermeulen, H. (Ed.) (1997) *Immigration Policy for a Multi-cultural Society*: Migration Policy Group, Brussels

Annex 2: Ethnic Groups and language/ communication

2.1 UK estimates of language ability

Adult's language ability

Three major national surveys have collected data in recent years which provide the opportunity to make some estimates of adult language capacity and literacy in the UK. In all cases, these show that among older people, and especially within the population of Bangladeshi origin, there is limited ability either to understand (spoken) English or to read (any language), more especially among women. Even in the 'middle-age' group (data report grouped ages, so that we have to rely on those aged 30-49 about ten years ago as a proxy for the younger half of the 'at-risk population of our study), there are significant numbers who cannot be expected to read English.

The first source (Rudat 1994) is based on data collected in 1991 (see Table 2.1). These data show very clearly that there is much less likelihood of Asian women, especially older and Muslim women, being able to read any communications received, especially if they are in English. Men of Bangladeshi origin, especially in the older cohort, also have very low levels of familiarity with English, and low levels of literacy generally. A significant minority, even in those aged 40-60 (now) will be essentially illiterate in any language. While this may also be true for White families (for whom we do not have equivalent data) there is at the same time unlikely to be much alternative support from other family members, especially where children have moved away from home, or have not learned fluency in their parental languages.

Table 2.1: Source: Rudat 1994 (Data collected 1991)

	Women 30-49	Men 30-49	Women 50-74	Men 50-74
'Speak English'	%	%	%	%
Indian	80	93	47	86
Pakistani	42	94	15	66
Bangladeshi	21	72	10	51
'Main Language English'	%	%	%	%
Indian	18	25	8	19
Pakistani	3	15	-	7
Bangladeshi	1	7	-	-
Main language spoken at Home: English	%	%	%	%
Indian	29	31	5	24
Pakistani	12	17	-	22
Bangladeshi	4	6	-	1
Read English	%	%	%	%
Indian	67	83	34	71
Pakistani	31	77	7	54
Bangladeshi	15	60	4	38
Read NO language	%	%	%	%
Indian	4	2	25	6
Pakistani	31	7	68	16
Bangladeshi	24	3	52	19

When asked about ‘languages best understood’, there were significant (and age-related) splits within the Pakistani and Bangladeshi population, as well as the Indian population breaking into groups of Gujerati, Punjabi and other major languages. The majority of Pakistani women reported that their preferred language was Punjabi (49%) followed by Urdu (18%), while the males of this ‘ethnic group’ were more likely to report preferring Urdu (39%) compared to Punjabi (23%). This may reflect exposure at school, since Urdu is the official language of instruction in Pakistan, and the script would be more familiar also to Pakistani people attending and learning ‘mother tongue’ classes in UK. Similarly, in Bangladesh, the official language is Bangla (Bengali) but the ‘home language’, Sylhetti, is not a written language and is not taught in UK schools. Consequently, over half of the ‘over-50s’ of Bangladeshi origin reported speaking Sylhetti: overall, the ‘language best understood’ among Bangladeshi women was Bangla (understood by 42% of men) but surprisingly, only 29% of women reported speaking Sylhetti, preferred by 41% of men. Very few reported that English was their ‘best understood’ language, although the numbers stating this has risen among the younger age groups, some of whom now report that they cannot speak their parental languages, and would be unable to translate materials sent to them in English, if they contained any complicated terms.

More recent information on the ability to read English (Johnson et al 2000), based on slightly more recent data collected in 1994 by the Second Health and Lifestyles Survey, shows similar but higher rates than those reported by Rudat (see Table 2.2).

Table 2.2: Johnson et al 2000 (Data collected 1994)

	Women 30-49	Men 30-49	Women 50-74	Men 50-74
Able to read English	%	%	%	%
Indian	78	98	43	79
Pakistani	55	82	31	55
Bangladeshi	37	87	13	62

The ‘Fourth National Study’ (Modood et al 1997) also collected data in 1994 for minority ethnic groups, but used a different set of age group boundaries. This study did not present data on literacy, although it is the only source of fluency in English for any groups other than the ‘Indian-Pakistani-Bangladeshi’ group (see Table 2.3). Chinese women under the age of 45 have a higher level of reported fluency in English than all other ethnic minority groups, except African Asians; whereas Chinese males show a level fluency similar to other ethnic minority groups. In contrast, for the 45-64 age group Chinese males now report the lowest fluency of all groups, although the fluency of Chinese women remains relatively high compared to other groups, although low in absolute terms.

Table 2.3: Modood et al 1997 (Data collected 1994)

	Women 25-44	Men 25-44	Women 45-64	Men 45-64
English spoken ‘Fluently or well’	%	%	%	%
Indian	73	88	53	68
Pakistani	47	81	28	56
Bangladeshi	27	75	4	54
Chinese	82	82	47	50
African Asian	92	94	71	87

Finally, Carr-Hill et al. (1996) have also explored the linguistic abilities of ethnic minority groups in England and Wales. The groups selected were adults aged 16 to 64 from the Indian sub-continent (Bengalis, Gujeratis, and Punjabis), from China, and from refugee groups (Bosnians, Somalis, Tamils and Kurds). Nineteen tasks were used to assess linguistic ability in the use of English and mother tongue. The completion of the task was used to indicate whether or not the respondent was at ‘survival level’ and above or ‘pre-survival level’. Tasks ranged from the completion of a library card, and use of a calendar to sentence completion and understanding benefits information. The study found that more than a third of Bengali speakers and Punjabi speakers scored zero on the written test, i.e. unable to fill in a library card application, read a school timetable or telephone directory. Further to this, only 14% of Bengalis, 29% of Gujeratis, 26% of Punjabis, 41% of Chinese and 32% of the refugees reached a survival level of competence. However, these figures are for those born outside the UK and, for Asian groups, they exclude those for whom English is the main spoken language and the preferred reading language, and those who had a British qualification. The study arrives at a best estimate for South Asian communities, whether born in Britain or not, of 16% of adult Bengalis, 44% of Gujeratis and 29% of Punjabis who would reach 'survival level' in terms of language competence. The study further estimated almost 600,000 people whose country of birth was China, Bangladesh, India or Pakistan having insufficient English communication skills to work and function socially in an English Speaking environment.

Children's language ability

An important source of information on cultural and linguistic diversity is the data from Local Education Authorities on censuses of ethnicity of schoolchildren and surveys of first languages spoken. A survey of 850,000 children in London schools has revealed that more than 300 languages are spoken by children. Although English remains overwhelmingly the most common first language, for more than a third of children it is not the language they speak or hear spoken at home. Under 68% of schoolchildren speak English at home. This was followed by Bengali+Sylheti (4.51%), Panjabi (3.32%), Gujarati (3.19%), Hindi/Urdu (2.91%), Turkish (1.74%), Arabic (1.23%), English-based Creoles (1.20%), Yoruba (1.16%), Somali (0.93%) and Cantonese (0.77%).

School-based data have also been used to estimate the total number of people speaking London’s top 40 languages, but data on children speaking other languages at home are difficult to convert into total population estimates (Storkey 2000). Also, although such sources have provided a picture of the linguistic diversity in London, information on other parts of the UK is more limited.

According to the most recent (2003) pupil census, more than 10% of primary school children and 9% of secondary pupils do not have English as their first language. Asians from the Indian subcontinent form the second largest ethnic group in schools. They account for more than 7% of primary children and 6% of secondary pupils. Children of Pakistani origin are the biggest Asian group in primary school children, but Indians outnumber Pakistanis in secondary schools. Primary schools now have more black African pupils than black Caribbean children - however, there are similar numbers from both these ethnic groups at secondary level. Mixed-race pupils make up the fourth largest ethnic group - a reflection of Britain's increasingly complex society. They now account for 3% of pupils in primaries and 2% in secondary schools.

2.2 Geographical distribution of language needs in England

In order to estimate language need by geographical location, it is necessary to derive a weighting measure that can be applied to data on population demographics available from sources such as the national Census. Estimates have been produced for 1996 by using country of birth as a proxy indicator (Szczepura et al 1998). This was translated into ability in the English language using data from the Family and Working Lives Survey (Research Services Limited Social Research 1995, King et al 1996). The data were then combined with 1991 Census data to produce geographically based estimates of language need. These estimates were further refined by including information on the number of asylum seekers and refugees who had settled since 1991, as provided by the Office for National Statistics.

The resulting estimates of language need by health authority are shown in Table 2.4. The average percentage of the total population with language difficulties in these old health authorities is 0.8%. Areas with twice or more the average level (1.6% plus) are mostly in London (nine health authorities) with five in other parts of the country (Bradford 2.9%; Birmingham 2.8%; Wolverhampton 2.1%; Sandwell 1.9%; Coventry 1.6%). Some areas such as Herefordshire are estimated to have extremely few individuals with language needs.

Other authors identify settlers from the Indian subcontinent - and in particular Panjabi, Urdu, Gujarati and Bengali speakers - as the largest linguistic minority communities. Panjabi speakers are usually held to be the largest of these south Asian groupings and certainly outnumber Welsh speakers. Sikhs from the Indian Panjab and Muslims from Pakistan are spread throughout the UK but have important settlements in London and the south, the Midlands and the north of England. Gujarati speakers are scattered throughout the country with particular concentrations in Greater London and the Midlands. Bengali speakers draw on a small, mainly Hindu, community from Indian West Bengal and a much larger Muslim Bangladeshi community which is concentrated in the London boroughs of Tower Hamlets and Camden, though smaller settlements are also to be found in cities such as Coventry and Bradford. The Chinese form another numerically important group, although - unlike the large south Asian communities - their patterns of settlement are more dispersed. Other ethnic Chinese include people from Hong Kong and a refugee community from Vietnam, both use Cantonese as a language of wider communication (Baker and Mohieldeen, 2000).

Table 2.4 Estimated percentage of population with language problems.

		Estimated population with language difficulties	
Health Authority	**1996 Population**	**Number**	**Percent**
Hillingdon	247718	3381	1.4
Kensington Chelsea & Westminster	369364	10574	2.9
Enfield & Haringey	478724	19291	4.0
Redbridge & Waltham Forest	439390	10417	2.4
Bedfordshire	545173	7603	1.4
Berkshire	797429	7697	1.0
Buckinghamshire	670230	4401	0.7
Cambridge & Huntingdon	450823	1188	0.3
Bexley & Greenwich	425128	3438	0.8
Bromley	295584	1943	0.7
Croydon	333787	4879	1.5
East Kent	596194	945	0.2
West Kent	961143	3739	0.4
Kingston & Richmond	321714	4042	1.3
Lambeth Southwark & Lewisham	742349	9858	1.3
Merton Sutton & Wandsworth	623987	8846	1.4
East Surrey	420663	1401	0.3
West Surrey	623363	2772	0.4
East Sussex	734857	1903	0.3
West Sussex	737282	2467	0.3
Barking & Havering	403614	1881	0.5
Barnet	319353	10411	3.3
Brent & Harrow	451933	14464	3.2
Camden & Islington	365109	11434	3.1
Ealing Hammersmith & Hounslow	659549	16979	2.6
East London & The City	604515	34506	5.7
North Essex	895336	1678	0.2
South Essex	683269	1395	0.2
South Lancashire	309385	276	0.1
Liverpool	467995	1045	0.2
Manchester	441767	5390	1.2
Morecambe Bay	309484	270	0.1
St Helen's & Knowsley	333536	228	0.1
Salford & Trafford	448072	1531	0.3
Sefton	289739	276	0.1
Stockport	291080	841	0.3
West Pennine	472657	5615	1.2
East Norfolk	619057	663	0.1

Northamptonshire	604351	1959	0.3
North West Anglia	417168	1947	0.5
Oxfordshire	601322	2146	0.4
Suffolk	656868	973	0.1
Barnsley	227213	140	0.1
North Derbyshire	371435	260	0.1
South Derbyshire	558796	2997	0.5
Doncaster	291804	509	0.2
Leicestershire	927463	11128	1.2
Lincolnshire	611533	539	0.1
North Nottinghamshire	391467	297	0.1
Nottingham	640305	3222	0.5
Rotherham	255342	893	0.3
Sheffield	530375	3155	0.6
Bury & Rochdale	378487	4160	1.1
North Cheshire	312050	334	0.1
South Cheshire	667977	666	0.1
East Lancashire	511763	7025	1.4
North West Lancashire	466592	1847	0.4
North & Mid Hampshire	543406	1253	0.2
Portsmouth & South East Hampshire	540888	1129	0.2
Southampton & South West Hampshire	532591	1790	0.3
Isle of Wight	125466	158	0.1
Somerset	482654	563	0.1
South & West Devon	589815	611	0.1
Wiltshire	604947	1401	0.2
Avon	983345	2188	0.2
Birmingham	1030003	28477	2.8
Wigan & Bolton	575235	3408	0.6
Wirral	329179	380	0.1
Bradford	483422	13978	2.9
County Durham	603960	418	0.1
East Riding	556634	430	0.1
Gateshead & South Tyneside	357046	532	0.1
Leeds	726939	4951	0.7
Newcastle & North Tyneside	475957	2089	0.4
North Cumbria	318042	212	0.1
South Humber	332384	594	0.2
Northumberland	307417	209	0.1
Sunderland	298416	487	0.2
Tees	557699	1493	0.3
Wakefield	317342	727	0.2
North Yorkshire	734680	699	0.1
Calderdale & Kirklees	581651	7657	1.3
Cornwall & Isles of Scilly	483326	429	0.1
Dorset	687465	1132	0.2
North & East Devon	469451	571	0.1
Gloucestershire	551022	1068	0.2
Coventry	306503	4964	1.6
Dudley	312194	1805	0.6
Herefordshire	165152	150	0.1

Sandwell	292196	5693	1.9
Shropshire	421251	764	0.2
Solihull	203922	480	0.2
North Staffordshire	471164	1412	0.3
South Staffordshire	584554	1174	0.2
Walsall	262593	3840	1.5
Warwickshire	500592	1910	0.4
Wolverhampton	244453	5048	2.1
Worcestershire	522009	1090	0.2
East & North Hertfordshire	496083	1718	0.3
West Hertfordshire	523372	3105	0.6
England Total	***49089083***	***376052***	***0.8***

2.3 Improving English language ability of refugees/ asylum seekers

The Report of the Working Group on English for Speakers of Other Languages (ESOL) on 'Breaking the Language Barriers' addresses the needs of adults who, because it is not their first language, need to develop skills in listening, speaking, reading and writing in English. It is estimated that there are between a half and one million such adults. They are not a homogeneous or static group but a diverse and dynamic one which encompasses both long settled minority ethnic communities and groups of refugees who have arrived in this country more recently. Potential learners range from those who may lack basic literacy and numeracy skills in their first language to those with a high level of education and qualifications in their home country, and from those who are not keen to re-enter formal education to those who are highly motivated to learn.

The NIACE report 'Divided by Language' demonstrates that there is real interest in language learning in England and Wales, contrary to popular belief. People are able to and do, in fact, use other languages in their daily lives. The report also shows the richness of the diversity of languages used, at all levels, in Britain today. The survey highlights the fact that language learners in Britain’s minority ethnic groups have fluency and ability to learn languages (Aldridge 2001).

Following on the Report of Working Group on ESOL the Home Office undertook a mapping exercise for ESOL provision for English language training for refugees as a part of 'Refugee Integration Strategy' (Griffiths 2003). The aims of the study were: (a) to assess the availability and quality of ESOL in parts of London and areas to which asylum seekers are dispersed by the Home Office; (b) to explore the views and experiences of providers and others involved in the provision of ESOL; (c) to highlight existing good practice, and (d) to identify ways of improving provision based on the needs of refugees. The study involved a preliminary literature review of English language in the UK and field work in 4 London boroughs. The report identifies that the main barrier for refugees wanting to access ESOL is the shortage of classes and long waiting lists across London and the regions. Recruitment and training of ESOL teachers is a priority, particularly in the regions where there is a real shortage of qualified ESOL teachers. Co-ordination between ESOL providers and Refugee Community organisations is crucial for sharing information and expertise, and for contacting some of the more ‘hard-to-reach’ communities. Differences between case study areas seemed to be rooted in specific settlement and immigration histories. This suggests that local strategies rather than general models may be more appropriate in meeting the new demands for ESOL.

The needs of asylum seekers and refugees mean that integration as well as proper support of asylum seekers are best served by beginning ‘further language’ training at as early a point as can be arranged. This might usefully be supplemented by parallel provision of mother tongue education (especially for children), which will speed their learning in Britain and may facilitate ‘re-entry’ to their society of origin.

Good Practice in language learning/teaching requires a liberal approach towards possible integration, while also permitting or providing ‘gender specific’ and other targeted provision to reach specific groups. Provision must also take account of the social and economic constraints on refugees and asylum seekers (including lack of disposable income for travel, indirect costs, books etc).

Courses are improved by the active participation of refugees and asylum seekers in their planning and provision, and in linking to social, economic and cultural activity to provide practice for skills. Access to courses is facilitated by networking through Refugee Community Organisations.

2.4 Cultural competence and communication with service users

It is important to remember that identity is not constructed by language alone and assuming that native language is 'inherently central to individual identity, so that those members of an ethnic group who natively speak a language particularly associated with that group are more "authentic" than those who do not' (Myhill 2003) is not true of all groups. Myhill singles out Jews, Greeks, Armenians, overseas Indians (South Asians) and Chinese as groups whose members may define their identity in other ways, including according to religion, tradition and/or ancestry, and not necessarily native language. These may choose not to use their ancestral language in everyday life, but still wish to retain a distinctive identity. Thus, the concept of "native speaker" is not 'a brute empirical fact but rather a social construct'. 'For a good many people, it is not very important which native language they or their children have, but it is extremely important which religious group they are affiliated with… The same is true of, e.g. many Christians, Muslims, Buddhists, and Bahais; while it cannot be said that their native language is of no significance to them, they would not consider this to be at the same level of importance as their religion' (Myhill 2003).

Cultural awareness is important, therefore, as well as language ability, since health is uniquely personal in many respects and requires sensitivity to elements of the individual and his/her identity (and social setting) as well as an adequate level of mechanical or clinical competence. Furthermore, with the implementation of the Race Relations Amendment Act 2000, health service providers must 'have due regard to the need to eliminate unlawful discrimination', and to make explicit consideration of the implications for racial equality of every action or policy. Delivery of healthcare depends upon effective communication (Ulrey & Amason 2001). Yet, there is hardly a term that is more difficult to define than 'intercultural communication' (Kramsch 2002). This requires more than simple language service provision or advocacy, and instead a re-thinking of concepts previously held in the NHS is needed if the needs of a diverse population are to be met:

> Diversity is a fairly new word in Britain. Prior to recognition of diversity, the idea was that some services for black and minority ethnic groups could be provided, but the quality of services and whether it reached the population was not an issue. When black and minority ethnic groups raised the issue of services not reaching them, the standard answer was, "but we are providing the services of a link worker or an advocate and we are meeting your religious and cultural needs." (Bahl 2001)

Nonetheless, 'advances in the articulation of multicultural practice and policy dealing with ethnic communities have focused almost exclusively on developing competency skills based on individual communication and understanding between formal service providers and clients rather than on exposing and altering institutional structures and power relations marked by racism' (Brotman 2003). The literature suggests that dealing with institutional racism first will result in clearing the air for the development of meaningful communication at the interface of health services and ethnic minority service-users.

