

We Have Listened

Feedback from Community
Engagement to inform the
development of the Health and Social
Care Strategic Plan 2023-26

Carol Hayden, Elaine Torrance and Paul Marshall



National Development Team for Inclusion

office@ndti.org.uk

Acknowledgements

This report details the key findings and themes from this engagement process. We would like to thank everyone who participated for their time and for sharing their views and experiences and look forward to the views in this report being reflected in the Strategic Plan.

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Executive Summary

The National Development Team for Inclusion (NDTi) was commissioned in June 2022 by the Scottish Borders Health and Social Care Partnership (HSCP) to undertake a range of public engagement activities to inform the Health and Social Care Strategic Plan for 2023-2026.

The engagement process involved a range of methods and opportunities for people to get involved and express their views, including:

- An online survey (details in a companion report)
- Face to face engagement sessions in locality venues
- Online engagement sessions including evening sessions
- Face to face and online meetings with 11 key stakeholder groups
- A limited number of one-to-one telephone conversations with those who were unable to access online sessions

The key questions we were keen to explore included

1. What aspects of health and social care work well where you live?
2. Thinking about you and your community, what are the things that help you to continue to live well and independently?
3. What aspects of health and social care could be improved where you live?
4. What do you think should be the key priorities for the strategic plan for the next three years?
5. How might your community and others play an active role in supporting health and care in the Scottish Borders?

Listening to voices from different localities and stakeholder groups

We received a total of **737 responses to the online survey** which was open for a period of five weeks in summer 2022. There was a good range of responses from across the Borders and different age groups. Full details are presented in a companion report.

The locality and online sessions were attended by 27 individuals. These included people who had had recent personal or family interactions with health and care services, NHS and Scottish Borders Council staff, independent and Third sector service providers, Elected Members and Community Councillors.

Drop-in sessions were held in each locality. As well as consistent themes raised by people across the Borders, the discussions also highlighted some specific local opportunities and challenges.

For example, people in Berwickshire, Cheviot and Eildon raised issues about **GP access** and the importance of having **local health and social care services** more than people in Teviot and Tweeddale. The rurality of these localities, the distance from larger towns and Borders General Hospital, and a lack of public transport may be contributing factors. In contrast, people in Teviot and Tweeddale raised addressing **staff shortages in the NHS and social care** as a higher priority than in the other three localities.

We engaged with **130 people from eleven groups of stakeholders** to listen to the views of people from different equality groups. The groups were: Physical Disability Group, See/Hear Group, Mental Health Forum, Self-Directed Support (SDS) Group, People with Learning Disabilities (from Local Citizens Panels), Dementia Working Group, Carers (through survey responses and noting the involvement of carers in a number of these stakeholder sessions), Borders Older People's Partnership, People from Ethnic Minorities (employees at Farne Salmon), People in the LGBT community, and a Homelessness workshop (part of Housing Strategy engagement).

In addition to many of the consistent themes, these conversations highlighted that some issues affected groups in specific ways. People in the See/Hear Group and Mental Health Forum, people with learning disabilities and people from the LGBT community all stressed the need to **improve awareness and reduce stigma among health professionals**. Suggestions for putting this into practice included listening to people with lived experience, staff training on equalities and human rights, providing information in a range of media and consistent use of good practice guidance in communicating with specific groups of people.

The Dementia Working Group, Self-Directed Support Group, and comments from carers at the session for People with Learning Disabilities group as well as through the Unpaid Carers Survey all stressed the need for **better support for unpaid carers**, including respite, and for people living in their own home.

Consistent themes

The survey and engagement findings highlighted the **important principles** of:

- **Maintaining independence** – staying in your own home, in your existing community.
- **Effective communication** - between services and you, knowing what's happening, when and how and between different parts of the health and social care system.

- **Living a good life** – helping you stay well, with opportunity for employment, meaningful activities, maintaining health and happiness

Although there were some positive responses about what is working well in the survey (e.g. skilled staff, rapid responses to emergencies), most people felt that the delivery of health and social care had worsened over the last four years, in part reflecting the impact of the pandemic; and that the priorities in the previous Strategic Plan were still mostly relevant. The engagement sessions supported the findings from the survey and provided a wealth of detail about people's experiences of services with useful suggestions about how things could be improved. In summary they showed us:

What is working well?

- **Strategic involvement of some groups** in developing strategies and service redesign
- **Crisis intervention.** An emergency response was there when needed for most people and many people reported positive experiences of in-patient care at the BGH
- **Role of Third Sector for community support.** This came to the fore during Covid and needs to be built on to harness community assets and expertise
- **Peer Support** services in mental health and for people living with dementia
- **The range of community and third sector groups that engaged** in this exercise so people with diverse lived experience had a voice about services in local communities

Where are the gaps – what needs improving?

