

## DOCTOR OF PHILOSOPHY

### Designing for disability: Guidance for designers when working with users with Specific, Critical, Additional Needs (SCAN)

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# **Designing for disability: Guidance for designers when working with users with Specific, Critical, Additional Needs (SCAN) Volume 1**

**Wesley David Scott**

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**Designing for disability:**

**Guidance for designers when  
working with users with Specific,  
Critical, Additional Needs (SCAN)**

**Volume 1**

**By**

**Wesley David Scott**

**September 2018**



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When I first started my PhD in 2008, I had no idea quite what to expect. I certainly did not think I would have as many trials and difficult times as I have had. However, it has brought me many joyful occasions' as well as dark times. I had a strong support network that I have been able to rely on to both lift my spirits and help me practically. It is of course impossible to thank everybody by name, so forgive me if you are not mentioned here; you have my deepest gratitude and I will always be in your debt. Having said that, there are several people and organisations who I feel I must thank personally. Most importantly, I must firstly thank my mother, step-dad, brother and wider family, without whose love, support, wise counsel and ever sympathetic ears I would not be where I am today. They have felt my pain and joy throughout my research journey as well as before and beyond it. Many times they have been my first port of call in times of crisis and joy, any words I say cannot convey my gratitude towards them but I thank them for laying a solid foundation on which I have been able to build and they have always supported me with whatever decisions I have made. It has not been an easy journey but they have always done their best to ensure that I have had the support I have needed in every aspect of my life. To them I will always be eternally grateful.

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## Dedication

This thesis is dedicated to the memory of Alex William Coppin who was born on the 30<sup>th</sup> August 2002 and sadly died 19<sup>th</sup> September 2015, aged just 13 years. During Alex's short life, like all of us he experienced joy, happiness, sadness and pain. However, unlike the majority of the population he was unable, through no fault of his own, to conform to the norms of society. He had severe spastic quadriplegic cerebral palsy and as a result could not speak, walk, feed himself or complete day-to-day tasks independently. This is not to say he did not bring immense joy, happiness, love and value to all those who knew him and had the pleasure of meeting him. He taught us all many valuable lessons, not least the perspective and value of differently abled persons and what they have to offer society. His legacy provides a powerful message to society 'do not disregard me, my views, feelings, thoughts and aspirations simply because I cannot conform to your norms' instead 'embrace me and listen to what I have to say'. To truly honour Alex's message we must develop greater tolerance and understanding. The findings of this research demonstrate that these aims are achievable, often costing us very little in terms of time and resources. It is my sincere hope that this work goes at least some way to enable society to better understand the needs, wants and aspirations of people like Alex. May he rest in peace and be forever in our thoughts and hearts.

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### **Designing for disability: Guidance for designers when working with users with Specific, Critical, Additional Needs (SCAN)**

This study provides guidelines to help designers make reasoned methodological choices when working with those that have disabilities, in order to enable the effective interpretation of the views of these users and to ensure that these are taken into account in the design of products and services.

A new way of categorising such users led to a definition by the researcher of Specific, Critical, Additional Needs (SCAN). Individuals with SCAN have additional needs that have to be met in order to maintain their quality of life, health, safety and wellbeing but are additional to those of everyday critical needs.

Following an extensive review of models of disability and design, together with the legal and social contexts (including public attitudes to disability), as well as resources from the design and ergonomics communities and existing research methods available to designers when working with SCAN users, it was found that there were relatively few studies that examined the appropriateness of methods for understanding the requirements of these users in design and evaluation processes.

Through focus groups, advice was gathered from designers, some of whom were experienced in working collaboratively with disabled persons. Following this, several semi-structured interviews took place with a representative sample of SCAN users, carers, support workers, health and social care professionals and family members. Analysis of these interviews, backed by evidence from the literature, led to the creation of guidelines. The guidelines take account of best practice in designing from a user-centred viewpoint, and a number of tried and tested research methods are reviewed in detail.

The study also highlights the range of disabilities that should be considered by designers in shaping specifications for new products and services, and the need to treat users appropriately to ensure an accurate account is taken of their needs.

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### 1.1 Context of the research

There are over 13.3 million disabled people in the UK alone (FRS, 2017) with a projection of 19 million elderly people by 2050 (Parliament UK, 2010). It follows that for some years there has been a growing impetus for design to meet the needs of an ever aging and diverse population. Despite this, little attention has been given to the methods by which designers elicit requirements and feedback (Scott, Woodcock and McDonagh 2015:1). This is surprising, given that the UK has one of the more developed legal frameworks which protects the rights of people with disabilities<sup>1</sup> and standards which support user centred inclusive design (ISO/NP 9241-230; BS7000-6 2005). As a disabled person myself, I have experienced many failures in design. For example, the toilet in figure 1.1 is meant to be suitable for use by people with disabilities. However, there are a number of issues which make it difficult for its intended user group to use, these are:

- The entrance is too narrow for users with bigger wheelchairs to gain entry.
- The flush on the toilet is too high and out of reach for many of those with restricted mobility (in that it cannot be easily reached from a sitting position).
- The handrail obscures the sink so that users are restricted when washing their hands.
- The room is small and cramped and does not leave sufficient space for wheelchair users to position themselves so they can transfer directly onto the toilet.
- The majority of wheelchairs have high backrests so that it is difficult for users to reach to close the door independently.

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<sup>1</sup> The Disability Discrimination Act 1995, Special Educational Needs and Disability Act (SENDA) 2001, The Disability Discrimination Act 2005, The Equality Act 2010.

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancaster Library - Coventry University.

**Figure 1.1 An “accessible” toilet (photograph by W.D. Scott)**

I have also had first hand experience of the limited understanding and empathy of design students. For example, when I was presenting a lecture to some first year undergraduate students I explained how I found it difficult to access wheelchair spaces on buses, due to the large size of my wheelchair and the relatively small size of these spaces. In asking the group to think about how they could design bigger spaces for wheelchair users I was met with the response from one student “*Instead of us designing bigger spaces on public transport why don’t you get a smaller wheelchair.*” I explained to him the National Health Service (NHS) had assessed me and deemed that the wheelchair was clinically necessary. This seemed to make little impact. It appeared that he still saw it as a failure of me as a disabled person refusing to adapt rather than a failure of design.

Attitudes such as these and failures in design often lead to disabled people struggling to find truly accessible facilities that enable us to participate fully in society. Proponents of the Social model of disability (such as Oliver, 1996:22) contend that this is due to *“The disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.”* These social attitudes seem too often to lead to a built environment in which disabled persons are disadvantaged.

But why is this the case? Designers already have some very good resources such as:

- Inclusive Design Toolkit ([www.inclusivedesigntoolkit.com](http://www.inclusivedesigntoolkit.com))
- Designing with People.Org ([www.designingwithpeople.org](http://www.designingwithpeople.org))
- University of Cambridge Inclusive Design Website (<http://www3.eng.cam.ac.uk/inclusivedesign/index.php?section=data>)
- The Methods Lab-User Research for Design (<http://www.edean.org/pdf/Tool039.pdf>)

These resources are intended to facilitate inclusive design. However, they lack clear guidance in relation to the extent to which specific research methods are able to elicit user requirements and gather feedback from disabled persons. The very methods used by designers may present barriers to inclusive design. Therefore research is required in this area to enable designers to use appropriate methods in order to develop a more holistic understanding of the person.

Prior to commencing the PhD, I had completed a dissertation for my Bachelors degree in Computing that involved the use of research methods with disabled people, and I began to see that standard research methods were not easily accessible to those with special needs. This became even more apparent when I wanted to undertake a study for my Master’s degree examining two e-learning systems WebCT Vista (now known as Blackboard) and Moodle.

It was while preparing to undertake this study that I began to realise that it may be the methods themselves that were the problem. I was offered the opportunity to undertake a PhD study and this gave me the freedom I needed to conduct an in-depth study. Initially, I wanted to produce a toolkit of methods that could be used with persons that have additional needs. After further consideration the idea was refined and it was decided to produce guidelines to assist designers to make reasoned methodological choices when working with participants with Specific, Critical, Additional Needs (SCAN).

I have likened completion of my PhD to being on a journey with challenges. I have encountered many obstacles such as inadequate funding to meet my study support needs as a disabled person, and coupled with this I have had the constant feeling that much of what I propose is common sense and therefore not worthy of a PhD. However, I have come to two conclusions:

- 1) There is no central repository for this common sense guidance.
- 2) The findings of this research may be common sense to me, a wheelchair user of some 33 years, but it is not common knowledge to many in the design community. Therefore it was important that the guidelines to be produced were based on evidence taken from the literature and elicited directly from users.

Therefore six important tasks were undertaken as part of the study:

- 1) A rigorous review of research methods (Appendix D).
- 2) A review of relevant UK legislation (Chapter 2).
- 3) A review of current standards for inclusive design (Chapter 2).
- 4) A review of material already available to assist designers when designing for those who have additional needs (Chapter 2).

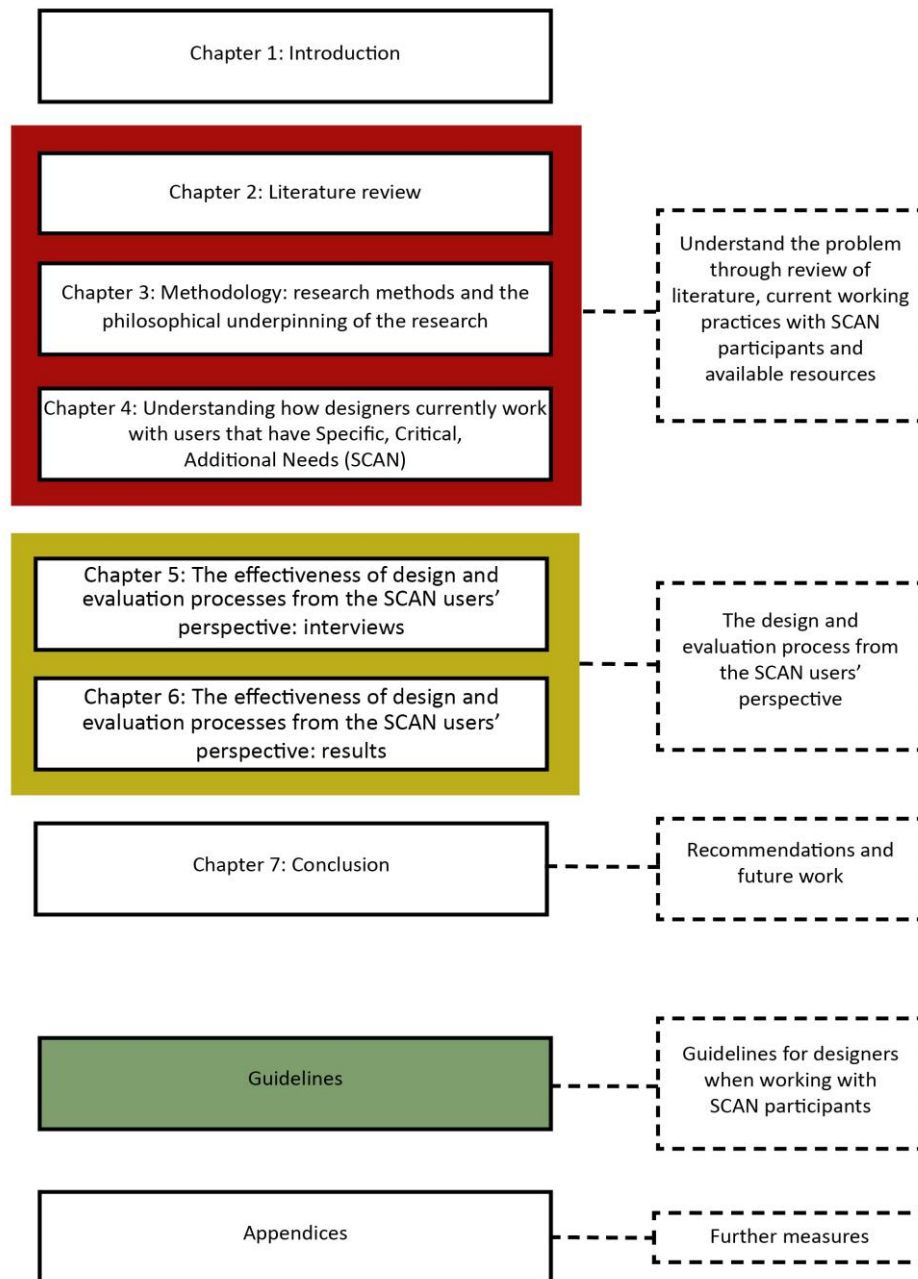
- 5) Focus groups with designers to understand how they work with users that have additional needs and any advice they would have on improving factors in this area (Chapter 4).
- 6) Interviews with SCAN users, their family members, support workers and related health and social care professionals to explore what advice they would give when working with those that have SCAN (Chapter 5).

SCAN users were divided into sub-groups based on their disability, for example: physical impairment; visual impairment; and hearing impairment. It proved impossible to recruit those with a learning disability.

A control group was also used to examine whether those without additional needs encountered the same or different problems when working with designers, and whether they would give similar or different advice to overcome such problems.

The responses were rigorously analysed in accordance with the methods documented in chapter 3, with the goal of determining the actual needs of SCAN users and the methods that could be used by designers to understand such needs. The guidelines that resulted from the analysis can be found in Appendix A.

**The thesis is structured as followed:**



**Figure 1.2 Thesis structure (adapted from Poo-Huat 2014:8)**

## 1.2 What is SCAN and why was it defined?

There are many ways of categorising disability. After careful consideration I felt that the terms used to describe users that have additional needs were not politically correct (and in some instances may be interpreted as degrading) for example: extra-ordinary users (Kroemer, 2006:1) users with additional needs (Macleod and Corlett 2005:131) and users with special needs (Peterson 2008:34). The spectrum of disability is so extensive, with some only being mildly affected whilst others will be completely reliant on support to live their daily lives. It was therefore decided to pinpoint what was unique about these users. After careful consideration, I determined that it was the additional critical needs of such users that made them unique. Therefore the term SCAN was developed which can be defined as individuals that have specific, critical needs (in relation to them, and these needs have to be met in order to maintain their quality of life, health, safety and wellbeing) but are additional to that of common everyday critical needs (needs we all have as human beings, for example, the need to sleep). An example of a Specific, Critical, Additional Need, is that of a person who is unable to feed themselves and thus needs assistance to eat (Scott, Woodcock and McDonagh *op.cit.*).

## 2. What are the aims and objectives of this research?

### **Aim:**

To produce guidelines to assist designers in the selection of the most appropriate methods to support user centred design at all stages of the process (as defined by ISO 9241-210:2010 (E)) when working with participants with SCAN, particularly to aid in:

- 1) **Understanding and specifying the context of use** i.e. use the appropriate methods that allow users to present and the designer to understand the context of use;

- 2) **Specifying the user requirements** i.e. use the appropriate methods that allow the user to specify their requirements and the designer to understand what is being specified;
- 3) **Producing design solutions to meet user requirements** i.e. use the appropriate method that enables both the user (where appropriate) and designer to create solutions to meet defined needs;

**Objectives:**

- 1) To investigate how SCAN users (including their carers) and other user groups are treated as part of design and evaluation processes;
- 2) To identify key themes and recommendations for designers that will form the basis of guidelines to assist in making reasoned methodological choices when working with SCAN participants, their carers and other user groups.
- 3) To produce guidelines that are based on direct evidence from users and that provide clear guidance for designers when working with SCAN users.

It is my sincere hope that this research has given those with a range of disabilities a means by which their voices can be heard and their needs articulated. I hope that the resulting analysis will help designers better understand the needs, wants and desires of disabled people so that they may design products and services that better meet these requirements. Of course, this is not the definitive work and it does not claim to be. It is simply a contribution to the field of design on behalf of those with disabilities and it is hoped that it will stimulate further work and discussion in this area.



## Chapter 2: Literature review

### 1. Introduction

A thorough literature search was undertaken of various aspects of design for disability in order to establish current practice, and to ascertain areas where improved guidance might be provided for designers.

The review was organised in sections dealing with various identifiable aspects of disability research pertinent to design and designers. It was recognised that there was a wide overlap between these sections. More detailed studies are listed in the appendices.

### 2. Scope of the review

This literature review attempts to outline the various models of disability and design, the legal and social contexts, and details the most prominent research methods available to designers working with SCAN users. An overview of methods appropriate to this study is provided here, and fully documented details of methods appropriate for user involvement are provided in Appendix D.

It is important to note that a clear definition of user involvement is difficult to find. It can be seen as a vague concept that covers several approaches, with the level of user involvement ranging from 'users as informants,' to 'users as designers,' to 'users as design managers'.

The literature search was international. Some aspects of disability studies such as legislative frameworks have focused more on UK legal requirements.

### 3. Terms

The terms used in this review are detailed in a glossary of terms used throughout the thesis, in Appendix E.

### 4. Legislation

In an increasing number of countries it is a legal requirement not to treat disabled persons less favourably (i.e. discriminate) than their able-bodied peers. In the UK, the Equality Act 2010 (Equality Act 2010) and its predecessors mandated that public facilities and shops needed to be “...*accessible and user friendly...*” which as a result would make these facilities “...*more suitable for people without mobility problems...*” for example, ramps assist mothers with push chairs (Swann, 2007:287, Bauer and Lane, 2006:68).

Worldwide, and at different times, various countries have implemented legal requirements to avoid discrimination against disabled people. It follows that some countries have more experience and are at a more advanced stage in terms of the sophistication of legislation and its practical implementation. Whilst it is recognised that many countries have now implemented such legislation, for the purposes of this review, the UK legislative framework is taken as a typical indicator of best practice.

The aim of the earlier Disability Discrimination Act (1995) states that it is:

*“Unlawful to discriminate against disabled persons and in connection with employment, the provision of goods, facilities and services of the disposal or management of premises: to make provision about the employment of disabled persons; and to establish a National Disability Council [8th November 1995].”*

This Act prohibits discrimination against disabled people in the following areas:

- Employment (Parts 2, Sections 4 and 5)
- Membership of trade organisations (Section 13)
- Discrimination in relation to goods, facilities and services (Section 19)
- Education (Section 29 of Part 4 of the DDA:1995)
- Premises (Section 19)
- Special Educational Needs and Disability Act (SENDA:2001) (Section 28A)
- (Part 4) amended by Special Educational Needs and Disability Act (SENDA) (2001)

This highlights the legal requirement for designers and evaluators to examine the way in which requirements for the design and evaluation of products and services are gathered, to ensure that the methods used are accessible to the widest possible population, and to ensure that they do not discriminate against people on the grounds of their disability when conducting design and evaluation activities. Such Acts do not only outlaw discrimination against disabled people but:

*“...point towards, a need for a design philosophy which will ensure the systems meet the needs of older people and people with disabilities, as far as possible, from the outset.”* (Nicolle and Abascal, 2001:8)

Further justification is provided by several government initiatives concerned with giving disabled people choice. One such initiative, a government white paper ‘Valuing People’ (2001:14), has at its centre the notion that ‘people with learning disabilities are people first’ but also states that the individuals’ aspirations, needs and views should be the driving force for providing services.

Legally, designers should therefore be including people with disabilities in the design and evaluation process, not least because of the Disability Discrimination Act 2005 and the Equality Act 2010, but also because failure to ask disabled people for their views - and to take them seriously - illustrates that policies, products and services are built and delivered in inappropriate ways (Cook and Inglis, 2009:56).

## 5. Models of disability

### 5.1 Introduction

There are two principal models of disability, often known as the Medical model and the Social model.

### 5.2 Medical model

The Medical model of disability places the cause of disability with the individual (Scullion, 2010:699). This model focuses on impairment of bodily systems or functions, irrespective of their origin (Scullion *ibid.* pp 699). This means that a person is impaired by a lack of all or part of a limb, or by having a defective limb, organism or some other mechanism of the body.

### 5.3 Social model

There is a movement away from the Medical model of disability towards a Social model which views disability as a concept created by society. This concept was developed in the 1970s by members of the Union of the Physically Impaired against Segregation (UPIAS). It was given academic credibility by the works of Finkelstein (1980, 1981), Barnes (1991) and particularly Oliver (1990, 1996) (adapted from Shakespeare and Watson 2002:3).

The core principle of the Social model claims that it is society which erects barriers that prevent disabled people participating, and thereby restricts their opportunities (Southampton Centre for Independent Living 2009). The most important component of the Social model is how it defines disability - that disability is caused by social oppression and not the impairment (adapted from Shakespeare and Watson *op.cit.*).

The Social model of disability therefore defines disability as:

*“The disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities.”* (Oliver *op.cit.*)

It is therefore society that disables and needs to remove any barriers found within the design and evaluation process that might exclude participants with SCAN. In order to achieve this, all aspects of the design and evaluation process need to be examined to ensure that there are no barriers that prevent the contribution of disabled people. This will ensure that designers and evaluators do not disadvantage participants with impairments and where there are found to be barriers, solutions need to be developed to overcome these.

According to Scullion (*op.cit.*) disability is not caused by individuals' contemporary impairments, but by collective thinking and actions which exclude, oppress or devalue disabled people. If it is the case that society disables people, it is also society that can remove such barriers through education and the provision of inclusive mechanisms to enable every individual to contribute regardless of disability.

## 6. Attitude

### 6.1 Introduction

Many people are not aware of the problems faced by disabled people or do not know what to do to address them (Curran, Walters and Robinson, 2007:448). This includes the general public as well as design professionals.

### 6.2 Public attitudes

There is a large body of evidence that clearly demonstrates negative attitudes towards disabled people. For example, a report commissioned by Scope found that two thirds of the British public feel uncomfortable talking to disabled people (Aiden and McCarthy, 2014:3) and one third perceive disabled people as being less productive than everyone else. It was also found that a quarter of disabled people have experienced attitudes or behaviours that meant other people expected less of them because of their disability (Aiden and McCarthy *ibid.* pp 3). Finally, the report concluded that disabled people and their families felt that negative attitudes affected every area of their lives - in the playground, at work, in shops and on the street (Aiden and McCarthy *ibid.* pp 3).

Following the 2012 Paralympic Games - a major movement for disability - a survey showed that over half of the disabled respondents said they had not noticed any change in people's attitudes towards them. 22% were of the opinion that people's attitudes had worsened, while just 9% believed people's attitudes had improved (Opinium, 2013). The report also showed a large majority of the public believing that disabled people need to be cared for, and 13% thinking that disabled people get in the way some or all of the time.

A national survey found that a growing body of evidence indicated that disabled people are more likely to experience the attitudes of others as a major barrier to education, leisure, transport, access to public services, social contact and accessibility outside the home (Office for National Statistics, 2014).

Negative attitudes that have been reported include being patronised or made to feel uncomfortable or in some cases being a victim of hostile aggressive behaviour and/or violence. Additionally, disabled people report experiencing a lack of understanding around their individual needs, including being in contact with members of the public who refused to make reasonable adjustments. The public's awkwardness around disabled people is reflected in self reports by both disabled and non-disabled respondents (Aiden and McCarthy *op.cit.*).

### **6.3 Designer attitudes**

The literature also suggests that designers have difficulty designing for others outside of their life experience, and this includes SCAN users. There may be several reasons for this, including inexperience, insufficient time to work with users, and lack of empathy.

For example, Keates and Clarkson (2003:1) comment that commonly cited reasons include inadequate access to product users, inexperience in dealing directly with users, and a lack of demand by commissioners of the designs.

Designers are typically young and able-bodied, and may find it difficult to relate to others in very different circumstances (Goodman *et al.* 2007:127). It is suggested that such designers are either unaware of the needs of users with different capabilities, or do not know how to accommodate their needs into the design, and instinctively design for other able-bodied users (Clarkson and Keates 2001b). In mitigation, design may be seen as challenging in gathering, analysing intangible qualitative data. In addition, it requires considerable skill and expertise (Bruseberg and McDonagh-Philp, 2001:435).

Several researchers highlight the use of empathy, another skill required to enable designers to produce solutions that meet a variety of user needs. Empathy is the ability to see a person's problem from the user's perspective (Mattelmaki and Battarbee, 2002), and can provide the motivation to seek out and utilise user information to produce more suitable designs for more diverse groups (Carmichael, Newell and Morgan, 2008:1-2). Empathy has been shown to influence the adoption of inclusive design (Tzekakis, 2008:1). Furthermore Clarkson *et al.* (2003:484) contend that using empathetic approaches in design enables the designer to connect with the user “...and respond to quality of life issues rather than physical problems alone” thus providing a holistic understanding of the user. Designers may not empathise because they lack the skills and ideas which allow them to feel competent and effective in this area (Blatner 1992:1).

Empathy is more than an intention to be sensitive, and is difficult to learn from traditional teaching methods, requiring instead experiential learning (Blatner *ibid.* pp 1). Blatner (*ibid.*) further acknowledges that how people empathise is dependent on the nature of the person and their life experiences: however, with practice anybody can improve their level of innate ability.

There is evidence that empathy can be taught, and different methods are highlighted such as personas, immersive experience, and capability loss simulators (Tzekakis *op.cit.*). Similarly, different methods of collecting user needs for inclusive design have been observed, for example, through the INCLUDE project (Newell and Gregor, 2000:40). Successful design requires designers to have empathy and access to relevant knowledge such as human factors (Newell, 2006:1).



## 7. Design and disability

### 7.1 Introduction

The literature review highlighted a number of legal, attitudinal and methodological aspects to working with disabled populations, but lacked specific detail in relation to designers working with and designing solutions that meet the needs of SCAN users.

There is a lack of published research concerned with working directly with disabled people. However, as an introduction to the field, four key studies have been identified as exemplars of published work. They are analysed to raise several important issues for this study, before a more general review of literature relevant to the study. The four exemplar papers are:

- Chandrashekar *et al.* (2006)
- Roberts and Fels (2005)
- Henderson *et al.* (1995)
- Dong *et al.* (2005)

## 7.2 Four studies

### 7.2.1.1 Chandrashekar *et al.* (2006)

The Chandrashekar *et al.* (2006) study was titled 'Using think aloud protocols with blind users: a case for inclusive usability evaluation methods'. The introduction states:

*“...users tend to have unique and different computer interactions when compared with their able bodied counterparts this prompted us to examine whether their interactions with UEMs (usability evaluation methods) would also be different, specifically with think aloud protocol (TAP).” (Chandrashekar *et al. ibid.* pp 251)*

### 7.2.1.2 Methodology

The work illustrates the authors' experiences of using think aloud protocol (TAP) with blind users. In this study, six visually impaired students evaluated a website. TAP is a popular method for this kind of evaluation.

### 7.2.1.3 Conclusions

The authors found that the TAP method requires participants to firstly read a passage aloud to prepare themselves for talking out loud. Given that the users' method of reading was to listen to a screen reader, TAP was not usable for this group (Chandrashekar *et al. ibid.* pp 251).

In a discussion of the study, the authors highlight a number of issues relating to using TAP with blind users, and concluded that TAP - in its popular form as a concurrent protocol method, may not be effective with blind persons who use a screen reader to access websites.

They suggest that further research is needed on how best to modify this protocol when working with these users (Chandrashekar *et al. ibid.* pp 252).

#### **7.2.2.1 Roberts and Fels (2005)**

These authors state that many of the popular usability evaluation methods (UEMs) are not designed to include users with disabilities. This study proposed the development of a UEM called 'Gestural Think Aloud Protocol' (GTAP).

#### **7.2.2.2 Methodology**

The study was divided into two parts: 1) a simple game study and 2) an actual usability study carried out using the GTAP method. By conducting two studies the authors aimed to examine different aspects of the GTAP method. The first study enabled comparison between verbal and GTAPs and the latter enabled evaluation and testing.

#### **7.2.2.3 Conclusions**

In their conclusions, the authors (*ibid.* pp 500) remark that similar methods are important in enabling developers to meet mandates in inclusive technology, and to help foster a universal design environment. They observed that developers cannot effectively meet the needs of disabled users unless such users are included in usability studies. They further state that analysing the data gathered in the usability study demonstrates the feasibility of using gestural TAP in an actual usability study (*ibid.* pp 500).

### 7.2.3.1 Henderson *et al.* (1995)

Henderson *et al.* (1995:412) evaluated four basic methods of usability evaluation, these were:

- Logged data
- Questionnaires
- Interviews
- Verbal Protocol Analysis

Henderson's work focused on the usefulness of the methods when used individually and in combination. Unlike the two previous studies these authors did not examine the creation and evaluation of a new method but rather the evaluation of existing methods. The study does not comment on the accessibility of each method for SCAN users; however, it does draw some general conclusions that are important to note.

### 7.2.3.2 Methodology

In the study, there were a total of 148 participants.

Software tested	Test sample
Spreadsheet	54
Word processor	48
Database	46

**Table 2.1 Sample size and software application tested**

Method tested	Test sample
Interview	37
Logged data evaluation method	40
Evaluation questionnaire	39
Verbal analysis method	32

**Table 2.2 Sample size and methods tested**

In the study, each participant was randomly allocated to a test condition, and then participants worked through the tasks being videotaped with all instances of help being recorded. After the completion of tasks, participants were then informed which experimental group they had been allocated to and were debriefed.

### 7.2.3.3 Conclusions

The logged data method generates large amounts of data. This can be a disadvantage especially if the method is used repeatedly. Because of these findings, the authors state their many concerns about the reliability, validity and practical utility of the logged data approach to software usability evaluation (*ibid.*).

The work also illustrates a number of issues related to the use of questionnaires. For example, if participants were asked to use a rating scale, often these did not indicate specific problems but rather indicated general problem areas and as a result of this it was difficult to isolate these.

The results obtained from the questionnaires are of concern as they give rise to questions about the validity of the data. This may be true of any study that uses questionnaires, especially where the data is not thoroughly analysed.

There was widespread failure to understand questions. The authors concluded that more care is required in designing and evaluating questionnaires. As a result of the above, it was felt inappropriate to add together the ratings to give an overall usability score.

Despite the problems with questions that required participants to use rating scales, it was found that participants gave valuable information in 'three response' questions. Because of this, Henderson *et al.* (*ibid.*) concludes these are not an appropriate way of evaluating a user interface, although they feel that this claim could benefit from further research. Lastly, mechanisms used to validate questionnaires need to be fit for purpose (adapted from *ibid.*).

In relation to the interview method, Henderson *et al.* (*ibid.*) concludes the following:

- 1) It was difficult to establish what exactly caused participants' problems.
- 2) It was felt that participants did not always report problems to the interviewer as they did not wish to show personal inadequacy when using the software.

- 3) If problems were overcome quickly, or had little impact on task completion this led to a high instance of non-reporting.
- 4) Interviews can prove to be time consuming especially where transcription is required.
- 5) The results support Bainbridge's (1979) conclusion that, when time and equipment are limited, the interview is the best method for soliciting ergonomic information (adapted from Henderson *et al. op.cit.*).

Where the verbal protocol method was used Henderson *et al. (ibid.)* drew the following conclusions:

- 1) The nature of the method was relatively straightforward; this also gave some insight into the problems encountered and possible solutions.
- 2) Freedom given to the participants; they often tended to discuss different situations to the ones being examined, thus often leading to vague descriptions of what they were referring to.
- 3) Both analysis and collection of the data were difficult and time consuming because of its qualitative nature.
- 4) Participants only verbalise what was happening when they encountered a problem and sometimes contradicted themselves.
- 5) The method of verbal protocol analysis used in this study proved very efficient "...in terms of highlighting usability problems."

- 6) As a result of the above, the verbal protocol method gathered useful and relevant information.
- 7) It can be used if time and resources are limited.
- 8) The method increased the participant's role from that of a subject being studied to an active participant in the evaluation process thus this may have resulted in increased commitment on the part of the participant and in turn more usable findings may have been generated as a result.
- 9) Verbal protocols were found to be the most effective method in this study.

When the methods were utilised in combination (methodological triangulation), Henderson *et al.* (*ibid.*) concluded the following:

- 1) Combining any two methods always resulted in an improvement, this indicated that each method added a unique way of understanding problems presented.
- 2) Some combinations (those that did not include the verbal protocol method) were often less effective.
- 3) When improvements were made relating to problem identification of the verbal protocol method, these were often seen when used in other combinations.
- 4) When combining these methods, this was most effective when the verbal protocol was used as a base method.



At first glance, this work does not appear to be related. However, it critically evaluates problems with four basic methods of usability evaluation.

#### **7.2.4.1 Dong *et al.* (2005)**

Dong *et al.* (2005) stated that inclusive design requires better understanding and empathy with all potential users. However, traditional research methods are limited in the extent to which they accommodate a wide range of users and therefore more appropriate methods of user research should be sought. Given the above, Dong *et al.* (*ibid.*) propose and evaluate the effectiveness of critical user forums with SCAN participants. Critical user forums involve direct interaction between design teams and a mixed group of users with SCAN needs (adapted from *ibid.* pp 1). Critical user forums are similar to focus groups but a major difference is that they are usually smaller in size (5-9 participants). They are generally conducted in an informal atmosphere with designers making use of a variety of information capture methods such as: written notes; video recording; and hands on interaction. This flexible atmosphere enables designers to interact with critical users effectively (adapted from *ibid.* pp 4).

#### **7.2.4.2 Methodology**

In order to achieve the stated aim of the study which was to evaluate the effectiveness of critical user forums, a series of interviews (14 in total) took place involving a range of different design staff. The interviews lasted between 90 and 120 minutes and were semi-structured with questions based on two key themes which were:

- 1) User involvement (in commercial projects and in Design Business Association Design Challenge projects);
- 2) Design and evaluation process (including the 'normal' and the 'inclusive' design and evaluation process).

Additionally, at the interviews, tape recordings and notes were taken and then transcribed (adapted from *ibid.* pp 4).

#### **7.2.4.3 Conclusions**

The main conclusion of this study was that critical user forums provide an effective method for involving SCAN users in design research. However, of the design consultancies surveyed in the study only one responded that they would consider including SCAN users in future projects. The authors themselves comment that this is surprising given the positive feedback they have received from designers in relation to this method. However, many of those questioned believe that the method would not be feasible in real world projects. This could be due to time and resource considerations, the authors state that the barriers to the adoption of critical user forums could best be overcome “...*through education to design professionals and business decision-makers.*” (*ibid.* pp 9)

#### **7.3 Discussion of the four studies**

The previous studies of UEMs only concentrated on two groups of users with SCAN. Roberts and Fels (*op.cit.*) used blind participants and Chandrashekar *et al.* (*op.cit.*) used hearing impaired participants. This indicates that there needs to be more work on the development of inclusive usability evaluation methods with a range of participants.

Furthermore, Kroll, Neri and Miller (2005:106) remark that “...*the combined use of multiple methods in disability and rehabilitation research is relatively novel.*” as well as creating new methods where traditional methods are found to be inaccessible to users. Future work might be focused on evaluating whether mixed methods, both quantitative and qualitative produce a better understanding of user needs.

Additionally, Bruseberg and McDonagh-Philp (*op.cit.*) remark that to some extent users may not be aware of their needs/or be able to articulate them. This perhaps needs further investigation - with the advent of the DDA and Equality Act 2010 it is no longer acceptable to exclude somebody on the grounds that they may have difficulty articulating their needs.

One important focus for future research might be to refine or create ways that allow all users to articulate their needs regardless of level of ability.

#### **7.4 Evaluation of usability**

It is clear that further work is required in the area of development relating to inclusive usability evaluation methods. This observation is supported by Roberts and Fels (*op.cit.*) as they comment that many of these methods are not designed to include users with disabilities and that legislation and good design practice should incentivise researchers to consider more inclusive methods.

Furthermore, Margolin (1997:227) suggests that more inclusive ways should be developed so that participation in a design and evaluation process can be broadened. Margolin (*ibid.* pp 232) states that a further challenge for designers in the development of new products is how to recognise the value of user experience. This is a particularly important challenge when designing for users that have SCAN because their experiences with a product or service can be more informative than designers' knowledge of improvements to a service or artifact, as the users will make use of it in their unique context. Blythe *et al.* (*op.cit.*) also comments that “...*there is little in the way of methodological guidance to the hard pressed researcher to facilitate understanding such settings...*” such as the specific settings in which SCAN users reside i.e. community based or institutional.

It is reported that traditional user research methods are restricted in accommodating a wider range of users, and therefore there is a need to find more acceptable methods (Roberts and Fels *op.cit.*; Dong *et al. op.cit.*). This view is reinforced by Rabiee, Sloper and Beresford (2005:8) who state that *"...the exclusion of disabled children from research and consultation says more about unsuitability of research and consultation methods."* Similarly, it is reported that eliciting requirements and evaluation data from groups such as older people, is not straightforward (Zajicek, 2004).

Kitellsaa (2009:1) remarks that literature about disabled people in research recommends the use of different methods in order to be able to shed light on people's lives from various perspectives (adapted from Kitellsaa *ibid.* pp 1). A similar conclusion was made by Lepisto and Avaska (2004:305). However, they also conclude that the methods used may need to be adapted to suit the characteristics of each participant (adapted from Lepisto and Avaska *ibid.* pp 305).

## **7.5 Using a mixed method approach**

Mixed research methodologies as defined by Brannen (2005:4) consist of

*"...adopting a research strategy; employing more than one type of research method" and "...it is suggested that the methods may be a mix of qualitative and quantitative methods, a mix of quantitative methods or a mix of qualitative methods."*

One of the characteristics of mixed methods research is it allows a deflection of: *"Attention away from theoretical work that is often specific to particular disciplines...thus it may encourage thinking 'outside the box', a practice to be welcomed."* Brannen (*ibid.* pp 5)

This facet of mixed methods research could be seen as being highly advantageous when working with participants who have SCAN, as researchers may need to 'think outside the box' in relation to how to include these participants in their research activities.

Brannen (*ibid.* pp 6) suggests that researchers are required to address the needs of both research stakeholders and users. Using mixed methods may in some circumstances help the researcher to include a variety of participants because it will enable a variety of data collection methods to be used, thus enabling participants with varying abilities to take part. This will help in meeting the needs of research participants who are also stakeholders in the research.

Brannen (*ibid.* pp 11) outlines several reasons why mixed methods should be used in research but she does not consider the abilities or disabilities of the research participants. In this case, mixed methods may also be advantageous to use, for example, participants may be given a questionnaire which is designed to provide background information, and they may also be observed carrying out tasks which may help the researcher to understand why the participant gave certain information in the questionnaire. Brannen (*ibid.* pp 11) also states that some methods are chosen because they fit better with complex phenomena. This may be the case in disability research; some methods may be selected because they are the most accessible to participants.

In addition, Brannen (*ibid.* pp 11) states that researchers that do disability research often claim that the methods are: *"Participatory or transformative and hence as 'new' or different from traditional methods...however it is not the methods per se that distinguish their approaches but what the methods are used for."*

As stated by Crump and Logan (2008:21) *"...each group brings its own agenda and expectations as to the outcome of the evaluation and will differ in their abilities to promote their views and being heard."*

Because of this, if researchers employ mixed methods it may make the research they conduct more accessible to a greater range of people. This is alluded to by Teddlie & Tashakkori (2003), who state that: *“To achieve a balance so that a greater diversity of divergent views are heard, questions are answered that other methodologies cannot, and stronger and better inferences are provided is to use a mix of qualitative and quantitative methods.”*

Crump and Logan (*op.cit.*) also conclude that the variety of data gathering approaches can suit a stakeholder sector that might otherwise not have had a voice in the evaluation. A similar point is made by Morse (2003:189) who states that by using more than one method, a more complex picture of human behaviour and experience may be gained.

Greene (1989) outlines five purposes of mixed methods research, these are:

- 1) Triangulation
- 2) Complementarity
- 3) Development
- 4) Initiation
- 5) Expansion

Triangulation can be defined as using different method types to assess the same phenomenon. It has two major advantages in:

- 1) Increasing, negating or counterbalancing deficiencies in a single strategy thus increasing the ability to interpret the findings (adapted from Thurmond 2001:253).
- 2) A triangulated approach to research can reveal detail that may be not be included in research that does not use mixed methods (adapted from Olsen 2004:20).

When conducting research with SCAN participants' methodological triangulation (using more than two methods) and in some cases, a mixture of qualitative and quantitative methods could prove highly beneficial. Methodological triangulation can enable a clearer understanding of problems faced by participants, for example, a quantitative method, such as a questionnaire may identify a problem and a qualitative method such as an interview may offer some detail about what that problem is and how it affects the participant (adapted from Thurmond *op.cit.*).

One disadvantage of this method is that it could result in over testing participants thus tiring them. This may then impact on the quality of the results gathered. Therefore researchers should consider carefully which methods to use and how they will be employed in order to minimise this risk.

- Complementarity- this involves using the results from one method to elaborate, enhance or illustrate the results from the other.
- Development- development design is stated to be the sequential timing of the implementation of different methods.
- Initiation- is intended to uncover any paradox and contradiction in the results.
- Expansion- intends to extend the scope, breadth, and range of the inquiry, and doing this by using different methods for different inquiry components.

A variety of mixed methods approaches in research may be considered, and should be made up of the characteristics above.

## 8. Models of designing

### 8.1 Introduction

There are many models that may be appropriate when designing for SCAN users. These vary from techniques used to simply elicit information for designing to take place, to working alongside users as partners in the process.

SCAN participants provide many challenges for designers of products and services. For example, product interfaces might be designed with less reliance on good memory and language abilities (Newell and Gregor *op.cit.*).

From this approach, the researchers outlined user-centred design measures (inclusive design and universal design) as strategies that designers could adopt to try to meet users' needs.

### 8.2 Collaborative design

As has been reported above, asking questions of users is not a trivial matter, and more so when dealing with SCAN users (cf. four exemplar studies).

One method of eliciting information from users is collaborative design, derived from the Latin term *co labore* which means to 'work alongside one another' and also joint problem solving which consists of "*working with others with shared goals for which the team attempt to find solutions that are satisfying to all concerned.*" Kvan (2000:410)

Shea and Guzzo (1987) outline four principles of successful collaborative projects of relevance to this study:

- 1) Must establish a definition of the team (in this research the team consists of designers in the focus group for stage one and the interviewer and the researcher for stage two).



- 2) Identify their outcomes (there are identified outcomes for this research set out in aims and objectives).
- 3) Ensure there is a purpose for the collaboration (in this research the purpose is to collaborate in order to develop guidelines to assist designers when working with SCAN users).
- 4) Clarify the interdependencies of the members (the guidelines cannot be produced without evidence from participants).

### **8.3 User-centred design**

Designing with the user at the heart of the process is known variously as user-centred design, inclusive design, and universal design. Each has certain distinct aspects, but there is a good deal of commonality of approach and overlap in the focus of involving users in the design and evaluation process. In particular, universal and inclusive design seeks to understand the needs of different populations with the intention of producing designs suitable for all.

User-centred design may be defined as a “...*process that places the user at the centre of the design rather than the object to be designed.*” (adapted from University of Minnesota Duluth: Information Technology Systems and Services 2009) User-centred design is focused “...*on user characteristics, their environment, on user tasks, on measurable user goals, on prototyping alternative designs, and on testing, improving, and retesting the winning design.*” Rauch, Soderston and Hill (1996:341)

The concept of user-centred design was developed at University of California San Diego in the 1980s (Abrams, Maloney-Krichmar and Preece 2004:763). It has evolved into a broad philosophy (Abrams, Maloney-Krichmar and Preece *ibid.* pp 763) that is implemented and supported by many of the methods outlined in this review, for example, interviews and questionnaires.

The ways in which UCD is employed in product development can vary widely. In some circumstances involvement may be relatively minor whereas in others, users may be consulted about their needs, observed and participate in usability testing or involvement may be intensive, with users participating throughout the design and evaluation process as partners in the design (adapted from Abras, Maloney-Krichmar and Preece *ibid.* pp 768).

<b>User-centred design approach</b>	
<b>Advantages</b>	<b>Disadvantages</b>
<p>Is valued by “...individuals, communities, and the public and private sectors.” (Sandler, 2010)</p> <p>A user-centred designed “...space can reduce dependence, ease burdens and strained relationships, and empower multiple members of the social sphere.” (Joines 2009:159)</p> <p>UCD features could allow mobility and independence for users (adapted from Nunn, Sweaney, Cude and Hathcote 2009:11).</p> <p>Incorporating UCD features into products can enhance their safety, accessibility and comfort. It also makes the products highly adaptable (adapted from Nunn, Sweaney, Cude and Hathcote <i>ibid.</i> pp 11, Bjork 2009).</p> <p>“...challenges designers to develop solutions that eliminate the safety and mobility barriers...” that older adults and those with SCAN face (Dumbaugh 2011:27).</p> <p>Employs a variety of people from different disciplines (psychology, anthropology) to help understand users’ needs, for example (adapted from Abras, Maloney-Krichmar and Preece <i>op.cit.</i>).</p>	<p>Inclusive design “...is widely used, other terminology used to describe the same or similar concept includes lifetime homes, Design for All, adaptable housing, and barrier free homes.” (Nielsen and Ambrose 1999, Preiser and Ostroff 2001)</p> <p>“...is still hindered by a lack of guidelines or certification.” (Pynoos, Caraviello and Cicero (2009:26)</p> <p>It is neither codified nor enforced but rather it is pursued, the principles are deployed and thought processes are explained (adapted from Universal Design and Lifespan Design 2009, Law, Yi, Chio and Jacko 2007).</p> <p>The UCD process demands a lot of resources, both in terms of monetary value, time and people to administer the approaches employed (adapted from Abras, Maloney-Krichmar and Preece <i>op.cit.</i>, Robert 2007, Sanders and Stappers 2008).</p> <p>Communication can be difficult between the different disciplines within a UCD team (adapted from Abras, Maloney-Krichmar and Preece <i>op.cit.</i>).</p> <p>May require many different perspectives to be involved in the design and evaluation process.</p>

User-centred design approach	
Advantages	Disadvantages
<p>UCD design philosophies may produce products that are “...<i>more efficient, effective, and safe.</i>” (adapted Abras, Maloney-Krichmar and Preece <i>ibid.</i> pp 763 and Dray 1995)</p> <p>“Assists in managing users’ expectations and levels of satisfaction with the product.” (Abras, Maloney-Krichmar and Preece <i>ibid.</i> pp 763)</p> <p>Can give users a sense of ownership of the product developed (adapted from Abras, Maloney-Krichmar and Preece <i>ibid.</i> pp 763 and Eid (2003:4).</p> <p>Products developed using UCD can “...<i>require less redesign and integrate into the environment more efficiently</i>” (adapted from Abras, Maloney-Krichmar and Preece <i>op.cit.</i> pp 767 and Dray <i>op.cit.</i>).</p> <p>The collaborative process employed by UCD can generate more creative solutions to the design problems outlined (adapted from Abras, Maloney-Krichmar and Preece <i>op.cit.</i>).</p> <p>UCD designs may lead to lower staff turnover and the workforce have better morale (adapted from Dray <i>op.cit.</i>).</p> <p>Can produce “...<i>more usable satisfying designs.</i>” (Abras, Maloney-Krichmar and Preece <i>op.cit.</i>)</p> <p>Can lead to improved customer satisfaction in a business context as productivity of employees’ increases thus leading to a faster turnaround of customer required operations (adapted from Dray <i>op.cit.</i>).</p>	<p>May be difficult to translate some types of data into design (Abras, Maloney-Krichmar and Preece <i>ibid.</i> pp 767).</p> <p>The product designed may have been designed for a specific user group therefore it might not transfer to other user groups well (adapted from <i>ibid.</i> pp 763).</p> <p>Sometimes, users do not know what they want or what technology can do for them this can lead to either unclear or unrealistic requirements or in the worse case no requirements from the user at all (adapted from D’Amico, 2004).</p> <p>Gaining access to users can be problematic, for example, if a communication aid is being designed it is not straightforward to gain access to this participant group because of their communication problems (adapted from Newell and Gregor <i>op.cit.</i>).</p> <p>Is a “...<i>way of thinking that can be applied in any design activity, business practice, program, or service involving interaction of people with the physical, social, or virtual worlds.</i>” (Steinfeld (‘n.d’)</p> <p>The principles that underlie user-centred design have been criticised as being “...<i>vague, incomplete and difficult to understand...</i>” (Steinfeld <i>ibid.</i>)</p> <p>“...<i>Little re-evaluation, reconsideration, or questioning of the principles has occurred since their introduction in 1997.</i>” (Bjork <i>op.cit.</i>)</p>

User-centred design approach	
Advantages	Disadvantages
<p>Can "...create a larger market for manufacturers..." (Bjork <i>op.cit.</i>)</p> <p>Encourages manufacturers "...to remove the barriers that exist between different groups of customers." (<i>ibid.</i> pp 124)</p> <p>"...promotes democratic values and reduces adaptation costs for society." (<i>ibid.</i> pp 124)</p> <p>"The number of individuals who require assistive technology products could be dramatically reduced..." if products were developed using UCD principles (<i>ibid.</i> pp 124).</p> <p>Product failure is reduced (Nielsen, 1993, Mayhew 1999, Kujala 2003, Shah and Robinson 2006, Lee 1999).</p> <p>May reduce costs and time associated with re-development (Bias and Mayhew 2005).</p>	<p>"Traditional inclusive design consideration, by themselves, are rarely enough to adequately facilitate appropriate and acceptable design. This may be because 'inclusive design' as an abstract principle and as applied to disabled people rarely amounts to more than 'wheelchair users'." (Dewsbury, Rouncefield, Clarke and Sommerville, 2003)</p>

**Table 2.3 Advantages and disadvantages of a user-centred design approach**

In relation to user-centred design for users with SCAN, Laux *et al.* (1996:96) contends that each user group has different needs, abilities, and preferences which must be determined to develop usable systems. The task of gathering these requirements is best completed with user-centred design. For example, "...blind expert computer users would be invaluable for developing and evaluating user requirements and guidelines for access to a hypermedia system for blind users." especially given the fact that as stated by Curran, Walters and Robinson (*op.cit.*) "...irresponsible and inaccessible web design causes unnecessary problems to certain website users." The reason for this is clear; if the website is aimed at blind users then it would be logical to surmise that the design and evaluation processes should include such users.

