



See Hear Strategy – lived experience consultation with ethnic minority people

An ALLIANCE Report for Scottish Government

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Introduction and background

This report contains the findings from research carried out by the Health and Social Care Alliance Scotland (the ALLIANCE) for the Scottish Government about the next See Hear Strategy.

The See Hear Strategy is the Scottish Government and COSLA strategy which shows their commitment to supporting children and adults who have Deafness, Deafblindness and Visual Impairment to access the support and social care they need. The current strategy was published in 2014 as a long-term approach.¹ Now after 10 years a new version is being written. Scottish Government advisors have agreed that the next See Hear Strategy will focus on "Living a Good Life with Sensory Loss Challenges".

The ALLIANCE was asked by Scottish Government to support consultations to help inform the See Hear Strategy refresh. This included a national report and engagement with ethnic minority people with Deafness, Deafblindness or Visual Impairment. The national report was published in December 2023.²

Based on the consultation findings, this report contains reflections and recommendations from the ALLIANCE for potential areas of action. These are also informed by our wider work in this area, for example research and lived experience engagement. Our reflections and recommendations are non-exhaustive but are indicative of further areas for consideration by Scottish Government in the co-design of Scotland's next See Hear Strategy.

A note about language

The online survey and focus group facilitation guide used the term "sensory loss", however both noted that the Scottish Government are aware that this is not necessarily the language that people find acceptable or relevant to them. Advisors to the Scottish Government will be doing further work to agree the language to use in the future.

The ALLIANCE also recognises that there is contested language and terminology, and that sensory language is an evolving area.³ We have used the terms “Deaf”, “Deafblind” and “Visual Impairment” in this instance to ensure consistency in this report with the consultation documents. We have also referred to “sensory care” in this report, as a way of referencing any type of care related to the senses which is necessary for a person’s communication, access to information, or mobility.

It should be noted that 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 inequalities in access to education, employment, healthcare, and public and social services, negatively impacting on a person’s cultural and emotional wellbeing. However, a Short-Life Working Group of the Cross-Party Group on Deafness, supported by Deafblind Scotland, have produced a Declaration that calls for the formal adoption of the Nordic definition of deafblindness in Scotland.⁴ This definition is currently being considered by the Scottish Parliament.

When discussing the experiences of people from specific ethnic groups and communities, we have avoided using the acronyms BAME (Black, Asian, and Minority Ethnic) or BME (Black and Minority Ethnic). Some communities are happy with the BAME/BME acronyms, but others are not.⁵ We have used the stated preferred terms of participants in writing this report. As such, we have opted to use the term “ethnic minority people” throughout, except in instances we are directly quoting from data or publications from other organisations.⁶

Ethnic minority people in Scotland and sensory care

Public Health Scotland estimate that 70.5% of people receiving social care in Scotland during 2022-2023 were White. An estimated 0.6% were Asian, 0.3% were listed as “Other Ethnic Group”, 0.2% as “Any Mixed or Multiple Ethnic Groups”, 0.1% were African, and 0.05% were Caribbean or Black. A further 28.2% were listed as ethnic information “Not Provided / Not Known”.⁷

Ethnic group	Number of people receiving social care services (2022-23)	Percentage of population receiving social care services (2022-23)
White	156,415	70.5
Not Provided / Not Known	62,465	28.2
Asian	1,410	0.6
Other Ethnic Group	640	0.3
Any Mixed or Multiple Ethnic Groups	405	0.2
African	260	0.1
Caribbean or Black	120	0.1

Cumulatively, only 2,835 ethnic minority people are reported as accessing social care services in Scotland during 2022-2023 – 1.3% of the population who accessed social care services overall.

If the responses categorised as “Not Provided / Not Known” are excluded from calculations, an estimated 98.2% of respondents are White, and 1.8% are ethnic minority people (0.8% Asian, 0.4% “Other Ethnic Group”, 0.3% “Any Mixed or Multiple Ethnic Groups”, 0.2% African, and 0.1% Caribbean or Black).⁸

Given that an estimated 4% of Scotland’s population encompasses people who are Asian, African, Caribbean or Black, “Any Mixed or Multiple Ethnic Groups” or “Other Ethnic Group”, these results indicate that uptake of social care and support within ethnic minority communities is lower than is representative of the population.⁹ This finding is supported by qualitative data and research on the subject, which indicates that ethnic minority people are less likely to receive information about social care services, or to be able to access them.¹⁰

No separate data is currently collected on sensory care requirements within the “client group” category within Public Health Scotland’s dashboard – it is included within the “Physical and Sensory Disability” category.¹¹ There is a need for better intersectional and disaggregated

data collection and analysis on the experiences of people who are Deaf, Deafblind, or who have Visual Impairments, to enable evidence-based policy and practice.

Health inequalities and data collection

Public Health Scotland monitors racialised health inequalities in Scotland. Their 2023 report outlines work underway to improve data collection, reporting, and use of evidence, and reflects that “more work is needed across other datasets to allow routine monitoring of racialised health inequalities across the health and care system.”¹² Specifically, the report highlighted issues around communication issues for ethnic minority people who are Deaf, Deafblind, or who have Visual Impairments:

“There were issues raised around communication including a lack of translated resources, a lack of support for people with sensory disabilities, the method of communication used, and the staff to whom patients were asked to disclose information. Inability to access appropriate interpreting services was a barrier to accessing healthcare, with a reliance on support from trusted third-sector organisations.”¹³

The Race Equality Framework for Scotland (2016-2030) outlines the need to acknowledge difference in prevalence rates, health outcomes, and treatment for ethnic minority people with “both physical and sensory impairment”.¹⁴ Further work is needed to ensure equal access and support for ethnic minority people with sensory care needs.

Ethnic minority people have a higher prevalence rate of Deafness, Deafblindness and Visual Impairment than the general population in the UK and have a low level of early intervention and uptake of assistive support.¹⁵ In particular, research shows that some ethnic minority people have a higher risk of developing specific sensory conditions (e.g. people of Black African and Caribbean ethnicity are four to eight times more at risk of developing certain forms of glaucoma than other population groups).¹⁶ There is also evidence that almost half of Muslims in the UK

(of any ethnicity, including people from ethnic minority communities) are concerned that using eye drops can break their fast during Ramadan, especially when excess drains down the back of their throat and can be tasted.¹⁷ Eye drops are a key part of treating glaucoma and other Visual Impairments, and not using them can damage people's sight.

Research also highlights the need for sight and hearing assessments to accommodate the requirements of people for whom English is an additional language, to ensure accurate results and support pathways.¹⁸ Additionally, evidence indicates that current assessments for Dementia do not meet the needs of ethnic minority people.¹⁹ Given the established issues with Dementia assessments not allowing for the high incidence of Deafblindness among relevant population groups, it is likely that ethnic minority people are facing a double barrier during diagnosis and access to services and support.²⁰

While there is limited Scotland-specific data, it is reasonable to expect prevalence rates for Deafness, Deafblindness and Visual Impairment among ethnic minority people to follow the same pattern in Scotland as in the rest of the UK. However, it is worth noting that evidence suggests that the provision of free eye tests within Scotland has improved early intervention rates and public awareness of eye health and conditions. This includes specific research on ethnic minority people's awareness of and access to eye care services in Scotland.²¹ This pattern is not replicated with regards to Deafness or Deafblindness where people acquire secondary hearing loss; a finding which the See Hear Strategy and associated policy and practice work across Scottish Government (including the implementation of the recommendations of the Independent Review of Audiology Services in Scotland) should consider.

Given this context, it is essential that Scotland ensures that the needs of ethnic minority people are explicitly considered within the new See Hear Strategy and wider policy support within the sensory sector. Proactive work in this area would also support wider equality commitments made in the Race Equality Framework for Scotland.

Equality and human rights context

The information below provides a snapshot of some relevant equality and international human rights law, principles, and standards. Further information can be sourced from relevant bodies including the United Nations, Equality and Human Rights Commission, and the Scottish Human Rights Commission, and links are provided in the references.

A series of declarations and treaties on human rights have emerged from the United Nations. These treaties codify a broad range of civil, political, economic, social, and cultural rights, as well as the rights of particular population groups like disabled people, women, and ethnic minority people. The UK, including Scotland, has signed up to – and is therefore bound by – many of these treaties, and the rights of people who are Deaf, Deafblind, or who have Visual Impairments can be found within them. Some of the most relevant for this work include the Universal Declaration of Human Rights (UDHR), the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD), the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR), and the Convention on the Rights of Persons with Disabilities (CRPD).

Also of relevance is the Equality Act 2010 (EA2010), which brings together over 100 separate pieces of legislation and sets out the characteristics that are protected by the law and the behaviour that is against the law.²² The protected characteristics under the EA2010 include age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation. The EA2010 makes it unlawful for public bodies to discriminate against, harass or victimise employees or people who access services because of these protected characteristics. Public bodies are also required to promote equality and make reasonable adjustments for disabled people. Reasonable adjustments can include measures like making sure information is available in accessible formats.

Inclusive communication is a key part of delivering on people's human rights, and ensuring that disabled people (including people who are Deaf, Deafblind, or who have a Visual Impairment) have equal access to services and support. A wide range of participants in this consultation commented on equality and human rights considerations around accessible information and inclusive communication.

Inclusive communication is normally considered to sit under the EA2010 and the UN CRPD within Scottish and UK legislation. Providing information in an accessible format and supporting people to communicate in a way that suits the person will help a public authority meet its reasonable adjustment duties, ensure that disabled people are not disadvantaged, and promote equality.²³

In 2023 Emma Roddick MSP, Minister for Equalities, Migration and Refugees, stated that the Scottish Government will include "a new duty on listed public bodies in relation to their use of inclusive communication" as part of the review of the effectiveness of the Public Sector Equality Duty (PSED) in Scotland.²⁴ This commitment to embed evaluation and assessment of inclusive communication work is welcome, and directly responds to the performance indicators recommended in the 2011 Principles of Inclusive Communication.

In England, the Accessible Information Standard (BCB1605 Accessible Information) has been in place since 2016. It requires all organisations that provide NHS care and/or publicly-funded adult social care to meet the accessible information needs of people who access or wish to access care and support. The Standard sets out a "specific, consistent approach to identifying, recording, flagging, sharing and meeting the information and communication support needs of patients, service users, carers and parents with a disability, impairment or sensory loss".²⁵

The Standard is not enshrined in law in Scotland, although current guidance for NHS Scotland states that it is recommended that NHS Scotland Boards comply with the Standard:

“The Standard is only legally enforceable to health services in England, but it is seen as best practice for the NHS Scotland Boards to help implement the duties in the Equality Act.

The aim of the Accessible Information Standard is to ensure that people who have a disability or sensory loss get information that they can access and understand, and any communication support that they need. This includes providing accessible information and communication support for people with a learning disability. Further information can be sought from the Scottish Accessible information forum.”²⁶

There are some fundamental human rights principles that are relevant to this report. This includes the five-point PANEL Principles of a human rights based approach (HRBA), which are “participation”, “accountability”, “non-discrimination and equality”, “empowerment”, and “legality”.²⁷ The PANEL Principles are one way in which rights can be put into practice – they are not simply words on a page.

Human rights are also ‘universal’ – which means that everyone has rights – and ‘inalienable’ – which means that rights can only be taken away in certain circumstances following specific processes.²⁸

There are also other principles that apply to economic, social and cultural rights, like the rights to health, education, work, and an adequate standard of living. These principles are:²⁹

- Minimum core – this means that governments are required, with immediate effect, to ensure the enjoyment of minimum essential levels of economic, social and cultural rights.
- Maximum available resources – this means that governments have a duty to use their maximum available resources for the progressive realisation of economic, social and cultural rights. Even if a government has inadequate resources at its disposal, it should still introduce low-cost and targeted programmes to assist

those most in need so that limited resources are used efficiently and effectively.

