TITLE: What influences decision-making for cochlear implantation in adults? Exploring barriers and drivers from a multi-stakeholder perspective.

Short title: Barriers and drivers to cochlear implantation.

Ebrahimi-Madiseh A^{1,2}, Eikelboom RH^{1,2,4}, Bennett RJ^{1,2}, Upson GS ³, Friedland PL^{2,6}, Swanepoel DW^{1,2,4}, Psarros C⁵, Lai WK⁵, Atlas MD^{1,2}.

- 1 Ear Science Institute Australia, Subiaco, Australia.
- 2 Ear Sciences Centre, School of Medicine, The University of Western Australia, Nedlands, Australia.
- 3 Telethon Kids Institute, Subiaco, Australia.
- 4 Department of Speech Language Pathology and Audiology, University of Pretoria, Pretoria, South Africa.
- 5 Sydney Cochlear Implant Centre, Royal Institute for Deaf and Blind Children, Sydney, Australia.
- 6 University of Notre Dame Australia, Fremantle, Australia.

Keywords: cochlear implant, uptake, adoption, concept mapping, barrier, driver, service delivery.

Conflicts of Interest and Source of Funding:

The authors report no declarations of interest.

Address correspondence to Azadeh Ebrahimi-Madiseh, Ear Science Institute

Australia, Suite 1, Level 2, 1 Salvado Road, Subiaco, WA 6008, Australia. Tel: +61 8

6380 4944. Fax: +61 8 6380 4901. Email: Azadeh.ebrahimi@earscience.org.au.

Abstract

Objectives- To explore factors influencing the uptake of cochlear implants in adults, the extent of impact for each factor and to conceptualise the journey of clients from a multistakeholder perspective.

Design- A mixed participatory method, concept mapping, was employed to integrate input from multiple stakeholders, each with their own experience and expertise to allow for qualitative and quantitative data collection and further quantitative analysis. There were two main cohorts of participants: clients (CI recipients, candidates and family members), and professionals (CI audiologists, Ear Nose & Throat surgeons, administration staff, managers and manufacturer representatives). A total of 93 people participated in the study: client cohort (n=60, M age=66.60y), professional cohort (n=33, M age=45.24y). Participants brainstormed statements in response to the question "What influences people's decision to get/not get a cochlear implant?" They subsequently grouped the statements, named each group and rated each statement for their impact (from a barrier to a driver), and prioritising the need to change/ improve (from low to high) using a five-point Likert scale.

Multidimensional scaling was used to produce visual representation of the ideas and their relationship in the form of concepts. Further analysis was conducted to determine the differences between the cohorts, sub-cohorts and concepts.

Results- 110 unique statements were generated and grouped into six concepts: *External influences* (awareness and attitude of non-implant professionals on uptake, cost, logistics, referral pathway, public awareness); *Uncertainties, beliefs and fears* (fears, negative effect of word of mouth, unsuccessful previous ear surgery, cosmetics of the device, misunderstanding of how a CI functions and eligibility and outcome); *Health problems*

(mental and physical health); *Hearing difficulties* (social, emotional and communication impact of hearing loss, severity of hearing loss, benefit from and experience with hearing aids); *Implant professionals* (implant team attitude, knowledge and relationship with patients, quality of overall service); and *Goals and support* (hearing desires and goals, motivation, positive impact of word of mouth, family support, having a CI mentor). Two overarching domains of the six concepts were identified; the Patient-driven domain included four concepts and the External domain comprising two concepts. The mean rating of concepts in terms of impact ranged from 2.24 (*External influences* was the main barrier) to 4.45 (*Goals and support* was the main driver); there was a significant difference between cohorts.

Conclusion- This study increases our understanding of factors influencing decision making to choose a CI as a hearing treatment option from a multi-stakeholder perspective. The magnitude of the generated statements in the patient-driven domain highlights the pivotal role of individualised care in clinical settings and understanding clients' needs and expectations. While clients' persistent hearing difficulties, goals and support network were identified as drivers to the uptake of cochlear implants, the identified barriers highlight the need for a collaborative multi- and inter-disciplinary approach to raise awareness and educate non-implant hearing professionals, as well as educating and empowering clients to make decisions and consider a CI as a hearing management option.

Introduction

Hearing loss negatively impacts many facets of a person's life, the impact of which is reportedly proportional to the severity of hearing loss. Those with more severe degrees of hearing loss have increased risk of cognitive impairment (Lin et al., 2013), a higher risk of

depression (Lawrence et al, 2019), higher degrees of reduced social activities (Gopinath et al., 2012b), higher incidence of reduced quality of life over time (Gopinath et al., 2012a), higher unemployment and lower household income (Kochkin, 2005), and greater degrees of perceived social and emotional loneliness (Weinstein et al., 2016). While a hearing aid can reduce the negative impacts in clients with mild to moderate hearing loss (Ferguson et al., 2017), those with more severe hearing loss may derive more benefit from cochlear implants (CI) (Arnoldner and Lin, 2013, Amoodi et al., 2012).

Cochlear implants are effective for the management of hearing loss primarily when the inner hair cells are partially or completely damaged (Wilson and Dorman, 2008). Taking a conservative approach to applying candidacy criteria, those with bilateral severe to profound hearing loss are considered eligible for a CI in many countries (Vickers et al., 2016a). Cochlear implantation is shown to improve speech perception, sound localisation, communication and as a result the quality of life of the recipients (Contrera et al., 2016, Wong et al., 2014, Arnoldner et al., 2014, Amoodi et al., 2012, Lenarz et al., 2012, Budenz et al., 2011). These improvements are reported to be the result of advancements in cochlear implant technology, which have allowed for more access to sound and speech cues (Gaylor et al., 2013, Holden et al., 2013). This has led to expansions in the candidacy criteria and larger pool of patients as potential recipients especially in the adult population (Sladen et al., 2017, Gifford et al., 2010). However, the global rate of CI uptake in adults has been estimated to be less than 10% (Sorkin and Buchman, 2016), although this rate is difficult to ascertain accurately. This is firstly because there is a wide variability between the methodology used in determining the prevalence of various degrees of hearing loss in adults in epidemiological studies (Stevens et al., 2011) and is often being based on older data.

Secondly, there is a large variability between the candidacy criteria in different countries (Vickers et al., 2016b) and between various manufacturers. Therefore, reporting on number of potential candidates would only be an estimate. Taking a conservative approach of including only those with severe to profound hearing loss as candidates for cochlear implantation, more than 105 million people globally can be considered as potential candidates (Stevens et al., 2013). The uptake rate have been reported to be approximately 5% in the United Kingdom (Raine, 2013), 6% in the United States (Sorkin, 2013), 1% in Japan (Oliver, 2013) and less than 10% in Australia (Looi et al., 2017).

Literature focused on potential and existing hearing aid users have identified several barriers and drivers to access and utilisation. The key drivers to help-seeking are reported to be the degree of hearing loss, self-efficacy, family support, and self-recognition of hearing loss (Barnett et al., 2017, Meyer et al., 2015, Grenness et al., 2014b, Laplante-Lévesque et al., 2012, Laplante-Lévesque et al., 2010, Jenstad and Moon, 2011). The primary barriers to accessing hearing aids were identified as general awareness, financial limitations, stigma of wearing hearing aids, inconvenience, competing chronic health problems, and unrealistic expectations (Nieman and Lin, 2017, Choi et al., 2016, Mamo et al., 2016, Bainbridge and Ramachandran, 2014, Jenstad and Moon, 2011, Wallhagen, 2010, Knudsen et al., 2010). Whether age is a factor in hearing aid uptake is uncertain, as some report an increase in uptake with increasing age (Meyer and Hickson, 2012, Lopez-Torres Hidalgo et al., 2009) while others report a decrease in uptake with increasing age (Uchida, 2008). Gender was also reported as either having no influence (Meyer and Hickson, 2012), as a modifying factor on the stigma of having hearing loss, the severity of hearing loss and locus of control in help seeking (Jenstad and Moon, 2011) and in influencing the occurrence of non-adoption as a

result of cost, poor experience of others with hearing aids or inconvenience of wearing them (Fischer et al., 2011).

There is, however, limited research specifically on the potential barriers and drivers to the uptake of a CI. From the professional's viewpoint, lack of awareness of and training of the referral network about CI candidacy criteria (Looi et al., 2017, Raine et al., 2016, Vickers et al., 2016b, Athalye et al., 2015, Chundu and Buhagiar, 2013, Haurt, 2009), the CI assessment process and lack of clinician continuity (Bierbaum et al., 2019) and the low number of funded CI surgeries as well as high surgical costs (Athalye et al., 2014, Sorkin, 2013) have been suggested as potential barriers to access CIs. From the patient's viewpoint, concerns about surgery and loss of residual hearing were identified to be the most prominent barriers whilst improving knowledge and awareness of hearing healthcare professionals about CI, their wish to improve communication and emotional responses to hearing loss were reported as the most prominent facilitators to CI uptake (Bierbaum et al., 2019, Dillon and Pryce, 2019). Bierbaum et al. concluded that the CI uptake in adults is influenced by a complex range of barriers and facilitators, and called for further research exploring the perspectives of ENT surgeons and quantifying the factors to better understand the impact and interrelationship. Given the important role that family support plays in the help seeking, uptake and successful use of hearing aids (Meyer et al., 2015), the role of family in the decision making process for CI uptake also warrants investigation.

