



Hidden crisis:

why millions keep quiet about hearing loss

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RNID • 

Changing the world for deaf
and hard of hearing people

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Summary

Hearing loss affects one in seven of the adult UK population, and 55% of people over 60¹. Moreover, previous research has suggested that people may wait up to 15 years between the onset of hearing loss and seeking medical advice about it². This delay is problematic because it is important that people find out about - and start wearing - hearing aids as soon as possible because it is harder to adjust to the amplified sound generated by hearing aids if you have become used to a 'quiet' world.

RNID conducted qualitative interviews with 24 hearing aid users throughout the UK to find out what prevents people from taking action and what finally triggers the motivation to address their hearing loss. In addition, we explored other factors that have an impact on people's ability to live a full life.

Patients' journey to diagnosis

- Experiences at work and interactions with spouses or partners were instrumental in both making participants aware of their hearing loss and making them seek help for their hearing loss.
- As such, cohabitation is an important factor in making people aware of hearing loss.
- However, hearing difficulties experienced at work or in education made people aware of their hearing loss in a way that their home life did not.
- Some participants delayed getting help for their hearing loss because they had other priorities, for example physical pain, or because they had only lost hearing in one ear.
- Other reasons for such a delay were a previous experience around hearing aids that had been unsuccessful, the participant not seeing themselves as someone with hearing loss or the association between hearing aids and ageing.

¹ Davis, A, *Hearing in Adults*, 1995

² Davis, A. et al (2007), Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models, *Health Technology Assessment*, 11:42.

Recommendations

RNID is currently campaigning for a national hearing screening programme for older people. This will be particularly effective for people who are not aware of their hearing loss, are reluctant to initiate action or are not aware of what a serious effect their hearing loss is having on themselves and others.

Therefore RNID recommends:

- Introduction of a hearing screening programme for older people in all parts of the UK.
- Introduction of a strategy to maximise the uptake of a hearing screening programme through targeted publicity.

Experiences of health services

- Participants were not provided with sufficient information by their audiologist or, where they were provided with information, the language used was overly technical.
- Some respondents said that audiologists are not able to spend enough time with patients and occasionally this translates into an unwillingness to look into problems that patients are experiencing with their hearing aids.
- There is criticism of the lack of a joined-up approach between health services and of a lack of co-ordination between health and social services.
- Participants had chosen to consult a private provider because NHS waiting times were too long or they believed that the hearing aids were of a better quality³.
- Participants who went to a private dispenser appreciated the perception that they could manage the relationship on their terms. However, issues of cost meant that this option is not available to everyone.

³ Waiting times have been dramatically reduced in the past year, since this study was conducted. Department of Health data for March 2009 reveals that 99.5% of people fitted with hearing aids had waited less than 18 weeks since being referred by their GP. In Scotland, a Scottish Government audit in 2006 found that the average wait for referral to fit was 33 weeks, with a national standard being 26 weeks. Since 2007, waiting times for audiology in Scotland are now included in the 18 week waiting time target by 2011. Further, since completion of the modernisation of hearing aid services in 2005, all hearing aids fitted on the NHS are now high-quality digital models, and the technology is regularly upgraded.

Recommendations

The delivery of healthcare services strongly influences the ease with which people adapt to their hearing aids, and the benefit they get from them. It is important that people who have been newly fitted with a hearing aid receive necessary and appropriate information in a timely manner. This was often lacking.

Therefore RNID recommends:

- An increase in the capacity of audiology departments to enable audiologists to spend more time with patients and to deliver a system more tailored to patients' needs.
- More investment in - and a focus on - rehabilitation, ensuring that hearing aid users make the most of their equipment, including hearing aids and other assistive devices, and benefit from alternative methods of communication.
- A review of the information needs of people fitted with hearing aids and an assessment of what investment would be needed to meet these.
- Primary Care Trusts/Health Boards should ensure that follow-up appointments are offered routinely to patients, as per Department of Health guidelines.
- Audiologists and other services should work together seamlessly to ensure that patients receive the appropriate information on a timely basis.
- New performance standards and quality standards are currently under development by the Department of Health and the British Academy of Audiology, while standards for adult audiology were published by the Scottish Government in 2009. We believe it is essential that compliance is monitored closely and reported in full.
- It is crucial that the current success in reducing waiting times and other improvements made to the service in recent years continues.
- RNID will conduct research with hearing aid users about how best they can manage their relationship with audiology departments and publish guidance accordingly.

Relationships, family and social life

- Spouses and partners were understanding about participants' hearing loss.
- Children tended to be less understanding or accommodating, something that could be distressing for parents.
- Family members initially took steps to mitigate the effects of hearing loss, but often forget after an initial period.
- Hearing loss made some participants withdraw from certain social activities, particularly those involving large groups.
- Even where participants continued to take part in these types of activities, their difficulties hearing could result in a sense of isolation.
- Some participants were unwilling to tell colleagues about their hearing loss because they believed they would be seen as less capable.
- Participants had mixed experiences of employers' willingness to make the adjustments necessary to allow them to continue successfully at work.
- Less frequently, hearing loss had led to dismissal or discrimination in one form or another. Others had themselves given up their job because they felt they weren't managing any more.

Recommendations

Untreated or unrecognised hearing loss has an impact not just on the individual but on their relationships, social lives and employment.

Therefore RNID recommends:

- RNID will work with people who are hard of hearing to make them aware of their rights in terms of reasonable adjustments at work.
- The Department of Health in all parts of the UK should provide information to families about the signs of hearing loss and where to go for help, and how to take steps to make communication easier for family members who are deaf or hard of hearing.
- All major employers and service providers should ensure that frontline staff and key managers have deaf awareness training.

Support and equipment

- Lipreading classes had been a positive experience for participants who had attended these, acting as a source of support and information as well as a counter to the isolation experienced by participants.
- Participants made use of equipment available to them, such as loops and listeners and had often obtained specialist equipment from social services.
- Typically participants did not use communication support such as speech-to-text reporters, because they didn't feel the need or were not aware of what support is available.

Recommendations

During recent years, funding cuts for further education in England and the lack of a clear funding structure in Scotland have had an impact on the availability of lipreading classes.

Therefore RNID recommends:

- The introduction of national guidelines in each part of the UK that prioritise lipreading classes, coupled with an increase in the number of lipreading tutors.
- Increased funding and lower course fees for lipreading classes.
- More information about the types of help with communication that people can receive.
- Investment in the infrastructure necessary to support people with hearing loss, including the training of communication support specialists, investment in new voice recognition technology and steps to ensure that induction loop systems are working.

Introduction

Hearing loss affects one in seven of the adult UK population, and 55% of people over 60⁴. Moreover, previous research has suggested that people may wait up to 15 years between the onset of hearing loss and seeking medical advice about it⁵. This delay is problematic because it is important that people find out about and start wearing hearing aids as soon as possible as it is more difficult to adjust to the amplified sound generated by hearing aids if you have become used to a 'quiet' world. Moreover, research undertaken by RNID shows that older people who are hard of hearing find it harder to access and benefit from medical advice, something that can result in poorer health outcomes⁶ and hidden social exclusion.

Quantitative research has provided us with some insight into the reasons why people may delay wearing a hearing aid, such as embarrassment and worries that they are getting old. However, to date, there has been no in-depth research that provides insights into patients' decision-making processes around diagnosis of their hearing loss. Therefore, the recognition of this delay and the lack of in-depth research acted as the starting point for this qualitative research that explores what prevents people from taking action and what finally triggers the motivation to address their hearing loss.

