

Health and Social Care Alliance Scotland (the ALLIANCE)

Dementia Assessments for People with Deafness, Deafblindness or Visual Impairment

A report for the Scottish Parliament's Cross-party Group on Deafness

April 2025



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HEALTH AND SOCIAL CARE
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people at the centre

Foreword

As an MSP, the opportunity to take part and immerse yourself in topics you wouldn't have originally thought about is a perk of the position that I particularly enjoy.

One such enjoyable perk is being the Deputy Convenor of the Cross-party Group on Deafness which has helped me to understand issues affecting people who are Deaf and Deafblind, and be involved in finding solutions. So imagine my delight at being asked to Chair the sensory care and dementia working group.

On a human level, with growing numbers of people living with both dementia and Deafness, Deafblindness or Visual Impairment, this is a topic that needs attention and action.

Too many people are facing undiagnosed Deafness, Deafblindness or Visual Impairment, especially older people. We know there are well documented links between sensory impairments and dementia so improving care pathways and support for people is fundamental.

Identifying Deafness, Deafblindness or Visual Impairment at the very beginning of a dementia assessment is essential. Proper understanding of people's sensory impairments and communication needs is important not only for people accessing dementia services - so they can access and receive information in a way suitable to them - but because the self-same communication barriers of Deafness, Deafblindness and Visual Impairment can be very similar to dementia symptoms, which could lead to misdiagnosis.

Just think what we could achieve with thorough sensory assessments.

I am excited to think that we are on the way to developing the first framework of sensory care standards for Scotland, which will support people who are living with both dementia and Deafness, Deafblindness or Visual Impairment. The need for joined-up thinking in this area has become more and more evident.

I am very proud of the work and engagement that has taken place to pull together and produce this excellent report and I thank all those that took part.

Roz McCall MSP, Deputy Convenor of the Cross-party Group on Deafness in the Scottish Parliament

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Introduction and background

This report contains findings and recommendations from research carried out by the Health and Social Care Alliance Scotland (the ALLIANCE) on behalf of the Scottish Parliament's Cross-party Group (CPG) on Deafness' sensory care and dementia working group. This working group is also supported by the Cross-party Group on Visual Impairment.

The working group is chaired by Roz McCall MSP, with secretariat provided by the ALLIANCE. Membership includes members of the CPG on Deafness, the CPG on Visual Impairment, and other experts with an interest in sensory care and dementia. This includes people with lived experience of dementia and sensory changes, Age Scotland, Sight Scotland, the ALLIANCE, the Care Inspectorate, Edinburgh Napier University, NHS Lothian, Queen Margaret University, and the University of Edinburgh.

The aim of the working group is to improve care pathways and provision of support for people with dementia who also experience Deafness, Deafblindness or Visual Impairment. It aims to develop the first framework of sensory care standards for Scotland. Sensory care in this context is defined as any type of care related to the senses which is necessary for a person's communication, access to information and mobility.

The framework of sensory care standards will centre around several core areas, one of which will be sensory assessment. Research shows that internationally, dementia care professionals and eye and hearing care professionals commonly do not work together to support people with dementia through a system of integrated care. This includes during the assessment of dementia:

“Hearing, vision, and dementia care professionals have historically worked independently, and therefore, there is limited sharing of information of relevance to clinical care across these healthcare disciplines.”¹

However, there are no studies on whether dementia care professionals, and eye and hearing care professionals work together in Scotland specifically, or whether sensory assessments feature as part of any dementia assessment pathway, or during post-diagnostic support. This report aims to fill that data gap, as the first stage of developing sensory care standards for Scotland.

Between August and October 2024, the ALLIANCE Scottish Sensory Hub carried out a small-scale research project exploring the practices of health and medical professionals who carry out memory/dementia assessments for people who are Deaf, Deafblind, or who have Visual Impairment, and the hearing care and eye care specialists who assess hearing and sight. The findings and recommendations will inform the assessment section of the sensory care and dementia working group's framework of sensory care standards.

A note about language

The ALLIANCE is committed to promoting human rights through using culturally responsive sensory language. This means adopting terminology which does not further discriminate against those individuals and communities who have been historically marginalised.

Sensory language is an evolving area, and while we use the terms Deafness, Deafblindness and Visual Impairment in this report to cover a spectrum including different language modalities (signed and spoken), we recognise this is not necessarily the language that people find acceptable or relevant to them.

At present, Scotland does not legally or formally recognise Deafblindness as a distinct condition and specialist disability. This is concerning because without a definition there can be significant inequality in access to education, employment, healthcare, and public and social services, negatively impacting on a person's cultural and emotional wellbeing. A short life working group of the CPG on Deafness, supported by Deafblind Scotland, have produced a Declaration that calls for the formal adoption of the Nordic definition of Deafblindness in Scotland. That definition is as follows:

“Deafblindness is a combined vision and hearing impairment of such severity that it is hard for the impaired senses to compensate for each other. Thus, deafblindness is a distinct condition. To varying degrees, deafblindness limits activities and restricts full participation in society. It affects social life, communication, access to information, orientation, and the ability to move around freely and safely. To help compensate for the combined vision and hearing impairment, the tactile sense becomes especially important.”²

Current research estimates more than 30,000 people in Scotland live with Deafblindness, and this number is set to rise in line with an aging population. Our use of the term throughout this report is in line with this proposed definition.

Prevalence of Deafness, Deafblindness and Visual Impairment in people with dementia

It is fundamental to any framework which aims to improve care pathways and provision of support for people with dementia who also experience Deafness, Deafblindness or Visual Impairment, that national prevalence data is available.

The Scottish Government’s 2014 See Hear Strategy contains a specific recommendation that data collection systems should be in place to identify individuals who are Deaf, Deafblind or who have a Visual Impairment. It also recommends that this data be accessible to health and social care providers and other agencies, as appropriate. The rationale for this recommendation is as follows:

“Reliable information is basic to understanding the prevalence of sensory impairment and then being able to monitor the reach of services, engage with service users and carers, identify and learn from best practice, and identify gaps and opportunities for service improvement. Currently there are no standard expectations in this regard.”³

Sensory prevalence data for people living with both dementia and Deafness, Deafblindness or Visual Impairment is vital for effective health and social care planning.⁴ Research shows that 70% of people living with dementia across the UK and Europe are Deaf and/or have a Visual Impairment.⁵

On 6 December 2024, the Scottish Government announced that work towards a refresh of the See Hear Strategy had ended in favour of focusing on areas where Deafness, Deafblindness and Visual Impairment was already mainstreamed.⁶ Examples given which support mainstreaming included the Scottish Government's Dementia Strategy.

In terms of data, the Dementia Strategy states that data collection will include, "people with a learning disability and neurodivergent people diagnosed and receiving dementia-specific support" and "protected characteristics breakdown" – there is no specific reference to people who are Deaf, Deafblind or who have a Visual Impairment.⁷ Scotland needs reliable data collection for people with dementia and Deafness, Deafblindness or Visual Impairment, to enable this information to be clearly integrated within the Dementia Strategy.

In Scotland specifically, sensory data is often not well defined or recorded through existing health and social care datasets, making prevalence rates difficult to report. These difficulties were discussed in a 2020 report *Deafness and Dementia: predicting the future in Scotland* which found that GP practices do not collect data on people with Deafness who access their services – though they do collect data on dementia.⁸ In addition, NHS Audiology departments do not collect data on the number of people with dementia who access their services. As a result of these limitations in national data, the *Deafness and Dementia* report used a new methodology to calculate projected regional prevalence figures for both dementia and acquired Deafness in Scotland up to the year 2038.

For adults whose first or preferred language is sign language, the British Deaf Association's (BDA) Deaf dementia toolkit describes consultation

with British Sign Language (BSL) users and their families. The BDA toolkit states that Deaf BSL users with dementia:

“Have a history of poor access to information; experience a lack of/limited access to resources in BSL; encounter services that have little understanding of the linguistic and cultural needs of Deaf people.”⁹

Scotland’s Census 2022 recently published data on the number of people using BSL. There were 20,840 people 60 years old and over who responded that they can use BSL; however, the number of people who are Deaf and consider sign to be their main language is likely to be substantially lower.¹⁰ There does not appear to be any data available on the number of BSL users living with dementia in Scotland. This data is important because while BSL users may not require hearing care services, monitoring of eye health and sight is essential to ensure optimal access to visual language, and to make sure accessible information on dementia care is available.

In 2022, Kösters and co-authors published a report on prevalence rates for people with dementia and Deafblindness in Scotland. Using a modelling technique involving population statistics similar to the study described above for Deafness and Dementia, the authors estimated that 2,951 people were living in Scotland with both dementia and Deafblindness.¹¹

For prevalence data for people with Visual Impairment, Sight Scotland stated in 2019 that, “there are around 12,500 people in Scotland living with dementia and sight loss today [...] in 2030 there will be around 15,000 people living with dementia and sight loss.”¹²

In care homes for older people, sensory prevalence rates are higher than those for people living in the community.¹³ The 2024 Scottish Care Home Census (SCHC) reported 63% of long stay older adults were living with dementia and only 11% and 8% were living with “hearing impairment” and Visual Impairment respectively.¹⁴ However, studies have shown care home prevalence of Deafness is 91%, and Visual

Impairment arising from age-related eye conditions is 64%.¹⁵ This vast disparity in statistics implies the methods the SCHC use to collect sensory data are not reliable when it comes to Deafness, Deafblindness, and Visual Impairment.

Scotland's research figures for care homes highlight a need for improved methods of data collection. It would also be welcome for data on "hearing impairment" to differentiate across the spectrum of Deafness to enable the number of BSL users to be documented, and for culturally appropriate language of Deafness to be adopted into SCHC reporting.

In summary, prevalence research indicates that for people living with dementia, there are many people who have co-existing Deafness, Deafblindness or Visual Impairment. Scotland does not reliably collect sensory data through health and social care datasets, and this is needed to inform effective health and social care planning. Understanding if or how sensory assessments are integrated into memory/dementia assessments highlights opportunities for improved data collection and reporting of prevalence figures. We intend for this evidence to inform a framework of sensory care standards.

The importance of sensory assessment in dementia diagnosis

There is growing evidence and public awareness of a connection between Deafness and Visual Impairment, and dementia. *The Lancet* medical journal first reported on acquired deafness in adulthood as the largest potentially modifiable risk factor for dementia in 2017.¹⁶ Their report in 2024 also added "untreated sight loss" to the list of potentially modifiable risk factors.¹⁷ Similarly, older adults with both Deafness and Visual Impairment, or Deafblindness, are also at significantly increased risk of cognitive decline.¹⁸

It is important to state that there is not yet any evidence that acquired Deafness or Visual Impairment directly causes dementia – so while there is an established association, this is not the same as causation. To promote ethical messaging to people receiving ear and hearing care services, professional hearing care bodies published a position

statement and practice guidance for professionals on correct interpretation of the evidence:

“Observational studies have shown that people with greater adult-onset hearing loss are likely to have greater cognitive decline. However, association is not causation. [...] This is not to deny the possibility that adult-onset hearing loss may cause dementia. This could occur due to reduced auditory input or lack of social stimulation (direct or indirect causes, respectively) but this has not been proven. [...] There is currently a lack of good quality evidence to settle this question.”¹⁹

Irrespective of whether Deafness, Deafblindness or Visual Impairment directly causes or influences cognitive changes, identification of any of these during the assessment of dementia is vital for two main reasons. Firstly, communication is a gateway to our human rights. Identifying Deafness, Deafblindness or Visual Impairment enables differentiated communication approaches, and for information to be delivered and received in an accessible format, to foster informed decision making and independence.

Secondly, Deafness, Deafblindness and Visual Impairment can cause communication barriers which present themselves in ways which mirror dementia symptoms. These include reduced comprehension, repeating questions, memory problems, and difficulties following conversations.²⁰ As Bruhn and Dammeyer state:

“An individual with dementia, who might not remember what he/she was recently told, or who does not recognize his/her visitors, may mistakenly be considered to be auditorily or visually impaired. By contrast, a person with DSL [Dual Sensory Loss], who has a restricted ability to access information and to participate in social interaction, may erroneously be suspected to be in cognitive decline.”²¹

The risks associated with not knowing a person is living with Deafness, Deafblindness or Visual Impairment are therefore that the severity of

dementia can be over-estimated, and Deafness, Deafblindness or Visual Impairment under-identified, or vice-versa. Inaccurate diagnosis means that support planning is unlikely to be appropriately tailored to the needs and rights of individuals.

Once Deafness, Deafblindness or Visual Impairment is identified, the choice of cognitive assessment by health and medical professionals should be determined by what is accessible for the person. Cognitive assessments which do not account for Deafness, Deafblindness or Visual Impairment can lead to incorrect conclusions about a person's cognitive abilities because tasks commonly rely on hearing and sight. The importance of sensory assessment prior to dementia assessment, and throughout post-diagnostic support, is aptly summarised by Pye and co-authors:

“Despite the high prevalence of concurrent sensory and cognitive impairment among older adults, commonly used tests of cognition consist mainly of test items presented through the visual or auditory modality. Accurate assessment of cognitive function is important for identification and diagnosis of dementia, differential diagnosis of cognitive versus sensory problems, facilitation of early intervention, and monitoring change in cognition over time.”²²

There is evidence that either sensory assessments are not part of cognitive assessment in the first instance, or even when Deafness, Deafblindness or Visual Impairment is identified, this is not taken into account during selection of cognitive assessments.²³ Where Deafness, Deafblindness or Visual Impairment, and dementia co-exist, it is important to distinguish between the two to enable appropriate assessment, management and support planning.²⁴

An example of the problems caused by unsuitable choices of cognitive assessments is described by Jorgensen and co-authors who investigated the effects of simulated Deafness in young adults using a commonly used screening test of cognition called the Mini-Mental State Examination (MMSE).²⁵ Even though participants were cognitively healthy, their scores falsely indicated a diagnosis of dementia. This

result was noted even for the 16% of subjects who performed the test under clinically defined mild levels of simulated Deafness.

Another widely used cognitive screening tool is the Montreal Cognitive Assessment (MoCA).²⁶ A recent systematic review and meta-analysis of the efficacy of the MoCA for participants with Deafness reported there is a significant risk of error in using this method to classify the severity of cognitive difficulties.²⁷ Similar conclusions were found through investigating both the MMSE and the MoCA in older adults with Deafness.²⁸ A full list of all dementia assessment tools mentioned in this report is available in Appendix F.

Bertone and co-authors performed a study by simulating blurred vision for non-verbal items of a cognitive assessment performed with young healthy adults. Results showed this modification significantly impacted participants' scores, highlighting the need for caution when interpreting results which rely on visual access to tasks if the pre-requisite level of visual acuity is not established.²⁹

Research has explored ways to overcome issues with cognitive assessments for people with Deafness and Visual Impairment, such as removing or substituting spoken items, providing amplification, and increasing the size of visual items.³⁰ However, such modifications must be validated for use with people with Deafness or Visual Impairment, and not compromise the integrity of the original assessment in meeting cognitive criteria:

“A cognitive test must have high sensitivity and specificity for identification of cognitive impairment and should measure multiple domains of cognition so as to be sensitive to different patterns of impairment associated with different subtypes of dementia.”³¹

There are versions of the MoCA which have been adapted for use with people with acquired Deafness, however the only version which has been fully validated and developed in collaboration with copyright holders MoCA Cognition is the MoCA-H by Dawes and co-authors. This is available in different languages including English and is free to

access.³² It should be noted that this assessment relies on reading and writing skills and is not suitable for Deaf sign language users.

For people with Visual Impairment, the MoCA Blind is also a validated assessment available free from MoCA Cognition. However, to make the tool accessible the items requiring visual perception have been removed. This means the integrity of the original MoCA assessment in covering different cognitive domains is impacted because, “this approach omits screening of some cognitive functions”.³³ A new version called the MoCA-VI which covers the required spectrum of cognitive domains and has been validated on people with Visual Impairment, is expected to be available for free on the MoCA Cognition website in the near future.³⁴

While access to validated cognitive assessments for spoken language users with Deafness is vital, so too is access for people whose first or preferred language is a sign language. Problems of assessment validity arise when cognitive tests validated on spoken communication are used for sign language users.³⁵

Atkinson and co-authors created the British Sign Language Cognitive Screening Test (BSL-CST) which is delivered entirely in video recorded BSL.³⁶ Assessment is therefore not dependent on BSL interpretation, or on the BSL user responding in written English; this is important as both factors can affect the accuracy of results. This validated test is now used in the first cognition/dementia assessment clinic in the UK for the Deaf community, though it is unclear if wider uptake has been adopted by health and medical professionals in Scotland (or the UK as a whole).³⁷

For adults with Deafblindness, there are challenges in developing cognitive assessments to separate sensory perception difficulties from those arising from memory or dementia.³⁸

Dumassais and co-authors recently conducted a scoping review of the strategies used for cognitive assessment for older people with Deafblindness. Only one study used a tactile assessment approach, responses were therefore not reliant on hearing or sight.³⁹ This Tactile

Test Battery (TTB) is not yet validated but does show promise for development into an available assessment tool in the future.

