QUALITY OF LIFE OUTCOMES IN ADULT COCHLEAR IMPLANT RECIPIENTS AND THEIR SIGNIFICANT OTHERS

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Abstract

This study aimed to investigate whether or not cochlear implants (CIs) change the quality of life (QOL) of postlingually deafened adult CI recipients and their significant others (SO), and to see which areas of daily life (if any) are impacted on most as a result of implantation.

Questionnaires were used to obtain QOL ratings. A total of 94 adult CI recipients (aged 20 to 83 years), and 70 adults on the waiting list (WL) for a CI, (aged from 20 to 86 years) returned the questionnaires. Of the SO groups, 83 questionnaires were returned from the CI-SO, and 58 were returned from the WL-SO. As an alternative perspective of the SO, 23 completed questionnaires were returned from parents of children with CIs. Responses returned showed that cochlear implantation has a significant positive impact on QOL; CI recipients had higher ratings in all areas of QOL and satisfaction, compared to adults on the WL for a CI. The greatest subdomain differences were seen in basic sound perception (37.81), social interaction (36.21), and activity limitations (32.27). QOL ratings were also significantly higher post-implantation than pre-implantation for the subgroup of 7 recipients who received their CI during the course of this study ($p < 0.05$)

The results of this study also suggested that CIs have a positive effect on the QOL of the SO; the CI-SO group had higher QOL ratings compared to the WL-SO group. Comparisons between the CI recipient and the CI-SO on how the CI had affected the CI recipient’s QOL showed that the SO had similar ratings to the recipient. This suggested that improvements seen for the CI recipients’ lives are also evident in the lives of the SO. When the QOL ratings for each of the SO groups were compared, the CI-SO group results were significantly better than the WL-SO group. The Parent group also reported positive effects of implantation. In addition to reporting significant improvements in their child’s self-reliance, self-confidence and communication, post-implant 69% of parents agreed that they were much happier with their own lives, with 86% feeling more confident since their child was implanted.

Overall, this study shows positive changes in QOL as a result of implantation, and suggests that these changes extend beyond the recipient. This is an important finding as it shows that the effects of implantation are far-reaching. This study also shows that examining non-audiological factors, such as QOL should be included in the assessment of benefit from a CI.

Chapter 1: Introduction

Cochlear implantation is a well-established alternative for both adults and children with severe to profound bilateral sensorineural hearing loss, who receive no useful benefit from hearing aids (HAs). Due to the success of cochlear implants (CIs), the number of individuals implanted has grown exponentially. For example, the number of CI recipients grew from 12 000, to nearly 100 000 between the years 1995 to 2005 (Lobo, 2007), and current estimations are that more than 130 000 adults and children have been implanted worldwide (The Ear Foundation, 2007), with numbers growing rapidly each year. A CI is in many cases, the only way to provide useable hearing for profoundly deaf people, and can provide improved audiologic performance in addition to improvements in quality of life (QOL) (Cohen, Labadie, Dietrich, & Haynes, 2004).

It is commonly reported in the literature that hearing loss is associated with a range of negative emotions that can include sadness, loneliness, depression, anxiety, a lack of self-confidence, and decreased social activity. The stigma attached to hearing impairment can also affect the self-image of the person; feelings of inadequacy or of being abnormal, prematurely old, diminished, or handicapped are reported (Hetu, Jones, & Getty, 1993). In addition to these, often those with a significant hearing loss report feeling that they are a burden on family members, due to their significant others (SO) having to act as interpreters, or respond for the person with a hearing loss (Kennedy, Stephens, & Fitzmaurice, 2008; Lormore & Stephens, 1994). In contrast, Tyler and Kelsay (1990) found that those who had received a CI reported fewer feelings of isolation and a decreased perception of being a burden on family members, compared to non-implantees. In conjunction with emotional considerations, both psychological and social behaviour can be affected by hearing loss (Lormore & Stephens, 1994). Hearing loss interferes with a person’s ability to communicate effectively, and a hearing-impaired person may prefer to withdraw socially rather than face embarrassment from being misunderstood or making inappropriate responses. As a result they may experience increased isolation and a poorer QOL. This is particularly applicable to those with a significant hearing loss.

Audiological treatments such as hearing aids (HAs) and CIs can help to reduce the negative consequences of hearing loss. HAs have been shown to improve QOL amongst hearing impaired individuals (Mulrow et al., 1990). There has also been research comparing the effects of HAs to CIs on QOL measures.

For most potential CI recipients, the main objective of receiving a CI is to improve their speech perception abilities. In most cases, this is a realistic expectation and there is a host of studies which report recipients achieving high levels of open-set speech perception, in quiet listening situations (Kou, Shipp, & Nedzelski, 1994; Mo, Lindbaek, & Harris, 2005; Parkinson et al., 2002; Skinner et al., 2002). However, although a CI can improve hearing for those who receive minimal benefit from HAs, it is important to realise that follow-on benefits from a CI cannot be assumed. The effect of audiological outcomes on QOL is not fully understood, and there is no simple connection (Knutson, Johnson, & Murray, 2006; Kou et al., 1994; Mo, Harris, & Lindbaek, 2004). In addition, individual outcomes from implantation are extremely variable and sometimes difficult to predict (Bai & Stephens, 2005; Maillet, Tyler, & Jordan, 1995). Further, QOL is a multi-dimensional concept and not just based on the ability to understand speech in quiet. Other auditory stimuli such as environmental sounds, music, hearing in different listening environments (for example background noise), and the ability to hear everyday devices (for example television, radio, telephone, alarms) contribute to a sense of connection and well-being in one's environment (Reed & Delhorne, 2005). That is, while speech perception and communication are important factors in improving QOL, they are not the only determining factors. For these reasons the general health status of CI patients, often referred to as health-related quality of life (HRQoL), (called QOL in this thesis), has more recently received increasing attention (Klop, Briaire, Stiggelbout, & Frijns, 2007).

There were four main aims of this study. Firstly, to obtain information about the changes in QOL in postlingually[1] deafened adults following implantation. Secondly, to determine which aspects of daily life that these changes (if any) were most noticeable. Thirdly, to look at the impact of a CI on a SO, and fourthly, to see whether the changes (if any) reported by the implantee are similar to that reported by the SO[*]. In order to achieve this, the thesis is set out as follows: Chapter 2 will provide a review on hearing loss and the role of HAs, CIs, CI candidacy requirements, and the implantation process. In addition, both the Southern Cochlear Implant Adult Programme (SCIP-A) and the Sydney Cochlear Implant Centre (SCIC) will be discussed, as the participants in this study were recruited from these programmes. Chapter 3 describes QOL and the impact of a hearing loss. Section 3.1 details outcomes of CI recipients, 3.2 outlines the view of the SO and section 3.3 discusses the parental perspective, while section 3.5 provides the

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[1] For this study, postlingually deafened adults was defined as and adult who was not born with a significant hearing impairment, and was able to learn speech and language normally (that is through an essentially normal hearing mechanism). This study did not explore prelingually deafened adults who differ from postlingually deafened individuals in that they have never experienced auditory input.

[*] For this thesis the term SO is used to cover married, unmarried, parental or sibling relationships.

rationale, aims, and hypotheses for this research. Chapter 4 describes the methodology, and as well as the questionnaires used in the present study (4.2), with Chapter 5 presenting the results of this study. In chapter 6, a discussion of the findings is offered in relation to aims and hypotheses of this study, along with general findings, and how these relate to current literature. Chapter 6 also discusses the limitations, and futher implications as a result of this research, while Chapter 7 provides a summary and conclusion.

Chapter 2: Background Information

2.1 Hearing and Hearing Loss

The mechanisms of normal hearing are presented in Figure 1. Sound waves travel through the air, are collected by the outer ear (pinna), through the ear canal to reach the tympanic membrane (TM). These waves cause the TM to vibrate which leads to the movement of the three small bones of the middle ear; the malleus, incus and stapes. This produces a piston-like movement of the stapes which moves the oval window of the cochlea. Inside the fluid-filled cochlea, pressure variations lead to the displacement of the basilar membrane (BM), where these mechanical vibrations must be coded into neural information, which the brain subsequently interprets (Yost, 2000).

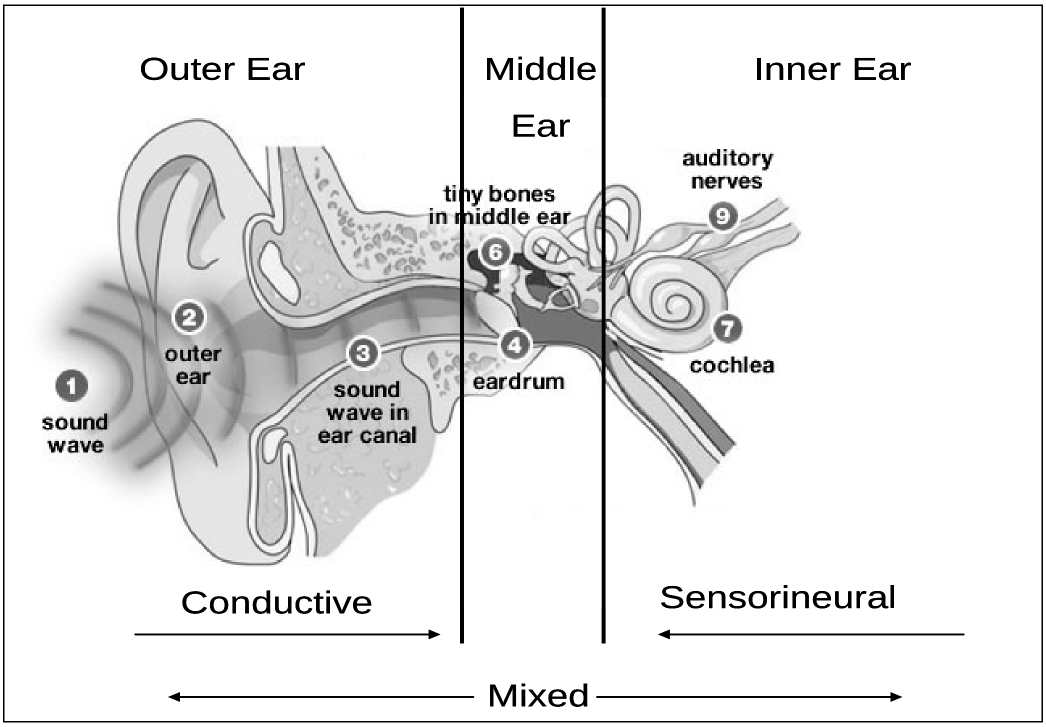

Figure 1: Components of hearing (adapted from Learning through Listening, 2009)

Hearing loss limits the auditory information available to the listener in a frequency-dependent manner (Noble, Byrne, & Lepage, 1994), and is classified by the type and severity. The three main types are: conductive, sensorineural, and mixed (Figure 1). A conductive loss frequently results in a reduction of perceived sound level, due to dysfunction, in the outer or middle ear.

Sensorineural hearing loss occurs when there is damage to the inner ear, sensory cells, or to the cochlea. Unlike conductive losses, sensorineural hearing loss is usually permanent and cannot be rectified by medical treatments and/or surgery. Therefore, individuals with sensorineural hearing loss are typically fitted with HAs, or if their loss is severe enough, a CI. The last category of hearing loss is termed mixed, which is a combination of sensorineural and conductive hearing losses. The severity of a person’s hearing loss is divided into six categories; normal, mild, moderate, moderately-severe, severe, and profound, which are illustrated in Figure 2. The results from a hearing test are recorded and plotted on an audiogram (Figure 2).

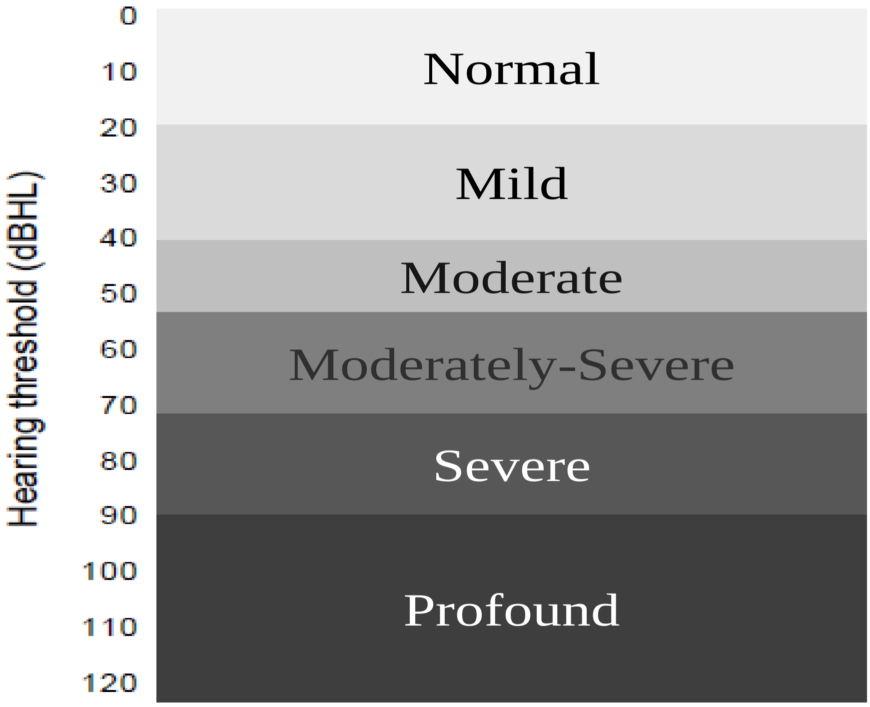

Figure 2: Audiogram detailing six categories of hearing loss

2.2 Hearing Aids (HAs) versus Cochlear Implants (CIs)

HAs and CIs work on different principles. HAs amplify sound and send these sounds through the outer and middle ear to the inner hair cells. Conversely, CIs convert sounds into electrical energy which subsequently stimulate surviving auditory neurons in the inner ear via electrical pulses.

2.2.1 Hearing Aids

HAs aim to overcome the deficits associated with hearing loss, including decreased audibility and the inability to hear speech. Most commonly, people with hearing loss miss high-frequency information of speech. This is due, in-part to these high frequency components being ‘masked’ by low-frequency components. In addition to reduced audibility, people with hearing loss have a reduced dynamic range, which relates to the difference between the level of audibility and the level of discomfort. Thus, to help overcome these deficits, it is necessary for HA(s) to provide appropriate amplification for frequencies where hearing loss is the greatest, as well as appropriate compression, which is responsible for decreasing the range of sound levels in the environment to match the reduced dynamic range of the person with hearing loss (Dillon, 2001).

2.2.2 Cochlear Implants

In order to provide hearing and improve QOL in hearing impaired individual’s, CIs function by electrically stimulating the surviving neurons in the auditory nerve via electrodes, bypassing damaged or missing hair cells. A historical overview can be found in Clark, (2008); Grayden & Clark, 2006; and Zeng 2004. Current CI systems comprise both internal and external components. Figure 3 shows the internal components which are surgically implanted in the skulls’ temporal bone, and consists of a receiver-stimulator unit with a magnet and receiving coil which are connected to an electrode array (Drinkwater, 2004).

The electrode array is inserted in the scala tympani to a depth of one and a half turns of the cochlea (Zeng, 2004), with the electrodes along the array stimulating different subpopulations of neurons (Wilson, 2004). The cochlea is arranged tonotopically, which implant systems attempts to mimic by electrically stimulating high frequency basal electrodes, followed the lower frequency apical regions (Wilson, 2004). Current multi-channel devices stimulate multiple sites in the cochlea, and have up to 22 intracochlear electrodes (depending on the manufacturer).

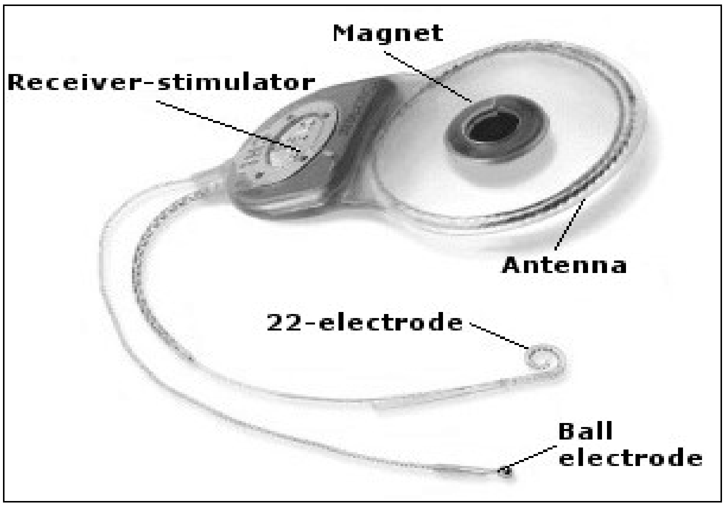

Figure 3: Internal component of a CI Retrieved from Bionic Ear, 2008

The external components are the speech processor (shown in Figure 4), and a microphone. The processor is typically worn behind the ear, and is connected to the receiver-stimulator package by a transcutaneous link, that is a link through intact skin. The microphone detects incoming sound and converts it into an electrical signal for input. The speech processor processes the incoming signal and the input is then transmitted to the implanted receiver-stimulator unit, which decodes the signal and controls an electrical current presented to each electrode in the array (Grayden & Clark, 2006). Within the speech processor is a speech-processing strategy, which determines the parameters which is presented to the implant.

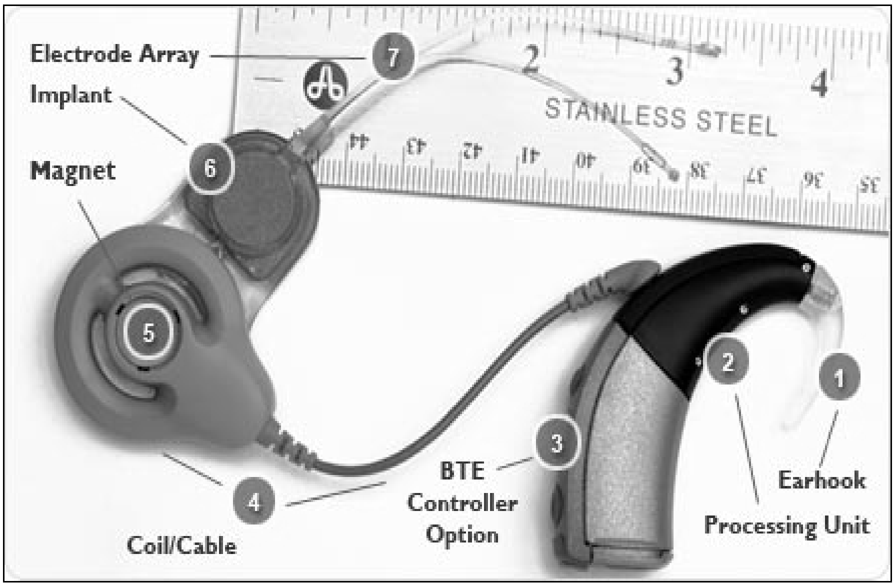

Figure 4: A cochlear implant system showing internal and external components Retrieved from Cochlear Ltd, 2005

Advancements in speech processing strategies have resulted in improvements in the speech perception of CI recipients. Some examples of speech processing strategies include Continuous Interleaved Sampling (CIS), Spectral Peak (SPEAK), and Fine Structure Processing (FSP). Speech processing parameters can be adjusted, thus affecting the sound perceived by each recipient, and each of these strategies has resulted in relatively high levels of speech reception for most recipients. It is beyond the purpose of this thesis to describe these speech processing strategies; more information can be found in Hochmair et al. (2006), Loizou (1998), and Vandali, Whitford, Plant, & Clarke, (2000).

2.3 CI Candidacy & Assessment

In the early-to-mid 1980s, CIs were limited to those with a total hearing loss, who received no useful benefit from HAs (Toner et al., 2004). However, with improvements in CI technology and outcomes, criteria have expanded to include those with greater levels of residual hearing. Implant clinics around the world are also constantly re-evaluating criteria for implantation, as the potential benefits of implantation become more evident (Fielden, 2006), and also relate to available funding. In order to determine whether a candidate meets the criteria for implantation, a detailed assessment is conducted in order to investigate the potential for benefit and/or the related risks. In terms of audiological criteria, the puretone audiogram is considered in conjunction with speech perception results. For most clinics, potential adult CI candidates generally have a bilateral moderately-severe to profound sensorineural hearing loss. For adults, speech perception scores are calculated using open-set sentences in quiet, in the best-aided condition.

For children, the criteria are slightly different to adults. Often, the most important indicator for implantation is when the child is not making auditory progress, or has reached a plateau in auditory development. Criteria also depends on the age of the child, with the current trend being to implant children under two years of age in order to make the most of neural plasticity in the auditory pathways. It has also been found that development of vocal and auditory preverbal skills in children is faster, and reached a higher level in children implanted between one and two years compared with children who were implanted older than two years (Tait, Nikolopoulos, & Lutman, 2007). As the specific criterion varies between individual clinics, the two programmes directly relevant to this thesis, which are adults of the SCIP-A, and children of the SCIC, are discussed individually as follows.

2.4 The Southern Cochlear Implant Adult Programme (SCIP-A)

For the ratings of CI recipients and waiting list (WL) participant groups in this study, potential participants were recruited from the SCIP-A, New Zealand.

The New Zealand CI Programme was established in 1986, and in 2003 the programme was divided into a Northern and a Southern Cochlear Implant Programme, to meet the needs of an increasing number of potential and existing recipients. The Southern programme covers the lower part of the North Island, and the whole of the South Island, as shown below in Figure 5, while the Northern Region covers the remainder of the North Island.

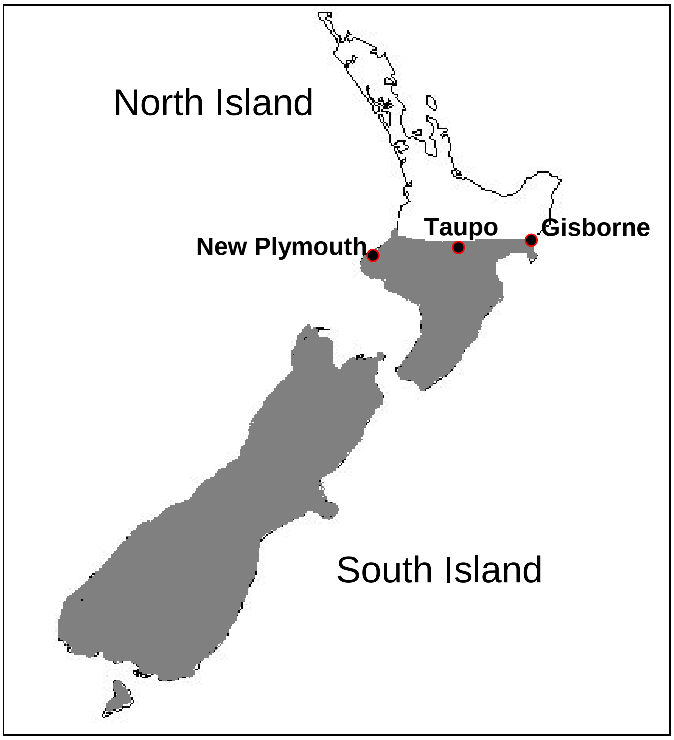

Figure 5: Map of New Zealand depicting the SCIP-A region (shaded grey)

Since the SCIP-A was established in 2003, approximately 160 adults have been implanted and remain under the management of the SCIP-A. The criteria for potential adult CI recipients are as follows:

- Bilateral moderate to profound sensorineural hearing loss (with thresholds worse than 90dB HL at 2000 Hz and above for the better ear);
- Postlingually acquired hearing loss with oral/aural communication skills;
- Limited benefit from optimally-fitted conventional hearing aids;

- Speech perception scores for open-set sentences in quiet in the best-aided condition less than 60%, and less than 40% in the ear to be implanted, or less than 30% for open-set word recognition;
- No medical or surgical contraindications to implant surgery;
- There is no maximum age for referral, patients with additional needs are not excluded, and those who do not meet the criteria but have other auditory conditions (e.g. Auditory Neuropathy) are also considered for implantation. In addition to the above criterion, relevant psychological assessments are undertaken where necessary.

2.5 The Sydney Cochlear Implant Centre (SCIC)

For the parent group in this study, participants were recruited from the SCIC, Australia.

The Royal Prince Alfred Hospital (RPAH) Adult Cochlear Implant Program was established in 1984, followed by the Children’s CI Centre two years later. In 2001 the adult and children’s programs amalgamated to form the SCIC. The criteria for implantation at the SCIP-A for children are:

- A moderate to profound sensorineural hearing loss (or worse);
- Limited benefit from optimally-fitted conventional hearing aids as determined by the CI clinical team;
- Lack of progress in basic auditory skill development (if age appropriate);
- Strong family support and commitment to oral/aural development;
- Medical, psychological, social work assessments are conducted as appropriate.

For children who are less than 2 years of age, or who cannot perform reliable behavioral testing, electrophysiological testing is performed under general anaesthetic. These tests include Electrocochleography (ECochG), and Acoustic Auditory Brainstem Response (AABR).

Chapter 3: QOL and Hearing Loss

For spoken communication, hearing is an attribute that is fundamental to develop language, learn, work, and for social functioning. These factors are highly relevant to QOL (Beck, 2000). Over the past 40 years, the concept of QOL has become an increasingly important measure for evaluating the outcome of various health care services and treatment options, including hearing loss. QOL outcomes can also affect how policy makers and funding bodies distribute funding for interventions such as CIs (Moons, Budts, & De Geest, 2006). However, QOL is a broad concept and there seems to be no consensus on its definition nor measurement (Hallberg, Ringdahl, Holmes, & Carver, 2005; Moons et al., 2006; Skevington, Lotfy, & O'Connell, 2004). In essence though, QOL is about the meaning that people derive from the important aspects of their life, thus it is a social construction, and is highly individualised. For the purposes of the present study, the World Health Organisation’s (WHO) definition of QOL will be adopted as:

> “Individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (Harper & Power, 1998 p. 551).

QOL is a subjective evaluation and is impacted on by cultural, social, and environmental factors (Harper & Power, 1998). It encompasses several life domains including physical, psychological, and social well-being. In addition to these domains, QOL incorporates other aspects such as economic, occupational, and family life. Therefore when evaluating QOL, these factors need to be considered (Zhao, Bai, & Stephens, 2008). These aspects are described in the *International Classification of Functioning, Disability and Health* (ICF) which was developed by the WHO as a theoretical model, in order to provide a uniform assessment on the impact of a health condition (such as hearing loss), on the lifestyle of the affected individual (WHO, 2001). The ICF is a multi-purpose *classification* and consists of *health* and *health-related* domains which are classified from the body, individual, and society perspectives, and are described by means of two categories: 1) Body Functions and Structure, and 2) Activity and Participation. These are also affected by environmental and personal factors (WHO, 2001). Depicted in Figure 6, is the relationship between the components of the ICF. Thus it can be seen that hearing loss is not just limited to an impairment of a body structure or function, but can lead to activity limitations, and/or participation restrictions, which could lead to a poorer QOL. Hence, the experience of hearing loss will differ amongst individuals due to differences the nature of the hearing loss, personalities, and psychological factors such as coping skills, and environmental considerations.

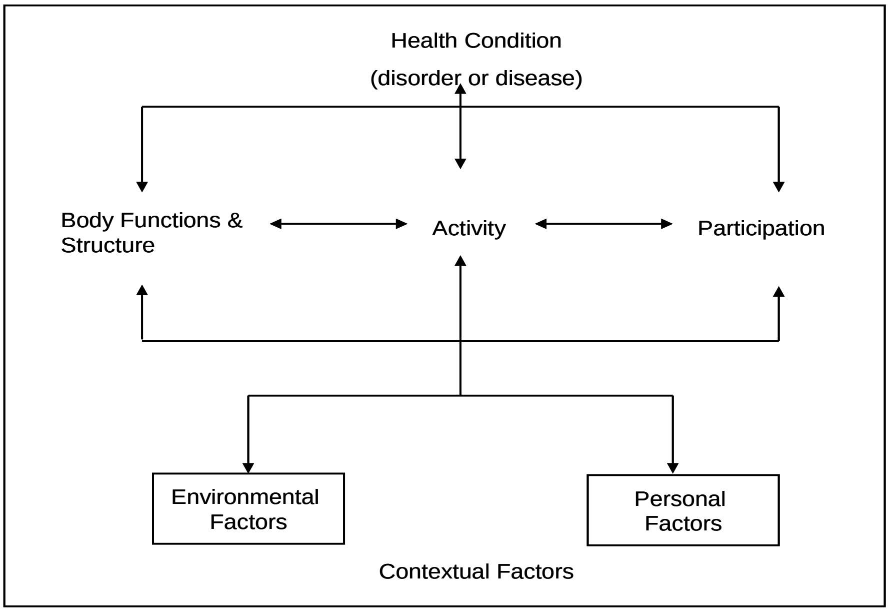

Figure 6: Interactions between the components of the ICF (WHO, 2001).

3.1 QOL Outcomes for CI Recipients

Technological developments of CI devices have resulted in higher expectations of outcomes, including new aspirations such as music perception (Lassaletta et al., 2007). However, great variability remains between individual outcomes. For example, while some CI recipients may only obtain an increased awareness of environmental sounds, others achieve open-set speech recognition, telephone use, and can integrate easily into the hearing world. In general however, much of the current literature has suggested that CIs have a large positive impact on recipients' lives, especially for improving communication (Castro et al., 2005; Cohen et al., 2004; Damen, Beynon, Krabbe, Mulder, & Mylanus, 2007; Faber & Grontved, 2000; Hirschfelder, Grabel, & Olze, 2008; Krabbe, Hinderink, & van den Broek, 2000; Zhao et al., 2008).

Early studies used open-ended questionnaires to establish how CIs affected QOL. Tyler and Kelsay (1990) asked 53 CI recipients to list advantages and disadvantages of their CI. The most frequently reported advantages (percentage of participants in brackets) included speech perception with speechreading (85%); environmental sounds (75%); psychological effects (70%); speech perception without speech reading (64%); lifestyle and social effects (42%); and speech production (32%). Consequently, it was reported that these benefits probably led on to improvement in other areas of daily life. A caveat of this 1990 study was that only better-performing CI recipients were used; thus the results may have been biased (Tyler & Kelsay, 1990). To address these issues, Tyler (1994), carried out another study that included a broad range of CI recipients, not just the better performing ones. A comparison of the findings of the two studies showed that similar results were reported, as shown in Table 1 below.

Table 1: Areas of CI Benefit as Reported by Participants.

Categories	1990* % of respondents (n=53)	1994* % of respondents (n=41)
Speech perception when speech reading can be used	85	86
Environmental sound perception	75	79
Psychological effects	70	49
Speech perception when speech reading cannot be used	64	56
Lifestyle and social effects	42	40
Speech production	32	14

*Comparisons of findings of the Tyler & Kelsay (1990), and Tyler (1994) studies.

CIs have also been found to reduce reported levels of hearing handicap and depression. Through the use of hearing handicap and self-rating depression measures, Proops et al. (1999) investigated the impact of CIs on the first 100 adult implant recipients of the Midland Cochlear Implant Programme (Birmingham), where in addition to speech perception measures, participants completed two QOL questionnaires – the Revised Denver Communication Scale, and a self-rating depression scale. Nine months post-CI, 95% of participants had improved speech perception and reported a reduced hearing handicap level. For the measures of depression, pre-implant it was reported that 28% of patients would be classified as clinically depressed. At nine months post-implantation, the mean rating on the depression measures were significantly reduced ($p < 0.001$). There was no further improvement at 18 months compared to the nine month scores. Thus, the most significant effects of implantation occurred in the first year following the receipt of the implant. This was also shown for the Revised Denver Scale where 86% of participants reported a reduced hearing handicap nine months post-CI. Also at the nine month post-implant stage, 45% of participants said the CI had improved their QOL “enormously,” 41% said “greatly,” and 12% said “slightly.” Only 2% said “not at all” (Proops et al., 1999). Similar results were found by Mo et al. (2004) who found a reduction in depression levels, in addition to reduced anxiety, and feelings of burden in CI recipients.

Increased satisfaction with life following receipt of a CI has also been reported. Maillet et al. (1995) evaluated changes in QOL for 84 postlingually deafened adults pre-and post-implant. In addition to speech perception tests, participants completed the Patient Quality of Life Form, the Index Relative Questionnaire Form, and the Performance Inventory for Profound Loss. These were issued pre-implantation, and subsequently at 3, 12, and 24 months post-implantation. There were three purposes: 1) to assess changes in satisfaction pre and-post-implant; 2) to see if there was an association between age, duration of profound deafness, and speech recognition ability with ratings of satisfaction with life; and 3) to examine the relationship of the three satisfaction questionnaires between the CI recipient and their significant others (SO). Pre and-post-implant there was a significant improvement in both QOL ratings and the CI recipients' ability to communicate, with nearly half (48%) of the respondents perceiving an improvement in their QOL 24 months following implantation ($p < 0.0001$). This study also showed that CIs have a significant impact on the SO's lives, which is reported in the CI-SO section (section 5.4).

Questionnaires were also used by Hogan et al. (2001) to assess how CIs affected social, psychological, physical, emotional and hearing handicap levels. They also incorporated the view of the SO. There were 202 participants where 148 were implantees and 54 were non-implantees with similar levels of hearing loss. Responses were also received from 136 partners; 105 were partners of the implantees and 31 were partners of the non-implantees. The two questionnaires used were the Assessment of QOL instrument (AQoL), and the Participation Scale (PS). The former is a generic measure of QOL that addresses broad aspects of QOL, and yields data that may be compared with population-based studies using the same instrument. It measures aspects of independent living, social relationships, physical senses, and psychological wellbeing. The PS was derived from the Glasgow Health Status Inventory (Gatehouse, 1997, as cited in Gatehouse (2001). It addresses psychological and social wellbeing, emotional factors, and hearing handicap. An overall comparison between implantees and non-implantees for the PS showed that there was a 31% difference in total mean scores, with CI recipients scoring better. Significant differences ($p < 0.01$) were noted in the areas of self-esteem, where the mean score was 37% higher in implantees compared to non-implantees. For social interaction there was a difference of 27%, and for hearing handicap there was a difference of 29%. However, for the AQoL only the differences in the physical senses domain was significant, with a difference between the two groups of 34% ($p < 0.01$). The overall difference between the two groups for both questionnaires was 50% (Hogan et al., 2001).

In contrast to these generic QOL questionnaires, a ‘disease-specific’ questionnaire was specially designed for the CI recipient population - the Nijmegen Cochlear Implant Questionnaire (NCIQ), was developed by Hinderink et al. (2000) to specifically address QOL in CI recipients. The NCIQ measured physical, psychological and social functioning and this questionnaire will be described in more detail in the methods section, as it was used in the current study. In their study Hinderink et al. (2000) compared ratings of 45 CI recipients to 46 postlingually deafened adults on the WL for a CI. The greatest differences between CI recipients and those on the WL were in the basic and advanced sound perception subdomains, where CI recipients scored better than non-implantees. Differences in the other four subdomains were smaller, but still significant. Similar findings were also reported by Hirschfelder, Grabel, & Olze, (2008) who administered the NCIQ retrospectively in a pre-and-post format to 56 postlingually deafened adult CI recipients. Results showed significant improvements ($p < 0.001$) in both the total scores of the NCIQ, and mean subdomain scores, when the two versions of the questionnaire were compared. Akin to the Hinderink et al. (2000) study, the largest differences in mean ratings pre- to post-CI scores were for the basic and advanced sound perception subdomains. Klop et al. (2008), also used this questionnaire to study QOL in postlingually deafened adult CI recipients, and found clinically relevant QOL benefits, with differences pre- to-post-implant being significant in all subdomains.

The NCIQ has also been used to study QOL outcomes in prelingually deafened adult CI recipients. It has been reported that prelingually deafened adult CI recipients have poorer outcomes than postlingually deafened adult recipients (Skinner et al., 1992; Waltzman, Cohen, & Shapiro, 1992; Zwolan, Kileny, & Telian, 1996). Klop et al. (2007) aimed to look at the effects that CIs had on the speech perception of 8 prelingually deafened adults, where QOL ratings would be an important aspect in evaluating outcomes for this population, especially as their speech recognition results were limited (Klop et al., 2007). QOL scores were evaluated pre and-post-implant at periods of 4 to 5 months, 12 months, and then 30 months following implantation. It was found that while speech perception scores differed amongst participants, they improved over time with phoneme recognition scores measured at 24 months post-implant showing significant improvements from 14% pre-CI, to 43% post-CI ($p = 0.001$), and mean word scores improved from 2% pre-implant to 15% post-implant ($p = 0.009$). For the NCIQ, there were significant improvements for the basic sound perception subdomain ($p = 0.002$), advanced sound perception ($p = 0.001$), and social interaction ($p = 0.009$) subdomains. This suggests that while speech perception outcomes may be varied, CIs can have a significant positive impact on QOL in prelingually deafened adults.

Castro et al. (2005) found that benefits obtained from the implant could allow CI recipients to undertake certain tasks such as telephone conversations and participating in social activities with greater comfort. Responses to two questionnaires were obtained from 30 CI recipients. One questionnaire was the Glasgow Benefit Inventory (GBI), which evaluated the changes that CIs produced in different aspects life. It consisted of 18 questions, divided into three subcategories: general, social, and physical. The other questionnaire referred to as “specific questionnaire” in the study, evaluated six different aspects relating to CIs: verbal discrimination, social relationships, use of telephone, self-confidence, family life, and satisfaction. To enable a pre- to post-implantation comparison, for each question the participant was asked retrospectively to rate the situation both one month before surgery, and then post-implant. Results reported from both questionnaires showed that there were considerable improvements in QOL. The specific questionnaire showed significant improvements ($p < 0.01$) in all areas stated previously. For the GBI, the average overall QOL benefit pre- to post-implant was greatest for the general subcategory (56.81), followed by social (17.80) and lastly physical (4.4).

Cohen et al. (2004) also found positive effects of implantation when comparing QOL ratings from 54 adult HA users to the ratings from 27 adult CI recipients. It was found that both HAs and CIs improved QOL when ratings were compared pre- to post-intervention ($p = 0.001$). However, the change in QOL was greater in the CI recipients; they had twice as much improvement in their overall QOL scores ($p = 0.003$), with the most difference noted for the basic sound perception category, where the benefit was almost three times that of the HA users ($p < 0.001$). The authors concluded that CIs offer similar benefits for those with profound hearing loss as HAs do for those with less severe hearing losses (Cohen et al., 2004). However, CIs cannot be equated with conventional amplification such as HAs due to the risks associated with CI surgery, greater costs, and more time and commitment required for CI recipients to adapt to their device (Dowell, 2005).

In sum, the studies mentioned have looked at the effect of cochlear implantation on QOL by means of questionnaires. Most commonly it has been found that CIs provided increased sound perception which facilitated greater communication abilities, improved psychological aspects including increased safety, independence, better opportunities in the work place, and reduced tinnitus (Kelsay & Tyler, 1990; Tyler, 1994). Others also have reported decreased hearing handicap, depression and anxiety following implantation (Proops 1999; Mo et al., 1994). Post-implantation, CI recipient’s have reported increased social participation and confidence (Hogan et al. 2001), with many being able to use the telephone, and experiencing improvements in family life (Faber & Grontved (2000). The studies that used the NCIQ (Castro et al., 2005; Hinderink, Krabbe, & Van den Broek, 2000; Hirschfelder et al., 2008; Klop et al., 2008) reported positive changes in QOL for physical, psychological, and social functioning. Hence it seems that cochlear implantation can lead to improved ratings on a range of QOL measures, however, there is much variability between individuals, and the impact that CIs have on the daily lives of recipients is yet to be fully explored, especially in the long-term.

3.1.1 Factors Affecting Outcomes for CI Recipients

As mentioned, there are various outcomes among CI recipients with many adults and children achieving high levels of open speech discrimination (Kou et al., 1994; O'Donoghue, Nikolopoulos, & Archbold, 2000). However, there are recipients who fail to gain benefit from their devices, despite having exactly the same implant system, and speech processing strategy (Ray et al., 2006; Wilson & Dorman, 2008). Some factors that have been linked to variability in outcomes include physiological factors, such as the number and location of neural survival (Incesulu & Nadol, 1998), central auditory processing ability, cognitive ability, maturation, and emotional state (Cooper, 2006; Dorman & Wilson, 2004; Zeng, 2004). Duration of profound deafness and residual hearing before implantation have been shown to be related to outcomes in some studies (Blamey et al., 1992). In addition, studies have shown that pre- and perilingual deafness has been linked to poorer speech recognition and a higher rate of non-use of the implant than postlingually (Waltzman et al., 1992). Nevertheless, overall current CIs continue to improve recipients' open-set speech perception, and there are no definite pre-surgical predictors of post-surgical performance in CI recipients (Hamzavi, Baumgartner, Pok, Franz, & Gstoettner, 2003).

3.2 QOL Outcomes for Significant Others (SO)

Hearing loss can bring about negative consequences. As communication is central factor in relationships, profound hearing loss often has significant affect as it impedes this process (Wexler, Miller, Berliner, & Crary, 1982). Consequently when communication breaks down, all people involved the relationship may be affected, and the impact of hearing loss often extends beyond the individual, afflicting the individual's family and friends (Kennedy et al., 2008). In addition to this, the SO may share the disability of hearing loss by experiencing feelings such as embarrassment, and reduced social interaction, leading to a reduced QOL (Stephens & Hetu, 1991). Expectations may be unfulfilled, leading to a sense of loss, frustration or resentment, as well as hampered spontaneity and reduced the opportunities for positive shared experiences (Hallam, Ashton, Sherbourne, & Gailey, 2008), thus all impacting negatively on relationships. Therefore people close to those with a significant hearing loss must also learn to cope with a range of related issues in their lives (Mo et al., 2004). Numerous authors have also emphasized the important role that spouses play in aural rehabilitation (Armero, 2001; Hallberg & Barrenas, 1993; Hetu et al., 1993). For studies that look at QOL, it is usually from the perspective of the person with the hearing loss, and few studies have examined the impact of the hearing impairment on their spouse or SO, thus the impact of hearing loss on the spouse largely goes unexplored (Kennedy et al., 2008; Wallhagen, Strawbridge, Shema, & Kaplan, 2004).

A review of the literature by Hetu et al. (1993), identified difficulties that both the person with the hearing loss and their SO can experience as a consequence of hearing loss. These are summarized and presented in Table 2. However, it should be noted that not all of these difficulties may be experienced in all relationships, and that there are other factors to consider, such as the nature and severity of the hearing impairment, the duration and stability of the relationship, adjustment to the hearing impairment, age and lifestyle to name a few (Hetu et al., 1993).

Table 2 : Summary of Difficulties Associated with Hearing Loss

Reported by the person with hearing loss	**Reported by the SO**
Effort, fatigue from:	Effort, fatigue from:
The need to ask for repetitions	Constant repeats
The need to pay attention	Having to always answer the telephone
	Playing the role as an interpreter
	Having act as an go-between in social situations
Frustration due to:	Frustration due to:
Not understanding conversations	Restriction of leisure activities
Missing out on conversations, being left out, being emotionally isolated	Having a reduced social life
Not able to hear the television properly	Irritation and impatience due to misunderstandings
Not hearing in background noise	Restriction of intimate conversations
Stress, anger resentment	Stress, tension, irritation
From intolerance of others not understanding	Television being too loud
Being made aware of imposing constraints	Worrying about SO being able to hear warning signals/alarms
	Embarrassment in social gatherings
	Guilt
	Because of expressions of impatience

(Adapted from Hetu et al., 1993)

Adding to this, in a study of 418 couples using questionnaires, Wallhagen et al. (2004), demonstrated that hearing loss resulted in the SO having poorer physical and psychological well-being. It was also found that the negative impact of hearing loss appeared to more evident when the person with the hearing loss was the husband. This study only investigated that it used older married couples.

