SUITCEYES

1 Jan 2018 - 31 Dec 2020

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Smart, User-friendly, Interactive, Tactual, Cognition-Enhancer, that Yields Extended Sensosphere
Appropriating sensor technologies, machine learning, gamification and smart haptic interfaces

[D2.3]

Best Practice Recommendations for Engaging Deafblind Participants in Research

Courtesy of LightHouse for the Blind and Visually Impaired, see http://lighthouse-sf.org

Dissemination level		
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CO	CONFIDENTIAL, restricted under conditions set out in Model Grant Agreement	
CI	CLASSIFIED, information as referred to in Commission Decision 2001/844/EC.	

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DEC	Websites, patents filing, press & media actions, videos, etc.	
OTHER	Software, technical diagram, etc.	

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Glossary	
Abbr./ Acronym	**Meaning**
ASL	American sign language
HIPI	Haptic, intelligent, personalised interface
WFDB	World Federation of the Deafblind

Contents

Executive Summary

This deliverable reports on best practice for involving people with deafblindness in research and particularly in interviewing potential users as research participants. This task involves:

- A literature review to identify best practice
- A discussion of examples of user centred design projects that have been carried out previously and the identification of lessons from these;
- A review of the experiences of researchers in the SUITCEYES project and discussion of learning that resulted from involvement.

In this summary we briefly set out some principles for involvement and draw on all three elements of the task. Each task and further relevant issues are described further in the main report that follows.

People with Deafblindness
- It is not very meaningful to talk of a single population of people with deafblindness or to draw generalised conclusions because people with deafblindness are very diverse.
- Impairment does not predict what people can do, or their needs and interests. Individual experiences and environmental and social context are equally important for understanding the design of relevant technological and non-technological solutions.
- Different models of deafblindness (ontology and epistemology) have implications for understanding the problems faced by people with deafblindness and the solutions. Although in part models reflect the subject of research that is being investigated (for example medical or social issues), they also reflect beliefs about people with deafblindness and their place in society.

Involvement in Research
- The involvement of people with disabilities in research is well established as good practice and there is a detailed literature on this.
- Literature on user involvement recognises various degrees of control over the research agenda, the range of potential roles and levels of decision making during the process of carrying out research.
- We did not find any examples of people with deafblindness being involved as researchers in the published design literature. All the identified studies involved people with deafblindness as the subjects (participants) of research.
- Just one article mentioned the desirability of people with deafblindness being involved as co-researchers, for example in carrying out interviews.

User Centred Design Projects
- We found few examples of user centred design projects that involved people with deafblindness.
- The few that we found had very little to say about best practice and lessons learned.
- There is clearly considerable scope for greater and more meaningful involvement by people with deafblindness in all stages of design.

Communication

For participation in research to be meaningful, it is essential that arrangements for effective communication are made with people with deafblindness. These resources are sometimes scarce. The World Federation of the Deafblind (2018) provides a non – exhaustive list of options for support services and technology for communication, mobility and description, summarised as follows:

- Interpreter - Guide: assistance, including with communication and mobility, according to individual requirements;
- Devices for hearing: hearing aids, cochlear implants, loop systems;
- Devices for reading and writing: Braille reader and / or display, which enables one and/or two-way communication via computers, smartphones and other devices using Braille;
- Mobility devices: red and white striped canes;
- Tactile communication: tactile sign language, tactile fingerspelling and tactile alphabet;
- Tadoma: communication through jaw movements, vibrations and the facial expressions of the speaker;
- Visual frame interpreting: sign language adapted to fit a limited field of vision with a person who has some degree of residual sight;
- Clear speech: effective for many people who have some degree of residual hearing;
- Braille: a system of representing letters through raised dots;
- Moon: similar to Braille but raised, adapted capital letters are used;

These are not stand-alone options and several may be used together, according to the requirements of each individual and the context where the communication takes place.

The Interviewing Process

- Dignity and respect for participants is paramount. Interviewers should adopt a reflexive stance and be open to questioning aspects of their own practice.
- Elements of this may include acknowledging the validity of what people have to say at all times, paying attention to participants rather than interpreter – guides, and sensitivity in all interactions.
- Interviewers should offer truthful personal information about themselves if this is asked for and not make promises that may not be kept (such as keeping in touch or sending information about the research, unless it will be definitely carried out).
- Enough time should be allocated for the development of materials and for explaining the content and process of the research to participants.
- Participants should be offered choices regarding where to meet, times and support arrangements.
- Consent for all forms of recording and data used should be sought.
- It is preferable that interviewers are able to sign, using hand under hand and / or visual national sign languages for people who communicate this way.
- Training and orientation for interviewers should be carried out at the start of the research process.
- Where there is a need to involve an interpreter, interviewers should be alert to other means of communication, including gesture, which may not take place at the same time as speech if

interpretation is used. (Some interviewers in the SUITCEYES project used video as well as audio recording to capture this information.)

- In international projects, it is important to be alert to cultural and language differences. (For example, in the SUITCEYES project there were differences between countries in the degree to which families are expected to be responsible for the welfare of people with deafblindness and / or this responsibility lies with the state. Differences in terminology were also apparent)

Introduction

This report aims to support active engagement of people with deafblindness in research and the engagement of researchers in ensuring the effective participation of people with deafblindness. We highlight aspects of best practice, through:

- A review of literature on involving people with deafblindness
- Examples of research and lessons learned from these studies, and
- Input from SUITCEYES researchers on their experiences of carrying out research in five countries.

From the outset, it should to be stated that the literature on involving people with deafblindness in research is very limited. There are only a few studies that engage with people with deafblindness and where they do, authors provide very few details about effective practice. Nevertheless, we draw attention to issues raised wherever possible and we also include wider literature on the involvement of people with disabilities in research.

This deliverable also discusses the experiences of interviewers working on the SUITCEYES project. We interviewed people with deafblindness in five countries (Germany, Greece, Netherlands, Sweden and the UK). In preparing this report, contributions were sought from all partners and we have analysed these and drawn conclusions.

The next section considers the population of people with deafblindness.

People with Deafblindness

Diversity is characteristic of people with deafblindness and sweeping generalisations in terms of impairment, life experiences and interests should not be made. Similarly, there is no single definition of deafblindness (Ask Larsen and Damen, 2014; Dammeyer, 2014; WFDB, 2018), although all definitions recognise the compounding effects of dual sensory impairment, which prevent compensation of one sense by the other, even in situations where people have residual sight or hearing. The term multi – sensory impairment is also used, recognising that people may experience difficulties processing sensory information, even with residual sight and hearing.[1]

The age of onset of deafblindness has important implications for opportunities for incidental learning and concept development, with earlier onset associated with greater disadvantage. Congenital or pre-lingual deafblindness describes the condition where a person is born with both sight and hearing impairments. Causes may include infections during pregnancy, premature birth, birth trauma and rare genetic conditions. Acquired deafblindness is a term used where a person develops sight and hearing impairments later in life. Causes may include illness, accident or ageing. Within the latter group, several further distinctions are often drawn by authors between:

• 	People with congenital deafness and who later acquire visual impairment;
• 	People with congenital vision impairment who later acquire deafness;
• 	People who acquire both vision and hearing impairments

Some authors (e.g. Jaisawal et al, 2018) describe four rather than three groups and further distinctions may be made among people with residual hearing and vision regarding age of onset and degree of impairment. A number of conditions such as Ushers syndrome, CHARGE syndrome, Alström Syndrome and others are associated with deafblindness and these conditions also vary in their degrees and effects.

Given this, a number of authors argue that the lack of precision and agreement about definitions make comparisons problematic (Ask Larsen and Damen, 2014; Jaiswal et al, 2018; Wittich et al, 2013).

Knowledge of specific impairments is valuable if it leads to understanding of conditions and relevant adjustments for communication and support, but it becomes problematic if it is used as a basis for assumptions about capabilities and eligibility decisions that lead to exclusion from opportunities. Categorisations of deafblindness should never replace engagement with people with deafblindness themselves (WFDB, 2018).

