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Cochlear Implants: Exploring the hopes, reflections and experiences of early deafened adults and their families

Vol 1 of 1

By

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ABSTRACT

Cochlear implantation is widely available to adults with a severe to profound hearing loss. Research has shown that early deafened adults have an uncertain outcome with cochlear implantation. Some recipients show no improvement on speech perception measures but do show improvements in quality of life measures. Knowing the pre-implantation expectations and post-implantation experiences will aid with the management of expectations and help with the provision of greater tailored support throughout their implant journey. Knowing what early deafened adults and their families want with regards to their expectations of an implant would allow families to be more informed and ready to adjust to the changes a cochlear implant can bring. This work aims to identify what the expectations of the recipient of a cochlear implant and their family members are and how the family experience and manage the effects of a cochlear implant on the family member's hearing.

This study was split into 3 phases due to the need for two exploratory phases before the main qualitative phase could commence. Phase 1 involved interviewing sign language interpreters to understand their views on working with interpreters in a research setting. This resulted in guidelines on how to work with British sign language interpreters in a research setting. Phase 2 was a patient and public involvement and engagement study, with a sign language user, to ensure relevancy of the research question. The Phase 1 and Phase 2 studies changed the focus of this thesis, they changed the study title and resulted in the inclusion of family members when the focus had been purely on cochlear implant recipients.

Phase 3 involved interviewing early deafened adults and their family members about their hopes and experiences. This Phase identified that they hoped to improve their communication and that the cochlear implant resulted in more benefits related to environmental sounds and improved confidence. They also shared that they gained improvements in more areas than they thought they would. Family members also shared their experiences of the process and the support they provided to their cochlear implant family member. The participants recruited to the study all used spoken English, no BSL users were recruited. This has enabled the perspective from the aural early deafened adult group to be explored. Aural early deafened adults may be put into the same category as BSL users or post-lingually deafened adults. Their voice has the potential to be lost or not considered at all as they could be excluded from each group due to their communication mode and onset of deafness.

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Academic Thesis: Declaration Of Authorship

I, SUZANNE JANE O'GARA declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

Exploring the hopes, reflections and experiences of early deafened adults and their families of a Cochlear Implant

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I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signed: .....

Date: 16/09/2022.....

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My thanks go to my The University of Southampton Auditory Implant Centre (USAIS) for supporting these research and allowing me the time to conduct the studies. To all my colleagues for providing encouragement to complete this work and having the confidence I could!

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- My colleagues at USAIS who looked at the research questions in Phase 1
- Jonathan Lightfoot for providing me with formatting support during the final stages of this thesis.

Finally, To the participants, thank you for your time and sharing your experiences with me. It was a privilege to have glimpsed into your world. In particular to the Phase 3 participants who were interviewed during the Covid 19 pandemic, thank you for reminding me of what cochlear implants can do and for talking to me in a time where everything was quite strange.

Definitions and Abbreviations

AB – Arthur Boothroyd

ASLI – Association of sign language interpreters

BAA – British Academy of Audiology

BCIG – British Cochlear Implant Group

BKB – Bamford Kowal Bench

BSL – British Sign Language

CASP – Critical Skills Appraisal Programme

CI – Cochlear implant

CUNY - City University of New York

HA – hearing aid

NHS – National Health Service

NHSP – Newborn Hearing Screening Programme

NICE – National Institute for Clinical Excellence

NRCPD – The National Registers of Communication Professionals working with Deaf and Deafblind People

PPIE – Patient and Public involvement and Engagement

QoL – Quality of Life

SASLI – Scottish Association of Sign Language Interpreters

SSE – Sign supported English

UoS – University of Southampton

USAIS – University of Southampton Auditory Implant Service

Chapter 1 Background

1.1 Introduction

This thesis aims to explore the experiences and hopes of pre-lingually deafened adults of receiving a cochlear implant (CI). Understanding their hopes will allow clinicians to inform and support these adults throughout their CI journey and may lead to improved CI experience for the recipient.

As a Clinical Scientist (Audiology) who works at an auditory implant service I have been involved in assessing and managing individuals with a hearing loss for a number of years. As part of my role at the centre I fit and tune cochlear implants, this can involve adults who were born with a hearing loss or developed their hearing loss later in life. Whilst in this role I become part of the journey for both the adults receiving a CI and their families, therefore I see the impact it has on their lives. I have always had an interest in the benefits that early deafened adults gain from their implants and how to support them through the implant process. This resulted in a study looking at what factors affected speech perception outcome in pre-lingually deafened adults, which was published in 2016 (O'Gara et al., 2016). This highlighted that even though not all the group improved on speech perception measures, they all reported other benefits from their implants. In my experience as a Clinical Scientist (Audiology) the reasons why early deafened adults choose to be assessed and then proceed to CI surgery, and their expectations of an implant were somewhat unknown.

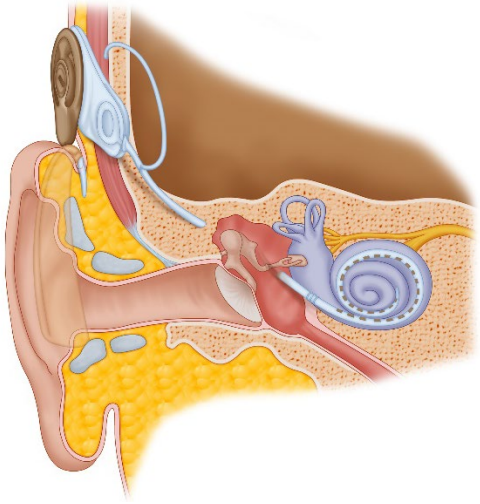
This chapter explains what a CI is and the candidacy issues surrounding this in relation to onset of deafness. It also discusses what is meant by pre, post and peri-lingually deafened and discusses outcomes and expectations of interventions.

1.2 What is a cochlear implant?

A CI is a surgically implanted electronic device designed to allow severe to profoundly deaf individuals to perceive sound. The device consists of two parts; 1a) the external processor which picks up sound signals and converts them into electrical impulses, and 1b) the internal electrode array which transmits these impulses to the hearing nerve, bypassing the damaged hair cells in the cochlea (Figure 1). In England, CIs were commissioned within the NHS for patients with a severe to profound hearing loss who derive inadequate benefit from acoustic hearing aids (HA) (NHS England, 2013, NICE, 2009, NICE, 2019). At the time of this study there were no criteria

within the NICE guidance relating to onset of hearing loss (NICE, 2009, NICE, 2019) and adults who had a pre, post or peri-lingual hearing loss were considered within the same guidance.

Figure 1 **A) Showing the external components of a cochlear implant. B) Showing the internal electrode array in the cochlea (Pictures from University of Southampton Auditory Implant Service stock pictures printed with permission)**

A)  B) 

1.3 Pre, post and peri-lingually deafened

Pre-lingually deafened refers to individuals who have had a hearing loss since before language acquisition, while post-lingually deafened describes a hearing loss acquired after language acquisition (Smith et al., 1999), and peri-lingual refers to onset of deafness in the period, when some language has been acquired between the ages of two and four years (Arndt et al., 2015). Accurately identifying onset of deafness in adult deaf individuals can be challenging. The Newborn Hearing Screening Programme (NHSP) was introduced into the UK in 2006 (Wood, 2015) as early identification of hearing loss and fitting of hearing aids is associated with better language development (Wolff et al., 2010). Before the NHSP was introduced, the 'Health Visitors screening test' was performed at eight months of age, but had a low sensitivity and low positive predictive value (Scanlon and Bamford, 1990). As pre-lingually deafened adults had no neonatal screening, it is difficult to confirm retrospectively that a hearing loss occurred at birth. This has led to a variety of descriptions of these adults within the literature, such as early deafened, pre-lingually deaf, congenitally deaf, and long term deaf. Individuals identified through NHSP would have been identified as having their hearing loss from birth.

Pre-lingually deafened adults are a group consisting of individuals who use varying communication modes (Aural/sign language/total communication), speech intelligibility (from pre-recognizable words in spoken language to connected speech intelligible to all listeners (Allen

et al., 2001)), residual hearing levels, HA use and nature of hearing loss (progressive/non-progressive). These factors had been shown to affect speech perception outcome of pre-lingually deafened adults (Loundon et al., 2000, O'Gara et al., 2016).

Pre-lingually deafened adults often describe themselves as culturally Deaf or deaf or hard of hearing. Deaf with a capital D is used to distinguish between culturally deaf signing individuals and adults who are deaf but communicate aurally (Lane, 2005, Obasi, 2014). Members of the Deaf community do not refer to their hearing loss as a disability and identify themselves as being part of a distinct minority culture (Hole, 2007).

There are some members of the Deaf community who are opposed to cochlear implantation of pre-lingually deafened children. If these children are not implanted it is likely they would be brought up using sign language as their main form of communication, whereas having a CI would mean they would be exposed to spoken language and may not use sign language that is seen as an important part of the Deaf culture (Ramsey, 2000). As the decision for a deaf adult to have a CI does not require parental consent and is made by a consenting adult, there appears to be less focus on this in the literature as it is not perceived as such an ethical debate (Hladek, 2001).

As members of the Deaf community use a visual, unwritten language with its own grammatical features, sentence syntax and expression, this is not regarded as a visual representation of English (Lee, 2012, Skelton, 2003, Sutton-Spence and Woll, 1999). This means that communication can become a challenge for Deaf individuals using sign language (such as British Sign Language (BSL)) as they require an interpreter to utilise healthcare and other services (Sheppard, 2014). Without interpreters BSL users cannot access services effectively, which can also be evident when accessing written information as they may not be fluent in written English (Mackinney et al., 1995). This is due to written/spoken English having a different grammatical and sentence structure and for many Deaf adults is a second language (Lieu et al., 2007).

In research studies, an inclusion criterion is often ‘English as a first language’, this excludes pre-lingually deafened adults whose first language may not be spoken English (Ingvarsdotter et al., 2012, Kapborga and Bertero, 2002). To recruit pre-lingually deafened adults in research is likely to involve working with sign language interpreters to allow them to access the research materials, understand what the study involves and to gain informed consent. Participants who use sign language would require an interpreter unless the researcher was fluent in sign language which is not always possible. Becoming fluent in sign language is like learning any language and to effectively communicate with BSL users you are likely to require an interpreter level qualification which can involve a 3 year university degree (SL First Team, 2015). Not including participants who require an interpreter biases the participant group to more aural participants.

Including adults who identify as Deaf and adults who identify as hard of hearing in one participant group results in two potentially very different subsets of participants with very different experiences of their hearing loss (e.g. one group will be adults raised using spoken language who have not accessed BSL, and the other group will be adults raised using BSL and not used spoken language). This has not always been considered within the literature and may be due to the difficulties in identifying the onset of deafness.

1.4 Candidacy and outcomes

To meet the 'CI candidacy criteria' adults need to have a severe to profound deafness (defined as greater than or equal to 80dB at two or more frequencies (500Hz, 1000Hz, 2000Hz, 3000Hz, 4000Hz) and not gain adequate benefit from acoustic hearing aids (described as a phoneme score on the AB word test of less than 50%). It was particularly relevant that no candidacy criteria were described in relation to onset and duration of deafness. There was a question if duration or onset of deafness should be included as a candidacy criterion. Previous studies exploring these candidacy issues showed that if duration of profound deafness exceeded 30 years, cochlear implantation had limited effectiveness (UK Cochlear Implant Study Group, 2004). At this time, pre-lingually deafened adults were then not considered as CI candidates but clinical practice changed with more adults being implanted (Craddock et al., 2016).

Pre-lingually deafened adults were generally considered not good CI candidates due to their long duration of deafness and the resulting minimal/no improvement in performance on speech perception measures after implantation (Caposecco et al., 2012, Green et al., 2007, Jeffs et al., 2015, Muller and Raine, 2013, Schramm et al., 2002). The main expectation of a CI for post-lingually deafened adults was an improvement in communication. Speech perception tests used to measure benefit are aimed at these adults, involving sentence and single word tests, mainly without lip-reading (Bamford-Kowal-Bench (BKB) sentence test (Bench, 1987), City University of New York (CUNY) sentence test (Alesky, 2007) and Arthur-Boothroyd (AB) word test (Boothroyd, 1968)). This means that the outcomes of pre-lingually deafened adults are measured in the same way for post-lingually deafened adults. These outcomes were measured using tests that were not designed for pre-lingually deafened adults and may have too high a language level. Therefore, poor outcome on these tests could be related to this rather than lack of CI benefit. Studies within the literature have shown pre-lingually deafened adults show improvements on speech perception measures but this was variable; from significant improvement to no change in measured performance (Bosco et al., 2013, Klop et al., 2007, Kos et al., 2009, Santarelli et al., 2008, Schramm et al., 2002, Teoh et al., 2004a, Waltzmann et al., 2002, Berrettini et al., 2011). Improvements in quality of life (QoL) have also been identified which can be recorded with no

improvement on speech perception tests. This may be related to the speech test used rather than no benefit being obtained, therefore outcome measures other than speech perception measures are necessary to determine CI benefit (Chee et al., 2004, Klop et al., 2007, Straatman et al., 2014). Pre-lingually deafened CI candidates were counselled not to expect an improvement in speech perception measures after implantation. Some of these candidates still chose to be implanted and reported benefit from their CI (Snell, 2015). Expectations of an intervention have been shown to affect outcome in other interventions, such as pain management (Cormier et al., 2016). Awareness of what these candidate's expectations were of a CI would improve the assessment, counselling, management, and improved patient reported outcomes. It would allow counselling that was aimed at supporting expectations to be focussed on ensuring their expectations are appropriately set and management to be specific to their needs. With expectations affecting outcomes (McRackan et al., 2021), ensuring these are appropriately set should ensure that patients are more informed about the CI experience and improve their outcomes.

1.5 Engagement of pre-lingually deafened adults in research

Engaging Deaf adults in research can involve time and patience (McKee et al., 2012). Previous researchers have recruited adults through email, posters, online forums and during community events (Athalye et al., 2014, Barnett et al., 2011). Community engagement is an important part of recruiting minority groups (Quinn et al., 2013, McKee et al., 2012, Williams, 2005), to effectively engage these communities can require researchers to adjust their approach (Quinn et al., 2013) and to work with gatekeepers (McAreavey and Das, 2013). Gatekeepers are individuals who have links within the community and can aid researchers in identifying and recruiting participants. A gatekeeper could be a community centre, local employer or an individual with a standing in the community (McAreavey and Das, 2013). Working with gatekeepers can be challenging as the gatekeepers wish to maintain their standing within the community and so this can result in them challenging researchers on their personal views and they may deny access to the community so preventing the researcher being able to conduct the research (McAreavey and Das, 2013).

Studies using surveys that were delivered in a written format or through telephone interviews may not engage pe-lingually deafened adults and thought is needed on how to make the research material accessible for them whilst still containing the information to allow pe-lingually deafened adults to give informed consent.

CI researchers who included pre-lingually deafened adults in their research did not always discuss how these adults were recruited to the study and if the consent or information sheets were

adapted (Duchesne et al., 2017, Jeffs et al., 2015, Moran et al., 2016, van Dijkhuizen et al., 2016). This may be due to the limited word count specified by the publishing journals. They did discuss changes made to accommodate these participants, such as questionnaires adapted from written format to being delivered in an interview (Duchesne et al., 2017) and the participants given a choice of communication mode for the interviews (Fryer et al., 2016, Jeffs et al., 2015). Other studies who included pre-lingually deafened adults in their participant group discussed no change in their methods between participants (Athalye et al., 2014, Moran et al., 2016). With no change in methods, you would propose that the adults in these studies were more aural and had a high literacy level. It may be adults whose first language was British Sign Language (BSL) or had a lower literacy level were not engaging with researchers.

1.6 Expectations affecting outcomes

Expectations are defined as "something looking forward to, whether feared or hoped for" (Collins Dictionary, 2022). In general expectations of a CI are described as improvements in communication, ability to hear environmental sounds, use the telephone, and social involvement (Illg et al., 2022).

In other fields, positive expectations of an intervention have been shown to positively influence outcomes. This had been shown in pain management (Cormier et al., 2016, Hill et al., 2007, Linde et al., 2007, van Wijk et al., 2008) and can contribute to placebo analgesia (Montgomery and Kirsch, 1996, Price et al., 1999). In these fields positive outcomes were reportedly maintained longer term rather than just directly after the treatment (Linde et al., 2007). This had not been seen in studies involving CI, with low expectations being associated with higher postoperative QoL scores (McRackan et al., 2021). However, it was unclear why these differences were seen in CIs.

The reasons why positive expectations contribute to improved outcomes compared with neutral/less positive expectations have been proposed to be related to five mechanisms (Flood et al., 1993). These are "triggering a physiologic response, acting to help motivate patients to achieve better outcomes, conditioning the patient psychologically to observe certain types of symptoms but ignore others, changing the understanding of the disease, or acting in concert with anxiety to heighten or reduce symptoms" (Flood et al. 1993 pg 1044). For some medical interventions, it has been suggested how the intervention was delivered may have a greater effect than the intervention itself (Grotle, 2011). This was unlikely to be the case for all medical interventions but shows delivery may have an impact on outcome.

Flood et al. (1993) found rather than expectations affecting the outcome, expectations influenced the patient's assessment of this improvement. With greater improvement being associated with

positive expectations, they showed a significant affect three months after surgery compared to pre surgery. They hypothesised there could be two explanations for this. The first explanation was "Patients distort the memory of their pre-surgical symptoms leading them to believe they have improved but they are not reporting their current status correctly" and secondly, "people who have a more positive view of their prospects from surgery are more likely to see the improvements they did make as more significant than patients with less positive expectations" (Flood et al. 1993 pg 1054). Therefore positive expectations have been shown to result in improved outcomes (Cormier et al., 2016, Hill et al., 2007, Linde et al., 2007, van Wijk et al., 2008) and reported outcomes (Flood et al., 1993).

Within CIs, McRackan et al. (2021) proposed two explanations for why low expectations were associated with improved QoL scores. Firstly, that low expectations meant that ~~patients meant~~ these patients were more likely to have their expectations met and so reported higher QoL scores, and secondly that low expectations motivated patients to work harder to exceed their expectations. Cochlear implantation and pain management are very different interventions and expectations of the intervention has opposite effects which may not have been expected.

Identifying what patients base their expectations on could explain why low expectations result in better outcomes and why this differs to other interventions.

1.7 What are expectations based on?

Studies investigating expectations and patients experience of surgery/disability have reported that patients use the reference of their prior experience of 'normal function' to base their expectations on (Carpenter, 1994, Denford et al., 2011, Ostler et al., 2014, Senra et al., 2012). Previous research exploring this concept of 'normal' has been carried out with patients with breast cancer. It has shown that patients identified that normality was based on internal (unique to the individual), external (society norms) and clinical (medical reference of normal) standards (Denford et al., 2011). This could mean that post-lingually deafened adults use internal references based on their previous hearing experience to form their expectations of cochlear implantation. While pre-lingually deafened adults use external references from society, this could include normal hearing family members, CI clinicians, pre-lingually deafened individuals with CI and information from the internet.

The current literature investigating normality focuses on conditions that had not been present since infancy, such as cancer, heroin use, and lung transplantation (Baker et al., 2016, Dabbs et al., 2004, de Boer et al., 2015, Nettleton et al., 2013, Walker et al., 2015). Or included interventions that resulted in completely normal function (Wilson et al., 2007). This gives insights

into post-lingually deafened adult's expectations and development of a new normal but comparisons cannot be drawn with pre-lingually deafened adults as being deaf is something they have always known.

1.8 Expectations and the internet

The internet has changed how people access information about health conditions (Krotoski, 2011), with patients using the internet and social media to search for information (Gong and Guo, 2022, Li et al., 2022, Smailhodzic et al., 2016). The use of the internet to find out information about symptoms or a medical condition had been described by Krotoski (2011) as 1) you discover something, 2) do a Google search, 3) believe the first result that confirms your expectations. This did not always result in self-diagnosis of the correct condition but shows how patients utilise Google searches for information on symptoms or interventions. Other conditions such as cancer (Yeo et al., 2021), atopic diseases (Drixler et al., 2018), orthopaedic conditions (Koenig et al., 2018) and psychiatric disorders (Brunault et al., 2017) have all shown patients accessing the internet for information on their conditions.

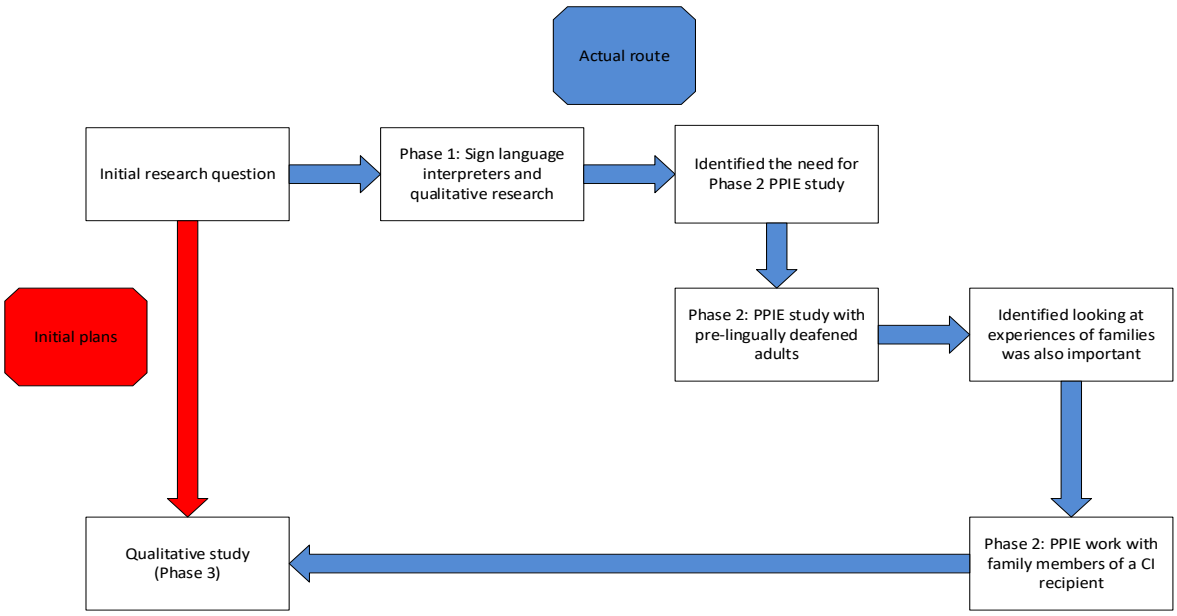
Yeo et al. (2021) found, when looking at information about treatments on the internet, that 47% of testicular cancer patients found it somewhat influential to very influential when making treatment decisions. 82% of their participants had searched for information on testicular cancer online. While Koenig et al. (2018), with orthopaedic conditions, found only half of their participants used the internet to research their condition and they reported were neutral or did not trust the internet information. This showed there was quite a contrast between how many of their participants accessed the internet and then the level of trust for the information found. These studies show that patients do access the internet and it can influence their treatment. This indicated that the internet could affect expectations of CI patients. No literature was found investigating CI patients' use of the internet to access information on their care.

1.9 Exploratory work

While planning this project, it was found that exploratory work was required before the project could commence as pre-lingually deafened adults first language may not be spoken English. This led to the development of 3 exploratory stages. The first was to identify how to effectively work with sign language interpreters and as far as I am aware, this is the first study that has interviewed BSL interpreters on how to work with them in a research setting. This highlighted the need to involve pre-lingually deafened adults in the project and ascertain what their views on the work were. This led to Phase 2, which contained two patient and public involvement (PPIE)

studies. The first was with pre-lingually deafened adults and the results of this changed the direction of the project to include families of pre-lingually deafened adults. Therefore, the second PPIE was with family members of CI recipients to review how to involve them in the project and facilitate their participation. These two developmental phases directed the focus of the main qualitative study and changed it to focusing on both the expectations of pre-lingually deafened adults and their families. Figure 2 shows the developmental phases of the study and how the initial study plans changed due to the need for developmental phases. The project was carried out part-time over seven years with the data collection in Phase 3 taking place during the Covid 19 pandemic.

Figure 2 Initial and actual plans



1.10 Layout of the thesis

This thesis is divided into chapters which cover the different phases of work.

Chapter 2 presents the literature review of the published literature on expectations of a CI and identifies gaps within the current literature.

Chapter 3 explores and justifies the methodology, research design and how this was affected by the Covid 19 pandemic.

Chapter 4 describes the qualitative Phase 1 work involving BSL interpreters and discusses how to work with them in a research setting.

Chapter 5 focuses on Phase 2 PPIE involving early deafened adults and family members of CI users.

Chapter 6 describes the qualitative Phase 3 work involving the hopes and experiences of early deafened adults and their families. This contains Phase 3a which focuses on a review of documents and websites, and Phase 3b which presented the interview data from CI participants and their family members.

Chapter 7 presents the overall discussion of the thesis and includes the key learning points, implications for service provision and policy development, future work, and limitations.

1.11 Summary

This chapter described the background to the PhD, what a pre-lingually deafened is, how expectations can impact outcomes, research in Deaf/CI populations and engaging pre-lingually deafened adults in research. To identify the published literature available on this topic a review of the literature was then performed.

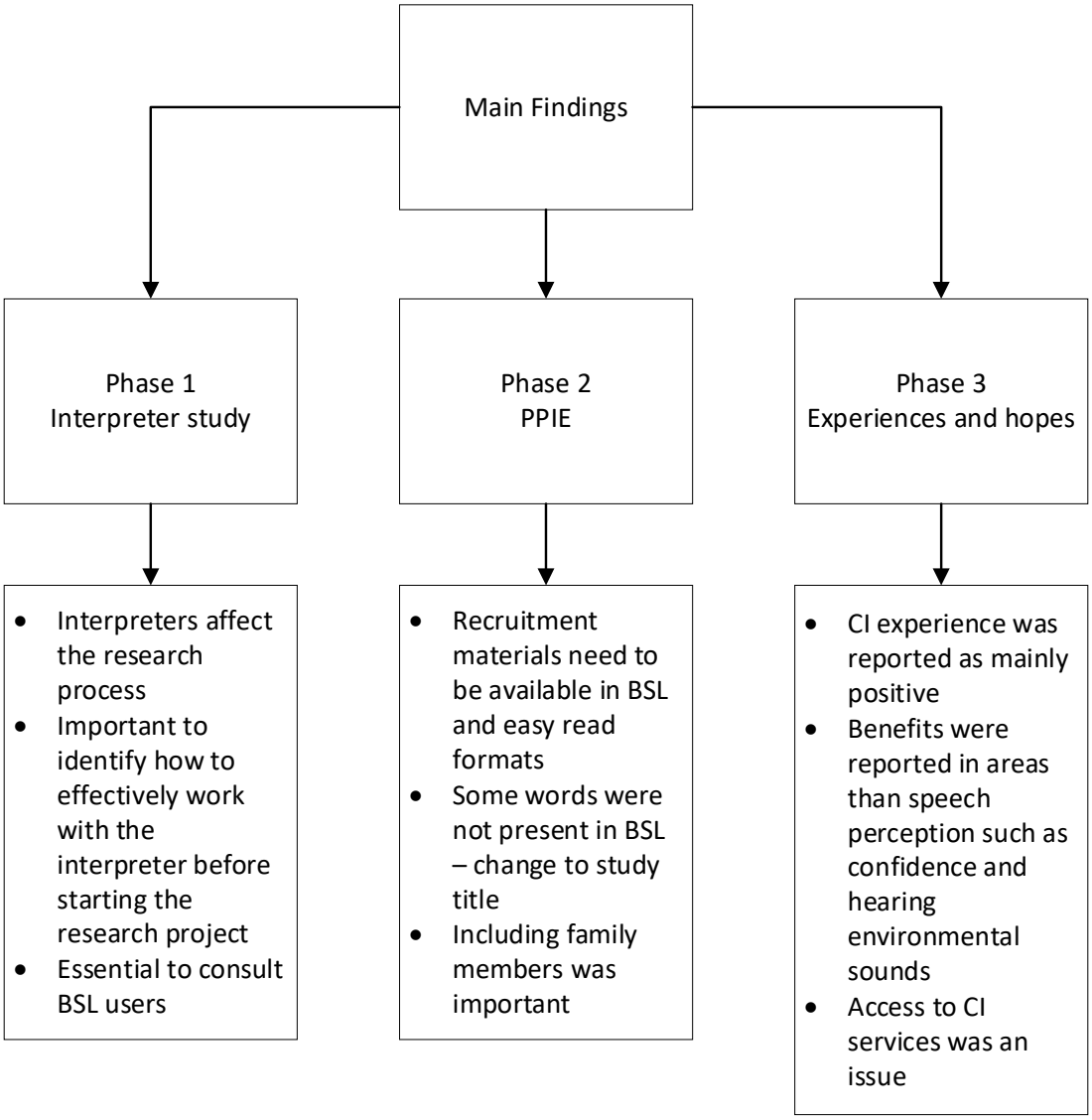
1.12 Thesis outline

This thesis contains 7 Chapters, Chapter 1 contains background information on cochlear implants, the participant group and introduces the area of expectations. Chapter 2 explores the literature on this topic and identifies gaps within this. Chapter 3 explains the methodology chosen and the changes necessary because of the Covid 19 pandemic. Chapter 4 presents the Phase 1 work determining how to work with a BSL interpreter. Chapter 5 describes the Phase 2 PPIE focusing on what BSL users want and the view of the family. This thesis had to cover all these stages before Chapter 6 could be planned and completed. These initial phases resulted in a change to the thesis title from pre-lingually deafened adults' expectations and experiences of a CI to early deafened adults and their families' hopes and experiences of a cochlear implant. Chapter 6 contains the Phase 3 study investigating the early deafened adults' experiences and hopes of a CI. This Phase 3 research was then affected by the Covid 19 pandemic which shifted the focus of the study as all CI operations were cancelled. This meant that CI participants could not be followed through the implantation process and their views were captured retrospectively. The main findings of each phase are shown in Figure 3.

The final Chapter looks at the thesis as a whole and describes the key learning points, impacts on service provision, how this thesis has added to the knowledge base, future areas to investigate,

limitations of this work and then a section reflecting on my role in the study and research and how this has developed through the course of this candidature.

Figure 3 Main findings from each study Phase



Chapter 2 Literature Review

2.1 Introduction

This chapter describes the search strategy and ~~literature~~ review of the published literature on expectations of a cochlear implant. Literature including both pre- and post-lingually deafened adults was included in this search. It was deemed necessary to include both sets of literature due to the differences between authors on the definition of pre-lingually deafened (related to onset of deafness) or authors not stating if their participants were pre- or post-lingually deafened adults. Post-lingually deafened adults go through the same CI process as a pre-lingually deafened adult and therefore their experience of the CI process is likely to be similar. The literature was explored in two stages, the first stage looking at the expectations of pre-lingually deafened, and the second stage post-lingually deafened adults. A comparison of the literature found at each stage was then performed to explore similarities and differences between the groups. Gaps in the literature were then identified and used to create the research questions.

2.2 Search strategy

2.2.1 Type of literature review

The search strategy for this scoping review of the literature involved an electronic search of the published literature. A scoping review was chosen to provide an overview of this area as the research question was quite broad and the available literature limited (Peterson et al., 2017). Although systematic reviews are rigorous they require a clearly defined research question (Charrois, 2015). With the limited studies available on this topic area and broad nature of the research question a scoping review was more appropriate for this search.

2.2.2 Databases

The literature search was performed using the Web of Science and PubMed databases. These databases were chosen as they included an extensive range of citations and databases to search within (PubMed, 2018, Web of Science, 2018).

2.2.3 Search terms

The search terms are shown in Table 1. As expectations and cochlear implant have different forms (for example expect, expectations, expecting) truncation was applied allowing all forms of the word to be included. As discussed previously, pre-lingually deaf adults had been described as congenitally deaf, late-implanted etc. To ensure that the scoping review included these papers, no reference to the onset of deafness was included in the selected search terms.

From an initial search of the literature the addition of the term 'experience' was included, as a patient's experience of implantation can give indications of their expectations from a CI.

Table 1 List of search terms and reasons for their inclusion in the review

Search term	Reasoning
Cochlear implant*	To ensure the literature was relevant to cochlear implantation. There were many terms using cochlear implant, cochlear implantation etc. so to capture all these a * was applied.
Experience* or expect*	The focus of the literature review was expectations of a cochlear implantation. Experience was included as this can be relevant to a patients' expectations.
Adult	The review focused on adult patients, adult was included to try and exclude the papers focusing on paediatric expectations.

2.2.4 Exclusion criteria

Only papers in scientific journals were included to ensure the papers had been peer reviewed. Papers looking at satisfaction and benefit were excluded as this was usually comparing pre- and post-implant performance and had no focus on expectations. The full exclusion criteria, the justifications for these, and stage they were applied are shown in Table 2.

Table 2 Exclusion criteria applied to the literature review screen

Exclusion criteria	**Rational**	**Applied**
Not written in English	Costs and difficulties with translation.	Initial search stage
Papers published before 1980 excluded	Cochlear implants were given FDA approval for implantation in adults in 1984, pre 1980s they were not widely available (Raine, 2013).	Initial search stage

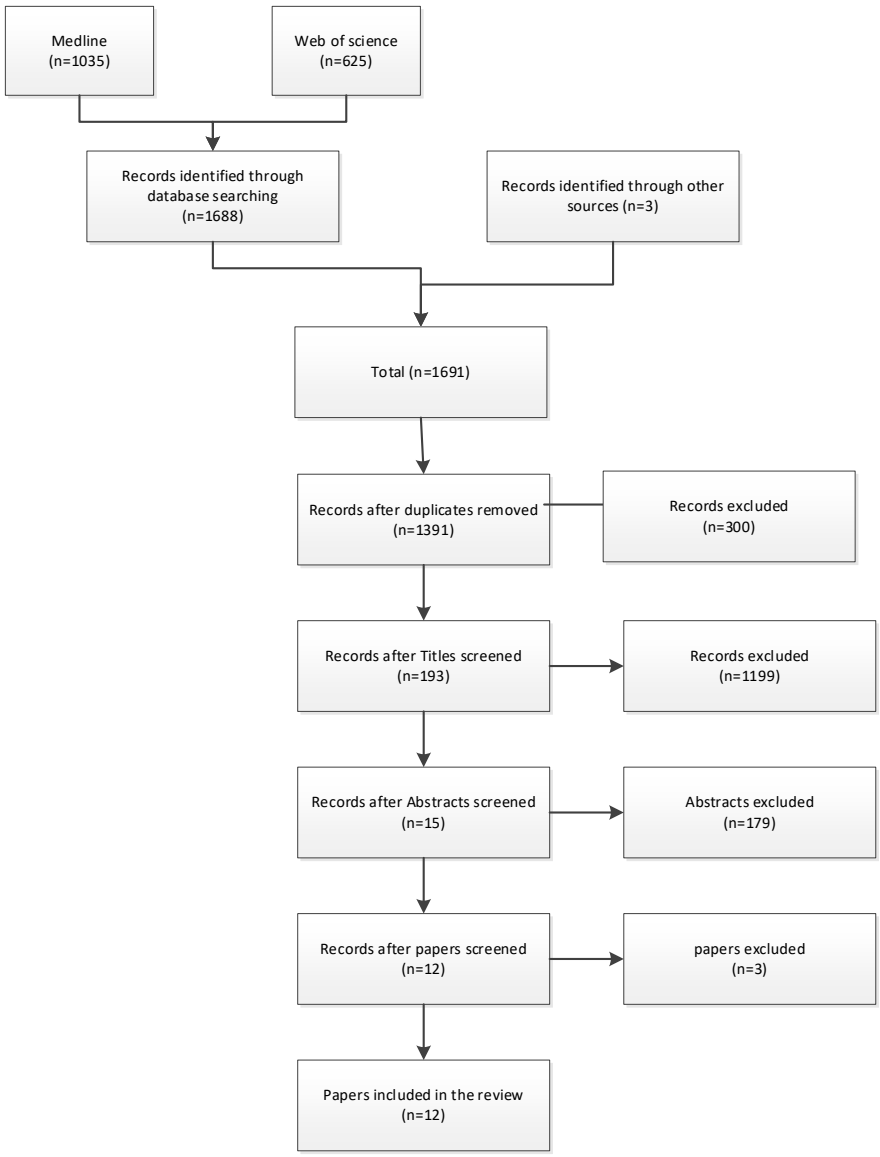
Not a published article in a peer reviewed journal	The literature has not been reviewed by experts within the field within scientific journals, this was to ensure the quality of the article.	Initial search stage
Literature was not relevant to expectations of a cochlear implant or focused on children	Literature which looked at implanting children focused on different topics which were not relevant when implanting adults. Literature not relevant to expectations or experience was not the focus of the review and so removed.	Title and abstract screening
Literature relating to satisfaction or benefit after implantation	This was not relevant to experience or expectations of an implant and was largely looking at if there was an improvement in outcomes post-implant. This could not be removed at the title search stage as it was unclear what methods were used to measure outcomes in all cases.	Abstract and paper screening

2.2.5 Search results

The search identified 1688 papers. A hand search of the literature using the search terms was performed using internet search engines and by checking reference lists of relevant studies. This identified 3 papers that were deemed relevant to the search terms in Table 1. This resulted in a total of 1691 papers, the process for refining and screening the papers is shown in Figure 4. Duplicates were identified and removed. Papers were then assessed based on their title; they were removed if not relevant to expectations or focused on children and/or their families. This resulted in 193 papers.

The abstracts of the papers were then assessed, and further papers were excluded based on the relevance to expectations and experiences of adult CI users. Papers related to satisfaction/benefit after implantation were removed as they did not relate to the experience of the CI or their expectations from the intervention. One paper (Newberry, 2011) was a report on the authors experience of an implant and although not a research paper, was included in the review as the paper was a first-hand account of the CI experience. All the papers were then read in full, and any further exclusions made based on exclusion criteria shown in Table 2. This resulted in twelve papers being included in the review (See Table 3 for a list of the papers included).

Figure 4 The literature review process (The Prisma Group (2009))



2.2.6 Critical appraisal

The quality of the qualitative papers was determined through using the CASP checklist (CASP UK, 2013). This tool was chosen as it assessed the validity, results, and relevance of the papers. This was not used to screen the papers due to the low number of papers found (The papers included in the review are shown in Appendix A). The papers with the CASP checklist applied are shown in Appendix B. The quantitative papers were assessed using a guide provided by Cathala (2018), this is shown in Appendix C. These tools assessed if the methodology and analysis used was appropriate and allowed a structured approach to reviewing the papers.

2.2.7 Synthesis of findings

After the papers were appraised, the papers were reread, and the content of the papers assessed with relevance to expectations. A worksheet was then used to go through the papers and note the research findings in relation to expectations which was used to organise the data and write the review.

2.3 Review of the papers

This section reviews the papers identified from the database search. It examines the participants included in the study, the methodology and methods applied and the findings of the review.

2.3.1 Participants

Four of these papers focused solely on pre-lingually deafened adults. One paper included both pre and post-lingually deafened adults in their sample (See Table 3 which shows the papers and the participants' onset of deafness included in the papers). Athalye et al. (2014) commented on expectations of pre-lingually deafened adults in addition to reporting findings of the whole sample. Snell (2015) included adults in their sample who had been implanted as children between the ages of 10 and 28 years of age, apart from one, who had been implanted age three and a half and then re-implanted at 18 years of age due to an implant failure. The age of onset of deafness was not mentioned, from this it was difficult to determine if the paper's participants were pre or post lingually deafened. For this reason, it was discussed as a post-lingually deafened paper.

All the studies including post-lingually deafened adults did not comment on the age of onset of deafness and if it was mentioned it was unclear if it was the onset of profound deafness. This meant that Tyler (1994), Rembar et al. (2009) and Hallberg and Ringdahl (2004) may have included participants who were pre-lingually deafened but it was unclear from their papers. These papers were considered as post-lingually deafened. These are discussed below.

Table 3 Papers included in the review and methodological approach

Paper	Onset of Deafness	Methodological approach	Data collection methods	Theory based	Qualitative analysis
Athalye et al. (2014)	Pre- and post-lingual	Qualitative	Interviews	No	Thematic analysis
Bosco et al. (2013)	Pre- and peri-lingual	Quantitative	Interviews, speech perception, language development and psychological evaluation	No	N/A
Chee et al. (2004)	Pre-lingual	Quantitative	Questionnaire	No	N/A
Finlay and Molano-Fisher (2008)	Post-lingual	Qualitative	Interview, participant observation, diary	Yes, Phenomenology	Existential analysis (occurred with all the data not restricted to the interviews)
Hallberg and Ringdahl (2004)	Post-lingual	Qualitative	Interviews	Yes, Grounded theory	Grounded theory analysis
Heywood et al. (2016)	Pre-lingual	Quantitative	Retrospective review of case notes	No	N/A
Jeffs et al. (2015)	Pre-lingual	Qualitative	Interviews	Yes, Grounded theory	Grounded theory analysis

Paper	Onset of Deafness	Methodological approach	Data collection methods	Theory based	Qualitative analysis
Maki-Torkko et al. (2015)	Post-lingual	Qualitative	Questionnaire	No	Content analysis
Newberry (2011)	Post-lingual	N/A	N/A	N/A	N/A
Rembar et al. (2009)	Post-lingual	Qualitative	Questionnaire	No	Descriptive analysis
Snell (2015)	Post-lingual	Qualitative	Interviews	No	Thematic analysis
Tyler RS (1994)	Post-lingual	Quantitative	Questionnaire	N/A	N/A

2.3.2 Methodology and Methods

The papers consisted of both qualitative and quantitative approaches as shown in Table 3. Most papers used a qualitative approach (Athalye et al., 2014, Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Jeffs et al., 2015, Maki-Torkko et al., 2015, Rembar et al., 2009, Snell, 2015), while four used a quantitative approach (Bosco et al., 2013, Chee et al., 2004, Heywood et al., 2016, Tyler, 1994); while one paper was a personal report of their experience of cochlear implantation (Newberry, 2011). Most of the papers using a qualitative approach did not use a theory based approach, of the three that did, two used grounded theory (Hallberg and Ringdahl, 2004, Jeffs et al., 2015) while one used a phenomenological approach (Finlay and Molano-Fisher, 2008). Of the papers using qualitative approaches, three collected their data using interviews (Athalye et al., 2014, Hallberg and Ringdahl, 2004, Snell, 2015), two used open ended questionnaires (Maki-Torkko et al., 2015, Rembar et al., 2009), while one used interviews, diaries and the researcher's personal reflections (Finlay and Molano-Fisher, 2008). The data were analysed using thematic analysis (Athalye et al., 2014, Snell, 2015), descriptive analysis (Rembar et al., 2009), grounded theory (Hallberg and Ringdahl, 2004, Jeffs et al., 2015), existential analysis (Finlay and Molano-Fisher, 2008) and content analysis (Maki-Torkko et al., 2015). This is summarised in Table 3. The quantitative papers used Wilcoxon signed ranks tests to compare pre and post-implant data (Bosco et al., 2013, Heywood et al., 2016) and used percentages to show the number of participants who responded in a certain way to each question (Bosco et al., 2013, Chee et al., 2004, Heywood et al., 2016, Tyler, 1994).

The interview data were mainly collected face-to-face (Bosco et al., 2013, Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Jeffs et al., 2015). Snell (2015) collected interview data through face-to-face interviews, skype, windows messenger and email. All the participants indicated their preferred language and mode of interview and so gave participants a choice in how they participated in the study. It is not clear how many of the interviews were signed, if an interpreter was present or if the researcher was fluent in BSL, it was not mentioned if one person or multiple interviewers were involved. Athalye et al. (2014) did not mention if the interviews they undertook were face to face, only that the BSL user typed their responses. Although Snell (2015) and Athalye et al. (2014) used different mediums to collect their interview data all the data collected was analysed using the same methods. Bosco et al. (2013) used structured interviews which were assumed to have taken place face-to-face, but this was not stated in the paper. No information on how the interview took place was shared in the paper. Finlay and Molano-Fisher (2008) used a phenomenology methodology which looked at the lived experience of the CI recipient. An unusual aspect of this study was that the researcher and participant knew each

other before the study began and the participant was co-author of the paper. This introduced a different aspect as the researcher was able to compare experiences with the participant before and after the CI and so, notice the changes in them because of this.

Two authors had a topic guide or list of topics which were not shared in their papers (Athalye et al., 2014, Jeffs et al., 2015) while (Bosco et al., 2010) had a structured interview but did not share the full interview questions. Finlay and Molano-Fisher (2008) focused on the general question "what is living with a CI like?" and asking the participant/researcher to "tell me the story – your story- of your cochlear implant". Hallberg and Ringdahl (2004) did not specify what questions they asked but commented that their interview questions "intended to facilitate exploration of the participants' experiences and meaning of living with a CI".

In three of the papers data were collected using questionnaires (Chee et al., 2004, Heywood et al., 2016, Tyler, 1994). These were administered at home (Chee et al., 2004), in a clinic waiting room (Tyler, 1994) or was not disclosed (Heywood et al., 2016).

2.3.3 Findings

This review of the literature presents the literature on expectation of both pre and post-lingually deafened adults. The literature review identified that participant expectations were discussed but were not always the focus of the study. Comparisons of the two groups was performed to highlight any differences or similarities between the two groups.

2.3.3.1 Expectations and experiences of pre-lingually deafened adults

Five papers discussed expectations of pre-lingually deafened adults. These are now presented with reference to the participants expectations. Athalye et al. (2014) included both pre and post-lingually deafened adults in their sample. In some sections they distinguished between the pre and post-lingually deafened adults, and due to this, the analysis with reference to pre-lingually deafened adults, was discussed in this section, and in the overall analysis in 2.3.3.2.

Only one paper reported what participants expected from a cochlear implant, and these expectations were better communication and to hear more sounds (Heywood et al., 2016). This was reported by no other papers in the review.

The papers identified that pre-lingually deafened adults' pre-implant expectations of an implant were different from their implant experience and they did not have all their pre-implant expectations met (Bosco et al., 2013, Chee et al., 2004, Heywood et al., 2016, Jeffs et al., 2015). Jeffs et al. (2015) found that the initial experience of an implant differed from their participant's

expectations, and five participants described the initial tuning appointment as distressing. Their experience then improved as they started to hear more sounds. This showed that the participant's experience of an implant changes over the course of the first year. Jeffs et al. (2015) and Bosco et al. (2013) both identified participants whose expectations were not fully met, but did not expand on what these expectations were. Some participants reported deteriorations in their performance from pre- to post-implantation and this could indicate that expectations of a CI have not been met (Chee et al., 2004). Heywood et al. (2016) mentioned that two of their participants did not have their expectations met but do~~es~~ not expand on which expectations. They also noted that participants reporting their CI as a success depended upon if their expectations had been met.

Even though expectations were not met, and some participants had negative emotions regarding an implant, only 2 of 43 participants would not consider an implant again (Bosco et al., 2013, Chee et al., 2004, Jeffs et al., 2015). The reasons why these adults would choose an implant again, or why they would not, were not discussed within these papers. More discussion regarding their expectations of a CI may inform why some pre-lingually deafened adult's expectations of a CI were not met and why they would/would not choose implantation again.

Jeffs et al. (2015), Athalye et al. (2014) and Bosco et al. (2013) used interviews in their studies but Bosco et al. (2013) used a structured interview while Jeffs et al. (2015) and Athalye et al. (2014) both used semi-structured interviews. Jeffs et al. (2015) had a larger sample size so was able to explore in more detail the experiences and reports of pe-lingually deafened adults. Of these two papers only the Jeffs et al. (2015) paper findings were solely related to pre-lingually deafened adults. Both Jeffs et al. (2015) and Athalye et al. (2014) produced themes from their analysis but as Athalye et al. (2014) included post-lingually deafened adults this was discussed in relation to the post-lingually deafened adults in 2.3.3.2. Bosco et al. (2013) performed a structured interview and a quantitative analysis with both adults and adolescents, results from the interviews were presented in percentages. They discussed the results of the adults and adolescents separately. This structured interview did not allow any exploration of the participant's responses, and the authors did not discuss why a structured interview was chosen over other methods such as questionnaires. However, as questionnaires can require a higher reading level, this may explain why a structured interview was performed.

The papers inclusion criteria were different, with Chee et al. (2004) and Heywood et al. (2016) including adults with an onset of deafness before the age of six years and Jeffs et al. (2015) before the age of two years. Bosco et al. (2013) included two participants with a peri-lingual hearing loss, which they defined as occurring between the ages of 12 and 36 months. Athalye et al. (2014) did

not provide a definition of what onset of deafness participants met to be referred to as pre-lingually deaf. These differences and lack of a consistent onset of deafness, made comparisons between the studies challenging as an adult who lost their hearing aged five would have more access to language that an adult born with a profound hearing loss which could impact on their experience and expectations of a CI.

Using questionnaires to assess pe-lingually deafened adults has been problematic with some questionnaires having too high a reading level for these adults (Connolly et al., 2006). Chee et al. (2004) study used questionnaires and had a response rate of 71%, the adults who did not respond may not have had the appropriate language level to complete the questionnaire. The adults in the Heywood et al. (2016) study all completed the questionnaire, but the language level of the questionnaire was not discussed. This could mean that the adults recruited had a high language level needed to complete it successfully. This skewed the results towards individuals with better language levels and may not be representative of the pre-lingually deafened group as a whole. The use of a questionnaire limits the ability to explore issues relating to the participants responses to the questions in each category.

These papers highlight that the expectations of a CI, for some pe-lingually deafened participants, were not met. What the expectations of these participants were, or what these expectations were based on, were not considered in depth within these papers.

2.3.3.2 Expectations and experiences of post-lingually deafened adults

The papers in this review included adults with varying onset of deafness, which was not always clearly presented, this could mean that the results were more relevant to post-lingually deafened adults. Papers that included both pre- and post-lingually deafened adults in their analysis are presented. The Athalye et al. (2014) paper is also discussed here as they clearly stated their analysis included both pre- and post-lingually deafened adults.

Onset of deafness refers to the age at which the adults acquired their deafness, or this could have been from birth, this was variable within the studies. One paper clearly included both pre- and post-lingually deafened adults in their sample and the numbers included (Athalye et al., 2014). Two papers stated the onset of deafness for the whole group; it is then not clear how many pre-lingually deafened adults were included in the study (Hallberg and Ringdahl, 2004, Rembar et al., 2009). Other authors did not comment on the onset of deafness (Snell, 2015, Tyler, 1994). Three studies defined their participants as post-lingually deafened adults. Two were clear that the age of onset was after 18 years of age (Maki-Torkko et al., 2015, Newberry, 2011). One author described the onset of deafness was five years of age and was included in the post-lingually deafened

literature as the authors, one of whom was the participant, defined the subject as a post-lingually deafened adult (Finlay and Molano-Fisher, 2008). These papers were considered together as the inclusion of post-lingually deafened adults in the sample may introduce different results from the papers solely focusing on pre-lingually deafened adults.

The expectations post-lingually deafened adults had of a CI were only discussed by one paper (Athalye et al., 2014), who reported that improvement in communication was the main expectation of a cochlear implant. They shared quotes from participants which included 'stop straining to hear' and 'improvement in social situations'. These quotes provided an insight into the expectations of these adults, however, as these adults did not proceed with implantation what their experience of implantation was or if these expectations were met cannot be discussed. The rest of the literature did not discuss the expectations of their participants as this was not the focus of their study. This was included in the review as with the limited literature found on this topic an insight into the experiences of a CI could give an insight into their expectations or how their expectations were formed or managed.

The literature contained differing reports on management of expectations by clinicians. Athalye et al. (2014) reported conflicting views on management of expectations, one participant noted their expectations were well-managed, while another reported they were negatively affected by talking to the implant team. Newberry (2011) reported their personal expectations were well managed by the staff at the implant centre, while Hallberg and Ringdahl (2004) found professionals contributed to low expectations of implantation. Snell (2015) gave an example where even when clinicians attempted to reduce expectations, this did not prevent disappointment at the initial switch on appointment. This highlighted that clinicians at CI centres did act to manage expectations of prospective implant candidates and influence the expectations the recipients have of a CI. Other CI recipients also act to manage prospective candidates expectations, with Athalye et al. (2014) finding that expectations were also re-evaluated after talking to other CI users.

Four papers used qualitative methods to investigate the experiences of adults with cochlear implantation (Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015, Rembar et al., 2009). With initial experiences of '*don't want to hope too much'* (Finlay and Molano-Fisher, 2008) and feelings of '*nothing to lose'* (Hallberg and Ringdahl, 2004). They describe the whole process of getting an implant as being an anxious and worrying time, with the outcomes of a CI being uncertain. Pre-implant participants reported a worry in their ability to communicate with others and isolation due to their hearing loss (Maki-Torkko et al., 2015, Rembar et al., 2009).

Only two authors discussed both the silence after surgery and the experience of switch on (Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004). The participants described the silence after surgery as they were unable to use their hearing aids or the loss of their residual hearing and how this was a worrying time for them. They reported different experiences of switch on with both positive and negative experiences reported, one of Finlay and Molano-Fisher (2008) participants described this as a '*not a positive experience'* while Hallberg and Ringdahl (2004) participants described this experience as very positive, though some participants were scared of hearing the new sounds. This showed that not all recipients experience '*switch on'* in the same way.

After implantation there was a period where the participants reported hearing new sounds and re-learning what these sounds were. It was described as a time of new experiences and of exploration (Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015, Rembar et al., 2009).

The main theme in two papers was 'a new life' (Rembar et al., 2009) or 'getting a new life' (Hallberg and Ringdahl, 2004) and demonstrated the positive changes that users reported with the implant. All papers reported changes to the participant's lives as a result of an implant; this could have been due to reduced isolation, easier communication, increased confidence and reductions in anxiety (Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015, Rembar et al., 2009). The papers supported that a CI significantly changed the participants lives (Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015, Rembar et al., 2009), and the experiences described showed similarities across the papers.

2.3.3.2.1 Effects on the family

Three of the papers commented on the effects on the family unit. Newberry (2011) mentioned it with regards to her personal experience of implantation and the effects this had on her family in relation to the change in her listening ability. Maki-Torkko et al. (2015) reported that the significant others noted a change in the CI users with regards to confidence, independence and as being seen by others as normal. Finlay and Molano-Fisher (2008) discuss how the family supported the recipient in the 'new world' she was now experiencing. There were few studies within the literature that focused on the adults' family's experience of cochlear implantation, most focused on the family of a child going through implantation.

2.3.3.3 Comparison of expectations between the two groups

Comparing pre-implantation expectations between the pre- and post-lingually deafened groups was challenging due to the different hearing experiences and outcomes post-implantation. This was highlighted by Athalye et al. (2014) who reported that the expectations of the two groups were managed differently by clinicians, with post-lingually deafened adults being managed more effectively. It was likely that post-lingually deafened adults based their expectations on previous hearing experience, whereas pre-lingually deafened adults did not have the same hearing experience which was likely to result in different expectations of a CI. No literature was found comparing expectations between the two groups.

2.4 Quality of the Research

The quality of the research papers are discussed with reference to the CASP checklist and with reference to data collection methods and participant inclusion criteria.

Using the CASP qualitative checklist tool (CASP UK, 2013), all the qualitative papers were reviewed (Appendix B). The questions in the checklist were then discussed. All papers used an appropriate qualitative methodology with all the papers using a theory-based approach. The Grounded theory analysis described by Jeffs et al. (2015) was referenced to the analysis only. Grounded theory is a complete methodology and analysis, which was not applied in this paper. The relationship between the researcher and participants were considered by three authors (Finlay and Molano-Fisher, 2008, Hallberg and Ringdahl, 2004, Jeffs et al., 2015). Although Finlay and Molano-Fisher (2008) did consider the effects of the researcher, Malono-Fisher (The author in the paper) had the role of both researcher and participant, the effects of this on their relationship going forward due to the sensitive and personal material discussed and the potential pitfalls of this relationship were not fully discussed. Rembar et al. (2009) and Maki-Torkko et al. (2015) collected their data using written questionnaires so their effect on the data would have been minimal. Snell (2015) and Athalye et al. (2014) collected the majority of their data from face to face interviews and did not discuss the potential effects on the data. Four papers collected their interview data through different mediums, i.e. BSL, spoken response, written responses (Athalye et al., 2014, Hallberg and Ringdahl, 2004, Jeffs et al., 2015, Snell, 2015). The differences in these response mediums and the potential effects on the data were not considered. BSL and Spoken English are different, as is spoken and written English. In particular, the meaning of something that is written to the intonation of spoken language can be interpreted differently. There was no consideration of this on the data collected. When the interview data were collected using sign language, the researcher

was either fluent in sign language (Jeffs et al., 2015), an interpreter was used (Hallberg and Ringdahl, 2004) or this was not discussed (Snell, 2015).

A guide provided by Cathala (2018) was used to assess the four quantitative studies (Appendix C). A clear statement of aims was provided by two of the papers (Bosco et al., 2013, Chee et al., 2004), one paper had no statement of aims but clear hypotheses were given (Heywood et al., 2016). Two of the papers used statistical measures to analyse their data (Bosco et al., 2013, Chee et al., 2004), but only Chee et al. (2004) discussed this in relation to the power of the study, stating it was under powered due to low participant numbers. This means that there was potential for type 1 and 2 errors within the data. It was likely this was the same for Bosco et al. (2013). None of the papers used validated questionnaires.

Of the twelve studies, the majority recruited participants after they were implanted with a CI. Using retrospective data collection could have affected the responses of these participants as they were recalling their expectations and experiences retrospectively. Only Heywood et al. (2016) recorded what participants expectations were and if they were met after implantation but did not explore these further as they used a questionnaire methodology, while Finlay and Molano-Fisher (2008) looked at the whole experience of an implant from pre to post-surgery. The main aims of the majority of papers discussed in this review were not to identify expectations of a CI, this makes the evidence reported by the papers difficult to compare as there was no particular focus on this area.

The papers varied in the language they used to describe pre-lingually deafened adults, they used language such as congenitally (Jeffs et al., 2015), early deafened (Chee et al., 2004, Jeffs et al., 2015), late implanted (Bosco et al., 2013) and non-traditional (Heywood et al., 2016). Only Athalye et al. (2014) referred to this group as pre-lingually deafened but then did not mention the criteria for this. They are the only authors to not include an age at onset as a way of including people in this category. Along with the language used in the papers to describe these adults, the age of onset also varied between the papers (for pre-lingual HL <6 years (Chee et al., 2004, Heywood et al., 2016), <3 years (Bosco et al., 2013, Jeffs et al., 2015) and for post lingual ≥5 years (Finlay and Molano-Fisher (2008)). As NHSP in England and Wales was only introduced in 2006 (Wood, 2015), the onset of deafness for adults was not always clear, as before its introduction children were not always diagnosed from birth even if the hearing loss was congenital. This can make the onset of deafness difficult to accurately pinpoint which may be why most of the papers use an onset of deafness which was not from birth. The papers used different values for age at onset of deafness for their inclusion criteria, a child deafened at five years of age would have had more access to

language compared to a child deafened at age one, this could introduce variation between the groups.

It was also likely that there were adults included in the post-lingually deafened papers who were deafened pre-lingually, but the papers were not clear that this was the case. For this review, to ensure that only adults who were pre-lingually deafened were included, if the age of onset was not clear of deafness they were discussed as a post-lingual paper. This may mean that some papers may have been included in the post-lingual group when they focused mainly on pre-lingually deafened adults. This may particularly be the case for the Snell (2015) paper.

2.5 Summary

This chapter presents a review of the literature on the expectations and experiences of pre-lingually deafened adults. The review of the literature identified the limited knowledge and understanding of adult's expectations of a CI and what they base these expectations on. Literature investigating the expectations of pre-lingually deaf adults was more limited. Understanding what pre-lingually deafened adults' expectation of a cochlear implantation are/were would allow greater understanding of their motivations for cochlear implantation and improve the patient experience of cochlear implantation assessment and management process. It would also allow us greater understanding of what their expectations are based on and what references they then use for these. These gaps within the literature have resulted in the research question for this study. Therefore, the overarching research question for the project is:

2.6 Overarching Research question

What are the expectations and experiences of pre-lingually deafened adults of cochlear implantation?

Chapter 3 Methodology

3.1 Introduction

This study followed a pragmatic approach using qualitative methods over three study phases. This chapter describes what a research paradigm is, pragmatism as a research paradigm and the reasons for its selection. Within this chapter the types of research design applied across the thesis are explored and the design choices discussed. The effects of the Covid 19 pandemic are presented and how the study adapted as a result and the decision-making processes in relation to this. An insight into the researcher's position within the study and their status in relation to the participants is provided.

3.2 Methodological theory underpinning the thesis

The main methodological theory underpinning the research within this thesis is pragmatism, taking a predominantly qualitative approach. Pragmatism as a research paradigm is described as flexible as the researcher uses a methodological approach that works most effectively for the research question being investigated (Tashakkori and Teddlie, 1998) and can be used across research methods (Morgan, 2014b). Morgan (2014b) highlighted that pragmatism goes beyond 'problem solving' and involves linking what the researcher believes and their actions within the research process, thus forming the basis of the research. Rather than focusing on epistemology and ontology, the emphasis of pragmatism is on experience and why decisions are made (Morgan, 2014b). Pragmatism has mainly been described in relation to mixed methods research, which can be restricted if following other paradigms (Doyle et al., 2009, Feilzer, 2010, Hanson et al., 2005, Morgan, 2007, Tashakkori and Teddlie, 1998). Through focusing on the methods it allows information gained from one method to be used to inform data collection using a different method (Morgan, 2007). This allows the information gained from each stage of the study to then be used to assess and reflect what methods would then be most appropriate. This allows the researcher to be open to unexpected data (Feilzer, 2010).

Pragmatism reports that researchers make decisions based on their knowledge and beliefs (Kaushik and Walsh, 2019). Pragmatists believe this knowledge is socially constructed (based on experiences and actions of society overall), with some versions of these social constructions matching individual experiences more than others (Morgan, 2014a). With no two individuals having identical experiences, this results in research being designed in different ways (Morgan,

2014b). The decisions around study design are made by considering the original research question/s and the purpose of the research (Morgan, 2014a).

Dewey (1933) proposed a model related to problem solving which was then updated by Morgan (2014a) in relation to pragmatist methodology.

1) Identify a problem (research question)
2) Reflect on the problem using your current knowledge – refine the problem
3) Look at ways to address the problem
4) Reflect on the choice of methods potentially reconsidering the research design and problem
5) Conduct the research

This model connects the research question to the research design and to the methodology. Pragmatism aims to address the research question using the most appropriate method (Feilzer, 2010), rather than the philosophical paradigm (Biesta 2014).

Pragmatist researchers consider themselves as part of the research process and not separate from it. They recognise that the results have been constructed between the researcher and the participants. The individual beliefs, experiences of the researcher and the participants are key to the results and conclusions presented (Teychenne et al., 2021).

This pragmatic approach was applied throughout this project as it was a flexible approach. It allowed the research design to be adapted based on new information, what was most appropriate for the participant group and to answer the overarching research question. Because the participant group used a variety of communication modes that are likely to be different ~~to~~ from the research team and were under-represented within research, there was limited research about their experiences with a CI (see Chapter 2). This illustrated that a flexible and adaptive approach was essential. It allowed information gained at each point in the study to be used to inform the next stage of the study and the methods to change to reflect the most appropriate method depending on the circumstances (Morgan, 2007). The Phase 3b study (6.4) took place during the Covid 19 pandemic and changes were required to allow the study to continue. Therefore, an element of reflection and adaptation of the research design was applied throughout the project, based on the new knowledge identified and the global situation at the time.

3.2.1 Qualitative, quantitative, or mixed methods

Qualitative and quantitative data collection methods collect data in different ways. Quantitative methods measure differences empirically, while qualitative methods focus on understanding the

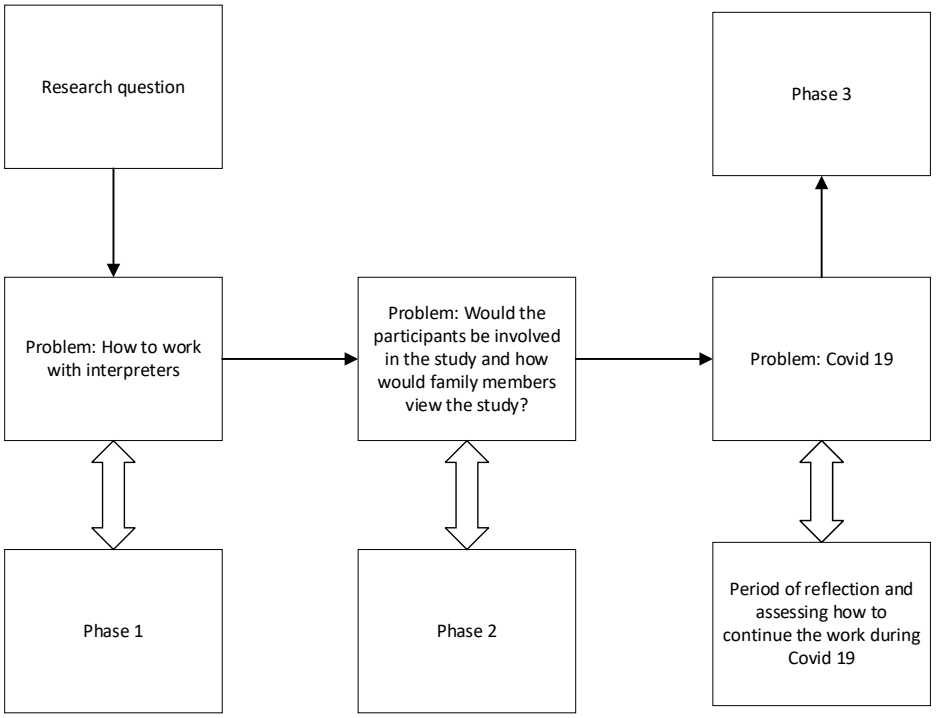
human experience and mixed methods combine the two approaches (Gerrish and Lathlean, 2015).

As the research question in this study related to the views of CI users, topics raised would need to be explored and discussed to fully understand their views. A purely quantitative approach was not practical for this research and would not have allowed this topic to be explored fully, which a qualitative study allowed. It also enabled the experiences and voices of the participants to be captured; a quantitative approach would not have accommodated this.

3.2.2 Overview of this study

Pre-lingually deafened adults have been an under researched group and the literature describing working with them in a research setting was limited, as was working with an interpreter in this setting. An exploratory study and 'Patient and Public Involvement and Engagement' (PPIE) were completed before the initial research question could be addressed. This was explained throughout the chapters, but an overview is shown in Figure 5. After each study or PPIE work the research question was reconsidered in relation to the new data or information collected.

Figure 5 Overview of each stage of PhD study



This PhD work involved two research studies which applied different research designs; the reasons for this are now described.

3.2.3 General qualitative approach

Methodologies to answer the research questions were considered including case study research, phenomenology, grounded theory, and ethnography. Due to the nature of the Phase 1 and 3 studies a general qualitative methodology was followed. General qualitative methodology was developed from the need to conduct qualitative research that did not fit into the four main methodologies shown in Table 4. This means the study was not bounded by a set of philosophic assumptions (Caelli et al., 2003). It can be used to understand views of the participants rather than focusing on building a theory (grounded theory) or analysing the culture (ethnography) (Merriam, 1998).

General approaches offer more flexibility than a defined approach and are likely to be used in research where limited studies or theories are available and/or where the current approaches do not fit the area being investigated (Lim, 2011).

There are issues when using general approaches as they are not well defined, which results in an issue with rigor (Kahlke, 2014), and some authors reported that mixing methodologies leads to contraindications within the research (Caelli et al., 2003, Neergaard, 2009). There was less literature which detailed how to conduct general qualitative methods which means that researchers have to justify clearly the decisions they make within the study (Caelli et al., 2003).

For Phase 1, a general approach was chosen as there was little known about the topic area, a flexible approach was desired and choosing one of the described methodologies would not allow this topic to be effectively investigated within the study timeframe. In Phase 1, following a pragmatic approach and using thematic analysis for the data analysis provided structure while the data validation tools for thematic analysis were used to ensure that the validity of the data was considered. Phase 3 planned to follow a case study methodology, but a general qualitative approach was applied because of the Covid 19 pandemic on the study (This is discussed in 3.4). Using a general qualitative approach was seen as beneficial for this Phase as it was flexible (Kahlke, 2014) and allowed different methods and research designs to be blended (Caelli et al., 2003). This meant that the tools that established methodologies offered could be applied and so a research design that fitted the research questions and data was used (Caelli et al., 2003, Merriam, 2009).

Phase 3 used case study research in the planning, data collection stages and during data validation. Case study validation tools were used as these were well established and thorough. In

Phase 3, using a case study approach to plan and validate the research, while following a pragmatic approach and using thematic analysis for the data analysis, provided structure to the research to negate general studies' poor definition and potential lack of consideration of rigor.

3.3 Study Phases

Each study phase is now described.

3.3.1 Phase 1

This study was exploratory in nature and was used to advise and inform the planned future research (Chapter 6). This study aimed to answer questions around how to work with BSL interpreters effectively in a research setting (My thoughts on working with BSL interpreters during the project are explored in Figure 6). With the study being exploratory in nature a general qualitative approach was followed.

Figure 6 Reflection on working with BSL interpreters

My knowledge of BSL interpreting and the Deaf world has changed throughout the course of this study. My clinical knowledge base influences my views and thoughts while undertaking this research. I worked with interpreters (BSL and other spoken languages) regularly as part of my role. While undertaking this project this was in the capacity that the interpreter came in with the patient to the appointment and I had very little interaction with the interpreter outside of this setting. I saw the interpreter as being there for the patient and felt this was particularly so as the interpreters and patients knew one another and so I was in a sense the outsider in the interaction.

3.3.2 PPIE (Phase 2)

Public Patient Involvement and Engagement (PPIE) is a term used to describe a partnership between service users and researchers (Preston et al., 2019). PPIE aims to produce research that meets the needs of the service users and their families. It gives an insider perspective, checks relevance of the study and can aid participant involvement in research. It can also empower service users and allow them to contribute to service development.

This PPIE took part in two stages. The first was working with BSL CI users to explore if they considered the research was relevant and if they suggested any further areas to explore. The first stage struggled to recruit BSL users and had to look at multiple ways of reaching these adults. The second stage was a result of the information shared from the first stage. This was as the one BSL CI user involved in the PPIE gave feedback that how family members were supported was also important. The second stage looked at the views of family members of research and areas to consider with regards to their involvement.

Phase 2 followed a pragmatic approach which allowed a flexible approach. This was necessary as multiple methods were used to recruit BSL users. The information shared from PPIE was then considered and led to a change in the research question.

3.3.3 Phase 3

After the Phase 2 PPIE, the initial research questions were adjusted based on the feedback received. This involved changing the language used and involving family members in the study. The four research design approaches were then considered in relation to the research questions. Focusing on the family units and analysing them as a whole fitted with a case study approach due to the viewpoint and the experience being different between the family member and the CI recipient. Case study research meant that each family unit could be treated as a single unit and it allowed insights to be gained when looking across the cases (Gerrish and Lathlean, 2015). It enabled multiple sources of evidence to be included (Merriam, 1998) and resulted in a more rounded and in-depth investigation, as it allowed other sources of evidence that may have impacted on expectations to be considered. Case study research meant that the uniqueness of each case could be explored in more detail (Simons, 2009). This was important as each CI recipient is unique, with different hearing history and onset of deafness. In addition each family unit is unique, with different experiences, values, and members. Case study research would have enabled the uniqueness of the family experience of cochlear implantation to be explored along with the expectations of an implant. It would also have facilitated some comparison of experiences across different families. See Table 4 for a summary of why the other approaches were not used. In conclusion, a case study methodology was planned for this study. The approaches to case study methodology were examined in detail and the choices made discussed (Appendix D) but this was not applied due to the Covid 19 pandemic. Table 5 compares the three approaches.

Table 4 Types of research in relation to the current study

Type of Research	Description	Why considered	Why not using
Grounded theory	Approach that develops theory from the data collected. The theory produced is grounded in the data collected. Used mainly in under-researched areas or when a new perspective is needed on an area	Little known about the area and theory would be grounded from the research. Can use a variety of sources of data	Does not allow for use of more formal sources of data such as test results. Need for a larger sample size to generate theory
Ethnography	Way of describing a culture or group/setting, "learning about the people from the people" pg 200 (Creswell and Poth, 2018). Researchers immerse themselves in the setting to identify the insider's view. Results of richly described to give a detailed account of the culture	Immersion in the culture/setting and richly describing the results would give a picture of the experiences of pre-lingually deafened adults. Can be a smaller sample size	Gaining an insider's view in a culture where the language was not shared was challenging. The researcher's dual role ethically could raise issues regarding this immersion. Potentially different cultures between the participants and difficulty in immersing in different cultures

Type of Research	Description	Why considered	Why not using
Phenomenological research	Looking at the lived experiences and find insights that go behind the experiences studied. Try to get the essence of that lived experience	Looking at lived experience which was what this study was about	To get an overview of the experience of the family including more sources of information is desired. This would not be possible using this method. The literature also advises - To prevent misconceptions no reading on the area. This was not really something the researcher could avoid due to their role

Table 5 Main aspects of the three main case study approaches

	Stake (1995)	Yin (2003, 2014)	Merriam (1998, 2009)
Definition of a case study	An investigation of a bounded and integrated system	Investigating a case in depth and within its real-world context especially when the boundaries between the phenomenon and context may not be clearly evident	An in-depth description and analysis of a bounded system
Theoretical position	Constructivism/interpretivism	Post-positivism/realist	Constructivism

	Stake (1995)	Yin (2003, 2014)	Merriam (1998, 2009)
Case study design	Flexible design where researchers can make major changes after starting data collection. The research questions structure the data collection methods. The direction of the study can be predicted in advance and there is no exact point when data collection begins	Detailed and structured approach. Detailed descriptions of the data collection methods, analysis, and interpretation of findings. Proposes looking at the strengths and weaknesses of any design before implementation. If any changes required the researcher needs to go back to the first step of the study design	Detailed study design with an element of flexibility
Type of data	Qualitative	Qualitative and Quantitative	Qualitative
Data analysis	Data analysed and collected simultaneously. Data analysis by categorical aggregation and direct interpretation	Structured data analysis with analytic guidelines and specific strategies (pattern matching, explanation building, time series analysis, program logic models and cross case synthesis)	Data analysed and collected simultaneously. Six analysis strategies (ethnographic analysis, narrative analysis, phenomenological analysis, constant comparative method, content analysis and analytic induction)
Data validation tools	Data source triangulation, investigator triangulation, theory triangulation and member checking	Construct validity, internal validity, external validity and reliability	Internal validity, external validity, and reliability.