Stark and Hickson (2004), found that the QOL of spouses significantly improved after their partner was fitted with a HA(s). They assessed the QOL of 93 older people with hearing impairment, along with 78 of their spouses. Prior to the HA fitting, spouses reported: difficulty with communicating with their partner in a variety of areas including background noise, the high volume of the television or radio, having to repeat what they say, and feelings of frustration and annoyance. Post HA fitting, there was a reduction in the reported level of these difficulties (Stark & Hickson, 2004). Similar findings were also reported by Scarinci, Worrall and Hickson (2008), where SOs also reported feeling frustrated over communication difficulties, when messages were misconstrued, and having to repeat themselves. In the same study it was also found that almost all tasks and activities in both the hearing impaired person and the SO’s lives were affected by hearing loss. In relation to communication problems, spouses reported avoiding conversations with their partner due to the increased time and effort required to communicate with them. Hearing impairment also encroached on everyday activities, including the volume of the television, hearing the telephone ring, having to make telephone calls for their partner, and safety issues relating to concern over their partner’s ability to hear traffic noises, and alarms, or responding to dangerous situations. Spouses felt that these factors added to their responsibilities, in addition to the impact of hearing loss on their social life, everyday activities; collectively these factors added a strain to the relationship. The WHO has suggested that the SO may experience a “third-party disability” in that the SO may have tasks imposed on them which can disrupt their lives (Kennedy et al., 2008). Other studies have also reported poorer reduced QOL in the SO (Donaldson, Worrall, & Hickson, 2004; Hallberg & Barrenas, 1993; Stephens & Hetu, 1991).

Of the small number of studies that have looked at the effects of cochlear implantation on a SO, Wexler et al. (1982) were the first to recognize the importance of the perspective of the “index relative” in relation to the SO. Through personal interviews they established a questionnaire that encompassed eight major themes: 1) sense of safety; 2) emotional reactions; 3) interpersonal relationships; 4) social activities; 5) sense of isolation; 6) communication problems; 7) employment and; 8) involvement with hobbies/recreational activities. The CI recipients reported that the CI gave them a greater sense of safety, independence, in addition to improvements in communication. Negative feelings were also reduced as well as feelings of burden. While participants also reported that while engaging in group activities was still difficult, participation was less threatening compared to pre-implant. Parallel questionnaires were constructed for the CI recipient and their SO, which were issued pre- and post-CI retrospectively. It was reported that both individual's lives were modified, often for the better, with the index relatives sharing the CI recipient's perceptions of improved independence, confidence, and social participation. As such, the SO reported as feeling less burdened and responsible (Wexler et al., 1982). Similarly, Kennedy et al. (2008) found the most common benefits affecting the SO were related to improved communication, with a decrease in communication and social burden. Although the SO of the CI recipient recognised hearing improvements because of the CI, they also valued the CI recipient's ability to be more involved in daily life activities and social interaction

In another study, Mo et al. (2004) compared the QOL outcomes for close relatives of CI recipients to the recipients themselves using the Index Relative Questionnaire Form (IRQF). The IRQF assessed the satisfaction of the SOs life, and also how the SO rated the hearing-impaired patient, and the effects of the hearing loss on both their daily lives. Results showed that the SO of the CI recipients had higher QOL scores than the SO of the non-CI group (Mo et al. 2004 & 2005). Maillet et al. (1995) also used the IRQF and issued it to SOs both pre- and post-implant. When the pre-to-post versions were compared it was found that while the recipients and their SO appeared to have similar perceptions of the patient's QOL prior to implantation, post-implant perceptions differed. Those SO's who saw their hearing-impaired partner as being dissatisfied with life before the CI perceived a greater improvement following implantation than the recipient themselves did (Maillet et al., 1995). Using a different questionnaire (the AQoL), Hogan et al. (2001) found there were no significant differences between the partners of implantees and non-implantees, and that when compared to normative population data, QOL scores were poorer from partners of both groups'. The reasons for this finding were unclear with the authors concluding that partner outcomes require further investigation.

In summary, existing studies on the effect of hearing impairment on the SO show that many aspects of the SOs lives are affected by their partner's hearing impairment such as communication, social participation, emotions, tension within the relationship, feelings of responsibility, and safety concerns. As a result of implantation, the CI recipient often report lessened feelings of isolation, burden, and social restrictions. SOs of the recipients have reported improvements in the CI recipient's satisfaction with life, with the increased ability to communicate, as well as a reduction in negative emotional tension, and improved QOL. It is important that studies looking at the SO's perspective are carried out, in order to aid rehabilitation and counseling; for example the SO should be incorporated into audiological rehabilitation process, and outcome measures to include the SO's perspective should be expanded.

3.3 QOL Outcomes for Parents* of Children with CI(s)

Cochlear implantation also affects the lives of both the children and their families (Incesulu, Vural, & Erkam, 2003). Since the FDA approved CI devices for children in 1990, the number of children implanted has increased dramatically. Due to better outcomes being associated with a younger age at implantation, eligibility requirements have also expanded to include young infants. The safety of implanting children aged 7 to 12 months has been established (James & Papsin, 2004), with many studies showing the relationship between young age at implantation (i.e. 0-3 years) and better speech perception and intelligibility outcomes (Baumgartner et al., 2002; Hassanzadeh, Farhadi, Daneshi, & Emamdjomeh, 2002; Svirsky, Teoh, & Neuburger, 2004). Implantation has also brought about increased educational opportunities and mainstream educational placement for children with CIs (Daya, Ashley, Gysin, & Papsin, 2000), as well as broader outcomes such as improved psychological well-being, social integration and QOL (Sach & Barton, 2007; Stacey, Fortnum, Barton, & Summerfield, 2006).

However, parenting a deaf child or a child with a CI(s) can make some of the common parenting demands more challenging, as well as create new demands. These may lead to parents feeling frustrated and/or with a diminished sense of competence and satisfaction (Zaidman-Zait, 2007). In addition to coping with the initial diagnosis, families must acquire a substantial and complex body of knowledge (Feher-Prout, 1996), where parents are responsible for deciding how their child will be treated and cared for in addition to other tasks relating to work and family (Spahn, Burger, Löschmann, & Richter, 2004). Furthermore, once the child is implanted, parents are responsible for ensuring the child wears the device, maintenance, as well attending clinical appointments. All of these factors may lead to parents experiencing "psychological distress" which can reduce QOL (Spahn et al., 2004).

Psychological stress in parents of children with CIs was reported by Spahn et al. (2004). Questionnaires used to assess parental stress were the Symptom Checklist 90-R, designed to

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* For this thesis the term 'parent' is used to incorporate parent as well as caregiver

ascertain various psychological symptoms over the past week, and the Everyday Life Questionnaire, a non-disease-specific, behaviour-oriented QOL assessment. Results showed that 21% of parents showed heightened psychological distress, with fathers showing slightly higher levels of distress. These results were compared with samples of those in poor health, as well as healthy persons. Parents of cochlear implanted children were found to be approximately halfway between the samples of ailing and healthy people. That is, parents of children with CIs still show signs of distress and reduced QOL compared to normative data (Spahn et al., 2004). Another study found that further stress may result when parents feel that their child is neither part of the deaf community, nor the hearing world. Furthermore, if the child has residual hearing, this could make the decision to implant even more difficult (Incesulu et al., 2003).

Despite the greater numbers of children receiving CIs, there are relatively few studies documenting changes in the parent's QOL. Similar to adult outcomes, outcomes for children have been assessed using clinical measures such as auditory skills, aspects of speech perception and production, and hearing thresholds. However, these would only represent a small portion of the effect that a CI has on a child's life (Lin & Niparko, 2006), and there have been fewer studies on outcomes from a broader perspective of QOL, especially the effects of implantation from a parental and family perspective (Kelsay & Tyler, 1996; O'Neill, Lutman, Archbold, Gregory, & Nikolopoulos, 2004). One of these rarer studies was carried out by Kelsay & Tyler (1996), and assessed the views of parents whose children had received a CI(s) by an open-ended questionnaire; parents had to list advantages and disadvantages associated with their child's CI. One year post-CI, benefits reported by parents included environmental sound perception (reported by 76% of parents), speech perception (64%), and speech production (52%). Similar levels of benefits were reported 2 and 3 years post-CI, suggesting that most parents reported positive changes from the CI, which continued over a period of several years post-implantation.

However, it must be considered that there are a whole host of other factors involved in the process of implantation, from assessment through to habilitation and beyond. From the moment that parents discover that their child has a hearing loss, the process can be stressful, for example having discussions with various health professionals and audiologists regarding the cause of deafness, rehabilitation options, and the long term prospects for the child (Incesulu et al., 2003). Incesulu and colleagues (2003) documented that 81.4% of parents reported that the decision to implant was the most difficult part of the implantation process, along with waiting for assessment results. Post-implant 89% parents reported being anxious about possible device malfunction, however all parents believed that their children would easily find a better position in professional life in the future (Incesulu et al., 2003). This would suggest that parents of children with CIs generally had a positive outlook for the future of their child.

However, it is also important to consider that one of the problems in measuring the QOL changes in children following medical intervention, such as CIs, is that it is hard to separate out the improvement seen as a result of the intervention from that which would have occurred anyway as a function of the child’s personal development (Sach & Barton, 2007). That is, it is inevitable that there would have been some changes in the child as a result of maturation, regardless of whether a child has a hearing loss. There is also the need to take into account the influence of the duration and type of rehabilitation the child has received (Spahn et al. 2004). This also applies to other children with hearing loss (non-CI recipients), where additional factors including resolution of grief, maternal-child interaction and bonding, parental stress, parent emotional and time availability, and the child’s self-development are all related to their language development (Kurtzer-White & Luterman, 2003). Thus there are many inter-related factors that impact on the child’s outcome, as well as overall QOL.

3.4 Summary of Outcomes

Although CIs have been highly successful for those with severe to profound hearing losses, it is important to remain objective and realistic when providing information to potential recipients and their families. Despite significant research, outcomes are varied, there is no reliable and accurate pre-surgical predictor of post surgical performance in CIs, which would allow the clinician to confidently predict how prospective candidates how will do with the implant (Zeng, 2004). In addition to this QOL is multi-faceted and subjective. The literature has identified several areas related to QOL outcomes for postlingually deafened adult CI recipients, and their SO. Firstly, outcomes from CI recipients are usually obtained in clinical or test situations, and thus do not represent the ease or difficulty an individual has in daily life. Secondly, there have been few studies carried out from the perspective of the SO, nor comparing the WL-SO to the CI-SO, or looking at the impact of CIs on QOL for the parent. This study aimed to integrate these five participant groups to make four comparisons as follows: the CI group and their SO; the WL group and their SO; the CI group and WL group; and finally, the CI-SO group and the WL-SO group. There are no studies in the literature that have incorporated all of these views.

3.5 Rationale for the Current Study

To reiterate, many studies have confirmed that CI’s provide benefit in terms of sound awareness and speech perception, and have focused primarily on perceptual improvements of the implantee alone. Although this is clearly important, changes cannot be assumed to represent the beneficial effects on the everyday lives of recipients. In addition, technological improvements have resulted in better speech perception outcomes, and the widening criteria means that potential recipients will have higher expectations pre-implant. Therefore, studies such as the present one are important to assess whether improvements in QOL are in line with improved audiological clinical outcomes, and that they meet pre-implant expectations. In addition, any effort to measure the overall benefit of a CI should consider the broader perspective, such as including the effects of the CI on a SO, as well as how the SO felt the CI had affected the recipient. Therefore, the overall aim of this study was to investigate QOL outcomes in adult CI recipients in New Zealand, and their SO in a range of domains relating to daily life.

In order to measure the effect of implantation on QOL, questionnaires were developed for each participant group. The responses of cochlear implantees’ and their SO were compared to those on the WL and their SO. In addition the responses of a subgroup of CI participants who received their CI during the course of this study (called the CI-New group in this thesis), and their SO, were compared to give true pre- and post-implant QOL outcomes. As an alternative view of the SO, parents of children with CI(s) completed a questionnaire. This was in order to compare their QOL prior to, and following their child’s implant. The results of this study will provide data for the SCIP-A, as currently there have been no studies carried out based solely on New Zealand recipients. It is possible that the results of this study can be used to influence funding bodies for increased funding for CI, so that more people would be able to benefit from implantation.

3.6 Justification for Using Questionnaires

A questionnaire was used for each participant group to assess QOL. The advantages of this method over other methods such as personal interview, include speed of data gathering, convenience for the participant, cost effectiveness, and repeatability (High, Fairbanks, & Glorig, 1964). Questionnaires also allow the researcher to obtain a more complete picture of the effect of hearing impairment (or cochlear implantation), beyond the information gained in a clinical setting (Weinstein & Ventry, 1983). Additionally, questionnaires reduce researcher bias; that is, the researcher’s own opinions would not influence respondent’s answers. Written questionnaires are also less intrusive than telephone or face-to-face surveys, and can be completed by the participant at a suitably convenient time. Further, in studies involving participants with hearing loss, their ability to use a telephone must also be considered.

In pointing out the advantages of questionnaires, the disadvantages must also be realised. These include the risk of low response rates, which can be due to a number of factors including questionnaire length, wording, clarity, ease of understanding, visual appearance, interest of the topic, and timing and response modes (Johnson & Danhauer, 2002). Other disadvantages are that the researcher cannot verify or validate responses, cannot ensure that participants answer all questions, nor ensure an accurate interpretation or understanding of the questions asked. One final consideration regarding questionnaires used in this study is that it did not include generic QOL instruments. The main reason for this was that this study did not aim to compare findings to norms, but rather to provide outcome data specific to New Zealand recipients. In addition, other researchers have found that generic instruments are insensitive to changes in hearing abilities of CI recipients (Hinderink et al., 2000; Krabbe et al., 2000; Mo et al., 2005), or older people with hearing impairment (Stark & Hickson, 2004), as well as providing ambiguous results (Hirschfelder et al. 2008).

3.7 Aims and Hypotheses

The goals of the present study were to further add to the existing literature and obtain information about the changes in the QOL in postlingually deafened adults following cochlear implantation, and to provide information about which aspects of the recipients' daily lives that these changes are most noticeable. It also aimed to assess whether the benefit (if any) provided by the CI impacted on a SO (e.g. spouse, sibling, parent, child), and whether the level of benefit (if any) reported by the implantee is similar to that reported by the SO. There were four aims for this study: 1) to obtain information about the changes in QOL in postlingually deafened adults following implantation; 2) to determine which aspects of daily life that these changes (if any) are noticed the most; 3) to look at the impact of a CI on a SO; and 4) to see whether these changes (if any) reported by the participant are similar to that reported by the SO. Four hypotheses were proposed. These were that: (i) the CI group will have higher QOL ratings than those on the WL for a CI; (ii) the CI-SO group will rate their QOL to be better than the WL-SO group; (iii) the participants will have similar QOL ratings to their SO; and (iv) parents of children with CI(s) will rate their QOL to be better post-implant when retrospectively comparing back to pre-implant.

Chapter 4: Method

Ethical approval for this study was obtained from both the New Zealand Health and Disability Ethics Committee, and the Human Ethics Committee at the University of Canterbury. All procedures performed were in accordance with these ethical approvals. The research process is outlined in this chapter, including the participants, procedures, materials, instruments, and data analysis used for the study.

4.1 Participants

There were five groups of participants for the present study:

1) Postlingually deafened adult CI recipients, who are current patients of the SCIP-A[a] (CI group);
2) SO of CI recipients in group 1 (CI-SO group);
3) Postlingually deafened adults on the SCIP-A's waiting list for a CI (WL group);
4) SO of adults in group 3 (WL-SO group);
5) Parents[b] of children with a CI, implanted at the SCIC[c].

Participants in groups 1 and 3, as well as the children of group 5, all met their respective clinic's CI candidacy criteria, as outlined in sections 2.3, 2.4, and 2.5 (Chapter 2). For group 5, only parents of children who had been implanted for 1 year or longer were included in this study. It was recognised that some of the participants from the WL group (group 3) would be implanted during the course of this study, and that this subgroup would provide the true pre-to-post results. Therefore this subgroup is referred to as the 'CI-New' group in this thesis. The results of these individuals were also included in the WL group's data. In addition, as the purpose of this study was to investigate changes of QOL pre- to post-implant, a follow-up questionnaire was also issued to the CI-New group post-implant, at approximately 2-3 months post-surgery, or once the MAP in the speech processor was stable.

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[a] SCIP-A Consists of Adults of the Southern Cochlear Implant Programme public programme. The SCIP is divided into the SCIP-A for adults and SCIP-P for children.

[b] For the purpose of this thesis the term "parent" is used to cover parents, caregivers and/or guardians.

[c] SCIC- Sydney Cochlear Implant Centre, Australia

Questionnaires were sent to participants to complete. The total numbers of questionnaires sent out were: Group 1 – 160; Group 2 – 160; Group 3 – 113; Group 4 – 113; Group 5 – 75.

4.2 Materials - Questionnaires

In order to select the questionnaires for the present study, a review of the major existing questionnaires developed for the hearing-impaired available in the literature was conducted. It was found that most of the existing questionnaires were designed for the hearing-impaired population in general, with very few being specific to CI recipients. From the few questionnaires available, the main questionnaire chosen for the current study to assess the CI group, and was also re-worded for the WL group, was developed by Hinderink et al., (2000), and called the Nijmegen Cochlear Implant Questionnaire (NCIQ). In addition to the NCIQ, a combination of questions from existing questionnaires were collated for each group, with the wording modified to suit each group. It was felt that these additional questions helped to provide a better view of QOL. The existing questionnaires are presented in Table 3. The questionnaires developed for this study also included some open-ended comment questions these were: CI group Q67-68 and 71; for the CI-SO group Q29; for the WL group Q61-66; for the WL-SO group Q21-26; for the Parent group Q72-75).

Table 3: Existing Questionnaires Used to Form the Questionnaires for the Current Study

Group	Original Questionnaire	Author (s)	Current Study Question No.
1) CI	Nijmegen Cochlear Implant Questionnare (NCIQ)	Hinderink et al. (2000)	1-60
	Cochlear Implant Satisfaction Questionnaire (CISQ)	Harsymczuk & Deane, (2007)	61-66, 69-70
2) CI-SO	Caregiver Strain Questionnaire	Robinson, (1983)	1-2
	Care Giving Burden Scale (CGBS)	Gerritson & Vanderende, (1994)	3,4,6, 13-14
	Quantified Denver Scale (modified for the SO)	Stark & Hickon, (2004)	5, 7-11, 15-17
	Index Relative Questionnaire Form (IRQF)	Wexler et al. (1982)	12, 18-26
	Client Satisfaction Questionnaire (CSQ)	Larsen & Attkinson, (1979)	27-28
3) WL	Nijmegen Cochlear Implant Questionnare (NCIQ)	Hinderink et al., (2000)	1-60
4) WL-SO	Caregiver Strain Questionnaire	Robinson, (1983)	1-2
	Care Giving Burden Scale (CGBS)	Gerritson & Vanderende, (1994)	3,4,6, 13-14
	Quantified Denver Scale (Modified for the SO)	Stark & Hickon, (2004)	5, 7-11, 15-17
5) Parents	Parental Perspective (PP)	Archbold et al. (2002)	11-67
	Cochlear Implant Satisfaction Questionnaire (CISQ)	Harsymczuk & Deane, (2007)	68-71

As shown in Table 3, the main questionnaire for the CI and WL groups was based on the NCIQ (Hinderink et al., 2000), which has been used and validated in other studies (Baumgartner et al., 2007; Cohen et al., 2004; Hirschfelder et al., 2008; Klop et al., 2008; Klop et al., 2007; Krabbe et al., 2000). The NCIQ is a disease-specific QOL instrument, and although it is longer than many other questionnaires (60 questions), it encompasses a larger number of domains that are important in assessing QOL. The NCIQ has been designed to measure outcomes relating to hearing, speech production, self-esteem, social, and physical functioning. It is composed of three general domains: physical, psychological, and social functioning. These domains are grouped into six subdomains: (1) basic sound perception, (2) advanced sound perception, and (3) speech production, which make up the physical domain; (4) self-esteem within the psychological domain; while (5) activity limitations and (6) social interaction encompass the social domain. These domains are illustrated in Figure 7 below.

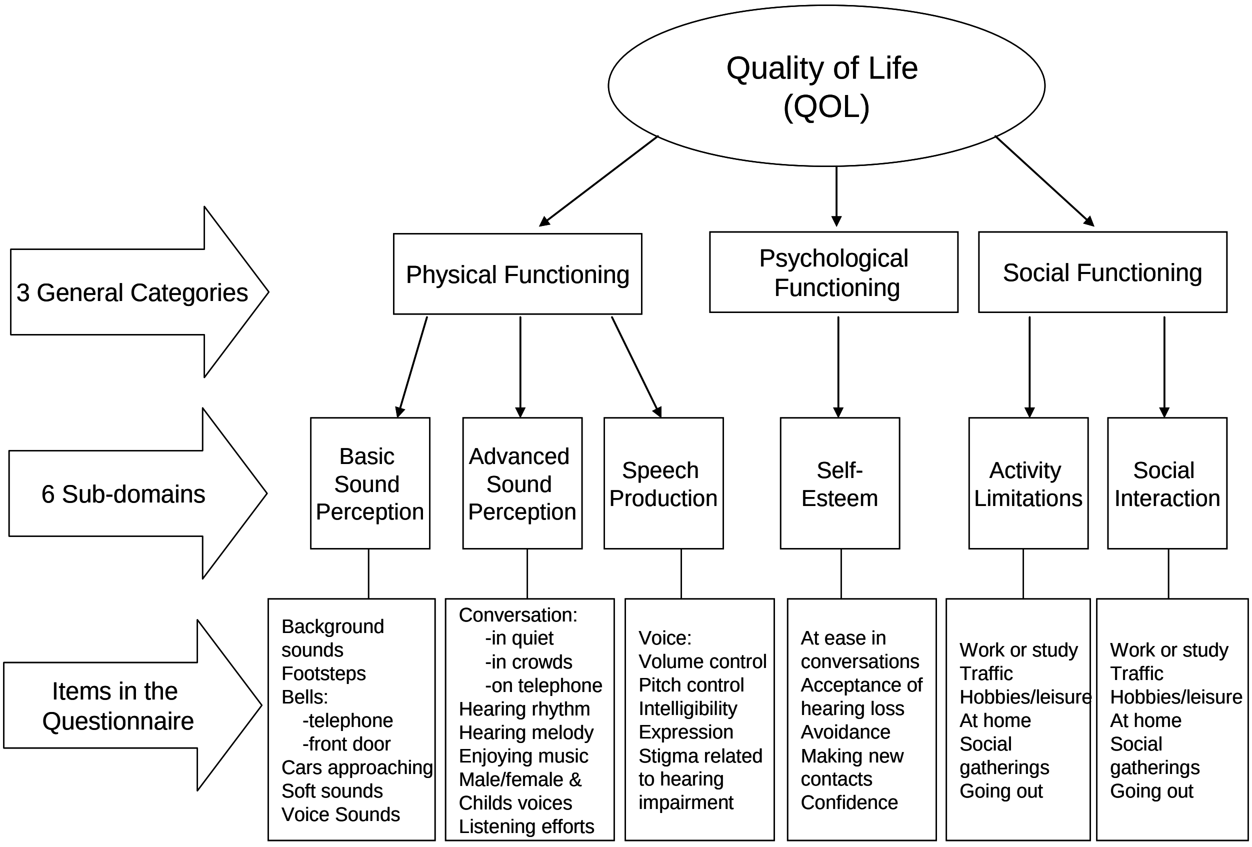

Figure 7: Diagram of the NCIQ constructs (adapted from Hinderink et al. 2000)

Each subdomain consists of 10 items formed as a statement with the following 5-point response scale: never (1), sometimes (2), regularly (3), usually (4), and always (5). There is also a sixth ‘Not Applicable’ response category. For items 55-60 the response categories were answered according to participant’s ability to perform the action in question. These response categories were as follows: no (1), poor (2), fair (3), good (4), quite well (5), and N/A (not scored). The questionnaire was scored as described by Hinderink et al. (2000) where scores ranged from 0 (very poor) to 100 (optimal). In the present study the same scales were used, however “often” was replaced with “regularly”, and “mostly” was replaced with “usually”. The changes were based on pilot testing performed in the early stages of the research. The results of these indicated that the terms “often” and “mostly” were too similar and therefore sometimes confused. In addition, some questions were re-worded in order to suit the group of participants responding.

In the Hinderink et al. (2000) study, the NCIQ was administered to participants twice in a crossover design. The first time the questionnaire was worded in past tense where recipients were asked to provide responses based on what their life was like pre-CI. Approximately 2 weeks later, the questionnaire was re-administered in present tense for respondents to rate their perceptions on their life post-CI. These ratings were then compared to give a pre to post comparison. Additionally changes were also compared to subjects on the WL for a CI. Unlike the Hinderink et al. (2000) study, the current study’s questionnaire asked CI recipients to make ratings based on their current opinion of their CI. It was not issued in a retrospective format, as it was felt that retrospective responses may be affected by inaccurate memory, and/or a “halo” effect based on the fact that they now had the CI. In addition, a test-retest or practice effect could have affected the validity of comparing the responses between the two administrations of the same questionnaire. As mentioned previously, the NCIQ had been used in other studies, and was been found to be reliable, valid, and sensitive to detect clinical changes, with good internal consistency (Hinderink et al. 2000).

The second part of the questionnaire administered to the CI group was based on the Cochlear Implant Satisfaction Questionnaire (CISQ), which was developed by Harsymczuk and Deane, (2007). These authors reported that the CISQ was the outcome of a combination of sections modified from the Satisfaction in Daily Life (SADL) Questionnaire (Cox & Alexander, 1999), and the Client Satisfaction Questionnaire-8 (CSQ) (Larsen, Attkisson, Hargreaves, & Nguyen, 1979). The SADL questionnaire has been used to evaluate the satisfaction hearing aid recipients derive from their hearing aids. The final scale of the questionnaire yields a Global Satisfaction Score and 4 subscale scores: service and cost, positive effects, negative effects, and personal image. It consists of 15 items, and can be applied clinically to compare statisfation obtained by the same patient under different conditions, to determine satisfaction in relation to group norms, and to gain insight into any dissatisfaction that a patient may have (Cox & Alexander, 1999). The CSQ is a brief 8-item instrument designed to be used across a wide variety of settings. Three questions from the original CSQ questionnaire (5, 6, 8) were excluded as they were not considered relevant for the participants in the present study. In the orginal questionnaire, each item was phrased as a question with answers made on a 4-point answer scale without the neutral position. For the present study, the original questionnaire was modified to a 5-point response scale, with an “unsure” category being added. Participants were asked to rate their response by circling the appropriate number where 5 = ‘a lot’; 4= ‘a moderate amount’; 3= ‘a little’; 2 = ‘very little’; 1= ‘not at all’; or O = ‘N/A.’ As with the case of the NCIQ, higher ratings were indicative of greater satisfaction with the CI, and the CISQ was modified to be applicable for each group (i.e. groups 1-4). For example, the first question for the CI asked the respondent to rate how satisfied they were with their CI in a range of situations such as: “How sastisfied are you with your CI when attending a restaurant?” For the SO of the implantee, the same question was asked with the instructions re-phrased to: “How much improvement has their been in your life since your partner had their CI when attending a restaurant?” The CISQ is in in Appendix 2

The questionnaire for the SO was also based combining a few number existing questionnaires designed for a SO to complete (Table 3). These were the Caregiver Strain Questionnaire (Robinson, 1983), the Care Giving Burden Scale (Gerritsen & Vanderende, 1994), the Quantified Denver Scale Questionnaire (modified for SO assessment) (Stark & Hickson, 2004), and the Index Relative Questionnaire Form (Wexler et al., 1982). The resulting questionnaire for the CI-SO (i.e. group 2) is included in the Appendix 1 (p.137), but to provide a general outline, it consisted of 29 questions. The first 17 items were statements in which the respondent was asked to mark on a 5-point scale the number which best matches their opinion, ranging from strongly disagree to strongly agree. Questions 18-26 asked about the SO’s participation in hobbies, and/or recreational activities, if they felt that their partner was a burden because of their hearing impairment, in addition to their adaptation to their partner having a CI. The remaining two questions related to the SO’s satisfaction ratings of how their partner’s CI had affected both of their lives, and the final question asked the SO for any further comments. The questionnaire for the WL-SO (i.e. group 4) consisted of 26 questions in total. The first 20 were the same as those for the CI- SO group. The remaining six questions were open-ended questions in which the SO was asked to list their expectations, desired benefits, and concerns regarding their partner’s future CI.

The questionnaire used for the parents (or caregivers) of children with CIs (i.e. group 5) was based on the Parental Perspectives Questionnaire (PP) developed by Archbold, Lutman, Gregory, O’Neill, & Nikolopoulos (2002). Archbold et al. (2002) based the PP on resulting themes from open-ended interviews conducted with parents of children with CIs. The PP has been shown to be robust, repeatable, reliable and valid in previous studies (Nunes, Pretzlik, & Ilicak, 2005; O'Neill et al., 2004). There are 10 themes covered in the closed-format version of the questionnaire: communication, general functioning, self-reliance, well-being and happiness, social relationships, process of implantation, education, effects of implantation, decision to implant, and supporting the child.

The original PP questionnaire consisted of 74 statements in which the parents were asked to tick their response to the statements. The questionnaire used for the present study included only questions that were of special interest to the SCIC and the researcher, that resulted in 63 statements being used in the current study. The first 10 of these consisted of general questions regarding the parent's relationship to the child, details of the child's hearing loss, information regarding implantation, educational setting, and whether the child had any additional disabilities. Questions 12-68 were adapted from the PP questionnaire, but were re-worded in order to get a retrospective comparison of how the parent viewed their child before their child got their CI, compared to now, post-CI. For example, the parent was instructed to think about how their child functioned before they got their CI(s) and then asked to agree or disagree with a statement such as: "I could rarely leave my child to do something on their own." The same statement was then repeated but with the parent instructed to rate the statement based on how their child now heard with the CI(s). Participants indicated their level of agreement with each question on a 5-point response scale which ranged from "strongly agree" (5), "agree" (4), "neither agree or disagree" (3), "disagree" (2), or "strongly disagree" (1), along with a 'not applicable' (N/A) option. An extra series of questions (69-72) were also added. These related to parents' satisfaction with their child's CI and how the CI has affected their QOL. Finally, Q73 to Q75 were applicable only for those whose child had bilateral implants, and asking the parents to rate the difference between bilateral CIs compared to a monaural CI. These last three questions were included at the request of the SCIC, in order to obtain specific information of interest to their programme. Modifications made to the original version were for improving the clarity of the questions, and/or allow specific comparisons to be made, in order to be suitable for the aims of the present study.

4.3 Pilot Testing

Each questionnaire used in this study was pilot tested on at least two people in order to ensure that the clarity, wording and validity of the questions, response modes, and the time taken to complete the questionnaire were appropriate. Based on pilot testing, it was estimated that the questionnaires would take participants no more than 30 minutes to complete.

4.4 Procedures

Staff of the respective clinics identified potential participants meeting the criteria for the present study. Questionnaire packs were then mailed out to all current patients of the SCIP-A, including those on the WL for a CI, all patients' SO, as well as parents of children of the SCIC. The packs contained the questionnaires, information letter, covering letter, and a pre-paid envelope addressed to return the questionnaire to the SCIP-A or the SCIC. Tracking lists were created where each questionnaire and pre-paid reply envelope were assigned a number corresponding to the participant's name. The tracking system allowed staff at the SCIP-A to check off returned questionnaires against the original list by their identifying numbers. This enabled follow-up letters to be sent to those who had not returned their questionnaire within the specified two weeks as stated in the information letter, three to four weeks after they were originally posted. The tracking system also provided the additional benefit in that the patient's audiological information could be obtained from the patient database, which saved the respondent's time, as they did not have to provide this information in the questionnaire, and ensured better accuracy of this information. It also protected participants' privacy and confidentiality from the researchers. For the SCIC, practical issues and difficulties in communication efficiency meant that the only information collected for the children in this group were the questionnaires that the parents completed.

Responses from the questionnaires were returned to the respective clinic (i.e. SCIP-A for groups 1-4, and SCIC for group 5), and were checked off by staff of the clinic. Any identifying information was removed before the questionnaire was returned to the researcher. For the SCIP-A, staff at the clinic also collated the de-identified audiologic information for each respondent. Information collected included audiological details, CI details such as the type of CI speech processing strategy used, duration of implant use, and speech perception scores post-surgery.

4.5 Data Analysis

Descriptive statistics of the CI and WL group were computed for the subject characteristics of: age, gender, reported age at onset of deafness, reported age implanted or received HAs, cause of hearing loss (if known), pure tone thresholds, and speech discrimination scores. Appropriate parametric and non-parametric two-tailed statistical analyses were performed using SPSS software, versions 15 and 16. A ‘p’ value of ≤ 0.05 was regarded as statistically significant. Correlational analyses were conducted using Spearmans’ calculations in order to assess for relationships between QOL scores and other subject variables.

Data from each of the questionnaires for all groups was extracted and assigned numerical values. The response “not applicable” and unanswered questions were treated as missing values. Depending on the question, a low score may have represented either a negative or positive response. In order to facilitate clear interpretation for the data analyses, question ratings were changed so that a more positive response always received the higher score, which indicated a better QOL rating. That is, for ‘reversed’ questions where a lower score suggested a better result, the scoring order was reversed for the data entry, so that a higher number indicated a more favourable response. These questions are listed in Table 4. All questions used a 5-point rating scale. For data analyses the 5-point rating scale responses were converted as follows: 1 = 0; 2 = 25; 3 = 50; 4 = 75; and 5 = 100; as described by Hinderink et al. (2000). Therefore possible scores were 0, 25, 50, 75 or 100, where 0 is the lowest (worst) score, and 100 is highest (best score), which corresponded to better QOL.

Table 4: Reversed Items for the Questionnaires

Questionnaire	Reversed questions *
CI recipients	2,6,8,10,12,14,16,18,20,22,24,26,27,30,34,36,38,39,41,43,46,48,49,50,51
WL	2,6,8,10,12,14,16,18,20,22,24,26,27,30,34,36,38,39,41,43,46,48,49,50,51,54,55
CI-SO	N/A
WL-SO	N/A
Parent/Caregiver	21,23,24,29,30,33,34,35,36,37,38,39,41,42,45,46,47,48,49,50,53,54,56,57,59, 60,63,65,66,67,68,69,70,71

* The response classifications for these questions were reversed for data entry so that a higher score is better.

For the WL and CI questionnaires, overall scores for each of the six subdomains, i.e. basic sound perception, advanced sound perception, speech production, self-esteem, activity limitations, and social interactions (Q1-60) were computed by adding together the scores from the 10 questions in each subdomain and dividing this by the total number of completed items. Total QOL scores were calculated by adding the score of each question and dividing the sum by the total number of questions completed in the questionnaire. It should be noted that during the process of analysis, it was discovered that the data presented in the Hinderink et al. (2000) article regarding the advanced sound perception and speech production categories were incorrectly labeled. Hence the subdomains were relabeled for the present study.

In order to get a pre- and post-implant QOL comparison, the responses of the CI recipients were compared to the responses of those on the WL. For the CI-New group these participants were originally part of the WL group, thus their responses were included in the overall WL data, as well as an individual subgroup in the results section. For all questionnaires, where applicable, to give a general view of overall QOL, mean ratings were calculated for: QOL; Satisfaction; and, how the SO (or parent) viewed the CI recipient’s QOL. Finally, for the SO comparisons for the WL and CI recipient groups, those without partners were omitted from statistical analysis which involved directly comparing the scores of CI recipients to those of their SO, but included in the results when SO groups were reported individually (i.e. between SO group comparison). Table 5 lists the questions that were collated to get average scores. The qualitative responses (as listed in Table 5) are not reported in the results, and are provided in Appendixes 3 to 8.

Table 5: Questionnaire Categories for Data Analysis

Group	QOL Questions	Satisfaction with CI/Quality of Results Questions	How SO rates participant is affected by CI/HL	Adjustment and/or effects from CI	Bilateral Implants	Qualitative Questions	Comments Provided
CI	1-60*	61-66,69-70	-	-	-	67-68	71
WL	1-60*	-	-	-	-	61-65	66
CI-SO	1-20	27	28	21-26	-	-	29
WL-SO	1-20	-	-	-	-	21-25	26
Parent	11-57	68-71	58-67	-	72-74	-	75

* These relate to the six subdomains as per Hinderink et al., (2000).

Chapter 5: Results

This chapter presents and summarises the results of this study, and is organised into four sections. The first section details response rates and demographic findings for each group (section 5.1); the second section details the results for each individual group (sections 5.2–5.6); the third section details comparisons of the results between the groups (sections 5.7–5.10); and, the fourth section details the correlational analyses of the questionnaire results (section 5.11). Section 5.12 provides an overall summary of the results.

Due to the quantity of data collected, only the findings most relevant to the hypotheses are presented here. This includes the raw means (M), standard deviations (SDs), and the number of respondents (N) for each question (Q). It should be noted that the number of responses differed for each question, as some participants did not answer all of the questions, thus ‘N’ refers to the number of participants who answered that particular question. Also for this reason, where appropriate, total scores are reported as the mean of the number of respondents who answered that particular question.

5.1 Response Rates and Demographics

Based on the inclusion criteria outlined in the methods section, 160 current adult CI recipients in the SCIP-A were identified, with an additional 113 adults being on their WL for assessment or funding. A total of 94 responses were received from the CI recipients (aged 20 to 83 years), providing a response rate of 58%. Of these 94 implantees, 36 were males and 58 were females. Seventy responses were received from WL participants (aged 20 to 86 years), providing a response rate of 62%. Those respondees consisted of 32 males and 38 females. Of the 160 questionnaires sent to the SO of the CI group, 83 were returned (response rate = 52%). Respondees from the CI-SO group included 26 wives, 33 husbands, 4 parents, 7 partners, 4 daughters, 4 sons, 2 siblings, 1 nephew, 1 daughter-in-law and 1 was not specified. Ages of the CI-SO ranged from 24 to 85 years. Of the 113 questionnaires sent to the SO of the WL group 58 were returned, (response rate = 51%). Respondees from the WL-SO group included 15 wives, 20 husbands, 5 parents, 10 partners, 4 daughters, 1 son, 1 sibling, 1 niece, and 1 friend. Ages for the WL-SO varied from 11 years to 83 years. For the Parent group, of the 75 questionnaires were sent out, 23 responses were returned (response rate = 30%). Demographics of the CI, and WL participants, are provided in Table 6, details of the children for the parental perspective in Table

7, with Table 8 providing information on the etiology of deafness, where available. All returned questionnaires were at least partially completed and were therefore included in analysis for this study.

Table 6: Demographic Characteristics of CI and WL Participants

		CI **(N = 94)**			**WL** **(N= 70)**	
Male		36			32	
Female		58			38	
	Mean	**SD**	**Range**	**Mean**	**SD**	**Range**
Age at study	56y, 6m	14y, 6m	20-83y	56y, 5m	15y, 3m	20-86y
Age at CI/HA*	51y, 11m	15y, 3m	5-83y	30y, 6m	20y, 9m	1-78y
Age reported HL°	25y, 5m	20y, 4m	0-72y	26y, 10m	21y, 10m	0-80y
Duration HL **	32y, 7m	18y, 4m	3 -72y	29y, 8m	17y, 6m	2-67y
Duration HA/CI use♦	4y, 1m	4y, 4m	1m–21y	24y, 10m	14y, 6m	3-60y

* Age at CI/HA is the age (years) at first CI or HA use.

° Age (years) relating to when participant reported losing their hearing. Nine CI recipients did not state this information on the questionnaires.

** Duration of hearing loss refers to current age of participant minus age at which they first reported having a hearing loss. Nine CI recipients did not state this information on the questionnaires.

♦ Duration of HA/CI for CI recipients this was calculated as the difference between the date implanted and 1/06/08 which was the approximate date the questionnaires would have been completed. For the WL group, the duration of HA use as reported by the participants on the questionnaires.

Table 7: Demographic Characteristics of Children with CI(s) (N=23**)

Male	13		
Female	10		
	Mean	**SD**	**Range**
Age at study	7y, 11m	4y, 1m	2-15y
Age received first CI	2y, 9m	2y, 5m	3-120m
Age reported HL°	14.30m	20.07m	0-84m
Duration HA/CI use♦	5y, 3m	3y, 6m	0-140m

** 11 of these children had bilateral implants.

° Age relating to when parent reported that the child lost their hearing.

♦ Duration of CI use is in years was the difference between the child’s current age, and the age that parents reported that the child received their first implant.

Table 8: Etiology of Hearing Losses for all Participants

Etiology	CI (N=94)	HA (N=70)	Children (N=23)
Congenital	16	9	8
Genetic	10	8	-
Cytomegalovirus	-	-	2
Measles	2	1	-
Meningitis	-	1	1
Auditory Neuropathy	1	-	1
Rubella	-	2	-
Noise/Industrial	5	9	-
Illness	11	11	1
Ototoxicity	4	-	-
Otosclerosis	4	-	-
Accident	3	1	-
Syndrome	1	2	-
Unknown	28	22	8
Other*	3	1	1
Not Specified	6	3	1

* Bloodgroup, infection, degenerative, Ménière's Disease.

As shown in Table 9, all but two of the CI participants had Cochlear Ltd devices (Nucleus CI24 Contour, or the Nucleus Freedom CI). These two participants had received the MED-EL Pulsar 100 implant and used Opus 2 speech processors. There were a range of speech processors and speech processing strategies used, which are listed below in Table 9.

Table 9: CI Processor Details for Adult CI Recipient Group

CI Processor type (manufacter)	(N=94)	Speech Processing Strategy
ESPrint 3G (Cochlear Ltd)	34	ACE
ESPrint 22 (Cochlear Ltd)	3	SPEAK
Freedom (Cochlear Ltd)	54	ACE
*Freedom (Cochlear Ltd)	1	SPEAK
Opus 2 (MED-EL)	2	HD-CIS/FSP

* Participant # 56 had recently upgraded to Freedom but is still currently using SPEAK.

For the parent/caregiver group there were 11 children that had bilateral implants. Of these 6 were male and 5 were female. The mean age of the first implant was 14 months (SD = 8m; range 3-30m). The mean age of the second implant was 60m (SD = 40m; range 3-120m). The mean time difference between the first and second implants was 47 months (SD = 37), and the mean duration of bilateral implant use was 10m (SD = 10m). This was the difference between the current age of the child (m) and the reported age that the child received the second CI (m). One child received simultaneous CIs at 3 months of age. The remainder of children were sequentially implanted. Audiological results including audiograms and CI device information were not available from the clinic involved. All individuals (N = 23) who completed the parent/caregiver questionnaire stated that they were the child’s parent, therefore the term ‘parents’, instead of parent/caregiver will be used from this point forward. The majority of children (34%) were in mainstream schools, with assistance from a visiting Teacher of the Deaf (TOD). Additional educational settings for the children are displayed in Table 10. The primary mode of communication reported by parents pre-CI was oral, i.e. spoken language (N = 11). As shown in Table 10, post-implant, 14 of the 23 parents reported using spoken language as the primary mode of communication.

Table 10: Educational Settings and Mode of Communication Reported by Parents

Education Setting	**N=23**
Early Intervention	4
Regular preschool, fully mainstreamed	2
Special Education Programme for deaf children in a regular school	1
Special Education Programme for deaf children in a special school	1
Regular school, fully mainstreamed	2
Regular school, fully mainstreamed, with visiting TOD	8
Regular school, partially mainstreamed	1
Combination regular mainstreams preschool and special preschool	1
Combination early intervention and regular preschool, fully mainstreamed	2
Other: Deaf/blind school	1

Primary Mode of Communication

Pre-CI	**N =23**	**Post-CI**	**N=23**
Spoken language	11	Spoken language	14
Sign/gesture	7	Sign/gesture	1
Spoken language supported with sign or gesture	3	Spoken language supported with sign or gesture	4
Other/not specified	2	Spoken language	4

For the CI group, audiograms representing average pure tone thresholds from 250 Hz to 8000 Hz and average loss are shown in Figure 8 (unaided) and Figure 9 (aided). The most recent speech discrimination scores, as recorded in the patient's file are presented in Table 11. For the WL group, mean pure tone thresholds are shown in Figure 10 (unaided) and Figure 11 (aided), with speech discrimination scores also reported in Table 11. For the WL data, average puretone thresholds were taken over a 4-frequency average of 250 Hz, 500 Hz, 1000 Hz, and 2000 Hz, as it would have been unlikely for these individuals to have had much hearing above 2000 Hz, based on the implantation criteria. For all data a maximum of 110 dB HL at 250 and 8000 Hz, and 120 dB HL at 500 to 4000 Hz were taken to be the limits of the audiometer, thus for patient audiological information where a 'NR' (no response) was recorded, these maximum values were entered.

