



# **Cochlear implants: what adult users really think**

## **Report to the Royal National Institute for the Deaf**

November 2009

### **Executive Summary**

A specifically designed questionnaire was used with adults with cochlear implants to ask about the services available to them and what they felt about these. Responses were received from 187 adults of which 120 were analysed. These issues were explored further in a follow-up study of interviews with ten of the respondents which looked in greater detail at their experiences of the whole implantation process and the support they had received.

- For many deaf people implanted now, the internet is a source of information, particularly before implantation.
- Twenty seven of the 120 responding to the questionnaire had been refused an implant at some time, because of funding difficulties.
- Criteria for implantation is changing to include more adults with congenital hearing loss (as opposed to acquired), including young adults who missed out on an opportunity to receive an implant as a child.
- Support groups, which have traditionally met the needs of older deaf people with acquired hearing losses may need to adapt to reflect the changing population. ,
- The experience of cochlear implant centres during the assessment period was nearly always reported positively.
- The decision as to which ear to implant could be difficult as the best option generally held by professionals is to implant the better ear which will have received the most stimulation, but some felt reluctant to risk losing the hearing in that ear.

- The processor switch on was very often a very emotional time, although it was experienced differently by different people.
- In general the benefits of a cochlear implant were perceived as in the areas of general communication and relationships and in use of the telephone
- Of the 120 questionnaire responses analysed, 10 had needed a replacement implant at some time.
- People felt the greatest support they received following implantation was from the cochlear implant centre, the next greatest being a significant other such as a spouse or partner.
- Twelve adults, ten percent, said they did not receive any support except from that provided by the cochlear implant centre
- There was a high level of satisfaction from those receiving support from the cochlear implant centre, however some found the distance they needed to travel to the implant centre was prohibitive.
- One quarter of those responding to the questionnaire did not feel they had had adequate therapy input since receiving their implant.
- A number of the interviewees commented on the lack of local support groups for newly implanted young adults
- Many of those with implants did not know that local services could also provide support, and of those that were aware, many did not know how to access the support.
- Some felt the support provided by local services was less likely to be as good as that provided by the specialist cochlear implant centre.
- Many felt that specialist training should be offered to local professionals who provide support after implantation.
- A number of those with implants felt that a professional visit to this place of work would have been useful in explaining about the implant
- Forty-six adults, thirty-eight percent, said that they would consider a second, sequential implant if offered, although a number acknowledged funding restraints.

## Introduction

In cochlear implant research there has been much focus on the needs of the paediatric population but the biggest recurrent demand is likely to be for adults. In addition to those already implanted, about 7,500<sup>1</sup> adults are audiologically suitable for an implant. The annual recurrent demand is conservatively estimated to be 1200, being 450 children and 750 adults. In many countries, increasing numbers of adults are receiving implants with considerable benefit.<sup>2</sup>

The questionnaire study reported here is a follow up to previous research carried out by the Ear Foundation looking at services for adults and children across Europe (funded by Cochlear Europe). Whilst there is a plethora of measures of outcomes both surgical and functional very few recent studies have focussed directly on adult satisfaction with post cochlear implant support

The European study (Archbold et al, in preparation) showed that cochlear implant programmes continued to be recognised as the centres of expertise for selection, surgery, switch-on and trouble-shooting with the responsibility for training others.

However it was found that there needed to be more transfer of skills to local professionals, particularly as the numbers of adults being implanted continues to grow and the support is lifelong. Concerns were expressed regarding local support and training of local professionals. Responding to the current focus on service delivery and cost-effectiveness of cochlear implantation, this project aimed to look in more detail at adult satisfaction with post implant services in the UK, both those provided locally and those provided by the cochlear implant centres, and also investigated a small group of individuals' responses to the experience of cochlear implantation.

In The interview study provides an in depth examination of the experiences of adults who have received cochlear implants. This report thus consists of the results of the questionnaire survey carried out by Sue Hamrouge and interviews, carried out by Alexandra Wheeler. These two studies combine to provide a rounded picture of the perceptions and experiences of implanted adults in the UK today. The findings are presented chronologically in terms of the experiences of the adults, starting with the decision to have an implant.

## Method

### The Questionnaire study

The questionnaire was designed to be clear and accessible to adults whilst providing as much detail as possible. The template for this survey was the European questionnaire which was modified to address particular issues that were thought to be pertinent to the current UK situation. It was piloted with adult cochlear implant users who accessed the Ear Foundation Sound Advice meetings and some minor modifications made to ensure clarity. Comments were also sought from other professionals.

The questionnaire was distributed via the National Cochlear Implant Users Group which has a wide membership across the UK and also through two local cochlear

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<sup>1</sup> Patient/carer group consultee submission by the National Cochlear Implant Users Association (NCIUA).Non-manufacturers submission. [www.nice.org.uk](http://www.nice.org.uk)

<sup>2</sup> Ref as above in Cochlear Implants: 2009 The Ear Foundation Factsheet.

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implant users group. Additionally it was promoted and available on the RNID website and the Ear Foundation website.

In total 187 questionnaires were returned, giving information on the adults who completed them and the services they received. Of these 120 were analysed (see Appendix 1.1 for details). The detail of the questionnaire group is recorded in Appendix 1.2. Of the group aged 25-50 years, 40% had been implanted for one year or less at the time of returning the questionnaire.

Of the group aged 50-60+, 11% had been implanted for one year or less.

There were 26 adults who reported a visual impairment – two of these people had bilateral implants. Seventy-Six adults indicated they would be happy to be interviewed further regarding the information they provided in the survey. Of the replies analysed (120) 94 adults wished to be included on a research database and be involved in further research.

### *Geographical Spread*

Adults were given the option of providing an address or e-mail if they wished. Of those who chose to give their location (90) the majority, as expected, were from England (79), with 8 from Wales, Scotland 2 and N Ireland 1. It is considered that the spread of responses across the UK reflects a fairly wide geographical range from Cornwall through to Suffolk and Sussex to the West Midlands, Eastern and Northern England. Proportionally there were a smaller number of responses from the North as compared to the South of England.

It should be noted that some cochlear implant centres draw (or have taken in the past) from a wide geographical base whilst other centres operate more locally.

### **The Interview study**

This group consisted of 10 adults from the cohort aged 18-50 who responded to the questionnaire and indicated their willingness to be interviewed. The details of the interview group are tabulated in Appendix 2.1

They were contacted by e-mail or letter and invited to take part. They were interviewed at a place of their choice; in most cases this was at home, in two cases at their place of work.

The Interviewer is experienced in communicating with hearing-impaired people and works on a paediatric cochlear implant programme.

The interviewees were informed that their details would be anonymised and that the information given would remain confidential to the study collaborators. Where information was disclosed about cochlear implant teams, hospitals or their staff, this information would be reported in a form which was unidentifiable.

No interviewees requested additional communication support and all interviews took place using spoken language.

A semi-structured interview format was used which ensured that a common range of issues was discussed whilst giving opportunity for further discussion around these. Occasionally these discussions became very emotional and not all that was said was recorded verbatim and instead the interviewer noted a summary of the discussion.

The time which had elapsed post implant ranged from 6 months to 20 years, thus covering the period from the first cohort of adults receiving cochlear implants in the UK to very recent implantation utilising the most recent technology.

Although the interviewees were not asked to identify their cochlear implant centres, they all did so and therefore it is known that their responses reflect experiences of five major cochlear implant centres across England.

This study group may be considered surprising because it contains a high proportion of adults who might be considered to be pre-lingually deaf. Historically only adults with late progressing or acquired hearing losses have been considered for implantation in the UK yet this group includes only two adults with acquired losses. However as described in Appendix 2.1 there is a history of progressive hearing loss in some cases.

## Results and discussion

### The Decision to go for a Cochlear Implant Assessment

The interview group was asked about their opportunities to have a cochlear implant assessment at a younger age. In some cases, clearly this would not have been appropriate as their hearing loss would not have been considered profound enough, especially according to the criteria of the time. However in two cases, parents were offered a cochlear implant assessment but turned it down. The parents of Study 1 wanted their child to make the decision for herself when she was older (father is deaf and the family use BSL as well as spoken language to communicate). The mother of Study 5 refused to allow her child to have an operation. In both cases the interviewees wished that their parents had allowed the assessment to take place. In the case of Study 5, her decision to request an assessment as a young adult caused a rift with her mother who continued to oppose the idea. She was obliged to pursue the assessment by herself although her mother did agree to support her on the day of the operation and at switch on and has subsequently acknowledged that the decision to go ahead with a cochlear implant was the right one.

