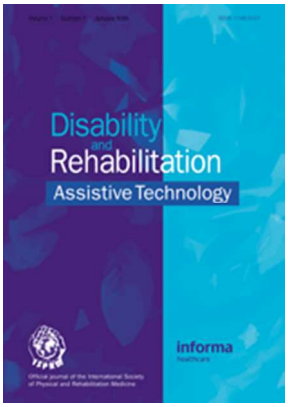


# The experience of living with stroke and using technology: opportunities to engage and co-design with end users

| | |
|---|---|
| Journal: | *Disability and Rehabilitation: Assistive Technology* |
| Manuscript ID: | TIDT-09-2014-001.R1 |
| Manuscript Type: | Original Research |
| Keywords: | Experience-centred design, home-based rehabilitation, user requirements, cultural probes, in-depth interviews, Robotic rehabilitation, stroke rehabilitation |
| | |

**Implications for rehabilitation**

- An understanding of how stroke survivors make sense of their experiences of living with stroke is needed to design home-based rehabilitation technologies.
- Linking stroke survivors' goals, motivations, behaviour, feelings and attitude to user requirements prior to technology development has a significant impact on improving the design.

## Introduction

Upper limb rehabilitation is strongly needed especially in the early stages following stroke. Research into motor relearning and processes of cortical reorganization after stroke has demonstrated that regular repetitive exercises support restoration of arm function [1, 2]. However, the exercises should be meaningful, personalised and goal-directed [3]. Robotic technology has the potential to provide people with stroke with the opportunity to independently perform intensive and repetitive exercises [4, 5]. One of the major advantages of technology-supported rehabilitation interventions such as those provided through robotics is that the technology enables users to perform exercises in their own homes thereby assisting them to have more active roles in their care. Facilitation of self-directed exercising provides opportunities for distributed practice sessions and variations within practice which are deemed to be more beneficial for the improvement of arm function [6]. Moreover, people with stroke are free to choose the number and length of practice sessions at their own convenience which is more likely to result in enhancement of performance and retention of tasks [7]. Although the significance of home-based rehabilitation technology has been underscored in the literature, the challenges of creating appropriate applications for the home environment are yet to be adequately addressed. Most commercially available rehabilitation robotics systems are bulky, large and expensive and are for use in clinical rather than home settings.

The challenges faced by technology developers in creating home based rehabilitation robotic systems mirrors the failure of most technology initiatives during the implementation phase in real situations [8] and is attributed to many factors including technical, behavioural, economical, organisational, policy and legislation [9]. There are still practical problems with translating a technology concept into real practice. Determinants that influence the

implementation of technology applications vary with the type of technology under consideration. However, involvement of end users and professionals as potential users of technology in the design process is crucial in determining how the resultant device is perceived and fits into people's lives [10]. This emphasis upon how users' perspectives can be used to develop and evaluate the feasibility and effectiveness of novel technologies has been accompanied by interdisciplinary and pragmatic research, where users are partners in the design and development process. Rather than focusing on functional dimensions, user-driven approaches focus on how people make sense of their experiences including their experiences of using technologies in everyday life and hence support the importance of deep and meaningful dialogue with users [10]. This user driven knowledge provides researchers with new conceptual tools for understanding complex conditions such as stroke and the potential role that technologies might play in the management of these conditions.

This approach continues to command the attention of researchers within health and social sciences as well as technology and design fields. For example, the potential of new technology has been previously used to design and develop stroke rehabilitation prototypes [11, 12]. A recent review of users' perspectives about virtual reality games for stroke rehabilitation showed the importance of incorporating user experiences into the design process [13].

This paper reports mainly the findings of the first phase of an interdisciplinary project called the Supervised Care and Rehabilitation Involving Personal Tele-robotics SCRIPT, funded partially by the European commission and involves researchers from several European countries. The first phase of the study examined the outcome of initial engagement with the potential users of a to-be-designed robotic technology for home-based rehabilitation of the hand and wrist following stroke. The aims of this first phase of the study were twofold: 1) to

understand users' experience of living with stroke and with technology in their home, 2) to envision their relationships with their social and physical environment and with the to-be-designed technology. Furthermore, the paper reports the findings of the initial evaluation of the very early prototype with the users and their feedback on the system requirements.

## Methodology

A hybrid of well-established health services research and user-engagement in design methods were used to capture views of people with stroke and their carers in three different European countries: the United Kingdom (UK), Italy and the Netherlands (NL). Data were collected through application of qualitative methods such as in-depth interviews as well as using diaries and photography activities. The first prototype system was evaluated using a participatory approach.

