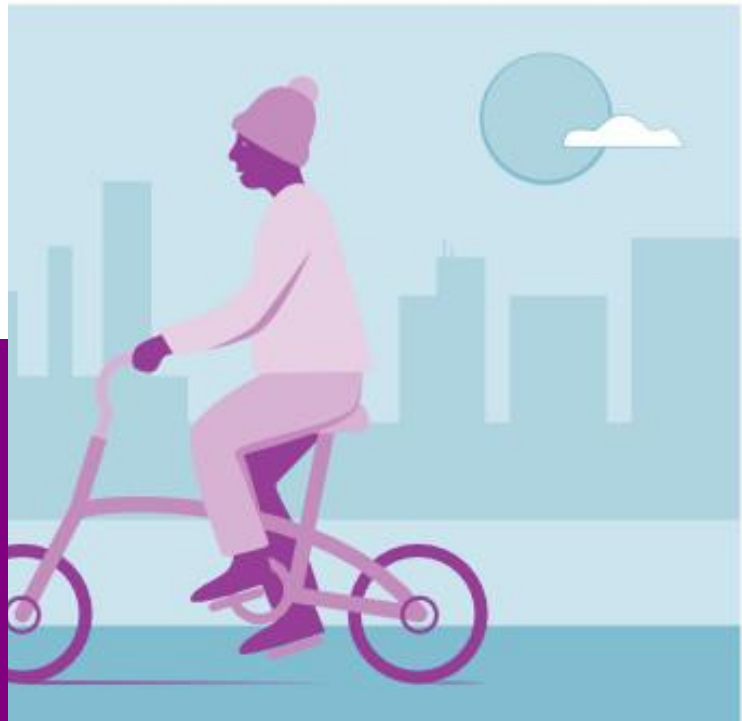




**The Health and
Social Care
Alliance
Scotland
(the ALLIANCE)**



**Response to National Care Service
Expert Legislative Advisory Group
discussion topics
May 2024**

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to participate in the National Care Service Expert Legislative Advisory Group (ELAG). As the Scottish Government will be aware, the ALLIANCE has supported the principle of the creation of a National Care Service (NCS) if implemented in a way that responds to the concerns and experiences of people accessing social care and the workforce and the recommendations in the Independent Review of Adult Social Care. We have contributed extensively to consultations, the co-design process and stakeholder advisory groups.

In consultation with our members, we prepared suggested amendments to the Bill as introduced and have shared and discussed these with the Scottish Government. We welcome the opportunity to contribute to the Scottish Government's amendments through the ELAG, and look forward to continuing to do so as the Bill continues its Parliamentary passage. To supplement our contributions in ELAG meetings, this document details our comments on the papers shared with the Group.

This document covers the topics up to and including the meeting on 23 May. We will share any written comments on following topics separately.

National Care Service Board

The ALLIANCE welcomes the proposed creation of a National Care Service Board. This presents the opportunity to improve accountability, consistency and the sharing of good practice, compared with current arrangements.

Board membership and embedding lived experience in decision making

We welcome the commitment to all members of the Board, including lived experience members being given full voting rights. Although it is not the only barrier to full participation of service user¹ and unpaid carer lived



experience members of Integration Joint Boards (IJBs), not having voting rights contributes to them not being fully included as equal and valued members of IJBs.

We would however recommend that what is intended by 'lived experience' for these purposes should be clarified. It is unclear from the paper whether this refers to membership being given to both service users and unpaid carers, service users only, whether one representative is intended to cover both, or whether workforce representatives are intended to be covered by this category.

We also note that the paper suggests that the Scottish Government plans to co-design additional membership categories. The ALLIANCE therefore recommends membership should be set out in primary legislation.

We would recommend membership of the NCS Board and local boards, with full voting rights, is given to the categories set out in Integration Joint Boards regulations², which requires an IJB to appoint at least one member in respect of the following groups:

- (a) staff of the constituent authorities engaged in the provision of services provided under integration functions;
- (b) third sector bodies carrying out activities related to health or social care in the area of the local authority;
- (c) service users residing in the area of the local authority; and
- (d) persons providing unpaid care in the area of the local authority.³

Third sector representatives are notably not mentioned in the papers and appear not to be included in the proposals for the NCS Board. It is not made clear why this is the case, especially if the other groups above are proposed to be represented on it.

