

“ A real, grown up conversation

Research on health and social care in Scotland



Contents

Executive summary	1
Aims	1
Method	1
Findings	2
Conclusions	3
Research aims and approach	4
Context	4
Participants	5
Deliberative sessions: a summary	6
Evolving views on health and social care	8
Trajectory of views	8
Session 1 - Experiences of health and social care	9
Session 2 - Person centred care	10
Session 3 - Finance and funding	11
Session 4 - Innovation	11
Session 5 - Policy and communications	12
Health and social care balance	13
Health and social care in Scotland today	17
Importance of health and social care	18
Perceptions of quality of care in Scotland	19
Views on what quality care consists of	20
Access and parity	23
Pressures facing health and social care	26
Prevention focused system	28
Complexity	28

Health and social care in the future	31
Openness to change and reform	32
Enablers for improvement	34
Innovation	36
Priorities for the future	37
Roles and responsibilities	39
Conclusions	42
Bridge the gap	43
Smart and transparent investment	44
Person centred care	44
Engagement and communication	45
Appendix A: Glossary	46
Appendix B: Overview of deliberative sessions	56
Session 1 - Experiences of health and social care	58
Session 2 - Person centred care	59
Session 3 - Finance and funding	60
Session 4 - Innovation	61
Session 5 - Policy and communications	62
About the Health and Social Care Alliance Scotland	64

Executive summary

Aims

The Health and Social Care Alliance Scotland (the ALLIANCE), a national membership organisation representing people, communities and the third sector across health and social care, wanted to better understand people's views on health and social care, what matters most to them, and their appetite for change.

To do this, the ALLIANCE commissioned Diffley Partnership to deliver a deliberative research project; a method of research that involves engaging participants in meaningful discussion, weighing up evidence, and considering different views.

The project included recruitment and management of a panel of residents in Scotland to engage with deliberative research sessions held between November 2025 and March 2026. This project aimed to increase understanding of:

Residents' views on health and social care, and what informs their views

Which issues are important to people and why

People's appetite for change and reform of health and social care

Whether and how views develop in relation to information and stimulus materials

Method

A combination of online and in-person sessions were themed as follows:

Session 1	Experiences of health and social care
Session 2	Person centred health and social care
Session 3	Funding and spending
Session 4	Innovations
Session 5	Policy and communications

Findings

Over the course of these sessions participants' views evolved from experience-led frustration to informed, system-level reflection.

Early discussions focused on personal experiences, both positive and negative, of accessing health and social care services; later sessions demonstrated greater awareness of structural constraints, governance complexity and the importance of prevention. By the final session, participants were able to engage constructively with difficult trade-offs, indicating increased confidence, system understanding and collective reasoning.

Across the five sessions, opinions evolved in four main ways:

From individual experience to system awareness

From frustration to informed critique

From idealism to delivery realism

From passive expectations to understanding of shared responsibility and trade-offs

Session 1 - participants entered the process with high concern but low systemic framing. Expression of views were grounded in lived experience coupled with feelings of frustration about health and social care in Scotland. Opinions were valid and strongly felt.

Session 2 - this session helped participants see health and social care through a person centred lens. By this point, opinions had moved from grievance to diagnosis.

Session 3 - participants were more system-literate and less reactive. Therefore, this session brought discussions on funding, governance and political realism.

Session 4 - during this session participants were focused on ways to ensure prevention and rebalancing the system.

Session 5 - this final session marked the most pronounced change in how opinions were formed. Participants demonstrated capacity to debate universality vs means testing and weigh fairness against affordability. They displayed acceptance that trade-offs are unavoidable. Decisions were explicitly framed as principled, not just personal, and collective, not individual. There was stronger articulation of desiring health and social care to ensure dignity and equity for the population and be planned for long-term sustainability.

Participants used more balanced language as they weighed up considerations. They qualified their views with “it depends” before explaining the conditions their suggestion may work under. This was also the session where opinions matured from preferences to considered judgements. In summary the participants understood trade-offs, universality and collective responsibility.

Notably, social care gained salience over time, but rarely displaced health care as the narrative anchor. This reflects the NHS’s visibility, universality and prominence in public debate, rather than a lack of concern for social care. Less regularly mentioned, social care was often discussed through specific experiences, for example care for relatives, experience as unpaid carers and discharge delays. Discussions of social care featured more strongly when prompted, for example when asked about social care workforce parity, prevention and digital technology.

Conclusions

This research strengthens the case for reform grounded in both values and practice.

Our conclusions can be summarised as follows:

Bridge the gap - participants see a gap between how the system should be and the current reality. They understand that bridging the gap takes change and reform, rather than striving to improving things as they are.

Smart and transparent investment - participants thought it was ethically and economically sensible to direct funds towards prevention and consider the distribution of spend between health care and social care services. Deliberation revealed a greater public appetite than often assumed for honest conversations about limits, trade-offs and sustainability, including how universality and needs might be balanced in practice.

Person centred - participants strongly supported person centred, preventative and equitable care.

Consider language - participants discouraged professionals using terms like burden or reducing people to numbers. Participants placed particular weight on respectful language, and feeling listened to, stressing the emotional dimensions of care often missing from system reform debates.

This deliberative project aligns with the ALLIANCE’s priorities especially their strategic priority of increasing meaningful involvement and impact of people with lived experience.¹ The research findings add valuable insight into how the public understands feasibility, fairness and implementation. These findings strengthen the case for reform by demonstrating both principled support and informed realism among the public.

¹ [Strengthening our Collective Voice - Health and Social Care Alliance Scotland](#)

Research aims and approach

Context

According to Audit Scotland, 40% of the Scottish Government Budget for 2023/24 went to health care.² Health care and the NHS regularly rates as a top issue facing Scotland.³ Based upon recent UK data, the top priority for health care is making it easier to get appointments at GP practices (39%), followed by improving A&E waiting times (34%) and reducing the number of staff leaving the NHS by improving working conditions (29%). Improving waiting times for routine hospital services ranks fifth (25%) for the public.⁴ This indicates health care is a priority and there is appetite for improvement.

The Independent Review of Adult Social Care in Scotland (2021) encouraged 'shifting the paradigm' to a social care system that is sustainable, high-quality, and centred on enabling people to live well.⁵ Brunner and Wallace (2025) explain this shift requires building public understanding of adult social care, understanding it as an essential and valuable service that benefits all of us, and to increase public demand for change.

Because coverage of debates on health and social care reform can fail to capture complexities, the ALLIANCE was interested in understanding the depth and nuance of public views. In particular they wanted a research project to explore:

Views of residents in Scotland on health and social care, and what informs their views

Which issues are important to people and why

People's appetite for change and reform of health and social care

Whether and how views develop in relation to information and stimulus materials

Diffley Partnership was commissioned to deliver a deliberative research project for the ALLIANCE.

The project included recruitment and management of a panel of residents in Scotland to engage with deliberative sessions held between November 2025 and March 2026. This report includes findings from the research and resulting conclusions.

² Transforming health and social care in Scotland | Audit Scotland

³ Understanding Scotland Economy Tracker - May 2026 - Understanding Scotland

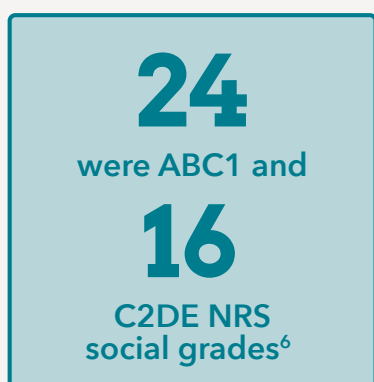
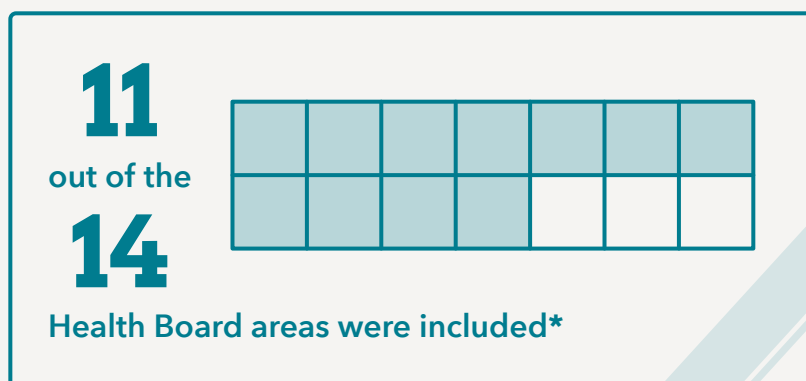
⁴ Mind the gap: public perceptions of the NHS and social care | The Health Foundation

⁵ Supporting documents - Adult social care: independent review - gov.scot

Participants

A panel of residents in Scotland was selected and recruited to represent a range of demographic, geographic and attitudinal factors. Recruitment was largely through a ScotPulse survey in October 2025 with 2,171 respondents, and supplemented by the research recruitment agency, Taylor McKenzie.

Of the 40 participants taking part in the deliberative research project:



*except Fife, Western Isles or Shetland

Diffley Partnership managed the panel, providing a regular a point of contact, and information on the research process and sessions, and addressing queries from individuals.

⁶ See Glossary in Appendix A for more information on these social grade classifications.

Short feedback forms after each session meant their suggestions fed into the later sessions. The final feedback displayed participants' enjoyment and interest:

“ I enjoyed the learning aspect of everything - thinking bigger picture instead of your own circumstances.

“ The interaction in small groups was very interesting as it covered all aspects of the subject and some other external influences.

“ I felt really involved and able to make any points I wanted to make without judgement.

“ Thank you for your efforts in involving us and listening to our thoughts and opinions.

Deliberative sessions: a summary

Five deliberative sessions were organised for Saturdays between 1 November 2025 and 7 March 2026. The first session and third session were online, and the rest were in-person. For both types of session there was a combination of presentations, discussions in groups and activities.

Session themes were as follows:

Session 1	Experiences of health and social care
Session 2	Person centred health and social care
Session 3	Funding and spending
Session 4	Innovations
Session 5	Policy and communications

Session content was designed to provide time and space for participants to consider a variety of sources, and session order to follow a logical path through learning and discussion. See Appendix B for more details of each session.

