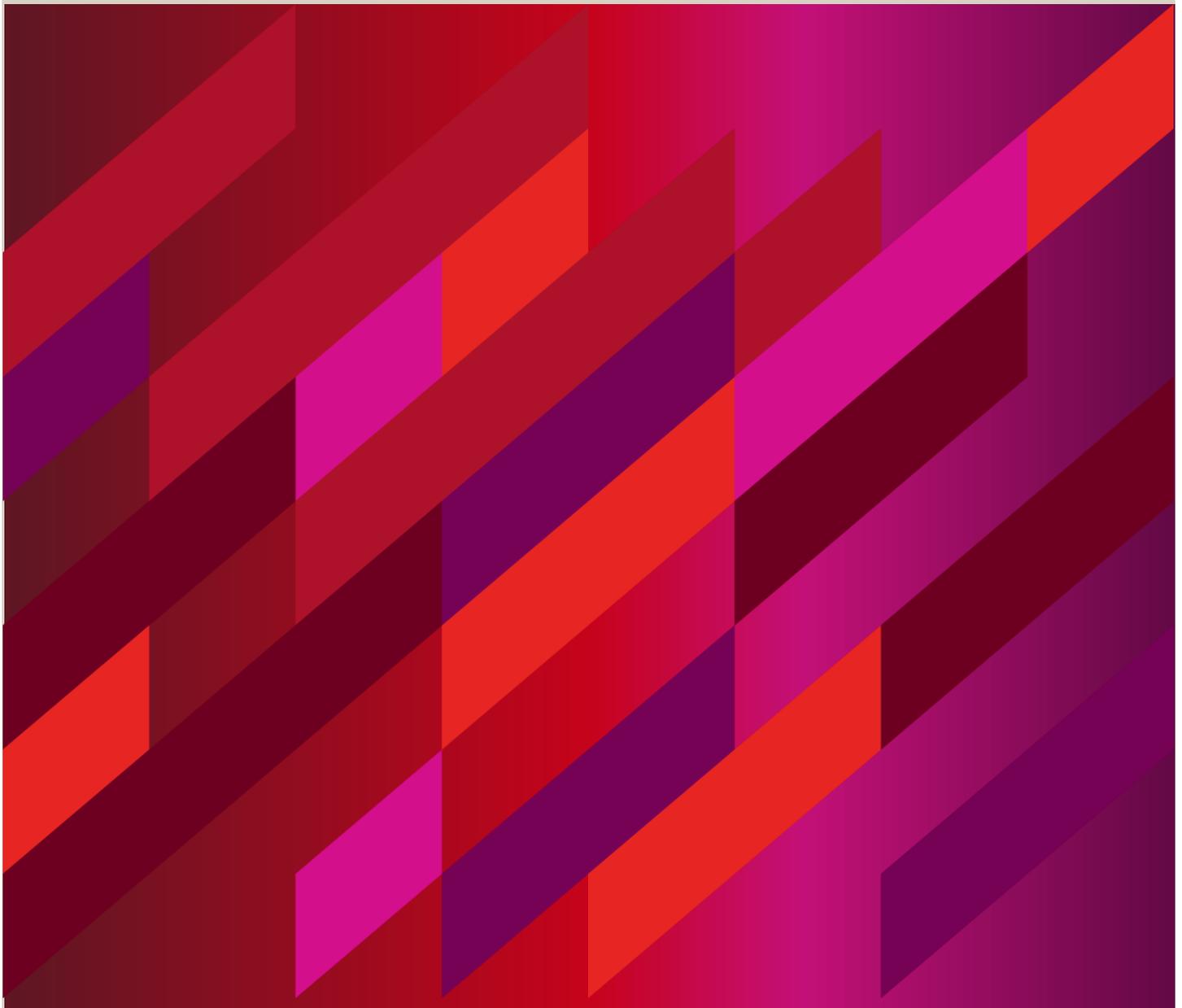




Final Report: Behavioural and Attitudinal Responses to Cochlear Implantation in Australia and the UK

May 2018



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Prepared for Cochlear Ltd

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Abbreviations

ACT	Australian Capital Territory
AQP	Any Qualified Provider
Aud.	Audiologist
CI	Cochlear implant
CI Aud.	Cochlear implant specialist audiologist
CI cand.	Cochlear implant candidate
DVA	Department of Veterans' Affairs
ENT	Ear, Nose and Throat specialist
FRACGP	Fellowship of the Royal College of General Practitioners
GP	General Practitioner
HA	Hearing aid
HA Aud.	Hearing aid audiologists
HCP	Healthcare professional
HREC	Human Research Ethics Committee
HrQoL	Health-related Quality of Life
MRCP	Membership of the Royal Colleges of Physicians of the United Kingdom
NDIS	National Disability Insurance Scheme
NHS	National Health Service (UK)
NSW	New South Wales
NT	Northern Territory
QLD	Queensland
WA	Western Australia
WHO	World Health Organisation
YLD	Years Lived with Disability

Executive Summary

Background, and aims: The growing prevalence of adults with ‘severe or greater’ late onset hearing loss globally is a major public health problem, leading to diminished communication, and reduced Health-Related Quality of Life (HRQoL). Cochlear implants (CIs) are a recommended device for people with severe or greater sensorineural hearing loss, who obtain limited benefits from conventional hearing aids (HAs). Through improved access to auditory information, improving speech perception and opportunities for social engagement, they can achieve a better HRQoL but despite this, CI utilisation worldwide is low. The reasons for the low uptake of this technology currently remain unclear. **This study aimed to:** a) determine perceptions of barriers and facilitators associated with CIs in adults aged ≥ 50 years, with severe or greater hearing loss; b) assess patients’ and healthcare professionals’ (HCPs) behaviours and attitudes towards implants; c) clarify how attitudes and behaviours impact on patient pathways across services, and d) define patients’ hearing health aspirations

Design and method: Qualitative, mixed-method, dual site study: Australia and the United Kingdom (UK), between June 2017 and April 2018. Following ethical approval from Macquarie University Human Research Ethics Committee (HREC: 5201700539) patients (HA users, CI candidates and CI users), General Practitioners (GPs), and audiologists were recruited in Australia, and audiologists, as a comparative HCP sample, were recruited in the UK. Purposive, timeframe sampling (predefined recruitment period ensuring eligible individuals have an equal chance of recruitment) ensured a wide mix of participant cohorts. Patients were: mixed gender, age, and area of residence. HCPs were: mixed gender, varying lengths of service, working across metropolitan and rural areas.

Participant inclusion criteria: Patient participants were 50 years or over, had severe or greater postlingual sensorineural hearing loss, proficient in English, capable of engaging in focus group discussions and completing a demographic questionnaire and qualitative proforma (open ended survey). GPs and audiologists had to have consulted with the target populations.

Study cohorts: 55 participants in total across Australian and UK sites

The pilot included: 12 participants: 5 CI users (aged 50 years+), and 3 audiologists in Australia, and 2 audiologists in the UK took part in 3 separate pilot focus groups, while 2 GPs took part in pilot interviews. The pilot phase tested the acceptability, timeliness and comprehensiveness of the questions, and ensured the methodology complemented the study’s aims and objectives.

The principal study included: 43 participants: In Australia: 5 GPs, 8 audiologists, 12 CI users (aged 50 years+) and 9 HA users (aged 50 years+) (including 2 CI candidates who had begun CI

assessment). In the UK: 9 audiologists (Table 1.0). Note sample overachievement; the original study plan proposed the recruitment of 28 participants, and 32 data capture events.

Table 1.0: Study participants

Participant cohort	Pilot phase	Principal study phase	Total
CI users	5	12	17
HA users	0	9	9
GPs	2	5	7
Audiologists in Australia	3	8	11
Audiologists in UK	2	9	11

Data collection and analysis: 143 separate data capture events took place. All participants were invited to take part in focus groups or individual interviews, and to complete a demographic questionnaire and qualitative proforma (open ended survey, adding detail to the focus group and interview data). Focus group and interview data were transcribed, and thematic analysis was undertaken of all datasets, with extensive group work achieving a consensus of opinion over the major themes and categories arising. Data findings will be reported, beside this final report, through academic publications which will include demographic data and participant characteristics.

Overview of Results:

Six themes arose from this study; Theme 1: *Barriers and facilitators to utilisation of CIs, from the perspective of patients and HCPs* (aim 1); Theme 2: *The burden of hearing loss* (Aim 2); Theme 3: *The impact of CIs on Quality of Life (QoL)* (Aim 2); Theme 4: *Professional practice – information and shared care by HCPs, from the HCP perspective* (Aim 3); Theme 5: *HCP support and care, from the perspective of patients* (Aim 3); Theme 6: *Patient aspirations for the future* (Aim 4).

The main facilitators for patients to progress to a CI are: being more informed, believing CIs will improve their quality of hearing, being advised to get implants before losing all residual hearing, becoming more frustrated as hearing loss impacts their relationships, work and mental health, with ineffective support from HAs, hearing CI recipient testimonials, feeling supported by knowledgeable HCPs and family, and the desire for increased communication and social interaction. HCPs thought that the high cost of HAs was a motivator for patients, as was patient fear of going completely deaf. The main facilitators for HCPs discussing CIs with patients are: their own CI awareness, knowledge and training, access to demonstration models and a CI referral sheet, patient-clinician continuity, access to positive CI testimonials, and support from other clinicians with knowledge of CIs.

Main barriers for patients to progress with CIs are: fear of surgery and complications (such as loss of residual hearing, uncertain outcomes, concerns about rehabilitation and time off work, concerns about perceived costs, cosmetics and misunderstandings around sound quality as well as having a HCP who isn't supportive or knowledgeable about CIs. HA users are concerned about the irreversibility of the procedure, not being ready for a CI, and not knowing enough about CIs or who to contact for more information. Perceived stigma of hearing loss was considered by some HCPs to be a barrier for patients, as well as limited access to services in rural areas, and the challenges associated with travel. The main barriers for HCPs discussing CIs with patients are: lack of knowledge and training about CIs and the candidacy criteria, lack of patient-clinician continuity, limited access to hearing services in rural areas for support and information, limited networking with CI centres, and limited shared care.

Patients express isolation and extreme listening effort which impacts detrimentally on their relationships, their ability to manage at work, and a wide range of socialisation issues. Patients are greatly affected by CI recipients' 'good news' stories, and buddying systems improve uptake and people's sense of belonging.

Patients want to be more informed about their hearing loss, the patient pathway through the healthcare system, from assessment to surgery, and the channels of support available to them. Patients need networks of HCPs to offer information and help them make informed decisions about their hearing health as they are currently influenced by the (potentially limited) experience of the people they talk about CIs with (HCPs, family, friends) and their own views and experiences. Hearing loss and listening effort clearly impacts negatively on patients' self-identity, leaving patients lacking in confidence, isolating themselves from society and reducing their interactions with others. Hearing loss impacts physical and psychosocial wellbeing.

HCPs, especially GPs, seem ill informed about CIs. Time poor, they need avenues to improve their own knowledge and skills asking for educational tools, information sheets and teaching sessions to increase CI discussions and referrals. Audiologists feel they work in isolation from CI specialist audiologists and their body of knowledge and express a concern that other audiologists' treatment recommendations are driven by HA sales targets. They are unsure how to refer on, or about the process of CI candidacy/surgery. Audiologists in Australia and the UK tell predominantly the same story, other than when it comes to financial/political considerations, where Australians say more about the cost of HAs and CIs (including implantation, rehabilitation and upgrades).

More research is needed on: Information provision, shared care, and HCPs' knowledge of CIs, and their impact on patients' QoL. Greater HCP awareness and more targeted training would improve patient care.

Ten Recommendations to Increase Awareness and Promote CIs Amongst Patients and HCPs

1. Increase awareness of, and access to, a standardised CI referral tool, to enable GPs and audiologists to streamline referral pathways, reduce unnecessary steps in the referral chain, and increase awareness of available resources
2. Increase the availability and awareness (amongst audiologists and patients) of CI recipient buddying schemes
3. Increase availability and awareness of information packages and online platforms for patients and professionals through regular dissemination of resources via self-help groups, GP surgeries and audiology clinics for ‘good news’ stories about implantation, dispelling myths and answering questions.
4. Advocate for CI-specific topics to be included in tertiary courses for audiologists to increase knowledge and awareness of CIs amongst GPs and audiologists (Australia and UK), while targeting GP Continuing Professional Development, and HA audiologists’ professional development courses.
5. Strengthen the community of practice between audiologists, GPs and CI teams (ENTs and CI audiologists), by offering events and Master Classes for those who infrequently deal with adults with severe or greater sensorineural hearing loss, with CI specialist programs to provide specialists for audiologists to consult with. Promotion of new networks should be disseminated through GP and audiologist newsletters and consumer and healthcare professional forums.
6. Commission further academic research about CIs, CI referral pathways, and eligibility criteria for publication in GP and audiology journals (generalist), peer reviewed academic publications, and conference presentations.
7. Monitor individual HA users who are not currently eligible, but who have shown an interest in CIs, for future tracking, ongoing update and assessment.
8. Increase awareness of the benefits of CIs amongst adult populations through extensive information provision and promotional materials (online and otherwise). Target GP surgeries, hearing associations and audiology clinics in both countries, and develop promotional material in consultation with adult CI recipients to reduce age-related stigma associated with CIs and other hearing devices.
9. Improve awareness and availability of self-administered online hearing loss tests that adults could access at home, and from which they could self-refer for an assessment if necessary.
10. Create a partnership between hearing care stakeholders, including HA audiologists and GPs, working to strict terms of reference, to design and define what an audiology network could do to ensure UK and Australian audiologists feel less isolated and more certain about how to help patients and each other.

1. Introduction

Prevalence of hearing loss

Hearing loss is a growing global burden, and was ranked as the third highest cause of years lived with disability (YLD) by the World Health Organisation (WHO), in 2006.[1] Hearing loss can limit communication, increase frustration, and social isolation.[2] Hearing loss is defined by the average pure tone hearing thresholds in the better ear (measured in decibels, dB), across various specific frequencies.[3] Approximately 1.2% of adult males and 1.0% of adult females globally have severe or greater hearing loss (≥ 65 dB, measured over 0.5, 1, 2 and 4 kHz frequencies),[3] approximately 60 million adults globally [4]. One in five adults in Australia have a hearing loss,[5] 11% of which have severe or greater hearing loss in one ear,[5] which is projected to exceed 573,000 adults by 2020.[5]

Benefits of Cochlear Implants

CIs are a recommended device for people with severe or greater sensorineural hearing loss, who obtain limited benefits from conventional HAs. CIs bypass damaged hair cells in the cochlea, and through direct stimulation to the auditory nerve, restore the perception of sound, with outcomes related to improved speech perception and enhanced quality of life (QoL) through improved opportunities for social interaction.[6-9] Despite these factors, utilisation of CIs globally remains low amongst the adult population.[10]

Utilisation of Cochlear Implants

Less than 10% of adults with severe or greater hearing loss are estimated to have received the device,[5] however the exact CI utilisation rate is unknown due to poor documentation of the prevalence of severe or greater hearing loss and CI utilisation. In most CI clinics, speech recognition ability with the use of HAs, is a greater determinant of CI candidacy, compared to hearing threshold severity.[11] There is currently no population data available on hearing (dis)ability, only pure-tone hearing sensitivity data. Further research is necessary to establish the current adult CI utilisation rates in Australia.

2. Method

This section describes the data collection methods used. Ethical approval for this project was obtained from the MQ Human Research Ethics Committee (Approval number: 5201700539).

2.1 Study design and context

This qualitative, multi-phase, multi-method and dual site study, was undertaken concurrently in Australia and the UK between June 2017 to April 2018.

The aims of this study were to:

- 1) Determine perceptions of barriers and facilitators associated with CIs in adults aged ≥ 50 years, with severe or greater hearing loss;
- 2) Assess patients' and healthcare professionals' (HCPs) behaviours and attitudes towards cochlear implants;
- 3) Clarify how attitudes and behaviours impact on patient pathways across services, and
- 4) Define patients' hearing health aspirations.

Study context: In Australia, HAs and unilateral CIs are available with public funding, through the Australian Government Hearing Services Program, State Government funding and the Department of Veterans' Affairs; for people who meet the eligibility criteria. The number of CIs that are publicly funded each year are limited, and vary state by state, resulting in waiting lists.[12] Private health insurance funds can also be used to reimburse implantation. [13, 14] In the UK, HAs are available through the publicly funded National Health Service (NHS) or are available from private dispensers via self-funding or private health insurance. Unilateral CIs are available through the NHS for adults who meet the eligibility criteria specified by the National Institute for Health and Care Excellence. [15] Alternatively, CIs may be self-funded or available through private health insurance plans. [16]

2.2 Participants:

Participants in Australia included: 1) GPs and 2) audiologists, currently working in their field with experience consulting with adults with hearing loss, and 3) adults over the age of 50 with severe or greater postlingual sensorineural hearing loss who were either a) bilateral or unilateral CI users; or b) HA users or CI candidates (in the process of being assessed for a CI). The UK cohort included audiologists only, to provide a healthcare professional comparison group from an international perspective.

2.3 Recruitment and Data collection

Recruitment occurred between June 2017 to February 2018 Australia-wide for the patient cohorts, and HCPs. Recruitment of audiologists in the UK was UK-wide. Promotion of the study occurred through the distribution of promotional flyers through a variety of outlets, including audiology clinics, conferences, GP clinics, HCP e-newsletters, and through hearing associations. The flyers included general information about the study, and research team contact information. Once eligibility was established, and informed consent obtained, participants were invited to participate in a focus group, or interview (over phone, skype or email), as they preferred. The study was conducted in two stages; **Stage 1:** Pilot focus groups and interviews were conducted. Principal study focus groups and interviews were then conducted, and all participants were asked to complete a demographic questionnaire. The purpose of the pilot phase was to test the acceptability, timeliness and comprehensiveness of the questions, and ensure the methodology complemented the study's aims and objectives. **Stage 2:** All participants were asked to complete a qualitative proforma (open ended survey, adding detail to the focus group and interview data), and to return it to the study team.

2.4 Analysis

All focus groups and interview data were transcribed verbatim. The transcripts were uploaded to NVivo (version 11)[17] and thematic analysis was undertaken of all datasets with extensive groupwork to achieve a consensus of opinion over the major themes and categories arising, alongside reporting of demographic and participant characteristics.

3. Results

The results are reported in 7 sections, the first of which, Section 3.1 describes the demographic characteristics of the participant cohorts. The remaining sections describe the 6 identified themes that addressed the aims of the study. Section 3.2 describes the first theme identified in the findings, Theme 1: *Barriers and facilitators to utilisation of CIs, from the perspective of patients and HCPs* (Aim 1). Section 3.3 describes the second theme identified in the findings Theme 2: *The burden of hearing loss* (Aim 2) and Section 3.4 describes Theme 3: *The impact of CIs on Quality of Life (QoL)* (Aim 2). Section 3.5 describes Theme 4: *Professional practice – information and shared care by HCPs, from the HCP perspective* (Aim 3) and Section 3.6 describes Theme 5: *HCP support and care, from the perspective of patients* (Aim 3). Section 3.7 describes Theme 6: *Patient aspirations for the future* (Aim 4).