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[1] For further information about deafblindness and multi-sensory impairment see for example: World Federation of the Deafblind: http://www.wfdb.eu/; Sense International: https://www.senseinternational.org.uk/about-deafblindness/what-deafblindness>; Deafblind International: https://www.deafblindinternational.org/

A Review of Literature

Involvement of People with Deafblindness in Research

Most empirical studies researching into deafblindness focus on health issues, with a smaller number concerned with other aspects of daily living. Even so, from their global review of literature on the participation of people with deafblindness, Jaiswal et al (2018:21) conclude that "individuals with deafblindness are often absent in rehabilitation research due to the complex nature of the disability and to methodological challenges involved with recruitment and data collection." They specifically highlight evidence to indicate that older adults felt embarrassed, offended and isolated due to communication issues. They also conclude that there is a relative lack of studies conducted from a social model perspective (for an explanation of this see Oliver and Barnes, 2012; Inclusion London, 2015), with most studies more focused on the effects of the impairment rather than that of the environment.

Jaiswal et al (2018) also found that the majority of the 54 studies they examined were quantitative in nature, relying on surveys that often involved either family members of people with deafblindness or professionals working with people with deafblindness (so called proxy participants). Where people with deafblindness were included as research participants, participation was strongest amongst those with acquired impairments, and rarely included people with congenital deafblindness. One reason for this is said to be the communication difficulties associated with conducting a research interview, but the consequence is that the experiences and challenges of people with congenital deafblindness are being under-represented. So, whilst there would seem to be a case for conducting further qualitative work, there may also be a need to carefully scrutinise how that qualitative work is conducted, so as to include a stronger representation of people with congenital deafblindness.

Other research gaps are noted in relation to people with deafblindness in developing countries and regarding women with deafblindness. The former is linked to the under-representation of congenital deafblindness in research, and the higher prevalence of congenital deafblindness in developing countries. Regarding the latter, concern is expressed as to whether women with deafblindness might be subject to particular "vulnerabilities". They highlight some evidence that people with congenital deafblindness, especially women, experience heightened vulnerability both in and outside their homes, and even in relation to receiving care.

Addressing the Needs of People with Deafblindness

Direct involvement of potential users in research and in design helps to encourage the development of more relevant solutions by addressing real, rather than assumed needs – it ensures that information about these needs is up-to-date and (approached properly) can help to highlight unforeseen problems and issues. User involvement is an important principle in many aspects of design and research but is particularly important when working with groups that have traditionally been marginalised. Directly involving users also improves the credibility of results with users and their allies, in line with the principle of "nothing about us, without us".

There is a long history of designing technological solutions for people with disabilities that have made more or less reference to user needs and the context in which they will be used. Designing technology for people with disability, but not in collaboration with them, has been shown to be problematic in

several important ways. Authors note that one third of assistive devices are abandoned after acquisition, with a poor match between person and technology often the reason (Scherer and Craddock, 2002). Problems have often arisen where technology has not made reference to needs that it may be instrumental in meeting, for example, researchers have set out to meet the needs of carers or service providers rather than users themselves and where there is insufficient account taken of the context of use (Harris, 2010; Larsson Ranada and Lidström, 2017).

Further, models of understanding of deafblindness have relevance for the design of research. At the simplest level, a particular viewpoint on the problem research is trying to solve will have implications for the solutions generated. If deafblindness is seen as a deficit and the problem conceptualised as being one of insufficient care funding, it may lead to the design of systems of technological surveillance and checking on persons with deafblindness. If the problem is seen as one of a lack of accessibility, it may lead to an emphasis on environmental adaptation. Although different conceptions of problems might direct the researcher to different solutions, it is also essential to understand the conceptual differences in how deafblindness is understood and how these are negotiated by persons with deafblindness in society as a prerequisite for relevant design solutions.

Levels and Types of User Involvement

There are many different levels and types of user involvement. An influential model was developed by Arnstein (1969) in relation to citizen participation in planning, where degrees of participation are likened to positions on the rungs of a ladder. Degrees of involvement are compared, ranging from manipulation and therapy at the lowest end, through informing, consultation and placation, to partnership, delegation and citizen control at the higher end. Greater control over processes is rated more highly and this has resonated with organisations of people with disabilities because of their historical exclusion from organisational agendas and processes.

More recently greater attention has been paid to research roles in the various stages of research. Potential roles in research include:

- Identifying topics for research
- Commissioning and tendering
- Advising
- Taking part in research
- Analysing results
- Testing of prototypes
- Reporting
- Evaluating
- Disseminating results

Druin (2002), for example, notes that children may be engaged in participatory design processes as users (market research at the beginning of a project), testers (testing and giving feedback on a nearly complete design), as informants (providing information and being consulted throughout the design process) and designers (taking an active role in generating and evaluating ideas).

The same issues are emphasised in the design literature. *ISO 9241-210:2010, Ergonomics of human-system interaction— Part 210: Human-centred design for interactive systems*, sets out six basic

principles: design is based upon an explicit understanding of users, tasks, and environments; users are involved throughout design and development; the design is driven and refined by user-centred evaluation; the process is iterative and the design addresses the whole user experience and the design team includes multidisciplinary skills and perspectives.

For people with deafblindness, involvement needs to be purposeful, well matched to tasks, properly supported and meaningful in terms of having an impact on the research process. People with deafblindness are more excluded than many other groups, are often left out of discussions due to the communication barriers they experience, and can find themselves excluded, even from the Disability movement (WFDB, 2018). Therefore, it is important that involvement is especially well planned in advance, not tokenistic, and with effective and reliable supports in place. Involvement often entails more time, effort and funding than is usually recognised and therefore specific resources need to be allocated.

Interviewing People with Deafblindness: research studies

Not many empirical studies that involve participants with deafblindness discuss methodological issues in any detail. Nevertheless, those that do are discussed in this section.

Methods

In line with the project task specifications we reviewed a more select literature on interviewing people with deafblindness. A search of Web of Science and Scopus databases, between 2010 and 2019 inclusive, using the search terms 'deafblind* + interview*' each gave fourteen results, ten of which were the same and four different. We also checked abstracts identified through wider Web of Science and Scopus searches using the term deafblind*, which yielded essentially the same results.

From this group of eighteen, five were excluded on the basis that three did not cover the subject sufficiently and two by the same authors covered the same material as others. A search was also carried out through Google scholar, resulting in two additional reports, which were also added to the total, resulting in fifteen publications. We carried out a further search of the database *Nationellt kunskapscenter för dövblindfrågor*, from which 38 papers were identified as relevant, of a total of 98. Elimination of repetitions, and those that did not involve interviews with people with deafblindness, or that concerned clinical trials or health – related diagnosis, left 17 papers. Three further literature reviews were also included, together with observations and recommendations from experts in the area of people with deafblindness. Articles included are listed in Appendix 1.

Research Studies

Only two articles (Arndt, 2011; Evans, 2017) were explicitly concerned with methods. Most of the publications were more centrally concerned with issues faced by people with deafblindness and contained shorter sections describing how the research was carried out. For example, Hersh (2103) interviewed people with deafblindness in several European countries about communication and accessibility issues in assisted technology. Other studies report on the travel experiences of people with deafblindness (Azenkot et al., 2011; Hersh, 2016) on inclusion in mainstream schools (Kamenopoulou, 2012), promoting learning and education in schools (Ingraham and Andrews, 2010), and on the perceptions of people with deafblindness on their social networks (Arndt and Parker, 2016).

