

# **ACTION ON HEARING LOSS**

# **QUALITY TIME**

**Do quality of life issues inform  
the advice that audiologists give  
to people with hearing loss?**

By Laura Matthews

# Acknowledgements

I would like to thank the participants who kindly gave up their time to be interviewed for this research.

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## Executive summary

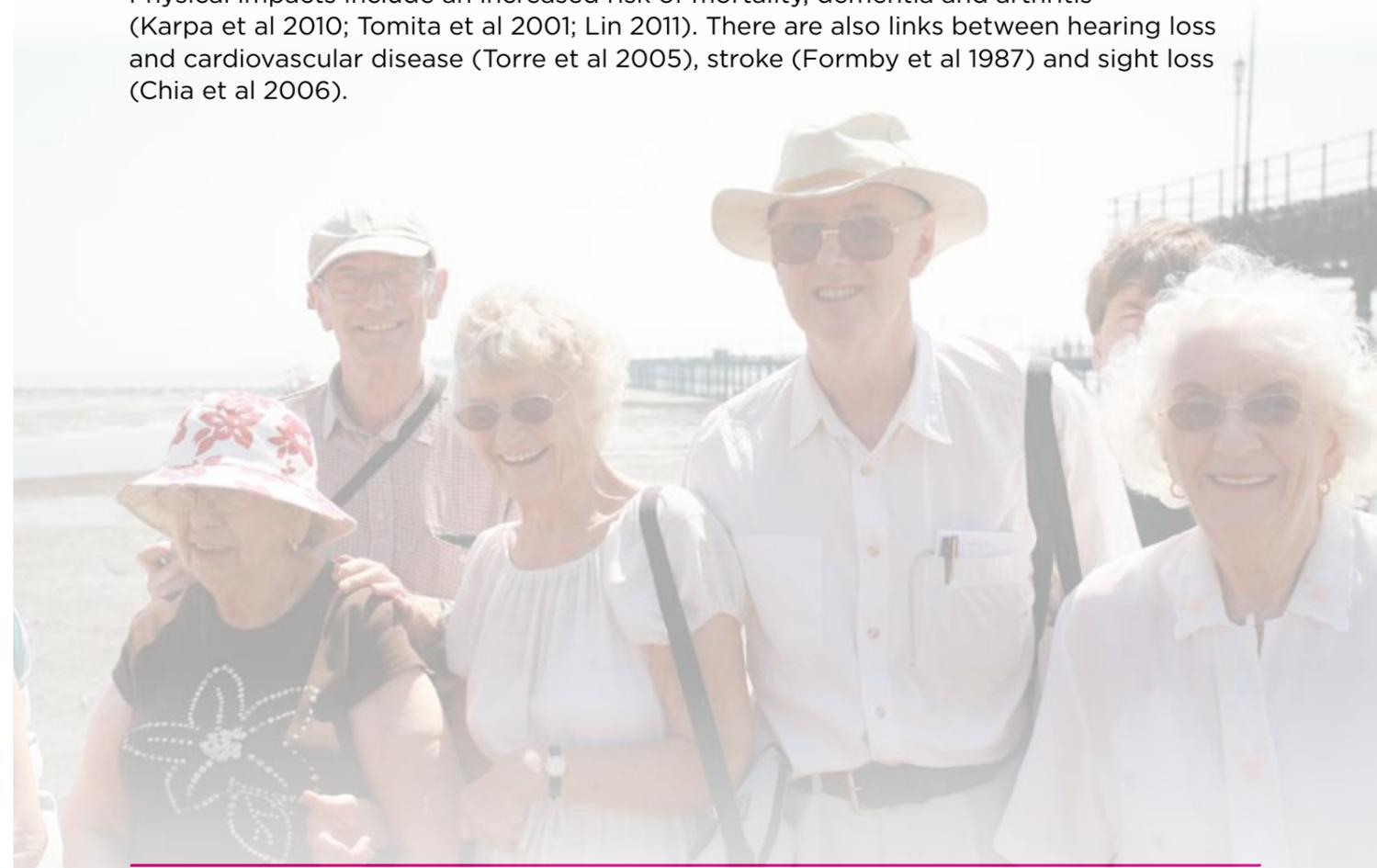
In the UK, 10 million people have hearing loss, a figure expected to rise to 14.5 million people by 2031 (Action on Hearing Loss 2011). The World Health Organisation (WHO) (2004) predicts hearing loss will be in the world's top 10 disease burdens by 2030.

Action on Hearing Loss's *Taking Action: Strategy 2013-18*, highlights three key outcomes that we as an organisation are striving to achieve. First, we are focused on supporting people with their hearing loss to ensure that: "Everyone has the right information, advice, care and support" (p6). To achieve this outcome it is vital that we understand the impact of hearing loss so that we can take steps to minimise it by providing effective audiology and rehabilitative services.

### Hearing loss and QoL

Quality of life (QoL) is a term commonly used to describe broader health status, in line with the WHO definition (1948): "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." There has been considerable research demonstrating the negative impact that hearing loss has on an individual's QoL.

Physical impacts include an increased risk of mortality, dementia and arthritis (Karpa et al 2010; Tomita et al 2001; Lin 2011). There are also links between hearing loss and cardiovascular disease (Torre et al 2005), stroke (Formby et al 1987) and sight loss (Chia et al 2006).



Psychological impacts can include depression (Cacciatore et al 1999; Tomita et al 2001; Saito et al 2010), anxiety and distress (Thomas 1984; De Graaf and Bijl 2002). Those with acquired profound hearing loss are at greater risk of psychological impact than those with a lower degree of acquired hearing loss (Hallam et al 2006). Mental health problems can also affect family members, particularly partners of people with hearing loss (Link 2005; Echalié 2010). Hearing loss can also lead to loss of employment (Link 2005; Matthews 2011) and problems finding employment (Baker 2006).

Finally, the social impacts of hearing loss can include loneliness, isolation (Cooper 1976; Eastwood et al 1985) and social exclusion (Du Feu and Fergusson 2003; Echalié 2010). How individuals manage their hearing loss can also affect QoL. Those who wear hearing aids have more positive outcomes than those who do not (Apollonio et al 1996; Kochkin and Rogin 2000; Mulrow et al 1990).

Despite all this, however, it is unclear whether those primarily responsible for offering advice to people with hearing loss are even aware of these potential impacts. If so, it is also unclear whether this awareness has had any influence on the advice they offer.

NHS audiologists are the gateway to NHS audiology services. They are the key healthcare professionals that the majority of people with hearing loss see, besides their GP. Audiologists assess, diagnose and help manage hearing loss, as well as tinnitus and balance problems. They are, therefore, the main source of information and support for people with hearing loss.

Therefore, the aim of the research was to understand whether QoL issues inform the advice that audiologists give to people with hearing loss and to identify any barriers preventing this.



The researcher conducted in-depth interviews with six NHS audiologists based in England. The interviews provided an opportunity to explore how aware the participants were of QoL issues and to determine the extent to which this awareness informed their advice and support. We also explored what barriers, if any, prevent the participants from supporting people with hearing loss effectively.

## Findings

Overall, the audiologists interviewed showed a good level of awareness of QoL issues, and, where possible, they use this to inform the advice they give.

All participants said they were aware that wearing hearing aids causes many patients anxiety, and that many are reluctant to wear them. For this reason, all of the participants provide some psychological support and attempt to manage their patients' expectations.

The participants encourage patients to use communication tactics, for example, telling people they have a hearing loss and facing the person speaking. They also adapt their advice to support patients with disabilities or other health issues. All participants had a good level of awareness of formal referral options and were willing to use them when necessary.

When it came to the social impacts of hearing loss, such as withdrawing from social situations, isolation and loneliness, the participants showed slightly lower levels of awareness.

Discussion generally focused on difficulties faced, such as problems hearing the telephone or television, rather than on the changes in patients' behaviour resulting from these difficulties. Awareness in this area was generally strongest in participants with personal experience of a relative with hearing loss.

Participants had some awareness of the impact of the behaviour of others on the person with hearing loss. In general, they try to help in this area by providing communications tactics for friends and family. These include providing tips such as facing the person with hearing loss when speaking, speaking clearly but not too slowly, and saying things in a different way if you have not been understood.

There was little evidence that participants were aware of the links between hearing loss and other physical health problems or of its impact on employment prospects. In both cases, this may be due to associating hearing loss with old age, as older people are more likely to be retired and to have physical health problems.

There was generally a low level of awareness of the psychological impact of hearing loss, such as depression and anxiety, and low awareness too of the possible impact on family members. Therefore, participants are less likely to offer support and advice in these areas.