Australia has been reported to have one of the most lenient CI candidacy criteria (Vickers et al., 2016a) offering bilateral cochlear implantation to a range of symmetrical and asymmetrical hearing losses where the best aided condition monosyllabic phoneme score is ≤67% (Leigh et al., 2016). Eligibility decision is predominantly made by multidisciplinary

Barriers and drivers to cochlear implantation

implant teams with CI audiologists and ENT surgeons having pivotal roles in the process. Potential candidates are usually referred by hearing aid audiologists, general practitioners, ENTs, or are self-referred. CIs are funded through governmental and private health institutions. This incorporates limited public funding to fully subsidise the costs of cochlear implantation, the Department of Veteran Affairs that fully covers the cost, and private health funds that fully or partially cover the costs depending on the health cover level of an individual.

Although recent studies have increased our knowledge of concepts that may influence CI uptake, further research is needed to better understand the perspectives of family involvement and key stakeholders such as ENT surgeons and CI audiologists. Furthermore, it is currently unclear whether there is any difference in the views of the various stakeholders. Such knowledge would help to understand the viewpoints of stakeholders and may improve access and service delivery to CI patients.

Accordingly, the purpose of this study was to (a) investigate underlying factors influencing the decision-making for cochlear implantation in a broad cohort of adults from a multi-stakeholder perspective; (b) to determine the impact of each factor, i.e. whether it is a barrier or driver to CI uptake, and prioritising the need to change/improve; and (c) to conceptualise the journey of a potential and existing CI recipient.

Materials and Methods

This study received ethics approval from the Human Research Ethics Committee of The University of Western Australia.

This study employed concept mapping, a mixed participatory method, to integrate input

from multiple sources each with their own experience and expertise in the matter under investigation. Concept mapping engages a group of participants to put forth statements describing their experiences, perceptions, thoughts or ideas about a specific topic, and to subsequently give meaning to these statements through grouping and ranking (Trochim and Kane, 2005). Where traditional qualitative research relies on the researchers interpretation of the data to identify themes, in the concept mapping approach participants play an active role in not just generating the statements, but also synthesising and interpreting the data through the sorting and rating activities resulting in increased validity of the results (Burke et al., 2005, Jackson and Trochim, 2002, Trochim, 1989b). Hierarchical cluster analysis is used to assist the researchers to identify themes (concepts) based on the participant's sorting data; computation of average rating scores for each statement and concept quantifies the impact related to the area(s) of interest. Results from the quantitative analysis are used to produce visual representations of concept maps demonstrating interrelationships of the ideas providing a basis for further discussion and action (Rosas and Kane, 2012).

Concept mapping is a rigorous method that has been used to better understand the context surrounding health-related outcomes and is recommended for healthcare research that aims to evaluate services and plan improvements (Trochim and Kane, 2005). Within the audiology context, concept mapping has been used to better understand the impact of clinicians on hearing aid adoption (Poost-Foroosh et al., 2011), to develop a framework for understanding hearing aid problems (Bennett et al., 2017), to develop a survey evaluating hearing aid handling skills (Bennett et al., 2018) and how hearing aid owners respond to problems that arise following hearing aid fitting (Bennett et al., 2019).

Barriers and drivers to cochlear implantation

Participants

There were two cohorts of participants. This cohort design allowed the collection of a wide range of ideas and experiences.

The client cohort comprised the following sub-cohorts:

- (a) CI recipients,
- (b) CI candidates (waiting to receive a CI),
- (c) CI potential candidates (deemed suitable to receive a CI but decided not to proceed), and
 - (d) family members/ significant others of any of the above groups.

The professional cohort comprised the following sub-cohorts:

- (a) CI audiologists (clinical audiologists providing CI services),
- (b) ENT surgeons (performing CI surgeries),
- (c) administration staff of hearing clinics providing CI services,
- (d) managers of hearing clinics providing CI services, and
- (e) clinical support representatives of CI manufacturers.

Participant recruitment varied between the two groups. The CI recipient sub-cohort was recruited from two of the largest implant clinics in Australia, in the states of New South Wales (the most populated) and Western Australia (the vastest). Patients from these two clinics were considered potential participants if they were assessed for CI candidacy, or were already a CI recipient. Potential participants were excluded if they had another type of hearing implant in the contralateral ear to the CI (i.e. one ear CI and one ear bone conduction implant/middle ear implant), to ensure the reports of their implant-related journeys were solely related to their CI or CIs.

For the recruitment of the professional group, individuals working in large implant clinics (>100 cochlear implant recipients) and with two or more years of CI experience were invited to participate, regardless of the role they played in the clinic. This was to ensure they had enough exposure to and experience with a variety of CI candidates. Representatives from all four hearing implant manufacturers operating in Australia were also invited to participate.

The literature describing concept mapping does not specify a minimum number of participants in the qualitative data-gathering phase, although a preference for groups of 10 to 20 people is indicated to ensure a variety of opinions are gathered (Trochim and Kane, 2005). However, at the sorting and rating phases, which require quantitative analysis, it is suggested to have at least 30 participants to ensure that a high reliability of sorting and rating data is achieved (Rosas and Kane, 2012, Donnelly, 2017).

The following variables were specifically considered in the sample for the client cohort to capture a range of difficulties that various groups might encounter in their journey to obtain a cochlear implant. Patients' age, gender and onset of hearing loss have been shown to influence hearing aid uptake and/outcomes. Considering the vastness of Australia as a country, remoteness (the distance between residence and health services) was considered

Age: categorised into 18-40, 41-65, 66-80, >80 years of age.

important to ensure we captured potential problems with access to services.

- Gender: Female/male.
- Onset of hearing loss: Pre-lingual /post-lingual.
- Remoteness: Residing in a metropolitan or regional area classified using the Australian Standard Geographical Classification (ASGC) (AIHW, 2004). The classification indicates level of access to goods and services in Australia and has five categories: Metropolitan

areas (R1) (having highest access), inner regional (R2), outer regional (R3), remote (R4) and very remote (R5) (having least access).

Procedures

Concept mapping method entails three stages of data gathering: brainstorming (in which the ideas and issues are generated), sorting (in which the generated ideas are grouped), and rating (in which the generated ideas are ranked, usually on a Likert type scale).

Each participant was involved in two sessions, firstly to complete the brainstorming task, followed by a second session to complete the sorting and rating tasks, approximately four weeks later.

Brainstorming

Participants completed the brainstorming session by either attending group sessions (of no more than 20 people) or individual meetings according to their availability and preference. All the sub-cohorts of participants participated in separate sessions to ensure they were able to freely express their experience. In total, nine group sessions and four individual sessions were held at the brainstorming stage.

Participants were asked to brainstorm in response to three questions presented sequentially. The first of these "What influences people's decision to get/not get a cochlear implant?" is reported here. The other two questions were independent of the scope of this study investigating CI maintenance and appointment attendance and will be separately reported. The question was carefully worded to be neutral, simple, and involving all participants. The brainstormed statements generated by the participants were typed without any modification by a member of the research team (AEM, RJB or RHE) on an Excel

spreadsheet projected on a screen visible to all participants. In the event of a lull, the researcher repeated the question or prompted the participants to complete the prompt focus "People get / do not get a CI because...". The sessions ended when all participants were given a chance to share their story and there were no new statements.

The statements from all sessions were compiled and reviewed by the research team prior to the sorting session. The statements were edited according to the concept mapping guidelines (Kane and Trochim, 2007) to obtain a list of unique statements where each statement represents only one idea, to ensure the ideas are relevant to the focus of the study, to reduce the statements to a manageable number and to edit the statements for clarity, grammar and comprehension. Redundant statements, those irrelevant to the question (N=88) (e.g. "We should all carry our ID card going through airport security") and duplicates (N=360) were deleted. There was a large number of duplicates as brainstorming was carried out in several sessions and participants were blinded to what was produced in other sessions. Similar ideas (N=438) were also merged into one statement (e.g. "My audiologist said not to get a CI and stick to hearing aids" and "My audiologist never mentioned a CI" and "My audiologist was reluctant to refer me and said I have to think very carefully as some completely hate it (a CI)" were merged to "Their hearing aid audiologists NOT recommending a CI" to form the final set of statements for the sorting and rating stages. Peer debriefing was used to improve the rigour of the statement reduction process. This involved one author (AEM) completing the initial analysis, which was crosschecked by two other authors (RJB & RHE) to strengthen the accuracy of the process and ensure that content validity of the original statements was maintained.

Sorting and rating

All participants who were involved in the brainstorming session were invited to participate in sorting and rating. Sorting and rating sessions were completed individually online (Concept System, Concept Systems Incorporated, 2011), or face-to-face (paper-based) in several sessions convenient to the participants. The literature on concept mapping shows no difference in reliability of the sorting and rating outcome based on the modality (Donnelly, 2017). The sorting and rating tasks took approximately an hour to complete, with participants first completing the sorting task (approximately 45 minutes) followed by the rating task (approximately 15 minutes).

