

# NHS Reform

**ALLIANCE lived experience review**



**ALLIANCE**  
HEALTH AND SOCIAL CARE  
ALLIANCE SCOTLAND  
people at the centre

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# Executive summary

## Quality

Many factors influence both the quality of services and support people access and their overall experience of those services. Through the evidence review, 20 themes emerged as key determinants of service quality.

Communication influences the quality of people's experiences when accessing healthcare services. Clear, consistent and empathetic communication was viewed as having a positive impact, whereas breakdowns in communication, unclear messaging and insufficient information negatively affected how people accessed and received healthcare and support. Effective communication was described as including regular updates, supporting clear navigation of healthcare systems, and characterised by kindness.

Healthcare professionals' skills and attributes, such as professionalism, compassion and responsiveness, significantly shape perceptions of care quality. Positive experiences were linked to instances when professionals demonstrated kindness, empathy and cultural sensitivity, supported by adequate training in areas like mental health, trauma-informed care and equalities. People we have engaged also recognised that understaffing and workforce pressures affect professionals' ability to provide holistic and compassionate care.

As a first point of contact, GPs were viewed as crucial in setting the tone for healthcare experiences, highlighting the need for person centred, consistent and accessible care.

People's views on communication, skills and attributes underscore the importance of person centred care, which involves seeing individuals as a whole and addressing their unique needs, preferences and circumstances. People highlighted the role of a holistic approach in improving outcomes, empowering individuals and enhancing their ability to manage their health. Compassionate, tailored care helps foster trusting relationships and can make navigating complex systems more manageable.

People strongly advocated for personalised care, rejecting a "one size fits all" approach. They value having the ability to choose when, how and with whom they access services. Flexible service models, such as extended hours, online booking systems and "Digital Choice" (blending in-person and digital care), were seen as empowering for individuals to manage their health in ways that align with their lifestyles and preferences. The COVID-19 pandemic highlighted gaps in choice, with some individuals reporting pressure to conform to restricted options, particularly in maternity and mental healthcare. There is a clear link between how people access services and the choices that are available to them and their experience of healthcare quality.

Improved coordination between services and better information sharing were identified as priorities to ensure seamless care pathways. Challenges included inconsistent data-sharing practices, disconnected communication channels and gaps in transitional care, such as moving from child to adult services.

Related to disjointed care experiences, a lack of continuity with healthcare professionals often leads to missed opportunities for early intervention, frustration and poorer outcomes. Continuity was particularly valued during transitions and in managing long-term conditions like chronic pain or mental health issues.

Coproduction, involving people with lived experience in decisions about the design and delivery of services, was recognised as essential to creating meaningful, effective care. Individuals consistently call for active participation in decisions about their care plans, valuing transparency and reduced power imbalances. Concerns about tokenistic engagement emphasise a need for genuine collaboration at all levels.

The themes explored above were also apparent throughout our engagement with people around their experiences of mental health care and audiology services. Experiences of mental health services were missed, with significant concerns about long waiting times, inconsistent support, and an over-reliance on medication. Perinatal mental health care and lack of tailored support for miscarriage and stillbirth were reported. People want to see more investment in community-based, person centred care and prioritisation of counselling and therapy over medication.

Individuals accessing audiology services and support for sensory impairments faced challenges in communication, care continuity and integration between and across services, like education and healthcare. Positive experiences were linked to compassionate, informed and proactive care tailored to individual needs. Calls for improvement included better training for professionals in British Sign Language, consistent audiology staff and seamless device management processes.



## Access

Previous ALLIANCE research has given insights into people's experiences when accessing healthcare services. This covered the full journey from identifying a health need, reaching out to, and engaging with services. Evidence was reviewed to gain a better understanding of most prominent themes. These included access to primary care, person centred care, choice and flexibility, communication, inequities in healthcare, sensory loss and Deaf culture, and access to secondary, alternative and private health services.

People's experiences were mixed and contradictory. However, there was a strong feeling that there should be equal access to appropriate spaces and services when people needed them.

Another strong theme across the evidence reviewed is a feeling that the access needs and requirements of disabled people, people with sensory impairments, or those whose first language is not English have been long overlooked by the health system, stemming back to before the COVID-19 pandemic. Mixed experiences have been exacerbated, not caused, by the pandemic. Barriers to accessing healthcare services is occurring across the board with evidence highlighting organisational cultures, institutional discriminatory practices, and structural barriers diminishing people's access to healthcare. People feel that the lack of access to services during the pandemic which, for example, monitor their health, provide ongoing support and keep them well has resulted in negative implications for their health and wellbeing.

In our analysis, the most referenced aspects of access were technology enabled care (TEC), communication, primary care, person centred care, sensory loss and Deaf culture, and secondary, alternative and private healthcare services.

The adoption of TEC solutions during the pandemic and the opportunities this presented in terms of access was beneficial for many people including people living in remote or rural areas and disabled people. However, people also cautioned against replacing face to face services with a digital first approach, emphasising the need to expand choice to people around how they access a service, and noting concerns that concentrating on such an approach could exacerbate inequalities to those already digitally excluded.

As with quality, communication can impact how people access services and information. The provision of accessible information is of key importance for many disabled people, including people with learning disabilities and people with sensory loss, neurodivergent people and those whose first language is not English. There was consensus amongst people engaged that information should be clear, use simple language and avoid jargon and abbreviations. It should also be available in a range of formats, media and settings beyond health and social care.

People have reported mixed experiences accessing primary care services, with experiences of accessing General Practices (GPs) being a particular theme. Pandemic restrictions limited people's access to healthcare, while inaccessibility issues raised additional barriers for disabled people, their families and carers, highlighting inequalities within the system. To prevent further inconsistencies and access issues, people saw it as vital to make changes to the GP system, such as co-locating with other primary care services.

The evidence we have gathered demonstrates that person centred care remains an aspiration for the healthcare system in Scotland. Although there are pockets of good practice, people experience a lack of dignity, respect and empathy from professionals and services. This is a prominent issue for those who are disabled, have sensory loss or are Deaf. Due to limited choice and flexibility, they also feel like they aren't decision makers or leaders in their health care. As a result, people were discouraged from accessing care and support even when they needed it most.

People with sensory loss or Deaf people told us that there were issues with several areas of healthcare, and they are often unable to access the care they want, need or expect. We heard about instances in which individuals' needs were not considered prior to attending an appointment and of professionals using inappropriate means of communication. Other concerns included access to technology, equipment, maintenance support and information in suitable formats.

Secondary healthcare services were negatively impacted during the pandemic as they were deemed non-essential and were closed. For example, people had issues accessing secondary health services such as pain clinics, psychiatry, neurosurgery, rheumatology and orthotics. Others told us that they had resorted to alternative remedies to treat their conditions and/or felt forced to pay for private healthcare services and support.

However, access continues to be limited or people felt as though they were brushed aside as services felt their issues were not treatable. For people, being told that they were non-essential or untreatable meant that they were unsure of where they could go for help or diagnosis. Others felt forced to seek private medical help due to long wait times, and limited availability and options. The desire and benefits of alternative therapies such as massage and acupuncture demonstrate that healthcare should be holistic and based on what people find helpful, which accompanies medical or clinical treatment.



## Prevention

To create a healthy society, Scotland must use all available levers to shift from treating illness to preventing its occurrence and investing in health creation. Whilst acknowledging the wider evidence base which highlights the most effective primary prevention interventions are those which support access to the positive social determinants of health – in terms of income, wealth, employment, housing, education, transport, food systems and so on – this review analysed what was important to people in terms of support for prevention through healthcare. This is in recognition that access to healthcare services is a human right and is a determinant of health.

ALLIANCE engagement around primary prevention, including support and tailored information to build knowledge, skills, confidence and understanding around risk factors and healthy habits (such as eating well, exercising, and not smoking), has demonstrated the benefits of personalised and community based education and awareness interventions. Tailored outreach programmes that emphasise achievable and healthy lifestyle modifications are considered highly impactful by individuals receiving services and the organisations delivering them. However, engagement rates with health literacy education remain low and often fail to reach communities at greatest risk.

The review of engagement emphasises the critical importance of secondary prevention, namely early diagnosis and intervention, particularly for early identification of long term conditions and mental health issues, and to prevent deterioration and improve overall wellbeing. Our engagement has documented an appetite for 'health check' community diagnostic services to be made more widely available, to allow people to better understand – and feel in control of – their health and empower them to take action before presenting to healthcare in crisis.

Tertiary prevention's role in the ongoing management and mitigation of long term conditions is also a critical element within prevention. Encouraging the adoption of self management approaches within the community, that can support better lifestyle choices and foster robust support networks is consistently raised as essential by programmes funded by the ALLIANCE Self Management programme and the people they support to live better, and on their own terms. Similarly, the role of prehabilitation must be elevated in order to reduce treatment-related complications, for example within cancer care and cardiovascular surgery, as must the role of rehabilitation in supporting people, including people affected by substance use to avoid reaching crisis.

To support the implementation of the prevention agenda, it is also clear that integration of healthcare services and stronger partnerships between public, independent, and third sectors are necessary to provide continuous and comprehensive care. The role of partnership with the third sector in particular was raised as necessary in filling in the gaps of care that exist across primary, secondary and tertiary prevention services, be it community diagnostics, self management or delivery of specialist care.

Broadly, ALLIANCE engagement regularly returns to the need for a shift of resources from acute care to the wider prevention agenda, and the wealth of proactive measures that can be better employed to prevent or mitigate long-term health issues and support healthy lifestyles from an early age throughout the life course. This review also highlights the positive potential of an expanded community care model in Scotland that might better engage communities who experience the greatest barriers to engaging in healthcare within the prevention agenda and allow them to lead healthier lives for longer.

## People and Place

To ensure that NHS reforms are sustainable, we must also consider the wider factors that impact on health and wellbeing, and how the NHS works with local and national partners to align improvements.

We have gathered extensive insights into what matters to people in relation to the role of systemic inequalities in shaping health, their relationships with and within communities, the impact of stigma, and how communities are designed in ways that both promote and limit health and wellbeing.

Systemic inequalities profoundly shape people's health and wellbeing and are shaped and experienced in the places where we are born, grow up, live, work and age. Disabled people, people living with long term conditions, women and people from ethnic minority communities, and LGBT+ groups often experience poorer outcomes and have distinct requirements and support needs that are not always met by the current healthcare system. These health inequalities are influenced by a range of factors including poverty, employment, housing, education, racialisation, microaggressions, discrimination and childhood experiences.

The pandemic and increased cost of living disproportionately impacted people from marginalised groups, while the rising cost of living resulted in a crisis for the sections of our society at highest risk, who were and continue to find themselves both with higher bills and less ability to pay. There continues to be a need for longer term action to address the root causes of the crisis which should be considered a form of preventative spending. Investing in broader measures to improve incomes and tackle poverty, including measures targeted to the needs of different groups, would go a long way toward improving people's health and wellbeing, support access to services and prevent deconditioning, thereby reducing the need for more costly acute interventions and pressures on the NHS. Additionally, NHS commissioning should adopt a human rights based approach to procurement and grant funding to prioritise services which realise human rights and uphold dignity.

Other societal factors have a significant impact on health and wellbeing. Negative attitudes, biases and stigma can impact people's sense of belonging and can in turn impact relationships within communities including between people accessing and providing support. Internalised stigma can be an additional barrier to building trusting relationships and seeking support, while bias can play a role in healthcare professionals' decision making. Education, awareness raising, training and capacity building for those working in health and social care could help tackle stigma and its impacts within healthcare services.

Finally, while the COVID-19 pandemic created challenges for people accessing care and support, it also accelerated new ways of working that were very beneficial. The shift to online delivery of services and more rapid delivery enabled more flexible approaches. As one person told us, these transformations "showed it was possible to meet the needs of housebound people." People's insights from this time provide invaluable learning for rethinking how the NHS works with local, community and third sector services to support everyone's health and wellbeing.

# Recommendations

The following recommendations draw from the evidence reviewed.

The report has highlighted the interplay between the four priority domains for health and social care reform and has captured the complexity of the NHS and the challenge of disentangling people's priorities for NHS reform from those related to primary care or social care. Furthermore, people spoke frequently about the importance of taking a whole system approach, taking into account the wider environment and public services which enable their health and wellbeing, including the contribution of the third sector.

Some of the recommendations are quite specific whereas others are broader, reflecting the context of wider system change.

**1**

**People want change, active involvement in implementation, and robust monitoring to ensure it delivers what is intended.**

**An overarching theme evident in this review is that people want to see reform delivered that is informed by their priorities. Furthermore, priority must be given to empowering the role of people with lived experience in health and social care reform.**

**2**

**This review highlights some key ALLIANCE evidence concerning what is known about people's priorities, however further work is needed to understand the wider evidence base.**

**Therefore, Scottish Government should undertake further work to review other existing evidence, including drawing on that of third sector organisations. This work should take an equality informed and intersectional approach to consider the experiences of different population groups including, but not limited to, people receiving end-of-life care, unpaid carers, people from racialised communities, LGBT+ groups and people with learning disabilities.**

There is a clear need to improve the monitoring of inequalities and evidence gathering across public services. In line with the recommendations by the Expert Reference Group on COVID-19 and ethnicity,<sup>1</sup> the Glasgow Centre for Population Health and LGBT Health and Wellbeing,<sup>2</sup> this work should include proactive public health surveillance of the health, wellbeing and inequalities faced by different groups including those with protected characteristics.

**3**

**Strengthen the mechanisms for whole system, longer term integrated planning of health and social care services – enabling greater coordination and coherence across and between Scottish Government, the national NHS Executive to Health Boards, Health and Social Care Partnerships and Local Authorities.**

**This planning should assess and forecast population needs now and into the future, monitor unmet needs, identify gaps in service delivery, plan for changing needs, and should be aligned to the Health and Social Care portfolio medium term financial framework.**

**There is also a need to strengthen the ongoing and meaningful involvement of people with lived experience in decision making – this should be done at both national and local levels.**

**4**

**Improve experiences of integrated health and social care and support.**

**Our evidence demonstrates that more must be done to improve integrated ways of working including across health services, between health and social care, and include the third sector, to address issues of disjointed pathways, delays, unmet need, a lack of accountability and follow up.**

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<sup>1</sup> Scottish Government (2020) 'Expert Reference Group on COVID-19 and Ethnicity: recommendations to Scottish Government.' Available at: <https://www.gov.scot/publications/expert-reference-group-on-COVID-19-and-ethnicity-recommendations-to-scottish-government/>

<sup>2</sup> Glasgow Centre for Population Health and LGBT Health and Wellbeing (2024), 'Examining the social determinants of LGBT+ health and wellbeing.' Available at: <https://www.gcph.co.uk/latest/publications/1174-examining-the-social-determinants-of-lgbt-health-and-wellbeing>

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## 5

**Scottish Government, Health Boards and Integration Authorities must review their arrangements for working with the third sector and identify areas for improvement.**

The ALLIANCE's evidence continues to demonstrate that more must be done to improve the engagement of the third sector as both a strategic and operational partner in health and social care. Despite strong evidence showing its vital role in providing support and services and essential social infrastructure to address health challenges, the third sector continues to be overlooked in governance arrangements and reform efforts.

This work must be underpinned by adopting the 'Fair Funding for the Voluntary Sector' proposals<sup>3</sup> and take into consideration the arrangements that are needed for the public sector to be effectively informed about, refer on and signpost to the third sector support that is available in their areas.

## Access

## 6

**Improve and clarify pathways to ease navigation of NHS services, paying particular attention to boundaries between services.**

The challenges people encounter when trying to navigate their way through the NHS - with regards to information sharing, the coordination and continuity of care, and barriers to accessing services - are well documented and require immediate improvement.

The King's Fund has identified that high-quality administration processes have the potential to improve a person's experience, reduce inequalities, promote better care and contribute to a better working environment for staff yet are rarely the focus of reform efforts.

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<sup>3</sup> [What is Fair Funding? - SCVO](#)

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## Our recommendations include:

- There needs to be a greater focus on guidance and support to create the conditions for multidisciplinary team working. The GIRFE team around the person toolkit provides an opportunity.
- The introduction of an integrated health and social care record to support the sharing of information across services and ensuring personal and proxy access.
- Focused action to ensure equal access for disabled people, people with sensory impairments, people whose first language is not English, and those who face structural and systemic barriers. After carrying out a review of existing evidence (Recommendation 2), if there are data gaps the Scottish Government may need to commission further community-based research to understand these issues and highlight solutions.
- Promote existing guidance on Inclusive Communication<sup>4</sup> and instigate a programme to raise awareness, support implementation, and monitor its application.

## 7

### Priority must be given to people's communication, information and support needs.

Key to being involved in maintaining one's own health and wellbeing is having access to the right information, in the right format, at the right time. This allows individuals to understand their health and wellbeing options, giving them greater control over their care and informed decision-making, and increases people's capacity to self manage.

Scottish Government and NHS Boards must improve and embed inclusive communication strategies and approaches which ensure people have access to the information they need to be informed about their health, to access support and services, and in relation to related matters. This includes, but is not limited to, information about accessing transport to health services, and support for digital inclusion. Access to appropriate information and resources are key enablers in supporting self management.

<sup>4</sup> Scottish Government (2011) 'Principles of Inclusive Communication: An information and self-assessment tool for public authorities.' Available at: <https://www.gov.scot/publications/principles-inclusive-communication-information-self-assessment-tool-public-authorities/>

8

People's access needs must be prioritised to ensure both individual and population needs are more equitably met. There should be a greater focus on choice, flexibility and availability in service models, which allow people to access services in ways that better meet their rights and needs and ensures that digital is a choice not a requirement or expectation.

9

The challenges of accessing certain NHS services must be addressed, for example; where there are long waiting lists, where the service is identified as 'fragile', and/or eligibility criteria are applied to manage waiting lists.

There must be greater transparency and participation of lived experience with the identification of 'fragile' NHS services and/or services where eligibility criteria are applied to manage waiting lists.

This must take into account regional variations, including where this affects remote and rural parts of Scotland.

Scottish Government and Health Boards should undertake and publish a review into which NHS services are fragile, in which parts of the country, and where access problems are most challenging. This review should involve people with lived experience in this process, have a focus on working towards solutions, and take into account the contribution the third sector plays in delivering services.

10

Enhance availability and accessibility of emotional and psychological support during critical life and health events, including but not limited to diagnosis, pregnancy loss, palliative and end of life care.

## Quality

11

Prioritise person centred and relational care as a guiding principle of reform.

Research and engagement by the ALLIANCE into experiences of person centred care, continues to highlight shortfalls. This creates barriers to access and negatively impacts health outcomes. We have identified the core elements of person centred care as:

- Feeling heard and listened to.
- Being treated with courtesy and dignity.
- Experiencing empowerment.
- Feeling trust during interactions.
- Feeling understood by healthcare practitioners, having good relationships, and not being judged.

These are strongly aligned to the GIRFE principles, which could prove to be a guiding approach to the NHS Reform Programme.

12

Prioritise training and professional development in person centred care as part of workforce recruitment, retention and development planning, ensuring a focus on equality, rights, inclusion and trauma informed approaches.

Related to Recommendation 11, the evidence review has highlighted the importance people place on person centred and person led care, and the negative impact where this is not encountered. It is essential that priority is given to ensure the workforce develop the training and skills required to deliver person centred care. Our evidence has highlighted the following to be of importance:

○	Trauma-informed approaches (e.g. the National Trauma Training Programme). <sup>5</sup>
○	Gender sensitivity.
○	Awareness of systemic inequalities and ability to take an intersectional approach such as Equality in Integration modules. <sup>6</sup>
○	Understanding mobility requirements.
○	Sensory awareness training, including a strong understanding of device management.
○	Cultural awareness.
○	Inclusive communication skills. <sup>7</sup>
○	Turas person centred care zone. <sup>8</sup>
○	A human rights based approach to dignity in care. <sup>9</sup>

<sup>5</sup> National Trauma Transformation Programme; Working with substance use, trauma and mental health, available at: <https://learn.nes.nhs.scot/19051/working-with-substance-use-trauma-and-mental-health>; Embedding Trauma Informed Care within Maternity Services in Scotland, available at: <https://learn.nes.nhs.scot/74167>

<sup>6</sup> Integration of Health and Social Care, available at: <https://learn.nes.nhs.scot/17860>

<sup>7</sup> Communication Skills, available at: <https://learn.nes.nhs.scot/79093/general-practice-education-hub/general-practice-management/resources-and-recordings/administrative-and-receptionist-masterclass/communication-skills-video>; Augmentative and alternative communications: introduction, available at: <https://learn.nes.nhs.scot/14904>; NHS Greater Glasgow and Clyde Staff Training resources, available at: <https://www.nhsggc.scot/your-health/equalities-in-health/information-resources/for-staff/staff-training/>

<sup>8</sup> Person-centred care zone, available at: <https://learn.nes.nhs.scot/18887/person-centred-care-zone>

<sup>9</sup> Human Rights-based Approach to Dignity in Care (DIGNISPACE), available at: <https://www.coursera.org/learn/human-rights-based-approach-to-dignity-in-care-dignispace/>

○	NES Introduction to Equality, Diversity and Human Rights. <sup>10</sup>
○	LGBT+ inclusive training.

### Adopt the House of Care approach, enabling person centred care and the practice of Realistic Medicine.

13

House of Care is a coordinated service model that enables people living with long term conditions to be in the driving seat of their care. It addresses health inequalities, builds health literacy and supports public health aims.

Underpinned by self management principles, House of Care builds people’s confidence and ability to manage their conditions. It does this through information gathering and sharing prior to a collaborative conversation which involves goal setting and action planning. With the person “knowing their numbers” (e.g. blood pressure, lipids and so on) in advance of a care and support planning conversation, they have a sense of empowerment which leads meaningful and informed conversations about their health and condition management.

Evidence shows that this type of supportive, collaborative relationship can lead to improved health outcomes, especially when it is fully integrated into primary care delivery.<sup>11</sup>

Though used mainly within the primary care and long term condition management context, the House of Care collaborative, person centred conversation can play a significant role in prevention. It can go further than where ‘health check’ initiatives have gone, by combining measurement of key risk indicators with motivational interviewing and goal setting techniques to influence behaviour change and reduce potential impact of unmanaged risk factors. This allows people to take part in shared decision making and be more in control of their own health and wellbeing.

