



# DESIGN4 HEALTH

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## Understanding the needs of users with disabilities when working with designers

Wesley David Scott<sup>1</sup>, David Durling<sup>1</sup>, Andree Woodcock<sup>1</sup> and Deana McDonagh<sup>2</sup>

<sup>1</sup>Coventry University, UK

<sup>2</sup>University of Illinois at Urbana Champaign, USA

### Abstract

*Although much attention has been given to the design of inclusive products for those with Specific, Critical, Additional Needs (SCAN), little attention has been given to the inclusivity of design research methods and the appropriateness of standard research techniques for this group. Failure to address the inclusivity of investigative techniques (from the manner of recruitment to the use of specific research instruments) may have negative consequences such as poor quality of participant experience, skewed samples, use of proxies, tokenism and failure to gain deep insight into a user's condition – leading to poor design outcomes.*

*This paper provides key findings from a pilot study conducted with SCAN users to develop recommendations and advice for designers. A total of 8 semi-structured interviews were conducted from which a series of 30 recurrent issues were found such as the use of language, flexibility and level of understanding of the whole person (i.e. not just the disability). The paper discusses the results and outlines some initial plans in relation to the content of guidelines for designers when working with SCAN users.*

**Keywords:** Specific Critical Additional Needs (SCAN), research methodology, guidelines, designers, disability, design and evaluation process

## Introduction

This paper relates to disability and design. It outlines key findings from a pilot study that examined users' perceptions of how they are treated as part of a design and evaluation process. There was a focus on the methods used to support these processes and whether these methods are accessible to users with Specific, Critical, Additional, Needs (SCAN). These are needs which have to be met in order to maintain quality of life, but are additional to those of everyday critical needs. An example of a SCAN is a person, needing assistance so that they can eat.

## Aims and objectives

The primary aim was 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 process when working with participants with SCAN, particularly to assist in:

- understanding and specifying the context of use - to use appropriate methods that allow users to communicate their wishes and the designer to understand the context of use
- specifying the user requirements - to use appropriate methods that allow users to specify their requirements and the designer to understand what is being specified
- producing design solutions to meet user requirements - to use an appropriate method that enables users (where appropriate) and designers to create solutions to meet agreed needs
- evaluating the designs against requirements - to use an appropriate method that enables users to evaluate designs against their requirements in a manner that is accessible to them.

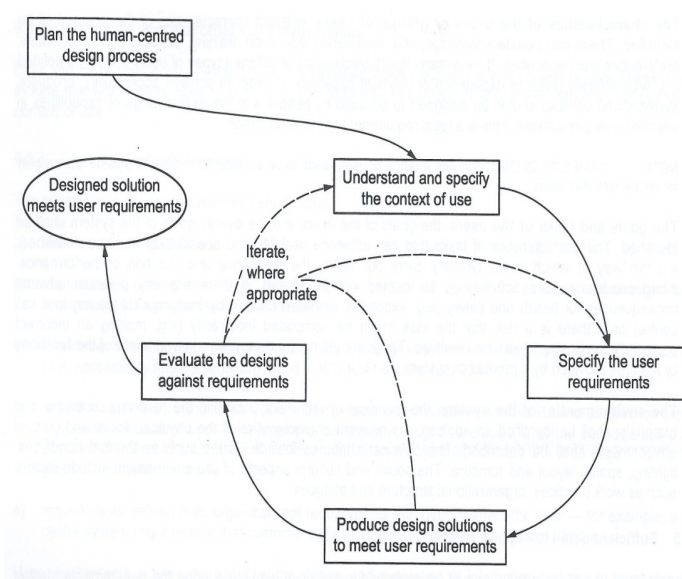


Figure 1: Shows the interdependence of human-centred design activities (ISO 9241-210:2010 (E))

The objectives of this pilot study were to:

- Establish how users with SCAN are treated as part of the design and evaluation process.
- 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.
- Determine optimal ways of working with different groups of SCAN users to develop appropriate research instruments.