All participants were given verbal and/or written instructions on how to complete sorting and rating tasks. For the sorting task, they were asked to group the statements into piles according to their meaning or themes in a way that made sense to them and subsequently name each pile. They were instructed that (a) there is no right or wrong way to put the statements together, (b) they can have as many piles as they felt necessary, (c) have at least five piles, (d) put the statement in its own pile if the meaning is unrelated to any other pile, (e) and no pile should be named as "miscellaneous" or "other". Sorting cards containing the statement were presented to the participants in a random order. A member of the research team (AEM) was present at the face-to-face sessions to assist with any questions and ensure all instructions were followed. Those who elected to complete the sorting and rating tasks online were provided with a unique username and password to access the concept mapping software to complete the tasks.

For the rating task, a list of statements was presented in the form of a survey and participants were asked to rate each statement on a Likert type scale in response to two questions: "How does each statement influences a person's decision to get a CI?" to assess

Barriers and drivers to cochlear implantation

the impact of each statement (1= barrier to 5= driver) and "To what extent does each statement needs to be changed/improved to help with the decision about a CI?" to determine the extent to which the participants prioritise a change/improvement in the situation reflected by the statement (1=no need to change/improve to 5=high need to change/improve).

Data analysis

Multidimensional Scaling (MDS) and Hierarchical Cluster Analysis

Brainstorming, sorting and rating data were analysed using the concept mapping software (Concept System Incorporated, 2011) and SPSS. Multivariate analysis was used to provide a geographical map of ideas as points in two dimensions and group the points to form concepts. This process is completed through three steps of (i) calculating the similarity matrix (a square symmetric matrix that shows how many of participants grouped each of statements together), (ii) multidimensional scaling of similarity matrices and (iii) hierarchical cluster analysis of multidimensional scaling (Rosas and Kane, 2012, Kane and Trochim, 2007).

Similarity matrices were used in multidimensional scaling analysis to plot points on a map known as a "point map" (Trochim and Kane, 2005). Each point represented a statement generated during the brainstorming. The closer the points were to one another the more often they were grouped together by the participants.

Hierarchical cluster analysis, using Ward's algorithm, grouped the points together to form concepts with similar meanings. The final number of concepts was determined by the need and specific characteristics of a project (Trochim and Kane, 2005, Jackson and Trochim,

2002) and was selected through a combination of statistical analysis (bridging and anchoring values) and researcher's judgment, to determine the appropriate number of concepts to represent the data. The bridging and anchoring values show how a concept is related to the adjacent ones; the lower the bridging value in a concept, the more the statements in a concept are related. The decision on which concepts to merge or split and the statements included in each cluster is entirely determined by the hierarchical cluster analysis and is not at the researcher's discretion or judgment. The naming of each concept was informed by the group titles given by the participants. The software uses a proprietary algorithm to choose one name out of ten names proposed by the participants that best matches the content of each concept (Rosas and Kane, 2012).

Two more analyses were conducted in the concept mapping software: pattern matching and go-zone analysis. The pattern matching displays a ladder-type graph comparing average concept ratings between demographic cohorts. In this case comparison was made between the professional and client cohorts to determine whether they had different ratings of concepts in terms of impact or need to change/improve. The go-zone is a scatter plot that displays an X-Y graph showing the average rating scores for each statement for two area(s) of interest, in this case the impact against the need to change/improve. The go-zone is divided into quadrants that facilitate identification of statements according to their impact (barriers/drivers) against the need to change/improve (lowest/highest).

Further analysis to determine the differences between the cohorts and sub-cohorts was conducted using ANOVA, t-Test and Cohen's d where appropriate.

Validity and reliability

Validity in concept mapping refers to the degree to which the conceptualised model (map) reflects the judgments made by participants in grouping information to produce the map (Rosas and Kane, 2012). First the degree of similarity between similarity matrices (input) and the Euclidean distances between all pairs of points on the final map (output) was measured by calculating a Pearson correlation coefficient (Trochim, 1989b). A second measure is the stress value, which is indicative of how the point maps fit the similarity matrices; aiming for a stress value of lower than 0.35 is recommended (Kane and Trochim, 2007). This is calculated in the concept mapping software.

Reliability of the participants' input in concept mapping is measured using the sorting and rating data. Two reliability measures were used for the map: a split-half reliability analysis was conducted using Spearman-Brown correlation (Rosas and Kane, 2012, Trochim, 1993). The two subgroups were formed by randomly assigning participants into two groups and generating two separate maps for each half. Similarity matrices and Euclidean distances of points on each map were analysed in SPSS (IBM Corp; 2016), a split half reliability analysis was also conducted for the sorted data to decide on whether to produce separate maps for the professional and client cohorts or to combine the data to generate one point map.

Interpretation

At this phase of the concept mapping process, the results were reviewed with a sample of participants to provide feedback on the coherence of the statements in each concept, the final number of concepts selected, naming, utility and meaningfulness of the concepts and

the average correlation among items (Rosas and Kane, 2012).

determining any overarching domain. This step is used in qualitative research to improve the rigor of the data. Fifteen participants, nine from the professional and six from the client group were involved in the interpretation phase. Participants at this stage of the study were conveniently selected based on availability, ensuring that there was at least one representative of each sub-cohort.

Results

In total 93 persons were recruited in the study of which 76 (47 in the client cohort, 29 in the professional) participated in all three stages including brainstorming, sorting and rating (17 participants who attended the brainstorming session were not available to take part in the second session due to travel or family commitments). The client cohort comprised representatives of all sub-cohorts (described above) that met the maximum variation required in the sampling, the majority of which were CI recipients and family members (Table 1). The professional cohort encompassed personnel from six large CI clinics across Australia (Western Australia N=3, Queensland N=2, New South Wales N=1) and three of the four cochlear implant manufacturers operating in Australia.

In total 886 statements were generated across all 13 sessions. Statements were edited and reduced resulting in 110 unique points of views of all stakeholders describing underlying factors to the uptake of a CI (appendix 1).

Participants grouped the statements during the sorting activity, which ranged from five to twenty-one groups (M=8.6, SD=3.4). Sorting data were used to form the point map through calculating similarity matrices and multidimensional scaling analysis. The Spearman-Brown correlation test showed a high consistency between the two randomly generated maps

(r=0.95) suggestive of a high reliability of the participants' generated sorting data.

Comparison between the professional and client cohorts' similarity matrices showed a high internal consistency (r=0.91); that is, the two cohorts sorted the statements in a similar way. Therefore, data from the professional and client cohorts were combined to form one point map. The stress index resulting from the MDS analysis was 0.214, indicative of a very good match between the participants' sort data (input) and the final two-dimensional point map (output) (Rosas and Kane, 2012, Trochim and Kane, 2005). The similarity of configurations was also tested using Pearson correlation showing a strong correlation (r=0.67, p<0.0001). Hierarchical cluster analysis of point maps formed the concept map by merging the points into concepts with similar meaning. A six-concept structure was decided as the final concept map as best representing the concepts influencing CI uptake (Figure 1). All six concepts were distinctly depicted on the concept map although the two concepts of Hearing difficulties and Goals and support were closely situated. The statements in these two concepts are, however, distinct in meaning and the combined bridging score for the concepts was higher than considering them as separate concepts. Therefore, the decision to keep these separate was made by the research team, and was later confirmed by the participants during the interpretation phase.

Two overarching domains emerged during analysis and interpretation of the concepts and statements: *External* and *Patient-driven* domains (Figure 1). Four of the six concepts containing 71/110 of the generated statements were identified as *Patient-driven* including concepts: *Goals and support, Hearing difficulties, Health problems,* and *Uncertainties, beliefs and fears.* Description of each concept and statements' numbers are summarised in Table 2.

Mean rating scores of individual statements in terms of impact was calculated to determine

whether participants viewed the statement as a barrier or a driver. There was minimal variability between the ratings of the statements between participants. The statement "Non-implant professionals being unaware of CI candidacy (30)" was rated as the biggest barrier (M=1.55, SD=0.84) while the statement "Confidence in their CI surgeon (3)" was viewed as the most significant driver (M=4.84, SD=0.40). The average rating scores were also computed for each concept, indicating whether a concept was viewed as a barrier or driver. The mean rating scores across the concepts were (a) External influences (M=2.24, SD=0.54), (b) Uncertainties, beliefs and fears (M=2.26, SD=0.54), (c) Health problems (M=2.88, SD=0.61), (d) Hearing difficulties (M=4.04, SD=0.37), (e) Implant professionals (M=4.22, SD=0.37), (f) and Goals and support (M=4.45, SD=0.34). These scores were significantly different from one another {(F 5,104)=104.11, p=0.005}.

Internal consistency (average correlation within statements in each concept) of ratings of impact within the concepts was high (Kline, 2005) for five out of six concepts (not the concept Health problems): (a) External influences (α =0.90, N of statements=24), (b) Uncertainties, beliefs and fears (α =0.90, N=25), (c) Health problems (α =0.54, N=7), (d) Hearing difficulties (α =0.74, N=18), (e) Implant professionals (α =0.72, N=15), (f) and Goals and support (α =0.84, N=20). The concept Health problems showed low correlation between the statements that may be the result of participants differently rating the statements in this concept (Rosas and Kane, 2012). The ratings of need to change/improve within the concepts showed high internal consistency for all concepts: (a) External influences (α =0.90, N of statements = 24), (b) Uncertainties, beliefs and fears (α =0.89, N=25), (c) Health problems (α =0.77, N=7), (d) Hearing difficulties (α =0.93, N=18), (e) Implant professionals (α =0.90, N=15), (f) and Goals and support (α =0.94, N=20).