The data for sections 3.2 to 3.7 will present the key concepts within of each theme, according to the participant cohort that reported them, with supporting verbatim quotes in parentheses, and listed in the proceeding tables (Tables 3.2 to 3.7). In addition, key concepts are presented in an overview box at the beginning of each section.

3.1 Demographic characteristics of the participants

3.1.1 Summary of Participants

In total, 55 people participated in this study across Australian and UK sites;

- 12 pilot study participants
- 43 principal study participants
- 143 data capture events

Note sample overachievement; the original study plan proposed the recruitment of 28 participants, and 32 data capture events.

Stage 1 - The pilot phase included;

12 participants; 5 CI users, and 3 audiologists in Australia, and 2 audiologists in the UK (Wales), who engaged in 3 separate pilot focus groups, while 2 GPs engaged in pilot interviews.

Stage 2 - The Principal study phase involved;

43 participants; including interviews with 12 CI users, 9 HA users (including 2 CI candidates who had begun CI assessment), 5 GPs, and 8 audiologists, in Australia, and 2 interviews and 2 focus

groups with audiologists in the UK (one with 5 audiologists, and the other with 2 audiologists), 2 in Wales and 7 in England.

There was a total of 143 data capture events including interviews, focus groups, questionnaires, and qualitative surveys (Table 3.1.1).

Table 3.1.1: Frequency of data capture events for the pilot and principal study per participant group

Participants (n=57)	P1 ¹ (n=17)	P2 ² (n=9)	GPs ³ (n=7)	Aud ⁴ (n=11)	Aud UK ⁵ (n=11)
Data Capture event					
Pilot focus groups (number of participants)	1 (5)	-	-	1 (3)	1 (2)
Pilot interviews	-	-	2	-	-
Pilot demographic questionnaire	5	-	2	3	2
Pilot qualitative proforma	5	-	1	3	2
Principal focus groups (number of participants)	-	-	-	-	2 (5, 2)
Principal interviews	12	9	5	8	2
Principal study demographic questionnaire	12	9	5	7	9
Principal study qualitative proforma	10	8	5	5	7
TOTAL	45	26	20	27	25

¹P1: CI user; ²P2: HA user and CI candidates; ³GP: General Practitioner; ⁴Aud: Australian audiologist; ⁵Aud UK: UK Audiologist

3.1.2 Demographics of the patient cohorts and their hearing device use

One third (6) of the 17 CI users were aged 50-64 years, three were aged 65-74 years, and almost half (8) were aged 75 years or older, nearly two thirds (11) were female, and just over two thirds (12) had private health insurance. Three quarters of the CI users (13) had a CI in one ear, and the remaining four were bilaterally implanted. Nearly two thirds (11) of the CI users, had had a CI for more than 5 years, and the rest (6) for 3-5 years. Nearly half (8) of the CI users were bimodal HA users, all of whom had used their HA for more than 5 years. Five of the bimodal users reported using their HA for more than 8 hours per day, one used their HA for 4-8 hours per day, one used their HA for 1-4 hours and the other CI bimodal user reported not using their HA at all. Almost all CI users (16) reported having used a HA for more than 5 years prior to their cochlear implantation, except for one CI user who reported not having a HA prior to implantation. Nearly half (8) of the CI users were from New South Wales (NSW), or from Queensland (QLD) (8), with one from Western Australia (WA). Most CI users (14) lived in metropolitan areas, one in a rural area, and three in regional areas, half (9) accessed local hearing services, and the other half (8) had to travel to access hearing services, with a reported range of 15kms to 1,700km. Most CI users reported experiencing comorbidities, such as arthritis and asthma, with over two thirds (12) reporting having one or two comorbidities (Table 3.1.2).

Nearly half of the HA users were aged 50-64 years (4), or 65-74 years (4), and one was aged 75 years or older. Two thirds (6) were female, and just under half (4) had private health insurance. All HA users were bilateral HA users, had had both of their HAs for more than 5 years, and most (7) used their HAs for more than 8 hours per day (one used their HA for 1-4 hours, and the other for 4-8 hours per day). Two HA users had started the CI candidacy assessment process. More than half of the HA users were from NSW (4), with the rest from QLD (3), and the Australian Capital Territory (ACT) (2). Almost all HA users (8) lived in metropolitan areas, with one in a rural area, seven accessed local services, and two had to travel to access hearing services. Over half (5) of the HA users reported having one or two comorbidities.

Table 3.1.2: Demographic data from patient groups

	CI users (n=17)	HA users (n=9)
Age		
50-64 years	6	4
65-74 years	3	4
75 years or older	8	1
Gender		
Male	6	3
Female	11	6
Had private health insurance	12	4
State of residence		
ACT	0	2
NSW	8	4
QLD	8	3
WA	1	0
Urban/Rural location of residence		
Metropolitan resident	14	8
Regional/Rural residents	3	1
Number of comorbidities		
None	3	1
One or two	12	5
Three or more	2	3

3.1.3 Sources of information about CIs

Half of the CI users (8) reported raising CIs with their HCP the first time they talked about them, with the remaining having CIs brought up by their HCP (6), work colleague (1), or family member (1). One CI user wasn't sure who introduced CIs to them. Half of the CI users (9) reported first discussing CIs with their audiologists, five with their ENT specialist, with the remaining CI users talking about CIs for the first time with work colleagues (1) or their GP (2). Over half (5) HA users had brought up CIs with their HCP the first time they discussed them, with three reporting that their audiologists raised CIs with them, and one hadn't discussed CIs with an HCP. Just over half of the HA users (5) reported that their audiologist was the first HCP they discussed CIs with, and three had first discussed CIs with their ENT specialist.

Nearly half (12) of the total CI and HA users reported received CI information from their audiologist or hearing associations (9) with the remainder accessing information from family and friends (7), their ENT (4), professional associations and colleagues (4), newsletters (3), the internet (3), GPs (2, both of whom were CI candidates), other HCPs (2), pamphlets (2), books (1) and other CI recipients (1) (Table 3.1.3).

Table 3.1.3: Most frequently used CI information sources for CI and HA users

	CI users (n=17)	HA users (n=9)
Sources of information about CIs		
Audiologist	8	4
Hearing associations	6	3
Family and friends	1	6
ENTs	4	0
Work colleagues	3	1
Newsletters	2	1
Internet	0	3
GPs	0	2
Other HCPs	1	1
Pamphlets	0	2
Books	0	1
Other CI recipients	1	0

3.1.4 Demographics of the HCP cohorts

Of the seven GP participants, one was under the age of 30, one was aged 30-49, four were aged 50-64, and one was aged 65 years or older, and four were female (Table 3.1.4). All participating GPs had a Bachelor of Medicine, and a FRACGP or MRCP. Most GPs (6) practiced in NSW, one in the Northern Territory (NT), with five practicing in metropolitan areas, and two in rural or remote areas. Most GPs (5) had been practicing for more than 10 years and two had been practicing 1-5 years, four practiced privately, one practiced publicly, and two practiced public and privately.

Of the 11 audiologists in Australia, 10 completed the demographic questionnaire. Eight of these 10 audiologists were female, eight were HA audiologists, two were CI audiologists. Eight were aged 30-49 years, two were aged 50-64 years. The majority (9) had Master's degrees in audiology, one had a diploma in audiology and a Bachelor of Arts. Most (9) practiced in NSW, one in QLD, five in metropolitan areas, one in rural areas, and four in both. Three were public providers, two were private clinicians, and five practiced both publicly and privately. Most audiologists (8) had been practicing for over 10 years, or 6-10 years (2).

Of the 11 audiologists in the UK, seven were HA audiologists, four were Clinical Scientists, audiology, and nine were female. The majority (9) were aged 30-49 years, one was aged under 30 years and one was aged 50-64 years. The majority (7) had Master of Science degree, in audiology, two had Bachelors of Science in audiology, one had a PhD and diploma in audiology, and one had

a certificate of higher education in audiology. Most (6) had been practicing for more than 10 years, four had been practicing for 6-10 years, and one had been practicing for 1-5 years. Seven were practicing in England, and four in Wales, with three practicing in metropolitan areas, two in rural areas, and six in both metropolitan and rural areas. Almost all (10) were public providers, with one a private and public provider.

Table 3.1.4: Demographic data from HCP groups

	GPs ² (n=7)	Aud ^{1,3} (n=11)	Aud UK ⁴ (n=11)
HCP type¹			
GP	7	0	0
HA audiologist	0	8	7
Other (CI audiologist)	0	2	0
Other (Clinical Scientist, audiology)	0	0	4
Gender¹			
Male	3	2	2
Female	4	8	9
Age group¹			
Less than 30 years	1	0	1
30-49 years	1	8	9
50-64 years	4	2	1
Over 65 years	1	0	0
State of work place¹			
NSW	6	9	0
NT	1	0	0
QLD	0	1	0
Country of work place			
Australia	7	11	0
England	0	0	7
Wales	0	0	4
Urban/Rural location of work place¹			
Metropolitan areas	5	5	3
Rural/ regional areas	1	1	2
Remote areas	1	0	0
Both metropolitan and rural areas	0	2	6
Metropolitan, rural and remote areas	0	2	0

¹data missing; ²General Practitioner; ³Aud: Australian audiologist; ⁴Aud UK: UK audiologists

3.1.5 Frequency of HCPs working with people with hearing loss

When asked about the frequency with which they work with adults with severe or greater hearing loss, GPs reported working with patients with hearing loss once or twice a year (5) or once or twice a month (2). Australian audiologists said they consult with patients from that population everyday (2), most days (2), once or twice a week (2), once or twice a month (2), or every few months (2). Audiologists in the UK said every day (1), most days (3), once or twice a week (5), or once or twice a month (2) (Table 3.1.5).

When asked about how frequently they discussed HAs with patients, over half of the GPs reported once or twice per year (4), with the others reporting once or twice per month (2), or once or twice a week (1). Australian audiologists reported every day (4), most days (4), or once or twice per week (2). UK audiologists reported every day (6) or most days (5). When asked about how frequently they discussed CIs with patients GPs reported never (4), once or twice per year (3). Australian audiologists reported once or twice a month (4), everyday (2), once or twice a week (2), or once or twice a year (2). Audiologists in the UK reported CI once or twice a month (5), once or twice a year (4) or once or twice a week (2).

Table 3.1.5: Frequency of HCPs working with people with hearing loss

	GPs ² (n=7)	Aud ^{1,3} (n=11)	Aud UK ⁴ (n=11)
Frequency working with patients with severe or greater HL¹			
Everyday	0	2	1
Most days	0	2	3
Once or twice a week	0	2	5
Once or twice a month	2	2	2
Once or twice a year	5	0	0
Other (every few months)	0	2	0
How frequently do you discuss HAs with a patient?¹			
Everyday	0	4	6
Most days	0	4	5
Once or twice a week	1	2	0
Once or twice a month	2	0	0
Once or twice a year	4	0	0
How frequently do you discuss CIs with a patient?¹			
Everyday	0	2	0
Most days	0	0	0
Once or twice a week	0	2	2
Once or twice a month	0	4	5
Once or twice a year	3	2	4
Never	4	0	0

¹data missing; ²General Practitioner; ³Aud: Australian audiologist; ⁴Aud UK: UK audiologists

3.2 Theme 1: Barriers and facilitators to CI utilisation, from the perspective of patients and HCPs

3.2.1 Barriers to CI utilisation: the patient perspective

- Fear of surgery, complications and side effects, and risk of losing residual hearing, uncertainty of outcomes and irreversibility of CI surgery
- HCPs not being knowledgeable or supportive of CIs, and patients themselves not being knowledgeable about CIs
- Not wanting to be reliant on a CI device, and not being mentally ready for a CI
- Delays to assessment and surgery due to denial about hearing loss severity or not meeting eligibility requirements
- Concern about travel to appointments, needing to take time off work, and the commitment to rehabilitation
- Cosmetics (mixed response) and perceived cost of a CI, concern about the sound from a CI, and being able to hear music

Participants from the patient cohorts were asked what the barriers were to CI utilisation. These are described below, with supporting quotations referenced in parentheses (see Table 3.2.1). When asked to identify the barriers that patients had either experienced (CI users) or perceived to be barriers for CI implantation in the future (HA users), almost all participants reported that **fear of surgery, surgical complications and side effects** was their main concern (Q1), as well as **the risk of losing their residual hearing** (Q2). Several CI users had initial concerns about the **cosmetics of a CI** (Q3), while others were unconcerned about this, wishing to display their hearing device to communicate to the world that they had a hearing loss (Q4). CI users recollected that the **perceived cost of a CI** was a concern during decision making (Q5), and this was a sentiment also echoed by HA users (Q6).

Several CI recipients and HA users talked about being **deemed ineligible for a CI** at some point, and how this had been emotionally difficult, commenting that the assessment process wasn't reflective of their daily hearing struggles (Q7). Delays to CI assessment and surgery occurred **when healthcare professional were not supportive of CIs (Q8) or knowledgeable about CIs (Q9)**, or when patients delayed seeking help out of **denial about the severity of their hearing loss (Q10)**. Not accepting the severity of hearing loss and realising the impact it has on one's Life (Q11) was a barrier to accessing hearing services, as well finding hearing tests daunting (Q12). Both patient groups had concerns around the **uncertainty of outcomes** with a CI (Q13; Q10) and had been worried about **taking time off work for surgery and rehabilitation** afterwards (Q14), with one CI user explaining that she had delayed surgery to give herself time to prepare mentally (Q15). Participants had also been concerned about the **commitment required for rehabilitation (Q16)**.

Several HA users (including CI candidates) suggested that they **resented the idea of being reliant on a CI device** (Q17). **Not being mentally ready for a CI** was another common barrier to CI utilisation indicated by HA users (Q18), with one CI candidate noting that she had initially avoided CIs as she wasn't expecting to live long, but now in her 80s, she felt healthy enough to proceed (Q19). Several HA users talked about how they **didn't feel knowledgeable enough about CIs** and weren't sure about what to do or where to go for more information (Q20). The **irreversibility of the implant** compared to the trial-and-see option with HAs was another concern for several HA users (Q6).

CI users recalled various delays to CI access, including, **long waiting times to see ENT specialists** for assessment (Q21), as well as their preference to not implant their ear with better hearing, until years later, when their hearing team agreed to implant their poorer ear (Q22). Several CI users had been particularly **concerned about not being able to hear music** well (Q23) and CI users and HA users alike were **worried about the quality of sound with a CI** (Q24). Other recipients were initially hesitant as they **thought children would get priority** for CIs, over adults (Q5).

Table 3.2.1: Barriers to CI utilisation: Verbatim quotations from patients

P	Q#	Quote
CIU404	1	<i>My initial reluctance was due to the thought of having my skull drilled into.</i>
HA701	2	<i>I didn't want to lose the residual hearing that I had. I value being able to hear some noise - that sense of aliveness and of the world around me.</i>
CIU402	3	<i>The vanity side of it... It's like going around with a big sign saying, 'I'm deaf'.</i>
HA702	4	<i>Well if it helps me I don't give a damn and I think it's good for people to see you wearing hear aids or a [CI]. And they realise that, oh that person's got a hearing problem maybe I need to speak a bit better or clearer or louder. So, I'm over vanity, I used to be a bit vain about it and didn't want people to see them but now I don't care, at 57 I'm past that</i>
CIU601	5	<i>I was aware of [CIs] but never considered because of costs and not aware that medical insurance provided. Also thought that children would get priority and at 60 years didn't even think that I had a chance.</i>
HA705	6	<i>My concern is the potential cost and also that it's a one-way decision. CI surgery - I understand - will destroy whatever remnant hearing I have... But if the alternative is deafness then it's an obvious choice.</i>
CIU602	7	<i>I had learned to cope very well with my hearing loss, to the best of my ability and the sound booth tests were not indicative of normal life situations and therefore I performed well in the sound booths... They turned me down and I felt dejected, but kept trying... I had to apply at least 3 times and go back a fourth time before I was approved for an implant</i>
HA702	8	<i>An old ENT I used to go to who did my father and my brother's [CI], he told me once to stick with [HA]s as long as you possibly can and don't go to CIs. And so that's always been in the back of my head thinking, oh no, I have to hang out with my [HA]s as long as possible.</i>
HA705	9	<i>I have had only a brief discussion about this with my audiologist...My impression was they were unclear at what point a [CI] becomes advisable.</i>
CIU402	10	<i>I had times of fear, despair, denial about hearing loss, embarrassment and uncertainty.</i>
HA705	11	<i>Realising that treatment is required depends on acknowledging that loss is significant... I sought assessment then treatment when I realised my loss had become a barrier to daily life.</i>
CIU403	12	<i>Just self-inflicted delays...it was a bit daunting because you had to go for various medical tests and psychological tests.</i>
CIU403	13	<i>it was always a question of whether it was going to work...my regular ENT, when I initially raised the subject he was saying, "Well yes, they've made a lot of progress but it's still not wonderful" ...always a doubt. There was no guarantee that it would work.</i>
HA702	14	<i>She said to me that I would be now eligible for [CI] and did I want to talk about it or go down that path and I said, "No, not really." That was me, I just cut it short because I just had all these negative feelings about it, all the problems that I can think of like trying to get time off work ...</i>
CIU402	15	<i>CI surgeon approval for implantation to actual implantation was six months (my choice) and I used that time to get used to the idea and prepare myself mentally for what was to come and the change it would make from HA user to CI</i>
HA705	16	<i>I know of other cases where it doesn't really work at all...So there's quite a bit of risk, and a lot of effort and a lot of commitment required from a person who gets an implant.</i>
HA703	17	<i>I don't like the idea that once I go down the [CI] path that I'm completely reliant on them to hear.</i>
HA701	18	<i>I don't know if I'm really at that stage. I'm not emotionally ready. If something happened and I lost a lot of hearing, then maybe</i>
Cicand 706	19	<i>I was not bothering before as my family do not seem to [live] to old age but I am 83 now and in reasonable health so am going to give it a go.</i>
HA707	20	<i>I am thinking hard about going to have an assessment done, but I am not sure about where to go and what I need to do also as I said before I am a bit scared.</i>
CIU406	21	<i>Every time I saw him I had to wait at least five weeks. Sometimes seven weeks</i>
CIU611	22	<i>At an assessment in 2000, 'they' would only do my (good) right ear. I would not agree to that for fear of losing the little hearing that I had. In 2008 'they' agreed to implant my left ear (hearing non-existent)</i>
CIU402	23	<i>I knew that [CIs] were really for speaking and that the music side of it could be lost so the decision to have the implant was a really hard one for me and I spent about six months just nervous, anxious, crying a lot, because if I could not play music I was going to lose who I was (402).</i>
HA705	24	<i>I'm fully aware that a [CI] is vastly better than being deaf, but it'll never be anything like a normal person's hearing... the nature of the information is very different to what you had with a normal ear. You have a long difficult transition to adapting to the new device, you have to train your brain to understand what the signals mean...people vary enormously on how successful that is.</i>

Note: The verbatim quotes are labelled according to the participant number (CIU, CI user; HA, [HA] user; Cicand, CI candidate) and the quotation number

3.2.2 Barriers to CI utilisation: HCP's perception of patient barriers

- Fear of surgery, and surgical outcome, and concerns about spending time in hospital
- Limited access and travel to services in rural areas and HCPs not making CI referrals
- Cosmetics of CI, and associated stigma of hearing loss device
- Denial about the severity of hearing loss and adapting behaviours accordingly, not following up on referrals, needing extra HCP support, and lack of family support
- Perceptions about cost and disengagement with services,
- Not being ready to talk about CIs, misconception of CIs and hearing negative stories about CIs

HCPs were asked to identify what they thought the main barriers are preventing or limiting patients from utilising CIs. These are described below, with supporting quotes referenced in parentheses (see Table 3.2.2).