However, people's experiences before they consult a doctor about their hearing loss only form part of the patient journey. We have anecdotal reports of hearing aids that have been fitted but are then left unused in a drawer. This research explores the factors that influence whether hearing aid users gain the utmost benefit from their hearing aid - whether they wear their hearing aid, obtain the best quality of sound possible, and whether they enjoy the benefits offered by using their hearing aid alongside other equipment and support. However, effective use of hearing aids is only one factor that influences the level of opportunity for people who are deaf and hard of hearing to live a full life. Therefore, the research also explores other factors that have an impact on participants' ability to live a full life.

⁴ Davis, A, *Hearing in Adults*, 1995

⁵ Davis, A. et al (2007), Acceptability, benefit and costs of early screening for hearing disability: a study of potential screening tests and models, *Health Technology Assessment*, 11:42.

⁶ RNID *A Simple Cure*, 2004.

In this way, we have conducted research interviews to trace events and people's feelings and perceptions from the time when they first noticed they had some level of hearing loss to the present.

Obtaining a hearing aid(s)

The current process

If patients feel they are losing their hearing and choose to obtain a hearing aid through the NHS, they would typically approach their GP who would refer them to an audiologist or to an ear, nose and throat (ENT) specialist at a nearby hospital. They should then have three appointments. The first is to test their hearing, the second is to fit their hearing aid and the third is to check how they are getting on and to make any adjustments that are required. In some cases, assessment and fitting are combined into one appointment. NHS waiting times for initial assessment and fitting have improved and targets are now being met in this area. However, there are concerns that existing hearing aid users are having to wait for re-assessments and upgrades.

Where patients obtain a hearing aid from the NHS, hearing aid batteries, replacements and repairs are free of charge. In some areas, patients need to go back to the audiology clinic for replacement batteries and repairs. In others, there may be a centre which is more local to them and some GP surgeries also run battery exchange programmes.

Some patients obtain their hearing aids through private dispensers. In this case, they do not have to wait as long for an appointment as they would under the NHS. Private hearing aid dispensers will also check the patient's hearing, and the waiting time for the hearing aid to be fitted is much shorter than in the NHS. The hearing aids may be available within about a week. In addition, private dispensers often offer more choice of hearing aid styles than the NHS. However, hearing aids obtained privately can be very expensive and patients have to pay for hearing aid batteries and repairs once the hearing aid guarantee runs out.



Research aims

The aim of the research was to gain a better understanding of people's decision-making around diagnosis of their hearing loss. In particular, the aim of the research was to identify those factors that lead patients to consult their GP or a private hearing aid dispenser, and those factors that act as barriers to consultation. The research also explores the factors that influence whether hearing aid users gain the utmost benefit from their hearing aid, as well as other related factors that have an impact on their ability to live a full life.

More specifically, the research objectives were:

- To capture the circumstances in which research participants first became aware of their hearing loss, including retrospective awareness.
- To explore the impact of interactions with other people on participants' decisions to consult a GP or specialist regarding their hearing loss.
- To explore delaying factors and barriers to participants seeking help about their hearing.
- To trace events from when participants first became aware of their hearing loss, including interactions with GPs and audiologists.
- To explore the impact of hearing loss on research participants' lives.
- To explore the use of support and equipment by research participants.

Scope of the research

We aimed to interview people who had acquired their first hearing aid within the last ten years.

All of the research participants had digital hearing aids and all of them had experience of NHS audiology services or private dispensers since the introduction of the Modernising Hearing Aid Services programme (MHAS). Therefore, even though participants' first experience of hearing aid services may have been several years ago, they had more recent experiences of audiology services and were therefore in a position to give their views about these since the introduction of MHAS.

We have included quotes from participants in the report to illustrate the themes that emerged from the research. However, in order to maintain participants' anonymity, we have not included their names. Instead, we have given details of their region, whether they are working and whether they are over or under 60 in order to provide some context, and to demonstrate that we interviewed a range of participants from different locations.

We indicate whether someone is over or under 60 because we found that participants' experiences and views tended to differ according to their age and whether they are in work. Moreover, age-related hearing loss increases from the age of 60. Therefore, obtaining an even distribution of participants between under and over 60 enables us to ensure that we have explored a range of experiences around hearing loss.

Report outline

The first section looks at the patient journey to diagnosis of hearing loss, including awareness of hearing loss, triggers to seeking help and factors which act as barriers to patients seeking help. The second explores findings around participants' experiences of the health service and of private hearing aid dispensers. The third section looks at the impact of hearing loss on participants' lives, while the fourth section explores their experiences around support and equipment. The fifth section pulls together findings from the research along with recommendations. The research methodology is the final section.

Chapter 1:

Patients' journey to diagnosis

1.1 Awareness of hearing loss

Participants had become aware of their hearing loss through interactions with their partner or, less frequently, other members of their family or because they were experiencing difficulties at work.

Interactions between participants and their partners in the context of their shared living arrangements had made either themselves and/or their partners conscious of disparities between their own and their partner's hearing, and their expectations about what they would be able to hear. Participants reported how differences in the levels at which they had the volume on the television, or not being able to hear their partner's voice because of background noise in the home, had made them aware of their hearing loss.

“ I think it is family members who notice it first... I first started realising that (husband) was at times talking to me and I wasn't hearing him. And you know you get noise from the television, in the kitchen I've got a television and I've got a boiler going, and if you are cooking with the extractor going and you know, all this, I just wasn't hearing anybody at all.”

(Female, over 60, not working, North West)

When asked why his wife had said that he needed a hearing aid a participant responded:

“ Because I was probably having, I think I had the TV too loud. And I was always saying sorry, I didn't catch that.”

(Male, over 60, not working, Midlands)

In some cases participants' partners or their family had explicitly pointed out that they had a hearing loss.

Cohabitation is an important factor in this context. Aspects of shared living arrangements, such as a shared television, enabled the comparison between the participant and their partner's hearing that made them aware of their hearing loss. Exceptionally, participants raised or illustrated this point in the interviews.

“ I was turning up the television too loud... which is one of the kind of things that you're aware of when there's two of you in the house... that you're not so aware of when you're on your own.”

(Female, over 60, not working, Scotland)



Another participant described how it was only when her son came to stay with her the evening before an operation that she became aware of her hearing loss.

Participant:

“Of course I live alone. I don’t normally watch television with anybody else. If they come to visit me we don’t put the television on.”

Interviewer:

“Because they have come to see you and to talk. Yes, of course.”

Participant:

“Yes. When I’m talking to people I’m normally facing them. My telephone is a good one so I hadn’t really realised that I had any significant hearing loss. Yes, he put the television on and I could not hear one thing.”

(Female, over 60, not working, South West)

This suggests that people living alone, even where they are part of social networks and are not isolated in other ways, may become aware of their hearing loss later than other people.

Exceptionally participants reported that other factors such as difficulties hearing speech over the telephone had made them aware of their hearing loss.

Hearing difficulties experienced at work or in education made people aware of their hearing loss in a way that their home life did not, particularly where they were working in open plan offices and realised that they could not hear what their colleagues were saying. Moreover, participants described sources of extraneous noise at work over which they had no control,

something which means that work can be a very challenging environment for people with hearing loss.

“I noticed it at work actually... because people tend to be in very large ...well I was... in a large communal office... photocopier going... printers going... people talking across desks... not one to one... then at that point I began to think I’m not hearing as well.”