3.3.4 Methodology chosen

Case study fitted methodologically with how to analyse the data and answer the research question. Although it had not been described in relation to pragmatism, case study research has been described as a pragmatic and flexible approach (Harrison, 2017). Pragmatism is about the researcher using the most appropriate methods to answer the research question. It accepts that there are multiple and singular realities (Creswell, 2008) and that approaches to research actually share many similarities (Hanson et al., 2005). This led to identifying that case study research would be an appropriate methodology to answer this research question. Due to pragmatism having been chosen as the approach/paradigm this allowed case study research to be applied.

Having a flexible design, as Stake (1995) described, was appealing but did not fit with ethical approval, with any changes to the study requiring to be approved and potentially resulting in delays in obtaining this. This study needed to follow a more structured approach incorporating a level of flexibility. Merriam's (1998) methodology allowed this. Within case study research, using aspects of different authors' designs was recommended to ensure that the approach used fits the aims of the research (Yazan, 2015). Therefore, this study followed Stake's theoretical position but followed a more structured approach as shown by Merriam.

Data analysis included direct interpretation and thematic analysis, which has previously been used in case study research. Using different analysis tools follows Stake's (1995) view that data analysis tools suit the research.

The data validation tools used were those described by Merriam (1998), rather than Stake (1995) or Yin (2003). Yin's (2003) data validation tools followed his positivistic viewpoint and so did not fit with the constructionist/interpretivist stance of this research. Stake (1995) used validation methods that required the interpretation of more than one researcher (investigator triangulation) or looking at different time points/situations to see if the case remains unchanged (data source triangulation). This study was a PhD study and needed to be an original study and contribute to the knowledge base of this topic. Working with more than one researcher could give the impression that this work was not the researcher's own and so lacked originality and could have introduced issues regarding who was contributing to the knowledge base. With regards to data source triangulation, in some of the cases as only one interview was carried out this would mean this validation tool could not be applied. Merriam's (1998) data validation fitted the qualitative nature of this study as this tool was aimed at qualitative studies, it included the researcher's position and disclosure of bias which were important considerations within this study.

3.4 Impact of Covid 19

This study was planned to follow a purely case study approach. However, during this research, Covid 19 resulted in significant changes being necessary to allow the research to continue. Overall, it has resulted in changes to the research study design and the data collected (these are described throughout Chapter 6). It was recognised that the study approach needed to be reconsidered and potentially revised based on the changes due to the data that could be collected. The next sections discus why this was necessary, the changes required and, and the new methods followed.

3.4.1 Changes that were necessary due to Covid 19

It was planned to recruit two groups of participants. One group were candidates for a CI who would be going through the assessment process. The other group were CI recipients who would have already received their implant. The CI candidate group could not be recruited due to all surgeries being suspended. To allow the PhD candidature to continue changes were made which meant that only CI recipients and their family members were recruited.

3.4.2 Issues with the study design and data analysis

The study followed a case study methodology until the data analysis; it was after this point that it was realised that the planned analysis could not be applied to the data collected, and this then led to a period of reflection (Figure 7).

Figure 7 Reflection: was this the right approach?

After initial data analysis started on one case, forming themes with only one source felt wrong and themes were being formed on limited information and basis. Could it be considered a case study with one interview?

It led to questioning if a case study approach was the right approach for this study. The options available were then considered. Continue with an approach that did not fit the data or change the approach of the study. Not collecting the data on CI candidates meant that I did not follow case study methodology. Could the approach be adjusted mid study? How would this sit with my PhD examiners? Was this right for the study? It was an uneasy and uncertain time; to try and make things clearer I considered the questions and reviewed the literature for examples of case study research.

Considering these and many more questions the decision was made by myself with support from the supervisory team that it was not in the best interests of the study to continue with this approach.

3.4.2.1 Decision to change study approach

A case study approach would have allowed all aspects of the 'case' to be examined. Case study research focuses on situations in context (Yin 2014). With the interviews of the candidates having surgery not able to take place, and only interviews of recipients who had been through this experience recruited, this separated the situation from the context. No studies were found using a single interview at one time point without other data (for example observational data). The case study approach was an approach that would have worked if the interview data could have been gained at different time points as was indicated initially. This had been done previously by Lawford et al. (2018) who interviewed participants before and after training which would have followed a similar path as the interviews following the CI experience. Therefore, a case study was the right approach when this research started but changes to the study have meant this was now not the case. The decision was then made to apply a general qualitative methodology which can be applied when the research questions do not fit within an established methodology (Kahlke, 2014).

To allow the study to continue during Covid 19, the decision was made to interview CI recipients only and not CI candidates. The reason for this was as all CI surgeries had been cancelled indefinitely. Also interviewing CI candidates at this time may not have been appropriate as it was

an uncertain time and they had been given no idea of when surgeries may start again. How not interviewing the CI candidates would affect the use of the case study approach was not considered until after data collection. During this period, I was reflecting upon how to continue the project and not seeing the overall study as whole and how this would impact on the approach or the data analysis. Decisions were made to allow the project to continue without the necessary reflexivity which could have resulted in these issues being considered before data collection. This was a limitation of the study. On reflection, the situation was fast moving and decisions had to be made regarding continuing the study or suspending the candidature. It was a complex situation and, as a result, the reflexivity needed to assess the impact on the overall study did not occur in the depth required. This has resulted in a situation where the data analysis did not fit with the approach used in the study. What to do next was then considered. The options available were to adjust the methods to fit with the data collected which allowed the research questions to be answered.

3.4.2.2 Changes in analytical approach

Considering the pragmatic approach and going back to Morgan's (2014a) model (described in section 3.2), the key problem was how to analyse the data. Looking at the research question again and reflecting on the data collected it was determined that analysing the participant' and family member' interviews either together or separately would be suitable to address the research question. One of the issues was the sufficiency of the data collected. In the CI user interviews, the topics raised in the interviews were similar and the experiences of the participants not hugely different. This indicated that the data was close to or at data saturation. There were no other participants who met the study's inclusion criteria who showed any interest in being in the study after two recruitment drives. To invite family members without input from the CI recipient's was indicated from PPIE as not being best practice (PPIE with family members). A clearer approach was to analyse all the interviews together. The options that were considered are shown in Table 6. The analysis of the data was then completed using thematic analysis as originally planned as this was still an appropriate method of analysis for this data. Thematic analysis is commonly used in studies which follow a general qualitative methodology (Braun and Clarke, 2006, Lim, 2011).

Table 6 Considerations for data analysis

	Benefits	Negatives
Analyse all the interviews together	Increases the number of interviews to be analysed Allows all views to be considered in one analysis Improves confidentiality	Some of the views may get lost as they are from two different groups
Analyse the interviews separately	Allows data from each group to be considered separately	Not enough data to analyse two family member interviews
Analyse as a case	Follows original research plan	Not appropriate for the data collected
Extend recruitment	More views can be considered in the analysis Increase number of family members views	Recruitment issues seen in original data collection Time constraints Interviews not required due to data saturation Issues of recruitment during Covid 19

3.4.2.3 What methods were applied?

Due to the necessary adjustments, this study changed from adopting a case study approach to a general qualitative methodology. This was possible as general approaches are used when the current approaches do not fit the area being investigated (Lim, 2011). A general qualitative approach has been described in 3.7.1.1.

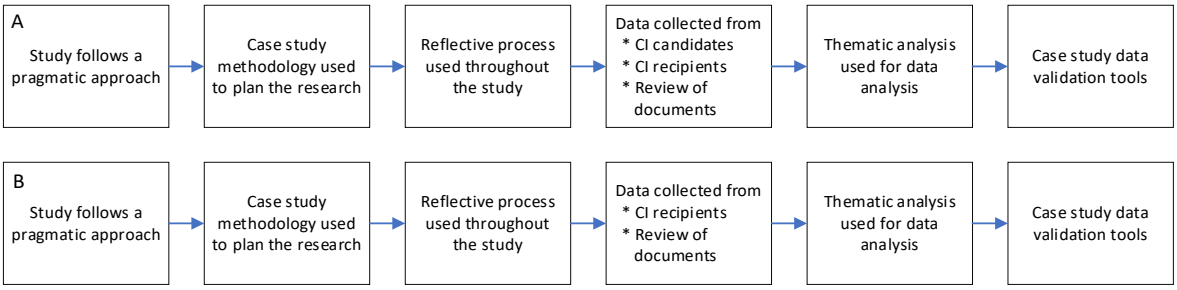
In this Phase, a case study approach was used to plan and validate the research. Using thematic analysis for the data analysis provided structure to the research. Following these approaches aimed to negate the poor definition of general studies and potential lack of rigor.

3.4.2.4 How is this different from what was proposed?

Three interviews would have been carried out with CI candidates and their families at different time points during the implant process. These interviews and the pre and post-implant data

would have been considered as a single case using thematic analysis (one case per CI candidate and family). This would have been compared to the document review data and the interviews from the CI recipients and their families. No CI candidates or their family members were recruited due to the suspension of all operations due to the Covid 19 pandemic, so these data were not collected or analysed (Figure 8).

Figure 8 A shows what was planned within the study; B shows what was carried out within the study



These changes to the study allowed the research question to be answered using a novel study design, combining aspects from different approaches, although this study answers it from a different perspective than may have first been first.

Changes made to the study have resulted in the CI experience not being documented as it happened. The study is now completely retrospective in nature and the participants' insights of the process as it happened cannot be reported upon. This would be a future area of research and was not within the scope of the study due to the impact of Covid 19. Using a case study approach would have allowed all the data relevant to the case to be analysed together and a real time view of that participant's experience to be captured.

3.4.3 Summary

Phase 3 intended to follow a case study approach; however, it was necessary to change the approach to that of a general qualitative methodology because of the effect of the Covid 19 pandemic on data collection. Using the pragmatic approach allowed the study to be adjusted and adapted based on the knowledge and experience that was gained throughout the project. This was essential for working with a minority group and it provided the required flexibility to adjust the project based on their feedback and the changing world situation.

3.5 Methods used at each stage of the Thesis

This section summarises the methods used in Phase 1 and 3, which are explained in more detail in 4.6 and 6.4.1. This is reviewed in Figure 9.

3.5.1 Phase 1

Phase 1 followed a general qualitative approach. Participants were recruited through contact with interpreter groups, posts were made on Facebook and Twitter and interpreters were emailed directly. Convenience sampling was applied. Semi-structured interviews were completed through telephone interviews. Data were then analysed using thematic analysis.

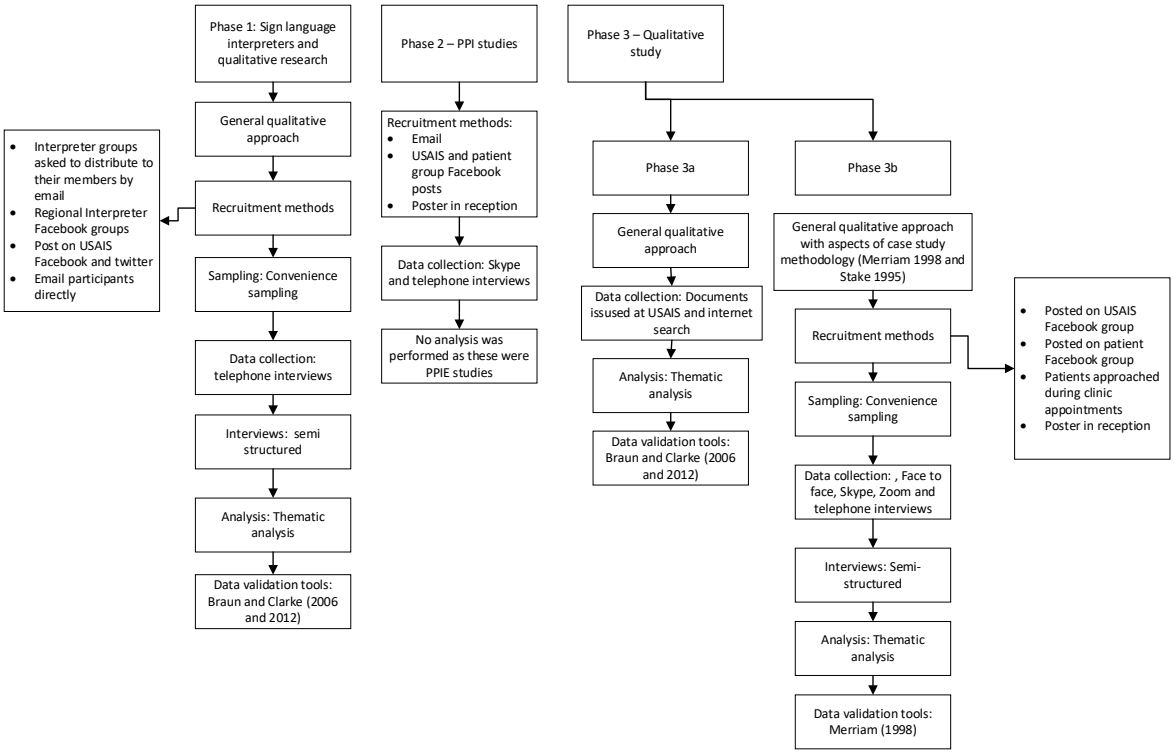
3.5.2 Phase 3a

A general qualitative methodology was applied for this phase. Documents were collected from two sources. These were the documents issued to patients at USAIS, and documents collected after an internet search. The documents issued from USAIS included documents available nationally and documents specific to USAIS. The search terms for the internet search were 'Cochlear implant experience' and 'Cochlear implant deaf'. Once the documents were collected, they were scanned to adobe files or copied and pasted into word documents. They were then transferred to NVivo and analysed using thematic analysis.

3.5.3 Phase 3b

Phase 3b followed a general qualitative approach. It applied case study methodology in the planning, data collection stages and during data validation and used thematic analysis to analyse the data. Two groups of participants were recruited, CI recipients and their family members. CI recipients were recruited through patient appointments, posts on USAIS and patient Facebook pages and posters in the clinic reception. Family members were recruited after they were nominated by the CI recipients recruited. Data were collected through semi-structured interviews. The interviews were performed using Zoom, Skype, telephone, and face to face. These interviews were transcribed into word documents and then transferred to NVivo. CI recipients and family members' data were analysed collectively.

Figure 9 Methods used at each stage



3.6 Reflexivity

Reflexivity, within the research process, has been described as where researchers review their background/position and recognise and acknowledge the effect this has on the research process and outcome (Berger, 2015, Finlay and Gough, 2003). The researcher's background can affect how the researcher poses questions, makes meaning of the interviewees' responses and shapes the findings of the study (Kacen and Chaitin, 2006). Reflexivity aims to acknowledge the effects of the researcher and so result in more credibility and trustworthiness of the findings (Buckner, 2005, Cutcliffe, 2003). Finlay and Gough (2003) described different ways of carrying out reflexivity; these methods were used interchangeably within this study, with introspection (personal reflections on situations that occur) and inter-subject reflection (looking at the relationship between the researcher and participant and its effects on the data). Ballinger (2003) used a reflective diary asking a range of questions. This was adapted for this study and the following questions used:

- What are the implications of choosing this?
- What do I understand by this?
- Why have I done it this this way?
- Why am I finding this difficult?
- How do I know I have done this well?

This was kept throughout the research study and was aided by feedback and discussions during my supervision meetings (Ballinger, 2003).

Reflexivity was applied to demonstrate that I was both a clinician and the researcher. There were some details that I knew from my experiences of working clinically with early deafened adults that would have affected the research process. For example, data collection and analysis would likely have generated different data and results due my knowledge and experience. It was important to highlight this and consider how it impacted on the research process.

3.7 My role as a clinician doing research: an insider or outsider?

Within this research I considered myself as a clinician doing research, which was like Lotty (2020) who described herself as a social worker doing researcher. This identity had elements of both research and practice (Lunt and Shaw 2017). Having this dual identity was quite isolating at times as I was different from my colleagues. This was also the first purely qualitative PhD that had been carried out within the department so I could not be supported by my colleagues as they had limited knowledge of the processes I was talking about. Being a part-time student, I also had a limited peer group, which was quite isolating at times and was made worse by the Covid 19 pandemic.

I considered if I was an insider or outsider within this research study; insider researchers share characteristics of the group they are studying and may be considered members of this group while outsider researchers do not (Chhabra, 2020). I would not identify as a member of the participant group. I was not a CI user and I was not early deafened. I could not understand what it was like to be deaf, hard of hearing or go through the CI assessment process and fitting. I was not a typical outsider researcher though, as I came with views of the CI users' experiences and experiences of CI appointments. I was a clinician who would do the initial tunings and be present for the assessment/switch on appointments and then six- and twelve-month appointments. I have heard CI user's experiences of their implant experiences and seen their struggles and triumphs. I brought to the research assumptions of what the CI users' experiences of an implant were based upon. My clinician role also gave me privileged access to participants and knowledge. I felt I occupied an undefined role as I was not a typical insider, but I could not be considered a typical outsider either, with the special privileges my role enabled. I have considered myself an insider in the context of this study. This highlights the experiences and views I carried throughout the research study and acknowledges that my experience, knowledge, and position impacted on the research. This would have influenced the research paradigm and methodology used.

3.8 Ethical issues

Ethical approval was sought from the University of Southampton Ethics and Research and Governance Online (ERGO) for Phase 1 and Phase 3s. The participants in Phase 3b included NHS patients and so Phase 3b required NHS Research Ethics Service (NRES) approval; this was applied for using their Integrated Research Application system (IRAS). University requirements also required ERGO approval after NRES approval was obtained. This is explained in more detail in Chapter 4 and Chapter 6. No ethical approval was necessary or sought for Phase 2 as this was PPIE.

3.8.1 Data collection

Phase 1 and 3b collected data from participants, while Phase 3b involved analysing documents which included an internet search. Phase 1 and 3b studies were not anonymous due to the participants providing their name and contact details. However here, owing to the need for anonymity of the data, the consent forms were kept separate to the interview notes and any information shared was anonymised in the findings/reports from the study. The interviews were audio recorded and it was possible that participants could have been identifiable with these audio-recordings; however, these files were stored on a secure password protected computer server. The audio files were kept until the end of the study. Audio recordings of the interviews were transcribed, and the text anonymised within 30 days of collection. Audio recordings were kept until publication of the evaluation report and then destroyed.

For Phase 3a each document collected was assigned a number and this was stored separately to the document data. Any paper documents were scanned and then saved in a pdf format. Internet sites that contained written information were copied and saved as a word document. Internet sites that included videos, were either transcribed by hand to a word document or, if a written transcript was provided, this was used. If the language used in the video was BSL and a transcript was provided this was not checked by a BSL interpreter. There were issues identified with using internet data which are explained in detail in 6.3.1.1.1.

3.8.2 Data management

All data were stored on password protected computers. After collection the data were anonymised. In Phase 1 and 3b participants were assigned a pseudonym during anonymisation. Anonymisation took place on 2 levels. Participants, and anyone mentioned in the interviews, were assigned pseudonyms and names of locations were either removed or made generic. The second

level was the use of methods to prevent other people being identified through descriptions. Level 1 aimed to take place during transcribing. Level 2 took place after the transcripts had been re-read to ensure no people could be identified. The interviews were transcribed into a word document. The audio file was played from the computer through headphones, and this was then typed up by hand. All data files were transferred to NVivo for data analysis.

In Phase 3b only, the data collected from clinical notes was anonymised and used to support the information given in the interviews.

In Phase 3a the documents were assigned a number, and the data were anonymised by removing names and references to locations. When quoting this data in the document, care was taken to make the quotes "Google proof". This was to make it difficult for the websites used to be identified. The reasons for this are explained in 6.3.1.1.1.

On completion of the project all data were transferred to University of Southampton (under the control of the project lead) to keep until 10 years after the conclusion of the study, as required.

3.8.3 GDPR adherence

All information was processed in accordance with the General Data Protection Regulation (GDPR) (2018). GDPR covers consent, transparency, safeguards and data subject rights (Health Research Authority, 2023). Consent was obtained to use confidential information. How the data were going to be handled and stored was provided and what will happen to the data after completion of the study by the sponsor was shared (Transparency). All data were securely analysed and stored; this was through any written identifiable information being kept in locked drawers or on password protected computers. The anonymised data and the participant information/document type were kept separately. Participants were able to contact the researcher to be removed from the study up until the study completion date as after this date the data would have been included in the final study report. Phase 1 data were collected before the publication of the 2018 regulations, but the same guidelines were followed.

3.8.4 Conclusion

This chapter describes the research paradigm and the methodological approaches chosen. It examines each study phase and the ethical issues identified.

Chapter 4 Phase 1 - The views of Sign Language Interpreters on the process of interpretation in Qualitative research

4.1 Introduction

The review of the literature in Chapter 2 has found limited knowledge and understanding of pre-lingually deafened adult's expectations of a CI and what they base these expectations on. Before the research questions could be investigated, initial work on Phase 3 indicated that exploratory work was needed due to the communication requirements of the pre-lingually deafened adult group.

The pre-lingually deafened adult group can have a variety of communication modes, namely, BSL, sign supported English (SSE) and/or spoken English. Therefore an interpreter may be required to bridge the gap when there is a difference in language. This literature identified the complexities of working with an interpreter and two views on how to effectively work with interpreters in a research setting. To not include interpreters would exclude adults who use sign language from research and prevent them from having a voice. Therefore, determining how to work with interpreters and identifying how they can affect the data were deemed necessary before the main study could begin. This was the aim of Phase 3.

Participants who use sign language would require an interpreter unless the researcher is fluent in sign language (which was not the case in this study). To become a sign language interpreter can take at least seven years or involve a 3 to 4 year full-time university degree course (SL First Team, 2015), which was not possible during PhD candidature. Not including participants who require an interpreter would bias the participant group to more aural participants.

Conducting the interviews using written questions and responses was considered. However English language proficiency varies between Deaf individuals as they may have learnt English as a second language (Lieu et al., 2007). Pre-lingually deafened adults should be asked which language they wish to be interviewed in; some adults may prefer not to have an interpreter but that was a choice for the individual to make to ensure accessibility for all.

Therefore, to undertake the main study within this PhD, there was a need to explore the process of carrying out qualitative research for participants who require an interpreter. This included

understanding the issues that may arise from working with a small cultural community, exploring ways to ensure anonymity and the best way of working with interpreters in a research setting. This chapter presents the literature review, research design and results of exploratory work with sign language interpreters. The latter includes interpreter views on increasing the accessibility of research for Deaf adults and working with them in a qualitative research setting. This chapter ends with recommendations on how to work with BSL interpreters in a research setting and key learning points to take forward for future work.

4.2 BSL interpreters

BSL Interpreters are hearing individuals fluent in both BSL and English. They can also interpret into SSE which uses the same structure of spoken English with BSL signs. They are regulated by The National Registers of Communication Professionals with Deaf and Deafblind People (NRCPD, 2016). Interpreters form the connection between two languages and cultures to allow effective communication (Dean and Pollard, 2005). Most sign language interpreting is done in simultaneous mode (Table 9) and there is considerable variation within the language which can be related to region, social group, and age. No interpreter will be familiar with all of these (Harrington, 2001).

The available literature was reviewed to establish what information was available on working with interpreters in a qualitative research setting.

4.3 Literature review on interpreters in research studies/Sign language and general interpreting

After an initial literature search, it was identified that the literature involving sign language interpreters in qualitative research was sparse. A literature search was undertaken identifying the literature available on the use of interpreters in research.

The search strategy for this scoping review of the literature involved an electronic search of the published literature using the Web of Science and PubMed search tools. The search terms Interpret* OR Translat* OR cross language AND Deaf AND qualitative AND adult were used and papers written in English from Jan 2000 – May 2016 (See Table 7 for further information). This resulted in 2590 papers.

Table 7 List of search terms and reasons for their inclusion in the review

Search term	Reasoning

Interpret* or translat* or cross language	These are all words that were reference interpreting from one language to another and were included to ensure no papers were excluded on the basis that they referred their interpreters as translators.
Qualitative	There were different issues when working with interpreters in quantitative studies to qualitative studies and therefore quantitative studies were excluded.
Adult	As the review focuses on adult patients, adult was included to try and exclude the papers focusing on paediatric expectations.

After removing duplicates and titles not related to the topic area this resulted in two papers relating to sign language interpreters in qualitative research and 61 papers to interpreters in general. Of these 61 papers the abstracts were reviewed, and a further 48 papers removed from the analysis. This was due to the interpreters not being used at the interview stage or not relevant to the research topic (See Table 8 for the exclusion criteria in full).

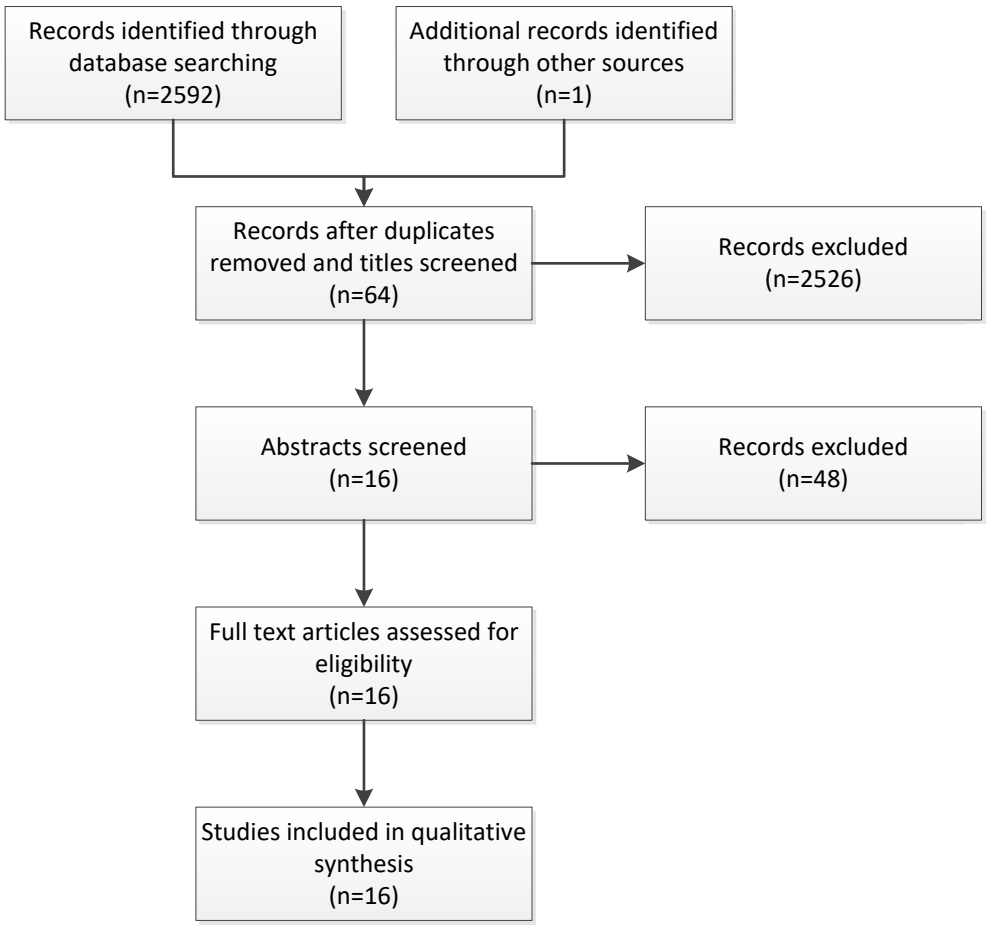
Table 8 Exclusion criteria applied to the literature review screen

Exclusion criteria	Rational	Applied
Not written in English	Costs and difficulties with translation.	Initial search stage
Papers published before 2000 excluded	To ensure that all the studies were relevant to current practise	Initial search stage
Not published articles in peer reviewed journals	The literature had been reviewed by experts within the field to ensure the quality of the article.	Initial search stage
Literature not relevant to interpreting	Interpreting studies were the focus of the review. The use of interpret* and translat* can mean different things in different contexts, any context not relevant to the search was removed.	Title, abstract and paper screening
Interpreters were not used at the interview stage	An interpreter or translator being used to translate transcripts was not the focus of the review and these papers were removed. This could not all be removed at the title search stage	Title, abstract and paper screening

Exclusion criteria	Rational	Applied
	as it was unclear in what role the interpreters or translators were used.	

Hand searching of the literature resulted in the addition of one paper. This resulted in 14 papers relating to general interpreting and 16 papers in total (Appendix A). No quality assessment of the papers was completed due to the small number of papers found; papers were included in the review if they included the use of interpreters in qualitative research. Authors who reviewed the literature of the use of interpreters in qualitative research have used a matrix review to do so (Shimpuku and Norr, 2012, Wallin and Ahlstrom, 2006).

Figure 10 PRISMA flow diagram of the literature review process (based on The PRISMA Group (2009))



4.3.1 Matrix framework

With previous authors using a matrix framework to review the published literature, a similar method was chosen. The matrix frameworks were then reviewed to determine if the topics were appropriate or further topics were required.

Wallin and Ahlstrom (2006) initial matrix framework included seven topics to describe the interpreters' role in research.

1) Number of interpreters
2) Background of interpreters (gender, age cultural background)
3) Interpreting style and seating during the interview
4) Competence of interpreters (previous experience interpreting, respect and trust on the part of the group being studied)
5) Extent of interpreter participation (knows the aims of the research, takes part in the transcription of the text and in the data analysis)
6) Interpreters' visibility in the research (Terms used 'with', 'through', 'assistance' etc, expressions made in third person with the use of quotation marks and if the interpreter/s were interviewed about their opinions and documentation exists
7) Trustworthiness (This was described in relation to Lincoln and Guba's (1985) criteria to evaluate validity or trustworthiness (This describes prolonged engagement, triangulation, and member checking), interpreter involvement in the study and interpreter training.

Shimpuku and Norr (2012) added two items to the matrix; competence of interpreters (so if the researchers had provided any training for the interpreters) and if participants and interpreters were matched. All the studies in this review were undertaken in the participants chosen language, and the interviews recorded. In addition to these topics an additional topic of anonymity of the interpreter and matching of participants and interpreter were added to the review. This resulted in nine topics in the matrix. The resulting data extracted from the papers can be found in Appendix F.

4.3.2 Number and background of interpreters

The matrix allowed information on the number of interpreters and background information recorded by the papers to be analysed. There were varying degrees of consensus between the areas identified by the matrix. This was particularly evident between the numbers of interpreters and recording of background information. The papers ranged from using one to five interpreters, with five papers using one interpreter (Ballantyne et al., 2013, Irvine et al., 2007, Pitchforth, 2005, Sanderson et al., 2013, Williamson et al., 2011) and 10 papers using multiple interpreters (Almalik et al., 2010, Baird, 2011, Bjork Bramberg and Dahlberg, 2013, Croot et al., 2011, Harris et al., 2013, Ingvarsdotter et al., 2012, MacKenzie, 2016, Murray, 2001, Sheppard, 2011, Skelton, 2003); there was no consensus on which was most successful. Recording of background information also varied with some studies declaring this and some not. Six studies gave no background information

(Almalik et al., 2010, Croot et al., 2011, Harris et al., 2013, Ingvarsdotter et al., 2012, Kosny et al., 2012, Sheppard, 2011), three studies gave either gender information or background information (Ballantyne et al., 2013, Bjork Bramberg and Dahlberg, 2013, Skelton, 2003), seven studies gave both gender and background information (Baird, 2011, Irvine et al., 2007, MacKenzie, 2016, Murray, 2001, Pitchforth, 2005, Sanderson et al., 2013, Williamson et al., 2011).

4.3.3 Interpreting style and seating during the interview

The majority of studies used consecutive interpretation, apart from Skelton (2003) whose participants used BSL. BSL is not a spoken language and therefore interpretation can occur simultaneously, using this mode of interpretation for spoken languages is uncommon. Only two studies mentioned seating arrangements, with both having the interpreter and researcher side by side (Bjork Bramberg and Dahlberg, 2013, Skelton, 2003).

Table 9 Modes of Interpretation

Simultaneous	Interpretation occurs at the same time as the person is talking/signing
Consecutive	Interpretation occurs after the person has finished talking/signing

4.3.4 Interpreter competence

The studies worked with both professional and lay interpreters (Lay interpreters were bilingual but had no professional interpreting qualifications). Training of interpreters had the effect of improving the competence of the interpreter and the trustworthiness of the data. If the interpreter had been effectively trained for the research process, they would be more competent and the interpretation they provide was more likely to meet the researcher's needs. Providing training had been recommended as a way of improving working relationships with interpreters (Almalik et al., 2010, Baird, 2011) and removing potential barriers to collecting rich data (Sheppard, 2011). What training should be provided was not specified and ranged within the studies from communicating the aims of the interview (Almalik et al., 2010, Ballantyne et al., 2013, Bjork Bramberg and Dahlberg, 2013, Pitchforth, 2005, Williamson et al., 2011) to practice interviews (Sheppard, 2011).There has been no literature found that identified what interpreters feel would be appropriate training for their involvement in research interviews.

Six studies used interpreters who knew the participants being interviewed, this was either as they had worked with them as an interpreter previously (Croot et al., 2011, Skelton, 2003, Sheppard, 2011) or they were members of the same community (Baird, 2011, MacKenzie, 2016). It was not always possible for researchers to work with professional interpreters. For example, Baird

(2011)'s study with the Dinka tribe, this is a small minority community in the USA and courses to be a professional interpreter may not be accessible.

4.3.5 Extent of interpreter participation

Interpreter participation varied from only being involved in the interview stage (Almalik et al., 2010, Bjork Bramberg and Dahlberg, 2013, Ingvarsdotter et al., 2012, Irvine et al., 2007, Kosny et al., 2012, Pitchforth, 2005, Skelton, 2003, Williamson et al., 2011) to being involved in all stages of the study (Murray, 2001, Sanderson et al., 2013). Nine of the studies' interpreters were involved in more than the interview stage, but they were excluded from the data analysis stage with only Murray (2001) and Sanderson et al. (2013) including their interpreters in this stage.

4.3.6 Interpreter visibility in the research

Visibility within the research was related to the approach the studies used to interpret. The literature described two different approaches on interpreters in qualitative research; The positivist view was that the effect of the interpreter was controlled, there was one correct translation, and the interpreter was made invisible within the research (Berman and Tyyskae, 2011, Edwards, 1998, Temple, 2004). Making the interpreter invisible involved including no quoted passages or the interview interpreted in first rather than third person. These methods did not clearly indicate that the participant's spoken words have been interpreted into spoken English and so hid the presence of the interpreter. This view aimed to control the interpreter so that the presence of an interpreter had no effect on the data collected. The constructionist approach indicates that how individuals view the world impacts on their understanding, resulting in no one correct viewpoint. This meant that how the interpreter viewed the world and their knowledge and understanding of it, impacted on their interpretation and so interpreters with different viewpoints and differing levels of background knowledge would interpret the same information in different ways (Berman and Tyyskae, 2011, Temple, 2002). This acknowledges that the interpretation affects the data, so rather than making the interpreters invisible within the study, the authors made the interpreters visible and acknowledged their potential effects on the data.

Ten of the 16 studies reviewed made their interpreters visible within the research. The studies varied in how they did this, and some studies make their interpreters more 'visible' than others. For example Sanderson et al. (2013) described the interpreters as co-researchers and their involvement was evident throughout the study, while Irvine et al. (2007) used language such as 'with' when describing working with interpreters. This showed that studies varied on how they chose to make their interpreters visible and much involvement they had.

Different languages can have subtle differences in meaning and some words cannot be translated (due to differences in culture or there are no word equivalents), so word for word translation could result in an unintelligible flow of words (Croot et al., 2011, Ingvarsdotter et al., 2012, Kapborga and Bertero, 2002, Murray, 2001, Temple, 1997, Temple, 2002). This supports the constructionist view-point of no one correct interpretation. Previous studies, who have reinterpreted the audio tapes from interviews to prove validity, found the reinterpreted translation was not exactly what was interpreted during the interview but the meaning conveyed was the same (Almalik et al., 2010, Ballantyne et al., 2013, Ingvarsdotter et al., 2012, Pitchforth, 2005, Williamson et al., 2011). Pitchforth (2005) highlighted this showing two translations from two different interpreters of the same audio tape. Translation 1 “There the doctors tried but failed to get my delivery. They tried to deliver by forceps also”. Translation 2 “The doctors tried to take the baby out by using a metal cup on the baby’s head but they were unsuccessful”. Pitchforth (2005) found previous knowledge of the interpreter resulted in different translations but the meaning of the translation was the same.

4.3.7 Matching participants and the interpreters

It has been suggested that matching participants and interpreters to try and ensure they have the same culture can provide more accurate data (Baird, 2011), which was linked to the positivist view point. The reviewed literature suggested interpreters should have good cultural knowledge of the group they are interpreting for as this can affect the translation (Baird, 2011, Ballantyne et al., 2013, Harris et al., 2013) but it does not state they should share this culture. Only one study stated they matched for gender and background (Baird, 2011). As no other studies appear to match participants and interpreters, this was deemed as not being an important factor. Matching gender and background may be a narrow view of interpretation and oversimplifies the culture of individuals by assuming their views can be matched based on this (Ingvarsdotter et al., 2012, Temple, 2002). The interpreters were likely to have a different culture compared to someone who was born deaf. No literature has been found that suggests this impacts on the accuracy of their translation, although a lack of cultural knowledge would (Hole, 2007).

Ten of the 16 studies reviewed made their interpreters visible within the research, while only one matched for gender and background. This suggests most authors share the constructionist viewpoint.

4.3.8 Trustworthiness, ethical implications, and anonymity of interpreters

Trustworthiness referred to the quality of the study (Schmidt, 2015), and had been described as a measure of a study's rigor and so the quality of the study in relation to the methodology, data collection and interpretation of the data (Lincoln and Guba, 1985). Within the constructionist style of interpretation, the aim was to make the interpreters visible through interviewing them to identify their views and potentially changing their perceived role to become more of a co-researcher. The interpreter as part of the research team has been described as improving the trustworthiness of the study (Squires, 2009). This may be a role the interpreter does not want. This could introduce issues for them in future interpretations if their views differ from that of the community. The interpreter role was also described as impartial (ASLI, 2014), identifying their viewpoints on a research topic may remove this impartiality and potentially make them vulnerable to criticism. No studies commented on the interpreters views on this topic. Skelton (2003) in the acknowledgements of their study commented, regarding the interpreters they worked with, that 'their anonymity is also important and so cannot be named'. This identifies that some researchers were considering the anonymity of interpreters. To improve the trustworthiness of the study, some studies had the audio recorded interviews reinterpreted without the interpreters permission, only one study raised this as an ethical issue (Harris et al., 2013). This has the potential rather than increasing interpreter's involvement in research to potentially limiting their involvement. Researchers not being clear with the interpreter what will happen to the recording after the interview raised the issue of what the interpreter was consenting to when interpreting in research studies. With not having interviews retranslated being described as an effect to validity as there was then no way to ensure the interpretation or translation was accurate (Irvine et al., 2007), and retranslating them without consent of the interpreter being an ethical issue, open discussions with interpreters regarding these issues are required.

Training of interpreters had the effect of improving the competence of the interpreter and the trustworthiness of the data. If the interpreter had been effectively trained for the research process would be more competent and the interpretation provided is more likely to meet the researcher's needs. Providing training was recommended as a way of improving working relationships with interpreters (Almalik et al., 2010, Baird, 2011) and removes potential barriers to collecting rich data (Sheppard, 2011). There was no literature found that identifies what interpreters feel would be appropriate training for their involvement in research interviews.

Other methods to increase the trustworthiness of the study were present in the literature. These were Interpreters' cultural knowledge (For example, words meaning one thing in one culture but

have a different meaning in another culture)(Baird, 2011, Harris et al., 2013, Sanderson et al., 2013, Sheppard, 2011, Skelton, 2003), triangulation (e.g., the use of multiple methods to look at the research question (MacKenzie, 2016)), use of a bilingual co-researcher (Sanderson et al., 2013), use of one interpreter (Pitchforth, 2005), interpreter competence (Bjork Bramberg and Dahlberg, 2013) interpreter cross checked transcription (Harris et al., 2013) and using criteria to assess quality of the project (Croot et al., 2011).

There was no agreement on which methods improve validity and trustworthiness in qualitative research, with different studies using a range of methods. Working with interpreters and educating them on qualitative research can only be of benefit to the research, interpreter, and participant.

4.3.9 Conclusions

The literature found identified that working with interpreters affected the research process. This could be through power dynamics within the interview (Sanderson et al., 2013), the reliability of the translation (Bjork Bramberg and Dahlberg, 2013, Ingvarsdotter et al., 2012, Murray, 2001), but they can also act to increase the accessibility of the study to different social groups (Croot et al., 2011).

The main requirement of an interpreter is to ensure an accurate representation of what the participant said. The best way to work with an interpreter needs to be determined before the involvement of pre-lingually deafened adults can be considered. Any interviews or face to face interviews would require the presence of an interpreter. f this was not considered then the data collected may be seen as untrustworthy and could mean that during the interpretations there are misunderstandings which could affect the data. This could be the questions using words which are not present in BSL, which then need to be changed during the translation, this would affect the data collected. The concerns regarding interpreter consent and anonymity need to be addressed with interpreters themselves to identify if this was something they would be concerned about or they see this as part of their role. There are likely to be different issues that may be present with sign language interpreters that are not in other languages, asking interpreters for their views on what they see these as being would increase the validity and trustworthiness of the data collected as part of the main research project. Asking sign language interpreters what they considered their role was within qualitative research and how they ensured the participant was accurately represented guided the main projects methodological decisions and provided support for the decisions made concerning the interview setup and the involvement of the interpreter within the research process.

4.4 Research Questions

1. What challenges do sign language interpreters encounter when they are providing an accurate interpretation for a Deaf individual?
2. What are the views and insights of sign language interpreters of an interpreters' involvement in qualitative research?

4.5 Objectives

1) To learn about the interpreting process in general
2) Identify if interpreters' feel that sign language users' experiences and views of services are considered.
3) Understand the positive and negative aspects of interpreting for a small cultural community.
4) Identify if there are any issues with consent and anonymity when interpreting for a small cultural community.
5) Explore interpreters' views on being involved in research and their role within the qualitative research process.
6) Explore what interpreters understand by 'being visible' in the research process
7) Understand what level of visibility interpreters feel is appropriate in the research process.
8) Discover how interpreters feel about being interviewed (and this information published) on their views of a research project.

4.6 Methods

This Phase 1 study followed a general qualitative methodology as discussed in 3.7.1. Different methods of data collection were then considered including interviews, questionnaires and focus groups. Interviews allow the participant to describe and explore the topic from their own personal perspective (Gerrish and Lathlean, 2015). Semi structured interviews contain predetermined interview topics with open ended questions allowing the interview to be guided by the participants, although control of the interview still remains with the researcher (Gerrish and Lathlean, 2015, Knudsen et al., 2012). This allows topics that may be discussed by the participants to be explored in more depth, which would not be possible with a structured interview. Unstructured interviews, although would explore the topic in detail, are labour and time intensive this could limit the recruitment of participants and so limit the data collected. Focus groups can be useful when comparing and contrasting different views of the topic being investigated

(Knudsen et al., 2012), but with no literature found discussing the topics it would be the first time these views were being investigated. The participants/interpreters shared a common language which the researcher did not, there was then potential to miss information. Interpreters were a small group, focus groups required travel to a common destination this then limits the geographical area from which the interpreters could be drawn from, some of the interpreters may know one another and this could affect the topics discussed. Questionnaires would not allow further discussion on any topics raised by the participants and would require validation, which was not within the scope of this preparatory work. Questionnaires would also not allow any areas raised to be expanded upon in more depth and could restrict the data collected, it could also result in the need for further research due to topics being raised, that with no further discussion, require further research. On this basis, this study would be more suited to an interview-based methodology than focus groups or questionnaires.

A telephone based interview was chosen as there were 32 registered sign language interpreters within 50 miles of The University of Southampton (NRCPD, 2016). Due to this small number of local interpreters, the geographical was broadened to recruit BSL interpreters across the UK. In recruiting individuals who were in a different geographical location, this raised the issue over how the interview were performed. Face to face interviews were preferred as this allows monitoring of participants body language and facial cues and to respond accordingly (Gerrish and Lathlean, 2015), this method provides rich data. Face to face interviews would involve travel for either the participant or researcher; this could involve large distances. Instead, Skype/FaceTime or telephone interviews were considered. Using Skype or FaceTime relies on the participant being competent to use this technology, this allows for monitoring of facial cues during the interview, but body language cues can be obscured. Telephone interviews, although collect less detailed information than face to face interviews, require less travel. It can be seen as a more sensitive approach which discussing difficult topics for the participant, it also can be more convenient to schedule (Gerrish and Lathlean, 2015). With these benefits in mind, telephone interviews were chosen as the method of data collection.

4.7 Research Design

This study used a qualitative approach with a telephone semi-structured interview design. The data were then analysed using a thematic data analysis. Before the study could begin, developmental work was carried out on the interview guide.

4.7.1 Developmental work with staff who interpret

The interview guide was developed based on a review of the literature, the information needed to work with an interpreter in a research setting, and the need to identify interpreters' views on their role within research in general. Although interpreters' views were being sought on the different views of interpreting, interpreters did not need to be aware of the constructionist and positivist viewpoints. This would have required detailed understanding which the interpreters may not have and would not be able to acquire before the interview. This could deter potential participants from being involved in the study. To avoid this, aspects of each of the views were asked about, for example rather than asking if an interpreter agrees with the constructionist viewpoint, they were asked if it is important for an interpreter's view on a topic to be known.

To ensure the interview questions were relevant and conveyed the questions as intended, four staff members who provided some interpretation for sign language users at University of Southampton Auditory Implant Service (USAIS) were recruited to go through the interview questions. They all had studied BSL to a minimum of level 2 and all used BSL regularly as part of their role. These staff members can interpret for patients in USAIS if they have arrived with no pre-arranged appointment, and no qualified interpreter can be arranged at short notice.

As part of the developmental process, the four staff members read through the interview schedule and then went through each question. Any questions that were confusing or were not understood were then relooked at and changed based on their comments. This was done to try and improve understanding of the questions and to ensure the interpretation by the participants would be as intended.

From this it was identified that some questions were not clear and required previous knowledge of the topic. Without this knowledge it meant they could not answer the questions. For example

1) What do you understand by the terms visible and invisible within the research process?

These people did not have previous knowledge of this area which meant they needed the topic explained to them. This created some problems when then asking for members of staff's views on the topic area as they did not have the understanding or knowledge to answer the questions even with the explanation. On reflection the interpreters did not need to have knowledge of these concepts so were asked the questions relating to this but not for their knowledge of the concepts directly. This question was changed to.

2) Some people say being neutral is very important for an interpreter, while others feel that in a research project it is important to gain the interpreters views on a project as part of the interpreters' role. Do you think that is important? What are your reasons for this?

The wording of some of the questions was altered on their feedback for example:

3) After an interview there are ways that could be used to confirm that the meaning of the interpretation has been conveyed. What are your views on
    i. Another interpreter reinterpreting what the patient said from a video/peer review
    ii. Relooking at the interview
    iii. Do you think these are feasible?

Was altered to -

4) How do you ensure that what is interpreted maintains the same meaning as what the participant said
    a. How would you do this after the interview
        i. Reinterpreting
        ii. Relooking at the interview

The developmental work resulted in a change to the order of the interview schedule so that the questions relating to the interpretation and research are grouped together. The final interview schedule can be found in Appendix E.

4.7.1.1 Interview guide

This guide was described as a semi structured interview guide, the questions were looked at in depth as I had never conducted an interview-based study before and wanted to be clear on the language that would be used. Having the questions looked at in depth could give the indication that the interview was more of a structured than a semi-structured interview. Although this could suggest this, this was not the case. The interview guide was used in a semi-structured way, if topics were discussed at early points, they questions were not repeated in the format on the interview guide but used to ensure that all the areas identified as of interest were discussed in the interview.

4.7.2 Participant recruitment

Participants were BSL interpreters who were registered with NRCPD and were working as an interpreter. This was the only inclusion criteria. No exclusion criteria were applied.

There were different methods of recruitment applied (Appendix G). Most BSL interpreters were members of the Association of Sign Language Interpreters (ASLI) or the Scottish Association of Sign Language Interpreters (SASLI); these were professional bodies for sign language interpreters in the UK. ASLI and SASLI were contacted to ask them for support in recruiting for this study. If

agreed to support, they were asked to provide a letter of collaboration in the form of an email or letter. They then distributed the information email (Appendix H) inviting interested participants to contact for more information (Appendix G 1a). There were regional interpreter groups with Facebook pages (not directly associated with ASLI or SALSI). The groups were contacted groups and asked for the advert to be posted using the same email format as previously described and for them to distribute an email to their members the information on how to contact for further information should they wish to be involved in the project (Appendix G 1b). USAIS also has a Facebook and twitter page (For twitter advert see Appendix I). Permission was given for the advert to be posted on these social media accounts (Appendix G 1c). Flyers were also available on the USAIS reception and distributed to relevant parties ((Appendix G 1d).

As these methods of collaboration did not recruit the sample size required over a six-week period further recruitment was necessary. Interpreters provided their contact details for BSL users to contact the interpreters directly through the ASLI website. The emailed addressed supplied were available in the public domain and so were used to contact the interpreters directly about this project (2a). Flyers (Appendix J) and the email advert were also be given/sent to professional groups that work with interpreters to distribute (2b; this included Teachers of the Deaf and sensory services). For the collection methods 1a-d and 2b, a letter/email of collaboration was obtained from the groups/organisations involved if they choose to support the study.

The interpreters who made contact were sent a participant information sheet and consent form (Appendix K and Appendix L). A convenience sampling approach was used and the first 15 participants who had returned a completed consent form were selected to take part in the study. They were given a minimum of 24 hours between receiving the participant information sheet (PIS) and the interview was scheduled. A sample size of 15 was chosen as this number will give views of the sample and can be collected a reasonable timeframe (Baker and Edwards, 2012). All the participants were registered interpreters and therefore the group was likely to be relatively homogenous and not require a larger sample size.

If more than 15 participants responded a letter would have been sent thanking them for their time and advising them that the study recruiment limit has been reached (Appendix M). This would have only been sent if 15 interviews were completed.

4.7.3 Data collection

Once a participant agreed to take part in the study a convenient time for the interview was scheduled and a telephone number was provided by the participant. The participant was reminded at the start of the interview that the interview was being recorded and the completed

consent form was read though. If the participant consented, then the interview began. The interviews were semi-structured and followed a semi-structure interview schedule (Appendix E). The interviews were scheduled for a maximum of an hour, only one interview exceeded one hour. At the end of the interviews all participants were thanked for their time and asked if they had any questions.

4.7.4 Ethical approval

Ethical approval was granted from the University of Southampton Safety and Ethics Committee (30129). Due to lack of recruitment an amendment was added to allow the flyer to be given to other professional groups to circulate (Appendix J: 1d and 2b).

4.7.5 Piloting the interview

Due to the small numbers of sign language interpreters, piloting the interview had the potential to limit participant numbers. Due to this, the interview was piloted on the first two participants recruited to the study, no significant changes were made to the semi-structured interview guide, so their data were included. Ideally the questions would have been piloted on more participants as this could have identified questions and topics which could have been used to enhance the richness of the data collected. This issue with piloting extensively in small participant groups was that this had the potential to limit the data collected due to those participants' data being excluded.

4.7.6 Interviews and transcription

Participants were asked open questions and the language was standardised between participants, this was not always possible as some participants required clarification of some questions. The interviews were audio recorded using a digital audio recorder.

The audio recordings were transcribed verbatim, this helped familiarisation with the data. The transcription took place as soon as possible after the interviews took place to try and prevent mistaken words being transcribed and to preserve the meaning of the interview. Some issues were encountered with the transcription, as some participants had an accent which made transcription more challenging and background noise and distortion also resulted in some words or passages being unclear. This was highlighted in the transcript.

Names and identifying information were then removed from the data and a number given which linked the consent form to the interview transcript. Any potentially identifying information was then removed and replaced with appropriate alternatives. A reflective summary was written following each interview to capture any areas of improvement, reflect interview dynamics, and issues with the recording or equipment.

4.7.7 Ensuring quality of the data analysis

A thematic approach to analysis was used as it allowed a more flexible approach to be applied to the data analysis. Thematic analysis allows researchers' to identify patterns within the data and to organise, analyse and report these patterns (Braun and Clarke, 2006, Braun and Clarke, 2012).

Braun and Clarke (2006) described a 15 point check list of criteria for a good thematic analysis, which was followed during each stage of the analysis and while producing the written report (Table 10). These, rather than other methods, were followed as these criteria were developed specifically for thematic analysis. Braun and Clarke (2012) discussed the importance of evaluating research based on the theoretical framework, which is why other methods were not applied.

An audit trail was maintained throughout the process, the theoretical maps at each stage of the analysis shows the interpretations of the analysis developed over time. A reflective account after each interview was made considering things that could have been handled more effectively and identifying any pre or misconceptions. This was useful as I only became aware of some preconceptions after the interviews took place.

Table 10 Fifteen-point checklist for thematic analysis (Braun and Clarke 2006)

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail and I checked the transcripts against the tapes for accuracy
Coding	2	Each data item has been given equal attention in the coding process
	3	Themes have not been generated from a few vivid examples but instead the coding process has been thorough, inconclusive and comprehensive
	4	All relevant themes for each theme have been collated

	5	Themes have been checked against each other and back to the original data set
	6	Themes are internally coherent, consistent and distinctive
Analysis	7	Data have been analysed – interpreted, made sense of – rather than just paraphrased or described
	8	Analysis and data match each other – the extracts illustrate the analytic claims
	9	Analysis tells a convincing and well-organised story about the data and topic
	10	A good balance between analytic narrative and illustrative extracts is provided
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately without rushing a phase or giving it a once over lightly
Written report	12	The assumptions about, and specific approach to, thematic analysis is clearly explicated
	13	There is a good fit between what you claim you do, and what you show you have done
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis
	15	The researcher is positioned as active in the research process: themes do not just emerge

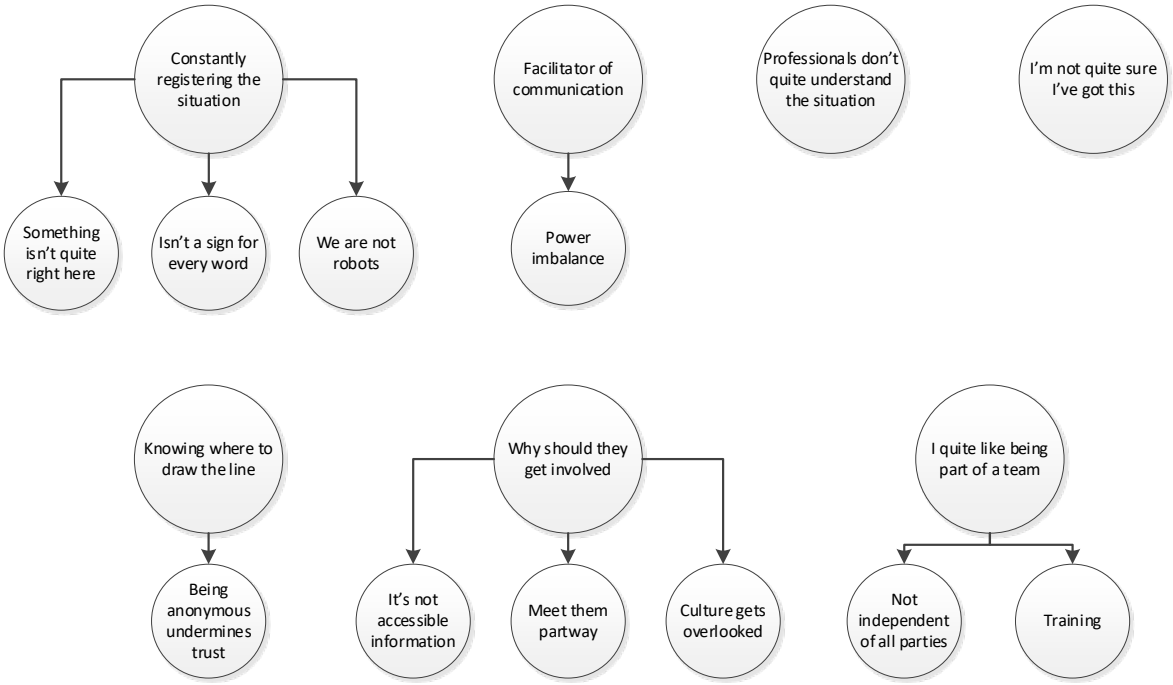
4.7.8 Data analysis

Braun and Clarke (2006) and (2012) describe a six stage process to thematic analysis a summary of these phases can be found in Table 11. The stages were followed (Appendix N) and resulted in a final thematic map (Figure 11).

Table 11 Phases of Thematic analysis based on Braun and Clarke (2006) and (2012)

Phase 1	Data familiarisation - repeated reading of the transcript, this is done in an active way looking for meanings within the data. Note taking can help with this active process. This is to ensure the researcher is immersed within the data and its contents.
Phase 2	Coding - Coding identify features of the data that are relevant to your initial research questions. It is the process of organising the data.
Phase 3	Searching for themes - This involves looking through the coded data for potential themes and then collating these codes within the themes.
Phase 4	Reviewing themes - this involves reviewing the identified themes, as some themes may merge while new themes might form. This process also ensures that the themes represent the data set. This results in a thematic map.
Phase 5	Defining and naming themes - This involves conducting a detailed analysis of each theme and how it fits in to the overall story of the data.
Phase 6	Writing the report - provides a story of the data in relation to the themes identified

Figure 11 Final thematic map of the data analysis



4.8 Ethical considerations

There were several ethical issues that were examined as part of this research. These included informed consent, anonymity and concerns around interpreters who currently work at USAIS.

4.8.1.1 Anonymity and confidentiality

As the numbers of interpreters were small, care was taken to ensure that any identifying or personal information was altered to ensure the subject could not be identified from the transcript.

4.8.2 Interpreters who have worked at USAIS

Interpreters who work in the South of England may interpret for Deaf individuals at USAIS; this may have resulted in them working with myself in clinic. These interpreters may feel this affects their professional role at the centre and may not feel comfortable discussing the topics investigated. These interpreters were not excluded from the study and it was explained in the PIS that any information provided would be anonymised. The interpreters were not asked if they worked at USAIS previously, and no reference to the implant service was made.

4.9 Results

4.9.1 Introduction

The target of 15 interviews was not met (See 4.10.4.7 for discussion on this); six interviews were performed, lasting on average 39 minutes. Participant's interview transcripts were analysed into seven themes. During the interviews participants used descriptions and abbreviations that may not be familiar to an individual without knowledge of interpreting and the Deaf community. Please see the abbreviations and definitions page XIX.

4.9.2 Demographic data

The importance of protecting the participant's anonymity was paramount due to their working relationship with the Deaf community and the small numbers of interpreters working in the UK. This meant that no demographic data were recorded. The interpreters were asked to provide their opinions confidentially and therefore there is the responsibility to ensure that is the case. The inclusion of data, such as age, sex, and/or location, may have resulted in the interpreters being identifiable on this basis or in conjunction with information they provided as part of the study. Participants were not asked these questions, if this was mentioned during the interviews this was anonymised in the transcripts.

4.9.3 Themes

The participants cross two communities with their language and cultural knowledge of the Deaf and hearing communities. They were hearing individuals, fluent in BSL, resulting in links with both hearing and Deaf adults. The topics discussed were varied and referred to topics of trust, power, communication, and research. The seven main themes were divided into sub-themes were indicated by the data. The themes and sub-themes are shown in Table 12.

The themes: 'constantly registering the situation' referred to participants monitoring, managing and their effects on the interactions they are working in. 'Facilitator of communication' related to the role of the interpreter and how they can affect the interaction. 'Professionals don't quite understand the situation' discussed the challenges of working with professionals during interpretations. The theme 'I'm not quite sure I've got this' represented how to ensure the interpretations are accurate. 'Knowing where to draw the line' related to how advocacy, professional boundaries, and trust. How to include and make research accessible to the Deaf community described the over-arching theme 'why should they get involved'. The over-arching theme 'I quite like being part of a team' referred to the participant's involvement in research.

Table 12 The Seven Themes

	Themes	Sub-themes
1	Constantly registering the situation	1.1 Something isn't quite right here
		1.2 Isn't a sign for every word
		1.3 We are not robots
2	Facilitator of communication	2.1 Power imbalance
3	Professionals don't quite understand the situation	
4	I'm not quite sure I've got this	
5	Knowing where to draw the line	5.1 Trust has been established
		5.2 Being anonymous undermines trust
6	Why should they get involved	6.1 It's not accessible information
		6.2 Meet them partway
		6.3 Culture gets overlooked
7	I quite like being part of a team	7.1 Not independent of all parties
		7.2 Supporting interpreters

4.9.3.1 Theme 1. 'Constantly registering the situation'

Participants described how during their interpretations they were monitoring the responses and the people in the interaction. They monitored the responses to ensure that both individuals were understood, and that the communication was flowing well between the two parties. They then acted if the communication had broken down. For example:

> *'assertiveness on my part so when something isn't working to not just allow things to carry on' (Participant 3;L39-40)*

The participants explained how they were doing more than interpreting from one language to another, they were checking the responses and understanding of both parties at the same time. They also managed the interaction and identified the need to do something if things were not working, rather than do nothing. They were not a passive party in the interaction as they could act

to change things by offering strategies and suggestions to improve the situation. Through this they were considering their translation and the understanding of both individuals. They assessed if they needed to change the level of the interpretation for an individual depending on their knowledge. As Participant 2 described:

> *'as if you are with an educated person then you have got to bring the language up to their level and if you are with somebody who has not as much education then you would bring it down but that's the job of the interpreter to ensure the language is where the Deaf person or the person receiving the English is at the appropriate level' (Participant 2;L35-39)*

Participants described assessing the understanding of the individuals they were interpreting for and deciding if they needed to change the language level of the interpretation or explain it differently for that individual. They were making decisions during the interpretation and needed to process and understand the information themselves to make an appropriate shift in the language level. This was something they would be doing throughout the interpretation. Participant 5 discussed how they are actively involved in the communication and were not separate from it; this allowed them to monitor the interaction and individuals because they were part of it:

> *'in all that probably goes across the board actually that you're not so much as a bystander in anything you're quite involved in as you're involved in everyone's conversation and you can't just take a step back you are involved in everybody's communication process so the more you get to know people and where people are coming from peoples little nuances or the way that they interact is always useful' (Participant 5;L312-316)*

With participants being so involved in the communication this allowed them to identify when things were not going well.

Sub-theme 1.1. 'Something isn't quite right here'

Identifying when communication has broken down and assessing if the individuals had understood what was being said, was discussed by participants. They acknowledged that involves them understanding the people and cultures who they work with.

> *'I think that the way the conversation flows is a good indication, so picking up on peoples facial expression and body language being aware of both parties thinking hang on*

> *somethings not quite you can tell from the way the flow is going something isn't quite right here' (Participant 5;L130-134)*

The interpreters were doing more than monitoring if the responses were correct, they were reading peoples body language/facial expressions to check if things were going well or there had been misunderstandings. To do this, they required a high level of cultural knowledge as a response, or a reply could be due to cultural reasons rather than a misunderstanding. Participant 2 indicated that they managed to assess this '*eight times out of ten*'.

With interpreters being so involved in the interpretation and reading the body language of both parties how to maintain the accuracy of the interpretation was raised.

Sub-theme 1.2. 'Isn't a sign for every word'

With the need to ensure what the speaker/signer said had been conveyed, participants were clear that word for word interpretation was not possible. As BSL is not a written form of English, there are signs and words which are not represented in each language. As they discussed:

> *'never, well not if you want to do a proper translation it's not a translation if you do it word for word I suppose yes or no, just one word maybe that would work' (Participant 3;L61-62)*

> *'obviously the structure of BSL is completely different to English so word for word you can't you can't directly translate there are some words you don't often find the little words that you have in English you don't need to sign them in BSL at all but you can do more of a literal thing if you are doing sign supported English' (Participant 5;L113-117)*

The participants discussed how if you were aiming for word for word translation it would more likely be sign supported English (SSE). In BSL although the word order may be different the meaning will still be maintained. Participants explained:

> *'some people you say could be saying exactly what I've said and I have to say it's a translation of what you said and so won't be verbatim but the meaning will still be there and will match what you said so I usually have to explain that one' (Participant 6;L87-90)*

> *'in terms of ensuring the message that is given can be transferred in a way that can be properly understood so that I'm not adding to it or taking away from it' (Participant 4;L11-13)*

Participant 6 discussed how although it would not be word for word the meaning would be the same which was supported by Participant 3 and 4. They aimed to translate the meaning of what was said but this does lead to the interpretations being different for different interpreters.

Sub-theme 1.3. 'We are not robots'

In this subtheme, participants discussed the effects their views and experiences had on their interpretations and how they were not perfect. Participant 2 mentioned how '*really sometimes we get that right and sometimes we don't'* and how *'we are not robots'.* Participants conveyed that they are human and therefore not perfect and so while they try to ensure everything was accurate, they can make mistakes. They also acknowledged that they do have an effect on the translation, but the effect does depend on the topic matter. Participant 3 discussed:

> *'in a qualitative interview I think it's possible I could completely unconsciously my attitudes around a topic might skew my interpretation as in my understanding of what the Deaf person or what the Deaf professional is saying' (Participant 3;L207-210)*

They also highlighted that they may not be aware their views were affecting the interpretation. The participants were clear that as people, interpreters all have different life experiences and beliefs which could influence the interpretation. For example:

> *'I can see that they can as we all bring our own life experiences with us so yes I think somebody's background somebody's knowledge somebody's experience can have an impact on how they interpret in a situation' (Participant 4;L219-221)*

But although these experiences can influence their interpretation, they also can make them better and more competent interpreters.

> *'Well that's tricky obviously we do try and remain neutral but first and foremost we are human beings, we all have our set of life experiences set of opinions and baggage that we bring into a situation usually I would say that makes you a good interpreter as the more life experiences you have I think helps you to deal with different things that you come across and a variety of situations you find yourself in' (Participant 5;L242-246)*

They identified that although their attitudes and life experiences can affect their interpretations, there were ways to manage this. This was through either choosing not to be involved in a project or identifying their views on a topic before their involvement, they can then act to control these views. For example;

> *'that's very similar to dealing with any situation you may have preconceived ideas or prejudgements or prejudices and if you're aware you have got them then you can manage them if you're not aware or you're ignorant of it will have an impact on it. It is about self-reflection and understanding how you feel about something' (Participant 4;L225-230)*

Participants were clear that their views can affect their interpretations, but they can manage this. Participant 2 stated '*we are not robots'* which was quite clear that they may be having no emotions, but the topics they interpret for can affect them. They shared that there was a need to acknowledge that there was a third person in the room with their own views, experiences and emotions. Participants also acted to empower hearing and Deaf adults in their interactions rather than the interpreters having or taking this power.

4.9.3.2 Theme 2. 'Facilitator of communication'

Participants discussed their role as interpreters as being 'neutral', '*independent*' and '*transparent'* as well as allowing two parties to communicate with one other. The participants reported it was important to not align themselves with either party and so not to be seen to influence the interaction or power dynamics.

They described their role as '*passing information*', '*provide smooth communication'* and '*translate the message'*, which fits with their detailed knowledge of two languages and cultures, they explained they had '*authority*' in the sessions. When asked to describe their roles as an interpreter, Participant 5 described their role as:

> *'is really facilitating communication between not just two different languages but being aware that there are different cultures involved as well but rather than just being as some people would tend to think a channel for that communication I really strongly believe that you as an interpreter are participant in the conversation so it's really more of a mediating role in that facilitation between two different cultures really' (Participant 5;L3-8)*

The words facilitating/facilitator were mentioned by Participants 4, 5 and 6; a facilitator was a powerful position to hold as they were allowing this communication to happen. They provided access to people and services that would not have been possible otherwise. They also discussed the cultural aspects where they were 'mediating' between the two cultures. With the powerful position that they held the risk of shifting the power balance was a concern.

Sub-theme 2.1. 'Power imbalance'

The participants acknowledged their position of power and identified they can shift the power balance between the individuals they were interpreting for, which they tried to avoid. They mentioned how they aimed not to influence the power balance between parties but ensure that all parties participated. The power balance topic was mentioned by three out of six participants. For example.

> *'one has to be careful about either actually doing things or perceived to be doing things, which shift the balance of alignment or power between parties' (Participant 1; L88-89)*

> *'just trying to facilitate a meeting so that everybody can have equal participation' (Participant 6;L17)*

It was important for the participants to not shift the power balance as this could be seen negatively by either individual and would remove participants from their desired position of neutrality and independence. It was important for participants not to disempowers the Deaf adult. Participants were aware there was a possibility of this occurring and tried to ensure that they did not intervene too much, they aimed to work with that adult to ensure they were happy with their involvement in the communication. Participant 3 stated:

> *'some Deaf people it can feel like the interpreter is intervening too much so I would check that out with them particularly with Deaf professionals who are more sensitive to interpreters disempowering them by taking over communication and have the conversation with the hearing person when they as a Deaf professional want to be able to have that conversation so it yes you have to be sensitive to people's desire to control a conversation themselves' (Participant 3;L53-59)*

Participants also tried to empower rather than disempower individuals. For example, if they did not have a sign for a word the Deaf adult chose the sign rather than the interpreter so not taking that power away from that individual. The Deaf individuals choose if they would prefer BSL or signed supported English and decided if they wished to work with the interpreter or not. For example:

> *'Deaf person will obviously decide on a sign or if you are working with that Deaf person suggest something and then you'll use it for that conversation to know where you are' (Participant 5;L95-97)*

There were power dynamics which the interpreters had to navigate through, whilst maintaining their neutrality, independence and allowing two parties to communicate.

4.9.3.3 Theme 3. 'Professionals don't quite understand the situation'

All participants described that professionals often lacked an understanding and awareness of their role. They reported that professionals can think the interpreter is "*with the Deaf person*" and may provide "*follow-up support*" after the appointment. Participants reported that professionals can misunderstand the role of the interpreter and think they were with the Deaf adult rather than being an independent party.

There could be a lack of Deaf awareness among professionals, with the environment not being set up appropriately. As shown by Participant 5:

> *'things that might be to do with the environment it can be very simple things like lighting not sitting in front of a window the most common one all the time is that people seem to think the interpreter wants to sit next to the Deaf person … I'm forever saying no I need to sit next to you so that obviously the Deaf person isn't playing ping pong tennis with their neck swinging to and fro but that's quite a common one' (Participant 5;L17-23)*

Some other misunderstandings or lack of knowledge of the professionals were walking in front of lines of sight, talking too slowly, talking to the interpreter rather than the Deaf adult, professionals talking over one another and professionals thinking the response was from the interpreter not the Deaf adult. Participants noted this was mainly due to a lack of Deaf awareness from the professionals, which could be related to a lack of experience of working with interpreters in general. As Participant 2 stated:

> *'some medics have never experienced using an interpreter with a Deaf person they may feel awkward and I would try to put them at their ease we are there to just assist communication between both parties so just lack of Deaf awareness is probably biggest block the biggest barrier' (Participant 2;L16-20)*

Participants acted in these situations to try and improve the communication by providing Deaf awareness training, which can be before or during the interaction. They acted to try and help the professionals on how to improve their skills rather than letting the situation carry on or prevent it occurring in the first place.

> *'A lot of people talk to slowly thinking that they are being really helpful by just slowing everything down, so you have to kind of do a bit of Deaf awareness, if you could just speak at your normal speed and if you are going to quickly then I will let you know, that's not a problem' (Participant 5;L24-27)*

With participants aiming for a successful interaction while interpreting, not addressing this could result in a breakdown of trust between individuals. While working with professionals and Deaf adults' participants reported the need to ensure that what was translated was accurate and methods of ensuring this.

4.9.3.4 Theme 4. 'I'm not quite sure I've got this'

Participants reflected on how to ensure an interaction was accurately interpreted during the session. They explained how they managed the session if they considered they had misunderstood the hearing or Deaf individual. There could be something that was ambiguous, and they would need to ask further questions to check their understanding was correct. They did comment that complete accuracy may not be possible, as described by Participant 3.

> *'if I had lots of time to prepare it and translate it I doubt it, live interpreting it's never ever 100 percent accurate' (Participant 3;L65-66)*

It appeared that ways of doing this after the interaction would require the interaction to be recorded and could be by independent or self-verification. Self-verification would involve the interpreter going back over the video recording to check the translation, it was noted that self-verification means that the interpreter may not see the errors. An independent checker may be more appropriate in some settings, for example this was regularly used when interpreters work in court room settings. The participants discussed how an independent checker would need to be suitable for the role and that it would be helpful for the original interpreter to be present for a professional discussion if discrepancies were highlighted. The participants expressed some anxiety about an independent checker as it can be "*daunting*" and "*anxious*" for someone to be checking your work, but others reported it something they would find "*helpful*". It was clear that the participants agreed that a process of verification does need to occur but appeared to want to be involved in the process and it to be carried out in a way that they would find acceptable.

> *'I think it would be useful to have both interpreters there so if there are any questions as to why somebody has interpreted it that way obviously they can then have a discussion so if I was doing the interview and another interpreter was say coming in later to have a look at that I might looking back think, oh hang on a second perhaps I should have done it this way or another interpreter might then say actually no you know its fine that's accurate you can have some sort of professional discussion about it so I would think it's very difficult for another interpreter to come in and maybe obviously they are just going to be giving their view on something which is fine but understanding the reasons why a particular choice was made is always a good thing' (Participant 5:L153-162)*

Participants worked regularly with adults in the Deaf community and report it was common to know the adults they are working with. This can put interpreters in situations where they act or are requested to act in an advocacy role.