## Barriers

The interviews highlighted organisational and individual barriers that prevent the participants from providing a fully effective support service for people with hearing loss.

Organisational barriers include a lack of continuity of care, with patients generally seeing a different audiologist at each appointment.

Services are not joined up. Patients do not receive all aspects of care from the audiologist or even from the audiology department. This means that audiologists often have to signpost patients to other services and support. In some cases, audiologists' knowledge of other services and support is low. Formal referrals, although possible, are normally made by GPs, because of the funding and organisational structure of the NHS.

Administration of services is sometimes poor. There are difficulties booking interpreters for patients with English as a second language, and issues with stock control of hearing aids.

Some of the study participants felt that hearing loss and audiology services are not a priority within the NHS, possibly because the condition is not considered life threatening, with the result that some GPs are reluctant to refer.

Finally, the fact that some people with hearing loss can be unwilling to accept or address their condition can be a substantial barrier in itself.

This research therefore demonstrates that while audiologists are interested in patients' subjective experiences, and are aware to some extent of the QoL impact of hearing loss, there are numerous barriers that limit the effectiveness of the support on offer.

## Recommendations

Audiologists would benefit from training on the full range of QoL impacts of hearing loss. This should be undertaken as part of the audiology degree and included in continuing professional development and training. Training should also include ways to address and reduce these QoL impacts, for example, through the provision of information and referrals to other appropriate organisations/professionals. It is clear from the participant interviews that counselling makes up a substantial proportion of an audiologist's role. It is, therefore, vital that all training reflects and recognises the importance of this skill.

It is also clear from the findings that there is a need for a review of processes in audiology departments to ensure that the rehabilitation pathway is clear, efficient and joined up. This would include clarifying referral pathways and investigating whether allocating patients to one audiologist would improve continuity of care.

In order to encourage people to address their hearing loss, they should also be made aware of the possible negative impact on their QoL, and the important role that hearing aids can play in reducing this impact.

Further research to explore the issues raised in this project would be beneficial. The study participants raised poor continuity of care as a barrier to good care. Do patients also see this as a barrier? Would they prefer to see the same audiologist throughout or to be seen by the first one available?

Research among GPs would also be useful to explore whether they are reluctant to refer people to audiology departments – and, if so, why. Also, if services worked more efficiently with each other, would patients benefit from shorter waiting times? And what would help people to accept and address their hearing loss?

The specific recommendations below could help to reduce the QoL impact of hearing loss and improve outcomes for people with the condition.

## We're asking for..

### Universities with audiology-related courses to:

- provide students with an understanding of the breadth and depth of QoL impacts of hearing loss
- recognise counselling skills as an important and specific part of course content, as well as throughout training opportunities, including conferences and continuing professional development.

### Audiology departments to:

- provide continuing professional development training on the QoL impacts of hearing loss
- raise awareness among patients of the possible QoL impacts of not addressing hearing loss
- investigate the benefits for patients by piloting trials in which they see the same audiologist throughout their audiology journey
- improve knowledge among audiologists of the services they can signpost locally, and have someone in the team responsible for keeping everyone up to date on developments with local services
- investigate models of care for increased integration between audiology and rehabilitation services, including those provided at the same location
- investigate quicker referral routes from the GP to audiology and between services, to make it quicker and easier for patients to get the help they need
- investigate self-referral routes so that people with suspected hearing loss do not need to be referred from their GP, but can instead contact the audiology department directly
- investigate ways to improve acceptance of their condition among people with hearing loss, and ways to increase their motivation to address it
- update and maintain counselling skills regularly as part of continuing professional development
- consider providing patients with counselling packs similar to those available from some private sector providers
- ensure that accessible, high-quality information is available to patients, through leaflets, for example, on the impacts of hearing loss and the services available to them



- allow some flexibility to provide longer appointment times for those with additional needs or in need of more support
- investigate the use of an outcome measurement tool that includes the range of QoL impacts and not just a person's hearing loss
- examine administration processes to ensure effective booking systems for interpreters and to monitor stock of hearing aids.

#### For GPs to:

- help patients to understand the QoL impact of hearing loss and encourage them to take action
- specialist ENT GPs to develop ways to spread their knowledge among other GPs, to raise awareness of the importance of managing hearing loss, for example, through training sessions, conferences and information.

#### For Action on Hearing Loss to:

- improve awareness among GPs of the QoL impacts of hearing loss and the need to refer all people with hearing loss promptly to audiology services
- consider research among GPs to learn more about their willingness to refer people with hearing loss onto audiology services
- continue to raise awareness among people with hearing loss of the full impacts of hearing loss and of the services available to them
- investigate ways to improve acceptance of their condition among people with hearing loss, and ways of increasing their motivation to address it.

## Introduction

Hearing loss currently affects more than 10 million people in the UK. By 2031, this figure will have increased to 14.5 million (Action on Hearing Loss 2011). Worldwide, the condition affects more than 250 million people (Mathers et al 2000). The risk of hearing loss increases with age, with 40% of people aged 50 and over experiencing some level of hearing loss; among people aged 70 and over, prevalence rises to 70% (Action on Hearing Loss 2011). According to the WHO (2004), hearing loss will be in the world's top 10 disease burdens by 2030.

A significant body of research demonstrates the negative impacts that hearing loss can have on an individual's quality of life (QoL), through, for example, restricted communication, reduced social activity and difficulties in employment (Marcus- Bernstein 1986; Baker 2006).

However, it is unclear whether those primarily responsible for offering advice to people with hearing loss are even aware of these potential impacts. If so, it is also unclear whether this awareness has had any influence on the advice they offer.

NHS audiologists are the gateway to NHS audiology services. They are the key healthcare professionals that the majority of people with hearing loss see, besides their GP. Audiologists assess, diagnose and help manage hearing loss, as well as tinnitus and balance problems. They are, therefore, the main source of information and support for people with hearing loss.

Action on Hearing Loss's *Taking Action: Strategy 2013-18* focuses on the need for everyone with hearing loss to get the right information, advice, care and support. It is, therefore, important to explore the level of awareness among audiologists of the QoL impacts of hearing loss, to ensure that people with the condition receive the correct support.

### Research aims

#### This research aimed to explore the following questions:

- are audiologists aware of the QoL impacts of hearing loss?
- does this awareness influence the advice and support they offer to people with hearing loss?
- are there barriers preventing audiologists from supporting people to minimise the negative QoL impact of hearing loss?

### Scope of the research

There are different levels of hearing loss. Some are born with no hearing, while others develop age-related hearing loss later in life. This research focused on people who have lost their hearing as adults and whose main language is English, rather than on people who use sign language, as this is the largest group of people seen by audiologists.

## Research methods

Six NHS audiologists working with adults with hearing loss were interviewed. Only audiologists based in England were interviewed because there are different organisational frameworks in each country in the UK. The audiologists were asked to describe both a typical journey through their department for someone with hearing loss, and a less typical journey. An example of the latter might be someone with another disability or long-term condition. The researcher asked further questions to examine the audiologists' answers in depth. All interviews were recorded and partially transcribed with detailed notes.

## Report structure

Chapter 1 explores the existing literature to understand the QoL impact of hearing loss. The findings from the interviews are then discussed in Chapter 2, including quotes from participants to illustrate themes that emerged from the research<sup>1</sup>. Chapter 3 outlines the conclusion and recommendations.

<sup>1</sup> Names are not used with quotes in order to maintain anonymity.

# Chapter 1: Literature review

## Health and quality of life

Measures such as mortality and morbidity have traditionally been the primary tools to measure health outcomes. However, these tools focus on life-threatening conditions and fail to measure the impact of treatment upon an individual, particularly those with long-term conditions (Bowling 2005). They also fail to take into account how individuals feel about their condition or the environment in which they live (Patrick 2003).

Increasingly, it is now recognised that an individual's health and the chances of recovery from illness or impairment are influenced by a broad range of factors such as personality, motivation, coping strategies, values and beliefs, social support and socio-economic status (Bowling 2005). This understanding has seen a recent move towards using a broader definition of health, in line with that defined in the Constitution of the World Health Organisation (WHO) (1948): "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."

Quality of life (QoL) has become an increasingly popular concept used to describe this broader health status. However, it is a contested concept with no agreed definition. It was first used in the United States to mean affluence. During the 1970s it became linked to health and illness, and is now often used interchangeably with terms such as health, well-being and functional status (Brock 1993; Nordenfelt 1994; Patrick 2003).

The WHO defines QoL as: "individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment" (1997, p.1). This definition recognises the subjective nature of QoL (Patrick 2003).