All HCP groups (GPs, Australian and UK audiologists) reported that they perceived patients to be **fearful of surgery** and concerned about potential **complications** and **comorbidities** precluding them from surgery. Audiologists reported older patients were particularly worried about the **risks of anaesthetic** and the **potential side effects of CI surgery** (e.g. vertigo) (Q1), as well as **acclimatisation concerns following surgery**. Patient fear of **losing residual hearing** was a frequently suggested barrier by all HCPs, as was **having time off work, or away from family commitments and responsibilities, to undertake surgery and rehabilitation** which worried patients (Q2). The **waiting list** for a publicly funded CI was reported to be off-putting for some, while several UK audiologists noted that **the time between assessment and surgery** was not long enough **to adjust to the idea of a CI** (Q3). HCPs felt that **accessing services** was problematic for patients living in poorly serviced areas (Q4), especially in **rural and remote areas**, as was **travel to cities or regional centres** and the **commitment required to attend multiple appointments** (Q5), and the expense of such travel. There were mixed views about whether the **cosmetic aspect** of a CI was a barrier for patients (Q6), with several Australian audiologists commenting that most CI candidates have a history of wearing HAs and have adjusted to the appearance of wearing a hearing device (Q7). Others remarked that the **perceived stigma** of hearing loss and devices remained a barrier for some (Q8; Q9).

HCPs acknowledged that by **not referring patients on for a CI assessment, they themselves acted as a barrier** to access (Q10). HCPs also suggested that many patients were in **denial about the severity of their hearing loss** or simply not aware of how severe their loss was (Q11). HCPs commented that patients with more severe hearing loss tended to **put up with their hearing loss and adapt their behaviours** accordingly (such as staying home and avoiding interaction), rather than seeking out treatment, while those still socially active, are more motivated to access treatment (Q12). HCPs also recognised some patients avoided **disclosing hearing loss in their workplace**, for fear of repercussions (Q13).

Australian audiologists and GPs saw patients' **perceptions about the cost of CIs**, including surgery, rehabilitation, mapping, and the device as another factor limiting access to CIs. Some Australian audiologists suggested that, with public funding and private health insurance, costs were not significant, while acknowledging that some patients signed up to private health insurance to fund their CI (Q14). Many GPs and Australian audiologists had a limited understanding of the partially-funded system in Australia, but costs were not raised as a barrier by the UK audiologists. One audiologist hoped future candidacy criteria would broaden and be more inclusive, with greater funding. The two CI audiologists agreed that stigma around hearing loss devices, age, or age-related health problems were a barrier for some patients (Q15), as well as fear of surgery, concerns about possible side effects post-surgery and loss of residual hearing. One didn't think cost was an issue for patients, if they had health insurance, whereas the other felt that cost was an issue for patients (Q16).

Audiologists in the UK and Australia noted that **uncertain surgical outcomes**, and the **lack of reversibility** of CIs was a serious concern that required extensive consideration, as CIs can't be trialled and rejected, unlike HAs (Q17). Australian and UK audiologists alike suggested that patients were often **not ready to talk about CIs** (Q18) needing more time to process the information, and that they could be discouraged by negative **stories from CI recipients**. Audiologists noted that some patients thought that **CIs were only available for children** or that they would be **denying children of CI funding** by accepting the implant. Australian audiologists reported that often patients **didn't follow up on their referrals** and needed extra support to transition to the assessment stage (Q19), highlighting a need for improved pathway management and support for patients in Australia. Two UK audiologists suggested that some **members of the deaf community** who weren't supportive of CIs influenced CI decision making, while **lack of family support** can also be a barrier for some people (Q20). UK Audiologists felt patients who are **poor HA users** are often reluctant to progress to a CI (Q21), and that the **process of CI assessment** can be difficult and onerous for some, make them reluctant about further testing (Q22). One UK audiologists talked about the current candidacy guidelines being restrictive (Q23). Furthermore, if patients get to pre-candidacy stage and are found to be ineligible (Q24), this can **lead to disengagement** with the whole hearing health system (Q25).

Table 3.2.2: Barriers to CI utilisation: Verbatim quotations from HCPs about patient barriers

ID	Q	Quote
Au1101	1	<i>Maybe they had vertigo before and as soon as the surgeon says, there is a risk of dizziness, they're like, "ok. I opt out".</i>
Au113	2	<i>She was a carer for her husband and she had a... really profound loss. I had had the discussion with her a few times about getting a [CI] and she really wanted it, but because there were so many trips...involved, she couldn't leave her husband.</i>
UK1	3	<i>Although a referral for an assessment is only an assessment, people can end up on a little bit of a conveyor belt because it's a bit of a shock to them that they would then expect to be implanted within 18 weeks. That's too fast for a lot of people, and that's quite scary.</i>
GP2206	4	<i>There are many locations where we have services for the [HA]... But there are not many for the implants at all</i>
Au106	5	<i>It is more the whole surgery and the travelling to get there and whether they can commit to having numerous appointments</i>
UK 6	6	<i>[patients] Have a very negative perception of what it looks like. "Oh, it's this massive, big thing that's on the ear that looks awful."</i>
Au107	7	<i>Where they're that deaf, I don't find that cosmetics is as much a barrier, I think they're past that, they just want to be able to communicate.</i>
GP2207	8	<i>People don't know a lot about [CIs] they might feel like certain judgment...more for young people if they're in the over-50 group</i>
CI Au111	9	<i>Hearing and communication difficulties are not prioritised for adults, and are still considered an intellectual weakness, leaving people hesitant to identify themselves as hearing impaired and unlikely to ask for help.</i>
GP2207	10	<i>If they're seeing a GP like me who doesn't, sort of, trigger thinking about [CIs] or checking if they're eligible then that probably is a barrier</i>
Au 106	11	<i>There is this, reluctance sometimes. Or maybe it is a bit of denial, "I'm not that bad. I am still okay. I can still cope pretty well." Without really thinking imagine if I just had better aided access in a nice, quiet ideal situation, I would be so much less exhausted.</i>
UK8.	12	<i>One thing that I think is a barrier for people is just people's ability to make the best of it. You get the impression that people with progressive hearing loss that their world gradually shrinks</i>
Au1101	13	<i>I think we underestimate the number of people who don't disclose to their work place that they have a hearing loss. ...with [HAs] or no [HAs]. Let alone something that's going to be a bit more visible again, like an implant</i>
Au1101	14	<i>I've had a couple of clients at least who got [HAs], then signed up for private health to start the waiting list, process</i>
CI Au108	15	<i>They feel like they are too old to have the implant and bounce back and recover, I guess, but to me that's more of a health issue rather than an age issue, we've got patients that are in their 90s that have implanted that are still highly active</i>
CI Au111	16	<i>I think, perception of the costs and then there's significant variability in the cost as well so the public funding devices for adults is pretty terrible in some states</i>
Au107	17	<i>The thing with a [HA] is you can trial it, you can take it on and off, it's not permanent. With a [CI] it's implanted in the head.</i>
UK8	18	<i>For this patient group any significant transitions often take a lot of preparation... Sometimes this means a drip feed of information about different options and implications over several visits until the patient is willing to explore a next step</i>
Au107	19	<i>I really think that the best success I've had is by taking them through it step by step with them, rather than saying here's the phone number, go and ring them...And nine times out of ten they don't...it's a long process usually.</i>
UK10	20	<i>I've definitely got, I think, a lady, quite elderly and desperately needs referring. She accepts it, but she won't, because she's carer for her husband, won't leave him alone, hasn't really got a lot of support at home.</i>
UK1	21	<i>There are also some people, particularly where their hearing loss is mild or moderate at low frequencies, who may fall within criteria for CI, but who have always struggled with consistent [HA] use. Here, it seems difficult to move onto considering a [CI] when they are not able to acclimatise to [HAs].</i>
UK11	22	<i>It's quite an onerous process, assessment...I've had it before where...they're put off by their previous experience, because they don't want to go through all that again if they're just going to get turned down again.</i>
UK1	23	<i>There is also a barrier due to the rigid NICE criteria for a [CI] to be offered in the UK. There are many [HA] wearers who struggle with hearing in day-to-day life but whose speech discrimination scores take them outside current CI criteria.</i>
Au106	24	<i>I have had a number of clients who we have gone through the process and they have attended their pre-candidacy only to be told actually no, they are not going to be suitable to have an anaesthetic</i>
UK1	25	<i>The impact of being told that you fall outside criteria can be quite devastating. I can think of at least one person who's disengaged from hearing services after that.</i>

Note: The verbatim quotes are labelled according to the participant number (Au, Australian HA audiologist; CI Au, Australian CI audiologists; UK, UK audiologist; GP, General Practitioners) and the quotation number

3.2.3 Barriers to CI utilisation: the HCP perspective

- Lack of knowledge and training about CIs and costs, and ‘Any Qualified Provider’ issues (UK)
- Lack of patient-clinician continuity, and concern that discussing CIs will lead to patient disengagement or transfer
- Other health conditions prioritised, and patients not raising hearing needs with GPs
- Lack of coordinated services in rural and remote areas
- Hearing aid sales targets limiting referral for CI assessment

HCPs were asked what they felt were the main barriers preventing them from making referrals for CI assessment. These are described below, with supporting quotations referenced in parentheses (Table 3.2.3).

All HCPs cohorts (GPs Australian and UK audiologists) indicated that their **lack of knowledge about CIs** and **eligibility criteria**, limited their ability to introduce and make referrals for CIs (Q1), or **judge when a patient was ready to discuss** a CI, which may be due to a **lack of tertiary CI training** (Q2). Other audiologists felt that there were **plenty of CI information sessions available** and indicated **CI information fatigue** with infrequent opportunities to apply the information, as they didn’t regularly consult with CI candidates (Q3). Contributing factors to this lack of knowledge may be due to the fact that HCPs **rarely get feedback from CI teams** about patients’ progress (Q4), and there is a disconnect between HA audiologists and CI technology (Q5) with the **subspecialties in audiology** creating an unnecessary barrier to CI referrals (Q6). GPs echoed that their **lack of training** in hearing loss was an issue (Q7), with several disclosing that they weren’t **aware that adults were eligible for CIs**. Patients’ **level of motivation**, and willingness to commit to the rehabilitation process, also influenced some audiologists’ decision to refer on (Q8; Q9), while others were concerned about **side effects of the surgery**, like balance issues (Q10). One CI audiologist felt that other audiologists’ lack of knowledge about CIs was a barrier and was important to overcome (Q11).

Australian and UK audiologists found that discussing CIs was challenging if audiologists **had poor patient-clinician continuity** (Q12). In these circumstances it could be unclear what has already been discussed, exacerbated by poor documentation practices, and some patients refusing to discuss CIs further (Q13). Audiologists expressed concern that continuously suggesting CIs over several appointments may be off putting for patients who may then **discontinue seeing them** (Q14). Developing patient rapport through patient-clinician continuity was particularly difficult in rural and regional areas where audiologist tend to work for a few years before moving back to metropolitan areas (Q15). Audiologists suggested that other audiologists were **concerned about losing patients**, if they referred them to a CI team (Q16) and some Australian audiologists felt that other audiologists working for certain HA providers had **HA sales targets to attain**, which potentially restricted them from referring for a CI (Q17). This was not a concern suggested by UK

audiologists. One CI audiologist suggested that other HCPs are uncomfortable introducing CIs to patients, due to the invasive nature of the surgery (Q18).

One UK audiologist indicated that if **they think the client is communicating adequately, and the patient's HA is working sufficiently**, then they wouldn't make a CI referral. **The 'Any Qualified Provider' (AQP)** program was also identified as a barrier to CI referrals in England, where National Health Service (NHS) audiology service providers may have varying levels of qualification (e.g. audiology assistants as well as audiologists may consult with patients), which may limit patients' opportunity to be supported by audiological staff with experience and knowledge of CI. The AQP tariff may also limit the time available to audiologists for counselling and information giving, meaning HCPs may not have time to discuss the option of CI with a patient, a finding which is supported by the literature [18] .

GPs found that the **lack of coordinated services in rural and remote** areas made it difficult to make CI referrals (Q19). **Other health conditions were typically prioritised** (Q20), and **patients rarely raised their hearing needs** with GPs (Q21). However, several GPs suggested that they might discuss hearing if they conducted a health check for over 75s. If GPs had concerns about a patient's hearing, they would **refer them to an audiologist or ENT specialist**, who may or may not refer potentially eligible patients for a CI assessment, introducing a potential break in the referral chain (Q22). GPs also indicated that **accessing resources** for hearing health support and services in remote areas can be difficult (Q23).

Table 3.2.3: Barriers to CI utilisation: Verbatim quotations from HCPs

ID	Q #	Quote
UK 6	1	<i>Awareness... is an issue around clinicians. They know they're out there, but they don't necessarily know where it fits into the patient journey and when they should introduce it and when they shouldn't... and some of it is about confidence in introducing that as an option</i>
Au113	2	<i>I did my Masters degree [recently], and like in my first year, we had a unit designated to hearing-aids. And then we had a unit in second year designated to hearing-aids as well. But ... there isn't like a unit dedicated to [CIs].</i>
Au1101	3	<i>I personally avoid some of the [CI] stuff because... it's not part of my daily work. I tend to look for opportunities to learn more about paediatrics, Or [HAs], 'cause that's what I tend to do. I find like, 2% of my clinical time involves [CIs], and 50% of my professional development time is on [CIs].</i>
Au113	4	<i>I can't even remember getting a report from the [CI] Centre lately, but you get them regularly with children.</i>
Au113	5	<i>We only really deal with hearing-aids...we don't adjust [CIs]...we fit listening devices to people with [CIs] but we don't do any of the mapping...I wish I was more trained in [CIs], and I wish we could actually adjust them.</i>
Au 109	6	<i>Patients who need bi-modal fittings ([CI] and [HA]) end up having 2 different audiologists, one looking after the right ear and the other looking after the left ear. Audiology is already a very specialised profession and it seems ludicrous that so many go on to subspecialise and to provide only one aspect of the services required by hearing impaired adult patients. Audiologists who provide [HAs] should be able to provide [CIs] as there is no real difference between the 2 services. It is just a matter of learning how to use new hardware and new software...</i>
GP2207	7	<i>I think a lack of understanding about the whole referral process, eligibility criteria. I don't remember being taught at all about hearing loss in medical school... even in GP training and it's such a common problem you'd think they'd touch on it a bit more but... it wasn't covered</i>
CIAu108	8	<i>We try and pinpoint those that seem highly motivated and have a good support network around them, so if they're living by themselves and quite reclusive, not a lot of support, then we're probably not going to – we'll probably look at other options rather than an implant unless they were highly motivated.</i>
Au110	9	<i>There's all these factors that become involved. If you're saying you can be suitable for a [CI] candidacy, but the major part of that candidacy evaluation is motivation and mental readiness</i>
UK1	10	<i>Where an elderly person who already has balance that's perhaps not very good, has an implant, and then they end up in a wheelchair. The balance between the potential improvement in communication abilities but a potential loss of mobility has made a few people think about possible outcomes of implant in the elderly wobbly</i>
CIAu111	11	<i>I think - there's lots of information targeting GPs but I don't think that's the way to go. I think it's for, you know, the front line (hearing) clinicians..., understanding, more clearly the potential benefit and what's involved and the whole process, the ins and outs, NDIS funding, OHS, like all that sort of stuff and how it might pertain to implants, I think, is important to kind of break down that barrier a bit more.</i>
UK3	12	<i>I don't feel like the patients see the same person...there are some people who would mention it but they won't write it down... the patient won't bring it up again...it's an off chance depending on who the patient is seeing whether it's going to be mentioned or not.</i>
Au107	13	<i>You might not have seen this client before, so if you're reading the notes from the previous time and ... in the notes it says adamantly does not want a [CI], it can be very hard to bring it up again... how the client's going to react, we don't want to appear like we're hassling them into it, we want it to be a collaborative thing, some clients can get very angry.</i>
Au113	14	<i>I kind of respect their wishes. I would say, "Why?" And, yes, they'll either give me their reason, but I don't like to push the point ... Because then it affects your relationship with them...they're perhaps less likely to come back... I don't think they like to be pushed, no. Especially if it's something like a [CI] which is... it requires surgery and things.</i>
Au113	15	<i>Will try and maintain the same clinicians. However, ... again this is just me being in a regional area, where the majority of audiologists are trained in the cities...audiologists will only come to [regional town] for a couple of years.</i>
CIAu108	16	<i>Clinicians are saying, "Well, we want to refer but we refer them, and we never see them again." I do get concerned that there are possibly clinics that... may have it in their protocol or they might be telling their aud's to probably only refer as a last resort because again they don't want to lose the patient</i>
Au105	17	<i>There's also, maybe the audiology clinics that don't deal with [CIs] and they just want to sell [HAs] and stuff like that so they don't care what their speech discrimination is like and they're just going to fit them with [HAs].</i>
CIAu111	18	<i>I think the block in the referral chain is at the point where people are seeing potential [CI] candidates but it understandably sounds like a very invasive and aggressive option, so I think people are scared to bring it up.</i>
GP2205	19	<i>Hearing teams would come intermittently to remote communities... it seemed uncoordinated to me, and I was the GP on the ground.</i>
GP2205	20	<i>I'm just battling with all the other problems let alone worrying about [CIs]</i>
GP2207	21	<i>Sometimes as a GP I get bypassed with hearing stuff</i>
CIAu111	22	<i>GPs have to understand such a breadth of information, they're going to send you through to someone who can tackle it but if that person trying to tackle it doesn't understand what they have to do then they're not going to refer you to the right source.</i>
GP2205	23	<i>Very difficult to access resources to manage hearing loss</i>

Note: The verbatim quotes are labelled according to the participant number (Au, Australian HA audiologist; CIAu, Australian CI audiologists; UK, UK audiologist; GP, General Practitioners) and the quotation number

3.2.4 Facilitators encouraging CI utilisation: the patient perspective

- Desire for better hearing to improve communication and increase social interaction,
- Ineffective HAs, and hearing loss affecting work
- Awareness of the impact of hearing loss on mental health
- Hearing CI success stories from recipients and HCPs, feeling supported, and having positive discussions with family
- Feeling fully informed and believing CIs will improve hearing
- Being advised to have a CI implanted before losing all residual hearing

Participants from the patient cohorts were asked what the motivators and facilitators were that encouraged them to utilise CIs. Motivators were defined as factors that were internally driven by the individual, and facilitators were those externally-driven factors that influenced them. These are described below, with supporting quotations referenced in parentheses (see Table 3.2.4).