The main finding from this scoping review was that strategies for assessing cognition in older people with Deafblindness fell into five categories; the assistance of experts to interpret the results of any cognitive screening measures was the most commonly used approach. The other strategies included: modifying test scoring, removing items relying on hearing and/or sight, using communication strategies, and making changes to the assessment environment.

The only validated cognitive assessment currently available for people with congenital Deafblindness is the Tactile Working Memory Scale. However, this has not yet been validated for people with dementia, or for people with acquired Deafblindness.⁴⁰

Given the lack of validated cognitive assessments for people with Deafblindness, it is important to explore the approaches used by health and medical professionals in Scotland. This would identify areas of good practice and gaps in learning to ensure everyone has equal access to dementia diagnosis and support.

In summary, research shows that identifying Deafness, Deafblindness or Visual Impairment is key – both for accurate assessment of dementia, and for ensuring communication and information is accessible throughout a person’s diagnosis and post-diagnostic support.

The assessment of dementia in Scotland – sensory considerations

The Scottish Government published a new 10-year dementia strategy on 31 May 2023. One of the major differences the strategy aims to make is that:

“People are supported by a skilled and knowledgeable workforce that accesses the highest quality dementia specialist education and training and implements evidence-based, including trauma-informed, practice.”⁴¹

In relation to dementia diagnosis the strategy states:

“An inclusive, rights-based, accessible and timely diagnosis, with the option to have someone close present, is an important start to someone’s dementia experience. **This is particularly relevant for people with sensory loss, including hearing loss where use of British Sign Language (BSL) is required.**”⁴²

Sensory assessment for identifying Deafness, Deafblindness or Visual Impairment are vital for providing differentiated communication approaches and accessible information, and to enable professionals to select appropriate cognitive assessments. As such, it follows that a skilled and knowledgeable workforce is one which values the importance of sensory care, and where sensory care skills are integrated into dementia specialist education and training.

Although the link between acquired Deafness or Visual Impairment and dementia is well established, it is not known if or how health and medical professionals in Scotland incorporate sensory assessments into cognitive assessments, or the role of hearing care and eye care services in this process.

Reviewing resources for health and medical professionals, Healthcare Improvement Scotland’s SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia states that acquired Deafness is a potentially modifiable risk factor for dementia. However, it does not state that unidentified Deafness, Deafblindness or Visual Impairment in older people is common, and that sensory assessments are a requirement of good practice. The guideline also does not describe how Deafness, Deafblindness or Visual Impairment can impact the outcome of commonly used cognitive screening tests such as the standard versions of the Montreal Cognitive Assessment and Mini Mental State Examination.

The guideline does not discuss the assessment of dementia for sign language users, and the BSL Cognitive Screening Test is not included in the list of screening tools.⁴³ Given that this is the national clinical

guideline for Scotland, these omissions may indicate there are low levels of awareness of the importance of sensory needs across health and medical professionals involved in the assessment of dementia.

The Royal College of Psychiatrists' Quality Standards for Memory Services contains two references to sensory considerations:

“Standard 1: The service has access to a variety of assessment tools to meet the needs of the people using the service. *Guidance: Consider needs associated with language, learning disability, **sensory impairment, etc***”.⁴⁴

“Standard 24: The assessment includes a physical health review, which takes place as part of the initial assessment or as soon as is practically possible. The review includes but is not limited to [...] A **check of vision, hearing, mobility and falls**”.⁴⁵

While no guidance is given on memory/dementia assessment tools for Deafness, Deafblindness or Visual Impairment, or good practice methods to check vision and hearing, the document links these recommendations to the NICE guideline for dementia. This includes a section on assessment in non-specialist settings with the following reference to sensory investigations:

“1.2.6 Refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if: reversible causes of cognitive decline (including delirium, depression, **sensory impairment [such as sight or hearing loss]** or cognitive impairment from medicines associated with increased anticholinergic burden) **have been investigated** and dementia is still suspected.”⁴⁶

And on making services accessible:

“1.3.6 Service providers should design services to be accessible to as many people living with dementia as possible, including:

people with learning disabilities, **sensory impairment (such as sight or hearing loss)** or physical disabilities.”⁴⁷

The NICE guideline also highlights using caution around cognition scores for certain populations, including people who are Deaf, Deafblind or who have a Visual Impairment:

“1.5.7 When using assessment scales to determine the severity of Alzheimer's disease, healthcare professionals should take into account any physical, **sensory** or learning disabilities, **or communication difficulties** that could affect the results and make any adjustments they consider appropriate.”⁴⁸

“1.5.8 When assessing the severity of Alzheimer's disease and the need for treatment, healthcare professionals should not rely solely on cognition scores in circumstances in which it would be inappropriate to do so. These include **if the cognition score is not, or is not by itself, a clinically appropriate tool for assessing the severity of that patient's dementia** because of the patient's learning difficulties or other disabilities (**for example, sensory impairments**)”.⁴⁹

Across the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, the Royal College of Psychiatrists' Quality Standards, and the NICE guideline, there are gaps in detail on what is good practice for sensory assessment. There should be more information available about the types of checks and investigations which should be performed, and how often these should take place. This lack of guidance creates the likelihood of variance in approaches.

It is therefore important to explore the experiences of health and medical professionals who are involved in the assessment of dementia for people who are Deaf, Deafblind or who have a Visual Impairment, to highlight areas of good practice, as well as any gaps in knowledge and skills which would inform dementia workforce learning, in keeping with the aims of the Scottish Government's Dementia Strategy. These

findings will inform sensory assessment protocols for a framework of sensory care standards.

Methodology and participants

Methodology

This project took the form of four online surveys, each one targeted at a specific group of health and medical professionals in Scotland. These were:

- General Practitioners (GPs)
- Health and medical professionals who perform memory/dementia assessments (not GPs)
- NHS Audiology services for adults
- Eye care specialists.

The ALLIANCE Scottish Sensory Hub drafted proposed survey questions for each group which were revised and finalised following discussion with sensory care and dementia working group members. Each survey contained a small combination of multiple choice and open question formats and was purposefully designed to be short and quick to complete, to encourage engagement from busy health and medical professionals.

The ALLIANCE Scottish Sensory Hub carried out a Data Protection Impact Assessment for the online surveys to ensure legal compliance and ethical process. Survey respondents were required to give consent by indicating they had read the privacy statement – a mandatory survey question. Each survey was created online using SmartSurvey and the data collection period spanned from August to October 2024.

Survey distribution

Approaches to survey distribution were customised for each group of professionals as described below.

General Practitioners

Distribution lists for GPs were collated in different ways. Liaising firstly with existing ALLIANCE networks made it possible to reach a subset of GPs working in NHS Greater Glasgow and Clyde through the

Community Links Workers (CLW) programme. CLWs currently work within 80 GP practices in Glasgow and 16 GP practices in West Dunbartonshire.⁵⁰ Agreement was reached with the CLW Manager at the ALLIANCE to distribute the survey for GPs to CLWs, with a request to distribute the survey internally to GP contacts.

In general, individual GP email addresses are not available in the public domain, but individual GP practices usually do have publicly available contact details. To our knowledge, there is not an accessible database with contact details for all GP practices in Scotland, though a list of surgeries for each Health Board is available.

Given that creating a list would be a very time-consuming process, it was decided to focus on collecting data which would be representative of the geographical diversity of Scotland to take in urban, rural and remote areas. As a result, three Health Boards were selected (NHS Dumfries and Galloway, NHS Grampian, and NHS Western Isles) and a manual search of each GP practice website was performed to create a list of email addresses in these areas.

At the same time, a search was made for any recent Freedom of Information requests for GP practices. This found that lists of GP practices had been published for NHS Ayrshire and Arran, NHS Forth Valley, NHS Fife, NHS Highland, NHS Tayside, and NHS Greater Glasgow and Clyde, enabling wider distribution of the survey.⁵¹ In total, the survey for GPs was distributed to 623 GP practices across nine Health Board areas in Scotland.

Health and medical professionals (not GPs)

Brain Health Scotland together with Alzheimer Scotland conducted the Scottish Cognitive Clinics Census in 2021,⁵² and Healthcare Improvement Scotland performed a survey of dementia diagnosis clinics in 2023.⁵³ These reports showed there is no standard structure for dementia diagnosis clinics in Scotland, and there is a wide range of health and medical professionals involved. These include nurses, psychiatrists, psychologists and Allied Health Professionals (AHPs).

Healthcare Improvement Scotland agreed to distribute the survey internally across their national network of around 90 Post-Diagnostic Support (PDS) leads, and also to members of the Royal College of Psychiatry Scotland.

The National Allied Health Professions Consultant at Alzheimer Scotland agreed to share the survey internally across AHP networks. They also sent on the survey for wider distribution by Alzheimer Scotland to other professionals involved in the assessment of dementia. These combined approaches meant that the range of health and medical professionals was covered through different distribution networks.

NHS Audiology services for adults

Email addresses for NHS Audiology services are available online in the public domain and in the NHS Scotland Audiology Service Directory.⁵⁴ This directory also contains email addresses for Heads of Service for each of the 14 Health Boards. These contact details were used to distribute the survey to all NHS Audiology services for adults in Scotland.

The survey was limited to the NHS and did not include private providers of hearing care in Scotland due to difficulties obtaining a distribution list. After the data collection period we discovered that as of 25 November 2024, there were 263 Hearing Aid Dispensers registered with the Health and Care Professions Council (HCPC) as working in Scotland.⁵⁵ The British Society of Hearing Aid Audiologists (BSHAA) are also a professional body for independent hearing aid dispensers who hold contact details for hearing care specialists in Scotland.⁵⁶

It should be noted that the professional scope of practice for an audiologist is different from that of a private Hearing Aid Dispenser. Audiologists are trained to a BSc degree level or equivalent and this training includes advanced diagnostic assessment and hearing rehabilitation beyond hearing aid dispensing. In comparison, Hearing Aid Dispensers complete a Foundation level degree, and their scope of practice is narrower. They focus primarily on dispensing hearing aids. This means they may not be trained in, nor have access to, the additional diagnostic assessment tools needed to meet the needs of

people with dementia.⁵⁷ Onward referral from GPs or other health and medical professionals for a diagnostic hearing assessment for a person with dementia is most suited to an audiologist because this is within their professional scope of practice.

It is recommended that future research should explore further engagement with HCPC and BSHAA to identify private sector protocols and referral pathways for people living with dementia who are also living with Deafness or Deafblindness or Visual Impairment.

Eye care specialists

In Scotland, regular eye examinations are fully funded by the NHS and can be accessed through community optometry practices, also known as opticians. Community eye care specialists can refer people to NHS hospital eye services such as ophthalmology if required. As such, eye care specialists span both the public and private sectors.

To ensure the survey for eye care specialists was distributed to both sectors, contact was made with Optometry Scotland – the representative body for Optometrists and Dispensing Opticians in Scotland.⁵⁸ Optometry Scotland agreed to distribute the survey to over 370 members, as well as across their social media platforms which have a wider audience including other eye care specialists. Additionally, the lead for community optometry at Scottish Government also agreed to distribute the survey, including to hospital ophthalmology contacts. Visibility Scotland, who provide patient support services across NHS Lothian and NHS Greater Glasgow and Clyde also agreed to share and promote the survey through their networks.

Questions on care homes

Two of the surveys – for GPs and for other health and medical professionals – included a specific question about care homes. The rationale for this was because the prevalence of both dementia and Deafness, Deafblindness and Visual Impairment is high in care homes, and those professionals are directly involved in dementia diagnoses in those settings. However, there is evidence of inequalities in access to sensory care in this population.⁵⁹ A survey question on care homes was

included to better understand what processes are in place to meet the sensory needs of care home residents during the assessment of dementia and post-diagnostic support planning.

Number of survey responses

In total, we received 317 responses across all four surveys. The number of responses we received for each survey was as follows:

- 84 General Practitioners
- 108 health and medical professionals (not GPs)
- 113 eye care specialists
- 12 NHS Audiology services for adults.

All responses within the free text boxes of the surveys were combined for coding purposes and tracked against each survey. Over 493 quotes were included in the analysis. Each quote was then coded to link it to a keyword, and where appropriate one or more subcodes to provide more detail on the initial keyword.

When including quotes in this report, we have made minor edits to correct typographical errors where required. We have also made minor changes to some quotes to ensure anonymity. As such, some participant details (e.g. mention of specific locations) have been changed slightly to preserve anonymity, while maintaining the most important information. Where changes have been made to quotations those alterations are indicated via square brackets (e.g. “I’m not aware of any staff using this within [name of hospital]”).

About the participants – demographic data

Three of the surveys gathered some basic demographic information from respondents. Demographic data for these professionals was collected to identify any regional trends in approaches to dementia assessments, and the integration of sensory services in these pathways, and to also highlight areas not represented by the data to inform future research. These questions were not mandatory, and not all respondents shared demographic information.

The survey for NHS Audiology services for adults did not ask for demographic information for reasons of anonymity – there are 14 Health Boards in Scotland each with an Audiology service, and professionals from this small group could be more easily identified than the other three survey groups if geographical data was collected.

General Practitioners

The survey for GPs asked respondents what Health Board area/s in Scotland they work in. 79 out of 84 respondents (94%) answered this question. The results represent eight Health Board areas across Scotland. The most represented Health Board was NHS Greater Glasgow and Clyde (30 respondents), followed by NHS Highland (15 respondents) and NHS Grampian (15 respondents). Further details of specific response rates by Health Board are available in Appendix A.

Health and medical professionals who perform dementia assessments (not GPs)

The survey for health and medical professionals other than GPs asked respondents to state what area of healthcare, allied health, or healthcare sciences they work in. This question was required to capture the breadth of the dementia workforce across Scotland. 89 out of 108 (83%) respondents answered this question. Respondents span occupational therapy, physiotherapy, podiatry, orthopaedics, nursing, mental health, speech and language therapy, rehabilitation, dietetics, old age psychiatry, dementia support services, social work, and social care. Further details of specific roles and response rates are available in Appendix B.

This survey also asked respondents what Health Board area/s in Scotland they work in. 93 out of 108 (86%) answered this question. Results represent all Health Boards across Scotland with the exception of NHS Orkney. One survey respondent stated they work in the “private sector” but did not state the Health Board area/s they cover. Further details of specific response rates of these health and medical professionals by Health Board are available in Appendix C.

NHS Audiology services for adults

No demographic data was collected in the survey for NHS Audiology services for adults due to the risk of identifying respondents.

Eye care specialists

The survey for eye care specialists in Scotland asked respondents to state their eye care profession. All 113 (100%) respondents answered this question. The majority of respondents (83.2%) are optometrists. The remaining 16.8% of respondents span the following roles: ophthalmologist, ophthalmic nurse, dispensing optician, orthoptist, and optical practice owner. Further details of specific roles and response rates by Health Board are available in Appendix D.

The survey also asked respondents what Health Board area/s of Scotland they work in. All 113 (100%) respondents answered this question. Several selected more than one Health Board area, as individual eye care specialists work across different regions of Scotland. Results cover every Health Board area, with the most selected areas being NHS Lothian (22 respondents), NHS Grampian (21 respondents), and NHS Greater Glasgow and Clyde (20 respondents). A detailed breakdown of responses is available in Appendix E.

Health and medical professionals assessing dementia

This section first presents results from the survey for GPs, and then the survey for other medical and health professionals, on the assessment of dementia in people who are Deaf, Deafblind or who have a Visual Impairment.

General Practitioners

The survey for GPs was completed by 84 respondents, representing eight Health Boards across Scotland.

Assessment of hearing and sight

Respondents were first asked if they assessed hearing and sight as part of a memory/dementia assessment. 78 out of 84 (93%) GPs answered this question.

The most common responses were that hearing and/or sight are only assessed when Deafness, Deafblindness or Visual Impairment was suspected (34 out of 78 respondents, 44%), or that the assessment of hearing and sight is not part of a memory dementia assessment (25 out of 78, 32%). Five out of 78 respondents (6%) stated that both sight and hearing would be assessed, and two out of 78 GPs (3%) were unsure if a sensory assessment would be part of a memory/dementia assessment. No respondent selected the option, 'we assess everyone's sight, but not hearing' or 'we assess everyone's hearing, but not sight'.

Twelve out of 78 respondents (15%) selected 'other' and had the option to provide further details. Six GPs stated they did not formally measure visual acuity or hearing levels (e.g. using basic assessments used by eye and hearing care specialists, such as Snellen chart or audiometry) but would take any noticeable hearing and sight difficulties into account when assessing memory/dementia.