<sup>10</sup> Equality and diversity zone, available at: <https://learn.nes.nhs.scot/3123/equality-and-diversity-zone/essential-learning/introduction-to-equality-diversity-and-human-rights>

<sup>11</sup> Cook, A. & Grant, A. (2020) ‘From fixer to facilitator: evaluation of the House of Care programme in Scotland’, <https://www.matter-of-focus.com/house-of-care-programme-in-scotland-evaluation-report/>

## Prevention

14

Create and publish a funded plan to shift resources over the medium to long term from acute care to prevention-focused, community-based and multi-stakeholder delivered care and support, including primary care.

Explore adoption of a community 'health hub' approach to prevention and diagnostics.

A community 'health hub' model of care that is planned and implemented in collaboration with healthcare partners and the third sector, and tailored to the needs of the local community, could transform everyday spaces into healthcare settings and move preventative care from a medicalised primary care setting to places such as shopping centres, places of worship and leisure centres.

15

Accessibility is increased by providing 'walk-in' and out of hours services closer in proximity and in more familiar locations, making appointments easier and cheaper to attend while balancing work and caring responsibilities. Health hubs can also reduce health inequalities by addressing barriers to attending more traditional, centralised spaces of care faced by deprived, minority ethnic and rural communities, as well as specific social-demographic groups including carers, disabled people, and younger and older people.

Community care plays a key role in creating health value, with NHS research showing that systems that invested more in community care saw 15% lower non-elective admission rates and 10% lower ambulance conveyance rates.<sup>12</sup> The health hub approach presents a dual opportunity: for individuals, in preventing ill-health and deterioration of existing health conditions, as well as the potential to relieve long-term pressure on primary and secondary healthcare services.

16

Strengthen community-based mental health services. This will improve accessibility and promote a sense of local, easily accessible and available support. It could include integrating perinatal mental health services and support for those experiencing miscarriage or stillbirth into community settings.

<sup>12</sup> NHS Confederation (2023) 'Unlocking the power of health beyond the hospital: supporting communities to prosper.' Available at: <https://www.nhsconfed.org/publications/unlocking-power-health-beyond-hospital>

Widen access to community led self management support for people across Scotland.

17

The value of support for self management is well evidenced including through Scotland's Self Management Fund. The investment Scottish Government has made to investing in community based self management approaches is an asset to build upon, yet there is a need to support the sustainability of these approaches and widen access to support for people across the country.

Providing greater support to the third sector should be seen as an investment, not a cost. Ensuring continuity of provision for the services people rely on to help them live well and better pay people employed within the sector will improve wellbeing and keep people out of poverty. As a result, people will be less likely to need more costly emergency interventions from statutory services, including the NHS, saving money in the longer run.

18

Guarantee sustainable investment for third sector services that help prevent people's health and wellbeing from worsening and placing more demand on NHS services.

By empowering individuals with long term conditions to better manage their health and providing resources, knowledge, and support to do so, people have a sense of empowerment, healthcare practices are enhanced and ultimately, the creation of a more sustainable and effective health and care system in Scotland.

Ensure people have access to flexible, person centred nutritional, physical and psychological support before, during and after treatment as part of a continuum of care based on individual need.

19

The role of prehabilitation and rehabilitation must be elevated to reduce treatment-related complications and enable people to return or maintain a quality of life, for example for people preparing for cancer treatment, cardiovascular surgery or to support recovery including from substance use.

## People and place

Recognise that many actions that are needed to tackle health inequalities sit outwith the health and social care system; this requires a joined-up, 'health and wellbeing first' approach across multiple policy areas, e.g. transport, education, housing, poverty reduction.

Maintain a whole systems approach to reform by embedding NHS reform within the broader programme of public service reform, ensuring that equality and human rights issues are integrated into reform metrics, including taking into account the needs of remote, rural and island communities.

20

Health Boards and Integration Authorities to use existing opportunities like the Public Sector Equality Duty outcome setting/monitoring process and the Population Health Framework to identify and target population groups who may require more specific, targeted action. This should also align with existing action plans such as the Transport to Health Delivery Plan.

Public bodies should ensure that robust Equality and Human Rights Impact Assessments (EQHRIAs) or Integrated Impact Assessments are completed at the earliest possible policy/planning stage to inform and direct decision-making, as well as used to monitor and evaluate the impact of interventions. EQHRIAs are comprehensive - they allow for planning to focus both on 'at risk' population groups and all relevant rights, like the right to health.



# Introduction

The Scottish Government is exploring priorities for the future of health and social care, including areas for NHS Reform. The Cabinet Secretary for Health and Social Care has set out intentions to hold a national programme of engagement to ensure that NHS Reform is inclusive and informed by people's experiences and priorities, as well as those of staff and professional bodies. A further priority is to ensure that any planned reform work takes account of previous national consultations.

The Health and Social Care Alliance Scotland (the ALLIANCE) undertook a desk based review of its existing body of evidence on people's lived experiences of health and social care to support this programme of work (hereafter referred to as the evidence review). The ALLIANCE and our members have a strong interest in informing the work of the Scottish Government's NHS Reform Programme, as well as invaluable knowledge and expertise to draw upon. We have a broad reach, a strong tradition of facilitating dialogue and discussion, and extensive experience of using different engagement approaches with a wide cross-sector of people and organisations across Scotland.

**Four broad areas were identified by the Cabinet Secretary to Scottish Parliament for future reform: improving population health; a focus on prevention and early intervention; providing quality services; and maximising access.<sup>13</sup> From this, four priority domains have been identified:**

**Quality:** Health and care is high quality, effective and value for money.

**Access:** Health and care is accessible, seamless and respects individual needs.

**Prevention:** Prevention, self-care and early intervention improve health and wellbeing.

**People and place:** Our living and working conditions create good health.

These domains broadly reflect the priorities described by people we engage with at the ALLIANCE regarding their health and care: prioritise prevention over crisis management, consider broader contribution to health, and improve equity of outcomes and access to services.

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<sup>13</sup> Scottish Government (2024) 'Vision for health and social care: Health Secretary Speech'

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# About this report

Since 2006, the ALLIANCE has produced a vast body of reports and engaged with thousands of people across diverse groups and circumstances. To meet the purpose of the brief, which was to inform the Scottish Government about existing engagement carried out by the ALLIANCE and deliver the insights in a timely manner, a sample of reports was selected which best addressed this objective. These reports were chosen to encompass a broad range of lived experiences, population groups, and circumstances relevant to the research question. This report does not capture the entirety of ALLIANCE's engagement activities, offering instead a well-rounded snapshot of key themes.

The evidence presented in this report reflects what we have consistently heard through our engagement, nevertheless it was not possible to definitively identify which groups may have been less represented in these findings.

Additionally, the COVID-19 pandemic significantly influenced health services and shaped people's perspectives on access, quality, and engagement. Disentangling findings from pre- and post-pandemic contexts posed challenges for the analysis as there were significant overlaps in the issues raised. We therefore prioritised highlighting enduring issues that predated the pandemic, as well as issues that were either exacerbated by the pandemic or emerged as a result of the extraordinary circumstances which are having, and will continue to have, consequences on people's health and wellbeing and the systems and services that support them.



# Scope and methodology

## Data collection, review and analysis

This evidence review aimed to address the research question: *What matters – to whom and in what circumstances – with regard to accessing acceptable, equitable, timely, and quality healthcare and support?*

Due to the significant volume of reports produced by the ALLIANCE, the decision was made to conduct a rapid review of key documents produced between 2014 and 2024. The ALLIANCE identified key publications for in-depth review and analysis. These publications were selected to ensure a diverse representation of lived experiences and population groups.

The selected publications were reviewed to identify sub-themes within the four categories. This involved coding sections of the documents and extracting relevant insights. Publications included:

○	Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future.
○	My World, My Health - Insights from a Dialogue on Data with the Scottish Public.
○	My Path, My Life, My Right to Live Well.
○	National Review of Audiology Services - Engagement Insights.
○	National Conversation on Creating a Healthier Scotland.
○	Experiences of Transitions to Adult Years and Adult Services.
○	Your GP and You: Ensuring access to the right person in the right place at the right time.

○	"Trauma, abandonment and isolation": Experiences of pregnancy and maternity services in Scotland during COVID-19.
○	Shaping New Mental Health Standards - A Lived Experience Perspective.
○	Emotional Support Matters: Emotional, and psychological support-needs of people with long term conditions.

The report 'Emotional Support Matters' was later excluded from review, as it did not meet the research criteria due to being published in 2011. Its findings however were felt to be reflected in later reports.

Evidence from each document was categorised under four priority domains identified by the Cabinet Secretary: quality, access, prevention and people and place.

The initial review provided significant insights into access and quality, though gaps were identified in the themes of prevention and people and place. To address this, additional ALLIANCE publications were reviewed. These supplementary documents also contributed to refining findings in the areas of access and quality.

**The full list of reviewed publications and their summaries is included in Appendix 1.**



# Quality

During the review, twenty sub-themes were identified within the evidence pertaining to quality. These provide a deeper understanding of what is important to people when they think about the quality of their health and care.

This section explores the most frequently occurring themes: communication, healthcare professionals' skills and attributes, person centred care, integration, continuity of care, mental health, sensory loss and Deaf culture, and co-production and shared decision making.

## Communication

Communication, both poor and effective, emerged as the most prominent theme when people reflected on their positive or negative experiences of healthcare. Issues surrounding unclear messaging, interruptions in the flow of information, information not taking account of people's individual needs and lack of clarity of explanation were evident. This undoubtedly had profound effects on individuals' experiences.

Breakdowns in communication can be a significant source of frustration for people, negatively impacting their experience. This was magnified during the COVID-19 pandemic, where breakdowns in communication at all levels (between services, between services and people accessing them, and national public health messaging), inconsistent messaging and an overall lack of effective communication were a common experience.<sup>1</sup>



The most annoying thing is no one has got back to me...I think it would help to have a letter or email even, which acknowledges I have been in touch and says we are dealing with you but it might take time. Otherwise you feel you are in a hopeless situation, you don't matter, your file has been lost, you don't exist, nobody cares - any number of very negative emotions, which aggravate your situation.

We have long heard calls for more support and encouragement for open discussions about topics like end-of-life planning, as well as better communication about waiting times, clear and proactive communication which provides information to people as they navigate between services, and about available support. People often reported being left without clear information on what to expect while waiting for services or how to access interim support.<sup>2</sup>

Examples of good practice demonstrate the difference effective communication can make in people's health journeys.

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<sup>1</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>2</sup> The ALLIANCE (2016) 'National Conversation on Creating a Healthier Scotland'

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It comes down to that communication again and I have not had to organise this myself. It has been a weight off my shoulders that it was all organised for me as it's not always the case.<sup>3</sup>

A key aspect of communication we hear about often is kindness and empathy from healthcare professionals. We have heard many examples of people being treated unkindly, feeling overlooked or neglected, which had a significant negative impact on people's experiences.



When I asked about when contraception services would be available, the worker that I spoke to advised me that she did not have a 'crystal ball' and therefore would not be able to advise.<sup>4</sup>



You have to push hard and argue for support rather than feeling welcomed. This isn't easy when you are unwell.<sup>5</sup>

People have also told us it is difficult to find and access clear and accessible information about services and navigating complex healthcare systems; this will be explored further in the next chapter.

Communication is the foundation of what matters to people with regards to care quality. Many are likely to understand and tolerate the challenges faced when accessing health service as long as they are treated with kindness and respect, receive regular and consistent updates about their healthcare journey, understand that they are not forgotten, and able access information that is clear, relevant and readily available.

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<sup>3</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>4</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>5</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

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# Healthcare professionals' attributes and behaviours

People regularly praised healthcare professionals' (HCPs) dedication, professionalism and compassion. This was particularly so in the context of the pandemic, with people acknowledging the efforts of the workforce under difficult circumstances.

Positive and negative experiences depended on whether HCPs were caring, responsive and proactive and shaped perceived quality of care received.<sup>6</sup>



I received amazing and incredibly compassionate care during my pregnancy by all NHS staff. I understood that a lot of the uncertainty and restrictions were due to Covid and not a reflection on the staff or board.



I was also upset that during this hospital stay a doctor used a speculum on me without asking for my consent first, this set back my healing quite significantly and has probably impacted difficulties I've had since getting a smear test (2 attempts without going through with it).



No one has asked how I am.

Engagement with people's experiences of transitions to adult services also highlighted specific qualities they value in HCPs – being approachable, proactive, practical, their expertise and the provision of guidance at key moments.<sup>7</sup>

However, pressures on the workforce can affect the quality of care people receive and reduce time for anything beyond meeting basic needs.



The services I have encountered are mostly staffed by good people, there just are not enough people to meet the needs.<sup>8</sup>

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<sup>6</sup> Engender and the ALLIANCE (2023) "'Trauma, abandonment and isolation': Experiences of pregnancy and maternity services in Scotland during COVID-19"

<sup>7</sup> The ALLIANCE and the Scottish Government (2017) 'Experiences of Transitions to Adult Years and Adult Services'

<sup>8</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

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I received very little empathy from overworked hospital midwives, and my experience has put me off ever getting pregnant again; I can't even visit the hospital as it would be intensely traumatic.<sup>9</sup>



I felt forgotten and that I was a burden to the staff when I had to buzz numerous times.<sup>10</sup>

While HCPs' knowledge, skills, and expertise are very important to people, they often focus on attitudes and behaviours over clinical skills.<sup>11</sup>



My gut would go to attitudes and behaviours. Of course we want them to be educated, professional, and know what they are doing. But how someone makes you feel - you never forget... they need to be educated to a certain level. But they need to have people skills. The right attitudes and behaviours. Some clinicians, they don't even look at you.



A health professional might be tired, might be having a bad day, but just remembering to be kind. Not just to the person coming in for the treatment, but the staff themselves.

When asked what makes a good healthcare practitioner, one person responded:



Passion, humility - there is no power imbalance, validity - being validated and understood, humanity - understanding that the individual sitting across from them is in a vulnerable position, openness and willingness to hear and join things up.<sup>12</sup>

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<sup>9</sup> Engender and the ALLIANCE (2023) '“Trauma, abandonment and isolation”: Experiences of pregnancy and maternity services in Scotland during COVID-19'

<sup>10</sup> Engender and the ALLIANCE (2023) '“Trauma, abandonment and isolation”: Experiences of pregnancy and maternity services in Scotland during COVID-19'

<sup>11</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>12</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

In terms of suggested learning, various areas were deemed important. We have heard calls for greater investment in training, particularly in areas like equalities, carer awareness, mental health, trauma-informed practice and dementia. Moreover, adopting a cultural and gender-sensitive approach was seen as key to ensuring that all people feel understood and supported.<sup>13</sup> This includes BSL classes for public services because Deaf people need better communication for information and access needs to be met.



When making a diagnosis they really need to think about the words they use.<sup>14</sup>



The ability to listen. Patience - to allow the patient to speak and not feel rushed out the door or off the phone. Flexibility - to treat the patient as an individual instead of assuming that all people are the same. Life is not always textbook. Empathy - to show a little bit of understanding for the patients experience and symptoms they are experiencing. Alternative knowledge - Offering alternative solutions rather than what happened to me where I had to research and find my own solution.<sup>15</sup>



GPs should listen to patient concerns.<sup>16</sup>

Medical education along with time for reflection by practitioners are also considered essential.<sup>17</sup>

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<sup>13</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>14</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

<sup>15</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>16</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>17</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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“ Another point [to add] was around ensuring enough up to date knowledge on disease areas and on my specific health profile in order to ask the right questions, spot red flags, make the right referrals, suggest appropriate courses of action etc.

“ I think the world that we are in now, it is so fast paced and everybody just needs to slow down, explain and reflect.

Similar sentiments were shared by people surrounding experiences of mental health care in Scotland, where repeated comments related to the attitudes that people perceive from professionals and services. These are generally not directed towards a particular person, but are more related to the culture of services:<sup>18</sup>

“ You have to push hard and argue for support rather than feeling welcomed. This isn't easy when you are unwell.

“ The power imbalance must be reduced so people can become equal partners in their own care.

This engagement highlighted that positive relationships between people with lived and living experience and professionals, marked by understanding, empathy and appropriate support, are highly valued. However, people often reflect that the limited duration of mental health crisis interventions and transitions back to broader mental health services leaves them feeling unsupported after initial care.

“ Staff that truly care for your wellbeing and show that it is their passion, despite all the barriers faced. Moments of true understanding and acceptance between patients and therapists/carers/professionals.<sup>19</sup>

Overall, the experiences shared across these reports highlight that HCPs play a key role in shaping care quality. Where staff are seen as compassionate, competent and communicative, experiences are often positive. Conversely, where there is a lack of support, empathy or adequate staffing, individuals may face negative experiences that can have lasting impacts on their perceptions of care. This highlights the need for adequate staffing levels as well as consistent training and support for staff in delivering person centred care, emphasising the benefits for those receiving care. It also emphasises the importance of training in equality and diversity, and a commitment to recognising and valuing the vital role HCPs play in delivering quality care.

<sup>18</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>19</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

## Person centred care

There are many definitions and dimensions of person centred care. The Healthcare Quality Strategy for NHS Scotland described it as: "Mutually beneficial partnerships between patients, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision making".<sup>20</sup>

In ALLIANCE research on person centred care, what mattered most to people accessing services reflects the definition above. These elements included: feeling heard and listened to; empowerment; courtesy and dignity.



Constructive conversations, that have more depth, more understanding, more listening, more humility, more human aspect, have led to much more effective, successful treatment strategies.<sup>21</sup>

As part of the research, people told us their mixed experiences of person centred care. They shared positive experiences of person centred care which involved clear and proactive communication, effective treatment strategies, collaboration across services and compassion:



I never felt like I was just a case, they kept that human touch by talking to me, and checking in on me and I think that made a lot of difference.



My local GP if I'm in the waiting room knows to come out and look for me and call me in. I won't take up the time with the embarrassments I've gone through when I've misheard and gone through to the wrong room and the wrong doctor. It has improved there!

However, there were also negative experiences which included the attitude and behaviours of health care professionals such as encountering a lack of honesty, stigma, being treated with disrespect, and the concerns of individuals being dismissed/not listened to.

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<sup>20</sup> Scottish Government (2016) 'Person centred care: guidance for non-executive directors', (Online) available at: <https://www.gov.scot/publications/Person-centred-care-non-executive-directors/>

<sup>21</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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The root of what was causing my condition wasn't investigated and it was framed as this is impossible for you to have, rather than taking on my concerns as patient. And that continued at all levels in primary care and in secondary care.

Across the evidence people described wanting to receive person centred care, with a strong emphasis on services that go beyond addressing symptoms or single conditions and see the person as a whole. People described person centred care as care that is tailored, individualised, holistic and delivered with the supported person at the centre.<sup>22</sup>



It is all of those things, but it is also taking into account why the person is seeking care in the first place. Really understanding the root of why they are there.



I never felt like I was just a case, they kept that human touch by talking to me and checking in on me and I think that made a lot of difference.

When people receive person centred care, they feel heard and listened to, as well as empowered and relieved, which were closely linked to feeling that they had been taken seriously by practitioners:<sup>23</sup>



It made me feel more positive, like I was more empowered and enabled to understand my condition and to manage it in a more effective way.



Listening can be huge. We deserve a voice and for our thoughts and experiences to be considered.



It made me aware of that medical support system, I didn't feel that I constantly had to build up the confidence to go in, to be armed and ready and to argue my case because that is exhausting.

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<sup>22</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>23</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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It is like a weight being lifted of my shoulders. Everything I went through was worth it. The battling, going back and forth, doing health admin, it was all worth it, it wasn't it my head.

The impact of person centred care was highlighted by parents and guardians of children with hearing loss, who felt that their child's diagnosis was not always handled with empathy and that they were left without sufficient emotional support:<sup>24</sup>



It could have been dealt with in a much more sympathetic way...When making a diagnosis they really need to think about the words they use.

In the context of COVID-19, relationships with HCPs who understood what matters to people and their families made a significant difference to their experiences. As described above, a common desire was for HCPs to listen actively, respect people with lived and living experience, and be kind and compassionate.<sup>25</sup>

A holistic approach was seen as fundamental to improving outcomes and experiences. Many respondents spoke about the need to consider a person's wider circumstances such as multiple health conditions, social determinants of health, protected characteristics and personal preferences.<sup>26</sup>



The recognition that the same illness impacts individuals differently is long overdue. It is and has always been vital that patients' voices are heard and that they are treated holistically.<sup>27</sup>

A holistic approach that involves people in decisions about their care, treatment or support, can be empowering, enhance self management and improve outcomes. Another key facet of person centred care is choice and flexibility. This will be explored further in relation to Access in the next chapter.

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<sup>24</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

<sup>25</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>26</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>27</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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Effective **communication, person centred care (PCC), and the role of healthcare professionals (HCPs)** are interconnected, collectively shaping the quality of healthcare experiences. Together, they create the foundation for compassionate, holistic, and tailored care, viewing individuals as a whole rather than treating them solely as 'patients' with a set of symptoms.

### Key areas of overlap

**Empathy and kindness:** Communication characterised by empathy enhances PCC by ensuring that people feel seen, heard, and valued. HCPs who take the time to listen and explain clearly contribute to more positive care experiences.

**Holistic understanding:** Communication that aims to understand a person's wider life circumstances, supports PCC, enabling HCPs to tailor interventions to individual needs and preferences.

**Clear and frequent communication:** This can help alleviate the stress of navigating complex care pathways and systems and contribute to PCC.

**Training and support:** Investment in HCPs' communication skills and PCC-focused training, including areas like trauma-informed care and cultural sensitivity, ensures they can meet individuals' diverse needs effectively.



## Integration

The desire for improved data and information sharing is a recurring theme which influences the quality of care received, with people recognising the benefits that better integration of information can bring to the entire health and social care system.<sup>28</sup> We often hear that people want a single narrative of their health, where they only need to share their story once, and all relevant services have access to that information to coordinate care effectively. Repeatedly having to share one's story is a significant cause of frustration, disrupts seamless provision of care, and reflects a lack of integration between services.

Well-coordinated partnerships and better communication within and between services, along with improved information sharing, are essential to providing joined-up care, improving both quality of care and people's experiences. Some of the challenges commonly raised include the need for improved partnership working and communication, especially regarding the use of joined-up IT systems for efficient information sharing.<sup>29</sup>

Often, individuals transitioning from one care setting to another, particularly between child and adult services, found that inadequate support and a lack of joined-up care led to gaps in service delivery and therefore health implications for those concerned.