Furthermore, healthcare providers frequently suffer from medical ethnocentrism and are typically only trained to deal with the dominant culture (Ulrey & Amason 2001). In fact, such providers need to know themselves and their culture as well as the culture of their patients. Communicating with people from other cultures can often cause anxiety and stress for both sides of the dialogue. Stress is raised to higher levels by learning new communication rules and behaviours, completing more complex tasks and increased lack of control in work situations. According to Ulrey and Amason, gaining effective intercultural communicative skills should lower such stress.

As service users, diverse racial and ethnic groups may also process health messages differently because of their particular culture affects, health beliefs and behaviours (Brach & Fraser 2000). Health professionals need to take into account cultural beliefs and values, especially since communication is an essential component of the physician's role, and is often the aspect of care with which patients are least satisfied (Stewart et al 1999). Reviews have found that 'the more information given to patients, the better the health outcomes' (Kaplan, Greenfield & Ware cited in Stewart et al 1999). This common sense science should be obvious, but in a meta-analysis of correlates of provider behaviour, nonwhites received less information that whites (Roter, Hall & Katz 1988 cited in Stewart et al 1999).

Several approaches to improve communication within a minority setting are coming to the fore through innovative practices and creative approaches to the concept of care as communication. For example, an American model of health ministry involves health professionals, frequently nurses, working with the culture of congregations to facilitate culturally congruent care (Chase-Ziokek 1999) and is seen as translatable to a UK setting. Nurses work with congregations in churches, synagogues and mosques promoting health through integrating religious beliefs and health knowledge. This is commonly referred to as parish nursing. The Tavistock Clinic in London provides another example of innovative practice. Following the war in the Balkans, it has begun to train therapist and counsellors to work with refugees to 'overcome traumatization and reconnect the broken threads of their life story so that integration into a new community becomes possible' (Mander 2003). With so many refugees struggling with a language that is not their own, many have difficulties in expressing the depth of their feelings. Through a storytelling model, refugees are able to recall terrible experiences, 'so necessary when they are seeking belief and understanding for what they are struggling to say'. Second languages are often used as "the language of living" whereas the mother tongue emerges to describe childhood experiences, cultural and religious issues and certain emotional experiences –the language of "feeling" (Mander 2003).

The community model as an intervention strategy for ethnic minority groups in the UK surfaces in Lodge's (2001) review of the literature identifying needs of ethnic minority groups with cancer within the community. 'There is a need to aim the interventions of educational messages and strategies specifically to the needs of the underserved, with guidance from the ethnic minority groups. This would involve finding out which minority groups are actually located within a given area; involving ethnic minority groups in the identification of their perceived needs; and involving them in meeting these needs and evaluating any healthcare outcomes' (Lodge 2001). Lodge illustrates the benefits of this model from the literature on a project looking at Native Hawaiian women, with positive results including improvements in health services and systems through education and screening in the community, enhanced community capacity for peer education; and local media coverage that would empower the community and its members.

Chen (1999) considers that 'empowering minority communities through *informal care* may be the most culturally appropriate approach for improving the health status of minority populations'. Informal care is described as culturally more compatible, relatively low cost and flexible. In addition, informal care in the form of traditional medicine is used by 80% of the world's population, according to the World Health Organisation. In the UK, an example is Dr. Pui-Ling Li who founded the London Chinese Health Resource Centre as a means of empowering the Chinese community to meet its own needs. At the Centre, English lessons are offered in addition to non-traditional health care. In the US, at least one-third of the US population is engaged in unconventional medical practices and perhaps, one half of the racial/ethnic populations use such forms of 'informal care' (Chen 1999).

2.5: National guidelines for culturally and linguistically competent health care

USA Guidelines

As the demographic make-up of the United States has become more culturally diverse, not only has the size of the ethnic minority population grown over time, but cultural diversity has also spread to suburbs and small towns. This has led to more stress being placed on culturally and linguistically appropriate health care provision for racial and ethnic minorities. The cultural competence imperative in health care was a direct outcome of these changing ethnic demographics (Shaw-Taylor 2002). As a result, the United States has recently made the transition from language assistance to *Culturally and Linguistically Appropriate Services (CLAS).* The provision of culturally and linguistically appropriate services to diverse patient populations was recognised to have the potential to improve access to health care, quality of care, health outcomes and ultimately reduce health disparities.

Furthermore, because most organisations and providers had no clear guidance on how to provide CLAS in health care settings, the Office of Minority Health (OMH) of the DHHS undertook the development of national standards to counter an existing patchwork of independently developed local definitions, practices, and requirements concerning CLAS. A final report was produced in March 2001 (Anderson et al 2003; Shaw-Taylor 2002). Fourteen individual standards were defined covering: *Culturally competent care; Language access services; and Organisational supports for cultural competence*, as follows:

Culturally competent care

- Standard 1. Health care organisations should ensure that patients/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.
- Standard 2. Health care organisations should implement strategies to recruit, retain, and promote at all levels of the organisation a diverse staff and leadership that are representative of the demographic characteristics of the service area.
- Standard 3. Health care organisations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.

Language access services

- Standard 4. Health care organisations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.
- Standard 5. Health care organisations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.
- Standard 6. Health care organisations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).
- Standard 7. Health care organisations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

Organisational supports for cultural competence

- Standard 8. Health care organisations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.
- Standard 9. Health care organisations should conduct initial and ongoing organisational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfaction assessments, and outcomes-based evaluations.
- Standard 10. Health care organisations should ensure that data on the individual patient’s/ consumer’s race, ethnicity, and spoken and written language are collected in health records, integrated into the organisation's management information systems, and periodically updated.
- Standard 11. Health care organisations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.
- Standard 12. Health care organisations should develop participatory, collaborative partnerships with communities and utilise a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.
- Standard 13. Health care organisations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.
- Standard 14. Health care organisations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

(http://www.omhrc.gov/omh/programs/2pgprograms/finalreport.pdf.

Reviews of Culturally and Linguistically Appropriate Services

Shaw-Taylor (2002) has reviewed the recommended US standards for culturally and linguistically competent health care delivery, and discusses their impact on health care organisations in terms of structural requirements, process requirements and outcome expectations. The author further states that health care organisations cannot achieve cultural competence by merely 'recruiting, retaining and promoting' minorities as the basis to improve workforce diversity, the diversity training must become an integral part. Diversity training must also seek to foster providers (physicians, nurses and allied health professionals) that are *cultural brokers*; i.e. providers who understand the biomedical model of treatment as well as the patient's/consumer's background. This paper also argues that the public health agency must play a pivotal role in the delivery of culturally and linguistically competent health care in the community. In an earlier paper, Shaw-Taylor and Benesch (1998) provide a discussion of workforce diversity in healthcare and its attendant requisite of cultural competency. Narayan (2001) has also reviewed the 14 standards for CLAS in health care and suggested strategies for meeting the cultural and linguistic needs of home health care patients. Brach and Fraser (2000) present a conceptual model of cultural competency's potential to reduce racial and ethnic health disparities. The authors identify nine major cultural competency techniques: interpreter services, recruitment and retention policies, training, co-ordinating with traditional healers, use of community health workers, culturally competent health promotion, including family/community members, immersion into another culture, and administrative and organisational accommodations. The authors conclude that while there is substantial research evidence to suggest that cultural competency should in fact work, health systems have little evidence about which cultural competency techniques are effective and less evidence on when and how to implement them properly.

Anderson et al. (2003) have undertaken a systematic review to examine whether culturally competent healthcare systems - those that provide culturally and linguistically appropriate services - have the potential to reduce racial and ethnic health disparities. The authors reviewed five interventions to improve cultural competence in healthcare systems; programmes to recruit and retain staff members who reflect the cultural diversity of the community served; use of interpreter services or bilingual providers for clients with limited English proficiency; cultural competency training for healthcare providers; use of linguistically and culturally appropriate health education materials; and culturally specific healthcare settings. The authors developed a conceptual model to evaluate the effectiveness of healthcare system interventions to improve cultural competence, but the review could not determine the effectiveness of any of these interventions, because there were either too few comparative studies, or studies did not examine appropriate outcome measures such as: client satisfaction with care, improvements in health status, and inappropriate racial or ethnic differences in use of health services or in received and recommended treatment.

Timmins (2002) has undertaken a systematic review of published studies from 1990 to 2000 examining language barriers in health care for Latino populations. Five (55%) of the nine studies examining access to care found a significant adverse effect of language; three (33%) found mixed or weak evidence that language affected access. Six (86%) of the seven studies evaluating quality of care found a significant detrimental effect of language barriers. Two of the three studies examining health status or outcomes found language to be a risk factor for adverse outcomes. Evidence was mixed as to the level of importance attributable to language when access to care is considered; however, non-English-speaking status was a marker of a population at risk for decreased access. Thus evidence shows that language barriers adversely affect quality of care.

Cioffi (2003) describes nurses' experiences of communicating with culturally and linguistically diverse patients in an acute care setting. Interpreters, bilingual health workers and combinations of different strategies were used to communicate with patients. The main recommendations were: prioritising access to appropriate linguistic services, providing nurses with support e.g. from bilingual health care workers who are able to provide more in-depth information, increasing nurses' understanding of legal issues within patient encounters, supporting nurses to translate their awareness of cultural diversity into acceptance of, appreciation for and commitment to patients and their families

McNamara et al. (1997) have evaluated the relationship between the competency levels of palliative care professionals in delivering cross-cultural care in Australia, and their experience and training. Information about difficulties encountered form the basis of guidelines for education programmes. The results indicate that specific education, rather than individual's experience, is needed to improve competence. Similarly, Riley and Thelian (1999) present ideas of attachment, guidance, and culturally sensitive nursing practice interventions when caring for patients who require home IV therapy. As trust is built, barriers to accurate communication between the nurse and the patient and family are removed, resulting in increased patient compliance and learning.

Kairys et al. (2002) have attempted to assess diversity and quality in US primary care through the multimethod assessment process in order to better understand disparities in relation to diversity, cultural competence, and quality improvement in clinical practice.

2.6 References:

Aldridge F. (2001). Divided by language: A study of participation and competence in languages in Great Britain. Leicester: NIACE.

Anderson, L. M., Scrimshaw, S. C., Fullilove, M. T., Fielding, J. E., and Normand, J. (2003). Culturally competent healthcare systems. A systematic review. Am. J. Prev. Med. 24; (3 Suppl) : 68 - 79.

Bahl, V. (2001). "Improving access and quality for ethnic minority women." Womens Health Issues 11(4): 348-54; discussion 354-70.

Baker, P. and Mohieldeen, Y. (2000) The languages of London's schoolchildren. In P. Baker, P. & J. Eversley (eds) Multilingual Capital – The languages of London schoolchildren and their relevance to economic, social and educational policies. London: Battlebridge.

Brach, C., Fraser, I. (2000). "Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model." Medical Care Research Review 57 Suppl 1: 181-217.

Brotman, S. (2003). "The limits of multiculturalism in elder care services." Journal of Aging Studies 17(2): 209-229.

Carr-Hill R., Passingham S., Wolf A., Kent N. (1996). Lost Opportunities: the language skills of linguistic minorities in England and Wales. London: Basic Skills Agency.

Chase-Ziolek, M. (1999). "The meaning and experience of health ministry within the culture of a congregation with a parish nurse." Journal of Transcultural Nursing 10(1): 46-55.

Chen, M. S., Jr. (1999). "Informal care and the empowerment of minority communities: comparisons between the USA and the UK." Ethnic Health 4(3): 139-51.

Cioffi, R. N. (2003). Communicating with culturally and linguistically diverse patients in an acute care setting: nurses' experiences. Int.J.Nurs.Stud. 40; (3) : 299 - 306.

Griffiths, D. (2003). English language training for refugees in London and the regions. London: The Home Office, Report 14/03.

Johnson MRD, Owen D, Blackburn C, Rehman H, Nazroo J (2000). *Black and Minority Ethnic Groups in England: The second health & lifestyles survey* London: Health Education Authority

Kairys, J. A., Orzano, J., Gregory, P., Stroebel, C., DiCicco-Bloom, B., Roemheld-Hamm, B., Kobylarz, F. A., Scott, J. G., Coppola, L., and Crabtree, B. F. (2002). Assessing diversity and quality in primary care through the multimethod assessment process (MAP). Qual.Manag.Health Care. 10(4): 1 - 14.

King, S. and Murray, K. (1996) 'Family and Working Lives Survey: preliminary results', Labour Market Trends, March 1996, pp. 115-119.

Kramsch, C. (2002). "In search of the intercultural: Review of FRED E. JANDT. Intercultural Communication: An Introduction. 3rd edition.; YOUNG YUN KIM. Becoming Intercultural: An Integrative Theory of Communication and Cross-Cultural Adaptation.; TONY SCHIRATO AND SUSAN YELL. Communication and Culture: An Introduction.; RON SCOLLON AND SUZANNE WONG SCOLLON. Intercultural Communication: A Discourse Approach. 2nd edition." Journal of Sociolinguistics 6(2): 275-285.

Lodge, N. (2001). "The identified needs of ethnic minority groups with cancer within the community: a review of the literature." European Journal of Cancer Care (England*)* 10(4): 234-44.

Mander, G. (2003). "The Women's Therapy Centre Language Project: Evaluation." British Journal of Psychotherapy 20(1): 97-102.

McNamara, B., Martin, K., Waddell, C., and Yuen, K. (1997). Palliative care in a multicultural society: perceptions of health care professionals. Palliat.Med. 11 (5) : 359 - 367.

Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon. (1997) *Ethnic Minorities in Britain: Diversity and Disadvantage* London: Policy Studies Institute

Myhill, J. (2003). "The native speaker, identity, and the authenticity hierarchy." Language Sciences 25(1): 77-97.

Narayan, M. C. (2001).The national standards for culturally and linguistically appropriate services in health care. Care Manag.J. 3 (2) : 77 - 83.

Research Services Limited Social Research (1995) Family and Working Lives: technical report, Harrow, RSL Social Research.

Rudat K, (1994) *Black and Minority Ethnic Groups in England: Health & Lifestyles* London: Health Education Authority

Shaw-Taylor, Y. (2002). Culturally and linguistically appropriate health care for racial or ethnic minorities: analysis of the US Office of Minority Health's recommended standards. Health Policy. 62(2): 211 - 221.

Shaw-Taylor, Y. and Benesch, B. (1998). Workforce diversity and cultural competence in healthcare. J.Cult.Divers. 5 (4):138 - 146.

Stewart, A. L. N.-S., A. Perez-Stable, E. J. Posner, S. F. Bindman, A. B. Pinderhughes, H. L. Washington, A. E. (1999). "Interpersonal Processes of Care in Diverse Populations." Milbank Quarterly 77(3): 305-340.

Storkey M. (2000) Using the schools' language data to estimate the total number of speaker of London's top 40 languages. In Baker P & Eversley J (Eds) Multilingual Capital – The languages of London schoolchildren and their relevance to economic, social and educational policies. London: Battlebridge.

Szczepura A, Clark M D, Johnson M R D, Owen D. (June 1998) *Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services'* Report to the NHS Executive; Technical Advisory Group (Resource Allocation Group).

Timmins, C. L. (2002). The impact of language barriers on the health care of Latinos in the United States: a review of the literature and guidelines for practice. J.Midwifery Womens Health. 47(2) : 80 - 96.

Ulrey, K. L., Amason, P. (2001). "Intercultural communication between patients and health care providers: An exploration of intercultural communication effectiveness, cultural sensitivity, stress, and anxiety." Health Communication 13(4).

Annex 3: Models for interpreting/ advocacy provision

Several approaches have been identified within the NHS for overcoming language barriers where verbal communication is required as part of the delivery of services in primary and secondary care. These will vary in their effectiveness or ‘adequacy’, costs, and generalisability to different locations. While at present there are no agreed national standards in services other than the criminal justice system, there are discussions underway to establish agreed levels of good practice within the NHS and interpreting profession, led by the Public Sector Advisory Group of the National Register of Public Sector Interpreters at the Institute of Linguists. In the interim, we offer a classification of current 'de facto' solutions to the problem of linguistic barriers between patient and clinician. They include:

i) Patient selection of GPs:
In some geographical areas it may be possible for patients to self select to enrol with a GP who is able to speak their language proficiently (Ahmad et al 1989). Evidence from the Bradford area suggests that patients who were less fluent “countered their linguistic disadvantage by consulting the Asian doctor who was fluent in their own language(s). Only 15% of the male patients who consulted the Caucasian doctor were poor or non-speakers of English compared with 30% of the Asian doctor’s patients.” (Ahmad et al 1989). However whilst such a strategy can be adopted by patients in some geographical locations, in others areas because of a paucity of GPs with suitable language skills (and of a suitable gender e.g. female) other strategies will need to be adopted. Furthermore one limitation of this approach is that if patients are forced to select GPs who can speak their language this could reduce a patient’s choice of physician, unless of course interpreters are available to patients should they choose to enrol with a GP who does not speak the same language. Secondly, it is now recognised that many of the Asian GPs in inner city areas are approaching retirement age and this route may not be available for much longer.

ii) Use of bilingual health care workers:
This is closely related to (i) above, but it applies more generally to other health care workers apart from GPs. The approach has been described as the “ideal option for most patients” because it removes the need for a third party to be involved in a consultation (Phelan and Parkman 1995). However, bilingual health care workers are few (Phelan and Parkman 1995) and the quality of language provision may be poor if bilingual workers have an inadequate grasp of a particular language, or if they lack the training to be sufficiently culturally sensitive. Nevertheless such provision could prove cost-effective if bilingual workers speak fluently and are well trained, particularly if they speak a language which is frequently required. It should be noted that the Race Relations Act (1976) does specifically allow employers to appoint using racial/ linguistic criteria on the basis of, for example, a genuine occupational qualification i.e. linguistic skills.

iii) Use of full-time professional interpreters or experienced sessional interpreters:
Some hospitals and health authorities use the services of either full-time trained interpreters (so-called 'linguistic model' interpreters: Turton 2003) or experienced interpreters employed on a sessional basis. These are typically either employees of NHS Trusts or, increasingly, projects and teams working for, or jointly sponsored by, Social Services Departments or outside voluntary agencies. As a general rule so long as such interpreters are adequately trained and experienced the quality of interpreting is high, with the result that many of the problems associated with inadequate communication can be avoided. Once the benefits to patients of such provision (including patient satisfaction and any improvements in health outcomes) have been taken into account, such provision is likely to prove more cost-effective than other forms of provision, except perhaps use of well trained, bilingual staff. Furthermore provision of such interpreting services can have an informing and empowering role. This may improve the health and well-being of patients of marginalised communities (Ntshona 1997).

iv) Use of tele- interpreter services:
American research has suggested that electronic simultaneous interpretation can be very effective and popular (Hornberger et al 1996). Telephone interpreter services such as ‘Language Line’ have been introduced in the NHS over recent years (Leman 1997). They can offer the advantage of 24 hour access to interpreting services. The obvious limitation of such provision is that it lacks a visual dimension. This may present difficulties for the interpreter for example if a patient wants to draw a physician’s attention to a particular part of the body. The service is also likely to be expensive if used as the main form of interpreter provision in trusts with significant numbers of patients requiring

provision. Thus the use of face-to face interpreting/ advocacy is likely to be more cost-effective in such a situation.