- Progressive realisation – this means that governments should progressively achieve the full realisation of economic, social and cultural rights over a period of time. Regardless of resource availability, governments have an immediate obligation to take appropriate steps to ensure continuous and sustained improvement in the enjoyment of these rights over time.
- Non-retrogression – this means that the duty to progressively fulfil economic, social and cultural rights includes a prohibition of measures that would diminish the current enjoyment of rights. For example, governments must ensure that their policies and measures do not undermine access to health care or social security.

Another contextual factor is the social model of disability and its relevance for people who are Deaf, Deafblind, or who have a Visual Impairment. As Inclusion Scotland note, “disability is caused by barriers that arise because society [...] is not designed to accommodate people who have impairments. It is these barriers that disable people who have impairments. They stop us from being included in society and participating on an equal basis. If these barriers are removed, a person may still have an impairment but would not experience disability.”³⁰ The human rights model of disability, which is grounded in the CRPD and complements the social model, considers societal barriers as breaches of disabled people’s human rights.³¹

We have included this brief overview of equality and human rights to provide a helpful context for the remainder of the report. We now turn to the consultation findings on ethnic minority people’s experiences.

Methodology and participants

Methodology

This project took the form of a small-scale mixed methods research study that drew on material from a national online survey and one focus group. The surveys sought input from ethnic minority people with lived experience of Deafness, Deafblindness, and Visual Impairments on the See Hear Strategy.

Scottish Government and the ALLIANCE agreed a draft of the proposed survey questions and focus group facilitation guide. After mutual discussion, a revised and final version of the survey was agreed by Scottish Government. A template facilitation guide was also agreed, which was tailored to suit the requirements of the focus group and interview.

The ALLIANCE carried out a Data Protection Impact Assessment for both the online survey and the focus group to ensure compliance. Survey respondents were required to show consent by indicating that they had read the privacy statement (mandatory survey question) and focus group participants indicated consent before discussions began.

The survey was created online using SmartSurvey and tested for accessibility. It was open from 11 September to 20 October 2023. The ALLIANCE publicised the survey on the internet (website, social media). The survey was also publicised via targeted emails (with reminders at regular intervals) to a wide range of contacts, including the See Hear Leads network, and over 200 organisations, clubs, and societies across Scotland. Information on the survey was shared in English and BSL. Extra calls for survey respondents were also put out to any local authority areas recording low response rates. 232 people completed the online survey; of those, 12 people were from ethnic minority communities. Their responses have been analysed alongside material from the focus group on the experiences of ethnic minority people.

On 7 February 2024, a dedicated focus group was held with ethnic minority people who are Deaf, Deafblind, or who have Visual

Impairments. This was facilitated by the Scottish Ethnic Minorities Older People Forum, in partnership with Age Scotland.

We received information about 24 people's experiences of living with the intersectionalities of Deafness, Deafblindness, or Visual Impairment as ethnic minority people. 12 ethnic minority people completed the online survey, 11 people attended the focus group, and one person shared their perspective and priorities in writing (read out during the focus group) as they were unable to attend. Given this response rate, there are limitations with the consultation, and care should be given to consider the sample range.

All responses within the free text boxes of the survey and transcripts from the focus groups were combined for coding purposes, tracked against whether each quote was provided by a focus group participant or a survey respondent. Randomised numerical references were used to distinguish between focus group contributors, to ensure that all participants' input was included in the report in a balanced fashion. These references were removed at final draft stage, to ensure total anonymity of participants.

Over 140 quotes were included in the analysis. Each quote was then coded to link it to a keyword and relevant survey or focus group question. For example, a quote may be categorised against the keyword "Access to services and support". This enabled the analysts to place contributions from the participants in the most relevant section of the report.

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 towns or geographical 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. "My social worker, [Name], was great").

About the participants

The focus group participants were recruited from the Scottish Ethnic Minority Older People Forum (SEMOP).³²

SEMOP works to influence policy change and challenges inequality and discrimination faced by ethnic minority older people, including poverty and barriers to accessing information and services.

The forum is chaired by Mrs Mukami McCrum MBE and has 20 members from a wide range of ethnic minorities. First established in 2018, it is now hosted and supported by Age Scotland, the national charity for older people.

Since its initial launch, the forum has been a catalyst for change in Scotland, raising the collective voice of ethnic minority older people and working to ensure that planning services take on board the complex and changing needs of older people from ethnic minority communities.

Participants described their ethnicities as follows (descriptions include survey respondents who chose to use the free text box to self-describe their ethnicity):

- African, Scottish African or British African
- Asian, Scottish Asian or British Asian
- Caribbean or Black
- Mixed race
- Jewish

Participants ranged in age from 18-25 years to over 75 years old. We heard from 14 women and eight men. The remaining participants elected not to share information about their gender.

Respondents included people who had experienced sudden hearing loss, hearing loss over time, who were born with no or low vision, who had experienced sight loss suddenly, sight loss over time, and who were Deafblind. Some were registered as Severely Sight Impaired (SSI). No

respondents within the focus group or this group of survey respondents were British Sign Language users.

Participants lived across a broad range of areas within Scotland, with a representative spread of those who live in cities, towns, and rural areas. While not all local authorities were represented, participants reflected on their experiences living in the North-East of Scotland, across the central belt, the West of Scotland, and southern Scotland.

Inclusive communication

“I think the main difficult part is lack of communication.”

One of the primary themes to emerge from participants' reflections on their experiences was the importance of good communication. Focus group participants described a range of situations where they faced multiple communication barriers. These ranged from sensory communication requirements (e.g. the provision of accessible information and inclusive communication suited for participants who are Deaf, Deafblind, or who have Visual Impairments), to professionals' cultural awareness and ability to support for people for whom English is an additional language. People also reflected on the adverse impact of not being able to communicate – and how that can cause isolation and loneliness when Deafness, Deafblindness, or Visual Impairment are not accepted or understood.

Accessible language and information

People discussed the need for professionals to use accessible language – particularly within health spheres, where terminology may be niche, especially for people for whom English is an additional language, and for people who rely on lipreading. Participants also reflected on the additional time it can take to communicate effectively with people who are Deaf or Deafblind:

“Remember that vast majority of hearing impaired people have English as their first language, not sign language. In the last few years, [there had been] lots of focus on [British] Sign Language, but this has not helped Deaf and deafened people [who don't use BSL].”

“But people suffering with that, Deafness and Blindness, sometimes talking in the group the ladies who are hard of hearing, they don't hear me properly. And that's frustrating to them, they don't listen, they say they didn't hear that. I say, 'sit near me, if you don't hear you can ask again.' These things affect community.

Sometimes they pick up the wrong message, and they're frustrated by that. I don't blame them! That's an ordeal for them because of their lack of hearing or seeing. These things affect people around them, the community, everybody suffers from that. One person has a problem but so many people suffer. I think there should be some kind of help for those people as well."

"The problem is if they don't know or don't admit they have hearing or eyesight problems, that's a big problem. We need awareness and then to do something about it. It's about communication but also information – there's not enough information about."

People suggested that there should be proactive work to improve sensory awareness among ethnic minority people, and specifically to share information on support services via community groups. They also discussed the need to address language barriers as part of this work, and ensure information is accessible, and communicated in language and formats suitable for the people who need support. One person summarised the discussion as follows:

"I agree that misinformation is worse and then again where to go what to do. [...] There needs to be proactive approach to go to the community, especially older people, as they don't know where to go. Most people [in this focus group] speak good English, but what about those who can't?"

Other people shared experiences where family members provided interpretation for them in health and social care settings:

"I went myself and was helped [...] because I had my wife to interpret, to see the GP."

Participants in the wider consultation activity the ALLIANCE carried out to inform the See Hear Strategy also indicated that there needs to be wider understanding of who is responsible for accessibility and communication in public leisure spaces (following the social model of disability). One focus group participant in that wider research recounted

being asked whether their young child could translate for them in a leisure facility: “My daughter is six, and people say, ‘can your daughter not tell you?’ And I say, ‘she’s six, the responsibility is on me.’”³³

The above concerns were frequently exacerbated by problems with internal communications within health and social care settings. Participants highlighted the need to provide feedback loops to help people navigate the system – including setting expectations on waiting times and what happens with referrals to other services. People shared the following examples:

“I went to my optician, and he says he has made a referral. But where had that referral gone? They have given all clinical information as well, but still I have no home appointment for my [partner], and others are still waiting.”

“I noticed there is a lack of communication between staff and patients. They don’t explain, and what they do is sent one letter for ‘ENT’ [Ear Nose and Throat Department], but they don’t explain if they’re going to clean your ear wax, or deal with [specific item of assistive technology]. Then you go and find out they’re doing something with [specific item of assistive technology]. Then a second letter, ‘attend ENT’, then they’re clearing my wax, and I’m confused. Lack of communication is a huge problem.”

The participant who received a letter informing them that they were to “Attend ENT” highlighted the need to provide a simple summary of expectations in routine communication. For example, “Dr [Name], at the Ear, Nose and Throat Department in [specific hospital] will examine your ears to see if [specific medical condition] has improved, and whether [specific medical intervention] may be appropriate.”

Digital inclusion

People also reflected on the need to support people in digital access – to avoid digital exclusion, particularly of older people. Key comments are as follows:

“I’m able to do things on the phone but I’m scared I can’t hear things. I say, “please speak slowly and clearly”, and sometimes it’s alright, but sometimes people speak too quickly or are foreign [group laughs] and that’s harder. Communication with patients and access paths are the main problem.”

“People here [in the focus group] are very capable people. They can do things, in their own communities. You ask, what is your experience – three times they say “what’s that? What do I know?” if you ask if they had infection or disease when young. Doctors say they’re too busy, they can’t see a Deaf person, they need [their medical] history, they need someone to come with them.”

“It’s not always the money thing that stops services being approachable, it’s small little things around it. If you want help then you have to deal with a big list, ‘press 1 for this department’ etc. A whole list of things before you get to where you want to. And that’s a definite closing door approach. Don’t try it unless you really want to carry on persevering. And nowadays everything seems to be online. Even attending meetings, health assessments on video calls. It’s fine to save money and all that but you’ve got to accept there are some people for whom it’s not possible, and who do they go to to make it possible? That’s what I mean about the impact of closing these [community] groups where people went to get support they need; they took that away.”

With regards to digital exclusion, one participant shared the following experience:

“When I’m talking [...] on the screen a couple of times I switched off because I can’t hear people. Voices are not clear, there are missing words. Just seeing person’s lips, lipreading. Then I can hear a little bit. Slightly better than that but when I’m without [assistive technology] if someone speaks, whispering when sitting next to me I can’t hear, so I just say ‘hmm mmm, yes, I just smile.

Because they're in public, I can't hear, but I'm not telling that person at the same time, 'can you speak up? I can't hear you.'"

It is important to note the participant's decision to imply engagement and understanding rather than asking the person they were speaking with to "speak up". This is a very common experience for people who are Deaf – but it is vital that health and social care professionals ensure that people have fully understood information to avoid problems at a later date.

Reflections and recommendations

The need for reflective and inclusive communication practices was the primary theme to emerge from this work. People discussed their experiences across a variety of environments, but inclusive communication was at the core of most of their comments. Participants highlighted the need for public bodies to improve their inclusive communication practices, including proactive consideration of the requirements of ethnic minority people, and for systems to enable good communication practices.