## Participants

A sample of ten households (ten stroke survivors and eight carers) was purposefully selected [14] to participate in the study (see Table 1 for details). The purpose was to select cases to yield rich and in-depth understanding of their experiences of stroke and technology rather than to generalise the findings. We were not looking for extreme, deviant, typical and representative cases but for a diversity of users to provide designers with detailed knowledge about their experiences. We used criterion sampling strategy [14] to select the participants based on our research questions. The criteria included time since stroke that is the target group for participation were people six months post stroke at the chronic stage and aged between 18 and 80 years old. Other inclusion criteria were having hand function to some extent, with no cognitive or other psychological or physical impairments that would hinder them from giving informed consent or participating in the proposed research activities. This criterion was of importance as the focus of the to-be-designed technology was to encourage

physical functional exercises for hand and wrist following stroke. Participants were required to live in the community, with a family or friend closely involved in their care. They also needed adequate language skills in order to understand and express themselves verbally in order to be able to engage in the proposed research and to provide designers with a clear picture of their livers. Carers were recruited once the person they cared for had agreed to participate in the study and were identified by the person with stroke.

Ethical approval was received from the School of Health and Related Research ethics committee, University of Sheffield and appropriate approval bodies in each participating country. All participants were provided with the study information prior to being asked to make a decision about participation, and informed consent and permission to record interviews and discussions was then obtained prior to them taking part. The identity of the participants was anonymised.

*Insert table 1 about here*

**Methods**

Participants selected for this study were visited in their homes on two successive occasions. The aim of the visits was to better understand the physical, personal and social aspects of participants' lives and the context in which they could envision using the proposed technology. The data from these visits would enable us to identify the user needs and abilities. In order to enhance our understanding of users' experiences, we combined traditional qualitative methods e.g. interviews with design approaches named cultural probes [15, 16]. A third home visit was made in which the usability of the first prototype was evaluated with only two participants.

We used cultural probes to promote motivational and creative responses and provide clues about participants' lives and thoughts. Their aim was to allow the participants to gather data about their personal lives and their experiences to be discussed later in the interviews [17]. Materials provided in the cultural probe pack in this study included a personal diary and a disposable camera to support self-reflection. Participants were given the option to select one or both of these items to record their views and perceptions between two home visits.

On the first visit, we introduced the participants to the cultural probes which were to be left with them for three weeks. Participants were presented with a guide leaflet to prompt them how to use the materials. Diaries prompted the participants to talk about themselves, their families and friends. They included some questions and tasks, like: What would you do in your dream day? And what would you like to receive from your friends and family as gifts? Why? Give a description of a perfect solution that could assist you to achieve your life goals, to support your home-based rehabilitation, to maintain/improve your relationships with family/friends and to assist you to accommodate to your new roles.

Participants were also asked to take photos based on two given assignments: A comfortable place in their homes and something they wanted to get rid of. The rest of the photos were unassigned and the choice of the target was subjective according to participants' decisions what they were willing to capture in their photos.

On the second visit, three weeks later, the content of the completed probe packs were discussed with the goal of establishing further empathy with the participants. The content of the probe packs including the photos were used as prompt to conduct one-to-one interviews with people with stroke and carers.

## Analysis

Cultural probes are often criticised for the lack of comprehensive data and prescribed analysis as the probe findings have detailed and fragmented nature [16]. We discussed the content of diaries and photos with the participants to facilitate the interviews. The qualitative data generated from the interviews were analysed using thematic analysis [18]. First we identified themes that were related to an individual interview account. Then we examined the interview accounts systematically and compared them in terms of similarities and differences. This resulted in themes that were concerned with our research question. The emerged themes were supported by the extracts from the participants' full interview accounts, which were produced by verbatim transcript.

## Results

### Cultural probes and interviews

All participants from the UK, the NL and Italy chose to use both diaries and photography activities in the probe packs but some of them did not complete all the activities involved. The photos reflected different aspects of their lives. For example, some photos told us about their relationships (e.g. photos of partners and other members of family), their home environment (e.g. photos of their gardens, kitchen, bathroom, living room, furniture, mobility devices, and used technologies), their hobbies (e.g. wood works, cooking and playing guitar), and their social activities (e.g. visiting family and friends).

When looking at Steven's photo album, there was a picture of his wheelchair that he wanted to get rid of and a few pictures of his living room where he spends most of his time watching television. Similarly, Alberto expressed his dislike of his exercise bicycle because he is not able to use it anymore and Beatrice and Sem wanted to get rid of their wheelchair and

computer, respectively. This activity led participants to reflect on their stroke as a relative experience and to compare their situations with the past.