One response reported that there is a high prevalence of Deafness and Visual Impairment in older adults and as such, hearing and sight

assessments are included in any consultation with this population, including memory/dementia assessments.

Two responses stated that as part of a memory/dementia assessment, they would signpost people to arrange a hearing and/or sight assessment. One GP indicated that the decision to refer or signpost might vary depending on the person's age, taking into account that older people are more likely to experience Deafness, Deafblindness and Visual Impairment:

“When I'm sending a referral to old age psychiatry I would usually send for a hearing test and ask them to go to [the] optician also. Younger patients probably not so much”.

Summary

The results for the question on the assessment of hearing and sight as part of a memory/dementia assessment indicate variance in GP practices with respect to the integration of sensory assessments with dementia assessments. The majority of GPs (59 out of 78, 76%) either do not include a sensory assessment or only include one if Deafness, Deafblindness or Visual Impairment is suspected. Given the established overlap between the presentation of dementia symptoms and those of Deafness, Deafblindness or Visual Impairment, this approach could lead to dementia assessments overestimating cognitive changes and under-identifying sensory-related barriers to communication, or vice versa.

Sensory assessment approaches

After asking whether GPs assess hearing and sight as part of a memory/dementia assessment, survey respondents were then asked how they would establish whether someone is Deaf, Deafblind, and/or has a Visual Impairment before commencing the assessment for dementia and/or support planning. The rationale for this question was to ascertain if there are standard approaches to sensory assessment used by GPs across Scotland.

This question had an open text format and was answered by 69 out of 84 (82%) respondents. Answers ranged from short statements such as,

“I ask them” to more detailed descriptions containing more than one approach. The range of different approaches included:

- Observation
- Checking medical records
- Asking the person or communication partners
- Sensory assessment tools
- Signposting/referral to vision or hearing care services.

Each of these approaches are detailed below.

Observation

24 out of 69 GPs (35%) reported they would use observation as a method to establish whether a person had any Deafness and/or Visual Impairment. Some descriptions of observation were quite general such as, “just if noticed during preamble”, while others gave more specific examples. Observational evidence for Visual Impairment included the person’s awareness of their surroundings, gait or walking pattern, use of glasses, and any noticeable difficulties with reading or writing tasks. For Deafness, examples included observing how well a person engages and responds to questions delivered at a conversational level, and use of hearing aids. Responses included:

“We notice it when we ask questions and when asking to read something.”

“If patient can hear without difficulty during a consultation with or without the use of a hearing aid the assumption is their hearing is ok.”

“Are they wearing hearing aids/glasses?”

Nine respondents used the terms “obvious”, “evident” or “apparent” within their descriptions of how they would establish Deafness and/or Visual Impairment before commencing an assessment for dementia and/or support planning. This indicates that these respondents considered that Deafness, Deafblindness, or Visual Impairments would

be identified when it was easily observable during consultations.

Responses included:

“Obvious impairment with conversation. Obvious impairment with movement on entering room.”

“Judge in the consultation. If no apparent issue proceed as normal.”

“If a problem is evident during assessment, probe further from there”

Checking medical records

Ten out of 69 GPs (14%) reported they would establish whether a person had Deafness and/or Visual Impairment by checking for information in medical records. One response simply stated, “case notes”, while others described that to establish if a person had Deafness and/or Visual Impairment they would review medical records in addition to at least one other approach such as observation or asking the person. Representative responses included:

“Often sensory impairment is recorded in the case record.”

“Really go from notes.”

“Looking at records for known issues too.”

Asking the person or communication partners

Thirty-five out of 69 (51%) GPs stated they would establish whether a person is Deaf and/or has a Visual Impairment by asking the person directly, or by asking those accompanying the person to the appointment such as family, friends or support staff.

In a few cases, respondents indicated that asking about hearing and sight is included within standard history taking when assessing memory/dementia:

“Usually ask them, part of my history [taking]”

“As part of the history taking – ask if there are any difficulties and observe for any difficulties”

Several responses reported that asking the person about hearing and sight was not considered a standard part of the memory/dementia consultation. However, if the person or their family, friends or staff raised concerns, this would prompt further investigation:

“Patient disclosure of sight and hearing issues.”

“If the patient brings this to the GPs attention.”

“If they or someone else mention it.”

Depending on input from people who know the person well was frequently referred to in GPs’ responses as an approach to establishing Deafness, Deafblindness or Visual Impairment:

“Rely on patient or corroborative history from family”

“I would hope that they would attend with a relative or friend who would be able to help with the assessment.”

“Assessments usually conducted with a partner/relative present. If this is not the case, then I try to speak with someone who is close to the patient who can offer this information as background.”

Additionally, one GP reported that their dementia nurse was particularly skilled in asking about Deafness and Visual Impairment:

“By asking if they have any issues with either. Our dementia assessment nurse has good experience with this.”

Asking was not always reported as a suitable method for both Deafness and Visual Impairment. One respondent stated they would specifically

ask about Visual Impairment to establish if a person had difficulties with sight. However, they would not use this approach for identifying Deafness, instead relying on observing the person's ability to reply to verbal information:

“Hearing loss is assessed by their ability to respond to questions...ask wrt [with respect/regard to] vision.”

Another respondent also felt asking was a more effective method for establishing Visual Impairment than Deafness because, in their experience, people are more inclined to openly discuss difficulties with sight than hearing:

“Hearing is more difficult if the patient does not admit to the challenges they may be facing.”

Some respondents advised they would ask the person when they last had their sight and/or hearing assessed. One GP stated they would look for a specific timeframe of a year for a sight assessment – this is consistent with NHS eye care recommendations for adults aged 60 years and over in Scotland.⁶⁰ There was no similar timeframe reference stated for hearing assessments in which to qualify what would be considered “recent” or “up to date”. This might imply that national guidance is less clear or awareness is poorer for hearing care and requires consolidation. Representative responses included:

“Enquire up to date eye test and hearing/audiology test.”

“I try to establish whether they have had recent hearing and vision tests.”

“Ask patient to seek optician review if they've not had a vision/eye health check in 12 months.”

Sensory assessment tools

Eleven out of 69 GP respondents (16%) stated they would establish whether a person is Deaf and/or has a Visual Impairment through an

assessment. In six of these responses, general terms such as “clinical assessment” or “clinical examination” were used without any further information.

One response expressed surprise that questions on how GPs established Deafness and/or Visual Impairment were included in a survey when this was standard practice for memory/dementia assessments. However, they did not provide any additional information on what their assessment approach included:

“All of these matters are part of ordinary assessment of potentially dementing patients.”

It should be noted in the quotation above that “potentially dementing patients” is the term used by the respondent and does not reflect the language used by the Cross-party working group on sensory care and dementia or the Scottish Government’s Dementia Strategy. This comment was in contrast to another GP respondent who acknowledged establishing Deafness, Deafblindness or Visual Impairment was challenging due to a lack of access to formal assessment tools:

“It is very difficult, I try to establish whether they have had recent hearing and vision tests otherwise it is based on a clinical examination without any ability to perform objective testing.”

Overall, we found broad differences in views and experiences among the General Practitioner community in Scotland on sensory assessment and dementia assessment.

Across the remaining four responses, two included performing an ear examination to check for wax and ear canal health, and two responses included performing a whisper test if concerns were raised about hearing either by the person or a familiar communication partner, or if the GP observed difficulties.⁶¹ One response included using tuning fork tests.⁶²

For establishing Visual Impairment, two responses included using a Snellen test to assess visual acuity,⁶³ and one response advised they would assess gait or walking pattern and perform an eye examination:

“If possible reduced hearing I would examine the ears to look for wax etc and do Rinne and Weber [tuning fork] test. If possible sight problems this is assessed by gait, awareness of surroundings. I would use an ophthalmoscope to check eyes.”

“Doing a whisper hearing test and using an eye chart for vision.”

Whisper tests and tuning fork tests are screening tools for Deafness. While both are listed in the recently published Royal College of General Practitioners Deafness and hearing loss toolkit, it also references the recommendation stated in the NICE guideline for hearing loss in adults which does not include either of these screening tools.⁶⁴ Instead, the NICE guideline advises for ear canals to be examined, wax removed, any acute infections treated, and then a referral made to audiology services for further assessment.

In addition, the NICE guideline provides specific guidance for adults with suspected or diagnosed dementia because this commonly co-exists with Deafness. This includes guidance on the frequency of hearing assessments:

“1.1.8: Consider referring adults with diagnosed or suspected dementia or mild cognitive impairment to an audiology service for a hearing assessment because hearing loss may be a comorbid condition.

1.1.9: Consider referring adults with diagnosed dementia or mild cognitive impairment to an audiology service for a hearing assessment every 2 years if they have not previously been diagnosed with hearing loss.”⁶⁵

With respect to tuning fork tests, the British Society of Audiology recommended procedures cautions that such tests “are particularly

subjective and response bias must be accounted for when determining their validity”.⁶⁶ In addition, tuning forks only assess the ability to detect a single low frequency sound meaning it is not a suitable screening tool for the majority of people with age-related Deafness, which is commonly associated with a reduction in high frequency sounds. A review of hearing screening for older adults living with dementia excluded tuning fork tests as suitable for this population.⁶⁷

For the whisper test, a systematic review highlighted concerns over the lack of standardisation. This was particularly with older people and the choice of letters and numbers to whisper to the person in order to cover an appropriate range of frequencies in which to identify reduced hearing sensitivity:

“In most Western countries, national health guidelines encourage general practitioners to screen elderly people for hearing loss. The whispered voice test is one test recommended for this screening, yet it has not been adequately evaluated in primary care settings.”⁶⁸

The review advised that more research is required with GPs, indicating that following NICE guidelines is more likely to lead to better outcomes for people with both Deafness and dementia.

Signposting/referral to vision or hearing care services

Thirteen out of 69 respondents (19%) described signposting or referring to vision or hearing care services for a diagnostic assessment as an approach to establishing whether a person had Deafness and/or Visual Impairment before commencing with a memory/dementia assessment.

Across responses, there was variation in how this decision was made. As described above, some respondents reported they would ask when the last sight and hearing assessment had taken place to determine if signposting or referral for a reassessment was required. In other cases, signposting or referrals would be indicated if sensory concerns were raised by the person or someone who knew the person well, or if the GP

had judged from observations based on professional expertise that the person had or was likely to acquire Deafness and/or Visual Impairment.

Notably, signposting to services was more commonly associated with sight assessments, and the terms “refer” or “referral” with hearing assessments. This pattern is likely connected to differences in access whereby private high street opticians are funded by the NHS to provide primary care eye examinations free of charge, and can make a direct referral to secondary care NHS Ophthalmology for management of eye conditions, if required.⁶⁹ For hearing care, accessing NHS funded audiology services requires the GP to make a referral. Alternatively, private hearing care providers can be accessed on the high street although these services may charge a fee.⁷⁰

“If carer/relative reports the patient may have hearing loss, I will refer them for audiology assessment.”

“Refer to optician for eye test if not been recently, refer to audiology for hearing test.”

“Direct questioning then referral to optician and/or audiology.”

Two out of the 13 GPs who included signposting or referral to vision or hearing services indicated that this was a standard part of their memory/dementia assessment framework. Both also included references to providers of ear and hearing care with one stating that a private hearing assessment is the only practical option available for signposting due to excessive NHS audiology waiting times which would delay access to results:

“Hearing test – either NHS or private depending on patient circumstances. Optician review and optimisation of vision.”

“Has to be private as such long waits for NHS.”

Concerns over NHS audiology waiting times were also raised by other respondents on the topic of referrals, highlighting that long waits for

hearing assessment results would delay progressing a person's memory/dementia assessment, diagnosis and post-diagnostic support. This implies that at present, NHS audiology services have a less progressive delivery model than eye care services by not being sufficiently accessible within memory/dementia care pathways. As such, it is difficult to achieve the aims of the Scottish Government's Dementia Strategy in achieving "accessible and timely diagnosis" without addressing this barrier.⁷¹ Two respondents reflected on these concerns:

"If family or examination highlighted concerns [I] would arrange referral to audiology or advise optician. I wouldn't wait for the result as audiometry waiting list is very long."

"Hearing assessments should be encouraged as standard, provided just as sight checks are provided. If [Deafness] is identified, the patient will have the capacity to learn how to use [hearing aids] before cognitive impairment sets in. Private hearing clinics are excellent by comparison. Everything can be done at the one appointment [...] and they are local/easy to access."

On the topic of NHS versus private hearing care services, there was no reference made to the scope of practice of audiologists compared with Hearing Aid Dispensers with regards to the assessment of hearing for people with dementia. This may indicate GPs are not well informed of the differences, and this has implications for making onward referrals to professionals with the most appropriate scope of practice to ensure people with dementia can access the most appropriate hearing care services.

Summary

GPs reported using a range of approaches to establish whether someone has Deafness and/or Visual Impairment before commencing the assessment for dementia and/or support planning. The approaches included: observation, checking medical records, asking the person or their communication partners, using sensory assessment tools, and signposting/referring to vision or hearing care services for a diagnostic assessment.

There was variance in use of these approaches between using one in isolation and combining one or more to build up evidence to support identification of Deafness, Deafblindness or Visual Impairment. Relying on professional observation or asking the person or communication partners may be useful when communication difficulties present an obvious barrier or source of distress. However, observation and asking as screening methods have been shown to be unreliable by missing milder levels of Deafness, Deafblindness or Visual Impairment which are less apparent during one-one conversation in a quiet environment, but do impact on communication and cognition.⁷²

Collectively checking medical records for previous eye care/hearing care assessment results, examining ears and eyes, and referring or signposting people to vision or hearing care services for formal diagnostic assessment are all welcome practices and in keeping with NICE guidelines. However, some of the other approaches described by GPs raise concerns because they are subjective and risk not identifying Deafness, Deafblindness or Visual Impairment prior to performing a memory/dementia assessment.

If signposting and referral to vision or hearing care services for formal diagnostic assessment is best practice in the absence of GPs having access to more formal diagnostic tools, this is only likely to be successful within an effective framework. This framework should support appropriate hearing assessment waiting times to enable timely access to these services for the person, and timely access to the results for the GP to support best practice in dementia diagnosis. This framework should also make clear which hearing and eye care professionals have the appropriate scope of practice to assess hearing and sight in people living with dementia and are therefore suitable professionals for GPs to signpost or refer to.

Specifically designed assessment tools

To find out more about the process of dementia assessment for people with Deafness, Deafblindness or Visual Impairment, GPs were asked if they used any memory/dementia assessment tools specifically designed for people who are Deaf, Deafblind, or who have a Visual Impairment,

including specific tools for BSL users. This was a multiple choice, single answer question and was answered by 68 out of 84 (81%) respondents.

Fifty-two out of 68 respondents (77%) reported that they were not aware of any tools designed specifically for people who are Deaf, Deafblind, or have a Visual Impairment, including sign language users. 11 out of 68 (16%) reported that they did not have access to any tools designed specifically for people who are Deaf, Deafblind, or have a Visual Impairment, including sign language users. Five out of 68 (7%) reported that they did use specific assessment tools in their practice.

From the five respondents who do use tools, one GP reported they used a modified version of the Montreal Cognitive Assessment (MoCA) called the MoCA blind. One advised they did not have access to modified assessment tools, but their dementia nurse did, and two respondents said if a person used sign language they would request an interpreter. One respondent specifically referenced signing support from Sense Scotland – a third sector organisation for people with sensory impairments. The remaining respondent who selected 'yes' stated:

“I'm aware of one that can be used for people who don't speak English but can't recall its name.”

The format of this question facilitated the option for additional comments from respondents on memory/assessment tools designed specifically for people who are Deaf, Deafblind, or have a Visual Impairment, including sign language users. From several additional comments, one respondent who was not aware of any specially designed assessments hypothesised that Old Age Psychiatry teams who specialise in dementia assessments would have access to the appropriate tools:

“Formal dementia assessment is done by old age psychiatry team- they are likely to have access to other resources to accommodate sensory difficulties.”

One respondent who also did not know of any specifically designed tools advised that they used a memory/dementia screening tool which was not

dependent on visual acuity and would be suitable for people with Visual Impairment. Another GP who used the Mini-Addenbrooke's Cognitive Examination (mini-ACE) commented, "I would appreciate a version of mini-ACE for people with hearing or visual loss or how to adapt it." This indicates that GPs welcome appropriately designed tools for Deafness and/or Visual Impairment to improve the practice of performing memory/dementia assessments.

Another respondent who also did not have any knowledge of specifically designed memory/dementia assessment tools said they would use a standard assessment but would factor in any sensory issues when calculating the person's cognitive score. No further details were provided on what guidelines or framework would be applied to ensure differentiated results did not compromise the integrity of the assessment.

