LATE COCHLEAR IMPLANTED ADULTS WITH PRELINGUAL DEAFNESS IN SOUTHERN NEW ZEALAND: EXPLORING THEIR LONG-TERM NEEDS

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Abstract

Background: To date, there is a lack of research that has focused on the needs of late cochlear implanted adults with prelingual deafness. The specific study aims were: (1) to explore the met and unmet long-term needs of late cochlear implanted adults with prelingual deafness from their own perspectives and those of the employees at SCIP; and 2) to identify a consensus of the most important met and unmet long-term needs of late cochlear implanted adults with prelingual deafness.

Method: This study used a modified Delphi technique with two rounds. In the first round, nine adults who were considered experts on this topic participated in semi-structured in-depth interviews. The participants were five late cochlear implanted recipients with prelingual deafness who were involved in the Southern Cochlear Implant Programme in New Zealand, and four clinicians from the programme. The interview transcripts were analysed using qualitative content analysis. The results from the first round were used to inform the development of the survey for the second round. The second round of the study involved surveying the same participants who participated in the first round. These surveys were quantitatively analysed so as to discover which needs were considered important and met, and important and unmet for the cochlear implant recipients, from the perspectives of the two categories of participants.

Results: The first round of the study revealed 42 met needs and 39 unmet needs that fell into 15 categories. Of these needs, 26 met needs and 18 unmet needs were identified as being important by a majority of the participants in the second round.

Conclusion: The results from the study may impact potential CI recipients' and their families' expectations of what the device can provide, as well as the development of future services and governmental policies in the area.

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List of Abbreviations

AL	Activity limitations
CI	Cochlear implant
dB HL	Decibels (Hearing Level)
HL	Hearing loss
ICD-10	International Statistical Classification of Diseases and Related Health Problems
ICF	The International Classification of Functioning, Disability and Health
NCIP	Nothern Cochlear Implant Programme
PR	Participation restrictions
SCIP	Southern Cochlear Implant Programme
TV	Television
WHO	World Health Organization

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Introduction

1.1 Overview

At present, over five percent of the world has a disabling hearing loss (World Health Organization, 2014). In New Zealand, approximately 16 percent of the population are considered deaf or hard of hearing (National Foundation for the Deaf Inc., 2014) and approximately nine percent are considered to have a hearing loss that causes them to be limited in their everyday activities with or without the use of hearings aids (Statistics New Zealand, 2013).

The development of cochlear implants (CIs) has been revolutionary for many people with severe to profound hearing loss who derive little or no benefit from hearing aids as implants have the ability to elicit the sensation of sound for many who have not experienced it for a long time, if ever (Finlay & Molano-Fisher, 2008). Unfortunately, as with any situation regarding life and health, the devices are not able to meet every need of every recipient (Looi, Mackenzie, & Bird, 2011). The purpose of this research, therefore, is to explore the experiences of adults who had hearing loss (HL) from before they developed language, but received CIs in adulthood, in order to find out more about their needs, including those that have been met and those that have not.

1.2 Hearing loss

1.2.1 Overview

HL can be categorised by its type, degree, configuration and age of onset. The three main types of HL are conductive, sensorineural and mixed losses. A conductive loss implies there is an issue with sound being effectively passed through the outer and/or middle ear. A sensorineural loss implies there is an issue with the inner ear or a part of the hearing system further on leading to the brain. A mixed loss implies there are both conductive and sensorineural elements to the loss (Namba, 2014; Schlauch & Nelson, 2009).

The degree of HL can be classified in several different ways, most commonly using thresholds measured in decibels hearing level (dB HL). These are measured using pure tone audiometry, during which a presenter plays tones of specific frequencies, typically octaves between 250 Hz and 8 kHz, including inter-octaves where necessary, to which a listener is required to respond when he or she hears each tone. The intensity of each tone is adapted based on the response of the listener and the lowest intensity is considered a threshold for a specific frequency when the listener responds in at least half of the presentations of increasing intensity (American National Standards Institute, 2004; American Speech-Language Hearing Association, 2005). In typical audiometric testing, the pure tones are presented using two methods: via air conduction using supra-aural headphones or insert earphones and via bone conduction using a bone vibrator positioned on the mastoid process behind the pinna (Schlauch & Nelson, 2009). When sound is presented via bone conduction the sound essentially bypasses the outer and middle ear, allowing for abnormalities in or beyond the cochlea to be picked up. Abnormalities in the outer or middle ear are able to be discovered by comparing air and bone conduction thresholds (Schlauch & Nelson, 2009).

There are several methods of classifying the degree of HL, based on audiometric thresholds. One of the most common classifications was developed by Goodman (1965) and uses categories of mild, moderate, moderately severe, severe and profound loss. Using Goodman's classification (1965), HL is considered mild when thresholds are between 26 and 40 dB HL, moderate when between 41 and 55 dB HL, moderately severe between 56 and 70 dB HL, severe between 71 and 90 dB HL and profound when greater than 90 dB HL. A pure tone average, consisting of the average of the thresholds at 500 Hz, 1 kHz and 2 kHz, is often used to summarise the degree of HL in dB and/or descriptive category, however multiple categories of degree of HL can be reported when thresholds fit within more than one band of the classification (Schlauch & Nelson, 2009).

The configuration of the loss refers to the shape of the loss across the frequencies plotted on an audiogram. An audiogram is a graphic representation of the audiometric thresholds plotted as a function of frequency. There are many different labels used to describe HL configuration. Some of the most common labels include: flat, with similar thresholds across the frequencies, all within 20 dB of each other; sloping, with thresholds increasing as frequency increases; and rising, with thresholds decreasing as frequency increases (Carhart, 1945; Lloyd & Kaplan, 1978; Schlauch & Nelson, 2009). Other labels include precipitous (also termed steeply sloping), trough, inverted trough, high frequency or fragmentary, with terms describing an extremely wide range of configurations (Roeser, Valante, & Hosford-Dunn, 2007).

There are several definitions of the term ‘deafness’ used in various contexts which can often create confusion (Byrne, 1998; Levine, 1981; Saar & Arthur-Okor, 2013). The definition can be based on a subjective view of severe difficulties with speech signals, a more objective view of the access to speech information and the degree of HL, the culture with which an individual identifies or any combination of these factors. A subjective definition of deafness in adulthood is, “the condition of having no or very limited functional hearing,” (Stach, 1997, p. 58). Similarly, but from the perspective of the diagnosis of a child, deafness has been defined as “a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification,” (Assistance to States for the Education of Children With Disabilities and Preschool Grants for Children With Disabilities: Final rule, 2006, p. 45,756). These definitions have been used in several studies involving participants with deafness (Ad Hoc Committee, 1975; Kreisman & John, 2010; M. D. Lucas, 2009; Okuyama & Iwai, 2011; Reich & Lavay, 2009). The latter description includes the ability to process speech signals, which can be determined subjectively using broad statements of inability to hear speech (Rogers, 1998) or objectively by using pure tone thresholds in relation to spectral information of conversational speech or specific speech perception testing (Qiu, Yin, & Stucker, 1999). The inclusion of a lack of benefit in relation to speech perception derived from hearing aids is also included in the definition of deafness used in several studies (Bradley, 1991; Lucas, 2009; Qiu et al., 1999; Stebnicki & Coeling, 1999). Some definitions of deafness focus solely on pure tone thresholds, though other descriptors can be used in these cases such as ‘severe deafness’, ‘profoundly deaf’ or ‘profoundly hearing-impaired’ (Gulliver & Ghinea, 2003; Qiu et al., 1999; Saar & Arthur-Okor, 2013). When focussing on the identifying culture of an individual, the term ‘Deaf’ is typically used with an upper case initial. This implies an association with the language, beliefs, experience and often schooling of members of the Deaf community (Byrne, 1998; Stebnicki & Coeling, 1999).

For the purposes of this study, the definition of deafness based on limited functional hearing (Stach, 1997) was chosen, with further description including inadequate access to speech information, with or without hearing aids, as described by the Assistance to States for the Education of Children With Disabilities and Preschool Grants for Children With Disabilities (Final rule, 2006). These were selected as they are more in line with the criteria used for referral to the Southern Cochlear Implant Programme (SCIP), which encompasses limited speech perception and limited benefit from hearing aids, with no emphasis on cultural affiliations (Southern Cochlear Implant Programme, 2014d).

HL and deafness can also be classified based on the age of onset. Prelingual deafness is, as its name aptly describes, defined by acquisition of deafness before the development of language. It is thought that approximately seven out of every 10,000 people worldwide have prelingual deafness, though this is only based on data from two developed countries: Italy and the United States of America (Fellinger, Holzinger, & Pollart, 2012). Prelingual deafness is typically considered to be before one year of age (Caposecco, Hickson, & Pedley, 2012). The term ‘peri-lingual deafness’ has been used to described the acquisition of deafness whilst language is being developed during early childhood, typically between one and three years of age (Bosco et al., 2013; Caposecco et al., 2012). This can be a helpful term when defining early-onset deafness as the age and duration of language acquisition is highly variable between children and does not happen instantaneously. The specific age at which deafness is considered postlingual is debated in the literature but is generally considered to be from around three years of age as this is when a considerable amount of language has typically been acquired (Caposecco et al., 2012). The present study focussed on individuals with prelingual or perilingual deafness. Here, individuals were considered to meet the criteria of deafness if they had a bilateral HL of at least a severe degree (pure tone average of 70 dB HL or greater), which was considered prelingual if the onset was under one year of age, or perilingual if the onset was between one and three years of age.

1.2.2 Impact of HL

Deafness can have a significant impact on the life of an individual (Most, Shrem & Duvdevani, 2010). This impact can be eminent in functional areas such as the ability to communicate, social and emotional wellbeing, and access to education and employment (World Health Organization, 2014). Frameworks have been devised in an attempt to describe and measure the impact of deafness in these areas and all other areas of functioning in life and society, such as the model described below.

1.2.2.1 The International Classification of Functioning, Disability and Health (ICF)

1.2.2.1.1 Background and rationale of the ICF

The ICF framework can be used to understand the impact of HL on people's lives and the impact of having CIs on people's lives. In 2001, in an effort to provide an internationally accepted framework and classification system to describe the impact of a health condition on a person's functioning and disability, the WHO developed the ICF. Prior to this development, the International Statistical Classification of Diseases and Related Health Problems (ICD-10) was used in health to classify diseases, disorders and other health conditions (World Health Organization, 2002). Though this framework was and continues to be used to classify disease incidence and prevalence, and causes of death, it does not provide information about functioning and health in relation to health conditions. The ICF also takes the view that every individual has some degree of functioning and disability, contrary to the belief that those with disabilities are in a separate category from the rest of society (World Health Organization, 2002). This creates a more holistic view of each individual's experience of life and provides a universal and inclusive language with which to describe these experiences.

The ICF is based on a biopsychosocial model of health and disability. This model combines the medical and social models of disability, leading to a more balanced and inclusive perspective than either model can provide individually (World Health Organization, 2002). From the perspective of the medical model, disability can be equated to having physical or mental limitations, and being sick or unhealthy (LoBianco & Sheppard-Jones, 2007). The natural result of this perspective is to provide these individuals with medical treatment by professionals based solely on their diagnosis, which is often conducted in an attempt to 'fix' the individual's problem (World Health Organization, 2002). In this model, the context in which an individual lives is not taken into account, which neglects the impact of culture, social policy and institutional practices on individuals with disabilities (Marks, 1997). The social model of disability considers the response of society to an individual with a disability, focussing on environmental barriers in society that lead to the experience of disability (Anonymous, 2009; LoBianco & Sheppard-Jones, 2007). The underlying assumption of this model is that disability would not exist if society responded effectively to the needs of individuals (LoBianco & Sheppard-Jones, 2007; World Health Organization, 2002). The biopsycosocial model is a combination of both the medical and social models of disability, taking into account both the physical nature of disability and the context in which an individual resides.

The ICF conceptualises functioning and disability as a complex interaction between a person's health condition and their environmental and personal factors, as depicted in Figure 1. The areas of functioning and disability include body functions and structures (or impairments in these areas), activities (or activity limitations), and participation (or participation restrictions). The contextual factors include personal factors, and negative environmental factors (barriers) and positive environmental factors (facilitators).

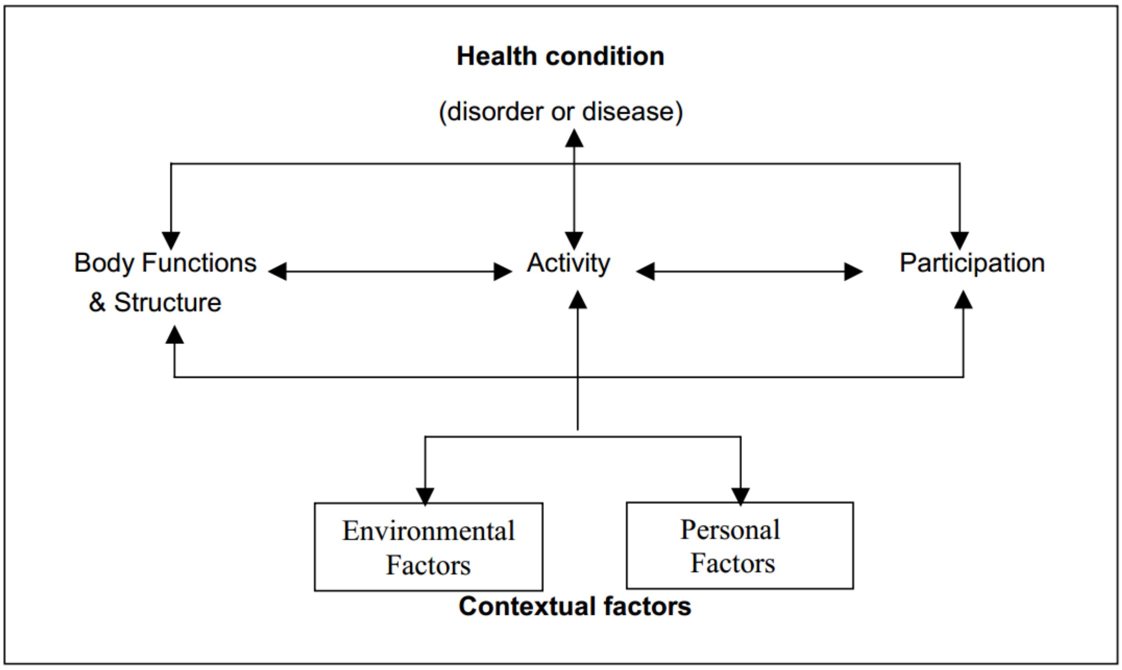

Figure 1. Model of disability that is the basis for ICF (World Health Organization, 2002).

Impairments in body function and structure refer to any physiological or psychological change as a result of a health or health-related condition, at an anatomical or emotional level (World Health Organization, 2002). Examples of functions include sound detection and sound discrimination, and examples of structures include the cochlea and tympanic membrane.

Activity limitations (ALs) refer to difficulties in the execution of activities such as difficulties listening, whereas participation restrictions (PRs) refer to problems experienced in involvement in life situations such as difficulties being able to engage in recreation and leisure roles (World Health Organization, 2002). Though this distinction is made, these two areas are highly linked (World Health Organization, 2002).

Finally the ICF incorporates contextual factors which describe the setting of any disability in the other areas of the model. These factors include negative environmental factors or barriers such as background noise, and positive environmental factors or facilitators such as positive societal attitudes toward disability. Personal factors refer to factors such as age, education and coping styles and are not currently classified within the ICF.

This model began being implemented in 2001 after its endorsement by all 191 WHO member states as an international standard (World Health Organization, 2015). Since then it has been used to classify the health status of the general population in many countries, as well as to provide better disability statistics. Furthermore, questionnaires and data sets have been developed in relation to the ICF model to further understanding in healthcare facilities and the ICF has influenced decision and policy-makers, contributing to legislation and health and social standards in various countries and communities (World Health Organization, 2002; World Health Organization, 2015). Among these many uses, the ICF model was designed for use in relation to needs assessments (World Health Organization, 2002), therefore it has been applied to this study in order to utilise its universality and descriptiveness in relation to the needs of CI recipients.

In order to use the most relevant portions of the ICF to individuals with HL, the core set for HL is referred to in the sections below. The framework for the development of core sets in many different areas of health was developed by the WHO and the ICF Research Branch to provide a scientifically-based method of determining the most relevant domains of the ICF to any one given health condition (ICF Research Branch, 2012). The core set for HL was published in 2014 and was developed using qualitative interviewing of adults with a wide range of HL (Granberg et al., 2014). The domains in which functioning was deemed to be affected by HL were recorded. These domains are listed below along with relevant literature regarding HL and deafness.

1.2.2.1.2 Body functions and structure in relation to HL

According to the ICF core set for HL, the functions of the body that can be affected by HL include hearing acuity but also potentially seeing and vestibular functions. Issues in functions aside from hearing are more common in individuals with HL as a result of a syndrome. Syndromic HL is present in between six and 30 percent of people with HL as reported across the literature (Bamiou, Macardle, Bitner-Glinzicz, & Sirimanna, 2000; Castiglione, Busi, & Martini, 2013). Pain was also listed in the ICF core set for HL. This functional impairment may relate to otalgia due to otitis media or externa, or hyperacusis in individuals with sensorineural HL.

HL is related to temperament, personality, energy and drive, emotional functions and potentially even memory functions. Some studies have looked at rates of depression and anxiety and discovered higher rates of symptoms present in those with deafness compared to those with normal hearing (Kvam, Loeb & Tambs, 2007). In some instances, depression due to having HL has even been dismissed as a natural consequence (Leigh & Pollard Jr., 2003).

Some studies have indicated that severe mental illness may be more prevalent in people with deafness (Vernon & Daigle-King, 1999), however this is debated in the literature when considering individual disorders such as schizophrenia, with some studies finding similar rates in those with HL and those without (Pollard, 1994). Many aetiologies of HL are comorbid with neurologic impairment, which may support a higher percentage of mental disorders in those with deafness (Leigh & Pollard Jr., 2003).

The structures of the external, middle and/or inner ear, as well as the brain, are potentially affected by deafness. This typically includes the outer and/or inner hair cells of the cochlea, but can include issues with the synapse connections between the hair cells and the auditory nerve fibres or issues with the nerve itself. This HL can be compounded by issues with the middle ear ossicles or tympanic membrane, or any other issues in the middle or outer ear, however, issues in these areas alone cannot produce more than a moderately severe HL (Schlauch & Nelson, 2009).

1.2.2.1.3 Activity limitations and participation restrictions in relation to HL

One of the most obvious areas of limitation for people with deafness is that of listening. This can include the full array of sounds available to individuals with normal hearing, such as listening to people speaking, music or the radio. This difficulty listening can cause many issues in other areas of life.

Carrying out daily routines can also be affected by HL, including going about everyday tasks with the same ease as those with normal hearing, as well as handling stress or other psychological demands. Very little research has been conducted on the relationship between stress and deafness, however there is some evidence to suggest there is a positive correlation (Jones, Ouellette, & Kang, 2006). This additional stress some people with deafness appear to have has been attributed in part to greater unemployment and underemployment, difficulties communicating with hearing individuals in certain settings and considering themselves part of a cultural and linguistic minority group when identifying with Deaf culture (Cohen & Williamson, 1988).

Several key areas of functioning present in the ICF core set for HL are related to communication. This includes receiving spoken messages and understanding implied meanings. Understanding implied meanings such as sarcasm, joking, irony and other nonliteral language involved in social communication have been shown to be difficult for adults with deafness (Gregory, Bishop, & Sheldon, 1995; O'Reilly, Peterson, & Wellman, 2014). Also relating to communication is the area of conversation, involving the beginning, sustaining and ending of conversation with others, whether vocal, written or other forms of language such as sign. The greater potential for language disfluencies, and literacy and knowledge base deficiencies for people with prelingual deafness may result in added difficulties for this population, as well as the challenges presented through having a visual-gestural language as a primary method of communication for native sign language users (Dean & Pollard Jr., 2001; Leigh & Pollard Jr., 2003; C. Lucas, Bayley, & Valli, 2001).

Using communication devices and techniques such as the telephone can also be affected by HL. Using the telephone can be extremely difficult or impossible for many people with deafness, therefore many people with deafness use other forms of communication technology such as e-mail, mobile phone text systems or fax machines (Price, Cole, & Chasin, 2009). Relay services are also available in some countries, using relay assistants to type, voice or sign incoming or outgoing phone calls so that people with deafness can call standard phone lines (New Zealand Relay, 2015).