(Female, under 60, working, South East)

“it was mainly through work... I work in a noisy factory and it’s just full of audible alarms... mechanical audible alarms... and it was just over time I sort of realised that I couldn’t hear a certain alarm...”

(Male, under 60, working, South West)

This heightened awareness of their hearing loss. Moreover expectations around performance at work gave those participants a sense of urgency so they sought help quickly once they were aware of their hearing loss, and took steps to speed up the process of getting hearing aids.



1.2 Triggers to seeking help

Again, the roles of work and partners were instrumental in making participants seek help once they were aware of their hearing loss.

Even where their hearing loss did not affect participants' ability to perform their core duties, there was a sense that they were missing the general chitchat at work, and they also found it difficult to take in information at lectures and work meetings.

Participants described how the realisation that their hearing loss was affecting them at work made them seek help.

“ It was so important that you did hear important things you know... you can manage so far with some things and then you think... no I have to do something about this... this is getting a bit too much.”

(Female, under 60, not working, Northern Ireland)

“ I was actually doing a pre-nursing course at my local college... I wasn't kind of like picking stuff up and I thought it was... I didn't think it was my hearing at all because I've never had any problems with my hearing so I kind of struggled so I went on to do my training... and six months into my training I was working up at (place name) and I was still finding it difficult

so one of the girls said to me ‘why don't you go downstairs and see if they'll do a hearing test?’”

(Female, under 60, working, Scotland)

Concerns regarding performance at work meant that those participants who had experienced difficulties hearing at work were more likely to push to get hearing aids as quickly as possible, in some cases, going for an initial consultation privately in an attempt to speed up the process.

As well as making participants aware of their hearing loss, partners had in some cases played a role in instigating their consultation with a doctor or hearing specialist.

“ When I eventually did have hearing test, it was my, my, then husband who said why don't you just try it.”

(Female, under 60, working, South East)

The role that partners can play is illustrated by a participant who described what would have happened if her husband had not urged her to have her hearing tested:

“ ...just carried on as I was, just got on with it, just adopted various strategies no doubt, to cope with it. But I think I would probably have been a lot further down the line in terms of hearing loss before I actually went to do anything about it.”

(Female, over 60, not working)

1.3 Delaying factors

The following factors had caused participants to delay in getting help:

- other priorities including health problems, disabilities or caring responsibilities
- a previous experience with hearing professionals or attempt at wearing hearing aids which had been unsuccessful
- only losing their hearing in one ear, or being able to manage
- not seeing themselves as someone with hearing loss or a hearing aid
- denial of any sign of the ageing process, including hearing loss

As mentioned previously, participants had occasionally not been aware of their hearing loss because they lived alone.

It is important to note that, in this research, we interviewed people who had hearing aids and, by definition, they had not delayed indefinitely and had eventually sought help. However, some participants had themselves delayed getting hearing aids for some time. Moreover, they had frequently discussed issues around hearing aids with others and were able to give insight into the barriers that other people face. Therefore, while some of the findings in this section are based on the experiences of the participants themselves, others are based on their discussions with - and observations about - other people. While these findings are subject to the limitations of secondary evidence, they still offer important insights into the barriers faced by some people.

1.4 Other priorities

Where participants or their families had other health concerns, this frequently led to a delay in their seeking help for their hearing loss. For

one participant the other symptoms of Ménière's disease, vertigo and tinnitus, were so distressing that her attention was diverted to alleviating these. For another participant, her husband's stroke meant that dealing with her own hearing loss was not a priority.

“The audiologist did the test and said no, you're not quite ready for hearing aids, come back in a year. A year later my husband had his first stroke. So everything just got put on the back burner.”

(Female, over 60, not working, North East)

1.5 Only losing hearing in one ear, or being able to manage

Where participants had only lost their hearing in one ear or they had felt that they were able to cope, they had often not sought help for their hearing loss. For instance, a former postman described how when he was working as a postman his hearing loss was not a problem. It was only once he moved to work in an open plan office that his hearing loss became a problem and he eventually decided to seek help for it. This demonstrates how the type of employment that someone has can influence their response to hearing loss. Similarly, participants had delayed seeking help because their hearing in one ear was good, and they were able to continue with their normal activities without too much difficulty.

“I think ...because my right ear was still very good at that point... erm... I cope very well without a hearing aid.”

(Female, under 60, working, South East)

“ I think if people have got a loss in one ear, (husband) has, and I did, I think they tend to think ‘oh well, I can still hear.’”

(Female, over 60, not working, Scotland)

1.6 Previous experience that was unsuccessful

Where patients had either had an unsatisfactory experience with an audiologist or hearing specialist, or they had unsuccessfully tried to wear hearing aids, this has resulted in a delay before they felt prepared to seek help for their hearing loss again.

Participant:

“ But they, he was a bit blunt, the um, the audiologist. He just said you’re going deaf, you’ll need a hearing aid. And I was like ‘nooooo’. An um, so I kind of, I got very cross with him, for being so blunt, well, or not saying look I’m terrible sorry, but.”

Interviewer:

“ So do you think it was his bluntness, it was just a reaction to the bluntness that made you sort of react in this way?”

Participant:

“ It was actually, I did have quite a strong reaction to that and I just didn’t want to go back near the place for a long time.”

(Female, under 60, working, South East)

1.7 Not seeing themselves as someone with hearing loss or a hearing aid

Less frequently, hearing aid users had delayed wearing a hearing aid because this did sit not well with their view of themselves. This may be because they see hearing loss as a disability and do not consider themselves to be disabled, or they see hearing aids as associated with old age and do not consider themselves to be old. For instance, a participant described how she had been in denial over her hearing loss for a long time.

Interviewer:

“ What do you think made you, sort of, deny the hearing loss?”

Participant:

“ Oh vanity probably. You know you don’t want to admit you’re going to wear hearing aids.”

Interviewer:

“ Right, what the actual appearance of the hearing aid, or?”

Participant:

“ Just I think just because erm. I didn’t want to think, you know, I had some kind of disability.”

(Female, under 60, working, South East)

Another described his reaction when he was told that he would benefit from a hearing aid.

“ I reacted like, very stupidly I, my first reaction was I’m too young to wear a hearing aid. I just assumed, I tie hearing loss with old people and things. And I was so bad I

actually had to go to the nurse again and ask could I go back in’

(Male, under 60, not working, Northern Ireland)

Similarly, participants described people they knew who were reluctant to wear a hearing aid because of worries about how this would make them appear.

“ And there’s another particular person that I know who won’t go and get help because he said he would look stupid wearing hearing aids.”

(Female, under 60, working, Northern Ireland)

“ I know one person, in particular, one of my friends, is very reluctant to have hearing aids, because she is smart and attractive and all the rest of it.”

(Female, over 60, not working, North East)



1.8 Denial of any sign of ageing, including hearing loss

In some cases participants saw their hearing loss as a natural part of the ageing process and something they could do little about. Others appeared to deny any sign of the ageing process, including their hearing loss.

“ Look, I am 77. You know you expect things to fall off and deteriorate.”

(Over 60, not working, South West)

“ A lot of people don’t really like the, really, really don’t like to admit they’ve got hearing problems... It’s a little loop that I think older people get into. They are getting older, things are getting worse, you’re getting close to death cos that’s another thing that’s going to happen next. And so on.”

(Male, over 60, not working, South East)

“ I think there’s a lot of reluctance to wear hearing aids. I think people think hearing aids are things old people wear. So I think there’s a lot of stigma attached to that.”

