

Barriers and Facilitators to Cochlear Implant Uptake in Australia and the United Kingdom

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Objectives: Hearing loss (HL) affects a significant proportion of adults aged >50 years by impairing communication and social connectedness and, due to its high prevalence, is a growing global concern. Cochlear implants (CIs) are effective devices for many people with severe or greater sensorineural HL who experience limited benefits from hearing aids. Despite this, uptake rates globally are low among adults. This multimethod, multicountry qualitative study aimed to investigate the barriers and facilitators to CI uptake among adults aged ≥50 years.

Design: Adult CI and hearing aid users with postlingual severe or greater sensorineural HL, general practitioners, and audiologists were recruited in Australia using purposive sampling, and a comparative sample of audiologists was recruited in England and Wales in the United Kingdom. Participants were interviewed individually, or in a focus group, completed a demographic questionnaire and a qualitative survey. Data were analyzed using thematic analysis.

Results: A total of 143 data capture events were collected from 55 participants. The main barriers to CI uptake related to patients' concerns about surgery and loss of residual hearing. Limited knowledge of CIs, eligibility criteria, and referral processes acted as barriers to CIs assessment referrals by healthcare professionals. Facilitators for CI uptake included patients' desire for improved communication and social engagement, and increased healthcare professional knowledge and awareness of CIs.

Conclusions: There are numerous complex barriers and facilitators to CI uptake. Knowledge of these can inform the development of targeted strategies to increase CI referral and surgery for potential beneficiaries.

Key words: Adult, Barrier, Cochlear implant, Facilitator, Hearing loss, Qualitative research, Sensorineural.

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INTRODUCTION

Hearing loss (HL) contributes significantly to the global burden of disease (Stevens et al. 2013; Vos et al. 2015), and with an aging population the prevalence of HL is projected to

increase significantly in the future (United Nations Department of Economic and Social Affairs Population Division 2017). Globally, 1.2% of males and 1.0% of females aged 15 years and older are estimated to have “severe or greater” HL (≥65-dB HL, 4-frequency average) (Stevens et al. 2011). In Australia, the number of adults with severe or greater HL is projected to reach 573,000 by 2020 (Access Economics 2006; Australian Bureau of Statistics 2018).

Across the lifespan, cochlear implantation is a cost-effective intervention (UK Cochlear Implant Study Group 2004b; Bond et al. 2009) which provides access to sound for many people with severe or greater sensorineural HL (SNHL), who receive limited benefits from hearing aids (HAs) (Gates & Mills 2005). For adults with this magnitude of HL, when compared with HAs, cochlear implants (CIs) are capable of offering improved sound and speech perception (Gifford et al. 2010; Gaylor et al. 2013) with positive consequences for recipients' quality of life, including improved wellbeing, increased participation in social events, and reduced social isolation (Damen et al. 2007; Gaylor et al. 2013; Mäki-Torkko et al. 2015; Contrera et al. 2016). However, postimplantation outcomes such as ability to understand speech, is variable for individual CI users (Green et al. 2007).

Despite the reported success of CIs (Gaylor et al. 2013; Aimoni et al. 2016), they remain underutilized by adults globally (Sorkin & Buchman 2016). For example, it is estimated that less than 10% of adults with severe or greater HL utilize this technology in Australia (Access Economics 2006), approximately 8% in the United States (Holder et al. 2018), and less than 5% in the United Kingdom (Raine 2013). There is also a large difference in CI uptake, the receipt of a surgically implanted CI device, between Western Europe (200 CI implantees per 1,000,000 people) and Eastern Europe (50 to 75 CI implantees per 1,000,000 people) (De Raeve & van Hardeveld 2014).

There is limited research that explores potential reasons for the low global CI uptake rate, among adults. Studies by Cohen et al. (2005) and Chundu and Buhagiar (2013) suggest that Healthcare Professional (HCP)-specific barriers to uptake include poor knowledge and awareness of CIs among HA audiologists and primary healthcare providers, while Looi et al. (2017) indicate that patient barriers include concerns about surgery, loss of residual hearing, and complications such as balance issues, which may also influence CI uptake rates. To fully understand the barriers to CI uptake, HCP barriers and patient barriers both must be investigated.

In comparison to CIs, considerable research has been conducted aiming to understand the barriers to uptake of HAs for adults which is also relatively low (Hartley et al. 2010; Bainbridge & Ramachandran 2014; Dawes et al. 2014; Moon et al.

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2015). Recent research has found that the key barriers to adults accessing general hearing health services include the cost of services and devices (Kochkin 2007), financial limitations (Laplante-Lévesque et al. 2010; Bainbridge & Ramachandran 2014), stigma of hearing devices (van den Brink et al. 1996; Wallhagen 2010), competing comorbidities (Cox et al. 2005; Öberg et al. 2012), the inconvenience of accessing services (Laplante-Lévesque et al. 2010), and self-minimization or denial of HL severity (Öberg et al. 2012). Severity of HL (Popelka et al. 1998; Chang et al. 2009), patient perceived benefits of HAs (Meyer et al. 2014), self-perceptions of HL (Chang et al. 2009), and perceived self-efficacy (Meyer et al. 2014) have been demonstrated as key motivators to seek hearing healthcare (Jenstad & Moon 2011; Barnett et al. 2017). Poost-Foroosh et al. (2011) identified factors relating to client-clinician interactions which can also influence HA adoption, including client-centered interactions and client empowerment, both which were positively associated with HA adoption. It is possible that many of these HA factors overlap with CI uptake barriers and facilitators despite differences in cost and complexity of the devices, as well as the surgical requirement of a CI. These studies have been valuable in developing an understanding of the barriers and facilitators to the uptake of traditional acoustic hearing devices. The next step is to build upon this work and explore, through in-depth accounts from multiple perspectives, those barriers and facilitators specific to the uptake of CIs.