The ICF core set for HL also lists walking and moving around as possible ALs, however, this is more relevant in those who have mobility issues, possibly as a result of a syndrome with HL as one symptom among others. However, moving around can include travel in various vehicles which can be difficult when instructions cannot be heard over loudspeakers or from a person speaking with their back turned, such as in an airport or train station.

A key participation area that can be affected by HL involves family relationships. In a study by Luckner and Stewart (2003), adults with deafness who were considered to be successful by their peers described family support and good communication amongst family as extremely important, especially throughout their childhood. There is very little published research on the impact of family relationships on people with deafness in their adulthood, especially those with prelingual deafness. There is some evidence linking self-efficacy to the ability to communicate easily with family members, especially those family members whose preferential method of communication is the same as that of the individual with deafness (i.e., sign language or oral due to having family members with deafness or normal hearing accordingly) (Adi-Bensaid, Michael, Most, & Gali-Cinamon, 2012; Atkin, Ahmad, & Jones, 2002). It should be noted, however, that all the participants with deafness in this study communicated primarily via an unspecified form of sign language, which may influence the dynamics of the family differently than the use of oral communication. Another study discovered a lower ability for spousal intimacy in adults with prelingual deafness compared to a control group of peers with normal hearing (Levinger & Ronen, 2010).

Along with family relationships, community life has also been shown to be affected in those with deafness. Atkin et al. (2002) found that deafness can be perceived as threatening full inclusion in society and the surrounding community, largely due to difficulties with communication with negative societal attitudes towards individuals with deafness also contributing. This study also mentioned some young people with deafness having diminished roles in the community, though only around a third of the participants of the study were adults (i.e., over 18 years of age).

School education and paid employment also fall under the core set relating to HL from the ICF. Higher unemployment rates have been identified amongst people with deafness (Leigh & Pollard Jr., 2003). This is supported by research conducted by Cohen and Williamson (1988), with the inclusion of underemployment as a major issue for individuals with deafness, with significantly higher rates of individuals with deafness having post-secondary qualifications but working in lower skilled jobs.

1.2.2.1.4 Contextual factors in relation to HL

Environmental factors that can contribute to the functioning of a person with deafness include the health professionals working with the individual as well as the provision and quality of health services, systems and policies. This can include audiologists, speech therapists, doctors and various specialists, and the services they provide. Cooper, Rose and Mason (2003) administered and evaluated an 'Attitudes to Deafness Scale' to human service professionals in an attempt to formulate a tool to use when training professionals in issues involving deafness. There is some evidence to suggest that training in deafness or deaf issues may produce more positive attitudes from mental health professionals towards individuals with deafness (Cooper et al., 2003). Information about deafness was found to be insufficient in India, according to a study by Gupta, Sharma and Singh (2010), in which a wide range of groups of people including health workers, doctors and clinicians were interviewed, finding that many family members and people working in health care had incorrect information and understanding about diagnosis and treatment for deafness.

The family that an individual with HL lives with or communicates with, along with the attitudes of those family members, can also influence the individual's functioning, according to the ICF's core set for HL. Interactions between individuals with deafness and their families and surrounding environments are inevitably affected due to the lifelong nature of deafness (Power, 2005).

Some studies have looked at the difference between the upbringing and cultural identity of people with deafness, specifically whether they identify as having a "hearing" identity, (i.e., being audiologically deaf and having a sense of identity with normally hearing people), having a Deaf identity (i.e., being culturally Deaf usually involving the language, beliefs and culture of the Deaf community), having a bicultural identity (i.e., identifying with both Deaf and hearing culture) or being "marginal" (i.e., not feeling affiliated with Deaf or hearing culture or people). It was discovered that self-esteem and satisfaction with life was highest for those identifying as culturally Deaf or bicultural, and lowest for those considering themselves to be marginal (Bat-Chava, 2000; Leigh & Pollard Jr., 2003; Maxwell-McCaw, 2001).

Societal attitudes can also be a key environmental factor. In general, societies made up predominantly of people with normal hearing do not communicate effectively with people with deafness, resulting in marginalisation of the minority (Atkin et al., 2002). This is supported by a study by O'Donovan, Doyle and Gallagher (2009) who found that people's attitudes were the most common barrier to participation for people with hearing disabilities. This was closely followed by income and access to information as other significant barriers. Awareness of cultural diversity, respect and effective communication skills were identified as important factors contributing to positive interaction between tertiary students with deafness and normal hearing, indicating the importance of societal attitudes for relationship-building (Coryell, Holcomb, & Scherer, 1992).

Another important environmental factor is the availability and quality of products and technology for communication. At present there is a multitude of options for people with deafness to be able to communicate with others with normal hearing or deafness. Included are technologies such as mobile phones using Short Message Service (SMS) or fax machines, used mostly for social interaction, or otherwise telephone typewriters (TTY) using a relay service if communicating with others without TTYs, or computers using e-mail or Internet chatrooms, which tend to be used for personal or business communications, according to research involving the Deaf community in Australia (Power, Power, & Horstmanshof, 2007). The environmental factor relating to the amount and type of sound around a person can also affect their functioning, such as the intensity, complexity and importance of sound in different activities or parts of everyday life.

Personal factors affecting an individual with deafness are specific to each person and are therefore hard to ascertain. Gender played a role in the integration into and communication within families for South Asian young people with deafness, though this is likely to include a combination of ethnic traditions and religious beliefs in relation to gender (Atkin et al., 2002).

1.2.3 Intervention for HL

Typical intervention for HL is the provision of hearing aids, which consist of microphones, amplifiers and receivers as basic components (Dillon, 2012). These are available in a wide range of sizes, styles and levels of technology. The most common styles are behind-the-ear and in-the-ear, with other styles including in-the-canal, completely-in-the-canal and body aids (Dillon, 2012). While hearing aids are the most commonly provided intervention for HL, there are other intervention options. The intervention option selected will depend on many factors. These factors include the type of HL and degree of HL present in the individual.

Those who have conductive, mixed or unilateral sensorineural losses and cannot wear traditional in-the-ear or behind-the-ear hearing aids may be derive benefit from bone conduction hearing aids (Garstecki & Erler, 2009). These aids are positioned on the mastoid process either in a headband on the exterior of the head or implanted into the mastoid bone under the skin with an external processor, known as a bone-anchored hearing aid (Dillon, 2012). These aids make use of bone conduction, much like the bone conduction used during pure tone audiometry, to better stimulate the inner ear by bypassing the outer and middle ear. This method of stimulation is only suitable for mild to moderate degrees of HL due to limitations in the power of the aids (Tharpe, 2009), and sound localisation abilities are poor if present at all, though there is some improvement with bilateral aids (Priwin, Stenfelt, Granström, Tjellström & Håkansson, 2004).

Along with bone conducted hearing aids, contralateral routing of signal, or CROS aids, can be appropriate for those with a significant loss on one side but normal hearing on the other side, also known as single-sided deafness. If there is an aidable hearing loss in the better ear then a BiCROS system can be used. These aids use a microphone on the poorer ear to pick up sound and transmit it to a receiver in the better ear, which has an additional microphone in the case of a BiCROS (Dillon, 2012). The use of this contralateral signal routing allows the aid user to hear sounds within a greater directional range than a single traditional hearing aid, though with the use of one ear only (Bentler & Mueller, 2009).

For individuals with bilateral deafness, hearing aids are typically unable to provide substantial benefit in the area of speech perception, which has been used as a measure of overall hearing aid benefit (Flynn, Dowell & Clark, 1998; Plomp, 1978). The dynamic range of individuals with sensorineural HL, meaning the range between their thresholds and uncomfortable loudness level, can be greatly reduced due to elevated thresholds. Individuals with deafness may be candidates for cochlear implantation: the insertion of an electrode array into the cochlea in the inner ear, connected to an external processor, which provides electrical stimulation of the auditory nerve creating a sensation of sound (Sandlin & Bongiovanni, 2002).

Cochlear implantation involves a surgery under general anaesthetic, usually lasting approximately two to three hours, during which the internal device components are inserted (Hearing House New Zealand, 2012a; Kimura & Hyppolito, 2013). These components include an internal processor, otherwise known as a receiving coil, which is embedded in the skull behind the mastoid bone, and an electrode array which is inserted into the scala tympani of the cochlea via the middle ear. Some models also include a ground electrode which is inserted under the temporalis muscle (Hearing House New Zealand, 2012b). Following the surgery, CI recipients are typically discharged from hospital within 24 hours (Zwolan, 2009) and the device is switched on by an audiologist within three to five weeks (Zwolan, 2009). The CI works through a system of changing mechanical sound waves into electrical impulses designed to stimulate the auditory nerve, as shown in Figure 2.

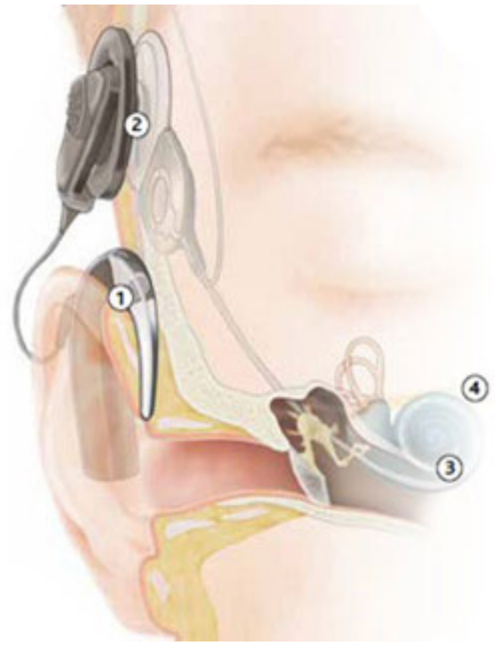

Figure 2. How a CI works. 1) Sound is transformed to digital sound. 2) Digital sound is sent to the internal implant. 3) Digital sound is converted to electrical impulses. 4) The auditory nerve is stimulated and the brain interprets this as sound (Southern Cochlear Implant Programme, 2014b). Reprinted with permission.

Various other assistive listening devices are also available to help in more challenging or more specific situations, and are usually used alongside hearing aids, bone-anchored hearing aids or CIs. The devices include amplified telephones, frequency modulation (FM) systems and television (TV) aids. They are able to send signals such as people speaking into microphones or sounds from a TVs directly to hearing aids or earphones to provide an improved signal-to-noise ratio, improving hearing potential (Thibodeau, 2014). Aside from or along with providing technology, other interventions for clients/patients with HL include counselling, participation in self-help groups and communication training, with or without communication partners (Garstecki & Erler, 2009).

1.2.4 Factors influencing intervention

One of the key factors influencing the success of intervention is the age of onset of deafness. For recipients with postlingual deafness, the benefits of cochlear implantation are significant, with communication abilities greatly enhanced, including speech perception scores at both a word and sentence level (Francis, Chee, Yeagle, Cheng & Niparko, 2002). For those who have prelingual deafness, the research has consistently shown the outcome of implantation is largely dependent on the age at which the recipient was implanted and the duration of their deafness, with smaller benefits recorded for those with a greater duration of deafness and later implantation, such as those implanted as adults having spent most or all of their life with a severe to profound deafness (Bradley, Bird, Monteath, & Wells, 2010; Teoh, Pisoni, & Miyamoto, 2004). For the purposes of this study, adult CI users can be considered late-implanted if they received their implant(s) at the age of 18 years or above. This is consistent with the description of late-implantation provided by Bradley et al. (2010). Other factors that can influence the performance of recipients with CIs include age, speech and language abilities, support from family and friends, expectations and motivation, additional disabilities, educational setting, key mode of communication, functional hearing, availability of support services, intensity of post-implantation rehabilitation and the anatomy of the ear as seen through radiography (Bradley et al., 2010).

1.2.5 Benefits of intervention

Earlier in the development of CIs it was thought that adults with prelingual deafness would not receive enough benefit from CIs to warrant proceeding with the implantation (Klop, Briaire, Stiggelbout, & Frijns, 2007). Since then, it has been discovered that implantation of these individuals can provide a significant increase in their quality of life as well as a greater awareness of environmental sounds and other benefits (Klop et al., 2007;

Zwolan, Kileny, & Telian, 1996). Bosco et al. (2013) found that cochlear implantation had long-term (mean of seven and a half years' experience with the CI) positive impacts on the recipients' lives, as indicated by the participants themselves. When considering the categories within the ICF, there are many benefits from late cochlear implantation of adults with prelingual deafness.

1.2.5.1 Body structures and function in relation to CIs

The CI has been one of the most successful neural prostheses developed thus far, with exceptional cost-effectiveness (Gunn, 2010; Wilson & Dorman, 2008). The most basic improvement in body function for CI recipients with prelingual deafness is being able to experience the sensation of sound, often for the first time. The insertion of the electrode array into the cochlea typically destroys any residual hearing due to the invasiveness of the procedure, though for those with some aidable hearing in the ear to be implanted, hybrid devices with custom-made electrode arrays are becoming more viable and popular (Golub, Won, Drennan, Worman, & Rubinstein, 2012; Zwolan, 2009). The CI takes on the role of a functioning cochlea, changing kinetic sound waves into electrical impulses to stimulate the auditory nerve, bypassing the hair cells of the cochlea which are most commonly the damaged or malformed portions of the ear when deafness is present due to the typically sensorineural nature of deafness. Though this does not replicate natural hearing, it does restore some of the function of hearing (Zwolan, 2009).

1.2.5.1.1 Emotional functioning

CIs have also been shown to produce significant improvement in the emotional functioning of individuals with prelingual deafness including a decrease in feelings of loneliness (Most et al., 2010) and an increase in self-esteem (Hinderink, Krabbe, & van den Broek, 2000; Straatman, Huink, Langereis, Snik & Mulder, 2010; Peasgood, Brookes, &

Graham, 2003), though the latter is debated in the literature with some studies suggesting no change pre- and post-implantation (Most et al., 2010).

1.2.5.1.2 Speech perception

A popular area of research with regards to adult CI users is speech perception pre- and post-implantation, or across several time intervals post-implantation. There is some debate about the length of time post-implantation at which improvements in speech perception plateau. A study by Bradley et al. (2010) suggested the plateau to be at six months post-implantation and Wilson & Dorman (2008) suggest it to be at 12 months post-implantation, along with Teoh et al. (2004). These differences may be impacted by the technology of the devices used by the participants as CI recipients may adapt to different speech processing strategies differently, or the rehabilitation programmes used as the studies were conducted through different cochlear implant programmes across the world.

Several studies have included specific data of speech perception for late implanted adults with prelingual deafness, relevant to the present research, however they also present differing results. One such study, conducted by Teoh et al. (2004), compiled speech perception scores from 103 late implanted adults with a range of brands of implants in three open set tests: two sentence tests and one word recognition test. They recorded a highly significant difference between patients with prelingual deafness and patients with postlingual deafness. There were minimal differences across the different devices. The patients with prelingual deafness reached a significantly lower plateau of percentage of correctly identified speech sounds than the patients with postlingual deafness, and all groups analysed reached their plateau in perception approximately one year post-implantation.

Bosco et al. (2013) found a significant increase in speech perception pre- and post-implantation in their adult sample, all of whom had prelingual deafness and were implanted at least five years prior to the collection of the post-implantation speech results, suggesting these were long-term results. It should be noted that the tests used to measure speech perception were in Italian, not English as the present research will use. This research by Bosco et al. (2013) is particularly relevant clinically as the speech perception tests used included sentence-based comprehension tests in which the patients were asked to respond to questions asked. There was a significant improvement in the number of correct responses to these questions from the adult participants, implying that CIs can aid conversation in at least a controlled environment. Despite the improvement, it should be noted that the average post-implantation score in the comprehension test was only 52.7%, implying the subset of CI users of interest in this study still have a significant deficit in open-set sentence-based speech perception abilities, even with their implants.

Kos, Degive, Boex and Guyot (2007) did not look at pre- and post-implantation comparisons but looked at post-implantation results only. They conducted a study using a French consonant identification test, in which they considered a score of 55 percent or above to be the minimum level needed to communicate without lip-reading. Their study looked solely at CI users who had postlingual deafness, with approximately 92 percent of the participants scoring above this minimum score. This implies that approximately eight percent of the participants were still unable to communicate without lip-reading, despite having developed language before developing deafness. Based on research comparing CI users abilities who had pre- and post-lingual deafness (Teoh et al., 2004), it is expected that this number (eight percent) would be even higher for CI users with prelingual deafness, implying numerous people are still unable to communicate without lip-reading including using the telephone (Kos et al., 2007). It should be noted, however, that the testing documented in the paper by Kos et al. (2007) was not conducted in English and the 55 percent benchmark was based solely on clinical experience, not any published research.

Although the studies described above are in agreement, perhaps the most relevant study depicts more favourable results with regards to speech perception in open-set sentence tests in quiet (Bradley et al., 2010). The Bradley et al. (2010) study consisted of data from patients from SCIP in New Zealand, the same programme from which the participants for the present study were recruited. In this study, auditory and auditory-visual speech perception tests results were obtained from 13 late cochlear implanted adults with prelingual deafness (Bradley et al., 2010). Results were obtained from the files of the participants before their implantation with the use of their hearing aid(s), at the time the implants were switched on and at one, three, six, nine, 12, 18 and 36 months post-implantation, when available. It was found that the mean long-term auditory and auditory-visual speech perception scores were higher than the pre-implantation auditory and auditory-visual scores respectively, with the greatest improvement shown for those who performed more poorly before their implantation. For those who scored zero percent in the auditory test pre-implantation, long-term results showed a mean of 82 percent, indicating a significant increase in the group's ability to perceive speech sounds in a quiet controlled environment. The differences between the studies involving analysis of speech perception in individuals with deafness could be explained by: the testing conditions, such as the presence of noise or competing talkers built into the speech perception tests; the type of tests, such as sentence or phoneme-based tests; or the age of the technology in the devices used by the participants.

It is important to note that some of the clinical results from the older studies may not be as valid as those from newer studies as the speech processing strategies have changed in each of the major brands of CIs, which have increased the speech perception abilities for most implant users (Teoh et al., 2004), therefore there is an opportunity for more updated research to be conducted. This difference in speech perception between older and newer models of CI has also been documented in New Zealand also (Bradley et al., 2010).

1.2.5.1.3 Awareness and discrimination of environmental sounds

Aside from speech perception, other clinical results that have been shown through research in relation to late cochlear implanted adults with prelingual deafness include awareness of surrounding environmental sounds (Berrettini et al., 2011; Peasgood et al., 2003). The study by Peasgood et al. (2003) showed an average percentage of recognised environmental sounds pre-implantation of zero percent and post-implantation of approximately 40 percent. This study also commented that the participants were often able to replicate the sounds even if they could not state what they were.

1.2.5.1.4 Localisation of sound

In addition to these clinical results, information about localisation of sound for late implanted adults with prelingual deafness has been observed by Nava, Bottari, Bonfioli, Beltrame and Pavani (2009). Though minimal, some localisation ability was found to be present in monaural recipients from this study, which emerged only following several years of use of the implant.

1.2.5.1.5 Oral language skills

The oral language skills of Italian-speaking late implanted adults were assessed by Bosco et al. (2013). These skills included lexical production, lexical comprehension and reception of grammar. The average language-equivalent age in years across these three tests for the adults was 13.1 pre-implantation, rising significantly to 19.3 post-implantation. Though the average results are presented, there was large variability in the data. Despite the averages, there was no significant improvement pre- and post-implantation long-term in the visual analogue scale (VAS), which consists of clinicians' perceptions of the patients' naturalness of articulation, intelligibility and grammar. The speech of the adults was not well articulated nor easily understood by the clinicians in most cases. Evans and Deliyski (2007) documented considerable variation in oral language across their subjects, though there were only three participants, but the study found some evidence to suggest lowered fundamental frequency post-implantation for individuals with prelingual deafness, and nasalance closer to the quality of individuals with normal hearing.

1.2.5.2 ALs and PRs in relation to CIs

1.2.5.2.1 Music perception and appreciation

Fuller, Mallinckrodt, Maat, Baskent and Free (2013) evaluated the quality of life for late cochlear implanted adults with prelingual deafness in relation to music appreciation with 60 percent of participants stating they found listening to music pleasant, however there was no correlation between this and quality of life measures. The enjoyment of music by only 60 percent of CI users was considered to be potentially due to the lack of auditory input and therefore perception of music throughout the participants' lifetimes. This may indicate that CI users have certain unmet needs around music appreciation, however further research was recommended by Fuller et al. (2013).