The ALLIANCE recommends that the third sector should be represented, with full voting rights on the NCS Board and local boards. The third and independent sector provides 78% of social care services⁴ and



consequently is a major stakeholder who should be included, as well as playing a considerable role in informing and influencing policy and practice improvements. The third sector also delivers and provides an invaluable perspective and expertise in community led health approaches, community capacity building and a range of activity addressing the social determinants of health and prevention work.

We welcome the recognition that people with lived experience will require support to meaningfully participate in decision making, and agree that this should be co-designed, and would not necessarily require to be detailed in primary legislation. The ALLIANCE has extensive experience of supporting people with lived experience to meaningfully participate in decision-making, including on IJBs and would be able to inform this activity. Further details of this are set out below.

National Care Service Local Reform

Overview of Local Reform and key aims

The ALLIANCE recommends that as well as enabling better care for people, that enabling measurably better personal outcomes for people should also be considered a key aim for efforts to improve integration authorities.

In addition to the action to deliver the key aim of increasing transparency and understanding of who is responsible for what, we would also draw attention to the Ministerial Strategic Group for Health and Community Care review recommendation which identified that there needs to be the ability for integrated finances and financial planning⁵.

Enhancing the voice of lived experience

As detailed above, the ALLIANCE recommends that the third sector should be represented, with full voting rights on the NCS Board and local boards. Similarly to the proposals for the NCS Board, there is no clear rationale



given for third sector representatives not to be given voting rights, but the other groups are.

We also feel that the use of ‘public partners’ to describe service user, unpaid carer and workforce representatives in the paper was unfamiliar and could cause confusion, especially as it would be easy to confuse it with ‘public sector partners’.

We welcome the commitment to ensuring appropriate support is provided to enable lived experience representatives on IJBs to carry out their roles, and agree with the suggested list of actions in the paper. The ALLIANCE is gathering evidence from the IJB Lived Experience Representatives Network, which we host, and has recently published ‘More Than Equal’, a joint report with the Coalition of Carers in Scotland making recommendations for how service user and unpaid carer representatives can be supported to play a meaningful role in decision making⁶. We would welcome the opportunity to support co-design activities in this area.

In relation to the suggestion that there could be greater use of participatory budgeting, we would note that there are mixed opinions on how well this is working. While some people think it demonstrates shared decision-making, others consider it nothing more than a small-scale grant-giving exercise that pits community groups against each other for small pots of money⁷. A more important aim could be to ensure that there are participatory and deliberative mechanisms for communities to identify and discuss issues of importance, alongside the opportunity to consider the budgetary implications and options available.⁸ For instance, this may include human rights budgeting.^{9,10}

In addition to the suggestion that localities may share best practice in working with local communities across integration authorities, we would also recommend resources need to be made available for community engagement and development.

Improving governance structures



The ALLIANCE disagrees with the proposal to rename integration authorities to NCS local boards (e.g. Orkney National Care Service local board). We believe this would risk confusion being caused due to the board being described as a 'national local' board, risk overlooking the contribution made to integration authorities by health, and overshadowing the integration agenda, which is still a work in progress.

We would favour integration authorities and Integration Joint Boards retaining their current names. If a change is felt necessary, for instance due to feedback at the Group that it is not clear from the name what an Integration Joint Board does, then 'Community Health and Social Care Board' (as proposed in the original NCS public consultation) might be an alternative that avoids the issues above.

The Boards' governance process and the way they function in practice also need to enable lived experience involvement, regardless of what name is used. For example, consideration needs to be given to how the agenda gets set and who gets to influence it, and it needs to be clearly articulated how decisions are made.

In relation to the proposal to empower integration authority Chief Officers in the relationship with NHS health boards and local government staff, guidance alone may not be sufficient to achieve this. Consideration should be given to whether the powers afforded to Chief Officers are sufficient. Integration authorities have faced significant challenges at times, and if local authorities and NHS Boards still have their own accountability processes to follow when signing off on decisions and budgets and reporting against specific targets and measures, this may not be addressed by guidance alone.