Transitioning to adult clinic was very messy, I am not sure if I have transitioned yet or when it started. I can't remember anyone explaining this. It wasn't bad, it was just very confusing.<sup>30</sup>

People also reported poor integration between specialist departments and services (for example, between audiology services and ear nose and throat clinics (ENT), or between audiology services and schools/education departments), describing it as either lacking or inconsistent. This leads to frustration, disjointed care, and, in some cases, out-of-pocket expenses.



We were supplied half a hearing aid from the NHS, but the education department was not able to supply the radio system, which is the bottom half of the same unit. If you attend a school not in the health board area, it gets complicated. We ended up buying the shoe for the hearing aid and providing it to NHS audiology.<sup>31</sup>

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<sup>28</sup> The ALLIANCE and Digital Health & Care Innovation Centre (2021) 'My World, My Health - insights from a dialogue on data with Scottish public'

<sup>29</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>30</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

<sup>31</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

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Services work too often in silos. They can be unaware of what else is there and don't communicate well with each other.<sup>32</sup>

Issues were also highlighted in relation to transitions between services, such as from mental health to general practice or from maternity ward to health visitor support.<sup>33</sup>

While there are positive examples of collaboration, significant gaps remain, particularly in transitions between services, such as inconsistent data-sharing practices, disconnected communication channels, and poorly coordinated social care packages, which often leave individuals feeling unsupported.

Integration of health and social care services has the potential to reduce inefficiencies while also improving pathways to treatment and support. The relevance of integration to accessing services is further explored in the next chapter.



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<sup>32</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>33</sup> Engender and the ALLIANCE (2023) "'Trauma, abandonment and isolation': Experiences of pregnancy and maternity services in Scotland during COVID-19'

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## Continuity of care

The Royal College of General Practitioners has defined continuity of care as “the extent to which a person experiences an ongoing relationship with a clinical team, or member of a clinical team.”<sup>34</sup>

In our evidence, we see that a lack of continuity often leads to frustration, duplication of effort, and missed opportunities to address people’s needs in an early, effective and holistic way. While the COVID-19 pandemic has exacerbated some of these issues, many challenges existed long before.<sup>35</sup>

People highlighted the importance of building good relationships with health and social care staff who understand what matters to them and their families. When continuity was maintained, people felt supported. However, the lack of continuity has often been a concern, disrupting these relationships and affecting the quality of care received.<sup>36</sup> In audiology for example, seeing a different audiologist at each appointment made it harder to build relationships and for the audiologist to gain insight into individuals’ specific needs and interests.<sup>37</sup>



You could “see” someone you never met before. A robot would show more compassion.<sup>38</sup>

Continuity of care was particularly important during transitional phases, such as the move from child to adult services. People valued having a lead professional to coordinate services for families within statutory health and social care and through third sector services, ensuring that individuals received consistent support as they navigate different care pathways.<sup>39</sup>

A recurring concern was the need for individuals to repeatedly tell their story to different professionals, which can be frustrating, and retraumatising, especially when dealing with complex or traumatic experiences.<sup>40</sup> This reflects the discussion above in relation to the integration of information sharing.

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<sup>34</sup> Royal College of General Practitioners (2021) ‘Continuity of Care work at RCGP.’ Available at: <https://www.rcgp.org.uk/blog/continuity-of-care-work-at-rcgp#:~:text=Continuity%20of%20care%20can%20be,parts%20of%20the%20health%20service>

<sup>35</sup> The ALLIANCE (2021) ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future’

<sup>36</sup> The ALLIANCE (2016) ‘Creating a Healthier Scotland: What Matters to You’

<sup>37</sup> The ALLIANCE (2023) ‘National Review of Audiology Services: Engagement Insights’

<sup>38</sup> The ALLIANCE (2021) ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future’

<sup>39</sup> The ALLIANCE and the Scottish Government (2017) ‘Experiences of Transitions to Adult Years and Adult Services’

<sup>40</sup> The ALLIANCE and VOX Scotland (2022) ‘Shaping New Mental Health Standards: A lived experience perspective’

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The lack of continuity was a significant issue in maternity services during COVID-19, where women often reported seeing different midwives at each appointment.<sup>41</sup> In relation to chronic pain management, people emphasised the need for consistent care to avoid disjointed treatment and to empower self management.<sup>42</sup>



The receptionist just puts you in to see a different doctor every time so it is frustrating to cope with this situation as well as coping with chronic pain.

Overall, continuity of care is seen as key in building trusting relationships with healthcare professionals, reducing frustration, and addressing needs effectively. A lack of continuity often required people to repeat themselves multiple times to different professionals, resulting in missed care opportunities, with challenges amplified during the COVID-19 pandemic. People valued consistent support, particularly during transitions such as moving from child to adult services, and in areas like mental health, chronic pain, audiology, and maternity care.

### Continuity of Care - The link that runs through different aspects of care

#### Mental Health

- Continuity promotes trust and stability in therapeutic relationships, reducing the risk of re-traumatisation and addressing systemic challenges like long waiting times and inconsistent support.
- Inconsistent care disrupts progress, leaving individuals feeling dismissed and unsupported.

#### Sensory Loss and Deaf Culture

- Continuity ensures healthcare professionals understand and adapt to diverse communication needs and preferences.
- Regularly seeing the same healthcare professional prevents confusion, facilitates relationship-building, and improves outcomes in areas like device management and follow-up care.

#### Primary Care

- GPs, as the first point of contact, play a critical role in delivering continuous care that addresses individuals' ongoing needs effectively.

<sup>41</sup> Engender and the ALLIANCE (2023) "'Trauma, abandonment and isolation": Experiences of pregnancy and maternity services in Scotland during COVID-19'

<sup>42</sup> The ALLIANCE and University of the West of Scotland (2021) 'My Path, My Life, My Right to Live Well'

## Mental Health

People's experiences with mental health services have been mixed, with a notable tendency towards negative outcomes. Many individuals reported a lack of consistent support and long waiting times. Mental health services can feel like a "tick box exercise" and participants raised concerns over lack of funding, service availability and over-reliance on medication in lieu of counselling or therapy.<sup>43</sup>

Engagement for 'Shaping New Mental Health Standards' made several recommendations in relation to what matters most to people including: being treated with dignity and respect; increasing accessibility and addressing shortage of mental health practitioners; locating services within communities to enhance accessibility and support; and achieving high standards of care through clear and transparent accountability and monitoring.<sup>44</sup>



My daughter's support over the years has been erratic, unreliable, inconsistent and at times damaging and detrimental to her mental health.



I was never diagnosed because I was never assessed. I begged for mental health support for depression and was told they could refer me, but I wouldn't be accepted.



I lost my son at 18 weeks in July 2020. I did not receive any mental health support from the NHS.



<sup>43</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>44</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

Individuals highlighted the importance of providing more opportunities for people accessing mental health services to choose appointment styles that suit them best, allowing for greater agency over their care. It was also suggested that services extend their opening hours to accommodate those needing support outside typical office hours.<sup>46</sup> The need for greater choice and flexibility in relation to healthcare services more broadly will be explored further in the next chapter on

In summary, while some individuals have positive experiences in relation to mental health support, systemic challenges such as limited funding, long waiting times, and over-reliance on medication, hinder the quality of mental health care. Respondents across various reports called for improved standards, better accountability, and more community-based, person centred mental health services.

## Sensory loss and Deaf culture

People who accessed audiology services described challenges in the quality and person centredness of the care received. Key themes such as communication, self management, information sharing, and relationship building were highlighted across multiple reports, underlining the need for more integrated, compassionate, and informed approaches to the quality of care for people affected by deafness and sensory loss.<sup>47</sup>



Consultant spoke over my deaf child and virtually ignored her talking about implant which confused and upset my child.



They should talk directly to me instead of talking directly to my parents.

Participants in sensory loss workshops expressed the need for improved data sharing between local and national authorities to streamline routine processes such as applying for disability benefits or parking permits. The WelcoMe app, which allows people to pre-register and specify their access requirements that are then forwarded to venues, was noted as an example of good practice, illustrating how technology can support better communication and service delivery. Descriptions of positive experiences show that people value when staff are proactive in explaining tests, device usage and follow-up care.

The importance of building strong relationships between audiologists, people who access services, and their families also emerged as a key theme. Maintaining a consistent point of contact and a better understanding of Deaf culture were seen as critical to creating a supportive care environment. When these relationships were not fostered effectively, participants reported feeling confused and disconnected.<sup>48</sup>

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<sup>46</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>47</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

<sup>48</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

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I would have liked to have more consistent audiologists. I feel this would have helped avoid confusion and make me feel a bit more comfortable when going to appointments.

Positive experiences were shared when families felt fully supported and involved in service provision:



We have always, as a family, been fully supported and everyone involved in service provision has been outstanding.

Managing devices, such as hearing aids, was another area highlighted - some individuals were left to cope with outdated, faulty, or broken devices without adequate support, highlighting a need to improve the quality of assistive technologies available to people who need them.



The plastic hoop at the top had a crack after 6 years so I was getting feedback. [...] The audiologist realised in the appointment they don't have the parts as too old and tried to fix with Sellotape, which hurt my ear and fell off.

Other areas where people felt improvements are needed include the adaptability of audiology services for children with learning difficulties, more training for audiologists (both BSL and specialist training), and follow-up appointments.

The experiences shared by individuals with a sensory impairment and their families highlight the importance of effective communication, person centred care, and informed relationship building. To improve services, better data sharing, holistic approaches to device management, and ongoing professional training are essential.



## Co-production and shared decision making

Co-production is a way of working that involves people with direct experience of health and care services, unpaid carers and communities working in equal partnership with decision makers and professionals...[It] acknowledges that people with 'lived experience' of a particular condition are often best placed to advise on what support and services will make a positive difference to their lives."<sup>49</sup>

Shared decision making is a person centred approach where an individual is supported by a healthcare professional work to discuss their treatment options and jointly agree on a plan.

Across the evidence, individuals expressed a desire to be actively involved in their health journey and to be part of decisions about their own care and treatment. Ultimately, they wanted and expected to be treated as experts in their own circumstances rather than passive recipients of care.<sup>50</sup>



You may have done training or this or that, but, if you are able-bodied, you don't live the experience of disabled people.

People felt strongly that they should be involved in decisions affecting their treatment, as doing so would give them more control over their lives and the freedom to live as they choose.



Quite simply, live the life we want to, not just survive or exist.<sup>51</sup>



Involve people in designing services from the start – this is a human system, and top-down is not best. We need to work together with professionals to look at what kind of services we want, need, and can afford.<sup>52</sup>

<sup>49</sup> Definition by Scottish Coproduction Network [What is co-pro? – Scottish Co-production Network](#).

<sup>50</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>51</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>52</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

Empowering people to understand and make decisions around data sharing was seen as a crucial aspect of their healthcare journey, with the need for transparency, education, and open communication being key to creating trust and mutual respect.<sup>53</sup>

Individuals also called for active involvement of those with lived experience in both the design and monitoring of their care, emphasising the need for transparent communication around decisions, with benefits, risks, and reasoning fully explained.



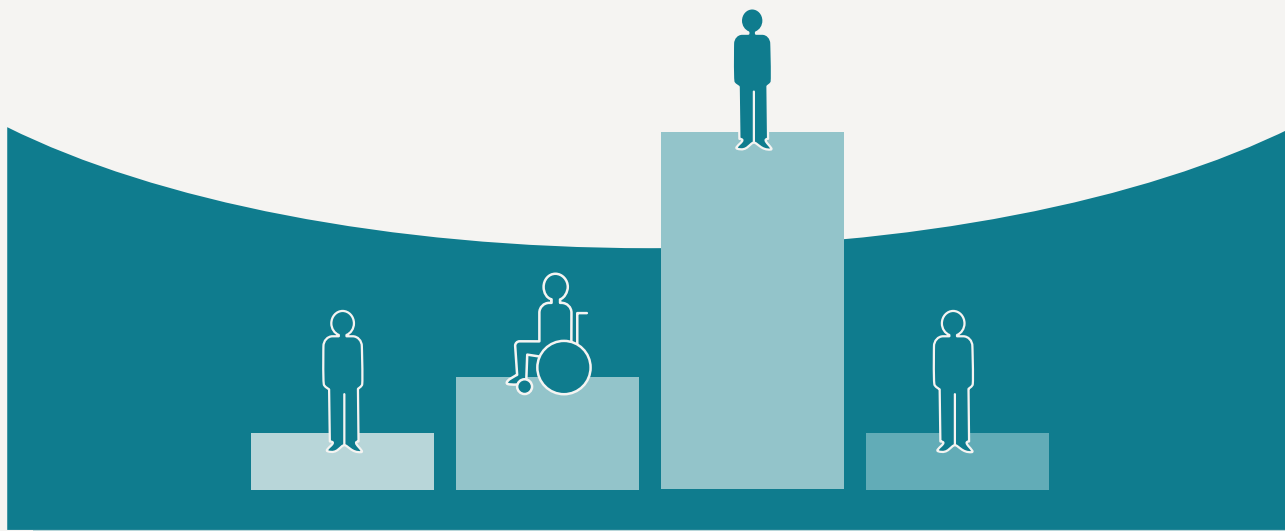
The power imbalance must be reduced, so, people can become equal partners in their own care.<sup>54</sup>

Related to this, was a consistent theme raising concern that the voices of people with lived and living and experience were not meaningfully listened to, particularly at the national policy level.



I was involved in a cross-party group...people were bullied by officials at the meeting. People with lived experience were not listened to. It was traumatising for people involved.<sup>55</sup>

Involving individuals with lived experience in the entire process of service design — at every level, from local services to national discussions — was identified as a valuable approach to improving the experiences of people accessing healthcare services.



<sup>53</sup> The ALLIANCE and Digital Health & Care Innovation Centre (2021) 'My World, My Health - insights from a dialogue on data with Scottish public'

<sup>54</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>55</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

# Access

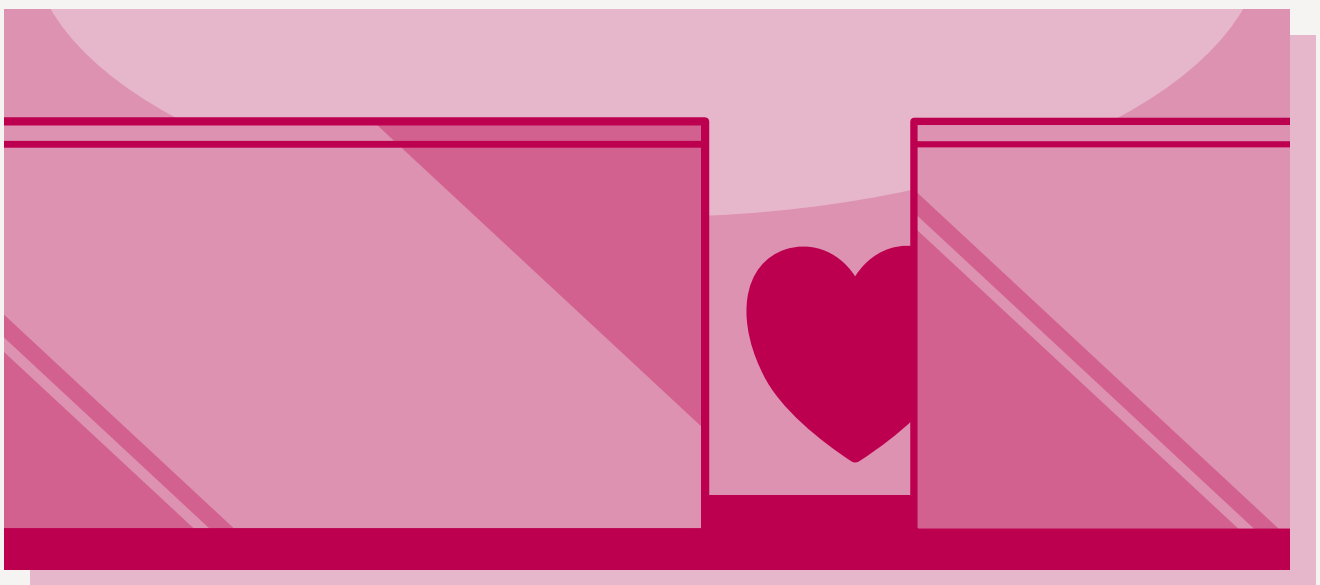
Previous ALLIANCE research has given insights into people's experiences when accessing healthcare services. This covered the full journey from identifying a health need, reaching out to, and engaging with services. Evidence was reviewed to gain a better understanding of most prominent themes, and these are discussed in this chapter. The themes included access to primary care, person centred care, choice and flexibility, communication, inequities in healthcare, sensory loss and Deaf culture, and access to secondary, alternative and private health services.

People's experiences of accessing healthcare services have been mixed. Whilst people generally recognise their role in looking after their health and wellbeing and living well, of equal importance is how accessible, affordable (in terms of financial barriers encountered), approachable and available healthcare services are, including mental health services. People felt strongly that they should be able to equally access appropriate spaces and services if and when they needed them.

We were told about how barriers make it difficult to access services when people need them, with evidence highlighting organisational cultures, institutional discriminatory practices, and structural barriers diminishing people's access to healthcare. A strong theme that emerged is a feeling that the needs of disabled people, people with sensory impairments, or those whose first language is not English have been long overlooked. Mixed experiences have been exacerbated, not caused, by the COVID-19 Pandemic.

An overall lack of access to healthcare services is occurring across the board. People feel that the lack of access to services which monitor their health, provide ongoing support and keep them well has resulted in negative implications for their physical wellbeing. The prioritisation of COVID-19 has had an impact on people with non-COVID-19 needs, whose care has been consequently interrupted and delayed and health needs not met.

It was highlighted by some that further intersectional and community-based research and evidence gathering on access to services, including urgent care, is required. Such research could highlight both solutions and gaps in healthcare.



## Primary care

Primary care is the first point of contact with the NHS, with General Practice being the primary route through which people access other services.<sup>1</sup> This includes contact with a range of community based services provided by general practitioners (GPs), community nurses, midwives, dentists, dental nurses, optometrists, dispensing opticians, pharmacists and pharmacy technicians. It may also be with allied health professionals (AHPs) such as physiotherapists, occupational therapists and dieticians. People's experiences of accessing primary care services are highly varied.

Prior to the pandemic the ALLIANCE engaged with people on the implications of the new GP contract on their access to and use of primary care services and support. We heard concerns that with a wider variety of primary care options, such as Pharmacy First and NHS Inform, some people would not know where to go, especially those who are digitally excluded.<sup>2</sup>



A mixture of drop in session and scheduled appointment times should be considered.



People might default to phoning 999 if they can't get a GP appointment - people need to know/be guided to appropriate alternatives.



Young people not using the GP - access is difficult and could be made worse.

People told us that they want effective communication about their health and care including the conveyance of information in an accessible and jargon-free way. We often found that people had not been communicated with or decisions had not been explained clearly or accessibly leading to confusion, lack of understanding and involvement in decision making. As referred to in the previous chapter, when communication is done effectively, people felt properly considered, listened to and cared for:<sup>3</sup>

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<sup>1</sup> Scottish Government (2024) 'Primary Care Services', (Online) available at: <https://www.gov.scot/policies/primary-care-services/>

<sup>2</sup> The ALLIANCE (2018) 'Your GP and You: Ensuring access to the right person in the right place at the right time'

<sup>3</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

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But what it meant to me is, they took the time, the effort, and the consideration of looking into my care.



They didn't rush off into the first direction, they took time, came back to me to have chats with me, and communicated with me 'this is what we are thinking, what do you think?'. I wasn't forced to make a decision; they gave me the time to think about things.



Medical jargon is very difficult to understand and if the person involved is taking the time to break that down it really, really helps.



Transitioning to adult clinic was very messy, I am not sure if I have transitioned yet or when it started. I can't remember anyone explaining this. It wasn't bad, it was just very confusing.

## Learning from the pandemic

People's experiences of accessing GP services during the pandemic were varied. A large portion of respondents were not able to access the care they needed and shared their difficulties in gaining access to their GP. Reasons for this included the availability and choice of appointments.



GP only running phone consultations meant that I still feel unsure about advice to simply ignore a lump I found, despite no physical exam being performed. I don't know what to do, but I feel like I won't get any help if I raise the issue again as they're not doing in person appointments.<sup>4</sup>

<sup>4</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future.'

Many people described experiences with GP receptionist and call handlers with incidences where people felt the reception staff operated as gatekeepers restricting access to appointments. These experiences left people feeling frustrated, unheard and that their health was harmed, and speaks to the evidence discussed in the previous chapter in relation to quality.<sup>5</sup>

“  
The questions & process of going through call handlers & receptionists makes me want to give up and try to manage on my own.

“  
Have decided to not try to access my GP any longer as it is hugely frustrating to constantly be told my reason for calling is not an emergency and therefore cannot be dealt with.

Limitations on access raised additional barriers for disabled people, their families and unpaid carers where barriers were encountered, for example when participating in remote consultations, highlighting inequalities within the system.<sup>6</sup>

“  
These GPs did not know background of my son's disability or medication. Unable to have face to face consultation, they were unable to help when, due to Covid, my son became very depressed and had physical problems which needed changes in medication. Phone consultations were hopeless and unhelpful.

“  
My GP insists on holding telephone consultations and I cannot listen for 10 minutes on the phone as the strain of trying to hear is too much. No matter how many times I have said to the receptionist that I cannot have a telephone consultation, she insists that because I speak and hear her I can do a telephone consultation. The lack of deaf awareness astounds me!

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<sup>5</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>6</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

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I wrote to the GP afterwards to explain that sighted guiding was formalised by the Scottish Government and it was not just me requesting it...

However, many people described positive experiences with GP services, such as timely replies and appointments and face-to-face support where necessary, though a general theme was of a mixed picture across Scotland. Many found value from regular communication which was described as “reassuring.” People described the value of the community pharmacy role working alongside General Practice to ensure people had access to repeat prescriptions and the availability, pace of service and the home delivery of prescriptions together with examples of well-coordinated care led by the General Practice.<sup>7</sup>



There’s never a good time to discover one has cancer, and the middle of the pandemic is not the best timing - but the support I’ve received in Fife, from a wide range of services, has been exemplary. The local GP’s prompt action, ensuring my hospital admission within two hours of a consultation when she took blood tests, may well have saved my life.

Breakdowns in communication impacted on people’s access to healthcare and as a result had negative consequences for their physical and mental health. Vaccinations, particularly the flu jab, have been shared by some as a positive experience, whilst others had difficulty accessing them.<sup>8</sup>



They [GPs] felt like they are inaccessible unless you have COVID. I received messages from GPs advising not to visit the surgery at all, but never received a message saying now was safe to do so.

