

Why urgent action is needed
on deafness, tinnitus and
hearing loss across the UK

 **ACTION ON
HEARING
LOSS**

A national charity since 1911

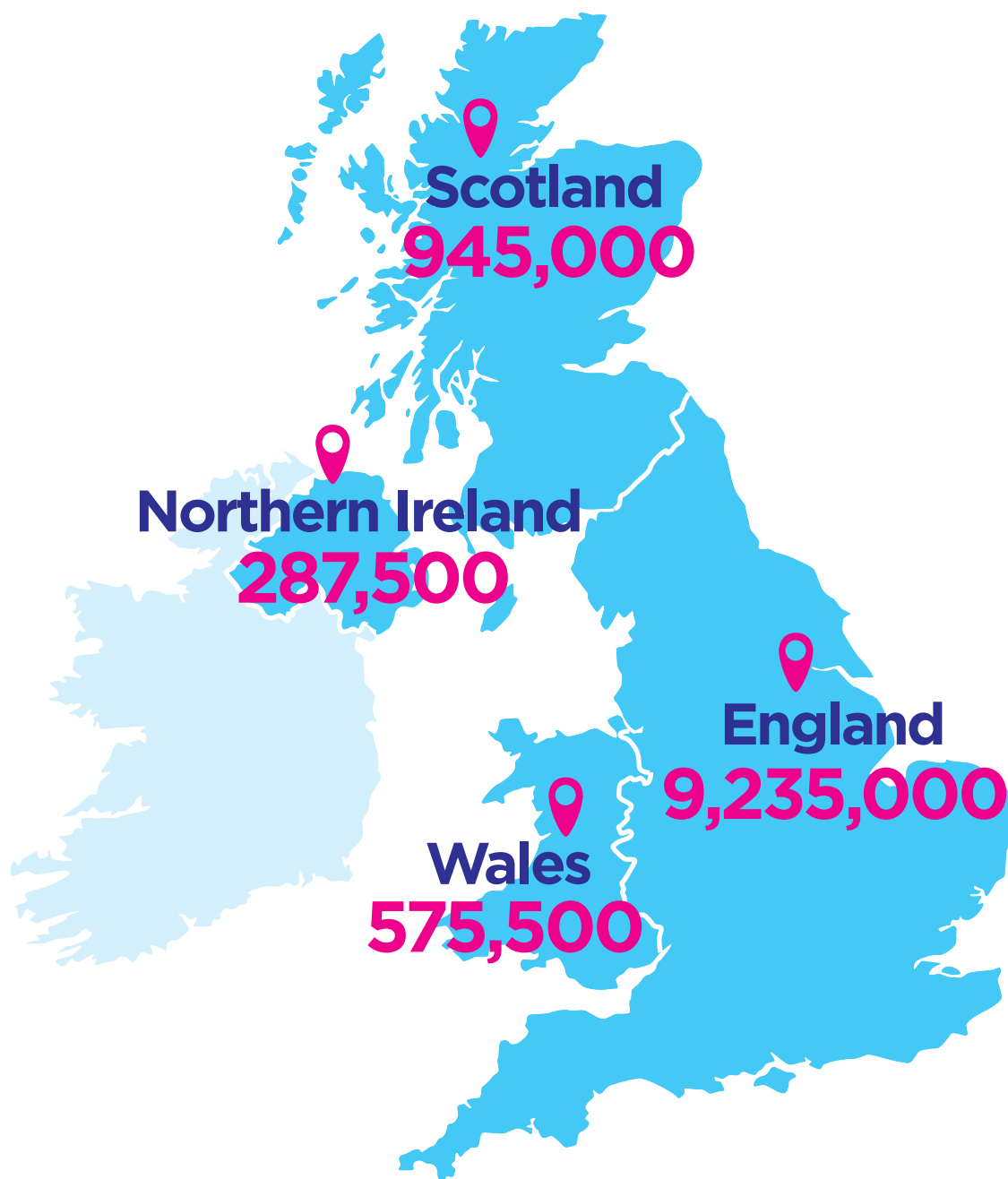
Hearing Matters



Across the UK

11 million people

have hearing loss



These figures are estimates - for full data, please see Appendix.

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Forewords

Hearing loss affects over 11 million people in the UK. By 2035, it'll be one-fifth of us. This comprehensive report sets out what must be done – across the UK – to tackle the growing prevalence and devastating impact of deafness, tinnitus and hearing loss.

As we called for in the original, 2011 *Hearing Matters*, our governments have committed to tackle hearing loss. But these national priorities must be translated into local action. Employers and health services need to plan for the increasing numbers of people with hearing loss, and all areas must continue to provide free NHS hearing aids for everyone who needs them – the UK Government must intervene if this does not happen. A hearing aid costs the NHS less than £100, but its impact in helping people communicate with friends and family, stay in work – and avoid costly care – is priceless.

With further investment, cures for hearing loss and tinnitus are within our grasp. But less than 1% of medical research spending goes on hearing – it's the only area that's seen a decrease over the last decade. New technologies are already transforming lives, yet all too often, people with hearing loss are left behind. The provision of subtitles is inadequate and people are excluded: from shops and services, health and social care, and employment. Responding to these challenges requires innovation and new ways of working. Public, private and voluntary sector organisations must work together to make sure people with deafness, tinnitus and hearing loss enjoy the same rights and opportunities as everyone else. In this collaborative spirit, I would like to thank Boots Hearingcare for sponsoring this report.

Deafness, tinnitus and hearing loss are major public health issues. Only with concerted, urgent action will we create a society where people can fulfil their potential and live the life that they choose.

Paul Breckell, Chief Executive, Action on Hearing Loss



I welcome this report by Action for Hearing Loss. It is important that we address the debilitating impact of tinnitus, hearing loss, and deafness on people; physically, emotionally and socially. There have been improvements in services for people with hearing loss, including the introduction of national neonatal screening, reduced waits for assessment and treatment, and greater choice of hearing aid services. However, there is more work to do on prevention, early diagnosis and support for those who have hearing loss.

The National Institute for Health Research is investing over £4million annually in research on hearing-related problems to improve patient outcomes. This includes ground-breaking work at the Nottingham Hearing Biomedical Research Unit.

In March 2015, we published the Action Plan on Hearing Loss with a range of actions for NHS England, Public Health England, the Department of Health, other Government departments and stakeholder organisations. This aims to support local commissioners improve non-specialised audiology services. NHS England will regularly review progress on its implementation.

Research has shown that deaf people are at higher risk of mental illness than the general population. We want to provide appropriate therapeutic support to deaf people. We expect local commissioners to recognise the importance of Improving Access to Psychological Therapies services that are accessible to British Sign Language users and deaf people.

The Care Act 2014 came into effect this year. It introduces reforms to the care and support system to shape it around people's individual needs and goals and to put them in control of their own care. The Act will help to improve support available to people who use care services, including people with hearing loss and deafness.

The UK Government is committed to continue working with partners and stakeholders to identify further steps to address issues that affect people with hearing loss, tinnitus and deafness.

Alastair Burt MP, Minister of State for Community and Social Care

Executive Summary

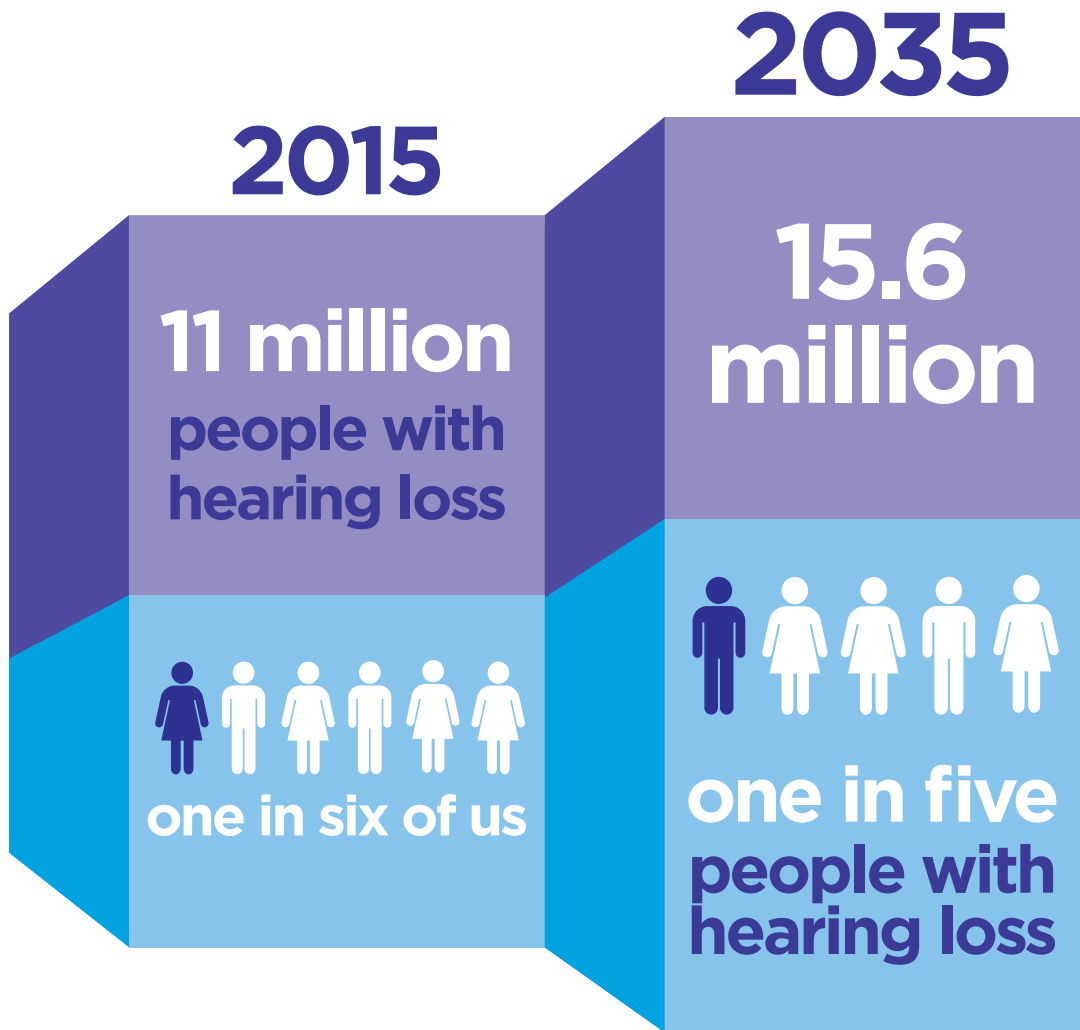
Governments across the UK say that more needs to be done to tackle hearing loss. This landmark report examines the scale and impact of hearing loss in the UK and sets out what needs to be done.

Unfortunately, progress in some areas has been accompanied by major steps backwards in others. Concerted effort is required to make sure hearing aids continue to be provided for free on the NHS. More investment is needed in research, technology and treatments; and employers, health and social care services and broadcasters must do more to meet the needs of people with deafness, tinnitus and hearing loss.

Hearing Matters outlines the prevalence and impact of hearing loss, deafness and tinnitus across the UK, then focuses on society's response and what needs to be done across three key areas – the growing level of need for better **support and care**, improved **technology and treatments**, and **equality** of access to services for people confronting deafness, tinnitus and hearing loss.

Deafness, tinnitus and hearing loss in the UK

Hearing loss is a major public health issue that affects over 11 million people in the UK – that's more than one in six of us. As our population ages, hearing loss will affect a growing number of people. We estimate that, by 2035, there will be more than 15.6 million people with hearing loss in the UK – a fifth of the population. Around 900,000 people have severe or profound deafness, at least



24,000 of whom use British Sign Language. One in 10 adults across the UK suffers from tinnitus. Deafness, tinnitus and hearing loss are serious health conditions that can have a significant impact on health and wellbeing. People with hearing loss are too often unable to communicate with friends and family, colleagues and health professionals.

Research shows that hearing loss doubles the risk of developing depression and increases the risk of anxiety and other mental health problems. There is now strong evidence that mild hearing loss doubles the risk of developing dementia – with moderate hearing loss leading to three times the risk, and severe hearing loss five times the risk. There is also evidence that hearing loss is linked to learning disabilities, cardiovascular disease, diabetes, stroke and obesity.

Estimates suggest that, in 2013, the UK economy lost more than £24.8 billion in potential output because people with hearing loss were unable to work. Communication barriers also lead to missed NHS appointments and increased health and social care costs.

There is incontrovertible evidence that hearing aids improve people's ability to communicate and their quality of life – and they reduce the risk of depression. Each hearing aid costs the NHS less than £100, but for many people with hearing loss they are a lifeline. Given the significant social, health and economic impact of hearing loss, it's vital that hearing aids remain free on the NHS for all who need them.

Support and care

Governments across the UK now recognise hearing loss as a major public health issue and are starting to take action to reduce its impact. National strategies on hearing loss have been launched in Northern Ireland, Scotland and England. To bring about real change, these commitments must be properly implemented at a national and local level across the UK.



Free NHS hearing aids must be provided for everyone who needs them

Urgent action needs to be taken to improve levels of diagnosis of hearing loss. Hearing aids are most effective when fitted early – people who wait until they have severe hearing loss find it more difficult to adapt. But evidence shows that there is an average of a 10-year delay in people seeking help for their hearing loss – and when people eventually do seek help, GPs fail to refer 45% of those reporting hearing loss to NHS hearing services. The UK Government should screen everyone for hearing loss when they reach 65, and they should launch a high-profile, public-health campaign to prevent avoidable causes of hearing loss, by raising awareness of the dangers of loud music and noise at work.

Vital NHS hearing services must be protected from the effects of budget cuts and increasing demand. Free NHS hearing aids must be provided to everyone who needs them, and more adults must have access to cochlear implants. In October 2015, North Staffordshire Clinical Commissioning Group (CCG) became the first area in the UK to stop providing hearing aids to most people who need them. Our research, earlier in 2015, showed that six services (four in England, two in Wales) only give people one hearing aid, even if they have hearing loss in both ears. Many others don't provide the ongoing support people need.

Social services must meet their duties under new legislation and standards to provide people with assistive equipment for the home, such as visual smoke alarms and amplified telephones; and to meet their communication needs, for example, by providing British Sign Language (BSL) interpretation and accessible information.

Anyone responsible for the diagnosis or management of other conditions should take into account people's hearing loss, and there must be improvements in the provision of tinnitus services, specialist mental health services for people who are deaf, and rehabilitation services such as lipreading classes.

What action needs to be taken...

Governments across the UK should:

- Make sure national strategies for hearing loss are in place and fully implemented.
 - In England, NHS England should meet the commitments in the **Action Plan on Hearing Loss** to produce and enforce national commissioning guidance, to ensure consistent, high-quality services are available – and to intervene if services do not improve.
- Improve the public's awareness of hearing loss and encourage people to get their hearing checked; fund research into the prevalence, and impact of hearing loss and the benefits of hearing aids; and assess the growing needs of people with hearing loss.
 - Public Health England must meet its commitments to improve the evidence on the prevalence and impact of hearing loss, and to provide tools for assessing local needs.
- Make sure organisations that plan and commission services are aware of the prevalence and impact of hearing loss – and of the benefits of hearing aids and other support services such as lipreading classes.
- Intervene if commissioners make decisions that run contrary to clinical evidence and local need, for example making unfounded restrictions to the provision of hearing aids.
- Make sure quality standards for NHS hearing services are in place and implemented across the UK.

What action needs to be taken...

The National Screening Committee should:

- Propose a hearing screening programme for all adults, over the age of 65, across the UK.