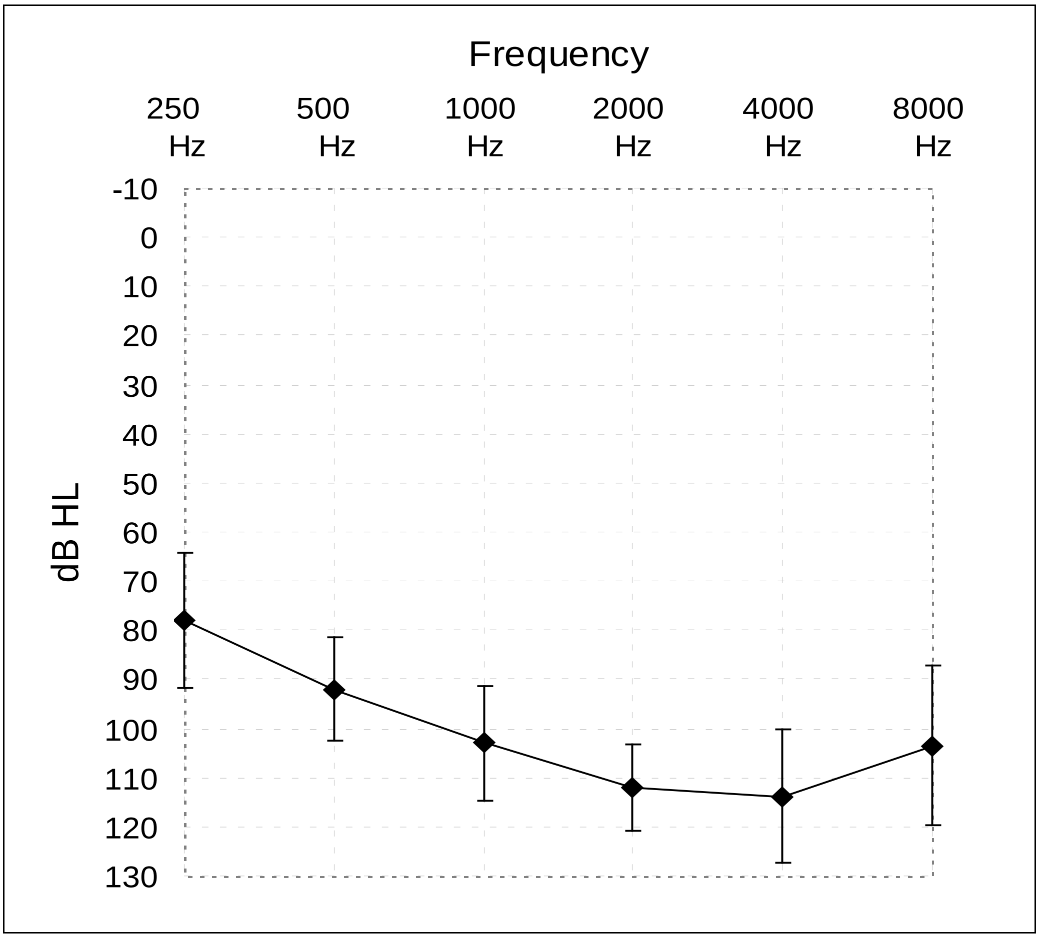

Figure 8: Mean pure tone thresholds unaided (implanted ear pre-surgery)
(n=85; error bars = 1SD)

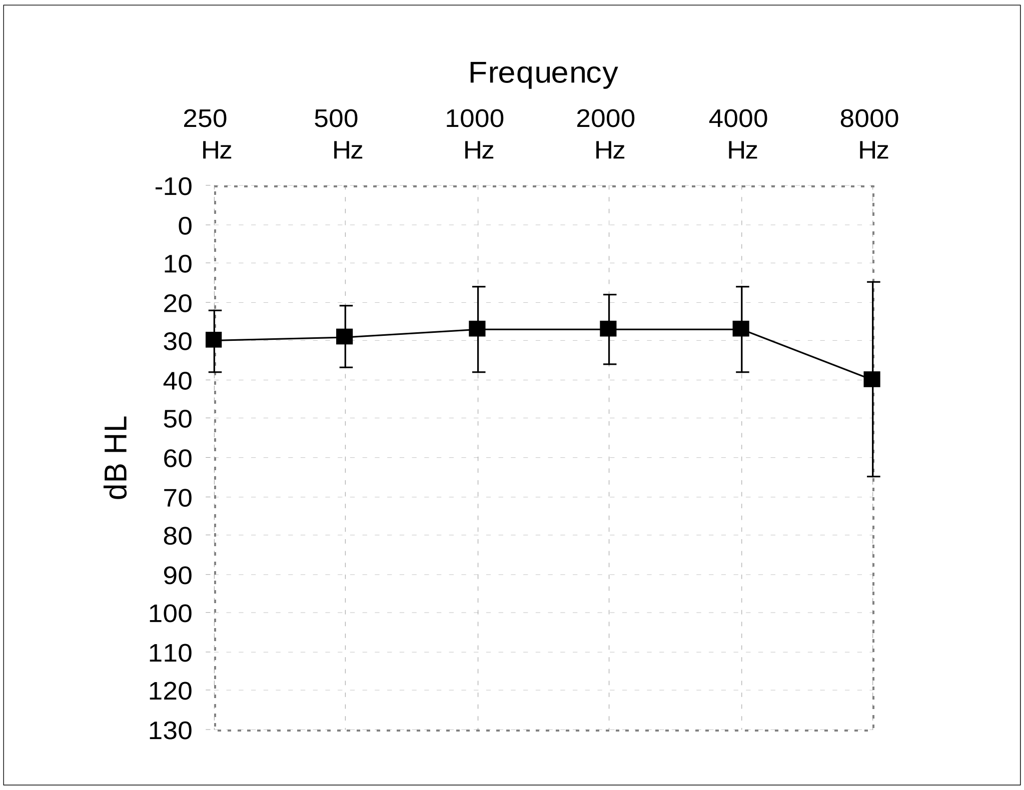

Figure 9: Mean aided pure tone thresholds for the implanted ear post-CI tested in the soundfield (n=85; error bars = 1SD)

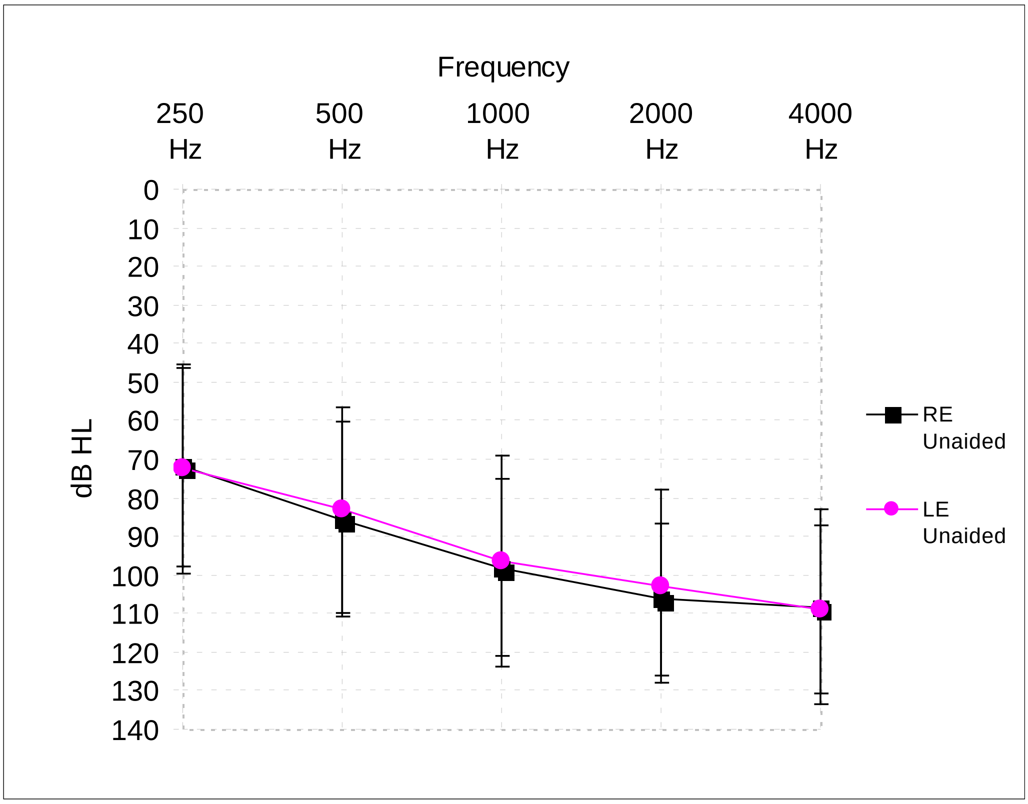

Figure 10: Mean unaided pure tone average thresholds for both ears for WL participants (n=60; Error bars = 1SD)

Note: Not all audiological data was available for all participants on the WL.

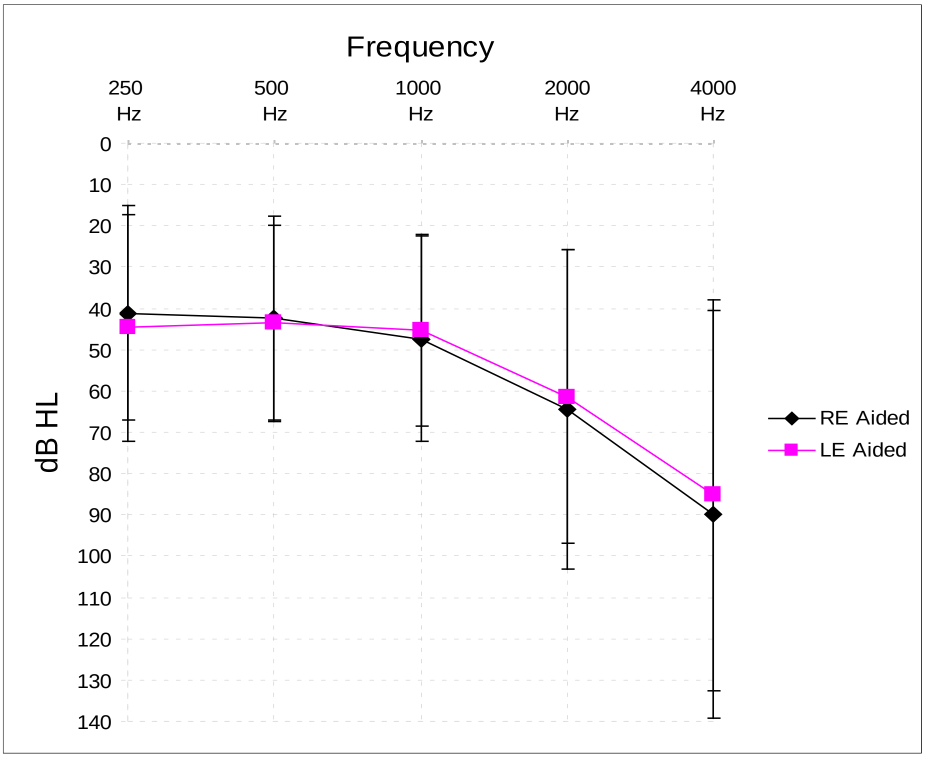

Figure 11: Mean aided pure tone average thresholds for both ears for WL participants (n=60; Error bars =1SD)

Note: Not all audiological data was available for all participants on the WL.

Table 11: Speech Perception Details for CI and WL Participants

****Pre-CI Speech Perception Measures (% correct)** (best-aided condition)	**CI** **Mean (SD)**	**WL** **Mean (SD)**
HINT Auditory + Visual (CI n = 79; WL n = 42)	67 (32)	72 (38)
HINT Auditory Alone (CI n = 72; WL n = 43)	17 (17)	32 (29)
****Post-CI Speech Perception Measures (% correct)** (best aided-condition)		
HINT Auditory + Visual (CI n = 79, WL n = 42)	95 (34)	NA
HINT Auditory Alone (CI n = 85, WL n = 43)	75 (31)	NA
****Difference Pre-to-Post (% correct)** (best aided-condition)		
HINT Auditory + Visual (CI n = 79)	28	NA
HINT Auditory Alone (CI n = 85)	58	NA

** Not all data was available, as some participants were still being assessed by the SCIP-A, thus ‘N’ is reported for each condition.

5.2 Results from the CI Group Questionnaire

To recap, the range of possible scores for all ratings was 0 -100. The overall mean rating of the CI questionnaire for QOL (Q1-60) was 69.97 (SD = 15.54). The mean satisfaction rating (Q61 and 62) was 74.33 (SD = 22.54). Table 12 presents mean scores for the six QOL subdomains; basic sound perception, advanced sound perception, speech production, self-esteem, activity limitations, and social interaction, while Table 13 and Table 14 present descriptive statistics for questions 61 and 62, relating to satisfaction, which incorporated areas of daily life.

Table 12: Mean Scores for the Six QOL Subdomains for CI Recipients Q1-60 (N=94)

QOL Subdomain	Mean	SD
Basic sound perception	68.66	17.95
Advanced sound perception	61.79	19.86
Speech production	80.68	15.56
Self-esteem	64.97	18.22
Activity limitations	70.63	21.07
Social interaction	73.00	18.87

Table 13: Descriptive Statistics for Q61 - CI Questionnaire (Satisfaction)

Area of Satisfaction	N*	Mean	SD
Restaurant	87	69.83	25.90
Public transport	69	71.38	28.53
Cinema	68	63.97	32.14
Concert	63	57.54	39.31
Car	91	75.82	25.94
Family	91	84.62	23.80
Small groups	93	78.23	25.86
Music	89	62.64	34.36
Meetings	88	64.77	27.50
Shopping	91	80.22	22.52
Social	89	68.54	27.05
Television	92	67.66	29.31
Radio	80	55.00	34.77
Telephone	90	63.06	33.36
Work	62	80.24	25.26

* The number of who provided a rating for each area.

Table 14: Descriptive Statistics for Q62 - CI Questionnaire (Satisfaction)

Area of Satisfaction	**N***	**Mean**	**SD**
Communication with others	91	85.99	26.14
Interconnectedness	90	86.94	22.87
Emotional	77	75.97	32.30
Contribute to society	86	77.62	29.21
Family relationships	87	82.76	28.35
New relationships	79	72.78	31.31
Independence	88	83.81	27.34
Interpersonal	85	80.00	26.95
Isolation	85	74.71	35.25
Personal safety	91	80.22	26.22
Self-esteem	88	80.97	30.08
Standing up for self	87	81.03	29.03

* The number of who provided a rating for each area.

The highest rated QOL subdomain score was for speech production (80.68), followed by social interaction (73.00), activity limitations (70.63), basic sound perception (68.66), self-esteem (64.97), and advanced sound perception (61.79). In order to see if there were any differences between the QOL subdomains, a 1-way ANOVA was conducted, the results of which are presented in the comparison section (section 5.9).

As can be seen in Table 13, for Q61 the highest rates of satisfaction were reported for the areas of family life (M = 84.62), work (M = 80.24), and shopping (M = 80.22). The least amount of satisfaction occurred for radio (M = 55.00) and concert (M = 57.54), followed by music (M = 62.64). As shown in Table 14, for Q62 the highest rated area of satisfaction was for interconnectedness (M = 86.94), communication with others (M = 85.99), and independence (M = 83.81). The lowest rated areas were for forming new relationships (72.78), emotional state (M = 75.97), and contribution to society (M = 77.62). Overall, satisfaction ratings were high, with a small range of difference (14.16) across all areas.

Questions 63-66 and Q69-70 of the CI recipient questionnaire also relate to participants' satisfaction with their CI. The following results are reported as the percentage of participants who provided the highest ratings, i.e. a 4 or a 5. For Q69, all but one of the CI participants would recommend a CI to other hearing impaired people who were in a similar situation. In addition, 88% reported that the CI had met "most" or "all" of their expectations (Q65), and 83% of the recipients reported that the CI had met "most" or "all" of their needs (Q66). Overall 91% rated the quality of results obtained from their CI as "good" or "excellent" (Q64), and 97% were "mostly" or "very" satisfied in general overall sense with their CI (Q70). In terms of satisfaction with the service, all of the CI recipients were happy with the quality of service provided by their clinic (Q63). All ratings and percentages for Q63-66 and Q69-70 are shown in Table 15.

Table 15: Ratings for Q63-66, 69 and 70 - CI Questionnaire (Satisfaction)

	Rating*							
Question No.	**5**	**4**	**3**	**2**	**1**	**N**	**Mean**	**SD**
63	69 (78%)	19 (22%)	0 (0%)	0 (0%)	0 (0%)	88	94.60	10.35
64	53 (58%)	30 (33%)	7 (8%)	1 (1%)	0 (0%)	91	87.09	17.23
65	29 (33%)	49 (55%)	8 (9%)	3 (3%)	0 (0%)	89	79.21	19.90
66	21 (23%)	54 (60%)	9 (10%)	6 (7%)	0 (0%)	90	75.00	19.47
69	80 (89%)	9 (10%)	0 (0%)	1 (1%)	0 (0%)	90	96.67	10.73
70	61 (68%)	26 (29%)	1 (1%)	2 (2%)	0 (0%)	90	90.56	15.74

* For question 63 ratings were: 5 = very satisfied, 4 = satisfied, 3 = dissatisfied, 2 = very dissatisfied, 1 = unsure.

Q64 ratings were: 5 = excellent, 4 = good, 3 = fair, 2 = poor, 1 = unsure.

Q65- 66 ratings were: 5 = all expectations (or needs) met, 4 = most expectations (or needs) met, 3 = some expectations (or needs) have been met, 2 = only a few expectations (or needs) have been met, 1 = no expectations (or needs) have been met.

Q69 ratings were: 5 = yes definitely, 4 = yes I think so, 3 = no I don't think so, 2 = definitely not, 1 = unsure.

Q70 ratings were: 5 = very satisfied, 4 = satisfied, 3 = dissatisfied, 2 = very dissatisfied, 1 = unsure. For data entry and analysis these ratings were scored as 5 = 100, 4 = 75, 3 = 50, 2 = 25, and 1 = 0.

(%) is the percentage of participants for each rating.

For the CI-New group, there was a difference between QOL ratings pre- and post-implant. Table 16 shows that when the means were compared pre-to-post-implant, the largest changes from implantation (i.e. pre-to-post) were seen for the subdomains of basic sound perception (59.66), social interaction (54.10), advanced sound perception (47.61), activity limitations (45.50), self-esteem (39.87), and speech production (13.53). Figure 12 shows that the highest subdomain pre- and post-implant was speech production (pre = 74.17; post = 88.15), and the lowest subdomain post-CI was advanced sound perception (66.70). Post-implant all group means for all subdomains were rated higher (Table 16). Mean individual scores for each subdomain for the CI-New group are in Appendix 8.

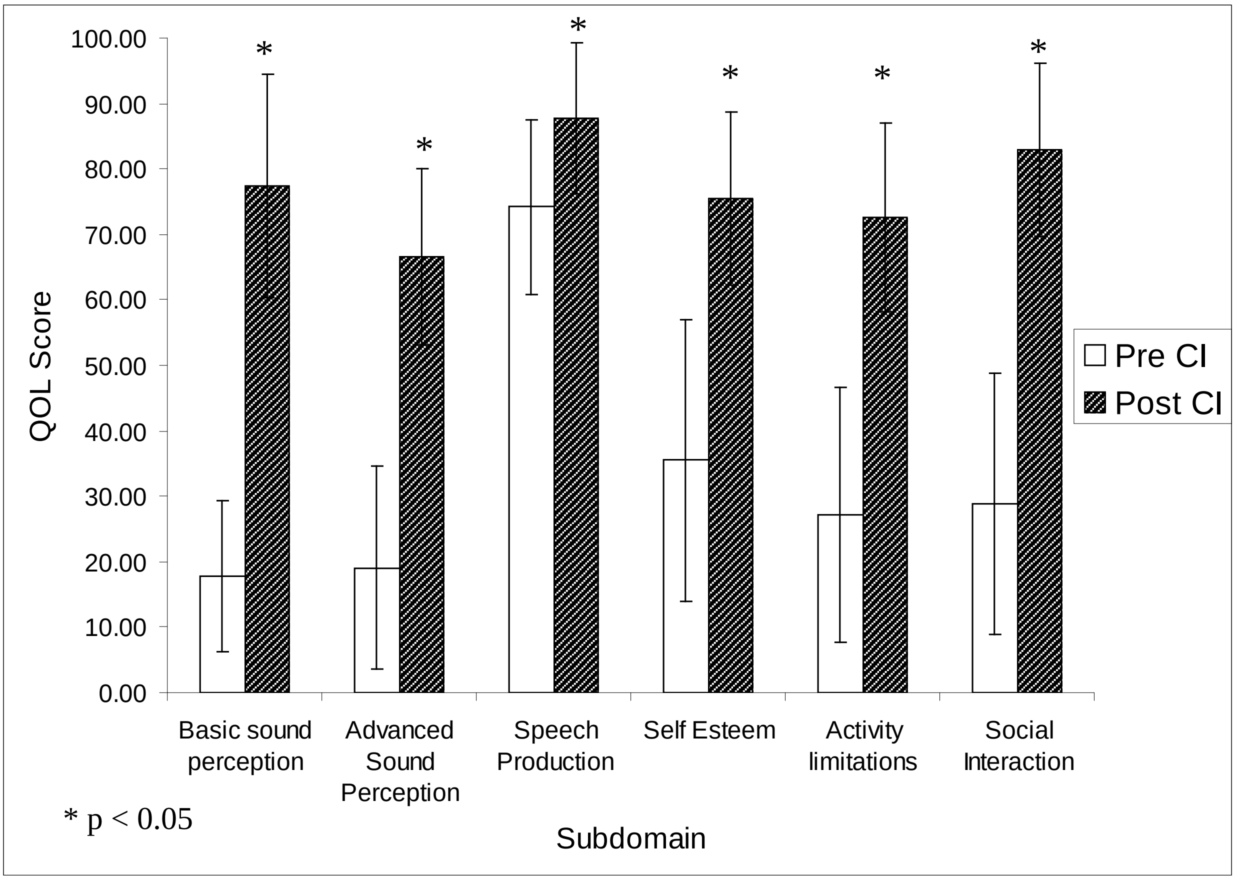

Figure 12: Pre-to-post subdomain scores for the CI-New group

Table 16: Group Mean Subdomain Scores* for the CI-New Group (N=7)

Subdomain	Pre Mean (SD)	Post Mean (SD)	Difference*
Basic sound perception	17.78 (11.45)	77.44 (17.13)	59.66
Advanced sound perception	19.09 (15.57)	66.70 (13.47)	47.61
Speech production	74.17 (13.35)	87.70 (11.62)	13.53
Self-esteem	35.50 (21.58)	75.37 (13.22)	39.87
Activity limitations	27.14 (19.39)	72.64 (14.41)	45.50
Social interaction	28.84 (19.92)	82.94 (13.21)	54.10

* This was calculated as the difference between the mean pre and post scores for the two groups.

Non-parametric Wilcoxon Signed Ranks tests showed that the group differences between the pre-and post-implant results were significant for all six subdomains, as follows:

- Basic sound perception (p = 0.018)
- Advanced sound perception (p = 0.018)
- Speech production (p = 0.028)
- Self-esteem (p = 0.018)
- Activity limitations (p = 0.018)
- Social interaction (p = 0.018)

In summary, the results from the CI questionnaire showed that CI recipients rated speech production as the highest QOL subdomain, followed by social interaction, activity limitations, basic sound perception, self-esteem, and finally, advanced sound perception. The highest rates of satisfaction were reported for work, shopping, and family life, with lowest satisfaction for listening to the radio, and for music. Moreover, since receiving their CI, recipients rated that they experienced increased interconnectedness with the world, communication with others, and independence. For the CI-New group, it was found that each subdomain was significantly higher post-implant, where the highest rated subdomain was for speech production, and the lowest was advanced sound perception.

5.3 Results from WL Group Questionnaire

The main findings for the WL group questionnaire, was that the overall mean rating of the subdomain analysis (Q1-60) was 41.24 (SD = 13.88). Table 17 presents mean scores for the six subdomains.

Table 17: Mean Scores for the Six Subdomains for WL Participants (N=70)

Subdomain	Mean	SD
Basic sound perception	30.85	18.92
Advanced sound perception	32.12	16.92
Speech production	66.64	20.72
Self-esteem	42.67	18.74
Activity limitations	38.35	19.78
Social interaction	36.79	16.88

As can be seen in Table 17, the highest rated subdomain score for the WL group was for speech production (66.64), followed by self-esteem (42.67), activity limitations (38.35), social interaction (36.79), advanced sound perception (32.12), and basic sound perception (30.85). Main findings from the responses from the qualitative questions (i.e. Q61-66) were that the WL participants excepted their lives to become easier following implantation, and also hoped that the CI would enable them to be more sociable, as well as to decrease the stress in their own as well as their SO's lives, due to better communication. These questions are further discussed in chapter 6 (section 6.5.1), with all comments provided in Appendix 4.

5.4 Results from CI-SO Group Questionnaire

The total mean QOL score (Q1-20) for the CI-SO group was 76.01 (SD = 15.62). As shown in Table 18, the lowest ratings on this questionnaire were for Q5 (M = 57.72) where 39% of SO's agreed that at times they got annoyed at having to repeat themselves because their partner did not hear them, and Q8 (M = 55.70), where 40% agreed that they could not talk to their partner in a noisy environment. In contrast, the highest QOL ratings for the CI-SO were for Q4 (M = 90.85) where 97% disagreed that they were embarrassed about their partner's hearing impairment, Q11 (M = 89.69) where 95% disagreed that they could not talk to their partner in a quiet environment, and Q20 (M = 89.06) where 91% of CI-SO's disagreed that their partner was a burden.

Table 18: Ratings for Q1-20 - CI-SO Questionnaire (Quality of Life)

		Rating*						QOL	
Question No.	**Description**	**5**	**4**	**3**	**2**	**1**	**N**	**Mean Score**	**SD**
1	Adjustments at work	26 (43%)	16 (27%)	6 (10%)	10 (17%)	2 (3%)	60	72.50	30.77
2	Financial implications	19 (27%)	27 (38%)	6 (9%)	13 (19%)	5 (7%)	70	65.00	31.68
3	SO social life	35 (47%)	24 (32%)	5 (7%)	10 (13%)	1 (1%)	75	77.33	27.32
4	Embarrassment	58 (71%)	21 (26%)	1 (1%)	1 (1%)	1 (1%)	82	90.85	17.35
5	Annoyed at having to repeat	20 (25%)	20 (25%)	9 (11%)	29 (36%)	3 (3%)	81	57.72	32.27
6	Partner social life	30 (38%)	30 (38%)	3 (3%)	14 (18%)	3 (3%)	80	71.88	30.13
7	SO meeting new people	47 (62%)	23 (30%)	2 (4%)	3 (4%)	0 (0%)	76	87.17	19.36
8	Communication in noise	21 (27%)	18 (23%)	8 (10%)	22 (27%)	10 (13%)	79	55.70	35.79
9	Stress	37 (46%)	29 (37%)	4 (5%)	9 (11%)	1 (1%)	80	78.75	25.81
10	Relationship	51 (62%)	22 (27%)	3 (4%)	5 (6%)	1 (1%)	82	85.67	22.92
11	Communication in quiet	54 (67%)	22 (28%)	1 (1%)	3 (4%)	0 (0%)	80	89.69	17.65
12	Safety	30 (37%)	24 (29%)	0 (0%)	22 (27%)	6 (7%)	82	63.11	35.19
13	Immediate family	31 (38%)	20 (24%)	8 (10%)	21 (26%)	2 (2%)	82	67.38	32.08
14	Interactions	32 (41%)	30 (38%)	12 (15%)	5 (6%)	0 (0%)	79	78.16	22.42
15	Annoyed at hearing loss	39 (48%)	22 (28%)	15 (19%)	3 (4%)	1 (1%)	80	79.69	23.90
16	Leave out of conversations	30 (37%)	36 (45%)	11 (14%)	3 (4%)	0 (0%)	80	79.06	20.06
17	Volume of TV/radio	45 (60%)	15 (20%)	14 (19%)	1 (1%)	0 (0%)	75	84.67	20.91
18	Involved with hobbies	16 (20%)	19 (23%)	31 (37%)	12 (15%)	4 (5%)	82	59.45	27.68
19	Hobbies altered	53 (65%)	19 (23%)	6 (7%)	3 (4%)	1 (1%)	82	86.59	21.94
20	Burden	53 (66%)	20 (25%)	6 (8%)	1 (1%)	0 (0%)	80	89.06	17.27

* Ratings for Q1-17 were: 5 = strongly disagree, 4 = disagree, 3 = neutral, 2 = agree, 1 = strongly agree. Q18 ratings were: 5 = very involved, 4 = quite involved, 3 = moderate involvement, 2 = to a small extent, 1 = no extent. Q19 ratings were: 5 = great extent, 4 = quite an extent, 3 = moderate extent, 2 = small extent, 1 = no extent. Q20 ratings were: 5 = very often 4 = quite often, 3 = sometimes, 2 = seldom, 1 = never. For data entry and analysis these ratings were scored as 5 = 100, 4 = 75, 3 = 50, 2 = 25, 1 = 0

(%) is the percentage of participants for each rating.

Questions 21-25 related to how the CI-SO rated adjustments to both of their lives as a result of the CI. Sixty-two percent of CI-SO's reported that it took "no time," or "hardly any time" for their partner to adjust to their CI (Q21), while 76% felt that they took "no time," or "hardly any time" to adjust to their partner's CI (Q22), and 81% of CI-SO's felt that the adjustment was "not difficult" (Q23). Thirty-six percent of the CI-SO had noticed changes in their partner's emotional state (Q24), and 86% felt that these changes were positive (Q25). Finally 83% of the CI-SO felt that the CI had had a positive affect on their own QOL (Q26). All ratings for Q21–26 are reported in Table 19. For Q27 which relates to satisfaction, the average score was 71.87 (SD = 18.19). Average scores for how the SO viewed the CI affected their partner's life (Q27 and Q28), are provided in Table 20 and Table 21.

Table 19: Ratings for Q21-26 - CI-SO Questionnaire Adjustments and Effects of the CI

	Rating*					
Question No.	**5**	**4**	**3**	**2**	**1**	**N**
21	8 (10%)	41 (52%)	14 (18%)	12 (15%)	4 (5%)	79
22	21 (27%)	39 (49%)	16 (20%)	3 (4%)	0	79
23	64 (81%)	8 (10%)	5 (6%)	1 (1%)	1 (1%)	79
24	15 (19%)	13 (17%)	11 (14%)	24 (31%)	15 (19%)	78
25	43 (59%)	20 (27%)	6 (8%)	4 (5%)	0	73
26	48 (61%)	17 (22%)	11 (14%)	3 (4%)	0	79

* For Q21-22 ratings were: 5 = no time, 4 = hardly any time, 3 = moderate time, 2 = quite some time, 1 = a very long time. Q23 ratings were: 5 = many changes, 4 = quite a few changes, 3 = moderate changes, 2 = some changes, 1 = no changes. Q25-26 ratings were: 5 = very positive, 4 = somewhat positive, 3 = neutral, 2 = Somewhat negative, 1 = very negative.

(%) is the percentage of participants for each rating.

Table 20: Descriptive Statistics for Q27 (CI-SO) Satisfaction with the CI

Area of Satisfaction	**N**	**Mean**	**SD**
Restaurant	67	70.52	31.66
Dinner at home	74	75.00	30.69
Public transport	33	71.97	35.77
Cinema	43	61.63	37.93
Concert	38	59.21	38.74
Driving a car	68	63.97	33.56
Passenger in a car	68	68.38	30.43
Family conversations	77	80.19	23.06
Small group conversations	77	79.55	22.84
Meetings	49	73.98	27.46
Shopping	66	70.83	28.95
Social	71	75.00	27.06
Church	29	63.79	35.09
Television	71	67.61	31.73
Radio	54	61.57	37.21
Telephone	73	68.49	34.37

Table 21: Descriptive Statistics for Q28 (CI-SO) How the SO Viewed the CI Had Affected the Participant's Life

	N	**Mean**	**SD**
Communication with others	82	86.59	21.59
Interconnectedness	82	83.23	25.78
Emotional	69	68.48	31.40
Contribute to society	77	70.45	27.42
Family relationships	78	77.88	25.79
New relationships	72	69.10	27.67
Independence	79	81.65	24.58
Interpersonal	77	79.22	24.80
Isolation	76	75.66	27.98
Personal safety	82	73.78	28.30
Self-esteem	78	77.56	27.50
Standing up for self	76	76.97	29.09

In summary, findings from the results for the CI-SO showed that it did not take much time for their partner or themselves to adjust to the CI. However, there were still some difficulties experienced by the CI-SO, such as having to repeat conversations because their partner did not hear them, as well as communication in a noisy environment. Overall though, most of the CI-SOs reported that they did not feel embarrassed about their partner's CI/hearing loss, and that they could communicate with the recipient in a quiet environment. The majority of CI-SO's (86%) also reported that the CI had made positive changes in their partner's emotional state, as well having a positive affect on their own QOL.

5.5 Results from WL-SO Group Questionnaire

Out of a maximum possible score of 100, the total average QOL score (Q1-20) for the WL-SO was 51.47 (SD = 15.68). For the following mean group ratings, the percentage of SO's that "agreed" or "strongly agreed" (i.e. proving a rating of 4 or 5 on the 5-point scale) were combined and reported. Table 22 presents the descriptive statistics for Q1-20. The lowest mean rating on the questionnaire was for Q8, with 84% of SO's reporting that they could not talk to their partner in a noisy environment (M = 20.98), followed by Q6, with 71% reporting that their partner's hearing loss stopped their partner from socialising (M = 28.24), and Q5, also with 69% reporting that they sometimes got annoyed at having to repeat themselves (M = 31.70). Sixty-six percent of SO's worried about the safety of their partner because of their hearing loss (Q12, M = 32.14), with 50% reporting that having a partner with a hearing loss meant that their social life suffered (Q3, M = 41.67), and 54% feeling that their partner's hearing loss had increased the stress in their lives (Q9, M = 43.18).

In contrast, the highest QOL ratings were provided for Q20 (M = 80.70) with 77% disagreeing that their partner was a burden, then Q19 (M = 71.88), with 65% disagreeing that their partner's hearing loss affected them participating in hobbies and/or recreational activities, and Q7 (M = 65.31) with 63% of SO's disagreeing that they hesitated to meet new people because of their partner's hearing loss. The remainder of questions were open-ended, and the written responses to these are provided in Appendix 6.

In sum, the main findings from the WL-SO group were that the SO found it difficult to communicate with their hearing-impaired partner in a noisy environment, and often felt annoyed due to having to repeat themselves. Seventy-one percent of the WL-SO's also reported that their partner's hearing loss stopped their partner from socialising (Q6), and many (66%) of the SO's reported being worried about the safety of their partner because of their hearing loss (Q12).

Table 22: WL-SO QOL Ratings for Q1-20

Question No.	Description	Rating*					N	Mean Score	SD
		5	4	3	2	1			
1	Adjustments at work	9 (27%)	5 (15%)	6 (19%)	11 (33%)	2 (6%)	33	56.06	33.67
2	Financial implications	6 (13%)	5 (11%)	14 (30%)	12 (25%)	10 (21%)	47	42.02	32.18
3	SO social life	9 (18%)	6 (12%)	10 (20%)	11 (21%)	15 (29%)	51	41.67	36.63
4	Embarrassment	19 (34%)	18 (32%)	11 (19%)	7 (13%)	1 (2%)	56	70.98	27.29
5	Annoyed at having to repeat	5 (9%)	6 (11%)	6 (11%)	21 (37%)	18 (32%)	56	31.70	31.80
6	Partner’s social life	5 (9%)	6 (11%)	5 (9%)	13 (25%)	25 (46%)	54	28.24	34.01
7	SO meeting new people	11 (22%)	20 (41%)	9 (19%)	6 (12%)	3 (6%)	49	65.31	28.78
8	Communication in noise	3 (5%)	4 (7%)	2 (4%)	19 (34%)	28 (50%)	56	20.98	28.52
9	Stress	8 (15%)	8 (15%)	9 (16%)	21 (38%)	9 (16%)	55	43.18	32.79
10	Relationship	9 (16%)	14 (25%)	9 (16%)	17 (32%)	6 (11%)	55	51.36	32.42
11	Communication in quiet	11 (21%)	23 (43%)	8 (15%)	8 (15%)	3 (6%)	53	64.62	28.77
12	Safety	3 (6%)	8 (14%)	8 (14%)	20 (36%)	17 (30%)	56	32.14	30.04
13	Immediate family	11 (21%)	7 (13%)	11 (21%)	14 (26%)	10 (19%)	53	47.64	35.45
14	Interactions	9 (18%)	13 (26%)	16 (32%)	8 (16%)	4 (8%)	50	57.50	29.56
15	Annoyed at hearing loss	6 (11%)	13 (23%)	26 (46%)	7 (13%)	4 (7%)	56	54.46	25.72
16	Leave out of conversations	6 (11%)	13 (23%)	31 (55%)	5 (9%)	1 (2%)	56	58.04	21.38
17	Volume of TV/radio	11 (22%)	16 (33%)	7 (14%)	7 (14%)	8 (17%)	49	57.65	35.06
18	Involvement with hobbies	7 (13%)	15 (27%)	14 (26%)	16 (29%)	3 (5%)	55	53.18	28.49
19	Hobbies altered	21 (38%)	15 (27%)	13 (22%)	6 (11%)	1 (2%)	56	71.88	27.41
20	Burden	27 (47%)	17 (30%)	12 (21%)	1 (2%)	0 (0%)	57	80.70	21.14

* Ratings for Q1-17 were: 5 = strongly disagree, 4 = disagree, 3 = neutral, 2 = agree, 1 = strongly agree. Q18 ratings were: 5 = very involved, 4 = quite involved, 3 = moderate involvement, 2 = to a small extent, 1 = no extent. Q19 ratings were: 5 = great extent, 4 = quite an extent, 3 = moderate extent, 2 = small extent, 1 = no extent. Q20 ratings were: 5 = very often 4 = quite often, 3 = sometimes, 2 = seldom, 1 = never. For data entry and analysis these ratings were scored as 5 = 100, 4 = 75, 3 = 50, 2 = 25, 1 = 0

(%) is the percentage of participants for each rating.

5.6 Results from Parent Questionnaire

Again, out of a maximum score of 100, for each section of the parent questionnaire, the overall group means were as follows: All pre-implant questions (i.e. Q11 to Q31) = 43.57; All post-implant questions (i.e. Q32 to Q57) = 72.35; and for Q58 to Q67 relating to how the parents' lives had been affected since the implant, the mean group score was 62.95. More specifically, in order to get pre-to-post ratings, paired questions (i.e. those questions posed in a pre-and-post format) were compared. These questions are listed in Table 23. All other questions were unpaired. Results showed the total average QOL score for all paired questions pre-CI was 40.00 (SD = 9.15) and 70.43 (SD = 16.53) post-CI.

Table 23: Paired Questions for the Parent Questionnaire

Paired Questions	**Description**	**QOL Category**
11 & 32	Communication with familiar people	Communication
12 & 33	Communication abilities	Effects of Implantation
13 & 34	Help given to child	Supporting the child
14 & 35	Benefit from hearing aids	General functioning
15 & 36	Relationship with grandparents	Social relations
16 & 37	Child being aware when their attention was wanted	General functioning
17 & 39	Leaving child on their own	Self-confidence/reliance
18 & 40	Quality of child's speech	Communication
19 & 43	Social isolation	Social relations
20 & 44	Lack of confidence	Self-confidence/reliance
21 & 45	Amusement activities	General functioning
22 & 46	Making new friends	Social relations
23 & 47	Sociable within the family	Social relations
24 & 48	Sharing in family situations	Social relations
25 & 49	Playing outside	General functioning
27 & 51	Child's future prospects	Decision to implant
28 & 52	Frustration due to child's hearing impairment	Well being & happiness
29 & 53	Fun and happiness	Well being & happiness
30 & 54	Engagement in conversations	Communication
31 & 55	Child's frustration due to his/her hearing difficulties	Well being & happiness

As the parent data did not meet the assumptions of normality, as tested with a one-sample Kolmogorov-Smirnov test ($p < 0.05$), non-parametric Wilcoxon Signed Rank Tests were used to compare the pre and-post-implant ratings for the paired items. Significant differences were found pre- to post-implantation, where scores were better post-CI for all of the following except for paired items 30 & 54 which related to the communication category:

- Communication (items 11 & 32) ($p < 0.001$)
- Effects of implantation (items 12 & 33) ($p < 0.001$)
- Supporting the child (items 13 & 34) ($p < 0.001$)
- General functioning (items 14 & 35) ($p < 0.001$)
- General functioning (items 16 & 37) ($p < 0.001$)
- Self-confidence/reliance (items 17 & 39) ($p = 0.002$)
- Communication (items 18 & 40) ($p = 0.005$)
- Self-confidence/reliance (items 20 & 44) ($p = 0.002$)
- General functioning (21 & 45) ($p = 0.010$)
- Social relations (items 22 & 46) ($p = 0.036$)
- General functioning (items 25 & 49) ($p = 0.002$)
- Decision to implant (items 27 & 51) ($p = 0.010$);
- Well being and happiness (items 28 & 52) ($p = 0.013$);
- Well being and happiness (items 29 & 53) ($p = 0.029$);
- Communication (items 30 & 54) ($p = 0.006$)

Paired items 19 & 43 for the social relations QOL category approached significance ($p = 0.057$). For other paired questions in the social relations category, there were no significant differences for the following items: 15 & 36; 23 & 47; 24 & 48. Nor was their any significance for paired questions 31 & 55 for the well being and happiness QOL category. Table 24 shows statistical information including means and standard deviations for the 11 domains of the questionnaire.

For the following mean group ratings, the percentage of parents that “agreed” or “strongly agreed” with the statement (i.e. had a rating of 4 or 5) were combined and are reported. The means for all questions are available in Table 24. As mentioned previously, some questions were reversed (as reported in Table 4); however this has been accounted for in the data entry and a higher score always suggests a better outcome. For example Q12 states: “before implantation his/her ability to communicate was poor,” with parents being asked to tick the relevant box from "strongly agree" (rating = 1), "agree" (rating = 2), "neither agree nor disagree" (rating = 3), "disagree" (rating = 4), "strongly disagree" (rating = 5). Ratings were then scored as 1 = 0, 2 = 25, 3 = 50, 4 = 75, and 5 = 100 for data entry and statistical analysis. Paired t-tests were used to compare the pre-to-post data, and the significant p-values are reported in the paragraphs that follow.

Decision for Implantation

There was a significant decrease in the number of parents who were worried about their child's future prospects pre- to post-implantation (Q27 pre: 96%; Q51 post: 74%; $p < 0.001$). Further, 34% of parents were concerned that their child may not be part of either the deaf, or the hearing world (Q62).

Effects of the Implant

There was a significant improvement in the child's communication abilities pre- to post-implantation (Q12 pre: 72%; Q33 post: 95%; $p < 0.001$), and 69% of parents agreed that they were much happier with their life (Q67), with 86% feeling more confident in themselves since their child was implanted (Q63). Thirty-five percent of parents reported that the process of implantation was stressful (Q61), with nearly a quarter (24%) reporting that other siblings resented the time and attention they gave to the child with the CI(s) (Q64).

Communication

There was significant decrease in the number of parents who reported that their child had difficulty communicating with people that were familiar to the child pre- to post-implantation (Q11 pre: 75%; Q32 post: 22%; $p < 0.001$), as well as a significant decrease in the number of parents concern about the quality of their child's speech (Q18 pre: 90%; Q40: post 56%; $p = 0.005$). Parents also reported a significant difference pre- to post-implant as to how talkative their child was and how much they engaged in conversations (Q30 pre: 40%; Q54 post: 92%; $p = 0.006$). Positive effects of implantation on communication were also reported where 76% of parents agreed that they could now talk to their child even when the child could not see their face (Q42), while 91% reported that their child's use of spoken language had developed greatly since implantation (Q57).