Across the board, improved communication (*Q1*; *Q2*; *Q3*) and increased social interaction (*Q4*; *Q5*) were key motivators for all patients, as was not being able to hear (*Q6*), getting ineffective support from HAs (*Q7*; *Q8*; *Q9*) and having uncomfortable HAs (*Q10*). Poor hearing health such as otitis media, and comorbidities such as tinnitus and Meniere's disease, were often the catalyst for a conversation about CIs with HCPs (*Q11*). Recognising the impact of hearing loss at work (*Q12*; *Q13*; *Q14*) and its effects on people's ability to engage in other activities (*Q15*) and remain independent (*Q14*) were motivators for all patient groups. Awareness that hearing loss and the associated communication difficulties was impacting one's mental health was another motivator for all patient groups (*Q4*; *Q2*).

Hearing CI success stories from CI recipients and HCPs (*Q16*; *Q17*) was a powerful facilitator during the CI decision-making process by all patient cohorts, as was feeling supported by HCPs and hearing associations, (*Q18*; *Q19*; *Q20*), and having access to Ear, Nose and Throat (ENT) specialists or CI specialists (*Q21*) in audiology clinics. Furthermore, feeling fully informed and believing CIs will improve hearing (*Q22*), having positive discussions with family and friends about CIs, (*Q23*), and feeling supported (*Q24*), were also considered to be helpful by CI users and candidates. Participants talked about being advised to have a CI implanted before they lost all residual hearing (*Q12*) and how this triggered their decision to have a CI implanted. Some CI users had been involved in CI research (*Q25*), and others had waited until the CI criteria changed to make them eligible for implantation (*Q23*).

Table 3.2.4: Facilitators encouraging CI utilisation: verbatim quotations from patients

P	Q#	Quote
CIU607	1	<i>I couldn't even communicate with my wife except my lip reading or notes to one another. That was a big motivator</i>
Clcand801	2	<i>Deciding factors: to communicate more effectively. Not being so isolated. Not being so vulnerable</i>
Clcand706	3	<i>I can no longer hear well enough to talk in conversation, especially to my children's children. I am missing too much in life.</i>
CIU402	4	<i>I couldn't go on the way I was. I was unhappy. Stressed out. Just thinking I don't need to sit home and knit all day. I didn't want to give up on being an active person in society any more so I got to a point I couldn't continue the way I was.</i>
HA707	5	<i>I am thinking that having implants done would have a positive impact on my life as I would be able to hear better... I will be able to live life better, instead of staying in the background. To be able to communicate better with others, instead of asking people to repeat themselves.</i>
CIU604	6	<i>I wanted to hear. We live in a hearing world. It is a joy to hear sound.</i>
CIU403	7	<i>I'd been through progressively stronger [HAs], which were virtually useless by the time I got to the [CI] stage. I thought well as long as it works, then it couldn't be any worse...It was incredibly better, of course.</i>
HA701	8	<i>Until the time I don't get that gain [from HAs], then maybe - but I don't think it's necessarily how much gain you're getting out. It's also about your ability to listen. I think the fatigue and demand comes in, and the social and emotional aspect.</i>
CIU609	9	<i>As I had gone beyond comfort with my two [HAs] which were no longer sustaining my advancing deafness it was with excitement that I could see the potential of a CI for me. I felt hopeful, stimulated and grateful.</i>
CIU602	10	<i>The [HAs] were not adequate... the moulds were awful and cause ear infections because there is no air getting into the ear all day.</i>
CIU601	11	<i>I had been a battery line, a severe case of otitis [media] for a couple of months and getting nowhere with a local ENT. I was recommended another ENT, and after getting a referral from my GP, attended that clinic. My otitis [media] was cured in one week it was during subsequent visits that [CIs] came up and the ENT name recommended me to see [CI clinic].</i>
CIU605	12	<i>I needed to work, and I was losing hearing in both ears. I was advised that it would be better to get an implant prior to losing all hearing.</i>
HA705	13	<i>In a less productive work environment I don't know if I could function, I'm extremely dependent on the goodwill and the willingness of people to accept my disability...And I think I'm probably not that far off [CI].</i>
CIU605	14	<i>I needed to hear in order to retain my job. This became imperative as I was considering leaving my partner which I eventually did after many years of struggling with hearing loss and ineffective [HAs]</i>
CIU607	15	<i>I also used to love flying...Even though I got a commercial flying licence I never used it. I only wanted to do it for recreational purposes but they were saying that I couldn't fly anymore because I couldn't pass the hearing test.</i>
CIU402	16	<i>Thankfully the audiologist put me in touch a lot of other people who are musicians who had [CIs] with varying results, some had not been able to do their music again and some were able to say it's as good as it ever was and they're fine</i>
HA703	17	<i>I know a few people who have taken the BIG step, and they have all reported how well it works... so, when and if the time comes, I know I will benefit from a [CI]</i>
Clcand706	18	<i>I have talked to my doctor who knows a few people with [CIs] and he says it is a great help</i>
CIU402	19	<i>But, the stories from CI recipients were so encouraging and the [CI clinic] audiologists were encouraging too – eventually I really looked forward to having the surgery done</i>
CIU609	20	<i>Anyway, in the good hands of a first-class surgeon, encouragement from a dedicated audiologist and support of my nieces and nephew, I had no hesitation in going ahead with the C.I. And I will always be thankful that I did.</i>
HA702	21	<i>But she's moved into rooms now with another audiologist but also an ENT who specialises in [CIs]. So thinking about that, that's making me think, "Well I might go and have a talk to him about what it's all about." ...And I haven't asked my audiologist particularly because she doesn't do [CIs], she has got a couple of clients who've moved to [CIs] but I thought that's not her area of expertise, so I haven't gone down that path.</i>
CIU612	22	<i>As a retired and trained teacher of the deaf for the last twelve years of my teaching career, I was fully au fait with all of my hearing options, knowing that a [CI] would substantially boost my speech discrimination it took no convincing for me to get one.</i>
CIU602	23	<i>After testing for many years and being turned down each time, I felt as though I wasn't going to be able to get a [CI], but ...I reapplied at the insistence of my middle daughter and found that the guidelines had changed, and I qualified. I was ecstatic and a little nervous. The guidelines changed to the testing being done on one ear at a time, instead of both ears with [HAs]. I struggled a great deal with only one [HA] and especially in the words coming through the speakers, as speakers distort.</i>
CIU606	24	<i>My audiologist very strongly advised my family to attend appointments with her and me to discuss the likelihood of success, the part family would be expected to play with after-care support for me (my three children)</i>
CIU604	25	<i>When I had my CI, it was experimental and very different to what it is like these days. It was a very exciting time and we were making history being among the first deaf people to hear. 32 years on getting a CI is like getting a [HA] except one is unable to try them out first!!!!</i>

Note: The verbatim quotes are labelled according to the participant number (CIU, CI user; HA, [HA] user; Clcand, CI candidate) and the quotation number

3.2.5 Facilitators encouraging CI utilisation: HCP's perception of patient facilitators

- Desire for improved hearing, better communication and enhanced relationships, reduced isolation and richer social lives
- Hearing aids that are no longer effective, and patients being frustrated by the listening effort and fear of going deaf
- Hearing recipients' CI success stories, seeing the same audiologists who are supportive of CIs and supportive families
- Patient awareness and understanding of the potential benefits of CIs
- Feeling prepared to commit to rehabilitation after surgery

When HCPs were asked what they thought would motivate patients to get assessed for a CI, several factors emerged, both externally facilitated factors and personally motivated factors. These are described below, with supporting quotations referenced in parentheses (see Table 3.2.5).

All three HCP cohorts (GPs, Australian and UK audiologists) suggested that the strongest motivators for patients to access a CI were the **desire for improved hearing** (Q1), better **communication** and improved relationships (Q2), an improved social life, as well as a desire to be less psychologically or socially isolated (Q3). One audiologist suggested that socially active patients are more reliant on hearing, and more motivated to have a CI (Q4). Being **well supported by family** was an important factor (Q5) and having family members in the consultation with the patient was helpful during CI decision-making (Q6). The increased frustration, exhaustion and listening effort patients experienced when their **HAs were no longer effective**, also motivated them for CI assessment (Q1; Q7) as did the **cost of ineffective HAs** (Q8). Several Australian audiologists and GPs suggested that **maintaining brain health** through increased auditory stimulation mattered to patients, particularly for dementia prevention.

Audiologists in Australia and UK felt that **hearing success stories** about CIs from other recipients (Q9) was a powerful facilitator for patients, as was having a doctor recommend a CI assessment (Q10). One CI audiologists highlighted that it is important for the recipients to be well matched to the candidates, with similar hearing loss experiences, and age group, to achieve the best outcomes from the interaction. Audiologists also thought that **being supported by knowledgeable audiologists** on a regular basis, also facilitated the CI decision making process (Q11; Q12). Several audiologists felt that seeing a new audiologist prompted different treatment options being offered and provide patients with an opportunity to have a CI discussion (Q13). For that reason, some UK audiologists felt that **open access HA services** available in the UK, increased the opportunity for CIs to be introduced, as patients can be instantly reassessed by an audiologist (as opposed to an audiology assistant), who is more likely to suggest CIs (Q14). **Ensuring good records** are kept of the consultations was also considered important by both groups of audiologists, so that patients do not have to repeatedly explain their hearing health history to new audiologists (Q15) as often these **conversations about CIs happen over many**

appointments (Q16). Patient awareness and understanding about CIs was considered essential although some audiologists suggested that “**switch on**” **videos** can mislead patients into believing that CIs are curative (Q17). **Having information packs** about CIs available was also considered important, to help patients make informed decisions and share the information with their family.

Audiologists commented that many patients were motivated for implantation by their **fear of going completely deaf** (Q18) and they stressed the importance of patients being intrinsically **motivated to commit to rehabilitation for successful outcomes** (Q19). Some patients are interested in the CI technology, while some delay implantation, waiting for technological improvements (Q20). As hearing loss progresses, audiologists noted that patients become concerned about **losing their jobs** (Q21).

Table 3.2.5: Facilitators encouraging CI utilisation: Verbatim quotations from HCP's about patient facilitators

Hcp	Q#	Quote
Au105	1	<i>I think it's a lot of just getting frustrated and wanting to hear a lot more and maybe we've tried - they remain wherever they were before, tried everything they could with [HAs] and there's only a limit to what can be done</i>
Au106	2	<i>I would say most of the time it is about communication... better connection with family and friends. Just being, less exhausted at the end of each day and maybe less reliant over time on having to constantly use tactics and strategies...to fill in the gaps.</i>
CI Au108	3	<i>I think definitely you just reach a point psychologically where you're so isolated socially and your family as well are probably getting quite stressed and worried and probably a little annoyed... by having to repeat things 30 times...the isolation factor is probably the biggest one.</i>
Au113	4	<i>Somebody who... is really active, and I suppose relies on their hearing, whether they're still really social, they attend meetings, they're a bit younger... younger people are more open to it...somebody who is still quite active and more reliant on their hearing... would be ...more motivated to get a [CI] than say someone who spends all their day at home and, isn't in many social situations.</i>
UK5	5	<i>You tend to find as well that people's families, so their hearing partners, will be a big factor in it as well. If they've got a supportive network and they're pushing them forward to have the implants for a better quality of life, then that helps</i>
Au106	6	<i>Often if we can try and get the significant other involved...it might even be that we will conference-call a daughter in</i>
Au107	7	<i>It's very isolating having hearing loss- 'I'm really left out, I'm really frustrated, I'm withdrawing socially', that's when I think clients will go okay, but they have to get to a point where they recognise there's nothing more we can do with the [HAs].</i>
CI Au111	8	<i>What motivates people is ... just the either lack of satisfaction with their [HAs] ... sometimes, that's related to how much they're paid</i>
Au107	9	<i>I've had a couple of clients who have been really reluctant but when they've talk to another person of a similar age who's just been through it they're going oh, maybe this is something I can do. But a lot of them think I'm too old for this</i>
UK3	10	<i>Because a doctor suggested it they were like, "You know, the doctor suggested it." I thought, "Is that something you're interested in?" "Yes, yes, yes. If the doctor's suggested it, it must be-" I feel like that was a thing.</i>
CI Au111	11	<i>What also motivates them is ... talking to clinicians that are comfortable and experienced with this, whether that's surgeons or audiologists</i>
Au113	12	<i>It can be a bit overwhelming I think for [patients] ... they can't really communicate over the phone. So, for a couple of my clients, I've had to...call up [the CI clinic] ... and help organise their appointments or send off emails and ensure they've got the client's email address or somebody else to contact to help them organise their appointment.</i>
Au113	13	<i>They've had a long-term relationship with their audiologist who is sort of like just happy to go with the flow type thing, and it's not [until] a new audiologist who suggests it, that they take it into consideration again.</i>
UK4	14	<i>Since we've changed our open access [HA] service, I think they're more likely to get referred on because quite often it used to be that they would maybe only see an audiology assistant for five, six, seven years if they weren't having any significant problems that required a reassessment. I think the knowledge and understanding at the different levels of staff does vary, so it might not have been in the clinician that they were seeing mind at all, but that might want to happen, whereas now because we have audiologists on that service and the ability to do instant reassessments, I think they're more likely to get brought up and more likely to get picked up and referred on.</i>
UK4	15	<i>We're very good at filling out all of our journals and everything, we're very detailed with that. So you can for the most part very easily pick up where the previous clinician has left off without having any problems.</i>
UK9	16	<i>It's not something that's achieved on one visit. It's an idea that you set the seed and develop it, feeding in information as it's appropriate, and get them to a position where they feel they can make a decision whether to be referred or not.</i>
Au1101	17	<i>Maybe they've seen a SWITCH ON video on social media....Sometimes it sets up that unrealistic expectation, that this is curative.</i>
Au110	18	<i>It is the desire not to be completely deaf and so it's fear... it's an insurance against that. Family, work, definitely social. Psychologically it's hideous to be deaf... It's a strong motivator. If they've just completely lost all their hearing or their remaining residual hearing has dropped away, then they are so motivated to get back into the hearing world</i>
UK6	19	<i>I think the patients do need to be motivated to help themselves. There is, probably, a difference in the attitudes of older patients now. They're doing a lot more. They're a lot savvier with different things, and the internet. They're much more open to ideas because they want to maintain their quality or improve their quality of life, but that is, obviously, an individual perspective.</i>
UK1	20	<i>There's another chap who is very strong technical background, very well informed, very sensitive to very small changes in hearing-aid settings, has a multitude of programmes on his [HAs]. The deciding factor for him is when to make that decision to go for an implant, because he would be in criteria, but he keeps on wanting to hold out for slightly better technology.</i>
Au110	21	<i>Definitely, oh, work – I've definitely had work – they're going to lose their job.</i>

Note: The verbatim quotes are labelled according to the participant number (Au, Australian HA audiologist; CI Au, Australian CI audiologists; UK, UK audiologist; GP, General Practitioners) and the quotation number

3.2.6 Facilitators encouraging CI utilisation: the HCP perspective

- Increased knowledge and awareness of CIs through tertiary training, information sessions, and publications in GP journals
- Patient-audiologist continuity, and availability of CI demonstration models
- Access to CI success stories, feedback from and networks with, CI audiologists, and a shared database of CI recipients
- Access to a CI assessment referral template, eligibility screening tools, and CI resources
- Introducing Quality of Life assessments to flag when patients are struggling

GPs and audiologists were asked what would support them to make more CI referrals. The facilitating factors have been described below, with supporting quotations referenced in parentheses (see Table 3.2.6).

All three cohorts (GPs and audiologists in Australia and the UK) spoke about how **increased CI awareness and knowledge, through tertiary training, would be useful to increase CI referrals** (Q1), as well as increased access to **professional development** courses (Q2), with presentations by doctors to effectively gain GPs' attention (Q3). GPs suggested **publications about CIs in medical journals** may also help to increase GP awareness of the benefits of CIs in the adult population (Q4).

Australian and UK Audiologists felt that **patient-audiologist continuity was important** to develop a rapport (Q5), as was access to CI **demonstration models** (Q6) to make it easier to discuss CIs with patients. Audiologists noted that they would like more access to CI recipient **testimonials** to learn about the patient experience of procedures and rehabilitation (Q7; Q8). This would help them feel more confident talking to CI candidates (Q9). Similarly, **talking to CI audiologists about the CI assessment**, surgery and rehabilitation journey and **getting feedback** about recipients was also seen as helpful (Q10). Networking and **developing relationships with local CI teams**, to discuss patients and access CI information was valued (Q11) as was **direct referral to CI clinics** to streamline the process (Q12). **Referral tools** circumvented the need for a GP referral, in the CI referral pathway, and reduced the need for clinicians to remember the CI criteria (Q13; Q14). Several audiologists suggested that a screening tool would help them identify potential CI candidates (Q15). Some UK audiologists had access to a **shared database of patients** with CI teams, sharing audiometric and speech discrimination tests results, which made referrals easier (Q16).

Audiologists noted that it would make the conversation easier if they had easy access to **high-quality hard copy resources** to help patients digest and share information with their family (Q17). Some audiologists however had received such resources in the past, which they **misplaced** when they weren't being used regularly (Q18). It was also suggested that it would be useful to have access to **videos about the CI and procedure**, to show patients (Q19), as well as access to **internet resources**, preferably not from a manufacturer, with up-to-date information about

referral pathways, eligibility criteria, contacts for support, and information about surgery and rehabilitation (Q20). Other audiologists reported that they already used the manufacturer and hearing association website resources, which were useful and easy to access (Q21).

Attending **information sessions about CIs** often hosted by manufacturers or CI teams (Q22) increased confidence and knowledge. Some UK audiologists felt that coproduction (patient-centred care) had also made CI discussions and referrals easier, with practices focused on patient-centred decision making (Q23). UK audiologists suggested that **introducing Quality of Life assessments** when testing patient's speech discrimination, could prompt them to explore additional treatment options such as CIs, highlighting patient communication deficits (Q24). They reflected that the introduction of referral-to-treatment targets in England, which limit patient waiting times from GP referral to treatment to a maximum of 18 weeks [19], had contributed to the reduction of CI waiting lists and that in their region a large proportion of audiology patients eligible for CI and who hadn't been implanted, had previously discussed CIs and decided against them (Q25).