Most studies acknowledged the difficulties involved in making contact and many recruited participants through organisations of and for people with deafblindness. Recent literature reviews conducted by Simcock (2017a; 2017b) have noted that research studies involving people with deafblindness have often recruited active members of organisations of and for deafblind people, with snowball recruitment often effective (Rector et al, 2015). As noted above, there is evidence about the lack of representation of individuals with deafblindness from ethnic minorities (Hersh, 2013), children and young people with deafblindness (Simcock, 2017a, 2017b), few narratives from women and from people with congenital deafblindness (Jaiswal et al. 2018). Some authors also note the limitations of their sample in that people who are less advantaged were absent due to not having access to the setting under investigation (Kamenopoulou, 2012).

Communication Arrangements

It is essential that arrangements for effective communication are made with the individuals concerned before interviews take place. The World Federation of the Deafblind (2018) provides a non – exhaustive list of options for support services and technology for communication, mobility and descriptions, as follows:

- Interpreter - Guide: assistance, including with communication and mobility, according to individual requirements;
- Devices for hearing: hearing aids, cochlear implants, loop systems;
- Devices for reading and writing: Braille reader and / or display, which enables one and/or two-way communication via computers, smartphones and other devices using Braille;
- Mobility devices: red and white striped canes

Various means of communication are also described:

- Tactile communication: tactile sign language, tactile fingerspelling and tactile alphabet;
- Tadoma: communication through jaw movements, vibrations and the facial expressions of the speaker;
- Visual frame interpreting: sign language adapted to fit a limited field of vision with a person who has some degree of residual sight;
- Clear speech: effective for many people who have some degree of residual hearing;
- Braille: a system of representing letters through raised dots;
- Moon: similar to Braille but raised, adapted capital letters are used;

These are not stand-alone options and several may be used together, according to the requirements of each individual and the context.

Arndt (2011) reports on the choices made in the course of her doctoral research when, as a hearing and sighted researcher, she conducted interviews with nineteen college students with deafblindness. Mindful that usually people with hearing take decisions affecting the wellbeing of people with deafblindness, she notes the importance of acknowledging deaf and deafblind cultures, while acknowledging that the reliance on visual means of communication within d/dDeaf culture (for an explanation of this see Ladd, 2002; Kusters and de Meulder, 2018) may leave people with deafblindness feeling excluded. Despite fluency in American Sign Language (ASL), challenges of "determining communication needs, finding an effective recording method and translating signed and spoken video-taped material into written English" are identified (Arndt, 2011:207). She took steps to

reduce the amount of translation by using ASL and Hersh (2013) by speaking in native languages during her European research.

Additionally, Evans (2017: 2334) highlights the importance of using '*Multiple Sensory Communication and Interview Methods*' (MSCIM) in order to acknowledge and address the individual's communication needs, which encourage participants to share their personal experiences. Each method can present limitations and strengths in relation to people with deafblindness, as follows (this table builds on Evans' work and adds findings from several studies):

Table 1: Strengths and Weaknesses of Interview Methods

Method	Strengths	Limitations
Telephone interview	Can give more control to the participant. Allows flexible geographical location.	Not possible for a sighted interviewer to observe body language.
Skype with video off	May be experienced as more equal and fair by the participant. (Neither the interviewer or participant can see the other). Allows flexible geographical location	Research process may be hindered by poor reception or transmission. This may interrupt the participant's or researcher's train of thought or discussion of sensitive issues.
Face to face	Enables use of residual sight and hearing. Participant can be spontaneous and interact with the researcher, supported by translators and family members.	The participant may feel uncomfortable in the presence of the researcher (as an unknown person). Negative previous experiences with assessment interviews can influence the process if it is a new experience.
E-mail interview	Participant can take more time to think about the questions and reply using assistive technologies e.g. voice, Braille.	Answers and opportunities to ask for clarification are likely to be more limited.
Visual frame sign language	Enables use of residual sight.	Participant may feel uncomfortable If their regular sign interpreter is not available
Hands on sign language	Allows the participant to use their sense of touch to communicate.	Numbers of sign interpreters are often limited. Participants may feel uncomfortable If known tactile interpreters are not available.

Clearly certain means of communication will necessitate various arrangements. Evans (2017) points out that in order to meet the needs of participants with deafblindness in research, it is necessary to consider different forms of communication and to allow individuals to choose their own way to

participate and communicate during the interview process. While some studies use samples from other contexts (i.e. USA, Japan) the findings have relevance for other countries as well. For instance, in Ingraham & Andrews (2010) the participants describe technologies that assist them in reading print for instance, visual and tactile kinaesthetic strategies. Results show that each participant has a unique configuration of sensory abilities and understanding these configurations will help to help to construct different scenarios. For instance, one participant received instruction in tactile sign language, Braille and sign language, while the others received instruction in large print, speech and later Braille. As previously noted, people with congenital deafblindness may face particular problems in participating in research activities.

Trust is identified as an important prerequisite for successful interviews. Research has shown that the geographical location has an explicit role and can affect the knowledge generated because it can allow participants to feel comfortable enough to share their experiences (Anderson et al, 2010; Evans, 2017). Likewise, where assistance is required, the opportunity to choose the interpreter is important. Evans (2017) mentions the importance of including voice-over in order to reduce misunderstanding in interpretation in those cases where sign language communication is selected by the participant. If a participant choses their own interpreter, a person they feel comfortable with, this can help to reduce the anxiety, apprehension and fear that could occasion misinterpretation. Signs may have multiple interpretations and consequently some signs may be lost or misunderstood in the process (Obasi, 2014).

As Hersh (2013) points out, much literature equates independence with the ability to carry out functional tasks without assistance and support is often considered as something necessary to accomplishing these functional tasks. However, disability studies literature and indeed current human rights law and policy, takes a broader view, where independence is seen in terms of interdependence with other people, inclusion as part of society and as a prerequisite to the opportunity to contribute. According to the social model of disability (Oliver and Barnes, 2012) necessary adjustments must be made to the environment to remove barriers and ensure full participation in society. Good practice in involvement and interviewing necessitates an orientation towards the latter, broad understanding.

Interviews with Research Participants during the SUITCEYES Project

This section covers the experiences of researchers from the SUITCEYES project in relation to interviewing people with deafblindness in the five countries (Germany, Greece, Netherlands, Sweden and UK). First, we discuss the methods used, then the issues that emerged from practice. The accessible materials used by interviewers are not covered in this deliverable: for examples of these, please refer to Deliverable 8.4 Project identity III.

Methods

A protocol was developed (see Appendix 2), with input from academics working on all the work packages and from expert advisors. Each work package developed questions, which were then rationalised and set out in a schedule. The overall aim of the interviews was to develop an understanding of whether and how new haptic technologies might be useful in everyday life, as well as the types of opportunities and barriers that affect their availability and use by persons with deafblindness. Because very little is known about the subject, we aimed to ask broad open-ended questions in order to not limit the potential information received. The overall questions for the interviews were as follows:

- What are the experiences and aspirations of persons with deafblindness in relation to independent living?
- What are the experiences and views of persons with deafblindness on gaining access to relevant and useful technology?
- What are the experiences and views of persons with deafblindness on using technology and haptic technology in particular?

Ethical approval for the study was secured in each country from appropriate authorities.

Fifteen interviews with people with deafblindness, family members, translators and others were carried out in each country, making a total of 75 interviews. Each team aimed to recruit a diverse sample in terms of age, geographical location, rural / urban living, household situation and impairment. The overall emphasis was on interviewing people with deafblindness themselves, in recognition of their frequent omission from research that is about them and following advice from expert advisors. It was recognised that by interviewing people with deafblindness we also frequently developed opportunities to interview others because professionals and family members were often gatekeepers. There were challenges in recruiting people with deafblindness (also noted above by other authors) and typically, sustained efforts were needed by interviewers to find and recruit participants.

Most interviewers approached a range of organisations of and for people with deafblindness as a source of contacts and combined this with snowballing. A range of materials were developed for recruitment purposes (see Deliverable 8.4 Project Identity III) and these were also customised when used in practice.