To better understand how each barrier and driver was ranked against their need to change/improve, the go-zone graph (Figure 2) was plotted. It is a visual representation of the average rating for each statement in terms of impact (barrier/driver) and need to change/improve in four quadrants. The top left quadrant includes statements that are ranked as barriers and with a high need to change/improve. This quadrant contains the largest numbers of the statements (38/110), representing many barriers included in two concepts External influences (15/38) and Uncertainties, beliefs and fears (20/38). The bottom left quadrant, however, represents barriers with a low need to change/improve. This quadrant contains 21 statements from four concepts: the Health problems (2/21), Hearing difficulties (2/21), External influences (9/21) and Uncertainties, beliefs and fears (7/21) concepts. The top-right quadrant represents 16 statements that, although they were ranked as drivers to the uptake of a CI, were still rated highly requiring change/improvement. The majority of these 16 statement were derived from the concepts Hearing difficulties (9/16) and Goals and support (4/16). The bottom right quadrant comprised 35 statements deemed to be drivers but with a low need to be changed/improved. These statements were from the concepts Implant professionals (6/35), Hearing difficulties (13/35) and Goals and support (16/35).

To determine whether there was any difference in the view points of the cohorts, the mean rating scores of the impact of each concept for the client and professional cohorts were compared (Figure 3). Although the visual inspection of the means may suggest they are similar, there was a statistically significant difference between the cohorts' rating scores of the barrier concepts *External influences* (p<0.001), *Uncertainties, beliefs and fears* (p=0.005), and the driver concept of *Goals and support* (p=0.001). The professional cohort

viewed these first two concepts to be greater barriers to the uptake of CI than the client cohort did. The two cohorts, however, did not have significantly different impact ratings for the remaining three concepts: *Implant professionals* (p=0.41), *Health problems* (p=0.28) and *Hearing difficulties* (p=0.22).

An examination of how the client and professional cohorts rated the concepts in terms of need to change/improve showed no significant difference between the cohorts; *External influences* (p=0.98), *Uncertainties, beliefs and fears* (p=0.28), and the driver concepts of *Goals and support* (p=0.49), *Implant professionals* (p=0.13), *Health problems* (p=0.46) and *Hearing difficulties* (p=0.89).

Further analysis of sub-cohorts was conducted to determine how various stakeholders viewed the impact and need to change/improve of each concept. Within the client cohort, the average rating scores of each concept, both for impact and need to change/improve, were compared for CI recipients and families. There were no significant differences between the two cohorts of the impact scores for all of the concepts. However, the family sub-cohort rated five out of six concepts (not the concept *External influences*) significantly higher than the CI recipients in terms of need to change/improve; *Uncertainties, beliefs and fears* (p=0.03, d=0.86), *Health problems* (p=0.001, d=1.66), *Hearing difficulties* (P<0.001, d=2.82), *Implant professionals* (p<0.001, d=1.89), *Goals and support* (P<0.001, d=2.21).

Within the professional cohort, the surgeon sub-cohort viewed the concept *External* influences to be a significantly greater barrier to CI uptake compared to the implant audiologists (p=0.01, d=0.81). There was also a significant difference in the mean rating scores for the concept *External influences* (p=0.01, d=0.98) when there was a separation of the professional cohort into those with non-clinical roles (manufacturer representatives,

managers and administration staff) and those with clinical roles (implant audiologists and surgeons), with those in non-clinical roles rating this concept as a greater barrier. The other concepts were similarly viewed by these sub-cohort comparisons, both in terms of impact and the need to change/improve.

Discussion

This study explored the underlying factors influencing CI uptake from the perspectives of multiple stakeholders, including CI recipients, potential candidates, their families, and professionals involved in CI implantation and rehabilitation. This novel contribution supports the limited but growing body of literature aiming to improve services to those needing cochlear implants. Understanding clients' decision-making process can have important clinical implications for counseling, and efficient use of clinical time and resources. The findings of this study may assist in strategic planning of implant units by giving a roadmap of the possible pitfalls in service delivery. The go-zone analysis in particular can assist with prioritisation of those barriers and drivers against their need to be changed/improved to facilitate planning.

The concept map clearly displayed the dominance of statements in the Patient-driven domain emphasising the client as the centre of the journey to CI uptake. This is a novel finding in the limited CI service delivery literature where the emphasis is often put on external factors such as cost and funding of a CI and referral pathway (Looi et al., 2017, Athalye et al., 2015). Although this study also found external factors as barriers to the uptake of a CI, it was identified only as a piece of a bigger picture.

The two concepts of *Goals and support* and *Hearing difficulties* were identified as drivers to the uptake of CI and described the psychosocial, emotional and functional impacts of hearing loss on social interactions and communication in a client's life as well as their needs and expectations. The factors elaborated and shared by the participants in these two concepts describe elements encouraging a potential CI candidate to seek further help. In the help-seeking process for hearing aids, the clients' own perception of their hearing problem, their desire to improve specific need or condition, motivation and the influence of family, friends and mentors have similarly been reported as drivers to adoption (Barnett et al., 2017, Meyer et al., 2015, Laplante-Lévesque et al., 2012, Laplante-Lévesque et al., 2010). Others have also found the patients' expectation to improve speech and communication (Athalye et al., 2014) and ineffective hearing aids and hearing aid discomfort (Bierbaum et al., 2019) as significant drivers in CI candidates. This study also found the degree of residual hearing and associated symptoms like tinnitus and balance problems as drivers to the uptake of a CI. Some of the statements raised by participants in the current study related to improving hearing in specific situations were ranked as drivers that need to be improved to promote uptake (top right quadrant in go-zone), for example, statements "The desire to improve hearing in background noise and social situation (61)", "The desire to improve hearing on the phone (63)". Given that the majority of the participants were CI recipients, it may be indicative of the shortcomings in available technologies in addressing these issues and meeting patients' expectations who have gone through the process. The client cohort significantly rated the concept Goals and support higher than the professional cohort, which highlights the importance of identifying the core needs of a patient and ascertaining their expectations of a hearing rehabilitation treatment plan.

In both medical and audiological proposed models of patient-centred care, individualised

515

516

care sets the tone (Grenness et al., 2014a, Mead and Bower, 2000). This involves the therapeutic relationship, (lay) technical knowledge, professionalism and interpersonal skills to build rapport with each client as an individual. The present study's findings are in agreement with the patient-centred care models, representing the knowledge of, relationship with and trust in the implant team as some of the prominent drivers to the uptake of a CI (e.g. "Confidence in their CI surgeon (3)" and "Trust in their implant audiologist (4)"). Appropriate management of the psychosocial and individual needs of clients as well as the involvement of family members has been emphasised as necessary for the delivery of patient-centred care in audiology (Meyer et al., 2015, Ekberg et al., 2014, Laplante-Lévesque et al., 2014, Poost-Foroosh et al., 2011). The discrepancy between the views of CI recipients and families participating in this study in how they viewed the need to change/improve the factors to help with the decision-making for a CI may highlight the role of family members in goal setting and success of the treatment outcome. Bierbaum et al. (2019) reasoned that "patient-clinician continuity to build relationship and trust" was both a facilitator and a barrier to CI uptake. While trust in and relationship with the implant team was identified as a significant driver in our study, clinician continuity was not mentioned as an influencer by the participants. One explanation for the different findings would be the differences in the cohorts of the studies. The Bierbaum et al. study had less focus on implant professionals and the service received at implant clinics (e.g. ENT surgeons and implant audiologists) and more focus on GPs and hearing aid audiologists. Another explanation could be related to the differences in CI service delivery in Australia and the UK e.g. assessment process and candidacy criteria (Vickers et al., 2016a). Research into the impact of clinician continuity on hearing aid outcomes suggests that this phenomenon is influenced

by (1) the use of patient management systems that enhance patient care, (2) clinician

23

training that emphasised the value of the therapeutic relationship in patient care, and (3) patient preference for clinician continuity (Bennett et al., 2016). Negative experiences with a previous assessment for a CI was also found as a barrier in the Bierbaum et al. study; this was not raised as an influencer to the uptake of a CI in our study. This difference again may be related to the factors described above.

Statements grouped within the concepts External influences and Uncertainties, beliefs and fears represented views of the participants in the journey to see implant professionals and as two of the prominent barriers to the uptake of CI. The influence of primary healthcare professionals involved in the help-seeking journey of a patient with hearing impairment has been reported as a barrier to hearing healthcare delivery (Raine et al., 2016, Sorkin, 2013, Schneider et al., 2010, Haurt, 2009, Cohen et al., 2005). Cohen et al. (2005), reported lack of knowledge of family practitioners regarding who and where to refer to for hearing management as two of the barriers in hearing healthcare. Statements like "Unclear referral pathway (29)", "GPs not having insufficient knowledge of CI to recommend it (6)" support this view. Participants ranked unawareness and misunderstanding of non-implant hearing professionals about the candidacy criteria and outcome of a CI as well as referral pathway as some of the most prominent barriers that require change/improvement. This includes hearing aid audiologists and their pivotal role in the CI referral process, especially given that around 70-90% of potential candidates wear hearing aids prior to cochlear implantation (Stevens et al., 2013, Sorkin, 2013, Kochkin et al., 2010). A recent survey investigating hearing aid owners skills and knowledge in managing their hearing loss found that 37% reported being unaware of CIs as an option for those receiving insufficient benefit from their hearing aids (Bennett et al., 2018). The statement "The patient being unaware of CI as

an option to treat hearing loss (24)" is in support of this finding. Raine et al. (2016) reported a lack of awareness of candidacy criteria amongst hearing aid audiologists as a barrier that improved with training. However, this could be a multifaceted problem, and a more complicated domain than just awareness of the candidacy criteria; it can encompass (i) unclear candidacy criteria for a CI (Vickers et al., 2016b), (ii) unclear and varying candidacy assessment at various implant units (Vickers et al., 2016a), (iii) lack of trust (D'Amour et al., 2008), (iv) lack of reliable, evidence-based and user-friendly tools to screen potential candidates and confidently recommend a CI (Author's unpublished data), or (v) lack of confidence and/or knowledge in counselling a potential candidate (Bierbaum et al., 2019, Raine et al., 2016). Recipients also indicated hearing aid audiologists as one of the most influential factors for CI uptake.