Suggestions included improving data collection around people's individual communication requirements and preferences (e.g. preferring telephone conversations to written letters, or vice versa), and the free provision of interpretation into people's preferred language when discussing complex topics. People shared that the latter was particularly important to consider and ask if it was appropriate when people have some spoken English, but not at a level to provide informed consent to a discussion of nuanced detail in niche language (e.g. in health and social care contexts). They recommended that professionals should take care to use accessible language (generally, and when communicating with people for whom English is an additional language) and avoid or explain acronyms. It should not be assumed that family or friends are available or suitable to provide translation from or to English.

People also highlighted the need to take a digital choice approach, and avoid excluding people via a reliance on digital technology – particularly

with older people. Constructive suggestions included reducing the length and complexity of automated systems (e.g. having to listen to multiple options and select several numbers in sequence to be connected to the right department), and ensuring that protocols are in place to confirm comprehension at multiple points during conversations. Finally, participants reflected on the need to improve sensory awareness within ethnic minority communities, to improve early diagnosis rates, and community support and understanding – a topic discussed in more detail later in this report.

Throughout, people framed communication as integral to their ability to live well and participate in their communities. As summarised in the *My Support My Choice* report on ethnic minority people’s experiences of social care, “without language, people have no rights. And thus, this is critical.”³⁴

Accessing care and support

Timely, accessible care and support was identified by many participants as crucial. One participant felt that any strategy for improving the lives of people with Deafness, Deafblindness or Visual Impairment should include a “fast track to health care services”.

Difficulty accessing appointments was highlighted not only for those waiting on appointments, but for community workers and carers supporting people to both make appointments and attend them.

“There is a lot of pressure on community workers and on the people who are main carers, like me.”

“I work with older people. I would like to highlight [...] all the older men and women out there who have difficulty getting their appointments for hearing loss and eye optician appointments.”

Waiting times

Waiting times were commonly attributed to problems accessing care and support. One participant described experiencing long waiting times for a Bone Anchored Hearing Aid (BAHA) operation due to staffing shortages, and then experiencing a long wait for a review appointment post-surgery to address sound clarity issues with the device.

“They took a long time to give me BAHA because they’re short staffed. I tried many times, I said, ‘I can’t hear when I go places, especially I have a problem with BAHA’, and they gave me a new BAHA, but still it is not working... Nobody is looking after me. I try to make an appointment, they say, ‘we will put you on a waiting list’, but I don’t know for how long. So that’s the main problem.”

Focus group participants raised particular concerns over greater waiting times if home or community appointments were requested for people where reduced mobility or other health and social care needs prevented travel. Key comments were as follows:

“My optician knows about it but we’re waiting a long time. That’s the biggest issue. It takes a long time to get an appointment and then if we press for a home visit then you don’t know when you’ll get it.”

“My [partner] is disabled, [they have] hearing loss and glaucoma. [...] I understand home visits can be scheduled but that is not happening as far as I know. It’s a nightmare to get a home appointment. People say, “we don’t do this, contact so and so”. I don’t know what to do, where to go. [...] Home appointments, I may as well forget about them as we can never get one.”

One participant described the impact of long waiting times for home appointments. They suggested that longer wait times are detrimental to the health and well-being of the person, and also incur greater costs for the NHS in the long-term because of worsening of existing health needs, instead of timely intervention:

“They have to employ not only doctors but others in pharmacy or whatever to support, because some people can’t come out of their house, and their problems increase.”

In addition to delays in receiving appointments, another participant commented on an excessive wait for assistive equipment after receiving a medical diagnosis – “even a white stick took us quite a long time for [my partner] to get!” These experiences highlight an important gap between identification and subsequent provision of support.

Rural experiences

Experiences of access to care and support for people living in rural communities also highlighted difficulties with information on, and provision of, assistive equipment. Participants described poor signposting at the point of medical diagnosis, meaning they had to navigate solutions on their own, sometimes finding out useful knowledge incidentally. The prolonged wait for adaptations and equipment led to unnecessary negative impacts on well-being:

“When my [partner] started losing [their] sight, there was nowhere to go for information or service. We’re in rural area. We didn’t know what to do! We were saved by strangers, people at conference, who commented on aids, things that let [my partner] continue feeling human and retain [their] dignity. And when we try to hear from health services, there was nothing that would help [my partner].”

“We had to buy big screens, keyboards, things in different colours. And all that was trial and error, from someone saying on the train, ‘you can get this’. So, we didn’t get the things that people got in the big cities, nor at the beginning of the problem.”

Another problematic area, particularly for rural communities, was a lack of local health services. Participants described long commutes to reach health centres and hospitals for services they felt should be available in their home area:

“I think information and looking at rural areas as well is important, because the service there is terrible, it’s a big trek. For us to go to [specific medical centre] it takes all morning”

“We need a more localised service, I don’t see why it should be so difficult for health centres near us to provide some of the things”

A discussion took place around provision of NHS hearing aid batteries which are provided free of charge to NHS hearing aid users. Participants agreed that pharmacies are well-placed to dispense them. In some areas, audiology departments provide medical centres or libraries with batteries for dispensing to improve accessibility. However, this is dependent on the agreements in place with each health board and Health and Social Care Partnership (HSCP), meaning distribution varies around the country. Participants highlighted the similarities between medication as a prescription for better health and well-being, and hearing aid batteries as a prescription for effective communication – which also leads to better health and well-being. It was confusing to the group that

pharmacies do not provide the latter when both were identified as of equal importance and are NHS funded.

“Why can’t pharmacies be part of that? If we don’t have hearing, we can’t communicate. It can be much more convenient for older people to go to a local pharmacy – they’re not able to travel or go places as easily. It’s a morning gone just to get batteries [under current system] and making it convenient and easy to get batteries would help.”

“They deliver medicine for my [partner] and one or two others [...] they said they’ve asked the pharmacist for batteries for the hearing aids, because the battery was finished, and they said ‘no, it’s not part of our service’ and they can’t do that. I take the point that life would be easier if they gave pharmacy permission to provide the batteries, so we don’t have to go all the time here and there.”

A particular issue around accessing NHS hearing aid batteries was described for a rural resident with Deafblindness who was unexpectedly transferred to hospital. The ward had no access to replacement batteries, so these had to be brought in from home a long distance away by a family member. During this time, the person’s communication was severely impacted being unable to hear the medical team and any information about their health and treatment plan.

“[My partner] had both hearing and sight loss, and [hearing aid] batteries were a nightmare. Eventually we could get them from the Doctor but in one instance [my partner] ended up in [specific urban] hospital. We don’t live in [specific urban location], and there was nowhere to get [replacement] batteries, and I had to come from [rural area] to bring batteries.”

Reflections and recommendations

In discussing access to care and support, participants highlighted the impact of waiting times – particularly for those who required home or community appointments, and who faced longer wait times as a result. Waiting times are a challenge for people throughout the process of

accessing any form of care or support service – from appointments and assessments through to follow-on care, and access to assistive devices. Participants suggested that greater use of community resources could reduce wait times, and make it easier for ethnic minority people to access support near where they live.

Those who lived in rural areas expanded on this topic, outlining the negative impact of travel time to attend appointments and collect supplies, and the cost of travel. There was widespread agreement that greater use of community pharmacies and other local centres would improve participants' access to support and reduce waiting times. This particularly applied to discussions around accessing replacement batteries for NHS hearing aids. Without easy access to replacement batteries, people do not have meaningful access to assistive technology to improve their hearing and communication.

Stigma and discrimination

Participants reflected on a range of examples of racism, ageism, and ablism, including experiencing intersectional stigma and discrimination. People shared that discrimination is often endemic in societal systems, despite many well-meaning intentions:

“Discrimination and ignorance are widespread even among those who have our wellbeing at heart.”

When asked about the naming of the new See Hear Strategy, one response was that “a much better name would be ‘Zero tolerance of Disability Discrimination’”, suggesting that the main aim of the strategy should be to eliminate discrimination.

Participants gave examples of situations where a lack of staff training and awareness on the legislation designed to protect people from discrimination resulted in poor implementation. They also highlighted instances where the people being discriminated against did not know their legal rights:

“Education of clients on the [Equality] Act [2010] so that they know their rights. Education of the Police or whoever is delegated to enforce the Act, i.e. where Guide Dogs/Assistance Dogs are permitted to go.”

One participant recounted that they felt that employers do not recruit people with a Visual Impairment: “most roles don’t want to hire because of sight loss.”

Ageism

Participants also highlighted experiencing agism as older people accessing health services. There was a feeling that after reaching retirement age, people were seen as less deserving of treatment than those of working age:

“[It’s] not just language issues, it’s self-confidence. If you’re being made to feel that you’ve lived your time... In hospital services, you’re always asked “what’s your job, what do you do for a living?” I always feel if I’m not working does that mean I’m not entitled to treatment? It makes you feel should I be bothering him [doctor]?”

“As we get older you still feel treated and seen as more demanding than others.”

Racism

Throughout the project, people reported rare but significant experiences of racism, echoing concerns raised in previous lived experience research in this area.³⁵

Participants discussed the financial impact of racism – including the need to move away from racial discrimination and harm to safer areas. One participant highlighted this issue within the context of the accumulative costs of installing necessary adaptations to new homes so that people with Deafness, Deafblindness and Visual Impairment can live as independently as possible:

“Minority ethnics don’t buy houses just because we like houses. It’s because you’re moving away from racism and discrimination. And as you age you can’t afford adaptations.”

Another participant reported feeling much more recognised as a citizen now, in comparison to their early experiences living in Scotland. However, the participant raised concerns about being a carer and spokesperson for their partner (who is White Scottish), and reflected on whether people’s attitudes towards their ethnicity may impact on their partner’s healthcare delivery:

“I never feel like an immigrant as I did when I came, but I do feel that I’m treated as if more demanding than other people. My [partner], [they’re] Scottish, but because I speak on [their] behalf

we wondered if that affected the treatment [they] got. I was at the front line.”

Another participant shared feelings of being perceived by health and social care staff as ‘demanding’. The participant also reflected on the damaging impact that societal stereotyping of ethnic minority people can have, and the need for this to be urgently addressed:

“We need to be treated as citizens who belong here, not as people who are demanding or scroungers. [...] We need to stop being treated like this, as if we go about with a begging bowl.”

Stigma

Stigma can result from personal characteristics which are culturally or societally perceived be negative. People then “develop strategies in order to protect their sense of self, or ‘self-esteem’”.³⁶ Participants identified that stigma associated with Deafness, Deafblindness and Visual Impairment could be a barrier for people seeking help and support. Key comments are as follows:

“There’s a stigma in the community. People say, ‘I don’t hear’, and other people laugh. They joke, ‘why don’t you hear?’, they make a funny face. There’s a stigma in the community as well.”

“When we say people laugh at things, it’s because they think it’s a joke, I can hear and you can’t.”

“People don’t want to admit they can’t hear, or they can’t see much. And I’m not being sexist, but I’ve done this work and particularly men in ethnic minority communities never want to admit hearing loss or vision loss.”

While participants agreed there were issues with stigma related to both sight and hearing, people reflected that uptake of hearing aids was poorer than glasses due to differences in cultural beliefs about the acceptability of Deafness. One person asked:

“We understand it’s OK to wear glasses when we can’t see, but how come we aren’t very good at using hearing aids when we can’t hear?”

These reflections from the focus group are supported by wider research. Inequalities in ethnic minority people’s hearing health have featured in recent research, as “hearing help-seeking and hearing aid uptake has tended to neglect ethnicity, meaning there is little evidence to draw upon to explain the ethnic inequalities”.³⁷ However, one study highlighted that a large UK dataset captured incidence of Deafness for ethnic minority people using a measurement which was language-based, which would be less appropriate for people for whom English is an additional language.³⁸

A follow-up study assessed whether there are inequalities in the number of people from minority ethnic communities reporting difficulties with hearing and using hearing aids. Results suggested that after correcting for language bias, men from ethnic minority communities were less inclined to identify as having problems with hearing than White British or White Irish men. In women, the same trend was recorded for Black African, Black Caribbean and Indian ethnic minority communities. As a result of lower levels of self-reported Deafness, use of amplification devices such as hearing aids was also lower. Wider research on the mental health and wellbeing of ethnic minority people who have visual impairments indicates that stigma around visual impairments is a significant factor in people’s well-being.³⁹

Participants in ALLIANCE lived experience research, and the study authors listed above, both recommended that more proactive work needs to be undertaken within ethnic minority communities to address stigma and improve sensory awareness.