However, Newell *et al.* (*op.cit.*) argues that “...*some significant differences must be introduced into the 'user-centred design paradigm' if users with disabilities are to be included.*” He proposes the development of a new paradigm which he refers to as ‘user sensitive inclusive design.’

In this proposed paradigm, the term 'sensitive' replaces 'centred' to illustrate the notion that when designing for users with disabilities it may be impossible to meet everybody's requirements. However, designers should still be aware of these and be sensitive to them (adapted from Newell *et al. ibid.* pp 42).

ISO16982 (*op.cit.*) indicates that many of the user-centred design methodologies are appropriate or recommended when working with participants that have SCAN and thus should be employed. In conclusion, the philosophy of user-centred design, if employed correctly, can be advantageous for designers when working with SCAN participants (cf. Laux's example on previous page).

However, one note of caution as stated by Newell (*op.cit.*) is that it sometimes can be impossible to cater for everybody's diversity even within specified user groups. Designers should also be aware that in some contexts it is not appropriate to cater for everybody's needs. Of course, designers and developers should endeavour to make the products and services they design and implement as accessible as possible to the widest range of people within the boundaries of economic and other constraints. Also, to be truly inclusive “...*it is not enough for these strategies to simply address the needs of one user group, no matter what their abilities, at the expense of others, including those whose needs are already well served under contemporary practice.*” (Dumbaugh *op.cit.*)

According to Doble (2002) if a new house is designed and built according to inclusive design principles, the need for future expensive renovations and changes could be substantially reduced or eliminated because inclusive design reduces the need for assistive devices (Swann *op.cit.*).

Nunn, Sweaney, Cude and Hathcote (*op.cit.*) take this further in suggesting that "*...adding universal design features to a home is one way to return to routine behaviours and restore order in one's life.*"

There are various misconceptions about the nature of universal design, for example, that it means only designing for the elderly and disabled (Keates, Lebbon and Clarkson, 2000).

To increase the appeal of inclusive design features homes could be marketed as 'easy living' therefore avoiding any negative implications of specialised design (Nunn, Sweaney, Cude and Hathcote *op.cit.*), and this could be a new strap line for companies that could benefit from developing an attitude of designing flexible products and environments that are universal in use (Bjork *op.cit.*).

It has also been observed that even where houses have been specifically designed to support people with varying impairments, in most cases it is their immediate physical environment that does not cater for their needs (Dewsbury, Rouncefield, Clarke and Sommerville *op.cit.*). Even though there may be widespread recognition that inclusively designed homes would benefit everyone, few home design professionals incorporate such features and products in homes, and few consumers request them (Nunn, Sweaney, Cude and Hathcote *op.cit.*).

The Centre for Universal Design (1997b) highlights consumers' lack of awareness, rather than lack of need, which contributes to consumers' low demand for inclusively designed housing. Thus marketing and education are among the keys to the future of inclusive design adoption (Nunn, Sweaney, Cude and Hathcote *op.cit.*). This may explain some of the reasons why designers may have difficulty in listening to users. In this context, Woodcock and Galer Flyte (1998:5) suggested that - in engineering design context - perception of the user is inadequate and inappropriate.

Pheasant (1988) observed that designers are content to design for themselves based upon their own experiences.

There are many views of the utility of the user in the design and evaluation process. For example, Norman (2005:17) states “...*ignore what users say: I know what’s best for them.*” He claims that experiences with purely user-driven design have shown that users are not always good designers. Another perhaps more conventional view expressed by Black (2008) is that “...*the best-designed products and services result from understanding the needs of the people who will use them.*”

In some cases users are viewed as designers, for example, in Beguin’s (2003) paper where design is seen as a learning curve between the user and designer. This approach indicates that design and evaluation of products is informed through its use. Another design approach is that of participatory design, this approach views “...*the users as the experts, the ones with the most knowledge about what they do and what they need and the designers as technical consultants.*” Schuler and Namioka (1993:xi)

Bailey (2005) also expresses the view that: “*Most designers seem to believe that having users involved in the design and development of new systems will lead to; the improved quality of the system because of more accurate user requirements, an improved level of user acceptance, and more efficient and effective use.*”

## 8.4 Users and designers

In a study conducted by (Goodman *et al. op.cit.*) designers were asked to conduct a guided card sort, sorting a selection of 57 design methods into two categories; these categories were:

- How often they used the methods.
- How they felt they would enjoy using them.

The analysis revealed that there were six distinct clusters of methods:

- Active user involvement.
- Getting information from users.
- Knowledge of the market.
- Understanding users without user contact.
- Visualisation and prototyping.
- Idea generation and analysis.

The most commonly used methods came from the latter three clusters. The initial ratings of methods according to formality and cost indicate that more commonly used methods tend to be informal and cheap and that designers tend to prefer less formal methods (Goodman *et al. ibid.* pp 135). It may be concluded that consulting with users is not viewed as crucial to the design cycle of the product or service. However, there could be many other reasons to this being the case, such as lack of resources or a practice rather than research based approach is conceptualising the product.

The literature studied presents mixed attitudes relating to the importance of the user in the design and evaluation process. If designers prefer to use methods that do not directly involve users they may not fully understand the difficulties faced by the users of their products.



In some cases user involvement in the design may not be appropriate; in such cases a clear rationale for this decision should be given. It should be noted that the reasons for selection of a method are many and varied. Of course, the design of products and services, specifically for SCAN users requires their needs to be of paramount importance. This should also be the case if the product is designed under the mandate of inclusive design, indeed, this should be the case for any product or service, but as expressed by Shah and Robinson (2007) "*The involvement of users in medical device technology development and evaluation requires resources, which are limited; however, this involvement is essential from both users and manufacturers perspectives...*" because people with SCAN are often willing to invest in using new technology, providing the expected outcomes are perceived as being beneficial (adapted from Melenhorst 2002) i.e. the principal factor that often prevents people from engaging with and using technology is the absence of benefits (adapted from Melenhorst *ibid.*).

This would seem to suggest that the medical device industry understand that the involvement of users is paramount to the success of their products but may be constrained by the availability of resources.

This may also be the case in other industries. It is not advisable to have no understanding of a user's abilities or life context because as Margolin (*op.cit.*) remarks "*...the product does not exist in a vacuum...it becomes meaningful only in relation to a user...*" so therefore if designers do not understand the need of the users they design for how can products be designed to meet their needs? This problem has been identified by (Norman *op.cit.*) when he suggests that designers do not understand well enough how users learn to operate devices such as cameras or computers.

It has been conjectured that perhaps the biggest problem that impacts upon designers' understanding of users is that there is no public community i.e. no specific knowledge that is open to all (public) that defines what a user is that in turn shares that understanding of how he or she relates to products (Margolin *op.cit.*).

## **8.5 Human Computer Interaction (HCI)**

In the ergonomics literature on usability methods supporting HCI (human-computer interaction design) it is particularly recommended that methods imply a close relationship between the user and the analyst, for example observations, interviews, collaborative design (ISO/TR 16982:2002(E):20).

## **8.6 Interaction design**

The concept of interaction design is described by Saffer (2007) as “...*the concept of facilitating interactions between humans through products and services.*”

Smith (2006) views design in a number of contexts, including traditional contexts such as usability. In addition to this, he also examines design in the context of sociability such as producing systems that are not only usable but socially acceptable.

To do this effectively, a key part of interaction design, is understanding the user's experience and their life context (adapted from *ibid.* pp 4). This is a point alluded to by Preece (2007:6) who states that “...*it is about creating user experiences that enhance and extend the way people work, communicate and interact ...it is about finding ways of supporting people.*”

In summary, interaction design is concerned with the fact that products should not only be usable but useful so that the product should be designed for a reason other than, for example, aesthetics or just because the designer can illustrate such an activity. Within the design it should take into account the usage context in which the product will be deployed and support this.

This philosophy of interaction design is an important development in the design community and could be applied to design for users with SCAN, as interaction design seeks to understand a user's life context and then tries to bring that life context into the product designed. This is important and valuable because users with SCAN often have extremely complex life circumstances. Understanding these circumstances will help designers to design products that better meet the needs of the wider population.

However, it could be concluded that to improve the effectiveness and efficiency of interaction design; designers should ensure they have, and utilise the appropriate tools to gain knowledge of users' experiences and life context because they must ensure they can effectively gather information on users of systems and the contexts in which they are deployed (the user's life context) before claiming to have designed appropriately for them.

## **9. Methods**

### **9.1 Introduction**

In order to determine appropriate methods, tools and techniques for understanding SCAN users and/or eliciting information from them, a comprehensive search was undertaken of available methods. From these, a selection was made of relevant methods and these were reviewed in detail. For readers requiring detail of these various methods, they are set out fully in Appendix D.

## 9.2 Comprehensive review

The comprehensive review covered the following:

- Focus groups
- Questionnaires
- Interviews
- Observations
- Card sorting
- User profiling
- Think aloud protocol
- Data logging
- Participatory action research
- Task load index
- Mental models
- Usability testing
- Cognitive walkthrough
- User diaries
- Lead user evaluation
- Prototypes/mockups
- Cultural probes
- Personas
- Capability simulators
- Role play
- Task analysis
- Immersive experience
- Technology biographies

In each case, the item is introduced in context, the main authorities are noted, and a detailed comparative analysis is made of the advantages and disadvantages of using this model in the context of SCAN users. See Appendix D for full details.

### 9.3 Multiple methods

Understanding SCAN users' needs may not be limited to a single technique. There is a large literature about the use of multiple methods (Brannen *op.cit.*).

However, in relation to disability and rehabilitation research, it has been shown that the combined use of multiple methods is relatively novel (Kroll, Neri and Miller *op.cit.*).

This is despite the notion that “...research needs to become more sensitive to the living environments of individuals with disabilities, and use more holistic approaches.” (Ozer & Kroll, 2002, Maher, Kinne, & Patrick, 1999)

Despite the lack of employment of multiple method strategies, these may be useful in disability research, as stated by (Kroll, Neri and Miller *op.cit.*) “*The combination of quantitative and qualitative methods enables researchers to generalise in quantitative terms and understand complexity in qualitative terms.*”

In conclusion, employing mixed methods would benefit research for SCAN users. However, this should be done with care, as repeatedly testing participants using a variety of methods may cause distress.

If it is possible to employ a variety of methods without tiring the participant, for example, by observing them and asking them questions at the same time, this could prove to produce high quality and valuable research data.

Work with SCAN users may employ mixed methods but these may not be standard research methods and may be defined by the participant.

In this way, the work may be comparable to that of Lepisto and Ovaska *op.cit.*) who found that the methods they employed needed to be adapted to fit the characteristics of each participant.

## **10. Review of resources to aid designers in user-centred design (UCD) practices**

The full guidelines (Appendix A) are intended to provide content for the production of published guidelines suitable for designers. It is beyond the scope of this study to operationalise the guidelines in any format suitable for publication, nor is it the intention to recommend any particular format. However, given that wide dissemination is most likely to be online, a review was undertaken of online materials, developed primarily by the design and ergonomics communities, to ascertain what was currently available, and to assess to what extent these had been designed to meet the needs of designers. This section is therefore confined to a review of some existing web based materials.

However, it is recognised that publication in suitable formats would involve other aspects such as: impact; ease of creation and updating of the resource; costs; as well as learning styles and other pedagogical considerations. Though these considerations are beyond the scope of this thesis, a further review of potential formats was undertaken, and an analysis made of the advantages and disadvantages of different formats. The results of this further review are contained in Appendix G.

## 10.1. Review of material currently available to designers

The review was conducted specifically to address the comments of two participants regarding the format of the guidelines; i.e. “...*you should use audio visual information rather than just a bunch of words [because] they...won't .... look at them...*”

**An analysis was undertaken of four frequently used design websites and one booklet:**

- Inclusive Design Toolkit<sup>1</sup>
- Designing with People.org<sup>2</sup>
- University of Cambridge Inclusive Design<sup>3</sup>
- The Methods Lab-User Research for Design<sup>4</sup>
- Helen Hamlyn Centre for Design<sup>5</sup>
- IDEO<sup>6</sup>

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<sup>1</sup> [www.inclusivedesigntoolkit.com](http://www.inclusivedesigntoolkit.com)

<sup>2</sup> [www.designingwithpeople.org](http://www.designingwithpeople.org)

<sup>3</sup> <https://www-edc.eng.cam.ac.uk/research/inclusivedesign/>

<sup>4</sup> (Booklet) Aldersey-Williams, Bound and Coleman (1999)

<sup>5</sup> <http://www.hhc.rca.ac.uk/4577/all/1/videos.aspx>

<sup>6</sup> <https://www.ideo.org/approach>

The analysis is summarised in table 2.4 which illustrates that the material appeared to be very visual, clean and uncluttered in layout using short paragraphs of text interspersed with appropriate images and other media.

Resource	Images/ diagrams & text combined	Case studies	Tables/ data	Video	Use of sub- headings	Navigation aids	Links to other resources & references
Inclusive Design Toolkit	✓	✓	✓	x	✓	✓	✓
Designing with people.org	✓	✓	x	✓	✓	✓	✓
University of Cambridge Inclusive Design Website	✓	✓	✓	x	✓	✓	✓
The Methods Lab-User Research for Design	✓	x	x	x	✓	✓	✓
Helen Hamlyn Centre for Design	✓	✓	x	✓	✓	✓	✓
IDEO	✓	✓	x	✓	✓	✓	✓

**Table 2.4 Summary of format of information**

**The content and tone of each website is discussed in more detail below:**

### **1. Inclusive Design Toolkit**

This website contains information relating to the processes and tools used to support inclusive design. Its content and tone is introductory and instructional, written using clear simple language. A key feature of this website is that each section contains hyperlinks which signpost the reader to other relevant sections. For example, in the ‘observe users’ section there are links taking the reader to other websites (such as [www.designingforpeople.org](http://www.designingforpeople.org)) which contain information on methods and ethics.



One of the tools on the website is the exclusion calculator. This helps a designer to determine how many users within a given population would be excluded by the product designed, based on its demands. After data is entered by the use of sliders or questions, exclusions are calculated. There are also options to order various capability simulators such as glasses. A purchasable software simulator is also available. In addition, a design log and checklist are available to help designers consider what they are designing and the requirements they need to meet. As well as practical tools in relation to inclusive design, there are tools to assist designers in building a business case for inclusive design. Lastly, there is an example set of personas based on a family.

However, despite the range of helpful and innovative tools on this website, it should be noted that a significant weakness of this website is that there is no specific information in relation to designing for SCAN users.

## **2. Designing with people.org (website)**

This website is divided into six sections entitled 'home', 'people', 'activities', 'methods', 'ethics', and 'contribute'; these sections provide an introduction to the subject. Within the 'people' section there are ten profiles of real people who have differing abilities, with each person providing the following information within the 'profile' section:

- What I can do
- What I cannot do
- Occupation
- My condition
- Good conditions
- How they improve my life
- A typical day
- Lessons for designers
- Poor designs

- How they impact my life
- Five most important aspects of my life
- Message for designers

The section 'message for designers' provides quite an impact. It is written in the first person and provides the reader with an insight into that user's life, both in terms of design and the wider context. The 'activities' section illustrates key activities relating to daily living which are outlined to enable the designer to explore the context of designing with people. It explores the tasks and routines that are part of peoples' everyday lives and sensitive issues such as bathing. Furthermore, it highlights how creative solutions can be designed, for example, lingerie for SCAN users. The 'methods' section outlines twenty research methods ranging from the conventional interview to the less well known, such as cultural probes. This section also offers advice on how to select the most appropriate method. However, there is no specific information in relation to working with SCAN users.

**The description of the methods includes:**

- What the method consists of.
- Which stage of the design and evaluation process it is most suited to.
- Inputs required, for example, staff costs and time.
- Characteristics of the method.
- Examples of how and where interviews can be used in the design and evaluation process.
- Further reading in relation to methods.

Lastly, the website provides a section on research ethics. This is, by its own admission, an introduction to the topic. It outlines six principles for ethical research. These are outlined in brief paragraphs which provide step-by-step guides on how to contact participants, gauge consent and has links for further reading. The last section allows designers to contribute their own knowledge. This could be a suitable outlet for the guidelines produced in this research.

### **3. Helen Hamlyn Centre for Design**

The website is divided into five main sections with each of the sections having sub-links.

- Section 3- Research Labs - this provides an introduction to each of the three main research areas of the centre. A link provides more information about each research area, such as age and ability. Under sub-section 3>Age and Abilities Research Lab>theme 4>the business of inclusive design, the website signposts users to a number of resources that will aid them in the inclusive design and evaluation process, for example, [designingwithpeople.org](http://designingwithpeople.org) and the Methods Lab. Both the Methods Lab (booklet) and [designingwithpeople.org](http://designingwithpeople.org) (website) do contain information in relation to methods. The website does not contain any information in relation to design research methods.

### **4. The Methods Lab**

Unlike the other resources, this is produced in a booklet format. Similar to [designingwithpeople.org](http://designingwithpeople.org) it offers information on the inputs required and the expected outputs for each method such as time taken and costs. Each method is divided into a typology: there is often more than one method in a typology. Each method has its own individual page where it is examined in more detail and further reading is suggested. The booklet also contains information from contributors explaining their own method preference. However, this booklet does not contain any significant information on the selection of methods when working with SCAN users.

## **5. University of Cambridge-Inclusive Design website**

This website contains eight sections. It is based on a book entitled 'Countering Design Exclusion: An Introduction to Inclusive Design' by Simon Keates and John Clarkson. The first section includes an introduction to inclusive design. The second section provides statistical information on disability. The third section provides some definitions of commonly used design terms. The fourth section outlines some approaches to design, for example, top/down or bottom/up.

In the fifth section (design process) under the sub-heading 'user expectations' some basic information in relation to research methods is given. These include 'questionnaires, interviews, user observation, focus groups and ethnographic methods'. This extends to a definition of what the method is and an outline of advantages and disadvantages is provided. Additionally, in the assessment, eight methods are outlined, four of which can be used with end users, for example, user observations, user questionnaires, user trials and user interviews. The information displayed on these methods is minimal. There is no information in relation to utilising the selected methods with SCAN users.

## **6. IDEO Methods Cards**

These cards are similar to flash cards and help designers to understand the people they are designing for. They explain and outline a number of different methods that can be used during design and evaluation processes. The information contained on these cards is limited to how and when the methods are best used and how they can be applied to real design projects. These cards are designed to assist researchers, designers and engineers when selecting appropriate research methods.

There are four decks of cards, these are:

- Ask
- Watch
- Learn
- Try

However, as illustrated in figure 2.1 whilst these cards are undoubtedly useful they do not contain any information on how these methods could be applied when working with SCAN users.

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancaster Library - Coventry University.

**Figure 2.1 An example of an IDEO method card**

## 11. Summary

This chapter has covered literature relevant to design research with SCAN users, including a review of current resources available to designers.

The literature has been presented in categories, though these are not discrete boundaries and there is considerable overlap.

Legislative frameworks have been outlined primarily from the UK perspective. These provide a legal context for designers' responsibilities in designing for SCAN users, and are identified to be typical of legislation in other countries some of which may be at an earlier stage of development.

Models of disability were outlined and discussed, the older, more limited Medical model versus the newer Social model.

Design and disability utilised four key papers to provide exemplars of some problems and opportunities for working with SCAN users. This was followed by discussion of additional studies outlining, for example, the value of mixed methods. Further details are in Appendix D.

Public attitudes showed still much ignorance of the nature of disability, as well as some hostility. Attitudes of designers may also lack knowledge and perhaps empathy or SCAN users' needs may not be sought due to the cost of further intervention in the design cycle. There are perhaps implications here for design education.

Models of designing showed methods for design in the context of SCAN users, including collaborative and other user-centred concepts. Studies of designers working with SCAN users showed varying attitudes. This section reinforced the notion of user-centred design and the movement towards design for a wider range of users.

Methods were summarised, and work on potential methods relevant to this study were reported, including working alongside users and the use of multiple methods to understand needs. The section also concentrated on a comprehensive review of 23 broad and well documented methods potentially for working with SCAN users. For reference, a full breakdown of these techniques is shown in Appendix D.

Additionally, websites and associated material provide useful and usable information for designers and academics and support ISO standards such as ISO/TR 16982:2002(E) and ISO 9241-210:2010(E) for user-centred design. In producing these resources, the design community is responding to the inclusivity agenda, that is how it develops cultures, policies and practices to include all users (adapted from Hayward, 2006:2). Many of the resources studied contain practical guidance with the information being presented in an accessible format.

However, although different research methods are described, and these overlap with those referred to in the focus groups, there is no detailed information on how to select the most appropriate research method for working with SCAN users, or how designers should approach working with this group.

The websites reviewed here also provide an indication of the mode of presentation for the guidelines. It may be highly advantageous for the success of any published guidelines to be presented in a similar way to the resources outlined, that is visual and includes more than one medium.

Though publication is beyond the scope of this study, a further review was undertaken of potential formats for publication, and an analysis made of the advantages and disadvantages of different formats. The results of this further review are contained in Appendix G.

Overall, although much has been written in relation to the many approaches designers can adopt when wanting to include users in design and evaluation processes there is insufficient literature related to the suitability of the methods used to support these processes. This is concerning because as Roberts and Fels (*op.cit.*) remark, many of the methods used to support design and evaluation processes are not designed to include SCAN users.



### 1. Introduction

When undertaking research it was important to consider whether the methods employed were appropriate and valid within the context of the research being conducted.

When considering the appropriateness of methods to be used, the following were evaluated:

- The type of data.
- Collection and analysis.
- The appropriateness of the method.
- The accessibility and acceptability of the chosen methods.

Given the above, this chapter provides an explanation of, and justification for the methods used and their philosophical underpinning and traditions. Additionally, this chapter also contains detailed information on the research design, analysis of data and the generation of guidelines.

### 2. Philosophical grounding of the method

This section provides an explanation and justification of the epistemological and ontological groundings of the research i.e. how the researcher viewed and understood knowledge (epistemology) and how the research is viewed in the world (its ontology) (Crotty, 1998:3).

**It was important to consider questions of epistemology and ontology for four reasons:**

- By selecting certain methodologies over others, an ontological position was implicitly or explicitly adopted.
- It may have been difficult to defend and understand the position taken.
- The position taken by the author informed the methods used to gather data and thus answer the research questions.
- Answering these questions helped establish the nature of social entities (people) involved and which types of knowledge about these entities were valid.

In research dealing with people and their views, there is often a common misconception that it will only employ qualitative methods. However, both qualitative and quantitative methods can be used effectively in combination. For example, a quantitative method could be used to explore what issues designers and users have in relation to their experiences, and qualitative methods could be used as a vehicle to enable the participants to provide further details. The adoption of a mixed method approach can test the validity of the research by using a variety of data types or methods.

A researcher will bring their own interpretation and understanding of the world to the process. They may, for example, make assumptions about the importance of certain types of knowledge. In the research there was no single dominant methodological approach but rather there were elements of post-modernism, constructivism, interpretivism and modernism because in the data gathering stage “...no single authority, method or paradigm” (Denzin and Lincoln, 1994:15) was privileged.

There were elements of interpretivism because when talking to both users and designers insights into the culturally derived and historically situated interpretations of the social life-world were sought (adapted Crotty *op.cit.*). Finally, the most prominent philosophy in the research was constructivism.

This is the view that;

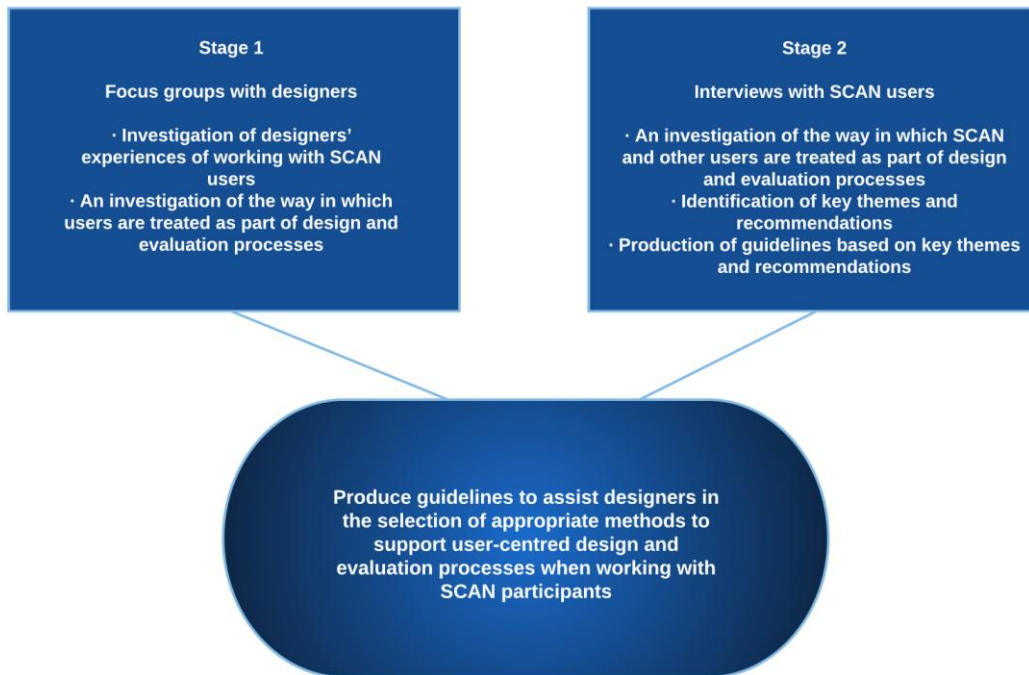
*“All knowledge and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context.”* (Crotty, *ibid.* pp 42)

The outcomes of the research were based and relied on human practices which were constructed as a result of interactions between the participants. The participants' environment and the knowledge that is created was developed and constructed within a social context.

### 3. Research design

The aim of the research was to produce guidelines to assist designers in the selection of the most appropriate methods to support user-centred evaluation or requirements gathering when working with SCAN participants.

The specific means to achieve the aims are detailed in the introduction and in figure 3.1.



**Figure 3.1 illustrates how the research objectives map to each stage of the research**

Note that, the term ‘designer’ in the context of this project referred to any member of a design team and/or clinician that have worked closely with end users. Users were defined as a single person, or a specified user group, that had or did not have SCAN.

The various procedures and processes that were used when conducting the research were outlined (adapted from Rajasekar, Philominithan and Chinnithambi 2006:2).

At this stage, great care was taken in the consideration of appropriate methods to support the research because as stated by Glasby and Beresford (2006:281) “...*the ‘best’ method for researching any given topic is that which will answer the research question most effectively.*” Additionally, the methods selected for the research have to be capable of not only answering the question effectively, but also being accessible to participants included at each stage of the research. Therefore, the methods used were similar to that as outlined in a report by Scope where they utilised a mixed methods project (adapted from Aiden and McCarthy 2014:5).

The following sections provide justification for the choice of methods employed. It is interesting to note that Glasby and Beresford (*op.cit.*) state that “...*proximity to the object being studied can be more appropriate than notions of ‘distance’ and ‘objectivity’*”. The aims and objectives of the research support this notion: the research involved close proximity to the area under investigation (SCAN users and designers) and the researcher has a disability which further increased his proximity to the research. However, objectivity was maintained.

Lastly, Glasby and Beresford (*ibid.* pp 281) remark that;

*“Our traditional quest for quantitative, ‘objective’, systematic knowledge will need to be replaced with a more questioning approach which constantly asks which stakeholders may be able to contribute to the debate, whose voices usually get heard in such debates and who decides what constitutes valid knowledge.”*

When selecting methods for the research, this point was also considered and thus it was hoped that the methods selected should enable all stakeholders to contribute to the debate and consider what constitutes knowledge.

### 3. 1. Positionality of the researcher

It was important to understand and consider positionality, as the positionality of the research would have implications for how the results were presented and thus how they were perceived. The fact that the author of the research could be considered as a user with an additional need was not in itself the issue but rather how he perceives his additional need and how those perceptions influence his view of the world. This may have some implications, for example, the credence given to one conclusion over another. Does the researcher's disability lead to systematic bias in the way participants interact with the research, or the way the results are interpreted by the researcher? Furthermore, the participants may be uncomfortable admitting in some cases that they either do not like or lack experience of working with users with additional needs to somebody that they may consider to have additional needs.

In stage 1, the researcher could be considered as an 'indigenous insider' as the research was being conducted from a design perspective but the researcher does not hold mainstream views in relation to the involvement of users in design and evaluation processes (Kirby, Greaves and Reid, 2006:39).

In reality, the user was viewed as having a role in the design and evaluation process at some level. The researcher considered that users should be involved in the design and evaluation process as much as possible and supported through the selection of appropriate methods although this does not always occur, for example, users may be involved but their views may not be fully represented due to the use of an inappropriate method.

In stage 2, the researcher's disability may have been advantageous as this stage involved talking to participants that have some form of additional need thus some commonality and empathy may be felt.

However, care was taken to ensure generalisations were not made, or that the researcher did not over interpret the responses. Thus the fact that the researcher is disabled could be the only common ground he shares with a participant. Given the above, for stage 2 the researcher may be viewed as both an ‘indigenous insider’ and an ‘indigenous outsider’ as some participants may feel that he has an empathetic understanding of their disability whereas others may not (Kirby, Greaves and Reid *ibid.* pp 39).

However there needs to be an acknowledgement by wider society that each disability is unique and thus the research was being conducted based on a research interest, an identified gap in knowledge and not primarily from the viewpoint of a person with an additional need. Furthermore, it was acknowledged that the researcher’s personal experience provided tacit knowledge and an ability to empathise which may have been valuable.

### 3.1.2 Reducing bias

Many types of bias can affect the validity and reliability of qualitative research, Table 3.1 outlines the most common sources and provides an explanation of minimisation strategies:

Type of bias	Description	Prevention strategy
<b>Facilitator bias</b>	This relates to the way in which a facilitator acts when conducting the focus group, for example, conveying obvious shock at a participant’s answer.	Instructed facilitator to remain neutral and objective.

Type of bias	Description	Prevention strategy
<b>Inappropriate questions</b>	The facilitator (or interviewer) asked the question but the participant misinterprets what was being asked and/or the question is badly structured or not appropriate.	<p>Piloted with representative sample.</p> <p>Questions were piloted for both stages 1 and 2 and any questions found to be leading or not neutral were removed.</p> <p>Simple, clear questions were produced to reduce the possibility of the participant misunderstanding.</p> <p>Unambiguous, appropriate language.</p>
<b>Question order bias</b>	The way in which questions were ordered could have given rise to bias.	<p>Use of introductory questions and prompts.</p> <p>General questions were asked before specific ones to put participants at ease.</p> <p>After the pilot stage, questions may be re-ordered.</p>
<b>Consistency bias</b>	The “...respondents try to appear consistent in their answers”.	If a participant’s responses seem to be following a consistent pattern, additional questions were asked to explore the reasons behind the pattern.
<b>Dominant respondent bias</b>	These were participants which dominated talk time.	Facilitators were told to be vigilant for dominant participants to ensure that every participant gets an equal amount of talk time.
<b>Error bias</b>	Participants can provide erroneous data.	Triangulation and verification against other sources of data.



Type of bias	Description	Prevention strategy
<b>Hostility bias</b>	Some participants may become angry with the facilitator or interviewer.	If this occurs persistently the interviewer/facilitator stopped or suspended to give the participant time to reflect on the motives for taking part in the research.  Piloting to remove any questions which may result in hostility.
<b>Facilitator acceptance bias</b>	Participants provide answers that they believe the facilitator/interviewer wants to hear thus giving answers that may not be a true reflection of their views.	Facilitators/interviewers were told not to reveal their personal views on a given subject.
<b>Mood bias</b>	Participants provide answers that reflect their mood.	Assess answers given by the participants.
<b>Overstatement bias</b>	Participants overstate their intentions or opinions.	Facilitators/interviewers were told to recognise and judge overstatements.
<b>Reference bias (Order bias)</b>	Participants develop a reference point from a previous question and carry it to the next question.	Focus groups and interview questions were logically ordered.
<b>Sensitivity bias</b>	Questions may raise sensitive subjects which participants may not wish discuss.	Trust was gained before broaching sensitive subjects.
<b>Social acceptance bias</b>	Participants provide socially acceptable answers, although they may think something else.	Facilitators/interviewers were instructed to challenge answers and use indirect questions that dealt with sensitive issues.

Type of bias	Description	Prevention strategy
<b>Biased sample</b>	A segment of participants that do not represent the group of interest.	Participants were screened for their eligibility against the criteria set out in this document before being invited to take part in the research.
<b>Biased reporting</b>	When a secondary factor, such as who is funding the research, or the journal in which it is published increases the likelihood that it's reporting is likely to be biased towards one position (Cochrane Biased Methods Group, 2011).	Being open-minded when analysing the research and maintaining an objective view point; asking for advice from supervisors and colleagues where appropriate.  Dual coding

**Table 3. 1 Descriptions of bias and minimisation strategies (adapted from focusgrouptips.com)**

### 3.1.3 Ensuring the rigour of the research

Research which is well planned explained and executed enables confidence to be placed in the results and conclusions and therefore demonstrates rigour. Rigour, in this context, was concerned with whether the research produced can undergo examination by an external party and whether that party can reach and justify the same conclusions based on what has been presented (adapted from Ryan, n.d:4). The following sections describe the steps that have been undertaken to ensure that rigour has been maintained in the execution of the research.

**Table 3. 2 (below) lists some threats to the rigour of the research and the strategies which were employed to minimise these threats:**

Threat	Minimisation strategy
<p>Questions asked and data gathering instruments used must reflect the stated objectives of the research stage<sup>1</sup>. Failure to do this would not only compromise rigour but also the research's validity. In terms of the four main types of validity, these are outlined in section 3.1.8.</p>	<p>Piloting of all research instruments with representatives from key participant groups and refinement of the tools based on feedback. This ensured the appropriateness of the research instruments.</p>
<p>Questions may have been asked that were relevant to the theory of research (objectives 1 and 2) but were inappropriate for the groups under study (Kirk and Miller, 1986). Additionally, if such questions were asked this may threaten the validity of the research<sup>2</sup>.</p>	<p>See above.</p>
<p>Response bias in the answers provided. This may occur through participants trying to assist the researcher by providing favorable answers, or trying to create a favourable impression.</p>	<p>Further information was sought where clarification was needed.</p> <p>Triangulation was used across methods and participants.</p>
<p>More credence may be given to responses given by certain groups.</p>	<p>The researcher maintained professional boundaries with participants at all times, thereby helping him maintain objectivity.</p> <p>The researcher ensured that focus group and interview notes and recordings were clear.</p> <p>Helping the researcher to report unbiased findings.</p>

<sup>1</sup> This relates to objective 1 and 2 for stage 1, and 2 for stage 2.

<sup>2</sup> The research may not measure its stated criterion and thus lack criterion-related validity.

Threat	Minimisation strategy
	<p>Ensured the researcher did not draw on on his own influences from the material analysed.</p> <p>Using supervisory team and critical friends to assist in moderating the analysis process.</p>
<p>It has been hypothesised that due to the positionality of the researcher (his disability), participants used for stage 2 may give answers that they see as pleasing to, or confirming of, the researcher's preconceptions.</p>	<p>It was accepted that in order to reduce bias it may have been preferable for the interviews to be conducted by a person who does not have an additional need. However, this may exclude some participants, for example, those that find it difficult to share their views and opinions with somebody who they perceive as having no empathy or understanding. It was for these reasons that a choice was offered and it was felt that this reduced bias as it enabled the widest sample of participants to be reached.</p>
<p>Interviewees and focus group participants may lack credibility or selection of participants may have been inappropriate (Rothe 2000:124).</p>	<p>Contact was made with participants before they were invited to take part in the research. The selection of participants was carefully considered and was based on an examination of literature and advice from relevant parties.</p>
<p>Insufficiency of data and lack of time allocated to sessions data or <i>"...an insufficient length of time may have been spent gathering data."</i></p>	<p>The output from focus groups and interviews were reviewed and adjustments made to the sample size and interview techniques if appropriate.</p> <p>Additionally, all investigators involved in the practical research ensured that participants fully expressed their views by:</p>

Threat	Minimisation strategy
	Offering participants frequent opportunities to re-visit what had been discussed and progressing the discussion at a pace acceptable to them.
Poorly trained facilitators and interviewers (Rothe <i>ibid.</i> 124).	Suitable training has been completed at doctoral level. Where assistants were used they were appropriately trained and briefed.
Bias in participant recruitment.	<p>The research strategy was approved by Coventry University Research Ethics Committee. The selection criteria were considered appropriate to a study at this level.</p> <p>Triangulation was used to reduce the effects of bias, for example, the data was examined from a variety of philosophical standpoints (theoretical triangulation).</p> <p>Recruitment bias was considered in the limitations to the study if appropriate.</p>

**Table 3.2 illustrates threats to the rigour of the research and the strategies used to minimise these threats (adapted from Rothe *ibid.* 124)**

### 3.1.4 Ethical approval of the research

Before commencement of each stage of the research, ethical approval was sought and gained from Coventry University Research Ethics Committee

(<https://ethics.coventry.ac.uk/about/ethics-at-cu.aspx>) It was this along with

piloting, double coding and reflection that minimised the threats (outlined above).

### 3.1.5 Ensuring the research has reliability

Reliability is “...*the repeatability of a particular set of research findings; that is, how accurately they would be replicated in a second identical piece of research.*” (The Association of Qualitative research n.d.a) Given the above, it could be argued that reliability is not an appropriate scale to measure qualitative research (due to the absence of “similar conditions”).

An unstructured interview is a dynamic encounter “...*between an active interpreting subject and an active interpreting researcher...in such circumstances, no interview will be the same...*” (adapted from Cormack 2000:37) because answers may arise from different circumstances of production (e.g. the participant’s mood).

Furthermore, reliability originates from the positivist paradigm (where qualitative research is not commonly situated). In addition, one such way of improving reliability was to ensure that measurement error was reduced. In this study, the following method was used to ensure that the themes extracted from the interviews and focus groups were both valid and reliable. 10% of transcripts from both the focus groups and interviews were sent to two different coders. If they agreed with more than 90% of the themes they were considered valid and reliable.

### 3.1.6 Ensuring the reliability in the data analysis

Reliability in any research extends to the procedures used to analyse data. In the first instance, the participant was asked to validate their answers, if a response was unclear. In addition to the above, a sample of the data was double coded and where there was a difference of opinion between researchers they were asked to give reasons for this and this difference of interpretation was noted in the results if a resolution could not be reached.

Type	Description	Prevention strategy
<b>Administrative</b>	Sources of administrative error can include:  Poor instructions;  Failure to follow experimental procedures;  Limited time available to elicit participants' maximum performance or complete responses.	Instructions given to focus group facilitators were clearly written and the facilitators were briefed and given an opportunity to ask any questions.  Experimental procedures were followed.  Sufficient time was given to allow participants to express their views.
<b>Environmental</b>	Environmental factors can be defined as "...noise, inadequate lighting, uncomfortable room temperature, crowded conditions" in research venues.	All venues used were fit for purpose and clearly labeled as "private."
<b>Measurement characteristics</b>	Measurement characteristics are characteristics of the measure, for example, type of scales used, Likert, bipolar.	Each participant in a focus group or interview had the opportunity to respond to, where possible, the same questions and measures of opinion.  Where questions are reworded or adapted, adapted versions were comparable.
<b>Intra-individual factors</b>	The individual factors brought by the participant to the focus group or interview such as boredom, ill health or fatigue were some of the most difficult measurement areas to control.	Participants in both focus groups and interviews were offered the opportunity to have breaks and refreshments.  They were also reminded that they can suspend or terminate participation in the practical research at any time without giving a reason.

Type	Description	Prevention strategy
		Participants were assisted in any way possible to ensure that their experience of participation in the research positive.

**Table 3.3 illustrates common sources of measurement error (adapted from Goodwin and Goodwin, 1996:78)**

### 3.1.7 Triangulation

Triangulation refers to the employment of multiple data sources, collection methods or investigators when conducting research and its purpose is to reduce the disadvantages associated with the use of any single source, method or investigator (Long and Johnson, 2000:34). Because triangulation has this effect, its use can also increase people's ability to interpret findings and whilst it does not strengthen a flawed study (Thurmond *ibid.* pp 253) it can help to increase:

- Rigour (as its use can increase confidence in research data) (Jick, 1979)
- Validity
- Strength

Increasing strength and interpretive validity could provide a threat to the rigour of the research because they were subjective that is based on opinion, whereas rigour should be objective (based on facts), thus an increase in subjectivity can decrease objectivity.

However, because triangulation reduces investigator bias it was an ideal strategy to use in research of this nature. Additionally, its use can help provide multiple perspectives which would be advantageous.



For example, what was said by a designer in stage 1 may also be an issue for an interviewee in stage 2 thus providing increased reliability and validity.

Denzin (*ibid.*) proposes four different types of triangulation; data triangulation, investigator triangulation, theoretical triangulation, and methodological triangulation.

- **Data triangulation**-gathering data through several sampling strategies.
- **Investigator triangulation**-refers to using more than one researcher to gather and interpret data.
- **Theoretical triangulation**-the use of more than one theoretical position when interpreting data.
- **Methodological triangulation**-the use of more than one method for gathering data (adapted from Denzin *ibid.*)

In relation to methodological triangulation, this may be possible, as the research employed mixed methods (focus groups for stage 1 and interviews for stage 2) and whilst these methods were employed at different stages of the research, the information gathered provided similar conclusions thus there may be some triangulation of the data.

Lastly, in relation to investigator triangulation, it was possible to use some aspects of this, in that the data gathering was conducted by different people using different methods. In addition to this, help and advice were sought from relevant parties when analysing the data.

### 3.1.8 Ensuring the research has validity

In the context of the research, validity refers to whether the research accurately measures or represents what it claims to (Association of Qualitative Research n.d.b). The most common forms of validity are outlined in table 3.4 and described in relation to the research.

Validity type	Description	How it was achieved in the research:
<b>Face validity</b>	Whether the research instruments appear to measure what they claim.	The questions have been informed by a literature review. All questions were piloted using critical friends and a pilot study.
<b>Content validity</b>	Does the research reflect the domain under study and its content?	See above.
<b>Criterion-related validity</b>	Do the research instruments used provide a measure of established criterion <sup>3</sup> ?	The questions have been designed to enable participants to reflect on their experiences of working with those that have additional needs, specifically, in terms of the user-centred design or evaluation methods they used to engage with such users.
<b>Construct validity</b>	This is “... <i>the degree in which an instrument measures the trait or theoretical construct that it is intended to measure.</i> ” (Miller n.d.:3)	The pilot stage provided an indication in relation to construct validity.

**Table 3.4 Validity types (adapted from Carmines and Zeller (1979) and Changing Minds n.d.)**

<sup>3</sup> Do the questions used in the focus groups provide a measure of designers' experiences in relation to working with those that have additional needs?

## 3.2 Position of the research question

There was also the aspect of positionality of the research, for example, in what context should the research be placed.

Is it a piece of research applicable to the design community only?

Is it research that examined methodological choices when conducting research with participants that have additional needs and thus would be better suited in the field of social science or disability studies? Is it a cross-disciplinary piece of research that could have implications for both fields?

Undoubtedly, the design community values involvement from users when designing or evaluating products. However, difficulties have been highlighted, for example by Goodman *et al.* (2007) in relation to many young designers, who may not be able to empathise with the users for whom they are designing. This can be especially true when designing for users that have SCAN thus it would be logical to conclude that research that looks at designers' attitudes, experiences and perceptions of designing for within this group, perceptions of design and evaluation processes, would be well positioned within the design research community.

However, the research also fits well within the field of disability studies and inclusivity as it seeks to produce guidance in relation to the appropriate selection of research methods when gathering the views of those with SCAN therefore it was positioned closely alongside advocates of the 'Social model of disability' (cf. Ch.2) because the research seeks to identify barriers to the participation of those that have SCAN needs in a design or evaluation process of a product or service, and propose solutions to these.

It is acknowledged that the research refers to research methods within a design context, however, it is hoped that practitioners in other fields may find the conclusions useful when conducting research with SCAN participants.

Given the above, it was concluded that whilst the research is conducted within a design context, it may have some use in a broad range of research disciplines. Additionally, because the research examined barriers to inclusion within the context of the design and evaluation process, it may have some relevance to the field of disability studies.

### **3.3 Pilot development stage**

The two stages of the project were piloted to ensure the data gathering materials, procedures and questions used in each stage were relevant, usable and accessible for all participants. The questions used in the focus groups were examined by experienced focus group facilitators and designers to ensure they were unambiguous, understandable and contribute to meeting the aims and the objectives of the research.

Similarly, the questions used for the interviews were sent to disability experts for their comment. All procedures were piloted in their respective settings using representative participants and critical friends.

Feedback gathered from the pilot stages informed the development of materials and procedures used, by, for example, removing ambiguity in questions or checking that a question provides the expected response. Amendments were made to the procedures, materials or questions if required.

### **The format of the pilot study was as follows:**

- One focus group consisting of two designers and two critical friends at least one of the designers had experience of designing for those that have SCAN (stage 1).
- Interviews (two with people that had SCAN and two with people that did not have SCAN, the interview questions were also reviewed by two critical friends (stage 2)).