Fallowfield (1990) describes the four core domains of QoL as psychological, social, occupational and physical. Psychological issues include an individual's adjustment to illness or disease, including, for example, whether they have depression or anxiety. Social issues include personal relationships and engagement in social and leisure activities. Occupational issues include the ability to undertake work or household tasks. Finally, physical problems include pain, discomfort and restricted mobility.

## Hearing loss and QoL

As with other medical conditions, hearing professionals have generally focused their attention on physical outcomes such as speech perception and sensitivity to noise. However, Kerr and Cowie (1997) suggest that more recent literature demonstrates a move away from a focus solely on audiological measures, and towards recognising the wider impact of hearing loss on an individual's life:

**“This impact results primarily from deficits in the activities of speech perception and communication and the limitations imposed by these deficits on participation in social interactions, in employment, in leisure pursuits, and in the enjoyment of sound.”**

(Boothroyd 2007, p.63)

There is substantial research demonstrating the negative impact of hearing loss on all four core domains of QoL as described by Fallowfield (1990), and these are explored next.

## Physical

Research has shown an increased risk of mortality for people with hearing loss (Karpa et al 2010). A study by Tomita et al (2001) found people with hearing loss experienced more illness, including arthritis, and more pain. People with mild hearing loss are nearly twice as likely to develop dementia compared to someone without hearing loss, which increases to nearly five times the risk for someone with severe hearing loss (Lin 2011).

While there is much debate around the links between hearing loss and other long-term conditions, there is research to demonstrate links between hearing loss and cardiovascular disease (Torre et al 2005), stroke (Formby et al 1987) and sight loss (Chia et al 2006)<sup>2</sup>.

## Psychological

There has been considerable research demonstrating an association between hearing loss and mental health, including depression (Cacciatore et al 1999; Gilhorne-Herbst and Humphrey 1980; Leigh et al 1989; Tomita et al 2001; Saito et al 2010) and anxiety and distress (Thomas 1984; De Graaf and Bijl 2002).

Thomas (1984) found the prevalence of anxiety and depression to be four times greater in people with hearing loss than the population average. A Dutch study found mental distress amongst 28% of postlingually deaf men and 43% of postlingually deaf women, compared with 22% and 27% respectively in the general population (De Graaf and Bijl 2002). More recent research in Japan found people with hearing loss were 2.5 times more likely to develop depression than those without hearing loss (Saito et al 2010).

However, the research is contradictory in terms of whether the severity of hearing loss is linked to the severity of the mental health problem, with some studies demonstrating a link (Thomas 1984; Nachtgaal et al 2009), while others have not (Gilhorne-Herbst and Humphrey 1980; Leigh et al 1989).

Acquiring a profound hearing loss, often referred to as ‘deafened’, has been found to have a greater psychological effect than a lower degree of acquired hearing loss (Hallam et al 2006). Research suggests this may be due to people undergoing a bereavement reaction to this hugely traumatic event (Aguayo and Woodcock 2000). In the UK, there are around 150,000 people with acquired profound hearing loss (Davis 1995).

Mental health problems can also extend to family and, in particular, to partners of people

<sup>2</sup> For further research on hearing loss and long term conditions, visit our website <http://www.actiononhearingloss.org.uk/joiningup>

with hearing loss (Link 2005; Echaliier 2010). Link (2005) found the rate of depression in hearing partners was around four times higher, and anxiety rates 1.5 times greater, than the UK national average. However, this research was undertaken with people who were using Link’s support services and were, therefore, likely to have substantial needs<sup>3</sup>.

## Occupational

People with hearing loss are also more likely to face problems with employment. Several studies have found that developing hearing loss can lead to loss of employment (Link 2005; Matthews 2011) and problems gaining employment (Baker 2006). Brock (1993) suggests that there may be a negative impact on QoL, particularly when impairment happens later in life, forcing individuals to make changes to their work, social and personal life. Some research suggests that employment can have a protective effect on mental health and prevent social isolation for people with hearing loss (Ringdahl and Grimby 2000).

## Social

Research has demonstrated links between hearing loss and loneliness and isolation (Cooper 1976; Eastwood et al 1985). People who lose their hearing later in life are at greater risk of social exclusion due to the problems they experience in communicating with friends and family (Du Feu and Fergusson 2003; Echaliier 2010). One longitudinal study found that people experience less support and have fewer social contacts, the greater the degree of hearing loss (Marcus-Bernstein 1986). With an increasing proportion of older people living alone (Tinker 1997), this is likely to be a growing issue.

Weinstein and Ventry (1982) measured social interaction objectively (for example, numbers of interactions) and subjectively (feelings about isolation, etc). They concluded that, while the number of interactions did not decrease as a result of hearing loss, the quality of the interactions did. As a result, people with hearing loss were left feeling unsatisfied by their interactions with other people. This is supported by Kerr and Cowie’s finding (1997) that “malinteraction by hearing people” is a factor in the negative impact of hearing loss (p.180). They describe this as reflecting “the perception by deafened people that hearing parties contribute to the success or failure of interaction between them” (p.180). Therefore, other people’s behaviour contributes towards the QoL of an individual with hearing loss.

## Management of hearing loss

Research indicates that the way individuals manage hearing loss can have an impact on their QoL. Hallberg et al (2008) found that behaviours such as pretending to hear, guessing what has been said and avoiding interactions had a significant negative impact on QoL. The researchers go on to suggest that cognitive, behavioural and attitudinal changes are necessary on the part of the individual to minimise the impact of hearing loss.

Rehabilitation can reduce and minimise the impact of hearing loss on QoL. In the UK, hearing aids are the main form of rehabilitation. Several studies have found a significant

<sup>3</sup> For further research regarding hearing loss and mental health visit <http://www.actiononhearingloss.org.uk/mentalhealth>

difference in QoL between those who wear hearing aids and those who do not (Apollonio et al 1996; Kochkin and Rogin 2000; Mulrow et al 1990). Hearing aid users were more likely to engage in activities than non-hearing aid users, less likely to report mental health problems such as depression and anxiety, and to have better physical health.

However, even when provided with hearing aids, some people do not wear them. Reasons include unrealistic expectations about what hearing aids can achieve (Brooks 1989; Meister et al 2008). People may not accept they have a hearing loss or the extent of their condition (Brooks 1985; Brooks 1989). Tinker (1997) suggests this may be as result of “a stereotype of old age which promotes expectations of ill health and decrepitude it is little wonder that older people refuse as long as possible to be labelled as sick” (p.71). Brooks (1996), however, argues that older people are more likely to accept their hearing loss as an inevitable consequence of ageing and are, therefore, not motivated to manage it. Meister et al (2008) suggested a pre-fitting appointment would help to ensure that outcomes are maximised for hearing aid wearers.

Brooks (1996) suggests that an individual living alone will be less motivated to use a hearing aid. Kapteyn (1977) supports this finding, and suggests friends and family will affect an individual’s use of a hearing aid, with an intolerant household making greater demands on the individual to use it. Those who rate their hearing loss as more severe are most likely to use their hearing aids (Meister et al 2008; Sorri et al 1984).

There are also more practical reasons for not wearing hearing aids. Many users have some difficulty handling and maintaining their hearing aids, resulting in a reduction or complete withdrawal of use (Brook 1985; Brooks 1996; Sorri et al 1984). Brooks (1996) suggests that difficulty handling the hearing aid is more acute in elderly people. As with hearing loss, the risk of disability or illness increases with age (Tinker 1997). Some people also find it difficult to adjust to the sound heard through hearing aids, particularly if they have already adapted to low sound levels as a result of long-term hearing loss (Brooks 1996). Boothroyd (2007) recommends extra support and instruction to ensure people obtain the maximum benefit from hearing aids.

However, while hearing aids have a positive impact on speech perception and can improve QoL, they cannot restore hearing (Boothroyd 2007). Therefore, it is important that audiologists recognise the limitations of hearing aids and are also able to offer other forms of support to people with hearing loss while ensuring that the benefits of the hearing aids are maximised. This could include signposting to other sources of support such as hearing loss charities, lipreading classes and assistive equipment.

## Hearing loss and QoL measures

This growing recognition of the range of factors that can influence someone’s health has led to a re-evaluation of the way the impact of treatment is measured. It is now increasingly important to establish whether treatment leads to improved QoL (Bowling 2005). It is clear that a broader model than mortality and morbidity is needed to evaluate health outcomes.

The concept of QoL has been used to develop outcome measurement tools. Brock (1993) discusses two key principles of a QoL measure. First, it focuses on functions such as work or relationships. Second, it is a subjective measure of an individual’s response to their physical condition. It is possible to measure objectively an individual’s level of functioning,

such as their level of hearing loss. However, this does not necessarily provide an accurate measurement of their ability to hear (Bowling 2005).