Reflections and recommendations

People discussed the varied impact of stigma and discrimination – particularly across the intersections of age, disability and ethnicity.

Recommendations to reduce cultural stigma and discrimination include mandatory sensory and cultural awareness training for public sector staff, particularly health and social care professionals. More work should be funded to inform people from ethnic minorities about their legal rights (including the Equality Act 2010 and associated legislation and guidance). People also highlighted the need for professionals within social care and housing departments in local authorities to be aware of the additional costs that can be faced by disabled people from ethnic minority communities – such as the cost of housing adaptation, particularly if people have had to move to avoid racism.

People spoke widely about the need to address community stigma around Deafness, Deafblindness and Visual Impairment. In particular, people suggested that more proactive work should be undertaken within ethnic minority communities to improve people's sensory awareness – including providing publications in multiple languages. Such actions could improve the support and acceptance offered to people who are Deaf, Deafblind, or who have Visual Impairments by their friends and families. It could also form part of the solution to improving early interventions in ear and eye health among ethnic minority people, enabling them to participate in their community and live well.

Community support

Family and peer support

Participants discussed the importance of support from family, friends, and community groups – including people who also have lived experience of Deafness, Deafblindness and Visual Impairment.

People reflected on the importance of support from family – and of ensuring that family members, as well as people receiving support, are provided with information on any assistive technology or medical interventions. One participant shared the following experience:

“Between the Christmas and new year holidays, I couldn’t find any help. I don’t have any sensation in my [...] ear at all, I was feeling so much [...] it was so hot, I didn’t know what to do. I went upstairs and I put ear drops in, and thought it may be a reaction to surgery. [...] They don’t explain this kind of thing. I don’t know! Suppose I’m ill – my family don’t know what’s happening to me. There’s a lack of communication.”

When the facilitator reflected that “it sounds like your family having information as well is important so they can support you”, participants indicated broad agreement. Another person stated that understanding of issues can be separated across generations, and that work needs to be done to improve understanding of Deafness, Deafblindness and Visual Impairments:

“Especially with younger people who don’t always understand – not always from a clinic point of view, and also family. You don’t really appreciate the issue until you face it yourself.”

People also highlighted that family and community understanding of sensory issues is key to enabling people to communicate and participate in their community and live well. One person discussed some simple techniques they used to support another person within their community, prioritising empathy and reflecting on the importance of peer support:

“I know someone who can’t speak English. [...] [They] had a hearing aid for two years but even then [they] can't hear. I ask [them] something and [they] answers a different question. I don't laugh, because I'm experiencing the same thing, I just repeat the question slowly and loudly. And then I get the right answer. I ask, 'have you done this or that?' then [they] answer me if [they're] very close.”

Community support

Participants repeatedly reflected on the importance of community facilities where ethnic minority people could access support in their local areas. One person shared that there had previously been a local centre in their area, but that it had closed for lack of funding, leaving people without tailored support:

“We had a day centre where everybody would come in, a group where they'd not otherwise be together, people with sight loss, hearing loss. But the funding went, and we lost that. And now there is a big gap between how people get support. Hearing aids do get some getting used to. Providing somewhere they could get a little more support was helpful but now people are getting isolated because there's no facility like that. In one way Scottish Government are saying we want to support that, but in other ways I feel they're taking away the services that were already there for people. I feel because it is not something anyone else could do. Say my [partner] had hearing problems, [they] can be given a hearing aid, but [they] need to adjust it to the way that suits [my partner], [my partner] needs that approachable environment which does not always happen.”

Participants shared frustrations over valuable community initiatives being withdrawn due to funding, or resources only being secured for a limited time. One person summarised the situation as follows:

“Working across Scotland there was a time when so many groups were working and funded at grassroots level to support people with

barriers to accessing services. Now there's a new way of funding, and funding has been cut off and closed. I don't know why it's happening across Scotland. [...] It's not fair to take someone's dignity away and support. It's so common – funding taken away or given space or building then that's taken away.”

The importance of social connection for health and well-being is well documented, so much so that researchers have called for it to be classified as a “public health priority” in line with other health issues which receive considerable attention and funding.⁴⁰ One participant highlighted the importance of the social interaction provided through community events as fundamental to promoting wellness and preventing ill-health. People suggested that before deciding to discontinue funding, local authorities and the Scottish Government should perform a long-term cost-benefit analysis to determine the financial impact on the NHS resulting from poorer health outcomes when human connection is limited:

“I think the Scottish Government ought to do some examination of the difference between when they close down centres, because we are social beings, we like to be together. There's so much research on community gatherings, that meeting people and going outdoors is more impactful than medicine. When they close those options to get together, share food, get outside, then I think we end up going to the doctor and using more money and more services than we would if we had community services.”

This participant's insight is supported by wider research; social pain or “the painful experience of actual or potential psychological distance from other people or social groups” has been shown to initiate or exacerbate physical pain.⁴¹ Conversely, improving social connection has been linked to management of physical pain and alleviating social pain. As such, positive social relationships are protective and can be therapeutic.⁴²

Research shows that the health of older people from ethnic minority backgrounds has been “disproportionately impacted” by the COVID-19 pandemic.⁴³ Participants acknowledged the impact of the pandemic on

preventing social gatherings and peer-support groups, and how re-instating beneficial community services has not been realised as part of any COVID-recovery plan:

“It was COVID-times, everyone was asked to isolate themselves [...] the whole world had changed in that time. But now I think people are being isolated in their own wee places and their own homes, and looking for somebody who could come and listen to them, or to be taken to somewhere where they could be part of a group, somebody who could listen to their needs. [...] The centre I’m talking about would be somewhere general they could reach out; [...] that’s been taken away now.”

People reflected on the ways in which community services and support could be accessed in a climate with limited financial resources. Participants suggested that it is possible to find efficient and effective solutions at a local level once problems are identified, if there is a shared space for discussion, support, and problem-solving:

“Anyone who can arrange meetings locally, sometimes, without spending too much, so people can come and hear and have somebody talk to them, that may be a good idea. Regionally, so people can go. We used to have meetings regionally, which benefited many people.”

“We need to reach out to communities and work on the accessibility of services, what are the costs, what can be done, the different types of hearing support.”

Third sector organisations were recognised as an essential source of support and information. Participants highlighted that better communication with ethnic minority communities was needed for people to know how and where to access them, suggesting that local “organisations need more contact with ethnic minorities.”

One participant described how volunteering for a third sector sensory organisation provided personal benefit when support for accessing NHS sight and hearing pathways was needed:

“If you’ve heard of [local hearing and sight loss charity], I volunteer there, and they helped.”

People also highlighted the need for facilities within their local community and area to be fully accessible for people who are Deaf, Deafblind, or who have Visual Impairments. One person shared the following:

“I miss out on stuff because I am disabled. I can’t read the screens at the cinema – I ask for the headphones and they say they have none or it’s not charged. Labels are so tiny in shops. The general public needs to be more aware of sensory loss. I asked a supermarket attendant once if a product was vegan and she said, “just read it”. Now why would I ask if I could read it, whether this means I can't read, or I can't see to read it? Awareness is key.”

Participants reflected on the positive impact of community facilities where staff, volunteers and attendees demonstrated a high level of sensory awareness and knowledge of specific ethnic minority people’s culture. One person summarised the positive impact of peer and community support as follows:

“The happiness we as individuals get from places like that cannot be measured in coins – so there has to be another way to showing commitment to this wonderful Scotland that we all believe in.”

Reflections and recommendations

Participants spoke in detail about the vital importance of community hubs that provide support, advice, and community meeting spaces for ethnic minority people. Participants reflected that in recent years many essential community hubs (particularly those run by the third sector) were closing due to lack of sustainable funding at local and national levels. They suggested that while these decisions were being made

because of the challenging financial landscape, there was a disproportionate and negative impact on ethnic minority communities when community hubs and support services are closed. This is particularly important in the context of lower uptake of social care and support services among ethnic minority people, and lower rates of early intervention for health conditions (including those relating to sight and hearing).

Participants suggested that when making funding decisions about services that support ethnic minority people, local authorities and the Scottish Government should perform a long-term cost-benefit analysis to determine the financial impact on the NHS resulting from poorer health outcomes. Such an analysis should also include an assessment of the equalities and human rights impacts of decision-making, including the intersectionalities of ethnicity and disability.

Health and social care professionals

A common point of discussion was experiences with health and social care staff. This included hearing and eye care professionals, as well as GPs, social work and care professionals, and those working in wider hospital and clinic-based settings.

Sensory awareness training

Participants agreed that improvements were needed to ensure staff were sufficiently knowledgeable on the impact Deafness, Deafblindness or Visual Impairment can have on a person's well-being and participation in everyday life.

One participant suggested that services to help ethnic minority people should be carried out by staff who have received specific cultural and sensory awareness training, as there could be cultural issues, especially for older people. They suggested that care was also needed to provide appropriate interpretation and any additional support to aid understanding and communication:

“Are they able to understand? Can they speak English? But even if they do speak English they may not understand the level of English, the terminology [used in a medical appointment]. We should be providing services by trained staff to ethnic minority older people.”

Participants also suggested that there is a general need to improve how health and social care professionals explain interventions and support planning, and ensure clear expectations are shared and understood by all parties. They also outlined the need to tailor communication and information to people's communication requirements. This could be as simple as marking that an individual with a Visual Impairment prefers telephone communication.

One participant commented that due to a lack of sensory awareness training, they felt primary care staff perceived Deafness as lower down

the hierarchy of health and well-being needs. As such, there appeared to be poor motivation for prioritising onward referral to sensory specialists. Others shared the following comments:

“Many [doctors] think hearing is a waste of time, but it’s really important.”

“Different people have different problems. Deafness come from a variety of sources. They have to explain and adapt treatment, to have a person with a specialism in that field rather than everyone going to the GP and all they see is ‘this person has Deafness.’”

“Doctors don’t have much time.”

Another participant described a hospital ward unequipped to care for people with Deafness. Despite the person in need of medical care having significant communication difficulties, hospital staff were unable to provide replacement hearing aid batteries. Instead, an unpaid carer had to travel a considerable distance to acquire batteries, leaving their partner unable to communicate in hospital. If hospital staff had been able to provide batteries, it would alleviate the barriers to informed care for that person – and reduced stress and pressure on family members. The participant summarised the experience as follows:

“[My partner’s] been smiling and nodding [...] everyone expected [my partner] to update me about [their] condition, and what the consultant had said – and [my partner] had no idea! And they said batteries are in available in [different urban area], and somehow [my partner] was expected to get batteries from there while [they were] in hospital! You wonder to what extent people live in silence because there is no immediate help. And they said, ‘there’s a shortage of staff, we can’t provide batteries.’ When it’s an emergency you don’t come [to hospital] with the things you need.”

A different focus group participant described communication breakdown during hospital-based care. During consultations for an ear operation, realistic expectations for improvements in hearing were not effectively

communicated, because staff did not check information had been accurately received. This led to frustration and disappointment with the post-surgery outcome. The participant asked, “why did they give me the wrong information before the operation?”

