



The Health and Social Care Alliance Scotland (the ALLIANCE)



**“A real, grown up conversation”:
Research on health and social care in
Scotland**

ALLIANCE response

21 October 2026

The Health and Social Care Alliance Scotland (the ALLIANCE) response to “A real, grown up conversation”: Research on health and social care in Scotland

There is growing focus on the need to reform health and social care in Scotland.

The Scottish Government’s commitment to addressing an “overly complex” social care system and promises to deliver the “most significant structural reform of our NHS”¹ in the next 5-year term are bold.

First Minister John Swinney has committed to engagement with partners, local governments, trade unions and the third sector. We welcome discussions on changes that will, as he said, “improve quality of life for thousands of Scots each and every year.”²

At the ALLIANCE we believe this conversation has been ongoing for many years. It’s just that it’s often felt like a one-way discourse.

Over the past 20 years, the ALLIANCE has played a leading role in listening, collaborating with and learning from people with lived experience, with thousands sharing experiences of health and social care. We have also worked with our members to understand their priorities to improve support and services.

The key aim of this work is to ensure the experiences and perspectives of individuals and organisations meaningfully influence and inform decision making.

Yet here we are again and we know from engaging with our members that there is a growing frustration about the lack of change in response to the insights people share. For example, despite thousands of hours of people's time invested in co-designing a National Care Service, the Scottish Government scrapped the proposals due to pressure from stakeholders with more powerful voices and influence.

This is just one of many examples where people's priorities have been overtaken by changing political and policy priorities. Experiences like this



undermine trust in the engagement process and lead people to ask whether they can genuinely influence decision making.

The Scottish Government's move to reform public services, including health and social care provision, must ensure people can see how the insights and experiences they share shape policy and service design.

People have been clear about what needs to change.

The ALLIANCE's 2026 election manifesto – Our Collective Voice – which was representative of our members voices sets out clear, practical, and transformative recommendations for the future³.

Last year, we compiled our collected learning from lived experience to inform the Scottish Government's NHS Reform plans⁴. This brought together evidence and insight from people's experiences and set out detailed recommendations for health and social care reform.

Our learning and wider research reinforces that the system is too complex and fragmented⁵. It also points to the burnout and harm this contributes to the experience of the workforce⁶ when trying to carry out their roles in a system which is not person centred. People tell us they experience this fragmentation first hand through duplicated assessments, difficulties navigating services and having to repeatedly explain their situation to access support.

Too frequently support is only provided when people reach crisis point or their health has worsened.

We often hear that the public have unrealistic expectations of the system, don't understand the tough decisions to be made, or at worst, a belief they wouldn't understand if it was explained to them.

It was for this reason that the ALLIANCE commissioned 'deliberative research' from the Diffley Partnership.

The findings indicate that instead of complex systems being misunderstood, or that headline grabbing statements are the only public discourse, people do understand the complexities of the system - but need



access to knowledge and information to understand the accountability, resources and delivery arrangements as well as policy choices available.

The research was held over five sessions with a panel of residents in Scotland being provided with the time and space to develop their understanding of the health and social care system. Through learning and discussion, participants considered reforms of the system.

The research found that over the course of these sessions participants' views evolved from experience led frustration to informed, system level reflection. When issues, evidence and concepts were explained, they identified the need for change and reform. Priorities which emerged were for preventative investment, person centred care, and respectful language.

The research demonstrated people's capacity to grasp and engage with complex reform. It indicated we don't need endless consultations but should move to shared decision-making power.

At the heart of this is ensuring we deliver change in a way which protects, respects and fulfils people's rights. We need to build a positive human rights culture with a focus on embedding a human rights based approaches across health and social care policy design and delivery.

Rights are not aspirational; they are the legal and moral obligations which help us all to live our lives with dignity. A human rights based approach increases the ability of organisations, including public bodies, to fulfil their human rights obligations and helps to strengthen accountability⁷.

Organisations who design and deliver services need to take positive steps to ensure they are fulfilling people's rights which aligns with a preventative approach. Incorporation of human rights would offer people a route to challenge when they feel their rights have not been met, ensuring they are empowered and can claim their rights.

The ALLIANCE is calling for two fundamental shifts to ensure public services work truly serves people across Scotland:

- A strengthening of free, active and meaningful participation
- Empowering, person-centred, inclusive prevention



The first shift requires greater participation of people with lived experience in decision making, both individually as an expert in their own experiences and collectively at the level of system reform.

Considering the findings from this research, engagement must be deliberative, inclusive of a diverse range of perspectives, and meaningful. People must be involved in shaping the solutions, reforms and decisions affecting them, with clear evidence of how their insights have influenced policy, service design and delivery.

“A lot of people get lost in the system between health and social care, how can we make this transition between both better and easier?” - Research participant

“It’s not only important now but it’s going to get more important in the future, especially with an ageing population and declining younger population – the problems are already here and they’re only going to get worse unless they are resolved.” - Research participant

The limited control and involvement available to people navigating their way through health and social care services is a key driver of the inefficiency that should be designed out of the system. We must build the health and social care system from a basis of respecting the rights and dignity of those who access and deliver services, building on the recommendation in the research for respectful language.

Change happens when power is shared. This aligns with one of the Five Ambitions for the Future of Health and Care⁸ which highlights the need to ‘Share Power’ to ensure that rights and wellbeing are at the centre.

Despite greater emphasis being placed on the involvement and value of lived experience in Scottish policy making, there are still very limited and constrained ways for people to have meaningful engagement in redesigning the system. There is a well-developed evidence base that outlines having control over one’s life is critical to an individual’s health and wellbeing⁹.