Discussions and activities were facilitated by Diffley Partnership to ensure a diversity of views and discussions not dominated by any individuals. These discussions were prompted by open questions and carefully considered prompts. These activities were carefully designed, drawing upon relevant published sources of information.

Sessions included presentations, including by the ALLIANCE and external experts. Slides were shared with participants following each session so they could further digest in between sessions.

Analysis started after the first session and climaxed in preparation of this final report. Where possible, this report uses plain English, but also contains a Glossary of key terms in Appendix A.



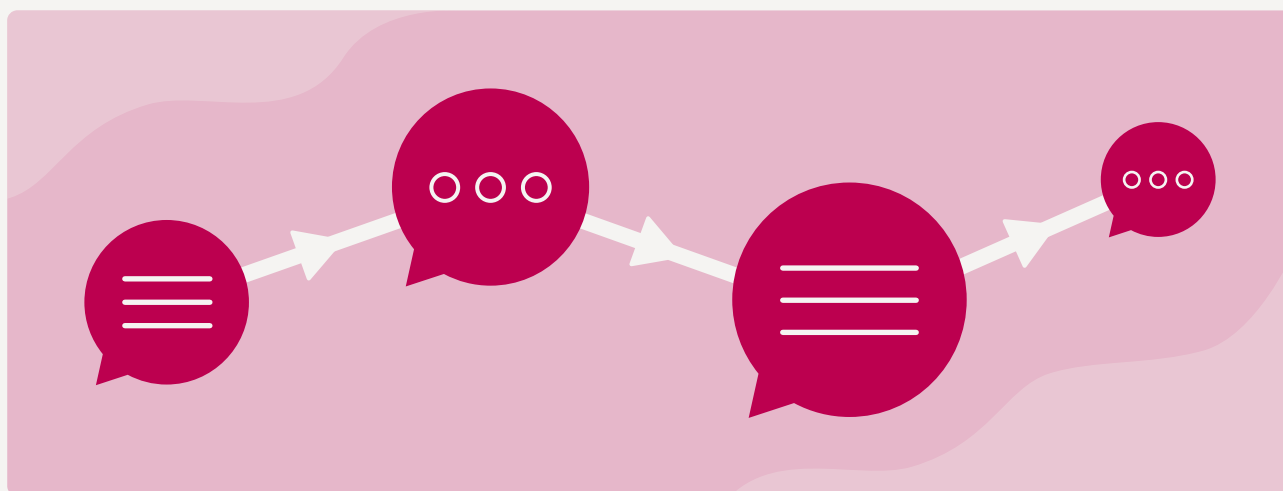
Evolving views on health and social care

This chapter explains how participants' views on health and social care developed during the deliberative project and then explains the balance in emphasis between health care and social care.

Trajectory of views

Over the course of the deliberative process, participants' views evolved from experience-led frustration to informed, system-level reflection.

Early discussions focused on personal encounters with health and social care services and challenges accessing these. Later sessions demonstrated greater awareness of structural constraints, governance complexity and the importance of prevention. By the final session, participants were able to engage constructively with difficult trade-offs, indicating increased confidence, system understanding and collective reasoning.



Across the project, we saw:

- Increased system literacy
- Reduced inclination to assign simple blame
- Greater acceptance of constraint and trade-offs
- More confidence in discussing policy options
- Shift from individual rights alone to collective outcomes

Notably, social care gained salience over time, but rarely displaced health care as the narrative anchor.

Across the five sessions, opinions evolved in four main ways:

From individual experience to system awareness

From frustration to informed critique

From idealism to delivery realism

From passive expectations to understanding of shared responsibility and trade-offs

This was not linear for every participant, but it was visible at group level. The sections below explain the trajectory for each session further.

Session 1 - Experiences of health and social care

Session 1 had been framed to ensure people could express their existing views and experiences of health and social care. Therefore, the dominant mode of this session was personal, experiential and emotive.

Participants did anchor their views almost entirely on direct experience of health care, especially on:

Waiting lists

GP access

Staff shortages

The impact of ill health on work, family and mental wellbeing

At this stage health and social care was seen as universally important, but mainly through the lens of things going wrong. Also, social care appeared mostly indirectly (discharge delays, caring for relatives).

Quality was understood as uneven and postcode dependent, but reasons for this were unclear. Blame was often diffuse – “the system”, “cuts”, “politics” – rather than structural.

This session was also where the NHS emerged as the implicit focal point. Dissatisfaction was expressed alongside recognition of high spending.

In session 1, early political frustration surfaced, but without a clear reform direction.

Participants entered with personal concerns rather than high-level policy analysis. Session 1 gave voice to valid, strongly held frustrations with Scottish health and social care, grounding the dialogue firmly in everyday lived experience.

See Appendix B for more detailed content about the session.

Session 2 - Person centred care

Exposure to people who use support and services and practitioner narratives shifted opinions in important ways. The mode was reflective, rational and value driven.

Participants began connecting physical health, mental health, relationships and social context.

The concept of person centred care expanded understanding beyond clinical treatment to:

- Continuity
- Coordination
- Respect
- Being listened to
- Holistic support

Frustrations became more specific towards lack of continuity in care, unclear accountability and needing to “re-tell my story”.

Crucially, this session marked recognition that good intentions exist, but the system makes person centred care difficult to deliver.

Participants shifted their focus from individual staff performance to systemic pressures, including workload, time constraints, and service design. Rather than simply writing off care as poor, discussions matured to recognise that an overstretched system actively prevents staff from delivering good care, distinguishing compassionate values from broken delivery conditions.

In summary, session 2 helped participants see health and social care through the lens of person centred care.

[See Appendix B for more detailed content about the session.](#)

Session 3 - Finance and funding

The mode of participants was analytical, pragmatic and sceptical.

Discussion of funding mechanisms prompted more realistic assessments of constraint and frustration with complexity rather than outright underfunding alone.

Key shifts included awareness that high spending does not automatically mean good outcomes. In addition, increased concern was expressed about fragmentation, opaque funding flows and mismatch between national priorities and local delivery.

Not strongly present earlier, there was critical attention on governance and bureaucracy.

Importantly participants did not simply call for “more money”, they asked where money goes, who decides and who is accountable.

By this point, opinions had moved from grievance to diagnosis. This was the first session where participants voiced the need for increased focus on prevention. Participants were more system-literate and less reactive. Therefore, this session brought discussions on funding, governance and political realism.

[See Appendix B for more detailed content about the session.](#)

Session 4 - Innovation

By session 4, participants were strategic and future-oriented. Key developments were a strong consensus that the system is too reactive, and acceptance that investment in prevention is morally preferable and economically sensible but currently underprioritised.

Participants began thinking in population terms, not just individual terms. Language and framing used by health and social care stakeholders came under scrutiny, for example, they were uncomfortable with the use of the term ‘burden’ within a report title one presentation referenced.⁷

⁷ Discussed in relation to [Scottish Burden of Disease Study - Scottish Burden of Disease Study - Publications - Public Health Scotland](#)

Participants expressed growing empathy for frontline staff trapped in constant "firefighting" mode. Crucially, they recognised that current system structures actively hinder joint working, preventing professionals across different services from functioning as a cohesive team.

Participants moved from "why isn't it working for me?" to "how should the system be designed to reduce harm overall?". Therefore, in session 4 participants were focused on ways to ensure prevention and rebalancing the system.

See Appendix B for more detailed content about the session.

Session 5 - Policy and communications

The final session marked the most pronounced change in how opinions were formed.

Participants demonstrated capacity to debate universality versus means testing and weigh fairness against affordability. They displayed acceptance that trade-offs are unavoidable.

Decisions were explicitly framed as principled, not just personal, and collective, not individual.

There was stronger articulation of desiring health and social care to ensure dignity and equity for the population and be planned for long-term sustainability.

Participants used less absolutist language as they weighed up considerations; they qualified their views with "it depends" before explaining the conditions their suggestion may work under.

This was also the session where opinions matured from preferences to considered judgements.

Participants showed they could hold competing values simultaneously.

In summary, the participants understood trade-offs, universality and collective responsibility.

See Appendix B for more detailed content about the session.



Health and social care balance

While participants consistently recognised the importance of both health and social care, discussions were more heavily weighted toward health care. This reflects the NHS's visibility, universality and prominence in public debate, rather than a lack of concern for social care.

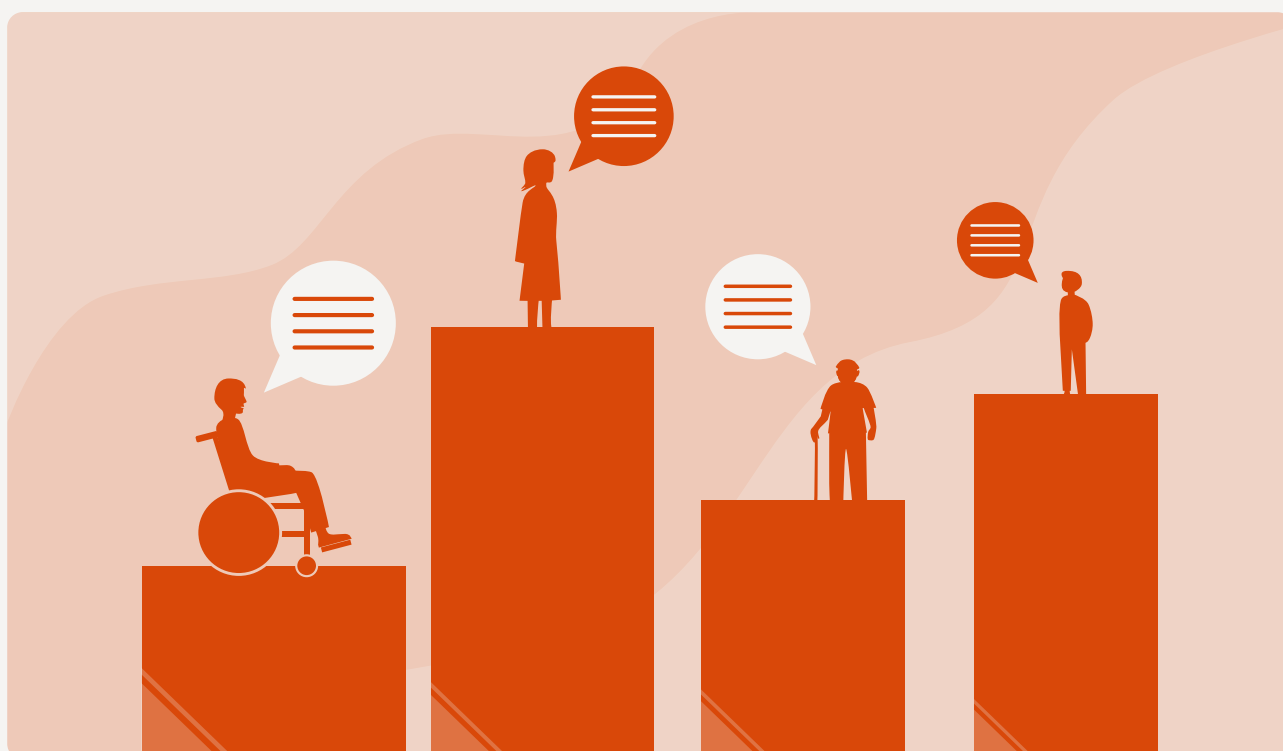
When prompted, participants articulated strong views on social care quality, workforce, consistency and fairness, often linking it directly to wider system pressures and person centred outcomes.