Table 24: Descriptive Statistics for the Parent Questionnaire

		Question				Rating*			N		
Domain		**No.**	**Description**	**5**	**4**	**3**	**2**	**1**	**(=23)**	**Mean**	**SD**
Communication	Pre	11	Communication with familiar people.	0 (0%)	3 (15%)	2 (10%)	7 (35%)	8 (40%)	20	23.75	27.48
	Post	32		7 (30%)	8 (35%)	3 (13%)	2 (9%)	3 (13%)	23	75	26.11
	Pre	18	Quality of speech.	0 (0%)	1 (5%)	1 (5%)	4 (21%)	13 (69%)	19	11.84	21.03
	Post	40		5 (22%)	3 (13%)	2 (9%)	6 (26%)	7 (30%)	23	42.39	39.48
	Pre	30	Talkativeness & engaging in communication.	5 (25%)	3 (15%)	2(10%)	5 (25%)	5 (25%)	20	47.5	39.65
	Post	54		13 (57%)	8 (35%)	0 (0%)	1 (4%)	1 (4%)	23	83.7	25.68
	Unpaired	42	Talking without seeing parent’s face.	8 (38%)	8 (38%)	1 (5%)	2 (10%)	2 (10%)	21	71.43	32.87
	Unpaired	57	Spoken language development.	15 (68%)	5 (23%)	0 (0%)	1 (5%)	1 (5%)	22	86.36	26.42
Effects of Implantation	Pre	12	Communication.	0 (0%)	3 (14%)	3 (14%)	3 (14%)	12 (58%)	21	21.43	28.82
	Post	33		15 (65%)	7 (30%)	1 (4%)	0 (0%)	0 (0%)	23	90.22	14.58
	Unpaired	61	Implantation being stressful.	3 (13%)	7 (30%)	5 (22%)	6 (26%)	2 (9%)	23	53.26	30.44
	Unpaired	63	Parent Confidence.	10 (43%)	10 (43%)	2 (9%)	0 (0%)	1 (4%)	23	80.43	23.78
	Unpaired	64	Other children resented time and attention.	2 (10%)	8 (38%)	6 (29%)	5 (24%)	0 (0%)	21	58.33	24.15
	Unpaired	67	Happier with life.	9 (39%)	7 (30%)	5 (22%)	2 (9%)	0 (0%)	23	75	25
Supporting the child	Pre	13	Help parent gave to child.	2 (9%)	8 (35%)	4 (17%)	3 (13%)	6 (26%)	23	46.74	34.79
	Post	34		16 (70%)	5 (22%)	2 (9%)	0 (0%)	0 (0%)	23	90.22	16.41
	Unpaired	58	Child needing more help.	0 (0%)	7 (30%)	8 (35%)	1 (4%)	7 (30%)	23	41.3	30.72
	Unpaired	59	More time for parent.	1 (5%)	9 (41%)	8 (36%)	3 (14%)	1 (5%)	22	56.82	23.38
General Functioning	Pre	14	Hearing aid benefit.	1 (5%)	9 (41%)	8 (36%)	3 (14%)	1 (5%)	22	56.82	23.38
	Post	35		13 (57%)	3 (13%)	4 (17%)	2 (9%)	1 (4%)	23	77.17	31.00
	Pre	16	Wanting child’s attention.	1 (4%)	1 (4%)	2 (9%)	8 (35%)	11 (48%)	23	20.65	26.81
	Post	37		16 (70%)	5 (22%)	1 (4%)	0 (0%)	1 (4%)	23	88.04	23.68
	Pre	21	Amusement activities.	6 (29%)	8 (38%)	3 (14%)	0 (0%)	4 (19%)	21	64.29	35.86
	Post	45		12 (52%)	10 (43%)	1 (4%)	0 (0%)	0 (0%)	23	86.96	14.83
	Unpaired	26	Coping in new situations.	1 (5%)	7 (35%)	2 (10%)	5 (25%)	5 (25%)	20	42.5	33.54
	Pre	25	Playing outside.	2 (11%)	3 (17%)	0 (0%)	6 (33%)	7 (39%)	18	31.94	36.18
	Post	49		10 (43%)	9 (39%)	3 (13%)	0 (0%)	1 (4%)	23	79.35	24.6
	Unpaired	50	Coping in new situations.	8 (36%)	11 (50%)	1 (5%)	6 (30%)	3 (15%)	22	78.41	22.22

Domain		Question No.	Description	Rating* 5	4	3	2	1	N (=23)	Mean	SD
Self reliance	Pre	17	Leaving child on own.	1 (5%)	7 (35%)	3 (15%)	7 (35%)	1 (5%)	20	46.25	30.65
	Post	39		17 (77%)	4 (18%)	0 (0%)	0 (0%)	1 (5%)	22	90.91	22.55
	Pre	20	Confidence.	1 (5%)	6 (32%)	4 (21%)	2 (11%)	6 (32%)	19	42.11	34.41
	Post	44		13 (57%)	8 (35%)	1 (4%)	1 (4%)	0 (0%)	23	85.87	19.69
Social relations	Pre	19	Social isolation.	5 (24%)	7 (33%)	3 (14%)	3 (14%)	3 (14%)	21	59.52	34.89
	Post	43		11 (49%)	9 (39%)	1 (4%)	1 (4%)	1 (4%)	23	80.43	26.06
	Pre	22	Making new friends.	4 (21%)	6 (32%)	4 (21%)	5 (26%)	0 (0%)	19	55.26	37.8
	Post	46		11 (50%)	7 (32%)	4 (18%)	0 (0%)	0 (0%)	22	82.95	19.5
	Pre	23	Sociable within the family.	9 (39%)	9 (39%)	2 (9%)	3 (13%)	0 (0%)	23	76.09	25.54
	Post	47		10 (45%)	8 (36%)	1 (5%)	2 (9%)	1 (5%)	22	77.27	28.77
	Pre	24	Shared in family.	7 (33%)	11 (52%)	1 (5%)	2 (10%)	0 (0%)	21	77.38	22.23
	Post	48		8 (35%)	7 (30%)	5 (22%)	2 (9%)	1 (4%)	23	70.65	28.85
	Unpaired	65	Relationship with brothers and sisters.	4 (17%)	4 (17%)	13 (57%)	2 (9%)	0 (0%)	23	60.87	22.39
	Pre	15	Relationship with grandparents.	11 (52%)	7 (33%)	2 (10%)	0 (0%)	1 (5%)	21	82.14	25.18
	Post	36		7 (37%)	3 (16%)	7 (37%)	1 (5%)	1 (5%)	19	68.42	29.86
	Unpaired	66	Improved family relations.	5 (22%)	11 (48%)	5 (22%)	2 (9%)	0 (0%)	22	70.65	22.17
Decision to implant	Pre	27	Future prospects.	1 (4%)	0 (0%)	0 (0%)	8 (35%)	14 (61%)	23	13.04	22.45
	Post	51		1 (4%)	2 (9%)	3 (13%)	13 (57%)	4 (17%)	23	31.52	25.25
	Unpaired	62	Neither part of the deaf nor hearing world.	6 (26%)	5 (22%)	4 (17%)	4 (17%)	4 (17%)	23	55.43	36.89
Well-being and happiness	Pre	28	Parent’s frustration.	0 (0%)	2 (9%)	1 (4%)	10 (43%)	10 (43%)	23	19.57	22.56
	Post	52		1 (5%)	3 (14%)	3 (14%)	12 (55%)	3 (14%)	22	35.23	26.34
	Pre	29	Happy and fun to be with.	14 (61%)	6 (26%)	2 (9%)	1 (4%)	0 (0%)	23	85.87	21.09
	Post	53		7 (33%)	4 (19%)	4 (19%)	4 (19%)	2 (10%)	21	61.9	35.02
	Pre	31	Child’s frustration	2 (10%)	2 (10%)	1 (5%)	8 (40%)	7 (35%)	20	30	33.05
	Post	55		1 (4%)	8 (35%)	2 (9%)	5 (22%)	7 (30%)	23	40.22	34.33
	Unpaired	56	Improvements in behaviour.	5 (23%)	4 (18%)	10 (45%)	2 (9%)	1 (5%)	22	61.36	27.52

Domain		Question No.	Description	Rating* 5	4	3	2	1	N (=23)	Mean	SD
Education	Unpaired	38	Mainstream schooling.	11 (58%)	5 (26%)	1 (5%)	1 (5%)	1 (5%)	19	81.58	28.68
	Unpaired	41	Keeping up with children their own age.	8 (36%)	4 (18%)	4 (18%)	4 (18%)	2 (9%)	22	63.64	35.13
	Unpaired	60	Happy with child’s progress at school.	7 (33%)	10 (48%)	3 (14%)	1 (5%)	0 (0%)	21	77.38	20.77

* Ratings for non-reversed questions were: 5 = strongly disagree, 4 = disagree, 3 = neither agree nor disagree, 2 = agree, 1 = strongly agree.

For data entry and statistical analysis these ratings were scored as 5 = 100, 4 = 75, 3 = 50, 2 = 25, 1 = 0.

For reversed questions (shaded grey) ratings were: 5 = strongly agree (100), 4 = agree (75), 3 = neither agree nor disagree (50), 2 = disagree (25), 1 = strongly disagree (0).

(%) is the percentage of participants for each rating.

Supporting the Child

Parents reported a significant difference pre- to post-implantation where they felt that the help they gave their child was more useful since implantation (Q13 pre: 39%; Q34 post: 92%; p = 0.001). Just under half (46%) agreed that they got more time to themselves because of their child's increased independence since implantation (Q59).

Self-Confidence / Self-Reliance

Parents recognised a significant improvement in their child's self-reliance and self-confidence after implantation; 40% of parents agreed that they could rarely leave their child on their own before implantation (Q17), to nearly all (95%) agreeing that since implantation they could leave their child on their own (Q39; p = 0.002). Similarly whereas 43% agreed that their child lacked confidence pre-implant (Q20), only one parent thought this was still true post-implant (Q44; p = 0.002).

Well-being and Happiness

Parents reported that the frustration they felt because of their child's hearing impairment was significantly reduced post implant (Q28 pre: 86%; Q52 post: 69%; p = 0.013). Forty-one percent agreed that their child's behaviour had improved since implantation (Q56), however there was no significant change in the child's frustration pre- to post-implant, with 52% of parents feeling that their child still showed signs of frustration in their behaviour post-CI (Q31 pre: 75%; Q55 post: 52%).

Social Relationships

Pre-implant 26% of parents reported that their child did not make friends easily (Q22), with the majority (82%) reporting that since implantation their child had made new friends (Q46; p = 0.036). Eighty-one percent also agreed that post-implant their child was more sociable within the family (Q47), although this had not changed a significantly from pre-implant (78%; Q23). Family relations were reported to have improved by 70% of parents (Q66), and 34% reported that their child's relationship with his/her siblings had improved (Q65) post implant. Pre-implant 28% of parents felt that their child was socially isolated (Q19), and post-implant this decreased to 8% (Q43), which approached significance (p = 0.57)

Education

As a result of implantation, 84% of parents felt their child would be able to cope with mainstream schooling (Q38), with just over half (54%) stating that their child was currently keeping up well with children of his/her own age at school (Q41). Moreover, most (81%) parents are happy with their child’s current progress at school (Q60).

General Functioning

Pre-implant, the majority of parents (82%) felt that their child obtained no benefit from their HAs pre-implant (Q14); with 70% stating that their child was now totally reliant on their implant (Q35). This difference was statistically significant (p = < 0.001). A significant difference was also reported pre- to post-implant where 83% of parents agreed that their child was not aware when they were wanted, as the child could not hear them (Q16), compared to post-implant where almost all (92%) of the parents felt that their child was now more aware (Q37; p = < 0.001). Further benefits post-implantation were evident in that 95% of parents agreed their child could amuse him or herself while listening to music, watching television, or playing games (Q45), compared to pre-implant where 67% agreed (Q21; p = 0.010). Pre-implant, 72% of parents agreed that they did not let their child play outside because they could not hear traffic (Q25), compared to post-implant where 82% percent now let their child play outside (Q49; p = 0.002). Also 86% of parents reported that since implantation their child was able to cope better in new situations (Q50).

The parent views of satisfaction with the CI (Q68-71) are presented in Table 25. The majority (87%) of parents were happy with the results their child obtained from the implant (Q68), and 87% felt the results were as they expected (Q69). Ninety-two percent of parents felt that the CI met most of their child’s’ communication needs (Q70), with 87% reporting being satisfied with the CI (Q71).

Table 25: Parent View of Satisfaction with their Child's CI

Question No.	**Rating*** **1**	**2**	**3**	**4**	**5**	**N (=23)**	**Mean**	**SD**
68	0 (0%)	1 (4%)	2 (9%)	5 (22%)	15 (65%)	23	86.96	21.15
69	1 (4%)	1 (4%)	1 (4%)	7 (30%)	13 (58%)	23	82.61	26.58
70	0 (0%)	2 (9%)	2 (9%)	12 (52%)	7 (30%)	23	76.09	21.95
71	0 (0%)	1 (4%)	2 (9%)	3 (13%)	17 (74%)	23	89.13	21.09

* Ratings for Q68-69 and 71 were: 5 = very satisfied, 4 = satisfied, 3 = neutral, 2 = dissatisfied, 1 = very dissatisfied. Q70: 5 = all needs met, 4 = most needs met, 3 = some needs met, 2 = only a few needs met, 1 = no needs met. For data entry and statistical analysis these ratings were scored as: 5 = 100, 4 = 75, 3 = 50, 2 = 25, and 1 = 0. (%) is the percentage of participants for each rating.

In summary, the responses reported in this section from parents showed the positive effects of implantation. Nearly all parents (95%) reported improved communication, along with improvements in their child's confidence and self-reliance, in addition to positive changes in speech and language development. While the most of parents also recognised improvements in their child's educational functioning, and that their child was able to attend mainstream schooling, approximately three-quarters of parents still worried about their child's future opportunities. Additionally, while half of parents agreed that their child was happier since they were implanted, and that family relations had improved, over half (69%) reported that they still got frustrated with their child.

5.7 Comparison of CI and CI-SO

Comparisons between the CI recipient and their SO on how the CI had affected the recipient's QOL showed that the SO had similar ratings to the recipient. Table 26 presents the results of paired comparisons between the recipient and their SO for the matching satisfaction questions – Q61 (CI recipient), and Q27 (CI-SO). In these questions, both parties are asked how the CI affects their own QOL across a range of situations. For example the CI recipient is asked how satisfied they are in a range of situations (e.g. attending a restaurant); similarly their SO is asked how much satisfaction there has been in their life since their partner received the CI in the same situations. Paired samples t-tests showed no significant differences between the groups in any of the categories except for shopping ($p = 0.040$), and car ($p < 0.001$).

Table 26: Paired ♦ and Descriptive Data for Q27 (CI-SO) and Q61 (CI Recipient) For Satisfaction

Area of satisfaction post-CI	Group	Mean	SD	N	P value*
Restaurant	CI	71.54	27.20	65	0.692
	SO	70.00	31.93	65	
Public transport	CI	80.00	28.92	30	0.265
	SO	71.67	35.80	30	
Cinema	CI	64.38	33.92	40	0.916
	SO	63.75	36.23	40	
Concert	CI	67.65	39.18	34	0.186
	SO	57.35	39.18	34	
Car[#]	CI	76.85	25.85	81	0.000*
	SO	50.02	36.65	81	
Family conversations	CI	85.14	24.10	74	0.079
	SO	80.07	23.40	74	
Small groups	CI	77.63	27.26	76	0.532
	SO	79.28	22.87	76	
Meetings or gatherings	CI	67.55	29.45	47	0.195
	SO	73.40	27.78	47	
Shopping	CI	79.76	24.53	63	0.040*
	SO	70.63	29.29	63	
Social situations	CI	69.57	28.07	69	0.155
	SO	74.28	27.11	69	
TV	CI	68.21	30.96	70	0.798
	SO	67.14	31.72	70	
Radio	CI	64.89	31.99	47	0.633
	SO	62.77	37.18	47	
Telephone	CI	63.93	33.42	70	0.267
	SO	67.86	34.62	70	

[#] Note that for the car item, the questionnaire for the CI-SO had 2 separate questions which asked how much improvement there had been in their life since their partner got their CI when i) driving a car and ii) as a passenger. However, for the CI questionnaire it was combined into one question i.e. how satisfied are you with your CI when driving or as a passenger in a car. Therefore the mean of the 2 questions for the SO was calculated and used for the paired t-test.

[♦] Only data from both the recipient and their SO who answered the questions were included.

* ‘p’ significant difference ($p < 0.05$) from paired samples t-test.

The similarity in ratings provided can be seen in Figure 13, and suggests that improvements seen for the CI recipients' lives are also evident in the lives of the SO.

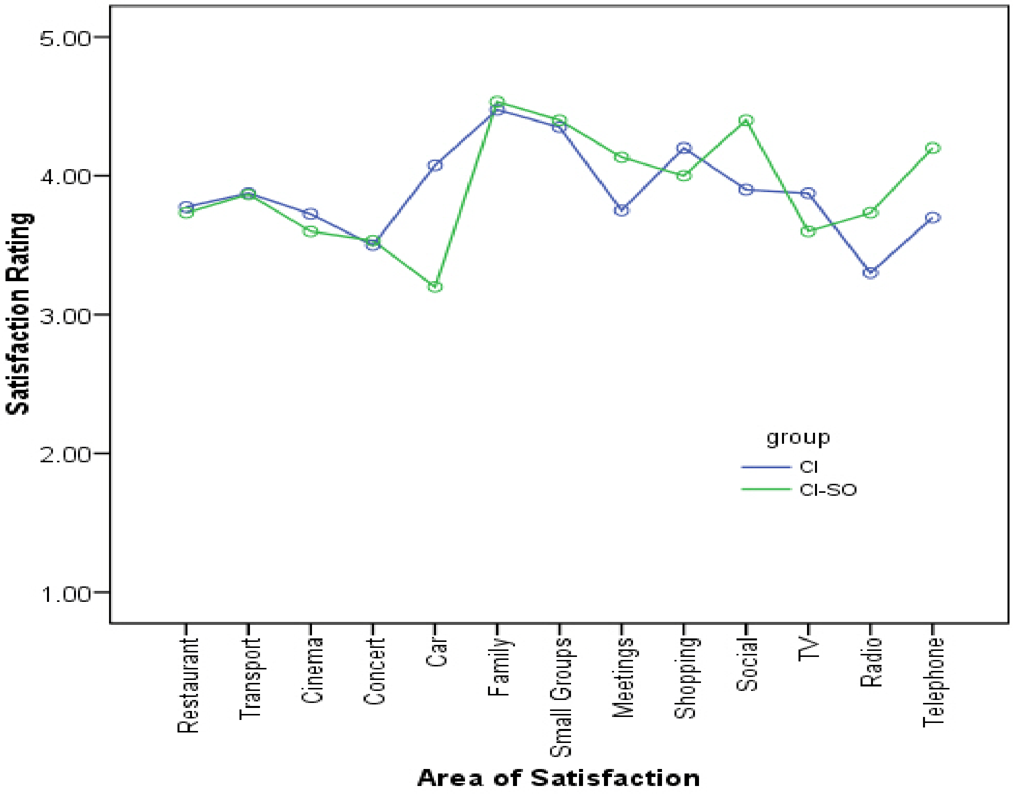

Figure 13: Mean comparison of satisfaction ratings of CI recipient (Q61) and their SO (Q27)

Question 62 of the recipient questionnaire asked recipients to rate how satisfied they were with the CI in improving specific areas of daily life. Similarly, Q28 of the SO questionnaire asked the SO to rate how they felt the CI had affected the recipient's life. In order to see whether there was a significant difference between the two groups, a paired samples t- test was carried out. Thus, a significant p-value (i.e. less than 0.05) would suggest that the CI recipients and their SO viewed the CI as impacting the recipients' life differently. As seen in Table 27, results of these tests showed no significant difference in all areas, except for personal safety (p = 0.030). Therefore, CI recipients and their SO had similar ratings regarding satisfaction with the CI for the daily life of both parties.

Table 27: Comparison - Q62 (CI Recipient) and Q28 (CI-SO) Areas of Satisfaction

Area of satisfaction post-CI	**Group**	**M**	**SD**	**N**	**P value***
Communication	CI	85.31	27.47	80	0.636
	SO	86.56	21.77	80	
Connectedness	CI	86.08	23.93	79	0.266
	SO	82.91	26.11	79	
Emotional State	CI	77.27	29.76	55	0.066
	SO	69.09	31.90	55	
Contribution to Society	CI	77.03	30.06	74	0.063
	SO	70.61	27.25	74	
Family Relationships	CI	83.68	27.88	72	0.141
	SO	78.82	26.09	72	
New Relationships	CI	70.56	34.03	62	0.490
	SO	68.15	28.69	62	
Independence	CI	82.89	28.64	76	0.649
	SO	81.58	24.96	76	
Interpersonal Skills	CI	78.77	27.54	73	0.910
	SO	79.11	25.35	73	
Isolation/loneliness	CI	72.54	36.39	71	0.644
	SO	74.30	28.34	71	
Personal Safety	CI	80.31	27.47	80	0.030*
	SO	73.75	28.66	80	
Self-Esteem	CI	80.48	30.12	73	0.359
	SO	77.40	28.00	73	
Standing up for self	CI	80.63	30.24	71	0.317
	SO	76.76	29.68	71	

Note: only data from both the recipient and their SO were included.
* $p < 0.05$ from paired samples t-test.

In summary, when the results of satisfaction for the CI recipient and their SO were compared, there were no differences reported except for when communicating in the car, and when out shopping. When the CI-SO was asked to rate how they felt that the CI had impacted on the recipient’s life, the only reported difference was for personal safety.

5.8 Comparison of WL and WL-SO Groups

Due to the qualitative nature of the data collected from the WL-SO and WL participant questionnaires, statistical analysis was not used on this data. A comparison of the two groups for Q23 to Q25 (for the WL-SO), and Q63 to Q65 (for the WL participant), are discussed in the discussion section, with all comments from all questions in Appendixes 4 and 6.

5.9 QOL Comparison of CI and WL Groups

Comparisons of the different QOL subdomains were made between the CI and WL groups to compare CI recipients to HA users. To briefly re-cap, three general QOL categories (physical, psychological and social functioning) were measured by using six subdomains (i.e. basic sound perception, advanced sound perception, speech production, self-esteem, activity limitations, and social activity). Table 28 provides the subdomain means for the CI (N = 94), and WL (N = 70) participants. As can be seen in Figure 14, out of a maximum score of 100, CI recipients scored significantly higher (better) than those on the WL, in all subdomains ($p < 0.001$) for all comparisons, shown by an independent samples t-test. The largest differences in mean scores between the CI and WL groups occurred in the subdomains of basic sound perception (difference = 37.81), social interaction (difference = 36.21), and activity limitation (difference = 32.27). Speech production had the smallest difference (difference = 14.03). As can be seen in Table 28, none of the mean scores for the CI group were worse the mean scores for the WL group for any of the subdomains.

Table 28: Mean Subdomain Comparison Between CI and WL Groups

Subdomain	**Mean (SD)**		**Range**		**Difference****
	CI Group	WL Group	CI Group	WL Group	
Basic Sound perception	68.66 (17.96)	30.85 (18.92)	15.0 - 100	0 - 87.5	37.81
Advanced sound perception	61.91 (20.01)	32.13 (16.92)	25.0 - 100	5.56 - 97.5	29.78
Speech production	80.68 (15.56)	66.64 (20.72)	2.5 - 100	0 - 67.5	14.04
Self-Esteem	64.97 (18.22)	42.68 (18.75)	17.5 - 92.5	8.33 - 83.33	22.29
Activity limitation	70.63 (21.07)	38.36 (19.79)	2.5 - 100	0 - 82.50	32.27
Social interaction	73.00 (18.87)	36.80 (16.89)	2.5 - 100	7.14 - 72.50	36.21

**This was calculated as the difference between the mean scores for the two groups.

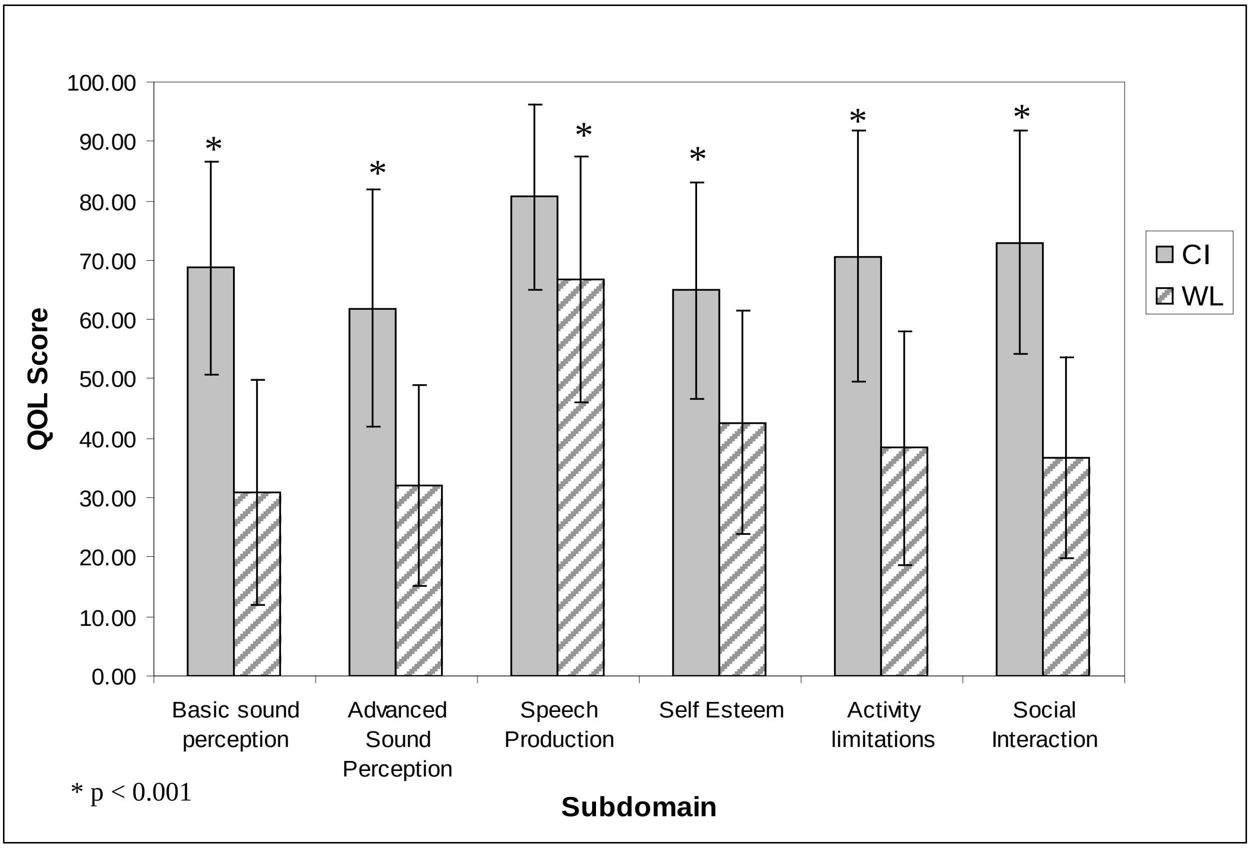

Figure 14: Mean comparison of subdomain scores between the CI and WL groups

Results from a 2-way repeated measures analysis of variance (ANOVA) showed that there was a significant difference for the between-subjects factor of group (i.e. CI vs. WL; $p < 0.001$), and a significant difference for the within-subjects factor of subdomains ($p < 0.001$), as well as a highly significant interaction between these two factors ($p < 0.001$) (Figure 15). In view of the highly significant interaction, separate analyses were conducted for each group to investigate where these differences were.

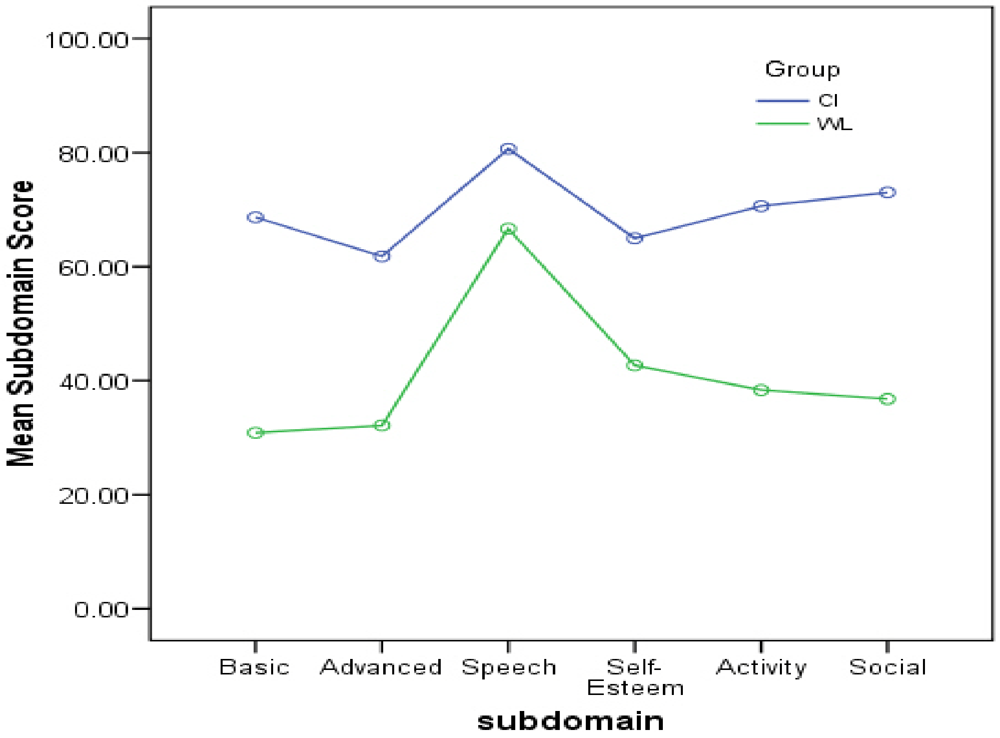

Figure 15: Mean scores across the subdomains for the CI (n=94) and WL (n=70) groups

One way ANOVAs were performed for the CI and WL groups individually to see where the significant differences in the subdomains lay. Bonferroni corrections were used to account for the multiple comparisons. For the CI group, this showed that there were significant differences between the highest rated subdomain of speech production, and all other subdomains except for the social subdomain:

- Speech production and basic sound perception ($p < 0.001$)
- Speech production and advanced sound perception ($p < 0.001$)
- Speech production and self-esteem ($p < 0.001$)
- Speech production and activity limitations ($p < 0.004$)

There were also significant differences between:

- Activity limitations and advanced sound perception ($p = 0.019$)
- Social interaction and advanced sound perception ($p = 0.001$)
- Social interaction and self-esteem ($p = 0.050$)

For the WL group, there were significant differences between the highest rated subdomain of speech production and all other categories:

- Speech production and basic sound perception ($p < 0.001$)
- Speech production and advanced sound perception ($p < 0.001$)
- Speech production and self-esteem ($p < 0.001$)
- Speech production and activity limitations ($p < 0.001$)
- Speech production and social interaction ($p < 0.001$)

There were also significant differences between:

- Basic sound perception and self-esteem ($p = 0.003$)
- Advanced sound perception and self-esteem ($p = 0.014$)

To compare between the groups, independent samples t-tests were used which showed a significant difference between the CI and WL groups for all six subdomains ($p < 0.001$ for all comparisons).

5.10 Comparison of CI-SO and WL-SO Groups

In order to see if there was a difference in ratings for the QOL items (i.e. Q1-20 of both questionnaires) for the two SO groups, independent samples t-tests were conducted. As shown in Figure 16 and Table 29, the results showed significant differences in ratings between the two groups for each question/category except for Q18 which asked the SO how their partner’s hearing loss affected their own participation in hobbies or recreational activities. These results suggest that the QOL of the SO of the CI recipients were significantly better than for the SO of those on the WL for a CI.

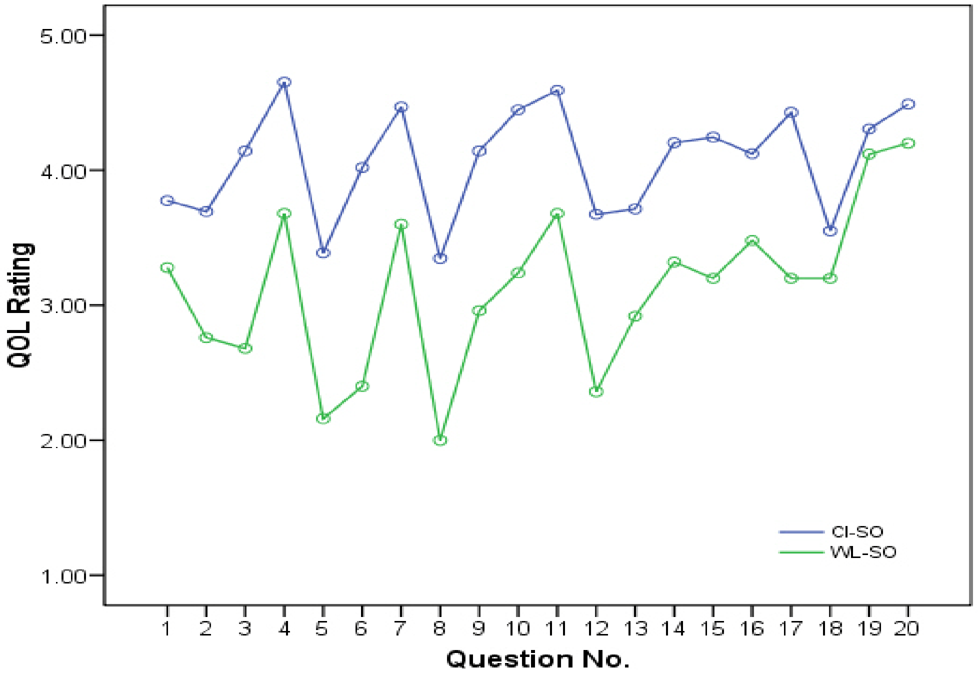

Figure 16: Mean QOL ratings for CI-SO and WL-SO.
Note: Refer to Table 2 for category description, or the questionnaire in Appendix 1 (p.137 and p.141) for the questions in full.

Table 29 also shows the differences between the two SO group scores. Questions 1-20 asked participants to rate on a 5-point scale from strongly agree (1) to strongly disagree (5). Responses were for "strongly agree" and "agree" and "strongly disagree" and "disagree," or "neither agree nor disagree." The most noticeable differences occurred in the ratings for social life (i.e. Q3, Q6, Q7), where the mean score WL-SO group was 45.06, while the CI-SO group was 78.79. Other noticeable differences were evident in the emotional category (i.e. Q4, Q, Q9, Q14, 15), where the mean score for the WL-SO group was 51.56 and the CI-SO was 77.04, and for the activities category (i.e. Q18 and Q19), where the mean score for the WL-SO group was 62.53, compared to the CI-SO group's mean score of 73.02.

In summary, it was found when ratings of both SO groups were compared, the implications of their partner's hearing loss were less on the CI-SO than the WL-SO. The largest differences between the two groups were found in the emotional category, as well as social life. There were also differences between the two groups for questions relating to relationships, communication, and personal safety.

Table 29: CI-SO and WL-SO Comparisons and Descriptive Statistics for Q1-20

					Rating*						
Category	**Q #**	**Group**	**1**	**2**	**3**	**4**	**5**	**N**	**SD**	**Mean**	**P value****
Social	3	CI-SO	1 (1%)	10 (13%)	5 (7%)	24 (32%)	35 (47%)	75	30.77	72.50	0.00
		WL-SO	15 (29%)	11 (21%)	10 (20%)	6 (12%)	9 (18%)	51	33.67	56.06	
	6	CI-SO	3 (3%)	14 (18%)	3 (3%)	30 (38%)	30 (38%)	80	30.13	71.88	0.00
		WL-SO	25 (46%)	13 (25%)	5 (9%)	6 (11%)	5 (9%)	54	34.01	28.24	
	7	CI-SO	0 (0%)	3 (4%)	3 (4%)	23 (30%)	47 (62%)	76	19.36	87.17	0.00
		WL-SO	3 (6%)	6 (12%)	9 (19%)	20 (41%)	11 (22%)	49	28.78	65.31	
Emotional	4	CI-SO	1 (1%)	1 (1%)	1 (1%)	21 (26%)	58 (71%)	82	17.35	90.85	0.00
		WL-SO	1 (2%)	7 (13%)	11 (19%)	18 (32%)	19 (34%)	56	27.29	70.98	
	5	CI-SO	3 (3%)	29 (36%)	9 (11%)	20 (25%)	20 (25%)	81	32.27	57.72	0.00
		WL-SO	18 (32%)	21 (37%)	6 (11%)	6 (11%)	5 (9%)	56	31.80	31.70	
	9	CI-SO	1 (1%)	9 (11%)	4 (5%)	29 (37%)	37 (46%)	80	25.81	78.75	0.00
		WL-SO	9 (16%)	21 (38%)	9 (16%)	8 (15%)	8 (15%)	55	32.79	43.18	
	14	CI-SO	0 (0%)	5 (6%)	12 (15%)	30 (38%)	32 (41%)	79	22.42	78.16	0.00
		WL-SO	4 (8%)	8 (16%)	16 (32%)	13 (26%)	9 (18%)	50	29.56	57.50	
	15	CI-SO	1 (1%)	3 (4%)	15 (19%)	22 (28%)	39 (48%)	80	23.90	79.69	0.00
		WL-SO	4 (7%)	7 (13%)	26 (46%)	13 (23%)	6 (11%)	56	25.72	54.46	
Work	1	CI-SO	2 (3%)	10 (17%)	6 (10%)	16 (27%)	26 (43%)	60	30.77	72.50	0.019
		WL-SO	2 (6%)	11 (33%)	6 (19%)	5 (15%)	9 (27%)	33	33.67	56.06	
Communication	8	CI-SO	10 (13%)	22 (27%)	8 (10%)	18 (23%)	21 (27%)	79	35.79	55.70	0.00
		WL-SO	28 (50%)	19 (34%)	2 (4%)	4 (7%)	3 (5%)	56	28.52	20.98	
	11	CI-SO	0 (0%)	3 (4%)	1 (1%)	22 (28%)	54 (67%)	80	17.65	89.69	0.00
		WL-SO	3 (6%)	8 (15%)	8 (15%)	23 (43%)	11 (21%)	53	28.77	64.62	

			Rating*								
Category	**Q #**	**Group**	**1**	**2**	**3**	**4**	**5**	**N**	**SD**	**Mean**	**P value***
Communication	16	CI-SO	0 (0%)	3 (4%)	11 (14%)	36 (45%)	30 (37%)	80	20.06	79.06	0.00
		WL-SO	1 (2%)	5 (9%)	31 (55%)	13 (23%)	6 (11%)	56	21.38	58.04	
Safety	12	CI-SO	6 (7%)	22 (27%)	0 (0%)	24 (29%)	30 (37%)	82	35.19	63.11	0.00
		WL-SO	17 (30%)	20 (36%)	8 (14%)	8 (14%)	3 (6%)	56	30.04	32.14	
Activities	17	CI-SO	45 (60%)	15 (20%)	14 (19)	1 (1%)	0 (0%)	75	20.91	84.67	0.00
		WL-SO	11 (22%)	16 (33%)	7 (14%)	7 (14%)	8 (17%)	49	35.06	57.65	
	18	CI-SO	4 (5%)	12 (15%)	31 (37%)	19 (23%)	16 (20%)	82	27.68	59.45	0.201
		WL-SO	3 (5%)	16 (29%)	14 (26%)	15 (27%)	7 (13%)	55	28.49	53.18	
	19	CI-SO	1 (1%)	3 (4%)	6 (7%)	19 (23%)	53 (65%)	82	21.94	86.59	0.00
		WL-SO	1 (2%)	6 (11%)	13 (22%)	15 (27%)	21 (38%)	56	27.41	71.88	
Burden	20	CI-SO	0 (0%)	1 (1%)	6 (8%)	20 (25%)	53 (66%)	80	17.27	89.06	0.016
		WL-SO	0 (0%)	1 (2%)	12 (21%)	17 (30%)	27 (47%)	57	21.14	80.70	
Relationships	13	CI-SO	2 (2%)	21 (26%)	8 (10%)	20 (24%)	31 (38%)	82	32.08	67.38	0.001
		WL-SO	10 (19%)	14 (26%)	11 (21%)	7 (13%)	11 (21%)	53	35.45	47.64	
	10	CI-SO	1 (1%)	5 (6%)	3 (4%)	22 (27%)	51 (62%)	82	22.91	85.67	0.00
		WL-SO	6 (11%)	17 (32%)	9 (16%)	14 (25%)	9 (16%)	55	32.42	51.36	
Financial	2	CI-SO	5 (7%)	13 (19%)	6 (9%)	27 (38%)	19 (27%)	70	31.68	72.50	0.00
		WL-SO	10 (21%)	12 (25%)	14 (30%)	5 (11%)	6 (13%)	47	32.17	42.02	

* Ratings for questions 1-17 were: 5 = strongly disagree, 4 = disagree, 3 = neither agree nor disagree, 2 = agree, 1 = strongly agree.

Ratings for Q18 were: 5 = very involved, 4 = quite involved, 3 = moderate involvement, 2 = somewhat involved, 1 = never. Ratings for Q19: 5 = no extent, 4 = small extent, 3 = moderate extent, 2 = quite an extent, 1 = great extent. Ratings for Q20: 5 = never, 4 = seldom, 3 = sometimes, 2 = quite often, 1 = very often.

For data entry all ratings were scored as 5 = 100, 4 = 75, 3 = 50, 2 = 25, and 1 = 0. ** $p < 0.05$, paired samples t-test. (%) is the percentage of participants for each rating.

5.11 Correlations

Non parametric Spearman’s rho calculations were used for all correlational analyses.

5.11.1 CI and WL Participant Groups

For CI recipients, calculations were made to investigate potential associations between QOL ratings or satisfaction with the CI, and the subject factors of: age, speech perception scores, pure tone average for the implanted ear, pure tone average for non implanted ear (both pre-CI), and time with CI, as reported in the participant demographics table (Table 6, page 49 in this chapter). There was a significant weak correlation between speech perception scores and satisfaction with the CI (rho = 0.300, $p = 0.006$), and a significant strong correlation between QOL scores and satisfaction with the CI (rho = 0.885, $p < 0.001$). This suggests that although improved speech perception provided by the CI is associated with greater satisfaction and QOL, there are other factors that also contribute to QOL and satisfaction. No other significant correlations were found. For the WL group the only significant correlation was between duration of HA use and QOL ratings (rho = 0.331, $p = 0.006$), where greater duration of HA use was associated with increased QOL. No other significant relationships were found for the subject factors of age, puretone averages or speech perception scores.

5.11.2 Participants and their SO

Correlational analyses were also performed to assess for relationships between CI recipients and their SO’s ratings for QOL, satisfaction, and the impact of the CI. Results showed a significant strong correlation between the QOL and satisfaction ratings of CI recipients (rho = 0.879, $p < 0.001$). In addition there were significant moderate correlations between the ratings of CI recipients and their SO for the following:

- CI QOL and CI-SO QOL (rho = 0.662, $p < 0.001$)
- CI QOL and CI-SO satisfaction (rho = 0.585, $p < 0.001$)
- CI QOL and CI-SO ratings of the impact of the CI on the CI recipient’s life (rho = 0.571, $p < 0.001$)
- CI satisfaction and CI-SO QOL (rho = 0.610, $p < 0.001$)
- CI satisfaction and CI-SO satisfaction (rho = 0.555, $p < 0.001$)

- CI satisfaction and CI-SO ratings of the impact of the CI on the CI recipient's life (rho = 0.579, $p < 0.001$)
- CI-SO QOL and CI-SO ratings of the impact of the CI on the CI recipient's life (rho = 0.421, $p < 0.001$)
- CI-SO satisfaction and CI-SO ratings of the impact of the CI on the CI recipient's life (rho = 0.492, $p < 0.001$)

These correlations suggest that on the whole, the SO is aware of the impact of the CI on their partner's QOL. For the WL and their SO, there was a moderate correlation between both groups' QOL (rho = 0.419, p = 0.001), which implies that the WL-SO's life is impacted on in a similar way by their partner's hearing loss.

5.11.3 Parents

In order to evaluate correlations between pre and-post-implant ratings the parent questionnaire, a total mean QOL score pre-implant (Q11-30) was calculated, along with a total mean QOL score post-implant (Q32-57). A total mean satisfaction score was obtained by averaging satisfaction scores from Q68-71. A moderate significant correlation was found between how parents rated their child's QOL post-CI and how the CI affected their own lives (rho = 0.582, p = 0.004), as well as between how the CI affected the parent's life and parent satisfaction with the CI (rho = 0.524, p = 0.012). In addition there was a strong significant correlation between how the parent rated their child's QOL post-CI and parent's satisfaction with the CI (rho = 0.837, $p < 0.001$). These correlations showed that there was an association between how parents rated their child's QOL and how they rated the impact of the CI on their own QOL.