The importance of raising awareness and empowering hearing-impaired clients of the available hearing management options was highlighted by participants in this study.

Misunderstanding and lack of knowledge of how a CI works and the process through which a potential candidate is assessed and receive a CI were identified as barriers to the uptake.

These findings are consistent with oral implant literature where lack of knowledge and awareness played a preventing role in adoption of the implantable treatments (Kranjcic et al., 2015, Saha et al., 2013). In particular fear of surgery and surgical risks influenced by hearing unsuccessful stories about cochlear implantation were amongst the most prominent barriers of this type shared by the participants in the current study. The latter is in line with recent studies where fear of surgical risks and weighing up risks and benefit to cochlear implantation were reported as influencers on CI uptake (Dillon and Pryce, 2019, Bierbaum et

(50)", "Fear of surgical risks... (28)" represent these views. These statements are grouped in the concept *Uncertainties, beliefs and fears*. This concept contained 25 statements of which 20 were ranked as barriers with a high need to be changed/improved (top-left quadrant in go-zone). This again highlights the pivotal role of awareness of and collaboration between the hearing healthcare professionals to better understand and share the current evidence with potential candidates.

Participant views regarding costs and logistics associated with CI uptake were ranked as barriers with low need to change/improve. Travel associated with CI appointments has been previously described as a barrier, negatively influencing the decision to adopt CIs (Bierbaum et al., 2019, Dillon and Pryce, 2019). Although there was a good representation of residents from regional areas in the present study, the low number of participants from remote and very remote areas could have impacted on the low ranking of these factors. These factors, however, may have different weighting in other countries depending on geography and funding models.

Limitations and future research

Although there was a wide range of stakeholders involved in various phases of this study, client participants were recruited from only two Australian-based clinics, and thus their experiences may not be representative of the greater Australian or global population. The invitation was extended to a wide range of potential and existing CI recipients, however, participants were self-selected and there was a low representation of those that decided not to proceed with a CI (n=2) as well as those residing in remote and very remote areas. This may have impacted the generated statements and/or rating of them, and biased the intra- sub-cohort analyses.

Further research is required to validate the findings on a broader range of potential CI candidates, in particular those who have not proceeded with or assessed for a CI and larger cohorts to determine the impact of each factor in different demographics. Given the diverse experiences of those eligible for CI, it could be useful to explore the experiences of the subcohorts in further detail, specifically the experiences of those CI candidates who choose not to proceed with a CI or be assessed. Nonetheless, findings of the current study support the need for improved models of care and development of tools that can be used by hearing healthcare professionals to improve accessibility for clients and their journey.

Conclusion

This study increases our understanding of factors influencing a CI candidate's decision-making process when considering a CI as a hearing treatment option. The two main strengths of this study are that it explores the problem from a multi-stakeholder perspective to provide an understanding of how those involved in a patient CI journey view this matter and the mixed method approach utilised that allowed quantitative analysis of various variables in relation to the concepts and individual statements. The magnitude of the generated statements in the patient-driven domain emphasises the pivotal role of understanding client needs and expectations providing individualised care in clinical settings. The barriers identified in this study highlight the need for a collaborative multi- and inter-disciplinary approach that could involve (i) raising awareness of and education of CIs amongst non-implant hearing professionals, (ii) developing simple, evidence-based and user friendly tools to identify the potential candidates and effectively communicate CI management options for non-implant professionals (iii) as well as raising awareness of, educating and empowering the client to make decision and consider a CI as a hearing

Barriers and drivers to cochlear implantation

treatment option. The novelty of the topic necessitates innovative approaches to be sought to alleviate the barriers in CI service delivery while retaining the benefits (drivers) of current service models.

Acknowledgments

The authors would like to acknowledge the involvement of all the participants who dedicated their time and knowledge to completion of this study. Authors would also like to thank the Ear Science Institute Australia (ESIA) and Sydney Cochlear Implant Centre (SCIC) with participant recruitment. We specially thank Ms Rachelle Hassarati for her contribution, assisting in recruitment and data collection at SCIC.

The authors would like to thank the Ear Science Institute Australia for financial support of this project. Azadeh Ebrahimi-Madiseh is funded by The Sarich and Stokes Research Scholarship, Gift of Hearing Appeal at the Ear Science Institute Australia.

Authors' contribution:

AEM was the principal researcher involved in the design of the study, collection of data at ESIA and SCIC, analysis and interpretation of data and writing the paper; RHE provided input into design, data collection at ESIA, data interpretation, and review of drafts and final version of the paper, RJB involved in the design, data collection at ESIA, data analysis and interpretation, and review of drafts and final version of the paper; GU provided input into design, data interpretation, and review of paper; PF was involved in recruitment and review of the final version of the paper; DWS was involved in review of the final version of the paper; CP was involved in recruitment and data collection at SCIC and review of the final

version of paper; WKL was involved in the review of the final version of the paper; MDA was involved in design, interpretation of the results and review of the final version of the paper.

References:

- AIHW 2004. Regional and remote health: A guide to remoteness classifications. *Canberra: Australian Institute of Health and Welfare AIHW Cat. No. PHE*, 53.
- AMOODI, H. A., MICK, P. T., SHIPP, D. B., FRIESEN, L. M., NEDZELSKI, J. M., CHEN, J. M. & LIN, V. Y. 2012. Results with cochlear implantation in adults with speech recognition scores exceeding current criteria. *Otol Neurotol*, 33, 6-12.
- ARNOLDNER, C. & LIN, V. Y. 2013. Expanded selection criteria in adult cochlear implantation. *Cochlear Implants Int*, 14 Suppl 4, S10-3.
- ARNOLDNER, C., LIN, V. Y., HONEDER, C., SHIPP, D., NEDZELSKI, J. & CHEN, J. 2014. Ten-year health-related quality of life in cochlear implant recipients. *The Laryngoscope*, 124, 278-282.
- ATHALYE, S., ARCHBOLD, S., MULLA, I., LUTMAN, M. & NIKOLOPOULOUS, T. 2015. Exploring views on current and future cochlear implant service delivery: the perspectives of users, parents and professionals at cochlear implant centres and in the community. *Cochlear implants international*, 16, 241-253.
- ATHALYE, S., MULLA, I. & ARCHBOLD, S. 2014. The experiences of adults assessed for cochlear implantation who did not proceed. *Cochlear implants international*, 15, 301-311.
- BAINBRIDGE, K. E. & RAMACHANDRAN, V. 2014. Hearing aid use among older U.S. adults; the national health and nutrition examination survey, 2005-2006 and 2009-2010. *Ear Hear*, 35, 289-94.
- BARNETT, M., HIXON, B., OKWIRI, N., IRUNGU, C., AYUGI, J., THOMPSON, R., SHINN, J. B. & BUSH, M. L. 2017. Factors involved in access and utilization of adult hearing healthcare: A systematic review. *Laryngoscope*, 127, 1187-1194.
- BENNETT, R. J., LAPLANTE-LEVESQUE, A. & EIKELBOOM, R. H. 2019. How Do Hearing Aid Owners Respond to Hearing Aid Problems? *Ear Hear*, 40, 77-87.
- BENNETT, R. J., LAPLANTE-LÉVESQUE, A., MEYER, C. J. & EIKELBOOM, R. H. 2017. Exploring Hearing Aid Problems: Perspectives of Hearing Aid Owners and Clinicians. *Ear and Hearing*.
- BENNETT, R. J., MEYER, C. & EIKELBOOM, R. H. 2016. Does clinician continuity influence hearing aid outcomes? *Int J Audiol*, 55, 556-63.
- BENNETT, R. J., MEYER, C. J., EIKELBOOM, R. H. & ATLAS, M. D. 2018. Evaluating Hearing Aid Management: Development of the Hearing Aid Skills and Knowledge Inventory (HASKI). *Am J Audiol*, 27, 333-348.
- BIERBAUM, M., MCMAHON, C. M., HUGHES, S., BOISVERT, I., LAU, A. Y. S., BRAITHWAITE, J. & RAPPORT, F. 2019. Barriers and Facilitators to Cochlear Implant Uptake in Australia and the United Kingdom. *Ear Hear*.
- BUDENZ, C. L., COSETTI, M. K., COELHO, D. H., BIRENBAUM, B., BABB, J., WALTZMAN, S. B. & ROEHM, P. C. 2011. The effects of cochlear implantation on speech perception in older adults. *J Am Geriatr Soc*, 59, 446-53.
- BURKE, J. G., O'CAMPO, P., PEAK, G. L., GIELEN, A. C., MCDONNELL, K. A. & TROCHIM, W. M. 2005. An introduction to concept mapping as a participatory public health research method. *Qual Health Res*, 15, 1392-410.