There were no instances in this study group of children being turned down by professionals and then subsequently re-assessed as adults.

When asked who had initially suggested a cochlear implant assessment, most reported that the initiative had come from professionals – not necessarily audiologists or doctors; in two cases teachers of the deaf suggested looking into implants (in one case this was a sibling who had qualified as a teacher of the deaf) and in another instance a speech and language therapist. One person was offered an implant assessment at age 19 but turned it down as she had only heard of negative experiences. Another who was offered an assessment by her specialist felt that it would affect her identity of herself as a deaf person. She changed her mind when she began to get frustrated with her ability to cope with her job and in particular, group discussions. This person commented that the ENT consultant was very tactful, and did not pursue the issue of a cochlear implant beyond giving her a brochure to look at, until she raised it again herself.

Only one interviewee referred to encountering opposition from the Deaf community and her deaf boyfriend. Her response to him was robust:

*'I said 'if being profoundly deaf is so good, take out your hearing aid and be completely deaf'. (3)<sup>3</sup>*

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<sup>3</sup> Quotes taken from the interviews are annotated with the study number in brackets and can be referenced against the data tables in Appendix 2.

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Most reported that they had relatively little information available to them initially. The sources used for gathering more information about cochlear implants reflect the times they were living in. For Study 9, implanted over 20 years ago, the technique of cochlear implantation was considered experimental and wearable speech processors were only just becoming available. She benefited from having a GP who was well informed and willing to refer her to the only centre in the region carrying out cochlear implants, over the head of her local ENT consultant. She commented *'the first one I saw was like a typewriter'*. (9)

More recently implanted adults often used the internet to garner more information, especially for making contact with other user groups and to find out about the differences between the two or three main brands available. Contact with other cochlear implant users was seen as valuable.

During the course of the interviews, some commented on the differences in needs between those who are older and have acquired hearing loss and those who are relatively young and may be deaf since early childhood or birth.

*'A lot of people went deaf later in life they sent me encouraging messages but I felt I couldn't relate to that because I was born deaf.'* (8)

This reflects a new and emerging population who are looking for advice and support from peers in similar situations.

Only two interviewees reported that some members of their family had been unsupportive of their decision to go for an assessment.

### **The Assessment**

No difficulties were reported regarding communication with cochlear implant centre staff and most seemed satisfied with their assessment. Some of the young adults took a parent with them to ask questions on their behalf. The only BSL user had an interpreter provided for her appointments.

For one person, the assessment process threw up further complications in that it was discovered that she had bilateral cataracts. She struggled emotionally as she had recently lost a lot of residual hearing very suddenly, moving from a severely deaf young person who was able to cope reasonably well with hearing aids to someone who could not. She began to worry that an implant operation might be unsuccessful, feeling that everything that could go wrong, would inevitably do so.

Another interviewee (Study 6) who lost the residual hearing in her only usable ear also struggled with the consequences of being suddenly unable to access any spoken language. She talked at length about the feelings of isolation, of no longer being able to attend her church and the consequences on her social life. She discussed the effects on her relationships with her young children and the impact that it had on her toddler son's development of his own spoken language skills.

### **The process:**

Not all interviewees were able to remember exactly how long the process from referral to operation had taken but in a number of cases this exceeded one year.

For those where there were no complicating factors (50% of the group), the time taken for the assessment ranged from 3 months to 8 months.

Study 6, despite losing additional hearing very suddenly and experiencing a high degree of stress as a result, had to wait for 16 months from referral to having her cochlear implant operation. She estimated that the assessment process itself took around 12 months. She reported that the reason for this was that she was pregnant at the time of the loss and that she was unable to attend appointments at the cochlear implant centre because there was no provision for her to breastfeed her new baby. She therefore decided to wait until her baby was weaned before

progressing further. Ironically she experienced the same problems again when her implant failed (see later).

In another case, where the assessment period lasted 10 months, the interviewee reported that the delay was the result of missed appointments. She was feeling nervous and uncertain and didn't always attend.

For Study 12 the process took 2 years- in this case complicated by a diagnosis of Ménière's Disease.<sup>4</sup>

*'Over the 2 years probably had 15 trips to the hospital in and out. The financial outlay was beginning to creep up- just kept thinking of the benefits.'* (12)

Study 5 was undecided (having rejected an implant assessment at younger age) and hence the assessment took 1 year.

### **Funding:**

Responses to the questionnaires showed that 27 adults had been refused a cochlear implant. Twenty two adults outlined the number of times they were refused; 14 adults were refused once; five adults were refused twice, one adult was refused four times and one adult said refusal occurred "many" times. Respondents were not asked to state whether the refusal was for the first implant or a request for a second implant, however two people added a comment that they had been refused for a sequential implant.

*'Small proportional further benefit anticipated against the brilliant success of the initial implant.'*

One person also commented:

*'Not refused exactly (2nd CI). Just told unlikely to get funding as I do not fill the criteria for justifying a second implant.'*

Another person has not requested a sequential implant because it would be *'too expensive for local hearing services'*.

A further person quoted the NICE decision as a reason for not requesting a sequential implant.<sup>5</sup> (These guidelines did not support the provision of sequential cochlear implants for adults.)

### **Reasons for Refusal (questionnaire data)**

Audiological	No Funding	Medical	Psychological	Disabilities	Age
12	8	3	3	2	1

Two people stated that they had resorted to private medicine:

*'We privately funded my implant, I was 35<sup>th</sup> on <hospital> list. Just been accepted by NHS for management. Would have appreciated more support.'*

<sup>4</sup> Lustig et al (2003), Cochlear implantation in patients with bilateral Ménière's syndrome. Otol Neurotol 24(3);397-403

<sup>5</sup> Cochlear implants for severe to profound deafness in children and adults National Institute of Health and Clinical Excellence TAG 166, Issued January 2009. [www.nice.org.uk/guidance](http://www.nice.org.uk/guidance)

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One had been implanted 8 ½ yrs ago and commented:

*'At the time when I was implanted biggest problem to convince NHS fund managers that C.I. was worthwhile. Eventually had whole process done privately out of frustration and have never regretted it but wouldn't mind having the cash back.'*

The only interviewee who did not have her cochlear implant funded by the NHS was Study 9 who was one of the first in the UK to receive one, at a time when Cochlear Implant Centres (CICs) were dependent on charitable donations. Study 4 had to wait 12 months for his operation. It is believed that this was due to funding being prioritised for children over adults.

Studies 3 and 6 needed funding for re-implantation. In the first case this was straightforward; in the second case, the cochlear implant centre decided to apply for bilateral funding which complicated the issue. Initially funding was refused but eventually provided on appeal.

One questionnaire respondent reported that they had been refused a cochlear implant earlier at 10 yrs of age on audiological grounds. This is an interesting finding, as it reflects the change in audiological criteria that has taken place over recent years. Another person was turned down aged 21 having been told that cochlear implants were for children but was finally implanted 4 months ago (he gave his age as falling in the 25-50 bracket).

### **Making the Decision**

The interviews revealed how much people's reactions on hearing that the cochlear implant centre was willing to offer a cochlear implant varied:

*'I was shaking afterwards. I was feeling very apprehensive, wondering what the future would hold. I worried slightly as I was told that it would sound very different and I would be having to live with a different type of sound for the rest of my life.'* (7)

One interviewee appeared frustrated with what she regarded as the lack of information about outcomes and reported that she was left to make a decision without having the information that she felt she needed. When asked what would have been better for her, she responded:

*'I know people are different but I feel they could have given me a cross –section of different examples so at least I would know the range. Also background information about their criteria, the numbers of implantees like me over the past year, their outcomes. The only thing they were definite about was that it would be at least as good as my hearing aid or better than the hearing aid.'* (8)

In some cases, it was a very difficult decision to make:

*'I still wasn't sure whether I wanted to go ahead. With the hearing aid I could only hear environmental sounds; they said if I had an implant I would only hear environmental sounds. Then I came to the Ear Foundation to meet three experienced implant users and that was what made me change my mind..... some were told that they might only hear environmental sounds but got speech as well and that encouraged me that if I went for it I had got nothing to lose. They said the cochlear implant had changed their lives.'* (1)

*'I wasn't too worried whether yes or no because I felt very unsure myself whether I wanted it. Part of me thought if it is not possible then I won't have to make the*

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*decision.....Maybe most people have decided if they want to have it. But I was unsure.*

Interviewer: "So what made you decide?"