Several studies have looked at music perception and appreciation in adults with postlingual deafness, describing participants' recollection of how music sounds (Looi & She, 2010; Looi, Winter, Anderson & Sucher, 2011). Zhao, Bai and Stephens (2008) stated that hearing music is still one of the greatest difficulties long-term with the CIs, though their participants were implanted between 1991 and 2000, and would therefore have older technology and processing strategies than are currently used.

1.2.5.2.2 Performance at work

Most et al. (2010) discovered a significant self-reported increase in the performance of late implanted adults with prelingual deafness at work post-implantation. Kos et al. (2007) researched patient satisfaction in relation to professional occupation for CI users, though only for adults with postlingual deafness, and discovered that patients were more likely to be satisfied with their implants if they were professionally active. It is assumed that "professionally active" means currently in employment, however this was not defined in the paper. Only 29 out of 60 participants were professionally active at the time of taking part in this study. This may indicate that there are needs in the area of employment for some CI users, or needs around general satisfaction with the CI for those who are unemployed.

1.2.5.3 Contextual factors in relation to CIs

1.2.5.3.1 Environmental factors

An environmental factor that can potentially influence people with health conditions is the support they receive from family, friends and professionals. This has barely been studied in relation to CIs, with one literature review stating the characteristics of this support can likely influence rehabilitation results and perceived benefit for older adults, but having no backing evidence (Clark et al., 2012). The family climate of late implanted adults with prelingual deafness has been proven to be impacted less than other realms of life such as communication or social skills, with no significant change before and after implantation (Most et al., 2010).

1.2.5.3.2 Personal factors

A paper by Klop et al. (2007) sought to provide evidence for or against personal factors in relation to speech perception for late implanted adults with prelingual deafness, specifically gender, communication mode, hearing aid use and education background, however there were no significant correlations once they removed the effects of outliers in their small sample.

1.2.5.4 Quality of life in relation to CIs

Measuring quality of life combines effects from different areas of the ICF. The WHO defines quality of life 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" (The WHOQOL Group, 1998, p. 551). Hawthorne et al. (2004) observed a significant positive increase in the health-related quality of life for CI users up to six months post-implantation, especially for those who fit within the top socio-economic band, however there was a mix of CI users with prelingual and postlingual deafness in the study and these needs cannot be considered long-term without further testing. The results in this study were supported by the results from a New Zealand study by Looi, Mackenzie et al. (2011) which used its own questionnaires to evaluate quality of life and satisfaction, showing an increase in both areas post-implantation, however the participants were all adults with postlingual deafness.

In a study on adults with prelingual deafness, it was observed that the participants' quality of life was improved significantly post-implantation (Klop et al., 2007). These results were recorded pre-implantation and at regular intervals post-implantation up to 30 months and can therefore be considered long-term results, implying a long-term improvement in quality of life for late cochlear implanted (though they considered this term to mean implanted from the age of 16 and older) adults with prelingual deafness.

When the Glasgow Benefit Inventory (GBI) was used to evaluate the quality of life of CI users post-implantation, an average score of 38.9 was recorded (on a scale of -100 to 100, with 100 being fully satisfied) (Peasgood et al., 2003). With regards to patient satisfaction, a subcategory of the GBI, Peasgood et al. (2003) found that there was large variation in scores between the participants. Half of the participants scored 100, implying they were fully satisfied with their implants at the time of completing the questionnaire. The mean satisfaction score was 82.7.

Gaylor et al. (2013) stated in their systematic review that, of the 16 studies that evaluated quality of life in adult CI users, participants typically showed either no significant change or a significant improvement in their quality of life, though this was not specific to those with prelingual deafness nor were they guaranteed to focus on long-term results.

1.3 CI in New Zealand

1.3.1 CI programmes in New Zealand

Cochlear implantation was first brought to New Zealand with the implantation of two women with postlingual deafness in 1987 (Gunn, 2010). The first implantations were provided through a small programme in Auckland (Bradley et al., 2010). Now, New Zealand has two CI programmes: the Northern Cochlear Implant Programme (NCIP) and SCIP, which serves the northern and southern halves of the population respectively. SCIP serves the entire South Island and the lower half of the North Island of New Zealand, with the boundary across Taupo (Hearing House New Zealand (2012c)), as shown in Figure 3.

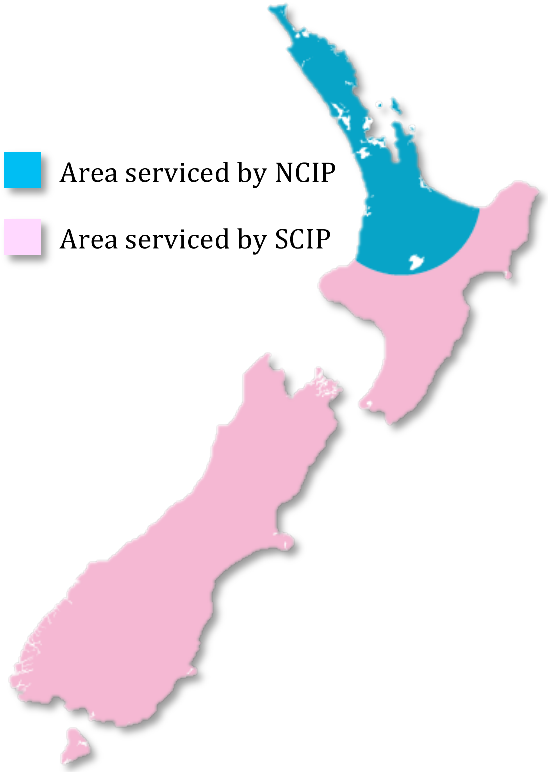

Figure 3. Map of New Zealand depicting areas serviced by the two CI programmes (adapted from Hearing House New Zealand (2012c)). Reprinted with permission.

1.3.2 The Southern Cochlear Implant Programme

SCIP is based in Christchurch and was established in 2003 (Southern Cochlear Implant Programme, 2014a). In late 2014 SCIP also opened a satellite clinic in Lower Hutt in the North Island (Southern Cochlear Implant Programme, 2014c). Within SCIP is an adult programme and a paediatric programme, with the transition between them occurring from 18 years of age (Bradley et al., 2010). As of the end of 2013 the programme had over 400 adult recipients on their database, with the number of adults being implanted growing consistently since 2010 as government funding increased (Southern Cochlear Implant Programme, 2013). Approximately five percent of these adults have prelingual deafness (N. Heslop, personal communication, March 13, 2014).

SCIP offers assessment and counselling through the pre-implant process and provides appointments with both audiologists and rehabilitationists post-implantation which gradually lessen in frequency throughout the first 18 months with the device. After this point, the recipients' contact with the programme involves annual follow up appointments with an audiologist unless extra appointments are requested by either the recipient or clinician (N. Cleine, personal communication, March 13, 2014).

1.3.3 CI outcomes for adults in New Zealand

There have been just a few published studies involving the adult CI population in New Zealand. Some have involved recipients from both the NCIP and SCIP and others have focussed on recipients from one programme only. One study has included adults with prelingual deafness from the SCIP database and the results were largely compounded with those with postlingual deafness, though some results were presented separately (Bradley et al., 2010). This study showed a significant difference between the auditory-alone speech discrimination of those with an onset of deafness before three years of age compared with those with an onset from greater than three years of age, consistent with literature from other CI programmes across the world.

Also consistent with international literature is the results of environmental sound perception of CI recipients including late cochlear implanted adults with prelingual deafness. Looi and Arnephy (2010) tested 10 experienced CI users, two of whom were late cochlear implanted adults with prelingual deafness. The study found a significant difference between participants with normal hearing and experienced CI recipients, with CI recipients displaying greater confusion of environmental sounds with similar temporal characteristics, such as keys jangling and glass breaking, even after extensive experience listening with a CI. Looi and Arnephy (2010) also compared the environmental sound perception of four people on the waiting list for CIs before their implantation and three months after, though only one of these had prelingual deafness. Every category of environmental sound showed improvement post-implantation, though it did not quite reach significance. It is possible that this difference in scores would reach significance if the participants were tested after having more experience with the CI as performance for other listening skills such as speech perception plateaus around six months for recipients with postlingual deafness, and after an even greater length of time for those with prelingual deafness (Bradley et al., 2010). Interestingly, Looi an Arnephy (2010) did not find any correlation between scores from the environmental sound test and age of onset of deafness, or duration of CI use.

It should also be noted that Bradley et al. (2010) discovered a significant difference between different implant models. From 2004, SCIP began fitting Cochlear Ltd.’s Freedom model; a change from the Nucleus 22 and 24 models implanted previously. The Freedom model, being updated technology, resulted in significantly greater long-term auditory-alone speech discrimination across the participant group as a whole.

1.4 Long-term needs

For the purposes of this study, the definition of an unmet need is “something that is desired or lacking but wanted or required to achieve a goal or attain a particular end” (Dunst, Trivette & Deal, 1988, p. 13). This is similar to another definition from Bailey Jr. and Blasco (1990, p. 196) of “a desire for services to be obtained or outcomes to be achieved,” and a simplified description provided by the Concise Oxford Dictionary of “a thing that is wanted or required” (Pearsall, 1999, p. 953). The definition of a met need used in this study is an adapted version of that defined in the aforementioned study by Dunst et al. (1988, p. 13), which is “something that is no longer desired or lacking, wanted or required, having achieved a goal or attained a particular end.”

The needs of CI users can be considered long-term after a certain period of time following implantation. During the process of receiving a CI and the associated set up, adjustment and (re)habilitation that follows shortly afterward, SCIP provides frequent appointments and support (N. Heslop, personal communication, March 13, 2014). The stage of interest in this research, however, is the stage after the frequent appointments with audiologists and rehabilitationists have been reduced to only an annual review with an audiologist. Within SCIP in New Zealand, this reduced frequency of appointments typically occurs around 18 months post-implantation, after which the cochlear implanted adults’ needs are considered long-term (N. Heslop, personal communication, March 13, 2014). This time-frame is greater than the time-frame suggested for plateaus in speech perception presented in the literature (Bradley et al., 2010; Teoh et al., 2004; Wilson & Dorman, 2008), therefore it is likely that speech perception results will have plateaued for the participants in the present study, which contributes to the support of this definition of long-term device use.

Though the aforementioned research has highlighted some of the improvements or lack thereof in various outcome measures for late cochlear implanted adults with prelingual deafness, very little research has been published on the long-term needs of this population. One study investigated the needs of adults with postlingual deafness in a questionnaire with only a single item asking whether the CI had met the recipients' needs (Looi, Mackenzie et al., 2011). Eighty-three percent of the participants responded that the CI met most or all of their needs. Though the duration of CI use ranged from one month to 21 years, the average was four years and one month, implying that a considerable proportion of the participants would have had their CIs for more than 18 months, therefore their needs can be considered long-term and are of interest to the present study. The nature of the recipients' needs was not explored, nor was the concept of a need defined.

Kos et al. (2007) conducted a study seeking to understand some of the relationship between cochlear implantation and professional occupation, but no tangible occupational needs were discovered. No other published studies have looked at any potential areas of need or broad overviews of need for CI recipients, either in New Zealand or elsewhere in the world.

To our knowledge, no studies have been published on the needs of late cochlear implanted adults with prelingual deafness, however some studies have looked at the quality of life for late-implanted adults with prelingual deafness using surveys or questionnaires. Hawthorne et al. (2004) administered two questionnaires, one assessing quality of life and one assessing hearing participation, to adult CI recipients pre- and post-implantation and discovered a significant increase in the quality of life of their participants over this timeframe. The participants included both adults with prelingual and postlingual deafness, though the study found the difference in age of onset of deafness did not correlate with quality of life scores. The sample size of the study was not large enough to analyse the different dimensions of the quality of life questionnaire, therefore there is no information on any specific areas of life that were impacted more than others in this participant group.

Klop et al. (2007) studied adults with prelingual deafness only, finding significant improvements in their quality of life overall, comparing pre- and post-implantation with the use of two questionnaires. The domains of life with significant differences were sensation, including vision, hearing and speech, basic sound perception, advanced sound perception and social interaction. All of the participants experienced increases in quality of life in some or all of these domains, though the sample size of this study was also small, involving just eight participants. The domains in which quality of life has improved or not improved, as provided by the questionnaires used in these studies, provide some insight into potential met and unmet needs of late cochlear implanted adults with prelingual deafness.

1.5 Study rationale

The needs of late cochlear implanted adults with prelingual deafness have not been explored in New Zealand. This includes both met and unmet needs. Whilst there has been some research conducted on the quality of life and/or client satisfaction pre- and post-implantation for CI users (Caposecco et al., 2012; Fuller et al., 2013; Hawthorne et al., 2004; Klop et al., 2007; Looi, Mackenzie, et al., 2011; Most et al., 2010; Peasgood et al., 2003; Zwolan et al., 1996), there has been no published research specifically focussed on exploring the needs of late cochlear implanted adults after the first 18 months with their device(s). This presents a unique opportunity for the exploration of the long-term needs of this group of people which can begin to fill this gap in the literature, with the hope that future research will be able to build on the findings from this study.

Research regarding late-implanted adults is also highly relevant from a clinical perspective. If more can be understood about the needs that are met by using a CI then implantation may be able to be discussed with better understanding within the population of adults with prelingual deafness, along with their family and friends (Most et al., 2010). In their paper involving late-implanted adolescents and adults, Bosco et al. (2013) concluded that addressing the specific needs of the implant recipients should be taken into consideration before implantation, however they did not specifically study these needs themselves. If these needs are explored then they could be used in a clinical setting, such as exploring the options around implantation. This research may also inform the development of future services and governmental policies in the area.

There has also been very little qualitative research conducted in the field of adult CI recipients, with Fitzpatrick and Leblanc (2010) and Hallberg & Ringdahl (2004) being some of the few researchers having used the approach. Qualitative research is particularly important as a part of the research base when human interaction is involved as it does not seek to impose the researchers' perceptions on the participants, but instead explores the subject of interest from the depth of personal experience expressed through interviews or similar data collection methods (Chow, Quine, & Li, 2010; Gooberman-Hill, 2012). This research will therefore be able to fill a gap in the range of research approaches presented in the literature on adult CI users.

1.6 Study aims

The overall aim of the research is to identify the long-term needs of late cochlear implanted adults with prelingual deafness within the southern half of the population of New

Zealand. This means exploring the needs of people who received CIs in adulthood but have had deafness from the age of three years or below, specifically looking at their needs at least 18 months after they received the implant. This study seeks to explore these needs from the perspectives of the CI recipients and service providers at SCIP.

The specific aims are as follows:

1. To explore the met and unmet long-term needs of late cochlear implanted adults with prelingual deafness from their own perspectives and those of the employees at SCIP.
2. To identify a consensus of the most important met and unmet long-term needs of late cochlear implanted adults with prelingual deafness.

2

Methods

2.1 Introduction – Modified Delphi Technique

2.1.1 Rationale for using modified Delphi technique

This study employed a modified Delphi technique, which is used to seek expert opinion and consensus through multiple stages or rounds of research (Nieswiadomy, 2012; Reynolds, Crichton, Fisher, & Sacks, 2008). This approach seeks to gain information from the experts in the field of interest, which is then summarised and presented anonymously back to these same experts for review.

The approach used for this research was modified from the original Delphi technique as it consisted of just two rounds, rather than three or more, as is more typical in Delphi research (Rowe & Wright, 2001). This simplified Delphi technique is not uncommon as there is often little change after three rounds and participants tend to dislike the repetition of completing multiple similar surveys (Delbecq, Van de Ven, & Gustafson, 1975; Linstone & Turoff, 1975). Two rounds only can therefore be considered sufficient (Delbecq et al., 1975; Keeney, Hasson & McKenna, 2011), as was the case in the Delphi technique for this particular topic, as it avoided excessive repetitions, similar to another health study conducted by Fletcher and Marchildon (2014).

The approach is also considered to be modified as the first round of research consisted of qualitative interviewing, as used in a Delphi study by Reynolds et al. (2008), rather than surveying. A qualitative research method was chosen for this round as the style allows for potentially emotionally laden and complex needs to be explored more thoroughly without assumptions from researchers (Gooberman-Hill, 2012). The interview method was chosen for the first round of this research so that the true needs of the participants could be conveyed with minimal restrictions on the responses each participant could give. This method allows for greater exploration of the participants' needs than quantitative surveys as the participants are able to guide the topics of discussion themselves, revealing elements of their perspectives that may not have been previously considered by researchers (Meston & Ng, 2012). Participants generally find it easier to talk about issues in person rather than via written communication, as long as the additional time required of the researchers for transcriptions and analyses is available (Delbecq et al., 1975). In addition, it is thought that having a face-to-face interviews for the first round of a Delphi study can increase the response rate as participants feel valued and therefore become more committed to future rounds (Keeney et al., 2011). In the present study, the semi-structured in-depth interviews (Whiting, 2008) were conducted with each participant individually, following which the transcripts were analysed, with the results used to generate the quantitative survey that was sent to each participant in the second round. The purpose of the survey in this second round was to gain a consensus across the participants.

2.1.2 Advantages and limitations of using Delphi technique

Two of the key advantages of the Delphi technique are the convenience with regards to accessing experts and the quasi-anonymity the method provides. When using this method, it is not necessary for the participants to be in the same place at the same time. If physical interviews are used, as in the present study, then a single participant and researcher are required to be at the same place at the same time, but the experts could be almost anywhere and still be able to contribute to the study (Fletcher & Marchildon, 2014). For the survey portion of the method, the participants can be anywhere and complete the survey at any time they choose, within the timeframe given. This adds considerable flexibility and possibilities for more expert opinions to be gathered and shared which may not have been possible otherwise (de Meyrick, 2001).

Any opinions or judgements provided through various rounds of a Delphi study are able to be kept largely anonymous. This is deemed quasi-anonymity due to the researchers knowing the source of the information, having met the participants face-to-face and analysed all interviews and surveys, but any information provided is strictly anonymous amongst the participants themselves (Keeney et al., 2011). It is also deemed quasi-anonymity as the participants may be in contact with one another outside of the study already, meaning the study cannot be truly anonymous, however they cannot tell which participant expressed which statement (Keeney et al., 2011). This means the participants are able to share their opinions without fear of the judgement of other experts causing embarrassment or pointing out naivety (de Meyrick, 2001; Fletcher & Marchildon, 2014). They are also able to change their mind in subsequent rounds without having to defend their original opinion, which can lead to participants feeling more willing to state their true opinions, along with a greater willingness to participate in the study in the first place (de Meyrick, 2001).

In addition, gaining the opinions and ideas of the participants separately, rather than through a method such as a focus group discussion, along with the anonymity the Delphi technique provides, ensures the views of the group are not distorted due to an overbearing participant or a participant with a more impressive reputation (de Meyrick, 2001; Fletcher & Marchildon, 2014; Schniederjans, Hamaker, & Schniederjans, 2004). Another advantage of the Delphi technique of gaining consensus is that any opinions that are unique to an individual participant can be identified and removed through subsequent questionnaire round(s), giving a final set of results that is more reflective of the group as a whole (Schniederjans et al., 2004).

This anonymity can also be a limitation of the Delphi technique as it can limit participant accountability, which can lead to participants making decisions based on speed of completing the task rather than accuracy of portraying their true opinions (Fletcher & Marchildon, 2014). This loss of interest or inaccurate portrayal of participants' opinions and ideas can result in an artificial consensus, meaning the accuracy of the results is reduced as the participants force a consensus that is not the true representation of their viewpoints (Fletcher & Marchildon, 2014; Gutierrez, 1989). Being physically distant from other participants can also decrease the motivation to begin and complete the tasks required of them as they may lose interest (Delbecq et al., 1975; Gutierrez, 1989).

The experts must be selected carefully to ensure a comprehensive array of opinions on the topic is gained, as well as ensuring the research questions or statements are clear and the analysis of the participants' responses is conducted adequately (de Meyrick, 2001; Fletcher & Marchildon, 2014). Due to the qualitative nature of portions of this method, it is also crucial that the researcher remain unbiased with the use of procedures such as reflexive journal entries and partial analysis of transcriptions and surveys by supervisors (de Meyrick, 2001).

2.2 Participants

The participants in this study were chosen based on the method prescribed by the Delphi technique, which is to approach those considered experts in the field. The group of experts chosen were required to be a "group of knowledgeable people: those who can provide relevant input to the process, have the highest authority possible, and are committed and interested." (Gutierrez, 1989, p. 33)

In this area of research, the experts were late cochlear implanted adults with prelingual deafness and service providers from SCIP in New Zealand including audiologists and rehabilitationists. These people are considered to have the most relevant information to contribute.