- CHOI, J. S., SHIM, K. S., KIM, K., NIEMAN, C. L., MAMO, S. K., LIN, F. R. & HAN, H. R. 2016.

 Understanding Hearing Loss and Barriers to Hearing Health Care Among Korean American
 Older Adults. *J Appl Gerontol*, 733464816663554.
- CHUNDU, S. & BUHAGIAR, R. 2013. Audiologists' knowledge of cochlear implants and their related referrals to the cochlear implant centre: Pilot study findings from UK. *Cochlear Implants Int*, 14, 213-24.
- COHEN, S. M., LABADIE, R. F. & HAYNES, D. S. 2005. Primary care approach to hearing loss: the hidden disability. *Ear Nose Throat J*, 84, 26, 29-31, 44.
- CONTRERA, K. J., BETZ, J., LI, L., BLAKE, C. R., SUNG, Y. K., CHOI, J. S. & LIN, F. R. 2016. Quality of life after intervention with a cochlear implant or hearing aid. *The Laryngoscope*, 126, 2110-2115.
- D'AMOUR, D., GOULET, L., LABADIE, J. F., MARTIN-RODRIGUEZ, L. S. & PINEAULT, R. 2008. A model and typology of collaboration between professionals in healthcare organizations. *BMC Health Serv Res*, 8, 188.
- DILLON, B. & PRYCE, H. 2019. What makes someone choose cochlear implantation? An exploration of factors that inform patient decision making. *Int J Audiol*, 1-9.
- DONNELLY, J. P. 2017. A systematic review of concept mapping dissertations. *Eval Program Plann*, 60, 186-193.
- EBRAHIMI-MADISEH A., E. R., BOIVERT I., BENNETT R., GOULIOS H. 2019. The role of hearing aid audiologist in cochlear implant referrals.
- EKBERG, K., GRENNESS, C. & HICKSON, L. 2014. Addressing patients' psychosocial concerns regarding hearing aids within audiology appointments for older adults. *American journal of audiology*, 23, 337-350.
- FERGUSON, M. A., KITTERICK, P. T., CHONG, L. Y., EDMONDSON-JONES, M., BARKER, F. & HOARE, D. J. 2017. Hearing aids for mild to moderate hearing loss in adults. *Cochrane Database Syst Rev*, 9, CD012023.
- FISCHER, M. E., CRUICKSHANKS, K. J., WILEY, T. L., KLEIN, B. E., KLEIN, R. & TWEED, T. S. 2011. Determinants of hearing aid acquisition in older adults. *Am J Public Health*, 101, 1449-55.
- GAYLOR, J. M., RAMAN, G., CHUNG, M., LEE, J., RAO, M., LAU, J. & POE, D. S. 2013. Cochlear implantation in adults: a systematic review and meta-analysis. *JAMA Otolaryngol Head Neck Surg*, 139, 265-72.
- GIFFORD, R. H., DORMAN, M. F., SHALLOP, J. K. & SYDLOWSKI, S. A. 2010. Evidence for the expansion of adult cochlear implant candidacy. *Ear Hear*, 31, 186-94.
- GOPINATH, B., SCHNEIDER, J., HICKSON, L., MCMAHON, C. M., BURLUTSKY, G., LEEDER, S. R. & MITCHELL, P. 2012a. Hearing handicap, rather than measured hearing impairment, predicts poorer quality of life over 10 years in older adults. *Maturitas*, 72, 146-51.
- GOPINATH, B., SCHNEIDER, J., MCMAHON, C. M., TEBER, E., LEEDER, S. R. & MITCHELL, P. 2012b. Severity of age-related hearing loss is associated with impaired activities of daily living. *Age Ageing*, 41, 195-200.
- GRENNESS, C., HICKSON, L., LAPLANTE-LÉVESQUE, A. & DAVIDSON, B. 2014a. Patient-centred audiological rehabilitation: Perspectives of older adults who own hearing aids. *International Journal of Audiology*, 53, S68-S75.
- GRENNESS, C., HICKSON, L., LAPLANTE-LÉVESQUE, A. & DAVIDSON, B. 2014b. Patient-centred care: A review for rehabilitative audiologists. *International Journal of Audiology*, 53, S60-S67.
- HAURT, S. 2009. Identifying Cochlear Implant Candidates in the Hearing Aid Dispensing Practice. *The Hearing Review*, 16, 24-5.
- HOLDEN, L. K., FINLEY, C. C., FIRSZT, J. B., HOLDEN, T. A., BRENNER, C., POTTS, L. G., GOTTER, B. D., VANDERHOOF, S. S., MISPAGEL, K., HEYDEBRAND, G. & SKINNER, M. W. 2013. Factors affecting open-set word recognition in adults with cochlear implants. *Ear Hear*, 34, 342-60.
- JACKSON, K. M. & TROCHIM, W. M. K. 2002. Concept Mapping as an Alternative Approach for the Analysis of Open-Ended Survey Responses. *Organizational research Method*, 5, 307-336.

- JENSTAD, L. & MOON, J. 2011. Systematic Review of Barriers and Facilitators to Hearing Aid Uptake in Older Adults. *Audiol Res*, 1, e25.
- KANE, M. & TROCHIM, W. M. 2007. *Concept mapping for planning and evaluation*, Sage Publications Thousand Oaks, CA.
- KLINE, R. B. 2005. *Principles and practice of structural equation modeling (2nd ed.)* New York: Guildford.
- KNUDSEN, L. V., OBERG, M., NIELSEN, C., NAYLOR, G. & KRAMER, S. E. 2010. Factors influencing help seeking, hearing aid uptake, hearing aid use and satisfaction with hearing aids: a review of the literature. *Trends Amplif*, 14, 127-54.
- KOCHKIN, S. 2005. The impact of untreated hearing loss on household income. *Better Hearing Institute*, 1-10.
- KOCHKIN, S., BECK, D. L., CHRISTENSEN, L. A., COMPTON-CONLEY, C., FLIGOR, B., KRICOS, P. B. & TURNER, R. 2010. MarkeTrak VIII: The impact of the hearing healthcare professional on hearing aid user success. *Hearing Review*, 17, 12-34.
- KRANJCIC, J., MIKUS, A., MEHULIC, K. & VOJVODIC, D. 2015. Knowledge and awareness of dental implants among elderly people in Croatia. *J Prosthodont*, 24, 37-42.
- LAPLANTE-LÉVESQUE, A., HICKSON, L. & GRENNESS, C. 2014. An Australian survey of audiologists' preferences for patient-centredness. *International journal of audiology*, 53, S76-S82.
- LAPLANTE-LÉVESQUE, A., HICKSON, L. & WORRALL, L. 2010. Factors influencing rehabilitation decisions of adults with acquired hearing impairment. *Int J Audiol*, 49, 497-507.
- LAPLANTE-LÉVESQUE, A., KNUDSEN, L. V., PREMINGER, J. E., JONES, L., NIELSEN, C., ÖBERG, M., LUNNER, T., HICKSON, L., NAYLOR, G. & KRAMER, S. E. 2012. Hearing help-seeking and rehabilitation: Perspectives of adults with hearing impairment. *International journal of audiology*, 51, 93-102.
- LEIGH, J. R., MORAN, M., HOLLOW, R. & DOWELL, R. C. 2016. Evidence-based guidelines for recommending cochlear implantation for postlingually deafened adults. *Int J Audiol*, 55 Suppl 2, S3-8.
- LENARZ, M., SONMEZ, H., JOSEPH, G., BUCHNER, A. & LENARZ, T. 2012. Long-term performance of cochlear implants in postlingually deafened adults. *Otolaryngol Head Neck Surg*, 147, 112-8.
- LIN, F. R., YAFFE, K., XIA, J., XUE, Q.-L., HARRIS, T. B., PURCHASE-HELZNER, E., SATTERFIELD, S., AYONAYON, H. N., FERRUCCI, L. & SIMONSICK, E. M. 2013. Hearing loss and cognitive decline in older adults. *JAMA internal medicine*, 173, 293-299.
- LOOI, V., BLUETT, C. & BOISVERT, I. 2017. Referral rates of postlingually deafened adult hearing aid users for a cochlear implant candidacy assessment. *Int J Audiol*, 56, 919-925.
- LOPEZ-TORRES HIDALGO, J., BOIX GRAS, C., TELLEZ LAPEIRA, J., LOPEZ VERDEJO, M. A., DEL CAMPO DEL CAMPO, J. M. & ESCOBAR RABADAN, F. 2009. Functional status of elderly people with hearing loss. *Arch Gerontol Geriatr*, 49, 88-92.
- MAMO, S. K., NIEMAN, C. L. & LIN, F. R. 2016. Prevalence of Untreated Hearing Loss by Income among Older Adults in the United States. *J Health Care Poor Underserved*, 27, 1812-1818.
- MEAD, N. & BOWER, P. 2000. Patient-centredness: a conceptual framework and review of the empirical literature. *Soc Sci Med*, 51, 1087-110.
- MEYER, C. & HICKSON, L. 2012. What factors influence help-seeking for hearing impairment and hearing aid adoption in older adults? *Int J Audiol*, 51, 66-74.
- MEYER, C., SCARINCI, N., RYAN, B. & HICKSON, L. 2015. "This is a Partnership Between All of Us": Audiologists' Perceptions of Family Member Involvement in Hearing Rehabilitation. *Am J Audiol*, 24, 536-48.
- NIEMAN, C. L. & LIN, F. R. 2017. Increasing access to hearing rehabilitation for older adults. *Curr Opin Otolaryngol Head Neck Surg*, 25, 342-346.
- OLIVER, J. 2013. New expectations: pediatric cochlear implantation in Japan. *Cochlear Implants Int,* 14 Suppl 1, S13-7.