The unassigned photos provided further insight into the participants' experiences of stroke. Lore's album included a range of photos of her going shopping with her mobility scooter, doing gardening and relaxing on a chair in the garden. For Sem, photos of his partner as his main support, his bike, his chair, and his brainteasers depicted his story of stroke. David took a number of photos that showed the importance of woodwork, gardening and playing guitar for him after stroke. Cristina took photos of herself while performing rehabilitation exercises and doing her make-up. She took photos of the bedroom and living room as comfortable places in her home. When reviewing the photos, she was asked why she had taken all the photos of herself, and she responded that she had developed an appreciation of how everything has changed since she had a stroke:

> 'Everything changed, even my living conditions. I live in my house, but I could not stay alone, so my daughter and my son-in-law have moved here. For me, it was a big change because I love to stay alone.' (Cristina)

In addition, the diary acted as a tool for participants to communicate better with the researchers and complemented the interview data. The heterogeneity of responses provided us with a multifaceted picture of potential users of technology who have a range of attitudes and expectations. For example, in the diary participants described a perfect or dream day in different ways. While David would play guitar and go for a walk with his grandchildren, a dream day for Sem would be a day free from planning and thinking about which obstacles he might face during the day. Cycling, going out, having fun, car driving and going on holiday are the features of Lore's dream day and Nick and Silvio described their dream days as follow:

‘I would go out in the country side and enjoy a good long walk.’ (Nick)

‘Having a normal life, doing things like driving the car, taking the train, listening to music, to be able to have and follow a conversation, be able to walk and to make plans for the future.’ (Silvio)

In the diary, participants were asked to describe gifts they wish to receive from friends and family. Some of these imaginary gifts were practical like Lore who wanted to receive flowers, Sem who wanted a macro-lens for his photo camera to use it for close-up photos of plants, or Nick who wanted to receive an iPad as it is simpler to use than a laptop. However, others envisioned the practical values of imaginary technologies. For example, David wished for a pair of shoes to enable him to walk with his family and friends. Sem wished for “appreciation and respect” as perfect gift from families and friends. Lore wished for everyone to act normally around her. The following quotes show how Alberto and his wife describe their favourite gifts:

‘A car with an automatic drive to be more autonomous and three cartons of cigarettes so that I could smoke in freedom.’ (Alberto)

‘More involvement in everyday life, even a phone call to escape from the routine. I don’t care for something material, because the presence of people who care for you represents already a gift.’ (Sofia)

Participants envisioned perfect solutions that could assist them to achieve their goals. David wants to have every machine available for rehabilitation in the clinic at home at his disposal. Similarly, Sem believes assistive devices with the capacity to provide feedback on progress could be a perfect solution to support his home-based rehabilitation. The following excerpt shows Alberto’s idea of a solution to support home-based rehabilitation:

'An efficient device, which can improve my condition without provoking terrible pain and that I can handle by myself, without the help of somebody else.' (Alberto)

## User requirements

The data obtained from the cultural probes and interviews was analysed and the following themes emerged:

*Network of relationships*

Participants' relationships with others and how the stroke changed their relationships and their personal and social roles is an important topic in their interview accounts. The cultural probes provided insights into the participants' relationships with others. For example, they compared their present situation with past times before stroke:

'(After I had the stroke) It was terrible, because I considered myself useless, worthless compared to the person I was before. It (my life) changed because I lost the relationships with the people I had known and I had cared for. This happened because I felt invalid and unable to keep these relationships. So, it was even my fault.' (Antonio)

'Everyone is different with a stroke. It does devastate your social life.' (Janet)

The findings of the study also showed that changes in roles and responsibilities could create negative feelings of frustration and stress for stroke survivors and their family carers.

'We (David and his wife) have been very near to blows because of the stroke. I push her and she pushes me, I don't mean literally but I have a stick and I have been very near to using it out of frustration. But the same goes for her, she is frustrated because I am like this, I can't move without her.' (David)

The following excerpt demonstrates how stroke could also affect relationships in positive ways:

> 'Your life just suddenly changes, suddenly he wasn't independent anymore. … He changed personality, but in a good way. He is now more cheerful, has to laugh about things more, and makes more jokes. He really enjoys life now.' (Ava)

Hence, the experience after stroke is used as a process in which the stroke survivor creates new identities in relation to self and others.

The findings also suggest that the person with stroke is involved in a network of relationships and his/her decision to use a home-based rehabilitation system is influenced by those who are part of this network such as friends, family, health professionals and peer groups. This was stressed in Sem's diary where he pointed out the importance of receiving feedback on progress and recovery from stroke:

> '(It is important) the confirmation of family and friends, therapists and fellow stroke sufferers, that they say you are on a good way or you are doing well.' (Sem)

*Attitudes towards technology*

People can experience different emotions in their interactions with technology and they are believed to have different effects on their behaviour [23]. These emotions can be induced by the product's quality, the meaning attached to the product, the interaction with the product, the function facilitated by the product, the impact of product on ourselves and the effects of other people's reactions to the product.

