

# 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

### Executive Summary



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## **Executive Summary**

This is an executive summary of a report by the Health and Social Care Alliance Scotland (the ALLIANCE). It was produced for the Scottish Parliament's Cross-party Group on Deafness' Sensory Care and Dementia Working Group. This working group is also supported by the Cross-party Group on Visual Impairment.

## **Introduction**

The aim of the working group on sensory care and dementia is to improve care pathways and support for people with dementia who also experience Deafness, Deafblindness or Visual Impairment, including BSL users. It aims to develop the first framework of sensory care standards for Scotland. We define sensory care 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. International 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, including during the assessment of dementia.

## **Why we did this research**

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:

1. People accessing dementia services have a right to receive information in an accessible format.
2. 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.

This report represents an executive summary of the full report, providing an overview of the main findings and recommendations.

## **How we carried out this research**

We developed four online surveys and collected responses from August to October 2024. Each survey was targeted at a specific group of health and medical professionals in Scotland. In total, we received 317 responses:

- 84 General Practitioners
- 108 health and medical professionals who perform memory/dementia assessments (but who are not GPs)
- 12 NHS Audiology services for adults
- 113 eye care specialists.

The health and medical professionals surveyed included GPs, 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. Eye care specialists included ophthalmologists, ophthalmic nurses, dispensing opticians and orthoptists.

## Main findings

The major findings from this research are that there are large variations in practice of the assessment of dementia in people with Deafness, Deafblindness and Visual Impairment, including BSL users. There is also a lack of integrated care pathways between dementia assessment and sensory assessment. The main findings from each group of health and medical professionals are described below.

### General Practitioners

84 GPs representing at least eight health boards across Scotland completed the survey. The survey explored to what extent sensory assessments feature as part of the diagnosis pathway for dementia, or during post-diagnostic support.

Most GPs (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. However, they relied on unreliable assessment methods such as observation, or asking the person or their communication partners if they had any concerns. This means Deafness, Deafblindness or Visual Impairment could be easily missed.

Only 6% of GPs specified that they would assess both sight and hearing as an integrated part of assessing memory/dementia. This result is concerning because standard assessments rely on the ability to hear and see. These cannot detect the difference between difficulties from brain changes caused by dementia, and those affecting communication from Deafness, Deafblindness or Visual Impairment.

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”.

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. Methods used varied widely and most risk not identifying Deafness, Deafblindness or Visual Impairment at all. 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.

Signposting or referral to vision and hearing care specialists was a welcome approach, but 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, instead of signposting and referral being an integrated part of standard practice. The results also indicated GPs are knowledgeable about national guidelines for how often a person should have a sight assessment, but not a hearing assessment.

The lack of integration within dementia pathways between memory/dementia assessments and NHS audiology services in particular was highlighted by some GPs as a barrier to referral. This was 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 the scope of practice of private Hearing Aid Dispensers is

narrower than qualified audiologists who hold a BSc degree in Audiology or equivalent. As such, private Hearing Aid Dispensers may not be trained in, nor have access to, the full range of hearing assessment tools needed to meet the needs of people 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.

The survey asked if GPs were aware of any memory/dementia tools designed specifically for people with Deafness, Visual Impairment, or sign language users. Most respondents (93%) were either not aware of any, or did not have access to them. From the 7% who were aware of

specific tools, only one respondent referenced a suitable assessment called the MoCA blind (a dementia assessment tool designed 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. 46% stated they would use the same approach and 13 advised this 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.

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”.

For care home residents who used sign language, GP respondents advised they would use an interpreter, without referencing the necessary requirement that medical professionals should use a memory/dementia 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.

## **Non-GP health and medical professionals**

The survey for non-GP health and medical professionals provides important insight into the wide variety of practices and approaches used in memory/dementia assessments for people with Deafness, Deafblindness or Visual Impairment.

Only 12% of survey respondents indicated they would assess both hearing and sight as part of a memory/dementia assessment. The other responses reported not performing sensory assessments at all, or only doing so if Deafness, Deafblindness or Visual Impairment was suspected. However, this approach depended on unreliable assessment methods such as observation, or asking the person or their

communication partners if they had any concerns. This means Deafness, Deafblindness or Visual Impairment could be easily missed. There was also evidence of variance of approaches within professions. For example, physiotherapists involved in memory/dementia assessments within stroke services reported that sight assessments are considered 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.