Advance arrangements were also made with participants on an individual basis for communication support. Some people needed no particular additional support and took part without others present. In other instances, interpreter- guides, family members and / or others took part in shared conversations, which were based on the presence of people with deafblindness. People with congenital deafblindness were more likely to require this kind of assistance. In other instances, family members or others took part in interviews as proxy respondents, offering their perspective on behalf of individuals with deafblindness and in further examples, professionals offered a more general point of view through interviews. (It should be noted however that this more general perspective was available to researchers through the Project Advisory Group so was less of a focus for interviews).

Consent was obtained before starting interviews and for recording the interview using audio and / or video. Following this, recordings were transcribed and translated into English and all were anonymised before they were shared with other members of the project. Analysis of user needs was carried out by the University of Leeds to inform the development of personas and scenarios.

We do not claim to have been able to follow all elements of best practice at all times in the project. The realities of time and funding impinged on what could be carried out in the time available and some interviewers were new to interviewing people with deafblindness. Some had also not anticipated the amount of effort necessary to find and recruit participants or to make arrangements for successful communication. Others did not initially fully understand the rationale for qualitative research, for asking open ended questions or about how to make adjustments to the style of questions as necessary. On the other hand, some interviewers had a good understanding of these issues and were very experienced.

In retrospect, it would have been beneficial to arrange training for interviewers and partners at the beginning of the project and to allocate resources for this. Work on the identification of user needs did not start until the project had been running for three months, due to administrative delays, by which time there less scope for preparatory work.

Nevertheless, we have been able to gain access to rich data and obtain an insight into the lived experiences of people with deafblindness and the context in which the Haptic Intelligent Personalised Interface - HIPI (see Deliverable 2.1) may be used. Interviewers who were new to the process learned rapidly and we were encouraged by the enthusiasm and interest of many participants.

The next section discusses some elements of good practice identified by the project from our experiences.

A Summary of Findings from Interviews in the SUITCEYES Project

Here we discuss a number of issues related to interviewing people with deafblindness and their supporters. Each country team offered a number of points based on their experiences and these are summarised below.

Information about the project

Although approval boards encouraged detailed information statements and consent forms, often more straightforward documents were more accessible for participants with deafblindness (Sweden, UK). Lengthy documents with complex words could be worrying and off-putting for some people and the expense and time involved of translating long documents was also problematic for people with low incomes and scarce access to translators (UK). Therefore, accessible formats were developed. It was important to allow enough time for drafting these and for getting them produced (e.g. audio recordings, Braille literature, easy read materials etc.).

Recruitment and Preparation

All interviewers opted to make contact with people through gatekeepers, mostly organisations for people with deafblindness. In some instances (Greece and UK) organisations themselves refused to participate, while others were enthusiastic.

Interviewers sent out information to potential recruits to explain the research and request applications. Broad, generic approaches, for example through social media, did elicit some replies but the overall rate was low (UK). Many of those who responded were people who were already well connected to the communities or groups of people with deafblindness (Netherlands, UK) and who were interested in new devices. It was more difficult to easily find potential participants without these connections.

Trusted people were very helpful in ensuring that people with deafblindness felt comfortable taking part (Greece, UK). For example, one interviewer remarked: "People accepted being interviewed only after a trusted organisation / association or caregiver approached them and suggested they should participate." Snowballing was an effective method, a finding echoed in the research literature described above.

Whether to involve carers and family members was a subject of considerable discussion by project partners. Input from a range of people was considered to be valuable for understanding the needs of people with cognitive impairments (Germany, Greece, UK) while for people with residual hearing often no additional interpretation was needed (Greece, Sweden, UK). Many people with deafblindness are well able to represent themselves (Sweden, UK). Project advisors strongly suggested that the emphasis should be on recruiting people with deafblindness themselves to ensure that they were not left out of the process and the discussion was resolved in this way, while also allowing for the inclusion of contributions from others.

Some interviewers (Greece, UK) noted the poor experiences of people with deafblindness with regard to research. For example, some had negative experiences of eligibility assessment by professionals

(UK) and / or experienced research fatigue through having been approached by students many times to take part in interviews for their college studies (Greece).

Where long distances were involved, interviewing at distance was sometimes a pragmatic option, for example, via phone or Skype (Sweden, UK). Another option was to use written communication (Sweden). In these instances, it was important to have a thorough grasp of any technology used and to make sure it was accessible to participants and they were comfortable with it (Sweden).

Carrying out Interviews

Advance preparations were necessary to ensure arrangements for communication, such as the availability of interpreters and / or interpreter – guides. This was not always necessary as many participants could communicate without intermediaries (Sweden). The recommendation from this was therefore for researchers to keep an open mind, to assume capability and also to ensure support was available as needed, on a scale of starting from less and moving to more, as needed.

More time was needed to set up interviews compared with typical interviews with non-disabled people, and the arrangements were more complex. It was important to allow sufficient time for this (Sweden).

Where tactile or sign language interpretation was necessary, many arranged it with services that participants relied on and interviews were likely to be held on the premises of support organisations (Germany, Greece, UK). This often meant that interpreters were known and trusted, but it also suggests that these participants had less choice about where to meet compared with people who did not use support from others.

Open ended questions were effective in helping many participants to explain what was important to them (Greece, Sweden, UK). It was important to allow enough time for participants to answer questions fully (Sweden). However, abstract concepts and hypothetical questions were more difficult for some participants who found narrower, more focussed questions more accessible. Therefore, it was important to tailor information to the individual and to respond flexibly to what people with deafblindness said in the interviews (Germany). The order of questions could be changed, the questions themselves adapted and additional questions asked (Germany, UK).

An empathetic stance and trying to understand how the interview might be experienced by participants with deafblindness was very important (Sweden, UK).

If interviewers are able to sign, this is clearly helpful. Unfortunately, this was not the case with the SUITCEYES project, although some interviewers did however learn some signs and were happy to be touched so participants could 'see' what they looked like (UK). This could perhaps be offset with the fact that many interviewers had technical knowledge about the technology under development and so could explain how it would work and the potential uses.

Recording and Analysis

All interviews were recorded, with the permission of participants. In some instances, video as well as audio recordings were made, to allow analysis of gestures and other expressions, which would be otherwise lost through the spoken translation of interpreters. Although this degree of detail is not a

requirement for the project, it would allow further analysis to be carried out in relation to non – verbal communication if wished (UK).

Several interviewers emphasised the importance of being familiar with equipment, making sure spare batteries were carried and knowing how to adjust equipment (Germany, UK).

Assumptions and Expectations

It was important to not make assumptions about what people could do based on their impairments (Netherlands, UK). For example, while many interviewees said that they avoided going to unfamiliar places by themselves, one participant who was completely deaf, had tunnel vision of only 5 degrees and who did not speak, went on international flights to unfamiliar places by himself (Netherlands). In another instance, a participant with little speech and who processed information very slowly, was an accomplished sculptor, taking on paid commissions to produce very professional work for public display (UK).

Interest in Participating

Many participants stated that they enjoyed the interviews and the conversations (Netherlands, UK), expressed interest in taking part in prototype testing during later stages of the project and in receiving information about progress (Netherlands, UK). It was considered important to be honest and not promise things such as opportunities to participate further if they were in fact unlikely to materialise for everyone involved (UK). Participants were given details of how to track the progress of the research and to keep in touch where this was possible.

Conclusion

In this deliverable we have aimed to describe best practice in engaging people with deafblindness in research. The discussion has emphasised that grouping people with deafblindness together on the basis of impairment is not always very meaningful, due to the diversity of the people involved.

From our review of previous research it is clear that people with deafblindness have been largely omitted in research studies and very little has been written on methods for involving people with deafblindness. In those studies that have been carried out, people with congenital deafblindness have often been omitted, even though they might be the greatest beneficiaries of new design and policy developments. This arises from a number of factors and is not always deliberate, but clearly a purposeful approach to involvement is necessary to reverse this.