*One main point that made the difference was that I felt frustrated to the point where I wanted to try something else- I was willing to take a risk.*

Interviewer: "You saw it as a big risk?"

*It seemed like a big risk.' (8)*

One interviewee had conflicting advice from her mother and the cochlear implant centre:

*'I wasn't too sure. I didn't know how it would benefit for me. Because I grew up to listen to small things that probably made me different.*

Interviewer: "How did you decide?"

*I was missing out on what people were saying, people were telling me I was really quiet in the pub- well that was because I couldn't hear my voice. So that's when I did some more research; within two months of research I met about 40 people with cochlear implants over the internet'. (5)*

For others, the decision to go ahead was relatively easy:

*'I based my decision on the fact that I needed a cochlear implant or without it I would struggle- I had nothing to lose.' (6)*

In some cases it was a relief to be offered a cochlear implant, but there was a difference of opinion about which ear to implant and further discussion was necessary.

*'So when I was offered an implant I was quite elated but a shock that they wanted to do the right side – quite a shock because I had spent two years saying that I wanted hearing in my left ear- I wasn't willing to give up the better ear for an implant. (They) went away and talked about it and they agreed to implant my worse ear.' (5)*

Interestingly this person is now asking to have a second implant in his 'better' ear having decided that the benefits of a cochlear implant are so much greater than using a hearing aid.

The issue of whether to implant an ear which was considered to be either 'dead' or unusable for some time versus an ear which has continued to be stimulated through a hearing aid represents an area of some debate within the field of cochlear implantation.<sup>6</sup> Received wisdom suggests that the best results are obtained from implanting an ear which has been stimulated recently, however poorly, rather than an ear in which significant deterioration of the auditory pathway may have taken place. However from the recipients' point of view this is by no means straightforward. It is difficult to potentially jeopardise the hearing in the only ear that is giving benefit and leave the worse ear untouched.

One person was given the choice:

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<sup>6</sup> UK Cochlear Implant Study Group. (2004). Criteria of candidacy for unilateral cochlear implantation in postlingually deafened adults: theory and measures of effectiveness. *Ear Hear* 25(4):310-35.  
Francis et al (2004), Central effects of residual hearing: implications for choice of ear for cochlear implantation. *Laryngoscope*. 114(10):1747-52

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*'I was told suddenly at the meeting. They gave me an offer to choose either ear. I went for the bad ear.'* (1)

There was some doubt about the wisdom of offering a cochlear implant to this person as not only had she been profoundly deaf from birth, but also scan results revealed that she had malformed cochleae with the likelihood that only a partial insertion of electrodes would be possible. She was counselled to expect only some awareness of environmental sounds.

Another person had a similar debate with her surgeon but in the end agreed to implant the better ear as he suggested although she found the decision very tough.

*'The surgeon said he would prefer to do the left ear- he didn't say I had to. I thought what he was saying made sense but I was disappointed because I thought I might be able to have a cochlear implant in the right ear . It made me nervous, the decision much harder because I felt that my better ear was all that I had.*

Interviewer: "But you agreed?"

*Yes I thought if I was having a cochlear implant operation I should have the best possible chance of hearing.'* (8)

For Study 6, the decision was taken to implant the better ear. She was subsequently offered a sequential implant in her 'dead' ear at the same time as having her first ear re-implanted. Having experienced implant failure, she was interested to try it in case it might provide a 'backup' for her better ear.

*'Then they said how would you like your other ear done? {Note: by e-mail}. So I thought about it – it might not work (but) It would be something to fall back on in case it happened again.'* (6)

She described the differences in responses to switch on between the two ears- the response in the second ear was *'just a tapping sound'*. However she worked with it and the responses have improved over time.

### **The Operation**

In general, people felt that they had been fairly well prepared for the operation. Many mentioned that they received clear information about the risks of surgery and outcomes.

One person saw a video of a cochlear implant operation afterwards and said that she was glad that she hadn't seen it beforehand. Another young adult stated that although she had been given information at the assessment stage, she hadn't really listened as she found it too painful. She also didn't want to hear that the operation would involve a lot of rehabilitation afterwards. She did understand the information given to her on the day of the operation.

The interviewees were asked about their experiences of communication on the ward. A couple of people were implanted at a specialist ENT hospital, but the others were on ENT wards in general hospitals. Experiences varied but a number reported that doctors were not the easiest to understand

*'Consultants are the worst in the world. They mumble at the bottom of the bed or talk to my husband. I dread going into any hospital.'* (9)

*'There were student doctors around the bed but thank God for a female doctor- women are understanding. One doctor was talking away – asked questions which I*

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*couldn't understand- he refused to write it down- a woman got out a pen and paper and he refused to write it down.'* (3)

Lack of general deaf awareness was also an issue.

*'I didn't think they were all deaf aware, deaf friendly. Some of the younger nurses were really good. (Another nurse) Temperature (Interviewer note: she needed to put the probe in the opposite ear)– I asked her to wait until I had taken my hearing aid out but she immediately whipped it out, pulling the tubing out, leaving the mould in the ear. I said ' I did ask you to wait' but she didn't apologise. Eventually another nurse came- I was panicking trying to get the hearing aid to work, I was very tired, drugged. I asked for someone to check it the next morning. I had to go down to x-ray without a hearing aid.'*

One interviewee commented on the difference when he had to be re-admitted to a different ward after developing a post-operative infection.

*'When I went back in with an infection not the same as the cochlear implant operation- I was in a totally different ward. I had a lot of communication difficulties with the doctors doing their rounds. Constantly asking them to repeat. I had to provide a pad and ask them to write it down. The nurses were helpful; when the doctors were there they had to step back but when the doctors went away, the nurse came forward and explained everything. The registrar doctor in my opinion, he was a bit poor, it almost felt like he was not looking, not really talking to me just saying things so that the nurses could hear.'* (4)

Post-operative experiences varied, with some having taste disturbance (n=3), balance problems (n=2) and dizziness (n=2) whilst others did not. One person had tinnitus for the first time three weeks later (but not since) and one person experienced mouth droop (indicating that the facial nerve had been affected) but this only lasted for a short while and was not considered a problem. One person also had problems with post-operative infection which necessitated re-admission to hospital.

### **Activation of the Cochlear Implant**

All the interviewees reported the usual gap between operation and switch on of 3-5 weeks apart from one, who asked for it to be delayed to enable him to attend a work event.

Accounts of the day their devices was switched on for the first time are varied and inevitably reflect their previous experience of hearing and duration of deafness.

For some, it was a very emotional event:

*'Me, my mum all started crying. It was good. Obviously it sounded like metal mickey. We were all crying and my speech therapist- that was a good thing not a bad thing.'* (3)

A couple of interviewees found it hard to believe that they had actually been switched on.

*'It was quite exciting – crunch time- it had taken nearly three years to be finally switched on. The journey was quite long but in some ways it makes me appreciate what I have now.*

*Heard my mother who has a high pitched voice- not sure if I understood the words. I heard my Dad's voice and knew it was my Dad- not difficult as the only male in the room! He said to me 'have they switched it on yet?' and I said ' I think so'.*(2)

*'I didn't believe I had been switched on. Did all the beeps then I heard a whirring noise all very high. Nothing clear at all- ooh ooh ooh sound. Didn't believe I 'd been switched on. They started banging the table, rattling keys and then I realised. Telling myself not to get too frustrated – go outside, go to café- hearing the fridge rattle was a shock. My mother and husband sounded funny. I had speech and language therapy in the afternoon, starting to do exercises. I could hear that the words were gradually coming through. Mum was convinced that within 3 hrs I was beginning to hear words. When I got home I was shattered.'* (10)

Most people seemed to find the process quite difficult at first. One man admitted that his expectations and those of others around him had probably been too high:

*'It was quite exciting- a lot of expectation. I think my expectations were a bit too high. I put on some favourite music which I hadn't heard in years- it wasn't quite there. I was quickly very tired. I remember the second day being a lot better.'*(4)

For many, the reality was quite hard to manage.

*'It was awful. I had my Mum and Dad, husband and a room full of audiologists and other people watching. It sounded like Pinky and Perky- all these noises. I could see people speaking and there was a time delay. Got told to go off for lunch – but don't take it off. Well you know what <road> is like- very noisy. It was terrible – wasn't a recognisable sound. But it was pretty rapidly that you started to recognise speech. I went every week for 6-7 weeks. I was given exercises to do. I remember feeling quite tearful- this is awful I can't live like this. Your own voice sounds bizarre.'* (9)

This person's experience was of a very early cochlear implant device but her description of the way the sound presented at first was mirrored by many of the interviewees using term such as 'metallic', 'Daleky' 'like cartoon characters'.