- **Consistency of access to GPs** – some good experiences but also real difficulties with seeing a GP, particularly in Berwickshire and for people with long term conditions
- **Workforce challenges and staff shortages in NHS and social care** – people were aware of these and the impact of this on waiting times and access to services
- **More support for family/unpaid carers** – particularly for carers of people with complex care needs through home care, specialist day services and respite
- **Post-diagnostic support for people with dementia** – there is a gap in GP and other support between a diagnosis and 24-hour care and support
- **Access to NHS dentistry** – which has worsened following the pandemic

- **Better links between services** and more joined up service responses
- **Better communication** – keeping people informed about waiting times, clearer more up to date information about what is available - where to get what, when needed
- **Engagement that involves people with lived experience** at an early stage of planning and designing services e.g. LGBT people, people with learning disabilities
- **Access to local health and social care services and improved transport**

How can people and the community get involved?

People and communities identified ways they could help maintain and improve their own health and care. This included accessing local community, sports and social activities. People spoke of being able to provide peer support and befriending and were eager to find out about employment opportunities and volunteering.

Priorities for the Strategic Plan

There was also consistency in the emerging priorities for the Strategic Plan, albeit with specific details and nuances for particular groups. The top priorities are:

- **Communication** about how services can be accessed when needed, likely waiting times, and information available in different media and formats.
- **Engagement of local communities and stakeholder groups** so people with diverse lived experience can participate in service planning, design and monitoring.
- **Consistent access to primary care.** Including to GPs, NHS dentists and community nursing services, especially for ongoing support for people with long-term conditions
- **Workforce planning and addressing staff shortages** - with suggestions for attracting people to the Borders and improving access to transport and affordable housing
- **Integration and joint working between services** for a person-centred approach
- **Improved access to social care and support.** Addressing waiting times for assessment, eligibility, Self-Directed Support, home care and respite
- **Support to carers.** Through opportunities for socialisation and stimulation for people with dementia and/or other disabilities and respite for carers

- **Preventative approach.** To reduce the need for crisis responses and pressure on acute services and enable early intervention and holistic, community-based support
- Reflecting the rural nature of the Border more access to **local health and care services and improved transport** to access appointments

Key messages from Community Engagement

The people of the Scottish Borders have engaged openly and actively around the HSCP Strategy, welcoming the opportunity to input, inform and shape decisions around services and support available in their localities. In many cases, people described the quality of services that they had received from health and care staff as good or even exceptional. Concerns tended to be about systems, communication and accessing services.

Whilst the availability of resources is an important factor in the determination of priorities in the Strategic Plan, a number of the improvements and ideas that are summarised in this report could be viewed as ones that may not require significant resources; rather they require a shift in approach, thinking or ways of working. This includes communicating with local communities for their involvement in health and social care, whether from participation in planning and service design, monitoring and giving feedback on services, setting up local activities, and volunteering and providing peer support.

Listening to the voice of local people to inform the development of the Health and Social Care Strategic Plan 2023-26 is the first step in genuine engagement, involvement and participation in the co-production of services. The HSCP can build on this platform by creating an ongoing partnership with local people and communities as well as with a wide range of services and stakeholder organisations.



Introduction and context

The National Development Team for Inclusion (NDTi) was commissioned in June 2022 by the Scottish Borders Health and Social Care Partnership (HSCP) to undertake a range of public engagement activities to inform the Health and Social Care Strategic Plan for 2023-2026.

The remit for the work was to capture the experiences, priorities and ideas from communities across the Scottish Borders. The information gathered was to be collated into themes and reported back to the HSCP. The HSCP would then use this information to inform the next stages of the development of the strategy, reflecting the different voices of specific groups and five localities.

It is important to note the context for this engagement work; acknowledging the ongoing impact of the pandemic, the growing concerns regarding the increase in the cost of living and the staffing challenges across Scotland and the UK. It was vital that we framed conversations with people in the Scottish Borders to include explaining these challenges, in an honest and open way. At the same time we wanted to ensure that we encouraged people's thoughts and creative ideas for solutions about how to improve and prioritise services and outcomes.



Our engagement timeline





Engagement methods

The engagement process involved a range of methods and opportunities for people to get involved and express their views including:

- An online survey
- Face to face engagement sessions in locality venues
- Online engagement sessions including evening sessions
- Face to face and online meetings with key stakeholder groups
- A limited number of one-to-one telephone conversations with those who were unable to access online sessions

The key questions we were keen to explore included:

1. What aspects of health and social care work well where you live?
2. Thinking about you and your community, what are the things that help you to continue to live well and independently?
3. What aspects of health and social care could be improved where you live?
4. What do you think should be the key priorities for the strategic plan for the next 3 years?
5. How might your community and others play an active role in supporting health and care in the Scottish Borders?

We also included other recent consultation exercises that have been undertaken by the HSCP in this report where appropriate (e.g. Unpaid Carers Survey) to avoid duplication and consultation fatigue.

We received a total of **737 responses to the online survey** which was open for a period of five weeks from the 18th July to 21st August 2022. A detailed analysis of the findings has been undertaken and the full report of the survey can be found in a companion report.

There was a good range of responses from across the Borders and across the age groups, detailed in the companion report. Approximately 40% of respondents to the survey work in health or social care and 28% of total respondents said that they are unpaid carers.