NHS services and commissioners should:

- Make sure all people with hearing loss, who could benefit from hearing aids, continue to receive them free of charge on the NHS.
- Invest in high-quality hearing services, including tinnitus services and cochlear implants, and services for people with hearing loss alongside other long-term conditions; and record and publish patient outcomes, including whether hearing aids are being used.
- Improve rates of referral to hearing services by making sure that GPs and other health professionals have the information, incentives, training and screening tools they need to recognise hearing loss – and encourage people with hearing loss to seek help.

What action needs to be taken...

Local authorities (Health and Social Care Trusts in Northern Ireland) should:

- Collect data on the number of people with hearing loss and assess their needs, so that they can provide appropriate support and equipment.
 - In England, local authorities and NHS commissioners must include hearing loss in their Joint Strategic Needs Assessments (JSNAs) and strategies, and provide incentives for services to improve awareness, diagnosis and management of hearing loss.
- Make sure people with hearing loss have access to communications and information on social services and social care, in line with equalities legislation and NHS standards.

Action on Hearing Loss will:

- Encourage people to seek help for their hearing loss, and to use our online Hearing Check.
- Continue to work with government, commissioners, hearing services, professional groups and patients to secure proper investment in high-quality hearing services – and to stop cuts to NHS hearing aids.
- Produce and share research findings on service provision and good practice, and provide evidence and guidance on hearing services to people with hearing loss, service providers and commissioners.

Technology and treatments

Advances in hearing aids and assistive technologies, along with new technologies such as speech-to-text, are removing barriers to communication for people with hearing loss. Rapid progress is also being made in our understanding of the biological causes of hearing loss and tinnitus. With proper investment, treatments for hearing loss and tinnitus could be available by 2020, and we believe we can find cures within a generation.

With proper investment, treatments for hearing loss and tinnitus could be available by

2020

However, hearing loss research remains significantly underfunded compared to other health areas. Less than 1% of the total investment in medical research by public and charity funders was spent on hearing research in 2014 – which is the equivalent of just £1.11 for every person affected. In comparison, £11.35 was spent on research into sight loss for every person affected, and £19.79 on research into cardiovascular conditions for every person affected.

There are currently no drugs on the market for tinnitus or hearing loss. More needs to be done to encourage investment in hearing loss research – and to ensure research findings translate into new technologies, treatments and cures for people with hearing loss and tinnitus. The Research Councils and National Institute for Health Research should be encouraged to work together to support cross-disciplinary research that could transform the lives of people with hearing loss.

The UK government should also maintain and develop the UK science infrastructure and increase sources of funding such as the Charity Research Support Fund to ensure charity research funding is used to maximum effect.

£19.79

spent on research into
cardiovascular conditions

£11.35

spent on research into sight loss

£1.11

spent on research into hearing loss
for every person affected

What action needs to be taken...

Governments across the UK should:

- Make research into hearing loss and tinnitus a national priority, to address the chronic underfunding of hearing loss research – and to ensure that support for research is increased to reflect the growing level of need for new technologies and treatments.
- Support charity research funding by investing in the UK science base and increasing the Charity Research Support Fund.

The Research Councils and the National Institute for Health Research should:

- Support cross-disciplinary research that could transform the lives of people with tinnitus and hearing loss.

Companies should:

- Develop and promote technologies such as text relay, video services and speech-to-text.
- Invest in developing new treatments for hearing loss and tinnitus.
- Ensure all new technologies are accessible for people with hearing loss.

Action on Hearing Loss will:

- Increase hearing research capacity within the UK by supporting the training of PhD students and the early careers of the most talented scientists.
- Raise public awareness of hearing research and target funding towards projects that will generate new discoveries that could lead to new treatments.

Equality



“In the operating theatre, two anaesthetists asked me a string of questions with masks over their mouths. I couldn’t understand a word”

Stephanie Bromley, 70, Devon

Despite the legal protection provided by the Equality Act 2010 (and the Disability Discrimination Act 2005 in Northern Ireland) which bans discrimination and requires employers and companies to make reasonable adjustments if a person with a disability is put at a substantial disadvantage, people with hearing loss often struggle to access education, employment and other crucial services, ranging from health, social care and transport to television and high-street services.

Communication needs, such as requiring a qualified BSL interpreter or a speech-to-text reporter, are not routinely identified or recorded. Travel information on public transport is not always accessible for people with hearing loss and subtitles are often unavailable for video on-demand content.

When accessing health services, our research shows that one in seven (14%) people with hearing loss have missed an appointment with their GP because they didn’t hear their name being called in the waiting room; and more than a quarter (28%) did not understand their diagnosis. We’ve also found that the communication needs of people who access social care are routinely overlooked.

More action needs to be taken to improve the education and employment prospects of people with deafness, tinnitus and hearing loss. Nearly two-thirds of deaf children (64%) failed to achieve the government benchmark of five GCSEs (including English and Maths) at grades A* to C, compared with less than half (43%) of all pupils.

People with hearing loss are less likely to have a job than others, and hearing loss often means people having problems finding a job, fulfilling their potential at work and staying in work. The UK Government must meet its commitment to halve the disability employment gap by 2020 and employer attitudes to hearing loss must improve.

What action needs to be taken...

Governments across the UK should:

- Enforce and raise awareness of the Equality Act 2010 (and the Disability Discrimination Act in Northern Ireland) to make sure people with hearing loss are protected from discrimination; and services and employers make reasonable adjustments.
- Make sure mandatory standards for accessible health and social care are in place and properly enforced. Performance against accessibility standards should be routinely monitored, including through inspections, and the results should be published.
- Extend legislation to require subtitles on television programmes, regardless of where and how they are delivered.
- The UK Government should develop and implement plans to meet its commitment to halve the disability employment gap, and to support an ageing workforce, including people with deafness, tinnitus and hearing loss.

What action needs to be taken...

Services should:

- Take steps to be as accessible as possible, for example, by: offering a range of contact methods, recording and meeting communication needs, providing deaf awareness training for all staff, installing and maintaining loop or infrared systems, providing communication support such as BSL interpreters when appropriate, and subtitling video content.
- Control and minimise background noise wherever possible.

Health and social care services and commissioners should make sure their services:

- Meet accessibility standards and equalities legislation by identifying, recording and meeting the communication needs of people with hearing loss; and providing accessible information, a range of contact methods, staff training, hearing loops and communication support such as BSL interpreters.
- Take into account hearing loss and deafness when providing diagnosis, management and care for people who also have other long-term conditions, including mental health problems, dementia, learning disabilities, sight loss, cardiovascular disease and diabetes.

What action needs to be taken...

Employers should:

- Develop and deliver plans to support an increasing number of employees with age-related hearing loss.

Action on Hearing Loss will:

- Provide information and guidance so that people with hearing loss know what they should expect from employers, health and social care and other services – and what action they can take if these expectations aren't met.
- Launch a campaign to improve employer attitudes towards employees with deafness, tinnitus and hearing loss.
- Work with the Disability Charities Consortium to ensure the UK Government develops and delivers a plan to meet its commitment to halve the disability employment gap; and make sure that progress is regularly monitored.

Introduction

National governments across the UK have finally recognised hearing loss as a major public health issue. Yet, for the first time since the birth of the NHS in 1948, one part of England has stopped providing free hearing aids to most people who would benefit from them.

In *Hearing Matters* we review the state of the nation's hearing and lay out the latest evidence of the significant impact of hearing loss on millions of Britons. We evaluate the support and care, technology and treatments, and steps towards equality for people with hearing loss, as well as the significant gaps in services and the very real barriers we must overcome. Finally, we set out our agenda for change, including critical actions that governments and others must take to meet the challenges to come.



What do we mean by hearing loss?

We use the term 'hearing loss' to cover all kinds of deafness. There are four different levels of hearing loss, defined by the quietest sound that you are able to hear, measured in decibels (dB).



Mild hearing loss

- Quietest sound: 25-39dB
- Can sometimes make following speech difficult, particularly in noisy situations or for long periods of time. People start avoiding social situations.



Moderate hearing loss

- Quietest sound: 40-69dB
- Often have difficulty following speech without hearing aids. Likely to avoid most or all social situations.



Severe hearing loss

- Quietest sound: 70-94dB
- Usually need to lipread or use sign language, even with hearing aids. May be eligible for cochlear implants.



Profound deafness

- Quietest sound: 95dB
- Usually need to lipread or use sign language. Hearing aids often not helpful, may benefit from cochlear implants.

Deafness, tinnitus and hearing loss in the UK

Prevalence and causes of hearing loss

Hearing loss is a major public health issue, which we estimate now affects more than **11 million** people across the UK. One in six of the population has hearing loss of at least 25dB in their better ear. This estimate includes around 6.7 million people who could benefit from hearing aids (as they have hearing loss of at least 35dB in their better ear). There are also an estimated 900,000 people in the UK who have severe or profound levels of deafness (hearing loss of at least 70dB in their better ear).

These figures are based on the most comprehensive study into the prevalence of hearing loss among the adult population (Davis, 1995), with prevalence rates applied to current population estimates (Office of National Statistics (ONS), 2015a). Prevalence estimates by age group and nation are provided in the appendix.

Age-related damage to the cochlea, known as presbycusis, is the single biggest cause of hearing loss. It is the result of a combination of environmental and genetic factors. Other causes and triggers include:

- regular and prolonged exposure to loud sounds
- ototoxic drugs that harm the cochlea and/or hearing nerve
- genetic predisposition: at least half of all childhood deafness is inherited (Nadol and Merchant, 2001) and, so far, scientists have identified 100 genes that relate to deafness
- some infectious diseases, including rubella
- complications at birth
- injury to the head
- benign tumours on the auditory nerve.

Breakdown by age

The vast majority of people with hearing loss are over 50 years old and the prevalence increases with age (Davis, 1995):

71.1% of over-70-year-olds have some kind of hearing loss:

- Mild: 26.7%
- Moderate: 36.8%
- Severe: 6.3%
- Profound: 1.3%

41.7% of over-50-year-olds have some kind of hearing loss:

- Mild: 21.6%
- Moderate: 16.8%
- Severe: 2.7%
- Profound: 0.6%

People wait,
on average,

10

years to seek
help for their
hearing loss

There are also more than **45,000 deaf children across the UK** (NDCS, 2015a) and many more children experience temporary deafness as a result of conditions such as glue ear. Half of all deaf children are born deaf, while half acquire deafness during childhood (NDCS, 2007).

Some people with severe or profound hearing loss use sign languages such as British Sign Language (BSL) and may consider themselves part of the Deaf community, with a shared history, culture and language. Based on the 2011 census, we estimate that there are at least **24,000 people across the UK who use a sign language as their main language** – although this is likely to be an underestimate.

There are approximately **250,000 people in the UK with both hearing loss and sight loss**. Of these, 220,000 are aged 70 or over. This number is set to grow substantially over the next two decades as the population ages (Sense, 2015).

The challenge of an ageing population

The UK's population is getting older. By 2035, it is projected that those aged 65 and over will account for 23 per cent of the total population (ONS, 2012).

Hearing loss is a condition that will have an impact on a growing proportion of the UK population. We estimate that, by 2035, there will be approximately 15.6 million people with hearing loss in the UK – which will be one fifth of the population¹.

¹ This is based on prevalence at each age group from Davis 1995 and ONS principal projections for 2035 (ONS 2012), rounded to the nearest 500.

Tinnitus

Around one in every 10 UK adults has tinnitus (Davis, 1989), with recent data showing that this increases to nearly 17% of 40 to 69-year olds and 25-30% of over 70s (Dawes et al, 2014; Holmes and Padgham, 2009). An estimated 32,000 new cases of tinnitus were diagnosed in England in 2015. Tinnitus can have a negative impact on a person's mental health, relationships with family and friends and their ability to sleep, concentrate and work.

Tinnitus is a ringing or buzzing sound in the ear or head that cannot be attributed to an external source. Most cases are related to ageing, hearing loss or noise exposure. It can also be a side effect of ear or head injuries, ear diseases or infections, and can be triggered or exacerbated by emotional trauma, illness or stress. Evidence suggests that tinnitus is linked to depression, which can worsen the perception of the condition (Dobie, 2003).

See page 53 for more information on the services available for people with tinnitus.



After a particularly busy month at work, I developed loud ringing in my ears. I knew I was under a lot of stress, and hadn't been sleeping well, but I was sure that, after an early night, the ringing would be gone. It didn't go away - and it never has.

Terrified I was having a nervous breakdown, I went to see my GP. Fortunately, he understood tinnitus and referred me to the audiology department for further tests. The audiologist diagnosed a mild hearing loss, which was exacerbating the tinnitus. She was frank: "There is no cure for tinnitus. You'll have to find a way of living with it". My GP referred me for Cognitive Behavioural Therapy, which was tremendous, and helped me to learn new ways to control my anxiety and panic attacks.

Everybody's tinnitus is different, so everyone's way of coping will be different too. For me, it's a mixture of medication, working less, regular exercise and noises that distract from the tinnitus.

Five years on, the noises have never stopped. You never get used to it or stop wishing for silence but with determination you can live well with tinnitus but it takes a lot of strength and I know for some it has drastically reduced their quality of life and each day is a struggle.

Bev Frowen, 56, Rhondda Cynon Taf

Social, health and economic impact

A significant body of evidence shows that hearing loss is a serious condition that can have an adverse impact on a person's health and quality of life (Chisolm et al, 2007; Mulrow et al, 1990; Ciorba et al, 2012; Dalton et al, 2003).

People with hearing loss are significantly more likely to experience emotional distress and reduced social engagement

According to WHO, by 2030 hearing loss will be in the top 10 disease burdens in the UK², above cataracts and diabetes (Mathers and Locar, 2006).

Social impact

People with hearing loss face barriers to communication, making it harder to interact with friends, family, health professionals and colleagues. This often results in people withdrawing from social situations and becoming isolated (Monzani et al, 2008; Héту et al, 1993; Arlinger, 2003). One study of 800 older people found that those with hearing loss were "significantly more likely to experience emotional distress and reduced social engagement" (Gopinath et al 2012). Another study found that hearing loss increased the risk of loneliness, but only for people who did not wear hearing aids (Pronk et al, 2011).

Barriers to communication are experienced not only by people with hearing loss, but also by those who spend time with and care for them. Research has shown that partners of people with hearing loss often experience frustration, loneliness, and social withdrawal and reduced quality of life (Echalier, 2010; Wallhagen et al, 2004).

² Disease burden is the impact of a health problem in an area according to set indicators. The disability-adjusted life year (DALY) is a measure of disease burden expressed as the number of years lost due to ill-health, disability or early death.



I have mild hearing loss in one ear and, more recently, I experienced sudden hearing loss in my other ear – a huge shock that was very difficult to cope with. I didn't want to admit my hearing loss to family and friends – it had a huge impact on my confidence. I felt frustrated that I always had to ask people to repeat themselves.

I had some counselling and this helped me become more accepting of my hearing loss and move forward. I also discovered a lipreading class through the Action on Hearing Loss website, which is a great support network.

It takes a lot of courage to face the outside world, which is largely unsympathetic to hearing loss. I'm just very lucky to have a supportive husband and family.

Sylvia Robertson, 61, Berkhamsted

Stigma

Stigma relating to hearing loss is both real and perceived. For many people, hearing loss and hearing aids are still associated with negative stereotypes, and fear of stigma itself can be strong, making people with hearing loss less likely to talk to others about their hearing loss and less likely to seek help (Doggett et al, 1998; Southall et al, 2010). One American study found that 48% of respondents cited stigma as a reason for not getting hearing aids (Kochkin, 2007). On average, people wait 10 years between noticing symptoms and taking steps to address their hearing loss. The longer the delay, the less likely they are to benefit from hearing aids (Davis et al, 2007; see page 38).



I'm 60 soon, but I think I had a high-frequency hearing loss from childhood – I couldn't hear the phone ring, for instance. By the time I was an adult, I couldn't hear the TV anymore. I finally got hearing aids in my mid-30s. The audiologist said: "Yes, you're deaf – you need hearing aids for both ears." It was like I'd been run over by a truck.

