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UNIVERSITY OF SOUTHAMPTON

FACULTY OF ENGINEERING AND THE ENVIRONMENT

INSTITUTE OF SOUND AND VIBRATION RESEARCH

Exploring the experiences of teenagers with cochlear implants

Victoria Kathryn Watson

Thesis for the degree of Doctor of Philosophy

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ABSTRACT

FACULTY OF ENGINEERING AND THE ENVIRONMENT

Institute of Sound and Vibration Research

Doctor of Philosophy

EXPLORING THE EXPERIENCES OF TEENAGERS WITH COCHLEAR IMPLANTS

by Victoria Kathryn Watson

Whilst much research has focused on the general health needs of adolescents, little is known about the specific needs of teenagers who wear cochlear implants. Thus it is important to widen the knowledge base regarding the experiences of this population, and to assist professionals to support this age group more effectively.

This qualitative study investigated teenage cochlear implant users' perceptions of deafness, surgery, fitting of the device and life as a cochlear implant wearer in order to gain a more comprehensive understanding of teenagers' experiences of living with a cochlear implant by putting their perspectives at the heart of the research. This was achieved by working with the teenagers collaboratively throughout the research.

Phase one of the study involved engaging with a small group of teenagers with cochlear implants to develop a website that would allow them to share their experiences. In phase two, ten semi-structured interviews were undertaken and nine were analysed using template analysis. Some teenagers experienced great pre-operative anxiety and significant post-operative pain. Anxiety and pain are physiologically linked so strategies for reducing their anxiety are discussed. There was also a mismatch between their expectations and the disappointing reality of adjusting to the device. Disconfirmation-expectancy theory suggests that expectations counselling may narrow this gap. However, over time they experienced significant functional and psychosocial benefits as a result of their lives being easier. Almost all described complex, flexible identities where they felt connections with both the hearing and deaf world. Theoretical models of deaf identity support this 'bicultural' state. However, the hearing world sometimes posed difficulties for them when the listening environment was challenging. By giving prominence to the teenagers' voices this study has added new knowledge concerning their experience of surgery. The findings also more fully revealed the challenges of adjusting to the device and the impact of having a cochlear implant on the teenagers' identities.

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Declaration of Authorship

I, Victoria Watson

declare that the document entitled

Exploring the experiences of teenagers with cochlear implants

and the work presented in the document are both my own, and have been generated by me as the result of my own original research. I confirm that:

- this work was done wholly or mainly while in candidature for a research degree at this University;
- where any part of this document has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
- where I have consulted the published work of others, this is always clearly attributed;
- where I have quoted from the work of others, the source is always given. With the exception of such quotations, this document is entirely my own work;
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- where the document 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;
- none of this work has been published before submission
- Signed:

Date:

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I would like to dedicate this thesis to my girls, Alys and Lily.

Chapter 1 Introduction

1.1 Background to the study

Cochlear implants have dramatically changed the hearing and communication possibilities for severe and profoundly deafened individuals who gain little or no benefit from hearing aids. In 2014, there were around 11,000 cochlear implant users in the UK, of those more than 500 were teenagers (13-19 year olds) and their numbers are growing (Ear Foundation, 2014; personal communication with UK cochlear implant centres).

Teenage cochlear implant users (defined in this study as individuals aged between 13-19 years) do not sit comfortably within the paediatric or adult services. They have distinct needs, dealing with both the challenges of adolescence and living with deafness and a cochlear implant. Ensuring this group are well supported during this potentially turbulent time is important. With rising numbers there is now an increasing interest in the outcomes of cochlear implantation in this age group.

Previous research involving teenagers with cochlear implants is limited, partly because it is only recently that those who were implanted as small children have reached adolescence (Mance and Edwards, 2012). The research that is available focused mainly on audiological outcomes. Improvements such as an increased awareness of environmental sounds, better speech discrimination and better speech perception without lip-reading have all been reported, including in those teenagers who were pre-lingually deafened (Kiefer et al, 1996; Schramm et al, 2002; Sarant et al, 1994). This is encouraging since pre-lingual deafness (being deafened before language is acquired) can be associated with poorer outcomes compared with post-lingual deafness, if there is a delay in implanting the child. This has been attributed to auditory deprivation, where peripheral neural degeneration and the brain's ability to process auditory information is limited resulting in reduced benefit from the cochlear implant (Shpak et al, 2009).

The aim of the present study was to explore wider outcomes to extend the base of knowledge and understanding about the impact on teenagers' everyday lives of having a cochlear implant. The literature describing the non-

audiological outcomes of cochlear implantation in teenagers is sparse and dominated by quantitative approaches, often using generic surveys or closed questionnaires not designed for teenagers with deafness or a cochlear implant. Part of the motivation for this approach was to allow comparison of results with a group of normally hearing teenagers. However, using an instrument designed for the general teenage population may not capture the important issues for teenagers with cochlear implants as their perspectives are not fully revealed by these methods.

Despite this limitation, the studies have highlighted some of the social, psychological and educational benefits experienced by teenagers with cochlear implants. For example, the educational achievement, mental health and self-esteem of teenagers with cochlear implants have been found to be comparable to their hearing peers (Huber et al, 2008; Sahli and Belgin, 2006, Sahli et al 2009; Huber and Kipman, 2011). The literature also indicates that teenagers with cochlear implants have good social skills and a positive self-image (Moog et al, 2011) Identity has been examined, with the results indicating that implanted teenagers feel a sense of belonging in both the hearing and deaf world, which is flexible depending on the situation (Rich et al, 2013). Research suggests that teenagers feel a sense of belonging to their peer group and this has been found to be associated with good psychological well-being, particularly if the peer group is hearing (Mance and Edwards, 2012).

Although these findings are encouraging, the methods used to explore these dimensions do not fully reveal the teenagers' own perspectives. The 'user perspective' of adult and, to some extent, children with cochlear implants has been sought by researchers using qualitative methods which have captured the subjective experience of deafness and living with a cochlear implant. Adult perspectives have been explored using semi-structured interviews, which highlighted their experience as a 'journey' which ended with them 'coming back to life' following the switching on of the device (Hallberg and Ringdahl, 2004 p 118). Children's views have been more difficult to examine and the lack of literature reflects this. The most successful approach has been to use 'proxy' reporting, where an adult (typically the parent/guardian) reports on behalf of the child. Using this method Archbold et al (2002) reported increased confidence and improved communication abilities in children following implantation.

There is a large gap in the literature regarding an understanding of teenager's experiences of having a cochlear implant and the issues that are important to them. Quality of life has been examined in a small number of studies. The questionnaires have typically been generic and not specific to teenagers with a cochlear implant (Huber, 2005; Duarte et al, 2014). This is problematic since the dimensions may be too broad to fully capture the effects of having a cochlear implant, particularly in this age group who are dealing with the additional challenges of increasing autonomy, peer relationships and identity formation (Huber, 2005). Using a cochlear implant specific module (questions that evaluate domains that are specific to the population of interest) in addition to the generic measures indicated that adolescents report less positive outcomes (Warner-Cyz et al, 2011). This further highlights the need to consider teenagers as a separate group as their perspectives are likely to differ from children.

Only three studies have been found that have directly explored the experiences of teenagers with cochlear implants. Wheeler et al (2007), Mather et al (2011) and Hilton et al (2013) conducted individual interviews with small numbers of teenagers. The research highlighted that the teenagers generally felt positive towards their cochlear implant as a result of improvements in their listening and communication abilities, although adapting to a cochlear implant, particularly if it is the second device, can be a long and difficult process. The teenagers struggled with some of the practical limitations of the implants but also found it difficult when others were not aware of their needs as it could make listening more difficult. Whilst illuminating studies, the scope for exploring the user perspective was limited since there was no involvement from the teenagers in the research process. When the perspectives of the teenagers are not central to the research process, the teenagers' perspectives are 'filtered through the interpretations of adult researchers' (Shaw et al, 2011 p4).

There is a need to use an approach where teenagers are actively involved in the research process, to enable their voices to be heard from the start so that issues of importance to them are not missed. Researching their experiences in this way will benefit this population through improvements in their clinical care, whilst also providing new insight into their experience of deafness and how having a cochlear implant impacts on different areas of their lives.

1.2 Aim and objectives of the study

This study aims to address this gap in the knowledge by putting the teenagers at the heart of the research process to explore their experiences of living with a cochlear implant. This will enable a deeper and broader exploration of the issues that are important to them than has previously been reported in the literature. In this study, the term 'experience' refers to the teenager's thoughts and feelings about the process of getting a cochlear implant and how it impacts on their life.

A wider understanding of these issues may benefit this population through improvements in clinical practice. It will also lead to scientific benefits as a result of increased knowledge of the experiences of this heterogeneous group.

The objectives of the study are:

- i) to explore the experiences of teenagers with cochlear implants, in order to gain more insight into the user perspective than has previously been achieved to date.
- ii) to identify the main issues of importance to this population to further understand their needs.
- iii) to develop methodology related to increasing understanding of deafness and adolescence.

At the start of the study it was anticipated that the objectives of the research would be met by working collaboratively with teenagers with cochlear implants to develop a website for them to record their experiences of living with a cochlear implant (Phase 1). Involving a group of teenagers in the design of a website was largely successful and this approach is evaluated in Chapter 5. However, due to low numbers of teenagers joining the website a different approach was adopted. In Phase 2 individual interviews were carried out since they can generate detailed and rich data about experiences and perspectives (Braun and Clarke, 2013).

The phases and stages of the study are summarised below.

Phase 1: Development work.

This phase comprised three stages, with three parts to stage 2 and two parts to stage 3.

- Stage 1:

A questionnaire was sent to 60 pupils aged 13-19 years who wore at least one cochlear implant at a school for deaf children in the south of England, in order to gather their views about designing a website for teenagers to share their experiences of using a cochlear implant.

- Stage 2:

Part i) A meeting was held with three teenagers at the school who worked with the researcher to design the website specification.

Part ii) Work with website designer to develop website.

Part iii) Meetings with two teenagers involved in Part i) to give their feedback on the website prior to the launch.

- Stage 3:

Part i) Launch of the website.

Part ii) Skype meeting with three teenagers who had used the website to give their feedback.

Phase 2: Individual interviews.

This phase comprised two parts.

Part i) Semi-structured interviews with 10 teenagers from a school for deaf children and a cochlear implant centre, both in the south of England. These did not include the teenagers who took part in the meetings to design the website in Phase

1 (Stage 2) but did include five of those who completed the questionnaire in Phase 1 (Stage 1).

Part ii) Template analysis of the interview transcripts and validation of findings with three teenagers from the school for deaf children.

1.3 Overview of the thesis

This chapter has discussed the background to the study and identified the gap in the knowledge which has led to the research aim and objectives. Chapter 2 reviews the literature relating to adolescence and deafness, cochlear implant candidacy, rehabilitation and outcome measures. It also discusses the experiences of cochlear implant patients from different populations. In chapter 3, the design of the study is presented and justified, along with the methods chosen and the analysis technique that was used. This chapter also outlines the considerations when involving young people in research, the justification for using online methods to collect data and why an alternative method was chosen. The two phases of the study are outlined and an overview of the technique used to analyse the interviews is given. The chapter concludes with a description of how the findings were validated by a group of teenagers.

Chapter 4 presents the findings which highlight the experiences of teenagers who have a cochlear implant at different stages of the implant process, from making the decision to have the device to what their life is like now. Chapter 5 discusses three key areas related to the findings: anxiety about the operation and outcomes of surgery, the gap between expectations and the reality of having a cochlear implant and belonging to both the hearing and deaf worlds. These findings are then considered in light of the relevant literature. In chapter 6 the key findings are summarised. There is also an evaluation of the study and suggestions for future research. In addition, recommendations are made for the benefit of researchers planning to work collaboratively with teenagers with cochlear implants in future studies. Finally, the clinical implications of the findings are discussed and recommendations are made for cochlear implant services that support teenagers.

Chapter 2 Review of the literature

2.1 Introduction

This chapter gives an overview of the key literature of relevance to this study. The chapter begins with an outline of the strategy used to select the literature. The main features of a cochlear implant, candidacy and outcomes in patients fitted with this device are then discussed. The process of rehabilitation is also outlined. A review of the literature on adolescent development and deafness in adolescence follows. Outcomes of cochlear implants in adolescents are then outlined, with a discussion of the experiences of adult, paediatric and adolescent cochlear implant users.

Throughout the chapter gaps in the knowledge are highlighted in order to justify and clarify the research question chosen. The chapter concludes with a summary of the gap in knowledge that this study aims to address.

2.2 Literature review strategy

The search strategy involved a comprehensive electronic search of the literature on adolescence and deafness, cochlear implants and the experiences of cochlear implant users. A 'Google' type search engine ('Delphis') provided by the University of Southampton library was used to search electronic and print articles inside and outside of the library's collection. Delphis includes all of the major online databases for health and social science including MEDLINE and CINAHL (Nursing and Allied Health Literature). The quality of the research papers was determined using checklists for qualitative studies or systematic reviews from the Critical Appraisal Skills Programme (CASP) Toolkit (CASP, 2013).

The literature was found mainly within audiology, psychology, nursing and medical journals and texts. The types of resources included in the search were published articles in peer reviewed journals, grey literature such as unpublished conference papers, policy documents and secondary sources such as texts. This identified the majority of the literature which is discussed in the review. A quality standard outlining guidelines for professionals working with children and young people with cochlear implants was downloaded from the National Deaf Children's Society website (www.ndcs.org.uk).

The search included date restrictions which were likely to give the most relevant literature. The literature relating to cochlear implants in teenagers was retrieved from 2000. Children were implanted from 1987 onwards so the numbers of teenagers were very small until around 2000. This is reflected in the number of research articles relating to this age group before 2000. Only 4 articles were retrieved before 2000, none of which were relevant to this study since they examined audiological outcomes in only one or two individuals. The literature relating to experiences and cochlear implants in adults was searched from 1980, when adult patients were first implanted. Studies from countries other than the UK were included in the search unless the school arrangements were substantially different from the UK. The literature mainly originated in the UK, USA and Europe.

Following initial scoping of the literature it became clear that there were multiple terms being used to describe the age group that this study was interested in. Many studies use the term 'adolescent' when referring to teenagers but also to young people in their early 20s. Few studies used the term 'teenager' to describe participants between the ages of 13-19 years. With this in mind, multiple search terms were used to locate literature relating to teenagers with cochlear implants. These included medical subject headings (MeSH) such as 'teenager' and 'adolescent'. Terms such as 'young person' and 'young people' were also included to access relevant literature from other databases that did not use MeSH terms.

The key search terms used to access the literature relating to teenagers with cochlear implants are detailed in Appendix 1. The terms (teenager OR adolescent* OR 'young person' OR 'young people') AND 'cochlear implant' AND (experience OR perspective OR views) between 2000 and 2015 yielded 467 results. All published papers were included. The papers that were included in the literature review were selected based on the relevance of the study to this project, for example the inclusion of young people aged 13-19 years. The first two 'screening' questions on the qualitative CASP checklist described previously were then used to help identify quality papers which were included in the literature review, based on the research aims and appropriateness of the methodology. The most recent papers were reviewed first since they included the largest numbers of teenagers with the most up to date technology. The rest of the literature was examined by following up key references from the recent papers.

2.3 Cochlear implants

Cochlear implants enable those with severe to profound deafness who receive little or no benefit from hearing aids to experience the sensation of hearing. This is possible as a result of electrically stimulating auditory nerve fibres, bypassing damaged or missing hair cells in the cochlea (Flynn, 2004).

The first clinically available cochlear implant did not appear until 1976, with a multichannel device becoming commercially available in the 1980s (Sheppard, 1994). Cochlear implants separate the acoustic signal into different frequency regions or speech features, to be sent to an array of electrodes sited at different places along the cochlea (Flynn, 2004). Advances in technology have occurred rapidly in this field with ongoing improvements in signal processing, microchip design, miniaturisation and battery consumption (Allum, 1996).

2.3.1 Components of a cochlear implant

There are four main implant manufacturers in the UK (Advanced Bionics, MED EL, Cochlear and Oticon Medical) (BCIG, 2014a). Although the underlying principles of how they function are similar, all vary in the number and position of electrodes, type of signal processing and how the external and internal components are linked (BCIG, 2014b).

A cochlear implant comprises external and internal components. The external components are worn on the head and comprise a speech processor, microphone and transmitter coil. There is also an internal component, the implant, which is surgically placed inside the cochlea. Figure 1 shows a cochlear implant in situ, with the external components shown.

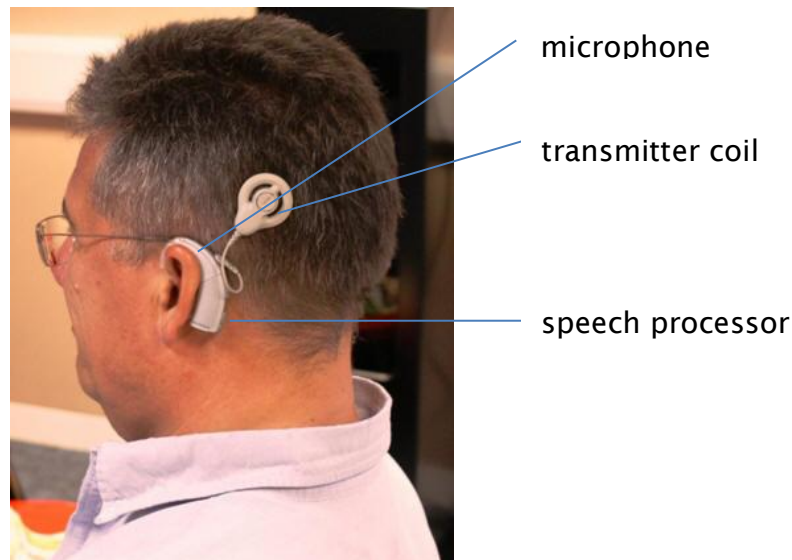


Figure 1. A cochlear implant in situ, showing the external components.

The microphone, which is housed in a casing much like that of a behind the ear hearing aid, picks up and then converts the sound into an electrical signal (Wilson and Dorman, 2000). The speech processor is usually positioned post-aurally and housed in the same casing, however body worn processors are also available if it is not practical to wear the casing behind the pinna (outer ear), for example if the pinna is malformed. Speech processors change the incoming acoustic signal by filtering, adjusting the amplitude and coding the signal to enable them to be transmitted to a magnetic coil (Flynn, 2004). The coil then transmits the electromagnetic signal to the internal magnetic receiver positioned beneath the skin, in the mastoid bone behind the pinna (Clark, 2003). An electronics package transmits the coded information almost instantaneously to the electrodes which pass into the cochlear. The electrodes then stimulate the auditory neurons (Wilson and Dorman, 2000). The result is the 'sensation' of hearing.

Although the basic components of each cochlear implant do not differ, each system differs in terms of how the signal that is created by the speech processor transmits the information to the auditory nerve fibres (Wilson and Dorman, 2000). Specifically, there are differences in the way in which the signal from the processor is transmitted to the internal components, the configuration of the electrodes, the number of electrodes, the number of channels and the placement of electrodes. The way in which the speech signal is manipulated for electrical stimulation (speech

processing strategy) can also vary and research is on-going to optimise strategies for different populations (Drennen and Rubinstein, 2006).

While a cochlear implant gives the user the ability to hear a range of environmental and speech sounds at lower levels than they would otherwise have been able to, they do not fully restore the individuals' hearing. This is because the implant simulates the normal ear's ability to convert sound waves into electrical signals and send these impulses to the brain where they are perceived as sound (Flynn, 2004). In a deafened ear, usually only a small number of hair cells remain. Hair cells change sound waves from the outer and middle ear in to electrical signals that travel via the auditory nerve to the brain (Clark, 2003). The cochlear implant bypasses the missing or damaged inner hair cells by directly stimulating the remaining neurons in the auditory nerve (Wilson and Dorman, 2008). For example, differences in pitch can be difficult to determine, which can present problems when listening to music. In addition, hearing in noise can be more challenging than for a person with normal hearing. It is the case that each patient derives a different amount of benefit from their cochlear implant and this is influenced by many factors including duration and degree of hearing loss and the status of the cochlea (Niparko, 2009).

2.3.2 Candidacy

Candidacy for cochlear implantation is determined by a number of criteria to ensure a successful outcome for the patient, both in the short and longer term. The decision to implant is case dependent, with professionals in the UK following guidance specified by the British Cochlear Implant Group (BCIG) (2014b, c) and the National Institute for Clinical Excellence (NICE) (2009).

These criteria have evolved from many years of auditing clinical practice and research and they are subject to annual change and revision. Currently NICE recommends that implantation should be considered for adult patients who fulfil the following criteria:

- A valid trial of an acoustic hearing aid for at least 3 months where adequate benefit from the hearing aid(s) cannot be demonstrated. Adequate benefit is

defined as 50% or more correct on a sentence recognition test (BKB) at 70 dB SPL.

- A bilateral severe to profound hearing loss (>90 dB HL at 2 kHz and 4 kHz). Adults with better thresholds but with poor functional hearing (for example as a result of an auditory processing disorder) may also be considered.

There is no upper age limit although the duration of deafness may have an impact on the success of the implant as a result of long term auditory deprivation. Fitness for surgery is also a consideration.

The guidelines for paediatric patients are as follows:

- Minimum of 3 months hearing aid trial, which has been optimally fitted but where hearing aid benefit cannot be demonstrated. This is defined as speech, language and listening skills appropriate to the child's age, developmental stage and cognitive ability.
- Profound (>90 dB HL) bilateral sensorineural hearing loss at 2 and 4 kHz, without acoustic hearing aids. Children with thresholds better than this but with poor functional hearing may also be considered.

In all cases, the decision to implant is the responsibility of a multidisciplinary team comprising audiologists, speech and language therapists and consultant otologists. Psychologists and Teachers of the Deaf may be involved in assessing candidates (BCIG, 2014a). The decision to implant focusses on whether the benefits outweigh the risks and if the benefits are likely to be substantially better than those experienced with a hearing aid (Niparko et al, 2009). Additional considerations are whether the patient has sufficient motivation and commitment to benefit from the device so the patient's own perspective is also factored into the decision, as is family and social background for younger patients (Pujol and Amat, 1996).

2.3.3 Bilateral and sequential cochlear implants

Since a review in 2009 by NICE, simultaneous bilateral cochlear implantation is recommended for children. Adults with additional needs (for example, limited sight) are also eligible for two devices. In addition, users of one implant may receive a

second implant at a later date (sequential cochlear implantation) if considered beneficial by the team involved in their care.

There is a body of evidence to show that wearing two cochlear implants is more beneficial than one (e.g. Crathorne et al, 2012; Litovsky et al, 2012). The benefits include being able to more easily understand speech in noise and an improved ability to localise sound and better language comprehension and expression in young children (Dunn et al, 2012; Sparreboom et al, 2015; Lammers et al, 2014). Adult patients have reported increased confidence and independence after receiving a second cochlear implant (Buhagiar, 2012).

As a result of the reviewed NICE guidance, many teenagers are now receiving a second (sequential) cochlear implant, in some cases several years after they were first implanted. The factors which predict success of a sequential implant have not yet been well established. For example, Graham et al (2009) suggested that young people aged 16-18 years receiving a second cochlear implant were unlikely to do well in terms of speech perception ability. However Galvin et al (2010) suggested that benefits in speech perception can be obtained from a second implant up to 19 years of age, even in pre-lingually deafened adolescents and where there is a large gap between the first and second implant.

Predicting outcomes in individuals who receive a second cochlear implant is not straightforward. Some teenagers take much longer to adjust to their second implant than others and the reasons for this are not yet clear. Possible factors include experiencing a very different and sometimes unpleasant sound from the second device and inconsistent use of the device in the early stages of adjustment (Redfern and McKinley, 2011). A recent small scale audit of six teenagers with sequential cochlear implants revealed that unrealistic expectations may lead to rejection of the second device; although more research is needed as there are likely to be other contributing factors (Emond et al, 2013). The needs of teenagers with two implants are likely to be different to those of younger children due to factors such as a longer duration between the first and second device, greater expectations of benefit and the pressures of education (Sparreboom et al, 2015).

Two studies have explored the experiences of teenagers who have received a sequential cochlear implant with particular attention to the psychosocial impact of a

second device. Interviews with the teenagers revealed that whilst they benefited from increased confidence and an improved social life, they also experienced challenges adapting to the sound of the second device. They reported both hearing and deaf identities but also a feeling of difference, despite being more integrated into the hearing world (Hilton et al, 2013). Rehabilitation following surgery may not be straightforward for teenagers as it requires patience and commitment, the extent of which may not be fully appreciated beforehand (Mather et al, 2011).

2.3.4 Pre- and post-lingual cochlear implantation

The outcomes of cochlear implantation are influenced by the age of the patient when the device is fitted and duration of deafness (Niparko, 2009). The duration of auditory deprivation, where neural degeneration occurs and there is poorer functioning of the central auditory processes, is often credited as explaining a lot of the differences in the performance of those deafened at birth or before around one year of age (pre-lingually deafened) and those who lost their hearing after acquiring language (post-lingually deafened) (Lazard et al, 2012).

Whether an individual receives the cochlear implant before acquiring language (pre-lingual) or after (post-lingual) has an impact on outcomes such as speech perception, speech discrimination and speech recognition (Kirk and Choi, 2009). To achieve maximum benefit it is important that the cochlear implant is given as soon as possible after confirmation of the degree of hearing loss. Improvements in quality of life have been reported by both pre- and post-lingually deafened individuals (Rembar et al, 2009).

The duration of time before a post-lingual teenager is hearing optimally (i.e. the time between the device being switched-on and when the performance plateaus following acclimatisation) varies considerably. Their performance is dependent on their duration of deafness but also their expectations and abilities, tending to achieve better performance on measures of speech perception more rapidly than pre-lingually deafened teenagers (Pujol and Amat, 1996).

Previously, older children and teenagers with pre-lingual deafness were not considered for cochlear implantation due to concerns over auditory deprivation. However, implanting teenagers who were pre-lingually deafened has been shown to

be successful. For example, Fitzpatrick et al (2004) and Arisi et al (2010) reported good speech recognition scores in teenagers implanted in early adolescence, although there is high variability in outcomes between individuals (Shpak et al, 2009). In addition, teenagers with pre-lingual deafness can receive benefit from a second cochlear implant, even if there has been more than 16 years between devices (Galvin et al, 2010). A recent study of a small sample of ten pre- and peri-lingually deafened (during the development of speech and language) teenagers showed a significant improvement in speech perception with benefits such as improved self-esteem and greater self-sufficiency, and high satisfaction with the device (Bosco et al, 2013).

Duration of deafness has also been found to influence identity. Bat Chava (2000) found that adults with 'culturally hearing' identities¹ were more likely to have been deafened after acquiring spoken language, whilst those with 'culturally deaf' identities² typically had congenital (from birth) hearing loss. This was attributed in part to the parents' role in the child's upbringing, where parents of post-lingually deafened children were more likely to raise them to communicate orally. Those who were culturally deaf were more likely to be from a deaf family, where pre-lingual deafness was more common due to genetic factors (Bat Chava, 2000).

2.3.5 Outcome measures

There is great variation in the benefits of cochlear implantation across individuals (Kirk and Choi, 2009). A number of factors may account for the high variability in performance. They include age at implantation, duration of deafness and degree of hearing loss. In children, additional factors include educational environment (use of oral communication) and co-existence of a disability. However some factors have been identified as strong predictors of good speech recognition. These include a short duration of deafness and good speech understanding before implantation (Niparko, 2009).

¹ using one's hearing, via amplification or cochlear implantation, to integrate into the hearing world

² associating mainly with other deaf individuals, using sign language and affiliating with deaf social and political groups

Benefit from a cochlear implant can be measured by evaluating the improvements in listening skills but also aspects such as quality of life, educational performance and communication in real world settings. These aspects have attracted research since they feed into a cost-benefit analysis that can highlight the wider impact of cochlear implants and inform economic measures by evaluating their effectiveness (Niparko, 2009).

Outcome measures can be used in different ways, such as monitoring the clinical care of patients and assessing candidacy. For example, assessing speech perception abilities pre and post implantation is an indicator of progress and assists the clinician in the tuning of the device. Measuring outcomes may also inform future research related to candidacy criteria, evaluation of different speech processing strategies and to explore patient and treatment related variables that may indicate success (Kirk and Choi, 2009).

It is important to select outcome measures that are relevant to the population being evaluated. For example, the benefits of post-lingually deafened adults may include improved speech perception recognition, whereas children may experience changes in other aspects of communication which need to be evaluated appropriately (Kirk and Choi, 1999). Typically, an assessment battery for adult patients consists of open-set tests of word and sentence recognition. These assess an individual's ability to communicate in typical listening environments, including in noise (Clark, 2003). For children with pre-lingual deafness, the development of speech production may be assessed alongside speech perception and spoken word recognition. In patients with bilateral implants, tests of localisation may be used to assess directional hearing (Clark, 2003).

Qualitative measures of subjective benefit such as changes in patients' quality of life can also be used alongside clinical tests to assess improvements which are not captured by clinical tests. For example, Health Related Quality of Life (HRQoL) measures, which examine subjective domains such as physical, social and emotional well-being, have been used to compare the costs and perceived benefits of cochlear implantation with other health interventions (Hawthorne et al, 2004).

2.4 Rehabilitation

Several weeks following surgery, the external components of the implant are fitted and the speech processor is set up to provide the most benefit for the patient (Flynn, 2004). Different parameters of the stimulus are adjusted by the clinician, such as the electrical threshold and comfort levels (Clark, 2003). Following this initial 'tuning', patients undergo a life-long programme of rehabilitation to help them to interpret and learn to use the new sounds they are hearing. Listening exercises focus on the abilities of the patient, in particular which features of speech are available to them. The provision of specific rehabilitation activities varies between cochlear implant centres, although the general approach will be the same. The rehabilitation programme includes training in speech reception, in quiet and in noise, and recognition of sounds in the environment (Clark, 2003). In addition, there may be the opportunity to talk about their experiences with the device, expectations and how they will manage the challenges of adjusting to the new sound. Some centres also offer the chance to meet with other implantees in addition to the regular clinic sessions.

It is recognised that the rehabilitation of teenagers who receive a cochlear implant is a challenging process, due to the additional difficulties they may present with as a result of psychosocial issues during this time (Pujol and Amat, 1996). For example, a more flexible approach is often needed, with a good understanding of the teenagers' background and wishes. More emotional support is perhaps needed than for adult patients and an awareness that their perceptions may change over time and their motivation may be difficult to maintain. Self-image and peer pressure are issues that may affect a teenagers' acceptance of the device and progress. However, careful rehabilitation where professionals work in partnership with this group has been found to be successful (Pujol and Amat, 1996). Small group rehabilitation has been shown to be effective at improving communication skills such as speech production, through the use of phonetic games for example (D'Agosta et al, 1999). This conclusion is based on a study of only six participants where the effect of the type of therapy was not studied independently to the effects of group working. However it highlights the potential benefits of working with teenagers in this way.

2.5 Adolescent development

Adolescence is typically a period of rapid development: physically, socially and psychologically. It may be defined as a period of transition between childhood and adulthood, with a re-configuration of biological, cognitive and emotional functions (Rathus, 2014). Definitions of adolescence reflect the fact that it cannot be defined according to just one criterion since there are several factors interacting during this time (biological, social, psychological) which influence the course of the development of the young person (Cook and Cook, 2010).

There are a number of challenges teenagers must negotiate, including the development of their identity, forming relationships with their peers and establishing independence and autonomy (Christie and Viner, 2005). There is much variation between individuals, both psychologically and physically, and so it is difficult to generalise about their functioning according to biological age. Rathus (2014) divided adolescence can be divided into three 'phases':

- early adolescence (11-14 years), characterised by rapid biological changes, reasonably high stress levels and limited coping ability
- middle adolescence (14-16 years) where the biological changes slow down, stress reduces and coping ability increases
- late adolescence (16-18 years) where there is a more adult like physical appearance, low stress levels and better coping than previously.