The second shift requires a shared vision for the system on improving health and wellbeing and reducing health inequalities



through a prevention focus. As the research progressed, participants notably demonstrated greater awareness of the importance of a system which was focused on preventing avoidable harms and improving outcomes through a person-centred approach. This was seen to be a better investment of public funds and would improve outcomes for people and communities.

“A lot of funding gets spent later down the path, when it’s too expensive.” - Research participant

“Long-term approaches are good but can you get the government to take them?” - Research participant

Prevention is impossible without communities being empowered. The circumstances in which we live have a greater role in shaping our health than the NHS. The focus must shift away from merely focusing on services delivered towards a strategy to working alongside and supporting the strengths and resources in communities. Yet the essential role of voluntary organisations, charities, social enterprises and community groups is still being overlooked and undervalued.

A person centred approach starts with recognising everyone has strengths that support their health and wellbeing. The purpose of care and support should be to build on these strengths and work in equal partnership with the person to help them live a good life.

Scotland has been pioneering in the field of person centred prevention: one example is the Self Management Fund for Scotland¹⁰. Set up in 2009, the Fund has invested £31 million to over 500 community led approaches, from supporting young people in Dumfries and Galloway to providing self management courses in Shetland. These projects all aim to empower and support people to live well.

The ALLIANCE has led and worked with the Scottish Government on this and other initiatives but has also been constrained by the limits of short-term funding and the absence of a strategy to sustain them. Lasting change requires more than successful programmes and pilot projects. It requires a commitment to sustain and scale what works. Fair, multi-year funding and meaningful partnership working must now move from aspiration to reality if



the third sector is to continue delivering the preventative, person centred support and outcomes that people and communities rely upon.

This research offers a valuable insight rarely captured through consultations. Rather than asking people to react to specific proposals, it supported informed discussion with the general public about the practical realities of health and social care reform.

The findings show that people can engage with complexity, understanding trade-offs, and consider what is fair, feasible and sustainable in the long term.

People with lived experience have been asked and answered.

What is needed now is not a national conversation or listening exercise, but action on the long term changes to health and social care that are needed. Decision making must be shared with the people and communities accessing health and social care, giving them greater and more meaningful say in the changes which are needed.

Crucially, this is the route through which to support people and communities to take a more active role in shaping their health, wellbeing and local services, but it will require a fundamental shift in culture, mindsets and practice. This should not be seen as a one-off exercise but an ongoing process of trust and relationship building. Together decision makers, services, staff and people with lived experience will need to collaborate to create a shared vision for the future. By doing this they can identify the steps that need to be taken to turn conversation into action.

The Scottish Government can be confident in the knowledge that people with lived experience, and a well-informed public, would be behind them if they did so.

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About the ALLIANCE

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

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

The ALLIANCE has three core aims.

We seek to:

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

The ALLIANCE is committed to upholding human rights. We embed lived experience in our work and aim to ensure people are meaningfully involved at every level of decision-making.



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

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¹ First Minister John Swinney, 'Programme for Government 2026 to 2031: First Minister's speech - 1 September 2026', (September 2026), available at: <https://www.gov.scot/publications/programme-for-government-2026-to-2031-first-ministers-speech/>

² First Minister John Swinney, 'Programme for Government 2026 to 2031: First Minister's speech - 1 September 2026', (September 2026), available at: <https://www.gov.scot/publications/programme-for-government-2026-to-2031-first-ministers-speech/>

³ The Health and Social Care Alliance Scotland (the ALLIANCE), 'Our Collective Voice. The ALLIANCE 2026 Scottish Parliament election manifesto for a fairer, healthier Scotland', (February, 2026) available at: https://www.alliance-scotland.org.uk/policy-and-research/wp-content/uploads/2026/02/ALLIANCE_Manifesto_2026_WEB.pdf

⁴ The Health and Social Care Alliance Scotland (the ALLIANCE), 'NHS Reform. ALLIANCE lived experience review', (April 2025), available at: <https://www.alliance-scotland.org.uk/blog/news/nhs-reform-learning-from-lived-experience/>

⁵ Coalition of Care and Support Providers in Scotland (CCPS), 'A fragmented picture of integration. How streamlined are the governance, planning and funding structures for social care at the local level?', (August 2026), available at: <https://www.ccpsscotland.org/wp-content/uploads/2026/08/CCPS-Report-A-Fragmented-Picture-Of-Integration.pdf>

⁶ Royal College of Nursing, 'Nursing workforce shortages and surging complexity are increasing the risk for patients and staff, warns nursing union', (May 2026), available at: <https://www.rcn.org.uk/magazines/News/last-shift-survey-2026-180526>

⁷ Scottish Human Rights Commission, 'A human rights based approach: an introduction', available at: https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf



⁸ The Health and Social Care Alliance Scotland (the ALLIANCE), 'Five Ambitions for the future of Health and Care', available at: <https://www.alliance-scotland.org.uk/health-and-social-care-integration/health-and-social-care-academy/five-ambitions-for-the-future-of-health-and-care/>

⁹ The Health and Social Care Alliance Scotland (the ALLIANCE), 'My Support My Choice', available at: <https://www.alliance-scotland.org.uk/policy-and-research/research/my-support-my-choice/>

¹⁰ The Health and Social Care Alliance Scotland (the ALLIANCE), 'About the Self Management Fund', available at: <https://www.alliance-scotland.org.uk/self-management/about-the-self-management-fund/>