2.2.1 Inclusionary and exclusionary criteria

For the CI recipients, the inclusion criteria comprised of having a bilateral HL of at least a severe degree (pure tone average of 70 dB HL or greater) from the age of three years or younger, as well as having received a CI for the first time at the age of 18 or above, with the implantation being at least 18 months prior to being interviewed for this study. These participants were also required to be on the SCIP database. For the purposes of this study, the severity of HL and the age at which it was acquired were based on the CI recipients' self-report due to a lack of reliable records and protocols from when the participants were first diagnosed. For the SCIP clinicians, the criteria included having the position of audiologist or rehabilitationist, being employed by SCIP at the time of the interview and having worked with late cochlear implanted adults with prelingual deafness in the southern New Zealand region (the region serviced by SCIP).

All participants were required to be available to participate in an in-depth semi-structured interview in English. Exclusionary criteria included having a close family connection with the researcher, in order to avoid potential biases.

2.2.2 Recruitment

SCIP invited all cochlear implanted adults and SCIP clinicians who met the study inclusion criteria to participate in the study by sending them an invitation letter, study information sheet and consent form (see Appendices A, B and C accordingly). All potential participants were asked to contact the researcher directly if they were interested in participating in the study.

The researcher screened the potential participants who made contact via phone, email or post to ensure that they each met the inclusion criteria for their participant category (CI recipients and SCIP clinicians). If the individual did not meet the criteria, they were informed that they did not meet the criteria for the study and were thanked for their interest in the study. If the potential participant did meet the criteria, the researcher arranged a time and mutually agreeable place for an interview.

2.3 Procedure

An overview of the structure of the study is depicted in Figure 4.

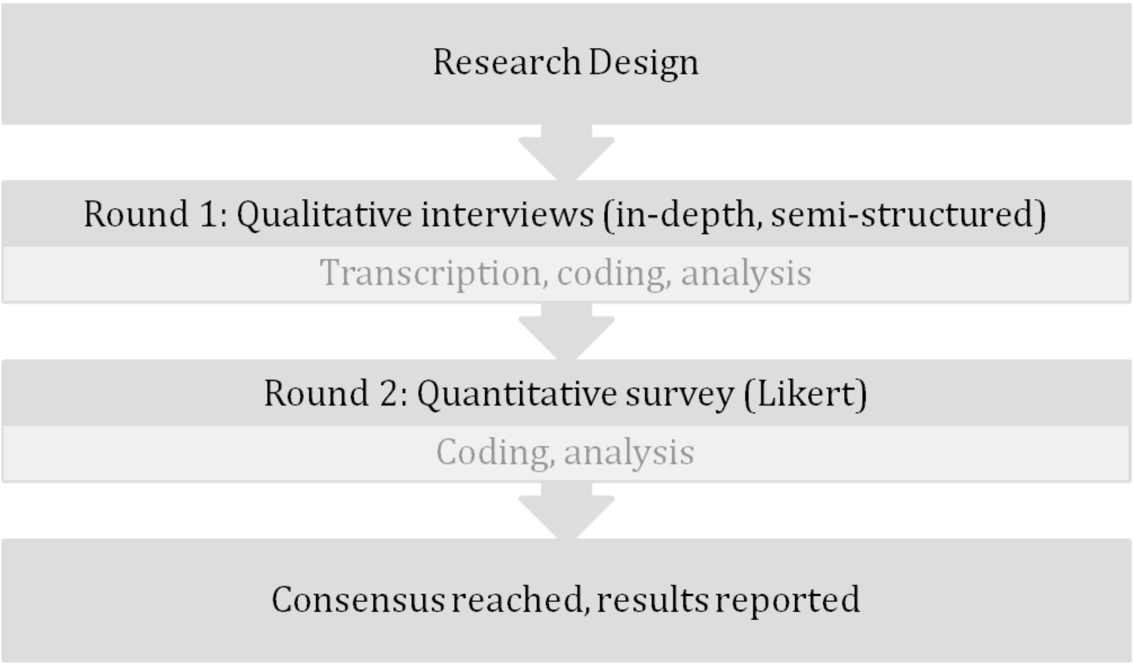

Figure 4. Overview of the study procedure.

2.3.1 Round One – Individual qualitative semi-structured in-depth interviews

The interviews took place in person, in the participant’s home, a quiet room within the University of Canterbury or at SCIP’s premises, or other quiet location of the participant’s choice. At the beginning of the meeting, prior to commencing the interview, the researcher explained the study to the participant and ensured that written informed consent had been obtained. The participant was then instructed to fill out a demographic form.

The qualitative semi-structured in-depth interview followed a topic guide. This guide included the following topics for discussion for the CI recipients: Long-term (18 months or more after implantation) experiences with the CI in the various roles/areas of his/her life; perceived long-term needs that have been met in relation to the CI; and perceived long-term needs that have not been met in relation to the CI. The SCIP clinicians guide included the following topics: Long-term experiences with CI recipients; perceived long-term needs of CI recipients that have been met; and perceived long-term needs of CI recipients that have not been met. The interviews were conducted with an emphasis on the participants themselves guiding the discussion around what they believed was important in relation to these topics.

Once the participant felt they had provided all the relevant information and the items on the topic guide had been discussed, the interview was considered to be complete. The participants were encouraged to contact the researcher via email or phone if they had any further information they wished to provide after the interview was complete.

All interviews conducted within the study were audio-recorded using a Sony ICD-BX112 recorder and transcribed verbatim based on conventions provided by Poland (1995). A copy of each participant's interview transcription was sent to them individually, if requested on their consent form, with the opportunity for any corrections or comments to be made within a specified timeframe (prior to the analyses being incorporated into Round Two of the study).

2.3.2 Round Two – Surveys

The statements of perceived long-term needs, compiled through the analysis of the interview transcripts in Round One, were used to develop a survey for Round Two. Surveys were sent to all the Round One participants in order to gain a consensus on the needs gathered in the previous round. The survey had two parts: one part that listed any identified met needs and one part that listed any identified unmet needs, with each statement of need accompanied by examples from the interviews. All information presented in the survey was deidentified so that the anonymity of the participants from Round One was preserved.

A copy of this survey was emailed and/or posted to each participant. They were asked to rate the extent to which they agreed or disagreed that each need in the survey was important and met (for the list of met needs) or important and unmet (for the list of unmet needs), for late cochlear implanted adults with prelingual deafness. The rating used a five-point scale with options of 'strongly disagree', 'disagree', 'neither agree nor disagree', 'agree' and 'strongly agree'. The participants were then instructed to return the survey via email or post in a self-addressed stamped envelope. A notification reminding the participants about completing the survey was sent to the individuals two weeks after the surveys were sent. The results of the study were then sent out to each participant who indicated he or she wanted a copy through his or her consent form.

2.4 Data analysis

2.4.1 Round One

After the transcriptions had been sent to the participants and any corrections had been made, the transcriptions were analysed using qualitative content analysis. This method of analysis was based on that previously described by Hsieh and Shannon, (2005) and was used to identify codes and categories of met and unmet needs. Specifically, this involved analysing the transcripts for important met and unmet long-term needs of late cochlear implanted adults with prelingual deafness 18 months or more after implantation. The first stage of analysis involved the researcher immersing herself in the data by reviewing the audiorecordings and reading and rereading the transcripts. Information in the transcripts that was irrelevant to the research aims was then identified (e.g., "You know"). This data was not part of the unit of analysis and was not analysed further. The researcher then divided the data into two content areas based on the research aims: perceived met long-term needs and perceived unmet long-term needs. Next, meaning units or words, sentences, or paragraphs that were related to each other through their content and context were identified and then condensed. Once all transcripts had been analysed in this way, meaning units that were similar were amalgamated and assigned codes, for example, "It's great to hear sounds like the birds tweeting," was labelled, "hearing environmental sounds". Once all meaning units in all transcripts were given codes, these codes were grouped together to form higher level categories, for example, "hearing environmental sounds" and "having more access to sound" were grouped into a category labelled "sound in general". The codes were then summarised as met and unmet needs, and put into a survey, which was sent out to each participant in Round Two.

2.4.2 Round Two

Once all surveys had been returned, each survey was quantitatively analysed to determine a ranking of the most important met and unmet needs of late cochlear implanted adults with prelingual deafness from the group as a whole and then from the perspectives of the CI recipients and the SCIP clinicians. For each item on the survey, the frequency of responses of either 'strongly agree' or 'agree' was calculated in order to find out the most important met needs and unmet needs in the corresponding lists. The literature on Delphi studies varies in its description of consensus, therefore, for the purposes of this research, consensus was considered to be 51 percent or more of the participants responding with either 'strongly agree' or 'agree' for each individual statement in the survey. If absent or multiple responses were indicated in a single item on the survey, the item for that participant was not included in the count. The identified met needs were then ranked with those achieving a consensus across 100 percent of the participants receiving the highest ranking, down to those achieving a consensus across 51 percent of the participants receiving the lowest ranking. The same ranking process was applied for the unmet needs. These analyses were conducted using the Statistical Package for Social Science, version 19 (IBM Company, 2010).

2.5 Rigour and reflexivity

To increase the trustworthiness of the first round of the research, triangulation of sources was applied (Israelite, Ower, & Goldstein, 2002). This allowed for the needs of the CI recipients to be more validly explored through the use of multiple perspectives, consisting of information from the two categories of experts: the CI recipients and SCIP clinicians.

The trustworthiness of the results was also increased through the use of peer debriefing during the analysis. The researcher carried out the qualitative content analysis with regular input from two supervisors whose role it was to challenge and question any conclusions made by the researcher that they felt might be biased or incorrect. Any biases were identified through the use of a reflexive journal kept by the researcher.

2.6 Ethical Considerations

This study was approved by the University of Canterbury Human Ethics Committee in October of 2014 (see Appendix D). Procedures including participant recruitment, consent and confidentiality were carried out in accordance with the approval granted. Approval was not required from the New Zealand Health and Disability Ethics Committee.

3

Results

3.1 Overview of results

Presented in this section are tables and descriptions of the characteristics of the two groups of participants: SCIP clinicians and CI recipients. The met and unmet needs from the first qualitative interview round are then presented, followed by the results from the second quantitative survey round.

3.2 Sample characteristics

The demographics of the two groups of participants are outlined in the tables below. Four SCIP clinicians and five CI recipients participated in both rounds of the study.

The demographic information from the SCIP clinicians and CI recipients who participated in this research has been summarised to preserve the anonymity of the participants from such a small pool.

Table 1. Demographic information from SCIP clinicians.

Demographic	Details
Gender	
Female	3
Male	1
Current age (years)	
Mean	40.5
SD	5.9
Range	33 – 49

Ethnicity	
New Zealand European	2
European	1
North American	1
Role with CI recipients	
Audiologist	3
Rehabilitationist	1
Frequency of contact with adult CI recipients with prelingual deafness	
Some days	3
Seldom	1
Duration of work with adult CI recipients with prelingual deafness (years)	
Mean	3.5
SD	1.5
Range	2 – 6
Frequency of contact with adult CI recipients with prelingual deafness >18 months past implantation	
Some days	2
Seldom	2

Table 2. Demographic information from CI recipients.

Demographic	Details
Gender	
Female	5
Current age (years)	
Mean	47
SD	7.4
Range	37 – 58
Age when received CI (years)	
Mean	43.2
SD	8.3
Range	33 – 56

Duration with CI (years)	
Mean	4
SD	1.8
Range	2 – 7
Unilateral/bilateral implantation	
Unilateral	5
Use of CI	
Everyday	5
Current HA use in non-CI ear	
None	4
Always	1
Aided pre-CI	
Both ears	4
One ear	1
Age when deafness present	
Before birth	2
<1 year	1
1 – 3 years	2
Aetiology/cause	
Hereditary	3
Neonatal jaundice	1
Unknown	1
Methods of communication used	
Oral (English)	5
Lip-reading (English)	5
Residential area	
City	4
Rural area	1
Number of adults living with	
0	1
1	4
Number of children living with	
0	2
2	2
3	1

Relationship status	
Married/de facto	4
Not in a relationship	1
Working status	
Full-time	2
Part-time	2
Not in the labour force	1
Household income	
$20,001 -$30,000	1
$30,001 -$50,000	1
$70,001 -$100,000	1
> $100,001	2
Highest level of education	
Completed some high school	1
Completed high school	2
Completed post-graduate qualification	2
Ethnicity	
New Zealand European	5

3.3 Met and unmet long-term needs

The first study aim was to explore the needs of late cochlear implanted adults with prelingual deafness. Analysis of the qualitative semi-structured in-depth interviews with nine participants (four SCIP clinicians and five CI recipients) revealed 39 met needs and 42 unmet needs that fell into 15 categories (see Table 3 and 4). Each of the 15 categories of needs is discussed below. Examples of participant quotes are provided to illustrate specific met and unmet needs within each category. It is noted that participant codes have been used to preserve anonymity (e.g., P1S for Participant 1 who was a SCIP clinician and P7C for Participant 7 who was a CI recipient).

Table 3. Met needs of late cochlear implanted adults with prelingual deafness as identified by SCIP clinicians and CI recipients.

Category	Code	SCIP	CI
Sound in general	Being more aware of environmental sounds	✓	✓
	Having more access to sound in general	✓	✓
	Having improved identification of sound	✓	✓
	Being better able to localise sound by following it		✓
Communication with other speakers	Having improved communication with others in general	✓	✓
	Improvements in own voice and own speech clarity	✓	✓
	Improved hearing and understanding of speech by listening only	✓	✓
	Being more aware of when being spoken to	✓	✓
	Being further from the speaker and still hearing them	✓	✓
	Increasing the volume of others' speech	✓	
	Enhanced lip-reading	✓	
	Improved understanding of speech in the car		✓
	Listening to more challenging speakers		✓
Challenging listening environments	Listening in more challenging environments		✓
Technology use	Being better able to use the phone	✓	✓
	Being better able to follow the TV	✓	✓
	Having better hearing over Skype/video calling		✓
	Being better able to hear speech on the radio		✓
	Being better able to use a Walkman		✓
	Having improved understanding of speech over the PA system		✓
Support	Having good professional support services	✓	
	Having further habilitation after the initial 18 months	✓	

Connectedness with environment and people	Being more connected to the surrounding environment and people	✓	✓
	Having improved functioning in the ‘hearing world’	✓	✓
	Having more independence	✓	✓
Social issues	Being part of a community with other CI recipients	✓	✓
	Having improved engagement in social activities	✓	✓
	Having improved engagement in recreational activities	✓	✓
	Feeling more positive		✓
Work issues	Being better able to begin employment	✓	
	Being better able to progress further in employment	✓	
	Being safer at work	✓	
	Being better able to understand customers, clients and colleagues		✓
Music	Having improved access to and appreciation of music	✓	✓
Safety issues	Being safer in general	✓	✓
	Finding it easier to care for family	✓	
	Being safer while driving		✓
Other	Understanding speech with less effort		✓
	Having better comfort		✓

✓ = the participant group(s)that mentioned the need

Table 4. Unmet needs of late cochlear implanted adults with prelingual deafness as identified by SCIP clinicians and CI recipients.

Category	Code	SCIP	CI
Sound in	Not being able to fully utilise sound information	✓	✓

general	Wanting more access to sound	✓	
	Difficulty identifying sound	✓	
	Difficulty telling where sounds are coming from	✓	
Communication with other speakers	Difficulty with the use of own voice and own speech clarity	✓	✓
	Difficulty hearing and understanding speech by listening only	✓	✓
	Difficulty when listening to more challenging speakers	✓	✓
Challenging listening environments	Difficulty listening in more challenging environments	✓	✓
Technology use	Difficulty using the phone	✓	✓
	Difficulty hearing speech over a radio transmitter (RT)	✓	
	Difficulty hearing everyone over Skype/video calling		✓
	Difficulty following the TV		✓
	Difficulty hearing at the movies		✓
	Difficulty hearing speech on the radio		✓
Support	Lacking good professional support services	✓	✓
	Wanting but not receiving further habilitation	✓	✓
	Lacking support in the workplace	✓	
	Lacking support from family and friends	✓	
Connectedness with environment and people	Difficulty connecting with environment, family and self	✓	
	Being unable to fully function in the ‘hearing world’	✓	
Social issues	Having more negative feelings	✓	
	Difficulty following jokes		✓
	Lacking a sense of community with other CI recipients		✓

	Difficulty engaging in recreational activities		✓
Work issues	Difficulty understanding speakers in meetings	✓	✓
	Finding work too noisy		✓
Music	Not having access to and enjoyment of music	✓	
Safety issues	Feeling less safe due to not being able to tell where sounds are coming from	✓	
	Feeling less safe in water		✓
	Feeling less safe at night		✓
Medical issues	Experiencing facial twitching	✓	
	Experiencing vertigo/dizziness		✓
	Experiencing pain		✓
Financial issues	Having financial concerns	✓	✓
	Being unable to afford a second CI		✓
	Having to pay for professional services		✓
Device issues	Being limited by technology	✓	
	Having to rely on technology		✓
Understanding of CI process and outcomes	Employers and colleagues not having reasonable expectations about CIs	✓	
	Lack of understanding by recipients of CI process and outcomes	✓	
	Others not having reasonable expectations and understanding about CIs	✓	✓

✓ = the participant group(s)that mentioned the need

3.3.1 Sound in general

A met need identified by all nine participants was being more aware of environmental sounds. Many of the participants expressed this awareness as being for enjoyment, such as hearing the waves on the beach, thunder, wind, rain on the roof, or the birds chirping while putting out the washing. Awareness of environmental sound was also described with regards to practicality, such as hearing the fridge beeping when the door is left open, the washing machine beeping when it completes its cycle, car indicators ticking, the phone ringing, footsteps or a dog barking:

> It's great to hear the sounds like the birds tweeting…the car indicators and know that you've got the indicators on instead of leaving it on and keep driving. [P5C]

> …you hear the washing machine…three rooms away. You know when it's finished without having to go backwards and forwards. [P7C]

Most of the participants also talked about the increase in access to sound in general, including a wider range of sounds of different frequencies and an increase in the quality of sound:

> It's more about…having that heightened awareness of sound and having…more sound and a range of sound…how much you miss even with your hearing aids. [P1S]

> For me, wearing a hearing aid was like blurred vision compared to this. [P8C]

> However, some participants said they wanted more access to sound overall.