A respondent who is also a professional with lived experience of supporting a relative with Deafness and now advanced dementia through diagnosis and post-diagnostic support, stated that if appropriate assessment tools had been used much earlier in the process, poor outcomes could have been avoided:

"Provision is drastically lacking for deaf/blind dementia patients [...] deafblind manual [users] are not considered – the hearing community typically thinks that it's all the same language."

Summary

This first-hand experience of the lack of provision and knowledge of the assessment of dementia in people who are Deaf, Deafblind or who have a Visual Impairment is consistent with the overall results of this survey question in indicating that the majority of GP respondents were not aware of, or did not have access to, specifically designed tools. In the absence of such tools adjustments to standard cognitive assessments can be made with the best of intentions, but which impact on the integrity of results in accurately measuring the required cognitive domains.⁷³

Care homes

GPs were asked if there was anything different in the memory/dementia assessments they use with people living in care homes, who also have Deafness and/or Visual Impairment, or are sign language users. This was an open text response question which 56 out of 84 (67%) respondents answered.

Twenty-six out of 56 respondents (46%) advised they would use the same approach for people residing in care homes as those living in the community. Thirteen out of 56 (23%) reported that performing memory/dementia assessments for care home residents was not part of their role. The different approaches the remaining GP respondents reported fell into the following categories:

- Adaptions
- Hearing aids/glasses
- Liaising with family and staff
- Sign language.

Adaptions

Ten respondents stated they consider adaptations when performing a memory/dementia assessment outside of their standard clinic room such as in a care home. Two GPs made a general statement of, “adapt according to issues” and “I adapt to the patient's needs but I don't use any particular resources”. Others gave more specific information about possible adaptations, including ensuring there was sufficient lighting in the assessment environment to enhance vision, availability of whiteboards or paper to write information down, taking time to check for understanding, and leaving out parts of cognitive assessments relying on hearing and sight as required then adjusting scores to reflect the omissions.

Two respondents commented that providing memory/dementia assessments in care homes was often more challenging due to the symptoms of dementia usually being more advanced, and time constraints on appointment times:

“More challenging [for care homes]. Work with staff to use tools such as white boards. Try to make appropriate environments e.g. quiet, well-lit etc.”

“I have to travel to the care home and find the patient and as time is very tight as a GP and as the functional status of the patient is often less, the assessments can be more difficult in this setting.”

One respondent highlighted that for people in care homes, the emphasis is usually on post-diagnostic support and the importance of implementing and monitoring management plans to ensure needs are met:

“It is very rare to be asked to do assessment in [a] care home - most patients have already got a diagnosis and the issue is about support and addressing health care needs already identified.”

This is a good example of the need to identify Deafness, Deafblindness or Visual Impairment at the diagnosis stage, to appropriately document a person’s communication needs with a process to monitor sensory changes which may be distinct from cognitive changes.

Hearing aids/glasses

Four respondents reported they would make sure a care home resident’s hearing and sight were optimised by ensuring any glasses or hearing aids were available and in working order before starting a memory/dementia assessment.

Liaising with family and staff

Six respondents advised that they would ask for feedback or input from other people such as family, care home staff, Allied Health Professionals (AHPs) or eye care professionals about a care home resident’s communication to help establish any difficulties with sight and/or hearing:

“Sight loss – don’t use anything in particular - would direct to occupational therapy for support if needed.”

“I would seek advice from Speech and Language Therapy or optometry.”

One respondent discussed post-diagnostic support for dementia, highlighting it was important to involve care home staff who are more familiar with the person to help identify any changes in communication, and implement strategies to support successful interactions:

“I haven't had to diagnose this in a care home so have not actually done this, we do however do monitoring of dementia and will utilise staff etc. for assistance in communication.”

Sign Languages

Five respondents referred specifically to care home residents whose first or preferred language was a sign language, advising that they would request a sign language/English interpreter to support memory/dementia assessments. None of these responses referred to any specifically designed assessment tools for sign language such as the BSL cognitive assessment. This indicates the validation problems which occur when translating a cognitive tool from English to sign language are not well known.⁷⁴ Representative comments include:

“Need support of translator for sign language.”

“Would use BSL interpreter if using sign language.”

Summary

69% of GP respondents reported that either they would use the same approach to the assessment of dementia for people who are Deaf, Deafblind or who have a Visual Impairment in care homes.

Examples of different approaches included making adaptations such as: allowing more time, optimising the communication environment and adopting good communication strategies, ensuring any glasses or hearing aids were functioning and in situ, and liaising with family, care staff and health professionals. The emphasis on post-diagnostic support being particularly pertinent to care home residents highlights the importance of monitoring sensory changes pre- and post-diagnosis.

Reflections and recommendations: GPs

Eighty-four GPs representing at least eight Health Boards across Scotland completed the survey on the assessment of dementia in people who are Deaf, Deafblind or who have a Visual Impairment. The survey explored to what extent sensory assessments feature as part of the diagnosis pathway for dementia, or during post-diagnostic support.

Results suggested that most GPs (59 out of 78, 76%) did not assess hearing and sight as part of a memory/dementia assessment, or only did so if Deafness, Deafblindness or Visual Impairment was suspected.

Only five out of 78 (6%) respondents specified that they would assess both sight and hearing as an integrated part of assessing memory/dementia. This result is concerning because common dementia assessments rely on hearing and sight. The degree of cognitive impairment can therefore be over-estimated and Deafness, Deafblindness or Visual Impairment unidentified. This means potentially modifiable communication barriers may not be addressed, nor inform care planning, inclusive communication practices and people's access to information. All these elements form an integral part of person-led dementia care, which prioritises people's human rights.

From these findings we recommend that:

1. Diagnostic level hearing and sight assessments should be integrated within standard memory/dementia assessment practices for GPs. These are stated as "considerations" in the NICE guidelines for the assessment of dementia, but we would recommend this wording be strengthened so that sensory assessments take place as standard.
2. Memory/dementia assessment practices should be compliant with the Adults with Incapacity (Scotland) Act 2000, which regards access to sight and hearing care services as a "fundamental healthcare procedure".⁷⁵

The survey asked how GPs would establish whether a person had Deafness and/or Visual Impairment prior to performing a dementia assessment or support planning. The data revealed variation in current methods, largely relying on subjective measures which risk not identifying Deafness, Deafblindness or Visual Impairment. These include:

- Clinical judgment based on behavioural observations of the person
- Reviewing medical records
- Asking the person, their communication partners or health and social care professionals about any difficulties with hearing or sight
- Using subjective sensory assessment tools
- Signposting or referring to vision or hearing care specialists for a formal assessment.

On analysis of the sensory assessment tools, ear examinations were examples of good practice in keeping with NICE guidelines. However, concerns were raised about the reliability of whisper tests and tuning fork tests for identifying Deafness. Clinical examination of the eyes and use of the Snellen test are in keeping with good practice for eye health and welcome as a sensory screening tool for Visual Impairment, but do not replace formal diagnostic sight assessments.

Signposting or referral to vision and hearing care specialists are also welcome approaches. However, in most cases this was prompted by the person or their family raising concerns over hearing and sight during the appointment, or the GP observing communication or mobility difficulties first-hand, as opposed to signposting and referral being an integrated part of standard practice. Checking when sight and hearing were last assessed is good practice, but responses highlighted that while GPs are knowledgeable about national guidelines for frequency of sight tests, there is a gap in knowledge for hearing assessments.

The lack of integration within dementia pathways between memory/dementia assessments and NHS audiology services was highlighted in particular by some GPs as a barrier to referral due to long waiting times, and perceived differences in quality of hearing care

between private and NHS hearing care services. GPs were not aware that private Hearing Aid Dispensers do not have the same scope of practice as audiologists, and may not have training in, nor access to, the diagnostic assessments and equipment required to assess hearing in people living with dementia.

From these findings we recommend that:

3. The SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, and the Royal College of General Practitioners' Deafness and hearing loss toolkit, should be updated to state appropriate methods of identifying Deafness, Deafblindness or Visual Impairment, and include national guidelines on when these assessments should be repeated.
4. These guidelines should also state which sight and hearing care professionals have the appropriate scope of practice to assess hearing and sight in people living with dementia and are therefore suitable to signpost or refer to.
5. The Scottish Government's Dementia Strategy, in partnership with NHS audiology and eyecare services, must work together to enable timely access to hearing and sight assessments for the person, and timely access to results for GPs.
6. Timely access to NHS audiology services for people being assessed for dementia should be considered a priority within Scottish Government's implementation of the recommendations from the Independent Review of Audiology Services in Scotland (IRASS). This would ensure appropriate service planning and resources are available to support the vast numbers of people with dementia in Scotland.⁷⁶

The survey asked if GPs were aware of any tools designed specifically for people who are Deaf, Deafblind, or who have a Visual Impairment,

including sign language users. Most respondents (63 out of 68, 93%) selected that either they were not aware of any, or they did not have access to any. From the five out of 68 GPs (7%) who advised they were aware of specific tools, only one respondent referenced a validated cognitive assessment – the MoCA blind (for people with Visual Impairments). From these findings we recommend that:

7. The SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, and the NICE guidelines for the assessment of dementia, should be updated with a list of suitable memory/dementia assessments for people with Deafness, Deafblindness or Visual Impairment, and clearly state that standard assessments are unsuitable.
8. Use of suitable memory/dementia assessments for people with Deafness, Deafblindness or Visual Impairment should be included in GP's dementia training and relevant assessment tools should be available for use across Scotland.

Finally, GPs were asked if they would do anything different for people with dementia living in care homes. Twenty-six respondents (46%) stated that they would use the same approach and 13 (23%) advised that assessing care home residents was not part of their role. The remaining respondents described adaptations they would make, including:

- Changes to the assessment environment
- Communication strategies
- Checking hearing aids and glasses were available and working where appropriate
- Asking for support from communication partners and health professionals.

Two GPs highlighted additional challenges of performing dementia assessments in care homes, and one emphasised the importance of post-diagnostic support.

From these findings we recommend that:

9. Sensory care standards should state that sensory assessments are an integrated part of a person's transition to residential care, with the results of assessments accessible to GPs through medical records and care plans.
10. Sensory care management plans should be accessible and clearly state when repeat sensory assessments should take place as part of post-diagnostic support to monitor both sensory and brain health changes.
11. Memory/dementia assessment practices in care homes should be compliant with the Adults with Incapacity (Scotland) Act 2000 which regards access to sight and hearing care services as a "fundamental healthcare procedure".⁷⁷

For care home residents who use sign language, GP respondents advised they would use an interpreter, without referencing the need for a cognitive assessment validated for sign language users. As such:

12. We recommend that the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, and the NICE guidelines for the assessment of dementia, should be updated to include clear statements on the assessment of dementia for people who are sign language users.

Health and medical professionals (not GPs)

In addition to the survey for GPs as described in the section above, a similar survey was also distributed to other health and medical professionals involved in the assessment of dementia, to provide a broad perspective of practices. This survey was completed by 108 respondents. Participants represented a wide range of disciplines including Allied Health Professionals, dementia support services, mental health, old age psychiatry, orthopaedics, nursing, rehabilitation, social work, and social care, as outlined earlier in this report and in Appendix B.

Assessment of hearing and sight

Respondents were asked if they assessed hearing and sight as part of a memory/dementia assessment. Ninety out of 108 (83%) answered this question.

Thirty-five out of 90 respondents (39%) selected that they did not assess hearing and sight as part of a memory/dementia assessment. Eleven out of 90 (12%) selected they would assess both sight and hearing. One respondent (1%) selected they would assess sight but not hearing. Seven out of 90 (8%) selected they would only assess when Deafness and/or Visual Impairment were suspected. Seven out of 90 (8%) respondents were unsure, and 29 out of 90 (32%) respondents selected 'other' which then provided the option for additional comments.

The one respondent (physiotherapist) who selected they assess everyone's sight but not hearing qualified that this is the case for stroke services – presumably because of the recognised high incidence of acquired visual impairment following stroke.⁷⁸ Another physiotherapist respondent stated a sight assessment would only be indicated in specific circumstances:

“Assess vision only if vertigo/vestibular symptoms are suspected.”
[Physiotherapy]

Most of the additional comments for respondents who selected 'other' stated that while they did not formally assess hearing and sight, any known or suspected Deafness, Deafblindness or Visual Impairment would inform their decision making when performing a memory/dementia assessment. For example:

"I do not formally assess hearing and sight, but take into account known impairments when selecting assessments and informally check at appointment". [Occupational Therapy]

"Depends what you mean by "assess"; being aware of hearing and sight impairment is a standard part of our comprehensive assessment. But we are not formally assessing it; more screening for it and then taking it into account when completing a cognitive assessment and/or referring on to appropriate hearing/sight services." [Mental Health Nursing]

Summary

Almost half of respondents (42 out of 90, 47%) reported that they either did not assess hearing and sight as part of a memory/dementia assessment, or only did so if Deafness, Deafblindness or Visual Impairment was suspected. A minority (11 out of 90, 12%) of health and medical professionals indicated that they would assess both sight and hearing, highlighting differences in practice.

In addition, there is evidence that specific protocols for sensory assessment are in place when specific symptoms present or there is an established risk of change, such as identifying Visual Impairment following stroke. This data suggests practices can vary within one health or medical profession depending on area of specialism.

Most of the respondents who selected 'other' (29 out of 90, 32%) advised there would not be any formal sensory assessment, but known or suspected Deafness, Deafblindness or Visual Impairment would shape their practice.

Taken as a whole, results imply that the integration of hearing and/or sight assessments with memory/dementia assessments varies across health and medical professions, and also within health and medical professions for specialist areas.

Sensory assessment timings

Respondents were asked when hearing and/or sight assessments take place for people, and how often are they repeated. Forty out of 108 (37%) respondents answered this open text response question.

Comments ranged from short statements such as, “ad hoc”, to more detailed descriptions of sensory assessment processes.

Unsure/don’t know

Eight out of 40 (20%) respondents stated they were not sure or did not know when hearing and/or sight assessments would take place, or how often they would be repeated.

At initial assessment

Five out of 40 (8%) respondents advised that a sight and/or hearing assessment would take place at the first visit for a memory/dementia assessment. Most, though not all, stated that sensory reassessments would be arranged as and when indicated, rather than at planned intervals during post-diagnostic support. Sample responses include:

“As part of the initial [memory/dementia] assessment, never repeated but if referrals need done they will be done accordingly.”
[Mental Health]

“Start of [memory/dementia] assessment and as needs change.”
[Mental Health]

“Not regularly repeated.” [Nursing]

Primary care follow-up

One Occupational Therapist working in Acute Medicine of the Elderly highlighted that a formal sensory assessment would not be performed on admission to secondary care, though they would take any Deafness,

Deafblindness or Visual Impairment into account for cognitive assessment when derived through observation or asking Next of Kin. If indicated, arranging formal sensory assessment would fall under the responsibility of a primary care physician:

“Rarely within admission – often followed up for review in community by GP.” [Occupational Therapy]

Not routinely

Sixteen out of 40 (40%) of respondents commented that sensory assessments were not a routine part of a memory/dementia assessments but would be integrated whenever indicated such as observing the person experiencing difficulties with hearing or sight. Planning for repeated sensory assessments would also be dependent on the needs of the person. For example:

“If problems are evident during memory screening process they will be directed to specific assessments.” [Occupational Therapy]

“Nothing routine. We would refer to other services.” [Occupational Therapy]

At every assessment

Three out of 40 respondents (8%) reported that they would assess both hearing and sight at every visit. This included two professionals who worked in mental health services and one Occupational Therapist working on an in-patient hospital ward:

“I would complete an assessment of vision and hearing each time I am completing an assessment or rehabilitation session with the person as this may fluctuate daily.” [Occupational Therapy]

Initiated by person

An Occupational Therapist working in Older Adult Mental Health services stated that sensory assessments would only take place as part of a memory/dementia assessment if the person raised concerns. Arranging vision assessments in particular would be the responsibility of the person or their family/friends to arrange. The Occupational Therapist

highlighted that for people with dementia who do not have any external support, there is currently no standard framework in place which provides assistance to access community eye care services. They stated:

“As far as I am aware, this is patient requested and not professional led. Some people with hearing aids do receive regular reviews but I am unaware of frequency. Unless they have a medical issue causing visual impairment, this would also be patient lead to book an optician and engage with appointments when reminders are sent. There is no specific pathway for people with dementia who would be unable to do this and relies on family and friends to facilitate.” [Occupational Therapy]

Recommended guidelines

Four out of 40 (10%) respondents referenced recommended guidelines for repeating sensory assessments. From these four, three (75%) referred to guidance as recommending eye examinations every two years. This is consistent with NHS Scotland’s guidance for adults up to the age of 59 years. For people aged 60 years or older, the national guidance recommends an annual examination.⁷⁹

When referring to recommended guidelines for hearing, two respondents referenced guidelines for hearing aid maintenance checks instead of hearing assessments. This may indicate that national guidance for hearing health checks in people with dementia is less well known:

“For most patients it would be within national guidance of a two-yearly eye test unless they were being seen by a specialist clinic. Hearing would be what guideline audiology recommends however from doing the job in the area I work people with hearing aids are advised to be seen six-monthly at audiology to have hearing aids checked/maintained.” [Mental Health Nursing]

One respondent stated that relevant professionals would arrange repeat hearing and sight assessments in accordance with guidance. This is presumably referring to ear and eye care services advising people at

recommended intervals to make a reassessment appointment, or advising them that an appointment has been arranged:

“Relevant professional would do this in accordance with their guidance.” [Allied Health Professional]

A professional working in Care of the Elderly and Dementia stated that they have a designated eye care company who oversees sight assessments for people with dementia, with hearing assessments arranged by referral to the NHS audiology services. Repeat assessment would therefore be decided by vision and hearing care professionals:

“We have a company called [company name] that takes over the eye assessments. Hearing assessments are at the local hospital, we would get an audiology referral.” [Care of the elderly and Dementia]

Summary

Health and medical professionals were asked when hearing and/or sight assessments take place for people, and how often are they repeated. This question had the lowest response rate of the whole survey (40 out of 108, 37%) which may indicate timings of sensory assessments prompt a high level of uncertainty.