You try to put on a 'brave' or 'normal' face; and you end up thinking it's wrong to feel fearful or anxious. I always felt socially inept. But I now realise that I was focusing so hard on people's lips all the time that I wasn't seeing other social cues, like body language. My social difficulties were to do with my hearing – not with who I actually am.

Now, I always tell people at the outset that I have a hearing problem. We all have our burdens, and to pretend otherwise not only diminishes ourselves, but also denies us the opportunity to share what really matters.

Natalie Sfakianos, 59, London

Hearing loss and other conditions

New evidence shows that hearing loss increases the risk or impact of various other long-term conditions, and many health conditions are associated with ageing, so are likely to occur alongside hearing loss. Our *Joining Up* research (Action on Hearing Loss, 2013) outlined the evidence and showed why the diagnosis and management of other health conditions needs to take into account a person's hearing loss, whether this is diagnosed or undiagnosed.

hearing loss
doubles
the risk of
developing
depression

Research shows that hearing loss doubles the risk of developing depression and increases the risk of anxiety and other mental health issues, and that hearing aids reduce these risks (Saito et al, 2010; National Council on Aging, 2000; Acar et al, 2011; Mulrow et al, 1992). Now, there is also strong evidence that mild hearing loss doubles the risk of developing dementia, with moderate hearing loss leading to three times the risk, and severe hearing loss five times the risk (Lin et al, 2011; Lin et al, 2013; Gurgel et al, 2013; Albers et al, 2015). Researchers are now looking into why hearing loss is linked to dementia, and there is some evidence suggesting that hearing aids may reduce the risk of developing dementia (Deal et al, 2015).

Recently, leading US and UK diabetes charities have highlighted the link between diabetes and hearing loss. In fact, you're twice as likely to have hearing loss if you have any form of diabetes (Horikawa et al, 2013). There is also evidence that hearing loss is linked to cardiovascular disease, stroke and obesity (Rosenhall and Sundh, 2006; Formby et al, 1987; Gopinath et al, 2009; Helzner et al, 2011). Some research suggests that vascular changes in the body related to diabetes, cardiovascular disease or obesity might contribute to risk of age-related hearing loss (Cruickshanks et al, 2015).

Evidence suggests that up to 40% of those with a learning disability have some level of hearing loss, and that this often goes undiagnosed or is misdiagnosed (Kiani and Miller, 2010; Foundation for People with Learning Disabilities, 2015).

There is some evidence suggesting that hearing loss in older people may be linked to sight loss and more frequent falls (Chia et al, 2006; Lin and Ferrucci, 2012), and because most hearing loss is age-related, many people with hearing loss will also have other health conditions, from physical impairment or sight loss to dementia or cancer. This can cause complications – for example, hearing loss can be misdiagnosed as dementia or make the symptoms of dementia appear worse (Burkhalter et al, 2009; van Boxtel et al, 2000). Diagnosing and managing hearing loss, and taking a person's hearing loss into account when diagnosing and managing other conditions, are essential to ensure good communication and care.

People with hearing loss face barriers accessing health and social care (see pages 71-77). BSL users, in particular, have problems accessing public health information – putting them at greater risk of health problems and worse care (Action on Hearing Loss, 2013).

Economic costs

Hearing loss can have a serious impact on a person's own finances and the wider economy. In 2014, The Ear Foundation calculated that, on average, people with hearing loss are paid £2,000 less per year than the general population – this amounts to an annual £4 billion in lost income across the UK (The Ear Foundation, 2014). Estimates suggest that, in 2013, the UK economy lost £24.8 billion in potential economic output because too many people with hearing loss are unable to work (International Longevity Centre UK, 2013). If nothing is done to address lower employment rates for those with hearing loss, by 2031 the UK economy will lose £38.6bn per year in potential economic output.

When the impact of hearing loss on quality of life and the costs to NHS and social care are also taken into account, The Ear Foundation calculated that the full economic cost of hearing loss across the UK is at least £30 billion per year (The Ear Foundation, 2014).

Health and care costs

NHS and social care services also waste millions of pounds each year by not making services accessible for people with hearing loss. NHS England has estimated that £14 million is wasted because of missed appointments, and The Ear Foundation suggested that, because of communication difficulties, people with hearing loss cost the NHS £76 million in extra GP visits and £60 million in increased use of social care (The Ear Foundation, 2014). Our own report estimated that at least £28 million per year could be saved in England by properly managing hearing loss in people with dementia (Action on Hearing Loss, 2013).

Hearing aids reduce costs

There is good evidence that hearing aids enable people with hearing loss to stay socially active, reduce the risk of depression and may even reduce the risk of dementia (Mulrow et al, 1990; National Council on Aging, 2000; Brooks et al, 2001; Pronk et al, 2011; Deal et al, 2015). Hearing aids are free on the NHS and provide huge benefits to people with hearing loss at a small cost to the NHS of less than £100 each. For more information, please see page 48.



Cutting-edge NHS hearing aids have helped me deal with my upper register hearing loss, which began in my 30s. Without them, I couldn't function working as a journalist in a busy, noisy newsroom. They also help with my tinnitus, a condition that caused me severe mental health problems when it first started.

Joyce Bishop, 56, Lancashire

Society's response

Governments across the UK have started to recognise the impact of hearing loss – and the need to co-ordinate efforts to ensure progress is made.

In 2012, the Northern Ireland Department of Health, Social Services and Public Safety (DHSSPS) launched the Physical and Sensory Disability Strategy and Action Plan 2012-2015 (DHSSPS, 2012). They committed to improve the quality of health and social care services for people with physical and sensory disabilities, and to improve access to housing and transport.

In Scotland, the 2014 *See Hear* strategic framework for sensory impairments highlighted the need for early diagnosis and intervention, clear routes to treatment, and greater partnership working between the public and voluntary sector (Scottish Government, 2014).

In 2015, the Department of Health and NHS England launched a cross-Government strategy, the Action Plan on Hearing Loss (The Department of Health and NHS England 2015). This makes clear that hearing loss is a “major public health issue” requiring urgent action across Government to reduce regional variations in hearing services, improve access to technology and to consider the needs of people with hearing loss when planning health and social care services (Department of Health and NHS England, 2015). The Government will produce evidence, tools and guidance to support commissioners in England, and they have committed to monitor the outcomes from the Action Plan to ensure improvements are made.

These strategies need to be properly implemented and the commitments met, so that people confronting deafness, tinnitus and hearing loss see real changes in their lives.

If we don't address the low employment rates for people with hearing loss, by 2031 we'll be losing

£38.6 billion
every year

In this section we set out what governments, health and social care services, medical researchers, broadcasters and other services are doing to help people with hearing loss across three key areas:

- [Support and care](#)
- [Technology and treatments](#)
- [Equality](#)

We outline the significant advances, but also the major steps backwards in what is being provided for people with deafness, tinnitus and hearing loss.

Support and care

Hearing loss is a neglected public health issue which requires urgent action at all levels across the UK, both to make sure that people with age-related hearing loss are diagnosed – and their hearing loss managed as early as possible – and to protect the hearing of people in environments with high levels of noise.

Hearing aids should remain free on the NHS to all those who need them and hearing aid wearers should have access to high-quality aftercare services. Social services and the benefits system are also key sources of support for people with hearing loss.

In this section we consider the recent efforts both to prevent noise-induced hearing loss in the workplace and the military; and to reduce the impact of loud music. We examine the case for a national hearing screening programme for adults over the age of 65. We look at the current state of health and social services for people with hearing loss, including the provision of hearing aids, tinnitus services, cochlear implants, mental health and social services, and the benefits system. We set out what needs to happen in the Agenda for Change section (see page 85).

“More needs to be done on prevention, early diagnosis and support for those who have permanent hearing loss”

Bruce Keogh,
Medical Director,
NHS England

Public health

Governments across the UK, as well as the Chief Medical Officer for England (Davies, 2014), have now stated that hearing loss is a major public health issue, and that more needs to be done to strengthen the evidence, raise public awareness of its prevalence and impact, and to assess and meet the needs of people with hearing loss.

In particular, urgent action is needed to make sure this is recognised by local services. Many local authorities and health services are ignoring the high prevalence and impact of deafness, tinnitus and hearing loss when they plan local services. In England, the Government has stated that hearing loss must be included in Joint Strategic Needs Assessments (JSNAs), so that all local services take into account the needs of the increasing numbers of people with hearing loss (Department of Health and NHS England, 2015).

But we found that only one in three (35%) local authorities in England included hearing loss as a specific issue in their JSNAs³ (Calton, 2012). As a result, people are increasingly failing to get the vital health and social services they need (see pages 44-56).

Age-related hearing loss

Age-related hearing loss is the most common type of hearing loss. The growing challenge and increasing costs this represents were recently highlighted in 2015 by the UK Government in the Action Plan on Hearing Loss. Public Health England has committed to improve the evidence on the prevalence and impact of hearing loss in older people (The Department of Health and NHS England, 2015), and the Scottish Government’s See Hear strategic framework for

³ Joint Strategic Needs Assessments are carried out by the NHS and local authorities to assess the needs of local populations, to develop a greater understanding of the causes of ill health – and co-ordinate polices on the prevention and management of long-term conditions.

sensory impairments highlighted the need for early diagnosis and intervention for hearing loss, stating that screening for sensory loss should be included in care pathways (Scottish Government, 2014).

Too often, people affected by age-related hearing loss and health professionals simply don't take action. Low levels of diagnosis mean two-thirds of people are not getting the treatment and support they need (Action on Hearing Loss, 2011).

GPs fail
to refer

45%

of those
reporting
hearing loss
to NHS
hearing
services

Evidence suggests that there is an average of a 10-year delay in people seeking help for their hearing loss (Davis et al, 2007), and when they do, research also suggests that GPs fail to refer 45% of those reporting hearing loss to hearing services (Davis et al, 2007). GPs have a vital role to play in ensuring people with hearing loss seek help, and more needs to be done to make sure they have the information, incentives, training and screening tools they need to encourage people to seek help – and to refer everyone who might benefit to hearing services.

Delays in treatment mean people with hearing loss are less likely to derive benefit from hearing aids. Evidence suggests that hearing aids are most effective when fitted early, and people with severe hearing loss find it more difficult to adapt to hearing aids (Davis et al, 2007). We need more research into how we improve earlier diagnosis, including through hearing checks or hearing screening.

With the ageing population, the number of people with unaddressed hearing loss will increase. Right now, there are no screening programmes in the UK for adults or older people with hearing loss, even though evidence shows that screening everyone for hearing loss as they get older would be cost effective – and improve quality of life (Davis et al, 2007; Morris et al, 2013).

A cost-benefit-analysis study found that a screening programme at the age of 65 would cost £255 million – for the screening, assessment, hearing aids and ongoing care for 10 years – but that

it would save £2 billion in this time (London Economics, 2010). The National Screening Committee, an independent body that makes decisions on what screening programmes should be provided across the UK, reviews the evidence for introducing adult hearing screening every three years⁴.

Hearing Check

The Action on Hearing Loss Hearing Check is designed to help identify people with hearing loss and encourage them to take action. The Hearing Check assesses a person's ability to hear speech when there is background noise, similar to being in a crowded room. During the check, a voice repeats a set of three randomly generated numbers which the user must then key in. The Hearing Check is not a full hearing assessment and anyone concerned about their hearing or their Hearing Check result should contact their GP. The Hearing Check is available online and as a mobile app (iOS only). For more information, go to our Hearing Check website page at www.actiononhearingloss.org.uk/hearingcheck

Noise-induced hearing loss

Noise-induced hearing loss occurs after prolonged exposure to excessive levels of noise – for example, in noisy workplaces or while listening to loud music. Usually, hearing will recover in around two days – this is known as 'temporary threshold shift' – but this will vary depending on the loudness of sound and how long you were

⁴ See www.screening.nhs.uk/hearing-adult

exposed to it. Repeated exposure to loud noise may cause damage to the cochlea and the hearing nerve and this can cause permanent hearing loss and tinnitus. Sometimes, the effects of noise-induced hearing loss are not evident until years after initial exposure.



Most staff in music venues say they never use hearing protection

WHO has identified excessive noise as the major, avoidable cause of hearing loss worldwide (WHO, 1997). After age-related hearing loss, noise-induced hearing loss is the most common form of hearing loss, and is a major contributing factor to other forms of hearing loss (Wong et al, 2013).

Noise at work

WHO analysis shows that 16% of hearing loss worldwide is caused by exposure to excessive noise in the workplace (WHO, 2002). People working in industries with high levels of noise, such as construction, the military, manufacturing or food processing are the most at risk of developing noise-induced hearing loss.

Under the Control of Noise at Work Regulations 2005, employers must assess and take steps to reduce the risk to the health of employees if daily or weekly noise exposures average 80dB (A)⁵ or peak at 135dB (C). Employers must then make personal hearing protectors available upon request to employees who are exposed to noise at or above these levels. Personal hearing protectors must be worn if daily or weekly noise in the workplace averages 85dB (A) or peaks at 137dB (C). No employee should be exposed to daily or weekly noise exposures averaging 87dB (A) or peaks of 140dB (C), even if they are provided with hearing protectors.

The Health and Safety Executive (HSE) is responsible for enforcing the noise at work regulations across England, Wales and Scotland.

⁵ In international and national standards, an A-weighting is used to measure noise/loudness levels. For high intensity sound a C-weighting is used.

The HSE has committed to review the feasibility of Otoacoustic Emissions Testing (OAE) as a way of detecting damaging levels of noise in the workplace (Department of Health and NHS England, 2015). OAE is a hearing test that measures the acoustic response the cochlear produces to an external sound. This is a positive step that would make sure the damaging effects of noise exposure on employees are identified early, so steps can be taken to prevent further damage.