This is confirmed by studies that found no direct correlation between the level of hearing loss and its impact on QoL (Kerr and Cowie 1997; Hallberg et al 2008). Therefore, simple audiological measures of hearing loss are not effective as a measure of the impact on QoL. Instead, it is important to explore individual perceptions to ensure that effective rehabilitation is provided. For this reason, QoL tools contain self-report measures, including interviews or self-completion questionnaires.

## Selecting measurement tools

Hunt et al (1986) identify some key issues to consider when choosing a measurement tool. Does the tool need to be disease specific? For example, the WHO (1997) developed QoL measures WHOQOL-100 and WHOQOLBREF to allow comparison across cultures and diseases. These tools focus on the individual’s self- perception and enable information to be gathered about the impact of the disease or illness on the person as a whole. The tools focus on six broad areas: physical, psychological, independence, relationships, environment, and spirituality/religion.

However, some argue that generalist QoL tools are oversimplified to ensure that they are applicable to a large population (Brock 1993). There may also be problems in comparing outcome measures across different cultures (Patrick 2003).

Hunt et al (1986) suggest it is important to consider whether the tool is reliable, sensitive and valid. Many measurement tools have been developed based on judgements made by medical professionals and may reflect a different viewpoint from those of individuals with an impairment (Bowling 2005).

There may also be problems comparing one individual to another, with the impact of their illness or disease varying depending on their personality and environment (Bowling 2005). QoL may mean different things to different people (McClimans and Browne 2012).

The tools may also not be effective in measuring change over time, as an individual’s subjective views may shift (Bowling 2005). Older people are more likely to accept illness and ailments as a natural part of life. Consequently, while the impact on their QoL may not change, their view of the impact may change. Gatehouse (1990) found older people with hearing loss reported less disability for a given level of hearing loss than younger people.

It is also important to consider whether the tool is appropriate and acceptable to the population being studied (Hunt et al 1986). QoL measures make assumptions that may not be correct, for example, in assuming that all life areas are equally important to an individual (Fitzpatrick and Albrecht 1994). This criticism has led to the development of tools that enable individuals to identify areas that they feel are important.

## Available QoL tools

Numerous tools have been developed for use with people with hearing loss to measure outcomes. For example, the Hearing Handicap Inventory for the Elderly (HHIE), commonly used in the United States, consists of 25 questions around hearing loss, on topics such as extent of embarrassment and frustration (Newman and Weinstein 1988).

Chisolm et al (2004) used the Communication Profile for the Hearing Impaired (CPHI) in their research, which includes questions about communication performance, the environment, use of communication strategies, and personal adjustment.

Ward et al (1978) used the Hearing Measurement Scale, combining subjective measures such as emotional response and opinion of hearing, as well as objective measures such as speech hearing ability and distortion.

Other scales include the Hearing Performance Inventory (Giolas et al 1979), the IOI- HA (International Outcome Inventory-Hearing Aids) (Cox et al 2000) and the IOI-HA- SO (for Significant Others) (Noble 2002). The views of significant others can be useful in helping an audiologist decide on the rehabilitation necessary for the person with hearing loss.

The most commonly used tools in UK audiology, alongside objective clinical measures, are the Glasgow Hearing Aid Benefit Profile (GHABP) (Gatehouse 1990) and the Client Oriented Scale of Improvement (COSI) (Dillon et al 1997). Both are questionnaires administered by the audiologist before and after a hearing aid fitting, and ask patients to rate their difficulty in different situations.

The COSI requires the patient to self-identify all situations, while the GHABP specifies four situations and allows the patient to add a further four. These tools focus on the degree of difficulty experienced as a result of the disease, rather than on broader QoL measures. In the UK, outcome measurement tools are recommended for use in NHS audiology services but are not a requirement (for example, DH 2007, NHS 2011).

## Summary

There has been a move away from solely using objective measures of health such as mortality and morbidity, and towards more subjective measures that encompass a broader definition of health. QoL has become an increasingly popular concept to describe broader health status, encompassing a range of life areas, including physical, psychological, occupational and social. Research clearly demonstrates the negative impact of hearing loss on an individual's QoL. However, the commonly used hearing loss tools such as GHABP and COSI measure the symptoms related to that disease, rather than broader QoL issues.

# Chapter 2: Findings and analysis

The researcher interviewed six NHS audiologists based in England. This chapter discusses the findings based on those interviews.

## Typical patient pathway

Participants were asked to describe a typical journey within their audiology department for an adult with hearing loss (see Figure 1 below). A referral is received from the GP or, occasionally, the Ear, Nose and Throat (ENT) department. The patient attends for an assessment, including a hearing test. If appropriate, the patient returns for hearing aid fitting. Progress is monitored at a follow-up appointment and repairs are available from the department or other locations when required. Two participants from the same NHS trust do not offer follow-up appointments.

**Figure 1: Typical NHS audiology pathway described in interviews**



As the participants described the NHS audiology pathway, they talked about the problems their patients experienced and the solutions they were able to offer, providing the researcher data on their awareness of quality of life (QoL) issues.

## Interest in the patient's subjective experience

The literature highlights a shift in focus among professionals, away from a purely objective interest in disease, and towards encompassing a more subjective view. The subjective view is important in helping audiologists understand the QoL impact of hearing loss.

All participants described undertaking both subjective and objective measures of their patients' hearing loss. The objective measures were related to the hearing test, and the subjective measures included taking medical and personal histories, using an outcome measurement tool and generally talking to individuals about their hearing loss. While these may be a requirement of the NHS audiology pathway, all the participants recognised the importance of understanding the view of the individual:

**“In the services I've worked in, there has always been a template for adults about what questions to ask. Whether the person is retired, whether they live alone, and identify what the individual actually requires rather than just fixing some hearing aids on their ears... So identifying and understanding the need is a big part of the appointment without a doubt.”**

Interestingly, the two participants most recent to the audiologist role spoke specifically of their interest in their patients and their desire to understand their viewpoint:

**“It’s very patient based. I get to spend a lot longer than a doctor would with a patient and really get to grips with their problem. ... You learn to do the technical stuff in the background and put the patient at the forefront of the appointment.”**

**“I am trained in the new way of making the appointment very patient focused, and so I am already talking about social situations or personal feelings about hearing loss and the patient’s individual needs.”**

In contrast, however, the most experienced participant suggested that the increasingly scientific focus of audiology meant that audiologists were most interested in the objective measures from the hearing test rather than the subjective view of the individual:

**“I think, unfortunately, we have become very scientific by nature. We are now very interested in the diagnostics and the social implications seem to have a less of an impact... I think in the medical field most of what we do is evidence based on quantitative assessment. Unfortunately, qualitative assessments are less provable, I guess.”**

The participant goes on to explain that this is because student audiologists are now required to have a maths and science background, and, with the introduction of digital hearing aids, the focus of the appointment is on programming the aids. This happened to a much lesser extent with analogue hearing aids. Therefore, this participant has observed a reduction in time spent on the subjective measures, and a greater focus on the objective measures.

## Outcome measurement tools

There are two main outcome measurement tools used in UK audiology as discussed in Chapter 1. All participants use the Glasgow Hearing Aid Benefit Profile (GHABP) in their appointments, with most stating that this was departmental policy. The questionnaire is undertaken in the assessment appointment and repeated at the follow-up appointment:

**“We ask them about four basic situations and they can then add four situations of their own that are more specific to their lifestyle. For example, if they attend Church... or if they take yoga classes or dance classes or anything like that, they can add it. After their hearing aid fitting, we can see whether the hearing aid is helping them with the level of difficulty, if it’s reducing it and, basically, improving their scores.”**

As described above, the GHABP allows individuals to highlight to the audiologist the areas of their life most affected by their hearing loss. However, several participants mentioned that patients struggled to suggest situations and invariably needed prompting. Therefore, there is a limit to how much these tools can genuinely be tailored to the individual.