4.9.3.5 Theme 5. 'Knowing where to draw the line'

All the participants described instances where they either found themselves acting as advocates for Deaf individuals or some advocacy was expected. This was described as being a challenging position to be in, as in one instance they may want to support that individual, but they identified the need to maintain their professional boundaries and to remain neutral and independent. As Participant 5 described:

> *'it is a fine line it can be a fine line and especially when you're dealing with a community where you can see the barrier they are facing and sometimes the unjustness of something that is happening not to sort of show yourself to get involved I mean I would still say that part of what we do we can be an advocate, you know part of that goes back to our cultural mediation and we can be an advocate for the Deaf person but its knowing where to draw the line and sometimes you do have to take a step back and do a bit of reflection and evaluation and say I can do this I can help this person up to a point but you still have to maintain your professional boundaries' (Participant 5;L191-199)*

Not all participants thought it was suitable for interpreters to act as advocates as this resulted in a loss of independency and resulted in the interpreter being aligned with the Deaf adult. There may also be misunderstandings from the professional that the interpreter was there for the Deaf adult when they are there for both parties.

It appeared that what was actually meant by advocacy may have varied between participants with an instance of advocacy described by Participant 3 as:

> *'I might ask the health professional whether they have a picture or a model of that part of the body and then ask them to explain what's going on in reference to that visual support' (Participant 3;46-48)*

While other participants mentioned '*barriers they (Deaf adults) face'* and assumptions made by the hearing person which can result in situations where interpreters can have a decision to make regarding advocacy for these adults.

Participants also considered their professional boundaries and how to maintain these in the Deaf community where they may have friends and family members who would require an interpreter.

Participants shared they would either choose to not work with them or want agreement that they were happy for them to be the interpreter. As Participant 3 discussed.

> *'I will either refuse to or I will agree to do something for a short period of time but not socialise with them during that time partly as although they might say that they are happy with it but I have to maintain stronger boundaries than them as I'm a professional' (Participant 3;L143-149)*

With the Deaf community being small, the same interpreters and Deaf adults work together regularly. The participants described it as being common for them to know the adults they interpret for. There were some situations that the Deaf adult and/or the interpreter considered it was not appropriate for them to work together, they were able to decide before the interaction that another interpreter may be more suitable. Both individuals having this control prevented situations potentially being uncomfortable.

Being able to choose an interpreter means that the interpreter must be known to the individual and not be anonymous. Participants then discussed that actually knowing people was a positive thing while interpreting.

Sub-theme 5.1. 'Trust has been established'

When participants knew the individuals they were working with they reported that this could '*make a more successful appointment*' and generated '*rapport*'. It also meant that the interpreter knew the signs that may be individual to that person. As shown by Participant 2:

> *'if I know the person I know their idiosyncratic signs they know mine and so yeah there is that rapport between us as we know each other' (Participant 2;L24-25)*

They reported if they knew the Deaf adult, they would feel confident to check they have understood something with them rather than not saying anything and the conversation breaking down. For example, clarifying a point later in the appointment when it was been clear there had been a misunderstanding. As Participant 1 described:

> *'what those things are about rapport and trust and other people checking my understanding could be an underlying part of that or whatever it can be part of them essentially checking they have understood and then clarifying things with me' (Participant 1; L97-100)*

Participant 3 discussed the importance of obtaining and maintaining trust:

> *'part of it is how I explain my role and trying get trust from both parties I think it's really important to be as transparent as possible about the process of interpreting so that and again that's about keeping and keeping trust' (Participant 3;L32-34)*

Most participants mentioned the importance of rapport or trust with Deaf adults and how this works better for all parties when this is present. Having this trust was described as a 'privilege' and a very 'positive' thing. Participants working in the Deaf community noted it was important to have this trust and if t broke down it was potentially negative.

Sub-theme 5.2. 'Being anonymous undermines trust'

Participants shared that being anonymous was not always possible for them and may actually act to negatively affect their relationship with the community they work with. It can be important for deaf adults to have a level of trust with interpreters which is based on knowing who the interpreter is going to be. Participant 6 described how they did not consider their own anonymity as they were '*busy protecting everybody else's anonymity' (L130-131)*.

Participants said they are required to be registered with the NRCPD who they require them to be easily identified at appointments. This means that during appointments they are never really anonymous.

> *'I'm not anonymous and I'm never anonymous I'm not anonymous because my registering body require me to carry identification to the appointments I have a badge you know similar to an NHS badge that I wear on a lanyard so that everyone who sees me particularly in the appointment knows that I'm there with some authority I'm qualified to do my work' (Participant 1;L215-220)*

Being involved in projects that would identify them as a contributor, participants reported that was good practice and would allow the Deaf community to see that there was an interpreter involved in the project. They also considered that how happy interpreters were with this would depend on the individual as Participant 5 discussed.

> *'it helps it probably helps the Deaf community to know there is a registered sign language interpreter sort of used as a proper professional in their capacity there also if other people did want to make comments or feedback about things they would have a go to person so yeah I think there are benefits' (Participant 5;L356-359)*

Outside of their work, they discussed how being anonymous was affected directly by the internet with interpreters being '*traceable on the web'* and was something that they do consider maintaining their private life.

4.9.3.6 Theme 6. 'Why should they get involved?'

The Deaf community's involvement in research was mentioned by most participants, with the community having been historically researched on rather than researchers working with them. If the community did get involved in research, they then had no feedback on the results or any benefit from their involvement. As Participant 3 described:

> *'Their experience is they have been researched on so much by outsiders and received no information about the outcomes of the trial or the research, whatever at the end of it, why should they get involved' (Participant 3;L167-170)*

The issue of access of researchers to the Deaf community was also discussed and participants reported the Deaf community can be difficult to reach and that the potential of these adults to be excluded due to a lack of knowledge or awareness by researchers. It was also discussed by Participants 1 and 3 how working with interpreters may not be as appropriate as a Deaf researcher conducting the research. Participant 1 stated:

> *'interpreters in research may not be the best way to bridge the gap culturally and linguistically' (Participant 1;L264-265)*

With the Deaf community being a minority community, the issue of not working with a Deaf researcher is that the community will not choose to be involved in the research or "*buy in*" to the research. To involve the community in research, researchers first have to access the community.

Sub-theme 6.1'It's not accessible information'

With access to the community described as challenging due to the differences in language, ways to reach the community were suggested by the participants. A signed version of information was thought to be the most appropriate. If written information was to be provided this needed to be in 'plain English' and questionnaires may not be suitable. As Participant 4 discussed.

'because sometimes and I've seen it in the past with questionnaires where they are worded questionnaires would you be prepared to get involved in this? And some Deaf people will switch off from that because it's not accessible information so what's the point whereas if there was a video signed subtitled to put the message over the invitation over in an accessible format that would be a good thing to do' (Participant 4;L420-425)

The feelings around cochlear implants and the Deaf community were also discussed, with two participants reporting that there are strong feelings regarding then in the community. The topic was discussed as having "*great feeling", "hot potato*" and having "*suspicion within the*

community". This was something they reported as requiring thought and understanding when approaching the community and to ensure the community were aware they would still have their "*Deaf identity*".

Sub-theme 6.2 'Meet them partway'

The attitude of the researcher when approaching and working with the community was considered important and understanding their views and culture. As Participant 2 described:

> *'I think as long as you are Deaf aware and you accept their views and accept them as a person I can't see you having any problems if they need an interpreter I'm sure you will provide them an interpreter and if they are quite happy lip-reading you are finding a form of communication that works for the pair of you' (Participant 2;L273-276)*

Participant 3 mentioned how the researcher knowing some sign language would also be helpful as this would indicate an intent and attitude to the community.

> *'you could counterbalance that by the non-interpreter researcher learning a bit of sign language and having a clip of themselves indicates that you have an attitude that you are prepared to meet them partway that's an attitude judgement the Deaf community might make' (Participant 3;L274-277)*

Approaching the community was mentioned with Participant 5 suggesting '*build up contacts with Deaf community yourself*' to ask those people to go in and approach people to see if they would like to be involved in the study. These approaches all needed to consider the differences between the Deaf and hearing communities.

Sub-theme 6.3. 'culture gets overlooked'

The differences between Deaf culture and hearing culture were discussed by most participants. They reported that the education level of the Deaf adult was likely to be lower, with participants research showing a lower reading level in the community. Participants discussed that this can impact the knowledge of these adults. For example:

> *'that Deaf people who are BSL users don't share the same understanding as perhaps you or I do about what goes on in hospitals what goes on in specific departments why things happen why things are asked how to answer certain questions and maybe a difference in expectation between clinicians and patient' (Participant 1:L16-19)*

The differences between the languages can be overlooked. As Participant 5 shared:

> *'Well oh you need to take these tablets well before you translate this you need to check and clarify how they are supposed to be taking those tablets are they oral are they inserted elsewhere obviously when you are signing that's very visual and if you sign taking a tablet by mouth and then obviously you find out later on you might need to place that tablet elsewhere that can obviously be very tricky so it's just checking all the time what might not seem obvious to a hearing person just speaking the English then you have to just obviously check as you are representing something visually' (Participant 5;L141-148)*

The participants were also concerned that the Deaf community could be overlooked, as they are a minority community and small there was a worry they could be forgotten about.

> *'Deaf sign users with BSL are simply not on most people's radar even their existence is not on most people's radar so to think of them as an additional native British language user population?' (Participant 3;L158-160)*

Participants made it clear the Deaf community was more than a group of adults communicating using sign language.

Sub-theme 6.4. 'More than just people with a common language'

The participants described how the community was more than just people using the same language they have understandings and knowledge that outsiders to the community would not have. As Participant 4 explained:

> *'there can be like a lamppost near the Deaf club that Deaf people would always congregate under while they (inaudible) as there is a light there and if you know that you're part of that community' (Participant 4;L390-393)*

They described the use of the word deaf with a capital D as being used to describe the community and the common experiences they share. As Participant 5 stated:

> *'more than just people with a common language it's a fact that they have a common experience and values, that there is a real strong Deaf identity there which embraces a whole culture and heritage really so they would not see themselves as being defined by their hearing loss and not anything to do with a medical model of Deafness' (Participant 5;L373-377)*

Participants reported it was essential to consult with the Deaf community regarding research and for researchers to ensure the research materials were accessible to the community.

4.9.3.7 Theme 7. 'I quite like being part of a team'

Only two of the six participants had experience of being involved in research as an interpreter. Being involved in research was something that participants were happy to be more involved in and saw it as more like a job with defined expectations of their role, they also discussed the need for guidelines around the role.

> *'it sounds like a job meaning that would be something that's probably be quite well defined at the start it would be something that an interpreter would maybe apply to or if they were invited to do it then there would be job type conversations at the beginning of the thing to make clear expectations look at timescales look at the role look at what that co-work partnering meant to me it sounds like a positive kind of thing that I would like good conversation so everyone knows where they are at' (Participant 1:L368-375)*

They mentioned barriers to their involvement in research, with opportunities to be involved in research limited and the lack of roles available. If an interpreter was involved in research then this was usually as part of their PhD studies. The need for paid roles in research was necessary with participants working full time unable to voluntarily be involved in research studies.

> *'there are people out there who are keen on doing research but in my area there is researcher who has done a PhD and other research and unless as they're a jobbing interpreter a supervisor and a manager they can't get research positions as there aren't none but I'm sure would be interested in doing their research' (Participant 3;L290-294)*

Although participants were keen to be involved in research, they considered a potential loss of independency for the interpreter.

Sub-theme 7.1. 'Not independent of all parties'

Four of the six participants discussed how becoming more involved in research could affect the independency of the interpreter. They noted that being more involved in a project could influence their interpreting as they would move away from being an independent interpreter to a team member. The participants noted this could result in a conflict of interests and it may be better to be either the interpreter or a team member.

> *'I would start to see the difficulties around that if I was in an interpreted encounter and one of the people I work with in the research team said something but I know from my background experience no we have moved away from that we are doing it a different way then I am in this situation where I am either part of the research team or I'm interpreting' (Participant 4;L320-324)*

With not all of the participants having experience in research, what measures to be put for them interpreters to feel able to do this were discussed.

Sub-theme 7.2. Supporting interpreters

Types of training that would allow interpreters to feel confident being involved in research studies, was considered. There were training opportunities for interpreters as part of their development, for example court training. Specific research training, including shadowing, mentoring and supervision by a more experienced interpreter would be useful. By shadowing this was discussed in the context of shadowing a more experienced interpreter or by shadowing someone in an area that the research was about. This was reported to give the interpreter as much knowledge as possible to prepare them for the research role.

> *'definitely opportunities for shadowing and maybe some mentorship supervision that sort of thing' (Participant 2;L181-182)*

Preparation was considered to be important. The interpreter needed an understanding of what was going to be discussed and what the aims of the research were, so that this was conveyed as the researchers were expecting. As Participant 4 stated:

> *'I think having an understanding of what the research's about, so preparation beforehand as opposed to on the day turning up and going straight in is beneficial, because if there are concepts around that research that need to be conveyed then it's important that the interpreter has a full understanding of that first' (Participant 4;L258-262)*

4.9.3.8 Summary

These themes discussed the interpreters' role in communication, their interactions with professionals and Deaf adults and the complexity of their role.

This data shows how interpreters are required to manage the professional, deaf adult and issues with empowerment, advocacy and still provide accurate interpretation. They highlighted a lack of knowledge of their role, understanding of Deaf culture and how there was a need for guidelines around the role of the interpreter within a research project.

4.10 Discussion

The main findings of this study were that the interpreter's role in an interaction was more than just as a translator, they have a wider role in the interaction. This role can involve advocacy,

establishing trust and taking control of interactions to improve the outcome. Participants highlighted how they are human; their interpretations may not be perfect and their feelings and emotions on a topic can come through in their interpretations. Interpreters have acted as cultural guides and aid professionals and Deaf adults in improving the communication and understanding between the two groups. As far as the author was aware this was the first study to consult BSL interpreters directly on working with them in a qualitative research setting.

4.10.1 Viewpoints on interpreting

This study supports the constructionist position; interpreters with different viewpoints with interpret information differently (Berman and Tyyskae, 2011, Temple, 2002). A person's view on a topic can be affected by their life experiences, knowledge and understanding. With interpreter's views affecting their interpretations, it was then important to know what their views to ensure that they are acknowledged. The participants supported the views of interpreters being known. Recognising and thinking about their views on a topic allowed them to manage these views and maintain their neutrality or not become involved in the project if they considered this would not be possible. Ensuring the interpreter's views did not affect the project does not necessarily mean their views need to be published. It could mean it was mentioned that they were discussed and so considered as part of the project.

Further support for the constructionist position was that Interpreters considered that word for word interpreting was not possible. There were some instances where this could be used for single words but was word dependent. Some words were not present in BSL and some signs were not present in English and so cannot be directly translated. This was supported within the literature (Croot et al., 2011, Ingvarsdotter et al., 2012, Kapborga and Bertero, 2002, Murray, 2001, Temple, 2002, Temple, 1997). A participant in Hsieh (2008) commented in their interviews ' I am not a robot' this was very similar to the comment from Participant 3 'we are not robots'. Interpreters across languages are highlighting they can be likened to a 'robot' in their role, which they feel was inaccurate. This indicates that professionals can view interpreters in a positivist way, expecting word for word interpreting and 100% accuracy, which the literature and this study do not support.

4.10.2 Advocacy, Trust and Anonymity

Neutrality and independency were important for participants in this study. Participants then talked about examples of advocacy and how it can be difficult to maintain their professional boundaries and act as an advocate in their role. Kaufert and Putsch (1997) commented how

neutrality for interpreters was difficult for interpreters to maintain. This was particularly difficult when one of the individuals in the interaction has not understood. This can mean they have to aid with this individual's understanding which can cause them act as an advocate and so lose their neutrality. They reported a negative attitude from healthcare to interpreters acting as advocates. A further example of interpreters acting as advocates was reported by Hsieh (2008) who found interpreters in their study acted as an advocate temporarily or all of the time. There was also a negative aspect to this, with the director of the interpreting agency in the study discussing that the advocacy role can be inappropriate for interpreters to take. In their study there were three forms of patient advocacy used by interpreters to empower patients. These were, to act on behalf of the patient, provide patients with access to resources and by elaborating on what clinicians say to improve the patients understanding. These methods were all done without the knowledge of the clinicians present in the interactions; it may be that clinicians were unaware of the advocacy role that interpreters can take in the interactions they are involved in.

Participants discussed how in their role they are not anonymous and that that could undermine the trust with the community they work with. There needs consideration of their role in research, their anonymity and potential reinterpretation of interviews as it could be nerve wracking and could generate anxiety. This could deter interpreters involving themselves in projects which do not discuss their wishes regarding anonymity with them. Other authors have not disclosed their interpreter's names to so protect their anonymity (Skelton, 2003). This may need to be considered with the interpreters who are involved in the study as they may wish to preserve their anonymity or wish their involvement to be highlighted.

The power of the interpreter discussed in this study has also been discussed by Becher and Wieling (2015). They examined the relationships between clinicians and interpreters and how interpreters can 'speak out' in clinical sessions. They discussed how the interpreters did this if they considered it was their professional responsibility, the client was being mistreated or did not understand the clinician. This identifies interpreters taking control of situations if communication has broken down and acting in an advocacy role.

Trust was important for participants to establish and maintain with the people they are interpreting for. This was also seen by Edwards (2013) who commented that in their project interpreters had already established a relationship of trust with the people they were researching and how there can also be some mistrust prevalent. Participants in the study mentioned the importance for both the interpreter and the Deaf adult to know who the interpreter would be on the day; this allows both parties to decide if it was appropriate and if it would be more appropriate for a different interpreter to be involved. The interpreters often know the people

they interpret for, with knowing people seen as very positive in relation to trust and a successful interaction. Knowing people can affect the interpretation as the interpreter brings their knowledge of this person to the interaction (Janzen and Shaffer, 2013). This needs to be identified as it could influence the interaction.

4.10.2.1 Involving Deaf adults in research

The participants shared their cultural knowledge of the Deaf community and discussed ways to approach the community in research, and present information in a way that was accessible. The importance of cultural knowledge of interpreters has been discussed in the literature (Baird, 2011, Ballantyne et al., 2013, Harris et al., 2013, Hole, 2007, Ingvarsdotter et al., 2012, Temple, 2002). The interpreters in this study do not share the same culture of the Deaf adults they interpret for, as they were not born Deaf. However, they work within the Deaf community they develop personal connections and gain understanding of the culture that aids their interpretations. The majority of researchers did not have knowledge of the Deaf community and its language and culture; interpreters have this knowledge and can help guide researchers in working with this community. Dawson et al. (2018), as part of their systematic review of involvement of Black and minority groups in health and social care research, found that participation in studies was improved by building trust, bilingual researchers, addressing concerns of patients and public and addressing concerns to explore culturally appropriate solutions. Dawson et al. (2018) did not include any studies involving the Deaf community in their review. The participants in this study suggested that a Deaf researcher could result in greater participation and insights that an interpreter would provide. Further involvement of the Deaf community within the project was now essential to identify the role they would like and how best to approach the community to be involved in research.

4.10.2.2 Role of the interpreter in research

Considerations regarding the role of the interpreter within the project needed to be considered, with the potential loss of independency, participants reported that you could either be a co-researcher or an interpreter on the project but not both. This requires consideration by researchers on how they involve interpreters and could involve different levels of interpreter involvement depending on the project.

Establishing how to work with interpreters in a research setting was an important part of the project and required collaboration with interpreters. There was a need for clear guidelines to aid both researchers and interpreters and input from both parties in their development was necessary. Interpreters have an important role to play in research as their cultural knowledge and

insights will benefit the project. How to train interpreters who have not worked in a research setting before or are unfamiliar with the research topic, was suggested by participants and would be dependent on the role of the interpreter in the project. Previous authors have either communicated their aims to interpreters (Almalik et al., 2010, Ballantyne et al., 2013, Bjork Bramberg and Dahlberg, 2013, Williamson et al., 2011, Pitchforth, 2005) or performed practice interviews (Sheppard, 2011). Interpreters who were not given training may come into the research interview not knowing the context of the interaction and therefore this could affect their understanding and so interpretation (Janzen and Shaffer, 2013).

With participants feeling there were two potential roles of an interpreter in research, the co-researcher or the research interpreter, the different roles would have different training needs. This could range from discussing the research, to shadowing interpreters working in a research setting and practice interviews.

4.10.3 Recommendations when working with interpreters in a research setting

Decisions will need to be made by future researchers on how they will involve the interpreter in their project. There were two roles described for interpreters involved in research studies, the interpreter as the co-researcher and the interpreter as the research interpreter. The same interpreter does not hold both roles in these recommendations. Two different interpreters may be involved in the project depending on the decisions made by researchers (See Figure 10).

Co-researcher – The interpreter was involved in all stages of the project, from developmental stages. This can take two forms in the interviews as they could be the researcher conducting the interviews or the non-BSL researcher could be. If the non-BSL researcher was performing the interviews a research interpreter (a different interpreter to the co-researcher) would need to be involved to interpret the interviews.

Research interpreter – will only be involved in the interpreting sessions will not have other involvement in the project.

The recommendations when working with interpreters for qualitative interviews are shown in Table 13.

Figure 12 Flow diagram showing the decision process for working with an interpreter in a research setting

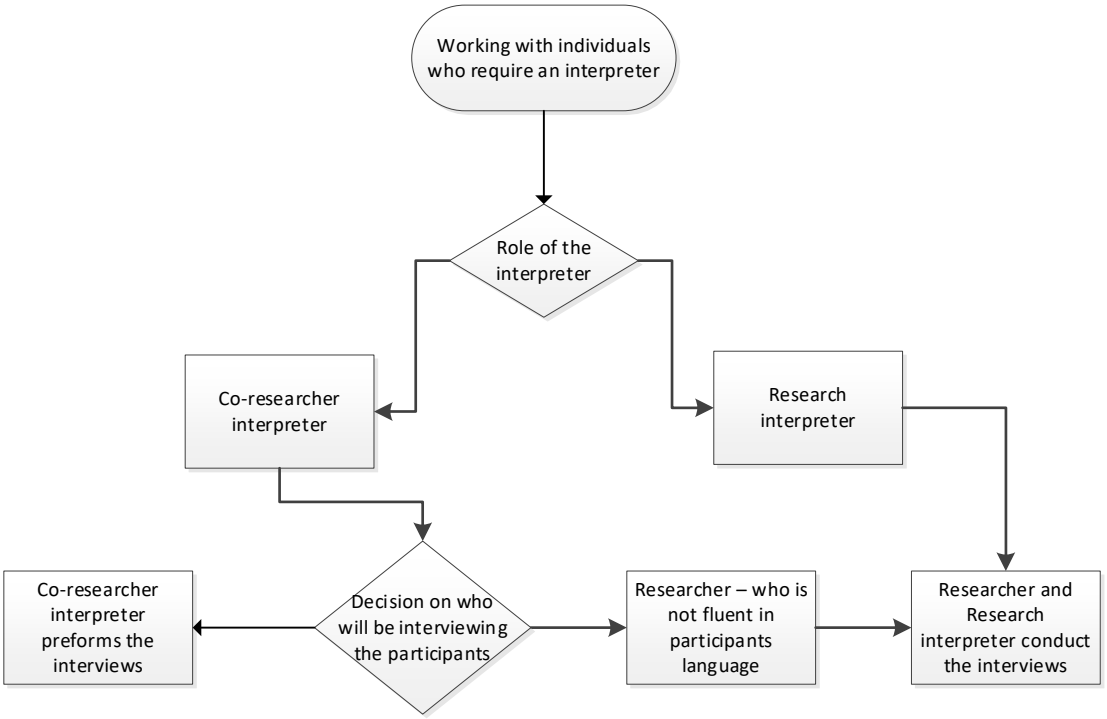


Table 13 Recommendations when working with interpreters in research

Recommendations	Reasoning
Discuss the aims of the project with the interpreter	The knowledge of the interpreter influences their interpretations they need to fully understand the project and what the area being investigated. Briefing the interpreter before the project with the aims of the project, answering questions and providing background information on the research will enable the interpreter to be fully informed. This would need to be undertaken before the interviews take place.
Identify the views of the interpreter on the project	The participants highlighted the need for interpreters to think about their views, to acknowledge them and this enables them to control them more effectively. It will allow the interpreter's time to decide if they wish to be involved in the project and to acknowledge if their views would prevent this as they feel they could not control these as part of the project.
Training	This would involve shadowing and practice interviews. By shadowing, this was meant as shadowing interpreters already

Recommendations	Reasoning
	working in a research setting. Practice interviews would be working with a volunteer adult who requires an interpreter, practicing the questions and getting experience of what the role they would be doing in a research project would involve.
Work with your interpreter	It was important to work with the interpreter, they have knowledge of a community that non members do not have and can aid with cultural understandings that may be missed. It was important to identify with them if they wish their role in the project to be acknowledged and how what sort of acknowledgement they would be happy with. They may wish to remain anonymous and that should be respected to ensure that interpreters continue to work in research projects to ensure the voice of minority cultures can be heard.

4.10.4 Reflections

After each interview and throughout the project I reflected on my views and interactions with participants. This study was the first time I had conducted research interviews with participants and areas for future consideration are discussed.

4.10.4.1 Excluding demographic data

As discussed in section 4.9.2, no demographic data were included in the study. This was due to small numbers of interpreters within the general population and the potential for identification. It was also to not discourage potential participants from taking part in the study. There was the issue that having excluded this demographic information it may then affect the readers understanding of the participants and how their views may have been formed. Upon reflection, demographic information would have aided further understanding of the data, such as years of experience as an interpreter, their current role as an interpreter and their interpreting qualifications. How long someone has been interpreting can also affect an interpreters views and their knowledge in certain areas. Questions regarding age, gender were not considered necessary to fully understand the data. Unfortunately, no questions were asked in relation to demographic data and consent was not obtained to use this information. This was a limitation in the study.

4.10.4.2 Building a rapport

Rapport can aid the interview to flow more naturally, allow participants to be more open and honest but can also cause participants to give answers that avoid embarrassment (Bell et al., 2016). For one participant interview rapport felt difficult to establish and maintain. The interview was stilted, the participant was interrupted repeatedly as I could not tell if a pause was due to the participant thinking or if they had finished their sentence. This was as facial and body language cues were not available using a telephone interview. In other interviews I realised I had worked with the participants before, and this was referenced in the interviews. This could have influenced what information was discussed during the interview, as they knew more about my professional role (Richards and Emslie, 2000). When the participants were approached, I described myself as a PhD student and disclosed I was a Clinical Scientist at USAIS. Participants would therefore have chosen to be involved in the study knowing my professional role. This may have affected the building rapport with the participant/s and so could have affected the data collected.

4.10.4.3 Difficulties transcribing interviews

The participants were interviewed using telephone interviews. This was more convenient and allowed participants from a wider geographical area to be invited to participate in the study. It also resulted in some difficulties in transcription due to interference and distortion present during the telephone interviews. This was evident in the interviews with Participant 1 and 6 and resulted in some words being missed, participants being asked to repeat information and affected the flow of the interview. The participants were asked to move location to try and improve the phone signal but in some instances this interference was intermittent and was not resolved. This made transcription more challenging. Suggesting that participants used a landline phone was considered but this could have affected recruitment as a mobile phone was more convenient and can be used in any location. Some participants may not have a landline, and this was not seen as an appropriate reason to exclude them.

4.10.4.4 Data collection methods

The data collected in this study was only from the semi-structured interviews. During the study a follow-up email was sent by one participant. Unfortunately this could not be used as part of the project as this was a different form of data to the interviews. Including more forms of data may have allowed further insights of interpreters to the project. This may have been too narrow and prevented insights being heard that would have been relevant to the project. In the future, expanding on the methods of collection to allow this email and other modes of data collection to be used.

4.10.4.5 Who should be the researcher?

Participants in the study raised the potential of a Deaf researcher which I had not considered prior to this. As this project was part of my PhD and so required to be my own work involving another researcher, although considered, would not have allowed this thesis to continue. I felt the decision to identify how to work with interpreters was the right decision, but this study highlights involvement of the Deaf community of CI users was now essential to the study. To do this required further exploratory work.

4.10.4.6 Power of the researcher

Another aspect that was not considered was the power of the hearing researcher and interpreter compared to the Deaf community. The hearing society was dominant in comparison to the Deaf community and then the power the researcher holds (Wurm and Napier, 2017). This requires consideration within the study, particularly with participants reporting that deaf adults have been researched on rather than with and the lack of trust within the community regarding research. Shifting this power back to the Deaf community means involving them in the design and focus of the study to ensure that this was relevant and appropriate.

4.10.4.7 Issues with recruitment

The study aimed to recruit 15 qualified interpreters from throughout the UK; only six were recruited to the study. With participant recruitment not reaching the numbers hoped, the reasons for low recruitment were considered. Were the methods of recruitment appropriate? Multiple resources were used including contacting of professional bodies and contacting interpreters directly. One of the participants, as part of their interview, stated that interpreters may not come forward as they see their interactions with Deaf adults as confidential. Talking about these they would be concerned they would break the confidentiality of the people they are working with. All the professional bodies and interpreter groups were approached by email correspondence. A way of making better contacts with interpreters could be by requesting to attend meetings of the ASLI either regionally or nationally. This would have allowed any questions interpreters may have had regarding the research to be answered in person. This would be considered if further work in this area was necessary, but due to the exploratory nature of the research it was not deemed possible at this stage of the study.

4.10.5 Key learning points

The key learning points from this exploratory study were collated to allow the main points of the research to be easily viewed.

- Word for word interpreting was not possible
- Interpreters may not interpret in the same way, but the meaning was the same
- Interpreters are open to having their work reviewed but this needs to be done sensitively
- In interpretation settings there are power dynamics which it was necessary to acknowledge
- The interpreter can both positively and negatively affect participant involvement
- The sign language users and BSL interpreters knowing each other can have a positive effect on the interaction
- How the interpreter is involved in a project can vary depending on the choice of the researcher

4.11 Summary

The current chapter presents the findings from interviews with interpreters on their role, the challenges they face and effective ways to work with them in a research setting. This project was performed with the basis to inform decisions within the main project.

This work has raised the consideration of the role of the interpreter within research projects. If the non-BSL researcher decides to take the interviewer role then a decision would need to be made whether to work with a research interpreter or two interpreters, one as a co-researcher the other as a research interpreter. How this would work was important to identify.

PPIE was necessary before the main project could commence. There was a need to consult with the pre-lingually deafened adults on the best data collection and recruitment methods. This work would also ensure that the project was relevant and something that pre-lingually deafened adults would want to be involved in.

Chapter 5 Phase 2 – Patient and public involvement (PPIE) Consultation with Pre-lingually Deafened Adults and Family members

5.1 Introduction

Chapter 4 presented how to effectively work with BSL interpreters in a research setting. This chapter identifies further areas that need considering before commencing the main research project.

The findings in Chapter 4 found the involvement of the Deaf community was essential and the methods to recruit Deaf adults differed from standard recruitment methods. The participants in Phase 1 suggested materials in plain English and a BSL version of the recruitment methods was necessary to approach these adults as some materials may have to high a language level (Connolly et al., 2006). Working with a Deaf researcher was also suggested. The participants were clear; access needs to be considered for this community. The role of the community within the work needed to be reflected upon and their views and insights into this work applied. This is to ensure the relevance of this work to the community and enable their participation. This involved consulting pre-lingually deafened adults about data collection and recruitment methods. This was to ensure that the project was relevant and something the Deaf community would want to be involved in.

If this work was not performed this could negatively affect recruitment and the data collected. This could also result in the study being irrelevant to pre-lingually deafened adults and an example of a further piece of research being performed on, rather than with them.

5.2 Previous research

There was limited research in how to recruit BSL participants with only four papers found (For papers see Appendix O). These studies used a variety of methods to recruit participants. Three of the studies had partnered with Deaf organisations or community groups (Kobayashi et al., 2013, McKee et al., 2012, Wurm and Napier, 2017) which, as well as keeping the studies Deaf focused, also highlighted them to potential participants. All the studies utilised social media outlets including Facebook and twitter in their recruitment strategies. None of the studies relied solely on social media for their recruitment and other methods included attending community events

(Kobayashi et al., 2013, McKee et al., 2012, Wurm and Napier, 2017), producing a website (Kobayashi et al., 2013), utilising shared networks (Young et al., 2016), producing brochures, postcards and flyers (Kobayashi et al., 2013), by word of hand/personal communication (Kobayashi et al., 2013, Wurm and Napier, 2017, Young et al., 2016) and working with gatekeepers (McKee et al., 2012).

Kobayashi et al. (2013) who recruited both sign language users and deaf English users; they found that community events were the best ways to recruit sign language users and mass media for deaf English users. This highlights that to recruit across early deafened adult group, different methods were essential not to bias your participant group. Multiple methods of recruitment were used across these studies and identified how one method was not enough to ensure participation.

Different data collection methods were used including questionnaires (Kobayashi et al., 2013, McKee et al., 2012, Wurm and Napier, 2017), interviews (Wurm and Napier, 2017) and focus groups (Young et al., 2016). The questionnaires used were in plain English (Kobayashi et al., 2013, Wurm and Napier, 2017) or completely signed versions were developed (McKee et al., 2012). The interviews and focus groups were conducted in BSL (Wurm and Napier, 2017, Young et al., 2016). The use of plain English and signed versions of documents identified how all the studies took steps to ensure the data collection methods were accessible to the Deaf participants.

All the research studies included Deaf researchers in the research team. Their roles ranged from project development (Wurm and Napier, 2017), recruitment (Wurm and Napier, 2017), data collection (Wurm and Napier, 2017, Young et al., 2016), data analysis (Young et al., 2016). Two studies did not state what roles the Deaf researchers took within their research teams (Kobayashi et al., 2013, McKee et al., 2012). All the studies noted that the projects were able to meet their aims based on the involvement and contribution of the Deaf researchers. The same participation from the community may not have been seen without this.

All the research studies identified used multiple methods to recruit participants, applied visual methods throughout their data collection, worked with Deaf community groups and with Deaf researchers. These are all aspects that need to be considered going forward with the PPIE work as this could encourage or, if not considered, discourage patients from being involved.

Wurm and Napier (2017) used a participatory approach with their study to ensure that Deaf views were considered. This involved putting the participants at the centre of every aspect of the study. The outcome was a combination of inputs from both the participants and the researchers, this acted to effectively involve the key stakeholders in the research. This method was considered along with the other qualitative approaches.

5.3 Objectives

After the exploratory work (Phase 1) and reviewing the published literature the objectives for this PPIE work were:

i) Understand what role the cochlear implanted Deaf adults felt would be appropriate for the community within the project
ii) Discover what data collection methods they considered appropriate
iii) Learn what recruitment methods they saw as being successful
iv) Discover how to successfully work with a minority community to produce a successful research project

5.4 Patient and public involvement and engagement in research

The results of the exploratory work (Chapter 4) have highlighted the need to involve pre-lingually deafened adults in this study, this was essential to guide this research and ensure it was relevant. These adults would be able to guide the research and identify the best methods to approach and inform members of their community. These users would bring a different perspective to the research. This would ensure the main study is relevant to the patient group it is aimed at and sensitive to their needs. This involves carrying out PPIE.

PPIE involves research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them (INVOLVE, 2012a). There are a variety of methods to involve the public in research and include, monitoring the quality of services, ensuring research meets the needs of the public and giving a perspective in development of research studies (Cartwright and Crowe, 2011). PPIE differs from research in that the public are not taking part in research as the subjects of the research; they are actively working with researchers within the research process. For example this could involve them advising them on the research design or choosing the research topics (INVOLVE, 2012a).

PPIE can involve working with patients or groups that are the easiest to reach, this can result in PPIE work involving the 'usual suspects', while groups that are not regularly involved in PPIE work can be described as 'hard to reach'. Rather than these groups being 'hard to reach' the research teams are not using the correct methods to reach these groups (INVOLVE, 2012b).

PPIE is particularly important in minority communities; these communities can be mistrustful of researchers due to negative experiences in the past and concerns that the research will reinforce negative stereotypes and stigmatise the community (Sullivan et al., 2001). Working with these groups can alleviate these concerns and increase participation in research studies.

The two main methods of PPIE are consultation and collaboration. Consultation directly asks the public for their views on a particular topic. There are benefits in that this allows you to identify the public's views and can explore sensitive issues. Collaboration is an ongoing working relationship between the researcher and the public, in this method decisions are hared between the researchers and public. Collaboration allows the research to remain relevant and can help with recruitment (INVOLVE, 2012a). The methods used can be dependent on the research and the members of the public you are working with. This study applied a consultation approach.

No ethical approval is necessary for PPIE unless the information collected is going to be analysed and published as research, then ethical approval would be necessary (Cartwright and Crowe, 2011, INVOLVE, 2012a). To ensure that it was clear to patients that this was PPIE and not research they were made aware of several points. There would be no recording of any demographic data, the interviews would not be recorded, and their participation would be confidential. It was made clear in the invitation email that this was PPIE and was different from being a participant in a research study.

5.5 PPIE for pre-lingually deafened adults

The PPIE involved asking pre-lingually deafened adults their views on topics relating to the research question, recruitment, data collection methods and study materials. Two sessions were planned so that information relating to the research question, recruitment and data collection methods could then be used to design the study and develop the study materials. The second session was intended to discuss the use of the data collection methods chosen and the study materials produced because of this, for example wording and presentation of written/visual material. Due to the points raised in Session 1, this has changed the basis that further developmental work was required before Session 2 could be arranged (See 5.5.5 for further discussion). The following sections present the discussions of Session 1.

5.5.1 Planning

Individual discussions were planned rather than a focus group due to the amount of information to be covered. As the volunteer/s may have required an interpreter, working with an interpreter in a focus group could be challenging and could result in key information being missed due to the differences in language used.

This was planned to be performed face to face, due to engagement issues this was changed to a skype interview. The individual requested a BSL interpreter for the interview. When the discussion was arranged, it was arranged on the basis that a BSL interpreter would be present. The

participant was informed of who the interpreter was during correspondence to organise the interview. The BSL interpreter was employed by USAIS, employing an external interpreter would have been costly and not within the scope of this PPIE. Before the call, a meeting was arranged with the interpreter to go through the topics to be covered in the meeting. The interpreter was experienced and had knowledge of CIs from her role working at USAIS. I had worked with the interpreter previously as part of my clinical role.

5.5.2 Engagement of users

Multiple methods of recruitment were applied. Initially staff at USAIS were asked to recommend patients who they thought would be open to being contacted and involved in PPIE. Due to a wish to contact these patients by email, patients who would be comfortable with this information in a written format were also requested (Email sent in Appendix P). The patients suggested did not respond to being contacted by email. A poster was also displayed in USAIS reception (Appendix T).

From the lack of response to the written format and determining that language level should not be a barrier to participating in PPIE, other ways of reaching out to BSL users were considered. Due to the visual nature of BSL a signed video featuring myself and a BSL interpreter was a way of reaching out to BSL users in their main mode of communication. After taking advice from the BSL interpreter based at USAIS on the content, a short film was recorded using an iPad and placed on the USAIS Facebook group site. This was also shared to a patient Facebook site. As of 30th October 2018 this had been viewed 375 times (See Appendix Q for screen grab of the clip and Appendix R for the video script). From this, one pre-lingually deafened adult made contact asking for more information and a skype call was set up with the BSL interpreter.

The topics covered in the discussions were recruitment methods, presenting of materials for recruitment and data collection methods

5.5.3 PPIE discussion

During the call the participant was asked about their views and opinions on the project. The participant noted that they did need information from other born Deaf CI users to aid in their decision making. Meeting and talking to people face to face helped with their expectations and helped them have an idea of what a CI might be like for them. They also found that their extended family members had a lot of questions as their family members did not know what to expect from the CI. This resulted in the participant feeling pressured to answer these questions which they found difficult to manage. They shared that having information specifically for families would have been helpful.

The participant was then asked about data collection and recruitment materials. They shared that all the materials used in the project needed to be visual and signed. The lack of confidence of some Deaf adults of written language could mean they would be put off by the written information and so this should be avoided. They shared that Deaf adults prefer information sharing face to face and so interviews would be better than other collection methods, they had concerns that a Facebook group could result in confidentiality issues. They reported that to make the Deaf adults aware of the study, posting information on the USAIS website and Facebook group would be the best options.

Ways of sharing the results of research with Deaf adults were discussed and they indicated an in-person meeting, a signed clip on the website and having a section in the USAIS newsletter would the best methods. The USAIS newsletter was a patient newsletter that was sent to patients twice a year informing about events, and changes and activities at the centre.

In summary, the participant noted that information about expectations would be useful to have and that looking at the families' experience of a CI would also be helpful as during the CI assessment it was challenging to answer and manage their expectations as well. They also shared that information provided to deaf adults needed to be in a visual format.

5.5.4 Reflections on PPIE

The reflections on the issues that were encountered during the PPIE work are presented.

5.5.4.1 Engaging the Deaf community

It was a challenge to engage these adults; even with the signed video it did not generate much interest. The interpreter shared that Deaf adult's may want more information, like what would it involve and was about accessing the community or asking for their input on a project. A follow up video would have been useful to address some of these issues.

Due to the Deaf adults potentially have literacy challenges, before emailing participants the language of the emails was checked by staff familiar with working with Deaf adults, the language of the text was completely changed (See Appendix S for before and after examples). This needed to be considered in any further correspondence.

5.5.4.2 Working with an interpreter

This work would not have been possible without working with the interpreter based at USAIS, their knowledge and experience of working with the Deaf community was essential in enabling this PPIE ~~study~~ to take place. The interpreter gave insights into how to structure the discussion to

ensure the best outcome. For example, first explaining the main study and then leading on to what the PPIE was then about. If a researchers did not have access to a interpreter in their workplace they should try build links with interpreters; this would likely have a financial impact.

5.5.4.3 Was one participant enough?

The PPIE recruited one participant, so this was one participant's views, this was not a representation of the whole community's views. Even with only one participant, this was the only insight into what was important to the community that was available. It was important to hear this individual's voice and adjust the project to reflect this. Ignoring these views continues the cycle of researchers not listening to BSL users. This could also have negatively affected participant recruitment; this participant could act as a gatekeeper to other members of the community and not adjusting the project could lead to this relationship to breaking down. This community's voice needed to be heard, researchers need a starting point and that means that one participant's voice was enough.

5.5.5 Implications for Phase 3

The implications for the main study were that all the materials needed to be in a written and visual format and the visual format needed to have a script in easy read English accompanying it.

The information from the PPIE had implications for the main study in terms of the topics investigated, with the potential of focusing on the expectations of the family and their experience of implantation, in combination with what adults expect of from an implant. Identifying the experiences of families would enable prospective recipients and their significant others to be informed about the experiences of family going through cochlear implantation. It was then important to determine how to capture information from families, and therefore further PPIE work was necessary.

5.6 PPIE with family members

A literature review was performed in this area and can be found in Appendix U. Due to the recruitment difficulties with pre-lingually deafened adults, the decision was made to focus PPIE work around the family of post-lingually deafened adults. This was due to the small numbers of pre-lingually deafened adults and to prevent the participant pool for the main study being depleted. It was thought that the issues in approaching family members and the feelings of CI users regarding this would be similar. It was also possible that the pre-lingually deafened adults have hearing relatives and so similar questions and insights would be evident, although there may

have been some variations. Staff at the centre were asked to recommend family members to speak to and the decision was made to speak to two individuals from different families who had a family member with a cochlear implant. One CI user who had links to USAIS approached their family member to ask if they would be happy to be involved in the PPIE, while the other was approached directly due to their links with USAIS.

Relationship with CI recipient – Adult child

The adult child spoke about how they and their parent (the CI user) went on a course covering the effects of hearing loss and living with hearing loss. As part of a course this participant had spoken about the process of implantation and found that it was more emotional than expected, as they had not actually focused on their experience at the time, it was more about the person who was having the CI. If their family member CI had said that they did not want them to be involved in the PPIE, they would not have been involved due to the effect on the relationship. They did not feel it was essential to approach CI recipients for their family members to be involved in research.

On the best ways to approach family members, they indicated that a letter would be appropriate but that it may actually need to go through the CI recipient as otherwise how would their details be found. They were away when their parent had an implant but did find that the parent shared the fears and concerns, they had about an implant and not really the positives of this. They ~~felt~~ noted that the information would have been useful.

Relationship with CI recipient – Partner

The partner reported it was important for families to be considered as they also go through the assessment process and through the whole implant experience with the recipient. Even after the CI has been implanted, they had a role in the rehab, taking part in homework for example. They indicated that it was difficult to exactly remember as this has happened a while ago now. They ~~s~~suggested that the family members could be approached directly but it was important for the CI recipients to be informed as this was related to their relationship with the recipient. They did feel that they had time to ask questions as part of the assessment and did feel as part of group sessions they did discuss impacts on the family.

5.6.1 Summary of information shared

Family members did not focus on their own experiences or expectations of a CI but more focused on the experience of the person receiving the implant. It may be that different family members have different experiences. Partners may be more involved and attending all appointments with the user while the wider family may not have the same support. Providing more information for

families would help them feel more supported. From the literature the experiences of families had not been investigated in depth in the papers found, further insights into these experiences would only benefit the CI recipients and their significant others. This exploratory work in Chapters 4 and 5 ensured that the research in the next stage was relevant. This work has influenced the study investigating the experiences and expectations into a study of experiences and hopes of families of early deafened adults of a cochlear implant.

Chapter 6 Phase 3 - CI experiences and hopes

6.1 Introduction

The Phase 1 interpreter study (Chapter 4) and Phase 2 PPIE with CI users and family members (Chapter 5) changed the focus of the initial research question. This was possible due to the pragmatic approach of the study, as it allowed the results of each exploratory phase to be considered in relation to the research question and methods. This resulted in changes to Phase 3, with the inclusion of the experience of the family based on the information gathered from Phase 2. The PPIE with CI users, led to changing the word 'expectations' to 'hopes' as the word expectations was not present in BSL, which may be the preferred language of the participants. The word 'hope' was identified from the PPIE CI user study as being more appropriate. Working with both the CI users and their families gives a different perspective on the CI experience and process. This was particularly focused on how information was given or shared with family members. This was as the PPIE participant reported that there was pressure around ensuring that they, as the patient, communicated all the information to their family. Focusing on information for families may help relieve the pressure that can be shared by the recipients, as they can direct family members to another resource rather than feeling they needed to answer all their family's questions.

After the initial exploratory phases of this thesis, Phase 3 was planned to adopt a case study methodology (Chapter 3). The case study was going to use a variety of data sources including documents, interviews with CI users, interviews with family members and comparing pre- and post-implant participant data. There were going to be two groups of participants, the first followed through the CI experience from before implantation to six months post-implant. The second group interviewed between one and five years after they were implanted. The written documents and pre- and post-implant data were going to be used for triangulation within the case studies. Phase 3 could not be carried out using its proposed methodology due to the Covid 19 pandemic.

The pragmatic approach involved constantly reassessing and reflecting upon the available knowledge at the time. This ensured the study was relevant and was following an appropriate method to answer the research question. This approach allowed reassessment of the Phase 3 case study methodology. It was considered as to whether it was feasible to use this approach during the pandemic and how it would be possible to collect the data and still answer the research question. After a period of reflection, it resulted in this Phase following a general

qualitative methodology (see 3.8 for a discussion on why a general qualitative approach was chosen) and it was split into two separate phases, Phase 3a and Phase 3b. Phase 3a assessed the documents relating to CI users' hopes and experiences of an implant. These included documents given to CI users from USAIS as part of their assessment and from an internet search looking for information about CIs. Phase 3b focused on CI users and their families' experiences and hopes. Phase 3a was not affected by Covid 19, but Phase 3b was affected due to Covid 19 resulting in all surgeries being cancelled. This meant no participants could be recruited who were going through the cochlear implantation process. This resulted in participants only being recruited if they had an implant or were a family member of a CI user.

Splitting of the study into two phases was necessary as presenting the two different sources of data together affected the structure, flow, and clarity. It allowed the write up of each study to flow and the story of each phase to be clearer. The results from Phase 3a and Phase 3b were then compared in 6.5.2. Table 14 shows the planned and actual methods that were applied and section 3.8.2 discusses the implications of changing the approach.

Table 14 Planned methods and the actual methods applied

Planned method	Actual method due to changes following Covid 19
Case study approach	General qualitative methodology
Recruiting CI candidates going through implantation (Longitudinal data collection)	CI candidates going through implantation were not recruited due to the cancellation of surgeries; only retrospective data were collected
Recruitment occurring through appointments	Most of the recruitment was through digital mediums as routine appointments were cancelled
Interviews face to face only	Interviewees had the option of virtual or face to face interviews

This chapter describes how the two phases were undertaken, their data analysis and findings. Both Phases used thematic analysis and Merriam's (2009) data validation tools. Phase 3a and Phase 3b are presented separately; the two Phases results are then compared and contrasted to identify any similarities or differences within each phase's data to look at the validity of the data. Reflexivity was incorporated throughout each phase and I describe myself in the first person, due to my experiences as a researcher/clinician and the nature of the study.

6.2 Phase 3 Research Question and Objectives

The initial research question (section 2.6) has been developed through the initial exploratory phases and was then affected by the Covid 19 pandemic. The research question for this Phase of the study was:

What are the CI recipients and their family members' hopes and experiences of a cochlear implant?

The other objectives as part of this Phase were to:

- Discover what the CI recipient and their family's hopes are of a CI
- Learn how the recipient and family adapts to the cochlear implant
- Understand how the family unit supports the CI recipient through cochlear implantation
- Learn what support could be provided that would aid in supporting the CI recipient and the family
- Understand what early deafened CI users and their family base their hopes on

Although the study has been split into two phases the objectives apply to both Phase 3a and b. Phase 3a is now presented.

6.3 Phase 3a document review

This Phase of the study investigated the hopes and experiences of early deafened adults of their CI through examining the documents that they receive, or may find when using the internet, before they have their CI. When coming for a CI assessment the patient may never have met someone with a CI or heard about CIs before. It was common for patients to use the internet or social media as a source of medical and health information (Diaz et al., 2002, Peyser et al., 2021). Some of the documents are provided as part of their assessment, and this information may influence their decision to have a CI or continue/consider being assessed for one and so affect their experience and hopes of a CI.

Document review enabled another source of information to be investigated which may have influenced patients' hopes of an implant. The internet had not been considered in relation to CI experiences but has been shown to be used by participants to investigate a CI (Snell, 2015). There were numerous webpages and marketing materials that were given to patients before they decided on an implant. Looking at all these documents would be overwhelming and not within the scope of the study. With the focus on early deafened adults, material relevant to these adults

was the focus of this search. The PPIE in Phase 2 was used as guidance within this study; these users did not share that they had used the internet but did explain that they spoke to other early deafened adults who had a CI. A way of using this information was ensuring that candidate stories were included in the internet pages in the review. In general, it was impossible to know what information early deafened adults searched for and this may have been different for each adult. Material that was signed and written was included in the search. This was as some early deafened adults had BSL as a first language or difficulty accessing purely audio material due to their hearing loss. Signed material required interpretation to be included in the study. In summary, data from an internet search and documents given to CI candidates as part of their CI assessment at USAIS were included in the review. The documents from USAIS included manufacturers' information and information specific to USAIS. This included information on the USAIS service and an FAQ sheet relating to the CI assessment process.

The data from the internet was pre-existing publicly available information. Online or written accounts of a CI experience focuses on what the individuals reported was important to them at the time rather than what was important to the researcher (O'Brien and Clark, 2012). This Phase of the study considered which documents to review, and the ethical issues associated with this data.

6.3.1 Method

Merriam (2009) described six types of documents, public records, personal documents, popular culture documents, visual documents, artefacts and physical materials and researcher generated documents (See Table 15 for examples of these documents). From considering these types of documents, this study used public records, popular culture, and visual documents. This included internet pages containing candidate experiences. These documents were accessed in two ways, by internet searching and a review of the documents issued to patients at USAIS. Documents issued at USAIS included manufacturer marketing documents that are used across implant centres in the UK and documents specific to the USAIS service, such as the team structure at USAIS.

I was aware that information was given to CI candidates at their assessment appointments. As a result of this written information given to patients at the assessment stage (such as USAIS information leaflets and information on the devices available), information on the USAIS website and information on manufacturer's website was included.

Table 15 Examples of the six types of documents as described by Merriam (2009)

Type of document	Examples
Public record	Census, police records, minutes of meetings
Personal	Diaries, letters, personal blogs
Popular culture	TV, film, radio, newspapers
Visual	Film, video, photography, web based media
Artefacts and physical materials	Tools, utensils
Researcher generated	Prepared by the researcher or for the researcher by participants e.g. a photo that represents the participants experience of an event

6.3.1.1 Ethics and internet data

Before starting the document analysis, I thought that as information on the internet was widely accessible there would be little or no issues with using this data, linking to the sites, and using verbatim quotes. Turning to the literature for guidance it was identified that the literature in this area was unclear, complex and presented conflicting views on using information from the internet with researchers usually adopting a case-by-case approach with responsibility resting with the researcher (Burles and Bally, 2018, Lapadat, 2019, Samuel et al., 2019). There were reports of internet users using public sites, but expected privacy in doing so (Markham, 2012) and there was a lack of clarity around the analysis of pre-existing publicly available information (Burles and Bally, 2018). After seeking advice from the ethics committee at the University of Southampton and from colleagues in The School of Electronics and Computer Science, who regular use internet data for research, ethical approval was sought from the Ethics and Research and Governance Online (ERGO) and obtained ERGO56773 (Appendix W). Ethical approval was obtained after the internet search was performed. The internet search was not repeated as aspects of the internet search were used to inform the ethics application. For example, the location of the websites and the type of websites included in the review. No data were collected from the websites or analysis was performed until after ethical approval was obtained.

The main issues around using information from the internet in the study were considered.

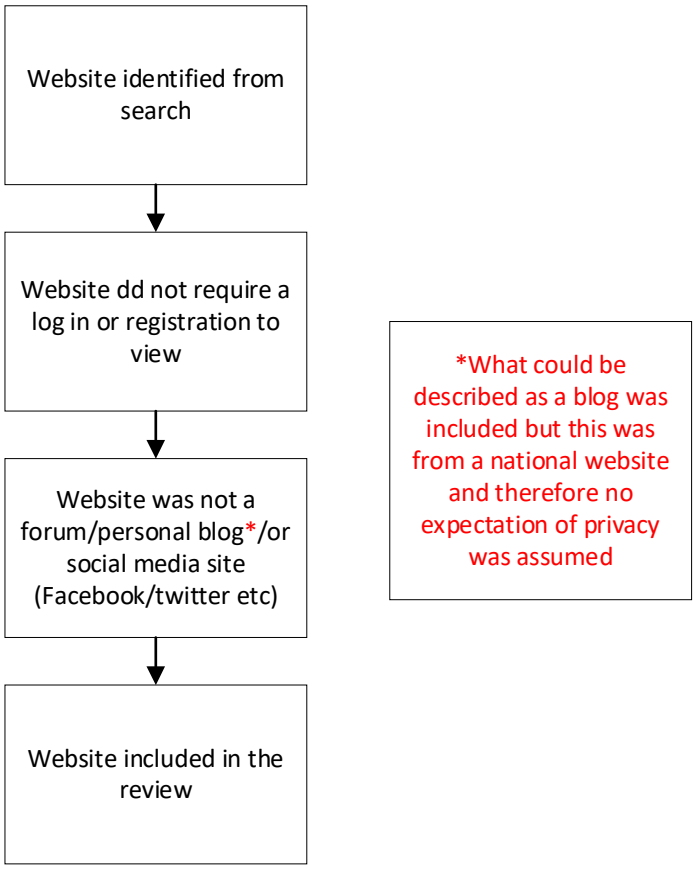
Public or private?

One of the first issues was whether the space was public or private and what was meant by these terms. The British Psychological Society (2017) deemed a public space as readily accessible to anyone and so where individuals “would expect to be observed by strangers”. Private spaces

would then be considered as spaces where membership was required to access the sites, or the information was not readily accessible. There was debate around what was considered a public space with twitter tweets being publicly accessible but users assumed some privacy (Fiesler and Proferes, 2018). In relation to social media sites, users can act like these are private environments when they are in fact public (Samuel et al., 2019). What was deemed a public space by researchers may not be deemed a public space by the authors or the owners of the websites. It has been reported in online communities that users feel their communication was for other community members and they had not considered that this information might be used for research (Bromseth, 2002).

In the Phase 3a study all the websites and information included in the analysis were publicly available. Any sites that required a log in or registration were removed from the analysis. Blogs were deemed to have an expectation of privacy, and were also excluded from the analysis. This was since bloggers have described their blogs as part of their identity and not to be treated as public data (Markham et al., 2012) All the sites that were in the analysis contained information which would be expected to be viewed by strangers. This included the patient stories which were either posted on national group websites or posted on company sites or by the owner of the site. The CI stories included on the sites would have required consent from the individuals posting the stories to post them on a publicly accessible site. From this it was deemed that the authors would have expected their stories to be viewed publicly and not produced for other community members. All the sites included in the analysis were considered publicly available documents and were treated as such (See Figure 11 for a summary of this).

Figure 13 Criteria for websites to be included in the analysis



This then leads onto issues around consent and if consent was necessary in what would be considered public spaces.

Consent

There were two conflicting views regarding consent in what would be considered a public space. One view was that informed consent was not necessary, or there was less obligation to have informed consent if the sites were clearly public (Markham et al., 2012, Mazanderami and Powell, 2013, The British Psychological Society, 2017). It was thought that individuals who shared their stories on websites that were publicly accessible were aware that their posts may be read by people they do not know (Burles and Bally, 2018). The conflicting view was that the information on the websites was not produced for research (Clark et al., 2015, Markham, 2012) and collecting this information could compromise the purpose that the page/group was intended for (Roberts 2015). Some authors indicated that consent from users was a requirement for inclusion in their analysis e.g. Grinyer (2008). Grinyer (2008) wrote that the authors may feel "violation and exploitation" when quoted without consent which was why they reported they needed consent to include the authors in their study.

There were difficulties around gathering consent, with the availability of contact details (Anabo et al., 2019, Burles and Bally, 2018) and it being unclear if asking for permission from the website owners was enough or should consent be asked from the people who posted the information. Requiring informed consent could actually prevent the research being performed (Webb et al., 2017). When looking at difficult or controversial topic areas, users may never provide consent. Webb et al. (2017) noted that this would mean researchers would look at areas that were easier with regards to ethics rather than looking at difficult but important areas (They used an example of a difficult area as hate speech, where it would be assumed users would not give their consent to be involved in research). Some authors have looked at the terms and conditions of the site and if the sites terms and conditions do not explicitly disclose research being performed then they have included these sites in their study (Lamprell and Braithwaite, 2018). Burles and Bally (2018) were clear that if no consent was sought the need to protect the authors from harm was essential. One of the ways the participants could be harmed was from their identity being made public (Sugiura et al., 2017).

For this Phase 3a study, there were over 30 websites and contacting all the authors or website owners would have been laborious and time consuming. Only including the sites that gave consent would be of detriment to the data analysis. Some of these websites were over five years old and there are issues regarding who could give consent, for example could the website owners give permission to use someone else's story for research. It was felt that realistically only a few sites would have responded to the contact email. With the data publicly available and with the issues around obtaining consent, no consent for use of the data were sought. Therefore, it was essential for steps to be taken to ensure participants' anonymity within the study and any published data.

Anonymity

There were different methods that could be used to protect the authors of online data from being identifiable if no consent was sought. Lamprell and Braithwaite (2018), when looking at patient skin cancer stories, used public sites whose terms and conditions did not prohibit the data being used for research. There were no clear methods to protect these authors and they appeared to have the view that as the data were publicly available no measures to protect the participants, other than not naming them directly, were required. They used extensive verbatim quotes, which could be traced back to the authors of the accounts. On the other hand, Malik and Coulson (2013) looked at permanent involuntary childlessness but did not name or give the address of the website they used. They anonymised all quotations, paraphrased them and checked in search

engines that they were not traceable. These studies show that within the literature there were different views on protecting participants' anonymity.

The British Psychological Society (2017) viewed that researchers should consider if using traceable quotes does require consent. This was particularly important if the harm to the subjects was potentially significant and if publishing the name and the address of the group/website could also result in harm not just to the participants, but to the whole community.

Different authors have proposed different methods to prevent harm, such as using pseudonyms (Anabo et al., 2019, Malik and Coulson, 2013, Roberts, 2015), general data (Anabo et al., 2019), paraphrased quotes (Anabo et al., 2019, Malik and Coulson, 2013, Roberts, 2015), ensuring that quotes could not be located using search engines (Malik and Coulson, 2013), not providing names or links to websites/forums used (Malik and Coulson, 2013, Sugiura et al., 2017) and using fabrication. For example where an original patient story was created that was representative of all the patient stories in the analysis (Markham, 2012). Most authors used a mixture of these methods as using only one may not guarantee anonymity (Sugiura et al., 2017). Bruckman (2002) described four levels of disguise, no disguise, light, moderate and heavy. In light disguise, group members could guess who was being discussed and with some investigations an outsider would be able to identify who the participant was. Heavy disguise was where some false details are introduced; someone seeking to identify the participant would not be able to do so and information harmful to the subject may be revealed if their anonymity had not been ensured. Moderate disguise was a compromise between these two.

This study has taken the view that, as the participants have not consented for their stories to be used for research, steps needed to be taken to protect their anonymity. Harm to participants and the community were also considered as I did not want to negatively affect my relationship with this community. If this study was using a forum/Facebook page, then the methods used would have been different. These websites were not all directly linked to one specific group. They were all adults with a hearing loss but some of the pages included were sites that would not be described as part of the deaf community, for example inter/national news websites. Due to this a moderate level of disguise was applied. The following methods were applied to protect the subject's anonymity. These were not giving the websites' name or address, using pseudonyms, and checking the quotes used did not link back to the websites or participants. No false details were introduced and the information that the study was investigating, in my view, contained no harmful information in the websites included in the study. As the terms used in a Google search were disclosed, it was possible to identify the websites included in the study (though these sites' prominence on a Google/Bing search may change over time) and so find the stories included in

the study. The aim of this disguise was so that the quotes from the participants could not easily be linked to them and they could not be directly searched for. As not all the stories or sites were included, the aim of the disguise was to make anyone looking for this information unable to determine where the quotes were from. It has been noted that it was difficult to remove all traces that link data to the participants (Zimmer, 2010). These methods were being applied to ensure that it was difficult to link individual participants to the quotes and so identify them.

6.3.2 Data collection

When patients attend their first appointment at USAIS they are given an information pack containing information about the service and the devices available. The information in this pack was collected, the documents scanned, and the date of collection recorded. All this material was in a written format.

How to access the internet data was considered. Internet users used single or multiple words to search for information using internet search engines. The search terms used in this study were cochlear implant, experience and deaf. These were identified from the PPIE (Phase 2) as those which family members would use to search for information. Terms such as AND/OR were not included. The terms were written in the search bars as: cochlear implant experience, and: cochlear implant deaf. Research has shown that when using search engines, the click through rate was higher for the first results page at 71% and then pages 2 and 3 had a combined click rate of 6% (Jacobson, 2017). From this, only the first three web pages were reviewed. Any pages that were shown as Adverts were excluded. Adverts were identified as having the words Ad next to the website address.

Any audio-visual data were changed into a written transcript for data analysis. Some of these videos were signed with a transcript of the video included. This transcript information was used for analysis.

The focus of the search was early deafened adults, and information that was identified as being from adults who lost their hearing after the age of six years was removed. Any materials that were scientific papers/journal articles or not aimed at CI users, but audiologists/researchers were removed. The material found may differ dependent on the date the search was performed. Searches were performed on Google and Bing, since these are the top two search engines with regards to market share in 2019 (Law, 2019). Validity checks were then performed (as shown in Appendix V) to ensure that the legitimacy of the documents had been assessed. It was considered as part of this review that some of this information accessed by pre-lingually deafened adults may not be accessed in the same medium as a hearing researcher would.

6.3.2.1 Data collection methods

The assessment pack was accessed on 1st March 2020. This contained a total of eight documents. These were scanned into a pdf format and uploaded to NVivo. These documents contained mainly marketing material regarding the CI devices available at this time point.

An internet search was performed on the 27th January 2020 using the search terms:

- Cochlear implant experience
- Cochlear implant deaf

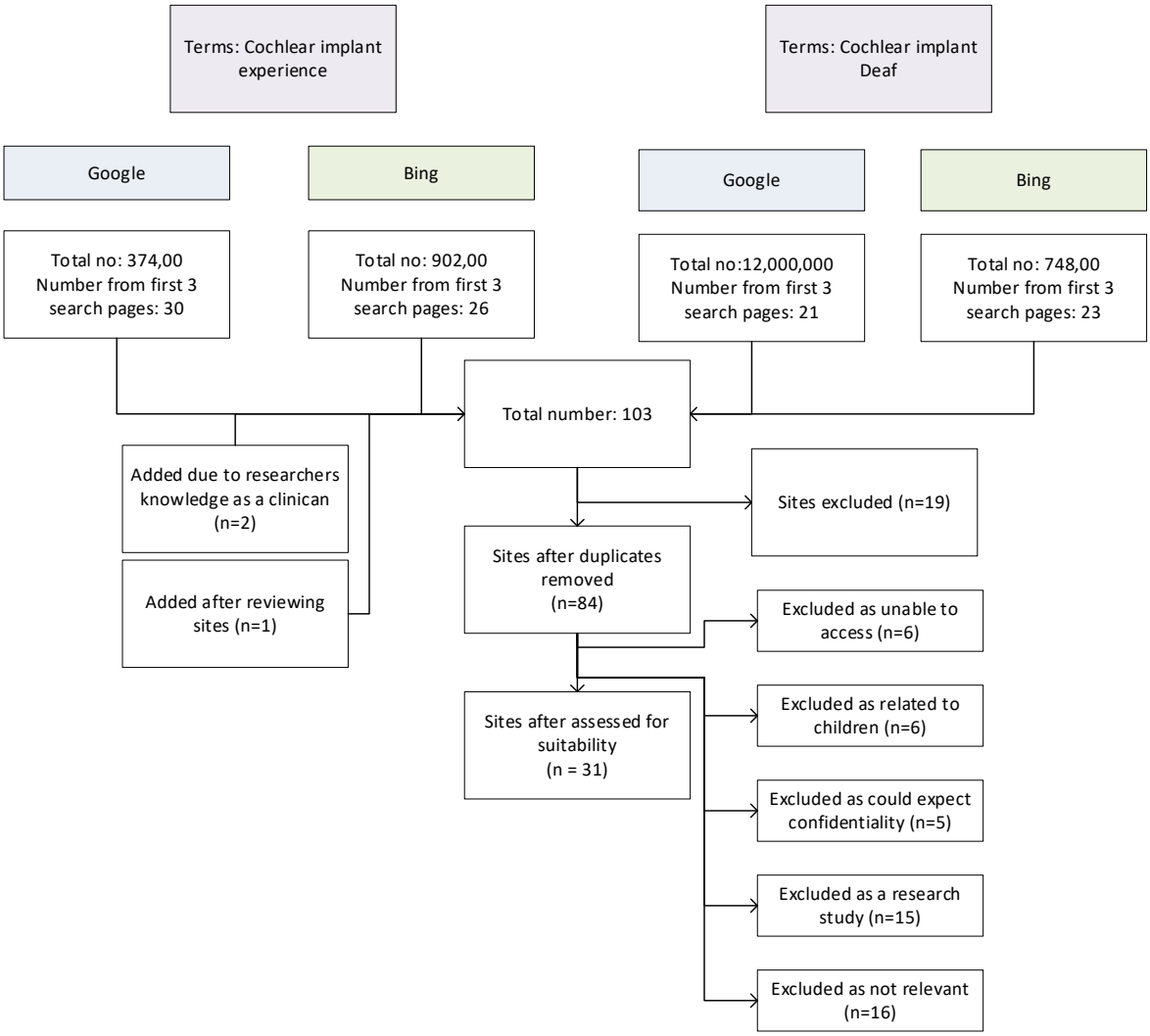
The total of results returned was large (Figure 12), and the websites on the first three pages of the search were copied into an excel file. The total number of results found from each search (this number was produced from the search engine used) and then total results from the first three pages were recorded. Any duplicates were removed. The type of website, document, relevance and if the document was going to be included in the study, were recorded. Three documents were added to the website list. One was found due to my previous knowledge, and two from links on sites found in the original analysis. The documents were then assessed for their relevance and if they were appropriate to be included in the document analysis. Sites were excluded if they were focused on children, access involved a subscription or signing up to the website, confidentiality would be expected (i.e. blog), they were research studies, or they were not relevant to experiences of CI's. Figure 12 shows the number of documents found and the resulting assessment process. The 31 sites that remained were searched for information relating to patients' experiences of a CI. Any videos on the sites were transcribed, and only videos relating to adults diagnosed with a hearing loss under six years were included. Where patient stories were in BSL or patients identified that their hearing loss developed under the age of six, these were included. Any other videos were excluded. Sites were deemed not relevant if the CI info was relating to CI criteria or looking at the parts of the CI equipment rather than information on experiences.

Websites were then numbered, and pseudonyms given to any contributors (Names were chosen from a list of historical baby names (Office for National Statistics, 2014)). The types of websites, the focus of the page, the location and if CIs were viewed positively or negatively were then recorded. Whether the CI was portrayed in a positive light was considered. If the information was mainly factual it was deemed neutral, it was deemed positive if it put CIs in a good light and negative if CIs were portrayed as not an option for patients or only negative aspects of the CIs discussed. The location of the website was noted. The UK has the National Health Service (NHS) providing a CI to adults who meet the funding criteria (NICE, 2019); this was different from the USA whose health care was mainly accessed through insurance policies and of whom 9.2% of the

US population have no access to insurance policies (Kelsler-Starkey, 2019). This meant, in the UK, CIs were available to all within the criteria, with no cost restrictions affecting treatment. This was in contrast to the USA, where treatment was dependent on insurance policies or for those who could afford treatment. Some of the content in the documents needed to be considered with this context. The content of the site was then copied over to a word document or transcribed into a word document. If the document was a pdf it was saved.

All the documents were then transferred to NVivo12. A computer data analysis programme was chosen as these boost the accuracy and speed of the analysis process (Zamawe, 2015). NVivo was chosen as I was familiar with it, having used it in Phase 1, and training courses were provided by the sponsor. Other qualitative analysis software such as MAXQDA, ATLAS.ti and Dedoose were not considered as they were not available through the University and would have incurred an extra cost when NVivo was readily available and suitable for the analysis performed.

Figure 14 The document review internet search analysis process



6.3.2.2 Access date

All the documents and websites were collected/accessed between February and March 2020. The websites and promotional material may have changed after this time. This was not updated as this was meant to be a snapshot of one time-point and representative of what a CI candidate/family member would find if they searched.

6.3.2.3 Date published

The website material was published/updated between 2008 and 14 February 2020. Information in one of the documents was from 2008. This was retained as it was a patient story and was still relevant to the study. Without this document the website material ranged from March 2011 to February 2020. The documents from the assessment pack were from 2018-2020.

6.3.2.4 Types of documents

The websites varied in their type, with many classed as health or websites of national bodies. The majority contained patient stories and were UK based sites. Overall, a positive view of the CI process was presented. The websites were assigned as positively or negatively CI focused based on my knowledge of CI and if they would encourage or discourage someone coming forward for CI. Discouraging someone to come forward for a CI relates to sites promoting the continuation with a hearing aid when they are suitable CI candidates. Neutral sites presented mainly factual information (Table 16).

Table 16 Types of documents and their focus

Types of website		Page focus		Website location		CI positive/negative	
Health	8	Patient stories/experiences	19	UK	17	Positive	25
National body	7	Information on a CI	16	US	11	Neutral	12
Patient information	3	Why a CI isn't for all	3	Australia	1	Negative	2
CI company	5	Advances in CI	1	India	1		
Provider (Hospital etc)	9			Unknown	1		
Newspaper	7			N/A (written document)	8		

6.3.2.5 Document validity

All documents included in the review were converted into a written format (if necessary), and the accuracy and validity of the document were then assessed. Merriam (2009) included questions regarding the validity of documents from Clark (1967). These questions were designed for written documents, before the internet was developed, but are still relevant for documents published today (Merriam, 2009). These questions were developed in 1967, and the questions and the language used were updated for this research (See Table 17). These questions were asked of all the documents reviewed (an example is shown in Appendix Z). No documents were removed from

the analysis after this validity check. To ensure anonymity of the websites and website contributors these were not included in the final thesis.

The documents were analysed using the research questions (see 6.2). Within the documents there were two main types, documents providing second or third hand information regarding a CI or the CI experience and documents giving first-hand experiences of a CI. The documents giving a first-hand account of the CI experience had more relevance than third hand information presented. The documents were analysed using thematic analysis.

Table 17 Clark's (1967) original questions and the questions used in this study

Original Question	Questions used in the current study
What is the history of the documents?	What is the history of the documents?
How did it come into my hands?	How were these accessed?
What guarantee is there that it is what it pretends to be?	What guarantee is there that it is what it pretends to be?
Is the document complete as originally constructed?	Was the document complete, what version of the document is this?
Has it been tampered with, or edited?	Has the document been edited? This is also relevant to the original form of document, I.e. videos may have been edited
If the document is genuine, under what circumstances and for what purposes was it produced?	If the document is genuine, under what circumstances and for what purposes was it produced?
Who was/is the author?	Who was/is the author?
What was he trying to accomplish? For whom was the document intended?	What were the authors trying to accomplish? Who was the document intended for?
What were the maker's sources of information? Does the document represent an eyewitness account, a second-hand account, a reconstruction of an event long prior to the writing, an interpretation?	What were the maker's sources of information? Does the document represent an eyewitness account, a second-hand account, a reconstruction of an event long prior to the writing, an interpretation?

Original Question	Questions used in the current study
What was or is the maker's bias?	What was or is the maker's/interviewee's bias?
To what extent was the writer likely to want to tell the truth?	To what extent was the writer/interviewee likely to want to tell the truth?
Do other documents exist that might shed additional light on the same story, event, project, program, context? If so, are they available, accessible? Who holds them?	Do other documents exist that might shed additional light on the same story, event, project, program, context? If so, are they available, accessible? Who holds them?