Compared with involving non-disabled participants, more time, effort and expense is required for effective involvement. This can raise problems in a research climate that emphasises efficiency and control over costs. It is important, however, to make good use of resources and we suggest that if a project such as this is to be truly user focussed, involvement should be planned for and ensured from the beginning. Training for researchers, especially if they have not worked before with the potential users, should be scheduled from the start and in an interdisciplinary project should incorporate guidance on the logic of research as well as an orientation to values, assumptions and models.

There is also much scope for increasing the participation of people with deafblindness in research beyond involvement as the subjects of research. Co-production in all stages of research should be a logical next step, to permit the development of further relevant research agendas and relevant design.

Bibliography

Anderson, J., Adey, P. and Bevan, P. (2010) Positioning place: Polylogic approaches to research methodology, *Qualitative Research*, 10(5), pp. 589–604.

Arndt, K., and Parker, A. (2016). Perceptions of social networks by adults who are deafblind. *American Annals of the Deaf*, 161(3), 369–383

Arnstein, S.(1969) A Ladder Of Citizen Participation, *Journal of the American Planning Association*, 35: 4, 216 — 224

Arndt, K. (2011) Conducting Interviews with People Who Are Deafblind: Issues in Recording and Transcription, *Field Methods,* 23(2) 204 – 214

Ask Larsen F. and Damen S. (2014) Definitions of deafblindness and congenital deafblindness. *Research in Developmental Disabilities*, 35(10):2568–76

Azenkot, S., Sanjana, P., Borning, A., Fortuna, E., Ladner, R.E., Wobbrock, J.O. (2011) Enhancing independence and safety for blind and deaf-blind public transit riders *CHI '11 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems,* Vancouver, BC, Canada — May 07 - 12 pp. 3247-3256

Dammeyer, J (2014). Deafblindness: A review of the literature. *Scandinavian Journal of Public Health,* 42(7) 554-562

Druin, A. (2002) The Role of Children in the Design of New Technology, *Behaviour and Information Technology* 21(1) 1-25

Evans, M. (2017). Empowering People Experiencing Usher Syndrome as Participants in Research, *British Journal of Social Work,* 47(8) 2328-2345

Fernandez-Valderas, C., J. Macias-Seda, et al. (2017). Experiences of deafblind people about health care, *Enfermeria Clinica*, 27(6) 375-378

Harris, J. (2010) The use, role and application of advanced technology in the lives of disabled people in the UK, *Disability and Society*, 25(4) 427 – 43.

Hersh, M. (2013) Deafblind People, Communication, Independence, and Isolation, *Journal of Deaf Studies and Deaf Education* 18(4) 446-463

Hersh, M. (2016). Improving Deafblind Travellers' Experiences: An International Survey, Journal *of Travel Research.* 55(3) 380–394

Inclusion London (2015) *The Social Model of Disability: Factsheet*, Available from: https://www.inclusionlondon.org.uk/disability-in-london/social-model/the-social-model-of-disability-and-the-cultural-model-of-deafness/

Ingraham, C. and Andrews, J. (2010) The Hands and Reading: What Deafblind Adult Readers Tell Us, *British Journal of Visual Impairment*, 28(2) 130-138

International Organization for Standardization (2015) *ISO 9241-210:2010 Ergonomics of human-system interaction -- Part 210: Human-centred design for interactive systems,* https://www.iso.org/standard/52075.html

Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M. and Finlayson, M. (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. *PLoS ONE* 13(9): e0203772. https://doi.org/10.1371/journal.pone.0203772

Kamenopoulou, L. (2012) A study on the inclusion of deafblind young people in mainstream schools: key findings and implications for research and practice, *British Journal of Special Education*, 39(3)

Kusters, A. and de Meulder, M. (2018) Understanding Deafhood: In Search of Its Meanings, American *Annals of the Deaf*, 157(5) 428-438

Ladd, P. (2002) *Understanding Deaf Culture: in search of deafhood* Clevedon, England: Multilingual Matters

Ladner, S. (2015) Design for User Empowerment, *Interactions,* 22(2) 24-29

Larsson Ranada, Å. and Lidström, H. (2017) Satisfaction with assistive technology device in relation to the service delivery process— a systematic review, *Assistive Technology*, DOI: 10.1080/10400435.2017.1367737

Obasi, C. (2014) Negotiating the insider/outsider continua: A black female hearing perspective on research with deaf women and black women, *Qualitative Research*, 14(1) 61–78.

Ogrinc, M., Farkhatdinov, I., Walker, R., and Burdet, E. (2017) Horseback riding therapy for a deafblind individual enabled by a haptic interface, *Assistive Technology*, 30(3) 143-150

Oliver, M. and Barnes, C. (2012) *The New Politics of Disablement*, Basingstoke: Palgrave Macmillan

Rector, K., Milne, L., Ladner, R.E., Friedman, B., Kientz, J.A. (2015) Exploring the Opportunities and Challenges with Exercise Technologies for People who are Blind or Low-Vision, *Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility*, 203-214

Scherer, M., & Craddock, G. (2002) Matching person & technology (MPT) assessment process. *Technology and Disability*, 14, 125–13

Scherer, M.J., MacLachlan, M., and Khasnabis, C. (2018) Introduction to the special issue on the first Global Research, Innovation, and Education on Assistive Technology (GREAT) Summit and invitation to contribute to and continue the discussions, *Disability and Rehabilitation: Assistive Technology*, 13(5) 435-436

Simcock, P. (2017a) One of society's most vulnerable groups? A systematically conducted literature review exploring the vulnerability of deafblind people, Health *and Social Care in the Community*, 25(3) 813–839. doi:10.111/hsc.12317

Simcock, P. (2017b) Ageing with a unique impairment: A systematically conducted literature review of older deafblind people's experiences, *Ageing &Society* 37(8) 1703-1742 doi:10.1017/S0144686X16000520

Wolsey, J. A. (2017). Perspectives and Experiences of Deafblind College Students. *The Qualitative Report*, *22*(8) 2066-2089

Wittich, W., Southall, K., Sikora, L., Watanabe, D.H., Gagné J-P. (2013) What's in a name: Dual sensory impairment or deafblindness? *British Journal of Visual Impairment* 31(3) 198–207

WFDB (2018*) At risk of exclusion from CRPD and SDGs implementation: Inequality and Persons with Deafblindness*, World Federation of the Deafblind: http://www.internationaldisabilityalliance.org/sites/default/files/wfdb_complete_initial_global_report_september_2018.pdf

Appendix 1: Literature on Interviewing People with Deafblindness identified through searches

(Note: the literature listed here overlaps with that in the bibliography)

Arndt, K. (2011) Conducting Interviews with People Who Are Deafblind: Issues in Recording and Transcription, Field Methods 23(2) 204 – 214

Arndt, K., and Parker, A. (2016) Perceptions of social networks by adults who are deafblind, *American Annals of the Deaf*, 161(3) 369–383

Azenkot, S., Sanjana, P., Borning, A., Fortuna, E., Ladner, R.E., Wobbrock, J.O. (2011) Enhancing independence and safety for blind and deaf-blind public transit riders *CHI '11 Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, Vancouver, BC, Canada — May 07 - 12 3247-3256

Azenkot, S. and E. Fortuna (2010) *Improving Public Transit Usability for Blind and Deaf-Blind People by Connecting a Braille Display to a Smartphone*, New York, Assoc. Computing Machinery

Evans, M. (2017). Empowering People Experiencing Usher Syndrome as Participants in Research, *British Journal of Social Work* 47(8) 2328-2345

Fernandez-Valderas, C., J. Macias-Seda, et al. (2017) Experiences of deafblind people about health care, *Enfermeria Clinica*. 27(6) 375-378

Hersh, M. (2013) Deafblind People, Communication, Independence, and Isolation, *Journal of Deaf Studies and Deaf Education* 18(4): 446-463

