CONSULTATION QUESTIONS

1. The strategy outlines a care pathway (page 10).

(a) If you are a service user and/or carer, please tell us what difference you believe the implementation of the pathway will make to the services you experience.

(b) How can we best ensure that services and support meet your needs?

(c) If you are a care provider, what changes will you need to make to implement the pathway?

(d) How will you make these changes?

2. The strategy identifies key factors that need to be in place to ensure the pathway is successful (Page 11 para 6.7).

(a) Which of the key factors are most important for a successful pathway?

- Ensuring referral routes are clear to those undertaking diagnosis is vital to producing a successful pathway for people with hearing loss.

  Early diagnosis of hearing loss can significantly achieve a better quality of life for people who are deaf or hard of hearing and reduce the risk of negative impacts such as social isolation and mental illness. Diagnosis of hearing loss in adults, however, is currently opportunistic and ad hoc – on average, there is a 10-year delay in people seeking help from the point that they first notice difficulty hearing (Davis et al, 2007). Stigma of hearing loss is a key factor in this delay as many people are worried that they will be viewed as being old, less able and treated differently (RNID, *Hidden Crisis*, 2009 and a Mori poll, 2005). Spouses / partners, family members or carers can have a key role to play in spotting a person has a hearing loss and encouraging them to get their hearing checked. They can ensure positive outcomes by supporting the person with hearing loss to persevere with their hearing aids if they are experiencing initial difficulties.

  Evidence suggests that GPs also contribute to the delay as they fail to refer 45% of people reporting hearing problems for interventions such as referrals for a hearing test or hearing aids (Davis et al, 2007). It is clear that GPs need to become more aware about how hearing aids and other support such as assistive equipment and lipreading classes can substantially help the rehabilitation of patients with age-related hearing loss. By encouraging people experiencing difficulty hearing to get their hearing tested, GPs can make a huge impact by reducing the risk of their patient exacerbating other long-term conditions, such as dementia, or requiring further, more costly treatments.

  Providing clear, accessible information about the full range of available support is crucial to enable individuals to make informed choices about how they would like to manage their hearing loss. All the support options should be clearly explained at the point of diagnosis so that people are aware about the benefits of hearing aids, assistive technology, learning to lipread as well as support services and befriending groups.

  Action on Hearing Loss supports the implementation of a full audiology pathway as outlined in the national Audiology standards. This should include rehabilitation and could be achieved by implementing multidisciplinary working. The Scottish Government has supported this model by funding the Lipreading Strategy Group, chaired by the Director of Action on Hearing Loss Scotland. Scotland is recognised as leading the way in the UK with this work. This project has already delivered training tutors to support this important aspect of the rehabilitation pathway. Many more lipreading tutors will need to be trained to meet future demand and consideration needs to be given about how a sufficient number of lipreading classes to serve people with hearing loss in every community across Scotland will be funded. Action on Hearing Loss Scotland would also like to see better joined-up working between audiology departments and lipreading classes in each health board area.

- There is currently a substantial gap in data collection at diagnosis of hearing loss. Action on Hearing Loss supports the implementation of a standard data set, to include individual communication support needs, being shared across all agencies that support people who are deaf or hard of hearing to ensure a single planned pathway depending on individual need. Action on Hearing Loss Scotland believes that collating such details are essential in order to map the types of hearing loss being diagnosed across the country, the profiles of people who are most likely to take action to address their hearing loss and to develop and accurately plan services to support future need. This approach would support the requirement for 'reasonable adjustments' as outlined by the Equality Act 2010.

  Our research (RNID, *A Simple Cure*, 2006) has shown that:

  - More than one in every four patients (28%) with hearing loss have difficulty getting an appointment with their GP because of communication difficulties.

  - More than one in every three patients (35%) who are deaf or have hearing loss have experienced difficulty communicating with their GP and the same amount have been left unclear about their diagnosis after visiting their GP.

  - Almost a quarter (24%) have missed an appointment because of poor communication, including not being able to hear staff calling out their name.

  The failure to record information about hearing loss in medical records often means patients who are deaf or hard of hearing need to continually alert reception staff or health professionals about their hearing loss and individual communication needs each time they visit. This can be especially problematic for people who communicate using British Sign Language (BSL) and, because of the shortage of qualified interpreters, need to book communication support well in advance of medical appointments. All interpreters booked by statutory services should be registered with the Scottish Association of Sign Language Interpreters (SASLI) or the National Register of Communication Professionals (NRCPD) to ensure they are adequately qualified to interpret in a medical setting.