While the usefulness of the GHABP was limited for two participants who, due to their NHS trust policy, do not offer follow-up appointments, in general it was considered useful, with most viewing it as a counselling tool that demonstrates the value of hearing aids to the patient:

**“It can demonstrate to the user that we have actually made an improvement. I think when you follow up patients... they are never 100% satisfied, and I think that’s because their expectations are too high. But I think to be able to say you were having this level of difficulty in this situation, and now, it’s not perfect, but you admit to much less difficulty in this situation.”**

Some participants said that while the GHABP can feel unnatural, the format can also encourage people who are not normally forthcoming to admit to and describe their difficulties:

**“I found the Glasgow [tool] clunky compared to a conversation where I might get the same information. But it does have its merits because I have seen in the past where we have spoken – the patient and I – and they have been adamant that they have no problems, they are getting on fine. And then we go through the Glasgow [questionnaire] and then, actually, they are a bit more honest. Usually, this is the case with men more than women where, in a kind of conversational setting, they are not very willing to tell you how they feel but when there are options on the screen, and they have to pick one, they seem more willing to say ‘yes that’s moderately difficult’, whereas when we spoke about it previously, they said they didn’t have any problems.”**

Four participants also mentioned the Client Oriented Scale of Improvement (COSI), with three having had direct experience of it in the workplace. They described it as having several advantages over the GHABP, including the ability to ask questions in their own way, prioritise issues and tailor it to the individual. However, this personalisation of the questionnaire makes comparisons difficult and therefore it may not be possible to show improvement over time:

**“When I was a trainee... I used the COSI... I very much liked it because it is more conversation based and so suits my personal counselling style more closely. So I was a big fan of that. But I think it does a very similar job to the Glasgow [tool] to be honest. It’s about identifying an area, looking at whether you have created an improvement with a hearing aid fitting and then using that to drive your further management.”**

The participants did not use any other outcome measurement tools. It is a positive finding that all participants use the GHABP, because the benefits of fitting hearing aids can be measured for those patients who have a follow-up appointment.

A few participants also mentioned that if the GHABP did not identify a decrease in

difficulty, they would consider other options to support the person with hearing loss. However, this tool does not give the audiologist insight into all the areas of a person's life that may be affected by hearing loss. Only four situations in general are discussed, with measurement very much focused on the outcome of the hearing aids, not on other advice or support offered by the audiologist.

## Awareness of the impact of hearing loss on an individual's QoL

According to the literature there are four main life areas affected by hearing loss: physical, psychological, occupational and social. The interviewees were not asked about each area in particular, but were instead asked to describe a typical and non-typical hearing loss journey. They were also asked a broad question about the impact of hearing loss. Therefore, the areas discussed were those that the participants mentioned themselves, rather than any raised through prompting, which implies that they have greater awareness of these areas, or view them as priorities.

### Physical

The existing literature finds a link between hearing loss and an increased risk of disease such as dementia, stroke, arthritis, sight impairment and cardiovascular disease. Although referrals were received from GPs, invariably these contained little information about the patient. All participants discussed carrying out a medical history with the patient, but the focus here was on hearing loss in particular and not on their physical health in general:

**“We take a detailed history. Finding out what's going on, how long they've noticed hearing loss. Has it been sudden or gradual? Any pain? Any discharge? Any vertigo? Any tinnitus? We just ask those standard questions to make sure they meet the criteria for hearing aids.”**

One participant linked learning disability with a higher risk of progressive hearing loss, explaining that these patients were seen on an annual basis. However, none of the participants mentioned the impact that hearing loss can have on an individual's physical health. This may mean that they are not aware of this link, or that they simply do not view it as a priority. As discussed in the literature review, the risk of disability and ill health increases with age, so the participants may take the view that poor health is to be expected because many of their patients are older.

A positive finding was that some of the participants discussed other physical or health problems – for example, arthritis, sight impairment, stroke, dementia or learning disability – in relation to how well individuals could manage their hearing loss. This implies that while the audiologists may not be aware of the link between hearing loss and other physical health problems, these issues are taken into account when providing support:

**“Visual impairment really makes a difference because you change your whole way of... assessing a patient. You know that their hearing is now a sense that they will rely on even more, so that's why they need some additional help.”**

One participant recognised the need to provide specialised support for patients with dementia and requested training from staff on a specialist dementia ward.

While the impact of hearing loss on physical health is likely to be a long-term issue, which may not be immediately apparent to an audiologist, it is important that audiologists are aware of this issue, and recognise that hearing loss can negatively affect an individual's mortality in the longer term. This underlines the need to ensure that people are effectively supported with their hearing loss.

### Psychological

The literature review highlighted links between hearing loss and mental health problems such as depression, anxiety and distress. These issues were raised only occasionally during the interviews. For example, one participant mentioned the negative impact hearing loss can have on self-esteem through feelings of embarrassment. The same participant and one other talked about people experiencing a change in personality as a result of hearing loss.

**“My grandma, she has hearing loss... I can see it because we will be talking in a room and she will be sitting quietly, just watching everybody. And you can see the change in someone's personality.”**

Two participants discussed patients becoming upset or emotional during appointments: Research shows that people experience a greater psychological impact as a result of becoming deafened. Two participants specifically mentioned the traumatic impact of losing hearing suddenly.

The literature review also raised the issue of the impact of hearing loss on an individual's family. Only one participant mentioned this and recommended involving partners of people with hearing loss in their care. Interestingly, this participant has a close family member with hearing loss and direct experience of the impact of hearing loss on family members:

**“One of the challenges of hearing loss is that it rarely affects the individual to the same extent that it affects the people around them. And we know that by having to constantly repeat yourself – like my father, for example – it's really frustrating... I think the significant other needs the opportunity to express their concerns and actually be part of building the management plan.”**

All of the participants talked about patients feeling anxious about getting hearing aids, with the issue raised several times throughout the interviews. This anxiety, if not dealt with, can mean that patients are not willing to get or wear hearing aids. Often, these anxieties were discussed in terms of the patient not wanting hearing aids or not liking the look of them:

**“Lots of people are quite anxious because they... don't really want hearing aids, they just want to see [sic] what their hearing is like and get some information. A lot of people have grandparents with hearing loss with massive hearing aids and they don't want the same.”**

The participant below describes how patients are often told negative stories about hearing aids, which makes them nervous when they return for a fitting:

**“They get these horror stories and so by the time they come back to me a month and a half to two months later, they are often much more anxious about it than when I saw them originally.”**

Overall, all of the participants had some awareness of the psychological impact of hearing loss, and in particular of the fears people had about wearing hearing aids.

## Occupational

The literature review highlighted the fact that people with hearing loss have problems gaining and staying in work. Five participants mentioned employment during the interviews, with two stating that the impact on employment is addressed in the template questionnaire they use. Where the subject was raised, however, it was discussed only briefly. This may be because most people with hearing loss are older and are likely to be retired. Audiologists may, therefore, consider this a lower priority issue.

## Social

The literature highlights several social impacts of hearing loss, including isolation, loneliness and lower-quality interaction. Of all QoL issues highlighted in the literature review, this was the area most commonly mentioned by the participants. All of the audiologists were aware of at least some of the social impacts of hearing loss, but they generally focused on areas where people experience difficulties rather than on the impact these difficulties create. For example, five participants mentioned problems hearing the television and four mentioned problems hearing when on the telephone. Most mentioned problems experienced in group situations, for example, in church or at parties.

There was some discussion about behaviour change as a result of the difficulties faced. Four participants talked about people with hearing loss reducing or ceasing activities as a result of their condition, and four mentioned isolation. Two participants had personal experience of hearing loss in their family and described in detail its impact on behaviour:

**“I think the biggest barrier is communication and that feeling of being left out... It has such a big impact on communication, just the ability to laugh at a joke or watch a [sic] conversation... It affects social life. My gran won't want to go out much anymore.”**

**“If you take elderly people living in a block of flats, you'll often find they don't watch TV because they are afraid it's so loud they are going to disturb their neighbours. And that's a very isolating condition. Equally, people find themselves doing fewer activities. Probably a lot of people that are socially isolated, it's because of their hearing. They often find themselves excluded, they don't understand the punchline of a joke... I think the impact in the longer term on the individual is cataclysmic. I think there are a lot of people suffering unnecessarily.”**

One participant who is also a hearing therapist explained the reasons for the withdrawal from activity:

**“You constrain yourself for certain reasons. You have some insecurities. That person has an insecurity – I cannot hear, I don't know if I am going to be able to speak to my friends the same way as before.”**

The literature also highlighted the negative impact of other people's behaviour on people with hearing loss, because they do not change how they communicate. Interestingly, four of the participants talked about this issue during the interviews:

**“It's not visible, so people don't have patience, don't have the desire to support the person. I think when you have a visible long-term condition, people are much more willing to help. If you take a person in a wheelchair, people are very likely to support that person with wheelchair ramps... but I think with hearing impairments, there isn't that desire, because it's not visible. The understanding is not there in the public.”**

**“It leads to isolation just because other people don't seem to understand... It does have a huge impact on someone.”**

The participants talked about the social impact of hearing loss more readily and in greater detail. However, to a greater extent they discussed the issue more in terms of difficulties experienced than in terms of the impact on the individual. This may be because it is easier to suggest solutions to specific difficulties rather than more general concepts such as isolation and social exclusion. As a result, the audiologists necessarily focus on those issues that they can help with.