- POOST-FOROOSH, L., JENNINGS, M. B., SHAW, L., MESTON, C. N. & CHEESMAN, M. F. 2011. Factors in client-clinician interaction that influence hearing aid adoption. *Trends Amplif*, 15, 127-39.
- RAINE, C. 2013. Cochlear implants in the United Kingdom: awareness and utilization. *Cochlear implants international*, 14, S32-S37.
- RAINE, C., ATKINSON, H., STRACHAN, D. R. & MARTIN, J. M. 2016. Access to cochlear implants: Time to reflect. *Cochlear Implants Int*, 17 Suppl 1, 42-6.
- ROSAS, S. R. & KANE, M. 2012. Quality and rigor of the concept mapping methodology: a pooled study analysis. *Eval Program Plann*, 35, 236-45.
- SAHA, A., DUTTA, S., VIJAYA, V. & RAJNIKANT, N. 2013. Awareness among patients regarding Implants as a treatment option for replacement of missing teeth in Chattisgarh. *J Int Oral Health*, 5, 48-52.
- SCHNEIDER, J. M., GOPINATH, B., MCMAHON, C. M., BRITT, H. C., HARRISON, C. M., USHERWOOD, T., LEEDER, S. R. & MITCHELL, P. 2010. Role of general practitioners in managing age-related hearing loss. *Med J Aust*, 192, 20-3.
- SLADEN, D. P., GIFFORD, R. H., HAYNES, D., KELSALL, D., BENSON, A., LEWIS, K., ZWOLAN, T., FU, Q. J., GANTZ, B., GILDEN, J., WESTERBERG, B., GUSTIN, C., O'NEIL, L. & DRISCOLL, C. L. 2017. Evaluation of a revised indication for determining adult cochlear implant candidacy. *Laryngoscope*, 127, 2368-2374.
- SORKIN, D. L. 2013. Cochlear implantation in the world's largest medical device market: utilization and awareness of cochlear implants in the United States. *Cochlear implants international*, 14, S12-S4.
- SORKIN, D. L. & BUCHMAN, C. A. 2016. Cochlear implant access in six developed countries. *Otology & Neurotology*, 37, e161-e164.
- STEVENS, G., FLAXMAN, S., BRUNSKILL, E., MASCARENHAS, M., MATHERS, C. D. & FINUCANE, M. 2011. Global and regional hearing impairment prevalence: an analysis of 42 studies in 29 countries. *The European Journal of Public Health*, 23, 146-152.
- STEVENS, G., FLAXMAN, S., BRUNSKILL, E., MASCARENHAS, M., MATHERS, C. D., FINUCANE, M. & GLOBAL BURDEN OF DISEASE HEARING LOSS EXPERT, G. 2013. Global and regional hearing impairment prevalence: an analysis of 42 studies in 29 countries. *Eur J Public Health*, 23, 146-52.
- TROCHIM, W. & KANE, M. 2005. Concept mapping: an introduction to structured conceptualization in health care. *Int J Qual Health Care*, 17, 187-91.
- TROCHIM, W. M. K. 1993. The reliability of concept mapping. *Paper presented at the Annual Conference of the American Evaluation Association.*
- TROCHIM, W. M. K. B. C. M. S. S. O. H. A. 1989b. Concept mapping: Soft science or hard art? . *Evaluation and Program Planning*, 12(1), 87-110.
- UCHIDA, Y., SUGIURA, S., ANDO, F., SHIMOKATA, H., YOSHIOKA, M., NAKASHIMA, T., 2008. 2008. Analyses of factors contributing to hearing aids use and both subjective and objective estimates of hearing. *Nippon Jibiinkoka Gakkai Kaiho*, 111, 405-411.
- VICKERS, D., DE RAEVE, L. & GRAHAM, J. 2016a. International survey of cochlear implant candidacy. Cochlear Implants Int, 17 Suppl 1, 36-41.
- VICKERS, D., KITTERICK, P., VERSCHUUR, C., LEAL, C., JENKINSON, L., VICKERS, F. & GRAHAM, J. 2016b. Issues in Cochlear Implant Candidacy. *Cochlear Implants Int,* 17 Suppl 1, 1-2.
- WALLHAGEN, M. I. 2010. The stigma of hearing loss. *Gerontologist*, 50, 66-75.
- WEINSTEIN, B. E., SIROW, L. W. & MOSER, S. 2016. Relating Hearing Aid Use to Social and Emotional Loneliness in Older Adults. *Am J Audiol*, 25, 54-61.
- WILSON, B. S. & DORMAN, M. F. 2008. Cochlear implants: a remarkable past and a brilliant future. *Hear Res*, 242, 3-21.
- WONG, M. C., SHIPP, D. B., NEDZELSKI, J. M., CHEN, J. M. & LIN, V. Y. 2014. Cochlear implantation in patients with chronic suppurative otitis media. *Otol Neurotol*, 35, 810-4.

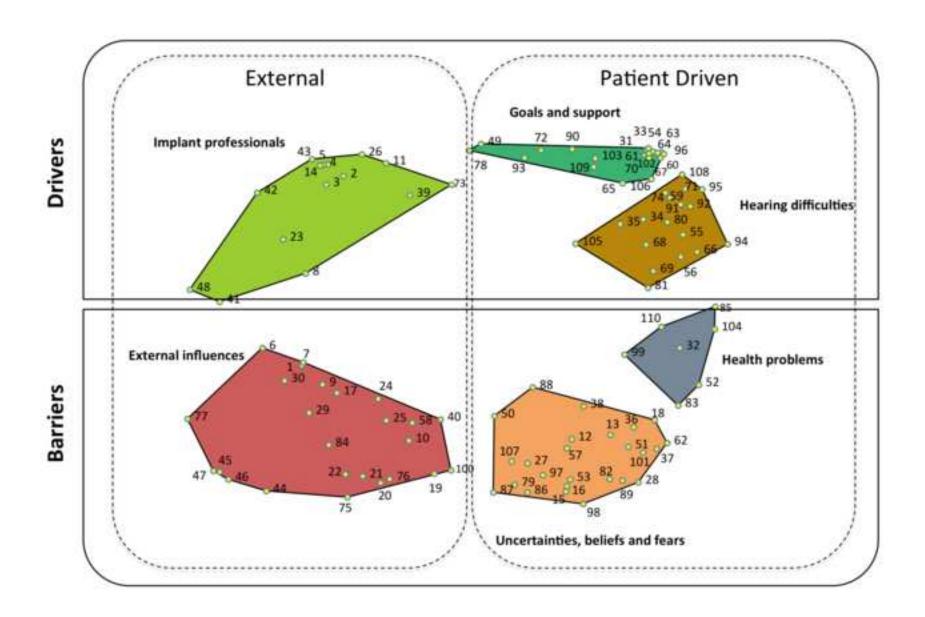
Barriers and drivers to cochlear implantation

Figure legends:

Figure 1. Concept map, showing the 110 statements or underlying factors influencing the uptake of a CI clustered into six concepts, and conceptualised into two overarching domains-external and patient-driven. Barrier and driver concepts were identified by the mean rating scores of each concept. Each point and the adjacent number show a brainstormed statement.

Figure 2. Go-zone graph of 110 statements addressing the question "What influences people's decision to get/not get a cochlear implant?" It displays the average rating values of impact versus need to change/improve for each statement.

Figure 3. Pattern matching graph comparing the mean rating values of impact (1=barriers to 5=drivers) of each concept for client and professional cohorts. The figures in brackets represent the mean rating score for each concept.



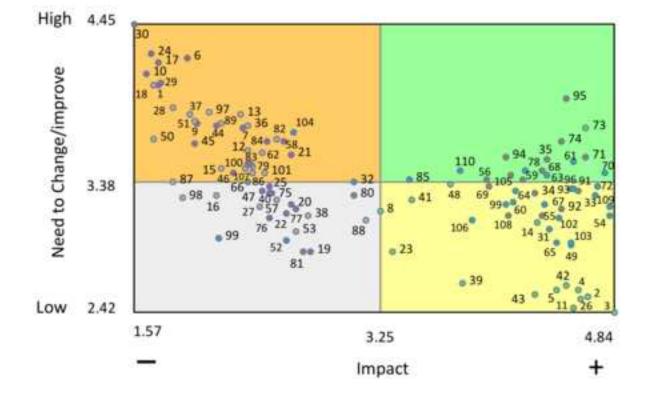




Table 1. Demographic characteristics of the participants. Remoteness classification indicates the level of access to goods and services and is based on the Australian Standard Geographical Classification (ASGC); Metropolitan areas (R1) (having highest access), inner regional (R2), outer regional (R3), remote (R4) and very remote (R5) (having least access).