Increasing clarity and understanding of responsibilities

We have concerns that the proposed role of the National Care Board appears to be only to have a focus on oversight of IJBs/local boards, rather than a focus on national consistency, improvement support, monitoring



progress and setting national standards. While ensuring scrutiny happens is important, it should also be recognised that some of the issues relate to systemic matters, statutory responsibilities and national targets set, such as the Local Delivery Plan Standards.

If there is not a recognition that the national picture may need to change to support the IJBs/local boards then change may not happen. We recommend the National Care Board's role should involve supporting the sharing of learning, good practice, and ideas across the country, monitoring progress and systemic issues including through identifying data gaps and trends, identifying where there is a need for, and undertaking, strategic commissioning of national service, as well as having an oversight function. As proposed, it appears that its main function could be seen as 'marking the homework' of local integration authorities.

In this light, it is problematic to see National Board having oversight of IJBs/local boards since there are likely to be national issues which make local implementation difficult, such as budget allocations, directions and policy siloes.

It also contributes to a broader issue of the proposed governance model assuming that having a Board made up of the various stakeholders will lead to different decisions being made. A significant part of whether the National Care Service can address long standing issues in social care rests on the National Care Board and its membership. However, discussions at the Expert Legislative Advisory Group demonstrate that many different stakeholders want a seat at this table. Given this, greater consideration needs to be given to how decisions will be made, issues identified, agendas set, and budgets decided, and how effective the accountability mechanisms are to enable robust scrutiny.

National Care Service Principles

Defining human rights



The paper does not provide sufficient information as to what this amendment would look like to be able to provide clear feedback. The ALLIANCE had previously recommended the Bill be amended to require Scottish Ministers to have regard to international human rights instruments in developing the Charter, in particular ICESCR and CRPD. We would also agree that ECHR and UNCRC are relevant to social care and the National Care Service.

In principle, we would welcome it being made clearer that the NCS is working towards the realisation of international human rights treaties and frameworks. Consideration should be given to how the legislation will be future proofed to be able to include any developments in this respect. For example, there have been deliberations within the UN around a convention on the rights of older people, which if agreed and ratified by the UK would be highly pertinent to NCS services.

Previously, the Scottish Government has suggested that the principles would cover all duties across the NCS, so it would be unnecessary to specify that human rights instruments should be taken into account in particular activities (such as in preparing the Charter as suggested above). It is unclear from the paper whether this will continue to be the case with the shared accountability arrangements, as detailed further below.

Palliative and end of life care and rehabilitation

ALLIANCE members have raised concerns about the current principles inadvertently excluding palliative and end of life care, and rehabilitation. We have previously supported amendments to address these in principle, so welcome adding suitable reference to them to the principles. There is not a great amount of detail included in the paper as to what the specific wording might be, so would welcome further information being provided before being able to make more detailed comments.

Appreciating that the principles would not simply seek to list specific services, one possibility for including palliative and end of life care and



rehabilitation may be that where references are made to ongoing and increasing care, making an amendment to add a reference to this being personalised/holistic so that there is a thread which brings this principle together – the need to ensure the services are responsive and personalised to the person.

Trauma informed practice

The ALLIANCE has called for NCS services to be trauma informed, so we would support the expansion of the principle around continuous improvement, to ‘take account of whole life experiences, including psychological trauma’.

Inclusive communications

There is insufficient detail in the paper to be able to meaningfully comment on the detail of the proposal.

We would suggest that the language currently used in the paper around Inclusive Communication should be altered to better align with existing legislation and human rights based approaches. At present, Principle 1(f) on inclusive communication is as follows:

“the National Care Service, and those providing services on its behalf, are to communicate with people in an inclusive way, which means ensuring that individuals who have difficulty communicating (in relation to speech, language or otherwise) can receive information and express themselves in ways that best meet their individual needs,”¹¹

The above principle is problematic in two ways. The use of the phrase “difficulty communicating” is a framing that assumes a deficit. For example, it is not in keeping with the recognition of British Sign Language (BSL) as a language in its own right, as described in the British Sign Language (Scotland) Act 2015, or the BSL National Plans. We recommend that the language used in the paper should be adjusted and reframed around



“ensuring that every individual in Scotland can communicate in ways that best meet their individual needs”, as a more inclusive representation of people’s communication requirements.