There are key cognitive changes during adolescence, all of which influence how the individual interacts with the world. For example, formal operational thought is developed which allows the individual to think about the future in hypothetical terms and consider more than one possible outcome (Rathus, 2014). This has implications for clinicians working with teenagers, in terms of whether they are capable of giving informed consent for an intervention or able to self- manage their treatment or rehabilitation (Christie and Viner, 2005).

These developments in the ability to think in abstract ways about themselves also help with the development of their identity, allowing them to compare their 'ideal' self with their 'real' and 'ideal' selves (Cook and Cook, 2010). There may be a discrepancy between their 'real' and 'ideal' self, particularly in relation to their appearance which gradually reduces from about the age of 13 years as they develop

social and academic skills which enable them to be less critical of themselves (Rathus, 2014). The support of family and peers, particularly in late adolescence, is key to having high self-esteem as they offer mutual understanding, acceptance and the opportunity for self-disclosure (Rathus, 2014).

Clinicians face challenges when working with teenagers who are undergoing such significant development. The cognitive and socio-emotional changes may impact on behaviours such as risk taking or adherence, such as wearing the cochlear implant or following a rehabilitation programme as directed. An approach where concrete examples are used and abstract ideas are avoided is recommended, as is putting the teenager at the centre of the discussions about their care (Christie and Viner, 2005). It is important for clinicians to maintain good relationships with teenagers, especially during the time when the responsibility for their health passes to them (Christie and Viner, 2005).

2.6 Deafness and adolescence

Teenagers with deafness may face a number of challenges which their hearing peers do not. Being part of a hearing world which does not easily accommodate their needs can lead to difficulties in different areas of their lives. Some of these aspects have been reported in the literature, such as perceived career barriers and the effects of being in a mainstream school. The impact of deafness on social and emotional adjustment has also been examined in order to assess to what extent deaf teenagers are similar to their hearing peers. Studies which have investigated the ways in which deaf teenagers see themselves have highlighted the multitude of factors which influence identity and the importance of strong relationships with peers.

2.6.1 Career barriers

The career aspirations of teenagers with a hearing loss has been discussed in the literature since these students are more likely to encounter obstacles both in the environment and in the attitudes of others, which may negatively impact on their success (Punch and Hyde, 2005; Punch et al, 2006). These studies highlighted a number of barriers that the teenagers perceived to be related to their hearing. They included difficulties using the phone which they believed would hinder their success at work as colleagues were unlikely to be aware of their needs. Those who perceived

more career barriers were less likely to be proactive in exploring career options. An attempt was made to tap into the issues of importance to this population by using generic questionnaires which were modified for teenagers with a hearing loss. This research indicated the need for appropriate support for this population who are facing important decisions about their future but may need additional, tailored support to help them manage and overcome these barriers. Conversely, the parents of teenagers with deafness were reported to have high expectations of employment opportunities and of a smooth transition in to higher education, although they assumed that appropriate support would be provided in the workplace which is not necessarily the case (Cawthorne et al, 2014).

2.6.2 Psychosocial well-being

The psychosocial well-being of hearing impaired teenagers has been explored in order to better understand the factors that impact on their social and emotional health. Although the literature is sparse, findings suggest that deaf teenagers' psychosocial development is generally comparable to that of their hearing peers.

In the largest study to investigate this area, Polat (2003) investigated the impact of student background and experience, parent-related variables, school-related and teacher-related variables on the psychosocial adjustment of over 1,000 deaf children in Turkey. An observational scale for measuring social and emotional adjustment and self-image in deaf students (the Meadow/Kendall Social and Emotional Adjustment Inventory (SEAI) was administered by teachers and other educational professionals. The results were correlated with a number of parent, school, teacher and student related variables. Hearing loss was shown to be negatively correlated with the psychosocial adjustment of students, with a positive relationship between social adjustment and self-image and use of hearing aids, speech intelligibility and academic achievement. Later onset of deafness was associated with poorer psychosocial adjustment, perhaps due to having more difficulties adjusting to a hearing loss at a later age. The authors concluded that environmental factors rather than deafness may have a significant influence on psychosocial adjustment. Although a large scale study which explored a wide range of variables the students themselves were not consulted, the results being based on the interpretations of teachers and educational staff.

Gent et al (2012) examined the self-concept and ego development of 68 deaf teenagers, compared with hearing peers. A standard measure of self-concept was adapted for deaf adolescents by the researcher so may not have accurately reflected the views of the participants. However, the results indicated that the teenagers discounted feeling socially accepted and did not perceive close friendships as important perhaps because they felt less competent in these areas of their life. Ego was less well developed in the deaf teenagers compared with their hearing peers. This study suggests that type of school may be an important determiner of ego development although language ability is also likely to be important but this was not explored (Gent et al, 2012).

Good communication ability has been identified as another factor which positively influences psychosocial well-being in deaf adolescents. Dammeyer (2010) reviewed the speech intelligibility, auditory performance, sign language production and understanding and psychosocial difficulties of 334 deaf children and adolescents who attended schools for the deaf in Denmark. Teacher-administered scales and questionnaires were used to collect the data. The results suggested that regardless of the mode of communication (sign language or oral) psychosocial difficulties were comparable to hearing children if the young person was a competent communicator. The conclusions are limited since there were not any mainstreamed children in the study group who may receive different, perhaps less effective, communication support. In addition, teacher reports were used which may be inaccurate due to poor knowledge of the pupils circumstances outside of school.

2.6.3 Education

There has been some discussion in the literature regarding the effects of placing hearing impaired children and young people in mainstream schools and the implications of this on academic performance and psychosocial development. For example, Kent (2003) explored the psychosocial correlates and health behaviours of a large sample of hearing-impaired students placed in mainstream schools and compared their responses to those of their normally hearing peers. Success at school has been shown in the literature to be linked to positive well-being and hearing impaired students may be particularly at risk of poor self-perceptions. The majority of students questioned did not identify themselves as 'hard of hearing' however those that did reported an increased frequency of feeling lonely and being

bullied. The reasons for these responses are not clear since a generic health questionnaire was used. Further exploration of the reasons for these responses using interviews would increase our understanding of the students' experiences.

Social loneliness was also explored by Punch and Hyde (2005) who used a mixed methods approach. The researchers used a generic survey of social loneliness and slightly modified the language for teenagers (although without consulting any teenagers to check for clarity), and semi-structured interviews to explore key areas of interest arising from the questionnaire. Whilst the survey revealed that students attending integrated schools did not feel significantly more socially isolated or participate less with their peers than the hearing students, data from the interviews revealed that many did have difficulties socialising with their hearing peers. The students reported feeling awkward and self-conscious, although the extent to which this worried them varied. The authors reported that this difficulty may explain why they have concerns regarding their career options. Many students were not aware of the support available in the workplace, which limited their decision making. This study highlights the important role teachers and career advisers have in facilitating the development of social skills that will help them in the workplace. A strength of this study is the mixed methods approach which allowed findings to come to light that had not been captured by the survey. This was a limitation demonstrated in the earlier study by Kent (2003).

It has been suggested that a mix of segregated and integrated educational environments may promote good social adjustment amongst hearing impaired adolescents, despite the preference to place these children in mainstream schools (Musselman et al, 1996). Overcoming social difficulties with hearing peers can be achieved in a supportive school environment according to Leigh (1999). Open-ended questionnaires were used to retrospectively explore the mainstream educational experiences of a group of deaf adults, in particular how the experience affected their self-perceptions, social functioning and personal development. They reported good relationships with hearing peers although interactions with them were less relaxed than with their deaf counterparts. The extent of mainstreaming was not determined and the reports were retrospective. However, experiences at school appeared to have influenced how the participants felt about themselves. For example, feeling positive about oneself was associated with a supportive environment at school. Leigh (1999) also suggested that those in mainstream

school need to try harder than their hearing peers in order to achieve peer acceptance.

At present, most deaf teenagers who have good spoken language will be partially or fully mainstreamed in a secondary school (Archbold and Mayer, 2012). A recent study using a quality of life measure developed for deaf students indicated that the type of school does not impact on quality of life and on measures such as participation, perceived stigma and self-acceptance (Schick et al, 2012). However, teenagers themselves have reported that careful support is needed as there can be a number of challenges such as the use of more complex language and concepts, poor listening conditions, several different teachers and more group work (Wheeler et al, 2007).

2.6.4 Identity development

Establishing 'who we are' is a key feature of adolescence and may result in difficulties in adulthood if not resolved during this period of development (Cook and Cook, 2010). The literature has highlighted four main identity types in deaf teenagers: Deaf (where the capital D indicates belonging to the Deaf community), deaf (in an audiological, rather than cultural, sense), bicultural (belonging to the hearing and deaf worlds), hearing, and marginal (belonging to neither the hearing or deaf world and experiencing communication and social difficulties as a result) (Glickman and Carey, 1993; Most et al, 2007; Hyde et al, 2010). Research indicates that 'marginal' identity is unusual in deaf adolescents (Most et al, 2007).

There is no published measure of identity that has been found that is specific to deaf adolescents so studies have used questionnaires based on deaf identity models developed using adults. The earliest of these was proposed by Glickman and Carey (1993). Their model explained the process of developing a Deaf identity (culturally, as oppose to audiological, deaf): culturally hearing (where hearing is 'normal' and deafness is seen as medical pathology), culturally marginal (where the individual fits between the hearing and Deaf worlds), immersion (where there is positive identification with Deaf culture) and bicultural (where individuals have positive feelings about being part of the Deaf culture and hearing world). This is the final stage of identity development according to Glickman and Carey, and is the desirable state as the individual has 'bicultural skills' which are advantageous to

communication (Glickman and Carey, 1993 p. 277). This model recognises that a variety of factors such as educational attainment, age of onset of deafness and whether one belongs to a hearing or deaf family can all influence which part of the model one orientates towards. This model led to the development of the Deaf Identity Development Scale (DIDS) (Glickman and Carey, 1993). However, a limitation of this questionnaire is that it only explores identity in relation to a culturally Deaf identity (with a capital 'D') and proposes that deaf individuals perceive their own deafness as pathological.

The acculturation model more accurately reflects how deaf individuals connect with both the Deaf and hearing worlds (Maxwell-Macaw and Zea, 2011). In this model, individuals acquire aspects of a Deaf identity whilst maintaining contact with hearing culture. The model suggests that full identification with the hearing world does not usually occur since deaf individuals will always feel psychologically 'different' due to their hearing loss. The Deaf Acculturation Scale was developed from the model which measures identification with hearing and Deaf cultures independently, to reflect that individuals have a connection with both at the same time. High scores on both subscales indicate a bicultural identity. As with Glickman and Carey's model, a deaf identity (in an audiological sense) is not represented.

Using the DIDS and similar measures, studies have attempted to identify the identity patterns among adolescents in different educational establishments where communication methods vary. For example, Sari (2005) explored the identity patterns of 90 deaf teenagers in Turkish schools for deaf children using a Deaf Identity Scale devised by Weinberg and Sterrit (1986) comprising three subscales: culturally hearing, Deaf and bicultural. The authors found that those students attending a school which used a predominately oral approach to communication reported a culturally hearing identity, with students at a school where speech and sign language was used were more likely to report a bicultural identity. This study did not explore to what extent the identities were influenced by other factors such as degree of hearing loss or contact with parents and how easily they communicated in the mode used at school.

Kobosko (2010) also explored the relationship between mode of communication and how deaf adolescents perceived themselves using the Deaf Identity Development Scale (DIDS). The study revealed that the adolescents' personal

identities did not depend on what mode of communication they used (sign language or oral). However, their deaf cultural identities did appear to be determined by the type of language, with signing deaf adolescents likely to be Deaf acculturated and oral deaf adolescents typically reported as hearing acculturated. These conclusions were drawn from a much smaller group of adolescents than in Sari's study with 20 deaf participants in total which may explain the difference in results when compared with Sari (2005).

In the largest study to explore identity in deaf adolescents, Most et al (2007) explored whether exposure to others with cochlear implants influenced their identity and views about cochlear implants. This study used the DIDS questionnaire and a questionnaire to examine attitudes towards cochlear implants in 115 deaf adolescents, the majority of whom wore hearing aids with some cochlear implant users. The majority of the participants used both sign and spoken language. The results revealed that adolescents identified more with the bicultural scale (feeling comfortable in both the hearing and Deaf worlds) than the Deaf or marginal ('do not belong to either') scales. Most participants had attended regular schools but were also exposed to other deaf/hard of hearing children which may explain this result. Mostly positive attitudes were held towards cochlear implants, with stronger deaf identity being weakly associated with more negative attitudes towards cochlear implants. The authors suggest that this was perhaps to conserve their identity and the positive elements of it, such as self-esteem. It is not known how students who do not interact with deaf/hard of hearing students perceive their identity since they were not included in the study.

2.7 Cochlear implant outcomes in adolescents

Measuring outcomes for adolescents with cochlear implants is important since there are inherent differences when compared with adult or paediatric populations. They are more involved in decision making, more independent and may be in more situations where the listening environment is less favourable or adapted for them, for example at school (Mather et al, 2011). Many teenagers are now receiving sequential cochlear implants, often several years after they were fitted with the first device, which can also present particular challenges. Outcomes have focussed on psychosocial functioning, identity development with some earlier research examining educational achievement and career aspirations. Quality of life has been

less well researched, although recent studies indicated that this is comparable to their hearing peers. Although the literature is sparse relative to other age groups with cochlear implants, particularly where teenagers views are sought, and earlier studies are limited by small numbers; it highlights the benefits of cochlear implantation on teenager's functioning in daily life.

2.7.1 Speech and language development

The speech and language abilities of pre-lingually deafened teenagers were reported to be good following implantation in early adolescence (Kiefer et al, 1996; Schramm et al, 2002; Sarant et al, 1994). However, there is variation between individuals and very small numbers of adolescents were studied which makes it difficult to assess how representative these conclusions are. The conclusions are also limited by possible learning effects and participants not understanding the task, although Schramm et al (2002) used both quantitative (speech recognition tests) and qualitative measures (self-report questionnaire rating speech perception) which enhances the validity of the conclusions.

2.7.2 Educational and occupational outcomes

A small number of studies have examined the education and occupational status of young people with cochlear implants. Longitudinal studies such as those carried out by Beadle et al (2005) and Huber et al (2008) indicate that the educational outcomes for adolescents with a cochlear implant are good, with most being educated in mainstream schools.

More recently, Spencer et al (2012) investigated the educational outcomes of 41 young adults aged 17-35 years in Iowa in the United States. Almost all were educated in mainstream schools and their educational attainment was found to be comparable to or exceed that of their peers. Although the authors recognised that many other factors influence educational success, such as language and cognitive skills, the research adds weight to the evidence that indicates the benefit of cochlear implantation on academic performance in young people. However, Rich et al (2013) asked 12 adolescents about their functioning in the educational setting and reported mixed results. The students also considered themselves to be achieving well at school, although their views were not corroborated with test results. The participants reported difficulties hearing in the classroom particularly

when there are several speakers and this resulted in them participating less in group discussions since they felt embarrassed to ask for help. However, they reported that their cochlear implant allowed them extra free time after school since they did not need to do additional work to catch up.

There is also evidence to suggest that although the career aspirations of young people with cochlear implants are as ambitious as their hearing peers; their actual occupation does not reflect this (Huber et al, 2008). Parents of implanted young people were also found to be more pessimistic regarding the future career of their child, recognising that there are restrictions on the opportunities available to them due to their deafness (Huber et al, 2008).

Although the numbers of adolescents included in these studies are small, there is evidence to suggest that the educational and career trajectories of adolescents with cochlear implants are largely in line with their hearing peers.

2.7.3 Identifying with hearing and deaf worlds

The development of identity in adolescents with cochlear implants has been explored by a number of studies since the benefits of improved hearing and communication and more integration with the hearing world may affect how adolescents make sense of who they are in relation to their deafness (Hilton et al, 2013). The research has highlighted the complexity and fluidity of the process of identity development in teenagers with cochlear implants.

Wald and Knutson (2000) found that adolescents with cochlear implants were more likely to report a hearing identity when compared to those without cochlear implants. Adolescents with cochlear implants are more likely to attend mainstream schools where their peer group will be predominantly hearing. The influence of one's peers on identity formation is recognised among hearing adolescents and studies have reported the same effect in deaf adolescents. Recent studies have shown that deaf adolescents with cochlear implants are more likely to identify themselves as hearing if they feel close to their hearing peers but other factors have also been identified such as having better communication skills and hearing levels (Mance and Edwards, 2012; Moog et al, 2011; Hardy, 2010). Whether one feels close to hearing or deaf peers, friendship experience with deaf or hearing peers and how well one communicates in a particular mode has also been reported by Hardy

(2010) as having a strong influence on identity. A strength of this study was the use of semi-structured interviews, since it allowed the adolescents to conceptualise their identity in their own way, rather than being constrained by the identities used in questionnaires such as the DIDS (see section 2.6.4). Feeling closer to one's peers has also been associated with better psychological well-being, although to a lesser extent if the peers have a deaf identity (individuals who uses speech rather than sign language to communicate) (Mance and Edwards, 2012).

However, the research indicates that most teenagers with cochlear implants choose to maintain a connection with their deafness. Many perceive themselves as 'bicultural', with their hearing and deaf identities being expressed to different degrees depending on to what extent the situation accommodates their deafness (Rich et al, 2013; Wheeler et al, 2007). Most (2007) also speculated that during adolescence, deaf teenagers are more likely to have contact with new social groups that are different to those provided by their hearing parents as they may include other deaf individuals. This exposure may increase the likelihood of identifying with the deaf community to some degree. Rich et al (2013) postulated that having a cochlear implant exaggerates feelings of being part of two different worlds. They suggest that an individual without any amplification is deaf in all situations, whereas receiving a cochlear implant when young allows them to function at near-normal levels in most, but not all, situations.

Despite reporting an affiliation with other deaf adolescents, studies have shown that teenagers with cochlear implants typically prefer not to identify with Deaf culture (e.g. Hilton et al, 2013; Wheeler et al, 2007). Mance and Edwards (2012) suggest that the emphasis placed on developing oral communication following cochlear implantation may encourage identification with a hearing or bicultural state rather than with the Deaf culture. In addition, some teenagers have reported negative feelings towards Deaf culture such as not being intelligent and not listening well, or a lack of awareness of this community due to their parents and others not encouraging them to seek it out (Mance and Edwards, 2012; Hilton et al, 2013).

A more recent conceptualisation of identity among adolescents with cochlear implants was presented by Hardy (2010) following a grounded theory study with 11 deaf teenagers attending a mainstream school. Semi-structured interviews were used to identify their preferences for being 'deaf' or 'hearing' and then to explore

how deafness impacted on their school and home lives. They were also asked what being a deaf teenager means to them. Using grounded theory, a theoretical model of deaf adolescent identity was developed. Identity was broadly classified into three types: aligning oneself with deaf peers, hearing peers or 'the bridge between two worlds' (p65). Group alignment was found to be the main factor in determining the teenager's identities. Whether they chose to belong to the deaf or hearing group appeared to be largely influenced by how well they communicated and their preferences and experiences with deaf and hearing peers. This theoretical model is supported by social identity theory which describes how there is a relationship between social settings and one's group alignment (Tajfel, 1981). Whether this model holds through early adulthood and beyond is not clear, however it adds important knowledge to the factors that influence identity in deaf adolescents and is the only model found in the literature that is specific to this population.

2.7.4 Psychosocial functioning

Much of the qualitative research involving adolescents with cochlear implants has focussed on the impact of the cochlear implant on psychosocial functioning. Although cochlear implants improve hearing, individuals may still experience difficulties in challenging listening environments so it is important to explore socio-emotional aspects such as peer relationships with hearing and deaf individuals and social inclusion (Punch and Hyde, 2011).

Social relationships for adolescents with deafness are complex, with some preferring to socialise with hearing peers, others with deaf friends whilst also maintaining links with hearing friends (Leigh et al, 2009; Wheeler et al, 2007; Moog et al, 2011). Punch and Hyde (2011) and Wheeler et al (2007) reported that adolescents with cochlear implants can experience difficulties integrating with hearing peers. This has been attributed to differences in communication ability and difficulties communicating in groups.

Cochlear implantation has been attributed to positive effects on adolescents' quality of life, in terms of depressive emotions and self-esteem, although the reasons for these effects have not been not explored so it is difficult to determine what aspects of having a cochlear implant might contribute to these positive outcomes (Sahli and Belgin, 2006, Sahli et al 2009). The mental health status of 32 cochlear implanted

adolescents has been reported to be comparable to that of their hearing peers in a study by Huber and Kipman (2011). They identified emotional problems, inattention-hyperactivity, conduct problems and pro-social behaviour problems. Some of these difficulties were found to correlate with attendance at a special school which the authors attributed to negative selection of pupils and the large geographical spread of the pupils homes, making it difficult for friendships to be maintained outside of school hours. However, teachers' ratings suggested adolescents were experiencing problems with peers despite parents feeling otherwise. The reason for this was not explored. Good mental health was associated with adolescents living in a two parent family, those with close friendships and those with good speech perception. Moog et al (2011) also reported high levels of self-esteem and good social skills in those whose main mode of communication was oral, suggesting that oral communication may help integration with the mainstream which has positive effects on psychosocial functioning. Bilateral users appeared to report more difficulties socially compared to those who wore one implant and this result could not be explained by developmental delay or speech measures. This effect was explained by the delay in older children adjusting to their implant, compared to younger users. However, only four bilateral users were consulted which is a limitation of this study.

The psychological impact of cochlear implantation and how deaf adolescents integrated into their family and educational surroundings was also explored by Filipo et al (1999), but only in six adolescents. Personality traits and integration with family and school were explored using a variety of generic measures administered to the adolescents' pre- and post- implantation. When the data were compared to normative data from hearing adolescents of the same age, good integration with the school and family environment was seen, along with an improvement in attributes such as being able to judge ones' own behaviours and an improvement in the ways in which they expressed themselves. A key limitation of this study is that only the parents and teachers were interviewed about family and school integration which brings into question the usefulness of these findings.

The relationship between state – trait anxiety scores (anxiety about events and anxiety that is part of one's character) and audiological benefit (as measured by speech perception) was measured in 25 adolescents with cochlear implants who were performing well with the device. This study was based on the premise that

adult users experience psychological benefits after cochlear implantation (Yucel and Sennaroglu, 2007). Adolescents with cochlear implants did not score significantly differently on the measure of anxiety when compared with normally hearing adolescents, which may indicate that they were as emotionally stable as their hearing peers. The authors deliberately selected good cochlear implant users so the results cannot be generalised to the wider adolescent population, some of whom will be performing less well. However, this early study was one of the first to highlight some of the positive psychological outcomes of cochlear implantation in adolescents.

Leigh et al (2009) explored the psychosocial functioning of a large group of adolescents with and without cochlear implants using validated measures completed by parents, adolescents and teachers. Adolescents with cochlear implants saw themselves as being more hearing than Deaf, although many reported a bicultural identity. Irrespective of implant status, psychosocial outcomes such as self-esteem, loneliness and satisfaction with life were the same. This may indicate that whether a young person perceives themselves to be part of the hearing or deaf world, there is no impact on their psychosocial functioning (Leigh 2009). However, the design of this study is potentially flawed, bringing into question these conclusions. It was difficult to match the groups of adolescents (those wearing cochlear implants and those who did not) for degree of hearing loss and type of school attended. As a result, the data was manipulated statistically in order to allow for comparisons to be made. Whilst this enabled conclusions to be drawn, analysing the data in this way sheds only limited light on the relationship between cochlear implants, psychosocial functioning and hearing identity. Some of the measures that were used in this study were not developed specifically for hearing impaired adolescents, for example the DIDS (as described in section 2.6.4). Exploring the relationships between identity and social and emotional outcomes using qualitative methods may have been a more appropriate approach.

2.7.5 Quality of life

The measurement of the quality of life of adolescents with cochlear implants has recently been the focus of some research with this population. Huber (2005) and more recently Warner-Czyz et al (2011) and Duarte et al (2014) have reported the health-related quality of life in adolescents with cochlear implants. The results

indicated that implanted adolescents had a similarly good quality of life compared to normally hearing individuals. However, studies have typically used generic instruments designed for normally hearing children and adolescents, and have studied adolescents together with younger children. Therefore it is difficult to elucidate to what extent the results relate to adolescents.

Warner-Czyz et al (2011) explored health related quality of life in different age groups using a generic health related quality of life instrument (KINDLr) and is the only study that has been found that has used a cochlear implant specific module for two different age groups (4-7 year olds and 8-16 year olds). The cochlear implant module that was developed required the adolescents to rate how successful they felt at school, how comfortable they felt using the device and how they felt about themselves while wearing it. In addition, the adolescents were asked more generic questions about their emotional well-being, self-esteem, family and friends. Thirty seven adolescents were questioned and the results revealed that there is an effect of age on quality of life ratings such that older children and adolescents report less positive outcomes related to friends, school and self-image. This indicates the need for a cochlear implant and adolescent specific instrument. The scores also correlated with outcomes of speech tests, duration of deafness and age at implantation. This may indicate that one's perceived health is closely linked to the ability to communicate using spoken language as the adolescents are mainly functioning in hearing environments. A limitation of this study is that only cross-sectional data was collected so changes in health-related quality of life could not be investigated. In addition, they did not compare the results with those of hearing children and adolescents. It is therefore difficult to reach firm conclusions regarding the impact of cochlear implantation on this population's health related quality of life.

2.8 Exploring the experiences of cochlear implant users

The literature exploring the experiences of cochlear implant users is sparse compared to other outcomes already discussed, and very few studies have focussed on teenagers. Three studies have looked at the experiences of adults, highlighting the socio-emotional benefits of cochlear implantation. The experiences of children are less well documented, due to the challenges associated with eliciting this

information from young participants. Instead, parent's views have been sought as an alternative way of evaluating the child's subjective benefit.

The methods used to explore experiences vary across the studies although all used questions that are based on themes already identified from the literature or deemed appropriate by the researcher. Whilst this approach allows the voices of the participants to be heard, the breadth and richness of the data may be compromised by the influences of the researchers involved. Nevertheless, several key benefits were highlighted by the studies, indicating that the impact of having a cochlear implant extends beyond simply an improvement in hearing ability.

2.8.1 Adult cochlear implant users

One of the most in depth qualitative studies of adult cochlear implant users experiences was carried out in Sweden by Hallberg and Ringdahl (2004). Seventeen, post-lingually deafened adult cochlear implant users were interviewed and grounded theory was used to explore their experiences. The main topic areas were life before implantation, the decision to have surgery, what it means to live with a cochlear implant, the present situation and their thoughts for the future. The use of open ended questions was successful in that the participants often volunteered additional questions which enhanced the authenticity of the data. Six categories were identified in the data. The core category was 'coming back to life', which incorporated the following themes (in order of time): preventing disappointment, waiting in silence, retraining the brain, significant revelation, strengthening of self-worth. This work highlighted that the meaning of having a cochlear implant extended beyond improved speech perception and communication to psychological and existential dimensions also. The research revealed that, after implantation, participants felt more satisfied with life, managed their work better, and became more socially involved. The data suggested that having a cochlear implant may lead to increased confidence, higher self-esteem and a greater sense of self-worth. Awareness of environmental sounds helped patients to feel part of the 'real world'. The participants also reported needing to balance their feelings between hope and despair and admitted having low expectations before getting the cochlear implant to protect themselves from disappointment. The authors argue that based on these findings other indicators aside from audiological outcomes should be considered

when evaluating success, such as improvements in self-esteem and occupational success.

In a much larger study using open-ended written interviews, 74 adult, post-lingually deafened cochlear implant patients also reported feeling like they had ‘a new life’ on receipt of the device, with life being easier and feeling more involved with the world around them (Rembar et al, 2009). They also highlighted how the high expectations of others could be difficult to manage. Patients reported feeling more relaxed, happy and confident. Although a larger group of participants was interviewed than in Hallberg and Ringdahl’s (2004) study, the interview schedule only comprised four questions which focussed only on the benefits and shortcomings of the cochlear implant and its’ effect on emotional well-being. These questions were chosen by clinicians working with this population so it is possible that other areas of importance to the patients were missed.

Pre-operative expectations and post-operative experiences were recently explored in 101 post-lingually deafened adult cochlear implant users (Maki-Torkko et al, 2014). This large, open-ended questionnaire study revealed similar findings to Rembar et al (2009) and Hallberg and Ringdahl (2004), highlighting the feeling of entering a new, more social world following implantation with a greater sense of autonomy. The views of the adults’ significant others were also sought and these echoed those of the patients, although it is possible that their views reflected those of the patient rather than their own. In addition, although the use of a questionnaire allowed a large number of patients to be contacted, it may have limited their responses and did not allow for in depth exploration of some of the key issues.

2.8.2 Paediatric cochlear implant users

Only one study has been found that attempted to capture the views of children themselves. Preisler et al (2005) interviewed eleven pre- and post-lingually deafened children aged between 8.5 and 10.5 years. Half of the children were in mainstream school; the rest attended a deaf school. Semi-structured interviews were carried out in the children’s homes and the topic areas included the operation and ‘switch-on’ of the cochlear implant; daily life with the implant; problems with the device, the types of sounds they could hear; communication with their family and friends, interactions with their peers and their identity. The children in this study recognised

the benefits of using sign language as well as spoken language in order to communicate more easily, but reported difficulties hearing in a noisy classroom. They had both hearing and deaf friends and one child indicated that she felt 'deaf' when she couldn't hear and 'hearing' when she was managing well.

Although the findings are authentic in that the children's responses were gathered rather than those of their parents or teachers, the relevance of the study is limited since the children only had one cochlear implant (whereas currently children are offered two implants). In addition, only the oldest child in the group was able to comment about her identity. Other studies have explored the experiences of parents who have a child with a cochlear implant and through doing so have highlighted some aspects of the child's experience. For example, Archbold et al (2002) carried out a qualitative study to identify key themes that reflected parents' experiences three years since their child received a cochlear implant. The parents felt that their child had increased in confidence and communication abilities since implantation.

2.9 The views of teenagers with cochlear implants

Only three studies have been found that have sought the views of teenagers in order to hear about the impact of having a cochlear implant on their life. Wheeler et al (2007) interviewed 29 teenagers aged 13-17 years who were involved in two cochlear implant programmes in the UK and who wore one cochlear implant. Experienced Teachers of the Deaf carried out semi-structured interviews in the teenagers homes in their preferred communication mode, to explore more deeply the issues of importance to them. Some participants struggled to understand the wording of some of the prompts such as 'do you see yourself as deaf or hearing?' which may have limited their responses. The teenagers were interviewed about six broad areas which were 'deafness and your implant', 'other people', 'your family', 'school/changing schools', 'friends' and 'deafness and other issues'. Although pilot interviews were held with three teenagers to check that the questions were clear, no teenagers were consulted about the content of the questions or to explore whether other relevant areas had been omitted.

The main themes that were developed were making the decision to have the device, communication, identity, using the technology (advantages, disadvantages and

understanding of the technology), education and advice to those considering implantation. The teenagers reported good usage of the cochlear implant but expressed distress and disappointment when they were unable to use the implant due to technical problems. Many cited various advantages of wearing an implant, such as easier interactions with friends and family, more awareness of sound and better speech production. They also reported a feeling of being at ease and being less embarrassed than when wearing hearing aids. The disadvantages cited included problems when playing sport, headaches and needing to have an operation. They also mentioned problems hearing in background noise or missing very quiet sounds. Others not being aware of their needs and the feeling that they depended on the implant and are anxious at the thought of something going wrong were also mentioned. It was apparent that the teenagers only had a very basic understanding of how their implant worked although the author recognised that this was not concerning since they seemed to be aware of what they needed to do if something was to go wrong. Most reported that their parents had made the decision to have an implant and that they were happy with this. When asked about preferred communication, they commented that they would use whichever mode was most appropriate to maximise their communication in a situation. Improved communication was also linked to improvements in family life.