This study aimed to investigate the perceived barriers and facilitators to CI uptake in adults with severe or greater SNHL (≥ 50 years), examining this from the perspective of:

- a. patients (CI users, HA users), and
- b. HCPs [including general practitioners (GPs) and audiologists, from three high-income countries—Australia, and England and Wales (the United Kingdom)].

The perspectives of patients (HA and CI users), as well as GPs and audiologists in Australia and audiologists in the United Kingdom have been compared to demonstrate how the perceived barriers and facilitators to CI uptake differ between patient groups, HCP groups and across different settings.

The accessibility of CIs is similar across the Australian and United Kingdom settings. In Australia, eligible candidates have access to publicly funded bilateral HAs and unilateral CIs through federal- and state-based funding programs, as well Department of Veterans' Affairs funding. This funding for CIs is restricted, however, limiting the number of CIs fitted each year and subsequently resulting in waiting lists (Cochlear Ltd 2017). Reimbursement of the first and second ear implant can be available through private health insurance, as can HAs (Bond et al. 2009; Foteff et al. 2016). Similarly, in the United Kingdom, HAs can be funded through the public National Health Service (NHS), or privately through private health insurance or self-funding. Eligible adults who meet the National Institute of Health and Care Excellence (NICE) (2019) criteria can obtain a unilateral CI through public NHS funding, private health insurance, or self-funding (British Cochlear Implant Group 2017; NICE 2019).

MATERIALS AND METHODS

Design

This multimethod, multisite, international, qualitative study was conducted by a research team comprising health

services researchers, audiologists, hearing health researchers and a CI center speech and language therapist, in Australia and the United Kingdom between June 2017 and April 2018. See the published study protocol for more detail (Rapport et al. 2018a). Following ethical approval from the lead organization's Human Research Ethics Committee (HREC: 5201700539), patients (CI users and HA users, including CI candidates), and HCPs (GPs and audiologists) were recruited in Australia. Audiologists in the United Kingdom provided a comparator HCP sample, to enable a richer understanding of barriers and facilitators to CI uptake, and to corroborate findings from the Australian cohort.

Participant Recruitment

Purposive timeframe sampling was used to recruit participants. The goal of purposive timeframe sampling is to recruit participants with specific characteristics over a predefined time period to ensure eligible individuals with those characteristics have an equal chance of being recruited into the study (Bowling 2002; Tongco 2007). In this study, recruitment took place over a 6-month period. Additional snowball sampling was also planned (Sadler et al. 2010) to support the recruitment of 28 participants or more. Promotional flyers were distributed to hearing associations, audiology clinics, and GP clinics, and people were asked to contact the research team to express an interest in participating.

Participant Inclusion Criteria

Patient participants, who were self-reported CI users, HA users, or CI candidates (HA users who had begun the CI assessment process), were enrolled in the study if they met the following inclusion criteria:

1. 50 years of age or older;
2. severe or greater postlingual SNHL; and
3. self-identified as being able and willing to participate in a focus group or an interview, and to complete a demographic questionnaire and survey, in English.

In the HCP cohort, GPs and audiologists were included if they:

1. consulted with the target patient populations; and
2. were willing to take part in a focus group or an interview and to complete a demographic questionnaire and a survey.

All participants provided written informed consent before data collection began and were advised that all data collected would be deidentified and confidential.

Setting

In Australia, focus groups were conducted in the lead Higher Education organization's offices and in audiology clinics, with a facilitator (M.R.B.), and an observer taking notes about engagement (I.B. during the CI user focus group, and a research assistant during the Australian audiologist focus group). All other face-to-face data collection, in the form of semistructured interviews, took place in GP offices. In the United Kingdom, focus groups occurred in audiology clinics and in NHS hospital meeting rooms, with a facilitator (S.H.). In both countries, data collection was face to face, over the phone, via video-conferencing, or via email.

Data Collection

Stage 1 • All participants took part in either a focus group or an individual interview depending on individual choice and accessibility to a focus group venue. Data collection was guided by a predesigned, semistructured interview schedule, individualized for each cohort (see Appendix A in Supplemental Digital Content 1, <http://links.lww.com/EANDH/A552>). Questions were given to participants beforehand. The same questions were used in Australia and the United Kingdom for data collection, to ensure consistency. To support the communication needs of participants with HL, the focus group with CI users utilized real-time captioning by a remote-stenographer, along with printed interview questions (Balch & Mertens 1999). CI and HA users who were interviewed were provided with written questions before the interview, and offered the choice of participating in the interview over the phone, teleconference, email, or face to face (if feasible). Focus groups and interviews were audio recorded. Focus groups ran for 90 min, while individual interviews ran from between 30 and 60 min. Following participation, participants completed a demographic questionnaire, individualized for each cohort (See Appendix B in Supplemental Digital Content 2, <http://links.lww.com/EANDH/A552>).

