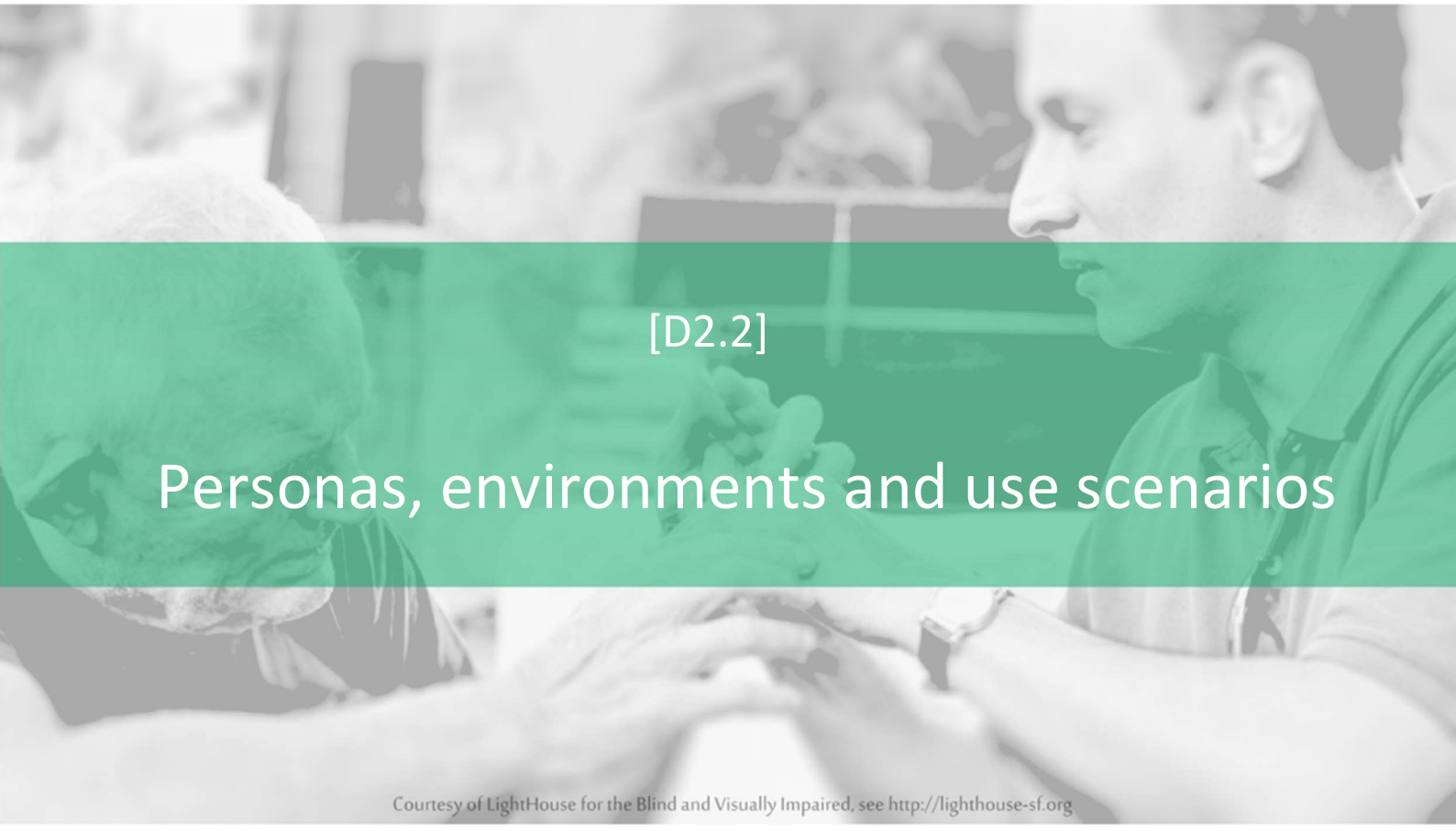
SUITCEYES

1 Jan 2018 - 31 Dec 2020

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



[D2.2]

Personas, environments and use scenarios

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

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VU	**Participation in interviewer meetings**	Astrid Kappers

Glossary	
Abbr./ Acronym	**Meaning**
HIPI	Haptic, intelligent, personalised interface

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Executive Summary

This is an initial report that makes use of data from interviews with persons with deafblindness to identify personas, scenarios and use cases to be employed in the development of the SUITCEYES HIPI (Haptic Intelligent Personalised Interface). The interview data used in this report is a subset of 10, and an additional two not written up, of 75 interviews that should be ready for analysis in spring 2019. This report will be updated at that point. Conclusions in the present version are therefore tentative and preliminary.