The main aim of the pilot study was to ensure methodological rigour and that the work had scientific validity (Lancaster, Dodd and Williamson, 2004) and through mock analyses the statistical and analytical procedures can be thoroughly checked to ensure that they were useful and correct (Woken, n.d.).

### **3.4 Stage 1: Focus groups**

The first objective of the research was to investigate designers' experiences of working with SCAN users, for example, "Was the experience positive or negative?" "What went well and why?" "What went less well and why?" and "What would they improve if they had to do similar work in the future?"

In order to meet this objective, a method that allowed designers to present their views in a friendly, non-threatening and supportive environment was needed to obtain the most appropriate recommendations and thus increase the overall impact of the research.

Additionally,

*“...group dialogue tends to generate rich information, as participants’ insights tend to “trigger” the sharing of others’ personal experiences and perspectives in a way that can more easily or readily tease out the nuances and tensions of complex topics and subjects-a dynamic that is not present during key informant interviews.” (OMNI 2004:15).*

It was this aspect of the focus group method that was highly advantageous as it was hoped designers would share their experiences of working with SCAN users.

Furthermore, given that an interview is usually conducted in a one-to-one situation with an interviewer asking questions and a participant responding, this can sometimes appear to be formal and threatening to potential participants, especially if they are asked to deal with subjects that could be highly emotive or personal. Additionally, participants could be reluctant to report problems to the interviewer as they may not wish to show personal inadequacy (Henderson *et al.* 1995).

In addition to the above, if a questionnaire was used it would not easily allow for responses to be clarified, whereas a focus group allows for this.

Focus groups also provide a feeling of safety in numbers (Kroll, Barbour and Harris, 2009). This again, is advantageous given that some designers may have to admit that interactions didn’t go as well as they had hoped.

**However, focus groups have their limitations; some of which include the following:**

- Can be subject to “facilitator bias” which can compromise the validity and reliability of data gathered-to reduce the effect of this, questions that require a yes/no answer or leading questions were avoided. Also facilitators were instructed not to pose questions in such a way that they cued the participant to give a certain answer (OMNI *op.cit.*). In addition to this, the themes used to aid the discussion were written in such a way so as not to be leading, judgemental, or threatening.
- The discussion can be side tracked or dominated by individuals. Facilitators were advised to pay careful attention and should either of these start to happen they should attempt to refocus the discussion and/or state that they wish to give everybody a chance to have their views heard (OMNI *ibid.* pp 9).
- In a group setting, some people may have difficulty thinking creatively and prefer to be interviewed or to undertake a survey (Langford and McDonagh, 2003:74).
- Where a research participant was contacted and they stated that they did not feel comfortable in a group setting they were offered the option of being interviewed over the phone using the same themes for discussion as the focus group or interview.
- Important information can be generated by focus groups, yet it often has limited generalisability to a whole population (OMNI *op.cit.*) Care was taken to ensure that the participants recruited had varying levels of experience and came from a diverse number of design backgrounds thus ensuring that the data gathered was reflective of the widest possible population.

Three focus groups were conducted, containing four participants as recommended by Kitzinger (1995).

The reason for the small size of the focus groups was to enable each participant to provide meaningful information on each of the themes presented. Two groups consisted of designers who have worked with SCAN users. The third group contained designers who have not worked with SCAN users (control group). The designers in this group had significant experience of designing within a user-centred context. This group also established the sorts of problems designers face when working with non-SCAN users to identify any differences or similarities.

Additionally, when the material was analysed, recurring themes were identified as these provided the basis for guidelines.

## **4. Experimental procedure**

### **4.1. Before the focus groups**

Participants that were recruited to take part in the focus groups were sent (either by post or electronically) a copy of the focus group themes relevant to them either SCAN or non-SCAN designers a minimum of two weeks before the focus group took place. This was to enable them to reflect on, and prepare for, the topics that were discussed in the focus group.



## 4.2 Format of the focus groups

**The focus groups were divided into three parts:**

- 1) An introduction (20 minutes)
- 2) The discussion (approximately 50 minutes with five key themes for discussion)
- 3) Debrief (20 minutes)

### 4.2.1 Stage 1: Introduction

During the introduction, participants were asked to talk about their level of experience in terms of designing for users with SCAN; the facilitator then outlined some expectations and the aims of the session, to ensure that the focus group proceeded in a calm, ordered and respectful manner. Furthermore, by stating the aims of the focus group the facilitator set out the boundaries for the discussion and participants were made aware of the content and the parameters. Once the expectations and the aims were outlined, the facilitator also summarised the purpose and format of the focus group that is an informal discussion to explore the participants' experiences of working with SCAN users; split into five topics for discussion, with each topic being discussed for 10 minutes.

Lastly, the facilitator stated that participants were required to participate in the discussion but that it was not a test and there were no right or wrong answers (adapted from USAID, 1996:4 and OMNI, n.d. *op.cit.*).

### 4.2.2 Discussion

In this section the five key themes of the focus group are discussed; the themes for discussion are outlined later in this chapter.

### **4.2.3 Debrief**

The debriefing allowed the participants and facilitator to clarify any remaining issues and summarise what was discussed during the session. Participants were given opportunities to ask questions, provided with a debrief letter and advised who they should contact regarding any further queries.

## **4.3 Set up of focus group venue**

The focus group was conducted in a usability lab in the Bugatti building at Coventry University. This was to enable the session to be audio and video recorded for analysis purposes. Participants were seated in a “u” shape format so that they could see each other (adapted from Simon, 1999:6).

### **4.3.1. Management of the focus group**

The focus groups were managed by a facilitator to ensure that the discussions taking place were relevant to the topics presented. This helped prevent the discussion being dominated by one single or a group of participants. A note taker was responsible for writing notes detailing the events of the session and was asked to pay particular attention to aspects of the session that may not be fully illuminated by the video recording, for example, a participant’s body language. It was important to do this as body language can often provide useful information that can support or refute what a participant was verbally communicating.

This is supported by Argyle *et al.* (1970) who states that;

*“50% of the meaning is inferred by observing the physiology of another person...his studies identified that non-verbal communication has three main functions: conveying interpersonal information through body language; to support verbal communication with additional non-verbal signals such as grunts or nods which offer and seek feedback.”* (Wake, 2010:43)

However, the note taker's primary job was to assist the researcher so that he could note down any observations he makes (as he cannot hand write). However, the note taker sat with the researcher in a separate room and was not present at the focus group.

As mentioned above, the focus group was video and audio recorded using the sound equipment and cameras located within the focus group venue. The note taker assisted the researcher as it supplemented the audio and video data and provided a richer analysis (Kitzinger, 1995). In addition to this, the note taker was also responsible for documenting exchanges of views and the general content of discussion and noted which statement was made by which particular individual, thereby supplementing the oral text and enabling a fuller analysis of the data (Kitzinger *ibid.*). Care was taken to ensure both the focus group and interview information accurately reflected the views or view being expressed by participants and where clarification was needed it was asked for. Where required, a response was summarised by the facilitator and discussed with participants, for example “so you are telling me ‘x’, is that correct?”

A facilitator was selected who could:

- communicate clearly,
- listen carefully and sensitively,
- guide the conversation,
- control the participants and encourage them to respond,
- make participants feel that their responses were valued,
- maintain discussions focused on the aim of the study (adapted from Barrett and Kirk, 2000:627).

In a study conducted by Barrett and Kirk (*ibid.* pp 627), where they utilised focus groups with the elderly they found that “...*facilitators of similar age were found to be effective in putting participants at ease.*” This suggests there may be some benefit in the facilitator being either closely associated with, or a member of the group under study, thus it may be beneficial to ask either a designer or a person with a design background to moderate the focus groups.

Participants were asked to contribute their experiences of working with SCAN users. Some semi-structured discussion questions were used as a stimulus if required. However, it was important that participants were given enough freedom to express their views whilst not deviating from the subject of the discussion. Participants were asked to discuss their experiences and reflect on how well the interactions with the SCAN users were conducted. It was acknowledged that no designer would admit to having conducted research that excluded participants due to the use of inappropriate methods.

During the session, participants were asked what they learnt from their interactions with SCAN users and if they would be willing to share their reflections about these experiences such as how they felt and what they learnt.

It was important to note, that due to the principal investigator's positionality it was not appropriate for him to be in direct contact with the focus group participants and he sat in a separate room, where he could witness the discussion and direct where needed.

The focus group did not only examine designers' experiences of working with SCAN users, but what they would do differently, or if they had any advice for their colleagues; these two aspects were important as they contributed heavily to the guidelines produced. Designers were asked to focus on the methods they used to evaluate the products they designed and the specific issues raised when using these methods with SCAN participants.

Designers were drawn from a wide range of sources (see section 7). Such recruitment took place by email and through personal and professional contacts.

#### 4.3.2 Analysis

Data collected from the focus groups was analysed using thematic analysis. This may be defined as “...a method for identifying, analysing, and reporting patterns (themes) within data. It minimally organises and describes your data set in (rich) detail. However, it also often goes further than this, and interprets various aspects of the research topic...” (Braun and Clarke, 2006:6, Boyatzis, 1998). Furthermore, it will allow “...high frequency patterns to emerge as meaningful themes in the research.” (Aronson, 1994)

The data (video, audio and written) was first transcribed, read and re-read to identify key themes; these themes were then categorised and coded. Using thematic analysis enabled the data to be grouped in terms of key theme.

It is important to note that any theories proposed as a result of the research largely came from structured analysis of the data (grounded theory) (adapted from Glaser and Strauss, 2009:2).

Information was extracted relating to designers' experiences of working with SCAN users and their reflections on these experiences as well as any advice. This included advice that designers might give in relation to working with SCAN users.

### **4.3.3 Summary**

By the end of this stage it was hoped that the data gathered provided an insight from the perspective of the designer in relation to issues faced when working with SCAN participants. It was hoped that the designers' perspective relating to how to resolve some of the highlighted issues were understood as a result of the sessions. The perspective of the designer informed the questions used in the face-to-face interviews with SCAN participants as it enabled an understanding of the issues faced by a designer when working with such participants and explored whether the issues were different or similar from the perspective of the user.

### **4.3.4 Justification for the selection of the focus group method**

The main reason for the selection of the focus group method was that it enabled participants to share experiences, observations, thoughts and feelings (adapted from Kuhn, 2000:310). Furthermore, the focus group method was appropriate because it facilitated knowledge sharing and exchange.

**Additionally focus groups:**

- allow people to air their views in a natural conversational way;
- enable a wide variety of perspectives to be sampled quickly;
- do not require special equipment;
- are comparatively easy to conduct if led by a trained facilitator;
- participants normally enjoy taking part in them (adapted from Maguire, 2003:73).

In this study it was considered important to create an atmosphere where designers felt comfortable and at ease, so they could share what may be challenging, difficult and in some cases highly emotional experiences of working with SCAN users.

A focus group that is conducted with proficiency can provide a friendly, supportive and informal atmosphere to facilitate the sharing of such experiences. In order to achieve the above, a trained facilitator was used to facilitate the focus groups; this helped put the designers at ease which in turn lead to a better quality of data being gathered.

During a focus group, a wide range of perspectives can be sampled quickly, this means that the time required to conduct the focus groups and analyse the data is kept to a minimum. Because a focus group does not require specialist equipment it can be thought of as an economically sound method when compared with other methods such as interviews. In addition, focus groups can be held at one time, in one place thus making the method ideal for designers, many of whom find time to be a valuable commodity.

However, contingency plans have been made should designers find it difficult or impossible to attend a focus group. Furthermore, as focus groups can be enjoyable, this factor may make it easier to recruit participants. According to Kuhn (*op.cit.*), focus groups guarantee a user-informed design process.

This again, made the method suitable for the research as the objective was to produce guidelines that will assist designers when working with SCAN users.

Another advantage of the focus group method as stated by many authors including Kitzinger (*op.cit.*), Kroll, Barbour and Harris (*op.cit.*), Kandampully, Mok and Sparks (2001:175), Greenbaum (2000:12), Bloor (2002:34), Wilkinson (1995), Rowley (2006:183), Patton (2002:389) was that the method can provide participants with the feeling of safety in numbers.

It was expected that this feeling will arise from the knowledge that all of the participants shared the status of “designer” (adapted from Bloor *op.cit.*) and thus encourage the participants to share experiences. The focus group may also act as a medium for designers to share advice between themselves as well as bring their knowledge together.

The decision to use this method was based on the factors outlined above and an extensive literature review which examined the suitability of other methods such as interviews, questionnaires and direct observation.

## **5. Stage 2: Exploring the experiences of SCAN users in relation to their involvement in design or evaluation processes**

The aims of this stage of the research were:

- To explore the experiences of SCAN users in relation to the design process, specifically, in relation to requirements gathering and evaluation.
- To discuss strengths and weaknesses of user requirements/evaluation methods the participant has had previous experience of, and if weaknesses were highlighted possible solutions to these were outlined.



- To enable participants to have their views heard in a friendly, non-threatening, relaxed, highly adaptable and flexible environment.

In order to fulfil these objectives, an interview format was used. An interview can be defined as a two-person conversation initiated by the interviewer (researcher) for the specific purpose of obtaining research relevant information (adapted from Cannel and Kahn *op.cit.*). In the case of this project, the opinions of SCAN participants who have been involved in design (and those who have not) together with evaluation processes were sought with a view to developing a set of guidelines that will aid designers with more appropriate selection of requirements gathering or user-centred evaluation methods.

Robson (*op.cit.*) states that semi- structured and unstructured interviews can be delivered informally. This was advantageous when working with SCAN participants as many may take longer to present their ideas thus an informal structure may help the participant feel at ease and further accommodate their needs such as rest breaks between questions.

As well as the factors outlined above, there were many other reasons why the use of interviews was highly appropriate, these included

- 1) Interviews were suitable when a large amount of open ended questions were asked. It was highly likely that a significant amount of open ended questions will need to be asked because of the unique nature of the participants' life circumstances and experiences.
- 2) Interviews can allow the research to be explained comprehensively thus minimising misconceptions. This was useful with SCAN participants as some may have difficulties in relation to comprehension and/or language processing, for example they may not understand an initial explanation.

Furthermore, an interview situation can allow explanation using different words and phrases until the participant understands.

- 3) Interviews can be highly appropriate for participants that have a physical impairment or have a reading difficulty. In these interviews some of the participants had physical impairments and/or had a reading difficulty.

However, it should be noted that some participants had other difficulties, it was hoped that by working with these participants, mechanisms can be found to enable them to contribute.

- 4) Body language can give additional information that may complement or refute a verbal response. In research involving SCAN participants their body language can be crucial as the participant may be non-verbal or may only have a limited amount of verbal communication, thus body language can act as an additional aid in understanding the users' contributions. It may also assist in tailoring the questions asked.

- 5) An interview can provide rich and highly illuminating material, for example, relating to a participant's life circumstance thus it can provide a medium that allows the participant to share highly valuable tacit knowledge. It was this that the proposed research sought to uncover as this material may help designers to better understand SCAN users and thus enable them to select appropriate methods to use when gathering their input.

- 6) An interview situation can allow the interviewer to ask additional questions based on responses given to previous questions thus enabling additional information to be uncovered (adapted from Oppenheim *op.cit.*, Brink and Wood *op.cit.*, Robson *op.cit.*)

Robson (*ibid.*) states that both semi-structured and unstructured interviews allow the style of questioning to be adapted based on:

- the participant;
- their needs;
- what questions were most relevant to them;
- their levels of understanding and comprehension, for example, simplified versions of the questions have been produced.

In addition, if the participant required the interview questions to be presented in a different format they were frequently reminded both in writing and by the researcher to contact him to discuss these requirements, then the necessary arrangements were made.

Given the above, a flexible interview structure was designed in which the interviewee was able to set many of the parameters of the interview (where, when and how they were interviewed).

Participants were given as much time as needed to respond to questions. They also determined how they presented their input such as how they answered the questions, for example, in a written format, speaking to the researcher or using a communication device. In order to enable this, when the participants were initially contacted, their additional needs and requirements were assessed, and provision made for this in the data collection procedures, for example, participants that struggle/have difficulty with verbal communication may prefer to receive questions in written form and respond in the same manner. They may write their responses to questions posed and therefore will require the interview questions to be written down and given time to respond in this format.

However, it was important to be able to have a mechanism for clarifying what was “said” by a participant; hence an adapted interview format where the researcher was present would be advantageous.

The interview questions were distributed to the participant as soon as they expressed an interest. This enabled the participant to have sufficient time to understand the questions and formulate responses.

However, it was acknowledged that standard interviews would not be accessible for non-verbal or deaf participants and thus these participants were consulted before their “interview.”

Additionally, the use of interviews was advantageous in a project such as this because according to Blaxter, Hughes and Tight (2006:173) interviews allow the participant to “...*discover, uncover or generate the rules by which they are playing this particular game.*”

This made the interview a particularly useful tool where participants were being asked to recollect their own experiences of being involved in design and/or evaluation processes.

When working with SCAN users it was important to hear the users’ voice in a way that is appropriate as they can have very diverse and challenging needs which can sometimes be difficult to meet, thus a highly flexible method was advantageous.

It was acknowledged that a structured interview where participants were asked set questions was not the most appropriate method to use with participants that have additional needs. With this in mind, the format of interviews was semi-structured these were an informal discussion with prompts being used where appropriate.

This methodology was not dissimilar to that used by Kitchin (2000:27-28) in that the themes discussed acted as the interview guide and interviewers were encouraged to, where appropriate “*vary the wording of the questions and the sequence in which the questions are tackled*” (Kitchin & Tate 1999).

This level of flexibility was required because some of the participants had one or multiple disabilities, including but not limited to:

- Communication difficulties
- Emotional and cognitive impairments
- Mobility issues
- A mental health diagnosis
- Sight impairment
- Hearing impairment or
- Learning disabilities

And therefore a rigid structure of interviews may be inappropriate.

An interview which has been designed to take into account the communication issues may require further structured tailoring at the level of the questions. In addition to the above, a participant with a mobility issue, for example, may require the interviewer to travel to them rather than vice-versa. Lastly, a major reason for using one-to-one semi-structured interviews was that some participants may require extended breaks in the interview for reasons related to their disability. It was felt that this method enabled these breaks to occur without causing too much disruption.

Given the above, it was reasonable to surmise that using semi-structured interviews allowed the interviewer, through flexible questioning, to ensure that the users’ voice and the users’ voice alone was heard and that their specific needs were met whilst still allowing them to participate.

To ensure that this was the case, once a question was answered and the participant gave an indication that they would like to move on to the next question, their response was summarised thus giving the participant the opportunity to correct, amend or add any additional information if they wished. If they decided to add additional information, the above process was repeated.

Additionally, at any time during the interview the participant could add, amend or correct information as they wished. At the end of the interview, responses to all questions were summarised and the participant was given a final opportunity to edit their responses to individual questions.

As stated above, if the participant had a communication difficulty they were given additional support. This could take the form of rewording the question, giving the participant sufficient additional time to answer the question, allowing them to present their input in a way appropriate to them and/or using support workers.

## **5.1 Format of interviews**

Interviews were held with SCAN participants who have participated in a design or evaluation process and a control group who have not. This necessitated the use of different interview protocols in order to explore barriers in participant selection and engagement processes. Questions were only used to aid discussion thus they were adapted to enable the participants to express their views.

Each semi-structured interview was conducted at a time, place and in a manner convenient to the participant. As a guide, it was anticipated that each interview would take approximately 90 minutes. Each interview was conducted by the researcher (or an assistant if the participant wished) and was video and/or audio recorded.

It was felt that the researcher was well placed to conduct the interviews with SCAN participants, as he himself is affected by disability and thus may have some empathy with some of the participants' circumstances. This enabled him to gain information from participants that they may have felt uncomfortable sharing with an able bodied researcher. According to Denscombe (2007:192) empathy is one of the qualities that make for a good research interviewer, some others are:

- 1) **Attentiveness** -this is ensuring that you are listening fully to the participant as well as looking for non-verbal cues and checking that the recording equipment is working properly.
- 2) **Sensitivity to the feelings of the participant**-it was hoped because of the researcher's personal experiences this increased his sensitivity to the needs of the participants, for example, checking the participant was happy and ready to move on or checking that all of the needs of the participant have been met to enable them to take part in the interview.
- 3) **Understanding silences**- a good interviewer will understand that a silence is not necessarily a bad thing. The participant could simply be formulating a response to a question. It was acknowledged that where participants have additional needs, for example, communication difficulties these silences can sometimes be very long but also from experience the researcher understands that, more often than not, these participants may require extra time to formulate and communicate their views.

- 4) **Knows when to prompt a participant-** whilst not forcing the participant to answer the question “...*the idea is to nudge the informant gently into revealing their knowledge or thoughts on a specific point.*” (Denscombe *op.cit.*).  
Prompts were only used as a last resort and extended to an explanation of the question or a rephrasing of it, for example, reword the question or repeat it.
- 5) **Knows when to use probes-** there were times in an interview where a participant’s response to a particular question warranted further explanation, for example, “can you give me any more detail about that?” In research of this nature, there was use for probes but only when they add something of real value to the questions asked. This was especially relevant to participants with additional needs, as when the participant has communication difficulties, they may become tired of having to repeat themselves several times.
- 6) **Asking for clarification-** one of the major advantages of interviews are that they offer the interviewer the opportunity to check that the information has been understood correctly. When working with those that have SCAN, one may frequently need to ask for clarification of what has been said to ensure that their views were not misrepresented.
- 7) **Does not judge-** a non-judgemental point of view should be adopted and as far as possible personal values should be suspended. Due to the researcher’s personal experience of seeing many disabilities at first hand he was aware that the judgement of people based on fragmentary glimpses was not advised. People can often make superficial judgements based on partial evidence or stereotypes.



- 8) **Respect interviewees**-understand that if a person does not wish to tell you something, for example, because the subject matter was sensitive, the individual's right to decline to answer a question should be respected (adapted from Denscombe *ibid.* pp 190-192).

The interviews were informal to allow the participant to feel comfortable when sharing what can sometimes be highly personal, yet valuable, insights into their life.

**Participants were encouraged to explore, but not be limited to:**

- Their experiences of being involved in design and evaluation processes (both product and service) in some cases they may not have been involved in formal product or service design. However, they may have been involved in processes such as social care assessments where their experience of these could offer insights for designers of products or services.
- This project specifically focused on the methods used to gather their feedback or requirements, for example, interviews, questionnaires and observations.
- Whether they felt their views were fully represented.
- Whether they felt their contributions were understood and acted upon.
- Any advice they have for 'designers' when interacting with SCAN participants.
- Relevant life experiences/background information.

Given the stated aims of the project, every effort was made to ensure that the research design was accessible to participants regardless of individual impairment. Input from all participants regardless of research group was given equal credence to ensure that the produced guidelines were usable and accessible to the widest possible population.

### 5.2.1 Sampling strategy- stage 1 and 2

Purposive sampling was used with chain or snowball sampling to widen the pool of potential participants, based on the recommendations of initial participants, friendship groups and industrial design staff. However, it was acknowledged that these strategies could have introduced bias and the generalisability of findings may be compromised. These risks were deemed acceptable since the study was intended as an in-depth exploratory investigation (adapted from Burrows, Mitchell and Nicolle (2010)).

It was acknowledged that this may only attract participants that have had difficulty in design or evaluation processes, but this added maximum value to the guidelines produced. This strategy allows access to a wider sample of participants than those known to the researcher.

It should be noted that just because a participant has an additional need does not automatically infer they have had difficulty when participating in design or evaluation processes. The same applies to designers, just because they have worked with participants with additional needs does not mean they have had problems doing so. However, in the first instance and particularly for stage 1, participants were drawn from the sources listed in section 7 below.

In stage 1, a wide variety of 'designers' were recruited for example; rehabilitation engineers, designers of assistive technology products and any other professional that has had significant involvement with end users in a design or evaluation process for those with additional needs, as it was important that the guidelines produced reflect the diversity of design roles and contexts that people were situated in when working with those that have these needs.

In stage 2, a wide spectrum of participants with differing SCAN needs (physical, learning and other disabilities) were sourced to ensure that the guidelines produced reflect the widest possible range of needs. However, given that the majority of disabled people within the UK have a physical disability (adapted from Office for Disability Issues 2008/09) the sample reflected this.

### 5.2.2 Focus group sampling

In the case of the focus groups, two of the groups were comprised of designers who have worked with users that have SCAN and one group who had not (control group). Care was taken to ensure that the participants recruited had experience of using a wide range of different user-centred design or evaluation methods.

### 5.2.3 Interview sampling

It was expected at least twenty five users would be interviewed from the following groups:

- Control participants (these will have no disability)
- Participants with a physical impairment
- Participants with a mental health diagnosis
- Participants with a hearing impairment
- Participants with a visual impairment
- Health/Social care professionals
- Family members/Support workers

A justification for having such a wide variety of participants is that *“...disabilities can range from a slight to severe... in fact only 3% of disabled people are wheelchair...[users]...other groups are more numerous, if less well recognised. For example, 8.7 million have some degree of hearing loss, one million have a learning disability and eight million are affected by some form of arthritis.”* (Sinclair, n.d.)

In addition to the above statistics, according to Loiacono (2004) 1.5 million people in the UK have a cognitive difficulty, 1.6 million with a visual impairment and 6 million with dyslexia.

A special effort was made to interview those with a learning disability and a mental health condition because according to a report by Scope, it was suggested:

*“...that negative attitudes and discrimination are worse towards people with mental health conditions and learning disabilities. This may be due to a generally poor level of understanding about these disabilities and how they affect people’s social participation or it may be an indication of the prevalence of negative stereotypes concerning these conditions.”* (Aiden and McCarthy, 2014:8)

These barriers were most likely to be encountered by disabled people of working age, with 52% of working-age disabled people stating that their needs were not understood (adapted from Aiden and McCarthy *ibid.* pp 11).

Furthermore, the report also contends that certain groups of disabled people were more likely to have experienced a lack of understanding of their needs, for example people with conditions relating to:

- Mental health problems (67%)
- Intellectual, social or behavioural learning disabilities (67%)
- Memory (62%)
- Dexterity (54%)
- Stamina breathing difficulties (51%)

(adapted from Aiden and McCarthy *ibid.* pp 11).

The above is further evidence for the assertion that research such as this needs to be conducted.

All these participants were involved in a design or an evaluation process of some sort, however some may not be able to talk about a physical product being designed, instead of talking about how their 'care package' was designed.

Given that the validity, meaningfulness, and insights generated from qualitative inquiry have more to do with the information-richness of the cases selected and the observational/analytical capabilities of the researcher than with sample size (adapted from Fridah, 2002), the sampling may be changed.

The rationale for including healthcare professionals was two-fold. The first reason was that during stage one it was noted that a large majority of the sample (60%) made use of some form of intermediary including a healthcare professional.

The second reason is that according to the Canadian Association of Occupational Therapists (n.d.) "*Occupational therapists have the knowledge and skills to be experts in universal design...[as it]...contributes to health and well-being by enabling engagement in self-care, productivity and leisure.*"

### 5.3.1 Analysis of the data

The data was grouped into themes (thematic analysis) that were central to the research issue. After the data was grouped once, it was read and re-read by the researcher (and colleagues where appropriate for sampling purposes) to see if there were any sub themes that emerge from those that were initially created. Instances of the themes and sub themes found in the data were highlighted and notes were made in relation to ideas and observations about the data.

Each part of the data was grouped into one of the created themes and for each theme there was a folder in which each piece of data was placed with the relevant theme highlighted. This allowed multiple categorisations of the data, for example, a designer may report the same difficulty as a user. It is likely that the researcher will use analysis software to assist with this process.

### 5.3.2 Research bias

There were many different forms of bias that can impact on the validity and reliability of research findings. It was noted, that some bias in research is inevitable however, it was understood that safe guards can be put in place to minimise the impact of bias. To reduce bias during the analysis stage, great care and time was taken to analyse the data as a whole and not to “cherry pick” the data that fits with or reinforces the researcher’s views about the subject being examined.

With this in mind, during the analysis the constraints of the research were clearly reported and equal merit was given to findings which support and refute the researcher’s position.

To further reduce the possibility of bias, care was taken to ensure that the procedure for interview and focus group sessions were closely followed. The interviewer also took great care not to lead the participant during questioning. Participants were not exposed to information related to the study which may lead them to give answers that fitted with what the researcher was wanting to hear. This was achieved by ensuring that the ‘Participant Information Sheet’ (PIS) clearly stated the purpose of the study in such a way that it did not influence participants to give particular answers.

Also, similar precautions were taken when asking interview questions.

Lastly, care was taken in the recruitment of participants to ensure that they did not have a detailed knowledge of the researcher's personal values, opinions and attitudes as this might also have influenced the responses they gave (adapted from Shuttleworth 2009).

In conclusion, reducing bias involves taking great care in conducting the research, reflecting on, and being mindful of, the aims of the research throughout its duration.

### 5.3.2.1 Reducing bias when analysing data

Bias when analysing data can occur when the data is analysed in a way which prioritises conclusions in favour of any research hypothesis or questions (for example Simundic, 2013:13).

**Some of the ways in which non-statistical analysis bias can be introduced include:**

- Fabricating the data “...reporting non-existing data from experiments which were never done.”
- Manipulating the data
- Abusing the data
- Eliminating the data “which do not support your hypothesis outliers, or even whole subgroups.”(adapted from Simundic *op.cit.*)

**In order to reduce the possibility of such bias being introduced in the research, the researcher undertook the following:**

- Used third parties (coders) to check that the data analysed was being placed in the correct theme, where discrepancies were discovered the researcher had discussions with coders to resolve the issues and came to an agreement. Coders were used throughout the research regularly to ensure that the research did not present findings that were biased towards the researcher's views. At least two coders were used; these were professional colleagues of the researcher that have no other involvement in the study.

At first, they were asked to analyse a sample of the analysis, if agreement was found in 90% + of the sample this was acceptable, where it was lower discussions took place as to what should be done. If appropriate, the discussions resulted in the analysis being repeated.

- Great care and time was taken to ensure that what was analysed was placed in the correct theme. The researcher read and re-read the data to ensure that he fully understood what was being said. If clarification was needed the researcher re-contacted the participant and asked for this. It was only after extensive reading and satisfactory understanding of the data that it was placed into a theme.
- The limitations of the study were clearly stated-its parameters and the sample size.
- The study was exploratory-therefore findings may not be generisable to the wider population.



#### **5.4.1 Analysis of focus group data**

The data was transcribed and analysed thematically to draw out issues relevant to working with SCAN participants and the methods used.

#### **5.4.2 Analysis of interview data**

The data derived from the interviews was split into themes, some of which were pre-defined and some of which emerged from the data. The data was read multiple times and carefully considered in terms of its meaning, tone and context before it was placed in an appropriate theme. The researcher discussed the placement of data into themes with a critical friend before making a final decision and also provided a rationale as to why particular data had been placed in a particular theme.

### **6. Generation and development of guidelines**

Guidelines were developed to address the concerns raised by the designers and the interviewees. It is hoped, in both cases, that some recommendations emerged related to how to conduct research with SCAN participants. The development of guidelines was supplemented by a literature review and critique of best practice/research guidelines in other fields. As well as the sources outlined above, it was likely that issues discovered in the focus groups provided sources of conversation when conducting interviews.

In this case, participants in interviews may be asked for their suggestions regarding what can be done from their perspective to resolve an issue outlined during a focus group session.

## **7. Sources of research participants (for one-to-one semi-structured interviews)**

A branch (in the London borough of Barking and Dagenham) of the national charity Carers (this charity supports carers of those with SCAN) was used.

It was easier to approach the carer first, and then the cared for to ask if they were willing to take part in the research (it was advantageous to include both in the interview where appropriate).

Participants from institutions such as Coventry University Health Design and Technology Institute (HDTI) and other inclusive design centres were invited to take part in the project.

Control participants were recruited; these were drawn from friends, family, and professional colleagues of the researcher.

### **7.1 Sources of research participants (for the focus groups)**

The sources of these participants were:

- Coventry University HDTI<sup>4</sup>
- Industrial Design staff (ID)
- Industrial Design students
- Contacts of ID staff
- Industrial Design Departmental staff mailing list

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<sup>4</sup> <http://www.coventry.ac.uk/business/our-services/strategic-partnerships/health-design-technology-institute/> (Coventry University 2017a)

## 8. Ethical considerations

The need to obtain ethical approval from Coventry University Ethics Committee<sup>5</sup> was acknowledged and approved for all stages of the research (before the practical research began). Additionally, DBS (Disclosure and Barring Service) clearance was required for stage 2 as direct contact with vulnerable members of society was required and therefore it is a legal requirement (this was obtained before the research began). The purposes of each stage of the research and other relevant information e.g. how the data was stored, was explained to each participant at the start of each session and in writing via the PIS.

In relation to recruiting participants, those aged 18 or over were used, as the use of under 18 year olds can prove ethically challenging.

For many reasons it is not advisable to use participants that may not be able to give consent by signing a consent form. However, eliminating this section of society could mean the loss of valuable data. It can be ethically challenging to work with such participants. However, these participants are often from the least vocal or under-represented groups because of their SCAN. Therefore this section of society may provide valuable insights and contributions to the research.

Any feedback that formed part of a guideline/comment was anonymised and phrased in such a way that it was not possible to identify individual contributions. It was important to recognise both contributions from the participant with SCAN, their personal assistant, close friends, family or professionals involved in the participant's life (where appropriate) as these provided additional insights that may prove valuable. With this in mind, these parties were offered the opportunity to take part in the one-to-one interviews, provided consent was obtained.

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<sup>5</sup> <https://ethics.coventry.ac.uk/about/ethics-at-cu.aspx> (Coventry University 2017b)

The need to obtain informed consent from all participants that took part in the project was acknowledged. In order to meet this requirement, before the start of any research activities, all participants involved were asked to sign a consent form stating that they wish to take part and that they had understood the project's purpose. Before participants signed the consent form they were given a copy of the PIS and had the opportunity to ask any questions. All participants were informed that participation in the research was entirely voluntary and they could withdraw from it at any time without repercussion or giving a reason for their withdrawal. Participants also had the right to refuse to answer a question.

Additionally, participants could stop, suspend or terminate interviews and/or their participation in focus groups at any time without giving a reason. However, participants were made aware (on the PIS) that it was not possible to withdraw their data after the analysis process had taken place; this was due to their data being in an anonymised form. Data collected that related to participants was stored in electronic and/or paper based forms. In the case of electronic data, this was stored securely either on the researcher's networked home drive at Coventry University (requires password for access) or on his personal computers (also password protected). Additionally back-up copies were stored on an encrypted hard drive.

All documents relating to the project were password protected and the researcher and his support workers were the only individuals that had access to these. In the case of hard copy data and DVD's, these were stored either in a locked box or filing cabinet when not in use.

All personal identifiable data was destroyed at the end of the project or shortly thereafter and only data that was in a fully anonymised form was kept.

To aid with the anonymisation process, each participant was assigned a code, for example, S1FG:P01 this indicated 'Stage 1 Focus Group: Participant 1' this was also how participants were referred to once the data was anonymised and written up in the thesis or any resulting publications.

**In conducting the research, relevant sections of the British Psychological Society's 'Code of Ethics and Conduct (2007)' was adhered to. The code states that:**

- 1) All research should be considered from the standpoint of the participant thus eliminating potential risks in relation to psychological well-being, physical health, personal values, or dignity.
- 2) When planning research, consider the variety of participants that may take part and their diverse life backgrounds and experiences e.g. race, gender, sexual orientation taking advice were appropriate from those knowledgeable about such affects.
- 3) Research participants should be asked on first contact about any personal factors that might reasonably pose a risk of harm when taking part in the research. Participants should also be advised relating to any precautions they should take to reduce or eliminate such harm.
- 4) Refrain from using financial compensation which may cause participants to expose themselves to excessive risk.

- 5) Participants should be informed on first contact that if they withdraw at anytime it does not affect their entitlement to any expenses or compensations.
- 6) In addition, participants should be informed that they may decline any questions put to them without giving a reason (adapted from BPS Code of Ethics and Conduct *ibid.* pp 19-20).

Although these guidelines were not specifically written for research with SCAN participants they provided a framework to ensure the interests and welfare of such participants were of paramount importance to the research.

In addition to the safeguards outlined in this section, participants were formally debriefed at the end of each practical research session.

**The purpose of the debriefing was to:**

- Inform participants of the outcomes and nature of the research.
- To identify any unseen harm, discomfort or misconceptions.
- Any assistance that is needed by the participant can be arranged (adapted from BPS Code of Ethics and Conduct *ibid.* pp 19-20).

Care was taken when discussing the outcomes of the research with participants; this was to ensure that the findings presented were not misrepresented or misconstrued (adapted from BPS Code of Ethics and Conduct *ibid.* pp 20).

In addition to the debrief letter, given at the end of each session, participants were provided with a summary of the research they had taken part in and details of how the results from the research would be used. The information also contained the contact details of who the participant should contact if they had any further questions.

In accordance with the code (outlined above) the research was designed to allow easy adaptation so that it meets the needs of the participants. Each participant was given the opportunity to present their views in a way that meets their needs. This reduced the likelihood of potential risks in relation to those outlined by the BPS Code. This was achieved by the use of flexible interview questions and preliminary discussions with the participant in relation to how best they can present their views. With this in mind, the participant would be contacted before the interview. However, if the participant wished, these discussions may also take place before the start of the interview.

In the planning of the research, careful consideration was given to the variety of participants that might take part. In addition, advice was sought (where appropriate) in relation to how best to accommodate these differences. A secondary purpose for the preliminary discussion was to establish if there were any personal factors that may pose risk of harm to the participant when taking part and if there were, the participants were also advised on how best to minimise these.

Financial compensation was only given to the participant to meet reasonable expenses, for example, travel expenses that occurred as a result of taking part. This measure was in place so that participants did not feel compelled to expose themselves to unnecessary or excessive risk.

Lastly, it was made clear on the PIS and by the researcher or facilitator that participants could withdraw at any time or refuse to answer questions, on any grounds, and this did not affect their entitlement to reimbursement of expenses incurred.

## 9. Conclusions

This chapter has provided a reasoned justification for the methodological approach and methods used throughout the project. Through the discussion of disability, its models and perceptions in society, the philosophical position of the research methodology was explained. Additionally, the empirical stages of the research were outlined, including a detailed explanation of the research methods used in each stage. Furthermore, because of the move towards the Social model of disability and the implications of such a move (the need for disabled people to be included in society) this provided further conceptual and theoretical grounding for the research.

In conclusion, by developing guidelines to assist designers in user requirements and/or evaluation method selection when working with those that have SCAN, it was hoped that the research will contribute to the development of more inclusive design and evaluation processes thus assisting designers in the development of products and services that better meet the needs of users, particularly those with SCAN.



### 1. Introduction

The aim of this research is to produce guidelines to assist designers in the selection of the most appropriate methods to support user-centred design and evaluation at all stages of the design and evaluation process when working with SCAN participants.

The specific objectives of this stage were to:

- 1) Investigate designers' experiences of working with SCAN users.
- 2) Investigate how users with SCAN, including their carers and other user groups are treated as part of design and evaluation processes.
- 3) Identify key themes and recommendations for designers that will form the basis of guidelines to assist them in making reasoned methodological choices when working with SCAN participants, their carers and other user groups.
- 4) Discuss the results by linking them to relevant research from the literature.

This study examines the views of designers. It will be complemented by a further study focusing on SCAN users and their carers to examine their experience of the design and evaluation process.

In following a human-centred design approach, designers have to interact with users in a professional and productive manner, throughout the process, for example as defined in ISO standard 9241-210:2010 (E).

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancaster Library - Coventry University.

Figure 4.1 Interdependence of human-centred design activities (ISO 9241-210:2010 (E))

**Figure 4.1 Interdependence of human-centred design activities (ISO 9241-210:2010 (E))**

**The four stages of user involvement may be described as:**

- a) **Understand and specify the context of use** i.e. use appropriate methods that allow both users to present and the designer to understand the context of use;
- b) **Specify the user requirements** i.e. use the appropriate methods that allow both the user to specify their requirements and the designer to understand what is being specified;
- c) **Product design solutions to meet user requirements** i.e. use the appropriate method that enable both the user (where appropriate) and designer to create solutions to meet their needs;
- d) **Evaluate the designs against requirements** i.e. use an appropriate method that enables users to evaluate the design against their requirements in a manner that is accessible to them.

Requirements gathering and user device evaluation require the designer to interact with users in order to ensure the artefact meets user needs. A designer may use the same methods to gather requirements and elicit feedback. Whilst these tasks have different purposes, information on how to effectively interview somebody with a communication difficulty, for example, will be applicable in both circumstances. The guidelines produced will be suitable for any stage of user involvement.

Additionally, British Standards Institution BS 7000-6 (2005) states that:

*“Due consideration should be given to customers and end users at each stage of development , and care taken to employ the most appropriate methods, for example, written questionnaires are not easily accessible to those with visual or cognitive impairments.”*

There is a need for a real engagement of representative end users: the following four areas add weight to this conclusion:

- 1) Equality Act (2010) which states it is unlawful to treat a person with a protected characteristic (e.g. disability) less favourably than another (adapted from Equality Act 2010 *ibid.*).
- 2) Economic (i.e. the size of the disability aids and equipment market which is reported to be “...£1.46 billion for 2008...” (Key Note Market Report, 2006). *“The market for equipment for people with a disability in the UK is estimated to have increased by 12.4% between 2009 and 2013. The mobility equipment sector, including daily living aids, wheelchairs and scooters, is the largest sector in the market for equipment for people with a disability, accounting for 31.3% of the market total by value in 2013.”* (Key Note Market Update, Equipment for the Disabled, 2014).

- 3) Social (the advent of the Social model of disability) which views disability as a concept created by society (Scullion 2010:699).
- 4) Ethical drivers i.e. a majority of people believe that discrimination is inappropriate (Griffin, 1993).

## 2. Method

Focus groups and Skype conversations (for those unable to attend) were used to enable participants to discuss issues related to the way in which they worked with SCAN and non-SCAN users during the design and evaluation process.

The main reason for the selection of the focus group method was that it enabled participants to share experiences, observations, thoughts and feelings (adapted from Kuhn 2000:310). Furthermore, the focus group method was appropriate because it facilitated knowledge sharing and exchange.

Additionally the focus group:

- allowed people to air their views in a natural conversational way;
- enabled a wide variety of perspectives to be sampled quickly;
- did not require special equipment; and
- was comparatively easy to conduct (Maguire 2003:73).

It was considered important to create an atmosphere where designers felt comfortable and at ease, so they could share what may be challenging, difficult and in some cases emotional experiences. The focus groups lasted between 45 and 90 minutes.

A template was drawn up to enable structured and purposive discussion. This was distributed to all participants in advance.

**The topics covered were:**

- 1) General introduction: this enabled participants to introduce themselves and outline their background, and also served as an icebreaker
- 2) The involvement of the user in the design and evaluation process
- 3) The design methods used by participants
- 4) The involvement of SCAN users in the design and evaluation process
- 5) The designer in the design and evaluation process
- 6) The suggested guidelines
- 7) The format of guidelines

The focus groups were conducted in a usability laboratory with a one-way mirror, which allowed the researcher to observe. The focus groups were video and/or audio recorded for analysis purposes with a note-taker taking some notes to aid in the analysis. The telephone conversations were conducted using Skype using a similar recording process.

The facilitator introduced the questions for discussion and made sure that all participants had an equal opportunity to contribute.

The facilitator encouraged discussion of topics that arose naturally during the course of conversation without prompting.

The reasons for using a facilitator were as follows:

- 1) To ensure that the discussions taking place were relevant to the topics presented.
- 2) To prevent the discussion being dominated by more vocal participants.

The facilitator was experienced in carrying out focus groups for a variety of projects. Participants were selected using purposive sampling.

Additionally, chain or snowball sampling was used to widen the pool of potential participants based on the recommendations of initial participants, friendship groups and industrial design staff. This strategy allowed access to a wider sample of participants than those known to the researcher.

In this stage, the participants were drawn from sources listed below:

- Coventry University Health Design and Technology Institute (HDTI) (One participant)
- Coventry University-Coventry School of Art and Design (CSAD)
- Department of Industrial Design (ID) Staff/Students (Four participants)
- Designers in Industry-based in the United Kingdom (UK) (Four participants)
- Bath Institute of Medical Engineering (Four participants)
- Designers based in the United States (USA) (Two participants)

In total, fifteen participants took part:

- The control group consisted of four male designers, with no experience of working with SCAN users.
- Two focus groups consisting of seven designers with experience of working with SCAN users formed the experimental groups (six male and one female).
- In addition, four Skype conversations were held with two US (female) and two UK (male) designers, who had experience of working with SCAN users.

### 3. Analysis

A thematic analysis was conducted in order to extract key themes from the data. Thematic analysis is “...a method for identifying, analysing, and reporting patterns (themes) within data... [that] minimally organises and describes your data set in (rich) detail ...however, it also often goes further than this, and interprets various aspects of the research topic...” (Braun and Clarke 2006:6, Boyatzis,1998). Transcripts of the focus groups and telephone conversations were read and re-read to both understand and identify emergent themes. Once the themes had been identified the relevant information was matched with and placed in the relevant theme.

The researcher felt it was important to conduct the analysis manually using a word processing package (Microsoft Word) to highlight and colour code each different theme. The document produced was printed out and divided into individual pieces that were then placed into physical folders.

The rationale for using a manual approach to data analysis was that:

- The researcher felt that this would enable him to immerse himself in the data and enhance his understanding of it.
- Manually sorting the transcripts into physical folders enhanced the researcher’s understanding of what was being said because of the need to physically place a portion of a transcript into a category that enabled him to reflect on the themes in which data was placed.
- This facilitated manual validation of the data.

Manual checking was also performed to ensure that statements made by participants were correctly reported and attributed to the correct participants. Re-reading the data also enabled the researcher to re-evaluate and ensure that the data was placed in the most appropriate theme.

In addition to this, validity and reliability checking was undertaken by a second coder who had no prior involvement in the research.

The results of this are that 81% of the data sampled were valid. It is accepted that this is not within the 90%+ range usually expected of good quality research but rather it was used as a learning exercise and will inform processes and procedures used during the next stage of the research.

## 4. Results

This section commences with an outline of the participant details. Followed by key findings from both SCAN and non-SCAN designers. The findings were presented in sections corresponding to the category that the relevant information was placed in at the analysis stage.

Given that both the focus groups and Skype conversations followed a similar format, and produced similar themes, the results from both studies have been amalgamated for clarity.

### 4.1 Participant details

Qualification	Number of participants	Percentage %
PhD	1	7
Masters	6	40
Undergraduate degree	2	13
None declared	6	40
Total	15	100

**Table 4.1 Academic qualifications of participants**

As illustrated by table 4.1, the spread of educational qualifications was varied from participants having an Undergraduate degree to PhD level. 60% of the sample declared having some form of recognised higher education qualification, with the modal class being that of a Masters degree.



Experience (Number of years)	Number of participants	Percentage%
1 – 5	6	40
15 -19	6	40
20 +	2	13
None Declared	1	7
Total	15	100

**Table 4.2 Design experience**

The spread of experience in the sample varied between 1 and more than 20 years.

Although the sample size is small (n=15), purposive sampling was employed to ensure that participants had expertise and/or experience in relation to the topic of interest.

#### **4.2 Results from designers who work with SCAN users**

This section summarises the results specifically raised in the experimental group or in the telephone interviews with designers who had worked with SCAN users. It is divided into the main themes which emerged from the discussion and which were deemed as relevant to this study.