The findings of the study showed that participants with technology experience before the stroke tend to have positive attitudes towards new technologies. They usually feel that their

abilities are not as good as before but there are willing to try new technologies and have hopes that they could help them to regain their lost capabilities. For example, Nick – who enjoys using his computer, phone, camera and playing video games - is content when using different kind of technologies which have positive effects on his behaviour. He is motivated to use these technologies as they give him some degree of independence. The following excerpts demonstrate other participants' opinions:

> 'I trust technology; there are great progresses in certain areas. Therefore, I think that technology could give great results even for my problems' (Antonio)

> 'I trust in new technologies and I really (have) hopes in its help. I would like to be able to use both hands' (Silvio).

*Skills and experiences*

The participants' capabilities to use a rehabilitation system at home were also studied. They had different levels of impairment on their affected arm and hand. Although some presented good shoulder and elbow activity, the majority had difficulties with hand movements, specially grasping small objects when fine manipulation is required. A rehabilitation system should therefore take into account the level of impairments of the users and address the movements that they need to improve.

Apart from different physical capabilities, the participants also had different levels of knowledge about computers that also need to be taking into account when designing the system. There is a wide range of users: from experienced technology users that are familiar with modern devices and enjoy playing computer games, to people that do not even use a simple mobile phone. Therefore, the rehabilitation system should be simple enough and have

as well different levels of complexity to motivate experienced users rather than creating negative feelings of frustration and or boredom.

*Motivations*

The reasons why the user will feel motivated to use a rehabilitation system were also identified as a significant factor which had a great impact on participants' behaviours.

In the case of stroke survivors, the motivation to regain control on their arm and hand movements is usually very strong as it will allow them to be independent and regain confidence in their own body. Therefore, they are usually interested in using rehabilitation systems that will help them continue their training and improve their capabilities.

The following excerpts exemplify participants' views when asked if they would consider using rehabilitation technologies:

> 'If it's needed, of course you would do that! If you like to make your life better, you will do everything you can do for it.' (Sem)

> 'It's very good to use technologies for rehabilitation. It's better/more fun to train with a device, so that's very good.' (Lore)

> 'Yes, but only if it is not a torture' (Alberto)

Also, they expressed their opinions about using robotic devices:

> 'You don't have the idea you are actually training, when you are e.g. playing a game with a robotic device.' (Sem)

*Goals*

Identifying participants' goals and relate them to the to-be-designed technology was central in this study. Goals are meaningful and challenging activities that the person with stroke is trying to achieve or regain after stroke [19]. Goals also represent the user's motivation for performing the task associated with using a specific product [20]. Their identification is important as they should be the focus of the product's design determining how the product looks, behaves, operates and feels.

The participants described activities that they would like to do but they feel they are unable to perform as a result of the stroke. They described general goals like being able to improve hand function, doing daily activities and reaching, grasping and holding objects. They also focused on specific goals that are more personal and related to their personal interests. A summary of the participants' goals before and after stroke is presented in table 2.

*Insert table 2 about here*

Participants compared their current goals with the past and provided accounts that showed how the stroke was perceived as a relative experience. For example, while some participants tried to regain their goals before the stroke, others reframed their expectations and created new and more realistic goals. For example, Alberto was very active before his stroke and enjoyed sailing and repairing boats. However, after the stroke he has developed a new goal. He regularly takes part in a mosaic workshop in order to learn how to do mosaic work with one hand. While Sem enjoyed cycling, photography and playing tennis before his stroke, he performs the same activities after the stroke in a different context and with more careful planning. For example, after the stroke he plays tennis with other stroke survivors in a stroke support group. However, Cristina seeks to regain her goal before stroke. She wants to be able to drive again as she enjoyed driving before her stroke.

**System requirements**

The information collected with the cultural probes and interviews was analysed to identify main issues concerned with target users. The next step was to envision and define the requirements of a home rehabilitation system which meets the goals and needs of stroke survivors. Table 3 shows a few examples of how we inspired by users' needs to envision system requirements. The to-be-designed system was envisioned as a customised hand orthotic device in conjunction with a user interface and therapeutic gaming environment which is remotely supervised by a healthcare professional using an offline therapy portal, developed for home rehabilitation of the hand and wrist following stroke. We grouped the requirements into four aspects: the usability of the system, the requirements for rehabilitation training, the feedback on training performance, and the requirements to ensure users' motivation. We initially evaluated the first prototype system with David and his wife Janet and with Steven and his wife Laura.