Respondents were asked how often sensory assessments take place and how often they are repeated. Only 37% of respondents answered this question indicating this may be a specific area of uncertainty for health and medical professionals. Most (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.

Respondents also suggested that sensory assessments were the role of GPs in primary care settings. However, the survey for GPs found that only 6% of GPs specified that they would assess both sight and hearing as an integrated part of assessing memory/dementia. This highlights 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.

Very few (10%) health and social care professionals referred to national guidelines for hearing and sight assessments for people with dementia, and there was more knowledge for eye care than hearing care. This was also a finding from 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.

Respondents were asked how they would establish Deafness, Deafblindness or Visual Impairment before commencing assessments for dementia and/or support planning. Again, a wide variety of different approaches were reported. Some of these were more thorough than others, but were mostly all subjective and lacking in formal diagnostic assessment. These included:

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

Checking medical records was one of the most commonly described approaches (59%), though this involved reliance on the GP or initial referrer to identify Deafness, Deafblindness or Visual Impairment. The GP survey found that only 6% specified they would assess both sight and hearing as an integrated part of assessing memory/dementia. This means there is a risk that Deafness, Deafblindness or Visual Impairment may continue to be unidentified throughout dementia diagnosis and post-diagnostic support pathways because health and medical professionals assume results of sensory investigations have already been reported.

Respondents were asked about specifically designed assessment tools for people with Deafness and/or Visual Impairment, or for sign language users. Encouragingly, over half (55%) of health and medical professionals reported that they did use specific tools. However, none of these assessment tools were suitable for people with both Deafness and Visual Impairment, which highlights an area for further training and guidance – one that recognises the recently developed Scottish definition of Deafblindness.<sup>1</sup>

Respondents referenced six different memory/dementia assessments. From these, two versions have been validated for use with people with Deafness and Visual Impairment. One additional assessment is likely to be suitable for use with people with Visual Impairment because it can be delivered over the phone. There is no evidence that the rest of the cognitive assessments reported by health and medical professionals are suitable for people with Deafness, Deafblindness or Visual Impairment.

Without specifically designed and validated cognitive assessments, respondents shared that they would adapt standard assessments, including taking out parts not able to be seen or heard correctly. This shows health and medical professionals understand the limitations of assessment tools for people with Deafness, Deafblindness or Visual Impairment. However, this approach risks impacting on the ability of the assessment tool to measure different areas of brain health. There was particularly poor knowledge that direct translation of standard assessments into sign language is not appropriate.

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.

For memory/ dementia assessment in care homes, 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 needed, 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. 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 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.

## **NHS Audiology services for adults**

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 (58%) selected there was no direct referral route, with 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 that 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. Most respondents (75%) 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 a hearing assessment clinic integrated within a memory/dementia assessment clinic to support health and medical professionals as part of memory/dementia assessments. This approach is used when NHS audiology services perform hearing assessments for people accessing Ear, Nose and Throat clinics. The results indicate that 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, this 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.

Almost all respondents (92%) advised there was no direct referral route to or from ophthalmology and/or eye care services.

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

The survey for eye care specialists was completed by 113 respondents, most of which were optometrists but which also included 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 (82%) reported that there was no direct referral route to or from memory/dementia clinics, and 14% stated that they were unsure.

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

One respondent described an integrated 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.

When asked about direct referral between eye care and hearing care services, most respondents (71%) advised there was no direct referral route, and 17% 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 a minority. These results are consistent with the corresponding question in the survey of NHS audiology services for adults where almost all respondents (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.

Some respondents reported that private providers had the advantage of integrated eye and hearing care services within a single location, which were easily accessible and avoided waiting times associated with a GP referral to NHS audiology services. One eye care respondent commented that they often also received requests for hearing assessments, 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.

## 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 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 Scottish Sensory Hub

The 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.

## Contact

**Amy White, Scottish Sensory Hub Senior Officer**  
[amy.white@alliance-scotland.org.uk](mailto:amy.white@alliance-scotland.org.uk)

**Hannah Tweed, Scottish Sensory Hub Manager**  
[hannah.tweed@alliance-scotland.org.uk](mailto:hannah.tweed@alliance-scotland.org.uk)

T: 0141 404 0231

W: <http://www.alliance-scotland.org.uk/>

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<sup>1</sup> Deafblind Scotland, 'Towards a Scottish Declaration on Deafblindness' (2025). Available at: <https://www.dbscotland.org.uk/defining-deafblindness/>

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