- ***Design and evaluation process***

In some design contexts, design briefs may be initiated formally by a client in relation to a market opportunity. Designs are often initiated by someone involved in the care sector.

Users are sometimes brought into the design and evaluation process, in accordance with ISO standards at the beginning, with one designer explicitly stating that this was in order to understand what the issues were as “...we couldn’t design something for her if we didn’t know what her issues were...”

This practice is encouraging because it may lead to designing products that better meet users' needs and according to Burrows, Mitchell and Nicolle (*op.cit.*) *"It is generally accepted that people use products that suit their needs and abilities..."* and provides obvious benefits to them.

This is a positive finding and is a similar view to that expressed by Rebola and Sanford (2011:1):

*"...without an understanding of the actual problems faced by older adults and the functionality, value, design, cost, privacy, trust and acceptance of all users, including older adults, their families, and service providers, new designs and technologies will not be successfully implemented...in order to bring about successful solutions, an effective design must solve a relevant problem..."*

However, it is contended by Rebola and Sanford (*ibid.* pp 1) that *"...designers are typically disconnected from the problems and needs of older adults in the community..."* therefore designers need to work closely with older adults and SCAN users to understand their needs.

This has to be completed in the *"...early formative stages to set the agenda for their projects, rather than waiting until it may be too late to make significant changes."* (Bjork *op.cit.*)

In particular, designers need to understand the problems faced by these user groups, how design and technology effectively attempts to solve the problems identified and lastly *"...how can we get new evidence-based design and technological solutions to market?"* (Rebola and Sanford *op.cit.*)

The limited interaction with users is revealed in the lack of interest displayed in evaluation.

A participant did allude to this as an integral part of his practice, commenting that the only way to assess if a product has met a user's needs is when they start using it. However, only one participant admitted to conducting evaluations/follow-up visits to establish whether the product is meeting the user's needs. This lack of interest could be explained, or at least given credit by the findings of a report commissioned by Scope which states "*...two thirds (67%) of the British public feel uncomfortable talking to disabled people.*" (Aiden and McCarthy 2014:3)

Only a few designers commented directly that user feedback had a direct influence on the design and evaluation process and/or was helpful. Those that did so tended to work more closely with their users as design partners.

To encourage constructive user involvement, many of the designers gave a lot of information to participants in advance.

- ***Designers attitudes and beliefs***

Some participants designed bespoke products or products which were designed to be inclusive which could be used by those with a range of SCAN. An advantage of this approach to designing is that these products are flexible and therefore "*...can be adapted to changes in needs and requirements with little time and cost implications, either within the development phase or during the rest of the product's life cycle.*" (Bjork 2009:118)

However, the remarks of Anderberg (2006:51) i.e. "*...it is tailor made to fit the needs of the individual...*" suggest that the thinking of the designers in this study does not conform to the traditional definition of assistive technology (AT). Some believed that it was easier to design inclusive products rather than those that met the needs of specific users.

However, this is not the case in some contexts; for example, in terms of home design in Australia, the West Australian newspaper indicated “...*there are very few signs that homes are being designed to meet the competencies of all people regardless of age, condition or ability...*” (Karol 2007:83) despite the fact that “...*universal design principles recommended for incorporation in building regulations (ANUHD, 2004) require simple changes.*” (Karol *ibid.* pp 83)

In addition, according to Bjork (*op.cit.*) a major factor that inhibits companies from following an inclusive design and evaluation process is that traditional product development models that guide the development processes in most companies lack the presence of user intervention. One reason for this is the belief that inclusive design and evaluation processes do not shorten development time and another “...*is the focus on production-efficiency, which inhibit flexibility and user intervention.*”

Further barriers to the adoption of inclusive design and evaluation processes according to Bjork (*ibid.* pp 117) include “...*lack of time, budget limitations...knowledge, tools or justifiable business case.*”

Furthermore, according to Nunn, Sweaney, Cude and Hathcote (*op.cit.*) while the value of inclusive design features are recognised by researchers, this still needs to be established in relation to consumers.

The adoption of ergonomics and user-centred approaches was revealed in the reported view that if you design one thing well to meet one specific set of user needs it may assist other people for whom it was not primarily designed, for example, OXO product range and many other devices such as non-slip matting and swivel-bladed peelers etc. (adapted from Swann 2007:286, adapted from Steinfield, 2002).

This assertion is given credit by the remarks of Monaghan (2010:1) who states that *“...advocates of universal design argue that good design by definition addresses a wide range of human ability...”* He also notes that *“...kitchen utensils and other consumer products are increasingly being designed for accessibility.”*

Additionally, *“...advocates for greater accommodation of people with disabilities contend that good design by definition caters to a wide range of human capability.”* (Monaghan *ibid.* pp 1) therefore it is surprising that design for disability *“...has only made an intermittent, marginal impression on the design world.”* (Monaghan *ibid.* pp 1) One reason for this could be that it is difficult to design for the average individual. It has been said that the average individual is a myth existing only in ergonomics and anthropometric tables (Joines 2009:159).

Indeed, there are examples in history such as the invention of the telephone that sprang out of such attempts at inclusive design:

*“...Alexander Graham Bell’s efforts to devise speech communication instruments for deaf people. Instead, by premising human speech and hearing as the isolated means of telecommunication, the telephone has served as the greatest technology disenfranchisement that deaf people have ever experienced.”* (Rosen 2007:14)

*“As a result millions of people with disabilities have experienced significant barriers in the use of telephones, including those with hearing loss, visual impairments, speech impairments, different manual dexterity or mobility capacities, or cognitive disabilities.”* (Rosen *ibid.* pp 15)

Participants felt that they would not distinguish between SCAN and non-SCAN users but would instead adopt a design and evaluation process that incorporates everybody and identifies what individuals' abilities are and produce solutions that focus on those rather than categorising people as SCAN and non-SCAN.

This is a positive finding; however, it fails to acknowledge that “...*inclusive design may provide “off-the shelf” products for a larger spectrum of society... [although]...a demand will remain for assistive devices. Specialised custom-made items, particularly wheelchairs, scooters... [etc.]*” (adapted from Swann *op.cit.*)

Participants felt “...*just because you have a very specific need...you shouldn't have to have a certain product...you should be able to choose the one that you want and it's an emotional choice...*”

Additionally, as remarked by Watson (2002) having a disability “...*might not be the most important aspect of a person's identity or social position.*”

Such considerations should already be important to designers. For example, in a discussion of industrial design Farstad (1998) typically sees design as an inter-play between aesthetics, ergonomics, technology, economy and market.

Design is responsible for appearance and functionality, as well as the effect of the design. From a different viewpoint, design may also be seen as “...*a special form of human communication...*” (Wilson *op.cit.*) providing a humanising link between product and user (Rebola and Sanford *op.cit.*)

Participants' feelings regarding a user's personal choice of products are given credit by the remarks of Ravneberg (2009:101) who emphasises the important links between design and aesthetics when shaping selves and self identities.

The arguments of both the designers and Ravneberg (*ibid.*) are justified given the reported size of the disability and equipment market that will continue to grow. Clarke *et al.* (2007) believe that a prerequisite of this growth is that more attention will have to be given to users' concerns, needs or wants.

However, the problem for designers of such products is as expressed by Woods and Watson (2004a and 2004b) “...most of the technologies have been produced as medical products and distributed as such since the first half of the twentieth century...” and as a consequence “...ethnicity, class, gender, sexuality, lifestyle and age are all neglected...” aspects of design for disability (Ravneberg *op.cit.*) and are often designed with the helper or carer in mind as opposed to the user. This may lead to the production of unusable or unacceptable products (adapted from Rebola and Sanford *op.cit.*). Wheelchair design is an example; manual wheelchairs have evolved slowly from being designed for the helper to being designed for the wheelchair user (Wood and Watson, *op.cit.*).

Although this progress is slow, it can often lead to products that are mismatched and make users “...lose their self confidence, feel uncomfortable or are unfitted for their age, sex or lifestyle.”(Ravneberg *op.cit.*)

Furthermore, it was felt that the designer should consider what is required before considering the disability. Lastly, as remarked by Pullin (n.d.);

*“Most devices designed for disabilities continue to seek to hide them, the way flesh coloured prostheses do? If the most common aid for disabilities, eyeglasses, can be fashionably hip, then so can, say, hearing aids...”*

Clearly, some designers had chosen to specialise in the design of assistive products. This may have been directly influenced by a life experience.

Designers who had freely selected to design for this market were more likely to stay in this area than those who had been directed to design a product to fulfil a design brief. It was felt that a designer who chooses to work with SCAN participants requires certain life skills and/ or has been exposed to their needs. Some designers who had specialised in this area felt reluctant to design for those without SCAN. They felt that they had specialised skills suited to designing for SCAN users.

One felt that, through working for a charity that helps users with severe SCAN, he often takes on “...*challenges that cannot be done...*”

- ***Working with SCAN users***

The view about designing for the person, rather than a disability was reinforced by comments indicating that SCAN users do not associate themselves with the disability they have.

The designers were varied in the difficulties they faced, with some admitting that there were:

- Communication difficulties when working with users with physical disabilities.
- Lack of awareness of manufacturing costs and complaints about overall costs.

One participant did not believe that the SCAN of the user made it difficult to obtain feedback from them as “...*the whole idea of designing for people with SCAN issues... [is that] you have to be able to work with their...disability.*”



- ***Empathy***

The relationship between designer and user is important if they are to have a fruitful relationship. They should both feel comfortable so that a product can be designed to meet the users' needs. These designers often employed co-design methodologies with their participants.

Two designers did have SCAN, and reported that they found it easier to gain trust. It could be surmised this may be because of the commonality that they share i.e. the disability.

- ***Use of information***

The most common information sources used by the SCAN designers are shown in the table below:

<b>Information source</b>	<b>SCAN designers</b>
Access to other experts e.g. academics	5
Evidence based research/practice	5
Internet sources	3
Networking	3
Design knowledge	2
External organisations	2
Anthropometric data	2

**Table 4.3 Information sources accessed by SCAN designers**

Participants felt the need for more information related to methods to elicit user requirements, the conditions and daily routine of the users. The SCAN designers tended to make use of a wider variety of sources of information than non-SCAN designers such as access to experts and evidence based practices.

- ***Ethical issues in the design and evaluation process***

The ethical issues associated with working with SCAN participants were acknowledged by both the control and experimental groups.

It was highlighted that there is a need to produce ethical guidance for private companies as this does not exist. It was also commented that some designers found the concept of ethics challenging because it was felt user needs needed to be established in order to design effectively. However, some ethical processes may prevent the designer from establishing what that need is.

Another issue highlighted was that of obtaining ethical approval as direct contact with SCAN users cannot commence until approval is granted. Sometimes this can prevent the designer from accomplishing the original task.

- ***Use of intermediaries***

It was highlighted that often, stakeholders such as carers will identify a need and propose a solution to it. However, sometimes they may be the cause of a problem or a need. As a consequence, McBride, Beer, Mitzer and Rogers (2011) state “...that identifying difficulties with care provision in the home is a critical step that must occur before interventions can be properly designed and implemented.” Nevertheless, it is important to understand team dynamics among health or social care professionals, carers and users as this information “...will allow for a clearer distinction of each individual’s role...” thus providing the basis for improved communication (adapted from McBride, Beer, Mitzer and Rogers *ibid.*).

Additionally, it was suggested that often the health or social care professional would have identified the need and the solution to it. It was also suggested that intermediaries often give different responses to that of end users.

Because of the ethical constraints often placed on the designer, it can be difficult for them to get access to end users, thus the designers questioned felt that by default you often work with intermediaries.

Whilst there are issues in relation to working with intermediaries it was felt that their insight is highly valuable because they see the individual and can offer a different perspective to that of the user or designer. It should be noted that designers in this study tended to work closely with health or social care professionals and parents, sometimes more so than the end user, with the health or social care professional often being the person who gives final approval of the design.

- ***Adoption of methods***

Many practical pieces of advice were exchanged during the focus groups, these included:

- Making sure there was adequate space to conduct a focus group with wheelchair users. Similar advice was given when conducting focus groups with hearing impaired participants, for example, in accommodating interpreters and making sure they could see the facilitator.
- Techniques for working with those that have dementia i.e. use of personas and the use of an object helping participants to focus and talk to the designer.
- Using methods that require a high level of interaction with end users such as the use of prototypes.
- The use of empathic modelling to enable the designer to experience life with a disability.
- The use of interviews, focus groups and usability studies to explore themes with end users.

- The use of “...*question by stealth*...” that is questioning that is made to look like causal chats in order to obtain information from participants in an informal way.
- The importance of listening and observation especially at initial assessment.
- ***Treatment of users in the design and evaluation process***

It was felt by some participants that their involvement of users in the design and evaluation process is poor. Some of the reasons given for this were:

- Can be difficult to establish needs from them because users may have difficulties with communication.
- The type of products being designed. However, it was acknowledged that it may be the process of working with users that is difficult rather than the actual engagement.
- The use of methods that require a high level of engagement were often the most successful, for example, observing users and then questioning them, allowing them to use prototypes then gathering feedback and making changes as necessary.
- ***An understanding of cognitive ability***

It was felt that an understanding of a user’s cognitive ability may help a designer to assess how they can better involve users in design and evaluation processes, thus identifying user needs more clearly.

- ***Methods***

11 of the 26 methods mentioned required interaction with users, indicating that the designers understood the necessity to involve SCAN users in the design lifecycle.

The methods most commonly used, along with their advantages, are shown in the table below.

Method	Advantage
Empathic modelling	Enabled the designer to view a snapshot of life from a user's perspective.
Questionnaires	Can provide structure to help establish what is required, can also be used to stimulate discussion or guide an interview. Can also be used to gain basic demographic information from participants.
User diary method	Enabled the designer to understand what was required by the participant.
Face- to-face methods, i.e. Interviews	<i>"...you get the most open and honest information from the individuals themselves."</i>
Focus group	Can allow the researcher to select participants and in some cases ensure diversity within that sample, (dependent on the sample size) this ensures that the feedback gathered would reflect the widest possible view point.
Immersive methods	Allows the participant to, <i>"...dress up and you can feel and see problems first hand."</i>
Observational methods	<i>"...are more revealing and give an insight, it shows why you do something... observation can provide answers to designers' questions."</i> The researcher may be able to observe user preferences i.e. directness (Robson 2002:310). Another strength of this method was that the design team identified problems with designs such as <i>"...conditions, problems or patterns many informants may be unaware of or unable to describe adequately..."</i> (Anon, USAID, 1996).
Participant observational methods	Said that <i>"... [you]are putting yourself in that person's place."</i>
Sketches	Enabled the user to choose what designs they wanted to test out and take further.
Informal conversation/ <i>"question by stealth."</i>	Is less intrusive and enables the designer to get the necessary information.
Personas	Can illustrate the fact that one person may have two different lives and that both need to be taken into account when designing e.g. when designing for dementia.

Method	Advantage
Structured interview	"A good source of information" and that listening to the user was really important.
Accessing blogs, websites and books etc.	Provided insights into certain conditions e.g. hearing loss.
On-line surveys	Anonymity
Indirect observation (videoing people)	Allowed the design team to "...learn quite clearly that they preferred one thing than the other, so, we saw the failings of one of the designs."
Telephone forum	Nice and regular, people do not mind being phoned up for five minutes, it is structured and you can ask them in a couple of weeks. However, this method was not utilised with SCAN participants but rather health and social care professionals (occupational therapists).
Surveys	Can produce direct answers to direct questions.
Face-to-face methods	Most important methods when working with SCAN participants.

**Table 4.4 Methods and their advantages mentioned during the focus groups**

Additionally designers commented on the disadvantages of certain methods, as indicated in table 4.5.

Method	Disadvantage
<b>Questionnaires</b>	<i>"...writing something out that's very clinical...it's like ...people always give you the answer that you're trying to get, when you're asking them questions..."</i> as well as the lack of control you have over the individual who is filling them in (especially at a distance). Questionnaires were also believed to not provide enough detailed information when used on their own as a way of testing prototypes.
<b>Symbols</b>	Some people may be unfamiliar with the use of symbols as a method of communication.
<b>Group methods</b>	The inappropriate use of group methods to gather requirements or elicit feedback.
<b>Observations/ Immersive methods/ Cultural probes</b>	Can be difficult to interpret.
<b>Focus groups</b>	The effort required to organise with the right constituency, in the right location, also explaining its purpose and the additional care that needs to be given to hearing impaired participants. Such participants need to be within visual range and special care must be taken to avoid the group being dominated by particularly vocal participants. This is similar to the views expressed by Langford and McDonagh (2003:74) who stated that some individuals may be inhibited by other group members.
<b>Interviews</b>	The tendency for people to <i>"...talk a load of crap..."</i> in interviews, which requires careful interpretation. However, it was not stated that participants will not write honest opinions about a product, instead they are more likely to give their views and so it was felt that questions asked in a controlled environment are more likely to produce in-depth results than those asked using a questionnaire.
<b>Surveys</b>	The inability of surveys to <i>"...give me the information I need to make sure that whatever I'm designing will actually work for a person with a disability."</i>
<b>Prototypes</b>	The ethical issues raised when users test working prototypes.

Method	Disadvantage
Facilitators/ Interviewers	The tendency to make assumptions being made about user's abilities/difficulties based on generic information.
Evidence based practice	<p>The contradictions the participant may feel between the evidence based research on the Social model of disability (Oliver 1990) and the everyday experiences of disabled people.</p> <p>This is not to suggest that the Social model is incorrect in the theoretical approaches it takes, rather theory does not always translate into every day experiences and so the theory of the Social model may not be adopted by all; thus one disadvantage of using evidence based research as reported by a participant is what is written in a source e.g. a book may be different to the practice and experience of day-to-day life.</p>

**Table 4.5 Methods and their disadvantages in this context**

All designers made use of some form of interview, combined with observational and ethnographic methods, perhaps especially important for those designers who were interested in understanding the user's daily routine. Such information may inform design work by enabling the designer to view the wider context of the user's experience and interpret information more accurately. A designer admitted to asking a few open ended questions and then allowing time to think these over (concording with the 'incubation' stage of design).

(Low fidelity) prototyping was used by only a minority of designers, with one stating "...this was more of...an ergonomic comfort response and not necessarily a functional response..." to the design brief, and another designer creating low fidelity prototypes referred to by the participant as models.

There was some evidence to suggest that designers used multiple methods when working with users (as shown in the table below) and that some slight adaptation may be required when applying standard methods.



User group	Methods
Hearing impaired user	One-to-one interviews, e-mail communications via questions and the participant's own reporting, focus groups.
Child	A measure of ability in the product and out of the product. Observation of a child using other equipment and follow-up observations of the product after six months.
Poor verbal communication	Ad-hoc observation and questioning of the primary end user although how this is done in practice is unclear. It is assumed that this could be achieved through yes/no questioning; questionnaires for other stakeholders such as clinicians.
SCAN users	Use of intermediaries to help a user convey their feedback

**Table 4.6 Methods used with particular SCAN and other user groups**

A participant stated that because of the varied nature of stakeholders (and users) no specific set of methods were used. Furthermore, he stated “...we don't see mega trends... [in relation]...to the methods we use.” This view tallies with that expressed by Blow (*op.cit.*) who remarked that “...I was to learn very quickly that there is no one clear method to achieve participation for people with learning difficulties.”

- ***Adaptation of methods and method selection***

The need to adapt methods to suit design and user involvement was a common theme. On a number of occasions, a participant stated, regardless of SCAN or non-SCAN, research methods had to be tweaked dependant on the user group, product and goal. However, it was admitted that the methods used to gather requirements or elicit feedback depended on “...what the user can or can't do.”

- ***Gaps in knowledge***

The lack of information related to methods to elicit user requirements was commented on. At least one participant admitted that he does not have access to information that explains the conditions and daily routine of the users he works with.

It is interesting to note that the SCAN designers in this sample make use of a wider variety of sources of information than non-SCAN designers such as access to experts and evidence-based practice, whereas the non-SCAN designers did not disclose any of the sources of information they make use of (see table 4.3 for more information).

- ***Context of use***

It was suggested that designers could benefit from an understanding of the reality of SCAN because “...you’d have to try and fob them off first of all...and say I like this you know, and if they persist, you know they get through the field test.”

### **4.3 Suggested best practices from all focus groups**

Combining the results of the two different focus groups, the following ‘best practices’ emerged. Numbers refer to number of mentions by non-SCAN and then SCAN designers respectively.

#### ***Overall design issues***

- Listen to the needs of the client (0,6)
- Design for the needs (0,6)
- Extract data from whatever sources possible (3,1)
- The process of obtaining requirements/gathering information is similar to working with users without additional needs, though the means of communication may differ (0,3)
- Set the parameters of any investigation/design work clearly, explain what you are doing, where you are from etc. before the session commences (2,1)
- Be prepared before you start engaging with users (0,2)

In adopting a user-centred (UC) approach, the interviewer should not only consider the ability or disability of the participant but also:

- The ability of the group
- What is being designed
- The type of information that is required (0,1)
  
- ***Use of intermediaries and stakeholders***

Where appropriate, a carer or spouse can be involved to support a greater understanding of the participant's lifestyle and daily routine (4, 4). However, there is a major disadvantage to this approach in that, as stated by Blow (*op.cit.*) support workers can only provide an interpretation of what they feel is being said or what the end user needs are. Indeed, this might not match the real requirements and there is no means available for designers of verifying this. However, if the designer spent some time before work started with a user and got to know how they communicated i.e. how they indicated agreement, it may be possible for the designer to be aware when the user is showing satisfaction or dissatisfaction with decisions and changes that have been made (Blow *ibid.* pp 6). Furthermore, it should be remembered that each person has "...*their own unique way of getting their message across...*" and the challenge for designers working with others (where appropriate) is to develop "...*techniques and technologies to help people express their needs and views...*" (Grant *op.cit.*). Another disadvantage to using a spouse is that they may not be able to/or may be inhibited in clearly explaining and elaborating in relation to problems faced.

A disadvantage to using a support worker is that they may not see the participant in every aspect of their life.

- Be aware of the user and the carer, all of whom may have different requirements. (0,3)
- The requirements of the primary and secondary users (client and the carer) may not overlap and may be conflicting. (0,3)

- Both the client and carer should be asked about their needs because they may notice things that the SCAN user does not. (0,3)
- Some carers and parents will accept a person's SCAN more readily than others.
- Additionally, parents with children or elderly people may not wish to accept the disability or the onset of old age. (0,2)

### ***User involvement during the lifecycle***

- State the required levels of involvement needed from users and other stakeholders at the start of the process. (0,6)

### ***Method selection and usage***

- Ask the user what method is appropriate for them when gathering either user requirements or evaluation feedback. (4, 2)
- Consider the method used to gather information in relation to the product or service being designed. (4,1)
- Use observation and empathic methods to understand and feel the difficulties the user faces. (4,0)
- Be creative when using methods to elicit feedback or requirements from users that have SCAN. (3,1)
- Listening and observation skills are important, the designer should then act on what they have heard and observed. (0,2)
- Listening and observation skills need to be intensive as it is the smallest detail you may notice that can impact on the design of the artefact. (0,2)
- Be sure that the actual comments of a participant have been noted. It may also need to be ensured that comments are analysed thoroughly. This will apply to observations made or interviews conducted. (0,2)
- Use personas to understand some of the common needs people with a disability have, for example the difficulties that their carer may be experiencing. (0, 2)

- Whatever design exercise is being conducted, e.g. an interview or focus group, understand what is required from the session and what the design goal is. This should be clearly defined at the start of each focus group or interview etc. (0,2)

### ***Working with SCAN users***

- Be aware of the cognitive load in terms of communication as the user may have to work harder to gain an understanding; also allow time for this, and how the message comes across. (0,4)
- May require additional time to complete tasks. (0,4)
- Explanations may have to be given more often because users may well have genuinely forgotten what was said. (0,4)
- Allow lots of freedom and time (be patient) to allow users to respond (0,4)
- Keep emphasising key information. (0,4)
- Make it clear that the participant is not being tested, in order to provide reassurance and allay fears of assessment. (0,4)
- Explain why the information they are providing is useful. (0,4)
- Check with users before starting work with them; how they see themselves e.g. disabled person, wheelchair user, deaf, hearing impaired, blind, sight impaired etc. The key to getting it right is to be considerate. (1,3)
- Direct user work may be difficult, for example it may be extremely noisy when working with hearing impaired participants. (0,3)
- Raising the idea that somebody has a disability when they do not believe they have is something that needs to be handled with sensitivity. (0,1)  
Screen participants to ensure they are the right participant for the study. (1,0)
- Expect the unexpected, for example some SCAN users may be incontinent and some may not be able to control their movements, for example one might get sneezed on unintentionally. (0,1)

- Facilitate participants to present their feedback in a way in which they are comfortable. (0,1)

### ***Design skills and training***

- Empathy is needed. (0,4)
- Attend a basic course on Disability Awareness.(0,4)

### ***Use of language***

- Language is an important factor to consider due to the need to get the best interaction and to have people engaged. (1,3)
- Be careful of the language used when working with users because the use of language can be diverse. For example, as one participant stated *“...it can be fairly straightforward to say...we’re talking about disability...whether the conversation matters that kind of thing...but if you then inadvertently, in a particular context start saying carers, instead of care giver, in some circles you’d be in trouble for that...but sometimes you won’t...”* (1,3)

### ***When running sessions***

- Provide room for interpreters and other necessary equipment. (0,3)
- If videos are used these should be subtitled. (0,3)
- Ensure content is mainly visual and have a maximum of eight participants per group. (0,3)
- Ensure appropriate physical access to the venue. (0,3)
- Gain informed consent. (2,1)
- Make sure intellectual property agreements are in place where appropriate. (2,1)

- To gain a user's confidence reassurance may need to be provided, put them at ease and say something like '*it's a bit of fun*'. This is especially true for those that have dementia and other age related impairments such as hearing or sight loss. However, this should be done for all users when needed. (0,2)
- SCAN users may often have health concerns which can make it difficult for them to take part in research. (0,2)
- SCAN users may also need to know if a member of the design team has an infection as they may not wish to be exposed to it. (0,2)
- Dropout rate may be higher when you are working with SCAN participants. (0,2)
- Be aware of the user group's condition but also recognise them as individuals. (2,0)
- Conduct background research into the condition of the user group. (0,2)
- When delivering information to users, show consideration for the abilities of the user group and remember that people are different and so therefore have differing abilities. (1,1)

### ***Focus groups***

- The facilitator should ensure it is conducted in a respectful manner allowing all participants to have the time and support to express their views. (0,3)
- To prevent the focus group being dominated by a single participant the facilitator may wish to have an object that they pass around and only when a participant is holding the object can they talk. (0,3)

### ***Designer related factors***

- Do not give personal contact details to users as this may have unintended consequences, for example, they may believe because the designer has solved some of their problems they may be able to solve all of their problems. (2,2)
- Keep a professional distance when working with users so that they can see the whole picture. (2,2)
- Designers should keep their emotions in check. (2,2)
- Do not make assumptions about situations in which one finds oneself, as someone's life may be very different to one's assumptions.(1,1)
- Be aware that people may have preconceptions in relation to the facilitator as a designer. (1,1)
- To effectively work with SCAN participants you have to be the sort of designer that likes to solve complex problems and enjoy the journey of investigation. (1,1)

### **Specific groups**

#### ***Dyslexics***

- It may not be advisable to ask the user to order a list of features because people with dyslexia may struggle with such exercises, as dyslexia affects the way information is processed, stored and retrieved, with problems of memory, speed of processing, time perception, organisation and sequencing (adapted from The British Dyslexia Association, 2015). (0,1)



### ***Dementia sufferers***

- Producing intuitive designs may be advantageous because a person with dementia may have a relatively low cognitive load. (0,1).
- When working with those that have dementia or elderly people it may be advantageous to chunk items into short statements because longer ideas may be too complicated. (0,1)

### ***Lack of handwriting***

- If a participant cannot handwrite, the use of questionnaires and how they are accessed and completed needs careful consideration. (0,1)

### ***Designing written material*** (0,1)

- When designing written materials it is best to simplify the question where possible, additionally, careful attention will need to be paid to the design of the question to ensure it elicits the required response. Materials should also be checked carefully so that the original meaning has not been lost.
- The language used needs to be easily understandable without being patronising.
- The terms used need to be defined as meaningful for the group.

## **4.4 Comparison between US and UK designers**

The two US participants were more inclined to embrace and to conduct work directly with SCAN users. Evidence for this assertion can be found when a participant stated “...*for the most part we did it on a very personal level, face-to-face...[and]...in the actual designing process they were involved from the beginning.*”

However, the participants from the UK were not on the whole as aware when it came to involving users. For example, a participant stated “...I would argue... with users we could improve, its poor if I’m being honest...”

With the American designers it is unclear, whether the willingness to involve SCAN users relates directly to US culture. It is conceivable that these participants would have a better understanding of the necessity to work with SCAN users, as the Americans with Disabilities Act was introduced in 1990, five years prior to the UK government providing legislation (Disability Discrimination Act, 1995).

It should be noted, however, that it is difficult to identify whether this is due to their country’s culture alone - as both of these participants have SCAN themselves-so this may be attributable to US culture or both. There were no other reportable differences in ways of working etc. between US and UK participants.

#### **4.5 Comparison between SCAN and Non-SCAN Designers**

- ***Design and evaluation process***

It was felt that current manufacturing processes mitigated against the design of products for SCAN users, owing to the economies of scale. However, some suggested that rapid prototyping may solve this problem.

The iterative approach to design and the importance of it was discussed by some in the sample, with a significant minority stating that as a result of user feedback their designs were modified.

However, some stated that this would only be taken into account where the feedback was achievable on a manufacturing basis and at a price point.

Only a single participant explained why it was the case a user's feedback was not taken into consideration.

A small number of those questioned involved their users in the evaluation of the design and modified it according to feedback although this did not appear to be a common practice within the sample questioned.

- ***Bespoke Design***

This result appears to suggest that only if bespoke solutions are designed can users be truly involved (see table below), as the 27% who involved the users heavily in the design and evaluation process exhibited this. A breakdown of these participants and what they designed is provided in the table below.

<b>Participant number</b>	<b>What they designed</b>
S1TC01	Playstation 3 adapter, joysticks, switches, circuits, table extensions, wheelchair mounts for communication aids
S1TC02	Switching supporting devices, devices to encourage play, toileting devices, sleep devices, recreational devices, wheelchairs, components for devices
S1TC03	Device for urinary incontinence, personalised hearing aids
S1TC04	A way finding device, urinary device

**Table 4.7 illustrates the individual participants and what they designed**

It can be seen quite clearly from the above that all of these participants designed at least one bespoke solution to meet the users' needs. Whilst the researcher accepts that four participants is a small sample size, it is a significant number, given the total number of participants in this study (n=15).

Can the practices of designers of bespoke (or tailored, one off) products in terms of user involvement be easily adopted by designers who design non-bespoke products? This may be needed, because the artefacts designed will need to be placed in real homes where people with additional needs lead real lives (adapted from Axelrod *et al. op.cit.*)

- ***Empathy***

Over half of the sample questioned acknowledged that empathy is an important skill to have when working with SCAN participants. A participant stated that designers' being able to empathise with the user is important especially where it is a difficult situation.

- ***Lack of understanding***

It was suggested by three participants that a possible barrier preventing designers working with those that have SCAN is a fear of what they do not know. According to a report by Scope (*op.cit.*) much of this lack of understanding may cause discomfort to people who have to deal with disability for the first time. For example, nearly half of the British public questioned (43%) admitted to not knowing a disabled person, with many being concerned about doing or saying the wrong thing (Aiden and McCarthy *op.cit.*). Firstly, it was highlighted that they may lack the skills and knowledge to effectively involve SCAN users in the process of design or evaluation.

Additionally, it was commented that these issues may be a particular problem for younger designers. This assertion is given credit by the remarks of Aiden and McCarthy (*ibid.*) who stated that “...one fifth (21%) of 18-24 year-old have actually avoided talking to a disabled person because they weren't sure how to communicate with them.”

Also a report by Opinium (2014):

*“...found that just a third 33% of British people said that they would feel comfortable, talking to disabled people, with many worried that they would seem patronising or say the wrong thing. The research suggests that one of the reasons behind such behaviours may be that 43% of people say that they do not know anyone who is disabled.”*

These attitudes appear to be most prevalent in men aged 18-34 as this group is least likely to interact with disabled people and most likely to hold negative views about them (Opinium *ibid.*).

Given the above, it is perhaps not surprising, especially where mental health and learning disabilities are concerned, that a lack of understanding of individual needs is the attitude or behaviour most commonly experienced by disabled people and is an aspect that users who have experienced such negativity most want to change (Aiden and McCarthy *op.cit.*). A consequence of these attitudes may be that designers can be criticised for not allowing active participation of users in design or evaluation processes (that is: using methods on the first four rungs of Arnstein’s ladder-see figure 4.3).

There are perhaps implications for design education. A partial solution to the above difficulty was proposed i.e. more education for designers in relation to physiological differences and different disabilities to prevent designers from fearing the unknown. This assertion is given credit by a report by Scope (*op.cit.*) that states;

*“...that both the general public and disabled people believe that more everyday interactions and greater public education about disability will increase understanding and acceptance of disabled people.”* (Aiden and McCarthy *op.cit.*)

This was a message that came through strongly in an OPM/ Ipsos MORI Research poll i.e. “...that public education could help tackle the discrimination and stigma associated with disability.” (Aiden and McCarthy *ibid.* pp 14) “Likewise, over a quarter (28%) of people say that getting advice from disabled people would make them feel more confident talking or interacting with disabled people.” (Opinium *op.cit.*)

According to a study conducted by Ipsos MORI Research, education is the key to overcoming these negative attitudes (adapted from Aiden and McCarthy *ibid.*). However public education alone may not be all that is required, Aiden and McCarthy (*ibid.*) suggest that what is needed is for non-disabled people to share positive interactions with their disabled counterparts, although these interactions may sometimes be few and far between because of negative attitudes towards disability (adapted from Aiden and McCarthy *ibid.* pp 15). Evidence for this assertion can be found in research conducted by Opinium (*op.cit.*) where it is stated that “...unsurprisingly, a third (33%) of people say that getting to know someone disabled would make them feel more confident around disabled people.” Whilst this may be what is needed, it may be harder to achieve than it first appears, as according to the same research by Opinium (*ibid.*), just over a quarter (27%) admitted they rarely come into contact with those with a disability and 43% not knowing anyone who is disabled, and lastly fewer than one in five (17%) stated that they have friends that are disabled (adapted from Aiden and McCarthy *ibid.* pp 15). The challenge for the design and the disability communities is therefore to create meaningful interactions between themselves.

These negative attitudes appear to be fostered from a young age as according to a survey by Scope and Mums.net 38% of parents of disabled children indicated that they rarely or never have the opportunity to socialise with their non-disabled peers (adapted from Scope analysis of Mums.net, 2014).

A parent commented that;

*“Parents - even in this day and age - seem to think my son is a leper with a contagious disease yet he has CP (cerebral palsy). If their kids ask questions they rush them away. People are very ashamed of disabilities - not the parents who have the disabled child - as I am more than happy to explain to their children what’s up with my son. But parents seem to not want their children to understand that some children have poorly legs or the like.”* (Scope analysis of Mums.net *ibid.*)

- **Ethics**

It was highlighted that ethical considerations can make it difficult to involve users with SCAN in the design and evaluation process especially where these are children and those with learning difficulties, and/or the products have not been properly tested. Given the above, the majority of those questioned felt that ethical guidance is needed in relation to working with SCAN participants. Some participants felt that they do not have a full understanding of ethical issues that can affect their work with these participants. A participant stated “...adequate ethical guidance for designers is pretty important really...” Furthermore, some in the sample felt that any ethical guidance produced would need to be specifically targeted at new designers as they may lack experience in dealing with issues such as research ethics.

- **Intermediaries**

It is concerning but perhaps not surprising to note that the most popular method when the results are combined is the use of intermediaries, carers, clinicians etc. This is concerning because of the problems this method has associated with it as stated by Blow (*op.cit.*).

The use of an intermediary (carer, family member, health or social care professional) was considered a useful way (by the majority of the sample 60%) of eliciting requirements or gathering feedback from or on behalf of the user. The use of the intermediary may be to clarify or wholly convey the users' wishes. Two of the participants stated that in some of their design practice it was the health or social care professional who asked for a solution to the problem. This is not surprising given the remarks of the Canadian Association of Occupational Therapists (CAOT) (n.d.) who state that "*...occupational therapists have the knowledge and skills to be experts in universal design...[as it] ... contributes to health and well-being by enabling engagement in self-care, productivity and leisure.*" Furthermore "*...universal design is a concept that can support the occupational performance of many persons regardless of ability level and age.*" And that such design principles guide decisions about the built environment, tools and materials (CAOT n.d. *ibid.*).

Given all these factors, it is not surprising that a participant stated that the relationship between him and the health or social care professional is vital because "*...they are the ones that will sign it off...*" Furthermore, this practice was noted by Swann (*op.cit.*):

*"Many product designers encourage therapists and users of their products to provide feedback and participate in the development process for new product ranges."*

Some authors such as Swann (*ibid.* pp 289) recommend that therapists:

*"...should work closely with designers and consumers to make products more functional and aesthetic for people with cognitive, sensory and physical disabilities."*



Also, in relation to carers, a participant acknowledged that they can add *“... value...and they give their perspective...which isn't the same as the end user...”* Some in the sample felt it is important to acknowledge the needs of the client *“...but you don't want to disregard some of the stuff that the carers are saying even though it's different...”*

It was felt that working with the carer was *“...much more of a normal interaction... [because]...you invite people to talk to you...”* therefore the process is less complex than talking to SCAN users. Another participant stated that *“...what you end up doing, is your first port of call...the carer of the expert and they end up speaking for.”*

It was recognised that a majority of the sample (87%) involve other stakeholders (such as parents) as well as or in place of the primary end user. Additionally, participants commented that they found this to be an important part of the design and evaluation process. A participant stated stakeholders other than end users may have a greater interest in the product.

#### **4.6 Results relevant to the control group**

This section summarises the results gathered from the control group ie. those who had not worked with SCAN users.

A minority in the sample (13%) stated that design is a creative problem solving process and the designers' job is to solve the problems to the best of their abilities.

Half of the control group (13%) indicated that it could be difficult to get information from product manufacturers thus making it harder to design, for example, if the manufacturer has designed a similar artefact they would understandably not wish to disclose the results of product tests etc. which may assist in the design of the proposed idea, for fear of compromising any competitive advantage.

A participant felt that you cannot draw the line between SCAN and non-SCAN. This may indicate that the concept of SCAN needs to be more clearly defined.

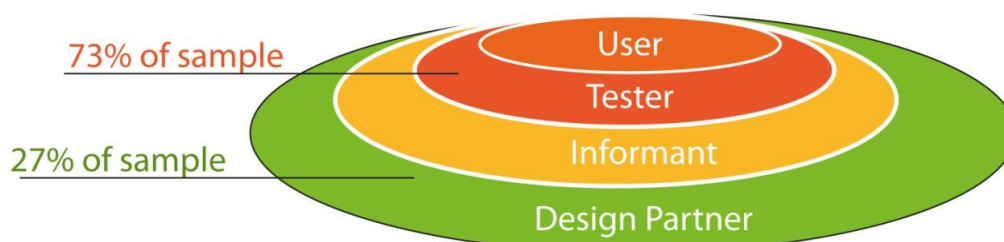
## 5. Discussion

The results will be discussed in terms of contemporary models of design and assistive technology, the themes that emerged from the analysis and the differences between the two groups: SCAN and non-SCAN designers.

### 5.1 The role of the user in the process: theoretical models

#### 5.1.2 Druin's model

Druin, among others, has discussed the different roles the user may take in the design and evaluation process. In this study, 73% of the sample had experience of using participants as testers and 27% had worked with users as design partners.



**Figure 4.2 Druin's (2002) model applied to this work**

For example, Druin (*op.cit.*) suggests there are four ways of involving children in design and evaluation processes (see figure 4.2). These are: children as the user, tester, informant and design partner. The same groupings could be modified and applied to this research simply by replacing the word 'child' with 'SCAN user'. A brief description of the components of the model will follow:

**User:**

*"The child is a user of technology while the adult looks to understand the child's activities with various methods."*

**Tester:**

*"Children test prototypes of emerging technologies...the goal of this role is for children to help in shaping new technologies..."*

**Informant:**

Children play "...some part in informing the design process...before any technology is developed the child may be observed with existing technologies, or they may be asked for input on paper sketches". The child can play a part in the design and evaluation process at various stages "...based on when researchers believe they can be informed by children."

**Design Partner:**

This role is similar to that of an informant, however, it suggests "...children will be a part of the research and design process throughout ..." and are equal stakeholders in the process. It is acknowledged by Druin (*ibid.* pp 19) that a child cannot do everything that an adult can do. However she feels they should "...have equal opportunity to contribute in any way they can to the design process."

Both this work and the work of Druin (*ibid.* pp 19) have one common thread i.e. the involvement of vulnerable groups within research and design and evaluation processes. With this in mind, the same model could be used to explain how SCAN users are involved in design and evaluation processes.

One participant had fifteen years experience and made use of seven methods that involved users indicating that experience may correlate with the use of methods to involve users in some cases.

In conclusion, based on the data collected it is not appropriate for this research to comment on whether a participant's experience of involvement in the design and evaluation process is improved by the use of methods that are accessible to them. However, it should be noted that a single participant stated that the methods he used are dependent on what the user can or cannot do. This assertion is given credit by the remarks of Blow (*op.cit.*) who states that "*...as levels of ability differ from person to person, so must the ways in which research is adapted to meet individuals' needs...*"

The evidence from this research appears to support Druin's (2002) theory i.e. the 27% of designers that viewed their users as Informant and Design Partner employed co-design methodologies.

However, it was concerning that the remaining 73% do not appear to use co-design methodologies when working with SCAN users, where co-design methods may be highly beneficial to the design process. Additionally, this 27% often employed methods that required a high level of engagement with the end user.

This result appears to suggest that only if bespoke design solutions are created can the user be truly involved (see figure 4.2) as the 27% who involved the users heavily in the design and evaluation process did this. A breakdown of these participants and what they designed is provided in table 4.7.

### 5.1.3 Arnstein's model of user participation

Arnstein's model of user participation is a diagrammatic ladder which defines levels of participation, from high to low. It is thought to be a guide to who has power when important decisions are made. Druin's model can be linked to Arnstein's ladder, for example, the designers that make use of methods on rungs 1-4 in this study would have involved their users as either a user, tester or an informant and those that make use of methods between rungs 5 -7 would have involved their users as design partners. An example of one participant involving a user as a design partner is:

*“So he got feedback...from him on what he felt was needed getting around campus and that sort of thing ...then I worked with him...and we co-designed this product.”*

An example of the role of user, tester or informant is: *“...the children would try a product ...and we will use some measure to establish their ability in the product and their physical ability out of the product...”* (see figure 4.2) showing how Druin's model has been applied to this work.

As stated above, the majority of designers questioned (73%) make use of methods at or below rung 4 of Arnstein's (1969) ladder (figure 4.3)

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### **Figure 4.3 Arnstein's ladder**

#### **5.1.4 Maslow's hierarchy of needs**

The results can also be discussed in terms of Maslow's hierarchy of needs which demonstrates that until basic needs are met, higher needs cannot be considered (Maslow, 1943). It may be argued that many designs of assistive technology and SCAN products were designed only to address functional needs and not experiential or higher needs.

However, this is not surprising, for five reasons:

- 1) Assistive devices are tools that have been developed to assist management of the environment and overcome problems of daily living (Swann *op.cit.*). Therefore before designers can design such devices effectively they must acknowledge some basics (Blythe *et al. op.cit.*).

It follows that technology employed to assist a user's daily routine must be designed effectively (Dewsbury, Rouncefield, Clarke and Sommerville *op.cit.*).

- 2) Many such devices arose from occupational therapy and included such functional items as bread boards etc. (Swann *ibid.* pp 286).
- 3) Such manufacturers are often small companies lacking the financial and technical resources of mainstream counterparts (Bayer and Lane *op.cit.*).
- 4) Markets may be small and highly specialised; therefore small companies find it difficult to design, develop, test, costly and sophisticated products (Bauer and Lane *ibid.* pp 69).
- 5) Markets are generally small and highly fragmented, together with a wide range of abilities, needs, ages and life situations (Bayer and Lane *ibid.* pp 69).

According to Dewsbury, Rouncefield, Clarke and Sommerville (n.d.) to help with the transition away from this, a qualitative shift is required to translate needs into design specifications. However, “...*the acceptance or rejection of assistive technology relies on the users perceptions of the designed technology as well as the appropriateness of the technology designed [because] ...a system that is not acceptable to users will simply not be used...* ”

This means that the way technology operates is a social as well as a technical issue: in some cases, technology is available but is not delivered in such a way that users find it helpful (adapted from Dewsbury, Rouncefield, Clarke and Sommerville *ibid.*) e.g.

*“...should the technology or the physical structure of the home not be fully acceptable or appropriate then the resident is unlikely to reap the full benefit and, at worse, there might be critical consequences.”* (Dewsbury, Rouncefield, Clarke and Sommerville *ibid.*)

Therefore by placing the social factor's conceptions and activities at the centre of the analysis, a more realistic and 'real worldly' grounded portrayals of the interrelationship between activities, technologies, and organised settings could be produced and be of more help to designers (adapted from Cheverst *et al.* 2003b)

The purpose of assistive devices is to minimise disability *“...and enable fuller participation in activities for people with profound impairments of function.”* (Swann *ibid.* pp 289) However, assistive technologies can offer benefits to the wider population-one example is that of predictive text which was first developed for disabled people who could not use a computer keyboard (Newell 2003, Arnott & Javed 1990, Pullin (n.d.), Gaver (n.d.). Although assistive devices are meant to assist people, some see such devices as being controlling and therefore threaten their independence (Axelrod *et al. op.cit.*).

Furthermore, some keep such devices out of sight for aesthetic reasons (Axelrod *et al. ibid.* pp 40) and that in order to prevent this from happening designers should consider such designs to be desirable (Axelrod *et al. ibid.* pp 41) or design better mainstream products to reduce the need for assistive devices (adapted by Keates and Clarkson, 2003).



However, where technology is concerned, some elderly and disabled people fear it as it is linked to the unknown. The solution to this may be to design products that do not have the appearance of technology and have on-going training and support schemes (adapted from Axelrod *et al. ibid.* pp. 41). More co-design will hopefully broaden designers' understanding of the user, enabling the design of products which fulfil higher level needs and are more aesthetically pleasing.

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**Figure 4.4 Maslow's hierarchy of needs mapped against Arnstein's ladder**

### 5.1.5 Users move to become SCAN users



An adapted Triangle of Care showing possible SCAN users

**Figure 4.5 (adapted from ADSS ‘All Our Tomorrows’ inverting the triangle of care)**

It is likely that old age and the onset of life changing conditions, for example dementia, may move more people into the SCAN category. However, as Dewsbury *et al.* (2004) note:

*“...it is important to consider that older people and disabled people constitute heterogeneous groups and as such need to be considered from a person centred perspective as individual needs will differ and cannot be based upon individual impairment, disability or medical conditions.”* i.e. it cannot be assumed *“...because you have this condition...you will need one of these devices.”* (Dewsbury, Rouncefield, Clarke and Sommerville *op.cit.*)

Failure to do this will, as outlined by Dewsbury, Rouncefield, Clarke and Sommerville (*ibid.*), lead to the design of unacceptable products because they have not determined how the person will use or want to them.