5.12 Summary of Results

In order to asses for changes in QOL as a result of cochlear implantation, QOL ratings obtained from current CI recipients were compared to those on the WL for a CI. Overall mean scores were higher for the CI group for all six QOL subdomains. The highest rated subdomain for the CI group was speech production, followed by social interaction, activity limitation, basic sound perception, self-esteem, and advanced sound perception respectively. The majority of CI recipients reported that the CI had met their needs and expectations, and that they were satisfied with their CI. In addition, all but one would recommend a CI to others if they were in a similar circumstance. For the CI-New group (i.e. the true pre-to-post group), significant differences were seen between the pre- and post-CI QOL ratings where QOL ratings were higher post-implant. For the CI-New group the greatest changes were seen in the basic sound perception category, followed by social interaction, advanced sound perception, activity limitations, self-esteem, and lastly, speech production.

For the WL group, QOL ratings were highest for the speech production category, followed by self-esteem, activity limitations, social interaction, advanced sound perception, and lastly basic sound perception. WL participants excepted their lives to become easier following implantation and hoped that the CI would enable them to be more sociable, as well as to decrease the stress in their own as well as their SO's lives, due to better communication.

For the SO groups, it was found that the CI-SO had similar ratings to how the CI recipient viewed their own QOL and the impact of a CI. In regards to satisfaction with the CI, the CI-SO and the CI recipient both scored similarly, suggesting that the CI affected the lives of both individuals' in a comparable manner.

Finally, the parent questionnaire showed that the CI had an affect on their QOL. Post-implant, parents reported that their child's communication and spoken language had improved. Parents also reported that both theirs and their child's confidence had improved, and that their child was happier and more fun to be with post-CI. Some parents however, were still worried about their child's future prospects, and that they worried that their child may never be part of either the hearing or the deaf world. Moreover, some parents had ongoing concerns regarding their child's speech post-implant, and some said that their child still got frustrated at times. On the positive side, most parents felt that their child could cope with mainstream schooling, and for those whose child was at school, they reported that the child was keeping up well with other children of the same age.

Chapter 6: Discussion

This study investigated the effect of CIs on QOL for adult CI recipients and their SO. Existing research on outcomes following cochlear implantation have tended to focus on the recipient themselves, with few studies including responses from a SO. Further, there have been few studies based solely on outcomes of New Zealand CI recipients, and none focusing on the outcomes for the SCIP-A programme. There were four main aims of this study: First, to obtain information about the changes in QOL in postlingually deafened adults following implantation. Second, to determine which aspects of daily life that these changes (if any) are noticed the most. Third, to look at the impact of a CI on significant others (SO); and fourth, to see whether the changes (if any) reported by the participant are similar to that reported by the SO.

There were five participant groups included in this study:
1) Postlingually deafened adult CI recipients, who are current patients of the SCIP-A (CI group);
2) SO of CI recipients in group 1 (CI-SO group);
3) Postlingually deafened adults on the SCIP-A's waiting list for a CI (WL group);
4) SO of adults in group 3 (WL-SO group);
5) Parents of children with a CI, implanted at the SCIC.

Existing research indicates a strong relationship between CIs and positive changes in QOL and thus four hypotheses were proposed. These were that: (i) the CI group will have higher QOL ratings than those on the WL for a CI; (ii) the CI-SO group will rate their QOL better than the WL-SO group; (iii) the participants will have similar QOL ratings to their SO; and (iv) parents of children with CI(s) will rate their QOL to be better post-implant when retrospectively comparing back to pre-implant. The results of this study supported all four hypotheses. For this chapter the term 'CI recipient' or 'recipient'will be used to refer to both current recipients and the CI-New group collectively. The term 'participant' will also be used to refer to the CI recipient, and/or a potential CI recipient (i.e. those on the WL), as opposed to their SO.

6.1 Effects of Implantation on Participants

Hypothesis 1: the CI group will have higher QOL ratings than those on the WL for a CI

To examine QOL in the present study, patients on the WL for a CI, as well as current CI recipients (including the CI-New group), completed a questionnaire developed for the purposes of this study. The responses obtained from the questionnaire indicated that CI recipients had significantly higher (better) QOL ratings than those on the WL for a CI, consistent with the first hypothesis. This makes intuitive sense, as it could be expected that participants on the WL for a CI were essentially not happy with their HAs and/or not getting sufficient benefit from them, which could have impacted on their QOL. As mentioned, the CI criteria is based on whether the potential recipient is likely to benefit more with a CI than their current HAs, thus, there would be a good chance that the WL participants would potentially benefit from a CI. If the WL participants were fully satisfied with their current communication ability and QOL, it would be unlikely that they would consider a CI accounting for issues such as surgery, costs, and the commitment involved.

Following is a discussion of the areas in which these changes in QOL in daily life were most noticeable, within the subdomains, as related to the first two aims of this study. To re-cap, the questionnaire covered three general QOL domains: Physical, psychological, and social functioning. These were further divided into six subdomains: Basic sound perception, advanced sound perception, speech production, self-esteem, activity limitations, and social interaction. All mean subdomain scores for the CI recipients were significantly higher compared to the scores of those on the WL for a CI.

6.1.1 Subdomain Analysis

Physical Domain

This encompassed both the basic and advanced sound perception, and the speech production subdomains. Speech production was the highest rated subdomain for both the CI recipient (M = 80.68) and WL (M = 66.64) groups. The greatest overall differences in QOL ratings between the two participant groups were seen in this physical domain, specifically in the basic sound perception category (mean difference in ratings = 37.81). The following factors may be attributed to the higher QOL ratings for the CI recipients: Most (79%) could hear soft sounds (Q31) such as keys on a keyboard of a computer, and the microwave beeping, compared to only 14% of those on the WL. Being able to hear footsteps (Q7) was reported by 67% of CI recipients compared to less than 10% of the WL group.

Upon further comparison of ratings, CI recipients were also reported to hear more background noises. For example, nearly all (93%) could hear the vacuum cleaner (Q1), compared to just under half (47%) of those on the WL. Additionally 87% of CI recipients could hear the telephone or doorbell ringing (Q13), compared to only 30% of those on the WL. Most (69%) of CI recipients reported being able to hear cars approaching in traffic (Q25), compared to only 20% of those on the WL. These findings were expected, given that those on the WL would have severe to profound hearing losses and may not have be able to reliably identify these sounds, even with HAs. Thus, a CI may allow recipients access to sounds that most individuals on WL are no longer able to hear, which may contribute to positive changes in QOL ratings.

For advanced sound perception, there was a marked difference in ratings between the CI and WL groups for the ability to hold a conversation with two or more people in quiet situations (Q11). Over 79% of CI recipients reported being able to carry this out, compared to 29% of those on the WL. Positive effects of implantation were also demonstrated in that approximately half (51%) of CI recipients reported they could use the telephone (Q60), compared to only 14% of those on the WL. Again, these lower scores for those on the WL were anticipated, given that these individuals would have more limited access to sounds in the speech frequency range. This was consistent with Faber and Grontved (2000) and Castro et al. (2005), who both found that many CI recipients were able to use the telephone post-implant, which contributed to increased QOL. Other differences noticed between group ratings in the advanced sound perception subdomain were that 46% of CI recipients stated they could understand strangers without lip reading (Q40), and only 4% of those on the WL reported being able to do this. Moreover, only a quarter of CI recipients felt tired when listening (Q50), compared to 58% of those on the WL. Those with significant hearing losses often develop other ways of communication and/or supplement their aural skills. For example by lip reading, or as some participants in this study commented, by writing things down. They may also rely more on visual cues for information. These alternatives may be very taxing, and hence a CI may reduce the effort required for communication.

Psychological Domain

This domain encompassed the self-esteem subdomain. As hypothesised, CI recipients showed significantly higher mean ratings in this subdomain than those on the WL ($p < 0.001$). The higher ratings may have been due to CI recipients being more able to accurately perceive and participate in conversation, allowing for increased conversational independence and confidence. Seventy-four percent of CI recipients reported experiencing improved self-confidence after receiving their CI (Q54). Only a quarter of CI recipients said they became irritated if they could not follow a conversation, compared to 48% of those on the WL (Q16). CI recipients were also more at ease interacting with others (68%) than those on the WL (36%; Q4), and felt more comfortable initiating conversation with strangers; 15% of CI recipients preferred to avoid strangers compared to over half (53%) of those on the WL (Q22).

Social Domain

This domain was divided into two subdomains; activity limitations and social interaction. Again, both mean subdomain scores were significantly higher for the CI group. For the activity limitations subdomain, the CI was associated with increased participation in employment and leisure. For example, 51% of the WL participants felt that their hearing impairment caused difficulties in their work or studies; this was the case for only 5% of CI recipients (Q6). Some respondents reported that the CI had enabled them to re-enter the workforce. Other recipients commented that the implant had increased work place participation, such as being able to hear in meetings, answer the telephone, and work in a team. The CI was associated with improved job satisfaction and broadened future employment opportunities. For example participant #11 reported that “The CI has enabled me to move up the ladder with my job.”

The CI also improved the quality of leisure activities, such as watching television. This was consistent with Tyler & Kelsay (1990) and Tyler (1994) who both reported that television viewing was the most commonly reported benefit following implantation. In the present study, only 24% of CI recipients reported experiencing problems when watching television (Q36) compared to 80% of those in the WL group; most of the latter group said that they were unable to watch television without subtitles. In the comments section, only 14% of CI recipients commented that even with their CI they were unable to follow the television dialogue without subtitles; for these 14% a lack of clarity was the main issue.

For the social interaction subdomain, further differences in mean scores between the two groups were apparent (difference = 36.21). This was consistent with Hogan et al. (2001), who reported a 27% difference in mean scores between CI recipients and non-implantees for social interaction. In group situations, 31% of CI recipients experienced communication problems compared to 82% of those on the WL. A further 16% of CI recipients mentioned having hearing difficulties in group situations. Only 7% of CI recipients reported that they felt left out at times (Q26), compared to 60% of those on the WL. The findings of the present study were also consistent with Tyler and Kelsay (1990) and Tyler (1994), where the most common areas of benefit reported by CI recipients included: speech perception, environmental sound perception, psychological effects, lifestyle and social effects, and speech production. The CI was reported to be of greatest benefit for speech perception, for situations such as hearing the television, and social communication. This was also consistent with Faber & Grontved (2000).

The results from the CI-New group (i.e. the 7 individuals implanted during the course of this study), also supported hypothesis one. The results from this group represented the true pre-to-post effects of cochlear implantation, as opposed to the other CI participants whose responses were gained retrospectively. Large changes in QOL ratings pre- to post-implant were apparent for all subdomains, and non-parametric Wilcoxon Signed Ranks tests showing all of these improvements to be statistically significant p value ($p<0.05$). As mentioned in the results section, pre-implant the mean questionnaire score across all subdomains was 33.75, with the highest rated subdomain being speech production (M = 74.17), followed by self-esteem, social interaction, activity limitations, advanced sound perception, and basic sound perception respectively. Post-implant the overall mean rating for the questionnaire increased by 43.38, to 77.13. Speech production was still the highest rated subdomain, followed by social interaction, basic sound perception, self-esteem, activity limitations, and advanced sound perception (see Table 16 page 45 in results section for mean subdomain scores pre-and post-implant). When the mean subdomain scores were compared pre- and post-implant, the largest differences were seen for basic sound perception, social interaction, advanced sound perception, activity limitations, self-esteem, and speech production respectively. Large changes in QOL ratings post-implant were apparent, and this is in agreement with current literature reporting positive effects of implantation (Cohen et al., 2004; Hallberg et al., 2005; Hirschfelder et al., 2008; Klop et al., 2008; Klop et al., 2007; Kou et al., 1994; Krabbe et al., 2000; Maillet et al., 1995; Nicholas & Geers, 2003; Robinson, Gatehouse, & Browning, 1996).

It could be speculated that increases in QOL are primarily due to improved communication. For example Castro et al. (2005) showed that the improved auditory benefit that the recipient obtained from their CI allowed them to carry out activities, such as telephone conversations or social activities, with more confidence which resulted in improvements in QOL. This was reflected in this study with the CI enabling new recipients improved conversation in quiet (Q11; difference pre- to post-CI of 81.50), as well as increased and more-frequent communication opportunities (Q26; difference of 67.86), along with telephone use. Pre-implant none of the 7 participants could carry out a simple telephone conversation (Q60). However, post-implant all recipients reported being able to carry out a simple telephone conversation. These telephone-related findings from the CI-New group are in agreement with Faber et al. (2000) who also found significant improvements in telephone use (p = 0.001).

The CI also enabled recipients to hear more environmental sounds which made recipients feel "more alive" (CI recipient #58) and in tune with the world. They also reported improved basic sound perception such as hearing the footsteps (Q7; difference of 75.00), and hearing cars (Q25; difference of 71.43). These findings are consistent with those who have found that CIs may play a role in a patient's social connection and overall well-being (Reed & Delhorne, 2005; Tyler, 1994; Zhao, Stephens, Sim, & Meredith, 1997).

The smallest differences in mean ratings pre- to post-implantation was for the speech production subdomain; specifically the questions related to making themselves understood by acquaintances without using gestures (Q33; difference of 7.14) and strangers without using gesture (Q15; difference of 7.14), and controlling the pitch of their voice (Q57; difference of 12.50). However, this subdomain was already rated the highest pre-CI (74.17), hence there was a smaller capacity for improvement. In other studies using the NCIQ, the speech production subdomain also showed the smallest amount of change when participant ratings were compared pre- and post-CI (Baumgartner et al., 2007; Hirschfelder et al., 2008; Klop et al., 2008; Krabbe et al., 2000). Changes in the QOL reported in this study can be compared to outcomes from other studies using the NCIQ. These include Baumgartner et al. (2007); Krabbe et al. (2000); Hirschfelder et al. (2008), and Klop et al. (2008). Table 30 shows a comparison of mean scores across all five studies using the NCIQ. As shown, scores for the present study are in agreement with all four studies.

Table 30: Mean Subdomain Score Comparison of Existing Studies using the NCIQ

Subdomain	Current Study (2008)	Baumgartner et al. (2007)	Krabbe et al. (2000)	Hirschfelder et al. (2008)	Klop et al. (2008)
Basic Sound	68.6	75.6	64.1	71.6	71.3
Advanced Sound	61.9	83.0	53.8	65.4	61.3
Speech Production	80.6	46.0	81.7	85.7	85.6
Self-esteem	64.9	64.6	66.7	60.8	70.2
Activity	70.6	77.6	72.9	64.5	75.7
Social interactions	73.0	75.6	71.9	67.8	74.6

Note: In the all but the present study all comparisons were made at least 1 year post-implant.

For basic sound perception, the average score across the other four studies was 70.6, which is similar to the present study (M = 68.6). For advanced sound perception the average across studies was 65.8 (present study M = 61.9). Speech production average across studies was 74.75 (present study M = 80.6), the self-esteem average was 65.6 (present study M = 64.9), the activity limitation average was 72.7 (present study M = 70.6), the social interaction average was 72.5 (present study = 73.0). These mean score comparisons are shown in Figure 17.

Baumgartner et al. (2007) aimed to determine if there were any surgical issues related to electrode insertion and preservation of low frequency hearing. The NCIQ was used to assess the QOL outcomes of 23 MED-EL CI recipients with bilateral severe to profound hearing losses, who were assessed pre-implant, then at 1, 3, 6 and 12 months after initial fitting of their speech processor. Consistent with the results in the present study, there was a significant improvement in QOL when ratings were compared pre- and post-CI (p = <0.001). Baumgartner et al. (2007) also found that all subdomain scores improved significantly over time, except for the advanced speech perception subdomain, which suggested that implantation may improve QOL, at least up to 12 months post-implantation.

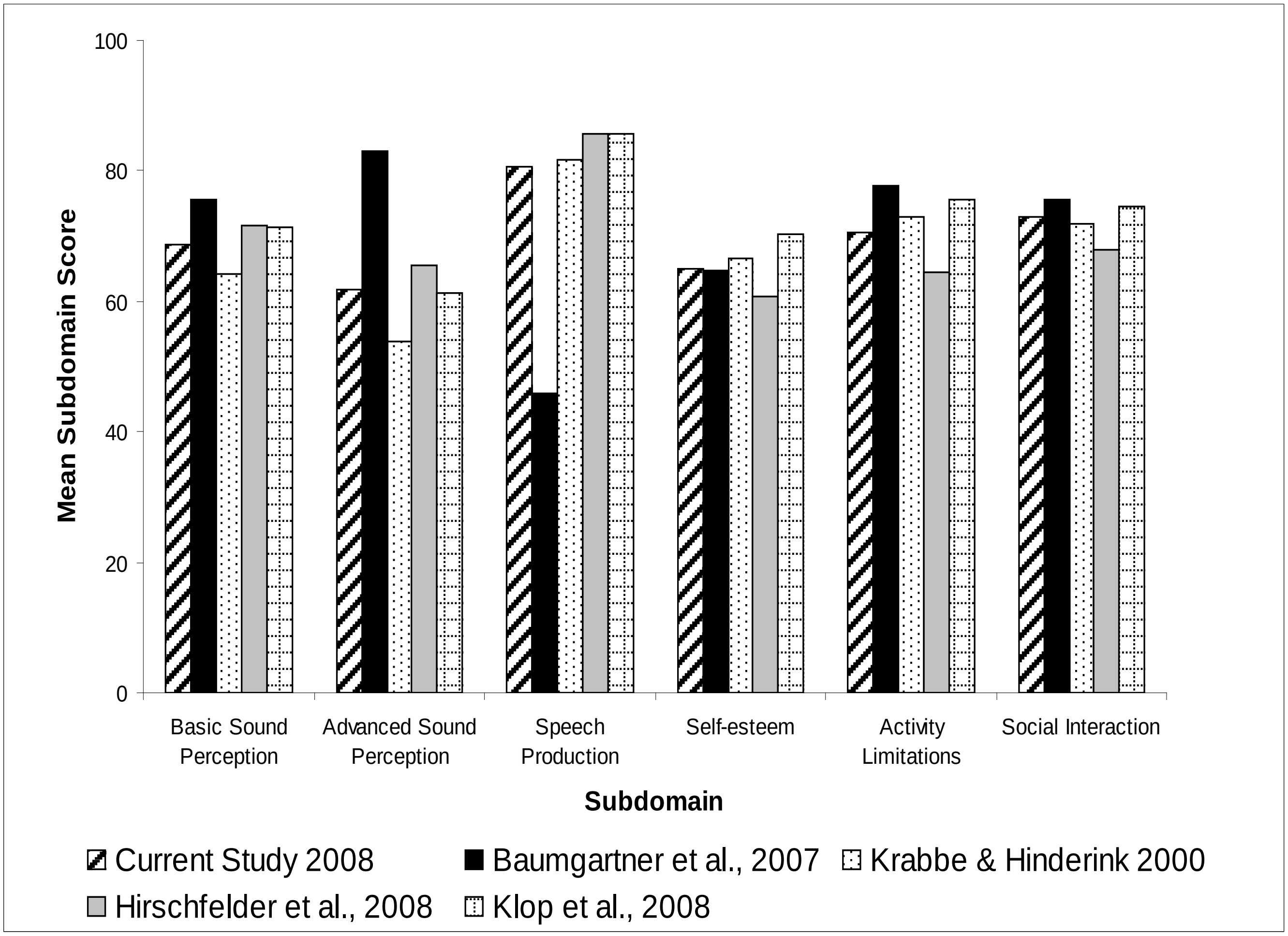

Figure 17: Mean subdomain scores for studies using the NCIQ

However, as also acknowledged by Baumgartner et al. (2007), the 'Hawthorne effect' needs to be accounted for in interpreting the results of the current, and other similar studies. The Hawthorne effect in these situations would be where the receipt of a new, expensive device (the CI) potentially results in an over-enhanced perception of improvement (Baumgartner et al., 2007). For example, in the present study, for the CI-New group, there was a large significant improvement in QOL pre- to post-implant. An unknown portion of this improvement may have been due to the Hawthorne effect, as opposed to actual improvements experienced by the recipient.

Despite the overall improvement seen for the CI group, there was individual variability in the results obtained. For example, 8.5% of the CI group had an average subdomain score of less than 50. Of those that provided comments, one stated that they were an unsuccessful recipient and this had been their second CI (i.e. they had been re-implanted). Others reported that although they had problems with understanding speech, they reported some level of improvement for example in hearing basic sounds, and hearing environmental sounds. This variability in outcomes is consistent with those studies that agree that there are no pre-implant indicator(s) that reliably predict how a person will do post-CI (Bodmer et al., 2007; Cooper, 2006; Dorman & Wilson, 2004; Gani, Valentini, Sigrist, Kós, & Boëx, 2007; Hamzavi et al., 2003; Incesulu & Nadol, 1998; Skinner et al., 2002; Waltzman, Fisher, Niparko, & Cohen, 1995; Zeng, 2004).

The findings from the present study are also consistent with Krabbe et al. (2000) where post-implant subdomain scores of the 45 postlingually deafened adult CI recipients, were significantly higher ($p < 0.001$) than the 46 controls on the WL. It should be noted however, that the Krabbe et al. (2000) study involved participants who had been implanted in the period 1989-1997, and used now-obsolete speech processing strategies (i.e. MPEAK, SPEAK and CIS). In addition to the NCIQ, the SF-36, a generic QOL questionnaire, and the HUI-2, a health classification questionnaire were used. For the NCIQ, the greatest differences were in the basic and advanced sound perception subdomains. When the results of the Krabbe et al. (2000) study were compared to the other four studies, the basic and advanced sound perception subdomain scores were slightly lower. This may have been due to the earlier technology that their recipients were using. Interestingly, Krabbe et al. (2000) found that when they compared the SF-36 questionnaire scores from those on the WL to the general (Canadian) population-based norms, the WL scores were lower than normal for social functioning. When compared to other studies investigating other diseases or medical interventions, it was reported that their scores were similar to those awaiting renal or heart transplantation (Krabbe et al., 2000). For the CI recipients, their post-implant scores were similar to the general population - normal hearing Dutch population sample showing the positive impact that a CI can have on QOL. The results of the present study were also in accordance with Hirschfelder et al. (2008), who gained retrospective responses from 56 adult CI recipients. The largest differences in ratings pre-to-post-implant were for the basic and advanced subdomains.

6.1.2 Summary of Findings for CI and WL Participants

Consistent with the literature, this study showed that those with CIs rated their QOL as significantly better than those on the WL for a CI in all subdomains. These positive effects of implantation included increased self-esteem, independence, and social functioning, in addition to improvements in sound perception. Lower QOL ratings from those on the WL was associated with not being able to use the telephone, lack of confidence, loneliness, and communication problems in daily life. These were also reflected in the comments provided by respondents (Q61–66), which cited problems particularly in the areas of basic sound perception, activity limitations, and social participation.

6.2 Effects of Implantation on the SO

Following is a discussion of the main findings for the effects of implantation on the CI-SO, and the CI-New SO, followed by a comparison between the recipient groups' SO and the WL-SO, as related to the second hypothesis, and the third aim.

Hypothesis 2: the CI-SO group will rate their QOL to be better than the WL-SO group;

As mentioned, the negative effects of hearing loss on the SO and their relationship have been reported by others (Hallam et al., 2008; Hetu et al., 1993; Kennedy, 2008; Scarinci et al., 2008). It has been found that HAs and CIs improve the QOL of the SO through improvements in the general ease of, and ability to have a conversation, as well as alleviate negative emotions associated with communication difficulties (Kennedy, 2008; Stark & Hickson, 2004). The results from the CI-SO in this study were in agreement with these studies where 83% of the CI-SO reported that the CI had had a positive affect on their own QOL (Q26). Factors contributing to positive QOL ratings included improved and greater ease of communication, which had resulted in a positive change in the relationships, for example following implantation some had reported having been able to recapture happiness in their relationship and bringing the partnership back to the level enjoyed prior to profound hearing loss. CI-SO #101 said "we have regained some laughter and spontaneity that was impossible before," while CI-SO #20 said:

> "Before my husband was accepted for a CI I could see our old age together as becoming increasingly difficult as he became deafer and more isolated and introverted. Since the CI he has changed into the person I want to grow old with."

These findings are in agreement with Hallam et al. (2008) who reported that profound hearing loss hampered spontaneity, and reduced the opportunity for positive shared experiences. Similar findings were also found by Hetu Jones and Getty (1993).

Eighty-three percent of CI-SO felt that the stress in their lives had not increased since their partner got their CI (Q9; M = 78.75), and 79% did not feel strained in their interactions since their partner got their CI (Q14; M = 78.16). In addition, 97% disagreed that they felt embarrassed about their partner's hearing impairment, (Q4; M = 90.85), and 91% of CI-SO's disagreed that their partner was a burden (Q20; M = 89.06).

Overall, out of the 52 CI-SOs that offered comments in Q29, 28 reported general improvement and positive results on how the CI had impacted on both theirs and the recipients lives, with their partner's increased confidence and social participation following implantation being often reported. For example CI-SO participant #61 said regarding her father:

> "The CI has allowed him to develop into a confident man who is keen to participate with others. He enjoys life a bit more, and has involved himself with others at sport and activities. It has removed a lot of the frustration he used to experience and his QOL has improved so much."

Further findings relating to social considerations were that 79% of the CI-SO did not feel that their social life had suffered since their partner received their CI (Q3), with only 4% of the CI-SO feeling that their partner had prevented them from meeting new people (Q7).

There were still areas of difficulties or concern for some of the CI-SO though. Thirty-nine percent of the CI-SO reported getting annoyed at having to repeat themselves (Q5; M = 57.72), and 50% agreed that they could not talk to their partner in a noisy environment (Q8; M = 55.70), suggesting that there may still be limitations in communication with their partner post-implant, in challenging listening situations. Several other studies corroborate these in background noise (Fetterman & Domico, 1999; Hamzavi, Franz, Baumgartner, & Gstoettner, 2001). Of the 52 comments offered by the CI-SO (Q29), 8 SOs reported that the CI had either no effect, or a negative effect on theirs and the recipient's lives. Nevertheless, overall, the high QOL ratings shown by the CI-SO suggests that the CI has a positive impact on the CI-SO.

Of the seven CI-New participants, five SOs returned a follow-up questionnaire, where they reported improvements in their and their partner's lives. This confirmed the second hypothesis. For example, pre-implant, participant #184 wanted to: "…Be able to have a conversation with people, and stop my wife getting so frustrated." Following implantation the same participant reported that he was now able to have a conversation with his wife “instead of a whiteboard.” SO #184 said post-CI “It is just so good to be able to talk again. When people come around it is entirely different, back to be what it used to be like almost…” Pre-CI participant #268 hoped that she would be less dependent on her partner and thus feel “much less of a burden.” She also hoped that her partner would talk to her more in the hope that “this experience should strengthen our relationship considerably.” Post-implant the same participant was “Amazed at all the new sounds that I can now hear.” She also commented on being less tired due to hearing efforts, and no longer felt “totally left out.” These findings collectively agree with Tyler & Kelsay (1990), and Wexler et al. (1982), who found that post-implantation, the CI recipient reported feeling less isolated, being less of burden on their family, relieved, and less emotionally strained.

6.2.1 Comparison of WL-SO and CI-SO Groups

The results of the present study also confirmed hypothesis two. Overall, the total mean QOL score for the CI-SO group was 76.01, while the total mean QOL score for the WL-SO was 51.47, giving an overall mean difference of 21.84. Communication and emotion were the main areas of difference between the two SO groups. Conversation with their partner in a noisy environment was difficult for 40% of CI-SOs, and 84% of the WL-SOs (Q8), while quiet environments were not so problematic, (4% of CI-SOs and 21% of the WL-SOs; Q11). Despite communication difficulties, only 4% of CI-SOs admitted leaving their partner out of conversations and 11% of the WL-SOs (Q16). These results collectively suggest that while a CI can improve communication between the recipient and their SO, the results suggest that a CI is not perfect, especially in noisy situations.

The findings of the present study are in agreement with Maillet et al. (1995), who found that 58% of their CI-SOs felt that the CI had a positive impact on the lives of the CI recipient, and that these findings were statistically significant ($p < 0.0001$). Stark & Hickson (2004) also found positive changes in QOL for both the person with hearing impairment and the SO following HA fitting. The most common problems reported by the SO pre-HA fitting were frustration at the volume of the television/radio, difficulty when conversing in a noisy environment, annoyance when asked to repeat, and frustration resulting from the hearing loss. The greatest improvements for the SO post-HA fitting, as were in the areas of the volume of the television/radio, frustration felt, the ease of conversing, repetitions required, and communication in a noisy environment.

Additional emotional factors reported in the present study included over half (54%) of the WL-SOs and 12% of the CI-SOs feeling that their partner's hearing loss had increased the stress in their lives (Q9). Almost all (97%) of the CI-SOs, and 64% of the WL-SOs did not feel embarrassed about their partner's hearing loss (Q11), with only 1% of CI-SOs and 2% of WL-SOs feeling that their partner was a burden. This was an interesting finding as it could be expected that there would be a greater difference between the two groups with the WL-SO more often reporting that their partner was a burden, due to their poorer communication skills. This finding has been reported by other studies (e.g. Hetu et al., 1993; Kennedy, Stephens & Fizmaurice, 2008; Lormore & Stephens, 1994; Tyler & Kelsay, 1990). For example, it would be expected that frustration and annoyance experienced by the SO resulting from frequent communication breakdowns, the need for repetition as reported in this study, could have led the SO to feel that their partner was indeed a burden.

6.2.2 Summary of the SO

In summary, the present study agrees with the findings in the literature showing that hearing loss impacts not only on the person with the impairment, but their SO as well. The results of the CI-SO questionnaire provided information about the impact of implantation on both the recipient and their partner's lives, and suggested that in addition to the benefits that a CI may provide for recipients, that these benefits extend to the SO as well. The CI group rated their physical, psychological, and social functioning as better than those on the WL, and this difference was apparent in the comparison between the CI-SO and WL-SO groups. Results showed that the CI-SO felt less stressed, frustrated, annoyed, and in general experienced less negative effects as a result of their partner's CI, and had higher QOL ratings compared to the WL-SO. Thus, the CI appears to facilitate improvement in the lives of the recipient and their SO.

6.3 Effects of Implantation on the Participant and their SO

Hypothesis 3: the participants will have similar QOL ratings to their SO.

The questionnaire for the CI-SO aimed to see how their partner's CI had impacted on their own life, as well as how they perceived the CI had impacted on their partner's life. While the WL-SO provided an insight into how having a partner with a hearing loss impacts on their lives. As mentioned in the QOL section (chapter 3), the WHO recognises the interactions between impairment, activities, and participation, on the health condition (e.g. hearing loss), as well as the influence of environmental factors such as personal, physical, social, and attitudinal. In addition to this, the WHO recognises that the SO share the consequences of hearing loss with their partner, such as communication problems, negative emotions, social, and activities in everyday life, and term it “third person disability” (WHO, 2001). For example, reduced social life and/or activity limitations may arise because their hearing-impaired partner cannot be involved. In addition, the SO may need to be more patient or tolerant, make more of an effort, and/or experience greater frustration from their partner’s hearing loss.

In order to see whether the effects of the CI reported by the CI recipient were similar to their SO, comparisons between matched satisfaction questions (Q61 CI recipient, Q27 CI-SO) showed that the both groups had similar ratings (see Table 26, p.63 of the results). Paired samples t-tests showed no significant differences between the groups in any of the categories except for ‘shopping’ ($p = 0.040$), and ‘car’ ($p < 0.001$). With regard to the differences in the shopping and car categories, it could be that factors such as background affected communication. Alternatively, it might be that the CI recipient does not shop with their SO, thus the SO cannot accurately judge their partner’s satisfaction with the CI in this situation. In regards to communication in the car, this may largely depend on which side the recipient had been implanted, and/or whether they are the driver or the passenger. For example if the SO was sitting on the passenger side and their CI was on the left side closest to the window, they may not receive the same benefit compared to if the CI was on the ear closest to the driver. In addition, background sounds such as the noise of the car and outside traffic may further hinder the recipient.

Question 62, (CI recipient) and Q27 (CI-SO) asked how satisfied both individuals were with the CI for improving the recipient’s life. Again there were no statistically significant differences in any of the areas, except for ‘personal safety’ ($M = 80.22$; $p = 0.030$), suggesting that both groups’ saw the CI as having similar impact on each others lives. This difference in personal safety may be reflecting that the SO still perceived the recipient as having a hearing loss. Overall, these findings indicate that the CI had impacted the recipient and their SO similarly. The pre-implant findings of this study are consistent with Maillet et al. (1995) who found that the CI-SO appeared to have had similar perceptions to the recipient regarding life pre-implant. However the authors found that post-implant perceptions of the CI recipient and the CI-SO differed, which was not the case in the present study.

The overall finding from the CI-SO group was that communication with their partner was reported as being “easier,” thus reducing emotional tension, is in agreement with Wexler et al. (1982). The findings of this study are also consistent with Stark & Hickson (2004), and Scarinci et al. (2008), where post-HA fitting, spouses reported a reduction in: communication difficulties, the high volume of the television or radio, having to repeat what they say, and feelings of frustration and annoyance towards their partner.

As mentioned in the results section, due to the qualitative nature of the data, statistical analysis was not used to compare the WL participant responses to the WL-SO responses. Therefore open-ended responses to Q21-26 (WL-SO) and Q61-66 (WL) were compared in order to get an idea of the expectations that these two groups had in regards to a future CI. A summary of responses for Q21 (WL-SO) and 61 (WL participant) are shown below in Table 31.

Table 31: Comparison of Expectations of WL Participant (Q61) and their SO (Q21)

Area	WL (N =*)	WL-SO (N =*)
General Conversation/Communication	40	24
Telephone	28	13
Social/Leisure	19	19
Relationships and/or Family	9	5
Negative Emotion (e.g. frustration through repeating conversation)	2	2
Television/Radio	12	4
Improve Speech	2	2
Music	17	6
Work/Study	14	11
Safety	1	3

* for WL N = number of comments out of a total of 55 offered.
* for WL-SO N= number of comments out of a total of 68 offered.

As shown in Table 31, not surprisingly many of WL-SOs hoped that the CI would enable better communication and conversations, allow their partner to talk on the telephone, as well increase social participation, and improve their relationship and family interactions. For example WL-SO #181 said:

> "It would be lovely to have whispered romantic conversation! Socially, we could go out again! He will be able to use the phone again and will be able to talk to his daughter and grandchildren."

Another area that respondents hoped for improvements was related to emotional aspects. For example asking for constant repetitions could result in the SO getting impatient and frustrated, which may consequently lead to a reduction in the quantity and quality of communication. Frustration and impatience were emotions reported by the hearing impaired person and their SO. Understandably both WL participants and their SOs hoped that the CI would result in less stress, less arguments, and less effort through the SO not having to raise their voice, and make constant repetitions.

The findings of the present study are in agreement with Stephens, (1994) who used an open-ended questionnaire to examine the experiences of the family and friends of 52 people with hearing impairment. The most common problem reported by both the SO and the person with hearing impairment was difficulty in understanding live speech (e.g. having to repeat). For the SO, the next most frequently reported problem was that the television/radio was too loud. This was followed by feelings of frustration reported by 19% of the SOs and 13% of those with hearing impairment.

Improved relationships were also commonly reported as an area in which respondents hoped that the CI would improve. Through improved communication it was hoped that the CI could facilitate re-establishing contact. This could, in turn, allow normality in the relationship; as reported by WL participant #280 "We could live a normal life." It was also hoped that the CI would help strengthen family relationships. For example from the SO's perspective, WL-SO participant #278 commented: "I think it will ease the burden of me being the sole parental ears and we will be able to get back towards being a more cohesive family unit." Similarly WL participant #268 hoped to be more included; "Family gatherings I can be included instead of [being] left out." Some also hoped that the CI would allow them increased independence and not relying on their partner so much, thus lessen feelings of burden.

Question 62 asked for areas where participants thought that the CI might not provide any benefit. Forty percent of participants reported that they could not see how the CI would not benefit them in some way. Nine percent were unsure or did not know. Twenty-four percent felt that the CI might not provide any benefit in background noise or noisy situations, 18% were concerned about listening to music, and 9% stated for using the telephone. Question 63 asked what kinds of concerns, if any, participants had regarding their future CI. The main concerns reported were that the CI might not work, that they would be disappointed with the results, or that it would not last forever (22%). Others were concerned about the ongoing maintenance of the device (17%), the surgery itself (15%), or of losing their remaining residual hearing and not being able to go back to using their HAs (12%). Some were also concerned about taking time off work for the surgery, and the resulting financial impact, as well as the costs of traveling to/from appointments (8%).

Overall, the WL-SO's expectations for the CI paralleled their hearing impaired partner's ones (Q63). Qualitative comments offered from the WL-SO for Q23 were related to whether the CI would work or live up to their partner's expectations (50%). Some were worried about the surgery itself (17%), while some were concerned about their partner's loss of residual hearing (8%), and/or financial burden (8%).

Question 65 asked the WL participants if they thought the CI would change anything about their relationship with their partner. Out of the 52 comments offered 33 said 'yes' and expressed similar opinions as they did for Q64. Nine said 'no' but did not offer any further comment, and three stated they did not think so/did not know. The remainder offered general comments, which are in Appendix 4. Of the WL-SO participants (Q25), 53 comments were also offered. Of these 30 said 'yes,' 21 said 'no,' 2 stated they 'hoped not,' with the remainder citing general comments, which are also in Appendix 6.

6.4 Parents

Hypothesis 4: Parents of children with CI(s) will rate their QOL to be better post-implant when retrospectively comparing back to pre-implant

As an alternative view of the SO, the perspective of parents was examined. As mentioned earlier in the literature review, parents not only play an integral part in deciding whether to have their child implanted, but they are also responsible for the child’s future education and upbringing, as well as being largely responsible for the ongoing maintenance of the CI itself. Parents also play a crucial role in the rehabilitation following implantation, requiring the investment of time, effort, and resources. As a result there may be more pressure on parents of a child with a CI than the SO of an adult CI recipient. In general though, this study found that parents appeared to perceive an improvement in the QOL of their child, as well as in their own lives post-implant, compared to pre-implant. This is in agreement with Castro et al. (2005), who suggested that audiological and intellectual improvements that can result post-implantation for a child, also improves the parent’s QOL. However, although there may be increases in QOL post-CI, it should also be considered that the CI presents many challenges including the surgery itself, rehabilitation, maintenance of the implant, and so forth.

This study looked at the effect that implantation had on both the child’s and parent’s QOL from the parent perspective using the broad categories of: decision to implant; effects of implantation; communication; supporting the child; self-confidence/reliance; general functioning; well-being and happiness; social relations; education, and general functioning. As mentioned in the results section, 11 of the children in this study had bilateral implants, and 3 children had multiple disabilities. The responses from the parents of these children are included in the main findings discussed below.

Positive effects of implantation were shown for items under the ‘decision to implant’ category. There was a significant decrease in the number of parents who were worried about their child’s future prospects pre- to post-implantation (Q27 & Q51; $p < 0.001$), although following implantation, 74% of parents were still concerned about their child’s future prospects. Although this may seem like a high percentage, it is worthwhile keeping in mind that even parents of children with normal hearing may worry about their child’s future. Implantation was also shown to have a positive effect on the child’s well-being and happiness, and this translated to improvements in the parent’s QOL. Many parents (69%) agreed that they were much happier with their life (Q67), and 86% felt more confident in their own life since their child was implanted (Q63). With regard to their child, almost all (95%) parents felt that their child’s communication ability had improved since implantation (Q33), where over half (52%) of the parents agreed that post-implant their child was happier and more fun to be with (Q53), and 41% of parents reporting that their child’s behaviour to have improved since implantation (Q56). Parent #17 said: “(Child) has come a long way in the last 2 years. He has developed language and speech [which] is much clearer, and his behaviour is 90% better.” However, some negative aspects were also identified. For example, nearly a quarter (24%) of parents reported that other siblings resented the time and attention they gave to the child with the CI(s) (Q64). This is consistent with Sach and Whynes (2005) who reported in their study that some of the parents were concerned that the focus of attention on the implanted child concealed the needs of their other children.

Positive effects of implantation were also evident in the child’s communication abilities where there was a significant improvement in communication pre- to post-implant ($p = < 0.001$). However, 22% of parents reported that post-implant their child still had communication difficulties with familiar people (Q32). This finding was similar to Zaidman-Zait (2008) who found that post-implant almost 40% of parents reported that communication problems between their implanted child and themselves still continued to be major sources of everyday difficulty. In that study many parents attributed this challenge to the child’s immature speech perception, production, and language level. Similarly, in this current study, although there were significant improvements pre- to post-implant relating to the child’s speech, 56% of parents still had concerns about the quality of their child’s speech after implantation (Q40).

Parents reported a significant difference pre- to post-implantation for the ‘supporting the child’ category where they felt that the help they gave their child was more useful since implantation (Q13 & Q34; $p = 0.001$). Additionally, just under half (46%) agreed that they got more time to themselves because of their child’s increased independence since implantation (Q59). This increased independence may have contributed to statistically significant improvements in the reported levels of their child’s self-reliance and self-confidence post-implant (Q17 & 39 and Q20 & 44; $p = 0.002$ for both comparisons), leading to positive effects on both the child’s and parent’s well-being and happiness. There was a significant decrease in parent’s frustration levels post-implant (Q28 & Q52; p = 0.013), however, there was no significant difference pre- to post-implant for the child’s frustration levels, where 52% of parents reported that their child still showed signs of frustration in his/her behaviour post-CI (Q55). A reason for this could be that behavior challenges occur among normal hearing children, and when this is combined with the difficulties related to hearing loss, existing communication problems may be more complex and/or exacerbated; it may be difficult for parents to distinguish between the confounds of hearing loss and normal development (Zaidman-Zait, 2008). Pre-implant 87% of parents agreed that their child was happy and fun to be with (Q29), with this number decreasing to 52% post-implant (Q53). This was an unexpected finding, as it could be anticipated that implantation would result in the child being happier due to being able to improved sound awareness. Possible contributing factors to this finding could have been that the question was ambiguous, thus was not clearly understood by parents, and/or that the parents thought that their child was happy and fun to be with despite having a hearing loss. Another factor could be that as the child would have matured since receiving their implant (M = 62.59 months), it may be that some parents have accounted for this natural maturation. For example, they saw their child as being less ‘fun and playful’ than when they were younger, but were now more ‘mature and responsible’.

Improvements in social relationships were evident post-implant, showing the positive effects of implantation. Only 8% of parents still felt their child was socially isolated (Q43), compared to 28% pre-implant; this difference approached significance (p = 0.057). There were also significant improvements when comparing the child pre- to post-implantation in the child’s ability to make new friends (Q46 & Q22; p = 0.036). Following implantation there had also been an improvement in family relations as perceived by 70% of parents (Q66), with 34% also reporting that their child’s relationship with his/her siblings had improved (Q65). These findings are consistent with Sach & Whynes (2005) who found that 57% of parents reported that family life had benefited from the implant. They also cited improved relationships with the child post-implantation ‘made life a lot easier.’ These findings are also in accordance with research that children’s social relationships can improve as a result of implantation due to improved communication skills (Bat-Chava & Deignan, 2001), thus affecting those around them.

A possible benefit of implantation is that it may enable the child to attend mainstream schooling. It has been reported that parents of children with CIs that were in mainstream schooling had pointed to the benefits of social integration and lack of stigma (Sach & Whynes, 2005). In the present study 69% of children were either fully or partially mainstreamed (Table 6, p.36 in the results); with 81% of all parents stating that they were happy with their child's current progress at school (Q60). However, other studies have found that parents often expressed concerns about their implanted child's academic performance (Archbold et al., 2002; Sach &Whynes, 2005; Zaidmain-Zait, 2008). Furthermore, Sach and Whynes' (2005) study found that regardless of educational setting, 13% of the implanted children in their study still had problems with basic skills, such as language/grammar, reading, writing, or mathematics. Although the parents in the present study indicated that they were generally happy with their child's educational progress and did not report any specific difficulties, this study had a small study sample (n=23), and the purpose of the questionnaire was to examine the parental QOL, rather than the child's educational outcomes.