*Insert table 3 about here*

*Usability of the system*

Taking into account the different levels of user skills, the system should be simple to start and operate allowing it to be used for people with little or no computer experience. Also, the system should be usable by both left and right sided affected patients and should be possible to be used by the stroke patients without the direct assistance of a healthcare professional at their homes. The system should fit their home environment and not interfere with other furniture or equipment such as a wheelchair. During the interviews, the participants were very open to accommodate the system at their homes:

'If it's needed, we really like to train at home. It's no problem to offer some space to place an extra device for training in ou home.' (Sem)

'It's no problem to place extra devices in the living room, even for a longer time. You want to do everything to have more arm and hand function. And I think this also concerns all other patients after stroke. … Besides, it's important to use the device by yourself (put the device on and off), without help from someone else to be more independent.' (Lore)

*Training for stroke rehabilitation*

Different aspects of the therapy should be considered when designing a system using games for rehabilitation, such as type of movements, game adaptation and therapy safety. The movements available in the games should train normal movement patterns needed for daily activities, promote active participation of the arm and hand, promote frequent movement repetition, offer different movements in one training session and train also movement coordination. Additionally, the games should provide training from gross to fine manipulation, which includes training of grasping gestures used in daily living given that this is one of the main goals desired by the stroke survivors. This is exemplified by the following expression:

'You concentrate enough on that hand and I wanted that hand back that much with playing guitar, and I got my thumb to move in bed when I was in hospital, just a twitch and I knew it was made contact and from there on I got it open every one finger at a time. Took months and months but it worked and now I can play tune and I can strum me guitar. I say, I couldn't bend that arm but it takes time and willpower up here, and believe me you've got to motivate people to think like that'. (David)

The games should be adaptable to the capabilities of each user. They should be challenging, so not too difficult but also not too easy that they become boring. This can be achieved at different levels, for example changing the assistance that the orthosis is given or changing the difficulty of the game such as increasing or decreasing its speed.

The safety of the therapy is an important aspect to take into account. The system should be designed to prevent further injuries or complications such as increasing the users' spasticity or changing secondary tissue because they are training with the wrong strategy. Direct involvement of healthcare professionals during the design of the system is a requirement to ensure the training would be safe and appropriate for post-stroke users.

*Feedback on performance*

In order to increase users' motivation, different feedback of their performance should be available in the system. This was emphasized by one of the participants:

> '(Using) a device you can have a kind of reward, a challenge, but the results should be shown very soon to be motivating. You should not wait too long before you receive feedback. It's also nice to have an overview of progress of the last time (e.g. progress during the last weeks). However, personal contact stays important, not only results shown on a device!' (Sem)

The feedback should be presented during the game to give information about the user current performance and to encourage them to try to achieve their goals. After the games, a summary of the performance should be immediately presented and there should be an option to review general summaries of the performance accessible at any time.

The feedback presented should not only include information about the game performance such as the scores achieved, but also information relevant to improvements in their arm and

hand capabilities such as changes in their range of motion or the number of repetitions performed for each movement.

It is important that the performance of the users is constantly reviewed by a healthcare professional, so the feedback should also be available for them to review and change the training program accordingly such as the games available and their difficulty.

*Motivational aspects*

As it was shown by the cultural probes, the stroke survivors have a strong motivation to use rehabilitation systems that will allow them to improve their capabilities. However, in order to motivate the users to continuously play the games, the system should be designed in such a way that it keeps the user motivated taking into account the users' differences. This was clearly pointed out by one of the participants:

> 'They (stroke survivors) will have the motivation by themselves, but the use of technological devices in rehabilitation might also be motivating. It will be more challenging with the use of devices. Furthermore, competition (training with other patients), and training with games/play-like might be very important. Also, the movements you are training should be meaningful. You have to think: if I do a certain movement again and again, maybe in future I can do this and that.' (Sem)

Using games to train different movements could be a good way to motivate the patients to do the therapy instead of asking them to perform a predefined set of exercises. In order to achieve this, the games should be simple, fun, engaging, tailored and encouraging. There should be various games that the users can choose according with their preferences. They should be interesting for men and women as well as for all age groups. Also, they should provide different levels according with the users capabilities and be adaptable so they can be

played by different patients. Also, they should be available in different languages so users from different countries can use the system. David expresses his view about motivation in the following excerpt:

> 'So you've got to find a way of saying how can we get people interested in using that system, and you've got to get them interested 'cause if the interest isn't there then they'll not take to it, will they? For example, you know get some music to match what the user is doing, it's all motivation, and the simpler the better'. (David)

An important aspect that was pointed out by many participants was their concerns about the lack of interaction from a real therapist having the system at home. Steven expressed his concerns in the following excerpt:

> 'There seems to be so little out there and I'm worried that people are going to feel more isolated' (Steven)

Therefore, having constant interaction with a real healthcare professional is very important to keep the users motivated. This interaction can be provided through an interface that allows the user to contact the professional through messages (using text or video) to ask any questions or concerns they might have about the system. This interface will also give the professional the opportunity to remotely interact with the users to offer them instructions, advice and motivation.