Health care (especially the NHS, GPs, hospitals, waiting lists, diagnosis) dominated discussions, with:

Early framing of importance and quality

Critiques of access and continuity

Discussions of funding, politics and public satisfaction



Social care appeared less regularly. It was often through specific experiences, for example care for relatives, experience as unpaid carers and discharge delays. Discussions of social care featured more strongly when prompted, for example when asked about social care workforce, parity, prevention and digital technology.

Five reasons for this emphasis on health care are examined below.

Health care is the most visible and universal public touchpoint

When participants talked about “health and social care”, they defaulted to:

- GP access
- Waiting lists
- Diagnosis delays
- Hospital and NHS experiences

This reflects near-universal contact with health services, clearer institutional identity (the NHS), and stronger public narratives around crisis and performance.

“ I think we all know we will need a doctor at some point, but don’t think so much about social care.

Unlike the NHS, social care is rarely perceived as a single, cohesive system. Participants primarily encountered social care indirectly through supporting family members, often viewing it as a service needed later in life rather than a universal, lifelong support mechanism.

Therefore, health care often framed the conversation, even when the intent was holistic.

Social care was present but usually as a pressure point rather than a system

When social care appeared, it was often in relation to health service strain:

- Delayed discharge from hospital
- Inability to assemble care packages
- Unpaid carers filling gaps
- Workforce shortages and low status

This suggests participants were aware of social care's importance but experiencing it mainly as an upstream or downstream constraint on health care rather than as a system in its own right.

In other words, social care mattered most when it failed or blocked health outcomes.

Person centred care discussions pulled focus back toward clinical encounters

Although participants defined person centred care holistically (including social care, transport, home support, mental health, community activities), their examples of poor practice tended to centre on:

- **GP appointments**
- **Fragmented diagnosis**
- **Retelling medical histories**
- **Being dismissed in requests for tests as "too young"**

This reflects where people feel least heard, most time-pressured and most disempowered.

Social care examples, by contrast, were often more positive (praise for carers) but less system-wide.

NHS politics overshadowed social care reform

Political discussion gravitated toward:

- **NHS funding levels (40% of Scottish budget)**
- **Falling satisfaction despite investment**
- **Health care being used as a "political football"**

Social care politics – including the National Care Service⁸ – appeared more indirectly, and later, often framed as uncertain, stalled and complex.

This mirrors wider public discourse: NHS debates are more prominent, polarised and familiar.

⁸ For more information on The National Care Service see - [The National Care Service – Where Now? - Health and Social Care Alliance Scotland](#)

Prompts mattered – social care surfaced more when structured activities made space for it

When the deliberative process explicitly invited consideration of social care, it came forward strongly. Participants discussed:

- Adult social care consistency
- Social care workforce parity
- Digital care technology
- Concerns about unpaid carers
- National vs Local standards

This suggests the issue was not lack of concern but lack of spontaneous system-level framing.

Comments in feedback showed that participants were thinking themselves about the balance in their thought and discussions during the sessions.

“ Our group began to touch on the differentiation between what is defined as health care and social care - almost an artificial if not arbitrary divide.



Health and social care in Scotland today

This chapter is organised into key topics on current health and social care discussed and deliberated by participants during the sessions, summary of their views, and quotes. Key topics included:

Importance of health and social care

Perceptions of quality care in Scotland

Views on what quality care consists of

Access and parity

Pressures facing health and social care

Complexity



Session 1	Experiences and impressions of health and social care
Session 2	Person centred health and social care
Session 3	Funding and spending
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Importance of health and social care

Right at the start of session 1, there was unanimous agreement that health and social care is important for Scotland. Participants saw it as a vital resource, used by everyone at some point in their lives.

Many participants discussed the demographics of Scotland, particularly an ageing population, as affecting current and future demand levels for health and social care.

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

When discussing health care, participants tended to focus more upon experiences and implications of poor health. For instance, some mentioned the impact of ill-health on the wider economy, particularly where working-age adults are unable to carry out their roles while on waiting lists for treatment.

Session 2 presentations prompted participants to discuss the ripple effect of poor physical health on their mental health and relationships with others. For instance, one participant shared how their health condition means they are unable to work, and discussed the shame and stigma of being unemployed, impacting their self-worth.

Throughout the sessions, health and social care were described as exceedingly important for participants for their own quality of life and for Scotland's success.

Perceptions of quality of care in Scotland

In session 1, when asked about quality of health and social care, there was acknowledgement that this varies in different parts of the country and for different types of services:

“Something could work really well for someone who lives a few towns over, but in your area it might not be so great and something different might be great for you and bad for them. So, I think it's one of these things where it's hard to say such and such is great all over.

Participants saw a plethora of factors as negatively impacting the quality of health and social care; some perceived a lack of competent staff, a lack of adequate staffing numbers and cuts to finances.

People with experience of social care for friends and family members were highly complementary of carers, describing them as professional and skilled. Community pharmacists were also praised for helping with minor ailments.

The first presentation delivered by the ALLIANCE focused on the current system structures in place for health and social care in Scotland. Participants reflected on the significant investment into the health care system, noting the Audit Scotland finding that 40% of the Scottish Government Budget for 2023/24 went to health care is in contrast with low satisfaction with the NHS (Scottish Social Attitudes Survey⁹). They acknowledged increasing demands on the public health care system, which now sits in a vastly different landscape from when it was originally founded.

There was a sense that it will struggle to continue in its current form, with some panellists noting a need to evaluate the services offered.

“It was quite alarming when you see the amount of money being poured into the system. [...] I think there needs to be a real grown up conversation about what's being funded. Because the National Health Service was set up over 75 years ago and diseases have evolved, treatments have evolved, it's becoming a bit of a beast. Politically, it becomes a football but we need to take it out of that spectrum and have a real grown up conversation about what services are provided.

In session 2, thinking about the challenges facing health care today, and reflecting on the practitioner's presentation about their experience with person centred care, several participants felt that there is little to no continuity in care. This included in primary care, particularly where “family doctors are no longer the norm”. For this reason, participants saw a need for people to have more time with their GP's and wider funding to deliver the desired level of care.

⁹ <https://www.gov.scot/collections/scottish-social-attitudes-survey/>

“ I receive secondary care for a lifelong condition. Over the past 3 years of twice-yearly check-ups, I'm yet to see the same person twice. I've also never had a face-to-face appointment with any of my GPs – I don't even know what they look like, but they do sound nice on the phone.

As emerged in earlier discussions, participants noted how some factors can impact the extent to which health care providers, in particular, approach diagnosis and treatment. These included people who use support and services being told they are 'too young' for certain conditions, leading to further problems, diagnosis at a later stage, and potentially poorer outcomes.

The presentation on individual experience of person centred care by a patient representative really resonated. Some participants shared their frustrations in having to "retell [their] story" to different professionals and being "bounced around different NHS services". Others without direct experience themselves still expressed sympathy and disappointment that our system has barriers to diagnosis and treatment for long-term health conditions.

Views on what quality care consists of

In the first discussion in session 2, taking place before any stimulus, facilitators at each table asked participants for their initial impressions of what person centred care could be. There were a number of interpretations, and a few participants said they had not heard the phrase before. Their ideas of what it could mean were: care centred around the individual, the individual being listened to and respected by professionals, a holistic package of care across health and social care. Some participants displayed their preferences for care as they age, such as "helping you stay in your own home" and "a budget available to run own care plan".

After the ALLIANCE presentation giving an overview of what person centred care is some saw this as a useful approach. Importantly, participants found it difficult to reconcile with the reality of the current health and social care system and their own experiences. Generally, it was felt that people in Scotland are not receiving person centred support, or at least not in all areas of Scotland. Person centred care was received as an "ideal world" scenario.

During their deliberation, they referred back to the complexity of the system, and the patchwork of provision in different parts of Scotland, discussed in the first session, as major barriers to person centred care. Echoing back to concerns in the first session, some groups discussed challenges in identifying who is responsible and accountable for any one person who accesses support and services, therefore making it difficult to resolve issues or complain if person centred care is not experienced.

They also raised examples of interaction with health care professionals which was at odds with person centred care. For example, their GP practice having a policy of "one person, one problem" so they could only discuss one health issue at each appointment.

Participants also emphasised how all agencies and individuals involved in a case need to work together to ensure a positive outcome, and that “one person in the chain not doing it [delivering person centred care] well can throw off the whole thing”.

After hearing the expert presentation from the practitioner on person centred care, participants agreed that the health and social care system needs to change in order to provide more person centred care.

They felt that the current system is complicated, particularly where access to some general practices is made more difficult by specific ways of, and time periods for, making appointments:

“ Appointments haven't even recovered post-pandemic, how can we change if we can't even get back to baseline after 5 years?

Some felt that an increasing level of responsibility for health and social care is placed on a person's family and friends, who are non-specialists and not paid for their work. While their input may be valuable to the principles of person centred care, some participants were concerned that this expectation placed a burden on unpaid carers.

Participants also discussed the ‘person centred, strengths-based approach’- which involved the consideration of physical, environmental, financial, spiritual, vocational, psychological/emotional and social factors support that could improve a person's life. Some felt this approach could be “unmanageably complex” and was potentially “good in theory, but difficult in practice”. They worried that GPs are already under immense strain and may struggle to integrate this approach into their work.