## Methodology

The sample of users consisted of an opportunistic sample of friends and acquaintances of the researcher and snowball sampling. Four participants had multiple disabilities, for example both sight and hearing impairments.

### Data Collection

Nine semi-structured interviews were conducted (eight face-to-face and one via telephone). This approach, as stated by Robson (2002:279), allows for informal delivery thus accommodating varying requirements of the user group, for example rest breaks between questions. All research materials were given to participants in advance of the interview. This enabled them to familiarise themselves and provide written feedback if they wished.

The interviews were conducted in a usability laboratory at Coventry University, equipped with a one way mirror (see figures 2 and 3) that enabled recording of sessions. Participants were given an option of audio or video recording. A note-taker made notes for analysis purposes. Sessions lasted between an hour and 90 minutes, depending on participants' needs.

The researcher asked the questions as set out in the relevant interview schedule. Participants were encouraged to give free responses to questions, with prompting only being used to either clarify or stimulate discussion. If required, the participant's support worker was present.



Figures 2 and 3: Layout of Usability Lab for interviews



Figure 4: Interview taking place

## Data Analysis

Data were analysed using a thematic analysis, described by Braun and Clarke (2006:6); Boyatzis (1998) as

“...1998) as larke (2006:6);d 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...”

Furthermore, according to Aronson (1994) it allowed

“urthermore, according to Aronson rge as meaningful themes in the (data). me

Thematic analysis enabled the researcher to immerse himself in the data and enhance his understanding. Data were placed into themes based on the question asked or the response given. Data were then read, and for each single item a theme was attached, for example provision for

meeting SCAN needs. Data were then re-read a second time to identify recurring themes. Anything identified by multiple participants was categorised as a key theme.

Participants were grouped in terms of their primary disability based on self disclosure, i.e. they were asked to define and describe how their disability affected them. Of the nine interviews conducted, eight met the criteria in providing sufficiently detailed responses to the questions, i.e. answering the questions to a level where sufficient data could be collected from which to draw conclusions. However given that the primary aim was to ensure that the research materials were fit for purpose, one participant focused solely on this and did not provide answers to the questions posed. Therefore this data has been excluded from the analysis.

Once the analysis was complete, a proportion of data (10%) was sent to a second coder to be re-examined to ensure that the themes extracted were both valid and reliable. If there were disagreements in the analysis between the second coder and the researcher, new themes were added after discussions had taken place. If needed, the data were re-analysed.

## Results

This section provides an overview of the key results from the study, i.e. themes that were discussed by 50% or more of the sample.

### Differences in the type of things being designed (Product or Service)

Participants had experience of a wide range of design and evaluation processes ranging from design of an app to the improvement of Council services. Both the health and social care professional and family member were experienced advocates for service users in design and evaluation processes, having performed this function many times on behalf of the service user or family member.

### Language

There are many different ways language can be interpreted and used, for example different spellings and meanings of words dependent on the context. Due to this there were some surprising results in the study. The issues highlighted included: interpretation; use of inappropriate language or technical jargon that is not understood; the specific language of disability; connection between intellectual ability and language; and appropriateness of language used in research instruments.

### Flexibility

Five participants talked about the need for flexibility on the part of the designer, in terms of the research method used, and the designers being flexible, for example about meeting locations and rescheduling at short notice.

## The importance of understanding the user's life circumstances/daily routine

Five participants highlighted the need for designers to understand life circumstances and/or daily routine for users. It was believed that this would assist designers to more effectively meet SCAN users' needs, better understand the target market, give the designer an understanding of the financial constraints faced by SCAN users, and increase designers' awareness of the fluctuating impairments of SCAN users.

## Provision for meeting SCAN needs

Five participants either reported provision being made for their needs or that there was an understanding that provision needed to be made, for example the provision of large print research materials, or the research taking place in an accessible room. With the advent of the Equality Act (2010), public institutions now have a duty to make reasonable adjustments in order to meet a person's needs.

## Communication and Design of Research Methods

Four participants mentioned the importance of communication, both in terms of allowing them sufficient time to communicate their views, and using research methods that take this need into account.

