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6/13/2023

"Is there a need for an advanced information tool to facilitate and support communication between individuals with deafblindness and their communication partners?"

Master Thesis

Master's Programme in Deafblindness,

Faculty of BSS,

University of Groningen.

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Date of Submission:	13th June 2023
Word Count:	11,421

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Abbreviations

Acquired Deafblindness = ADB

Congenital Deafblindness = CDB

Congenital Rubella Syndrome = CRS

Diagnostic Intervention Model = DIM

General Data Protection Regulation = GDPR

International Classification Model = ICF

Irish Sign Language = ISL

RuG = University of Groningen

Social Role Valorisation = SRV

The Convention on the Rights of Persons with Disabilities = CRPD

World Health Organization = WHO

Acknowledgements

Firstly, I would like to start by giving my warmest thanks and gratitude to both my supervisors, Dr. Marja Cantell and Prof. Dr. Beppie van den Bogaerde. Their expertise and guidance have carried me through all stages of this thesis.

I would like to express my sincere gratitude to my employer, for their unwavering support and belief in me throughout both this experience and my career to date.

Next, I would like to acknowledge my classmates for their patience throughout this experience. For providing a place where questions and concerns could be shared and advice and support given. Furthermore, I would like to thank the participants of this research without their contributions this research would not have been possible.

Finally, I would like to thank my family and friends for their constant support and encouragement, without them, not of this would indeed be possible.

Abstract

This research project aimed inventorize whether there is a need amongst the deafblind community for a modern information tool that supports communication between individuals with deafblindness and their communication partners. A mixed method approach was identified as the most suitable methodology as it allowed the inclusion of various forms of data gathering, which included interviews, focus group, observation and questionnaire. It also allowed the inclusion of more participants with deafblindness who have diverse communication needs. The research aimed for triangulation by including not only individuals with congenital and acquired deafblindness (5 participants), but also their family members (5 participants) and professionals (6 participants) in the field of deafblindness.

The participants shared their opinions on whether there is a need for an advanced information tool, and if so, what should be included in this information tool. The results presented positive feedback on the concept of having access to a modern tool, however there were some concerns about over reliance on such a tool, in other words, the tool should not replace the personal interaction between individuals with deafblindness and their communication partners. Overall, this study provides a good foundation for future research into the development of an advanced information tool that would facilitate and support communication between individuals with deafblindness and their communication partners.

Chapter One. Introduction and theoretical background

Communication is a fundamental human right (McLeod, 2018), but for individuals with deafblindness, this right is often hindered due to difficulties they face in their day to day lives. Deafblindness is a term used to describe the dual sensory impairment of the visual and auditory senses which can make it difficult for individuals to communicate (Ask Larsen et al., 2014; Dammeyer, 2014; Wittich et al., 2013). The severity of the impairment varies from person to person, though the impact of this impairment affects how deafblind individuals engage and participate with the world around them (Dammeyer, 2014). There is no definition of deafblindness that is widely accepted across literature nor countries. The inconsistent use of terminology and inclusive practices supports the lack of clarity surrounding the notion of deafblindness (Saunders & Echt, 2007). There are differences between definitions of deafblindness which are based on sensory impairment assessments (medical definitions) and those that are based on functional outcomes (functional definitions) (Ask Larsen et al., 2014). While functional definitions concentrate on broader observations such as assessing how each person's vision and hearing loss affects daily life and involvement in society, medical definitions concentrate on audiological and visual criteria (Dammeyer, 2012). There is, however, a consensus that the word "deafblindness" refers to individuals with residual vision and hearing as well as those who are entirely deafblind in both the medical and functional definitions. For the purpose of this study the Nordic definition of deafblindness will be used.

Nordic Centre for Welfare Social Issues (2018), definition for deafblindness states *"deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct disability."*

There are two different types of deafblindness which depend on when an individual became deafblind. Congenital deafblindness (CDB) occurs before the age of two, either during pregnancy or soon after birth. Congenital Rubella Syndrome, premature birth, womb infections, traumatic births and hereditary disorders can all lead to CDB (Dammeyer, 2014; Perfect et al., 2019). Congenital Rubella Syndrome (CRS) is the most common cause of CDB. CRS refers to the group of congenital anomalies that occur in a child as a result of a rubella infection during pregnancy (Chauhan et al., 2016). The diagnosis of acquired deafblindness (ADB) often emerges after the age of two. Usher Syndrome, severe accidents, and other age-related problems with hearing or vision loss are some of the potential reasons of ADB (Dammeyer, 2014). Usher Syndrome is the most common cause of acquired deafblindness. It is a genetic condition that affects both the auditory and visual senses, causing a progressive deterioration of senses over time (Vernon, 1969).

A literature review was undertaken to better understand the communication needs of individuals with deafblindness. Several topics, including communication, participation and assistive technology emerged in literature. This chapter will discuss these themes and their relevance to the research topic. This research project aimed to determine if there was a need for an advanced information tool that supports communication between individuals with deafblindness and their communication partners. This was achieved by examining the experiences and perspectives of individuals with deafblindness, their families and staff members and the communication challenges they face while also exploring the benefits of a modern communication tool.

Communication

Undoubtedly, communication is a major challenge for individuals with deafblindness (Ask Larsen et al., 2014). Subsequently communication is considered one of the most important areas of educational intervention as many learners with deafblindness struggle with language development. Deafblindness restricts opportunities that individuals have to develop communication skills through observation, imitation and implicit learning (Parker et al., 2008). Due to these struggles, individuals with deafblindness are reliant on teachers and others who have knowledge surrounding deafblindness and communication interventions (Bruce et al., 2016). As is the case with many disabilities, deafblindness can present a number of challenges in daily life. Communication issues, orientation in the daily environment, accessing information and learning a language are a few examples of these obstacles. For individuals with deafblindness, social interactions and social isolation are also a common challenge (Dammeyer, 2014).

According to Trevarthen and Aitken (2001) there have been a number of important studies into infant intersubjectivity. One of these approaches focused on early communication and support for social interaction. This was the primary approach to congenital rehabilitation in many European and North American countries. The interactionist approach focuses on developing the prelingual communication and social interaction amongst children with deafblindness. The purpose of this approach is to overcome social isolation and sensory and language deprivation (Trevarthen & Aitken, 2001). Individuals with deafblindness form a diverse population, with varying degrees of sensory impairment, onset of impairments, age, medical history, additional disabilities, mental health and behavioural disorders. Due to this, a multifaceted approach is required when supporting the deafblind population. Those with acquired deafblindness usually have developed language prior to their deafblind diagnosis and therefore the focus in rehabilitation is supporting communication and not on language development. For those with congenital deafblindness, they are more likely to never have developed a first language, in this case, rehabilitation should focus on language acquisition and development (Saunders & Echt, 2007).

The Convention on the Rights of Persons with Disabilities (CRPD), 2006, acknowledges the wide variety of communication tools, including braille and tactile communication, as well as sign language and non-verbal communication that individuals with deafblindness may use (Serpa et al., 2018). The CRPD also outlines the states' obligations to ensure individuals with deafblindness have access to information, communication and other services to allow them to live independently and be an active member of society (Serpa et al., 2018).

Participation

The International Classification of Functioning (ICF) developed by the World Health Organization (WHO) defines participation as the *"involvement in life situations"* and conceptualises human functioning and disability in relation to its context (World Health Organization, 2013). The ICF model has six components; body function, body structure, activity, participation, personal factors and environmental factors (Jaiswal et al., 2019). According to the report *"*Using the ICF to identify contextual factors that influence participation of persons with deafblindness*",* it was found that societal attitudes play a role in how individuals with deafblindness live, participate, and feel supported or ignored in society. Some individuals with deafblindness reported instances where they felt left out and lacked the support from other people (Jaiswal et al., 2019). This study also highlighted the importance of having a proactive outlook on personal factors and how they can impact the level of support with deafblindness receive from others in relation to participation. Other factors that were found to support participation include having appropriate access to assistive technology, access to information and social support. The study called for support from social policy and government to advocate for awareness of deafblindness along with providing access to services, adopting a positive attitude and providing opportunities for individuals with deafblindness, all which are vital for improving participation of the deafblind population (Jaiswal et al., 2019).

So far, research on participation mainly focused on experiences of participation for people with mobility-related issue. Moreover, the challenges found may not directly reflect the problems and challenges faced by the deafblind population in relation to participation (Jaiswal et al., 2018). Individuals with deafblindness struggle with participation due to the restrictions they have with their vision and hearing. Their sensory impairments limit social contact which can lead to challenging behaviours. A way of supporting involvement and participation is providing their communication partners with the appropriate training and supports (Janssen et al., 2003). To support interactions between individuals with deafblindness and their communication partners, Janssen et al. (2003) developed the Diagnostic Intervention Model (DIM). The purpose of this model is to support interactions between individuals with deafblindness and their communication partners. The DIM focuses on improving the insights and skills of educators in terms of three aspects; 1) recognising the signals of the individuals with deafblindness and evaluating the capabilities of their behaviours, 2) attuning to their behaviours, 3) adapting the interaction to promote and encourage particular behaviours (Janssen et al., 2003). Once the intervention has been developed and tailored to the individual's needs, progress is then monitored to identify the effectiveness of the intervention. By assessing the effectiveness of the intervention, changes can be made to ensure the individuals needs are being met. DIM combines the diagnostic process of identifying needs or challenges with specific interventions to provide support and assistance to individuals with deafblindness. DIM takes on a methodical and individualised approach which aims to facilitate growth, development and improvements in different aspects of an individual's life (Janssen et al., 2003).