Table 3.2.6: Facilitators encouraging CI utilisation: Verbatim quotations from HCPs

ID	Q #	Quote
UK5	1	<i>If you're going through a university degree and it's a three or a four-year programme, I think having something more advanced to do with Bahas and implants... straight away from the word 'go' to have that input would be massive.</i>
GP2207	2	<i>Training specifically...about how to introduce the idea to a patient... knowing the referral process and the results that they could expect ...would enhance that rather than me just referring them to someone else and not having that skill.</i>
GP2206	3	<i>The [ENT] specialist can bring some pamphlets and have a brief talk...this kind of thing is quite beneficial</i>
GP2202	4	<i>If you want to access a lot of people, you want to have the article when they are doing the ENT theme, of Australian doctor, or medical observer, tabloidy things they always have an educational bit about different topics</i>
UK8	5	<i>That [patient-clinician] continuity definitely makes it easier.</i>
Au1103	6	<i>You can get these little demo models and can show people...sometimes when they see that it is so small... for somebody to hold something physically in their hand, and just look at it, it takes a lot of the "what is it" out of the whole process.</i>
UK6	7	<i>It's actually nice when you get the patients in, you go, "Oh, you've had your implant? How is it?" ...and seeing how well they're doing. That's actually really helpful, as an audiologist, and that doesn't generally happen</i>
UK8	8	<i>Wouldn't it be nice if implant teams encouraged patients at one year to go back to their audiology departments and talk to them about how they'd got on ...I think would change audiologists practice: if they saw ...what a difference it had made.</i>
Au106	9	<i>Once you have a couple of lovely stories in your repertoire, I think it is really powerful to be able to then have the confidence to say to someone, "Actually, I have seen a client very similar to you."</i>
UK11	10	<i>I think it's a basic human conditioning response, isn't it? If you do something and you get good feedback, you'll do it again...you make a referral, you get the positive feedback that the patient's doing really well, improved quality of life, improved functional benefit. You'll then think more about it.</i>
UK4	11	<i>[for UK5]'s team it's a lot easier for because the CI team are on site, you're working with them every day.</i>
UK1	12	<i>We already have a setup where we try and optimise people's [HAs], do some rough checks to see whether they're likely to be in criteria... and simply just have to write a letter or place an order and that's the referral. It's that easy for us.</i>
UK6	13	<i>People thought you had to go through the GP or through ENT...and that was a problem because it didn't happen. Now, we refer directly. That is much better, and we have, on our audit-based system, a template set up so people can do it.</i>
Au107	14	<i>We've got some referral pads coming... that's really helpful for [audiologists] because it's got all the information on it...they don't have to remember. The more simplified the process is... the more we will have people recognising and referring</i>
Au110	15	<i>It's not just a speech perception score. It's the other things that go into it. So I can appreciate it's hard- if they had some sort of screening tool that would be great.</i>
UK10	16	<i>Working off the same system, we don't have to send all the results with a letter. [CI teams] use the same system as we do, so they've got access to all the information, [HA] settings, measurements.</i>
Au107	17	<i>Easy to follow, clear literature...available at the appointment so you don't have to hunt around for it ...that's really important that clients get literature to read, it helps to absorb it and they can have think about it and show their family members</i>
Au1101	18	<i>We might have those resources, front of mind for a little bit, but if you don't use them [you]...tend to forget you have them.</i>
UK107	19	<i>Just have a DVD of information where family members can perhaps hear how it's going to sound. I think we could do a really good pack that includes the Channel 4 documentary on [CIs]</i>
AU1102	20	<i>Clear, online resources would be good.... a website that would be, this is what it looks like... how the surgery is done, this is what the... recovery period is like. [the CI clinic and CI manufacturer websites are] very specific to those particular places, so something more general would be good.</i>
Au106	21	<i>The websites are fantastic. There are some great resources.... There is a lot of stuff online. It is really easy and there is those online e-learnings and, yeah, lots of ways to keep current, I think.</i>
UK6	22	<i>We did get [CI audiologist] to come in recently to do a talk and that really did help me and the rest of the department... She talked about patients that we'd sent and things like that, so that was really, really good. I think more of that is needed because people keep away from [CIs].</i>
UK2	23	<i>Just through discussion. If a patient has gone through all the range of [HAs] ... Adjusted all settings on the [HA] and they're just not getting on, then it would be probably approached through coproduction. You'll say, "Another option could be an implant. Have you thought of an implant? Do you know what it is?" Open the discussion that way then.</i>
UK11/ UK9	24	<i>UK11: Yes, and whether we need to incorporate more quality-of-life aspects, as well as crude audiometric. UK9: It makes it hard to know when's the best time to refer, because, if you refer too early, they'll have the negative experience of being declined. If you refer too late, they're struggling needlessly and potentially their auditory processing performance is deteriorating, and they're getting more isolated and harder to socially integrate, again.</i>
UK1	25	<i>That's also meant that the make-up of people coming to our clinics has changed and so we have a lot of people who have decided they don't want [CIs] but they've already thought about [CIs]...quite often I find myself, rather than introducing the subject for the first time, just checking in with them as to where they are in thinking about it.</i>

Note: The verbatim quotes are labelled according to the participant number (Au, Australian HA audiologist; CIAu, Australian CI audiologists; UK, UK audiologist; GP, General Practitioners) and the quotation number

Differences between UK and Australian Audiologists' perceptions of barriers and facilitators to CI utilisation

The vast majority of barriers and facilitators to CI utilisation were echoed between the UK and Australia. By including the UK audiologist cohort, several contextual differences in service provision between the UK (Wales and England) and Australia were highlighted including differences in funding structures, and the implications this had on the perception of cost as a barrier. UK audiologists also reported better networking with CI clinics, compared to Australian audiologists (See Table 3.2.7 for examples of differences between the sites).

Table 3.2.7 Differences between UK and Australian audiologists' perceptions of barriers and facilitators to CI utilisation

Perceived barriers unique to Australia.	Perceived barriers unique to the UK
Costs	Short wait list time between assessment and surgery in England
HA sales targets	More UK audiologists reported networks with CI clinics and shared databases
	AQP scheme (facilitators and barriers) in England

3.3 Theme 2: The burden of hearing loss: the patient perspective (Aim 2)

- Hearing loss makes communication more challenging, affects mental health, and impacts work opportunities
- The cost of hearing devices is an ongoing burden
- Hearing loss impacts self-identity, perception of communication ability and engagement with community

Patient cohorts were asked about their experience with hearing loss. The key concepts have been described below, with supporting quotations referenced in parentheses (see Table 3.3).

CI and HA users expressed that **communication** was more challenging with a hearing loss (Q1) especially when people speak rapidly, or unclearly, making it difficult to piece conversations together (Q2). Many participants found that communicating **one-to-one** worked well, but once in a larger group (Q3) could often break down, even with CIs or HAs supporting them. Talking on the **phone** was an ongoing issue for many (Q4) which CIs helped to relieve (Q5). Hearing **announcements on public transport** (Q6) and **communicating with doctors** was also challenging (Q7). Consequently, many participants talked about the **listening effort required with a hearing loss**, and how this could be exhausting (Q8). As hearing loss progressed, participants needed **strategies to communicate**. They tried lip reading, asking people to speak clearly, positioning their good ear to face the speaker, choosing quiet places with good acoustics for conversations, and were more dependent on written communication, and CapTel phone devices, which convert speech into text, and apps connecting their phones to their HA or CI. Participants spoke about how these communication strategies often had to be learned. **Comprehending languages other than English**, was also found to be more challenging with a hearing loss (Q9). Several participants talked about how it was frustrating to be **reliant** on a hearing device to participate socially.

Participants reported that their hearing loss and resulting communication breakdowns **impacted their mental health** (Q10; Q11), and the emotions of other people around them (Q12). **Relationships with friends and family** (Q13) were affected resulting in participants isolating themselves and withdrawing from social situations (Q14). Added to this, hearing loss **impacted work and educational opportunities** (Q15; Q16), forcing some participants to **take early retirement**. Hearing loss often rendered adults **reliant on other people**, and on others' understanding of their hearing loss needs (Q17), in the face of some people's lack of empathy.

Several HA and CI users explained how the **burden of the cost of HAs** was an ongoing issue that caused resentment and strain on families. Many participants were advised to take out private health insurance, to cover hospital costs and CI upgrades, rendering them reliant on the insurance company, for future upgrades. For others, who reported that they couldn't afford private health insurance, concerns were expressed about how a processor upgrade could be afforded. Many

participants discussed being reliant on financial support from the Australian Department of Veterans' Affairs (DVA), to cover costs of their CIs, while a minority of participants reported being well supported by the National Disability Insurance Scheme (NDIS).

Participants also commented that **hearing loss impacted their self-identity** and felt frustrated by their loss, sensing that on occasion others treated them like they were **stupid** (Q13; Q18; Q19). In this respect, for some, hearing loss has **limited their ability to be active members of society**, leading to extensive **adaptive behaviours** (Q20), and the sense of being a poor communicator, often missing social cues, making them perceive themselves as less effective in their role as a parent or employee.

Table 3.3: The burden of hearing loss: Verbatim quotations from patients

ID	Q	Verbatim quotations
HA701	1	<i>It's difficult for people to communicate, to engage ... it halts or stops your spontaneous communication.</i>
CIU605	2	<i>What is so often overlooked is that hearing impaired and deaf people do not hear everything often they try to piece the story together and miss important points...it truly is soul destroying having to ask people to repeat themselves constantly.</i>
CIU401	3	<i>If you have a big family group, then the noise just echoes around and it's quite difficult to follow conversations and for me to feel as though I'm part of the group, so you can affect that feeling of isolation sometimes</i>
HA702	4	<i>We don't talk to each other much on the phone because we both find it just a little bit difficult to always hear each other, understand each other.</i>
CIU403	5	<i>I couldn't hear on the phone before the [CIs]. That's actually a huge change because your friends can suddenly ring you up... Prior to having the [CI], or even with earlier versions, I just avoided the phone.</i>
CIU401	6	<i>When I travel, I always make sure I sit right near the notice board or I tell them I won't be able to understand the announcements</i>
HA707	7	<i>My GP is not good with my hearing loss as sometimes he gets impatient with me but he has an accent which is hard for me to understand</i>
CIU602	8	<i>I would suffer from dreadful tiredness and exhaustion from trying to communicate all day. It used to take so much out of me to listen. Now I forget how much trouble I had and how tired and depressed it used to make me.</i>
CIU405	9	<i>I've been studying Latin for the last 15 years ... and I have just these last two weeks suddenly come to the realisation that I just can't cope with it any longer. I haven't got the energy because you have to be able to hear words that aren't English... I find it very sad that I just feel like I'm going to have to give that up because I simply can't hear enough.</i>
Clcand706	10	<i>I cannot communicate with my great grandchildren, have very few friends, and get quite upset trying to get shopping done. Even talking to my doctor is hard to get information right. I live alone and can be upset if the phone rings and I cannot identify the caller. My children text me now as I cannot hear on the phone.</i>
CIU602	11	<i>I would say my hearing loss has had an enormous impact on my life and has also affected my mental health a great deal in my ability to communicate my feelings... my thinking that hearing loss was a stigma to a healthy person was all wrong and I felt very depressed to be suffering from hearing loss.</i>
HA703	12	<i>My wife is understandably a little less patient...She has to repeat herself endlessly, which I know frustrates her at times.</i>
HA707	13	<i>My hearing loss has greatly affected me emotionally as felt that people thought I was retarded, and with that I retreated into my shell and stayed in the background, so I wouldn't be called stupid and rude names. I lost a lot of friends from my hearing loss as they didn't and still don't understand that though I have a hearing loss I'm still a person who has a brain and that I went to school and got an education.</i>
CIU405	14	<i>I tend to isolate myself... It's made me retreat in some relationships.</i>
HA707	15	<i>At present I'm not working but looking for work but basically at every interview I have been to, the interviewer has quietly stated that the position I have applied for may be a bit noisy for me with my hearing loss</i>
CIU611	16	<i>My formal education virtually stopped when I lost my hearing.</i>
HA705	17	<i>You're completely dependent on the goodwill and the ability of other people to appreciate and understand your situation</i>
CIU406	18	<i>Sometimes people think you're stupid because you can't hear properly</i>
HA701	19	<i>It's almost like hearing loss actually makes you inferior... People seem to be more comfortable helping someone with vision problems. They're less patient with people who have communication difficulties.</i>
CIU610	20	<i>Relationships will always be a challenge and reminding people that you still can't hear...So it is using all those strategies. It is the self-advocacy and I am actually a very, very shy person but having a hearing impairment forces me out.</i>

Note: The verbatim quotes are labelled according to the participant number (CIU, CI user; HA, [HA] user; Clcand, CI candidate) and the quotation number

3.4 Theme 3: The impact of CIs on Quality of Life (QoL) (Aim 2)

The impact of CIs on Quality of Life

- Improved ability to verbally communicate, reduced listening effort, and ability to use the phone, and hear music
- Improved mental health, confidence, and engagement with friends, family and the community
- Being a role model for others

Remaining challenges include;

- Communication, especially in large groups, or in languages other than the individuals' first language
- Costs of upgrades, and travel to hearing services for rehabilitation, mapping and upgrades
- Batteries going flat regularly, dissatisfaction with the quality of sound of CIs
- Limited access to entertainment options.
- The need for safety devices such as flashing fire alarms, when not wearing CIs at night.

Patients (CI users and HA users) and HCPs (audiologists in the UK and Australia, and GPs) were asked about their perception of the impact of CIs on recipients' Quality of Life (QoL). The majority of CI users were largely positive about their experience and described an improved QoL, highlighting their **improved hearing and ability to communicate** (Q1), being able to hear on the **phone**, and being more sociable. Improved hearing often led to greater **confidence** (Q2), and the ability to be **more active** in the community. Most participants reported their CI contributing to **improved mental health**, through reduced stress, the ability to **reconnect with family and friends** (Q3), and **less listening effort**. However, recipients still got tired from concentrating during conversations (Q4). Several recipients commented on being able to **enjoy music** again (Q5), while others enjoyed being able to **switch their CI processor off**, for time out from the hearing world. Several CI users commented that they **enjoyed being a role model** for people with hearing loss as supporting people through their hearing loss journey was empowering.

Remaining challenges with CI(s)

While the majority of recipients were positive about their CI, there were several remaining challenges (Q6). These included: **perceived side effects of CIs**, such as tinnitus (Q7), and **communication challenges**, in noisy environments with large groups (Q8). The hearing world was described as **loud and stressful** (Q9), making it challenging to listen to what people said (Q10). One CI user commented that their **fear of loss of remaining hearing** in their non-implanted ear was a concern, making them protective of the hearing they had left by avoiding noisy environments. Talking on the **phone** remained a problem for many recipients (Q11), as did **appearing to cope better than they actually did** (Q12), which meant that others do not always provide the support that recipients need. Several participants were **self-conscious** of their CI and their appearance, but for the most part this was resolved by upgrades that were more discrete (Q13). **Costs** associated with CIs were frequently discussed as an ongoing concern, particularly for upgrades (Q14; Q15), and **travel to CI services** was another ongoing problem, particularly for those living in rural or remote regions with limited service availability (Q16),

requiring travel to cities to access care (Q17), though one recipient still found **travel preferable to remote mapping. Batteries going flat** (Q18), and the **quality of sound** were other issues that participants experienced (Q19). Several participants talked about their **need for additional safety devices** when they took off their CI at night, such as visual and vibrating smoke alarms (Q20). Fear of non-compatibility of implants with future processors was mentioned (Q21) as was problems of **access to entertainment options**, such as the movies, with a preference to watch from home with captions (Q22).

Almost all audiologists felt that CIs would eventually lead to long-term improvements in QoL for most patients (Q23), noting that the initial period of acclimatisation was time consuming, required commitment to rehabilitation, and fine-tuning of the MAP to get the sound right. Audiologists reported that the few times they were aware of CIs not being effective was when the patient had conflicting medical problems or didn't adequately persevere with rehabilitation (Q24).

Table 3.4: The impact of CIs on Quality of Life: Verbatim quotations from CI users and HCPs

ID	Q	Quotation
CIU403	1	<i>I was still hearing impaired, but I knew that if I... asked people to repeat themselves because I hadn't heard them the first time, I knew that at least with the [CI] I had a chance on the second go around...prior to that, I could ask them a dozen times to repeat themselves and still not hear it. So of course, I didn't ask them to repeat themselves.</i>
CIU403	2	<i>It certainly gave me a lot more confidence. I guess it was confidence to address the situation as much as confidence that I probably would hear what was said anyway.</i>
CIU602	3	<i>I am getting sound that I could never have dreamed of previously. I can communicate in conversations with more than one person. I am no longer in a bubble being left out of conversations and relationships with others...I have regained respect from others and also my own self esteem. ... I feel much more confident and outgoing</i>
CIU406	4	<i>It's only one-on-one, I can't join in the overall conversation...I find it terribly exhausting and tiring, sometimes can't make the effort as the evening wears on my energy levels drop.</i>
CIU601	5	<i>It's only over the last couple of years that I've been able to enjoy music again, which I do and strangely enough I'm listening to stuff that my teenage daughters listened to. I could never hear what it was. It was just a noise.</i>
CIU402	6	<i>Every day is still a challenge...what are going to be the hearing difficulties here today</i>
CIU611	7	<i>Since the implant I also experience intermittent tinnitus.</i>
CIU612	8	<i>The challenge will always remain trying to follow conversations in either group settings or settings with ambient noise.</i>
CIU610	9	<i>The hearing world is very stressful, very noisy... I am getting what I need to survive in a hearing world as a hearing-impaired person. [the CI] has made me go from being profoundly deaf to hearing impaired.</i>
CIU405	10	<i>I was an English teacher ...I'm used to analysing things and looking for meaning beneath the surface and I'm used to doing that with people too, not just hearing what they said but...what's going on underneath here. Now I'm just struggling for the superficial what are they saying and to me that's been the biggest loss, that I've lost that part of myself that's so closely analytical... Instead of looking into people's eyes to see what they're on about, I'm looking at their necks.</i>
CIU604	11	<i>I am unable to understand speech using a phone. I would say it is 50/50.</i>
CIU610	12	<i>Everyone forgets that you have a hearing impediment because you can cope so well and because you can bluff it.</i>
CIU402	13	<i>I wear my hair up and gives me a bit of freedom there and other people I talk to that I know are resisting getting it ...my response is if only you knew how good it was and what a difference it is, you would live with it, you wouldn't care anymore</i>
CIU601	14	<i>Down the track I've got to think about upgrading, probably between three and five years and it's something that I'll just have to worry about when the time comes, but if I've got any gripes about it, it's just that, the expense of it all.</i>
CIU403	15	<i>I don't have any control over the funding of upgrades...I have no control over [CI manufacturer]'s decisions to no longer support earlier versions of the speech processor, which means in some cases I MUST take an upgrade. So in some ways I must maintain private health cover (which is fine because it is so generous).</i>
CIU607	16	<i>Being in a provincial centre means there are no trained CI audiologists... I have to travel to the capital city for attention. At times I feel quite isolated from the professionals who are responsible for my well-being in relation to hearing.</i>
CIU603	17	<i>I would say the main challenge at the moment is the distance that I have to go to get mappings done, to get replacements, things like that. I live in a town called [name], which is about 220kms south of [city]... about two-and-a-half-hour journey from home... So, distance involved and changing the process that is probably the main challenge</i>
CIU602	18	<i>I carry spare batteries in my bag, as they quite often go flat when I am out somewhere.</i>
CIU611	19	<i>I don't like the tinny sound. I can hear fairly well, but don't always understand what I'm hearing.</i>
CIU403	20	<i>I do have a smoke alarm that has a shaker and a strobe light thing. At least I'm relatively safe.</i>
CIU601	21	<i>You can't think about them failing because what's going to happen in the future is some of the later technology upgrades are not going to be compatible with those implants. At the moment they're compatible with anything that they bring out.</i>
CIU405	22	<i>I can't go to films or to the theatre or listen to the radio. I can't do so many things that that I've loved doing and that's just sad. [I] wait for things to come on DVDs ...with captions...do all my watching at home. It's isolating but it's totally pleasant.</i>
Au109	23	<i>CI helps to significantly improve quality of life to the majority of recipients in the short and long term. There are, however a number of patients who do not obtain optimal benefit from an implant and therefore quality of life remains compromised. Other factors such as patients' cognition and motivation, aetiology and duration of hearing loss, dedication to post-op auditory training, amongst others, significantly affect outcomes.</i>
Au106	24	<i>In all of my years I can only remember two clients who were implanted where it hadn't worked out and in both occasions, it was... medical issues... in all those years with all those clients I have seen, everybody else has I think had an improvement in confidence, less listening effort, less overall stress. Not doing that mental check every day of trying to piece together what they heard and what they thought they heard and trying to make sense of it and trying to cope.</i>

Note: The verbatim quotes are labelled according to the participant number (CIU, CI user; HA, [HA] user; CIcand, CI candidate) and the quotation number

3.5 Theme 4: Professional practice, information sharing and shared care: the HCP perspective (Aim 3)

- CIs are first introduced when patients report inadequate hearing aid support, get poor audiogram results, or are recommended as a future treatment option
- Reports are sent to GPs, ENT specialists and CI clinics, but audiologists rarely receive feedback
- Acknowledging hearing loss, accessing services, having a HA fitted, a CI assessment and the CI implant are key patient decision points for patients
- Audiologists' perception of their role in the patient hearing loss experience varied
- GPs perceive themselves as playing a coordinating role when it comes to supporting patients with hearing loss
- Hearing health is typically reviewed by audiologists annually, with options for patients to request more frequent consultations.