## Accessing other services via primary care: learning from Long Covid

The particular challenges encountered by people living with long term conditions of receiving a coordinated approach to their care is a frequent theme across ALLIANCE engagement. This is exemplified by the experiences of people living with Long Covid and which will be covered in this section. Access to secondary, alternative and private health services more generally will be considered later in this chapter.

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<sup>7</sup> The ALLIANCE (2021) ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future.’

<sup>8</sup> The ALLIANCE (2021) ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future.’

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When gathering experiences from people living with Long Covid about the types of services which have been accessed, there was a range of services highlighted by respondents with the services reflecting the variety of symptoms related to Long Covid. This ranged from Cardiology and Respiratory services, as well as physiotherapy, CT scans, CBT (Cognitive Behavioural Therapy), ENT (Ear, Nose and Throat), Neurology and blood tests. Where available, respondents also used Long Covid clinics. However, it was shared that many respondents did not feel that this was available in the area they live in. When respondents felt that NHS help was unavailable, they sought private health care services.<sup>9</sup>

When asked about their experiences of accessing services, many respondents felt that there was not a lot of help their GP could offer them, or services for them to be referred to.<sup>10</sup>



I am listened to. But frustrating as GP can only offer so much.

Many respondents were grateful to be referred to other services, such as respiratory specialists, as this gave them confidence through gaining information and knowledge about their symptoms, as well as the feeling that something was being done to help them. However, despite being seen by specialists this did not necessarily lead to treatment and help for their symptoms:



I have attended a few services where the people were very nice and sympathetic to my situation although still couldn't help treat my condition [...] I must stress though that although the people made th[is] a positive experience, the lack of treatment they could offer was also negative.

Some people found their GP to be understanding and helpful but there were many responses by people who had negative experiences with their GP. The term “gaslighting” was frequently used. Respondents said that they felt their symptoms were dismissed by their GP, and there was limited understanding about the severity and impact of symptoms:



Being dismissed, ignored or being called a liar when discussing symptoms.

This was linked to what respondents saw as a lack of understanding and knowledge of Long Covid from healthcare professionals. Frequently, respondents advised that GPs did not know where to refer them and were unaware of any services that would help them.

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<sup>9</sup> The ALLIANCE (2024) ‘Accessing Long COVID services in Scotland: to be believed, listened to and supported’

<sup>10</sup> The ALLIANCE (2024) ‘Accessing Long COVID services in Scotland: to be believed, listened to and supported’

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No pathway for Long Covid, my GP doesn't know where to send me.

It is important to note that people we spoke to about Long Covid, identified their main 'Long Covid service' to be their GP, as their Health Board may not have had a dedicated Long Covid service especially those living in rural areas who may lack access to specialist services. Rather than having positive or negative experiences when accessing healthcare services for Long Covid, the majority of respondents have been "unable to engage in the first place." Respondents felt abandoned and that no one is able, or wants, to help them.<sup>11</sup>

## Integration and primary care

To help overcome issues of access, people saw it as vital to support further reform to the primary care system. Many people felt that healthcare services should be co-located or contained within multi-disciplinary local teams. This would make it easier for them to access a variety of teams in one place, and ask for help, without having to repeat their stories multiple times if records were shared.<sup>12</sup> This would also enable easier referrals and signposting or alleviate demands on GPs. If planned with, and tailored to the needs of the community,<sup>13</sup> co-location of services might also make travelling to medical appointments easier.<sup>14</sup>



Opportunity to develop a central point of contact within the GP practice to help people navigate services post diagnosis. This is also important to new carers.



Transport provision needs to be considered when looking at how people will access primary care services.



Border issues with GP cluster spread over partnership boundaries.

<sup>11</sup> The ALLIANCE (2024) 'Accessing Long COVID services in Scotland: to be believed, listened to and supported'

<sup>12</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>13</sup> The ALLIANCE (2022) 'Exploring Scotland's 20-minute neighbourhoods'

<sup>14</sup> The ALLIANCE (2018) 'Your GP and You: Ensuring access to the right person in the right place at the right time'



You don't want to repeat your story...it's distressing. It's difficult enough to ask for help. What could improve is a one-stop shop - you tell your story to one person and they advocate on your behalf.

Due to the general lack of awareness and knowledge of rights, local, accessible wellbeing hubs could break down the barriers to services and support. Hubs could provide information, guidance and policies about rights and help available for the public, professionals and staff.<sup>15</sup>



I have no clue where to go for information or who to ask. A one-stop information point - somewhere you can ring with a 'no stupid questions' attitude, to ask about services and not be laughed at or told 'that's not our remit.

Currently, good practice is not always effectively shared. A centralised point would be a positive step for signposting, sharing knowledge, learning and making referrals.



<sup>15</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

## Person centred care

Throughout the evidence, person centred care is described as supporting access to services.

A clear consequence of person centred care by staff and services is that people feel confident to seek support and are motivated to access services when there is trust in them:

“ [because of that confidence] I felt I could go up and ask those daft questions that might not have been relevant to my care (that I wanted clarity on).

“ [Person centred care] gave me the confidence to communicate and trust the [oncology] team.

Through engagement to support development of the Scottish Learning and Improvement Framework (SLIF) for Adult Social Care and Community health, participants described rights-respecting care and support as person-led, driven by individual needs and personal outcomes, rather than budgets and targets, and not limited by strict eligibility criteria.<sup>16</sup>

Participants told us how they would feel about accessing support if they felt their rights would be respected, protected and upheld. This included feeling safer when accessing services and feeling able to ask for help, while also not feeling like you have to “prepare to fight” or to repeat your stories.

“ It is traumatising to have to keep repeating your story. We need to tell our story to one person and for them to then advocate for you and then to arrange to organise the NHS and social care that is needed. People need to feel listened to and some empathy.

“ I would get what I needed out of services rather than apprehensive to discuss things.

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<sup>16</sup> The ALLIANCE (forthcoming) ‘Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health’

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In relation to dental services, interviewees identified areas for improvement and examples of good practice which illustrate what works well in supporting access to dental services.<sup>17</sup> People told us that care grounded in person centredness could help to improve access levels by tackling appointment avoidance due to fear and anxiety. For example, suggestions were made that dental care records should identify patients with vulnerabilities (e.g. panic attacks) to dental staff. A person centred approach to service delivery could result in more unified consistent care and would aid people's understanding of services.

Asked what aspects of care they were happy about, respondents spoke of friendly, empathetic, professional and welcoming staff. Staff also carefully discussed dental care and treatment options:



The dentist was kind and patient with me. I have a phobia of dental treatment. I feel stressed when I go for any treatment or check-up. [The dentist] made my experience pleasant as [they] explained each step. Overall, I was very happy with my treatment.



Treated with care and understanding.

Specialist dental services, like Child Smile and special needs dental services, were highlighted as having rapid response rates, "exceptional" service, and offering care and support that "reduce[s] anxiety and stress" which is "empowering for participants."

People, however, described occasions where dental staff had been rude or failed to explain treatments. They instead wanted dental teams to be "more welcoming, [have] more empathy," and to be "non-judgemental with carefully planned approaches which are calm and have a positive approach."

A lack of person centred care can lead people to feel disinclined to engage with their healthcare professional or giving up entirely on pursuing further treatment. Feeling like "passive" or inactive recipients of care is strongly linked to disengaging from healthcare services.<sup>18</sup>



It takes away your security and makes it less likely to reach out for support in the future.

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<sup>17</sup> The ALLIANCE (2022) 'Experiences of Accessing Dental Services in Scotland'

<sup>18</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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Additionally, lack of involvement in one's care and treatment, and feeling that targets are prioritised over individual needs, was also highlighted as a reason for disengaging.<sup>19</sup>



Working to targets and outcomes - they're not actually dealing with what you need. So it puts people off asking, leading to more stress and not getting the help they need. If people were asked at the first stages it would be easier.

Disengagement could also take the form of self-doubt or feeling gaslighted – this was sometimes described in relation to having to repeatedly advocate for oneself, or having their own knowledge of their conditions dismissed.<sup>20</sup>



Because I was so deflated, and I felt I couldn't fight anymore - I had done this for years now - if no one is going to believe me then? And I actually started to doubt myself, started to gaslight myself like right it must just be me.



So internally I started to doubt myself. You are being gaslighted by one person who is not acknowledging what you are saying.



When challenging that in a respectful way, to say look I have read these journals, medical based journals, this is the information that I am understanding and this aligns with my experience and they refuse to discuss it.



All I wanted to understand was why they were saying it was impossible for me to have this condition despite the fact that I had read so much (contrary) information. That is all I was asking for. But they totally disengaged and sent me away, and that caused me to disengage and if it hadn't been for my husband I would not have gone back.

<sup>19</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>20</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

This feeling of not being believed, or feeling 'gaslighted', has come out strongly in engagements with people with chronic pain, long Covid, and with experiences of transvaginal mesh. People identified issues including the lack of access to basic services, being passed repeatedly around services without receiving support, the categorisation of support as 'non-essential' and the postponement or suspension of care.<sup>21</sup>

## Choice and flexibility

People want to have choices and flexibility in their healthcare. As referred to in the previous chapter, people also want to be the leaders and decision makers in their care as the experts in their lives. However, too often healthcare still reverts to the medical model where care is clinical and done to someone not with, by or for them.



Connecting with people and asking 'what do you need,' 'what would you like me to do?' Giving people a choice and a voice instead of thinking you know better about what they need.<sup>22</sup>

There remains a lack of choice, flexibility and availability across healthcare services. It was highlighted by some that they do not feel like they are the decision-makers in their care, and that services are structured in a way that is not personalised, so needs or issues are not necessarily addressed. Due to the demands experienced by services, timely access to services is also limited.<sup>23</sup>

Choice is a core aspect of person centred care. It is delivered when health and social care professionals work together with people to tailor services to support what matters to them. It ensures that care is personalised, co-ordinated and enabling so that people can make choices, manage their own health and live independent lives, where possible.

Many individuals emphasised that healthcare should not take a "one size fits all" approach; rather, services should be tailored to meet people's varying needs, preferences, and circumstances.

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<sup>21</sup> The ALLIANCE and University of the West of Scotland (2021) 'My Path, My Life, My Right to Live Well'

<sup>22</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>23</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

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People would like the ability to choose when, how, and with whom they access services. Whether it involves the method of consultation (e.g., digital or face-to-face), the timing of appointments, or the professional they see, people valued having options that align with their personal needs and preferences.<sup>24</sup>

Individuals have told us that:<sup>25</sup>

“ I want it understood by the healthcare professionals that I interact with that I am an expert in my experience and there should be respect for this. I am the most important stakeholder in my health, not a peripheral inconvenience to be patronised.

“ For someone with a chronic condition that varies a lot, flexibility is needed. It would mean your needs are actually being met at the time needed, not what I am experiencing now which is the way we structure our services doesn't meet you, so you don't get anything.

Examples of good practice show that choice and flexibility can be achieved in simple ways such as allowing people time to reflect and decide on their options:<sup>26</sup>

“ I wasn't forced to make a decision; they gave me the time to think about things.

Key to ensuring that people can make choices that are right for them is that everyone can access information about their care, regardless of disability or language.<sup>27</sup> This will be explored below in relation to communication.

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<sup>24</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>25</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>26</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>27</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'.

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Choice and flexibility also come down to how people want to receive their care. For example, people suggested considering a mixture of drop in sessions and scheduled appointments for GPs in particular. People have highlighted the need for services to fit more conveniently into people's lives, offering options like extended opening hours, online booking systems, and digital consultations.<sup>28</sup>

Overall, the emphasis on choice and flexibility reflects the need to tailor care to individual circumstances, needs and preferences. Flexible service models, such as a "Digital Choice" approach, extended hours, and accommodating appointment preferences, help empower people in managing their health effectively.

## Technology Enabled Care

Used sparingly before the pandemic, healthcare quickly moved remotely with face-to-face appointments cancelled and services, consultations and support being delivered via telephone or digital platforms. For many, virtual services improved access. It was often described as more convenient, not requiring people to travel long distances for appointments, especially for those living in rural communities, and being able to connect with peer support easily online. There were also significant benefits for disabled people and others who may find it difficult to attend appointments.



Saves time, travel and fuel.<sup>29</sup>



Online access [has been] such a lifeline for me...knowing that it can be done because the technology is there, but not-yet-disabled people don't care enough to offer online access to therapy and culture, too. That is so heartbreaking to me.<sup>30</sup>



The pandemic showed it was possible to meet the needs of housebound people.<sup>31</sup>

<sup>28</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>29</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>30</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>31</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

Pockets of good practice were evidenced throughout the documents. For example, people shared instances of specialist nurses arranging regular Zoom and telephone calls for information and support, as well as examples where people continued to receive planned care and the adaptations in delivery, such as virtual consultations, which supported this. Others praised Audiology Departments for using email correspondence and called for this to be implemented across the country as a more accessible option.



Online booking - fantastic for inclusive communication for the deaf.<sup>32</sup>



Use of text messages should be rolled out more widely as it is accessible and unobtrusive.<sup>33</sup>

Although there was general support for digital health and care developments, some were worried that this could exacerbate inequalities. People also expressed concern about reduced choice and feel it is important that face-to-face services remain available.



Digital (online or telephone) consultations are great for many, but not for everyone. Real choice is required.<sup>34</sup>



...difficulty accessing virtual health appointments when a translator was required as the use of timeslot appointments meant both the individual attending and the translator needed to be available for the entire period.<sup>35</sup>



I don't know what other people's experiences have been with hearing difficulties but for me, it's been extremely inaccessible for me. In the future, we need to protect the phone to text translation service.<sup>36</sup>

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<sup>32</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>33</sup> The ALLIANCE (2018) 'Your GP and You: Ensuring access to the right person in the right place at the right time'

<sup>34</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>35</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>36</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

One significant digital health and care development has been Near Me. Near Me is a video consulting service that enables people to attend appointments from home or wherever is convenient. The service is widely used across NHS Scotland, Social Security Scotland, Local Authorities and other organisations for appointments across a wide range of public services.<sup>37</sup> While valuable, it is not suitable for everyone.



Near Me has also been problematic for people who have deafness, particularly when they are asked to keep repeating things. In one case a man had to depend on his wife as he was deaf- she had to repeat everything. This meant the call took twice as long: unhelpful as the call was about memory. It is also difficult to respond because of pauses and sound distortions.<sup>38</sup>

Other complex or specific needs may not have been met with the shift away from in-person care, including for women experiencing coercive control, young women accessing abortion, and women with previous experience of miscarriage or baby loss.

Digital exclusion has become a significant barrier to healthcare access for some people in Scotland. The ALLIANCE's Community Links Practitioners (CLPs) described people who were unable to access the internet due to little or no access, affordability or inability to work the technology which are amongst the reasons why an individual may be digitally excluded.

Although technology enabled care services can improve access, there remain availability issues due to limited resources and capacity combined with high demand. Timely appointments must be available to people whether they are held face to face or remotely, however, this should be explored in relation to remote appointments further in the future as it is currently an evidence gap.

## Timeliness

The NHS Charter of Patient Rights and responsibilities states that people “have the right to safe, effective, person centred and sustainable care and treatment that is provided at the right time, in the right place, and by the most appropriate person”.<sup>39</sup>

Despite these commitments care and treatment being provided and received at the right time, people have experienced delays in accessing appointments, diagnosis, care and treatment. This was a particular concern in relation to accessing specialist psychology and psychiatry services.

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<sup>37</sup> NHS Scotland, “Near Me – Video Appointments”

<sup>38</sup> The ALLIANCE (2021) ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future’

<sup>39</sup> Scottish Government (2022) ‘Charter of Patient Rights and Responsibilities’. Available at: [https://www.ohb.scot.nhs.uk/sites/default/files/publications/charter-patient-rights-responsibilities-revised-june-2019%20\(1\).pdf](https://www.ohb.scot.nhs.uk/sites/default/files/publications/charter-patient-rights-responsibilities-revised-june-2019%20(1).pdf)

Individuals described having to “fight” to be heard and taken seriously. The length of time it took to receive a diagnosis or support not only made people feel ignored and dismissed, but delayed access to care and treatment.<sup>40</sup>

“ If you look at it from 18, I wasn’t diagnosed until I was 29 that is nearly half my life that I was being dismissed and that was huge.

“ She wasn’t getting any investigations... GP refused to authorise the MRI and was obstructive.

“ The root of what was causing my condition wasn’t investigated and it was framed as this is impossible for you to have, rather than taking on my concerns as a patient. And that continued at all levels in primary care and secondary care.

As a result of feeling like they had not been listened to, people experienced significant and varied negative consequences. This included an exacerbation of their existing physical systems, an impact on their mental health, independent living and social life and self esteem.<sup>41</sup>

“ Unfortunately I had the experience of where I was told that I couldn’t have the condition that I have now – even though it is now at a severe stage.

“ The damaging interactions that have led to delays or things being missed.

“ There have been significant delays to diagnosis in some aspects of her health conditions that have had really wide implications not only for her health but also her life outcomes, her family and relationships.

<sup>40</sup> The ALLIANCE (forthcoming) ‘Person centred care: what it means to me. Report to support NHS Education Scotland’s refresh of their person centred care learning resources.’

<sup>41</sup> As a result of feeling like they had not been listened to, people experienced significant and varied negative consequences. This included an exacerbation of their existing physical systems, an impact on their mental health, independent living and social life and self esteem.



And that early journey, it just felt so heavy - every appointment you just got knocked back. If you think of like a hole and you are trying to climb out and people just keep throwing rocks in and it gets harder and harder. You stand up on a rock and you think this is great, I can build steps to climb out of here, but then someone knocks you back off. It's exhausting, it makes you mentally drained. It makes you doubt yourself as a person, it makes you doubt your value, your self-worth, your self-image.

## Communication

Communication is key to people's experiences of healthcare. When referring to communication, this section refers to the verbal, written and physical. It also encompasses inclusive and accessible information and public health guidance.

### Communication and information preferences

The pandemic highlighted the need for tailored, person centred approaches to information provision throughout health and social care interactions to accommodate people's different lived experiences and communication requirements. For example, the provision of accessible information is of key importance for many disabled people, including learning disabled people and people with sensory loss, neurodivergent people, and those whose first language is not English.<sup>42 43</sup>

Accessible information, using a range of formats and languages alongside guidance and support from healthcare professionals, helps empower people to make informed choices about their health and care. It needs to be proactively available online, printed, by telephone or at drop in facilities to reach as many people as possible.

Some groups experience additional barriers as they need information in their own spoken language, or in a format that is accessible to them. Having to ask for information in another format adds another level of need to some groups and makes them feel that they are a greater drain on resources.



If you can't read in English, you're not as important.

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<sup>3</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

<sup>4</sup> The ALLIANCE (2024) 'Cardiovascular disease (CVD) prevention: engaging those at greatest risk'

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There were concerns that individuals had to frequently repeat themselves to healthcare services regarding their accessibility needs and how information should be communicated to them. It was strongly suggested that information on people's accessibility requirements should be routinely and automatically available to healthcare professionals together with consideration of accessibility requirements being implemented into routine practice.

Having the right information is particularly important for groups such as unpaid carers, especially as it is a role which can be extremely isolating. Unpaid carers told us that their needs were being ignored and they were not receiving information to support them in their caring roles:



Unmet need - emotional needs, pragmatic needs i.e. how to actually care for (partner) at home, information in terms of what symptoms I was meant to look out for throughout the process.<sup>44</sup>

Communication preferences also relate to the location in which people want to access information relevant to their health and care. For instance, information does not always have to be given in a health or social care setting. Some would like to get information in community hubs, hairdressers, libraries, shops, supermarkets and workplaces. Pharmacies were highlighted as places where this is already happening, with a suggestion that the Pharmacy First programme in particular needs better promotion.

## Navigating services

Another consistent theme across the evidence reviewed is the lack of information on the services which are available and how to access them, including related information such as travel arrangements and other relevant information. There can be inconsistent messages, with services sometimes referring to each other, resulting in the person being passed back and forth between them, including where this related to public health information.



Communication was extremely limited, poorly conveyed, and frequently appeared to be poorly understood by healthcare staff. I do not say that to blame the individuals in question, but to highlight inconsistencies with information sharing and staff support.



Constantly changing, inconsistent message or decisions that it felt like a roulette.<sup>45</sup>

<sup>44</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>45</sup> Engender and the ALLIANCE (2023) "'Trauma, abandonment and isolation": Experiences of pregnancy and maternity services in Scotland during COVID-19'



My husband has Parkinson's, a complex illness in itself and on top of that, I am faced with the complexities of finding the right support and benefits - it's a maze, at both national and local levels. I want to know I can connect quickly with the people and services we need and be met with compassion and understanding but this is not the reality.<sup>46</sup>

A 'one-stop shop' for signposting and helping people navigate their way around services was talked about as ideal. Good practice was not always effectively shared and again a central point where this could be found would really help, however services that can offer a central point of contact and accessible information were identified as gaps. People with long term conditions often find it challenging to find out where to go in their local communities to either get support or to access information.



There is a need for improvement in access to local information about resources and processes. Information about local pathways is needed to help individuals, parents and professionals navigate local systems and to signpost support. Local areas should consider the potential application of vehicles such as ALISS (A Local Information System for Scotland) as a platform for a locally self-generating directory.<sup>47</sup>

People have told us that they feel like they are pushed from pillar to post between different services and healthcare professionals. This has meant that they do not get consistent or continuous care, support and treatment plans. People want to be able to access the right care in the right place by healthcare professionals and services they trust and know.



You feel shunted from A to B without knowing what your rights are and all of that makes it difficult to get through the minefield of the clinical world.<sup>48</sup>

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<sup>46</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>47</sup> The ALLIANCE and the Scottish Government (2017) 'Experiences of Transitions to Adult Years and Adult Services'

<sup>48</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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GP[s] have no training and tend to be dismissive. Nothing is joined up and the poor GPs do their best with NO support. Hospital consultants don't want any more work so palm you off to another department or back to GP and the wild goose chase starts again. There are no set medication for the symptoms so you have to go private.<sup>49</sup>

## Rights awareness and advocacy

Alongside this, many people currently don't know their rights and what they are entitled to which means they are unable to advocate for themselves and be leaders in their own care.

We heard that people want their rights to be respected, protected and upheld. They want healthcare and support that is person-led, and where they are able to access improved complaints procedures and free, local and independent advocacy services when necessary. However, we were told that there is not enough independent advocacy support available and people are not always signposted or directed to it.<sup>50</sup>



We need in every service someone on duty who can respond to your issue immediately. Someone taking responsibility for that. People don't want to complain, they just want the issue dealt with.