Hersh, M. (2016). Improving Deafblind Travellers' Experiences: An International Survey*, Journal of Travel research* 55(3) 380–394 DOI: 10.1177/0047287514546225

Hierholzer, A. C. and J. Bybee (2017). Working with Randolph-Sheppard Entrepreneurs Who Are Deafblind: A Qualitative Analysis. *Journal of Visual Impairment & Blindness* 111(1) 61-71

Ingraham, C. and Andrews, J. (2010) The Hands and Reading: What Deafblind Adult Readers Tell Us, *British Journal of Visual Impairment,* 28(2) 130-138

Jaiswal, A., Aldersey, H., Wittich, W., Mirza, M. and Finlayson, M. (2018) Participation experiences of people with deafblindness or dual sensory loss: A scoping review of global deafblind literature. PLoS ONE 13(9): e0203772. https://doi.org/10.1371/journal.pone.0203772

Kyle, J. and Barnett, S. (2012) *Deafblind Worlds* Bristol: Deaf Studies Trust and Sense, http://www.deafstudiestrust.org/files/pdf/reports/Deafblind%20Worlds-%20final.pdf

Martens, M.A., Janssen, M.J., Wied, A.J.J. Ruijssenaars, J.M., Huisman, M. and Riksen – Walraven, J.M. (2017), Fostering Emotion Expression and Affective Involvement with Communication Partners in People with Congenital Deafblindness and Intellectual Disabilities, *Journal of Applied Research in Intellectual Disabilities*, 30 874-884

Nakajima, S., Okochi, N., Iizumi N., Tsuru, M., Mitobe, K. and Yamagami, T. (2017) The Possibility and Challenges for Deaf-Blind Individuals to Enjoy Films in Theater, Journal *of Advanced Computational Intelligence and Intelligent Informatics* 21(2) 350-358

Rector, K., Milne, L., Ladner, R.E. Friedman, B., Kientz, J.A. (2015) Exploring the Opportunities and Challenges with Exercise Technologies for People who are Blind or Low – Vision, *ASSETS '15 Proceedings of the 17th International ACM SIGACCESS Conference on Computers & Accessibility*, Lisbon, Portugal — October 26 – 28, 203-214

Scherer, M.J., MacLachlan, M., and Khasnabis, C. (2018) Introduction to the special issue on the first Global Research, Innovation, and Education on Assistive Technology (GREAT) Summit and invitation to contribute to and continue the discussions, *Disability and Rehabilitation: Assistive Technology*, 13(5) 435-436

Wolsey, J. A. (2017). Perspectives and Experiences of Deafblind College Students. *The Qualitative Report*, 22(8) 2066-2089

Appendix 2: SUITCEYES Work Package 2 Interview Protocol

SUITCEYES

Work Package 2 Interview Protocol

Current Version: 3

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NOTE: This protocol was developed as an internal working document rather than a final complete version for publication

Introduction

This protocol provides a framework for qualitative interviews with people with deafblindness[2], as a core task for WP2. Interview data will provide information on user needs that can inform the project as a whole about the context in which haptic technology is used and the personas and scenarios for which the HIPI might be developed.

From this wide and general understanding of important opportunities, problems and issues, we aim to develop an understanding of:

- How (and if) haptic technologies can be useful in everyday life, and
- The types of opportunities and barriers that affect their availability and use by persons with deafblindness.

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[2]Terminology is both important and a complex issue and in each country the most culturally respectful terms should be used. This is almost always the term(s) preferred by people who themselves have the particular condition concerned. In many countries 'people with disabilities' is the most respectful term. In the UK and in some international organisations people with impairments prefer the term the 'disabled people' over 'people with disabilities' because here 'disability' is used to refer to societal discrimination rather than impairment.

The specific research questions we aim to answer through the interviews are:

1. What are the experiences and aspirations of persons with deafblindness in relation to independent living?
2. What are the experiences and views of persons with deafblindness on gaining access to relevant and useful technology?
3. What are the experiences and views of persons with deafblindness on using technology and haptic technology in particular?

The reasons why these questions are important for the project are discussed in the section below.

1. Independent Living

Independent living is central to the concerns of persons with deafblindness and to people with disabilities as a whole. The following quote from the European Network on Independent Living (ENIL) sets out the main features:

> Independent living is possible through the combination of various environmental and individual factors that allow disabled people to have control over their own lives. This includes the opportunity to make real choices and decisions regarding where to live, with whom to live and how to live. Services must be available, accessible to all and provided on the basis of equal opportunity, free and informed consent and allowing disabled people flexibility in our daily life. Independent living requires that the built environment, transport and information are accessible, that there is availability of technical aids, access to personal assistance and/or community-based services. It is necessary to point out that independent living is for all disabled persons, regardless of the gender, age and the level of their support needs.

In line with the description above therefore, independent living is not about doing everything for oneself but about having the same choices and control over everyday life, with appropriate assistance. This is in contrast with the marginalisation from society that has often been a mark of service provision and lack of control over daily life.

The right to independent living, environmental accessibility and other key human rights are enshrined in law in Article 19 of the United Nations Convention on the

Rights of Persons with Disabilities (CRPD)[3]. All countries taking part in the SUITCEYES project have signed up to being bound by the CRPD, with many signing and ratifying an Optional Protocol[4] that brings the Articles into national law. The European Commission, as an international body, is also a signatory of the CRPD.

2. Use of Technology

People with disabilities are often enthusiastic about the potential benefits that technology can offer but research has noted that devices have often been abandoned early and remain unused (Harris, 2010; Larsson Ranada, & Lidström, 2017; Perfect et al., 2018). Problems identified include a lack of involvement of people with deafblindness in product design as well as problems in how products are made available to users. The early identification of user needs therefore presents an opportunity to identify scenarios where the HIPI can be of most use.

In the WP2 interviews we are less concerned with the fine detail of how individual people will use the technologies in practice (which will be covered in the feedback consultations carried out in WP4 and WP7) and more with the wider issues about what would be most useful to people with deafblindness. However, we intend that these interviews will make it easier to recruit people with deafblindness later on in the project.

While we should not anticipate the results of interviews, a few issues have been noted in previous studies. Access to information may be an issue. With rapid developments in technology, users may simply not be aware of already available technology that could be useful to them. This includes access to learning about how to use devices, for users and others such as assistants and family members.

The cost of devices has also been reported as a problem. A few people may be wealthy enough to afford devices from their own funds but this is often not the case as persons with deafblindness often experience poverty (World Health Organization, 2011). Further, people with deafblindness have reported having to spend a high proportion of their income on support (European Deafblind Network, 2014). Consequently, they must often rely on being judged eligible for government or social insurance funding, the pathway for which is usually through an assessment of need. In

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[3] CRPD: http://www.ohchr.org/EN/HRBodies/CRPD/Pages/ConventionRightsPersonsWithDisabilities.aspx see especially Articles 9, 19 and 26

[4] European Agency for Fundamental Rights: *Has your country accepted the CRPD?* http://fra.europa.eu/en/theme/people-disabilities/ratified-crpd

this instance, cost savings or other priorities may override the actual needs or preferences of the individual user.

However the rapid pace of change and availability of new apps and devices at lower cost means that the situation may be changing. New apps have recently been made available at low cost or free. Interview data will allow us a picture of the international situation in several European countries that is up to date, with an eye to the future.

3. Methods

Guidance on how to arrange the qualitative interviews that are part of WP2 is set out in this section. It does not provide a complete and comprehensive guide to the method of qualitative interviewing for those who are new to this, because this is such a large subject. It is assumed that interviewers will have some knowledge and experience of this already, even if some aspects of the task are new.

However, we aim to provide additional guidance in interviewing methods, if needed, through monthly meetings that will be held throughout the interviewing phase. Please note that at this point this protocol also does not provide full details on the analysis and use of data generated in the interviews, which will be elaborated further by the User Data Working Group (UDWG).