HCPs were asked about the role they play in the patient hearing loss journey. The range in confidence about CI eligibility criteria, and general knowledge about CIs was on a broad spectrum, for audiologists in both Australia and the UK, with many admitting they had **limited knowledge and confidence identifying patients who are eligible for CIs**. Several audiologists noted that the **eligibility criteria had changed** (Q1), so they weren't confident referring, but would **assess speech discrimination**, how well a patient **functions with deteriorating hearing loss** (Q2), and a patient's **level of family support** (Q3) when determining whether a patient should be assessed for a CI. **GPs had minimal confidence and knowledge about hearing loss**, and would refer patients on to audiologists or ENT specialists. The **key patient decision points** identified by audiologists and GPs included: recognising the severity of their hearing loss (Q4); accessing hearing services at onset of hearing loss and regularly after that; accessing HAs, and; accessing CIs. The decision to be assessed for a CI was seen as a major event that could take patients a long time to agree to, due to their numerous concerns about CIs (Q5), and also required patients to accept the limitations of their HA (Q6) (See section 3.2.1 Barriers to CI utilisation: the patient perspective).

Introduction of CIs to patients and the type of Information provided

Many audiologists were prompted to discuss CIs **when patients reported inadequate HA support**, in conjunction with **poor audiogram results**. Others reported **introducing CIs early on** so patients could adjust to the idea (Q7) often with initial difficulty (Q8). Often patients had already discussed CIs with a HCP. The CI audiologists commented that they try to encourage early intervention by discussing CIs with patients when their functional listening is being significantly impaired. In the UK, poor patient-clinician continuity meant CI referrals weren't always made after they the notion was introduced, especially if patients saw different audiologists subsequently (Q9). One UK audiologists commented that they rely on patients making an appointment for a hearing review, rather than proactively following up on patients (Q10). Audiologists typically provided **basic verbal information**, trying to avoid overwhelming patients, and relied on the ENT specialist or CI team to provide more detail. Others reported

explaining to patients what test results meant, about limitations of HAs and the general benefits of CIs and what CI candidacy meant. Some talked about the referral process, others about rehabilitation and expectations, surgery, costs and cosmetics. One Australian audiologist showed patients a demonstration model of a CI and arranged for them to meet a CI recipient. Some audiologists reinforced the fact that the surgery was voluntary, to encourage autonomy (Q11), and some told recipients that the CI sound was not always liked by recipients at first, but that successful outcomes are dependent on a long process of rehabilitation (Q12). Some audiologists provided patients with manufacturer or hearing association-produced **pamphlets about CI procedures and the device**, to help reinforce verbal information (Q13). However, these could be misplaced. One audiologist transcribed consultations and emailed the notes to patients while several others directed patients to **websites and forums about CIs, social media groups** (Q14), **online videos**, and **peer reviewed articles**, and arranged for patients to meet a **CI recipient**.

CI referral pathways

Audiologists in Australia reported that the **typical CI referral pathway** involved patients seeing their **GP for a referral to an ENT specialist, consulting with the ENT specialist who then referred the patient to a CI audiologist**. Alternatively, a **GP may refer a patient to an audiologist, who would then refer the patient to a CI audiologist** or suggest they got a referral (from their GP) to see an ENT specialist. While patients can self-refer to a CI audiologist directly, this does not happen often (Q15). Some Australian audiologists reported sending patients to CI clinics, hearing associations, ENTs, GPs or to a CI manufacturer. In the UK, audiologists reported that they would either send patients to senior audiologists for referral or refer them on to the CI clinic, as well as a variety of hearing associations. Working closely with the CI team was seen as important. One UK audiologist talked about following local guidelines and policies for adults and engaging the patient during the development of individualised hearing plans. GPs felt that they knew very little about CI candidacy, instead referring patients to an audiologist or ENT specialist for a hearing test and more information (Q16). Other GPs reported referring patients to CI centres, a CI manufacturer, and Australian hearing.

Shared care

Audiologists reported **sharing reports and audiogram results with GPs and ENT specialists**, while some sent CI referral sheets to GPs to help them refer patients to CI centres. **Audiologists rarely received feedback** from those clinicians (Q17), while GPs reported rarely receiving reports from audiologists (Q18). Some audiologists made appointments with the CI team on behalf of the patient (Q19) and sent test results and a referral form, and others shared

information with physiotherapists and speech pathologists, depending on the patients' needs. However, **the lines of communication between HCPs appeared to be haphazard** (Q20). UK audiologists typically sent referrals directly to CI teams along with reports to GPs (Q21) and ENTs, although many did not feel confident in their knowledge to make referrals. Care was clearly not shared once the CI team started to manage the patient, unless the patient had bimodal hearing devices (Q22). Audiology clinics that co-located with CI teams had more bi-directional communication, with shared databases of patient information (Q23). The development of Multi-Disciplinary Team meetings with audiologists and CI clinics was suggested as a way of enhancing shared care (Q24).

Perceived role of HCPs

Some audiologists saw their duty of care being fulfilled once they provided patients with basic information and a CI assessment recommendation. From there it was the patient's responsibility to pursue the assessment with the CI specialist, and the ENT or CI team to explain the finer details (Q25). Other audiologists felt that it was their role to provide a comprehensive summary of treatment options, so that patients could make informed decisions (Q26), and to support patients in making an appointment with a CI clinic. GPs felt their role was to provide a referral to an ENT specialist (Q27) or audiologist, and to monitor whether patients did access hearing services (Q28).

Long term management of hearing loss

Audiologists reported reviewing patients on an annual basis (Q29), with occasional emails (Q30), while also creating short and long-term hearing health plans collaboratively with patients. Hearing tests, however, are not conducted at every appointment, as many patients dislike them (Q31). Two GPs identified that the over 75-year-olds' health assessment had questions relating to hearing health, which may be used to identify patients as eligible for a chronic GP management plan, enabling GPs to coordinate care with an audiologist and ENT specialist (Q32). Only one audiologist mentioned a GP healthcare plan, noting that they are rare (Q33).

Commonly used resources by HCPs

GPs reported using academic journals, as well as their colleagues' views and presentations for information about CIs, as well as the internet. Australian audiologists reported getting CI information from professional bodies, and from their colleagues, as well as from academic journals, the internet, Australian hearing protocols, social media, and professional development courses. Audiologists in the UK most commonly got information about CIs from their colleagues, professional bodies, and academic journal articles.

Table 3.5: Professional practice, information sharing and shared care: Verbatim quotations from HCPs

ID	#	Quote
Au1103	1	<i>The candidature often changes. In comparison to when I started in 2000, it's vastly different now</i>
Au107	2	<i>We do speech testing. We look at how the clients are functioning day to day...we see if they're really struggling in any area...talk early on to start to plant the seed, especially if their hearing is deteriorating or if their functioning is deteriorating. It can take a long time for clients to get to the point where they're ready to start looking at [a CI].</i>
Au105	3	<i>Sometimes you can't really follow the exact criteria. They'll be certain cases where...it's not going to match exactly but you do feel that they're a candidate. It really depends on the audiological history...it also depends medically what the patient's like...making sure they have a good support system, family members at home.</i>
GP2203	4	<i>Recognising/accepting that treatment will be beneficial, weighing up risks and benefits</i>
Au107	5	<i>Moving onto receiving a [CI] is where I see the biggest transitional barrier, despite telling the patient for years about the CI it takes a lot to get them to this next step. Patients whose profound hearing loss is more sudden appear to be more open to CI's than long term deafened patients.</i>
UK6	6	<i>Barriers are accepting the implications of a hearing loss and limitation of hearing aids, prior to referral for CI assessment and also going through the CI assessment process. All of these are around acceptance of the impact of the hearing loss on their life.</i>
UK9	7	<i>It's not something that's achieved on one visit. It's an idea that you set the seed and develop it, feeding in information as appropriate, and get them to a position where they feel they can make a decision whether to be referred or not.</i>
Au 107	8	<i>I would probably introduce [CIs] ... by discussing their results and then saying, there are other avenues that we can have a look at and I will then introduce [CIs] in a very basic way...most of the time the reaction is not great.</i>
UK3	9	<i>I've seen a patient and then I've discussed [CI]. Then they've seen somebody...Then the patient won't come back again. I wouldn't know what happened to them... and there's no closure to if they wanted one or not.</i>
UK1	10	<i>We tend to be reactive, rather than pro-active in this respect, relying on patients to contact Audiology if they have a problem or to request a routine hearing and hearing aid review. Patients are able to contact Audiology by e-mail, by phone or by post.</i>
Au110	11	<i>Make them feel comfortable ... This is an elective procedure, so they are made to feel in control of the process.</i>
Au1103	12	<i>Information potentially about surgical procedures, the fact that there is a lot of rehab time, that's involved, that it's not just about a switch on and away you go... they need to be aware, it's not quite like the sound quality of [HAs]</i>
Au106	13	<i>We counsel about CIs and provide written information (less than 1/3 of information conveyed during appointments is retained by many clients unless supplemented with take home materials).</i>
CI Au108	14	<i>We'll provide them with the manufacturer required information pack, so we direct them with those websites, so we send them to a lot of forum websites and also recommend they go onto Facebook as well if they're Facebook savvy and join some of the [CIs] Facebook pages</i>
Au110	15	<i>The person contacting a CI professional themselves through social media...but that's not the typical way. Usually it's through the professional and typically it comes via an ear specialist...But less likely is one audiologist who doesn't deal in implants to then contact an audiologist who does implants. Although you do sometimes get the audiologist or audiometrist [to] contact the ENT directly.</i>
GP2203	16	<i>I wouldn't want to pre-empt any other options [or] exclude other options that might be available...I wouldn't want to be pushing an option over another and that's why I'd be getting them to see a specialist to talk about those things</i>
Au107	17	<i>Often, I've had clients just turn up with a [CI]... it's done... that's all gone all on behind the scenes but there's been no liaison or no negotiation or no input from us and we might have been seeing the client for 20 years.</i>
GP2207	18	<i>I don't tend to get many audiograms at all... I've probably had one or two in the last 12 months</i>
Au106	19	<i>Recommending that they either contact someone else who may be implanted or attend a pre-candidacy appointment at an implant clinic... send a report to the GP with current audiograms, aided history, aided access for that person and we send the referral sheet so that they have an idea of where to send them on... [CI clinic] are wonderful and they book the client in just with us calling but we also still do that audiological report to the GP and...copy to client.</i>
Au1102	20	<i>We find ourselves sometimes chasing up communication from medical professionals (particularly specialists), as the communicating mainly takes place between the GP and the specialist. Sometimes ensuring the lines of communication are open falls to the client.</i>
UK2	21	<i>The referral would go to the implant team but then a copy would go to the GP</i>
UK7	22	<i>Care is sometimes shared with the CI centre and we will assist with moulds etc. We have attempted working more closely with CI team pre-referral e.g. joint clinics etc but as yet have not found an efficient delivery method for this.</i>
UK9	23	<i>The hospital notes (electronic) and audiology patient management systems are also shared by the [HA] and CI department so information about what has happened in both services is accessible to the other service, but this is reliant on us keeping a note of who we have referred and checking on their progress as often we don't get a letter.</i>
UK9	24	<i>It would be really nice, wouldn't it, if we got to go to MDT when they were discussed? I think, considering we are physically close and have shared systems, we could do a lot better between us and the implant team, couldn't we? It feels like we don't always get brilliant information back without going and looking for it.</i>
CI Au108	25	<i>We...explain the basic concerns with the medical aspects and then it's up to our ENT surgeon then to follow through with the medical explanation booklet.</i>

Au1102	26	<i>Negotiating plans will always be done with consultation of the client. At the end of the day it is not our job to tell people or 'prescribe' the solution or "treatment" for our clients, it is our job to recommend, give appropriate unbiased advice, and offer solutions that are tailored to the person as a whole, not just an audiogram</i>
GP2201	27	<i>I don't think I'm well versed in all the processes of all this, so I think I would have to refer to an ENT surgeon</i>
GP2208	28	<i>The most I would do is make sure they are seeing the hearing health provider regularly</i>
Au106	29	<i>We see all of our complex adults at least annually and many are seen biannually or if there are fluctuations in hearing levels</i>
UK9	30	<i>For some patients...email is often used to continue to support the patient between visits if appropriate</i>
Au1101	31	<i>Any client with long-standing loss may prefer to contact us when ready. Some people really hate hearing tests, so I offer people the choice of a 6 or 12-month review and explain we don't need to necessarily perform a hearing test</i>
GP2202	32	<i>I don't think I create specific plans for their hearing. You often follow them up when they do need their ears syringed/checked prior to [HA] review. Plans related to their hearing loss may be part of a health assessment (>75 years) or part of a GP management plan (if they have other chronic disease). Technically they would qualify for a GP management plan based on their hearing loss alone if it has been present for longer than six months</i>
Au107	33	<i>Unless there is a formal healthcare plan in place (which is initiated by the patients GP, but is very rare to see) then the only sharing of information is done via reports on updated hearing levels/needs to GP's/ENT's...</i>

Note: The verbatim quotes are labelled according to the participant number (Au, Australian HA audiologist; CIAu, Australian CI audiologists; UK, UK audiologist; GP, General Practitioners) and the quotation number

3.6 Theme 5: HCP support, information provision and care: the patient perspective (Aim 3)

- Patients or audiologists were the first to suggest CIs, not GPs or ENT specialists
- The majority of CI users were happy with the information provided by HCPs and felt well-supported.
- Most participants found that audiologists had been supportive, while some weren't seen as knowledgeable about CIs and several were sales-driven. The lack of patient-clinician continuity was also problematic
- There were mixed reports about experiences with ENT specialists with some being supportive, others not.
- Patients felt GPs prioritised other health conditions and weren't knowledgeable about hearing health
- Most CI users valued attending hearing association functions, for information provision, to meet CI recipients, to make new friendships, and support other CI recipients and candidates

HA and CI users were asked about their experiences with HCPs and the support they received. Many HA and CI users reported that they found **accessing information for decision making difficult** with a hearing loss (Q1). The decisions about having a CI implanted were generally made through **discussions and shared decision making with CI audiologists** (Q2) but several felt that many decisions were made by audiologists alone who had expertise and knowledge (Q3). HA and CI users identified the **key decision points** as becoming aware of and getting their severe hearing loss diagnosed, and having HA fitted stages, while CI users also identified that deciding to have a CI, and getting the implant were the next key decisional points for them.

Most HA and CI users reported either **raising CIs themselves**, or having them introduced by an **audiologist** as a treatment option (Q4) and overall, most CI users felt well supported (Q5) and content with the information they received during their decision-making process (Q6). Several participants saw various audiologists before finding one that was knowledgeable about CIs (Q7), particularly those living in rural areas, a symptom of the subspecialties in **audiology** (Q8). Several HA users commented that their audiologists and ENT specialist hadn't explained whether they would benefit from CIs, nor provided them with information on where to get further advice or an assessment. **Lack of clinician-continuity was also problematic** if new clinicians were unaware of the patient's history and past discussions about treatment (Q9). One CI user felt that **children got more comprehensive hearing health support than adults** (Q10). Most HA users didn't feel knowledgeable about CIs or informed enough to pursue a CI assessment, and several complained that their audiologists had been **HA sales-driven** (Q11). Many participants **sought information from hearing associations**, and one CI user raised CIs with their GP but didn't receive any useful information. Most participants felt that **GPs weren't knowledgeable about hearing health treatments** (Q12), with **other health conditions generally taking priority** (Q13). **Participants' reported experience with ENT specialists as mixed**, with most CI recipients noting positive experiences and support from ENT specialists, who introduced CIs during consultations for other hearing issues (Q14), though several CI users also reported negative experiences (Q15).

Many CI and HA users talked about the benefits of **attending hearing association events and functions for information provision, to meet other CI recipients (Q16), make friendships, feel supported (Q17) and to support other CI recipients and candidates (Q18; Q19) about what kind of questions they should ask their HCPs. Volunteer work and involvement in hearing associations, also enabled participants to keep abreast of information about new hearing loss technology (Q20).**

Table 3.6: HCP support, information provision and care: Verbatim quotations from patients

ID	#	Quote
CIU602	1	Just being deaf does make it difficult to communicate with health specialists... I rarely suffer from communication difficulties now like I used to and heaven knows how I ever communicated with my doctor in the past about important health issues
HA705	2	Being part of the decision process is my responsibility. It's up to me to be informed, to ask the right questions, find out who to trust, and make the final call myself. Nobody can or should do that for me. Do not be intimidated by the medical professional. They do their best but they often they don't know either.
CIU609	3	The audiologist is the expert and the only decisions needing to be made belong with her expertise.
HA705	4	I felt like I'd crossed the threshold with my latest hearing loss, but I've gone from being able to cope okay to being really on the borderline, so I mentioned it.
CIU402	5	They're very, very helpful. All of the people I've had to see, the surgeon, the specialist, the audiologists have been the most sympathetic the most helpful, most understanding.
CIU402	6	I have felt supported by the [CI clinic] hearing professionals throughout this journey and I have complete confidence in their supporting me through this.
CIU607	7	So as far as the audiologist is concerned, most of the audiologists are all right. I find that I have become selective... audiologists that don't know anything about it and bad audiologists and upper laryngologists who won't talk to you because I think they're frightened of it.
CIU610	8	[audiology] Have two separate arms and they have a [HA] arm and they have a [CI] arm and they are very, very specialised. So I think it really depends on the audiologist you go to.
Cicand706	9	Very hard... I see a different person almost every appointment which is quite confusing having to go over everything each time, some of these people are very easy to talk to, some not so easy. I feel to old sometimes to bother, sometimes too frustrated with my hearing disappearing so fast and not getting answers
CIU610	10	I think it is easier for children where the services are much more comprehensive. They go to [audiology clinic] or they go to all of those. Whereas in the adult world there is more open slather and you have got the audiometrists out there
HA703	11	Audiologist just want to sell you a new set of [HAs]
HA707	12	My GP is no good as he doesn't know much himself and has no idea where I need to be referred.
CIU601	13	The GP is really not interested in my hearing. He's more into keeping me alive I suppose
CIU609	14	I had reason to consult an ENT specialist because of severe ongoing vertigo, and it was at that appointment that the Doctor suggested that I would benefit greatly from a [CI]. I had no hesitation and went straight ahead, with much advice beforehand from an allotted Audiologist.
CIU607	15	I was very disappointed with [the ENT specialist] ...he had a window behind him and I couldn't lip read him.
CIU402	16	At [CI hearing association] we heard people talk about their experiences in formal presentations and then over a BBQ we (husband and I) could ask CI recipients various questions – ranging from – will I still be able to wear my expensive sun glasses – through to how is your experience with music now, how do you get on in the workplace etc
CIU609	17	Had I been younger I would have delighted in offering help to other CI recipients in any way I could. I enjoy belonging to [CI clinic] and [hearing association] and participated in all aspects of their functions. I attend [hearing association] meetings and functions whenever I can and am thankful for those contacts and support.
CIU601	18	We just meet every month for a couple of hours and have a yak and they're all people that have got [CIs]. Some of them have trouble and one in particular, he's having trouble and so we just talk it out
HA705	19	So, if people around you, who have the same situation as you, and you can ask their opinion, and that, as we were saying earlier, when you do go to get advice then you know what questions to ask. And you know who to talk too, to trust. So, I think these support groups are really essential.
CIU401	20	My involvement with [CI association] also means that I am able to keep up with change/ in improvements.