## Influence of awareness on advice and support

It is clear that the participants are interested in their patients' subjective views, and are aware of at least some of the QoL impacts of hearing loss. The main benefit of understanding these impacts, however, is incorporating this understanding into solutions for the individual, to help reduce and minimise the negative impact of hearing loss. As demonstrated by the literature, effective management of hearing loss can help to negate the impact on QoL.

On a positive note, all of the participants talked about solutions they could offer to people, depending upon their particular needs:

**“Depending on your patient, you are adapting your appointment to suit them.”**

These solutions can be divided into either psychological support or communication support, and both can help to reduce the impact of hearing loss on all four QoL areas.

## Psychological support

Psychological support includes solutions that focus on the emotional impact of hearing loss, such as counselling, hearing therapy and managing expectations. All participants talked about supporting people with counselling during appointments. This includes encouraging acceptance and management of hearing loss, and ensuring that patients have realistic expectations of their hearing aids:

“That’s more important to me, the counselling side of things, making sure that the patients [are] completely happy with everything they are doing. Because sometimes they feel like they are railroaded. If they’ve come with family, they feel like ‘this has been chosen for me’. But I give them the opportunity to talk about it and let them know that it’s not something that we are going to force on them.”

“If they live on their own, obviously that completely changes our management plan because their motivation is – well, I’m at home on my own, I don’t need to hear anything. But if they do have a significant hearing loss, we have to counsel on the safety aspects of it.”

Participants use a variety of tools to provide psychological support. These include the GHABP, which some consider useful for people in denial about their hearing loss because it helps to demonstrate the problems that patients experience. It can also help to manage expectations by showing the benefit of wearing hearing aids. During an appointment, participants would talk through the hearing test and explain to the patient how hearing aids can help them in specific situations:

“People say to me, ‘I cannot hear when there is a whole load of noise’, and I say, ‘Well people with normal hearing also can’t hear when there is a whole load of noise.’ It’s a lot about how you adapt to your environment, not just about your ears. I don’t want them to think a hearing aid is a magic quick fix.”

A hearing therapist works with people with hearing loss to provide specialist counselling as well as advice on practical solutions such as equipment. While audiologists are trained to provide this to some extent, they generally refer a patient to a hearing therapist if the person needs a greater level of support, for example, someone who has lost their hearing suddenly and may be struggling to cope:

“I might see someone who has... quite a significant hearing loss that came on suddenly, say, and they might be struggling to cope with all the changes that’s brought for them, so I might refer them straight away to hearing therapy, which will run alongside my fitting and follow-up.”

## Communication support

Communication support comprises solutions that help people to communicate or hear better, such as hearing aids, communication tips, equipment and lipreading. Hearing aids

were the main focus for the participants, who discussed how to programme them to suit the individual:

“If you can see where their main difficulties are, and what their lifestyle is like, you can tailor the programmes and the hearing aid to suit them. If they are into music, or go out socially quite a lot, you can build it in. Obviously, it’s important to assess the patient’s abilities and how much they can absorb.”

All of the participants said they provide patients with information on communication tactics, either in conversation and/or through a printed leaflet. As discussed previously, the behaviour of other people can have an impact on a person with hearing loss and, promisingly, four of the participants talked about also giving information on communication tactics to friends and family:

“I often bring a patient’s family into the room and explain everything to them. I think that’s important because, let’s say the patient was motivated by the family, the family also has to know how to communicate, so it’s not only for the patient. It’s always the patient [who] is blamed because they cannot hear.”

Some information was provided about equipment that can support the individual, such as amplified telephones or flashing doorbells, for example, through leaflets, catalogues or signposting to local social service teams that may be able to provide or loan equipment.

However, participants said that they gave this information to specific people, such as younger patients or those who were still having difficulties after several appointments. There was a general feeling that the participants did not want to overwhelm patients with too much information during appointments. This could mean that some patients miss out on vital information and support.

All participants also considered referral to other services as an option. For example, referral to ENT for any medical problems with the ears, to social service teams for equipment, and to hearing therapy for general advice or information about local voluntary services and counselling. Only one participant mentioned lipreading classes.

## Barriers

The participants highlighted numerous barriers that prevent people from being supported in the most effective way. These barriers can be divided into two categories: organisational and individual.

### Organisational barriers

#### *Continuity of care*

All participants stated that they do not usually see patients at every stage of their journey. They therefore rely on notes made by colleagues at a previous appointment in order to tailor the service to individuals. Patients can request to see a particular audiologist but this may not always happen:

“I might see someone for their assessment but not necessarily fit their hearing aid, and I may not see them at follow-up. So, I guess from a personal, more emotional support point of view, I think that’s probably a barrier to patients opening up to us – that they don’t always see the same person.”

Seeing the same patient can benefit the patient, in terms of a more personalised service, building trust and reducing the need to repeat conversations, and benefit the audiologist through feedback on the service they provide:

**“That journey, I feel, is very broken in this department. It would be nice to have everything flow so that you follow that patient right through from the beginning to the end. I think it makes a big, big difference, because there is that familiarity. Patients get frustrated when they come in and see somebody different every time. For a clinician to have control over their workload, I think, is really, really important. To organise their own time and be accountable for their own patients and their journeys.”**

**“I think that can be really valuable actually and I think it would be of benefit for both the clinician and the patient to see it through. Sometimes, when you fit a hearing aid, you think you’ve done a really good job, but if you don’t see or speak to that patient afterwards, you get no feedback on your own performance, on your own fitting.”**

However, one participant suggested that seeing different audiologists was preferable to patients waiting longer for an appointment. Generally, the audiology department covers more than one hospital, with audiologists working across different locations, so a request for a particular audiologist may increase the waiting time.

Two participants from the same NHS trust do not offer follow-up appointments to patients once they have been fitted with hearing aids:

**“If you know that a patient is anxious, living on their own, we just leave them to it and [say] ‘call us if there is a problem’. More often than not, they do call us because there is a problem... they are a bit worried about something quite small. If they had a follow-up [appointment], it would give them more confidence.”**

Offering continuity of care, with each audiologist responsible for allocated patients, could help to engender trust and build relationships, enabling the audiologist to provide more personalised care and to receive feedback on their service. However, this could also lead to longer waiting times for patients.

#### *Joined-up service*

As the participant quoted above recognises, hearing aids are not the only solution, so it is vital that patients have easy access to other services that may support them to manage their hearing loss and reduce the negative impact on their QoL. However, services such as audiology, hearing therapy, equipment and information are not always integrated:

**“It’s a huge barrier... we are not a holistic team where we can say we are helping with everything in order to help you hear better all the time. And sometimes it doesn’t just come with hearing aids. It comes with hearing therapy and having some devices around the house.”**

This participant has recognised that they are not able to provide all the support that someone with hearing loss may need. While hearing aids are important, other services and support can also be hugely beneficial to someone with hearing loss.

In principle, all participants can refer patients on to other services. In reality, however, most audiologists have to write a letter to a patient’s GP, requesting referral to a particular service. This increases waiting times and may also prevent an individual from accessing a service at all if the GP does not agree that the referral is necessary. Several participants said this was a result of their NHS trust’s policy, which is likely to be a funding issue:

**“As audiologists, we don’t have that much power to make referrals, so it often has to go back to the GP and round that way.”**

**“We have to stick to the pathways that we are given... I can’t just refer directly to the Ear Nose and Throat department. We have to stick to the protocols.”**

Some participants also suggested that a lack of knowledge on their part prevented them from providing the best information, advice and support, particularly in relation to other equipment available:

**“I definitely think that in audiology we need to know more about these things. It’s more useful coming from one place than sending the patient to different places... A lot of patients would be willing to pay for things, so if we could point them in the right direction and give them a little bit more advice... I think it would make a huge difference.”**

One participant made the point that an audiologist may not always be the best person to go to for advice and support, as they cannot be expected to know everything. This implies that an audiologist’s role is partly about signposting individuals to the services that can provide the best support – but this entails having that knowledge.

Some participants talked about sharing knowledge within their department through team meetings and newsletters. Several participants, however, did not feel they were being kept up to date with developments in audiology:

**“We are never going to reach a point where you know everything. Things are changing and [there’s] always scope to learn more. I think it makes your job more interesting if you can come in and talk intellectually about what’s happening in audiology. And I feel that’s not happened at all here [in their audiology department].”**

The participants did not feel able to provide a holistic, joined-up service, with barriers to referrals and lack of knowledge preventing them from signposting effectively. A joined-up

rehabilitation pathway would improve the patient's experience by reducing waiting times and providing the best information.