Assistive Technology

Assistive technologies are developed to improve the individuals' abilities, reduce environmental barriers, improve the quality of life and participation and independence of people with disabilities. Due to the nature of deafblindness, many assistive technologies are not accessible to them, which can lead to social isolation and exclusion (Wittich et al., 2021). According to Dyzel et al. (2020), future research and development of technologies should actively include members of the deafblind community. In order to design, develop and implement effective and sustainable communication assistive technology, it is vital to include individuals with deafblindness in research, and recognise them as 'co-creators' (Dyzel et al., 2020). The gap between academic research that aims to create assistive technology for internet access and the transition into practical application of this technology must also be addressed. There is in general a low level of social participation and inclusion amongst the deafblind population and low quality of life (Jaiswal et al., 2018). As a way of improving the psychological wellbeing and quality of life of the deafblind population, there is a strong argument for developing tools and interventions that would increase their communication abilities. Perfect et al. (2019) state that the majority of assistive technologies focus solely on single sensory impairment, which is not suitable for individuals with deafblindness.

According to Jaiswal et al. (2019), participants stated having access to technology also enabled their participation in society. The study found all participants used some sort of technology in their daily lives. By using technology, participants were supported with mobility, communication and accessing information. The report supports the argument of having an online resource would support communication between individuals with deafblindness and their communication partners. Technology is being introduced progressively and individuals with deafblindness are becoming aware of the benefits technology can bring to their lives. Although Jaiswal et al. (2019) stated that technology has benefited those with deafblindness, it also noted that participation experiences vary considerably between those with congenital and acquired deafblindness. Furthermore, Jaiswal highlighted the potential technology can have on the lives of individuals with deafblindness if given the right supports and assistance. Individuals with deafblindness can overcome barriers they may face in participation when given the help of technology, environmental adaptations and societal support (Jaiswal et al., 2019). The conclusion points on one hand to a need for a multilevel approach that society needs to become aware of and considerate of the needs of the deafblind community. On the other hand, individuals with deafblindness also need to be willing to inform and educate others about their condition and be proactive about getting the appropriate supports from themselves. By understanding the dynamic relationship of personal and environmental factors that affect participation of individuals with deafblindness, participation can be improved and collaborated to support inclusion within society (Jaiswal et al., 2019).

When working with individuals with deafblindness, it is important to have the appropriate skills and familiarity with the individual. Due to the range of different tactile sign language needs, communication partners may not always be able to meet the needs of the individual with deafblindness (Skilton et al., 2018). Assistive technology is an evergrowing department that aims to assist individuals with deafblindness to communicate with the wider community. Braille is the main communication tool; however, the challenge is that it is difficult to learn later in life. In addition, there are many ‘wearable’ technologies that are being introduced, including sensory gloves and hand tapping devices. These technologies are being continuously developed and updated to improve accuracy and accessibility (Skilton et al., 2018).

Education and Awareness

Due to the nature of deafblindness, as it impacts both senses people use to acquire information, there is a challenge for communication but also for learning and education and social interaction (Correa-Torres & Bowen, 2016). Receiving a diagnosis of deafblindness can have a profound impact on the family and other care givers. Family members need to mourn the loss of aspirations and dreams they may have had for their child. It is suggested the physical loss of a loved one is hugely different to the loss of the ‘ideal’ child. For many years the diagnosis of the disability was thought to be devastating and to have only a negative impact on the family. This is due to the uncertainty about their child’s health, education and challenges they may face (Correa-Torres & Bowen, 2016).

Providing early and continuous support to families and other care givers of individuals who are deafblind relieves stress they may experience (Correa-Torres & Bowen, 2016). It is important education is made a priority and provided in natural settings while also ensuring professionals providing these supports are competent and trained to provide these supports. They conclude that supporting families of children with deafblindness is vital to supporting child adjustment and development. Supports can include stress management, communication strategies and problem-solving skills. The aim of these supports is to allow parent and siblings to cope with daily stressors and provide positive supports to their family member with deafblindness (Correa-Torres & Bowen, 2016).

There is a lack of research into the field of deafblindness which consequently leads to the exclusion of individuals with deafblindness from making decisions, developmental programmes and participation in society (Jaiswal et al., 2018; World Federation of the Deafblind, 2018). Furthermore, the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) principle of ‘leave no one behind’ is seen as lacking according to the World Federation of the Deafblind as they argue that the deafblind population has been left behind from international development programmes (Simcock & Wittich, 2019). Although the CRPD (2006) recognises the distinct needs of the deafblind population, the World Federation of the Deafblind found from data available, only 37% of countries recognise deafblindness as a distinct disability. It is suggested the lack of recognition is a factor in the limited statistics, policies, programmes and services available to the deafblind community and furthermore, supporting the exclusion of the deafblind population (Simcock & Wittich, 2019). Ireland's 2016 census showed there were 13,635 people who identified as both deaf and blind or had a major vision impairment. However, the census did not expressly refer to deafblindness as a separate disability because Ireland to date, does not recognise deafblindness as a distinct disability and therefore the number stated in the census is not a true representation of the actual population of individuals with deafblindness in Ireland (Types of Disability - CSO - Central Statistics Office, 2020). In June 2014, there was a study conducted across Europe which highlighted the difference in services and supports from member states who recognised deafblindness as a distinct disability and those member states who did not (Jarrold et al., 2014). The study stressed the importance of official legal recognition at a state level (English, 2014).

This study

From the literature it became apparent that assistive technology might be very helpful to support and improve the communication between persons with deafblindness and their communication partners. The aim of this research is to determine whether or not there is a need for an advanced information tool that would support communication between the individuals with deafblindness and their communication partner. In order to include as many participants as possible individuals with deafblindness, family members and professional in the field of deafblindness were all included in this research. This research sought answers to the form, function and the content that may be included in the communication too. The following are questions this research seeks to answer:

- Is there a need in the deafblind field to have an advanced information tool that supports communication between individuals with deafblindness and their communication partners?
- What do individuals with deafblindness, their family members and professionals want from an advanced information tool that would support their individual communication styles and care provided?
- In what form would this advanced information tool be most suitable to assist in communication between a person with deafblindness and their communication partners?

Summary

The five themes identified from literature, that is, communication, participation, assistive technology and education and awareness were used to develop the research questions. From the emergence of these themes, I sought to find out what individuals with deafblindness, their families and professionals thought about these themes in relation to modern technology.

There are many different interventions that aid in supporting communication in individuals with deafblindness. Assistive technology is still in the early stages of supporting communication for individuals with deafblindness. It was for this reason that an inventory study was chosen for this research study, to allow the researcher to gather experiences and perspectives directly from those who assistive technology may be beneficial to.

Chapter Two: Methodology

This method chapter outlines the procedures followed in order to conduct this research. It gives a detailed explanation on the steps that were taken by the researcher to ensure this study is transparent, reliable and relevant to the focus of this study. The subheadings that are discussed are research population, research design, sources and materials used, analysis method and the ethical aspects of this research.

Research population

This study focuses on individuals with deafblindness, family members and professionals working in the field of deafblindness. As this is a small demographic of the population within Ireland, the strategy for sampling was non-probability. The participants were contacted directly by the researcher and invited to participate. In order to ensure participation amongst the deafblind population, the inclusion criteria had to be expanded from the original idea, which was to interview individuals with deafblindness and people in their social circle to allow for triangulation (Carter et al., 2014). In practice, this would have included five people with acquired deafblindness, five family members related to the participants with deafblindness and five professionals with a relationship with the participants with deafblindness. The recruitment criteria were altered to include individuals with acquired or congenital deafblindness, family members and professionals within the field of deafblindness. The reason participants with acquired and congenital deafblindness were included in the study was it was found that due to the population of individuals with deafblindness being so small the number of eligible participants became too narrow, if the inclusion criteria allowed only participants with acquired deafblindness. Once the inclusion criteria allowed for participants with congenital deafblindness, the recruitment process was straightforward. The participants with deafblindness had a range of different communication styles which a mixed method approach allowed for. With the altered inclusion criteria, there were three participants with deafblindness that were interviewed, one participant with deafblindness who filled out a short questionnaire and a fifth participant with deafblindness who engaged in a video observation. By including people from both types of deafblindness, acquired and congenital deafblindness allowed for examining communication in a broader perspective (Shorten & Smith, 2017).

This study originally planned on achieving triangulation between the research population. Triangulation is the use of multiple methods or data collecting. There are four different ways to reach triangulation; method, investigator, theory and data source triangulation (Carter et al., 2014). However, when recruitment began for this study, it became clear that recruiting five family members directly from the five participants with deafblindness became a challenge. In order to achieve triangulation, three participants with deafblindness had family members involved in the study. In total five family members took part in interviews, three participated in solo interviews with the final two family members participating in a pair interview. While five family members of three of the deafblind participants could be recruited, for two of the deafblind participants this was not possible. In order to include as many family members as possible, these two participants had two family members interviewed. The family members that were interviewed consisted of one parent, three siblings and one in-law. As there were multiple relationships represented here, it allowed for different perspectives to be included in this research.