These examples highlight the importance of meeting sensory care needs in primary and secondary care environments. Improving communication has been shown to improve health outcomes, quality of care and clinical safety.⁴⁴ However, the communication needs of people who are Deaf, Deafblind, or who have Visual Impairments may not be recognised if sensory awareness training does not feature in mandatory training pathways for health and social care staff.⁴⁵ It is not clear to what extent hospital and social care services link with NHS sensory services such as audiology and ophthalmology for advice and support on communication, and whether wards routinely stock assistive devices such as low vision aids and personal listeners – although these have been shown to improve person centred care.⁴⁶

Audiology

Across the consultation, participants referred to audiology services. One person initially described feeling happy with the service but felt abandoned when a staff member left the department and there was a lack of transition to another audiologist with the required specialism:

“The [audiologist] had been promoted and gone to [name of hospital]. I tried many times to contact her, she said, ‘I’m not working there anymore’, so no one is looking after me anymore.”

NHS hearing aids were another common topic. When asked to select the most important topics to consider in the Scottish Government’s See Hear Strategy refresh (with multiple options available to select), one ethnic minority survey respondent selected “hearing aid support and signposting” as their only priority.

Positive experiences with NHS hearing aids included one participant encouraging more people to access audiology services and seek help with their hearing:

“In my experience you get hearing aids, then every two years you go back to check them, maybe your hearing is getting worse, and they change the tube. [...] That’s my experience over ten years, I’ve had both [tubes] changed.”

Notably the advice given to change hearing aid tubing every two years is at odds with current guidance of around every six months.⁴⁷ This may suggest accessible hearing care and hearing aid information is not always available, resulting in inaccurate communications being perpetuated through communities, potentially leading to delayed help-seeking and poorer outcomes. Other people reflected on interim solutions being used while awaiting healthcare interventions:

“[Family member] is aware of what [they’ve] got, those items were common in India, they don’t go to the doctor immediately, they put oil etc. in their ears. It’s not bad, if the wax levels are not bad then the oil will loosen, and it can be removed. But it’s not an answer.”

People involved in the consultation demonstrated curiosity over hearing aids. This included uncertainty as to why hearing aids did not always result in improved communication, reasoning that this may be due to having blocked ears from wax or being prescribed a less effective device. One person shared the following query:

“I don’t understand why people can’t hear with a hearing aid. Maybe their ears need to be cleaned or it’s the quality of the product. I don’t know.”

Participants shared contrasting views on whether private or NHS hearing aids were better which may indicate there is insufficient access to information on how hearing aids work and what factors can impact on the ability to accurately follow a conversation.⁴⁸ Key examples are as follows:

“I spoke to that lady and asked if she got a hearing aid from a private company and she said ‘yes’. I said do you think it’s better than the NHS version and she said not much difference.”

“I wear hearing aids myself. The impact can be so huge. I went private because I had got checks done and went to get it done privately. It’s a life changing experience.”

Perceptions of private health services also included discussions about eye care. People shared concerns of a two-tier system, with those who could afford to go private gaining access to better opportunities and health outcomes:

“Someone mentioned private care – when I got my cataracts removed, the consultant told me if I’d gone private I could have got lenses, contact lenses that allow me to read and see long distance. If I went private I could get that at a cost of £3000 per eye. Why do we have this system where if you have money you can get quality, hearing aid quality or sight, and if you rely on Government services you have to be second rate? That does not give us the dignity or self-respect we want to feel as citizens of Scotland. And this is not just minority ethnic people! This is everyone.”

Knowledge of support services

Across both hearing and eye care services, participants described healthcare professionals prioritising the diagnosis of a condition, but not providing signposting to services for peer support and self management skills to enable people to live well. One person shared the following experience:

“I explain [my problem] to audiology, and say, ‘who should I speak to?’ and they say, ‘we don’t know’. Third sector organisations, who should I speak to then, if they say, ‘I don’t know’?”

“The optician just said, ‘you have macular degeneration.’”

Connected to knowledge of support services is the way in which sensory needs are communicated across the NHS and out into wider services to ensure people receive information in a suitable format (as discussed earlier regarding inclusive communication practices). One survey respondent expressed frustration at the lack of safeguarding processes around provision of accessible information:

“I can never read a letter from school without a magnifier, I have to use it or take it home then read it. We need individual plans set up which is made public to each service but cannot be amended without authorisation.”

Connecting with communities

Improving relationships between health and social care professionals and ethnic minority communities was seen as important for encouraging people to engage with services and take a proactive approach to their sensory health. One way of doing this would be for health specialists to attend community events to give talks and be available to answer questions:

“You could hear their experiences, and one or two doctors, even one doctor who is ENT specialist, and a GP – people are very happy to come if they can shine on the stage. So that would be a good idea.”

Reflecting on what works for other health conditions, one participant suggested using positive community engagement in addressing sensory health through arranging targeted community sessions, instead of waiting for people to attend their GP for referral. People highlighted that this type of model may also be more cost-effective:

“Even things like chiropody – I know that’s not the topic today – but a person came in one day and we [community group] got all the groups who need support there and in one afternoon they got

through ten individual support visits. Looking at support that can work for people who need the support, that's important. We have to look at money, or we won't get anywhere but it's about going beyond that – we don't have the money to do this this way, what's another way of doing it? To make sure it still happens”

Reflections and recommendations

People suggested that health and social care professionals should have sensory awareness training built into their mandatory training programmes. They also highlighted the importance of taking a whole systems, person centred approach – with awareness of different parts of the health and social care landscape, and staff able to signpost people to different sources of support, including within the community. The latter may be better managed by use of systems such as A Local Information System for Scotland (ALISS), which would enable health and social care professionals to signpost to local resources for people seeking support.

Participants' reflections on how often they and others of their acquaintance had not fully understood health interventions for Deafness or Visual Impairment indicate the need for better communication checks to ensure full understanding and accurate expectations about the impact of specific interventions. People also discussed the benefits of healthcare settings across Scotland (particularly hospitals) stocking assistive devices, to ensure people have the best possible communication within healthcare settings. Suggestions included stocks of low vision aids, personal listeners, replacement hearing aid batteries, personal handheld buzzers to notify people when they should move through to an appointment, and tablets to enable connection to online BSL interpretation (e.g. Contact Scotland BSL) and electronic notetakers. It would also be useful to assess current provision, and evaluate the impact of any new assistive devices (with intersectional analysis of results).

Additional findings

Across the project, several topics were raised that did not align with specific survey or focus group questions, but which are pertinent to a discussion of ethnic minority people's experiences of living with Deafness, Deafblindness or Visual Impairment. They are included in this section of the report.

Travel and transport

As in the ALLIANCE's national lived experience report on the See Hear Strategy, access to transport emerged as a key issue for participants from ethnic minorities – particularly those living in rural areas.

Access to transport is needed so that people can enjoy a raft of human rights, including equal participation in society, independent living, work, education, and more. Unfortunately, as data from other sources and research suggests,⁴⁹ people who are Deaf, Deafblind, or who have Visual Impairments frequently experience ongoing breaches of their right to access transport equally with others.

Several people described difficult experiences with travel and transport, for example:

“I think information and looking at rural areas as well is important, because the service there is terrible, it's a big trek. For us to go to [specific medical centre] it takes all morning – from us we need to get two buses, and the bus timetable doesn't overlap with the appointments, and it takes all morning.”

“You mentioned transport – I live in dread of the time I can't drive, because the few times I use buses, they're so hostile. When I use my bus pass, they want me to prove it's my bus pass. I feel really embarrassed, and I don't use buses a lot, it's just occasionally. I have a bad back, bad knees, and they start moving before you sit down. And I've seen older people falling flat because of the way they drive. And you're expected to come up and out quickly. I don't

know whether they can train them to be better but I don't want to use public transport, I know I will have to but I really dread it.”

“And bus passes – I know for example in London you can use the train and rail on the same freedom pass for older people on any service, but we can't do that, and there are so many places with different concessions and you need to know. For example, in [specific location] there used to be a reduced ticket to [city] and [city] but not to [town]. There has to be a sensible way of dealing with this!”

“I think we need support in every way – public transport, it's hard get onto if you have other mobility issues, that's not an easy thing to jump onto. Sometimes it's not about money, it's about understanding.”

When discussing solutions to these issues, people highlighted the need for better sensory awareness among bus and train drivers, and greater consistency of travel costing in public transport planning across Scotland.

Housing

Housing also emerged as a key priority for participants. The right to housing is an essential element of the right to an adequate standard of living, as contained in Article 11 of ICESCR. Disabled people's right to independent living is also enshrined in Article 19 of the CRPD. The principles underlying the CRPD recognise that disabled people are the experts in their own lives, and are best placed to identify and determine the housing and support they require.

Participants reflected on a need for more accessible housing in their areas, and specifically for those concerns to be included in civic planning for the future. They also commented on the need to ensure that ethnic minority people are accommodated within accessible housing in their local area. People stated that this is a wider concern for people across Scotland, but that ethnic minority people are more likely to experience

discrimination than other population groups, and so it is doubly important that they be able to live in suitable housing within areas they deem safe. As outlined earlier in this report, one participant summarised the issue as follows:

“I know some people are doing things on adapting houses for people; it seems a critical area, when people need aids to move about their houses, but it’s not that easy to get, you either have to wait – if you’re in a council house you can get special adaptations – but if you’re in a private house you have to pay yourself, at an age when people have sacrificed so much to buy a house. And minority ethnics don’t buy houses just because we like houses. It’s because you’re moving away from racism and discrimination. And as you age you can’t afford adaptations.”

Justice and legal advice

Ethnic minority respondents to the See Hear Strategy survey also raised concerns around the need for people to be able to have full and equal access to the justice system – without facing any additional costs over the need for translation, in cases where disability discrimination is pertinent. Participants also highlighted the disproportionate costs on Deaf BSL users of having to pay for interpreter fees (in addition to any other legal fees) within legal and justice spheres. People offered the following comments on this issue:

“Legal aid should be available to bring actions for disability discrimination cases under the Equalities Act 2010. Those who have suffered from disability discrimination and who are also on means-tested benefits should have an automatic right to legal aid.”

“There can be no good life without access to the courts. The Equalities Act 2010 is an excellent piece of legislation but it is being ignored by large companies because they know that the Scottish government is refusing to allow disabled people to get legal aid for small claims”

Research and data collection

Within the focus group, participants suggested that there is a need to develop a more detailed understanding of different groups of people's experiences of access to services and support. In particular, they suggested that work was needed to understand the intersectional experiences of communities – not grouping ethnic minorities together as a ubiquitous group, but unpacking where their experiences differ:

“Is it possible for you do a survey of the different communities, you group all the blacks, whites, people from here, there, and ask what are their experiences? [...] See if their experiences are the same?”

“So, the first thing is maybe a survey of people, what are their experiences? Asking, ‘do you know what kind of Deafness you have? When do you feel your problem is exacerbated?’ Sometimes if they don't like their [partner] they say, ‘I can't hear you’ as avoidance! We have to know what exactly we are going through.”

One participant also suggested that dedicated work was needed to understand if ethnic minority people who are Deaf, Deafblind or who have Visual Impairments are more or less likely to attend medical appointments. They suggested that intersectional analysis of this information could enable tailored communication and support, and improve health inequalities for ethnic minorities:

“They list who misses appointments, but they send letters, and there should be dedicated people who can keep an eye on missed appointments, for Ear, Nose and Throat [services]. [...] We should be seen.”

Auditing who attends or misses appointments against the provision of tailored, accessible information could improve the proportion of ethnic minority people who access appropriate care and support for Deafness, Deafblindness, or Visual Impairments.

Involving people with lived experience in decision-making

Participants also highlighted the need for co-production rather than consultation, and meaningful involvement of ethnic minority people in decision making. Key comments are as follows:

“We have had so many consultation sessions, so many meetings, no one knows how long I am gone. But I don’t know where that information goes. It needs to be improved. People are getting older, their needs are different, and they have wanted this before, so these are things I would like to highlight.”