6.3.2.6 Validity checks

It was likely that the validity of the documents was not considered by anyone accessing these sites for information about CIs. This was assessed to understand the origins and trustworthiness of the documents used. Previous authors have noted a lack of quality control of web based materials and the accuracy of some of the information published (Zaidman-Zait and Jamieson, 2004).

All the documents had an unknown history, and it was challenging to know the history of webpages when they are accessed for the first time. Upon reflection this should have been removed from the validity checks.

Most of the websites were found using the direct links on Bing or Google. Two pages were found through links from the original page on Bing or Google. The information on the linked pages was more relevant to experiences that the initial page found using the search engine. It was also difficult to make an assessment if the document was complete as there were limitations as to what was possible to assess from a website; this also applied to the version number. Not all websites were clear if they had updated the page since it was produced. This was clearer on the news pages.

There were no guarantees that could be given with regards to whether the document was what it intended to be. The documents coming from respected websites helped with this guarantee. I was able to assess the accuracy of the information presented based on my CI knowledge.

Most of the webpages had some bias. The authors had an agenda regarding whether to promote themselves, services or to be CI positive. Thirteen of the documents (1-10, 12, 14 & 16) were CI stories which were assessed as mainly positive. They were biased towards CI as they had a

positive experience with their CI. There were no stories found from patients who had a CI who did not recommend them as a treatment option. Documents 18 and 25 were encouraging potential patients to visit their centres. Document 25 listed all the negatives of a CI which was interpreted as encouraging patients to continue with a hearing aid.

It was also important to note that people with extreme views are more likely to share their views than people with moderate views. This is because people with extreme views believe that their views are in the majority (Miller and Morrison, 2009). No negative views were shared but this could be as more positive views were shared. However, it was difficult to determine if the CI users who shared their experiences had extreme views as what is classed as an extreme view from a CI outcome perspective? From my experience, these CI users had good outcomes which is what I would expect from this population as a whole, and less experiences would be shared from contributors with a more average outcome.

6.3.3 Data Analysis

The documents were analysed using thematic analysis (Braun and Clarke, 2006) (See Table 11). Thematic analysis is not bounded to a particular theoretical framework or approach (Braun and Clarke, 2006). It has been widely used in document analysis (Sanz-Valero et al., 2012, Trarieux-Signol et al., 2018, Vetrovsky et al., 2019). This method of analysis was familiar having been used in Chapter 4.

The data were coded with reference to the research questions but included some inductive elements. This was to ensure that any area raised within the documents that was not covered by the research questions could be investigated.

The quality of the thematic analysis was assessed using Braun and Clarke (2006) 15 point check list of criteria for a good thematic analysis (Table 10). See section 4.7.7 for further information. Theoretical maps at each stage of the analysis showed how the analysis developed over time and themes were compared to the original data set. An audit trail was maintained throughout the study.

Most of the documents were in a written format and did not need transcribing. For the webpages that did need transcribing, a verbatim account was made, and the original audio recordings were then checked to ensure the accuracy of the transcription. Most of the documents were ~~already~~ in a written format. This meant that reading the documents in detail was essential to ensure there was a thorough understanding of the data. My knowledge of the CI process was extensive. This would have affected the generation and synthesis of the themes, and a researcher with no CI

knowledge may have taken different meaning from the data. The stages of thematic analysis were applied (See Appendix X). This resulted in four themes (Table 19).

The presentation of the themes aimed to tell the story of the data and provided evidence to support this. Quotes were selected that represented the theme well; it was ensured that quotes from different documents were included to show evidence from different sources to support the interpretation of the data. Due to the need to ensure the anonymity of the contributors, quotes were shortened to ensure they were "Google" proof. This did mean that some quotes were not included as they were easily found when using internet search engines. Using single words was found to be effective at allowing the participants' voices to be heard but preventing them being identified. Some of the longer quotes used in the analysis were from videos and did not appear on internet searches. This did result in describing some of what was in the data rather than quoting specific documents. This affected the evidence provided within the themes and was a limitation of the analysis using these data.

6.3.4 Data validation

This study used the data validation tools described by Merriam (1998) and (2009). This involved internal validity, external validity, and reliability. Not all these tools were applied due to changes to the study. Table 18 shows the tools that were applied with reference to the current study. Appendix Y shows all the tools and the discussions around their application. After an examination of the tools to ensure the data were valid, the data were then collected.

Table 18 Merriam's (1998) data validation tools with reference to the current study

Internal validity	Member checks	Websites or contributors were not asked to check the findings. There were issues around locating and accessing the contributors as it was not always clear who had posted the information. The availability of these details and difficulty accessing these meant that it was not possible to use member checking. (There were similar issues noted in obtaining consent which were discussed in 6.3.1.1.1)

	Peer examination	This study, as part of my doctoral work, was reviewed during supervisory meetings and comments on the findings recorded and used to enhance the analysis. No external review outside of the supervisory group was sought as this research was required to be my own. This study was reviewed as part of the doctoral examination/for publication.
	Participatory modes of research	PPIE was carried out to ensure this study's relevance to the participants (Chapter 5)
	Researchers' biases	This has been discussed in 3.6
Reliability	Investigator's position	This has been discussed in 3.2
	Audit trail	Reasons for decisions made were documented as part of this thesis. Methods for data collection and analysis were described. One of the reasons thematic analysis was chosen as the data analysis method, was to ensure a clear audit trial was present.
External validity	Use of rich thick description	One of the steps taken to prevent the participant being identified was ensuring the quotes were Google proof. This meant that large sections of text could not be used as they could be easily searched for. In some cases the quotes were from online videos, the text in these videos could not be searched for using a internet search engine.

6.3.5 Results

The topics found in the document search were varied and referred to the Deaf community, the pre and post implant periods of CI and support. Three of the main themes were divided into sub-themes as indicated by the data. The themes and sub-themes are shown in Table 20.

Table 19 The themes

	Themes	Sub-themes
1	Deaf community	1.1 Hearing world
2	Why I chose a CI	2.1 My hearing aid
		2.2 Knowledge and expectations
		2.3 Individual choice
3	Life changing	3.1 Emotional time
		3.2 Training the brain
		3.3 Negative aspects of the CI
4	Taking this journey	

6.3.5.1 Theme 1: Deaf community

The Deaf community and CIs appear to have a complex history, which has developed since CIs where first available. Within the data there was discussion using the term oralist/oralism. This term meant using spoken language to communicate rather than sign language. The introduction of CIs resulted in children, who would have been raised using sign language, now having access to sound to allow them to be raised to communicate using spoken language. This could result in "*eradication of a minority group*" (Document 32). This could also be seen as correcting for deafness or viewing deafness as a disability. This conflicts with the Deaf community which sees deafness as a culture rather than a disability, with cochlear implants being viewed as affecting the "*preservation of… culture*" Document 15.

The main issue was with the implantation of children and babies with reports of "*struggling with the ide*a" Kate (Document 14). This was as someone who was implanted with a CI were more likely to be brought up with spoken language rather than becoming a signer and part of the Deaf community. There was a lack of understanding between the deaf and the hearing communities, with one person feeling implants were unnecessary and the other feeling not providing implants would be "*abuse*" (Document 20). There appeared to be a necessity to provide choice, and having a CI was seen as removing that choice as they would not then learn sign language and the child would be taught spoken language. This was viewed negatively and as a danger to, and a loss, of "*Deaf culture*" Document 15. There was also the comment about "*fixing*" or "*curing*" deafness when the Deaf community did not feel it was something that needed changing (Documents 20/21/29/32). They wanted a decision regarding an implant to wait until the child was able to

choose which culture they wished to join. This allowed the individual to make a choice rather than their parents making the decision for them.

For adults, CIs were also seen as "*betraying*" their culture, posing a risk of being "*shunned*" for having a CI, or being concerned that having a CI would affect their "*love*" of their culture (Document 15/16/20). There was less of an issue for adults to be implanted as they were making the choice for themselves.

Things do appear to have started to change with reports of more Deaf students at education institutions that were previously against cochlear implantation. Members of the Deaf community indicated that CIs were becoming more accepted "*as part of Deaf culture*" Thomas (Document 1) and Document 19. More Deaf adults were choosing to get implants after seeing their friends get implanted first; they saw the benefits they received from the CI and then decided themselves to be implanted. These adults were making decisions based on the experiences and outcomes of their peers.

It was acknowledged that even though they have a cochlear implant, they were not hearing and were a minority group in a hearing world.

Sub-theme 1.1 Hearing world

The documents show that the contributors reported they were different from people who were born with hearing.

The contributors shared that hearing people had a lack of knowledge about the Deaf community or even its existence. This could result in a lack of Deaf awareness or even acknowledgement that they were a minority group and that they have faced discrimination in the workplace, from healthcare professionals and from people within their social networks.

"I was…discriminated against" Jon Document 9

"People… are not… deaf aware" Document 19

Contributors mentioned the benefits that hearing people have with regards to hearing. Adults who have heard since they were children were able to tune out some sounds and hear better in background noise. They reported that these adults could ignore some sounds while they cannot, and hearing adults could pursue any career while Deaf adults were restricted by their hearing loss. For example, a job mainly using the telephone was something a Deaf adult who signs would find very difficult if not impossible. This was because hearing using a telephone involves no lip-reading which makes this a difficult listening environment. Contributors wanted to be as good as any

hearing person or be the same as everyone else.

''I thought I could do anything… some things you couldn't do" Emma Document 14

These adults realised that having a CI did not change them, they were still deaf. In the next theme, contributors indicated that they had different reasons why they chose to consider cochlear implantation, their hearing aids and what they hoped to gain from an implant.

6.3.5.2 Theme 2: Why I chose a CI

The contributors discussed what made them choose a CI and they ranged from a drop-in hearing, experiencing tinnitus, having nothing to lose and struggling with conversations. For example.

"I would just like to chill out and…enjoy the conversation" Lauren, Document 10.

Others wanted to improve their communication skills in social and work situations, with communication becoming a "*barrier*" Vicky (Document 4) and a "*chore*" Lauren (Document 10).

"I watched people withdrawing from me" Vicky (Document 4*).*

Frances, Rebecca, and Emma all reported having '*nothing to lose'* which shows that their hearing gave them so little that they did not feel it was a huge risk for them; with nothing to lose if the CI did not work, they were in the same position as they were before. It appeared that when CIs were first mentioned to some individuals there was some uncertainty about the suggestion but after thinking about it, they felt more comfortable being referred for assessment. The person who mentioned the CI gave them the opportunity to think about it more seriously than they had before.

"I was upset with his suggestion" Katie (Document 14*)*

"I was very against this decision but, over time, I changed my mind" Phyllis (Document 6)

There was the mention of situations that changed their minds about have a CI. This related to a situation where they were unable to hear a loved one or realising that their hearing levels had dropped so their hearing aids were no longer beneficial. For example:

"*He had been shouting [at] me… I had not heard*" Phyllis (Document 6)

"*But then as I got older it would deteriorate for a little bit… and then deteriorate again*" Catherine (Document 7)

There was also hope that they would do better with the cochlear implant. This may have been through hearing more environmental sounds or by helping with their communication. It was now

the right time for them to do something about it.

"Could see the benefits it would bring" Evelyn (Document 4)

"*do something about it*" Catherine (Document 7)

There was also the potential of what the implant could give them in comparison to their current hearing aids.

Sub-theme 2.1: My hearing aid

There was mention of not getting much from their HAs and how they struggled with their hearing aids before getting a CI. There was a variety of reports about HAs, with some contributors finding that their HAs were not helpful. They may never have given them much benefit or their hearing could have deteriorated to the point where they were now providing limited benefit. For instance:

"didn't help that much" Evelyn (document 4)

"I was unable to understand speech" Tom (document 15)

Conversely, others reported that they did get some benefit from them.

"*I could tell the difference between people talking or people laughing but I was unable to distinguish the individual words that were being spoken" Catherine (Document 6).*

Although the benefit they received from hearing aids varied between contributors, there appeared to be a consensus that the hearing aid was not providing a lot of benefit which led to the consideration of a CI. This led to the developing expectations of what a CI would bring.

Sub-theme 2.2: Knowledge and expectations of a CI

The documents in this sub-theme were more varied than the previous sub-theme as they included documents that were more fact based than contributors' first hand reports of cochlear implantation.

From the data, the outcomes were described as to "*obtain some benefit*" from an implant (Document 13). The view was that adults born with hearing did not have the same outcomes as adults "*who were profoundly deaf all their lives"* (Document 15) and that these adults "*benefit less*" (Document 27) than adults whose hearing loss developed later in life. Some contributors said that a CI for someone born deaf was "*challenging*" (Document 25). This may be why contributors were clear that it was important to keep their expectations low to avoid disappointment.

They described their hopes of a CI as "*opening up a new world of hearing*" (Document 33) and

being "*better access to sound than… hearing aids*" (Document 34).

Patients described their expectations as "*realistic"* (Document 6), *"very low*" (Document 14) and "*not... high*" (Document 8), with others were clear that CIs were not "*magic*" (Document 25) and it is not like you "*flip a switch" (Document 15).* The importance of realising this was due to some patients "*ending up disappointed*" Phyllis (Document 6).

The documents suggested that patients and clinicians were unclear what benefit they would gain from an implant. An audiologist reportedly told one patient they "*end up with no improvement... I might be able to hear*…" Alice (Document 19). Or that the CI would give a "*sensation of sound*" (Document 24) or be "*very different*" Frances (Document 9) to what they had experienced before.

While contributors hoped they would gain from an implant:

"*less frustration… understand people while lipreading*" Bethany (Document 14)

"*understand much more*" Connor (Document 9).

The data did not give clear information on what early deafened adults would gain from an implant, but indicated that outcomes with an implant were somewhat unknown, with potential for variation between patients.

Candidates then considered the potential negatives of an implant including the risk of facial nerve damage, worsening balance/tinnitus, along with the risks associated with any surgery (summary of risks from Documents 13/11/19/27). The decision to have an implant was made after the candidates had contemplated all the risks, along with the uncertain outcomes but with the hope to gain more than what they do now. This then makes the decision to have a CI very individual.

Sub-theme 2.3 Individual choice

Throughout the documents, the message that having a CI for early deafened adults was presented as a personal decision and there was no right or wrong choice. This was portrayed in the use of terms such as "*respect every… decision*" (Document 15) and not to "*judge*" (Document 19) other people's decisions. This language indicates that there were some people who disagreed with the individual's decision. This can also lead to a need for candidates to "*defend"* (Document 15) their decisions to other members of the community who were against CIs, which was unnecessary when the choice was individual.

Cochlear implants were not the "*default option*" for everyone (Document 19). It appeared that there were two separate groups, one who found the CI changed their lives while the others found CIs were not an option they wished to consider as they were "*happy as they are*" Alice (Document

19) and their hearing loss was described as "*just who I was*" Stephanie (Document 30).

Other documents described how implants were not a "*cure*" for deafness (Document 8/15) and that they would be deaf for the "*rest of my life*" Jack (Document 12). There was acknowledgement that when the implants were then switched off, they were still deaf. Having an implant would not change who they were.

The data showed that some people gain great benefit from their implants while others shared that an implant was not the right choice for them. The documents were clear that the decision for an implant was a personal one and no one should be made to feel the decision was the wrong one for them, with it being clear that a CI was "*not the only way*" (Document 20).

6.3.5.3 Theme 3: Life changing

There were two different groups of adults describing their experiences. One who have never had any hearing and the other who had lost some of their residual hearing through the course of their life. Although these adults may have a different hearing history, they were both still classed as early deafened adults. The experiences of these two groups were likely to be different as the adults who have lost some of their residual hearing would have access to more sound throughout their life. For this analysis they have been included together as it was impossible to gain a full assessment of their hearing history from the information provided. Some of these adults recognised that they were hearing sounds for the first time "*hearing at last*" (Thomas document 1), while others reported they had been given their "*life back*" (Document 4) or *"feel like me again*" (Document 10). In this case, CI was the "*right decision*" (Document 12) and had changed their lives for the better, saying it was the "*best thing I've ever done*" (Document 8).

In the main, contributors reported that the experience of an implant was a "*roller-coaster ride*" (Document 15) and it changed their lives. This was related to "*confidence*", "*independence", "control", "safer", "connected"* hearing speech, and hearing things they had not heard in "*many years*", hearing on the telephone, improved lipreading, hearing music and hearing environmental sounds such as "*birds twittering",* and *"traffic*" (document 8/9/12/14/16/30)

The terms control, confidence, safer, connected and independence show how much these adults received from their implants, and that it was more than an improvement in hearing. It was suggested that these adults were relying on others more as a result of their hearing loss. After their CI, these adults were able to take this independence back. It showed how much more they gained from an implant. This was indicated by how they described the implant, using terms such as the "*best thing*" (Document 8/10/14), "*changed my life*" (Document 8/14)*, "Empowering*" (Document 14), "*Life back*" (Document 4) and "*without it… I am lost*" (Document 9). The language

used to describe their implants was highly emotive and showed the emotional connection they had to their implants and what impact the implants had had on their lives. The language used to depict the implant was also similar with changing life/life back and best thing mentioned in three of the documents with the way it was described being practically identical.

Some had the realisation that they were hearing better through an experience they had, for example being in an environment where they could hear much better and wondering if something had changed in that setting rather than they could hear better. Some discussed finding socialising with friends easier or recognising their name when called, while others commented that their test results had improved so that gave them reassurance they were doing well. The overall benefits that were described of having a CI were speech understanding, improvements in quality of life, awareness of environmental sounds and improvement in career opportunities (Document 33/13/15/27).

Sub-theme 3.1 Emotional time at switch on

Most of the patients talked about switch on, the first time their CI was activated, what they heard and how they felt on the day. The variety of what they experienced was evident. The emotion, stress and relief from the day was also clear. There was a risk that it might not be what they thought it would be like, they might not be happy with the sound and it could have not worked for them.

What they heard at switch on was described as "*weird", "crazy", "confusing", "emotional", "amazing", "overwhelming", "disappointing", "strange", "unreal", "awful", "exhausting"* and *"painful*". (Document 1/4/6/7/9/10/12/14/30). This shows the differences between experiences with some saying the experience was amazing but others awful. It was quite a contrast. It demonstrates how variable the initial switch on appointment was.

Seven of the 15 Documents in the sub-theme used the term "*emotional*". The CI switch on had a profound effect on these individuals. The term 'emotional' did not indicate if it was a positive or negative experience which may have explained why it was used by so many individuals. The experience being emotional was not surprising since they have been through an elective procedure for the hope of something better. Switch on they saw as a point where they found out if what they had been through was worth it and if what they hoped for was going to come through. What was heard at switch on was variable from hearing voices to hearing nothing, which could explain why the word emotional was so commonly used.

Those that did hear sounds at switch on explained that all the sounds they heard were the same pitch, with high frequency sounds being uncomfortable. Examples of these were the clipping of

heels and "S" sounds. They reported that voices sounded strange, electronic, and unclear (Document 1/5/9/31).

The contributors reported that the CIs were not perfect, and, in some cases, they reported they heard better with their hearing aids. The CIs were not picking up the nuances in speech that they felt their hearing aids did (Document 1). The implant was also limited as it has a small number of electrodes, so it was never going to be as good as normal hearing (Document 1 and 22). In some cases, the users had a negative relationship with the implant and rejected it or were keen to go back to their hearing aids (Document 1/9/20).

This showed that not all experiences of CIs were positive. However, in the documents reviewed, this was not the overriding view of CIs.

Switch on was the first step in the CI journey; after switch on the brain adjusted and acclimatised to the new sounds, which could involve training.

Sub-theme 3.2 Training the brain

The period after switch on was described as a time to adjust to the new sounds and performing exercises to help their brain adjust to this. They recognised that what they heard, or did not hear at switch on, was just the starting point and further work was required with their implants.

There was discussion around the need for *"practice", "training", "hard work", "push… myself", "let it come", "training for a marathon"* and a *"period of adjustment"* (Document 1/6/11/12/14/15/19/20). Most of the terms used showed that the patients were aware that getting used to the CI would take some time and they needed to contribute to the process to make the CI work for them.

The type of training they did ranged from *"exercises", "audiobooks*", telephone training, "*auditory training programme", "practise apps"* (Document 8/9/12/14/18). This showed the range of options but some of these were vague. What was meant by an auditory training programme? This could have varied considerably between contributors.

They acknowledged a need to complete training and the results they saw varied from not "*achieving anything*" (Jack Document 12) to sounds becoming *"natural", "meaningful*" (Document 13). Five of the documents mentioned how this process takes "*time*" or they needed to have "*patience*" with the whole process (Document 1/6/11/12/26).

Most of the documents contain very positive views on a CI, with users being very happy with their outcomes. There were a few negative views of the CI experience shared.

6.3.5.4 Theme 4: "Taking this journey"

The patient stories showed support from clinicians, family, friends, and national and regional support groups. The support could be pre or post implant with the support from family throughout their lives. Examples of this were relatives ensuring that their children were aided and supported with language development, with parents described as needing to "*advocate*" or ensure "*appropriate intervention*" (Charlotte and Bethany (Document 14)). They explained that family members did all the training with them and any tasks given by clinicians were done with family support.

Family and friends go on to provide support through the CI process. Family and friends were described as "*taking this journey*" with them (Phyllis (Document 6)). They helped with the rehab, through being involved in doing the exercises with them and providing emotional support through the whole process. They were described as being there when they "*couldn't manage everything*" (Jack (Document 12)) and always being supportive. This support could be exploring sounds with them to emotional support through the CI journey.

Clinician's support differs to that of family and friends with mainly providing reassurance, rehabilitation, and information as part of the CI process. Information provided was mentioned as mainly regarding their expectation's pre-implant and ensuring they could access all the information, while rehabilitation was to help with their adjustment to the CI, providing "i*ntensive*" rehabilitation or documents to aid this.

6.3.5.5 Summary

The four main themes looked at different aspects of the CI experience and other areas that were relevant for adults born with a hearing loss. The themes discussed the reasons why they chose an implant, with the hope for more access to sound, to the potential impact of their choice on their community being explored. The community views appear to have changed over time. It also showed the support that these contributors received from their communities, family, and clinicians and how they guided them through the whole process. The benefits of a CI were explored and what it was like having a CI was shared. Many of the views shared were very positive. In my view reading these web pages or literature would give a candidate a very positive view of a CI and would encourage patients, or families to encourage family members, to seek a referral for assessment. The Phase 3a study has focused on information found from internet searching and written information. The Phase 3b study changes this focus to be asking participants about their experiences.

6.4 Phase 3b

Phase 3a considered the written materials available regarding hopes and experiences. This Phase of the study investigates the hopes and experiences of early deafened adults through interviewing CI recipients and their family members. It considered their pre and post-implant test results in relation to their experiences. This was a different focus and allowed data related to the research question to be examined.

This section presents which participants were recruited, how recruitment materials were made accessible for BSL users, data collection methods and analysis of the results. This Phase took place during the Covid 19 pandemic and how this affected the study's data collection is discussed throughout chapter 6.

6.4.1 Methods

This study investigated the experiences and hopes of early deafened adults and their families. This was designed as a study which used quantitative data to support the qualitative data. Data were collected using semi structured interviews and results were analysed using thematic analysis and a comparison of pre- and post-implant test results to support the information shared by participants.

6.4.1.1 Study design

6.4.1.1.1 Ethics

Ethical approval was obtained from the University of Southampton Ethics committee (ERGO52273) and from NHS Research Ethics Service (NRES) using their Integrated Research Application system (IRAS) (NRES; IRAS271439). The research proposal and IRAS form are in Appendix CC and Appendix DD. Four amendments to the proposal were submitted. These were three non-substantial and one substantial amendment submitted to IRAS (Appendix EE). The substantial amendment involved the approval of easy read Consent forms. Non substantial amendments were related to changes to PIS regarding an option of the interviews being performed remotely and the tools used to facilitate this. The reasons for the amendments were discussed within section 6.4.1.3. Personal information relating to participants was kept on University password protected computers. Participants were assigned a pseudonym, and this was stored in a separate file. Data relating to pre- and post-implant data were accessed through a review of participants' files or through the patient database. Interview data were fully

anonymised before analysis. No consent was obtained to collect data relating to ethnicity, specific age of onset, CI manufacturer or cause of deafness.

6.4.1.1.2 Sample

To identify an appropriate sample required the term 'early deafened adult' to be explored and defined for the context of this study. The literature varied in what it described as a pre-lingually deafened adult (See section 1.3). This research referred to these adults as early deafened and used an onset of deafness of under six years of age. This age of onset was used as their deafness was diagnosed during language acquisition as had been the case previously within the literature (Chee et al., 2004, Heywood et al., 2016). With the NHSP being introduced in England and Wales in 2006 (Wood, 2015), anyone born before may not have been screened at birth and therefore date of deafness was difficult to determine. Date of diagnosis was often referred to as this date of deafness in these cases. This introduced variability within the study as the actual date of diagnosis cannot be determined. Babies born in 2006 would be approximately 14 years of age at the time of the study and so would not meet the participant requirements of being 18 years and older. This was why age of onset could not be from birth. Having a date of deafness as birth would have reduced the participant pool significantly and may have prevented participants being recruited. This study used an onset of deafness of less than six years as this has been used in previous studies (Chee et al., 2004, Heywood et al., 2016). The full inclusion criteria for early deafened adults are now described.

The sample size was outlined from a case study perspective (see Chapter 3). The aim was to recruit six early deafened adults and their families. The sample size was reassessed during the study after the changes had been made to decide whether the sample size should be increased if, during the study, it was considered that saturation had not been reached. It was determined that this was not necessary and was discussed in 6.4.1.8.

6.4.1.1.3 Inclusion and exclusion criteria for early deafened adults

Inclusion criteria for CI candidates

The inclusion criteria are shown in Table 20.

Table 20 Inclusion criteria for early deafened adults

Inclusion criteria	Justification
Adult identified with a hearing loss from birth to <6 years of age	Identified at birth was not used as an inclusion criterion due to NHSP only being introduced in 2006. This age range was used to capture adults born with a hearing loss who were not identified at birth. This does mean that some adults included may have an acquired hearing loss before the age of six years. This range was used in previous studies (Chee et al., 2004, Heywood et al., 2016).
Implanted within the last 1-5 years	This was to try and gain as much recent information as possible from the participants about the CI process and ensure there was access to a suitable number of potential participants.
All participants must be able to give informed consent to be included in the study	As participants were discussing a significant medical intervention, details of which would be published, it was important they could understand the implications of this and so consent to it.

If desired, early deafened adult participants could have identified up to two family members to be involved in the study, who must be over 18 years of age. Participants were not excluded from the study if they did not wish to identify family members to participate. This was to ensure the focus stayed on the early deafened adult participants.

Exclusion criteria for CI candidates

Any adults who could not communicate in BSL or spoken English or required the PIS and consent forms in languages other in BSL or English were excluded from the study.

6.4.1.1.4 Inclusion and exclusion criteria for family members

There were no restrictions defining what a family member was. This could have resulted in adults with a range of relationships to the early deafened adult being nominated, which would have provided a diverse range of views. Family members of CI candidates/ recipients were over 18

years of age and able to give informed consent. If the family members were not UK based, they were still included in the study.

The inclusion criteria for family members are shown in Table 21. Any adults who could not communicate in BSL or spoken English or required the PIS and consent forms in languages other in BSL or English were excluded from the study.

Table 21 Inclusion criteria for family members

Inclusion criteria	Justification
Nominated by a CI candidate/recipient who met the inclusion criteria above	This was as this study was going to be carried out in a case study format. It ensured that they were considered as family by the CI recipient and the CI participants then gave access to the participants which may have been more difficult if they had not nominated them.
Aged over 18 years	This was to ensure no children were included in the study as this brings in other considerations which were not within the scope of this study.
Able to give informed consent	As participants were discussing a significant experience, details of which would be published, it was important they could understand the implications of this and so could consent to it.

6.4.1.1.5 Participants

Five CI users were recruited (three women and two men) and two family members (one man and one woman). The family members were all nominated by their CI user family member.

6.4.1.2 Recruitment

The development of the recruitment materials, the effects of the Covid 19 pandemic and the methods used to recruit participants are now explored.

6.4.1.2.1 Development of recruitment materials

This section describes the development of the recruitment materials used in the study. For the study to be accessible the presentation of these materials needed to be considered.

6.4.1.2.1.1 PIS

The PIS were designed to be clear and easy to read. The University stated that a data protection section needed to go on the bottom of all PIS. This section I felt could not be removed or changed into an easy read format as it was required by the University, who was the study sponsor. This section could not be described as easy to read and the language was complex. For example, language such as “highest standards of research integrity” and “lawful basis” could require further elaboration and explanation which I had no control over. Changing this section would have involved working with the University and informing them of the easy read format requirements and how to ensure that the information they required to be presented was given in a simpler way. This was not within the realms of this study due to the time constraints and regulatory requirements of this section.

6.4.1.2.1.2 Consent forms

The consent forms were developed based on examples provided by the University and from previous studies that I had undertaken. After working with the interpreter to translate this into BSL it was identified that the consent form was not user friendly. For example, the use of language such as “data”, “anonymous” and “transcriptions” were words which were not used in BSL and the interpreter thought that the language was not appropriate and potentially made the form inaccessible even with a BSL version. From this, an easy read version was developed with the BSL interpreter who felt that interpreting this version into BSL would be appropriate and relevant. Before this was submitted to ERGO and IRAS this was sent to the participant who was involved in the Phase 2 PPIE for feedback to ensure this was accessible to BSL users. These easy read consent forms required a substantial amendment to the study. Although this delayed recruitment, this was necessary, and it would have been inappropriate to start recruitment without this step. Not doing this would have made this study potentially inaccessible which was not acceptable for this study. The new consent forms were then approved by ERGO and IRAS.

There was also an error identified on the consent form which had been approved by ERGO; a section for permission to use hearing and speech data had been left off in error, and this was included in the same amendment as the easy read consent forms (See Appendix AA and Appendix BB for the consent forms).

6.4.1.2.1.3 Video development

The BSL videos of the PIS and consent forms were developed with a BSL interpreter; the videos were recorded on a mobile phone in .Mov format (Multimedia format used on iPhones) and, in editing, the sound was removed. As part of this process, the videos were converted to an mp4 format. The video recording session involved coordination of a specific room and the availability of myself and the interpreter. This was difficult to coordinate with clinic bookings and staff availability. There was one booking where the interpreter, due to work commitments, was unable to make this session and this was rearranged. The room chosen had a space which was clear and with a white background which was the best place to allow the signing to be seen clearly. A busy background would have detracted from the signing. The interpreter wore similar clothes on all recording days to ensure some continuity.

The sound was removed from all videos as they were recorded in a clinic room which was next door to other clinic rooms. On one of the recording days there was a session going on in the other room, so, to ensure no sound was picked up from that room, sound was removed from all the audio recordings. This was done using iMovie software.

Filming took place on three days in two-hour sessions; these were each spaced approximately a week apart due to difficulties in booking all necessary parties. The videos were then edited to remove any sections for which the interpreter needed clarification. The whole section was not re-filmed, only part of the section for the reason of time.

Some of the videos were recorded in small sections; these sections were then added together to ensure that under each heading one video was present rather than numerous videos. This involved identifying which software would be appropriate and using editing material which was unfamiliar.

The videos were checked by the BSL interpreter before being sent to the PPIE participant.

6.4.1.2.1.3.1 Distribution of the videos

How to distribute the videos was then considered. The PPIE feedback identified that having the video link on the consent form would enable the participant to look at the video if they needed further clarification or help understanding the written format. As every BSL user was different this allowed greater accessibility. A full length BSL video of the PIS and consent form were deemed not to be appropriate because of this work. To ensure the written information was still present, sending a document with the written PIS on and the link to the corresponding BSL video was

considered most effective. The videos were uploaded to a Google account and a link included on the PIS and consent forms so participants could link to this.

The videos could only be uploaded once they had been approved and the links could only be developed after this occurred. This then required further approval. At first, this was thought to require a substantial amendment but after further discussions IRAS agreed that this would be a non-substantial amendment. This took two weeks from first queries of the amendment type to amendment approval.

6.4.1.2.2 Reflections on development of recruitment materials

The recruitment materials required adjustments which delayed recruitment. The reasons for these amendments were reflected upon. To ensure all the documents were at a suitable language level, the BSL interpreter reviewed and then translated them into BSL. When the interpreter reviewed the consent forms, they identified that the language level used was too high to be accessible to BSL users and they required adjustment. The need for further development of the consent forms highlighted that, in the drive to get ethical approval, the need for accessibility had been lost sight of. In the reflective diary I wrote "*the accessibility of the documents had not been kept at the forefront of the study*"; this was addressed by further PPIE being carried out. I questioned why this focus on accessibility had been lost. Upon reflection, I felt it was due to the concerns with regards to obtaining REC approval. This was expected to be a difficult process and I had concerns about getting approval, how long approval would take, would approval be gained and if this Phase of the study would be completed. The actual process for this study was not entirely straightforward, but once the documentation was submitted, approval was obtained fairly quickly and the corrections required minor. The delays that were generated were caused by losing sight of one of the important aims of the study. Being in regular contact with the ethics review board really helped this study. It allowed me to understand the processes rather than misreading or misunderstanding the information on the website, due to my inexperience in applying to REC.

Video development was challenging and time consuming. The videos took a long time to film due to the number of takes required and availability of staff and appropriate clinic rooms. The videos were filmed in sections to aid this process but the number of clips for one form was still larger. For example, the consent form (Appendix BB) contained eleven separate clips. The editing process also took time particularly as it was unfamiliar. It highlighted an important aspect; although this study was my priority, it was less of a priority for individuals involved in helping with the filming. This was completely understandable as this study (at that time) had been a part of my life for almost five years, and I stood to gain something from completing this research. For someone else

playing a minor part, they may have had little or nothing to gain from this, so their other commitments were of a higher priority. I reflected upon how to share ownership of the study and how to ensure this was a priority for the other parties involved in the successful delivery of the study, but this was not possible with this being my PhD work. Future research needs to consider this as it will aid in the development and delivery.

Working with staff members at USAIS increased the study's relevance but it also made some situations challenging. Being both a clinician and a PhD student meant I had a dual role of working with staff as a clinician and as a PhD student. Difficulties working in one setting can carry over into the next. Further, some of the difficulties I am unable to discuss within the final thesis due to a need to protect the confidentiality of staff and maintain our working relationships.

6.4.1.2.3 Coronavirus pandemic effects on Phase 3b

Although ethical approval was obtained to start recruitment on 2nd February 2020, recruitment did not commence on this date. This was as the study materials needed development due to issues with accessibility as discussed in 6.4.1.3.4. The process would have resulted in adults who did not use BSL being recruited and adults who did being excluded. This was not deemed appropriate or within the aims of the study.

The recruitment process started around the same time as Covid 19 was starting to become an issue in the UK. On the 20th March 2020, all routine operations were cancelled at UK hospitals. This included all adult CI surgeries. On the 23rd March, the government ordered a UK wide lockdown to prevent the spread of Covid 19. All but essential travel was restricted, gatherings of more than two people were banned, and social distancing was applied. The application of these measures to slow the spread of the virus resulted in families and friends who were in different households being separated. USAIS effectively ran a skeleton staff to answer queries, all other work was done from home, and no patients were seen in clinic.

Recruitment was suspended due to the virus and the resulting cancelations in surgeries and appointments. This was as any interviews had the potential to require a BSL interpreter present. Doing this using an online platform was considered, as interviewing participants by Skype was already an option, but this would require a three-way phone call with staff at home. It would also have prevented patients who did want a face-to-face interview participating; these patients are a group who are likely to rely significantly on one-to-one interaction. During the PhD I tried to ensure accessibility was at the forefront of it. Not having the interview options had the potential to exclude some participants. After eight weeks of lockdown with no change to the government's requirements and social distancing rules on the horizon, further consideration was made

regarding this study. It was decided that if the issue around how to perform the interviews was resolved, it would be appropriate to recruit participants. (See Table 22 for the options considered). It was decided that recruitment should begin with the option of a remote interview and, if a face-to-face interview was requested, they were informed that this may not be possible depending on restrictions at the time and their interview would be delayed. It was not known, at the time, when and if restrictions would be relaxed and if this would be within the time frame of the study. Table 22 was produced after consulting with a BSL interpreter who had been working with patients remotely over the lockdown period based on their experiences of using the different types of technology as at May 2020.

Table 22 Considerations to allow the interview data collection to commence

Option	Positive	Negative	Decision on use
Option of the interviews being in a written format	Allowed the study to continue during Covid 19. Gives participants the opportunity to respond when they wish. May restrict follow up questions.	Language levels have been shown to be lower.	No. This would compromise the data collected due to the language level and I may not be clear on what was mentioned. This method allowed no clarification with the participant.
Skype calls with just the interpreter on video, the researcher on another line- audio only	Allowed the study to continue. This would allow me to respond to what the participant said and allows the interpreter/interviewer relationship to continue. Allows the interviewer to respond to what was said.	Set up would be challenging. Recording of the call would need to be planned. Potential issues with internet signal? Interviewer not seen.	No. The interviewer not seen. Could be seen that the interpreter was the interviewer and therefore not appropriate.
Interpreter as the interviewer	Would allow the interview to flow and would avoid any changes in language/meaning due to the interpretation. Interpreter would be responding to the questions.	Would change the role of the interpreter from interpreter to research assistant. Would involve training. Would be the interpreter responding to the Q rather than the researcher. May affect the data collected.	No. The Interpreter felt that this would change their role, and would not be appropriate.

Option	Positive	Negative	Decision on use
Using MS Teams for the interviews	Would allow both myself and the interpreter to be on the screen.	Not all users are familiar with use. Requires some knowledge of the technology. Teams favours the person talking, so can remove the interpreter from the screen.	No. Not suitable as the interpreter needed to be always seen. If the interpreter was not speaking, they were not in the picture.
Record the Q and then ask participants to respond either live with the interpreter or record their answers	Allow the study to continue. All participants would be asked the same Q.	No follow up questions, more like a survey than an interview.	No. Would hinder data collection and the data collected would not be as rich. Would turn an open interview into a survey.
Use Zoom for the interviews	Clearest, precise way can see everyone. Every picture the similar size. No contact info rather than email, no further personal information shared.	Security issues. Does involve some IT knowledge.	Yes, this was the only method that allowed the confidentiality of staff to be protected and both myself and the interpreter to be on the same screen
Use Facetime for the interviews	Allows both myself and interviewer to be on the screen at the same time.	Confidentiality as using personal Facebook profiles. Needed to be an Apple phone. Looks like you were online and personal messages could come through.	There was no current option of having 2 University phones. Issues with confidentiality on personal accounts.
Use WhatsApp video call for the interviews	Good in terms of view as the interpreter was always seen.	Confidentiality as using personal WhatApp accounts. Pictures of participants were different sizes. Mobile screen smaller. It looks like you are online and personal messages can come through.	There was no current option of having 2 University phones. Issues with confidentiality on personal accounts.

After reviewing the options available, Zoom video calls were the most effective option to allow recruitment to commence. There were some concerns regarding security, but the University had provided guidelines for staff using Zoom if necessary and these were followed (University of Southampton Internal communication 01.04.2020). They were:

- Change screensharing to “Host Only”
- Disable “Join Before Host” so people can’t cause trouble
- Disable “File Transfer” so there’s no digital virus sharing.
- Disable “Allow Removed Participants to re-join” so ejected attendees can’t slip back in.

This resulted in the PIS being updated and new videos being filmed. Filming of these videos was required to be completed before recruitment could commence (The decision to use remote interviewing was reflected upon in Figure 13).

Figure 15 Reflection on remote interviewing

After adjusting to changing the documents, I did question why I had not considered remote interviewing before. It had the potential to make the study more accessible as participants have more choice about when and where they are interviewed. I felt this was not the norm and that I may have missed information when doing a qualitative interview.

The new PIS was ready to be videoed at the same time as USAIS introduced a new IT system and the clinic was reopened to see patients, effectively making the interpreter unavailable to film the videos. When they were available the interpreter then damaged their hand meaning they were unable to film the videos as they were not able to make the appropriate handshapes for the signs correctly. From obtaining approval to filming took twelve weeks. Once they were filmed and links added to the PIS recruitment commenced (See Appendix FF and Appendix GG, the standard PIS was kept and used if the patient did not require easy read or BSL (Appendix HH and Appendix II).

After starting recruitment one of the participants requested to use Skype rather than Zoom for the calls as they were more familiar with this. The reason Zoom had been chosen was that it was more suitable when working with an interpreter. This participant did not require an interpreter and so the method of video call was not an issue. The PIS for adults who did not require a BSL interpreter was updated to show this, and an amendment submitted (The reasons for only one group being considered were reflected upon (Figure 14)).

Figure 16 Reflection on why only one group was considered

Up to this point the study materials were considered from the perspective of the participants being BSL users and all the adjustments for remote interviewing were considered from this perspective. This was potentially unusual in research in general but did result in losing sight of the accessibility of the study by only considering one group. In hindsight, I should have allowed all the options for remote video calling and allowed the participants to decide (whilst informing them of the potential security issues).

The Covid 19 pandemic caused a pause in recruitment; once it was realised that social distancing would need to be maintained for the foreseeable future options on how to continue the study were considered. The study was changed to allow the interviews to be performed remotely by video call and participants who were implanted were the only group recruited. This resulted in recruitment through digital mediums, to minimise patient contact. The Covid 19 pandemic resulted in changes to the study which required ethical approval as these were remote interviews and there was a need to include Skype as another method of remote interviewing. These changes were each approved within a week. The adjustments to the study took longer to implement due to the issues of recording the BSL videos.

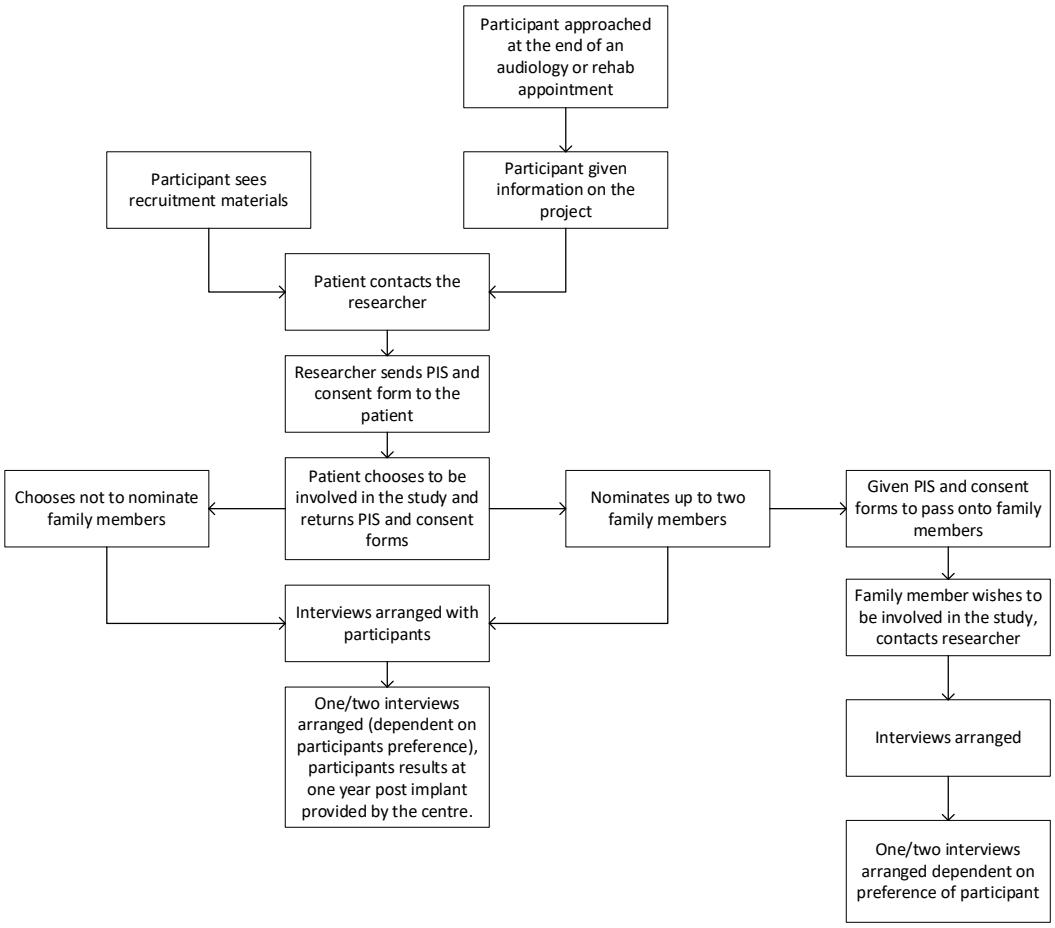
6.4.1.2.4 Recruitment

The recruitment methods used within the study were varied from Phase 2, as difficulties were experienced in recruiting a BSL user for the PPIE. Using a range of approaches ensured as many potential participants as possible were reached (For a summary see Figure 15). All the CI users recruited were patients at University of Southampton Auditory Implant Service (USAIS). No attempt was made to recruit CI users from other CI centres.

The following methods were applied.

1) Through USAIS
    - While in clinic during routine annual reviews. Patients were approached by clinicians in their appointments (Clinicians refers to Audiologists and Rehabilitationists). Clinicians were advised to use language “Have you heard about this study, if you would like to be involved here are the details of who to contact” and they were directed to online videos (See Appendix JJ for screen shots of the video).
    - Advert/video on the USAIS website, Facebook page and twitter feed (Appendix JJ)
    - Poster’s advertising in the USAIS reception (Appendix KK)
2) Through participants recruited to the study
    - CI recipients provided information on the family members who they wished to take part
    - CI recipients may have informed other CI recipients about the study (word of mouth)
3) The Southern counties cochlear Implant group (SOCO; this was a patient group mainly consisting of CI users and their families who are patients at USAIS)
    - Advert/video on the SOCO group Facebook page (Appendix JJ)

Figure 17 Recruitment methods



There was a reduced number of clinic appointments and it was likely that most participants were not approached during a clinic appointment.

After a new database installation at USAIS identifying potential participants became more challenging. A report on congenital deafness identified one patient within the service, information that was known to be incorrect. To identify participants involved hand searching the database.

6.4.1.2.4.1 Participants

Potential participants included all who made contact through email and were happy to be contacted in this manner. All the participants used spoken language as their main mode of communication and did not require easy read format or a BSL interpreter. Five CI recipients and two family members were recruited over a period of two months. It took over four months to complete all the interviews. The interviews for five of the participants were completed in the six weeks due to scheduling around my work commitments. The remaining interviews took longer to complete due to issues around the recordings; this resulted in rescheduling the interviews and then arranging for the participant to attend USAIS for the interview to take place in person. This

interview took place after the second lockdown at the patients request, which extended the time taken to complete the interviews. One participant indicated their family member would be interested in being involved but then did not make contact. This was intended to be followed up in January, but due to the national lockdown, it was deemed inappropriate to contact this potential participant at the time. Two family members were recruited, and with the change from a case study to a general qualitative methodology these interviews were analysed with the CI user interviews. This decision was made due to the limited family members recruited. The participants' pseudonyms and whether they were CI users or family members is shown in Table 23.

Participants were emailed the consent form and PIS and they either returned the signed consent form by post or by email. An interview was only arranged after the consent form was returned.

Consideration was given to extending the recruitment to gain more CI users but, due to the data from the participants being similar, a decision was made that saturation had been reached for participants who used spoken language.

Table 23 Participant pseudonyms

CI user	Claire	David	Emma	Nicola	Richard
Family member	Mark	--	--	--	Lisa

6.4.1.2.4.2 Recruiting a BSL user

As all the participants recruited used spoken language, extending recruitment was considered with the aim to recruit a BSL user as this would have resulted in additional depth to the study. Although this would have added another perspective it was decided not to extend recruitment. All documents were available in BSL and a variety of methods had been used to contact these CI users. These users may have been recruited more effectively if approached by staff at USAIS during their clinic appointments. Attempts to recruit a BSL user were limited by the current clinic

Figure 18 Reflection on why a BSL user was not recruited

Throughout the study how to make the research accessible to BSL users was considered but resulted in no participants being recruited. Could more have been done? The effects on appointments at the recruiting centre likely affected recruitment of this group. Discussing this with a BSL interpreter present may have allowed BSL users to have received the information more effectively. As no BSL users came forward it is clear that although the study details may have been in an accessible format, how to inform them of the study was not appropriate.

situation and a different decision may have been reached if clinics were at a normal level. (The reason for not recruiting a BSL user was considered in Figure 16).

6.4.1.3 Data collection

The data collection methods and the process of data collection are now explored.

6.4.1.3.1 Data collection methods

This study collected data from interviews and pre and post-implant test results. Results of pre and post-implant tests enabled information on the user's performance with the CI to be determined. This was as the user's CI benefit (improvement on speech perception measures) may have influenced their CI experiences.

6.4.1.3.1.1 Interviews

These were semi-structured interviews. CI recipients and their families were interviewed a maximum of twice, within a two week period. As they were retrospectively looking back at their experience and hopes there was no need to interview them at different time points. Since the interview for the CI recipient was likely to be longer (ninety minutes) they were given the option of being interviewed twice to make this more manageable.

The interview guide was developed with a BSL interpreter to ensure the questions and the language were relevant, appropriate and were suitable for adults who use BSL or adults who used spoken English (For the interview guides see Appendix JJ and Appendix KK). The interviews were conducted either by phone, Skype, Zoom or face to face. Participants were given the option of audio or a video recording. For the interviews that were audio recorded, this would record the participant's voice or the interpreter's voice if the participant was a BSL user. The audio recordings were made using an AV recorder and were uploaded to a password protected computer. The files were then deleted on the audio recorder. The computer audio files were deleted at the end of the study. If the interviews were conducted via Zoom they were not recorded using Zooms recording feature; rather they were audio recorded using the AV recorder.

For the video recordings these were planned to be made on a video camera and the files uploaded to a password protected computer, these would then have been deleted off the camera. This video data would have been used to comment on the reliability of the interpretation. The interpreter who performed the interviews would have been responsible for going back through the video to check the interpretation. This would have been performed within

30 days and the video file then deleted. If a video recording was made of a BSL participant interview, which was taking place on Zoom, this would have been from a separate camera not using Zoom's recording feature. At the time of the study the safety and security of these features was unknown and so a cautious approach was taken.

6.4.1.3.1.2 Pre-implant and post-implant test results

During their CI assessment, data were recorded on the participant's unaided hearing levels, and their performance with their hearing levels on speech perception measures (this could include Bamford-Kowal-Bench (BKB) sentence testing, City University of New York (CUNY) sentence testing, Arthur-Boothroyd (AB) words and the ASSE test). The CUNY sentence test involved sentences being presented to the participants and scoring the key words they identified correctly. This was generally presented with lip-reading and could be with or without sound. The BKB sentence test involved using short sentences, with no lip-reading, and key words correct were scored. The AB word test used single words, with no lipreading and was scored as phonemes and words correct. In the ASSE test, two different speech sounds were presented and scored correct if the participants were able to detect the presentation of the different sound.

After implantation the tests performed included aided audiometry and aided speech testing (This can include BKB, CUNY, AB words or the ASSE test). If the test data were available pre and post implant it was compared. At the 12-month appointment the patients were asked if their QoL had improved (yes or no answer) and this was recorded; this was included for CI recipients. All the data described was accessed through case note review. These data were transferred anonymously to a password protected computer and stored under the same pseudonym as the interview data. The data were included to identify if the interview data were supported by the post-implant test results.

6.4.1.3.2 Data collection

The data were collected in 2 stages. In stage 1 the interview data were collected, in Stage 2 the pre- and post-implant results were collected. A reflective diary was kept during the interview and data analysis stages of the study. The pre and post-operative data were only collected after the interview was completed. This was because if the participant then withdrew from the interview their data would have been accessed unnecessarily. The QoL data were excluded from the data collected. This was as the QoL measure was asked as "do you feel your quality of life has improved" with a yes or no answer, not by a standardised QoL measure. This method of collecting ~~this~~ data was only discovered during data collection.

The data were then collected using the methods described.

6.4.1.3.2.1 Interviews

All the interviews were audio recorded (using Olympus, WS-852) and the files were transferred to a password protected computer and hand transcribed. This was a time-consuming process but allowed me to be fully familiar with the data. Reflections regarding the interview was made after each interview and memos were made during the interview to aid in these reflections. If necessary, these reflections were then added to during the process of transcribing. These reflections were used during the analysis stage to help fully understand the data.

Interview methods

All CI participants were given the option of face-to-face interview or Zoom. Family members were given the same options with an additional option of a phone call interview. One participant requested Skype and ethical approval was obtained to use this method. Ethical approval to use Skype was obtained after three interviews were completed. Skype was deemed suitable as this participant did not require a BSL interpreter.

Three CI recipients chose to be interviewed face to face and two choose Zoom. One of the participants who chose Zoom was re-interviewed face to face after 2 failed attempts at a Zoom and Skype calls (See Table 24). I was based at the University for all of the interviews, no phone or video calls were made from home. This was to ensure no disturbances during the interviews. One family member chose to be interviewed by phone; the second family member was going to be interviewed by video but due to issues with interviewing their CI recipient family member this was switched to the phone. Interviews were performed from October 2020 to January 2021. One interview was attempted to be recorded five times. As attempts using Skype and Zoom were unsuccessful.

Table 24 Method of interviews

Interview method	CI recipients (5)	Family member (2)
Face to face	4	0
Zoom	3 (2 unsuccessful*)	0
Skype	2 (All unsuccessful*)	0
Phone	0	2

**One participant had three separate interviews ~~arranged~~ as two were abandoned due to connection issues. These interviews involved an attempt at Zoom and Skype. This participant was then interviewed face to face.*

The interview questions were focussed around three parts, pre implant, initial tuning and at one-

Figure 19 Reflection on potential influences the previous interviews may have had

The initial interviews may have influenced the subsequent interviews and led them in a different direction than they would have been. This could have prevented topics from being discussed by the researcher and the participant. I felt it was impossible not to be influenced by previous interviews. This may not be negative as it allowed me to be more informed about potential issues that the participants may have experienced and so be more knowledgeable and able to ask more relevant questions on topics they may not have discussed without this previous knowledge. There was no way of preventing these effects on the data even whilst conscious of this. There was a need to acknowledge this and consider the data within this context.

year post implant. This was to allow the participants to lead through each stage rather than moving back and forth from stage to stage. This was not always possible due to the participants directing the interview and in some of the interviews clarification was needed and the participants were asked to expand on what was previously mentioned (This was discussed in Figure 19). The interviews took place during a pandemic which would have affected the focus of both the participants and myself. This was likely to influence the data collected through the topics discussed and by the effects on mine and the participants' lives at the time.

In person interviews

Interviews were planned to take place in a University Building which was separate from where participants were seen for clinic appointments. Due to the Covid 19 pandemic, all buildings requiring a staff presence required a risk assessment in place. This was in place at USAIS for patient appointments (Appendix LL). As participants requested a face-to-face interview, and they had additional communication needs to warrant this, this was accommodated by moving the interviews to the USAIS building. Participants were seen in this building for clinic appointments and were familiar with its location. How in person interviews were performed was described:

- Covid 19 screening questions were emailed prior to all participants attending the centre and response received to indicate no to all questions
- They entered the building reception and were seated in a designated area by the receptionist
- I collected the participant from the reception and took them to the interview room
- Masks were worn to and from the interview room and within the building
- Masks were optional for the interview
    - Lipreading partners were excluded from wearing a mask

    - No clear masks were available until the last interview (and were then worn)
- Participant and interviewer were at a two-metre distance at all times. Two metres was aimed for even when wearing a mask
- Ventilation was ensured in all rooms (window was open)
- Scrubs were worn during the session to ensure that their clothing could be washed at 60 degrees

After the interview the participants were offered to have their travel expenses refunded and were provided with a form to complete. One participant who had a face-to-face interview did not wish to claim their travel expenses (See Figure 20 for a discussion of the issues around changing the room location).

Figure 20 Reflection on the issues regarding room location

The changes to the face-to-face interview put the participant in an environment they associated with their clinical CI appointment and the interviewer in clinical scrubs. This would have affected their impression of the interview and may have made them feel they were in a clinical setting rather than a neutral interview setting. The majority of the participants knew me from their clinical role or were made aware of my dual role from the research advert. It was therefore likely that the clinical attire did not influence all the participants as they may have already formed views on myself being a clinician before the interview took place. This likely influenced what the participants discussed in their interviews. The participants had all been to USAIS previously and were aware that the procedures they were experiencing were not normal but because of the pandemic. This would have highlighted the current situation the country was in and may have influenced the topics discussed in the interviews. The situation at USAIS and the pandemic could not be controlled and the interview was influenced by what was going on in the participant's life at the time; this aspect was a constant for all the face-to-face interviews. Although the changes described were not ideal it allowed the interviews to take place and the study to continue.

Remote interviews

Interviews performed remotely using Zoom and Skype were recorded at USAIS but in a room that looked less clinical with a plain background. The background was not blurred as this could have been distracting, particularly if movement caused the blurring effect to change. A room which was not in clinical use at the time of the interview was organised. These interviews were conducted in

normal clothing and were unlike the face to face interviews in which scrubs were worn. A laptop was used rather than a desktop to ensure the sound quality was the same for all sessions. Due to signal issues the laptop was plugged into the network after the third participant interview to ensure my equipment was not contributing to any poor signal quality.

Review of interview methods

These are reviewed in Table 25. Some of the issues described in Table 25 occurred during the interviews. During one interview the doorbell rang on the Zoom call. In another the signal was so poor it had to be abandoned twice (both Zoom and Skype were used to see if either made the situation better). The rapport was also affected by the method of interview with the in-person interviews having a better rapport from my perspective (See Figure 21 for a discussion as to whether the interview method affected the data and the rapport). Although the rapport was affected by the interview method it was difficult to determine if the content of the interviews had been affected. This was as one CI recipient and two family members were interviewed remotely. The data collected from recipients and family members were different due to their different experiences of an implant. When comparing remote interviews with the CI recipients no difference in content was noted but this could not be checked for the family members as no family members were interviewed face to face.

Table 25 Review of Interview methods

Method	Positive	Negative
Zoom	• Allowed interview to take place remotely • Participant was clear and each face was visible so could read facial cues and see when the participant was thinking or had finished talking	• There was a possibility of interruptions • Internet signal could affect the call • Rapport was harder to generate through a video • Requires some technical knowledge • Need to ensure sound quality was good for recording

Method	Positive	Negative
Face to face	• Rapport easily generated Facial and body cues visible	• Participant required to travel • Modifications required for Covid 19 may have affected the data collected
Skype	• Allowed interview to take place remotely	• Requires some technical knowledge • Affected by internet and signal quality • Possibility of interruptions
Telephone	• Allowed interview to take place remotely • Limited technical knowledge required	• Cannot read facial cues • Unable to tell when the participant has paused or finished • Issues with the signal

Figure 21 Reflection on whether the interview method affected the data

Did the interview method affect the data? With less rapport generated and more difficulties in telling when participants had finished speaking it felt like it affected the data collected.

On the Zoom call I felt there were difficulties in generating a rapport that were not present in the in person interviews; this may have been related to not seeing all the cues relating to body language from both parties. I felt this interview was more challenging due to this and may have resulted in less rich data. Although this interview was challenging due to the technology aspects and rapport, I felt I learnt that the technology did work and in future Zoom interviews I was more prepared.

During the telephone calls I felt that I was continually interrupting the participants as I was unsure when they had finished a sentence or if they were thinking or waiting for me to respond. It made rapport difficult to generate as I felt like I was interrupting their flow without really meaning to. This may have been helped if I had known the participants as I may have then been able to gauge when they had paused or had finished speaking. This also had the effect of not being able to read the participant's facial cues or body language; this seemed to have less effect in the rapport as my continual interruptions impacted this more from my perspective.

Collecting all data through one method would have been preferable but not possible in the situation at the time of data collection.

Interview style

The interview style was casual and informal. The interviews were like a conversation and the participants were able to go off topic if they wished. The setup of the interview was not rigid and the aim was for the participants to feel comfortable and relaxed in the interview setting.

Positives

- Participants seemed comfortable and relaxed and able to guide the interview should they wish too
- More flexible as allows topics to be investigated in depth which was important to the participant
- They may have discussed more information as they felt comfortable

Negatives

- May mean topics in the interviews were not consistent as different aspects covered depending on the participant
- Harder to compare interviews

The interview style was planned to allow participants to feel comfortable and secure to talk about their experiences. There were positives and negatives of this style, but this also fits with my clinical style and trying to interview using a style that I was not comfortable with could have negatively affected the interviews. There were times in all the interviews where the participant and I laughed together over a story or experience that they had shared. This was an example of how comfortable the participants were in the interviews as they were able to share experiences and then laugh at them. The style of interviewing was likely to have been affected by having previously met some of the participants.

Knowing the participants

As I was a clinician at USAIS it was likely the participants had either seen me in a clinical setting as part of their care or made aware of my name due to information provided through USAIS communications with patients. It was not clear if there was a negative effect on the interviews where I was known to the participants, but it was difficult to tell. The topics covered by the participants were not particularly negative about USAIS or clinicians and this was either that there were no negatives or that they did not feel comfortable sharing them with me due to my role as a clinician. There were instances where I was asked about clinical care, or it was discussed by the participant. Participants were then directed to contact USAIS to ask their queries. The participants were aware of my clinical role and asked me to clarify points, for example the name of the surgeon. This was very difficult not to answer, as they were aware I knew the answer and it could have affected the rapport of the interview and answering the queries appeared to help participants share their stories. Although knowing the participants can give researchers power, it also gives the participants a view of the researcher they may not have had before. They knew me in a clinical setting whereas this was a different environment which could be giving the participants more power. They could gain more knowledge about the researcher than they would do if it was a researcher that they did not know and with whom they would have no further encounters (See Figure 22 for a description of my situation at the time of the interviews).

With participants knowing I was a clinician at USAIS, this could have meant they withheld information that they assumed to be obvious or I overlooked aspects of the participant's story (Berger, 2015). Knowing the participants could also have helped with the rapport of the interviews, being more knowledgeable on topics raised and a having a greater level of detail when probing or responding to questions (Teychenne et al., 2021).

Review of the interviewer

The transcriptions of the interviews were reviewed to identify if leading questions were asked or if the questions were clear. One thing that was obvious from this was that sometimes, even though I had undertaken the interviews and was transcribing them, it was not always clear what questions were being asked of the participants. The sentences were disjointed and sometimes the questions were stopped before they had finished. This improved through the interviews and may have been due to experience and knowing the participants could have influenced this. Lots of positive reinforcement was provided during the interviews allowing participants to talk about other topics should they wish too, which appeared to aid the building of a rapport.

Figure 22 Reflection on my situation at the time of the interviews

At the time of the interviews I felt very disconnected from family, friends and from work (colleagues and patients). The isolation required to prevent the spread of Covid 19 had the effect of detaching people from their social groups and lessened general interactions. This was evident at the time to in my clinical role. My clinical role involved me doing the best I could to prevent my patients, and myself, catching or transmitting Covid 19. This involved cleaning, mask wearing and being as far as possible from my patients but still completing my clinical role. The interviews reminded me why I do the work I do, in that these interviews were extremely important and valuable to me. They were a reminder in a time of separation that my clinical role results in people connecting with others.

Anonymisation and transcription

Anonymisation took place on two levels. Participants, and anyone mentioned in the interviews, were assigned pseudonyms and names of locations were either removed or made generic i.e. Manchester was changed to a northern city. Pseudonyms were assigned, a Google search of popular names provided a list which was used to assign to participants (British Baby Names, 2011). The second level was methods to prevent staff members or patients being identified through descriptions. For example, someone described by a physical feature could easily be identified from the small number of staff who work at USAIS. This was then adjusted or removed to ensure that no staff members could be identified. Level 1 aimed to take place during transcribing. Level 2 took place after the transcripts had been re-read to ensure no people could be identified. It also allowed any anonymisation that should have taken place at transcription to be checked and performed if missed. The interviews were then transcribed into a word document. The audio file was played from the computer through headphones, and this was then

typed up by hand. There were instances where the audio file was intelligible which could have been due to the poor signal/interference or due to the participant's speech not being understood. Some of the participants' speech was unclear or with an accent and affected the transcribing. When it could not be determined what had been said this was noted on the transcript as (unintelligible) thus providing a record that something was said. Pauses on the transcript were noted by () and the length of the pause was recorded.

6.4.1.3.2.2 Collecting pre and post implant data

USAIS had recently changed to a new data management software at the time of data collection. The data were collected through review of the participants' online case notes through the patient management system called Cellma. Using this system was more challenging as I was less familiar with this system compared to the old patient management system. The paper file was reviewed if the data were not found on the patient management system. Some speech tests were not repeated at twelve months post implant. Therefore, only data from both tests pre and post implant were compared. Some assumptions could be made from data not recorded. For example, if a speech test was not completed the clinician felt that the participant would not perform well on this test at the time.

6.4.1.3.3 My dual role

As both a Clinical Scientist (Audiology) managing a patient caseload and a PhD student, these roles could come into conflict at certain points as potential participants may know or knew me from clinical practice. Therefore, I did not approach any patients directly and this was carried out through gate keepers (Clinicians at USAIS). To prevent any conflict of interests, I was not involved in the clinical care of any patients in the study for the duration of the study period nor did I approach potential participants about the study to ensure they felt under no undue pressure to participate. This was managed by staff and clinicians at the centre approaching participants; any participants who were involved in the study had their appointments checked to ensure I was not their clinician throughout the study period. This involved some coordination with the administration and management teams to ensure procedure was followed, such as checking their diary and informing management if any participants were booked in with me as patients. This may have resulted in some clinicians having a higher workload as they are seeing patients I would have seen but it was only short term.

My clinical background affected the data collection and resulting analysis which was discussed in more depth in 3.6.

6.4.1.4 Data analysis

The interview data were analysed using thematic analysis (the principles of thematic analysis were described in 4.7.8). A reflective diary was kept and used to aid analysis of the data.

This study applied convenience sampling; with a small participant pool this method was the most effective at recruiting the sample size required for the study. The first six CI participants to complete the consent forms and arrange interview dates from each group were recruited to the study. A sample size of six was chosen when this study was designed as a case study. This was also due to the number of early deafened adults at CI centres. At USAIS, of 126 patients who were referred to the CI centre for a CI assessment (from April 2018 to March 2019 (USAIS, 2019)), 24 developed their hearing loss under six years of age. If the data from 2018 to 2019 was average for the year this would mean that 96 patients would meet the study's inclusion criteria for being one to five years post-implant. These are small numbers, and a large sample size was not appropriate.

The first five CI users who emailed met the study criteria; one individual who contacted after five participants were recruited did not meet the study criteria as they were deafened over the age of six years.

In case study research a sample size of one can be sufficient (Van Wynsberghe and Khan, 2007). The sample size was assessed during data collection to determine if this needed to be increased due to the change in methodology. In qualitative research a sample size is appropriate if it answers the research question and saturation is achieved. Saturation is described as when no further data collection would result in any new themes (Daniela, 2020). After five participants were recruited, saturation was assessed. The data collected from the five CI users was very similar and thus saturation was deemed to have been achieved and no further data collection was necessary.

The interviews were audio recorded and the audio file was then transferred to a password protected computer. Interviews were kept in separate folders. The interview data were transcribed and anonymised (described in 6.4.1.9.1). All data were transferred to NVivo for analysis. The stages of thematic analysis were applied (see Appendix NN).

6.4.1.4.1 Inductive and deductive coding

The data were coded with reference to the research questions, but this also included some inductive elements. This was to ensure that as this was the first time these families had been asked about these experiences all areas were covered.

6.4.1.5 Data validation

As described previously, this study used the data validation tools described by Merriam (1998) and (2009). This involved internal and external validity and reliability. Table 26 shows these tools with reference to the current study; the full list of tools is shown in Appendix MM. One of these tools required further discussion around its non-use.

Table 26 Merriam's (1998) data validation tools with reference to the current study

Internal validity	Member checks	Participants were not asked to check the findings. This was discussed in 6.4.1.8.1
	Researcher's biases	This was considered in more depth in 3.6
Reliability	Investigator's position	This was reviewed in 3.2
	Audit trail	Reasons for decisions made were documented as part of this thesis. Methods for data collection and analysis were described within this section.
External validity	Use of rich thick description	Quotes of the situations participants describe were included to allow decisions of generalisability to be made. This allows the reader to determine if the research matches the area they are investigating and if the findings are transferrable to situations they are studying (Merriam, 2009).
	Typicality of the case	Discussions regarding typicality of participants was discussed. All participants used spoken language and had similar school settings

6.4.1.5.1 Member checking

Participants were not asked to member check the findings of the case. Member checking involves asking participants to review the transcripts, findings and interpretations to ensure accuracy (Stake, 1995). Returning transcripts can allow participants to change the transcripts and so adjust what they said (Birt et al., 2016, Thomas, 2017). At the point the decision was made not to use member checking I was not aware that no BSL users would be recruited to the study. I decided

not to use member checks as any information sent to participants may have required translation into BSL, which had the potential to change the meaning from the researcher's interpretation to what the interpreter understands of the information they have been given. There also may be language used in the documents that would not translate into BSL. This could have introduced misunderstandings and generated distress.

Member checking can identify that the participant does not agree with the researcher's interpretation of the case, which would result in an awkward position, and raises the question as to whether this part should be removed from the analysis. That could result in sections of the interviews/analysis being removed. Another outcome was that it could result in coercion as the participants may feel they cannot disagree with my interpretation (Birt et al., 2016). This would be particularly relevant for my dual role, with Estroff (1995) data suggesting that patients accepted all that the researcher said. In addition, Thomas (2017) found that problems with member checking can include a lack of response, additional intrusion for participants, little change in research findings and the need for additional resources for this to be carried out.

An advantage of member checking would have been to allow participants to remove any quotes they were unhappy with or indicated would have identified them. Considering the potential advantages and disadvantages it was felt there were too many potential issues with member checking to be included in this study.

After this decision was made, I then did not go back to reconsider it following recruitment or data analysis. Being a researcher who has never used member checking before I thought about the negatives of member checking rather than considering the potential gains. After completing this thesis, I reflected on whether it was the right decision. The literature indicates that there are positives and negatives of member checking but the main message is that member checking requires thought, planning and consideration of how to deal with discrepancies (DeCino and Waalkes, 2019). This was not built into the initial research application and not discussed with participants I did not feel it was appropriate to change this decision.

6.4.1.6 Summary

This section has described the approaches used to recruit participants and the development of the materials used to inform participants. The methods to collect and analyse the data have been outlined. The results of the data analyse are now presented.

6.4.2 Results

Results from the interview and the pre and post-implant data are presented. Demographic data were not collected, due to the small number of early deafened adults and the potential for identification if more details were recorded, but all participants were born before 1980 and were within the same 20-year age bracket.

The themes from the interviews relate to the participant's journey with a CI, before, during and after implantation. This was not surprising as the interview questions were focused on the participant's experience and hopes of the implant. As the data were collected between October 2020 and January 2021 during the Covid 19 pandemic, there was an additional theme focusing on participant experiences during this time. In total, there were five key themes, and three of these themes contained subthemes (Table 27).

Table 27 Phase 3b themes

Theme	Subtheme
1. Growing up with a hearing loss	1.1 Families and teachers advocating in the early years
	1.2 School was challenging
2. The need for a cochlear implant	2.1 Hearing deteriorating and limits of hearing aids
	2.2 Trying to get someone to do something about it
3. The CI journey	3.1 No going back
	3.2 What I want from the implant
	3.3 Listening for something
	3.4 It's an incredible world
	3.5 I understand why it's called a cuckoo
	3.6 People forget
	3.7 It can be inconvenient
	3.8 Why didn't I do this before?
4. Behind me the whole way	
5. It would be much better if people didn't have masks on	

6.4.2.1 Theme 1: Growing up with a hearing loss

This theme focuses on the accounts participants shared regarding their journey growing up with a hearing loss relating to experiences of their initial diagnosis, experiences throughout their school life, and obstacles that they had faced since their diagnosis.

Subtheme 1.1 Families and teachers advocating in the early years

Participants described how the effects of their hearing loss were seen from childhood with parents and teachers recognising that the children had a hearing issue, and with families ensuring they were diagnosed and accessed the support required.

"*Mum realised I wasn't hearing through the sheer fluke of the door slamming shut and it made them jump but I didn't respond"* Emma L5-6

"I *can remember saying to my mum I can't hear it"* Nicola L30-31

Both Emma and Nicola discussed how their hearing loss was identified. Nicola, by telling someone she could not hear and then by Emma's mother noticing she was not able to hear loud sounds. One participant's hearing loss was picked up by a teacher.

"Primary school a teacher was watching me and watching the other kids and he was suspicious that I was lipreading rather than listening to him so he told my parents that I appeared to be lipreading and that I could be deaf so shortly after that arrangements were made for audiology to look at it and they found I was profoundly deaf in both ears; lord knows how I was able to react as I was" Richard L3-7

Claire described a very difficult time for her parents trying to get professionals to identify she had a hearing loss. They had to fight to get her the help she needed.

"They thought my mother was neurotic… she had a hard time" Claire L13-15

Claire's description of her mother being described as neurotic by professionals when she was trying to get help for her daughter was powerful. Claire's statement that "*she had a hard time*" showed she was aware of the struggles her mother faced.

Participants shared how their parents were also supportive in helping them develop their language skills and encouraging them to wear their hearing aids. For example, Emma described how her mother helped her with her language and understanding.

"She would sit next to me and she explained everything that was happening, touch me, explain things when we were going up the stairs she would count we would count the stairs together you

know she would say one two three and I copy one two three everyday everyday we went up the stairs and down the stairs so that's how I got my speech" (L27-30).

Emma explained that her mother was very supportive whilst she was growing up. When Nicola was not happy to wear her hearing aids her family used different ways to encourage her to wear her hearing aids:

"I think I actually got bribed with wearing it if you wear it five days you will get a star chart kind of thing and you can get a packet of sweets at the end kind of thing" Nicola L55-56

Richard shared how his father acted to get him 'behind the ear' hearing aids rather than a body worn aid as this was affecting how other children were perceiving him.