Note: The verbatim quotes are labelled according to the participant number (CIU, CI user; HA, [HA] user; Cicand, CI candidate) and the quotation number

3.7 Theme 6: Patient aspirations for the future (Aim 4)

- Better public awareness of the challenges of hearing loss
- Improved hearing support infrastructure like captions and subtitles
- Additional psychosocial support
- Improved access to CIs, and support for people with hearing loss
- Continued support from CI manufacturers, and hearing organisations
- Improvements in technology, to enhance communication
- Involvement in hearing research to keep abreast of latest improvements to support people with a loss

When HA and CI users were asked what their aspirations were for the future, in terms of their hearing health, many CI users hoped for **better public awareness of the challenges of hearing loss** (Q1), **greater accessibility to hearing support infrastructure like captions and subtitles** (Q2), **additional psychosocial support** (Q3), **improved access to CIs, and support for people with a hearing loss** (Q4). One CI candidate commented that they plan to be an advocate for CIs after implantation. Several CI users talked about their hope of **accessing CI accessories** in the future that would enhance their hearing and expressed a desire for **their CI to continue functioning** (Q5). One recipient hoped that their CI would continue to support them as they gradually lost their vision with age (Q6).

Many hoped for **continued support from CI manufacturers** (Q7), and **hearing organisations**, as well as from the **insurance companies who could help them to access CI upgrades** (Q8). One HA user hoped that the cost of hearing devices would be better covered by insurance in the future (Q9). HA users hoped for **improved hearing and better communication with future devices, potentially CIs** (Q10), while CI users hoped for more natural sounding CIs (Q11), and improvements in technology to reduce current hearing challenges (Q12), enabling **access to more entertainment options like going to the theatre, and hearing music** (Q13). Some participants hoped for **stabilised hearing loss or a cure, through developments in stem cell therapy** (Q14), and others wished to continue to **be involved in research to keep abreast of the latest technological improvements** (Q15).

Table 3.7: Patient aspirations for the future: Verbatim quotations from patients

ID	#	Quote
CIU611	1	<i>That people in the everyday world, which includes health professionals, will develop more understanding of hearing loss, and not consider a [HA] or a [CI] as something that restores hearing to normal function!!! That is one of our greatest barriers in life!!</i>
CIU609	2	<i>I believe the public should be made more aware of the difficulties faced by deaf persons and the need to face a person and speak slowly and clearly. Similarly, public address systems could be geared to hearing problems also. Above all, for me, is the need for more captions in cinemas, hospitals and the like.</i>
CIU602	3	<i>I would say the only thing missing at the beginning of my discovery of my hearing loss was emotional support to cope with the hearing loss.</i>
CIU603	4	<i>In the future, I hope that my role will be to continue to help my students get the best possible use out of their CI and/or [HAs] and to live happy and productive futures, secure in the knowledge that although their hearing probably will not return, there is always going to be technical and biomedical advances that will enable them to embrace their hearing loss and not allowing this to be a barrier to any achievements in life.</i>
CIU612	5	<i>I am hoping that both the processor and the array continue to function until i am in the grave. If that happens then i'll be perfectly satisfied as regards my hearing health.</i>
CIU604	6	<i>I have glaucoma (inherited) and I have only 20% sight in my right eye. The glaucoma is also in my left eye, so I will be really needing my [CIs] as I age</i>
CIU403	7	<i>[I hope the CI manufacturer] continues to support what I've got. Obviously, I would think there would be a progression. But if I only had what I have now, that's fine. As long as they don't drop out of the market and I'm left high and dry. But apart from that, everything else is a bonus.</i>
CIU610	8	<i>I am always worried that I won't be able to get an upgrade. I am worried about the health fund eventually turning around and saying no and that means I will have old technology.</i>
HA701	9	<i>Assisted listening devices also need to be part of the health funds</i>
Clcand 801	10	<i>I have two hopes/desires, that I will be able hear better and more clearly (Meniere's & poor speech discrimination) therefore, communicate better in every situation</i>
CIU405	11	<i>That technology will keep getting better and they'll keep improving the program so that it's more natural.</i>
CIU401	12	<i>I'm looking forward to when they invent a processor that cuts out backgrounds sound and you can understand it. In the noisy situation, even the programs where it does cut down backgrounds sound, it also cuts down the volume of your own voice so your own voices sounds really weird. I am really looking forward to the day when they can cut down the background sound and you can still maintain a normal voice.</i>
CIU606	13	<i>That continued research will continue to improve on my ability to hear clearly when with groups of family and friends, the train announcements, films, plays and musicals.</i>
CIU402	14	<i>Everything with a [CI], it's not fixing anything with the problem, it's bypassing it. The whole technology is bypassing the difficulties that you have and my hope is that in the long-term there will be a cure with stem cells or any other means that will fix it. That's what my hopes are for.</i>
CIU611	15	<i>I wish to remain involved both in the short and long-term management and be involved as much as possible in research.</i>

Note: The verbatim quotes are labelled according to the participant number (CIU, CI user; HA, [HA] user; Clcand, CI candidate) and the quotation number

4. Key findings

This qualitative study has identified key barriers and facilitators to CI utilisation rates that influence attitudes and behaviours of patients and HCPs to CI uptake.

While some of the barriers contributing to low utilisation rates, such as **patients' concerns about surgery risks**, cannot be easily addressed, several barriers can be tackled. In particular, those relating to: **a) difficulties patients face accessing or finding appropriate information, and, b) the lack of relevant advice patients are receiving from HCPs**. Our study has clearly identified that HA users feel information is not easily available for them to make an informed decision about ongoing support and care. This was an unexpected finding, considering the authors' a-priori perception that CI-related information is readily available (see Table 4 below). In addition, as shown in Table 4, HCPs are being given targeted training so that they can provide expert professional advice and information to patients, when needed.

To add to this, **many HCPs still feel that they require training about CI implantation and about patient eligibility and referral requirements**, without which they perceive themselves as continuing to lack the confidence to refer patients for CI assessment.

The major barriers identified in Table 4 below, prevent greater CI utilisation. From these, we suggest that **improved dissemination of information, targeting HCPs and patients is critical**. It is anticipated that improved dissemination will increase awareness of CIs, and lead to increased referrals for CI assessment and greater device utilisation (*See 'Study Recommendations' for further detail*).

Our findings are supported by the literature

Several findings from this study, around the barriers preventing CI utilisation, are supported by the literature [7, 20-23], especially around the restrictions that limited HCP knowledge and training places on CI promotion [21, 23]. Cohen *et al* (2005), for example, found poor awareness of, and knowledge about, CI eligibility criteria amongst primary care providers in the United States (the equivalent to GPs) and recommended increased training and outreach by CI specialists. Chundu and Buhagiar (2013) found a similar lack of CI knowledge in a UK study of audiologists [21, 23]. In a retrospective file review and questionnaire with audiologists, Looi *et al* (2017) identified that patient concern about the surgery, potential loss of residual hearing and balance-related complications were barriers to CI utilisation, while they also reported that audiologists do not refer patients if they do not feel ready for a CI. [20] Our findings, that patients are concerned about the risk of surgery and anaesthesia, is echoed in the literature [22], as are the benefits of CI

candidates meeting CI recipients during their decision making, which is published in a Swedish study on a similar topic [7].

However, literature regarding adult barriers and facilitators to CI utilisation is limited. Table 4.0 summarises the main barriers and facilitators identified by this study.

Table 4.0 Summary of the main barriers and facilitators to CI utilisation

Main barriers to CI utilisation	<ul style="list-style-type: none"> The uncertain outcomes of cochlear implantation Fear of surgery, complications and side effects, and risk of losing residual hearing Concern about the having time off work for surgery and rehabilitation The perceived inconvenience of accessing CI rehabilitation Concerns about the cost of the device and maintenance Concerns about cosmetics Misunderstandings around sound quality Having a HCP who isn't supportive or knowledgeable about CIs Concerns about the stigma associated with hearing devices Concerns about the irreversibility of the procedure Not being ready for a CI Not wanting to be reliant on a CI device Denial about hearing loss severity and not following up on referrals Lack of family support Hearing negative stories about CIs Not knowing enough about CIs or who to contact for more information Limited access to services in rural areas, and the challenges associated with travel
Main barriers for HCPs discussing CIs with patients	<ul style="list-style-type: none"> Lack of CI awareness, knowledge and confidence to identify candidates and make referrals for assessment Lack of patient-clinician continuity (ongoing consultation with the same clinician) Concern that discussing CIs repeatedly will lead to patient disengagement or transfer Limited HCP networking with CI centres Limited shared care Lack of coordinated services in rural and remote areas Other health conditions prioritised, and patients not raising hearing needs with GPs
Main facilitators for CI utilisation:	<ul style="list-style-type: none"> Desire for better hearing to improve communication and increase social interaction, and reduced isolation Patients being more informed Believing CIs will improve their quality of hearing Being advised to get implants before losing all residual hearing Becoming more frustrated as hearing loss impacts relationships, work and mental health Ineffective support from HAs Hearing CI recipient testimonials Feeling supported by knowledgeable HCPs and family Feeling prepared to commit to rehabilitation after surgery Fear of going completely deaf
Main facilitators for HCPs discussing CIs with patients	<ul style="list-style-type: none"> HCP CI awareness, knowledge and training Access to CI demonstration models Access to a CI referral sheet Patient-clinician continuity Access to positive CI testimonials Support from other clinicians with knowledge of CIs Feedback from CI teams about patient progress

This Study's Unique Qualities

While several of our study findings are closely aligned to the research literature [7, 20-23], it is worth noting aspects that are unique, as this study:

- 1) Offers extensive detail to clarify nuance in barriers and facilitators to CI utilisation that other studies lack,
- 2) Has successfully utilised multiple patient and HCP cohorts' views, through sampling that has far surpassed the original study requirements. It should be emphasised that this study obtained 143 data capture events through the recruitment of 55 participants, (the original intention was to recruit 28 participants for 32 data capture events),
- 3) Presents data of international interest, from comparative Australian and UK sites that is richly described,
- 4) Presents findings validated through rigorous group work activities, deriving a widely-acknowledged consensus of opinion on study findings, across multiple datasets.
- 5) Identifies, for the first time in this context, a link between face-to-face interviews, telephone interviews, focus groups, demographic data and proforma data through data triangulation using datasets collected across sites, while indicating similar global views, that add impact and veracity to the results.

The International Context

The inclusion of the UK cohort enabled the examination of comparative data across healthcare contexts, and highlighted differences in healthcare system use and its effect on service provision. As there is limited cross-cultural literature regarding hearing loss, and CI utilisation our study's comparative data is invaluable. [24] Most significantly, the collaboration and networking between some UK audiologists and CI specialists, as a result of audiology/CI clinic co-location, and the shared databases audiologists hold with CI clinics, clearly helps UK professionals facilitate CI referrals, while these networks and relationships are less common in Australia.

Furthermore, while all HCPs saw cost as a global barrier to CI utilisation [25] perceptions of this, across the two countries differed. In the UK, audiologists were more aware of the funding structures available to them and knew about government funding regulations and government funding systems. In Australia, audiologists perceived cost as posing an extensive barrier for some patients and but had limited knowledge of government funding structures, which may be a reflection of the complex and variable funding structures across States.

Strengths and Limitations

Limitations of the study include the extended recruitment period that was necessary to derive the study cohorts and lengthy process of recruitment, which also required patients to self-select to participate. This may have impacted on data representation. However, as a result, participants were able and willing to share their experiences in great depth, a clear strength of the study for all cohorts, and participants answered questions fully addressing study aims and research questions. Demographic data was missing from one Australian audiologist.

5. Conclusion

This qualitative study was conducted to define the barriers and facilitators to CI utilisation in adults over the age of 50, with severe or greater sensorineural hearing loss. The results of this study suggest that rates of CI uptake are influenced by a complex set of behavioural and attitudinal factors (and their inter-relationships) across various levels (i.e., patients, HCPs, the system). There are many perceived barriers to CI uptake that persist across patient and HCP groups, despite current initiatives and strategies by HCPs, service providers, and manufacturers to turn this around. These findings will help inform future development of new strategies targeting these population groups, to increase CI utilisation.

Further research is now needed to determine how existing pathways and resources are addressing these perceived barriers and how existing resources are being used in relation to our study recommendations – with the longer-term aim of informing the development and implementation of evidence-based, co-created solutions to improve CI utilisation.

6. Ten Study Recommendations resulting from this study

The results of this study have highlighted several key areas that require further research and development to improve service provision for patients and increase CI utilisation in adults. Ten recommendations are outlined below, along with suggested future research strategies. While several of these strategies are currently being implemented, the study findings detailed in this report suggest barriers to the effective implementation of these strategies exist and that currently, they are ineffectively addressing the needs of patients and HCPs and could be improved. See Table 5.0 for examples of how the ten recommendations align with current initiatives for patient and service support, and our proposed future research to improve implementation of such strategies.

Recommendation 1:

Increase awareness of, and access to, a standardised CI referral tool

Audiologists and GPs indicate that having a standardised CI referral tool would help them identify eligible adults and understand how to make more targeted referrals for CI assessment. Only a few audiologists in the UK and Australia use such tools, but those that do, find them helpful in enabling them to make CI referrals. In combination with increased HCP awareness of CIs, a support resource such as a standardised referral tool could simplify the referral process. This could also streamline the referral pathway and reduce unnecessary steps in the referral chain, such as patients returning to a GP to get an ENT referral, rather than being referred directly to a CI centre.

Next steps: While there are various websites and CI information sheets available (see Table 5.0), many HCPs are unaware of them. Further research is required to determine whether CI referral tools are appropriate and useful in content and format. Effective and broad dissemination of CI referral tools in Australia will be fundamental if they are to be embedded in standard practice for audiologists and GPs (see Table 5.0).

Recommendation 2:

Increase the availability and awareness of CI recipient buddying schemes

CI users were highly positive about the impact of CI testimonials and buddying schemes during CI decision-making. Buddying schemes provide opportunities for candidates to ask recipients questions about their experience and the outcome of implantation, and often help allay fears and concerns. Increasing the availability of such schemes and promoting awareness of existing schemes, before referral for a candidacy assessment, would enhance patient and HCP decision-making, and encourage eligible adults to access CI assessments sooner. Several HCPs emphasised that hearing CI success stories could also help them understand patient treatment pathways, empathise with patients, and provide more useful information when making referrals to CI centres.

Next steps: While CI recipient meetings are common in CI clinical assessment, they do not tend to occur before candidacy assessment. Future research is needed to determine how to increase the promotion of buddying programs to Hearing Associations, HCPs and patients, before CI candidates are referred to CI clinics for assessment (Table 5.0) and to better understand and confirm the benefits of these programs being undertaken prior to CI assessment.

Recommendation 3:

Increase availability/awareness of information through targeted resource dissemination

HA audiologists and GPs clearly lack confidence in their knowledge of CIs, which limits their ability to identify and refer eligible adults for CI assessment. Information about CIs is broadly accessible and widely disseminated but appears to be ineffective for non-CI specialists. Audiologists want more information about CIs to be better-informed and boost confidence, and better access to appropriate professional courses and information sources. Future research is required to determine how to make the information targeting HCPs more appropriate, relevant, and effectual, and what barriers hinder information being effectively utilised and translated to the clinic, to enhance knowledge translation. [26]

Next steps: Websites, pamphlets and newsletters are available, from manufacturers, CI clinics, research groups, and Hearing Associations, and yet this information is not effectively reaching audiologists and GPs. We need to improve dissemination and promotion of information, from trusted sources. Provision of CI demonstration models may also aid CI discussions (Table 5.0).

Recommendation 4:

Advocate for cochlear implant-specific topics in tertiary courses to optimize Continuing Professional Development

Increasing levels of awareness and understanding about CIs amongst HCPs will increase CI assessment referrals ensuring eligible patients are able to access specialist CI assessment services. It is anticipated that improved patient access to CI assessment will contribute to enhanced uptake and utilisation of CIs. There is the need for A) professional development courses that are relevant and appealing for non-CI specialists, B) the inclusion of CI-specific topics during audiology and GP tertiary training courses, and C) stronger collaborations between stakeholders, targeting HCPs underpinned by high-quality evidence from CI referral-focused research.

Next steps: While CI-focused professional development courses exist for both audiologists and GPs, HCPs continue to lack confidence about their CI knowledge. Future research is required to answer the following questions: 1) How can we increase awareness of, and attendance at, existing CI-related training events for non-CI specialists, 2) How can we ensure the hearing-related

content is part of National Education Standards for HCPs and appropriately linked to implant-specific topics, and 3) How can we increase HCP confidence in their knowledge about CIs? (Table 5.0).

Recommendation 5:

Strengthen the community of practice (audiologists, GPs and CI teams) while promoting new networks.

With greater numbers of HA audiologists aware of CIs and their benefits, it is anticipated that discussing CIs with patients will ultimately increase CI referrals. Audiologists, particularly in the UK, who are professionally connected to CI-specialists, value the professional relationships that help facilitate referrals. Developing stronger links between audiologists and GPs will improve information sharing and shared care. [27] Events such as Master Classes, and better contact with CI-specialists could improve familiarity, awareness and understanding of CIs, while stronger connections between HA audiologists, Hearing Associations, and CI clinics, could provide useful contacts and new referral pathways. Promoting new networks, through GP and audiology newsletters and consumer and healthcare professional forums is suggested.