Stage 2 • After Stage 1 data had been transcribed and coded, participants completed a qualitative proforma survey (open-ended, brief question format) comprising six open-ended questions to clarify preliminary data findings from Stage 1. The proformas were individualized for each cohort (See Appendix C in Supplemental Digital Content 3, <http://links.lww.com/EANDH/A552>). Participants returned the demographic and proforma surveys by post or via email. Recruitment and data collection continued iteratively during the recruitment timeframe. Data were analyzed as they were collected, to ensure data saturation and inform the next stage. Data collection was conducted by researchers in Australia (M.B.) and the United Kingdom (S.H.).

Data Analysis

Focus group and interview recordings were transcribed verbatim, and email interview transcripts were collated. These datasets (HCPs and patients) were analyzed iteratively, themed initially, with themes refined as more data were accessed. All anonymized transcripts (stage one) and proforma data (stage two) were then uploaded into NVivo (version 11) (QSR International Pty Ltd 2015), and a fuller thematic analysis was undertaken based on the initial thematic frameworks (Denzin & Lincoln 2011). This enabled the development of full coding frameworks for HCPs and patient groups, and the categorization of data into major and minor themes and categories (Joffe 2012). M.R.B. coded the transcripts and engaged in consensus-building team discussions with other study team members. This led to detailed discussions about: (a) data saturation, (b) Australian and UK data comparisons, (c) emerging themes, (d) triangulation of survey, interview, and focus group data, and (e) agreement on final themes and their concomitant categories. Teamwork interactions at the analysis stage were designed to promote rigorous findings, and have been noted as leading to greater data trustworthiness (clear, dependable reporting of data findings) than can be achieved by individual researchers working alone (Rapport et al. 2018c), enabling the comparison of data and the corroboration and triangulation of findings (Denzin 2012). Clinical and patient perspectives were compared to corroborate findings from different sources, perspectives, and settings.

RESULTS

Sample

One hundred forty-three separate data capture events (interviews/focus groups/demographic surveys/proformas) were undertaken with 55 study participants across Australian and UK sites, including: 12 pilot study participants and 43 principal study participants. The pilot study involved three face-to-face focus groups; one with five CI users, one with three HA Audiologists in Australia, and one with two HA audiologists in the United Kingdom, as well as two pilot interviews with GPs in Australia (one face-to-face and one over the phone). The pilot-study tested the acceptability, timeliness, and comprehensiveness of the focus group/interview schedules and ensured that data capture methods could address the study aims. As no changes were made to the interview and survey questions as a result of the pilot focus groups and interviews, the pilot data were included in the main analysis. The main study involved; telephone-based interviews with seven audiologists (six HA audiologists, and one CI audiologists), five GPs, four CI users, and four HA users (including one CI candidate who had begun CI assessment), and one interview via teleconference with one CI user; as well as email-based interviews (with up to two emails exchanges to clarify meaning of responses) with one CI audiologist, four HA users, one CI candidate, and seven CI users in Australia. In the United Kingdom, one pilot focus group was conducted with two HA audiologists, followed by a focus group with five HA audiologists, another focus group with two HA audiologists, and two face-to-face interviews with two HA audiologists. In the United Kingdom, seven audiologists were based in England, and four were based in Wales. The 143 separate data capture events included five focus groups ($n = 17$), 38 individual interviews ($n = 38$), 54 completed and returned demographic questionnaires and 46 completed and returned qualitative proforma surveys (10 from 17 CI users, eight from nine HA users, five from seven GPs, five from 11 Australian audiologists, seven from 11 UK audiologists) (Table 1) (Rapport et al. 2018a).

Barriers and Facilitators to CI Uptake • Participants from the patient and HCP cohorts addressed what they perceived to be the main barriers and facilitators to CI uptake, with CI users reflecting on their experiences prior to CI implantation and post implantation, and HA users discussing current concerns and motivating factors to future CI implantation. HCPs provided their views on the barriers and facilitators for patients, as well as the factors that hindered or supported them in making an appropriate and timely CI assessment referral (Table 2). Barriers and facilitators will be presented according to patient factors (HA and CI users), HCP (GP and audiologist) perceived patient factors, and factors that influence HCP practice.

Barriers

Participants were asked to identify barriers that they thought impeded CI uptake, from their own experience (CI users), or those perceived to have been barriers to past or future CI uptake (HA users). HCPs (GPs, Australian audiologists, and UK audiologists) were asked to identify barriers that they thought impeded patient CI uptake, as well as the barriers that limited them from supporting CI uptake. The main barriers to CI uptake, reported by patient and HCP groups, concentrated on the key factors: (1) fears and concerns; (2) lack of support and

TABLE 1. Demographic data from participant cohorts

	CI users (n = 17)	HA users (n = 9)	General practitioners (n = 7)	Audiologists* (n = 10)	Audiologists UK (n = 11)
Age					
Less than 30 years (HCPs only)	na	na	1	0	1
30–49 years (HCPs only)	na	na	1	8	9
50–64 years	6	4	4	2	1
65–74 years	3	4	0	0	0
75 years or older	8	1	0	0	0
Over 65 years (HCPs only)	na	na	1	0	0
Gender					
Male	6	3	3	2	2
Female	11	6	4	8	9
Had private health insurance	12	4	na	na	na
State of residence (patients)/workplace (HCPs)					
ACT	0	2	0	0	na
NSW	8	4	6	9	na
QLD	8	3	0	1	na
WA	1	0	0	0	na
NT	0	0	1	0	na
Urban/Rural location of residence (patients)/workplace (HCPs)					
Metropolitan	14	8	5	5	3
Regional/rural	3	1	1	1	2
Remote areas	0	0	1	0	0
Both metropolitan and rural areas	na	na	0	2	6
Metropolitan, rural and remote areas	na	na	0	2	0
Number of comorbidities					
None	3	1	na	na	na
One or two	12	5	na	na	na
Three or more	2	3	na	na	na

*Demographic data missing from one audiologist in Australia.