#### Administration

Some participants discussed the administration issues that prevent them from providing effective support. The participants from London all mentioned the need for interpreters due to the various minority ethnic groups living in their area. In reality, interpreters are not always booked for appointments, leaving the audiologists to rely on family members or other staff members in the department to translate:

**“We have quite a mixed cultural group in this part of London, so we do have a lot of difficulty with language barriers. Some patients do understand English but it's not their strong point when it comes to expressing themselves, and they feel more comfortable with somebody coming along.”**

**“In London, a lot of people need an interpreter. Those people sometimes come in on their own even if they are aware that their English is not strong enough.”**

Having no interpreter booked can mean patients having to wait longer for their diagnosis and hearing aid fitting. Also, they may not fully understand what is said during the appointment and so are unlikely to receive the most effective support.

One participant mentioned stock problems, describing how there were not enough hearing aids available in the department, and moulds being sent to the wrong hospital, all of which creates further delays for patients.

#### Priority

There was some discussion around hearing loss not being a priority issue for the NHS. Two participants suggested that GPs are reluctant to refer people to audiology services, creating a barrier to managing hearing loss effectively:

**“The other main restriction, if you like, to access are GPs. The overwhelming majority of GPs know nothing about hearing at all... They are there to try and stop you accessing a tertiary service because ultimately that is incredibly expensive. Making people go through [GP referral] is an incredibly huge barrier. It takes a lot of people a lot of courage and thought to go to their GP... And when they do go and are fobbed off 29 out of 30 times, I think they probably go home and think ‘oh well I won't worry’. And, of course, the idea of that is to restrict access. GPs want fewer people to take these services up, of course they do, because if one in six people turned up wanting a hearing aid, that would be a real problem for the government.”**

**“I think sometimes the GP can be a little bit of a barrier. I think that we often see people quite late, when they may have been struggling with hearing problems for three or four years, and they have gone through a kind of cycle of having their ears syringed and being told it's a cold and then being prescribed decongestants and things like that, before the audiology referral is made. I think people can sometimes be quite desperate by the time they get to us.”**

The clear perception emerged then that GPs effectively restrict access to the audiology service by delaying referrals. Further, two participants argued that this view of audiology as a low priority is more widespread in the health service:

**“The main barrier is audiology... getting it on the agenda is incredibly difficult. And getting people to understand the importance and the value of audiology is incredibly difficult.”**

**“The hospital as a whole, I don't think they put a high priority on hearing loss because they don't see it as life threatening, or the audiologist's job as life saving.”**

Clearly, participants feel that some people across the health service view audiology as a low priority, particularly as hearing loss is not recognised as a life-threatening disease. As a result, the government is not interested in the audiology service and is unwilling to fund improvements.

### Individual barriers

#### Motivation and acceptance

The issue that came up most frequently during the interviews was the extent to which individuals have accepted their hearing loss and their level of motivation to manage it. The literature review identified this as an issue that can prevent effective management of hearing loss.

One participant stated that the initial assessment appointment had a higher rate of non-attendance than the fitting appointment, demonstrating that some people are unwilling to manage their hearing loss:

**“If their expectations and their motivations aren't addressed, it is very difficult to teach somebody something new in the hearing aid fitting appointment. It's important that they have accepted their hearing loss, are motivated to give it a go and understand what that involves.”**

**“They are putting their trust in you... this massive thing in their life, they probably haven't told anyone about. They're anxious about it, it's affecting their quality of life and how isolated they feel. Now they are doing something that's a visible change, that will identify them as older, and you have to be able to manage all that in one appointment.”**

As discussed in the literature, it is common for family members to encourage patients to take action. This can suggest that they themselves have not accepted their hearing loss and have low motivation to manage it:

**“We... get people who are pushed by their family. They communicate by shouting but the patient still denies hearing loss... Those [patients are], I think, the most difficult to manage because they don't really... believe they have any hearing problems.”**

**“We see an awful lot of people referred by their GP and [they] say, ‘I don't have a problem. I'm here because my wife keeps nagging me...’ or ‘I am here because my daughter made me come...’. So, it's often a struggle in that initial appointment to find the motivation of the individual sat in front of me. It's not that common for people to come in and say there is something wrong with their hearing and ask for your help. It's more common that they come along begrudgingly, and [aren't] so keen at the initial stage.”**

In these situations, no matter how much support an audiologist gives, patients need to be willing to help themselves. Are these individuals aware of the QoL impact of hearing loss, and would such awareness help to motivate them to take action over their hearing loss? Otherwise, even when these patients are fitted with hearing aids, very often...

**“The hearing aid ends up in the drawer and they don't wear it.”**

Overall, therefore, the participants were interested in the subjective experience of the individual and made use of outcome measurement tools. They were also aware of at least some of the QoL impacts of hearing loss and tried to incorporate these into the support they offer. However, the participants also described numerous barriers, organisational and individual, to providing effective support.

## Chapter 3: Conclusion and recommendations

The literature identifies four key quality of life (QoL) areas where hearing loss can have a negative impact on an individual: physical, psychological, occupational and social.

The participant interviews demonstrate differing levels of awareness of the QoL impacts among audiologists, and differences too in how this knowledge influences their behaviour. All of the participants were interested in at least some aspects of patients' subjective experiences. Again, however, the extent to which this interest influenced their actions varied among the participants. The most recent graduates suggested they were very interested in the subjective experience, while the most experienced participant argued that the profession has become increasingly focused on objective measures.

### Awareness of QoL issues

Generally, there was a good awareness of QoL issues among the audiologists, and they make use of outcome measurement tools to draw out some of the subjective measures.

All of the participants said they are aware that many patients feel anxiety about wearing hearing aids and are reluctant to wear them. For this reason, all participants provide some psychological support and attempt to manage their patients' expectations. They also all encourage patients to use communication tactics and adapt their advice to support patients with disabilities or other health issues.

All participants showed a good level of awareness of different formal referral options and said they are willing to use these when necessary. However, awareness of other support services, to which they can signpost patients, was lower.

Slightly lower levels of awareness were also evident regarding the social impacts of hearing loss, such as withdrawing from social situations, isolation and loneliness. Discussion generally focused more on the difficulties people face, such as problems hearing the telephone or television, rather than on the resulting changes in patients' behaviour.

Awareness was generally strongest in participants with personal experience of a relative with hearing loss.

There was some awareness of the impact of other people's behaviour on the person with hearing loss. In general, participants try to help in this area by providing friends and family with communications tactics.

There was little evidence of awareness of links to other physical health problems or of the impact on employment prospects, both of which may be because participants associate

hearing loss with old age, as older people are more likely to be retired and to have physical health problems.

There was generally a low level of awareness of the psychological impact of hearing loss, such as depression and anxiety, as well as low awareness of the possible impact on family members. Therefore, support and advice in these areas was less common. These QoL impacts can be substantial, so it is important that audiologists are aware of these issues and can support people effectively in these areas.

## Barriers

The research identified numerous barriers that prevent the participants from providing a fully effective support service for people with hearing loss. Organisational barriers include a lack of continuity of care, with patients generally seeing a different audiologist at each appointment.

Services are not joined up, with the audiologist, or even the audiology department, not providing all aspects of care. Instead, audiologists often have to signpost patients to other services and support. Yet, some participants stated that their knowledge of other services and support was low. Formal referrals, while possible, must normally be made via the GP because of the funding and organisational structure of the NHS.

Administration of the service can sometimes be poor. There are problems in booking interpreters for patients with English as a second language, and issues around stock control of hearing aids.

Some participants feel that hearing loss and audiology services are not a priority within the NHS, possibly because the condition is not considered life threatening. As a result, some GPs are reluctant to refer.

Finally, among people with hearing loss there are also substantial barriers, with many unwilling to accept and address their hearing loss.

## Recommendations

Our strategy, *Taking Action: Strategy 2013-18*, highlights the key outcomes that we as an organisation are striving to achieve. The first of these is focused on supporting people with their hearing loss to ensure that: "Everyone has the right information, advice, care and support" (p6). To achieve this outcome, it is vital that we understand the impact of hearing loss in order to take the necessary steps to minimise it through the provision of effective audiology and rehabilitative services.

Audiologists would benefit from training on the full range of the QoL impacts of hearing loss. This should be undertaken as part of the audiology degree and included in continuing professional development and training.

Training should also include ways to address and reduce these QoL impacts, for example, through the provision of information and referrals to other appropriate organisations/professionals. It is clear from the participant interviews that counselling makes up a substantial proportion of an audiologist's role, so it is vital that all training reflects and recognises the importance of this skill.

