The Ear Foundation

Using Ida Telecare tools: The perspectives of adults with cochlear implants

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Background

Cochlear implants are widely recognised as an effective option for adults with severe to profound hearing loss. It is estimated, however, that in the UK only about 7-8% of adults meeting eligibility criteria actually go on to receive a CI. Making the decision to go ahead with a CI is complex and personal and is just the start of the journey; rehabilitation requires ongoing appointments to maximise the benefits of the technology and a process of learning to use it effectively in everyday life.

In the UK, the rehabilitation process typically involves the CI user returning to the centre where they received their implant and includes sessions with the audiologist to manage the equipment and any issues that arise. However, changing times mean that current and future users are becoming better informed and more discerning about the services they receive. People expect to be more involved in their own care, to access services which offer greater flexibility and which utilise their existing technology, such as smart phones and tablets (Ferrari and Bundesden, 2014). Telehealth is rapidly developing in response to these changing expectations. Whilst it is a relatively new and evolving approach, encompassing a broad range of terminology and methods, fundamentally the purpose of telehealth is to improve health outcomes by providing clinical support to people who are not in the same physical location by using information and communication technology (ICT) (Ryu, 2012).

Ida Telecare from the Ida Institute is an online platform providing a suite of tools and resources for people with hearing difficulties which is designed to support person-centred care (Lockhart, 2018). The goal of person-centred care (PCC) is to create a genuine partnership between the professional and the individual, enabling shared decision-making based on an understanding of the person's everyday needs and values. Evidence suggests that using PCC promotes positive patient outcomes by engaging people through what really matters to them, tailoring interventions to their everyday life and involving their family and friends (for example, Grenness, Hickson et al., 2014; Mead & Bower, 2002; Oates, Weston et al., 2000; Wolf, Lehman et al., 2008).

The Ida Telecare tools are designed to help people reflect on real-life situations, to structure their thoughts in preparation for appointments and to support decision-making and rehabilitation goals.

My Turn to Talk identifies the individual's most important communication partners and questions they wish to discuss in their appointment by considering four key questions: I hope…/ I am concerned about…/ I need help with…/I want to talk about…

Living Well Online is designed to help an individual reflect on and describe their communication needs, to explain where and when it is most important for them to communicate well and to consider steps to improve this situation.

Purpose of the study

Whilst Ida Telecare tools are already used by some audiologists in the UK, little is known about their potential usefulness in the cochlear implantation pathway. Key to this issue is understanding what CI users value throughout their rehabilitation journey. This study was designed to explore the rehabilitation needs and experiences of adult CI users in order to consider the potential of the Ida Telecare tools *Living Well Online* and *My Turn to Talk* in UK practice. Given that telehealth methods are a possible barrier, this study reflects on the ability of the Ida Telecare tools to support person-centred care in meeting these rehabilitation needs.

An online survey and semi-structured qualitative interviews sought the views of adult CI users to:

- Consider what adults need and want from rehabilitation
- Better understand current rehabilitation practice, including the support received and what else they would have liked
- Explore the ease of use and usability of the Ida Telecare tools within UK practice, identifying potential benefits and challenges

Procedure

This report is based on three sets of data:

1. Online survey of adults with a CI to explore their rehabilitation experience, what they need, value and wish for in the process. Thirteen people responded to the survey, 12 with less than five years' CI experience.
2. Qualitative findings collected through a focus group conducted at The Ear Foundation. Six adult CI users with varying duration of CI experience took part.
3. Ethnographic videos of three adult CI users following use of the Telecare tools, Living Well Online and/or My Turn to Talk.

The research was carried out in accordance with The Ear Foundation's ethical procedures based on the Ethical Guidelines for Educational Research (British Educational Research Association, 2011). It was subject to internal and external ethics review and approval. Recruitment took place through The Ear Foundation database and social media channels. Initial purposive selection criteria included those with less than 18 months CI experience; however, this was extended to five years to reach a broader population. Data collection was managed in line with the Data Protection Act (1998); this included gaining informed consent, anonymization of participant data and secure storage of all data with access only by The Ear Foundation research team.