CI, cochlear implants; HA, hearing aid; HCP, healthcare professional; HL, hearing loss.

knowledge; (3) practical inconvenience; (4) social barriers; and (5) system and organizational barriers. These categories are discussed in turn, with representative quotations. Participant identifiers are indicated by a group code and number. There was extensive overlap in the barriers reported by CI and HA users, and by the HCP groups. When barriers were only reported by one or two groups, this is highlighted.

Fears and Concerns • The Patient Perspective • Multiple fears surrounded cochlear implantation. HA and CI users shared their fears of the CI surgery failing, including the possibility of medical complications, potential side effects of surgery, and concerns about the potential loss of residual hearing as a result of CI surgery. HA and CI users also expressed concerns about the uncertainty of outcomes of surgery in relation to CI sound quality, and improvements in hearing. Several CI users reflected that they had felt concerned about the effect of a CI on how they would hear music, before they were implanted.

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. (CI user 1)

HA users expressed concern about the irreversibility of a CI, in comparison to HAs, which can be trialed and then chosen not to pursue.

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. (HA user 5)

Not being mentally ready for a CI was another barrier to CI uptake, identified by HA users, as well as concern about being reliant on a CI device for hearing.

I don't like the idea that once I go down the [CI] path that I'm completely reliant on them to hear. (HA user 703)

The HCP Perspective • All HCP groups reported that they perceived their patients to be fearful about CI surgery, complications, and losing their residual hearing. Audiologists in Australia and the United Kingdom perceived their patients to be concerned about the irreversibility of the CI procedure, and the uncertainty of outcomes of a CI, and suggested that their patients were concerned about CI surgery side effects such as the potential for vertigo or other balance issues as well as acclimatization issues, following surgery.

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 (UK Audiologist 1)

TABLE 2. Main identified barriers and facilitators to CI uptake [adapted from (Rapport et al., 2018c)]

	Main barriers to CI uptake	Main facilitators for CI uptake
Patients	<p><i>Fear</i></p> <ul style="list-style-type: none"> • Fear of surgery, complications, and side effects • Fear of losing residual hearing, vertigo, and other balance issues • The uncertain outcomes of cochlear implantation • Concerns about CI sound quality • Not being ready for a CI • Concerns about the irreversibility of the procedure • Concerns about the cost of the device and maintenance • Concerns about how they will hear music with a CI <p><i>Lack of support and knowledge</i></p> <ul style="list-style-type: none"> • Having a HCP who is not supportive or knowledgeable about CIs • Not knowing enough about CIs or who to contact for more information • Denial about HL severity and not following up on referrals • Perception that CIs are only available for children • Lack of family support <p><i>Practical inconvenience</i></p> <ul style="list-style-type: none"> • Concern about the having time off work for surgery and rehabilitation • The perceived inconvenience of accessing CI rehabilitation • Dislike of hearing tests • Poor history of HA use • Not wanting to be reliant on a CI device <p><i>Social barriers</i></p> <ul style="list-style-type: none"> • Hearing negative stories about CIs • Concerns about cosmetics • Concern about social stigma of CIs <p><i>System and organizational barriers</i></p> <ul style="list-style-type: none"> • Limited access to services in rural areas, and the challenges associated with travel • Negative experience being assessed for a CI in the past • Waiting list can be off-putting 	<p><i>Social motivators</i></p> <ul style="list-style-type: none"> • Desire for better hearing to improve communication • Desire for increased social interaction • Desire for reduced isolation • Hearing CI recipient testimonials <p><i>Knowledge, confidence and support</i></p> <ul style="list-style-type: none"> • Feeling supported by knowledgeable HCPs and family • Patients being fully informed about CIs • Believing CIs will improve the quality of hearing • Feeling prepared to commit to rehabilitation after surgery <p><i>Frustration related to the HL and a desire to improve wellbeing</i></p> <ul style="list-style-type: none"> • Ineffective support from HAs, HA discomfort, and increased requirement for listening effort • Becoming more frustrated as HL impacts relationships and mental health • Fear of going completely deaf • Being advised to get implants before losing all residual hearing <p><i>Practical and system factors</i></p> <ul style="list-style-type: none"> • Becoming more frustrated as HL impacts work • Patient-clinician continuity to build relationship and trust • High cost of HAs • Seeing a new clinician who is more knowledgeable about CIs than previous clinician
HCPS	<p><i>Lack of support and knowledge</i></p> <ul style="list-style-type: none"> • Lack of CI awareness, knowledge, and confidence to identify candidates and make referrals for assessment • Limited HCP networking with CI centers • Perceived limited access to information sessions and resources • Misperception that CIs are for children • Limited tertiary training about CIs • CI professional development information fatigue • Limited shared-care • Referrals to audiologists not knowledgeable about CIs <p><i>System and organizational barriers</i></p> <ul style="list-style-type: none"> • Lack of patient-clinician continuity (ongoing consultation with the same clinician) • Lack of coordinated services in rural and remote areas • HA sales targets • Other health conditions prioritized, and patients not raising hearing needs with general practitioners <p><i>Social barriers</i></p> <ul style="list-style-type: none"> • Concern that discussing CIs repeatedly will lead to patient disengagement or transfer 	<p><i>Knowledge, confidence, and support</i></p> <ul style="list-style-type: none"> • HCP CI awareness, knowledge, and training • Access to peer-reviewed publications about CIs <p><i>Practical and system factors</i></p> <ul style="list-style-type: none"> • Support from other clinicians with knowledge of CIs • Patient-clinician continuity • Access to positive CI testimonials • Access to tertiary training about CIs • Access to a CI referral sheet • Access to CI demonstration models and resources • Networking with and feedback from CI teams about patient progress