## Feedback

The issue of feedback - either being asked to give, or getting feedback from a designer - was highlighted by four participants. Issues related mainly to: the stage in the design process at which feedback was provided, for example if feedback is required late in the design process then users found this unsatisfactory; and lack of information about how their input subsequently informed the design. One participant remarked

"unsathe design teams have usually already designed the product by the time theyhey informed the design. One particio evaluate...and so by that time it's already a done deal..".

## The existence of tokenism

### Tokenism is

"okenism isce of tokenismy already designed the product by the time theyhey informed the design. One particio evaluate...and so by that time it's already a done deal..".ample (Oxford Dictionaries, 2014).

Four participants commented on the existence of tokenism in relation to how feedback was gathered or implemented. For example, this was seen in lack of flexibility or inadequate feedback.

## Emotional responses

Five participants had experienced negative feelings when questioned by designers. These ranged from feeling frustrated, to concerns about a participant's self-esteem when advocating for them.

## Advocacy

The family member felt that the role of advocate was important because

"he they might be needed to translate ...and partly they might be needed to ... tell the designer actually you're winding this person up..." .

However another participant felt that advocacy can be difficult especially when it is not done face to face.

## Perception of Disability

Four participants made an interesting point in relation to how they perceive themselves as people and how they perceive their additional needs. Two of the participants' perceptions were rooted within the Social Model i.e. viewing disability as a concept created by society (Scullion, 2010:699)

"2010:699)ed within the Social Model i.e. viewing disability as a concept created by society (Scullionhow they perceive their additional needs disability because I'm able to do things as independently as I'm able to ...but I have difficulties in doing those things sometimes..."

and

n...because the impairment like as it were is sort of part of me... therefore ...yeah I done impairment like as itility, I think I have an impairment..." and she thinks she has impairments "...because the world's not accessible, [this] means that I'm disabled and I have difficulty accessing it..."

However, the third participant stated that

" wevitwe kind of, I donird participant stated that I think I have an impairment..." and she thinks she has impairments "...because the world's not accessible, [this] means that I'm disabled and I have difficult

This perception does not fall within the Social Model. A fourth participant remarked that

"...fourth participant remarked that n the Social Model.ave an impairment..." and she thinks she has impairments "...because the world's not accessible, [this] means that I'm disabled and I have difficulty accessing it..hole myself...and I think just to simplify and make it easier for the people, yeah I do refer to myself as being disabled..."



An interesting result was uncovering how disabled people perceive themselves, for example one participant stated

“n interesting have the disabilities that I had I wouldn’t look at life around me in the same way...”

## Limitations of the study

As a pilot study with a small sample size, the findings may not be generalisable across disability populations, and may not represent an exhaustive list. Additionally it was not possible to recruit a person with learning disabilities.

Another issue is that depth perception can affect those on the autistic spectrum as for example they may (Kaplan, 2006: 2712)

“200mis-judge inter-personal distance during social interaction...ct

This is a factor to be included when producing the guidelines as users that have SCAN may include those with an autistic spectrum disorder. This will be followed up in future work.

## Discussion

The pilot study demonstrated that there is a core set of skills that designers need if they are going to work with those who have additional needs. These are illustrated in figure 5 below.