Advocacy is not really accessible to many people; seeing the emergence of paid advocacy which is another barrier. We should have access to free advocacy.



Centralisation of advocacy means face-to-face is disappearing.



Exacerbating inequalities where some people are gaining access to advocacy and others aren't.<sup>51</sup>

<sup>49</sup> The ALLIANCE (2024) 'Accessing Long COVID services in Scotland: to be believed, listened to and supported'

<sup>50</sup> The ALLIANCE and VOX Scotland (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>51</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

A lack of awareness and knowledge of rights is a barrier to accessing services and support. Participants thought it would be helpful if they could be provided with information about the most relevant rights in different circumstances:<sup>52</sup>



Sometimes the services and carers don't know our rights either which can cause significant issues.



Sometimes I do wonder if the fact we don't know our rights means the services don't have to do as much work, or they don't have to be on the ball and considerate.



You get the feeling that we are conveniently not informing the public about basic human rights as it suits a dysfunctional system.



None of us know where to go. Nobody is pointing us. There should be some way of being pointed in the right direction.

It was suggested that people providing care and support should ask people if they know what their rights are and provide them with information relevant to their circumstances, for example a leaflet that describes their rights and entitlements. They also felt that there should be more rights-based training for people working in health and care.

Our engagement on the right to health highlighted several key barriers experienced by people in realising their rights. Respondents underlined how consideration of power dynamics in the relationship between the individual and healthcare providers is important and underlined that the right to health is not perceived as a universal right.<sup>53</sup>

Respondents pointed to how marginalised groups can feel that they don't 'deserve' healthcare or support provision, or are treated as outsiders, resulting in their likelihood to not attend healthcare appointments, instead waiting until they are in crisis. This chimes with the evidence base around missingness in healthcare and of the concept of 'candidacy' which refers to the extent to which an individual will see themselves as a 'candidate' for health services and this being influenced by a range of factors including the structural and cultural qualities of services.

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<sup>52</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>53</sup> The ALLIANCE (2023) 'Investigating knowledge and understanding of the right to health'

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Communities have been told for generations that they are a burden on the state, they don't belong here, they should 'go home'. They feel guilty for placing additional requirements on systems that are already under high levels of pressure.



(They feel that) we are not worthy; we do not have the same value.

## Other barriers to access

Those experiencing chronic pain wanted support and information to learn about different options that may help them manage their pain. They also placed high importance on information about what services and health and care teams are available locally and how they might help to manage their pain close to home. This included wanting information about the different types of treatment available for chronic pain and when they are used.<sup>54</sup>



<sup>54</sup> The ALLIANCE and University of the West of Scotland (2021) 'My Path, My Life, My Right to Live Well'

## Sensory loss and Deaf culture

The previous chapter described issues related to the quality of services and support experienced by Deaf people and people with sensory loss. This section explores specific challenges and barriers to accessing services.

People with sensory loss, impairments and Deaf people told us that there were issues with several areas of health and care. These areas include access to medical aids and technology, communication barriers, professionalism, appointments and data. This section also evidences some people's experiences of audiology services which focus on the prevention and identification of deafness and hearing loss.<sup>55</sup>

Several people told us about communication styles that were not accessible for people with hearing loss, including within Audiology departments. This included staff talking to people while wearing a mask making lip-reading impossible; speaking to individuals after asking them to take off their aids; speaking to people when not facing them and shouting names in the waiting room where people struggle to hear.<sup>56</sup>

COVID-19 also magnified existing and highlighted new barriers people with sensory impairments and Deafblind people encounter. Several people highlighted having issues around the accessibility of communication. These included difficulties in: lip reading due to face masks; booking appointments online or accessing face to face appointments without a support worker; navigating shops if visually impaired; coping with the impact on public spaces due to changing use of parking spaces; and not receiving a shielding letter on time. Another big issue raised was the difficulties with lip to text translation online.<sup>57</sup>



I just felt awful, like a lot of people assume if you're deaf you're not the full shilling.



I also feel that those who have hearing challenges should also have their preferred means of communication on offer - phone, relayUK or equivalent, text, email, STTR, ENT or equivalent STT Apps enabling the client to read the consultation on a screen.

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<sup>55</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>56</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

<sup>57</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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If you have a newborn, how do you get information [as a Deaf parent]? There's just barrier after barrier after barrier. Huge failure of meeting the needs of BSL users.



Not a good start as you had to ring the bell and the receptionist was not aware or willing to do the sighted guiding. Thankfully I was with the taxi driver, and he guided me to my chair in reception.

Healthcare professionals' sensory inclusion awareness was also an issue in other health departments. This indicates a clear gap in training, understanding and awareness of sensory inclusion and a lack of person centred care.<sup>58</sup>



Not having anyone with me during labour after admission was very difficult. It was difficult emotionally, but also practically - I am very short sighted (close to threshold for legally blind) and after I removed my glasses at one point a midwife moved the table they were on. Without them I could not find or operate the call button for help, and so was left on my own with no access to food, water, light, or any supplies.

Several people told us of their frustrations about the unfair variation in technology available. Frustrations were expressed that minor repairs, fittings or extra batteries for hearing devices were not easier to access. These issues were brought to the fore when COVID-19 restrictions were put in place.

Young people in particular experienced difficulties accessing support for their sensory loss. For example, they hoped that improvements in medical technology would better support their hearing in future and be more accessible to them.<sup>59</sup>



My department is so outdated, that the hearing aids are useless. I'd like Bluetooth hearing-aids (can get in other departments except mines) to be able to connect with the world easier and make my life more accessible.

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<sup>58</sup> Engender and the ALLIANCE (2023) "'Trauma, abandonment and isolation": Experiences of pregnancy and maternity services in Scotland during COVID-19'

<sup>59</sup> The ALLIANCE (2023) 'National Review of Audiology Services: Engagement Insights'

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Due to COVID-19 restrictions, as with other services, audiology had to cancel and cut appointments, making it difficult for people to access what is essential treatment for them to live well.<sup>60</sup>



Deafblind people are becoming increasingly isolated. Communication barriers have increased because of social distancing. Vital service for deafblind people and lack of access to this specialist guide communication service which has been cut over the years has had a negative impact on health and wellbeing.

When speaking to participants about their experiences relating to sensory loss, they highlighted the barriers to access and the unique cultural considerations that should be taken into account. A key insight of our Macmillan Transforming Cancer Care Insights report was the belief that the health care system and cancer care services are not designed for individuals with sensory loss and that this hinders their ability to use services effectively.<sup>61</sup>



They didn't know how to, they didn't have the words, the vocabulary, or the awareness, their systems and processes in place weren't for me, they were for cited people.

For people living with sensory loss, the importance of having access to information in suitable formats was a recurrent theme. Applying universal design and inclusive communication principles to all aspects of healthcare services, including the food they serve, could help make the experiences of people with sensory loss far more positive, easy and accessible.



<sup>60</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>61</sup> The ALLIANCE and Macmillan Cancer Support (2023) 'Peer Evaluator Insights Report – Macmillan Transforming Cancer Care Lived Experience Programme'

## Secondary, alternative and private health services

A number of people have described issues accessing specialist health services including, but not limited to: pain clinics, psychiatry, neurosurgery, rheumatology, orthopaedics and orthotics. Others told us that they had resorted to alternative remedies to treat their conditions and/or felt forced to pay for private healthcare services and support.

Specialist or secondary care services were particularly impacted by the pandemic as they were deemed non-essential and they closed. However, access continues to be limited and people have on occasion felt as though they were brushed aside by services who have decided that their issues were not treatable. For people, being told that they were non-essential or untreatable meant that they were unsure of where they could go for help or diagnosis.<sup>62</sup>



With chronic pain clinics closed throughout Scotland, no emergency help was provided. That led to some patients having to appeal to England to help them and pay privately, two happenings which are shameful for Scotland...



I feel like we need better access to specialist pain services as a whole especially for those with undiagnosed conditions.



I have MS and very difficult to access neurologist or a MS nurse not seen them in years as was told there was nothing they could do for me.

For those seeking treatment and care for Long Covid, although referrals were put in place through the NHS, the waiting times for responses and appointments was felt to be too long, and when the services are finally accessed, they were described as unsatisfactory. Respondents felt that they are often passed from one department to another and don't seem to get a coherent treatment plan. Often, this leads to people accessing non-NHS services, and paying for private treatment:<sup>63</sup>



GP[s] have no training and tend to be dismissive. Nothing is joined up and the poor GPs do their best with NO support. Hospital consultants don't want any more work so palm you off to another department or back to GP and the wild goose chase starts again. There are no set medications for the symptoms so you have to go private.

<sup>62</sup> The ALLIANCE and University of the West of Scotland (2021) 'My Path, My Life, My Right to Live Well'

<sup>63</sup> The ALLIANCE (2024) 'Accessing Long COVID services in Scotland: to be believed, listened to and supported'

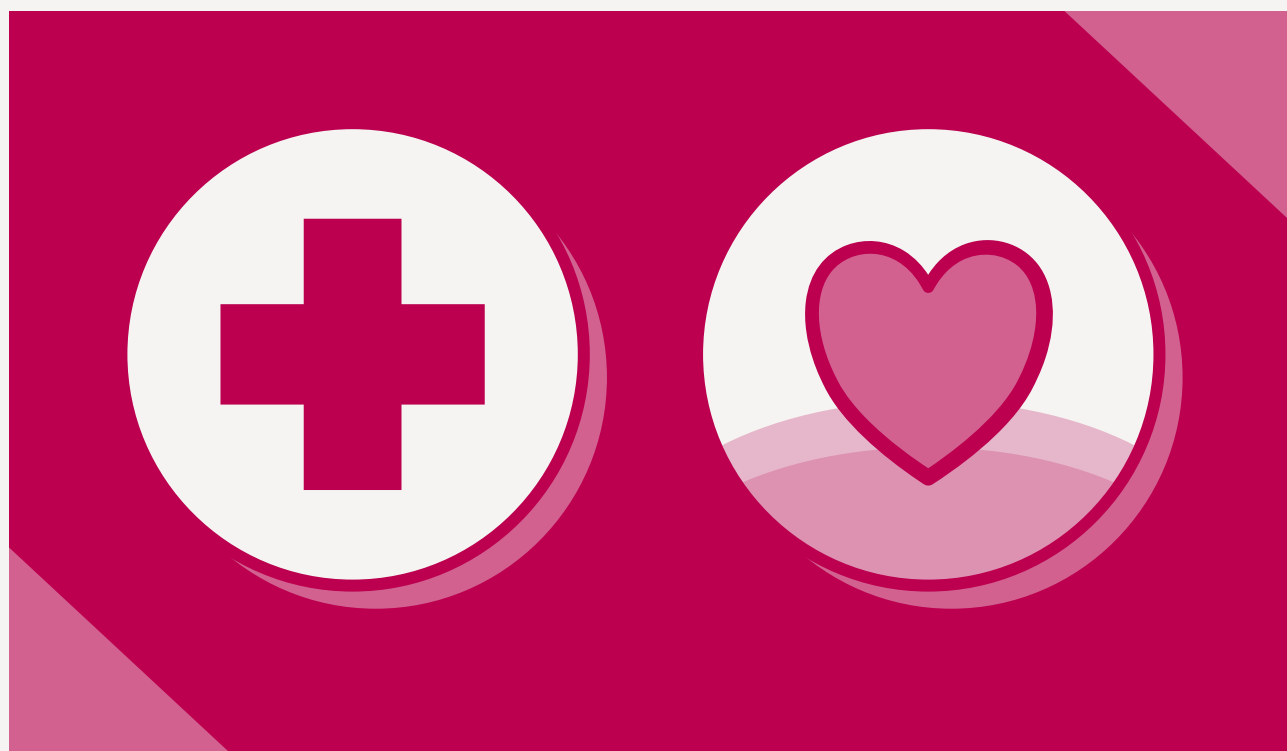
Some people have felt forced to seek private medical help due to long wait times, limited availability and options. This demonstrates that barriers to access could widen inequalities.<sup>64</sup>

“ Unable to be seen at early pregnancy unit when bleeding, advised pre covid I would have been seen but told to wait and see if bleeding got worse - had to pay for private scan to provide reassurance that I hadn't had a miscarriage.

People would also like to have access to a range of alternative remedies and relaxation techniques, demonstrating that healthcare should be holistic and based on what people find helpful which accompanies/complements medical or clinical treatment.<sup>65</sup>

“ Pain clinic, Pain Concern meetings, stress control classes, relaxation, reiki, yoga.

“ Peer support and access to physical, creative and mindfulness activities at a local centre for people with long term conditions.



<sup>64</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>65</sup> The ALLIANCE and University of the West of Scotland (2021) 'My Path, My Life, My Right to Live Well'.

# Prevention

The wider evidence base around prevention is clear that social and commercial determinants of health remain the primary drivers of health behaviours and outcomes and that interventions which address these determinants through structural changes, removing barriers, prioritising income support and introducing legislative and regulatory controls will be most effective. The ability to improve outcomes via individual or healthcare system level preventative measures will always be constrained by these factors. However, there are interventions available to government, health and social care providers, and voluntary and community partners, to build better foundations for a healthier society. Some of this would be addressed by improving the accessibility and quality of services discussed in the other chapters of this report.

Access to healthcare services is a human right and is a determinant of health. This review has therefore analysed what was important to people in terms of support for prevention through healthcare.

Developing new approaches to health creation, prevention and early intervention is about empowering people and communities with the resources to look after their own health and wellbeing, adopting behaviours that can help avoid or mitigate the onset of long term conditions, and creating a more resilient health and care system that proactively responds to the needs of people before they reach crisis.

This chapter presents evidence across primary, secondary and tertiary prevention to show where good preventative practice is taking place, where people are being left behind, and where there are opportunities for expansion of the prevention agenda.



Prevention, defined as an action that can be taken to reduce the impact of health problems and disease, can be broadly categorised into three areas:

**Primary prevention:** Actions taken to prevent problems from happening and promote healthy lifestyles. Examples include vaccinations, tailored health education about risk factors, and population-level smoking cessation programmes.

**Secondary prevention:** Actions taken to detect problems early and intervene before symptoms develop, such as by performing screenings or tests. Examples include cancer screening, cardiovascular 'health checks'.

**Tertiary prevention:** Actions taken to manage the consequences of a problem or condition after it has occurred and prevent further deterioration, by helping people to manage long term conditions. Examples include self management approaches and rehabilitation.

## Primary prevention: Health literacy education

### Health education and positive behaviour changes

The ALLIANCE conducted engagement into the public's awareness of cardiovascular disease (CVD) and its risk factors; their preferences for accessing CVD prevention-focused information; and how they may be better empowered and enabled to take preventative action on their cardiovascular health (engaging specifically with groups at increased risk due to genetic, socioeconomic, lifestyle and other systemic factors, including South Asian communities, women, and people living with socioeconomic deprivation).<sup>1</sup>

Staff from community link workers that we spoke to within this engagement shared that, in their experience, successful health education efforts involved placing the focus primarily on enabling practical behavioural changes that are realistic for the individuals and families involved, rather than solely clinical information sharing. By choosing this focus, they find that it "makes information real to people":

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<sup>1</sup> The ALLIANCE (2024) 'Cardiovascular disease (CVD) prevention: engaging those at greatest risk'

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In the initial stage, very few people signed up for our Group Education sessions. On analysing why this was happening, we concluded that our sessions were aimed at providing information and increasing knowledge rather than activating change. If people were to be empowered to take charge of their health, they needed to hear some 'hard hitting' facts, and have the hope that the risk can be reduced and gain confidence in their ability to act on that knowledge.

## Communication, accessibility and inclusion

As discussed in the previous chapters on Quality and Access, poor communication and fragmented information sources were common concerns in relation to accessing services, however there are issues regarding healthcare communication of specific relevance to the prevention agenda.

We heard a consistent call across groups, particularly in minority ethnic communities, for healthcare information to be presented in a more culturally tailored manner that they can relate to. Conversations with community link workers supporting minority ethnic communities repeatedly stressed the importance (and success) of considering cultural and lifestyle diversity within preventative health messaging:<sup>2</sup>



In our communities it is prevention that is key, but they don't have the right information they need. If it was available in their own language and culturally appropriate, then we would see greater success.



Making changes is difficult for people. They are trying to find things they can change within their culture, not just doing it the Scottish way. Having information culturally rooted is the most effective way.

<sup>2</sup> The ALLIANCE (2024) 'Cardiovascular disease (CVD) prevention: engaging those at greatest risk'

Furthermore, something we have consistently heard in relation to NHS Inform and other text-based health information websites, is that due to the reality of people’s “time poor” lives, people don’t feel they have the time to “trawl” through the information, especially in a preventative capacity (i.e., if they are not experiencing symptoms).<sup>3</sup> Participants frequently discussed feeling overwhelmed by the amount and style of information on NHS Inform, which leads to either frustration or abandoning research altogether.



You panic when you are given too much information. When you hear a term like cardiovascular disease, and you are told there are big changes you need to make, but there is no support to make them, what do you do? She was just given pages and pages of information, but it was too much for her to take on.

Community health practitioners consistently raised concern about the disparity between the clinical language used by many health information sources and the level of health literacy within their communities, highlighting the need for simplified, accessible, and culturally appropriate explanations:



For online resources, I think we need less wording more pictures. We’re moving away from language like ‘physical activity’ to things like ‘movement matters’, trying to make it sound less clinical and more accessible.

There exists a gendered barrier to health awareness also, as many women participants hold the perception that health information is not tailored to them, referencing that, for example, symptoms of heart disease are presented primarily from the male experience within awareness raising campaigns. The concern for many of the women we engaged with is the impact that this has on women’s underestimation of their own risk factors, and a lack of awareness that their symptoms may present differently to the examples they typically see.

The issues experienced with traditional methods of preventative health awareness and education indicate that one-size-fits-all approaches leave some communities behind, and for many, more personalised and community-based interventions may better reach those less likely to engage with healthcare.

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<sup>3</sup> The ALLIANCE (2024) ‘Cardiovascular disease (CVD) prevention: engaging those at greatest risk’

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## Secondary prevention: Early diagnosis and intervention

### Early diagnosis and access to preventative services

Access to early diagnosis and preventative services is consistently emphasised as crucial for managing long term conditions and preventing deterioration.

As discussed in the chapter on access, issues with availability and accessibility of routine and preventative services, especially during the COVID-19 pandemic, were frequently raised across all reports. In some cases, the regular social support provided by social care providers available to people pre-pandemic was paused during the lockdown period.<sup>4</sup> This meant that some people were unable to engage with the things that kept them well, as one participant explains:



The stopping of non-essential services means we stopped a lot of prevention work, and my long-term condition was physically a mess by the time I could re-access services. That could have been prevented. Some of us got sicker.

Within our CVD prevention engagement, we demonstrated strong appetite across all engagement groups for a free ‘health check’ service (measuring key health indicators including blood pressure and cholesterol levels), to support them in taking preventative action. Among participants, there was an awareness that ideas around high blood pressure and cholesterol remain too “abstract” if they have no way of measuring their levels, and the absence of health check services as a “reality check” makes behaviour change less likely.<sup>5</sup>



Because the ideas around heart health are so general, it doesn't focus the mind in the same way. Having more targeted outreach, offering health checks so people are presented with numbers to actually take action on, is really beneficial.

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<sup>4</sup> The ALLIANCE (2021) ‘Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future’

<sup>5</sup> The ALLIANCE (2024) ‘Cardiovascular disease (CVD) prevention: engaging those at greatest risk’

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Community link workers working with minority ethnic communities raised the important role that such early diagnosis services play in the prevention agenda, and highlighted the appetite they are seeing for these services:

“ Raising people’s awareness to prevent diabetes and CVD, which are invisible diseases, is not adequate, as ‘crisis presentation’ is well known in BME communities. People only seek help when there is no other choice. Participants for group education faced barriers when they requested blood tests from GPs... Health services need to ‘be geared up’ for the prevention agenda.

This feedback demonstrates the demand for a community-based ‘health hub’ model of diagnostics and early intervention, where prevention is moved away from medicalised primary care settings to non-traditional settings at the heart of the community. This differs to previous ‘health check’ approaches situated in primary care in Scotland, including the ‘Keep Well’ programme (which produced limited impact on CVD outcomes<sup>6</sup>), by instead providing services with greater accessibility, both due to timely access via ‘walk-in’ appointments and co-location with existing community spaces such as places of worship or shopping centres:<sup>7</sup>

“ Before Covid, there were health checks at the mosque after prayer but that hasn’t returned since Covid. It would be useful if they could come back. People would use the service.

“ We have a wellbeing nurse who sees the women at the community centre and the men at the mosque. We discuss any health concerns we have and find it quicker and more effective than going to our GP.

<sup>6</sup> Geue, C., Lewsey, J. D., MacKay, D. F., Antony, G., Fischbacher, C. M., Muirie, J., & McCartney, G. (2016) ‘Scottish Keep Well health check programme: an interrupted time series analysis’, *J Epidemiol Community Health*, 70(9), 924-929

<sup>7</sup> The ALLIANCE (2024) ‘Cardiovascular disease (CVD) prevention: engaging those at greatest risk’

## Peer support opportunities

The success of direct, in-person community outreach is commonly raised within ALLIANCE engagement as having the greatest impact on health awareness, education and problem identification. Our cardiovascular prevention engagement also highlighted the additional benefits that community group settings have for providing peer support opportunities and reaching digitally excluded people:<sup>8</sup>



The knowledge we gain from the group, from friends and passing this on to others has been the best thing for the group. A lot of us have changed our lifestyle and diet and have lost weight.



People are unlikely to search for this information and this needs to be taken into consideration. There's this fear factor of getting checked, but community group settings and easily available services can get past this.

## Mental health

Mental health and prevention/early intervention services are consistently raised as areas for increased system focus and investment, clearly indicating people's desire to have access to a healthcare system which supports them to live well, prevent severe episodes and improve overall wellbeing.<sup>9</sup>

Post-diagnostic support was also discussed as critical to ongoing emotional and psychological wellbeing, and participants would like to see this more embedded within services.<sup>10</sup>

When discussing prehabilitation support needs with people preparing for cancer treatment, the most recurring theme by far during all discussions was the need for more emotional and psychological support to be made available.<sup>11</sup> This remains a neglected aspect within the continuum of care for people living with long term conditions, as consistently heard by the ALLIANCE across its engagement programmes; people often find that following a diagnosis of a long term condition they are only treated for that condition, with less emphasis placed on the emotional impact that a diagnosis can have as they adjust to living with a new condition. A more holistic approach to wellbeing post-diagnosis would include a greater emphasis on fostering good mental health and wellbeing.