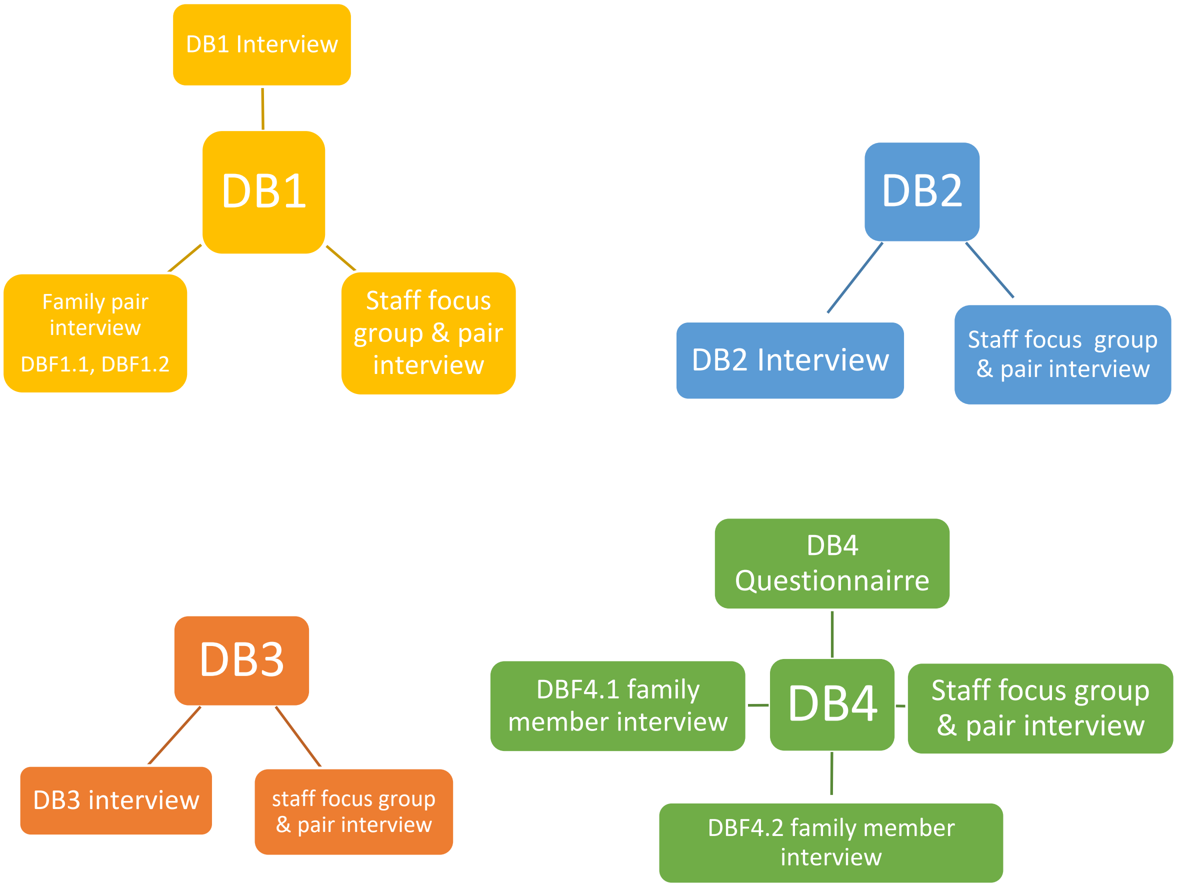
Finally, professionals with experience in the field of deafblindness were included in this study. This allowed for the research to include different levels of experience with deafblindness. A focus group of four professionals was conducted along with a pair interview**.** The professionals that took part in the focus group and the pair interview all had experience in working directly with individuals with deafblindness. The professionals in this study were all employed by a service in Ireland that provides a wide range of supports to adults with deafblindness. All departments of this organization were represented within the focus group and the pair interview. The departments that were represented include residential, day service, outreach, advocacy and management. See Figure 1 for the breakdown of the sample group and methods used for data collection.

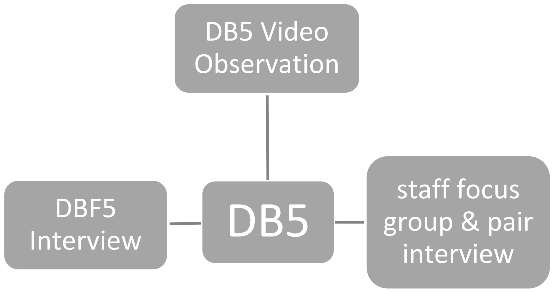
Research design

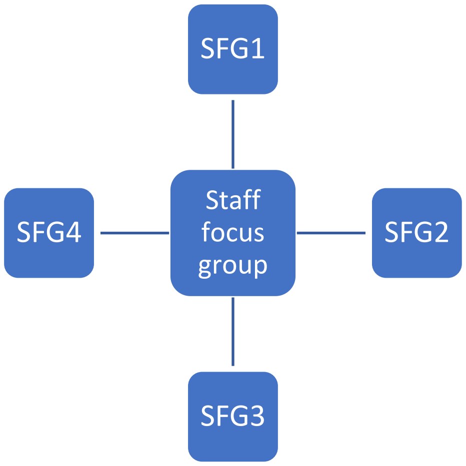
When exploring the different research methods that may be used for this project it became apparent early on that a mixed method approach would be appropriate. A mixed method approach combines both qualitative and quantitative research methods (Shorten & Smith, 2017). Although this study is a mixed method study, the majority of the data collected followed a qualitative approach, applying interviews and a focus group (See Figure 3). Qualitative research methods are an umbrella term that covers a wide range of research techniques and approaches. It allows the researcher to examine people's experiences in detail by using certain research methods (Hennink et al., 2020). As the recruitment process progressed, challenges arose that required amendments to the research methodology. As stated in the previous section it became difficult to recruit participants with deafblindness that had the communication skills to conduct interviews. In order to ensure there was sufficient data to answer the research question, one short questionnaire and observation were included as additional data collection methods (Shorten & Smith, 2017). Thus, interviews, focus groups, observations and a questionnaire became all part of the data analysis. This reflects the heterogeneity of the study population and enabled the researcher to identify issues from the perspective of the study participants and understand their meaning. By conducting a mixed method research approach, including interviews, focus group and observation, it allowed for the research to be open-minded, curious, empathetic and flexible when people were telling their personal experiences.

Figure 1

Breakdown of the sample group and the methods used to collect the data.







Sources and materials used

In order to facilitate the participation of as many participants as possible, the data was collected in five different forms, interviews, pair interviews, focus group, questionnaire and video observation. The interviews and focus group followed a similar list of structured questions, to ensure consistency. Structured interview questions also allowed for the results to be analysed more efficiently (Jamshed, 2014). By implementing a deductive approach, this allowed the research to compile structured questions using the themes identified earlier form the literature study, these questions were then asked during the data collection period of this study.

Procedure

Below is a breakdown of the procedure conducted during the collection of data for this research. This includes a timeline of when the interviews, focus group, observation and questionnaire took place. There is also a key to the participants codes, DB = individual with deafblindness; FM = family member of individual with deafblindness; SF = member of the staff focus group; SP = member of the staff pair interview.

Figure 2

Data collection timeline.

Beginning 27th February 2023, finished 30th March, 2023

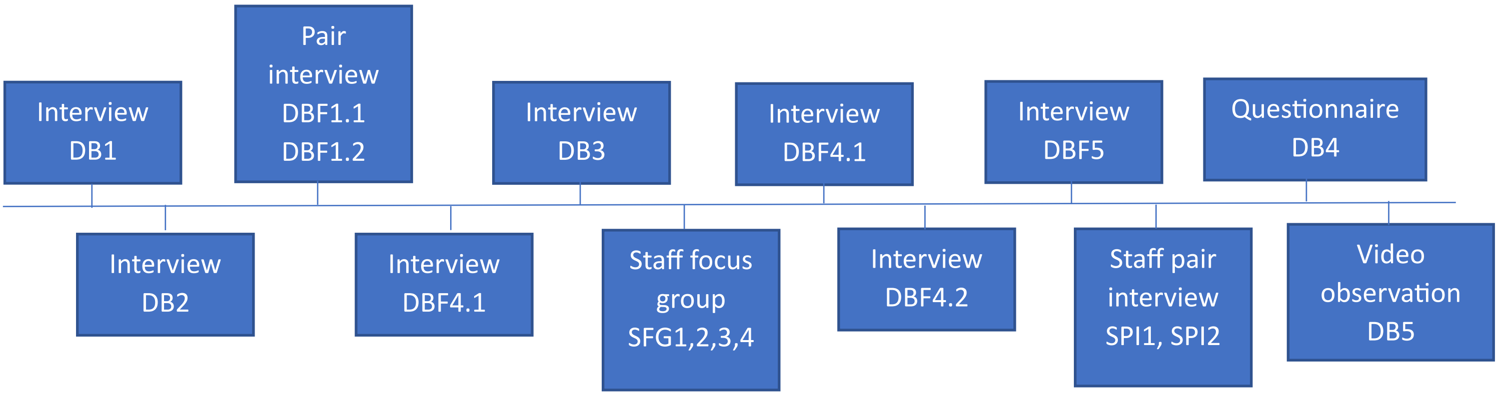
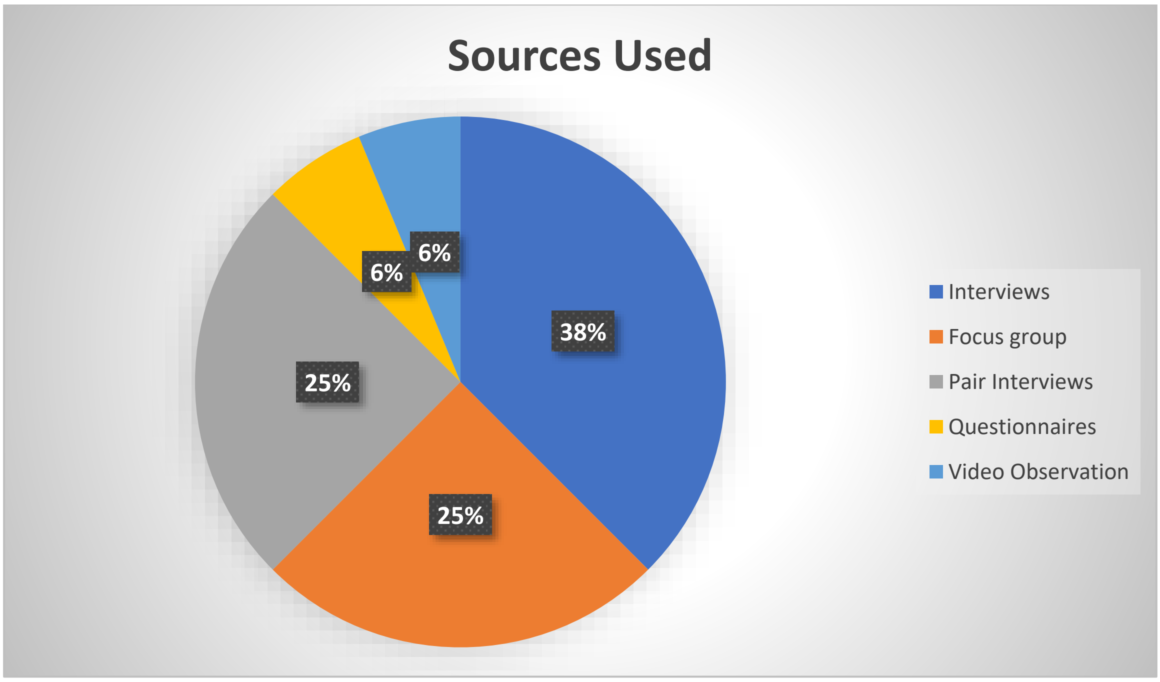


Figure 3

The proportion of the five types of data collection methods.