(Female, under 60, working, South West)

This association with ageing was mirrored by the reaction of younger people when they were told that they needed a hearing aid. In some cases, they had initially rejected the idea that they would need a hearing aid or had at least taken some time to get used to the idea.

A participant described her reaction when she was referred to be fitted with a hearing aid:

“ Scary! Oh no I’m old now, I need a hearing aid.”

(Female, under 60, not working, Wales)

1.9 Overcoming barriers

Where participants themselves had overcome or resisted barriers it was because, in some cases, they had taken a pragmatic line.

“ And I think you just say ‘oh well, I’m getting older. These things happen.’”

(Female, over 60, not working, South West)

“ if you’ve got difficulties go and do something about it.”

(Female, over 60, not working, North East)

In other cases, they had simply realised that their hearing loss meant they were missing out on too much so they had to act. Therefore they had to either obtain a hearing aid or wear the hearing aid they had already obtained.

“ I just got to the stage when where I thought well it doesn’t matter like I was saying I shall just have to use it because if I didn’t it held me back kind of thing in my work and things that I enjoyed.”

(Female, under 60, not working, Northern Ireland)

Less frequently, participants had come to consider their hearing loss or their hearing aid as

a part of their identity, regarding their hearing loss in a positive way.

“ I don’t care what your reaction is because it’s part of who I am, I’ve accepted it you know.”

(Female, under 60, working, Northern Ireland)

“ I am so, sort of pro, sort of hard of hearing and in your face.”

(Male, under 60, not working)

1.10 Other factors

Participants occasionally mentioned other factors which were either personal to them or, in their view, delayed people in getting help for their hearing. For instance, a participant did not like things in her ears whilst another compared hearing aid providers with opticians, pointing out that hearing aid providers are not visible in the same ways as opticians, and seeing this as a delaying factor.

1.11 Discussion

Where patients delay seeking help, this can have significant consequences in terms of how easy it is for them to adapt to the amplified sound of hearing aids. The findings above highlight concerns that older people who live alone, in particular, will become aware of their hearing loss later than if they were living with others.

This is of particular concern because we know that it is harder to adjust to a hearing aid the longer that people have untreated hearing loss. Moreover, it appears that factors, for example work and active family networks, that are already indicators of a person’s ability to actively participate in family or community life, are also

factors that make people aware of their hearing loss earlier.

Therefore, there is the danger that for some people who live alone there may be a downwards spiral. In this scenario they do not have the networks at work, or in their family, that would act to make them aware of their hearing loss and consequently become more socially isolated because of their hearing loss. In turn they become even less likely to have their hearing loss diagnosed because they do not have the social contact which would alert them to it.

These findings suggest that older people who live alone may be particularly susceptible to delays in having their hearing loss diagnosed.

RNID is currently campaigning for a hearing screening programme for older people in all parts of the UK. Hearing screening will be particularly effective for people who are not aware of their hearing loss, for instance where they have left the workplace and are among the increasing number of people who live alone. They may be reluctant to initiate or unaware of what a serious effect their hearing loss is having on themselves and others. Similarly, where other concerns have taken precedence, a screening programme could act as a trigger to consultation.

The perception that they could manage, despite their hearing loss, had prevented some people from getting help. Conversely, the realisation that they were missing out on everyday communication had spurred others to take action. This demonstrates how it is essential that people value their hearing both in terms of protecting hearing and because they are more likely to

seek help for their hearing loss if they value their hearing.

RNID has designed a simple telephone/internet hearing check that acts as an effective tool for initial assessment of a hearing problem. This can be taken in advance of a visit to a GP and helps to identify people who have a hearing loss, and encourages them to seek further advice.

Hearing loss becomes more common as people get older. RNID is working to change the association that people make between hearing loss and general deterioration during old age. This association is of particular concern where people see hearing loss as part of a battery of unavoidable conditions associated with old age that they must simply put up with.

The costs of unrecognised hearing loss to the individual are considerable – and so are the costs to the economy. For instance, estimates published in 2006 suggest that £13bn is lost to the UK economy every year through unemployment linked to hearing loss⁷. A hearing screening programme in all parts of the UK would work to combat this by demonstrating that hearing loss is something that can be overcome.

However, our findings also demonstrate other factors that dissuade people from getting hearing aids, for instance, concerns around the appearance of hearing aids. It is therefore important to consider the ways in which the uptake of hearing screening and, ultimately, of hearing aids can be maximised. As wearing hearing aids becomes as common as glasses, much of the stigma associated with them would be removed.

⁷ Bridget Shield, *Evaluation of the Social and Economic Costs of Hearing Impairment*, October 2006.

Chapter 2:

Experiences of health services

Key to people's attitudes to hearing loss and hearing aids are their experiences of the help they get from health professionals.

Participants had extensive experience of both NHS audiology and private hearing aid dispensers.

2.1 Provision of information

Participants frequently complained that the information NHS audiologists provided at the time of hearing aid fitting was insufficient. However, there was also the recognition that it may be audiologists are providing the information, but patients are not taking it in.

“ I think the one thing definitely that is lacking and it still is lacking is the information that people get at the beginning when they first start wearing hearing aids.”

(Male, under 60, not working, Northern Ireland)

There were specific complaints, amongst other things, about the lack of an explanation as to the different hearing aid programmes and information about cleaning the hearing aid tubes.

“ It's not always explained by the people who do the hearing aid test and fit you with a hearing aid, make sure the programme is the right one etc. They are a bit pushed for time.”

(Male, over 60, not working, South East)

“ She put the hearing aids in my ears and said to me I needed to clean them every week. But she

didn't show me how to do that. Erm, other than just saying well just take the tubes off and wash them and put the tubes back on. It was only when I went home and started thinking about that and came to do it myself. I was really worried then because, you know, pulling at the tubes I was worried about breaking them.”

(Female, under 60, not working, Scotland)

Participants said they did not receive the following information from their audiologists:

- an explanation as to the cause of their hearing loss
- information regarding low frequency hearing loss
- more explanation regarding the audiology and ENT pathways (i.e. what tests are being conducted at different times)
- whether the T switch is activated
- information regarding how the different programmes should be used
- what the experience of wearing a hearing aid will be like
- information as to how the tubes should be cleaned
- information about other services that could be of use to them
- more information about how to cope with hearing loss

Participants frequently said that the language used by their audiologist was too technical or contained jargon. They felt the use of this type

of language increased the risk that they may not take on some of the information provided.

“ They do explain what they’re going to do. But still, if you don’t know the language terms in terms of the audiology department language.”

(Male, under 60, working, South West)

Exceptions to this occurred where participants themselves had worked in a scientific or technical sector. Where this was the case, they wanted audiologists to include more scientific information.

“ I mean ideally it’s great to be able to sit down with a consultant... somebody who really knows the illness inside out and then may be a hearing therapist as well... and talk through the science of the illness and all the things you need to know about.”

(Female, under 60, working, South East)

In this way, all participants simply wanted audiologists to discuss issues on their level and in a way that made sense to them.

Where participants had had a procedure or a condition which was commonly related to, or sometimes led to hearing loss, they felt it would have been helpful if either their GP or an ENT specialist had been more explicit about the fact that they may experience hearing loss at some date.

“ I think it would have been really useful to have known that a really serious side effect of Ménière’s is hearing loss.”

(Female, under 60, working, South East)

2.2 Lack of time

There was recognition on the part of participants that GPs and audiologists were only able to spend a limited amount of time with them. However, this lack of time occasionally left participants with the impression that they were unwilling to look into their problems, or give them adequate information.