The most frequently reported barriers and facilitators are highlighted in bold.
CI, cochlear implants; HA, hearing aid; HCP, healthcare professional; HL, hearing loss.

Two Australian audiologists thought that patients' ineligibility for anesthetic may act as a barrier to CI surgery.

Lack of Support and Knowledge • The Patient Perspective • Having an HCP that is unsupportive or poorly informed about CIs was noted by HA and CI users to limit the opportunity to be referred for a CI assessment. HA users reported not feeling knowledgeable about CIs and not knowing where to get more information, and one CI user recounted that their decision to get a CI was delayed as they initially thought children would get priority over adults.

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. (CI user 601)

The HCP Perspective • All HCP groups felt that some patients were not aware of how severe their HL was, and that they adjusted their lifestyle to be less reliant on their hearing.

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." (Australian Audiologist 6)

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. (UK Audiologist 8)

Several Australian audiologists also suggested that patients not following up on referrals on their own, was a barrier, and highlighted that patients need additional support to progress to a CI assessment.

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. (Australian Audiologist 107)

Several Australian and UK audiologists suggested that a lack of family support could also be a barrier for patients.

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. (UK Audiologist 10)

Australian audiologists also noted that some patients thought that CIs were only available for children or were concerned that they would be taking away the opportunity for a child to be implanted. Several GPs acknowledged that they had not realized that CIs were available for adults, and additional tertiary training about CIs was suggested.

Many GPs, and Australian and UK audiologists indicated that they lacked confidence and knowledge about CIs, including knowledge of current eligibility criteria. They acknowledged that this often prevented them from introducing patients to CIs and making referrals for CI assessments. They recognized that by not referring patients for CI assessments, they themselves

were acting as a barrier to CI uptake, and partly attributed this to a lack of tertiary training about CIs. GPs suggested that limited access to audiology and CI information contributed to their lack of confidence to refer a patient to audiology services.

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. (GP 7)

In contrast, some Australian audiologists noted that they experienced CI-focused professional development information fatigue, with many CI-focused professional information sessions available, despite their infrequent opportunities to apply the information about CIs in their daily practice.

I personally avoid some of the [CI] stuff because ... it's not part of my daily work ... I find like, 2% of my clinical time involves [CIs], and 50% of my professional development time is on [CIs]. (Australian Audiologist 1)

GPs and Australian audiologists also reflected that the referral pathway could be disrupted if a patient is referred to an HA audiologist who lacked knowledge about CIs.

Practical Inconvenience • The Patient Perspective • Concerns about taking time off work (or other commitments) for surgery and the commitment required for rehabilitation were raised by CI and HA users as barriers to CI uptake.

I just had all these negative feelings about [CIs], all the problems that I can think of like trying to get time off work. (HA user 2)

The HCP Perspective • Both groups of audiologists reported that their patients had been concerned about taking time off from work and from family commitments for surgery and rehabilitation. The UK audiologists suggested that a poor history of HA use can make HA users reluctant to pursue hearing tests, which can act as a barrier to CI uptake.

That's a little bit of a barrier because they've already got this bulk of experience of not liking the sound from their hearing aids, not wanting to wear their hearing aids, and then trying to weigh up whether an implant which they can't take out and which might affect their low-frequency hearing is going to be any better. (UK Audiologist 1)

Some Australian and UK audiologists commented that patients' levels of motivation to commit to CI rehabilitation, postsurgery, also influenced their decision to refer a patient on for CI assessment.

There [are] 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. (Australian Audiologist 110)

Social Barriers • The Patient Perspective • A small number of CI users had been concerned about the cosmetics of a CI.

The HCP Perspective • Several GPs, Australian audiologists, and UK audiologists perceived that the cosmetics of a CI was a concern for some patients; however, most audiologists said that they did not view cosmetic issues as a barrier to CI uptake, as patients typically prioritize resolving their hearing issues over cosmetic concerns.

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. (Australian Audiologist 107)

All groups of HCPs thought the perceived stigma of HL was a barrier for some patients and several UK audiologists suggested that hearing negative stories or testimonials about CIs could act as a barrier to cochlear implantation for prospective candidates.

I've got somebody that I'm working towards implants at the moment who has an idea that the sound will be terrible because of a documentary he saw on TV, which apparently was about somebody that was congenitally deaf, so a very different situation to him, but that's a real stumbling block for him. (UK Audiologist 9)

System and Organizational Barriers • The Patient Perspective • Limited access to services, CI assessment and postimplantation rehabilitation as well as the challenges associated with traveling to, and committing to, services, particularly for patients living in rural areas, were barriers for CI and HA users. The perceived cost of a CI was also considered to be a barrier to CI uptake by several CI and HA users.