There were also significant improvements reported post-implant for the 'general functioning' category where 92% of the parents felt that their child was now more aware when they were wanted as the child could now hear them (Q37), compared to pre-implant where 83% agreed that their child was not aware of this (Q16; $p < 0.001$). Other significant effects post-implantation were evident in that 95% of parents agreed their child could amuse himself or herself while listening to music, watching television, or playing games (Q45), compared to pre-implant (Q21; $p = 0.010$). Significant differences were also noted pre- to post-implant where pre-implant 72% of parents agreed that they did not let their child play outside because they could not hear traffic (Q25), compared to post-implant where 82% percent now letting their child play outside (Q49; $p = 0.002$). Also following implantation, children were able to cope better in new situations, as reported by 86% of parents (Q50). Seventy percent of parents also stated that their child benefited from and is totally reliant on their implant(s), compared to using HAs prior to implantation (pre Q14, post Q35; $p = < 0.001$). However, not all children had adapted to wearing their device. In the qualitative comments (Q75), two parents struggled to get their child to wear the CI. For example parent # 4 said:

> "My son hates his implant and resents wearing it. I believe it will take him a very long time to accept it. It would be more useful if it made a noise when he takes it off, as he hides it and can't tell us where it is."

6.4.1 Bilateral Implants

The last three questions of the parent questionnaire related to bilateral implants, and were included at the request of the participating clinic. This was in order to obtain specific information of interest to their programme. These findings are discussed only briefly, as this aspect was not one of the main aims of this research.

The benefits of bilateral CIs are related to the advantages of binaural hearing for sound localisation and speech understanding in noise. Of the 23 parents who answered the questionnaire, 11 of the children had bilateral implants. Of these, one child had received simultaneous implants; with the remainder being implanted sequentially. When asked if they felt there was a difference between the first and second implant 80% of parents said ‘yes’ (Q72). The same percentage of parents also reported bilateral benefits for general sound awareness. Other commonly reported benefits of bilateral implants (Q73) included listening to music, as reported by 70% of parents, environmental sounds (70%), sound localisation (66%), being able to call the child from another room (60%), watching television (60%), speech in noise (55%), and identifying the speaker (45%). All parents would recommend a second CI to others (Q74). These positive findings are in accordance with the literature citing bilateral benefits (Galvin, Mok, Dowell, & Briggs, 2008; Litovsky et al., 2006).

6.4.2 Other Factors Relating to the Parental View

In interpreting the results from the Parent group, it is acknowledged that the maturational process of the implanted children needs to be accounted for. For example, it must not be assumed that the CI is responsible for all changes observed by parents; some changes could have occurred regardless of whether the child received a CI or not. One also needs account for the potentially influencing factors such as the duration and type of rehabilitation a child has received, mode of communication, educational placing, and other sources of parental stress, in addition to coping with the child’s hearing impairment (Spahn et al. 2004). Some of these other factors may include the resolution of grief related to their child’s hearing loss, maternal-child interaction and bonding, vocational and familial considerations, parent emotional availability, and the child’s own self-development (Kurtzer-White & Luterman, 2003). The parents’ emotional responses and coping skills will also affect family adjustments, the child’s outcomes, and overall QOL. These issues were not assessed in this study’s questionnaire.

6.4.3 Summary of Parents' QOL

Improved hearing, which resulted in better communication, was reported by the SO of adult CI recipients. Similarly, these benefits were also the commonly cited outcomes of cochlear implantation of children, as reported by 95% of parents, which as expected, engendered in positive effects on parents' QOL. Beyond just hearing improvements, the results suggested that their child's confidence and independence had increased, along with speech development. As a result the majority (69%) of parents agreed that they were much happier with their life, and 86% felt more confident since their child had been implanted. As shown in the correlation results, there was an association between how parents rated their child's QOL, how they rated the impact of the CI on their own QOL, and their satisfaction with the CI. Overall this suggests that from the parent perspective, QOL improves as a result of their child's CI(s), despite the potential to initially bring increased stress in the short term, due to the new challenges faced with the implant(s).

6.5 Expectations of Cochlear Implantation

Due to widening of criteria for cochlear implantation, through improved technology as well as reduced risks associated with surgery, potential recipients may have higher expectations from implantation. Therefore, it is important examine if these expectations are realistic, which have implications for counseling. Section 6.5.1 discusses the expectations of potential CI recipients and their SO, while section 6.5.2 discusses whether the expectations are being met post-implantation, for the CI recipient. This could establish whether the outcomes from implantation are in line with speech perception outcomes.

6.5.1 WL Group Expectations

Participants on the WL for a CI were asked to list their expectations for their future CI (Q61), and what benefits they thought the CI would bring to them and their partner (Q64). There were 68 comments offered for Q61. These comments covered a wide range of areas; however certain areas were commonly reported, such as general communication (53%). Others expected that they would be able to use the telephone (38%), enable them to listen to music (29%), improve their social life (22%), and employment/study (16%), which would lead to improved confidence (13%). There were 66 comments offered for Q64. Thirty-four percent hoped for communication and general improvements in conversation with their partners (34%), a decrease in levels of negative emotions such as stress (16%), increased social participation with their SO (15%), and increased independence (9%).

Question 24 asked the WL-SO what impact the CI would have on their relationship. The same question was asked for the participant on the WL (Q 64). Many of the SOs hoped that the CI would enable their partner to regain their social life and become more involved with life, as well as improve their partner's QOL. Others expressed that they hoped the CI would lessen the stress and frustration caused by their partner's hearing loss. Finally Q25 asked the SO if they thought that the CI would change anything about the relationship they currently had with their partner. The same question was asked for the participant on the WL (Q64). The majority of SOs said 'yes' and hoped that the CI would improve their current situation. Once more, comments suggested that the SO felt that improved communication would lead to reduced frustration levels, making life easier, increased social participation, and reduced loneliness.

6.5.2 CI Recipients' Expectations

As the criteria for implantation has extended to include those with greater levels of pre-surgery residual hearing, potential recipients have 'more to lose,' and therefore have higher expectations of the CI. Hence, it is important to assess if the expectations are being met, as this would impact on the patient's satisfaction with the CI. In this study, the comments from some of the open-ended items reflected the major effects that implantation had on participants' lives. As reported in the results section, CI recipients were asked if their expectations (Q65), and needs (Q66) regarding the CI had been met. In both questions over 80% of recipients reported that the CI had met all most of their needs and expectations. When probed for more detail (Q67), 80 comments were offered. The general pattern of responses offered indicated that there had been improvements with most areas of life, with the most commonly reported acoustic benefits being general communication (39%), environmental sounds (27%), and using the telephone (25%). Psychological benefits included self-confidence, employment, and relationships (all 11%). Some comments were more general in nature, such as 9% commenting that their expectations were "all met," while others wrote specific, personal comments. For example CI recipient #23 commented that they "did not feel like a deaf person now." Similarly another CI recipient (# 42) said: "I function almost normally as a hearing person…Without the CI I probably would have shot myself by now!"

Zhao et al. (1996) reported that the main acoustic benefits for their participants were environmental sound awareness (77%), general conversation (62%), and telephone use (46%). Psychological benefits included improved self-confidence (62%). Findings from the present study are also consistent with Tyler & Kelsay (1990), Tyler (1994), and Mo et al., (2005).

Many respondents commented on the ability to hear environmental sounds again such as hearing birds, footsteps, and household or everyday sounds, which contributed to feelings of involvement in every day life. For example CI recipient #61 commented that the CI “has opened a whole new world of sound, every day sounds, and birds.” In addition, hearing sounds such as footsteps and cars approaching, and being able to hear their name being called, could all contribute to increased security and confidence resulting in psychological benefits and improved QOL (Reed & Delhorne, 2005). These findings were also consistent with Hallberg & Ringdahl (2004), who reported that having a CI was expressed as getting a new life, making a new start, or being ‘whole’ once more. For some recipients having a CI meant being able to leave the world of silence and be a part of the living world. In addition, increased sound awareness and hearing background sounds contributed to feelings of being involved in everyday social life, and re-connected recipients back with the living world, thus providing feelings of social connectedness.

Another component of QOL is satisfaction, which was evident for the CI recipients in this study; all but one of the CI participants would recommend a CI to other hearing impaired people who were in a similar situation, with 97% being satisfied overall. Hirschfelder et al. (2008) reported 89.2% of their recipients being satisfied with the changes in QOL after implantation, with Faber et al. (2000) reporting that all participants in their study would recommend a CI to a deaf friend. Francis and colleagues (2002) and Cohen et al. (2004) found a trend for higher QOL ratings for CI recipients than HA users. In this study correlational analysis showed there was a significant weak correlation between speech perception scores and satisfaction with the CI (rho = 0.300, $p = 0.006$), and a significant strong correlation between QOL and satisfaction with the CI (rho = 0.885, $p < 0.001$). This suggests that individuals’ satisfaction with life may be related to their ability to communicate.

Music appreciation is becoming an increasing expectation for potential recipients, and is an area that shows wide variations in outcomes. Music plays a central role in all human cultures, and may be an important contribution to QOL. For example, Lassaletta et al. (2007) found that mean QOL scores were higher for CI recipients who spent more time listening to music post-implantation, compared to those that did not spend as much time listening to music following implantation. Current literature shows that most CI recipients enjoy music less post-implantation than pre-implantation (Leal et al., 2003; McDermott, 2004). However, CIs are designed primarily for speech discrimination, and speech processing strategies are not able to provide the fine temporal structure information necessary for accurate perception of music. In the present study, 52% of CI recipients were able to recognise rhythm in music compared to only 16% of those on the WL (Q35). This figure is surprisingly low given the research that suggests that CI recipients' rhythm discrimination skills are equal to normal hearing and HA users (Gfeller & Lansing, 1991, 1992; Looi, McDermott, McKay, & Hickson, 2008). Overall the literature indicates that CI recipients do significantly poorer than normally hearing listeners and HA users for pitch perception tasks, instrument identification and/or melody recognition (Fujita & Ito, 1999; Gfeller & Lansing, 1991; Gomaa, Rubinstein, Lowder, Tyler, & Gantz, 2003; Leal et al., 2003; Looi et al., 2008), thus appreciation of music is one area many CI recipients that are not satisfied with

Question 68 also provided useful insights into CI recipients' satisfaction with music. Out of the 63 comments offered, 27% of CI recipients commented that they experienced problems listening to music, such as music sounding 'unnatural.' However there is much variability in music perception outcomes for adults and children with CIs. There are a whole host of other factors which have been shown to contribute to this variability including knowledge of music, location and number of surviving neurons in their cochlea, positioning of the electrode array, pathological processes, central auditory processing, and speech processing strategies (Fujita & Ito, 1999; Gfeller, Turner, & Mehr, 2002; McDermott, 2004). However, while this study showed variability in CI recipients' satisfaction with music, the comments in this study also suggested that for some, listening to music is noticeably better post-implant, or that it was improving.

Background noise is another issue for many CI recipients. Difficulties in understanding speech in noise were cited by 30% of CI recipients in the comments section (Q68) in this study. Additionally, for meetings or gatherings, and group situations (Q61; Q14) the CI recipients' mean scores were lower compared to other areas (Q61 M = 64.77; Q14 M = 55.75). These issues related to perceiving speech in background noise are similar to accurate music perception with current speech processing strategies in CIs not being able to provide enough spectral resolution and fine temporal information to accurately identify speech in noise (Drennan & Rubinstein, 2008; Gfeller, Witt et al., 2002; Lassaletta et al., 2008). Other areas reported in the comments section where the CI did not meet recipients' expectations were the telephone (31%), and television (14%). Some respondents mentioned difficulties related to the maintenance and/or malfunction of the implant or external hardware while a small number of CI recipients (6%) reported that their speech processor was too large or bulky, and thus was awkward to use. It is interesting to contrast this later figure to Zhao & Stephens' (1996) study, where 46% of recipients reported that their processor was cumbersome, as this in-part indicates how much technology has improved in the last decade.

6.6 Limitations of the Present Study

When interpreting the results of this study, potential limitations must be identified. Firstly, due to the complexity of QOL it is not possible to fully measure or interpret QOL by single questionnaires. For example, factors that are important to one person's QOL may not be important to another person, and/or may not have been included in the questionnaire. Furthermore, individuals would weight different factors differently as to how much each contributed to their QOL; the questionnaires in this study did not ask respondents to weight how important different factors were in determining their QOL. Additionally, comparisons between participants' QOL in this study to those of the general population were not been conducted, as the purpose of this research was to look at the effect of implantation on QOL, rather than investigating the QOL of CI recipients compared to the general population. Similarly, the parental questionnaire in the present study was not administered to a control group of parents of hearing impaired children fitted with HAs, and/or children with normal hearing.

Another limitation of this study was the limited time frame for the study, which prevented norms and re-test validity measurements for this questionnaire being obtained. The limited time frame also prevented longer term or follow-up evaluations being collected. For example, for the WL group, a second follow-up questionnaire at 12 and 24 months post-CI would have provided beneficial information. Studies have found that the most significant improvements occur around 6-12 months post-implantation (Klop et al., 2007; 2008). After 12 months, although some individuals continue to demonstrate ongoing improvement, most reach a plateau (Hamzavi et al., 2003). This is also reported by Tyler & Kelsay (1990) where it was reported that 91% of CI recipients indicated that they achieved maximum benefit from their devices in the first 7 months (Tyler & Kelsay, 1990). Zhao et al. (2008) found that most individuals' improvements in psychological domain reached a plateau at 1.5 to 2 years post-implantation. However improvements in daily life such as using the telephone, music, watching television, and social life often plateaued later at approximately 1.5 to 3 years post-implant (Zhao et al., 2008).

The small sample size in the CI-New group makes generalisation of this data difficult. Further, as mentioned the potential of a 'halo' effect or the Hawthorne effect must also be considered in interpreting their post-CI ratings. Similarly, for the parental perspective, the small subject numbers (N = 23), further confounded by the fact that 11 were parents of children with bilateral implants makes generalisation of the data difficult.

6.6.1 Limitations of Questionnaires

One factor inherent to many questionnaire-based studies, including the present one, is that the population sampling may be biased in that respondents chose to answer this optional questionnaire. That is, it may not necessarily be a true reflection of the population of CI recipients and their SO (or parents). Those that responded may have had a particular motivation or reason to respond. In addition, the closed-set format of many of the questions meant that participants were not free to explore other issues that they may have felt to be important, nor the freedom to comment on issues that are important to them (Incesulu et al., 2003; Scarinci et al., 2008). Similarly, the 5-point rating scale used may have not provided sufficient precision for CI recipients to accurately convey their opinions. However, both the closed-set format and the 5-point scale provide advantages with regard to time efficiency, ease of response interpretation, and therefore possibly increased participant response rates.

Another limitation of the questionnaires that were used in the current study was that even though these questionnaires were based on existing questionnaires, the modified versions used in this study have not been evaluated, and there were no existing norms (Stark & Hickson, 2004). Further, in regards to the NCIQ which had been translated from Dutch, it was necessary to re-word some of the questions in to make them clearer, and grammatically correct.

6.7 Future Directions

Despite the above limitations, the results from this study have not only provided interesting information and outcome data, but have also highlighted areas for potential research. Some of these include conducting a larger, more detailed study based on the parental perspective alone, and a comparison of the effect of implantation on the child versus the parent. A larger study could also look at parents' everyday problems in relation to their child's age group, and time following implantation. The results of this study could also be used as a base-line and continued with a follow-up study in years to come, in order to monitor the longer-term outcomes of implantation on QOL. For the adults, there could be continuation of pre- and post-implant assessments. For example, administering questionnaires to all future SCIP-A patients pre-surgery and subsequently at set time frames post-implantation. The SO comparison could also be researched further, such as how the SO rates their hearing impaired partner's QOL as well as how the recipient views changes to their SO and family's QOL. The need for a specific, validated, normalised questionnaire on the QOL outcomes for CI recipients with a matching SO perspective questionnaire has also been demonstrated. Such a questionnaire would need to be administered across a large population group, with normative and reliability data being collected. Furthermore, additional factors that have not been taken into account in this study are: stage of adjustment to hearing loss, stage in the life cycle, employment, financial security, or personality, or psychological measurements, all of which may be important influences on QOL.

Chapter 7: Summary and Conclusions

QOL is made up of several components that people derive from the important aspects of their lives. It is subjective and incorporates social, cultural, and environmental considerations. General satisfaction with life, as well as an individual's self-esteem and personality are also essential factors in QOL (Hintermair, 2008). This study aimed to obtain information regarding changes in QOL in CI recipients, and to assess where the changes were most noticed in daily life. Results showed that CIs had a positive impact on the QOL of CI recipients, where changes occurred in the subdomains of basic and advanced sound perception, speech production, self-esteem, activity limitations, and social interaction. It was also found that the CI recipients' ratings were significantly better ($p < 0.001$), than those on the WL for a CI, thus supporting the first hypothesis. In particular, positive effects on QOL provided by the CI were evident where recipients reported improved family life, interconnectedness, communication, and independence. The CI-New subgroup of CI recipients also reported improved confidence, self-esteem and independence, compared to their pre-implant state. They felt more able to participate in conversations, and reported better vocational prospects, with decreased feelings of loneliness, depression, and social isolation. Comments from CI recipients also showed the high value placed on a CI, and the ability to be able to hear again; a number of CI recipients expressed that the CI was the best thing that had ever happened to them. Recipients' satisfaction with their implants was also shown in that all but one would recommend a CI to others, with 88% of reporting that the CI had met their expectations, and 83% reported that the CI had met their needs. Overall, 97% of recipients were satisfied with their CI.

Nevertheless, satisfaction with the CI was diminished for some areas over others. It was apparent that satisfaction in listening to music, as well as when in noisy environments was lower than that in other areas. This corroborates with a host of other studies that have identified music and background noise as problematic issues for recipients, despite the advances in implant technology.

This study also aimed to look at the impact of the CI on the participant's SO. The CI-SO group showed that the CI had positive effects on their QOL especially in the areas of communication, as well as a reduction in negative emotions such as embarrassment and burden. When the CI-SO group and the WL-SO group ratings were compared, the QOL of the CI-SO group was significantly better than the latter, particularly in for the categories of emotion and social life, as well as for relationships, communication, and personal safety, which confirmed the second hypothesis. These results also suggested that the positive effects of CIs were evident in the lives of the SO, where the CI-SO group had better QOL ratings than the WL-SO group. In addition to these findings, it was found that recipients and their SO also had similar ratings on how the CI had affected the recipient's QOL where comparisons made between the CI recipient and their SO regarding satisfaction with the CI, showed that the SO had similar ratings to the recipient, thus confirming the third hypothesis.

Finally, as an alternative view of the SO, the parent view offered additional insights into how the CI had affected the QOL of both the child and the parent. A comparison of pre- to post-implant questions showed significant improvements following implantation for the categories of decision for implantation, effects of implantation, communication, supporting the child, well-being and happiness, social relationships, and general functioning, as well as positive effects on the child's education. These findings supported the fourth hypothesis.

In summary all four hypotheses were confirmed, thus showing that examining both disease-specific and generic QOL factors should be included in the assessment of benefit from a CI. As technology continues to improve, the future of CIs is even more promising. Overall, this study has shown that CIs have made vast differences in many recipients' lives, providing them and their SO with a better QOL. As CI recipient #161 wrote: "It has given me back my life."

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List of Appendices

Appendix 1 Questionnaires Used for the Present Study[*]

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[*] Note: The questionnaire sizes have been reduced for inclusion into this thesis in order to fit the page formatting requirements required for this document.

QUESTIONNAIRE FOR RECENT OR CURRENT COCHLEAR IMPLANTEES

(Please note that CI stands for Cochlear Implant)

What is your age? ____ Are you: ☐ Male ☐ Female

How would you classify yourself? ☐ Deaf ☐ Hard of hearing

How old were you when you lost your hearing?
_____

What was the cause of your hearing loss (if known)?

☐ Congenital (at birth) ☐ Illness ☐ Unknown Other __________

How old were you when you got your CI? _____ How long have been using your CI?: ____

Please tick the appropriate answer for the following questions.

Please answer the questions based on what your life is like since you had your CI.

If you think the question does not apply to you, please tick not applicable (N/A).

	When wearing your current CI:	Never	Sometimes	Regularly	Usually	Always	N/A
1.	Can you hear background noises (e.g. toilet flushing, vacuum cleaner etc)?	☐	☐	☐	☐	☐	☐
2.	Do you have problems communicating with people who do not have a hearing loss?	☐	☐	☐	☐	☐	☐
3.	Are you able to whisper if you have to?	☐	☐	☐	☐	☐	☐
4.	Do you feel at ease when you are interacting with other people?	☐	☐	☐	☐	☐	☐
5.	Can you hold a conversation in a quiet place with one other person?	☐	☐	☐	☐	☐	☐
6.	Does having a CI pose any problems with your work or studies?	☐	☐	☐	☐	☐	☐
7.	Can you hear the footsteps of other people in your house (e.g. in the hall or on the stairs)?	☐	☐	☐	☐	☐	☐
8.	Does having a CI present problems in your contact with hearing-impaired people?	☐	☐	☐	☐	☐	☐
9.	Are you able to shout if you need to?	☐	☐	☐	☐	☐	☐
10.	Since you had your CI do you see yourself as being hearing-impaired?	☐	☐	☐	☐	☐	☐

Please continue on the next page

<u>When wearing your current CI</u>:		Never	Sometimes	Regularly	Usually	Always	N/A
11.	Are you able to hold a conversation with 2 or more people in a quiet place?	☐	☐	☐	☐	☐	☐
12.	Do you have problems having a conversation in a car?	☐	☐	☐	☐	☐	☐
13.	Can you hear sounds such as the telephone or doorbell ringing?	☐	☐	☐	☐	☐	☐
14.	Do you have problems if you are with a group of people (e.g. hobbies, sport, holidays)?	☐	☐	☐	☐	☐	☐
15.	Are you able to make yourself understood to strangers without using hand gestures?	☐	☐	☐	☐	☐	☐
16.	Do you become irritated if you cannot follow a conversation?	☐	☐	☐	☐	☐	☐
17.	When you are in a busy shop, can you understand the shop assistant?	☐	☐	☐	☐	☐	☐
18.	Do you have problems when you take part in recreational/leisure activities?	☐	☐	☐	☐	☐	☐
19.	Can you hear (not feel) the door slam when you are busy at home?	☐	☐	☐	☐	☐	☐
20.	Do you have problems communicating with the people you live with (e.g. family/partner etc)?	☐	☐	☐	☐	☐	☐
21.	Are you able to adjust your voice to different situations (e.g. noisy environment, quiet environment)?	☐	☐	☐	☐	☐	☐
22.	Do you avoid talking to strangers?	☐	☐	☐	☐	☐	☐
23.	Are you able to enjoy listening to music?	☐	☐	☐	☐	☐	☐
24.	Do you have problems functioning in the home?	☐	☐	☐	☐	☐	☐
25.	As a pedestrian are you able to hear cars approaching in traffic?	☐	☐	☐	☐	☐	☐
26.	Do you ever feel left out because of your CI?	☐	☐	☐	☐	☐	☐
27.	With your CI can strangers tell from your voice that you were deaf or hearing-impaired?	☐	☐	☐	☐	☐	☐

__When wearing your current CI__:

		Never	Sometimes	Regularly	Usually	Always	N/A
28.	Do you ask people to speak more loudly or clearly if they are speaking too softly or unclearly?	☐	☐	☐	☐	☐	☐
29.	Are you able to recognise certain melodies in music?	☐	☐	☐	☐	☐	☐
30.	Do you have problems when you are shopping (e.g. in a shopping mall)?	☐	☐	☐	☐	☐	☐
31.	Can you hear soft noises (e.g. key falling, microwave beeping)?	☐	☐	☐	☐	☐	☐
32.	Since you had your CI do you go to places where your previous hearing impairment may have presented a serious handicap?	☐	☐	☐	☐	☐	☐
33.	Can you make yourself understood to acquaintances without using hand gestures?	☐	☐	☐	☐	☐	☐
34.	Do you feel anxious when talking to strangers?	☐	☐	☐	☐	☐	☐
35.	Are you able to recognize certain rhythms in music?	☐	☐	☐	☐	☐	☐
36.	Do you have problems hearing when watching TV?	☐	☐	☐	☐	☐	☐
37.	Can you hear (not feel) someone approaching you from behind?	☐	☐	☐	☐	☐	☐
38.	With your CI do you have problems when you are in contact with others in your community?	☐	☐	☐	☐	☐	☐
39.	How often does it annoy you that people can tell from your voice/speech that you have a hearing problem?	☐	☐	☐	☐	☐	☐
40.	Can you understand strangers without lip-reading?	☐	☐	☐	☐	☐	☐
41.	Do you experience communication problems at parties (e.g. birthday)?	☐	☐	☐	☐	☐	☐
42.	Can you hear (but not necessarily understand) people talking on the radio?	☐	☐	☐	☐	☐	☐
43.	Do you experience communication problems when you are with friends?	☐	☐	☐	☐	☐	☐
44.	Can you make contact easily with other people?	☐	☐	☐	☐	☐	☐

	***When wearing your current CI*:**	Never	Sometimes	Regularly	Usually	Always	N/A
45.	Can you tell the difference between a man’s voice, woman’s voice, and a child’s voice?	☐	☐	☐	☐	☐	☐
46.	Do you have problems when dealing with formal matters (e.g. insurance, solicitor etc) in person?	☐	☐	☐	☐	☐	☐
47.	Can you hear when someone calls your name?	☐	☐	☐	☐	☐	☐
48.	Since you had your CI does it cause communication problems with other family members?	☐	☐	☐	☐	☐	☐
49.	Since you had your CI are there situations in which you would feel happier?	☐	☐	☐	☐	☐	☐
50.	Do you feel it tiring to listen?	☐	☐	☐	☐	☐	☐
51.	Do you have problems when you go out or go on trips (e.g. shopping, holidays)?	☐	☐	☐	☐	☐	☐
52.	Can you hear voices from another room (e.g. children playing, baby crying)?	☐	☐	☐	☐	☐	☐
53.	Do you feel that people take you seriously?	☐	☐	☐	☐	☐	☐
54.	Since you had your CI do you feel that your self-confidence has improved?	☐	☐	☐	☐	☐	☐
55.	Do you stick up for yourself (e.g. at work, in relationships)?	☐	☐	☐	☐	☐	☐

Please note that the answer categories have changed

	With your CI:	No	Poor	Fair	Good	Quite well	N/A
56.	Can you make your voice sound angry, friendly, happy or sad?	☐	☐	☐	☐	☐	☐
57.	Can you control the pitch of your voice (e.g. high, low)?	☐	☐	☐	☐	☐	☐
58.	Can you control the volume of your voice (e.g. loud, soft)?	☐	☐	☐	☐	☐	☐
59.	Does your voice sound “natural” when you talk?	☐	☐	☐	☐	☐	☐
60.	Are you able to hold a simple telephone conversation?	☐	☐	☐	☐	☐	☐

The following questions are asked in order to rate your experiences with your current CI

Satisfaction with Cochlear Implant

61. When in the following situations, how satisfied are you with your CI:
(Circle the appropriate number for each area – if you do not believe any of the areas apply to you tick N/A)

	A Lot	A moderate amount	A Little	Very Little	Not at all	N/A
Attending a Restaurant	5	4	3	2	1	☐
Catching public transport	5	4	3	2	1	☐
Cinema	5	4	3	2	1	☐
Concert	5	4	3	2	1	☐
Driving a car or as a passenger	5	4	3	2	1	☐
Family conversations	5	4	3	2	1	☐
Small groups	5	4	3	2	1	☐
Listening to music	5	4	3	2	1	☐
Meetings or gatherings	5	4	3	2	1	☐
Shopping	5	4	3	2	1	☐
Social situations	5	4	3	2	1	☐
TV	5	4	3	2	1	☐
Radio	5	4	3	2	1	☐
Telephone	5	4	3	2	1	☐
Work	5	4	3	2	1	☐

62. How satisfied are you with your CI improving the following areas of your life?
(Circle the appropriate number for each area – if you do not believe any of the areas apply to you tick N/A)

	A Lot	A moderate amount	A Little	Very Little	Not at all	N/A
Increased communication with others	5	4	3	2	1	☐
Increased connectedness with the world	5	4	3	2	1	☐
Decreased negative emotional state (e.g. depression)	5	4	3	2	1	☐
Increased feelings that you are contributing to society	5	4	3	2	1	☐
Improved family relationships	5	4	3	2	1	☐
Forming new relationships	5	4	3	2	1	☐
Increased independence	5	4	3	2	1	☐
Increased interpersonal skills	5	4	3	2	1	☐
Decreased isolation/feelings of loneliness	5	4	3	2	1	☐
Increased personal safety	5	4	3	2	1	☐
Improved self esteem	5	4	3	2	1	☐
Standing up for yourself	5	4	3	2	1	☐

63. With regard to your CI, overall, how satisfied are you with the quality of service provided by the Southern Cochlear Implant Program (SCIP)? (Tick one box only)

Very Satisfied	Satisfied	Dissatisfied	Very Dissatisfied	Unsure
☐	☐	☐	☐	☐

Please continue on the next page

64. How would you rate the quality of the results you obtained with your CI?

Excellent	Good	Fair	Poor	Unsure
☐	☐	☐	☐	☐

65. To what extent has the CI met your expectations?

All expectations have been met	Most expectations have been met	Some expectations have been met	Only a few expectations have been met	No expectations have been met
☐	☐	☐	☐	☐

66. To what extent has the CI met your needs?

All of my needs have been met	Most of my needs have been met	Some of my needs have been met	Only a few of my needs have been met	None of my needs have been met
☐	☐	☐	☐	☐

67. In what areas (if any) has your CI met your needs and expectations? (Please list)

____

____

____

____

68. In what areas (if any) has your CI not met your needs or expectations? (Please list)

____

____

____

____

Please continue on the next page

69. If a friend were in need of a similar procedure would you recommend a CI to them?

Definitely not	No I don’t think so	Unsure	Yes I think so	Yes definitely
☐	☐	☐	☐	☐

70. In an overall, general sense, how satisfied are you with your CI?

Very Dissatisfied	Dissatisfied	Indifferent	Mostly Satisfied	Very Satisfied
☐	☐	☐	☐	☐

71. Do you have any other comments?

____

____

____

____

____

____

Thank you for taking the time to complete this questionnaire.

QUESTIONNAIRE FOR PARTICIPANTS ON THE WAITING LIST FOR A COCHLEAR IMPLANT OR PRE COCHLEAR IMPLANT

(Please note that CI stands for Cochlear Implant and HA stands for Hearing Aid/s)

What is your age? ____ Are you: ☐ Male ☐ Female

How would you classify yourself? ☐ Deaf ☐ Hard of hearing

How old were you when you lost your hearing? _____

What was the cause of your hearing loss (if known)?

☐ Congenital (at birth) ☐ Illness ☐ Unknown Other __________

How old were you when you got your HA/s? _____ How long have you used your HA/s? _____

Please tick the appropriate answer for the following questions.

If you think the question does not apply to you, please tick not applicable (N/A).

When using your current hearing aid/s:	Never	Sometimes	Regularly	Usually	Always	N/A
1. Can you hear background noises (e.g. toilet flushing, vacuum cleaner etc)?	☐	☐	☐	☐	☐	☐
2. Does your hearing impairment cause problems when you are communicating with people who do not have a hearing loss?	☐	☐	☐	☐	☐	☐
3. Are you able to whisper if you have to?	☐	☐	☐	☐	☐	☐
4. Do you feel at ease when you are with other people despite your hearing impairment?	☐	☐	☐	☐	☐	☐
5. Can you hold a conversation in a quiet place with one person (with or without lip reading)?	☐	☐	☐	☐	☐	☐
6. Does your hearing impairment cause problems with your work or studies?	☐	☐	☐	☐	☐	☐
7. Can you hear the footsteps of other people in your house (e.g. in the hall or on the stairs)?	☐	☐	☐	☐	☐	☐
8. Does being hearing-impaired present problems in your contact with other hearing-impaired people?	☐	☐	☐	☐	☐	☐

Please continue on the next page

		Never	Sometimes	Regularly	Usually	Always	N/A
9.	Are you able to shout if you need to?	☐	☐	☐	☐	☐	☐
10.	Does it bother you that you have a hearing impairment?	☐	☐	☐	☐	☐	☐
11.	Are you able to hold a conversation with 2 or more people in a quiet place (with or without lip reading)?	☐	☐	☐	☐	☐	☐
12.	Does using your hearing impairment create problems when you are having a conversation in a car?	☐	☐	☐	☐	☐	☐
13.	Can you hear your own telephone or doorbell ringing?	☐	☐	☐	☐	☐	☐
14.	Does your hearing impairment cause problems if you are with a group of people (e.g. hobbies, sport, holidays)?	☐	☐	☐	☐	☐	☐
15.	Are you able to make yourself understood to strangers without using hand gestures?	☐	☐	☐	☐	☐	☐
16.	Do you become irritated if you cannot follow a conversation?	☐	☐	☐	☐	☐	☐
17.	When you are in a busy shop, can you understand the shop assistant?	☐	☐	☐	☐	☐	☐
18.	Does your hearing impairment cause you problems when you do recreational/leisure activities?	☐	☐	☐	☐	☐	☐
19.	Can you hear (not feel) the door slam when you are busy at home?	☐	☐	☐	☐	☐	☐
20.	Does your hearing impairment cause problems with people you live with (e.g. family/ partner/ flatmates)?	☐	☐	☐	☐	☐	☐
21.	Are you able to adjust your voice to different situations (e.g. noisy environment, quiet environment)?	☐	☐	☐	☐	☐	☐
22.	Do you avoid talking to strangers?	☐	☐	☐	☐	☐	☐
23.	Are you able to enjoy listening to music?	☐	☐	☐	☐	☐	☐
24.	Does your hearing impairment present a problems for functioning in the home?	☐	☐	☐	☐	☐	☐

Please continue on the next page

		Never	Sometimes	Regularly	Usually	Always	N/A
25.	As a pedestrian are you able to hear cars approaching in traffic?	☐	☐	☐	☐	☐	☐
26.	Do you ever feel left out because you have a hearing impairment?	☐	☐	☐	☐	☐	☐
27.	Can strangers tell from your voice that you are deaf or hearing-impaired?	☐	☐	☐	☐	☐	☐
28.	Do you ask people to speak more loudly or clearly if they are speaking too softly or unclearly?	☐	☐	☐	☐	☐	☐
29.	Are you able to recognise certain melodies in music?	☐	☐	☐	☐	☐	☐
30.	Does having a hearing impairment cause problems when you are shopping (e.g. in a shopping mall)?	☐	☐	☐	☐	☐	☐
31.	Can you hear soft noises (e.g. key falling, microwave beeping)?	☐	☐	☐	☐	☐	☐
32.	Do you go places where your hearing impairment might present a serious handicap?	☐	☐	☐	☐	☐	☐
33.	Can you make yourself understood to acquaintances without using hand gestures?	☐	☐	☐	☐	☐	☐
34.	Do you feel anxious when talking to strangers?	☐	☐	☐	☐	☐	☐
35.	Are you able to recognize certain rhythms in music?	☐	☐	☐	☐	☐	☐
36.	Do you have problems hearing when watching TV?	☐	☐	☐	☐	☐	☐
37.	Can you hear (not feel) someone approaching you from behind?	☐	☐	☐	☐	☐	☐
38.	Does your hearing impairment cause difficulties when you are in contact with people in your community?	☐	☐	☐	☐	☐	☐
39.	How often does it annoy you that people can tell from your voice/speech that you have a hearing problem?	☐	☐	☐	☐	☐	☐
40.	Can you understand strangers without lip-reading?	☐	☐	☐	☐	☐	☐

Please continue on the next page

		Never	Sometimes	Regularly	Usually	Always	N/A
41.	Does your hearing impairment present problems at parties (e.g. birthday)?	☐	☐	☐	☐	☐	☐
42.	Can you hear (but not necessarily understand) people talking on the radio?	☐	☐	☐	☐	☐	☐
43.	Does your hearing impairment cause problems when you are with friends?	☐	☐	☐	☐	☐	☐
44.	Can you make contact easily with other people despite your hearing impairment?	☐	☐	☐	☐	☐	☐
45.	Can you tell the difference between a man’s voice, woman’s voice, and a child’s voice?	☐	☐	☐	☐	☐	☐
46.	Does your hearing impairment present problems when dealing with formal matters (e.g. insurance, solicitor etc) in person?	☐	☐	☐	☐	☐	☐
47.	Can you hear when someone calls your name?	☐	☐	☐	☐	☐	☐
48.	Does your hearing impairment cause problems when you are communicating with other family members?	☐	☐	☐	☐	☐	☐
49.	Are there situations in which you would feel happier if you were not hearing impaired?	☐	☐	☐	☐	☐	☐
50.	Do you find it tiring to listen (with or without lip reading)?	☐	☐	☐	☐	☐	☐
51.	Does your hearing impairment present problems when you go out or go on trips (e.g. shopping, going on holiday)?	☐	☐	☐	☐	☐	☐
52.	Can your hear voices from another room (e.g. children playing, baby crying)?	☐	☐	☐	☐	☐	☐
53.	When you are in a group, do you feel that your hearing impairment prevents people from taking you seriously?	☐	☐	☐	☐	☐	☐
54.	Does having a hearing impairment undermine your self-confidence?	☐	☐	☐	☐	☐	☐
55.	Does having a hearing impairment stop you from sticking up for yourself (e.g. at work, in relationships)?	☐	☐	☐	☐	☐	☐

Please continue on the next page

Please note that the answer categories have changed:

	No	Poor	Fair	Good	Quite Well	N/A
56. Are you able to make your voice sound angry, friendly, happy or sad?	☐	☐	☐	☐	☐	☐
57. Can you control the pitch of your voice (e.g. high, low)?	☐	☐	☐	☐	☐	☐
58. Can you control the volume of your voice (e.g. loud, soft)?	☐	☐	☐	☐	☐	☐
59. Does your voice sound “natural” when you talk? (so that it does not sound like a deaf person’s voice)?	☐	☐	☐	☐	☐	☐
60. Are you able to hold a simple telephone conversation?	☐	☐	☐	☐	☐	☐

61. To get an idea of your expectations for when you receive your CI, please list areas in which you are hoping that the CI will provide benefit in.

____

____

____

____

62. What areas (if any) do you think that your future CI might not provide any benefit?

____

____

____

____

Please continue on the next page

63. What kinds of concerns (if any) do you have in regards to your future CI?

64. What benefits do you think the CI will have on both you & your partner's life?

65. Do you think that the CI will change anything about the relationship you currently have with your partner? Yes /No. If yes, please detail.

66. Do you have any other comments?

Thank you for taking the time to complete this questionnaire.

QUESTIONNAIRE FOR SIGNIFICANT OTHER OF CURRENT (OR RECENT) COCHLEAR IMPLANTEE

Please note that CI stands for Cochlear Implant
The following questions should be answered by the significant other, (e.g. husband/wife, parent, sibling, partner etc.), or the person closest to a person with a CI.
This is to get an idea of how your life has been since your partner had their CI.
Please do not consult your significant other for their opinion, as I am interested in obtaining your perspective.

What is your age? ___________ Are you: ☐ Male ☐ Female

What is your relationship to the CI user? (Please tick)

Wife ☐ Husband ☐ Partner ☐ Sibling ☐ Parent ☐ Other _______

Did you know the CI user when they first got their CI? YES ☐ NO ☐

*** For the purpose of this questionnaire, the term “my partner” has been used to represent the hearing impaired person, regardless of your relationship to them.**

(Please circle your response or tick not applicable (N/A) if you believe the question does not apply)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
1. Having a partner with a CI means that I have had to make adjustments at work (e.g. having to take time off).	5	4	3	2	1	☐
2. My partner’s CI has caused financial implications.	5	4	3	2	1	☐
3. Having a partner with a CI means that my social life suffers.	5	4	3	2	1	☐
4. I feel embarrassed about my partner’s hearing impairment, even with their CI.	5	4	3	2	1	☐
5. At times I get annoyed at having to repeat myself because my partner did not hear me.	5	4	3	2	1	☐
6. I find that my partner’s CI stops them from socialising.	5	4	3	2	1	☐
7. I hesitate to meet new people because my partner has a CI.	5	4	3	2	1	☐
8. I cannot talk to my partner in a noisy environment, even with their CI.	5	4	3	2	1	☐
9. I feel that having a partner with a CI has increased the stress in my life.	5	4	3	2	1	☐
10. I feel that our relationship is affected negatively by my partner’s CI.	5	4	3	2	1	☐
11. I cannot talk to my partner in a quiet environment, even with their CI.	5	4	3	2	1	☐
12. I worry about the safety of my partner because of their hearing impairment/CI.	5	4	3	2	1	☐
13. My partner’s hearing loss has impacted negatively on others in our immediate family.	5	4	3	2	1	☐

(Please circle your response or tick not applicable (N/A) if you believe the question does not apply)	Never	Rarely	Sometimes	Often	All the time	N/A
14. I feel strained in my interactions with my partner.	5	4	3	2	1	☐
15. At times I get annoyed with my partner because she/he has a hearing loss/CI.	5	4	3	2	1	☐
16. I leave my partner out of conversations.	5	4	3	2	1	☐
17. Even when they are wearing their CI, I am bothered by the volume of the TV/radio that my partner needs to have it at.	5	4	3	2	1	☐

(Please tick the box for the following questions)

18. To what extent are you involved in hobbies and/or recreational activities?

Very Involved	Quite Involved	Moderate Involvement	Somewhat Involved	Never
☐	☐	☐	☐	☐

19. In general, to what extent does your partner's hearing loss alter these activities?

Great Extent	To quite an extent	To a moderate extent	To a small extent	No extent
☐	☐	☐	☐	☐

20. How often do you feel that your partner is a burden?

Very often	Quite often	Sometimes	Seldom	Never
☐	☐	☐	☐	☐

21. About how long would you say it took your partner to adjust to their CI?

No time	Hardly any time	Moderate time	Quite some time	A very long time
☐	☐	☐	☐	☐

22. About how long did it take you to adjust to your partner wearing their CI?

No time	Hardly any time	Moderate time	Quite some time	A very long time
☐	☐	☐	☐	☐

23. How difficult was this adjustment to you?

Not difficult	Somewhat difficult	Moderately difficult	Quite difficult	Extremely difficult
☐	☐	☐	☐	☐

24. How much change have you noticed in your partner's emotional state since their CI?

No changes	Some changes	Moderate changes	Quite a few changes	Many changes	N/A
☐	☐	☐	☐	☐	☐

25. Would you rate this change (if any) as positive or negative?

Very positive	Somewhat positive	Neutral	Somewhat negative	Very negative	N/A
☐	☐	☐	☐	☐	☐

26. In general, how has the implant affected your own quality of life?

Very positive	Somewhat positive	Neutral	Somewhat negative	Very negative	N/A
☐	☐	☐	☐	☐	☐

Satisfaction with Cochlear Implant (CI)

27. How much improvement has there been in your life since your partner got their CI?

If you did not know your partner before they had their CI please tick ☐ and ignore this section.

(Please circle your response or tick N/A)	A Lot	Moderate amount	A Little	Very Little	Not at all	N/A
Attending a Restaurant	5	4	3	2	1	☐
Dinner at home	5	4	3	2	1	☐
Using public transport	5	4	3	2	1	☐
Cinema	5	4	3	2	1	☐
Concert	5	4	3	2	1	☐
Driving a car	5	4	3	2	1	☐
As a passenger in a car	5	4	3	2	1	☐
Family conversations	5	4	3	2	1	☐
Small group conversations	5	4	3	2	1	☐
Meetings (e.g. work or community)	5	4	3	2	1	☐
Shopping	5	4	3	2	1	☐
Social gatherings (e.g. party, BBQ)	5	4	3	2	1	☐
Church	5	4	3	2	1	☐
TV	5	4	3	2	1	☐
Radio	5	4	3	2	1	☐
Telephone	5	4	3	2	1	☐

Please continue on the next page

28. In your opinion, how much has the CI affected your partner's life?

(Please circle your response or tick N/A)	A Lot	A moderate amount	A Little	Very Little	Not at all	N/A
Increased communication with others	5	4	3	2	1	☐
Increased connectedness with the world	5	4	3	2	1	☐
Decreased negative emotional stage (e.g. depression, anxiety)	5	4	3	2	1	☐
Increased feelings that they are contributing to society	5	4	3	2	1	☐
Improved family relationships	5	4	3	2	1	☐
Forming new relationships	5	4	3	2	1	☐
Increased independence	5	4	3	2	1	☐
Increased interpersonal skills	5	4	3	2	1	☐
Decreased isolation/feelings of loneliness	5	4	3	2	1	☐
Increased personal safety	5	4	3	2	1	☐
Improved self esteem	5	4	3	2	1	☐
Standing up for themselves	5	4	3	2	1	☐

29. Do you have any other comments?

____

____

____

____

____

Thank you for taking the time to complete this questionnaire.