Most respondents (24 out of 40, 60%) reported that they did not know, or that sensory assessments were not performed routinely. A minority of respondents (5 out of 40, 8%) stated that a sensory assessment would be performed at the initial memory/dementia assessment, but any repeated sensory assessments would be performed when indicated rather than at planned intervals.

One response suggested that GPs would be responsible for arranging sensory assessments as part of primary care support. This assumption is important in light of the findings of the survey for GPs, where only five out of 78 GPs (6%) specified that they would assess both sight and hearing as an integrated part of assessing memory/dementia. Without a clear framework on professional responsibilities and appropriate

recording to provide alerts when an aspect of dementia care has not been completed, sensory assessments may be overlooked as an integrated part of dementia assessment and post-diagnostic support.

Finally, four out of 40 (10%) respondents referred to national guidelines for hearing and sight assessments for people with dementia. Results indicated health and medical professionals have greater awareness of recommendations for eye care than for hearing care. Notably this was also a finding in the survey for GPs. This universal gap in knowledge of guidance for hearing assessments needs addressed to ensure people's sensory needs are identified throughout dementia diagnosis and monitored during post-diagnostic support.

Sensory assessment approaches

In keeping with the survey for GPs, respondents were asked how they would establish Deafness, Deafblindness or Visual Impairment before commencing assessments for dementia and/or support planning. Sixty-six out of 108 (61%) answered this open text response question.

Some responses were limited in detail, such as stating this would be established “through initial assessment” and “we would monitor/assess on a daily basis and feedback” without providing more information on what that assessment and monitoring process would entail. Other responses were much more detailed including some which described not only the initial memory/dementia assessment but also included post-diagnostic support. Approaches covered the following categories:

- Observation
- Checking medical records
- Raised by person, communication partners or staff
- Ask person, family or staff
- Referral to sensory services.

Observation

Nineteen out of 66 (29%) respondents stated they would rely on observations to help establish whether a person is Deaf, Deafblind, or has a Visual Impairment. In most cases observation was described in combination with at least one other subjective approach:

“If they struggle to hear me speaking before assessment this would help identify issues. Same if they are struggling to see assessment. No formal means of assessing though.”

[Occupational Therapy]

“Make clinical judgement based on observations/engagement.”

[Occupational Therapy]

Consistent with some GP responses to the same question, a physiotherapist reported that Visual Impairment was evidenced by observing difficulties with reading or navigating the environment, such as “Poor sense of direction with walking aid.” In terms of hearing difficulties, one respondent reported that these can be reliably identified through talking with the person:

“Just through conversation hearing deficit can be obvious.”

[Nursing]

Observations also extending to noting if the person had hearing aids and/or spectacles:

“Use initiative if you can see they use aids or wear glasses.”

[Mental Health Professional]

“We would look visually also for any hearing aids or spectacles.”

[Care of the Elderly and Dementia Professional]

Another respondent’s approach whose role included consultation with people over more than one visit rather than a single appointment, was to aggregate observations over time to build up a picture of communication needs and any changes:

“Base on observation during previous visits.” [Mental Health Professional]

Checking medical records

The most common approach (39 out of 66, 59%) cited as evidence for Deafness, Deafblindness or Visual Impairment was to check a person’s medical records or case notes. A few responses indicated they would rely on these as the only source of identification, while most used medical documentation in conjunction with at least one other method:

“Only if it is noted on the referral.” [Mental Health Professional]

“Refer to past medical history.” [Nursing]

Several respondents highlighted the importance of the referral letter from the GP or the initial referrer to relay information about sight and/or hearing. Here there is an assumption that initial referrers will enquire about sensory health as standard protocol, and any relevant information will be formally recorded for other health and medical professionals to access as people transition through their dementia care pathway:

“We would hope that this information was included on the referral form from GP/other referrer.” [Psychiatric Nursing]

“Looking at medical history provided by GP.” [Medical Professional]

Some respondents described checking different sources of medical records or patient information such as those from eye or hearing care services, nursing or admission notes. This underscores the need for NHS IT systems across different health and medical disciplines involved in dementia care to be integrated so that results and management plans are easily accessible, with relevant information ideally being held in one place so not to be missed or overlooked. Representative comments included:

“I would also read the clinical notes before seeing a patient to see if audiology have assessed in the past or if there are notes from ophthalmology/eye clinic etc.” [Occupational Therapy]

“I would check the nursing and clinical notes for any information on sight/hearing issues as well as the Admission Record for that patient.” [Dietetics]

“TRAK notes [electronic patient record] [...] Information board above patient's head.” [Physiotherapy]

Raised by person, communication partners or staff

Eight out of 66 (12%) respondents commented that Deafness, Deafblindness or Visual Impairment would be established in whole or in part by the person accessing the service sharing this information unprompted, or their family/friend or staff familiar with them doing so. For example:

“Rely on observations, friends or family, or even the person themselves to disclose this information on first meeting.”
[Occupational Therapy]

“Hope that if there are issues nursing staff report these.” [Stroke rehabilitation]

Ask person, family or staff

In contrast to some respondents relying on sensory information being disclosed externally, most health and medical professionals – 41 out of 66 (62%) - reported they would routinely ask about this directly as part of standard history taking. This indicates that health and medical professionals largely recognise the importance of identifying sensory needs during memory/dementia assessments. Representative responses included:

“Check with the person themselves, family etc. As part of our assessment structure questions re visual/hearing impairment are routine screening questions.” [Nursing]

“Prior to completing any standardised assessment, I complete an initial assessment that includes questions about vision, hearing and if indicated other sensory impairments such as perception.”
[Allied Health Professional]

Respondents covered a range of people they would ask, often if the person accessing the service found it difficult to provide this information through verbal interaction. Discussion of sensory needs was also described by some respondents as taking place during staff handovers to ensure this information was passed on after scheduled interactions with the person had ended. For example:

“Discussion with MDT [Multidisciplinary Team] or NOK [Next of Kin] or carers.” [Physiotherapy]

“We would get information from family or social work if the resident couldn't speak for themselves.” [Care of the Elderly and Dementia]

“Medical, nursing, AHP handovers.” [Physiotherapy]

One respondent described that they would use the information gained through asking the person, their communication partners or staff to help identify communication changes as part of post-diagnostic support:

“If the patient is cognitively able to answer questions about their baseline I will have a discussion with them... If I cannot get the baseline from the person due to cognitive decline I will speak with the next of kin. I would then review this at each assessment.”
[Occupational Therapy]

Some respondents asked about the use of hearing aids and/or glasses to identify sensory needs, and to help optimise communication throughout the consultation and assessment process:

“Normally on first introduction to the patient and when I am telling them what the assessment entails I ask them about their sight and hearing asking them to make sure their hearing aids are in and

working if they have them or that if they need or use glasses that they will need them for the assessment.” [Nursing]

“Ask patient and/or carer as appropriate to determine visual/hearing status, to ensure that the individual can participate in the assessment to the best of their ability by wearing appropriate aids” [Occupational Therapy]

Referral to sensory services

In contrast to the 19% of GPs (13 out of 69) who stated they would establish whether someone is Deaf, Deafblind or has a Visual Impairment before commencing assessments for dementia and/or support planning by arranging a referral to vision or hearing care services, only two out of 66 (3%) non-GP health and medical professionals advised they would do the same. This highlights that referral to sensory services may be perceived as primarily the role of GPs rather than other professionals involved in supporting people accessing dementia services.

Sensory assessment tools

Although the survey for GPs described some use of specific sensory assessment tools such as the Snellen test for sight, and whisper and tuning fork tests for hearing, no respondent from the non-GP health and medical professional survey referenced any similar tools. One respondent reported that beyond asking a person about their vision they would perform, “a more comprehensive vision exam” under certain circumstances, though what this involved was not described. It is therefore not clear what access health and medical professionals have to sensory assessment tools to help establish Deafness, Deafblindness or Visual Impairment. One respondent stated that they would:

“Do a more comprehensive vision exam if any neurological symptoms have presented (or, if an abnormal movement pattern/gait is detected during assessment and treatment).”
[Physiotherapy]

Summary

Health and medical professionals were asked how they would establish Deafness, Deafblindness or Visual Impairment before commencing assessments for dementia and/or support planning. A variety of methods were described with some used in isolation, or as part of a combined approach. These included: observation, checking medical records, Deafness, Deafblindness or Visual Impairment being raised by the person, communication partners or other health and medical professionals, directly asking as part of history taking, and referring or signposting to sensory services.

The most common method (41 out of 66, 62%) reported by respondents was to directly ask the person, their communication partners or other health and medical professionals as part of standard history taking. This indicates that the importance of identifying sensory needs during memory/dementia assessments is largely recognised by health and medical professionals. However, research shows self-report is not a reliable strategy for identifying Deafness and/or Visual Impairment when compared with formal diagnostic assessment.⁸⁰

Checking medical records was also a commonly referenced approach among respondents (39 out of 66, 59%). However, there was a particular reliance on the GP or initial referrer to identify Deafness, Deafblindness or Visual Impairment. This is an important finding because of the results of the GP survey, which found that only five out of 78 (6%) specified they would assess both sight and hearing as an integrated part of assessing memory/dementia. The resulting risk is that if sensory assessments are not integrated during initial referrals, Deafness, Deafblindness or Visual Impairment may continue to be unidentified throughout dementia diagnosis and post-diagnostic support pathways. This is because health and medical professionals may assume sensory investigations have already been completed and reported accordingly.

Two out of 66 (3%) non-GP health and medical professionals advised they would establish whether someone is Deaf, Deafblind or has a Visual Impairment before commencing assessments for dementia and/or support planning by arranging a referral to vision or hearing care

services. This figure was higher in the survey for GPs (13 out of 69, 19%) which highlights that referral to sensory services may be perceived as primarily the role of GPs, rather than other professionals. This finding is consistent with the reliance on GPs or initial referrers to identify Deafness, Deafblindness or Visual Impairment, as described in the checking medical records method above.

Without a clear framework on professional responsibilities and appropriate recording to provide alerts when an aspect of dementia care has not been completed, sensory assessments may be overlooked as an integrated part of dementia assessment and post-diagnostic support.

Finally, in contrast to the survey for GPs, no non-GP health and medical professional referenced using any formal sensory assessment tools – diagnostic or screening. This indicates variations in access to tools between the two groups. If referral to vision or hearing care services is not taking place as standard in most cases, this limits the ways in which non-GP health and medical professionals can identify people who are Deaf, Deafblind or who have a Visual Impairment before commencing a memory/dementia assessment. Official guidance is required on best practice approaches to identification and monitoring across all professionals involved in memory/dementia assessments and post-diagnostic support planning.

Specifically designed assessment tools

Respondents were asked if they used any memory/dementia assessment tools designed specifically for people who are Deaf and/or have a Visual Impairment, or for BSL users. Sixty-four out of 108 (59%) answered this question. Twenty-nine out of 64 (45%) respondents selected that they were not aware of any specifically designed tools and 35 out of 64 (55%) respondents selected that they did use specifically designed tools. There were no respondents who indicated that they were aware of tools but that their Health Board did not have access to them.

All respondents were given the option to add any additional comments on the topic of assessment tools designed specifically for people who

are Deaf and/or have a Visual Impairment, or for BSL users. The respondents who selected 'yes' were asked to specify the assessment tool/s they used. Thirty-three out of 35 (94%) of these respondents provided more information. Comments ranged from listing formal cognitive assessments, as well as adaptations professionals would make during a cognitive assessment.

Cognitive assessments

No respondents reported using assessment tools for people with both Deafness and Visual Impairment, or Deafblindness.

Only one respondent referenced a cognitive assessment specifically designed for sign language users, highlighting that further training was needed to understand how to use it:

“We also looked into a BSL based cognitive test but couldn't work out how you could administer it unless you had a member of staff who could speak BSL – didn't seem to be possible to use a BSL interpreter?” [Occupational Therapist]

Another respondent did not know of any cognitive assessments for sign language users but welcomed the opportunity for training:

“I'm not aware of BSL friendly assessment tools, would love to learn more!” [Mental health nurse]

The most commonly used specially designed cognitive assessment for people with Visual Impairment was the MoCA Blind, referred to by 22 out of 33 (67%) health and medical professionals across different disciplines.

One respondent reported they would use the TICS (Telephone Interview for Cognitive Status) assessment for people with Visual Impairment:

“I use the TICS assessment for visually impaired.” [Psychiatric Nursing]

Although this cognitive tool was designed to be used over the phone, it can also be conducted in-person, and the questions are all presented orally meaning they do not rely on visual acuity.⁸¹

Nearly a third (10 out of 33, 30%) of respondents referred to the Addenbrookes Cognitive Exam (ACE) III cognitive assessment in different ways. Most reported they would adapt this assessment to meet the sensory needs of the person. An example of adaptations included omitting items not able to be seen or heard correctly, or using larger print versions to enhance visibility. Sample comments include:

“I can use and will adapt the ACE to utilise the parts that they are able to complete” [Mental Health]

“I have used enlarged copies of the ACE III” [Occupational Therapy]

There was divergence in knowledge of whether versions of the ACE III designed specifically for people who are Deaf and/or have a Visual Impairment existed. Two respondents noted that they were not aware of any different versions, while another two stated that they knew of a version adapted for people who are Deaf.

The Hearing Impairment ACE III (HI-ACE III) was developed by the University of Sydney’s Brain and Mind centre and is available to download online.⁸² Particularly relevant to health and medical professionals in Scotland is the following guidance on the website regarding accessibility of free online training on the suite of ACE III cognitive assessments:

“We encourage health practitioners and researchers to utilise the available training programme for the ACE-III provided by Professor Jonathan Evans, Dr Leigh Whitnall and Dr Stephanie Crawford at the University of Glasgow in conjunction with NHS Education for Scotland.”⁸³

One of the survey respondents who did know about the HI-ACE III advised they could access materials online but had not been formally trained on its use, and did not know of anyone in their Health Board using it. This highlights that professionals involved in the assessment of dementia across Scotland may not have equal access to training and updates on developments on cognitive assessment. Other participants shared the following:

“I have also used at times written versions of parts of the ACE III with a disclaimer that I have done this as this does not have an adapted version (as far as I am aware).” [Occupational Therapy]

“Most recently became aware of the ACE for hearing impaired which I will incorporate into my practice.” [Psychiatric Nurse]

Three respondents referred to the Large Allen Cognitive Level Screen (LACLS). This is a modified version of the Allen Cognitive Level Screen designed to include people with Visual Impairment or reduced hand dexterity, though some level of visual acuity is required, making it unsuitable for people who are Blind. The tool itself is a practical-based task using motor skills and increasing in difficulty.⁸⁴ There was some divergence across responses on the suitability of this cognitive assessment for people who are Deaf and/or have a Visual Impairment, with one advising it was not appropriate and the other stating this is what they would use. In addition, one respondent reported that they had successfully used the assessment with a BSL user. Comments include:

“Our standardised screening tool – LACLS – requires good eyesight and hearing (to hear instructions). If these are compromised, we rely on observation.” [Occupational Therapist]

“There is nothing specifically used for those with hearing loss, but our go to assessment as OTs [occupational therapists] is the Large Allen Cognitive Level Screen (LACLS).” [Occupational Therapist]

“I have used LACLS with [family member as interpreter] using BSL in the past.” [Allied Health Professional]

From the remaining responses on the topic of memory/dementia assessment tools designed specifically for people who are Deaf, Deafblind or who have a Visual Impairment, or for BSL users, one respondent said they would make adaptations to the Six Item Cognitive Impairment Test known as the 6CIT instead of using standard versions of the MoCA or ACE III. Another stated that their team of Occupational Therapists use the standard Assessment of Motor and Process Skills (AMPS)⁸⁵ tool and this would be suitable for people with Deafness, Deafblindness or Visual Impairment. This assessment measures performance of activities of daily living through observation:

“Most of our OTs are also trained in Assessment of Motor and Process Skills (AMPS). As this relies on observing someone doing a familiar activity, this would be an appropriate standardised assessment for someone with any type of sensory loss.”
[Occupational Therapist]

Communication support for assessments

While the question asked respondents if they used any memory/dementia assessment tools designed specifically for people who are Deaf, Deafblind, or who have a Visual Impairment, including for BSL users, most responses included additional information about how people could be supported when undertaking a memory/dementia assessment.