For instance, a participant described how her private provider compares favourably with NHS audiologists who she felt did not have the time to work through problems with her.

“ (they) have more time to say OK let’s treat that let’s try and do this let’s try and do that... whereas I never had that with the NHS ones I always felt a bit like go and get them... and so well there’s your batteries and off you go because you know you’ve had fifteen minutes or something.”

(Female, under 60, working, South East)

In some cases participants also felt that they had had to be pro-active and manage the relationship with health services. For instance, they had to return several times in order to improve the quality of sound they heard or to have the mould adjusted. These participants frequently felt they had to be pushy to get what they wanted.

“ And then a couple of years ago I went back to the GP again to be asked to be referred back to ENT... to try and make the hearing, the hearing aids better again. And also to ask them to find out if, why have I got a hearing loss, to see if

it's genetic. Because if it is genetic whether my lads would have it as well. So he said well I can't refer you to ENT because their lists are too long. So I will refer you to audiology. And I've been a pain in the arse to them basically."

(Female, under 60, not working, Wales)

"I kept phoning after about, I should think about 9 months, I would phone and say 'where am I on the list?'"

(Female, over 60, not working, North East)

2.3 Lack of joined-up health service

Related to this finding was participants' perception that health service provision, for instance ENT and audiology, was not joined-up. Similarly, they found that health and sensory teams did not provide a co-ordinated service, something that again meant that some participants had to be resourceful in navigating their way around health and social services.

For instance, a participant described her search that had resulted in her contacting the sensory team:

"There (were) no proper signs or information to say (how to) contact these people. Just a little scrappy piece of paper said that the council social services could be contacted. And then I went on the internet and found this sensory

support. So there was this piece of paper... It wasn't obvious and I don't think a lot of people would even notice it was there. I was just hunting through the magazine for something to read."

(Female, under 60, not working, Scotland)

Participants said the lack of co-ordination in the following areas made it more difficult to deal with health services:

- having to go back to their GP to request a hearing test
- not being told about available follow-up care, such as a local centre that provides batteries
- poor links between different geographical locations. For instance, a participant had to go to the bottom of the hearing aid list because she had moved area
- being told by audiology to go back to their GP in order to have an appointment with ENT
- not being told about or referred to equipment teams

2.4 Adequacy of NHS services

This section considers the adequacy of NHS services with reference to and comparisons with private provision where appropriate.

Unsurprisingly experiences of NHS audiologists' attitudes were varied; and had an impact on participants' feelings about the whole process of obtaining a hearing aid. Audiologists could play a role in facilitating participants' acceptance of their hearing aid.

“ I had a lovely audiologist, a lovely guy the day the mould impressions were taken. And he sort of sat me down and explained ‘you know it’s OK to wear a hearing aid and... it wasn’t a big stigma and things.”

(Male, under 60, not working, Northern Ireland)

Conversely, there were reports of audiologists who were dismissive of their patients’ concerns, something that could have a negative impact on the benefit that participants were able to obtain from their hearing aids.

“ Anyway, we went back, then they said oh that’s not right. I know it’s not right, I told you that x number of weeks ago. But it’s still there all these years later. There’s still that noise there. It’s slower than it was. They treat me like I assume they treat an old person. Oh never mind you don’t know what you’re talking about. There probably isn’t a noise there, you’re probably making it up.”

(Female, under 60, not working, Wales)

2.5 Decision-making regarding private provision

All of those participants who had consulted private hearing specialists had also used NHS hearing aid services. For example, they may have had a hearing test privately and been referred back to the NHS or they may have both a private and an NHS hearing aid.

Participants had chosen to consult a private dispenser because NHS waiting times were so long or they believed that they were too long, or because they felt that the hearing aids provided by private dispensers were of a better quality⁸. However, we should bear in mind that, in some cases, they took this decision some years ago and there may have subsequent improvements in waiting times. Exceptionally participants had been to a private dispenser as a result of a friend’s recommendation of one particular dispenser or because a private dispenser was willing to conduct the hearing test in the participant’s home. In this case, the participant did not want other people to know that she was having a hearing test.

Where participants had had their hearing tested privately in order to speed up the process, their work had given them a sense of urgency about the process of obtaining hearing aids. In these cases, they often had private health care provided through work that they used to access the hearing test privately. For instance, a

⁸ Waiting times have been dramatically reduced in the past year, since this study was conducted. Department of Health data for March 2009 reveals that 99.5% of people fitted with hearing aids had waited less than 18 weeks since being referred by their GP. In Scotland, a Scottish Government audit in 2006 found that the average wait for referral to fit was 33 weeks, with a national standard being 26 weeks. Since 2007, waiting times for audiology in Scotland is now included in the 18 week waiting time target by 2011. Further, since completion of the modernisation of hearing aid services in 2005, all hearing aids fitted on the NHS are now high quality digital models, and the technology is regularly upgraded.

participant described how he had been asking for support at work and, at the same time, he would pursue hearing aids outside of work. This was despite the fact that he wouldn't be able to wear hearing aids at work.

“ yeah it was mainly work trying to get... or to prove to work that I was doing something for myself... you know work can be really really funny... so I wanted to show them... I'm willing to do the backbone of the work.”

(Male, under 60, working, South West)

Some participants chose to obtain their hearing aids privately because they felt that they would be of a better quality.

“ I just felt the quality of the sound wasn't as good as it probably could be if I bought some privately... I kind of felt that it was worth making the investment because I could.”

(Female, under 60, working, South East)

Once they started to use a private dispenser, some participants appreciated the fact that the private provider was able to spend more time with them and had more time to resolve any problems that they might have. In these cases, the relationship with the hearing dispenser could operate on the patient's terms. For instance, they felt able to go back to the private dispenser as necessary. Similarly there was the sense that they could work as part of a team with the private dispenser to resolve any problems.

“ (they) have more time to say OK let's treat that let's try and do this let's try and do that... whereas I never had that with the NHS ones I always felt a bit like go and get them... and so well there's your batteries and off you go because you know you've had fifteen minutes or something.”

(Female, under 60, working, South East)

“ you see what she was able to do which they would not have been able to do on the NHS, was to say to me, she said look you've got this, the hearing loss is not enough to make a difference. If you would like to try two hearing aids, she said, 'are you going shopping?' I said yeah, she said OK. And she set a second hearing aid up and let me borrow it. I went and spent two hours shopping and she said come back and see me in a couple of hours and we have a word.”

(Female, over 60, not working, North West)

In this way, the reasons why participants initially go to a private hearing aid dispenser and the reasons why they continue to consult a private dispenser are not necessarily the same. Participants are more likely to consult a private dispenser because they believe that they offer

better quality hearing aids or because they have shorter waiting times. However, those participants who had used a private dispenser had come to appreciate the more flexible personalised service that enabled them to make the most of their hearing aids, something that contributed to their decision to continue to consult a private hearing aid dispenser.

2.6 Discussion

The delivery of healthcare services strongly influences the ease with which people adapt to and the benefit that they get from hearing aids. It is important that people who have been newly fitted with a hearing aid receive necessary and appropriate information in a timely manner. Much of this information will be specific to the participant and their hearing aid and, as such, an audiologist or audiology assistant is best placed to provide this information and support. This was often lacking. Sometimes the most basic information was omitted, such as how to use a loop system effectively and how to make sure that hearing aids are kept clean and in working order.

Participants also criticised the lack of joined-up working by the health service, in particular the fact that they had had to be referred between audiology and ENT by their GP, which added to waiting times.