Receiving feedback on progress could be linked to the motivational aspects of rehabilitation. Feedback and motivation could also be related to users' relationships with family members and friends. While some participants seemed to be motivated with scores as a means of receiving feedback on their progress, others believed that effective feedback may take more than one form. Users of different backgrounds can become motivated when they receive

meaningful and culturally-responsive feedback. For example, involving a family member or friend in the rehabilitation training at home might increase motivation and encourage engagement. This is demonstrated by the following expression:

> 'You know when my brother comes in I show off, it makes me show off 'cause he's seen what I was like when I first come out of hospital, I couldn't get out of this wheelchair and when I walking again a bit better, course I've nearly fallen over like but that's beside the point, I'm motivated knowing. … There's nothing more good in my opinion for a stroke victim is to know people care'. (David)

At the end of the first and second home visits we were quite optimistic that we have reached an agreed understanding with the users about the issues they face day to day when living with stroke. We identified their life goals, their attitudes and capabilities towards technology and the acceptability of technology. These individual data provided rich description of the potential users of technology and helped designers capture key aspects of their lives, activities and situations in which the to-be-designed technology will operate. The findings informed the design of the first prototype which was initially tested with two participants who were also involved in the first phase of the study.

**Evaluation of the prototype**

We evaluated the first prototype by using a participatory design approach which is used at the early stage of system development and involves users by encouraging them to think aloud about the structure, functionality, usability and acceptability of the system [21]. The formative evaluation comprises a series of tasks prepared by the researchers and are presented to the users. Users are asked to perform the tasks, narrate their ideas, think aloud and ask the evaluator for advice where they are unsure what to do. Users are allowed to make mistakes and the researchers ask questions to find out about the nature of usability

problem. Participants' interactions with the devices are audio and video recorded upon permission from the participants.

We took the system to David's and Steven's house to elicit their views on the system requirements and to find out whether the proposed system would be perceived valuable by them. We aimed to find out how easy/difficult the system is to use by them and to understand what problems the system poses and how these problems could be improved. The outcomes of the first evaluation were fed back to the developers, and alterations were made to the design for the next iteration of the prototype. A few major usability problems were identified and the participants suggested that the next iteration of the system should consider the following solutions:

**Compact**

David and Steven both live in small semi-detached houses with small living rooms. We set up the system in their living rooms but they believed that the system was too bulky and unmanageable in people's homes. David suggested that users should be able to simply connect the system to their own TV and play the games. He was concerned that the current system would be in the way when they have visitors especially when their grandchildren visit them.

**Easy to use and operate**

David and Steven managed to put on the hand orthosis with the assistance from their carers. However, they preferred to be able to don and doff the orthosis independently. They managed to start the system with some prompts from the researcher but they found the instructions confusing and suggested that some texts should be reworded.

**Different formats for providing feedback**

The system gives feedback using different formats including scores, graphs and bar charts. While Steven preferred to receive feedback in the form of simple scores, David believed that people with stroke would not like the idea of graphs and bar charts as a means of receiving feedback. He stated:

> 'The person with stroke will realise when they progress by looking at the function of their hands and they gain the sense of improvement through experience by doing the exercises and observing the progress'. (David)

**Different types of communication**

The system provides the user with an opportunity to communicate with their therapist by sending a text message. This was problematic for Steven because after his stroke he does not leave space between the words and that could be confusing for the recipient of the text message. He suggested that sending an audio or video message to the therapist would be easier for him.

**Motivation**

They believed that the concept behind the system is very interesting and it is rather simple to use. However, David suggested that there should be a mentor talking to the user and having dialogue with them all through the programme, from the start when the user logs in to the system, through the calibration phase, playing the games, receiving feedback and sending messages. He emphasised the significance of having a personalised human interaction with the user to motivate them to perform the therapeutic games. For example, seeing a therapist talking to the user and instructing them during the programme could be encouraging for

them, the presence of a human agent either a therapist or a mentor could be uplifting for the user.

**Discussion**

The purpose of this study was to understand the user not only as an individual with plans and goals but also to address their whole experiences including the emotional aspects to provide technology developers with insight into users' values, thoughts and feelings. Qualitative and user-centred design methods such as cultural probes have been used to develop home-based rehabilitation technologies for stroke [19]. These methods provide researchers with insights into the subjectivity of patients' experiences of stroke and of technology and yield detailed empirical knowledge grounded in their personal and social contexts.