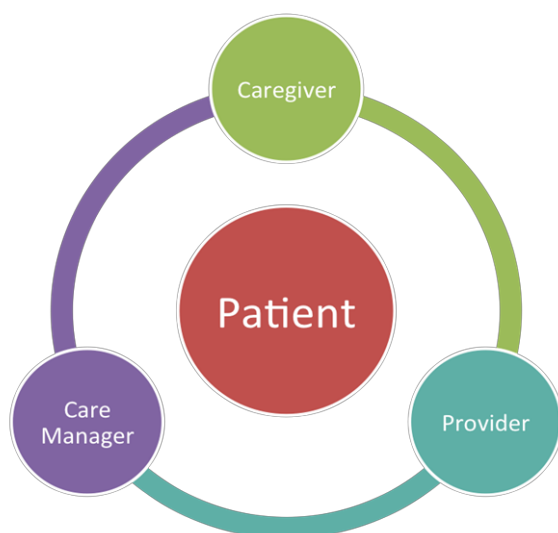
When SCAN is viewed within the context of the triangle of care (see figure 4.5) SCAN users are likely be placed at the top of the triangle i.e. frail older people and those requiring acute care, as the percentage of people dealing with a disability increases with age (Curran, Walters and Robinson *op.cit.*). Also, Burrows, Mitchell, Nicolle (2010) (and adapted from Kang and Yoon, 2008) acknowledges that there is a decline of ability occurring naturally with aging, for example, in cognition and vision as well as physical impairments. Huppert (2003) goes one step further and claims “...*older users are us...*” because eventually we will all be over the age of 50 (adapted from Huppert *ibid.*)

Furthermore, Wales (2004) contends that “...*older people like to be like others.*” This can be applied to older people and SCAN users, given the aging population and the number of laws, for example the Equality Act (2010) which seeks to ‘level the playing field’ for those with additional needs.

It is both these factors and societies increasing reliance on technology that will provide significant challenges for designers to create products to meet the expectations and needs of an increasingly diverse user population (Burrows, Mitchell and Nicolle *op.cit.*)

Bichof and Blessing (2008) suggest that the best products are those that do not have to be adapted when changes occur because this is pre-empted in the original design. Furthermore, Bauer and Lane (2006:67) suggest that mainstream manufacturers, being attuned to market trends, will position themselves to respond to the demands of an aging population. However, they may lack experience of this sector.

Users who have developed SCAN may have higher expectations and demands of products than those who have lifelong SCAN. Additionally, people with disabilities are demanding products that segregate and stigmatise them less (Monaghan, 2010:2).



**Figure 4.6 Circle of care**

During the study many of the participants outlined advantages to the use of advocates/carers and whilst these are acknowledged we must ensure that the advocate does not focus on or represent their own needs instead of those of the primary user. In following a user-centred design approach the designers should be naturally considering primary, secondary, tertiary and indirect users. Given the above, it was pleasing to note that in the focus groups, there was some discussion to the effect that everybody who interacts with the product is a user. However, many designers and companies will view the Commissioning Agent, for example, the Clinical Commissioning Group (CCG) as the end user.

This may lead to conflicts of interests between the end user as viewed by the designer/company and what may be called 'true end users' i.e. the people that will be using the product rather than those that commission a product. Given current climates these conflicts are likely to centre around costs and budgets rather than being wholly focused on whether the equipment meets the ends users' needs. Evidence for this assertion can be found when a participant remarked;

*“...but at the end of the day...if your products going to be successful if [you want]...to sell it ... [and] commissioners don't buy it for some reason...because of price or because of whatever...then that clearly impacts the success of the product from a sales point of view...”*

He does however concede that design success would not simply be measured from a sales point of view, but it would be an important consideration.

However, certain distinctions were made in that some participants who were questioned distinguished between users by introducing the term 'end user'. This was clarified further when it was observed the primary end user may be the individual with SCAN (also referred to as a direct end user), but a secondary end user may be a carer (also referred to as an indirect end user). It was also acknowledged that different responses may arise from the primary end user and the carer.

These remarks are given credit by Bjork (2003) who suggested that end users are either primary or secondary users. Hansen (1993) similarly remarks that different user categories often have different requirements and motivations, for example, a primary user may employ a product or service in the intended way, whereas a secondary user may use or handle the product or service differently.

As outlined by Blow (*op.cit.*) whilst support workers may provide an interpretation of what they think is being said, designers just relying on this have no real means of verifying the validity of this unless they know the participant and are able to understand how the participant indicates agreement or disagreement. It is important when using intermediaries the appropriate safeguards are in place as they may not be interpreting the end user's needs accurately and/or may have a vested interest.

The use of intermediaries is not uncommon. Cogher (*op.cit.*) states that

*“...in the implementation of consultation and involvement where there is a language or communication difficulty, a support worker or family member takes responsibility for interpreting what an individual wants or needs.”*

However, this approach relies on a shared understanding between two people Blow (*op.cit.*) and is a situation where reception may be as difficult as expression. Concannon (*op.cit.*) suggests that the process is filled with potential challenges, not only in understanding what is said but also understanding the hinterland that lies behind it.

## **5.2. Discussion of themes which emerged from the focus groups**

It may be difficult to define when a user has SCAN, and it could be argued that the researcher is presented with a choice, to either produce guidelines that are inclusive or guidelines that specifically address those with the most extreme needs.

It is not the intention to produce guidelines that positively discriminate and thus where possible, the guidelines produced will be inclusive.

However, it should be noted that those with the most extreme needs are often the least heard, for example, people with learning disabilities are among the most socially excluded and vulnerable in society (Valuing People, 2001:9).

It is therefore intended that the final guidelines will offer advice on how to include those with the most extreme needs. Those that are excluded from research - such as those with learning difficulties-may be a small, yet vital part of the population, but if these people can be included it may make it easier for everybody else. This is important because where some users are excluded; many more are likely to have frustrations or difficulties Bjork (*op.cit.*).

It is reported that people seem to be more comfortable around individuals with obvious, visible disabilities than they are with those that have less visible disabilities such as mental health issues or learning difficulties, therefore it is not surprising that negative attitudes and discrimination are worse towards such persons. It is thought that this may be due to poor understanding of how these disabilities affect people's social participation, or may indicate the prevalence of negative stereotypes (Aiden and McCarthy *op.cit.*).

It has also been suggested that designers conceive of disabled bodies as simply mobility or ambulant impaired, with limited perception of a wider range of physical and/or mental impairments which need to be addressed. There may be an undue tendency by designers to design principally for wheelchair users (Imrie, 2002).

An example of this thinking, reported by Dewsbury, Rouncefield, Clarke and Sommerville (*op.cit.*) was that a dwelling designed for people with disabilities was inhabited by someone with different disabilities to the design specification. In these circumstances a more exclusive approach to design may serve to provide better outcomes for a specific user group.

However, whatever approach is taken it is vital to make the users' wishes known to designers (adapted from Swann *op.cit.*).

Below are some of the challenges faced by designers when working with SCAN participants.

- ***Sensitivity to uncommon issues***

These can include the instance of being confronted by unexpected behaviour, for example “...all dribbly you know any orifice they can dribble from you know...that's fine...and you work, you know, you find yourself getting sneezed on and...you might find yourself being bitten, hair being pulled...” and also the need to be sensitive to stigmatisation that people might feel.

*“...raising the idea that someone has dementia if they currently don't believe they have or feel they have...is a big deal, so you have to be very, very sensitive about that when you're handling it...and that can be a big difference to the design...”*

As outlined in the results section, only a single participant stated that the methods used should depend on what the user can or cannot do. This statement is given credit by the remarks of Blow (*op.cit.*) who suggests that research should be adapted to the needs of individuals.



See table 4.4 for some examples of how research can be adapted to meet a defined SCAN user groups needs.

- ***Lack of guides***

It was noted that some participants stated there was limited literature published in relation to methods selection. This is worrying, though as Roberts and Fels (*op.cit.*) remark, methods are not generally developed to include disabled users, therefore good design practice and legislation should provide incentives for researchers to develop methodologies that are more inclusive.

- ***Empathy***

To enable a designer to enhance/gain a sense of empathy they may choose to make use of a capability simulator or empathy suit (see below). These were first developed in the 1980s (Tzekakis, 2008) and can be defined as devices that are worn either alone or in combination to simulate desired effects, for example, impaired movement or vision (Inclusive Design Toolkit, 2007).

- ***Communication***

In terms of communication with participants, it was highlighted that there was difficulty when communicating with users via e-mail. This would appear to be related to the user understanding what the participant is saying. However, the participant does propose a solution to this i.e. “... *you can give examples by pointing stuff on the Internet...*”

- ***SCAN Designers***

As indicated in the results section, two participants had SCAN and found it easier to gain the trust of SCAN participants. This may indicate that a detailed education in relation to SCAN could be beneficial.

In addition to this, they will need to be equipped with the skills, confidence and design methods required to successfully engage with and elicit requirements from SCAN users. In order to achieve this they will require safe, non-threatening environments in which to both learn and practice these skills.

Given that the designers work with SCAN users it is not surprising that some of the most popular methods included interviews and direct observation which require a high level of engagement with the end user. The use of such methods has been recommended by ISO/TR 16982:2002 (E) Ergonomics of Human System Interaction-Usability Methods supporting Human-Centred Design (Technical Report) when working with such users.

It was interesting to note that some participants felt “...*just because you have a very specific need... you shouldn't have to have a certain product...you should be able to choose the one that you want and it's an emotional choice...*” This may be an important factor given the increasing size and choice within the disability aids and equipment market which will continue to grow (Key Note Market Report *op.cit.*).

Approximately 15% of those in the western world are born with a disability (Bjork *op.cit.*). In addition to these, the world also has an aging population moving towards disability, and this group has considerable spending power. Therefore users with disabilities are not an insignificant market for manufacturers (Bjork *ibid.* pp 118). It has been noted that statistics for disability tend to refer only to those registered as disabled. The consequence is that such statistics almost certainly underestimate the true figure (Bjork *ibid.* pp 118).

This should send a clear message to businesses that more inclusively designed products and services are profitable and competitive (adapted from Bjork *op.cit.*; (adapted from Sinclair *ibid.*). The UK Design Council has demonstrated that designing better products helps businesses. Good design is also reported to be good for stock market performance (IET, 2006) and can improve the business's public image (adapted from Curran, Walters and Robinson *op.cit.*).

It is also claimed that more inclusive design better informs business decisions according to the diverse needs of real-world users, enables products to reach wider markets, improves customer satisfaction and reduces costs associated with customer support (Waller, Langdon and Clarkson *op.cit.*).

Furthermore, if manufacturers of products and services do not design inclusively they risk legal action similar to mobile phone manufacturers who did not make substantial progress in regards to inclusive design until a blind customer threatened to pursue this course of action (adapted from Rosen 2007:16).

This is not surprising given that as stated by Rosen (*ibid.* pp 16), a market focused approach may be insufficient to create products designed to be used widely, and that typically a civil rights programme is needed to effect change. This assertion is given credit by the remarks of Bauer and Lane (*op.cit.*) who state that the disability rights movement, in fostering the concept of accessible design; this led to accessibility standards and their enforcement through public policy.

Lastly, as design becomes more global, it should cater for different sizes, abilities and ages (Swann *op.cit.*). In a project undertaken by the Centre for Technology and Inclusive Design (CITD) it was found that the main barriers to the uptake of universal design were 1) a lack of knowledge, 2) a lack of tools, and 3) a lack of a justifiable business case for doing so (IET *op.cit.* 1). This leads to the non-involvement of users for the above reasons, and as stated by a participant “...*I would argue...with users we could improve, its poor if I'm being honest...but it's difficult.*”

However, this would appear to be dependent on individual designers because a participant with two years experience used a variety of methods to involve users (for example one-to-one interviews, focus groups etc.)

As a result of the high level of use of intermediaries by the sample in this study, the next stage of the research will be modified to include interviews with carers and users to see how this process can be facilitated.

Although a neutral stance is taken in the research regarding the use of intermediaries, research will be undertaken to determine how tokenism and misrepresentation of users can be avoided; e.g. through observations of the SCAN user and empathic techniques which enable the designer to understand communication intentions i.e. how they indicated agreement. It may then be possible for the designer to know when the user is showing satisfaction or dissatisfaction with decisions and changes that have been made, or statements made by intermediaries (adapted from Blow *op.cit.*).

Given that the aim of this research is to produce guidelines to assist designers in the selection of the most appropriate methods to support user-centred evaluation and design when working with participants with SCAN. It may be appropriate to use an intermediary when:

- There is a language or communication difficulty (as suggested by Cogher, *op.cit.*).
- Users are unable to communicate their needs e.g. because of disability.
- Users lack insight into their condition e.g. age related issues.

Chandrashekar *et al.* (*op.cit.*) focused on the appropriateness of methods for SCAN users.

### 5.2.1 Control group

A minority in the sample highlighted that they felt it was important to design inclusively both from a user's and a business perspective. This assertion is encouraging to see, as much has been written about the benefits of inclusive design from both perspectives, for example, according to BS 7000-6:2005:

*"...those adopting a pro-active approach based on a better understanding of consumer needs and aspirations stand to benefit from an improved quality of products; increased sales and customer satisfaction and loyalty; stronger brand values and enhanced brand recognition; greater profitability and improved returns on investment."* In short everyone benefits.

As seen from the results section it may be difficult to define when a user has SCAN and when a user does not. However, it is accepted that there are other activities such as observations and simulation suits a designer can use/conduct that would allow them to ascertain a clearer understanding of user needs without using an intermediary.

One example of a simulation suit was the 'Third Age Suit' (see figure 4.7), this was developed by Ford. The goal of this was to empathise with older users by allowing the researchers to experience some of the difficulties faced by such drivers (adapted from Keates and Clarkson, 2003) which may include according to Dumbaugh (2011:30) a decline in:

- Coordination
- Reaction times
- Flexibility
- Visual acuity

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### **Figure 4.7 Third Age Suit**

To use carers as advocates requires additional safeguards. Any guidelines about the use of carers will need to explain clearly the advantages and disadvantages of this approach.

The information gathered from this stage was used to inform the questions to be addressed in the interviews with end users.

A brief description is given here of the main findings from designers that are used to shape questions for stage 2 of the research with SCAN users. For clarity, full descriptors are provided in Appendix F.

The research indicates that designers do have problems when working with SCAN users in the following areas:

- **The ethics of working with SCAN users:**

The importance of ethics was raised by participants in all groups as they felt ethical issues could limit the level of testing that can be undertaken and thus reduced the amount of feedback they could gather.

- **Use of intermediaries**

Guidance is needed on the appropriate use of carers/support workers in the design or evaluation process. The suggestion that a user's carer or spouse can be used as a design informant by designers will also be tested by questioning SCAN users about their preferences and experiences in this matter.

- **Engaging users**

The majority of designers questioned (73%) made use of methods that may not fully involve users i.e. those between rungs 1 and 4 on Arnstein's ladder. The UK and US designers reported different experiences, and in this respect this may highlight cultural differences.

- **Use of language**

A significant minority (27%) of designers reported a need to be careful in the language they use when working with SCAN users. This can be problematic for a number of reasons.

- **Maintaining professional boundaries**

A significant minority (27%) reported that the giving of personal contact details is not advised as this may have unintended consequences. Also, designers need to keep a professional distance when working with users so that they can see the whole picture.

- **The nature of working with SCAN participants**

Some highlighted that a problem when working with SCAN participants is that they may have health related difficulties which may make it difficult for them to partake in research.

## **6. Superordinate and subordinate themes**

The results above show the main findings of sessions with designers. In order to better understand the important issues that designers had reported, these results might be meaningfully regrouped into superordinate and subordinate themes. Criteria for selection were established. A detailed rationale for this further analysis is set out below.

### **6.1. Rationale for superordinate and subordinate themes**

In total, the analysis identified twenty six themes. These were subsequently categorised into a smaller number of superordinate themes under which all other themes could be subordinated. After careful consideration, three superordinate themes were identified, these were:

- Design issues
- Working with SCAN users
- Methods

The subordinate themes were identified as being related to the superordinate themes by the following method:

#### **Design issues:**

Definition: What needs to be considered by a designer when producing a product or service.



This may involve design considerations ranging from the actual design process itself to how users were treated and what designers' attitudes were. This is by far the biggest superordinate theme with eleven subordinate themes, which is not surprising for two reasons; 1) the research focused on designers and 2) it must be remembered that design in itself is quite broad and thus many issues can arise and many factors will need to be considered.

### **Working with SCAN users:**

Definition: a SCAN user is defined as an individual that has “...*specific, critical needs (in relation to them, and these needs have to be met in order to maintain their quality of life, health, safety and wellbeing) but are additional to that of common everyday critical needs.*” Because of the nature of SCAN users they have additional barriers and complexities in their life.

With this in mind, this theme outlines what needs to be considered when working with such users, for example, designers will need to have an awareness of ethical issues especially around the gaining of informed consent (as this can present additional challenges when working with these users). Furthermore, they will also need to carefully consider how written material is designed. Lastly, they will need to understand the variety of needs in this group ranging from dyslexia to dementia and each users differing level of ability.

### **Methods:**

Definition: a definition of method is “*A particular procedure for accomplishing or approaching something, especially a systematic or established one.*” (Oxford Dictionaries, 2018a)

Subordinate themes: there were six subordinate themes in this category.

All of the themes related to how designers employed methods (ways of doing things) when working with users, for example, the use of focus groups, what method they selected, how they adapted those methods to meet the needs of users, and practical advice when conducting sessions.

Participants also felt there was a lack of information related to methods used to either elicit requirements or gather feedback.

## 7. Conclusions

Despite a comprehensive web and literature review conducted at the start of the research, only four exemplar studies (Henderson *et al.*, 1995; Chandrashekar *et al.*, 2006; Roberts and Fels, 2005 and Dong *et al.*, 2005), three websites with resources (Inclusive Design; Inclusive Design Toolkit; Designingwithpeople.org), and one booklet (Methods Lab) were found to have findings directly applicable to this area of study.

However, this information does not extend to offering advice on appropriate research method selection when working with SCAN users. It is expected that the proposed guidelines will go some way to addressing the issues raised.

Designers provided a number of helpful indicators for the improvement of understanding SCAN users' needs in the design of goods and services. These results are intended to inform the principal survey of end users set out in chapters 5 and 6.

As a means to better understand the main issues arising from the advice offered by designers, an additional analysis was undertaken to regroup the results of interviews into superordinate and subordinate themes. In order to undertake this further analysis, criteria for selection were established. Three superordinate themes were established, with all other themes being systematically subordinated to these.

### 1. Introduction

Many of the studies of the methods used by designers to involve users in the design process during requirements and evaluation stages have simply considered the development of the methods or the outcomes, rather than the insights of users. To redress this imbalance, this study takes a phenomenological approach to investigate the attitudes of users with Specific, Critical, Additional Needs (SCAN) (and members of their circle of care) towards their involvement and the accessibility of the selected research methods<sup>1</sup> (cf. Chapter 3). In this context, accessibility is seen as a systematic and objective means of describing and quantifying phenomena (Elo and Kyngas 2008:108; (Krippendorff 1980; Downe-Wamboldt 1992; Sandelowski 1995). Such an approach allows the researcher to make replicable and valid inferences from data in context, to provide knowledge, new insights and a representation of facts (Elo and Kyngas *op.cit.*; Krippendorff 1980 *op.cit.*)

In this study, accessibility is concerned with whether users of all capabilities can access research methods, for example, interviews or questionnaires in order to make a meaningful contribution to the development of a product or service. Accessibility in this context can be defined as allowing the SCAN user to make their contribution to a design and/or evaluation process by the selection of appropriate research methods. Accessibility and usability are intrinsically linked. As Jeffels (2011) has stated “*The lower the level of accessibility of a resource for an individual, the less usable it will be for them.*”

Content analysis of semi-structured interview transcripts were used to develop practical guidance for designers to assist them in developing the skills, knowledge and expertise required for more effective engagement with such users.

Whilst the guidelines are primarily for designers, they may be of equal, if not greater value to design lecturers as they will have the unique opportunity to influence future practice. Content analysis showed that developing empathy and insight is crucial to understanding the practical considerations of both working with, and meeting the needs of SCAN users.

This chapter outlines the methodology employed in interviewing SCAN users to investigate how they are treated in design and evaluation processes, and the subsequent analysis of data.

During the study, feedback was gained from users in relation to any advice they would give to designers when working with SCAN users.

**This stage of the research was supported by the following objectives:**

- 1) To investigate how SCAN users, their carers and other user groups are treated as part of design and evaluation processes;
- 2) To identify key themes and recommendations for designers that will form the basis of guidelines to assist them in making reasoned methodological choices when working with SCAN participants, their carers and other user groups.

## 2. Methodology

### 2.1 Data collection

A total of twenty two semi-structured interviews were conducted (thirteen face-to-face and nine via telephone). The main purpose was to explore how users are treated as part of a design and evaluation process. Users were given the opportunity to give advice to designers to help them improve their practice. The data gathered forms the basis of this chapter. The face-to-face interviews were conducted on campus at Coventry University in a usability lab (see figures 5.1, 5.2 and 5.3 below).

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**Figures 5.1 and 5.2 Layout of usability lab for interviews**

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancaster Library - Coventry University.

### **Figure 5.3 An interview in progress**

The researcher asked questions as set out in the interview schedule and a note-taker was in the same room taking notes for analysis purposes. Also, if required, the participant's support worker was present. The sessions were either audio or video recorded for analysis purposes and lasted between 60 and 90 minutes according to the participants' needs. Participants were encouraged to give a free response to questions with prompting only being used to either clarify or stimulate discussion points.

This method was used because as stated by Robson (2002:279) it can be delivered informally as it met the varying requirements of the user group, for example, rest breaks between questions. In common with the work of Devices for Dignity Healthcare Technology Co-operative (D4D) the research methods and the interviewer style were flexible to accommodate the needs of participants (adapted from Moody (2015a:4), Thieme *et al.* (2014) and Clarke *et al.* (2011)).

Another similarity with the work of D4D was that face-to-face and telephone interviews were used. These methods acknowledged the participants' needs and preferences (adapted from Moody (*op.cit.*) (a), Judge and Townend (2010) and Clarke *et al. op.cit.*).

To enable participants to provide feedback, they were provided with all research materials well in advance, this then enabled them to familiarise themselves with such materials and provide written feedback if they wished.

## 2.2 Ethical approval

The study was given ethical approval by Coventry University Research Ethics Committee on 25<sup>th</sup> September 2013 as a medium to high-risk project.

## 2.3 Data analysis

Once the data had been collected and transcribed, a content analysis was conducted.

The researcher found the sharing of in-depth personal insights to be extremely valuable (adapted from Moody and McCarthy 2011c).

Using the transcripts and interview protocol, the data was chunked and assigned into a category. These categories emerged out of the analysis of the interview transcripts, for example, information on involvement in design and evaluation process was placed in that category. These categories then formed themes around which the results were presented, for example:

- Demographics
- Involvement in design or evaluation processes
- SCAN users versus family members/support workers/ health and social care professionals
- Users taking risks
- At what stage are users and other stakeholders involved in design or evaluation processes?
- Exclusion of SCAN users from research
- Challenges when working with designers or researchers
- Challenges of working in the National Health Service (NHS)

- Challenges faced by SCAN users or their family members
- Challenges faced by designers
- Challenges faced by the elderly
- Strategies employed to overcome challenges
- Advice participants would give to designers when working with SCAN users
- Advice for designers when working with Health or Social care professionals
- Advice for improving design education
- Evidence of lack of consultation/tokenism with SCAN users
- Understanding user requirements
- The motives of health and social care professionals to work in their professions
- External factors which prevent users' needs being met
- The importance of giving accessible feedback
- The importance of using accessible methods to gather requirements/feedback
- Evidence of good practice
- The role of the health or social care professional in inclusive design
- Guidance for advocates
- Skills designers require to work effectively with SCAN users
- Information on accessible methods when working with SCAN users
- The importance of good after sales support
- Perceptions of disability
- The difficult language of disability
- The difficult debate about language
- Evidence that supports the assertion that designers' need guidance; what form should this guidance take?
- Ideas for designers for future project
- The influence of advocates



The data was then read and for each single item of data a theme was attached, for example, 'the difficult debate about language.' The data was then re-read a second time to identify recurring themes; anything that occurred more than once and had been identified by multiple participants was considered to be a key theme.

Lastly, after the analysis was completed a proportion of the data (10%) was sent for validity and reliability checking. The results of this exercise were as follows; one coder agreed with 99% of the themes and the other 97% of the themes; themes were agreed without any changes being made therefore it can be concluded that the themes are valid and reliable.

The researcher found the sharing of in-depth personal insights to be extremely valuable (adapted from Moody and McCarthy 2011c). However, processing these views was time consuming and difficult due the nature of the researcher's own disability.

## 2.4 Sample size

Chain or snowball sampling were used to recruit participants: this may be defined as a technique for gathering research participants through the identification of initial participants who are used to provide the names of other participants (adapted from Atkinson and Flint 2004).

Participants were grouped in terms of their primary disability based on self-disclosures. It should be noted, that in common with the work of D4D many of the participants:

- Had complex needs and impairments affecting their mobility and communication, and
- Were reliant on carers to facilitate their transportation, access and participation.

- The organisation of user involvement sessions therefore took into account these constraints (adapted from Moody (*op.cit.*) (a:4), Joss and Oldenburg *op.cit.*, Scott, Woodcock and McDonagh *op.cit.*, Judge and Townend *op.cit.* and Clarke *et al. op.cit.*)

In addition, because family members and support workers are often secondary users (and have their own insights), it is often reasonable to consider them part of the participants' circle of care that has been described as "*...a multi-directional flow of care between healthcare professionals and their colleagues, patients and carers.*" (Clod Ensemble and Guy's and St Thomas' NHS Foundation Trust, 2016:3, adapted from Moody (*op.cit.*) (a), Moody and McCarthy, 2015, Clarke *et al op.cit.*).

It is important that all those involved in the circle of care are consulted to ensure clear requirements for every stakeholder are obtained. However, there are dangers to this approach, particularly in relation to advocacy (see chapter 6 section 2.18).

In addition to SCAN users, their carers and the health and social care professionals, a control group was also established (comprising five participants who did not disclose any disabilities). The purpose of establishing this group was to investigate whether those without disabilities encountered similar or different issues when taking part in a design or evaluation process.

For analysis purposes, the data was merged with data from the other participant groups and has not been reported separately. This decision was taken primarily due to the small sample size.

Research group	Number of participants
Family member or Support worker	5
SCAN users with a physical impairment	5
Health and Social care professional	4
SCAN users with a visual impairment	2
SCAN users with a hearing impairment	1
Control group (users without disability)	5

**Table 5.1 Total number of participants = 22**

### 3. Analysis of results

In common with the pilot study, participants had experience of designing or evaluating a wide range of products or services, for example, social care services such as care plans or market research, (brand names and types of deodorant). All of the family member group had been involved in design, evaluation or research processes from the perspective of an advocate. This also applied to two members of the health and social care professionals group. These findings were not surprising as it is usual for members of these groups to be involved in such a capacity. For example, carers and family members are often thought of as natural advocates (Social Care Institute, 2006). Additionally, it is thought that in patient care, nurses often play the role of advocate in supporting each patient's emotional well-being: in this way they speak on their patients' behalf and contribute to the healing process (Krischke, 2011).

Product or service	Number of participants
Social care services (for example, care plan)	7
Advocacy/Proxy (for parents and children in terms of health services)	5
Market research (for example, car servicing and deodorant)	4
Support groups (for example, Transport for Greater Manchester Disability Design Reference Group)	2
Specification/assistance to evaluate aids for people that have communication difficulties	2
Design or evaluation of software	2
Service Design for the Centre of Independent Living in Greater Manchester	1
Completed questionnaire for friend's dissertation	1
Provided feedback for companies in terms of the usefulness of equipment for people with disabilities (for example, shower chairs)	1
Research in relation to people with autism	1
Developing person-centred plan transition reviews	1
Product evaluation (for example, product packaging)	1
Website accessibility evaluation	1
Experimental studies	1
Academic research	1
Completing surveys	1
Transport designs	1
Has been involved in research but was unable to recall details	1

**Table 5.2 illustrates the number of participants and the product or service that they had either helped to design or evaluate**

Multiple participants may have been involved in multiple processes hence the number of participants in the above table exceeds the total number of participants in the study.

### 3.1 Reducing sampling bias

Although the sample was small (twenty two participants) it should be noted that many of these had a disability thus reducing the available population. It has been stated that, in developmental studies, researchers often utilise fewer than 30 participants per group due to the difficulties and cost of recruiting participants with disabilities." (Urbano and Hodapp, 2007:103). Therefore the sample could be considered valid because of the following:

Bias in sampling may be defined as systematic error in sampling procedures that can lead to distortion in the results of the study. For example, bias may be introduced through the sample not being representative of the study population due to improper sampling procedures. Hardon, Hodgkin and Fresle (2004:63). Great care was therefore taken to avoid sampling bias by ensuring:

1. The sample had experience of both product and service design in a number of different contexts.
2. The sample had experience of a variety of methods such as focus groups, questionnaires and one-to-one interviews.
3. The sample also had experience of being involved in research at a number of different stages, for example, product evaluation and service design, the design of software (two participants), design of social care services (seven participants) and market research (four participants).
4. Participants had a wide range of disabilities, from physical disabilities such as cerebral palsy to mental health impairments and learning disabilities. The researcher accepts, however, that those with severe learning disabilities were not included in this sample. This was not deliberate and efforts were made to try and include this most vulnerable section of society. However, after discussion and a preliminary meeting with a senior occupational therapist (who works with this user group), it was decided that the adaptations required<sup>2</sup> could not be made within the agreed timescale for completion. It is hoped that this shortcoming may be rectified in future work.

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<sup>2</sup> Simplifying language and the research practices themselves i.e. using theatre to act out a research method being used.

It should also be noted that participants had experience of a variety of roles such as end users, secondary users (support workers) and advocates (particularly health and social care professionals and family members).

#### 4. Summary

Twenty-two participants were interviewed either over the telephone or face-to-face. These were audio and /or video recorded and then transcribed.

Transcripts were analysed using content analysis. As a result of this analysis, themes were identified which took the form of a detailed commentary with links to supporting literature.

The participants were drawn from the following groups:

- SCAN users with a physical impairment (5)
- Family member or support workers (5)
- Control group (users without disability) (5)
- Health and Social care professionals (4)
- SCAN users with a visual impairment (2)
- SCAN users with a hearing impairment (1)

It is clear to see that the results of the study are both interesting and would be of benefit to both designers that wanted to work with SCAN users and designers generally.

Whilst the research has undoubtedly gone some way to closing the knowledge gap in relation to information for designers regarding appropriate method selection when they work with SCAN participants, it does have its weaknesses which the researcher readily acknowledges.

These are:

It has been difficult to recruit participants who have severe disabilities. This is a well-known difficulty and has been discussed in relevant literature, for example, Lazar (2007:412). Primarily, the already small population of those with disabilities was made even smaller when faced with the requirement to have taken part in a design or evaluation process in order to participate.

However, once they were recruited, users were keen to engage and to assist in any way they could. This is not dissimilar to a conclusion made by Moody (*op.cit.*) (a) who stated that their experience was that, once recruited, participants were keen to engage in projects and remain involved: this provides an opportunity to talk and explain problems and to share stories in an environment that is non-threatening.

Projects such as this face some challenges; some of these are outlined in table 5.3:

<b>Challenge</b>
Gaining access to appropriate research participants i.e. SCAN users, family members and health and social care professionals.
Contacting and engaging with relevant stakeholders.
Maintaining a user's interest and involvement.
Ensuring that appropriate time, equipment and other resources were available to facilitate the user's involvement.
Ensuring that appropriate methods were used to meet an individual's needs that allowed them to participate effectively.
Ensuring the appropriate resources and timescales were in place to manage the resulting data.
Accommodating differences in knowledge, working practices and differing perspectives.

**Table 5.3 outlines some of the challenges faced in this study (adapted from Moody (*op.cit.*) (a))**

### 1. Introduction

This chapter provides the results of interviews conducted with SCAN users to investigate how they are treated in design and evaluation processes. This research focused on the methods used to support these findings and whether they were accessible to users that have SCAN.

A summary of key findings is provided that have led to draft guidelines that will assist designers to make reasoned methodological choices. The presentation of results is ranked in order of the number of participants indicating that particular theme, highest number first.

It was considered to be important to link supporting evidence from the literature review to each of the main findings. These are contained in footnotes.

As an aide-memoire, some elements of Chapter 5 are repeated here where necessary.

An additional analysis was made to establish a small number of superordinate themes under which all other themes could be subordinated. The rationale for this analysis and its results are reported.

The chapter concludes with a discussion of issues arising together with recommendations.



## 2. Results

The themes emerged out of the analysis; categories were then created based on these.

Each participant was given a code, for example S2-CG-01 refers to stage 2-control group-participant number 1; this is represented as number '1' in the table. These codes were used to indicate when a participant had highlighted a key theme, for example, participants 1, 2, 3, 4 and 5 in the control group referred to the reality of life lived as a SCAN user.

### 2.1 Superordinate themes for stage 2

Theme	Participant groups						Total
	Control group	Family members/ support workers	Health and Social care Professionals	Physical Impairment	Visual Impairment	Hearing Impairment	
The reality of life lived as a SCAN user	1,2,3,4,5	1,3,4,5	1,3,4,5	1,2,3,4,5	1,2,3,4,5	1	24
Methods	1,2,3,4,5	1,2,3,4,5	1,2,3,4	1,2,3,4,5	1,2,3,4,5	1	25
Professionalism	1,2,3,4,5	1,2,3,4,5	1,2,3,4	1,2,3,4,5	1,2,3,4,5	1	25
Language	1,2,3,4,5	1,2,3,4,5	1,2,3,4,5	1,2,3,4,5	1,2,3,4,5	1	26

Table 6.1 illustrates superordinate themes for stage 2

### 2.1.1 Themes subordinated under reality of life lived as a SCAN user

Theme	Participant groups						Total
	Control group	Family members/ support workers	Health and Social care Professionals	Physical Impairment	Visual Impairment	Hearing Impairment	
Money and wealth	2,3,4	1,5	1,4	1	1,4,5		11
Choice, control and power		1,5	1,3,4	2,5		1	8
Disability as a social construct	3	1,3		1,2,4			6
Perceptions of disability		1,3		4,5		1	5
How does a “user” perceive themselves?	1,2,3,4,5						5
Users experience of designers	1,2,3					1	4

**Table 6.2 illustrates themes subordinated under the reality of life lived as a SCAN user**

## 2.1.2 Themes subordinated under methods

Theme	Participant groups						Total
	Control group	Family members/ support workers	Health and Social care Professionals	Physical Impairment	Visual Impairment	Hearing Impairment	
Insights expressed in terms of methods used to support design and evaluation processes		1,2,3,5	1	3,4,5		1	9
Human support and assistive technology		1,2,4,5	1		3		6
Difficulty when conducting research with SCAN users					2,3,4,5	1	5

**Table 6.3 illustrates themes subordinated under methods**

### 2.1.3 Themes subordinated under professionalism

Theme	Participant groups						Total
	Control group	Family members/ support workers	Health and Social care Professionals	Physical Impairment	Visual Impairment	Hearing Impairment	
Time	1,2,5	1,3,5	1,2,3,4	1,2,3,4,5	1,2,3,4,5	1	21
Education and training	4	1,2,3,4	3,4	1,4,5	1,3,4,5	1	15
Maintaining professional boundaries	4,5	3,4,5	1	1,2,3	2,3,4,5	1	14
Value and respect	4,5	1,3,5	2,3	1,3,5	1,2,4		13
Ethics and confidentiality	1,2,3,4	3,4,5		1,3	1,3,5	1	13
The making of incorrect or wrong assumptions	4	1,3,4	1,3	2,3	1,3,4,5		12
Knowledge and expertise	1,2,3,4	1,3,4	3	5	1,5		11
The importance of follow ups/feedback		3,4	1,2,4	5	1,2,4,5	1	11
Empathy and a day in the life of	2,3,4,5	1,2,3,5	1,3		1		11
Flexibility	1,4	1,4	2	2,4	4,5	1	10
Consultation and advocacy	3	2,3,4,5	1,4	1,5	5		10
Making adjustments or accommodations	1,4	1,4		1	2,3,5	1	9
The importance of mutual understanding between designers and the user	2,3,4,	1,2,3,5	1			1	9

Theme	Participant groups						Total
	Control group	Family members/ support workers	Health and Social care Professionals	Physical Impairment	Visual Impairment	Hearing Impairment	
Understanding users life circumstances		1,4		3,4,5	1,4,5	1	9
Putting people at ease	1,4	3		3,5	1,2	1	8
Relationship building	1,3	5	2,3		1,3		7
Creativity and innovation	2	1,3	2	5	1		6
The need for thinking 'outside the box'		1,3	2				3
Patience	4	3	1	2,4	2		6
People skills	4,5	3			2,4		5
Humour				2,4,5	1		4
Objectivity, integrity and impartiality	1,4				2		3
Examples of good practice	4		4		3		3

**Table 6.4 illustrates themes subordinated under professionalism**

## 2.1.4 Themes subordinated under language

Theme	Participant groups						Total
	Control group	Family members/ support workers	Health and Social care Professionals	Physical Impairment	Visual Impairment	Hearing Impairment	
Use of inappropriate language	1,2,3,4,5	1,3,4,5		1,2,3,4,5	1,2,4,5		18
The difficult language of disability		1,3,4,5		1,2,3,4,5	1,2,3,4,5	1	15
Use of technical language and jargon	4	1,2,3,5	1,2,3,4	1	3,5	1	13
Communication skills and listening	1,2,4,5	1,5	2,3	2,4,5	1	1	13
Simplifying language		1	3,4,5	1,5	2		7
Language used in research materials	2,3			1,2,5	2	1	7
The importance of understanding body language	3,4	1,5			4,5		6

Table 6.5 illustrates themes subordinated under language

## 2.2 Time (21 participants)

Time was discussed by the majority of participants, aspects included:

- The need to allow extra time for SCAN users to present their views or complete tasks.
- If a designer works in a commercial organisation, formal methods may not be employed due to lack of time.
- Designers not having sufficient time to speak to users.
- Some participants felt their time had not been used wisely.
- Participants need to be given the required time to process information; this may be longer than usual in a case of a learning disability such as dyslexia<sup>1</sup>.
- Users may not have time to complete questionnaires.

## 2.3 Use of inappropriate language (18 participants)

The study found no evidence of designers using foul, insulting or abusive language during the course of their work. However, inappropriate language was identified as a complex issue<sup>2</sup>. The study did find evidence of what may be considered inappropriate language towards users who have SCAN which consisted of:

- Politically incorrect language<sup>3</sup>.
- The use of inappropriate language and humour<sup>4</sup>, for example, it may be inappropriate to refer to somebody as 'disabled'<sup>5</sup>.

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<sup>1</sup> Because it affects the way information is processed, stored and retrieved, with problems of memory, speed of processing, time perception, organisation and sequencing (adapted from British Dyslexia Association, 2015).

<sup>2</sup> "...people have different [sensitivity] levels." (a control group participant)

<sup>3</sup> "...the word they used ...that he'd never ... [heard] that he was mentally retarded." (a family member/support worker)

<sup>4</sup> Participant: "...I always tell (my friend) how special he is ..." Researcher: "And...why do think people do that...when they are around other disabled people?" Participant: "I think ...we feel safe and we don't have [to] prove and explain things ... where [as] if it was someone else it might be more... offensive." (a participant with a physical impairment)

<sup>5</sup> Because some people consider themselves not to be disabled but instead disabled by society thus preferring to be referred to as a person with a disability (adapted from Scope, 2015c).

- The use of language to bully or intimidate others<sup>6</sup>.

The above illustrates that language can be used in many ways and even the use of acceptable language in some circumstances can be unacceptable in others.

## 2.4 Methods (18 participants)

Participants discussed a wide range of methods, including common methods, for example, questionnaires and some less common, for example, mind-mapping. It was felt that co-design could be a useful strategy to use where a product such as prosthesis is being developed.

Below is a summary of what was found in relation to individual methods:

### 2.4.1 Questionnaires

Many of the participants highlighted advantages and disadvantages of questionnaires that are well-known within the literature, for example, questionnaires have a poor rate of return<sup>7</sup>.

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<sup>6</sup> “...there has been times where... people have been nasty like ‘oh you spastic.’” (a participant with a physical impairment)

<sup>7</sup> Kirklees Council Research and Consultation Guidelines (*op.cit.*), Pinsonneault, & Kraemer (1993), University of Central England (2006) and others.



What gives these findings credibility is that they are not stated by academics or researchers but real individuals with SCAN, participants identified the following:

<b>Questionnaires</b>	
<b>Advantages</b>	<b>Disadvantages</b>
Useful for gathering statistics and gathering trends (The University of Sheffield, 2014).	Sometimes they ask more than one question within one question; this can lead to uncertainty about what is actually being asked (Dornyei and Taguchi, 2009: 42).
Can be used to confirm requirements (Satzinger, Jackson, and Burd, 2012:51).	They are not accessible to those that have literacy difficulties (Kirklees Council Research and Consultation Guidelines, 2008).
Maybe useful if you are trying to attract people that are geographically remote (Kirklees Council Research and Consultation Guidelines ( <i>op.cit.</i> )).	Often have a poor rate of return (Kirklees Council Research and Consultation Guidelines ( <i>ibid.</i> )).
May have an important role in evaluation (Sears and Jacko, 2003:1096).	Often do not represent your entire target group, for example, those that have poor literacy skills (Kirklees Council Research and Consultation Guidelines ( <i>op.cit.</i> )).
“Easy to analyse.” (Gillham, 2008:2)	May result in poor quality feedback, as you cannot assess people’s understanding of the questions asked (Dempster, Hanna, Wiley, 2015:96).
	People may have difficulty returning the questionnaire (Carlisle, 1986:12).
	It can be challenging to write questionnaires that people fully understand therefore you may not get the required answers (Lehto and Landry, 2012:527).
	Should be avoided if honest views are required (McBurney and White, 2009:264).

Questionnaires	
Advantages	Disadvantages
	May not be appropriate where discussion of themes is required (Cudny, 2016:62).
	Only provides simplistic data (Browne 2011:59).
	Often used as a default method (Olson and Boll, 2001:309).
	Does not enable users to explain in detail what they mean or why they feel like they do <sup>8</sup> (Kirklees Council Research and Consultation Guidelines ( <i>op.cit.</i> )).
	Because of the limited nature, such as a rating scale, participants may not be able to truly express what they feel (Kirklees Council Research and Consultation Guidelines ( <i>ibid.</i> )).
	If closed questions are used, you may risk not capturing all the information required (Clifford and Gough, 1990:117).
	Can be difficult to write a good questionnaire <sup>9</sup> .
	Online questionnaires are dependent on people having the right technology to access them (Reynolds, Woods and Baker, 2006:61).
	Paper-based questionnaires do not allow for easy editing <sup>10</sup> .
	SCAN users may not be able to write long paragraphs (Nadash, 1993:47).
	Badly written questionnaires may introduce bias into research (Paz and Groft, 2010: 92).
	Can be hard for a user to express themselves (Keates <i>op.cit.</i> ).

<sup>8</sup> As a participant remarked "...it's not your detailed view...it's a limited view..."

<sup>10</sup> "Paper surveys do have their design limitations." (Wyse, 2012)

Questionnaires	
Advantages	Disadvantages
	If multiple-choice questions are used, these can restrict participants to a number of options, all of which may not be appropriate (Diem and Moyer, 2005:109).
	If questionnaires used closed questions this may lead to participants being manipulated to give certain responses <sup>11</sup> .

**Table 6.6 Advantages and disadvantages of questionnaires**

#### 2.4.1.1 Questionnaires- the tick-box issue

Some participants felt that they had their views sought to validate the system that had been designed<sup>12</sup> because of this, some participants often felt that research is conducted not to consult or to improve but to ‘tick a box’<sup>13,14</sup>.

Participants also felt frustration, reporting at times, they felt their opinions are not valued and their time had been wasted. It is important to realise that participants like feeling valued. In addition, they felt that tick-box style questions were un-stimulating and did not allow them to share their views. Lastly, it was also felt that some questions can be repetitive.

#### 2.4.1.2 Participants felt that a good questionnaire was one that:

- Does “...not lead the ...recipient...” (Khan, 2011:101)
- “...one that actually ... achieves the outcome that you want i.e. in the sense of information...” (Race and Smith, 2009:113)

<sup>11</sup> “... the manufacturers were asking very closed questions, so it was very much leading the witness.” (a visually impaired participant)

<sup>12</sup> “...it’s almost like they’re looking for validation of what they’ve done rather than looking for information ...” (a control group participant)

<sup>13</sup> “Consultation can feel tokenistic to service users and be perceived as a ‘tick-box’ exercise.” (Wallcraft, Schrank and Amering 2009:155)

<sup>14</sup> “Consultation may turn out to be about simply relaying information. At worst, it may be a tick-box exercise on a form.” (Reynolds et al. 2003:33)

- “... is readily understood” (Lubin, 2010:2)
- “...specific and unambiguous...” (Khan *op.cit.*)
- “...specifically written...to capture all the information...” (Khan *ibid.*)
- “...and not just the information you particularly want to hear.” (Vogt 2005:93)
- Contained open-ended questions to help them better express their needs.

### 2.4.2 Observations

As with questionnaires, many of the findings in relation to observations are already well-known and publicised within the relevant literature, for example, participants felt that this method allowed people to be observed in their natural environment<sup>15</sup>. Furthermore, it was felt that it can be an effective method<sup>16</sup>. However they are only effective if people are given sufficient time to conduct them.

Additionally, it was also felt that observations offered the designer a chance to get “...explicit... data.” (a control group participant)

With regards to conducting observations, participants felt that you should “...talk to people while they’re doing stuff and ask them why they do it certain ways.” (a control group participant)

### 2.4.3 Phone Interviews/Questionnaires

As with the above, participants highlighted a well-documented advantage of phone interviews because they allow both the researcher and participant to clarify what they are asking or what they are being asked<sup>17</sup>.

<sup>15</sup> Robson (*op.cit.*), Bowling (2009) and Kawulich (2005)

<sup>16</sup> “...observation is the best they have.” (a control group participant)

<sup>17</sup> Blessing and Forister (2013), Valente (2002:131) and Fox and Bayat (2007) and others.

The study suggested that telephone questionnaires have a major advantage over their paper-based or online counterparts, this being they allow conversation in relation to complex or difficult issues, whereas written questions may allow free responses but do not allow for clarification.

#### **2.4.4 Prototyping**

Participants commented that prototypes were particularly useful because it gave users a physical object which may help them visualise the final design. It was felt that prototyping would work particularly well for small-scale products as it would allow users to experience a prototype of a design.

#### **2.4.5 Face-to-face methods (Interviews and focus groups)**

- Participants felt that these methods were particularly advantageous as they allowed for clarification<sup>18,19</sup>.

Participants highlighted the following advantage in relation to focus groups

- That they can enable the sharing of ideas<sup>20</sup>.

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<sup>18</sup> Brink and Wood (1988), Gill *et al.* (2008) and Adams and Lawrence (2015:108)

<sup>19</sup> It was felt that face-to-face communication was particularly advantageous as it allows for clarifications of misunderstandings (Sigel 2009:9).

<sup>20</sup> Chalofsky (2001), Sagoe (2012), Krueger & Casey (2000) and Miller and Twining-Ward (2005:140).