The participants were emailed an information sheet about the study and consent forms for participation in this study. Once consent was received, interviews and focus group were scheduled. All the interviews were recorded using an audio device, these recordings were stored on an application called KeepSafe, which requires a pin code to access. This ensured the security and confidentiality of the participants. The interview questions were available in many different forms in order to facilitate all forms of communication. The interview questions were emailed to the participants prior to the interviews where applicable, they were also printed both in written words and braille. Interviews were conducted both in person and via video calls. In-person interviews were held with the three participants with deafblindness, this allowed for the researcher to adjust to the needs to the participant, e.g., speaking louder, speaking slower, rephrasing the question if required. For the interview one participant had an Irish Sign Language (ISL) interpreter. One individual with deafblindness participated in a short questionnaire. This questionnaire was printed using large font size to ensure the participant could read the questions. Finally, one individual with deafblindness was observed in a conversation with a staff member. This video was recorded by the researcher in the home of the participant, the video was also stored on the KeepSafe application. This video was later analysed to gather data for this research, the video was used solely for the purpose of this research.

All family members were interviewed via video call. There were three solo interviews and one pair interview, all conducted via video calls. Video calls were determined to be the most suitable approach for conducting the interviews as two family members from the pair interview lived in the UK and the two family members from the solo interviews lived in different regions of Ireland. The professionals participated in an in-person focus group and pair interview. The focus group was held within the workplace in a large open plan meeting room, while the pair interview took place in another, smaller meeting room. Upon conclusion of this research the audio and video collected during this research will be destroyed, however, the transcripts of the pair interviews, solo interviews and focus group will be stored for future study.

Ethical aspects

There were a number of ethical precautions taken during this research. Each participant was given an information sheet and a consent form. These were given either through email, printed in English or Braille, or both depending on the needs of each participant. Consent was given directly by each and every participant except for one. The individual with deafblindness who did not have the capacity to give consent, had consent given by her legal guardian in order to be observed for a video recording. Furthermore, all the names of the participants were altered to ensure anonymity, the participants were given a code name that was used as a way to identify them within the study. Along with the names being altered to codes, pronouns she/her were used regardless of the participant's gender. This will add another level of anonymity.

As the interviews and focus groups were being recorded, each participant had been made aware of this on the information sheet, the consent form and once again prior to conducting the interviews and focus group. This allowed for the participants to express their wishes in relation to being recorded, participants were also informed they could withdraw from the study at any time. The collected data were stored on a secure application that requires a pin to gain access. The only individuals that have access to the data are the researcher and examiners from RUG, upon request.

Analysis

In order to ensure the data was analysed and represented effectively and efficiently this research data were analysed in two different ways. By completing two different approaches of analysis this allowed the research to be more reliable and credible. The first way of analysing the data involved uploading the transcript of the first interview to the ATLAS.ti programme, from here the researcher reviewed the transcript and identified codes, (see Appendix A1 & A2 for the final codebooks). Once the first transcript was coded, the remaining transcripts from the interviews and focus group were uploaded and coded using this original codebook. However, during this process, additional codes were identified. Once all the transcripts were coded, using the final codebook, all transcripts were reviewed and checked for consistency. Upon completion of the analysis, the codes were grouped into relevant themes as there was a large number of codes that were only mentioned a couple of times, and thus too specific. For clarification, please see Appendix A1 & A2. By completing a preliminary analysis, it allowed the researcher to become accustomed to the ATLAS.ti programme and determine the best method of analysing the data. Transcripts of interviews and focus group available upon request.

The second analysis used the same programme, ATLAS.ti, but created the codes using a different method. The codes used in the second analysis were predetermined by the research as per the questions asked in the interviews and focus group. From here, all transcripts were uploaded to the ATLAS.ti programme and coded using the predetermined codebook. Once all transcripts were analysed, the codes were categorised into the themes identified during the literature review. For clarification, please see Appendix A1 & A2. By coding the transcripts according to the interview questions, it allowed the researcher to identify any similarities or difference in the answers provided in the data collected. This allowed the researcher to gain a better understanding of the contents and meaning of the data collected.

Summary

This study used a mixed method approach. The data was collected in different forms, depending on the needs and abilities of the participants. The sources used to collect the data included solo interviews, pair interviews, a focus group, a video observation and a questionnaire. The participants included individuals with acquired or congenital deafblindness, family members of individuals with deafblindness and professionals within the field of deafblindness. The questions that were asked during the interviews and focus group were deductive and developed based on the themes of communication, participation, assistive technology, education and awareness that emerged during the literature review described in the theoretical background chapter of this study. Once the data were collected these were then submitted to an online coding programme, ATLAS.ti. This programme allowed the researcher to upload the transcripts of the interviews and focus group to be analysed. The transcripts were coded in two different ways; first, by identifying codes from the first transcript and applying these codes to the remaining transcripts and second, using the interview questions were used as codes and used to analyse the data gathered from the interviews and focus group. From there the Results Chapter of this study was written.

Chapter Three: Results

Outline here includes the results from all the collected sources, that is, solo interviews, pair interviews, focus group, video observation and questionnaire. The purpose of this chapter is to present the reader with a clear interpretation of the analysis of all the data collected during this study, including the predetermined themes and subthemes that were used during the analysis of the data, communication, assistive technology, security, education, inclusion and awareness.

Communication

Three subthemes emerged which consisted of: 1) barriers to communication, 2) building trusting relationships between individuals with deafblindness and communication partners and finally, 3) important information staff should know in order to support clients with deafblindness and their communication partners. The answers given by participants varied from person to person but there was some overlap of views. An example of this can be seen when both DBF5 and SFG3 commented on the importance of having a consistent approach to communication and can building the relationship between individuals with deafblindness and staff, SFG3 stated, *"having a good consistent structure in place for communication is really important and having a consistent staff approach*."

1.1 Barriers to communication

A subtheme emerged that highlighted barriers to communication between individuals with deafblindness and their communication partners. Individuals with deafblindness encounter many different barriers in their everyday life. One barrier that was mentioned throughout the data collection was the level of ISL amongst communication partners. Family members spoke very highly of the staff within the service where their families attend, complimenting the level of signing amongst staff. This can be seen during the pair interview when DBF1.1 states, *"it's brilliant as well for us to see because we have a weekly video call with (DB1), and we can see that staff progression over time in their signing."* During the staff focus group, knowledge of ISL was discussed and SFG2 stated that staff being employed over the last few years appear to be more familiar or aware of ISL.

Despite the observations of DBF1.1 described above, the level of signing within families appeared to be still very limited. DBF5 commented that she was the person who attended sign classes when her child was younger, to help teach her signs and to communicate with her better, but her siblings and stepparent did not attend. DBF5 suggested this was a factor that resulted in DB5's level of signing being limited and supported with a poor language environment at the family home. DBF5 stated that DB5 had better ISL communication with staff compared to her family, as she was exposed to it more when staying in the residential service. DBF5 - "*I think that's a bit of a barrier that (DB5) doesn't get to have more communication let's say because I'm the only person in my house who could have a good bit of a chat with (DB5)".*

DBF4.1 also mentioned that her level of ISL played a vital role in creating a barrier to communication. DBF4.1 stated that as her family member had residual sight, they have relied heavily on lip reading as a form of communication and as such never felt the need for learning ISL. Although families commented how well staff communicate with their family members with deafblindness, one of the participants with deafblindness, DB1, stated there was a noticeable difference between the quality of ISL between day and night staff. DB1 stated that night staff do not have the same standard of ISL, when compared to the day staff. DB1 noted that at times staff appear nervous when signing to her and that she has difficulty understanding what they are trying to communicate as she uses tactile sign language which means she relies heavily on her sense of touch. This issue can be seen when DB1 states, *"sometimes people are nervous, and their hands are shaky".*

1.2 Building trusting relationships

During the interviews and focus group there were concerns that emerged in both the pair interviews and focus group about over reliance on the online resource and the importance of developing a relationship directly with the person with deafblindness. DBF1.2 was concerned that by putting too much information on the online resource, staff would not feel the need to communicate directly with DB1, "*I wouldn't wanna put too much information on the app that compromised a member of staff getting to know (DB1) and actually talking to her about (DB1) likes and telling her what she likes and actually have a conversation that builds trusts with her."* This concern was shared by DBF1.1 when she expressed concern that if staff become too reliant on the information tool this might compromise the relationship between the person with deafblindness and the communication partner. DBF1.1 stated, *"I think our concern was that it wouldn't be anything that would take away from the personal interaction and building that trust as well between the staff member and (DB1)".*

This concern was expressed by professionals also. SFG2 mentioned during the focus group that as long as it doesn't take away from the actual time from the personal interaction and building trust, the online resource would be positive support. SFG2 argued that it is important to learn directly from the person themselves, *"As long as it's done correctly, and it doesn't replace the actual time spent with the other person"*. DBF1.2 also had a worry that the person with deafblindness may become uncomfortable if a new staff knew a lot of information about them, without having built a trusting relationship directly with them.