"While a lot of the kids at school didn't like it so my father decided that when the time came… after school and I was going into college to study something he was looking to behind the ear hearing aids when they first came out… so private audiologist who came up with a powerful behind the ear hearing aid and found I could hear reasonably adequate with it so he decided to purchase it" Richard L10-16 Interview 3

Richard described wearing a body worn device (which was very common before the introduction of behind the ear hearing aids). Richard did not expand on saying "*the kids at school don't like it*", but the way it was said in the interview suggested that they had not reacted positively to him wearing one. This led his father to look at different options. The participants revealed situations in which their parents had advocated for them relating to their hearing loss when they were children. Participants then shared their experiences at school; schooling was mentioned as a challenging time for all the CI recipients in the study.

Subtheme 1.2 "School was a struggle"

Several participants described situations where they have found the school environment difficult, this was related to both making academic progress and social situations. Nicola discussed how:

"school was a struggle I had to sit in the front and (unintelligible) missed what had written down I had to ask someone if I could copy them because you can't write and hear of you rely on lipreading and that was where the teachers just didn't get it so I used to copy somebody's notes they did normally mind" Nicola L71-74

Claire explained*: "I don't have many pleasant memories… most of them turn your backs to write on the board and then you're thinking what are they talking about"* L40-43

Participants indicated that their schools at that time did not know how to manage or work with them in relation to their hearing loss as they shared situations where their hearing loss was not managed well. For example, teachers turning their backs on the participants meant that they were then unable to lipread them to help them understand what was being said.

David found school difficult and one of his comments was compelling: "*somebody says I'm shouting a lot and I'm not hearing myself which gave you an inclination to end up in a field somewhere*" L132-133. David explained that as he could not hear his own voice due to his hearing loss, he was unable to monitor his voice level and so shouted rather than speaking at a normal voice level. During the interview he did not go into what was meant by "*end of up in a field somewhere*" but it was likely he meant that he just wanted to get away from it all. This showed the frustration. It indicated how school was challenging for these participants.

Participants explained that hearing support was present in some of the schools but there were issues with its provision. Hearing support in school would usually have been carried out by a teacher of the deaf (another term for teacher of the deaf was peripatetic teacher). Emma's description of her teacher's support highlights the connections children can make with their support staff and how changes can be disruptive and impact on the affected students.

"When I was five I had the help of a peripatetic teacher from the South as we were in the South then and she was marvellous and then when I went to senior school we changed boundaries… the world fell apart a bit then" Emma L36-39

Emma and Nicola both declined any additional help during their secondary education due to their experiences with support staff.

"I think I was about 14 I wrote to the audiologist and said I don't want any help anymore I don't want them coming to take me out of class and I'd rather go it alone" Emma L56-61

"The teacher that came in was useless when we she started talking about careers she wanted me to do catering or something… she wouldn't have any of it and she was so useless I eventually said I didn't want her to come anymore" Nicola L67-70

Emma refused the help as the teacher kept taking her out of classes she enjoyed, and it was made an issue while Nicola reported the staff were not helping, underestimated her abilities and did not expect much from her. The participants shared that the management of these situations, by the schools and support staff, caused them to reject their input. How this affected the participants' education long term was unknown but Emma shares that she feels she may have done better academically at a school with more support: "*if I went to the school, academically I would have*

been better as I would have had one to one" L46-47. This shows the barriers and difficulties the participants had to overcome which were influenced by the people who were trying to help them.

Participants also shared positive descriptions of professionals providing support, such as teachers providing support in school. Teachers either helped with understanding in classes and/or providing quiet spaces for participants.

"I would perhaps miss in maths classes or geography classes or not understood properly maybe he was there was there to say it was this that and the other it was that kind of one-to-one facility that I got so that was particularly helpful so yes it was having that somewhere to go away from the maddening crowd it was good" David L140-144

Or helping them to ensure they did not fall behind with any schoolwork due to their hearing loss:

"Primary school I eventually had a special needs teacher of the deaf come in just to help me catch me up on things" Nicola L61-62

Or their support being described very positively by participants.

"*She was marvellous"* Emma L33, when describing a teacher.

The participants also shared social situations at school in which their hearing impacted. For example, Claire hid her hearing loss "*from all my friends*" L47 throughout her education; the effort to do that must have been significant and the fact she felt she needed to. She did not discuss why she did not share this with them but shared that "*some of them must have realised but it was never talked abo*ut" L47-48. Nicola described the social situation at school as being difficult "*I did feel really isolated and lonely*" L66. This showed how participants hearing loss also impacted on social situations at school, as well as academically.

The participants' experiences during their early years and education show the difficulties they have faced. A CI would not have been offered to them when they were children as this was not an option available at this time. The realisation of their need for a CI was then explored.

6.4.2.2 Theme 2: The need for a Cochlear implant

This theme looked at participants' difficulty with their hearing and identifying the need for a CI.

Subtheme 2.1: Hearing deteriorating and limits of hearing aids

All the participants used hearing aids before being referred for a CI. Having been referred for a CI would mean that the participants' current hearing aid/s were deemed not to be providing adequate benefit. The participants and family members described moments where professionals

told them their hearing had deteriorated or they realised hearing aids where not giving them enough access to sound. Nicola showed she was aware her hearing was changing as does Mark in relation to his family member's hearing.

"*I was just really struggling and I just thought why is my hearing going down now"* Nicola L17-18

"*She was missing a lot and obviously I had to make sure I was seeing her face-to-face erm before she could really understand what I was saying"* Mark L23-24

Nicola communicated the frustration with her hearing and the lack of control. Her hearing was going down and she had no control over this.

Claire, Emma and Richard were told by their audiologists that hearing aids were not able to meet their needs. They were told "*there is nothing really hearing aids can do for you anymore"* Claire L98-99*,* the audiologists couldn't *"find an aid powerful enough"* Richard, and they were not getting much from their current aid *"you know you should throw those hearing aids away for what you're hearing from them"* Emma L142-143.

Emma highlighted how she did not consider her hearing to be an issue, with her "*never worried about it*" L141.

Participants reported that before the CI they or their family member were just used to not hearing well and had accepted this as something that they had to live with. They were not aware there was another option available that could help them hear better.

"I wasn't hearing very much at all but because I didn't know any different" Emma L146

"*He was told he was getting deafer and hearing aids wouldn't work for him in the future… I don't think he appreciated how little he heard you just take for granted that's what you hear you know"* Lisa L5-7 and L35-36

Lisa and Emma used terms such as: "*didn't know any different*" and "*take for granted*". There was no awareness that there was a reason to think differently or that there was another option available.

David explained the change from analogue to digital[1] was when he realised his new digital hearing aids could not provide the same access to sound as they did before. There was no option to

[1] Analogue hearing aids were obsolete. Analogue aids provided more gain/volume than digital aids, but they acted to amplify all sounds (speech and noise); they did not have access to advanced features (e.g. noise reduction/direction microphones) and were not as programmable as current digital aids. Digital aids act to

continue with an analogue aid as these were removed from stock due to digital aids being an advance in hearing aid technology.

"*I was still using analogues yep and they started we are going into the digital age as it where and I thought oh ok a hearing aid is a hearing aid erm and they said try this one try these that and the others and the first thing that struck me about both the difference between the two is they are not so gutsy… rightly or wrongly I would always think I need more sound would need clarity being able to discern the different words and so on but I just wanted to hear things birds tweeting anything and I think a bit of that got lost with the digital bit because although it was providing clarity it wasn't picking up the clarity from over there… I did struggle with it for quite a while and I thought I can't be doing with this I need something else there must be something somewhere*" David L145-158

The participants were made aware their hearing was going down or hearing aids were unable to provide adequate benefit in different ways. For Emma it appeared to have been quite a shock in some respects as she had lived with her hearing loss for so many years. To be told she was not hearing well she became defensive at first: "*I got on my high horse*" L143-144. Other participants were more accepting as they were aware their hearing was changing, and they were not hearing as well as they had previously. The next step was being referred for an implant.

Subtheme 2.2: "Trying to get someone to do something about it"

At USAIS there needs to be a referral made from a health professional for patients to be seen for a cochlear implant. This was usually a GP, audiologist or Ear, Nose and Throat (ENT) doctor who have access to an audiogram (hearing test results). This was a common structure around the UK at the time of the study. The participants reflected upon how they were referred for a CI with some participants struggling to access the service. Claire shared her referral experience:

"Of *course the next step is trying to get the GP to do something about it he needed evidence which meant I had to go back to my audiologist to get her to write a letter to say I was profoundly deaf provide the audiogram and once he had that evidence it meant that he could put it forward"* L112-121

Other participants discussed how they were not referred earlier as they were deemed to be doing too well with their hearing aids or were told they were not suitable for a CI. David's experience showed how he was missed as he was appearing to manage well in the environment he was in:

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focus on the speech signal while reducing background noise. They were set to match the users hearing loss which analogue aids could not.

"*Where I have fallen through the crack because of doing so well in the environment the fact that it's come along recently I don't know whether that's a good or bad thing I couldn't honestly say one way or the other I would say (0.5) better late than never that's probably the best I can offer on that one"* David L235-239

Nicola showed the frustration with the fact that she was not referred and how she later found out that it was not within that professional's role. She had accepted this but acknowledges that this was not appropriate for her.

"I saw a consultant at the hospital and she was talking to me about cochlear implants this was when I just noticed she sat right up to me knee to knee and said your hearing is too good for an implant and I now realise it shouldn't have been her decision she should have referred me to the team so I could have had it done a lot earlier but that's the way it turned out" Nicola L20-22

Emma also discussed how she was denied access.

"I've always been told I couldn't have one" Emma L137-138

This showed that Emma enquired about cochlear implants more than once before and had been told she was not suitable. She did not expand at the time who had told her she was not suitable. Cochlear implants were again raised with Emma by a work colleague who had knowledge of CIs who thought she might be suitable and encouraged her to seek a referral.

All the CI participants mentioned difficulties accessing a CI and how this delayed receiving a CI. It highlighted the issues with access mainly around professional's lack of knowledge about CI's and the delays to referral. This was important when you consider this in relation to the benefits that participants reported with their CIs'.

6.4.2.3 Theme 3 The CI journey

This theme follows the CI recipients through their CI journey from the decision to have a CI to their initial experiences with a CI.

Subtheme 3.1 "No going back"

Outcomes with the CI and the operation were some of the worries participants had before they were implanted. Participants had no guarantees the CI would work for them and there was no option for them to go back to a hearing aid. They shared the effects that this could have on their lives. As David explained:

"*At the time they said the thing is there is no going back that's the difference between different*

types of hearing aid you can chuck away and get a different one you have still got some hearing but you put the implant in it doesn't work there is no going back" David L184-187

David was made aware that CI surgery could result in total hearing loss in the implanted ear. This meant there would be no usable hearing in the implanted ear and a hearing aid could not provide any benefit. Participants could not change their minds after the CI surgery and this was something they would have for life. The outcome of the surgery was not guaranteed. This resulted in mixed levels of anxieties and apprehension about the outcome of the operation as it could significantly impact on the participant's hearing abilities. The participants were considering the potential positives and negatives of what a CI could mean for them. Richard and Emma indicated they had something to lose:

"*It's difficult because you think about the surgery and you think if anything goes wrong you are going to be minus an ear"* Richard interview 3 L93-94

"*You know it is quite frightening you know you've got that operation to go down there and all although there is quite a high success rate there is that five percent and I'm thinking what if it was me what if I lost my hearing completely that would change my life*" Emma L272-275

For some of the participants the concern about the CI and the surgery was less as they indicated "*I didn't think I had anything to lose*" (Nicola, L10). This showed how little Nicola thought she was hearing. This was in contrast to Emma and Richard who shared they had something to lose and how they feel this would significantly impact on their lives.

How the participants viewed their hearing appeared to impact on their anxieties about the surgery and the risks associated with it. What they hoped to gain from the CI was also considered.

Subtheme 3.2 What I want from the implant

What the participants and their family members hoped they would gain from the CI was varied. All the participants had different expectations of an implant. David wanted a "*better volume*", Emma "*to hear better*", Lisa (family member) that the family member wouldn't "*lose their hearing*", Mark (family member) "*improve communications*", Nicola "*join in conversations*" and Claire "*to understand speech without lipreadin*g". Mark, Nicola and Claire, from my perspective had higher expectations than David, Emma and Lisa. Claire reported after the CI she was "*disappointed I couldn't go further*" in relation to what situations she could hear well in.

This could have been related to how their expectations were managed at USAIS but both Claire and Nicola reported being told to keep their expectations low.

"They managed my expectations and kept it very very low" Claire L306

"I was warned to go in with low expectations" Nicola L127

Those participants with lower expectations before the CI reported that the CI exceeded their expectations. David shared how his expectations of the CI were quite:

"*I think I've probably gained a bit more as I say I didn't have massive expectations that's the truth of it really as it progressed I'm thinking it's working well hearing well"* David L571-573

Lisa and Emma commented how they or their family member has heard things they did not expect them to.

"I didn't think I would hear as much as I did you know I expecting to hear better but I didn't expect to hear the birds that's been amazing" Emma L548-549

"I mean I didn't expect him to gain as much as he has… but yeah I certainly didn't expect him to hear as well as he does you know certainly the higher notes" Lisa L28 and L36-37

Although all the participants expected to hear better, how happy they were with the gains they had made were variable, with some participants wishing they had gained more. This suggested that the participants' expectations or hopes of what they might gain from the CI appeared to affect their satisfaction overall as those with lower expectations reported they were happier with their outcomes.

Subtheme 3.3 "Listening for something"

The CI switch on appointment was the beginning of the participants' journey with the CI. It took time to adjust to the change from acoustic amplification to electrical stimulation. For participants who had limited access/or no access to sound before it can take longer for the brain to adjust. All recipients attended several appointments over the first six months with stimulation levels being gradually increased over this period.

Claire described that her switch on appointment was quite a strange experience for her as she went from hearing nothing after the operation to now listening for something, which she heard from her head not her ears. She also explained how the sound from the CI changed quite quickly from just a noise to her starting to understand speech.

"*You just sit there listening for something then you suddenly realise there is something going on in your head not coming in this way it's just here (*pointing to the ear then the middle of the head) *it's really strange how a noise can come through your head rather than through your ears and*

then it's a case of oh ok you hear them pitch is not easy to tell but the volume is fairly easy to tell erm and then she starts talking first it's just like eh its squeaky sort of Donald ducky and can't really make anything out and then eventually as you listen more and more and more you get used to it and that its working yay I didn't get 100% speech recognition straight away I thought I could hear something and I could just about make out what was being said with lip-reading" L400-412

Emma also described speech as sounding like a Disney character. *"it was squeaky like Micky mouse mememem I'm thinking oh my god you know after 20 minutes it all went normal"* L325-326

The other participants shared how their implants took some time to adjust to and initially their implants did not actually sound great and how this changed over time.

"*Where the sound if you can imagine was graduating itself into and formulating itself as you went along does that make sense quiet bit and then all of a sudden it kind of kicks in a little bit more and more so it's been good that way absolutely fine*" David L281-284

"Gradually developed it started off poor and gradually got better and better the test for the first time I was going to have to work on it you know" Richard L201-202 Interview 3

The participants all had different experiences of an implant, although their experiences did share some similarities. For Emma, Claire and Richard's speech started off sounding strange. Emma perceived that hearing speech improved to sound "*normal*" within 20 minutes, but things took longer for the other participants. The improvement was not as quick as some of the participants expected and this resulted in some frustration in their how fast they were progressing, as noted by family members.

"*I think she was frustrated she wasn't advancing as quickly as she thought she would*" Mark family member L139-140

David's reflections on this day showed how positive it was for him. *"That first day was like I say that was the first day of the rest of the life shall we say*" David L492. There was no typical CI experience, some were positive, some participants were disappointed. Both Richard and Nicola acknowledged they were going to have to "*work on it*", by which they were referring to the listening training they were undertaking to improve their performance with a CI. Participants then explained what the CI gave them.

Subtheme 3.4: "It's an incredible world"

Having received their CIs, all the participants described gaining some benefits from the implant. Some participants used the results of the tests to reassure themselves they were getting benefit

while for others they noticed the benefit they were getting from the situations they could now manage in. They and their family members shared:

"He hears upstairs now which he never used too if I call him from downstairs he'll answer me which you know he never used too you used to have to go up to him if you wanted anything" Lisa family member L43-45

"Hearing these sounds and get on and look at it the other benefit is social conversation especially in places like restaurants where there is a lot of noise I find I'm able to figure out the voices better And relax more and enjoy my conversation" Richard L63-66 Interview 3

Lisa and Richard both described situations where the CI improved their, or their family members', communication and interactions with others. Lisa could now call her husband and not have to go to him every time she wanted to talk to him. That was significant for Lisa and it appeared that the effort to communicate with her husband was less and it was not as frustrating for her. Similarly, Richard was now able to relax and enjoy social situations which he was not able to before.

Participants noticed benefits other than those relating to hearing, which they may not have realised would occur after receiving the implant.

"I gained confidence I also gained confidence to be able to go out and try and do some voluntary work" Claire L447-448

"I've gained a lot more confidence even tried to start driving again" Richard L295-296 Interview 3

This showed how the CIs were improving their lives in ways they may not have thought, such as providing greater confidence. This also showed that hearing loss affected people's lives more than just affecting their hearing. The benefits the users and their families described were "*phenomenal*", "*extremely pleased*", "*positive", "amazing", "fantastic", "best thing*". This was powerful language, emphasising the changes the participants reported the CI had brought to their lives and they say how grateful they were for being able to have it, which was captured by David *"it's a stage where I'm thankful of everything".*

Using the phone was a situation specifically mentioned by two participants. The phone was a listening situation which was extremely difficult as there are no facial or lipreading cues.

"It was it was an amazing experience being able to take a phone call something you take for granted for me it's a big thing" Emma L510-511

"I'm extremely pleased I am able to use the phone again cos I've never been able to use the phone since my early twenties" Claire L456-457

The participants managing in these difficult listening situations were examples of how well they were doing with their implants. The participants examined the effects of the CI on their families and how the participants' families shared in their experience of the CI. They were part of their success.

"I recognise the song and say oh is that so and so or I relay to him what I've heard on the radio he say gosh you heard all that you see I've never heard it and I would have never heard it before pre implant" Emma L189-192

The experiences shared in the interviews were moving. Participants explained how the CI had given them access to sounds and impacted not only on their lives, but their family's lives as well. Richard sums up what hearing with the CI means to him and how this has opened up new things for him *"it's an incredible world out there"* Richard L335-356 interview 3

The interviews showed the impact that the CI had on participants. Hearing environmental sounds was also described as a benefit the participants gained from their CIs.

Subtheme 3.5 "I now understand why it's called a cuckoo"

Participants described hearing environmental sounds with great feeling. Environmental sounds included anything that was not speech perception; they ranged in their volume level and some were bold and powerful while others were softer and more delicate in nature. They explained how they can detect and recognise these sounds now. One of the most mentioned environmental sounds was birdsong. Participants explained that birdsong was a sound they showed great joy in hearing. Two examples are shown below.

"Things like birds, black birds, oh my god thank you it's amazing robins, blackbirds, pied wagtails the lot I'm hearing these different sounds that's one of them that's one of those I mean robins have got the loudest voice have you listened to them I can hear a robin 30 feet away in a tree like he is sitting on my shoulder and it's great I think it's wonderful you know" David L308-312

David explained the nuances and differences between different birds' songs that he can now hear and the pleasure he gained from this. He was not just detecting a sound, he was recognising and identifying that different birds have different songs. While Mark told how his partner was able to hear and identify that the sound that the bird was making and then understand why it matched their name.

"(I) can remember the first time she heard the cuckoo she just turned round and said I now understand why it's called a cuckoo…the big moments like that and it was fantastic" Mark family member L83-88

Mark showed how it was a significant moment for him being able to share in the experience with this family member and understanding of what that meant to them both.

Hearing birdsong was described as *"I was just overwhelmed" and "the most positive thing for me".* They describe hearing the birds with great emotion and how much joy they gain from this simple sound. It was something many people take for granted.

Birdsong was an environmental sound described as being very important to participants. Other environmental sounds were also described as significant, these varied more between participants. These ranged from sounds at home, like alerts on kitchen appliances, and/or sounds from other people like footsteps.

For Emma hearing her husband snore was very important to her:

"I've never heard my husband snore the first time I heard him snore I cried because I'd never heard him snore before…for me it was such a big thing I'd never heard it so it was a lovely touching moment you know" Emma L655-656

Other participants shared sounds they had not heard before and the potential surprise of this.

"Hearing all the noises clocks ticking in the lounge when it's quiet, birds squeaking and singing in the garden and out on walks all sorts of things of different I haven't heard before" Richard L52-53 interview 3

"I think the shock of actually hearing things I've never heard before was a bit of an eye opener" David L340-341

Hearing these sounds was not something they expected to gain. The moments when participants first heard some of the environmental sounds were discussed with more feeling than the first time they heard speech. It may have been that they were aware they were missing some parts of speech, but they had not realised they were not hearing these environmental sounds. The participants then went onto discuss other people's expectations of what they would or should gain from the implant.

Subtheme 3.6 People forget

Participants shared that having a CI did not mean they no longer had any hearing difficulties, although this may be assumed by the people around them.

"People seem to assume once you have had an implant miracle and you can hear that's not the case (laughing) everything is still the same I can hear better but I can't I'm not I'm still deaf at the

end of the day" Emma L244-246

Participants also described people as forgetting that they were deaf after the CI but they did still need some help. Claire discussed how she must remind her partner she can still struggle in some situations.

"He always forgets, I remind him every now and then" Claire L150

While David reported that people forgot as he does not have a visible disability.

"I think they have actually forgotten that I'm hard of hearing I mean not as hard of hearing as I was but the whole concept of having the processor there they can't to some degree you can't see it from here to here I don't think you can actually see the thing that much the processor I think I still need a little bit of help" David L393-396

David stated he still needs "*help*" this was likely relating to still needing some lipreading when talking to people. David and Emma both described themselves as still being "*deaf*" or "*hard of hearing*" even though they have a CI it has not changed their identity as having a hearing loss. The CI was not a "*miracle*" and Claire conveyed that when talking to people she can "*probably grab 80% of it*" but not all of it. This showed the CI was not the same as having normal hearing.

Subtheme 3.7 It can be inconvenient

There were aspects of having a CI that the participants found challenging, such as some sounds being piercing.

"There are still some noises which make my eyes water my brain goes no no" Nicola L242

"The refrigerator even me when I'm moving around those things to me are really I wouldn't say unbearable as I'm getting used to them but they are sounds I would prefer not to be aware of and I can't switch them off" Claire L632-634

Claire wanted to not hear some sounds; it was likely she was not aware of these sounds before she had the CI. The CI could not discriminate between sounds recipients did and did not want to hear. The sounds she was hearing were there, but normal hearing listeners could tune these sounds out, but this was something that some CI users were unable to do.

The equipment breaking was an issue, with it getting fixed "*put you back on track*" and batteries running out being "i*nconvenient*". The equipment issues, which meant the processor was not working as well, unsettled the participants as they lost their ability to hear. On reflection this was not unexpected, taking away someone's ability to hear would of course impact on them but the

ability to resolve this quickly was viewed as important. As Richard explained, he now ensures he carries batteries to make sure he was not without sound "*once you get used to it and you know what to do and you can go out or something like that it's fine*" L356-357.

This showed the adjustments that the CI recipients made when using an implant. Taking it off and having no sound Emma described as "*switched you off*" L692 and Nicola discussed as "*being back to square one*" L221. It explained the reliance they had on their CIs and that taking it off affected the user and had a different impact to their hearing aids. This may have been as they had access to more sound with the CI than they did with the hearing aid.

Having a CI involved having a magnet inserted as part of the surgery. Two recipients described situations where the magnet attached to something other than their head when they were wearing it.

"*If I'm near something metal so working under a lawn mower or something like that suddenly the hearing will go magnet attached to the lawn mower and the hearing has gone look the thing on the handle of the lawn mower looking at me*" Richard L117-119 Interview 1

"*I wasn't hearing I was standing beside a piece of metal shutter close by the metal shutter and the magnet jumped across to the other side*" David L607-608

This showed that participants needed to consider the environment they are in and there were situations where they may need to adjust what was close to them to enable them to continue hearing. Although the participants noted limitations with the CI this did not mean they would not have chosen to have the CI.

Subtheme 3.8 Why didn't I do this before?

Most of the participants reflected on their experiences with a CI, mentioning that it would have been of benefit for them to have had the CI earlier.

"*Having it earlier oh it would have made so much difference I'm sure it would have made a lot of difference*" Lisa Family member L171-172

Claire explained that if she was implanted as a child she could have had two rather than the one CI and the benefits that may have come from this (This was as the current guidance allowed adults to have one CI but children were implanted with two): "*when I was born or even in my teenage years I think it would have been so much better… yes and I could have had two which would have helped a lot"* Claire L189-194

Participants gave specific examples of situations in which having a CI earlier would have helped. It showed how they thought the CI would have improved their lives.

"The only thing I would have changed maybe I would have had it done earlier before the kids were born so I would have heard them in the night you know I didn't hear them cry or anything" Emma L710-711

"*Why didn't I go through all the implant business before why didn't I have a cochlear implant before I would have been a lot better in hearing and a lot more relaxed a lot more confident in myself and might have had better prospects in my life that's what I say to myself because it's made an enormous amount of difference to what I was I would never go back to 2 hearing aids if I could"* Richard L454-457 interview 3

Emma and David had different reasons for wanting a CI earlier. Emma, to help her in more practical situations to alert her to when her children were distressed, while Richard noted it would have improved his confidence and it would have potentially changed the course of his career.

The situations participants shared where they would have benefited ranged from work, family and general life. It showed how their hearing loss impacted on all aspects of their lives. The participants shared that after having had the CI they realised how beneficial it was and could reflect that it would have helped them throughout their lives had they have been implanted earlier.

The reason why it had taken them so long to be implanted ranged from *"being born at the wrong time", "it just wasn't offered to me"* and clinicians deeming them unsuitable. David also understood why it took some people longer to come forward with their being *"the fear of what was going to happen".* David related this fear to being around the CI process in general; it was an operation and it was quite an unknown situation. He became quite emotional discussing this as he found the whole process before coming to USAIS was a worrying time because of the lack of information available to him locally.

This subtheme showed how participants wished they had been implanted earlier and some of the obstacles they encountered which prevented this. They then discussed the support they were provided with.

6.4.2.4 Theme 4 "Behind me the whole way"

There were varied levels of support provided during the CI assessment or after the CI. This support was provided by implanted adults, clinicians at AIS and family members.

Family and friends were a key part of the CI process by providing support, being interested in what was happening and being there for the participants. This could have been after the CI when the participants were hearing new sounds.

"*He gets so excited you know if I hear something new*" Emma L189

Or supporting them through the CI process so they knew they were not alone through the process. They were described as "*supporting me*", "*behind me the whole way*", "*encouraged me*" and "*not me against the whole world*". The descriptions of family were quite powerful; they were the behind-the-scenes support and there when clinicians were not. Richard explained how his partner supported him through the initial tuning period.

"*She said to me when they were fitted she said listening to you in a room she said I think you are hearing better already she said I'm not joking I think you're hearing better already than you have done and that was just after it was fitted you know she had noticed a difference already in what your hearing she said you might say it's electronically but it's better it's a lot better she said just keep it going she said don't give up she said it's better actually a lot better*" L253-258

There were other instances of family members providing support. Claire and Richard described situations where family members helped with their rehab.

"We would go through days of the week months and numbers and so while we had noise going on he would go through numbers and stuff like that and then he would practise reading things to me whilst I wasn't looking" Claire L423-426

"Words to practise with my partner to see if I could pronounce them right and stuff like that had sentences and words and things and I did that at home in between appointments to establish words" Richard L209-211 interview 3

This showed the importance of the family members in the CI process; they were the people who supported, advised, and encouraged the participants.

Adults already implanted were described as supporting some participants through the CI process. The implanted adults gave the opportunity to talk to someone who had been through the CI process. This was mainly through a patient Facebook group.

"*I talked to them better to actually talk to someone about how they got on all very positive"* Claire L285-286

"*They were just telling me about their journeys and how amazing it is and how (unintelligible) in the pub really positive really really positive and so helpful*" Nicola L185-186

Talking to another CI user gave participants the opportunity to share their story and have the support from a peer group who knew what was going to happen next. Only two of the participants discussed this during the interviews as something they had been involved with. This may have been as the other participants did not seek out this peer group (this was accessed through Facebook and independent of USAIS) or were not informed about group during their assessment.

The themes shared so far explain the whole CI process and the experiences of participants after this. The next theme was quite different as it relates to what was happening in the world at the time of the interviews and although was not the focus of the interviews, was explored as this was important to participants at the time.

6.4.2.5 Theme 5: "It would be much better if people didn't have masks on"

This was a theme produced due to the Covid 19 pandemic taking place at the time of the interviews. Participants mentioned the issues with people wearing masks and how the changes to society, due to the virus, were impacting on their daily lives. People wearing masks was a big issue for several participants.

"*It would be so much better if people didn't have masks on"* Claire L463

"*Then it's actually quite hard I think that's interfering with the whole understanding thing if that sounds fair so it's causing a problem in that respect"* David L398-399

"There's the challenge of wearing the mask it's going to be more tiring" Nicola L297

Masks acted to prevent lipreading that people with a CI rely on to hear well. Two participants mentioned clear masks which they thought were great, as they allowed lipreading, but then we not actually Conformite Europeene (CE) tested so could not be used in a health care setting and the frustration of this.

"It would be nice if everybody had the clear masks because I said to the audiology department why don't you wear clear masks and they said it doesn't comply with CE certification… the government needs to wake up and realise you know" Emma L404-406

"It wasn't true because they weren't CE tested" Nicola L313-314

There were other situations where the participants struggled, for example Emma shared:

"*There was an Intercom so they wouldn't let me in so they were talking to me through the intercom and I said I'm sorry I said I can't understand what you are saying I'm deaf I need you to*

come to the door or to let me in so I can come see you I was stood out there for 5 minutes waiting for them to let me in I'm thinking I was really glad it wasn't raining and this is the problem that's going to happen with Winter coming you can't you can't walk into surgeries can't walk into pharmacies you have to be let in they've got all intercoms" L421-426

This impacted on the participants and they reported frustration and tiredness. This was due to the worry about how they were going to manage in situations where people were wearing masks and the effects on their own health and wellbeing.

"I have my days where I come home and I'm in tears with exhaustion" Nicola L308

"It's making me more frustrated I'm very easy going and very happy but this corona virus has really sort of affected me" Emma L565-567

Nicola and Emma both used the terms exhaustion and frustration relating to mask wearing and the affects this had on them. People with implants used lip-reading to aid their communication and removing this makes communication harder and so tiring. This was along with potential other factors of being in a pandemic and the removal of social contact may have acted to affect participants.

The Covid 19 pandemic affected the world in many ways, the experiences of these participants showed how wearing masks, and reducing face to face communication, negatively affects someone with a hearing loss.

"He said oh have you got the sunflower thing lanyard and I said no and he gave me one and then I've ordered the card really helpful so I can wear that if I go shopping I don't like drawing attention to myself but if think if you're like you say having a barrier of communication you need a bit more support so the only way you're going to get that is to make other people aware but that means wearing a badge or lanyard it doesn't make you silly" Nicola L327-344

Nicola explained that she needed more support at this time and that the lanyard has given her a way of showing that in a way she shared was appropriate.

The Covid 19 pandemic was mentioned by the CI recipients but not their family members. This may have been as the effects of mask wearing did not affect them in the same way. None of the family members were CI users and all used a telephone call for their interviews which identified they had reasonable hearing. Four out of five of the CI users were interviewed in person and had to attend the interview site wearing a mask and following Covid 19 protocols. This may have impacted on what was discussed in the interviews. It was noted that removing lip-reading cues for hearing adults would not have the same impact as they would for a CI user.

6.4.2.6 Summary

Most themes within this analysis looked at the participants' journey to the CI. The initial themes focused on their early lives living with a hearing loss and then move to identifying their need for a CI, their CI experience, and the support they received from others. It showed the effects of their hearing loss were felt throughout their lives from before they were implanted, to the how it affects them with after the CI and how it affected them during the Covid 19 pandemic. The CI journey was explored, from seeking a referral, considering the risks, the initial switch on appointment, exploring a new world, to considering why they had not sought out a referral sooner. All participants were very positive about CIs, with some negative views shared about managing the device and frustration with other people's lack of knowledge about CIs.

6.4.2.7 Pre and post-implant data

All the participants were positive about the effects of the CI on their, or their family member's, life. To determine if this was indicated in their test results their pre- and post-implant test results was examined. This was planned to be using audiometry and speech testing data. During data collection it was realised that sound field aided testing was not always carried out pre-implant so could not be compared post-implant. This meant that only speech test results were examined (See Table 28).

Most participants showed improvement on speech perception measures with four (4/5) of the participants improved on BKB testing with an average improvement of 84% (Range 78-94%). One participant had no BKB post-implant data. It could be assumed as this test was not performed that there was no expected improvement, but this could not be confirmed.

All of the participants who had post-implant BKB sentence data had no CUNY post-implant data recorded. This was likely as clinicians found an improvement on one test measure so did not test another measure. The participant who had no BKB sentence test result showed an increase of 7% on the CUNY sentence test. There was no data for the CUNY sentence test on what exceeds the test retest limits. It was likely a change of 7% was not related to an improvement in performance on this test, but there was no data to support this.

The CUNY sentence test was an easier test for patients as it involved lipreading cues, the BKB test did not provide these cues and was more challenging for participants.

Most of the CI recipients showed improvement on speech perception measures. It was unknown if the one participant that did not show improvements went onto experience improvements after this time as this was not within the scope of the study.

Table 28 The pre and post-implant speech test results for participants

Participant	BKB score pre-implant (%)	BKB score post-implant (%)	CUNY score pre-implant (%)	CUNY score post-implant (%)
Claire	10	93	71	Testing not completed
Richard	21	Testing not completed	72	79
Emma	0	78	94	Testing not completed
Nicola	14	95	Testing not completed	Testing not completed
David	0	94	100	Testing not completed

6.5 Discussion

This study explored the hopes and experiences of pre-lingually deafened adults of a CI using multiple sources of data. This included written documents, participant interviews and pre and post-implant test results. These data sources were used for triangulation and were then compared to the literature. My reflections on the data were included to give context to the data analysis.

The interview data were collected during the Covid 19 pandemic. This likely influenced the data collection through the technology used to collect the data, and the mindset of both the participant and myself at the time of the interviews. The interviews were completed at a time where, as a society, people were trying to reduce their face-to-face contact and families were unable to meet in person. The exact affects were not easily identifiable, but the data should be considered within this context. Throughout this section I described myself in first person due to the nature of my clinical role and insights I can provide regarding the CI process.

6.5.1 Considerations on the data analysis

On doing the analysis for Phase 3b, on re-reading what the participants gained from their CI, I became quite emotional. I was able to see the change and the benefits they received from a CI, when in clinic you do not always focus on the overall impact it had on their lives but ensuring they are hearing optimally. Reading the transcripts again, in a more focused way, really emphasised what an amazing device the CI is. It highlighted my involvement with the participants and my empathy with them. I had difficulty choosing some of the quotes as there were so many examples of situations which were so impactful. I felt I had a responsibility to represent their stories which added extra pressure. This was not the case during Phase 3a, this may have been as I did not know the contributors to the document data. I did not have the same connection to them, so the data had less of an impact.

During the data analysis I felt my positive views of an implant may have biased the analysis. I went back through the analysis with the aim of making myself a more neutral voice. This was challenging as the participants were so positive. There was a need to not lose this whilst ensuring I was more neutral. This was not the case during the internet data analysis, and I questioned why this was. I felt it was because I did not feel connected to this data. I had not spoken to these people directly, I had not laughed with them and empathised with them. The data felt very different to me.

The participants acknowledged my status as a hearing adult and a clinician with mentions of "*you take for granted*" (referring to me being hearing), "*I'd rather thank you Suzanne*". Even though only two of the participants acknowledged me as a hearing adult/clinician it would have been obvious to the participants that I was different from them; I did not have a hearing loss and I was a clinician that could be involved in their care, while one of the participants acknowledged my input in their care. It showed that my role at the centre impacted on the study and likely influenced what was discussed. Participants may have felt uncomfortable discussing negative aspects of their care or experience. This may have biased the data to more positively slanted towards CIs. There was no way to avoid this with me conducting the interviews. This would be an area to consider in future research.

When looking at the post-implant measures, one participant recorded limited or no benefit on speech perception measures. This participant reported benefit with their CI, and their interview gave no indication they did not improve on speech perception measures after twelve months of implantation. There is a need to consider that these participants, at the time of the study, had been implanted from one to five years. Previous literature has shown improvements in early deafened adults after one year (O'Gara et al., 2016) and this participant may have improved after the one year anniversary of their implant. The other reason was that the CI gave them other benefits than what can be recorded on speech perception tests.

6.5.1 Objectives

This study set out to answer the research question and meet the objectives described in 6.2. This study has answered the research question from the perspective of an aural early deafened adult. This study has met the objectives of discovering what CI recipients hoped to gain from the CI and how they recipient adapts to the CI. An insight into the views of the family members has been given. Due to the lack of family members recruited, what they base their hopes on and the adaptations they made for CI users could not be clearly determined.

6.5.2 Comparing the data sources

Pre and post-implant data were used to assess if what was reported in the interviews was supported by outcome measures. The themes shown in the participant interviews were mainly positive about the CI and several of the themes focused on the benefits the participants had gained from their CI. The pre and post-implant test results indicated that the majority of participants showed an improvement on speech perception measures compared to their pre-

implant scores. This showed that the benefits participants were reporting from their implants were also shown on their post-implant test results.

Comparison of the results of the thematic analysis of Phase 3a and 3b was used to establish if the participants and contributors reported similar outcomes and experiences. This was determined by comparing the main themes in each analysis to understand the similarities and differences between the two data sets. The two groups of participants were first assessed to determine any differences which may have affected comparisons of the data.

There were differences between the participants in each Phase. The interview participants (3b) onset of deafness was confirmed as being 6 years of age and under. There was no way of confirming the onset of deafness of the contributors to the internet documents (3a). This could mean that participants were included whose onset of deafness was over six years of age. This could have skewed the internet document data to be more related to post-lingually deafened adults than early deafened adults.

The duration of CI use could not be compared between the two groups as there was limited reference in the internet documents to how long they had their implants for. For the participants interviewed this was one to five years. The documents could have contained information from participants implanted for longer or shorter durations. This could have meant the internet documents were less accurate as participants were reporting on an experience that happened some time ago. This was also an issue regarding the point at which the experiences they shared had occurred. Participants in the interviews were asked about their experiences up to one year after the CI but it could not be confirmed that the stories shared were from one-year post-implant only. This would likely have been difficult for participants to remember. At what time point the experiences referred to within the document data occurred could not be determined. It was also not possible to determine at what time point after implantation the accounts were made, so for example was the participant within the document data account written/recorded 10 years after their CI or one year. These data were not available.

Comparisons between the themes from the two thematic analyses were then made, with three sets of themes being very similar. These are shown in Table 29. These themes covered similar areas and included identifying that a CI was an option, the benefits of the CI and the support they received.

The similarities between these sets of themes shows that the experiences reported by participants were evident within another data set.

Table 29 Comparison of themes

Interview analysis (3b)	Document analysis (3a)
The need for a CI	Why I chose a CI
CI journey	Life changing
Behind me the whole way	Taking this journey

Three themes were only seen in one analysis, the 'Deaf community' (3a) from the document review and the themes 'Growing up with a hearing loss' (3b) and 'it would be much better if people didn't have masks on' (3b) from the interview data. The D/deaf community theme was initially a theme within the interview analysis (Phase 3b: Stage 2 analysis) but was too small a theme to be in the final thematic map. It may have been given more prominence in the document review data as some of the documents were from adults who were signers rather than using spoken language. Coronavirus was not present at the time the documents reviewed were written and so would not have been evident within the document review. It was expected that this theme would only be seen within the interview analysis.

The document and interview data showed similarities in the data analysis. As the two sets of data were similar it allowed validity to be given to both data sets. It was surprising that both data sets were so similar with some members of the Deaf community viewing CIs in a negative light. I felt that this may influence the internet data to have a negative views of CIs compared to the interview data. There was some expectation that as the two data sets were from different mediums there would be differences in the themes found. This showed that, although the document data contributors could not be confirmed as having the same onset of deafness, the experiences they reported were similar to participants who were implanted at USAIS.

6.5.3 Comparison to the literature

This study aimed to identify the hopes and experiences of early deafened adults of a CI. The information from the documents and CI users and their families showed improvements in hearing which were reported as hearing speech and environmental sounds. The data discussed how they obtained a referral for a CI, what they expected from a CI and their CI experience, with both positive and negative aspects to this. Support from significant others and clinicians was also mentioned. As far as I was aware this was the first time data from documents/internet had been analysed to give information on CI experiences.

6.5.3.1 The referral processes

Participants and contributors were referred for a CI through hearing deterioration, clinician recommendation or it was participant driven. This was seen within the literature with hearing difficulties (Bierbaum et al., 2020, Dillon and Pryce, 2020, Ebrahimi-Madiseh et al., 2020, Snell, 2015), hearing deterioration (Dillon and Pryce, 2020, Snell, 2015), support of hearing professionals (Bierbaum et al., 2020, Ebrahimi-Madiseh et al., 2020) and positive experiences of others (Dillon and Pryce, 2020) being drivers for why participants were referred or sought a CI referral.

The results of this study showed that hearing difficulties were a factor for most participants to seek a referral. They explained that these hearing difficulties were related to general communication, social situations, and hearing at work. In the literature, the main reason participants sought a referral was due to hearing difficulties, but other factors were reported. Hearing difficulties were identified as social difficulties (Bierbaum et al., 2020, Dillon and Pryce, 2020, Ebrahimi-Madiseh et al., 2020, Snell, 2015) and difficulties managing at work (Bierbaum et al., 2020). Social difficulties were a very broad area including communication with partners, increased isolation, concerns regarding their independence and ability to function in social situations.

Hearing deterioration was reported by both participants and their family members, with concerns they would be unable to function in society or manage as a family with the worsening of their/the CI users' hearing levels. This was supported in the literature with (Bierbaum et al., 2020), Snell (2015) finding participants reported they could not cope or they were concerned about the future if they did not consider CIs. Dillon and Pryce (2020) participants were post-lingually deafened, so their hearing loss was gradually deteriorating, and had concerns about ending up with no hearing if they did not consider a CI. Participants also shared that they saw how well other CI users were doing and this made them consider CIs as an option for them (Dillon and Pryce, 2020).

Two of the factors that made participants consider a CI within the literature were not seen in the present study; these were the cost of HAs (Bierbaum et al., 2020) and social identity, with participants wanting to be 'normal' (Dillon and Pryce, 2020). The cost of hearing aids may have been a factor in the (Bierbaum et al., 2020) study as this study was performed in Australia, where patients paid for their hearing aids, but CIs were state funded. This was different from the NHS where both hearing aids and CIs were fully funded. Dillon and Pryce (2020) reported that a reason for participants choosing CIs was that they wanted to be normal; in their study a participant shared they lived in a hearing world and so to have a normal life meant they had to be hearing.

This study showed that health professionals were usually the people who first raised the potential of a CI with early deafened adults. This could be met with some hesitation and suspicion from potential candidates as it was not something they were seeking, while others had to very much convince health professionals to give them a CI referral or were concerned about what the CI process involved. There were quite different experiences relating to this. Both showed how health professionals were the gate keepers to services and they made decisions on referral suitability. With health professionals in some cases not referring, it questions what information health professionals based their decisions on and the lasting impact that their decisions had on the participants. For some, this delayed their referral to CI services for several years, while others it meant they considered a CI for the first time. This study highlighted the difficulties early deafened adults had in obtaining a CI referral. The explanation of a CI by local audiologists also caused some concern about what was going to happen to the participants when they were referred which did make them consider whether to be assessed. It was estimated that only 5% of the eligible CI candidates receive CIs (Raine, 2013). Within the literature the barriers to a CI referral were health professionals being unaware of CI candidacy, assessment process and outcomes (Bierbaum et al., 2020, Ebrahimi-Madiseh et al., 2020, Looi et al., 2017, Rapport et al., 2020). This has been reported by CI candidates and CI users (Bierbaum et al., 2020, Ebrahimi-Madiseh et al., 2020, Looi et al., 2017, Rapport et al., 2020) and CI professionals (Bierbaum et al., 2020, Ebrahimi-Madiseh et al., 2020, Rapport et al., 2020). HA professionals reported they lacked confidence discussing the referral and wanted better links with the CI centres (Bierbaum et al., 2020, Rapport et al., 2020). It was worth noting that all these studies focused mainly on post-lingually deafened adults. It may be that different factors act as a barrier to these groups which were not seen for post-lingually deafened adults. In my experience, from working in a local audiology department 10 years ago, this is due to discussing a CI being something they felt they did not know a lot about. The time constraints audiologists are working within and talking about CIs felt like you were breaking bad news to the patient as their hearing aids were not providing adequate benefit.

Within the UK, attempts have been made to address this within the hearing profession, with centres running information days, and the British Academy of Audiology (BAA) and the British Cochlear Implant Group (BCIG) encouraging referring centres to appoint a ‘CI champion’. A CI champion refers to an audiologist within the department who has had further training on CIs and has a liaison with the CI centres they refer to. The aim has been to try and reduce the lack of information and concern around CI referral and give professionals more confidence to refer (BAA, 2020). An internal presentation by Cullington (2022) indicated that, in local audiology departments, when a severe to profoundly deafened adult presented, in up to 50% of cases no CI referral was considered. This needs further review as 18 months into this process 50% of cases

were not having a CI referral discussed with them. There was no comparison to pre 2020 before the scheme was launched, so this could be an improvement, but this showed that cases were still being missed. One of the participants in this study suggested that, to improve this process, having CI clinicians in the local audiology centres would mean that CI candidates would be seen by someone who knew about the process. They felt this would reduce misinformation and would have reassured them at the time of their referral. There were difficulties around doing this for CI centres, since many centres cover a large geographical area and the ability to send staff out to local audiology sites regularly from a logistical and financial point of view may not be possible. How this could be adapted requires consideration.

Other barriers to a CI in the literature were the CI conflicting with Deaf culture (Dillon and Pryce, 2020) and hearing negative experiences of CIs (Bierbaum et al., 2020). These were not seen in this study. This may be that all of the adults in the study were aural and they did not appear to be actively involved in the Deaf community.

6.5.3.2 Hopes/expectations of the implant

The participants and contributors discussed their hopes and expectations of the implant and how these were managed. The participants all hoped to gain better communication and the majority of participants had their hopes exceeded. One participant wanted more than they have been able to gain from their CI in relation to communication. Of the seven participants, all but one felt their hopes had been met or exceeded. Participants did not share any more examples of what they hoped to gain, all the examples they gave were associated with communication. This may have been the most important aspect of getting the CI for them or they did not appreciate they would gain anything else. This may have been why the environmental sounds were so important as they did not realise what they were missing.

From my experience as a clinician, some patients who come for assessment come in with expectations that the implant may not be able to meet. This could be using the phone or understanding conversation in background noise, which were situations that implant users may not benefit in. It was important to ensure that the patient went into the CI with appropriate expectations. If they went in expecting outcomes they were unlikely to achieve, this could affect the relationship of trust between the patient and the service. It was a difficult balance, as patients were having a surgical intervention with all the associated risks and then may have their expectations or hopes from the implant lowered, but it was important to ensure the patient was making an informed decision regarding the implant.

Participants and contributors reported that they were advised to keep their expectations low which was common across studies with other studies reporting participants being told to not have "too high expectations" (Maki-Torkko et al., 2015), that their initial switch on appointment would be disappointing (Snell, 2015), or not to "expect too much" (Hallberg and Ringdahl, 2004). Hallberg and Ringdahl (2004) found these expectations were kept low to avoid disappointment. Snell (2015) found some patients were surprised how well they heard while others were disappointed, while Hallberg and Ringdahl (2004) found post-lingually deafened adults did not report any disappointment on how they were hearing with their implants. This could be related to the difference in onset of deafness. This showed that each participant's journey was unique to them. Previous literature reported that greater improvements were associated with more positive expectations (Flood et al., 1993). In this study clinicians were found to be actively lowering expectations, and participants with lower expectations were happier with their progress. There may be a difference between positive expectations and higher expectations. The literature regarding positive expectations improving outcomes was related to pain management (Cormier et al., 2016, Hill et al., 2007, Linde et al., 2007, van Wijk et al., 2008). McRackan et al. (2021) found, when looking at expectations in CIs, that patients with low preoperative expectations were associated with high postoperative QoL. They felt there were two potential interpretations of this. One, that patients with low expectations were more likely to have those expectations met, and two, low preoperative expectations may motivate patients to work harder to perform beyond their expectations. This study would follow the McRackan et al. (2021) study's first interpretation that having low expectations resulted in patients who had all their expectations met, while higher expectations did not. The potential outcomes for this participant group were related more to their onset of deafness; working harder would not significantly impact on their outcomes which were limited by their duration of deafness. Therefore, this could not follow the second proposed interpretation.

In the current study it was mainly clinical staff managing participants hopes/expectations which was also the case in the Maki-Torkko et al. (2015) and Snell (2015) studies. This was unsurprising from my perspective, as clinical staff usually end up seeing the patient more than medical staff and so act more regularly to manage hopes/expectations. In general, there was limited information found on both post lingually and early deafened adults' hopes/expectations within the literature. This may be as the research into CIs has mainly focused on outcomes and what the patients hope to gain from the implant, which was an under researched area. Snell (2015) was the only study found that included the expectations/hopes of pre-lingually deafened adults.

Within the literature, expectations of some interventions were discussed with reference to normal function. This was in relation to lower limb amputation (Ostler et al., 2014, Senra et al.,

2012) breast reconstruction surgery (Denford et al., 2011) and spinal cord injury (Carpenter, 1994). These were very different interventions to a CI and all participants in the studies started with normal function as a reference point. There was no discussion of this within the data or the literature found relating to hearing loss. This may have been as these adults were born with a hearing loss and so it was what was normal for them. They did not have a reference as to what having normal hearing was. There was discussion of wanting to be normal, but this was in relation to living in a hearing world (Dillon and Pryce, 2020) but not as a reference to normal function or what this participant defined normal as.

6.5.3.3 CI outcomes

Outcomes of the CI were included as hopes and outcomes were linked. If a user did not have their hopes met this means that they did not gain the outcome from the CI they expected. This could also relate to their hopes being exceeded with better outcomes or improvement in areas they did not expect. This results in hopes and outcomes being closely linked. In both the Phase 3a and 3b studies, very positive experiences and benefits of CIs were reported. These were mainly related to gains in hearing, but improvements seen in other areas such as confidence. This had been reflected within the literature for pre-lingually deafened adults with benefits reported for communication (Caposecco et al., 2012, Chee et al., 2004, Debruyne et al., 2020, Heywood et al., 2016, Lammers et al., 2018, Snell, 2015), increased confidence (Snell, 2015), independence (Chee et al., 2004), greater sense of safety in their environment (Chee 2014) and QoL (Chee et al., 2004, Debruyne et al., 2020). An improvement in communication was presented as either an improvement in speech perception measures (Caposecco et al., 2012, Debruyne et al., 2020, Heywood et al., 2016, Lammers et al., 2018) or through participants reporting improvements in communication (Caposecco et al., 2012, Chee et al., 2004, Snell, 2015). This study indicated improvement in communication through patient report and speech perception measures. Caposecco et al. (2012) also showed this through both mediums but the participants reported improvements in communication through a questionnaire and not interview techniques used in this study.

Snell (2015) showed confidence was improved with a CI with their participants relating this to managing better in social situations. In this study, improved confidence was related to participants doing activities that they would have never considered before their CI. The dissimilarities between the studies may be due to the examples participants used to explain why their confidence had improved. You would expect that improved confidence relating to managing in social situations was also experienced by participants in this study, they just did not share this. Chee et al. (2004) found improvements in safety and QoL and used questionnaires that specifically

asked about these topic areas. This study did not specifically ask about these areas which may be why it was not seen in the data.

Lammers et al. (2018) found a high rate of non-users with 21% (10) of adults having stopped using their implants. They had a higher rate of signers within their group with all (4) reporting no benefit from their implants. This high rate of non-use was not seen in this study (although smaller participant numbers) or by Chee et al. (2004) who reported the majority of their participants were using the implant all waking hours. This could be related to the hearing history of the participants, but this was difficult to tell from the information provided by both studies. CI users not wearing their implants could mean that their hopes of the CI were not met. There was limited qualitative data within the literature involving early deafened adults, as most studies had investigated outcomes in relation to case note review or performance on outcome measures (Caposecco et al., 2012, Debruyne et al., 2020, Heywood et al., 2016, Lammers et al., 2018, van Dijkhuizen et al., 2016). The studies that applied a qualitative methodology used open (Hallberg and Ringdahl, 2004) and semi structured interviews (Snell, 2015). This study gave a qualitative focus to the outcome literature using semi structured interviews and document review to the mainly quantitative data in the literature. Including two different data sources gave a new perspective and gave each source of data additional validity by comparing and contrasting their findings. Hearing research has had a more quantitative focus and hearing researchers are becoming more aware of the benefits qualitative research can bring (Rapport et al., 2020).

There were similarities and differences between the results of this study and the literature on early deafened adults. The results of this study were considered in relation to the literature on post-lingually deafened adults. In studies with post-lingually deafened adults improvements were reported in communication (Boisvert et al., 2020, Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015), confidence (Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015), reduced isolation/improved social life (Kennedy et al., 2008, Maki-Torkko et al., 2015, Rembar et al., 2009), hearing environmental sounds (Rembar et al., 2009) and going back to normal (Kennedy et al., 2008, Maki-Torkko et al., 2015, Rembar et al., 2009). The increased confidence reported in the Hallberg and Ringdahl (2004) study was associated with increased participation, which was the same as this study with early deafened adults. The report of hearing environmental sounds was mentioned in the Rembar et al. (2009) in regards to “being wonderful” but lacked the emotion seen in the current study.

Two of the themes within this study were “Life Changing” and “CI journey”, and these were similar to themes found by Rembar et al. (2009) (a new life), Maki-Torkko et al. (2015) (alienation – normality) and Hallberg and Ringdahl (2004) (coming back to life). These themes showed the

positive impacts of the CI which was seen throughout the literature, although there were differences compared to this study. Hallberg and Ringdahl (2004) described the theme "coming back to life" as about a new start and the ability to connect with people in a different way, while Rembar et al. (2009) found the theme "a new life" to be about the implant allowing them to enjoy life more and for their lives to be like they were before the hearing loss. Maki-Torkko et al. (2015) found participants reported themselves as going back to normal, with participants going from alienation (not hearing) to normality (hearing). The Rembar et al. (2009), Hallberg and Ringdahl (2004) and Maki-Torkko et al. (2015) studies were with post-lingually deafened adults which would explain why they had reports of coming back to life or returning to normal being seen in the themes. This was not seen in the current study and was likely related to the participant group having lost their hearing rather always being hearing impaired. Losing your hearing as an adult would result in different expectations to someone who had always been hearing impaired. Having had hearing post-lingually deafened adults know what having good hearing is like and how losing their hearing has affected their interactions and communication. Someone who has always had a hearing loss does not know what it is like to have hearing and so must base their expectations on other factors. This was a clear difference between the studies and could be related to participants reporting that having the implant did not change them and they were still deaf. The papers shared a similar report of hearing more and showed the impact of the CIs on participants' lives.

There was limited qualitative literature on the experience of early deafened adults but more available for post-lingually deafened adults. This was due to studies' recruitment materials mainly being written or researchers choosing to only recruit post-lingually deafened adults. Early deafened adults were likely seen as a hard-to-reach group and more difficult to recruit so research with post-lingually deafened adults was more common and likely easier due to the difficulties with recruitment. Although early deafened adults have different hearing histories compared to post-lingually deafened adults, both groups reported similar outcomes (Hallberg and Ringdahl, 2004, Kennedy, 2008, Maki-Torkko et al., 2015).

6.5.3.4 Negatives aspects of a CI

This study highlighted that having a CI was not all positive and there were negative aspects relating mainly to equipment, batteries, and the expectations of others. Issues with batteries and equipment were a common report in studies looking at users experience with concerns about equipment breaking (Hallberg and Ringdahl, 2004, Kennedy, 2008), batteries running out (Hallberg and Ringdahl, 2004, Maki-Torkko et al., 2015, Snell, 2015) and cosmetic aspects relating to the processor (Dillon and Pryce, 2020, Ebrahimi-Madiseh et al., 2020). When these issues arose participants reported feeling vulnerable (Maki-Torkko et al., 2015) or being reminded how deaf

they were (Hallberg and Ringdahl, 2004, Snell, 2015). There were no reports of issues with uncomfortable sounds within the literature which was indicated in this study. There were concerns around the expectations of others which had been shown previously within the literature, with people thinking that as they had the implant their hearing was 'normal hearing' (Maki-Torkko et al., 2015) or 'perfect' (Kennedy, 2008) which was not the case. Another aspect that was not seen in this study was in relation to the look of the devices which was reported by participants in Ebrahimi-Madiseh et al. (2020) and Dillon and Pryce (2020) studies. Dillon and Pryce (2020) participants reported they considered the look of the processor in deciding to have a CI but this was not a barrier to them choosing the CI. One of their participants reported that at least she could cover it with her hair. The Ebrahimi-Madiseh et al. (2020) study did not expand on exactly what cosmetic influences participants reported.

6.5.3.5 Environmental sounds

The participants' descriptions of hearing new environmental sounds were powerful with some of these sounds being heard for the first time. There was limited data in the literature regarding early deafened adults' experiences with environmental sounds. Snell (2015) participants reported that the experience of hearing new sounds was emotional and powerful for participants. For example, "*(I) press the bell on a bus stop I never knew it made a noise*". The limited qualitative data available means that the experiences regarding these sounds have not been captured in depth.

Hallberg and Ringdahl (2004) found that hearing environmental sounds was important for their participants but the experiences reported did not have the emotional impact seen in the early deafened adult studies. This may have been as the post-lingually deafened adults in their study had experience of hearing these sounds before their implant and early deafened adults hearing these sounds for the first time experienced a bigger emotional impact. The participants in the Hallberg and Ringdahl (2004) study reported experiences relating to hearing speech again as being emotional, which was reported less by the participants in this study. This may be as hearing speech took longer to be of benefit compared to the participants in the Hallberg and Ringdahl (2004) study. This study showed that environmental sounds were an important benefit for these participants and have an emotional impact which had not been focused on within the literature previously.

6.5.3.6 Significant others

The small number of significant others involved in this study meant that conclusions about the effects of the implant were not clearly evident. This study found that significant others took

satisfaction in their CI users' progress and provided support throughout the CI process. Other studies looking at the effects of implants on the significant other have found benefits to the CI users' significant other. This was reported as reduced stress and a decrease in burden to the significant other, as they were no looking being relied on for communication (Kennedy, 2008, Maki-Torkko et al., 2015). This aspect was not reflected in this study, but this may have been as only two significant others were recruited, a more focused approach on the family members may have shown this. Both studies involved post-lingually deafened adults' significant others (Kennedy, 2008, Maki-Torkko et al., 2015).

6.5.3.7 Improving the CI process

All participants were asked if they were happy with the information received as part of the assessment process and all reported that they were happy with the information provided. They did not feel any more/different information was required. One participant suggested improving the referral process and this was discussed in 6.5.3.1. Another participant reported that it needed to be clear that there was potential for early deafened adults to have a different outcome from someone who was not born deaf and that this could have been emphasised as part of their assessment. They felt that they had not appreciated that some of the people they saw doing very well was due to the fact they had previously had hearing and were comparing themselves to them. This was also shared in the document data but not seen within the literature found. There was very little information about the CI process as in general there has been more focus on trying to ensure patients get referred than how to improve the CI journey. In the main participants reported being happy with their CI journey which could explain why this area has not been a focus of research, particularly when it is evident there is a number of eligible CI candidates not being reached. This also could be related to hearing research having in the past a more quantitative focus (Rapport et al., 2020). More qualitative research would allow these areas to be investigated and may indicate future areas of research.

6.5.3.8 Covid 19

Mask wearing significantly impacted on the participants with a CI. Covid 19 resulted in mandatory mask wearing in healthcare settings and members of the public now more commonly wear face coverings in some settings. Masks prevent lip-reading by hiding lip patterns, facial expression and muffle high frequency sounds important for speech understanding (Goldin, 2020).

Participants reported issues with communication which impacted on their wellbeing and their ability to go about their day to day lives. The negative effects of masks had been seen by Saunders et al. (2021). Saunders et al. (2021) found when surveying members of the public that face masks

that from their report face masks affected sound transmission, removed lip-reading cues, impacted on the interpersonal connection having a negative effect on anxiety, stress, and confidence. Their participants also shared that it made communication tiring, frustrating and embarrassing. Masks impacted people with a hearing loss more due to their reliance on lip-reading cues (Moberly, 2019). This would indicate why the CI participants in this study reported issues with masks while the significant others did not.

Clear masks could allow access to these lip-reading and facial cues but at the time of the study were not CE marked. This has now changed and clear masks are available which are now CE marked (ClearMask, 2021). With clear masks now CE marked they may be more widely available to help individuals with a hearing loss. How widely these are worn by healthcare professionals and by the public was unknown.

6.5.4 Distinction between hard of hearing and Deaf

The participants in the Phase 3a and 3b studies described themselves as deaf, Deaf or hard of hearing. There were differences in what these terms refer to and what individuals were referring to themselves as when they called themselves D/deaf or hard of hearing.

Someone who described themselves as Deaf (with a capital D) viewed themselves as a cultural minority, they did not feel their deafness was a disability and can feel alienated by the hearing community (Calgaro et al., 2021, Hole, 2007, Valentine and Skelton, 2008). Someone who was aural and has a profound hearing loss would not necessarily describe themselves as Deaf but refer to themselves as deaf or hard of hearing. In the Phase 3b study none of the participants labelled themselves as culturally Deaf (with a capital D), they were all brought up with spoken English as their first language. Only one of the CI recipients spoke about learning sign language as an adult and none of the others had learned sign language. The differences between a person whose first language is spoken English and someone whose first language is BSL were distinct.

There have been differences reported in the brain structure between Deaf sign language users and normal hearing adults (Shibata, 2007). It has been shown that when sign language users were visually stimulated it resulted in activation of the auditory cortex which would usually be activated in response to sound in normal hearing listeners. It was demonstrated that a silent lip-reading task with normal hearing listeners resulted in activation of the auditory cortex, while pictures of signs activated the auditory cortex in sign language users (Calvert et al., 1997, Nishimura et al., 1999). There were no studies comparing sign language users with early deafened adults who were aural. These studies suggested that there had been reorganisation of the brain structure to focus on visual stimuli for sign language users. It was likely this impacted on the benefits obtained from

the CI, as the auditory cortex has been reorganised to focus more on visual stimuli. The silent lipreading task activated the auditory cortex in hearing adults (Calvert et al., 1997), this suggested it could be the case in aural adults who will rely on lipreading. Teoh et al. (2004b) reported that using aural communication as the educational modality could reduce this brain reorganisation. Osberger et al. (1998) showed in a study with pre-lingually deafened children that outcomes were significantly higher for children who used aural communication compared to total communication.

They have been reports within the literature around identity issues of deaf children and young adults, with reports of participants not feeling they belonged to the Deaf or hearing communities (Olsson and Gustafsson, 2022). This has been seen regarding psychological wellbeing with adults who reported a marginal identity (Deaf nor hearing) had lower levels of psychological wellbeing than hearing, Deaf or bicultural (Deaf and hearing) adults (Chapman and Dammeyer, 2016). Olsson and Gustafsson (2022) asked hard of hearing young adults about their deaf identify; they found these young adults found it easier to socialise with others who were hard of hearing, and felt they were in-between hearing and Deaf groups and did not fit anywhere. They also reported it was difficult to be part of the Deaf group as they did not sign and could feel excluded by both groups. These reports about identity and exclusion were not reported in this study and were not raised by participants. All participants in the Phase 3b study attended mainstream school, with one participant attending a mainstream school with a deaf unit attached. Participants reported feeling excluded and singled out but did not share that this was related to not belonging to one group or the other; this may have been as this was not specifically asked about. All CI participants discussed their schooling but no issues regarding deaf or hard of hearing identity.

6.5.5 Summary

This study identified that early deafened adults benefited from a CI and gained more than an improvement in speech perception, with the CI affecting their confidence and experience of the environments they are in. This study highlighted areas that the participants reported would have improved their CI journey. This was the first study I was aware of that reviews the document/internet data to gain a view of the CI experience. The recommendations, implications for practice and key learning points are discussed in Chapter 7.

Chapter 7 Discussion and Conclusions

7.1 Introduction

This thesis has aimed to explore the expectations and experiences of early deafened adults of a CI. Since starting this research in 2015 it has evolved to include a focus on the family and a discussion on how to include a minority group in research. The language used in the thesis has changed, based on the participant group and a need to ensure accessibility. It has developed from one study into four study phases and covers a much wider topic area than was first proposed. At the beginning of the project, the challenges carrying out research with minority group of participants who use a visual language and require an interpreter were not fully recognised. There was also a lack of awareness of how to work with a BSL interpreter and the knowledge required to make research documents accessible.

The development and evolution of this study has been possible due to it following a pragmatic approach. This flexible approach uses a methodology focused on effectively answering the research question. It allowed this study to change its approach, based on the results of different phases and use methods which focused on answering the research question. At each Phase of the study, the research question was considered in relation to the information gained from each Phase. This was to ensure the methods being used were still appropriate or to ascertain whether they required adjusting (Morgan, 2007). It allowed this study to change from a case study methodology to a general qualitative approach due to the effects of Covid 19 pandemic. Although the use of a general qualitative approach has been criticised for the lack of validity measures (Lim, 2011; Kahlke, 2014), the flexibility of this approach was needed. Phase 3 incorporated aspects of case study research, including its validity checks, which helped ensure a valid and rigorous approach was taken.

7.2 Key learning points

These key learning points were based on the main findings of each study phase and also considered my dual role. The key learning points from this study were as follows:

7.2.1 Aural early deafened adults

The aural early deafened adult group were a distinct group and different from adults who were Deaf with a capital D. This Phase 3b provided insights for a distinct group around the support,

identifying their need for an implant and their journey to get a CI. They were different from post-lingually deafened adults, as they had grown up with a hearing loss and distinct from culturally deaf early deafened adults, as their chosen language was not BSL. The literature highlighted how they felt as if they do not belong to either group (Olsson and Gustafsson, 2022) and their experiences were likely to be different from the culturally Deaf group who may have been educated in an environment with access to sign language. This had not been routinely considered within the current literature on CIs. Within the literature there was little reference to the culturally Deaf or hard of hearing as being distinct groups; they were considered in the literature as the same participant group as they were deafened within the same age range. Within a study using a qualitative method, Jeffs et al. (2015) included three adults who were aural and five adult BSL users, whilst Bosco et al. (2013) included 14 purely aural participants and nine who used a mixture of sign and bimodal (aural and sign). They did not distinguish or compare the two groups of participants. In relation to the papers that used quantitative methods, Heywood et al. (2016) included eight aural participants and four oral and sign or sign/total communication, while Chee et al. (2004) included one participant who was a signer and 28 who used lip-reading/hearing/lip-reading and hearing. None of the papers discussed a difference between the two and the Chee et al. (2004) paper with one signer was likely skewed towards the aural group but this could not be fully investigated as individual data were not presented. My study was different from the Chee et al. (2004) paper as it used semi-structured interviews, rather than a questionnaire, and focused on the whole experience of cochlear implantation. Papers that included both groups had the potential to have skewed results depending on the number of participants in each group. A focus on aural early deafened adults was not seen within the literature but has been the focus of my study. More studies concentrating on BSL and aural early deafened adults could show the similarities and differences between the two groups as they are likely to have different needs and experiences.

7.2.2 The importance of environmental sounds

Historically the outcomes of CI have been viewed as improved speech perception and quality of life (Boisvert et al., 2020). Hallberg and Ringdahl (2004) showed that environmental sounds were important to post-lingually deafened adults as was found with the early deafened participants in the current study. The emotional impact was much greater for this study's participants compared to the post-lingually deafened adults in the Hallberg and Ringdahl (2004) study. This was likely as the post-lingually deafened adults had heard these sounds before as they had lost their hearing as adults. The greater impact for early deafened adults was due to it being the first time they were hearing these sounds and how they helped their understanding of the world they lived in. This

study highlighted how important environmental sounds were for participants and how powerful the experience of hearing these sounds for the first time was. This had not been considered within the literature for early deafened adults (further discussion can be found in 6.5.3.5).

7.2.3 Family members

Family members were an important part of the CI process, providing support and encouragement to CI users. There has been limited research within this topic. Although Maki-Torkko et al. (2015) showed the CI affected the CI users significant others this had not been shown for early deafened adults as all the previous authors focused on post-lingually deafened adults or did not specifically recruit early deafened adults users significant others (Kennedy, 2008, Maki-Torkko et al., 2015, Wexler et al., 1982). This was the first study that I was aware of that focused on the experiences of early deafened adults' family members and showed how they provided this support and how they were part of the CI journey.

7.2.4 The need to include BSL users in research

BSL users' views on healthcare can be missed as the methods used to collect these data were not suitable for them, for example using written questionnaires without a BSL version. These users were CI candidates but their views on CIs were not prevalent within the literature. Involving BSL users within research means considering accessibility of recruitment materials, working with an interpreter, and working with this community to ensure the research is relevant to them.

This study discussed ways of recruiting BSL users but none were recruited. All the information was made as accessible as possible and involved BSL users in PPIE. It highlighted that recruiting BSL users can be challenging. BSL users required adaptations to study materials and changes in approach that would not always be considered when researching CI users as a whole.

Why were no BSL users recruited?

It may have been that these BSL users were not approached in the correct way. Due to the reduced appointments, most participants were recruited by posts on the department's social media channels. These may not have been regularly used by the participants, or the study may not have been of interest to them. This study aimed to make the study relevant to BSL users through PPIE (Chapter 5) but more PPIE may be required. This study identified that even if information was accessible more needs to be done to reach this group. Researchers who worked with BSL users have usually recruited them through deaf clubs, deaf organisations or were known

to researchers through their contacts in the field of Deaf studies (Snell, 2015, Valentine and Skelton, 2008).

How could this be overcome?

As the research was carried out as part of a PhD programme and needed to be an independent piece, this limited what could be done to overcome some of these issues. Having a BSL user involved in the project was considered an important aspect of recruiting more BSL users. This could be in the capacity as a BSL researcher, interpreter co-researcher or the researcher knowing BSL. Having involvement of a BSL user was important as they have knowledge of the community, they know what research would be important to the community and they have links to the community which can aid recruitment. How to involve BSL users as researchers requires more consideration within the research community.

Snell (2015) and Valentine and Skelton (2008) successfully recruited users through Deaf clubs and organisations. It is likely that for higher engagement, in research and PPIE, researchers will need to make links with these organisations. An example of this was Valentine and Skelton (2008) who visited deaf clubs/societies in twelve cities in the United Kingdom to answer questions on their research. They then received 419 responses to their study, which shows how engaging with the community resulted in their involvement in research. This thesis has provided novel insights into the design issues around including BSL users and highlighted the challenges of recruiting BSL users in research.

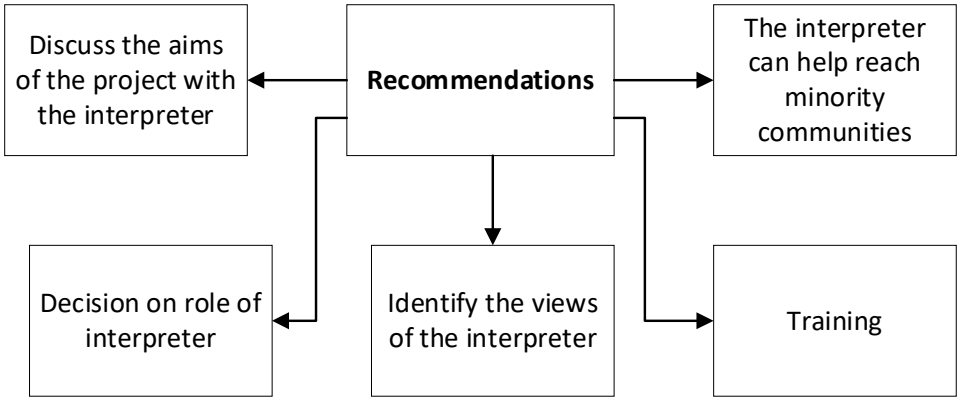
7.2.5 Working with interpreters

Working with an interpreter was essential to make this study accessible to BSL users and the wider research community. The application of this depends on the role the interpreter has within the research. Recommendations for working with interpreters can be found in 4.10.3, a summary of the main recommendations is shown in Figure 23.

Interpreters affect the data; acknowledging that is important within a research study, and ignoring it suggests the data has been word for word interpreted and shows a lack of understanding of the interpreting process. Training of interpreters is also important to ensure they understand the area they are interpreting in order to avoid any misunderstandings during the interviews and affect the data collected. If all or part of the research team are unfamiliar with BSL then having the interpreter involved early on, with significant input into the recruitment and design of the study, would aid the study's relevance to the BSL users. With a BSL researcher, an interpreter would be important to allow communication between the research team (if it includes

non-BSL users) and interpreting this for publication or dissemination to the wider research community.

Figure 23 Summary of recommendations on how to work with interpreters in research



7.2.6 Accessibility of research materials

How to make research accessible is an important consideration for research studies. This study has set out how to make research materials accessible for BSL users and how to ensure that the study was accessible for all, not just one group. This meant considering how BSL users would access the materials and through which medium.