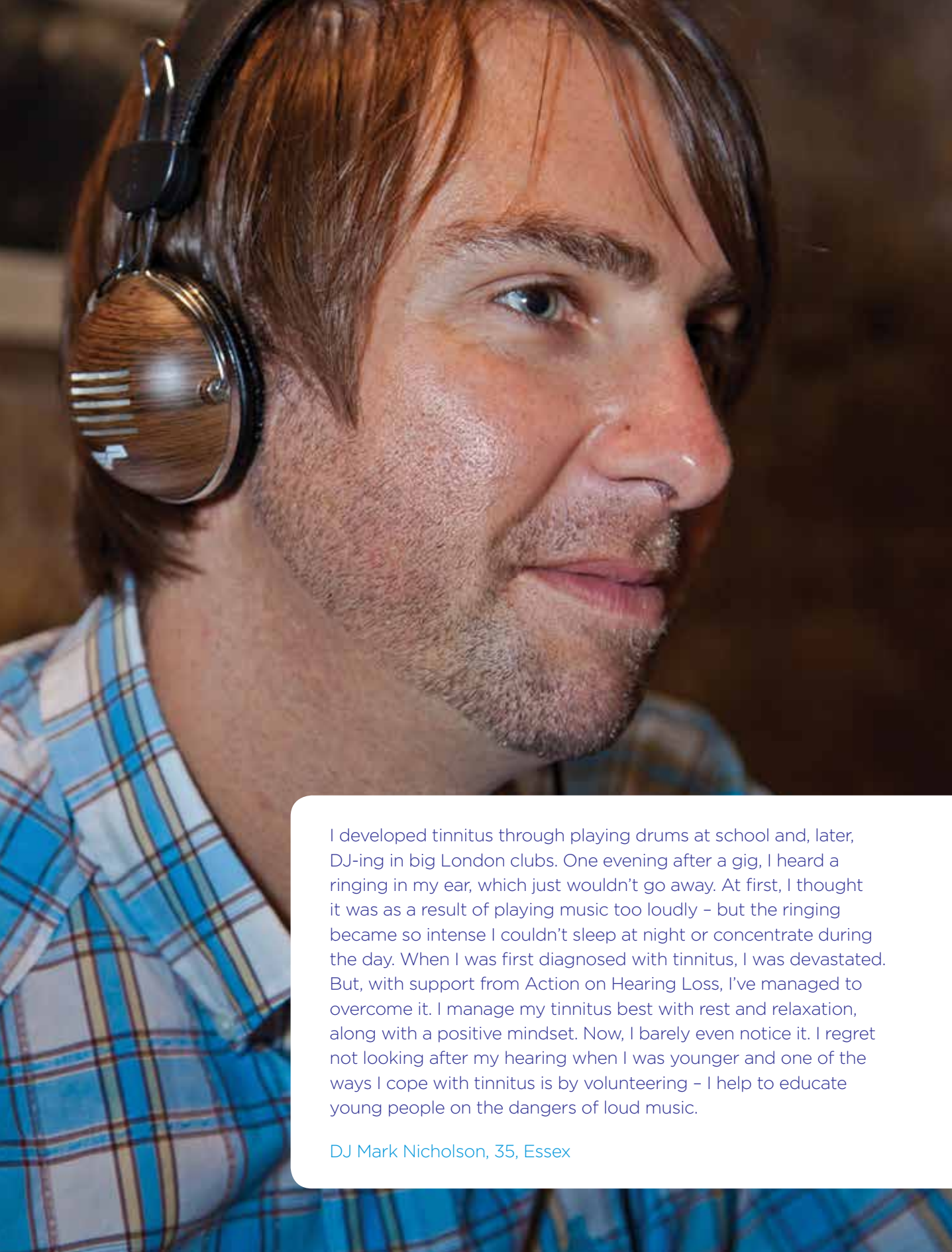
Military

The risk of noise-induced hearing loss amongst members of the armed forces, and the need to properly support those who are at risk of hearing loss or who have hearing loss – has received increased recognition over recent years. The Royal British Legion has developed a major campaign on the issue and we contributed to the Lost Voices report (Royal British Legion, 2014). Following this, the Ministry of Defence funded the Royal British Legion £10 million, over five years, to support ex-members of the armed forces with long-term hearing issues, and has committed to introduce new hearing-protection measures for UK armed forces personnel (House of Commons Debate, 8 June 2015).

Loud music

While the prevalence of people exposed to noise at work has decreased, the number of people exposed to high levels of noise at nightclubs, live-music gigs, or through a personal music player has trebled since the 1980s (Smith et al, 2000). Approximately 5-10% of people using personal music players such as MP3 players or smartphones listen at high volumes for sustained periods of time, putting themselves at risk of developing noise-induced hearing loss (European Commission, 2008).

In 2013, the European Committee for Electrotechnical Standardisation introduced a new safety standard for personal music



I developed tinnitus through playing drums at school and, later, DJ-ing in big London clubs. One evening after a gig, I heard a ringing in my ear, which just wouldn't go away. At first, I thought it was as a result of playing music too loudly - but the ringing became so intense I couldn't sleep at night or concentrate during the day. When I was first diagnosed with tinnitus, I was devastated. But, with support from Action on Hearing Loss, I've managed to overcome it. I manage my tinnitus best with rest and relaxation, along with a positive mindset. Now, I barely even notice it. I regret not looking after my hearing when I was younger and one of the ways I cope with tinnitus is by volunteering - I help to educate young people on the dangers of loud music.

DJ Mark Nicholson, 35, Essex

players. The risk of noise-induced hearing loss from these devices was a major focus of our Don't Lose The Music campaign and, in 2009, we were invited to present to the European Commission's Personal Music Players Stakeholders' Conference, which paved the way for the development of the standard.



Awareness of the dangers of noise exposure is still low – more people must be made aware of the risks

Under the standard, personal music players, including smartphones, must have a sound limit of 85dB (A). The user can choose to override this limit and increase the sound level up to 100dB (A). If so, the user must be warned about the risks of listening at high volumes for every 20 hours of listening time. Personal music player regulations are a major step forward, but awareness of the dangers of noise exposure is still low – more people must be made aware of the risks.

From 2008, the Control of Noise at Work Regulations 2005 have also applied to those working in the music and entertainment industry. But research suggests that the regulations need to be better enforced. One study found that a majority of staff (70%) in music venues were exposed to noise levels above the daily recommended limit. Worryingly, 70% reported that they never used hearing protection, and only 15% reported using hearing protection regularly (Barlow and Castilla-Sanchez, 2012).

Newborn hearing screening

Since 2006, all parents of new babies in the UK have been offered a hearing test soon after birth. One in every 900 babies born every year has some degree of hearing loss. For babies born in intensive care, this figure increases to one in every 100 (*NHS Choices*, 2015). Hearing loss in children can affect their understanding and development of spoken language. It is vital that it's detected early, so that their communication skills and educational attainments are not affected in later life. These days, hearing aids can be fitted when a baby is two to three months old – and parents can start to use sign language even earlier. Over five million babies have been screened in the UK. But referral rates to audiology services are variable and

there are often long waits for treatment. In England, over 47% of audiology services are failing to meet key performance indicators on the timeliness of treatment (Public Health England, 2014).

Hearing services

After first contacting their GP, people with deafness, tinnitus and hearing loss are usually referred to their local NHS hearing services (such as an audiology department or AQP (Any Qualified Provider)) or Ear, Nose and Throat (ENT) department. Some choose to pay for hearing aids through a private hearing aid dispenser. All NHS hearing services and private hearing aid dispensers carry out hearing assessments and fit digital hearing aids. They also repair and maintain hearing aids for existing hearing aid users. People who require complex ENT assessment, surgery or medical treatment will usually require an initial referral to an ENT consultant.

Locate and Rate

There are many different hearing services available and choosing the right one for your needs can be difficult. That's why Action on Hearing Loss launched Locate and Rate, which enables people to search for NHS and private hearing services in their local area. People can review services based on their experiences and see how other users have rated services. Locate and Rate asks service users to rate their experiences based on ease of access, quality of service and whether they would recommend it to others. For more information please see the Locate and Rate page on our website www.actiononhearingloss.org.uk/locateandrate

The vast majority of hearing aid users (83%) receive their hearing aids free of charge on the NHS. Around one in seven people (17%) pay for hearing aids privately (European Hearing Instrument Manufacturers Association, 2012).

There are almost 2,200 registered, private hearing aid dispensers in the UK (Health and Care Professions Council, 2015).

Hear to Help – aftercare for hearing aid users

Action on Hearing Loss's Hear to Help services provide a range of support for people with deafness, tinnitus and hearing loss, in their communities. Staff and volunteers – many of whom have a hearing loss – carry out minor repairs to hearing aids, and replace batteries, ear moulds and tubing. We provide training on how to maintain hearing aids, give information and advice on managing hearing loss, and tell people about services such as lipreading and hearing therapy. We also provide guidance on assistive equipment that could benefit people with hearing loss, such as amplified telephones and TV listeners. Funding for these essential services must be maintained across the UK, as part of a comprehensive NHS hearing aid aftercare service.

NHS hearing services

NHS hearing services are a valuable source of treatment and support for people with deafness, tinnitus and hearing loss. They provide hearing assessments and free digital hearing aids as well as a free follow-up appointment and ongoing 'aftercare', including adjustments, batteries and repairs. Many also provide – or refer to – specialist services for people with complex or severe hearing loss, or for those with additional needs linked to hearing loss, such as

learning disabilities or dementia. In general, people with hearing loss don't have to wait long for their GP referral to NHS hearing services, and there is a clear pathway once they are referred.

Under the Any Qualified Provider (AQP) scheme in England, any licensed NHS, private or voluntary-sector service can bid to provide hearing services under contract to the NHS. According to the National Community Hearing Association (NCHA), since AQP was introduced in 2013, people with hearing loss can now be seen for free, on the NHS, in over 500 new locations (NCHA, 2015) – many on local high streets. A report by the health service regulator, Monitor, shows that AQP has increased the number of people getting help, and has made services easier to access, but that 9 out of 10 people were unaware they could now choose their hearing service (Monitor, 2015).

Quality standards for NHS hearing services have been introduced in Scotland, Wales and Northern Ireland (NHS Scotland, 2008). In England, the National Institute for Health and Care Excellence (NICE)



I was a singer and my husband, Harry, was a pianist. I was the glamorous one at the front of the band. All our songs were popular and I have them all on record. Everything was amplified, so maybe that's what damaged my hearing... that, or my age. It went gradually, bit by bit – the music, the phone ringing – I lost it all. My hearing aids are my life now. But they're not easy. The pieces are so small and fiddly that it's impossible for me to clean them. Unfortunately, I can't get out much on my own anymore, so I rely on Steve, from the local Hear to Help service, who comes to my house to do my repairs. I can't praise the service enough. It's absolutely essential because nobody should be without their hearing!

Edna Poole, 98, Wanstead

will start developing clinical guidance and quality standards for adult-onset hearing loss in 2016. NHS, private and voluntary-sector hearing providers in England can also register for the Improving Quality in Physiological Diagnostic Services (IQIPS) accreditation to show they are improving the quality and safety of their service.

Performance against these standards is not monitored consistently. Governments across the UK must do more to make sure NHS hearing services meet the standards – and intervene if services do not improve.

Good practice in hearing services

During our *Under Pressure* (Lowe, 2015) research we came across many innovative examples of good practice in hearing services, which helped people to manage their conditions – and reached out to vulnerable people in the community. Examples included providing information and support on hearing aid maintenance, outreach services that provided hearing aids in local libraries and GP surgeries, a 24-hour hearing aid repair service, and engaging with patients on the design of services through focus groups and patient-satisfaction surveys⁶.

Protecting hearing aids on the NHS

Many vital NHS hearing services are under threat, because of budget cuts and increasing demand. This is leading to people, in some areas of the UK, not getting the help they need.

⁶ For more examples, please see our *Under Pressure* website: www.actiononhearingloss.org.uk/underpressure

Despite our concerted campaigning, in October 2015 North Staffordshire Clinical Commissioning Group (CCG) became the first CCG to stop providing hearing aids to most people who need them – people with mild hearing loss will no longer get hearing aids, and people with moderate hearing loss will have to pass an eligibility test to get them⁷. This CCG decision runs contrary to all the evidence – the Government must intervene to overturn the new policy.



Our hearing aids are under threat – they must continue to be provided for free on the NHS

Studies have consistently shown that 80-90% of people use and get benefit from their hearing aids (Perez and Edmonds, 2012; Monitor, 2015), and there's robust evidence that hearing aids improve the quality of life of people with hearing loss (Chisolm et al, 2007; Mulrow et al, 1990). Restricting the provision of hearing aids will reduce the ability of people to communicate with others, increase social isolation and lead to worse health outcomes (Ciorba et al, 2012; Mulrow et al, 1990; Arlinger, 2004; Cacciatore et al, 1999), and increase costs to the NHS and social care services in the longer term. Yet each hearing aid costs the NHS less than £100. No evidence has been put forward to make the case for not providing hearing aids on the NHS.

Contrary to professional guidance (British Academy of Audiology, 2014) and quality standards across the UK (NHS Scotland, 2008), our *Under Pressure* research (Lowe, 2015), published in 2015, found that six services (four in England, two in Wales) only give people one hearing aid – even if they have hearing loss in both ears. Research shows that people benefit from having two hearing aids – it improves localisation of sound, reduces strain and helps people to understand speech (Dreschler and Boymans, 1994; Kolber and Rosenhall, 2002; Leeuw and Dreschler, 1991). It is crucial that two hearing aids are available to all those who could benefit, otherwise many people with hearing loss will be unable to communicate with others, for example, at work or in social situations.

⁷ For updates and more information, see www.actiononhearingloss.org.uk/hearingaidcuts



I would be lost without my hearing aids. Before I had them I was becoming very withdrawn and I was really struggling at work, using colleagues to help me out in meetings. I couldn't believe the difference as soon as I had them fitted. I could hear the birds singing! I'd forgotten that you could hear them! I also enjoy the theatre, which is something I wouldn't have entertained doing before I had my hearing aids; there would have been no point.

Wendy Bursnell, 50, Stoke on Trent

After being fitted with hearing aids, two-thirds of people (66%) have trouble using them and need further support (RNID Cymru, 2009). Yet our research found that only half (49%) of NHS audiology services offer patients that crucial face-to-face follow-up appointment (Lowe, 2015). Quality standards and British Academy of Audiology guidance (NHS Scotland, 2008; British Academy of Audiology, 2014) state that a follow-up appointment should be provided within 12 weeks of the hearing aid fitting.

After the follow up, people with hearing aids will need new batteries, and many need more help using their hearing aids; or repairs or adjustments. This 'aftercare' should be easy to access, preferably somewhere in the community.

Hearing services should also monitor levels of satisfaction and other outcomes from the service, and refer or signpost people to other services that could help them, such as social services (which provide important support services and equipment – see page 54), counselling, hearing therapy, lipreading classes, support groups and help with benefits if appropriate.

Almost a quarter (24%) of NHS services admit they do not signpost patients to counselling and hearing therapy (Lowe, 2015); only 9% of people with hearing loss in Scotland are signposted to social services

(Edmond, 2012); and research from 2008 found that four out of five people with hearing loss said they did not receive information about other support and equipment that could help them (RNID, 2008). Everyone should know how to access these services.

Cochlear implants and bone-anchored hearing aids

For people who gain little benefit from hearing aids, bone-conducting hearing devices, middle ear implants or cochlear implants may be appropriate. Bone-conducting hearing devices transmit sound directly to the cochlear by vibrating the skull, and are used by about 15,000 people in the UK (The Ear Foundation, 2013). Middle ear implants help to transmit sound information to the inner ear, by mechanically vibrating the ossicles or the cochlea itself. .

People with a functioning auditory nerve who are severely or profoundly deaf – and who gain little benefit from hearing aids – can be referred to a specialist centre for assessment for cochlear implants. There are over 12,000 cochlear implant users in the UK. Around 650 adults and 500 children receive them each year (British Cochlear Implant Group, 2015).

In England and Wales, the NICE guidance for cochlear implants was last updated in 2009 (NICE, 2009). This recommends only one cochlear implant for adults – two are recommended for adults with sight loss, and for children. This guidance needs to be reviewed.

Research suggests that governments across the UK should do more to make sure cochlear implants are available to all those who would benefit. Only 5% of adults who could benefit from a cochlear implant receive one (Raine, 2013). Research also shows that the UK has lower rates of adult cochlear implantation than other European countries (De Raeve and Van Hardeveld, 2013).



I got cochlear implants last year. It's like meeting up with an old friend you haven't seen in a long time and rediscovering the things you have in common and what you can remember about them. I'm constantly surprised and amazed at the sounds I remember and can suddenly hear so clearly again. Yesterday, for instance, I heard a sound I didn't recognise. It was the sound of my dog, Jake's, paws as he walked across the laminate floor in the lounge. It's the everyday sounds that I now find truly amazing.

Richard Turner, 43, Woodford



I lost my hearing in my right ear overnight, two months after a car accident. It totally devastated me. I also had chronic tinnitus and balance problems and, as a result, I became very withdrawn. I would miss out on things that had been said during conversations with my husband and with friends. I would avoid going to social events because it was just too isolating.

Then I attended a beginners' lipreading and managing hearing loss course at City Lit in London. I can't begin to tell you what a positive effect lipreading has made to my life. Everyone with a hearing loss should have these classes made available to them. Before lipreading gave me my confidence back, I was depressed and lonely. I can now socialise in places that I thought I'd never go to again.

Cathy Roach, 50, London

Tinnitus services

People with tinnitus go to their GP for referral to tinnitus services, usually provided by audiology departments. But GPs only refer, on average, 37% of their tinnitus patients (El-Shunnar et al, 2011). Even when they are referred, there is substantial variation in what services are available across the UK (Action on Hearing Loss, 2015a), meaning many people with tinnitus are not getting the help they need.