All participants expressed a wish to do ordinary activities that non-disabled people frequently take for granted. However, it was not always easy for people with deafblindness to express an interest in doing things that they were not familiar with. Therefore, opportunities to try out new activities are needed, especially for people who may not be able to express abstract concepts.

We present three personas, each based on two or more real people, and developed to illustrate a range of the issues identified in the interviews. Each persona has also been further developed with additional insights provided by experts from the SUITCEYES advisory group and from previous peer – reviewed research and grey literature. The three personas are:

- Johan 38, who is married, and has two young children. Born deaf, he became deafblind in his early 30s. His goals include working and better communication with his family.
- Grace, 67, who lives on her own. She became deafblind later in life and has become very isolated. Divorced, she enjoys her independence but wants contact with more friends and acquaintances as a matter of priority.
- Ana, 26, who lives with two other people with impairments in sheltered housing. She acquired deafblindness early in childhood, being born deaf following premature birth, becoming deafblind aged four. She worries that technology could be used to cut off social contact but would like to go shopping, to work and to socialise more.

At the same time, we found important differences between individuals and it will be important to not gloss over these in the construction of scenarios. All used other forms of technology and marked differences in knowledge and use were very evident. It will be important to include the greatest degree of personalisation possible if the HIPI is to be relevant to a broad section of the population of people with deafblindness.

Introduction

This report outlines three initial personas, scenarios and use cases to inform the development of the Haptic Intelligent Personalised Interface (HIPI) for the SUITCEYES project. In line with a user centred perspective, it summarises the situations and activities that people with deafblindness interviewed by the project have identified as important but not available to them. The report is intended as a working document that will be updated in spring 2019 as more data from interviews carried out with potential users becomes available.

Our initial findings indicate considerable diversity in the population of persons with deafblindness, in terms of life situations, backgrounds, lived experiences, degrees of impairment and impairment effects[1]. This diversity, which is also consistently identified in peer reviewed and grey literature, challenges the idea that there is a clearly identifiable homogeneous group of persons with deafblindness for whom narrowly specified communication and navigation devices can be developed. Flexibility and personalisation by individual users will be needed if the HIPI is to be relevant to a broad section of the deafblind community.

Nevertheless, three broad user groups are identified in this report. These groups are based on similarities in interview participant characteristics and also expert advice and other research[2] in this area. The life course stage that people acquire deafblindness has implications for cognitive development, including concept formation, with implications for the development of relevant technology. The groups are as follows:

- People with congenital or pre-lingual deafblindness;
- People with acquired or post-lingual deafblindness developed in the course of their lives. This group includes people who were born with either deafness or blindness and who subsequently acquire the other impairment;
- People who acquire age related dual impairments later in life.

In this report, we use the tools of personas, scenarios and use cases. These concepts are used in different ways by different authors and for clarification we use the following definitions[3] here:

Persona: Personas represent archetypal users of products and services. Their goals and personal characteristics are indicative of the needs of larger groups of users;

[1] See for example: Arndt, K. (2011) Conducting Interviews with People Who Are Deafblind: Issues in Recording and Transcription, *Field Methods* 23(2) 204 – 214; and Zatta, M. and McGinnity, B. (2016) An Overview of Transition Planning for Students who are Deafblind, American Annals of the Deaf 161(4): 474-485.

[2] See for example Atul, J., Aldersey, H., Wittich, W., Mirza, M., 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

[3] We have taken the definitions of personas and scenarios from: Clarkson, J, Coleman, R., Hosking, I. and Waller, S. (2007) *Inclusive design toolkit* Cambridge: University of Cambridge www-edc.eng.cam.ac.uk. For use cases see Jacobson I, Christerson M, Jonsson P, and Övergaard G, (1992) *Object-Oriented Software Engineering - A Use Case Driven Approach*, Wokingham: Addison-Wesley.