The findings of this study help technology developers detect a number of issues that cluster around what is commonly referred to as user requirements. Research related to assistive technology is often dominated by the functionality and usability of systems and fails to recognise experience and human factors that would enhance design and subsequently would have a meaningful impact on people's lived experiences. By adopting a mixed-method of user engagement in design, the study showed useful insight into the experiences of stroke survivors and their carers. The experiential data that emerged transcend the limits of functional user requirements to illustrate a bigger picture that presents a holistic approach to support future design development.

The findings further suggest that the person with stroke is involved in a network of relationships and his/her decision to use a home-based rehabilitation system is influenced by those who are part of this network such as friends, family, health professionals, and peer groups. Hence, the experience of stroke and technology use could be a process that the person with stroke and the carer create new identities in relation to self and others. Being entangled

in the network of relationships would create a complex, dynamic, changing and adaptive situation [22] that requires continuing meaningful dialogue with the user to encourage participation and engagement.

This study has important implications when designing home-based rehabilitation technology for stroke survivors. Prior to design, designers and developers need to clear any doubts about the context in which the to-be designed technology is expected to operate. They should have a clear understanding of how stroke survivors make sense of their experiences of living with stroke and their perception of using technology. Users' goals, motivations, behaviour, and relationships should be identified to not only create desirable rehabilitation technology but to enrich the lives of stroke survivors who decide to use them in their homes [10].

Owing to the relatively small sample in this study, we are limited to generalise the findings. However, the participants were selected purposively and their narratives were used to establish a dialogue with the researchers to bring their experiences into the process of design as co-designers.

The findings of first formative evaluation raised a number of usability issues about the system that need to be addressed in future iterations of the system.

**Conclusion**

The findings of the study helped us understand the potential users of a robotic rehabilitation technology, their goals, their network of relationships, and the context in which the technology is meant to operate. In other words, user characteristics as well as contextual characteristics were identified which would play into the process of design and development. During next stages of our research, we continue to engage with target users to evaluate and implement the prototypes into stroke survivors' homes. This will enable us to continue the

process of user-centred and participatory design, while ensuring that development stays close to the needs of the potential users.

**Acknowledgements**

We sincerely thank all the participants who agreed to be involved in this study. We are thankful to SCRIPT consortium for their support. This work has been partially funded under grant FP7-ICT-288698(SCRIPT) of the European Community Seventh Framework Programme.

**Declaration of Interest**

The authors report no conflicts of interest.

## References

[1] Schaechter JD: Motor rehabilitation and brain plasticity after hemiparetic stroke. Prog Neurobiol 2004, 73: 61-72.

[2] Krakauer JW: Arm function after stroke: From physiology to recovery. *Seminars in Neurology* 2005, 25: 384-395.

[3] Birkenmeirer RL, Pranger EM, Lang CE: Translating animal doses of task-specific training to people with chronic stroke in 1-hour therapy sessions: a proof-of-concept study. *Neurorehabi Neural Rep* 2010, 24:610-635.

[4] Prange GB, Jannink MJA, Groothuis-Oudshoorn CGM, Hermens HJ, Ijzerman MJ: Systematic review of the effect of robot-aided therapy on recovery of the hemiparetic arm after stroke. *J Rehabil Res Dev* 2006, 43:171-183.

[5] Kwakkel G, Kollen BJ, Krebs HI: Effects of robot-assisted therapy on upper limb recovery after stroke: A systematic review. *Neurorehabil Neural Rep* 2008, 22:111-121.

[6] Winstein CJ, Campbell SJ: Conditions of task practice for individuals with neurologic impairments. In A Textbook of Neural Repair and Rehabilitation. Edited by Selzer ME, Clarke S, Cohen LG, Duncan PW. Cambridge: Cambridge University Press; 2006:89-102.

[7] Shea CH, Lai Q, Black C, Park JH: Spacing practice sessions across days benefits the learning of motor skills. Hum Movement Sci 2000, 19:737-760.

[8] Berg M: Patient care information systems and health care work: a social technical approach. *Int J Med Inform* 1999, 55:87-101.

[9] Broens THF, Huis in't Veld RMHA, Vollenbroek-Hutten MMR, Hermens HJ, van Halteren AT, Nieuwenhuis LJM: Determinants of successful telemedicine implementations: a literature review. *J Telemed Telecare* 2007,13: 303-309.

[10] Wright P, McCarthy J. Experience-centred design: designers, users and communities in dialogue. NY: Morgan and Claypool; 2010.