**Participants expressed the following disadvantages of the focus group method:**

- They may struggle to express themselves fully<sup>21</sup>.
- They may have difficulty in knowing when to contribute. This is not discussed within the literature and may be as a result of the person's additional needs, for example, the physical process of speech may take longer.
- It does not provide a natural environment<sup>22</sup> and therefore can feel clinical.
- It was also felt that for certain disabilities it may be more appropriate to conduct a one-to-one interview<sup>23</sup>.

**Participants expressed the following advantages in relation to interviews:**

- They are useful for eliciting in-depth information.
- *“People with...disabilities...may prefer the flexibility associated with in-depth interviews ...where they are able to discuss issues in their own words rather than answering according to pre-defined response categories in a questionnaire.”* (Farmer and Macleod 2011:36 and Borsci 2014:206)

Methods such as focus groups and interviews work particularly well, whereas questionnaires can be very limited.

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<sup>21</sup> It is because of this that some participants expressed a preference for a one-to-one, face-to-face interview.

<sup>22</sup> Catterall and Maclaran (1997), Croucher and Cronn-Mills (2015:184) and Gottbetter (n.d.)

<sup>23</sup> Such as severe neck pain as this will not require the participant to turn their neck and thus minimise their pain.

### 2.4.6 Mind-mapping

The results suggested that mind-mapping can be a useful method for participants as it can enable them to contribute in a variety of ways, for example, using a mixture of symbols and words. The versatility of mind-mapping is recognised within the literature<sup>24</sup>.

### 2.4.7 Talking Mats

Some materials have been removed due to 3rd party copyright. The unabridged version can be viewed in Lancaster Library - Coventry University.



#### Figure 6.1 Example of a Talking Mat (Talkingmats.com 2015)

The use of a method called Talking Mats may be advantageous as it is designed to “...*improve the lives of people with communication difficulties, and those close to them, by increasing their capacity to communicate effectively.*” (Talkingmats.com *ibid.*)

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<sup>24</sup> Meier (2007:1), Mento, Martinelli and Jones (1999) and Polson (2004)

How a Talking Mat is used:

- It involves the use of a physical or digital space (mat).
- The mat contains picture symbols divided into topic, options and a rating scale (see above).
- The topic can be anything relevant to the user, for example, likes and dislikes.
- The options relate specifically to the topic, for example, how strongly you feel about a particular item.
- The top scale allows participants to indicate their general feelings about a specific topic, for example, 'I dislike the colour yellow' (adapted from Talkingmats.com *ibid.*).
- The Talking Mat concept is fairly flexible and can be made as difficult or as easy as required, dependent on the needs of the participant (adapted from Talkingmats.com *ibid.*).
- It may be particularly suitable for product evaluation<sup>25</sup>.

#### 2.4.8 Evidence of inaccessible methods

One participant, a health and social care professional, readily admits that her organisation uses inaccessible methods<sup>26</sup>.

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<sup>25</sup> "...you could use a Talking Mat about what would be good, what would be bad, what wouldn't you like, what would you like..." (a health and social care professional)

<sup>26</sup> "...we hand out a paper, a tick box form that they're supposed to...read and tick." (a health and social care professional)



These methods are inaccessible because according to the participant what happens;

*“...is you end up giving the piece of paper to the parent or the husband or wife...and they sometimes get around to filling them in and sending them back...and if they sit with the person ...and go through it with them or not I have no idea...if they send the piece of paper back in the envelope in the end then it comes back anonymously anyway...so you never know, what’s happened.”*

It was found that the NHS, in particular, uses inaccessible methods. It is not clear why these methods are used. It could be surmised that it is due to the lack of resources and time coupled with the high case loads<sup>27</sup>.

The methods used are inaccessible because most of the users that this participant works with have profound and multiple difficulties which impacts on their ability to write<sup>28</sup>.

## **2.5 The difficult language of disability, the changing nature of language and the connection between language and culture (15 participants)**

Given that there is a multitude of different ways that disabled people are defined, for example, ‘disabled person’, ‘person with an impairment’, the results may be surprising to some as all of the participants that had a disability had a preference for being referred to by their first name rather than language that implied they had a disability.

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<sup>27</sup> “... at the same time that the UK is experiencing the most challenging economic crisis since the 1930s and adjusting to an era of much tighter public finances.” (NHS n.d.:15)

<sup>28</sup> “...people who are illiterate, have learning disabilities, are visually impaired, suffer with mental health problems elderly people...are unlikely to complete questionnaires.” (Chambers and Wakley *op.cit.*)

50%<sup>29</sup> of those questioned felt that they liked to be described as a person who has a disability thereby highlighting “... *the person comes before the disability*”<sup>30</sup>. No participant made reference to language used in the Social or Medical model of disability (Scullion, 2010). However, the language they preferred is situated within the Social model. It was also felt that “...*person with a disability...puts the emphasis on the person, not the limitation or disability.*” (Rural Access, 2000) In addition, how language changes over time was discussed,<sup>31,32</sup> for example, the use of the word ‘spastic’<sup>33</sup> and how the word is no longer in use<sup>34,35,36</sup>. Additionally, it was felt that self-labelling further complicates the issue of language<sup>37</sup>.

Participants also acknowledged the connection between language and culture, for example, in certain cultures particular language is viewed as acceptable when in others it is not<sup>38</sup>.

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<sup>29</sup> Eleven participants

<sup>30</sup> “...*the term ‘people with disabilities’ [indicates] that they are people first with a disability second...*” (adapted from Playforth 2003: 8)

<sup>31</sup> “*The language used to talk about disability and disabled persons have changed over time.*” (Baglieri and Shapiro 2012:40, Cooke and Philpin 2008)

<sup>32</sup> “*Social acceptance and rejection of terminology changes over time. For example, many years ago, individuals with mental retardation were classified as and referred to by such terms as idiot, moron or feeble-mindedness.*” (Holbrook and Koenig 2000)

<sup>33</sup> “...*undergraduates...they don’t actually know what that word means... international students haven’t a clue what that word means.*”(a family member/support worker)

<sup>34</sup> In recent years the word ‘spastic’ has been used as an insult by shortening it in many cases to its colloquial name of ‘Spaz’ or ‘You Spaz’ in this context it means that somebody is somehow inferior or stupid (adapted from Galvin, 2003 and adapted from Anti-Bullying Alliance n.d.).

<sup>35</sup> “*Colloquial use of terms for mental retardation have become school-yard and mass media insults; many individuals use them to deride those they loathe.*” (Walsh, 2002)

<sup>36</sup> “*These terms (moron, imbecile, idiot, and now retarded), which now strike our sensibilities as derogatory and belittling, clearly demonstrate how terminology used in the past to describe this population acquires negative connotations over time.*” (Walsh op.cit.)

<sup>37</sup> “...*anybody can self-label [for example]... you got the... deaf with the big D that’s all about the community of ...deaf people...so it’s a capital D because they see themselves as belonging to a community... it’s your self-label and that’s why it confuses things.*” (a family member/support worker)

<sup>38</sup> “... *we ... get medical evidence ... from America or India it will say ‘retarded’...and ‘handicapped’... so the words we don’t use anymore.*” (a family member/support worker)

In addition, the cultural differences in terms of language between Dutch and British individuals were discussed<sup>39,40,41</sup>.

## 2.6 Professionalism: Education and training (15 participants)

Participants felt that educationalists need to adopt approaches that are inclusive within their teaching styles and promote the value of user-centred or user sensitive methodologies (Newell and Gregor, 2000).

### 2.6.1 Skills designers need:

It was felt that designers needed training in the following areas:

- Undertaking interactions with users without leading them.
- User participation and experience.
- Communicating with people and asking the right questions.
- Ethical issues.
- Maintenance of professional boundaries.
- Requirements gathering or evaluation methods.
- Inclusive design.
- Exposure to those that have differing abilities, such as the elderly and the physically impaired.
- Handle information given by users.
- Disability awareness.

A question was raised by a participant that related to what education designers actually need. Is it in relation to specific disabilities or differences in general? In reality it is highly likely that training in both will be needed.

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<sup>39</sup> "...there is a major cultural difference between British people and Dutch people...in the general sense that Dutch people will speak their minds." (a control group participant)

<sup>40</sup> "The Dutch aren't exactly hot-blooded, but given the chance they will speak their minds and expect to be looked in the eye." (Bedford and Sellars 2001:33)

<sup>41</sup> In the Netherlands "people speak their minds freely, are averse to authority and dogma, and tolerate different opinions and religions." (Besamusca and Verheul 2010:267)

Additionally, it was felt that designers could benefit from a broad skill-base including ergonomics, engineering and design. First-hand experience of the products that designers are asked to design would help improve their understanding of what is required<sup>42</sup>. First-hand experience can be gained by capability simulators such as the Third Age Suit (Keates, Clarkson and Maguire, 2003). Both speaking to users and gaining first-hand experience will help designers to place the design into its context of use and generate data to assist the designer. However, it was contended that users can generate lots of useful data but help may be needed from an ergonomist or other professionals to fully understand it. As well as the input offered by users and other professionals, designers may need to undertake their own research before they commence work.

Additionally, it was felt that if designers were given a holistic education they may be able to better appreciate, or at least to empathise, with the differing perspectives with which their users view life. This would then help them to understand and to design for these perspectives in mind. However, it was acknowledged that working with disabled people can present certain challenges, for example, isolation.

The creation of databases that could be used to share information was discussed. This idea is not dissimilar to the work of [designingwithpeople.org](http://designingwithpeople.org)<sup>43</sup>, the Methods Lab<sup>44</sup> and the Cambridge University-Inclusive Design website<sup>45</sup>. All of these resources contain the information relating to design, particularly design for people that have SCAN.

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<sup>42</sup> If they were designing a stretcher for an ambulance firsthand experience may help them appreciate how uncomfortable and sensitive to bumps in the road stretchers can be.

<sup>43</sup> <http://designingwithpeople.rca.ac.uk/>

<sup>44</sup> <http://www.edean.org/pdf/Tool039.pdf>

<sup>45</sup> <http://www.eng.cam.ac.uk/inclusivedesign/index.php?section=casestudies&page=overview>

In addition to the above, it is likely that one of the outputs of this research will be a website which contains guidelines and other useful resources.

Some participants felt that improvements to design education were not needed due to the fact that design firms often have experts in other fields such as ergonomics. Whilst this may be the case for large design firms, training for freelance designers and smaller design firms may be harder to access.

It was also felt that in order to foster an ethos of inclusive design within organisations non-design personnel, such as those in sales and marketing, would benefit from training. This would then ensure that all of the key personnel involved in bringing a product to market would understand the key principles of inclusive design and its importance.

## **2.7 Maintaining professional boundaries (14 participants)**

In common with the pilot study, participants highlighted the importance of building professional relationships and maintaining boundaries<sup>46</sup>. Participants felt that it was important to establish relationships that take account of their needs whilst at the same time promoting and maintaining appropriate boundaries.

These boundaries are important because they define the limits of acceptable behaviour<sup>47</sup> (adapted from Nursing and Midwifery Council, 2013).

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<sup>46</sup> "...clearly established limits that allow for safe connections between service providers and their clients." (Wolf, 2008)

<sup>47</sup> This relationship is based upon trust, respect and the appropriate use of power (adapted from Nursing and Midwifery Council *op.cit.*).

## Discussions related to this topic raised some interesting points:

- The need for guidance in relation to professional boundaries<sup>48</sup>.
- Professional relationship building<sup>49</sup>.
- The creation and maintenance of professional boundaries.
- The blurring of professional boundaries<sup>50</sup> (adapted from Forchuk: n.d.:129).

It is clear that this topic presents complex issues, for example, it is not always apparent when a professional boundary has been breached (adapted from Trevithick, 2003:165). This may be due to the close working relationships that can be formed when working with SCAN users.

## 2.8 Value and respect (13 participants)

Participants felt that respect and value is an important part of any interaction that designers have with users. The key points can be summarised as follows:

- Users not feeling valued and respected<sup>51,52</sup>.
- The importance of valuing people<sup>53,54</sup>.
- Everybody is equal<sup>55</sup>.

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<sup>48</sup> “...I think it would be good if designers of products were given information.” (a hearing impaired participant)

<sup>49</sup> “...if you want people to provide you with...good feedback you need to establish a relationship.” (a control group participant)

<sup>50</sup> “... but unfortunately in this world we all know that no matter where you are in the spectrum of life... you can act inappropriately, you can say inappropriate things ... and you cannot legislate for that.” (a visually impaired participant)

<sup>51</sup> “... no respect to think 'oh I'm actually gonna call them first and cancel it.” (a family member/support worker)

<sup>52</sup> “...disabled people have a valuable contribution but often don't feel valued.” (Glasgow Disability Alliance, 2014)

<sup>53</sup> Researcher:“...but they also value you, so is it about being equally valued?” Participant: “I think so...” (a control group participant)

<sup>54</sup> “...researchers need to value the contribution; knowledge and skills of the participants.” (Booth, 1999:78)

<sup>55</sup> “...it's about seeing people as equal...and not seeing people ...as a source of information.” (a control group participant)

Participants felt that it was important for researchers and themselves to have a mutual respect for each other.

Value can be shown by a researcher in many different ways<sup>56</sup>. In addition, it was also felt it was important to view users as equal partners in the process, not solely sources of information<sup>57</sup>. A contributing factor for this may be the lack of feedback provided<sup>58</sup>.

Additionally, the results suggest that financial incentives may also entice participants. However, it was highlighted; that some researchers may not have the resources to provide these. In addition it was felt that sometimes just an acknowledgement of a user's input can be enough to make participants feel valued.

Furthermore, where an advocate is used they must respect the user and their wishes<sup>59</sup>.

### **Respect incorporates several linked skills:**

- Taking time to build a relationship with the participant.
- Effective communication.
- Designers need the ability to give effective and respectful feedback<sup>60</sup>.

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<sup>56</sup> Compensating participants for their time often shows respect (adapted from Liamputtong 2007:63).

<sup>57</sup> *"For people with disabilities, research should respect their freedom to choose to participate or not, their privacy and their confidentiality. It should respect and accommodate their difference as research subjects, for example through choosing accessible venues for focus-group research, or through facilitating alternative forms of communication that may be required."* (National Disability Authority 2009:19)

<sup>58</sup> *"Giving feedback is very important for building relationships."* (Baker et al.1996:24)

<sup>59</sup> *"...I always try and be respectful to Joe... and... ask him his permission."* (a family member/support worker)

<sup>60</sup> Researcher: *"Yeah, so obviously respect is [an] important... skill for designers...to develop?"* Participant: *"Yeah definitely"* (a family member/support worker)

Some evidence from the study appears to suggest that users do not feel valued because of the lack of feedback given by designers<sup>61</sup>. There is also evidence to suggest the opposite that when users are given feedback they do feel valued<sup>62</sup>.

- **The importance of mutual respect**<sup>63</sup>

A participant also acknowledges that in a health and social care professional's training they are only likely to come across service users whilst on a practice placement, the implications of this are that they may have little or no time to properly engage with and understand them or their views. He suggests that what is needed is closer involvement with service users in terms of teaching and learning for health and social care professionals. This is similar in the case of undergraduate designers.

- **Users like their opinion to be acknowledged**<sup>64</sup>

It would appear that respect is also linked to the skills that designers need to develop, to show respect to participants takes time and effort; it also is about how you communicate.

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<sup>61</sup> "... I never seem to get much feedback on anything." (a participant with a physical impairment)

<sup>62</sup> "Well... a valued participant,...particularly with transport for Greater Manchester...when you make suggestions to changes in policies... they have a system whereby you said, we did...so they regularly go round and say look you said this and we did that." (a participant with a physical impairment)

<sup>63</sup> "...I just feel like they should be either paid or if it's gonna effect their benefits give them a voucher." (a family member/support worker)

<sup>64</sup> "Yes, it's just an acknowledgement that they valued your opinion." (a visually impaired participant)



## 2.9 Ethics and confidentiality (13 participants)

The diagram below outlines what is required from the participant's perspective to conduct ethical research:



**Figure 6.2 outlines ethical research practice from a participant's perspective**

Participants also felt that:

- Researchers may be fearful of doing or saying the wrong thing when working with SCAN participants.
- Participants raised a number of issues in terms of ethics. Many of these issues have already been highlighted in the literature<sup>65</sup>.

It can be difficult to research with hard to reach groups or on subjects which may be considered sensitive, for example, incontinence<sup>66</sup>.

<sup>65</sup> "...some people are uncomfortable around people with disabilities [because] they're afraid that they will "say the wrong thing." (adapted from Henry 2007a)

<sup>66</sup> "...being incontinent is unpleasant, undignified and embarrassing. For many ... people it is not something they like to talk about or admit to." (Wagg, 2008:3)

- It may be difficult for some participants to provide informed consent<sup>67</sup>.
- Any guidance produced should be flexible and should still enable the designer to make their own decisions.
- Guidance on ethical issues is either not available or harder to access for those working in private sector businesses.
- Guidance may make it easier for designers to conduct research with SCAN users.

In addition, participants felt that it can be difficult to work with harder to reach groups such as those with a learning disability<sup>68</sup>; an explanation for this may be given by the work of McDonald and Raymaker (2013)<sup>69</sup>.

It was also felt that guidance should be produced and delivered by disabled people. This is an aim of this research therefore it is hoped that the knowledge gap in this area can be closed. Many guidelines are produced by academics after conducting research<sup>70</sup>; they are not produced by people who regularly engage with those that have a disability, let alone a researcher who experiences life as a disabled person on a day-to-day basis.

Participants may also struggle to discuss complex and/or sensitive issues<sup>71</sup>, despite the complexities generated by ethical approval:

- Requiring specific details about the product being tested.
- Participant sampling.
- Timeframes.

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<sup>67</sup> “...the problem of gaining informed consent from people with a ....disability... [is that it] can be a very complicated process, especially when people with severe... profound and multiple...disabilities are participating.” (adapted from lacono & Murray op.cit.)

<sup>68</sup> “...researchers continue to struggle to access, engage and retain participants.” (adapted from Bonevski et al. 2014:1)

<sup>69</sup> “...many people with...disabilities harbour feelings of suspicion and distrust toward research, which may influence participation decisions.” (McDonald 2012, McDonald, Kidney and Patka 2012 and Stalker 2010)

<sup>70</sup> “Guidelines for [conducting] research are [primarily] produced by academic institutions, funding bodies and disciplinary organisations.” (adapted from Lunn 2014:1)

<sup>71</sup> Garcia, Crocker and Wyman (2005), Kavanaugh, and Lioness (1998),Joss, and Oldenburg (2013)

- Multiple applications for ethical reviews (adapted from Moody (*op.cit.*) (a)).

There is a need to work with these users because if we fail to do so, the products made may not meet their needs<sup>72</sup>.

## 2.10 Use of technical language/jargon (13 participants)

The use of technical language appeared to be quite prevalent in research materials or processes.

The study highlighted situations where participants were exposed to language that they did not understand, these included during:

- Medical appointments<sup>73,74</sup>
- Design and evaluation processes<sup>75</sup>

Participants also discussed the following issues in relation to language:

- Acronyms<sup>76</sup>
- Over complication<sup>77,78</sup>
- Use of jargon<sup>79,80, 81</sup>

<sup>72</sup> "The chances for successful or increased take-up of the product, device or service you are developing will be improved because you have taken the needs of users into consideration." (Beamish et al. 2012:10)

<sup>73</sup> "...when they show the x-rays...and they've gone like this is this and I've gone right let's start from the beginning ...and I've said and you tell me ... in layman's terms...what that actually means please." (a family member/support worker)

<sup>74</sup> "Doctors and nurses use a kind of secret language, comprised of words unlikely to be found in a medical textbook or heard on television." (Goldman, 2015)

<sup>75</sup> "...I've been doing this kind of stuff with communication aids for about 15 years now, so I kinda understand... if somebody ... has got a board rate of this...I've got some basic idea of what that means or how much RAM (Random-Access Memory) it's got all those kinds of stuff... I kinda get it ... but that obviously is hard for people who are new to it and I only have a sketchy idea of what those kind of things mean..." (a health and social care professional)

<sup>76</sup> "...I remember one particularly...where the designer used a lot of TLAs (Three Letter Acronyms)." (a visually impaired participant)

<sup>77</sup> This was the experience with a participant who states that sometimes when health and social care professionals find something difficult they often "...throw more language at it." (a health and social care professional)

<sup>78</sup> "...using more words does not necessarily provide greater clarity." (Naidu, 2008)

- Not adhering to the rules of language<sup>82</sup>
- Intellectual ability and language<sup>83,84</sup>

It was also felt that questions can sometimes be ambiguous and the assumption is made that lay people will understand technical language.

Despite the fact that some participants reported designers using technical language, it would appear they employed many strategies to overcome this, these included:

- Stating that they do not understand the language being used
- Asking for explanation/clarification
- Advocating the use of glossary sheets where technical language is used in written research materials<sup>85</sup>
- Advising that people should use every day English
- Use the 'Grandma test'<sup>86</sup>

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<sup>79</sup> There was some evidence that researchers made use of technical jargon, although this happens infrequently there are rare occasions where this occurs and may create a barrier between both participants and the research's intended audience (adapted from Bibace, Dillon and Downs 1999:7).

<sup>80</sup> "...I went to a research seminar yesterday when the researcher...spoke in such a fashion that 80% of the audience didn't understand what she was talking about because we weren't of her discipline." (a visually impaired participant).

<sup>81</sup> "...I think ...yes it did to start with... but as I say whether they've all been on training courses now." (a family member/support worker)

<sup>82</sup> "I mean sometimes they seem to be written by a 14 year-old...they are full of spelling mistakes" (a control group participant). This can may raise questions in relation to the credibility of the research (adapted from Andres 2012:87).

<sup>83</sup> "Well, for me,... because I've got a Master's degree and I've been offered a PhD I don't struggle with language." (a participant with a physical impairment)

<sup>84</sup> "...intellectual ability has a great effect on the comprehension process...poor intellectual ability has a negative effect on the comprehension process." (Holen and Sundberg, 2000)

<sup>85</sup> "...necessary technical terms, definitions and important abbreviations or acronyms can be explained in a glossary." (Freeth *et al.* 2005:179)

<sup>86</sup> i.e. "does your Grandma understand what the strategy is when you explain it to her?" (Speculand, 2017)

It was felt that acronyms can be particularly problematic in disability research “*I think... in order...to make research for disabled people accessible for everybody you should conform to easy read guidance and very often it doesn't... people use technical language and acronyms which is a barrier for those [with] learning disabilities...or intellectual impairments.*” (a participant with a physical impairment)

Acronyms can also be problematic in large organisations, such as universities “*...a Learning Support Co-ordinators Meeting...so every faculty in the University ...has a disability person...and we were talking about, somebody was using an acronym, oh what I thought was an acronym over and over again but it turned out it wasn't.*” (a family member/support worker).

Participants provided advice in relation to acronyms, this being to avoid using them or to explain them<sup>87</sup>. This advice could equally be applied where jargon is used.

A participant who had a high level of intellectual ability reported no issues in understanding the language used in research materials; this may suggest a link between intellectual ability and language which could suggest that the higher a person's intellectual ability the less likely they are to have issues of comprehension.

It was felt that the connection between intellectual ability and language should be considered for two reasons:

- 1) To ensure that those with disabilities can understand what's required.
- 2) If simple language is used this will assist the widest possible population<sup>88</sup>.

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<sup>87</sup> “*Explain abbreviations the first time you use them.*” (May and Holmes, 2012:109)

<sup>88</sup> “*...writing your materials in plain language is cost effective and an important step towards making your information accessible to the widest possible audience.*” (Compass Disability Services, 2007)

## 2.11 Communication skills and listening (13 participants)

A key theme emerging from the study is that of communication. Communication incorporates lots of different mediums<sup>89</sup>; the most common being oral and written but it can include body language and listening skills. The key aspects of communication highlighted by this study are summarised as follows:-

- The importance of listening<sup>90</sup> and communication skills<sup>91</sup>.
- Inappropriate or lack of communication can lead to the design of products that fail to meet users' needs<sup>92</sup>.
- Miscommunication<sup>93,94</sup> and communication breakdown<sup>95,96</sup>.
- Designers need more training in the art of effective communication<sup>97</sup>.
- The importance of two-way communication<sup>98</sup>.
- The importance of good communication<sup>99</sup>.
- Communicating effectively with somebody that has SCAN.<sup>100</sup> They may for example use augmentative and/or alternative communication (AAC)<sup>101,102</sup>.

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<sup>89</sup> Communication "...breaks down like this: 7 percent verbal (words), 38 percent vocal (volume, pitch, rhythm) and 55 percent body movements." (adapted from Barbour, 1976 and Sama, n.d.:4)

<sup>90</sup> "I think it's then about listening to what you found." (a control group participant)

<sup>91</sup> "...it's...communication skills and that's nearly in every single job." (a control group participant)

<sup>92</sup> "...If you don't talk to people you get crap products." (a control group participant)

<sup>93</sup> "... there could be some miscommunications." (a control group participant)

<sup>94</sup> "...I don't feel valued because they don't take the time to listen..." (a participant with a physical impairment)

<sup>95</sup> "...there was no practical communication I had to do all the chasing" (a control group participant).

<sup>96</sup> "...Well if it ...fits in with their policy then they're quite happy...to listen...and very often...when a civil servants taking notes ... if [you say] something they don't wanna hear... they won't write notes." (a participant with a physical impairment)

<sup>97</sup> "...people that are in marketing and...know how to talk to their target audience...I think designers are less trained on that." (a control group participant)

<sup>98</sup> "...as part of their people skills...they've gotta have 2-way communication." (a control group participant)

<sup>99</sup> "...communication is the key to learning things." (a visually impaired participant)

<sup>100</sup> "...I think...if you're not in communication with children like Joe...yes I do think that they find it hard..." (a family member/support worker)

<sup>101</sup> "...includes all forms of communication (other than oral speech) that are used to express thoughts, needs, wants, and ideas." (American Speech Language Hearing Association, 2015)

- The advantages of written communication<sup>103</sup>.
- The importance of clarification<sup>104</sup>.

It should be noted that some of these aspects, for example, written and verbal, SCAN users may struggle with<sup>105</sup>.

In order to effectively communicate, participants felt that it was important to:

- Listen as this would enable concerns of the users to be heard<sup>106</sup>.
- Have good communication skills<sup>107</sup>.

There was also some evidence of poor written communication where questions were ambiguous on questionnaires (Brace 2008:23).

## 2.12 The making of incorrect or inappropriate assumptions (12 participants)

Participants felt that designers who wanted to understand the views of SCAN users often made incorrect or inappropriate assumptions, these can be summarised as follows, that:

- Users may have difficulty finding employment<sup>108</sup>.
- Users are sick and needy<sup>109</sup>.

<sup>102</sup> It was also discussed that SCAN users can struggle to make themselves understood and sometimes require support from an interpreter to help them make their views known. However, when using interpreters, clarification should be sought to ensure the views of the SCAN user is fully understood.

<sup>103</sup> Researcher: "... so you... find it easier to write things down as it enables you to refer back to them?"  
Participant: "Yeah, then I don't get nervous and then my speech isn't affected." (a participant with a physical impairment)

<sup>104</sup> "Yeah and clarifying so if I don't understand then I can ask you." (a control group participant)

<sup>105</sup> "Some people with an intellectual disability are very articulate...however others may struggle to find the words to communicate." (Read 2014:108)

<sup>106</sup> "Listening is the most important constituent of verbal communication." (A, 2015)

<sup>107</sup> "...communication skills are important in all jobs." (Yate, 2014:40)

<sup>108</sup> "...teachers would say things like...that I couldn't get a job working with...people where I would have to talk." (a participant with a physical impairment)

- The disability may appear to be more severe than it actually is<sup>110</sup>.
- Users may not be able to make themselves understood<sup>111</sup>.
- Academic achievement will be lower than that of their able bodied peers<sup>112</sup>.
- Users are brave because they are doing everyday tasks<sup>113</sup>.
- Their disability is not understood<sup>114</sup>.
- It is assumed that users have specialist medical knowledge<sup>115</sup>.
- The disabled person has to earn the approval of others<sup>116</sup>.
- That the effects of a condition can vary on an hourly or day-to-day basis<sup>117</sup>.
- Assumptions are made on insufficient evidence about intellectual capacity<sup>118</sup>.
- Participants being clear about what researchers require<sup>119</sup>.

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<sup>109</sup> A leading disability rights charity (Scope) perpetrate the notion that “...disabled people are ... in some way ...sick and needy.” (a participant with a physical impairment)

<sup>110</sup> “...he comes across like he’s got really bad learning disabilities [and so people won’t think he’s got a degree].” (a family member/support worker)

<sup>111</sup> “... couldn’t speak to people if they were asking about finance and information like the bank...because they wouldn’t understand me.” (a participant with a physical impairment)

<sup>112</sup> “...I wouldn’t pass exams or...it makes me feel really frustrated because I have an National Vocational Qualification (NVQ) ... I think people think...that I’m stupid.” (a participant with a physical impairment)

<sup>113</sup> “...I got told I was brave the other day for being out because it was raining...” (a participant with a physical impairment)

<sup>114</sup> “...some people don’t mean it but it’s just... they can be ignorant and not understand.” (a participant with a physical impairment)

<sup>115</sup> “... I’ve worked with a guy recently about a PA (Pulmonary Artery) line that’s going to go in...and that’s going to sit above his heart and there was an assumption that he knew what his heart did.” (a health and social care professional)

<sup>116</sup> “...they see...him as a disabled person and they’re doing him a favour.” (a family member/support worker)

<sup>117</sup> “...I mean Mum can read, she can read The Telegraph [a newspaper]...and she will take in a story...and she will use quite coherent words...and it will sound like there’s absolutely nothing wrong with her...but then later on it will be gone.” (a family member/support worker)

<sup>118</sup> “...the housing people told her she needs to go and get...court of protection... and I said to her why ... have you done that? ‘because he doesn’t speak’ I said the fact that he doesn’t speak doesn’t mean he can’t communicate to you.” (a family member support worker)

<sup>119</sup> “...don’t make assumptions that we know what you’re talking about.” (a visually impaired participant)



Users reported a variety of feelings about the making of assumptions, these included:-

- Not feeling valued<sup>120</sup>.
- Being annoyed<sup>121</sup>.
- Sadness and anger<sup>122</sup>.

Participants also felt that the making of assumptions can not only be dangerous<sup>123,124,125</sup> but inappropriate<sup>126,127,128</sup>. In addition, it was felt that the behaviours that result from assumptions can often be difficult and challenging for a disabled person to deal with<sup>129</sup>. They may also result in the promotion of stereotypes,<sup>130,131</sup> therefore there is a link between assumptions that are made and the stereotypes that result (see figure 6.3).

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<sup>120</sup> "... I don't feel valued because they don't take the time to listen...and find out what I really think and what I deal with." (a participant with a physical impairment)

<sup>121</sup> "...I hate people thinking they know what I'm thinking." (a visually impaired participant)

<sup>122</sup> "...you can so easily become an angry person." (a participant with a physical impairment)

<sup>123</sup> "... I always say when you work with one person with Autism that's it...that's all you've met... and I think that's the same for every single medical condition or disability." (a family member/support worker)

<sup>124</sup> Are often "not based on facts" instead based on a person's experience of their past (adapted from Reiss 2012:11).

<sup>125</sup> Assumptions "...are truly dangerous in that they stigmatise and delimit the social roles of people with disabilities." (Dolmage, 2014:143)

<sup>126</sup> "...people will prove you wrong every single time." (a health and social care professional)

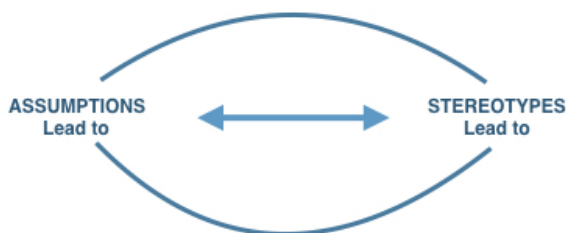
<sup>127</sup> Gabel and Conner (2014:32) where a parent in an interview stated "I have cerebral palsy and people make assumptions about me all the time based on my physical appearance. Because it's difficult for me to talk, people assume I can't understand them and they raise their voice and talk both slower and louder as though I'm cognitively impaired and deaf..." and "people make unwarranted assumptions about who I am as a person because of my disability." (Norman) (Rix et al. 2010:20)

<sup>128</sup> "...stereotype assumptions about disabled people are based on superstition, myths and beliefs from earlier less enlightened times. They are inherent to our culture and persist partly because they are constantly reproduced through the communications media." (Barnes, 1992)

<sup>129</sup> "...sometimes... [the] behaviours [of society]...can be rather...more...negative...and for a disabled person that can be hard to deal with." (a participant with a physical impairment)

<sup>130</sup> Isaacs (n.d.: 158) "...stereotypes are preconceived assumptions based upon the characteristics and behaviours of all members of a particular group."

<sup>131</sup> "...numerous recent studies have shown that activating stereotypes can influence people's behaviour. Typically, activating a stereotype leads people to behave in stereotype-consistent ways." (Wheeler and Petty, 2001:797)



**Figure 6. 3 illustrates the link between stereotypes and assumptions**

Furthermore, a participant rather eloquently explains that disability and assumptions appear to be intrinsically linked<sup>132,133</sup>. In addition, the notion that people with disabilities are people first<sup>134</sup> was also related; however, in practice this may be difficult to do<sup>135</sup>. With the above in mind, it is not surprising that a major piece of advice given by participants was “*don’t make assumptions.*” (a participant with a physical impairment) Additionally, participants also felt that if assumptions were made these should be based on facts<sup>136</sup>. Assumptions based on empathy can sometimes be misguided<sup>137</sup>. Despite this, some assumptions made about people with disabilities are sadly proven true<sup>138</sup>.

Given the above, assumptions can have a dramatic impact on disabled people, including:

- Low self-esteem.
- Increased levels of anger.

<sup>132</sup> When people “...see the disability that’s when ... assumptions and stereotypes come in.” (a participant with a physical impairment)

<sup>133</sup> “...stereotypes [is that they] lead back to assumptions and assumptions lead back to stereotypes.” (DeGeneres, 2011)

<sup>134</sup> “... they are always people first and disability second.” (a health and social care professional)

<sup>135</sup> “...sometimes when you see someone in a chair...you see someone in a chair rather than you see a person.” (a control group participant).

<sup>136</sup> “...you should avoid making assumptions where possible ... [however if you have to make assumptions they should be] ... backed by ....actual facts.” (a control group participant) These kinds of assumptions according to Agustiady (2014:82) are called hard assumptions.

<sup>137</sup> “...fostering empathy is not, on its own an effective strategy for challenging disablist assumptions.” (Marks,1999:134)

<sup>138</sup> “Disabled people continue to experience lower levels of education, have poorer housing and fewer employment opportunities and are more likely to live in poverty.” (Thomas and Smith,2009:147)

- Frustration<sup>139</sup>.
- Increased likelihood of depression or mental health difficulties<sup>140</sup>.

One of the strategies that can help people to avoid making assumptions about SCAN users is to consider them as ordinary people with additional needs. This is the view point that the Social model of disability endorses<sup>141,142</sup>.

## 2.13 The importance of follow-ups/feedback (11 participants)

Participants felt that follow-up visits are important because:

- They can ensure equipment meets users' needs.
- Ensures the equipment is being used correctly.
- The equipment is providing value for money.

If an opportunity for feedback is not given it may result in the equipment being unused<sup>143</sup>. However, the usefulness of such visits was sometimes called into question as it was felt that it is not always possible to know for certain if the equipment has been used<sup>144</sup>.

<sup>139</sup> "...people with disabilities deal with added frustration in life-their disability- is not going away." (Lefan, 1992:16)

<sup>140</sup> "...depression does appear...to be indirectly related to having a disability..." Field, Jette and Martin (2006:237) "and "...having more chronic conditions is associated with an increase in depressive symptoms." (Peek, Perez and Stimson 2012:58)

<sup>141</sup> "...to see people with disabilities as people first...and as citizens with rights and expectations to participate on an equal basis." (David, 2012:53)

<sup>142</sup> "...it is important that we see that person as a whole person and not just as a 'disability'". (Scott *et al.*, 2011:466)

<sup>143</sup> "...the importance of follow-up visits cannot be stressed enough. Studies carried out by the institute of Ergonomics at Loughborough University have shown that at least 50% of ...equipment delivered to people's homes were not used." (Maczka *op.cit.*)

<sup>144</sup> "...it is not clear if visits are effective." (National Institute for Health and Clinical Excellence (NICE), 2007:22)

Receiving feedback from designers was felt to be an important part of the cycle because it enabled participants to understand whether the feedback they had given was used<sup>145</sup>. However, it is acknowledged that there are difficulties with this approach<sup>146</sup>.

## 2.14 Empathy and a day in the life of (11 participants)

A key finding of this research was that of empathy. Participants felt that designers did not make an effort to understand their lives and consequently lacked empathy. It was felt that this lack of empathy would be detrimental to the final design of products or services. Furthermore, if designers possessed empathy they would be able to “...*build a better product...that’s more suited to that person...because they understand [their] needs.*” (a control group participant) Such a view is in common with the work of McDonagh and Fornosa (2010:98).

The issues raised can be summarised as follows:

1. Whether designers were (or even could be) taught to be empathic (Blatner *op.cit.*).
2. The skills that empathic designers should exhibit.
3. Research methods which enable them to be empathic, for example role play.

Interviewees were able to recall situations which caused them difficulty or frustration.

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<sup>145</sup> “...it is very important to give feedback to participants and to explain why decisions were taken.” (Parycek and Edelman, 2014:557)

<sup>146</sup> “...obtaining explicit feedback is not always easy and sometimes unfeasible.” (Lee, Park and Park, 2007:385-368)

For designers and those working with SCAN users it is important that they have an awareness of the complex life that SCAN users lead<sup>147</sup> therefore designers must make the best use of the time they have, being careful to select appropriate venues, times, methods and environments that allow users to fully express their views.

Much of this guidance is well publicised within the research literature, for example, Atkinson (2007:138), Jenny and Kelso (2007:61) and The Open University (2016).

### 2.14.1 Disability and bureaucracy

SCAN users, family members and health and social care professionals were able to highlight a range of issues that they have to deal with on a regular basis which are probably beyond the everyday experiences of most designers.

Examples include:

- Lack of resources in health and social care:
  - Waiting for services<sup>148</sup>.
  - Having to fight for everything<sup>149</sup>.
  - Frustration with dealing with health and social care professionals, for example, in terms of communicating needs, finding best treatment and shortage of professionals with specialist skills<sup>150</sup>.
  - Regular changes in the personnel (both those providing medical and social care)<sup>151</sup>.

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<sup>148</sup> "...we had to wait 6 months" (a family member/support worker participant), these remarks are supported by Anderson, Camacho and Balkrishnan (2007).

<sup>149</sup> "...parents of children with disabilities particular... children with the very severe disabilities that ...have felt like they've had to battle forever for everything" (a health and social care professional). These remarks are supported by Marshall *et al.* (2009:84).

<sup>150</sup> "...we need more Physios and OTs [Occupational Therapists]" (a family member/support worker). This finding is given credit by the remarks of Finkelman and Kenner (2010:518).

<sup>151</sup> "... they couldn't guarantee times or who would be coming to see me" (a participant with a physical impairment). These findings are given credit by the remarks of Beresford *et al.* (2011:4).

- The constant need for detailed information in relation to life experiences; particularly when the same information is requested and/or methods of capturing this information are poorly designed. *“I can remember the form filling...everything you do has to have a form filled in.”* (a family member/support worker)
- Dependency on the NHS, for example, they may not be able to easily access a design setting, they may have to arrange support workers to accompany them and transport to the building.
- Inflexible services *“...there was just no flexibility...”* (Audit Commission 2003:21).

These examples resonate with previous literature, for example:

- The bureaucratic nature of service provision<sup>152</sup>.
- Poorly designed forms<sup>153</sup>.
- Delays and cuts to benefits<sup>154, 155</sup>.

Whilst these feelings are not directly related to design and evaluation processes they provide an illustration of the complexities which some SCAN users may deal with. They may also provide some guidance in relation to where designers may need to exercise caution.

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<sup>152</sup> *“Many submissions expressed frustration with the bureaucratic nature of service provision. They describe the system as difficult to navigate, excruciatingly slow and unresponsive. Endless assessments and endless forms seem to lead only to a frustratingly inadequate service.”* (Deane *op.cit.*)

<sup>153</sup> *“...questions on forms are often not independently intelligible; often include long preambles and signature declarations...questions that are too vague, open-ended or susceptible to different meanings.”* (National Audit Office, 2013)

<sup>154</sup> *“Disabled people are facing “distress and financial difficulties” owing to the slow processing of [benefit] claims.”* (adapted from BBC News *op.cit.*)

<sup>155</sup> *“Research by Demos/Scope show that by 2017-18 around 3.7 million disabled people will collectively lose £28 billion in benefits.”* (Demos/Scope Research 2013)

## 2.14.2 How these challenges may affect SCAN users and their advocates:

Given the above, SCAN users may come to design sessions with a very different mind-set.

1. Their motivation and degree of commitment to the design may be greater.
2. Expert knowledge of their own conditions, this may mean that users may be able to provide insights into limitations of the product in their particular context of use.
3. Level of personal cost and investment in the design activities will be greater. This may lead to strong emotions<sup>156</sup>, for example, the need to ensure tasks are completed<sup>157</sup>.
4. Levels of fatigue may be greater, for example, through lack of sleep<sup>158</sup> or the effort expended on travel to the destination.
5. Frustration and impatience-this may happen when:
  - Designers have not made sufficient provision for the participants, for example, in terms of organisation of the session.
  - They need to expend effort repeating information about their life circumstances.
6. Not wanting to inconvenience others.
7. Communication styles may differ and range from being assertive, to open and friendly. Some may have a greater awareness of their effects on others<sup>159</sup>.

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<sup>156</sup> -“...my emotional feeling is a factor of whether I get involved in something.” (a hearing impaired participant). This finding is supported by the remarks of (Lerner,2014:4).

<sup>157</sup> “Just... the way I am ...I guess... it must be something to do with my cerebral palsy.” (a participant with a physical impairment), this finding is given credit by the remarks of Collins-Bride *et al.* (2017:347).

<sup>158</sup> “...sleeping you're turning your head...trying to get comfortable...I mean I actually sleep probably 3 or 4 hours...a good night's sleep for me ... most people would sleep 8 hours...6 hours so ...if I have 8 hours it's like winning the lottery.” (a participant with a physical impairment) This finding is given credit by the remarks of Cavanaugh and Blanchard-Fields (2015:117).

<sup>159</sup> “...but what I do has an influence on... somebody else ...so I have to think about how my reactions are affecting that person otherwise I could upset and hurt them” (a visually impaired participant). This finding is given credit by the remarks of Hasson (2017:109).

### 2.14.3 Useful information for designers:

1. Everyday tasks can be very difficult<sup>160,161</sup>  
This should have a bearing on the products and services being designed, that is, they should follow the principles of universal design. Additionally, it will impact upon how research is conducted<sup>162</sup>.
2. Certain situations will need to be avoided to minimise the effect of disability, for example, using written activities when writing may be difficult or impossible for those in your user group.

### 2.14.4 Strategies that can be used to enhance the understanding of designers:

Empathy, co-design and an awareness of culture were all highlighted as strategies that could enhance a designer's understanding of SCAN users and their life circumstances thus allowing them to design products that better meet the needs of users<sup>163</sup>. Additionally, it was felt that designers should give careful consideration to a number of factors, for example, their level of knowledge, before using approaches based on empathy<sup>164</sup>. This is because empathy is difficult to teach in isolation<sup>165</sup>.

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<sup>160</sup> "When people are disabled as a result of a chronic condition, they have difficulty doing daily tasks, such as house hold chores [and] personal care." (adapted from Cavanaugh and Blanchard-Fields, 2015:117)

<sup>161</sup> "It is difficult pushing a grocery cart, placing items in, and to top it off trying to reach items on a shelf out of reach from a seated position [wheelchair]...it is even more difficult to hold a handheld basket on the lap, for once the basket is full it becomes heavy and uncomfortable." (a participant with a physical impairment) This finding is given credit by the remarks of Shakelford and Edmo (2011:87-88).

<sup>162</sup> For example, methods used and how interactions are conducted.

<sup>163</sup> "...build a better product...that's more suited to that person...because they understand the need." (a control group participant)

<sup>164</sup> "...empathy based on knowledge." (a visually impaired participant)

<sup>165</sup> This finding is given credit by the remarks of Blatner (1992:1) who states that empathy is "teachable but it requires experiential learning [and] practice."



Blatner (*ibid.*) also acknowledges that how people empathise is dependent on:

- 1) The nature of the person.
- 2) Their life experience.

Given the above, it is reasonable to suggest that empathy is a complex skill to develop and the use of empathic approaches poses challenges. However, if used appropriately these approaches may add value. Additionally, it was suggested that empathy would help designers to develop insight into the users' perspective. This is because designers generally do not lead lives similar to those they are designing for therefore they need to have an awareness of user needs in order to help develop this essential skill<sup>166,167</sup>.

Participants also highlighted that it would not be advisable to use empathy when discussing personal issues<sup>168</sup>. Additionally, empathy in relation to practical considerations could be particularly advantageous for designers to develop<sup>169</sup>.

Lastly, it was also highlighted that students should be given the opportunity to evaluate the role of capability loss simulators. This is something that should be considered with great care<sup>170</sup>.

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<sup>166</sup> Rommes (2006:675) states that in the past designers have been criticised for designing for "...the dominant group in society, the notorious young, white, able-bodied highly educated male." Empathy needs to be based on "... knowledge..." as without knowledge "...it's sympathy." (a visually impaired participant)

<sup>167</sup> "... a lot of people...haven't got that skill of empathy." (a visually impaired participant)

<sup>168</sup> "...your imagination of a person's life might be different...to how their life is." (a family member/support worker)

<sup>169</sup> "...I think it's good to have... knowledge and understanding to feed that into ...your research... so thinking about things like ...the interviews gonna take possibly about an hour...you might want to think I'll give 2 hours." (a family member/support worker)

<sup>170</sup> "... I had quite a lot of trouble with the use of ...an empathic approach because ...one of the things that was in my mind was that I didn't want my students to think that simulating disability ... in the design of products...was necessarily a good thing, I wanted them to be critical about that process." (a health and social care professional)

## 2.15 Money and wealth (11 participants)

It was felt that monetary incentives should be given (where appropriate) for disabled people to take part in research<sup>171</sup>. This links with the notion of showing mutual respect (see section 2.8 value and respect for more information).

## 2.16 Knowledge and expertise (11 participants)

Participants felt that designers and users need to have some first-hand experience as this can provide valuable insights. In order to gain such experience some design teams will specifically employ disabled people, for example, RICA (Research Institute for Consumer Affairs) RicaWatch<sup>172</sup> panel. A participant highlighted that this insight and knowledge will ensure “...usable, acceptable and desirable solutions are developed that meet the needs of users.”<sup>173</sup> It was also felt that designers should make reference to appropriate standards and research literature where necessary<sup>174</sup>.

Although having background knowledge was highlighted as useful, others felt it would be advisable to test products with users as they are more likely to identify flaws or encounter difficulties. In addition, participants felt that designers must understand “...what they’re trying to achieve...[for example] if it’s a product ...what gap are they trying to fill?” (a control group participant) It was also felt that it was important for designers to ask questions that provide an understanding of users’ needs.