Scenario: A scenario represents a context of use; it is a snapshot of a specific user with a certain task and goal in a particular environment;

Use case: A use case is a sequence of actions or steps that typically define the interactions between an actor and a system to achieve a goal.

Before discussing the data itself, the methods used for this initial analysis are explained below.

Methods

As noted above, to develop the personas in this report, we analysed transcript data from 10 interviews with people with deafblindness in order to construct the three examples. Data from two interviews that had taken place but had not been written up was also included for Persona 3: Ana. At the time of writing, a further 25 interviews had been completed but the data had not been written up and analysed to the point where it could be included. Other sources of information drawn on for this report include recommendations of the SUITCEYES project advisory board, several of whom have deafblindness, and advice from other members of the design team, based on knowledge of the needs of persons with deafblindness.

Interviews were carried out with a diverse group of participants from three countries (Germany (2), Greece (2) and UK (8)) and they are also underway in Sweden and the Netherlands. Interviewers spoke to individuals with deafblindness, using a pre-agreed semi – structured interview schedule that was drawn up with input from many project members working on all work streams. Although broad question areas were agreed in advance, interviewers made adjustments before and during interviews, according to the communication needs of participants and to follow up unforeseen new points raised by participants.

Some interviews took place with only the interviewers and participants present, while in others, translators, guide interpreters, supported housing staff, family members or others were present and / or took part. To the greatest extent possible, additional people attending were there at the invitation of persons with deafblindness themselves. We also conducted interviews with other people who know persons with deafblindness well, in order to gain their insights.

Interviews lasted for approximately one hour each, with considerable variation in the amount and type of data generated. Data was transcribed and translated by the project teams, either fully or in note form, so it was accessible for analysis.

In analysing the data, transcripts and notes from interviews and other recommendations were analysed cross – sectionally using NVivo, with common themes and differences noted. This data was then again cross – referenced with attribute data provided by participants to develop personas. Given that we are working with a partial data set, we have not drawn as firm conclusions as should be possible when all interviews have been completed.

A summary of the participants and the issues they raised, is provided in the next section. Names, but not other details, have been changed.

Summary of participants' situations and interests

Pseudonym	Gender	Age	Impairment	Living arrangements	Communication	Scenario / Goal	Communication Examples	Navigation Examples
Emma	F	82	Born deaf, lost vision later in life	Lives alone with day assistance	Tactile hand under hand interpretation	To meet and get to know more people	To be able to meet and communicate with more people	Possibly information that would help with walking around (she also has difficulty walking)
Linda	F	76	Partial hearing. Lost much of her vision in her 40s.	Lives with son	Loud speech. Has digital hearing aids.	To find a way to listen to music. To communicate with people in more settings	Having a computer that can be adjusted for reading and keeping in touch. Being able to join in a conversation in a social group To understand what is on TV	Help with navigation outside by knowing what is in the environment, as long as it is possible to do this safely.
Bob	M	37	Born deaf, used hearing aids from age 3. Lost all vision in early 30s.	Lives with wife and children. Has a guide dog	Clear speech	To be able to work To be able to communicate with children	To play games with his children. Technology that will identify individual voices and work with hearing aids	To have access to accurate description of what is going on in the environment
Susan	F	53	Born deaf. Gradual vision loss.	Lives on own with day assistance.	Lip-reading/ voice / Braille Has one digital hearing and one cochlear implant	Information about new environments	Talking directly to people (e.g. in a bank), Distinguishing individual speakers in a group conversation	Information about the physical environment when outside, e.g. shopping and using the gym Identifying food in kitchen correctly