Previous studies were not clear if or how they made their studies accessible. Heywood et al. (2016) used a questionnaire at twelve months, but this could have been performed in clinic with an interpreter present or posted home. The fact that this was unclear means an assessment of if or how they made their study accessible was difficult to ascertain. Snell (2015) successfully recruited BSL users through their recruitment methods and ensured their interviews were accessible by ensuring they were carried out in the participants preferred language but there was no mention if the consent forms or participant information sheets were available in BSL or how/if they made these accessible. This was common for the studies found in the literature (Jeffs et al., 2015, Skelton, 2003, Snell, 2015, Valentine and Skelton, 2008). In some instances this was likely to be that the accessibility of these materials was not a priority but this was unlikely to be the case for Snell (2015), Valentine and Skelton (2008) and Skelton (2003). These authors successfully recruited BSL users, and they were likely to have then made these documents accessible but did not share this within the written paper. This could be related to the style of journals they were writing for or the limits of the word count for published papers. Not discussing how these materials were accessible means it may not be clear to researchers who have not worked with this community before how to successfully recruit this group.

Making this study accessible meant it was important that accessibility had been considered from all perspectives, as not being a BSL user, I could not be an expert in what was necessary to make research available to this group. Carrying out the Phase 2 PPIE with a BSL user and providing the materials in a BSL format were the first steps in this process. Through the Phase 2 and 3 studies it was realised that accessibility for all participant groups needed to be considered and what might be accessible for one group may not meet the needs of another. This needs to be considered in any future work.

7.2.7 Clinicians as researchers

Being both the researcher and a clinician was a help and a hindrance. Knowing in detail about the participants' experiences allows clinician researchers to ask more appropriate questions but also assumes understanding of some points. It allows clinician/researchers access to participants which the non-clinical researcher would not have (Lotty, 2020). A researcher who did not know about the CI experience may have focused on different aspects and therefore collected different data. It meant creating a balance between the two roles as they were not independent of one another and any conflict with other staff had the potential to be carried across into either role. Being both the clinician and the researcher resulted in me feeling more responsible for the participants as I knew the participants and had in some cases been part of their CI journeys. It made me consider what data were presented more than an independent researcher may have. Being a clinician and a researcher was a privilege as it allowed me to hear the participants' stories and become part of their journey; it gave them a position of trust which someone they did not know would not have. There were more aspects that needed consideration when having a dual role, but it was likely that the data collected was richer as a result.

Within the research papers included in the literature review it was likely that some of the papers were completed by researchers who were also clinicians. This was potentially the case for the Jeffs et al. (2015) and Heywood et al. (2016) as the corresponding addresses were hospitals with an implant programme and I was aware of the authors having clinical backgrounds. The clinician's exact role in the papers was not clear and so their effects on the data cannot be determined.

7.2.8 Accessing CI centres

Participants reported that accessing CI services was an issue. This was related to them not being identified as a CI candidate or being told incorrectly they were not suitable. One participant felt they very much drove their CI referral and they may not have been seen at all if they had not taken control of this situation. Accessing CI services has been reported as an issue previously

(6.5.3.1). It was unclear if participants were not referred as they were deemed unsuitable candidates due to their duration of deafness, were seen to be doing too well to benefit from a CI or it was not considered by the clinicians seeing them. This is discussed further in 7.3.

7.3 Implications for service provision

The participants raised points within their interviews which could improve the service provision. This was mainly relating to the initial referral process and counselling for pre-lingually deafened adults.

1) Difficulty being referred for a CI means that large numbers of adults are not aware they are CI candidates and potentially struggling with their hearing loss. Making the initial referral process easier for these adults first involves training the local audiology departments. This is a big topic within the field of audiology as there are large numbers of adults who meet the criteria for a CI but are not being referred. The CI champions discussed in 6.5.3.1 show how local audiology and CI centres are working together to try and improve this referral process. This relationship aims to have more informed and aware local audiology departments to ensure that candidates are given accurate information and audiologists feel comfortable having conversations about a CI with them. An unpublished study by Helen Cullington (2022) found that only 50% of people who met CI criteria attended an audiology department, had CIs mentioned to them and, of those who were referred, approximately 25% of the group dropped out or did not wish to be assessed. This was supported by Thompson et al. (2022) who found that, of their 18 patients who met the audiogram levels for CI referral, only five (28%) had been offered a CI referral. These studies show that audiologists are still not comfortable discussing CI referrals and there is the question as to why these candidates then decided not to be seen for CI assessment. More training with audiology departments would be the first step but potentially there is a need to go beyond this and ask referrers what they feel prevents them discussing a CI with adults who meet the CI referring criteria. Potential areas for future work are discussed in 7.6. Another way of making adults aware they were CI candidates was making patients and the public more aware of CIs. CIs, and more generally hearing aids, are not routinely seen in the media and therefore the general public's awareness of cochlear implants is limited. On the basis of previous campaigns it has been proposed that this should be focused on adults who have been identified as having a hearing loss but what forms this should take was unclear (D'Haese et al., 2020). The differences in access for BSL users and aural deafened adults was unknown. All the adults in the Thompson et al. (2022) study were aural and they did not record onset of deafness.

Access for BSL users would be expected to be more challenging as they have difficulty accessing NHS services generally due to their communication needs not being met (McKinnell, 2019), and limited deaf and cultural awareness (Hulme et al.).

2) Outcome measures need to be considered for early deafened adults. Previous research has identified early deafened adults to be poorer CI candidates due to lower improvements on speech perception measures compared to post-lingually deafened adults (Teoh et al., 2004a). This study has shown that the adults in this study have improved outcomes on speech perception measures but also in other areas such as confidence. QoL measures were important to consider as these participants all reported benefits with their CIs and spoke of how having a CI had changed their lives. These data indicated that the early deafened adults in this study were good CI candidates and that measures, other than speech perception, need to be included to show improvements in other areas such as confidence and hearing environmental sounds which were not considered in a speech perception test. Applying a test for environmental sounds in a clinic setting was then considered. A systematic review of the literature was performed by Shafiro et al. (2021) on using these tests with CI users. They found no overall improvement in environmental sound improvement after implantation. In their review only one study focused on early deafened adults (Peasgood et al., 2003). Peasgood et al. (2003) found early deafened CI users had comparable scores to post-lingual CI users on environmental sound identification. Of their participant group, six of the 10 used aural language exclusively. These authors used the University College London Cochlear Implant team/Royal National Institute for the Deaf (UCL/RNID) recorded lists (Summerfield, 1995) as part of the Prediction of Outcomes of Cochlear Implantation in Adults (POCIA) test battery (Summerfield et al., 1997), while other authors have used Familiar Environmental Sounds Test-Identification (FEST-I) (McMahon et al., 2018). The POCIA test battery was used widely within the UK but after withdrawal of the POCIA this test has not been made available on its own (as far as I was aware).
3) Different outcomes were evident for early deafened adults and post-lingually deafened adults. In this study participants, although benefitting from the CI, were aware they were not doing as well as CI users who had lost their hearing as an adult. This was seen in the document data with post-lingually deafened adults being able to tune some sounds out (6.3.4.1). Claire shared that she spoke to someone who was late deafened and did not realise she would not have the same outcome: "*what I hadn't realised was that Amanda was late deafened and if I'd been a bit more sort of clued up on that then I wouldn't have fallen for that*". This was related to a situation where she could write information down without looking at the participant. If early deafened adults were counselled incorrectly

this could lead to unrealistic expectations and disappointment. Counselling patients who were born with a hearing loss that they would not get the same outcomes as someone who was born with hearing was highlighted as being important. This would involve discussing this with the clinical staff and ensuring that, even if the patient gets benefit from their hearing aids, different outcomes were likely compared to post-lingually deafened adults.

4) Involving family members in the CI process allows CI candidates to be more supported. Family members were identified by participants in Phase 2 and Phase 3 as being an important part of the CI process; they provided support to the participants in many ways such as a communication partner and acting to encourage the participants to continue with their CI journey. The family members in the study reported they had received appropriate information. Due to small participant numbers this area needs further research before any firm conclusions can be made.
5) Masks were identified as an issue for CI recipients accessing healthcare services due to the barrier to lipreading and resulting effects on communication. This needs consideration by all healthcare providers. Wearing clear masks enables anyone with a hearing loss to access lipreading and facial cues to aid their understanding. Ensuring that all clinicians were aware of this and wearing clear masks during their appointments was essential to provide appropriate provision to this group.

7.4 Implications for policy development

The main policies for cochlear implantation were the candidacy criteria (NICE, 2019) and then outcomes measures that were recorded at the twelve month review appointment. The candidacy criteria for a CI were hearing thresholds equal to or greater than 80dBHL at two frequencies (500, 1000, 2000, 3000 and 4000Hz) and a phoneme score on the AB word test of less than 50%. The outcome measures related to benefit were an improvement in quality of life and an improvement on a speech perception test compared to pre-implant levels. There were no other policies affecting CI selection and outcomes.

The results of this study support having no onset of deafness criteria for CIs. Having an early onset of deafness may have excluded the adults in this study from having a CI. If an assessment of candidacy was proposed that included age of onset of deafness this would need to be considered carefully as this research indicates that adults who were early deafened showed benefit with their CI. This could prevent adults with similar experiences, not having the access to CIs. It was difficult to completely determine age of onset of deafness if the adult was not screened as a newborn, so how this could be accurately determined would need consideration. It had been suggested in the

literature that, for early deafened adults, the candidacy criteria of aural communication should be applied (Teoh et al., 2004b) as the outcomes of aural communicators exceeds those who use total communication (Kirk et al., 2002, Osberger et al., 1998). The studies comparing aural and total communication outcomes both involved children and not adults. The differences in outcomes were thought to be due to brain reorganisation (Teoh et al., 2004b) which means comparable outcomes with adults would be expected, although this was not confirmed. This study showed that aural communicators benefited from an implant and therefore supports criteria where they are not excluded from CI. This study cannot comment on the benefits of total communicators or BSL users as none of these users were recruited to this study.

Most of these adults showed benefit on speech perception measures and all have reported benefits in all areas of their lives. Based on this, outcome measures other than speech perception need to be included in measuring CI outcomes. If this was not considered, then this participant group could show no improvement but report improvements in other areas which were not measured. The majority of studies in the literature have focused on speech perception; a review of the CI literature by Boisvert et al. (2020) showed 16 different QoL measure were used across 36 papers. This makes comparing outcomes challenging. It also showed that out of the 102 papers in the review only 36 included QoL measures. This shows that QoL measures were not routinely used to consider CI outcome. Using a more consistent measure across studies and centres would then allow some comparisons between the groups. The language level of these measures needs to be considered and their suitability for both pre and post-lingually deafened adults.

CI centres report their outcome measures and a QoL measure was included in this but again the quality of life measure used was not indicated and not all centres may be using validated QoL measures if not indicated.

7.5 Contribution to the knowledge base

This study contributes to the knowledge base information on the hopes and experiences from the perspective of the early deafened adult who was aural. This was a perspective that was not always evident within research. Aural early deafened adults' perspectives can be lost within the early deafened adult group, as early deafened adults can include a variety of communication modes, or within the post-lingually deafened adult group which contains adults who lost their hearing after language acquisition. They were a distinct group, not BSL users but brought up with a hearing loss. As far as I was aware this was the first time the family members of aural early deafened adults' views were sought on the CI process.

This study reported on their experiences with an implant, the referral process, the benefits they gained, and the negative aspects of a CI. I was aware of no studies within the literature that have reported exclusively on aural early deafened adults' experiences and hopes of an implant.

The steps required to make a study accessible and methods to do this were highlighted. This study showed that even when accessibility was considered there were more considerations needed when recruiting a minority group.

This study added how to work with an interpreter in a research setting and shared the perspective of BSL interpreters which was not present within the published literature. These interpreters are different from other language interpreters as they are interpreting from a visual language, in simultaneous mode, while the majority of interpreters translate from one spoken language to another.

This study showed the importance of environmental sounds to early deafened adults and that they reported greater benefits in this area than reported in the literature for post-lingually deafened adults.

In summary this study adds

- Perspective of the early deafened aural adult

This study shared a new perspective of early deafened adults' experiences of implantation, how they were referred for a CI, their experiences of hearing speech and environmental sounds and why they did not have an implant earlier and what this means to them. Aural early deafened adults can be lost within the early deafened user group as they are within the same group as BSL users, not included as they are not BSL users, or they are included in a group with participants with were deafened as adults. These aural early deafened adults do not fit in either group.

- Perspective of early deafened aural adult family members

This gives an insight into the family members views of the CI process and allows them to voice what they feel would have improved their and their family member's experience. This was a new insight, as the literature found that either they did not state the onset of deafness or included post-lingually deafened adults (Kennedy et al., 2008, Maki-Torkko et al., 2015, Wexler et al., 1982)

- Insight into the experiences of adults during the Covid 19 pandemic

This study showed the effects of masks on CI users' day to day interactions during the pandemic and how the more common use of masks would be expected to continue to affect their interactions and communications.

- Discussed how to recruit and make a study accessible for BSL users

This work has provided new insights into the design issues around including BSL users as how to make studies accessible has not always been considered. Including BSL users in research is important to allow them to share their experiences and share services to meet their needs. This study highlighted the challenges of recruiting BSL users in research and discussed how to improve this in future work.

- Perspective of a BSL interpreter of their role within a research setting

Working with interpreters in research was not common. Discussing with the interpreter their role in a research study and learning from them helps reach minority groups and allows clinicians and services to build links with d/Deaf communities.

- Recommendations on how to work with interpreters in research

After interviewing and working with interpreters, recommendations from a researcher's perspective have been provided. This aims to aid future researchers when considering how to work with interpreters and avoid some of the questions and confusion around working most effectively with interpreters.

This study has added this information to the knowledge base but there were still gaps in the knowledge that this study first set out to identify.

7.6 Future work

There were different areas that require future research based on the results of this study.

7.6.1 BSL users

The hopes and experiences of BSL users of a CI were not identified from this work. Identifying their views and experiences would have improved their experience of the implant process. Previous research has identified participants whose expectations were not met but what expectations were not met has not been discussed (Bosco et al., 2013, Jeffs et al., 2015). All the papers that included early deafened adults included both BSL users and aural participants (Bosco et al., 2013, Chee et al., 2004, Heywood et al., 2016, Jeffs et al., 2015) which prevented each group's voice being the focus of the research. This remains a gap within the literature.

7.6.2 Family members

Only two family members were interviewed in this study; more widely seeking the views of family members of the CI process would allow what support family members need (if any) to be identified. This would be from the perspective of both early deafened and post-lingually deafened adults. The views of family members have been captured using questionnaires (Kennedy et al., 2008, Maki-Torkko et al., 2015, Wexler et al., 1982) but not using interviews. They did not specify the age of onset of deafness of the CI user whose family member they approached but it was likely post-lingually deafened adults (Kennedy et al., 2008, Maki-Torkko et al., 2015, Wexler et al., 1982). Involving family members in hearing aid management has been reported to be beneficial in the rehabilitation process (Armero, 2001, Mamali et al., 2020) and was an important factor in enabling participants to seek help for their hearing loss (Meyer et al., 2014). More research had been performed on this topic from a hearing aid perspective.

7.6.3 Longitudinal study

Following adults through the CI process would give more information about what they experience, their hopes and how this changed over a year after implantation. Interviewing adults before an implant, after initial tuning and then at one year would provide more information on the assessment process and how to improve it. Few qualitative longitudinal studies have been published with adult CI users; the only study found explored the benefits of music workshops on participants (van Besouw et al., 2014). The majority of these studies focused on paediatric CI users and their families. At the time, no qualitative longitudinal studies were found which related to CI users' experience of a CI.

7.6.4 National study

This research has recruited participants from one implant centre in the UK only; a UK wide study would give a greater insight into what was important for these adults and would likely reach a larger participant pool. Valentine and Skelton (2008) and Snell (2015) advertised and recruited across the UK through online platforms and Deaf clubs. A national study does not necessarily mean working with implant centres across the UK but could mean working more with Deaf clubs or online platforms.

7.6.5 Covid 19

The effects of masks on communication have been clearly shown in this study. As the long-term effects of the pandemic continued how these effects were impacting on these individuals and

ways of overcoming the barriers in communication needs further investigation. Early deafened adults would be disproportionately impacted due to their reliance on lip-reading. Homans and Vroegop (2021) used questionnaires to assess the effects of Covid 19 on communication in adult CI users, and found that face masks considerably affected the communication of participants and reduced their quality of life. Using interviews would allow participants to share the impacts of Covid 19 that affected them most and to share their experiences of the Covid 19 pandemic which closed set answers in questionnaires do not allow.

7.6.6 Access to CI services

How to address the issues with access to CI centres needs further investigation. Work has been performed investigating the barriers to CI referrals (Bierbaum et al., 2020, Ebrahimi-Madiseh et al., 2020, Looi et al., 2017, Rapport et al., 2020). Further qualitative work with audiology centres and patient groups can help understand the reasons why patients were not referred and then why they choose not to attend for assessment.

7.6.7 Changes over time

Raine (2013) noted that there was a lack of awareness among professionals of the candidacy criteria and the advantages of cochlear implantation. The patients including in Phase 3b were implanted between 2014 and 2019 and were referred by audiologists during this time period. Since then the candidacy criteria for a CI changed (NICE, 2019) and the CI champion scheme was launched (BAA, 2020). The role of a CI champion was to train their teams, to ensure all eligible patients make an informed choice when considering a CI and to audit their CI referrals (BAA, 2020). The potential impacts of these changes on audiologists discussing expectations is unknown and is an area for further research. It is thought that experienced CI clinicians communicating about expectations would have changed, due to the scientific evidence showing benefit, but not local audiologists who are not CI experts.

7.6.8 Did the internet data affect patients' hopes?

This study focused on comparing what the expectations were between the document and the interview data. It did not identify if CI users' hopes were influenced or changed by information they found on the internet. This would be a future area of research.

7.7 Challenges and Limitations

This section discusses the challenges, limitations and areas of improvement within this study.

7.7.1 General qualitative approach

The Phase 1 and 3 studies followed a general qualitative approach. General qualitative approaches were described as ill-defined and limited due to their lack of validation (Kahlke, 2014). They can be moulded to suit the methods required and aspects of different methodologies/ combined to make new approaches (Caelli et al., 2003). These new methods were not validated but allow questions that would otherwise remain unanswered to be addressed. This has been included as a limitation as it could be a limitation by readers and other researchers so requires discussion. This was not viewed as a limitation in this study but a method that allowed the data to be collected, analysed and the research question addressed. Methods to validate the data were put in place from well described methodologies in the literature (Braun and Clarke, 2006, Merriam, 2009). There was awareness of the potential limitation of using this approach and an attempt was made to minimise this by ensuring validity measures from other methodologies were applied.

7.7.2 Data limitations

This data gave an insight into the experiences of early deafened adults who were aural. It cannot be applied across all early deafened adults as BSL users were not represented within this study. Due to the small numbers and participants being from one CI centre it may be that different participants have different experiences of a CI. The data were supported by the literature but a larger study involving more participants and including BSL users would enable more conclusions about the early deafened adult group to be made.

Due to the sample of participants and the risk of breaching anonymity data regarding CI history, heritage and diagnosis were not collected. This means that this data needs to be considered without detailed information about each participant. This is a limitation but it would not have added additional insight into the data analysis.

7.7.3 Covid 19

Covid 19 had significant effects on the Phase 3 study. It changed the structure of the Phase 3 work which has been described throughout Chapter 6 and Chapter 3. This was shown by Covid 19 being a theme in the data analysis. This was a limitation as it did not allow the planned study to proceed. Using a case study approach and recruiting adults going through the assessment process would have given a real insight into their hopes and if these changed across the period of implantation.

The study continuing during the pandemic allowed a different aspect to the captured which may not have been otherwise. Although Covid 19 has changed the study it did allow the participants' views of Covid 19 to be captured during the pandemic rather than retrospectively.

7.7.4 Longitudinal data

The changes to the study meant that no longitudinal data were captured. This meant that all the data were retrospective. Capturing the phenomena as they occurred may have resulted in richer data as the CI experience would have been captured as it happened. This requires further investigation.

7.7.5 Document review

The internet search looked to include CI stories from adults deafened under the age of six years. It was impossible to ensure that the stories included were from adults deafened with a severe to profound loss as this was not mentioned in the stories. This may have introduced bias in the analysis with stories showing greater benefits from a CI than are evident from a population born or who developed with a severe to profound hearing loss under the age of six.

7.7.6 Participants

This study recruited five CI users and two family members. All the CI users were aural. No BSL or sign supported English communicators were recruited. This would have added another aspect to the study and allowed the experience of someone who uses a visual language to be captured. BSL users would likely have a different experience to an early deafened adult who uses spoken English which was not always considered. The current literature groups aural and BSL users together and did not consider the difference between the two groups (Bosco et al., 2013, Chee et al., 2004, Heywood et al., 2016, Jeffs et al., 2015). This prevents the BSL voice from being heard.

How to recruit BSL users' needs to be considered as although the recruitment materials were all in BSL, no BSL user was recruited to the study. Effectively recruiting BSL users was considered in 7.2.4 and identified that linking with Deaf clubs or forums should be considered when recruiting this group.

The small number of family members did not allow this group's experience of cochlear implantation to be investigated in depth. Recruiting more family members and then analysing their data separately would have allowed this and potentially have provided greater insights into their experience of implants and their effect on them.

7.8 Has this thesis changed how I view myself?

At the beginning of this thesis, I discussed the insider/outsider view and how I viewed myself as a clinician doing research rather than a researcher clinician (section 3.6). Has completing this thesis changed this view? Other researchers have reported a shift where they change to a researcher clinician (Lotty, 2020). Lotty (2020) describes this researcher/practitioner (clinician) as being both an insider and an outsider. For example, an insider in that they are a clinician who influenced the research process, but also a researcher (outsider) who aimed to reduce bias and complete a thorough research process. When I first came to reflect on this, I was adamant I was still a clinician doing research and did not fit the outsider role. I felt like saying that I was an outsider took something away from my clinical role. On reflection I then considered why this was, was it a lack of confidence in my abilities? Did I feel that changing to an outsider took some of my abilities as a clinician away? I have never completed a research thesis and in some instances find myself wondering is this enough, have I completed a high-quality research project? Having completed this thesis over seven years, I realised I have changed to a researcher clinician and the difficulty acknowledging this is related to the fact I have not submitted this thesis yet and therefore the final step in being a researcher/clinician feels like it is incomplete. Lunt and Shaw (2017) noted that clinician researchers have an identity that is not a researcher or a clinician but it is both, which then can be isolating. Completing this thesis has been at times isolating but also an extremely rewarding process. I have learnt so much about qualitative research and how to perform a qualitative research project, which I intend to use in the future. On consideration, I feel that this research project has made me a better clinician. It has ensured that I am evidenced based and that I work to answer the questions or issues of the patient, while then reflecting on how these experiences could improve my practice. This thesis has opened different avenues of research that I would never have considered before. I came to this thesis from a quantitative background and performing a qualitative project has been at times challenging and frustrating but one of the main things I have left this project with is an understanding of the importance of asking service users what their views and thoughts are. Clinicians and researchers do not know what patients' experiences are, and therefore involving patients and service users in improving their care is important to drive service development.

This researcher clinician aimed to be a researcher who completes high quality research that improves the patient experience while protecting and supporting participants. As a clinician I strived to provide the best care I can for my patients.

7.9 Conclusions

This thesis aimed to identify the hopes and experiences of early deafened adults of their families and has shown this from the perspective of the aural early deafened adult. The limited knowledge base regarding early deafened adults' experiences and hopes of a CI has been expanded upon with the addition of this thesis' findings. This knowledge focused on aural early deafened adults who were not regularly the focus of research studies as aural and sign language users were usually gathered into one participant group. Few studies have looked at their experiences using qualitative interviews. This thesis highlighted the limited knowledge of the role of early deafened adults' families in cochlear implantation and ways of supporting and providing information about a CI to early deafened adults. Ways of designing research to be accessible to BSL users were described and the issues with recruiting BSL users discussed.

The Phase 1 and Phase 2 studies changed the focus of this thesis. They provided additional information which complemented the original research question, from identifying how to work with interpreters in a research setting to discovering what was important to CI users and their families. This resulted in the study title changing to what early deafened adults and their families hope and experience of a CI. Over the seven-year candidature this thesis has evolved due to the needs of the study and the findings of each study phase.

This study has identified that early deafened adults hoped to improve their communication and the CI actually resulted in more benefits than they expected. These unexpected benefits were related to environmental sounds and improved confidence. Participants suggested ways of improving their experience such as improving the referral process which need to be considered within CI services as a whole as this was not an issue only affecting early deafened adults.

The participants recruited to the study all used spoken English, no BSL users were recruited. This has enabled the perspective from the aural early deafened adult group to be explored which may be grouped with BSL users or post-lingually deafened adults. Their voice has the potential to be lost or not considered at all as they could be excluded from each group due to their communication mode and onset of deafness.

Appendix A Table showing the papers included in the literature review

Paper
Athalye S, Mulla I and Archbold S (2014) The experiences of adults assessed for cochlear implantation who did not proceed. *Cochlear implants international* 15(6): 301-11
Bosco E, Nicastri M, Ballantyne D, Viccaro M, Ruoppolo G, Maddalena AI and Mancini P (2013) Long term results in late implanted adolescent and adult CI recipients. *European Archives of Oto-Rhino-Laryngology* 270(10): 2611-2620
Chee GH, Goldring JE, Shipp DB, Ng AHC, Chen JM and Nedzelski JM (2004) Benefits of cochlear implantation in early-deafened adults: The Toronto experience. *Journal of Otolaryngology* 33(1): 26-31
Finlay L and Molano-Fisher P (2008) 'Transforming' self and world: a phenomenological study of a changing lifeworld following a cochlear implant. *Medicine Health Care and Philosophy* 11(3): 255-267
Hallberg LRM and Ringdahl A (2004) Living with cochlear implants: experiences of 17 adult patients in Sweden. *International Journal of Audiology* 43(2): 115-121
Heywood RL, Vickers DA, Pinto F, Fereos G and Shaida A (2016) Assessment and Outcome in Non-Traditional Cochlear Implant Candidates. *Audiology and Neuro-Otology* 21(6): 383-390
Jeffs E, Redfern K, Stanfield C, Starczewski H, Stone S, Twomey T and Fortnum H (2015) A pilot study to explore the experiences of congenitally or early profoundly deafened candidates who receive cochlear implants as adults. *Cochlear implants international* 16(6): 312-20
Maki-Torkko EM, Vestergren S, Harder H and Lyxell B (2015) From isolation and dependence to autonomy - expectations before and experiences after cochlear implantation in adult cochlear implant users and their significant others. *Disability and Rehabilitation* 37(6): 541-547
Newberry E (2011) 'I wish I had known to prepare for that'. Wife, mother, and patient: the impact on family dynamics post-implantation. *Cochlear implants international* 12 Suppl 2: S24-6
Rembar S, Lind O, Arnesen H and Helvik A-S (2009) Effects of cochlear implants: a qualitative study. *Cochlear implants international* 10(4): 179-97
Snell L (2015) Documenting the lived experiences of young adult cochlear implant users: 'feeling' sound, fluidity and blurring boundaries. *Disability & Society* 30(3): 340-352
Tyler RS (1994) Advantages and disadvantages expected and reported by cochlear implant patients. *American Journal of Otology* 15(4): 523-531

Appendix B CASP checklist for Qualitative studies

	Athalye et al. (2014)	Finlay and Molano-Fisher (2008)	Hallberg and Ringdahl (2004)	Jeffs et al. (2015)	Maki-Torkko et al. (2015)	Rembar (2009)	Snell (2015)
Clear statement of aims	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Qualitative methodology appropriate	Yes as looked at the experiences of this group	Yes – looked at lived experience	Yes looked at what it meant to have a CI.	Yes – looking at experiences of a CI	Yes – looked at experiences	Yes – wanted insights into effects of a CI	Yes- looked at lived experiences
Was the design appropriate to address the aims of the research	Yes – used an exploratory design.	Used existential phenomenology to present a narrative account	Yes used grounded theory and followed this method	Yes – used grounded theory analysis. Unclear if they used the rest of the theory for this paper – i.e. interviewing to saturation etc	Yes- no theory used	Yes – used questionnaires	Yes- No theory used thematic analysis
Was the recruitment strategy appropriate	Yes, first 10 who met the study criteria were approached and agreed to take part – purposive sampling	No recruitment, worked together and decided to explore the experience together. Participant was the author	Say that sampling followed grounded theory method and continued until saturation	Yes – contacted all pts who met inclusion criteria.	Included all participants that met inclusion criteria	Invited all patients who met inclusion criteria	Yes- used a range of methods. Included all that contacted her

	Athalye et al. (2014)	Finlay and Molano-Fisher (2008)	Hallberg and Ringdahl (2004)	Jeffs et al. (2015)	Maki-Torkko et al. (2015)	Rembar (2009)	Snell (2015)
Data collected in a way that addressed the research issue	Yes – semi structured face to face interview. No mention of data saturation	Yes, interviews, personal reflections and notes.	Yes, data collected using open interviews	Semi-structured interviews	opened ended questionnaire – interviews would have explored the topics raised more but large numbers in the study	Did not justify why used questionnaires and not interviews.	Yes, interviews
Has the relationship between the researcher and participants been considered	No they did not consider their own role. No consideration if data affected by typing responses rather than spoken/interpreter. Why did they choose to type?	Yes and no, they considered their relationship to be beneficial but did not consider how it could impact on the data collected and if it would affect their relationship going forward	Yes they considered the interviewer and used someone who had not met the participants before. They used an interpreter and did not discuss the effect on the data collected/if any	Yes – discussed researcher induced bias. Used someone not involved in patient care. Used an interpreter and then transcripts interpreted (by either the person doing the interviews or someone else. Main interviewer then checked transcripts – did not comment on any effect on the data.	As questionnaire not performed with researcher – no effects considered	As questionnaire not performed with researcher – no effects considered	No effects seem to have been considered. Did not mention the effect of the data on the different mediums of data collection (BSL/ MSN interview). Relationship between the interviewers considered.
Have ethical issues been taken into consideration	Ethical approval from the ear foundation internal review	No ethical approval sought. Participant gave informed consent.	Yes these were considered, ethical approval was obtained	Yes, NRES approval obtained	Ethics committee approved	Study was approved by ethics committee	Did not mention ethics or ethical approval.

	Athalye et al. (2014)	Finlay and Molano-Fisher (2008)	Hallberg and Ringdahl (2004)	Jeffs et al. (2015)	Maki-Torkko et al. (2015)	Rembar (2009)	Snell (2015)
Was the data analysis rigorous	Clear how themes were derived from the data. Some themes were quite descriptive	Yes – clear how this was performed and what was considered	Yes, clear how data were analysed. Themes came from the data	Themes seemed to be relevant to the data. Some were descriptive	Themes relevant and linked to the data. Analysis is well described	Themes linked to data – some themes were more descriptive than related to the data.	Thematic analysis, themes linked to the data. Not much information on the analysis
Clear statement of findings	Yes	Yes	Yes	Yes	Yes	Yes	Yes
How valuable is the research	Results were discussed with reference to current literature, they did identify further research topics	Addresses compared to current literature, they do identify further research areas to consider	Compared findings to current literature. Made recommendations for practice	Small sample size but feel it is representative. Compared to previous research	Compared to previous research and gave future areas to look at	Did relate back to previous research. First time looked at this group. Did discuss further research	Related back to previous research

Appendix C Review of Quantitative papers included in the literature review

	Bosco et al. (2013)	Heywood et al. (2016)	Chee et al. (2004)	Tyler (1994)
Statement of aims	Yes	No but clear hypothesise	Yes	No
Rationale	Looked at outcomes after implant in early deafened adolescents and young adults	Determined if meeting expectations can be a measure of successful CI and if post-op speech scores can be determined by a number of listed factors	Looking at benefit from a CI from early deafened adults	List advantages and disadvantages pre implant and then post-implant listed what adv and disadv they experienced
Sample size	23 (2 groups - adolescents 10 young adults 13)	13	30	41

Appendix C

	Bosco et al. (2013)	Heywood et al. (2016)	Chee et al. (2004)	Tyler (1994)
Data collection tool	Used formal speech and language tests. Repeated tests were carried out under the same conditions. Structured interviews and psychological assessments were also performed	Listing of expectations pre implant then rating if these had been met post implant. Questionnaire related to expectations given post-implant Speech perception tests pre and post-implant. Demographic data were also collected	47 item survey	Questionnaire with two questions given twice.
Procedure	Speech, language and psychological tests were performed pre and post implant. The interview was performed post-implant only.	Patients listed 3 most important expectations pre-surgery and then 1 year after if these had been met using a 1-5 scale. Speech tests performed pre and post-implant	Survey posted home, with opened ended and multiple choice questions	Questionnaire completed pre-implant then 9-12 months after implantation
Data analysis tools	For the speech test results the Wilcoxon Matched pairs	Used a Wilcoxon Matched pairs signed ranks test	Recorded percentages and numbers of	Responses were collated and given a percentage that

	Bosco et al. (2013)	Heywood et al. (2016)	Chee et al. (2004)	Tyler (1994)
	signed ranks test was used to compare pre and post-implant results. Participants results were compared overall and then into adolescents and adult groups. The results of the interview were converted into percentages of the group that responded to each question answer.	was used to compare pre and post-implant results. Recorded percentage and numbers of patients whose expectations had been met.	patients selecting each answer.	had responded with the same answer. These were then grouped into categories chosen by the researcher.
Ethical issues	No ethical issues raised	None raised		None raised
Limitations	Retrospectively asked to judge improvements. Participants had been implanted for over 7 years so this could have affected what they reported. Sample size was quite small when splitting into two groups.	Study under powered due to participant numbers. They did not disclose if interpreters were used	Survey not validated. Language level. Which questions were open questions was unclear.	The researchers assigned responses to categories. They did not clarify what the patients responses meant as it was a questionnaire.

Appendix C

	Bosco et al. (2013)	Heywood et al. (2016)	Chee et al. (2004)	Tyler (1994)
Biases	No control group so they felt improvements could not be totally attributed to the implant.	None raised. Who conducted the questionnaires or speech testing was not discussed. This could have affected what was reported in the questionnaires	None raised	None raised. The questionnaire was administered in a clinic waiting room which was likely at the implant centre though this was no disclosed.
Conflict of interest	None disclosed. The authors likely worked at the implant centre or the testing took place at the centre as its pre-implant testing performed under the same conditions as post-implant	None disclosed. Questionnaires and testing likely took place at the implant centre. This information was not provided	None raised. Survey likely administered from the implant centre	The administering of the questionnaire was likely in a clinic setting this could be a conflict of interest depending on how it was administered by the information provided was not clear

Appendix D Approaches to case study research

There was no consensus on the design or how effectively to conduct case study research (Yazan, 2015). There were three main methodological approaches to conducting this research developed by Stake (1995), Merriam (1998) and Yin (2003). The authors differed with regards to what was a case study, their theoretical positions, case study design, data collection, data analysis and validation. However it was important to note that there was some overlap between the authors.

What is a case study?

Schwandt and Gates (2018) note there are there were multiple definitions of what a case study was and they significantly varied between authors. Stake (1995) defines a case study as 'the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances' pg xi, he also described a case study as being an investigation of a bounded and integrated system (Stake, 1995). While Yin (2014) described a case study as investigating a case 'in depth and within its real world context especially when the boundaries between the phenomenon and context may not be clearly evident' pg 16. He described the boundaries as not being clearly evident, this referred to real life situations as the context in which the case was viewed was not always easily defined. This approach described a case study as an 'empirical inquiry' (Yin, 2014) pg 16, so as the researcher you remove your views and biases from impacting the data, and looked at the how or why questions relating to the case (Yazan, 2015). To completely remove any bias that the researcher, with their dual role as a clinician/researcher, brought to the study would be challenging. Merriam (2009) p37 describes a case study as 'an in depth description and analysis of a bounded system', this was similar to Stake's (1995) description of a case study as being an investigation into a bounded system.

With the varying definitions Schwandt and Gates (2018) argue that apart from a case study methodology being an 'in-depth investigation of a phenomenon' (pg 344), what truly is a case study is hard to define. For this study a case study is defined as being an in-depth investigation and analysis of a phenomenon of a bounded case. This takes aspects from all the authors' descriptions of case study research but shares more similarities with Stake (1995) and Merriam (2009) definitions.

Theoretical positions

Stake (1995) held the view that aligned to constructivism/interpretivism (Harrison, 2017), where "knowledge is constructed rather than discovered" (Stake 1995 pg 100) he also felt the researcher held an interpretive role in the construction of the knowledge. He stated that there were

"multiple perspectives" of the case, but you cannot establish what the right or best view was. This was in contrast to Yin (2003) whose methodological approach aligned with post-positivism/realist (Harrison, 2017, Yin, 2014), this approach focused on objectivity. A post-positivist view was that they wished to understand the nature of reality but acknowledged that the ways to measure this were imperfect (Harrison, 2017). This view held that they were trying to establish facts or get close to the true explanation of what was happening in reality through maximising methods of quality control (Harrison, 2017, Yazan, 2015). Merriam (1998) had a similar viewpoint to Stake (1995) with a constructivism perspective. She felt that reality was constructed by individuals with multiple perspectives, which is similar to Stake's (1995) viewpoint. She differed to Stake (1995) in that she did not require researchers to be involved in this construction (Yazan, 2015). Case study analysis fit methodologically with how to analyse my data and so answered the research question but it had not been described in relation to a pragmatism.

This PhD used a pragmatic approach. Although Case study research has been described as a pragmatic and flexible approach (Harrison, 2017) in relation to constructionism and post-postivism (Yazan, 2015, Harrison, 2017). Pragmatism viewed constructionism and post-positivism as approaches to inquiry or research (Morgan, 2014b). Pragmatism was about researcher using the most appropriate methods to answer the research question and accepted that approaches to research actually share many similarities (Hanson et al., 2005). The researcher identified case study research as being the appropriate methodology to answer the research question. Due to pragmatism having been chosen as the approach/paradigm this allowed the researcher to use case study research even though the author's described this in relation to constructionism and post-postivism as they were being viewed as approaches rather than philosophical paradigms.

Case study design

Stake (1995) proposed a flexible design where researchers can make major changes after starting data collection. The design focused on the research questions which aimed to help structure the data collection methods. He did not feel the study's direction can be predicted in advance or that there was an exact point when data collection begins (Yazan, 2015).

The flexibility seen in Stake's (1995) approach was in contrast to Yin (2003) who used a detailed and structured approach to case study design. This included detailed descriptions of the data collection methods, analysis and how the findings were interpreted. He also proposed looking at the strengths and weaknesses of any design before implementation. The study design was decided before the study commences with only minor changes after data collection, if major changes were needed the researcher needed to go back to the first step of the study design (Harrison, 2017, Yazan, 2015, Yin, 2003). Merriam (1998) approach has been described as a

combination of both Yin (2003) and Stake's (1995) approaches (Yazan, 2015). With Merriam (1998) presenting a detailed study design, which she suggested should be flexible to a degree. With the limited literature on experiences of early deafened adults a flexible approach was appealing as it allowed the researcher to make changes based on the data collected. The flexibility described by Stake (1995) was not always possible when submitting studies for ethical approval and being the first time the researcher has conducted case study research structure to the design to desired. Using Merriam's (1998) design allowed both the structure that was required with some added flexibility which allowed the researcher to respond to the data collected.

Type of data

All the authors recommended using data from multiple sources but the types of data used differ. Stake (1995) and Merriam (1998) suggested that this data should be exclusively qualitative, while Yin (2003) supports using both qualitative and quantitative methods. For a list of the data gathering tools used by each author see Table 30. The Phase 2 study suggested that patients found out from other users who had an implant what to expect, while family members used internet resources. Therefore Interviews and internet resources were used in this study. Physical artefacts and archival records were not used as they were not resources that had been identified to influence expectations from the Phase 2 study. Observations were not used in this study due to the researcher's dual role and resulting conflict of interests. Pre and post-implant test results were included as a type of documentation.

Table 30 Data gathering tools used by each author

Yin (2003)	Merriam (1998)	Stake (1995)
Interviews	Interviews	Interviews
Direct observation	Observations	Observation
Documentation	Document analysis	Document review
Archival records		
Participant observation		
Physical artefacts		

Analysing the data

The three authors approach to data analysis differs. Yin (2003, 2014) promoted a highly structured data analysis with analytic guidelines and described specific strategies for this. He promoted five methods for analysis which were described in detail. This had a focus on the data

collected being both qualitative and quantitative (pattern matching, explanation building, time series analysis, program logic models and cross case synthesis).

Stake (1995) described analysing and collecting data simultaneously and then two ways to analyse the data, categorical aggregation and direct interpretation. While describing two methods he also discussed a need for the researcher to identify a type of analysis that suits them.

Merriam (1998, 2009) was similar to Stake in describing data collection and analysis occurring simultaneously. She explains how this can be performed and how the data analysis becomes intensified when all the data are collected. Merriam (2009) description of category construction was comparable to Stake's (1995) description of categorical aggregation. Merriam's description of category construction was more detailed with a step by step process provided. Merriam (1998, 2009) included a section on how to use computers for data analysis, which was also presented by Yin (2014) but in less depth. She described six analysis strategies (ethnographic analysis, narrative analysis, phenomenological analysis, constant comparative method, content analysis and analytic induction).

This study collected qualitative and used thematic analysis to analyse the interview and document review data. Thematic analysis identified patterns within the data and was similar to other methods of coding qualitative data described by Yin (2011). Thematic analysis shared characteristics with categorical aggregation and category construction described by Stake (1995) and Merriam (1998, 2009). Thematic analysis was widely used within case study research (Abdi et al., 2019, Carey et al., 2019, McDonald et al., 2012, Nowell et al., 2017, Pomare et al., 2019, Power et al., 2019) and the researcher has previous experience using this method of data analysis. Stake's (1995) description of categorical aggregation shares similar characteristics with thematic analysis such as coding and arranging codes into coding categories which could be described as themes. Braun and Clarke (2006) gave a detailed description of the stages of thematic analysis, categorical aggregation, although described by Stake (1995) this is not as thorough. Thematic analysis had been applied within a theoretical framework it also gave a more structured framework for the analysis to follow with a clear audit trail. With the researcher being new to case study research and having previous experience with thematic analysis this method was chosen for analysis of the interview data.

Data validation

All the authors recommended different methods for data validation. Yin (2003, 2014) differs significantly from Stake (1995) and Merriam (2009) due to their theoretical positions. With Yin's (2003, 2014) positivistic view compared to constructionist elements of both Merriam (1998) and

Stake (1995). The authors descriptions of validity and reliability differ as do their methods for achieving them (Yazan, 2015).

Yin (2003, 2014) described how the quality of a study can be determines through four tests, construct validity, internal validity, external validity and reliability (See Table 31 for a description of these and methods for achieving these. Yin (2014) also gave the phases in the research that these occur in with a requirement that these were considered throughout the study.

Table 31 Yin's methods for validating data based on Yin (2003) & (2014)

Validation tool	Meaning	How this is performed
Construct validity	Use appropriate methods for the case being studied	Triangulation, chains of evidence and member checking
Internal validity	Eliminating alternative explanations for a finding and ensuring your explanation is the true explanation	Using analytic techniques (pattern matching, explanation building, addressing rival explanations and using logic models)
External validity	Generalising findings to other situations/studies	Analytical generalisation (either modifying, rejecting or advancing theory used as a basis for the case or identifying new concepts from the case study)
Reliability	The study can be repeated with the same results	Case study protocol and databases

Both Stake (1995) and Merriam (1998) included validation tools with a focus on qualitative data and that took into account their constructionist viewpoints. Stake (1995) described triangulation protocols including data source triangulation, investigator triangulation and theory triangulation (See Table 32 for a summary). Stake (1995) also included member checking where participants gave feedback on the interpretations of the case. Stake's (1995) validation tools had a focus on the data collection methods being mainly observational or from interviews.

Table 32 Stake's (1995) data validation tools

Tool	How this is performed
Data source triangulation	Looking at the case at different times, in different environments and different peoples' interactions.

Tool	How this is performed
Investigator triangulation	Multiple researchers looking at the same case or observe the same session and their interpretations
Theory triangulation	Using different theories to view the case. Stake (1995) describes this as researchers with different theoretical standpoints looking at the case and their interpretations.
Methodological triangulation	Collecting data through different methods, such as observing an appointment and then interviewing someone who also was present in the same appointment for their view on what happened.

Merriam (1998) used tools with a focus on qualitative methods of data collection. These were more comprehensive than Stake (1995) and look at internal validity, reliability and external validity. Merriam (2009) defined these as –

- Internal validity, how the study's findings match with reality.
- Reliability, the consistency and dependability of the data
- External validity, how generalizable are the study's results.

Merriam (1998) used multiple tools to look at each of these, see Table 33 for an explanation of the tools used. With Yin's (2003, 2014) data validation tools not being appropriate within a constructionist viewpoint, these tools were not considered. Merriam's (1998) tools looked at aspects of the study that the researcher had identified as a potential affect to validity, using them as a more formal method to identify them was considered necessary, while Stake's (1995) tools did not consider these in depth, for example researchers biases.

Table 33 Merriam's 1998 tools for data validation

Tool	Methods within this	How this is performed
Internal validity	Triangulation	Using multiple investigators, multiple sources of data or multiple methods to confirm the findings.
	Member checks	Asking participants if the results are reasonable
	Long term observation	Gathering data over a period of time

Tool	Methods within this	How this is performed
	Peer examination	Asking other researchers to comment on the findings
	Participatory modes of research	Involving participants in the research design
	Researchers' biases	Documenting the researcher's theoretical position at the start of the study
Reliability	Investigators position	Investigator explains the theory or assumptions behind the study
	Triangulation	Multiple methods of data collection and analysis
	Audit trial	Descriptions of the data collection and analysis and how decisions were made in the study documented to allow future researchers to replicate the study
External validity	Use of rich thick description	Providing detailed descriptions allows others to judge if the results can be generalised to other situations/people
	Typicality of the case	How typical the case is with others
	Multi-site designs	Using more than one site

Appendix E Semi Structured Interview Guide

1) Introduction to the project and answer any questions the participant may have

2) Go through completed consent form

5) Can you describe your role as an interpreter?

6) What difficulties do you encounter when you are interpreting
    a. Professionals understanding of your role
    b. Knowing the person you are interpreting for
    c. Different signs that you are familiar with
    d. Language level of the person you are interpreting for

7) Is there one interpretation when interpreting?
    a. Word for word translation is that possible in BSL and SSE?

8) How do you ensure that everything is accurately interpreted and the person's views are represented?

9) After an interview there are ways that could be used to confirm that the meaning of the interpretation has been conveyed. What are your views on
        i. Another interpreter reinterpreting what the patient said from a video/peer review
        ii. Relooking at the interview
        iii. Do you think these are feasible?

10) People talk about the Deaf community, what does this mean to you?

11) As part of your role are there ever concerns about your anonymity?
    a. Is there ever any concerns about the personal relationship with the people you interpret for

12) Most research studies exclude adults who use BSL or SSE, what do you think are the reasons for this?

13) What is your current knowledge about interpreting in research studies?
    a. Any previous experience in this area
    b. Awareness of two different views on interpreting in research

14) What do you think are the differences (if any) between interpreting generally and interpreting in research?

a. Do you think sign language interpreters would like to be involved in research?
b. Are there any barriers to interpreter participation/what are these barriers to participation?
c. What support do you think would be required for interpreters with no experience of research to move into research interpreting?

15) Some people say being neutral is very important for an interpreter, while others feel that in a research project it is important to gain the interpreters views on a project as part of the interpreters' role. Do you think that is important? What are your reasons for this?
    i. Would topic matter affect your answer?
    ii. Do you feel personal views on a topic affect the interpretation?
        1. How does the interpreter prevent this from happening?

16) How would you feel if part of a research project you were?
    i. Working with the researcher as part of the team them rather than as a conduit
    ii. Becoming a co-researcher
    iii. Your expertise in an area highlighted as part of your involvement in the project
    iv. Would any of these stop you from being involved with a project
    b. How do they feel about being visible within a project
        i. Benefits
        ii. Disadvantages

17) Would being involved in research change the role of the interpreter?

18) I am going to be asking Deaf patients who are being assessed for a cochlear implant and who have a cochlear implant about their expectations of a cochlear implant.
    a. Do you have any insights or advice for me undertaking this project
        i. Recruitment
        ii. Interviewing Deaf adults

Appendix F Matrix showing the output from the literature review

Author (year)	Number of interpreters	Background	Interpreting style and seating	Interpreter competence	Participation in the research	Interpreter visibility in the study	Trustworthiness of the study	Anonymity of the interpreter	Matching participants and interpreter
Almalik (2010)	3	not available	Consecutive, verbatim translation	Lay interpreters. Training provided.	Only involved in interview stage not involved in data analysis	Invisible - Used terms like involve. No quoted passages and not in third person. Interpreters not interviewed.	Check with another interpreter.	Not available	not available
Baird (2011)	2	Gender and background available.	Not available	Lay interpreters. Training given to one interpreter with no professional qualification. Main interpreter was known to the participants	Assisted in recruitment of participants, was known to many of the participants. Knowledge and cultural skills utilised at each step. Did not discuss whether interpreter involved in data analysis	Visible - discussed meaning of words to ensure conceptual equivalence	Check with another interpreter.	Not available	Matched for gender and cultural background

Appendix F

Author (year)	Number of interpreters	Background	Interpreting style and seating	Interpreter competence	Participation in the research	Interpreter visibility in the study	Trustworthiness of the study	Anonymity of the interpreter	Matching participants and interpreter
Ballantyne (2013)	1	Limited background information available	Consecutive. Free translation.	Lay interpreter. Previous interview experience. Training provided	Interpreter set up the interviews and interpret - no other role	Invisible - No quoted passages and not in third person. Interpreters not interviewed.	Check with another interpreter.	Not available	not available
Bjork Bramberg (2013)	5	Gender information	Consecutive. Verbatim translation. Interviewer facing participant and interpreter seated to one side.	Professional qualifications. Training provided.	Only involved in the interview stage	Invisible - no quoted passages, not in third person, interpreter not interviewed.	Discusses that use of interpreter can affect validity	N/A	Not available
Croot (2011)	Not available >2	Not available	Changed from word by word to more free style due to difficulties with interviews	Professional interpreters were known to participants. Also used co-investigators who have 4x2 hour training sessions.	They were involved in interpretation and confirmed transcription of the translated data. Involved in data analysis	Visible- quoted passages, used language like 'with'. They did not interview the interpreters	Interpreters confirmed transcription of the data to ensure an accurate interview account. Also discussed presence of interpreter influenced the data	N/A	Not available

Author (year)	Number of interpreters	Background	Interpreting style and seating	Interpreter competence	Participation in the research	Interpreter visibility in the study	Trustworthiness of the study	Anonymity of the interpreter	Matching participants and interpreter
Harris (2013)	3	Not available	Consecutive	Lay interpreters, Training provided	Not involved in the development but involved in other aspects of the work, partoke in mock interviews.	Visible, co-researchers. Acted as cultural guides. Do not use quoted passages or third person but discuss this. Did not interview interpreters	Interpreter cross checked transcription. Then sent for an independent second round translation. Discuss limitations with regards to an interpreter as a co-researcher	Not available, but does discuss potential issues for interpreters involved in these projects	Not available
Ingvarsdotter (2012)	2	Not available	Consecutive	Professional interpreters	Only involved in the interview stage	Visible - Used language 'with' but did not interview interpreters or use quoted passages.	Interviews retranslated. Interpreter did not translate all information.	Not available, does mention ethical implications of this (interpreters voices were electronically disguised)	Not available
Irvine (2007)	1	Gender and background information	Consecutive, verbatim translation	Training provided	At interview stage	Visible - Used language like 'with'	Had audio taped interviews transcribed and retranslated	Not available	Not available

Appendix F

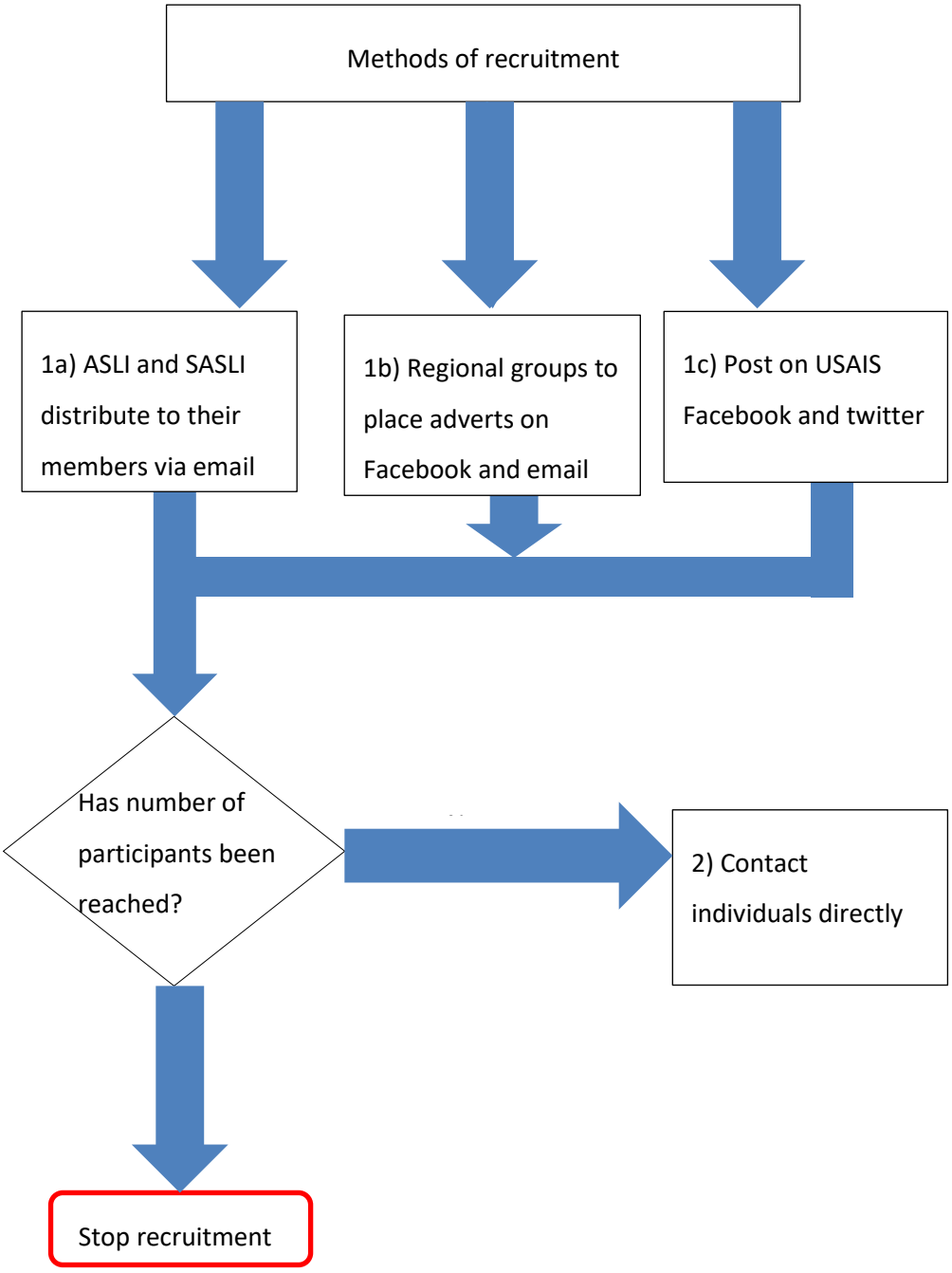
Author (year)	Number of interpreters	Background	Interpreting style and seating	Interpreter competence	Participation in the research	Interpreter visibility in the study	Trustworthiness of the study	Anonymity of the interpreter	Matching participants and interpreter
Kosny (2012)	Not available	Not available	Consecutive, verbatim translation	Professional interpreters	At interview stage	Invisible - (conduit/research tool) did not interpret in 3rd person, no quoted passages	Discuss effect of interpreter on the data and how different interpreters varied in how they interpreted and the quality of this	N/A	Not available
MacKenzie (2016)	2	Gender and background	Consecutive	Lay interpreters, briefed before the study started. Were respected by the participants	Involved in all stages but not analysis.	Visible - interpreter interviewed. No quoted passages	Discusses the effect of the interpreter on the data	Not available	Not available
Murray (2001)	2	Gender and background	Consecutive, free interpretation	Briefed interpreters	Involved in all stages	Visible - translation in 3rd person	Discussed the effect of the interpreter on the data	N/A	Not available
Pitchforth (2005)	1	Gender and background	Used 2 models (Consecutive and independent) seating info not available	Lay interpreter with experience of interpreting. Training provided.	Involved in the interview stage	Visible - quoted passages	Interviews reinterpreted	Not available	Not discussed but did match for some characteristics

Author (year)	Number of interpreters	Background	Interpreting style and seating	Interpreter competence	Participation in the research	Interpreter visibility in the study	Trustworthiness of the study	Anonymity of the interpreter	Matching participants and interpreter
Sanderson (2013)	1	Gender and background	Free interpretation,	Has interpreting experience but does not mention if professional qualification. Did not mention respect	Involved in all stages including analysis	Visible - acted as co-researcher and evident throughout the study as having a large role. Did not use quotes or third person but does specify it was in a different language	Discusses views of interpreter and researcher and go through interpretations to analyse	N/A	Not available
Sheppard (2011)	3	Not available	Not available	Professional interpreters. Training provided. Knew Participants	Interview and transcription stage. Cultural guide	Visible - (worked with the interpreters). did not interview interpreters and no quoted passages.	Reviewed tapes with 2 interpreters if any concerns about the translations were present. Interpreter voiced words that were not said.	N/A	Not available
Skelton (2003)	2	Gender for one interpreter. No background	Simultaneous (but in BSL)Seating discussed	Professional interpreter. Trusted by the participants	At interview stage	Invisible - No quoted passages, not in 3rd person. Did not interview interpreters	Not available	N/A	Not available

Appendix F

Author (year)	Number of interpreters	Background	Interpreting style and seating	Interpreter competence	Participation in the research	Interpreter visibility in the study	Trustworthiness of the study	Anonymity of the interpreter	Matching participants and interpreter
Williamson (2011)	1	Gender and background	Consecutive, free interpretation, did do some interviews alone	Lay interpreter, training provided and had experience of interpreting. Knew family members of the participants	At interview stage	Invisible - facilitator	Reinterpreted data with a different interpreter, consistency in meanings between the interpretations. One Interpreter did not always report what had been said	Not available	Not available

Appendix G Methods of recruitment



Appendix H Email and Advert for Facebook

Recruiting UK registered Sign Language Interpreters!

My name is Suzanne O'Gara and I am a PhD student and Audiologist at the University of Southampton. I currently work with cochlear implant patients and I am looking at ways to ensure BSL users are invited to be involved in service development and research projects. To ensure these users views are heard involves working with a BSL interpreter. I am looking to interview BSL interpreters about how best to work with them in an interview setting. This study would involve a telephone interview.

If you would like to find out more about this project then please email me at sjog1v07@soton.ac.uk.

Thank you

Suzanne

Appendix I Twitter advert

Twitter advert

Looking for BSL interpreters to be involved in a research study to improve access of research to BSL users. Please contact Sjog1v07@soton.ac.uk for further information.

Appendix J Poster and Leaflet

Recruiting sign language interpreters

This project is looking at ways to ensure BSL users are invited to be involved in service development and research projects.

Appendix K Consent form

CONSENT FORM (*1.3*)

Study title: Sign language Interpreters and qualitative research

Researcher name: Suzanne O'Gara

Ethics reference: 25015

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet (Version __ Date __/__/__) and have had the opportunity to ask questions ☐

I agree to take part in this research project and agree for my data ☐

I agree to the interview being audio-recorded ☐

I understand my participation is voluntary and I may withdraw at ☐

Data Protection

I understand that information collected about me during my participation in this study will be stored on a password protected computer and that this information will only be used for the purpose of this study. All files containing any personal data will be made anonymous.

Name of participant (print name)……

Signature of participant……..

Appendix K

Date……

Name of person taking verbal consent at the interview ……

Signature……

Date……

Appendix L Participant Information sheet

Participant Information Sheet

Study Title: Sign language interpreters and qualitative research

Researcher: Suzanne O'Gara **Ethics number**: 25015

Please read this information carefully before deciding to take part in this research. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is being completed as part of a postgraduate degree, the overall aim of which is to find out about the experiences of congenitally or long-term deaf adults who receive, or are assessed for, cochlear implantation. To ensure that this research is comprehensive and inclusive, it is important that the views of cochlear implant recipients or candidates who use BSL are not excluded from research. The research could be used for service development or planning and so result on their views not being taken into consideration.

This first aim of the study we are asking you to participate in is to gather interpreters' views on how the interpreting process might affect the conduct of research with BSL users.

The second aim of this study is to identify any considerations that would need to be taken when working with interpreters and the Deaf community in research. The Deaf community within the UK regularly work with interpreters when they need to communicate with healthcare services. In these interactions the interpreters and Deaf community work with each other regularly. This is quite unique and may introduce other considerations when working with interpreters and the Deaf community in research.

Why have I been invited?

You have been asked to participate as you are a sign language interpreter registered with NRCPD and regularly interprets for individuals who use BSL. We are trying to increase access for BSL users to research studies they wish to be involved in. To do this consulting with BSL interpreters about the research process is essential.

What will happen to me if I take part?

If you decide to take part you will be asked to participate in an individual telephone interview with the researcher. If you are interested in taking part, you will need to email

the researcher via sjog1v07@soton.ac.uk or phone on 02380599590. This interview is expected to last for about an hour and will be scheduled at a time and date that is convenient for you. You would be asked to provide a telephone number that we can phone you on the time and date you specify. You will be asked to consent to be involved in this study, and will be emailed or posted the consent form and we ask you either to return this via email or in the prepaid envelope we will provide. On the day of the interview the researcher will read the consent form out loud to you and you can confirm that you are happy with everything that you previously agreed to. The interview will be audio recorded.

If participant numbers exceed our expectations and we are unable to interview everyone who shows an interest in being involved in the study, you will be contacted to explain this and unfortunately will not be able to be interviewed as part of this study.

Are there any benefits in my taking part?

There will be no personal benefit for participating in this study. The information you give will make participation in research more accessible to sign language users and be used to advise other researchers on best practice when working with interpreters in a research setting.

Are there any risks or disadvantages involved?

This study would involve you giving up an hour of your time. We do not expect there to be any further disadvantages or risks to you in taking part in this study.

Will my participation be confidential?

Any centres or individuals you may identify during the interview will not be named in the write up or publication of this research. You will also be given an ID number to help protect your identity which will only be known to the researcher.

Only your ID number will be used to identify you during write up of the study. All information and audio recordings will be kept securely in a locked file during the course of the study. Personal information will be kept in a separate secured file. Once the study has been completed the University of Southampton will store all information securely for 10 years in accordance with current policy.

What happens if I change my mind?

If you do decide to participate in this study you are still able to withdraw at any time without explaining the reason for this.

What happens if something goes wrong?

If you have a concern or a complaint about this study you should contact T Bartlett from the Research Governance Office (Address: University of Southampton, Building 37, Highfield, Southampton, SO17 1BJ ; Tel: +44 (0)23 8059 5058; Email: rgoinfo@soton.ac.uk. If you remain unhappy and wish to complain formally the Research Governance Office can provide you with details of the University of Southampton Complaints Procedure.

Where can I get more information?

If you require any further information or have concerns about the research that you wish to discuss with the researcher you can Suzanne O'Gara: Office number 02380 593522, or email: sjog1v07@soton.ac.uk. The main supervisor for this project is Dr Maggie Donovan-Hall: Email: M.K.Donovan-Hall@soton.ac.uk.

Appendix M Rejection letter

Sign language interpreters and qualitative research **DATE**

Dear ….

Thank you for your interest in being involved in the above study. Participant numbers have exceeded our expectations and we have had to close recruitment. We much appreciate your interest in being involved in this study.

Best wishes

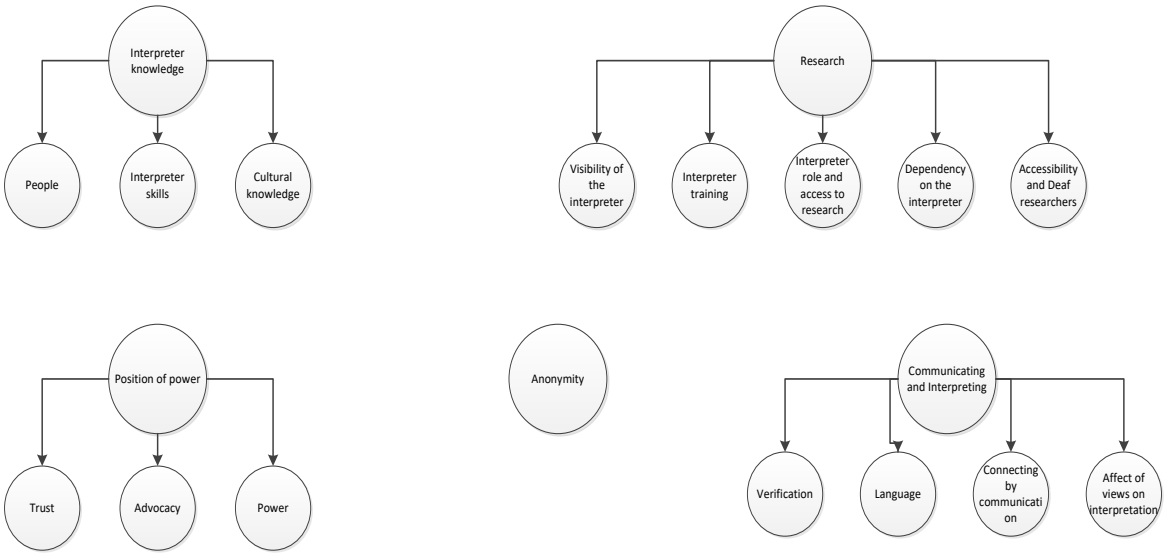
Suzanne O'Gara

PhD student

Appendix N Stages of Thematic analysis of the Phase 1 data

The data were read and re-read to allow the researcher to immerse themselves in the data and this stage allowed the researcher to fully understand the data; initial ideas for the codes were noted in this stage (Phase 1). All the transcripts were first hand coded, with reference to the research questions. The codes identified the data that was meaningful in relation to the research questions. The codes could be any size, this allowed the data to be organised into groups (Phase 2). The transcripts were uploaded onto the Nvivo software. The codes assigned from hand coding were inputted into the software. This was then used to look for patterns across the coded data. To identify patterns in the data, the codes and the data coded were reviewed to see how the codes interacted, potentially combined and as a result organised into initial themes and sub-themes (Phase 3). The initial thematic map is shown in N.1.

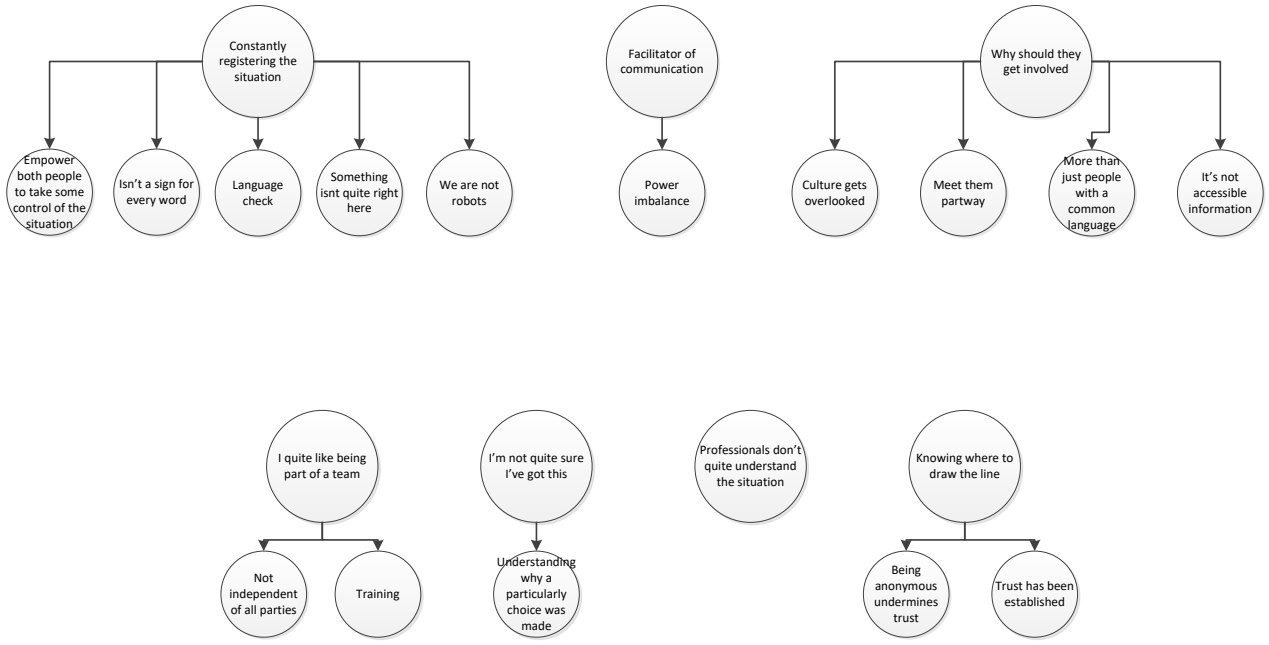
N.1 Initial thematic map of the data analysis



The themes identified were then refined after discussions with the researchers supervisory team as it was felt that overall the themes did not appear to be connected to the data. The themes were very similar to the topics in the interview guide rather than reflecting the data and that the researcher needed to get deeper into the data rather than the current analysis being on a superficial level. The themes were also quite large and codes did not form a coherent story of the theme. Some of the themes covered a large topic area and splitting some themes allowed a more

coherent pattern of the data to be identified. All the codes were then re-analysed and this resulted in the development of new themes connected with the data and a deeper analysis was gained. This resulted in the over-arching theme titles being quotes from the participants in the data (Phase 3). This analysis took both an inductive and deductive approach by using the research questions to code but then going through the data and using the quotes of the participants ensures that the themes are very connected to the data. The seven themes and the thematic map are shown in N.2.

N.2 Thematic map of seven themes



The themes were then considered in relation to the data set and relationships between each theme examined. This allowed further refinement and development of the themes to occur and ensured the validity of the themes (Braun and Clarke, 2006). This resulted in the subtheme 'language check' and 'understand why a particularly choice was made' deemed too small for a subtheme and so merged into their over-arching theme. The themes were checked to ensure the names of the themes gave the reader a sense of what the themes were about and were relevant to the data coded (Phase 5). The themes were described, and the analysis written up. The write up tells the story of the data and provides relevant evidence for the themes and why they are important aspects of the data in relevance to the research questions (Phase 6).

Appendix O Table showing the papers found relating to the literature review in Phase 2

	Papers found relating to the search using the terms Deaf community AND recruitment AND Research and duplicates were removed
1	Kobayashi Y, Boudreault P, Hill K, Sinsheimer JS and Palmer CGS (2013) Using a social marketing framework to evaluate recruitment of a prospective study of genetic counseling and testing for the deaf community. *Bmc Medical Research Methodology* 13
2	Mckee M, Thew D, Starr M, Kushalnagar P, Reid JT, Graybill P, Velasquez J and Pearson T (2012) Engaging the Deaf American Sign Language Community: Lessons From a Community-Based Participatory Research Center. *Progress in Community Health Partnerships-Research Education and Action* 6(3): 321-329
3	Wurm S and Napier J (2017) Rebalancing power: Participatory research methods in interpreting studies. *Translation & Interpreting-the International Journal of Translation and Interpreting* 9(1): 102-120
4	Young A, Oram R, Dodds C, Nassimi-Green C, Belk R, Rogers K, Davies L and Lovell K (2016) A qualitative exploration of trial-related terminology in a study involving Deaf British Sign Language users. *Trials* 17

Appendix P Email sent to BSL users for PPIE

Hello, my name is Suzanne. I am an audiologist and PhD student at the University of Southampton.

I am looking to speak to adults who are BSL users and who have had their cochlear implant for more than 5 years. I wish to develop a research study that looks at adults who were born with a hearing loss expectations of a cochlear implant. This initial work is not research but is about developing the project to ensure the study meets the meets of adults who use BSL. I want to ensure that adults who use BSL are able to be involved in the project if they wish and therefore it needs to be accessible to them. I wish to ask about four things:

1) I wish to ask about the best ways to present the study information
2) How to invite adults who sign to be involved in the research study
3) Are there ways to collect information that are more effective
4) How to ensure the information materials are clear

I wish to discuss these topics to ensure that patients who use BSL can be involved in research if they choose. This will also ensure that research is done in the best interests of the patients. You would be helping to ensure this.

This would involve two sessions of an hour. If you would like to find out more please contact me at sjog1v07@soton.ac.uk

Appendix Q Screen shot of video

Appendix R Video script

Hello,

Suzanne, a member of staff here at the Implant Centre is an audiologist and is also studying for her PHD at Southampton University. Suzanne is reaching out for people who use BSL (British Sign Language) to communicate for their support in how she can make her PHD project fully accessible for everyone as its understood BSL users do face barriers in having equal access to information.

If you have any ideas in how Suzanne can make her project accessible for BSL users please contact her on sjog1v07@soton.ac.uk she would really appreciate your support.

Appendix S Before and after email examples

First version

Yes your help would be gratefully appreciated.

My research project is looking at how to provide information to adults who were born with a hearing loss and are going through the assessment process. This would be providing them with information from people who were in a similar position to them and what they hoped to gain from a cochlear implant and if these hopes were met.

I am looking for your advice on –

1) Do you think that information on what other adults who had their implant hoped to gain from their implant, would have been useful when you were considering having a cochlear implant?
2) How to ensure that adults are aware this research is happening
3) Ensuring the information about research is accessible

Updated version

I would appreciate your help.

My research project is looking at how support adults who were born Deaf and are looking to get a cochlear implant. We want to give them information from other born Deaf people about their cochlear implant.

This would be providing them with information from people who were in a similar position to them and what they hoped to gain from a cochlear implant and if these hopes were met.

I would like your opinion on -

1) Thinking about your assessment. Do you wish you had information from other born Deaf adults? Would it be helpful to know what they hoped for and what their results were?
2) How do I tell born Deaf people about this?
3) What formats are most useful for born Deaf people for this info?