Sequential cochlear implantation is a relatively recent practice so the views of teenagers with bilateral devices have been sought to explore whether the benefits of better hearing lead to improvements in other areas of their lives. Hilton et al (2013) explored the experiences of teenagers aged 12-18 years with sequential cochlear implants to highlight the benefits and difficulties of having two cochlear implants. The study focussed on the reasons why teenagers choose to have a second implant and the impact of a second device on their identity and psychological and social well-being. Interpretive phenomenological analysis was used to explore the experiences of 11 participants. A semi-structured interview schedule was used and was based on the literature and discussions with the researcher's supervisors, one of whom had clinical experience with cochlear implants. Advice was sought from a speech and language therapist regarding the language and content of the interview questions. Another strength of this study was that a teenager with a cochlear implant and his parents were consulted about the interview questions to ensure wording and content was appropriate, although they were not involved in the development of the interview schedule.

The main aim of the study was to explore the decision making process and their experience of living with a cochlear implant, using a phenomenological approach which emphasises how individuals make sense of their experiences. The study focussed on the teenager's identity, the challenges they faced with their implant and the impact it had on their lives. The teenagers reported that were persuaded to have a cochlear implant by the potential benefits of better hearing, despite having reservations about surgery. They reported some fear about surgery and pain and discomfort following the procedure. The teenagers felt excited about the prospect of better hearing although one was surprised about how difficult she found the adjustment process and the additional responsibility for looking after the device. They reported a range of social benefits related to being able to hear better, such as enjoying socialising more, feeling more positive about their future, more confident and feeling as though they fitted in better with their friends. The teenagers described a 'bicultural identity' which is similar to earlier studies as discussed in section 2.7.3. They also reported feelings of 'difference' and isolation in the hearing world. They felt this was because they looked different to their friends when wearing the cochlear implant.

Another qualitative study that examined the perceptions of young people with sequential cochlear implants was carried out by Mather et al (2011) and similar benefits were cited, in addition to an improved ability to localise sound. Fifteen young people aged between 10 and 18 yrs were interviewed about their decision to have a second device, the adjustment process, school, friends, expectations and advice to others. A more comprehensive schedule of questions was used than Hilton et al (2013), covering all aspects of their lives with the implant. As in Hilton et al (2013) and Wheeler et al (2007), a pilot interview was carried out to identify any necessary amendments, although it is not clear with whom. Their experiences varied but were mostly positive regarding improvements in hearing, particularly in noise and being more easily able to localise sound. A key finding of this study was the young people's struggle with rehabilitation. The teenagers indicated that it was an unexpectedly lengthy process which required support and perseverance (Mather et al, 2011). This had not previously been highlighted in the literature. Parental support and help from their cochlear implant centre were seen to be important in helping them make the transition from one to two implants.

These studies generated rich accounts of how having a cochlear implant may impact on different areas of teenagers' lives. Although generally robust research, none of the studies involved the teenagers in the research process beyond requesting them to comment on the interview schedules. This researcher-driven approach may have missed other key issues.

2.10 Conclusion

Adolescence is a time of great change, both physically and emotionally, and can present particular difficulties for teenagers who are coping with deafness and managing a cochlear implant. Teenagers with cochlear implants have a generally positive view of the device since it allows them to function better in a hearing world, even if they were deafened pre-lingually (Moog et al, 2011). However, the literature also highlights some of the challenges they may face, even for those with two cochlear implants, such as coping at school in challenging listening environments, managing the device and the restrictions it imposes on some activities (Rich et al, 2013; Wheeler et al, 2007). Difficulties adjusting to the implant and the commitment needed during rehabilitation were highlighted by Mather et al (2011). Their identity evolves throughout this transitional period and this is a complex process. It is not fixed, with the majority of adolescents feeling comfortable in both the hearing and deaf worlds which they connect with where it is advantageous to do so such as when the listening environment is not optimal (Mance and Edwards, 2012; Rich et al, 2013; Wheeler et al, 2007; Hilton et al, 2013). Despite reporting hearing difficulties at school, educational outcomes are comparable to their hearing peers and positive effects on their quality of life have also been documented (Beadle et al, 2005; Spencer et al, 2012; Rich et al, 2013). The evidence does not suggest they are experiencing particular social or emotional difficulties as a result of having the cochlear implant, which is encouraging (Leigh et al, 2009; Moog et al, 2011).

Whilst these findings increase our understanding of some of the issues of relevance, there remains a gap in the scientific knowledge. Filling this gap will increase understanding and inform professionals working with teenagers so that services can better meet the needs of this age group. Many of the studies used generic measures which may not have accurately captured the views of the adolescents which are likely to differ from adults and children. Studies that have explored experiences from the perspective of the teenagers have captured some of the issues

of importance to this group. However, the topics under investigation were largely determined by professionals, rather than allowing the young people themselves to shape the direction of enquiry. This may mean that the young person's interpretations of and feelings about the experience are not fully explored (Punch and Hyde, 2005).

Chapter 3 outlines how this study worked collaboratively with teenagers with cochlear implants throughout the research process to fully reveal their perspective. It also outlines the considerations and challenges associated with this approach.

Chapter 3 Methodology, research design and methods

3.1 Introduction

The aim of this study is to explore the experiences of teenagers who use cochlear implants, in order to understand in more depth and breadth the issues of importance to them. The literature relating to this area is sparse, with only three published studies looking at their experiences using a qualitative approach (Wheeler et al, 2007; Mather et al, 2011, Hilton et al, 2013). Although some interesting findings emerged, the studies were limited by the methodology. For example, interview questions were used that were designed by the researcher and other professionals, which may have reflected their views on what issues were important rather than those of the teenagers they were questioning. In Wheeler's study some teenagers struggled to understand the questions asked of them, and the use of closed questions may have biased their responses (Wheeler, 2007).

Therefore there remains a gap in the knowledge of how the teenagers themselves conceptualise their experiences with a cochlear implant. This study aims to explore this, using methods which allow unexpected insights to be revealed. An increased awareness of the issues teenagers face should lead to a better understanding of the teenagers' needs among professionals involved in their care. It is hoped that in addition to advancing the scientific knowledge of deafness and cochlear implants in teenagers, these findings will inform further improvements in service delivery for this age group which is growing in numbers but still not well understood. It may also be useful for teenagers considering having a cochlear implant to have access to the views of their peers, before going ahead with the operation and following implantation, to help adjust unrealistic expectations.

This chapter starts with a discussion of the qualitative approach used in this study, including the rationale for the methodology which has evolved over time. The reasons for this will be discussed. The early stages of the study involved working collaboratively with the teenagers to develop a data collection tool (a website). The particular considerations when working collaboratively with teenagers are discussed. This is followed by a justification for the use of online methods with this population and the ethical and logistical considerations when using an online data

collection tool. The first phase of the research is then described, including the three stages involved in the development work. The second phase is then outlined, including the rationale for adopting the method for data collection that was eventually used, in-depth interviews.

3.2 Research paradigm

This study is underpinned by a naturalistic, interpretivist philosophy, in that the focus is on understanding experiences through the eyes of the teenagers themselves. Interpretivism recognises that individuals construct their own understanding of the world, so there are multiple interpretations that need to be sought (Houghton et al, 2012). A qualitative design was chosen as it allowed the teenagers perspectives to be uncovered ‘in the context of their own lives’ (Holloway and Wheeler, 2013 p 25). This enabled them to conceptualise the issues individually rather than being led by the researcher’s imposed framework (Braun and Clarke, 2013). This approach was combined with a collaborative process with teenagers in the early stages of the research in order to develop a data collection tool which would enable their perspectives to come to light.

3.3 Methodological approach

As described in Chapter 2, the research in this area has tended to be limited to objective measures of performance on audiological assessments such as speech discrimination, with a much smaller number of studies taking a more holistic approach and exploring psychosocial and educational outcomes.

The literature critiqued in chapter 2 indicated that it is apparent that health and education professionals working with teenagers have limited insight into the issues they face during this time. As discussed, recent attempts to explore the views of teenagers with cochlear implants uncovered some illuminating findings regarding their experiences (Wheeler, 2007, Hilton et al, 2013; Mather et al, 2011). However, the current understanding of what it is like to be a teenager with a cochlear implant lacks breadth and depth since the methods were developed entirely by professionals. It is questionable how true a reflection of the teenagers’ voices the findings were.

To address this shortcoming, it was considered important to use an approach where the user's knowledge is emphasised and is central to the research process (Woodgate, 2001). Qualitative approaches capture the experiences of the participants and can generate rich data that are personal to the individual (Yardley and Marks, 2004). An open-ended approach can be used to allow new information which has not previously been generated to be revealed (Knudsen et al, 2012). In addition, qualitative methods more easily lend themselves to teenagers' collaboration in the research. This can result in a number of benefits, including identifying issues and questions that professionals may have missed or not recognise the importance of, maximising the chances of research tools being accessible to their peers, and helping the researcher to stay focussed on the young people's perspectives throughout the process (Kirby, 2004).

The first phase of this qualitative study involved the development of a novel data collection tool that would capture the views of the teenagers in as meaningful a way as possible. In order to achieve this, a collaborative approach was used. Working together with young people has been shown to be successful in healthcare projects where the individuals may be difficult to work with and it can be inherently motivating for them (Veale, 2005). Following some difficulties in maintaining a joint research approach and unsuccessful engagement of the teenagers during the first phase, the second phase of the study used in-depth interviews in order to hear the views of the teenagers about living with a cochlear implant.

Semi-structured interviewing was chosen as an appropriate way to access the teenagers' perspectives and to try to understand them. Interviews can uncover issues that may have previously been deemed irrelevant and give context to the participants' experiences, using broad questions with probes such as 'can you tell me more about that?' to encourage further elaboration (Wilkinson et al, 2004). Section 3.7.1 discusses the rationale for choosing semi-structured interviews over possible alternative methods in more detail.

3.4 Involving teenagers in research

There is a growing recognition that involving teenagers in research can lead to higher quality and more valuable data (France, 2004; Cooper-Robbins et al, 2011). For example, the validity of the findings can be enhanced as a result of accessing issues most relevant to teenagers, through researchers staying aware of their

perspectives during the research process (Shaw et al, 2011). Credibility can also be enhanced for other teenagers through devising appropriate tools for data collection using language understood by their peers (Shaw et al, 2011). Their involvement can also increase the recruitment of participants, with young researchers being better placed to contact their peers than the researcher in most instances (Kirby, 1999). As a result, a number of voluntary sector organisations such as Save the Children and INVOLVE have produced 'good practice' guidelines for researchers using a participatory approach with this age group (Kirby, 2004). There are also a number of benefits for the teenagers involved in the research beyond their contribution to the research process itself. These include personal development (such as increased confidence and self-esteem), meeting new people (including peers and professionals), enhancing their CVs and the opportunity to learn about research processes and acquiring a range of skills that may benefit them in future careers (Kirby, 2004).

Working collaboratively with teenagers gives rise to costs and benefits; these are discussed in the following section.

3.4.1 The benefits and costs of collaborative research with teenagers

Working collaboratively with teenagers can benefit both the individual and the research itself. However, the costs to the teenager need to be carefully considered before deciding to use this approach.

As discussed, young people can enhance the relevance and focus of the research, due to the perspective they will have on a particular issue (McLaughlin, 2006). Other benefits of involving young people in research include increased recruitment, particularly if this involves the participants' peers and improvements in the quality and robustness of the data (Kirby, 2004). Their involvement increases the likelihood that the study will be ethically sound and outcome measures will be appropriate and meaningful (Kirby, 2004).

In addition, there are benefits for the participants that include new skills and knowledge (regarding the research process and the area under investigation), personal development (e.g. increased self-esteem and confidence), forming friendships and gaining support from peers, enjoyment and satisfaction from taking

part in a meaningful activity (McLaughlin, 2006; Kirby, 2004). McLaughlin (2006) also reported that the adult researcher may learn new skills from working with young people who can bring energy and enthusiasm to a project.

The disadvantages of being involved in a study are much less widely reported in the literature, but for the young person these can include feeling overburdened with work, with inadequate support (McLaughlin, 2006). For the adult researcher, challenges can arise around recruiting the young people, their enthusiasm for participating in some elements of the research process being less than for others, (for example, checking data analysis), with the consequence of some stages taking longer than others (McLaughlin, 2006).

There are a number of factors to consider when planning to involve teenagers in research, from how much involvement it is reasonable to expect to safety and ethical issues.

3.4.2 Recruitment and involvement

Recruitment and retention of participants can be difficult, especially when the young people are in a transient phase of their lives, so commitment to a long term project may be problematic. France (2004) recommended recruiting from already established groups, where relationships with the young people may be already sound. Involving the young people from as early a stage as possible is also recommended, as it may foster greater commitment and enthusiasm (Petrie et al, 2006).

Determining how to involve young people in the research, and the level of that involvement requires careful consideration. In order to avoid power imbalances between the researcher and the young people, it is considered important to motivate the young people by involving them in all aspects of the research process from an early stage (Kirby, 2004). However, in practice this can be difficult due to time limitations and lack of resources.

Bostock and Freeman (2003) identified a number of 'barriers to participation' in their study, which included the geographical constraints which hindered collaborative working and a constantly changing group of participants. These

barriers are likely to apply to the current study. However Bostock and Freeman (2003) considered that in spite of such limitations, with careful planning it is still possible to work successfully with young people which results in a positive experience.

3.4.3 Ethical issues

There are several important ethical issues to take into account when working with teenagers. Acquiring 'informed consent' from young people can be challenging since it must be relevant and understood by the young person (Shaw et al, 2011). Detailed information should be given in advance regarding the aims of the research and its contribution to knowledge, the rights of the young people, that they are free to withdraw at any time from the process, and details of the research team and how to contact them (Alderson and Morrow, 2011). In addition, young people should be informed about how to complain about their experience and how the confidentiality and storage of data will be managed (France, 2004). The teenagers in this study were reassured of the confidentiality of the data before the start of the interview, in order to put them at ease and allow them to express their thoughts openly. A continual review of consent during the research is considered good practice to ensure that the participants are happy to continue at each stage of the process, as is emphasising their right to withdraw at any point. This may include declining to answer a question or withdrawing completely from the study. It is also important to consider that the language used by adults, particularly in a research context, may not be appropriate to a young person's level of understanding. This should be reflected in the information provided and when obtaining consent (Hill, 2005).

Parental consent needs to be sought for young people under 16 years of age, in addition to obtaining the young persons' consent (Alderson and Morrow, 2011). In this study, parents of young people aged over 16 were also informed that their child was being contacted by letter since parents would probably be required to bring their child to an interview so their agreement was necessary. The letter encouraged the young person to discuss their participation in the study with their parents, although they were not required to give consent as such. The researcher was also careful to confirm with the teenager at the start of the interview that they were happy to take part (Shaw et al, 2011).

3.4.4 Ensuring safety

It is also important to consider how best to protect the teenagers from any potential harm that might occur. The types of venues and places they are invited to need consideration to ensure their safety to and from the location. In this study, parents were invited to stay in the interview room at the request of the cochlear implant centre, for the protection of both the researcher and teenager (Shaw et al, 2011). There is also a need to consider any risk to their emotional well-being so it is sensible to consider what they are being asked to do and to identify any potential areas for this. The teenagers in this study were advised to contact their clinician or speak to their parents in case of issues arising from the interview that could not be addressed by the researcher.

In addition, France (2004) suggested informing the young people from the start of the process that if they disclose information such as abuse then there is a responsibility on the part of the researcher to pass this information on to the relevant authorities.

3.4.5 Ethical approval

Ethical approval was granted from the National Research Ethics Committee (South Central) (reference number 10/HO501/28). An amendment was subsequently approved following the decision to abandon the website and interview the teenagers instead. Additional approval was granted from the University of Southampton Institute of Vibration Research Human Experimentation Safety and Ethics Committee, at the request of the cochlear implant centre where the interviews were carried out. A risk assessment was also carried out. A research committee at the school for deaf children granted permission to carry out interviews on site under supervision.

3.5 Online data collection

3.5.1 Justification for use of online methods

Internet use among hearing impaired teenagers has been shown to be more prolific than compared to their hearing peers, with more use of personal and group communication tools (Barak and Sadovsky, 2008). This was irrespective of age or

gender. There is also a suggestion in the literature that hearing impaired teenagers experience a sense of personal empowerment through using the internet, as a result of the anonymity it provides and because it is text based, so the hearing status and usual communication mode of the user is irrelevant (Barak and Sadovsky, 2008).

Online methods have been successfully used to explore the experiences of teenagers in relation to a wide variety of health conditions and relationship issues (e.g. Suzuki and Calzo, 2004; Fox et al, 2007). Online peer discussions have generated responses which were rich in personal opinions, advice and accounts of their own experiences. This may be attributable to the high degree of anonymity that exists in a non-threatening environment which can encourage honest communication and empathy with peers. Suzuki and Beale (2006) noted that teenagers who had created their own webpages were comfortable discussing personal experiences openly via diary entries, personal essays or even poetry. Information sharing was also popular, although to a lesser degree. The authors noticed that the sites were providing important information and emotional support for individuals (Suzuki and Beale, 2006). Similarly, Valaitis and Sword (2005) found that a website originally set up to gather the views of pregnant and parenting teens evolved into a support tool for the young people, who reported that they felt less isolated and had more friends as a result of using it. Although there are many benefits to the researcher and teenager in using an online tool to record experiences, limitations of this approach include needing to clarify with the teenagers the purpose of the study so that the relevant issues are discussed and the risk of teenagers censoring their comments to avoid sharing any socially unacceptable views with other users (Valaitis and Sword, 2005).

There are examples in the literature of online groups for hearing impaired - adults and teenagers, which have been shown to offer valuable emotional and informational support, and a means to try out and confirm beliefs about sensitive issues with like-minded individuals (Dunham et al, 1998, Cummings et al, 2002). Peer support may also emerge as a result of the discussions where participants share similar experiences and as a result a group identity may form (Fox et al, 2007; Flicker et al, 2004). Dunham et al (1998) also found that levels of stress were reduced in teenage mothers who used a website to share their experiences.

3.5.2 Methodological considerations in online research of relevance to this study

A number of additional methodological considerations informed the design of this study. These included the decision to use asynchronous communication (a discussion board) since the timing of responses was not crucial and a more considered response could be given (Brownlow and O'Dell, 2002). A targeted approach to recruitment was chosen, whereby specific groups were made aware of the research and encouraged to participate. The response rate was maximised in this study by presenting a well-designed website, with good transferability between web browsers (Whitehead, 2007).

Contacting participants and establishing good relations with them can be more difficult when researching online compared to face-to-face interactions. Allowing sufficient time in the early stages of the study to build relationships with the website users to encourage participation is key (Mann and Stewart, 2000). Having met several of the teenagers in the development phase of the study it was anticipated that this would encourage them to participate and to invite others to do so.

Internet research presents the researcher with a number of ethical dilemmas, in addition to those encountered when using more conventional methods. Consent and issues around ensuring participants are not exposed to risk or harm from other participants are key considerations (Flicker et al, 2004). Consent in this study was obtained by asking participants to e-mail a consent form to the researcher. Although a written signature is not provided, consent can still be considered to have been given since the act of completing the form and sending it is sufficient (Whitehead, 2007). In order to ensure fully informed consent, the website associated included the researchers work contact details (Whitehead, 2007). Regular emails reminding users to visit the website were sent to encourage participation.

Ensuring participants are not exposed to undue risk or harm was achieved by regular monitoring of the website by the researcher for inappropriate contributions. To ensure confidentiality the website was password protected and information from the web server was printed and kept in a locked research office. Ground rules for using the website were established in phase 1 of the study as these can also remind

users to respect the confidentiality of other users' responses (Whitehead, 2007). To maximise the chances that participants were genuine, four questions about their cochlear implant were emailed to them. Although it was not possible to check their responses with the information held by their cochlear implant centre they were questions that an imposter would be very unlikely to answer accurately

Involving hearing impaired teenagers in web-based activities requires some consideration of their ability to use online resources. Smith (2006) identified a number of difficulties encountered by deaf teenagers when searching online which are of relevance to this study. These included difficulties navigating complex text, a preference for information represented graphically rather than textually and problems locating information which required using a hypertext link (i.e. a link embedded within text or an image). These findings reflect the comments received from the teenagers consulted during phase 1 of this study where they expressed a preference for a website with very little text and lots of pictures, and one which was simple to navigate.

3.6 Phases of the research study

The study was divided into two phases (Figure 2). Phase 1 was informed by the principles of collaborative research and consisted of three stages which involved work to develop a suitable online tool for data collection. In Phase 2, an alternative data collection method was adopted. A discussion of the reasons for changing the approach is given in section 3.7.1. In phase 2, semi-structured interviews were carried out and the findings were validated by a small group of teenagers.

Phase 1: Development of a website

Stage 1

Questionnaire to gather views of teenagers with cochlear implants about designing a website for teenagers with cochlear implants to share their experiences

Stage 2

Part i) Meeting with three teenagers to design the website

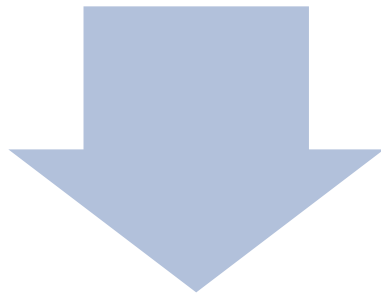
Part ii) Work with website designer to produce website

Part iii) Meeting with two of the teenagers involved part i) to check website prior to launch

Stage 3

i) Launch of the website

ii) Skype meeting with three teenagers to give feedback on the website



Phase 2: Individual interviews

Part i) Semi-structured interviews with 10 teenagers

Part ii) Template analysis of 9 transcripts and validation of findings with three teenagers

Figure 2. Phases and stages of the study.

3.7 Phase 1: Development of a website

The aim of this phase was to develop a novel, online tool to record the experiences of teenagers with cochlear implants. The work took place intermittently over several months, starting in February 2009 and was carried out over a series of three stages. Stage 1 involved sending a questionnaire to a large group of teenagers with cochlear implants at a school for deaf children and a cochlear implant centre, both in the south of England. This allowed me to gauge their views of a website designed to record teenagers' views on their cochlear implant and how they thought it should look. Secondly, it allowed me to make contact with a large number of teenagers with cochlear implants so that I could identify those who might be willing to work with me later in the study. Stage 2 involved a meeting with teenagers at the school to refine ideas for the website which would be used to write a website design specification document. A website designer developed the website based on the specification and the website was checked prior to its launch by two of the teenagers who participated in the initial design meeting. In stage 3 the website was launched and a Skype meeting was held with three teenagers so that they could give their feedback on the website.

The three stages of phase 1 are outlined below in more detail.

i) Stage 1

A website development questionnaire was sent to 50 teenagers aged 13-19 years with at least one cochlear implant at a school for deaf children and 60 teenagers of the same age with at least one cochlear implant who attended the cochlear implant centre. The school for deaf children accepts pupils aged 5-19 years from all over the UK. It advocates an auditory- oral approach to communication to enable students to more easily integrate into wider society upon leaving the school.

The aim of stage 1 was to gather the views of a large number of teenagers regarding the design and content of a website which would allow them to talk to one another about what it is like to have a cochlear implant. A short questionnaire was considered the most appropriate method to use since it would be easy to administer and quick to complete (Appendix 2). A group meeting was considered, however it proved difficult to organise a time and location for a large number who lived across a wide geographical area. Involving potential users this early in the

development of a web site can lead to better website accessibility for future users and can be a more efficient way of developing a website that will work for the teenagers (Caldwell et al, 2008).

The questionnaire comprised five open-ended questions which asked the teenagers to suggest ideas for the content and design of the website. It also asked how they would feel about talking to others about their experiences as a cochlear implant user, to assess whether talking to others online about their experiences appealed to them. It also gave them the opportunity to add suggestions to make the website more appealing. Finally they could enter their name if they felt they would be interested in getting involved in a group meeting to decide on the design of the website. The information collected from this stage was to inform stage 2, a group meeting, where the design of the website would be finalised.

The questionnaires were given to teenagers at the school to complete by their form tutor before the start of a lesson. The questionnaires for the teenagers at the cochlear implant centre were posted to their homes, with a letter also sent to their parents to inform them that their child had been contacted. A self-addressed envelope was included in the mailing to encourage return of the questionnaires. The questionnaires were anonymous and no demographic information about the respondents was recorded.

All of the questionnaires were returned from the school. This was expected since the teenagers were asked to complete the questionnaires at the start of lessons, supervised by their teacher. None of the questionnaires sent to teenagers from the cochlear implant centre were returned, possibly because I was not known to them and they did not feel motivated to participate. With hindsight, a higher return rate may have been achieved by distributing the questionnaires in person during a teenagers' group meeting at the cochlear implant centre, perhaps with the support of a clinician known to the young people. This approach was considered but during the time over which this stage of the research ran meetings were not arranged or were cancelled at short notice. Nevertheless, a broad range of views were collected.

Although only the views of teenagers at one school for deaf children in the south of England were sought, the pupils originated from different parts of the UK and attended different cochlear implant centres. In order to ensure the views of the

teenagers in mainstream education were included in the development of the website, I encouraged all users to give their comments about the usability of the website once it became active.

Eighteen teenagers from the school indicated that they would like to attend the meeting in stage 2.

ii) Stage 2

A meeting was organised to refine the ideas collated from the questionnaires, in order for the researcher to put together a website specification document for the web developer. During July 2011 the researcher met with three teenagers from the school who had indicated on the questionnaire that they would be interested in being involved in the study. An information sheet outlining the purpose of the meeting and a consent form were sent to the teenagers at school and to their parents, where appropriate. Although the principal aim of this meeting was to gather ideas for a website design specification document, a secondary aim was to start to engage the teenagers in the project so that they might participate in the subsequent stages of the project. The meeting lasted 30 minutes and was arranged during a lunchtime break at the school. A member of school staff was also present but was briefed beforehand so that she had no direct involvement in the meeting.

The teenagers were 1 female (14 years) and 2 males (both 15 years), each wearing one cochlear implant. They were asked to consider two websites currently aimed at teenagers with cochlear implants (<http://youngpeople.ndcsbuzz.org.uk/>; <http://soundingboard.earfoundation.org.uk/teens/>), to stimulate some discussion and act as an ice-breaker. Their comments highlighted the general issues that individuals face when using a website, such as ease of navigation and text size. The teenagers were then asked to consider the design of this study's website including the home page, chat/discussion pages and information pages. They worked enthusiastically together for about 30 minutes and a variety of ideas were noted, with some facilitation by the researcher.

I adopted an observer role during this meeting, as did the member of staff who was chaperoning the teenagers. Prompts were used to further the discussion, where necessary. The teenagers were keen that the website should be somewhere for

young people to have fun as well as contribute to a research study. They also suggested ways to advertise the website, including via an article in the National Deaf Children's Society (NDCS) newsletter and posters around school. The teenagers worked well together, and this was also noted by the member of staff present. This was a very productive session which also helped me to start to build a relationship with the teenagers who were enthusiastic about their future involvement in the study.

The responses from the questionnaire and suggestions from the meeting are now discussed. The ways in which they informed the development of the website are also highlighted.

Questionnaire results

The questionnaire data revealed that there was a preference for a colourful, easy to navigate website and for being able to talk to other website users through chat rooms or blogging. They were generally positive about blogging, and one respondent even felt it could help others make their decision on whether or not to have a cochlear implant. They felt it would be a good source of information about the emotional impact of having an implant and how it might affect day to day life. It was generally thought to be a good way of sharing experiences.

The questionnaire indicated several areas which the teenagers thought should feature on the website. There were a number of requests for information about the implant, and particularly information that was accessible to them such as in a visual format (e.g. 'video of how they do it', 'good drawing of CI'). There were also requests for the information to be easy to understand (e.g. 'without the jargon', 'how the cochlear works but as simple as possible'). These comments would suggest there is a desire among the teenagers to increase their knowledge of cochlear implants and the surgical procedure via a range of different mediums.

Information about new technology and research related to cochlear implants was also requested, suggesting that some were looking ahead to the future and wanting to maximise the potential of their implant. When asked 'What sort of other things would you like to be able to do on the website?' accessing information about their cochlear implant and games or quizzes were the most frequently cited ideas.

Hearing about others personal stories was also frequently mentioned. The teenagers wanted to connect with others like them, to share experiences and ask for advice from others in the same situation, indicating a preference for interaction with their peers. Comments such as ‘people’s stories about how they begin and how they feel about it’, ‘people can reply with stories of their own’, ‘help other people decide if CI is useful’ indicate a preference for this to be an interactive experience where information is exchanged between peers. However, there were also requests to be able to contact manufacturers and a ‘chance to talk to the experts’, suggesting a desire to learn more than is currently available to them. Access to the latest research also interested them.

Another popular request was the desire to troubleshoot problems they were experiencing with their implants, through a ‘Q&A’ section and chat forum. As with information seeking, there were requests for two distinct sources of information; from their peers and from professionals; indicating that these teenagers value both. There were several requests for an area on the website where solutions to common problems with their implant could be found, and in one case this extended to difficulties one might encounter through being deaf.

Results from the meeting

A number of references to deafness were made when the teenagers were prompted to discuss what content they would like on the website. For example, ‘news – generally about deafness’, ‘Defness (sic) in art’ were suggested. ‘I’m all ears’ was suggested as the name of the website which they agreed on. When prompted to think about what topics other teenagers could talk about on the website, ‘deafness’ was listed first. Help and advice was also mentioned, and the use of equipment ‘associating (sic) with deafness’. However, other more generic topics were also included such as film reviews (subtitled films), video games, general chat, hobbies and suggestions for improving the website; highlighting the importance of focussing on other aspects of their lives, apart from their deafness. The teenagers wanted to keep things simple, with requests for ‘simple clothes (sic)’. There was also a request for information from peers with a suggestion that website users could blog about their life and how they coped with their cochlear implant.

In part ii) the researcher worked with a website developer to design the website. In addition to the comments from the teenagers, the Web Content Accessibility Guidelines (WCAG, 2.0) were consulted in order to ensure the content of the website was as accessible as possible to the teenagers, some of whom may have sight difficulties(for example by using adequate line spacing in the text) (Caldwell et al, 2008). A second meeting was held in January 2012 (part iii) in order for the same teenagers that had met in Stage 1 to give feedback on the website, prior to its' launch. Two of the three teenagers who attended the meeting in part i) were present (one female 14 yrs, one male 15 yrs). They were asked to think about how to best promote the site to other teenagers, in addition to their thoughts on the look and content of the website. They were chaperoned by the same member of school staff who was involved in the first meeting.

A number of constructive comments emerged from the meeting. The website was generally well received by both of the teenagers; although one felt the text could be bigger. They were asked to consider the 'threads' (topic areas) on the discussion board and to suggest any other areas of relevance to their experiences with their cochlear implants. There were requests for a page where teenagers could discuss their favourite music and recommend albums. They discussed adding some games to the site and adventure and role playing games were favoured. The teenagers were emailed once the website went live to check if they were happy with the final design, however no responses were received. This was disappointing as it was not possible to return to meet with them again due to their school commitments.

iii) Stage 3

The website (www.imallears.org) was launched in March 2012. It comprised several areas, with the aim of it being as interactive as possible. The home page consisted of a welcome message, with instructions on how to register to use the website. In order to register the teenager needed to email the researcher to request a consent form, complete a demographic questionnaire (Appendix 3) and answer the following questions relating to their cochlear implant, to ensure that they were genuine:

- What is the make of your cochlear implant?
- What is the serial number on the processor?
- Which processing strategy do you use?

- If you use a radio aid, what type of lead do you use to connect it to your processor?