QUESTIONNAIRE FOR SIGNIFICANT OTHER OF HEARING IMPAIRED PARTNER ON THE WAITING LIST FOR A COCHLEAR IMPLANT, OR PRE-COCHLEAR IMPLANT

Please note that CI stands for Cochlear Implant

The following questions should be answered by the significant other, (e.g. husband/wife, parent, sibling, partner etc.), of a hearing impaired person on the waiting list for a CI, or who are about to receive a CI. Please do not consult your significant other for their opinion, as I am interested in obtaining your perspective.

What is your age? __________ Are you: ☐ Male ☐ Female

What is your relationship to the hearing impaired person? (Please tick)

Wife ☐ Husband ☐ Partner ☐ Sibling ☐ Parent ☐ Other________

*** For the purpose of this questionnaire, the term “my partner” has been used to represent the hearing impaired person, regardless of your relationship to them.**

	(Please circle your response or tick not applicable (N/A) if you believe the question does not apply)	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	N/A
1.	I have had to make adjustments at work because of my partner’s hearing impairment (e.g. having to take time off).	5	4	3	2	1	☐
2.	My partner’s hearing impairment has caused financial implications.	5	4	3	2	1	☐
3.	Having a hearing impaired partner means my social life suffers.	5	4	3	2	1	☐
4.	I feel embarrassed about my partner’s hearing impairment.	5	4	3	2	1	☐
5.	At times I get annoyed at having to repeat myself because my partner did not hear me.	5	4	3	2	1	☐
6.	I find that my partner’s hearing impairment stops them from socialising.	5	4	3	2	1	☐
7.	I hesitate to meet new people because my partner has a hearing impairment.	5	4	3	2	1	☐
8.	I cannot talk to my partner in a noisy environment.	5	4	3	2	1	☐
9.	I feel that having a partner with a hearing impairment has increased the stress in my life.	5	4	3	2	1	☐
10.	I feel that our relationship is affected negatively by my partner’s hearing impairment.	5	4	3	2	1	☐
11.	I cannot talk to my partner in a quiet environment.	5	4	3	2	1	☐
12.	I worry about the safety of my partner because of their hearing impairment.	5	4	3	2	1	☐
13.	My partner’s hearing loss has impacted negatively on others in our immediate family.	5	4	3	2	1	☐

Please continue on the next page

(Please circle your response or tick not applicable (N/A) if you believe the question does not apply)

		Never	Rarely	Sometimes	Often	All the time	N/A
14.	I feel strained in my interactions with my partner.	5	4	3	2	1	☐
15.	At times I get annoyed with my partner even though he/she has a hearing impairment.	5	4	3	2	1	☐
16.	I leave my partner out of conversations.	5	4	3	2	1	☐
17.	I am bothered by the volume of the TV/radio that my partner needs to have it at in order to hear.	5	4	3	2	1	☐

(Please tick the box for the following questions)

18. To what extent are you involved in hobbies and/or recreational activities?

Very Involved	Quite Involved	Moderate Involvement	Somewhat Involved	Never
☐	☐	☐	☐	☐

19. In general, to what extent does your partner’s hearing loss alter these activities?

Great Extent	To quite and extent	To a moderate extent	To a small extent	No extent
☐	☐	☐	☐	☐

20. How often do you feel that your partner is a burden?

Very often	Quite often	Sometimes	Seldom	Never
☐	☐	☐	☐	☐

21. To get an idea of your expectations for when your partner receives their CI, list areas in which you are hoping that the CI will provide benefit in:

____

____

____

22. What areas (if any) do you think that the CI may not provide any benefit?

____

____

____

23. Do you have any concerns in regards to your partner's future CI?

24. What impact do you think the CI will have on both you & your partner's life?

25. Do you think that the CI will change anything about the relationship you currently have with your partner? Yes/No. If Yes, please detail.

26. Do you have any other comments?

Thank you for taking the time to complete this questionnaire.

PARENTS/CAREGIVERS VIEWS AND EXPERIENCES

(Please note that CI stands for Cochlear Implant)

1.	Are you the child's?	☐ Parent	☐ Caregiver	☐ Other
2.	How old is your child? ___________			
3.	Is your child	☐ Male	☐ Female	
4.	How old was your child when his/her hearing loss was first identified?	__________		
5.	What is the cause of your child's hearing loss (if known)?			
	☐ Congenital (at birth) ☐ Meningitis ☐ Illness ☐ Unknown ☐ Other __________			
6.	How old was your child when they had their CI?	__________		
7.	Does your child have a second (bilateral) implant?	☐ Yes	☐ No	
8.	If yes, how old was your child when they had their second CI?	__________		
9.	If no, does your child wear a hearing aid in the un-implanted ear?	☐ Yes or nearly all the time	☐ Yes Some situations only	☐ No
10.	Does your child have any additional impairments/disabilities?	☐ Yes	☐ No	

If yes, please detail: ____

Which of the following best describes your child's current educational setting?

☐ Early Intervention
☐ Regular preschool, fully mainstreamed
☐ Regular preschool, partially mainstreamed
☐ Special Education Program for deaf children in a regular preschool
☐ Special Education Program for deaf children in a special preschool
☐ Regular school, fully mainstreamed
☐ Regular school, fully mainstreamed with a visiting teacher of the deaf
☐ Regular school, partially mainstreamed
☐ Special Education Program for deaf children in a regular school
☐ Special Education Program for deaf children in a special school
☐ Not at school/preschool
☐ Other (please specify) _______________

Before your child had their CI(s) what **main mode** of communication did you use?

☐ Signing/gesture ☐ Spoken language Other ____________

Please answer the following questions based this method of communication

Thinking about how your child was before they got their CI(s):

(Please tick the relevant box)

		Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A
11.	Communication was difficult even with people he/she new well.	☐	☐	☐	☐	☐	☐
12.	Before implantation his/her ability to communicate was poor.	☐	☐	☐	☐	☐	☐
13.	The help I gave my child before their CI was not productive because of his/her hearing difficulties.	☐	☐	☐	☐	☐	☐
14.	He/she obtained no benefits from his/her hearing aids.	☐	☐	☐	☐	☐	☐
15.	My child did not have a close relationship with his/her grandparents.	☐	☐	☐	☐	☐	☐
16.	My child was not aware when I wanted their attention because he/she could not hear me when I called out to them.	☐	☐	☐	☐	☐	☐
17.	I could rarely leave my child to do something on their own.	☐	☐	☐	☐	☐	☐
18.	His/her quality of speech concerned me.	☐	☐	☐	☐	☐	☐
19.	He/she was socially isolated.	☐	☐	☐	☐	☐	☐
20.	He/she lacked confidence because of his/her hearing loss.	☐	☐	☐	☐	☐	☐
21.	He/she amused him/herself by listening to music, watching, TV or playing games.	☐	☐	☐	☐	☐	☐
22.	He/she did not make new friends easily.	☐	☐	☐	☐	☐	☐
23.	He/she was sociable within the family.	☐	☐	☐	☐	☐	☐
24.	He/she shared in family situations.	☐	☐	☐	☐	☐	☐
25.	I did not let him/her play outside because I was concerned he/she could not hear traffic.	☐	☐	☐	☐	☐	☐
26.	He/she was unable to cope in new situations.	☐	☐	☐	☐	☐	☐
27.	I worried about my child’s future prospects (e.g. educational and employment opportunities).	☐	☐	☐	☐	☐	☐
28.	I sometimes got frustrated because of my child’s hearing impairment.	☐	☐	☐	☐	☐	☐

29.	He/she was a happy child and was fun to be with.	☐	☐	☐	☐	☐	☐
30.	He/she was talkative (i.e. communicative) and engaged in conversations.	☐	☐	☐	☐	☐	☐
31.	My child got frustrated because of his/her hearing difficulties.	☐	☐	☐	☐	☐	☐

Thinking about your child now since they have had their CI(s):

What main mode of communication do you now use with your child?

☐ Signing/gesture ***☐ Spoken language*** ***Other ________***

		Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A
32.	Communication is still difficult even with people he/she knows well.	☐	☐	☐	☐	☐	☐
33.	Since their CI, my child's communication has improved.	☐	☐	☐	☐	☐	☐
34.	The help I give my child is more productive since he/she has been implanted.	☐	☐	☐	☐	☐	☐
35.	She/he is now totally reliant on their implant.	☐	☐	☐	☐	☐	☐
36.	Since implantation he/she has a closer relationship their grandparents.	☐	☐	☐	☐	☐	☐
37.	My child is now more aware that I want his/her attention because he/she can hear me with the CI.	☐	☐	☐	☐	☐	☐
38.	He/she is now able to cope with mainstream schooling.	☐	☐	☐	☐	☐	☐
39.	Since my child's CI, I can often leave him/her to do something on their own.	☐	☐	☐	☐	☐	☐
40.	His/her quality of speech still concerns me.	☐	☐	☐	☐	☐	☐
41.	He/she is keeping up well with children of his/her own age at school.	☐	☐	☐	☐	☐	☐
42.	We can now chat even when she/he cannot see my face (for example in the car).	☐	☐	☐	☐	☐	☐
43.	Since their CI he/she is socially isolated.	☐	☐	☐	☐	☐	☐
44.	Since implantation he/she lacks confidence.	☐	☐	☐	☐	☐	☐
45.	He/she amuses him/herself by listening to music, watching TV, or playing games.	☐	☐	☐	☐	☐	☐

46.	Since implantation, he/she has made new friends.	☐	☐	☐	☐	☐	☐
47.	Since he/she got her CI, he/she is more sociable within the family.	☐	☐	☐	☐	☐	☐
48.	Since getting her CI he/she shares more in family	☐	☐	☐	☐	☐	☐
49.	Since he/she had her CI, I now let him/her play outside.	☐	☐	☐	☐	☐	☐
50.	He/she is able to cope better in new situations.	☐	☐	☐	☐	☐	☐
51.	Since implantation I still worry about his/her future (e.g. educational and employment opportunities).	☐	☐	☐	☐	☐	☐
52.	Since he/she got his/her CI, I sometimes get frustrated.	☐	☐	☐	☐	☐	☐
53.	Since their CI he/she is happier and more fun to be with.	☐	☐	☐	☐	☐	☐
54.	Since his/her CI he/she is more talkative and engages in conversation.	☐	☐	☐	☐	☐	☐
55.	He/she still shows signs of frustration in his/her behaviour.	☐	☐	☐	☐	☐	☐
56.	His/her behaviour has improved since implantation.	☐	☐	☐	☐	☐	☐
57.	His/her use of spoken language has developed greatly.	☐	☐	☐	☐	☐	☐

	Since your child has had their CI(s) how much has it affected YOUR life?	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A
58.	Since implantation, my child has needed more time and help from me, which leaves me less time for myself.	☐	☐	☐	☐	☐	☐
59.	I get more time to myself because of his/her increased independence.	☐	☐	☐	☐	☐	☐
60.	I am happy with his/her progress at school.	☐	☐	☐	☐	☐	☐
61.	The whole process is still stressful.	☐	☐	☐	☐	☐	☐

		Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly disagree	N/A
62.	I worry ultimately that she/he may neither be part of the deaf world, nor the hearing world.	☐	☐	☐	☐	☐	☐
63.	I feel more confident since my child's implant.	☐	☐	☐	☐	☐	☐
64.	Other children in the family resented the time and attention taken up by the implant. (Tick ☐ if no other children).	☐	☐	☐	☐	☐	☐
65.	His/her relationship with brothers and sisters has improved (Tick here ☐ if no other children).	☐	☐	☐	☐	☐	☐
66.	Overall family relations have improved since the CI.	☐	☐	☐	☐	☐	☐
67.	I am much happier with my life since my child got their CI.	☐	☐	☐	☐	☐	☐

Satisfaction with CI

68. How would you rate the quality of the results your child has obtained with their CI(s)? (Circle one number only)

Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
5	4	3	2	1

69. Did you get the results you wanted /expected?

Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
5	4	3	2	1

70. To what extent has the CI met your child's communication needs?

All needs Met	Most needs met	Some needs met	Only a few needs met	No needs met
5	4	3	2	1

71. In an overall, general sense, how satisfied are you with your child's CI(s)?

Very Satisfied	Satisfied	Neutral	Dissatisfied	Very Dissatisfied
5	4	3	2	1

If your child has had a second (bilateral) implant please answer the following questions, if not please go to question 75

72. Have you noticed any difference between the first and second CI?

YES ☐ NO ☐

If yes, please detail: ____________________

____

____

____

73. Do you notice any difference for the following daily tasks?

(Please tick one box only)	Yes	No	Unsure
Localising sound	☐	☐	☐
Listening to music	☐	☐	☐
Speech in noise	☐	☐	☐
Hearing their name called from another room	☐	☐	☐
Identifying the speaker	☐	☐	☐
Watching TV	☐	☐	☐
Hearing environmental/everyday sounds	☐	☐	☐
School performance	☐	☐	☐
General sound awareness	☐	☐	☐
Other:	☐	☐	☐

74. Would you recommend a second CI to others?

YES ☐ NO ☐

Comment: ____________________

____

____

75. Do you have any other comments? ____________________

____

____

____

Thank you for taking the time to complete this questionnaire.

Appendix 2

CISQ Harsymczuk & Deane, (2007)

COCHLEAR IMPLANT SATISFACTION

1. How **satisfied** are you with your cochlear implant for <u>each</u> of the following activities in your life ?
   (Circle the appropriate number <u>for each activity</u> – if you do not participate in any of the activities please leave the row blank)

	A lot	A moderate amount	A little	Not at all
Attending a Restaurant	1	2	3	4
Catching public transport	1	2	3	4
Cinema	1	2	3	4
Concert	1	2	3	4
Driving a car or as a passenger in a car	1	2	3	4
Family conversation	1	2	3	4
Small groups	1	2	3	4
Listening to music	1	2	3	4
Meeting or gathering (e.g. Church)	1	2	3	4
Shopping	1	2	3	4
Social situations	1	2	3	4
TV	1	2	3	4
Radio	1	2	3	4
Telephone	1	2	3	4
Work	1	2	3	4

2. How **satisfied** are you with your cochlear implant improving the following areas of your life ?
   (Circle the appropriate number <u>for each area</u> – if you do not believe any of the areas apply to you please leave the row blank)

	A lot	A moderate amount	A little	Not at all
Increased communication with others	1	2	3	4
Increased connectedness with the world	1	2	3	4
Decreased negative emotional state (e.g. Depression, Anxiety)	1	2	3	4
Increased feelings you are contributing to society	1	2	3	4
Improved family relationships	1	2	3	4
Forming new relationships	1	2	3	4
Increased independence	1	2	3	4
Increased interpersonal skills	1	2	3	4
Decreased isolation	1	2	3	4
Increased personal safety	1	2	3	4
Improved self-esteem	1	2	3	4
Standing up for yourself	1	2	3	4

3. With regard to your cochlear implant, how satisfied are you with the quality of service provided by your chosen practitioner ?
   (Tick one box only)

Very satisfied	Satisfied	Dissatisfied	Very Dissatisfied
☐	☐	☐	☐
4	3	2	1

4. How would you rate the quality of the results you obtained with the cochlear implant ?

Excellent	Good	Fair	Poor
☐	☐	☐	☐
4	3	2	1

5. Did you get the results you wanted ?

No, definitely not	No, I don’t think so	Yes, I think so	Yes, definitely
☐	☐	☐	☐
1	2	3	4

6. To what extent has the cochlear implant met your needs ?

Almost all of my needs have been	Most of my needs have been met	Only a few of my needs have been met	None of my needs have been met
☐	☐	☐	☐
4	3	2	1

7. If a friend were in need of a similar procedure would you recommend a cochlear implant to them ?

No, definitely not	No, I don’t think so	Yes, I think so	Yes, definitely
☐	☐	☐	☐
1	2	3	4

8. In an overall, general sense, how satisfied are you with your cochlear implant ?

Quite dissatisfied	Indifferent or mildly	Mostly Satisfied	Very satisfied
☐	☐	☐	☐
1	2	3	4

Thank you for taking the time to complete this questionnaire !

Appendix 3
Summary of Results

CI recipients’ comments in answer to all qualitative questions are as follows:

Q67 In what areas (if any) has the CI met your needs and expectations? (Please list)

Participant #

2 General communication. Use of telephone. Great success in most circumstances.
9 Able to do volunteer work for the Salvation Army. Communication on one to one basis. I venture out more often.
10 Music is great. After 2 months I am able to hear more than before CI but hoping for improvement in months to come.
11 Communication with others. Telephone, TV radio. Self-confidence. Allowed me to move up the ladder with my job.
13 Without my CI I’d have no hearing. I can function quite normally in most situations.
14 Able to talk with my mother on the phone. The CI has exceeded my expectations.
16 I can hear basically. Has enhanced my lip reading.
18 Able to enjoy relationships with family and friends. Was quite withdrawn before my CI and avoided meeting people. Doesn’t happen now. Can hear birds for the first time.
20 Communication with my wife, family and friends. Being able to use the phone on most occasions. Being able to hear music with the right headphones. Hearing natural sounds i.e. birds, etc. Feel more secure.
21 Outside hearing birds. Hearing microwave.
23 Being able to hear so many sounds in general. I really don’t feel like a deaf person. Thank you CI.
24 Work, telephone, having a conversation in the dark with my husband. Hearing birds, wind, rain. Having a conversation in a coffee group - now fantastic.
27 All met.
30 On a personal level and ability to cope with everyday life.
32 Independence, confidence, ability to use telephone, hearing in business and other meetings. Ability to have a conversation in the dark.
35 Music. Conversation in small groups. Employment. Hearing grandchildren. Environmental noise. Less stress and fatigue. New contacts. Alarm and warning sirens.
38 Some improved communication one on one.
39 Can hear phone, birds, different high frequencies.
40 Increased my confidence when communicating with others.
42 I function almost normally as a hearing person, however we learn to cover and adapt to our disability. Without the CI I probably would have shot myself by now! However I understand and accept the limitations of a CI.
43 Communication, using telephone etc.
44 To be able to hear the birds.
45 At the moment my CI is not worth the time and effort put into it. I am trying to stay positive and hope there will be a massive improvement in the very near future.
49 Speech has improved. More confidence. Go out more. Can hear microwave and dishwasher, wind and birds.
53 Communication with others. Confidence, joy of hearing, even the tick tock of the clock.

54 Conversation both groups and individual. Music, telephone, my confidence levels, household sounds.

55 Independent communication with hearing people without having to lip read. Able to use the phone, watch TV, see movies, work as NZ sign language communicator.

56 I am NZ first implantee. Belong to many clubs. Enjoy theatre and have taken up re-learning the piano.

58 Conversation with friends and family. Ability to have simple conversation on phone. Can hear the birds. Feel more alive.

60 Huge transformation after being fully deaf for 14 years. At 6 months post switch-on could understand 96% speech in quiet without lipreading.

61 Family talking, has opened a whole new world of sound, every day sounds, birds.

62 I can hear something. I could not before.

63 The list is endless. There is no area where there has not been an improvement.

65 One on one conversation, environmental sounds, has enabled me to work.

66 General communication. Music. Birds singing. Water running. Electric jug boiling.

68 Had no real expectations (not encouraged to raise hopes) connecting to people is the biggest plus.

76 Able to hear speakers at meetings. Able to hear telephone. Able to communicate with others.

77 Bigger awareness of sounds. Greater appreciation of environmental sounds and some musical instruments.

78 Can hear cat purr. My hearing is getting better. Can understand instructions better. Am able to understand TV more without subtitles. Enjoy music and though I like singing I'm still out of tune.

80 Able to communicate.

81 Able to hear better, conversation, telephone etc.

82 Sound awareness. Mentally stimulating. Feelings of isolation and impotence greatly reduced.

83 Speech understanding is fantastic, ability to use phone great. Increased communication with all family and friends. More involved in home, work, family life, environmental sounds, more relaxed communication with my husband.

84 Communication and loss of isolation.

85 When you cannot hear, a little is a lot. This covers everything.

87 Self-confidence. Able to hear family especially grandchildren speak and sing. Great support from CI follow-ups. Learning to play the ukulele.

90 Allowed me to return to work, answer phone and communication.

91 My confidence has continued to improve with everyday use of the phone and listening to music. I believe I hear better now than even when I was HOH.

93 Communication - wonderful. Music - catching up, DVDs - great if subtitled,
Phone - NZ relay service if required.

96 HAs used to hurt with certain sounds. A CI hardly ever does. Can now hear cicadas, sirens, whispers, beeps, telephone conversations.

97 Socially, work, family, environmental sounds, TV, radio, music, listening to other peoples conversations when they think I don't hear.

99 General everyday living. Talking and hearing a 6 year old read.

100 All.

101 Speech, communication, social, wellbeing.

102 Easier to talk to family friends and others.

106 Confidence, self esteem, communication, social.

111 To be able to hear sounds again.

113 Conversations, music, TV, telephone. It’s been fabulous. I just act like a person with normal hearing in all situations. Only occasionally I am reminded that I’m not normal. Huge benefit in talking to friends and family.
114 The best thing ever happened to me with everything life is great.
121 Family, friends, radio, TV everything.
122 Beyond my wildest dreams.
123 Communication. Telephone. Environmental.
124 Better general communication with family and friends. Better on phone and good at work.
128 I went in with very low expectations so I wouldn’t be disappointed. I’m very surprised what I can hear. Sometimes think I’m still trying to work out what the sound is.
129 One to one conversation with family. Able to conduct simple phone conversation. Able to follow TV and hear music I am familiar with.
130 Most areas.
131 All met.
135 Allows me to live life normally. Aesthetically pleasing (discreet).
139 Less frustration and being able to communication with people in general.
141 Telephone, family conversations, small things hearing people take for granted e.g. car indicators, birds, sirens.
142 Improvements in conversation with up to 3 people.
143 Communication. TV.
144 Communication and retain practice certificate.
145 Hearing small but distinct sounds such as texting on mobile phone.
146 Personal life family life, attending concerts, movies, going dancing, social events with friends and family. Help children with homework and have their friends over. Assist elderly parents. General contribution and interaction with society and life.
148 All met.
149 Using the phone and having a conversation. Washing machine/ dryer/ microwave/ being able to hear person from another room.
154 Communication. Listening to grandchildren. Hearing sounds I haven’t for 30 years (birds).
163 Better discrimination with soft speech. However do feel somewhat negative as never know if what I’ve heard is just what was said. Possibly confuse what I thought I’d heard over what was actually heard. Better able to pick up speech in music but not a great extent.
164 Communication, self-esteem and confidence, work, independence.

Q68 In what areas (if any) has your CI not met your needs or expectations?

2 Music sometimes sounds unnatural.
9 TV, Radio, Music, Telephone - but improving as time goes by.
10 Speech not loud enough, but environmental sounds are at right level.
13 Deep male voices are difficult. Music is terrible. Background noise too much. Conversations with more than 2 or 3 people too much.
14 Still need to work on certain sounds and need to practice more on phone.
16 Phones, Music, Confidence, ability to communicate.
18 Music. Still not enjoyable but improving. Still have difficulty with fast speech and background noise.
20 Music - would love to hear without using head phones. Telephones are a challenge. Children’s voices are difficult. Background noise.
21 Hard to hear people talk.

23 The weight of Nucleus freedom, hook dents ear and is sore.

30 Perfection of speech, hearing and telephone. Communication which hampers moving forward.

32 Two main areas - difficulty in noisy situations. Some cell phones.

35 Improved communication with partner, but brought out other problems in relationship masked by deafness. Still struggle with background noise and directional hearing. T-switch great but design makes it hard to manage. RSI in left thumb b/c of switching back and forwards in meetings. Remote would solve prob.

38 Group situations. Background noise.

39 Struggle with voice, not clear at all.

40 In all honesty I had very low expectations due to my circumstances, as not to have my hopes up too high. This has far exceeded my expectations and reality.

42 Telephone, listen and follow music and follow more dialogue. But maybe these are wants more than needs.

43 Still problems with wind noise, when cycling or being outside in the wind. Can’t drive car with window down or sunroof open and hear passengers’ conversation.

44 Still have poor listening skills. Prefer to lip read. Still can’t use the phone.

45 If I don’t wear a HA in the other ear to rely on my CI would be very poor.
This is my second implant as first one was removed.

49 Background noise. Clock ticking drives me mad!

53 Quality of speech from radio and TV. Seldom go to movies as not able to hear clearly. Telephone is impossible.

55 Processor is clumsy, heavy, and awkward to use. Also could be better in terms of sound quality given technology available.

56 Telephone.

58 Unable to follow group conversations. Unable to hear TV without subtitles. Unable to follow dialogue in cinema, music, concerts, live shows.

62 Group, strangers, crowds and background noise.

65 No music appreciation. Telephone continues to be difficult. Groups and meetings difficult.

66 Telephone - difficulties when seeking work. Developed tinnitus, resulting in lack of sleep subsequent memory loss. Now on drug for Alzheimer’s.

68 Music, TV, background noise.

76 Music, but improving as time goes on. Difficulty in background noise.

77 Taken longer to get used to phone. Some music appreciation e.g. miss hearing bass sounds.

78 Baby screaming. Switch my processor off while shopping because of noisy children. Also switch off at bus stop as traffic is too loud.

80 Group conversations, telephone, movies, TV, radio, music, background noise, ability to filter out unwanted noises.

84 Radio and music sometimes phone.

85 Don’t like taking it off.

89 Telephone.

90 Music, radio.

93 Hearing through microphones. Will get t-switch on upgrade so can use loop system.

96 Cannot hear phone ringing if in laundry and background noise. Hearing in car still hard. Would like to wear at night if grandson staying but falls off. Need to have it turned off for half an hour each day to rest. Doorbell still hard to hear.

97 Sometimes have difficulty on the phone. People still consider me deaf and start mouthing, one friend still shout at me despite me telling her not to.

101 Music, background noise.

102 Groups and restaurants hard to understand.
103 Telephone.
104 Not meet for music, radio, concerts.
111 Not being able to hear the radio or use the phone
113 Groups, background noise. Airport announcements tricky.
123 Noisy environments.
124 Background noise, group conversations.
129 Music.
130 Audio Sound.
135 Wish I could swim with it on!
139 Telephone.
141 Music and talking to people with accents.
142 No improvement with TV without sub-titles. Difficulties hearing people from behind.
143 Not able to drive. Group situations.
144 Still difficulty with TV at times.
145 Very poor sound quality. I could hear better with my HAs, also could use the phone with my HA now with CI I can hardly use it at all.
146 Fell off during a game of netball and football. If I had a negative it would be that it’s a little large.
148 Telephone.
149 None but still only very early.
154 Has met all expectations the DVD led me to believe it would not be this good and is getting better all the time.
156 Telephone, TV, radio - but improving.
160 Music, telephone, background noise.
163 Music. Increased isolation in social environment in bars and clubs. Less able to focus on work - confusion over received sounds/speech/words.

Q71 Other comments?

10 Q would be more effective if I was asked in a few more months when my hearing is better.
11 my CI is the best thing that has happened to me. It has improved my QOL.
13 I have utmost praise for the people and SCIP-A. They do a wonderful job.
14 Thanks to Darran Murray and SCIP-A.
16 Because only have CI in one side sound dangerous in work place and traffic. Great difficulty in places such as bus, trains, airports.
18 Went backwards in hearing after death of husband. With help of the SCIP-A have improved and regained my confidence. Continue to improve. Am grateful having had a CI.
20 I feel very fortunate that I can hear very well most of the time. The CI has made an enormous difference. I know I still have work to do and I know that it will only get better. Would recommend it to anyone considering a CI to go for it, have a positive attitude it will work for you.
21 Shorter time between mapping.
24 At the end of the day I’m still a deaf person with the help of an aid. It’s helped enormously in my life but I still get the odd time I don’t hear but so do hearing people. I am still so deaf when I take my CI so I am grateful when I put it on and can hear my son - its wonderful. I still feel that deaf people need to understand that a CI is not a quick fix you still have some problems with background noise but that is just everyday life, it never goes away but how we

manage it contributes how you can hear better. That has to be stipulated before a CI is fitted. But it does give you so much more freedom and confidence. I am so thankful for this chance.

27 A CI has given back my life. I call my CI my precious. I have strived to get back all I lost when my hearing went.

30 I continually give thanks for my CI. Made a mistake on first mapping which resulted in too high a setting. Three days on from a new setting I feel I hear male voice much better and hope to move forward further still.

32 The CI has been a totally liberating experience for me. I think part of that is down to how SCIP-A does it's work. Not sure if the Northern programme is successful?

35 Immediate improvement with CI, but some things have taken time e.g. music required persistence and determination. Had been deaf 25 years before CI but still got excellent results. Still improving all the time.

38 When I have my testing done at the SCIP I score at the top of the scale. In the real outside world only function at 50% these contradictions are very frustrating.

39 I am improving but being realistic and know that it will take time.

40 Receiving a CI has changed my life and made me explore myself as a person. Yet at the end of the day I am still deaf - having a CI has enhanced who I am and what I am as a person. Wonderful thanks to those at SCIP-A priceless!

42 The CI was a life saver for me. I couldn't cope without it. Sure there are limitations and frustrations, but the benefits outweigh any negatives. I also look forward to an upgrade in the near future, which of course depends on funding.

43 My only regret is that I can't afford to go bilateral. If I was offered one for my other ear I would take it in a heartbeat.

45 Without the good work of the staff at SCIP and my wife's perseverance I would've sent my CI back. I'm hoping there will be major improvements in the near future as I'm told and perhaps feel that things can only improve in time.

49 Staff of SCIP-A were very good, I was treated like a new person. Felt good going to clinics.

53 Would wish to hear clearly when using telephone, watching TV/Movies & radio. Would love to be able to listen to music.

54 Having a CI has changed my life. It has made everything so much easier to cope with. Being able to hear my children and my husband, I really feel like part of the family again. Experiencing music, cinema, concerts etc. participating fully in conversation with friends is life enhanced.

55 One effect of the CI was that when I came ill e.g. manic I could not longer process spoken English and had to return to NZSL and take processor off. As I had been working as a NZSL communicator for 6 years this was devastating. CI programme needs to be open to NZSL and CI together. Stats show implantees who use them both have the most success.

56 While I would always recommend a friend seeking advice on a CI. I should emphasise the guidance of medical specialists and audiologists. I also stress the need for re-habilitation.

58 There are activities I can't indulge in e.g. cinema, music. But the CI has nonetheless made a dramatic and positive difference in my life. I have no regrets and wouldn't be without it.

59 Only been switched on for 2 months. There seems to be so much going on in the world, that until you receive a CI, you don't know how much you are missing out on. Emotional and mind-blowing experience. Nice to hear my family again and my grandson for the first time.

60 Government funding is crucial. As even if they had the money it is unknown how their life will change. Integrates individuals into society. Thank you.

61 It has changed my life for the better. I am a much happier person now.

65 Although some areas are still difficult, I'd be lost without my CI it's given me back a QOL I didn't have before.

66 Being able to hear again is just so precious!

70 I have had difficult personal matters, at times I just switch off for peace of mind. But don’t get me wrong, I find the CI is the best thing I’ve ever had in my life, can’t be without it.

76 Relief of not having to wear HAs. No sore ears or infections. Pleasure in hearing birds and rain is marvelous.

77 Wearing HA in other ear gives better balance of sound.

82 X describes her recent exposure to the world of hearing as “eyes wide, almost like joyful”

83 Has been hugely successful and exceeded my expectations. The support from staff at SCIP-A has been a vital part of rehabilitation, it would have been more difficult without it.

85 Some of the comments are rated lower because only have CI in one ear. So can’t hear on other side. Remade my life thank you.

87 It is a marvelous piece of equipment that has huge benefits for those who are not born deaf. For children especially who are born deaf and can learn with a CI from the age of 3 on.

91 That cochlear continue to provide a wonderful implant with continued improvements.

93 If I didn’t have my CI I could not cope at all. With my CI I am like a hearing person but I can turn off noisy situations. At least I can turn them off. If its noisy at night I can sleep and they can’t.

96 I could not hear sirens, car indicators etc so was a danger driving before I got my CI. Can hear everything now. Keep implanting old people as they are much more lonely than anyone else. They need the comfort of using a telephone and safety for hearing alarms, etc. They can’t learn (or see well) to lip read. They need the safety of hearing cars back out or coming closer to them.

97 I have just received an upgrade to Freedom processor. It’s like being switched on again. Can hear so much more.

99 I am very grateful to be given my hearing back to me in my retiring years. Thank you.

100 Hate to turn off my CI as I am deaf. Very happy with most things, but wish my processor could be updated every 3-4 years.

101 It would be nice to listen to music as I used to.

104 retired a few years before CI. Deal mainly with family, friends in small groups and one to one situations. Have been ill with heart problems. Very thankful to be able to communicate with specialists in hospital.

113 I think I am quite privileged. I have taken to it like a duck to water. I pretty much do everything I used to do before I went deaf. I set myself high standards and given it 110%. Noisy situations are the only time I don’t hear excellently and even then I hear much better than what I did before the CI. I’m over the moon with it only after 9 months!

114 The best thing I love it.

121 Have had an incredible time listening to all the sounds heard many years ago. Amazing to be part of the hearing world. Would not be without my CI, even loud noises are welcome.

122 Would like another one on the other side.

128 I’m very happy with my CI and grateful to the staff for all their help to make it happen.

129 I am personally thrilled to be where I am in life as opposed to pre-CI.

130 CI is wonderful.

131 The CI has changed my whole life for the good. My only wish is that I’d had it some years ago as it would have saved a lot of stress.

139 Just the telephone. When I am out walking passing noisy cars and trucks is still an issue.

141 Best thing that’s ever happened to me. Wouldn’t be without it, it’s nice to be able to laugh again.

143 Would not like to be without it.

144 The CI has changed my life. Given back self-confidence and I now feel I can tackle any obstacle. Without it I would stay at home and be very isolated.

145 I think most CI users gain a lot from their CI and I guess I am one of the unlucky ones that have not gained any improvement. I coped much better with HAs.

146 It’s the most amazing thing to have happened to me. I was scared of having the operation but not a scared as losing my husband and children which I would have done if I remained deaf (not physically but emotionally). I literally got my life back!

148 To have another CI for my other ear would be great.

149 My hearing disability hasn’t stopped me from doing anything previously. Am hoping for further improvements relating to TV/radio/phone.

161 It has given me my life back.

163 Bilateral is the way to be - God gave 2 ears not one. Implant has definitely helped but need to feel complete I’m just a half person which contributes to increased isolation.

164 I truly life-changing procedure. I shudder to think where I’d be without it.

Appendix 4
Summary of Results

WL participants' comments in answer to all qualitative questions are as follows:

Q61 Expectations for CI

Participant #

171 Communication, hear on phone, hear family, grandson, music, TV.

172 Mainly social, feeling more confident to talk to people knowing that I'm hearing them and not getting the wrong end of the stick because I haven't caught the whole conversation. Leisure activities, to be able to enjoy movies, theatre, music, dining out, holidays.

175 Phone, conversations with more than one person, anything has to better than what I have.

176 Communication. Hear sounds. Hear far away sounds. Pick up more info. Loop system is beautiful. I can hear. Knowledge to learn more. Socialising

178 Hope it would help to communicate with people more.

180 Telephone, social situations, group conversations, speakers at talks, doc, lawyer, business dealings.

181 Relationship, employment. Socialising. General confidence.

182 Be able to participate in group meetings. Speak to anyone on the phone. Hear radio, TV, music. Understand without lip reading.

184 Help stop me being a hermit. Be able to converse with people and stop my wife getting so frustrated.

185 To hear better, to hear people especially from behind.

186 To help understand what people are talking about. Also sounds.

187 Make life easier.

188 I would be hoping for it to be returned to how it was when I was 21.

189 Communication in social, business, personal. TV, theatre, movies, parties, functions, pubs, cafes, jokes. Travel – talking and listening in the car, bus, driving, crossing the road, shopping. Telephone, work. General awareness, hearing people behind me, better speech & volume, getting jokes the first time, and better understanding.

190 Being able to progress further in my career. Being able to listen without lipreading. Being able to hold a phone conversation with friends, family, clients. Being able to participate in group discussions and meetings. Being able to contribute to conversations. Learn to speak another language.

195 Social life, telephone, TV without subtitles, radio, alarms, beeps for new batteries on hearing aids, regain groups I have given up on.

201 Hear my family better also hear better with groups of people. Hear better when talking with a few people in a noisy environment. Hear TV, radio, telephone.

204 Regaining some of the social interaction I enjoyed prior to my hearing loss. Being able to work in chosen profession.

205 Social situation, with more internal conversation, background noise, workplace, meetings, training. Hear on phone again.

206 As I have never met or spoken to anyone with a CI I really can't answer what I would expect.

207 General communication and conversation. Restaurants, TV, music. Hearing children's voices. Attending meetings.

208 Having a conversation on the phone. Hear music and TV on a low setting.

210 Everything - at home, work, sport

211 To hear speeches at weddings, eulogies at funerals, my grandchildren, cars coming from behind, birds singing, stags roaring.

212 Back to controlling a bowling tournament that I have done for 30 years. Help to help other people

214 Hearing in a crowd. Hearing high and low volumes.

216 Telephone, business, marriage and family, community assistance, social and leisure activities.

217 In loud environments like restaurants, bars etc. At work when teaching or in meetings. Watching TV, talking on the phone, talking in the car, listening to music.

219 Communicate with confidence. Understanding what’s being said in meetings and lectures. Being able to travel in car without an interpreter. Being able to understand phone messages.

220 Hear people talking to me. Hear the phone ring. Hear music. Hear birds, children.

221 Living alone presents many hurdles. I look forward to being able to hear music, maybe talk on the phone, be able to have the confidence to speak at functions. I rely on lip-reading. There’s just so much to look forward to.

222 Speech understanding in most situations.

223 Better hearing, no more lip reading and being left out of conversations. I’d feel more relaxed when talking to people for the first time, more likely to be able to make friends. I’d be able to talk to my dad on the phone, be able to watch TV without subtitles, radio, music, do anything a hearing person can do.

227 Clarity, understanding others without lip reading, able to converse on telephone.

228 To follow and take part in conversations. Being able to socialise.

229 General conversation, telephone, crowed rooms, listening and enjoyment of music.

231 Communicate better with family members especially my adult children, also co-workers so as able to follow verbal instructions correctly. To be able to socialise and communicate properly not giving wrong answers. Hopefully be able to hear the birds sing. Most of all to know that life can be meaningful.

232 Work, personal life, social life - everything.

235 Hear on the telephone. Communications with others.

236 Social contact.

238 Make sounds clearer. Pick up speech better and clearer. My speech may improve.

240 Better hearing, better communication.

244 Improved speech recognition.

245 Word discrimination. Being able to hear people who naturally speak fast or soft.

246 Hope to use the telephone, listen to music, gain confidence.

247 Communication, socialising, studying.

250 Even though I’ve read of other people’s reactions when CI is switched on I still don’t know what to expect. I hope my LF hearing will enable me to enjoy music again ad the CI will give clarity to conversations that I don’t have now.

251 Better communication with people. Be able to hear grandchildren. Feel more confident in crowds.

252 Phone, people, TV.

253 A general improvement in QOL. My hearing has got worse over the years and is now non-existent.

254 Hearing music, telephone conversation.

255 Telephone conversations. Dealing with and hearing people.

258 Group situations. Wife and friends. Bird song etc. Control of own voice. Relationships meetings, grandchildren. Coping better in noisy situations, general improvement in communication.
260 Telephone/mobile, better speech, employment chances greater, understanding children better, enjoy movies music, TV.
261 Overall improvement in hearing. Better in groups, meetings and family. Listening to TV and radio.
264 With the CI be more included in group situations, discussions. That the CI will increase my self-confidence. Hoping to get some of my music back too.
265 Being able to have normal discussions with family and friends. Able to take part in social interactions. Return to playing the piano and organ and musical appreciation.
268 Volume and clarity of speech will improve so I can understand and communicate with people better. I want to hear people talking to me!
269 Make social and family situations more comfortable and to be included more, be more confident talking to strangers, give me music, make my life less stressful.
270 telephone, understanding speech with or without lipreading, improve working environment.
272 Would hope to get better quality, clarity and definitions of sound, to enable me to get my self-confidence back.
273 Clarity if my biggest problem - can hear a lot but can’t understand.
274 I look forward to hearing sound, speech, music, telephone, doorbell etc.
276 Hear co-workers better. Hear music, TV, son and everyone else better.
277 Being able to hear speech better would improve my self-confidence. To be able to use the telephone would help my business. I used to love dancing, it would be lovely to do that again.
278 One-to-one situations. Telephone, teaching, meetings, sound of music, attending professional development
280 Be able to communicate better. Not feel so frustrated. Be able to participate in conversations. Feel safer e.g. be able to hear alarms, sirens etc. socially I would be able to hear music, dance, watch TV, use phone to communicate with family overseas etc.
281 Music, telephone, someone knocking on the door, general conversation.

Q62 What areas (if any) do you think the CI might not provide benefit?

171 Hopefully none.
172 Very noisy situations? Telephone? Driving
175 Don’t know.
176 Frightened of loss of residual hearing.
178 Don’t know
180 Listening to music, maybe telephone.
181 None
182 Concert, home theatre, foreign accents, background noise
185 Don’t know.
186 If only one of us has CI it won’t work as both of us need one to have better conversations.
188 None
189 Sleeping or when needing to wearing cap/hat/beanie pulled over my ears and possibly prevent pick up.
195 Can’t think of any.
201 Maybe it won’t provide the Q 61 benefits.

204 Scuba diving and having to listen to drunk people.
205 Excessive background noise.
206 I feel that it’s much too late for me to have a CI. Had I been aware 8 years ago that they were available, I would have eagerly looked forward it.
207 Crowded situations it may be still difficult to carry out conversations.
208 None at this time.
210 I doubt there would be any.
211 From what I have been told I will have near to normal hearing.
216 None at all.
217 Water related activities. Sleeping.
219 I don’t see how improved hearing can’t provide benefit.
220 Don’t know.
221 I’m full of hope that anything will be a bonus.
223 Won’t be able to talk to my partner in bed when it’s dark with my CI turned off.
227 Cutting out of background noise especially in a group of people
228 Can’t think of any.
229 I’m hoping there won’t be any.
231 None, only heard positive results.
232 Hearing children’s voices i.e. grandchildren.
235 Perhaps on telephone.
238 None.
244 Music appreciation
245 Crowded situations.
246 Loud and noisy situations.
250 Music, will it sound too trebly? Being able to hear partner as we get older, will I be able to hear if she calls out especially in an emergency.
252 voice change and speech clear
253 I can’t think of any situations it would not benefit.
258 Music, telephone
260 Noisy environments and having a conversation. Full telephone conversation.
261 Doubt it will help with music and have no expectations of hearing being normal.
264 Appreciating music may not happen for a long time.
265 I don’t know anything about a CI but any improvement would be great.
268 Hopefully none. I am expecting noisy, busy environments to still be a challenge but hopefully not as much as present. I’m not sure how well I’ll hear TV radio, cinema.
269 Don’t think that there will be any areas it does not benefit me in some way.
270 Socialising in background noise, TV, music, radio may not be any clearer.
272 In crowds, parties, BBQ’s, restaurants, hobbies
273 Music
274 Don’t know
277 Possible some sport or leisure activities i.e. swimming or contact sports
278 Background noise, lyrics on a CD
280 None

Q63 Concerns regarding future CI?

171 That it doesn’t work.
172 That there will still be times when my HL will still be frustrating when showering at night and when switched off. My ability to adjust to the new way of hearing.
175 One day at a time.
176 Loss of residual hearing. Scary.
178 May affect hearing in my good ear, that there will be a difference in sound from each ear.
180 That the operation will be successful and I’ll eventually be able to understand most things. Afraid it won’t work or not very well despite being told 99.5% have huge improvements.
181 Control of tinnitus
182 The kinds of sounds and noise levels that might make me feel uncomfortable.
184 Hope that it will work forever.
186 Loss of hearing and not being able to wear HA
187 Swimming, showering, what happens to the CI?
188 It may not pass the medical test for surgery.
189 The durability and resilience of the device. Cost to replace/repair, batteries. Settings, are they adjustable, obvious attachment on a bald head. The ability of the brain to set up sound recognition pathways for quicker, better understanding. Having to wait - delaying benefits of a better QOL.
190 That I may not hear clearly and also music.
194 It will hopefully solve my problems.
195 Feel my age might be a disadvantage to be considered for a CI.
201 If the sound of speech is different could I get used to it? Speech sounds too mechanical “quack like” and unpleasant. Nervous about the operation.
204 Losing all my hearing.
205 Upgrades, permanent damage.
206 I feel it would be very stressful as I do not have any support.
207 Worried that the incidence of vertigo may increase. A little concerned about losing what hearing I have left.
208 Being able to hear better than with hearing aids.
211 None really, but will require a lot of trips to Christchurch.
214 The operation itself.
216 Possible side effects. Ability to adapt quickly.
217 Am a bit apprehensive about the operation.
220 How long will the recovery be? Will there be long term pain?
221 None, after meeting a CI recipient.
222 Only in regards to other people’s expectations of how well I will be able to perform, but I have strategies thought out to deal with this.
223 That it’s not going to work on me. Having to change batteries all the time. Not being able to afford to get it fixed if it breaks.
227 Time needed to take off from work and time traveling away from home (financial).
229 The operation, once inserted - the physical dangers. Not being successful.
231 How well it will work for me, or will I be better off with 2 hearing aids. Will I have problems with airport security and in planes?
232 That it will work.
235 None, look forward to be able to hear better.
236 Fear of hospital accidents.