These findings are supported by research with RNID members. 79% of respondents who had been fitted with a hearing aid did not receive any further information regarding services and organisations that are available to help them⁹. People could benefit from a wide

range of information covering areas such as communication support and assistive technology, lipreading classes and support at work.

Some of the advantages that private aid dispensers offer patients, namely a more personalised and flexible approach, would be of benefit to NHS patients. However, this type of approach relies on audiologists having enough time to fully meet each patient's needs. Audiologists are still under pressure to reduce waiting times and participants recognised that audiologists are too busy to spend sufficient time with patients.

There is guidance in this area, for instance, new performance standards and quality standards are currently under development by the Department of Health and the British Academy of Audiology. In Scotland the Government has 18 Week Principles and Definitions¹⁰ that sets out referral pathways between the GP and audiology or ENT, alongside the recently published Adult Audiology Standards¹¹. However, this research suggests that in order to meet patients' needs, there should be an increase in the capacity of audiology services.



⁹ RNID Annual Survey 2008.

¹⁰ Scottish Government (2009), *Referral to Treatment: Principles and Definitions*.

¹¹ Scottish Government (2009). *Quality Standards for Adult Hearing Rehabilitation Services*. Available from: <http://www.scotland.gov.uk/Publications/2009/04/27115807/0>

Chapter 3:

Impact of hearing loss

Hearing loss had had an impact on particular areas of participants' lives, in particular their working lives.

3.1 Relationships, family and social life

Participants' partners were, for the most part, supportive regarding the impact of their hearing loss. However, some participants expressed an appreciation of their partner's patience or their concern that their hearing loss was frustrating for their partner. They felt that the need for their partner to repeat themselves or to get the participant's attention before speaking must be frustrating.

“ He (partner) obviously gets a bit frustrated himself sometimes because he's got to keep repeating things to me but he's very very good.”

(Female, under 60, not working, Scotland)

“ I think living with the hearing loss... as frustrating as it is I don't think it's as bad as for people who don't have a hearing loss who are trying to live with somebody with a hearing loss.”

(Male, under 60, working, South West)

Children, however, tended to be less understanding or accommodating, something that could be distressing for parents. For instance, a participant described how she had bought a textphone but her sons had subsequently refused to have telephone conversations with her via Text relay as they did not like the idea of a third party listening in to the conversation. Another

described how her friends treated her hearing aid as a joke, something that she found unhelpful.

“ I've got three sons and... they won't speak to me on that (Text Relay) so I have to text... They're like, I'm not speaking when somebody else is listening in.”

(Female, under 60, working, Scotland)

“ the only thing was I had a few friends who would come out with remarks 'turn that hearing aid up' sort of thing... you know and joke about it... which is not very helpful... it sounds funny to them you know.”

(Female, under 60, not working, Northern Ireland)

Participants also described how family members initially take steps to mitigate the effects of hearing loss, but often forget after an initial period.

“ they would try to speak more loudly and clearly for a while... that would usually dwindle after a bit.”

(Female, under 60, working, South West)

Some of the effects of hearing loss had wider social ramifications, leading to feelings of isolation. Some felt their hearing loss had made them likely to withdraw from certain social activities, particularly those involving large groups of people. However, even where participants continued to take part in these types of activities, their difficulties in hearing could likewise result in a sense of isolation.

“ You know there’s times when I feel isolated... you know there’s times when I feel isolated like going out as a group... I don’t do that now.”

(Male, under 60, working, South West)

In particular, participants found that aspects of the physical environment, for instance, the acoustics or layout of a room, added to the difficulties that they experienced when socialising.

“ it is the acoustics... I think anywhere without carpet is a problem... a lot of modern restaurants are very difficult for that reason.”

(Female, under 60, working, South West)

Even where participants had continued socialising with large groups their hearing difficulties meant they frequently experienced a sense of isolation. A participant described going for a meal with his family:

“ so there’s all these conversations going on and to me it doesn’t mean anything and then I’ve got my partner and she’s sort of looking at me talking and she’s talking down the table and for the five conversations and all I hear is crumble so I’ve lost it totally.”

(Male, under 60, working, South West)

3.2 Work

As well as affecting family and social life, participants also recorded that their hearing loss could lead to problems at work.

Some participants were unwilling to tell their colleagues about their hearing loss because they believed they may be seen as less capable, and the expectations of others would have of their performance and professionalism would change.

“ I’m (still) not able to tell people if I’m in a meeting at work... I think that’s (a) sort of fear of being regarded as less professional.”

(Female, under 60, working, South East)

“ when you work with colleagues you want them to respect you professionally... you tend to think oh I don’t want them to sort of see that... because they may see it as a downside or they may see it as a weakness.”

(Female, under 60, working, South East)

On a positive note, participants reported that their colleagues tended to be supportive about their hearing loss, being happy to repeat themselves or taking phone calls for the participant.

Participants also expressed the concern that some people may not tell their employer about their hearing loss because they may worry that this will affect their job security.

“ There’s a lot of people that are still afraid to tell their employers that they are hard of hearing in case it affects their jobs you know.”

(Female, under 60, working, North West)

This is worrying because, if employees do not tell their employers about their hearing loss, they cannot request the reasonable adjustments that might enable them to continue working effectively.

Participants also had mixed experiences of employers’ willingness to make the adjustments necessary to allow them to continue successfully at work. In one case, hearing loss led directly to a participant being dismissed from their job, and others had experienced discrimination in one form or another. Other people had themselves given up their job because they felt they weren’t managing any more. Where they had decided to give up their job this tended to be because they had a hearing loss and other symptoms, for instance hyperacusis and vertigo.

“ Where I worked before that, I worked in (place name) and they were a nightmare. The manager was just so nasty to me all the time, any time I made a mistake. He was like that to everyone who had a disability’.”

(Female, under 60, working, Northern Ireland)

“ And my vertigo came back and I just couldn’t cope with being ill again and trying to go to work. I knew I was going to be off months and months and I was. That’s why I gave up. But I still do lipreading.

You know, that’s my bit of work that I do now.”

(Female, under 60, working, North West)

Less frequently participants had lost their job because of their hearing loss.

“ It got to the point at busy times I couldn’t hear. And so I stopped serving, and then it was causing confusion with customers because they couldn’t work out why there was a man there who wasn’t serving. And at the end of it my boss decided because I wasn’t there working with the team eight hours a day my effectiveness as a manager was lessened and maybe it was time to look for something else.”

(Male, under 60, not working, Northern Ireland)



In these cases it was not uncommon for participants to subsequently pursue a career or undertake voluntary work related to their hearing loss, for instance training as a lipreading teacher. However, there may be a selection bias in this respect as people involved in this type of work are more likely to have an existing relationship with RNID and, as such, may be more likely to take part in this type of research.

Where participants had remained in work they reported that they sometimes feel inadequate or as if they are not doing their job properly.

“ phoning can be a problem
but again some of the girls are
understanding and they will help
me take the phone call for me
and that but it’s still you feel...
I’m an E grade you feel like
you’re not doing the job properly.”

(Female, under 60, working, Scotland)

“ I feel stupid every time I take food
to the wrong table and then I’m like
there’s not much I can do about it,
just get on with it.”

(Female, under 60, working, Northern Ireland)

3.3 Discussion

Untreated or unrecognised hearing loss has an impact not just on the individual but on their relationships, social lives and employment.

The finding that participants are often unwilling to tell their colleagues or their employers about their hearing loss is of concern, as this suggests that some people are not requesting the reasonable adjustment that would help them to work more effectively and that may help them to stay in work. Moreover, the fact that they worry that their hearing loss will make them appear less professional or capable, demonstrates the stigma that remains around hearing loss.