Although a more laborious process than might be experienced on other websites, these steps were considered necessary in order to ensure the safety of the teenagers using the website. On receipt of these documents the researcher emailed a unique username and password to the teenager. Once registered, the teenager could view the other pages of the website which included the ground rules, a page to write a blog about their experiences, a wiki page (entitled 'My cochlear implant'), to contribute to information about how a cochlear implant works, 'new stuff' where information about upcoming events were posted and a games page.

There was also a discussion board which comprised eight 'threads'. These were based on the themes that had been identified in the literature (e.g. Wheeler et al, 2007, Mather et al, 2011) and on the discussions that had taken place between the researcher and the teenagers involved in the early stages of the research, in particular the meetings in phase 2. For example, a thread about their experience of surgery was included as some teenagers had mentioned wanting more information about cochlear implant surgery. This suggested this aspect was important to them. The topics were deliberately broad in order to allow for a wide ranging discussion. They included: 'life before my cochlear implant', 'the decision to have a cochlear implant', 'the operation', 'life with my cochlear implant', 'friends and family', 'school/college/work', 'advice to others thinking about having a cochlear implant', 'my hopes for the future', 'other stuff - whatever you want to talk about!'. Screenshots of the home page, discussion board and games page are shown in Figures 3-5.



Figure 3. 'I'm all ears' home page.



Figure 4. 'I'm all ears' discussion board.

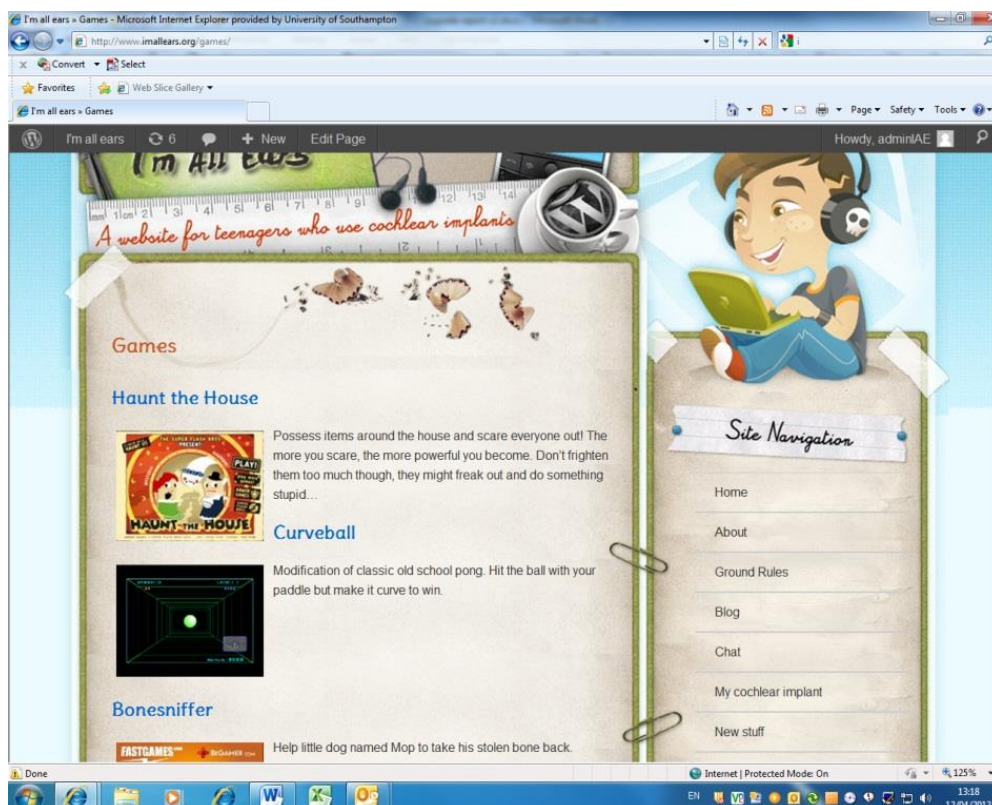


Figure 5. 'I'm all ears' games page.

As suggested by the teenagers involved in stage 2, the website was publicised at the British Cochlear Implant Group Conference, through fliers, and also on websites that teenagers with cochlear implants might visit. These included 'Buzz', the website of the National Deaf Children's Society, 'Sounding Board', the online newsletter of the Ear Foundation; 'I want to hear', the website of the implant manufacturer Cochlear and the website of a cochlear implant centre in the south of England. In addition, fliers and posters were sent to all UK cochlear implant centres to display in their waiting areas.

Initially there was great interest in the website from the teenagers and the professionals working with them. However, registration on the website was slower than anticipated. Over the course of five months, 16 teenagers emailed the researcher to request log in details; however only seven completed the necessary steps to be able to register. Although it was anticipated that asking for these documents to be emailed back to the researcher would encourage a good return rate, this proved not to be the case. Despite a number of email reminders, very few teenagers completed the required paperwork hence the low number of users.

Following this disappointing start a Skype meeting using instant messaging was held with three teenagers who had registered to use the website. The teenagers who had attended the earlier meetings were no longer available to continue with the study. The aim of the meeting was to evaluate the website, focussing on how effective they perceived it to be and ways in which it could be improved to attract more teenagers to register. As a result of this meeting it was decided to introduce SMS (short message service) on to the website to hopefully attract more users and to enable the researcher to interview teenagers on line if necessary. One of the teenagers present at the Skype meeting was keen to help the study progress as she felt it was important that teenagers engaged with the website to meet others who had implants. For example she felt an online focus group, using SMS, would appeal. All users of the website were emailed to invite them to participate in an online focus group but unfortunately there were no replies so this idea was abandoned.

Of the seven users that registered, two were initially quite active on the site. Between them they posted 13 comments on the discussion board. These are discussed in Chapter 4, section 4.2. The blog and wiki were never populated, despite email encouragement. No other comments were received from the remaining five users, despite encouragement to do so via email.

3.7.1 The use of an alternative method of data collection

The recruitment of new users eventually stopped altogether, with very few contributions to the website. In addition, the collaborative relationship with the teenagers who had been involved in previous stages of the research broke down, despite numerous emails. This was probably due to their other commitments and the length of time it had taken to develop the website. The most likely reason for the low number of teenagers registering to use the website is the registration process, which was cumbersome and time consuming for the teenagers to complete. More e-mail prompts may have helped maintain momentum, since several teenagers signed up to use the website but did not participate. Mason and Ide (2014) were successful in interviewing teenagers online in two weeks, with an email reminder every 72 hours. A reminder email was sent to the teenagers in this study on two occasions, but over a much longer period of time which may have been a factor in the high attrition rate. Another possible reason for the teenagers' lack of engagement may have been my communication style. Mason and Ide (2014) found that changing her communication style and email structure resulted in a better

response from the teenagers she was interviewing. For example, a more relaxed tone was adopted, with shorter more conversational like paragraphs. The teenagers felt as a result that she was more approachable and were more willing to engage in the project.

For these reasons, I reconsidered the use of an online tool. In order to gather the necessary data in the time remaining, semi-structured interviews were instead chosen as the most appropriate method to use.

Semi-structured interviews were used in phase 2 because they allowed the teenagers to tell their own stories, using broad topic guides rather than pre-defined questions (Knudsen et al, 2012). This allows the participant to explore ideas on their own terms, making connections and introducing other topics which may be new to the researcher. The flexible nature of the interview guide facilitates the researcher being able to explore in more depth the themes that have emerged (Heath et al, 2009). Another advantage of this method is that it allows the researcher to compare across individuals, since every participant is asked the same question (Braun and Clarke, 2013). In addition, the interviews were relatively straightforward to arrange in a short time period and had been successfully used with teenagers with cochlear implants in previous research (eg. Wheeler et al, 2007, Mather et al, 2011).

Focus groups were considered since they offer some benefits when interviewing teenagers, which may be valuable. For example, a group setting may overcome the issue of the teenager responding in a way they believe will please the interviewer when being interviewed by an adult (Gibson, 2007). In addition, being in a focus group removes the pressure to speak if the question is not understood (Gibson, 2007). Despite these advantages, the data generated by focus groups is a product of group interaction. The aim of this study was to capture each individual's 'reality', to achieve a deep understanding of their worlds (Houghton et al, 2012). For this reason a focus group was not considered to be appropriate since individual stories can be lost in group discussion (Braun and Clarke, 2013). The communication abilities of the teenagers who participated in this study varied widely so it was unlikely to be practical to involve them all in a group situation. In addition, there may be sensitive issues that they are not prepared to share with the group. There were other barriers to using this approach. For example it is recommended that the age range of the group should be no more than one to two years and that same sex

groups work better in general in terms of productivity. Scheduling such groups involving teenagers who attend school and mostly live some distance away was considered impractical (Gibson, 2007).

3.8 Phase 2: Interviews

3.8.1 Considerations when interviewing teenagers

Several methodological issues were considered before the interviews started, since interviewing teenagers can be challenging and safety and ethical issues require particularly careful thought (Moolchan and Mermelstein 2002; Shaw et al, 2011). Recruitment can be difficult since parental consent is required if the young person is under 16 years of age. Parents will need some reassurance as to the worth of the research (Shaw et al, 2011). Trust is therefore required between the researcher and the family (Bassett et al, 2008). This can be achieved by formal communications, such as sending letters or emails, when requesting their involvement. This was the approach used in this study as it was familiar to the parents and teenagers who are often approached for research purposes by the cochlear implant centre.

The interview process itself also required careful planning. The presence of the tape recorder can, in some instances, 'formalise' the interaction between the researcher and the teenager. If this is a concern it can be helpful to minimise the conspicuousness of it and to make an effort to create a relaxed atmosphere (Bassett et al, 2008). Using appropriate body language, self-disclosure and informal language can also help to put the teenager at ease. Finding an appropriate interview space was important. A location that was private but yet visible to others for reasons of safety was required for this study. Ideally this would be a space chosen by the teenager that is neutral and risk free, so as to minimise any 'power imbalance' between the researcher and participant and to avoid the young person feeling uncomfortable (Heath et al, 2009). For practical reasons the interviews were conducted in a meeting room at the cochlear implant centre or in the Audiology clinic room at the school for deaf children. This location may have also influenced their willingness to speak openly. It was a requirement of the ethical approval from the researchers' University that a member of staff also be present, which further limited the choice of venue. Skype interviews were conducted with teenagers who were unable to visit the cochlear implant centre. The drawbacks of this approach include difficulty reading the non-verbal cues that are available in a face to face

interview which can lead to difficulties establishing a good rapport; however this was a good solution to reach those unable to travel (Whitehead, 2007).

Another consideration was whether to allow parents and staff to be present during the interview. A condition of the ethical approval granted for this study by the cochlear implant centre and school that hosted the interviews was that a member of staff was present at all times. The member of staff was known to the teenagers being interviewed so she was carefully briefed beforehand to minimise the influence of her presence in the room which may have inhibited their responses. It was also a requirement of the cochlear implant centre where the interviews were held that a parent be present during the interview. This may have resulted in the teenagers not giving as full or detailed answers as they may otherwise have done, since confidentiality was compromised (Bassett, 2008; McDonagh and Bateman 2012). However the teenagers were asked to imagine their parent was not present during the interview and to speak as openly as possible about their experiences. Other attempts were made to minimise any influence the parent might have on the responses of the teenager. For example, the parent and staff member were briefed before the start of the interview and they were seated out of view of the teenager during interview. In addition, the staff member was asked to leave the room when questions regarding the teenagers' experience of service provision were asked. The teenagers were also reassured at the start of the interview that their responses would in no way affect their care, wherever that was delivered.

Encouraging the teenagers to engage with the interview can present the biggest challenge. Bassett (2008) observed that the interviewer may resort to asking questions which only require one word answers if the teenager is reluctant to engage in conversation. One approach is to establish good rapport before the start of the interview, for example by asking about their interests and disclosing information about oneself. Mack et al (2009) stressed the importance of devising interview questions where the meaning is clear to the teenager and there is the degree of detail that is required by the interviewer. It is necessary to consider the teenagers cognitive abilities when devising interview questions since adolescence is a time when the ability to respond to open ended questions can be challenging if the teenager is not able to think abstractly and about possibilities ('formal operational stage of thinking'), rather than just seeing the world according to the here and now and how they physically perceive it ('concrete operational stage of thinking'). Re-phrasing the question should determine whether the teenager who

gives a brief answer to a question is nervous and needs more time to consider their answer, or whether they have not yet reached the required level of cognitive development. Detailed prompts, using concrete terms and more specific questioning were used in this study to help the teenager who is struggling to give a fuller response (Mack et al, 2009). For example, if a teenager replied to the question 'tell me about your life before the cochlear implant' with 'I don't know', a more focussed and specific question was used to help elicit a more substantial response, for example 'how is your life at school and at home?'.

I am an adult researcher working at a University, with which the cochlear implant centre is associated. This put me in a position of power which may have negatively influenced the teenager's responses (Braun and Clarke, 2013). In order to minimise the teenager's perception of the researcher's power, an effort was made to create a relaxed environment, for example by having a brief chat about their journey to the interview (Shaw et al, 2011). They were also reminded that all of their responses were valuable and there were no right or wrong answers. I tried to manage the situation by setting the room up to reflect equal status. I dressed informally and used only my first name. I also reassured them that I was separate from the cochlear implant centre or school and reminded them that their responses would be anonymised. I have professional experience with young people with deafness which enabled me to be sensitive to their communication needs. This also helped to build a rapport and put them at ease.

3.8.2 Recruitment

The parents of every teenager between the age of 13 and 19 years of age who attended the cochlear implant centre were emailed by a member of staff at the cochlear implant centre to ask if they would consider allowing their child to be interviewed about their experiences of having a cochlear implant. Sixty parents were contacted and seven agreed to bring their child for interview. They were emailed the appropriate consent form and an information sheet about the interview. The teenagers were also asked to complete a demographic questionnaire when they attended the interview (Appendix 3). Six interviews (S1, S2, S3, S4, S5, S6) were carried out at the cochlear implant centre, four on a Saturday morning and two immediately before an appointment at the centre, since these were the most convenient times for them to attend. The interviews were carried out in a clinic room with a member of staff from the cochlear implant centre and the parent of the

teenager. Two of the interviews (S3, S4) were carried out via Skype because the teenager lived too far away to travel to the cochlear implant centre. The same member of staff was also present.

The remaining four interviews (S7, S8, S9, S10) were held at a school for deaf children at the end of the school day. Ten teenagers were approached by a member of Audiology staff at the school to ask if they would like to participate, including those that participated in phase 1. This was the preferred method of recruitment of the school and the member of staff was carefully briefed to avoid the pupils feeling coerced. None of those who had attended the meetings in phase 1 agreed to be interviewed. The reasons for this are not known. During the interviews at the school a member of Audiology staff was present in an adjoining room.

Ten interviews were considered sufficient as this number generated very rich data. This number of interviews was considered large enough to demonstrate patterns across the data but was also small enough to allow deep analysis of the data in the time available and to retain the focus on the individual experiences (Braun and Clarke, 2013).

3.8.3 Phase 2: Individual interviews

Stage i) Interviews

Each interview was scheduled for one hour. The interview schedule comprised 15 questions (Appendix 4). The interview guide was informed by different sources in order to ensure that the questions were comprehensive enough and remained true to the research question. The sources used were key research papers (Wheeler, 2007; Mather et al, 2011), contributions to the website and comments received during the development of the website (as described in sections 3.7 and 4.2.1). Open questions were used to allow the teenagers to give as full an answer as they wished and follow-up questions such as ‘could you tell me more about that?’ or ‘why do you say that?’ were used to extend the interviewees answer to a previous question.

The interviews were recorded on a digital audio recorder. The recordings were transcribed as soon after the interview as was practically possible. This allowed for the addition of questions to the schedule as a result of a new idea being introduced by the interviewee. For example, a question about how well prepared they felt

before the operation was included in later interviews as several teenagers spoke about not knowing what to expect. The researcher attempted to standardise the language used during the interviews but some rephrasing was sometimes necessary in order for the interviewee to fully understand the question.

King (2004) commented that it is important for the researcher to be reflexive in their practice when interviewing and to consider the nature of your involvement in the interview process. With this in mind, I noted any preconceptions before starting the interview and briefly reflected on the experience at the end of each interview.

Part ii): Template analysis of transcripts and validation of findings

The recorded interviews were transcribed verbatim since this approach requires immersing oneself in the data and as a result becoming more aware of the issues of importance (Holloway and Wheeler, 2010). Transcribing the interviews by hand was also beneficial as it resulted in familiarisation with the data which was helpful for coding and interpreting patterns across the data. Transcribing was done as soon after the interview as possible, to minimise the risk of recording mistaken words or omissions (Braun and Clarke, 2013).

Names and other identifying information were removed from the transcripts of the interviews, which were coded with numbers to link to the consent forms.

3.8.4 Analysis of the interview data: justification for using template analysis

The interviews were analysed using template analysis. Template analysis is a set of techniques for thematically organising and analysing data (Crabtree and Miller, 1999; King, 2014b). It fits with an interpretivist approach since reflexivity, capturing different perspectives and obtaining rich descriptions are all key elements of this method (King, 2004). Themes are identified in advance ('a priori') by the researcher, but remain provisional, and are organised hierarchically in a template which is then used to code the rest of the data (King, 2014b). It is an iterative process, whereby the template is continually modified in light of new data.

Template analysis is a flexible approach which allows the researcher to make a detailed study of individual cases whilst also paying attention to patterns in the data between cases (King, 2004). In addition, segments of text that are related are

brought together earlier on in the analytical process which may help to make it easier to make connections between them (Crabtree and Miller, 1999). However, organising data into a structure from such an early stage in the analysis process may lead to focussing on the template itself rather than appreciating the data as a whole (King, 2014). An awareness of this potential pitfall is needed during the analysis process in order to stay open to the data (King, 2004).

The following section describes the way in which template analysis was carried out in this study and discusses how quality and rigour within the data were achieved.

3.8.5 The process of data analysis

i) Identifying 'a priori' themes

A small number of 'a priori' themes were identified in advance of coding order to construct an initial template (King, 2014b). Themes consist of codes which represent some pattern of response or meaning in the data, having a 'central organising concept' (Braun and Clarke, 2013 p224). Themes were derived from the major topics from the interview schedule, since these reflected the main aspects of the teenagers' experiences. For example '*life before my cochlear implant*' and '*identity*' were chosen as initial codes. The interview topics were drawn from the literature and discussions with the teenagers in Phase 1 so were considered appropriate sources for codes (King, 2004). King (2014b) warns that caution is needed when identifying themes 'a priori' as other codes of relevance may be missed or the researcher may not notice that the initial codes are no longer a good fit. To avoid these pitfalls during this stage the themes were viewed as provisional and subject to revision or deletion as the analysis progressed. Themes were organised hierarchically, with broader, main themes at the top and narrower, sub-themes within.

ii) Coding

Two transcripts (S1, S2) were then coded. Coding is the process of labelling sections of text which are relevant to the research question (King, 2004). Coding was carried out by hand rather than by using coding software since the number of interviews was small. Words, phrases or chunks of text were coded and written definitions for each code were created to help define each one (Braun and Clarke, 2013).

Template analysis does not differentiate between analytic and descriptive coding, since there is an assumption that descriptive coding requires a degree of interpretation and that interpretation involves some descriptive element (King, 2004). Codes were derived both from the data, for example '*hated it*' while others were more researcher-generated and reflected meanings within the data, such as '*a burden to wear*'. This helped to facilitate interpretation later on in the process to beyond a descriptive level (Braun and Clarke, 2013). Codes were developed more extensively where the data was richer, for example their experiences of surgery. Other transcripts were then scrutinised to ensure the template captured all of the ideas within the data. Codes that related to a theme were attached to it. Where there was no appropriate theme, a theme was modified or created, ensuring that each theme was both discrete from the others but fitted well with the other themes (Braun and Clarke, 2013). An excerpt of coded data is given in Appendix 5.1.

When generating themes, consideration was given to the teenagers' different hearing histories. Consequently some themes were generated that relate only to particular circumstances, whilst others captured the experiences of all of the participants.

iii) Developing the template

The remaining transcripts were coded and the template was then applied to the whole data set, with themes modified where necessary. The coded data was checked against the themes to check they worked in relation to each other and to check that the themes were a good representation of the meaning of the data (King, 2014b). Themes were inserted, deleted and the scope of themes was changed if later coding indicated the focus was too broad or narrow.

The template was considered final when no sections of text which were considered relevant to the research question remained un-coded. In addition, modifications to the template stopped when it was considered that a good description of the data had been achieved but without so much detail so as to hinder interpretation (Brooks and King, 2012).

3.8.6 Interpretation of the data

A number of strategies were used in order to identify patterns across the data. King (2014b) suggests techniques such as examining the frequency of occurrence of themes, although he warns that frequency is not in itself an indicator of importance. Another, more useful, approach used in this study was to study each transcript in order to identify any themes which appeared to be more prominent than others. Prominence was defined as the number of times a participant mentioned a topic or if any emotional words were used when talking about a particular aspect of their experience. Visual thematic maps were developed in order to explore the relationships between themes (Braun and Clarke, 2013). 'Over-arching' themes were used to organise themes into meaningful groups such as those relating to the operation and post-operative time. These over-arching themes did not contain themes; but helped to 'organise and structure the analysis' so that the different components of the teenagers' experience were clear (Braun and Clarke, 2013 p 231).

3.8.7 Ensuring quality of the analysis

Braun and Clarke (2013) comment that it is important to adopt those quality criteria that are underpinned by the theoretical framework that guides the research. Interpretivism recognises the subjective element to knowledge generation. Therefore criteria such as reflexivity, dependability and credibility were considered appropriate indicators of quality (Houghton et al, 2012, Holloway and Wheeler, 2013). Another approach to ensuring the quality of the study was maintaining an 'audit trail'. The process of template analysis involves the development of successive iterations of templates, which show how interpretations of the data developed over time and the decisions that were made (King, 2014a).

A self-critical, reflexive approach was adopted throughout the study. Holloway and Wheeler (2013) note the importance of an awareness of the relationship between the researcher and participant and how the researcher's preconceptions may influence interactions with participants or interpretations of the data. King also (2004) commented that it is important for the researcher to be reflexive in their practice when interviewing and to consider the nature of your involvement in the interview process. A technique employed in this study was to note any preconceptions before starting the interview and refer back to them, particularly

during analysis. This helped me to be mindful of my part in eliciting the views of the teenagers and what influences I may be exerting on the process.

Credibility and dependability were achieved by asking three students at a school for deaf children to consider and comment on the findings from the interviews.

‘Participant checking’ of the analysis can help reduce the likelihood of misinterpreting participant’s accounts (Goldblatt et al, 2011). Braun and Clarke (2013) recognised that checking the findings with participants is particularly important for research such as this where subjective experiences are sought. However, it is important to be mindful that the teenagers may have different perspectives on their stories at different points in time. In addition, the researcher has a different perspective on the data due to the audience they may have in mind which may also result in a different interpretation from the participant (Goldblatt et al, 2011; Mays and Pope, 2000). With this in mind, Braun and Clarke’s (2013) description of a ‘reflexive elaboration’ of the results was adopted, rather than using the technique as a check of whether the researcher had got their views ‘right or wrong’ (p285).

A draft of the analysis was presented to a group of three teenagers with cochlear implants during a short meeting at the school for deaf children. All of the teenagers who had been interviewed at the school during phase 3 were contacted and the staff member also invited others who may be interested in participating. Three teenagers participated in the session, all of which had been previously interviewed. The teenagers received an information letter about the meeting and a copy of the analysis approximately one week before the meeting. The meeting was facilitated by myself and a member of staff known to the teenagers. The teenagers were asked to consider a visual map of the over-arching themes, themes and sub-themes, similar to that presented in Chapter 4, section 4.4. Following the recommendations of the National Children’s Bureau, the findings were presented in a way that was deemed accessible to the teenagers, for example some of the wording was adjusted slightly to reflect the different ages of the group (Shaw et al, 2011). Since the names of most of the themes were derived directly from the transcripts it was anticipated that the teenagers would not have any difficulty understanding them.

However, there are a number of potential pitfalls associated with this approach, including the teenagers being reluctant to criticise the credibility of the analysis due to the perceived power of the researcher (Braun and Clarke, 2013). Given my role as

a researcher I was careful to reassure the teenagers that I valued their feedback and I considered them to be the 'experts'. It is also possible that the participants are giving feedback which is not in the interests of advancing the study, for example if there are tensions within a group. The results of the meeting are described in Chapter 5, section 5.7.

3.9 Summary

This chapter has described the development of the methodology of this study, from the early development work of phase 1 through to template analysis of the interview data in phase 2. A key and novel feature of the study was the participation of the teenagers at key stages of the research process, with each phase being informed in some way by the views of the participants. Involving teenagers in this study required careful planning and particular attention was given to the safety and ethical aspects of this approach.

This chapter also highlighted that although online data collection is an approach with much potential, there were numerous challenges associated with using it successfully with teenagers with cochlear implants in a research setting. Interviewing teenagers with cochlear implants required an awareness of the various influences that may shape their responses and how to manage these. Template analysis was used to thematically organise and analyse the data and the quality of the study was ensured by adopting a reflective approach throughout the process and by asking the teenagers to validate the interpretation of the results. Chapter 4 presents the findings from the interviews.

Chapter 4 Findings

4.1 Introduction

The aim of this study was to explore the experiences of teenagers with cochlear implants aged 13-19 yrs. In Phase 1, a website was designed to allow the teenagers to share their experiences online. This was detailed in chapter 3 (section 3.7). The contributions to the website are detailed in section 3.7. As discussed in section 3.7.1, an alternative approach was adopted in order to gather further data. Semi-structured interviews were carried out with 10 teenagers at a cochlear implant centre and at a school for deaf children in the south of England.

This chapter firstly presents the contributions to the website, some of which informed the interview schedule as discussed in 3.8.3. The findings from the interviews are then presented. As described in section 3.8, the interviews were transcribed and then analysed using a template analysis approach. The attributes of the teenagers are discussed, followed by a presentation of the main themes that were developed from the analysis, with supporting excerpts from the transcripts to illuminate the discussion.

4.2 Contributions to the website

Two teenagers, with the pseudonyms 'Ears 1' and 'Ears 2', added comments to the discussion board of the website 'I'm all ears'. 'Ears 1' is a 16 year old female with two cochlear implants. She received her first cochlear implant aged 4 years following meningitis. Her second was implanted when she was 15 years old. 'Ears 2' is an 18 year old male with a congenital hearing loss. He received his first cochlear implant aged 4 years and the second aged 13 years. 'Ears 1' reported that she uses her implants all of the time. 'Ears 2' only uses his second implant occasionally.

Each teenager posted 3 comments. The comments were made under the following threads (topic areas for discussion): 'life before my cochlear implant', 'the decision to have a cochlear implant', 'using my implant' and 'communication with friends and family'. 'Ears 1' added the sub-heading 'life before a miracle' to the thread 'life before my cochlear implant', giving an indication of how positively she views having her cochlear implant. Neither could remember what it was like for them before having a cochlear implant since both were implanted at a very young age. However,

‘Ears 2’ reported that his parents found it very difficult to communicate with him. ‘Ears 1’ expressed her feelings about the cause of her deafness, which was not congenital:

‘I wasn’t born deaf, I was hearing. Then Meningitis caused me (sic) deafness, which is quite annoying to bear the fact’.

Ears 2 finished his post with a footer which read:

‘Remember...there are deaf people less fortunate than us...so you should all be grateful for having cochlear implants’.

Both were able to recall making the decision to have their second implant. Their decision was clearly very considered. For example, Ears 2 described the variety of questions and uncertainties he had around the decision which he found difficult to make, and highlights how he considered how it might impact on many different parts of his life, both in the short and longer term.

‘The decision for me was VERY hard when I had my second implant. I had to balance up the advantages and disadvantages and think, is this right for my future? Do I want this? Maybe it’ll help me with my driving test? Maybe it’ll help me at work? But I guess every single one of us has to decide.’

In contrast, Ears 1 felt it was a fairly straightforward choice, although remembers weighing up the pros and cons.

‘It was almost like an easy decision for me...I had that feeling when you just sooo (sic) had to take the option to have a sequential second implant. So I took the offer, but of course I did balance the advantages and disadvantages’.

Under the thread ‘using my cochlear implant’ the teenagers added a heading called ‘which do you think is the worst part of cochlear implants?’ It is interesting that they chose to talk about the disadvantages of having a cochlear implant under the thread ‘using my implant’ rather than any other aspect of using one. Both cited batteries running low as an annoyance, especially during lessons or when talking to friends. Discomfort was also mentioned.

Comments were also posted about how they communicated with friends and family. Ears 1 asked what mode of communication was used (‘oral speech, BSL or other?’) and whether others communicated with ‘deaf people, hearing people or both’. Ears

2 replied to say he used both oral speech and BSL, depending on who he was communicating with and that he talked with both hearing and deaf friends.

4.2.1 How the contributions to the website informed the interviews

Although only two teenagers contributed to the website, their comments gave insights on what the important issues might be which then informed the interviews. For example, in those teenagers who remembered getting their cochlear implant I tried to fully explore their decision making since 'Ears 2' indicated that weighing up the 'pros and cons' of having an implant was a difficult process, with different amounts of difficulty experienced by the two teenagers. In addition, Ears 2 comments about communicating with both deaf and hearing people informed a question about the teenagers' identity. The teenagers' use of the terms 'deaf, hearing or both' indicated the ways in which they conceptualised their identity so these terms were used in the interview question. The disadvantages of having a cochlear implant were also mentioned by both contributors so a question asking what they would change about the device was also included.

4.3 Attributes of the interviewees

Ten teenagers were interviewed. Participant S2 experienced difficulties speaking due to a disability and so was accompanied by a sign language interpreter. In an effort to help him through the interview she changed some of the wording of the questions and suggested answers that he might give. In addition, his father interrupted on occasion and diverted the course of the interview. Therefore it was felt that the interview could not be considered to be an accurate reflection of this participant's views and a decision was made to exclude this interview from the integrated data. Therefore the findings are based on nine participants.

Four female and five male teenagers were included in the analysis. The average age of the participants was 14 years (range = 14-16 years). All were congenitally or pre-lingually deafened. Participant S6 did not know the cause of his deafness. Five teenagers had undergone sequential cochlear implantation, most recently one year prior to the interview (S9). Seven of the teenagers were implanted pre-lingually (S4, S5, S6, S7, S8, S9, S10). All reported being good users of their implant(s).

The age at implantation of the first cochlear implant ranged between 14 months and 10 years. For those with two implants, the second implant was received between 1 and 7 years ago, with an average of 4.5 years since implantation of the second. The age at which they received their second cochlear implant ranged from 7-14 years. The duration between the first and second implant was an average of 8.5 years (range=6-12 years).

All communicated mainly with spoken English although S10's speech was unclear. Four teenagers attended the same school for deaf children in the south of England, the remainder were in different mainstream schools. All except two teenagers had received their implant(s) at the same cochlear implant centre in the south of England. Participant S8 had a visual impairment. The remaining participants did not report any additional needs. Table 1 summarises this information.

Participant	Age at time of interview	Gender	Aetiology/age at onset of hearing loss	Age at first CI	Age at second CI
S1	16 yrs	Female	Unknown/ 12 months	14 yrs	-
S3	15yrs	Male	Cytomegalovirus (CMV)/2 yrs	10 yrs	-
S4	16 yrs	Male	Congenital	4 yrs 6 m	-
S5	14 yrs	Female	Meningitis/12 months	14 m	7 yrs
S6	15 yrs	Male	Unknown	3 yrs	-
S7	16 yrs	Female	Congenital	3 yrs 6 m	12 yrs
S8	16 yrs	Male	Meningitis/12 months	18 m	12 yrs
S9	15 yrs	Male	Congenital	2 yrs	14 yrs
S10	14 yrs	Female	Congenital	2 yrs	8 yrs

Table 1. Attributes of the interviewees.