Assistive devices to support communication included non-technological interventions such as Talking Mats, providing white boards to write down instructions, large print materials with good colour contrast, and magnifiers. There were also more technological-based supports including assistive listening devices such as amplifiers and loop systems. Representative examples from respondents included:

“Large print books, or custom design tools/interventions.” [Mental Health]

“I have in the past used flash cards for the deaf or if they struggle with other languages, and large magnifying glass for reading.”
[Mental Health]

Several respondents also stressed the importance of checking hearing aids and glasses were working and in situ, as well as adopting good communication strategies to enable a Deaf person to lipread. Another approach was to liaise with other professionals such as BSL/English interpreters, Speech and Language Therapists and third sector sensory organisations.

More training

The survey collected 15 additional voluntary comments on the topic of assessment tools designed specifically for people who are Deaf, Deafblind, or who have a Visual Impairment, including for BSL users. Several respondents welcomed more training and awareness so that they could embed this into their practice, feeling that this was a definite gap in knowledge and skills. For example:

“Absolutely agree that this is an area misrepresented and often overlooked.” [Dietetics]

“I would be happy to be trained on this, so that I can add this to my current assessment.” [Occupational Therapist]

“I am very passionate about cognitive assessment and am keen to explore ways in which this can be improved for those with sight and hearing loss.” [Occupational Therapist]

“I feel there could be more that could be developed for this.”
[Mental Health]

Summary

Health and medical professionals who are not GPs were asked if they used any memory/dementia assessment tools designed specifically for people who are Deaf, Deafblind, or who have a Visual Impairment, including for sign language users. Over half of respondents (35 out of

64, 55%) reported that they did use specifically designed tools, however none of these included assessment tools for people with both Deafness and Visual Impairment, or Deafblindness. One respondent was able to reference a cognitive assessment specifically designed for sign language users, with the caveat that they required further training to know how to use this in practice.

The most commonly used cognitive assessment tool for people with Visual Impairment was the MoCA Blind, referred to by 22 out of 33 (67%) of respondents across different health and medical professions. This was followed by 10 out of 33 (30%) of respondents who used the Addenbrookes Cognitive Exam III (ACE III). However, only two of these health and social care professionals indicated that they knew this assessment had a version validated for use with people who are Deaf – the Hearing Impairment ACE III (HI-ACE III).

One respondent advised they used the Telephone Interview for Cognitive Status (TICS) assessment, and three respondents referenced the Large Allen Cognitive Level Screen (LACLS). This latter test is designed to include people with Visual Impairment or reduced hand dexterity, but not for people who are Blind. There was uncertainty over the suitability of this cognitive assessment for people who are Deaf and/or who have a Visual Impairment, highlighting more guidance is required. Other cognitive assessment tools used included an adapted version of the Six Item Cognitive Impairment Test (6CIT), and the Assessment of Motor and Process Skills (AMPS) for the assessment of activities of daily living.⁸⁶

Notably, in the absence of specifically designed and validated cognitive assessments, respondents shared that they would adapt standard assessments including omitting items not able to be seen or heard correctly. This strategy shows health and medical professionals understand the limitations of assessment tools for people who are Deaf, Deafblind, or who have a Visual Impairment. However, it risks impacting on the integrity of the assessment tool in measuring different cognitive domains,⁸⁷ and in presenting these in a different language modality via a sign language interpreter.⁸⁸

An important finding from asking the question about specifically designed cognitive assessment tools for people who are Deaf, Deafblind and who have a Visual Impairment was the request for more training in this area. This offers confirmation that there is a gap in the knowledge and skills of health and medical professionals.

It is also welcome to note that most respondents included additional information about how people could be supported when undertaking a memory/dementia assessment through the use of communication tools and strategies. This demonstrates professional awareness of the potential barriers faced by people who are Deaf, Deafblind, and who have Visual Impairments. A list of the cognitive assessments covered in this report is available in Appendix F.

Care homes

Health and medical professionals were asked if there was anything different in the memory/dementia assessments they use with people living in care homes, who are also Deaf and/or have a Visual Impairment, including sign language users. This was an open text response question answered by 45 out of 108 (42%) respondents.

Sixteen reported that assessment in care homes was not part of their role, 10 responded they would not do anything different, and one stated they did not know. Key comments are as follows:

“Assessment wouldn't be different within a Care Home; however, often people in Care Homes are frailer or more impaired than our average assessment.” [Nursing]

“No [I don't do anything differently], I will however be more careful about the environment I complete assessments in when in a care home.” [Social Worker]

Seven respondents (16%) referred to non-technological and technological adaptations to support communication similar to those described previously, such as good communications strategies and using amplifiers, a communication App, picture cards and checking any

hearing aids or glasses are working properly and in-situ. Similar to one of the GP responses on the topic of care homes, one respondent commented on the challenges of memory/dementia assessment in this population stating, “It is very difficult therefore psychiatrist makes a judgement call.”

Sign Language Users

Several respondents gave specific reference to the assessment of sign language users living in care homes. This included one respondent who was not aware of any memory/assessment tools designed specifically for sign language users and four who stated they would use sign language interpreters or liaise with relevant professionals and experts where required. One respondent stated they would refer a sign language user to a Specialist Mental Health professional for their assessment, acknowledging that this was not their area of expertise.

One respondent shared their experience of using a BSL/English interpreter for the first memory/dementia assessment of a person in a care home, and then using basic BSL at follow-up visits. This professional also noted being aware of behavioural symptoms of dementia in a sign language user and the importance of observing changes in signing:

“I have experience of using BSL interpreters and would always use an interpreter for any initial assessment. I have some basic BSL myself so will just use that for any follow-up. However, I have noticed the importance of informal assessment and being able to recognise repetitive conversation in a BSL user with suspected dementia so I think informal observation and conversation plays a big part in assessment and should not be overlooked.”

[Occupational Therapist]

Summary

Health and social care professionals were asked if they would do anything differently when carrying out memory/dementia assessments in care homes. This question had the second lowest response rate in the survey (45 out of 108, 42%) after the question on when hearing and/or

sight assessments take place for people, and how often are they repeated. This relatively low response rate for care homes may indicate there is less engagement with this population across the range of non-GP health and social care professionals. Notably, 26 out of 45 people (58%) reported that either assessment in care homes was not part of their role or that they did not know if anything different would be involved. Seven of out 45 (16%) respondents shared they would use communication adaptations and strategies, similar to those described under the section on memory/dementia assessment tools designed specifically for people who are Deaf and/or have a Visual Impairment, including for sign language users.

For sign language users in care homes, one respondent stated they were not aware of any memory/assessment tools designed specifically for this population, highlighting the need for more training. Most respondents stated they would use sign language interpreters or relevant professionals and experts where required. It is welcome that one respondent advised they would refer sign language users to a Specialist Mental Health professional. This provides an example of good practice in understanding the scope of expertise and the specific needs of sign language users in accessing appropriate memory/dementia assessment diagnosis and post-diagnostic support pathways.

Reflections and recommendations: non-GP health and medical professionals

The survey for non-GP health and medical professionals provides important insight into the vast variety of practices and approaches used in memory/dementia assessments for people who are Deaf, Deafblind or who have a Visual Impairment.

Only 12% of survey respondents indicated they would assess both hearing and sight as part of a memory/dementia assessment. The remainder of responses reported not performing sensory assessments, or only do so if Deafness, Deafblindness or Visual Impairment is indicated. There is also evidence of variance of approaches within professions, for example, physiotherapists involved in memory/dementia

assessments within stroke services where sight assessments are standard practice.

These results are similar to those from the GPs survey. As such, we recommend that:

13. Diagnostic level hearing and sight assessments should be integrated within standard memory/dementia assessment practices for all health and medical professionals involved in the assessment of memory/dementia. This work should include updates to any relevant standards of practice across each profession so that sensory assessments take place as standard.
14. All health and medical professionals involved in the assessment of memory/dementia should ensure memory/dementia assessment practices are compliant with the Adults with Incapacity (Scotland) Act 2000 which regards access to sight and hearing care services as a “fundamental healthcare procedure”.
15. The SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia should be updated to state appropriate methods of identifying Deafness, Deafblindness or Visual Impairment. This should be shared with all health and medical professionals involved in the assessment of memory/dementia.

On the topic of when sensory assessments take place and how often they are repeated, only 37% (40 out of 108) of respondents answered this question indicating this may be a specific area of uncertainty for health and medical professionals. Most (24 out of 40, 60%) did not know, or stated that sensory assessments would not be performed routinely. Those who stated a sensory assessment would be performed at the initial assessment also inferred that repeat assessments would be undertaken “as indicated” rather than at planned intervals.

There was also a suggestion that sensory assessments were the role of GPs in primary care settings, however, the survey for GPs found that only 6% (five out of 78) of GPs specified that they would assess both sight and hearing as an integrated part of assessing memory/dementia highlighting that there is uncertainty over whose role it is to coordinate sensory assessments.

We recommend that:

16. A clear framework of professional responsibilities and appropriate recording for sensory assessments should be developed by professional bodies, with oversight by Scottish Government's Dementia Strategy. This should include alerts when sensory assessments have not been completed or are overdue, so that they are not overlooked as an integrated part of dementia assessment and post-diagnostic support. These responsibilities should be stated within each profession's standards on the assessment of dementia, as well as included in the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.
17. The Scottish Government's Dementia Strategy should address the lack of an alert system for gaps in fundamental healthcare procedures which span primary and secondary care through the creation of a dedicated working group or similar framework. This should include NHS Education for Scotland and other relevant stakeholders.

A minority (four out of 40, 10%) of health and social care professionals referred to national guidelines for hearing and sight assessments for people with dementia. These professionals demonstrated more knowledge of recommendations for eye care than hearing care, a finding also found in the survey for GPs. This universal gap in knowledge of guidance for hearing assessments needs addressed to ensure people's sensory needs are identified throughout dementia diagnosis and monitored during post-diagnostic support. We recommend that:

18. All professional standards and guidelines for the assessment of dementia should be updated to reference the NICE guidelines for hearing assessments, and national guidelines for sight assessments. We also recommend that any third sector organisations involved in supporting people with dementia are also supported with relevant information to ensure appropriate signposting for people who access these services.

On the topic of how health and medical professionals would establish Deafness, Deafblindness or Visual Impairment before commencing assessments for dementia and/or support planning, again a vast array of different approaches were reported, some more thorough than others but largely all subjective and lacking in formal diagnostic assessment.

Encouragingly, the most common method (41 out of 66, 62%) reported by respondents was to directly ask the person, their communication partners or other health and medical professionals as part of standard history taking. This indicates the importance of identifying sensory needs during memory/dementia assessments is largely recognised, and this is welcome. However, research shows self-report is not a reliable strategy for identifying Deafness and/or Visual Impairment when compared with formal diagnostic assessment.

Another common approach (39 out of 66, 59%) was to check medical records, though this involved reliance on the GP or initial referrer to identify Deafness, Deafblindness or Visual Impairment. The GP survey found that only five out of 78 (6%) GPs specified they would assess both sight and hearing as an integrated part of assessing memory/dementia meaning there is a risk Deafness, Deafblindness or Visual Impairment may continue to be unidentified throughout dementia diagnosis and post-diagnostic support pathways. This is because health and medical professionals assume results of sensory investigations have been reported accordingly.

A minority (two out of 66, 3%) of health and medical professionals reported they would establish Deafness, Deafblindness or Visual Impairment before commencing assessments for dementia and/or

support planning by arranging a referral to vision or hearing care services. The corresponding figure was higher in the survey for GPs (13 out of 69, 19%), again indicating there may be a reliance on GPs or initial referrers to identify Deafness, Deafblindness or Visual Impairment.

This may be in part because non-GP health and medical professionals do not appear to have access to any formal sensory assessment tools – diagnostic or screening, whereas the survey for GPs included references to some, albeit these were largely subjective. Official guidance is required on best practice approaches to identification and monitoring of Deafness, Deafblindness and Visual Impairment across all professionals involved in memory/dementia assessments, and post-diagnostic support planning. We recommend that these should be included with a framework of sensory care standards, and also across all guidelines for the assessment of dementia, and with professional training updates.

On the topic of specifically designed assessment tools for people with Deafness and/or Visual Impairment, or for sign language users, encouragingly over half (35 out of 64, 55%) of health and medical professionals reported that they did use specifically designed tools. However, none referenced specific assessment tools for people with both Deafness and Visual Impairment, which highlights an area for further training and guidance.

Respondents referenced using five different cognitive assessments (MoCA, ACE III, TICS, LACLS and 6CIT) and one assessment of the activities of daily living (AMPS). From these, two versions were referenced which have been validated for use with people with Deafness and Visual Impairment (HI-ACE III and MoCA Blind). The TICS assessment is likely to be suitable for use with people with Visual Impairment, given that it can be delivered over the phone meaning it is not reliant on visual acuity. It is not evident that the rest of the cognitive assessments reported by health and medical professionals are suitable for people who are Deaf, Deafblind or who have a Visual Impairment. In the absence of specifically designed and validated cognitive assessments, respondents shared that they would adapt standard assessments including omitting items not able to be seen or heard

correctly. This strategy shows health and medical professionals understand the limitations of assessment tools for people who are Deaf, Deafblind or who have a Visual Impairment. However, it risks impacting on the integrity of the assessment tool in measuring different cognitive domains⁸⁹, and in presenting these in a different language modality via a sign language interpreter.⁹⁰ This indicates that more training and guidance is required on suitable assessments and acceptable modifications. The requests for more training in this area, and confirmation that this was a gap in the knowledge and skills of health and medical professionals is a welcome finding.

In keeping with recommendations derived from the results of the survey for GPs, we recommend that:

19. Recommendations 7 and 8 should be extended to all health and medical professionals who assess memory/dementia.

In terms of care homes, the results of the survey make it evident that many health and medical professionals who responded were not involved in working with this specific population. For those who were, respondents noted that either they did not know if anything different would be involved, or they would use communication tools and strategies to support memory/dementia assessments.

For sign language users in care homes, most respondents stated they would use sign language interpreters or relevant professionals and experts where required. It is welcome that one respondent advised they would refer sign language users to a Specialist Mental Health professional. This provides an example of good practice in understanding scope of professional expertise and the specific needs of sign language users in accessing appropriate memory/dementia assessment diagnosis and post-diagnostic support pathways.

We suggest:

20. Recommendation 12 should extend to include all health and medical professionals who assess memory/dementia.

Sensory assessment services

This section reports on the findings of the survey for NHS Audiology services for adults, and the survey for eyecare specialists.

Adult audiology services

The survey for NHS Audiology services for adults was distributed to the Head of Service for each Health Board in Scotland. The survey comprised three questions. The first two questions related to the relationship between NHS Audiology services for adults and memory/dementia clinics, and the last question asked about the relationship between NHS Audiology services for adults and eye care services.

The survey was completed by 12 respondents. As no demographic data was collected for reasons of anonymity, it was not possible to report on how many Health Boards are represented within the data. Health Boards can have audiology departments in different locations and Heads of Service may have distributed the survey internally to each department lead to capture local protocols. For example, NHS Greater Glasgow and Clyde has audiology services across eight sites and intersects with different local authorities. It is not then clear if or how referral protocols differ within this one Health Board due to local variations in service provision. The results of the 12 survey responses were therefore analysed in the context of this NHS infrastructure.

Referral routes between audiology and memory/dementia clinics

The survey for NHS Audiology services for adults asked respondents if their audiology service has a direct referral route to or from memory/dementia clinics. All 12 (100%) respondents answered this question. Seven (58.3%) selected that there was no direct referral route and three (25%) selected that a direct referral route was available from memory clinics to audiology services.