238 Cost of CI if can’t get done through public. WL is very long, lack of funds.
240 That it would not work properly.
244 May not meet my expectations.
245 Ongoing maintenance.
250 None at the moment. I’ve just been accepted and I’m still in shock. I’ve never been in hospital
251 Will it be successful.
252 I worry make sure CI must 100% doing well in my head.
253 None, just eagerly awaiting to have my CI.
255 Time off work.
258 Running costs, repairs. How others will react to a more obvious aid.
260 How successful will it be? Ease of adapting to the CI.
261 Might make hearing worse. Not sure technology is not yet near its potential. Worry that procedure cannot be reversed.
264 How long will it last? How likely is it to break down?
267 Broken parts that need to be repaired - costs
268 Loss of residual hearing if implanted in my best ear. Very scary being totally reliant on the CI for all my hearing and having absolutely no hearing without it.
270 How much benefit will I get - will it be effective? Risks of surgery, follow-up costs, having to travel out of town for procedures and rehab.
272 Would my age affect my eligibility?
273 Having a hole cut in my head!
274 Not sure
277 Since there is a possibility the CI won’t work for me, I could be left with no hearing at all.
278 Other people’s expectations.
280 If there is a life span, e.g. hearing aids only last x amount of years. Maintenance of CI.
281 Cost of maintenance, trips to Christchurch.

Q 64 Benefits CI will bring to you and your partner?

171 Communication, being able to do things for myself.
172 Less stress. Not getting as grumpy or tired. Better communication and less mis-communication, less arguments. More enjoyment out of social activities.
176 More socialising, less stress.
178 Probably better communication and no more shouting and arguments
180 I hope we will become closer because we can communicate better.
181 Every benefit.
182 Quiet conversations in quiet, able to communication in the dark, able to hear every spoken word, able to communicate verbally, on phone and mobile.
184 It will be extraordinary.
186 Enjoy conversations and socializing.
187 Better understanding in conversing and being able to use the phone.
189 Tremendous - to be able to converse freely, readily and often to have immediate understanding. Talk to each other in different rooms, in noisy environments, with other people, talk while doing different tasks without having to stop and concentrate. A quieter environment.
190 I won’t be too dependant on him. Enjoy socialising more if I could participate in conversations. My self-confidence will improve greatly.

194 A big difference to understanding and be able to have a conversation with my husband. It will lessen the stress.

195 Widow, but hope a CI would help me cope better with my life and not be too much of a drag to my children in the future also communication with my grandsons.

201 My husband would feel less frustrated with me if I could hear better. Would enable to interact with people and feel more confident and not isolated. Maybe I could join my husband at some of his social activities.

204 Spontaneous conversation instead of having to write everything down.

205 Enable greater, meaningful conversations, more detail, tone of speech. Less effort required by the speaker.

207 We are both retired and I think will just enjoy more conversation and outings to theatre and films, and social gatherings.

211 TV will not need to be turned up to hear.

212 A lot brighter.

214 Hopefully a better life all round.

216 Momentous (of great significance).

217 So many, I think it will be a complete change of lifestyle.

219 Live alone, but CI would make me less afraid at night to be able to hear better, fewer misunderstandings, people might avoid me less if I hear better.

221 My family and close friends will get benefits as much as myself, quieter times and heaps of fun!

222 I will be less tired and communication will be less stressful. I will have a much greater opportunity to succeed in my workplace and access equal opportunity. I will feel less isolated and more able to participate in my family and community.

223 My partner would be glad not to repeat himself all the time. I should make our lives better and easier.

227 Will there be more benefits with a CI than hearing aids? Both are simply mechanisms used on a routine basis. If hearing is greatly improved then the reluctance to approach or communicate with others would ease.

228 Huge, at the moment its been like this for years. I’m very reclusive and dread going out. That would change.

229 Being able to have a conversation without him having to repeat things many times. Make more conversation instead of being "too hard" to get my understanding.

231 Be able to hear correct things being said as sometimes normal conversations can turn into heated arguments.

232 I may be able to function as a real person again.

235 I expect to be able to join in with people more.

236 Re-establish contact.

238 Talk to each other easier. Less stress.

240 Better communication.

244 I look forward to being able to have a normal conversation.

245 Less stress.

246 Be able to enjoy doing more things together e.g. music, films, conversations in the dark.

250 It will alleviate a lot of frustrations. We will be able to talk without her having to raise her voice and repeat everything. To be able to converse in the car. To hear her call out if something is wrong.

251 Improve communication. Take away frustrations.

252 One of us with good hearing.

253 From what I have see and heard from implantees I feel that it would be possible to improve our well-being 100%.
255 Hopefully benefit.
258 Improved, less stressful conversing. Improved confidence on my part. Spouse more likely to enter conversation.
260 Being able to communicate without being face-to-face i.e. being able to hear husband talking to children in another room, and being part of it.
261 If it works, very significant benefits.
264 Generally less stress for both of us.
265 Make it easier to comm. Resume social interaction within the community.
267 Clearer communication with family members. Hopefully more energy to socialise with others.
268 Being able to talk without my partner having to raise his voice, repeat everything, get my attention before speaking; Being able to socialise together with me being able to participate. We can go out more. Family gatherings I can be included instead of left out
270 Better, clearer comm. Less misunderstanding, be able to socialise together. Less reliance on him to repeat or translate messages/conversation.
272 My disabled daughter lives with me, we rely on each other.
273 Understand better what is being said. Less "ayes and beg you pardons" easier for my wife as she's my rock.
274 Make it easier.
276 Better communication and understanding.
277 I am currently single, my last partner found it hard to cope with repeating conversation regularly. I hope better hearing would make it easier to travel overseas, but would probably not do this on my own, due to hearing loss.
278 Huge, it will be a partnership in all areas of our lives e.g. our tamaiti, extended whanau.
280 We could live a more normal life.
281 Live on my own. Go out more, feel safer if hear alarms and door knocks.

Q65 Do you think that the CI will change anything about the relationship you currently have with your partner? Yes /No. If yes, please detail.

171 Same as Q 64
172 Same as Q 64
176 Less nagging, keep your voice down.
178 After 33 years no I don't think so.
180 Trying new hearing aids soon.
181 Yes, better communication and will make life a lot less stressful.
184 Yes it will mean decent 2-way conversation again, plus getting out of the house.
186 Yes - Have quieter conversations and help keep voice down.
189 Yes - better communication, more humor, less impatience, less stress, less repeats, better social interaction, better self-esteem, able to handle awkward situations better. Better understanding, speech and pronunciation, less correction, better memory, less forgetfulness, no annoying feedback. Less gesturing or sign language.
190 Yes - he won't be so grumpy and impatient with me.
194 Yes - it will take us back to the harmonious relationship we had before my hearing deteriorated.

201 Yes, maybe it would improve our relationship as we may spend more time together if I could enjoy hearing at the social activities he is involved in.

204 No

205 Enable greater hearing when meeting new people. Should pick up more detail.

207 He is very patient about repeating things but I’m sure he gets tired so that should improve.

208 No

211 Yes, we have been married 42 years, I’m sure life will be easier for my wife and family.

212 Mainly the family and at bowls.

214 No

216 Yes - better communication, understanding, team work and happiness.

217 The CI will give me confidence for me to take part in large/noisy social gatherings.

222 Yes, it will enhance communication. It will lessen the responsibility of my partner having to make calls and communicate on my behalf - including using NZSL.

223 It might make us talk more and go out and do activities that we wouldn’t have done before because of my hearing impairment, e.g. the movies.

227 No - it will not change the relationship between me and my son.

228 Yes definitely.

229 Yes, converse more.

231 Yes, better communication and understanding.

232 Yes - improve it - how could in not?

235 My husband had no problem at all when he was alive. He died 20/02/08.

236 Yes as q 64

238 No

240 No

245 Yes - definitely improve

246 Yes -should make it better

250 Yes, I back away from socialising somewhat. That should improve. But we don’t lead much of a social life anyway, usually just with friends and family. I never attend work functions as I can’t stand the noise.

251 Yes - the stress of having to repeat statements

253 Yes - I realise that the pressure on my partner would be equally as great as what I feel myself. In fact hers may be greater because she has a choice and I don’t.

255 The relationship should benefit.

258 Yes - I tend to shout too much, we should feel more relaxed and enjoy each others company more. I rely too much on her hearing.

260 Yes, with disciplining children CI will allow me to hear my husband talking to children, so I’m not confused why children have been told off when I’m not in the room.

261 Yes it will improve communicate between each other.

264 Yes - I’ll probably go back to being more independent. I rely on my husband a lot. I’ll probably stand my ground about some things more than now - like turning off sport!

265 Our relationship has not suffered but my deafness does place a burden on my husband.

267 Yes hopefully improve

268 Yes - be much less dependant on my partner and much less of a burden. I hope my partner will talk to me more as he talks to others. Should strengthen our relationship considerably.

270 Yes - possibly less stress, more likely to do more together, less financial stress if I am still able to work.

272 I rely on my daughter especially when shopping and have to take her with me everywhere I go.

273 Probably not, just make life easier.

274 Don’t know
276 Yes - better
278 Yes, it will reduce some of the pressures in our lives and possibly be more relaxed.
280 Not really as she understands my problem and what goes with it.
281 Yes - family, feel more included.

Q66 Other comments?

171 It looks like a wonderful thing, can’t come soon enough.
182 Nervous that everything will sound very different. I’m not sure if I’ll be able to stand the noise/volume. I usually turn my hearing aid off when it gets noisy.
184 I am concerned about the eternal wait to even be assessed. Also read that being left can ruin any chance of a CI working as the nerves lie flat and become useless. Have gone to the trouble of getting all possible tests done elsewhere. Maybe I should head to Auckland for service.
186 If will benefit more for both of us to have a CI.
189 When people are deaf or HI, some others think they are stupid and either ignore them or treat them as though they are mentally disabled. Deafness seems with some to be an excuse to be impatient, yell, get irritated, or be a source of amusement. Telling others you have a hearing loss makes them yell, not slow down and speak clearer. Hearing for me requires great concentration, which is mentally and emotionally draining.
194 Being not able to pick up what people are saying on the phone. This will be so very important to me if my husband is not here I can’t deal with matters on the phone.
201 My responses to this Q may have been different if answered when I was in my 20’s or 30’s but with time I have leaned to avoid, as much as possible, those social situations where I can’t hear and thus avoid being frustrated, irritable, depressed about not being able to hear - as I used to feel when I was younger because I was more often in challenging environments.
205 You get what you put in. Other parties might be more tolerant, understanding & supportive.
207 Am looking forward to being able to fully participate in social groups and take a more complete interest in the lives of my children and grandchildren.
210 It will benefit me in all areas of my life.
211 I am looking forward to having my CI.
214 Will there be a cost to run them?
216 Deafness is a profound and hidden disability. The real cost to the community resulting from loss of production, marriages etc is not understood and needs to be for more effective funding.
217 Waiting for a CI has put my life on hold, can’t do my OE or all the social things I want to do until it happens.
219 Relationships with other people have always been strained and slightly unnatural I’m very aware that I cause difficulty communicating so tend to back away from social situations, it’s an isolated life being so deaf - a CI would be a god-send.
221 I have enjoyed being able to express myself through this research study. Thanks
223 I have just recently had an operation that took away all hearing in one ear so I’m still trying to get used to even decreased hearing loss from what I had. I had to have this operation before I could have the CI but now have to be like this for 6-9 months for it to heal, then wait for the WL. It’s very hard. Please get more funding!

227 Being “borderline” in hearing loss I have concerns over losing what hearing I do have in exchange for something that I may really struggle with. However my job as a teacher so desperately lies on communication.

228 You ask about talking loudly or speech sounding like an impaired person. I don’t really know, I’m told I talk loud but to me I don’t. Same with speech if it’s different I would have no idea.

235 Found some questions a bit difficult as my social life has been quite restricted owing to having to care for my husband the last 12.5 years after his stroke.

247 It’s a lonely life being deaf.

250 This is one of the biggest things to happen in my life. I don’t know really what to expect but if I can talk to people without having to say "sorry" it will be a success for me.

253 I only wish that it was my time to have the operation at this moment.

258 Hope to be implanted before too long.

265 I can’t understand dialogue on TV and radio. I am tending to withdraw from social interactions and pursue interests on my own.

267 It has been hard to cope with my daily life on a day to day basis lately and to cope with re-assessments for CI over 8 years.

268 My family is important to me and I hope having a CI will help me hear better. At the moment I feel very much a burden and left out despite their best efforts to include me in conversation.

270 "Major concern is employment. How much deafer am I going to get? Hearing loss already major problem for me at work, will I be able to continue working if I have CI?

272 When people are born Deaf, society is more understanding and accommodating. This is frustrating and dispiriting. I have withdrawn socially, recreation and hobbies due to a lack of confidence and not wanting to look like a twit, because I have not comprehended what has been said.

273 I am 78 years young am on no medication and in fine health. I come from a family noted for its longevity.

277 I tend to avoid meeting new people because of deafness and any conversation is an effort with some people. I currently have not spoken with another CI user, one on one. That should be a plan.

278 The programme needs to be a little more courageous and transparent about where the client is on the WL.

281 I hope my assessment happens soon.

Appendix 5
Summary of Results

CI-SO general comments as follows:

Q29 Other comments?

Participant #
9 It has made an improvement in her lifestyle.
18 The CI has been very positive for the whole family.
20 Before my husband was accepted for a CI I could see our old age together as becoming increasingly difficult as he became deafer and more isolated and introverted. Since the CI he has changed into the person I want to grow old with.
21 My wife has often asked me to lower the volume of the TV as it’s affecting the CI. We watch TV a lot and she is only comfortable wearing the CI with subtitles. She interacts well with up to three visitors at a time.
23 There are no words to describe the difference in QOL since the CI.
27 So thankful she has had it.
30 My wife’s recognition of female voices with her CI is ok, but with male voices is not so good. Various adjustments have been made with limited success but it is my opinion that the sound processor in the CI is at fault in this regard.
32 Having a CI has been a positive wonderful experience to the family and our friends. My husband can now be more independent, use the phone. We can now talk in the car on long trips to family plus many other activities. Everything is easier.
35 You appear to skew the questions towards the view is being the most positive option. My mother was deaf, I was born Deaf prior to her CI. Communication was with NZSL and lipreading. I find Q 4 strange, as having a CI means less HI and there are many people who are proud to be Deaf and see it as cultural not a disability.
38 There is some anxiety/negative emotion regarding the total reliance on the CI i.e. if it goes wrong or doesn’t work then he has no hearing at all and can get panicky at the thought of that occurring. Overall I feel it has been a positive experience but is not as good as it was initially.
39 My spouse has only been fitted with the device a couple of months ago. Like most implantees they couldn’t see the benefits yet. All they are feeling at the moment is an extreme struggle or pain. This has an incredible effect on their ways of life. However, in the next few months things will be different, it will be better.
40 Huge changes in day to day life. Response to noises and sounds is great. Improvement in speech and clarity. Confidence and self-worth increasing. Feel that the CI has been very successful and we will continue to see changes/improvements over the next couple of years.
42 It is difficult to determine whether having the CI makes a difference or not taking into consideration, length of time without hearing prior to CI, personality types etc.
44 While the CI has given marvelous new sounds in higher frequencies (can hear birds etc) it has not made much of a significant difference in the ability to hear conversation as yet.
45 My husband has had to have 2 surgeries as the first one was of no benefit. We still don’t know if it was due to technical failure or him. The second CI is giving more gain, but we still have an extremely long way to go and are ever hopeful of a better result second time around.

46 I work with [participant X] auditory training. He is much more open and accepting. Certainly improved interaction between us post CI. Others have commented as well regarding improvement in communication ability.

54 The CI has been hugely positive for my wife.

55 I knew my wife 15 years prior to her CI but not as closely, so haven’t noticed as many changes as someone might have if they’d been with her right after the CI, we’ve been together for 6 years.

56 In the questionnaire do you recognise the effect that other technology has on a HI person, which although may be attributed to the implant, in fact has a bearing on the person’s emotional state & outcomes? Refer to teletext, subtitled DVDs, email, fax, TTY and the greater acceptance generally of HI people socially and in the workforce.

58 Have found a comfortable volume for TV for myself but is still too loud for my partner. Overall the quality of our life together has greatly improved.

60 The CI has been amazing for my Dad and our family. It has really improved our relationship with dad and has been fantastic. The SCIP is very well run and is an asset to NZ. I hope all the people who want and need a CI can get one.

61 Having a CI has allowed him to develop into a confident man who is keen to participate with others. He enjoys life a bit more, and has involved himself with others at sport and activities. It has removed a lot of the frustration he used to experience and his QOL has improved so much.

62 The CI has been a great help, but due to health problems his hearing has deteriorated a lot.

63 Only positive results from the CI all round for both of us. It was one of the best things that ever happened to us after 40 years of deafness.

65 It has been a godsend and has reduced stress and frustration in communication.

68 I am eternally grateful Ian had the opportunity to have a CI. It has made a huge positive impact on our family QOL. We put in a lot of work at the beginning and there are some situations where it isn’t perfect but it has enabled a huge normality in our interactions within the family, business and our community.

70 Dealing with situations where CI turned off due to background noise but hearing person not told. So communication standoff. Better life not good. Limited effected range of CI, poor performance on phone. Latching onto “odd” words of conversations and redirecting conversations. Having to get implantees attention.

77 Overall the CI has been tremendous benefit to both [participant X] and those she comes in contact with.

81 The CI has been a great help for [participant X], especially at work as we have owned shops.

82 Because [participant X]was born deaf many of these questions are unanswerable until she learns a great deal more about sound and learns to understand speech, music etc.

85 Sometimes I think it is selective hearing, but most times I realise it is the CI. It has been wonderful that he can talk on the phone. A lot of people ring him and they certainly didn’t want a woman’s voice on the other end especially when it was about building or painting.

87 As a family we have learned a lot from [participant X] CI and for the better - she is our number 1 person. We have all changed for the better.

93 I feel that my partner’s only problem is if the CI gets a fault and it has to be checked and she does not have her hearing switched on.

101 For me, the best part is not having to write down every single comment, explanation etc wonderful! Even with no hearing my husband behaved safely and independently. His hearing didn’t affect my hobbies etc just communication. He still misses a bit of conversation, but we have regained some laughter and spontaneity that was impossible before. All in all his CI is a huge improvement and we feel blessed to have it.

102 [Participant X] was a functioning member of society and family before the CI but the improvement is an absolute miracle. There are no negatives at all and the improvement in quality of communication is amazing. My only regret is the long wait and battle to get the CI in the first place, but it was all worthwhile.

103 Enormous improvement in communication.

113 The investment of a CI has transformed my husband’s sense of self and vastly improved the number and quality of interactions with other people.

114 The CI has been brilliant. It has changed our lives in a great, great way, unbelievable. We as a family are so grateful to have our wife and mother back. Deafness is a terrible thing to have to live with.

120 I always considered [participant X] coped extremely well given is level of HI. However, there is no doubt that the CI has been a great advantage to him and given him a new lease of life.

122 Very hard to imagine that the CI would have worked as well as it does. It has really changed both of our lives.

124 I think its early days yet and I believe most of my answers will be a lot different in 4-6 months.

128 The CI has been good as it has enabled him to have a relationship with children, where before it tended to be 3 way conversations, so this tends to outweigh any negatives affects it has, i.e. him not being able to handle a lot of background noise at once, especially when he is tired at the end of the day.

129 I feel that the CI has been a very positive change in both our lives, and for that we feel grateful.

130 Just wonderful! In wet weather the covers are hard to put on and cause loss of sound.

131 The CI has made an unbelievable impact on my partner’s QOL and of course for me, as well as friends and family.

135 The last section is difficult to answer, I have not had any changes to my life, its still the same as it was before my son got his CI."

139 Since [participant X] was able to hear before losing her hearing, to be able to hear again is brilliant. It has picked up her near normal life again. Many more adults and children should have this opportunity - we pay enough tax.

142 Initially there was a fantastic difference especially socializing, however lately this has declined somewhat.

154 I think that the CI has certainly helped with our family and friends and in particular our grandson when my husband has been able to interact with him.

156 Mums CI was a total success and it’s bought her a lot of joy and for us all as a family as well.

163 The form should have been more about my partner, as I don’t have a CI but my partner does.

164 A wonderful piece of technology.

Appendix 6

WL-SO participants’ comments in answer to all qualitative questions are as follows:

Q21 Expectations for areas in which the CI will provide benefit.

171 Let him feel more involved. Be able to communication in all areas.

172 TV, radio, theatre. Social and hearing others (including me).

176 Change in his voice. He speaks too loudly at the moment. Improve speech. More socialising with hearing people. He has on-going problems with hearing aids and moulds.

178 Being able to talk to him and get a response the first time. He is totally deaf without his hearing aids. Being able to answer the phone. Speak to people with broad accents. I have to interpret every time.

180 Telephone, group situations.

181 Our personal homelife, business phone calls, ability to get full time work
getting our social life back, him hearing me call him, every area of our life will improve.

184 Back to normal hearing life where we can talk to each other. That he could again listen to music, hear the birds and be able to join in conversation with friends and family again.

185 Help her in talking to people and understanding what is being said. Help her in employment.

186 Help voice and adjust tones. Improve speech. Be involved with hearing world. Less frustration to have CI than hearing aids.

187 Increased hearing to help dad. Socialise and be socially active. Day to day listening and conversations. Be able to interact with his grandson more easily. Answer the phone.

188 Generally better hearing.

189 Don’t know - not likely to get it as no re-assessment has been arranged.

190 Confidence in ability to progress in her career.

194 Make conversation easier.

195 Listening to and conversing with others, particularly in a group situation.

201 Improved social interaction. Joint participation with wider group of social contacts. Improved self-confidence.

204 He hopes to return to his career of being a chef

205 Being able to understand without lip reading.

207 Enabling her to socialise in groups, attend church and other public speaking areas. TV and cinema.

210 In every aspect of his life.

211 It would be wonderful for him to be able to hear his grandchildren. To be able to take part in family discussions and social events. Talk on the phone.

214 General indoor talk.

216 Using the telephone again. Conversation without having to look at him. His safety around machines.

217 Socialising, work, play.

221 Not missing out things in conversation

223 Her hearing and talking to people.

227 I feel my mother doesn’t need a CI as she’s fine the way she is.

228 Conversation, social life, work.

229 To participate in all family life which requires good hearing.

231 Grandchildren. Work

232 Confidence in social situations, participation, safety. Being happy at work.

235 Be able to join in family conversations and make it easier to socialise.

236 Normal one-to-one contact.

238 Music, socialising. Be more confident.
240 Better hearing, confidence to have a better conversation, especially with friends and strangers.
245 Better hearing in a crowd, less BGN and interference.
246 Telephone, music, films, TV, dances.
250 Not having to repeat myself constantly. Friends say I almost yell at [participant X]
251 Hope I can talk to him without having to get his attention first.
253 Easier life, as he has no hearing at all.
255 Using the telephone.
258 Ordinary conversation. One-to-one or with friends. Able to speak on phone, TV quieter if no teletext.
260 General communication, group situations, possible telephone use.
261 Improve conversation. Help him hear his grandchildren, help in his social life, sports and clubs he belongs to.
264 General interaction with people. Music enjoyment, play piano. Hearing in loud situations be able to use the phone, most things we hope. Hear birds chirping.
265 Telephone conversations, hearing alarms, hearing TV and radio, playing piano and organ.
267 I hope she'll be able to hear better and ultimately allow her to become more independent.
268 Social life, self-esteem, being able to get a job.
269 That she can hear music again. Can talk to people without having to fill in the gaps of understanding, especially in her business.
270 Work, socialising.
273 Communication without the struggle it can be.
274 Ability to socialise and not feel left out of conversations, or lectures at University. She had to work doubly hard to achieve any success at work or study, not be able to take part in sport.
276 Hear music, listen to other people with more ease. Gain more confidence in new listening skill be re-educated.
278 Eventually, we will be able to talk in the car, she will be able to use the phone and hear the kids.
280 Give him more confidence in social circles - mainly to be included in conversations. Communication with people by phone, particularly with family. Hear TV, music. It would be a safer environment i.e. at moment can't hear alarms, phone etc.
281 Family network, converse more freely. Hear grandchildren.

Q22 Any areas in which the CI may not provide benefit.

172 Noisy situations. Communication in bedroom/bathroom when device not worn.
176 Unsure
178 People have a tendency to speak too fast where there are many people present.
181 I can't imagine any area. The ability to communication (or not) affects every part of our lives
186 At night when asleep.
187 Adjusting to a CI, increased noise, foreign sounds, tiring after a life time of not hearing.
205 I am concerned that it might not work as well as he hoped.
207 Only in activities such as showering when it will have to be removed.
216 His ability to enjoy music again.
217 Water sports/activities. Sleeping.
223 When it's off.
227 Will she be able to hear messages on the phone?
229 Electric shocks, airport scanners, MRI scans. Failure to deliver benefits.

236 Potential difficulties is partner’s inability to understand and apply instructions on operating and caring for the CI

238 In bed, once it’s turned off they hear nothing - security.

240 No idea.

251 Adjusting to the "voice" sound will be frustrating.

253 Will help a lot if he can hear and use the phone, I have taken all calls for the last 6 years.

260 Telephone.

264 We are positive but realistic and from our consultations we don’t think there are many areas of no benefit

267 I dread the early phases when she has to put in huge effort to maximise the best from the CI.

268 When it’s not used at night in bed, I still can’t talk to her.

269 Give that a CI still only provides a very limited number of "cilla" compared to normal "cilla" numbers I do not expect a return to normal hearing.

273 None - it can only be good.

278 In crowded noisy situations

280 None, everything must improve if can hear better.

Q23 Any concerns regarding partner’s future CI?.

171 That it will work for him.

172 Nothing that further information won’t resolve.

176 Yes maybe if he loses his hearing. What if it’s not successful.

178 It should be implanted into the ear with no hearing not in the better ear in case he loses all his hearing.

180 If it will help her a lot.

181 I think he’s forgotten to listen, that might take a while to relearn, his listening attention span is around 10 seconds then he gives up.

184 I worry that something could go wrong during the procedure.

185 It is a big undertaking. I hope it comes up to her expectations.

186 Yes - will it be successful or not?

187 Reduce my father’s loneliness by being able to socialise more easily and develop a closer relationship with his grandson.

189 None, except that he may get it when he’s much older when he would benefit now.

201 That it may not meet our expectations.

204 None, all to gain

205 He will become more relaxed and happy in general

214 Can it be worse than the hearing aids she has now?

216 Risks, side effects, that it does not meet his expectations.

221 None really

227 Will she look ugly after the CI.

231 Only if it doesn’t work.

232 Not really.

236 I don’t think it will ever eventuate.

240 Yes, scared that he will lose his hearing completely.

251 If it doesn’t work he’ll be totally deaf.

255 Might not regain hearing.

258 Hope my husband is not disappointed if CI is not all he expected.

261 That it may not be successful

264 I only share with her the anxiety of the operation.

267 Yes, worry about the operation - close to the brain, in case something goes wrong and she’ll be worse off. Risk of anaesthetic etc.

269 No, she is realistic enough to understand the limitations of a CI.
270 Financial, going out of town for treatment.
273 Absolutely none.
274 Without a CI she won’t be able to fulfil her potential in study or social life. The length of WL is quite stressful. You live in hope but wonder if it will ever come.
278 No, keen to get started.
280 Maintenance - trips to Christchurch from Wanganui

Q24 Impact on both you and your partner’s life?

171 He will be able to enjoy life and communication all round.
172 Improve our relationship, better for us socially, having her hear more in group situations. She will enjoy TV, radio, theatre etc more than currently.
176 Love to hear people. Hear what’s going on. Hear conversation. Fully participate. Hate feeling left out. Easier socialising. Then to associate more with hearing people than Deaf. Lots of people understand me, but I don’t necessarily understand them
178 A relief to be able to have a conversation without repeating. He reads my body language and if I get impatient he does too.
180 Hopefully a better social life and a partner more involved with life.
181 I hope the impact will be immense. I’m at the stage I only tell him really important things because it’s just too hard to chat. The repetition eventually turns to frustration, and I can’t wait for him to hear music again.
184 Can’t begin to say - I am dependant on a wheelchair for mobility and if I need help e.g. get stuck or fall, I cannot call out. That worries me. I hope that with a CI that worry will be eliminated. I would hope we may be able to travel to Australia to visit family. I think that life will be almost normal again.
185 She is keen to have a CI and is looking forward to hearing more.
186 Love to hear each other talking and conversations. Enjoy meeting people without being left out. We are more understanding as hearing people as they understand us more than other deaf people.
187 No
188 A big benefit.
189 He won’t be so ratty with others.
190 Better ability to communication and enjoy music and films without needing special showings and subtitles
194 It will make life easier.
195 It will certainly make conversation easier between my mother and I. It will definitely improve my mother’s social life, and communication with everyone around her.
201 Improved ability to jointly enjoy social and work functions.
204 I would not have to act as a go between, phone calls etc and telling people to write things down.
205 No
207 It will remove some of the tension of having to repeat conversations. It will re-open my wife’s life which has been gradually closing in as her deafness has increased in the last few years.
210 It will change and enrich his life further.
211 Will greatly improve my husband being able to communicate at meetings and in social situations, and noisy events. He’ll be able to hear speeches at weddings and funerals. It will be amazing.
214 A better future
216 Positive, it would turn our lives around. We have a business to run.

221 It will just be so awesome to have her being able to hear everything.
223 A lot better than what it is now.
228 Great improvement.
229 Better QOL
231 Be great hearing things again.
232 Better conversation, understanding, less misunderstandings and arguments. Be able to go out and socialise. Full participation in social situations.
235 It will make life easier in general.
238 Will be a better communicator
240 Better communication.
245 General improvement in socialising.
246 Positive.
250 A very positive one
251 Socially it should help. Hope he can enjoy music, TV, films.
253 It will be positive
255 Positive impact if it works.
258 Great impact. The great relief of having an ordinary conversation. Husband being able to join in group conversations. Perhaps learn new skills e.g. computer.
260 Improved communication, greater independence, greater self-confidence for my partner.
261 Hopefully will return to a more normal lifestyle and he will not miss out on what is going on around him.
264 Early on I think things will be hectic and unsettled with the travel for Mapping etc. and all the adjustments that must occur. But obviously things will slowly but surely settle and improve.
265 If successful a lot.
267 Ultimately hope it will make it easier for all of us. Hope she'll want to be more sociable.
268 A huge improvement in QOL
269 She will get a lot of joy out of hearing music again.
270 Should make work more secure. Make him more outgoing.
273 It will make day to day communication and living so much easier and remove a lot of frustrations we both have had to cope with.
276 Where do I start?
278 I think it will ease the burden of me being the sole parental ears and we will be able to get back towards being a more cohesive family unit.
280 No
281 Huge impact.

Q25 Change current relationship with your partner?

171 No
172 Yes, same as Q24
176 Hope not.
178 Yes, because I will be easier to live with I hope.
180 Make it easier to have conversations. Hopefully a better social life.
181 It would be lovely to have whispered romantic conversation! Socially, we could go out again! He will be able to use the phone again and will be able to talk to his daughter and grandchildren.
184 Yes, we'd be able to talk - that would be just great as now sometimes I find it too tiring writing out a story on the whiteboard. We can only communicate via a whiteboard. We go through heaps of pens, it gets expensive.
185 No

186 No

187 No

189 He will hear me more often, hopefully hear everything I say.

194 No

195 No

201 Yes, allow for more participation in more of my outside interests.

204 No

205 No

207 Yes, it will enable better family dialogue, take pressure from me having to answer the phone or interpret other people.

210 It should make his life so much easier.

211 No - we have a strong committed marriage, but he has become a recluse, so hopefully he'll be more social and outgoing in crowd situations.

214 Yes, communication will improve.

216 Yes, reduce the relentless struggle to communication, the frustration, misunderstandings, mis-interpretation.

221 Yes, it would be great to ring up and have a conversation on the phone.

223 Yes, be easier to talk to her.

228 Better conversation, less misunderstandings.

232 Yes, will be better, no more misunderstandings, better conversation and communication.

235 Yes, would make it easier to have a conversation.

238 No

240 The change will be for the better.

245 No

246 Yes, for the better, won't have to yell. Will share more.

250 Hopefully life will be a bit easier. [Participant X] will understand what I say the first time.

251 Yes less frustration.

253 Yes it will change everything for the better.

255 Better communication.

258 Yes, be more relaxed. Sometimes lonely because he hasn't heard or understood what I've said (for him as well). Less lonely, more flowing conversation.

260 Yes, not sure though.

261 No

264 I think we will both be more relaxed.

265 Yes, will be able to have a good conversation together.

267 Yes, increase social skills and inclusiveness.

268 No

269 No

270 No

273 No

274 I believe it will greatly relieve my concerns for her future. While she has great abilities it's very difficult for her to communicate freely with others and be confident that others not only understand but are able to be sure she can achieve what she is asking other to do for her. Lawyers, doctors, dentists and other business needs.

276 Yes, better talking.

278 Yes, I think we will both be less tired as my partner won't have to strain so much to work out what's happening. Hopefully we will both eventually be more relaxed.

280 Concerned once implanted can it always be adjusted, will it screech in the head?

281 No

Q26 Other comments.

171 Hopefully it will work.

172 Am hoping for a favourable outcome but am realistic about possible results. More government funding is needed.

178 I would love him to be able to hear the birds in the morning. He deserves to be able to hear music and rhythm rather than only the middle tones.

181 We are desperate to have the CI. It’s a light at the end of the tunnel and the most important thing in our lives. Seriously, it will change our lives, [participant X] really needs this soon.

184 I would like to think that this will happen in the very near future.

188 To have his hearing restored is my one wish.

194 I have a medical problem that has affected my memory. When I forget she has a hearing problem I sometimes get a bit short with her and have to repeat something but it never lasts.

195 I am very hopeful that my mother will be selected for a CI as it will dramatically improve her QOL.

207 Because of the high cost of apparatus perhaps a way of partial payment by the patient could be instituted. This would increase the number of recipients in total if extra government funding is not forthcoming.

211 We feel very privileged to have been chosen to go on this programme. I am more excited than my husband, as he has become used to his quiet world.

216 The isolation coupled with depression and hopelessness that often comes with profound deafness makes for a very bleak future at a time when we have so much to give family and community.

221 We have all coped so very well with having a deaf mum - we’ve been brought up knowing no difference. She is a wonderful, friendly, and outgoing person.

223 The cost of the batteries.

250 Can’t wait for the operation to take place.

253 It’s been hard over the years watching his confidence diminish. I hope with the CI he will be more confident in his life.

258 At times when having a conversation with my husband I get frustrated and withdraw, it becomes hard for both of us.

264 I am positive about the future with the CI. [Participant X] is a positive person who is also very determined. We are confident that she will adjust and learn quickly, and we are excited about the future with the CI.

267 Very stressful to do assessments, getting hopes up then being told "too good" to get CI although I understand why.

269 Bring it on. The sooner the better especially for her enjoyment, and business.

274 It would be great to have better communication with those organising the CI especially regarding when the operation may take place.

278 Not knowing where you are on the WL is unnecessary.

Appendix 7
Summary of Results

Parent comments as follows:

Q72 Differences noticed between the first and second CI.

3 Yes - was able to do a lot better with 2 implants.
5 Yes - not much yet only had it a few months, still working on it very slowly, she can be reluctant at times.
7 Yes, still some debate over whether there was a problem with the first one and being so young it was difficult for him to wear it enough. Most progress has been made since second CI, more localised sound
8 Yes. In louder settings and localising sound, he can also follow conversation in the house, car and outdoors.
11 No, I don't notice a great difference, however [child X] said things sound clearer with 2 implants.
12 No, not when worn together. On its own, his hearing is not yet at the same level with the second implant.
13 Yes, habilitation seemed harder/slower second time around
14 Yes, turns to direction of sound, previously was confused by direction of where sound was coming from. Generally more responsive to sounds and we believe he's hearing everything now.
16 Yes, his audiograms show he hears much better with both CIs rather than just one.
21 Yes, with the second CI she is hearing some sounds but not understanding the words yet.

Q74 Would you recommend a second implant to others - comments

3 Yes, hearing with 2 ears is a lot better for the child to pick up words and sounds and make them feel happy with themselves.
5 Yes, she wanted hers but is having a few moments about it lately.
6 Yes SCIC are fantastic and very supportive.
7 Yes, I had no desire for a second one until it was offered to us and his audiologist and rehabilitationist were all for it. He didn't seem to get as much from his first one as my daughter did.
8 Yes. When one of his CI's broke I noticed a difference.
11 Yes, I would as it has given him use in both ears.
12 Yes, gives option of another feasible ear if anything happens to the first CI. Our son is not old enough to tell us if he hears better with 2 implants. We have not noticed any obvious differences, but are glad he had his second one.
13 Yes, important to stimulate the auditory nerve after 9 years of deafness.
14 Yes, bilateral implants give more clarity and greater range of all sounds.
16 Yes, trouble-shooting is much easier. Localisation of sound is better when wearing two. He asks to wear the second one if it's fallen of etc. If one falls off at least he can hear in one ear.
21 Yes, the main reason why we decided on a second implant is even if she can't hear perfectly but she can know where the noise is coming from.

Q75 Other comments

2 Life is great with the CI. [Child x] has made amazing progress in the 12 months since implant. Hard work that is totally worth the effort.

4 My son hates his implant and resents wearing it. I believe it will take him a very long time to accept it. It would be more useful if it made a noise when he takes it off, as he hides it and can’t tell us where it is.

5 She has always had an amazing personality and had something about her that captured anyone she met, and still does, that has never changed. The CI benefit is that she can talk - this wasn’t an option otherwise.

6 It’s an individual/personal thing. My son states he doesn’t want a second CI probably because port-op was traumatic for him. I’m still concerned about his future e.g. employment, social, despite the fact that he does so well at school.

7 Have a 7 year old daughter also with bilateral implants.

8 Would recommend it to most people in same situation. Hard work getting son to wear new CI but worth it.

10 Our child is deaf in both ears. We live 850km West of Sydney. CI was our only choice to our child to live in a community where spoken language is the only form of comm. It was the best choice we make, our daughter is main stream school and at the top end of her class.

11 [Child x] does not love his second implant - he tends to be more “noise sensitive” on that side and seems to suffer with “zaps” from it related to loud noises.

12 Without a CI our son would be using sign language as hearing aids didn’t help at all. With is first implant, his language and speech were age appropriate by 4 years of age. He is a normal "hearing" child who has many friends and will attend mainstream schooling next year. We love his implants (as does he) and would recommend them to anyone.

13 I feel our results have been due to such early intervention 10 years ago. I wish we were able to implant the second ear much earlier.

14 Thank you to SCIC not only have they changed our sons life, they’ve changed all our lives. My son can hear me tell him I love him and has an improved balance which has helped dramatically with his cerebral palsy."

15 The CI is great and has helped a lot but at the end of the day, she is still deaf which impacts, sometimes positively and sometimes negatively on us and her.

16 Mapping 2 CI take a bit more organisation but having them implanted close together make habilitation easier.

17 [Child x] has come a long way in the last 2 years. He has developed language and speech is much clearer, and his behaviour is 90% better.

22 Parents need to be aware of after the operation all recovery time 3 months to adjust to the sound as it can be frightening for them so you need to be there at all times. So 3 months for recovery and 3 months to learn where the sound is coming from. Even though to hear from a HA side is very different to the CI side.

23 It would be interesting to see the research. We do not meet many other children with CIs - hard to judge how well my child is doing, can only judge against hearing at school.

Appendix 8

Mean Individual Pre-to-post Ratings for WL (N=7)

Participant No.		**Subdomain* Mean Scores** **1**	**2**	**3**	**4**	**5**	**6**	**Total Pre**	**Total Post**	**Diff** pre-to-post**
278	Pre	15.00	5.00	72.50	32.50	12.50	27.50	27.50		65.83
	Post	97.50	72.50	100.00	100.00	92.50	97.50		93.33	
276	Pre	16.67	11.11	46.43	8.33	25.00	21.88	21.57		46.86
	Post	56.25	57.14	66.67	65.63	85.71	79.17		68.43	
205	Pre	35.00	30.00	82.50	72.50	65.00	72.50	59.58		17.50
	Post	75.00	72.50	80.00	70.00	75.00	90.00		77.08	
184	Pre	27.78	25.00	72.50	13.89	17.50	17.50	25.63		45.09
	Post	97.50	87.50	90.00	69.44	77.78	88.89		70.72	
216	Pre	0.00	0.00	87.50	31.25	10.00	25.00	31.25		34.17
	Post	86.11	47.22	97.22	70.00	55.00	68.75		65.42	
268	Pre	10.00	17.50	80.00	47.50	20.00	12.50	29.03		56.16
	Post	57.50	57.50	95.00	65.00	55.00	62.50		85.19	
175	Pre	20.00	45.00	77.78	42.50	40.00	25.00	41.71		38.03
	Post	72.22	72.50	85.00	87.50	67.50	93.75		79.75	

* subdomains (1 = basic sound perception, 2 = advanced sound perception, 3 = speech production, 4 = self-esteem, 5 = activity limitations, 6 = social interaction)

** Diff pre-to-post CI is the total average difference pre-to-post implant for each individual

CI-New SO

Individual Pre-and-post total average scores for Q1-20 – CI-SO users implanted during the course of this study (n = 5)*

	Pre-CI QOL Score	Post CI QOL Score	Total Difference Pre to post CI
SO for Participant 278	27.50	93.33	65.83
SO for Participant 276	21.57	68.43	46.86
SO for Participant 268	29.03	85.19	56.16
SO for Participant 184	25.63	70.72	45.09
SO for Participant 216	32.25	65.42	34.17

* Note that participant 205 and 175 did not return a SO questionnaire.

** Note that worst possible score = 0 and best possible score = 5

Comments for the CI-New Participant

Q67 Areas in which CI has met needs and expectations

184 Conversations with my wife instead of a white board. Slowly getting better in contact with others.
205 Phone usage, work meetings, social situations, car noises.
216 At 2 weeks all of my expectations have been met for the right time frame as it is still early days. I am probably halfway (50%) of where I expect to finish up.
268 Improved communication ability, improved personal interaction. BEING ABLE TO HEAR!
278 In all areas of my life the CI has exceeded every expectation I had. I never thought I would have the clarity in speech, the easy use of the phone, the melody of familiar music, and the distinguishing environmental sounds so quickly….if at all……

Q68 Areas in which the CI has not met needs or expectations.

184 Able to hear and understand music.
205 Car radios/loudspeakers (some).
216 Refer above (Q67) but I expect improvement in telephone use, crowded situations, outdoor activities, music and general clarity and awareness.

Q71 Other comments?

Participant #

175 I would like some bass
205 While I was happy with hearing aids the CI has been so much more useful. Work and social situations are much easier and more enjoyable. It has certainly changed my life for the better
216 Great opportunity and supportive and professional team. I feel very lucky and grateful.
268 After being severely HOH all my life I am amazed at all the new sounds that I can now hear. It is amazing how easy it is to hear other people and understand them. The implant has been a dream come true.
278 This gift I have received has given my life back, add to my ever relationship and every day is a surprise and joy. I am extremely grateful and one incredibly amazed CI recipient.
276 Much better than hearing aids.

Comments for the CI-New Participant's SO

Q29 Comments

268 Excellent result, better than expected.
276 So far so good – interesting – still plenty to learn yet.
184 It is just so good to be able to talk again. When people come around it is entirely different, back to what it used to be like almost. Can't say enough about how good the team is at SCIP
216 The CI has been life changing for us both – positive, enriching – a bright future. Thank you.