Only two seemed to find the whole process an upbeat one:

*'It was quite exciting – crunch time- it had taken nearly three years to be finally switched on. The journey was quite long but in some ways it makes me appreciate what I have now.*

*Heard my mother who has a high pitched voice- not sure if I understood the words. I heard my Dad's voice and knew it was my Dad- not difficult as the only male in the room!'* (2)

*'It was like a Dalek- high pitched voice. Even my husband's voice was high pitched. I was laughing. It was challenging.'*

Interviewer: "In what way?"

*'All the different sounds- I had to learn to interpret them in a different way'.*(6)

In three cases the interviewees reported that they felt the need to have the sound 'turned up'. It is common for maps to be set fairly conservatively at first but none of the interviewees indicated that they knew this in advance:

*'I was quite bewildered because I was given this seat behind the beeps- everything sounded quiet- could hear things but not quite; I didn't ask if the volume was loud enough. I arrived home and said I need the volume turned up.'*

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*'I realised I had to ask for the beeps to be louder- then 'this is better I can hear, could actually hear.'* (7)

Most of the interviewees reported that the initial unpleasant or difficult sound sensations improved over time; in some cases this happened during the course of the initial switch on appointments, in others it took longer – up to six months before the sound sensations became more comfortable and made sense.

One person who had a progressive hearing loss with a sudden loss of remaining hearing, reported that her memory of sound returned after just one day.

Another person had some difficulties with non-auditory stimulation during follow up switch on appointments, but this was resolved by changing the mapping strategy. The main disappointment was the need to re-learn how to listen with the new strategy having just begun to get used to the initial sound through the implant, but ultimately it was successful.

However for one person (Study 8) the whole experience was very unpleasant and was followed by further complications.

*'The sound was awful- when they switched it on it was not a nice sound- like having an electric shock. It was difficult because I had imagined what the sound might be like- distorted or strange but I did not expect that it would not be like a sound. It was unexpected. It was only gradually that I started to recognise it as sound. It felt uncomfortable. I went home on the Tube with my mum. I burst into tears because it was so uncomfortable- it felt like an electric shock. It seemed very strong but that's because they were high-pitched sounds that I had never heard before. At home I went into the kitchen and opened the fridge and I knew it was working because every time I moved something it made a noise. I felt it was so strong it was almost hitting me!'* (8)

One month later she decided that she could not continue wearing the speech processor and that she needed a break. After 2-3 weeks she recommenced wearing it. Then she developed severe dizziness for seven weeks and was frustrated at being unable to get a definite explanation from her consultant. It was not clear whether this was implant-related.

Interviewees were asked whether they felt supported through the switch on process. In the case described above (8), she was referred to a clinical psychologist who encouraged her not to give up. In fact this annoyed rather than helped her.

In the case of a young adult, she was given a lot of support from her mother who encouraged her to keep going through the initial disappointment and also from the cochlear implant centre hearing therapist and speech therapist:

*I couldn't hear sounds just like beeping, if I was to clap my hands every clap was a beep. When the audiologist talked to me every syllable was all beeps.*

Interviewer: "Were there immediate consequences?"

*A little bit disappointed because when I went home the beeping didn't stop. Almost to the point where I wanted to give up but my mum persuaded me to keep going.*

*At three months the mapping got better that's when I started to hear environmental sounds. I didn't like it at all. Then at six months the sounds started to get better; first I heard my mum's voice then I went home to try and listen to other's voices.*

Interviewer: "Did you feel well supported through this?"

*The hearing therapist and the speech therapist supported me a lot.*

Interviewer: "Did you tell them you felt disappointed?"

*Yes they told me to keep trying and it will get better and it did get better. As my results got better and the tests got better it gave me the confidence to keep trying.'*  
(1)

Interestingly this person, a BSL user, was counselled to expect only environmental awareness from her cochlear implant but less than one year later was able to take part in the interview using only spoken language.

### **Post cochlear implant follow up**

Results from the questionnaires (see Appendix 1.4) showed that almost all adults (99%) felt that implant centre staff were involved in follow up after they were implanted. The second most important input was support from a significant other e.g. spouse, partner (38%), then the local audiologists (30%) local hearing therapists (30%) and local speech and language therapists (28%). Of the local speech and language therapists (LSLTs) 5 adults (4%) paid for this support and in these cases this was the only SLT input.

One of the adults above also paid for private audiology and hearing therapy support. All other provision recorded above was provided by the state.

Twelve adults (10%) recorded that they did not receive any follow up support apart from that provided by the CIC. Fifty three adults (44%) reported receiving support (recorded in 'Other' section) from various sources such as LINK, social services, lip reading classes, psychologist, local centre for the deaf and the Ear Foundation.

However a common theme which prevailed through many annotations to the questionnaires was that adults were not aware that there were local services available and even if they knew there were they did not know how to access them.

A wide range of issues was mentioned under the 'other category' for support Three adults reported that follow up care was not available locally and two commented that they had never tried to access support locally and one went further to say that they did not even know if local care existed. One adult expressed the need for more intensive speech and language therapy and more frequent appointments after the first year post implant. One adult stated that local services were based in the same building as the CIC. Two adults commented about the distance they had to travel, 60 miles and 112 miles respectively, to access the support provided by the CIC as none was available locally.

### **Specific Support Following Activation of the Cochlear Implant**

In total one quarter of the adults who responded to the questionnaire felt that they should have more therapy available to them (see Appendix 1.5.1). 18% of adults felt they needed more intensive therapy from the CIC and 7.5% felt they needed more intensive therapy from local professionals. (See Appendix 1.5)

One person commented:

*'Local follow up is important and should also be available on-line for people in the country.'*

A small number of adults (6.5%) felt that visits by CIC staff to home/employment would be beneficial.

One of the respondents commented that she would like staff from the CIC to visit her work colleagues *'to explain to employers re: implants and deaf awareness of implants.'*

Five adults (4%) felt this input should be provided by local professionals.

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One person commented on the attitude of local professionals:

*'many healthcare professionals seem to think that CI replaces normal hearing patterns and therefore no further adjustment is needed on their part!'*

Five interviewees made very positive comments about the support they received from their cochlear implant centre.

*'All the way through it was good. I know that if anything went wrong I would be straight back.'* (3)

*'Oh yes fantastic support very good team. The audiologist responds to e-mails, <name> in the office and <hearing therapist> and ,<speech therapist> are always helpful. She gave me some really good advice. Also talking to a counsellor about deaf issues at work. No complaints at all.'* (7)

One person had moved and therefore changed cochlear implant centres and was positive about her experience with the first centre but less sure about the second. Study 9 has lived in a different part of the country for sometime but has refused to change cochlear implant centres because she feels more comfortable continuing with the staff she has got to know over the years.

The suggestions on what could be done better were varied -the comments were often very specific to the individual's own experience. One young adult pointed out that CI support groups tend to be focussed on older people as this was the group most commonly receiving implants, and that her needs were different. She got her support from the Ear Foundation. Another interviewee who received her implant at a relatively young age also commented that there is no support for the specific group of young people who have been born deaf and received an implant as an adult. Study 6 wanted more local support groups and was actively involved in trying to set them up. She suggested a system of telephone buddies. She also pointed out that adults get no local intervention. Another interviewee made a similar point about speech therapy, suggesting that cochlear implant centre staff should be training local speech therapists to deliver habilitation. Another suggestion was for support in the workplace (this was also mentioned elsewhere in the interviews):

*'The people who did all the assessment were good however I think if someone could go into the workplace to explain- deaf awareness. Also this is what she is going through at the moment. What the implant is and that post cochlear implantation you need to be given time to build up confidence. Even just a DVD to produce- going through the process etc.'* (10)

### **Getting help**

Adults were asked whether they felt that they could get help from certain implant centre professionals if they needed it. Seventy five per cent of the respondents felt that they could get help from an implant centre audiologist and 70% from their implant centre hearing therapist. (See Appendix 1.5.2)

### **Training Needs of local professionals**

One comment was made in a questionnaire response that it would *'be good if all professionals had the training for all aspects of implant.'*

In the questionnaire a choice of options was offered to select the way in which training should be provided for local professionals. The strongest responses were

that it should be delivered using courses at cochlear implant centres, followed by web-based resources (see Appendix 1.6.)