Survey data were initially summarised in SurveyMonkey® and exported to Microsoft Excel for further analysis. Frequency tables were generated for closed questions, showing numbers and percentages of respondents and descriptive statistics where appropriate. Open questions were exported to Microsoft Excel for further content analysis. Thematic frequency and content analysis were conducted as described by Simpson et al. (2012). The content and themes within the open questions were cross-checked independently by two researchers.

The focus group was facilitated by The Ear Foundation staff with clinical experience of working with adults with CIs. The two hour session was audio-recorded and transcribed in full. Prior to the focus group, participants were sent a link via email with a brief introduction to My Turn to Talk and Living Well Online asking them to complete each tool and be prepared to discuss the experience. The group was also given the opportunity to use the tools online during the session. They did this in groups of two or three; their comments were recorded during the activity and in the subsequent feedback discussion. The transcript of the focus group was checked for accuracy, analysed using thematic frequency and content analysis (Simpson et al., 2012) and cross-checked independently by two researchers. Quotations used within this report are used as illustrative examples of key issues that were common across respondents.

Findings

Gaining a better understanding of the rehabilitation experience from the perspective of existing CI users highlights what is valued in the process as a basis for considering the relevance of Ida Telecare tools. This section presents these key messages.

Rehabilitation is about me

Listening to the rich and varied accounts of rehabilitation by the users themselves illustrates the individual nature of experiences and rehabilitation needs:

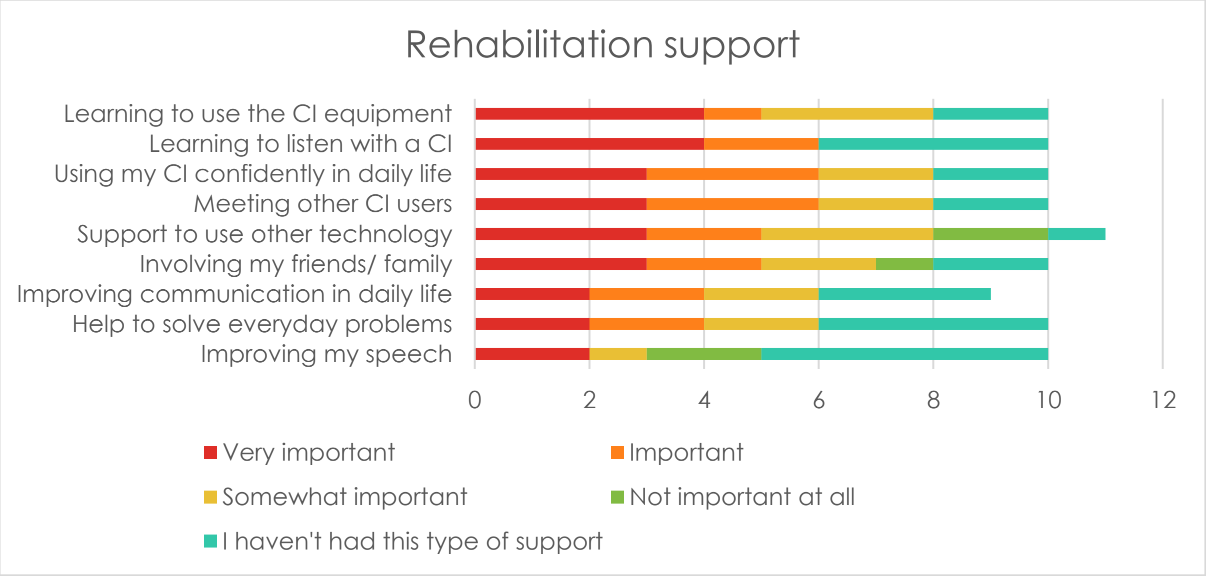
> *It's a very individual thing. Yes, hearing is a very individual thing. (P4)*

Participants shared their feelings and experiences openly and this demonstrates clearly how hearing difficulties affect more than just listening and communication:

> *I continued to remain with those hearing friends but felt very different to them, and realised that socially I wasn't managing. This is after the implant. I felt I had become a different person you know I could kick myself, because I wasn't proactive because I felt I didn't have the confidence to be proactive. (P2)*
>
> *First of all I was worried about my job. (P4)*

Findings suggest a range of rehabilitation support is currently provided in UK CI centres. When asked about the *types* of support received in their rehabilitation, survey respondents reported that learning to manage the CI equipment and use it confidently in daily communication were the most important to them, although interestingly, they are not perceived to be routinely provided (Fig.1).