The profiles of the teenagers interviewed in this study were compared with the wider teenage population who wear cochlear implants. This was judged to be a good indicator of whether the experiences described here are typical of other teenagers who wear cochlear implants. In order to make this comparison, variables including duration of deafness, gender ratio and age at first implantation were examined in the group of teenagers in this study and compared with the teenage population at a cochlear implant centre in the South of England. These teenagers represent about one fifth of the total UK population of teenagers with cochlear implants (111 individuals) so this was considered to be a valid comparison group.

The average age of the teenagers in this study was found to be comparable to the cochlear implant centre group (average age = 14 yr 7 m, range = 12 yr 1 m -17 yr 11 m). There were an approximately equal number of males and females in this study and this distribution was also seen in the cochlear implant centre group. Duration of deafness in the cochlear implant centre teenagers was also comparable, at 14 years. The group of teenagers in this study comprised approximately equal numbers of individuals with unilateral and sequential cochlear implants, a trend also seen in those attending the cochlear implant centre.

4.4 Analysis of the transcripts

The stories of the nine participants whose interviews were transcribed are given in section 4.4.1. These are presented in order to highlight the individuality of the experiences of the teenagers who took part in the study. The teenagers' with sequential cochlear implants are describing their experience with the second device since they received their first at a very young age.

The main themes are then discussed in section 4.4.2, their experiences being presented as a 'process', starting from before they received their cochlear implant to the present day. Extracts from the transcripts are used to illuminate the discussion and to preserve the voices of the teenagers.

4.4.1 The teenagers' stories

i) S1

S1 is a 16 year old female who received her cochlear implant two years ago, having previously worn hearing aids. She was deafened at 12 months of age and did not know the cause of her deafness. She attends a mainstream school. She described how she relied on her mum for help making the decision to have the device, following information that she had read that was given to her and also that she had found herself. She had particularly vivid memories of the operation as there were some complications which resulted in a number of unpleasant side effects such as face swelling and vision problems. She clearly remembered how horrible she felt at this time and how she was not prepared for this. After a slow recovery she now feels that it was a big thing to have but that it has made a big difference to her life. For example, she is now able to join in conversations at school that previously would have been difficult to hear which has helped her confidence to grow and enabled her to be more independent. This participant likes the convenience that having a cochlear implant gives her, for example when listening to music, but is frustrated by the need to be careful when wearing it as she enjoys dancing. She found the question about identity difficult to answer, feeling that it was hard to label herself as deaf or hearing. She said that she considered herself deaf, although wanted to point out that she was not a member of the Deaf community.

ii) S3

S3 is a 15 year old male who was interviewed via Skype. He was deafened at the age of two, as a result of CMV. He received his cochlear implant aged 10. He attends a mainstream school. He struggled to answer some of the questions related to more abstract concepts such as the effects it has had on his life; however the interview was also challenging because of technical problems. He had difficulties hearing me and so the conversation was quite stilted which made developing a good rapport problematic. He recalled feeling nervous before the operation and found the sound initially 'weird and awkward'. He spoke about the audiological benefits of having a cochlear implant such as hearing environmental noise but also how it allows him to interact better with friends and family, the former thinking he was strange when he was unable to hear them with hearing aids. However he chose to tell me about how happy his grandparents were to have a conversation with him on the phone, as

previously this was not possible without the help of his Mum. He was reluctant to recommend a cochlear implant to others due to practical issues with the device.

iii) S4

S4 is a congenitally deaf 16 year old male who received his cochlear implant aged four and a half. He was also interviewed via Skype. He attends a mainstream school. He was unable to recall anything about the early stages of having the implant and was generally rather reluctant to answer questions about how life had changed. He struggled to hear the questions at times which resulted in quite a stilted interview as it was difficult to develop a good rapport. He liked his cochlear implant as 'it gives you hearing' and his comments largely related to the fact he could hear more and that is why he liked it. He commented that he was "hearing fine" so did not see the point in getting a second cochlear implant, although earlier in the interview admitted to sometimes having difficulties hearing the teachers at school.

iv) S5

This participant is a 14 year old female who wears two cochlear implants. She received the first aged 14 months, following meningitis at 12 months, and the second device was fitted when she was seven years old. She attends a mainstream school. She gave a detailed account of how having a cochlear implant affects her life. She was able to recall how difficult having the operation was and what a big impact it had on her life at the time. She spoke about how painful it was after the operation and how at that time she did not like it at all. She felt a responsibility for wearing it and for getting used to it. She was irritated by how difficult the initial acclimatisation period was, which involved her changing her behaviour to avoid loud sounds and asking others to do the same. She suggested that she looked forward to taking the implant off as she felt very tired and suffered from headaches during the early weeks. Despite this, she talked at length about the benefits of having cochlear implants, beyond the ability to hear and communicate better. She attributed many improvements in her life to the implants, such as improved confidence and a better social life. School has also been easier since the second implant, in that she now feels that she learns more quickly and can concentrate less which means it is less tiring for her. She feels generally better about herself as a result. She felt that it was a good decision to have a second implant but that it was something that needed to be 'got out of the way'. For her it was not a pleasant

experience but worth it in the end. She identified more with the hearing world although was frustrated when others did not make allowances for her hearing loss.

v) S6

S6 is a 15 year old male with one cochlear implant. He attends a school for deaf children in the south of England. At the time of being interviewed he was being considered for a second implant and had that day attended the implant centre for an appointment to find out more. He felt nervous and excited about the prospect. His anxiety arose from uncertainty about the outcome of the operation, having heard stories about unpleasant after effects and things going wrong. He wanted to just 'get past it and see what happens'. He commented on feeling overwhelmed by the volume of information that had been presented to him, joking that it was 'too much!'. His hopes were to be able to hear better in challenging situations such as a noisy restaurant, and to hear his friends better. He was keen to discuss the decision with his family and to avoid missing college work. He was due to start college in a few months' time and his thoughts focussed on meeting new people which he was anxious about. He was concerned about how challenging that might be for him. He saw himself as between the hearing and deaf world, where he could benefit from two different modes of communication (sign language and speech) to maximise his hearing.

vi) S7

S7 is a 16 year old congenitally deaf female who had received her first cochlear implant aged three and the second device four years ago. She attends a school for deaf children in the south of England. She recalled her parents asking her if she wanted a second implant and her initial reluctance. She changed her mind when her parents spoke to others whose children had received a second implant and were doing well. She also sought the advice of a friend who had two implants. She described the operation as 'scary' although was excited to see how the implant would benefit her. She recalls feeling unwell after the operation and needing to stay in hospital which annoyed her. At first she really disliked the implant; in particular she mentioned the sensation of having it on her head but also the difference in the sound. Now she feels she listens and speaks better and is enjoying hearing the detail in music which previously she was unable to do.

vii) S8

S8 is a 16 year old male. He was deafened at 12 months of age, following meningitis, and received his first cochlear implant aged 14 months. His second implant was fitted when he was 12 years old. He attends a school for deaf children in the south of England. He remembered his parents wanting him to have a second implant, but also felt that he had a choice. Attending user group meetings at the implant centre persuaded him to go ahead with it. He was clear that the reason he was initially reluctant was fear of the operation, and his fears centred around the fact that it would involve cutting his head open which frightened him. He admitted that for a while he would have liked a second implant but the thought of the operation was stopping him from going ahead. He found it helpful to discuss the operation with other young cochlear implant users he met, who reassured him that it would be a good outcome. Despite this, he did not like the operation and vowed he would never have another one again. He recalled that it was very painful, and he also experienced dizziness. He commented that he was not expecting any of these symptoms and had not really considered how he would feel immediately after the operation. The recovery period was boring but uneventful and he persevered with wearing the implant. He sees himself as deaf but is pleased that sometimes his friends and family, and even himself, forget he is deaf. He is pleased with the improvement in sound and how it feels on his ears compared to hearing aids. He has also noticed that it is easier to learn, and that it has 'just turned my whole life into an easier life'.

viii) S9

S9 is a 15 year old male with congenital deafness. He received his first implant aged 2 years and the second aged 14 years. He attends a school for deaf children in the south of England. His memories of getting the second cochlear implant are quite recent. Like S8, he had not wanted to consider the possibility of a second cochlear implant because of his fear of operations, but decided that it was something he needed to get over with as he recognised the potential benefits. His fears involved waking up mid operation, despite talking about what was going to happen beforehand with a clinician. He recalled that the experience of the operation was largely consistent with what he had been told but that he was very anxious beforehand. He managed this by distracting himself with other activities on the morning. His concern was that he would 'be having a nervous breakdown about it

and it will never happen'. He described the recovery as boring but fast, and was excited about the switch on. However, he was disappointed that he could hear very little through the second implant and still finds it worse than the first implant but is 'still working on it' almost a year later. This agitates him as he feels impatient, although has noticed significant benefits. These included hearing and communicating with his teachers more easily and socialising with friends more. He feels he 'understands the world a lot more'. He was the only participant who felt strongly that he was deaf. He explained how he 'wasn't like hearing people', suggesting that they had different interests and a different culture which he did not fit in with and alluded to possible difficulties at a previous school. He felt that having a second implant was risky but worth it, and that it requires a significant amount of work to be able to benefit from it.

ix) S10

S10 is a 14 year old congenitally deaf female who received her first cochlear implant aged 2 years and the second when she was aged 8. She attends a school for deaf children in the south of England. This was a difficult interview as her speech was unclear so it was difficult to transcribe accurately. It was also difficult to know whether she was hearing the questions clearly as her responses were often not related to what she had been asked. Nevertheless, she was able to recount that her parents had decided she should try a second implant and that it has generally been successful. She is able to hear her family speaking and can understand them better now, although is irritated when the batteries run out.

4.4.2 The themes

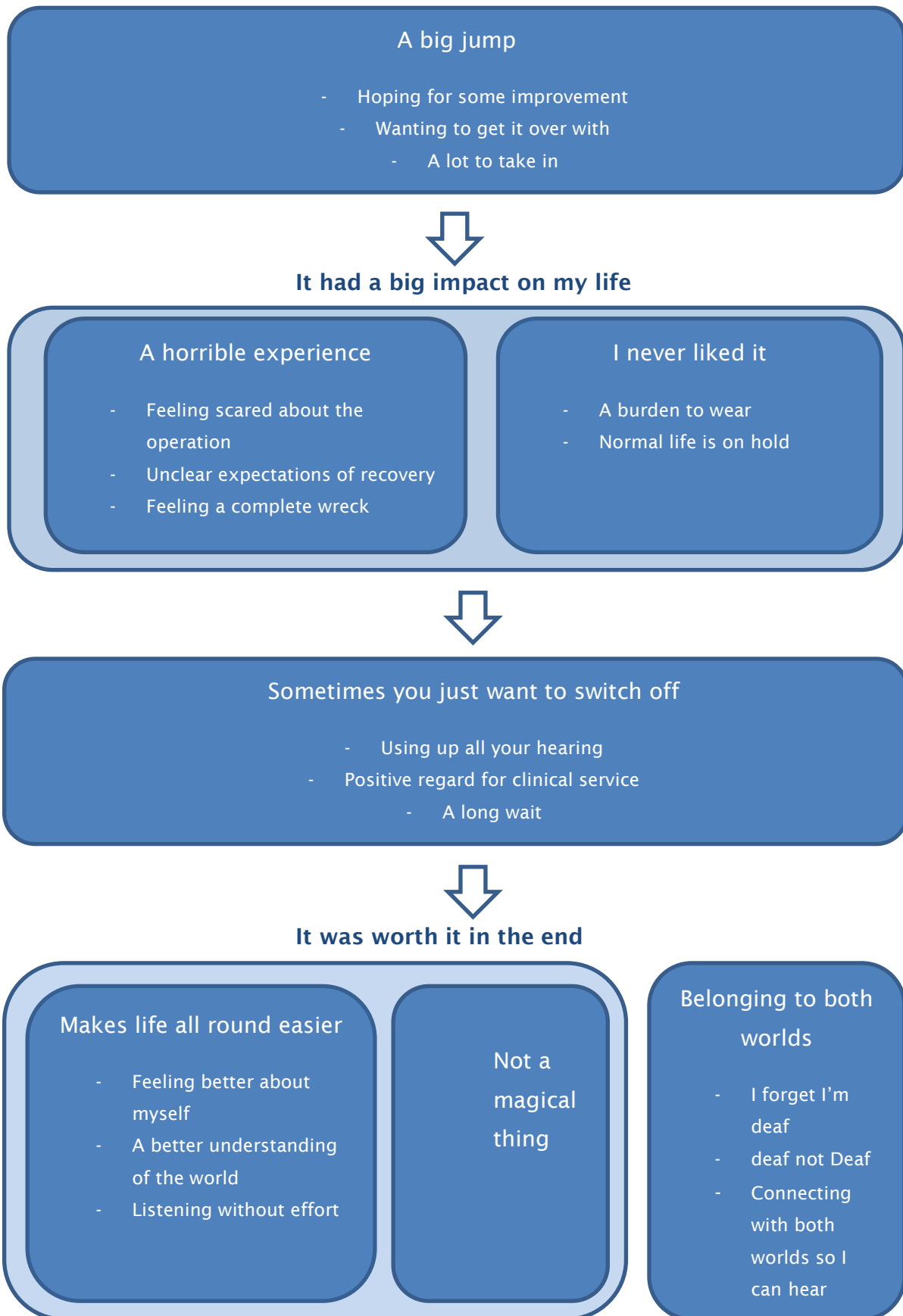
In the interviews the teenagers reported a series of living experiences related to all aspects of the process of having a cochlear implant, from making the decision to have the device through to different aspects of their current life. This is represented in the flowchart below which presents the themes associated with various stages of the process they described (Figure 6).

The key aspects of the process were represented by seven themes, sub-divided into sub-themes where appropriate. Two over-arching themes, 'It had a big impact on my life' and 'it was worth it in the end' were developed to group themes which related to a particular aspect of the process of having a cochlear implant.

‘A big jump’ relates to their experiences of making the decision to have the cochlear implant and their feelings about going ahead. The over-arching theme ‘It had a big impact on my life’ includes themes which capture their experiences of surgery, recovery and the early days with the implant: ‘a horrible experience’ and ‘I never liked it’. ‘Sometimes you just want to switch off’ captures the difficulties adjusting to the device and the experience of rehabilitation. Their experiences of, and frustrations with, living with the cochlear implant are represented by the themes ‘makes life all round easier’ and ‘not a magical thing’, grouped by the over-arching theme ‘It was worth it in the end’. ‘Belonging to both worlds’ captures their experiences of being part of the hearing and deaf worlds.

As highlighted by table 1 and the teenagers’ stories, the group was heterogeneous in terms of duration of deafness, age at fitting of implant and number of implants. Consequently, not all of the themes that are presented relate to every participant, and this is indicated where relevant.

Figure 6. Overarching themes (in bold), themes and sub-themes.



Theme: A big jump

The theme, 'a big jump', captures the feeling expressed by five of the participants who were able to recall their decision to go ahead with a cochlear implant (S1, S6, S7, S8 and S9). S1 and S9 were teenagers when they made the decision. S7 and S8 were 12 years old. Participant S1 spoke about her experience of deciding to have her first cochlear implant whilst S7, S8 and S9 recalled their decision to have a second device. Participant S6 was going through the decision- making process at the time of interview.

However, despite the differences in their circumstances they all recalled a similar time. Their accounts indicate that the decision was not taken lightly and they were very aware, and anxious, about the enormity of what they were about to consent to.

Three sub- themes were developed within this theme: 'hoping for some improvement', 'wanting to get it over with' and 'a lot to take in'.

Sub-theme: Hoping for some improvement

The teenagers' all recalled feeling optimistic that their lives would improve following cochlear implantation. They had hoped for benefits such as hearing more easily in difficult environments such as in background noise or when trying to localise sound and to understand friends more easily. For example:

'...going to a restaurant or going to a big dinner party when lots of people are there it can get a bit noisy um it make me can't hear what people are saying so I want that to change...so I'm hoping that to change' (S6)

'Um one of the things I found really irritating was when people would call out my name and normal hearing people know where they are cos they've got directional hearing, I did not have any directional hearing at all and one time it took me 5 minutes to work out where the sound was coming from and I just found that really agitating so I just got a second implant (inaudible)' (S9)

However, their expectations were not always in line with the reality of listening with a cochlear implant as illustrated by participant S6 who hoped for near perfect hearing once he received a second cochlear implant:

'I can't understand them 100% so I want to change that...to hear them better' (S6)

Sub-theme: Wanting to get it over with

The teenager's comments about the decision-making process were characterised by feelings of worry and uncertainty, and this was overwhelmingly due to concerns about the operation. Their fears of the operation featured highly in some participants' decision making.

Worries about what the procedure involved contributed to their anxieties. For example:

'I thought that, you know I would wake up in the middle and find my (inaudible) completely gone' (S9)

'they did say they have to cut open my head and that sounds horrible' (S8)

It was perceived as something to 'get out of the way', to allow them to move forward and enjoy the benefits of having a cochlear implant. It was a particular concern of S6, who was at the time of interview going through the pre-operative stage, gathering information to help him make his decision. Despite being several months away from having the operation, he had already decided it was something he needed to be stoic about:

'I just want to do it, get past it and see what happens'

Another teenager, S9, had also resigned himself to his fate:

'it's something that's going to have to happen'

In addition to feeling the need to get past the operation was a desire to avoid the operation altogether, although they were aware that this was not realistic. Two teenagers expressed how they had initially refused to consider a second cochlear implant due to fears about the operation, even though they were too young to recall their first operation, for example *'because I was really scared of having operations I tended to avoid there' (S9)* and *'...at the time I would have liked to have a left cochlear but without involving the operation' (S8)*.

A possible explanation for this may be in their anxieties about the surgical procedure, in particular that it was risky and that the outcomes were unpredictable. There was a feeling that 'anything could happen' and that they had no control over the outcome. This perception was informed by 'hearsay' for one participant:

'I'm hearing when people say they're having 2 cochlear (sic) this happens or this happens or this happens it's just... different things happen to different people and I'm not sure what's going to happen to me' (S6)

Sub-theme: A lot to take in

This sub- theme captures their feelings about the amount of information there was to take on board but also dealing with their emotional reaction to having an operation. Although active in seeking information from websites and talking to others, some felt overwhelmed. While they were grateful for the information given to them by professionals they also felt that it was a lot of information to make sense of.

Hearing the experiences of their peers, either through events arranged by the cochlear implant centre, or from friends already known to them, reassured many of the participants. For example, one teenager had previously had been ready to give up on the idea of a cochlear implant due to his fears about the operation. However, he felt reassured after speaking to other teenagers at the cochlear implant centre:

'Well mainly I was asking about the operations and they were saying it's just fine going to be in hospital have a couple of shots and relax and that sort of thing' (S8)

The teenagers reported that it was very much a joint decision between themselves and their parents. Given their young ages they were happy and grateful to their parents for helping them to make the decision to go ahead. One participant described the decision making process as a 'team' effort, indicating how he perceived the decision as a joint venture they were all entering in to:

'I'll talk to my parents to make the final decision and then if we want to do it we just go and do it!' (S6)

Over-arching theme: It had a big impact on my life

The over-arching theme 'It had a big impact on my life' contains two themes: 'a horrible experience', which relates to the operation and 'I never liked it, which captures their experiences post-operatively and in the early days with their cochlear implant, including when it was switched on for the first time.

With the exception of S4 and S6 who were very young at the time of implantation, all of the teenagers interviewed were able to clearly recall their experiences of the operation and of the days that followed. Those who had experienced more recent surgery, such as S9, were able to give more detailed accounts, although S5 spoke at length about the post-operative difficulties she had experienced seven years previously.

The themes capture both the experiences of S1 and S3, who spoke about their experiences of getting the first cochlear implant, and the rest of the teenagers who recalled getting their second device (S5, S7, S8, S9, S10). Irrespective of which device they were speaking about their accounts were similar and so the main concepts are reflected in the themes described here.

The teenagers described the operation and recovery as unpleasant and disruptive to their normal lives. Most of the teenagers spoke in detail about the operation and its effects which is perhaps an indication of the significance of this event which was, as one teenager recalled, *'quite a difficult time'* (S5).

Theme: A horrible experience

Almost all of the teenagers had very vivid memories of the operation and the days following surgery. They reported that feelings of anxiety and worry dominated their thoughts at this time. Three sub-themes were identified: 'feeling scared', 'unclear expectations about recovery' and 'feeling a complete wreck'.

Sub-theme: Feeling scared

Feeling scared of what lay ahead characterised many of the accounts of the pre-operative period. Uncertainty about different aspects of the operation was commonly reported. Their feelings of anxiety were related to three different aspects of the operation: what the operation involved (*'I didn't have any idea of what it's going to be'* (S1)), the possibility of something going wrong and concerns about the after effects of surgery.

As S8 commented:

'Well...it's just cutting open my head and...it doesn't sound good!'

'I'm nervous if it goes wrong, I mean there is a chance of going wrong, just not very likely'

Sub-theme: Unclear expectations about recovery

This concern may be related to another sub-theme that emerged from the analysis: 'unclear expectations about recovery'. Expectations about recovery were either unclear or the teenagers had not given any thought at all to what that period would be like, perhaps because they perceived it to be a straightforward process. This is illustrated in the following extract from an interview with S8:

I: Oh yeah...and did you, before you had your operation, did you know what to expect?

P: Um, well, I thought I'd just have an operation and go]

I: [OK

P: That's what I thought

I: OK

P: I didn't think about after.

Another teenager explained that his anxieties were focussed on the recovery period:

'I was more worried about the after effects of the operation' (S1)

One teenager reported that the audiologist had discussed 'all what it was about' but despite this he had still had found it difficult to overcome his fears. This perhaps raises the question whether the information they received was the right kind of information, or whether other aspects of the experience of having an operation were not discussed which would have been helpful.

Sub-theme: Feeling a complete wreck

The sub-theme 'feeling a complete wreck' captures their physical and psychological symptoms which included pain, dizziness, tiredness and in two instances, other atypical symptoms arising from complications during surgery. One teenager (S1) clearly remembered that this was a very unpleasant time for her:

I: So how were you feeling around that time?

P: Horrible! (laughs)

I: Right, OK

P: Actually it was quite painful

I: Was it?

P: Hated it

The significance of the operation for these teenagers is reflected in one participant's response when asked what advice he would give to others considering an implant. Despite being too young to remember his own experience of the operation at 3 years of age, he was keen to highlight the importance of it to others:

'Well, think about the operation, that's the important part' (S6)

Theme: I never liked it

The theme 'I never liked it' and sub-themes 'a burden to wear' and 'normal life is on hold' capture that the post-operative period was an unpleasant experience for all of the teenagers in this study, irrespective of whether it was their first or second implant. When asked to describe their experiences of the early days with their cochlear implant, the teenagers recalled feeling dissatisfied with the device and the slow pace of their recovery which limited their usual activities.

Sub-theme: A burden to wear

The teenagers recalled that the early days with their cochlear implant were difficult. Some experienced significant amounts of pain following the operation. For one teenager, (S5), the pain was such that she '*always regretted putting it on and (I) never liked it*'. Another teenager, S1, also expressed dislike of the implant due to the pain associated with wearing it at first:

P: I actually it was quite painful

I: Was it?

P: Hated it

The teenagers were rather underwhelmed when the cochlear implant was switched on and they had access to sound. No one recalled any positive emotions. Many experienced an unpleasant sound which they found difficult to get used to. An uncomfortably loud sound was reported by some, for example:

'if there was like a tap or anything it wouldn't just be quiet you know...it would be like...a massive drum being beaten in your ear' (S5)

An unnatural and robotic sound, like 'Dr Who' (S3), was also experienced.

Other symptoms that were experienced included headaches and feeling very tired. Some of the teenagers also recalled having to coming to terms with taking some responsibility for the device in terms of needing to remember to wear it consistently and avoid damaging it. The demands of recovering from surgery and wearing the device which was, for some, very painful, meant that this was a challenging time for these teenagers.

Sub-theme: Normal life is on hold

The teenagers recalled struggling to temporarily adapt their lifestyle during the recovery period. They were unable to do their usual activities and some were bored and frustrated at home, suffering from '*cabin fever*' (S7) while they recuperated at home. Another remembered not being able to properly relax until she had removed the processor, due to the unpleasant sound in the early days:

'I really hated having it, you know, having to put it on because when I took it off I felt relaxed like 'phew!' I can have it off!' (S5)

School was interrupted as they recovered, with one teenager only attending part-time due to tiredness. One teenager, S5, recalled that it was '*difficult to act normal*' as she could hear '*every tiny sound*'. She tried to adapt her behaviour, and asked her family to do the same, so that sounds were more comfortable. These findings indicate that the teenagers were unable to follow their normal routines in the early days and weeks following surgery and switch-on of the implant, which was difficult for some.

Theme: Sometimes you just want to switch off

For all of the teenagers in this study, attending appointments at the cochlear implant centre and participating in a rehabilitation programme was hard work. The over-arching theme 'sometimes you just want to switch off' captures their feelings of wanting to escape the difficult process of getting used to their cochlear implant. Three themes reflect their experiences of this aspect of the process: 'using up all your hearing', 'positive regard for the clinical service' and 'a long wait'.

Sub-theme: Using up all your hearing

The appointments were tiring for the teenagers, with long distances travelled by some of the participants. Even those travelling a relatively short way found the day quite draining since lots of concentration is required. Some teenagers were frustrated by the repetitive nature of the tests and were bored. Feeling unwell afterwards was a feature of some of the accounts, for example one teenager, S5, reported suffering from headaches and dizziness.

Sub-theme: Positive regard for clinical service

Despite these difficulties, the teenagers had a positive experience with the clinicians involved in their care. The teenagers appreciated a friendly face and helpful manner, speaking about how the importance of a welcoming atmosphere. They also reported that despite the day being long and arduous, they enjoyed finding out more about their implant, and recognised that the appointments were a good opportunity for this. For example:

'They're really nice, friendly, helpful...and yeah it's just been so great and been talking a lot about how it works' (S3)

'It's good fun to test out like different sounds and that and seeing if you can hear' (S4)

'It's quite interesting when you learn things every time you go' (S5)

Sub-theme: A long wait

The teenagers seemed surprised how long it had taken them to get used to their implant, and some were still adjusting to the sound which they were frustrated about. For example:

'It's a bit agitating...cos I can expect some waiting but I didn't expect like two years' (S9)

For those teenagers who had recently received a second cochlear implant, there was an acceptance of the rehabilitation process being far from quick or straight-forward. There was also an acceptance that they had a responsibility for the process and that they were actively engaged in their care:

'to make it work you also have to work with it as well, you can't just put it on' (S9)

'you have to be patient, to get used to it. I mean some people are just, operation then take their cochlear out, it not sound the same...they have to be patient' (S8)

'It's not going to be easy, so don't have high expectations' (S1)

Their comments show a maturity in dealing with the challenges of having a cochlear implant as a young person which bodes well for their futures as adult cochlear implant wearers.

Over-arching theme: It was worth it in the end

All of the teenagers described feeling that despite the difficulties associated with the operation and a long and sometimes challenging process of rehabilitation it was worth the effort and they did not express any regrets. As one teenager reflected:

'It's helped me so much, I have to say that...even if it doesn't work it's still worth giving it a try cos if it works to its full extent then the benefits you get from it is (sic) just extraordinary' (S9)

The theme 'makes life all round easier' captures the teenagers' perceptions of the wide-ranging benefits afforded by the cochlear implant. 'Not a magical thing' is a theme that reflects the teenagers' awareness of the limitations of living with the device and wanting to hide it from others.

Theme: Makes life all round easier

'...the cochlear just turned my whole life into an easier life' (S8)

All of the teenagers described benefits far beyond an improvement in their ability to hear sound, with an increased sense of well-being as a result of being able to interact more easily with the world around them. This theme captures the experiences of the teenagers with one cochlear implant (S1, S3) and those who recalled how their life changed for the better as a result of getting a second device (S5, S7, S8, S9, S10).

Three sub-themes were developed: 'feeling better about myself', 'a better understanding of the world', 'hearing things I haven't heard before' and 'listening without effort'.

Sub-theme: 'Feeling better about myself'

The teenagers felt that the cochlear implant(s) enabled them to feel more independent, confident and relaxed around people. They also reported feeling happier and more sociable, as they did not have to worry about not hearing well. The teenagers also noticed that others treated them differently as a result of their improved hearing, even in more challenging listening situations where previously they may have struggled. For one teenager his deafness was no longer noticed by his friends, following his second implant:

'when it's like playing football and there shouting things and when I drop my cochlear they 'oh yeah you're deaf', I forgot' (S8)

Sub-theme: 'A better understanding of the world'

As a result of being able to interact more easily with friends and family, without drawing attention to their deafness, the teenagers felt that they had regained their place in the hearing world as equal communication partners. For example:

'I'm actually making conversation with them instead of blushing and saying 'I'm sorry I don't know' (S1)

'it just helps me hear, like you know what people say, instead of going 'what?' like every single time...they can just come up to me and say '() what do you think of this?' and I'll just say 'Oh I think that's very...'. I won't have to say 'pardon?'...that's really helpful' (S9)

The ability to interact normally with others was also attributed to an increased awareness of others emotional state, due to hearing subtle changes in the way someone was speaking. Prior to his second cochlear implant one teenager had struggled with this:

'it's better because...sometimes when people talk you can't tell the tone of their voice, like you ...don't know (if) they're angry or not and it's like they could be really angry and you have no idea? And like you go 'yes, yes' they

could be really angry and...it just helps you know what emotions they're having and that sort of thing' (S9)

The cochlear implant also allowed them to worry less about what others might think of them when they struggled to hear:

'And my friends think I'm a bit strange because I can't hear that well with my hearing aid...but if I'm in a quiet room I can hear my friends and family so it's brilliant than my hearing aids were' (S3)

Sub-theme: Hearing things I haven't heard before

All of the teenagers cited a range of new sounds that they could now hear, including birdsong, music, train announcements and the speaker on the telephone. They also noticed a greater awareness of environmental sounds such as traffic noise.

Life at school improved in other ways. Two teenagers who had received a second cochlear implant commented that learning became easier. This was as a result of hearing the teacher better and being able to explain oneself more clearly, in addition to having a better understanding of what was being taught:

'teachers speak clearer, louder... and nice voice' (S7)

'it's also really helped me with like trying to explain things to the teacher cos when I first got this implant I couldn't really talk so it was really hard to explain to teachers what I wanted and now I just, if I need something I can easily ask for it' (S9)

Sub-theme: Listening without effort

Hearing in noisy, social situations became easier for many. As one teenager with two cochlear implants explained:

'it's a lot easier in that you are able to hear what everyone's saying cos I think before I was I kind of got lost in all this noise' (S5)

There were also examples of where the teenagers no longer needed to modify their behaviour in some way, or go to extra effort in order to understand what was going on. Their listening had, for the most part, become much less of an effort. For example

'I don't have to worry about listening really hard again...recently I went to the cinema and I can actually pick up, not everything, but most of the things they were saying cos when I went to the cinema I had to watch it and basically guess what was going on and research what the film's about beforehand' (S1)

These findings suggest that the teenager's cochlear implants allowed them to restore their place in their social worlds. Participating fully in everyday life was now much less of a struggle for them, irrespective of the number of devices worn.

Theme: 'Not a magical thing'

However, some of the teenagers were under no illusions that life with their cochlear implant was always easy. Feelings of self-consciousness were reported, which is unsurprising given the age of the interviewees. Three expressed the wish to hide it, in different ways. For example:

'sometimes I feel...a tiny bit self-conscious about how I look' (S5)

'sometimes it's annoying because my hair, and I have really brown hair, so it keeps showing a lot at school so I have to make sure I cover it' (S1)

'I would actually get one that you could put on the inside and that would be really helpful' (S9)

These feelings were expressed by both male and female participants, indicating that anxiety about the visibility of the cochlear implant is an important issue for both genders.