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<sup>171</sup> “...maybe give disabled people a little bit of money for their time and effort, I think... particularly in the private sector... cus they generally wanna go off and make some money out of it ...” (a participant with a physical impairment)

<sup>172</sup> <http://www.rica.org.uk/content/join-ricawatch-panel> (Research Institute for Consumer Affairs, 2017)

<sup>173</sup> Moody (*op.cit.*) (a) and adapted from Abras, Maloney-Krichmar and Preece (2004), Sanders and Stappers (2008), Norman (1998)

<sup>174</sup> International Standards Organization (ISO) or British Standards Institute (BSI)

SCAN participants felt that it was important for the designer to have some knowledge of the conditions for which they were designing. This may extend to:

- What activities the participant has difficulty with.
- An understanding of their condition and health conditions, for example, epilepsy or dementia.

Participants felt that “...if people don’t understand where I’m coming from... they’re not gonna be able to help me.” (a participant with a physical impairment)

The notion that disability is becoming more normalised was discussed. This will hopefully contribute to designers’ better understanding disability and make it easier for them to engage with such user groups. It was also highlighted that if the participant has knowledge they will be empowered to contribute.

## 2.17 Flexibility

Participants felt flexibility was needed by designers when working with all users, this included practical flexibility, for example, in relation to the time interviews take place and methods used to either gather requirements or feedback.

### 2.17.1 Flexibility in terms of methods employed

It was felt that semi-structured interviews offered flexibility<sup>175</sup>. Designers need to consider if their choice of methods empowers or disempowers disabled people to give their views. Designers may also need to think about how to gather requirements or feedback with different audiences, for example, you may need to produce different versions of questions such as easy read or modified language.

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<sup>175</sup> A participant stated that “...you’ve got to have a range of methods that suit individuals...and that you need to think very clearly about whether you’re being inclusive or you’re excluding people.” (a health and social care professional)

## 2.17.2 Flexibility on the part of designers

It was highlighted that if designers want to engage with SCAN users they may have to be flexible in terms of arrangements, for example, offering the participant a telephone interview at a time convenient for them<sup>176</sup>. In relation to hearing impaired participants it is advisable for the designer to offer them a choice of where they may sit for an interview so they can hear or lip read with ease<sup>177</sup>.

It was also highlighted that it may not be an impairment that makes a participant different, it may just be a preference. Therefore designers should do their best to accommodate these. Finally, flexibility in terms of meeting the requirements of clients, for example, a small business may have different requirements to a large university funded research project was discussed.

## 2.18 Consultation and advocacy (10 participants)

It was highlighted, that occasionally, service and product evaluations are conducted with those with a mild disability, these participants may not be able to represent or give the views of those with a severe disability.

### 2.18.1 A lack of real choice

It was also discussed that in some circumstances SCAN users' choices are limited or non-existent, for example, there are only a limited amount of disability equipment manufacturers. This lack of choice can also be true in terms of service provision where it may only be that one service provider that can offer the services a user needs. According to a participant, these circumstances can be at best frustrating for the user, or at worst, not appropriate.

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<sup>176</sup> "...we are people at the end of the day we are not just a list of needs that can be fitted into a timetable, life still happens." (a participant with a physical impairment)

<sup>177</sup> "...anything that makes it easier for me...and enables me to be more relaxed...is going to make it a more pleasant experience for me and I'm gonna give better feedback." (a hearing impaired participant)

## 2.18.2 Consultation with users

There was some evidence of good practice<sup>178</sup>. However, it was highlighted that such events take a lot of organisation and resources, despite these constraints, there is now, more than ever a focus on person-centred care within the NHS and social care settings given the events that occurred at Winterbourne View and Stafford hospitals (Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry (2013), Winterbourne View-Summary of Government Response- Department of Health (n.d.)).

It was discussed that there is a limit to the amount of user consultation that you can reasonably expect therefore it may be advisable to consult with a cross section of users.

However, SCAN users are often found within the extremes and because of this it is advisable to test products with a wide cross section of the intended user group<sup>179</sup>. A disadvantage with this approach is that you cannot possibly test with all the extremes.

It was also felt that to enable real consultation with users that have disabilities they would need to understand both the questions the researcher is asking and what the researcher intends to do with the information<sup>180</sup>.

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<sup>178</sup> "... a long time ago our organisation did try and have like a group where we invited people who use communication aids to come and tell us a bit more about our services." (a health and social care professional)

<sup>179</sup> "...if you can get people in at the initial stage from a whole range of ages, abilities...then you've got a lot of information." (a visually impaired participant)

<sup>180</sup> "...you gotta make sure that...they're understanding...what you're asking them and what you're doing with that information." (a visually impaired participant)

### 2.18.3 Representation of SCAN users' views

The study found evidence of communication support being provided to SCAN users in the following ways by:

- Acting as an intermediary<sup>181</sup>.
- Helping users to understand specialised and complex terminology<sup>182</sup>.
- Helping somebody with speech difficulties to communicate.
- Helping autistic students to interpret situations<sup>183</sup>.
- Helping SCAN users to express themselves<sup>184</sup>.
- Supporting around the giving of a diagnosis<sup>185</sup>.

The dangers of advocacy were discussed<sup>186</sup>. However, advocates can sometimes find themselves in a complex situation<sup>187</sup>.

It was also highlighted that people with learning disabilities may not be able to consider and protect their own interests. It may also be advantageous to advocate for somebody if they cannot make themselves understood due to a speech or communication difficulty.

In this role, advocates should simply provide clarification. It was also felt that to be an effective advocate you need to be informed. The importance of self-advocacy was also discussed.

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<sup>181</sup> "...I might be kind of a funnel so people I work with understand what they are being asked and the people asking...understanding what the person is [saying]." (a health and social care professional).

<sup>182</sup> "...interpret medical information so that somebody within the general public has a better understanding...of terminology." (a health and social care participant)

<sup>183</sup> "...it might be a student's got a meeting with their dissertation supervisor...and there's been a misunderstanding." (a family member/support worker)

<sup>184</sup> "I'm sort of like ...making sure that he's kind of saying things that he wants to say to the doctor...and if he doesn't I'll advocate on his behalf..." (a family member/support worker)

<sup>185</sup> "... supporting both the family and the doctor around the giving of a diagnosis." (a health and social care professional)

<sup>186</sup> "...being a Mum I can completely take over his life." (a family member/support worker)

<sup>187</sup> "...if I feel that something's happening and Joe is not asking the right questions...I have to feel I'm doing that in his best interests." (a family member/support worker)

There was some evidence of severely disabled people having their views represented by a traditional advocate<sup>188</sup>.

It was felt that people often made assumptions about advocates, for example, “...*their advocate knows everything about them.*” (a family member/support worker)

There were examples of advocacy which safeguarded a user’s well-being<sup>189</sup>. There was also evidence of advocacy to protect SCAN users’ interests.

#### **2.18.4. Use of proxies**

The study found some limited evidence of the use of proxies. This occurred where “...*they’re anxious...so thinking about somebody with Asperger’s...a meeting with...their tutor and somebody else might be too much for them.*” (a family member/support worker)

The study produced some helpful guidance for advocates that covered many different and challenging issues (see figure 6.4).

According to the National Autistic Society (2009) “...*advocacy is a process of supporting and enabling people to express their views.*” This illustrates good practice and is borne out by the results of this study.

It was also highlighted that certain skills were needed to be an effective advocate and that as stated by Singer (2010:50) “...*most people don’t have the knowledge, strength or energy to be the most effective advocate.*” This suggests that advocacy services should offer training to family members and people that may find themselves in the role of advocate. However, with the drive towards austerity such training may be increasingly hard to find or access.

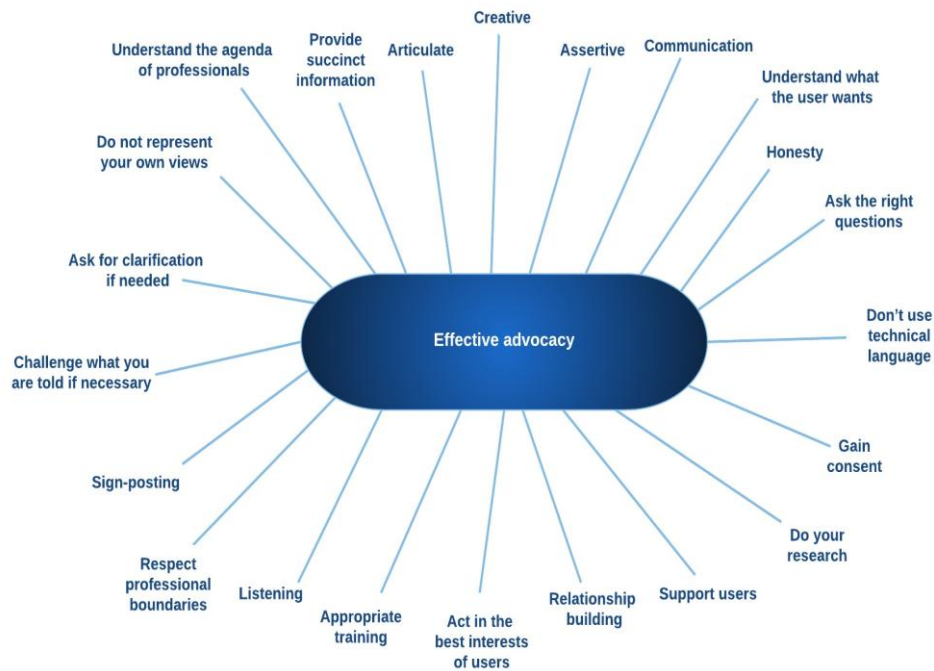
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<sup>188</sup> “a person [that] puts a case on someone else’s behalf.” (adapted from Oxford Dictionaries,2015)

<sup>189</sup> “...*I still have to design posters to put on the wall...to reiterate what is wrong with Mum.*” (a family member/support worker)

## 2.18.5 Guidance for advocates

Some guidance for advocates was suggested by participants:



**Figure 6.4 Effective advocacy**



## 2.18.6 The positive influence of advocates

There was some evidence that advocates can have a positive influence on those they advocate for. This influence appears to be in the form of positive role-modelling<sup>190</sup>. In addition to this, further positive evidence was found when a participant explained how she helps her son to make his views known<sup>191</sup>. This can be seen as positive advocacy as she always looks out for his interests<sup>192</sup>.

It was felt that in order to be an effective advocate, people need:

- The right education
- The right skills set
- Access to appropriate support
- To present what the user wants or requires
- To remember they will not understand everything about a user's life

A strategy that can be used to ensure that the above is taken into account is to say 'I think what Joe is trying to say is this...'<sup>193</sup>.

## 2.18.7 The negative influence of advocates

The study found some negative influences of advocates, or advocates not understanding their role<sup>194</sup>. This advocate had made the assumption that because somebody could not speak, they could not communicate.

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<sup>190</sup> "... anything to do with learning disability and Autism (Joe) will be really happy... to get into and gage with... because he sees the role that I play in the community and... he's modelled himself on me." (a family member/support worker)

<sup>191</sup> "...I'm able to come in on that and say just to clarify...this is what (Joe) was trying to tell you just in case you've missed parts." (a family member/support worker)

<sup>192</sup> "I always try and be respectful [and]...ask ... his permission." (a family member/support worker)

<sup>193</sup> Also, you may wish to use yes/no questions to ensure validity.

<sup>194</sup> "...I said to her why... have you done that? 'Because he doesn't speak' I said the fact that he doesn't speak doesn't mean he can't communicate to you." (a family member/support worker)

A health and social care professional felt that those in his profession are not the best equipped to advocate for disabled people this is because:

- 1) An advocate is a highly specialised role and some health and social care professionals may not have the required skills<sup>195</sup>.
- 2) There are too many demands and/or conflicts of interest, for example, cost, time and organisational ties<sup>196</sup>.
- 3) It was felt that in order to advocate for somebody you have to have a true understanding of that person.
- 4) Advocates cannot have split allegiances, for example, if the health and social care professional is attached to an organisation that provides services or equipment<sup>197</sup>.

It was also felt that health and social care professionals are not experts when it comes to advocating for the user, this is despite the fact that in some health and social care professionals job descriptions it states they should act as an advocate<sup>198</sup>.

It was acknowledged by a participant that she attempts to get the views of everybody concerned and she tries to be very creative; using mind-maps to draw out the key issues for all stakeholders. However, this method requires time and resources.

Additionally, it was felt that particularly in large groups it could be somewhat intimidating and difficult to fully understand what the SCAN user wants or needs. It was also acknowledged that health and social care professionals could improve their practice in this area.

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<sup>195</sup> "...I wouldn't consider myself to be an advocate. I think advocacy is a certain kind of skill." (a health and social care professional)

<sup>196</sup> "...there's too many vested interests in professionals like OT's (Occupational Therapists) acting as true advocates for older ...and disabled people...because they're tied to the organisation they work for..." (a family member/support worker)

<sup>197</sup> "...but you also have ...to truly be with the person that you're advocating for ...and I don't think you can necessarily do that and still be employed by an organisation." (a health and social care professional)

<sup>198</sup> "...act as a client advocate."(An extract from a job description of a registered Nurse) (NHS Jobs, 2017)

## 2.18.8 Advocating for somebody with dementia

It was felt that it was particularly difficult to advocate for a family member who has dementia because “...*she is listening to me...and she’ll probably say ‘Yes it’s perfectly alright’...and I know it’s not... [but] she thinks that whatever they’ve bought we should use.*” (a family member/support worker)

To avoid these situations, great care should be taken to explain to the person with dementia why something may not be appropriate. A participant feels it is almost like a change of roles<sup>199</sup>.

## 2.19 Consultation of SCAN users (10 participants)

Participants felt that sometimes products and services were tested with those that had a mild disability thus leading to results that do not represent the whole population<sup>200</sup>.

### 2.19.1. A lack of real choice

It was also discussed, that in certain circumstances, SCAN users’ choices can be extremely limited, in terms of service provision and product design<sup>201</sup>.

This combination of factors leads to disabled people having to make choices they may not usually make, sometimes having “...*choices made for them.*” (adapted from McKay-Moffat 2007:57)

It was also discussed that some SCAN users may not use a communication aid despite the fact that this may seem to be an unwise choice that could have the potential to further alienate them.

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<sup>199</sup> “...*it’s like I’m my Mum’s mother now.*” (a family member/support worker)

<sup>200</sup> “...*one cannot ignore the heterogeneity of disability...such as...type, age, age of onset, its effects and limitations.*” (Zamfir and Maggino, 2013:70)

<sup>201</sup> “...*persons with disabilities can buy accessible products, like a Smartphone or a TV set, but they are often more expensive than other products and there is less choice.*” (European Disabilities Forum, n.d.)

This is often because of a variety of reasons<sup>202</sup> therefore users may take the decision that they do not wish to expend the energy required to learn new skills.

The study found some evidence of good practice when communicating with users. However, the major obstacle to such practice was usually the time and resources required. Despite this, “...adequate time and resources need to be identified to make the process of consultation meaningful.” (Minogue, 2008:165) This is because as stated by Victoria State Government (2011) “...it is important to consult with people with a disability. They should have as much input into the planning and development of services and activities...obtaining the views of people with a disability ensures the results will be more representative.” In addition, as stated by Playforth (2004:7) “...including disabled people in consultation about services in general helps to break down barriers and increase disability awareness.”

Furthermore, this may also start a whole new creative process leading to new ways of thinking that may benefit the wider population (adapted from Disability Right Cymru, 2015). However, the difficulty with SCAN users is that there are so many variations even within sub-sets of disability. This means that it can be difficult testing with every possible user group “...ideally you would include several users with different disabilities...[if possible]...” (Henry *op.cit.a*) Furthermore, it can be difficult to recruit all users required to ensure that what you produce is a valid reflection of the needs of those with a disability.

It was also felt that people with SCAN need to understand what they were being consulted about so they can make a meaningful contribution<sup>203</sup>.

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<sup>202</sup> “...despite the technological advances evident in high-tech modern communication aids, a number of key challenges remain...first ...is the much slower rate of communication typically achieved when using such aids.” (Abu-Faraj, 2012:128)

<sup>203</sup> “...anything we say...must be done in a way that [people can understand].” (adapted from Wilmore 2013:25)

It should be noted that SCAN users may have many different ways in which they communicate, some of these include:

- “...*facial expressions*,
- *eye gaze [technology]*,
- “*body language*” [*and*] *gestures*,
- *signs*
- *communication books*
- *charts with pictures or symbols*,
- *objects*,
- *electronic aids.*” (adapted from Grove and McIntosh, 2005:2)

As a society we need to be able to communicate in many different ways so that people with disabilities can be included.

People with additional needs should be consulted because:

- They want to be included
- Have valuable views to contribute
- Have personal experience
- Can offer creative solutions

## 2.19.2 Representation of SCAN users' views:

- Use of advocates<sup>204, 205</sup>
  - The advocacy role is often taken by “...family members or personal assistants, who do not operate under professional guidelines or code of ethics.” (Blackstone, Beukelman and Yorkston, 2015:20)

The study found many different ways in which people are supported to communicate, these include:

- Advocates are “...a carer, friend or relative” (Cambridge Training and Development *op.cit.*) often they represent “...users at case conferences, assessment meetings or in care plan reviews.” (Cambridge Training and Development *ibid.* pp 94)
- Advocates are useful when helping users to understand information or terminology<sup>206</sup>.
- Advocates have a role when a user has speech or communication difficulties<sup>207</sup>.
- Can help “...people with autism... interpret and process information...” (National Autistic Society, 2016). This support is often required because they may not be able to explain their wants, needs or know how to engage in social situations (adapted from Saeki and Powell, 2008:6).
- Can have a role in explaining complex terminology, for example, those with dementia because it “...impairs a person’s ability to communicate effectively.” (Zembrzuski, 2013)

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<sup>206</sup> “...family members serve as advocates for patients helping them with each provider they see and often interpreting complicated health care information or directions.” (Mayer and Villaire, 2007:39)

<sup>207</sup> “Advocacy can have a significant role to play in empowering people with communication problems.” (Gray and Jackson, 2002:171)

- Helping those with communication difficulties to express themselves. They *“are able to provide information and participate in the interaction... [this] may help [users to understand]... and they may provide second opinions or additional information...”* (adapted from Meyer, Pawlack and Kliche, 2010:317-318). Those with specialist knowledge such as nurses can support the doctor, SCAN user and the family member with a diagnosis.

Often many people are confused after an interaction with a health or social care professional such as a doctor. However, a specialist nurse may have more time to explain to a user or their family member what has just been said in a language they can understand (adapted from Mayer and Villaire, *op.cit.*).

### 2.19.3 The danger of advocacy

Some of the dangers of advocacy were highlighted:

- If a parent advocates on behalf of their disabled child they can *“become over-protective...which restricts the ability of the child to make friends, gain independence and become part of...wider society.”* (Tyano *et al.* 2010:306)
- Advocates can be seduced into abusing their role (adapted from Mayer and Villaire *op.cit.*)
- Advocates feel they have to ‘step in’ when the best interests of the service user are not being met<sup>208</sup>. However, some authors felt that where family members are used as advocates *“...one of the dilemmas...is that [they] may be seen to be acting against...”* the best interests of the cared for (adapted Forbat and Atkinson, 2005:324).

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<sup>208</sup> *“Advocacy is the process of expressing the views and standing up for the interests of a person who is not able to do so independently. It can involve safeguarding their rights, arguing their corner and contributing to decision making from a perspective of understanding the person’s wishes.”* (Jenkins, Ginesi and Keenan, 2016:143)

#### 2.19.4 The effective self-advocate

Participants felt in order to be a good advocate you need to be:

- Informed
- Know when it is and is not appropriate to advocate because advocacy is about putting somebody back in control of their own life, not taking control from them (adapted from British Institute of Learning Disabilities, 2016).

The role of an advocate is difficult and complex as it is important to only provide the minimum amount of support that is needed to ensure the user's voice is effectively heard<sup>209</sup>.

#### 2.19.5 The challenges of advocating for users with learning and communication difficulties

Advocacy may also be used when somebody needs help to express their views fully<sup>210</sup>. Furthermore, as stated by Gray and Jackson (*ibid.*) “...one of the biggest barriers facing people with significant communication difficulties is how they are perceived and valued by others.” It was also highlighted that sometimes professionals such as social workers do not make the best advocates because they are tied to an organisation. In addition to this, they may not understand the intricacies of someone's life. This often leads to family members being in the best place to fulfil the role of an advocate (adapted from Nind, 2008).

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<sup>210</sup> “Advocating for someone who has significant limitations in their ability to communicate can present enormous challenges...what is not in question is that it is extremely important.” (Gray and Jackson, 2002:170)



### 2.19.6 Advocating for people with dementia

It was discussed that it can be extremely difficult to advocate for those with dementia. This is because they may lack the cognitive abilities to understand which can lead to decisions that are “...taken on their behalf (or made in the interests of other organisations, or other individuals, rather than the service user themselves.” (Jenkins, Ginesi and Keenan, 2016:143) However, effective advocacy for people with dementia is crucial as it may be needed to ensure their safety and that their voice is being heard. Furthermore they may appear to have abilities which are beyond their cognitive function<sup>211</sup>. Additionally, a person with dementia may have difficulty understanding all aspects of a situation as the disease progresses<sup>212</sup>.

Finally some participants felt because their family member had Alzheimer’s their roles had been reversed, where daughters may become the mother and the parents become the child<sup>213</sup>.

### 2.19.7 Use of proxies

The use of proxies was limited, for example, assisting people to represent themselves, particularly in relation to disabilities where social situations, such as meetings may be difficult. This is an acceptable use of proxies<sup>214</sup>.

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<sup>211</sup> “...as the illness progresses, they will experience a gradual deterioration of their ability to communicate...and to understand what others say.” (Alzheimer’s Society of Canada, April 2015)

<sup>212</sup> “This language degeneration is known as aphasia. Individuals with aphasia experience difficulty understanding the words heard.” (Alzheimer’s Society of Canada *ibid.*)

<sup>213</sup> “Being a caregiver isn’t easy, but it’s even more difficult when your “patient” is someone who has cared for you your entire life.” (Kindly Care,2016)

<sup>214</sup> Proxies can be used to assist people who “will not respond for themselves.” (Wunderlich,2009)

## 2.20 The reality of life lived as a SCAN user (10 participants)

Participants shared many insights in relation to their life as a consequence of having SCAN. There were a number of strategies employed by SCAN users or difficulties they faced as a result of their SCAN:

The strategies included:

- Avoidance<sup>215,216</sup>
- Having to adapt to situations<sup>217</sup>

The difficulties included:

- Frustration<sup>218</sup>.
- Being known as difficult<sup>219</sup>.
- Not being able to hold and carry products<sup>220</sup>.
- Feelings of isolation.
- Stress/Anxiety<sup>221</sup>.
- Lack of instructions for equipment<sup>222</sup>.

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<sup>215</sup> "Participants [with a hearing impairment] would avoid noisy [situations]." (adapted from Echaliér *op.cit.*)

<sup>216</sup> "Yeah...sometimes actually [I feel like] an outcaste." (a participant with a physical impairment) This finding is given credit by the remarks of Linton (1998) (adapted) who states that "...the sick and the disabled ordinarily [feel] like outcastes."

<sup>217</sup> "...but we learn to adapt...to the situation" (a participant with a physical impairment). This finding is given credit by the remarks of Sharkey (2007) who states that "...individuals have to adapt to their impairment."

<sup>218</sup> Frustration with health and social care professionals was reported, for example a participant stated "...she stood there and went it's not... might, it's when...and I thought well you're not gonna win." (a family member/support worker)

<sup>219</sup> "...if they think you're a difficult person...they will avoid your call." (a family member/support worker) This finding is also given credit by the remarks of Barnes, Mercer and Shakespeare (2003) (adapted) "...disabled people [and their carers] are often considered to be...difficult."

<sup>220</sup> "...I'm buying some products like food and... shopping ...in a supermarket...so I can't carry loads of them" (a participant with a physical impairment). This finding is given credit by the remarks of Shakelford and Edmo (2011:87-88) who state that "...it is ...difficult to hold a handheld basket on the lap, for once the basket is full it becomes heavy and uncomfortable."

<sup>221</sup> "...when I feel anxiety that increases my ... stammering" (a participant with a physical impairment). These remarks are given credit by Rustin *et al.* (2013:4) who state that "...anxiety and stammering in talking situations, which can, in turn, make the stammering worse."

<sup>222</sup> "...we don't get ...instructions for equipment... it's like we got a hospital bed...so I have to go to the internet to download instructions" (a family member/support worker). This finding is given credit by the remarks of Mandelstam (1997) "A research report into aids and equipment for elderly people commissioned by the Department of Trade and Industry published in 1992...found [equipment] with inadequate instructions."

- Cuts to support<sup>223</sup>.
- SCAN users, their family members and associated health and social care professionals may not have access to the most up-to-date equipment available<sup>224</sup>.
- Accessing public transport<sup>225</sup>.
- Having a stable income because they may be reliant on state benefits<sup>226</sup>.
- User manuals for equipment are not always user friendly<sup>227</sup>.

It is accepted that these feelings are not directly related to design and evaluation processes. However, they are useful to demonstrate some of the challenges and fears SCAN users or their families face in their everyday lives. They may also be useful as information for designers in relation to where they may need to exercise caution or sensitivity when working with SCAN users.

In addition, the study showed some evidence of the personalities that SCAN users or their family members develop, these included:

- Assertiveness<sup>228</sup>.
- Wanting to take control of their own life<sup>229</sup>.
- Feeling distressed if tasks are not completed<sup>230</sup>.

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*Most of the instructions that were supplied related to assembly only; aspects such as safe use, cleaning and maintenance of the equipment were inadequately dealt with."*

<sup>223</sup> "...they're streamlining the criteria for DSA [Disabled Students Allowance]...which is basically a posh word for cutting." (a participant with a physical impairment) (Gov.uk, 2015)

<sup>224</sup> "...I had to licence a piece of software onto the laptop of a child in hospital...I couldn't get on the Wi-Fi." (a health and social care professional)

<sup>225</sup> "Transport options for disabled people are very limited because of the need to use only transport that are accessible, and these tend to be expensive." (Equality and Human Rights Commission, 2017:117)

<sup>226</sup> "Many disabled people rely on state benefits for part or all of their income." (Housing Options Scotland, 2016) and Douglas Campbell of the DDA states that "A lot of disabled people have a low income or are on benefits and finance can be a problem." (Shaw, 2001)

<sup>227</sup> A Royal College of Nursing Survey (2004:10) found that "[there is a] lack of access to up to date IT equipment or indeed to any IT equipment at all."

<sup>228</sup> "I always try the nice approach first ... and then you have to get a little bit firmer... I never get nasty cus that's not gonna get me anywhere." (a family member/support worker)

<sup>229</sup> "he wants full-time staff didn't come from me ...it came from him... I think I might have pissed him off and he thinks right ...I want my own staff." (a family member/support worker).

- The need to prove people wrong/conquering people’s misconceptions<sup>231</sup>.
- Pride<sup>232</sup>.
- Not wanting to inconvenience people<sup>233</sup>.
- Willingness to talk to anybody/open and friendliness<sup>234</sup>.
- Participants’ personality may be lost because of their disability<sup>235</sup>.

It is surprising to note how the strategies suggested by participants are in many cases known and discussed in published literature. This is not dissimilar to many aspects of the findings of this study, for example, in relation to advantages and disadvantages of methods that participants had experience of.

Finally, many SCAN users are eligible for a free bus pass that is only valid between 09:30am and 11:30pm (Network West Midlands *op.cit.*) therefore some consideration will need to be given to the timing of research activities so that such users are not excluded.

A participant feels that an understanding of a user’s life circumstances may be beneficial to a designer because if you “...ask [a user] about [their] lifestyle this may help the designer get a better picture of how a product should be made or adapted to [user’s] needs.” (a family member/support worker)

Additionally, designers will need to understand that some of the users they work with may not have an understanding of concepts such as pain and thirst.

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<sup>230</sup> “Just... the way I am...I guess... it must be something to do with my cerebral palsy.” (a participant with a physical impairment) This assertion is given credit by the remarks of Brooker and Waugh (2013:257) who state that “damage to the central nervous system may lead to a reduced tolerance to environmental stimulation.”

<sup>231</sup> “...I feel I’ve conquered a little bit I feel better than an able person.” (a participant with a physical impairment) This finding is given credit by the remarks of Smith (2015:60) who states that “disabled people may feel a need to conform to social and cultural expectations by overcoming their impairments.”

<sup>232</sup> “...I’ve always had a bit of ...pride...but I’ve kept it very secret.” (a participant with a physical impairment) This finding is given credit by the remarks of Karp (2009:129) who states that “some people take pride in what they learn about themselves through their disability.”

<sup>233</sup> “...if it’s too much inconvenience you may just stay there where you are.” (a participant with a physical impairment) This finding is given credit by the remarks of Welfel and Ingersoll (2001:318) who state that “disability, of course, will present frustration, inconvenience and grief to the person.”

<sup>234</sup> “...I think it’s part of my personality, I’ll talk to anybody” (a visually impaired participant). This finding is supported by the remarks of Moody (2015a) who states that “our experience suggests that, once recruited, participants are keen to engage and remain involved in projects. They have the opportunity to talk and explain problems and share their stories.”

<sup>235</sup> “I sometimes think...every time I have a massive seizure I lose a bit of my brain.” (a participant with a physical impairment). This finding is given credit by the remarks of Schachter, Krishnamurthy and Combs-Cantrell (2008:83) who state that “I also noticed that my personality changed. I was very moody.” Both of these participants discuss the impact that epilepsy may have on personality.

## **2.21 Insights expressed in terms of methods used to support design and evaluation processes (9 participants)**

### **2.21.1. Insights when working with participants with physical impairments**

Verbal methods such as interviews may be advantageous for participants with physical disabilities because the act of writing can be tiring and take longer which may cause frustration.

### **2.21.2 Insights when working with participants that have hearing impairments**

- It was found that it can be difficult to utilise verbal methods if the person speaks in a quiet tone.
- Written methods may be preferable to these participants.
- If you plan to conduct focus groups you may wish to advise participants to bring their hearing aids as this may achieve a better experience.

### **2.21.3. Insights when working with those that have communication difficulties**

- Written methods may be preferable to those with severe stammers<sup>236</sup>.
- If interviews are to be used it can help members of this group if they already know the person that's going to be conducting the interview, this may reduce their nervousness thus leading to better responses to the questions and improving the interview experience.
- Yes or no questions can be advantageous with these participants because they can make it obvious by their body language, for example, shaking their head.
- It was highlighted that some participants may not have the confidence to ask questions when they do not understand.

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<sup>236</sup> Irishhealth.com (2015) states that people with speech difficulties can avoid speaking situations.

- It was felt that some designers are not willing or able to understand others' perspectives.

## 2.22 Understanding users' life circumstances (9 participants)

The importance of understanding a user's life circumstance cannot be underestimated. However some participants felt that it very much depended on the context, for example, one of the participants in the study was colour blind<sup>237</sup>.

It would be highly beneficial to understand a user's life context where their conditions are multiple and complex<sup>238</sup>.

It was also felt that there was a difference between understanding a user's life context and considering it<sup>239</sup>. Consideration may be where you take an overview and understanding could be regarded as the development of detailed knowledge.

## 2.23 Making adjustments or accommodations (9 participants)

The Equality Act (2010) which states changes or adjustments should be made to ensure that the person can access the following:

- Education
- Employment
- Housing
- Goods and services<sup>240</sup> (adapted from Citizens Advice, 2016).

Participants felt that designers need to “...judge the audience and...adapt accordingly.” (a control group participant)

<sup>237</sup> “...if they design something in...green with a purple background I wouldn't be able to see it...” (a visually impaired participant)

<sup>238</sup> If you are conducting “...a needs test ...then... [the] people [doing the test would]...need...to...understand their situation.” (a participant with a physical impairment)

<sup>239</sup> “...if you don't consider it, then you're not gonna have the understanding.” (a visually impaired participant)

<sup>240</sup> “...like... banks [and groceries]...associations and private [members] clubs ... [for example] golf ... and working men clubs.” (adapted from Citizens Advice op.cit.)

The majority of participants questioned, stated that “...people are quite prepared to make adjustments...I quite often ask to sit on a certain side...so I sit on my good side.” (a hearing impaired participant) However, a participant stated that “most of them didn’t.” (a visually impaired participant)

**Examples of reasonable adjustments requested from participants include:**

- Accessible research venues.
- More space to write on questionnaires.
- Sitting in a position that enables the designer and participant to communicate effectively.
- Using numeration as opposed to colour to denote changes of headings.
- Taking rest breaks during research activities.
- Enlarging research materials.
- Ensuring research areas are quiet (National Disability Authority *op.cit.*).

When working with wheelchair users, designers may have to be proactive<sup>241</sup>.

A participant outlined the difficulties that designers face when doing research with SCAN users it can be difficult to:

- “...get people in a room together,
- .. find a space that’s accessible...
- get the transport to get them there,
- get them there at the same time,
- ...get their carers there...”

(Moody (*op.cit.*) (a))

Participants felt that whilst some adjustments can be anticipatory<sup>242</sup>.

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<sup>241</sup> “...thinking on your feet ... [as for example, the room the interview is due to take place in may not be accessible].” (a family member/support worker)

<sup>242</sup> “...an organisation [not waiting] until a disabled person wants to use its services, but [thinking in advance] (and on an ongoing basis) about what disabled people with a range of impairments might reasonably need.” (adapted from Equality and Human Rights Commission, 2016)

Some adjustments cannot be anticipated and may need to be discussed with users before they attend research interviews, for example, the provision of special equipment to enable them to take part in the research.

Some examples of anticipatory adjustments taken from the literature and the results of this study are:

- Different ways of conveying information, for example, audio and video (Nind & Seale, in press, Brooks & Davies, 2008:30).
- Modification of research materials (Nicolaidis *op.cit.*, Raymaker, McDonald and Stack 2013, Raymaker and McDonald *op.cit.*)
- “...making physical changes to the research setting...” (Raymaker and McDonald *ibid.*)
- Easy to read research materials “... with the questions spaced out clearly.” (The Open University, 2016)
- Accommodations for those with colour blindness (Jenny and Kelso, 2007:61).
- Rest breaks during research activities (Atkinson, 2007: 138).

Participants felt that designers were willing to make adjustments; there is some evidence to support this in the literature<sup>243</sup>.

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<sup>243</sup> In relation to communication difficulties, cognitive impairments or the anxieties and preferences of individuals (adapted from Michael, 2008).



## 2.24 Choice, control and power (8 participants)

An imbalance of power may be experienced by SCAN users<sup>244</sup>.

Consequently, the power that is exercised over people that have disabilities can be damaging. Family members can feel intimidated because it appears that power lies with health and social care professionals, those interviewed were aware of this imbalance. Additionally, there was evidence showing that real power often lies with those who are responsible for the SCAN user such as a teacher or partner.

Participants also reported instances of being patronised; this is linked to power and control<sup>245</sup>.

A participant felt that the views of users are given equal importance at least when she's involved because *"...that's [what] I've been asked to do."*

It was also felt that commissioners have little interest in the thoughts of health and social care professionals. The participant refers to this as 'non-sultation'<sup>246</sup> (the idea of consulting people but not actually acting on what you've found). Given this, the validity of the consultation is called into question<sup>247</sup>. The participant also reports incidents where she has been asked to ask a service user if they consent to a move when there was no real choice<sup>248</sup>.

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<sup>244</sup> *"...sometimes we think because our children have disabilities... [we are] meant to cocoon them."* (a family member/support worker)

<sup>245</sup> An example of this was reported by a participant who stated *"when people finish your words off for you...that's what's frustrating."* (a participant with a physical impairment)

<sup>246</sup> *"... the kind of thing that we've...coined 'nonsultation' this idea of consulting people [but] not actually [consulting them]."* (a health and social care professional)

<sup>247</sup> *"I get frustrated at meetings where they go...'have we asked if they can consent to moving and make a choice of where they're gonna go'...and...I say, there isn't a choice ...so why am I asking somebody to make a choice."* (a health and social care professional)

<sup>248</sup> *"Campbell (1996) and McLaughlin et al. (2004) have argued that service user involvement is all too often 'tokenistic' and unproductive."*

A participant uses the following strategies to ensure the users views are represented appropriately:

- 1) The use of allies<sup>249</sup>.
- 2) Attending meetings which allow her to represent the users she works with.
- 3) Debating with people.
- 4) Makes it known when she feels you cannot effectively represent the views of users.

In addition, it was felt that caution may need to be exercised, for example, in relation to how they sit because sometimes people's natural reactions is to please whoever is sitting across from them. Furthermore, it was suggested that family members of SCAN users need to be mindful of the power they have as some may have more power and knowledge than the professionals responsible for their care. However, it could be the case that SCAN users or their family members "*...are [isolated].*" (a family member/support worker).

The study found some limited evidence that those questioned felt there is a need for and a lack of real choice, control and power. A participant felt that designers need to embrace meaningful co-production<sup>250</sup>.

A participant experienced this first-hand, through living in a supported accommodation placement and then moving into the community, she felt that whilst she was in supported accommodation "*...there [were] people who would try and take over and deal with my needs for me.*" (a participant with a physical impairment) this can lead to feelings of frustration.

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<sup>249</sup> Somebody that may have similar views to herself.

<sup>250</sup> "*...refers to the contribution of service users to the provision of services...*" (Realpe and Wallace, 2010:8)

There is also evidence of health and social care professionals having to do consultations which are meant to engage users but in practice may not<sup>251</sup>. The study found some evidence of co-design working as it should, that is, enabling users to shape the design of services<sup>252</sup>.

However, it should be remembered that co-design is “... *not suitable for every project.*” It is most appropriate, where, the product or service has an “...*impact on someone’s life.*” (a control group participant) an example of this would be the design of a prosthesis.

Finally, it was highlighted that some users may decline to use a communication aid when they may benefit from the provision of one<sup>253</sup>.

### **2.24.1 The power dynamics between SCAN users, family members and health or social care professionals**

It was highlighted that family members have a vital role to play in supporting SCAN users to lead a full and active life.

This includes:

- Communication support, with the user’s consent, for example, at hospital appointments and school reviews.
- Providing love and emotional support.
- Being an informed and effective advocate.

Additionally, it was highlighted that family members lacked research and advocacy skills and that because of this; their ability to act in the best interests of their family member was not necessarily as effective as it could be.

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<sup>251</sup> “... *the kind of thing that we’ve.. coined ‘nonsulation’ this idea of consulting people [but] not actually [consulting].*” (a health and social care professional)

<sup>252</sup> “...*it was like a warm neighbourhood’s project called ‘Around Me’ where we worked with a group of stakeholders to kind of identify [what] the issues were...and then from that we used...a series of workshops and focus groups [to] ... create methodologies, to design a service blue print...I think we got a very thorough well thought through result.*” (a health and social care professional)

<sup>253</sup> “...*it’s slower...than speaking, it’s clumsier, it means that people start looking at the aid, not at you, and you stop being the person they’re talking to.*” (a health and social care professional)

With the advent of person-centred planning in the 1980s (keystoinclusion.com, 2015) there has been a change in how SCAN users are viewed, they are no longer passive recipients of services but rather should be placed at the centre of decisions about them; this can present certain challenges for advocates<sup>254</sup>. The study above provided some evidence that user's with severe learning difficulties can contribute to society and make meaningful decisions<sup>255</sup>.

With the advent of personal budgets<sup>256</sup> family members and SCAN users now have more choice and control in how, where and when their care is delivered.

In addition, the study found evidence that there may be tension between the family member and health and social care professionals in relation to the service user's best interests<sup>257</sup>. To try and negate this it may be advisable to say 'my opinion is' as this is less confrontational.

A health and social care professional stated that in some circumstances, they exercise power as they know what equipment they can and cannot prescribe. This can lead to family members feeling intimidated or ignored. Additionally, these situations can be challenging for all concerned because it may mean that a service will spend thousands of pounds on the purchase of a very expensive piece of equipment, for example, a communication aid.

The study highlighted situations where the user may have severe impairments but their ideas are very clearly defined. This can create tension as it may not be what the family member wants. This results in a compromise being needed. Conversely the reverse may occur.

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<sup>254</sup> "...I had to really change the way that I see him...and realise that even though his communication level was very, very low ...I had to find ways in which I can get Joe's opinion about certain things." (a family member/support worker)

<sup>255</sup> "...he's a member on the Learning Disability Partnership Board and his PA (Personal Assistant) supports him...[and sometimes he] comes up with a good idea." (a family member/support worker)

<sup>256</sup> "...money... [a] local authority allocates for...care, based on its assessment of your needs." (adapted from NHS Choices 2015)

<sup>257</sup> "...the family use iPads or the school have got iPads and everybody wants an iPad for that child...even though it may not be the most appropriate solution." (a health and social care professional)

Most health and social care professionals in the study worked in the NHS, as a result they often work under the following constraints:

- Budgets
- Rules
- Regulations
- Long waiting lists

This means that often service users and family members are in ‘fight-mode’ before an appointment has taken place. This can be damaging because they may not be able to think or express themselves clearly.

### **2.25 Putting people at ease (8 participants)**

It was felt that the ability to put people at ease was important. To do this, participants offered the following advice:

- Offer a drink.
- Tell them they are free to leave at any time.
- Ask the participant how they would like their interactions to be recorded.
- Do not ask leading questions.
- Ensure participants are comfortable and their needs are met.

## 2.26 Relationship building (7 participants)

The importance of relationship building was eloquently discussed by a participant;

*“I think they need to be cautious...and I think you need to make a judgment with the situation you’re in and you do need to stay professional but at the same time if you want...good information...you need to establish a relationship with them.”*

(a control group participant) These remarks are similar to the views expressed by McDonald, Kidney and Patka (*op.cit.*)<sup>258</sup>.

It therefore follows that if trust is built between a designer and an end user the end user is more likely to contribute thus ensuring the final design produced will be more likely to meet a user’s needs. Furthermore, the building of an effective relationship may help designers to understand why certain research methods or surroundings may not be preferable<sup>259</sup>.

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<sup>258</sup> *“The role of trust permeated participants’ views. First, several participants noted they prefer to learn about research from people they know and trust to help them assess the value or appropriateness of participation.”*(McDonald, Kidney and Patka *op.cit.*)

<sup>259</sup> *“... I might refuse to take part in research because I don’t want to go into the city centre...[due to] my hearing impairment.”* (a participant with a hearing impairment)

The diagram below highlights some of the key aspects required for effective relationship building:



**Figure 6.5 illustrates the suggested skills and qualities for effective relationship building**

### 2.26.1 The interdependence of skills required to build effective relationships

Many of the skills required to build effective relationships are inter-linked<sup>260</sup>. Many of the skills such as empathy are difficult to teach but yet so crucial when designing for SCAN users<sup>261</sup>. Additionally, Clarkson *et al.* (2003:484) contend that using empathetic approaches in design enables the designer to connect with the user<sup>262</sup>.

Many of these skills will also be important for those who support SCAN users to have knowledge of because like a designer they will need to build an effective working relationship with the person they're supporting.

<sup>260</sup> Trust is gained by spending time with and getting to know a user. Similarly listening to people takes time.

<sup>261</sup> "Empathy is shown to influence the adoption of inclusive design by providing awareness of the issue to those who have a direct impact on the production of goods and services." (Tzekakis, 2008:1)

<sup>262</sup> "...and respond to quality of life issues rather than physical problems alone...thus providing a holistic understanding." (Clarkson *et al.* 2003:484)

## 2.27 Simplifying language (7 participants)

The study found evidence that there is a need for written research materials to be simplified<sup>263</sup>.

According to Zupanci *et al.* (1999:409) “*Simplified language is:*

- *...a modification of normal language*
- *...sentences are short...*
- *...the structure of the sentences is plain and unambiguous*
- *...the words that are used are taken from common everyday language.”*

This would appear to match with some of the goals as identified by participants.

Participants observed that simplified language:

- Is needed to explain difficult concepts<sup>264</sup>.
- To ensure key points are understood<sup>265</sup>.
- Help identify unnecessary technical language<sup>266</sup>.
- Should reduce the amount of information people have to process (adapted from Mencap, 2002).
- Can enable people to understand processes such as research<sup>267</sup>.
- Can help avoid misunderstandings<sup>268</sup>.

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<sup>263</sup> “...research...[includes] big words...and not everyone...understands [them]...” (a family member/support worker)

<sup>264</sup> Simplified language can be used to explain “*difficult concepts or terminology.*” (May and Holmes *op.cit.*)

<sup>265</sup> When trying to simplify language people should “*remember that less is more (i.e. shorter is better) (brevity).*” (May and Holmes (*ibid.*) pp 109)

<sup>266</sup> It does comment on the fact that technical or scientific language should be limited (US Department of Health and Social Services, 2009).

<sup>267</sup> Therefore, if done correctly, simplified language should make complex processes such as research more accessible to people (Mencap, *op.cit.*)

<sup>268</sup> “*By being clear, concise and readable-but not simplistic – writers can avoid misinterpretation.*” Additionally, it was felt that simplified language can make written language less complicated. (International Standards Organization, n.d.:1)



**Participants felt that there were a number of reasons as to why language may need to be simplified, these included:**

- To help explain key points<sup>269</sup>.
- To reduce cognitive load<sup>270</sup>.

There was evidence that there is a need for written research materials to be simplified<sup>271</sup>.

To ensure that the interaction with people who require simplified language is effective, the following considerations may be helpful:

**People with intellectual disabilities may have difficulty with the following:**

- “...in the recognition of facial expressions.” (Hogg and Langa, 2005)
- “...making themselves understood.” (Hassiotis, Barron and Hall, 2013)
- “...using language in an appropriate manner.” (Hassiotis, Barron and Hall *ibid.*)

**Use of symbols and pictures:**

- Simplifying language requires skills that go beyond the ability to place pictures in a document.
- The use of symbols is not always appropriate because your user group may not understand them<sup>272</sup>.
- It may be easier to use images, as this can be the best way to aid understanding.
- Explaining complicated concepts will often be easier with a drawing or photo (adapted from Mencap *ibid.*).

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<sup>269</sup> ‘You say what you mean in the simplest words possible.’ (International Standards Organization, *ibid.*)

<sup>270</sup> “...people with an intellectual disability may have difficulty understanding language that is complex and contains abstract concepts or technical jargon.” (Centre for Developmental Disability Health Victoria, 2014)

<sup>271</sup> “...research... [includes] big words...and not everyone...understands [them]...” (a family member/support worker)

<sup>272</sup> “Some people find too many symbols on a page confusing. Unless your readers like symbols above most words, it is better to use symbols just for key words or ideas.” (Mencap *op.cit.*)

- *“Do not rely heavily on abstract symbols unless...your readers are confident symbol users. Choose one or two simple, pictorial symbols and put them to the side of the words.”* (Mencap *ibid.*)

### **Use of language:**

- Ensure the language you use is not patronising, or demeaning<sup>273</sup> (adapted from Nomura, Nielsen, and Tronbacke, 2010:10).
- *“It is important to convey simple messages.”* (Intellectual Disability Rights Service).
- *“Use everyday language whenever possible and reduce jargon.”* (International Standards Organization, n.d.:1)
- *“Use inclusive language where possible.”* (International Standards Organization *ibid.* pp:1)
- *“Remove complex phrases.”* (May and Holmes *ibid.* pp 109)
- *“Avoid abstract language.”* (Nomura, Nielsen, and Tronbacke *op.cit.*)
- *“Use vocabulary that is appropriate for your readers.”* (Appleyard and Appleyard *op.cit.*)

### **Sentence structure:**

- *“The hallmark of clear sentences is simple, uncluttered language that readers can immediately understand.”* (Butterfield *ibid.* pp 31)
- *“The longer the sentence, the harder it is to read and understand.”* (Butterfield *ibid.* pp 30)
- *“Keep your sentence length between 10 and 25 words.”* (Butterfield *ibid.* pp 30)
- *“Shorten your sentences by removing unnecessary words and using ...direct language.”* (Butterfield *ibid.* pp 31, Nomura, Nielsen, and Tronbacke 2010:10, Appleyard and Appleyard *op.cit.*)
- *“Avoid difficult words.”* (Nomura, Nielsen, and Tronbacke *op.cit.*)

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<sup>273</sup> *“Don’t use language that sounds stuffy or demeaning.”* (Butterfield *op.cit.*)

- “Questions should be clearly worded so they can be readily understood.” (Mayberry, 1993:35)
- “All questions should be...phrased in a logical fashion.” (Mayberry *ibid.* pp 35, (Nomura, Nielsen, and Tronbacke *op.cit.*)
- “...it is known that chunking facilitates remembering larger quantities of information.” (Glick, 2011:149)

### **General guidance:**

- *Encourage writers and illustrators to get to know their target audience and be informed about what it means to have reading difficulties. Let them meet their readers and hear about their experiences.* (Nomura, Nielsen, and Tronbacke *ibid.* pp 10, Appleyard and Appleyard *op.cit.*)
- *“Test the material with actual target groups before it goes to press.”* (Nomura, Nielsen, and Tronbacke *ibid.* pp 10)
- Consider the amount of information displayed on a page<sup>274</sup>.