Pseudonym	Gender	Age	Impairment	Living arrangements	Communication	Scenario / Goal	Communication Examples	Navigation Examples
Brenda	F	30	Born partially blind and deaf. Gradually losing her vision.	Lives with partner	Voice. Has 2 cochlear implants	To know where things are when swimming. Cooking food	Identification of food Identifying layout and pieces of board games Loop system to work with more than one person (e.g. shop assistants as well as guide interpreters)	Orientation when swimming Would try a navigation device for getting from one place to another if confident it was reliable Identifying obstacles when walking outside
Peter	M	37	Born blind, hearing loss in teens.	Lives with wife.	Voice. Has 2 cochlear implants.	Better information about environment	Being able to read cash machines Affordable face recognition	Identifying obstacles when walking outside Identifying layout and objects in unfamiliar rooms
DE1 (name to be added)	M	36	Born deaf, continuous loss of sight during childhood	Living on his own in a flat	Sign language	To go to a party or disco Communicate after dark To learn Braille	To avoid obstacles in busy places, such as a train station[4].	Finding a way to get around in new rooms.
DE2 (name to be added)	M	42	Born deaf, later loss of sight. Completely blind for 6 years. Cognitive impairment	Lives in sheltered housing	Tactile sign language	Translate TV shows into tactile sign language	Would like to know what is on TV and to be able to search the internet To meet more people To go on dates	To be able to use the train and avoid obstacles in the station
EL1 (name to be added)	M	60	Now fully blind and partially deaf (has hearing aid).	Lives in sheltered housing	Voice	To go out alone in the city	To have a way of reading using a smartphone	To know what is around in the environment outside
EL2 (name to be added)	M	30	Now fully blind and partially deaf, autism.	Lives in sheltered accommodation; weekends with his foster mother.	Interview was carried out with his mother.	Specific scenarios were not identified in this interview[5]	Enjoys conversation and the presence of other people. This could be explored further.	Possibly based on walking in good weather

[4] DE1 expressed a preference for a guide interpreter but would find it helpful to have a way of avoiding obstacles.

[5] This interview was carried out with EL2's mother. While she did not specify instances where technology could be helpful, EL2's interest in the activities described could be the basis for trying out new technology in a practical way, allowing further investigation of his preferences and interests.

Personas and Scenarios

Before discussing particular personas, it is worth mentioning some issues that were common to all participants.

All Participants

All participants shared a concern with being able to do everyday things that non – disabled people often take for granted. People with deafblindness expressed interests in activities, such as going out, going shopping and doing exercise such as walking, swimming and going to the gym. All talked about the importance of social relationships and connections with people. For technology to be relevant to the needs of people with deafblindness and for it not to be rejected, it will be essential that the HIPI builds on and improves existing and potential social connection rather than replaces it.

Many participants (although not all) led restricted lives, with few opportunities to take part in activities. It is important therefore that we do not rely solely on the accounts of people themselves about what they want to but also are imaginative about developing opportunities to try new things, taking into account their interests. The personas below therefore include the recommendations of advisory group members that are in line with participants' aspirations.

For many, impairments were not described as stable. People spoke of progressive conditions that mostly became more problematic over time. Participants also described variable impairment effects. For example, participants who had residual vision described problems with night vision, while several using hearing aids described their poor function in crowded and noisy places. The efficiency of equipment also varied with weather conditions, such as light levels, wind etc.

Conversely, situations also improved for participants as they became more proficient in new ways of sensing information over time. For example, for those who could read it, Braille could be immensely useful. Some participants talked of vastly improved sensitivity to touch following loss of sight and hearing and others of new ways of identifying people, such as though smell, touch or air movement, that had developed after the onset of deafblindness.

Three example personas and scenarios are described below.

Persona 1: Johan, 38

Johan is 38, married, and has two young children. He lives in a rented house with his family and is currently unemployed, although worked for many years as a skilled tradesman. Work is important to him but he left his recent job following further loss of his sight. Johan was born with a hearing impairment and learned to sign as a result of attending a school for deaf children. After a number of years he was sent to a mainstream school instead, where he learned oral speech. More recently, following loss of sight, he is learning Braille. His hearing aids are not reliable, and he cannot lip read any more.

He regrets having left his job following a deterioration in his sight and is currently at college doing re-training with the hope of returning to work. He has recently experienced a period of depression but now feels he has 'turned the corner' and is keen to be more active again.

Scenarios

Johan's priorities include:

- Having better information about what is happening in the environment;
- Using that information to help with moving around;
- Communicating more effectively with other people, especially family members;
- Being able to play games with his children;
- Getting access to stories, such as from the television or books;
- Being able to go out at night because he has night blindness;
- Being able to exercise more effectively, e.g. swimming, going to the gym
- Being able to identify food in the kitchen (e.g. tins, bottles)

Persona 2: Grace, 67

Grace became deafblind later in life and has now no sight or vision. She is a widow who was divorced some years ago and lost friends as her impairments became more serious. Although she has tried, she has found learning Braille very difficult and has given up. She enjoys dancing, meeting other people and lives as independent a life as possible. She does not want more carers to be involved with her in everyday life but would like more contact with people as friends and acquaintances as a matter of priority. She also enjoys knitting and sewing. Although she uses a cane she does not use a striped one (indicating deafblindness), having found that other people avoided her more frequently compared with one that is just white (indicating visual impairment).