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<sup>8</sup> The ALLIANCE (2024) 'Cardiovascular disease (CVD) prevention: engaging those at greatest risk'

<sup>9</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>10</sup> The ALLIANCE (2022) 'Shaping New Mental Health Standards: A lived experience perspective'

<sup>11</sup> The ALLIANCE (2022) 'Cancer prehabilitation focus groups: Insights report'

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# Tertiary prevention: Self management and ongoing care

## Self management

Self management is a way of living and working that means people living with long term conditions feel more in control of their own health and wellbeing. It supports people to live their lives better, on their terms, helping them to be better informed about their condition(s); better prepared for everyday challenges; and better supported when they need it.

Self management is effective across the prevention spectrum (primary, secondary, and tertiary) by establishing a pattern for health early in life and providing strategies for mitigating illness and managing it in later life. Learning from projects funded by the ALLIANCE Self Management programme demonstrate the key benefits of increased awareness and adoption of self management approaches (two of which are detailed below).<sup>12</sup>

Participants with long term conditions in Your Voice Inverclyde's self management course found that learning self-advocacy techniques empowered them to make their appointments more impactful:



I was better prepared for and made better use of MS nurse specialist appointment - what I needed to get from the appointment I wrote down in advance; being honest with a health professional for the first time about how MS is affecting me, how I'm coping, writing it all down and sharing with them, whereas before I used to pretend everything was fine.

The organisation 'Finding Your Feet' was funded for a range of holistic activities helping people who had recently lost limbs, including fitness classes:



Before the fitness classes I felt very low and barely did any exercise. I couldn't put much weight on my prosthetic. I am now the fittest I've been since my amputation.

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<sup>12</sup> The ALLIANCE (2024) 'Learning from the Self Management programme'

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## Prehabilitation and rehabilitation

Prehabilitation sits within tertiary prevention, due to its goal of targeting prevention of treatment-related complications and improving post-intervention outcomes, and rehabilitation is focused on enabling and supporting individuals to recover or adjust, to achieve their full potential, and to live as full and active lives as possible.

The ALLIANCE's engagement with people's experiences of cancer prehabilitation not only highlighted the value that individuals gain prehabilitation interventions, but also the lack of service availability to properly support them in their journey:<sup>13</sup>



I feel like I got advice nine months down the line about physical activity, which I have taken up and I am enjoying. But nutrition wise and for your mental wellbeing, I didn't really get any support at all.



People's heads are in a mess when they get the diagnosis. So I think that idea of someone stepping in and, as far as possible, trying to tailor to people's needs and just pushing people in the direction is something that certainly was missing in my case.

There was a strong consensus that prehabilitation support and services need to be an integral part of a person's longer-term rehabilitation journey, within a continuum of care, with interventions and support available before, during and after cancer treatment:



It's not just about the prehabilitation, it's got to follow through. It's got to be something that starts when you're diagnosed and keeps going through all the different stages of where you are, during and post treatment even if it's three or four years down the line.

Similarly, a key theme throughout the ALLIANCE's lived experience engagement on human rights in relation to substance use was that many people do not know what rights they have, or how to access them, which often means people don't know where to go for help and support related to their rehabilitation journey.<sup>14</sup>



Some people might not know what services are available to them, how to access these services or that they are eligible for these services.

<sup>13</sup> The ALLIANCE (2022) 'Cancer prehabilitation focus groups: Insights report'

<sup>14</sup> The ALLIANCE (2023) 'National Collaborative Call for Evidence – Analysis Report Summary'

It was reported by participants that it can be difficult to find services and groups as they are not well advertised or visible, with people often relying on word of mouth and relationships for connecting to support. GPs tend to rely on the medical model and are often unaware of the range of services that exist within their own communities.



More promotion of services that are available would make a huge difference, such as posters in pharmacies for instance.

Furthermore, the short term project funding approach to service commissioning was described as limiting availability of services, with resources targeted at crisis and not enough being spent on prevention:



We are constantly 'setting people up to fail' rather than providing support in early adulthood, increasing diversion schemes and community resources.

## Integration and community-based care

### Community support networks

The role of social support and community resources in preventing illness and maintaining health is consistently raised across the ALLIANCE's engagement.

Some people have shared that their wellbeing has been negatively impacted by the lack of access to public services during the pandemic, including pools and libraries, whilst others miss self-care habits such as attending the gym or going to the hairdresser.<sup>15</sup>



Devastated that library closed as reading keeps me sane.



Not being able to swim daily has had an incredibly detrimental effect on both my physical and mental wellbeing.

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<sup>15</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

Within this engagement, 70% of participants stated that they have no support network and that they often feel a sense of shame and are embarrassed to ask for help, meaning their needs go unnoticed until they reach crisis. While these experiences may have changed and access to public services improved as recovery from the pandemic continues, evidence gathered by the ALLIANCE into the impact of the cost of living crisis continues to highlight the demand for third sector services. The feedback signals the value that people place on these community assets as part of their health and wellbeing routine, and highlights what they would lose should they be deprived of access again.

Among people undergoing cancer care, there was also a desire for greater access to peer support and companionship from other people affected by cancer as part of any prehabilitation support offer:<sup>16</sup>



Although I've said that I really want that professional input. Having gone through it and now that I've helped others... From the honour amongst thieves, that you've got that familiarity with someone who's been through it.

## Integration and partnership

As discussed in chapter 1 (Quality), the need for better integration and partnership between different healthcare services and other sectors to provide continuous and comprehensive care is consistently raised across ALLIANCE engagement.

When discussing prehabilitation for people preparing for cancer treatment, the need for services to be better integrated was also a recurring theme. People reported that the current system feels disjointed and compartmentalised with different professionals and different services working in their own silos. It was highlighted that the third sector plays a key role in this regard, filling what was described as the 'gaps' in specialist cancer support.<sup>17</sup>

Similarly, in conversations with people affected by substance use, individuals commented not only on the power imbalances which exists between people seeking support and professionals, as well as between statutory services and the third sector.<sup>18</sup>



Third sector not considered equal in relationships with statutory organisations.

<sup>16</sup> The ALLIANCE (2022) 'Cancer prehabilitation focus groups: Insights report'

<sup>17</sup> The ALLIANCE (2022) 'Cancer prehabilitation focus groups: Insights report'

<sup>18</sup> The ALLIANCE (2023) 'National Collaborative Call for Evidence – Analysis Report Summary'

With regards to use of data, some participants felt that increased use of data could support joined up services and guarantee continuity of care for at-risk individuals, as well as support tailored interventions. It was argued that linking data between the third and public sectors in particular could lead to such benefits. There were also suggestions that automatic prompts might get people to check in with support services or GPs, particularly in the current circumstances.<sup>19</sup>

However, many felt the risks outweighed the positives. The greatest concerns were linked to the potential misuse of data by insurance companies or health providers, bias inherent in data collection, disempowerment (focusing more on sharing data instead of supporting individuals through their journeys) and concerns about privacy and mistrust of sharing information. There is a strong preference for personal approaches, involving face-to-face outreach and education, rather than relying on data collection to identify risky situations. These findings particularly date back to before the pandemic, and therefore engaging with people about improving data sharing for more integrated and proactive support from services could be a topic for further engagement.



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<sup>19</sup> The ALLIANCE (2021) 'My World, My Health - insights from a dialogue on data with Scottish public'

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# People and Place

This chapter presents evidence of what matters to people about their communities. The first section considers the role of systemic inequalities in shaping health. The second section looks at what matters to people in terms of their relationships with and within the community, and the impact of stigma. The third section explores the attributes we have heard are important to people about the physical environments in which we live. The final section outlines learning from the COVID-19 pandemic into people's experiences of community support and services.

## Inequalities: social determinants of health

During a series of events on 20-minute neighbourhoods, we heard a lot about what matters to people about their communities more generally, particularly about how we can shape communities to be inclusive and uphold the rights of everyone.<sup>1</sup>

Systemic inequalities profoundly shape people's health and wellbeing and are shaped and experienced in the places where we are born, grow up, live, work and age. There is a significant gap in healthy life expectancy between the richest and poorest areas of Scotland. Disabled people, people living with long term conditions, women and people from ethnic minority communities often experience poorer outcomes and have distinct requirements and support needs that are not always met by the current healthcare system as evidenced in other chapters. These health inequalities are influenced by a range of factors including poverty, employment, housing, education, racialisation, and childhood experiences.<sup>2 3</sup>

The pandemic and cost of living crisis disproportionately impacted people belonging to marginalised and more vulnerable groups. Learning from this time highlights the ways in which people who experience health inequalities were more vulnerable to changes in services and the economy.

The pandemic created additional anxiety and uncertainty for people with existing mental health needs living in areas of multiple deprivation, while others experienced anxiety for the first time.<sup>4</sup> At the same time, people had increased difficulties accessing support, leading to a sense of being abandoned. People described postcode lotteries affecting standards of care and level of communication. Furthermore, within and across geographical areas there was variation in the type of services available.

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<sup>1</sup> The ALLIANCE (2022) 'Exploring Scotland's 20-minute neighbourhoods'

<sup>2</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>3</sup> Health inequalities are also influenced by sexuality and gender identity, but these are not referred to specifically in the ALLIANCE's evidence reviewed in this report. For further information, see GCPH and LGBT Health and Wellbeing Scotland (2024), 'Examining the social determinants of LGBT+ health and wellbeing.'

<sup>4</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

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The wellbeing impact was unequally distributed among the population groups who experienced barriers and disadvantage before the pandemic. Disabled people were more likely than non-disabled people to report feeling more anxious and lonely, while also facing significant barriers to accessing public spaces. In addition, concerns were expressed about the somewhat stigmatising narratives which were evident during the pandemic which seemed to suggest only those 'with underlying health conditions' were at risk.<sup>5</sup>



I found that I couldn't go to the shops. After having to stand in line to get in, by the time I got to the front I was too sore to actually go into the shop. A lot of disabled spaces were cordoned off to make walkways with social distancing. Disabled and elderly were completely forgotten about.

Many people experienced anxiety and depression caused by job insecurity and the financial implications of potential job loss for themselves and their families, demonstrating the link between employment, income and wellbeing. The financial impact also varied according to individual circumstances. Disabled people were affected by shutdown in some sectors due to their higher share of employment in those. This was also true for people from minority ethnic communities who felt the economic impact of the crisis harder. Generally, people in the most deprived areas were most likely to have lost their job or been made redundant, to have applied for universal credit or to have received support from care workers or a charity versus those in less deprived areas.<sup>6</sup>



Poverty might kill more people than COVID.

The subsequent and sudden rising cost of living resulted in a crisis for the sections of our society at highest risk, who were and continue to find themselves both with higher bills and less ability to pay. The "disability price tag" – disabled people already face additional costs while also facing limitations on their income – remains a longstanding problem.<sup>7</sup>



I have a small, travel powerchair for hospital visits and a larger one for shopping. They both take 4 hours to charge up. My bath raiser takes 16 hours to charge! I cannot manage without them. I feel cold all the time and dread the winter now with my Arthritis. I will not be able to afford the bills.

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<sup>5</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>6</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>7</sup> The ALLIANCE (2022) 'Disabled People, Unpaid Carers and the Cost of Living Crisis: Impacts, Responses and Long Term Solutions'

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Poverty and inequality, even when alleviated or reduced after the fact, can cause long term damage to mental and physical health, which may be felt for years after the acute crisis is resolved. There continues to be a need for longer term action to address the root causes of the crisis which should be considered a form of preventative spending. This includes investing in poverty reduction measures as well as taking an approach to budgeting and economy that put wellbeing and human rights at the centre.

In summary, our evidence demonstrates the need to treat the cost of living as a matter of public health. We have previously highlighted that poverty is not only a crisis of income but of dignity and human rights. Investing in broader measures to improve incomes and tackle poverty, including measures targeted to the needs of different groups, would go a long way toward improving people's health and wellbeing, support access to services and prevent deconditioning, thereby reducing the need for more costly acute interventions and pressures on the NHS. Action to address poverty, particularly inadequate and unaffordable housing, food insecurity, energy costs and the social security system are essential. While beyond the immediate scope of NHS Reform, the wider context in which the NHS operates will continue to exert further pressure on the health system without long term sustainable action. Additionally, NHS commissioning should adopt a human rights based approach to procurement and grant funding to prioritise services which realise human rights and uphold dignity.

## Societal factors

Good relationships with family and friends, and with the wider community, can significantly impact individual and community health and wellbeing and we often hear about how important these are to people.<sup>8 9</sup>

This section explores evidence we have gathered around the impact of stigma and the importance of social connections to people's wellbeing. Stigma affects both the quality of care and treatment people receive and their ability to access services and therefore should be considered alongside the evidence presented in the chapters on quality and access. However, it has been included here as stigmatising attitudes and behaviours are influenced by wider social factors and relate to people's ability to feel connected to their communities.

People have told us that being treated with dignity and respect helps them feel included in their communities. But we have also heard from disabled people and people living with long term conditions that this is not always the case, and that they feel more people could be better informed about living with disabilities, particularly "invisible" conditions such as chronic pain.<sup>10 11</sup> (Barriers to inclusion relating to infrastructure, transport and service access will be explored in the next section).

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<sup>8</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>9</sup> The ALLIANCE (2022) 'Exploring Scotland's 20-minute Neighbourhoods'

<sup>10</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>11</sup> The ALLIANCE (2022) 'Exploring Scotland's 20-minute neighbourhoods'

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## Reducing stigma

Negative attitudes and biases about disabilities can have an impact on people's sense of belonging and general wellbeing, and we have heard that this can have an impact on relationships within communities including between people accessing and providing care. This can act as an additional hurdle to building trusting relationships and make it harder to seek support.<sup>12</sup>



As a neurodivergent person, what would make a massive difference would be: training by actually neurodivergent people to all care staff – the stigma and myths attached to my neurotypes create so much additional trauma that then I don't have anyone to help me deal with.



When you have a disability or condition that is invisible, it can be difficult for people to understand. When you're not understood by the services you're engaging with it can reinforce ideas that it's all in your head. For a carer to have an understanding of variable conditions is helpful – just because someone can get to the door to meet you last time doesn't mean that they're able to do that today.

Experiencing self-stigma is a common experience for many disabled people, people living with long term conditions, unpaid carers and people experiencing poverty. Self-stigma is 'characterised by individuals internalising feelings of guilt or shame about themselves, their behaviour, or a combination of both'.<sup>13</sup> This can be a barrier to accessing care; people may be reluctant to seek support if they have low self-esteem and feelings of unworthiness. Stigma may also co-occur and interact with other forms of social identity, and we have heard about different types of stigma, such as those linked to mental health, weight, poverty, gambling harms, addiction, homelessness, suicide and physical health conditions.

Participants often described negative experiences when accessing public services including the attitudes and behaviours of healthcare professionals, such as a lack of honesty, respect and listening as well as stigmatising attitudes. Individuals described how they understood bias to have played a role in healthcare professionals' decision making, leading to significant delays in getting treatment and ultimately resulting in poorer outcomes.

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<sup>12</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>13</sup> The ALLIANCE (2022) 'Reducing Stigma, Emphasising Humanity'

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There is almost an underlying assumption that things are psychosomatic; it's probably anxiety, it's probably stress, it's probably low mood.<sup>14</sup>



Change [...] diet, lose some weight and things will improve. I tightened up my already drastic diet and continued to lose weight. My symptoms did not improve. In fact, they worsened.<sup>15</sup>

This is particularly evident in relation to substance use, and frequently results in people being denied support, care and medication. A range of stereotypes negatively label people affected by problem substance use and their families, which can enable discrimination when engaging with their communities and accessing healthcare. For example, women affected by problem substance may be described as unfit mothers, and opiate users known to services may be denied access to pain medication. People who use substances are commonly unwilling to talk to their GP about mental ill health, and report anxiety that this will involve changes to their medication.<sup>16</sup>

It is important to understand the ways in which societal stigma reinforces self-stigma. More attention needs to focus on underlying and deep-rooted society issues, including addressing poverty and health inequalities, rather than on individual behaviours. It has been suggested that the provision of better education, awareness raising, training and capacity building for those working in health and social care could help tackle stigma and its impacts within healthcare services.

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<sup>14</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

<sup>15</sup> The ALLIANCE (2022) 'Reducing Stigma, Emphasising Humanity'

<sup>16</sup> The ALLIANCE (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'



## Relationships and social connections

Relationships are crucial to challenge feelings of self-stigma. Participants have highlighted the importance of developing relationships underpinned by trust, whether through peer support or with healthcare professionals. Breaking down labels like 'patient' and 'professional' can help rebalance power dynamics between people accessing and providing support, and can support the workforce to take a more trauma-informed and rights based approach.

Supportive and understanding health and care professionals can help people overcome challenges such as internalised stigma and ablism by helping people to break patterns of negative self-thoughts, build self-esteem and confidence to ask for support.<sup>17</sup>



What that good relationship could look like is not having a constant low level of confidence - you're always waiting for someone to put you down, to question how disabled you really are. To be listened to, to be understood, treated with compassion. People need real training in this. People not coming in and questioning your abilities.

Social carer professionals and others providing support can play an important role in helping people to access and participate in their communities.



With my carer I was able to go for a walk with my dog, get my prescription, get my driving license. She helped me build my confidence. We had a lot in common... I wasn't aware what was available in my community when I moved here so having someone there to support [me] and encourage independences was really helpful.

We also heard that improving support and services at the community level could help people to feel more connected to their communities and increase opportunities to participate in employment and other activities.<sup>18</sup>

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<sup>17</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>18</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

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I think another measure for those who receive reliable and safe care would be that there would be more people able to remain in work (either paid work or voluntary work), as if don't receive care that is needed then you are more likely to have to reduce hours or have to leave employment or voluntary work.



More people will feel involved and valued in their community.



We could tell [care has improved] if isolation is reducing.

Social isolation has long been a key issue for people in Scotland of all ages, and people find befriending services and peer support helpful for overcoming feeling lonely or isolated.<sup>19</sup> Community based activities that meet a range of diverse needs are important to supporting social connection and reducing isolation.<sup>20</sup>

## Support networks: maternity care during COVID-19

The ALLIANCE partnered with Engender to gather women's experiences of accessing pregnancy and maternity services at the height of the COVID-19 pandemic. Two themes which emerged in this research are the importance of support networks and impact of isolation.

Many women said that isolation stemming from COVID-19 restrictions negatively impacted their experiences of pregnancy, accessing fertility and perinatal services, and giving birth. Women had to attend appointments, scans and procedures alone, meaning that extremely difficult news was received without support. This was sometimes described as being traumatic and inhumane.

Many respondents described being separated from friend and family networks during restrictions and how this affected their mental health and wellbeing. Extended isolation from loved ones, communities and support services continued to negatively impact life for families in the post-birth period, with some experiencing ongoing trauma. Mothers told us they were unable to connect with other new mothers and worried about how the lack of social connection would affect their newborns.<sup>21</sup>

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<sup>19</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>20</sup> The ALLIANCE (2022) 'Reducing Stigma, Emphasising Humanity'

<sup>21</sup> Engender and the ALLIANCE (2023) "'Trauma, abandonment and isolation": Experiences of pregnancy and maternity services in Scotland during COVID-19'

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When I look back on my maternity leave, it is a time of trauma, abandonment and isolation. The one walk we were allowed a day to see other people was an absolute lifeline, which I clung to for eight months. There were no baby classes, no cafes, no going inside to see other people. The only person who came into my house was my health visitor. This was made all the harder by the inconsistency where in England a parent with a child under one year was able to form a 'bubble' with another household - when myself and my daughter, because we were in Scotland, had to cope alone.



Most of our family and friends were unable to meet my baby until he was about six months old. It was incredibly difficult and my mental health suffered hugely. I tried to do classes online (including one provided by NHS) but it was difficult and I also feel I missed out on building a support network of other mums at baby classes etc.

While these insights relate specifically to the impact of public health measures within these services, these experiences highlight the relevance of wider support networks and social connections to individual and community wellbeing, as well as early childhood wellbeing and development through the life course. There must be a greater appreciation of family and social connection when considering service reform as well as in future pandemic planning.

## The built and natural environment

Many aspects of our physical environment influence our health and wellbeing.

### Getting around

Physical and environmental factors have been identified as a particular barrier for people with disabilities in getting around their local community and accessing public spaces.<sup>22</sup> This can limit people's independence and ability to participate in activities, contribute to becoming more isolated and it speaks to the experience of feeling less valued than other people in their communities.<sup>23</sup>

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<sup>22</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

<sup>23</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

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For people with disabilities and limited mobility the “first and last mile” can often be a challenge to getting around. Poor pavement infrastructure, lac of dropped kerbs, road works, poor lighting, lack of places to rest and other obstacles can make it difficult or impossible for people to connect to transport.<sup>24</sup>

Access to various public transportation is essential to being able to get around communities and access services. Transportation links to healthcare services need to be considered at the local level, in line with many of the commitments set out in the Scottish Government’s Transport to Health Delivery Plan.<sup>25</sup> This requires partnership working across health boards, private, and the third and voluntary sectors.

## Access to food

The affordability and availability of healthy food is seen as a major barrier to people living healthy lives. There is significant support for cheaper fresh and healthy food, and some people have called for raising taxes on sugar and other unhealthy foods. Workplaces, prisons and care settings were some of the places people felt their opportunities to eat healthily were restricted.<sup>26</sup>

## Social care

Social care is essential to support some individuals, including some disabled people, to live full and independent lives. It also helps older people with long-term conditions live at home or in a homely environment. We have heard how it enabled people to have a choice about how and where they live their lives. It can help alleviate pressure on the health system but also has a distinct role from that; social care supports people to live and participate within the community.<sup>27</sup> However, older people, even in low SIMD areas, are at risk of losing their house to pay for social care costs.<sup>28</sup> Furthermore, we have heard that living in a homely setting has an impact on wellbeing.