Just over two-fifths (41%) of NHS audiology providers offered a range of tinnitus services: specialist support, information, tinnitus retraining therapy and cognitive behavioural therapy (CBT). Worryingly, only just over half (56%) offered CBT, despite strong evidence that it helps people with tinnitus (Hoare, 2011; Hesser et al, 2011; Martinez-Devesa et al, 2010). High-quality support services should be provided for all people with tinnitus.

Mental health services for people who are deaf

Research suggests that people who are deaf are more likely to develop mental health problems than people with normal hearing (Kvam et al, 2006). Across the UK, only three mental health trusts and four local community mental health teams currently provide specialist, mental health services for adults who are deaf (including sign language users). These services require staff trained in BSL to ensure effective communication and, therefore, accurate diagnosis and treatment. The low number of specialist services suggests the mental health needs of many deaf people are going unmet.

Lipreading classes

Lipreading is an essential skill for people with all levels of hearing loss. At lipreading classes, you learn to recognise lip shapes and patterns – and how to use context and facial expression to help make sense of conversations. This includes how to identify the more visible lip shapes, how to distinguish different lip patterns – and how to be aware of which sounds might have similar lip patterns.

Classes also incorporate a broad range of information about wider communication tactics, products and equipment, and give you the opportunity to meet others. Our research has shown that lipreading classes lead to demonstrable improvements in lipreading ability and enhanced communication, with class members saying they feel less isolated and can manage work meetings better (Ringham, 2013).

However, research suggests that many more lipreading classes are needed to meet the level of need. Our 2010 findings show there are approximately 450 lipreading classes in England and Wales, enough for only 5,000 people (RNID, 2010). Some are not free, few are put on outside working hours, and lipreading-teacher-training opportunities are limited.

The Department for Business, Innovation and Skills (BIS) has provided funding for us to explore other models of delivery for lipreading and related support, to establish if other mechanisms could be used to deliver this support to more people at an earlier stage.

Social services

Across the UK, local authority social services provide support and equipment to help people with deafness, tinnitus and hearing loss (as well as social care services – see page 74). What is available varies, but it can include access to support groups, counselling, specialist social workers, BSL interpretation, advocacy, guidance on managing finances and benefit claims, help with skills development and at work, and assistive equipment such as flashing alarms or doorbells, amplified telephones, textphones and personal listeners.

Under the Care Act 2014 in England and the Social Services and Wellbeing Act in Wales 2014, local authorities must provide a range of support services and equipment. In our report *Life Support*, we found that all local authorities (that responded) provided equipment for the home; and a high proportion offered support work and



Local
authorities
have a duty
to provide
accessible
information



Being unable to hear everyday things (such as the phone and doorbell) can be very isolating. When people are at the door, they often have to text me first or look through the window to get my attention. I was given advice by Action on Hearing Loss about a very simple, but very efficient, doorbell and phone ringer that works off any appliance. At first, I was sceptical, but it works! Even better, I can take the 'box' (which makes a loud ringing noise but also flashes) with me, anywhere in the house and also into the garden. It's given me my independence back.

Susan Dufty, 59, Shard End

occupational therapy. But one in 10 (10%) did not offer crucial interpretive support (Calton, 2012).

Local authorities also have a duty to communicate in a way that people can understand, and to provide information on social services and social care in accessible formats, in line with equalities legislation and standards for accessible information – for information see page 76.

To apply for PIP, people are often told to telephone the DWP – which can cause difficulties for people with hearing loss

Benefits

People who have hearing loss, and are eligible for Personal Independence Payment (PIP), may get help to meet additional costs, such as communication equipment or lipreading classes. They may also be able to apply for Employment and Support Allowance (ESA). ESA provides financial support for those unable to work due to illness or disability, but it's been criticised for assuming people can return to work when this is unlikely – and for removing all benefits if a person appeals against an ESA decision.

Since PIP was launched in 2013, many people have experienced long delays waiting for their claims to be processed: approximately 78,000 people are still waiting for a decision on their PIP claim without receiving any payments, with a third (29%) having waited five months or more (Department for Work and Pensions, 2015a).

The eligibility criteria for PIP, which state that a person can only claim if they are affected at least half of the time, and for ESA which only looks at a person's ability to do a task once, can exclude people with some serious but unpredictable hearing conditions. For example, Ménière's disease causes unpredictable attacks that can include serious balance problems, hearing loss and tinnitus, but leaves people unaffected for periods of time.

People can qualify for PIP on the basis of communication difficulties, but the criteria do not take account of the fact that these difficulties may vary in different settings. To apply for PIP, evidence suggests that people with hearing loss are often told to telephone the

Department for Work and Pensions (DWP) – which can cause difficulties for people with hearing loss (Gray, 2014). The DWP should review current guidance to make sure people are aware they can also apply by post. When applications are being considered, people with hearing loss tell us that communication equipment or BSL interpreters are not being provided during face-to-face assessments.



I'm profoundly deaf in both ears. For me, all communication with other people is difficult. I have to rely on lipreading, which is a big help, but it rarely works smoothly. People often have to continually repeat and rephrase what they're saying or, in the end, write things down. That was the picture I tried to paint in my application for Personal Independence Payment, but it was turned down flat. The assessors said if the conditions are right, I can lipread and take part in a conversation – but, of course, the conditions aren't always right. The assessors seem to lack any understanding of how being profoundly deaf affects your ability to communicate with others.

John Bailey, 64, Oxford

Technology and treatments

This section sets out the exciting, recent developments in hearing research and technologies – the prospects for future treatments and cures for hearing loss and tinnitus are bright.

But, if we are to make sure people with hearing loss benefit from new medical discoveries, investment in hearing research must be increased to match the growing level of need. Our recommendations are set out in the Agenda for Change section (see page 94).

Technology

Technology plays a vital role in the lives of people who are deaf, have tinnitus or hearing loss, in the form of hearing aids and cochlear implants, sound generators, and a wide range of assistive equipment.

Hearing aid technology is improving, including new advances that can help improve sound quality, reduce background noise and connect with other devices such as smartphones. But there's still a huge need for further improvements, in particular, around speech intelligibility in the presence of background noise.

Stress and anxiety can make tinnitus worse. Sound generators can help distract people from listening to their tinnitus by producing a range of relaxing sounds such as rainfall and ocean surf. Others come with extra features such as aromatherapy fragrances and coloured lights.

Assistive equipment includes alerting devices such as flashing doorbells, relay services, smoke alarm systems and alarm clocks – as well as technology to help people hear, such as amplified telephones, listening devices or hearing loop and infrared systems.

The pace of technological change is rapid and exponential, providing new and unexpected benefits for people who are deaf, have tinnitus or hearing loss. For example, ongoing developments in text relay, video services, speech-to-text and gesture-recognition technologies have huge potential for application in new devices, better communication and access to services – and companies should continue to develop and promote these technologies. But new technologies can also raise barriers because of a lack of foresight. For example, the absence of subtitling on video-on-demand services (see page 82).

Hearing aid technology is improving, including new advances that can help improve sound quality and reduce background noise



Relay services enable people with hearing loss to access the telephone network. All telecomms providers in the UK are legally obliged to give their customers access to a Text Relay service. A relay assistant acts as an intermediary to convert speech to text and vice versa for the two people conversing. In 2014, BT launched **Next Generation Text (NGT)**, which enables deaf people to make calls, through an app on a smartphone, tablet, or computer. Relay services can also be accessed through a textphone.



A **video relay service (VRS)** offers communication between a sign language user, a hearing person and an interpreter, each in a different place. This has huge advantages for BSL users; if English is their second language they may find conversations in English difficult. But there's no legal obligation for a VRS in the UK, therefore it's limited to people who can afford to pay the full cost, or those in work who can apply for funding through **Access to Work** (see page 81) and have access to suitable broadband internet. Some companies now offer VRS as a contact option for sign language users.



Hearing loops and infrared systems help people with hearing loss hear sounds more clearly by reducing the background noise. Hearing loops can be used almost everywhere, from the bank to watching TV at home. Hearing loops transmit sound signals in the form of a magnetic field that can be picked up by most hearing aids and cochlear implants. Infrared systems, which use infrared light to transmit sound signals, are used mostly in cinemas, theatres, at home for watching television – and anywhere where privacy is needed. The person receiving the signal uses a listening device with headphones or hearing aids.

Treatments

We're making rapid progress in improving our understanding of the biological causes of hearing loss and tinnitus. The first of a new generation of treatments to silence tinnitus and protect and restore hearing is in clinical testing. If these are successful, with proper investment, drug treatments to prevent specific types of hearing loss, and treat some forms of tinnitus, could be available by 2020, and we believe we can find cures within a generation.

Preventing hearing loss

Genetic factors, exposure to loud noise, ototoxic drugs used to treat life-threatening conditions and viral infections, and 'lifestyle choices' (such as smoking) are all known to contribute to loss of hearing. Researchers are discovering which parts of the auditory system are affected, and the biological processes involved – processes that are now being targeted in an effort to prevent hearing loss.



Previously, only a few of the many deafness genes could be routinely tested, meaning that an accurate diagnosis could only be given in one-fifth of cases. A new test we have developed uses advanced DNA sequencing technology which can, in principle, screen all known deafness genes at the same time. It's a major development from being able to test one or two genes, to being able to screen all known genes that cause deafness, meaning far more affected people can be correctly diagnosed at a fraction of the old cost. The test is now available to all NHS patients through the NHS UK National Genetic Testing Network.

Professor Guy Van Camp, University of Antwerp

The cochlea is the sense organ that translates sound into nerve impulses. Exposure to noise can damage the sensory hair cells in the cochlea that detect sound vibrations. Hair cells use a lot of energy

and, as a result, produce toxic by-products called free radicals. SPI-1005, one of the drugs currently being clinically tested as a treatment to prevent some noise-induced hearing loss, works by boosting the cells' ability to neutralise free radicals (Kil et al, 2007). AM-111, another drug in clinical development for the treatment of noise-induced hearing loss, prevents the death of hair cells by blocking a process called apoptosis (Auris Medical, 2015).

Restoring hearing

Once lost, the specialised cells of the cochlea cannot re-grow, so hearing loss is permanent. But, now, progress is being made towards developing new cell-, gene- and drug-based therapies able to repair damage to the cochlea (Géléoc and Holt, 2014).

Action on Hearing Loss has pioneered the development of stem cell treatments for hearing loss by funding research at the University of Sheffield. Our research shows that human stem cells can be used to repair damage to the auditory nerve in animals to restore hearing (Chen et al, 2014). At the end of 2014, the pharmaceutical company Novartis started the world's first clinical trial of a gene therapy to restore hearing – this repairs damage to the cochlea by reactivating the biological processes that control the formation of hair cells during development.

Silencing tinnitus

Research we funded has shown that damage to the cochlea can result in the parts of the brain that process sound becoming oversensitive and hyperactive. This hyperactivity is perceived as sound and is believed to be a major cause of tinnitus.

There appear to be two stages in the development of tinnitus. Initially, the hyperactivity is dependent on signals from the cochlea. Blocking these signals reduces the hyperactivity within the auditory parts of the brain and tinnitus-like behaviour in animals. AM-101, a drug in clinical trials for tinnitus, works by interfering with the signalling between hair cells and the auditory-nerve fibre.



Less than
1%
of the total
investment
in medical
research is
spent on
hearing loss

Over time, the tinnitus-related hyperactivity becomes established within the brain – and independent of signals from the cochlea. AUT00063, another drug in clinical development for tinnitus, works by reducing tinnitus-related neural activity.

Hearing research investment

Despite the scale of the issue and the clinical need for new treatments to prevent hearing loss, restore hearing and silence tinnitus, hearing research is significantly underfunded compared to other health areas. More investment and support is needed from governments, research councils and companies.

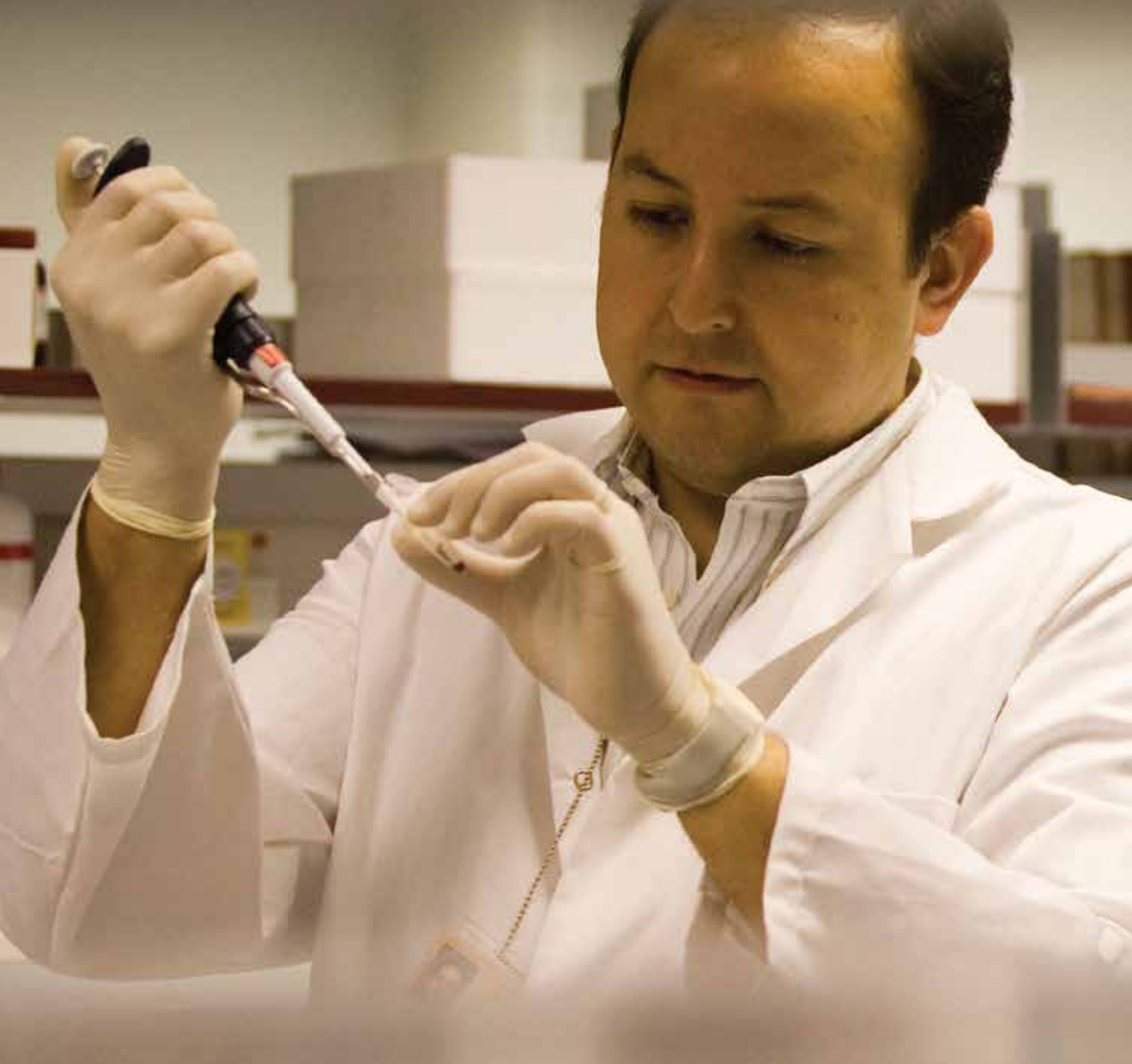
A report, published by the UK Clinical Research Collaboration in 2015, showed that, in 2014, the UK's main public and charitable funders of medical research funded £2.03 billion-worth of research projects (UKCRC, 2015). This figure does not include the indirect costs of supporting research, such as administration and building costs. The analysis shows that only £12.3 million (less than 1% of the total) supported hearing-related research. This is equivalent to just £1.11 being spent on hearing research for every person affected⁸.