The issue of simplifying language can be broken-down into sub-issues, these included:

#### **2.27.1 The goal of simplifying language**

The goals of simplifying language as stated by participants are that it should be:

- Understood by its intended audience (adapted from a visually impaired participant).
- Clear, simple and direct (adapted from a hearing impaired participant).

Participants also felt that it is also important to have a clear understanding of what is being asked and what is expected of them, this should be communicated in a format that is accessible to them.

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<sup>274</sup> You should break information down into small logical chunks with plenty of white space (adapted from Mencap, 2002).

A strategy that could be used to assess understanding is to:

- Ask participants what they think the key points are in relation to the research and what they understand their involvement to be.

### 2.27.2 Why language needs to be simplified

Language needs to be simplified for a number of reasons, these included:

- To explain difficult concepts such as bail conditions and informed consent.
- To convey key points.
- To help identify unnecessary technical language.
- To reduce the amount of information people have to deal with.
- To make processes such as research more accessible to people.
- To reduce the possibility of misunderstandings.
- To make language less complicated.

## 2.28 Language used in research materials (7 participants)

The study found a number of themes related to language used in research materials, these were:

- Confusing language<sup>275</sup>.
  - The participant does not understand what the research material is asking<sup>276</sup>.
  - Use of inappropriate language based on the user's intellectual ability<sup>277</sup>.
- The researcher however, accepts this can be complicated especially when you're producing research material for people with diverse needs.

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<sup>275</sup> "...the last...Care Quality Commission (CQC) inspection...two questions like ...what is the support like from the support workers and what's the support like from the care agency- same sort of thing." (a visually impaired participant)

<sup>276</sup> "...I have to read that sentence very carefully... I... think it's very import[ant]... when you're in the position of the subject as I am today." (a hearing impaired participant)

<sup>277</sup> "...the ways that they reviewed the care plan that was a bit patronising and really annoyed me like marking things on a star chart." (a participant with a physical impairment)

Therefore a solution to this is to provide different versions of the same materials.

- Designers have difficulty producing effective research materials because they primarily use pictures and diagrams to communicate with their audience<sup>278</sup>.
- Sometimes the language used in research materials is too complicated<sup>279</sup>.

It should be noted that the majority of participants in the control group reported no issues in relation to the language used in research materials.

## 2.29 The importance of understanding body language (6 participants)

It was highlighted that it is important to understand what body language means. This is especially important in situations where users have no or limited verbal communication, the results from this study appear to suggest that body language can help a family member or a support worker to understand when a person with SCAN:

- Is indicating discomfort or pain<sup>280</sup>.
- Requires a critical need to be met for example being fed or needing help to use the toilet<sup>281</sup>.
- Is indicating their emotional state<sup>282</sup>.
- Is indicating changes in their condition for example, the start of an epileptic fit<sup>283</sup>.
- To supplement oral or written communication<sup>284</sup>.

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<sup>278</sup> "...designers are mostly guided by what is visual...when you prompt designers to get in to interviews and questionnaires and to understand those... they will be like 'oh this is just such a waste of time.'" (a control group participant)

<sup>279</sup> "...when someone asks a lot of questions... with a lot of different words in it ...I get a bit lost sometimes as ...I'll just get stuck on a certain word and start thinking about that." (a control group participant)

<sup>280</sup> "...because he can't tell me he's uncomfortable, all he can sit there and do ooourgh...and I know it's not right." (a family member/support worker)

<sup>281</sup> "...even if he's due to go to the toilet...right I mean it may not come for 8 hours or 6 hours but he'll start like 'uuugh' 'uuugh'...it's like a little moan all the time." (a family member/support worker)

<sup>282</sup> "...he does laugh...so you know when he's happy." (a family member/support worker)

<sup>283</sup> "...if he's going into a fit because it will be a different sound." (a family member/support worker)

- To indicate a change in behaviour<sup>285</sup>.
- Indicating agreement or disagreement<sup>286</sup>.

However, it is reasonable to surmise that a close relationship with a person that has a disability is vital to understand their body language<sup>287</sup>.

### 2.30 Creativity and Innovation (6 participants)

Participants felt that in order to be creative, designers needed time to generate their own ideas. However, it was also felt that some designers lacked creativity, participants felt that both creativity of the mind and practical creativity were important<sup>288</sup>. It can be particularly important to be creative with those that have dementia<sup>289</sup>. Some SCAN users will need to have experience of situations, the implications of this are that designers will need to be creative in how they get their views or feedback. However, a participant stated “...a lot of designers are...artists... and...they want to design something that they can say well that was great...I done a great design here...but they forget ...that somebody’s gotta use that product...and...there’s a balance there...in an excellent design...and the user... so that’s where they seem to get it wrong sometime.” (a participant with a physical impairment. Therefore it is reasonable to surmise that designers need to balance creativity with usability.

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<sup>284</sup> “...body language and non-verbal messages can supplement and complement the oral message.” (Madhukar, 2010:63)

<sup>285</sup> “...by looking at Joe we know when his mood is changing.” (a family member/support worker)

<sup>286</sup> “...people that know a person well...are gonna be the best placed people to say that’s what they’ve just said or this is what their feelings are.” (a family member/support worker)

<sup>287</sup> “...through their body language and the way their presenting...they can offer information.” (a family member/support worker)

<sup>288</sup> “...be creative, think of ways around it.” (a family member/support worker)

<sup>289</sup> “...if the pictures are there ... it’s something visual and it will stay in the mind....whereas if you’re just talking ... like you say she’ll have a conversation but she’ll forget...” (a family member/support worker)

### 2.31 Patience (6 participants)

It was discussed that a designer needs to be patient when working with SCAN users<sup>290</sup>. It was felt that if you are patient and understanding the interaction will be positive.

### 2.32 Disability as a social construct (6 participants)

This is a construct that is created by society and is not concerned with physical impairments (Oliver, 1996:22). The implications of this are that designers need to understand the social nature of disability and that it is created by society<sup>291</sup>.

Given the above, designers need to understand that *“...defining people by their impairment is wrong.”* (a participant with a physical impairment) As stated by a participant *“...I can feel like I’m an outcaste...so it’s always like...a challenge ...to ...actually...do different things in everyday life.”* (a participant with a physical impairment) Furthermore, it was felt that designers *“...don’t...see the user at all...for example if you look at some car designers who are basically making beautiful lines on a car... they don’t see a user.”* (a control group participant) This could suggest that disabled people are more at risk of social exclusion, isolation and associated health difficulties such as depression; this was the experience of a participant who states that *“...it’s kind of being...noticed and being wanted and because I wasn’t...it got me down.”* (a participant with a physical impairment)<sup>292</sup>

Additionally, the notion of attitude was discussed and it was felt that it is important for designers to be open-minded when working with those that have SCAN as this will help them to be aware of the differences between their expectations and reality.

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<sup>290</sup> *“...being able to make your point again and again ...so they might not be understood the first time, it might still not be understood the second time but that’s no reason to shout it the third time.”* (a family member/support worker)

<sup>291</sup> *“...which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream.”* (Oliver *op.cit.*)

<sup>292</sup> *“...23% of disabled people reported being lonely on a typical day and 6% have no friends.”* (The results of a survey by Sense, 2015:5)

The study found some evidence of negative attitudes towards disabled people, these included:

- **Being patronising**

However, it was suggested by a participant that there is sometimes no malicious intent, rather it is deep seated within their social upbringing and life which can cause people to behave in a manner that is offensive without thinking.

- **Negative attitudes**

There was evidence of health and social care professionals having unhelpful attitudes thus leading to family members not following their instructions; this demonstrates that these attitudes can cause harm. Furthermore, there was evidence that it dissuaded people from taking part in research processes.

- **Seeing is believing**

People will have a more sympathetic attitude if the disability is visible.



## 2.33 Human support and assistive technology (6 participants)

Those who seek the views of SCAN users should be aware that they may need the support of some assistive technology:

- A scribe<sup>293</sup>
- A reader<sup>294</sup>
- Communication support such as interpreting or reiterating what was said.
- The provision of a support worker.
- Use of equipment such as a hearing aid.

This is not an exhaustive list.

Despite the above, it was felt that it may not always be appropriate for someone who knows the participant to perform this role. This is because there may be a conflict of interest. A solution to this would be to provide impartial support.

In relation to equipment design, it was highlighted that sometimes if it is not designed appropriately and does not meet users' needs, it can do more harm than good<sup>295</sup>.

### 2.33.1 Use of support staff who do not speak fluent English or the user's first language

There was evidence of a common difficulty faced by SCAN users and their family members; this is support staff who do not speak the user's language fluently. This can often cause difficulties and frustrations<sup>296</sup>. Health and social care professionals also highlighted this challenge<sup>297</sup>.

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<sup>293</sup> Somebody who writes down a person's verbal answers to written questions (adapted from Coventry University, 2015).

<sup>294</sup> Someone who reads aloud accurately what is written, in for example, a questionnaire (adapted from Coventry University *ibid.*)

<sup>295</sup> "...they just send the commode out...not taking into account height of Mum ... who is quite tiny, so when she's on the commode she can't get herself off the commode." (a family member/support worker)

<sup>296</sup> "...I think I asked him six times if he could repeat himself..." (a family member/support worker)

<sup>297</sup> "...they're having to employ staff who do not have English as their first language." (a health and social professional)

This is a common difficulty within the care sector due to the lack of incentives (for example, money and training). BBC news reported that an informal carer had experienced a similar problem to a participant<sup>298</sup>.

## 2.34 People skills (5 participants)

Below is a diagram that outlines what participants considered to be essential people skills:



**Figure 6.6 outlines people skills from a user's perspective**

### 2.34.1 Why are these skills important?

Participants felt it was important for designers to engage because they need to be able to communicate effectively with the person they're interviewing. Being sympathetic and friendly was important because it can be easy to upset people if they're not sure what is required of them. Also, if mutual respect is shown the interaction is likely to be of maximum benefit for both parties. Many of these skills are inter-linked<sup>299</sup>.

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<sup>298</sup> "I found some of them exceptionally difficult to understand, which meant my brother, in his condition, was never going to understand them and the reaction from him was to hide or get slightly violent." (Day, 2014)

<sup>299</sup> To be engaging and friendly you will need to be an effective communicator.

Participants felt that people skills, such as being respectful, friendly, and polite, were important for designers to have and develop. This links closely with professional boundaries and illustrates the importance of designers having the soft skills such as communication.

## 2.35 Perceptions of disability (5 participants)

The study identified two broad categories:

- 1) How the disabled person perceives themselves.
- 2) How they were perceived by other people.

The key findings are reported below: -

- Disability is normal for SCAN users<sup>300</sup>.
- The diverse nature of disability<sup>301</sup>.
- Self-consciousness<sup>302</sup>.
- Not liking the use or feel of disability equipment<sup>303</sup>.
- Sometimes having a disability is advantageous<sup>304</sup>.
- People perceive disabled people as different<sup>305</sup>.
- It can be difficult to accept disability<sup>306</sup>.

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<sup>300</sup> “...when he’s asked questions about his disability, he finds it hard to answer it...he just sees it as... it’s normal life for him.” (a family member/support worker)

<sup>301</sup> “...disability is huge...it’s so diverse.” (a family member/support worker)

<sup>302</sup> “...if I’m ever having my hair cut ... I will keep it long to cover that hearing aid.” (a hearing impaired participant)

<sup>303</sup> “...I don’t like the feel of it...I don’t want to fuff...don’t like the look of it either.” (a hearing impaired participant)

<sup>304</sup> “...there are ... advantages ...in not using [a hearing aid] sometimes in that it makes life a lot quieter and you can concentrate more.” (a hearing impaired participant)

<sup>305</sup> “...anywhere I go...I...get a look...it’s like I’m different.” (a participant with a physical impairment)

<sup>306</sup> “...it’s difficult to accept first yourself...that you have a problem.” (a participant with a physical impairment)

## 2.36 How does a “user” perceive themselves? (5 participants)

There are many different terms used to describe people that take part in design or evaluation processes<sup>307</sup>.

Some participants felt this depended on:

- The context
- The intended audience of the research.

Participants acknowledged that perceptions of oneself can be a complex issue and care should be taken not to cause offence. Some felt that if they have prior knowledge of the product and experience then they should be referred to as an ‘expert user’. Furthermore, some felt the term ‘user’ was objectifying them and they had a preference for the term ‘participant’. There was also a preference for being referred to by their first name because this indicated a human touch.

Given that language is such a complex issue it may be sensible for designers to check what participants like to be referred to as before work commences thus avoiding the potential use of inappropriate language.

## 2.37 Difficulty when conducting research with SCAN users (5 participants)

### 2.37.1 General difficulties

- Recruiting participants-the population of recruitable participants is smaller by virtue of them having SCAN.
- Reading difficulties-this will most likely be an issue if the research has a high proportion of written materials.
- Having too much information.
- Older people may lack confidence.

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<sup>307</sup> ‘user’, ‘participant’, ‘expert user’

### 2.37.2 Difficulties for hearing impaired participants

The study found the following challenges:

- Difficulty conducting a telephone interview.
- Face-to-face interviews may be difficult if they are conducted in public locations which are noisy. However, this may be overcome by the use of a hearing aid.
- Low tone of voice/people speaking quietly. This may frustrate participants as they are likely to miss parts of a question or discussion.
- Lip reading can be difficult if you are not directly looking at somebody therefore configure the room to facilitate this.
- Hearing aids can be uncomfortable to wear.
- People will sometimes speak loudly because the person has a hearing impairment.
- Ageing into deafness.

### 2.38 Users' experience of designers (4 participants)

Users discussed their experiences of working with designers “[a]...young chap thought he knew it all but couldn't get his point across...so from my experience ... designers can be very blinkered.” (a visually impaired participant) In order to prevent this designers' need to be exposed to those with different abilities.

Additionally, some designers either do not understand or are unwilling to accept that there are people with different abilities. The participant gives an example of car designers; she states that in her experience designers cannot think ‘outside the box’. Additionally, she feels that designers perceive design as something for young people. Furthermore, it was discussed that “...design involves having a personal style, a personal taste and even doing things a certain way ...” (a control group participant) this can create conflict.

Lastly, it was felt that designers need to provide more formal invitations to enable users to influence design. In addition, it was also felt that the design community can be quite harsh when providing feedback on products designed by its members.

## 2.39 Humour (4 participants)

Some participants used humour to help them cope with either their disabilities or the implications. This is particularly true in the case of a participant<sup>308</sup>.

There was evidence of:

- Black humour<sup>309</sup>.
- Participants finding the way society describes disabled people humorous<sup>310</sup>, see section 'use of inappropriate language for more information'. A possible explanation for the use of black humour in this context could be *"...we feel safe and we don't have [to] prove and explain things...cus we get it and most of the time it's light hearted."* (a participant with a physical impairment)

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<sup>308</sup> *"...I'm one lens of a guide dog...I will use humour to cover up my...problems."* (a visually impaired participant)

<sup>309</sup> *"...a humorous way of looking at or treating something that is serious or sad."* (Cambridge Dictionaries Online, 2015)

<sup>310</sup> *"...management had said...they think you're a different species just cus you're in a wheelchair."* (a participant with a physical impairment)

## 2.40 People that want to understand the views of SCAN users, need passion, drive and to enjoy what they do (4 participants)

It was felt that those who work with SCAN users “...need to want to work ...for people ... with [a] disability.” (a family member/support worker) and have passion<sup>311</sup>, drive and a love for what they do<sup>312</sup>. This may be because as a participant indicated support workers that work with her son must be able to give something to enrich his life.<sup>313</sup> To enable them to do this effectively and successfully<sup>314,315</sup> it is reasonable to surmise they must have passion<sup>316</sup>.

Not having passion in any job may lead to a person not completing tasks to the best of their ability. However when working with people that have a disability it can often be challenging<sup>317</sup>, low-paid<sup>318</sup>, under-resourced<sup>319</sup> and requiring working unsocialable hours.<sup>320</sup> Therefore if you do not have passion<sup>321</sup>, it can become very difficult to complete work to a standard that meets both the needs and expectations of users.

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<sup>311</sup> “...an emotion that comes from within you. It is your enthusiasm, your zeal, your drive and your motivation.” (Grier, 2017)

<sup>312</sup> “...I love the work that I do...it's always interesting.” (a health and social care professional)

<sup>313</sup> “I can say to them it's not the money... you want to work with him because you really feel what you're doing is really interesting...I keep saying to people what can you give Joe...what are you bringing to the table?” (a family member/support worker)

<sup>314</sup> “...if you have passion for what you do you will be more successful...” (McConnell *op.cit.*)

<sup>315</sup> “People ...work harder and enjoy work more when they have something to believe in.” (McConnell *ibid.* pp 49)

<sup>316</sup> “We need support workers who are positive, committed and passionate about changing the lives of people with a learning disability.” (Mencap, n.d.)

<sup>317</sup> “Careers in social care are often challenging; you'll need the patience to deal with frustrating situations and the resilience to bounce back from setbacks.” (Smith, 2016)

<sup>318</sup> “The care industry, which employs about 1.4 million people in UK, has long been associated with low pay.” (Merrill, 2016)

<sup>319</sup> “Working conditions are often under-resourced and heavy caseloads are common.” (Prospects,2015)

<sup>320</sup> “...to work unsociable hours, such as evenings and weekends.” (Smith *op.cit.*)

<sup>321</sup> “Matching belief and passion and liking your job is a key to being successful.” (McConnell, 2008:49)

## 2.41 The need for thinking ‘outside the box’ (3 participants)

Participants highlighted the fact that “...*one size doesn’t fit all.*” (a family member/support worker) therefore designers may need to “...*think outside the box.*” (a health and social care professional) this is because when you work with SCAN users they have specialist requirements. The implications of this are that a product or service may need to be person-centred (Royal College of Nursing, 2015).

It is unclear why designers may not choose to do this; it could be that they make assumptions about SCAN users or that they simply do not wish to cause offense with radical design solutions. Equally, it could be that designers expect SCAN users to adapt to the way something has been designed rather than designing something based on user needs. A key claim of this research is that assumptions should not be made therefore if the making of assumptions is a reason for not thinking outside the box, this needs to change. Additionally, if designers expect users, especially those with disabilities to adapt, to accommodate what has been designed this may not be possible and therefore the product will not be suitable for these users. Lastly, if designers are worried about offending SCAN users, it should be noted that in the researcher’s experience, often, such users are only too happy to provide input when asked. This conclusion is given credit by the work of Moody (*op.cit.*)(a).

## 2.42 Objectivity, integrity and impartiality (3 participants)

Participants felt that objectivity was important and that designers should not “...*disregard what you have found and...hand-pick...those bits...to reinforce your view.*” (a control group participant) Additionally, it was also felt that designers should have integrity. Furthermore, the notion of not being judgemental was discussed. Lastly, it was also highlighted that designers should strive to be impartial, act with integrity<sup>322</sup> and remain objective<sup>323</sup>.

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<sup>322</sup> Impartiality ensures that what you conclude is fair and without bias.

<sup>323</sup> Objectivity requires you to look at the evidence that is free from influence of outside factors such as cost.



## 2.43 Examples of good practice (3 participants)

It was encouraging to note that participants shared some examples of good practice:

- Accommodation of access needs, for example, sitting in appropriate positions for hearing impaired participants.
- Designers acting on user feedback.
- Consultation at the early stage of a design or evaluation process.

It should be noted, however, that these examples of good practice were only reported by three participants out of twenty-two therefore the researcher does not want to speculate as to whether good practice is the exception rather than the rule.

## 2.44 Ideas for design projects (3 participants)

Participants suggested some project ideas for designers, these were:

- Re-design a hearing aid to make it more comfortable<sup>324</sup>.
- Re-design a wing-mirror so that it can be easily adjusted<sup>325</sup>.
- A device for keeping in contact with elderly relatives when their carer is away<sup>326</sup>.
- Re-design of a hospital-style bed table so that they can be easily pushed out of position<sup>327</sup>.

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<sup>324</sup> "...if I had one which was more comfortable I would probably wear it more." (a hearing impaired participant)

<sup>325</sup> "...it's difficult to turn far enough...to check so I have to adjust my mirror ...and my neck in order to take the manoeuvre and... that's very painful... so if they could do something about that, that would really be a big help." (a participant with a physical impairment)

<sup>326</sup> "...so it would be nice if there was...somewhere where you could log on and...keep my eye on Mum." (a family member/support worker)

The research did not specifically ask for these ideas, they were freely given in response to questioning and are repeated here as findings of this research. They also may provide ideas for future projects in relation to design and disability.

## 2.45 Teamwork (2 participants)

It was felt that design requires teamwork by its nature<sup>328,329</sup>.

Furthermore, participants felt that it was important for every member of the team to be respected and to have their views taken into account. It was however highlighted that one of the difficulties of working in teams with designers is that they have their own ideas so therefore it may be difficult to reach a consensus<sup>330, 331</sup>.

Team dynamics were discussed in terms of mutual respect<sup>332</sup>, understanding and power<sup>333</sup>.

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<sup>327</sup> "...it's on one side of the bed...not on the other and it's like Mum can only use...a certain side of her body...so it's things like is... the table designed to fit on both sides...of the bed." (a family member/support worker)

<sup>328</sup> "...it's not about the designer not about the engineer...they have to work in teams." (a control group participant)

<sup>329</sup> "Design is most often a social activity when carried out professionally; it involves teams of designers, specialist consultants and of course clients and other interested parties." (Lawson, 2012)

<sup>330</sup> "...it's tough to manage and to tell them what to do because they have their own ideas." (a control group participant)

<sup>331</sup> "Diverse teams, with different "design upbringings," can make collaboration difficult. Designers tend to be emotionally attached to their own work, their own ideas." (Ene, 2012)

<sup>332</sup> Researcher: "...and understanding and respecting members of the team?" Control group participant "Respecting... at a certain ...level."

<sup>333</sup> "...somebody's got power in that meeting." (a health and social care professional)

## 2.46 Analytical Skills (1 participant)

It was felt that it was important for designers to develop their analytical skills<sup>334,335,336</sup>. Developing these skills will assist designers to produce designs that better meet the needs of users because they will have skills that enable them to evaluate information effectively thus helping them to understand what is required.

In turn, this will improve their attention to detail, their ability to persevere and maintain their focus. Developing these skills may be the difference between a good and a great designer<sup>337</sup>.

## 2.47 Peer review (1 participant)

The importance of peer review<sup>338</sup> was discussed<sup>339</sup>, it was felt that this was a useful source of feedback for designers, especially where these are accredited or attached to a competition as it may help to market the product or increase consumer confidence.

Peer review also has the following advantages:

- Can promote quality and productivity in design processes.
- The data collected can be used to correct defects in a design process.
- Can assist in evaluating and improving the product and service development process (adapted from Garousi, 2011:1).

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<sup>334</sup> Analytical skills “are the thought processes required to evaluate information effectively. Examining a problem thoroughly requires attention to detail, perseverance and maintaining your focus.”(University of Manchester, n.d.)

<sup>335</sup> “Designers ... need to have strong analytical skills.” (Barton and McGregor, 2015:154)

<sup>336</sup> “I suppose analytical skills being focused.” (a family member/support worker)

<sup>337</sup> “Great designers suspend their creativity minds for a bit and use their analytical skills during briefs and design critiques.” (Wallace, 2009:22)

<sup>338</sup> “The review of work [or] products performed by peers during the development of the work [or] products.” (adapted from Capability Maturity Model Integration (CMMI) CMMI-DEV v1.2 cited in Kelemen, 2013:86)

<sup>339</sup> “... if you had some sort of peer review mechanism... you [could] consult about certain issues.” (adapted from a control group participant)

To ensure the peer review process is conducted properly it should be:

- Independent, unbiased and fair.
- Be conducted by experts within the subject specialism.
- Provide justification for the decision taken (adapted from Durling, 2013).

This could be particularly useful when designing products or services for SCAN participants because often SCAN users are experts in their own conditions<sup>340</sup> and can provide valuable feedback.

However, caution will need to be exercised to ensure that the peer reviewing panel has the appropriate balance of experts with a wide range of experiences and/or disabilities<sup>341</sup>.

### 3. Superordinate and subordinate themes

The raw results above are ranked in order of the numbers of interviewees stating that particular finding. It was suggested that in order to better understand the main issues involved in advising designers, these results might be meaningfully regrouped into superordinate and subordinate themes. Criteria for selection were established.

A detailed rationale for this further analysis is set out below.

#### 3.1 Rationale for superordinate and subordinate themes

In total, the analysis identified forty themes. These were subsequently categorised into a smaller number of superordinate themes under which all other themes could be subordinated.

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<sup>340</sup> "Disabled people are experts in their own lives." (Roulstone, 2014)

<sup>341</sup> "Peer reviewers should be selected based on their expertise and ability to provide high quality, constructive, and fair reviews." (World Association of Medical Editors (WAME), 2015)

After careful consideration, four superordinate themes were identified:

- Methods
- Language
- Professionalism
- The reality of life lived as a SCAN user

The remaining subordinate themes were then grouped under one of the superordinate themes. The subordinate themes were identified as being related to the superordinate themes by the following method:

## **Methods**

Definition: a definition of method is *“A particular procedure for accomplishing or approaching something, especially a systematic or established one.”* (Oxford Dictionaries, 2018a)

Subordinate themes: there were three subordinate themes in this category.

The first subordinate theme relates to insights that were expressed by participants in relation to methods used in design or evaluation processes, essentially these were the procedures used in design and evaluation processes to accomplish given tasks.

The second subordinate theme in this category was human support and assistive technology. This theme examined how tasks may be accomplished via the use of either of both of these therefore it can be classified as a method for completing tasks.

The final theme examined the difficulties current methods (ways of doing things) might present when conducting research with SCAN users.

## Language

Definition: one definition of language is “*A system of communication used by a particular country or community.*” (Oxford Dictionaries, 2018b) This defines language as a system of communication. However, it is recognised that language is a complex issue with many different aspects.

Subordinate themes: each of the subordinate themes under language describes various aspects of the system utilised by designers and users who took part in this study, for example the use of body language, inappropriate language and technical language or jargon.

## Professionalism

Definition: professionalism can be defined as “*The competence or skill expected of a professional.*” (Oxford Dictionaries, 2018c)

Subordinate themes: the subordinate themes in this category are essentially what both designers and users felt was needed from designers in order to conduct themselves in a professional manner. For example, they would need to think outside the box, not make incorrect assumptions, act ethically with information they are given whilst maintaining confidentiality, be flexible with participants, maintain objectivity, integrity and impartiality. These are examples of some of the skills required by professional and competent designers.

All of the subordinate themes are in some way related to professionalism, for example, humour can be used appropriately or inappropriately.

## **Life lived as a SCAN user**

Definition: a SCAN user is defined as an individual that has “...*specific, critical needs (in relation to them, and these needs have to be met in order to maintain their quality of life, health, safety and wellbeing) but are additional to that of common everyday critical needs.*” Because of the nature of SCAN users they have additional barriers and complexities in their life.

Subordinate themes: this outlines and groups together some themes relating directly to life lived as a SCAN user found in this study. For example, SCAN users may perceive themselves as being different, and they may have varied and different experiences of working with designers.

## 4. Advice

A wide range of advice was given by participants ranging from communicating with all stakeholders during a design or evaluation process to the less obvious<sup>342</sup>. The most frequent advice given was that designers should not make assumptions based on what they first see. For convenience, only advice given by four or more participants is reported here. For a full breakdown of advice see Appendix A.

Advice	Number of participants
Communicate in a meaningful way with all stakeholders throughout a design project <sup>343</sup> .	6
Talk to the people you are designing for and not just those you perceive you are designing for. If you do not talk to people, there is a risk of developing products that will not meet their needs <sup>344</sup> .	5
Think about /take into account what you've been told <sup>345</sup> .	4

**Table 6.7 Advice relating to communication between users and designers**

<sup>342</sup> Consider what you wear when you work with users that communicate using sign language.

<sup>343</sup> "I think just to reiterate communication is the key." (Brenda-a visually impaired participant).

<sup>344</sup> "The main advice is to actually talk to their audience." (Brenda-a visually impaired participant)

<sup>345</sup> "Listen to the user." (Tony-a control group participant)



Advice	Number of participants
Do not make assumptions. Try to go into every project with an open mind. Assumptions are often incorrect and sometimes can be dangerous. If you do have to make assumptions try to ensure that they're based on evidence <sup>346</sup> .	9
Be aware of the sorts of constraints the users you are working with may face <sup>347</sup> . An understanding of this will help you design products and services that more effectively meet users' needs <sup>348</sup> .	6
Remain professional but be aware of the need to build a relationship that allows people to work with you, for example, they need to be prepared to talk to you and trust you. This will undoubtedly take time and cannot be rushed <sup>349</sup> .	5
Adapt to the needs of users <sup>350</sup> , for example, choose research venues that are physically accessible if you are going to be working with those that have physical impairments.	5
If your participants have mobility difficulties and you intend to conduct face-to-face research ensure that the venue you use meets their needs, for example, if a user cannot climb stairs, ensure that the room is on the ground floor or has lift access <sup>351</sup> .	4
When working with users, remember everyone has value and something to contribute no matter how small <sup>352</sup> .	4

**Table 6.8 Advice relating to designers when working with users**

<sup>346</sup> "...don't make assumptions, be non-judgemental." (Mary-a family member/support worker)

<sup>347</sup> 1) Lack of wealth, 2) Reliant on state benefits, 3) Complex health conditions.

<sup>348</sup> "...when I first got DLA (disability living allowance) it was a 3 year or a 5 year one ...and then I got put on indefinite ...[award]." (Erin-a visually impaired participant)

<sup>349</sup> "I think there's something about...establishing rapport while being a credible professional." (Lucy-a control group participant)

<sup>350</sup> "Adapting, tailoring things... because somebody can't get into this room for this meeting." (Diane-a family member/support worker)

<sup>351</sup> "...another thing as well is it's gotta be accessible..." (Tony-a control group participant)

<sup>352</sup> "...it's just an acknowledgement that they valued your opinion." (Julie-a visually impaired participant)

Advice	Number of participants
Ask your users what format they prefer their written materials to be presented in, for example, large print, easy read, audio <sup>353</sup> .	4

**Table 6.9 Advice on doing research with the participant**

Advice	Number of participants
It is important to have some foundation knowledge of how various disabilities will affect the users for which you are designing <sup>354</sup> .	5
Continue professional development by keeping your skills and knowledge up-to-date <sup>355</sup> .	5

**Table 6.10 Advice on using relevant standards/guidance**

Advice	Number of participants
Be friendly, respectful, polite and approachable <sup>356</sup> .	6

**Table 6.11 Advice given by users relating to qualities of a designer**

<sup>353</sup> "...everything's gotta be produced in...accessible formats." (Tony-a control group participant)

<sup>354</sup> "Everybody's different... somebody else with autism will be completely different...so I think ...understand your cliental." (Mary-a family member/support worker)

<sup>355</sup> "...researchers need to and designers need to definitely...have ...training." (Linda-a family member/support worker)

<sup>356</sup> "...respect...you have to show...and [be] friendly." (June-a family member/support worker)

## 5. Summary and discussion

Twenty-two participants were interviewed either over the telephone or face-to-face. These were audio and/or video recorded and then transcribed. Transcripts were analysed using content analysis. As a result of this analysis, themes were identified which took the form of a detailed commentary with links to supporting literature.

The participants were drawn from the following groups:

- SCAN users with a physical impairment (5)
- Family member or support workers (5)
- Control group (users without a disability) (5)
- Health and Social care professionals (4)
- SCAN users with a visual impairment (2)
- SCAN users with a hearing impairment (1)

It is clear that the results of the study are both interesting and would be of benefit to both designers that wanted to work with SCAN users and designers generally.

The results suggest the following:

- The making of assumptions is not desirable as they can often be incorrect and sometimes dangerous. However, this may not be intentional, for example, the researcher made an assumption during an interview with a colour-blind participant having used red and green to denote headings; he was embarrassed to find out that by doing this he may have inadvertently made the written research materials inaccessible to those who are red /green colour blind<sup>357</sup>.

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<sup>357</sup> People who have this condition are "...collectively known as red-green colour blind and they generally have difficulty distinguishing between reds, greens, browns and oranges." (Colour Blind Awareness, n.d.)

To prevent assumptions being made, designers should ask users what they require in terms of assistance. Additionally, the results would appear to suggest that negative attitudes are harmful but are rare in today's society.

However “...*there are barriers...[faced by] disabled people and a lot of [the] barriers are to do with attitudes..., practices...[and] procedures that are manmade so...if they're manmade you can undo them.*” (a participant with a physical impairment)

The importance of effective two-way communication was highlighted, it was felt important to allow users to communicate their input in a way that is accessible to them, for example, giving sufficient space in questionnaires for participants to respond. This may require use of a variety of communication styles, for example, visual aids; this will help gain a clear understanding of users and their views. It was also felt that designers should communicate in a professional, friendly, polite, approachable, honest, respectful and supportive manner which puts people at ease.

Additionally, care should be taken to ensure that all stakeholders in the design and evaluation process are communicated with. Communication incorporates many aspects apart from spoken language. This includes body language, listening and non-verbal clues. Designers must be proficient in all aspects of communication. Lastly, it was felt that some understanding of body language may be beneficial.

- Language was seen as a complex issue. It was highlighted that often it can be contextually and culturally specific and that participants should be asked how they like to be referred to when a designer first starts working with them. This will minimise any difficult situations and the possibility of any unintended offence being caused. Technical language such as acronyms should be avoided where possible<sup>358</sup>. It was also felt that designers should be mindful of the body language they use.
- People skills were highlighted as essential, especially the ability to empathise with and adapt to the needs of users, for example, conducting research at a time convenient for the participant. It may also be advisable for designers to gain some firsthand experience in what they are designing, for example, spending some time in a wheelchair. However, this should not be substituted for first-hand knowledge from users, as often they are experts in their own condition. This means that users should be treated as equals and should be at the forefront of the designers thinking throughout the process therefore early engagement with users is crucial. It should also be remembered that there are many different types of users for a product, for example, primary and secondary users (in the case of a wheelchair, the primary user would be the person sitting in the chair and the secondary user could be a carer).

Furthermore, it was also highlighted that power dynamics are complex. In some circumstances, it is those responsible for the SCAN user who exercise such power. When working with users, designers will need to consider this, as this will enable them to better empower users to share their own views and be mindful of the unequal power that exists in some situations. It is worth considering who holds the real power if you design a mobility aid? It may be that services are looking for equipment to meet certain specifications whereas users will be looking for equipment to meet their needs. The final product may be a compromise.

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<sup>358</sup> If these are used they should be explained.

- It was felt that designers could benefit from improved education in terms of disabilities and the constraints these may place on users, for example, if you are required to conduct research with those who have mobility difficulties, you will need to find an accessible venue. Additionally it was also felt that it was important for designers to keep their skills and knowledge up-to-date and refer to appropriate standards, guidance, experts, colleagues or other resources when required. Reflective practice was seen as beneficial especially where mistakes had been made.

It was also felt that it would be important for a designer to gain experience working with a variety of different user groups as this may help them understand different personalities and the pressures faced by different users.

- Creativity was seen as important both allowing the designer to be creative in the solutions they develop and the way they interact with different users. It was also seen as beneficial to incorporate as many different views as possible and where appropriate give users a choice.
- The importance of having clear, easily understandable and accessible research materials, for example, questionnaires and interviews were also highlighted. It was felt that such materials should be piloted to ensure they offer maximum value and are appropriate<sup>359</sup>. Additionally, questions should be clear, straightforward and to the point. They should not lead the participant or be negative. Furthermore, questionnaires, where detailed responses are needed, should be avoided. Multiple choice questions may be useful for gathering statistical information. However, a mixed-method approach was considered to be beneficial when working with SCAN users. The benefits of observing people in their natural environment were also discussed.

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<sup>359</sup> Good research is made up of objective and subjective components, the objective will help you gather statistics and the subjective will help you explain trends and users' views.

Additionally, it was highlighted that focus groups and interviews are particularly suitable for gathering in-depth information. These methods will also allow for clarification of what is being asked/said. Despite these advantages you will need to consider group dynamics to get the most from this method.

- Objectivity was also seen as important. It was felt that designers do have an interest in research methods and knowledge of them. However, data is sometimes gathered by a person(s) other than a designer therefore the designer will have no control over the methods used or how those methods are employed. Additionally, it was felt that designers prefer methods that involve direct interaction with users such as focus groups and interviews but questionnaires and other similar methods can make it difficult for designers to understand requirements. This could be due to the fact that the responses given by respondents to questionnaires can sometimes be difficult to interpret.

One of the best reasons for completing this work is inaccessible research methods “...lead to a lack of understanding...[about] the needs, wants and desires of disabled people.” (a participant with physical impairment) which then may lead to products that fail to meet their needs and ultimately fail to make profit.

Many of the conclusions, for example, the importance of feedback are widely discussed within the literature. It is hoped that this research will bring both the pertinent literature together and the insights of designers and users so that the guidelines created can assist designers in making better methodological choices when working with SCAN users.

However, there is not a central repository for this knowledge. This research hopes to go some way to closing this gap and does not claim to be the definitive resource for designers when working with SCAN users but rather a starting point on which the designer can base further exploration of the issues that are important to consider.

As a means to better understand the main issues involved in advising designers, an additional analysis was undertaken to regroup the results of interviews into superordinate and subordinate themes. In order to undertake this further analysis, criteria for selection were established. Four superordinate themes were developed, with all other themes being systematically subordinated to these. The intention was to provide indicative categories of superordinate and subordinate themes that might influence the development of practical guidelines in the future.

Guidelines arising from SCAN users' commentaries are contained in Appendix A.



## Chapter 7: Conclusion

### 1. Introduction

The purpose of this final chapter is to:

- Summarise the main objectives and how these have been met.
- Expressly state the contributions to knowledge.
- Summarise the research.
- Highlight key findings and discuss limitations.
- Outline possible future work.
- Offer some general conclusions.

### 2. Aims and objectives

The overarching aim of this research has been to produce guidelines to assist designers in the selection of the most appropriate methods to support user-centred design at all stages of the process (as defined by ISO 9241-210:2010 (E)) when working with participants with SCAN, particularly to aid in:

- 1) understanding and specifying the context of use i.e. use appropriate methods that allow users to present, and the designer to understand the context of use;
- 2) specifying the user requirements i.e. use appropriate methods that allow the user to specify their requirements and the designer to understand them;
- 3) producing design solutions to meet user requirements i.e. use a method that enables both the user (where appropriate) and designer to create solutions to meet defined needs and, where possible, to evaluate the design against users' requirements in a manner that is accessible to them.

The specific means to achieve those aims included the following objectives:

- 1) To investigate how SCAN users (including their carers) and other user groups are treated as part of design and evaluation processes.
- 2) To identify key themes and recommendations for designers that will form the basis of guidelines to assist in making reasoned methodological choices when working with SCAN participants, their carers and other user groups.
- 3) To produce guidelines that are based on direct evidence from users and that provide clear guidance for designers when working with SCAN users.

### 3. Summary of the research

A comprehensive and systematic literature review was undertaken (Chapter 2). The findings of the review indicated that the literature concerning methodological choices when working with SCAN users was relatively sparse. This was summarised as four key studies:

- Chandrashekar *et al.* (2006)
- Roberts and Fels (2005)
- Henderson *et al.* (1995)
- Dong *et al.* (2005)

Typical legislative frameworks were stated in the context of designers' responsibilities for ensuring that the needs of SCAN users are recognised. British Standard BS 7000-6 (2005) also states that:

*“Due consideration should be given to customers and end users at each stage of development, and care taken to employ the most appropriate methods, for example, written questionnaires are not easily accessible to those with visual or cognitive impairments.”*

Examples of different categories of research methods suitable for informing the design and evaluation process were highlighted, and a detailed examination is reported of twenty three existing methods available to designers in eliciting knowledge from SCAN users.

Following the literature review, two stages of primary research were undertaken.

Stage 1 used focus groups (and Skype conversations for those unable to attend) which examined issues related to the way in which designers worked with SCAN and non-SCAN users.

Stage 2 used one-to-one, face-to-face or telephone interviews to understand the experiences of both SCAN, non-SCAN and other users (such as healthcare professionals, informal carers and paid support workers) when taking part in research processes. The interviews explored the participants' experience of being involved in these processes and how designers interacted with them; they were also given the opportunity to provide advice to designers on how to improve their practice when working with SCAN users. This advice formed the basis of the guidelines produced. Once the interviews were conducted they were accurately transcribed and subjected to content analysis.

The findings were reported in chapter 6 and systematically linked to the relevant research literature. This direct advice from users and others formed the basis of the guidelines produced.

#### 4. Key findings

From both the literature and the primary research, the key findings that led to production of guidelines can be summarised as follows:

- 1) SCAN users need sufficient time in order to complete tasks or process information. This may be longer than that required by their able-bodied peers. In order to accommodate this, designers will need to be flexible, both in terms of the methods they use and practical considerations, for example, offering to conduct research at a participant's home.
- 2) Language is a complex issue that permeates all interaction between designers and SCAN users, for example the use of outdated or condescending language. Language in relation to disability can be an extremely complex issue that should be handled with care.
- 3) It is important for designers to undergo training and education that is user-centred. The outcome of this education should equip designers with the skills, knowledge and expertise required to produce designs that meet the needs of the widest possible population.
- 4) It is important for designers to maintain professionalism and have an understanding of professional boundaries in order to build relationships rooted in mutual respect and value. It was suggested that this could be achieved, by, for example, offering compensation that remunerates the participant for the time spent assisting with research.

- 5) It is vital that designers understand how to conduct ethically appropriate research that respects a participant's confidentiality and contributions.
- 6) The use of technical language was prevalent in research materials and processes.
- 7) It is vital that clear and appropriate communication with participants is established; this can take many different forms including verbal, written and body language.
- 8) Incorrect or inappropriate assumptions were made about participants; this led to feelings of frustration and anger.
- 9) It is important to obtain appropriate feedback as this provides a mechanism for assessing whether the product or service is meeting the identified needs of users.
- 10) There was a perceived lack of empathy from designers. This is possibly due to participants feeling that designers lacked understanding of the situations in which SCAN users may find themselves.
- 11) It is vital to use methods that enable an appropriate consultation to take place. In order for this to happen, an advocate may need to be used to help represent the views of users. However, this should be considered with the upmost care and caution. It was found that a major barrier to effective consultation is lack of time and resources.

- 12) SCAN users face many difficulties in everyday life and cuts to support can exacerbate these. As a result of this, SCAN users often develop strategies to help them. These can include avoiding difficult situations and having to be highly adaptive.

## 5. Contributions to knowledge

The research has met the objectives in the following ways:

- 1) Using the evidence gained from the interviews with SCAN and other users this research has established current working practices employed by designers.
- 2) It has identified key themes from the interviews with SCAN users which, where possible, have been systematically cross referenced with supporting literature, and developed into evidence-based quick reference guidelines (Chapter 6 and Appendix A) written in non-jargon English.
- 3) A comprehensive resource has been created (Chapter 2 and Appendices) in relation to research methods.

The findings of this work are supported both by anecdotal evidence obtained from informal sources and relevant academic literature.

## 6. Limitations of the work

It is acknowledged that this work has the following limitations:

- 1) It was difficult to recruit sufficient numbers of participants in all categories. It is therefore a small-scale study based on twenty two one-to-one interviews undertaken with SCAN and other users, and fifteen designers who took part in focus groups. However, the insights gathered were rich and enabled the researcher to meet the stated aim.
- 2) It proved impossible to recruit participants who had a learning disability despite the researcher's best endeavours. However, given the nature of learning disabilities this was not surprising, although it was disappointing.
- 3) It was initially intended to validate the guidelines to assess whether they were useful and relevant for designers. However, a conscious decision was taken to omit this stage of research. This allowed the researcher to conduct a comprehensive analysis of the rich data resulting from the interviews with SCAN participants. It also ensured that the needs of each participant were fully met.
- 4) There was one participant who said 'no' to many interview questions or refused to say anything of note.

## 7. Scope for future work

The research has been necessarily constrained by time, resources and the researcher's own abilities. There is therefore much scope for future work to build upon the findings. This may include validating the guidelines with an expert group of users and designers in order to test them in use and further refine them.

Practical work could be undertaken with designers to implement the guidelines in the design of a product or service.

Furthermore, interviews could be undertaken with those that have a learning disability; this would help add to our understanding of these users and improve the guidelines; this would be highly recommended but would however, require more time and may present issues, particularly around gaining informed consent for this user group. There may also be some methodological challenges, as users with learning difficulties may be disadvantaged in accessing standard research methods.



## 8. Concluding thoughts

Having reflected on the research, several points, both positive and negative became apparent. In summary, these are:

- 1) The researcher identifies as a disabled person and shares many of the personal experiences of participants in this study.
- 2) It is a matter for debate as to whether the researcher's clear identity as a disabled person provided comfort for the participants in this research therefore it is impossible to surmise whether this had any bearing on the sometimes intimate and difficult discussions held.
- 3) The interviews with SCAN users were conducted in order to give a voice to this under represented user group. However, in some cases the interviews had the unexpected benefit of being therapeutic for participants. As a result of this several participants were very emotional and appeared to have had an opportunity to express themselves in ways they had previously not been able to.
- 4) It quickly became apparent that the interviews with SCAN users provided rich data, therefore in retrospect the decision to thoroughly analyse the data gathered from interviews and link to supporting literature, at the expense of validating the resultant guidelines (as originally planned) provided a much greater understanding of the needs of SCAN users.

- 5) The researcher also learnt much from the experience, for example, he inadvertently gave information containing text that was red and green to a red-green colour blind participant. This was highly embarrassing given the aims of the research. However, it was a valuable learning experience and reinforced the need to be sensitive to the needs of all participants.
- 6) The open-ended interview technique employed and the role of disabled interviewer may provide an example of best practice for other researchers. This was because through this respectful approach, all participants spoke freely and also had an opportunity to remove anything from transcripts which they did not want recorded.
- 7) This research cannot claim to be the definitive resource for designers when designing for users that have SCAN. However, it is hoped that the findings will provide a deeper understanding of the needs of these users thus assisting designers to both understand and meet their needs in the designs they produce.

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