> …they'd like to hear better… [P3S]

Some participants also commented on the increased ability to identify sound, though others described finding this difficult:

> …learn to link up that particular noise with what it is… [P3S]

> …hear a strange sound…and not know what it is… [P1S]

Being better able to localise sound was also identified as a met and unmet need by different participants, with some expressing difficulty with telling where sound is coming from and others stating that with the CI they are able to localise sound by following it:

> …still have to…use…visual means to try and work out where the sound is coming from… [P3S]

> …if you hear a noise you can…follow the sound to the location… [P7C]

An unmet need identified with regards to sound in general was not being able to fully utilise sound information. This included having a limited tolerance to some sounds, the brain being unable to cope with the sound information and feeling overwhelmed by the sound all coming through one ear:

> …a proportion would still have difficulty with certain sounds that are given back to them like…the high-pitched sounds they find pretty intrusive…and don't really get used to it. [P3S]

3.3.2 Communication with other speakers

Along with improvements in several specific areas of communication, having improved communication with others in general was identified as a met need. This included being better able to carry on a conversation:

> …provide them access to sound and more ability to communicate… [P4S]

A more specific area of met need identified in relation to communication was the CI increasing the volume of others' speech:

> I think it's just…bringing people's voices up more. [P1S]

Alongside this increased volume of speech was an increase in the ability to detect when others are speaking to the CI recipients, was also brought up by several participants as a met need. Scenarios brought up included hearing a name called out in the dentist's or doctor's waiting room and hearing others calling from different rooms:

> …hearing…their child calling out from another room or things like that are of benefit. [P3S]

> …it's being more aware of when you're being spoken to or of what's going on around you. [P1S]

Being better able to hear and understand speech without solely relying on lip-reading or sign language was also identified by most of the participants as a need that had been met. This included speech sounding clearer along with being able to hear the crisp consonant sounds at the beginnings and endings of words. Some, however, reported difficulty hearing and understanding speech by listening through the CI without visual cues, including still having to rely on lip-reading during conversation:

> Just being able to hear speech more…I can pick up voices a lot more clearly. [P6C]

> …I'm hearing all these esses and ee-dee's and that sort of thing for the first time and never really noticed it before. [P5C]

> …able to...make a friend a coffee and instead of have to turn around and ask them, do they have sugar, I can just yell out, "Do you need sugar?" "Yes," "right," and carry on. [P5C]

> …an unmet need might be somebody who wanted an implant because they wanted to be able to…do auditory-alone activities: understand speech without looking…they may still be having to use those other communication techniques to get by. [P1S]

More specifically, improved understanding of speech in the car was identified as a met need:

> …talking to my husband in the car…and my mum… [P8C]

Improvements when listening to more challenging speakers was considered met by some participants, including those with foreign accents or people who talk too quickly or slowly, though some difficulties were also identified in this area:

> Not everybody speaks clearly. And you have some people with…accents…you can actually carry on with the conversation…it'll have to be short and sweet, though…like weather, general, or stuff they're buying. [P5C]

Enhanced lip-reading was also mentioned by some of the clinicians, due to having more access to speech sounds to compliment lip-reading:

> …this would've still given them…a better ability to lip-read…it's just enhancing that. [P3S]

Some also mentioned being able to hear someone speaking from further away with their CI, from places such as the other end of the house or outside:

> "I can now hear my…wife. She can call me and say, 'Would you like a cup of tea?' or something"…rather than having to physically be next to somebody, you can actually be some distance and still be able to be contacted. [P3S]

Experiencing improvement in or difficulty with the CI recipients' own voice and own speech clarity was identified as both a met and unmet need respectively, across the participants. When considered a met need, this included speaking with increased clarity and a more appropriate volume and tone. When considered an unmet need, this included how easily others understand the speech of the CI recipients:

> …I have had people said to me my speech sounds a bit more clearly…I'm putting esses and…ee-dee's…so I'm actually speaking a little bit more clearly because I can hear what I'm saying. [P5C]

> I can’t control my tone of my voice. So I could…sound rude, blunt or…loud... [P5C]

3.3.3 Challenging listening environments

Difficulty listening in more challenging environments was identified as an unmet need by most of the participants, including when background noise or reverberation is present, such as in a classroom, a meeting or in a crowd:

> …a challenging…listening environment is…a room with poor acoustics…lots of hard surfaces, reverberation…things like that can impact on listening performance…background noise because your brain doesn’t have two ears to choose from, it’s just got to go with the old one and it’s a machine. [P1S]

However, listening in more challenging environments was considered a met need by some, particularly in group situations:

> …if I’m in a…group, I can actually hear what they’re saying… [P8C]

3.3.4 Technology use

Several needs were identified by SCIP clinicians and CI recipients in relation to the use of technology. The first was an improved ability to use the phone. Some of those who considered this a met need mentioned this was only with friends or family with a hearing impaired phone, and others mentioned they could speak to strangers without any assistive devices:

> …I can talk on the phone to family…with a hearing impaired phone with volume control and in a quiet setting. [P6C]

> …I used the hook…and now I don’t need to use that and it’s great…I don’t mind the telephone at all now. [P8C]

Others identified having difficulty using the phone as an unmet need. This included people who had never been able to use the phone and still could not, as well as those who could use it but still struggled in certain situations such as when talking to people with accents or in call centres:

> Well what I was hoping is to be able to use the phone but I can't use the phone…years later it still hasn't happened. [P7C]
>
> …with the phone…it can be a little bit hard…when you ring the call centre… [P5C]

Communication with others via Skype or video calling was considered both met and unmet due to an increase in the ability to hear speech but also difficulty hearing the speech of some people:

> Skype…much easier than it was…hear most of what they say… [P7C]
>
> …Skype…hard to follow…I can't…hear everybody first…hear most of what they say but not everybody… [P7C]

Another need that was considered met and unmet by different participants was in relation to an ability to follow the TV. Some who identified an increased in this ability described being able to hear the TV more clearly without requiring captions or headphones. Others still preferred to use captions but found it easier to follow and therefore still considered it a met need:

> So if I'm watching TV, I can hear the voices more…I've got more auditory input than I had. [P6C]
>
> The TV's clearer. I used to wear earphones with the hearing aids but now nothing. [P8C]

Those who considered difficulty following the TV an unmet need described having difficulty picking up dialogue without the use of captions, particularly when the characters are not facing the viewer:

> …still use captions though…because if they turn around and they're talking, I don't really know what they're saying… [P8C]

> …when you're watching TV, like a movie, they're not all looking at the screen…background noise, music and that, when you've got two people talking…you have trouble understanding them…when they're laughing or…saying too fast…you can't understand what they're saying…just can't be bothered…trying to…work it out… [P5C]

Having difficulty hearing at the movies was also identified as an unmet need:

> …I don't think I pick up enough at the movies to follow it all… [P6C]

Being better able to hear speech on the radio was considered a met need by some but difficulty with this was considered an unmet need by others due to radio presenters being perceived to be speaking too quickly:

> …listen to the radio for news… [P9C]

> …listening to the radio…I don't like it because they talk too fast…advertisement, never get pits and pieces, and then I think, "Is it worth my listening?" So I just, nah… [P5C]

Difficulty hearing incoming speech over a radio transmitter (RT) was also considered an unmet need:

> …hoping to be better on the RT than he is… [P1S]

Additional met needs identified by CI recipients included being better able to use a Walkman for music and hearing instructions and specials over a PA system in retail and grocery stores:

> …I can listen more, with…Walkmans…improve a lot… [P9C]

> …going out…to supermarkets and things…I can hear the specials that come over the…yeah… [P8C]

3.3.5 Support

Social, workplace and professional support were all brought up as needs by the participants. Social support was considered an unmet need by some, including support from family members and social circles. Lacking support from employers and colleagues was also considered an unmet need:

> …if you're not getting much support in the workplace…from family and friends… [P1S]

Having good professional support services, including follow-up and customer service from organisations such as SCIP, was considered a met need by some SCIP clinicians:

> …they get good…support and follow-up and customer service…customer support, client support here. [P1S]

These services, however, were said to be lacking by some CI recipients and SCIP clinicians, including issues knowing where to get help and receiving a less than ideal number of appointments for audiology, rehabilitation, counselling and training in the use of communication strategies:

> …having to go…somewhere else to get a remap…not local. [P6C]

> Being an adult…there's very little support. So you feel kind of…lost…don't know where to go or how to get help…we kind of miss out… [P7C]

With regards to professional support, wanting but not receiving further habilitation after the initial 18 months of appointments was also identified as an unmet need:

> …our hands are tied by funding and workloads but I think that would be another area where they really could benefit…from a more aggressive rehabilitative approach or programme than what…we currently have. [P4S]

> …I think if there was better rehabilitation for the adults, I might have done better. [P7C]

However, further habilitation after the initial 18 months was also considered a met need due to the support provided:

> …we do provide good…rehabilitative support in a functional aspect… [P4S]

> …they have had support and…if they wanted more support, it would be available… [P3S]

3.3.6 Connectedness with environment and people

Feeling an increased connection to the surrounding environment and people was mentioned, including being more aware of what is going on in the surroundings. Conversely, difficulty feeling connected with people was considered an unmet need for some:

> So it's all about…feeling more present in the world and feeling more connected to your environment through sound…it helps people just get more in the moment… [P1S]

> …feeling more connected with themselves and…family and…environment… depending on performance… [P1S]

Having improved functioning in the ‘hearing world’ was also considered a met need with people mentioning having fewer practical problems in life, though one participant believed that being unable to fully function in the ‘hearing world’ could also be an unmet need:

> …functioning in life in general…it might help them to integrate into just the day-to-day life… [P4S]
>
> …might not fully function in the hearing world… [P1S]

Some participants mentioned having more independence in relation to using the phone, travelling and when having to make appointments, which they considered a met need:

> I’m more independent…I don’t have to rely on my husband or my boy to help me on the phone. [P5C]
>
> …that’s more about independence…being independent enough that people can…travel and…visit family or travel to somewhere they’ve always wanted to travel to. [P2S]

3.3.7 Social issues

Being part of a community with other CI recipients was considered a met need by some of the participants, who mentioned having a sense of identity through having others with a similar device and being able to use a social media webpage facilitated by SCIP, as well as having a connection with famous people who also have CIs:

> …we have…the facebook page, we have other social networks which I’m sure has been a benefit to people who might’ve been quite isolated before. [P3S]
>
> …just a confidence in a social point of view…through part of being linked up to others with a similar device in their area or go to user groups or just the fact that they now belong to a little niche group. [P3S]

Some CI recipients, however, mentioned a lack of connection with other CI recipients, particularly locally to them:

> …a CI get-together in the…region…seeing how it's going for other people…and socialising…and having that connection…the same hearing device…how they are managing with it… [P6C]

A few participants brought up having improved engagement in social activities such as clubs or meetings with groups of friends:

> …we belong to the…club…and I just didn't want to go anymore because I couldn't be bothered hearing, I couldn't be bothered concentrating. It was too hard…I love going out now. I'm a people person and nothing holds me back now. [P8C]

Engaging in recreational activities was considered by some to have improved, with the ability to hear teammates and not having to deal with whistling feedback from the device whilst wearing a helmet during sporting activities, as well as being better able to follow along from the audience at productions and school events:

> …the good would be just everyday listening…going to school events and following those…snowboarding, wearing a helmet, a bike helmet too. [P6C]

Some difficulty engaging in recreational activities was also identified and described as an unmet need due to some vertigo experienced as a result of the CI surgery and the inability to wear the CI near water:

> …themepark…can't go on the rollercoasters anymore [due to dizziness]…husband would have to go on it with the kids… [P7C]

> …take it off when I go swimming…not a waterproof one…kayaking or…paddleboarding or…watersports…too valuable… [P6C]

More personally, both feeling more positively about life in general and having more negative feelings including isolation at parties or in groups were identified as met and unmet needs respectively, though there was a stronger emphasis on an increase in positive feelings:

> …feeling of loneliness…isolation… [P1S]

> …makes everything…easier…so you don't get frustrated and get pissed off and get depressed because you can't hear… [P5C]

> …your life changes…it's amazing…if you go back to where you were before, you get depressed, you get frustrated… [P5C]

> …even the look on my face has improved…just opened up my whole life… [P8C]

One participant also described having difficulty following jokes, whether in person or on TV:

> …I don't follow jokes very well. Unless someone explains it to me. Listening on TV all the jokes, I'm like, "Oh, can't be bothered,"… [P5C]

3.3.8 Work issues

A range of met and unmet needs in relation to work issues were identified by the participants in this round. Being better able to understand customers, clients and colleagues was largely considered a met need, whether via telephone or in person:

> …makes my job easier…not everybody will look at you. Some will mumble, some will look down…so you can actually hear them… [P5C]

> …talk on the telephone a lot more…used to get…my husband…to do all the secretary work for me but…it's reversed now…I can make a lot of the phone calls for him…the…business…can make my own appointments now… [P8C]

Conversely, difficulty understanding speakers in meetings at work was an unmet need for some, due to being unable to see speakers' faces and often having background noise present:

> Sometimes when you have a meeting and you've got the boss up here and…someone else starts in the background…you don't know what they're saying…because…they said it so quick, you haven't got a chance…to catch up…you do tend to get missed out in a meeting. [P5C]

One participant identified finding his workplace too noisy as an unmet need:

> …at my work it's very noisy… [P9C]

According to some SCIP clinicians, being better able to begin employment was considered a met need, including having better access to employment:

> …providing someone a cochlear implant does…allow people to start employment where they…wouldn't otherwise. [P2S]

Being better able to progress further in employment was also mentioned, including opportunities for increased efficiency and a higher income:

> …enabling them to…be more efficient and therefore progress more forward… [P4S]

Another met need identified with regard to work issues was an increased feeling of safety at work. This included an increased awareness of sirens and alarms, allowing employers to worry less:

> …it's all about…being more aware of…the forklift driving around and being more aware of…alarms that go off in the workplace…more aware of when a colleague's trying to get their attention… [P1S]

3.3.9 Music

Having improved access to and appreciation of music was identified by many participants as a met need. An increase in the volume of music and the use of a programme within the CI dedicated to music were mentioned, but most of the participants who mentioned music appreciation said being able to follow singing and lyrics with some practice was a need that had been met:

> I love listening to music and try and understand what they're singing…they've got the programme which takes the music and makes it great sound. Bring it up more volume. Make it…better to understand what the words are…everybody loves music but to me it's just great sound. [P5C]

A SCIP clinician, however, considered not having access to and enjoyment of music as an unmet need for some:

> …restore access to music…often that's not the case… [P2S]

3.3.10 Safety issues

Being safer in general was identified as a met need, with the ability to hear sirens and fire alarms and footsteps approaching:

> …if I'm out walking or running…I can hear if someone's coming up behind me…footwear on the pavement…from a safety point of view, that's good. [P6C]

Specifically, participants identified being safer whilst driving as a met need due to being able to hear warning sounds:

> …if you're busy, not looking where you're going, I could have someone in the background yell out "stop" and hear them to stop…like go on the road…or…backing the car… [P5C]

An unmet need identified in relation to safety was feeling less safe in water due to being unable to wear the CI whilst participating in activities involving water:

> …I can't wear my implant when I go swimming or kayaking…what happens if you fall in the water…someone yelling in the background…want your attention…beach…shark…people trying to tell you to get out of…the water…you won't hear them… [P6C]

Another unmet need was feeling less safe at night, due to being unable to retrieve the CI in an emergency, having taken it off at night, or being unable to hear warning signals such as alarms:

> …night time…don't hear anything…take it off…if my husband was out of town for work…or home alone, and my biggest nightmare is…house on fire, someone banging on the door…fire alarm…not gonna hear it… [P5C]

Feeling less safe generally due to not being able to tell where sounds are coming from was also identified as an unmet need:

> …safety-wise…lack of directionality… [P1S]

One SCIP clinician also discussed the possibility of CI recipients finding it easier to care for family members:

> …if they're caring for family, then…there are safety issues there. [P2S]

3.3.11 Medical issues

Three medical issues were identified across the participants as unmet needs. These included experiencing vertigo and dizziness, particularly when situated in certain positions, pain including headaches, and facial twitching as a result of the implantation:

> …now and then I might have a dizzy spell…can't sleep on my right side…otherwise I get vertigo…have to be careful when I lie down… [P7C]
>
> …implant causing a lot of pain… [P7C]
>
> …it's a headache… [P9C]
>
> …non-auditory side effects like…the face can twitch… [P3S]

3.3.12 Financial issues

Some mentioned an unmet need of having financial concerns, particularly in relation to purchasing or repairing parts of the CI devices themselves:

> …financial needs…batteries and replacement parts and other things like that…that would certainly be a concern for some people…if you have to pay extra for insurance…ongoing prices for batteries when your rechargeables give up the ghost and your coils and cables… [P1S]

Not only was paying for parts considered an unmet need, but also having to pay for professional services beyond 18 months, such as speech therapy:

> …if you want help you've got to pay for it out of your own pocket. Like…speech therapy… [P7C]

Another financial issue was identified around being unable to afford a CI on the other side to the current CI, considering all CI recipients interviewed were unilaterally implanted:

> …having two…funded…would be a great thing…'cause the money side of it does put you off going for a second one [P6C]

3.3.13 Device issues

Some participants mentioned being limited by the current technology as an unmet need, as well as having to rely on technology since receiving their CI:

> …the technology can only go so far… [P3S]
>
> …being reliant on technology…not always having to have batteries on hand…[P6C]

3.3.14 Understanding of CI process and outcomes

Issues were raised around others not having reasonable expectations and understanding about CIs, including the general public not knowing how to communicate with someone with a CI:

> Can be quite frustrating. You can have people…they're rude talking to you. They talk to you like this, "hello-o-o-o-o,"…some people just don't get it. Or they talk loud. And I'm thinking, "oh, you don't have to talk loud, not with this [cochlear implant]"…

As well as the general public, employers and colleagues were also described as not having reasonable expectations about CIs:

> …employers…colleagues…not really understanding the concept of a cochlear implant and the fact that it's not a real ear and it never pretended to be. [P1S]

An unmet need also raised was a lack of understanding by CI recipients of CI process and outcomes, including confusion over outcomes through comparison with others.

> …people might meet other people who they think, "Well, I'm just the same as that person, why is that person doing so much better than me?" [P3S]

3.3.15 Other

Other met needs identified by the participants included being able to understand speech with less effort, and having increased comfort:

> …talking to people and make sure I'm looking at their lips, so it's more hard

> work to do. Whereas now, it's easier…not so…tiring…I can do it without lip-reading… [P5C]
>
> …not having to wear an earmold in your ear… [P6C]

3.4 Important met and unmet long-term needs

The second aim of this study was to identify a consensus of the important met and unmet needs of late cochlear implanted adults with prelingual deafness. The survey of collated met needs and subsequent collated unmet needs from Round One included 39 and 42 needs respectively and is attached in Appendix E. This round sought to find a consensus amongst the participant group as a whole through the use of quantitative surveying.

All nine participants from Round One participated in this second round, indicating a response rate of 100%.

Data from the survey was missing from three met needs and one unmet need relating to employment, with the CI recipient referring to her unemployment instead.

Data from one SCIP clinician participant was disallowed for two met needs ('being more aware of when being spoken to' and 'being further from the speaker and still hearing them') due to multiple numbers reported. It was commented that his/her response was dependent on the individual on seven met needs ('increasing volume of others' speech', 'improved hearing and understanding of speech by listening only', 'being more aware of when being spoken to', 'being further from the speaker and still hearing them', 'understanding speech with less effort', 'having improved engagement in recreational activities' and 'having better comfort'), including the two with responses that were disallowed.

The tables below present the needs identified as important by the majority (51% or greater) of participants. These are separated into CI recipients only, SCIP clinicians only and both combined, and met and unmet needs are also presented separately. Each table of needs is ordered from the needs that had the strongest consensus down to those had the weakest consensus.

3.4.1 Results of the surveys for the participant group as a whole

Of the 39 met needs identified in Round One, 26 were considered important and met by the participant group as a whole.

Table 5. Important met needs of the participant group as a whole.

Ranking	Need
1	Being more aware of environmental sounds
2	Having more access to sound in general
3	Being more connected to the surrounding environment and people
4	Being more aware of when being spoken to
5	Being safer in general
6	Having better comfort
7	Having improved communication with others in general
8	Having good professional support services
9	Having improved engagement in recreational activities
10	Understanding speech with less effort
11	Being safer at work
12	Having improved identification of sound
13	Increasing the volume of others' speech
14	Improved hearing and understanding of speech by listening only
15	Having improved engagement in social activities
16	Finding it easier to care for family

17	Being further from the speaker and still hearing them
18	Listening in more challenging environments
19	Being better able to follow the TV
20	Being better able to understand customers, clients and colleagues
21	Having more independence
22	Being part of a community with other CI recipients
23	Having improved engagement in recreational activities
24	Having improved functioning in the ‘hearing world’
25	Improvements in own voice and own speech clarity
26	Enhanced lip-reading

Of the 42 unmet needs identified in Round One, 18 were considered important and unmet by the participant group as a whole.

Table 6. Important unmet needs of the participant group as a whole.

Ranking	Need
1	Not being able to fully utilise sound information
2	Difficulty hearing speech on the radio
3	Difficulty telling where sounds are coming from
4	Difficulty listening in more challenging environments
5	Difficulty following the TV
6	Difficulty hearing speech over a radio transmitter
7	Others not having reasonable expectations and understanding about CIs
8	Wanting more access to sound
9	Difficulty when listening to more challenging speakers

10	Difficulty using the phone
11	Difficulty hearing at the movies
12	Difficulty following jokes
13	Being unable to afford a second CI
14	Having financial concerns
15	Difficulty understanding speakers in meetings
16	Finding work too noisy
17	Being limited by technology
18	Employers and colleagues not having reasonable expectations and understanding about CIs

3.4.2 Results of the surveys for SCIP clinicians

Of the 39 met needs identified in Round One, 21 were considered important and met by the majority of the SCIP clinicians.

Table 7. Important met needs identified by the SCIP clinicians.

Ranking	Need
1	Being more aware of environmental sounds
2	Having more access to sound in general
3	Being more connected to the surrounding environment and people
4	Understanding speech with less effort
5	Being safer at work
6	Enhanced lip-reading
7	Having improved communication with others in general
8	Having good professional support services

9	Having improved engagement in recreational activities
10	Finding it easier to care for family
11	Improvements in own voice and own speech clarity
12	Being more aware of when being spoken to
13	Being safer in general
14	Having better comfort
15	Having improved identification of sound
16	Increasing the volume of others’ speech
17	Improved hearing and understanding of speech by listening only
18	Having improved engagement in social activities
19	Being part of a community with other CI recipients
20	Having improved engagement in recreational activities
21	Having improved functioning in the ‘hearing world’

Of the 42 unmet needs identified in Round One, three were considered important and unmet by the majority of the SCIP clinicians.