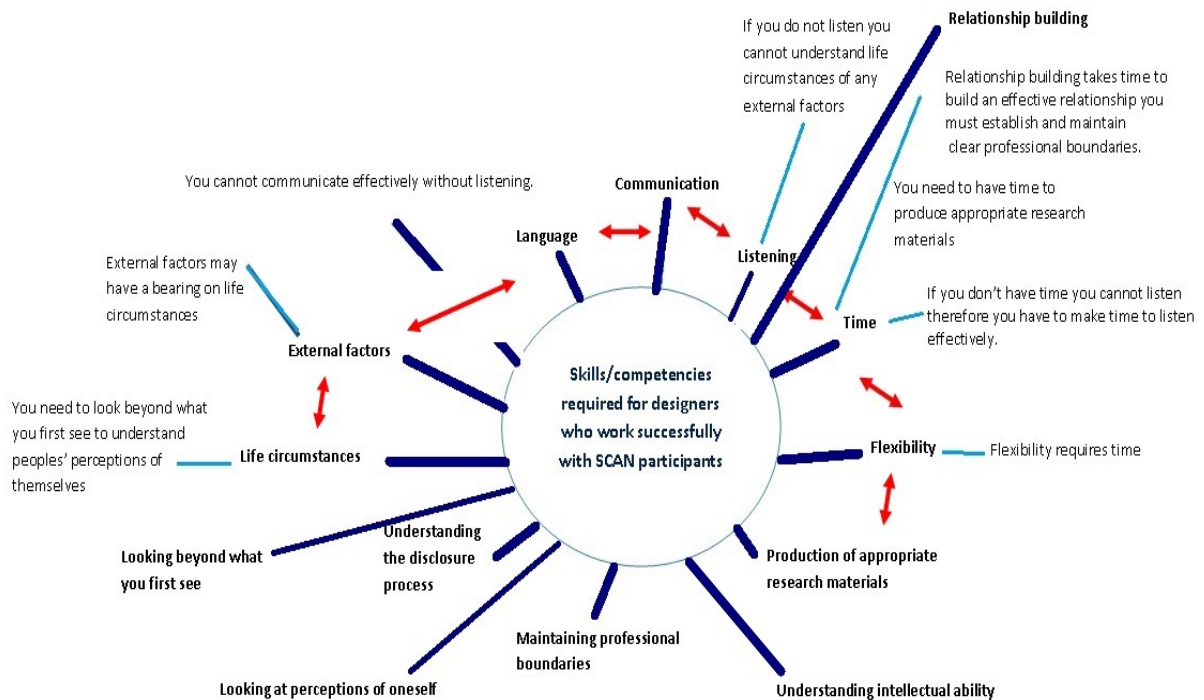


Figure 5: Skills needed to work with SCAN users, and their dependencies

Issues concerning advocacy were raised by the health and social care and family member/support worker. However, the benefits of advocacy need to be considered in relation to the extent to which the advocate truly represents the participant's views and interests. Communication, as stated by Blow (2008)

"...ultimately relies on a shared understanding between two people"

The following should therefore be considered when an advocate is being used (Concannon, 2005)

"...005)non used is a two-way process but one where reception may be as difficult as expression. If an advocate is included, having another person involved in the process is in itself filled with potential challenges. It is not only understanding what is said that is the problem, but also the hinterland that lies behind it".

Despite the above, the views of this user group are important because, as stated by Hogg (1999:4)

“people with profound intellectual and multiple disabilities present significant challenges to those who care for them, and those who commission and manage the services they receive it

Therefore it is important that we understand the views of this highly vulnerable user group whilst using appropriate safeguards to ensure their views are truly represented.

In a previous study Scott *et al* (2014) that interviewed designers about their perceived difficulties in engaging with SCAN users. One finding confirmed the difficulties which arose in relation to the language of disability. For example a designer stated

“...rose in relation to the language of disability. For example a designer stated users. roup whilst using appropriate safeguards to ensure their views are truly re particular context start saying carers, instead of care giver, in some circles you’d be in trouble for that...”.

## Conclusions / draft guidelines

Participants were able to suggest areas where designers might need more formalised guidance. These included:

- Ethical issues
- Maintaining professional boundaries
- Involving a proxy
- Interacting with SCAN users and putting them at ease
- Awareness of SCAN users’ needs and how these may affect them, for example impact of multiple and complex disabilities
- Use of language appropriate to the person
- Empathy
- Not having preconceptions

These findings correlate with the findings from Scott *et al* (2014) study of designers, for example, in relation to ethics. However, it should be noted that different groups considered different issues important. For example, themes related to physical access were only seen within the physical and visually impaired SCAN user groups. Similarly, the effects of poor depth perception were noted by people knowledgeable about autism. This means that guidelines may struggle to include all circumstances. However, a key message emerged that SCAN users wanted to work more closely with designers. Perhaps designers can reciprocate by adopting more participatory approaches when working with SCAN users?

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