Taking part in a final exercise in session 2 of what person centred care means to them, participants raised several attributes of good person centred care:

- Personal, tailored care, designed for them and their medical and health needs was commonly mentioned, as they felt they should be treated as whole individuals, not in a “one size fits all” manner
- Some also felt that personal circumstances should also be factored into the approach to providing treatment
- Others felt that good person centred care meant that professionals took time to speak with people accessing their service and were fully informed not only about their medical needs but also their background and any issues that mattered to them. Having the time to process and to ask any questions they might have about their treatment was also deemed important
- Being listened to was seen as key to good person centred care. Participants were keen that their views, feelings, and concerns are being taken into account. This needed time, good listening skills and a sympathetic ear, which would help people feel as though they are being taken seriously, and their input is of value to providers

- On-going support and follow-up were raised. Participants wanted reassurance that they could easily access follow-up support, whether that be from the health service but also from third parties, peer groups or other services
- The phrase “Putting the patient first” was frequently mentioned, whereby the individual should be the focus throughout the process of their diagnosis, treatment, and care. Indeed, “feeling part of the treatment process” was cited by several participants, in order to have a sense of agency
- Some expressed a feeling of wanting to be treated with respect, to have their views, needs, and circumstances considered. There was a sense that, if this respect was in place, outcomes could be improved
- There was a desire for joined up/end-to-end care, meaning that there would be no “gaps” in the care or treatment they received. Participants wanted to avoid feeling as though they were being passed from “pillar to post”, but part of a coordinated programme where all professionals involved would work in harmony to provide the best treatment and outcome
- Some participants felt that seamless access to information would make it easier for individuals, and professionals, to be fully informed about decisions on care.



Participants explained how good person centred care could feel:

- Participants associated good person centred care with a range of positive feelings, including a sense of safety, reassurance, empowerment, and being valued, listened to and heard
- Many linked person centred care with feeling that their views mattered and that they were respected and valued as an individual
- Some participants felt good person centred care would help them feel reassured and at ease about the process, plan and outcome, particularly if this approach was the norm rather than the exception
- Feeling more actively involved in their care was also seen to increase participant’s confidence in discussing their care, offering further benefits.

Quotes below sum up what participants desire for person centred care in Scotland:

“ Taking notice of the patient's feelings. Taking account of the patient's overall needs and situation.

“ Being considered as a complete human being, not as collection of my symptoms and conditions.

“ Time to enable me to speak about issues and full involvement in treatment pathway.

“ Given time to process information and ask questions about my care.

Access and parity

Ensuring people get access to the care they need was a major topic of conversation for participants.

In session 1, stories were shared on difficulties of accessing care. A few participants perceived non-medical staff, namely GP receptionists, as important in determining their access to care. GP receptionists were generally seen as 'gatekeepers' to primary care.

“ Even between local practices, like a ten or fifteen mile radius, it's vastly different in terms of being able to be seen for [GP] appointments. A lot of times it can be Pharmacy First and if you need an appointment the receptionist will decide who you need to see, even when it's probably the wrong service, or go through a questionnaire with you to decide what you need.

People explained how advocates are essential to get access to health care and gave examples of where persistence had resulted in being able to see medical professionals and get treatment. There were descriptions of "getting into the system" and then getting to see the right part of the system as being difficult, even if subsequent treatment was high quality. Being passed around parts of health care, and having to re-explain health concerns and continuously advocate was described by a few participants. This led to people having concerns about inequalities of access and the barriers that people who may not be able to advocate for themselves may face.

The ability to access quality mental health support was described as a major challenge for Scotland, given a higher demand for services post COVID-19 pandemic.

One participant shared their attempts to access this, and how their experience differed to that of their partner.

“ I think there could be more done for mental health because I think it's really oversubscribed, and I know when I've asked for help, they've given me something temporary, like three sessions with somebody and then that's it – like there's nothing ongoing. Yet I think if you're in the system then you get it, because my husband gets support. But it's getting into that system – there's a huge waiting list which I've never quite managed to break into.

Access was discussed again in session 2. Some participants acknowledged strengths of peer support in hearing the perspectives of others who are in the same position as them, with one describing it as a “game changer”.

While these participants were largely part of online groups for peer support, they felt that this is mainly on a localised scale.

“ It's less common to be able to connect with peers or people with other conditions on a national scale.

In session 5 participants reviewed a list of services selecting those they think should be universal (for everyone) and which should be means-tested (on income). They then discussed their considerations and thought processes. Discussions were respectful and all tables managed to come up with a list of services they thought should be universal and those which could be means tested. These findings should not be taken as representative or used to inform decision makers. Rather, the exercise shows how members of the public can have difficult conversations and come to informed choices.

Arguments for universal services included:

- Those who selected universal services said their decisions would not change if budgets were reduced, as “it's about principles, not budget circumstances”.

Arguments for means testing included:

- Many participants said their choices were led by their own personal views and experiences.

Suggestions were made to factor in needs-testing rather than means-testing.

Turning more to parity, in session 1 discussions naturally turned to the availability of social care, describing this as a “patchwork”, with the perception that local authorities set different standards and have different services available. Concern about availability of social care services where they live was expressed especially for those outwith large cities.

Another point of concern was cuts to community transport services, making it harder for people in rural areas to get to medical appointments or social day care provision.

There were mixed feelings on paid-for health care services. People were sympathetic to people accessing private care when they are unwell and there are long waits for NHS services.

However, they were also reflective on how people paying to access health care more quickly is a form of inequality.

“Pharmacies are now offering a lot of paid services because you just can’t get them on the NHS – and if people can afford to pay for them, they will. And that raises the topic of equality- and that gap does feel like it’s getting wider.

After a presentation in session 2 participants considered the inverse care law, where people who most need health and social care are least likely to receive it. Following a presentation on person centred care from a practitioner’s perspective, participants noted how GPs working in areas of high socio-economic deprivation see more people with more problems in less time, reducing people who use support and services’ abilities to comprehend and manage their health issues and increasing practitioner stress. They recognised the importance of alternative means of support, including from the third sector, particularly where people may not be able to advocate for themselves or require more help than the health service is able to provide.

Others touched on the point that the voice of those who use support and services is “missing” from literature on the definition of person centred care, particularly for socially vulnerable populations. Participants agreed that some groups have a limited voice and need to be understood, noting that disengagement and other negative behaviours can be due to past experiences and feelings of mistrust.

Some felt that programmes like the Scottish Deep End project- referenced during the presentation - need to be supported and advertised to raise awareness among the general population, with a view that greater education on the inverse care law will help to drive change.¹⁰

In the second session a few participants had expressed some scepticism about the role of Community Link Workers. After reading more about this scheme in session 4, and having discussed concepts including deprivation and early prevention, views were markedly different. Participants now saw Community Link Workers as a “useful service”, “addressing areas of deprivation” and an “effective information-sharing resource”.

¹⁰ University of Glasgow - Schools - School of Health & Wellbeing - Research - General Practice and Primary Care - The Scottish Deep End Project

In session 3, a key theme arising from breakout room discussions was that the Barnett formula appeared to be a “very manual and difficult to interpret method”. They also discussed the “trickling down” of funds from the Scottish Government to local authorities, “who then decide how they spend that”. There were concerns that funded activities and services may not match the unique demands of individual areas, and that some communities and people may “miss out” as a result.

Pressures facing health and social care

In session 1, many participants saw staffing and workforce pressures as a key issue for health and social care. They were conscious of the demands of the sector on those working in it, as well as factors affecting staff satisfaction and morale, such as pay and conditions. Participants most often identified the pressures facing primary care and GP practices, given this is a common touchpoint with the NHS.

While many acknowledged that short (up to ten minutes) appointments are in place to allow as much demand to be met as possible, these can leave people feeling rushed and unheard.

“ I think GPs are pushed because there are not many of them and there is a lot of demand. If they're limited to a ten minute timeslot and trying to fit everything in, then questions will inevitably be missed. You want a quality review from your doctor, not just a “What's wrong with you? Here, take this. Get out” kind of script.

Participants also mentioned the disconnect between hospital care and social care, particularly where delays in assembling social care packages extend people's hospital stays. Of note, they explained how framing people as “bed blockers” de-personalises them, and framing social care delays as blocking beds is negative towards that part of the system. Therefore, the terminology and the concept are unhelpful and negative.

Participants thought that the social care sector faces ongoing issues with staff retention and recruitment. Some felt that the roles in social care are not held in the same esteem as health care, with workers facing issues of stigma, low status and low pay.

Many saw a need to improve the sector's status, morale and sense of being valued.

“ Certainly in social care, it's not really regarded as a high status profession. I think they need to somehow find ways of giving people proper training and an idea that they're going into something that is valued and has some kind of career progression and encourages people to stay and develop.

Participants discussed findings from Public Health Scotland's 'Scottish Burden of Disease study' (2022),¹¹ which were highlighted in a presentation in session 4. They were particularly surprised by the projection that the disease burden in Scotland will have risen by 21% between 2019/20 and 2043. They acknowledged the added pressures this would place on health and social care systems.

Participants were critical of the use of the word 'burden' in the study's title, feeling it could be stigmatising to people affected by health conditions or make them feel as though their condition is an additional burden on the health service.

Taking part in a final exercise in session 2 of what person centred care means to them, participants discussed the barriers they saw in the current system:

- Funding was one of the most frequently mentioned barriers to achieving person centred care. Participants acknowledged the potential costs of person centred care and wondered how this could be resourced, with one asking "How can the system provide this level of bespoke care when there is a struggle to provide standard care under current funding formulas?".
- Participants mentioned reduced capacity in staffing as a barrier, and felt that staff would need to be willing to take on this new approach. They mentioned the potential for staff training on person centred care, which would require time and money.
- Several participants felt that person centred care would be more time consuming than standard care. They saw GPs as having a key responsibility for undertaking a person centred care approach, and were wary of increasing their workload.
- Others believed that a person centred care approach would be reliant upon continuity of care, which could be difficult to deliver within the current systems.
- Although the term 'health inequalities' was not used explicitly, participants explained they thought there were health inequalities experienced by different groups within our population.
- A "postcode lottery" was mentioned occasionally, with participants thinking that health and social care access and quality vary in different parts of the country.
- Some participants worried that current data sharing processes were unsuitable for the adoption of person centred care.