Two respondents selected “other”, with one stating their audiology department has direct referral pathways in place from all medical professions for people from the age of 50 years. Another stated that,

“any hospital medical specialty can refer via the SCI [Scottish Care Information] Gateway to audiology.”

The SCI Gateway is implemented in every Health Board in Scotland integrating primary and secondary care services for secure access to patient information. This means that every audiology department has the infrastructure in place to receive memory/dementia clinic referrals. Given that over half of respondents indicated that there is no direct referral route either to or from memory/dementia clinics, this highlights an area for further investigation to better understand why an awareness of the SCI Gateway for this purpose does not seem to be widely known or used.

Dementia pathways and support for hearing assessments

Respondents were asked if their audiology service offers support for hearing assessments as part of an established memory/dementia assessment pathway. Nine out of twelve (75%) respondents selected “no” and one selected “unsure”.

Two respondents stated they did have an established memory/dementia assessment pathway. Providing more details on this pathway, both responses described modifications made to the format of hearing assessment clinics at audiology for people with dementia. One respondent said a longer appointment time would be allocated, and the other advised of a special Cognition Clinic within the audiology department which people could access via referral triage by audiology.

None of the respondents indicated that they had a hearing assessment clinic embedded within a memory/dementia assessment clinic to support clinicians in their cognitive assessment selection, similar to those embedded within Ear, Nose and Throat clinics to support consultants to make clinical decisions about people accessing their services. From this perspective, there does not appear to be formal integration of NHS audiology services within dementia pathways.

Referral to ophthalmology and eye care services

The final question on the survey for NHS audiology services for adults asked if the audiology service has a direct referral route to or from ophthalmology and/or eye care services. All 12 (100%) respondents answered this question. From the four options, 11 out of 12 (92%) advised there was no direct referral route to or from ophthalmology/eye care services.

However, one respondent highlighted that referral can be made to audiology from any medical professional, but that this does not extend to those eye care professionals delivering private eye care in the community:

“Any medic within the [Health] Board can refer for a patient for [a hearing] assessment but not from the high street.” [Audiology professional]

Reflections and recommendations

The survey for NHS Audiology services for adults was completed by 12 respondents, each representing different services for adults across Scotland. In terms of referral routes between audiology services and memory/dementia clinic/s, there was some ambiguity in responses. Most respondents (seven out of 12, 58.3%) selected there was no direct referral route, with three out of 12 (25%) reporting that a direct referral route was available from memory clinics to audiology services.

In contrast, one respondent advised all medical professions for people from the age of 50 years could refer to audiology services, and another referred to the Scottish Care Information (SCI) Gateway which is implemented in every Health Board in Scotland and enables referral from all medical professions. This implies a framework exists across Scotland for memory/dementia clinics to refer to NHS audiology services for adults.

As such:

21. We recommend further research with NHS audiology services for adults to clarify how well known the SCI Gateway referral pathway is. We suggest that data should be collected and analysed on the number of referrals received by audiology services for adults from memory/dementia clinics, along with waiting times from referral to hearing assessment. This would enable the effectiveness of this referral pathway to be evaluated and further recommendations made on ensuring timely access to sensory assessment for the person, and timely access to results for the memory/dementia clinic/s.

Respondents were asked if their audiology service offers support for hearing assessments as part of an established memory/dementia assessment pathway. Nine out of twelve (75%) respondents selected “no” and one selected “unsure”. Two respondents described modifications made to the format of hearing assessment clinics within audiology for people with dementia.

None of the respondents described the provision of a hearing assessment clinic embedded within a memory/dementia assessment clinic to support health and medical professionals as part of memory/dementia assessments. Precedence for hearing assessment support in this form is seen at Ear, Nose and Throat clinics to support consultants with clinical decision-making.

At present, there does not appear to be any formal integration of NHS audiology services for adults within dementia pathways.

We recommend that:

22. As part of the Scottish Government’s See Hear Strategy mainstreaming approach, the gap in integration should be covered both by implementation of the recommendations from the Independent Review of Audiology Services in Scotland (IRASS) in improving access to audiology services, and the

Scottish Government's Dementia Strategy, to achieve "accessible and timely diagnosis" of dementia. A cross-policy working group between the policy area responsible for audiology services and the Dementia Strategy should be formed to develop an effective integrated care pathway. Such an approach would ensure specific and realistic resourcing is allocated to NHS audiology services, and the model could take a similar form to the audiology support provided for Ear, Nose and Throat clinics.

In terms of a direct referral route to or from ophthalmology and/or eye care services, almost all respondents (11 out of 12, 92%) advised there was no direct referral route. One respondent again referred to what is presumably the SCI Gateway where any medical professional can make a referral to audiology services, the exception being that this cannot be done from a high street eye care provider.

A limitation of the survey for NHS audiology services for adults was that a comparable survey was not distributed to private providers of hearing care, of which there were 263 Hearing Aid Dispensers registered as working in Scotland as of 25 November 2024.

We recommend that:

23. Future research should address the gap in data collection to inform timely referral pathways for people accessing memory/dementia assessments, and timely access to results in the form of shared and accessible sensory data for health and medical professionals.

Eye care specialists

As previously described in the methodology section of this report, eye examinations are fully funded by the NHS in Scotland and can be accessed through community optometry practices, also known as opticians. Community eye care specialists can refer people to NHS hospital eye care services such as ophthalmology if required. As such, eye care specialists span both the public and private sectors.

This makes eye care distinct in structure from delivery of hearing care whereby initial access to NHS audiology services for adults is largely via referral from primary care health and medical professionals such as GPs. In addition, NHS funded hearing assessments are not available from private hearing care providers.

These differences in frameworks lead to questions over the integration of sensory services between each other (eye care and hearing care), and each with memory/dementia clinics to ensure professionals can access relevant information about hearing and sight to inform appropriate dementia diagnosis and post-diagnostic support planning.

The survey for eye care specialists was completed by 113 respondents, the majority of which were optometrists (83.2%). The remaining 16.3% of respondents spanned the following roles: ophthalmologist, ophthalmic nurse, dispensing optician, orthoptist, and optical practice owner.

Referral routes between eye care services and memory/dementia clinics

Similar to the survey for NHS Audiology services for adults, respondents were asked if their eye care service has a direct referral route to or from memory/dementia clinics. All 113 (100%) participants answered this question. The vast majority of respondents, 93 out of 113 (82%), selected that there was no direct referral route to or from memory/dementia clinics. One (0.9%) selected there was a direct referral to memory clinics and one (0.9%) selected that there was direct referral both to and from memory clinics. Sixteen out of 113 (14%) selected that they were not sure.

From the remaining two respondents who selected 'other', one respondent advised there was, "just standard referral either way as every other referral is", and the other stated that direct referral was only an option for people living in a care home.

Dementia pathways and support for sight assessments

Respondents were asked if their eye care service offers support for vision assessments as part of an established memory/dementia assessment pathway. All 113 (100%) participants answered this question with the majority, 86 out of 113 (76%) selecting 'no'. Twenty-three out of 113 (20%) stated they were unsure, and 4 out of 113 (4%) selected yes, their eye care service did support for vision assessments as part of an established memory/dementia assessment pathway.

The four respondents who answered yes gave further details on the assessment pathway between eye care services and memory/dementia clinics. One stated that, "low vision clinics [are] available but [I] do not know whether as part of established memory/dementia assessment pathway", indicating that further enquiry is required to confirm an assessment pathway exists. Another respondent simply stating "RNIB", referencing a major third sector organisation for people who have Visual Impairments.

The third respondent stated that referral pathways were not clear, and more training is required to raise awareness of support for people with visual perception differences and dementia:

"There is no clear referral pathway and eyecare and other healthcare professionals do not appear to understand what support can be offered to patients with visual processing issues as a result of dementia." [Eye Care Professional]

A link to possible improvements or changes in referral pathways was highlighted by a respondent whose eye care services participated in clinical trials for memory clinics. The outcome of these trials and any information on the integration of eye care services and

memory/dementia assessments is worth exploring to keep informed of any national developments in this area:

“We are involved in some clinical trials with [name of specific memory clinic]” [Eye Care Professional]

Referral to hearing care services

Survey respondents were asked if their eye care service has a direct referral route to or from audiology and/or hearing care services. All 113 (100%) participants answered this question. The majority of respondents, 80 out of 113 (71%), selected that there was no direct referral route. Three out of 113 (3%) selected that there was a direct referral to audiology/hearing care services, 1/113 (0.9%) selected that there was a direct referral from audiology/hearing care services, and 6 out of 113 (5%) selected that there was a direct referral route both to and from audiology/hearing care services. Nineteen out of 113 respondents (17%) selected they were unsure, and 4 out of 113 (4%) selected ‘other’.

Additional comments highlighted the integration of vision and hearing care services within a private provider and the ability to assess both hearing and sight from a single location without referring to NHS services:

“We provide private hearing care services in practice but there is no direct link to NHS provision.” [Eye Care Professional]

“Although no direct referral route, we do offer in practice hearing care including testing.” [Eye Care Professional]

One eye care specialist indicated that requests for referral for hearing assessment when people are attending eye care appointments occur frequently showing people need to access both services. This might be related to the growing numbers of people in Scotland with both age-related Deafness and Visual Impairment.⁹¹ The respondent shared the following comment:

“Often we are asked by families for referral to an audiology and/or hearing care service.” [Eye Care Professional]

Reflections and recommendations

The survey for eye care specialists was completed by 113 respondents, most of whom were optometrists, but which also spanned ophthalmologists, ophthalmic nurses, dispensing opticians, orthoptists, and optical practice owners.

Respondents were asked if their eye care service has a direct referral route to or from memory/dementia clinics. The majority (93 out of 113, 82%) reported that there was no direct referral route to or from memory/dementia clinics, with 16 out of 113 (14%) selecting they were unsure. Only one respondent reported there was a direct referral route to memory clinics, and one respondent stated that there was direct referral route both to and from memory clinics. Notably, one respondent highlighted an exception to there not being a direct referral route to memory/dementia clinics, with one available only for care home residents.

This data is consistent with references by GPs and other health and medical professionals reported in corresponding surveys described in earlier sections of this report. Specifically, on the use of signposting to eye care services instead of making referrals, due to the widespread availability of community eye care services.

Eye care specialists were asked if their service offers support for vision assessments as part of an established memory/dementia assessment pathway. Most respondents (86 out of 113, 76%) stated they did not, and a further 20% (23 out of 113) stated they were unsure. This implies that there is no provision of a vision assessment clinic embedded within a memory/dementia assessment clinic in which to support health and medical professionals as part of memory/dementia assessments.

From the remaining four respondents, only one described an embedded framework of support for vision assessments as part of an established

memory/dementia assessment pathway. This example was for eye care services participating in clinical trials for memory clinics.

We recommend that:

24. Health Boards and Scottish Government should publish data about the integration of eye care services and memory/dementia assessments at regular intervals, alongside plans for national developments to integrate eye care and memory clinics. This would inform the assessments and post-diagnostic support section of a framework of sensory care standards.

An important point was made by one eye care professional on referral pathways to and from memory/dementia clinics, stating that there are no clear referral pathways to and from eye care services for people with dementia and visual processing difficulties. As such, more training is required for health and medical professionals to raise awareness of the support available.

We recommend that:

25. Clear guidance should be developed and published by the Scottish Government's Dementia Strategy to ensure timely onward referral and appropriate management options for people experiencing changes in sensory perception as a result of dementia.

In terms of direct referral between eye care and hearing care services, most respondents (80 out of 113, 71%) advised there was no direct referral route, and 17% (19 out of 113) stated they were unsure as to whether one existed. This implies that those services who do offer any direct referral pathway, to or from hearing care services, are in the minority. These results are consistent with the corresponding question in the survey of NHS audiology services for adults where almost all respondents (11 out of 12, 92%) advised there was no direct referral

route to eye care services. In short, the connection between eye care services and NHS audiology services for adults is largely limited. An advantage reported for private providers was the integration of eye and hearing care services within a single location, these were easily accessible and avoided waiting times associated with a GP referral to NHS audiology services. One eye care respondent commented that requests by families for hearing assessments were common, indicating there is an established interest in monitoring sensory health across both hearing and sight.

We recommend:

26. The integration of sensory assessment services with memory/dementia clinics should be improved through updating the Scottish Government's Dementia Strategy and SIGN 168. Streamlining sensory assessment services with each other would mean people with dementia and Deafness, Deafblindness or Visual Impairment can access NHS funded sensory care in a timely and accessible manner. Clear guidance should be developed and published by Scottish Government in collaboration with relevant stakeholders, so that both eye care and hearing care specialists across public and private provision are clear in their responsibilities. Guidance should also include the requirements for information sharing across sensory assessment providers, and with health and medical professionals involved in diagnosing dementia and post-diagnostic support. This would help consolidate an integrated care model for sensory assessment and memory/dementia assessment in keeping with the aims of the Scottish Government's Dementia Strategy. A Dementia Strategy working group or similar involving key stakeholders such as eye and hearing care professionals would be well placed to develop guidance.

Overall reflections and recommendations

The aim of the working group on sensory care and dementia is to improve care pathways and provision of support for people with dementia who are Deaf, Deafblind or who have a Visual Impairment, through developing the first framework of sensory care standards for Scotland.

The framework of sensory care standards will centre around several core areas, one of which will be sensory assessment. Research shows that dementia care professionals, and eye and hearing care professionals, commonly do not support people with dementia through a system of integrated care, which includes during the assessment of dementia.⁹²

We wanted to know if or how sensory assessments feature as part of any dementia assessment pathway in Scotland, or during post-diagnostic support. Identifying Deafness, Deafblindness or Visual Impairment before commencing a dementia assessment is vital for two main reasons:

- People accessing dementia services have a right to receive information in an accessible format.
- Deafness, Deafblindness and Visual Impairment can lead to communication barriers which mirror dementia symptoms. For example, reduced understanding, repeating questions, memory problems and difficulties following conversations. Standard memory/dementia assessments used by professionals are often not suitable – these assessments cannot detect the difference between difficulties from brain changes caused by dementia, and those affecting communication from Deafness, Deafblindness or Visual Impairment.

This research explores the practices of health and medical professionals who carry out memory/dementia assessments for people who are Deaf,

Deafblind or who have a Visual Impairment, including BSL users, and the hearing care and eye care specialists who assess hearing and sight.

The major findings from this research are that there are large variations in practice of the assessment of dementia in people who are Deaf, Deafblind, or who have a Visual Impairment, including BSL users. There is also a lack of integrated care pathways between dementia assessment and sensory assessment. These findings will inform a framework of sensory care standards. Throughout this report, we have included our reflections and recommendations. For ease of reference, the recommendations from this research are listed below.

1. Diagnostic level hearing and sight assessments should be integrated within standard memory/dementia assessment practices for GPs. These are stated as “considerations” in the NICE guidelines for the assessment of dementia, but we would recommend this wording be strengthened so that sensory assessments take place as standard.
2. Memory/dementia assessment practices should be compliant with the Adults with Incapacity (Scotland) Act 2000, which regards access to sight and hearing care services as a “fundamental healthcare procedure”.
3. The SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, and the Royal College of General Practitioners’ Deafness and hearing loss toolkit, should be updated to state appropriate methods of identifying Deafness, Deafblindness or Visual Impairment, and include national guidelines on when these assessments should be repeated.
4. These guidelines should also state which sight and hearing care professionals have the appropriate scope of practice to assess hearing and sight in people living with dementia and are therefore suitable to signpost or refer to.

5. The Scottish Government's Dementia Strategy, in partnership with NHS audiology and eyecare services, should work together to enable timely access to hearing and sight assessments for the person, and timely access to results for GPs.
6. Timely access to NHS audiology services for people being assessed for dementia should be considered a priority within Scottish Government's implementation of the recommendations from the Independent Review of Audiology Services in Scotland (IRASS). This would ensure appropriate service planning and resources are available to support the vast numbers of people with dementia in Scotland.
7. The SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, and the NICE guidelines for the assessment of dementia, should be updated with a list of suitable memory/dementia assessments for people with Deafness, Deafblindness or Visual Impairment, and clearly state that standard assessments are unsuitable.
8. Use of suitable memory/dementia assessments for people with Deafness, Deafblindness or Visual Impairment should be included in GP's dementia training and relevant assessment tools should be available for use across Scotland.
9. Sensory care standards should state that sensory assessments are an integrated part of a person's transition to residential care, with the results of assessments accessible to GPs through medical records and care plans.
10. Sensory care management plans should be accessible and clearly state when repeat sensory assessments should take place as part of post-diagnostic support to monitor both sensory and brain health changes.