Fig.1. Importance of rehabilitation support



Although support to learn to listen, improve speech and communication were not consistently reported, this may simply reflect the individual nature of rehabilitation needs, as responses to the CI vary:

> *I left the [CI centre] talking to my wife in the car for the first time in years, but other people will leave but nothing but squeaks. (P3)*
>
> *Obviously you do think 'I am hoping' but I wasn't expecting anything until they turned it on and then it was great. (P6)*
>
> *I heard speech 'straight out of the box.' (S)*
>
> *I still can't listen to music […] so everybody is different. (P4)*

Respondents described the various rehabilitation approaches they'd used; some used prescribed exercises:

> *I valued the exercises I was given. I made a rota of family and friends so that I had an hour morning and afternoon. I soon went through the exercises and used so many that they had a job finding me new material so I found some myself on my book shelves (S)*

Others tried online listening programmes, websites provided by manufacturers or other practical solutions using technology

> *[I use] Tedtalks.com on web browser as you get a transcript to follow (S)*

Simple everyday life worked for some:

> *Given that I was working full time I was exposed to everyday situations to help train the ear to its max. (S)*
>
> *I found the best thing was just having conversations with my family […] For me it was about going to different places, playing out different scenarios, rather than sitting in front of the computer, doing things like having the TV on and taking the subtitles off helped me. (P6)*

Many experiences of rehabilitation appeared to be very clinical in their approach rather than reflecting the support individuals actually wanted, which is to be focussed on 'me' rather than just the technology:

> *If you speak to most audiologists, when you talk about rehab, they are almost automatically thinking about how can we adjust or change the technology, whereas you actually are talking about something else. (S)*
>
> *Rehab is very medical focussed rather than emotional. (S)*
>
> *[They ask] how have you got on with the homework […] it's too clinical…it's about* ***me*** *not the programme. (S)*
>
> *What I really wanted, was […] not just to have that half an hour or hour with the clinician and then go away and fit back into my hearing world of friends and family […]you have to adapt tremendously to suddenly go back into the hearing world. It's a scary, frightening, fantastic time, but I found it absolutely bewildering at times, and sometimes I just wanted to throw it off and not have it […] saying that ['how are you?'] would have been good. (P2)*

The right people at the right time; relationships are important

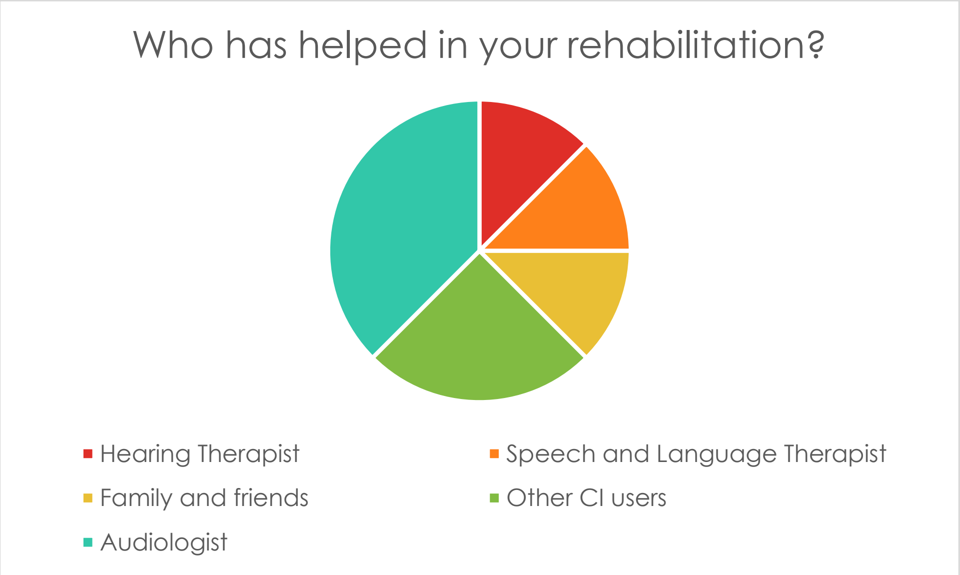
Their relationships with the people involved in their rehabilitation pathway are significant to many adults with CI, as this quote illustrates:

> *This massive wave of hearing and relief, just joyous and thinking they didn't let me down and I didn't let the team down, I was beholden to the programme […] and I have to be forever grateful to them. (P2)*

The CI team

CI pathways and rehabilitation support vary between CI centres in the UK. Whilst all respondents reported that audiologists had helped in their rehabilitation, not all had received support from hearing therapists or speech and language therapists suggesting that they are not routinely provided (Fig.2).

Fig.2. Sources of rehabilitation support



The feeling of a personal connection with the CI team, particularly with the audiologist, appears to be very important, and people valued continuity in their care to maintain this connection:

> *I always ask for the same person as she always did my tuning. I don't like it when they say it could be anybody […] when you see different members of staff they don't know you, and you don't know them. (P4)*
>
> *I feel like my own personal team have people looking after me and that actually gives me what I want. (P5)*

Other CI users

Many people reported that other CI users had a significant role in their rehabilitation and all respondents who had opportunity to meet other CI users rated it as important. In fact, the value of contact with other CI users was a strong message throughout the findings:

> *That made me feel so much better, somebody was going through a similar experience to me then, and it helped […] it was nice to meet people who had had the implant, or who were going through it as well. (P6)*
>
> *I was really scared in that time, terrified, and that is the point when I would have loved to have somebody who I could really relate to. (P2)*

However, it is clearly not a matter of simply signposting individuals to other CI users; participants talked about the value of meeting other CI users who share similar experiences suggesting that CI teams need to better understand individuals:

> *They did a talk that you had to go to as part of your process, where you met someone with a cochlear implant. I found it a bit awkward actually, because I wanted to meet somebody who was similar to me […] I wanted to hear from someone who worked in a similar setting to me. (P6)*
>
> *I needed a commonality, and I felt we'd just been lumped together because we couldn't hear or because we had had the implant but I couldn't relate in any other way. (P2)*
>
> *It should be someone similar: maybe a peer/mentor/buddy system as early as possible. (S)*

Some respondents had experienced CI users involved in their care working as part of the CI team, and this was seen as beneficial both for providing clinical insight:

> *The lady who's with the senior audiologist is a CI user. She can actually understand when I say I have got this 'squeaky' noise, this tinny noise. They are brilliant. (P1)*

And also for the empathy that comes from sharing the lived-experience:

> *Get people on board that aren't just highly skilled as they are, get people who don't hear, get people with implants and hearing aids. Like the emotional side of it, it's the nurturing side of it. (P2)*

Although many people are comfortable with accessing resources online, it is clear that this should not be seen as a replacement for personal contact:

> *[CI users] need somebody to talk to – they need somebody from the other side of the equation who has been there and done that. (P3)*

Family & friends

Managing the CI in everyday life is a priority for most CI users and involving family and friends is key to this aspect of rehabilitation

> *In between appointments is what rehab's about isn't it?* (P2)
>
> *When you are somebody who has lost their hearing and you are depending on somebody being with you all the time, I think that is really a big part of the rehabilitation process, having that support with you from the very start, before you even have the operation. Coming straight back onto to the ward, having*

> *that familiar person who knows how you communicate best. That's just the start of it, you know, someone who understands you. (P6)*

Help to solve everyday problems and to involve family and friends in rehabilitation are valued by those who received this type of support (add table 70% valued involving family and friends).