[11] Torsi S, Nasr N, Wright P, Mawson S, Mountain G: User-centred design for supporting the self-management of chronic illnesses: an interdisciplinary approach. *In Proceedings of the second International Conference on Pervasive Technologies related to Assistive Environment: 9-13 June 2009; Corfu, Greece. ACM.*

[12] Nasr N, Torsi S, Wright P, Mawson S, Mountain G: Supporting the self- management of stroke by applying a user-centred design approach [abstract]. *Clinical Rehabilitation* 2010, 24: 276-287.

[13] Lewis GN, Woods C, Rosie, JA, McPherson, KM: Virtual reality games for rehabilitation of people with stroke: perspectives from the users. *Disabil Rehabil Assist Technol* 2011, 6:453-463

[14] Patton MQ (1990). *Qualitative Evaluation and Research Methods*. California: Sage; 1990.

[15] Gaver W, Dunne T, Pacenti E: Cultural Probes. *Interactions* 1999, 6: 21-29.

[16] Gaver WW, Boucher A, Pennington S, Walker B: Cultural probes and the value of uncertainty. *Interactions* 2004, Sep/Oct: 54-56.

[17] Mattelmaki T, Battarbee K: Empathy probes. In Proceedings of PDC: 23-25 June 2002, Malmo.

[18] Coffey A, Atkinson P: Making sense of qualitative data: Complementary research strategies. London: Sage; 1996.

[19] Mawson S, Nasr N, Parker J, Zheng H, Davies R, Mountain G: (2013). Developing a personalised self-management system for post-stroke rehabilitation, utilising a user-centred design methodology. *Disabil Rehabil: Assist Techn* 2013; http://informahealthcare.com/idt ISSN 1748-3107 print/ISSN 1748-3115 online.

[20] Cooper A, Reimann R, Cronin D: About Face 3.0: The essentials of interaction design. Wiley; 2007.

[21] Monk A, Wright P, Haber J, Davenport L: Improving your human-computer interface: A practitioner's guide. Prentice Hall; 1993

[22] Patton M Q: Developmental Evaluation: Applying Complexity Concepts to Enhance Innovation and Use. The Guilford Press: New York; 2011

**Table 1**: Participants' characteristics

| Country | Name | Age | Gender | Time since stroke | Occupation before the stroke | Carer |
|---|---|---|---|---|---|---|
| UK | David | 70 | M | 5 years | Guitarist | Janet |
| UK | Steven | 60 | M | 4 years | Business man | Laura |
| UK | Nick | 69 | M | 2 years | Teacher | Ann |
| NL | Sem | 65 | M | 6 years | Purchasing assistant | Ava |
| NL | Lore | 67 | F | 7 years | Data typist | Hendrik |
| Italy | Alberto | 69 | M | 2 years | Boat mechanic | Sofia |
| Italy | Antonio | 70 | M | 5 years | Policeman | - |
| Italy | Silvio | 60 | M | 4 years | Employee of IBM | Cara |
| Italy | Beatrice | 72 | F | 2 years | Tailor | - |
| Italy | Cristina | 77 | F | 1 year | Housewife | - |

**Table 2**: Life goals described by participants

| Specific goals before and after stroke | | |
|---|---|---|
| **Participants** | **Pre-stroke goals** | **Post-stroke goals** |
| Lore | Gardening, photography, cycling, driving | Improve relationships with family/friends |
| Sem | Cycling, going on holidays, photography, playing tennis, going to gym | Doing the same things but with careful planning, e.g. playing tennis in a stroke support group |
| David | Playing guitar | Playing guitar, learning how to do woodwork, going for a walk with grandchildren |
| Steven | Fishing, playing golf, fundraising | Cooking with his wife support, using computer (key boards and mouse) |
| Alberto | Sailing, repairing boats | Taking part in a mosaic workshop to do art with one hand |
| Antonio | Doing sports, driving car | Going to seaside, walking within targeted distance |
| Silvio | Reading, listening to music, going for a walk, making plans for future | Being able to use both hands |
| Beatrice | Sewing, cooking | Washing herself, walking the dog, shopping, regain relationships with children |
| Christina | Driving, shopping, | To be able to drive again |
| Nick | | Going for long walks, spending time with grandchildren, using technology to gain independency |

**Table 3**: Envisioning systems requirements

| User requirements | Systems requirements |
|---|---|
| Motivational reasons to use the system | Simple, easy to use system with fun, engaging and tailored games |
| The importance of network of relationships | Involving family members in the rehabilitation training and receiving feedback on progress from them |
| Users' skills, background and experiences | Design solutions tailored to a range of users |
| Users' goals and the importance of hand function in performing daily activities | Games should provide grasping gestures and promote repetition of movements |