To feel well, safe and secure and bright in your spirit, your surroundings need to be nice.<sup>29</sup>

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<sup>24</sup> The ALLIANCE (2022) ‘Exploring Scotland’s 20-minute neighbourhoods’

<sup>25</sup> Scottish Government (2024) ‘Transport to health: delivery plan’

<sup>26</sup> The ALLIANCE (2016) ‘Creating a Healthier Scotland: What Matters to You’

<sup>27</sup> The ALLIANCE (2016) ‘Creating a Healthier Scotland: What Matters to You’

<sup>28</sup> The ALLIANCE (2018) ‘Your GP and You: Ensuring access to the right person in the right place at the right time’

<sup>29</sup> The ALLIANCE (forthcoming) ‘Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health’

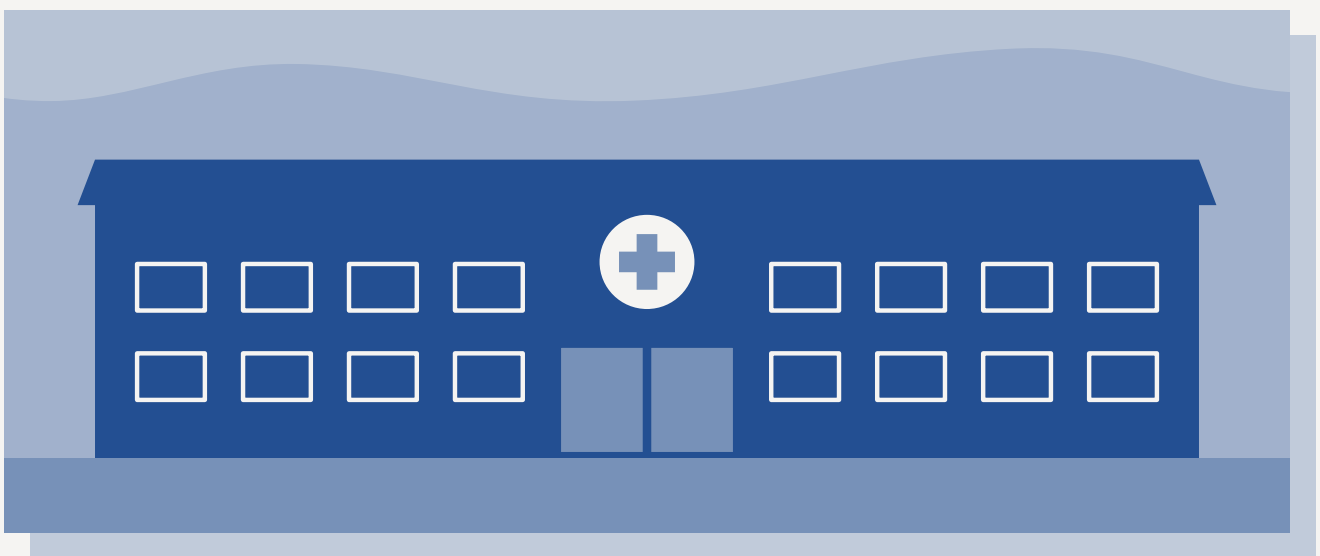
## Housing

Safe, quality housing is essential to meeting people's right to an adequate standard of living, yet housing insecurity remains a persistent issue that affects many people across Scotland. As highlighted in our report 'Exploring Scotland's 20-minute neighbourhoods,' ensuring that a range of diverse housing options are available in communities is vital to meet the needs of a range of groups, and being able to have a choice of different housing options is essential.<sup>30</sup> This includes accessible, affordable housing to cater for disabled people, people with complex needs and a growing aging population; housing should also be easy to adapt to meet individuals' changing needs. A mix of housing options also supports people to feel less divided within their communities, and can therefore help tackle the negative impacts of isolation and build community resilience.

## Primary care

Engagement with people around their experiences with GP services highlighted priorities in relation to how GPs are embedded in and engage with their communities. People felt GPs should spend time looking at the communities they serve and think more about general public health. They suggested that GPs could tailor practices to the needs of the area and needed to do more to reach people who are not in a group or part of an organisation. It was also felt that GPs should be able to highlight social determinants of health to the local authority or the Health and Social Care Partnership, particularly issues relating to housing.<sup>31</sup>

This engagement also found that some people are looking for someone to talk to about wider things impacting on their health, but are reluctant to trouble a doctor. As highlighted in the Access chapter, people have told us that they value social prescribing and would like a wider range of alternatives to medication.<sup>32</sup> The Community Link Programme has significant potential to meet the desire for more community-based, non-clinical forms of support.



<sup>30</sup> The ALLIANCE (2022) 'Exploring Scotland's 20-minute neighbourhoods'

<sup>31</sup> The ALLIANCE (2018) 'Your GP and You: Ensuring access to the right person in the right place at the right time'

<sup>32</sup> The ALLIANCE (2016) 'Creating a Healthier Scotland: What Matters to You'

## Communities: learning from the pandemic

The community-focused action that took place during the pandemic demonstrated the many examples of individual and community assets that exist across Scotland, and provides important learning for building community resilience. The community response highlights the value and contribution of asset-based approaches, and what empowering communities can achieve.<sup>33</sup> Investment and development in local areas contribute to creating the conditions for communities and their individual members to flourish.

People told us about an increase in community spirit, with new connections made between neighbours and people in local areas. Some people have shared how these connections have been instigated and nurtured by regular, group activities such as the Clap for Carers, or organising a daily, socially distanced street dancing session to keep spirits and fitness up during lockdown. People drew upon friendships, neighbours and networks for support in creative and innovative ways, identifying what is working well for them and their families.

People and communities actively supported the response to the COVID-19 pandemic by not only complying with guidance themselves, but by creating the conditions locally by which people could reduce physical contact and keep themselves safe whilst maintaining access to necessary social contact and healthcare support.

Another key point raised was the importance of partnership and how it helped address local challenges. Organisations, individuals and communities worked together to provide innovative, adaptable and effective services. People cited the third sector and their local communities as coming together during this time as key to mitigating and buffering against the many impacts of the pandemic, addressing newly presenting needs, and in some cases bridging the gap left by the withdrawal of healthcare services.<sup>34</sup>



Our community approach is far more than providing food; it's connecting on a human level, raising self-esteem and worth. Our engagement is always about treating people with respect, who have rights, strengths and aspirations. Our team is viewed as a trusted provider of assistance, returning weekly and carrying out any actions agreed.

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<sup>33</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>34</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

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The ability of third sector organisations to respond quickly to emerging need was also highly valued. The temporary removal of common barriers also enabled organisations to work creatively and collaboratively, demonstrating that things could be done differently. We heard about the difference this made for disabled people and people living with long term conditions.<sup>35</sup>



A whole new world opened up to me.

Rural versus urban areas were also raised as being important contextual considerations when exploring what services should be available and how they should be delivered.

Ease of access to services in remote and rural areas is influenced by their availability and transportation options. Issues relating to variation in access are frequently raised, particularly the importance and distinct role general practice can play in remote areas. As discussed in chapter 2 (Access) the shift to telehealth during the pandemic was beneficial for many people who cannot easily access services in their areas, however, people have also raised concerns around the reliability of broadband in rural areas as a potential barrier.<sup>36</sup>

Codesigning digital services with community members might be a route to ensure online services are adapted to target population: one example is a project based in the Isle of Skye which aimed to codesign the use of the NHS Near Me platform in a wider goal of reforming outpatient appointments. The project learned from users to adapt the platform to their needs.<sup>37</sup>



<sup>35</sup> The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

<sup>36</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

<sup>37</sup> The ALLIANCE (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future'

# Conclusion

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This report sets out the findings of a review of some of the ALLIANCE's key engagement evidence to understand what matters, to whom and in what circumstances, with regard to accessing acceptable, equitable, timely and quality healthcare and support. The review is being undertaken in support of the Scottish Government's NHS Reform Programme, with the aim of ensuring that the programme takes account of existing evidence before undertaking further engagement and consultation.

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We analysed the evidence across the four priority domains identified by the Cabinet Secretary for Health and Social Care: Quality, Access, Prevention and People and Place. These reflect what people with lived experience of accessing health and social care consistently ask be prioritised: prioritise prevention, consider broader contribution to health, and improve equity of outcomes and access to services.

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# Recommendations

The following recommendations draw from the evidence reviewed.

The report has highlighted the interplay between the four priority domains for health and social care reform and has captured the complexity of the NHS and the challenge of disentangling people's priorities for NHS reform from those related to primary care or social care. Furthermore, people spoke frequently about the importance of taking a whole system approach, taking into account the wider environment and public services which enable their health and wellbeing, including the contribution of the third sector.

Some of the recommendations are quite specific whereas others are broader, reflecting the context of wider system change.

**1**

**People want change, active involvement in implementation, and robust monitoring to ensure it delivers what is intended.**

**An overarching theme evident in this review is that people want to see reform delivered that is informed by their priorities. Furthermore, priority must be given to empowering the role of people with lived experience in health and social care reform.**

**2**

**This review highlights some key ALLIANCE evidence concerning what is known about people's priorities, however further work is needed to understand the wider evidence base.**

**Therefore, Scottish Government should undertake further work to review other existing evidence, including drawing on that of third sector organisations. This work should take an equality informed and intersectional approach to consider the experiences of different population groups including, but not limited to, people receiving end-of-life care, unpaid carers, people from racialised communities, LGBT+ groups and people with learning disabilities.**

There is a clear need to improve the monitoring of inequalities and evidence gathering across public services. In line with the recommendations by the Expert Reference Group on COVID-19 and ethnicity,<sup>1</sup> the Glasgow Centre for Population Health and LGBT Health and Wellbeing,<sup>2</sup> this work should include proactive public health surveillance of the health, wellbeing and inequalities faced by different groups including those with protected characteristics.

**3**

**Strengthen the mechanisms for whole system, longer term integrated planning of health and social care services – enabling greater coordination and coherence across and between Scottish Government, the national NHS Executive to Health Boards, Health and Social Care Partnerships and Local Authorities.**

**This planning should assess and forecast population needs now and into the future, monitor unmet needs, identify gaps in service delivery, plan for changing needs, and should be aligned to the Health and Social Care portfolio medium term financial framework.**

**There is also a need to strengthen the ongoing and meaningful involvement of people with lived experience in decision making – this should be done at both national and local levels.**

**4**

**Improve experiences of integrated health and social care and support.**

**Our evidence demonstrates that more must be done to improve integrated ways of working including across health services, between health and social care, and include the third sector, to address issues of disjointed pathways, delays, unmet need, a lack of accountability and follow up.**

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<sup>1</sup> Scottish Government (2020) 'Expert Reference Group on COVID-19 and Ethnicity: recommendations to Scottish Government.' Available at: <https://www.gov.scot/publications/expert-reference-group-on-COVID-19-and-ethnicity-recommendations-to-scottish-government/>

<sup>2</sup> Glasgow Centre for Population Health and LGBT Health and Wellbeing (2024), 'Examining the social determinants of LGBT+ health and wellbeing.' Available at: <https://www.gcph.co.uk/latest/publications/1174-examining-the-social-determinants-of-lgbt-health-and-wellbeing>

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## 5

**Scottish Government, Health Boards and Integration Authorities must review their arrangements for working with the third sector and identify areas for improvement.**

The ALLIANCE's evidence continues to demonstrate that more must be done to improve the engagement of the third sector as both a strategic and operational partner in health and social care. Despite strong evidence showing its vital role in providing support and services and essential social infrastructure to address health challenges, the third sector continues to be overlooked in governance arrangements and reform efforts.

This work must be underpinned by adopting the 'Fair Funding for the Voluntary Sector' proposals<sup>3</sup> and take into consideration the arrangements that are needed for the public sector to be effectively informed about, refer on and signpost to the third sector support that is available in their areas.

## Access

## 6

**Improve and clarify pathways to ease navigation of NHS services, paying particular attention to boundaries between services.**

The challenges people encounter when trying to navigate their way through the NHS - with regards to information sharing, the coordination and continuity of care, and barriers to accessing services - are well documented and require immediate improvement.

The King's Fund has identified that high-quality administration processes have the potential to improve a person's experience, reduce inequalities, promote better care and contribute to a better working environment for staff yet are rarely the focus of reform efforts.

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<sup>3</sup> [What is Fair Funding? - SCVO](#)

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## Our recommendations include:

- There needs to be a greater focus on guidance and support to create the conditions for multidisciplinary team working. The GIRFE team around the person toolkit provides an opportunity.
- The introduction of an integrated health and social care record to support the sharing of information across services and ensuring personal and proxy access.
- Focused action to ensure equal access for disabled people, people with sensory impairments, people whose first language is not English, and those who face structural and systemic barriers. After carrying out a review of existing evidence (Recommendation 2), if there are data gaps the Scottish Government may need to commission further community-based research to understand these issues and highlight solutions.
- Promote existing guidance on Inclusive Communication<sup>4</sup> and instigate a programme to raise awareness, support implementation, and monitor its application.

## 7

### Priority must be given to people's communication, information and support needs.

Key to being involved in maintaining one's own health and wellbeing is having access to the right information, in the right format, at the right time. This allows individuals to understand their health and wellbeing options, giving them greater control over their care and informed decision-making, and increases people's capacity to self manage.

Scottish Government and NHS Boards must improve and embed inclusive communication strategies and approaches which ensure people have access to the information they need to be informed about their health, to access support and services, and in relation to related matters. This includes, but is not limited to, information about accessing transport to health services, and support for digital inclusion. Access to appropriate information and resources are key enablers in supporting self management.

<sup>4</sup> Scottish Government (2011) 'Principles of Inclusive Communication: An information and self-assessment tool for public authorities.' Available at: <https://www.gov.scot/publications/principles-inclusive-communication-information-self-assessment-tool-public-authorities/>

8

People's access needs must be prioritised to ensure both individual and population needs are more equitably met. There should be a greater focus on choice, flexibility and availability in service models, which allow people to access services in ways that better meet their rights and needs and ensures that digital is a choice not a requirement or expectation.

9

The challenges of accessing certain NHS services must be addressed, for example; where there are long waiting lists, where the service is identified as 'fragile', and/or eligibility criteria are applied to manage waiting lists.

There must be greater transparency and participation of lived experience with the identification of 'fragile' NHS services and/or services where eligibility criteria are applied to manage waiting lists.

This must take into account regional variations, including where this affects remote and rural parts of Scotland.

Scottish Government and Health Boards should undertake and publish a review into which NHS services are fragile, in which parts of the country, and where access problems are most challenging. This review should involve people with lived experience in this process, have a focus on working towards solutions, and take into account the contribution the third sector plays in delivering services.

10

Enhance availability and accessibility of emotional and psychological support during critical life and health events, including but not limited to diagnosis, pregnancy loss, palliative and end of life care.

## Quality

11

Prioritise person centred and relational care as a guiding principle of reform.

Research and engagement by the ALLIANCE into experiences of person centred care, continues to highlight shortfalls. This creates barriers to access and negatively impacts health outcomes. We have identified the core elements of person centred care as:

- Feeling heard and listened to.
- Being treated with courtesy and dignity.
- Experiencing empowerment.
- Feeling trust during interactions.
- Feeling understood by healthcare practitioners, having good relationships, and not being judged.

These are strongly aligned to the GIRFE principles, which could prove to be a guiding approach to the NHS Reform Programme.

12

Prioritise training and professional development in person centred care as part of workforce recruitment, retention and development planning, ensuring a focus on equality, rights, inclusion and trauma informed approaches.

Related to Recommendation 11, the evidence review has highlighted the importance people place on person centred and person led care, and the negative impact where this is not encountered. It is essential that priority is given to ensure the workforce develop the training and skills required to deliver person centred care. Our evidence has highlighted the following to be of importance:

○	Trauma-informed approaches (e.g. the National Trauma Training Programme). <sup>5</sup>
○	Gender sensitivity.
○	Awareness of systemic inequalities and ability to take an intersectional approach such as Equality in Integration modules. <sup>6</sup>
○	Understanding mobility requirements.
○	Sensory awareness training, including a strong understanding of device management.
○	Cultural awareness.
○	Inclusive communication skills. <sup>7</sup>
○	Turas person centred care zone. <sup>8</sup>
○	A human rights based approach to dignity in care. <sup>9</sup>

<sup>5</sup> National Trauma Transformation Programme; Working with substance use, trauma and mental health, available at: <https://learn.nes.nhs.scot/19051/working-with-substance-use-trauma-and-mental-health>; Embedding Trauma Informed Care within Maternity Services in Scotland, available at: <https://learn.nes.nhs.scot/74167>

<sup>6</sup> Integration of Health and Social Care, available at: <https://learn.nes.nhs.scot/17860>

<sup>7</sup> Communication Skills, available at: <https://learn.nes.nhs.scot/79093/general-practice-education-hub/general-practice-management/resources-and-recordings/administrative-and-receptionist-masterclass/communication-skills-video>; Augmentative and alternative communications: introduction, available at: <https://learn.nes.nhs.scot/14904>; NHS Greater Glasgow and Clyde Staff Training resources, available at: <https://www.nhsggc.scot/your-health/equalities-in-health/information-resources/for-staff/staff-training/>

<sup>8</sup> Person-centred care zone, available at: <https://learn.nes.nhs.scot/18887/person-centred-care-zone>

<sup>9</sup> Human Rights-based Approach to Dignity in Care (DIGNISPACE), available at: <https://www.coursera.org/learn/human-rights-based-approach-to-dignity-in-care-dignispace/>

○	NES Introduction to Equality, Diversity and Human Rights. <sup>10</sup>
○	LGBT+ inclusive training.

**Adopt the House of Care approach, enabling person centred care and the practice of Realistic Medicine.**

House of Care is a coordinated service model that enables people living with long term conditions to be in the driving seat of their care. It addresses health inequalities, builds health literacy and supports public health aims.

Underpinned by self management principles, House of Care builds people’s confidence and ability to manage their conditions. It does this through information gathering and sharing prior to a collaborative conversation which involves goal setting and action planning. With the person “knowing their numbers” (e.g. blood pressure, lipids and so on) in advance of a care and support planning conversation, they have a sense of empowerment which leads meaningful and informed conversations about their health and condition management.

Evidence shows that this type of supportive, collaborative relationship can lead to improved health outcomes, especially when it is fully integrated into primary care delivery.<sup>11</sup>

Though used mainly within the primary care and long term condition management context, the House of Care collaborative, person centred conversation can play a significant role in prevention. It can go further than where ‘health check’ initiatives have gone, by combining measurement of key risk indicators with motivational interviewing and goal setting techniques to influence behaviour change and reduce potential impact of unmanaged risk factors. This allows people to take part in shared decision making and be more in control of their own health and wellbeing.

**13**

<sup>10</sup> Equality and diversity zone, available at: <https://learn.nes.nhs.scot/3123/equality-and-diversity-zone/essential-learning/introduction-to-equality-diversity-and-human-rights>

<sup>11</sup> Cook, A. & Grant, A. (2020) ‘From fixer to facilitator: evaluation of the House of Care programme in Scotland’, <https://www.matter-of-focus.com/house-of-care-programme-in-scotland-evaluation-report/>

## Prevention

14

Create and publish a funded plan to shift resources over the medium to long term from acute care to prevention-focused, community-based and multi-stakeholder delivered care and support, including primary care.

Explore adoption of a community 'health hub' approach to prevention and diagnostics.

A community 'health hub' model of care that is planned and implemented in collaboration with healthcare partners and the third sector, and tailored to the needs of the local community, could transform everyday spaces into healthcare settings and move preventative care from a medicalised primary care setting to places such as shopping centres, places of worship and leisure centres.

15

Accessibility is increased by providing 'walk-in' and out of hours services closer in proximity and in more familiar locations, making appointments easier and cheaper to attend while balancing work and caring responsibilities. Health hubs can also reduce health inequalities by addressing barriers to attending more traditional, centralised spaces of care faced by deprived, minority ethnic and rural communities, as well as specific social-demographic groups including carers, disabled people, and younger and older people.

Community care plays a key role in creating health value, with NHS research showing that systems that invested more in community care saw 15% lower non-elective admission rates and 10% lower ambulance conveyance rates.<sup>12</sup> The health hub approach presents a dual opportunity: for individuals, in preventing ill-health and deterioration of existing health conditions, as well as the potential to relieve long-term pressure on primary and secondary healthcare services.

16

Strengthen community-based mental health services. This will improve accessibility and promote a sense of local, easily accessible and available support. It could include integrating perinatal mental health services and support for those experiencing miscarriage or stillbirth into community settings.

<sup>12</sup> NHS Confederation (2023) 'Unlocking the power of health beyond the hospital: supporting communities to prosper.' Available at: <https://www.nhsconfed.org/publications/unlocking-power-health-beyond-hospital>

Widen access to community led self management support for people across Scotland.

17

The value of support for self management is well evidenced including through Scotland's Self Management Fund. The investment Scottish Government has made to investing in community based self management approaches is an asset to build upon, yet there is a need to support the sustainability of these approaches and widen access to support for people across the country.

Providing greater support to the third sector should be seen as an investment, not a cost. Ensuring continuity of provision for the services people rely on to help them live well and better pay people employed within the sector will improve wellbeing and keep people out of poverty. As a result, people will be less likely to need more costly emergency interventions from statutory services, including the NHS, saving money in the longer run.

18

Guarantee sustainable investment for third sector services that help prevent people's health and wellbeing from worsening and placing more demand on NHS services.

By empowering individuals with long term conditions to better manage their health and providing resources, knowledge, and support to do so, people have a sense of empowerment, healthcare practices are enhanced and ultimately, the creation of a more sustainable and effective health and care system in Scotland.

Ensure people have access to flexible, person centred nutritional, physical and psychological support before, during and after treatment as part of a continuum of care based on individual need.

19

The role of prehabilitation and rehabilitation must be elevated to reduce treatment-related complications and enable people to return or maintain a quality of life, for example for people preparing for cancer treatment, cardiovascular surgery or to support recovery including from substance use.

## People and place

Recognise that many actions that are needed to tackle health inequalities sit outwith the health and social care system; this requires a joined-up, 'health and wellbeing first' approach across multiple policy areas, e.g. transport, education, housing, poverty reduction.

Maintain a whole systems approach to reform by embedding NHS reform within the broader programme of public service reform, ensuring that equality and human rights issues are integrated into reform metrics, including taking into account the needs of remote, rural and island communities.

20

Health Boards and Integration Authorities to use existing opportunities like the Public Sector Equality Duty outcome setting/monitoring process and the Population Health Framework to identify and target population groups who may require more specific, targeted action. This should also align with existing action plans such as the Transport to Health Delivery Plan.

Public bodies should ensure that robust Equality and Human Rights Impact Assessments (EQHRIAs) or Integrated Impact Assessments are completed at the earliest possible policy/planning stage to inform and direct decision-making, as well as used to monitor and evaluate the impact of interventions. EQHRIAs are comprehensive - they allow for planning to focus both on 'at risk' population groups and all relevant rights, like the right to health.