I was aware of [CIs] but never considered because of costs and not aware that medical insurance provided. (CI user 6)

Several CI and HA users suggested that they disliked annual hearing tests, finding them daunting, and avoided them, potentially restricting their own access to hearing services and support. CI and HA users also reflected on the experience of being deemed ineligible for a CI in the past. In their accounts, the CI assessment did not reflect their daily hearing struggles, such as conversing in a noisy setting with multiple people.

I had to apply at least 3 times and go back a fourth time before I was approved for an implant. The problem being, I suppose, that I had learned so well how to communicate one on one with lip reading, and putting sentences and sounds together. (CI user 602)

The HCP Perspective • The UK audiologists talked about patients having negative experiences with the assessment process and suggested that this could lead to emotional challenges and disengagement with hearing health services, if they are found to be currently ineligible for a CI.

It's quite an onerous process, assessment ... they're [the patient] 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. (UK Audiologist 11)

Audiologists in Australia and the United Kingdom felt that it was difficult to introduce the notion of CIs with patients if they had limited patient-clinician continuity, and that this can be exacerbated by poor patient documentation records and practices.

I don't feel like the patients see the same person ... there are some people who would mention [CIs] 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. (UK Audiologist 3)

The UK audiologists suggested that CI knowledge among audiology staff was variable, influenced, in part, by service-delivery models impacting negatively on CI referrals.

GPs reported that in rural areas, lack of coordinated hearing services made it difficult to refer patients for CI assessment, and that they often prioritized other health conditions over hearing health, while they concluded that patients rarely raised hearing health issues with them anyway.

I'm just battling with all the other problems let alone worrying about [CIs]. (GP 5)

GPs and Australian audiologists generally suggested that waiting lists were off-putting for patients, but audiologists in England suggested that their waiting list was not long enough to allow patients to adjust to the idea of the CI surgery.

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. (UK Audiologist 1)

Some Australian audiologists were concerned that other audiologists may not refer patients for CI assessment if they had HA sales targets to attain as they were worried about losing the patient. Several Australian audiologists and GPs lacked confidence in their knowledge of the costs associated with a CI in Australia, and several perceived their patients to be concerned about the cost of CIs. Costs were not raised by the UK audiologists.

Facilitators

CI and HA users were asked what were the main facilitating factors that influenced them getting a CI implant (CI users) or thinking about getting a CI in the future. HCPs were asked what they thought the main facilitating factors for CI uptake were for their patients, as well as the factors that would support them to make more CI assessment referrals. The main facilitating and motivating factors contributing to CI uptake, reported by all groups, included: (1) social motivators and frustration related to the HL; (2) knowledge, confidence, and support; and (3) practical and system factors.

Social Motivators and Frustration Related to HL • The HCP Perspective • CI and HA users' desire for better hearing to improve communication, and through that, improved relationships, increased social interaction, better participation in activities, and maintaining independence were strong facilitators that encouraged CI uptake:

I couldn't go on the way I was. I was unhappy. Stressed out ... I didn't want to give up on being an active person in society any more. (CI user 1)

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]. (CI user 605)

For CI users, hearing success stories from other CI recipients was a strong facilitating factor that encouraged patients towards CI uptake.

Having ineffective HAs that were uncomfortable and as a result, being frustrated by the increased requirement for listening effort, and being advised to get an implant before losing all residual hearing, motivated many CI users to pursue CI assessments.

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. (CI user 605)

Realizing that HL had begun to affect their work-life motivated many CI users to pursue a CI, as well as one HA user.

Well I was still at work, so that was the first kicker I suppose. If I was going to continue to work, I had to be able to hear. I'd worn hearing aids for about 15 years I suppose - progressively stronger hearing aids. And they were obviously no longer working. Actually, I take that back. I actually retired from my first profession and although I probably could have found another job within the company, it was my hearing loss that triggered people to say you can no longer do your job. (CI user 403)

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]. (HA user 705)

The HCP Perspective • Audiologists in Australia and the United Kingdom suggested that sharing CI recipients' success stories with candidates was a powerful way to support patients to progress in their CI assessment.

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. (Australian Audiologist 107)

Knowledge, Confidence, and Support • The HCP Perspective • Feeling fully informed about CIs and having support from knowledgeable HCPs, family and friends were also facilitators that supported the decision to progress to a CI for CI and HA users.

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. (CI user 609)

The HCP Perspective • GPs, Australian and UK audiologists echoed a similar sentiment to the patients, in their perception that patient awareness and knowledge about CIs, through the provision of information packs or by talking to a CI recipient, were important factors that supported the decision to go ahead with the CI surgery. All HCP groups also perceived that family and HCP support was important to their patients and were facilitators toward the CI decision-making process.

All HCP groups noted that developing their own knowledge and awareness of CIs through professional information sessions either helped in the past, or would help them in the future, feel more confident about recognizing eligible candidates and making CI assessment referrals.

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. (GP 7)

GPs suggested that having publications in a peer-reviewed, GP-focused journal would increase their profession's awareness of CIs in the adult population, and lead to a more informed practice amongst the GP community, and that targeted presentations by other doctors may also help engage GPs with the topic. Audiologists in the United Kingdom and Australia reflected that attending CI information sessions held by CI teams or manufacturers had been helpful to increase their knowledge about CIs.