Table 8. Important unmet needs identified by the SCIP clinicians.

Ranking	Need
1	Not being able to fully utilise sound information
2	Difficulty using the phone
3	Others not having reasonable expectations and understanding about CIs

3.4.3 Results of the surveys for CI recipients

Of the 39 met needs identified in Round One, 33 were considered important and met by the majority of the CI recipients.

Table 9. Important met needs identified by CI recipients.

Ranking	Need
1	Being more aware of environmental sounds
2	Having more access to sound in general
3	Being more connected to the surrounding environment and people
4	Being more aware of when being spoken to
5	Being safer in general
6	Having better comfort
7	Being further from the speaker and still hearing them
8	Listening in more challenging environments
9	Having improved communication with others in general
10	Having good professional support services
11	Having improved engagement in recreational activities
12	Having improved identification of sound
13	Increasing the volume of others' speech
14	Improved hearing and understanding of speech by listening only
15	Having improved engagement in social activities
16	Being better able to follow the TV
17	Being better able to understand customers, clients and colleagues
18	Having more independence

19	Listening to more challenging speakers
20	Being better able to use the phone
21	Having improved access to and appreciation of music
22	Understanding speech with less effort
23	Being safer at work
24	Finding it easier to care for family
25	Being part of a community with other CI recipients
26	Feeling more positive
27	Having improved functioning in the ‘hearing world’
28	Having improved understanding of speech over the PA system
29	Being safer while driving
30	Being better able to localise sound by following it
31	Improved understanding of speech in the car
32	Having better hearing over Skype/video calling
33	Being better able to use a Walkman

Of the 42 unmet needs identified in Round One, 25 were considered important and unmet by the majority of the CI recipients.

Table 10. Important unmet needs identified by CI recipients.

Ranking	Need
1	Difficulty hearing speech on the radio
2	Being unable to afford a second CI
3	Wanting more access to sound
4	Difficulty telling where sounds are coming from

5	Difficulty listening in more challenging environments
6	Difficulty following the TV
7	Difficulty hearing at the movies
8	Difficulty hearing speech over a radio transmitter (RT)
9	Difficulty following jokes
10	Having financial concerns
11	Lacking a sense of community with other CI recipients
12	Difficulty understanding speakers in meetings
13	Finding work too noisy
14	Being limited by technology
15	Not being able to fully utilise sound information
16	Difficulty with the use of own voice and own speech clarity
17	Difficulty hearing and understanding speech by listening only
18	Difficulty when listening to more challenging speakers
19	Not having access to and enjoyment of music
20	Finding live music too loud
21	Difficulty engaging in recreational activities
22	Feeling less safe in water
23	Feeling less safe at night
24	Others not having reasonable expectations and understanding about CIs
25	Employers and colleagues not having reasonable expectations and understanding about CIs

3.5 Summary of results

Figures 5 and 6 graphically present the identified met and unmet needs of late cochlear implanted adults with prelingual deafness, showing the proportions of each participant group that contribute to the overall consensus (those that cross the dotted line representing the percentage required in order to reach consensus). The participants' individual responses were weighted equally, giving the SCIP clinicians group (four participants) up to 44% and the CI recipients group (five participants) up to 56% of the total percentage of responses.

Eleven important met needs were identified by the CI recipients only, with seven of those reaching consensus amongst the CI recipients, including two that reached 100% consensus. Six important unmet needs were identified by the CI recipients only, with four of those reaching consensus amongst the CI recipients, including one that reached 100% consensus. These are depicted by the bars coloured solely in green in figures 5 and 6 respectively. There were no important met or unmet needs identified solely by the SCIP clinicians.

The CI recipients responded more strongly (with more 'agree' and 'strongly agree' responses) than the SCIP clinicians across both the met and unmet needs as a whole. This is depicted by the larger proportion of green than blue within the bars in figures 5 and 6.

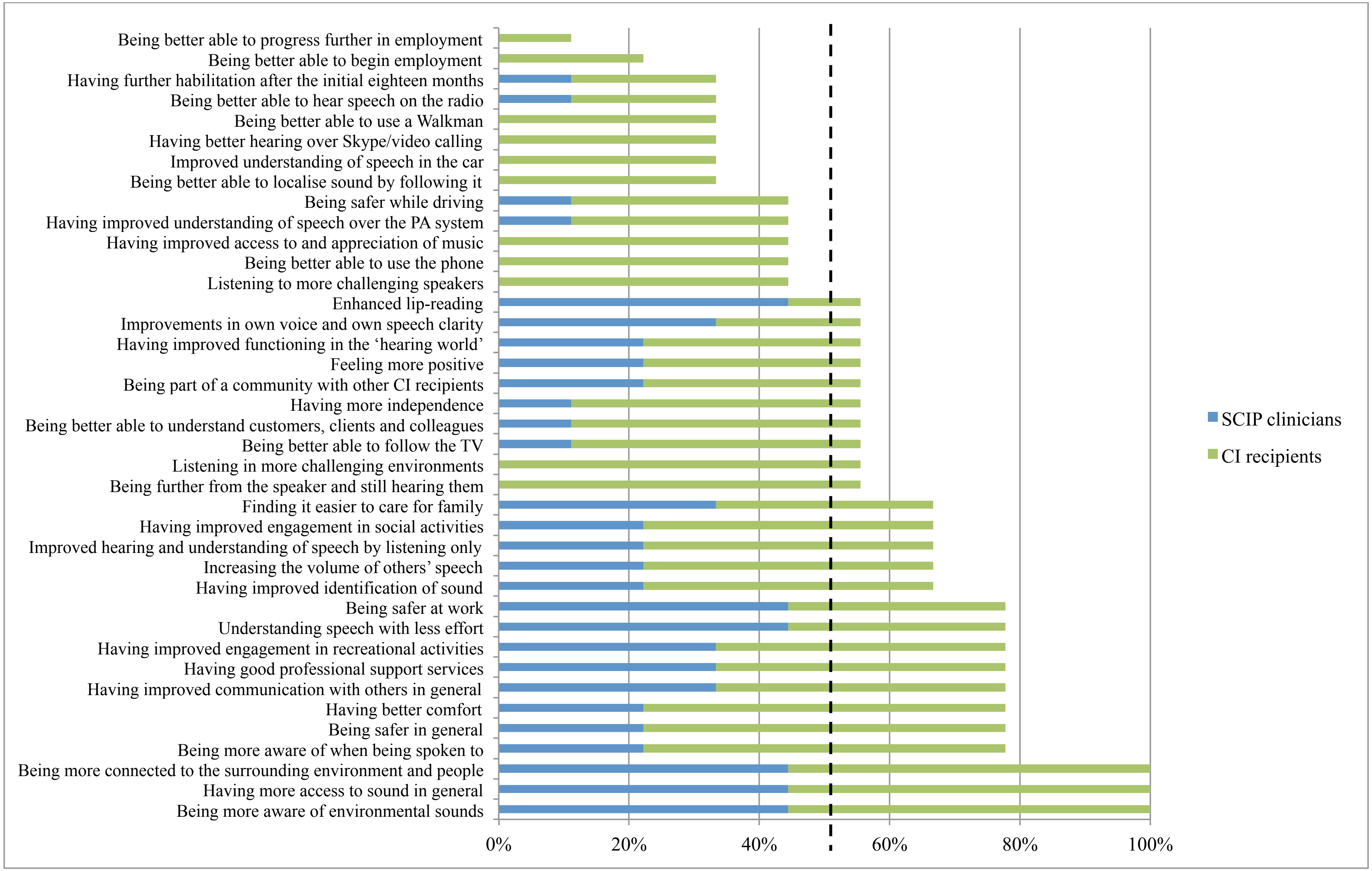

Figure 5. Percentages of participants' identification of important met needs. The dotted line (51%) represents consensus amongst this group.

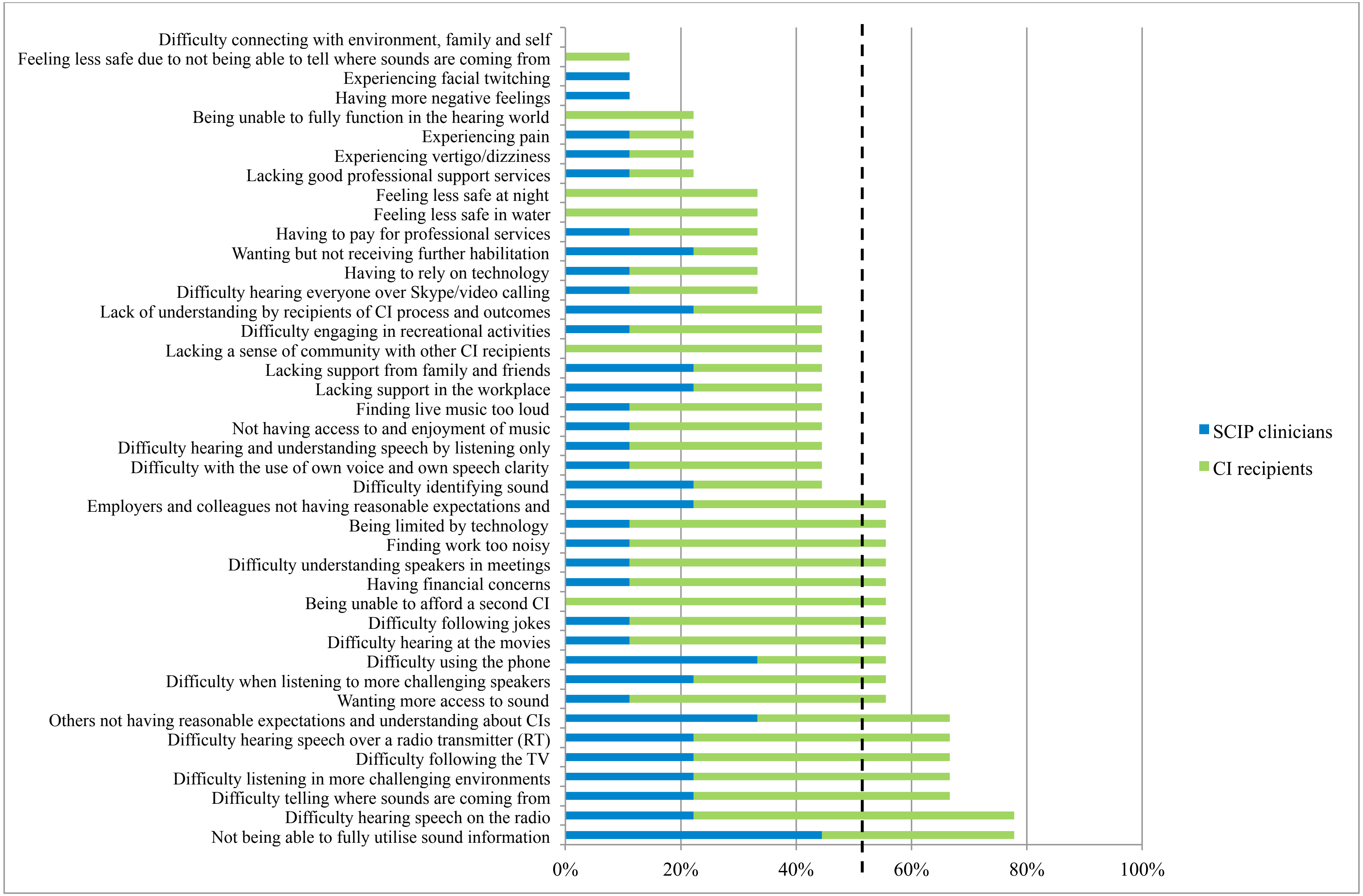

Figure 6. Percentages of participants' identification of important unmet needs. The dotted line (51%) represents consensus amongst this group.

4

Discussion

4.1 Overview

The study investigated the met and unmet long-term needs of late cochlear implanted adults with prelingual deafness. Round One consisted of qualitative in-depth semi-structured interviews with four SCIP clinicians and five CI recipients, and resulted in 42 met needs and 39 unmet needs being identified within 15 categories. Round Two consisted of administering a survey to the same nine recipients. The survey was developed based on the analysis of the data obtained in Round One. This second round identified 26 needs as important and met, and 18 needs as important and unmet. These results are discussed below, followed by an outline of the clinical implications, limitations of the study and suggested areas for future research.

4.2 Met and unmet long-term needs

The initial aim of this study was to explore the met and unmet needs of late cochlear implanted adults with prelingual deafness from their own perspectives as well as the perspectives of their clinicians at SCIP. This was achieved through Round One of this study, with the analysis of the nine transcripts yielding numerous needs, both met and unmet. One of the key observations from this round was the heterogeneity of the population expressed. An example of this is the area of telephone use. Each of the CI recipients interviewed expressed different gains received in this area, with one participant able to adequately understand people she had never spoken with over the phone, and another participant lacking any ability to use the phone, with the rest somewhere in between. The survey used in Round Two therefore sought to identify the met and unmet needs of the majority of late cochlear implanted adults with prelingual deafness, to discover what the most common outcomes were in each of these areas. The heterogeneity of CI recipients' experiences with their CIs long-term, in relation to the needs that gained consensus, is discussed further under the section entitled "study limitations and directions for future research".

4.3 Important met and unmet long-term needs

The second aim of this study was to reach a consensus of the important met and unmet needs of late cochlear implanted adults with prelingual deafness from the perspective of the CI recipients and the SCIP clinicians. The 26 important met needs and 18 important unmet needs and their corresponding categories that were identified through Round Two of this study are outlined below and compared to the current literature.

4.3.1 Important met needs

4.3.1.1 Sound in general

There were three important met needs identified in relation to sound in general. Having more access to sound in general and being more aware of environmental sounds were unanimously considered important met needs. These needs are consistent with literature suggesting that significant improvements in awareness of sound including environmental sound can be attained through CIs for this population (Berrettini et al., 2011; Klop et al., 2007; Peasgood et al., 2003; Zwolan, 2009).

The third important met need in this category was having improved identification of sound. Previous literature has indicated some benefit in this area for individuals with prelingual deafness and CIs, however, this benefit appears to be limited (Peasgood et al., 2003). The significance of this improvement in identification of sound is difficult to measure as a minor improvement in test measures of environmental sound awareness may be considered a met need depending on the importance that improvement has for the individual concerned. Regardless of the objective level of benefit in test measures, the improvement in identification of sound as a result of cochlear implantation was subjectively considered a met need for the majority of the participants of this study.

4.3.1.2 Communication with other speakers

Improved communication with others in general for this population was identified as an important met need. More specific areas of improvement in communication included being more aware of when being spoken to, being further from the speaker and still hearing them, and increasing the volume of others' speech. These areas of met need are consistent with the increase in access to sound and awareness of environmental sound as stated in the literature (Berrettini et al., 2011; Klop et al., 2007; Peasgood et al., 2003; Zwolan, 2009), but are specifically focussed on speech as the sound of interest. Improved hearing and understanding of speech by listening only is consistent with literature describing improvements in speech perception in this population (Bosco et al., 2013; Bradley et al., 2010). This may be considered a met need regardless of the actual speech perception ability of individuals within this population, depending on what they consider to be a significant improvement compared with pre-implantation speech perception. This may explain the identification of this as a met need despite research suggesting poor speech perception abilities for this population (Bosco et al., 2013). Enhanced lip-reading was also identified as a met need for this population. This was predominantly identified by the SCIP clinicians and is likely to be highly linked with improvements in speech perception.

Improvements in own voice and own speech clarity was also considered a met need This supports studies by Evans and Deliyski (2007), and Bosco et al. (2013), though with English as the language used by participants instead of Italian. Though the majority of participants described this as a met need, there was some variability between participants, similar to the above-mentioned studies.

4.3.1.3 Challenging listening environments

Listening in more challenging environments such as group situations was considered to be an important met need. This was unanimously identified by CI recipients, but not identified as an important met need by any SCIP clinicians. Listening when in a group of people can be considered a more challenging environment than one-on-one conversation, and is consistent with previous research indicating a significant increase in this area post-implantation (Looi et al., 2011).

4.3.1.4 Technology use

In relation to technology, many met needs were identified in Round One, but just one reached consensus as being an important met need in Round Two, which was being better able to follow the TV. Though some participants had comments about the lack of captions on many TV programmes, which they claimed would further aid their comprehension of these shows, they did consider improvements in their abilities to follow the TV to be a met need, regardless. This is likely to be highly related to increases in speech perception post-implantation in general, implying improvements should also be observed in the ability to follow dialogue from the TV. These results were shown in a study by Looi et al. (2011), but for adults with postlingual deafness.

4.3.1.5 Support

Having good professional support services was also considered an important met need. The support services mentioned in Round One included those provided by SCIP and Life Unlimited, however the survey did not specify any services. The two services named include many different areas of support such as audiology, rehabilitation and hearing therapy.

4.3.1.6 Connectedness with environment and people

Whilst deafness has been shown to negatively affect inclusion in society and the surrounding community (Atkin et al., 2002), being more connected to the surrounding environment and people, and having improved functioning in the 'hearing world' were identified as important met needs for CI recipients in this study. This is consistent with research indicating increases in quality of life in the area of social interaction for this population (Klop et al., 2007). This is likely to be due to the increase in access to sound provided by CIs, and therefore the increase in hearing ability in general, diminishing the effects of hearing loss described above. All participants of this study considered being more connected to the surrounding environment and people a met need, confirming that aspects of life other than basic hearing acuity are affected by cochlear implantation for adults with prelingual deafness.

Having more independence, also identified as an important met need, is consistent with research regarding self-efficacy, with increases in this area correlating with increases in ease of communication with family members (Adi-Bensaid et al., 2012; Atkin et al., 2002). This greater ease of communication has been established through met needs in this study described above, which implies that this population may also experience increases in self-efficacy, and therefore independence, as a result.

4.3.1.7 Social issues

The majority of the participants considered being part of a community with other CI recipients as an important met need. This included having a sense of identity and a decrease in isolation. Identity has been researched in relation to deafness, however, no known research has been published on identity and sense of community for adults with CIs. The present research therefore opens up a realm of possibilities for future research in this area, to further understand the impact of cochlear implantation on the whole individual and how they perceive themselves and those around them.

Having improved engagement in both social and recreational activities was also identified as an important met need for this population. This is consistent with research indicating increased socialisation and self-confidence in individuals post-implantation (Looi et al., 2011). This may relate to many other areas of life and need identified in the present study, including increased awareness of speech and other environmental sounds, increases in understanding of speech, improved listening in more challenging environments or even increases in positive feelings, perhaps instilling confidence to engage in various activities that may have been more intimidating or challenging with poorer access to sound.

The majority of participants reported that feeling more positive was an important met need for this group of people. This compliments the research on loneliness in CI recipients, which shows improvement in these areas for many people post-implantation (Most et al., 2010). It also complements research indicating increased self-esteem in adults post-implantation (Hinderink et al., 2000; Straatman et al., 2010; Peasgood et al., 2003), though Most et al. (2010) did not observe any change in this area. An increase in positive feelings may also be expected due to the literature suggesting an increase in rates of depression and anxiety in amongst people with HL (Kvam et al., 2007; Leigh & Pollard Jr., 2003), as well as an increase in stress (Jones et al., 2006). If the HL is lessened, such as with the use of CIs giving increased access to sound, then the rates of depression and anxiety may also be diminished, leading to more positive feelings post-implantation.

4.3.1.8 Work issues

Being safer at work was one of two important met needs identified under the category of work issues. The work safety of CI recipients is likely to be highly linked to their increased awareness of environmental sound (Berrettini et al., 2011; Klop et al., 2007; Peasgood et al., 2003; Zwolan, 2009). This awareness allows for sirens, reversing vehicles and other warning signals to be picked up more often than previously.

The second important met need within this category, being better able to understand customers, clients and colleagues, is consistent with research undertaken by Cohen and Williamson (1988) who suggested HL can create employment issues including difficulties communicating with hearing individuals. This implies that decreasing some of the effects of HL using cochlear implantation may produce improvements in this area. This may also be related to increases in the work performance of adults with prelingual deafness post-implantation (Most et al., 2010), particularly for occupations that involve regular communication with others.