Use of the service might be justified to provide out of hours provision, or to provide interpreter services for patients speaking very rare languages. Telephone interpreting provision might also be justified if a trust's demand for interpreter services is very low. In these circumstances, use of services such as Language Line may prove more cost-effective than face-to-face interpreting if a trust cannot access other locally available service provision. The NHS Plan states that by 2004, tele-interpretation support will be provided nationally through NHS Direct, and a contract has recently been signed to supply a service, but at present, there is no information about quality standards or evaluation of the service, although the Audit Commission (2001) reviewed one local provider in London Borough of Hounslow.

v) Use of patient advocates:

The distinction between interpreter and advocacy (or cultural broker) roles is not clear cut, but in the UK an advocacy role clearly involves more than just interpreting (Chiu 1991). 'Health advocates' have been defined as those who "mediate between patients and professionals to make sure that clients are offered an informed choice of health care. If there are clinical or cultural problems they will negotiate, although ultimately they see themselves as advocates for their people." (Parsons and Day 1992). Such a role is likely to be appropriate in contexts in which the patient is unable or unlikely to do this themselves. Moreover, advocacy can be used to "improve the access of all groups to the health service" (Chiu 1991) and to inform patient choices. Some evidence suggests that patients who are more in control (i.e. they ask more questions, make more attempts to direct conversation flow and physician behaviour) report fewer days off from work, health problems, and functional limitations because of illness, whilst rating their health more favourably during follow-up (Kaplan et al 1989). This would tend to suggest that, in so far as advocates are able to put patients in control, they may be able to improve patient well-being and health status.

Advocates may or may not act as interpreters as well. Clearly, if they perform a dual role the effectiveness of using advocates as interpreters will depend upon the extent to which they are sufficiently trained and experienced as interpreters.

There is some evidence that would seem to suggests that advocates are able to affect the nature/ quality of service obtained by patients. A retrospective study was conducted in Hackney, East London which compared 1,000 non-English speaking women delivering at the Mothers' Hospital in 1986 when accompanied by an advocate with 1,000 women delivering at the same hospital in 1979, and similar deliveries at a reference hospital (Parsons and Day 1992). The study identified significant differences between the 3 groups in terms of outcomes such as antenatal length of stay, and induction and mode of delivery. Rates of caesarean section rose from 11% to 17% at the reference hospital, but fell from 10.8% to 8.5% at the Mothers' Hospital. Whilst these findings may not necessarily be causally linked to provision of advocacy services "it was considered reasonable to deduce that improved communication could have influenced clinical practice". It was therefore suggested that health advocacy might provide a mechanism to redress adverse obstetric outcomes amongst some ethnic minorities. Health advocacy services may be able to generate similar benefits for mental health patients.

Health advocacy, as opposed to straightforward interpretation, may also provide a useful way of bridging gaps in cultural understanding. During a survey (Meadows 1992) it was noted that doctors identified a gulf between medical knowledge about a specific condition and the cultural and neighbourhood beliefs of patients relating to the cause of illness. Health advocates might be in a better position than interpreters to actually address this lack of patient understanding. This is because their role may extend to persuading patients of the value of a particular treatment approach.

Advocates may be especially appropriate in geographical areas with substantial refugee populations. They may also be particularly necessary in order to support those who have been victims of torture prior to obtaining refugee status in the United Kingdom. As a result of their experiences such individuals may well be apprehensive and not able to seek out the provision they require. In such circumstances, advocates are likely to fulfil an invaluable role.

vi) Use of volunteer and ad hoc interpreters:
Some UK hospitals use volunteer interpreters. This usually involves introducing systems to enable existing bilingual staff to provide interpreter services when required on a voluntary basis. In some hospitals voluntary provision from the local community is utilised. Whilst this approach may have the merit of flexibility it may cause difficulties if it takes staff away from another job. Registers of staff availability and language competence have also proved to be notoriously inaccurate and imprecise, and require considerable administrative costs in upkeep.

Furthermore, whilst training can be provided for volunteers, it has been reported that usually volunteers “have not received any training in interpreting” (Phelan and Parkman 1995). Moreover, volunteers who provide interpreting input on an irregular basis are less likely to acquire the same expertise as trained interpreters with considerable work experience, and thus the standard of interpreting may not be as high. Volunteer and ad hoc provision is perhaps best deployed to deal with emergency situations where a professional, trained interpreter is not available when required.

vii) Use of English speaking family members and friends as an interpreter("Bring Your Own")
Evidence suggests that this strategy should be pursued with caution, although a recent review suggests that this is the strategy used by 70% of service providers (Turton et al 2004). The use of relatives and friends, has the disadvantage that the quality of interpretation may be poor, and patient confidentiality may be violated if the patient does not want a family member or friend to have access to medical information about them. Also “family, friends, and ad hoc interpreters pose problems. They may lack sufficiently good language skills and frequently commit stereotypical errors, including omissions, additions, substitutions, or other editing, which may result in serious semantic distortions” (Woloshin et al 1995). Particular problems may arise if children are used to interpret since “both the parent and the child may be embarrassed by the problem and the information that the doctor or patient receives may thus be censored.” (Ahmad et al 1989). The use of a family’s children may also “upset the family’s social order.” (Poss and Rangel 1995). Distorted communication and confidentiality are especially problematic in cases involving issues such as sexuality and child abuse (McPake & Johnstone 2002)..

References

Ahmad, W. Kernohan, E. & Baker M. (1989), “Patients’ choice of general practitioner: influence of patients’ fluency in English and the ethnicity and sex of the doctor”, Journal of the Royal College of General Practitioners, vol. 39, pp. 153-155.

Audit Commission (2001) Community language, translation and interpretation unit London Borough of Hounslow Best Value Audit, London: Audit Commission

Chui, L. (1991), "Advocacy; the Leeds experience", Community Dental Health., vol. 8, pp. 253-256.

Hornberger JC, Gibson CD, Wood W et al. (Aug 1996) Eliminating language barriers for non-English speaking patients. Med-Care.; 34(8): 845-856.

Kaplan SH, Greenfield S, Ware JE. (1989), Assessing the effects of physician-patient interactions on the outcomes of chronic disease. Med-Care; 27(3): S110.

Leman, P. (1997), "Interpreter use in an inner city accident and emergency department", J.Accid.Emerg.Med., vol. 14:98-100, pp. 98-100.

McPake J, Johnstone R (2002) Translation, interpreting and communication support services across the public sector in Scotland Edinburgh: Scottish Executive Central Research Unit

Meadow, R. (Jun 1992); Difficult and unlikeable parents. Arch-Dis-Child. 67(6): 697-702.

Ntshona, MS. (Sep 1997), Are professional interpreters needed in the South African health care services. S-Afr-Med-J.; 87(9): 1143.

Parsons, L. & Day, S. (1992), "Improving obstetric outcomes in ethnic minorities: an evaluation of health advocacy in Hackney", Journal of Public Health Medicine., vol. 14, no. 2, pp. 183-191.

Phelan, M. & Parkman, S. (1995), "Work with an interpreter", *BMJ.*, vol. 311, no. 26 Aug, pp. 555-557.
Poss, J. & Rangel, R. 1995, "Working Effectively with Interpreters in the Primary Care Setting", Nurse Practitioner., vol. 20, no. 12, pp. 43-47.

Turton J, De Maio F, Lane P (2003) Interpretation and translation services in the public sector (unpublished) report to the Home Office by University of East London HARP social inclusion research programme

Woloshin S, Bickell N, Schwartz L, et al. (1995), Language barriers in medicine in the United States. JAMA.; 273: 724.

Annex 4: Literature searches

4.1 Background

A number of preliminary search strategies were tested, looking at the question of 'communication' using the MeSH terms available, and 'ethnicity', using MeSH terms and a combination of other key words.

Table 4.1 below shows the searches carried out and the number of resultant hits. Further searches were conducted as the review progressed, including updates to 2004, and these are shown in Table 4.2.

Further details of searches are provided in sections 4.2 - 4.3.

Table 4.1: Initial literature searches and numbers of articles identified

Database	**Dated covered**	**Topic/Brief strategy**	**Hits**
PubMed	1998-2003	Ethnic Communication*	66
PubMed	1966-2003	Anderson related articles from *	110
Medline, Premedline, Embase	1998-2003	Ethnic communication – delivery of healthcare	234
CINAHL		Ethnic communication	129
HMIC	1998-2003	Ethnic communication and health	74
Medline, Premedline, Embase	1998-2003	Speech and language therapy – first strategy (many false drops)	552
PubMed	1998-2004	Arblaster (255), Bell (137), Cooper (120) related articles	512
Medline, Premedline, Embase	1998-2003	Speech and language therapy – second strategy	61
NRR and ReFeR	Various	Ethnic communication	41
CRER database	Various	Communication	91

Table 4.2: Further literature searches and numbers of articles identified (up to 2004)

Database	**Dated covered**	**Topic/Brief strategy**	**Hits**
Medline	1966-2004	Blood transfusion/donation – attitudes/beliefs	46
British Nursing Index	1994-2004	Ethnic communication	65
Caredata	None given	Ethnic communication (includes grey literature)	14
Medline	1966-2004	Ethnic consent, concordance transplantation	1345
Psycinfo	1967-2004	Concordance and consent to treatment	419
Ageinfo	None given	Ethnic communication	65
Psycinfo	1990-2004	Ethnic communication	593
Psycinfo	1967-2004	Organ donation and ethics	17
Medline	1966-2004	Ethnic organ procurement/ethics committees	94
Psycinfo	12967-2004	Psychotherapy	314

4.2 Initial searches

ETHNIC COMMUNICATION

A simple search was carried out on **PubMed**

Ethnic* AND communication
Limited to English, human, review, 1998-2003

This produced **66 hits**, amongst which was an article by L M Anderson "Culturally competent healthcare systems. A systematic review" in the American Journal of Preventive Medicine in 2003. A related articles search was then performed on this item which yielded a further **110 hits**.

More extensive searches were then run on **Premedline, Medline and Embase**.

The development of the strategy is shown below.

Ethnic element

The strategy developed for the ethnic screening project was used but excluded individual Groups eg Indian/Chinese as gave too many irrelevant hits.

Communication element

MESH heading of "Communication" includes

Communication barriers
Duty to Recontact
Information Dissemination
Interdisciplinary Communication
Language
Narration
Negotiating
Nonverbal Communication
Persuasive Communication
Propaganda
Verbal Behavior

"IAT" (information and technology) produced articles on Intra-arterial thromboses so was not included in the final strategy.

The terms "leaflet, brochure, handout, video, CD,DVD, cassette", were introduced but even the addition of "information" to this set produced too many false drops, so this aspect of the search was restricted to Communication and Patient information.

Final strategy

1. ethnic$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
2. minorit$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
3. (multicultural or multi-cultural).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
4. (crosscultural or cross-cultural).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
5. (transcultural or trans-cultural).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
6. (multiethnic or multi-ethnic).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
7. (multiracial or multi-racial).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
8. (migrant$ or immigrant$).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
9. refugee$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
10. cultural diversity.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
11. (multilingual or multi-lingual).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
12. or/1-11
13. communication.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]

14. Patient advocacy.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
15. Patient counsel$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
16. advoca$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
17. interpret$4.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
18. translat$4.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
19. Patient information service.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
20. verbal communication.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
21. access to information.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
22. exp Communication/
23. or/13-22

This produced **234 hits**.

A search was then run on **CINAHL** using a very simple strategy

Ethnic*.mp. Or Expl ethnic groups/
Communication
Transcultural nursing

This produced **129 hits**.

A further search was carried out on HMIC (Health Management Information Consortium -= DH-Data, Helmis, King's Fund) database

#2 (ethnic*)and(Communication)and(health) and ((PY:HMIC = 1998-2003) or (PY:HQ >= 1998)) gave **74 hits** – **51 hits** selected as being useful.

Simple searches were also performed on NRR and ReFeR, giving **41 hits.**

The database at the Centre for Research in Ethnic Relations (CRER) was also investigated and yielded a further **91 hits**.

ETHNIC SPEECH AND LANGUAGE THERAPY (SALT)

Initial searches were carried out on **Medline** and **Embase.** The first Medline and Embase strategies in this category produced **552 hits** but there were so many false drops that the strategies were not retained. However, scanning the titles in these two searches produced 2 items which looked promising.

Arblaster L
A systematic review of the effectiveness of health service interventions aimed at reducing inequalities in health
JHSR and policy 1996 1(2); 93-103

Bell TS
Interventions to improve uptake of breast screening in inner city Cardiff general practices with ethnic minority lists.
Ethnicity and Health 1999 4(4): 277-284

These two items were entered on **Pubmed** and the "related articles" link selected.

Entering Arblaster produced 275 items This set was limited to 1980-2003 in English, which decreased this to **255 hits**. The selection criteria used were, any general systematic review on health inequalities or any with possible ethnic component or social or health inequalities. Items dealing with road/transport, child abuse, nutrition, or dental aspects were excluded. This set included a number of false drops eg "Bell's inequalities"!.

137 hits were chosen at this stage but examination of abstracts of these meant that only **20 hits** were finally kept including "Designing and evaluating interventions to eliminate racial and ethnic disparities in health care" by Cooper LA, Hill MN, Powe NR.

The same procedure was followed for the article by Bell (GPs – Cardiff). 152 items were retrieved and limited to 1980-2003 and English (NB system picks up English language abstracts from foreign language journals). The titles were checked and then abstracts examined. Methods for improving uptake were included even if there was no specific ethnic content as well as lessons from abroad and outreach work. **117 paper (hits)** were kept as possibly being useful.

The item by Cooper was then entered on **PubMed** and the related articles link again picked up. This produced a further **120 papers (hits)**, most of which appeared useful.

The earlier SALT strategy was amended and re-run on using Medline and Embase. This produced **61 items (hits)**.

4.3 Further searches

It was decided that certain specific areas needed their own searches or that earlier searches should be taken back further in time than the original cut off date of 1998.

BLOOD TRANSFUSION/DONATION

Medline 1966 – 2004.

1. ethnic$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
2. minorit$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
3. (multicultural or multi-cultural).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
4. (crosscultural or cross-cultural).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
5. (transcultural or trans-cultural).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
6. (multiethnic or multi-ethnic).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
7. (multiracial or multi-racial).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
8. (migrant$ or immigrant$).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
9. refugee$.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
10. cultural diversity.mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
11. (multilingual or multi-lingual).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
12. 1 and 2
13. or/3-12
14. 1 or 13
15. (Blood and (donation or transfusion)).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
16. exp Blood Transfusion/
17. exp Blood Donors/
18. or/15-17
19. 14 and 18
20. limit 19 to english language
21. limit 20 to human
22. (attitude$ or approach$ or View$).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
23. (belief$ or practice$ or ethic$).mp. [mp=ti, ab, sh, tn, ot, dm, mf, rw]
24. 22 or 23
25. 21 and 24

Set 25 produced **46 hits**.

ETHNIC COMMUNICATION

British nursing index (1994-2004)

Strategy “ethnic and communication” = **65 hits**

ETHNIC COMMUNICATION

Caredata

No coverage dates given, but does include grey literature.

"Ethnicity and communication" produced **14 hits**

CONCORDANCE AND CONSENT TO TREATMENT

Psycinfo 1967-2004

Search History
#29 (health and (LA:PY = ENGLISH)) and (((transcultural or (trans-cultural)) or (crosscultural or (cross-cultural)) or (multicultural or (multi-cultural)) or (minorit*) or (cultural diversity) or (ethnic*) or (refugee*) or (migrant* or immigrant*) or (multilingual or (multi-lingual)) or (multiracial or (multi-racial)) or (multiethnic or (multi-ethnic))) and (((trial*) and (inclusion or includ*) and (consent)) or (consent) or (treatment plan*) or (concordance) or (bone marrow transplant*) or (privacy or private) or (organ donation*) or (informed consent) or (transplant*) or (consent to treatment)) and (LA:PY = ENGLISH)) and (LA:PY = ENGLISH**)**

419 hits

ETHNIC COMMUNICATION

AgeInfo

A bibliographic database of over 40,000 books articles and reports from the specialist collection on Social Gerontology held at the Centre for Policy on Ageing – no years given of coverage as dependent on their stock.