The data on user needs will later be analysed in several ways, as follows:

i) cross – sectionally , where answers to the same questions are compared with each other. This comparison will allow the identification of themes that can in turn be used to ensure relevance to a wide range of users' needs.

ii) non-cross sectionally, where answers to all questions for one person are considered, to get a picture of how all the issues fit together. This data can underpin the development of personas for the project.

In this way the data will be used to understand user needs and to develop personas and scenarios for the project. They will also inform the related policy analysis.

4.1 The Sample

The project will benefit from including a diverse sample of persons with deafblindness, reflecting the population as a whole. Therefore, each country should recruit a balance of men and women, different ages, and a mix of people who have been born deafblind and those who have developed deafblindness in later life, as well as those with more or less impairment. We should also aim to interview people in a range of situations, for example urban / rural locations, variety of living arrangements, various parts of the country, etc. The aim is not to create a statistically representative

sample, but to reflect a broad variety of experiences and views in each country in order to capture as diverse a range of views and experiences as possible.

4.2 Recruitment

Fifteen adult people with deafblindness should be interviewed in each of five countries (Germany, Greece, Netherlands, Sweden and United Kingdom). In line with advice from PAB members knowledgeable about deafblindness and related issues the focus is on interviewing persons with deafblindness themselves as informants. Others (e.g. interpreters, family members, carers etc.), should be involved as appropriate, rather than as the main respondents. Reflecting the basic premise of the World Deafblind Union of 'Nothing About Us Without Us', and advice from the Association of the Swedish Deafblind, involvement of others should be with the agreement and instigation of persons with deafblindness themselves. It is recognised that many people with deafblindness will opt to have other people present in the interview and involvement of others may allow people who need more support to take part in interviews. This issue is an area where interviewers need to use their judgement according to circumstances.

In all countries it is appropriate to ask organisations *of* Deafblind, Deaf and / or blind people to gain their advice on recruiting strategies. Where there are none, it is also appropriate to contact organisations of people with disabilities and international organisations of persons with deafblindness, as well as service providers. We suggest that interviewers aim to ensure that participants are recruited from a number of different points of contact rather than just one organisation.

People should want to participate and interviews should only take place with informed consent. Potential participants should be given information beforehand and a way of contacting researchers within a given time. This information should be given to participants before the interview in an easy to understand format. Project descriptions should be in everyday, national language, without specialist academic words and in forms accessible for each person (e.g. Braille, voice recording etc.).

If it is possible to attend a meeting beforehand, this can be a very useful way for potential participants to decide whether they want to take part, through asking questions and finding out more information. The arrangements for interviews should also be agreed beforehand, including the choice of place to meet, communication requirements and other relevant issues.

4.3 Interviews

All interviews should be arranged at accessible locations that are convenient, safe and non-threatening for participants. In many instances this will be the participant's home

but where this is not the case, the venue should be decided upon together with the participant. Interviews should not take place in public spaces, such as cafes or public meeting halls where others not participating in the interview are present. (In other words, the interviewer should make sure that the information is confidential to the people taking part in the interview).

A semi – structured interview format should be used, to provide an overall structure that is comparable between individuals and countries, while allowing flexibility in practice to ask follow up questions about individual circumstances. Interviewers should use the schedule in this protocol, which gives main questions with additional sub – questions that can be asked as appropriate. While some informants may give answers that cover these sub – questions, others may find prompting helpful. Culture, processes and systems differ in the various countries and therefore questions are likely to need to be adapted as appropriate. Interviewers should use their initiative in asking questions and feel free to ask their own follow up questions as well.

Questions that have a yes / no answer have been avoided in order to not close down the conversation. Those that have short answers have been left until the end, for this reason.

Questions about the details of participants' impairments or disabilities have also been left until the end of the interview, in line with a person first rather than disability first approach. (As noted above however, access requirements should be clearly identified in advance).

4.4 Consent

An accessible information and consent form should be made available (e.g. Braille and other forms), at the interview but before it starts. Consent can be written or if necessary recorded in audio or visual form, as appropriate for the participant.

Consent should be informed, so it is important to make sure that participants understand the purposes of the research and how information will be used. They should know that while every effort will be made to anonymise the data, absolute and complete anonymity cannot be guaranteed because others may recognise them, depending on what is disclosed. If it becomes apparent that sensitive data is involved, we can take additional steps to ensure anonymity and these issues can be discussed with the Leeds team during the monthly briefings. They should also know how long the interview will probably last and interviewers should not go over this time without consent. If participants do not want to answer a question they should be free to not answer. Similarly, interviewers should be willing to answer questions about themselves and their circumstances if asked.

4.5 Communication

Persons with deafblindness are the key stakeholders in our research and it is important that we build rapport and treat people with warmth and respect. People with deafblindness may use a wide range of means of communication and arrangements should be made in advance so that we are able to communicate effectively. Signers, where needed, may be people known to participants or recruited by interviewers. There are advantages and disadvantages to various arrangements but participants should have as much choice in this as possible.

National organisations can provide details about communication methods as well. In the UK, a number of organisations provide general guidance on communication options with people with deafblindness. For example:

Action on Hearing Loss: Tips on Communicating with deafblind people

https://www.actiononhearingloss.org.uk/live-well/communicate-well/communication-tips/tips-for-communicating-with-deafblind-people/

Sense: Communication (see the menu on the right hand side of the web page for communication options)

https://www.sense.org.uk/get-support/information-and-advice/communication/

Deafblind UK: Communication (more details will be provided at the Leeds partner meeting in July 2018)

https://deafblind.org.uk/deafblindness/communication/

For a recent academic overview of communication technologies, please see:

Francesca Sorgini, Renato Caliò, Maria Chiara Carrozza & Calogero Maria Oddo (2018) Haptic-assistive technologies for audition and vision sensory disabilities, *Disability and Rehabilitation: Assistive Technology*, 13:4, 394-421, DOI: 10.1080/17483107.2017.1385100

Interviews should be carried out in person wherever possible, because this almost always gives richer data. However they can be carried out in other ways, for example, via Skype, email or other appropriate means, with the agreement of all parties. If this is done, interviewers should still use the interview schedule as a structure for a conversation and not as a questionnaire to be filled in by the person participating.

4.6 Recording

With the consent of participants, interviews should be recorded so that content can be reviewed afterwards. Please arrange for either audio or video recording so that it will be possible for interviewers and analysts to check back on the accuracy of what was

said and to reflect on this. Recording should also make it easier for interviewers to listen carefully to what is being said rather than to have to take notes at the same time. Another reason for recording the interviews is because information on user needs will be used by different work groups, including both technological and policy work packages. Therefore it is likely that the data will be needed by people whose detailed requirements are not known in all aspects by interviewers.

4.7 Payment

It is good practice to pay people or recognise their contribution with a token gift. Many EU funded projects pay about 20 euros to research participants for each interview but we recognise that there are different practices in different research fields and countries. In the UK we plan to pay each person 12 euros, in line with national practice in Engineering. While this is a small amount in terms of the project costs, it recognises that participants' time is valuable and indeed essential to completing the project goals.

4.8 Writing Up

a) Interview data

The interviews should be written up afterwards so we record the main points raised. As much detail as possible should be noted, as we are aiming to understand the point of view of people with deafblindness, rather than our own thoughts at this point in the process. Quotes from participants will be important also for future articles so it is better id participants own words are used.

Notes should be written or translated into English so that the information can be compared across the countries and collated by the Leeds team. We appreciate that there are logistical difficulties in this process but we can take heart from the fact that we are breaking new ground in interviewing persons with deafblindness in several countries and basing our work on their perspectives in innovative ways.