It is also clear from the findings that there is a need for a review of processes in audiology departments to shape a rehabilitation pathway that is clear, efficient and joined up, to ensure that people with hearing loss are supported at each stage of their journey. This should include clarifying referral pathways and investigating whether to provide continuity of care by allocating patients to one audiologist. Continuity of care can help to build patient trust and rapport, and in the process enable audiologists to give full and effective support to people with hearing loss.

In order to encourage people with hearing loss to address their condition, they should also be made aware of its possible negative impacts on their QoL, and of the important part that hearing aids can play in reducing this impact.

Further research would be beneficial to explore the issues raised in this project. The participants highlighted continuity of care as a barrier, but is this also a barrier from the point of view of the patient? Would patients prefer to see the same audiologist throughout or to be seen by the first one available?

Research among GPs would also be useful to explore whether they are reluctant to refer people to audiology departments – and, if so, why? Also, if services worked more efficiently with each other, would patients benefit through shorter waiting times? And what would help people to accept and address their hearing loss?

The specific recommendations below could help to reduce the QoL impact of hearing loss and improve outcomes for people with the condition.

## We're asking for...

### Universities with audiology-related courses to:

- provide students with an understanding of the breadth and depth of QoL impacts of hearing loss
- recognise counselling skills as an important and specific part of course content, as well as throughout training opportunities, including conferences and continuing professional development.

### Audiology departments to:

- provide continuing professional development training on the QoL impacts of hearing loss
- raise awareness among patients of the possible QoL impacts of not addressing hearing loss
- investigate the benefits for patients by piloting trials in which they see the same audiologist throughout their audiology journey
- improve knowledge among audiologists of the services they can signpost locally, and have someone in the team responsible for keeping everyone up to date on developments with local services
- investigate models of care for increased integration between audiology and rehabilitation services, including those provided at the same location
- investigate quicker referral routes from the GP to audiology and between services, to make it quicker and easier for patients to get the help they need
- investigate self-referral routes so that people with suspected hearing loss do not need to be referred from their GP, but can instead contact the audiology department direct
- investigate ways to improve acceptance of their condition among people with hearing loss, and ways to increase their motivation to address it
- update and maintain counselling skills regularly as part of continuing professional development
- consider providing patients with counselling packs similar to those available from some private sector providers
- ensure that accessible, high-quality information is available to patients, through leaflets, for example, on the impacts of hearing loss and the services available to them
- allow some flexibility to provide longer appointment times for those with additional needs or in need of more support
- investigate the use of an outcome measurement tool that includes the range of QoL impacts and not just a person's hearing loss

- examine administration processes to ensure effective booking systems for interpreters and to monitor stock of hearing aids.

### GPs to:

- help patients to understand the QoL impact of hearing loss and encourage them to take action
- specialist ENT GPs to develop ways to spread their knowledge among other GPs, to raise awareness of the importance of managing hearing loss, for example, through training sessions, conferences and information.

### Action on Hearing Loss to:

- improve awareness among GPs of the QoL impacts of hearing loss and the need to refer all people with hearing loss promptly to audiology services
- consider research among GPs to learn more about their willingness to refer people with hearing loss onto audiology services
- continue to raise awareness among people with hearing loss of the full impacts of hearing loss and of the services available to them
- investigate ways to improve acceptance of their condition among people with hearing loss, and ways of increasing their motivation to address it.

In conclusion, while audiologists are interested in the subjective experience of patients and are aware to some extent of the QoL impact of hearing loss, numerous barriers exist that reduce the effectiveness of the support they can offer. These organisational and individual barriers need to be addressed to ensure that each person with hearing loss is fully supported to reduce the potential impact of their condition on their QoL.

## Appendix: Research methods

In order to explore the views of audiologists in depth, we took a qualitative approach with semi-structured interviews. As different operational frameworks for audiology exist in each country of the UK, recruitment was limited to England. We used non-probability convenience sampling to identify the participants.

Six NHS audiologists who work with adults with hearing loss were recruited, although most also do some work with children. The participants ranged in seniority over three bands, with three participants in band 5, two in band 6, and 1 in band 7. NHS experience ranged from one to 12 years. Four of the audiologists worked in two different NHS trusts in London, and two in one NHS trust in another city. Two participants were male, and four were female.

Most people with hearing loss go to the NHS because it provides free hearing aids, although these are also available privately in the UK. The study focused on NHS audiology only.

### Selection criteria

Heads of departments were excluded from the research because they are likely to spend less time in direct contact with people with hearing loss. Student audiologists were also excluded because they are still undergoing training and are therefore likely to have different views from fully qualified audiologists with work experience in this area. Finally, the audiologists working within Action on Hearing Loss were also excluded because they have substantial awareness of the wider needs and problems of people with hearing loss.

### Interview plan

The interview plan listed areas to cover in each interview, so that the same range of issues could be explored with every participant, while providing an opportunity to examine individual responses in more detail.

An interview guide was developed using the existing literature, as well as the researcher's knowledge of the audiology pathway (see Table 1 below). This was tested with the audiologists within the researcher's organisation to ensure that the questions were clear and easily understood by that particular audience.

Because quality of life (QoL) is not necessarily a term that the participants would be familiar with, it was omitted from the interview plan.

The interview plan was designed to prevent the researcher leading the participants. They were asked to describe both a typical and non-typical journey for someone with hearing loss through their hospital. The researcher asked further questions to explore their answers in more detail in order to elicit their knowledge about the impact of hearing loss and the way in which this knowledge affects the advice and support they give.

Participants were asked last of all about the impact of hearing loss. This was to avoid

prompting them earlier in the interview, as the research was interested in finding out what level of priority participants allocated to various issues.

**Table 1: Key topics included in interview plan**

Key topics	Prompts
Typical audiology journey	Referral, medical history, family background, work, social life, expectations, attitudes, reviews, follow ups, repairs, information
Use of outcome measures	GHABP, COSI, other tools
Non-typical audiology journey	People needing more support, e.g. with dementia, learning difficulties
Referral to others	Hearing therapists, ENT, social services, GP
Barriers and improvements	Are they able to provide the support they would like to? What could be improved?
Best practice	Are they aware of any examples of best practice? From their hospital, other hospitals or abroad?
Impact of hearing loss	On individual and others

### The interviews

The interviews in London were conducted face to face, mainly in the participants' workplace, or, in one case, in the researcher's work place. The remaining two interviews were conducted by telephone. All interviews lasted up to one hour, were recorded with a digital recorder and later partially transcribed with detailed notes.

The researcher followed the Social Research Association's Ethical Guidelines (2003). Every participant gave informed consent, including permission to record the interview. All participants were provided with an information sheet giving an overview of the project, and guaranteeing anonymity and the ability to withdraw from the project at any point. Participants also had the opportunity to ask questions before and during the interview.

The guarantee of anonymity encouraged participants to be open and honest during the interviews. They were speaking in a professional capacity. Had names been used and hospitals identified, they may have felt less willing to talk freely about their views or discuss perceived barriers to effective care.

Audio files were transferred to the computer as soon as possible and deleted from the recorder. Participants were allocated a number, which was used on all files instead of their name. Audio files and the participants' personal details were saved in a computer file accessible only by the researcher. Identifiable data has been removed from the report, such as names and places of work. These steps also helped to ensure adherence to the Data Protection Act.

## Findings

The findings were analysed using the thematic framework method, developed by the National Centre for Social Research (Ritchie et al 2008). This identifies themes and sub-themes within data and is one of the most popular methods for analysing qualitative data (Bryman 2012). The researcher became familiar with the data through undertaking the interviews, listening to the recordings, taking detailed notes and transcription. This helped the researcher to identify recurring themes and to develop a framework to apply to the data (Ritchie et al 2008). The key themes were based around the existing literature and key questions for the research.

There is much debate about whether qualitative research findings are relevant to the wider population from which the sample was drawn, and whether, therefore, they can be generalised (Lewis and Ritchie 2008). However, rather than generalising to audiologists as a population, the findings can be used to develop a hypothesis that can then be tested by further research (Lewis and Ritchie 2008).

## Difficulties

There were some difficulties in undertaking this research, particularly in recruiting participants. This may simply be because audiologists are busy and just do not have the time to speak with a researcher. Potential participants may also have been concerned about the topic and how the research would be used – for example, to criticise the profession.

The information sheet was designed to help allay these concerns. However, this issue was effectively resolved by personal recommendation. While this research has limitations in that it rests on a small sample size, it does nevertheless raise some interesting issues that merit investigation through further research.

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