1 Text: ethnic* OR minorit* OR multicultural OR multi-cultural OR crosscultural
OR
2 Text: transcultur* OR multi-ethnic OR multi-ethnic Or multiracial OR
multi-racial
OR
3 Text: migrant* OR immigrant* OR refugee*
OR
4 Keywords: ethnicity/"ETHNIC GROUPS@"
OR
5 Text: cultural and diversity
AND
6 Text: communicat*

65 hits

ETHNIC COMMUNICATION

Psycinfo 1990-2004

#16 (health) and (communicat*) and ((transcultural or (trans-cultural)) or (crosscultural or (cross-cultural)) or (multicultural or (multi-cultural)) or (minorit*) or (cultural diversity) or (ethnic*) or (refugee*) or (migrant* or immigrant*) or (multilingual or (multi-lingual)) or (multiracial or (multi-racial)) or (multiethnic or (multi-ethnic))) and (LA:PY = ENGLISH)

593 hits

ORGAN DONATION AND ETHICS

Pscyinfo 1990-2004

#14 (organ donation* and (LA:PY = ENGLISH)) and ((transcultural or (trans-cultural)) or (crosscultural or (cross-cultural)) or (multicultural or (multi-cultural)) or (minorit*) or (cultural diversity) or (ethnic*) or (refugee*) or (migrant* or immigrant*) or (multilingual or (multi-lingual)) or (multiracial or (multi-racial)) or (multiethnic or (multi-ethnic))) and (LA:PY = ENGLISH)

<u>17 hits</u>

ORGAN DONATION/CONSENT

Medline

Database: Ovid MEDLINE(R) <1966 to January Week 2 2004>
Search Strategy:
----
1 ethnic$.mp. [mp=title, abstract, name of substance, mesh subject heading] (44191)
2 minorit$.mp. [mp=title, abstract, name of substance, mesh subject heading] (19626)
3 (multicultural or multi-cultural).mp. [mp=title, abstract, name of substance, mesh subject heading] (829)
4 (crosscultural or cross-cultural).mp. [mp=title, abstract, name of substance, mesh subject heading] (2875)
5 (transcultural or trans-cultural).mp. [mp=title, abstract, name of substance, mesh subject heading] (961)
6 (multiethnic or multi-ethnic).mp. [mp=title, abstract, name of substance, mesh subject heading] (795)
7 (multiracial or multi-racial).mp. [mp=title, abstract, name of substance, mesh subject heading] (235)
8 (migrant$ or immigrant$).mp. [mp=title, abstract, name of substance, mesh subject heading] (9673)
9 refugee$.mp. [mp=title, abstract, name of substance, mesh subject heading] (4319)
10 cultural diversity.mp. [mp=title, abstract, name of substance, mesh subject heading] (4256)
11 (multilingual or multi-lingual).mp. [mp=title, abstract, name of substance, mesh subject heading] (224)
12 or/1-11 (78202)
13 organ donation$.mp. or exp Organ Procurement/ (7739)
14 exp ETHICS COMMITTEES, RESEARCH/ or exp ETHICS, NURSING/ or exp ETHICS COMMITTEES/ or exp ETHICS/ or exp ETHICS, CLINICAL/ or exp ETHICS CONSULTATION/ or ethic$.mp. or exp ETHICS, PROFESSIONAL/ or exp ETHICS, MEDICAL/ or exp ETHICS COMMITTEES, CLINICAL/ (98921)
15 12 and 13 and 14 (94)

<u>94 hits</u>

PSYCHOTHERAPY

Psycinfo 1967-2004.

#20 (((evaluat*)or(best practice)) or ((effectiveness)or(good practice)or(implementation))) and (((psychotherapy)or(cognitive behavio$r therapy)or(familty therapy)) or (counselling)) and ((transcultural or (trans-cultural)) or (crosscultural or (cross-cultural)) or (multicultural or (multi-cultural)) or (minorit*) or (cultural diversity) or (ethnic*) or (refugee*) or (migrant* or immigrant*) or (multilingual or (multi-lingual)) or (multiracial or (multi-racial)) or (multiethnic or (multi-ethnic)))

<u>314 hits</u>

ETHNIC CONSENT

Medline

Database: Ovid MEDLINE(R) <1966 to January Week 2 2004>
Search Strategy:
----
1 ethnic$.mp. [mp=title, abstract, name of substance, mesh subject heading] (44191)
2 minorit$.mp. [mp=title, abstract, name of substance, mesh subject heading] (19626)
3 (multicultural or multi-cultural).mp. [mp=title, abstract, name of substance, mesh subject heading] (829)
4 (crosscultural or cross-cultural).mp. [mp=title, abstract, name of substance, mesh subject heading] (2875)
5 (transcultural or trans-cultural).mp. [mp=title, abstract, name of substance, mesh subject heading] (961)
6 (multiethnic or multi-ethnic).mp. [mp=title, abstract, name of substance, mesh subject heading] (795)
7 (multiracial or multi-racial).mp. [mp=title, abstract, name of substance, mesh subject heading] (235)
8 (migrant$ or immigrant$).mp. [mp=title, abstract, name of substance, mesh subject heading] (9673)
9 refugee$.mp. [mp=title, abstract, name of substance, mesh subject heading] (4319)
10 cultural diversity.mp. [mp=title, abstract, name of substance, mesh subject heading] (4256)
11 (multilingual or multi-lingual).mp. [mp=title, abstract, name of substance, mesh subject heading] (224)
12 or/1-11 (78202)
13 exp Informed consent/ or consent to treatment.mp. (22730)
14 consent$.mp. [mp=title, abstract, name of substance, mesh subject heading] (16422)
15 clinical trial$.mp. [mp=title, abstract, name of substance, mesh subject heading] (169523)
16 (includ$ or inclusion).mp. (865602)
17 14 and 15 and 16 (306)
18 priva$.mp. [mp=title, abstract, name of substance, mesh subject heading] (36698)
19 transplant$.mp. or exp Kidney Transplantation/ or exp Transplants/ (245969)
20 exp Bone Marrow Transplantation/ or Bone marrow transplant$.mp. (35248)
21 concordance.mp. (9487)
22 exp Patient Care Planning/ or treatment plan$.mp. (43933)
23 13 or 17 or 18 or 19 or 20 or 21 or 22 (360063)
24 12 and 23 (3097)
25 limit 24 to (english language and yr=1998-2004) (1345)
26 from 25 keep 1-1345 (1345)

<u>1345 hits</u>

Annex 5: Findings from our earlier reviews

5.1 The Unavoidable Costs of Ethnicity[1] (1998)

This scoping report was commissioned by the NHS Executive to review the evidence concerning the degree to which the presence of populations of minority ethnic origin was associated with 'unavoidable additional costs' in health service delivery. While local health authorities retained full autonomy in their use of funds allocated to them under the Hospital and Community Health Services formula, the size of that budget was governed by a set of weightings applied to their population, to allow for factors known to influence levels of need, and the costs of providing services.

The scoping exercise was literature-based and identified two types of unavoidable cost. The first was the *additional cost of providing the same service* to an ethnic population. This principally reflects language needs i.e. the cost of providing interpreter, advocacy, and translation services. The second was the *additional cost associated with necessary differences in provision of services* to ethnic populations compared with non-ethnic populations, caused by variations in the incidence or prevalence of specific diseases combined with differences in treatment patterns.

Existing published evidence relating to ethnic health and disease treatment in medical, social science, academic and practitioner literature was reviewed. Additional evidence was located through trawls of 'grey' literature in specialist collections, and through contacting all English health districts with a request for information. A number of authorities and trusts provided written and oral evidence (see below), and a bibliography of key materials was produced.

Key issues considered included:

- the need for and use of, interpreter and translation services;
- the incidence of 'ethnically-specific' disease, and;
- variations in the prevalence and cost of treating 'common' conditions in minority ethnic populations.

The literature provided a range of estimates which could be used in a modelling exercise, but it was deficient in many respects, particularly in terms of precise costs associated with procedure and conditions, or in associating precise and consistent categories of ethnic group with epidemiological and operational service provision data. Certain other activities required fixed funding to set them up, and might not be directly related to population size. There was considerable variation in the approaches adopted by different health authorities, and many services were provided by agencies not funded by NHS budgets.

Conclusions and Recommendations

The report concluded that :

- the presence of minorities is associated with the need to provide additional services in respect of interpreting and translation, and the media of communication;

- in order to achieve clinical effectiveness, a range of advocacy support facilities or alternative models of provision seem to be desirable;

- ethnic diversity requires adaptation and additional evidence in order to inform processes of consultation and commissioning;

- minority populations do create demands for certain additional specific clinical services not required by the bulk of the majority population: it is not yet clear to what extent the reverse can be stated since research on 'under-use' is less well developed;

---

[1] Johnson MRD, Clark MD, Owens D, Szczepura A. *The Unavoidable Costs of Ethnicity: A review of evidence on health costs*. Centre for Health Services Studies, University of Warwick, Coventry, UK. June 1999. ISBN 0953 5430 05.

- some variations in levels of need, particularly those relating to established clinical difference in susceptibility or deprivation, are already incorporated in funding formulae although it is not clear how far the indicators adequately reflect these factors;

- costs are not necessarily simply related to the size of minority populations;

- the provision of services to meet minority needs is not always a reflection of their presence, but has frequently depended upon the provision of additional specific funds.

There was a consensus that the NHS research and development strategy should accept the need for more work to establish the actual levels of need and usage of services by ethnic minority groups, and that effort should be made to use and improve the growing collection of relevant information through ethnic monitoring activities.

A variety of modelling techniques were suggested, and shown to have the potential to provide practical guidance to future policy in the field. Although data availability at a national or regional scale was inadequate to provide estimates of the ‘additional costs of ethnicity’, locally collected data and the existence of relevant policy initiatives suggested that a focused study in selected districts might provide sufficiently robust information to provide reliable estimates.

The review demonstrated that there are costs associated with the presence of minority ethnic groups in the population which can be shown to be unavoidable and additional, but that others are either ‘desirable’ or ‘alternative’. It would be wrong to assume that all cost pressures of this nature are in the same direction. The study also drew attention to deficiencies in data collection and budgeting which might hinder investigation of the effectiveness of the service in general. The process of drawing attention to ethnic minority needs might itself lead to developments in services which are functional and desirable for the majority population.

Survey of Directors of Public Health in England

Directors of Public Health in each of the English health districts were asked to provide any data that might be relevant to the study, including if possible a copy of their annual report, and to pass the enquiry to any specialist officers. Of the 100 contacted, sixty replied, as did five of the regional offices of the NHS Executive. It was not necessarily those with the highest proportions of minority ethnic population that replied, and several that were known to have specific policy developments and activities did not respond. Information on these was drawn from our own resource collection, when possible.

Key issues highlighted in these documents and correspondence included:

- specific illnesses such as Sickle Cell Diseases, Diabetes etc;

- ability to speak and read English, and various proposals to develop interpreter, language line or similar services - sometimes related to other forms of disability;

- needs for specialist officers and access workers along with research and health needs assessment, including development of consultation and inputs to commissioning processes;

- the need for staff training and the provision of local directories of resources and ethnic specific information;

- the growing availability of ethnic monitoring data.

In addition, a selection of other matters were raised rather less frequently, but deserve consideration, or provide additional insight into local needs and issues that should be incorporated in future service planning and costing:

- the problems of disassociating ethnicity and deprivation using existing data
- the costs of developing ethnic monitoring
- ethnic-specific health promotion work

- workload implications for GPs and facilities offering ‘culturally sensitive’ services
- rurality or the problem of reaching and serving small, dispersed groups.
- problems of registering (minority) donors (kidneys, bone marrow etc)

A further significant comment was the need to take into account a variety of different ethnic groups, many of which could not be identified from Census or other routine data. Even when groups were named in the Census, it was often suggested that these estimates were inaccurate, usually underestimating current population numbers because of migration, population growth, or exclusion of locally significant groups which may have been subsumed under ‘other’ categories. Some were differentiated by religion, nationality or status, and some might not fall within the ‘conventional’ definitions of ethnic minority. Others were ‘new’ groups. All, however, had been found locally to have specific needs and/or require particular attention in service development. Those listed included: Irish, Somali, Yemeni, Sudanese Copts, Arabs, Travellers/Gypsies/Romani, Armenians, ‘Muslim lifestyles’.

Sixteen (one in four) of the districts replying provided us with some financial data which was readily distinguishable as related specifically to ethnic health care costs. However, there was very little consistency in this, and none covered all aspects on which data were requested. It was not possible to link these data with service levels or the size of minority populations, or even to be sure that they covered all the costs of the services mentioned. Equally, not all of these amounts were charged to NHS budgets but ‘matching’ funding would only be released against NHS contributions.

5.2 Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services[2] (1998)

This report was commissioned by the Technical Advisory Group (TAG) of the Department of Health following the initial scoping exercise on the ‘unavoidable costs of ethnicity’ carried out by the University of Warwick (Johnson et al 1998). Following the scoping exercise, a further study was commissioned to look in greater detail at one category of unavoidable cost i.e. language needs. The aim of the study was to quantify the costs to the NHS arising from the provision of interpreter, advocacy, and translation (IAT) services and to relate these to ethnic population figures with a view to improving the workings of the national formula for resource allocation.

After a preliminary analysis, 13 representative health authorities (HAs) were identified for data collection, and information on the costs of IAT provision within these HAs was obtained. The relationship between identifiable IAT costs and a range of population measures was explored graphically and statistically for this sample of health authorities, and it was found that:

- there was little relationship between the costs quoted and the overall size of the HA population;

- IAT costs and census data on the size of the minority population were more closely related; IAT costs, and various estimates of the number of people who had difficulty speaking English were considered - as expected this revealed an even stronger relationship;

- a variety of potential functional forms were considered for the relationship between average IAT costs and the share of a HA’s population estimated to have difficulties in the English language; it was concluded that a quadratic equation was the most appropriate functional form to adopt;

- of the 13 health authorities surveyed, IAT provision was deemed to be inadequate in 7 authorities either because of a lack of comprehensive IAT provision or because of poor quality provision;

- a dummy variable was therefore included in the equation in order that the costs of adequate as opposed to inadequate provision could be established; the use of the dummy variable increased the degree of ‘fit’ of the equation;

---

[2] Szczepura A, Clark MD, Johnson MRD, Owen D,. ‘*Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services*’ Centre for Health Services Studies, University of Warwick, Coventry. September 1999. ISSN 0964-7902.

- The resulting Warwick formula enables calculation of resource allocation at health authority level to cover both ‘adequate’ and ‘inadequate’ levels of provision;

- the total cost for all 100 (old) health authorities in England of allocating resources to cover IAT provision was calculated to be £9.40 million for ‘adequate’ levels of provision and £6.87 million for more basic provision (1997/98 prices);

The use of the Warwick formula suggested that in order to provide adequate IAT provision an average of £16.54 per person with language needs was required, compared to an average of £9.80 for more basic provision. The actual average cost in a HA would vary according to the extent of language needs in the authority. This was reflected in the resource requirement projections for each health authority contained in the report.

The report made a number of recommendations in terms of funding IAT provision, including:

- .that, as an interim measure, the Warwick formula be used to ‘fine tune’ the existing York resource allocation formula, and that allocations be made to HAs which were sufficient to fund adequate IAT provision;

- to further improve the Warwick formula, we suggested that the 2001 Census of population should include a question relating to language needs; that more routinely updated information could be compiled if ethnic monitoring data relating to language needs were collected by all trusts; and that this improved information on language needs could then be used to refine the Warwick formula relating to IAT costs to the NHS.

The report pointed out that the Audit Commission (1994) had identified numerous managerial failures associated with IAT service provision, and more recent evidence gathered during the course of our study indicated that many of the Audit Commission’s criticisms still applied in some trusts and health authorities. Such managerial deficiencies would need to be addressed if adequate IAT services are to be provided on a nation-wide basis. Consideration of management issues led to the following suggestions:

- having considered a number of potential funding models, it was concluded that a non-ring fenced formula based approach would provide the most appropriate basis for distributing resources to meet IAT needs;

- the study identified failings associated with the organisation and provision of IAT services in the cross-section of health authorities surveyed, and these would not necessarily be rectified through adequate financial provision alone;

- one possible approach might be to assign a statutory responsibility to each health authority to provide adequate IAT services for its resident population.

5.3 A systematic review of ethnicity and health service access in London[3] (2001)

This report was commissioned by the London Regional Office of the NHS Executive. The main aim of the research was to gather and assess the existing research-based evidence on differences in access and uptake of health services by minority ethnic groups. In particular, the research team undertook a systematic review of the published and unpublished research literature which could provide useful insights into inequalities in access to services for minority ethnic groups, and possible interventions which could help reduce such inequalities or imbalances in provision and uptake. The team was also asked to provide information on the demographic profile of London, and how this was predicted to change.

A number of key messages emerged from the review, as follows:

---

[3] Atkinson M, Clark M, Clay D, Johnson M, Szczepura A. *Systematic review of ethnicity and health service access for London*. Centre for Health Services Studies, University of Warwick, Coventry, UK. February 2001. ISBN 0-9535-4300-6.

- The research described, both in peer reviewed articles and the grey literature, exhibited an inverted evaluation 'pyramid'. In terms of information relevant to issues of access, the majority of research was focused on the preliminary task of gathering epidemiological data and of demonstrating differential uptake patterns. Somewhat less research was focused on the higher level task of identifying barriers to access and of describing possible interventions to address these. No, or very little, research was devoted to the highest level task of evaluating interventions designed to improve access. The overall result was a focus in the literature reviewed on 'defining the problem' and a lack of research on ways of addressing this effectively and efficiently. There is therefore a need for research to be funded which will break through the higher levels of evaluation, and which focuses on implementation and assessment of interventions aimed at improving access.

- There was a complete absence of economic evaluations of interventions designed to improve access. More thought needs to be given to how analysis of cost-effectiveness can be integrated into studies which evaluate interventions to improve access.

- There was a need to improve ethnic monitoring data in London, including improved recording of ethnicity in existing registers (e.g. cancer), and consideration of the potential value of primary care electronic patient records with ethnic record keeping. While not strictly a ‘research priority’, it was clear that until political and policy emphasis was placed on the collection and use of these data, discussion of questions of access, and the entire related research agenda, would be significantly handicapped.

- Booster samples should be considered as a matter of course in studies which are funded for other purposes so that more information specific to black and minority ethnic groups can be produced.

- The current research profiles, and therefore the main research gaps, differ depending on the disease area being considered. Firstly, in some disease areas long-term research is still required to provide basic epidemiological data or information on access and uptake patterns (e.g. in the area of access to specialist management of heart disease). Secondly, in other areas where these aspects are already well researched and understood, studies now need to investigate barriers to access and provide a better understanding of interventions which might address these (e.g. in the area of mental health). Thirdly, in virtually all disease areas there is a need for more studies which implement and evaluate interventions designed to improve access. On the basis of the review findings, it should be possible to prioritise key research evidence in relation to the disease areas examined and the needs of London, and to map out a strategy to address these. It should also be possible to identify key research gaps and commission research to address these.

- The research base was somewhat different for the service areas considered. But, for these areas also it was possible to identify key research evidence which might require London-wide action, as well as defining the remaining research gaps which still need to be addressed.

- There was a need for investment in methodological research, which could benefit studies in all service areas and disease groups. Fundamental research is needed which can (i) improve understanding of the *dimensions of ethnicity* to be used in so-called objective/science paradigm research such as prospective trials (e.g. language, religion, country of origin etc) and their significance in terms of hypothesis generation, testing and appropriate ethnic analysis; (ii) assess the appropriateness of *outcome measures* currently used and their sensitivity to ethnic diversity; and (iii) identify appropriate and acceptable *general labels for use across a number of comparable studies* (consensual ethnic groups plus language and religion categories), compatible to 2001 census categories.

- Furthermore, longer-term research (i.e. fundamental research, longitudinal studies or epidemiological research) also remains an important need in several areas. At present, it is unclear who will sponsor and champion such studies and how they will be coordinated to address strategic requirements. Discussion between funding bodies should be organised in order to address this issue.