Those participants who worked often reported that their employees were unwilling to make adjustments. RNID works with large employers who have an understanding of their obligations; however much of the UK workforce is employed by smaller employers. In 2006 over half of the UK workforce was employed by small and medium-size enterprises¹¹. We believe that there is a role for the government to raise awareness of the legal obligations employers have to their workforce.

Participants also reported mixed experiences of families’ level of understanding and willingness to take steps to mitigate the effect of hearing loss.



¹² <http://stats.berr.gov.uk/ed.sme/smestats2006-ukspr.pdf>

Chapter 4:

Support and equipment

4.1 Support

The two sources of support, outside audiology, most frequently accessed were sensory teams and lipreading classes. Some participants attended hard of hearing clubs.

4.2 Sensory teams

Where participants had obtained advice from a sensory team at times they had to be proactive, seeking out help. There was no smooth pathway in place between audiology and sensory teams.

Participants mentioned that they would have liked information regarding equipment in general, specific pieces of equipment or sources of equipment earlier than they had.

“ More crucial is that initial bit. Right. Having that information and you can then decide which information that you wish to pursue, which one you wish to pursue or nothing at all, put it all in the bin. But at least you’ve got the information. Whereas I picked it up in dribs and drabs, you know, it’s coming from all sorts of different sources.”

(Female, over 60, not working, North West)

4.3 Lipreading classes

Those participants who had attended lipreading classes were positive about these. The classes had the potential to act as a source of support and information as well as a counter to the isolation experienced by participants, particularly in cases where participants did not get the support they required from any other sources.

“ Lipreading classes... was something that I found really really helpful. It was the place where I probably got more support and good advice than anywhere else. Because I’m talking to people who have got exactly the same problem as me who’ve been through the same trials and tribulations with the bloomin’ hospital I’ve been through.”

(Female, under 60, not working, Scotland)

Unsurprisingly, lipreading classes were more difficult to access for people who worked. Where the lipreading classes themselves or the enrolment process took place during the working day, participants found it difficult to access these classes.

“ I’ve been on a really good lipreading class... and that was excellent... I mean I’d like to do more of it... I tried to enquire about it but they’re not running them in the evenings now they’re only running them in the day time.”

(Female, under 60, working, South East)

“ And I think the enrolment was like in July for September. And erm you seemed to have about five days to enrol and you had to go for an interview. Which was impossible for me at the time because I was working.”

(Female, under 60, working, South East)

4.4 Equipment

The equipment and assistive technology most commonly used were loop systems, telephone volume controls and subtitles. Other equipment used by participants were doorbells and smoke alarms designed for people who are deaf and hard of hearing, and occasionally listeners. In some cases participants had received advice or obtained specialist equipment from sensory teams in social services.

Participants were generally sanguine regarding the type of equipment available, having used a process of trial and error to find out which types of equipment suited them. Exceptionally, participants described equipment as having a transformative impact on their life. For instance, a participant had received advice about equipment from RNID.

“ I spent an hour around the table with (name), who loaned me a Contego. I had it for a week. I discovered that you know that the future isn't so black.”

(Male, under 60, Northern Ireland)

While participants made use of the equipment available to them, they occasionally mentioned ways in which equipment could be better adapted to their lifestyle. For instance, participants described how it is difficult to use a loop if you're watching television with other people.

“ I find that if you're watching TV using the loop system, if somebody comes in to the room and talks to you, you can't hear anything that they're saying. Because when you turn the hearing aids to the loop system it sort of turns off everyone else.”

(Female, under 60, working, Northern Ireland)

4.5 Communication support

Typically participants did not use communication support such as speech-to-text reporters, because they don't feel the need or are not aware of what support is available.

4.6 Discussion

Support and equipment can play a central role in helping people to adapt to their hearing loss. During recent years, funding cuts for further education have had an impact on the availability of lipreading classes. In Scotland, in particular, there is not enough funding for classes as no one body has responsibility for this area. Formal evaluation of lipreading classes may well not pick up the ancillary benefits, such as increased confidence and social contact, that

are so important to people who are deaf or hard of hearing. It is important that any guidelines about lipreading classes take into account these benefits.

There is a wide range of technological and personal assistance that people who are deaf or hard of hearing can take advantage of, and it is important that everyone has the information available to them to make the best choice for their needs. People are frequently unaware of what support is available and when it is available it often does not work, for example induction loop systems in public places. Moreover, there is a chronic shortage of some communication support specialists such as speech-to-text reporters.



Chapter 4:

Conclusions and recommendations

5.1 Patient's journey to diagnosis

The research found that both families and work played an important role in making participants aware of their hearing loss and making them seek help for their hearing loss. Interactions between participants and their partners in the context of their shared living arrangement had made either themselves or their partners conscious of their hearing loss. As such, cohabitation is an important factor in making people aware of hearing loss. However, hearing difficulties experienced at work or in education made people aware of their hearing loss in a way that their home life did not. Similarly concerns regarding performance at work meant that those participants who had experienced difficulties hearing at work were more likely to push for hearing aids as quickly as possible.

Those participants who delayed getting help for their hearing loss may have done so because they had other priorities, for example physical pain, or because they had only lost hearing in one ear. Other reasons for such a delay were a previous experience around hearing aids that had been unsuccessful, the participant not seeing themselves as someone with hearing loss or the association between hearing aids and ageing.

RNID recommends:

- Introduction of a hearing screening programme in all parts of the UK for older people.
- Introduction of a strategy to maximise the uptake of a hearing screening programme through targeted publicity.

5.2 Experiences of health services

Participants were not provided with sufficient information by their audiologist or, where they were provided with information, the language used was overly technical. Participants had had to be pro-active and manage the relationship with their audiologist, and there was also criticism of the lack of a joined-up approach by health services and of a lack of co-ordination between health and social services. Moreover there was a consensus that audiologists are not able to spend enough time with patients, and occasionally this translates into an unwillingness to look into problems that patients are experiencing with their hearing aids.

Where participants had obtained their hearing aids privately, they had done so because waiting times were so long or they believed waiting times were too long. In addition, they may have felt that the quality of hearing aids offered by private dispensers would be higher. However, once they had used private dispensers some participants had also come to appreciate the extra time and the flexible and personalised approach that private dispensers are able to take with patients.

RNID recommends:

- An increase in the capacity of audiology departments to enable audiologists to spend more time with patients and to deliver a system more tailored to patients' needs.
- More investment in - and a focus on - rehabilitation, ensuring that hearing aid users make the most of their equipment, including hearing aids and other assistive devices, and benefit from alternative methods of communication.
- A review of the information needs of people fitted with hearing aids and an assessment of what investment would be needed to meet these.



- Primary Care Trusts/Health Boards should ensure that follow-up appointments are offered routinely to patients, as per Department of Health guidelines.
- Audiologists and other services should work together more seamlessly to ensure that patients receive the appropriate information on a timely basis.
- New performance standards and quality standards are currently under development by the Department of Health and the British Academy of Audiology, while standards for adult audiology were published by the Scottish Government in 2009. We believe it is essential that compliance is monitored closely and reported in full.
- It is crucial that the current success in reducing waiting times and other improvements made to the service in recent years continues.
- RNID will conduct research with hearing aid users about how best they can manage their relationship with audiology departments and publish guidance accordingly.