¹¹ Scottish Burden of Disease Study - Scottish Burden of Disease Study - Publications - Public Health Scotland

Prevention focused system

Session 4 saw a consultant in Public Health using a football pitch analogy when describing prevention. This formed the basis of an activity in session 5. During this activity, participants worked in pairs to choose from a selection of eleven personas, with roles across health and social care and situated across urban and rural areas of Scotland.

They were encouraged to place where each would be positioned on a football pitch as follows:

- **Forwards - health creation and opportunity**
- **Midfielders - prevention and determinants**
- **Defenders - early detection and intervention**
- **Goalkeepers - health care treatment.**

Participants spent time discussing the unique context of each, including the impact of urban, rural and island locations and levels of staffing, partnership and support.

There were several occasions where participants noted the personas' 'ideal' placement on the football pitch was different to where they were placed in reality. For instance, some personas who participants felt should 'help make things happen' as 'forwards' or proactively help prevent threats to health as 'midfielders' were downgraded to 'defenders' or 'goalkeepers', as challenges relating to high demand or a lack of resourcing push them into a 'firefighting' role.

Indeed, participants believed that almost all personas would ask for better recruitment and retention of staff, an increased level of stable funding, improved infrastructure, and awareness raising around support organisations.

Several participants felt that the health care landscape tends to follow a downstream approach, with some commenting that "there is a lot of firefighting in the sector" and the different groups and actors in the health care system "are not working as a team". Participants also acknowledged the costs associated with a more reactive approach, particularly where more and greater intervention and treatment is required.

Complexity

In session 1 the first point of entry to health care was framed as a daunting prospect.

“ It's difficult to understand where you go and who you talk to, especially when things go wrong.

The presentation by the ALLIANCE on the system served as confirmation of its complexity. It provided people with some explanation of their experiences of a hard to access, hard to navigate system.

“ There must be a way to streamline this. It seems like there's an awful lot of complex elements involved and it's not much wonder people get lost.

Some participants felt that communications from health care providers, in particular, can be overly generic and unclear about actions or outcomes. For instance, one participant described their experience of receiving a vague email from their hospital, asking whether they wished to stay on a waiting list. The email did not include the context of their condition nor what they were on the waiting list for, which the participant felt could cause confusion for those with multiple conditions. Other participants described a lack of information and clarity about people's position in waiting list “queues”, meaning people have no indication of when they might be “called forward”.

Many participants said they had not realised the level of fragmentation across the health and social care sector. Indeed, several were surprised by the extent to which the third sector plays a role, and worried that more bodies increased the risk of disjointed communication and fragmented working. At the same time, participants discussed the rationale behind the third sector's involvement, feeling that it plays an important role in providing necessary services and “plugging the gaps” not filled by public or private sectors.

“ I think [charities] take a lot of slack for our health and social services.

In session 3, participants felt there should be greater transparency about what funding allocated to health and social care is spent on.

“ One of the things I found interesting was how the spend was broken up between NHS services and social care – the fact that it goes to local government but there doesn't seem to be any responsibility as to how local governments report back how much they've actually spent on social care.

They thought any actual breakdowns of spend on social care should be made publicly available so that people get a better sense of, and can perhaps offer their views on, the outcomes of funding decisions.

“ You get a very high-level pie chart but there is no visibility around specific budgets. So it should be a requirement on local authorities that they publish detailed financial records as to how they are spending our money.

“ The statistics speak for themselves but it's hard to relate those figures to what happens on the ground, so you're left thinking 'what does that mean in reality?'. The topline spend figures are what they are, but what is that delivering – that is the main question. You can't judge the quality.

Please see Appendix B for more detail on the deliberative sessions referenced in this chapter.



Health and social care in the future

This chapter is organised into key topics on current health and social care discussed and deliberated by participants throughout the project:

Openness to change and reform

Enablers for improvement

Innovation

Priorities for the future

Roles and responsibilities

The chapter includes summaries of views and illustrative quotes from participants.

Session 1	Experiences and impressions of health and social care
Session 2	Person centred health and social care
Session 3	Funding and spending
Session 4	Innovations
Session 5	Policy and communications

Openness to change and reform

This research supports not only the Scottish public's openness to change and reform, but also the sentiment such change is necessary given their lived experience, understanding of pressures on the system and its complexity, and budget constraints.

Progress and improvement are expected as quality health and social care is important to everyone.

A budgeting exercise in session 3 was intended to provoke discussion on allocating funds and to see what participants raised and considered.

Participants found the exercise challenging and it opened their eyes to how allocation of spend is difficult, but needs context and deliberation.

“ The budgeting exercise was fun but also daunting knowing that we couldn't fully fund any one area of need without it being detrimental to the others. So, I guess knowing that explains things, to me, why Local Authorities have the final say [because they should have a better localised understanding] in where they spend their allocated Scottish Government grants.

“ The task of trying to allocate the funding was really good as it shows just how difficult it is to prioritise what the greatest needs are.



When considering what they would say to the Cabinet Secretary, many participants offered encouragement, expressing the view that difficult debates and decisions were necessary. They wanted collaboration, engagement and honesty throughout this process.

“ I would say the whole system needs reforming. We are paying to train really good staff across NHS and social care who then leave because we are not giving them jobs. We need to prioritise preventative care as this will save money on the long run. Make better use of technology and AI to improve the workload [of staff], like apps to track our [patients'] own health care/appointments etc. Involve patients in their own care and make community a big part of services, offering open days/weeks, collaborate with lots of professionals in one place - it would be more beneficial.

In the final feedback survey, participants included encouragement for reform:

“ It's [the ALLIANCE's mission] a difficult task and not one that's going to get solved soon, but progress is important.

“ You need to raise public awareness of the need for reform by any and all means possible!

“ People want to see practical and costed suggestions and solutions to problems that are already glaringly obvious.

“ Keep pushing for improvement – roll out tried and tested but innovative ideas quickly.



Enablers for improvement

Taking part in a final exercise in session 2 of what person centred care means to them, participants articulated enablers of person centred care:

- Several participants wrote that joined up approaches across health and social care services would need to be adopted to deliver person centred care. This would require better communication between parties, comprehensive data sharing, and continuity of approach
- Funding was again a major topic. This would need to be significant and far reaching to cover all areas and all demographics, with some sensing a need for “massive financial investment”
- Participants saw adequate staffing levels and staff training as key enablers of person centred care, including training on “soft skills” to ensure the “warm-handed” approach mentioned in one of the presentations
- Relatedly, some participants felt that the way in which individuals are currently looked after would need to be overhauled or tweaked, and that professionals – particularly GPs – would require more time with individuals
- Participants also felt there was a need for public education about person centred care, so that people are aware of a different approach and understand its benefits. Some noted that the public may need assistance finding services and support
- Others called for improved allocation of resources across regions, to improve the availability of services more generally
- There were also a few comments about the need for political traction to get momentum behind the greater adoption of person centred care approaches
- There was an isolated mention of promoting careers in care services to younger people, so that the increased need for such employees that person centred care would precipitate could be met.

In session 3 participants shared and developed their views on health and social care funding and spending throughout the session:

- They discussed the “trickling down” of funds from the Scottish Government to local authorities, who then make spending decisions for their area on social care. Some were concerned that spending decisions across local authorities are not based on the same method or criteria, with the potential for inconsistent interpretations and therefore unequal outcomes
- They considered the health and social care funding landscape south of the border, comparing it with Scotland. A few participants were surprised that there are charges for care at home south of the border, and that social care south of the border is means-tested. While they appreciated that people in Scotland face fewer costs, they wondered whether government payments towards in-home personal care in Scotland are increasing the strain on social care funding and resources.

In session 3, an activity using spending allocation scenarios prompted participants to allocate £10,000 to improve health and social care in one of four Scottish locations. Each breakout group spent time weighing up the advantages and disadvantages of the options, and some participants countered the views of others. They each chose to fund different elements and aimed to tailor these to the specific needs of their given area. All participants acknowledged the difficulties in “making their money stretch” - particularly where they saw the merits of multiple options - and related this to the challenges facing decision-makers.

In session 4, participants also discussed the three streams of prevention:

- **Primary prevention (upstream - trying to stop problems happening in the first place, either through actions at a population level that reduce risks or those that address upstream drivers)**
- **Secondary prevention (mid-stream - focusing on early detection of a problem to support early intervention and treatment or to reduce the level of harm)**
- **Tertiary prevention (downstream - more reactive, trying to minimise the negative consequences (harm) of a problem through careful management)**

Deliberation resulted in participants feeling that directing spend towards prevention would save money.

“ A lot of funding gets spent later down the path, when it's too expensive.

Following the consultant in Public Health’s presentation on prevention-focused systems, participants were aligned on the view that Scotland’s health care landscape follows a ‘downstream’ approach to prevention. They felt the current health care system has a high level of tertiary prevention, in reacting to, or “firefighting”, issues once they arise, instead of stopping them from happening in the first place. While they acknowledged a need for change, they felt that factors such as low attendance at screenings or a lack of political will could stall moves towards greater primary or secondary prevention.



Participants discussed wider enablers for improved health and wellbeing, including:

- Vaccination schemes
- Screening for diseases
- Policies which may lessen addictions to harmful substances including alcohol and high sugar and salt foods
- Promotion of healthy lifestyles to encourage behaviour change using positive messages, rather than negative warnings
- Initiatives for children to exercise, including school provision of swimming
- Legislation to protect mental health of young people, for example considering banning of social media.

Some participants felt that a prevention approach – ideally, primary prevention – needs to be rolled out across all four nations of the UK to be fully effective in promoting good health and reducing the personal, societal and cost impacts of ill health.

The general sentiment was prevention of poor physical and mental health is better than cure, from an economic standpoint and also to prevent unnecessary harm.

Innovation

In session 4 participants' impressions of the word 'innovation' before any explanation or stimulus were broadly similar. Several saw innovation as linked to new technologies, systems and processes, or new ways to approach problems. Some made reference to medical and technological advances, and "new ideas for the improvement of health care".

Most comments related to technological innovations in health rather than social care. Participants were less certain of recent innovations in social care, with many noting they were not aware of any.

Some mentioned potential changes to social care systems in their local area, while others pointed to self-directed support/personal budgets for social care. However, innovation was also seen as "forward thinking" and "shifting perspectives" across health and social care.