- Many evaluations of interventions to improve access were reported in the grey literature, often associated with fixed-life projects funded by the NHS or other bodies. Although some data was usually collected as part of these projects, this was not necessarily collected from the outset within a pre-defined evaluative framework (e.g. a 'before and after' study design) and the data collected were not always fully analysed. Many of these grey literature reports were of a high standard and some research did find its way into peer reviewed journals, although we could find very few examples. Furthermore, systems for tracking down this grey literature are less well developed and far more laborious than for published articles. There is therefore a need both to facilitate improved evaluation of funded fixed-life projects and also to encourage publication in peer-reviewed journals of the findings of any evaluations carried out.

- There is a need for improved mentoring of research in practice (e.g. of public health registrars) and a need for partnerships with academic organisations to ensure that appropriate skills/ expertise are available for evaluations to be completed;

- An improved dialogue needs to be developed between research funders and academics with respect to the types of evaluative studies required. Some evaluations may need to be carried out to support immediate priority and planning needs and therefore have to be conducted quickly (i.e. 'quick and clean' or 'rapid and rigorous' studies). However, many studies which are considered publishable (and therefore attractive in terms of academic career advancement) tend to be longer term. Therefore, a new form of 'close to service' policy and practice research may need to be developed which can produce more rapid results, while maintaining academic rigour.

- Internal evaluations might be based on self justification unless conducted objectively and rigorously. Therefore, partnerships are needed between academics and project leaders, with development of joint evaluative protocols and full integration of evaluation from the outset through the life of a project. Interventions to improve access are essentially organisational or management interventions, and therefore ideally require the development of a ‘learning organisation’ approach across London for continuous quality improvements in ethnic access, rather than local 'reinvention of the wheel'. A commitment to follow through and implement any interventions proved to be effective and cost-effective was also required.

- Further research is needed to identify, where projects have survived and had an impact, why this is the case. This could build on existing studies of management of change and diffusion of innovations. The importance of factors such as key ‘champions’, senior management support, the external context, and the type of change being proposed could all be considered among others. Such information is essential for any roll-out and implementation of research findings demonstrating the value of particular types of organisational or managerial interventions to improve ethnic access.

- There should be acceptance also that the search for 'best practice' in organisational terms may overlook interventions which are effective and do some good in one location and which might be developed further in another setting. Development and further assessment of any such promising interventions is required, as well as transfer of generic interventions from one type of patient to other groups of patients or services e.g. link workers.

- More thought needs to be given to a policy which will reverse the observed pattern of short-term projects, without evaluation, and with discontinuation of projects after piloting. There may be a more receptive environment for investment in a more strategic approach to such projects across the region with the increased Government focus on Inequalities in Health.

- Questions of access to services, and other aspects of ethnic health and well-being, need broadening from the current narrow horizons to incorporate local government services as well as health services. There is currently a failure to learn from ethnic initiatives in non-health fields.

- There is a need for improved dissemination of research evidence on access to services for black and ethnic minority groups, together with other issues which affect ethnic health and well-being. A strategy is required for assertive acquisition of reports and articles and active dissemination of findings of any evaluations of good practice which are identified in the UK or elsewhere. Furthermore, there is also a need to disseminate negative findings in order to prevent resources being invested in ineffective interventions which might be better used in other ways.

- There is also a need to ensure that data collected by funded projects in London and elsewhere, which may only have been partially analysed or never used, is collated centrally and used as a resource to inform future policy and practice.

- There is a need to discuss further the role of Regional Observatories. Black and minority ethnic groups are one of the four Regional Priorities, and consideration needs to be given to how the London Observatory can support the London Health Strategy in this area.

Annex 6: Master Bibliography

6.1 Articles and Reports

1. (1999). "Guatemala -- strength is NGO cooperation." JOICFP News(298): 3.

2. (2000). "Interventions to prevent HIV risk behaviors. National Institutes of Health Consensus Development Conference Statement February 11-13, 1997." Aids 14 Suppl 2: S85-96.

3. (2000). "Looking back at the century of population." Popul Today 28(1): 1-2.

4. Abbotts, J. W., Rory Ford, G. (2001). "Morbidity and Irish Catholic descent in Britain: Relating health disadvantage to socio-economic position." Social Science & Medicine 52(7): 999-1005.

5. Abbotts, J., Williams, R.,Ford, G.,Hunt, K.,West, P. (1999). "Morbidity and Irish Catholic Descent in Britain: relating health disadvantage to behaviour." Ethnicity and Health 4(4): 221-230.

6. Ahmad, W. Kernohan, E. & Baker M.(1989). “Patients’ choice of general practitioner: influence of patients’ fluency in English and the ethnicity and sex of the doctor”, Journal of the Royal College of General Practitioners, vol. 39, pp. 153-155.

7. Ahmad W.I.U. (1996). Family obligations and social change among Asian communities. In Ahmad W.I.U and Atkin K. (ed.). *Race and Community Care*. Buckingham: Open University.

8. Albernaz, E. V., C. G. (2003). "[Impact of face-to-face counseling on duration of exclusive breast-feeding: a review]." Rev Panam Salud Publica 14(1): 17-24.

9. Anderson, L. M., Scrimshaw, S. C., Fullilove, M. T. ,Fielding, J. E. ,Normand, J. (2003). "Culturally competent healthcare systems - A systematic review." American Journal of Preventive Medicine 24(3): 68-79.

10. Anthony D. (2000) 'Are nurses excluded from the Web?' Current Perspectives in Healthcare Computing Conference, Harrogate

11. Appasamy, P. (1995). "Doing brief therapy in India". Ch. in: Propagations: Thirty years of influence from the Mental Research Institute. J. H. Weakland, W. A.. Ray (Eds), Haworth marriage & the family series,pp. 157-173. New York, Haworth Press, Inc:

12. Atkinson M, Clark M, Johnson M, Szczepura A. (2001). Systematic review of ethnicity and health service access for London. Report to NHS Executive London February 2001.

13. Audit Commission. (1994) What seems to be the matter: Communication between hospitals and patients. Audit Commission report. HMSO.

14. Bagley, S. P., Angel, R., Dilworth-Anderson, P., Liu, W., Schinke, S. (1995). "Adaptive health behaviors among ethnic minorities." Health Psychology 14(7): 632-40.

15. Bahl, V. (2001). "Improving access and quality for ethnic minority women." Womens Health Issues 11(4): 348-54; discussion 354-70.

16. Baines LS, Joseph JT, Jindal RM (2002) “A public forum to promote organ donation amongst Asians: the Scottish initiative.” Transplant International 15(2-3) :124-131

17. Baker D.W., Parker R.M., Williams M.V., Coates W.C. and Pitkin K. (1996). Use and effectiveness of interpreters in an emergency department. JAMA. 275(10): 783-8.

18. Balabil, S. D. (1992). "A cross-cultural evaluation of expectations about psychological counselling." British-Journal-of-Medical-Psychology 65(4): 305-308.

19. Barnard, H., Pettigrew, N. (2003). Delivering benefits and services for black and minority ethnic older people. Department for Work and Pensions. Research Summary. Available at: http://www.dwp.gov.uk/asd/asd5/summ2003-2004/201summ.pdf.

20. Barrett, S. (2001). "Improving Access and Quality for Ethic Minority Women". Women's Health Issues 11, 4: 345-348).

21. Bauerlein (2001). Social Constructionism: Philosophy for the Academic Workplace. Partisan Review LXVIII, (2). Available at: . http://www.partisanreview.org/archive/2001/2/bauerlein.html

22. Baxter, C. and Baxter, D. (2000). "Serious neurological disorders and minority ethnic people: A problem service, access needs immediate attention". Public Health Medicine 2; (2) : 74 - 79.

23. Bekaert, S. (2000). "Minority integration in rural healthcare provision: an example of good practice". Nursing Standard.14(45):43-5..

24. Belgrave, F. Z. (2002). "Relational theory and cultural enhancement interventions for African American adolescent girls." Public Health Rep 117 Suppl **1**: S76-81.

25. Bell, C. C., Williamson, J. (2002). "Articles on special populations published in Psychiatric Services between 1950 and 1999." Psychiatr Serv 53(4): 419-24.

26. Bell, D. L. R., D. F. Cohall, A. (1999). "Cross-cultural issues in prevention, health promotion, and risk reduction in adolescence." Adolesc Med 10(1): 57-69, vi.

27. Benjamin, E. J., Smith, S. C. Jr., Cooper, R. S., Hill, M. N., Luepker, R. V. (2002). "Task force #1--magnitude of the prevention problem: opportunities and challenges. 33rd Bethesda Conference." J Am Coll Cardiol 40(4): 588-603

28. Bernstein J., Bernstein E., Dave A., Hardt E., James T., Linden J., Mitchell P., Oishi T., and Safi C. (2002). Trained Medical Interpreters in the Emergency Department: Effects on Services, Subsequent Charges, and Follow-up. Journal of Immigrant Health. 4(4): 171-176.

29. Bhui, . K. Fletcher., A (2000). "Common mood and anxiety states: Gender differences in the protective effect of physical activity." Social-Psychiatry-and-Psychiatric-Epidemiology 35(1): 28-35.

30. Bickell, N. A. (2002). "Race, ethnicity, and disparities in breast cancer: victories and challenges." Womens Health Issues 12(5): 238-51.

31. Bischoff, A., Tonnerre, C., Eytan, A., Bernstein, M., and Loutan, L. (1999). "Addressing language barriers to health care, a survey of medical services in Switzerland". Sozial- und Praventivmedizin. 44; (6) : 248 - 256.

32. Bischoff, A., Tonnerre, C., Loutan, L., and Stalder, H. (1999). "Language difficulties in an outpatient clinic in Switzerland". Sozial- und Praventivmedizin. 44; (6) : 283 - 287.

33. Borson, S., Brush, M., Gil, E., Scanlan, J., Vitaliano, P., Chen, J., Cashman, J., Sta Maria, M. M., Barnhart, R., and Roques, J. (1999). "The Clock Drawing Test: utility for dementia detection in multiethnic elders". Journals of Gerontology Series A-Biological Sciences & Medical Sciences. 54; (11) : M534 - M540.

34. Bottorff, J., Johnson, J., Venables, L., Grewal, S., Popatia, N., Hilton, B., Clarke, H., Sumel, P., Bilkhu, S., Sandhu, G. (2001). "Canada Voices of immigrant South Asian women:

Expressions of health concerns." Journal-of-Health-Care-for-the-Poor-and-Underserved 12(4): 392-403.

35. Bowes, A., Wilkinson,H. (2003). "'We didn't know it would get that bad': South Asian experiences of dementia and the service response." Health and Social Care in the Community 11(5): 387-396.

36. Bowler, I. M. W. (1993). "Stereotypes of women of Asian descent in midwifery: some evidence". Midwifery.9(1):7-16.

37. Box V. (1998), Cervical screening: the knowledge and opinions of black and minority ethnic women and of health advocates in East London. Health Education Journal. 57(3): 3-15.

38. Brach, C., Fraser, I. (2000). "Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model." Medical Care Research and Review 57 Suppl 1: 181-217.

39. Brenner, B. (2002). "Implementing a community intervention program for health promotion." Soc Work Health Care 35(1-2): 359-75.

40. Brett, J. A. H., J. Boender, C. Morin, C. Marshall, J. A. (2002). "Using ethnography to improve intervention design." Am J Health Promot 16(6): 331-40.

41. Brooks, -. N. M., -P; Bhatti,-G; Briggs,-C; Buckley,-S (2000). "Asian patients' perspective on the communication facilities provided in a large inner city hospital." Journal of Clinical Nursing **9**(5): 706-712.

42. Brotman, S. (2003). "The limits of multiculturalism in elder care services." Journal of Aging Studies 17(2): 209-229.

43. Brown, C., Abe-Kim, J.S., Barrio, C. (2003). "Depression in Ethnically Diverse Women: Implications for Treatment in Primary Care Settings." Professional Psychology: Research and Practice 34(1): 10-19.

44. Brune, M., Haasen, C., Krausz, M., Yagdiran, O., Bustos, E., Eisenman, D. (2002). "`Belief systems as coping factors for traumatized refugees: A pilot study." European-Psychiatry 17(8): 451-458.

45. Brunton, M., Thomas, D. R. (2002). "Privacy or life: how do women find out about screening mammography services?" N Z Med J 115(1161): U168.

46. Bulma, K. H. and McCourt, C. (2002). "Somali refugee women's experiences of maternity care in west London: A case study". Critical Public Health 12; (4) : 365 - 380.

47. Burleson, B. R. (2003). "The experience and effects of emotional support: What the study of cultural and gender differences can tell us about close relationships, emotion, and interpersonal communication." Personal Relationships 10(1): 1-23.

48. Burman, E., Gowrisunkur, J., Walker, K. (2003). "Sanjhe Rang/Shared colours, shared lives: a multicultural approach to mental health practice." Journal of Social Work Practice 17(1): 63-76.

49. Bynum, A. B., Cranford, C. O., Irwin, C. A., Denny, G. S. (2002). "Participant satisfaction with a school telehealth education program using interactive compressed video delivery methods in rural Arkansas." J Sch Health 72(6): 235-42.

50. Calderon-Rosado, V., Morrill, A., Chang, B.-H., and Tennstedt, S. (2002). "Service utilization among disabled Puerto Rican elders and their caregivers: Does acculturation play a role?" Journal of Aging & Health 14; (1) : 3 - 23.

51. Callender CO, Hall MB, Branch D (2001) "An assessment of the effectiveness of the Mottep model for increasing donation rates and preventing the need for transplantation - adult findings: program years 1998 and 1999." Seminars in Nephrology 21,4 :419-28

52. Campbell Collaboration (2005). http://www.campbellcollaboration.org/FraAbout.html (accessed 3/10/05)

53. Cameron E., Badger F. and Evers H. (1989). District nursing, the disabled and the elderly: who are the black patients? *J Adv Nurs*. 14(5): 376-82.

54. Campanelli, R. M. (2003). "Addressing racial and ethnic health disparities." American Journal of Public Health 93(10): 1624-1626.

55. Campbell, J. L., Ramsay, J., and Green, J. (2001). "Age, gender, socioeconomic, and ethnic differences in patients' assessments of primary health care". Quality in Health Care. 10; (2) : 90 - 95.

56. Carlisle D (1995) "Life-Giving Fatwa" Nursing Times 91,29 :14-15

57. Carrasquillo O., Orav E.J., Brennan T.A., Burstin H.R. (1999). Impact of language barriers on patient satisfaction in an emergency department. *J Gen Intern Med*. 14(2): 82-7.

58. Cauce, A. M., Domenech-Rodriguez, M., Paradise, M., Cochran, B., ,Shea, J. Munyi,Srebnik, Debra Baydar, Nazli (2002). "Cultural and Contextual Influences in Mental Health Help Seeking: A Focus on Ethnic Minority Youth." Journal of Consulting and Clinical Psychology 70(1): 44-55.

59. Chamba R. and Ahmad W.I.U. (2000). Language, communication and information: the needs of parents caring for a severely disabled child. In Ahmad W.I.U. (ed.). *Ethnicity, Disability and Chronic Illness*. Buckingham: Open University.

60. Chase-Ziolek, M. (1999). "The meaning and experience of health ministry within the culture of a congregation with a parish nurse." Journal of Transcultural Nursing 10(1): 46-55.

61. Chen, M. S., Jr. (1999). "Informal care and the empowerment of minority communities: comparisons between the USA and the UK." Ethnic Health 4(3): 139-51.

62. Chevannes, M. (2002). "Issues in educating health professionals to meet the diverse needs of patients and other service users from ethnic minority groups." J Adv Nurs 39(3): 290-8.

63. Chow, T. W., Ross, L., Fox, P., Cummings, J. L., and Lin, K. M. (2000). "Utilization of Alzheimer's disease community resources by Asian-Americans in California". International Journal of Geriatric Psychiatry. 15; (9) : 838 - 847.

64. Chui, L. (1991). "Advocacy; the Leeds experience", Community Dental Health., vol. 8, pp. 253-256.

65. Cioffi, R. N. (2003). "Communicating with culturally and linguistically diverse patients in an acute care setting: nurses' experiences". Int.J.Nurs.Stud. 40; (3) : 299 - 306.

66. Clough, A. (2002). "Community care policy and end-of-life care: one patient's story." Br J Community Nurs 7(3): 153-7.

67. Cohen S., Moran-Ellis J. and Smaje C. (1999). Children as informal interpreters in GP consultations: pragmatics and ideology. *Sociology of Health & Illness*. 21(2): 163 - 186.

68. Coker, -. N. (2001). Racism in medicine: an agenda for change. London, King's Fund Publishing**:** 241.

69. Comas-Diaz, L. (2003). "Cultural Competency: A Practical Guide for Mental Health Service Providers." Journal-of-Nervous-and-Mental-Disease 191(8): 556.

70. Commission for Health Improvement. (2002). Brent, Kensington, Chelsea & Westminster Mental Health NHS Trust: Clinical Governance Review Report -Executive summary. August 2002. http://www.chi.nhs.uk/eng/organisations/london/brent/2002/exec_sum.shtml

71. Comstock RD, Castillo EM, Lindsay SP (2004) 'Four year review of the use of race and ethnicity in epidemiologic and public health research' American Journal of Epidemiology 159,6 :611-619

72. Cone, D. C., Richardson, L. D., Todd, K. H.,Betancourt, J. R.,Lowe, R. A. (2003). "Health care disparities in emergency medicine." Academic Emergency Medicine 10(11): 1176-1183.

73. Conroy, S.P,.Mayberry, J.F. (2001). "Patient information booklets for Asian patients with ulcerative colitis." Public Health 115(6): 418-420.

74. Cooke, M., Margerison, C. (2003). NHS Direct –impact and effectiveness: available at: http://www.nelhec.warwick.ac.uk/ECL_Toolkit/source%20files/NHS%20Direct%20Rapid%20Review%20feb2003.pdf.

75. Cooper L.A, Roter D.L., Johnson R.L., Ford D.E., Steinwachs D.M. and Powe N.R. (2003). Patient-Centered Communication, Ratings of Care, and Concordance of Patient and Physician Race. *Annals of Internal Medicine*. 139: 907-915.

76. Cortis, J. D. (2000). "Perceptions and experiences with nursing care: a study of Pakistani (Urdu) communities in the United Kingdom". Journal of Transcultural Nursing.11(2):111-118.

77. Courtenay, W. H., McCreary, D.R. & Merighi, J.R.Courtne (2002). "Gender and ethnic differences in health beliefs and behaviors." Journal of Health Psychology 7(3): 219-231.

78. Cox, J. L. (1996). "Transcultural aspects of perinatal psychiatry." European Psychiatry 11(Supplement 4): 162s.

79. Culley, L. (2001). "Equal opportunities policies and nursing employment within the British National Health Service." J Adv Nurs 33(1): 130-7.

80. Daker-White, G., Beattie, A. M., Gilliard, J., and Means, R. (2002). "Minority ethnic groups in dementia care: a review of service needs, service provision and models of good practice". Aging Ment.Health 6; (2) : 101 - 108.