Next steps: Future research will determine how to increase opportunities to develop, strengthen and maintain cross-disciplinary HCP networks (Table 5.0).

Recommendation 6:

Commission further research about referral pathways and eligibility criteria for publication in GP and audiology journals

GPs have identified medical journals as a common and trusted source of information. They suggest increased exposure to CIs through published research would help them to focus on eligibility criteria and referral pathways and would ensure greater awareness of CIs. Targeting HA audiologists with similar research publications would ensure greater CI awareness.

Next steps: Research from the CI and hearing health fields is not reaching intended HA audiology and GP audiences. Future research that is widely published could help to reach HCP audiences, while supporting multi-national priority setting, the promotion of a new CI research agenda and a strong evidence-base for CI referral (Table 5.0).

Recommendation 7:

Monitor individual HA users' current ineligibility for CIs, for future tracking, ongoing update, and assessment

CI assessment processes are perceived as onerous by some patients, while being assessed and found ineligible for CIs may lead to disengagement with the hearing health system. Appropriate referral systems, and good patient support is vital across the whole patient care pathway. HA users

must feel adequately informed if they are to be encouraged to re-engage with the CI referral process at some point in the future. Information that dispels myths, and allays fears may also reduce concerns about surgery. While it is recognised that surgery is regarded as safe and minimally invasive [22, 28, 29], increasing awareness of this would reduce concerns, particularly amongst older candidates.

Next steps: Develop guidance protocols, for monitoring potential CI candidates (Table 5.0).

Recommendation 8:

Increase awareness of CIs amongst adult populations through better information provision

Being fully informed about CIs and other treatment options is an important facilitator for CI decision-making, yet information is lacking for HA users to be able to make informed choices about further assessment. More effective dissemination of information, to reach the target audience of adults aged over 50 years is necessary. Further research is needed that dismantles and explores in-depth the current barriers to information accessibility, examining information accuracy, distribution, relevance to patients, reach and comprehension [30]. This should be undertaken in consultation with CI candidates and recipients while resource use by patients receiving information needs urgent clarification.

Next steps: While CI resources exist, many audiologists and GPs are not accessing them, and we know little about how information is being used by patients. Future research is required to determine the barriers and facilitators to effective dissemination of CI information to patients and HCPs (Table 5.0).

Recommendation 9:

Improve awareness and availability of self-administered online hearing loss tests that adults could access at home, to self-refer

The findings suggest that HCPs are failing to refer patients for CI assessment, even though some patients are proposing CIs to their audiologists. Patients need to be empowered to access the CI candidacy assessment process themselves, to overcome this barrier. By increasing awareness of self-referral, with an appropriate and easily accessible screening tool that informs adults where to get more information and how to make an appointment with a CI clinic, a greater proportion of eligible adults will be able to access a CI assessment, with an anticipated increase in CI utilisation rates.

Next steps: Online self-administered tests already exist, but there is the need to increase awareness and use of these tests. Future research is required to assess whether appropriate patient self-referrals to CI clinics can be increased, with the development and promotion of a tick box-

type hearing loss checklist for patients (with links to self-referral options for CI assessment) (Table 5.0).

Recommendation 10:

Create a partnership between hearing health stakeholders to improve patient care

The development of further collaborative partnerships between hearing healthcare stakeholders will help to strengthen support networks and a community of practice and help inform future research for effective referral pathways for patients. This is an important task given that currently there is little overlap between the subspecialties in audiology (Table 5.0).

The following table outlines the recommendations from this study (*Study recommendations*), with examples of current strategies addressing these issues, in Australia (*Current situation, Australia*) and the UK (*Current situation, UK*), and further research that is required to improve the implementation of these strategies (*Still to be resolved*).

Table 5.0: Study recommendations, current strategies addressing barriers, and future research to improve implementation of these strategies

Recommendations	Current situation (Australia)	Current situation (UK)	Still To be resolved
1. Increase awareness of, and access to, a standardised CI referral tool, for GPs and audiologists to streamline pathways, reduce unnecessary steps in the chain, and improve knowledge of available resources	No standardised referral tool or guide exists. Numerous websites and information sheets are available, providing varying amounts/quality of information, with many HCPs unaware of them <ul style="list-style-type: none"> • SCIC web contact form: What are my hearing options¹ • HEARing CRC is currently developing standard referral tools with Australia's 9 main CI clinics² 	<ul style="list-style-type: none"> • Team-implemented solutions (will vary across teams/regions) • The EAR Foundation information sheet³ • BCIG referral flyer⁴ 	<p>Are the current/developing referral tools appropriate and useful (content and format)?</p> <p>How would HCPs access and use the referral tools in their current practice?</p>
2. Increase the availability and awareness (amongst audiologists and patients) of CI recipient buddying schemes	1:1 meeting with CI recipients is common in CI clinic assessment (Australia and UK) but rarely happens before candidacy assessment <ul style="list-style-type: none"> • Cochlear awareness network⁵ • Associations such as CICADA⁷ 	<ul style="list-style-type: none"> • Cochlear Volunteer program⁶ • National CI user association⁸ • Regional support groups 	How can we increase promotion of buddying programs to associations, HCPs and patients, for access before CI candidates are referred to CI clinics for assessment?

Recommendations	Current situation (Australia)	Current situation (UK)	Still To be resolved
<p>3. Increase availability and awareness of information packages and online platforms for patients and professionals through regular dissemination of resources: for ‘good news’ stories about implantation, dispelling myths and answering questions</p>	<p>Various websites, pamphlets and newsletters are available, from Manufacturers’, CI clinics’, research groups’, and associations’ websites^{9,10,11} showcasing information, stories, and addressing myths (in both Australia and the UK)</p>		<p>How can we increase HCPs’ awareness of CIs to enhance discussions with patients? Can we increase promotion of this information to patients via trusted sources? Can we offer demonstration models to aid CI discussions?</p>
<p>4. Advocate for cochlear implant-specific topics to be included in tertiary courses for audiologists, to increase knowledge and awareness of CIs amongst GPs and audiologists, target GP CPD courses, and HA audiologists’ CPD courses</p>	<ul style="list-style-type: none"> • Audiology Australia conferences and CPD activities often address CI topics • Mention of CI-focused training-fatigue by some HA audiologists • AHH GP education seminar¹² • Audiology and Medical training following National Standards regarding tertiary course content 	<ul style="list-style-type: none"> • BSA and BCIG and other groups’ conferences and CPD activities often address CI topics • Audiology training (undergraduate/po stgraduate levels) includes content on cochlear implants (including referral criteria/pathways) 	<p>How can we increase awareness in attending existing CI-related training events for non-CI specialists?</p> <p>What CI and general hearing-related content is part of National Education Standards for HCP? Is this appropriate and relevant?</p>
<p>5. Strengthen the community of practice between HCPs offering events (Master Classes) for those who infrequently deal with the CI eligible adult cohort. Disseminate the promotion of new networks through HCP newsletters and consumer and HCP forums</p>	<ul style="list-style-type: none"> • Audiology Australia Workshop in May, to discuss CI referral pathway-collaboration with HEARing CRC • SACIC: consultant CI audiologist visiting HA clinics for assessments • CI clinicians meeting with HA clinics to discuss referrals 	<ul style="list-style-type: none"> • BSA and BCIG co-hosting upcoming conference • HEI led Master Classes (e.g., UCL Ear Institute) • Local initiatives by the individual CI centres to provide training and clinical forums for non-CI hearing health professionals 	<p>How can we increase opportunities to develop, strengthen and maintain cross-disciplinary HCP network?</p>
<p>6. Commission further academic research about CIs, CI referral pathways, and eligibility criteria for publication in GP and audiology journals (generalist), peer reviewed academic publications, and conference presentations</p>	<p>Multiple publications and presentations related to CIs exist globally, focusing on criteria and innovation, rather than effective referral pathways</p> <ul style="list-style-type: none"> • Majority of guidance based on clinical agreements <p>Current initiatives:</p> <ul style="list-style-type: none"> • HEARing CRC systematic reviews about evidence/guidelines - with CI clinics • Cochlear Standard of Care project • HEARRING group publishing guidelines and 	<ul style="list-style-type: none"> • Current review of TA166 (NICE) • UK BCIG candidacy guideline project²¹ 	<p>Conduct a multi-national priority-setting exercise to develop the research agenda for CI, to provide a strong evidence-base to the clinical recommendations.</p>

Recommendations	Current situation (Australia)	Current situation (UK)	Still To be resolved
	quality of care protocols ¹³		
7. Monitor individual HA users who are not currently eligible, or have refused CIs in the past, but have shown an interest in CIs, for future tracking, ongoing update and assessment	<ul style="list-style-type: none"> Dependent on protocols of referring clinics, or clinicians 	<ul style="list-style-type: none"> Dependent on protocols of referring clinics, or clinicians 	Development of guidance/protocols for monitoring of borderline patients
8. Increase awareness of the benefits of CIs amongst adults through information provision and effective dissemination (materials developed in consultation with adult CI recipients)	<p>While CI resources exist, many audiologists/ GPs do not access them, such as:</p> <ul style="list-style-type: none"> Online videos of testimonials, SCIC¹⁴ Recipient stories, Cochlear¹⁵ Manufacturer brochures Hearing association brochures 	<ul style="list-style-type: none"> BCIG awareness campaign (GP flyers) Bending the Spend¹⁹ (BSA) Manufacturer-led awareness programmes²⁰ 	Determine the barriers to effective dissemination of CI information to patients and HCPs
9. Improve awareness and availability of self-administered online hearing loss tests that adults can access at home, and from which they can self-refer for assessment	<p>Online self-administered tests already exist, but there is the need to increase awareness and use of tests:</p> <ul style="list-style-type: none"> Online hearing test, Cochlear¹⁷ National Acoustic Laboratories¹⁸ 		Could appropriate patient self-referrals to CI clinics be increased with promotion of a tick box-type hearing loss checklist for patients (with links to self-referral options for CI pre-candidacy assessment)?
10. Create a partnership between hearing health stakeholders, including HA audiologists and GPs.		There is little crossover between CI/HA audiology professional groups and other HCPs (Australia and UK).	Could Cochlear help foster this type of network?

Table References

- ¹<http://www.scic.org.au/useful-information/about-cochlear-implants/>
- ²<https://www.hearingcrc.org/xr3-1/xr3-1-1-determining-candidacy-for-different-types-of-hearing-devices/>
- ³<http://www.earfoundation.org.uk/hearing-technologies/cochlear-implants/cochlear-implant-information-sheet>
- ⁴<http://www.bcig.org.uk/referring-for-a-ci/>
- ⁵<https://www.cochlear.com/au/home/connect/community-and-networks/cochlear-awareness-network>
- ⁶<https://www.cochlear.com/uk/home/connect/volunteer-advocates;>
- ⁷<http://www.cicada.org.au>
- ⁸<https://www.nciua.org.uk/your-implant/user-experiences/>
- ⁹<https://www.cochlear.com/au/home/understand/i-have-hl>
- ¹⁰<https://www.cochlear.com/au/home/connect/personal-stories>
- ¹¹<https://hearprint.com/>
- ¹²<http://hearinghub.edu.au/about-us/news/hearing-healthcare-gp-education-seminar/>
- ¹³<http://www.hearing.com>
- ¹⁴<http://www.scic.org.au/useful-information/useful-links-and-videos/>
- ¹⁵<https://www.cochlear.com/au/home/discover/cochlear-implants/hearing-stories-from-cochlear-implant-recipients>
- ¹⁶<https://www.cochlear.com/us/home/stories-and-community/watch-recipient-videos>
- ¹⁷<https://www.cochlear.com/au/online-hearing-quiz>
- ¹⁸<https://knowyournoise.nal.gov.au/hearing-test>
- ¹⁹<http://www.thebsa.org.uk/bending-the-spend-better-ways-of-expanding-access-to-hearing-technology/>
- ²⁰<http://www.thebsa.org.uk/towards-connected-future-bsa-baa-bshaa-event-feedback/>
- ²¹<http://www.bcig.org.uk/candidacy-action/>

7. Future Research

Further research is needed to determine how existing initiatives (designed to encourage CI uptake) address these barriers. Specifically, further research to address the provision and dissemination of information on CIs to patients and their HCPs is recommended.

Study aim:

Drawing on the findings from our current study, we want to examine the relationship between our identified barriers and facilitators, and the current resource provision, including processes already in place to ensure CI facilitation and uptake.

Study design:

1. Mixed-methods study using interviews, focus groups, questionnaires and stakeholder (consumer and HCP) forums to explore how the current resources available are being utilised and to determine the barriers and facilitators to their uptake and ways to improve uptake.

Participants:

1. HCPs
2. HA users
3. CI recipients
4. Patient representatives
5. Patient advocates

Proposed budget:

- \$192,000 (incl. wages + on costs, event venue hire, participant stipends and refreshments, advertisement, interview transcription, postage, and dissemination of outputs (conferences and peer reviewed publications)).

Proposed time frame:

- 12 months

Table 6.0: Proposed future research outline

Problem	Inputs	Activities	Outputs	Outcomes
<ul style="list-style-type: none"> Perceived barriers to CI uptake persist despite resource provision to address under utilisation 	<ul style="list-style-type: none"> HCPs Patients (including participants from current study) Patient advocates Funding and other resources 	<ul style="list-style-type: none"> Interviews and focus groups Surveys Stakeholder workshops 	<ul style="list-style-type: none"> Identification of barriers and facilitators to the implementation of current study recommendations Co-creation of evidence-informed, measurable solutions to address barriers and support the development and implementation of resources, standards, and pathways to increase CI uptake 	<ul style="list-style-type: none"> Reduction of barriers through implementation of evidence-informed, co-created solutions More accessible care (i.e., increased CI uptake) More empowered and confident patients More empowered and confident clinicians

8. References

1. Vos, T., et al., *Global, regional, and national incidence, prevalence, and years lived with disability for 301 acute and chronic diseases and injuries in 188 countries, 1990-2013: a systematic analysis for the Global Burden of Disease Study 2013*. The Lancet, 2015. **386**(9995): p. 743.
2. Sindhusake, D., et al., *Validation of self-reported hearing loss. The Blue Mountains hearing study*. International journal of epidemiology, 2001. **30**(6): p. 1371-1378.
3. Stevens, G., et al., *Global and regional hearing impairment prevalence: an analysis of 42 studies in 29 countries*. The European Journal of Public Health, 2011. **23**(1): p. 146-152.
4. United Nations, D.o.E.a.S.A., Population Division, *World Population Prospects: The 2017 Revision, Key Findings and Advance Tables. Working Paper No. ESA/P/WP/248*. 2017.
5. Access Economics, *The economic impact and cost of hearing loss in Australia*. A report by Access Economics P/L, Canberra, 2006.
6. Contrera, K.J., et al., *Quality of life after intervention with a cochlear implant or hearing aid*. The Laryngoscope, 2016.
7. Mäki-Torkko, E.M., et al., *From isolation and dependence to autonomy—expectations before and experiences after cochlear implantation in adult cochlear implant users and their significant others*. Disability and rehabilitation, 2015. **37**(6): p. 541-547.
8. Damen, G.W., et al., *Cochlear implantation and quality of life in postlingually deaf adults: long-term follow-up*. JAMA Otolaryngology-Head and Neck Surgery, 2007. **136**(4): p. 597-604.
9. Gaylor, J.M., et al., *Cochlear implantation in adults: a systematic review and meta-analysis*. JAMA Otolaryngology–Head & Neck Surgery, 2013. **139**(3): p. 265-272.
10. Sorkin, D.L. and C.A. Buchman, *Cochlear implant access in six developed countries*. Otology & Neurotology, 2016. **37**(2): p. e161-e164.
11. Leigh, J.R., et al., *Evidence-based guidelines for recommending cochlear implantation for postlingually deafened adults*. International journal of audiology, 2016. **55**(sup2): p. S3-S8.
12. Cochlear Ltd, *Funding options for Cochlear Implants in Australia*, in https://cicadaqld.com.au/wp-content/uploads/2017/02/Funding_Options_for_Cochlear_Implants_Australia_Final_LR.pdf. 2017.
13. Foteff, C., et al., *Cost–Utility Analysis of Cochlear Implantation in Australian Adults*. Otology & Neurotology, 2016. **37**(5): p. 454-461.
14. Bond, M., et al., *The effectiveness and cost-effectiveness of cochlear implants for severe to profound deafness in children and adults: a systematic review and economic model*. HEALTH TECHNOLOGY ASSESSMENT, 2009.
15. National Institute for Health Clinical Excellence, *Cochlear Implants for Children and Adults with Severe to Profound Deafness*. 2009: National Institute for Health and Clinical Excellence.
16. British Cochlear Implant Group. *How do I get one?* 2017 [cited 2017 20 Dec 2017]; Available from: <http://www.bciq.org.uk/assessed/get-one/>.
17. QSR International Pty Ltd, *NVivo 11 qualitative data analysis software, Version 11*. 2015.
18. Jones, L. and N. Mays, *Early experiences of any qualified provider*. British Journal of Healthcare Management, 2013. **19**(5): p. 217-224.
19. National Health Service. *Referral to treatment; resources*. 2018; Available from: <https://www.england.nhs.uk/resources/rtt/>.

20. Looi, V., C. Bluett, and I. Boisvert, *Referral rates of postlingually deafened adult hearing aid users for a cochlear implant candidacy assessment*. International Journal of Audiology, 2017: p. 1-7.
21. Cohen, S.M., R.F. Labadie, and D.S. Haynes, *Primary care approach to hearing loss: the hidden disability*. Ear, nose & throat journal, 2005. **84**(1): p. 26.
22. Coelho, D.H., et al., *Cochlear implantation is associated with minimal anesthetic risk in the elderly*. The Laryngoscope, 2009. **119**(2): p. 355-358.
23. Chundu, S. and R. Buhagiar, *Audiologists' knowledge of cochlear implants and their related referrals to the cochlear implant centre: Pilot study findings from UK*. Cochlear implants international, 2013. **14**(4): p. 213-224.
24. Zhao, F., et al., *Exploring the influence of culture on hearing help-seeking and hearing-aid uptake*. International journal of audiology, 2015. **54**(7): p. 435-443.
25. Zeng, F.-G., *Cochlear implants: Why don't more people use them?* The Hearing Journal, 2007. **60**(3): p. 48-49.
26. Rychetnik, L., et al., *Translating research for evidence-based public health: key concepts and future directions*. J Epidemiol Community Health, 2012: p. jech-2011-200038.
27. Cunningham, F.C., et al., *Health professional networks as a vector for improving healthcare quality and safety: a systematic review*. BMJ Qual Saf, 2012. **21**(3): p. 239-249.
28. Hamerschmidt, R., et al., *Cochlear implant surgery with local anesthesia and sedation: comparison with general anesthesia*. Otology & Neurotology, 2013. **34**(1): p. 75-78.
29. Labadie, R.F., et al., *Clinical validation of percutaneous cochlear implant surgery: initial report*. The Laryngoscope, 2008. **118**(6): p. 1031-1039.
30. Green, L.W., et al., *Diffusion theory and knowledge dissemination, utilization, and integration in public health*. Annual review of public health, 2009. **30**.