“Nothing about us without us. Money has been invested in projects without consultation with Blind people e.g. Broad Street in Aberdeen where consultation was only included once the project had been completed. The idea that the sighted know better than the Visually Impaired themselves about how to treat VIs is rife, i.e. what is done for the disabled is a ‘gift’ from the non-disabled.”

Funding and policy implementation

The final unprompted theme amongst participants centres on the need for longer-term funding and meaningful implementation of policies. People spoke bluntly about the need to fund essential services to support ethnic minority people – and included community-based services in that definition (as discussed earlier in this report). One participant summarised the need for this concern to be addressed at national rather than local level as follows:

“And some money is necessary. And the NHS say we don’t have any money, and the GPs say they only have so much time, and this many patients.”

Several people suggested that Scotland has a range of good policy – but that implementation does not fulfil the promise of that work, and needs to improve:

“Most organisations are very good at making the policies, making it look right; the language is all perfect but the delivery is not there. The intention might be but there’s no overlap. And sometimes it’ll be your neighbour for 30 years and they’ll say “I didn’t know you needed to do things this way”, which makes you feel as if you’re an alien just landed on earth!”

“What happens when you come to consultation, they say it’s human rights, but it becomes a talking shop. You say the right thing in policy, but when it comes to implementation it comes down to money. When it comes to delivery there’s no money. We’re cutting this, we’re cutting that. Something’s not right between what’s said and what’s done. It’s a huge gap.”

“Stop promising so much if you can’t deliver! When I read what they say about Scotland it’s wonderful, but when you go to get a service you are told you don’t qualify or can’t get that. It takes away the feel-good factor.”

The participant who shared the last quote also reflected on the importance of community-based services and support, and the value that they bring to local communities – especially for ethnic minority people.

Reflections and recommendations

Across the topics that arose as unprompted themes, people highlighted the need for better sensory awareness among transport staff, and called for greater consistency of travel costing in public transport planning across Scotland. They also discussed the need for more accessible housing – particularly considering sensory care requirements – as part of civic planning.

Participants mentioned difficulties with accessing parts of the justice system, and specifically issues with additional costs for people for whom sign language (BSL or other sign languages) is their preferred language. They called for interpretation to be provided to all who needed it, rather

than being paid for by individuals who wish to access the justice system and can afford to do so.

Focus group participants discussed the need for more research on ethnic minority people's experiences and use of services and support across Scotland. In particular, they suggested that work was needed to understand the requirements and experiences of specific ethnic minority communities, as discrete groups (rather than viewing "ethnic minority people" as a single unit) – and adjust communication and planning accordingly. People also highlighted the need to understand why some ethnic minority people have poorer uptake of health and social care services, in order to inform policy and practice and counter health inequalities. They spoke of the need to research support for people with all levels of Deafness, Deafblindness and Visual Impairment – not simply those who have the most significant presentation (e.g. Severely Sight Impaired (SSI)).

At the conclusion of the focus group, participants spoke in detail about the need for ethnic minority people to be meaningfully involved in co-production of solutions, with effective feedback loops and opportunities for ongoing influence on decision-making – not simply consultation. They also stressed again the importance of tailored community support, particularly with sensory and cultural awareness, and the need for community support services to be sustainably funded. Participants presented local community organisations, who can provide tailored resources and have ongoing relationships with the people they support, as key to the delivery of Scotland's policy promises on equality and human rights.

Reflections and recommendations

This report contains the findings from a consultation carried out by the Health and Social Care Alliance Scotland (the ALLIANCE) for the Scottish Government about the next See Hear Strategy. From September to November 2023, the ALLIANCE carried out a small-scale mixed methods research project (a national online survey and focus groups), with adults with lived experience of Deafness, Deafblindness, and Visual Impairment about what the next See Hear Strategy should contain. On 7 February 2024 we also carried out a dedicated focus group with ethnic minority people who are Deaf, Deafblind, or who have Visual Impairments. This was facilitated by the Scottish Ethnic Minorities Older People Forum, in partnership with Age Scotland.

Throughout the report, the ALLIANCE has included our reflections and recommendations. These are based on the consultation findings and informed by our wider work in this area. Our reflections and recommendations are non-exhaustive but are indicative of further areas for consideration by Scottish Government in the co-design of Scotland's next See Hear Strategy.

Inclusive communication

The need for reflective and inclusive communication practices was the primary theme to emerge from this work. People discussed their experiences across a variety of environments, but inclusive communication was at the core of most of their comments. Participants highlighted the need for public bodies to improve their inclusive communication practices, including proactive consideration of the requirements of ethnic minority people, and for systems to enable good communication practices.

Suggestions included improving data collection around people's individual communication requirements and preferences (e.g. preferring telephone conversations to written letters, or vice versa), and the free provision of interpretation into people's preferred language when discussing complex topics. People shared that the latter was particularly

important to consider and ask if it was appropriate when people have some spoken English, but not at a level to provide informed consent to a discussion of nuanced detail in niche language (e.g. in health and social care contexts). They recommended that professionals should take care to use accessible language (generally, and when communicating with people for whom English is an additional language) and avoid or explain acronyms. It should not be assumed that family or friends are available or suitable to provide translation from or to English.

People also highlighted the need to take a digital choice approach, and avoid excluding people via a reliance on digital technology – particularly with older people. Constructive suggestions included reducing the length and complexity of automated systems (e.g. having to listen to multiple options and select several numbers in sequence to be connected to the right department), and ensuring that protocols are in place to confirm comprehension at multiple points during conversations. Finally, participants reflected on the need to improve sensory awareness within ethnic minority communities, to improve early diagnosis rates, and community support and understanding.

Throughout, people framed communication as integral to their ability to live well and participate in their communities. As summarised in the *My Support My Choice* report on ethnic minority people's experiences of social care, "without language, people have no rights. And thus, this is critical."⁵⁰

Accessing care and support

In discussing access to care and support, participants highlighted the impact of waiting times – particularly for those who required home or community appointments, and who faced longer wait times as a result. Waiting times are a challenge for people throughout the process of accessing any form of care or support service – from appointments and assessments through to follow-on care, and access to assistive devices. Participants suggested that greater use of community resources could reduce wait times, and make it easier for ethnic minority people to access support near where they lived.

Those who lived in rural areas expanded on this topic, outlining the negative impact of travel time to attend appointments and collect supplies, and the cost of travel. There was widespread agreement that greater use of community pharmacies and other local centres would improve participants' access to support and reduce waiting times. This particularly applied to discussions around accessing replacement batteries for NHS hearing aids. Without easy access to replacement batteries, people do not have meaningful access to assistive technology to improve their hearing and communication.

Stigma and discrimination

People discussed the varied impact of stigma and discrimination – particularly across the intersections of age, disability and ethnicity. Recommendations to reduce cultural stigma and discrimination included mandatory sensory and cultural awareness training for public sector staff, particularly health and social care professionals. More work should also be funded to inform people from ethnic minorities about their legal rights (including the Equality Act 2010 and associated legislation and guidance). People also highlighted the need for professionals within social care and housing departments in local authorities to be aware of the additional costs that can be faced by disabled people from ethnic minority communities – such as the cost of housing adaptation, particularly if people have had to move to avoid racism.

People spoke widely about the need to address community stigma around Deafness, Deafblindness and Visual Impairment. In particular, people suggested that more proactive work should be undertaken within ethnic minority communities to improve people's sensory awareness - including providing publications in multiple languages. Such actions could improve the support and acceptance offered to people who are Deaf, Deafblind, or who have Visual Impairments by their friends and families. It could also form part of the solution to improving early interventions in ear and eye health among ethnic minority people, enabling them to participate in their community and live well.

Community support

Participants spoke in detail about the vital importance of community hubs that provide support, advice, and community meeting spaces for ethnic minority people. Participants reflected that in recent years many essential community hubs (particularly those run by the third sector) were closing due to lack of sustainable funding at local and national levels. They suggested that while these decisions were being made because of the challenging financial landscape, there was a disproportionate and negative impact on ethnic minority communities when community hubs and support services are closed. This is particularly important in the context of lower uptake of social care and support services among ethnic minority people, and lower rates of early intervention for health conditions (including those relating to sight and hearing).

Participants suggested that when making funding decisions about services that support ethnic minority people, local authorities and the Scottish Government should perform a long-term cost-benefit analysis to determine the financial impact on the NHS resulting from poorer health outcomes. Such an analysis should also include an assessment of the equalities and human rights impacts of decision-making, including the intersectionalities of ethnicity and disability.

Health and social care professionals

People suggested that health and social care professionals should have sensory awareness training built into their mandatory training programmes. They also highlighted the importance of taking a whole systems, person centred approach – with awareness of different parts of the health and social care landscape, and staff able to signpost people to different sources of support, including within the community. The latter may be better managed by use of systems such as A Local Information System for Scotland (ALISS), which would enable health and social care professionals to signpost to local resources for people seeking support.

Participants' reflections on how often they and others of their acquaintance had not fully understood health interventions for Deafness or Visual Impairment indicate the need for better communication checks to ensure full understanding and accurate expectations about the impact of specific interventions. People also discussed the benefits of healthcare settings across Scotland (particularly hospitals) stocking assistive devices, to ensure people have the best possible communication. Suggestions included stocks of low vision aids, personal listeners, replacement hearing aid batteries, personal handheld buzzers to notify people when they should move through to an appointment, tablets to enable connection to online BSL interpretation (e.g. Contact Scotland BSL), and electronic notetakers. It would also be useful to assess current provision, and evaluate the impact of any new assistive devices (with intersectional analysis of results).

Additional findings

Across the topics that arose as unprompted themes, people highlighted the need for better sensory awareness among transport staff, and called for greater consistency of travel costing in public transport planning across Scotland. They also discussed the need for more accessible housing – particularly considering sensory care requirements – as part of civic planning.

Participants mentioned difficulties with accessing parts of the justice system, and specifically issues with additional costs for people for whom sign language (BSL or other sign languages) is their preferred language. They called for interpretation to be provided to all who needed it, rather than being paid for by individuals who wish to access the justice system and can afford to do so.

Focus group participants discussed the need for more research on ethnic minority people's experiences and use of services and support across Scotland. In particular, they suggested that work was needed to understand the requirements and experiences of specific ethnic minority communities, as discrete groups (rather than viewing "ethnic minority people" as a single unit) – and adjust communication and planning

accordingly. People also highlighted the need to understand why some ethnic minority people have poorer uptake of health and social care services, in order to inform policy and practice and counter health inequalities. They spoke of the need to research support for people with all levels of Deafness, Deafblindness and Visual Impairment – not simply those who have the most significant presentation (e.g. Severely Sight Impaired (SSI)).

At the conclusion of the focus group, participants spoke in detail about the need for ethnic minority people to be meaningfully involved in co-production of solutions, with effective feedback loops and opportunities for ongoing influence on decision-making – not simply consultation. They also stressed again the importance of tailored community support, particularly with sensory and cultural awareness, and the need for community support services to be sustainably funded. Participants presented local community organisations, who can provide tailored resources and have ongoing relationships with the people they support, as key to the delivery of Scotland's policy promises on equality and human rights.

Appendix

Focus group facilitation guide

See Hear Strategy Lived Experience Consultation

ALLIANCE – SEMOP Focus Group Facilitator Notes and Topic Guide

About this document

This document has been written by Scottish Government with input from the Scottish Sensory Hub for people facilitating focus groups as part of the lived experience consultation to support the next See Hear Strategy.

Content in italics is facilitator guidance and for your information only. Do not read out this information to the focus group participants.

Start – *Introduce yourself and others in the room, and explain who everyone is, e.g. the notetaker and anyone else involved (e.g. anyone attending to observe or as an organiser).*

Thank the participants for taking part.