There was an awareness of the fragility of the implants, nearly all of the teenagers recalled a time when something had accidentally happened to the implant and it had broken. Frustrations were around the hardware, for example, the ear hook or earmould not staying securely on the ear, leading to requests for the whole device to be implanted inside the head from two of the interviewees. The teenagers also wished for the device to be waterproof as swimming was challenging for them, although as one teenager put it

'the only thing I can't do is hearing when I swim and even so, when you're underwater you can't exactly listen to things! (S9)

Theme: 'Belonging to both worlds'

The teenagers' identities were complex and varied. Some of the teenagers found the question about their identity difficult to answer so this theme captures the ideas expressed by five of the participants (S1, S5, S6, S8, S9).

Two teenagers described themselves as deaf (S1, S9). Others reported feeling connected to the hearing world, with varying degrees of also feeling deaf (S5, S6, S8). All of the teenagers, except S1, had two cochlear implants, although S9 did not consistently use the second device. Their identity appeared to be flexible, with a hearing identity being more pronounced in situations where listening was easy and a deaf identity being emphasised where difficulties communicating with others were experienced.

None of the teenagers reported a culturally deaf identity (Deaf), with one teenager (S1) clarifying that although she considered herself to be deaf she did not feel part of Deaf culture.

Three sub-themes were developed: 'I forget I'm deaf', 'deaf not Deaf' and 'connecting with both worlds so I can hear'.

Sub-theme: 'I forget I'm deaf'

The teenagers who aligned themselves mostly with the hearing world (S5, S6, S8) explained how their cochlear implants allowed them to forget about their deafness, as S8 explained:

'Sometimes I forget I'm wearing my cochlears (sic) so yeah I mean when I'm in my home town and stuff like that no one really talks about cochlears and stuff like that and deaf people and hearing people are no different.'

Being able to function more like a hearing person allowed the teenagers to feel less different than their friends. Friends' perceptions were naturally important and for one teenager, S5, they reinforced her identity as a hearing person:

'I think all my friends see me as hearing as well because I'm not actually, you know, I don't appear any different to them.' (S5)

For some of the teenagers in this study, fitting in with their hearing peers was important. Some of the teenagers were pleased that they 'look so normal' (S1) while wearing their cochlear implants. Although their communication behaviour was

now more similar to their hearing friends they were keen to minimise the difference even further by also hiding their cochlear implant. For example, two of the teenagers interviewed reported wanting to cover the cochlear implant with their hair, or wanted to make it much smaller and less noticeable.

Sub-theme: 'deaf not Deaf'

Whilst a mainly hearing identity was embraced by some of the teenagers two participants considered themselves to be deaf (S1, S9). It seemed that being 'audiologically deaf', with a small 'd', was acceptable but to be Deaf, and so part of the Deaf community, with a different mode of communication and culture; was not:

'I'd probably say that I'm deaf, but I'm not one of those people who say like they're in the Deaf community.' (S1)

Her comment indicates that the Deaf community perhaps represents an identity which is too different from the mainstream.

Participant S9 also chose to identify with the deaf rather than Deaf world. The difficulties hearing with his second cochlear implant had brought his deaf identity to the fore:

S9: I definitely think of myself as a [deaf person

I: [Do you?

S9: Because even though hearing helps me I don't really actually like hearing, () I genuinely don't like having to hear everything so like, you know, I tend to act very differently when like when I'm at home, when I'm on my own I often take them off or something'.

He also referred to his hearing friends as being culturally very different from him, with different interests that he did not enjoy.

His rejection of a hearing identity was also due to feeling alienated by the hearing culture:

'They're just interested in things that I don't really like. I do like music but um completely different taste in music than hearing people. I mean they say 'oh have you hear of this person' and I say 'no' and they say 'uhh oh my God you've never heard of him?'

For this teenager a Deaf identity is perhaps too different from the mainstream, even if the hearing world is rejected due to perceived cultural differences. Although from a hearing family he had rejected a hearing identity, seeking instead to align himself with the deaf world.

Sub-theme: 'Connecting with both worlds so I can hear'

Being deaf in the hearing world presented challenges for some of the teenagers (S5,S6,S8). Some wanted to hide their deafness and function like a hearing person, although they also needed those around them to sometimes adjust their behaviour when the listening environment was difficult. Others not making allowances for the teenagers' deafness could be annoying and difficult to cope with:

'...and I mean sometimes it's a bit... it's a really good thing but sometimes it's quite frustrating because ...um... because you know () everyone's like 'she hears fine' and everything but um actually its quite frustrating sometimes because I have to put in extra effort and um so it's just a bit irritating' (S5)

Many saw the advantages of also being part of the deaf world as a way of overcoming these frustrations. It was a good compromise for one teenager in this study who recognised the benefits of bimodal communication and wanted to '*bring everything together*' (S6). He took advantage of being able to communicate with sign language or speech, depending on the situation. Most of the teenagers in this study had both hearing and deaf friends. Maintaining a bicultural identity enabled him to communicate more easily:

'Most of the deaf people sign so much that they don't speak that much so it's kind of hard for me to communicate with them cos I want to speak but if I go to hearing only some things can be quite difficult listening to them, it's very hard but in between, both together, much easier' (S6)

4.5 Summary of findings

The teenagers interviewed in this study talked at length and, for some aspects of the process, in depth about how their life had changed as a result of having a cochlear implant. Those that spoke about their experience of surgery and recovery gave similar accounts of it being a difficult time, irrespective of whether they were receiving their first or second device. The clarity with which many of the teenagers

recalled the pre- and post-operative periods was perhaps an indication of the significance of the surgery for these individuals.

They showed an appreciation of the unpredictable nature of rehabilitation and a good awareness of, and their responsibility for, an active role within the process. All reported significant benefits beyond an improvement in hearing indicating that unilateral or bilateral cochlear implantation can have a positive impact on these young people's lives. For many, life was now more straightforward and enjoyable and there was a sense that, despite the bumpy start, they were very glad to have gone ahead with the surgery. The cochlear implant allowed them to have an easier life through improved audibility which helped them to interact more easily with the world around them. When asked about their identity, the teenager's aligned themselves with both the hearing and deaf worlds, to varying degrees and this did not seem to depend on use of one or two cochlear implants or the type of school attended. However, their identities were flexible, and this was often a reflection of their frustrations with the hearing world where communicating could be difficult in challenging environments.

Although, in parts, a difficult process; these findings indicate that having a cochlear implant has transformed many aspects of these teenagers lives for the better. As one teenager reflected:

'It's big the cochlear implant, it's a big thing to have, but I think it's a good thing to have' (S1)

Chapter 5 Discussion

5.1 Introduction

The findings of this study presented in chapter 4 give a detailed insight into the experiences of living with a cochlear implant as a teenager. In this chapter the findings are compared and contrasted to the literature discussed in chapter 2, highlighting how they have added to the knowledge base. Where appropriate, new literature and theory is discussed to help shed light on the teenager's stories and to offer possible explanations for their thoughts and feelings. This chapter also highlights how this study has added to what is currently understood about their world, and how this may benefit teenagers through better support from the professionals working with them.

Three key aspects of the teenager's accounts of their time with their cochlear implant(s) are considered, two of which have important clinical implications for this population. This study involved methodological challenges associated with working with teenagers with cochlear implants in a collaborative, research capacity which have not been previously explored in the literature. These are discussed here. The possible benefits to the study and to the participants which may have arisen as a result of the teenagers participating in a more active way than in previous studies are presented, along with a discussion of the quality checks that were integral to the study.

5.2 Fear of the unknown

Feelings of fear and anxiety characterised the teenager's accounts of the time leading up to the operation. It seemed that their anxieties were related to not knowing, or not fully understanding, what was likely to happen, both in terms of the operation and in the weeks and months that followed. For seven of the teenagers interviewed who could recall this time, their accounts of going for surgery and the period afterwards were filled with more emotion than any other aspect of their 'journey' with their cochlear implant. Indeed one teenager (S8) reported that he was so afraid of having another operation that he had initially discounted the idea of a second cochlear implant. He also remarked that his main line of questioning for other teenagers when he was considering a second cochlear implant was about the operation. Another key feature of their accounts of this time was a feeling of

uncertainty about what lay ahead. Although most of the accounts related to experiences of getting a second cochlear implant, the two teenagers' experiences of the pre-operative time with their first implant were similar. This suggests that already having a cochlear implant does not necessarily negate anxieties about getting another one. The teenagers in this study with two cochlear implants had received their first at a very young age and so were unlikely to recall this experience, with the surgery for the second device being experienced as if it were their first time. This may explain the similarity of their reports.

The strength of negative feelings about the operation, and post-operative time, and the frequency with which they were reported in this study had not been previously documented in the literature. In addition, the extent of the post-operative pain and discomfort reported by some of the teenagers in this study had not previously been highlighted in similar studies. This may be because previous studies exploring the experiences of teenagers with unilateral and sequential cochlear implants did not directly ask about their recollections of the operation. For example, Mather et al (2011) noted that most were 'slightly worried' about the operation but this did not feature in their decision to go ahead with it (p158). Mather et al (2011) was the only study to allude to this event, asking the general question of 'what worries did you have about the second implant?'. This was then followed up by the prompt 'what worries did you have about the operation?'. The teenagers in Hilton et al's (2013) study described a period of uncertainty and were scared of the pain, worrying about the risks associated with surgery and the potential for the implant to fail. However, this was not highlighted as a key theme. Wheeler et al (2007) found that teenagers perceived the operation as a 'disadvantage' of implantation, with a small number of participants feeling scared. By contrast, words and phrases such as 'horrible' and 'hated it' were used by four participants in the present study, with the theme 'a horrible time' reflecting the extent to which this was an unpleasant event.

Pre-operative anxiety among adolescents has been well documented in the literature for a range of elective surgical procedures (Chieng et al, 2014b; Jjala et al, 2010, Fortier et al, 2011). Teenagers have expressed strong emotions related to major surgery, including fear of the procedure and feelings of helplessness, which can last some time beyond the recovery from surgery itself (Rullander et al, 2013). After surgery there can be difficulties associated with a lack of social contact with friends

in the early stages of recovery. The result of this increased anxiety can be an increased perception of pain post-operatively, and an unpleasant recovery period as a result (Chieng et al, 2014a, b). Anxiety invokes a similar physiological response to pain in the sympathetic nervous system and so increases in anxiety may exacerbate pain (Walding, 1991). Two teenagers in this study recalled substantial post-operative pain. This had not previously been reported in the literature. It is possible that if they are better supported to manage their feelings leading up to the operation, for example by receiving pre-operative counselling, some of the discomfort following surgery may be reduced.

The teenagers all reported that they had received lots of information and had been given opportunities to meet other teenagers with cochlear implants before deciding to go ahead. They talked about the kinds of information they had accessed before going ahead with the operation, including information from professionals, their peers and online. However, this did not seem to leave them feeling reassured. Hearsay from peers about what might go wrong during the operation further exacerbated one young person's anxiety (S6). This suggests that the information the teenager's had access to in the time leading up to surgery was not effective in reducing their uncertainties and did little to allay their fears. Self-regulation theory may help to explain the mechanism responsible for the effect of lack of understanding of the procedure and the fear and anxiety that was reported (Johnson, 1999). It outlines how individuals' expectations about an experience such as surgery influence their coping mechanisms, and how their expectations can be modified by appropriate information giving. According to self-regulation theory, uncertainty is reduced by having accurate information related to the procedure itself (such as the sensations one might expect). This reduces the likelihood of a mismatch between expectation and actual experience as patients can anticipate the experience of surgery and plan for how to manage their responses to it (Jaaniste et al, 2007).

The way in which information modifies an individual's response to surgery has been further considered by Jaaniste et al (2007), who presented a theoretical framework which integrates self-regulation theory and schema theory. It outlines how past experiences and exposure to different sources of information effect schemata (patterns of thought) related to health. According to their 'Information Provision model', fear associated with not knowing or understanding what is going to

happen, as expressed by some of the teenagers in this study, can be attributed to poor schemata based on previous experiences and inaccurate expectations. Inaccurate schema may result from poor reconstructions in memory or exaggerations, and can be modified by providing the patient with appropriate information so that they can make better sense of events and experiences. Providing accurate information can help individuals identify the most helpful schemata for the upcoming event, which have an impact on expectations and coping style. Jaaniste et al (2007) suggest that information should comprise content that allows the individual to reconfigure their schemata so that they are appropriate and can adjust their expectations so that they accurately match the reality of the experience.

More effective information provision that is tailored to the individual based on their needs may increase understanding and modify expectations. Indeed, the literature indicates that young people are keen to actively seek information before surgery so teenagers who are awaiting cochlear implant surgery are likely to be receptive to additional input (Fortier et al, 2009). A review of the literature on adolescents information needs before surgery highlighted several recommendations which could be applied to a cochlear implant setting. Specific recommendations for service are discussed in chapter 6, however the guiding principles include:

- giving comprehensive details about the procedure; in particular about the pain they are likely to expect, possible complications, side effects of medications, feelings and what the hospital environment will be like (Korus et al, 2011; Fortier et al, 2009; Smith and Callery, 2005)
- offering choices about what information to receive, when and how; to suit the individual's learning style. A website including a video tour of the hospital, footage of the procedure and stories from other teenagers may be effective (Fortier et al, 2009; LaMontagne et al, 1993; Jlala et al, 2010). This gives the young person the opportunity to access the information as many times as they need and in a comfortable environment away from the clinic (Srai et al, 2013)
- providing information gradually to avoid feeling overwhelmed (Jaaniste et al, 2007)

- using online resources to provide peer support/mentoring (Fortier et al, 2009). Although there is evidence to suggest that providing information online is popular with teenagers, talking with a health professional is highly valued; as is talking to peers (Stephens et al, 2013)
- conveying the information at least five days prior to the procedure and minimising new information immediately before the procedure (Jaaniste et al, 2007).

Tailoring information to the individual can also be achieved by encouraging the teenager to identify their own information needs prior to surgery. The professional can then highlight any issues regarding the individuals 'script' of what the operation will be like. This gives the professional the opportunity to work with the young person to fill in any gaps and adjust their ideas so that they more closely match what will actually happen, thus reducing their anxiety (Fortier et al, 2009). The teenagers in this study did not report experiencing this approach to information provision, although they were not directly questioned about it. This suggests there is an opportunity to introduce a specific service implementation to address this shortcoming. This is discussed in chapter 6. Smith and Callery's (2005) study of children's pre-operative needs also highlighted that parents may be unsure of what the operation would be like for their child and therefore could not offer appropriate support. This suggests that the information needs of parents with teenagers receiving a cochlear implant may also need to be considered carefully since they are an important source of information and reassurance for their child (Stephens et al, 2014).

Some of the teenagers in this study reported that they struggled to cope with their feelings before the operation. One participant explained that he almost had 'a nervous breakdown' (S9) waiting to go to theatre on the day of surgery. Predictors of high anxiety among teenagers in the preoperative period may include pre-existing anxiety, depression, emotional difficulties being expressed as physical problems (somatising behaviour) and having a fearful temperament (Fortier et al, 2011). Although only tentative indicators, since the study sample was small, this suggests it would be worthwhile exploring these possible predictors of anxiety among teenagers with cochlear implants using individual interviews, in order to better identify those individuals who may benefit from psychological interventions

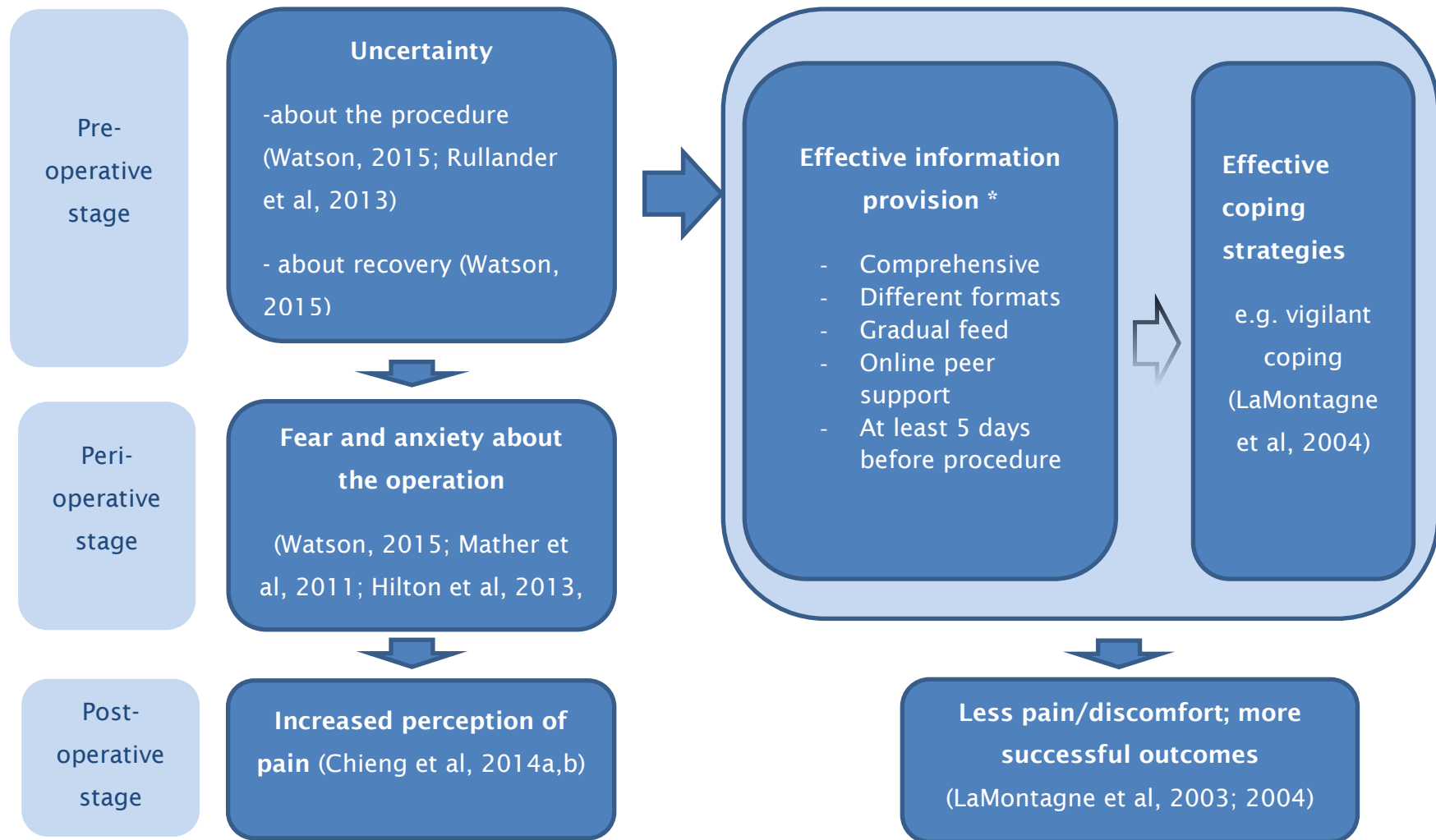
to help them cope with their feelings before and after surgery. The types of stressors experienced by teenagers undergoing major surgery have been reported by Korus et al (2011). Teenagers undergoing kidney transplant experienced stress associated with pain and discomfort, not being able to carry on with their normal routine and feeling unprepared for the operation, both in terms of not fully understanding what to expect, or experiencing something different to how it had been explained by the health care professional.

Although not explicitly asked in the interview about how they coped with their anxiety at this time, some reported that they had dealt with their feelings by persuading themselves that the operation was something that needed to be got out of the way, feeling that the 'cost' of going through with the operation was worth the end result. One teenager remarked that he would never consider having another operation again as the experience of having surgery for a cochlear implant was so unpleasant. Another commented that he felt as though he might have a 'nervous breakdown' on the morning of surgery. There was a feeling that all they could do was to 'grit their teeth' and get on with the operation, suggesting they lacked the appropriate coping skills. It is possible that these teenagers would have benefited from learning some coping mechanisms to help them manage their emotions before going in for surgery. Given their age and limited life experience, adolescents are unlikely to have effective coping strategies to deal with the effects of stressors in the pre-operative environment (Monahan, 2014).

Information alone may not be enough to address fears about surgery. Adult cochlear implant wearers have expressed similar concerns about the possibility of something going wrong during the operation, in part due to limited knowledge about the brain and how susceptible it is to injury (Hallberg and Ringdahl, 2004). This concern was also voiced by two of the participants in this study. Hallberg and Ringdahl (2004) suggested that more attention to the patient's 'thoughts and fears about potential risks of harm' was needed (p119). This highlights that this issue is therefore not limited to younger patients but given that adult patients with greater life experience and potentially better coping skills still experience difficulties.

Providing psychological support to cope with their emotions prior to surgery, in addition to factual information about the procedure and typical recovery has been reported to reduce postoperative anxiety and pain in a randomised controlled trial

of a large number of adolescent patients undergoing spinal surgery (LaMontagne et al, 2004). Combining clear, succinct information with advice on how to use different coping strategies has also been reported to better prepare teenagers for surgery (LaMontagne, 1993). Cognitive behavioural interventions have been shown to be effective in reducing anxiety and distress about a procedure, and may reduce post-operative distress and pain (LaMontagne et al, 2003). Cognitive behavioural interventions can change the individuals' thoughts about the stressors and the way in which they interpret them, by enabling them to feel more in control and able to cope with the situation. Combining information with coping strategies such as relaxation techniques was shown to be effective, although the authors note that it is important to consider the starting anxiety level of the patient, as overloading them with different modalities may be counter-productive if it raises their anxiety levels. Providing information about pain might also focus the mind of the patient to consider how they might manage it effectively. Figure 7 illustrates how combining effective information provision with appropriate coping strategies prior to and immediately after cochlear implant surgery may mediate teenagers' uncertainty and anxiety about the operation and potentially reduce post-operative pain.



*Korus et al, 2011; Fortier et al, 2009; Smith and Callery, 2005; LaMontagne et al, 1993; Jlala et al, 2010; Srail et al, 2013; Jaaniste et al, 2007.

Figure 7. The role of effective information provision and coping strategies in managing pre- and post-operative anxiety and pain.

As illustrated in Figure 7, coping is partly mediated by the provision of information. Coping has been described by Lazarus and Folkman (1984) as an emotional response to a stressful event and the coping behaviour of an individual depends on how they perceive the event. Coping may be 'emotion-focussed', where the aim is to manage the unpleasant emotions associated with the event, or 'problem-focussed', where attempts are made to alter the event through efforts of the individual.

The coping literature on adolescents awaiting surgery indicates that many do not have or use effective coping skills. Stevens (1989) notes that in order to plan the correct coping strategy to use to cope with post-operative pain and other stressors the teenager needs an awareness of those stressors beforehand through timely and appropriate information. If this does not occur, incorrect strategies might be used. Although not directly questioned about this aspect of their experience during the interview, some of the teenagers in this study commented on how they coped with their feelings before surgery. For example, one described how he tried to distract himself from his anxiety by playing computer games (S9). Three participants said that they managed to convince themselves it was just something that needed to happen, an unpleasant event to get out of the way so that they could move on. These are examples of two different coping strategies, distancing and self-control, which were identified in a study exploring the coping strategies of 57 teenagers awaiting surgery (Stevens, 1989). Distancing is described as an emotion-focussed coping strategy, where an individual tries to distract himself to manage negative emotions that have resulted from a stressful experience. Self-control is an attempt to control one's feelings or to avoid disclosing feelings in order to not appear as if one is not coping (Stevens, 1989). Unfortunately the effectiveness of these strategies were not measured and the effect of gender, age or past experiences was not explored, however 'emotion focussed coping' was the most often used strategy.

LaMontagne et al (2004) did evaluate the strategies of adolescents coping with surgery over a 9 month period. They conceptualised coping strategies in to two categories: avoidant (e.g. not admitting to feeling worried about the operation, or to having worries; being unreceptive to information) and vigilant (e.g. seeking out comprehensive information about surgery and recovery). The teenagers in this study gave examples of avoidant coping, such as S8 (*'I just thought I'd have an operation and go...I didn't think about after'*). The literature suggests that vigilant

strategies are likely to be the most effective, using level of engagement in usual activities as an outcome measure (LaMontagne et al, 2004). DeMaso et al (2013) also suggest coping techniques that could be used with young people before surgery, such as 'active distraction', where attention is directed away from their anxieties about the situation to more positive, enjoyable thoughts. Relaxation techniques, such as diaphragmatic breathing or progressive muscle relaxation can also be an effective distraction, particularly from pain. These techniques can be useful in strengthening the young person's feelings of having some control over the situation since they are simple activities that they are able to do which also focus their attention away from the unpleasant situation (DeMaso et al, 2013).

Coping style during recovery has also been examined. A longitudinal study exploring the coping strategies of adolescents undergoing surgery for scoliosis indicated that individuals who were more successful at adopting a vigilant/problem-solving approach to coping were quicker to return to their normal activities and adopt new activities (LaMontagne et al, 2004). Vigilant coping, such as information seeking and problem-solving such as planning (e.g. resolving practical difficulties associated with the surgery) and seeking social support was identified as quickly returned to their activities. The authors concluded that preparing teenagers appropriately with information that helps them develop problem solving skills to help manage their symptoms is important. The literature suggests that older adolescents are better at employing vigilant coping strategies, presumably due to being more cognitively advanced (LaMontagne et al, 2004).

Cochlear implant surgery is a major life event for teenagers. Finding ways to provide information which is both relevant and effective, ensuring they fully understand what lies ahead and can develop effective coping strategies to reduce their anxiety may be the key to better supporting them during this crucial time.

5.3 Great expectations

The days following the switch on of their cochlear implant were difficult for all of the teenagers in this study who could remember this time, as described in section 4.4.2. Irrespective of whether they were talking about their first or second implant, the teenagers described a period of adjustment which was challenging for them in some way. Following the switching on of the cochlear implant there was an initial

sense of disappointment in the sound. There was also an awareness of needing to show commitment and effort to adjust, alongside the physical demands of recovering from surgery. As one teenager (S5) explained

'it had a lot of impact on my life and um and I had to () remember to have my cochlear implant on all the time cos if I didn't then I wouldn't get used to it as quick, so ...and I remember it was really painful. I was always, you know, regretting putting it on and () I never liked it'

This sentiment was echoed by the participants in Mather et al's (2011) study, where the teenagers were struggling to deal with the responsibility for wearing and getting used to the implant, whilst feeling anxious and unhappy that they were not making quick progress.

A likely reason for these difficulties was a mis-match between their expectations and the reality of getting used to a cochlear implant. This was particularly true for those with a second cochlear implant, presumably because they had a direct comparison. This may lead to poor motivation to use the implant so addressing this issue is important. Galvin et al (2010) recognised that adolescents with sequential cochlear implants had high hopes for additional benefit as they had 'invested a significant amount of time and emotional energy' into the process (p376). In this study, participant S6 was awaiting his second cochlear implant at the time of interview. He expressed a wish to hear well in noisy situations such as restaurants, mentioning that at the moment he could not hear his friends' 100% which he hoped would improve. Although not directly questioned about this aspect, he did not go on to express any awareness of the time and commitment involved in achieving this wish, or an appreciation of the how ambitious his hopes were.

Recent evidence from indicates that adjustment to a second cochlear implant may take up to 12 months, with most individuals benefiting from improvement by 6 months, depending on duration of deafness and with some variation in benefit in background noise or group situations (Reeder et al, 2014; Galvin et al, 2010). Outcomes such as feeling comfortable using the second implant alone or being happy using both together were found to be reached slower or not at all in some individuals who questioned the benefit of a second implant and who had a more negative attitude towards the device. Conversely, in two teenagers who

demonstrated more positive and realistic expectations such as an appreciation for the difficulties of being part of the hearing world, more areas of improvement were reported, such as better self-monitoring of their own speech, easier communication in groups and better spatial awareness (Galvin et al, 2010). Although this perception was only identified in four individuals, this anecdotal evidence suggests that an awareness of the pitfalls and an appreciation of the work involved for the teenager may lead to better outcomes.

This study highlighted that teenagers' expectations were for a straightforward, easy process. For example:

'I just knew I was going to be having another implant and I thought it was going to be like, you know, not too bad' (S5)

'Yeah I expect to have um yeah to have an operation and to have a bandage and stay at home for 3 weeks and go to Southampton up at cochlear implant to switch on' (S7)

A number of aspects about the period of switch-on of the implant and adaptation were highlighted by the teenagers. The extent of the physical pain and discomfort following surgery was frequently mentioned when asked to recount the early days with their implant. The sound of the implant after it was switched on was unexpected for many, being loud and unnatural. Other studies have also reported that teenagers' expected the initial sound to be different (Emond et al, 2013; Mather et al, 2011).

Having unrealistic expectations about the benefits of a second implant and about the challenges of adjustment may be related to non-use of the device (Emond et al, 2013). For some of the teenagers in this study there was a sense of frustration that the process of adjustment was not straightforward and took longer than was anticipated. These feelings are not unusual among young people during this stage, with Hilton et al (2013) also reporting that teenagers were surprised by the effort and commitment needed to progress. Adult patients have also reported a desire for information about the timescale from operation to being able to differentiate between sounds and first-hand information from others about what to expect at the different stages of the process (Maki-Torkko et al, 2014).

A mis-match between teenagers' own and parental expectations has also been reported in the literature (Mather et al, 2011; Emond et al, 2013). Parents and teachers of the deaf have also reported difficulties supporting young people getting used to a second cochlear implant, feeling that it was a different experience to the first and commenting that more help was needed to help them support their child after the operation (Mather et al, 2011).

There is at present no literature that has been found which explores the relationship between expectations in teenagers with cochlear implants and outcomes. However, studies exploring the expectations of adult hearing aid wearers and the resulting satisfaction suggest this is an important concept that warrants attention. There is some evidence to suggest that realistic expectations may result in increased satisfaction with the device, and better use, although the relationship is complex and not generalizable (Cox and Alexander, 2000; Schum, 1999). Expectations have generally been found to be higher than the reported outcome, with more discrepancy between measures for more challenging listening situations such as hearing conversation in noise or when there are no visual cues. Having experience of a hearing aid previously appeared to result in more realistic expectations of listening ability in a variety of conditions, whereas new hearing aid users expectations were equally high for all listening situations (Schum, 1999).

The disconfirmation-expectancy model describes the relationship between expectations and satisfaction (Oliver, 1980). The relationship between expectations and satisfaction is mediated by whether performance of the device meets expectations (confirm), exceeds (positive disconfirmation) or is less than expected (negative disconfirmation). Negative disconfirmation may result in dissatisfaction (Churchill and Suprenant, 1982). Positive disconfirmation was recommended as the optimal state, which could be brought about by managing patient's expectations so that they understood the probable benefits of hearing aids in different situations, in addition to possible problems they may encounter with the hardware or patient discomfort (Meyer et al, 2014). Disconfirmation describes the difference between a patient's expectations and performance of a device. Positive disconfirmation was seen in hearing aid wearers in a study by Wong et al (2009), where despite having very high expectations before fitting their evaluations of performance of the hearing aid were also high. Larger gaps between expected benefit and actual performance resulted in more dissatisfaction. The authors noted particularly that satisfaction was

very highly correlated with expectations for loud sounds, leading the authors to suggest that exploring patient's expectations for loudness comfort is important through careful counselling (Wong et al, 2009). One of the teenagers in this study reported that their cochlear implant was 'a massive sound' when it was first switched on so addressing this issue with them is important.