Appendix T PPIE recruitment poster

Are you over 18 and use a cochlear implant?

I am a PhD student and Audiologist looking

to improve access for BSL users to research.

Can you help?

Suzanne O'Gara

Please email me at sjog1v07@soton.ac.uk

Appendix U Literature review of papers focusing on the families experience of a CI

Literature review

To determine what effects on the family are present within the literature a review of published literature was performed.

Search strategy

The search strategy for this scoping review of the literature involved an electronic search of the published literature using the web of science and Medline search tools. All literature included in the review was from published articles in peer reviewed journals.

The search was performed three times, once for the search terms, cochlear implant*, family and adult, the second for cochlear implant*, significant other and adult and the third for cochlear implant*, spouse OR partner and adult (Table V1). This was to ensure all papers relating to the family were covered. No terms relating to the onset of Deafness were included in the search strategy. Some papers are not clear on the onset of deafness of their participants, this was to ensure all papers relating to the family and deafness were included in the review.

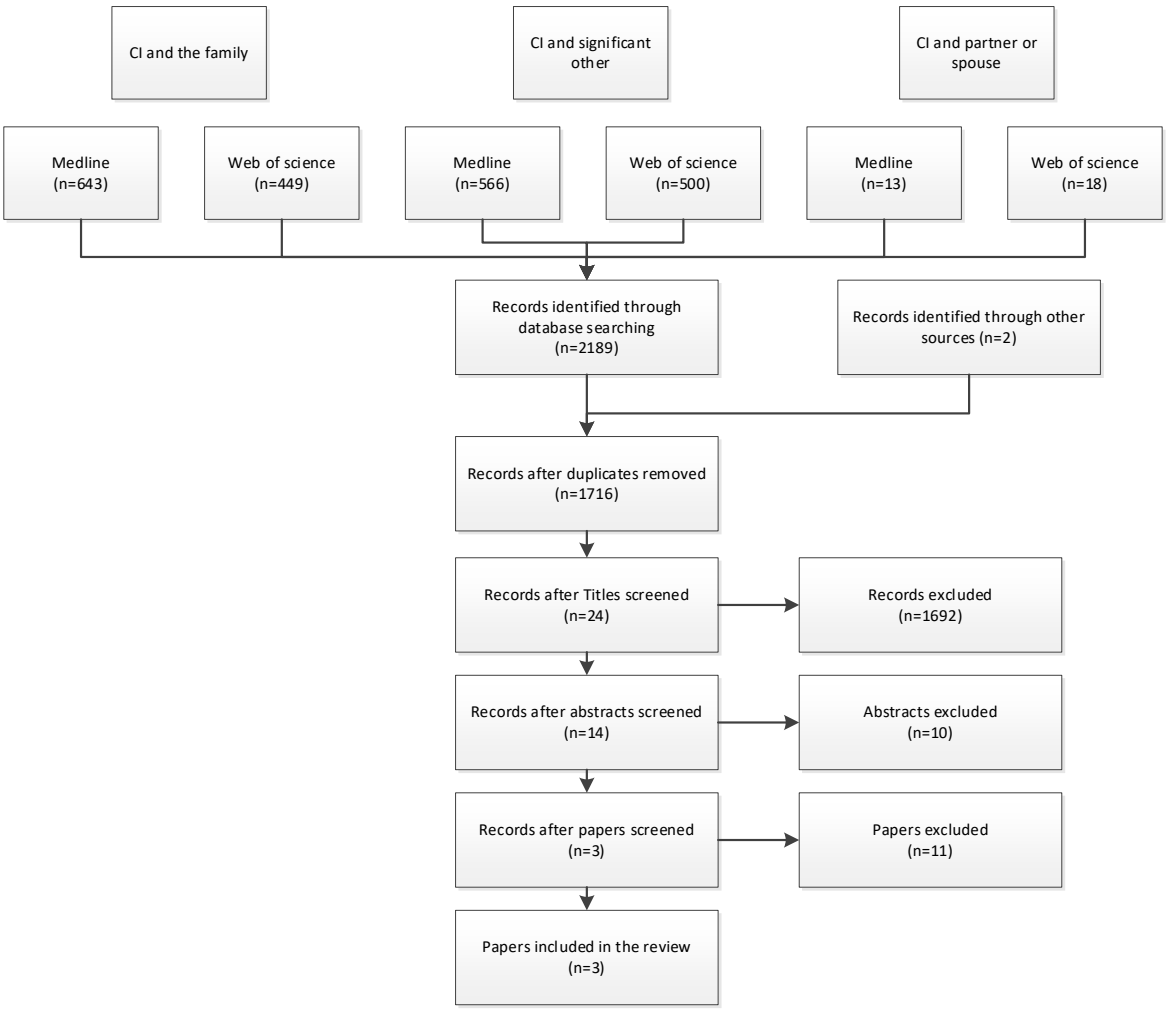
Table V.1. List of search terms and reasons for their inclusion in the review

Search term	Reasoning
Cochlear implant*	To ensure the literature was relevant to cochlear implantation. Many terms using cochlear implant, cochlear implantation so to capture all of these a * was applied.
Family	The focus of the literature review was the experience of the family, so the term family was included
Significant other	The focus of the literature review was the experience of the family, as the reference to family can be significant other this was also included.
Spouse OR Partner	The family/significant other could be referred to as the spouse or partner, so this was included.

Adult	As the review focuses on adult patients, adult was included to try and exclude the papers focusing families of paediatric patients.

The three searches were merged, this resulted in 2198 papers. Two papers were added after looking at the reference lists of significant papers (Knutson et al., 2006, Wexler et al., 1982). Duplicates were identified and removed. Title and abstract screening then followed. The process for screening papers is shown in Figure V.1.

Figure V.1 The literature review process (The Prisma Group (2009))



Title and abstract screening resulted in twelve papers. All papers were then read in full and any exclusions made on the basis of the exclusion criteria in Table V.2. This resulted in three papers included in the review (See Table V.3 for a list of papers included in the review). One paper had been included in the previous literature review in Chapter 2 (Maki-Torkko et al., 2015) and was discussed in the context of the family.

Table V.2. Exclusion criteria applied to the literature review screen

Exclusion criteria	Rational	Applied
Not written in English	Costs and difficulties with translation	Initial search stage
Papers published before 1980 excluded	Cochlear implants were given FDA approval for implantation in adults in 1984, pre 1980s they were not widely available (Raine, 2013)	Initial search stage
Literature focused on children	Literature looking at implanting children looks at different topics which are relevant when implanting an adult.	Title and abstract screening
Literature not relevant to the experience of families/significant others of a cochlear implant	This did not relate to the family experience and was largely looking at if there was an improvement in outcomes post-implant or was about other outcomes from a cochlear implant.	Title/abstract and paper screening
Literature not focused on cochlear implants	This related to the families experience of hearing loss not of cochlear implantation.	Paper screening

Table V.3 Papers included in the literature review

	Paper
1	Kennedy V, Stephens D and Fitzmaurice P (2008) The impact of cochlear implants from the perspective of significant others of adult cochlear implant users. *Otology & Neurotology* 29(5): 607-614
2	Maki-Torkko EM, Vestergren S, Harder H and Lyxell B (2015) From isolation and dependence to autonomy - expectations before and experiences after cochlear implantation in adult cochlear implant users and their significant others. *Disability and Rehabilitation* 37(6): 541-547
3	Wexler, Miller S, Berliner KI and Crary (1982) Psychological effects of cochlear implant: patient and "index relative" perceptions *The Annals of otology, rhinology & laryngology. Supplement* 91(2): 59-61

Findings

The three papers found used different ways to investigate the effects on the family. The papers also have a focus on the effects on the CI user of cochlear implantation which was not discussed in the context of this review.

Appendix U

Terminology

The three papers used different terminology to describe the 'family'. The family was mentioned as significant other (Kennedy et al., 2008, Maki-Torkko et al., 2015) and index relatives (Wexler et al., 1982). Which index relatives completed the questionnaires was not explored in Wexler et al. (1982). There may be a different view from a partner than a family member who did not live with the CI user. Kennedy et al. (2008) reported that 22 spouses, five children, three parents and one friend completed the significant other section of their questionnaire. In Maki-Torkko et al. (2015) the quotes in their paper were from family members to close friends, they did not discuss what relationship the family member was. In the context of this review, to avoid confusion due to the varied terminology used to describe the 'family', the term significant other was used to describe all the terms mentioned previously.

Methodology

Two papers used a quantitative approach (Kennedy et al., 2008, Wexler et al., 1982), one used a qualitative approach (Maki-Torkko et al., 2015). All the studies used a questionnaires (Maki-Torkko et al., 2015, Kennedy et al., 2008, Wexler et al., 1982).

Wexler et al. (1982) asked 13 significant others, 23 questions regarding their views of the CI users functioning pre and post-operatively. They examined if there were any significant differences between the results pre and post-implantation. While Kennedy et al. (2008) used an open ended questionnaire with 31 significant others providing responses. There were two questions looking at the positive and negatives of their significant other having a cochlear implant. The numbers of significant others reporting similar effects were added and then the responses were then analysed with reference to the International classification of Functioning, Disability and Health, which was a classification to assess the effects of a health condition on the lifestyle of the affected individual, in this case the CI user.

Maki-Torkko et al. (2015) used open ended questionnaires. They sent these to the CI users and asked them to choose a significant other to complete the significant other section of the questionnaire. Nine questions were relevant to the significant other. Eighty-seven responses were received for the significant other questions. This was analysed using content analysis. The CI users and significant other responses were analysed together.

Using questionnaires did not allow exploration of the significant others views in more detail. They were not asked to explain or expand on their views to add more depth to the responses.

CI and effects on the family

Wexler et al. (1982) reported that the significant others felt that the CI had resulted in a positive change for the CI user. They found greatest statistical improvement was seen for '*concern for patient's safety', 'patient's negative emotional reactions', 'frustration in communication'* and the *'quality of the patient's voice'*. The least change was seen in the significant others relationship with patient. They felt that the family members were in '*denial*'. The range of time between implant also varied between six months to 10 years and the family members completing the questionnaires may have not accurately recalled their views.

In Kennedy et al. (2008), the family members reported the CI resulted in improved communication, confidence, decreased isolation and independence for the CI user. They also found the family members reported increased independence. Negatives of the CI were related to the aesthetics of the device and that the user would still struggle if they were not wearing the device.

Maki-Torkko et al. (2015) identified that the CI as well as changing the CI users life also changed the significant others life as well. They found three categories emerged from the data analysis, wellbeing and life satisfaction, shortcomings and information. The wellbeing and life category was made up of three subcategories alienation-normality (changing from feeling separated to a sense of normality), fear-autonomy (from fear about having to the CI to being able to manage in society) and living social life.

All the studies found positive affects for the significant others as a result of the CI user being implanted. These ranged from less frustration during communication (Wexler et al., 1982), a reduction of emotional tension (Wexler et al., 1982), independence (Kennedy et al., 2008) and well-being and life satisfaction (Maki-Torkko et al., 2015).

Onset of Deafness

The papers included in this review do not specifically state the onset of deafness of the adults they have included. From the data provided by Kennedy et al. (2008) on duration of hearing impairment and age of CI user it was judged that their group only included post-lingually deafened adults. The other papers do not state this specifically but it was likely they included mainly post-lingually deafened adults. No papers found specifically looked at the effects on the significant others of pre-lingually deafened adults.

Quality of the Research

Wexler et al. (1982) and Kennedy et al. (2008) questions focused on the significant others perspective with reference to the CI user. Maki-Torkko et al. (2015) was the only paper in the

review that asked significant others what the effects the CI had on them, as the analysis was performed on both the CI users and significant others it was harder to pick out the effects that were just seen by the significant others.

Wexler et al. (1982) found that their significant others had conflicting responses with the respondents reporting the CI users were not a burden pre-implant but then reporting communication issues with them. Sending questionnaires did not allow the researcher to control where and when these are completed and the CI user and significant could have completed these together or did not feel they could respond in a certain way due to the other seeing their responses. This could explain the conflicting response, the word burden was also quite emotive and they may not want to respond negatively for this reason. This may have affected the responses to the questionnaires.

The range of time between implant and completing the questionnaire varied from six months to 10 years (Wexler et al., 1982), mean of five years (Standard deviation 4.2 yrs.) (Kennedy et al., 2008) and 1.2-16.9 years (Maki-Torkko et al., 2015). The family members completing the questionnaires may not have accurately recalled their experiences which added variability to the results.

Both Kennedy et al. (2008) and Maki-Torkko et al. (2015) studies were performed in the last 15 years, the Wexler et al. (1982) study was performed in the 1980's. The 1980's onwards was a time when the CI technology changed dramatically with the introduction of multi-channelled implants, new processor strategies, noise reduction algorithms and direction microphones (Wilson and Dorman, 2008, Lenarz, 2017). There was no mention if the CI devices used were single or multi-channelled. This may mean that the study was not relevant to today's CI users.

Summary

Cochlear implantation was seen as having positive effects on the significant others. The effects of the CI at different stages, for example switch on and during the initial tuning period, were not discussed. All the papers in the review included questionnaire based methods, using interviews would allow more detailed analysis of the effects on the significant others and how this changes during cochlear implantation. The literature was sparse with information on the effects of CI on the family, more investigation on these effects may allow the family and so the CI user to be appropriately supported throughout the CI process.

Appendix V Table showing the document validity checks

What is the history of the documents
How were these accessed
What guarantee is there that it is what it pretends to be?
Is the document complete, what version of the document is this?
Has the document been edited? This is also relevant to the original form of document, I.e. videos may have been edited
If the document is genuine, under what circumstances and for what purposes was it produced?
Who was/is the author?
What were the authors trying to accomplish? Who was the document intended for?
What were the maker's sources of information? Does the document represent an eyewitness account, a second-hand account, a reconstruction of an event long prior to the writing, an interpretation?
What was or is the maker's/interviewee's bias?
To what extent was the writer/interviewee likely to want to tell the truth?
Do other documents exist that might shed additional light on the same story, event, project, program, context? If so, are they available, accessible? Who holds them?

Appendix W Phase 3a ERGO application form

Ethics Application Form for SECONDARY DATA ANALYSIS

Version September 2019

Please consult the guidance at the end of this form before completing and submitting your application.

1. Name(s): Suzanne O'Gara

2. Current Position: PhD student/ Senior Clinical Scientist (Audiology)

3. Contact Details:

Division: Health Sciences

Email: sjog1v07@soton.ac.uk

Phone:

4. Is your research being conducted as part of an education qualification?

Yes ☒ **No** ☐

5. If Yes, please give the name of your supervisor:

Maggie Donovan-Hall, Carl Verschuur and Vicky Watson

6. Title of your research project / study:

Experiences and hopes of cochlear implantation among early deafened adults and their families

7. Briefly describe the rationale, aims, design and research questions of your research

Please indicate clearly whether you are applying for ethics approval for a specific piece of research, or for overarching ethics approval to use certain datasets for a range of research activities. Approval for the latter will only cover the datasets specified here, for a maximum of 3 years and then subject to renewal.

This application is part of a larger case study (ERGO 52273 – this has been granted ethical approval), during completion of the work it was identified that the analysis of internet data now requires ethical approval for analysis and this was not specified in the original application.

Research Q –

What are the experiences and hopes of the recipient and their family members of a cochlear implant?

Rationale

This work is part of a larger case study project (ERGO 52273) that will collect data from multiple sources including interviews, document review (including an internet search) and pre and post-implant test results. Document review allows other source of information to be investigated, which may also affect and impact on expectations regarding cochlear implants. The internet is widely used by all to research health and most cochlear implant candidates will have looked on the internet for information and received information from the centre before attending their assessment appointment. This information will likely influence what they feel their experience and expectations of a CI will be before they arrive which is why this has been included in the larger case study. Document review includes information given to assessment patients, information from CI companies and information available on the internet.

<u>Methods used to collect the internet data</u>

Before applying for ethical approval an internet search was carried out to identify the websites. Advice was and advice was sought regarding analysis and processing of the data. It was identified that before any data should be collected from these sites that ethical approval was required. The methods used for this search are so in past tense as the search has been carried out. The analysis stage is then in present tense as this has not yet been performed.

PPIE work identified search terms that candidates and their families would use to look for information on cochlear implants. These terms and two widely known search engines (Google and Bing) were used to collect the internet data. Search terms were cochlear implant, experience and deaf. When searching the web you do not include terms such as AND/OR the terms were written in the search bars as: cochlear implant experience, and: cochlear implant deaf. From this only the first three web pages were reviewed as there is evidence that the click rate beyond this is very low (Jacobson, 2017). Any pages that show as Ads were not included.

Any audio visual data will be changed into a written transcript to be used in data analysis. The focus of the search was early deafened adults any information that were identified as being from adults who lost their hearing after the age of 6 years will be removed. This may not be possible for all cases. Any materials that were scientific papers/journal articles or not aimed at CI users but audiologists were removed. The material found may differ on the date collected. Searches were performed on Google and Bing, these are the top 2 search engines with regards to market share in 2019 (Law, 2019).

What does need to be considered is some of this information may not be accessed in the same medium as, what the researcher, a hearing adult would. This will need to be considered as part of the review.

The websites will be given a number and any stories included a pseudonym. They will be then be transferred to Nvivo for thematic analysis.

8. Describe the data you wish to analyse

Please give details of the title of the dataset, nature of data subjects (e.g. individuals or organisations), thematic focus and country/countries covered. Indicate whether the data are qualitative or quantitative, survey data, administrative data or other types of data. Identify the source from where you will be obtaining the data (including a web address where appropriate).

From the search the websites include:

Types of website		Page focus		Website location	
Health	8	Patient stories/experiences	18	UK	17

National body	7	Information on a CI	9	US	11
Patient information	3	Why CI isn't for all	3	Australia	1
CI company	2	Advances in CI	1	India	1
Provider (Hospital etc)	4			Unknown	1
Newspaper	7				

This is a qualitative study. The content of the websites ranges from patient stories to information about cochlear implants. The websites were identified from a Google/Bing search. See attached for a list of all the websites included.

The information is in either a written or video format. These are the patient's stories of their CI experience. The written stories will be cut and pasted into Nvivo while the videos will be transcribed (if no transcripts available)

There are over thirty websites

9. What are the terms and conditions around the use of the data? Did data subjects give consent for their data to be re-used? If not, on what basis is re-use of the data justified?

Please state what (if any) conditions the data archive imposes (e.g. registration, signing of confidentiality agreement, specific training etc.). In many cases the data controller will have given explicit permission for data re-use. Please explain how you justify the use of data if approval and consents for the original data collection and re-use are not in place. This may be the case where, for example, the original data collection predated requirements for ethics review or occurred in a jurisdiction where explicit consent and approval are not required.

People who have contributed to/produced these websites have not given consent for their data to be used for research. They will have consented for their data to be on a public website. The information on these websites are publicly available. The British Psychological Society (2017) deem a public space as readily accessible to anyone and so where individuals "would expect to be observed by strangers". Private spaces would then be considered as spaces where membership is required to access the sites, or the information is not readily accessible. This the researcher deems that the authors would

have expected their stories to be viewed publicly and not produced for community members. All the sites included in the analysis are considered publicly available documents and were treated as such.

There are two conflicting views regarding consent in what would be considered a public space. One view is that informed consent is not necessary, or there is less obligation to have informed consent, if the sites are clearly public ((The British Psychological Society, 2017, Mazanderami and Powell, 2013, Markham et al., 2012). It is expected that individuals who share their stories on websites that are publicly accessible are aware that their posts may be read by people they do not know (Burles and Bally, 2018). The conflicting view is that as the information on the websites were not produced for research (Markham, 2012, Clark et al., 2015) and collecting this information could compromise the purpose that the page/group was intended for (Roberts 2015).

There are then difficulties around gathering consent, with difficulties with availability of contact details (Anabo et al., 2019, Burles and Bally, 2018) and if asking for permission from the website owners is enough or should consent be asked from the people who post the information. It could be that requiring informed consent could actually prevent the research being performed (Webb et al., 2017). Some authors have looked at the terms and conditions of the site and if the sites terms and conditions do not explicitly disclose research being performed then they have included these sites in their study (Lamprell and Braithwaite, 2018).

For this study, there are over thirty websites, contacting all the authors or website owners would be laborious and has the potential of limiting the study data. Gaining consent from some but not all the sites would be of detriment to the data analysis. Some of these websites are over 5 years old and there are issues regarding who could give consent so could the website owners give permission to use someone else's story for research.

The potential for harm with no consent being sought has been assessed. There is potential for harm if the contributors are identified. Steps will be taken to prevent these contributors being identified. See Q13 for steps to be taken.

10. Do you intend to process personal data (https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-

definitions/what-is-personal-data**) that are sensitive ('special category') personal data as defined by the the Data Protection Act 2018 following the General Data Protection Regulation (GDPR) (**https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/**), or data relating to a person's criminal convictions, even if such data are publicly available and/or have been pseudonymised (**https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/what-is-personal-data/what-is-personal-data/**)?**

Yes ☒ **No** ☐

If YES, please specify what personal data will be processed and why.

Data will have the subjects first name included as this is what is posted on the public webpages. The researcher will identify if the subjects are adults and their hearing loss developed before the age of 6 years, with their CI implanted as an adult. If this is not clear or the hearing loss developed after this or they were implanted as children, this patient story will be removed.

This information will then be pseudonymised (new names will be assigned; any personal information will be removed/geographical locations/names of centres will be removed) and the website it was from will not be identified. The identities of all the websites will be hidden to protect the organisations as well as the patients sharing their stories. No personal data will be used in the study but to be included in the study subjects must be an adult and deafness before the age of 6 years. This may be considered personal data.

11. Do you intend to link two or more datasets?

Data linkage refers to merging of information from two or more sources of data to consolidate facts concerning an individual or an event that are not available in any separate record. Please note that for the purposes of research ethics we are not interested in the merging of different waves of a particular survey, or the merging of data from different countries for the same survey.

Yes ☐ **No** ☒

If YES, please give details of which datasets will be linked and for what purposes.

The interview subjects will be patients at the University of Southampton Auditory Implant Service and will be consented to be part in the study using PIS and consent forms and will have been implanted in the last 5 years. The data on the internet is worldwide and the contributors to the websites are likely to have been implanted longer than that and from a wide range of locations worldwide.

12. How will you store and manage the data before and during the analysis? What will happen with the data at the end of the project?

Please consult the University of Southampton's Research Data Management Policy (http://library.soton.ac.uk/researchdata/storage and http://www.calendar.soton.ac.uk/sectionIV/research-data-management.html), and indicate how you will abide by it.

The data will be stored on a password protected computer. The data will be assigned a number and that number will then be associated with that webpage. Any patient stories on the page will be given a pseudonym. Each patient story will be given a different pseudonym. Data will be stored for 10 years in line with University policy and then destroyed.

13. How will you minimise the risk that data subjects (individuals or organisations) could be identified in your presentation of results?

Please consider whether disclosive ID codes have been used (e.g. date of birth) and whether it is theoretically possible to identify individuals by combining characteristics (e.g. widow in Hampshire with 14 children) or by combining datasets. How will you protect individuals' anonymity in your analysis and dissemination?

Websites will not be named

Pseudonyms will be given, and any identifying information removed

Quotes will be paraphrased

Quotes will be checked to ensure they cannot be found when using internet search engines (google and Bing)

14. What other ethical risks are raised by your research, and how do you intend to manage these?

Issues may arise due to the nature of the research you intend to undertake and/or the subject matter of the data. Examples include: data or analysis that are culturally or socially sensitive; data relating to criminal activity, including terrorism, and security sensitive issues.

The ethical risks are related to the use of internet data with no consent and the potential identification of subjects. See Q9 for why no consent obtained.

These are being managed by ensuring anonymity of the participants. See Q13 for how this is being managed.

15. Please outline any other information that you feel may be relevant to this submission.

For example, will you be using the services or facilities of ONS, ADRN, or HSCIC and/or are you obtaining ethical review from NRES (through IRAS) or other? Please confirm whether the data being used are already in the public domain.

Ethical approval has been sought for the main study, the analysis of internet material is secondary to this

Data being used is in the public domain. In the current study all the websites and information that I wish to include in the analysis are publicly available *Any sites that required a log in or registration were removed Blogs were deemed to have an expectation of privacy were also excluded (this has been done*). All the sites that will be in the analysis contained information which would be expected to be viewed by strangers. This included the patient stories which are either posted on national groups websites or posted on company sites as background to the owner of the site. The CI stories included on the sites would have required consent from the individuals posting the stories to post them on a publicly accessible site. This the researcher deems that the authors would have expected their stories to be viewed publicly and not produced for community members. All the sites included in the analysis are considered publicly available documents and were treated as such.

16. Please indicate if you, your supervisor or a member of the study team/research group (including any institution that they act for, if different from the University) are a data controller and/or data processor in relation to the personal data you intend to process as defined by the Data Protection Act 2018 following the GDPR, and confirm that you/they understand your/their respective responsibilities (https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/key-definitions/controllers-and-processors//)

There will be no data controller due to the measures taken to ensure anonymity as described above.

Guidance on applying for ethics approval for secondary data analysis

If your research PURELY involves the following, you do not need to apply for ethics approval:

- analysis of aggregated data on individuals or organisations (e.g. GDP, labour force participation rates, fertility rates);
- meta-analyses (i.e. the analysis of studies);
- literature reviews or reviews/analyses of reports, policies, documents, meeting minutes, newspaper articles, films.

Filling in the online submission form on ERGO II:

- Please give your application a title that includes 'SDA' (Secondary Data Analysis).
- Please refer to the "**ERGO II Guidance for Applicants**" document (downloadable from the ERGO II site) on how to answer the submission questionnaire correctly..

Additional Forms:

If your study PURELY involves secondary analysis of data, you only need to fill in the 'Ethics Application Form for Secondary Data Analysis'. You do not need a Risk Assessment Form.

If your study is a mixed-method study involving secondary data analysis AND some component of data collection (e.g. interviews, online survey), then you need to fill in additional forms:

- Ethics Application Form (for studies other than secondary data analysis)
- Risk Assessment Form
- Participant Information Sheet
- Consent Form
- Draft research instrument

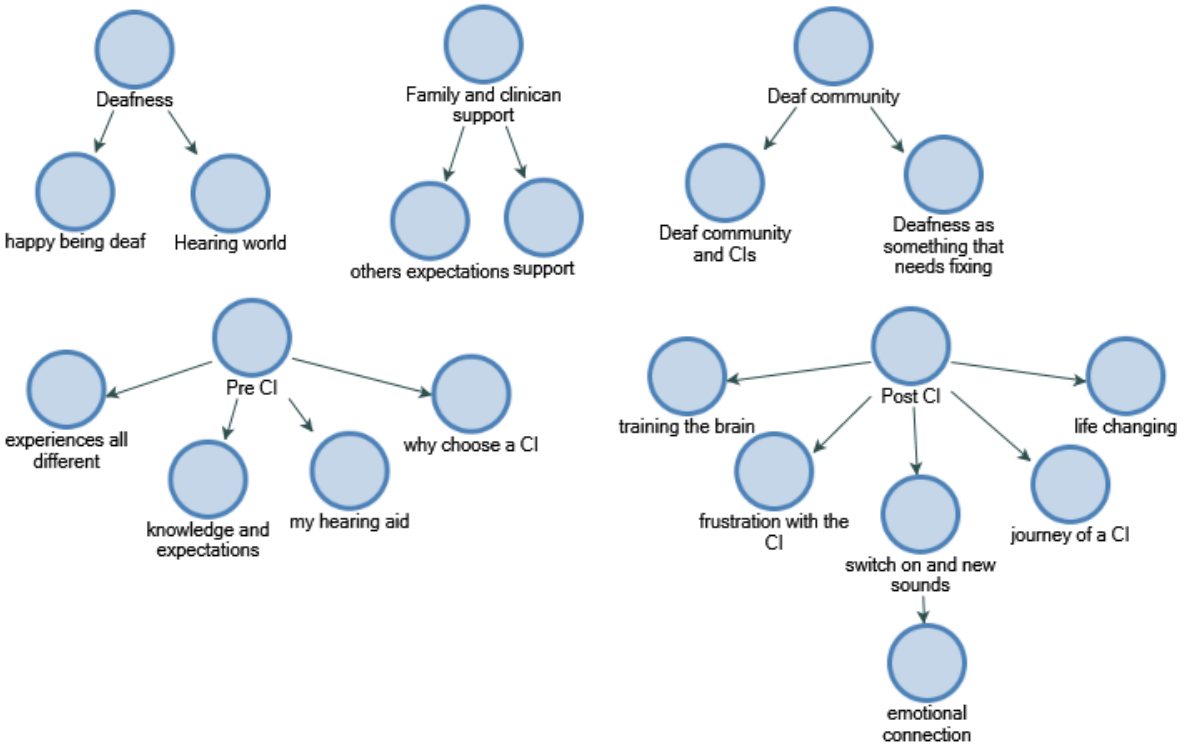
Please note:

- You must not begin data analysis until ethical approval has been obtained.
- It is your responsibility to follow the University of Southampton's Ethics Policy and any relevant academic or professional guidelines in the conduct of your research. This includes ensuring confidentiality in the storage and use of data.
- It is your responsibility to provide full and accurate information in completing this form.

Appendix X Phase 3a - Stages of Thematic analysis

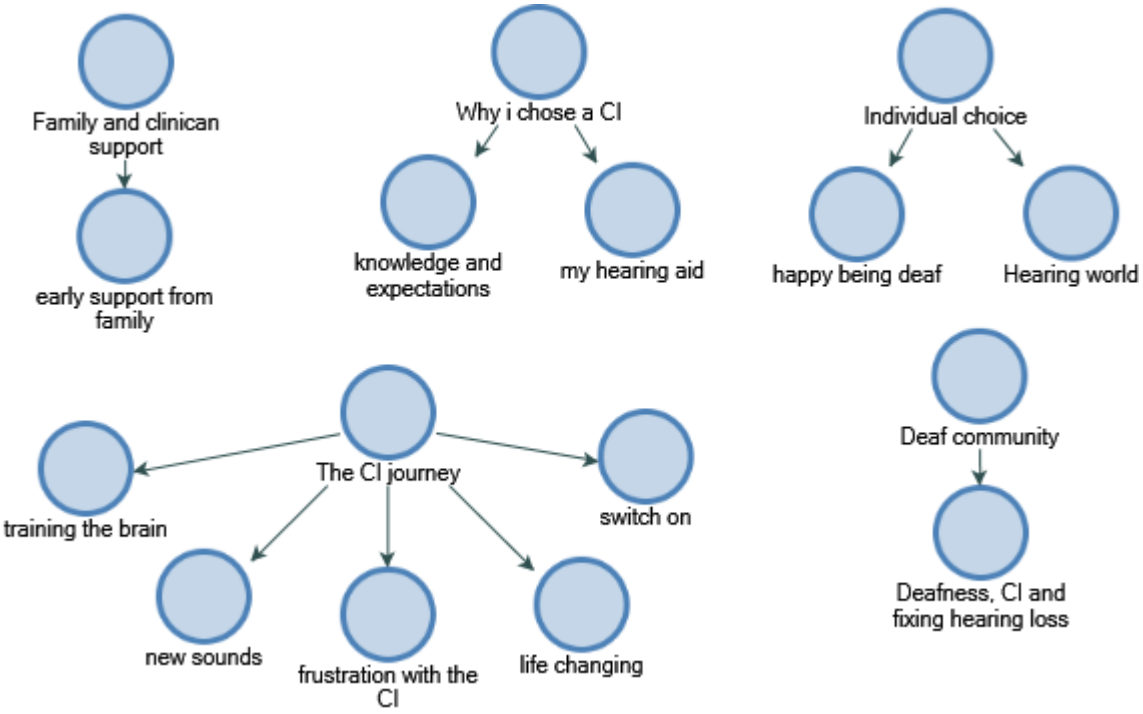
The data were read and re-read to allow the researcher to become immersed in the data (Phase 1). The documents were uploaded into Nvivo and coded using this software. Sections of the text were highlighted within each document and named based on the information they contained. Codes were generated using both inductive and deductive approaches as discussed in 6.3.3. All relevant data were coded (Phase 2). The coded data were then examined to look for potential themes and the codes were then grouped into themes. The codes were combined if they shared a similar meaning or related to the same event. Exactly how this synthesis occurred was difficult to describe as this was based on the researchers knowledge, background and judgement (Thomas and Harden, 2008). No codes were removed from the analysis at this stage. (Phase 3). This resulted in an initial thematic map (Figure Z.1).

Figure Z.1 - Initial thematic map



The generated themes were then reviewed (Phase 3). The review of the themes took place at two levels. One reviewing the codes within the theme and the secondly, across the whole data set. In level 1, there were a large number of sub-themes which were actually very similar to content in other themes and some sub-themes that did not fit with the data set and were very small. Some codes were removed from the analysis as they were singular and did not fit into the themes generated. Certain sub-themes didn't always match the story of the overarching theme. This resulted in new themes emerging with other themes merging or being split into smaller themes (Figure Z.2). This generated a second thematic map.

Figure Z.2: second stage thematic analysis



The themes and sub-themes were then considered in depth their relationship to the dataset. Some of the sub-themes and themes still did not feel like they fit the story of the data. This resulted in the data being reanalysed and some codes being recoded. This then resulted in five themes becoming four themes. The theme 'individual choice' became a sub-theme of 'why I chose a CI'. While the 'hearing world' theme became a sub-theme of 'deaf community' and the sub-themes 'happy being deaf' and 'deafness, CI and fixing hearing loss' merged into the 'Deaf community' theme. The sub-theme new sounds was merged with switch on and renamed 'Emotional rollercoaster'.

The names of the themes were then assessed to ensure they gave the reader a sense of what the themes were about and were relevant to the data coded (Phase 5). The theme 'Family and clinician support' was renamed ' Taking this journey'. The themes were described, and the analysis written up (Phase 6).

Appendix YValidation tools used in Phase 3a study

Internal validity	Triangulation	This was not possible within this Phase. Phase 3a and Phase 3b are compared in 6.5.2.
	Member checks	Websites or contributors were not asked to check the findings. There were issues around locating and accessing the contributors as it was not always clear who had posted the information. The availability of these details and difficulty accessing these meant that it was not possible to consider member checking for this Phase of work. (There were similar issues noted in obtaining consent which were discussed in 6.3.1.1.1.
	Long term observation	This was not possible as this data were collected through the internet at one timepoint. Some of the experiences may have been recorded over time but this was not confirmed.
	Peer examination	Peer examination usually involves another researcher looking at the data and commenting on the findings. This study, as part of my doctoral studies, was reviewed during supervisory meetings and comments on the findings recorded and used to enhance the analysis. No external review outside of the supervisory group was sought as this research was required to be the researchers own. Due to this no external review was sought as part of this doctoral study. This study was reviewed as part of the doctoral examination/for publication therefore another view of the data analysis was obtained.
	Participatory modes of research	PPIE was carried out to ensure this study's relevance to the participants (Chapter 4Chapter 5)
	Researchers' biases	The researcher was a clinician who worked with CI users as part of their clinical role. This has been discussed in more depth in 3.6.
Reliability	Investigator's position	This has been discussed in more depth in 3.2

	Audit trial	Reasons for decisions made are documented as part of this thesis. Methods for data collection and analysis are described. One of the reasons thematic analysis was chosen as the data analysis method, was to ensure a clear audit trial was present.
External validity	Use of rich thick description	This was not possible as one of the steps taken to prevent the participant being identified was ensuring the quotes were google proof. This meant that large sections of text could not be used as this could be easily searched for. This was possible in some cases as the quotes were from online videos and so could not be searched for.
	Typicality of the case	Not applicable as did not follow a case study approach and little information was known about the contributors sharing their experiences.
	Multi-site designs	Not applicable as this involved internet data

Appendix Z Example of validity checks for the written documents

What is the history of the documents?	Unknown
How were these accessed?	Internet search
What guarantee is there that it is what it pretends to be?	the information is from a well respected organisation within the field
Is the document complete, what version of the document is this?	Yes as far as I am aware. Version: unknown
Has the document been edited? This is also relevant to the original form of document, I.e. videos may have been edited	unknown - but it is written information produced by the patients. Could have been edited before published
If the document is genuine, under what circumstances and for what purposes was it produced?	produced to inform CI candidates
Who was/is the author?	Patients are the authors of their stories
What were the authors trying to accomplish? Who was the document intended for?	Information for CI candidates/parents of children having implants
What were the maker's sources of information? Does the document represent an eyewitness account, a second hand account, a reconstruction of an event long prior to the writing, an interpretation?	Stories used are an eye witness accounts. Some information is not relevant to this study
What was or is the maker's/interviewee's bias?	interviewee's bias is that they have been successful with their implant - only one view
To what extent was the writer/interviewee likely to want to tell the truth?	Large extent but they may downplay negative aspects
Do other documents exist that might shed additional light on the same story, event, project, program, context? If so, are they available, accessible? Who holds them?	None - the patients experiences are individual.

Appendix AA Consent forms

UNIVERSITY OF Southampton

IRAS ID: 271439

Study Number: 52273

CONSENT FORM – CI candidate/recipient

Title of Project: Experiences and hopes of cochlear implantation among early deafened adults and their families

Name of Researcher: Suzanne O'Gara

Please initial box

1. I confirm that I have read the participant information sheet dated January 2020 (version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I agree to take part in this research project and agree for my data to be used for the purposes of this study ☐
3. I agree that anonymous direct quotes from the study may be used in the publication and reports of the findings ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care being affected. ☐
5. I understand my hearing test and speech test results will be accessed for the study ☐
6. I understand that all files containing any personal data will be made anonymous ☐
7. I understand that the interview will be audio *and video recorded* (please delete if you do not wish your interview to be video recorded) I understand that any video recordings will be destroyed after 30 days ☐
8. All data, including transcriptions of the audio recordings will be kept until the conclusion of the study and then securely transferred to University of Southampton to retain until 10 years after the conclusion of the study ☐
9. I understand audio files will be stored on a password protected computer so reasonable measures are in place to maintain confidentiality. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file
Version 1.4 05 February 2020

UNIVERSITY OF Southampton

IRAS ID: 271439

Study Number: 52273

CONSENT FORM – family member

Title of Project: Experiences and hopes of cochlear implantation among early deafened adults and their families

Name of Researcher: Suzanne O'Gara

Please initial box

1. I confirm that I have read the participant information sheet dated October 2019 (version 1.3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I agree to take part in this research project and agree for my data to be used for the purposes of this study ☐
3. I agree that anonymous direct quotes from the study may be used in the publication and reports of the findings ☐
4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care being affected. ☐
5. I understand that all files containing any personal data will be made anonymous ☐
6. I understand that the interview will be audio *and video recorded* (please delete if you do not wish your interview to be video recorded) I understand that any video recordings will be destroyed after 30 days ☐
7. All data, including transcriptions of the audio recordings will be kept until the conclusion of the study and then securely transferred to University of Southampton to retain until 10 years after the conclusion of the study ☐
8. I understand audio files will be stored on a password protected computer so reasonable measures are in place to maintain confidentiality. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file
Version 1.3 13 January 2020

Appendix BB Easy read consent forms with BSL links

Easy Read

RAS ID: 271439/Study Number: 52273

PERMISSION/CONSENT FORM

Title of Project: Experiences and hopes of cochlear implantation among early deafened adults and their families

Name of Researcher: Suzanne O'Gara

https://drive.google.com/open?id=1RQhl0TDXm4daxCoZZXzTE1Wu7ig9qv-e

Please put your initials in the box
https://drive.google.com/open?id=11fhqiq2ypyflNHbT0KaP4nnSRGrO7Sg_

1. I confirm that I have read the information or watched the video of the signer explaining about the research (Dated (version)) I have been given time to ask questions and I fully understand what is involved ☐
   https://drive.google.com/open?id=1Gad9KQ9jiGfUiMQ-sn9NPQ1nO5xlVS3w
2. I agree to be involved in this research and agree my information (hearing history, interview information) will be used in this research project ☐
   https://drive.google.com/open?id=1TA2UaBfGiObFmHX-k3kqjNjCrekpdYlo
3. I understand my name will not be shown and that anything that I have said may be published and used in the final report ☐
   https://drive.google.com/open?id=1CFleuvZ_Vm0jgIoZUASHcrFgvbyVCg1y
4. I understand I can pull out of this research at any time. I am a volunteer to this research I can stop with no reason. It will not affect my care at the implant centre. ☐
   https://drive.google.com/open?id=1NsjFoxVhvepMu_0qTO8TTmenbSb9HUnH
5. I understand my personal information will not have my name on it ☐
   https://drive.google.com/open?id=1fm78E8hjps_xNq0Q73Ce2kYvO4rwPr_i
6. I understand my hearing test and speech test results will be accessed for the study ☐
   https://drive.google.com/open?id=1SgruVj4qr3eTLoaru9JEjDnSKqxX9b_D
7. I understand that the interview (questions and answers) will be recorded on video. If you do not want to be on video please put an cross in the box next to this sentence ☐
   https://drive.google.com/open?id=1SujXGvAX0LSJjyW3AvNw55Xn_zXsALU8
8. I understand the video will record the voice of the interpreter (interpreting what you say) and the person who will ask the questions ☐
   https://drive.google.com/open?id=1bamMfsUhBDQGep1gP9MkAphEOOpqlNGf

When completed: 1 for participant; 1 for researcher site file
Version 1.2 09 March 2020

Easy Read

9. All information written and voice recordings will be kept until the end of the research. The University of Southampton will keep the research information for 10 years https://drive.google.com/open?id=1QnyknNX2yJoKwgTTOqQhe_lxl3R5OxY0 ☐

10. I understand the information in the interview (recording of the voices) will be put onto a computer with a password to keep it safe for confidentiality https://drive.google.com/open?id=10tSSnuEeReowfrdo_dnZyDT4bHj4fOdl ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file
Version 1.2 09 March 2020

Appendix CC Research proposal

Experiences and hopes of cochlear implantation among early deafened adults and their families

Short title: CI: Experiences and hopes

PROTOCOL VERSION 1.3 11 November 2019

Previous versions
1.1 submitted to PhD Supervisors for review
1.2 Submitted to ERGO for review

Research reference numbers

IRAS Number:	271439
SPONSORS Number:	ERGO52273

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SIGNATURE PAGE

The undersigned confirm that the following protocol has been agreed and accepted and that the Chief Investigator agrees to conduct the study in compliance with the approved protocol and will adhere to the principles outlined in the Declaration of Helsinki, the Sponsor's SOPs, and other regulatory requirement.

I agree to ensure that the confidential information contained in this document will not be used for any other purpose other than the evaluation or conduct of the investigation without the prior written consent of the Sponsor

I also confirm that I will make the findings of the study publicly available through publication or other dissemination tools without any unnecessary delay and that an honest accurate and transparent account of the study will be given; and that any discrepancies from the study as planned in this protocol will be explained.

For and on behalf of the Study Sponsor:

Signature: Date: ...../...../....
..

.....

Name (please print):

.....

Position: .....
.....

Chief Investigator:

Signature: ..... Date: ...../...../....
.....
..

Name: (please print):

.....

LIST of CONTENTS

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KEY STUDY CONTACTS

Chief Investigator	Suzanne O'Gara University of Southampton Auditory Implant Service (USAIS) Highfield Southampton SO17 1BJ United Kingdom Tel: 023 80 599590 Email: sjog1v07@soton.ac.uk
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STUDY SUMMARY

Study Title	What are the experiences and hopes of adults who are early deafened and their families of a cochlear implant?
Internal ref. no. (or short title)	CI: Experiences and hopes
Study Design	Case study design
Study Participants	Adults with a severe to profound hearing loss diagnosed before the age of 6 years and up to two family members (over 18 years of age) nominated by the patient. Group 1 – adult cochlear implant (CI) user implanted with a cochlear implant for between 1-5 years and up to two family members Group 2 – adult CI recipient who has not yet been implanted. The adult and their family members (up to two) will be followed up at 3 time points. Before implant has been fitted, one month after the cochlear implant has been fitted, six months after the cochlear implant has been fitted.
Planned Size of Sample (if applicable)	Six, this will ideally be three from each group. Due to this being a very specific and small group of individuals, there may be difficulties in recruitment and a pragmatic approach needs to be taken. It is anticipated that there will be more participants in Group 1 than Group 2. However, no more than six CI patients will be recruited.

Follow up duration (if applicable)	For Group 2 interview data will be collected over a 6-8 month period. The first interview will take place before the implant has been fitted and would need to be pre-surgery, waiting list times may mean that some patients are followed up for longer. This then results in a wider time frame and could mean the follow up time is longer for some participants.
Planned Study Period	Feb 2020 to Jan 2021
Research Question/Objectives	What are the hopes and experiences of the recipient and their family members of a cochlear implant? • Discover what the CI recipient and their family's hopes are of a CI • Learn how the recipient and family adapts to the cochlear implant • Understand how the family unit supports the CI recipient through cochlear implantation • Learn what support could be provided that would aid in supporting the CI recipient and the family • Understand what early deafened CI users base their hopes on

FUNDING AND SUPPORT IN KIND

FUNDER(S) (Names and contact details of ALL organisations providing funding and/or support in kind for this study)	**FINANCIAL AND NON FINANCIALSUPPORT GIVEN**
University of Southampton Highfield Southampton SO17 1BJ United Kingdom	This is a PhD project, my fees are being paid by the University of Southampton.

ROLE OF STUDY SPONSOR AND FUNDER

This study is part of my doctoral studies at the University of Southampton. The University assumes overall responsibility for the initiation and management of the study. The sponsor has no other role in the study. The decisions of the study are made by the researcher with support from their supervisory team.

ROLES AND RESPONSIBILITIES OF STUDY MANAGEMENT COMMITEES/GROUPS & INDIVIDUALS

Chief investigator is a PhD student and is responsible for management of the study. The

Supervisory team will be providing support throughout the process.

PROTOCOL CONTRIBUTORS

The contributors to the protocol were the researcher and supervisory team.

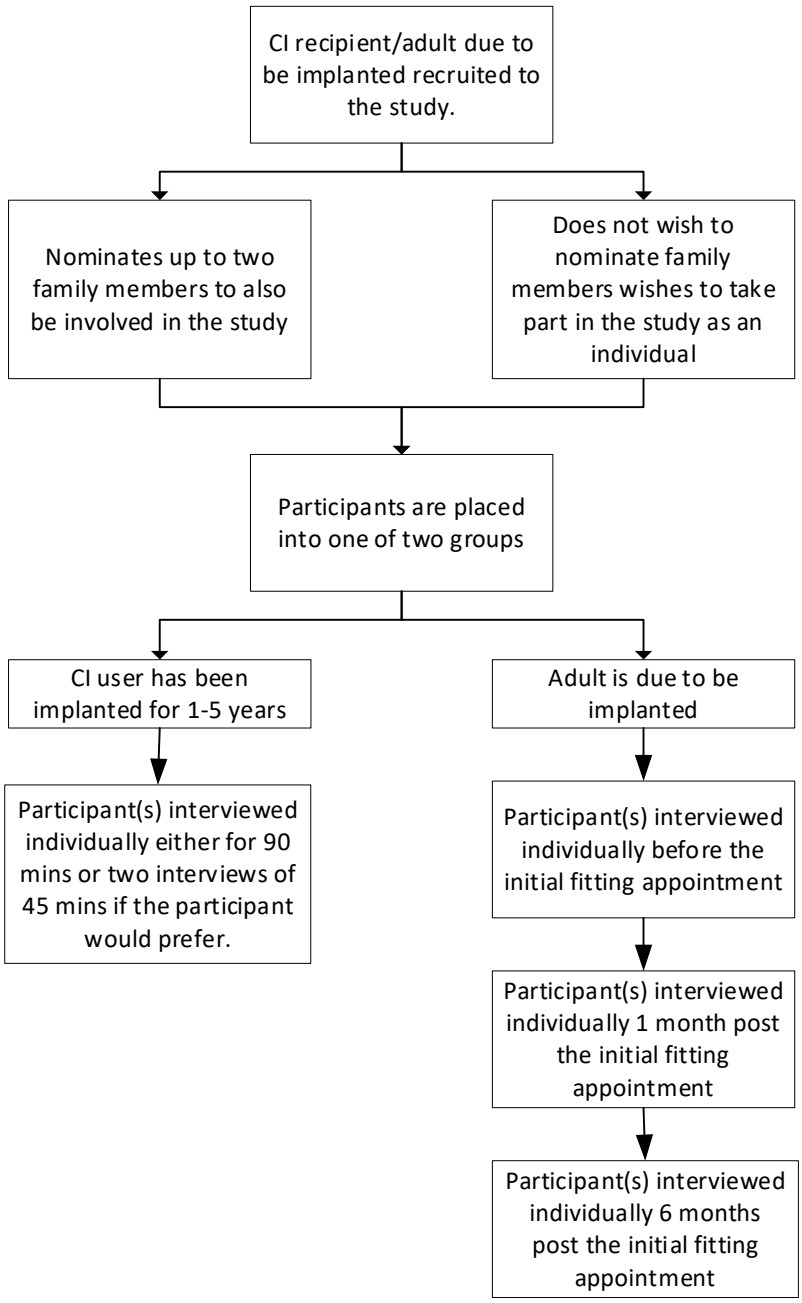
Feedback has been given on the project title, methods and research questions from a early deafened adult who is a British Sign Language (BSL) user. A family member of a CI receipient gave feedback on the research questions.1

A BSL interpreter has also provided feedback on the language and changed the documents into an easy read format and BSL.

KEY WORDS: pre-lingual, cochlear implant, late implanted, long-term deaf, hopes, experience, born D/deaf

STUDY FLOW CHART

Appendix CC



Abbreviations and definitions

CI – Cochlear Implant

BSL – British Sign Language

NICE – National Institute of Clinical excellence

USAIS – University of Southampton Auditory Implant Service

Early deafened – deafened before the age of 6 years (this is the definition for this study)

Post-lingually deafened - deafened after language acquisition

STUDY PROTOCOL

What are the experiences and hopes of adults who are early deafened and their families of a cochlear implant?

1 BACKGROUND

This study aims to look at the hopes and experiences of an early deafened deaf adult and their family. Early deafened adults have been historically less likely to receive a cochlear implant or have evidence of good outcomes in the literature compared to adults who are deafened after language acquisition (An example of this is discussed below). Knowledge gained could help to inform clinical decision-making and support to prospective implant users I will first discuss what this study defines as an early deafened adult, what a cochlear implant is, current literature, and the proposed study.

There is a variety of language used in the literature to describe an adult whose hearing loss was acquired before language acquisition. This was born D/deaf, early deafened, congenital, long-term, and pre-lingual deafness. For this study I will refer to hearing loss acquired before language acquisition as early deafened, as the terms such as pre-lingual or congenital may be unfamiliar to the target group. The early deafened adult group consists of individuals with varying communication modes (Oral/sign language/total communication (using both sign and spoken language) and speech intelligibility (from pre-recognizable words in spoken language to connected speech intelligible to all listeners (Allen et al., 2001)). Early deafened adults can describe themselves as culturally Deaf (with a capital D) or deaf or hard of hearing. This makes the group diverse in their culture and language. Members of the Deaf community do not refer to their hearing loss as a disability and identify themselves as being part of a distinct minority culture (Hole, 2007).

A cochlear implant is a surgically implanted electronic device designed to allow severe to profoundly deaf individuals to perceive sound. The device consists of two parts; the external processor which picks up sound signals and converts them into electrical impulses. The internal electrode array then transmits these impulses to the hearing nerve, bypassing the damaged hair cells in the cochlea. In England, it is commissioned within the NHS for patients with a severe to

profound hearing loss who derive inadequate benefit from acoustic hearing aids (HA) (NICE, 2009, NHS England, 2013). This does not define an onset of deafness, therefore adults who were deafened at birth are covered in the same guidance as an adult who lost their hearing later in life.

The majority of the studies used as the basis for the National Institute or Clinical Excellence (NICE) commissioning guidance is from adults with a post-lingual deafness (acquired loss after language development). There is a wider issue with the speech material used in assessing CI benefit with the measures used having a high language level or being a test without lip-reading cues which is limited in this group after a CI (Craddock et al., 2016).

The expected outcomes of cochlear implantation between the two groups are different (Teoh et al., 2004a) yet their outcomes are measured using the same methods and language level. It is reported in the literature used may have too high a language level for this group (Craddock et al., 2016, Connolly et al., 2006). Studies within the literature have shown early deafened adults do show improvements on speech perception measures but this was variable; from significant improvement to no change in measured performance (Bosco et al., 2013, Klop et al., 2007, Kos et al., 2009, Santarelli et al., 2008, Schramm et al., 2002, Teoh et al., 2004a, Waltzmann et al., 2002, Berrettini et al., 2011). Improvements in quality of life (QoL) have also been identified, but these improvements are not related to improved performance on speech tests (Klop et al., 2007, Zwolan et al., 1996, Chee et al., 2004). With improvements on speech perception tests not evident but improvements in QoL recorded, it suggests that outcome measures other than speech perception measures are necessary to determine CI benefit within this group (Klop et al., 2007, Straatman et al., 2014, Chee et al., 2004). Currently early deafened CI candidates are counselled not to expect an improvement in speech perception measures after implantation. These candidates still choose to be implanted, and report benefit from their CI. Awareness of what these candidate's hopes and expectations of a CI would improve the assessment, counselling and management of these patients.

Five papers have been identified in the published literature that discussed this groups expectations. One paper reported that the expectations were for better communication and to hear more sounds (Heywood et al., 2016). Four of the papers found that the participants expectations of an implant differed from their actual experience and the implant did not meet all of their expectations (Bosco et al., 2013, Chee et al., 2004, Jeffs et al., 2015, Heywood et al., 2016). The papers did not discuss what expectations were not met and of the 43 participants only two would not consider an implant again (Bosco et al., 2013, Chee et al., 2004, Jeffs et al., 2015). The reasons why expectations were not met and why participants would or would not consider a

CI again are not discussed within the papers. One of the main points was that data collection methods used did not allow for further exploration of the points raised, for example using postal questionnaires means that any answers cannot be further described or clarified. Interestingly, Heywood et al. (2016) found that participants reporting that their CI were successful depended upon if their expectations had been met. This highlights the need for further discussion of expectations, using data collection methods such as interviews would allow the topics raised to be discussed in detail to expand on any points raised.

In the general population early deafened adults are a minority group with approximately 0.13% of the UK population being a deaf BSL user (ONS, 2018, British Deaf Association, 2019) within the CI population approximately 13% of the adult CI users (USAIS, 2018, BCIG, 2018) (data on BSL users at USAIS extrapolated to the whole of the UK using BCIG data) use BSL. There is no data on the numbers of adult's who are early deafened and not BSL users in the UK.

These adults have been unknowingly excluded from research studies due to the accessibility of the studies. This can include a requirement of English as a first language (Ingvarsdotter et al., 2012, Kapborga and Bertero, 2002) or the study materials including written material with too high a language level (Connolly et al., 2006). This prevents this group accessing research which if accessible they may wish to be involved in, it can also mean that only one view is being presented when this group are active service users. This is particular evident in audiology services which provide hearing aids and cochlear implants to this group. At USAIS approximately 10% of the population are early deafened (USAIS, 2018). This is a percentage of the population that these services in particular should be considering in their planning and management strategies. The starting point for this would be Participant and public involvement (PPI) work.

This study involved an early deafened BSL CI user in PPI work, they identified that although expectations were important, the families expectations were just as important and information to support the family would be helpful as when they were going through the process they found it difficult to tell their family what to expect. There has been no literature found which discusses the experiences and expectations of an early deafened family member's family and how this affects them going through the CI process. Three papers were found that looked at the family's experience of a CI when the adult was post-lingually deafened (deafened after language acquisition), all used questionnaires (Maki-Torkko et al., 2015, Kennedy et al., 2008, Wexler et al., 1982) which allow no further discussion of the topics raised. All the papers found a positive impact on the CI user, with Maki-Torkko et al. (2015) finding that participants reported both the

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CI recipients and the family members life changed significantly as a result of the implant due to increased wellbeing and independence.

This identifies that there are gaps within the literature exploring the CI recipient's expectations of an implant using different methods such as interviews to allow more in-depth knowledge of what their expectations of an implant are. There are also gaps when looking at the family's experience of a CI with no papers found focusing on this for the early deafened group.

The early deafened CI user involved in the PPI also felt that the word 'expectations' would not be understood well by Deaf BSL adults. There is no sign for expectations and this would not help in the understanding of this if communicating in BSL, this also would have the issue of using different signs to explain this. They suggested the word 'hope' rather than expectations. Up to that point the study had been titled the Experiences and expectations of early deafened CI users. This title was updated on this feedback. Using the word hope rather than expectations still does allow the study to look at expectations as what some hopes to gain from an implant is similar language to what do you expect from an implant. Using the word 'hope/s' is not common in scientific literature and no studies were found looking at the hopes of patients of cochlear implants (search October 2019 using Medline and Web of Science).

This study proposes to use a case study approach to investigate the hopes and experiences of the CI recipient and their family of a cochlear implant. This study aims to put the views of the early deafened view at the forefront of the study. This means listening and considering their views, Even though the PPI work involved one early deafened adult (the PPI work aimed to recruit more but was unable to), this view is still important and needs to be considered. Not considering this view means that as researchers again we are not listening but putting our own agenda forward. As far as the researcher is aware it is the first time that this methodology has been used with this group, the first time this group has been interviewed about their hopes/expectations and the first time the hopes/expectations of this group's family and the effect on their CI experience considered. Using a case study approach enables a detailed description of the participants experience to be captured using a variety of data sources, this approach enables the experiences to be explored and understood from their lived experience. Some CI candidates/recipients may not wish to nominate family members, these adults will not be excluded from the study. These adults are part of small minority group whose views have previously not been considered (Benedict and Sass-Lehrer, 2007), excluding any of these patients goes against the inclusivity of the study, with this topic being under investigated all views will add to the knowledge base in this area.

What is defined as the CI recipient's family/significant others, will be defined by the CI recipient, all family members will be required to be over 18 years of age. A limit of two family members will be made to ensure each case was investigated in detail. This may then include, siblings/children/parents/partner and friends. Family members without blood or legal ties are documented within the literature (Braithwaite et al., 2010). This study is going to take the individual's perspective on who makes up their family is and impose no boundaries on this.

There may be participants who do not wish their family members to be involved in the study, rather than exclude these adults they will still be included. Although the views of the family members have been highlighted as being important as this is a small group the research team do not wish to exclude these adults on the basis that they do not wish to involve their family members.

There will be two groups of participants

- Patients going through the CI assessment process and their family members
- Patients who have a CI and their family members

Looking at patients who have had a CI and then patients who are going through the initial tuning process will give two different insights. It will allow the patients and family members experience of a CI to be followed in relation to their performance with the CI. Patients and family members who have had their CI will be able to look back retrospectively and consider what information would have been useful for them during the process after a period of time to adapt to the cochlear implant. As although there may be initial changes over the period of initial tuning, there may be longer term changes that the recipients and their families will be able to discuss.

2 RATIONALE

The research questions have been devised through consultation with a CI recipient to understand what would have been useful for them to know before going through the CI process. Early deafened adults are a minority group and their views and opinions are not regularly sought with planning CI care, there is a need to listen to this group and ensure their voices can be heard. Although the Patient and Public involvement work (PPI) only involved one adult, this adult worked in partnership with the chief investigator to ensure the study would be relevant to this group and accessible. They provided guidance with regards to cultural aspects of the study and developed the study to ensure that the results would be applicable and effect the experience of

this group during CI assessment. This only being one voice does not mean the impact on the study has been less. This study will hopefully improve access of the community to research by showing the community their views are important and by demonstrating to researchers the adjustments and modifications that are necessary to ensure access to early deafened adults. This highlights why it is important to include their views even if they do not wish to nominate family members to be involved in the study, excluding members of this group who have shown an interest in the study has the potential of excluding this individuals views which may limit participation.

3 THEORETICAL FRAMEWORK

A case study can be defined as 'the study of the particularity and complexity of a single case, coming to understand its activity within important circumstances' (Stake, 1995). A case study approach allows the views of the CI recipient and their family (one case) to be considered independently while allowing comparisons across the cases to be made (Stake, 2006). There are different methodological approaches to case study research, developed by Stake (1995), Merriam (1998) and Yin (2014). These approaches differ due to authors theoretical positions and a summary of the differences is provided by Yazan (2015). This study will be using Stake's (1995) conceptual approach as this orientates to the researchers position that reality is subjective, aligning with reported experiences being based on previous knowledge and understanding. The researcher will be interpreting participant's descriptions of their experience and is an active participant in this. The researcher also identifies with Stake (1995) view that there are multiple potential views of the case. The data validation strategies proposed by Stake (1995) are all related to triangulation (data source, investigator, theory and methodological) do not seem as extensive as the strategies proposed by Merriam (1998) which have specific techniques for internal validity, reliability and external validity. Therefore this study will be based on the approach of Stake (1995) but use the data validation strategies of Merriam (1998). Other authors have also used a combined approach for their case studies (Yazan, 2015).

When investigating the family experience there is a need to represent the views of the family members with the understanding there is no one correct view. The individuals view or reality is constructed by them and by their interactions with their reality (Merriam, 1998, Stake, 1995). This follows the constructionist viewpoint, where reality is constructed by the individuals. In this

viewpoint the reality is not objective, it is constructed by individuals and there can be multiple interpretations of the same reality (Merriam, 1998). Stake (1995) views researchers as interpreters of the information they have gathered and then construct in their research. This study has two potential interpretations at different stages of the research. It has the interpretation by the researcher throughout the study but some participants will have the interpretation by the BSL interpreter. This adds an extra layer of interpretation and construction of reality which will need to be considered throughout the analysis.

Case study methodology can use a variety of data sources to explore and describe the case. Therefore, to complement the interview data, the pre and post-implant test results of the participants will be included to allow further insights into the participants' experience and hopes of a CI.

Stake (1995) defines two types of case study, intrinsic and instrumental. An intrinsic case study, when there is interest in a specific case; an instrumental case study is used when there is a need to explore a particular effect. The methods used to for each case study will be dependent on the type of case study chosen and the purpose of the study (Stake, 1995, Simons, 2009). Stake (1995) describes investigating multiple case studies as a collective case study, this will be used in this study to give an insight into different family experiences of a CI, as every patient will not have the same outcome with a CI, just as every families experience will be different. This also allows comparisons between the cases to be made.

This study will be an instrumental collective case as the effect of a CI on the family is being investigated on more than one family (or case).

4 RESEARCH QUESTION/AIM(S)

What are the experiences and hopes of the recipient and their family members of a cochlear implant?

4.1 Objectives

- Discover what the CI recipient and their family's hopes are of a CI
- Learn how the recipient and family adapts to the cochlear implant

- Understand how the family unit supports the CI recipient through cochlear implantation
- Learn what support could be provided that would aid in supporting the CI recipient and the family
- Understand what early deafened CI users base their hopes on

4.2 Outcome

This study aims to result in materials that will be used to develop materials to and support family members through the CI process and inform clinicians to improve the service provided to early deafened adults while being assessed for a CI. The development of these materials is not within the scope of this PhD study. This study will also present its findings in BSL and have plain English versions to ensure that all groups can access the findings.

5 STUDY DESIGN and METHODS of DATA COLLECTION AND DATA ANALYIS

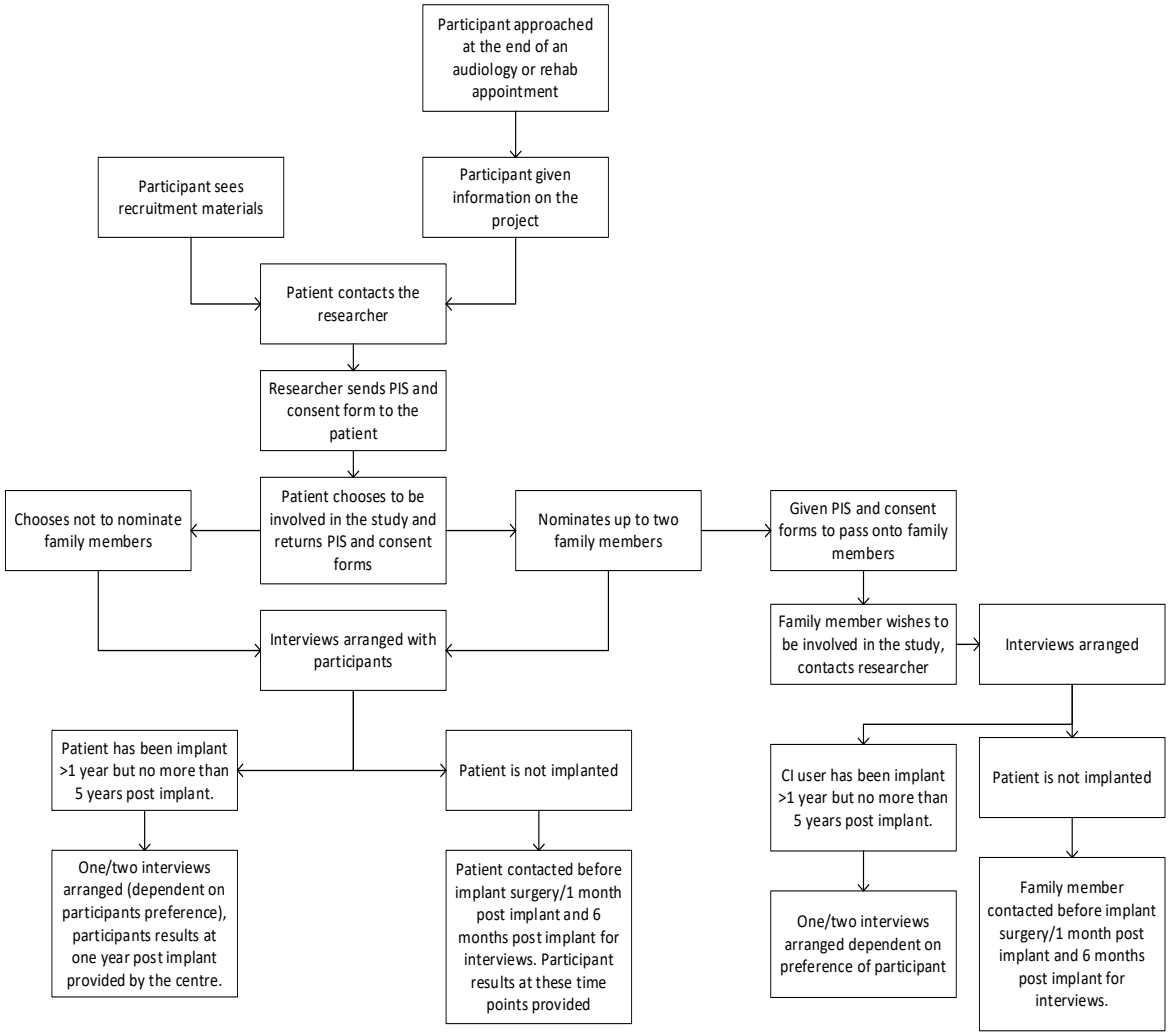
Each case would be formed of the CI recipient/candidate and up to two of their family members. There may be some CI recipients who wish to be involved in the study but not to involve their family members, due to the exploratory nature of this study and the small pool of participants, these participants will not be excluded but involved in the study but the views of their family members not considered. If the CI recipients do not wish to involve their family members then the interviews will slightly differ from adults who do nominate family members as they will be asked about their relationship to the participants they have nominated (See Figure 0.1 for a flow chart showing the participant pathway in the study).

- Pre-implant and post-implant test results

During a CI assessment, data is recorded on their unaided hearing levels, and their performance with their hearing levels on speech perception measures (This can include Bamford-Kowal-Bench (BKB) sentence testing, City University of New York (CUNY) sentence testing, Arthur-Boothroyd (AB) words and the ASSE test). The results recorded after implantation can include aided audiometry and aided speech testing. At the twelve month appointment the patients are asked if their QoL is improved and this is recorded, this will also be included for CI recipients. CI candidates will be followed until their 6 month appointment and so will have no QoL data. All of the data described would be accessed through case note review. This data will be transferred

anonymously to a password protected computer this will be stored under the same pseudonym as the interview data.

Figure 0.1 The patient and family member pathway



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- In-depth interviews

The interview guide was developed with a BSL interpreter to ensure the questions and the language used were relevant, appropriate and could be used for adults who use BSL or adults who use spoken English. The principal investigator will be conducting the interviews either by phone, skype or face to face. Participants will be given the option of audio or a video recording. For the interviews that are audio recorded, this will record the user if the language used is spoken or the interpreter if the language used is BSL. The audio recordings will be made using an AV recorder provided by the University of Southampton and this will then be uploaded to a password protected computer. The files will then be deleted on the audio recorder. The audio files will be deleted at the end of the study.

For the video recordings this will be made using a video camera and the files uploaded to a password protected computer, these will then be deleted off the camera. This video data will be used to comment on the reliability of the interpretation. The interpreter who performed the interviews will go back through the video to check the interpretation. This will be performed within 30 days and the video file then deleted.

- Transcription

After performing the interviews the audio tapes will first be transferred to a password protected computer and then transcribed by the Principal Investigator. After transcription the transcripts will then be anonymised, each case will be given a pseudonym for the family name and for each family member. Any potential identifying data will be changed to prevent identification, for example any locations identified.

- Coding

The transcripts will be transferred to NVIVO software for analysis. Before coding of the transcripts a detailed description of the case would be produced, for example the history of deafness, the make-up of the family, the family relationship and the journey to a CI. For each case the transcripts will be coded to the research questions for each individual case and corresponding themes identified. Then cross case analysis would occur to identify common themes present across the cases. This would be performed using thematic analysis (Thomas, 2011, Gerrish and Lathlean, 2015, Creswell and Poth, 2018). This would allow greater understanding of what it is like for families when a family member undergoes implantation.

- Stored/transferred

The audio files will be deleted at the end of the study. The transcripts will be stored on password protected computers. Any paper documents will be stored in a locked cabinet in an office with restricted access.

- Accessed

The data will be accessed by the principal investigator and the supervisory team. No other individuals will have access to the transcripts.

- Archived

After completion of the PhD the study materials (including hard copy consent forms) will be transferred to University of Southampton (under the control of the project lead) to keep until 10 years after the conclusion of the study, as required.

7 SAMPLE AND RECRUITMENT

7.1 Eligibility Criteria

This section lays out the inclusion and exclusion criteria for the study. There are two groups of participants in the study, CI candidates/recipients and their family members. The CI candidates/recipients will be recruited from the patients at USAIS.

The family members may live across the UK and the world. Should the family members not be UK based they will not be excluded from the study.

7.1.1 Inclusion criteria

- Adult was identified with a hearing loss from birth to <6 years of age.

- Implanted with an implant within the last 1-5 years **or** meet the NICE guidance for cochlear implantation and have decided to proceed with an implant.

- If desired they are able to identify up to two family members to be involved in the study, who must be over 18 years of age. Participants will **not** be excluded from the study if they do not wish to identify family members to participate.

All participants must be able to give informed consent to be included in the study.

7.1.2 Exclusion criteria

- Hearing loss identified at 6 years of age and above,

- They do not have a cochlear implant and/or do not wish to proceed with cochlear implantation.

- Unable to give informed consent

7.2 Sampling

The aim is to recruit 3 CI candidates and 3 CI recipients. Due to the numbers of CI candidates affected by referral rates if 3 months into the study and it has not been possible to recruit 3 CI candidates, the remaining participants will be sought from the CI recipient group. The number of CI participants and therefore cases will be limited to 6.

Convenience sampling will be applied. The first 3 CI participants to complete the consent forms and arrange interview dates from each group will be selected.

7.2.1 Size of sample

The sample size is small which is suitable for a case study approach as the data collected is rich and in-depth. This is also due to the referral rates of early deafened adults to CI centres. At USAIS of 126 patients who were referred to the CI centre for a CI assessment (from April 2018 to March 2019 (USAIS, 2019)), 24 developed their hearing loss under the age of six years and so would meet the study's inclusion criteria. These are small numbers and with the time frame of data collection recruiting a larger sample size is not appropriate. There are larger numbers of early deafened adults who have been implanted in the last 1-5 years but again these are not large numbers when comparing to adults who were deaf as adults.

7.2.2 Sampling technique

This study will use two different approaches to sampling. The first is to identify the CI recipients/candidates, this will be through convenience sampling to meet the inclusion criteria. The family members will be recruited through snowball sampling as the CI recipients/candidates will then be asked to identify the family members who they wish to be involved in the study and provided with the PIS and consent forms to distribute to them. The family members would then need to contact the researcher directly to be involved in the study. Two methods of sampling are

used as the CI recipients need to meet centre inclusion criteria and the boundaries of the case, while the family members need to be identified by the recipient. It may be that family members of CI recipients approach the researcher to be involved in the study but the researcher will require the consent and participation of the CI recipient/candidate before family members can be recruited to the study.

As this is the first time this topic has been investigated using this methodology, if the CI recipient does not wish to identify family members to be involved in the study they will not be excluded.

The family members are likely to be a diverse group due to the different relationships with the recipient/candidate.

7.3 Recruitment

Recruitment will be an important aspect of this study as this is an under researched group who require adjustment of conventional recruitment methods. Participants will be recruited through a variety of different methods:

4) Through the University of Southampton Auditory Implant Service (USAIS)
    - While in clinic during their assessment appointments or during routine annual reviews, clinicians will provide patients with participant information sheets or direct them to online videos (PIS are included in application; See Appendix 1 for screen shots of the video – due to the costs and time needed to record the video, the videos will not be recorded until ethics approval is obtained.). Patients will be approached by clinicians in the appointments (Clinicians refers to Audiologists and Rehabilitationists). Clinicians will be advised to use language “Have you heard about this study, if you would like to be involved here are the contact details of the researcher”. For patients who have a CI, they attend clinic routinely for their 1/2/3 year audiology and rehabilitation appointment, they can also attend for additional appointments which the patient requests. Patients who are undergoing assessment will be approached at their ‘choosing my implant and planning for hospital appointment’ (For a summary see Figure 0.1).

    All patients would be approached by audiology staff or rehabilitation staff and the end of the appointments.