Privacy statement and consent form – *Make sure all participants have been given a copy of the privacy statement and have signed/agreed the consent form before the focus group begins.*

Explain that the focus group is being recorded to help with the notes, and that the recording will be deleted after the notes have been written up.

Ask participants to also complete the ‘About Me’ form – this is to help gather anonymous information about who is taking part. It is voluntary but very helpful.

Introduction

The See Hear Strategy is the Scottish Government and COSLA strategy which shows their commitment to supporting children and adults with deafness, sight loss and deafblindness. The strategy was published in 2014. After ten years, a new version is being written.

The next See Hear strategy will focus on “Living a Good Life with sight, deafness or deafblindness challenges”. It will contain actions to improve people’s lives. Links will be made to health but the strategy will not focus only on health.

The Scottish Government has spoken to people with sight loss, deafness and deafblindness and the staff who take action on the See Hear strategy in each local authority. These discussions have shaped the questions we are going to ask you in this focus group.

The focus group will last one and a half hours.

To enable the focus group to work well, we ask you to follow these ground rules:

- Please communicate one at a time (so that people can follow and for the recording and notetaker)
- Please allow time for each other to communicate
- Please respect each other’s views and diverse opinions
- Please share your views as openly and honestly as you feel able.

As we are going through the discussion, we might ask you to move on to another question or go back to a previous question according to the time available.

All views and opinions expressed during the focus group will be confidential and anonymised. We ask that participants please respect this, and not repeat discussion, opinions or experiences outside of the focus group.

When writing our report, we may use anonymised quotes, and may change non-material details to avoid identifying you. This is accepted

practice in focus group research and will protect you from being identified.

Thank you for your participation.

Theme 1: Social care and support services

The Scottish Government want to know about your experiences of social care and support services that directly relate to deafness, sight loss, or deafblindness. These are services delivered by your Health and Social Care Partnership or maybe a local charity designed to support you specifically because you are a person with deafness, sight loss, or deafblindness.

Question 1: Can you give examples of good social care and support you have received as a person living with deafness, sight loss, or deafblindness?

Question 2: Can you tell me why that social care and support was good?

Question 3: Can you give examples of where things have not been so good regarding social care and support as a person living with deafness, sight loss, or deafblindness.?

Question 4: How could your social care and support have been better?

Question 5: Are there broader issues that you are aware of? i.e. not relating to yourself but those that you know of?

Theme 2: Living a good life

The Scottish Government wants equality, inclusion and human rights to be at the heart of all that we do, including access to services. This means that people with deafness, deafblindness or sight loss should enjoy all of their human rights and have an equal experience of services as any other population group, and not experience discrimination or disadvantage because of their protected characteristics, such as

disability or age. The Scottish Government want to know about your experiences of services that you use which aren't directly related to deafness, sight loss, or deafblindness, like housing, healthcare, transport, and social security.

Question 6: Can you give examples of where these services were delivered well for you in terms of sensory care?

Question 7: Can you give examples of where services were not delivered well for you in terms of sensory care?

Question 8: Can you say what needs to be done or should have been done differently for you to get a better outcome from these services?

Question 9: Is there anything else you wish to say?

Explain that the anonymous notes from this focus group will be combined with the notes from the other focus groups and the findings from the online survey and written up into a report for the Scottish Government. Thank communication professionals and all participants, and indicate email address for any questions (sensory@alliance-scotland.org.uk).

Thank you for your time and input.

Focus group materials

- Background information sheet for participants
- Consent form.

Focus group consent form

See Hear Strategy - Lived Experience Focus Group with Scottish Ethnic Minorities Older People Forum

Focus groups conducted by the Health and Social Care Alliance Scotland (the ALLIANCE) Scottish Sensory Hub, on behalf of Scottish Government

Consent Form

I confirm that:

1. I understand that I am agreeing to take part in a focus group carried out by the ALLIANCE for the Scottish Government. The purpose of the group is to gather my insights, experiences and opinions to inform development of the next See Hear Strategy. I am aware that my personal experiences may be discussed during the focus group.
2. I have been informed of the ALLIANCE's privacy policy (available here: <https://www.alliance-scotland.org.uk/privacy-policy/>) and information on the project and understand that the ALLIANCE will not sell, distribute or lease personal information to anyone else without my written permission unless required to do so by law.
3. I agree to provide the ALLIANCE with my name and contact details for the purpose of this project.
4. I understand my participation is voluntary and I may withdraw at any time without giving a reason.
5. I agree the focus group setting will be considered "safe spaces" and I shall not share any information discussed during the focus group outside of them.
6. I am willing to be video/audio recorded as part of the project.

7. In the event that the ALLIANCE cannot meet my accessibility requirements, I agree that the ALLIANCE will use external staff or resources to make the focus group inclusive.
8. I understand that I should not expect to gain any personal benefits from my participation in the focus group.
9. I am 18 years old or older.
10. I agree that the ALLIANCE can use my personal information as described here and in the privacy statement.

Name:

Date:

Signature:

About me

I have lived experience of (please tick or write “yes” next to all that apply):

- Deafness (Deaf, deafened, hard of hearing, hearing loss).
- Sight loss/Vision Impairment/Blind.
- Deafblindness/Dual sensory loss.

Contact preferences

How would you prefer us to contact you? You only need to provide contact details if you are happy for us to contact you in that way.

Email (if yes, please share your email address):

Post (if yes, please share your postal address):

Telephone (if yes, please share your telephone number):

Additional Support Needs

Do you have any additional support needs, such as communication support requirements or other accessibility requirements, that it would be helpful for us to know so that we can best support you to participate in a discussion? If so, please share them below:

Final Report

Would you like us to send you a copy of the final report?

Are you happy for us to keep a copy of your contact details so that we can get in touch with you again should we have any follow-up questions, or so that we can offer you opportunities to get involved in other ALLIANCE work?

Would you like to receive the ALLIANCE bulletin?

Thank you for your time.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision, which is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect.

We are a strategic partner of the Scottish Government and have close working relationships with many NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our purpose is to improve the wellbeing of people and communities across Scotland. We bring together the expertise of people with lived experience, the third sector, and organisations across health and social care to inform policy, practice and service delivery. Together our voice is stronger and we use it to make meaningful change at the local and national level.

The ALLIANCE has a strong and diverse membership of over 3,300 organisations and individuals. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects; working with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

We aim to:

- Ensure disabled people, people with long term conditions and unpaid carers voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.

- Support transformational change that works with individual and community assets, helping people to live well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner, and foster cross-sector understanding and partnership.

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 this link will take you away from The Alliance website and engage with organisations and individuals across the sensory landscape.

Contact

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References

¹ Scottish Government and COSLA, *See Hear: A strategic framework for meeting the needs of people with a sensory impairment in Scotland* (April 2014). Available at: <https://www.gov.scot/publications/see-hear/>.

² Health and Social Care Alliance Scotland (the ALLIANCE), *See Hear Strategy Refresh – Lived Experience Consultation Report* (Dec 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/see-hear-strategy-refresh-lived-experience-consultation-report-published/>.

³ Health and Social Care Alliance Scotland (the ALLIANCE), “An explanation of the language used by the Scottish Sensory Hub” (March 2024), available at: <https://www.alliance-scotland.org.uk/policy-and-research/scottish-sensory-hub/sensory-loss/>

⁴ Deafblind Scotland, “Towards a Scottish Declaration on Deafblindness” (March 2024), available at: <https://www.dbscotland.org.uk/defining-deafblindness/>

⁵ Zamila Bunglawala, “Please, don’t call me BAME or BME!” (July 2019), available at: <https://civilservice.blog.gov.uk/2019/07/08/please-dont-call-me-bame-or-bme/>; Cheryl Carty, “To BAME or not to BAME – Do we need an alternative term?”, *Inclusive Employers* (2023), available at: <https://www.inclusiveemployers.co.uk/blog/bame-or-not-to-bame/>; Kenan Malil, “Don’t call me BAME. We need a new political language”, *The Guardian* (25 July 2020), available at: <https://www.theguardian.com/commentisfree/2020/jul/25/the-term-bame-isnt-fit-for-use-we-need-a-new-political-language>.

⁶ Zamila Bunglawala, “Please, don’t call me BAME or BME!” (July 2019), available at: <https://civilservice.blog.gov.uk/2019/07/08/please-dont-call-me-bame-or-bme/>. See also Scottish Ethnic Minority Older People forum, *About us* (July 2022), available at: <https://www.ageuk.org.uk/scotland/what-we-do/scottish-ethnic-minority-older-people-forum/>.

⁷ Public Health Scotland, “People Supported through Social Care Services: Support provided or funded by health and social care partnerships in Scotland 2022/23” (12 March 2024), available at: <https://publichealthscotland.scot/publications/people-supported-through-social-care-services/people-supported-through-social-care-services-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-202223/>. Breakdown of ethnicity data available via connected dashboard (People Supported>Ethnic Group): <https://publichealthscotland.scot/publications/people-supported-through->

[social-care-services/people-supported-through-social-care-services-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-202223/dashboard/](https://www.nhs.uk/healthcare/social-care-services/people-supported-through-social-care-services-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-202223/dashboard/).

⁸ As above.

⁹ Scotland's Census, "Ethnicity" (20 Oct 2023). Available at: <https://www.scotlandscensus.gov.uk/census-results/at-a-glance/ethnicity/>.

¹⁰ Health and Social Care Alliance Scotland (the ALLIANCE) and Self Directed Support Scotland (SDSS), *My Support My Choice: Black and Minority Ethnic Peoples' Experiences of Self-directed Support and Social Care in Scotland – Thematic Report* (Dec 2020). Available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.

¹¹ Public Health Scotland, "People Supported through Social Care Services: Support provided or funded by health and social care partnerships in Scotland 2022/23" (12 March 2024), available at: <https://publichealthscotland.scot/publications/people-supported-through-social-care-services/people-supported-through-social-care-services-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-202223/>. Breakdown of ethnicity data available via connected dashboard (People Supported>Ethnic Group): <https://publichealthscotland.scot/publications/people-supported-through-social-care-services/people-supported-through-social-care-services-support-provided-or-funded-by-health-and-social-care-partnerships-in-scotland-202223/dashboard/>.

¹² Public Health Scotland, *Monitoring racialised health inequalities in Scotland* (30 May 2023), p. 40. Available at: <https://publichealthscotland.scot/publications/monitoring-racialised-health-inequalities-in-scotland/monitoring-racialised-health-inequalities-in-scotland-30-may-2023/>.

¹³ As above, p. 43.

¹⁴ Scottish Government, *Race Equality Framework for Scotland 2016 to 2030* (March 2016). Available at: <https://www.gov.scot/publications/race-equality-framework-scotland-2016-2030/>.

¹⁵ Nikki Neinze and co-authors, "A rapid review of evidence relating to service use, experiences, and support needs of adults from minority ethnic communities along the eyecare pathway in the United Kingdom", *Frontiers in Public Health* (2023), available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10011697/>. Mark O Scase and Mark R. D. Johnson, "Visual impairment in ethnic minorities

in the UK”, *International Congress Series* (Sept. 2005), pp. 438-42, available at:

<https://www.sciencedirect.com/science/article/abs/pii/S0531513105008423>. Harry Taylor and co-authors, “Investigating ethnic inequalities in hearing aid use in England and Wales: a cross-sectional study”,

International Journal of Audiology (Jan 2023), available at:

<https://pubmed.ncbi.nlm.nih.gov/34908513/>. Harry Taylor and co-

authors, “Understanding ethnic inequalities in hearing health in the UK: a cross-sectional study of the link between language proficiency and performance on the Digit Triplet Test”, *BMJ* (2020), available at:

<https://bmjopen.bmj.com/content/10/12/e042571>. NDCS, “Deaf children from ethnic minority groups” (2020), available at:

<https://www.ndcs.org.uk/media/6795/ndcs-literature-review-deaf-children-from-ethnic-minority-groups-final.pdf>.