***How should training be provided?***

This response was mirrored in the responses to a question asking who should provide the training, where again implant centre staff were seen as the primary trainers. However cochlear implant manufacturers were also felt to have a role in this

***Who should provide the training?***

One adult wrote *'not sure who should provide it as it could come from many places'*. The spontaneous comments reveal a high level of satisfaction and the users are happy with the support received at the CIC. However there is surprise expressed that the question was asked about local services as the users did not know they existed and in some cases this raised awareness about lack of local provision. The reliance is still on the CIC and reluctance to source provision from local centres as the users feel there is a lack of expertise. It was widely felt that local services did not exist or if they did considerable time and resources were needed to gain user's confidence that local services were not Cinderella services. There were comments that had local services been available, time and effort would have been saved on long journeys to the CIC.

**Benefits of Cochlear Implantation**

The interview study found that for 9/10 interviewees, the process has been ultimately a positive one, even if there had been difficulties along the way. Overall most people seemed to think that the implant had either come up to expectations or had provided more than they had dared expect.

Tinnitus was mentioned by some as a problem prior to implantation; following implantation it seems that either the problem disappears in the implanted ear or that the sound from the speech processor masks it. However people may continue to have problems in the contralateral ear.

Interviewees were questioned about the time taken to get full benefit from the cochlear implant and the responses varied from a few days (1), 1-4 months (3), 6-8 months (2), to 9 months (2). One person did not feel that she had gained much benefit. Study 9, who was implanted over 20 years ago was very appreciative of the benefits she received but pointed out that there were a lot of things that she still couldn't do, as she remains dependent on lip-reading.

Using the telephone was the most frequently cited benefit (4) along with social communication (4). One person commented how she could now hear her own voice more clearly.

A couple of people reported that they could now watch television without needing to rely on subtitles. In general it seemed that the general ease of being able to hear better and deal with social situations were the main advantages.

*'Being able to hear the telephone, listen to music, take part in activities, talk more freely and more comfortably without asking to for repetition; communication, being able to have a laugh, have a banter without feeling constrained.'* (10)

When the question was turned around to ask what other people comment on, the most common feature was the improvement in speech skills and the ability to listen and take part in conversations.

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Further discussion took place on the subject of relationships and how these might be affected by deafness and subsequent cochlear implantation.

A couple of people reported that they had moved from being part of the deaf community to socialising within the hearing community. In one case, a young implanted adult, she felt almost guilty that she now no longer spent time with her 'deaf' friends. Another person felt that she had to leave the Deaf community in order to make her decision in the first place:

*'Everyone was amazed at what difference it made. It meant that I did have to leave the Deaf community because at the time.. the argument that it causes (meant) I had to come out of the Deaf community to make sure that the decision was mine and not the hospital's.*

Interviewer: 'Did you ever go back?'

'No.' (3)

The two male interviewees talked about the effects of hearing loss on their social relationships with friends and how this had improved since cochlear implantation.

*'I can definitely get on a lot better with my friends and feel like less of a nuisance now. Before they had to give me a helping hand. '(4)*

However this person still finds social situations quite taxing:

*'Still if an event is happening I do sometimes try to get out of it because I know I'll be uncomfortable and not hear anything. I try to avoid going out in large groups unless it is family or close friends who understand' (4)*

One person commented on how being able to use the phone is socially liberating:

*'The cochlear implant must have made it easier for me to be meet people. Being able to use the telephone plays a big part because that is how people keep in touch. When I couldn't use the phone friendships were difficult to maintain because people ring each other up.' (9).*

A couple of people found that their parents only realised how difficult things had been once they saw the difference that a cochlear implant made to their daughters' lives. One woman who had gradually lost hearing from childhood felt that her parents had not really believed how deaf she was, thinking that she was just being 'difficult'. Another mother had failed to realise how much her daughter was relying on lip-reading.

Very few Interviewees chose to discuss the impact on relationships with their spouses but one did comment:

*'It has certainly improved things between me and my husband. Sometimes we'd end up shouting just to try and communicate.' (10)*

### **Re-implantation**

Of those responding to the questionnaire, there were 10 adults who reported they had received a replacement cochlear implant. For the detail of the group, see Appendix 2.2.

The time lapse between initial implant and failure in this group ranged from 1.5 years to 16 years and the median was 4 ½ years.

Nine of the ten reported that they definitely wanted a replacement cochlear implant; no information is given for the other one.

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Half of this group reported that their new system was better than the old one, 3/10 thought it was the same and one person said it was not as good as before.

One person reported that they were experiencing problems with electrode failure resulting in channels being switched off and that it was likely that a re-implantation would be necessary in the future. Draft Quality Standards issued by the BCIG/RNID in June 2009 state that where implant failure is suspected the patient should be seen within 7 days and if re-implantation is agreed with the patient then this should be carried out as soon as is medically possible.<sup>7</sup> The time taken for implant centres to replace implants varied hugely from one week to 18 months. However further examination of the questionnaires showed that there were clear reasons for this. In the case of one person interviewed (study 3, see below), she had problems when her original implant moved and had to be re-sited in an operation which was quickly known to be unsuccessful hence the re-implantation within one week. Two people had problems for a while and there was a joint decision with the surgeon to monitor over time:

*'Re replacement 2 weeks from complete failure to second implant operation. Problems with implant for 1.5 years before during which time it was discovered that <company> had supplied parts from a faulty batch. It was decided by myself and surgeon to wait for complete failure before replacing.'*

One respondent annotated her questionnaire as follows:

*'By mutual agreement 18 months approx as gradual failure'. By this she appears to mean that she and her surgeon chose not to re-implant immediately after electrodes began to fail but only at a later stage once the problem became more severe.*

Another respondent had two replacement implants; the first was a single channel implant 20 years ago which was replaced with a multi-channel implant three years later and then replaced again nine years ago although he does not state why (he did not tick the box for implant failure).

In one case it was not possible to re-implant:

*'I had my first cochlear implant in 1994 which failed due to cochlea turning to bone in 2006. The surgeon attempted two further implants but could not insert them for the same reason. I no longer have any useful hearing but would like to say over the years the implant team at the Hospital were absolutely brilliant.'*

One person was awaiting a replacement at the time the survey was carried out.

The detail of the interview group is tabulated in Appendix 2.2. Two of the interview group needed to have their internal cochlear implants replaced. For Study 3 this was due to the receiver moving from its position in the skull, requiring an operation to re-site it as discussed above. Unfortunately this was not successful and the implant had to be removed and replaced with another one.

For Study 6, her implant failed only 9 months after the operation and was quite traumatic.

*It was fantastic, then it started to have intermittency- I was hoping it wouldn't be an implant failure. There was more and more intermittency- I thought it may have been one electrode. It was a sad day. I thought gosh not now just when I'm pregnant. I*

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<sup>7</sup> Quality Standards for Cochlear Implantation in Adults. Draft June 2009. [www.bcig.org.uk](http://www.bcig.org.uk)

*went quite depressed. It affected everyone around me because there had been so much happiness.(6)*

It transpired that she had been given an implant from a batch that had subsequently been identified by the manufacturer as faulty. In theory she should have been re-implanted swiftly, but again she was pregnant and the same difficulties which had caused the delay in receiving her first implant presented themselves. As has been reported earlier there were difficulties over funding because the cochlear implant centre recommended bilateral implantation and again she had to wait.

Although she received some habilitation follow up after the operation, she commented that she felt that the cochlear implant team were not quite sure how to handle the situation as she was such an unusual case. She had to research the internet for ideas about how to develop her listening skills. When asked how much speech and language therapy she received she responded *'not as much as I thought I would get.'*

She reported that her re-implanted ear adapted very quickly: *'I think it was because the ear was keen to get back to normal.'*

### **Disappointing Aspects of Cochlear Implantation**

This was a question which was posed during the interviews. A couple of people were unable to think of any disappointments with their cochlear implant. One person reported that the only thing she could think of was that it took some time to get used to it. Another interviewee who had been implanted quite recently talked about the difficulties of getting the settings right during mapping sessions- trying to work out what was loud and what was not. Three people commented on problems with background noise, one talking more specifically about wind noise through the microphone.