  There is also a requirement that other types of essential communication support meeting individual needs – such as lipspeakers, notetakers, deafblind interpreters or speech to text reporters (there are currently no trained palantypists working in Scotland) – should be provided when requested by people who are deaf or hard of hearing.

  Fully working induction loops (i.e. switched on, are operating well and staff know how to use), should also be installed as they can be vital for hearing aid wearers to follow conversations. There are many other small, inexpensive changes (e.g. altering seating arrangements and ensuring areas are well-lit to assist lipreading) which can be made to ensure healthcare settings are accessible for people who are deaf or hard of hearing (NHS Greater Glasgow and Clyde Guidelines for Sensory Impairment, January 2011).

GP surgeries, hospitals and other health or social care services can also be inaccessible for people who are deaf or hard of hearing when initially trying to arrange an appointment if they are required to communicate by telephone. Other forms of communication methods such as textphones, text relay, email, SMS or instant messaging should be available for people who are not able or comfortable using telephones.

- Crucial early intervention can be achieved by GPs and community nurses integrating hearing checks into routine health assessments – particularly those targeting older people.

  Residential, nursing or care homes and social work services should also have clear procedures in place to assess, record and manage people's hearing loss and include individual needs in personal care plans. This is particularly important to effectively support older people with hearing loss as their carer may mistake the symptoms of hearing loss as being a sign of dementia, and vice versa. Better management of hearing loss for people who have severe dementia in their community can ensure they do not need to enter costly residential care.

  Action on Hearing Loss Scotland supports person-centred solutions for people with sensory loss and an expansion of 'one stop services'. Our research shows that just 10% of respondents with hearing loss were told about support – such as assistive equipment that would enable them to live safely and independently – that they are entitled to through social services (RNID Scotland, *Hear me out: Audiology services in Scotland – services provided, patients' experience and needs*, 2011). People with hearing loss want access to 'one stop shops' where they can get information about social services, demonstrations of equipment as well as access to lipreading classes and support groups.

  Action on Hearing Loss Scotland currently runs joint sensory services in partnership with RNIB Scotland, local authorities and health boards in Ayrshire and Arran, Borders, Glasgow and Tayside. These joint sensory services are ensuring that people with sensory loss receive practical help and technology / products which improve everyday life, as well as sign-posting to other supportive services. Similar projects based on this model would benefit many other people with sensory loss across the country.

- Action on Hearing Loss Scotland supports a national hearing screening programme being introduced for adults. There are currently 340,000 people in Scotland who could benefit from hearing aids but don't have them. Cost benefit analysis shows that the benefits of hearing screening for older people clearly outweigh the costs. At a cost of £255m over 10 years, hearing screening for people over-65s could save £2bn on treatment – representing a benefit ratio of more than eight to one (RNID and London Economics, 2010).

  There could be opportunities for hearing screening to be implemented by non-specialist staff in very low cost models. For example, community nurses or care home staff could direct people to Action on Hearing Loss's free online hearing check (www.actiononhearingloss.org.uk/check) which can be used in any location that has Internet access or on an Android tablet which can be used anywhere with access to a mobile phone network.

- Action on Hearing Loss Scotland agrees that a single point of access and recording of information related to a person's sensory loss would reduce duplication or information gaps across health, social care and council departments and provide a fuller picture of the potential need for several interventions in each individual's care pathway.

- Action on Hearing Scotland agrees that local sensory impairment care pathways should be designed to meet local demands for rehabilitation services and be focused on implementing an outcomes based approach.

  People across Scotland currently have less opportunity to access adult hearing services on the high street in comparison to eye care services. Action on Hearing Loss Scotland would like to see people with hearing loss given equal opportunity to access life-changing hearing services in town centres and major footfall venues. NHS audiology is currently housed primarily in hospital settings and consideration should be given to following the optometry model of community provision similar to the Forth Valley Sensory Centre model. This would not only provide community access and make audiology services more accessible, but would also help tackle the issue of hearing loss being a hidden disability. People with diagnosed hearing loss – particularly those who are older or have other long-term conditions – would greatly benefit from being able to access audiology services closer to their homes.

  Action on Hearing Loss Scotland's trained 'Hear to Help' volunteers, many of whom have hearing loss themselves, deliver basic hearing aid maintenance and support in community venues across Ayrshire and Arran, Borders, Glasgow and Tayside. Community-based projects delivered on the 'Hear to Help' model not only increase opportunities for people to more easily access hearing aid support but also benefits the local NHS service by significantly reducing the demand for further audiology specialist support when people experience initial difficulties adjusting to wearing a hearing aid. Such services are especially valued by people with hearing loss living in rural, remote locations which are furthest from audiology departments and don't benefit from the same level of public transport services that are found in urban areas.