11. Memory/dementia assessment practices in care homes should be compliant with the Adults with Incapacity (Scotland) Act 2000 which regards access to sight and hearing care services as a “fundamental healthcare procedure”.
12. We recommend that the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia, and the NICE guidelines for the assessment of dementia, should be updated to include clear statements on the assessment of dementia for people who are sign language users.
13. Diagnostic level hearing and sight assessments should be integrated within standard memory/dementia assessment practices for all health and medical professionals involved in the assessment of memory/dementia. This work should include updates to any relevant standards of practice across each profession so that sensory assessments take place as standard.
14. All health and medical professionals involved in the assessment of memory/dementia should ensure memory/dementia assessment practices are compliant with the Adults with Incapacity (Scotland) Act 2000 which regards access to sight and hearing care services as a “fundamental healthcare procedure”.
15. The SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia should be updated to state appropriate methods of identifying Deafness, Deafblindness or Visual Impairment. This should be shared with all health and medical professionals involved in the assessment of memory/dementia.
16. A clear framework of professional responsibilities and appropriate recording for sensory assessments should be developed by professional bodies, with oversight by Scottish

Government's Dementia Strategy. This should include alerts when sensory assessments have not been completed or are overdue, so that they are not overlooked as an integrated part of dementia assessment and post-diagnostic support. These responsibilities should be stated within each profession's standards on the assessment of dementia, as well as included in the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

17. The Scottish Government's Dementia Strategy should address the lack of an alert system for gaps in fundamental healthcare procedures which span primary and secondary care through the creation of a dedicated working group or similar framework. This should include NHS Education for Scotland and other relevant stakeholders.
18. All professional standards and guidelines for the assessment of dementia should be updated to reference the NICE guidelines for hearing assessments, and national guidelines for sight assessments. We also recommend that any third sector organisations involved in supporting people with dementia are also supported with relevant information to ensure appropriate signposting for people who access these services.
19. Recommendations 7 and 8 should be extended to all health and medical professionals who assess memory /dementia.
20. Recommendation 12 should extend to include all health and medical professionals who assess memory/dementia.
21. We recommend further research with NHS audiology services for adults to clarify how well known the SCI Gateway referral pathway is. We suggest that data should be collected and analysed on the number of referrals received by audiology services for adults from memory/dementia clinics, along with waiting times from referral to hearing assessment. This would enable the effectiveness of this referral pathway to be

evaluated and further recommendations made on ensuring timely access to sensory assessment for the person, and timely access to results for the memory/dementia clinic/s.

22. As part of the Scottish Government's See Hear Strategy mainstreaming approach, the gap in integration should be covered both by implementation of the recommendations from the Independent Review of Audiology Services in Scotland (IRASS) in improving access to audiology services, and the Scottish Government's Dementia Strategy to achieve "accessible and timely diagnosis" of dementia. A cross-policy working group between the policy area responsible for audiology services and the Dementia Strategy should be formed to develop an effective integrated care pathway. Such an approach would ensure specific and realistic resourcing is allocated to NHS audiology services, and the model could take a similar form to the audiology support provided for Ear, Nose and Throat clinics.
23. Future research should address the gap in data collection to inform timely referral pathways for people accessing memory/dementia assessments, and timely access to results in the form of shared and accessible sensory data for health and medical professionals.
24. Health Boards and Scottish Government should publish data about the integration of eye care services and memory/dementia assessments at regular intervals, alongside plans for national developments to integrate eye care and memory clinics. This would inform the assessments and post-diagnostic support section of a framework of sensory care standards.
25. Clear guidance should be developed and published by the Scottish Government's Dementia Strategy to ensure timely onward referral and appropriate management options for

people experiencing changes in sensory perception as a result of dementia.

26. The integration of sensory assessment services with memory/dementia clinics should be improved through updating the Scottish Government's Dementia Strategy and SIGN 168. Streamlining sensory assessment services with each other would mean people with dementia and Deafness, Deafblindness or Visual Impairment can access NHS funded sensory care in a timely and accessible manner. Clear guidance should be developed and published by Scottish Government in collaboration with relevant stakeholders, so that both eye care and hearing care specialists across public and private provision are clear in their responsibilities. Guidance should also include the requirements for information sharing across sensory assessment providers, and with health and medical professionals involved in diagnosing dementia and post-diagnostic support. This would help consolidate an integrated care model for sensory assessment and memory/dementia assessment in keeping with the aims of the Scottish Government's Dementia Strategy. A Dementia Strategy working group or similar involving key stakeholders such as eye and hearing care professionals would be well placed to develop guidance.

Appendix A

Number of General Practitioner survey respondents by Health Board area

(Respondents could select more than one Health Board)

Health Board	Number of respondents
NHS Ayrshire and Arran	2
NHS Fife	8
NHS Forth Valley	4
NHS Grampian	10
NHS Greater Glasgow and Clyde	30
NHS Highland	15
NHS Tayside	8
NHS Western Isles	2

Appendix B

Number of health and medical professional (not GPs) survey respondents by profession

Health and medical profession	Number of respondents
Allied Health Professional	
Unspecified	8
Dietetics	2
Occupational Therapy	17
Physiotherapy	12
Podiatry	1
Speech and Language Therapy	5
Nursing	11
Dementia care	6
Mental health services	17
Rehabilitation	3
Medical	
Medical professional (unspecified)	1
Old age psychiatry	1
Orthopaedics	1
Social work	1
Social care	
Care at home services	1
Housing association	1

Appendix C

Number of health and medical professional (not GPs) survey respondents by Health Board area

(Respondents could select more than one Health Board)

Health Board	Number of respondents
NHS Ayrshire and Arran	4
NHS Borders	4
NHS Dumfries and Galloway	2
NHS Fife	13
NHS Forth Valley	2
NHS Grampian	6
NHS Greater Glasgow and Clyde	23
NHS Highland	4
NHS Lanarkshire	6
NHS Lothian	21
NHS Shetland	1
NHS Tayside	5
NHS Western Isles	1

Appendix D

Number of eye care specialist survey respondents by specialism

Eye care specialism	Number of respondents
Optometrist	94 (83.2%)
Ophthalmologist	8 (7.1%)
Ophthalmic nurse	1 (0.9%)
Dispensing optician	4 (3.5%)
Orthoptist	5 (4.4%)
Optical Practice Owner	1 (0.9%)
Total	113 (100%)

Appendix E

Number of eye care specialist survey respondents by Health Board area

(Respondents could select more than one Health Board)

Health Board	Number of respondents
NHS Ayrshire and Arran	8
NHS Borders	8
NHS Dumfries and Galloway	3
NHS Fife	9
NHS Forth Valley	12
NHS Grampian	21
NHS Greater Glasgow and Clyde	20
NHS Highland	11
NHS Lanarkshire	28
NHS Lothian	22
NHS Orkney	1
NHS Shetland	1
NHS Tayside	17
NHS Western Isles	2
NHS National Waiting Times Centre	2

Appendix F

Glossary of cognitive assessments

Assessment of Motor and Process Skills (AMPS)

The AMPS is commonly used by Occupational Therapists. It is an observational assessment examining Activities of Daily Living (ADL). This assessment is not currently included the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia

Addenbrooke's Cognitive Examination (ACE)

The ACE III is a screening tool suitable for people over 50 years old. It takes about 15 minutes to complete and is scored out of 100. The tool measures five different cognitive domains: attention, memory, verbal fluency, language and visuospatial abilities. Questions rely on hearing and sight.

The Mini ACE is a shorter version of the ACE III. It is scored out of 30 and can be completed in around five minutes. Questions rely on hearing and sight.

Both the ACE III and the Mini ACE are available free of charge to the NHS and have been included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

The Hearing Impairment ACE III (HI-ACE III) is a version of the ACE III for people with Deafness who use spoken language (it is not suitable for BSL users). It is presented via slideshow so that the questions and tasks can be read. This assessment is available for free alongside other the other versions of the ACE III on the University of Sydney Brain and Mind Centre's website. It is not currently included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

British Sign Language Cognitive Screening Test (BSL-CST)

The BSL CST is a validated cognitive assessment tool for BSL users from 50-89 years old. The tool measures six different cognitive domains including memory, language, executive function, visuospatial ability, orientation and attention. The assessment is designed for qualified clinical psychologists with BSL qualifications to a fluent level. It is not designed for use with BSL/English interpreters.⁹³ This assessment is not currently included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

Large Allen Cognitive Level Screen (LACLS)

The LACLS is a modified version of the Allen Cognitive Level Screen (ACLS). This cognitive screen involves a physical stitching tool whereby the person is asked to perform stitches which increase in complexity. The LACLS was designed for people with Vision Impairment or hand function difficulties. This assessment is not currently included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

Mini Mental State Examination (MMSE)

The MMSE is an 11-item cognitive screening tool which measures six different cognitive domains including: orientation, registration, attention and calculation, recall, and language. It takes up to 10 minutes to complete and is scored out of 30. This assessment is included within Healthcare Improvement Scotland's national clinical guideline for the assessment of dementia.

Montreal Cognitive Assessment (MoCA)

The MoCA has different versions, all validated and available for free on the MoCA Cognition website⁹⁴. The full version measures several cognitive domains including: short-term memory, visuospatial abilities, executive functions, attention, concentration, and working memory, language, and orientation to time and place. It takes around 10 minutes to complete and is scored out of 30.

The MoCA-H is a validated version of the full MoCA for people with Deafness who use spoken language (it is not suitable for BSL users).

Instructions and questions are presented in written format instead of spoken. The MoCA Blind is also an adapted version of the full MoCA and can also be used over the telephone because the visual items have been removed. This takes around 10 minutes to complete and is scored out of 22.

The standard MoCA is included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia - the MoCA Blind and MoCA-H versions are not.

We understand that both the MoCA Blind and the MoCA-H will be renamed at a future date. The MoCA Cognition website will list the new names as follows:

- **MoCA-V Audio Version:** This can be used with people with Visual Impairment
- **MoCA-H Visual Version:** This can be used with people with Deafness who use spoken language (not sign language users).

Six-item Cognitive Impairment Test (6CIT)

The 6CIT is a validated cognitive screening assessment containing six items including: orientation, counting backwards, reciting a list in reverse order, and recalling an address. It takes up to 10 minutes to complete. The 6CIT is included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

Tactile Working Memory Scale (TWMS)

The TWMS is an assessment tool for working memory which uses tactile modality meaning it relies on touch instead of hearing and sight. It has been validated for use for people with congenital Deafblindness, and brain-related Visual Impairment and Deafness. It has not yet been validated for use in people with dementia and is not included within the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

Telephone Interview for Cognitive Status (TICS)

The TICS is a cognitive screening assessment which was designed to be delivered over the telephone. It covers several cognitive domains including: orientation, concentration, short-term memory, language, praxis, and mathematical skills. It was not specifically designed for people with Visual Impairment but it does not contain any visual items. The TICS is included in the SIGN 168 national clinical guideline for the assessment, diagnosis, care and support for people with dementia.

Appendix G

Survey questions for GPs

1. What NHS area of Scotland do you work in?
2. Do you assess people's hearing and/or sight as part of a memory/dementia assessment?

No

We assess both sight and hearing

We assess everyone's sight, but not hearing

We assess everyone's hearing, but not sight

We only assess when hearing and/or sight loss is suspected

Unsure

Other (please specify):

3. How do you establish whether someone has sight and/or hearing loss before you commence assessments for dementia and/or support planning?
4. Do you use any memory/dementia assessment tools designed specifically for people with hearing loss and/or sight loss? This includes tools for sign language users.

No - I'm not aware of any tools designed specifically for people with hearing loss, sight loss or sign language users

No - I don't have access to any tools designed specifically for people with hearing loss, sight loss or sign language users

Yes (please specify assessment tools used):

Please use the space below to provide any comments on memory/assessment tools designed specifically for people with hearing loss, sight loss or sign language users:

(Free text box)

5. Is there anything different in the memory/dementia assessments you use with people living in care homes who have hearing loss, sight loss or who use sign language?

(Free text box)

Survey questions for health and medical professionals (not GPs)

1. What NHS area of Scotland do you work in?
2. What area of healthcare, allied health, or healthcare sciences do you work in?
(Free text box)
3. Do you assess hearing and sight as part of a memory/dementia assessment?

No

We assess both sight and hearing

We assess everyone's sight but not hearing

We assess everyone's hearing but not sight

We only assess when hearing and/or sight loss is suspected

Unsure

Other (please specify):

4. When do hearing and/or sight assessments take place for people and how often are they repeated?
(Free text box)
5. How do you establish whether someone has sight and/or hearing loss before you commence assessments for dementia and/or support planning?
(Free text box)
6. Do you use any memory/dementia assessment tools designed specifically for people with hearing/sight loss? This includes tools for sign language users.

No - I'm not aware of any assessment tools designed specifically for people with hearing/sight loss or sign language users

No - my Health Board does not have access to any assessment tools design specifically for people with hearing/sight loss or sign language users

Yes (please specify assessment tool/s used)

Please use this space to add any comments on memory/dementia assessment tools for people with hearing/sight loss or sign language users:

(free text box)

7. Is there anything different in the memory/dementia assessments you use with people living in care homes with hearing/sight loss or who are sign language users?

(Free text box)

Survey questions for NHS audiology service for adults

1. Does your Audiology department have a direct referral route to or from memory/dementia clinics?

Yes - direct referral to memory clinic/s

Yes - direct referral from memory clinic/s

Yes, both to and from memory clinic/s

No direct referral route

Unsure

Other (please specify):

2. Does your Audiology department offer support for hearing assessments as part of an established memory/dementia assessment pathway?

No

Unsure

Yes (please specify):

3. Does your Audiology department have a direct referral route to or from Ophthalmology and/or eyecare services?

Yes - direct referral to ophthalmology/eye care services

Yes - direct referral from ophthalmology/eye care services
Yes, both to and from ophthalmology/eye care services
No direct referral route
Unsure
Other (please specify):

Survey questions for eye care specialists

1. What is your eye care profession?

Ophthalmologist
Ophthalmic nurse
Optometrist
Dispensing optician
Orthoptist
Other (please specify):

2. What NHS area of Scotland do you work in?
(Answers are a list of Health Boards to select from)

3. Does your eye care service have a direct referral route to or from memory/dementia clinics?

Yes - direct referral to memory clinic/s
Yes - direct referral from memory clinic/s
Yes, both to and from memory clinic/s
No direct referral route
Unsure
Other (please specify):

4. Does your eye care service offer support for vision assessments as part of an established memory/dementia assessment pathway?

No
Unsure
Yes (please specify):

5. Does your eye care service have a direct referral route to or from audiology and/or hearing care services?

Yes - direct referral to audiology/hearing care services

Yes - direct referral from audiology/hearing care services

Yes, both to and from audiology/hearing care services

No direct referral route

Unsure

Other (please specify):

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector membership organisation for the health and social care sector. We bring together over 3,500 people and organisations dedicated to achieving our vision of a Scotland where everyone has a strong voice and enjoys the right to live well, with dignity and respect. Our members are essential in creating a society in which we all can thrive, and we believe that by working together, our voice is stronger.

We work to improve the wellbeing of people and communities across Scotland by supporting change in health, social care and other public services so they better meet the needs of everyone in Scotland. We do this by bringing together the expertise of people with lived experience, the third sector, and organisations across health and social care to shape better services and support positive change.

The ALLIANCE has three core aims. We seek to:

- **Empower people with lived experience:** we ensure disabled people, people with long term conditions, and unpaid carers are heard and that their needs remain at the heart of the services and communities.
- **Support positive change:** we work within communities to promote co-production, self management, human rights, and independent living.
- **Champion the third sector:** we work with, support and encourage co-operation between the third sector and health and social care organisations.

The ALLIANCE is committed to upholding human rights. We embed lived experience in our work and aim to ensure people are meaningfully involved at every level of decision-making. Working together creates positive, long-lasting impact.

We work in partnership with the Scottish Government, NHS Boards, universities, and other key organisations within health, social care, housing, and digital technology to manage funding and develop successful projects. Together, our voice is stronger, and we can create meaningful change.

The ALLIANCE Scottish Sensory Hub

The ALLIANCE Scottish Sensory Hub provides a platform for the voice of lived experience for anyone in Scotland with lived experience of Deafness, Deafblindness or Visual Impairment. It was launched in 2021 and draws experience from deafscotland (formerly the Scottish Council on Deafness) and SCOVl (Scottish Council on Visual Impairment).

Lived experience is at the heart of everything the Scottish Sensory Hub does. The Sensory Hub acts as a bridge between the Scottish Government, public bodies, the third sector, and individuals, and enshrines a human rights-based approach for all. The Scottish Sensory Hub was founded to provide a strategic forum for cross-sensory input into policy and practice. It focuses on three key areas to promote living a good life – communication, information, and mobility.

The Scottish Sensory Hub looks to support partnerships which uphold the strategic aims of the Scottish Government's See Hear strategy and engage with organisations and individuals across the sensory landscape.

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