While participants were impressed by many of the examples of innovation in health and social care shared by the Director of Digital at the ALLIANCE, they were particularly keen for practical 'day to day' innovations, like digital access to one's own medical records and a log of interactions. During an activity with examples of innovations, most selected the MyCare.scot App¹² as one of the top three most important innovations,

¹² Introducing MyCare.scot

citing it as “convenient” and “useful for things like appointment notifications and information on your care”. Participants also expressed a preference for innovations that present “bigger benefits for end users”, promote early intervention and reduce the need for acute care, such as the Accelerated National Innovations Adoption (ANIA) programme, an initiative aimed at fast-tracking proven innovations into health care services across NHS Scotland using technology.¹³

Several participants were keen to have easier access to their own medical records and health and social care information through the use of their phones. Several mentioned how, for many, “our lives are on our phones”, with the ability to make contactless payments, manage bank accounts and keep in contact with people. They felt that whilst making other arrangements for those who are digitally excluded, phone technology was under utilised as a way to get out information to people.

A few participants emphasised the importance of monitoring the outcomes of digital innovations in health and social care, and suggested asking for public views on the potential usefulness of some innovations before implementing them.

“ We can put all these in place but it's asking do they make things easier in the long-run? We're having a move to digital but is it necessarily better? There's a need to find out whether it's worth having access to records and things - do a poll, ask whether people would like this.

Artificial Intelligence was seen as a useful tool in helping to join up information between sources and generate transcripts of consultations, so they did not have to note or remember everything themselves. The assumption was that any AI solutions should be designed to handle personal information safely and appropriately.

Priorities for the future

In session 5 a prioritisation activity utilised a grid where each group were asked to write their thoughts on what health and social care should do less of, more of, continue, start and stop. Findings are summarised below.

Participants considered the impact of pressures on the health and social care system on the perceptions of people who use support and services, with several participants asking health services to “stop making patients feel like a burden”.

Participants raised that parts of the system seem to be competing against one another, rather than working together, for example, hospital discharges needing suitable social care packages in place.

¹³ Accelerated National Innovation Adoption (ANIA) pathway

Furthermore, some participants felt that distribution of budget should be revisited.

“ These two areas are co-dependent, and integration is essential for the future wellbeing of Scotland's population. The disparity in the finances is not acceptable and spending more on social care would save much more money in health care.

There was also support for initiatives which they see bring health services to communities in a convenient way. Examples given were 'drop-in' services for blood pressure checks and blood tests and the 'Pharmacy First' initiative, particularly where pharmacists can "provide a variety of treatments and prescribe [medications], reducing the need to see a GP". People also expressed their support for innovations and the use of technology in health and social care, including personalised medicine, AI and the adoption of new drugs.

From health care, participants wanted:

- Greater continuity of care and joining up between different parts of the health and social care system, including joined up records, to mitigate having to retell stories, and important linkages being missed
- Professionals helping people in a holistic manner to improve their quality of life, potentially utilising Allied Health Professionals,¹⁴ and Community Link Workers
- To easily see their upcoming health appointments, rather than confusing text and letters that could go missing or be delayed. "Bring all digital services together, they are currently too fragmented"
- Some participants saw a need for more health education, particularly in schools, with some suggesting greater state support to encourage healthy living.

From social care, participants wanted:

- More information on options available to them and loved ones
- Clarity on what social care is free, means tested or paid for, as comparing notes they had different experiences in different local authorities.

¹⁴ Allied health professions | NHSScotland Careers

From health and social care, participants wanted:

- **More community empowerment, as well as “more effective community plans with genuine community engagement, delivering the national health and social care plan”**
- **High quality services across Scotland, including in rural and remote areas.**

Roles and responsibilities

Regarding sectors, participants questioned the role of public, private and third sector in delivery of health and social care. There was scepticism towards all three sectors.

The public sector itself was seen as overly bureaucratic, with too much administration and “form filling”. The number of Quangos (quasi-autonomous non-governmental organisations) in health and social care was regarded as a form of inefficiency and duplication. Their perception was that public sector structures have lots of managers that are “in different roles but doing the same job”.

Some were sceptical of the private sector, for example agency staff, in social care, as part of a public service. Their basis was that profits are being made from delivery of essential services. On the other hand, some participants explained that companies have a role as providers of goods and services to the public sector, and as long as checks and balances are in place, this should continue.

Some also questioned the role that the third sector should take in public services. In the case of the third sector, the concern was that charities can have insecure or unconfirmed budgets and without this stability, expecting them to provide public services, represents a risk.

Turning to the roles of politicians, as early as the first presentation in session 1, participants started to bring up the role of political representatives in improving the system. Treating health care quality as a “political football” was described as adding to the problem and avoiding “grown up conversations” on what services should be included in health and social care.

There was a clear appetite for cross-party working to create a vision for health and social care outcomes, even if the parties had different views on funding models and ways of getting to these outcomes.

In session 2, participants set out some ideas around what should change for person centred care to happen. Many saw the need for a “trail-blazing politician” who can make radical change. Others called for all political parties to work together towards improving health and social care, particularly where this is a shared policy area and impacts all in society. Investment in resources and services was seen as crucial, with some feeling that nothing will change until the current system is overhauled.

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

In session 4, they discussed general perceptions of social care as perhaps negative, and being seen as a drain on resources, despite its importance.

“ Politicians don't want to talk social care because it's not glamorous and costs a lot.

A couple of participants, who agreed with the need to focus more on primary and secondary prevention in health care, felt the matter “isn't a vote winner during elections”.

There were also concerns that important policies or matters relating to health care can get “lost in the noise” when politicians are discussing or deciding on proposals from opposition parties, with a sense that wider, more public-led discussions could be useful.

“ We need to take politics out of health care provision because opposition parties might vote against a government bill [put forward by a party and relating to health care] even though it is a good idea.



In session 5 each participant wrote a short note of what they would say to the Cabinet Secretary. Many of their pitches combined points on multiple areas of health and social care, while others were separate, more general pleas.

- There were calls for better integration of the health and social care sectors, with participants wanting improved joined-up working between the two. They also saw the need to increase funding for social care, which currently receives less investment than health care
- Relatedly, other participants advised the Cabinet Secretary to focus on long-term planning for health and social care, and to involve professionals working “on the ground” in this process
- Others requested improved continuity of care, sharing experiences of “re-telling their story” to multiple health professionals or not receiving face-to-face consultations with their GP
- Several participants highlighted a need to improve access to mental health services, observing the ties between mental health, physical health and wider wellbeing. They were particularly concerned about the time it takes to access mental health services
- Participants also called on the Cabinet Secretary to create more joined-up health and social care systems, and make valuable investments in digital technology to aid collaboration
- A few participants felt that work should be undertaken to identify and address causes of poor NHS performance, including looking to the private sector to identify potential improvements and innovations
- One participant said they would like to speak to the Cabinet Secretary about improving and further promoting public health information, to educate and raise awareness of how to access the care they need
- Another participant called for outright reform of the health and social care system, citing a requirement for better training and staff retention, greater use of technology, preventative approaches and more involvement of people who use support and services and communities.

Please see Appendix B for more detail on the deliberative sessions referenced in this chapter.

Conclusions

This deliberative project reinforces the ALLIANCE's priorities, especially their strategic priority of increasing meaningful involvement and impact of people with lived experience.¹⁵ The research findings include valuable insight into how the public understands feasibility, fairness and implementation. These findings strengthen the case for reform by demonstrating both principled support and informed realism among the public.

The public recognises the scale of the challenge facing Scotland's health and social care system. They are prepared to engage seriously with difficult choices - but expect honesty, fairness, long-term thinking, and meaningful reform that puts people, not processes, first.

Based upon this project, we reflect that further public deliberation can bring:

Understanding of a complex system

Willingness to debate trade-offs

Deep sensitivity to language, respect, and lived experience

Overall, deliberation adds delivery realism, lived experience detail and public legitimacy to the asks by the ALLIANCE and its members, strengthening the case for reform grounded in both values and practice.



¹⁵ Strengthening our Collective Voice - Health and Social Care Alliance Scotland

Below are conclusions of this research, based upon our analysis findings.

Bridge the gap

Scotland has an established vision for health and social care, but there is a gap between this vision and public experience, and no formally agreed, cross-party consensus on long-term outcomes and delivery.

What participants were responding to was not the absence of a vision on paper, but:

Lack of cross-party ownership - participants explicitly asked for cross-party agreement to stop health becoming a “political football”

Fragmentation across documents and systems - participants repeatedly referenced a “patchwork” system where, at a national level, there are multiple relevant strategies and frameworks, while on the ground experiences are highly localised and inconsistent

Weak translation into lived experience - person centred care is prominent in policy but often absent in practice. Participants feel the system fails most in regards to access to care, continuity of care and accountability for quality of care

Limited public visibility and understanding - many participants had not heard terms like person centred care. They welcomed the idea of difficult, informed conversations about trade-offs – something current vision documents do not explicitly facilitate.

The project findings support strengthening and formalising the existing vision by:

Explicitly linking the vision to lived experience, delivery realities, and trade-offs

Ensuring the shared vision is visible, coherent, and publicly owned

Encouraging different political parties at Holyrood to come together in support of the shared vision

While participants strongly supported person centred, preventative and equitable care, they consistently emphasised the gap between policy ambition and their lived experience. The deliberations highlighted the importance of aligning vision with realistic delivery conditions, including workforce capacity, time pressures, and system constraints.

Smart and transparent investment

There was strong recognition that prevention is economically and socially more effective than cure. They strongly supported more upstream investment, giving examples of vaccination, screening, healthier food and physical activity initiatives and mental health prevention. They saw these as saving money for Scotland in the medium to long-term.

Deliberation surfaced strong frustration with the perceived complexity, fragmentation and bureaucratic weight of the health and social care system. Participants prioritised clearer lines of responsibility, simpler navigation for people who use support and services, and confidence that funding reaches front-line care.

Participants consistently observed that the system is overly reactive and costly. Participants wanted clarity on where money goes and who is accountable.

Our participants had strong attachment to NHS universality and free access. Participants demonstrated an appetite for “grown up conversations” about limits, priorities and trade-offs, including debates around universality, needs based support and sustainability. This suggests there may be greater public readiness for transparent discussions about reform choices than is often assumed.