Though identified as met needs in the first round, being better able to begin employment and being better able to progress further in employment were at the bottom of the ranking of met needs and did not reach consensus as being an important met need. This may indicate that difficulties observed in these areas for many adults with deafness may not be resolved post-implantation (Leigh & Pollard Jr., 2003; Cohen & Williamson, 1988). Nonetheless, the needs were not identified as important and unmet either, possibly indicating a lack of importance of these issues. This is consistent with research conducted by Kos et al. (2007), which did not discover any needs in relation to the connection between cochlear implantation and professional occupation.

4.3.1.9 Safety issues

The important met needs of CI recipients feeling safer in general is consistent with work safety discussed above, along with heightened awareness of environmental sound (Berrettini et al., 2011; Klop et al., 2007; Peasgood et al., 2003; Zwolan, 2009). This sense of safety may arise from abilities such as being able to hear footsteps approaching, cars backing out of driveways and fire alarms. Interestingly, sound localisation abilities are often linked to a feeling of safety, however, unilateral CI recipients have minimal, if any, localisation abilities (Nava et al., 2009; Preece, 2010). Due to the lifelong nature of deafness for the adults of interest in this study, it is likely that this sound localisation has never or barely been present (Preece, 2010), therefore an increase in awareness of their surroundings through sound may be sufficient to feel significantly safer.

The majority of participants indicated that finding it easier to care for family was an important met need for late cochlear implanted adults with prelingual deafness. This has not specifically been revealed in the published literature concerning CI recipients, though it is likely to be linked to other needs discussed here such as increased awareness of environmental sound and being more aware of when others are speaking.

4.3.1.10 Other

Another need that reached consensus as met and important was understanding speech with less effort. Studies assessing listening effort in adult CI recipients have indicated higher levels of listening effort for unilateral compared with bilateral CI recipients and participants with normal hearing (Hughes & Galvin, 2013), but the research is sparse on the comparison of listening effort of late cochlear implanted adults with prelingual deafness pre- and post-implantation. The present study suggests some subjective improvement, which has the potential to impact many other areas of life for the CI recipients, therefore further research is encouraged in this area.

Having better comfort was identified as an important met need by all CI recipients who participated in the study, and half of the SCIP clinicians. Round One indicated that this was due to CIs not requiring an earmold in most instances, leaving the ear unblocked.

Earmolds for high-powered hearing aids suitable for severe to profound losses are typically large and full with minimal venting so as to provide the least sound leakage out of the external auditory canal and therefore the greatest sound pressure at the ear drum (Bentler & Mueller, 2009). No important met needs were identified in Round Two of this study within the following categories: music; medical, financial or device issues; or understanding of CI process and outcomes.

4.3.2 Important unmet needs

4.3.2.1 Sound in general

Not being able to fully utilise sound information as an important unmet need for adult CI recipients is supported in the literature with studies suggesting CI recipients do not perform as well in speech perception tests as adults with normal hearing using CI simulators (Zeng & Bhattacharya, 2007). It has been suggested that this may be due to the interaction of the electrodes with the nerves (Fu, Shannon & Wang, 1998) or the number and quality of the surviving neurons within the cochlea and auditory nerve (Zeng & Bhattacharya, 2007). This need likely also relates to the significant involvement of the brain in the process of hearing, not just the peripheral hearing organs, and the lack of development throughout childhood due to the lack of adequate exposure to sound for the population of interest in this study (Zwolan, 2009).

CI recipients wanting more access to sound aligns with the concept that a CI provides the sensation of sound but does not restore natural hearing (Zwolan, 2009). Outcomes in adults with prelingual deafness are usually significantly worse than those of adults with postlingual deafness (Bradley, Bird, Monteath, & Wells, 2010; Teoh, Pisoni, & Miyamoto, 2004), indicating there are still significant deficits in overall sound access or interpretation for this population.

Difficulty telling where sounds are coming from was unsurprising based on minimal localisation of sound abilities recorded in monaural CI recipients (Nava et al., 2009; Preece, 2010). It is possible that this may not be considered an unmet need for bilaterally implanted adults, as all CI recipients participating in this study were unilaterally implanted, although localisation abilities in bilaterally implanted individuals still did not match the abilities of those with normal hearing (Preece, 2010).

4.3.2.2 Communication with other speakers

Difficulty when listening to more challenging speakers, including people who speak too quickly or slowly or have accents other than the CI recipient's native accent, was considered an important unmet need in this study. Supporting this is a study by Ji, Galvin, Chang, Xu and Fu (2014) that found that non-native speakers were more difficult for CI recipients to understand than they were for individuals with normal hearing, and significantly more difficult than native speakers.

4.3.2.3 Challenging listening environments

Difficulty listening in more challenging environments was identified as an important unmet need, with examples including being in large crowds, meetings, rooms with poor acoustics and in the presence of background noise. When reverberation or background noise are present, outcomes can be significant worse than in simpler, quiet environments (Fetterman & Domico, 1999; Loizou & Kim, 2011; Looi et al., 2011; Tobey et al., 2012), supporting the present research.

4.3.2.4 Technology use

Difficulty using the phone appears to remain challenging for the majority of late cochlear implanted adults, as documented for adults with prelingual deafness (Price et al., 2009). This is likely to be highly linked with listening to more challenging speakers and in more challenging environments as the acoustic signal transmitted across the phone is limited in frequency and often a degraded signal, and no visual cues are available. Hearing speech over a radio transmitter was also considered to be an important unmet need in this study, which is unsurprising as the signal is often even more degraded than the signal across a phone.

Difficulty following the TV, hearing at the movies and hearing speech on the radio are all consistent with difficulties understanding speech without visual cues (Bosco et al., 2013; Teoh et al., 2004) such as when the characters speak without facing the camera or audience, and when background noise is present (Fetterman & Domico, 1999; Loizou & Kim, 2011; Looi et al., 2011; Tobey et al., 2012) such as when music or background talking is accompanying the dialogue.

4.3.2.5 Social issues

Difficulty following jokes has been described as an important unmet need, which has been documented for adults with HL (Gregory et al., 1995; O'Reilly et al., 2014), but not yet adults with CIs. This difficulty may be related to higher rates of language, literacy and knowledge deficiencies among people with prelingual deafness (Dean & Pollard Jr., 2001; Leigh & Pollard Jr., 2003; Lucas et al., 2001), which have been established throughout childhood and adolescence, pre-implantation, for late cochlear implanted individuals.

4.3.2.6 Work issues

Difficulty understanding speakers in meetings is supported as an important unmet need by research concerned with reverberation and background noise (Fetterman & Domico, 1999; Loizou & Kim, 2011; Looi et al., 2011; Tobey et al., 2012), along with auditory-alone speech perception (Bosco et al., 2013; Teoh et al., 2004), all of which can contribute to the challenge of a meeting environment. The majority of participants also identified an unmet need of finding work too noisy. This depends largely on each individual's work environment as many environments would be considered too noisy by adults with normal hearing also, therefore it is difficult to make generalisations in this area.

4.3.2.7 Financial issues

The majority of participants considered having financial concerns to be an important unmet need. Research involving adults with deafness states income and financial concerns as barriers to participation (O'Donovan et al., 2009), without including maintenance and repairs of CI devices and accessories for recipients, which may compound these issues.

Furthermore, being unable to afford a second CI was considered an important unmet need by all CI recipients interviewed but not SCIP clinicians. It is possible that many CI recipients do not meet the criteria for a second implant, and may be ineligible due to audiological or cost-benefit reasons, which may be known by the clinicians but not necessarily by the recipients if they have not pursued the option. The expectations of what a second implant can provide may also be falsely elevated by recipients who may lack the professional knowledge in this area compared with highly trained clinicians.

4.3.2.8 Device issues

Another important unmet need was being limited by technology. Advancements in CI device and processing technology and subsequent improvements in some areas of hearing acuity have been documented, implying the technology is still developing (Bradley et al., 2010; Teoh et al., 2004). This is also confirmed by the inability of CIs to provide individuals with normal hearing acuity (Looi & Arnephy, 2010; Zwolan, 2009).

4.3.2.9 Understanding of CI process and outcomes

Employers, colleagues and others not having reasonable expectations and understanding about CIs were also identified as important unmet needs, and are likely to be related to insufficient understanding of deafness by individuals such as family members and health care workers reported in the literature (Cooper et al., 2003; Gupta et al., 2010), as well as negative societal attitudes toward deafness (Atkin et al., 2002; O'Donovan et al., 2009). This is of concern due to research indicating a positive correlation between awareness, respect and effective communication, and positive attitudes amongst hearing adults and adults with deafness (Coryell et al., 1992). No important unmet needs were identified in Round Two of this study within the following categories: support; connectedness with environment and people; social, safety or medical issues; or music.

4.3.3 Needs identified as important and both met and unmet

Interestingly, some needs reached consensus within both the met and unmet groups of need. Though this may appear contradictory, it is most likely due to differences in the examples provided by the participants in Round One, which were recorded under the needs in the survey, within the met and unmet versions of the statement of need. An example of this is (difficulty) listening in more challenging environments. For the need that was considered met, the example provided related to listening in groups of people. For the need considered unmet, the example provided related to large crowds, meetings, rooms with poor acoustics and the presence of background noise. Listening when in a group of people can be considered a more challenging environment than one-on-one conversation, and has been shown to improve for individuals post-implantation in previous research (Looi et al., 2011), therefore it is unsurprising that this need has been considered met by the majority of the participants in the present study. Listening when reverberation or background noise are present, however, has proven difficult for CI recipients based on previous studies (Fetterman & Domico, 1999; Loizou & Kim, 2011; Looi et al., 2011; Tobey et al., 2012). Therefore, it is also unsurprising that the majority of the participants in the present study considered this need to be unmet. Likewise, having more access to sound in general and wanting more access to sound were considered met and unmet respectively. This discrepancy may be related to the examples provided in the survey. For the met need, having a wider range of sound and a heightened awareness of sound were provided as examples. For the unmet need, the specific example provided was wanting to hear better. Research suggests that a wider range of sound (Klop et al., 2007; Zwolan, 2009), along with a greater awareness of sounds in general (Berrettini et al., 2011; Klop et al., 2007; Peasgood et al., 2003; Zwolan, 2009) is provided by CIs than is available through hearing aids. However, some areas of sound and hearing may not have been enhanced as much as CI recipients would have liked. Consequently, these needs may be perceived to be both met and unmet depending on which key aspects of the need are being considered.

4.3.4 Needs in relation to the ICF

The needs that reached consensus in Round Two of this study covered various domains of life for late cochlear implanted adults with prelingual deafness. When aligned with the WHO ICF model, the identified needs fall within the areas of body functions and structures, and activity and participation, with significant interaction between the domains and the individual needs. Increases in awareness of environmental sounds (sound awareness) and hearing and understanding of speech by listening only (speech perception) can be categorised under body functions, however, they can highly influence multiple areas within activity and participation, such as improved engagement in social and recreational activities, being more connected to the surrounding environment and people, and having more independence.

There is considerable overlap of the met and unmet needs identified through this study and the areas of functioning and disability within the core set for HL based on the ICF (Granberg et al., 2014). In some cases the areas relating to HL are considered areas of functioning or met needs with CIs. These areas include emotional function (e.g. the met need of feeling more positive) within body functions, and conversation (e.g. the met need of having improved communication with others in general) within activity and participation. In other cases, areas of the core set for HL are areas of disability or unmet needs with CIs. These areas include the inner ear and brain (e.g. the unmet need of not being able to fully utilise sound information) within impairments in body structures, and understanding implied meanings (e.g. the unmet need of having difficulty following jokes) within activity limitations and participation restrictions.

Several contextual factors influencing these areas of met and unmet need were identified. These included the provision and quality of health services (e.g. the met need of having good professional support services) and needs relating to family and society (e.g. the unmet need of others not having reasonable expectations and understanding about CIs).

These examples of areas of functioning and disability help to better identify and understand the long-term impact of cochlear implantation on the lives of adults with prelingual deafness, and the core set for HL allows for some comparison between research on individuals with HL and research after intervention for this HL, such as the present study.

4.4 Clinical implications

This study aimed to explore and identify a consensus of the important long-term met and unmet needs for late cochlear implanted adults with prelingual deafness. Determining these needs is relevant to the practice of clinical audiology as part of an audiologist's role is to establish appropriate expectations for their clients. The survey that was developed following Round One of this study could be used to inform clinical practice, including determining expectations of adults with prelingual deafness pre-implantation, as well as determining the long-term impact of cochlear implantation on many different areas of an individual's life. Identifying the needs of individuals pre-implantation has been recommended by Bosco et al. (2013), which could be accomplished using this survey. The findings from this study may also be used to better inform the development of government policies, particularly the funding provided by the government for CIs for adults with prelingual deafness, who previously were not considered to gain enough benefit to warrant implantation at all (Klop et al., 2007). Other policies and services involving late cochlear implanted adults with prelingual deafness may also be informed by this research. For example, the study findings suggest that it may be important to provide more education about CIs for the general public including employers and work colleagues of late cochlear implanted adults with prelingual deafness.

It is also beneficial clinically to be aware of any differences between the two perspectives obtained through this study: the SCIP clinicians and the CI recipients. These differences, such as being further from the speaker and still hearing them, and being unable to afford a second CI, should help to further educate clinicians on this specific population, and/or challenge the understanding of CIs by the recipients. Further research in these areas may provide additional information and understanding in these areas.

4.5 Study limitations and directions for future research

One of the major limitations of this study is the small sample size. Only nine participants responded to the invitations mailed out and were eligible to participate in the study. For qualitative research, specifically the Delphi technique, a sample size of 10 to 15 is typically desired (Delbecq, 1975).

The small sample size also prevented meaningful analysis involving the demographic information provided by the participants, therefore the relationship between the needs of late cochlear implantation of adults with prelingual deafness and other factors such as age, gender, household income and type of deafness remain unexplored. Future studies, if possible, should obtain a greater sample with more balanced demographics, particularly gender, as the sample in the present study was almost entirely female.

The response rate for the first round was unable to be reliably calculated due to incorrect identification of experts. Invitations to participate in the study were sent to five SCIP clinicians and 32 CI recipients from the SCIP database, who were believed to have met the inclusion criteria. Seven of the 32 CI recipients agreed to participate in the study, however, of the seven CI recipients who responded, two of the respondents did not fit the criteria for the study. It was therefore not possible to determine the total number of CI recipients who met the inclusion criteria for the study. It should also be noted that individuals became participants of this study by opting in which may skew the results, as individuals may be more likely to participate in a needs study if they have had a more positive experience with the CI overall.

Furthermore, there is significant heterogeneity amongst late cochlear implanted adults with prelingual deafness, making it difficult to gain consensus. In this study, some participants agreed and others disagreed with the same need. This was the case for many different areas of need, indicating significant variation in needs, even between the small number of participants in this study alone. The needs identified in this study should therefore be considered the most common needs rather than the needs of all late cochlear implanted adults with prelingual deafness.

There is also currently no published research on the needs of frequent communication partners of CI recipients, despite research indicating the impact of hearing loss and cochlear implantation on significant others, family and friends (Newberry, 2011; Knutson, Johnson & Murray, 2006). Many needs identified in the present study may have a significant impact on family and friends, including needs relating to independence and awareness of speech and other sounds in the surroundings. The modified Delphi technique could also be used to gather initial data on the needs of these people.

Participants in this study were not asked about their type of deafness, however, one participant mentioned her diagnosis of auditory neuropathy spectrum disorder (ANSD), which may influence her outcomes with the CI. ANSD is diagnosed when an individual's auditory brain response is absent or abnormal, but otoacoustic emissions and/or a cochlear microphonic are present (Guidelines Development Conference, 2008). This implies difficulty in the hearing system further along the pathway than the outer hair cells. There are many possible sites of dysfunction within the diagnosis of ANSD. There can be issues with the inner hair cells, the synapses between the inner hair cells and the nerve fibres, or the synchrony of the responses of the nerve fibres (Norrix & Velenovsky, 2014). The level of difficulty individuals with ANSD have with speech perception and language acquisition is difficult to predict from their audiograms and varies greatly between individuals (Berlin et al., 2010). CIs were previously considered inappropriate due to the neural nature of some subtypes of ANSD, however, significant improvements in speech perception and language acquisition have since been observed with cochlear implantation even in those with neural dysfunction (Berlin et al., 2010; Breneman, Gifford & DeJong, 2012; Rance, 2005).

The participant who reported having ANSD experienced a progressive loss, which is present in approximately 14 percent of ANSD cases (Sininger & Arnold, 2001), and lost her hearing perilingually. It is difficult to tell whether her needs were influenced by her progressive loss (rather than a congenital loss) and/or the neural nature of her deafness, and/or any other aspects of her life that may influence the needs of an individual with a CI such as age and support from family and friends (Bradley et al., 2010).

There is no consensus across the literature currently available regarding the outcomes of cochlear implantation of individuals with ANSD compared with sensory deafness.

Omidvar, Jafari, Hashemi and Zarei (2013) found no significant difference in recessive language, expressive language or speech skills between children with CIs and ANSD, and children with CIs and sensorineural deafness. They did, however, find a significant difference in these skills based on the age of onset of deafness, with children with earlier onset having poorer results. Conversely, Blamey et al. (2013) studied speech perception of 2251 adult CI recipients with post-lingual deafness and discovered significantly poorer speech perception in adults with ANSD compared with adults with various other aetiologies of sensorineural deafness. The comparison of CI outcomes for individuals with ANSD compared with sensory deafness is therefore an area requiring further research, which should be taken into account in future studies involving the population of interest in the present study.

4.6 Conclusion

This study identified several important long-term met and unmet needs of late cochlear implanted adults with prelingual deafness. These results can be used to inform the development of services and/or government policies in the future order to improve the quality of life of late cochlear implanted adults with prelingual deafness.

5

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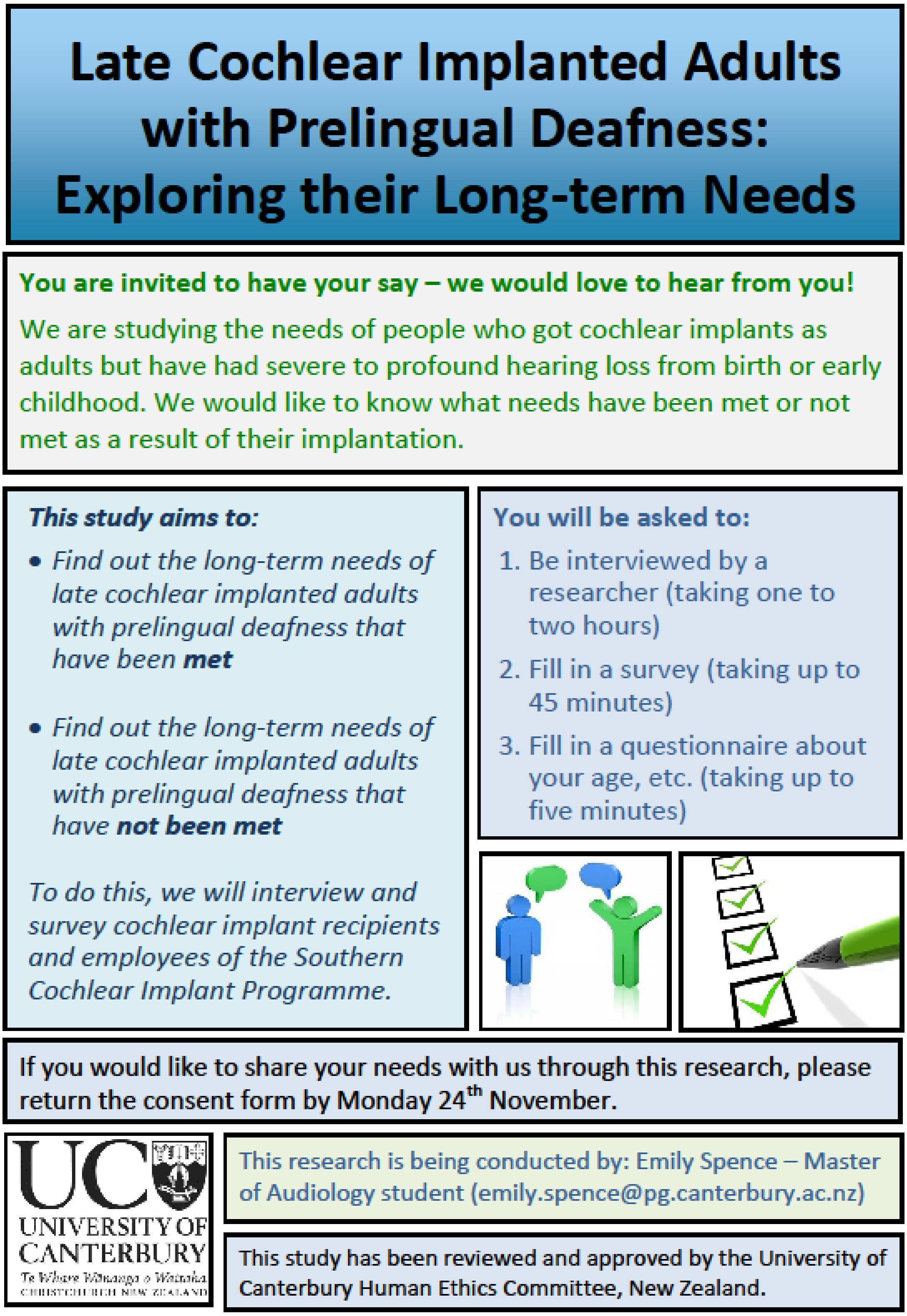
Appendix A: Invitation flyer



Late Cochlear Implanted Adults with Prelingual Deafness: Exploring their Long-term Needs

You are invited to have your say – we would love to hear from you!