81. Davies, M. M., Bath, P. A. (2001). "The maternity information concerns of Somali women in the United Kingdom." J Adv Nurs 36(2): 237-45.

82. Davies, S. C., Cronin, E., Gill, M., Greengross, P., Hickman, M., & Normand, C. (2000). "Screening for sickle cell disease and thalassaemia: a systematic review with supplementary research.", Health Technol Assess, vol. 4, no. 3, pp. 1-150.

83. Department of Health (DoH)/Mental Health Policy & Performance. (2003). “Delivering Race Equality: A Framework for Action.” London: Department of Health.

84. Department for Transport (2003) - Public Transport Needs of Minority Ethnic and Faith Communities Guidance Pack Report by Social Research Associates (accessed online at www.info4local.gov.uk March 2004)

85. Derose K.P. and Baker D.W. (2000). Limited English proficiency and Latinos' use of physician services. *Med Care Res Rev*. 57(1): 76-91.)

86. Dignam, J. (1993). "Transcultural perspectives in nursing". Concept Media (4 videocassettes: sound, color, 0.5 inch) 2493 DuBridge Avenue, Irvine CA 92606-5022; Phone: (800) 233-7078; Fax: (949) 660-0206. (4 videocassettes: sound, color, 0.5 inch).

87. Drennan G. (1996). Counting the cost of language services in psychiatry. *S Afr Med J*. 86(4): 343-5.

88. Drewnowski, A. M., E. Birkett, D. Gunther, S. Vendeland, S. Su, J. Marshall, G. (2003). "Health Screening and Health Promotion Programs for the Elderly." Disease Management and Health Outcomes 11: 299-309.

89. DuBray, W. and Sanders, A. (1999). "Interactions between American Indian ethnicity and health care". Journal of Health & Social Policy. 10; (4) : 67 - 84.

90. Duff, L. A., Lamping, D. L., and Ahmed, L. B. (2001). "Evaluating satisfaction with maternity care in women from minority ethnic communities: development and validation of a Sylheti questionnaire". International Journal for Quality in Health Care. 13; (3) : 215 - 230.

91. Dundas, R. M., Morgan, M., Redfern, J., Lemic-Stojcevic, N.,Wolfe, C. (2001). "Ethnic differences in behavioural risk factors for stroke: implications for health promotion." Ethn Health 6(2): 95-103.

92. Dwairy, M. (2002). "Foundations of psychosocial dynamic personality theory of collective people." Clinical Psychology Review 22(3): 343-360.

93. Emerson, J. (1995). "Intercultural communication between community health nurses and ethnic-minority clients". Ph. D. Thesis. George Mason University.

94. Emsley, R. A., Waterdrinker, A., Pienaar, W. P.,Hawkridge, S. M. (2000). "Cultural aspects of psychiatry." Primary Care Psychiatry 6(1): 29-32.

95. Enguidanos, E. R. and Rosen, P. (1997). "Language as a factor affecting follow-up compliance from the emergency department". J Emerg Med. 15(1): 9-12.

96. Erim, Y. S., W. (2002). Psychotherapy for minority patients. Cross cultural affairs in psychotherapy. Psychotherapeut(Berlin) 47(6): 336-446

97. Eshiett, M.U., Parry, E.H. (2003). "Migrants and health: a cultural dilemma." Clinical Medicine 33(3): 229-231.

98. Exley C, Sim J, Reid N, Jackson S, West N (1996) "Attitudes and beliefs within the Sikh community regarding organ donation: a pilot study." Social Science and Medicine 43,1 :23-28

99. Fagan M.J., Diaz J.A., Reinert S.E., Sciamanna C.N. and Fagan D.M. (2003). Impact of interpretation method on clinic visit length. *J Gen Intern Med*. 18(8): 634-8.

100. Farooqi, A., Nagra, D., Edgar, T., and Khunti, K. (2000). "Attitudes to lifestyle risk factors for coronary heart disease amongst South Asians in Leicester: a focus group study". Family Practice. 17; (4) : 293 - 297.

101. Ferguson, W. J. and Candib, L. M. (2002). "Culture, language, and the doctor-patient relationship". Fam. Med. 34 (5): 353 - 361.

102. Fischer, A. R., Jome, L. M., Atkinson,D. R. (1998). "Reconceptualizing multicultural counseling: Universal healing conditions in a culturally specific context." Counseling-Psychologist 26(4): 525-588.

103. Forster A, Young J (1996) 'Specialist nurse support for patients with stroke in the community: a randomised controlled trial' British Medical Journal 312 :1642-1646

104. Frank, N. C., Kendall, S.J. (2001). "Religion, risk prevention and health promotion in adolescents: a community-based approach." Mental Health, Religion & Culture 4(2): 133 - 148.

105. Free, C., White, P., Shipman, C., and Dale, J. (1999). "Access to and use of out-of-hours services by members of Vietnamese community groups in South London: a focus group study". Family Practice. 16; (4) : 369 - 374.

106. Fried, O. (2000). "Providing palliative care for Aboriginal patients". Australian Family Physician. 29 (11) : 1035 - 1038.

107. Friedman, E. (2003). "Minority report." Hosp Health Netw 77(8): 40-2, 51.

108. Fuller J. (1995). Challenging old notions of professionalism: how can nurses work with paraprofessional ethnic health workers? *J Adv Nurs*. 22(3): 465-72.

109. Gabbe, S. G., Mueller-Heubach, E., Blechner, J. N., Pearse, W. H., Depp, R., Creasy, R. K. (1998). "A blueprint for academic obstetrics and gynecology." Obstet Gynecol 92(6): 1033-7.

110. Gallant, M. P. D., G. P. (2001). "Gender and race differences in the predictors of daily health practices among older adults." Health Educ Res 16(1): 21-31.

111. Garrett, C. R., Treichel, C. J., and Ohmans, P. (1998). "Barriers to health care for immigrants and nonimmigrants: a comparative study". Minnesota Medicine. 81 (4) : 52 - 55.

112. Gentry D, LaVert T (2003) Meeting the Challenges of Organ Donation and Transplantation. *Ethnicity and Renal Failure: Disparity or Diversity* London: South West Thames Institute for Renal Research and Renal and Transplantation Unit (National Symposium report, British Library, London, 9 May 2003) :12-13

113. Georgiou M., Silverstone, R. (2001). Diasporic Minorities and their Media in the EU: a Mapping. Available at EMTEL II Research: http://www.lse.ac.uk/collections/EMTEL/Minorities/project_home.html.

114. Georgiou, M. (2001). Mapping minorities and their Media: The National Context – The UK. Working paper available at: http://www.lse.ac.uk/collections/EMTEL/Minorities/papers/ukreport.doc.

115. Gergen, Kenneth J (1997). The place of the psyche in a constructed world. Theory & Psychology 7/6: 723-746.

116. Gergen, Kenneth J. (1985). The social constructivist movement in modern psychology. American Psychologist 40: 266-275.

117. Gerrish K, (2000). Researching ethnic diversity in the British NHS: methodological and practical concerns. J Adv Nurs. Apr;31(4):918-25.

118. Gerrish, K. (2001). "The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers". Journal of Advanced Nursing 33, 5: 566-74.

119. Glasby, J., Lester, H., Briscoe, J., Clark, M., Rose, S., England, L. (2003). Cases for Change A Review of the Foundations of Mental Health Policy & Practice 19976-2002. London, NIMHE.

120. Goldman, R., Hunt, M. K., Allen, J. D., Hauser, S., Emmons, K., Maeda, M., Sorensen, G. (2003). "The life history interview method: applications to intervention development". Health Education Behavior 30, 5: 564-81.

121. Grant, -. K.-J. H., -Arden; Kean,-Mary (2001). "The journey after the journey: Family counselling in the context of immigration and ethnic diversity." Canadian-Journal-of-Counselling 35(1): 89-100.

122. Gravely, S. (2001). "When your patient speaks Spanish -- and you don't". RN. 64(5):65-67.

123. Graz B., Vader J.P. and Raynault M.F. (2002). Refugees, migrants, language barrier: opinion of physicians on translation aids [Article in French]. *Sante Publique*. 14(1): 75-81.

124. Green, G., Bradby, H., Chan, A., Lee, M., and Eldridge, K. (2002). "Is the English National Health Service meeting the needs of mentally distressed Chinese women?" Journal of Health Services & Research Policy. 7; (4) : 216 - 221.

125. Greenfield, S. M., Anderson, P.,Gill, P. S., Loudon, R., Skelton, J., Ross, N., Parle, J. (2001). "Community voices: views on the training of future doctors in Birmingham, UK." Patient Educ Couns 45(1): 43-50

126. Greenwood, N., Hussain, F., Burns, T., Raphael, F. (2001). "Asian in-patient and carer views of mental health care. Asian views of mental health care." Journal of Mental Health 9(4): 397-408.

127. Griffiths, C. F., G. Barnes, N. Eldridge, S. Tate, H. Begum, S. Wiggins, M. Dawson, C. Livingstone, A. E. Chambers, M. Coats, T. Harris, R. Feder, G. S. (2004). "Specialist nurse intervention to reduce unscheduled asthma care in a deprived multiethnic area: the east London randomised controlled trial for high risk asthma (ELECTRA)." BMJ 328(7432): 144.

128. Guadagnoli E, McNamara P, Evanisko MJ, Beasley C, Callender CO, Poretsky A. (1999) The influence of Race on approaching families for organ donation. American Journal of Public Health 89,2 :244-247

129. Haour-Knipe, M. F., F. Dubois-Arber, F. (1999). "HIV/AIDS prevention for migrants and ethnic minorities: three phases of evaluation." Soc Sci Med 49(10): 1357-72.

130. Harper-Bulman, -. K. M., -Christine (2002). "Somali refugee women's experiences of maternity care in west London: a case study." Critical Public Health 12(4): 365-380.

131. Harris, R. J. (2002). "Is Milk Best for Infants and Toddlers?" Journal of Nutritional and Environmental Medicine 12(3): 145-152.

132. Harrison, A., Busabir, A.A., al-Kaabi, A. O., al-Awadi, H. K. (1996). "Does sharing a mother-tongue affect how closely patients and nurses agree when rating the patient's pain, worry and knowledge?" J Adv Nurs 24(2): 229-35.

133. Hatton, D. C. (1992). "Information transmission in bilingual, bicultural contexts". Journal of Community Health Nursing. 9(1):53-9.

134. Hawthorne, K., Rahman, J., Pill, R. (2003). "Working with Bangladeshi patients in Britain: Perspectives from primary health care." Family Practice 20(2): 185-191.

135. Hayes L. (1995). Unequal access to midwifery care: a continuing problem? *Journal of Advanced Nursing*. 21(4): 702-707.

136. Hayes-Bautista, D. E. (2003). "Research on culturally competent healthcare systems. Less sensitivity, more statistics." Am J Prev Med 24(3 Suppl): 8-9.

137. Heaney, C. and Moreham, S. (2002). "Use of interpreter services in a metropolitan healthcare system". Aust.Health Rev. 25(3) : 38 - 45.

138. Henley, -. A. S., -Judith (1999). Culture, religion and patient care in a multi-ethnic society: a handbook for professionals. London, Age Concern England.

139. Hornberger JC, Gibson CD Jr, Wood W, Dequeldre C, Corso I, Palla B, Bloch DA. (1996). Eliminating language barriers for non-English speaking patients. Med-Care. Aug; 34(8): 845-856.

140. Houston, A. M. and S. Cowley (2003). "Health needs assessment in the health visiting service and the impact on the ethnic community". International Journal of Nursing Studies 40,1: 85-94.

141. Howard, C. A., Andrade, S. J., and Byrd, T. (2001). "The ethical dimensions of cultural competence in border health care settings". Fam.Community Health. 23 (4) : 36 - 49.

142. Howell, S. R. B., A. G. Underwood, M. R. (2001). "The use of pre-conceptional folic acid as an indicator of uptake of a health message amongst white and Bangladeshi women in Tower Hamlets, east London." Fam Pract 18(3): 300-3.

143. Howitt R (2003) “Religious perspectives on organ donation.” UK Transplant Bulletin 43 :13-15

144. Hunt, M. K. S., A. M. Barbeau, E. Goldman, R. Wallace, L. Gutheil, C. Sorensen, G. (2003). "Cancer prevention for working class, multiethnic populations through small businesses: the healthy directions study." Cancer Causes Control 14(8): 749-60.

145. Husband, C. (2000). "Recognising diversity and developing skills: the proper role of transcultural communication." European Journal of Social Work 3(3): 225-234.

146. Hutchinson, G., Gilvarry, C. (1998). "Ethnicity and dissatisfaction with mental health services." British-Journal-of-Psychiatry 172(Jan): 95-96.

147. Hyyppa, M. T. and Maki J. (2003). "Social participation and health in a community rich in stock of social capital." Health Educ Res 18(6): 770-9.

148. Hyyppa, M. T. M., J. (2001). "Why do Swedish-speaking Finns have longer active life? An area for social capital research." Health Promot Int 16(1): 55-64.

149. Isaac, K. (2001). "What about linguistic diversity? A different look at multicultural health care." Communication Disorders Quarterly 22, 2: 110-113.

150. Ismail, A. I. (1998). "Prevention of early childhood caries." Community Dent Oral Epidemiol 26(1 Suppl): 49-61.

151. Jack, C. M., Penny, L., and Nazar, W. (2001). "Effective palliative care for minority ethnic groups: the role of a liaison worker". International Journal of Palliative Nursing. 7; (8) : 375 - 380.

152. Jackson M, Peters J (2003) 'Introducing touchscreens to black and ethnic minority groups - a report of processes and issues in the Three Cities project' Health Information and Libraries Journal 20 :143-149

153. Jacobs, E. A., Lauderdale, D. S., Meltzer, D., Shorey, J. M., Levinson, W., and Thisted, R. A. (2001). "Impact of interpreter services on delivery of health care to limited-English-proficient patients". Journal of General Internal Medicine. 16 (7) : 468 - 474.

154. James, S. A. (2003). "Confronting the moral economy of US racial/ethnic health disparities." American Journal of Public Health 93(2): 189-189.

155. Jandt, F. E., Tanno, D.V. (2001). "Decoding Domination, Encoding Self-Determination: Intercultural Communication Research Processes." Howard Journal of Communication 12(3): 119-135.

156. Jeffrey RF, Woodrow G, Mahler J, Johnson R, Newstead CG (2002) “Indo-Asian experience of renal transplantation in Yorkshire: results of a 10-year survey.” Transplantation 73(10):1652-7

157. Jeffreys, L. W. (2000). "Ethnicity and Ethnic Media Use: A Panel Study." Communication Research 27(4): 496-535.

158. Jewel, P. (2002). Multicultural counselling research: An evaluation with proposals for future research. Multicultural counselling: A reader. S. Palmer. housand Oaks, CA, Sage Publications, Inc.: 240-267.
159. Jirojwong, S. M., L. (2002). "Physical health and preventive health behaviors among Thai women in Brisbane, Australia." Health Care Women Int 23(2): 197-206.

160. John-Baptiste A., Naglie G., Tomlinson G., Alibhai S.M., Etchells E., Cheung A., Kapral M., Gold W.L., Abrams H., Bacchus M., and Krahn M. (2004). The Effect of English Language Proficiency on Length of Stay and In-hospital Mortality. *J Gen Intern Med*. 19(3): 221-8.

161. Johnson, C. S. and Garcia, A. C. (2003). "Dietary and activity profiles of selected immigrant older adults in Canada." J Nutr Elder 23(1): 23-39.

162. Johnson, M., Noble, C., Matthews, C., and Aguilar, N. (1998). "Towards culturally competent health care: language use of bilingual staff". Aust.Health Rev. 21 (3) : 49 - 66.

163. Johnson MRD. (1996). Ethnic Minorities, Health & Communication. Coventry, Centre for Research in Ethnic Relations**:** 33.

164. Johnson MRD (1999) 'Communication in health care: a review of some key issues' Nursing Times Research 4,1 :18-30

165. Johnson MRD, Clark MD, Owens D, Szczepura A (1999). The Unavoidable Costs of Ethnicity: A review of evidence on health costs. Centre for Health Services Studies, University of Warwick, Coventry, UK. June 1999. ISBN 0953 5430 05.

166. Johnson MRD, Owen D, Blackburn C, Rehman H, Nazroo J (2000). *Black and Minority Ethnic Groups in England:* The second health & lifestyles survey London: Health Education Authority

167. Jones D. and Gill P. (1998). Breaking down language barriers: The NHS needs to provide accessible interpreting services for all. *BMJ*. 316:1476-1480.

168. Jones, K. (2004) Mission Drift in Qualitative Research, or Moving Toward a Systematic Review of Qualitative Studies, Moving Back to a More Systematic Narrative Review. The Qualitative Report Volume 9 Number 1 March 2004 95-112. Available at: http://www.nova.edu/ssss/QR/QR9-1/jones.pdf

169. Jones, R. (2002). Evaluation of NHS Direct Kiosks. Seminar archive, University of Plymouth.

170. Abstract available at: http://www.plym.ac.uk/assets/HSC/abstract%202002%20-%20Jan%2016%20evaluation%20of%20NHS%20Direct%20kiosks.pdf.

171. Kai, J., Spencer, J., Wilkes, M., Gill, P. (1999). "Learning to value ethnic diversity: what, why and how?" Medical Education 33(8): 616-623.

172. Kakai H, Maskarinec G, Shumay DM, Tatsamura Y, Tasaki K (2003) Ethnic differences in choices of health information by cancer patients using complementary and alternative medicine: An exploratory study using correspondance analysis. Social Science and Medicine 56,4 :851-862

173. Kalister, H., Newman, Robert D., Read, Laura, Walters, Cyndy, Hrachovec, Jennifer, Graham, Elinor A. (1999). "Pharmacy-Based Evaluation and Treatment of Minor Illnesses in a Culturally Diverse Pediatric Clinic." Arch Pediatr Adolesc Med 153: 731-735.

174. Kar, S. B., Pascual, C. A., Chickering, K. L. (1999). "Empowerment of women for health promotion: a meta-analysis". Social Science & Medicine 49, 11: 1431-60.

175. Karliner L.S., Perez-Stable E.J., and Gildengorin G. (2004). The language divide. The importance of training in the use of interpreters for outpatient practice. *J Gen Intern Med*. 19(2): 175-83.

176. Katbamna, Katbamna S, Baker R, Ahmad W, Bhakta P, Parker G. (2001). "Development of guidelines to facilitate improved support of South Asian carers by primary health care teams." Quality in Health Care 10(3): 1166-172.

177. Katbamna, S., Bhakta, P., Ahmad, W., Baker, R., and Parker, G. (2002). "Supporting South Asian carers and those they care for: the role of the primary health care team". British Journal of General Practice. 52; (477) : 300 - 305.