1.3 Important information

Participants were asked about what information should be included on the advanced information tool when applied to a population with deafblindness. Popular answers included 1) the client's communication modes, 2) preferred method of communication, 3) likes/dislikes, 4) daily schedule and routine. Other answers included 5) having information about triggers for challenging behaviours, 6) how to support clients during these times, 7) warning signs/ triggers for medical needs, 8) how clients are given medication, 9) procedures and techniques for certain activities. DB3 stated that she would like to have access to information or supports and activities happening in the local area. Different modes of communication that were mentioned throughout data collection include ISL, tactile signing, communication boards, concrete symbols, timetables, written words, Braille and pictures.

During the interview with DBF5, she mentioned that her child uses ISL but also refers to written words and pictures. She used an example of how she would explain to DB5 that family were visiting. She would do this by signing to DB5 about who was visiting paired with written words on paper and showing photos of the visitors. She stated that DB5 would often refer back to the pictures to confirm the information given, as seen when DBF5 states, "*I usually write it down for DB5 as well, but I think visual is how it works for DB5, it confirms things."* During the video observation of DB5, this method of communication was confirmed when staff communicated to DB5 regarding which staff members were working that day. On the video of DB5, you can see staff communicating to her which staff will be supporting her that day. Next DB5 is observed signing back to staff, but she signed their name sign incorrectly. When staff corrected her, you can see her signing the right staff's name, which is subsequently confirmed by staff.

Assistive Technology

When analysing the rich data collected from the participants, it became clear there were many areas related to assistive technology which will be discussed within subheadings.

The three subheadings are form of communication tool, function of assistive technology and experience with assistive technology.

2.1 Form of communication tool

At the beginning of this study, it was important not to assume that having an advanced information tool was the most appropriate form of support. Therefore, participants were asked if having an online communication would be the best method of storing the data, or would another form be more suitable, such as paper or audio. All participants were in agreement that online would be the best form to store the data in. However, there was one concern regarding the age of the individual accessing the communication tool. DBF4.2 expressed a concern surrounding the elderly population and whether their education around modern technology may be a barrier to access the communication tool. The question of who would be best suited to updating the information tool was also raised during the interviews and focus group. As the family members that were interviewed all had relatives with deafblindness living within a residential service, their consensus along with the professionals was that professionals who work closely with the client should be involved with updating the information when needed, along with close family members. It was also stated the clients themselves should be involved in updating the information, where appropriate. As seen from the questionnaire that was given to DB4, she did not wish to having information on her family included on the tool.

2.2 Function of assistive technology

Although there were differing opinions about the function of assistive technology, there appeared to be some consensus when discussing, for example, the Braille email machine that DB1 is familiar with. DBF1.1 mentioned the Braille machine that DB1 uses to communicate through emails with family, friends and staff. DBF1.1 praised this technology, but DBF1.2 had a wish for "*Something more portable".* Along with wanting a more portable device that supports communication through email, having video's that support communication between staff and individuals with deafblindness was mentioned in interviews and focus group with individuals with deafblindness, family members and staff. It was the consensus in the interviews and the focus group that videos which supported the education on the different communication styles each resident uses, schedule boards, medication administration, using a cane and other supports would be of great support to staff and individuals with deafblindness. As mentioned within the staff focus group, there are so many different communication modes within the organization that it can be difficult to remember them all, especially if a staff member does not work with a certain individual for long periods of time. SFG1 stated if there were videos that show the different communication styles, residents likes/ dislikes, their challenging behaviours, triggers to look out for, these are all positive reasons for having such an online app available. SFG1: "*If I was like helping on the floor I could watch a few videos beforehand, before I even stepped in, so I know how that person communicates and what their likes and dislikes are.*" The focus group agreed that if staff had access to videos showing in detail the difference communication style each resident prefer, along with some individual information, it would improve the quality of service that staff could provide. Moreover, new staff would be able to build relationships quicker if they had access to information and videos explaining each individual's communication styles.

2.3 Experience with assistive technology

The participants were asked about their experience with assistive technology. Within the focus group there were different opinions on the importance of assistive technology. SFG2 had the opinion that at times there is too much emphasis on new assistive technology. In response to this comment SFG3 had the opinion that depending on the needs of the individuals with deafblindness, the level of understanding of assistive technologies varies. DB2 had extensive knowledge of the different assistive technologies that are available. She discussed different assistive technologies that she is familiar with, including Braille sense, Braille display and Braille notetaker. Her main concern for assistive technology was that there needed to be more funding and training for individuals with deafblindness to learn how to operate different assistive technologies, *"you can only ask for funding once a year."*

Security

This study sought to assess the worries and concerns that the participants may have in relation to the security of their personal information. Security was explored throughout a number of interview questions. When the participants were asked if they were worried about their personal information being stored online, there was a variety of answers given. Firstly, the three participants that completed an interview had different opinions on this issue. DB1 did not have any concerns with their information being stored online while both DB2 and DB3 expressed some concerns. The main concern was ensuring their information was protected from outside individuals accessing their information. This concern was reiterated during the pair interview with DBF1.1 and DBF1.2, they also raised the question on whether the clients would be identifiable, would the tool display their names, faces, or would they be given a pseudonym. People in the focus group and pair interview mentioned General Data Protection Regulation (GDPR) (Mondschein & Monda, 2019), the consensus from the professionals was once the tool followed the GDPR guidelines, they had no further concerns surrounding security of the information on the tool. In contrast to the concerns of the other participants around security, DBF5 gave a light-hearted answer when asked if she had any concerns about information being stored online. DBF5 answered, "*I don't, and I mean if anyone hacked it what are they going to do with it? Learn sign language?"*

Participants were also asked about the accessibility of the tool and there were some conflicting responses. The individuals with deafblindness and family members were all in agreement that the tool should be accessible outside the working environment, but there was a difference of opinions amongst the professionals. It was argued that for a residential service, there would be limited need for the tool to be accessible outside the working environment, but from a day service and outreach standpoint, having the tool accessible within the community would be of great benefit as clients are based all over the community, not just in a residential setting.

Education

Education was a theme that was expressed heavily when the participants were asked about their hope for the deafblind sector. DBF5 advocated for sign language to be taught to children in mainstream school, she found that "*small kids I always found were so interested in learning a bit of sign language.".* Education was also at the forefront of the wishes of DBF4.2 when asked about hopes for the deafblind sector, she expressed her wish: "*Main thing is just educating people you know, outside of deafblindness."*

DB2 related the many challenges that she faced in higher education, one of these challenges being that there were no appropriate supports available to meet her needs within the education system. DB2 argued that if society became more aware of deafblindness and challenges that may occur, that may lead to society being more accepting and understanding of the support individuals with deafblindness may require. DB2 made the following two statements with regards to her experience with people in the community, *"it feels like they're scared, it might feel that they are excluded or treated differently", "we're the same people, we're still humans we just have a disability".* According to the data collected from both DB2 and DBF5, people's fears around deafblindness play a role in isolating individuals with deafblindness. They argue that if there was more education around deafblindness, people would be less afraid. DBF5: *"It's the unknow, people are afraid of something they don't know anything about, they don't want to make fools out of themselves. You know so it is that just around education and information."*

Inclusion and awareness

The themes of inclusion and awareness were analysed together in order to provide the reader with the full context of communication in deafblindness. The participants were asked near the end of their interviews and focus group about what their hope were for the deafblindness sector. Most of the participants mentioned the themes of inclusion and awareness. Family members who participated in this study expressed their wish for their deafblind family member to be included more, whether that be in the environment or with the information that would be added into the app, they should be included in the planning stage if they had the capacity. DBF1.1 expressed her wish for society to become more accessible, with Braille traffic signs more widespread. DBF1.2 argued for more knowledge around ISL and more education around what deafblindness means. DBF1.2 also stated that bigger companies or organization should have the facilities or supports in place to communicate with an individual with deafblindness, and for more awareness surrounding deafblindness. She gave the example of an airport, they have staff that can speak French to a passenger when required, but less likely to have a staff that can communicate through sign language.

SFG2 expressed her hopes for the deafblind sector which included the work she is doing on getting deafblindness recognised as a distinct disability, they believe that once this happens there will be more funding and resources available to support individuals with deafblindness, which in turn will support inclusion within society. This can be seen when SFG2 mentions: *"A lot of things would follow such as some more funding, better resources for a lot of our individuals"*. SFG2 is also currently training in social role valorisation (SRV) which aims to provide individuals with deafblindness more valued roles within their society. Again, their hope is this will lead to individuals being included more within society, which in turn will lead to greater awareness of deafblindness (Thomas, 2023).

Summary

This Results Chapter included all the data that were collected during this research. The data collected included both deductive and indictive approaches. In other words, all solo interviews, pair interviews, focus group, video observation and questionnaire were included here. This Discussion chapter gives the reader a clear analysis of the data collected during this study. To summarise the results of this research the data collected have been presented here in the themes of communication, assistive technology, security, education, inclusion and awareness. The questions asked of the participants followed a structure which allowed for the researcher to present the results under the themes mentioned above. Analysis of the data showed some relevant subheadings highlighted by the participants. Due to the extent of the data surrounding communication, this theme was divided into three subheadings: 1) barriers to communication, 2) building trusting relationships and 3) important information. Assistive technology theme was also broken into three different subheadings of 1) experience with assistive technology, 2) function of assistive technology, and 3) form of communication tool. The subheadings provided additional information that enabled more detailed and in-depth description of the data. The remaining themes of security, education and inclusion and awareness were also discussed. The results set the stage for a comprehensive discussion in the following chapter, where we will delve deeper into the implications and significance of the findings.