¹⁶ RNIB, “Key information and statistics on sight loss in the UK”, available at: <https://www.rnib.org.uk/professionals/health-social-care-education-professionals/knowledge-and-research-hub/key-information-and-statistics-on-sight-loss-in-the-uk/>.

¹⁷ Glaucoma UK, “Ramadan – can I use eye drops while fasting?”, available at: <https://glaucoma.uk/care-support/ramadan/>. See also N.

Kumar and co-authors, “Ramadan and eye-drops: perspective of Muslims in the UK”, *British Journal of Ophthalmology* (April 2009), available at: <https://pubmed.ncbi.nlm.nih.gov/19321480/>.

¹⁸ Harry Taylor and co-authors, “Investigating ethnic inequalities in hearing aid use in England and Wales: a cross-sectional study”, *International Journal of Audiology* (Jan 2023), available at:

<https://pubmed.ncbi.nlm.nih.gov/34908513/>; Harry Taylor and co-

authors, “Understanding ethnic inequalities in hearing health in the UK: a cross-sectional study of the link between language proficiency and performance on the Digit Triplet Test”, *BMJ* (2020), available at:

<https://bmjopen.bmj.com/content/10/12/e042571>.

¹⁹ Somjing Tsai and co-authors, “Assessment of Dementia in Minority Ethnic Groups in Scotland”, *Alzheimer Disease & Associated Disorders* (Jan-March 2024). Available at:

https://journals.lww.com/alzheimerjournal/fulltext/2024/01000/assessment_of_dementia_in_minority_ethnic_groups.13.aspx.

²⁰ W. A. Monaco and co-authors, “Prevalence of Vision Loss and Associations With Age-Related Eye Diseases Among Nursing Home Residents Aged ≥65 Years”, *Journal of the American Medical Directors Association*, June, (2021), available at:

<https://pubmed.ncbi.nlm.nih.gov/33041233>. J. D. White and co-authors,

“Inequality in access to hearing care for older adults in residential homes”, *Journal of Public Health* (March 2021), available at: <https://academic.oup.com/jpubhealth/article/43/1/172/5542119>.
DataFakts *Prevalence rates for those with dual sensory loss and dementia in Scotland* (2022). Available at: https://www.datafakts.com/reports/DualSensoryLossDementia_Scotland.pdf.

²¹ S. Gulati and co-authors, “Awareness and knowledge of Glaucoma in ethnic minority groups in Scotland”, *European Journal of Public Health*, vol. 28 (May 2018), available at: https://academic.oup.com/eurpub/article/28/suppl_1/cky048.244/4973566. Heather Dickey and co-authors, “Utilisation of eye-care services: the effect of Scotland’ free eye examination policy”, *Health Policy* (2012), available at: <https://pubmed.ncbi.nlm.nih.gov/23063565/>.

²² Equality and Human Rights Commission, *The Purpose of the Equality Act* (Aug 2018). Available at: <https://www.equalityhumanrights.com/equality/equality-act-2010>.

²³ Scottish Government, *Principle of Inclusive Communication* (2011), p. 8. Available at: <https://www.gov.scot/publications/principles-inclusive-communication-information-self-assessment-tool-public-authorities/pages/8/>

²⁴ Emma Roddick MSP, “Public sector equality duty: stakeholder letter” (4 October 2023). Available at: <https://www.parliament.scot/-/media/files/committees/equalities-human-rights-and-civil-justice-committee/correspondence/2023/public-sector-equality-duty-in-scotland-4-october-2023.pdf>.

²⁵ NHS England, “Accessible Information Standard” (Aug 2017). Available at: <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/>.

²⁶ Scottish Government, *NHS Scotland learning disability employment: tools and guidance* (Feb 2019), p. 3. Available at: <https://www.gov.scot/publications/nhsscotland-learning-disability-employment-tools-guidance/pages/3/>.

²⁷ Scottish Human Rights Commission, “Human Rights Based Approach” (2024). Available at: <https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/>.

²⁸ UN Office of the High Commissioner for Human Rights, “What are human rights?” (2024). Available at: <https://www.ohchr.org/en/what-are-human-rights>.

²⁹ SNAP 2, *SNAP 2 – Scotland’s second national action plan for human rights* (March 2023). Available at: <https://www.snaprights.info/wp-content/uploads/2023/03/SNAP-2-March-2023-FINAL-PDF.pdf>.

³⁰ Inclusion Scotland, “The Social Model of Disability” (2024). Available at: <https://inclusionScotland.org/get-informed/social-model>.

³¹ The human rights model of disability was introduced by Theresia Degener, a disabled activist and academician, and former member of the UN CRPD Committee. For more information, see Theresia Degener, “A New Human Rights Model of Disability”, *The United Nations Convention on the Rights of Persons with Disabilities*, eds. V. Della Fina and co-editors (2017). Available at: <https://www.ncbi.nlm.nih.gov/books/NBK558160/>.

³² Scottish Ethnic Minority Older People forum, *About us* (July 2022). Available at: <https://www.ageuk.org.uk/scotland/what-we-do/scottish-ethnic-minority-older-people-forum/>.

³³ Health and Social Care Alliance Scotland (the ALLIANCE), *See Hear Strategy Refresh – Lived Experience Consultation Report* (Nov 2023), p. 63. Available at: <https://www.alliance-scotland.org.uk/blog/news/see-hear-strategy-refresh-lived-experience-consultation-report-published/>.

³⁴ The ALLIANCE and SDSS, *My Support My Choice: Black and Minority Ethnic Peoples’ Experiences of Self-directed Support and Social Care in Scotland* (Dec 2020), p. 35. Available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.

³⁵ As above.

³⁶ Fei Zhao and co-authors, “Exploring the influence of culture on hearing help-seeking and hearing-aid uptake”, *International Journal of Audiology* (March 2015). Available at: <https://www.tandfonline.com/doi/full/10.3109/14992027.2015.1005848>

³⁷ Harry Taylor and co-authors, “Investigating ethnic inequalities in hearing aid use in England and Wales: a cross-sectional study”, *International Journal of Audiology* (Jan 2023), available at: <https://pubmed.ncbi.nlm.nih.gov/34908513/>

³⁸ Harry Taylor and co-authors, “Understanding Ethnic Inequalities in Hearing Health in the UK: A Cross-Sectional Study of the Link between Language Proficiency and Performance on the Digit Triplet Test.”, *BMJ* (Dec 2020). Available at: <https://bmjopen.bmj.com/content/bmjopen/10/12/e042571.full.pdf>

³⁹ Nikki Heinze and Claire L. Castle, “Exploring mental well-being, the emotional impact of visual impairment and experiences of prejudice and

discrimination among adults from minority ethnic communities in the UK”, *Frontiers in Public Health* (Sept. 2023). Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10558210/>.

⁴⁰ Julianne Holt-Lunstad and co-authors, “Loneliness and social isolation as risk factors for mortality: a meta-analytic review”, *Perspectives on Psychological Science* (March 2015), available at: <https://pubmed.ncbi.nlm.nih.gov/25910392/>; World Health Organization, “Determinants of Health” (February 2017), available at: <https://www.who.int/news-room/questions-and-answers/item/determinants-of-health>; Julianne Holt-Lunstad and co-authors, “Advancing social connection as a public health priority in the United States”, *The American Psychologist* (Sept 2017), available at: <https://pubmed.ncbi.nlm.nih.gov/28880099/>.

⁴¹ Naomi, I. Eisenberger, “The pain of social disconnection: examining the shared neural underpinnings of physical and social pain”, *Nature Reviews, Neuroscience* (May 2012). Available at: [The pain of social disconnection: examining the shared neural underpinnings of physical and social pain | Nature Reviews Neuroscience](#); Ming Zhang and co-authors, “Interaction between social pain and physical pain”, *Brain Science Advances* (May 2020). Available at: [Interaction between social pain and physical pain - Ming Zhang, Yuqi Zhang, Yazhuo Kong, 2019 \(sagepub.com\)](#)

⁴² Nicholas V. Karayannis and co-authors, “The Impact of Social Isolation on Pain Interference: A Longitudinal Study”, *Annals of Behavioral Medicine* (Jan 2019). Available at: [The Impact of Social Isolation on Pain Interference: A Longitudinal Study - PubMed \(nih.gov\)](#); Keiichi Onoda and co-authors, “Decreased ventral anterior cingulate cortex activity is associated with reduced social pain during emotional support”, *Social Neuroscience* (Sept 2009). Available at: [Decreased ventral anterior cingulate cortex activity is associated with reduced social pain during emotional support: Social Neuroscience: Vol 4 , No 5 - Get Access \(tandfonline.com\)](#)

⁴³ Centre for Ageing Better, “Ethnic health inequalities in later life: The persistence of disadvantage from 1993-2017” (Nov 2021). Available at: <https://ageing-better.org.uk/resources/ethnic-health-inequalities-in-later-life>

⁴⁴ Jan Blustein and co-authors, “Tackling hearing loss to improve the care of older adults”, *BMJ* (Jan 2018). Available at: [Tackling hearing loss to improve the care of older adults | The BMJ](#)

⁴⁵ Jamie M. Cohen and co-authors, “Studies of Physician-Patient Communication with Older Patients: How Often is Hearing Loss

Considered? A Systematic Literature Review”, *Journal of the American Geriatrics Society* (Aug 2017). Available at:

<https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.14860>

⁴⁶ Raphaëlle M. Koerber, “The clinical use of personal hearing amplifiers in facilitating accessible patient–provider communication: A scoping review”, *Journal of the American Geriatrics Society* (Feb 2024).

Available at:

<https://agsjournals.onlinelibrary.wiley.com/doi/full/10.1111/jgs.18784>;

Qiaoling Zhou and Nicholas F. Walker, “Promoting vision and hearing aids use in an intensive care unit”, *BMJ Open* (Feb 2015). Available at:

<https://bmjopenquality.bmj.com/content/4/1/u206276.w2702.info>

⁴⁷ RNID, “What to do if you need new hearing aid batteries or tubing” (Jan 2024). Available at: [https://rnid.org.uk/information-and-](https://rnid.org.uk/information-and-support/hearing-loss/hearing-aids/what-to-do-if-you-need-new-hearing-aid-batteries-or-tubing/)

[support/hearing-loss/hearing-aids/what-to-do-if-you-need-new-hearing-aid-batteries-or-tubing/](https://rnid.org.uk/information-and-support/hearing-loss/hearing-aids/what-to-do-if-you-need-new-hearing-aid-batteries-or-tubing/)

⁴⁸ Nicholas A. Lesica, “Hearing Aids: Limitations and Opportunities”, *The Hearing Journal* (May 2018). Available at:

https://journals.lww.com/thehearingjournal/Fulltext/2018/05000/Hearing_Aids_Limitations_and_Opportunities.12.aspx

⁴⁹ See, for example, Inclusion Scotland, *Nothing about us without us! United Nations Convention on the Rights of Disabled People-Scottish Civil Society Shadow Report* (2022). Available at:

<https://inclusionScotland.org/wp-content/uploads/2022/03/2022-CRPD-Shadow-Report.pdf>.

⁵⁰ The ALLIANCE and SDSS, *My Support My Choice: Black and Minority Ethnic Peoples’ Experiences of Self-directed Support and Social Care in Scotland* (Dec 2020), p. 35. Available at: <https://www.alliance-scotland.org.uk/blog/resources/my-support-my-choice-peoples-experiences-of-self-directed-support-and-social-care-in-scotland-reports/>.

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