In comparison, £11.35 was spent on research into sight loss for every person affected and £19.79 on research into cardiovascular conditions for every person affected⁹. The report also shows that hearing-related research was the only health area to show a decrease in real terms funding by the UK's main public and charitable research funders over the last 10 years (2004-2014).

Drug
treatments
to prevent
hearing loss
– and treat
tinnitus – could
be available by
2020

8 Calculated from data from UK Health Research Analysis Report 2014, (UKCRC, 2015) and Action on Hearing Loss figures on the number of people in the UK with hearing loss.

9 Calculated from data from UK Health Research Analysis Report 2014, (UKCRC 2015), and the numbers of people living with sight loss and cardiovascular problems, according to RNIB and the British Heart Foundation.



The advances being made in stem cell research are an important step towards restoring hearing. We now have a method to produce human cochlear sensory cells that we can use to develop new drugs and treatments – and to study the function of genes in hearing. Even more importantly, we have proof-of-concepts that human stem cells can be used to repair the damaged ear. However, much more research is needed. For instance, we need to understand the long-term implications of this treatment – and its safety.

[Professor Marcelo Rivolta, University of Sheffield](#)

The pharmaceutical industry is reluctant to invest in an area where the perceived risks are high

The funders supported only £481K of hearing research in Scotland and £379K in Wales in 2014. No active hearing-related research grants were reported for Northern Ireland in 2014.

Translational research

Whilst progress is being made, both in understanding the causes of hearing loss – and developing strategies to both protect and restore hearing and silence tinnitus, progress in moving promising new approaches into clinical trials has been steady but slow. This type of research – to refine a promising new treatment to a point where it can be safely tested in patients – is called translational research.

The challenge is two-fold. First, many academics lack the experience and know-how needed to translate their research into treatments. Second, as there are no drugs on the market, the route through clinical trials, gaining regulatory approval, and getting hearing therapeutics adopted by healthcare providers is unknown and largely untested. This means that the pharmaceutical industry, whilst recognising the huge commercial opportunities and unmet need, is reluctant to invest in an area where the perceived risks are high.

Cross-disciplinary research

The most transformative technologies and treatments often arise when different disciplines and sectors are brought together. Hearing research is unique in that it draws on expertise from a wide range of disciplines, from neuroscience, psychology, and engineering to computer sciences.

A good example was a recent effort by the Medical Research Council (MRC) and the Engineering and Physical Sciences Research Council (EPSRC) to encourage research that will transform hearing aid technology. A jointly organised workshop brought together scientists from the engineering and biological sciences, to explore and develop new ideas. A subsequent funding call resulted in the MRC funding 'Hearing Aid Networks' and the EPSRC supporting over £4 million

of research to advance hearing aid technology. The Research Councils and NIHR (National Institute for Health Research) should be encouraged to work together – and with medical research charities – to better support cross-disciplinary research and direct more funding to areas of most need.

For example, as part of a recent initiative in partnership with the Biotechnology and Biological Sciences Research Council (BBSRC), we encouraged the research community to develop project proposals to better understand how the auditory system ages. This led to an extra £4 million investment into hearing research.

Supporting charity funding

Charity funding is a vital component of the UK's medical research sector. In 2013, medical research charities invested over £1.3bn in UK research, more than the MRC (£767m) and NIHR (£959m) (Association of Medical Research Charities, 2014). Charities are dependent on governments, through Higher Education Funding Councils and other sources, to maintain and develop the UK's science infrastructure and train the next generation of scientists. It's vital that governments increase investment in science, so charity funding is used to maximum effect developing new treatments in the UK.

The Charity Research Support Fund (CRSF), distributed by the Higher Education Funding Council for England (HEFCE), provides support to universities to offset the fact that charities do not pay the full economic costs of the research they fund. Charitable funding of UK research is increasing year-on-year, and it's vital that the governments now increase this fund in line with charity spending.

AcoRD (Attributing the costs of Research and Development) guidance, published by the Department of Health and adopted by the corresponding health departments in Scotland, NI and Wales, has identified specific costs, associated with carrying out clinical research within the NHS, that medical research charities do not need

to pay. These indirect costs include the cost of co-ordinating studies, collecting data and complying with regulations.



On average, for every £1 we invest in research, projects we support attract a further

£10

in follow-on funding¹⁰.

Action on Hearing Loss-funded research¹¹

Since 1999, we have funded world-class research and training and, in 2013, we merged with Deafness Research UK to create the world's largest charitable-funding programme dedicated to advancing treatments for hearing loss and tinnitus.

We have invested over £25 million into hearing research from which people are already benefiting, through the technology used to screen the hearing of newborn babies, cochlear implants and advances in the fitting of hearing aids. We have launched the careers of research leaders, funded key scientific advances, and opened up areas of research that may lead to new treatments.

We have been able to increase the biotechnology and pharmaceutical industries' involvement in developing new treatments, with the first drugs for hearing loss and tinnitus in clinical development. Our sector-leading Translational Research Initiative for Hearing is providing vital support to companies and academics to translate research into promising treatments.

Finally, we have worked in partnership with Age UK, cochlear implant companies and the Biotechnology and Biological Sciences Research Council to increase investment in hearing research. We will continue to work with a range of partners to build on these successes, making sure new treatments and cures for hearing loss and tinnitus are developed as quickly as possible.

Equality

Despite improvements in legal protection, people with hearing loss often face barriers when trying to access health and social care, education, employment and entertainment.

In this section, we outline how services are often unaware of the communication needs of people with hearing loss and fail to provide communication equipment or properly qualified BSL interpreters. In the Agenda for Change section we set out what needs to be done – see page 96.

The Equality Act

The rights of people with disabilities are underpinned by two major pieces of legislation in the UK: the Equality Act 2010 (the Disability Discrimination Act in Northern Ireland) and the Human Rights Act 1998. The Equality Act bans discrimination and requires employers and service providers to make reasonable adjustments if a person with a disability is put at a substantial disadvantage in comparison with people who aren't disabled. The Equality Act also places further requirements on public bodies through the Public Sector Equality Duty. Public bodies must have 'due regard' to the need to eliminate discrimination, advance equality of opportunity and promote mutual understanding. Having 'due regard' means public bodies must think consciously and carefully about these aims in their day-to-day work.

Human rights provide a basic set of rules for public bodies to follow, to ensure that all individuals are respected and protected. Human rights apply to everyone, but they carry particular importance for

10 A survey carried out in 2014 of researchers who have had an Action on Hearing Loss grant showed that, on average, every £1 we invest in hearing research attracts a further £10.45 in follow-on funding.

11 For more information on how we fund hearing research, please see our *Hearing Progress* report: www.actiononhearingloss.org.uk/hearingprogress

people with disabilities, and older people. For example, the right to be 'free from inhuman and degrading treatment' can be used when challenging poor care in health and social care settings, such as in hospital, a care home or your own home. The 'right to a private life' also provides important protections for people with disabilities. For example, we all have a right to participate in the community and to make our own decisions. This would be important if, say, your local authority wanted to place you in residential care when you would rather stay in your own home.

The 'right not to be discriminated against' and the 'right to education' provide strong backing for the argument that a local authority and school should ensure that a deaf child is fully supported to participate in class. Or, if a deaf person is charged with a criminal offence, they have a right to a fair trial. If they use sign language, this could mean providing them with a sign language interpreter.

British Sign Language (Scotland) Act 2015

In 2015, the Scottish parliament enacted important legislation which aims to increase the use of BSL in Scotland. The British Sign Language (Scotland) Act 2015, the first of its kind in the UK, places a duty on the Scottish Government and local authorities to promote the use of BSL in Scotland. The Scottish Government must produce a national BSL plan, in each session of parliament, which sets out a national strategy for promoting BSL, engaging with BSL users. Local authorities must also set out how they plan to increase the use of BSL. Performance against both national and local plans will be reviewed and published. But, whilst the Act seeks to raise the profile of BSL, it does not place a legal requirement on services to provide BSL interpreters, specialist services or BSL classes. Local authorities must be given the necessary resources to improve services for BSL users.

Access to services

People with hearing loss are often excluded or face barriers when accessing services, from housing, high-street bars and shops to banks, utilities and multinational companies. Providing only a telephone number will exclude many deaf people. There is a lack of awareness in companies of text relay and video relay – and limited knowledge about how best to communicate with someone with hearing loss. And they're missing out on business: in a members' survey (Action on Hearing Loss, 2009) three-quarters said deaf-aware staff would make them more likely to use a service.

Companies rarely identify, let alone record, the communication needs of their customers. For face-to-face contact, some people may need communication support, such as a BSL interpreter or a speech-to-text reporter, but these are rarely provided. People with hearing loss sometimes ask a friend or family member to make a call on their behalf, but services often refuse to talk to someone else. Information is often provided in a way that is not accessible to people with hearing loss, such as through a public address (PA) system or in videos without subtitles.

People with hearing loss can find it difficult to differentiate between speech and other noise, so music or poor acoustics can create huge difficulties in understanding. The increasing trend for hard surfaces such as wooden floors, tiled walls and no soft furnishings can make rooms much noisier, as they cause sound to echo. As a result, many people with hearing loss have difficulties in, and avoid, some cafés, bars and restaurants.

A hearing loop or infrared system can help hearing aid users (or someone using a loop listener/infrared receiver) hear sounds more clearly by reducing or cutting out background noise. But many venues don't have hearing loop systems at reception and other key places, and those that do often don't publicise the fact, or even switch them on – and staff may not know how to operate them.



At 69, I've suffered from tinnitus for 20 years. I now wear hearing aids. Being out and about is no longer a pleasurable experience because of loud music in shops and restaurants. Shopping becomes a complete assault on my hearing and it's mentally draining. When I complain to shop assistants, all I receive is a shrug and "it's head office's responsibility".

Eating out is also challenging. The music is so loud, I have to limit my company to three or four people, or I can't hear what's being said.

Brenda Sands, 69,
Kingston Upon Thames

Health services

People with all levels of hearing loss face difficulties accessing all types of health service. Although GPs are often the first step to getting help, our *Access All Areas* (Ringham, 2012) report found that simply contacting and visiting them is often a challenge. Most of the people with hearing loss we surveyed were forced to struggle with the phone or go in person to book an appointment with the GP, because of a lack of other options such as online booking, SMS or text relay. One in seven (14%) had missed an appointment because they didn't hear their name being called in the waiting room. When they did get to see their GP, alarmingly, more than a quarter (28%) said that they didn't understand their diagnosis, and one in five (19%) were unsure about their medication.

The diagnosis and management of all types of health condition are often inaccessible for people with hearing loss. This can all too easily lead to poor care, a lack of diagnosis or even misdiagnosis (Action on



I've had a few bad experiences at hospitals recently. At an outpatient appointment, the consultant's face was half in shadow and – coupled with his strong regional accent – I couldn't understand what he was saying. Seeing that I was struggling to lipread, he pointed to a diagram on the screen. But that just made things worse. I can't look at the screen and lipread at the same time! On another occasion, this time in the operating theatre, when my hearing aids had been taken away, two anaesthetists with masks over their mouths asked me a string of questions: I couldn't understand a word. In a different hospital, during the ward round, all the medics had their backs to the light so I couldn't see their lips. Was I going to be discharged? Kept in? Or sent for more tests? When I asked the consultant if the ward sister could repeat what he'd said, he just scowled and walked off – taking his team with him.

Stephanie Bromley, 70, Devon

Hearing Loss, 2013; Foundation for People with Learning Disabilities, 2015), particularly when people have conditions that are linked to hearing loss, such as mental health problems, dementia, learning disabilities, sight loss, cardiovascular disease and diabetes. So we've identified the simple steps that hospital staff can take to improve the experience, and their care for people with hearing loss – such as recognising that someone has hearing loss, using our communication tips, learning and carrying out basic hearing aid maintenance – and providing somewhere for in-patients to store their hearing aids¹².



Even when they ask for a BSL interpreter, two thirds of BSL users don't get one

The situation is even worse for many profoundly deaf people, many of whom use BSL and need a properly qualified BSL interpreter (registered with the National Registers of Communication Professionals for the Deaf (NRCPPD)) at their medical appointments. Even when they ask for an interpreter, around two-thirds of BSL users (68%) don't get one; and almost half of those who do find the quality of interpretation isn't good enough (Our Health in Your Hands, 2012; SignHealth, 2014). Research by SignHealth suggests that people who are deaf are more likely to have undiagnosed high blood pressure and receive less effective treatment due to confusion

NHS Choices

We are working with NHS Choices, the NHS's health information website, to increase the number of webpages accessible for BSL users. At the moment, only 10 of the 900 video clips on the NHS Choices website have been translated into BSL. As more and more people go straight to the internet for information about health and care, substantial efforts are needed to improve the accessibility of relevant websites for people with hearing loss.

12 See www.actiononhearingloss.org.uk/nursingtoolkit

about their medication and health information being provided in written English rather than BSL (SignHealth, 2014).

NHS 111

The NHS 111 service, replacing NHS Direct, provides advice on non-life-threatening situations and directs people to local services. In 2015, NHS 111 launched a video relay for BSL users. Using a computer, tablet or phone that is connected to the internet, a BSL user can make a video call to a BSL interpreter who will call NHS 111 and speak to an NHS 111 adviser on their behalf. In Scotland, the advice line NHS 24 offers a similar service.

We worked closely with the NHS in Wales and England to develop and publish standards for accessible information in healthcare settings (NHS Wales, 2013; NHS England, 2015). Under these, healthcare organisations must ensure that a person's communication or information needs are recorded, met and shared when they are referred to another service. Correspondence and health information must be made accessible for people with all levels of hearing loss, for example, in written form or in BSL video-translated text; communication aids such as hearing loops must be made available for consultations; and communication support, such as BSL interpreters, must be provided for people who need them. In England, the standards – which will be mandatory by 31 July 2016 – also cover adult social-care services.

These standards give clear direction about the adjustments people with hearing loss should expect when accessing health services. But, of course, they're only effective if they're enforced. In our *One Year On* report, published in collaboration with RNIB and Sense (Action on Hearing Loss Cymru et al, 2014), we were disappointed to find that standards in Wales were not being implemented properly.

Just under two-thirds (63%) of survey respondents said they did not receive the support they needed when accessing primary care; and less than a tenth (9%) reported a noticeable improvement in the way hospitals communicate and share information. So we're working with the Welsh Government and local health boards to agree a timetable and deadline for the full implementation of the standards in Wales. Simultaneously, we're working with NHS England to ensure their standards are enforced properly.

We also provide support and information for health professionals; as part of this we worked with the Northern Ireland Health and Social Care Board to develop guidance for GPs (Health and Social Care Board et al, 2014).

Social care

People with deafness, tinnitus and hearing loss sometimes need to access social care services. Local authorities (Health and Social Care trusts in Northern Ireland) are ultimately responsible for them, but different services may be delivered by local authorities, independent firms, charities or other organisations.

Social care services are provided for older people, and for working-age adults and children with hearing loss, and/or other forms of sensory loss, learning disabilities, mental health problems and long-term conditions. Depending on the level of need, social care usually consists of practical help with household chores, shopping or running errands; but also more personalised forms of care, such as help with preparing meals and eating, washing and bathing in the home or in nursing homes. These services often focus on supporting people in the long term, including identifying and mobilising support from the voluntary sector to help them maintain their independence, as well as preventing any further deterioration in health and wellbeing.