Chapter Four: Discussion and Conclusion

The goal of this inventory study was to determine if there was a need for an advanced information tool that would support communication between individuals with deafblindness and their communication partners. Mostly qualitative data were collected using a mixed methods including solo interviews, pair interview, focus group, video observation and a questionnaire. A summary of the key findings can be seen below.

Key Findings

1. Agreement from the participants about the information tool improving communication between individuals with deafblindness and their communication partners. Having access to important information readily available would speed up building a trusting relationship.
2. Videos and individual information should be available on app, (likes/dislikes, medication, schedule boards, process for different activities). This would be a great resource for both new and old staff that are not familiar with a certain mode of communication. The tool would provide a quick and concise way of accessing important information.
3. Accessible to both families and professionals, individuals should be included in what information would be made available on the tool where appropriate.
4. Differing of opinions between professionals on whether the tool should be restricted to the workplace environment or allowed to be accessed in society.
5. Information In the tool should be concise and easily accessible for all levels of ability, as older population may not be technology literate.
6. Professionals need to be aware of the concerns raised about the possibility of becoming over reliant on the information tool as a way of receiving information on the client. Staff should be conscious not to use the tool to replace the personal interaction between the staff and the client as this may impact the relationship and trust needed.

The results gathered in this study confirm there is a need for developing an advanced information tool that would support the communication between individuals with deafblindness and their communication partners. Both the Convention on the Rights of Persons with Disabilities (CRPD), 2006, and the research conducted by Jaiswal et al., (2019) on using the International Classification of Functioning (ICF) model to influence participation with deafblindness support this statement. In the data collected participants stated having videos and information specific to each individual with deafblindness would have a positive impact on communication. According to the participants, information should include both personal and environment factors specific to each individual with deafblindness. Examples of information that should be include communication modes, likes/dislikes, daily schedule and routine, warning signs/ triggers for medical needs, how clients are given medication, procedures and techniques for certain activities.

However, there were also concerns raised about the advanced information tool that will be discussed further on in this chapter. By offering suitable tools and interventions to individuals with deafblindness and their communication partners, you are fulfilling the obligations outlined under the CRPD (2006) which require the state to provide assistance and supports to individuals with deafblindness. This information tool would also store an online inventory of each mode of communication, including both tactile sign language and sign language. Although this study did not target spoken language, this may also be included on the information tool as it may be relevant to certain individuals with deafblindness. By including videos and information about different communication modes, it would allow for a consistent approach from all staff and communication partners. This is expected to improve the quality of sign language that communication partners have.

This advanced information tool would benefit everyone in the deafblind community, not just the individual with deafblindness. As mentioned in chapter three, DB5 is exposed to a poor language environment in the family home. This information tool would help families and professionals to build and strengthen their tactile communication abilities. If this tool was made available to family members and friends, this would open more opportunities for interaction and inclusion. The individual with deafblindness would not be restricted to just their staff having access to important information that would support communication. This leads into the concern which was raised about where the information tool should be accessed from. Participants were asked if the tool should be limited in where it is accessible from, should it be limited to just the workplace environment or available out in society. The majority of the respondents agree the tool should not be restricted in where it is accessible from with one family member saying if the tool was widely available to approved people such as close family members and staff, it would open the opportunities available to her relative. In spite of this, there were conflicting responses from the professionals within the focus group. It was the opinion of SFG4 that the online resource should only be available within the workplace environment (residential setting). However, SFG1 works primarily in the advocacy and outreach department and argued that the information tool should be made available outside the working environment as the organization supports individuals with deafblindness out in the community and would not be suitable if the information tool was limited to the workplace environment. This is an area that would need to be studied further.

Assistive technology is still in the early stages in the field of deafblindness, this resulted in the participants having a limited understanding of the technologies that are available. The participants with deafblindness use different forms of assistive technology, all specific to their own individual requirements, including Braille sense and Braille note-taker. However, it is important to note there was no assistive technology mentioned in the data collected that supports communication between individuals with deafblindness and staff/ professionals supporting them. It is for this reason that it is important to provide communication partners support which include but not limited to; communication methods, different assistive technologies available and how they operate, schedule boards and procedure for working with challenging behaviours. As mentioned previously in this study, there are many different communication methods, and due to the wide range of tactile communication, communication partners may not always have the skills required to meet these requirements (Skilton et al., 2018). It is strongly recommended that all staff are trained in the same communication modes, in particular tactile sign language. This way they can become role models for the family members too, besides having good communicative skills to communicate with the individual with deafblindness. The advanced information tool would allow videos and information on the many different communication modes to be stored and readily available to staff when necessary.

The results of this study also show that having access to videos and information regarding different communication modes each individual with deafblindness uses would support communication and improve the relationship between them and communication partner. Staff members and close family members were identified as the most suitable people to upload information to the communication tool, but it is important to also include the individual with deafblindness in this process where possible. The idea behind this information tool is to support individuals with deafblindness, and one wat of achieving this is to ensure they are included in every element researching and developing the information tool where applicable. This can be seen when Dyzel et al. (2020) suggests members of the deafblind community should be involved in future research.

When discussing the security of the communication tool, the only concern was ensuring the tool followed GDPR law. Participants stated once the information tool followed the GDPR guidelines (Mondshein & Monda, 2019), they had no concerns surrounding security of the information stored on the communication tool. The remaining concern surrounded whether the individuals with deafblindness would be identifiable on the communication tool. The practicalities of the information tool such as security and confidentially would need to be researched in greater detail.

Education around deafblindness highlighted the hopes for the deafblind sector. Participants stated they wished for ISL to be taught in schools for all children, believed this would help reduce the fear around deafblindness. In Ireland, there is currently calls on government to recognise deafblindness as a distinct disability, to adhere to the recommendation made in the report conducted in 2018 by the World Federation of the Deafblind. If deafblindness was recognised as a distinct disability, more funding and supports would be made available to the deafblind community which may be used to improve inclusion of individual with deafblindness within their local community which in turn increase the awareness of deafblindness. Professionals from the focus group attended the social role valorisation (SRV) training which focus on finding valued roles within society for individuals with deafblindness. The guiding principle behind the SRV training is provide more opportunities for individuals with deafblindness to become more involved in society (Thomas, 2023). The information tool may serve as a portal for information shared regarding opportunities for individuals with deafblindness, which may work towards reducing isolation and stigma associated with deafblindness.

A concern highlighted during this research was particularly valid and was not considered by the researcher. Family members and professionals raised concerns regarding communication partners becoming too reliant on the information tool to learn the likes/dislikes of the individual with deafblindness. They were concerned communication partners may overlook the importance of the personal interaction between individuals with deafblindness and their communication partners. They were concerned this may become a barrier to building trusting relationships directly with the individual, they would not like the information tool to replace interacting directly with the individual with deafblindness, having conversations. In order to combat this concern, where applicable, the individuals with deafblindness should be included and consulted on what information would be made available on the communication tool. It would also fall to the responsibility of the professionals to be aware of this concern and ensure there is a balance between the use of the information tool and retrieving information directly from the individual with deafblindness.

One issues that appeared while analysing the data and which was also found in a report written by Laura English (2014) which discussed the recognition of deafblindness as a distinct disability. Currently deafblindness is not recognised as a distinct disability in Ireland. Professional in the focus group mentioned this as a challenge when creating awareness and improving inclusion of the deafblind community. They believe once deafblindness is recognised as a distinct disability, there will be more funds and supports made available, but until that happens there is a challenge to improve inclusion and awareness. This view can be seen in the report, *'Mapping Opportunities for Deafblind People'* (2014). This report outlines the difference in services and supports available to individuals with deafblindness in member states that recognised deafblindness as a disability compared to member states where deafblindness is not yet recognised legally by the state (Jarrold et al., 2014).

Limitations and strengths

Due to the nature of deafblindness, this research was limited in a number of different ways. Firstly, the sample size of this research was limited due to the population of individuals with deafblindness in Ireland. The 2016 census completed in Ireland showed there were 13,635 people in Ireland who declared themselves as both deaf and blind (Types of Disability - CSO - Central Statistics Office, 2020). This was small-scale research that included five individuals with deafblindness, while also including people in the daily environment of the five individuals with deafblindness. The recruitment took place in the context of one deafblind specialized organization in Ireland. This was a first step towards a larger study and considered sufficient for a master's project.

Communication was a limitation of this research due to the nature of deafblindness, the three participants with deafblindness were provided with the interview questions prior to the interview in various different forms, including email, printed and braille questions. This meant the interviews did not allow for the interviews to evolve and expand the questions asked, but this also allowed for consistency across participants. Time was another limitation that was found when collecting data from professionals. It was a challenge to identify dates and times suitable for all professionals, especially due to staff shortages the organization was facing at the time. Due to this there was one focus group conducted with four professionals and a pair interview completed at a later date. This meant there was limited discussion among professionals that a focus group aims to entice. This lack of time for professional to be made available may also be an indicator to the lack of funding available to allow professionals to engage in education and research.

Other limitations of this research include the professionals included in this research were all employed by the same organization, which primarily supports adults with deafblindness living in a residential setting. This study did not include any children or adolescents with deafblindness or parents or professionals who work with children with deafblindness. Lack of research and literature is another limitation needed to be accounted for. As assistive technology is a relatively new area in the field of deafblindness, there is a lack of research to review (Dyzel et al., 2020). There is a need for continued and further research into assistive technology in relation to deafblindness. Most research on assistive technologies focused on single sense impairment (Wittich et al., 2021) which is not suitable to individuals with deafblindness.