There can be other consequences of unmet expectations, apart from feeling less satisfied with a hearing device, and these have been well documented in the literature. Discrepancies between expected and actual adjustment to outcomes following major surgery or a chronic illness have been reported to negatively affect well-being such as depression or anxiety (Cao et al, 2014). Self-discrepancy theory (Higgins, 1987) postulates that this arises due to a conflict between one's beliefs about the 'self'. Any divergence between the 'actual self' and who they would like to be (ideal self) may result in a depressive state. Individuals with high expectations but lacking a realistic perspective might lead to a gap between the 'real' and 'ideal' self which self-discrepancy theory suggests may increase the likelihood of a depressive state (Higgins, 1987). Guite et al (2014) reported that aligning expectations in order to avoid this possibility could be achieved by discussing expectations at the initial contact after surgery, in a way which facilitates a desire to pursue the intervention but maintains hope for a good outcome.

Unmet expectations in parents with children with cochlear implants have been associated with stress and feelings of sadness (Hyde et al, 2010). Disappointment at switch-on and the subsequent months was also voiced (Hyde et al, 2010). Hyde et al (2010) recommend that ensuring expectations are realistic before making the decision to have a cochlear implant, and after surgery once the many months of rehabilitation has started, is essential to counteract this response.

However, understanding what is to come does not necessarily translate into realistic expectations. Mather et al (2011) reported that the teenagers felt as though they were fully aware of the challenges, including needing to work hard at rehabilitation, and the emotional impact of getting a second implant. Despite this, Mather et al (2011) reported that the adolescents were often not prepared for the sound quality of the initial switch on and the time it would take to get used to it. Additional demands such as school exams were also impacting on them, with less rehabilitation support compared to the first implant. Parents have also expressed

expecting much from the switch on of their child's implant, and that these turned out to be unrealistic. This was despite thorough counselling from professionals about the lack of an immediate improvement in speech and hearing. The parents found this difficult to accept but eventually realised that it was a time consuming process and challenging, requiring perseverance and determination. They saw the switch-on as the moment their child could hear and speak again, they were anxious to see immediate results (Penaranda et al, 2011). Some teenagers have expressed feelings of anger, disappointment and guilt at not meeting the hopes of their parents and clinicians, which is concerning (Mather et al, 2011).

Treatment burden has been described in the literature as referring to the impact of engaging in interventions in patients with chronic conditions (Sav et al, 2013). Engaging in treatment or rehabilitation can be overwhelming where adherence to regimes can be experienced as 'work'. Although applied to chronic illness, the concept may be relevant to adolescents undergoing intensive rehabilitation, particularly as they will be experiencing additional pressures in their lives such as school work and exams (Mather et al, 2011). Pressures of time, travel and finances were also cited. This concept should be explored among teenagers with cochlear implants. These negative experiences need to be managed more carefully so as to avoid a generally negative perception about the cochlear implant and the potential for rejection of the device. Teenagers have suggested how more help dealing with the emotional challenges of having a second cochlear implant might help them adjust and accept it, both before and after implantation, perhaps by talking to other users (Emond et al, 2013).

It seems that information alone is not enough to equip these young people for the challenges of having a cochlear implant, especially if it is their second. Emond et al (2013) reported that teenagers are asking for expectations counselling and more careful, sustained support to help close the gap between what they anticipate it will be like and the reality. Highlighting the realities of recovery may help teenagers feel more secure about what is to come, also providing support groups for teenagers to talk to others who understand how they are experiencing this stage of their rehabilitation, working jointly with the clinical staff (Astin et al, 2008; Penaranda et al, 2011). This is illustrated in Figure 8 which highlights how appropriate support and information provision may 'bridge the gap' between expectations and reality.

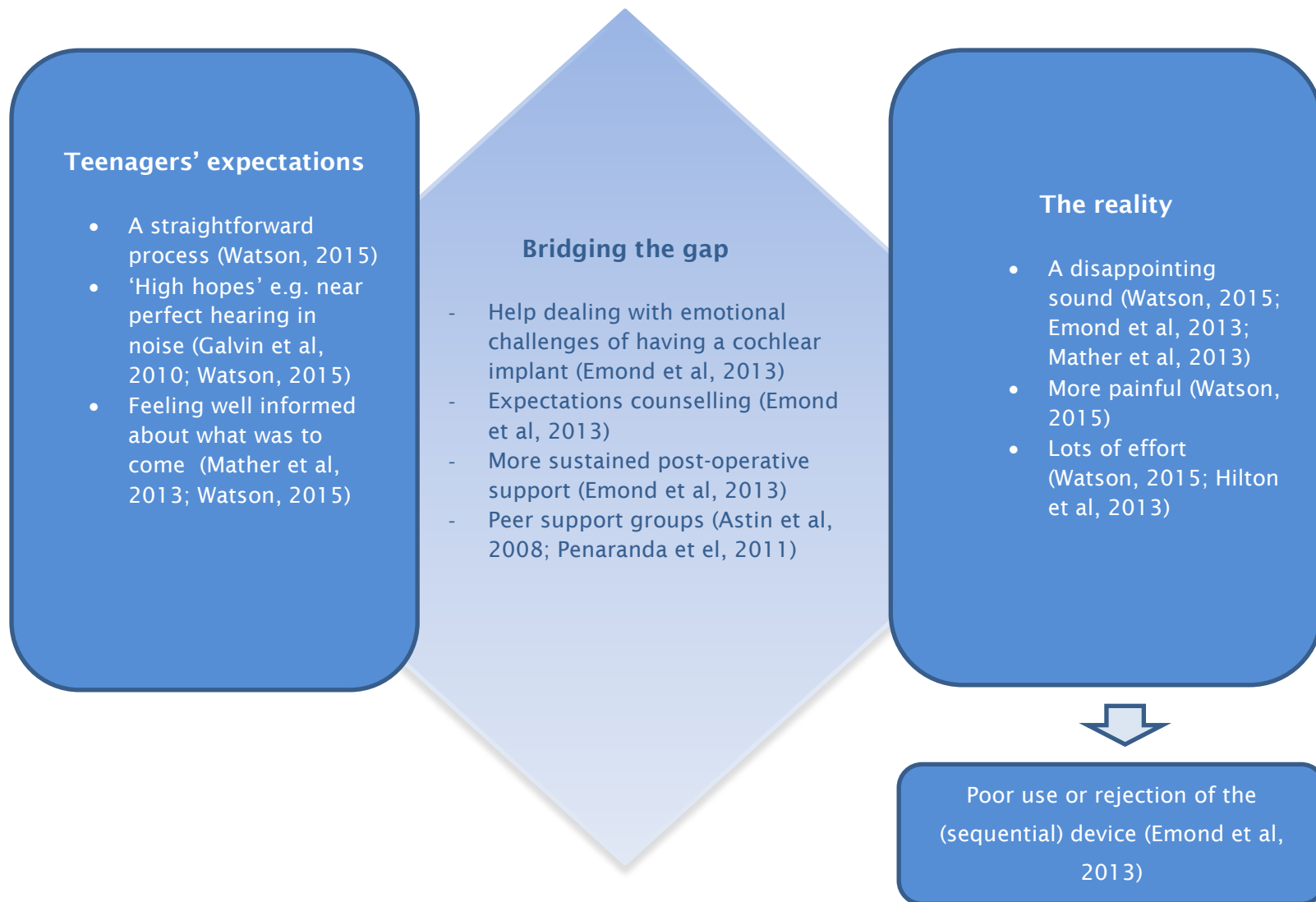


Figure 8. Bridging the gap between teenagers 'expectations and the reality of having a cochlear implant.

The counselling literature recognises that adolescence involves great deal of work in order to make the transition from childhood to adulthood and that managing a hearing loss in addition to the many other adjustments that need to be made such as finding one's own identity, becoming independent and peer group affiliation can lead to difficulties coping (Clark and English, 2014). For example, the ownership of hearing loss needs to shift from the parent to the teenager and careful support of teenagers to enable them to mutually agree goals for rehabilitation and to establish what they need to do to reach those goals can be effective in facilitating this. Strategies such as these which can be used by professionals working with teenagers during this period may enable them to cope better with what is likely to be a difficult adjustment (Clark and English, 2014).

5.4 Being in the middle of two worlds

Adolescence is a critical time in identity development. Erikson (1968) believed that adolescents need to be able to resolve who they are to enable them to go forward in to adulthood with a definite sense of self to face the challenges that lie ahead (in Cook and Cook, 2010). For teenagers with cochlear implants, their hearing status and mode of communication are additional considerations when establishing their identity as they try to align themselves with a particular group (Mance and Edwards, 2012). They are re-evaluating their deafness and where it fits into their future lives (Punch and Hyde, 2011).

Of the five teenagers in this study who spoke about their identity, three explained the ways in which their cochlear implant allowed them to fit more easily into the hearing world whilst maintaining a connection with their deafness. Two teenagers reported identifying more with the deaf (oral) world. This finding of differences in group alignment is well supported by the literature. For example, Mance and Edwards (2012) reported a similar trend when they assessed the identity constructs of 22 teenagers with cochlear implants, finding that teenagers were just as likely to perceive themselves as similar to a hearing or deaf oral person and less likely to feel similar to a deaf signing individual. Punch and Hyde (2011) reported that parents noticed their child behaved more like a hearing person with a cochlear implant yet felt comfortable with both a deaf and hearing identity. In addition, teachers perceived that it was during adolescence that there was a move towards this bicultural state. Although adolescents with one cochlear implant indicated a strong bicultural identity in a study by Wald and Knutson (2000), they rated a

hearing identity more favourably than those without a cochlear implant. Leigh et al (2009) also found that those with cochlear implants, although typically identifying themselves as bicultural, also showed a strong hearing identity. This was seen in this study, where two teenagers spoke about forgetting about their deafness, their integration into the hearing world was so successful.

The literature suggests several factors which may account for the teenagers' describing their identity in this way. Contact with hearing peers, either inside or outside of school may be associated with identifying with the hearing community to some degree (Moog et al, 2011). This is in line with this study, where despite five teenagers attending a school for deaf children, all reported having hearing friends outside of school. This is encouraging since Mance and Edwards (2012) tentatively reported a significant positive relationship between feeling close to hearing or deaf peers and psychological wellbeing, perhaps because they feel less different. Bat - Chava (2000) also proposed that by identifying positively with other members of the deaf world, which the teenagers in this study did by maintaining friendships with both hearing and deaf peers, they may achieve a positive social identity through perceiving that having a cochlear implant is normal.

It was not surprising that some of the teenagers in this study were more hearing acculturated since all had been engaged in oral rehabilitation and attended either mainstream schools or one where the oral approach to communication is emphasised. In addition, most of the participants were implanted pre-lingually and all but one had good spoken language. A similar finding was reported by Sari (2005) in their study of identity patterns in deaf Turkish students. Expectations for developing spoken language among teenagers with cochlear implants may result in perceptions of hearing being the ideal state, with teenagers in one study associating British Sign Language with poor communication skills and being less intelligent (Mance and Edwards, 2012). These young people may not want to disappoint the cochlear implant team or their parents by not meeting their expectations for oral communication which is emphasized and may lead to negative feelings. Children in mainstream schools are more likely to report bicultural and hearing identities, and this is an important determiner of self-esteem, regardless of how well they are doing with their cochlear implant (Moog et al, 2011; Bat-Chava, 2000; Leigh et al, 2009). Hilton (2013) also concluded that being in mainstream education was key to feeling part of the hearing world. This may be attributed to

the teenagers' good communication skills which make it easier for them to identify with hearing peers (Moog et al, 2011). Social comparison theory supports the notion that having a cochlear implant means better identification with hearing peers who may be perceived to be better off. Having a cochlear implant makes accessing the mainstream easier, and as a result they are achieving a positive social identity by using their hearing to assimilate into the hearing world (Tajfel, 1981; Bat-Chava, 2000). However, the use of spoken language did not predict a mostly hearing identity for all of the teenagers interviewed in this study, suggesting other factors may be important.

The deaf identities described by two of the teenagers in this study indicate that they felt deaf in an audiological rather than cultural sense, (the latter usually denoted with a capital 'D'). One teenager, S1, was keen to point out that she was not part of the Deaf community when explaining that she most closely identified with the deaf world. This may be related to the mode of communication since Deaf culture is characterised by signing. Teenagers with cochlear implants are likely to have good spoken language, as in this study. Leigh (1999) reported that deaf adults saw Deaf culture as 'a foreign concept that separated deaf persons from the mainstream' since it reduced opportunities for interactions because of differences in the preferred mode of communication and poor attitudes towards hearing (Leigh, 1999 p 240).

This distinction is not reflected in most of the theoretical models of how deaf individuals develop their identity. For example, Glickman and Carey (1993) presented in a model to show how some deafened individuals come to embrace a Deaf identity (as described in section 2.4.9). The acculturation model more closely supports the views of the teenagers in this study, although also only defines two possible identities of hearing or Deaf (in the cultural sense), with a bicultural identity being a combination of both. In this model, acculturation occurs when individuals acquire and maintain aspects of Deaf culture, whilst at the same time acquiring aspects of the (dominant) hearing culture, through behavioural and psychological changes (Leigh et al, 2009). The model shows that identification with the hearing world does not usually occur since they will always feel psychologically 'different' due to having the hearing loss. Some feel that they will never be completely hearing even if they participate fully in the hearing world.

A more recent conceptualisation of identity among adolescents with cochlear implants, and which most closely reflects the views of the teenagers in this study, was presented by Hardy (2010). Identity was broadly classified into three types: aligning oneself with deaf peers, hearing peers or 'the bridge between two worlds' (p65, with group alignment being influenced by how easily they communicated with deaf or hearing people and friendship preference and experience. The teenagers in this study also spoke about how they felt more hearing or deaf depending to some extent on who they were communicating with. Wheeler et al (2007), Rich et al (2012) and Ahmad et al (2002) also reported that identity is not fixed among young people with cochlear implants. It is flexible, with benefits to be gained from aligning oneself with the hearing world but also from being able to communicate using sign language.

One teenager, S9, strongly identified as a deaf individual. He had received his second cochlear implant one year ago and was struggling to get used to the sound. As a result he was choosing not to wear it. He reported that he had rejected his hearing friends, possibly because communicating with them had become difficult, which lead to less satisfactory experiences with his hearing peers he felt who were culturally different to him in some way. Ohna (2004) proposes that the way in which identity develops in deaf individuals is closely linked to how they interact with deaf and hearing people, and their experiences of interacting with hearing people are important. He conceptualised deaf identity into four phases, the third of which is an 'affiliation' phase, where one identifies with deaf persons and feel that hearing people are different. This sentiment was voiced by the teenager in this study. This is followed by a fourth phase, where the individual is ambivalent to hearing people. However, Ohna (2004) points out that most young people do not have sufficient life experience to reach this final stage until early adulthood. Hilton et al. (2013) also reported on a teenager with sequential cochlear implants, who was struggling with the emotional effect of having a second cochlear implant. He identified with the deaf world, suggesting that it was because he felt more dependent and needed more help to adjust. However, feeling different from their peers was valued by some of the teenagers in this and Hilton's study, as deafness was seen as an important part of their identity.

Despite positively identifying with the hearing world, the teenagers also expressed feelings of frustrations when the situation did not allow for easy communication.

There was a sense that being part of the 'hearing world' has its drawbacks since managing these frustrations can be difficult. This is consistent with previous studies examining the identities of teenagers with sequential cochlear implants (Hilton et al., 2013) and unilateral cochlear implants (Wheeler et al., 2007; Moog et al., 2011; Wald and Knutson, 2000). Hilton et al (2013) noted that the teenagers in their study were comfortable being 'deaf', as long as they could hear, and whether they felt deaf or hearing was mediated by how well they could understand. These difficulties may result in them feeling different and perhaps explains why they also prefer to maintain a link with the deaf world. These difficulties have resulted in teenagers feeling frustrated, as in this study, and sometimes excluded (Hilton et al., 2013). The teenagers in this study did not report feeling socially isolated, perhaps because some were in a school for deaf children where difficulties communicating orally are usually overcome by pupils by using sign language. In addition, many of the pupils are likely to be facing similar challenges so there is unlikely to be a feeling of difference. Five of the teenagers in this study were in mainstream education but despite this were not overly troubled by the difficulties communicating at times, although they were performing well with their cochlear implants. For them it was considered merely a nuisance, and they did not indicate that coping with it was problematic.

Two of the teenagers in this study felt that they were less different with their cochlear implant, commenting that their friends perceived them as 'normal', often forgetting they were deaf. This finding was also reported by Hilton et al. (2013). A grounded theory study with 10 adults with unilateral cochlear implants reported that adult patients felt like they had re-joined the 'real world' again following implant surgery, as they were not constantly reminded of their deafness as it no longer disrupted their ability to function (Hallberg and Ringdahl, 2004). This sense of 'fitting in' has been linked to good hearing aid use in teenagers and this effect may apply to teenagers with cochlear implants who may struggle to accept the device, particularly if it is their second (Kent and Smith, 2006; Emond et al., 2012).

The findings of this study and related literature highlight that the development of identity in teenagers with cochlear implants is influenced by several factors. Figure 9 highlights these factors and the fluid nature of this dimension.

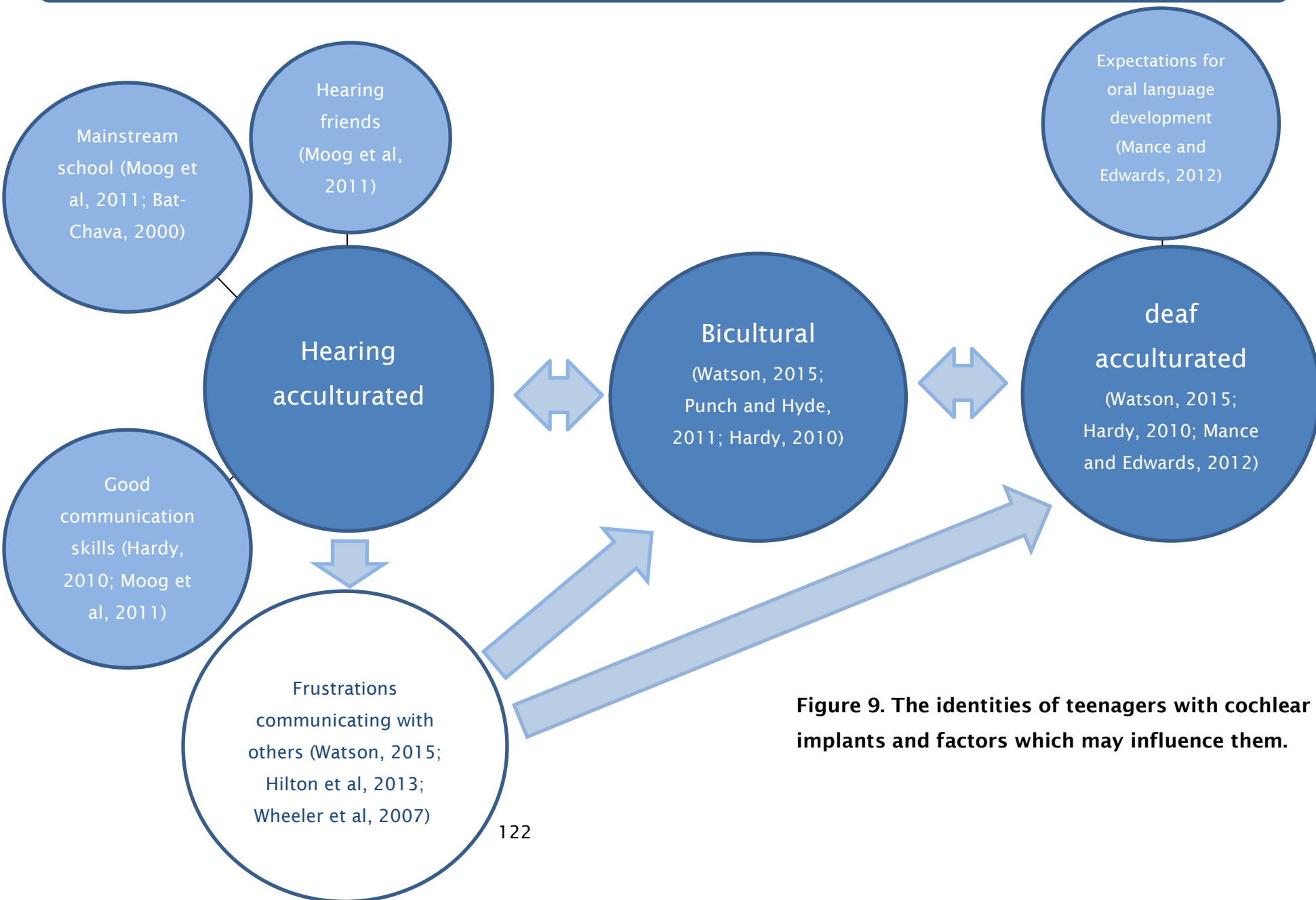


Figure 9. The identities of teenagers with cochlear implants and factors which may influence them.

It is not yet clear how identity in teenagers with cochlear implants develops throughout adolescence since the current theoretical models are inadequate. Further research is needed to explore this complex process.

5.5 Methodological challenges of researching teenagers with cochlear implants

As anticipated, conducting collaborative research with teenagers with cochlear implants was not a straightforward process. For the benefit of future researchers considering adopting this approach, the methodological challenges that were experienced in this study are outlined in order to highlight issues and possible solutions.

5.5.1 Recruitment and retention

Recruitment of participants

Due to time restrictions, participants were self-selecting, and in some cases were selected and invited to participate by a teacher or clinical staff member, based on the teenager's willingness to attend. Although this was not intended at the start of the study, recruitment was very challenging as I was working on the project one day a week and this was the most feasible method. Advertising in all of the UK cochlear implant centres, via posters, flyers and email was attempted however this approach yielded very few respondents. It is possible that some of the teenagers who did participate did so because they had a particular reason for wanting to do so, their experience being particularly extreme. This is unlikely since the teenagers' stories, although all unique, shared similar highs and lows, suggesting the group of participants in this study is fairly typical.

Parents as 'gatekeepers'

Due to the age of the participants, even in cases where the teenager was able to give their consent as they were aged 16 or older, it was necessary to also obtain the approval of their parent. This proved time consuming. When organising the interviews, emails were sent to parents to invite their child to participate. It was important to convince both the parent that the research was worthwhile in order for them to give consent for their child (if under 16 years). As the interviews were held at the cochlear implant centre the parent was required to drive the child to the

centre which may have dissuaded some parents from taking up the offer to participate. The preferred timings for interviews were in most cases immediately before or after a scheduled appointment at the cochlear implant centre which required a large amount of flexibility on behalf of the researcher which was not always possible.

Maintaining interest and level of participation

Engaging teenagers in this type of research is often fraught with difficulties, as the literature documents (e.g. Bostock and Freeman, 2003; Mack et al, 2009) and this was experienced in this study. During phase 1 of the study recruitment was not problematic. However, following the launch of the website it proved difficult to attract more than a few participants. Sixteen teenagers requested access to the website, however the process of registering may have deterred them as only seven returned their documents and consent forms. Only six comments were posted on the discussion board.

The lack of activity on the website may have discouraged other teenagers from contributing. Difficulties recruiting adolescents for an online focus group to explore their perspectives of rehabilitation care (such as occupational and speech therapy) were also experienced by Krol et al (2013). Poor response rates of 2% on the online forum were attributed to disinterest in talking about their care and the lure of social media (Krol et al, 2013). This study was competing with other, well established and popular social media websites with more attractive functionality and considerably more activity. Using an established online forum may be effective, although van der Velden and Emam (2012) reported that teenagers used social media sites such as Facebook as a place to be normal, not to disclose information about their health that marks them out as different. They used these websites for managing their social life, rather than as places to meet others with similar conditions.

5.5.2 Interviews

A number of challenges were associated with carrying out interviews with the teenagers in this study.

Building a rapport

Several teenagers that were interviewed in this study were difficult to engage with, answering questions with 'yes/no' responses. Building a rapport is important as it may result in a more engaged participant (Bassett et al, 2008). Asking the teenagers about themselves and building a rapport, albeit in a matter of minutes, helped on some occasions but a longer interaction prior to the interview, such as an informal chat in the waiting area, may have resulted in a more successful encounter. This is particularly relevant in cases where the researcher is not known to the participants, such as in this study.

Building rapport online via Skype was particularly difficult to achieve in this study, as a result of poor sound quality and interruptions during the early stages of the interview from family members. This was distracting for the teenager. Nevertheless this was a good solution where a teenager was unable to travel to the interview location, although their responses to the questions were shorter in length and breadth than some of the responses in the face to face interviews.

Interview environment not conducive to honest responses

Interviews were conducted at a cochlear implant centre or school for deaf children, due to it being more convenient for the participants. The teenagers may have perceived this environment as not private, with preconceived ideas about who was 'in charge'. It is possible they may have associated it with their other experiences where the adult, clinical staff are experts and they are the patient (Shaw et al, 2011). It therefore may have been difficult for them to speak confidentially about their experiences, or to give full or accurate answers (McDonagh and Bateman, 2013). Adolescents like to be perceived as socially acceptable and popular with their friends, which may lead them to be reluctant to talk about having few friends or struggle in social situations (Punch and Hyde, 2011). In this study the presence of a parent and a member of staff from the cochlear implant centre or school during the interview is likely to have heightened this feeling and desire to present themselves as doing well.

A number of teenagers with cochlear implants also have additional difficulties and health issues. It is likely that these teenagers' experiences will be different to those expressed here as they face additional challenges. Two participants in this study

reported having additional health problems, (S2, S8) neither teenager requiring any particular modification to the interview environment or procedure. Techniques for interviewing, location of interview and timings may need to be modified to accommodate the individual's needs, for example interviewing at home or via email if travelling is difficult.

The presence of 'gatekeepers' such as parents or clinicians is not generally recommended in interview situations, since the young person is less likely to give full or honest responses or may feel that they need to answer in a way that is acceptable to those present (Shaw et al, 2011). However, when working with teenagers it is unavoidable due to ethical constraints. To mitigate the effect of their presence, parents were fully briefed about their role during the interview and were seated out of view of the teenager. Paired or triad interviews may be an alternative approach which could counteract the power imbalance between the researcher and the young person. Although not suited to topics of a sensitive nature, it could work well if teenagers who knew each other were paired (Shaw et al, 2011).

Question suitability

One of the key aims of the research was to allow the voices of the teenagers to be heard, in order to do this open questions were asked during the interview to allow the teenagers as much flexibility as possible with their answers, whilst still addressing the main areas of interest. However, this presented some challenges. Prompts were included that presented the question in more concrete terms, to accommodate those teenagers whose cognitive abilities had not yet moved to the formal operational stage and questions were rephrased (Mack et al, 2009). This may account for some of the brevity of some of the answers, which can also be due to anxiety. As a relatively inexperienced interviewer, it was difficult to assess which of these applied to some of the less talkative participants. Future studies could give examples of how others have answered particular questions to give the teenager a feel for the level of detail and scope that is being sought.

Difficulties transcribing interviews

Transcribing some of the interviews was challenging, due either to unclear speech or a poor recording on the audio tape. Video - taping interviews may overcome this issue in future studies, although it may increase feelings of nervousness or self-

consciousness in the teenagers which may curtail their responses. Careful arrangement of the room so as to minimise the presence of a camera and time spent building a rapport with the teenagers may help counteract this problem in future studies.

Non-oral participants

Only one non-oral participant was interviewed in this study. This interview was not included in the analysis due to poor briefing of the sign language interpreter and an interview which did not reflect the views of the teenager as a result. Sign language interpreters have been used in previous interview studies, although very careful briefing of the interpreter is needed in order to record as closely as possible the 'voice' of the teenager (Wheeler et al, 2007). The wider literature also highlights some of the challenges of working with an interpreter in a research capacity. For example, interpreters may not provide a direct translation of concepts, simplifying or abbreviating responses instead. This results in a poor representation of what was actually said. Richness of the data may be compromised by shorter and less comprehensive interviews where interpreters are used (Jones and Boyle, 2011). It can also be more difficult for the researcher to build rapport with the interviewee where an interpreter is involved since the natural flow of a conversation can be compromised if there are interruptions due to misunderstandings. Researchers carrying out further studies with deaf teenagers should carefully brief the interpreter which may help clarify the researcher's expectations, as can giving the interview questions in advance (Kosny et al, 2014). In addition, videoing interviews that are voiced by sign language interpreters and asking the interpreter to verify the transcription by comparing it with the video recording is recommended to enhance the quality of the data (Jones and Boyle, 2011).

5.5.3 The use of online methods to collect data

The literature suggests that online discussions are generally viewed favourably by teenagers and have been successfully used in previous studies with this age group, investigating sensitive topics (Valaitis and Sword, 2005). However, this was not the case in this study, where engagement with the website was poor. There are several barriers to online discussions which include a lack of time, lack of access to a computer, difficulties using the website and lack of interest in the topic being discussed (Valaitis and Sword, 2005). It is possible that some, if not all, of these

barriers apply to this study although it would be interesting to investigate these among teenagers with cochlear implants for future research. Another issue that has been discussed in previous studies engaging teenagers with online discussions is the misunderstanding on the teenagers' behalf that it would be an opportunity for synchronous chats, with the expectation that someone would always be available to talk to (Mason and Ide, 2014). In this study very few teenagers initially accessed the website and to a new user it probably appeared to be an unpopular website to visit.

The question of how to increase participation for this type of data collection is difficult to answer. Monetary incentives vary in their effectiveness, being more effective for younger male participants (Valaitis and Sword, 1995; Punch, 2002, Cooper-Robbins et al, 2011). Social benefits have been cited as an attractive reason for participating in research, meeting new people being particularly attractive to female participants (Cooper-Robbins et al, 2011). Online methods of data collection are well suited to facilitating this interaction, perhaps future studies using websites would benefit from a greater emphasis on the social aspects of the research.

Possible barriers to participation experienced in this study include concerns about confidentiality or being judged by the researcher. Mason and Ide (2014) report that email interviewing can overcome these issues, teenagers citing benefits such as being able to respond in their own time without concerns about privacy. Teenagers felt more in control and appreciated having the distance to reflect on their answers. In addition, participants responded well to the researcher reminding them to participate. Faster methods, such as instant messaging, were cited by the teenagers as preferable, however (Mason and Ide, 2014). Although a preliminary study, this suggests that future research with teenagers might benefit from such an approach.

The successful use of social media to engage teenagers with cochlear implants in future studies may not be guaranteed, despite the obvious advantages.

5.6 Experiences of working in a collaborative way with teenagers with cochlear implants

There is no literature that has been found that describes involving teenagers with cochlear implants in the research process in the ways described in this study. Although quantifying the benefits of collaborative working was not an aim of this

study, it is an important area for future research. Therefore, the benefits of working with teenagers with cochlear implants in a collaborative way, for the teenagers and the study, are now outlined.

5.6.1 Reflections on the process of involving teenagers in the research

Several benefits of working with the teenagers were identified during this study and it is an approach which is recommended for future research with this population, despite the obvious challenges which can mostly be overcome with thoughtful planning and the use of the right approach to engage them.

In section 3.4, the potential benefits to the research process of involving teenagers were discussed. The ways in which the teenagers contributed to this study, and how future studies could benefit from the involvement of teenagers are highlighted below:

- They provided valuable input to guide the development of an appropriate method to use and subsequently its design. Participants showed a keen interest in the topic and freely shared ideas in a group setting.
- Accessing participants was facilitated by some of the teenagers in this study. For example, the two initial members of the website forwarded the website recruitment email to others.

Benefits to the teenagers are harder to quantify, particularly as these were not measured. However, my observations were that:

- During the Skype meeting in stage 3 of phase 1, several of the teenagers recognised each other online from their participation in other social activities. They spent some time chatting online before we started the discussion. This indicates that there may be some social benefit to them taking part in the research process since it allows them to catch up with friends. This could be exploited in future studies.

- The facilitated group work in phase 1 was very successful. Staff members at the school where the meetings commented on how well the teenagers interacted and that it was a good opportunity to develop group working skills.

For future studies, formally evaluating the benefits to this population of participation in research in this way is worthwhile since the literature suggests that participation may enhance their personal development (e.g. increased confidence, self-esteem) and extend their social networks (Shaw et al, 2011). These are particularly desirable outcomes for a population which may face challenges in developing these skills otherwise.