5.3 Relationships, family and social life

Hearing loss had an impact on participants' home life. It had made participants withdraw from certain social activities, namely ones involving large groups of people. Moreover, where participants continue to take part in these types of activities where they have difficulty hearing, they experience a sense of isolation.

Partners tended to be understanding about participants' hearing loss, while children were less understanding as a rule, in some cases treating the hearing loss as a joke. Family members initially took steps to mitigate the effects of hearing loss, but often forget after an initial period.

Hearing loss also had an impact on participants' work lives. Participants were unwilling to tell colleagues about their hearing loss because of expectations around performance at work and a desire to be viewed as 'professional'. There was also the sense that hearing loss had narrowed the range of employment opportunities open to participants. Exceptionally, participants had experienced direct discrimination at work or lost their job because of hearing loss.

Participants had mixed experiences of employers' willingness to make reasonable adjustments.

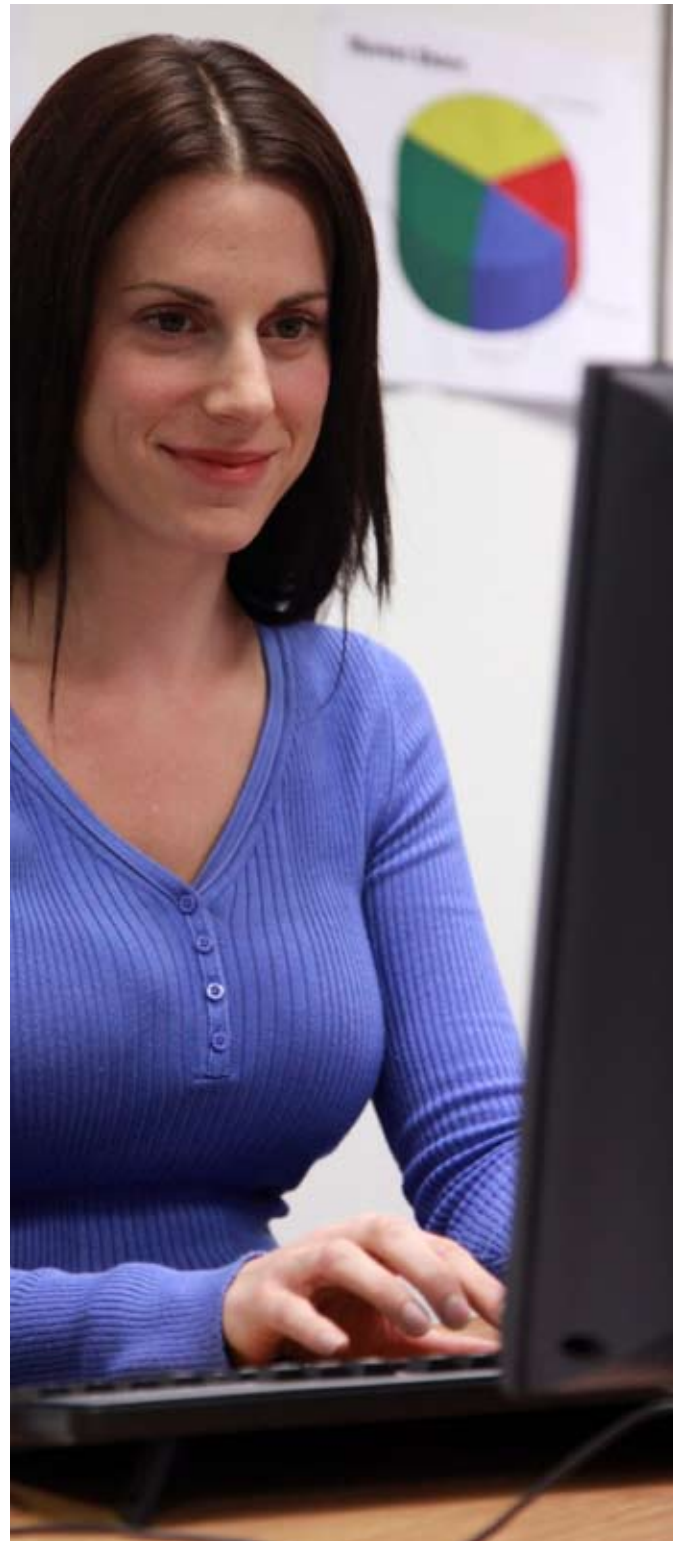
RNID recommends:

- RNID will work with people who are hard of hearing to make them aware of their rights in terms of reasonable adjustments at work.
- The Department of Health in all parts of the UK should provide information to families about the signs of hearing loss and where to go for help, and how to take steps to make communication easier for family members who are deaf or hard of hearing.
- All major employers and service providers should ensure that frontline staff and key managers have deaf awareness training.

5.4 Support and equipment

Lipreading classes had been a positive experience for participants who had attended these, acting as a source of support and information as well as a counter to the isolation experienced by participants. However, participants who were working found it harder to access lipreading classes.

Participants made use of equipment available to them, such as loops and listeners and had often obtained specialist equipment from social services. However, typically, participants did not use communication support such as speech-to-text reporters, because they didn't feel the need or were not aware of what support is available.



RNID recommends:

- The introduction of national guidelines that prioritise lipreading classes, coupled with an increase in the number of lipreading tutors.
- Increased funding and lower course fees for lipreading classes.
- More information about the types of help with communication that people can receive.
- Investment in the infrastructure necessary to support people with hearing loss, including the training of communication support specialists, investment in new voice recognition technology and steps to ensure that induction loop systems are working.

Methodology

This research adopted a wholly qualitative methodology of face-to-face interviews. Qualitative methods are ideal for exploring peoples' experiences and the meanings that these experiences hold for them.

Social research is either quantitative or qualitative. Quantitative research typically takes the form of a survey and is used to measure experiences and beliefs, producing numerical data. Qualitative research typically takes the form of in-depth interviews or focus groups and is used to gain an insight into peoples' lives and the processes that inform their behaviours and experiences. We selected a qualitative methodology for this research in order to explore the factors that influenced their decisions around hearing aids. These findings would not have been so accessible using a quantitative methodology. However, whilst this type of qualitative research enables us to identify the range of peoples' experiences, it does not look to produce statistics.

Recruitment of participants

The interviews took place in a variety of places, to ensure that participants were recruited from both urban and rural locations. We included an advertisement for participants in the RNID membership magazine, *One in Seven*, and RNID staff in other offices also helped to recruit participants from their contacts.

The interviews

24 interviews took place between June 2008 and February 2009. The interviews were conducted by two members of the Social Research and Policy team. The breakdown of participants in terms of sex, age and working status as follows:

Sex Male 10 participants	Female 14 participants
Age Over 60 11 participants	Under 60 13 participants
Working status In work or education 9 participants	Not in work or education 15 participants

Of these, 15 participants had first used a hearing aid during the last ten years.

The interviews took place in either the participants' homes, in a public place, such as a café, or in an RNID office. The interviews lasted between 30 minutes and 70 minutes each. We recorded the interviews, as agreed by the participants.

Analysing and interpreting the findings

The interviewers produced written transcriptions of the data from 23 of the interviews to provide a full anonymised record of each interview, and a summary of the remaining interview. Each of these transcripts was then coded in terms of emerging themes. This report outlines findings from the information provided by the people who chose to take part in this study. We have drawn out themes on the basis of what the participants said and remembered during the interviews.

We have included quotations in the report in order to illustrate some of the themes which emerged. These quotations are taken directly from the verbatim transcripts of the research. All the quotations are anonymous.

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