We are studying the needs of people who got cochlear implants as adults but have had severe to profound hearing loss from birth or early childhood. We would like to know what needs have been met or not met as a result of their implantation.

This study aims to:

- *Find out the long-term needs of late cochlear implanted adults with prelingual deafness that have been **met***
- *Find out the long-term needs of late cochlear implanted adults with prelingual deafness that have **not been met***

To do this, we will interview and survey cochlear implant recipients and employees of the Southern Cochlear Implant Programme.

You will be asked to:

1. Be interviewed by a researcher (taking one to two hours)
2. Fill in a survey (taking up to 45 minutes)
3. Fill in a questionnaire about your age, etc. (taking up to five minutes)

If you would like to share your needs with us through this research, please return the consent form by Monday 24th November.

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CHRISTCHURCH NEW ZEALAND

This research is being conducted by: Emily Spence – Master of Audiology student (emily.spence@pg.canterbury.ac.nz)

This study has been reviewed and approved by the University of Canterbury Human Ethics Committee, New Zealand.

Appendix B: Information sheet

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Te Whare Wānanga o Waitaha
CHRISTCHURCH NEW ZEALAND

Study Title: *Late cochlear implanted adults with prelingual deafness in southern New Zealand: Exploring their long-term needs.*

Investigators:

Emily Spence
Master of Audiology student
Department of Communication Disorders
University of Canterbury
Email: emily.spence@pg.canterbury.ac.nz

Dr Tami Howe
Research supervisor
Department of Communication Disorders
University of Canterbury
Email: tami.howe@canterbury.ac.nz
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Dr. Rebecca Kelly-Campbell
Associate research supervisor
Department of Communication Disorders
University of Canterbury
Email: rebecca.kelly@canterbury.ac.nz

Phone: (03) 364 2987 ext 8327

Invitation to be part of the study:

You are invited to take part in the following study: *Late cochlear implanted adults with prelingual deafness in southern New Zealand: Exploring their long-term needs.*

You have been invited to participate in this study because we believe that you will be able to provide a valuable perspective in relation to the focus of this study.

What is the aim of the study?

- to find out the **long-term met and unmet needs of people with prelingual deafness who received cochlear implants as adults**

Who do we need for the study?

We need 2 groups of people:

- **Adults who have had a severe to profound hearing loss since birth or under 1 year old**; and
  - who got their cochlear implant as an adult
  - who have had their cochlear implant for at least 18 months

- **Southern Cochlear Implant Programme employees:**
  - Who work and/or have worked with late cochlear implanted adults with prelingual deafness in the southern New Zealand region.

What will happen in the study?

This study has two parts.

Part 1:

Emily Spence will interview you. She will ask you about the long-term needs of adults with prelingual deafness and cochlear implants that have been met, and the needs that have not been met. The interview will be audio-recorded. The interview will take place at your home, the university, or other quiet place of your choosing. The interview will be about 1 to 1 ½ hours.

You may receive a copy of the transcript of the interview by ticking the box on the consent form.

Part 2:

The results from Part 1 will help to make a survey for Part 2.You will receive the survey in the post. It will contain a list of the general categories of needs (with examples) that were identified by all the participants in part

1. No material that could identify individual participants will be included in this survey. You will be asked to say how much you agree with the importance of each of the needs. The survey should take about 15 to 30 minutes.

Participation:

Your participation is entirely voluntary. You do not have to take part in the study.

You can withdraw from the study at any time, without giving a reason. This will NOT affect any future interactions you have with the university. If you withdraw, I will remove all information relating to you if it is practically achievable.

Potential Benefits:

This study will help to improve our understanding of the long-term needs of late cochlear implanted adults with prelingual deafness in southern New Zealand. However, there are no direct benefits to you.

Potential Risks:

There are no direct risks when participating in this study. The researcher will be careful to understand and respect the culture of all participants throughout the study. You may have whanau or a friend present to help you understand the risks and/or benefits of this study.

Confidentiality:

The results of the project may be published, but your identity will be kept private throughout the study. No information that could identify you will be used in any reports in the study or in the survey in part 2. Any information collected will only be able to be seen by the researcher and her supervisors.

The data will be stored in a locked filing cabinet and/or in a password-protected electronic format. This data will be destroyed five years after the completion of the study.

A thesis is a public document and will be available through the UC Library.

How do I find out about the study findings?

You may receive a copy of the study's findings by ticking the box on the consent form.

Statement of approval:

The project has been checked and approved by the University of Canterbury Human Ethics Committee. If you have a problem or complaint about this research, contact:
The Chair, Human Ethics Committee, University of Canterbury, Private Bag 4800, Christchurch (humanethics@canterbury.ac.nz).

Please feel free to contact the researchers if you have any questions about this study.

If you agree to take part in this study, you are asked to complete the consent form enclosed and return it to me using the pre-addressed envelope also enclosed. Please return this by Monday 24th November.

Thank you for your interest in this study.

Emily Spence
Master of Audiology Student
Email: emily.spence@pg.canterbury.ac.nz

Appendix C: Consent form

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CONSENT FORM

Study title: *Late cochlear implanted adults with prelingual deafness in southern New Zealand: Exploring their long-term needs.*

- The information about this research project has been explained to me to my satisfaction. I have had a chance to ask questions.

- I understand what I need to do if I take part in the study.

- I understand that I can choose whether or not I take part in this research. I understand that I may withdraw from the study at any time, without penalty. If this happens, any information I have provided will also be withdrawn as long as it remains practically achievable.

- I understand that any information or opinions I provide will be kept confidential to the researcher and supervisors. I understand that any published or reported results will not identify the participants.

- I understand that a thesis is a public document and will be available through the UC Library.

- I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.
- I understand that my interview will be audio-recorded and that only the researcher and two supervisors will have access to this recording.

- I will be given a copy of this form and the Research Information Sheet.

- I wish to have a copy of the transcript from my interview. Yes ☐ No ☐

- I wish to have a copy of the final results of the study.
  Yes ☐ No ☐

- I understand that I can contact the researcher (Emily Spence, emily.spence@pg.canterbury.ac.nz) or supervisor (Dr Tami Howe, tami.howe@canterbury.ac.nz or (03) 364 2987 ext 3619) for further information. If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch (human-ethics@canterbury.ac.nz)

By signing below, I agree to take part in this research project.

Name (please print):

....

Signature: .... Date: ....

Please tick the appropriate box below:

☐ I am a cochlear implant recipient
☐ I am a current employee of the Southern Cochlear Implant Programme (SCIP)

Preferred method of contact: ....

Contact details: ....
....
....

Please return this form by Monday 24th November. After sending this in, you will be contacted using the means provided above to organise when and where the interview will be held. Thank you for considering taking part in this study.

Emily Spence
Master of Audiology Student

Appendix D: Human Ethics Committee approval letter

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CHRISTCHURCH NEW ZEALAND

HUMAN ETHICS COMMITTEE

Secretary, Lynda Griffioen
Email: human-ethics@canterbury.ac.nz

Ref: HEC 2014/123

2 October 2014

Emily Spence
Department of Communication Disorders
UNIVERSITY OF CANTERBURY

Dear Emily

The Human Ethics Committee advises that your research proposal “Late cochlear implanted adults with prelingual deafness in southern New Zealand: exploring their long-term needs” has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your email of 29 September 2014.

Best wishes for your project.

Yours sincerely

Lindsey MacDonald
Chair
University of Canterbury Human Ethics Committee

University of Canterbury Private Bag 4800, Christchurch 8140, New Zealand. www.canterbury.ac.nz

F E S

Appendix E: Survey

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Dear research participant,

Late last year you participated in the first round of a research project to explore **long-term met and unmet needs** for late cochlear implanted adults with prelingual deafness. We have used the results from the first round of interviews with all the participants to develop this survey. It is hoped that you will participate in this second round also.

This survey forms the second and final round of the research project. It should take about **30 minutes to complete**. Your participation is greatly appreciated and valued.

Instructions

Please circle **ONE** number per item that **best represents** your response to each statement below. The items are presented in two lists: one to find out important met needs and one to find out important unmet needs. Please answer the questions in relation to experiences eighteen months or more after having an implant.

Once you have completed this survey, please return it as soon as possible by email (emily.spence@pg.canterbury.ac.nz) or post (using the self-addressed envelope contained in the package posted to you).

Kind Regards,

Emily Spence

Section 1: Important met needs

Based on my experience, an **important met need** for late cochlear implanted adults with prelingual deafness, **eighteen months or more after** their implantation, is:

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Being more aware of environmental sounds *e.g. hearing a dog barking, washing machine turning off, birds, car indicators, rain, thunder, fridge beeping, wind, phone ringing, footsteps*	1	2	3	4	5
Having more access to sound in general *e.g. able to hear a wider range of sound, heightened awareness of sound*	1	2	3	4	5
Having improved identification of sound *e.g. knowing what a specific sound is such as a siren*	1	2	3	4	5
Being better able to localise sound by following it *e.g. hearing a sound and being able to tell where it is coming from by following the sound*	1	2	3	4	5
Having improved communication with others in general *e.g. having more ability to communicate, carry on a conversation*	1	2	3	4	5
Improvements in own voice and own speech clarity *e.g. having better volume of own voice, others understanding it better, better tone of own voice*	1	2	3	4	5
Increasing the volume of others' speech *e.g. making other people's voices louder*	1	2	3	4	5
Improved hearing and understanding of speech by listening only *e.g. not having to always rely on lip-reading, hearing crisp letter sounds in words like esses, speech being more clear*	1	2	3	4	5

Section 1: Important met needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Enhanced lip-reading *e.g. being able to lip-read better, having more information to work with*	1	2	3	4	5
Being more aware of when being spoken to *e.g. hearing a name called out at the doctor'd or a child calling, knowing when someone is saying something*	1	2	3	4	5
Being further from the speaker and still hearing them *e.g. hearing a child from another room, a partner outside or at the other end of the house*	1	2	3	4	5
Improved understanding of speech in the car *e.g. hearing someone talking in the passenger seat*	1	2	3	4	5
Understanding speech with less effort *e.g. less tiring than just lip-reading*	1	2	3	4	5
Listening to more challenging speakers *e.g. better understanding of people with accents*	1	2	3	4	5
Listening in more challenging environments *e.g. better hearing when in groups of people*	1	2	3	4	5
Being better able to use the phone *e.g. talking to friends, strangers, with or without a special phone or ear hook*	1	2	3	4	5
Having better hearing over Skype/video calling *e.g. hearing what is said more easily*	1	2	3	4	5
Being better able to follow the TV *e.g. hearing the TV more clearly, understanding with or without captions, not needing to wear headphones*	1	2	3	4	5

Section 1: Important met needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Being better able to hear speech on the radio *e.g. listening to the news*	1	2	3	4	5
Being better able to use a Walkman *e.g. being able to listen to music from a Walkman or portable music player*	1	2	3	4	5
Having improved understanding of speech over the PA system *e.g. promotions or specials in a supermarket or shop over the loud speaker, short messages with repetitions*	1	2	3	4	5
Having improved access to and appreciation of music *e.g. being able to understand the lyrics better, hearing singing, instruments, listening to music in the car*	1	2	3	4	5
Having good professional support services *e.g. having good long-term support, follow-up, customer service from organisations such as SCIP and Life Unlimited*	1	2	3	4	5
Having further habilitation after the initial eighteen months *e.g. getting help with listening exercises and habilitation long-term*	1	2	3	4	5
Being part of a community with other CI recipients *e.g. decrease in isolation, sense of identification, using the SCIP facebook page, having something in common with some famous people*	1	2	3	4	5
Having improved engagement in social activities *e.g. going to clubs, meetings, keeping up with social group conversations*	1	2	3	4	5
Having improved engagement in recreational activities *e.g. hearing people calling during sport, wearing a helmet without having whistling (feedback), going to productions, school events*	1	2	3	4	5
Feeling more positive *e.g. being less frustrated, less depressed, fewer arguments with others, more confidence*	1	2	3	4	5

Section 1: Important met needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Being better able to understand customers, clients and colleagues *e.g. understanding in person or on the phone, in work meetings*	1	2	3	4	5
Being better able to begin employment *e.g. starting work, having better access to employment*	1	2	3	4	5
Being better able to progress further in employment *e.g. being able to be promoted, have a higher income, be more efficient*	1	2	3	4	5
Being safer at work *e.g. being aware of forklifts, alarms, warning signals, colleagues wanting attention*	1	2	3	4	5
Being safer while driving *e.g. hearing someone yell "stop" in the car*	1	2	3	4	5
Being safer in general *e.g. hearing footsteps approaching from behind while walking or running, fire alarms, sirens*	1	2	3	4	5
Finding it easier to care for family *e.g. finding it easier to care for children*	1	2	3	4	5
Being more connected to the surrounding environment and people *e.g. feeling more present in the world, being more aware of what's going on, being connected to the environment through sound*	1	2	3	4	5
Having improved functioning in the 'hearing world' *e.g. having fewer practical problems, integrating into day-to-day life*	1	2	3	4	5
Having more independence *e.g. not having to rely on family or others to help on the phone, with travel, making appointments*	1	2	3	4	5

Section 1: Important met needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Having better comfort *e.g. not having to wear an earmold*	**1**	**2**	**3**	**4**	**5**

Section 2: Important unmet needs

Based on my experience, an **important unmet need** for late cochlear implanted adults with prelingual deafness, **eighteen months or more after** their implantation, is:

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Not being able to fully utilise sound information *e.g. finding some sounds intrusive, like high-pitched sounds, being overwhelmed by sound coming through one ear*	**1**	**2**	**3**	**4**	**5**
Wanting more access to sound *e.g. wanting to hear better*	**1**	**2**	**3**	**4**	**5**
Difficulty identifying sound *e.g. not being able to tell what a sound is, hearing strange sounds, being unable to tell that a noise is a siren*	**1**	**2**	**3**	**4**	**5**
Difficulty telling where sounds are coming from *e.g. having to look around to see where sounds are coming from rather than being able to tell by hearing*	**1**	**2**	**3**	**4**	**5**
Difficulty with the use of own voice and own speech clarity *e.g. struggling with the tone of own voice, how easily others understand it*	**1**	**2**	**3**	**4**	**5**
Difficulty hearing and understanding speech by listening only *e.g. still having to ask for repeats, rely on lip-reading or sign language a bit*	**1**	**2**	**3**	**4**	**5**
Difficulty when listening to more challenging speakers *e.g. struggling with individuals who have accents, speak too slowly, too fast, too loudly*	**1**	**2**	**3**	**4**	**5**
Difficulty listening in more challenging environments *e.g. not being able to understand and localise sound in background noise, in meetings, in large crowds, in rooms with poor acoustics*	**1**	**2**	**3**	**4**	**5**

Section 2: Important unmet needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Difficulty using the phone *e.g. struggling to understand people with accents, calling call centres, being unable to use the phone at all*	1	2	3	4	5
Difficulty hearing everyone over Skype/video calling *e.g. only being able to understand some people, not hearing everything first time*	1	2	3	4	5
Difficulty following the TV *e.g. lack of captions available, still requiring captions, not understanding dialogue with background music/noise*	1	2	3	4	5
Difficulty hearing at the movies *e.g. finding it hard to follow along and pick up what's going on*	1	2	3	4	5
Difficulty hearing speech on the radio *e.g. presenters talking too fast, only getting bits and pieces*	1	2	3	4	5
Difficulty hearing speech over a radio transmitter (RT) *e.g. not hearing instructions from the transmitter, not understanding the person on the other end of the RT*	1	2	3	4	5
Having to rely on technology *e.g. having to have batteries on hand, needing to replace parts*	1	2	3	4	5
Not having access to and enjoyment of music *e.g. not being able to hear and enjoy music*	1	2	3	4	5
Finding live music too loud *e.g. not being able to tolerate bands at weddings*	1	2	3	4	5

Section 2: Important unmet needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Difficulty following jokes *e.g. struggling to follow jokes unless someone explains them*	1	2	3	4	5
Wanting but not receiving further habilitation *e.g. not getting more habilitation after 18 months of having the implant*	1	2	3	4	5
Being unable to afford a second CI *e.g. not having CIs on both sides for financial reasons*	1	2	3	4	5
Having to pay for professional services *e.g. not having speech therapy funded*	1	2	3	4	5
Having financial concerns *e.g. having to pay for batteries, replacement parts, coils, cables, insurance*	1	2	3	4	5
Lacking good professional support services *e.g. having to travel to a distant locality for audiology/habilitation, not receiving information about services, not having spare parts provided*	1	2	3	4	5
Lacking support in the workplace *e.g. not receiving support from colleagues or employers*	1	2	3	4	5
Lacking support from family and friends *e.g. not receiving support from other familiar people*	1	2	3	4	5
Lacking a sense of community with other CI recipients *e.g. not having a local get-together of CI recipients, not socialising with others with the same device*	1	2	3	4	5

Section 2: Important unmet needs

Statements	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
Having more negative feelings *e.g. feeling isolated, lonely, disconnected at parties or elsewhere*	1	2	3	4	5
Difficulty engaging in recreational activities *e.g. having to take off the CI when involved in watersports like swimming, kayaking*	1	2	3	4	5
Difficulty understanding speakers in meetings *e.g. struggling to understand people who talk fast, not being able to see everyone's face, having other people talking in the background*	1	2	3	4	5
Finding work too noisy *e.g. children at work being too noisy, equipment at work being too noisy*	1	2	3	4	5
Experiencing vertigo/dizziness *e.g. feeling dizzy when sitting/standing/lying in certain positions related to the CI*	1	2	3	4	5
Experiencing pain *e.g. having headaches related to the CI*	1	2	3	4	5
Experiencing facial twitching *e.g. having strange feelings in the face in relation to sound*	1	2	3	4	5
Feeling less safe due to not being able to tell where sounds are coming from *e.g. being in danger and unable to tell where a sound is around you*	1	2	3	4	5
Feeling less safe in water *e.g. not hearing people who want your attention, not being able to wear the CI in the water*	1	2	3	4	5

Section 2: Important unmet needs

Statements	**Strongly disagree**	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
Feeling less safe at night *e.g. not hearing a fire alarm, banging on the door, being able to retrieve CI in an emergency*	**1**	**2**	**3**	**4**	**5**
Being limited by technology *e.g. having issues that cannot be resolved with the current technology*	**1**	**2**	**3**	**4**	**5**
Difficulty connecting with environment, family and self *e.g. not becoming more connected with the world and other people*	**1**	**2**	**3**	**4**	**5**
Being unable to fully function in the hearing world *e.g. not being able to integrate fully into the hearing world*	**1**	**2**	**3**	**4**	**5**
Others not having reasonable expectations and understanding about CIs *e.g. general public not knowing how to communicate with someone with a CI, thinking a CI user has been "fixed" and now has a real ear*	**1**	**2**	**3**	**4**	**5**
Employers and colleagues not having reasonable expectations and understanding about CIs *e.g. employers not having the right information and expectations, colleagues not understanding what a CI is and does*	**1**	**2**	**3**	**4**	**5**
Lack of understanding by recipients of CI process and outcomes *e.g. negatively comparing to other people with CIs, not understanding why others seem to have better or worse outcomes*	**1**	**2**	**3**	**4**	**5**

*You have completed the survey. I ask that you please return the survey as soon as possible either via email (emily.spence@pg.canterbury.ac.nz) or post (*using the self-addressed envelope contained in the package posted to you*).*

Thank you for your time and the contribution of your valuable perspective.

If you have any questions or comments about this survey or the research project, please do not hesitate to contact me at emily.spence@pg.canterbury.ac.nz.