178. Kennedy, J., Seymour, D. J., and Hummel, B. J. (1999). "A comprehensive refugee health screening program". Public Health Reports. 114 (5) : 469 - 477.

179. Khan, FA, Warnakulasuriya KA, Newton J T, Gelbier S, Gibbons DE. (2000). "Predictors of tobacco and alcohol consumption and their relevance to oral cancer control amongst people from minority ethnic communities in the South Thames health region, England." J Oral Pathol Med 29(5): 214-9.

180. Khanchandani, RGS. (1999). "The ethnic minority linkworker: a key member of the primary health care team?" Br J Gen Pract 49(449): 993-4.

181. Kim MJ, Cho HI, Cheon-Klessig YS, Gerace LM, Camilleri DD. (2002). "Primary health care for Korean immigrants: sustaining a culturally sensitive model". Public Health Nursing. 19 (3) : 191 - 200.

182. King, S. and Murray, K. (1996) ‘Family and Working Lives Survey: preliminary results’, Labour Market Trends, March 1996, pp. 115-119.

183. Kirmayer, L. J., Groleau, D., Guzder, J., Blake, C., and Jarvis, E. (2003). "Cultural consultation: a model of mental health service for multicultural societies". Canadian Journal of Psychiatry - Revue Canadienne de Psychiatrie. 48 (3) : 145 - 153.

184. Kirsty S (1998) “Toward understanding Vietnamese attitudes, beliefs and practices regarding blood donation.” Social Sciences in Health 4,3 :154-162

185. Kleinman, A. (1978). "Clinical relevance of anthropological and cross-cultural research: concepts and strategies." Am J Psychiatry 135(4): 427-31.

186. Kleinman, A. (1987). "Anthropology and psychiatry. The role of culture in cross-cultural research on illness." Br J Psychiatry 151: 447-54.

187. Kleinman, A. (1991). "Suffering and its professional transformation: toward an ethnography of interpersonal experience." Cult Med Psychiatry 15(3): 275-301.

188. Kleinman, A. (1998). “Rethinking Psychiatry: From cultural category to personal experience.” New York: Free Press.

189. Knowles, E., O'Cathain, A., Morrell, J., Munro, J. F., and Nicholl, J. P. (2002). "NHS Direct and nurses--opportunity or monotony?" International Journal of Nursing Studies. 39; (8) : 857 - 866.

190. Kodjo, C., Auinger, P. (2003). "Racial/ethnic differences in emotionally distressed adolescents receiving mental health care." Journal of Adolescent Health 32(2): 132-133.

191. Koff, M. D. and McGowan, J. J. (1999). "MedSpanish: a language tool for the emergency department". Proceedings / AMIA Annual Symposium. 565 - 569.

192. Kramsch, C. (2002). "In search of the intercultural Review of Fred E. Jandt. Intercultural Communication: An Introduction. 3rd edition.; Young Yun Kim. Becoming Intercultural: An Integrative Theory of Communication and Cross-Cultural Adaptation.; Tony Schirato and Susan Yell. Communication and Culture: An Introduction.; Ron Scollon and Suzanne Wong Scollon. Intercultural Communication: A Discourse Approach. 2nd edition." Journal of Sociolinguistics 6(2): 275-285.

193. Kravitz R.L., Helms L.J., Azari R., Antonius D., and Melnikow J. (2000). Comparing the use of physician time and health care resources among patients speaking English, Spanish, and Russian. *Med Care*. 38(7): 728-38.

194. Kwan, S. Y. (2000). "Transcultural oral health care: 2. Developing transcultural oral health promotional materials." Dent Update **27**(7): 346-8.

195. Kwan, S. Y. and Williams, S. A. . (1998). "Attitudes of Chinese people toward obtaining dental care in the UK". British Dental Journal. 185; (4) : 188 - 191.

196. Labun, E. (1999). "Shared brokering: the development of a nurse-interpreter partnership". Journal of Immigrant Health.1(4):215-22.

197. Lam, A.G., Sue, S. (2001). "Client diversity." Psychotherapy:-Theory,-Research,-Practice,-Training 38(4): 479-486.

198. Lamb, G., Anfield, A., Sheeran, A. (2002). "Access to a child mental health service: A comparison of Bangladeshi and non-Bangladeshi families." Psychiatric-Bulletin 26(1): 15-18.

199. Larcher, V. F., Bourne, J., Aitken, C., Jeffries, D., Hodes, D., Sloan, D., Ramsay, M., Goldberg, D., and Bramley, C. .(2001). "Overcoming barriers to hepatitis B immunisation by a dedicated hepatitis B immunisation service". Archives of Disease in Childhood 84; (2) : 114 - 119.

200. Law, J. (2000). Factors affecting language development in West African children: a pilot study using a qualitative methodology. Child: Care, Health and Development 26, 4: 289-308.

201. Lawrenson, R., Leydon, G., Freeman, G., Fuller, J., Ballard, J., and Ineichen, B. (1998). "Are we providing for ethnic diversity in accident & emergency (A&E) departments?" Ethnicity & Health. 3; (1-2) : 117 - 123.

202. Lee S.J., Back A.L., Block S.D. and Stewart S.K. (2002). Enhancing Physician-Patient Communication. *Hematology*. 1: 464-83.

203. Leininger, M. (1984). "Transcultural nursing: an overview." Nurs Outlook (2): 72-3.

204. Leininger, M. (1997). "Overview of the theory of culture care with the ethnonursing research method." J Transcult Nurs (2): 32-52.

205. Leman, P. (1997). "Interpreter use in an inner city accident and emergency department", J.Accid.Emerg.Med., vol. 14:98-100, pp. 98-100.

206. Leman P. and Williams D.J. (1999). “Questionnaire survey of interpreter use in accident and emergency departments in the UK.” J Accid Emerg Med. 16(4): 271-4.

207. Lévy, Pierre (2003). The evolution of the concept of knowledge in the computer age. Presented in Venice, 07-03-1997. Available at: . http://www.siliconyogi.com/andreas/2003/doc/2003-1454.htm

208. Li, P. L., Logan, S., Yee, L., and Ng, S. (1999). "Barriers to meeting the mental health needs of the Chinese community". Journal of Public Health Medicine. 21; (1) : 74 - 80.

209. Lodge, N. (2001). "The identified needs of ethnic minority groups with cancer within the community: a review of the literature." European Journal of Cancer Care *(England)* 10(4): 234-44.

210. Lowenthal, K.-M., Cinnirella M. (1999). "Beliefs About the Efficacy of Religious, Medical and Psychotherapeutic Interventions for Depression and Schizophrenia among Women from Different Cultural-Religious Groups in Great Britian." Transcultural Psychiatry 36(4): 491-504.

211. Maas, W. (2000). "Early detection of speech and language delays in the Netherlands. The case for integrating primary and secondary prevention." Child Care Health and Development 26, 2: 150-162.

212. Madhok, R., Hameed, A., and Bhopal, R. (1998). "Satisfaction with health services among the Pakistani population in Middlesbrough, England". Journal of Public Health Medicine. 20; (3) : 295 - 301.

213. Maltby, H. J. (1999). "Interpreters: a double-edged sword in nursing practice". Journal of Transcultural Nursing. 10(3): 248-54.

214. Mander, G. (2003). "The Women's Therapy Centre Language Project: Evaluation." British-Journal-of-Psychotherapy 20(1): 97-102.

215. Mandl KD, Feit S, Pena BM, Kohane IS 2000 'Growth and determinants of access in patient e-mail and Internet use' Archives Pediatric Adolescent Medicine 154,5 :508-511

216. Mansell, D. H., J. (1998). ""We picked the wrong one to sterilise": the role of nursing in the eugenics movement in Alberta, 1920-1940." Int Hist Nurs J 3(4): 4-11.

217. Marshall, J., Atkinson, J., Thacker, A., and Woll, B. (2003). "Is speech and language therapy meeting the needs of language minorities? The case of deaf people with neurological impairments". International Journal of Language & Communication Disorders. 38; (1) : 85 - 94.

218. Martin, J., Nakayama, T (1999). "Thinking dialectically about culture and communication." Communication Theory (1): 1-25.

219. Marwaha, S., Livingston, G. (2002). "Stigma, racism or choice. Why do depressed ethnic elders avoid psychiatrists?" Journal of Affective Disorders 72(3): 257-265.

220. Maskarinec, G. S., D. M. Kakai, H. Gotay, C. C. (2000). "Ethnic differences in complementary and alternative medicine use among cancer patients." J Altern Complement Med 6(6): 531-8.

221. Matthews, C., Johnson, M., Noble, C., and Klinken, A. (2000). "Bilingual health communicators: role delineation issues". Aust.Health Rev. 23 (3):104 - 112.

222. Mays, V. M., Ponce, N. A.,Washington, D. L.,Cochran, S. D. (2003). "Classification of race and ethnicity: Implications for public health." Annual Review of Public Health 24: 83-110.

223. McNamara, B., Martin, K., Waddell, C., and Yuen, K. (1997). "Palliative care in a multicultural society: perceptions of health care professionals". Palliat.Med. 11 (5) : 359 - 367.

224. Merleau-Ponty M. (1964). The Primacy of Perception (J. Edie, Translation) Evanston IL: North Western University Press.

225. Middleton, J. (1998). "Crime is a public health problem." Med Confl Surviv 14(1): 24-8.

226. Mihalopoulos, C., Pivkis, J., Dunt, D., and Naccarella, L. (1999). "Shared mental health care and people of non-English-speaking backgrounds: A qualitative study of key informants' views". Primary Care Psychiatry. 5 (1) : 19 - 24.

227. Miller C, Lewis D (1999) Wayfinding: Guidance for HealthCare Facilities. London: Stationery Office

228. Minnis, H., Kelly, E., Bradby, H., Oglethorpe, R., Raine, W., and Cockburn, B. (2003). "Cultural and language mismatch: Clinical complications". Clinical Child Psychology and Psychiatry 8; (2) : 179 - 186.

229. Mir, -. G. N., -Andrew; Ahmad,-Waqar; Jones,-Lesley. Learning difficulties and ethnicity: report to the Department of Health. London, Department of Health.

230. Mir, G. and Tovey, P. "Cultural competency: professional action and South Asian carers". (2002). Journal of Management in Medicine. 16; (1) : 7 - 19.

231. Mitchell AA, Sedlacek WE (1996). "Ethnically sensitive messengers." Journal National Medical Association 88,6 :349-352

232. Mitchell P, Jones B (2002) Patient Profiling in Primary Care: Report to Liverpool PCT Liverpool: Primary Care Trust

233. Mitchell, P. M., A. Small, D. (1998). "Bilingual professionals in community mental health services." Aust N Z J Psychiatry 32(3): 424-33.

234. Modell, M., Wonke, B., Anionwu, E., Khan, M., Tai, S. S., Lloyd, M., and Modell, B. (1998). "A multidisciplinary approach for improving services in primary care: randomised controlled trial of screening for haemoglobin disorders". *[comment]* BMJ. 317; (7161) : 788 - 791.

235. Modood T, Berthoud R, Lakey J, Nazroo J, Smith P, Virdee S, Beishon S. (1997) Ethnic Minorities in Britain: Diversity and Disadvantage London: Policy Studies Institute

236. Mogudi-Carter, M. (2001). "Challenges experienced by a therapist working with multicultural families: Case studies." International Journal for the Advancement of Counselling 23(4): 237-243.

237. Morgan, C., Mallett, R., Hutchinson, G., Leff, J. (2004). "Negative pathways to psychiatric care and ethnicity: the bridge between social science and psychiatry." Social Science and Medicine 58(4): 739-752.

238. Murphy, J. L. G., J. N. Davidhizar, R. (1994). "Strategies for designing culturally relevant client education materials." J Healthc Educ Train 8(3): 8-12.

239. Murphy, K. and Clark, J. M. (1993). "Nurses' experiences of caring for ethnic-minority clients". Journal of Advanced Nursing. 18(3):442-50.

240. Myhill, J. (2003). "The native speaker, identity, and the authenticity hierarchy." Language Sciences 25(1): 77-97.

241. Narayan, M. C. (2001). "The national standards for culturally and linguistically appropriate services in health care". Care Manag.J. 3 (2) : 77 - 83.

242. Narayanasamy, A. (2002). "Transcultural nursing. The ACCESS model: a transcultural nursing practice framework". British Journal of Nursing. 11(9):643-50.

243. National Center for Cultural Competence (2003). "A Guide to Choosing and Adapting Culturally and Linguistically Competent Health Promotion Materials".. Georgetown

University Center for Child and Human Development University Center for Excellence in Developmental Disabilities. Available at: . http://gucchd.georgetown.edu/nccc/documents/Materials_Guide.pdf

244. Naylor, M. D. (2002). "Transitional care of older adults". Annu.Rev.Nurs.Res. 20:127-47.

245. Newman, J. (1998). "Managing cultural diversity: the art of communication". Radiologic Technology. 69(3):231-46, 249.

246. Ngo-Metzger, Q., Massagli, M. P., Clarridge, B. R., Manocchia, M., Davis, R. B., Iezzoni, L. I., and Phillips, R. S. (2003). "Linguistic and cultural barriers to care". J.Gen.Intern.Med. 18 (1): 44 - 52.

247. Nicoll S (1998). Patients & Visitors. Wayfinding Study Report London: Royal London Hospital

248. Ntshona MS. (1997). Are professional interpreters needed in the South African health care services. S-Afr-Med-J. Sep; 87(9): 1143.

249. Nwachuku, U., Ivey, A. E. (1992). "Teaching culture-specific counseling using microtraining technology." International-Journal-for-the-Advancement-of-Counselling 15(3): 151-161.

250. O'Loughlin, J. P., G. Kishchuk, N. Barnett, T. Renaud, L. (1999). "Prevalence and correlates of physical activity behaviors among elementary schoolchildren in multiethnic, low income, inner-city neighborhoods in Montreal, Canada." Ann Epidemiol 9(7): 397-407.

251. O'Loughlin, J., L. Renaud, et al. (1998). "Prevalence and correlates of early smoking among elementary schoolchildren in multiethnic, low-income inner-city neighborhoods." Ann Epidemiol 8(5): 308-18.

252. Parsons, L. & Day, S. (1992). "Improving obstetric outcomes in ethnic minorities: an evaluation of health advocacy in Hackney", Journal of Public Health Medicine., vol. 14, no. 2, pp. 183-191.

253. Patel, K., Winters, M., Bashford, J., Bingley, W. (2003). “Engaging and Changing Developing effective policy for the care and treatment of Black and minority ethnic detained patients.” National Institute for Mental Health in England (NIMHE) and University of Central Lancashire. London: Department of Health.

254. Patel, V., Sumathipala, A. (2001). "International representation in psychiatric literature. Survey of six leading journals." British-Journal-of-Psychiatry 178: 406-409.

255. Pennington S. (2001). Language matters. *Nursing Times*. 97(6): 28–29.

256. Pert, S., Stow, C. (2001). "Language remediation in mother tongue: a paediatric multilingual picture resource." International Journal of Language Communication Disorders 36 Suppl: 303-8.

257. Petersen, -. A. K., -Renata; Hansen,-Susan (2002). Consumerism and mental health care in a culturally diverse society. Consuming health: the commodification of health care. S. H. a. A. Petersen. London, Routledge**:** 121-139.

258. Pfeffer N. and Moynihan C. (1996). Ethnicity and health beliefs with respect to cancer: a critical review of methodology. *Br J Cancer*. Suppl.29: S66-72.

259. Pharoah C. (1995). *Primary Health Care for Elderly People from Black & Minority Ethnic Communities*. London: HMSO.

260. Phelan, M. & Parkman, S. (1995). "How to do it: Work with an interpreter", *BMJ.*, vol. 311, 26 Aug, 555-557.

261. Phul, A, Bath, P.A., Jackson, M. G. (2003). The provision of information by health promotion units to people of Asian origin living in the UK. Health Informatics Journal, 9, 1: 39-56.

262. Pierre, S. A. (2002). "Legal, social, cultural and political developments in mental health care in the UK: the Liverpool black mental health service users' perspective." Journal of Psychiatric Mental Health Nursing 9(1): 103-10.

263. Pollock, S. E. (1999). "Health-related hardiness with different ethnic populations." Holist Nurs Pract 13(3): 1-10.

264. Pope-Davis, D. B., Liu, W. M., Toporek, R. L., Brittan-Powell, C. S. (2001). "Fifteen Years of the Journal of Multicultural Counseling and Development: A Content Analysis." Journal of Multicultural Counseling and Development 29(4): 226-238.

265. Pope-Davis, D. B., Toporek, R. L., Ortega-Villalobos, L., Ligiero, D. P., Brittan-Powell, C. S., Liu, W. M., Bashshur, M. R., Codrington, J. N., Liang, C. T. H. (2002). "Client Perspectives of Multicultural Counseling Competence: A Qualitative Examination." Counseling Psychologist 30(3): 355-393.

266. Poss, J. & Rangel, R. (1995). "Working Effectively with Interpreters in the Primary Care Setting", Nurse Practitioner., vol. 20, no. 12, pp. 43-47.

267. Poss, J. E. (1999). "Providing culturally competent care: is there a role for health promoters?" Nurs Outlook 47(1): 30-6.

268. Powell B. (1999). *Improving Assessibility and information services for Asian communities, relating to cancer and palliative care*. Leicester: Cancer Care - Ethnic Minorities Group.

269. Presley F; Shaw A. (1995). Race and health: an information sources guide. SHARE, King's Fund Centre, London.

270. Public Health Sector Group (2000) Ethnicity Profiling in Primary Care: The Princes Park Health Centre Model Liverpool: Public Health Sector Group, School of Health & Human Sciences, Liverpool John Moores University

271. Rai-Atkins, A., Jama,A-A., Wright, N., Scott, V., Perring, C. (2002). Best practice in mental health: advocacy for African, Caribbean and South Asian Communities. Bristol, Published for the Joseph Rowntree Foundation by the Policy Press.

272. Randhawa G (1998). "An exploratory study examining the influence of religion on attitudes towards organ donation among the Asian population in Luton UK." Nephrology Dialysis Transplantation 13 :1949-1954

273. Randhawa, G., Owens, A., Fitches, R., and Khan, Z. (2003). "Communication in the development of culturally competent palliative care services in the UK: a case study". Int.J.Palliat.Nurs. 9; (1) : 24 - 31.

274. Ready AR (1998) "Transplanting an ethnic community: approaches to the crisis." Nephrol. Dial. Transplant 13 :2490-2493

275. Ready AR, Trafford J, Hooker A, Briggs D (1997). "Impact of a large non-indigenous population on the Renal Transplant waiting list." Transplantation proceedings 29 :3724-3725

276. Reppucci, N. D. W., J. L. Fried, C. S. (1999). "Social, community, and preventive interventions." Annu Rev Psychol 50: 387-418.