Due to the communication challenges, the data were collected with various methods. This can be seen as a strength of the study due to the variety of data gathered through interviews, focus group, video observation and a questionnaire. Due to this study taking a qualitative approach, it allowed for the views and opinions of the participants to be expressed, which resulted in providing the researcher with more detailed information in order to explain the complexity of this study. This study included participants with both acquired and congenital deafblindness, this allowed for greater representation of the deafblind community. Due to the variety of both methods used and participants in this study, the concept of triangulation was allowed to be explored. By conducting a mixed method study, the research was cost efficient, however, the process of analysing the data with a qualitative online tool was time consuming.

Recommendations

For the future studies there a few recommendations I would like to make. First, including children with deafblindness should be made a priority. Children with deafblindness should be included as they will be the one's engaging with more and more assistive technologies and have grown up in a world where technology plays a major role in everyday life. Therefore, their expectations and readiness to use assistive technology is different from an adult population. Also, children will have different views and opinions on communication and the information they may want to include. Further on from this, professionals from different organizations should also be included, this can include both national and international organizations. With regards to international organizations, it would be interesting to understand the assistive technologies used in different countries and how they support communication between individuals with deafblindness and their communication partners. More time available should be allocated to staff to attend research and education to further develop research in the field of deafblindness.

As mentioned previously in Chapter 2, the Diagnostic Intervention Model (DIM) works to improve the insights and skills of communication partners. It outlines three aspects; 1) identifying signals and evaluating capability of individuals with deafblindness, 2) attune to their behaviours, 3) adapt interactions to promote and encourage behaviours (Janssen et al., 2003). The results of this research would support the DIM as it would provide a tool that would enable staff to implement these three aspects. Including information on the tool such as different communication modes, daily schedules, interventions, staff would have the tool necessary to support individuals with deafblindness that is aligned with DIM (Janssen et al., 2003).

The idea of this advanced information tool is for all participants to have personalised profiles that would store information surrounding important information such as preferred communication modes, daily schedule, medications and likes and dislikes. As each participant with deafblindness would have a profile, it may be useful for staff to also have similar profiles. The staff profiles could store information such as experience, their sign language skill level, hobbies and interests. This would allow the participants with deafblindness to explore and interact with staff that may have a specific skill they may want to utilise. For example, if an individual with deafblindness had an interest in gardening, they could search for a staff with similar interests and reach out and ask for support here. This would allow for the two-way interaction and contribution between individuals with deafblindness and communication partners. It would allow the individual to have more independence and autonomy.

Dyzel et al. (2020) mentions the concept of ‘co-creators’ when it comes to research in the field of deafblindness. This is an important concept and could be seen in the research during the interview of DB2 as she offered to assist in the future developing and creation on the communication tool. This shows there is an interest and a want for individuals with deafblindness to be included in research, which is vital for researchers to encourage and nurture. This will contribute to the well-being, autonomy and confidence of individuals with deafblindness and their communication partners. The final recommendation for future research would collaborate with and invite communication information technology experts to be involved. This would provide the research to have professionals with expertise in the field of technology and the challenges that may arise in future research.

Conclusion

Due to the complexity of the dual sensory impairment experienced by individuals with deafblindness, communication is a major barrier that can have significant impacts on many areas of their lives including cognitive development, language acquisition and participation in society. This research began with the question *"is there a need for an advanced information tool that supports communication between individuals with deafblindness and their communication partners?".* In order to answer this question, research was conducted to allow for a greater understanding of the communication needs of individuals with deafblindness. This study took a mixed method research approach which allowed the researcher to examine the views and opinions of the participants in greater detail. To ensure there was a variety in responses and perspectives, triangulation was identified as an appropriate concept and included different methods for collecting the data (interviews, focus group, video observation, questionnaire) but also sources of the data collected (individuals with deafblindness, family members, professionals). Participants in the research included individuals with both acquired and congenital deafblindness, family members and professionals in the field of deafblindness. Ideally, an information tool would support communication partners by providing information about the individual with deafblindness such as communication methods, daily schedule, likes/dislikes.

This study suggests a well-targeted and secure information tool would have a positive effect on the deafblind community. The views and opinions presented in this study all lead to the conclusion that anything that would benefit and support the communication and relationships between individuals with deafblindness and their communication partners would be welcomed and encouraged.

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Appendix A. Codebooks

A1. Codebook from first analysis of data collected

Codebook One

- Awareness
    - Attitudes
    - Awareness of deafblindness
    - Fear and stigma around deafblindness
    - Improvements/ hopes for deafblind sector
    - Independence
    - Negative of online resource
- Assistive technology
    - Access and updating information on resource
    - Assisitve technology
    - Storing methods
    - Videos on supporting learning
    - Who would benefit from resource
- Communication
    - Any further comments/ questions?
    - Barriers to communication
    - Building relationships
    - Consistency in communication
    - Communication modes
    - Important information stored on resource
    - Relationship between staff and individual with deafblindness
- Opinions
    - Interacting with others with deafblindness
    - Struggles with deafblindness

- Education
  - Education on disabilty/ deafblind in schools
  - Training
- Inclusion
  - Building relationships
  - Inclusion within community and society
- Security
  - Access outside organization
  - GDPR and internet security
  - Privacy of information

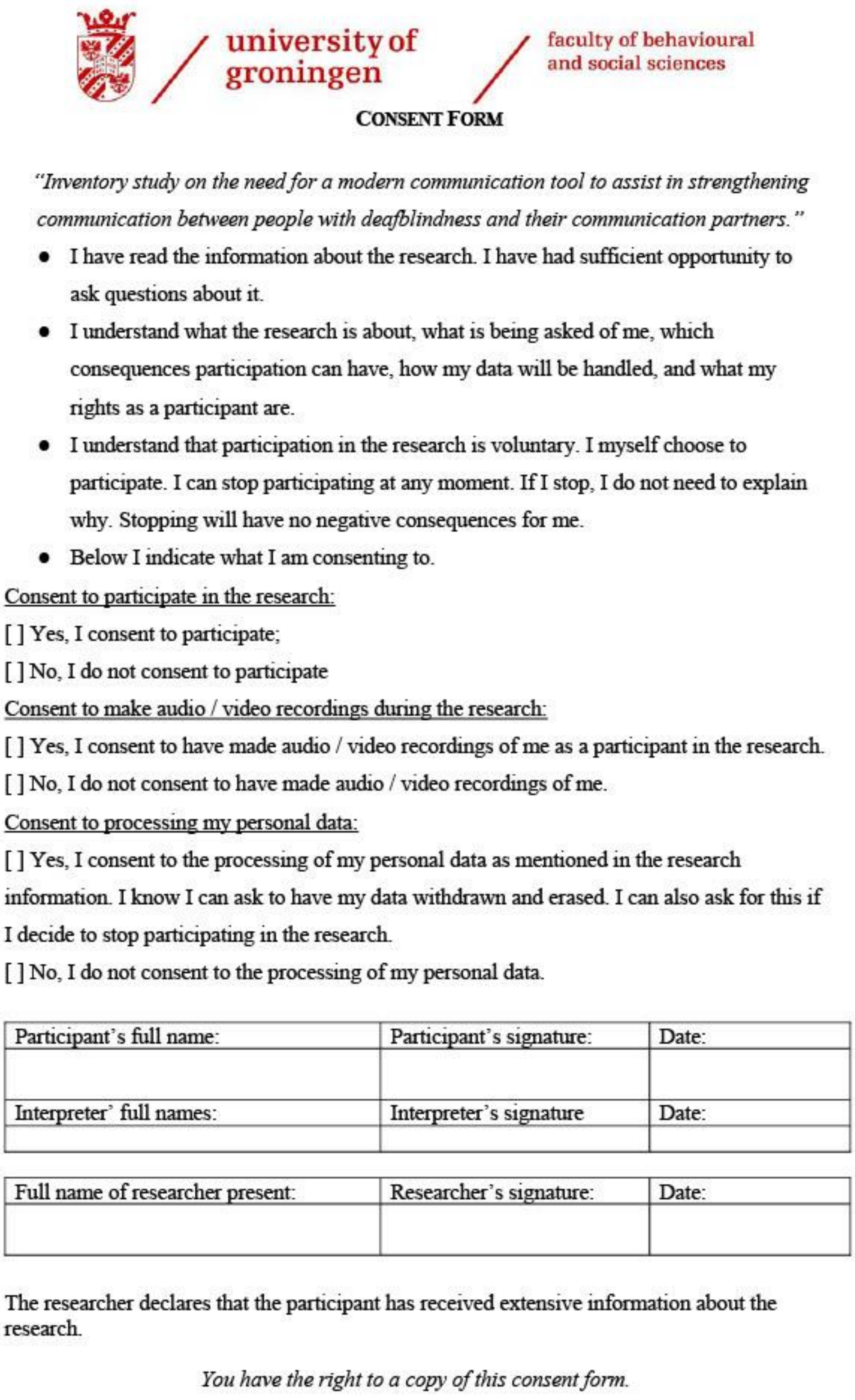
A2. Codebook from second analysis of data collected

Codebook Two

- Awareness
  - Hopes for deafblind sector
- Communication
  - Concerns
  - Would families like access to the resource?
  - Positive/ negative results of resource
  - Communication with others with deafblindess
  - Mains barriers to communication
  - What information should be the resource?
  - Would the resource improve communication?
- Environment
  - Should the resource be available outside the working environment?
- Improvements
  - Hopes for the deafblind sector

Appendix B. Consent Form

Thesis Consent Form



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CONSENT FORM

"Inventory study on the need for a modern communication tool to assist in strengthening communication between people with deafblindness and their communication partners."