Person centred care

Participants defined person centred care as holistic, respectful, joined-up, and tailored. Many struggled to reconcile current experiences with policy rhetoric.

Lack of continuity (e.g. seeing different GPs) was a persistent concern. Fragmentation between hospital, community, social care, and third sector services was seen to cause delays, confusion, and harm. This was because people feel they are being passed from “pillar to post”.

The system was described as opaque, confusing, and difficult to navigate. Poor communication was a consistent source of frustration.

Participants described a “patchwork” of provision by area. Rural and island communities faced additional transport and access barriers. Concerns about inverse care law and unequal ability to self-advocate were prominent.

Staffing shortages were seen as a root cause of poor quality and lack of person centred care. Social care workers were praised yet seen as undervalued, underpaid, and stigmatised. Heavy reliance on agency staff and burnout was raised.

To help person centred care, there was strong support for access to personal health records, apps, and joined-up systems. Artificial Intelligence was seen as a potential tool to support coordination, reduce repetition, and generate consultation records. At the same time, they emphasised safeguards, outcome monitoring and attention to digital exclusion.

Participants wanted person centred care to be the norm, not an “ideal world” exception. Furthermore, they recognised the desire of the workforce to deliver this, including those working in health care and social care.

Engagement and communication

Participants placed particular weight on feeling listened to and treated with dignity when trying to access services and experiencing health and social care.

Moreover, they were sensitive to language that frames people as a “burden” on services or reduces people using the system down to numbers. Language should be considered in any communication and engagement exercises.

Their points underline the emotional and symbolic dimensions of care that matter to public trust and engagement.



Appendix A: Glossary

To provide definitions of words used in the report that are in line with current the ALLIANCE guidelines that aims to follow the Six Principles of Inclusive Communication.

Adult social care

Support services that help adults live independently, but safely and with dignity. This can include personal care, help at home, day services, supported housing and other forms of assistance with daily living.

AI

Artificial intelligence (AI) refers to developed computer systems capable of performing tasks that typically require human intelligence. For example, tasks like reasoning, learning, problem-solving and perception. AI systems process vast amounts of data to identify patterns and make decisions based on this collected information.

Agency staff

Workers supplied by an external staffing agency to fill temporary vacancies or staffing shortages.

The ALLIANCE

The Health and Social Care Alliance Scotland are a national organisation that represents people who use health and social care services, unpaid carers and third-sector organisations.

ANIA

The Accelerated Nationals Innovations Adoption (ANIA) programme is a NHS Scotland and Scottish Government backed pathway. Its primary goals is to identify, assess and implement proven health technologies and innovations for rapid national adoption and integration into clinical pathways.

Audit Scotland

An independent public body that audits how public money is spent in Scotland and assesses the performance of public services.

A&E

This term stands for Accident and Emergency, a hospital department that provides urgent treatment for serious illnesses and injuries requiring immediate medical attention.

Baby box

A Scottish Government scheme that provides every newborn baby in Scotland with a box containing essential items to support a child's first 6 months. The box also serves as a functional crib.

Barnett formula

The mechanism used to calculate changes in funding allocated in Scotland, Wales and Northern Ireland based on spending decisions made by the UK Government.

Cabinet Secretary for Health and Social care

The Scottish Government minister responsible for health and social care policy and services in Scotland. The current Cabinet Secretary for Health and Social Care as of June 2026 is Angela Constance.

Care package

A planned combined set of support services designed to meet an individual's assessed care needs. A package can include various services such as, personal care, nursing care or social support.

Carezapp Care Technology

This is an umbrella term for technology used to support people remotely in their homes and other social care settings, like telecare or remote monitoring. The term comes from Carezapp which are a care technology platform that help peoples deliver care and support in homes and other social care settings. The aim of such technology is to safeguard while enhancing independence, safety and wellbeing.

Caring responsibilities

The unpaid duties and support provided by someone who looks after a family member, friend or neighbour who needs help due to illness, disability or other circumstances. Caring responsibilities can be short or long-term, whether helping someone recover from an accident or someone with a chronic illness.

Clinical treatment

Medical care provided by health care professionals to manage or treat health conditions. It is a form of direct patient care delivered by trained and licensed professionals in clinical settings like hospitals or clinics.

Condition

In terms of health and social care, condition refers to a specific health issue that affects an individual's wellbeing. Conditions vary widely, including physical illnesses, mental health issues, and chronic conditions.

Cross-party ownership

Support for a policy or approach from multiple political parties rather than a single party.

Deliberative research

This term refers to a research approach that emphasises careful consideration and discussion of issues by participants, rather than relying solely on immediate opinions or person experiences through one-to-one interviews. Deliberative research often involved a few structured sessions, like workshops or interactive events, where participants are provided balanced information and multiple perspectives before forming conclusions. The aim of this approach to research is to generate well-informed and reflective viewpoints that help to inform decision-making.

Deliberative session

Session conducted by the Diffley Partnership that involved structured discussions and activities in which participants receive information, consider different viewpoints and reflect on issues before sharing their opinions.

Diagnosis

The identification of a disease, condition or health issue by a health care professional, like a doctor or a nurse.

Discharge

The process of leaving hospital or another care setting when treatment or support there is no longer required.

Downstream

Actions focused on responding to existing health or social care needs after problems have already occurred.

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End-to-end care

A coordinated approach that supports an individual throughout their entire care journey, from prevention and diagnosis to treatment and ongoing support.

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Essential services

Services considered necessary for people's health and wellbeing, in order so they can go about their daily living.

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Facilitator

A person who guides discussion, encourages participation and helps ensure everyone has an opportunity to contribute.

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GP

This term refers to a General Practitioner which is a doctor who provides primary health care services in the UK and is usually the first point of contact for non-emergency medical concerns.

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GP practice

The organisation or clinic where GPs and other primary care staff provide health care services across the UK.

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Health and social care

This term refers to, either together or independently, the system of services that support individual's physical health, mental health, wellbeing and independent living.

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Holistic support

Support that considers all aspects of a person's life and wellbeing, including physical, emotional, social and practical needs.

Independent review of Adult Social Care in Scotland

A review published in 2021, led by Derek Feeley, that examined Scotland's adult social care system and aimed to recommend recommendations for reform, including proposals for a National Care Service.

In-home personal care

Support provided in a person's own home with tasks like washing, dressing, eating or mobility.

Integrated care

An approach that aims to coordinate health and social care services, so people experience seamless support across different services and providers.

MyCare.scot App

NHS Scotland's new app that allows those who use support and services in health and social care to access their information, book appointments, check test results and letters more conveniently and quickly. The app is a part of the national Digital Front Door (DFD) programme which has been led by NHS Education for Scotland in partnership with the Scottish Government. The first version of the app launched in Lanarkshire in December 2025 and a full rollout happened across Scotland in April 2026.

Means-tested

Eligibility determined by a person's income or financial circumstances.

Mid-stream

Actions that target people who may be at risk of poorer outcomes and aim to prevent problems from worsening.

National Care Service

This term refers to a proposed reform intended to improve consistency, quality and accountability across social care services in Scotland.

National Health and Social Care Plan

A strategic plan setting out priorities and actions for improving health and social care services.

Needs-tested

Eligibility determined by an assessment of a person's care or support needs.

NHS

This acronym stands for the National Health Service, which provides publicly funded health care services across the UK.

Non-medical staff

Staff working within health care settings, like hospitals and clinics, who do not provide medical treatment, such as GP receptionists and administrators.

NRS Social Grades

The NRS social grades are a system of demographic classification used in the United Kingdom. They were originally developed by the National Readership Survey (NRS) to classify readers, but have since been used by many other organisations for wider applications and have become a standard for market research. They were developed in the late 1950s and refined in following years and achieved widespread usage in 20th century Britain. Their definition is maintained by the Market Research Society. NRS social grade is not the same as social class. The distinguishing feature of the NRS social grade is that it is based on occupation, rather than income, wealth or property ownership.

Panel

A group of individuals recruited to participate in research activities and provide their opinion across time.

Participant

A person who takes part in a research study, in the case of this report that refers to the people involved in the deliberative research sessions.

Parity

The principle that different services, conditions or groups of people should be treated with equal importance and fairness.

People living with long-term conditions

This term refers to individuals who have a long-term health condition, like arthritis, that significantly impacts their quality of life and require ongoing management. This term has been used instead of words like patient, service user or client to recognise the lengthy management of their conditions and the subsequent practical and emotional impacts this has, including the relevant support they receive from health and social care.

People who access support and services / people who use support and services

These terms broadly describe the people who use the support and services offered by health and social care. The term recognises the lived experience of receiving services and the identities and roles such people have beyond these services, instead of defining the person solely by their service use. Words like service user or patient offer similar descriptions of what these terms represent.

Person centred care

This is a term used to describe the approach to care that focuses on tailoring care provided to the unique needs of an individual rather than the needs of the service or system.

Pharmacist

A health care professional who specialises in medicines and provides advice on their safe and effective use.

Policy

A set of principles or plans that entail actions developed to guide decisions and practice. In reference to health and social care, this can refer to policies made by public bodies and third sector bodies to aid the development of health and social care for more equitable and efficient care.

Postcode lottery

A situation where access to services or quality of support varies depending on where a person lives.

Practitioner

A professional who delivers health or social care through support services.

Preventative care

Actions and services designed to prevent illness and reduce risk of future illness, aiming to support long-term health and wellbeing.

Private sector

Businesses and organisations that operate independently of government ownership and may provide health or social care services.

Public sector

Organisations funded and operated by government to provide services for the public.

Quangos

Publicly funded organisations that operate independently from government departments while carrying out specific public functions.

Recruitment

The process of identifying and inviting people to participate in research.

ScotPulse survey

This term refers to a survey conducted by ScotPulse, Scotland's largest online research panel. The research panel has over 44,000 members from across Scotland and is utilised, in close collaboration and bespoke survey design, by the Diffley Partnership for gathering wider national data on opinions.

Scottish Deep End project

An initiative involving GP practices serving Scotland's most socioeconomically deprived communities, aimed at reducing health inequalities.

Scottish Social Attitudes Survey

A large-scale annual survey ran by ScotCen Social Research that explores public opinions and attitudes on social, political and policy issues in Scotland.