*'There is a major downside- as soon as I am in a noisy environment a pub or today a BBQ where someone decided to play background music it immediately overrides my ability to communicate with the person that I am talking to. But it was exactly the same with my hearing aids – I was hoping that it would change.'* (4)

Another interviewee, who had been a musician prior to losing her hearing, had been forced to come to terms with no longer being able to enjoy music. Another talked about the risks of scuba diving and not being able to wear her speech processor in the swimming pool.

One person simply did not feel that the level of benefit that she achieved with her implant was much greater than she had before with her hearing aids:

*'I hoped that it would make lip-reading a little easier. I think I rely on lip-reading but I think I use my hearing for the beginning of the sentence but it doesn't really make that much difference. I can turn round when someone starts speaking and then once I look at them I have to carry on. I think my comprehension of other people is more or less the same.'* (8).

### **Bilateral Implantation**

In the questionnaire responses, 46 (38%) of people said they would consider a second implant. One person was unsure and the remainder did not want another implant. Nine people (7.5 %) reported that they had bilateral implants.

One of these respondents was interviewed (study 6 reported below). She was originally implanted unilaterally but received simultaneous bilateral implants when her original implant failed.

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The range of time between first and sequential implant was from 2 to 12 years and the median was 6yrs. Five of the nine are in the 60+ age range. It was noted that that one of this group reported that they had been implanted as part of a manufacturers research study into bilateral implantation. The other four respondents were split equally between the 18-25 and the 25-50 age ranges.

All the interviewees were asked about bilateral implants. The details of the interview group can be found in appendix 2.2. Three people had been offered bilateral implants, including Study 6 quoted above. When Study 6 was asked about the advantages of now having bilateral implants, she reported that her family saw an improvement:

*'My family were very supportive. They said that the bilateral was much better for me. It helps with hearing traffic in the streets, cars coming (because you know which side) also because you know where your mobile phone is coming from.'*(6)

Interestingly two people have so far decided against a sequential implant

*'They have offered me a bilateral CI. I did go and did listen- I felt that as I've done so well the gain in having two cochlear implants would be minimal and would only give me directional value – not worth it for the stress of going through a cochlear implant operation. I would rather keep this ear for future technology even though I'm aware that not using something may mean that you lose the ability. I'll wait until they are doing totally implantable implants- then maybe I'll have another operation.'*(3)

Study 9 also cited possible further developments with hair cell regeneration as one reason for not going ahead.

*'I have considered a sequential as there was no state funding for the first one so should be able to get funding for a second. Asked <ENT Surgeon> and he said possibly but the only way to know is to do one. {interviewer note concerns are around the degree and length of deafness}. Also waiting for hair cell re-generation – problem if ear is destroyed. A little bit of vanity as well- having two implants on my head. I just can't take the time off work...'*(9)

Later further discussion took place 'off the record' about this issue and in particular whether having a second implant would help deal with her severe problems with tinnitus in her contralateral ear. She began to consider again whether she should at least go for an assessment.

Two other people have reservations about a sequential implant. One was aware of research outcomes:

*'I don't think that I would consider having a second cochlear implant. I realise that having a second implant a long time after the first you don't get that much benefit. This is the only tiny bit of natural hearing that I have left.'* {note she is now using a hearing aid again on her contralateral ear}. (8)

The second person was really not sure:

*'I am not sure I would want to go through it again. I've never really worn two hearing aids and so I wonder if I would find it daunting to have two hearing aids.'*(7)

Of the remaining group, three people are actively asking for a second implant; one is aware that there is no funding following NICE and two are going to try and fight for one. Another has asked and been told that he does not fit the criteria. A further

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person responded that she would probably have a sequential implant if offered one but has not requested an assessment.

When asked why they thought that it would be a good thing, one responded as follows:

*'It would help with group discussions; I sit in the middle and I hear friends in the middle and I lip-read to the left hand side but I have to lip read a lot on the right hand side. It would help with balance- I am not good in the night time. I could hear traffic coming that way on that side (gestures). Maybe speech while driving. It feels so blank on that side. I have tried using a hearing aid but it doesn't sound right- when the phone rings I hear it on the left hand side the other side sounds muffled.'* (1)

This person was refused two implants under NICE guidelines.

Study 2 commented on the difference between listening through hearing aids and a cochlear implant:

*'The volume difference- like having a Mini v a Ferrari on my head. But those closest around me notice if I'm not wearing my hearing aid. I hate it if the (CI) battery goes flat and I have forgotten the spare pack- I have even left a family dinner driven home*

### **Advice to others considering cochlear implantation**

At the end of each interview a question was asked about the advice that people would offer to others in a similar position to themselves who were contemplating cochlear implantation. Although they were positive about cochlear implantation the interviewees were virtually unanimous in saying that this was a decision that should be thought over carefully and not one that should be imposed on an individual. Several cautioned that results vary and that some perseverance might be necessary.

*'I would definitely say nothing to worry about- do whatever you think and go for it. Talking to another friend the other day gave her a bit of confidence to go ahead and make a decision. I told both of them 'don't have any illusions that you will be normally hearing because you won't. How well you hear with it will depend on how much you work at it. Don't expect too much, you have to work at it.'* (7)

A number were already involved in 'counselling' others, either formally as part of their job, in an advocacy role, or informally. One of these still emphasised the benefits of hearing aids:

*'It happens to me all the time in my work. A lot of people who come in are using hearing aids and I think if they get any benefit they should stick with them. I always say I don't have anything bad to say about implants- I've had a very good experience. I speak very positively.'* (9)

### **Concluding Remarks**

Adults are receiving cochlear implants across the age range from 18 years to 60 years plus. Some of these are congenitally deaf, and many have been deaf for a considerable length of time. There appears to be a trend of implanting younger age adults over the last few years and cases have emerged of young adults receiving implants who were not given the opportunity of implantation as children. Individual stories suggest that more complex cases are also receiving implants, for example cochlear abnormalities and so called 'dead' ears which have not been capable of being stimulated by hearing aids. The interview results suggest that results from

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these operations are very satisfactory. The process of adapting to a cochlear implant is often challenging in the early days but the strange sensations become easier to interpret during the first six months post-implantation. However one quarter of the questionnaire respondents would have like more therapy input, either at their CIC or locally, post implant.

Sixty percent of adults would not consider a sequential implant. This proportion was also reflected in the interview group. Comments from the interviews and some questionnaires suggest that those who would like to pursue this option are aware that funding may not be available. Implant failure is an issue, and may be sudden or occur over a period of time.

This study explored the views of adults from throughout the UK by questionnaire and interview, revealing overall a high level of satisfaction with implants and the services offered in those who responded. However, there were a number of issues, mostly concerning the period following implantation, relating to the provision of support. As cochlear implantation grows in practice, and as criteria expand with new groups being implanted, more studies are needed to explore the long-term outcomes and needs in these adult groups, in which there is currently little research.

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## Appendix 1

### Questionnaire

#### 1.1 Data

##### *Geographical Spread*

Adults were given the option of providing an address or e-mail if they wished. Of those who chose to give their location (90) the majority, as expected, were from England (79), with 8 from Wales, Scotland 2 and N Ireland 1. It is considered that the spread of responses across the UK reflects a fairly wide geographical range from Cornwall through to Suffolk and Sussex to the West Midlands, Eastern and Northern England. Proportionally there were a smaller number of responses from the North as compared to the South of England.

It should be noted that some cochlear implant centres draw (or have taken in the past) from a wide geographical base whilst other centres operate more locally.

##### *Analysis of Data*

Of the group 120 returns were analysed. The group was divided into 4 age bands: 18-25 years (4 returns; 3.3% of sample); 25-50 years (30 returns; 25% of sample); 50-60 years (21 returns; 17.5% of sample); 60+ years (65 returns; 54.2% of sample). The 60+ age group had a total of 122 returns but the decision was made to analyse only half of these as preliminary inspection of the forms showed there was nothing to gain by further analysis of the total number of returns in this group. Fifty percent of the returns were selected randomly for analysis.

#### 1.2 Cochlear implantation detail

Ages and the number of years which had elapsed since the implant operation were rounded up to the nearest year. Twenty adults were still in the first year post implant. The range of years post implant for the whole group was <1 to 20 years.