Scenarios

Grace would welcome technology that helps her to stay as independent as possible but that does not cut off social connections. Therefore, the following are important:

- Being able to recognise objects in the home;
- Being able to move around more freely through identifying obstacles
- Knowing where people are and who visitors are, when outside the door;
- Being able to tell who is speaking and what is being said, when with a group of people;
- Being able to initiate conversations with others.
- To enjoy more opportunities for walking, with others.

Persona 3: Ana, 26

Anna acquired deafblindness very early in childhood. She was born deaf, following premature birth, and lost her sight aged four, when an operation that aimed to restore sight to one eye was not successful. She is now totally blind and uses hand under hand signing to communicate. Currently she lives in a residential home with two other people who also have sensory impairments.

She is lively, loves talking to people and going swimming and shopping. Although she likes going out she also considers it potentially unsafe and does not think she could go out on her own. She meets

her boyfriend once a week in a pub, organised by the residential service where she lives, as part of a group activity.

Ana says that technology is not useful and is especially concerned about the way that it could be used to reduce social contact. For this reason she is categorical about not wanting to try out new things. At the same time she has clearly used technology, for example to enjoy musical vibrations and other people say that she has previously used technology very effectively to communicate through Braille with other people with sensory impairments. Although she has a Brailler[6], it has been broken for two years and the staff there have not made an effort to get it mended.

Her goals include getting a job, preferably working with children. This is something that she might do with others as part of a job share or with help from an assistant.

Scenarios

Anna would find the following useful:

- Being able to recognise objects (what and where they are) when shopping;
- Being able to navigate in busy spaces without bumping into people;
- Being able to communicate with other people over distance;
- Being informed about who is in the environment (for people she does not already know) and events that are taking place around her; whether people are present and where they are;
- Having TV shows translated into tactile sign language;
- Being able to listen to music.
- Opportunities to go to new places and discover new interests.

[6] See for example: https://www.perkins.org/assets/downloads/research/story-of-brailler-11-17-09.pdf
The organisation Sense states that: "Braille is a system of writing and printing for people who are blind or visually impaired, in which raised dots represent letters and numbers, and are identified by touch. Although originally intended to give information on paper, braille can now be used as a digital aid to conversation. Some smartphones offer braille displays, and braille computer keyboards provide access to instant messaging software, Skype and social media." https://www.sense.org.uk/get-support/information-and-advice/communication/tactile-alphabet/

Discussion

Many of the goals identified were general rather than specific. Participants often talked about whole areas of activity rather than particular aspects or sequences of activity that they would like to do. All issues identified were however concerned with communication and orientation; therefore, there is a clear alignment of the SUITCEYES research with the priorities of people with deafblindness. Given this, it may make sense to further specify exemplar use cases that include overlapping features that might aid generalised learning.

Participants had a very diverse range of interests and goals. Examples ranged from sculpture, playing a musical instrument, cooking, metal detection, sewing, knitting, dancing and many more. Some people were highly organised and had found ways of arranging possessions and activities very efficiently to ensure completion of tasks, especially in their own homes.

As well as asking participants about the activities they wanted help with, it is important to consider activities that participants did not know of. It was difficult for participants to identify objectives for navigation and orientation because they often were not able to identify unknown places and opportunities. Some had existing ways of getting to places (e.g. a guide dog, cane or guide interpreter, which was often preferred) but this does not mean that their appreciation of environments could not be enhanced through technological solutions.

More data will undoubtedly allow a clearer picture of how technology can address needs. However, given what we have found so far, it is more than likely that the diversity of people with deafblindness will remain very evident, also because the HIPI will be used in combination with other technology that is likely to undergo updates and change. Therefore, we recommend that as much as possible the design process of the SUITCEYES HIPI should be also informed by individual people with deafblindness and their supporters.