5.7 Evaluation of the quality of this study

As detailed in section 3.8.7 participant checking of the analysis was undertaken to examine whether the findings were a credible reflection of the teenager's experiences. The teenagers agreed with the themes, and cited the decision making and operation as the most significant aspects of the experience for them. The sub-theme 'I wanted to get it over with' particularly resonated with them. They all strongly agreed that the operation was a difficult time because they were worried about what was going to happen. They reported that their fear was associated with it being an operation involving cutting into their head which worried them more than if it had been another area of the body. This confirmed my interpretation of the operation being a significant event and that a lack of understanding underlies at least some of the anxiety around the operation.

A reflective approach was adopted throughout the study so that the impact of the researcher on the research was clear (Houghton et al, 2012). The processes involved in template analysis encouraged reflexivity, for example successive versions of templates were kept with comments justifying why it was developed in such a way. Reflective notes were also kept during the development phase of the study to encourage self-awareness. The notes included my impressions of working with the teenagers, my possible influences on the processes, such as my preconceptions about the group meetings; and how these may impact on the study. For example, as discussed in section 3.8.1, I considered whether my status as an adult female who works at the University may influence the teenager's perception of me as a person

of power, which may have shaped their responses. To minimise the power differential an informal, relaxed environment was created for the interviews and I wore informal clothing.

Individual interviews were well suited to this paradigm since they capture the meanings that individuals make of their interactions with the world (Weaver and Olson, 2006). The challenges and issues need to be identified by those who have experienced the event as meaning is unique to each individual (Houghton et al, 2012). Silverman (2011) discusses some key indicators of reliability in interviews which were present in this study. For example, to ensure I interpreted the interview transcripts accurately, pauses or overlaps were included to preserve the meaning and context. To attempt to standardise the teenager's understanding of the questions a schedule was followed and the wording remained the same (unless the teenager could not understand the question). Credibility was also ensured by asking open questions, so that the participants could talk about issues of importance to them.

5.8 Summary

This chapter explored three key aspects of the teenagers' experiences that were highlighted by the findings. It also outlined the methodological challenges encountered and possible benefits for the participants and the researcher.

This chapter highlighted how the pre- and post- operative period can be a difficult time for teenagers awaiting a cochlear implant. As discussed in section 5.2 this study generated new and important knowledge of this time that had not previously been reported in the literature. This demonstrates the importance of involving teenagers in the development stages of a study in generating more valid data that reflects the actual issues of relevance to this population. The teenagers also reported significant post-operative pain which had not been highlighted in previous studies. Better pre- and post- operative support is indicated, such as individualised information provision and help to develop coping skills to manage their anxiety. This tailored support may also positively impact on their recovery such as reducing post-operative pain.

Adjusting to a cochlear implant, whether the first or second device, is challenging for these young people and careful management of their expectations is needed to

ensure a positive experience and to avoid rejection of the implant. Theory relevant to understanding the complexities of identity among teenagers with cochlear implants was discussed, such as Hardy's (2010) conceptualisation of dual identity ('the bridge between two worlds') and the acculturation model of Maxwell-McCaw and Zea (2011) to explore why the young people reported being part of the hearing world yet still choose to maintain a connection with the deaf, but not Deaf, world.

The findings highlight that living with a cochlear implant as a teenager can be challenging. This study increases an understanding of the issues of importance of them by extending the current knowledge of key aspects of their lives and adding new insight into their experiences of surgery.

Chapter 6 includes a summary of the main findings, reflections on the research process and suggestions for future research. Clinical recommendations are also made, based on the findings of this study.

Chapter 6 Conclusions and recommendations

6.1 Introduction

This chapter concludes the thesis by drawing together the clinical implications for services supporting teenagers with cochlear implants, based on the findings of this study. There is also a discussion of my reflections on my involvement in the study. Directions for future research in this area are also outlined.

The aim of this study was to explore in more depth and breadth the experiences of teenagers with cochlear implants, than had previously been documented. This was achieved by including elements of collaborative working to give prominence to the teenagers' perspective. To date, the literature concerning teenagers with cochlear implants is sparse, particularly where it explores psychosocial outcomes. Only three other studies have explored the experiences of teenagers with cochlear implants using qualitative methods. These studies did not attempt to involve the user in the early stages of the research process, using interview schedules devised by professionals. This study used a more collaborative approach which revealed new knowledge about the significant impact of surgery and added to the current understanding of the benefits and challenges of living with a cochlear implant as a teenager.

The findings revealed a detailed picture of the experiences of teenagers who have cochlear implants. They faced challenges before and after cochlear implant surgery. In the days leading up to the operation the teenagers had to manage conflicting feelings of optimism and a desire to 'get it over with', whilst needing to make sense of all of the information that was presented to them. Great anxiety about the operation was expressed by most participants, relating to an uncertainty about what was to happen and facing unknown outcomes. Their comments suggested that more effective information provision and help managing the emotional response to the event is warranted. The extent of their anxiety had not previously been reported in studies such as Wheeler et al (2007), Mather et al (2010) or Hilton et al (2013). This study therefore adds important knowledge to further the understanding of the pre-operative experience.

Following this difficult time, the teenagers encountered further struggles recovering from surgery whilst also learning to adapt to the new device. They were faced with

the responsibility of managing their cochlear implant and needed to commit to an intensive rehabilitation programme all of which took longer than anticipated. The findings indicated how the mis-match between their expectations and reality might impact on this time. This gap between expectations and reality has not previously been discussed in detail in the literature. This study adds further weight to an argument for more effective management of expectations and better more sustained support following surgery to help them cope with the demanding process of rehabilitation. This seems to be particularly relevant for teenagers receiving a second cochlear implant.

Despite this trying time, the teenagers mostly expressed feelings of satisfaction and relief, feeling that the results were worth the struggle. The teenagers reported benefits which impacted on many different areas of their lives, such as helping them to feel more independent and more socially involved as they were now able to interact with others more normally, which helped them to feel relaxed. The cochlear implant made a difference to many areas of their lives, resulting in them being able to more easily function in the hearing world. This finding has added knowledge to our understanding of the psychosocial outcomes of cochlear implantation in teenagers that are often overlooked. The teenagers also demonstrated a maturity in their reflections on the process, indicating that whilst they enjoyed many benefits they were accepting of the limitations of the implant.

The ways in which teenagers who wear cochlear implants conceptualise their identity has also been revealed in detail in this study. The cochlear implant allowed most to forget about their deafness as they felt less different than their peers. The teenagers who considered themselves to be hearing also spoke of the difficulties associated with being deaf in a hearing world. For some, maintaining their connections with the deaf world became particularly prominent when trying to listen in challenging situations. They recognised that letting go of their deaf identity entirely could lead to difficulties hearing when others stopped making allowances for their hearing loss. The two participants who reported a deaf identity made a clear distinction between being deaf and being culturally Deaf, the latter being less desirable perhaps due to this culture's norms which are very different from the mainstream. Some of the other teenagers' accounts highlighted that they were comfortable being part of two worlds, some seeing it as an advantage when they were able to benefit from the best parts of both. These findings support previous

work which also highlighted the complex and flexible nature of group identification in teenagers with cochlear implants.

6.2 Reflections on my involvement in the study

Working part-time on this PhD presented challenges related to the collaborative element of the approach which I did not anticipate. When trying to recruit teenagers to use the website I realised the importance of being available to respond quickly to email requests, particularly with teenagers who lead busy lives with other online resources competing for their attention. This was not always possible due to my working hours and suspending my PhD registration for two years to have children. Due to my sporadic working pattern it was difficult to maintain contact with the teenagers who volunteered to participate in the early stage of the study, or to respond to requests to join the website in a timely manner. As a result, several participants were 'lost' at this stage of the registration process. Working successfully in a collaborative style with individuals requires sustained effort on the part of the researcher, and this is particularly true when working with teenagers who lead busy lives. The teenagers that contacted me were eager to be involved in the development phase of this study, suggesting there is the potential for successful collaborations if the process is managed carefully.

I am a Clinical Scientist and have worked with teenagers with hearing aids in a previous role within the NHS. I do not have any clinical experience of working with patients with cochlear implants. Whilst this may have disadvantaged me when talking to the teenagers about their experiences, it may have resulted in the teenagers disclosing details that they might not have otherwise mentioned to someone with more knowledge of the field. Although I was not known to the teenagers and this may have been disadvantageous in terms of rapport building, I hoped it meant they felt able to talk openly without implications for their clinical care. Unfortunately I had limited time in which to get to know the participants before interviewing them as the interviews needed to be scheduled immediately before an appointment at the cochlear implant centre or after the final school lesson of the day. I tried to ensure that the interviews were not compromised by chatting to the participants whilst setting up the room and recording equipment.

The teenagers that met to design the website in part i) of Phase 2 worked together better than I had expected. As a result I did not allow enough time for the session which ended with comments from the teenagers expressing disappointed that they could not continue for longer. However, in the time that we had there was a lively discussion and many helpful suggestions were made. This indicated to me how my assumptions of teenagers not wanting to engage with each other in a group setting might negatively impact on the process, and that this was something I was conscious of when planning future meetings or interactions with the teenagers.

I realised the importance of monitoring how I was feeling during reading of the transcripts to avoid any feelings I had towards the interviewee influencing my interpretation of the data. One participant talked about how he had decided to distance himself from the hearing world as he did not enjoy associating with hearing people. My impression of him during the interview was of a teenager who was different to his peers and my overriding feeling, due to the way he spoke and his slightly awkward behaviour was that he had been subject to some exclusion from his hearing peers which had led to him rejecting them. I was careful to avoid this assumption as he did not describe this happening but it highlighted how I needed to be vigilant against feeling sorry for him and interpreting his comments as spoken by a 'victim'.

Approximately half way through carrying out the interviews I enrolled on a counselling course for Audiologists, to develop my teaching role at the University. I noticed that the course had an effect on my interview technique where I had learnt skills designed to help me to more effectively identify and manage when a patient is giving an emotional response. Techniques such as allowing the participant space to think and respond during recounting a difficult time such as the operation enabled me to draw out more of the response. Making more use of non-verbal cues to demonstrate empathy and that I would like the participant to continue talking also enhanced my interviewing technique, allowing for fuller responses from the participants. As I was new to interviewing and found this to be challenging, this training proved invaluable, particularly when interviewing an age group which can be difficult to engage with.

6.3 Future research

Although the findings of this study add much to the current knowledge base, there is still a dearth of qualitative research exploring the needs of this group, relative to the paediatric and adult cochlear implant populations. This may be partly due to relatively small numbers and teenagers being a difficult group to recruit and retain. Future research needs to address this gap so that better support can be provided. Suggestions based on the findings of this study are:

- There are no published patient-reported outcome measures (PROMs) for teenagers with cochlear implants, although this study suggests some domains which may be relevant. Further in depth interviews with teenagers from the wider population are needed in order to generate items for a preliminary instrument. Only teenagers with pre-lingual deafness were interviewed in this study. Individuals with post-lingual deafness may have a different experience since they are fewer in number and this needs to be explored in future studies. In addition, further work is needed to better understand how the experience of the first and the second cochlear implant differs and whether different support is needed for these two groups.
- A more accurate theoretical ‘model’ of adolescent identity with unilateral and sequential cochlear implants is needed if we are to understand more about the impact of being acculturated with the hearing and deaf worlds as teenagers move into adulthood. In depth case studies may reveal the factors which influence identity in teenagers with cochlear implants, in particular the ways in which their hearing histories influence their alignment with the deaf or hearing world. The number of devices worn, use of spoken language and type of schooling did not appear to predict identity in the teenagers in this study so further work is needed to explore these and other factors.
- There is the potential for development of a website for information and support, teenagers in this study indicating that they would use an online resource to socialise and gain support from other teenagers.
- The findings of this study highlighted the importance of realistic expectations before receiving a cochlear implant. Further research is needed

to explore the expectations of adolescents before getting their cochlear implant and to assess whether these were met, to identify what could be done to close the gap. A questionnaire could be developed based on interviews with teenagers with cochlear implants to identify appropriate expectancy domains.

Although the interviews increased the knowledge of a number of important aspects of the teenagers' experiences beyond what was already known, the number of participants was small and the interviews were limited by the time commitments of the participants and their willingness to talk at length to a researcher.

Consequently, some issues raised by the teenagers were not fully explored during the interviews, although they stood out as aspects of their experience which merit further investigation. They included:

- The teenagers' experiences of being on the hospital ward. This was not explored in this study so there is a gap in the understanding of this aspect of getting a cochlear implant. The teenagers who attended the cochlear implant centre in this study were admitted to a paediatric ward, rather than one organised around the needs of teenagers. Interviews with young people admitted for planned surgery revealed that being on a paediatric ward could be difficult due to sharing their space with very young children and not having access to age appropriate entertainment (Bray, 2007). In the past, nursing staff have received training from staff at the cochlear implant centre involved in this study, in order to ensure the communication needs of deaf teenagers are met whilst they are on the ward. However, this has not occurred recently and the teenage co-ordinator reported that the nursing staff are likely to have changed over time. It is important for the cochlear implant team looking after the teenager to have knowledge of their time on the ward since although their key worker visits them following surgery this contact is brief and not re-established until the teenager is at home several days later. This 'gap' in service delivery requires investigation as it may account for some of the findings in this study which were related to the post-operative time such as difficulties coping with the physical effects of surgery and the impact of recovery on their everyday lives.
- Non-use of the second implant and identity. Participant S9 was a 'lone voice' in this study, identifying himself as deaf and disliking the sound of the

second implant to the extent that he chose to remove it. This was not the case for the other teenagers with bilateral implants in this study, who continued to wear both and felt connected to both the hearing and deaf world. Factors which lead to non-use of implants have been identified in a recent study although the role of identity was not explored (Emond et al, 2013).

- The decision to have a sequential cochlear implant as a teenager and the roles of others in this process. Participant S6 commented on the involvement of his parents in making the decision to have a second implant but the roles of the teenager and other significant people in their lives in making this decision have yet to be fully explored. This may have implications for the support clinical teams provide for those involved in the decision making process.

6.4 Clinical implications and recommendations

Although there is a gradually increasing awareness of the issues faced by teenagers with cochlear implants, this has not yet informed service provision. This study has highlighted gaps in the current guidance. For example, the most recent Quality Standards document from the National Deaf Children's Society and the British Cochlear Implant Group detailing guidelines for professionals working with deaf children and young people, does not include guidance on information provision or other support prior to surgery or in the early stages of getting used to the cochlear implant (NDCS, BCIG; 2010).

There is scope for further development of service provision for teenagers with cochlear implants. The findings from this study suggest a number of clinical recommendations:

- Adjusting to a second cochlear implant was difficult for five of the teenagers interviewed in this study. Expectations need to be managed more carefully in the pre-operative stage and once rehabilitation has started when the challenges of adjustment to the sound of the implant and the responsibility for wearing it begin. The teenager's key contact (usually a rehabilitationist) and psychologist could jointly provide this support to ensure a comprehensive approach to managing expectations, which is offered over a

longer period of time. This seems to be particularly important when the teenager is adjusting to the second implant where the sound is likely to be less acceptable.

- Psychologists and other clinical staff involved in the care of teenagers who are awaiting their cochlear implant should pay more attention to the significant emotional impact of surgery, which for one young person in this study was so extreme he had decided against any further operations. Whilst there appears to be a good deal of information detailing the practicalities of having a cochlear implant, such as the arrangements for the day of the surgery and some aspects of the recovery process, little attention is currently given to the emotional impact of the procedure and how to manage these feelings. The teenager's rehabilitationist could establish early on in the process the information needs of each individual and how these can best be met, working with the psychologist to help the teenagers learn coping skills to be able to manage their anxiety before surgery. Paying more attention to their thoughts and feelings and perhaps giving them the opportunity to express these, individually or in a group, may be beneficial; both pre and post operatively. Whilst there may be an assumption that teenagers receiving their second implant may require less input than those being fitted with their first device, the findings from this study indicate that teenagers receiving their second implant require the same level of support in coping with the pre and post operative time than those who are experiencing it for the first time.
- Long, tiring appointments at the cochlear implant centre were mentioned by almost every teenager interviewed in this study. Many travelled long distances and found the experience at the implant centre draining. More outreach services for teenagers who lead busy lives may be appropriate, or remotely carrying out the appointments where possible. Although one of the teenagers in this study joked that missing school to attend appointments could be a positive outcome, teenagers are often concerned about falling behind with their work. This was mentioned at the participant checking meeting in this study and in Hilton et al (2013).
- Information and support about the likely difficulties they will encounter with their cochlear implant may reduce some of the teenagers' frustrations as they

strive to be part of the hearing world but with the restrictions that being deaf imposes. Having two cochlear implants does not entirely mitigate listening difficulties so ensuring that they and those they are communicating with have an awareness of the limitations of their cochlear implant, particularly when they have two (when expectations may be even higher), and how best to cope with situations where the environment is not conducive to good communication, is important.

The findings of this study indicate that the model of support and information giving that is used by the cochlear implant centre featured in this research may not be fully meeting the needs of teenagers. At this centre, patients meet with a clinical psychologist to discuss their thoughts and feelings about getting a cochlear implant around two months before surgery. Following this there is likely to be an opportunity to meet with their 'key contact', a rehabilitationist who talks the patient through what to expect before, during and after surgery; including what the tuning of the cochlear implant might be like. There may be an opportunity to visit the hospital if the patient is particularly anxious but this is not routinely offered. The patient meets with the surgeon a few days before the surgery to discuss the procedure and what to expect afterwards in medical terms. The key contact is present on the day of surgery to address any last minute concerns and offer support.

Therefore, based on the findings of this research, it is recommended that:

- the information about the procedure should be given earlier, perhaps during the meeting with the psychologist where the rehabilitationist could facilitate a discussion,
- information is presented in a variety of formats, including utilising online resources,
- peer support/mentoring is used, perhaps via an online information tool
- there is more comprehensive information based on the key elements identified in the literature.

These recommendations were shared with the co-ordinator of the teenage service, the teenage rehabilitationist and psychologist at the cochlear implant centre involved in this study. The teenage rehabilitationist and psychologist agreed that there was a need to better support teenagers following surgery and that the

findings from this study regarding the difficulties adjusting to the device and coping with post-operative recovery reflected their own experiences with the teenagers at the centre. Consequently a change in service delivery for teenagers has been implemented. An appointment with the psychologist will be offered to all teenagers following surgery, in order to address any issues which previously would not have been identified for up to two weeks following surgery, and not usually with a psychologist. In addition, there were discussions regarding how to more effectively present information regarding the process, including the surgical procedure and expectations following switching on of the device. The team proposed recording videos of teenagers discussing their experiences which could be accessed by teenagers online, with the opportunity to discuss with their rehabilitationist.

6.5 Summary

This research has highlighted the issues of importance for teenagers with cochlear implants, adding new insights to what was already known. This was achieved by involving the teenagers in the development stage of the study which gave more prominence to their voices than had been achieved in previous studies. The value of this approach was demonstrated as it highlighted aspects of their experience of surgery that had not been previously reported in the literature, leading to clinical recommendations to better support this population.

As the numbers of teenagers receiving sequential cochlear implants are increasing, there is emerging evidence that non-use of the second device is becoming more prevalent. For example, in one UK cochlear implant centre the partial or non-use rate was reported to be 15% (Emond et al, 2013). Under-use of the implant has also been reported in adolescents with monaural devices, even where hearing outcomes such as speech perception are good (Bosco et al, 2013). Possible reasons for rejection have been eluded to this in research, such as unmet expectations, but there are likely to be other factors involved which need to be explored. Research such as this adds important knowledge of teenagers' unique needs but there is more to be done if services are to fully address them. It is more important than ever to listen to the voices of teenagers.

Appendix 1 Examples of literature search terms used

Key search terms
<p>Adolescent, adolescence, teenager, young person, young people</p> <p>Deaf, deafness, hearing impaired</p> <p>Experience, perspective, views, voice</p> <p>Qualitative, interview</p> <p>Cochlear implant</p> <p>Education, school, career</p> <p>Friends, family, psychosocial, quality of life</p> <p>Identity</p>
Boolean operators used
<ul style="list-style-type: none"> • 'AND' was used to combine terms which were different (e.g. 'adolescent AND 'cochlear implant' AND 'experience') • 'OR' was used to search for literature including similar concepts (e.g. 'teenager' OR 'adolescent') • Truncation (*) was used to ensure literature outside of UK was included e.g. 'p*ediatric' and used at the end of words to retrieve articles indexed with variations of the word (eg. 'adolescen*' retrieved 'adolescent' and 'adolescence') • Parentheses were used (e.g. (adolescent OR teenager) and 'cochlear implant') to ensure that only the cochlear implant literature regarding teenagers or adolescents was retrieved.

Appendix 2 Phase 1: Website development questionnaire



Would you like to help design a website?



Hi

My name is Vicky Watson. I am a researcher at the University of Southampton. Before I joined the University I worked in hospitals for several years. Part of my job was fitting young people with hearing aids. I am now interested in finding out more about what it is like to be a young person who wears a cochlear implant.

I would like young people with cochlear implants to help me design a website. The website will be for other young people to use, so that they can talk about what it is like to have a cochlear implant. I can then read what they have written on the website to try to understand if having a cochlear implant affects their lives, and in what kinds of ways.



This questionnaire is your chance to give me your ideas about what the website should look like. I would like to make it interesting and fun to use, as it may be seen by young people from all over the world! So your ideas really matter! Think about what would make YOU want to use it.

Q 1. What should the website look like? You could think about your favourite websites – what do you like/dislike about them?

Q 2. Would you like to be able to talk to other young people on the website about having an implant? If so, how would you like to do this? (e.g. chat room, discussion board).

Q 3. Would you like to be able to write about your own experiences of having an implant? If so, how would you like to do this? (e.g. blog)

Q 4. What sort of other things would you like to be able to do on the website?

Q 5. Do you already use a website or internet group for young people with cochlear implants?

If so, please tell me about it:

Do you have anything else to say?

THANK YOU VERY MUCH FOR YOUR HELP!

Appendix 3 Phase 1: Demographic questionnaire

Title of study: Exploring the experiences of teenagers with cochlear implants

REC number: 10/H0501/28

Participant identification number:

Thank you for answering these questions. The information you give will help me understand more about your experiences with a cochlear implant.

Questions about you	
What year were you born?	
Are you male or female?	
Do you have any health problems?	
What school do you go to?	
Questions about your hearing loss and cochlear implant(s)	
Do you know what caused your hearing loss?	
How long have you had a hearing loss for?	
How old were you when you got your cochlear implant?	
Who decided that you should have a cochlear implant? – myself/parents/professional/ don't know	
How often do you use your cochlear implant?	

Questions about your hearing loss and cochlear implant(s)	
Do you wear 1 or 2 cochlear implants?	
If you wear 2, did you get them both at the same time or one at a time?	
Do you wear a hearing aid in the other ear? If yes, how long for?	

Appendix 4 Phase 2: Interview topic guide

Introduction:

There are no right or wrong answers. It is your views that I want to explore.

Are you happy for me to record the interview?

1. Did you decide to have a cochlear implant or did your parents? How did you/they decide?
2. (If answer to Q1. Is 'no') Do you know anyone who decided to have a cochlear implant? How did they decide?
3. What was life like before your cochlear implant?
4. How did you feel about having the operation? What was it like?
5. Tell me about the recovery/early days with your implant.
6. What was the switch on like?
7. What do you like about having a cochlear implant?
8. What do you dislike about having a cochlear implant?
9. Tell me what it's like coming to the cochlear implant centre for your appointments.
10. Is there anything you would change about them to make the experience better?
11. Do you think having a cochlear implant affects how you are with your friends and family?
12. Do you think having a cochlear implant affects work/school/college?
13. How do you see yourself? Deaf, hearing, or both?
14. What advice would you give to someone thinking about having a cochlear implant?
15. Is there anything you would change about your cochlear implant?
16. Is there anything else you want to say that would help me understand what it's like to have a cochlear implant?

Appendix 5 Phase 2: Data analysis excerpt

Appendix 5.1 The development of codes

Data excerpt	Coded data	Code
<i>S5: Um yeah I think I did and then I had to have it you know because if there was like a tap or anything it wouldn't just be quiet you know</i>	if there was like a tap or anything it wouldn't be just quiet	Hearing every sound
<i>it would be like you know a massive drum being beaten in your ear</i>	it would be like a massive drum being beaten in your ear	A big sound
<i>it was like that and um you know so every tiny sound I could pick up and it wasn't quiet, every sound was you know twenty times as big so it was um it was um when it first switched on like it was you know like a massive commotion</i>	Every tiny sound I could pick up and it wasn't quiet Every sound was twenty times as big Like a massive commotion	Hearing every sound A big sound A big sound A big sound
<i>and um when I was walking around the house I'd have to walk quite quietly and everyone else would have to speak really quietly to me because you know it was such a big sound and everything</i>	I'd have to walk quietly Everyone else would have to speak really quietly to me It was such a big sound	Difficult to act normal A big sound A big sound

<i>I think I was I felt quite um I would feel kind of sort of irritated sometimes</i>	I would feel sort of irritated	Feeling irritated
<i>cos it was a bit you know um it was a bit difficult to kind of um you know act normal without having to you know be really careful</i>	A bit difficult to act normal Having to be really careful	Difficult to act normal Needing to be careful
<i>and also you know I think I got you know I really hated having it you know having to put it on because when I took it off I felt relaxed like 'phew I can have it off'</i>	I really hated having to put it on When I took it off I felt relaxed 'phew I can have it off'	Hated wearing it Unable to relax
<i>and then when I you know had to put it back on you know it was um it was I had to you know kind of sometimes got a lot of headaches and I got um a lot quite tired quite a lot as well because I was having to you know concentrate a lot so</i>	A lot of headaches Quite tired a lot Having to concentrate a lot	Headaches Tiring Needing to concentrate

Appendix 5.2 The development of codes into sub-themes and a theme

Codes	Sub-themes	Theme
Feeling irritated Hated wearing it Hearing every tiny sound A big sound Tiring Headaches Pain*	A burden to wear	I never liked it
Difficult to act normal Needing to concentrate Unable to relax Unable to do usual activities* Cabin fever*	Normal life is on hold	

*these codes were not identified in this data excerpt but were identified in other transcripts

Appendix 6 Final template

Over-arching theme	Theme	Sub-themes
	A big jump	<ul style="list-style-type: none"> • Hoping for some improvement • Wanting to get it over with • A lot to take in
It had a big impact on my life	A horrible experience	<ul style="list-style-type: none"> • Feeling scared about the operation • Unclear expectations about recovery • Feeling a complete wreck
	I never liked it	<ul style="list-style-type: none"> • A burden to wear • Normal life is on hold
	Sometimes you just want to switch off	<ul style="list-style-type: none"> • Using up all your hearing • Positive regard for clinical service • A long wait
It was worth it in the end	Makes life all round easier	<ul style="list-style-type: none"> • Feeling better about myself • A better understanding of the world • Hearing things I haven't heard before • Listening without effort
	Not a magical thing	
	Belonging to both worlds	<ul style="list-style-type: none"> • I forget I'm deaf • deaf not Deaf • Connecting with both worlds so I can hear

Appendix 7 Transcript excerpt

I: Alright, so first question I guess is when you got your implant? How long have you had your implant for?

S5: Um well I had I got my right one when I was 14 months and um I got my left one when I was [8

I: [OK

S5: [So that's quite a big difference [yeah

I: [Yeah OK. And do you remember anything about when you got your left implant, do you remember anything about that time?

S5: Um well I think it was when I when I was having my operation I remember it was it was quite a difficult time because it was a lot of um you know a lot to kind of take in... and um it was quite a big jump, and I remember when I was putting on my implant it was it was really quite painful it was you know a massive you know a massive sound because I haven't had it um you know I haven't had um in it in my ear for quite a long time so it was really um it was quite painful and having the operation was quite a big thing as well so um so [yeah]

I:[OK] so when you say it was quite a big thing having the [operation

S5: [Yeah

I: What do you mean by that?

S5: Um well it kind of um it had a lot of impact on my life and um and I had to you know remember to have my cochlear implant on all the time cos if I didn't then I wouldn't get used to it as quick so um and I remember it was really painful I was always you know regretting putting it on and I was I never liked it but now it's fine I like having it on [so]

I: [OK], ok. And were you worried about having the implant at all? Do you [remember any]

S5: [Well] at the time I was quite young so I didn't I didn't really worry about it too much cos I wasn't old enough to really know what it was all gonna be um

you know all about I just knew I was going to be having another implant and I thought it was going to be like you know not too bad cos obviously I don't remember having the first [one

I: [Yes

S5: So um yeah I think it um yeah

I: Mmm. OK, ok. And do you remember when the implant was switched on; do you remember what that was like?

S5: Um yeah I think I did and then I had to have it you know because if there was like a tap or anything it wouldn't just be quiet you know () it would be like you know a massive drum being beaten in your ear it was like that and um you know so every tiny sound I could pick up and it wasn't quiet, every sound was you know 20 times as big so it was um it was um when it first switched on like it was you know like a massive commotion and um when I was walking around the house I'd have to walk quite quietly and everyone else would have to speak really quietly to me because you know it was such a big sound and [everything

I: [Mmmm. And how did you feel about that at the time?

S5: I think I was I felt quite um I would feel kind of sort of irritated sometimes cos it was a bit you know um it was a bit difficult to kind of um you know act normal without having to you know be really careful and also you know I think I got you know I really hated having it you know having to put it on because when I took it off I felt relaxed like 'phew I can have it off' and then when I you know had to put it back on you know it was um it was I had to you know kind of sometimes got a lot of headaches and I got um a lot quite tired quite a lot as well because I was having to you know concentrate a lot [so

I: [OK and how are things now?

S5: Everythings yeah I enjoy having them on all the time.

I: Good, good. What is it particularly that you enjoy about them?

S5: Um well I mean um well I mean having you know the left one you know I can um it just makes life all round easier because you know when Im talking to someone I don't have to worry about necessarily being on their right side and you know when Im you know listening to music with my headphones you know

its you know I can have it at a reasonable I don't have to have it extra loud because its um easier and its easier in every way really.

I: OK so how would you say it's affected your life having the implants?

S5: Um well its its definitely made me like more confident because I think I was a lot worried having to say 'pardon' a lot and um I think I think I was just um I think I not only was I a lot more confident I sort of um was more um uh you know kind of you know speaking to more people and it's just me being more happier I think.

I: Great

S5: Yeah

I: So how is um how is school? How do you think it affects things at school or does it affect things at school?

S5: Yeah well it does affect things at school because um I can learn things more quickly and also um I can you know if theres a bit cos you know in a class you know if where you know talking or you know having a group discussion. and um we're allowed to talk then it's a lot easier in that you are able to hear what everyone's saying cos I think before I was I kind of got lost in all this noise and now it's a lot more um easier and um yeah and I think its just you know I've been able to learn things quicker because I have a radio aid um I could I can catch everything with that but I can do without the radio aid I could probably get away with it but it's a lot more easier I don't have to focus as often I can be a bit more relaxed about you know it's a lot more concentration if I haven't got the radio aid so it's a lot more relaxed I think it

I: Good, good. And do you think it affects how you are with your friends? Does it have an impact on how you are with them at school?

S5: Well I think the fact that I'm more confident um um I think that kind of I kind of was more comfortable around people but I don't really know because I've always been quite you know um I've always had quite a lot of friends so you know it's been ok but um so um but I think um I think it definitely brought confidence, so I suppose that that obviously you know made me feel better about myself.

I: Great, fantastic. Um is there anything you don't like about your implants?

S5: Well I don't I don't always like it that um when I go swimming I have to take them out and also um sometimes you know um like sometimes I feel a bit sometimes a tiny bit self conscious about how I look and things so with them on but I mean I really like them I just guess its just about I'd love to have them you know waterproof in some way.

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