    - Advert/video on the USAIS website, Facebook page and twitter feed (Appendix 2)

- Posters advertising in the USAIS reception (Appendix 3)

5) Through participants recruited to the study
    - CI recipients/candidates will need to provide information on the family members which they wish to take part
    - CI recipients may inform other CI recipients/candidates about the study (word of mouth)
6) The Southern counties cochlear Implant group (SOCO; this is a patient group mainly consisting of CI users and their families who are patients at USAIS)
    - Advert/video on the SOCO group Facebook page (Appendix 2)
7) The video adverts may be seen by CI candidates/recipients at other CI centres and may approach the researcher to be involved in the study

7.3.1 Sample identification

The CI recipients/candidates will be identified by USAIS or will directly contact the researcher through the research materials in the public domain such as posters/adverts/websites.

The participants identified through USAIS will be identified by the researcher through the clinical database, the researcher works at USAIS as a clinician and already has access to this material as part of their clinical role. All potential participants contacted by USAIS will have specified that they can be contacted for research purposes. The researcher will not initiate contact with patients unless patients have requested this. Initial contact will be made by a clinician at USAIS unrelated to the study (See Figure 0.2 for an overview of how will participants will be approached if they are patients at USAIS).

The interviews can be conducted face to face or through skype. If the participants wish a face to face interview all reasonable travel expenses will be covered.

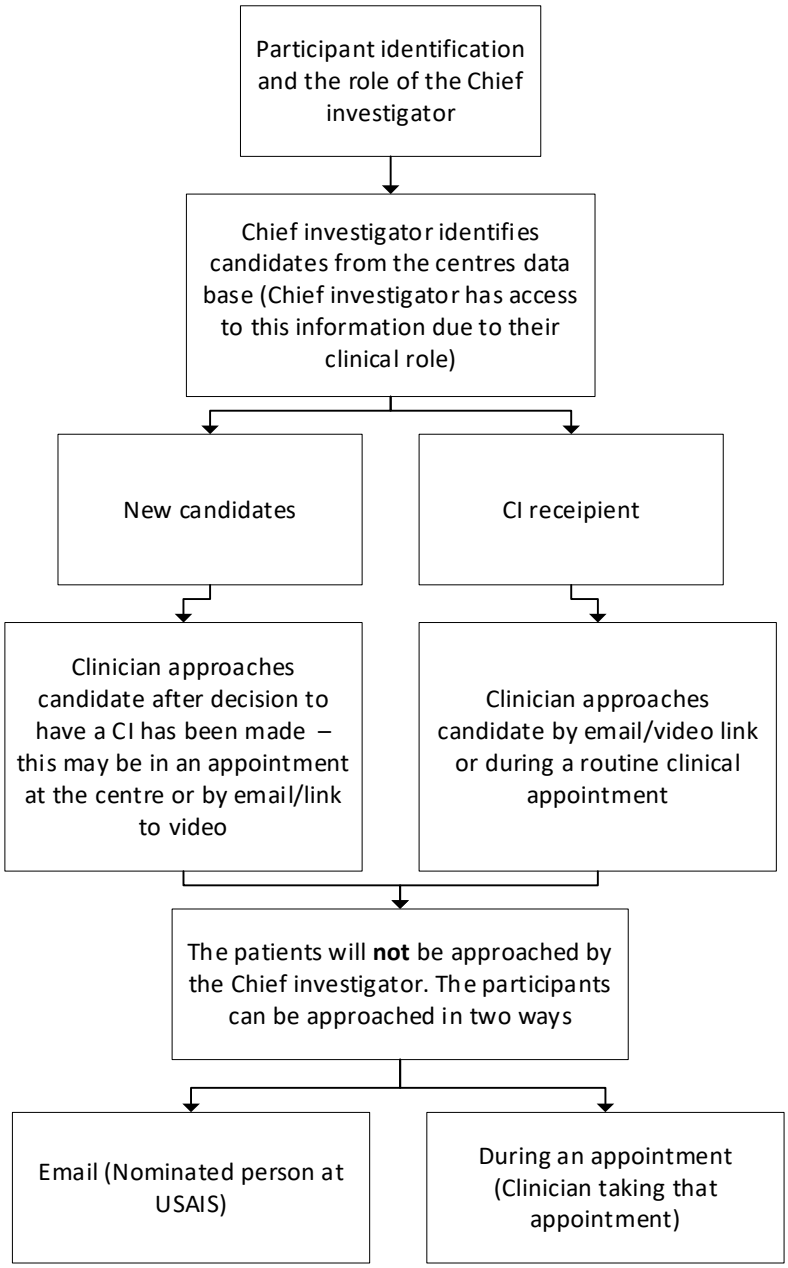

Figure 0.2: Flow chart identifying how patients will be identified and approached regarding their involvement in the study.

7.3.2 Consent

Informed consent must be obtained prior to the participant undergoing any activities that are specifically for the purposes of the study.

Once the CI recipient/candidate have been identified and shown interest to be involved in the study, the will be directly contacted by the researcher. This is likely to be through email, this can establish the communication mode the participants require for any further correspondence. If the recipient/candidate requests an interpreter a time to contact them with an interpreter

present will be arranged. They will be given an opportunity to ask any questions at this point in the process, at this time they will also be sent all the study information materials (PIS and consent forms) in the format they have requested. If BSL format requested they may be directed to a webpage due to the size of the video files.

They will be given twenty hours to consider the information provided and given an opportunity to discuss any points raised. If they have no questions and still wish to be part of the study, they will be asked to return the consent form and to contact the family members they wish to take part in the study and get their consent to provide the researcher with their contact details. Once these details have been received the researcher will send the PIS and consent forms to the family members identified. They will be given twenty hours to consider the information provided and given an opportunity to ask any questions. If they still wish to take part they will be asked to return the consent form.

There may be instances where family members contact the researcher before the CI recipient they are related to does. They will be provided with the study materials to pass onto the recipient and advised to ask them to contact the researcher should they wish to be involved in the study, the family member will not be recruited to the study until the consent form is received from the CI recipient/candidate.

Some of the participants (both the CI recipients/candidates and family members) may be BSL users/ All participants will be provided with a written consent form, this material will have also been sent to them in a signed format if requested. It is important to note that the participant's main language may be BSL and so any consent form will need to be read through in the presence of a BSL interpreter before the interview commences to check that the participant has fully understood the written information and has understood what they have consented to and is happy to commence with the interview.

During the interview the CI recipient/candidate can change their mind and the interview terminated, this would then remove the whole family case from the study. If a family member withdrew this would not remove the whole case but only the family member's interview.

8 ETHICAL AND REGULATORY CONSIDERATIONS

This project is defined as research and requires NHS REC ethical review because 'participants identified from, or because of their past or present use of services (adult and children's

healthcare within the NHS and adult social care), for which the UK health departments are responsible'

Ethical implications

- Patient burden through taking part in this process

Patients and their family members are free to withdrawn at any time, the information they have already provided will be kept unless they request this is not included. The withdrawal of the CI user will result in the withdrawal of the whole family unit, the withdrawal of a family member will not result in the rest of the participants in the case being withdrawn. After the interview if participants wish to discuss any topics raised in the interviews further they will be given contact details of the Chief investigator and the supervisory team. If they wish to discuss a topic relating to the cochlear implant, they will be asked to contact staff at their Implant centre.

- Language requirements of participants

A specific consideration for this group are language, some of the group may be BSL users so all documents need to be available in BSL and any interviews or requested meetings will take place with a BSL interpreter if so requested. It is important to ensure that all materials are accessible to the participants.

- The chief investigator's dual role

The chief investigator is completing this project as part of a PhD, they are also a Clinical scientist (Audiology) at the Implant centre from which patients will be recruited. This means they may have seen or will see potential participants as patients. Once patients are recruited to the study the Chief investigator will ensure that they are not the clinician seeing that patient until patients data collection period is completed. The Chief investigator will not discuss the study during any clinical sessions unless asked for questions regarding this, other staff members at the centre will approach and inform the participants of the study, this will not be the chief investigators role.

- Video recording

The participants will be given the option of being video recorded or audio recorded. The video recordings would be used to comment on the reliability of the interpretation, they would be performed by the same interpreter that took part in the interview. There is an issue of anonymity as they will be identifiable from the video. This will be stored on a password protected computer and deleted within 30 days.

- Support for the researcher

Appendix CC

During the interviews topics may be raised that have an emotional impact on the researcher. Participants have options to ask for extra support set out in their PIS, but this is not as clear for the researcher. If the researcher does wish to discuss the emotional impact of what was raised in the interviews then support can be accessed from the supervisory team or from Psychologists working at USAIS.

8.1 Assessment and management of risk

It is possible that the topics discussed with the participants may cause some distress, participants will be advised to contact their GPs if they wish for any further support. If participants are patients at the centre they will be provided with the centres contact details for further support.

It is possible that participants may disclose, that they or someone close to them, is at risk of harm. If this is the case this information will be disclosed to the clinical team at USAIS for advice and further management. USAIS has an adult safeguarding procedure which will be followed.

8.2 Research Ethics Committee (REC) and other Regulatory review & reports

Before the start of the study, a favourable opinion will be sought from the REC for the study protocol, informed consent forms and other relevant documents.

- Substantial amendments that require review by NHS REC will not be implemented until that review is in place.
- All correspondence with the REC will be retained.
- The Chief Investigator will notify the REC of the end of the study.
- An annual progress report (APR) will be submitted to the REC within 30 days of the anniversary date on which the favourable opinion was given, and annually until the study is declared ended.
- If the study is ended prematurely, the Chief Investigator will notify the REC, including the reasons for the premature termination.
- Within one year after the end of the study, the Chief Investigator will submit a final report with the results, including any publications/abstracts, to the REC.

Regulatory Review & Compliance

Before any participants are recruited to the study, the Chief Investigator will ensure that appropriate approvals from participating organisations are in place. Specific arrangements on how to gain approval from participating organisations are in place and comply with the relevant guidance.

For any amendment to the study, the Chief Investigator will submit information to the sponsor (University of Southampton) and if appropriate REC for them to issue approval for the amendment.

Amendments

The chief investigator will be responsible for amending the protocol. The decision if an amendment is substantial or non-substantial lies with the sponsor. Any amendments will be submitted to the Sponsors ethics committee for consideration (ERGO).

If the amendment is substantial the decision will be documented and documents submitted to REC for consideration. If the amendment is non-substantial, REC will not be notified but the version number and date of amendment will be updated on any affected documents. If there is a later substantial amendment then the non-substantial amendments will be included in the substantial amendment submission.

Non-substantial amendments will result in changes to the protocols and study materials version number and date of amendment included.

8.3 Peer review

The study materials, protocol, PIS, consent forms and all relevant documents have been peer reviewed by the Supervisory team.

8.4 Patient & Public Involvement

To ensure the relevance of the study to the early deafened adult population, PPI work has been carried out. The study's interview guide, semi-structured interview guide and recruitment

materials have been developed with input from an early deafened adult. They advised that to ensure accessibility a summary of the study's findings should be available in BSL.

A family member of a CI user also commented on the interview guide to ensure that the family's perspective was considered during its development.

8.5 Protocol compliance

A "serious breach" is a breach which is likely to effect to a significant degree:

(a) The safety or physical or mental integrity of the participants of the project; or

(b) The scientific value of the project

The sponsor (University of Southampton) will be notified immediately of any case where the above.

Safety monitoring and reporting of adverse events will occur according to requirements of the local and national ethics committees. Details for the HRA are given here https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/safety-reporting/.

8.6 Data protection and patient confidentiality

We cannot guarantee anonymity because adults with cochlear implants are still rare in the general population (approximately 0.01% of the UK population, or approximately 1 in 10,000 people). From the USAIS data this would correspond to a early deafened adult of approximately 1 in 100,000. This makes anonymity more challenging.

Interviews will be audio-recorded and transcribed. Any names, place names and immediately identfable information will be removed during transcription and a puseudoym assigned. Due to the nature of family groups, and several family members taking part there is a possibility that family members may idenitfy themselves and or family members from the data presented.

The file linking the orignal names to the pseudoyms will be kept separate to the interview data on a password protected computer. The transcripts will only be accessible to the chief invesitgator and study team.

All information will be processed in accordance with the Data Protection Act 1998 with regards to the collection, storage, processing and disclosure of personal information and will be securely analysed and stored.

On completion of the project all data will be transferred to University of Southampton (under the control of the chief investigator) to keep until 10 years after the conclusion of the study, as required.

The only time confidentiality would be broken is if participants disclose during the interview that indicates they, or someone else, are at serious risk of harm. This is detailed in the participant information sheet.

8.7 Indemnity

University of Southampton Insurance will apply to meet potential legal liability for harm to participants arising from the management, design and conduct of this research.

For payment of compensation in the event of harm to the research participants where no legal liability arises – No, The University of Southampton will consider provision of this cover if it is a requirement of the NHS Ethics Committee.

8.8 Access to the final study dataset

Access to the interview transcripts will be restricted to the researcher and their supervisory team, all data analysis will be performed by members of this group. No other individuals will have access to this raw data.

The data will not be used for any further projects or secondary analysis than described here.

9 DISSEMINIATION POLICY

9.1 Dissemination policy

Results will be presented locally, nationally and internationally. Dissemination will include but not be limited to peer-reviewed publications both online and in print, conference and meeting presentations, posters, newsletter articles, website reports, and social media.

Appendix CC

To ensure the dissemination of the results is accessible to all participants, a BSL video will be produced to disseminate the final findings and made available to BSL users. To inform people of the results, they will be sent to the USAIS patient newsletter along with a link to an accompanying BSL video.

The final study report will be shared with the sponsor (University of Southampton).

9.2 Authorship eligibility guidelines and any intended use of professional writers

The authorship of the study will be limited to the Chief investigator and the study team.

There is no intended use of professional writers.

Appendix DD IRAS forms

NHS REC Form | Reference: | IRAS Version 5.13

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please complete the questions in order. If you change the response to a question, please select 'Save' and review all the questions as your change may have affected subsequent questions.

Please enter a short title for this project (maximum 70 characters)
CI: Experiences and hopes

1. Is your project research?

(●) Yes ( ) No

2. Select one category from the list below:

( ) Clinical trial of an investigational medicinal product
( ) Clinical investigation or other study of a medical device
( ) Combined trial of an investigational medicinal product and an investigational medical device
( ) Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice
( ) Basic science study involving procedures with human participants
( ) Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology
(●) Study involving qualitative methods only
( ) Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)
( ) Study limited to working with data (specific project only)
( ) Research tissue bank
( ) Research database

If your work does not fit any of these categories, select the option below:

( ) Other study

2a. Please answer the following question(s):

a) Does the study involve the use of any ionising radiation?	( ) Yes	(●) No
b) Will you be taking new human tissue samples (or other human biological samples)?	( ) Yes	(●) No
c) Will you be using existing human tissue samples (or other human biological samples)?	( ) Yes	(●) No

3. In which countries of the UK will the research sites be located? *(Tick all that apply)*

[x] England
[ ] Scotland

☐ Wales
☐ Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

○ England
○ Scotland
○ Wales
○ Northern Ireland
◉ This study does not involve the NHS

4. Which applications do you require?

☐ NHS/HSC Research and Development offices
☐ Social Care Research Ethics Committee
☑ Research Ethics Committee
☐ Confidentiality Advisory Group (CAG)
☐ Her Majesty's Prison and Probation Service (HMPPS)

5. Will any research sites in this study be NHS organisations?

○ Yes ◉ No

6. Do you plan to include any participants who are children?

○ Yes ◉ No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ Yes ◉ No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

○ Yes ◉ No

9. Is the study or any part of it being undertaken as an educational project?

◉ Yes ○ No

Please describe briefly the involvement of the student(s):
This is part of my doctoral studies. I am a Clinical member of staff at the University of Southampton and I am registered with the Health and Care Professionals Council as a Clinical Scientist (Audiology) and have been for nine years. These doctoral studies are part of my continued professional development I will be in charge of all aspects of

the study, development, data collection analysis, write up with the support of my supervisory team.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

(●) Yes ( ) No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

( ) Yes (●) No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

( ) Yes (●) No

Integrated Research Application System
Application Form for Research involving qualitative methods only

NHS
Health Research Authority

Application to NHS/HSC Research Ethics Committee

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting Help.

Please define any terms or acronyms that might not be familar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
CI: Experiences and hopes

Please complete these details after you have booked the REC application for review.

REC Name:

REC Reference Number: **Submission date:**

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Experiences and hopes of cochlear implantation among early deafened adults and their families

A2-1. Educational projects

Name and contact details of student(s):

Name and contact details of academic supervisor(s):

Academic supervisor 1

	Title	Forename/Initials	Surname
	Dr	Maggie	Donovan-Hall
Address	University of Southampton		
	B67, Highfield		
Post Code	SO171BJ		
E-mail	mh699@soton.ac.uk		
Telephone	02380598880		

Fax

Academic supervisor 2

	Title	Forename/Initials	Surname
	Prof	Carl	Verschuur
Address	USAIS		
	University of Southampton		
	B19, Highfield		
Post Code	SO1671BJ		
E-mail	C.A.Vershuur@soton.ac.uk		
Telephone	02380593522		
Fax			

Academic supervisor 3

	Title	Forename/Initials	Surname
	Dr	Vicky	Watson
Address	University of Southampton		
	B13, Highfield		
Post Code	SO171BJ		
E-mail	V.Watson@soton.ac.uk		
Telephone	02380592287		
Fax			

Please state which academic supervisor(s) has responsibility for which student(s):
Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.

Student(s)	Academic supervisor(s)

A copy of a current CV for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.

A2-2. Who will act as Chief Investigator for this study?

- (●) Student
- ( ) Academic supervisor
- ( ) Other

A3-1. Chief Investigator:

	Title	Forename/Initials	Surname
	Ms	Suzanne J	O'Gara
Post	PhD student/ Senior Clinical Scientist (Audiology)		
Qualifications	BSc Biological Sciences (Immunology) MSc (Audiology)		
ORCID ID			
Employer	University of Southampton		
Work Address	USAIS		

	B19 University of Southampton
Post Code	SO171BJ
Work E-mail	sjog1v07@soton.ac.uk
* Personal E-mail	
Work Telephone	02380593522
* Personal Telephone/Mobile	
Fax	

** This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent.*
A copy of a current CV (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.

A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project?
This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.

	Title	Forename/Initials	Surname
	Dr	Alison	Knight
Address	Head of Research Integrity and Governance		
	University of Southampton, Room 2029, Building 28		
	Highfield, Southampton		
Post Code	SO171BJ		
E-mail	rgoinfo@soton.ac.uk		
Telephone	02380598580		
Fax			

A5-1. Research reference numbers. *Please give any relevant references for your study:*

Applicant's/organisation's own reference number, e.g. R & D (if available):	
Sponsor's/protocol number:	ERGO52273
Protocol Version:	1.3
Protocol Date:	12/11/2019
Funder's reference number (enter the reference number or state not applicable):	N/A
Project website:	

Additional reference number(s):

Ref.Number Description	Reference Number

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

○ Yes ◉ No

Please give brief details and reference numbers.

Appendix EE Notice of Amendment IRAS Version 5.13

Welcome to the Integrated Research Application System

IRAS Project Filter

The integrated dataset required for your project will be created from the answers you give to the following questions. The system will generate only those questions and sections which (a) apply to your study type and (b) are required by the bodies reviewing your study. Please ensure you answer all the questions before proceeding with your applications.

Please enter a short title for this project *(maximum 70 characters) CI: Experiences and hopes*

1. Is your project research?

Yes No

2. Select one category from the list below:

○ *Clinical trial of an investigational medicinal product*

○ *Clinical investigation or other study of a medical device*

○ *Combined trial of an investigational medicinal product and an investigational medical device*

○ *Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice* ○ *Basic science study involving procedures with human participants*

○ *Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology*

◉ *Study involving qualitative methods only*

○ *Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)*

○ *Study limited to working with data (specific project only)* ○ *Research tissue bank*

○ *Research database*

If your work does not fit any of these categories, select the option below:

○ *Other study*

a) Does the study involve the use of any ionising radiation?	Yes	◉ No
b) Will you be taking new human tissue samples (or other human biological samples)?	Yes	◉ No
c) Will you be using existing human tissue samples (or other human biological samples)?	Yes	◉ No

3. In which countries of the UK will the research sites be located?(Tick all that apply)

- [x] *England*
- [ ] *Scotland*
- [ ] *Wales*
- [ ] *Northern Ireland*

3a. In which country of the UK will the lead NHS R&D office be located:

- ( )
- (•) *England*
- ( ) *Scotland*
- ( ) *Wales*
- ( ) *Northern Ireland*

4. Which applications do you require?

☐

NHS/HSC Research and Development offices ☐

Social Care Research Ethics Committee

☑ *Research Ethics Committee*

☐ *Confidentiality Advisory Group (CAG)*

☐ *Her Majesty's Prison and Probation Service (HMPPS)*

5. Will any research sites in this study be NHS

○ *Ye* ◉ *N*

6. Do you plan to include any participants who are children?

○ *Ye s* ◉ *N o*

---

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent for themselves?

○ ◉

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of

○ .. ◉ ..

9. Is the study or any part of it being undertaken as an educational project?

◉ *Ye* ○ *N*

Please describe briefly the involvement of the student(s):
This is part of my doctoral studies. I am a Clinical member of staff at the University of Southampton and I am registered with the Health and Care Professionals Council as a Clinical Scientist (Audiology) and have been for nine years. These doctoral studies are part of my continued professional development I will be in charge of all aspects of the study, development, data collection analysis, write up with the support of my supervisory team.

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

◉ *Yes* ○ *No*

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

○ *Yes* ◉ *No*

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

○ *Yes* ◉ *No*

3 271439/1409649/13/29/102138

Appendix EE

Please use this form to notify the main REC of substantial amendments to all research other than clinical trials of investigational medicinal products (CTIMPs).

Notice of Amendment IRAS Version 5.13

NOTICE OF SUBSTANTIAL AMENDMENT

Details of Chief Investigator:

	Title Forename/Initials Surname
	Ms Suzanne J O'Gara
	USAIS
Work Address	
	B19 University of Southampton
PostCode	*SO171BJ*
Email	*sjog1v07@soton.ac.uk*
Telephone	*02380593522*
Fax	

For guidance on this section of the form refer to the guidance

Experiences and hopes of cochlear

Additional reference number(s):

Ref.Number Description Reference Number

01/02/2020 - no recruitment has occurred due to

Protocol reference (if applicable), current

Type of amendment

(a) Amendment to information previously given in IRAS

Yes No

If yes, please refer to relevant sections of IRAS in the “summary of changes” below.

4 271439/1409649/13/29/102138

Notice of Amendment IRAS Version 5.13

(b) Amendment to the protocol

Yes No

If yes, please submit either the revised protocol with a new version number and date, highlighting changes in bold, or a document listing the changes and giving both the

(c) Amendment to the information sheet(s) and consent form(s) for participants, or to any other supporting documentation for the study

Yes No

If yes, please submit all revised documents with new version numbers and dates,

Is this a modified version of an amendment previously notified and not approved?

Yes *No*

Summary of changes

Briefly summarise the main changes proposed in this amendment. Explain the purpose of the changes and their significance for the study.

If this is a modified amendment, please explain how the modifications address the concerns raised previously by the ethics committee.

If the amendment significantly alters the research design or methodology, or could otherwise affect the scientific value of the study, supporting scientific information should be given (or enclosed separately). Indicate whether or not additional scientific critique has been obtained.

This study sets out to be inclusive.

When signing the consent forms, the British Sign Language (BSL) interpreter I was working with reported that the consent forms did not meet the needs of the BSL users. The language used was not appropriate for this group and an easy read format was required. Not producing this document has the risk of preventing this group accessing this study. Based on this new consent forms were produced.

These consent forms have been produced in conjuction with a BSL interpreter.

The version 1.4 consent form is added as CI recipients/candidates need to give consent for their hearing and speech test results to be used in the study. this is mentioned in the PIS and study protocol, but was not included in the consent form in error. To ensure the study is clear on what consent is being given for this has been added.

Any other relevant information

Applicants may indicate any specific issues relating to the amendment, on which the opinion of a reviewing body is sought.

List of enclosed documents

Document	*Version*	*Date*
Easy read consent form - CI candidate/receipient	1.1	22/01/2020
Easy read consent form - family member	1.1	22/01/2020
Consent form - CI candidate/recipient	1.4	05/02/2020

Appendix EE

Declaration by Chief Investigator

5 271439/1409649/13/29/102138

Notice of Amendment IRAS Version 5.13

1. I confirm that the information in this form is accurate to the best of my knowledge and I take full responsibility for it.
2. I consider that it would be reasonable for the proposed amendment to be implemented.

This section was signed electronically by Ms Suzanne O'Gara on

Job	*Clinical Scientist*
Organisati	*University of*
Emai	*sjoa1v07@soton.*

Declaration by the sponsor's representative

I confirm the sponsor's support for this

This section was signed electronically by Ms Research Governance Team

Job	*Head of Research Integrity and*
Organisati	*University of*
Emai	*rgoinfo@soton.*

6 271439/1409649/13/29/102138

Appendix FF Participant Information Sheet Easy Read for CI user with BSL links

Participant Information Sheet – Cochlear implant (CI) recipients 1 year to 5 years post implant

Study title: What are the experiences and hopes of adults who are early deafened and their families of a cochlear implant?

ERGO ethics number: 52273

IRAS ethics number: 271439

https://drive.google.com/open?id=1K4Q5FmoGRG2PI3yCeHyCGrRZngJN-J4d

Invitation

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

This information sheet explains why we are doing the study and what it would involve for you. The researcher can go through this sheet with you, to help you decide if you would like to part and answer any questions you may have.

https://drive.google.com/open?id=1zM-j2ZXZc-JTIQshSNiVWYzhzGHchfey

What is the study about?

We would like to better support adults who are early deafened and their families who choose to have a cochlear implant. This involves finding out about their experiences and what they hoped to gain from a cochlear implant.

By doing this study we hope to be able to provide more information to CI candidates and their families regarding what to expect from the assessment process and provide more effective support.

We aim to understand:

- The effect of the CI assessment process on the CI user and their family
- How the family supported the CI user through cochlear implantation
- What the CI user hoped to gain from a cochlear implant
- What the family hoped the CI user would gain from a cochlear implant
- The support that could be put in place to support the CI user and the family and what the CI user and family feel this would look like

https://drive.google.com/open?id=1A7d8sKQ6g1V75sQ0Za290e3nHkmyQ1rq

Why have I been asked to participate?

You have been asked to participate as you lost your hearing at birth or before the age of 6 years. There will be up to six participants and their families in the study.

https://drive.google.com/open?id=1jcpmfZI2OzEFX-nqVg9X4NDUdwVR7d-h

What will happen to me if I take part?

Taking part in this study would involve you being interviewed regarding your experiences and what you hope to gain from a cochlear implant

This could also involve up to two of your family members asking them about how they supported you through the CI journey and what they thought you would gain from an implant. **This is optional**. You can take part in the study without involving your family members.

This will involve an interview with the researcher, this will take no more than 90 minutes and can take place in a mutually convenient location or through skype. If you prefer this can be split into two interviews of 45 minutes each.

We would ask you to sign a consent/permission form which records your agreement to take part in this interview

https://drive.google.com/open?id=1XxYJ3Q55Uc5vIu2H3AQmfUANbF_lA9PE

What are the possible benefits of taking part?

There are no immediate benefits to you as an individual for taking part in this study. Future patients may benefit from the learning of this study.

If you have any travel costs from taking part in this study, your travel costs will be reimbursed. The study researcher will provide you with more details.

What are the possible disadvantages and risks of taking part?

There are no anticipated risks to participants who take part in this study. Contact details for the researcher have been included in this information sheet in the event that you may require any support following the interview.

https://drive.google.com/open?id=1o3Cm1Iy68flIaKtqak9Yu8LrAACI-QMB

What data will be collected?

As well as the interview. The researcher would have access to the results you scored during your assessment for a cochlear implant and after you were fitted with your cochlear implant. This would be your hearing test levels and the results on any speech tests. You would not have to provide this, this information would be accessed from your notes.

https://drive.google.com/open?id=1ZDGu1CjAPbVyrIZp1_RI-Ux4OZlOGhuC

Consent/permission process

To gain your consent/permission to take part in this study we will ask you to complete and sign a consent/permission form. A copy of the consent/permission form will be given to you to keep. We will keep a copy of the signed consent/permission form.

https://drive.google.com/open?id=1MVmaV6OkW5_4eNA1xpSbAGnyj_bJQox-

What will happen if I don't want to carry on being part of the study?

You can change your mind at any time and choose to no longer take part. If you choose to not take part we will remove you and your family from the study.

If you do change your mind, we will respect your decision and there will be no negative consequences. It will not affect any of the care that you receive.

It will not be possible to delete your data from the project after the study completion date as the data will have been included in the final study report.

https://drive.google.com/open?id=1_wgndjpVJM7N1i7gEwIg0c3MBcLlfTVr

Will my information be kept anonymised and kept confidential?

In order to obtain your written consent, you will need to provide us with your name, contact details and signature. This means that the study is NOT anonymous, but, if you agree to take part, we will keep your consent form separate to your interview notes and any information you share will be anonymous in the findings/reports from the study.

The interview, these will be audio or video recorded to ensure we accurately capture all the issues participants wish to raise. You will be asked which method you would prefer. You will be identifiable from the video recordings and it's possible you will be identifiable on these audio-recordings; however, these files will be stored on a secure password protected computer server. The video files will be deleted within 30 days. The audio files will be kept until the end of the study.

Audio recordings of the interviews will be transcribed by the researcher who interviews you (and the text anonymised) within 30 days of collection. Transcribing means 'writing out' what was said. Audio recordings will be kept until publication of the evaluation report and then destroyed.

The data collected from your notes will be anonymised and used to support the information you have given in your interviews.

On completion of the project all data will be transferred to University of Southampton (under the control of the project lead) to keep until 10 years after the conclusion of the study, as required.

All information we use about you will be processed in accordance with the General Data Protection Regulation (2018) and will be securely analysed and stored.

The only time we would break confidentiality is if you tell us something during your interview that indicates you, or someone else, are at serious risk of harm.

https://drive.google.com/open?id=1fF8aHf1mrVgE4EquqBJ_0Tf8sA1w6hxt

What will happen to the results of this study?

The results of this study will be published as part of the researcher's doctoral thesis.

The results will be shared with USAIS and be used to produce information for patients coming forward for a CI assessment.

All data and information included in the report will be anonymous.

https://drive.google.com/open?id=1blLHVGUKJtbnlGjd5Ul1JULw1E2ba_f3

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

https://drive.google.com/open?id=1tnGV3KwM-d9tUEb86uOr6yezWkEDXzQP

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been given a favourable opinion by the East Midlands Derby Research Ethics Committee.

https://drive.google.com/open?id=1AdKSXRO1czdIXec_cUgOkWDH4oS3FMhw

Further information and contact details

If you wish to find out more about this study please contact:

Suzanne O'Gara, PhD Student and Clinical Scientist (Audiology) at University of Southampton

- sjog1v07@soton.ac.uk

In the unlikely case of concern or complaint, you should contact the University of Southampton Research Governance Office:

Research Governance Office

Building 28

University of Southampton
Highfield
Southampton SO17 1BJ
rgoinfo@soton.ac.uk
Telephone: 02380 595058
https://drive.google.com/open?id=1aWJwKgIeUvfGUtHO3HrDHztu2Z3ElvVZ

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions (Suzanne O'Gara, sjog1v07@soton.ac.uk).

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

https://drive.google.com/open?id=1j0DkdSlFsCoLZ76PP8fLwya6TMU_xLCO

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at

http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

https://drive.google.com/open?id=1joucCwoVftZ8nJL2e20CrLwkpSq9pTfm

Appendix GG Participant Information sheet Easy Read

Family Member with BSL links

Participant Information Sheet – family members

Study title: What are the experiences and hopes of adults who are early deafened and their families of a cochlear implant?

ERGO ethics number: 52273

IRAS ethics number: 271439

https://drive.google.com/open?id=1K4Q5FmoGRG2PI3yCeHyCGrRZngJN-J4d

Invitation

We would like you to take part in our study looking your family's experience of a cochlear implant.

Taking part is entirely your choice and voluntary

This information sheet explains why we are doing the study and what it would involve for you. The researcher can go through this sheet with you, to help you decide if you would like to part and answer any questions you may have.

https://drive.google.com/open?id=1w1Mpdb6lt7QtRCsVYBQy0DLVZ5JdSlJ6

Brief summary of what is involved

We would like to better support adults who are long term deafened and their families who choose to have a cochlear implant. This involves finding out about their experiences and what they hoped their family member would gain from a cochlear implant.

By doing this study we hope to be able to provide more information to Cochlear Implant (CI) candidates and their families regarding what to expect from the assessment process and provide more effective support.

We aim to understand:

- The effect of the CI assessment process on the CI user and their family
- How the family supported the CI user through cochlear implantation
- What the CI user hoped to gain from a cochlear implant
- What the family hoped the CI user would gain from a cochlear implant
- The support that could be put in place to support the CI user and the family and what the CI user and family feel this would look like

https://drive.google.com/open?id=1A7d8sKQ6g1V75sQ0Za290e3nHkmyQ1rq

What would taking part involve?

Taking part in this study would involve you and up to two of your family members being interviewed regarding your experiences and what you hoped your family member would gain from a cochlear implant.

You would be taking part with up to two other members of your family (including the family member with a cochlear implant)

This involve an interview with the researcher, this will take no more than 90 minutes and can take place in a mutually convenient location, through skype or by telephone.

We would ask you to sign a consent form which records your agreement to take part in this interview

https://drive.google.com/open?id=1R_3cdQX-VoaN_K5cK97L6pdiiM7_EthT

Consent process

To gain your consent to take part in this study we will ask you to complete and sign a consent form. A copy of the consent form will be given to you to keep. We will keep a copy of the signed consent form.

https://drive.google.com/open?id=1MVmaV6OkW5_4eNA1xpSbAGnyj_bJQox-

What are the possible benefits of taking part?

There are no immediate benefits to you as an individual for taking part in this study. Future patients may benefit from the learning of this study.

If you have any travel costs from taking part in this study, your travel costs will be reimbursed. The study researcher will provide you with more details.

What are the possible disadvantages and risks of taking part?

There are no anticipated risks to participants who take part in this study. Contact details for the researcher have been included in this information sheet in the event that you may require any support following the interview.

https://drive.google.com/open?id=1o3Cm1Iy68flIaKtqak9Yu8LrAACI-QMB

What will happen if I don't want to carry on being part of the study?

You can change your mind at any time and choose to no longer take part. If you choose to not take part we will remove you from the study. We will not remove your family from the study without the CI user informing us of this.

If you do change your mind, we will respect your decision and there will be no negative consequences. It will not affect any of the care that you receive.

It will not be possible to delete your data from the project after the completion date as the data will have been included in the final study report.

https://drive.google.com/open?id=1_wgndjpVJM7N1i7gEwIg0c3MBcLlfTVr

Will my information be kept anonymised and kept confidential?

In order to obtain your written consent, you will need to provide us with your name, contact details and signature. This means that the study is NOT anonymous, but, if you agree to take part, we will keep your consent form separate to your interview notes and any information you share will be anonymous in the findings/reports from the study.

If you take part in an interview, these will be audio-recorded to ensure we accurately capture all the issues participants wish to raise. It's possible you will be identifiable on these audio-recordings; however, these files will be stored on a secure password protected computer server and deleted at the end of study.

Audio recordings of the interviews will be transcribed by the researcher who interviews you (and the text anonymised) within 30 days of collection. Transcribing means 'writing out' what was said. Audio recordings will be kept until publication of the evaluation report and then destroyed.

On completion of the project all data will be transferred to University of Southampton (under the control of the project lead) to keep until 10 years after the conclusion of the study, as required.

All information we use about you will be processed in accordance with the General Data Protection Regulation (2018) and will be securely analysed and stored.

The only time we would break confidentiality is if you tell us something during your interview that indicates you, or someone else, are at serious risk of harm.

https://drive.google.com/open?id=1fF8aHf1mrVgE4EquqBJ_0Tf8sA1w6hxt

What will happen to the results of this study?

The results of this study will be published as part of the researcher's doctoral thesis.

The results will be shared with USAIS and be used to produce information for patients coming forward for a CI assessment.

All data and information included in the report will be anonymous.

https://drive.google.com/open?id=1blLHVGUKJtbnlGjd5Ul1JULw1E2ba_f3

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been given a favourable opinion by the East Midlands Derby Research Ethics Committee.
https://drive.google.com/open?id=1AdKSXRO1czdIXec_cUgOkWDH4oS3FMhw

Further information and contact details

If you wish to find out more about this study or require further support after the interview please contact:

Suzanne O'Gara, PhD Student and Clinical Scientist (Audiology) at University of Southampton

- sjog1v07@soton.ac.uk

In the unlikely case of concern or complaint, you should contact the University of Southampton Research Governance Office:

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Telephone: 02380 595058

https://drive.google.com/open?id=1aWJwKgIeUvfGUtHO3HrDHztu2Z3ElvVZ

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This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly,

it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

https://drive.google.com/open?id=1joucCwoVftZ8nJL2e20CrLwkpSq9pTfm

Appendix HH Participant Information sheet CI user

Participant Information Sheet – Cochlear implant (CI) recipients 1 year to 5 years post implant

Study title: What are the experiences and hopes of adults who are early deafened and their families of a cochlear implant?

ERGO ethics number: 52273

IRAS ethics number: 271439

Invitation

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

This information sheet explains why we are doing the study and what it would involve for you. The researcher can go through this sheet with you, to help you decide if you would like to part and answer any questions you may have.

What is the study about?

We would like to better support adults who are early deafened and their families who choose to have a cochlear implant. This involves finding out about their experiences and what they hoped to gain from a cochlear implant.

By doing this study we hope to be able to provide more information to CI candidates and their families regarding what to expect from the assessment process and provide more effective support.

We aim to understand:

- The effect of the CI assessment process on the CI user and their family
- How the family supported the CI user through cochlear implantation
- What the CI user hoped to gain from a cochlear implant
- What the family hoped the CI user would gain from a cochlear implant
- The support that could be put in place to support the CI user and the family and what the CI user and family feel this would look like

Why have I been asked to participate?

You have been asked to participate as you lost your hearing at birth or before the age of 6 years. There will be up to six participants and their families in the study.

What will happen to me if I take part?

Taking part in this study would involve you being interviewed regarding your experiences and what you hope to gain from a cochlear implant

This could also involve up to two of your family members asking them about how they supported you through the CI journey and what they thought you would gain from an implant. **This is optional**. You can take part in the study without involving your family members.

This will involve an interview with the researcher, this will take no more than 90 minutes and can take place in a mutually convenient location or through skype. If you prefer this can be split into two interviews of 45 minutes each.

We would ask you to sign a consent/permission form which records your agreement to take part in this interview

What are the possible benefits of taking part?

There are no immediate benefits to you as an individual for taking part in this study. Future patients may benefit from the learning of this study.

If you have any travel costs from taking part in this study, your travel costs will be reimbursed. The study researcher will provide you with more details.

What are the possible disadvantages and risks of taking part?

There are no anticipated risks to participants who take part in this study. Contact details for the researcher have been included in this information sheet in the event that you may require any support following the interview.

What data will be collected?

As well as the interview. The researcher would have access to the results you scored during your assessment for a cochlear implant and after you were fitted with your cochlear implant. This would be your hearing test levels and the results on any speech tests. You would not have to provide this, this information would be accessed from your notes.

Consent/permission process

To gain your consent/permission to take part in this study we will ask you to complete and sign a consent/permission form. A copy of the consent/permission form will be given to you to keep. We will keep a copy of the signed consent/permission form.

What will happen if I don't want to carry on being part of the study?

You can change your mind at any time and choose to no longer take part. If you choose to not take part we will remove you and your family from the study.

If you do change your mind, we will respect your decision and there will be no negative consequences. It will not affect any of the care that you receive.

It will not be possible to delete your data from the project after the study completion date as the data will have been included in the final study report.

Will my information be kept anonymised and kept confidential?

In order to obtain your written consent, you will need to provide us with your name, contact details and signature. This means that the study is NOT anonymous, but, if you agree to take part, we will keep your consent form separate to your interview notes and any information you share will be anonymous in the findings/reports from the study.

The interview, these will be audio or video recorded to ensure we accurately capture all the issues participants wish to raise. You will be asked which method you would prefer. You will be identifiable from the video recordings

and it's possible you will be identifiable on these audio-recordings; however, these files will be stored on a secure password protected computer server. The video files will be deleted within 30 days. The audio files will be kept until the end of the study.

Audio recordings of the interviews will be transcribed by the researcher who interviews you (and the text anonymised) within 30 days of collection. Transcribing means 'writing out' what was said. Audio recordings will be kept until publication of the evaluation report and then destroyed.

The data collected from your notes will be anonymised and used to support the information you have given in your interviews.

On completion of the project all data will be transferred to University of Southampton (under the control of the project lead) to keep until 10 years after the conclusion of the study, as required.

All information we use about you will be processed in accordance with the General Data Protection Regulation (2018) and will be securely analysed and stored.

The only time we would break confidentiality is if you tell us something during your interview that indicates you, or someone else, are at serious risk of harm.

What will happen to the results of this study?

The results of this study will be published as part of the researcher's doctoral thesis.

The results will be shared with USAIS and be used to produce information for patients coming forward for a CI assessment.

All data and information included in the report will be anonymous.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part.

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been given a favourable opinion by the East Midlands Derby Research Ethics Committee.

Further information and contact details

If you wish to find out more about this study please contact:

Suzanne O'Gara, PhD Student and Clinical Scientist (Audiology) at University of Southampton
- sjog1v07@soton.ac.uk

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Research Governance Office

Building 28

University of Southampton

Highfield

Southampton SO17 1BJ

rgoinfo@soton.ac.uk

Telephone: 02380 595058

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions (Suzanne O'Gara, sjog1v07@soton.ac.uk).

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Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 10 years after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Appendix II Participant Information Sheet family members

Participant Information Sheet – family members

Study title: What are the experiences and hopes of adults who are early deafened and their families of a cochlear implant?

ERGO ethics number: 52273

IRAS ethics number: 271439

Invitation

We would like you to take part in our study looking your family's experience of a cochlear implant.

Taking part is entirely your choice and voluntary

This information sheet explains why we are doing the study and what it would involve for you. The researcher can go through this sheet with you, to help you decide if you would like to part and answer any questions you may have.

Brief summary of what is involved

We would like to better support adults who are long term deafened and their families who choose to have a cochlear implant. This involves finding out about their experiences and what they hoped their family member would gain from a cochlear implant.

By doing this study we hope to be able to provide more information to Cochlear Implant (CI) candidates and their families regarding what to expect from the assessment process and provide more effective support.

We aim to understand:

- The effect of the CI assessment process on the CI user and their family
- How the family supported the CI user through cochlear implantation

- What the CI user hoped to gain from a cochlear implant
- What the family hoped the CI user would gain from a cochlear implant
- The support that could be put in place to support the CI user and the family and what the CI user and family feel this would look like

What would taking part involve?

Taking part in this study would involve you and up to two of your family members being interviewed regarding your experiences and what you hoped your family member would gain from a cochlear implant.

You would be taking part with up to two other members of your family (including the family member with a cochlear implant)

This involve an interview with the researcher, this will take no more than 90 minutes and can take place in a mutually convenient location, through skype or by telephone.

We would ask you to sign a consent form which records your agreement to take part in this interview

Consent process

To gain your consent to take part in this study we will ask you to complete and sign a consent form. A copy of the consent form will be given to you to keep. We will keep a copy of the signed consent form.

What are the possible benefits of taking part?

There are no immediate benefits to you as an individual for taking part in this study. Future patients may benefit from the learning of this study.

If you have any travel costs from taking part in this study, your travel costs will be reimbursed. The study researcher will provide you with more details.

What are the possible disadvantages and risks of taking part?

There are no anticipated risks to participants who take part in this study. Contact details for the researcher have been included in this information sheet in the event that you may require any support following the interview.

What will happen if I don't want to carry on being part of the study?

You can change your mind at any time and choose to no longer take part. If you choose to not take part we will remove you from the study. We will not remove your family from the study without the CI user informing us of this.

If you do change your mind, we will respect your decision and there will be no negative consequences. It will not affect any of the care that you receive.

It will not be possible to delete your data from the project after the completion date as the data will have been included in the final study report.

Will my information be kept anonymised and kept confidential?

In order to obtain your written consent, you will need to provide us with your name, contact details and signature. This means that the study is NOT anonymous, but, if you agree to take part, we will keep your consent form separate to your interview notes and any information you share will be anonymous in the findings/reports from the study.

If you take part in an interview, these will be audio-recorded to ensure we accurately capture all the issues participants wish to raise. It's possible you will be identifiable on these audio-recordings; however, these files will be stored on a secure password protected computer server and deleted at the end of study.

Audio recordings of the interviews will be transcribed by the researcher who interviews you (and the text anonymised) within 30 days of collection. Transcribing means 'writing out' what was said. Audio recordings will be kept until publication of the evaluation report and then destroyed.

On completion of the project all data will be transferred to University of Southampton (under the control of the project lead) to keep until 10 years after the conclusion of the study, as required.

All information we use about you will be processed in accordance with the General Data Protection Regulation (2018) and will be securely analysed and stored.

The only time we would break confidentiality is if you tell us something during your interview that indicates you, or someone else, are at serious risk of harm.

What will happen to the results of this study?

The results of this study will be published as part of the researcher's doctoral thesis.

The results will be shared with USAIS and be used to produce information for patients coming forward for a CI assessment.

All data and information included in the report will be anonymous.

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been given a favourable opinion by the East Midlands Derby Research Ethics Committee.

Further information and contact details

If you wish to find out more about this study or require further support after the interview please contact:

Suzanne O'Gara, PhD Student and Clinical Scientist (Audiology) at University of Southampton

- sjog1v07@soton.ac.uk

In the unlikely case of concern or complaint, you should contact the University of Southampton Research Governance Office:

Research Governance Office

Building 28

University of Southampton

Highfield

Southampton SO17 1BJ

rgoinfo@soton.ac.uk

Telephone: 02380 595058

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Appendix JJ Interview guide for CI users

Semi structured interview Q for CI recipients

3 sections

About them

About their relationship with their family

About the implant

Introductions

Who I am

What the interview is for

Thank them for being involved

About them

Tell me a bit about yourself

How long have you been deaf for?

What was having a hearing loss like growing up?

With your hearing loss where there any situations you struggled in?

About the relationship with their family

Tell me about your family (siblings/parents/children others etc)

What relationship are the two other people in the study

Howe often do you see your family members?

- Live together etc
- How do you communicate? BSL/spoken English
- How often do you see them

Has having a CI change the relationship with your family?

- Communication
- Interaction
- Relationship
- dynamics

About the implant

What made you consider having an implant?

Why was this the right time for you to be assessed?

What did you hope to gain from an implant?

Tell me about your implant journey

- operation
  - who went with you communication support
- first apt
  - what did you hear
  - who was with you
- later
  - any changes
- example of a positive and negative experience with your implant

is there anything that stands out as a bad experience with your implant

Who did you talk to about to find out what you would gain from an implant?

- Clinicians
- Internet
- Other CI users

What was your experience of having an implant like?

Family and CI

What did your family think about you having an implant?

How did your family support you during the assessment process?

- After surgery
- During initial tuning
- Examples of this

What did your family notice about your hearing?

- After initial tuning

- After 6 m
- After 1 yr

What support would you have liked from your family?

What would you tell someone else who was going through the process after your experience?

What information do you think we could provide to help your family support you more or know what you will gain from an implant?

Is there anything you wish you could change about the whole experience both for -

- yourself
- family

If you were able to go back in time and give some advice to you before you came to be assessed for an implant what advice would you give?

Appendix KK Interview guide for family members

3 sections

About them

About their relationship with their family

About the implant

About them

Tell me a bit about yourself

What is your relationship to x?

How long have you known them for?

What was having a hearing loss like growing up?

With your hearing loss where there any situations you struggled in?

About the relationship with their family

Tell me about your family (make up/siblings/parents/children others etc)

What relationship are the two other people in the study

Tell me about your relationship with them

How do you communicate with x?

Did x having a hearing loss affect your family in general?

About the implant

How did you feel about x having an implant?

What did you hope they would gain from an implant?

What was the experience of having an implant like for you as a family member?

What did you think about x having an implant?

How did your support x during this time?

Is there any other support you would have liked to have provided?

Did the implant affect your relationship with x?

Did you feel informed about what the implant process would mean for x?

Is there anything you wish you could change about the whole experience both for yourself and for x?

Appendix LL Advert/video for USAIS website

Screen shot from the video advert

Written text under the video

Research study looking at the experiences and hopes of ear deafened adults of a cochlear implant.

My name is Suzanne O'Gara and I am a, PhD student and audiologist at the implant centre in Southampton. I wish to find out more about what patients hope to gain from an implant and their experiences will help other patients being assessed for an implant. If you were born with a hearing loss or your hearing loss was present before the age of 6 years of age. Please contact me at sjog1v07@soton.ac.uk for further information.

Appendix MM Poster advert for recruiting CI users and candidates

I am a PhD student and Audiologist looking at experiences and hopes of a cochlear implant among early deafened adults and their families for a research project

Can you help?

Suzanne O'Gara
Please email me at sjog1v07@soton.ac.uk

Study title: Experiences and hopes of cochlear implantation among early deafened adults and their families ERGO: 52273 IRAS:271439 v1.3 13 January 2020

Appendix NN Risk Assessment

Risk Assessment Brief – All Staff

The guidelines set out below have been established to provide guidance for USAIS clinical and support staff to run clinic activities in Building 19, including seeing patients for appointments and a limited amount of normal office based work.

- They are drawn from the University of Southampton generic risk assessment, created for the COVID-19 return to work guidelines, and adapted specifically for use within USAIS.
- They will only apply to activities that cannot be carried out remotely, are deemed business critical by the University, and where safe working can be followed.
- The UK Government, NHS and professional bodies have set out guidelines for working safely in a healthcare environment and our principles are consistent with these.
- In some cases, our principles may be stricter to ensure the safety of staff and the wider patient population.
- Our principles may need to be revised as guidelines evolve.
- There is copy of the formal risk assessment available on Teams

Please read and digest these guidelines, managers should use them as a basis for creating localised instructions where required. All staff must adhere to the principles set out below, ensuring that staff and patient safety is maintained to the highest standards at all times. If you have any questions then please ask your line manager.

1. Shared Working Spaces

1.1: Staff should follow official guidance and self-isolate at home if they, or someone in their household show the signs or symptoms of Covid-19, informing their line manager, the university and NHS 111.

1.2: A rota will be in place so that staff on the premises are able to work at desks that have a minimum 2 metres distance around them. If staff are concerned about the safety of their work environment then they should raise this in the first instance to their line manager. If they don't believe that the line manager has addressed their concerns they should contact their local Health & Safety advisor or employee representative. If staff believe that there is a reason which puts them or their household more at risk from returning to campus they should inform their line manager but can also contact their local Health & Safety advisor, employee representative and/or HR.

1.3: Staff should not travel to work if they are not scheduled to be at work, continuing to work from home. Should there be a need to visit the premises then the staff member should clear this directly with their line manager, stating the reason and proposed times for the visit.

1.4: In line with UK Government guidance, staff should drive, walk or cycle to campus where possible and use of public transport should be minimised. In the current situation, the university offers free on-site parking on the University campuses for those who drive in, again to avoid use of public transport. Any member of staff using public transport to travel to work should discuss this with their line manager, only travelling if work cannot be carried out at home.

1.5: Good hand hygiene remains one of the most effective means of countering the spread of Covid-19. All USAIS staff are to have carried out the mandatory hand hygiene training. There will additional hand sanitiser around the building and clear directions to the hand washing facilities. Clear and numerous signage around the building will remind staff and visitors of the importance of regular hand hygiene measures.

1.6: Clinicians will be assigned to a clinic room and can work in the room all day. This will minimise social contact. The audiologist will also be responsible to do daily checks for that room and maintain the hygiene and cleaning routine (see section 3 for a full clinic area risk assessment).

1.7: Staff are to enter/exit building 19 on level 1, being mindful to keep to 2 metres social distance. A hand sanitiser has been sourced for this entrance and must be used on entry (Staff that need to use the lift should use the level 2 entrance).

1.8: Although socialising with colleagues in the building is not discouraged, all staff must adhere to social distancing at all times and lead by example in front of patients.

1.9: Use of the kitchen facilities should be minimised as much as possible. All users should adhere to strict hygiene standards, please see local guidance on this.

1.10: Meal breaks should be staggered, when not in use the seminar room can be used for meals where social distancing can be adhered to. Outdoor eating areas with social distancing should be considered in preference to indoor areas. Staff should bring in their own food and avoid using shared cutlery and plates. Eating areas should have suitable self-cleaning arrangements in addition to daily professional cleaning.

1.11: The amount of support staff working in rooms 2043 and 1021 will be limited, those present are responsible for maintaining social distancing measures between desks, re-

organising workspaces under the guidance of their line manager. Other members of staff should avoid entering these rooms unnecessarily, using phone or electronic means of communication instead. Local signage will be provided to reinforce this message.

1.12: Where possible, and in accordance with local fire restrictions doors should be propped open to aid hand hygiene measures as staff move around the building. Where this is not possible, a means of opening the door without touching should be provided i.e. paper towels with a bin outside.

1.13: Lifts should be avoided where at all possible. If their use is required for manual handling purposes or for those with a mobility need they should be limited to one person at a time. After use the person should ensure they wash their hands thoroughly and the lift control panel should be subject to a frequent cleaning regime

1.14: The Customer Services Team are responsible for coordinating with the university post team and commercial courier companies for arranging deliveries and collections from reception and Ocean. Ensuring social distancing and safe working practices are adhered to, scheduling deliveries for times when the waiting room is quiet.

1.15: The USAIS admin team should coordinate the collection and distribution of post across the organisation, minimising the need for staff to transit the reception area with one drop-off/pick-up per day as preferable.

1.16: Communal staff toilets should be used by one person at a time, all staff should adhere to the hand hygiene instructions provided in local areas.

1.17: Shared printers and photocopiers will provided with cleaning equipment and printed directions for all staff to clean before and after use. Staff that use these facilities regularly are to liaise closely within their teams to minimise traffic around the printing unit to maintain social distancing.

2. Level 2 reception, clinic corridor areas and patient contact

2.1: In every instance a remote appointment should be the preferred option of patient contact, only when this is not possible should an appointment be arranged. Patients are empowered to not attend the site if they do not feel safe, or if they feel that they are at an increased risk due to health complications. In the case of patients at a heightened risk that must attend an appointment, USAIS will work with the patient to make their visit as safe as possible, tailoring the visit if required to include additional control measures. Patients in at risk groups include:

- Expectant Mothers
- Those with underlying health conditions
- Older patients (over 60)

2.2: Patients will be contacted the day before their appointment to ensure that they, or members of their household, do not have; a high temperature, a new, continuous cough, a loss of sense of smell or taste, or if they or a member of their household has been asked to self-isolate. In these instances, if confirmed then the appointment will be immediately deferred.

2.3: In line with current government guidance, patients are discouraged from using public transport to travel to the clinic.

2.4: Patients will be advised beforehand on specific arrival instructions, including; not arriving more than 5 minutes before the start of an appointment. On arrival, patients will be encouraged to call/text reception from their car with any questions they may have, and to advise reception staff of their arrival.

2.5: Patients will use the main entrance on level 2.

2.6: Clear guidance on hand hygiene along with a hand sanitising station will be available in the lobby.

2.7: If the patient has called/texted ahead of their arrival, Customer Service Team staff will open the reception door in anticipation of their arrival, reducing the need to use the doorbell.

2.8: Patients are discouraged from bringing family members with them to the clinic, or limiting the numbers if they do need to bring someone.

2.9: On arrival, reception staff will ask patients (not including young children) to use a fluid resistant face mask (if they haven't brought their own). If they have any concerns, reception staff can ask patients and anyone accompanying them to confirm that they, or members of their household, do not have; a high temperature, a new continuous cough, a loss of sense of smell or taste, or have been asked to self-isolate. In these instances appointments will be immediately deferred. Written and BSL accessible versions of these questions will be available.

2.10: Reception staff will direct patients to the handwashing facilities and encourage them to use them.

2.11: The reception desk will be equipped with a clear screen to reduce the risk of transmission from visitors.

2.12: Patient contact sheets and other documents that need to be given to the patient will be passed to the clinician in advance of the appointment and handed to the patient during the appointment.

2.13: People will be generally discouraged from attending the site to pick-up/drop-off equipment. Where this is not possible, there will be a pick-up/drop-off area in reception for repairs. This area will be a part of the cleaning schedule. People waiting for equipment will be asked to wait away from the reception area and be called back when their equipment is ready.

2.14: Equipment returned by the patient which is of low value or not in warranty should be disposed of in the normal waste bin. Other items, such as processors, will need to be cleaned with a sanitising wipe conforming to EN14476 standards and then left in quarantine for a minimum of 72 hours.

2.15: All non-essential storage of magazines, books and toys will be removed from the reception and waiting room areas.

2.16: Seating in the waiting area will be moved so the benches are more than 2 metres distant, and labelled A, B, C. Patients will be directed to a specific bench and asked to only use this seat for the duration of their visit. Customer Service Team staff will monitor the cleaning of these seating areas, carrying out the cleaning when required.

2.17: Patient toilets, these will be in receipt of an enhanced cleaning schedule with a cleaning team coming in during the day. Signage reminding patients and visitors on the importance of hand hygiene will be installed along with clear guidance on cleaning technique. Additional hand sanitiser will be provided outside of the toilets.

2.18: Clinicians are to organise their own collection and return of patient folders, liaising with other staff members who may be using the file store to reduce the chance of crowding within the file store.

2.19: The access controlled door into the clinic corridor will be propped open to reduce the chance of cross infection of the handles. The Customer Services Team are responsible for monitoring this.

2.20: Clinicians will collect their patients from reception at the start of the appointment time. Groups entering the clinic are to have priority access in the corridor area, clinicians leaving the clinic area are to wait in rooms until the exit is clear. This priority system will be clearly

signposted but it is the clinicians responsibility to manage their patient groups as they move through the clinic area.

2.21: The handwash station in the medical room will be clearly signposted, the medical room will be kept solely for use as a handwashing station with the door propped open (unless there is a surgeon holding a clinic). This facility will be monitored and additional handwashing facilities could be installed if required. When this room is in use the toilet hand washing facilities should be used.

2.22: All staff working in the building will have done the online fire-warden training. The rota system will ensure that it is clear at all times who is in the building and all patients are booked into clinic and can be evacuated accordingly. All staff in the building will be instructed to act as potential fire wardens.

2.23: In an emergency, USAIS staff are responsible for evacuating patients safely from the building in accordance with the normal evacuation plan. In this instance the immediate preservation of life takes priority but social distancing measures should be adhered to once any immediate risk has passed.

2.24: First Aid cover will be ensured by faculty coordination, additional first aid cover will be provided by Security staff. First aiders are likely to require additional PPE as they may be called upon, for example, to perform CPR on possible COVID-19 patients (a CPR facemask with a one-way valve will be with the first aid kit in reception).

2.25: All surfaces which the patient has come into contact within the waiting room should be cleaned by a member of the Customer Service Team with a sanitising wipe conforming to EN14476 standards.

3. Clinic Rooms

3.1: Clinicians will be assigned to a clinic room and can work in the room all day. This will minimise social contact. The audiologist will also be responsible to do daily checks for that room and maintain the hygiene and cleaning routine.

3.2: An enhanced cleaning regime will be carried out by the university overnight, any issues with the standard of cleaning should be quickly communicated to efhelp@soton.ac.uk, copying in USAIS managers.

3.3: It is recommended that clothes worn in clinic are changed/washed daily and washed separately from other garments. USAIS will provide scrubs to those staff that request them.

3.4: All surfaces which the patient has come into contact within the clinic room should be cleaned by the clinician with a sanitising wipe conforming to EN14476 standards, once the patient has left.

3.5: Surfaces or equipment within 2m of the patient should also be cleaned with a sanitising wipe conforming to EN14476 standards, even if not touched or used during the appointment.

3.6: 'Clean surface' stickers will be provided to clearly denote which surfaces have been cleaned.

3.7: Hand hygiene should be carried out before and after each patient contact within the appointment and also after the patient has left the room and before the clinician leaves the room.

3.8: All surfaces should remain clutter free and movement of 'dirty' items and equipment between areas should be prevented. It is advisable to keep all items which will need cleaning in the same place, rather than spread out around the clinic room.

3.9: There will be separate containers for 'dirty' items such as equipment returned by the patient and items used during the appointment which need cleaning, these will be clearly labelled.

3.10: Reusable equipment should be cleaned between each patient and after patient use with a sanitising wipe conforming to EN14476 standards. One wipe should be used per piece of equipment. The following will require cleaning between patient encounters (if used or located within 2m of patient during the appointment):

- Otoscope
- Tympanometer
- Headphones/BC/response button etc. including cables and hooks
- Tuning cables/wireless tuning pods/manufacturer pods on the desk
- Audio switch box/PC switch box in observation room
- Toys required during testing (these should be kept to a minimum and no other toys should be in use in the appointment)
- Keyboard and mouse (both in clinic room and observation room)
- Children's table
- Tymp trolley
- VRA towers
- Chairs
- Doors/door handles

3.11: Used masks and sanitising wipes will be disposed of in then standard waste bins, these are reserved for clinical waste that DOES NOT contain chemicals or pharmaceutical medicines.

3.12: If possible do not take paper records into appointments, if they are required then attempt to complete them away from the patient at a distance of 2 metres, if this is not possible then mark the folder with Covid-19 and leave for 72 hours in a secure location before returning to the file store.

3.13: Equipment returned by the patient which is of low value or not in warranty should be disposed of in the normal waste bin. Other items, such as processors, will need to be cleaned with a sanitising wipe conforming to EN14476 standards and then left in quarantine for a minimum of 72 hours.

3.14: Any new items of stock (e.g. processor spares) which were taken into the clinic room will need to be cleaned with a sanitising wipe conforming to EN14476 standards and then left in quarantine for a minimum of 72 hours.

3.15: Should a third party clinical specialist be required to attend an appointment, or technicians from an outside company need to carry out work within the clinic area then they must be able to provide their own health and safety policy/arrangements / or RAMS (risk assessment and method statement) regarding COVID-19.

4. Staff Wellbeing

4.1: Regular communication is in place (individual and group) to ensure staff are not ill-informed about returning to work safely.

4.2: New workplace/controls put in place to reduce risk of exposure to COVID 19 are documented in procedures and process and disseminated to employees through line managers.

4.3: Line managers within USAIS are mindful of how big changes to working arrangements may cause additional work-related stress and affect their employees' mental health and wellbeing. Staff are encouraged to talk directly to their line manager should they have any concerns. If they feel their concerns are not being met they should raise the issue with HR.

4.4: USAIS Managers will hold regular informal discussions with the team and look at ways to reduce causes of stress.

4.5: Concerns on workload issues or support needs are escalated to line managers.

4.6: Managers should familiarise themselves with the signs and symptoms that a person is working beyond their capacity to cope and deal sensitively with employees experiencing

problems outside of work. More information is available from the Health & Wellbeing SharePoint site.

4.7: Staff who are in vulnerable groups themselves or caring for others are encouraged to contact their line manager to discuss their support needs and an individual risk assessment can be carried out for that individual.

4.8: This risk assessment will be under constant review to reflect the new working arrangements. Where significant adjustments to employee's working practices have been made, a review must be undertaken.

4.9: Employees are made aware of supportive mechanisms available to them (e.g. counselling, occupational health, Employees Assistance Programme etc.) through line managers.

Appendix OO Validation tools used in Phase 3b

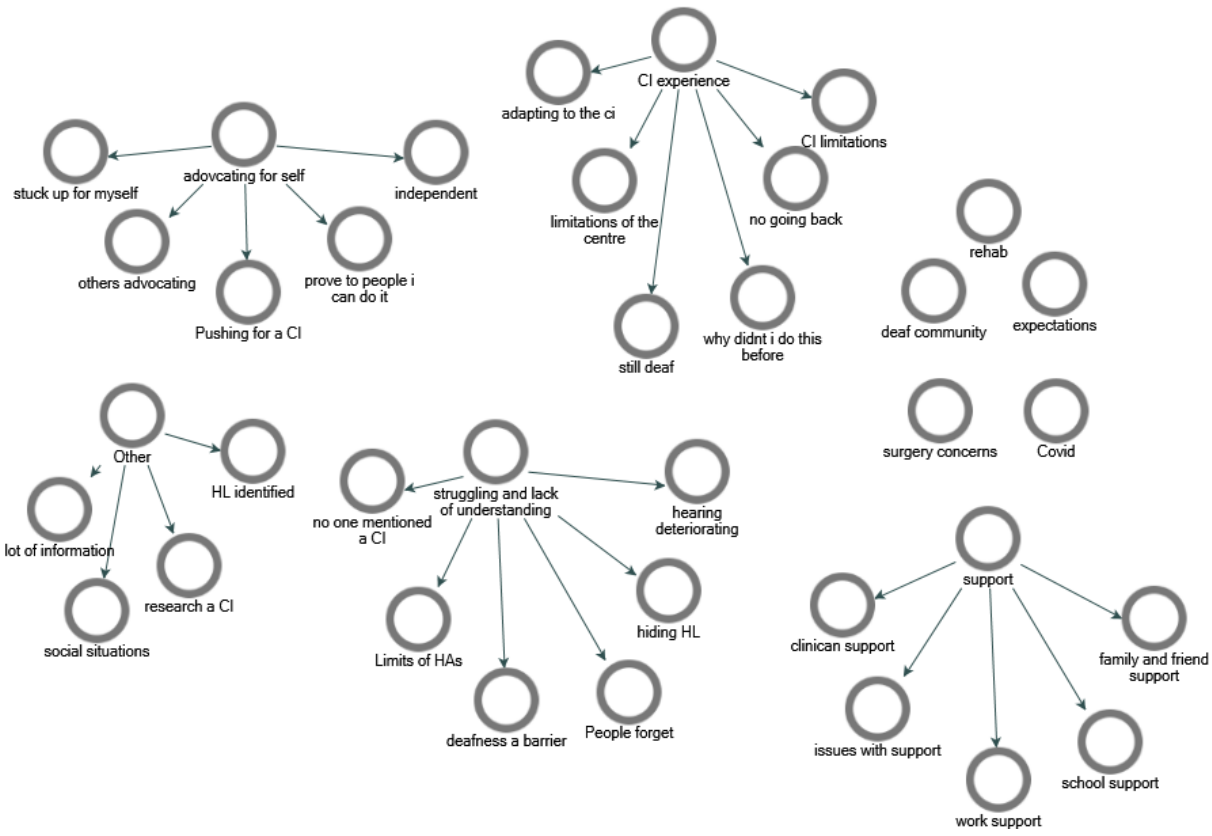
Internal validity	Triangulation	This was not possible within this Phase. Phase 3a and Phase 3b were compared in 6.5.2
	Member checks	Participants were not asked to check the findings. This was discussed in detail in 6.4.1.8.1.
	Long term observation	This was not possible due to the changes required as a result of Covid 19. Participants were retrospectively looking back at their experience.
	Peer examination	This study, as part of my doctoral studies, was reviewed during supervisory meetings and comments on the findings recorded and used to enhance the analysis. No external review outside of the supervisory group was sought as this study was required to be the researchers own.
	Participatory modes of research	PPIE work was carried out to ensure this study's relevance to the participants (Chapter 5)
	Researchers' biases	The researcher was a clinician who worked with patients as part of their clinical role. This has been discussed in more depth in 3.6.
Reliability	Investigator's position	This has been discussed in more depth in 3.2.
	Audit trial	Reasons for decisions made are documented as part of this thesis. Methods for data collection and analysis were described
External validity	Use of rich thick description	Quotes of the situation's participants describe were included to allow decisions of generalisability to be made. This allowed the reader to determine if the research matched the area they are investigating and if the findings were transferrable to the situations they are studying (Merriam, 2009).

	Typicality of the case	Discussions regarding typicality of the cases was planned but due to changes required this study did not follow a case study approach. Discussions regarding typicality of participants was discussed. All participants used spoken language and had similar school settings
	Multi-site designs	This was considered but it was not within the scope of this study. The issues with recruiting from other centres were with the approvals needed and the potential time issues meant that this was not considered. There were considerations of how to support the CI patients should they become distressed, being part of the USAIS allows this to be taken into consideration for these participants. How to provide support for patients at other CI centres was an issue that was not resolved

Appendix PP Phase 3b – Stages of thematic analysis

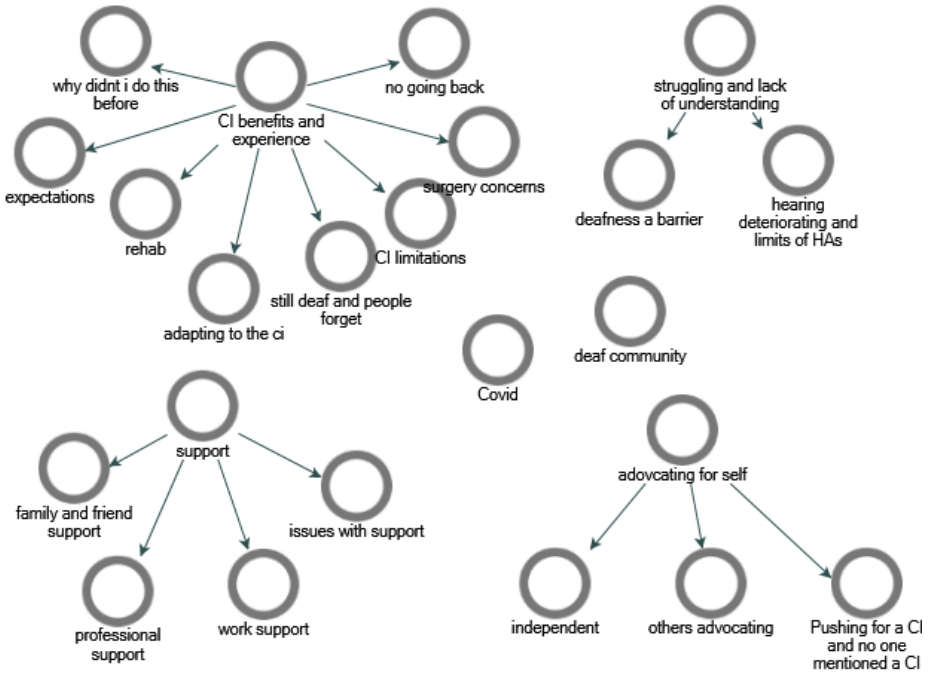
The transcripts were read and re-read to allow the researcher to become immersed in the data (Phase 1). Transcribing the interviews aided this phase this allowed refamiliarization with the data as transcribing transcripts was an active process. The documents were uploaded into Nvivo and coded using this software. Sections of the transcripts were highlighted and given named codes based on the information they contained. Codes were generated using both inductive and deductive approaches as discussed in 6.4.1.7.1. All relevant data were coded (Phase 2). The coded data were then examined to look for potential themes and the codes were then grouped into themes. The codes were combined if they shared a similar meaning or described similar events. This synthesis was based on the researchers knowledge, background and judgement (Thomas and Harden, 2008) exactly how this occurred was difficult to describe due to this. The synthesis of the data would likely be different for a different researcher with different background knowledge and experience. No codes were removed from the analysis at this stage. (Phase 3). This resulted in an initial thematic map (Figure PP.1).

Figure PP.1 Initial thematic map



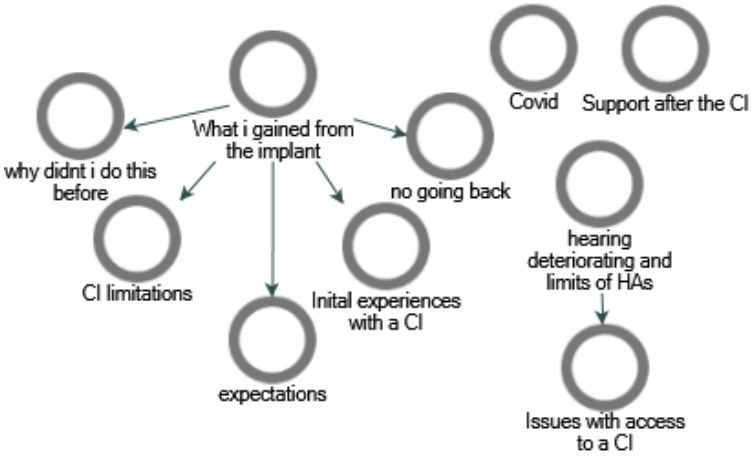
The generated themes were then reviewed (Phase 4). This took place at two levels. One reviewing the codes within the theme and the secondly, across the whole data set. A large number of themes were generated from the initial analysis (Figure PP.2).

Figure PP.2 Stage 2 thematic map



These themes were further reviewed, this resulted in a substantial changes to the themes with some themes merging to form a larger theme while other smaller themes being removed. The names of the themes were assessed to ensure they were relevant to the data coded. This resulted in a Stage 3 thematic map (Figure PP.3) consisting of 4 themes and 6 subthemes (Phase 5). The themes were then described and the analysis written up (Phase 6). At this point the data were reviewed during a supervision meeting. Feedback was given that some of the theme names needed revisiting as they did not represent the data within them sufficiently.

Figure PP.3 Stage 3 Thematic map



The themes and subthemes were reassessed which resulted in changes to the number, names and structure of the themes. Previously the main theme containing the subthemes also contained data, and this was changed for that the overarching theme contained no data but represented the subthemes it contained.

The theme ‘what I gained from an implant’ became a subtheme of ‘the CI journey’. The two subthemes ‘initial experiences of a CI’ and what I gained from the implant were split to ‘I know understand why it’s called a cuckoo’, ‘listening for something’ and ‘it’s an incredible world’. The subtheme expectations was renamed ‘what I want from the implant’. The subtheme ‘CI limitations’ was split to ‘people forget’ and ‘It can be inconvenient’. The theme support after the CI was split into ‘growing up with a hearing loss’ and ‘behind me the whole way’. The theme ‘Covid’ was renamed ‘it would be much better if people didn’t have masks on’ as this fitted more with the data in the theme.

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