Self-directed support (SDS)

A system that gives people greater choice and control over how their social care support is arranged and delivered.

Social justice

The principle that everyone should have fair access to opportunities, resources and support regardless of their circumstances.

Socioeconomic deprivation

Disadvantage experienced because of factors such as low income, unemployment, poor housing, or limited access to resources and opportunities.

Staff retention

An organisation's ability to keep employees and reduce staff turnover.

Stakeholder

An individual, group or organisation with an interest in, or affected by, a policy, service or decision.

Stimulus materials

Information, evidence, presentation, videos or other materials provided to participants to support discussion during research activities.

System

Throughout the report, this term refers to the collection of organisations, services and processes that work together to deliver health and social care.

System reform

Changes designed to improve how a system is organised, funded or delivered.

Third sector

This term includes not-for-profit organisations such as charities, voluntary organisations, community groups and social enterprises that operate independently of government and the private sector.

Universality

The principle that services should be available to everyone based on need rather than ability to pay.

Unpaid carer

This term refers to someone who provides care or support to a family member, friend or neighbour without receiving payment.

Upstream

Actions that address the root causes of poor health and wellbeing before problems develop.

Vaccination scheme

A programme designed to provide vaccinations to protect individuals and communities from infectious diseases.

Vocational

Relating to practical skills, training or employment-focused development.

Waiting lists

In terms of health and social care, this term refers to lists of people waiting to receive health care assessment, treatment, or support services.

Workforce

The people employed to deliver health and social care services, including clinical, care, administrative and support staff.

Appendix B: Overview of deliberative sessions

Session	Session Theme	Stage	Stimulus
1	Experiences of health and social care	First discussion	None - open questions on their experiences
		Discussion following presentation	Presentation - Sara Redmond, Chief Officer, the ALLIANCE, on system structures in Scotland
2	Person centred care	First discussion	None - open questions on what this means to them
		Discussion following presentation	Presentation - Margaret Reid Arbuckle, Director of Development, the ALLIANCE, on models of person centred care
		Discussion following presentation	Expert speaker - Dr Marianne McCallum, Academic GP on practitioner experience of person centred care
		Discussion following presentation	Expert speaker - Caroline Brocklehurst, Patient Expert on individual experiences of person centred care
		Activity	Template on what person centred care means to them
3	Finance and funding	Discussion following presentation	Expert speaker - Dr João Sousa, Fraser of Allander Institute, on funding of health and social care
		Activity	Budget setting scenarios

Session	Session Theme	Stage	Stimulus
4	Innovation	First discussion	None - open questions on what this means to them
		Discussion following presentation	Expert speaker Dr Rishma Maini, Consultant in Public Health and Co-lead of Clinical Health Intelligence and Research Division at Public Health Scotland, on prevention focused systems
		Discussion following presentation	Expert speaker - Chris Mackie, Director of Digital at the ALLIANCE, on digital innovations
		Activity	Innovation examples
5	Policy and communications	Activity	'Football pitch' personas activity
		Activity	Universal versus means tested
		Discussion following presentation	Expert speaker - Professor Anne Hendry, Director, Integrated Foundation for Integrated Care Scotland; Honorary Professor, University of the West of Scotland discussed value-based care and support
		Activity	Prioritisation activity
		Activity	Elevator pitch template to Cabinet Secretary for Health and Social Care
		Throughout	Repeat poll questions

Session 1 - Experiences of health and social care

The online session included:

- Initial impressions of health and social care in Scotland - break out groups
- Health and Social Care in Scotland - overview by Sara Redmond, the ALLIANCE
- Impressions after presentation - break out groups

During the first session, time was taken to explain the overall project and what to expect across all the sessions.

Before any information on the topic was provided, break out rooms took place to elicit participants' initial impressions of health and social care in Scotland. This was purposefully done before any information on the topic was provided to obtain the views and experience of the participants before any prompting. The second discussion took place after the presentation.

This was as a really successful introductory session in two respects. It gave Diffley Partnership and the ALLIANCE an introduction to the views and experience of the participants before any prompting.

After the initial discussion, the participants were given an introduction to health and social care in Scotland. This helped them understand more about the many structures, supporting their views that this system is complex. They gained more context to frame their own experiences of access and quality of care.



Session 2 - Person centred care

The second session took place in person in Glasgow. The room was set up in cabaret style with a facilitator on each of the five tables set up for participants.

The session was designed so discussions were interspersed with presentations by three expert speakers. There was a group activity towards the end and an individual activity to close the session.

The agenda included:

- Initial discussion on person centred care at tables
- Presentation by Margaret Reid-Arbuckle, the ALLIANCE, on models of person centred care
- Discussion at tables
- Presentation on practitioner experience of person centred care by Dr Marianne McCallum. Marianne is an Academic GP with various roles including Fellowship in General Practice, University of Glasgow
- Discussion at tables
- Presentation on individual experiences of person centred care by Caroline Brocklehurst, who champions improved patient voice and shares her experiences of diagnosis and treatment of Inflammatory Bowel Disease (IBD) & Axial Spondyloarthritis (AxSpA)
- Discussion at tables
- Temperature check activity at tables
- Individual activity

Participants began the session by sharing their initial impressions of person centred care. Expert presentations were then interspersed with discussion. At the end of the session, participants shared what good person centred care would look like to them in an individual activity.

Session 3 - Finance and funding

The third session took place online, with a focus on funding and spending. The agenda included:

- Short quiz based upon demand, costs, spend and hidden costs
- Health and social care funding and spending in Scotland - presentation by João Sousa, Deputy Director of the Fraser of Allander Institute, University of Strathclyde
- Impressions after presentation - break out groups
- Activity on spending allocation scenario - break out groups

The session began with a short quiz, during which participants were surprised to learn that just 4% of the Scottish population receive social care and that 40% of the Scottish Government Budget for 2023/24 went to health care.

João Sousa presented available figures for spend on health care at UK and Scottish levels. He explained data limitations, such as the difficulty establishing what is spend on social care.

Participants shared and developed their views on health and social care funding and spending throughout the session.

An activity using spending allocation scenarios prompted participants to allocate £10,000 to improve health and social care in one of four Scottish locations. Each breakout group spent time weighing up the advantages and disadvantages of the options.



Session 4 - Innovation

The fourth session took place in person in Glasgow. It was designed so small-group discussions and activities discussions were interspersed with presentations by two expert speakers.

The agenda included:

- Initial impressions of innovation in health and social care - discussion at tables
- Presentation on prevention-focused systems by Dr Rishma Maini, Consultant in Public Health and Co-lead of Clinical Health Intelligence and Research Division at Public Health Scotland
- Discussion at tables
- Presentation on innovation and change in health and social care by Chris Mackie, Director of Digital at the ALLIANCE
- Discussion at tables
- Discussion and ranking exercise on current innovations in health and social care in Scotland
- Activity on future innovations in health and social care.

Participants began by sharing their initial thoughts on what is meant by the term 'innovation', and their impressions of the current level of innovation in health and social care in Scotland. They heard from expert speakers on prevention-focused systems and digital innovations.



Panellists spent time reviewing six case studies of innovations in health and social care in Scotland:

- **Community Link Workers**
- **Accelerated National Innovations Adoption (ANIA) programme¹⁶**
- **MyCare.scot App¹⁷**
- **Carezapp Care Technology¹⁸**
- **Scotland's Baby Boxes¹⁹**
- **Health Monitoring Technologies - Diabetes.²⁰**

Next, panellists worked in pairs at their tables to review grids featuring future innovations in health and social care. Distribution was split across the tables, with some looking at future health care innovations, while the others looked at future social care innovations.

Session 5 - Policy and communications

The fifth and final session also took place in-person, in Glasgow. The agenda included:

- **'Football pitch' personas activity - exercise and discussion at tables (based on an analogy shared during the 'prevention-focused systems' presentation in Session 4)**
- **Universal care activity - exercise and discussion at tables**
- **Presentation by Professor Anne Hendry, Director, Integrated Foundation for Integrated Care Scotland; Honorary Professor, University of the West of Scotland, discussing value-based care and support**
- **Prioritisation activity - individual and paired discussions, discussions at tables, then reviewing responses at other tables**
- **Communications activity - elevator pitch to Cabinet Secretary for Health and Social Care.**

¹⁶ [ania-post-ida-brief-march-2025.pdf](#)

¹⁷ [Introducing MyCare.scot](#)

¹⁸ [Care technology for people who care - Learn more: - Carezapp](#)

¹⁹ [Scotland's Baby Boxes - mygov.scot](#)

²⁰ [Diabetes technology | Diabetes UK](#)

Participants completed a personas activity based on the football pitch analogy shared by Dr Rishma Maini (Consultant in Public Health and Co-lead of Clinical Health Intelligence and Research Division at Public Health Scotland) in session 4. Participants worked in pairs to choose from a selection of eleven personas, with roles across health and social care and situated across urban and rural areas of Scotland. They discussed the unique context of each personas' work, marking their perceived placement on the football pitch (i.e. as forwards [health creation and opportunity], midfielders [prevention and determinants], defenders [early detection and intervention] or goalkeepers [health care treatment]).

Participants at each table completed short individual surveys on five overarching health and social care services:

Table 1	Disability support
Table 2	Adult social care services
Table 3	Children and young people
Table 4	Public health
Table 5	Health services

Participants reviewed the list of services on their allocated survey, selecting those they think should be universal (for everyone) and which should be means-tested (on income). They then discussed their considerations and thought processes.

The last activity prompted them to imagine they had 90 seconds to talk to the Cabinet Secretary.



About the Health and Social Care Alliance Scotland

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

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

The ALLIANCE has three core aims.

We seek to:

- **Empower people with lived experience:** we ensure disabled people, people with long-term conditions, and unpaid carers are heard and that their needs remain at the heart of the services and communities.
 - **Support positive change:** we work within communities to promote co-production, self management, human rights, and independent living.
 - **Champion the third sector:** we work with, support and encourage co-operation between the third sector and health and social care organisations.
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The ALLIANCE is committed to upholding human rights. We embed lived experience in our work and aim to ensure people are meaningfully involved at every level of decision-making.

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

The ALLIANCE is supported by a grant from the Scottish Government. The ALLIANCE is a company registered by guarantee. Registered in Scotland No.307731. Charity number SC037475. VAT No. 397 6230 60.