Local authorities now have a statutory duty to provide a comprehensive social care service that meets local needs and

Best practice in care and support

Action on Hearing Loss provides 47 services across the UK including residential care, supported housing, and other types of community service. We have over 80 years' experience of providing support for people who are deaf with complex needs such as deafblindness, dementia, autistic spectrum disorders, mental health problems, learning disabilities and acquired brain injuries. Our staff use all forms of sign language, including BSL and hands-on signing for deafblind people; and communicate clearly using pictures and objects. We seek to help people express themselves and participate fully.

promotes the wellbeing of social care users. Under the Care Act 2014 in England and the Social Services and Well-being Act 2014 in Wales, local authorities must assess someone's social care needs against national eligibility criteria – and provide information and advice on available services. This legislation could help reduce regional variations in services but, without proper funding and proper recognition of the communication needs of people who are deaf and have hearing loss, many people will not get the help they need.

In *Life Support* (Calton, 2012), we found that an individual's communication needs are often ignored when their social care budget is assessed. This was the case in a third of Welsh authorities (33%) and two-fifths (41%) in England (Calton, 2012). These needs have to be taken into account; otherwise people can't access the support they need. We also found that three-quarters of the local authorities we surveyed in Wales (75%) – and just over a quarter (26%) in England – did not offer a textphone number or special

Lucy's story

The world is a challenging and scary place for Lucy, a loving and curious 37-year old who relies on sign language to communicate. But in the past, the anxious Lucy dominated: eating has always been an issue, causing her major distress, with meals thrown and attacks on others. In 2009 she was so unwell she was sectioned and spent three weeks in a psychiatric ward. Six years on, we've helped Lucy transform her life. As her mother, Jennifer, told us, "Lucy fulfilled a dream – we went on our first holiday as a family for 20 years. The days were wonderful: swimming in the sea, chatting at our house in Spain, playing games and eating out. This never would have been possible without the dedication, calmness and professionalism of the Action on Hearing Loss team who made this holiday a fabulous reality."

telephone service for people with hearing loss. Most failed to provide suitably qualified BSL interpreters during assessments, and one in four did not provide advocacy support for people with hearing loss.

Now, under the recent legislation, local authorities must provide information and communication in accessible formats – and make sure people with all levels of hearing loss are fully involved in discussions about their care. Advocacy support must be provided to all those who need it (in England this is defined as anyone who has substantial difficulty participating in assessments and discussions).

Under these acts – and equalities legislation and the Accessible Information Standards in England – information and communication, including booking appointments, correspondence and advice, must be made accessible for people who are deaf and have hearing loss. In practice, this means providing alternatives to the telephone, or providing BSL video translation. Support such as BSL interpreters

and assistive equipment must also be made available during social care assessments. Social care for BSL users must be sensitive to their cultural and communication needs.

Between
2010 and 2014,
funding for
adult social
care was cut
by a third -
that's

**£3.5
billion**

Under the Care Act regulations in England, at least 340,000 people with social care needs **won't** be eligible for care and support (Care and Support Allowance, 2014). The restrictions in adult social care provision reflect the scale of local authority budget cuts in recent years. The Association of Directors of Adult Social Services in England (ADASS) says that funding for adult social care has been cut by a third (£3.5 billion) since 2010 (ADASS, 2014). Unless adult social care funding is increased and eligibility criteria are revised, many people who are deaf and have hearing loss won't be able to access the vital social care services they need.

Our research report, *A World of Silence* (Echalier, 2012), also shows that, despite the high prevalence of hearing loss in older people, large numbers of older care-home residents have undiagnosed hearing loss. Many didn't want to address their hearing loss - and care home staff found it difficult to encourage them to seek help. The care staff we spoke to admitted that hearing loss was sometimes seen as less important than sight loss, pain or safeguarding. Some care workers were unaware of hearing loops and other assistive equipment, such as amplified telephones and listeners. Others lacked the know-how to carry out basic hearing aid maintenance.

Alongside other charities, we persuaded the health and social care inspectorate for England, the Care Quality Commission (CQC), to train their inspectors in the needs of people with hearing loss. We will continue to push the CQC to carry out routine inspections to see if care settings are accessible for people with hearing loss. And we will be working with the NHS, care providers and care inspectorates to make sure that adult social care services can recognise and help people with hearing loss - and that they meet their legal duty to record and meet their communication needs.

Education

Children and young people who are deaf or have hearing loss are not getting the support they need. Many children underachieve throughout their education.

In 2014 in England, nearly two-thirds of deaf children (64%) failed to achieve the Government benchmark of five GCSEs (including English and Maths) at grades A* to C, compared with less than half (43%) of all pupils (NDCS, 2015b).

In Scotland, evidence shows that, in comparison to school leavers with no additional support needs, deaf school leavers were more likely to leave school with no qualifications (8.9% compared with 1%), and were less likely to qualify for entry into higher education (NDCS Scotland, 2014).

Teachers of the deaf can provide crucial support to deaf children, their parents and family; and to other professionals involved in a child's education. But numbers are declining and around half of the people currently working as teachers of the deaf will retire in the next 10 to 15 years (Consortium for Research in Deaf Education, 2014).

The Children and Families Act 2014 in England focuses squarely on desired outcomes – and on education providers making sure that children and young people have the information and skills they need to gain independence and prepare for adulthood. There is also an increased emphasis on making sure that parents, children and young people are actively involved in discussions and decisions about their support (NDCS, 2015c).

As we go to press, the governments in Wales and Northern Ireland are proposing a range of changes to their special education needs frameworks. These are expected to come into effect from 2016.

8 out of 10
people with
hearing loss
tell us that
employer
attitudes
are the most
significant
barrier to
employment

Employment

People with hearing loss are less likely to be employed (65% are in employment) when compared with people with no long-term health issue or disability (79%) (ONS, 2015b). The current Government has made an ambitious commitment on disability employment, aiming to halve the disability employment gap (Department for Work and Pensions, 2015b). To be achieved, it will be essential people have access to specialist, tailored support to meet their employment needs.

Our research shows that developing hearing loss can lead to loss of employment (Matthews, 2011) and problems gaining employment (Baker, 2006).

Our *Hidden Disadvantage* research, published in 2014, found that two-thirds of people with hearing loss (70%) felt their hearing loss sometimes prevented them from fulfilling their potential at work, and a similar proportion of respondents to the same survey (68%) said that it left them feeling isolated at work (Arrowsmith, 2014).

Attitudes to and the impact of hearing loss can also lead to people leaving the labour market. Alarming, two-fifths (41%) of people surveyed, who had retired early, said that this was related to their hearing loss, highlighting that when an organisation fails to effectively support an employee with hearing loss, it can have significant consequences (Arrowsmith, 2014).

In 2014, The Ear Foundation calculated that, on average, people with hearing loss are paid £2,000 less per year than the general population. This amounts to £4 billion in lost income across the UK (The Ear Foundation, 2014).

The proportion of people aged 50 to 64 in employment increased from 62% in 2001, to 67% in 2013 (DWP, 2013). With an ageing workforce and rising retirement age, it is likely that more people will experience the onset of hearing loss in the workplace – and when

seeking work. More than ever, employers need to be well-informed about hearing loss, and how to provide practical workplace support.

People with hearing loss consistently cite the attitude of employers as the most significant barrier to employment – our recent research found that 8 out of 10 people with hearing loss identified employer attitudes as the major barrier to employment (Arrowsmith, 2014; Baker, 2006). The UK Government's 'Disability Confident' campaign, aimed at employers, aspires to remove barriers and increase understanding so that people with disabilities have the opportunity to fulfil their potential. It is vital that the campaign's impact, particularly on employer attitudes, is properly evaluated.



Nobody wants to employ a deaf person. Even in the most lowly of jobs. I never got interviews. I just never heard back. I did follow it up with one organisation and asked, “Why have I not got an interview?” And the reply was, “Well you are deaf, you couldn’t possibly manage.”

So I did cleaning for two or three years – it was the only thing I could do. I didn’t like it very much but I did it because I needed to work. It was very hard and very disheartening. Just that feeling that nobody wants you. And that feeling that you cannot contribute anything.

I ended up going back to study with the Open University and heard about a now-closed government scheme which was funding a theatre company devising performances for deaf children. That was the start of a long career in the arts and I am now strategic director of Disability Arts Cymru. But not everyone is as lucky as I was.

Maggie Hampton, 64, Pontypridd

Evidence suggests that people with hearing loss can find it difficult to access support from Job Centres and specialist employment agencies. Job Centre staff aren't always trained to provide

The Government's decision to limit Access to Work awards will affect deaf people who use the scheme to access communication support

appropriate support, and there's sometimes a lack of awareness of specialist employment agencies and the support they can give to people looking for work (Boyce, 2015).

Having access to the right support and adjustments can make all the difference. The Government's Access to Work scheme gives people with a disability or specific health condition a grant to pay for practical support and specialist equipment at work. People with hearing loss can use Access to Work to access communication support, for example, a BSL interpreter or speech-to-text reporter, or specialist equipment such as a personal listening device or hearing loop system.

In March 2015, the Government announced a number of changes. Many of these, such as the introduction of personal budgets, and plans to make Access to Work a digital service, will improve the service and deliver more choice and control to scheme users.

But the recent introduction of a limit on the value of Access to Work awards (set at £40,800) will affect deaf people who use the scheme to access language and communication support in work. This limit could make it difficult for people to get the support they need and it's essential that the impact of this change is monitored, to ensure the limit does not create a situation where people with hearing loss using Access to Work are left without adequate support. The limit on awards was introduced in October 2015 for new scheme users, while existing scheme users will be subject to the limit from April 2018.

Transport

Without transport people can't get to their job, attend a hospital appointment, go to school, or socialise. Despite our technological advances, passengers with hearing loss still face innumerable information and communication challenges when travelling on public transport.

Announcements are often relayed by audible means only, leaving passengers with hearing loss clueless about travel updates. Real-time visual-information displays (on trains, buses and throughout stations) are invaluable to people with hearing loss, but the use of these systems varies widely across the network. On buses, there is still no legal requirement for audio-visual information to be provided.

Communication with staff can often be problematic, due to a lack of deaf awareness. Staff-training requirements vary massively across different modes of transport.

Television and video on demand

People with hearing loss depend on subtitles to follow dialogue and plot on television. These should be provided regardless of where and how the programme is delivered. Traditional television channels are required, by legislation, to provide a minimum amount of subtitles and signing, and this has led to a huge increase in the amount of accessible content available. But newly established channels, and channels with a lower audience share, are exempt from the quotas. Unsurprisingly, they have few subtitles.

There are no accessibility requirements for catch up or on-demand services, such as ITV Player, Amazon Prime and Sky, and only 15% offer subtitles via their websites (Authority for Television on Demand, 2014). Information about the availability of subtitles on a service is unlikely to be advertised. So people purchase a programme or sign up to a contract without realising no subtitles are available. In a recent survey of people with hearing loss, 73% said they pay for a service that they can't take full advantage of because of their hearing loss. Over three-quarters also said they hadn't been able to watch a programme, film or series because of the lack of subtitles (Action on Hearing Loss, 2015b).

Subtitles for live programmes are notoriously error-prone – and there's often a time lag between the subtitles and the live broadcast.

Watching TV programmes and films is important to me - most of all because I'm happy and relaxed while watching them. It's fantastic when subtitles are provided - I can understand the content and enjoy it. But subtitles often aren't available, especially now that more content is 'on demand' on smart TVs, tablets and mobile phones. While the rest of my family watches a movie, I just play on my iPad. I'm missing out on having fun with my two little brothers - it's quite upsetting.

Jamie Danjoux, 16, Newcastle upon Tyne



And there are the pre-recorded programmes supplied with 'live' subtitling, when not enough time has been left between production and broadcast. We found that three-fifths (62%) of problems experienced with subtitles were due to delays, and 45% caused by problems with accuracy (Matthews, 2013). Since October 2013, the regulator, Ofcom, has been monitoring the quality of live subtitles. Its report in May 2015 did find improvements in accuracy, but delays continue to be a problem – the average delay is 5.1 seconds, compared to the recommended 3 seconds.

Background noise, such as music, sound effects and ambient noise, can make it difficult for people with hearing loss to follow dialogue. Strong accents and poor enunciation can also affect the audibility of speech.

Cinema and theatre

There are now more subtitled cinema screenings and captioned and signed theatre productions than ever before. Every week there are around 1,200 subtitled screenings at over 400 UK cinema sites (Yourlocalcinema.com, 2015). However, the choices for people who need subtitles – or rely on BSL – are severely restricted because so few shows throughout the week are accessible. Technology that provides personalised subtitling, where the subtitles are only visible to the person who needs them, would improve accessibility significantly.

Agenda for change

In this report, we have outlined the social, health and economic costs of hearing loss in the UK, and evaluated the response to hearing loss from governments, various industries, professionals and academics. We found a mixed picture – progress in some areas accompanied by significant steps backwards in others.

This section concludes with our vision for the future across three key areas, where we set out what action must be taken to tackle deafness, tinnitus and hearing loss in the UK:

- **Support and care**
- **Technology and treatments**
- **Equality**

Support and care

Three government strategies across the UK now specify hearing loss as a major public health issue. These strategies should act as catalysts for change, and improve awareness and the quality of services for people confronting deafness, tinnitus and hearing loss.

Hearing screening should be introduced for all adults over the age of 65, so hearing loss is diagnosed at the earliest opportunity. Governments and employers must take action to reduce the harmful effects of high levels of noise in the workplace.

Free NHS hearing aids must be available for everyone who needs them. The quality and provision of hearing services, tinnitus services and services for people with hearing loss alongside other conditions must be improved, and cochlear implants should be available to all those who could benefit.

Social services, social care and the benefits system must be improved – and made more accessible – so that they meet the needs of people with deafness, tinnitus and hearing loss.



Free NHS hearing aids must be provided to everyone who needs them

What action needs to be taken...

Governments across the UK should:

- Make sure national strategies for hearing loss are in place and fully implemented.
- Fund further research to determine the full social and economic costs of hearing loss, including the impact on communication, health, employment, socialising and the quality of life of people with hearing loss, and those around them.
- Campaign to overcome the stigma associated with hearing loss, and raise awareness of the benefits of seeking help and of hearing aids.

Action on Hearing Loss will:

- Work with governments across the UK to support the implementation of the national strategies for hearing loss.
 - This includes working with the Hearing Loss and Deafness Alliance, a coalition of the leading professional, private and voluntary organisations working for people with hearing loss, to ensure the UK Government meets its commitments in the Action Plan on Hearing Loss.
- Carry out further research and continue to raise awareness of the impact of hearing loss on health, quality of life and the economy.

Public health and screening

Governments across the UK should:

- Fund a randomised controlled trial to ascertain the most effective way to screen people for hearing loss – and to show the long-term benefits of screening.
- Fund research and develop resources for assessing the growing needs of people with hearing loss.
 - Public Health England must meet its commitments to improve the evidence on the prevalence and impact of hearing loss, and to provide tools for assessing local needs.
- Make sure that public health information and campaigns are accessible to people with hearing loss, including BSL users.
- Raise awareness of the need for people to get their hearing checked and of the dangers of loud music and noise at work.
- Explore ways to better protect members of the armed forces from noise-induced hearing loss and make sure that veterans with hearing loss receive adequate support.

Local authorities and local health and social care services should:

- Collect data on the number of people with deafness and hearing loss and assess their needs to inform the provision of local services.
 - In England, local authorities and NHS commissioners must include hearing loss in their Joint Strategic Needs Assessments (JSNAs) and strategies, and provide incentives for services to improve awareness, diagnosis and management of hearing loss.

The Health and Safety Executive should:

- Monitor employee compliance with noise at work regulations and take action when standards are not met.

The National Screening Committee should:

- Propose a hearing screening programme for all adults, over the age of 65, across the UK.

NHS services should:

- Improve rates of referral to hearing services by making sure that GPs and other health professionals have the information, incentives, training and screening tools they need to recognise hearing loss – and encourage people with hearing loss to seek help.
- Integrate opportunistic and targeted hearing checks into other services and settings, such as in GP surgeries, pharmacies and care homes, and during consultations and tests for other conditions.