Age Range	Years post CI		
	Range	Median	Average
18-25 (n=4)	1 to 3	1 1/2	2.5
25-50 (n=30)	1 to 20	3	5.2
50-60+ (n=84)	1 to 20	7	12.1

#### 1.3 Education background

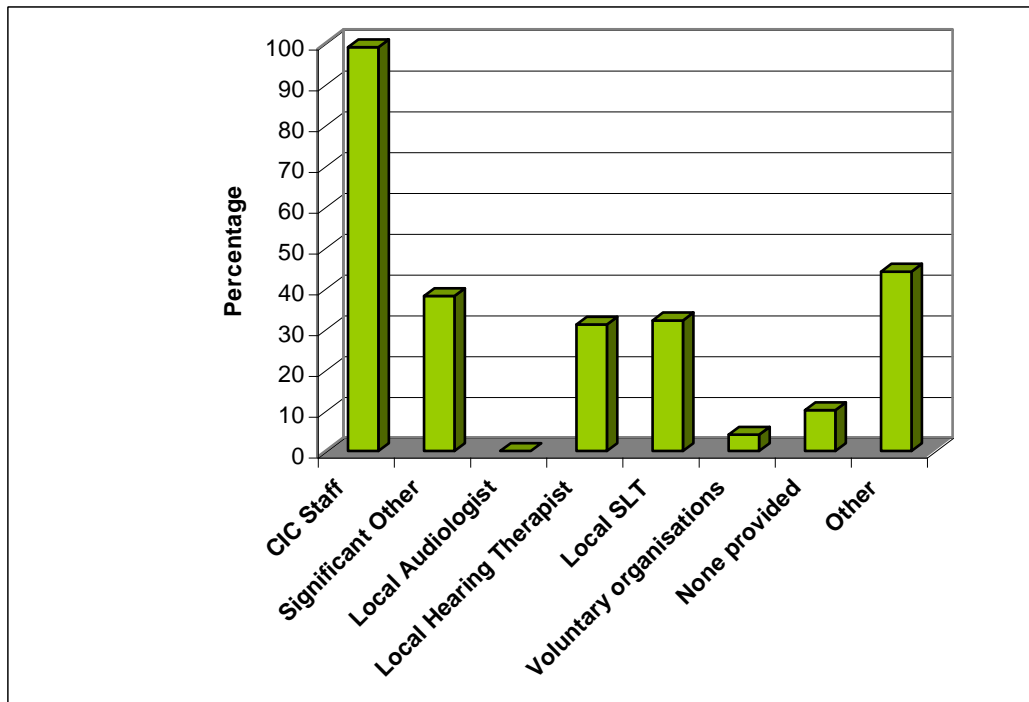
Seven stated they attended mainstream school with a resource base, seven attended a School for the Deaf, one attended a hearing impaired unit and two attended a special school. Within the responses there was indication of movement of placement with six recording they had started off in one placement and moved to a different provision at a later date e.g. hearing impaired unit initially and mainstream at seven years; mainstream primary school and then school for the deaf. There was one adult who did not record a response. For the majority of the respondents (deafened adults) the education background was mainstream school.

#### 1.4 Concerns about follow up

There were concerns expressed about follow up care. The detail of the responses is recorded in the table below.

Technical Support	Lack of Knowledge	Lack of Expertise	Lack of Finance	Other
33% (40)	24% (29)	18% (22)	25% (30)	11%(20)

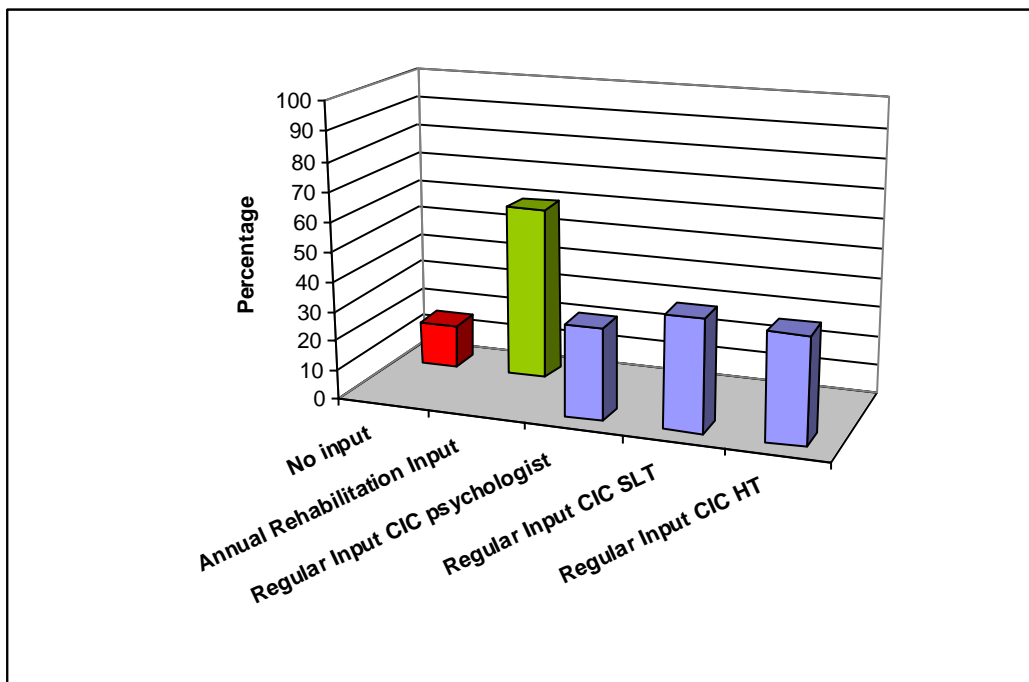
**Who provided input following the cochlear implant operation?**



**1.5 Support from cochlear implant centre staff**

The following chart shows the overall input provided by cochlear implant rehabilitation staff for adults post implant. The adults were asked to record contact with the CIC psychologist, hearing therapist (HT) and speech and language therapist (SLT) when regular input was more than once per year. The frequency of input was also recorded for annual input and for no input at all.