  Securing employment, training or education opportunities can be extremely challenging for people who are deaf or hard of hearing, as they continue to be disadvantaged and not supported to reach their full potential. Research in Glasgow found that 100% of responding people who are deaf or hard of hearing said they faced difficulties finding a job (Deaf Connections, 2007). It is important that people who are deaf or hard of hearing and significantly far from the job market are adequately supported in to work.

  Through our 'On the Move' project in central Scotland, funded by the Big Lottery Fund, Action on Hearing Loss Scotland supports 115 people aged between 16-25 who are deaf or hard of hearing to develop their life skills and take up work experience or volunteering opportunities as well as move in to full-time employment, training or education placements. Research shows that, between 2005 and 2011, S4 deaf pupils attained an average tariff score of 137, which is 38 points lower than the average for all S4 pupils, and the gap widens at the general and credit stages (University of Edinburgh, *Deaf Achievement Scotland*, 2012). Since 'On the Move' was established in 2009, more than 70% of participants have progressed to a positive destination.

Similar projects based on this model around the country would support many other young people with hearing loss to get closer to fulfilling their potential. A major concern remains, however, about the lack of support in to work for adult job-seekers who are deaf.

There are also unnecessary barriers facing employed people who are deaf or hard of hearing remaining in employment. Our research found that more than one in three (36%) of 4,000 respondents said they took early retirement and one in seven (14%) changed jobs because of their hearing loss (Action on Hearing Loss, *Unlimited Potential?*, 2011). The Access to Work (AtW) scheme supports employers by helping fund adjustments needed to enable disabled people to work, but our research found a general lack of awareness about Access to Work amongst both employees with hearing loss and their employers. The Federation of Small Businesses (FSB) amongst others have said that "Access to Work is the best kept secret in the DWP" (Work and Pensions Committee – Third Report, House of Commons, 2009). The Department of Work and Pensions (DWP) has a vital role in raising awareness of Access to Work funding and employers' legal responsibilities to ensure that people with hearing loss are fully supported to stay in work and gain the same opportunities as other staff to fulfil their career potential.

- Action on Hearing Loss Scotland would like to see statutory agencies work towards achieving a consistent approach in delivering equal access to support services for people with hearing loss living across the country.

- Action on Hearing Loss Scotland believes that all frontline health and social care professionals across the country should receive mandatory deaf / sensory loss awareness training as part of their undergraduate training and, in the cases of reception / office staff, as part of their employer's induction programme. Deaf awareness training will help remove the unnecessary and frustrating communication barriers often experienced by people with hearing loss when accessing services.

(b) Which are the most challenging to put in place?

A national hearing screening programme for adults in Scotland could result in an additional 340,000 people across the country benefiting from hearing aids. Audiology departments are currently resourced with the aim of meeting the Scottish Government's 12 weeks treatment time guarantee (TTG), therefore consideration will need to be given as to how this substantial potential additional demand for audiology services will be met.

(c) Do you think that any key factors have been missed?

3. The strategy identifies areas for action that should be addressed going forward (Page 13-16)

(a) Which of the areas for action will be the most challenging to implement?

(b) Which of the areas for action will make the biggest difference and why?

Recommendation 3

Action on Hearing Loss Scotland agrees that all frontline health and social care professionals (especially those working on older people's services) should receive mandatory deaf / sensory loss awareness training as part of their undergraduate training and, in the cases of reception / office staff, as part of their employer's induction programme.

Research shows that GPs can be the first significant barrier when people want to address their hearing loss so there should be a positive impact in terms of increased referral rates to audiology departments if doctors are more aware about how hearing aids can substantially help the rehabilitation of older patients who are deaf or hard of hearing.

(c) Are there any other areas for action that you would like to see included within the strategy?

4. Please comment on the current provision of sensory impairment services as either a service provider or service user. If you have any experience of sensory impairment services, please let us know what you think of them: this should include any experience of one-stop shops.

5. What difference will the implementation of the strategy make to your life?

6. Does this strategy properly reflect the current climate and developments in policy and practice for children and young people particularly in relation to the Getting it Right for Every Child approach and the Doran Review?

7. Do you have anything you wish to add to the Sensory Impairment Strategy or any other general comments that have not been covered by the questions?