It is welcome to have inclusive communication explicitly acknowledged within the NCS. However, there is a wide body of evidence demonstrating that, for example, people who are Deaf, Deafblind, or who have Visual Impairments have reduced access to community and services, and experience poor emotional and mental health.¹² They are also likely to encounter barriers to accessible information and inclusive communication – which in turn limits people’s access to health and social care services and support, and to wider community engagement.¹³

If we are to see meaningful action on the principle of inclusive communication, the NCS must include a duty on all public bodies to provide inclusive communication at all levels. This should include a duty to record all requests for inclusive communication, and report on whether people’s inclusive communication needs were met, and in what timescale. This reporting should be published at regular intervals, shared with Scottish Ministers, and available to the public - along with reporting on work to improve any areas where people are not being given equitable access and appropriate communication support.

Finally, the duty as it stands emphasises how people receive information. Inclusive communication, as outlined in the Scottish Government *Principles of Inclusive Communication* (2011), is a two-way process; it is not the dissemination of information to a passive object. It is essential that the NCS acknowledges that services and staff need to take notice of and actively respond to a person’s communication back to them, in order to meet the needs of Scotland’s citizens, and ensure the equal provision of communication for everyone.

Application of the NCS principles, standards and outcomes



This section of the paper is slightly confusing, as it has not previously been made clear during the Bill process that all of these things would have been replaced by the NCS principles in the first place. ALLIANCE members have however previously queried the interaction between the NCS principles and some of the named sets of standards, as well as with the SDS principles contained in the Self-directed Support (Scotland) Act 2013.

It is not clear why this has not been raised as a potential issue by the Scottish Government before now, given that the NCS principles were contained in the Bill when it was introduced in June 2022, or since the shared accountability agreement was signed in July 2023. With limited time available as part of the ELAG process, it is not possible for us to advise in detail where there may be conflicts with other agreed standards and principles, nor what the risks and benefits are with replacing current principles and/or standards with the NCS principles.

Although the rationale for the NCS principles superseding the integration planning principles would make sense as it has the potential to simplify the accountability mechanisms and scrutiny instruments. The ALLIANCE has raised this previously, and we are also aware that Health and Social Care Partnerships have also requested. However, this would be on the condition that there is not a risk of losing anything from the planning principles. As outlined above, the ALLIANCE has not been able to review these in detail in the time available.

We would have some concern about removing the national outcomes, as the NCS principles are not expressed as outcomes which people should expect to be supported to realise based on the services and support they receive. We would want to understand what would replace the national outcomes in this regard – for example, whether it was intended that the health and social care standards or other outcomes frameworks would fulfil this role. Further to this, and referring to the point made previously, it is essential that the success of a National Care Service is assessed according to the personal outcomes it contributes to. Therefore, we would



be seeking some assurance that replacing the national health and wellbeing outcomes would not jeopardise an outcomes focused approach.

Effect of the principles

In addition to the issues raised in the papers, we would seek clarity as to what the change to shared accountability means for the effect of the principles. In the Bill as introduced, Scottish Ministers would have responsibility for social care and everything they do in discharging this duty would have to reflect the principles. For this reason, it was considered that it was not necessary to specify that the Charter must reflect human rights, or be available in accessible formats for instance, as it would be covered by the duty to reflect the principles.

However, it is not clear who would have the duty to reflect the principles in everything they do, and how widely they apply – it is not clear if the duty would continue to rest with Scottish Ministers, or be transferred to the NCS Board, and whether this duty would continue to extend to integration authorities. It is important that the principles are considered in all aspects of commissioning, procuring and delivering services and support within the scope of the NCS, nationally and locally, and if this would no longer be the case, we would recommend further amendments are made to ensure that they do.

Additional principles

There is not sufficient detail in the paper for the ALLIANCE to comment on whether any of the additional principles mentioned (integration of services; safety and public protection; individualised support; and expanding continuous improvement) should be added.

People have expressed frustration at times about the lack of transparency about the decisions which have been reached after an assessment has been undertaken and then the resource allocation is made. One possible



addition could be to give the right for a person to have a copy of decisions taken and the rationale, plus the right to appeal a decision.