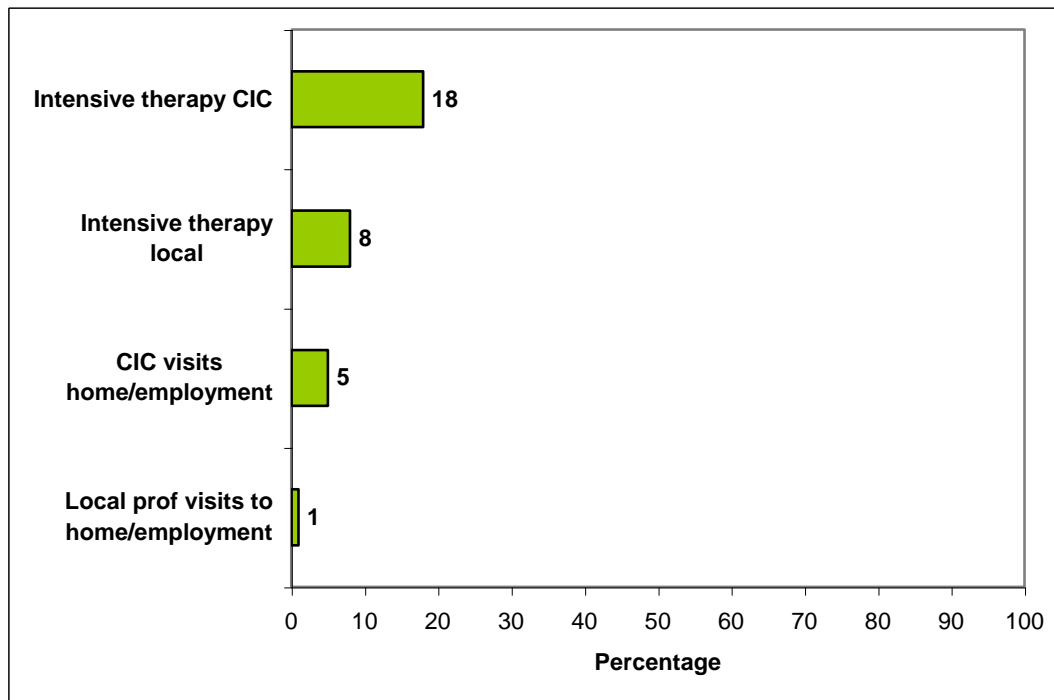
**What happens now?**



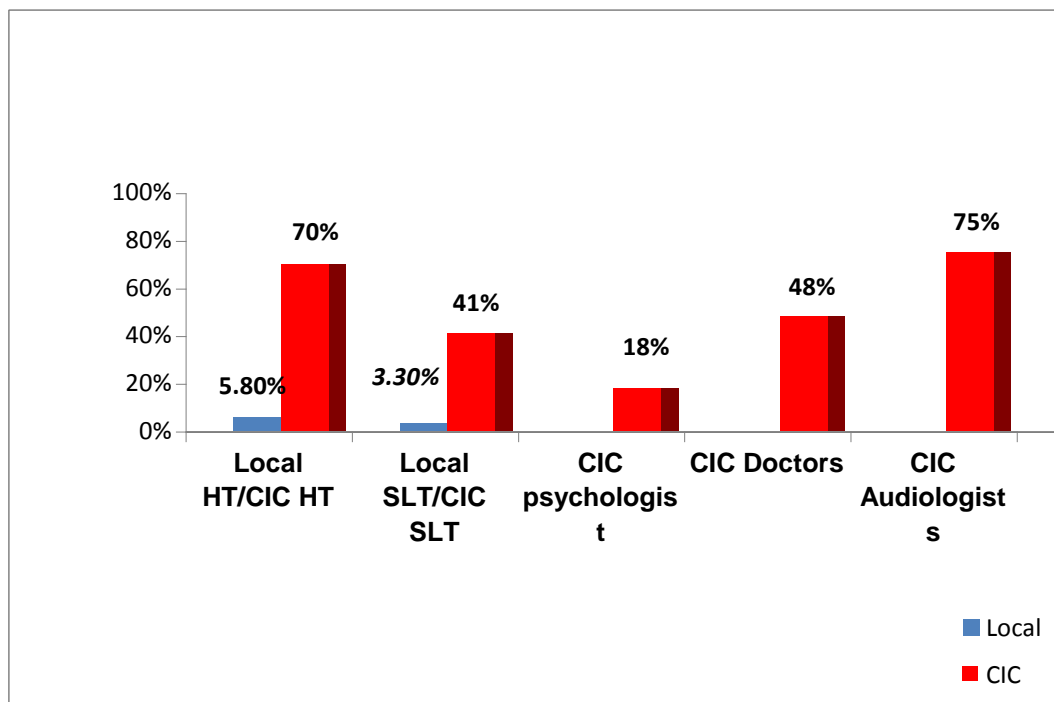
*Sequentially implanted adults*

In general these adults appeared to be getting some but not full support following the second operation both from implant centres and locally.

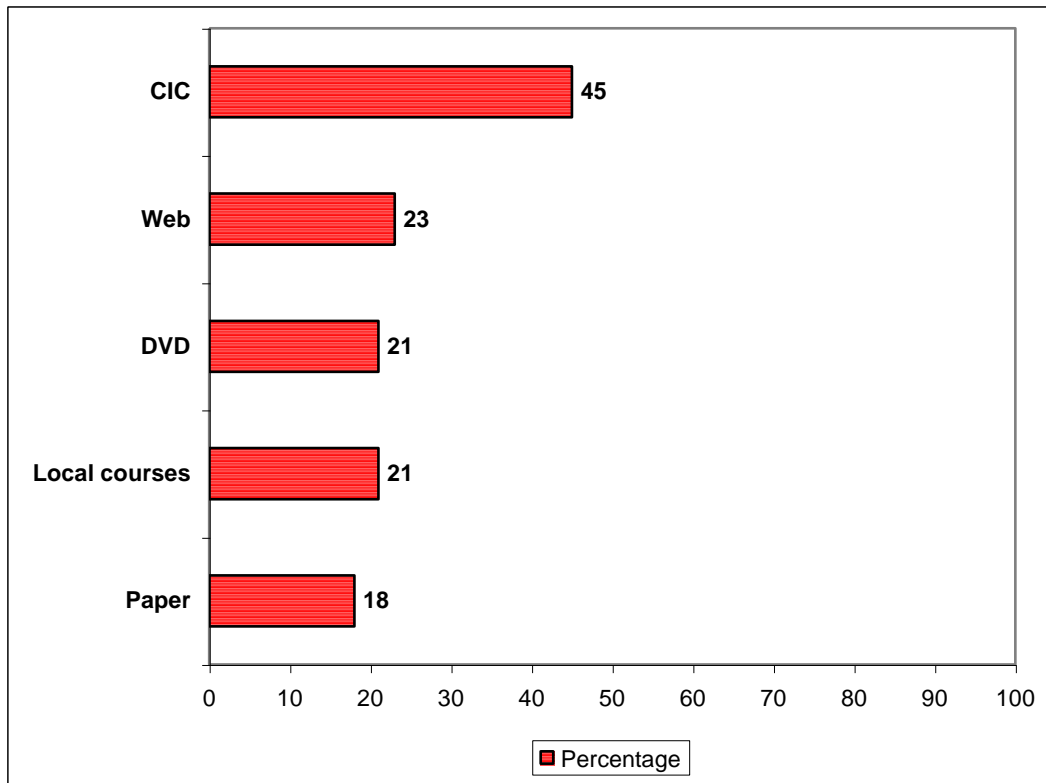
**1.5.1 I feel I need more...**



**1.5.2 If I have difficulty I can get help from....**



**1.6 Training Delivery**



## Appendix 2

### Interviews

Quotes from the interviewees in the report are annotated with their study number and can be related to the charts below.

#### 2.1 Study Group Detail:

Study	Age at Interview	Age Diagnosis	Age at CI1	Hearing Loss
1 (F)*	19yrs	Birth	19yrs	Congenital profound
2 (M)	35yrs	3 1/2yrs	32yrs	Presumed Congenital
3 (F)	37yrs	9 <sup>8</sup> ; 20 <sup>9</sup> yrs	21yrs	Progressive
4 (M)	27yrs	3 1/2yrs	21yrs	Presumed Congenital
5 (F)	28yrs	3yrs	28yrs	Acquired
6 (F)	39yrs	3m	35yrs	Congenital
7 (F)	47yrs	1m	46yrs	Congenital
8 (F)	33yrs	15m	31yrs	Presumed Congenital
9 (F)	47yrs	24yrs	27yrs	Acquired
10 (F)	37yrs	6-9m	36yrs	Congenital Progressive

\* F=female, M=male

The range of age at interview was 19yrs to 47 yrs and the median age was 36. The range of age at implantation was 19yrs to 46 yrs with a median of 29 ½ yrs.

The information about onset of deafness is based on interviewee report and is not substantiated by independent medical or audiological evidence.

Seventy per cent of the group stated that they had been severely or profoundly deaf since birth. The 'late' diagnosis interviewees are described as 'presumed congenital' (3/10) and included within this group as they felt that they had been deaf since birth although there remains the possibility that these were in fact progressive losses which were only picked up once the loss became more severe. In two cases parents suspected a hearing loss but were not believed; the third case parents were unaware that their child might have a hearing loss, as she was a first child, until a friend raised the issue at 15months.

Study 1 is presumed to be genetic as she has a hearing-impaired father and similarly Study 8 has a severely deaf brother. Study 6 was born deaf as a result of maternal Rubella. Study 9 acquired her hearing loss in traumatic circumstances as a young mother; the definitive cause was never established. Study 5 also has no known diagnosis for the sudden onset of her deafness.

A number of the interviewees reported progression in their hearing loss; in one case from 'hard of hearing' to severe then profound as a young adult (Study 3); Study 10 reported that she progressed gradually from a severe to profound hearing loss, losing all residual hearing in one ear. Others also experienced sudden loss of residual hearing; in three cases this left them with one, unaidable 'dead' ear and in one case with a more profound loss in both ears. In one case this resulted in severe tinnitus

<sup>8</sup> Onset of partial deafness

<sup>9</sup> Onset of severe deafness

## 2.2 Cochlear Implantation Detail

<b>Study</b>	<b>Duration post CI</b>	<b>Uni or bilateral</b>	<b>Re-implanted</b>	<b>Sequential CI &amp; Re-implant Detail</b>
1	1yr	Unilateral	N	Refused sequential CI under NICE guidelines
2	3yrs	Unilateral	N	Asking for sequential CI
3	15yrs	Unilateral	Y	Re-implanted; does not want a sequential implant
4	4.5yrs	Unilateral	N	CIC refused sequential CI; HA giving benefit
5	<1yr	Unilateral	N	Asking for a sequential CI but advised no funding
6	4/1.5yrs	Bilateral	Y	Sequential cochlear implants & re-implant
7	1yr	Unilateral	N	Not asked for sequential (unsure)
8	1yr	Unilateral	N	Not interested in a sequential CI
9	20yrs	Unilateral	N	Considered sequential CI but not pursued
10	<1yr	Unilateral	N	Interested but has not requested sequential CI