# Appendix 1: Document overview

For this desk based literature review, the ALLIANCE team read and coded 22 documents. Below we provide an overview of each document.

## 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources' (forthcoming)

The ALLIANCE was commissioned by NHS Education Scotland (NES) to support the refresh of their person-centred care (PCC) learning resources.

The ALLIANCE engaged with the public to understand their perspectives on what good person-centred care should look and feel like. This feedback enabled NES to identify learning priorities for staff, informed by the experiences of individuals accessing services and their families or carers.

Reflections on care experiences highlighted seven key elements of PCC, including feeling heard and listened to, being treated with courtesy and dignity, feeling empowered, trusting healthcare interactions, and feeling understood by healthcare professionals. Participants emphasised the critical role of healthcare professionals' attitudes, communication, and a holistic approach in delivering effective PCC. The report also explored the negative impact experienced by those who did not receive PCC, contrasted with the positive outcomes described by those who did. Additionally, it offered suggestions for staff learning to enhance PCC delivery.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (forthcoming) 'Person centred care: what it means to me. Report to support NHS Education Scotland's refresh of their person centred care learning resources.'

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## 'Adult social care support and community health: what it means to me' (forthcoming)

This report sets out the findings of an engagement programme undertaken by the ALLIANCE in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health (SLIF). The ALLIANCE held focus groups with people with lived experience of accessing or delivering health and social care to understand how improvements would benefit people's lives, and how it might be clear that progress is being made. These explored the SLIF outcomes that: people are connected and supported in their communities; people have an active role in maintaining their health and wellbeing; people experience coordinated care and support; and the workforce work effectively together across the system.

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**Reference:** The ALLIANCE (forthcoming) 'Adult social care support and community health: what it means to me – Report to the Scottish Government in support of the Scottish Learning and Improvement Framework for Adult Social Care Support and Community Health'

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## 'Accessing Long Covid Services in Scotland: to be believed, listened to, and supported' (2024)

The ALLIANCE have established a lived experience network for people affected by Long Covid, to gather a wide range of feedback to inform the design and development of Long Covid service delivery across Scotland. Working closely with the NHS National Services Scotland (NSS) Strategic Network for Long Covid, the ALLIANCE conducted engagement with people with experience of Long Covid around why people in Scotland are disengaging from Long Covid services.

This report summarises the learning from this engagement, which found that the majority of participants did not feel that there was a service available to them to disengage from, and were hoping to see a more robust, wrap-around, holistic Long Covid specialised service in the future. People reported there should be more communication and information about services, and what to expect from that service, more widely available. This should be available for the general public and healthcare professionals, and many felt this would help in rebuilding trust.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2024) 'Accessing Long Covid services in Scotland: to be believed, listened to and supported', available at: <https://www.alliance-scotland.org.uk/blog/resources/long-covid-report-accessing-long-covid-services-in-scotland-to-be-believed-listened-to-and-supported/>

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## 'Learning from the Self Management programme' (2024)

Included in this report ('NHS Reform: Learning from lived experience') are informal quotes, findings and recommendations taken from projects funded by the ALLIANCE Self Management programme, which demonstrate the key benefits of increased awareness and adoption of self management approaches. This learning is captured within the ALLIANCE's internal reporting processes as part of the Self Management Fund programme.

## 'Cardiovascular disease (CVD) prevention: engaging those at greatest risk' (2024)

The ALLIANCE was commissioned by Scottish Government and NHS Inform to conduct engagement into the public's awareness of cardiovascular disease (CVD) and its risk factors; their preferences for accessing CVD prevention-focused information; and their experiences of using this information to take action on their cardiovascular health.

Additionally, to address inequalities within CVD risk factor awareness and management, the ALLIANCE conducted targeted engagement with groups at increased risk due to genetic, socioeconomic, lifestyle and other systemic factors, including South Asian communities, women, and people living with socioeconomic deprivation. This engagement also endeavoured to address specific challenges faced by digitally excluded people.

This engagement highlighted that people's preferences for accessing health information are shifting away from traditional text-based websites, towards shorter, video-based, and culturally relevant content on a greater range of digital and social media platforms. This change highlights the need for a new CVD prevention strategy that understand these trends; reaches people with less clinical and more accessible language; communicates creatively through storytelling; and that supports direct community outreach to deliver culturally tailored and personalised support.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2024) 'Cardiovascular disease (CVD) prevention: engaging those at greatest risk', available at: <https://www.alliance-scotland.org.uk/blog/resources/report-cvd-prevention-engaging-those-at-greatest-risk/>

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## 'National Collaborative Call for Evidence - Analysis Report Summary' (2023)

The work of the National Collaborative in the creation of a Charter of Rights for People Affected by Substance Use contributes to the Scottish Government's National Mission to reduce deaths and improve the lives of those impacted by substances. The National Collaborative is supported by a team from Scottish Government Drug Policy Division facilitated by the ALLIANCE.

This report provides a summary from a Call for Evidence launched by the National Collaborative, to gather views from around Scotland about people's experiences of substance use and human rights. Between May and August 2023, this brought together people affected by substance use, their families and people working across a wide range of services, and feedback primarily covered experiences of stigma and support services. More than 650 people took part, and the findings from this Call for Evidence were used to inform and shape a draft Charter of Rights for people affected by substance use.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2023) 'National Collaborative Call for Evidence – Analysis Report Summary' available at: <https://www.alliance-scotland.org.uk/lived-experience/engagement/national-collaborative/call-for-evidence-findings/>

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## 'Investigating knowledge and understanding of the right to health' (2023)

The Health and Social Care Academy commissioned research to investigate the accessibility of information for different groups on the right to health. The report incorporates input from organisations representing diverse communities and highlights limitations in accessing information about health rights, challenges in making complaints, and barriers faced by specific groups in achieving equitable access to the highest attainable standard of health.

The findings revealed that many people struggle to navigate the complex complaints processes, making it difficult to understand when their rights have been violated or how to seek redress. Respondents noted that only a small minority, typically those with sufficient resources, education, experience, and time, are able to lodge complaints.

A lack of trust in public institutions and services also negatively affected people's willingness to engage with information about their health rights. Additionally, respondents expressed concerns about the disproportionate burden placed on individuals to claim their rights, instead of ensuring that duty bearers proactively uphold and fulfil these rights.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2023) 'Investigating knowledge and understanding of the right to health', available at: <https://www.alliance-scotland.org.uk/blog/news/new-report-investigating-knowledge-and-understanding-of-the-right-to-health/>

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## 'National Review of Audiology Services - Engagement Insights' (2023)

In January 2022 the Cabinet Secretary for Health and Social Care announced that a National Audiology Review would be established to examine audiological services provided to both children and adults in health boards across Scotland. A distinct Reference Group was established to ensure the involvement of people with lived experience was considered by the review. The ALLIANCE worked with the Reference Group to design and deliver a programme of engagement with people in Scotland with experience of accessing Audiology Services. This was to also include multi-disciplinary professionals involved in the wider patient pathway such as teachers of the deaf and speech and language therapy professionals. The purpose of the engagement was agreed as follows:

- Capture recent experiences around quality and effectiveness in Audiology Services using the 'What matters to you?' approach.
- Better understand the patient journey and where and how improvements can be made.
- Highlight from a person centred perspective what good practice looks like to ensure consistent, high-quality experiences for those affected by deafness, regardless of service or geography.
- Understand the perspectives of those with lived experience and representative groups, and those who work with them, on what strategic changes might be needed to Audiology Services in Scotland.
- To allow input from those with lived experience of deafness and their representative groups, and those who work with them, into any recommendations for a national plan for improvement for audiology in Scotland.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2023) 'National Review of Audiology Services: Engagement Insights', available at: <https://www.alliance-scotland.org.uk/blog/resources/national-review-of-audiology-services-engagement-insights>

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## Pregnancy and Maternity Services during COVID-19' (2023)

This report sets out experiences of accessing pregnancy and maternity services in Scotland at the height of the COVID-19 pandemic between March 2020 and November 2022. The purpose of the research was to inform and influence the COVID-19 inquiry. It also highlights pre-existing systemic issues that were raised by women. The standard of care that women received was insufficient, with participants highlighting a lack of in-person support and antenatal provision, poor attitudes and treatment from staff, and the impact of staff capacity on care and treatment. Information on COVID-19 in relation to pregnancy and related services was significantly lacking, including with regard to the vaccine, and this exacerbated anxiety for many.

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**Reference:** Engender and the Health and Social Care Academy (2023) "Trauma, abandonment and isolation": Experiences of pregnancy and maternity services in Scotland during COVID-19, (2023) available at: <https://www.alliance-scotland.org.uk/blog/resources/trauma-abandonment-and-isolation-experiences-of-pregnancy-and-maternity-services-in-scotland-during-COVID-19/>

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## 'Peer Evaluator Insights Report - Macmillan Transforming Cancer Care Lived Experience Programme' (2023)

The Macmillan Transforming Cancer Care Lived Experience Programme sought ways to meaningfully involve people affected by cancer in the national Transforming Cancer Care Programme (TCC). This report contains the main themes and findings from the engagement conducted with people affected by cancer from December 2023 to April 2023. Engagement sought to gather the lived experience of different population groups in relation to overall cancer experiences, evaluation of services and barriers to accessing services. All participants were asked what they would change to improve cancer experiences either as someone accessing services for a personal diagnosis, or to provide support and care for an individual with a cancer diagnosis.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) and Macmillan Cancer Support (2023) 'Peer Evaluator Insights Report – Macmillan Transforming Cancer Care Lived Experience Programme', available at: <https://www.alliance-scotland.org.uk/blog/resources/peer-evaluator-insights-report/>

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## 'Experiences of Accessing Dental Services in Scotland' (2022)

The report identified areas for improvement and examples of good practice in delivering dental services. It highlighted the importance of ensuring lived experiences actively inform service redesign, contributing to primary care reform at both local and national levels.

To gather insights, the ALLIANCE distributed an online survey and conducted interviews with representatives familiar with the challenges faced by underrepresented groups, such as ethnic minority communities and individuals living in areas of deprivation. These methods explored barriers to access and unmet needs within these groups.

Key themes from the findings include:

- The importance of person-centred care.
- The need for accessible translation services and greater cultural awareness among dental practice teams.
- Increased public messaging to improve awareness of services.
- Challenges related to transport, including availability and cost.
- Broad support for making all dental treatments free of charge

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2022) 'Experiences of Accessing Dental Services in Scotland' [Not published – report available on request]

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## 'Disabled people, unpaid carers and the cost of living crisis' (2022)

This report looks at the impact of the cost of living crisis on individuals in Scotland. Through engagement alongside Disability Equality Scotland with disabled people, people living with long term conditions, and unpaid carers via polls and events, the report highlights some of the difficulties arising from sharply increasing costs. Considering how the crisis exacerbated preexisting inequalities, the report recommends longer term actions to address root causes and prevent similar crises from recurring in the future.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2022) 'Disabled people, unpaid carers and the cost of living crisis', available at: <https://www.alliance-scotland.org.uk/blog/resources/disabled-people-unpaid-carers-and-the-cost-of-living-crisis-impacts-responses-and-long-term-solutions/>

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## Reducing stigma, emphasising humanity' (2022)

Recognising the prevalence of stigma, three ALLIANCE programmes collaborated to explore this topic in greater detail through the event series, Reducing Stigma, Emphasising Humanity. This series explored people's experiences, key learning, current work being done to tackle stigma and practical tools, tips and resources for this. This report summarises learning generated through this series and highlights five key areas for action: encouraging open and honest conversations; co-producing anti-stigma work; training for health and social care professionals; human rights approaches; and prevention.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2022) 'Reducing stigma, emphasising humanity', available at: <https://www.alliance-scotland.org.uk/blog/news/reducing-stigma-emphasising-humanity-new-report/>

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## 'Cancer prehabilitation focus groups: Insights report' (2022)

The ALLIANCE worked in partnership with Macmillan Cancer Support from 2021-2023 to make sure that the needs and views of people affected by cancer informed and influenced the redesign of cancer services in Scotland.

The findings in this report reflect the views expressed by 14 people affected by cancer who attended four focus groups at the end of 2021, who shared their lived experience of cancer as well as their views on proposed cancer prehabilitation services in Scotland. A key recommendation from this engagement was to ensure that people affected by cancer have access to flexible, person centred nutritional, physical and psychological support before, during and after cancer treatment as part of a continuum of care based on individual need.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2022) 'Cancer prehabilitation focus groups: Insights report', available at: <https://www.alliance-scotland.org.uk/blog/resources/cancer-prehabilitation-focus-groups-insights-report/>

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## 'Exploring Scotland's 20-minute neighbourhoods' (2022)

This report gathers learning from the event series 'Exploring Scotland's 20-minute neighbourhoods' hosted by the Health and Social Care Academy, a programme of the Health and Social Care Alliance Scotland (ALLIANCE), in partnership with Disability Equality Scotland (DES) and Mobility and Access Committee for Scotland (MACS). Participants discussed people's views and experiences of 20-minute neighbourhoods including areas such as 20-minute neighbourhood including: getting around and accessing services; social connection; housing and greenspace; and designing in the community. The purpose of the series was to explore the benefits and challenges of a 20-minute neighbourhood and viewed this concept through the lens of inclusion, diversity, and accessibility.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) (2022) 'Exploring Scotland's 20-minute neighbourhoods', available at: <https://www.alliance-scotland.org.uk/blog/news/exploring-scotlands-20-minute-neighbourhoods-final-report-published/>

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## 'Shaping New Mental Health Standards - A lived experience perspective' (2022)

This report outlines the findings from engagement with people with lived experience and organisations who work with them to collect their experiences of Adult Secondary Mental Health Care in Scotland and Psychological Therapies. It was also carried out to support the development of the Scottish Government's Mental Health Standards. The ALLIANCE and VOX heard from people and organisations about what worked well when accessing services, where barriers existed and what was important to them. Comments from participants related to access, information and support, consistency of care and treatment, communications and attitudes.

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**Reference:** Health and Social Care Alliance Scotland and VOX Scotland (2022) 'Shaping New Mental Health Standards – A lived experience perspective', available at: <https://www.alliance-scotland.org.uk/blog/resources/shaping-new-mental-health-standards-a-lived-experience-perspective/>

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## 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future' (2021)

This report outlines the lived health and wellbeing experience of people living in Scotland during COVID-19 pandemic. It provides insights into how they have viewed health and care services and shares their experiences and stories. The document also highlights that people experienced patterns of experience including:

- reduced and disrupted access
- poor communication being a barrier to accessing healthcare
- health inequalities were exacerbated with population groups disproportionately impacted
- reduced person centred care
- responsive services
- the important role of the third sector and communities
- better partnership working

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**Reference:** Health and Social Care Alliance (the ALLIANCE) (2021) 'Health, Wellbeing and the COVID-19 Pandemic: Scottish Experiences and Priorities for the Future', available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2021/02/Health-Wellbeing-and-the-COVID-19-Pandemic-Final-Report.pdf>

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## 'My Path, My Life, My Right to Live Well' (2021)

This report contains an analysis of people living with chronic pain across Scotland. The ALLIANCE wanted to understand what steps can be taken to ensure equal access to chronic pain services across Scotland. Respondents were asked to think about how chronic pain impacts their day-to-day life and what importance they place on more public information about what chronic pain is, its impact on people in Scotland and how to access support.

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**Reference:** Health and Social Care Alliance (the ALLIANCE) and University of the West of Scotland (2021) 'My Path, My Life, My Right to Live Well', available at: <https://www.alliance-scotland.org.uk/wp-content/uploads/2021/11/My-Path-My-Life-My-Right-to-Live-Well-November-2021-1.pdf>

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## 'My World, My Health - insights from a dialogue on data with the Scottish public' (2021)

The My World, My Health project aimed to explore how people living in Scotland felt about data on wider determinants of health being used within public and health services. The ALLIANCE wanted to broaden the general thinking on this topic by considering the wider factors that influence people's wellbeing and what data is linked to these factors. We also wanted to consider how this data might be used by different services to provide better outcomes for individuals and society and understand what public attitudes would be about these matters.

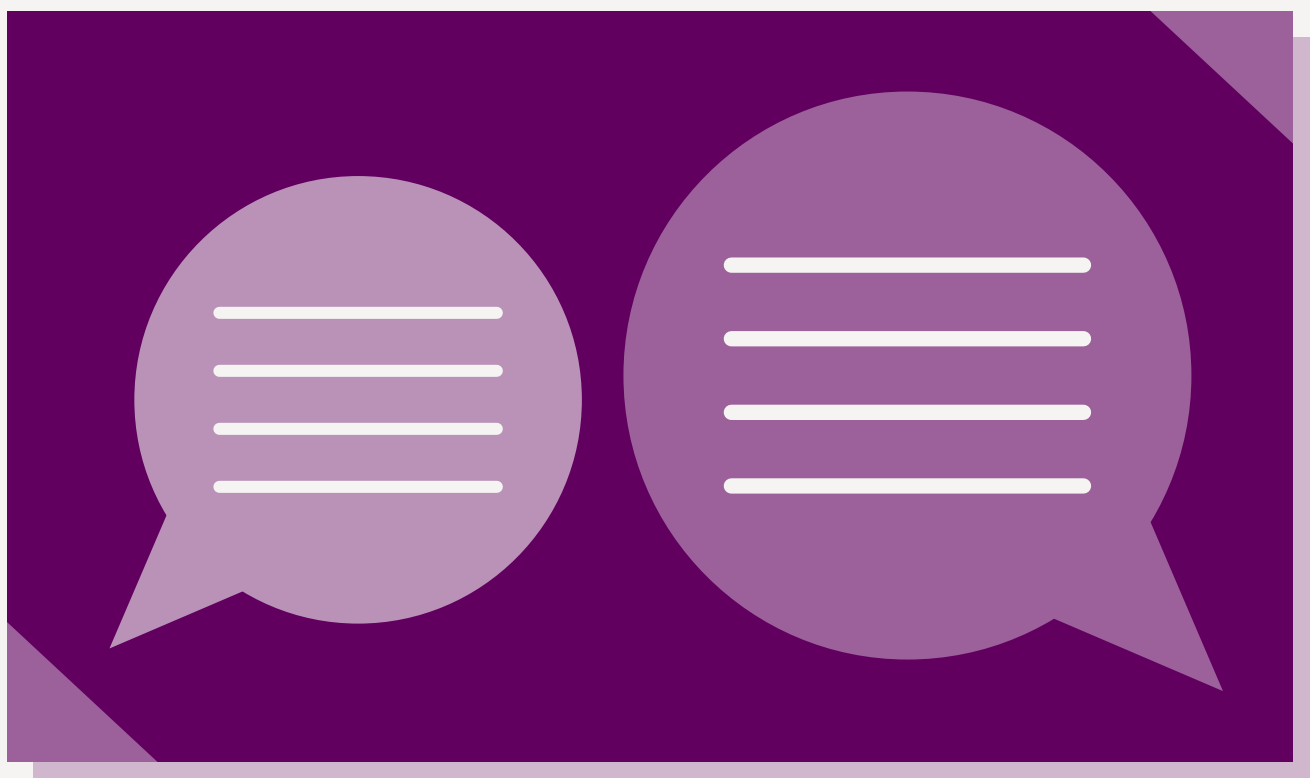
The research set out to explore the following questions over the course of the project:

- 1.** What factors contribute to individuals' wellbeing - "what keeps you well?"
- 2.** Reflecting on the above, what types of data are people more willing to share, with whom and in what contexts?
- 3.** How can data on determinants of health be used in practical ways for public health and preventative approaches?
- 4.** What trade-offs are people willing to make around data and health/wellbeing?
- 5.** What safeguards do people want around this type of data collection and sharing?

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**Reference:** Health and Social Care Alliance (the ALLIANCE) and Digital Health & Care Innovation Centre (2021) 'My World My Health: Insights from a dialogue on data with the Scottish public', available at: <https://www.alliance-scotland.org.uk/blog/resources/my-world-my-health-report/>

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## 'Your GP and You: ALLIANCE workshop summaries' (2018)

These reports are summaries of workshops facilitated by the ALLIANCE. As part of these engagement workshops, patients, third sector and NHS staff gathered to discuss the implications of the then new GP contract on their access and use of primary care services and support. A number of themes recurred in the conversations:

- People were openly challenging around the budget set aside for this fundamental change in Primary Care.
- People felt that while it makes sense that more professionals will be centred on the GP surgery, they were unsure where these professionals were going to come from (the group referenced reports/articles around NHS staff shortages already).
- People were worried that with a wider variety of Primary Care options (pharmacists first, NHS Inform, etc...) some sections of society will not know where to go (people who are digitally excluded).

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**Reference:** Health and Social Care Alliance (the ALLIANCE) (2018) 'Your GP and You: ALLIANCE workshop summaries', available at: <https://www.alliance-scotland.org.uk/blog/resources/your-gp-and-you-alliance-workshop-summaries/>

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## 'Experiences of Transitions to Adult Years and Adult Services' (2017)

The aim of this report was to inform improvements in transitions by highlighting themes and suggestions arising from people's lived experiences. Central to the research was assessing people's experiences of the implementation of the Getting it Right for Every Child (GIRFEC) approach and how it was applied in practice. Key recommendations from the report include the need to improve information, training, outreach and resourcing.

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**Reference:** Health and Social Care Alliance Scotland (the ALLIANCE) and the Scottish Government (2017) 'Experiences of Transitions to Adult Years and Adult Services', available at: <https://www.alliance-scotland.org.uk/blog/resources/experiences-of-transitions-to-adult-years-and-adult-services/>

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## 'Creating a Healthier Scotland: What Matters to You' (2016)

On behalf of the Scottish Government, the ALLIANCE behalf work on what a healthier Scotland would look like. This report was a summary of what people told us about their views and experiences of health and social care, and what they would like to see happen in the future. For example, they spoke about lifestyles, diet, mental health and wellbeing that affect them and their families. They also told us about caring for relatives and supporting people to live independent lives. The key question members of the public were asked were:

1. What support do we need in Scotland to live healthier lives?
2. What areas of health and social care matter most to you?
3. Thinking about the future of health and social care services, where should our focus be?

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**Reference:** Health and Social Care Alliance (the ALLIANCE) (2016) 'Creating a Healthier Scotland: What Matters to You', available at: <https://www.gov.scot/publications/creating-healthier-scotland-matters/documents/>

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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 3,700 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.

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## 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.