The right time

Interestingly, when asked about what rehabilitation means to them as CI users, participants felt strongly that it starts during the decision-making process **before** receiving the CI. For these adults, rehabilitation begins with the information provided by the CI team to help understand the process and set appropriate expectations

> *[I would have liked more] information before implant. (S)*
>
> *I think the expectation management is key and it comes up time and time again on Facebook groups. (P3)*

It's important to note that it is not just about providing information; without paying attention to the needs of the individual, problems may still arise. As one participant explained:

> *Prior to surgery [there was] a process of a year of counselling, and a year of tests, and it was really thorough.* (P2)

However post-CI, the same person reported a stark contrast:

> *For me, the point from surgery to switch-on was the most difficult period in my life […] I felt very much stuck out there in the wilderness […] you are talking about a very scary time, because you think 'I know I have lost that residue bit of hearing, I have made that choice what if it's not there, and who is going to be there for me'. (P2)*

The concept of rehabilitation pre-CI may challenge traditional ways of thinking, suggesting rehabilitation is open to a wider interpretation than the one professionals typically employ. However, research shows that preparation and understanding make a significant difference to outcome; the better prepared an individual is, the more successful the outcome is likely to be.

Do the Ida Telecare tools meet these rehabilitation needs?

By understanding what CI users value in their rehabilitation, the potential use of the Ida Telecare tools, My Turn to Talk and Living Well Online, can be considered within this context.

Rehabilitation is about me

CI users report that their hearing difficulties affected more than just listening and communication and they want rehabilitation to be focussed on them as individuals. They valued support to improve communication and solve the problems they faced in daily life.

However Ida Telecare is a new and different approach, perhaps challenging traditional ways of thinking about rehabilitation; engaging people in using them is an essential first step. Encouragingly, descriptions of the various rehabilitation approaches used suggest that people are largely comfortable using technology and online materials

> *I use […] software to help with hearing therapy. (S)*
>
> *We use Messenger now, it is much quicker than email. (P3)*

They also had innovative ideas about using them.

> *[I suggest] using Kindle app with Audible app together so book is read out loud and the text is highlighted as it is read. (S)*

Although it was noted that this might not always be the case and alternative options should also be available:

> *[It might be] hard if you're not techy. (P4)*
>
> *I think that they need a hard copy as some people don't have access to computers or internet or email. So think about people who don't use the internet. (P6)*

The way the tools are introduced to people also seems to be important in engaging them. During the study, limited background information was provided with the original email link to the tools and this initially caused some confusion and a sense of 'why am I doing this?'

> *The questions aren't that clear. (P4)*
>
> *'I hope…' can mean anything, I hope I can hear in the meeting, I hope I can go into a church and hear a wedding service… it is not very clear. (P1)*

Although several did complete the tools beforehand, participants valued the additional explanation that was provided during the focus group with several similar comments, such as:

> *The theory behind it is really good.*

One person offered a simple, succinct introduction:

> *We want to help get the best benefit out of your technology and using this tool will help us to help you.*

Interestingly, once people had used the tools, their reactions became more positive:

> *Once you do know what it's for, you realise how helpful it can be to you. (P6)*
>
> *My first reaction to it was it was very child-like […] but no it's not, because it makes you stop and think […] it was real eye-opener for me. The more I sat and did it, I really enjoyed doing it […] I could really apply it to my life. (P2)*
>
> *Really easy to use, nice and colourful. (P4)*
>
> *For me I found it really useful, I can only see it as being a positive tool for people to use and it's really simple and really easy and quite fun as well. (P6)*

Tailoring support to individual needs not only makes it more relevant and useful, but also actively engages the user in their own care rather than simply being a passive recipient.