Action on Hearing Loss will:

- Campaign for the introduction of hearing screening for all adults over the age of 65.
- Encourage people to seek help for their hearing loss, and to use our online Hearing Check.
- Research what changes are needed so that GPs improve referral rates; for example, better information, incentives, training, and/or screening tools.
- Support local authorities (Health and Social Care Trusts in Northern Ireland) and care providers to assess needs and improve the provision of services.
- Continue to campaign to raise awareness about the dangers of noise-induced hearing loss, reduce levels of noise in the workplace and increase the number of employees using hearing protection.

Hearing services

Governments across the UK should:

- Make sure national strategies for hearing loss are in place and fully implemented.
 - In England, NHS England should meet the commitments in the Action Plan on Hearing Loss to produce and enforce national commissioning guidance, to ensure consistent, high-quality services are available, and to intervene if services do not improve.
- Make sure organisations that plan and commission services are aware of the prevalence and impact of hearing loss and of the benefits of hearing aids and other support.

- Intervene if commissioners make decisions that run contrary to clinical evidence and local need, for example, putting unfounded restrictions on the provision of hearing aids.
- Fund further research into the benefits of hearing aids and other support services.
- Make sure quality standards for hearing services are in place and implemented across the UK.
 - In England, NICE should prioritise the development of its quality standard for adult-onset hearing loss.
 - The Welsh, Scottish and Northern Irish governments should consistently monitor performance against quality standards and publish the results.
- Review current guidelines to ensure cochlear implants are available to all those who could benefit, and raise awareness of cochlear implants among the public and NHS services to make sure people who could benefit are referred to specialist cochlear implant centres.
- Develop evidence of what works to support people with tinnitus; engaging professionals, patient groups and people with tinnitus.
- Recognise lipreading as a vital tool in helping people adjust to and manage hearing loss, and improve the provision of lipreading classes.



“I can’t begin to tell you what a positive effect lipreading has made to my life”

Cathy Roach,
50, London

Organisations responsible for commissioning NHS services should:

- Make sure all people with hearing loss who could benefit from hearing aids continue to receive them free of charge on the NHS.
- Monitor, evaluate and publish patient outcomes, including whether hearing aids are being used.
- Make commissioning decisions based on the needs of the local population and on the evidence of the increasing prevalence and impact of hearing loss and the benefits of hearing aids.
- Invest in high-quality hearing services that meet the needs of all people with hearing loss in the community.
 - In England, commissioners should invest in hearing services, provide guidance for GPs and information for patients about the services available, align service specifications and monitor patient outcomes.
- Maintain and increase funding for Hear to Help services and other community-based aftercare across the UK.
- Invest in high-quality support services for people with tinnitus.
- Invest in high-quality mental health services for deaf people.

Hearing services should:

- Record patient outcomes to improve service quality and prove the benefits of their service.
- Follow national standards and guidance, making sure that patients have their needs met – and can easily access ongoing support after their hearing aids are fitted.
- Refer or signpost to other services that people with hearing loss can benefit from, including social services, counselling,



“My hearing aids are my life”

Edna Poole, 98,
Wanstead

hearing therapy, lipreading classes and, where appropriate, cochlear implant services.

- Share good practice with other hearing services.
- Provide specialist services for people with hearing loss and other conditions such as mental health problems, dementia, sight loss and learning disabilities.

Action on Hearing Loss will:

- Continue to work with governments, commissioners, hearing services, professional groups and patients to secure proper investment in high-quality hearing services – and to stop cuts to NHS hearing aids.
- Work in partnership with hearing services to provide high-quality hearing aid aftercare and support for people with hearing loss.
- Produce and share research findings on service provision and good practice, and provide evidence and guidance on hearing services to people with hearing loss, service providers and commissioners.
- Promote the benefits of lipreading classes and campaign for better access to those classes.

Social services

Governments in England and Wales should:

- Enforce local authorities’ requirements under new legislation and standards to:
 - provide equipment and support for people with hearing loss.
 - make sure their communication and information is accessible for people with hearing loss.

Local authorities in England and Wales should:

- Make sure equipment and support is available for all those who need it.
- Provide accessible advocacy support for people with hearing loss.
- Make sure communication and information on social services is accessible for people with hearing loss.
 - In England, this should include meeting the mandatory Accessible Information Standard.

Action on Hearing Loss will:

- Provide information and advice for local authorities (Health and Social Care Trusts in Northern Ireland) on how to make their services accessible for people with hearing loss.

Benefits

The UK Government should:

- Reduce waiting times for Personal Independence Payment (PIP) to make sure people with hearing loss have timely access to the financial support which helps them meet costs associated with their condition.
- Revise the eligibility criteria for PIP and the Work Capability Assessment for Employment and Support Allowance (ESA) so they take account of hearing conditions that fluctuate over time.
- Revise the eligibility criteria for PIP to meet the communication needs of people with hearing loss.
- Make the PIP application process more accessible for people with hearing loss and ensure communication support is provided during face-to-face PIP assessments.

Action on Hearing Loss will:

- Continue to campaign with our partners in the Disability Benefit Consortium to ensure the benefit system is fair, transparent and meets the needs of people with hearing loss.

Technology and treatments

Despite recent improvements in our knowledge and understanding of hearing loss, hearing loss research is underfunded and charities must be supported to make technology and treatments for hearing loss and tinnitus a reality.

What action needs to be taken...**Governments across the UK should:**

- Make research into hearing loss and tinnitus a national priority, to address the chronic underfunding of hearing loss research – and to ensure that support for research is increased to reflect the growing level of need for new technologies and treatments.
 - The governments in Wales and Northern Ireland should work to build capacity around growth areas of hearing research to stimulate inward investment.
 - The Scottish Government should protect funding for the Institute of Hearing Research in the Chief Scientific Office strategic review.
- Invest in the UK's science base, so charitable funding for medical research is used to maximum effect.

- Increase the Charity Research Support Fund in line with increased charity spending.
- Maintain commitments made through the acoRD guidelines to ensure charities do not fund indirect costs of co-ordinating studies, collecting data and complying with regulations when clinical research is being undertaken through the NHS.
- Introduce a nationwide video relay service available to the user at the cost of a standard call.

The Research Councils and the National Institute for Health Research should:

- Work in partnership with each other and with medical research charities to help direct funding to areas of most need.
- Support cross-disciplinary research that could transform technology and treatments for people with hearing loss and tinnitus.

Companies should:

- Prioritise making new technologies and innovations accessible, including for people who are deaf, or have tinnitus or hearing loss.
- Develop and promote technologies such as text relay, video services and speech-to-text and make them more accessible for people with hearing loss.
- Invest in developing new treatments for hearing loss and tinnitus.

Action on Hearing Loss will:

- Increase hearing research capacity within the UK by supporting the training of PhD students and the early careers of the most talented scientists.
- Target funding towards research projects that will generate discoveries that could lead to new treatments.
- Support the translation of promising discoveries into treatments ready to be tested in the clinic, and work with the pharmaceutical sector to make sure new treatments are clinically tested and quickly brought to market.
- Raise public awareness of hearing research to aid recruitment into clinical trials and encourage donations for research.
- Fund research and work with technology developers and manufacturers to support the development of new and improved technologies, and raise awareness of new technologies to make sure that people confronting deafness, tinnitus and hearing loss can benefit.

Equality

Many services continue to be inaccessible for people with hearing loss. Communication barriers are preventing people with hearing loss from accessing and benefiting from health and social care, getting a good education, finding a job, using public transport, watching television and video on demand, and socialising with friends and family.

Services must meet their obligations, under equalities legislation and accessibility standards for health and social care, to make reasonable adjustments and provide communication support and equipment for people with hearing loss.



“It takes a lot of courage to face the outside world, which is largely unsympathetic to hearing loss”

Sylvia Robertson,
61, Berkhamsted

What action needs to be taken...

Access to services

Governments across the UK should:

- Protect the Human Rights Act.
- Enforce the Equality Act (and the Disability Discrimination Act in Northern Ireland) to make sure people with hearing loss are protected from discrimination, and that services and employers make reasonable adjustments.
- Raise awareness of equalities legislation amongst service providers, employers and the public.
- Regulate to make public transport accessible for people with hearing loss, and ensure that operators across the transport network give people with hearing loss equal access.

Services should:

- Take steps to be as accessible as possible, for example, by: offering a range of contact methods, recording and meeting communication needs, providing deaf awareness training for all staff, installing and maintaining loop or infrared systems, providing communication support such as BSL interpreters when appropriate, and subtitling video content.
- Control and minimise background noise wherever possible.

Action on Hearing Loss will:

- Continue to work with governments and businesses to make services more accessible for people with hearing loss.
- Provide information and guidance so that people with hearing loss know what to expect from services – and what action they can take if these expectations aren't met.

Health and social care

Governments and NHS bodies across the UK should:

- Make sure mandatory standards for accessible health and social care are in place and properly enforced. Performance against accessibility standards should be routinely monitored, including through inspections, and the results should be published.
 - In England, NHS England should provide funding, resources and training to help health and social care services meet the requirements of the Accessible Information Standard.
 - In Wales, Local Health Boards should set out and enforce a timetable for the full implementation of the All Wales Standards for Accessible Communication and Information for People with Sensory Loss.
- Make NHS 111 and NHS Choices accessible for BSL users.
- Fund research to develop better diagnostic tools, specialist services and guidance to support people with hearing loss who also have other long-term conditions; and make sure these are used.
- Make sure that resources are allocated in a cost-effective way by properly managing hearing loss in people with other long-term conditions. For example, the lack of resources allocated to hearing loss within the National Dementia Strategy for England should be reviewed.
- Increase social care funding to ensure people who are deaf or have hearing loss get the support they need.
 - In England, the eligibility threshold for social care should be lowered to the 'moderate' level.

NHS services and local authorities (Health and Social Care Trusts in Northern Ireland):

- Make sure the communication needs of people with hearing loss are identified, recorded and met.
- Provide information in accessible formats to make sure people with hearing loss, including BSL users, understand information on health, social services and social care. This includes health promotion campaigns.
- Provide a range of contact methods, hearing loops and communication support such as BSL interpreters, so people with hearing loss can participate fully in decisions about their treatment.
- Provide training for staff on accessibility issues for people with hearing loss.
- Take into account hearing loss and deafness when providing diagnosis, management and care for people who also have other long-term conditions, including mental health problems, dementia, learning disabilities, sight loss, cardiovascular disease and diabetes.
- Consider communication needs when commissioning social care services, particularly for BSL users, and when allocating funding for personal budgets.

Health and social care inspectorates should:

- Enforce accessible health and social care standards and review the experience of people with hearing loss when they inspect social care settings.
 - In England, the Care Quality Commission (CQC) should carry out thematic inspections and continue to train its inspectors in the needs of people with hearing loss; and they should develop a full quality standard for addressing hearing loss in care homes.

Action on Hearing Loss will:

- Work with the NHS and local authorities (Health and Social Care Trusts in Northern Ireland) to make health and social care services more accessible for people with hearing loss.
- Raise awareness of the standards for accessible health and social care and provide information and guidance so that people with hearing loss know what they should expect from health and social care services – and what action they can take if these expectations aren't met.
- Work with other leading charities, as part of the Care and Support Alliance, to campaign for a properly funded social care system that gives people with hearing loss the support they need.
- Support local authorities (Health and Social Care Trusts in Northern Ireland) and care providers to assess needs and improve the provision of services.
- Expand and promote our own specialised services for BSL users, which provide a gold standard for others to follow.

Education and employment

The UK Government should:

- Develop and implement a plan to meet its commitment to halve the disability employment gap, including for people with deafness, tinnitus and hearing loss.
- Develop and deliver plans to support an ageing workforce and the increasing number of people with age-related hearing loss, including ensuring employment support is accessible for people with deafness and hearing loss.
- Ensure that people who are looking for work are able to access adequate support from providers who understand hearing loss. This should include access to personalised, specialist support, commissioned locally, where needed.
- Evaluate the success of its 'Disability Confident' initiative, including its impact on employer attitudes.
- Make sure the Access to Work scheme provides sufficient support for employees with hearing loss.
- Monitor the introduction of the Access to Work award limit, to ensure it does not have a detrimental impact on the employment opportunities of deaf people.
- Monitor provision of teachers of the deaf.

Employers should:

- Become familiar with the information and resources available to people with hearing loss so they can be proactive in properly supporting employees who tell them that they have hearing loss.
- Develop and deliver plans to support the increasing number of employees with age-related hearing loss.

Action on Hearing Loss will:

- Launch a campaign to improve employer attitudes towards employees with deafness, tinnitus and hearing loss.
- Work with the Disability Charities Consortium to ensure the UK Government develops and delivers a plan to meet its commitment to halve the disability employment gap, and ensure that progress is regularly monitored.
- Provide information and guidance, so that people with hearing loss know what they should expect when they are seeking to develop their skills, enter the workforce or develop their careers – and what action they can take if these expectations aren't met.

Television and video on demand

The UK Government should:

- Extend legislation to require subtitles on television programmes, regardless of where and how they are delivered.

Ofcom should:

- Review quotas for subtitling on traditional television.
- Continue to monitor the quality of live subtitles.

The television and video-on-demand industry should:

- Increase the amount of subtitles for on-demand and other online content.
- Increase the amount of subtitles provided on linear TV, particularly for new and smaller channels.
- Reduce the unnecessary use of live subtitles and invest in improvements for live subtitling.
- Investigate technology solutions to reduce the impact of background noise on television.
- Broadcasters in Wales need to ensure that subtitles are available to both Welsh and English-speaking people who are deaf or have hearing loss.

Action on hearing loss will:

- Continue to work with government and the television and video-on-demand industry to improve the availability and quality of subtitles.

Appendix

Hearing loss prevalence estimates

These estimates of people with all levels of hearing loss and deafness are based on the most robust and best available data for prevalence at each age group (Davis, 1995), updated with Office for National Statistics (ONS) population estimates for 2014 (ONS 2015a), and rounded to the nearest 500.

Table 1. People with hearing loss – by age and area

Age band	UK	England	Northern Ireland	Scotland	Wales
17-29	188,000	158,000	5,500	15,500	9,000
30-39	234,000	199,000	6,500	18,500	10,000
40-49	743,000	625,500	21,000	62,500	34,000
50-59	1,569,000	1,305,000	44,500	142,500	77,000
60-69	2,524,000	2,101,500	65,000	221,500	135,500
70-79	2,879,000	2,395,500	75,500	251,000	157,000
80+	2,887,000	2,434,500	68,500	232,000	152,000
All ages ¹³	11,043,000	9,235,000	287,500	945,000	575,500

Table 2. People who need hearing aids

Age band	UK	England	Northern Ireland	Scotland	Wales
17-29	44,000	37,000	1,500	3,500	2,000
30-39	117,000	99,500	3,500	9,000	5,000
40-49	362,500	305,000	10,500	30,500	16,500
50-59	647,500	538,500	18,500	59,000	32,000
60-69	1,080,500	899,500	28,000	95,000	58,000
70-79	1,909,500	1,589,000	50,000	166,500	104,000
80+	2,518,500	2,124,000	59,500	202,500	132,500
All ages ¹³	6,699,500	5,609,000	171,500	567,500	351,000

Table 3. People with severe/profound hearing loss

Age band	UK	England	Northern Ireland	Scotland	Wales
17-29	11,000	9,500	500	1,000	500
30-39	8,500	7,000	0	500	500
40-49	27,000	23,000	1,000	2,500	1,000
50-59	58,000	48,500	1,500	5,500	3,000
60-69	125,500	104,500	3,000	11,000	6,500
70-79	157,500	131,000	4,000	13,500	8,500
80+	522,000	440,500	12,500	42,000	27,500
All ages ¹³	910,000	763,500	22,500	76,000	48,000

¹³ This estimate includes those under the age of 17

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