Procurement

Definitions of ethical commissioning and procurement

The ALLIANCE has consistently recommended that a definition of ‘ethical commissioning’ should be added to the Bill. Without this, there is a risk of multiple definitions and understandings of what ‘ethical commissioning’ is being created, and risk making it ineffective in practice, with commissioning processes being described as ‘ethical’ when they are not.

The paper also refers to ‘ethical procurement’ (which does not appear in the Bill as introduced) and provides an outline definition. From discussions in the Group, our understanding is that the Scottish Government intends for a single definition of ‘ethical commissioning and procurement’ and for it to be provided in guidance. The ALLIANCE would recommend that the definition is included in primary legislation, to ensure compliance with it, which would be less likely if it were in guidance alone.

Although the paper defines commissioning as “when decisions are made about how services and support will be provided”, that does not entirely encompass commissioning. It is the whole cycle of assessing the needs of a population, reviewing what provision is available in the community (gap analysis), working out the priorities, identifying options for achieving these, and then moving to plan for how the services and support will be provided.

The Scottish Government’s definition from 2012 was:

“Commissioning is the term used for all the activities involved in assessing and forecasting needs, linking investment to agreed desired outcomes, considering options, planning the nature, range and quality of future services and working in partnership to put these in place.”¹⁴



We would also note that there is nothing in the paper about linking the procurement back to the commissioning strategy, that the procurement has to deliver on the strategic priorities identified through the commissioning process. There is also nothing about ensuring that the procurement itself does not undermine the viability of the provider or the sector - that the contract value is actually reflective of the work, and allows the provider to provide management structure, training, supervision and communication support where required. We would recommend that these were considered as part of the policy development in this area.

Extension of the reserved procurement process

The ALLIANCE is broadly content with the definition of third sector organisations outlined in the document. We would consider it would cover our relevant third sector members.

We would also agree that the clause on limiting contract years should be removed.

We would also suggest that consideration should be given to how the reserved procurement process will be reviewed to enable transparency, for instance by requiring a local procurement strategy to set out why the reserved process has been utilised, or why it has not.

Making procurement strategies tell us how they will deliver integration authorities strategic plans and meet ethical commissioning principles

As detailed above, the ALLIANCE recommends that a definition of ethical commissioning (and procurement) is added to the Bill.

Power to amend the light touch regime threshold for community health and social care services



In principle, we would agree with a provision to give the Minister the power to change the light touch regime threshold for community health and social care services. We would suggest that any limitations to this power are also set out (e.g. whether the level must be based on particular factors, or whether there the increase would be unlimited).

We would also suggest that there could be a role for the National Care Service Board in advising the Minister on when to use their power to increase the threshold.

Including the National Care Service Board in Procurement law

It has not been previously made clear that the National Care Service is to be set up as a public body. We would recommend that the Scottish Government set out what this would involve beyond the NCS Board – for instance, whether the NCS would have a staff and a Chief Executive.

NCS Complaints and Redress, NCS Charter, Independent Advocacy

NCS Complaints and Redress

We would be content with the proposed amendments, which would appear to be due to the shared accountability agreement changes. The ALLIANCE were content with this section of the Bill as introduced.

NCS Charter

We would be content with proposed amendments which would allow Scottish Ministers to delegate future work and changes to the Charter to the National Care Service Board, provided it does not remove the requirement to consult (or in practice, co-produce with) people with lived experience.



The ALLIANCE warmly welcomes the proposed amendment to consult with unpaid carers and family members, as well as people who access NCS services, and those who provide them.

We also welcome the proposed amendment to add a duty to the NCS Board to promote the Charter, which the ALLIANCE has also previously recommended. Inclusive communication is vital to this, and we would seek clarification, as detailed above, that the inclusive communication duty in the NCS principles would also extend to the promotion of the Charter.

Independent Advocacy

Whilst the consideration of independent information and independent advice, in addition to independent advocacy is welcome, we would suggest that further information is set out as to what regulations about them it would be proposed the Scottish Ministers would be empowered to make. We would also recommend specifically consulting organisations funded through the Support in the Right Direction fund on this proposal.