> *How can I make it better for me, that's what it's about. (P6)*
>
> *I think this tool is brilliant at allowing you to analyse and find a strategy and plan from it. (P4)*
>
> *It made me think and I really enjoyed the thinking process. (P2)*

All the participants reported that using the tools would help them feel more involved in their own care:

> *It gives you a chance to think about how you can fix it too if something is a struggle for you which I think is a good thing to do rather than passing it off and thinking I just have to cope with it, you have to think about how you can change it for the better for yourself.*
>
> *With this it prompts you to think about scenarios you struggle in and to think, this is what I want to be able to do afterwards, which is really helpful. (P6)*

The right people at the right time

CI users clearly value the relationships they have with people in their rehabilitation pathway, particularly when these are consistent and have a focus on personal connection. All the participants felt that using Ida Telecare tools would develop their relationship with the audiologist:

> *This might be more of a two-way process isn't it? I think it might be good. (P2)*

Most felt the tools would help them to prepare for appointments by thinking about their needs and concerns ahead of time and would value the opportunity to use the tools with their audiologist:

> *It puts a personal focus on your appointment doesn't it? If you put the emotional side of what is going on come out and actively say 'well, this is going on, this is what I need help with'… it would give you the opportunity to say those bits. (P2)*
>
> *It gives you more power doesn't it because what you're actually able to do is to tell them [audiologist] real-life scenarios […] so that they empathise and understand what you're really struggling with, which I think is really important because it's your life isn't it? (P2)*
>
> *For me it would work because you're able to say this is me and this is what I'm struggling with and they've already seen a copy of it and can see where they can help you. (P4)*
>
> (Could you see yourself using this with your audiologist?) *Yes definitely! It prompts you to think before going to your appointment to maybe think about things you are struggling with rather than just talking about it on the day. I think sometimes you might turn up to an audiologist appointment without thinking about all those everyday things […] it gives you time to really analyse all the different things that you do daily [before the appointment]. (P6)*

Participants valued continuity in the relationship with their audiologist in part because the shared knowledge developed over time enables more individualised care; where this continuity is not possible, Ida Telecare tools might provide a bridge to this individualisation.

However, there were concerns about whether the audiologist would consider the tools a priority or have time with all the other demands on appointment time:

> *A challenge is for the audiologist to find time. (P5)*
>
> *The trouble is when you have an appointment with the audiologist and you are given an allocated time, and there have been many things I wanted to ask afterwards, and I have been more or less rushed because they are waiting for the next person coming in. (P1)*

Although users commented about the time constraints of adding the tools to an appointment, they did feel that they could help focus both the individual and the audiologist before and during the session which could help make it more productive

> *I think it makes you concentrate your mind. Most of us have done it, you sit at home and think I must talk about this when I go in, and must talk about that, and ask her about that. (P3)*
>
> *More focussed instead of the 'going round the houses' chat. (P2)*
>
> *I think it is really a good idea, to focus yourself into thinking about what is it that you want to get out of the appointment, the things you want to say […] so you are able to say to them exactly what it is you are missing. Instead of it being based on tests you can say 'I used to be able to hear children, now I can't hear children'. (P6)*
>
> *Having the email helps the audiologist prepare. It gives them a chance to – in the five minutes before your appointment – to have a look at what you are talking about. (P4)*

There was a strong sense of the potential usefulness of the tools, but importantly that they cannot exist as a 'standalone' intervention. Tools help to focus the mind, but in order to be effective they should be used by trained people who understand the purpose and are skilled in using them to support discussion, rather than in a prescriptive fashion or as a checklist.

> *Puts a personal/emotional side to the appointment…if the audiologist is familiar and skilled in using it. (P5)*
>
> *[It could be a problem] I think if it's being used by somebody who doesn't really know what to do. (P2)*

Additionally, the 'buy-in' of the professional is seen as an influencing factor in the effectiveness of the tools:

> *(I would want) them to have read it, for them to be acknowledging of it, for them to be understanding of the different things and for them to help you to try to solve what's on here (the tool)…for them to want you to use it […] if you know that they're positive about it, then you're positive about it so it can be a positive outcome. (P6)*
>
> *I think it depends on whether they (the professional) like it and see it as a positive tool, whether they think it will benefit what they are doing from their side of things. (P2)*

Interestingly, several people felt they might feel uncomfortable to take a lead with the professional:

> *Taking the tool PDF to an appointment might make me feel anxious. (P1)*
>
> *If it [the professional] was somebody you knew and trusted and they suggested a new tool, you may be more confident to discuss, but if you didn't, you may be anxious to question it. (P5)*

However, if adopted by a service, they felt this would be a useful addition, particularly if it was introduced early in the CI process:

> *Especially for people going through that first audiology bit, if that (tool) would be implemented as a system. You would be working to that system with every appointment. (P4)*

These users told us that rehabilitation starts earlier than the traditional concept of post-CI. Introducing the tools during the decision-making phase may provide benefits in a number of ways. Establishing appropriate expectations is important to perceived success: Using the tools early in the CI process may help both the adult and the professional to better understand what the person is wanting from their CI and to address expectations early.

Participants rated the opportunity to meet other CI users as important, they would value meeting others in a similar position to themselves and suggested that these tools may provide a way to better understand the individual and match them to an appropriate CI user. When asked if they could see the tools being used by a trained CI user rather than a professional, participants felt it could be an interesting option:

> *It's definitely a really positive thing to do to be able to sit and talk to another CI user, it's just really helpful cos they understand where you're coming from and the things you might be struggling with and they could give you strategies…or even to do it in a group of people. (P6)*

Managing the CI in everyday life is a priority for most CI users; involving family and friends is key to this aspect of rehabilitation and to successful outcomes and was valued by participants who received this type of support. Participants did not initially see this as a benefit of the tools, with only two people agreeing that it would help them to involve their key people or to communicate better with them. However, having used the tools, others could see how they could help, for example in providing a different perspective:

> *Maybe even partners filling it out, saying what they can see their partner's struggling with […] cos the way they look at it may be totally different. I might be in complete denial about something where they can see quite clearly I'm struggling with it […] so maybe involving partners like that, it could be really beneficial.*

Or to acknowledge and address issues with those around you:

> *It makes you think about who you talk to about your problems […] this tool makes you think about other people and maybe it's about breaking down barriers of actually talking to other people about it, about where you struggle and why you struggle. [It made me think about] who else I should have been talking to really, it did make me think about that and what I needed help with.*

Conclusion

Whilst managing audiological and technical issues are an essential aspect of the cochlear implant pathway, these CI users demonstrate that their rehabilitation needs are much broader than this narrow focus and start even before they receive the CI. Whilst the principles of person-centred care are clearly important to them, CI users report that many elements of this approach are not routinely provided.

Telehealth is an important and growing presence in modern healthcare with many potential benefits to the system as a whole; the challenge is to ensure that the recognised benefits of person-centred care are developed within this approach. Used within the context of a relationship with a skilled facilitator, the Ida Telecare tools *Living Well Online* and *My Turn to Talk* successfully provide a way to deliver the core principles of person-centred care with adults who choose a cochlear implant. For UK CI centres, the introduction of such tools into practice early in the pathway could deliver benefits for both individuals and services.

References

Ferrari, D., & Bundesen, L. L. (2017). A person-centred approach to telehealth. *ENT and Audiology news,* 26(1).

Grenness, C., Hickson, L., Laplante-Lévesque, A., & Davidson, B. (2014). Patient-centred care: A review for rehabilitative audiologists. *International Journal of Audiology*, *53*(sup1), S60-S67.

Lockhart, F. (2018). Tele-audiology and person-centred care. Available at: https://idainstitute.com/tools/university_course/module_5.

Mead, N., & Bower, P. (2002). Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient education and counseling*, *48*(1), 51-61.

Oates, J., Weston, W. W., & Jordan, J. (2000). The impact of patient-centered care on outcomes. *Fam Pract*, *49*(9), 796-804.

Ryu, S. (2012). Telemedicine: Opportunities and developments in member states: Report on the second global survey on ehealth 2009 (global observatory for ehealth series, volume 2). *Healthcare informatics research*, *18*(2), 153-155.

Wolf, D. M., Lehman, L., Quinlin, R., Zullo, T., & Hoffman, L. (2008). Effect of patient-centered care on patient satisfaction and quality of care. *Journal of nursing care quality*, *23*(4), 316-321.