	Client group	Professional group
Number of participants (total)	60	33
<u>Sub cohorts</u>		
CI recipients	44	N/A
CI candidates	1	N/A
CI potential candidates	2	N/A
Family members	13	N/A
Implant audiologists	N/A	14
Surgeons	N/A	6
Administration staff	N/A	5
Managers	N/A	3
Manufacturers' representatives	N/A	5
Age – Mean (SD; range) in years	66.61 (13.39; 26 – 84)	45.24 (9.61; 26 – 65)
Professional Experience – Mean (SD; range) in years	N/A	11.1 (5.56; 2 – 25)

Onset	Pre-lingual N=12	N/A
	Post-lingual N=35	
Gender (N)		
Female	35	26
Male	25	7
Remoteness (N)		
R1	38	31
R2	15	2
R3	6	0
R4	1	0
R5	0	0

Table 2. Domains and concepts of barriers and drivers to the uptake of CIs, description and corresponding statements' numbers in each concept.

Domain	Concept	Description	Statements in each concept
External	External influences	Awareness and attitude of non-implant professionals on uptake (Family practitioners, hearing aid audiologists, general ENTs); Logistics (Cost, appointments, travel); Referral pathway; public awareness.	40,24,10,58,100, 25,17,19,21,29,22,4 7,75,30,20,9,76, 46,45,1,44,84,7,6, 77
Patient-driven	Uncertainties, beliefs and fears	Fears; risks; negative effect of word of mouth; unsuccessful previous ear surgery; cosmetics of the device; misunderstanding of how a CI functions, eligibility and outcome.	13,97,51,12,16,27, 107,36,15,37,57,82, 50,53,79,89,28,38,6 2,88,101,18,86, 98,87

Patient-driven	Health problems	Mental and physical health and other associated comorbidities with hearing loss.	99,110,85,32,83,
Patient-driven	Hearing difficulties	Social, emotional and communication impact of hearing loss; severity of hearing loss; benefit from and experience with hearing aids.	108,71,91,74,59, 92,95,34,80,55,68, 35,66,56,69,94, 105,81
External	Implant professionals	Implant team attitude, knowledge and relationship with patients; quality of overall service.	5,4,26,14,73,2,11, 3,39,43,42,23,8,41, 48
Patient-driven	Goals and support	Hearing desires and goals; motivation; positive impact of word of mouth; family support; having a CI mentor.	54,63,33,96,64,31,6 0,70,67,61,102, 106,65,103,109,90, 72,93,49,78

Appendix 1. List of statements and corresponding numbers.

- Their usual ear specialist (not their implant surgeon) NOT recommending a cochlear implant
- 2. A good relationship with their cochlear implant surgeon
- 3. Confidence in their cochlear implant surgeon
- 4. Trust in their implant audiologist/therapist
- 5. A good relationship with their implant audiologist/therapist
- 6. GPs not having sufficient knowledge of cochlear implants to recommend this option
- 7. The general public not knowing about cochlear implants (Lack of public awareness)
- 8. Access to information on cochlear implants through social media
- Reading misinformation online about cochlear implant (e.g. Facebook, forums)
- Their hearing aid audiologists recommending NOT to get a cochlear implant
- 11. Their hearing aid audiologist recommending to get a cochlear implant
- 12. No guarantee of improved hearing following cochlear implantation
- 13. Having doubts regarding whether the improvements are worth the risks
- 14. Knowledge and experience of the implant audiologist/therapist
- 15. Waiting for a cure for hearing loss such as hair cell regeneration

- 16. Waiting for a less intrusive technology
- 17. Receiving misinformation from non-implant professionals on how a cochlear implant device works
- 18. Denial of how severe their hearing loss is
- 19. Being locked in to one manufacturer after cochlear implantation (i.e. the internal part works only with an external part from the same manufacturer)
- 20. Having to commit to attending numerous therapy appointments after surgery while juggling family and work responsibility
- 21. The long waiting period for cochlear implant surgery
- 22. The high number of appointments required for therapy (rehabilitation) after surgery
- 23. Large amount of information provided at counselling sessions about a cochlear implant before surgery
- 24. The patient being unaware of cochlear implants as an option to treat hearing loss
- 25. Lack of assistance in device choice
- 26. The professionals involved having a positive view of cochlear implants
- 27. Feeling rushed into undergoing cochlear implant surgery
- 28. Fear of surgical risks; such as balance problem, tinnitus, facial nerve damage, dementia or infection after CI surgery.

- 29. Unclear referral pathways for implantation
- 30. Non-implant professionals being unaware of cochlear implant candidacy

 (i.e. who is suitable for a cochlear implant) and therefore not
 recommending it
- 31. The desire for improved hearing for the TV, radio, when going to concerts, movies and conferences.
- 32. Having a progressive or an additional disability (e.g. blindness, mobility problem).
- 33. Wanting to be able to understand and communicate with kids, grandkids and family.
- 34. A drop (deterioration) in hearing
- 35. Lack of benefit from hearing aids
- 36. Wanting to wait until there is no hearing left before getting a cochlear implant
- 37. Fear of losing residual hearing after implantation (losing what hearing they currently have)
- 38. Cosmetics, shape, size and visibility of the cochlear implant device.
- 39. Confidence in cochlear implant manufacturers
- 40. Being offered solutions other than a cochlear implant
- 41. High cost of hearing aids
- 42. High quality of services received at a cochlear implant clinic

- 43. A welcoming clinic environment
- 44. The out-of-pocket costs of surgery being unclear
- 45. The high cost of cochlear implant surgery
- 46. The high cost of maintenance of a cochlear implant device
- 47. The high cost of appointments
- 48. Reimbursements from private health funds or other sources
- 49. Hearing SUCCESSFUL stories about cochlear implantation
- 50. Hearing UNSUCCESSFUL stories about cochlear implantation
- 51. Fear of the unknown
- 52. A change in the feeling of who they are following implantation
- 53. The perception that they will be a burden on the health system after cochlear implantation
- 54. The desire to improve their quality of life
- 55. Being embarrassed asking others to repeat themselves
- 56. An inability to wear a hearing aid/mould due to an ear condition
- 57. The inconvenience of wearing a cochlear implant device (with hat, helmet, in shower, etc.).
- 58. Lack of familiarity with technology
- 59. Experiencing reduced job prospects due to having a hearing loss
- 60. The desire to hear music better

- 61. The desire to improve hearing in back-ground noise and social situation
- 62. Fear of experiencing complete deafness when their cochlear implant external device is taken off
- 63. The desire to improve hearing on the phone
- 64. The desire to improve the ability to get the direction of sounds
- 65. Being completely deaf and therefore having nothing to lose
- 66. Relying on lip-reading to communicate and therefore not seeing the need for a cochlear implant
- 67. The desire to hear environmental sounds (e.g. alarms at home/work)
- 68. The severity/degree of hearing loss or disability before cochlear implantation
- 69. Experiencing an UNSUCCESSFUL hearing aid trial (no benefit from a hearing aid)
- 70. The desire to improve hearing and communication
- 71. Not being able to hear well enough at work
- 72. Being confident that a cochlear implant will improve hearing and communication
- 73. Understanding the potential benefits of cochlear implantation
- 74. The pressure, inconvenience and frustration that hearing loss puts on the family; especially partners.
- 75. Living a long distance from the cochlear implant clinic

- 76. Being dependent on others for transport to the cochlear implant clinic
- 77. The high cost of parking
- 78. Meeting other cochlear implant users
- 79. The belief that cochlear implants are only for children
- 80. Possibility of drop (deterioration) in the better hearing ear
- 81. Having good hearing in the better ear
- 82. Being concerned that having a cochlear implant will prevent the ability to have MRIs in the future
- 83. Experiencing complex or other health/ear problems
- 84. Long waiting period to see surgeons
- 85. Fear of developing dementia as a result of untreated hearing loss
- 86. Cochlear implantation being major surgery
- 87. Unsuccessful previous experience with ear/general surgery
- 88. Cochlear implantation being a permanent option
- 89. Fear of having surgery
- 90. Pressure/influence of family, friends, peer group and community to improve hearing.
- 91. Frustration of not being able to hear and interact
- 92. Exhaustion from concentrating to hear better
- 93. Support of family, friends and community to make a decision about a

cochlear implant.

- 94. Being subject to discrimination and harassment due to having hearing loss
- 95. Withdrawal from social situation and increased social isolation
- 96. The desire to increase independence
- 97. The belief that one is too old for cochlear implant surgery
- 98. Cultural and religious beliefs against having surgery
- 99. Being satisfied with how their hearing aids currently perform
- 100. The belief that audiologists are only interested in selling products
- 101. The stigma of wearing a cochlear implant device (e.g. embarrassment, fear of being judged).
- 102. The desire to improve self confidence
- 103. Having a positive attitude towards change
- 104. Mental health (e.g. depression, anxiety).
- 105. Having high expectations on the outcome of cochlear implantation
- 106. The desire to improve balance problem (e.g. Meniere's disease)
- 107. Discouragement of the deaf community towards getting a cochlear implant
- 108. The desire to improve tinnitus/ringing in the ear
- 109. Being motivated to get a cochlear implant
- 110. The stigma of having hearing loss