The data should be anonymised in the countries where it is gathered / generated. This usually involves changing the names of participants and, if necessary, places. The Leeds team will provide further guidance on how to deal with potential identification of participants and other ethical issues that may arise.

b) Field notes on the interview process

We would ask that interviewers make field notes on the interview process itself, in order to feed back issues at monthly Skype meetings with interviewers and for helping to complete deliverables. These notes are thoughts about the process of the interview

and other observations not directly to do with the content of the interview itself. They should again be written after the interview, not during it. We also are required to deliver a report on good practice in interviewing persons with deafblindness to the European Commission at the end of the process. It would therefore be very helpful to record issues as they arise so that this report can reflect an international perspective.

c) Field notes - Ideas for Articles

Field notes should also include a separate section where we document ideas for articles that we can follow up later. Although these ideas are obviously related to the analysis of data, they should be kept separately from both the content of the interviews and clearly marked as ideas for articles, for reasons of clarity.

4.9 Reviewing progress

We plan to check fairly early on whether the approach is resulting in the kinds of information needed and to make adjustments if they are necessary. Therefore we will review progress and any issues raised, after two interviews have been carried out in each country, with the first two pilot interviews included in the total number of interviews.

Monthly Skype meetings (more often if needed) will be held between all interviewers to assess progress and report on any problems. These meetings will also provide an opportunity to assess the data that is being gathered in relation to work being carried out in other work packages.

Once all the interviews have been completed, the researchers conducting the interviews will hold a final debriefing session in Month 10 to review what worked well or less well and to flag up any key lessons learned for the project as a whole.

4. References

European Deafblind Network (2014) *European Deafblind Indicators* file:///C:/Users/Owner/Documents/Suitceyes/Articles/Final-Report-Deafblind-Indicators.pdf

Harris, J. (2010) The use, role and application of advanced technology in the lives of disabled people in the UK, *Disability and Society,* 25:4, 427 - 439

Larsson Ranada, Å. & Lidström, H. (2017) Satisfaction with assistive technology device in relation to the service delivery process—A systematic review, *Assistive Technology*, DOI: 10.1080/10400435.2017.1367737

Perfect, E., Jaiswal, A., and Davies, T. Claire, (2018) Systematic review: Investigating the effectiveness of assistive technology to enable internet access for individuals with deafblindness, *Assistive Technology,* DOI: [10.1080/10400435.2018.1445136](10.1080/10400435.2018.1445136)

World Health Organization and World Bank (2011) *World Report on Disability*, http://www.who.int/disabilities/world_report/2011/report/en/

5. Interview Questions

Notes about the questions

The list of questions below is intended as a guide for the interviewer during the semi – structured interview and not a questionnaire or list to be given to the participants. The questions are quite unspecific and wide: this is deliberate. Asking very broad questions allows the participant to answer in the way they want and to draw our attention to important things that we may have missed. It is useful in situations where we do not know a lot about a subject.

It is often better to follow the thought process of the person being interviewed and to ask questions in an order that is logical for them. To make this easier, the interviewer can write the questions on record cards so it is easier to flip forwards and backwards, covering missed questions later on in the interview.

Additional optional questions are suggested in the interview. These can be asked if people have difficulty with broader questions or need help to think of specific situations. It is fine to ask your own questions too if they help to answer the larger questions but please do not introduce new topics.

Questions for Participants

Introduction

When introducing the project, interviewers should cover the following:

- Agree interpreting and communication arrangements for the interview (if any) and how they will work.
- Explanations about the project, its purpose and what the information they will give will be used for. How participants will hear about the results of the project.
- If different people (for example the person with deafblindness, a carer, relative, etc.) is participating during the interview, is important to be explicit that the interpreter must assure that the deafblind person can follow all the interventions of all the persons involved (interviewer, relatives, carers, etc.). Agree on communication When relatives and sometimes carers participate in answering questions or complementing the answers, there is a risk of interrupting the interpreter while they are talking to the interviewer.
- The questions: interviewers should give an overall description of what will be asked and how long the interview is likely to take. Explain that it does not matter if they answer other questions when they reply and that you will adjust your questions. We are aiming to get an idea from participants of the issues that

are important to them and how they link together from their point of view, rather than exact answers to specific questions.

- Recording: explain to participants why this is useful for us (to make sure we are accurate and spend time listening rather than writing); check that participants agree to recording and how it will be done. Explain that information will be anonymised and their details will not be made public.
- Consent: ask people to confirm that you have given a full explanation and that they agree to take part. Please ask participants to record their consent to the interview and the use of data.
- Questions for the interviewer: ask if there is anything they would like to ask the interviewer and explain that you are happy to tell them about yourself and what you do. Offer information about yourself so that the exchange of information is balanced but do not clutter the interview with personal observations.

A. Introductory Questions: Aspirations and Interests

1. Can you tell me a bit about yourself?

2. What kinds of things do you do at the moment? (e.g. daily routines, regular activities)

3. What kinds of things do you like to do?

4. Are there things you try to avoid or do not like?

5. Are there things you would like to do but do not do at the moment?

   Possible additional questions:
   - Education
   - Employment
   - Leisure activities
   - Friends, family, personal relationships?
6. If there are limitations on the things you like to do, why is this?

B. Help and Assistance

6. What sort of assistance to do things (if any) do you get at the moment?

Possible additional questions:

- From personal assistants you employ?
- From assistants employed by other people?
- From family and friends?
- From interpreters?
- From anyone else?

C. Use of Technology

7. What systems or devices do you use at the moment? (If so) Can you tell us about it / them? (for example hearing aids, magnifying glass, canes, etc.)

Possible additional questions (if needed)
- What do you use it for?
- How often?
- How useful is it?
- Did you have to pay for it – was it affordable?
- How reliable is it?
- Did you have a choice of device (if there is more than one kind)?
- If you stopped using it, why was that?

8. Do you use apps and software? (Explain the ones that are available if they do not know about them – e.g. for communication, appearance, moving around)

Possible additional questions (if needed)
- (If so) Can you tell us about how you use it / them?
- (If not) why not?
- Are there apps or software that you would like to use but cannot for some reason – please explain?
- Do you use apps that use touch (haptic technology)?

D. Future Technology

(This section asks about what you think is important in developing technology in the future and if there are any possible problems we should think about. Please explain what haptic technology is if the participant does not know about it.)

9. Are there particular ways you think the technology could be useful?

SUITCEYES

10. a) For each of the following, can you say how you do these things at the moment and if any of them could be improved? (note to interviewer: only ask each question if it is applicable and does not result in repetition)

- Identifying people you know
- Detecting items of interest (e.g. keys, cell phone etc.).
- Getting around a room you are familiar with
- Getting around a room you don't know
- Talking to another person
- Talking in groups, including meetings
- Walking or getting around outside
- Travelling on public transport
- Education (e.g. taking notes in class, answering questions in class, help to learn)
- Employment (e.g. job interviews, in work meetings etc.)
- Shopping (e.g. online, in stores)
- Leisure time (e.g. playing games, doing other things for fun)
- Getting chores / tasks done
- For any other important things (e.g. looking after a baby / child)

b) For the things we have talked about, how could haptic technology make this easier? (Note to interviewer – only ask about the things where improvement was mentioned)

11. How do you think it could fit with other kinds of help you get?

12. Are there any particular problems you can think of?

E. Learning about New Technology

13. How do you usually learn about new things, such as new apps or devices?
14. What help do you have to learn new things?

Additional questions:

- What is most helpful?
- What is least helpful?

15. What kind of games do you play at the moment?

Additional questions:

 Do you use technology to play games?
 What is good about it?
 What is not so good about it?

F. Additional Information

16. Is there anything we did not ask but should have?

17. Is it OK to get back in touch with you if we have more questions, either now or later on in in project?

About Participants

18. Can you confirm your details? (Note to interviewer: these questions should only be asked if you do not already have this information.)
    - Age
    - Gender
    - Address
    - Contact details
    - How you would describe your impairment / disabilities
    - How / when you became Deafblind (congenital / age impairment acquired)
    - Living arrangements

Thank you for your participation.