The HCP Perspective • Audiologists in Australia and the United Kingdom perceived that listening effort was a big motivating factor for their patients and noted that they had patients whose fear of going deaf motivated them to get implanted.

Most of the time it is just to connect - better connection with family and friends. Just being, I guess, less exhausted at the end of each day and maybe less reliant over time on having to constantly use tactics and strategies and all of that to fill in the gaps. (Australian Audiologist 106)

It is the desire not to be completely deaf and so it's fear ... 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. (Australian Audiologist 10)

Practical and System Factors • The Patient Perspective • Having easy access to CI specialists encouraged CI and HA users to consider CIs.

[My audiologist has] 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. (HA user 702)

The HCP Perspective • GPs and audiologists in Australia suggested that the high cost of HAs encouraged their patients to transition to CIs, which could be publicly funded. Several audiologists in Australia and the United Kingdom noted that patient-clinician continuity was important and key to building rapport and trust with the patient, as was comprehensive record keeping, to ease the transition for patients between clinicians, and reduce the need for patients to repeat their hearing history to new audiologists. It was also recognized by a UK audiologist that seeing a new clinician could enable CI uptake, by creating the opportunity to talk to an audiologist who is more knowledgeable about CIs.

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 [CIs], that they take [CIs] into consideration again. (Australian Audiologist 13)

Some UK audiologists reported that the open access HA service provided opportunities for CIs to be introduced, as patients can be easily reassessed by a more highly skilled audiologist, as opposed to an assistant, and to be referred for assessment.

[CIs] might not have been in the clinician that they were seeing[’s] mind at all, ... 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. (UK Audiologist 4)

Audiologists from the United Kingdom and Australia suggested that access to the following resources would enhance their knowledge and confidence in making a CI referral, and assist clinicians to identify eligible patients who may benefit from a CI: CI recipient testimonials; CI demonstration models; eligibility screening and referral tools; and readily-accessible patient resources; as well as opportunities for networking and sharing care with, and receiving feedback from, CI audiologists and clinics, and access to a shared database of CI recipients.

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”. (Australian Audiologist 6)

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. (UK Audiologist 11)

DISCUSSION

Globally, CI uptake is currently low for adults, despite CIs being a safe and effective technology for those with severe or greater SNHL who obtain limited benefits from conventional HAs (Bond et al. 2009; Berrettini et al. 2011). The barriers and facilitators to CI uptake and utilization have not, up to now, been well understood. This qualitative study is the first of its kind. These findings have been presented to demonstrate an in-depth exploration of the perceived barriers and facilitators to CI uptake in adults with severe or greater SNHL (≥ 50 years), from the perspective of patients (CI users and HA users), and HCPs (Audiologists and GPs). The inclusion of the UK audiologist cohort both supports the findings from the Australian audiologist cohort and reveals similarities and differences in perceived barriers and facilitators to CI uptake between different countries—Australia, England, and Wales. Comparisons between countries indicate extensive overlap between the barriers and facilitators that patients reported, and that HCPs perceived their patients to experience.

These findings map to the literature on HCP-associated barriers to CI uptake, such as limited HCP knowledge and awareness of CIs which affect referral for implantation, and influence HCP discussions with patients about assessment and referral (Cohen et al. 2005; Chundu & Buhagiar 2013; Sorkin & Buchman 2016; Holder et al. 2018). The results contribute to the literature by demonstrating that HCP knowledge and confidence to discuss CIs is influenced by factors such as limited

opportunities for networking with CI specialists and sharing patient care, lack of patient continuity, perceived limited tertiary education around CIs, and limited access to relevant and appropriate training and information courses. An Australian study which retrospectively reviewed audiological records of 18 potential CI candidates, coupled with a questionnaire of the eight Audiologists supporting their care, found that patients’ concerns about surgery, loss of residual hearing and balance-related complications, were barriers to CI uptake and that patient disinterest and competing comorbidities, limited HCPs from making referrals for CI assessment (Looi et al. 2017).

These findings extend the understanding of patient-associated barriers to CI uptake in the literature by articulating concerns of patients, such as worries about the irreversibility of the CI procedure, the sound quality following surgery, time off work for surgery and rehabilitation, and the challenges in accessing services. Hearing other patients’ testimonials and meeting CI recipients have been discussed in the literature as strong facilitators for potential candidates considering CIs (Mäki-Torkko et al. 2015). Our study extended this understanding of facilitators for CI uptake, to include the patient’s fear of going completely deaf, getting ineffective support from HAs, and the patient’s sense of frustration from the effect of HL on communication, relationships, work, education, and wellbeing.

Information about CIs was a key matter for both patients and HCPs. Patients wanted more access to CI information and support, and many HCPs lacked confidence in their knowledge about CIs [including CI candidacy, which has been demonstrated in the literature (Manrique et al. 2018)], despite being aware of CI resources and professional development courses. These findings are unexpected, given the a priori perception that there is a diverse range of resources available for HCPs and patients (British Cochlear Implant Group 2018a; Health Direct 2018; National Institute for Deafness and Other Communication Disorders 2017). These findings suggest that the available CI resources are not addressing the practical needs of HCPs, or effectively reaching non-CI specialist HCPs or patients. To be effective, these resources must be targeted (Johansson et al. 2005) and designed in consultation with key stakeholders to ensure acceptability and appropriateness (Hoffmann & Worrall 2004), including catering for different levels of health literacy (Nair & Cienkowski 2010), and disseminated in a sustainable manner (Rapport et al. 2018b).