277. Research Services Limited Social Research (1995). Family and Working Lives: technical report, Harrow, RSL Social Research.

278. Riley, M. A. K. and Thelian, K. (1999). "Attachment impacts a culturally diverse population in the homecare setting". Journal of Intravenous Nursing.22(6):325-30.

279. Ring F, Jones M (2004) 'NHS Direct usage in a GP population of children under 5 years: is NHS Direct used by people with the greatest health need?' British Journal of General Practice 54 :211-213

280. Riordan, J., Gill-Hopple, K. (2001). "Breastfeeding care in multicultural populations." J Obstet Gynecol Neonatal Nurs 30(2): 216-23.

281. Risch, N., Karter, A. (2003). "Genetic and environmental influences on racial/ethnic health disparities." American Journal of Human Genetics 73(5): 1229.

282. Robinson L. (1998). *'Race', Communication and the Caring Professions*. Buckingham: Open University.

283. Robinson, M. (2002). Communication and Health in a Multi-Ethnic Society. Bristol, The Policy Press.

284. Robinson, M. and Gilmartin, J. (2002). "Barriers to communication between health practitioners and service users who are not fluent in English". Nurse Educ.Today. 22 (6): 457 - 65.

285. Robinson, R. (2002). Communication and health in a multi-ethnic society. Bristol, The Policy Press. [Review by Pamina Mitter Health Expectations Volume 6 Issue 1 Page 90 - March 2003]

286. Roderick P, Clements S, Diamond I, Storkey M, Raleigh VS (1998). "Estimating demand for renal replacement therapy in Greater London: the impact of demographic trends in ethnic minority populations." Health Trends 30,2 :46-50

287. Rothschild, S. K. (1998). "Cross-cultural issues in primary care medicine". Dis. Mon. 44; (7) : 293 - 319.

288. Rudat K, (1994) Black and Minority Ethnic Groups in England: Health & Lifestyles London: Health Education Authority

289. Rudd AG, Wolfe CDA, Tilling K, Beech R (1997) 'Randomised controlled trial to evaluate early discharge scheme for patients with stroke' British Medical Journal 315 :1039-1044

290. Ruelas, S. R., Atkinson, D. R., Ramos-Sanchez, L. (1998). "Counselor Helping Model, Participant Ethnicity and Acculturation Level, and Perceived Counselor Credibility*1." Journal of Counseling Psychology 45(1): 98-103.

291. Rybak, C.J., Leary, A., Marui, A. (2001). "The Resiliency Wheel: A training model for enhancing the effectiveness of cross-cultural interviews." International-Journal-for-the-Advancement-of-Counselling 23(1): 7-19.

292. Sadler, G. R. D., S. K. Shah, N. B. Shah, R. B. Ko, C. Anghel, M. Harshburger, R. (2001). "Asian Indian women: knowledge, attitudes and behaviors toward breast cancer early detection." Public Health Nurs 18(5): 357-63.

293. Sainsbury Centre for Mental Health (SCMH). (2002). "Breaking the Circles of Fear." London: Sainsbury Centre for Mental health (SCMH).

294. Salvendy, J. T. (1999). "Ethnocultural considerations in group psychotherapy". Int.J.Group Psychother. 49 (4) : 429 - 464.

295. Sanderson RJ, Ironside JAD (2002) 'Squamous cell carcinomas of the head and neck' British Medical Journal 325 :822-827

296. Sarver, J. and Baker D. W. (2000). "Effect of language barriers on follow-up appointments after an emergency department visit". J Gen Intern Med. 15(4): 256-64.

297. Sashidharan, S., National Institute for Mental Health (NIMHE). (2003). “Inside Outside Improving Mental Health Services for Black and Minority Ethnic Communities in England.” London: Department of Health.

298. Satcher, D. (1999). "A decade of many gains in Americans' health." Acad Med 74(7): 808-9.

299. Schaafsma, E. S. R., T. D. de Jong-van den Berg, L. T. (2003). "Accessing medication information by ethnic minorities: barriers and possible solutions". Pharmacy World Science 25, 5: 185-90.

300. Scragg, R. L., M. Robinson, E. (2003). "Parental smoking and related behaviours influence adolescent tobacco smoking: results from the 2001 New Zealand national survey of 4th form students." N Z Med J 116(1187): U707.

301. Semela, J.J. M. (2001). "Significance of cultural variables in assessment and therapy." Folia-Phoniatrica-et-Logopaedica. 53(3): 128-134.

302. Sensky T. (1996). Eliciting lay beliefs across cultures: principles and methodology. *Br J Cancer*. Suppl.29:S63-5.

303. Shapiro, J., Hollingshead, J., and Morrison, E. H. (2002). " Primary care resident, faculty, and patient views of barriers to cultural competence, and the skills needed to overcome them". Med.Educ. 36 (8): 749 - 759.

304. Shaw-Taylor, Y. (2002). "Culturally and linguistically appropriate health care for racial or ethnic minorities: analysis of the US Office of Minority Health's recommended standards". Health Policy. 62(2): 211 - 221.

305. Shaw-Taylor, Y. and Benesch, B. (1998). "Workforce diversity and cultural competence in healthcare". J.Cult.Divers. 5 (4):138 - 146.

306. Sheldon T, Chalmers I (1994). ‘The UK Cochrane Centre and the NHS Centre for Reviews and Dissemination: Respective Roles Within the Information Systems Strategy of the NHS R&D Programme, Coordination and Principles Underlying Collaboration’ Health Economics 3: 201-203.

307. Shetty, K. V. J., N. W. (1999). "Knowledge, attitudes and beliefs of adult South Asians living in London regarding risk factors and signs for oral cancer." Community Dent Health 16(4): 227-31.

308. Shipman, C. and Dale J. (1999). Responding to patients with particular needs. In Dale J., Hallam L., Salisbury C. (eds.). 24-hour primary care: choices and challenges. Oxford: Radcliffe Medical Press.

309. Shire, N. (2002). "Effects of race, ethnicity, gender, culture, literacy, and social marketing on public health". Journal of Gender Specific Medicin*e* 5, 2: 48-54.

310. Sleath, B., Rubin, R. H. (2002). "Gender, ethnicity, and physician-patient communication about depression and anxiety in primary care." Patient Educ Couns 48(3): 243-52.

311. Small, R., Rice, P. L., Yelland, J., and Lumley, J. (1999). "Mothers in a new country: The role of culture and communication in Vietnamese, Turkish and Filipino women's experiences of giving birth in Australia". Women & Health. 28 (3): 77 - 101.

312. Smart, H., Titterton, M., Clark, C. (2003). "A literature review of the health of gypsy/traveller families in Scotland: the challenges for health promotion". Health Education 103, 3: 156-165.

313. Smedley, B., Stith, A.,Nelson, A. (2003). Confronting racial and ethnic disparities in health care. Washington DC, National Academies Press.

314. Solomon, A. (1992). "Clinical diagnosis among diverse populations: A multicultural perspective." Families-in-Society 73(6): 371-377.

315. Somerville, J. (2001). "Palliative care: the experience of informal carers within the Bangladeshi community". International Journal of Palliative Nursing.7(5) : 240 - 247.

316. Sproston, K. A., Pitson, L. B., and Walker, E. (2001). "The use of primary care services by the Chinese population living in England: examining inequalities". Ethnicity & Health. 6; (3-4) : 189 - 196.

317. Stam, H. J. (2002), Introduction: Varieties of Social Constructionism and the Rituals of Critique. Theory & Psychology 12 (5): 5712-576. Available at : http://www.psych.ucalgary.ca/thpsyc/abstracts/abstracts_12.5/Stam.%20into.html

318. Stevens, G. (2003). "Academic representations of `race` and racism in psychology: Knowledge production, historical context and dialectics in transitional South Africa." International Journal of Intercultural Relations 27(2): 189-207.

319. Stewart, A. L. N.-S., A. Perez-Stable, E. J. Posner, S. F. Bindman, A. B. Pinderhughes, H. L. Washington, A. E. (1999). "Interpersonal Processes of Care in Diverse Populations." Milbank Quarterly 77(3): 305-340.

320. Stewart, J. A. D., R. Howard, R. S. Rudd, A. G. Wolfe, C. D. (1999). "Ethnic differences in incidence of stroke: prospective study with stroke register." BMJ 318(7189): 967-71.

321. Stolk, Y., Ziguras, S., Saunders, T., Garlick, R., Stuart, G., and Coffey, G. (1998). "Lowering the language barrier in an acute psychiatric setting". Aust.N.Z.J.Psychiatry. 32(3): 434 - 440.

322. Storkey, M. (2000) Using the schools' language data to estimate the total number of speaker of London's top 40 languages. In Baker P & Eversley J (Eds) Multilingual Capital – The languages of London schoolchildren and their relevance to economic, social and educational policies. London: Battlebridge.

323. Sue, S. (1988). "Psychotherapeutic services for ethnic minorities: Two decades of research findings." American-Psychologist 43(4): 301-308.

324. Szczepura A, Clark MD, Johnson MRD, Owen D (1999). Assessment of the costs to the NHS arising from the need for interpreter, advocacy and translation services. Centre for Health Services Studies, University of Warwick, Coventry. September 1999. ISSN 0964-7902.

325. Tabassum, R., Macaskill, A., and Ahmad, I. (2000). "Attitudes towards mental health in an urban Pakistani community in the United Kingdom". International Journal of Social Psychiatry 46; (3) : 170 - 181.

326. Tang, S. Y. (1999). "Interpreter services in healthcare. Policy recommendations for healthcare agencies". J.Nurs.Adm. 29(6) : 23 - 29.

327. Tervalon, M. (2003). "Components of culture in health for medical students' education." Academic Medicine 78(6): 570-576.

328. Thakker, J., Ward, T.,Strongman, K. T. (1999). "Mental disorder and cross-cultural psychology - Where did it come from and where should it go? II: Empirical studies, innovations and recommendations." Clinical Psychology Review 19(7): 843-874.

329. Thomas V, Richardson A, Saleem T, Baylav A, Hall A, Richards M, Gallagher C, Patel M, Ramirez A. (2000). "The efficacy of bilingual health advocacy in ethnic minority patients with cancer". Nurs Stand. 14(26): 32-3.

330. Timmins, C. L. (2002). "The impact of language barriers on the health care of Latinos in the United States: a review of the literature and guidelines for practice". J.Midwifery Womens Health. 47(2) : 80 - 96.

331. Tobin, M., Chen, L., Edwards, J. L., and Chan, S. (2000). "Improving the utilisation of bilingual counsellors within a public sector mental health service". Australian Health Review. 23(2):190 - 196.

332. Tocher T.M. and Larson E.B. (1999). Do physicians spend more time with non-English-speaking patients? *J Gen Intern Med*. 14(5): 303-9.

333. Tribe, R. (1999). "Bridging the gap or damming the flow? Some observations on using interpreters/bicultural workers when working with refugee clients, many of whom have been tortured". British Journal of Medical Psychology. 72 (Pt 4) : 567 - 576.

334. Tsianakas, -. V. L., -Pranee (2002). "What women from an Islamic background in Australia

335. U.S. Department of Commerce (2000) 'Falling Through the Net: Toward Digital Inclusion' http://www.ntia.doc.gov/ntiahome/fttn00/contents00.html

336. Ulrey, K. L., Amason, P. (2001). "Intercultural communication between patients and health care providers: An exploration of intercultural communication effectiveness, cultural sensitivity, stress, and anxiety." Health Communication 13(4).

337. US National Center for Cultural Competence. . http://www.omhrc.gov/omh/programs/2pgprograms/finalreport.pdf.

338. Valdiserri, R. O. H., D. R. West, G. R. (1999). "Promoting early HIV diagnosis and entry into care." Aids 13(17): 2317-30.

339. van der Wal, M. F. de Jonge., G. A. Pauw-Plomp, H. (1999). "[Ethnic origin and care giving styles relevant to cot death]." Ned Tijdschr Geneeskd 143(43): 2141-6.

340. van der Wal, M. F., de Jonge, G. A. et al. (2001). "[Increased percentages of breastfed infants in Amsterdam]." Ned Tijdschr Geneeskd 145(33): 1597-601.

341. van Wieringen, J. C. H., J. A. Bruijnzeels,. (2002). "Intercultural communication in general practice." Eur J Public Health 12(1): 63-8.

342. Verble M, Worth J (2003). “Cultural sensitivity in the donation discussion.” Progress in Transplantation 13(1):33-7

343. Vertinsky, P. (1998). ""Run, Jane, run": central tensions in the current debate about enhancing women's health through exercise." Women Health 27(4): 81-111.

344. Vonderheid, S. C. M., K. S. Norr, K. F. (2003). "Ethnicity and Prenatal Health Promotion Content." Western Journal of Nursing Research 25(4): 388-404.

345. Wai-Wan, M. (2001). "Ethnic culture, distress and clinical measurement: A CORE outcome comparison between the British Chinese and white Europeans." Journal-of-Mental-Health-UK 10(3): 301-315.

346. Walker, K. L., Chestnut, D. (2003). "The Role of Ethnocultural Variables in Response to Terrorism." Cultural Diversity and Ethnic Minority Psychology 9(3): 251-262.

347. Wan, M. W. (2001). "Ethnic culture, distress and clinical measurement: A CORE outcome comparison between the British Chinese and white Europeans." Journal of Mental Health 10(3): 301-316.

348. Wang, H. H. (1999). "Predictors of health promotion lifestyle among three ethnic groups of elderly rural women in Taiwan." Public Health Nurs 16(5): 321-8.

349. Watt, R. S., A. (1999). "Inequalities in oral health: a review of the evidence and recommendations for action." Br Dent J 187(1): 6-12.

350. Welsh Government (2003). Health information needs of ethnic minority groups Key findings from a literature review. Cardiff, Public Health Strategy Division, Office of the Chief Medical Officer**:** 8.

351. Whaley, A. L. (2003). "Ethnicity/race, ethics, and epidemiology." J Natl Med Assoc 95(8): 736-42.

352. Wilkinson, -. D. (2000). "Rethinking the concept of "minority": A task for social scientists and practitioners." Journal-of-Sociology-and-Social-Welfare 27(1): 115-132.

353. Wilkinson, J. M. T., P. V. (2003). "Health promotion in a changing world: Preparing for the genomics revolution." American Journal of Health Promotion 18(2): 157-161.

354. Wimmer, B. and Ipsiroglu, O. S. (2001). "Communication barriers in the management of immigrants and their children. An analysis and possible solutions based on case reports". [Article in German]. Wien.Klin.Wochenschr. 113 (15-16) : 616 - 621.

355. Winter, K. (1999). "Speech and language therapy provision for bilingual children: aspects of the current service." International Journal of Language Communication Disorders 34, 1: 85-98.

356. Wolfe, W. S. F., E. A. Cassano, P. A. (2001). "Evaluating brief measures of fruit and vegetable consumption frequency and variety: cognition, interpretation, and other measurement issues." J Am Diet Assoc 101(3): 311-8.

357. Wong, M. L. W., S. Pin, C. H. Gan, G. L. Ye, H. C. (1999). "Sociodemographic and lifestyle factors associated with constipation in an elderly Asian community." Am J Gastroenterol 94(5): 1283-91.

358. Woollett, A. and Dosanjh-Matwala, N. (1990). "Postnatal care: the attitudes and experiences of Asian women in east London". Midwifery.6 (4) : 178 - 184.

359. Yuen CC, Burton W, Chiraseveenuprapund P, Elmore E, Wong S, Ozuah P, Mulvihill M. (1998). “Attitudes and Beliefs about organ donation.” Journal National Medical Association 90,1 :13-18

360. Zambrana, R. E. (2001). "Improving access and quality for ethnic minority women--panel discussion: Intersections of institutional racism, socioeconomic status, language, and culture on women's health." Women's Health Issues 11(4): 354-359.

361. Zhu, S. H., Anderson, C. M., Johnson, C. E., Tedeschi, G., and Roeseler, A. (2000). "A centralised telephone service for tobacco cessation: the California experience". Tobacco Control. 9; Suppl - 55.

362. Ziguras, S., Klimidis, S., Lewis, J., and Stuart, G. (2003). "Ethnic matching of clients and clinicians and use of mental health services by ethnic minority clients". Psychiatr.Serv. 54(4): 535 - 541.

363. Zust, B. L. M., K. (2003). "Identifying underserved ethnic populations within a community: the first step in eliminating health care disparities among racial and ethnic minorities." J Transcult Nurs 14(1): 66-74.

6.2 Selected Websites and electronic resources identified during the search process

Academic

1. *Centre for Evidence in Ethnicity Health & Diversity - University of Warwick/DMU*
   http://ethnic-health.org.uk

2. *Research Centre for Transcultural Studies in Health, Middlesex University*
   http://www.mdx.ac.uk/www/rctsh/userguide.htm

Practitioner and User Oriented

3. *HARPWEB: (Health for Asylum Seekers and Refugees Portal)*
   www.harpweb.org.uk/index.php
   This also includes information for professionals, electronic copies of translated information leaflets and forms, and links to language support services and multi-lingual health information

4. *Language Line Interpreting Service*
   www.languageline.co.uk

5. *National Interpreting Service*
   NISUK.co.uk

Community-Based

6. *Guidelines for Health Care Providers Interacting with Patients of the Sikh Religion and Their Families*
   www.sikhwomen.com
   Approved by the Committee on Clinical, Administrative, Professional & Emergency Services - November 29, 2000; Metropolitan Chicago Healthcare Council

7. *Muslim Health Network (MHN) : Islamic Health and Lifestyle information website*
   www.muslimhealthnetwork.org

8. For African and African-Caribbean health staff
   www.africanhealthprofessional.com

National Health Service (UK)

9. NeLH - the National electronic Library for Health
   www.nelh.nhs.uk/

10. *NWPHO - North-West Public Health Observatory*
    www.ethnichealth-northwest.net/main.asp
    With the aid of a grant from the Department of Health this site has been developed by the North West Public Health Observatory to provide access to information on the health of minority ethnic communities in the North West of England and to facilitate the exchange of information between local groups working to improve ethnic health. The website aims to cover issues relating to all aspects of 'health' including related factors such as housing, employment and social support.

11. *LPHO - London Public Health Observatory*
www.lho.gov.uk
Also has many useful links, reports on health of Londoners and the Ethnic Health Information Project
www.lho.org.uk/hil/bme.htm

12. *Minority Ethnic Communities & Health*
www.minorityhealth.gov.uk/index.htm

Sources of Epidemiological Data

13. Gill P S, Kai J, Bhopal R S and Wild S
Health Care Needs Assessment: Black and Minority Ethnic Groups
http://hcna.radcliffe-online.com/bemgframe.htm

14. Department of Health 1999
Health Survey for England: The Health of Minority Ethnic Groups DoH:
www.doh.gov.uk/public/england/htm