- I have read the information about the research. I have had sufficient opportunity to ask questions about it.
- I understand what the research is about, what is being asked of me, which consequences participation can have, how my data will be handled, and what my rights as a participant are.
- I understand that participation in the research is voluntary. I myself choose to participate. I can stop participating at any moment. If I stop, I do not need to explain why. Stopping will have no negative consequences for me.
- Below I indicate what I am consenting to.

<u>Consent to participate in the research:</u>

[ ] Yes, I consent to participate;

[ ] No, I do not consent to participate

<u>Consent to make audio / video recordings during the research:</u>

[ ] Yes, I consent to have made audio / video recordings of me as a participant in the research.

[ ] No, I do not consent to have made audio / video recordings of me.

<u>Consent to processing my personal data:</u>

[ ] Yes, I consent to the processing of my personal data as mentioned in the research information. I know I can ask to have my data withdrawn and erased. I can also ask for this if I decide to stop participating in the research.

[ ] No, I do not consent to the processing of my personal data.

Participant's full name:	Participant's signature:	Date:
Interpreter' full names:	Interpreter's signature	Date:

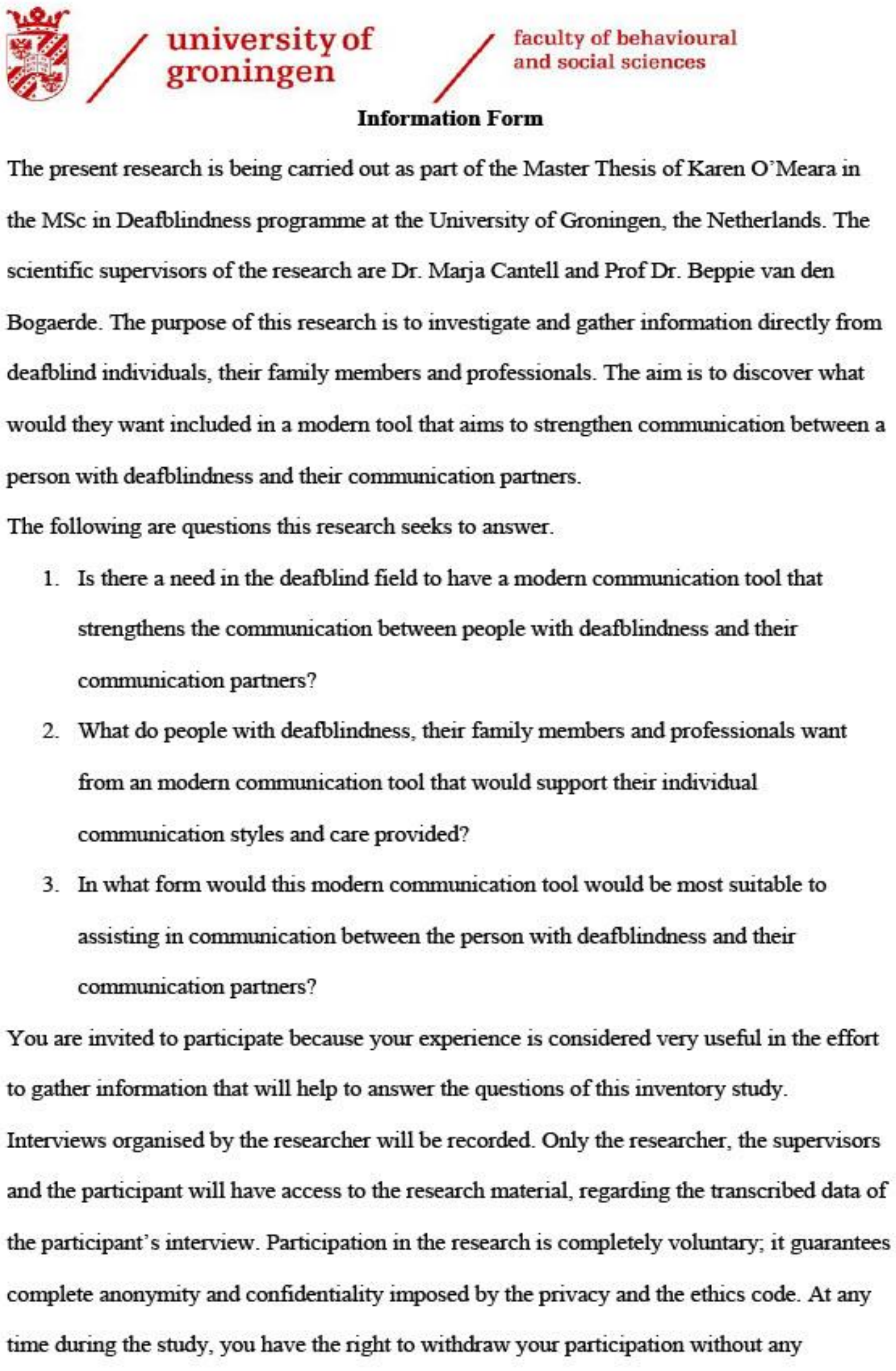
Full name of researcher present:	Researcher's signature:	Date:

The researcher declares that the participant has received extensive information about the research.

You have the right to a copy of this consent form.

Appendix C. Information Sheet

Thesis Information Sheet



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Information Form

The present research is being carried out as part of the Master Thesis of Karen O'Meara in the MSc in Deafblindness programme at the University of Groningen, the Netherlands. The scientific supervisors of the research are Dr. Marja Cantell and Prof Dr. Beppie van den Bogaerde. The purpose of this research is to investigate and gather information directly from deafblind individuals, their family members and professionals. The aim is to discover what would they want included in a modern tool that aims to strengthen communication between a person with deafblindness and their communication partners.

The following are questions this research seeks to answer.

1. Is there a need in the deafblind field to have a modern communication tool that strengthens the communication between people with deafblindness and their communication partners?
2. What do people with deafblindness, their family members and professionals want from an modern communication tool that would support their individual communication styles and care provided?
3. In what form would this modern communication tool would be most suitable to assisting in communication between the person with deafblindness and their communication partners?

You are invited to participate because your experience is considered very useful in the effort to gather information that will help to answer the questions of this inventory study. Interviews organised by the researcher will be recorded. Only the researcher, the supervisors and the participant will have access to the research material, regarding the transcribed data of the participant's interview. Participation in the research is completely voluntary; it guarantees complete anonymity and confidentiality imposed by the privacy and the ethics code. At any time during the study, you have the right to withdraw your participation without any

Appendix D. Interview Questions

D1. Interview Questions. Family/ Professionals

1. Can you please introduce yourself and tell me a little about your experience in the area of deafblindness?
2. What are the main barriers that you can see in relation to communication between staff and people with deafblindness?
3. In your opinion, what is done well in relation to communication between staff and people with deafblindness?
4. If there was an online resource available, what type of information do you think is important for staff to have access to?
5. In relation to updating information on this resource, who do you think are best suited to update the information available?
6. Do you think having an online resource that stores individual information, such as communication methods, clients likes/dislikes would benefit the relationship/ communication between staff and client? If yes, how so?
7. What is the most suitable method of storing information, would online be best or another form of storing the data, if so what? (paper, offline documents/ videos?) Why is that method preferred?
8. Can you identify any areas in the deafblind field that you think could be improved by modern technology?
9. In relation to communicating with people with deafblindness, are there any assistive technologies that you have found that has improved communication?
10. Would you (family members) benefit from having such an online resource available to you?
11. Would having videos detailing the communication methods each resident uses be useful to staff?
12. Should this online resource be available outside the working environment?
13. What would the positive/negative results of having access of this online resource provide to the deafblind individual and their communication partner?

D2. Interview Questions, Individuals with Deafblindness.

1. Can you please tell me a little about yourself, name, age, diagnosis?
2. What are the main struggles you face in your daily life in relation to communication?
3. What is done well in relation to communication between staff and people with deafblindness?
4. What are the main problems you face when communicating with staff?
5. Do you use assistive technology and or the internet?
6. Would you feel comfortable with your personal information being store online with the purpose of staff to access during working hours?
7. Do you have any concerns for the safety of your information being stored online?
8. What do you think is the most important information you think staff should know about you before they work with you?
9. Would you prefer an online resource or a different method?
10. What information would you like stored on this online recourse?
11. Would you like staff to have access to this information when out in the community?
12. When needed, who do you think is best suited to update information on this online resource?
13. Are there any problems to communication that you think staff could improve on?
14. If an online resource was available, would you like to have videos showing your style of communication, how you complete certain tasks?
15. Have you came across negative attitudes or experiences with online communication methods?
16. Do you communicate with other people with deafblindness? If yes, what form of communication do you use? (email, text, in person communication, sign language, oral language).
17. If no, would you like to communicate with other members of the deafblind community?
18. Do you have the same obstacles in communication with other deafblind individual as with staff?
19. What improvements would you like to see in the deafblind community?
20. Do you have any comments or questions regarding this research?

Appendix E. Questionnaire

Questionnaire

1. How does DB4 like staff to talk with her?
    - Sign Language ☐
    - Lip Reading ☐
    - Facial Expressions ☐
    - Head Movements ☐
    - Voice ☐

2. What technologies does DB4 use?
    - Mobile Phone ☐
    - Computer ☐
    - Tablet ☐
    - Emails ☐
    - Text Messages ☐

3. What does DB4 do every day?

4. What can staff do to help talk to DB4 better?

5. Would DB4 like to learn new ways to talk to staff?

6. Is there anything that DB4 doesn't like about how staff talk to her?

---

7. What do you think staff should know before working with DB4?

- How DB4 talks to staff ☐
- Sign Language ☐
- DB4's likes/dislikes ☐
- How DB4 walks with staff ☐
- DB4 family ☐
- DB4's staff ☐
- What DB4 likes to do everyday ☐

8. Would DB4 like to say anything more to help with this project?