Providing clear and practical information to address risks, prognostics, and candidacy criteria is currently limited by the published evidence-base. To date, this has focused on the general effectiveness of CIs in adults with postlingual SNHL who have obtained a limited benefit from their HAs (Gaylor et al. 2013), without systematically quantifying the existing probability of a decrease or absence of change in speech perception abilities in comparison to preimplantation results (UK Cochlear Implant Study Group 2004a). Adding further complexity to the provision of clear information, CI candidacy criteria are quickly evolving and variable between countries (Vickers et al. 2016). Despite the existence of general guidance, there is also wide variability in the assessments conducted by individual CI clinics to determine candidacy (e.g., criteria based on words or sentence repetition scores, in quiet, or in either adaptive or fixed noise environments) (Carlson et al. 2018). Many CI surgeries are also identified as “off-label,” where patients have listening abilities that are beyond an established criteria—which occur

when criteria are perceived as too restrictive (Carlson et al. 2018). Cost-effectiveness data for the majority of these off-label surgeries are lacking.

Regarding global differences in CI uptake, comparing the UK and Australian data has provided a useful comparator of cross-country differences in hearing care (Zhao et al. 2015). Many issues raised by Australian audiologists were echoed by UK audiologists. One clear difference lay in perceptions regarding CI-related costs, identified as a global barrier to CI uptake (Zeng 2007). Australian patients and audiologists believed that costs of the CI device and surgery were a concern to many patients. Australian HCPs lacked knowledge about the costs of CIs, which reflected, in part, the complex and variable funding structures between Australian states. In Australia and the United Kingdom, unilateral (single ear) CIs are available through public funding, for those who meet the CI eligibility criteria (National Institute for Health and Care Excellence 2009; Cochlear Ltd 2017). However, provision is constrained by funding limitations (Cochlear Ltd 2017; British Cochlear Implant Group 2018b). While the majority of eligible adults in the United Kingdom are provided with a single CI, a CI for the second ear may be publicly provided only in rare cases (British Cochlear Implant Group 2018c). In Australia, a second CI can be privately funded or reimbursed by private health insurers or the Department of Veteran Affairs (Foteff et al. 2016). The UK audiologists did not raise costs as a barrier to CI uptake. This may be a reflection of the UK healthcare system in which care is free from the point of entry through the National Health Service (2015), despite offering only the possibility of one CI and only for adults with more severe HLs, in comparison to the Australian criteria.

Another difference that was raised as a concern by Australian audiologists, but not the UK audiologists, was that HA sales targets could influence audiologists' CI referral rates. This concept is aligned with recent discussions prompted by the Australian Competition and Consumer Commission (2017). This calls for greater transparency regarding the limitations of HAs for people with severe or greater SNHL and public awareness of CIs. The funding models of CI clinics were not raised by participants in this study.

While the results from this study represent the views of the sample, future research, to quantify these findings and determine if they are generalizable, is necessary. Ongoing research to support a holistic approach to improving CI uptake is warranted, to cater for the complex hearing healthcare system and to take account of the many interrelationships between the barriers and facilitators to CI uptake. This is a complex task, requiring the publication of up-to-date cost-effectiveness studies for off-label surgeries, changes to CI training in primary, community, and tertiary care, the reconceptualization of professional development and accreditation, as well as development of targeted promotional materials and public awareness campaigns, improved information dissemination, enabled patient networks, and the timely access to patient support programs, especially for eligible CI candidates.

Strengths and Limitations

This study involved an extended recruitment period, required to achieve data saturation. These data enabled a rich exploration of the barriers and facilitators to CI use and led

to an in-depth understanding of the data across cohorts and countries. The recruitment involved participant self-selection, including a large cohort of CI users who were keen to share their stories. This self-selection may have introduced a potential bias by including participants who were motivated to tell their story, while excluding patients who were less empowered. However, data from the multiquantitative methods utilized, yielded data that described in extensive detail about personal experiences of the delivery and receipt of hearing healthcare, enabling the study aim to be addressed. Demographic data were incomplete, and one demographic survey was not returned by an Australian audiologist. The study may also have benefited from including the perspective of Ear Nose and Throat specialists and CI surgeons. The inclusion of audiologists in the United Kingdom enabled comparison of the barriers and facilitators to CI uptake across different health systems, to corroborate data. Another strength of this study was that participants chose the method of data collection, according to their preference, which meant that adults with HL, who felt they could not participate in a verbal interview, were able to participate via email. A notable limitation was that analysis was not conducted to compare participants who did and did not complete the proforma.

CONCLUSION

The participant accounts indicate that CI uptake is affected by a complex range of both barriers and facilitators that affect patients and HCPs. Many of these barriers to the access of hearing services, CI referral, CI assessment and implantation, particularly those that relate to misinformation or limited information provision persist, despite initiatives by HCP stakeholders to provide access to high quality, accessible sources of information. This insight into the multitude of factors that influence CI uptake, reinforces the importance of an integrated, holistic and multifaceted approach to CI uptake reform.

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The authors would like to disclose that another manuscript has been prepared reporting results from this study, not reported in this manuscript, which will be submitted to another journal.

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