It appears that the proposed amendment to change Section 13 (Independent Advocacy) of the Bill to make regulations covering all the services provided by different bodies who will be part of the NCS, is a consequential amendment due to the shared accountability agreement, although this is not explicitly clear. We would welcome clarification of whether this is the case.

The ALLIANCE would in principle support the proposal to include in regulations a right to independent advocacy, a definition of independent advocacy services, and the development of independent advocacy service standards. We had previously recommended that a definition of independent advocacy be added to the Bill, and are aware that the Scottish Government has developed proposals in this area in close consultation with the Scottish Independent Advocacy Alliance (SIAA).



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 3,500 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.

Contact

Rob Gowans, Policy and Public Affairs Manager

E: rob.gowans@alliance-scotland.org.uk

Sara Redmond, Chief Officer of Development

E: sara.redmond@alliance-scotland.org.uk

T: 0141 404 0231

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

¹ We have used the term ‘service user’ in this section for consistency with the IJB membership regulations below.

² The Public Bodies (Joint Working) (Integration Joint Boards) (Scotland) Order 2014. Available at <https://www.legislation.gov.uk/ssi/2014/285/article/3/made>

³ As above.

⁴ National Care Service – adult social care workforce: evidence, Scottish Government, 21 June 2022. Available at <https://www.gov.scot/publications/national-care-serviceadult-social-care-workforce-scotland/pages/3/>

⁵ Health and Social Care integration: progress review, Scottish Government Ministerial Strategic Group for Health and Community Care, 4 February 2019. Available at <https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/documents/>

⁶ ‘More Than Equal – Valuing and supporting the expert contribution of people with lived experience, the ALLIANCE and Coalition of Carers in Scotland (April 2024). Available at <https://www.alliance-scotland.org.uk/wp-content/uploads/2024/05/More-Than-Equal-Report-2024-WEB.pdf>

⁷ Participatory budgeting, community engagement and impact on public services in Scotland, O’Hagan and others, October 2019. Available at https://www.researchgate.net/publication/336867542_Participatory_budgeting_community_engagement_and_impact_on_public_services_in_Scotland



⁸ Six Ways to Democratise City Planning, DemocracyNext, 13 February 2024. Available at <https://www.demnext.org/news/six-ways-to-democratise-city-planning-new-democracynext-report>

⁹ Human Rights Budget Work, the ALLIANCE. Available at <https://www.alliance-scotland.org.uk/policy-and-research/policy/human-rights/human-rights-budget-work/>

¹⁰ Human Rights Budget Work, the ALLIANCE. Available at

¹¹ National Care Service (Scotland) Bill [as introduced]

¹² The ALLIANCE, “Accessible information on Self-directed Support” (March 2024), available at:

<https://www.alliance-scotland.org.uk/blog/news/accessible-information-on-self-directed-support-lived-experience-research-report/>; The ALLIANCE, “See Hear Strategy Refresh – Lived Experience Consultation Report” (Nov 2023),

available at: <https://www.alliance-scotland.org.uk/blog/news/see-hear-strategy-refresh-lived-experience-consultation-report-published/>;

The ALLIANCE, “See Hear Strategy – lived experience consultation with ethnic minority people” (March 2024), available at: <https://www.alliance-scotland.org.uk/blog/news/see-hear-strategy-lived-experience-consultation-with-ethnic-minority-people-report-published/>.

¹³ Andrena McMenemy and co-authors, “Mental Health and Deafness in Scotland: Exploring the Data” (deafscotland, 2021), available at: <https://eresearch.qmu.ac.uk/bitstream/handle/20.500.12289/11282/11282.pdf>;

S. Cosh and co-authors, “The association amongst visual, hearing and dual sensory loss with depression and anxiety over 6 years: The Tromsø Study”, International Journal of Geriatric Psychiatry (33:4, 2017), available at: <https://onlinelibrary.wiley.com/doi/10.1002/gps.4827>.

¹⁴ Joint Strategic Commissioning – A Definition, Scottish Government Strategic Commissioning Steering Group, June 2012. Available at

<https://web.archive.org/web/20221006143404/http://www.jitscotland.org.uk/action-areas/commissioning/>