People were asked to comment on the priorities of the past strategic plan, their experiences of using health and social care services, and priority areas for improvement in the next plan.

The locality and online sessions were attended by 27 individuals. These included people who had had recent personal or family interactions with health and care services, NHS and Scottish Borders Council staff, independent and Third sector service providers, Elected Members and Community Councillors.

Drop-in sessions were held in each locality. As well as consistent themes raised by people across the Borders, the discussions also highlighted some specific local opportunities and challenges.

Though attendance was relatively low at both the drop in and online sessions, the recent or current experiences of those taking part – in particular their personal stories - and local knowledge and connections, made for valuable and rich information on what is working well, what could be improved, what people felt the HSCP should set as priorities in the 2023-2026 Strategy and how they could be involved in the future.

We engaged with **130 people from eleven groups of stakeholders** to listen to the views of people from different equality groups. The groups were:

- Physical Disability Group
- See/Hear Group
- Mental Health Forum
- Self-Directed Support (SDS) Group
- People with Learning Disabilities (from Local Citizens Panels)
- Dementia Working Group
- Carers (through survey responses and noting the involvement of carers in a number of these stakeholder sessions)
- Borders Older People's Partnership
- People from Ethnic Minorities (employees at Farne Salmon)
- People in the LGBT community
- Homelessness workshop (part of Housing Strategy engagement)

In the sessions (some face to face, some online, some via telephone) we encouraged people to share their experiences and views on **what was working well** and **what needs improving** – as well as their **top priorities for the Strategic Plan**.

Building on engagement for co-production

Throughout the engagement with people in the Scottish Borders there has been a constant positive response from those involved in the process on how the HSCP is reaching out and seeking to hear the voices and experiences of service users and stakeholders. The engagement has been both welcomed and valued and provides good foundations for the HSCP to move onto the process of focus and prioritisation.

It is clear that those who have engaged want to continue this discussion with and this provides a real opportunity for the Health and Social Care Partnership and the communities of the Scottish Borders to build and take the next key step toward genuine co-production of the strategy and services it encompasses.

Overview of survey findings

We started most of the engagement sessions by sharing an overview of findings from the survey, where people had raised:

The **important principles** of:

- **Maintaining independence** – staying in your own home, in your existing community
- **Effective communication** - between services and you, knowing what's happening, when and how
- **Living a good life** – helping you stay well, with opportunity, health and happiness

And the need to improve:

- Waiting times for services and treatments
- Having access to health and social care services in your community
- Systems working better e.g. information, appointments, discharge and follow-up care for hospital inpatients and outpatients
- People having face to face appointments, shortages of NHS staff (including GPs and dentists) and carers, mental health provision, getting the services when needed

Although there were some positive responses about **what works well** in the survey (e.g. treatments received in Borders General Hospital, skilled staff, rapid responses to emergencies), most people felt that the delivery of health and social care had worsened over the last four years, in part reflecting the impact of the pandemic; and that the priorities in the previous Strategic Plan were still mostly relevant.

Within the survey people were asked what they consider to be the **gaps in health or social care services** at the moment as an open text question.

The top 10 most frequent responses were:

- **Adequate staffing** (identified by 91 respondents)
- **Access to GP** (40 respondents)
- **Supply of carers** (33 respondents)
- **Sufficient funding** (31 respondents)
- **Long waiting times** (31 respondents)
- **Communication between services** (29 respondents)
- **Dentistry** (24 respondents)

- **Appropriate care locally** (21 respondents)
- **Communication between professionals and service users** (19 respondents)
- **Collaboration between health and social care** (17 respondents)

With the exception of access to GPs, people tended to identify the wider systemic gaps such as staffing (specifically carers) and funding, rather than identifying specific services.

In the survey's open text questions, there were also consistent messages about areas that respondents would like to see prioritised and improved. These were:

- a) **Primary care** – enabling people to get a timely GP appointment and see their GP in person
- b) **Getting the right care at the right time** – being able to access treatment, to prevent deterioration whilst waiting
- c) **Being able to get appropriate care locally** and in the community reducing the need for people to go into hospital
- d) **To address the staffing crisis** by recruiting more staff and improving pay and conditions for existing staff
- e) **Improving how services work together** including better communication between services and better integrating health and social care

The full survey responses are shown in the companion report which accompanies this.

The following two sections of the report cover our findings from the **locality and stakeholder engagement** sessions. The Summary section pulls out the consistent and interrelated issues arising from these conversations and discuss the overarching themes and key messages from all the engagement work.



Locality engagement

Whilst there were a number of consistent themes across the Borders, the discussions that we had with people about living in their own local area highlighted some specific opportunities and challenges locally. This is detailed below for each of the five locality areas.

There were some comments about national policies and services which are under the remit of the Scottish Government (e.g. free prescriptions, National Care Service) which are not included in this section as they are outside the remit of the HSCP.

It should be noted that the majority of those responding to the survey in all localities were female and in all areas there were a significant number of unpaid carers providing their views. (See the companion survey report for a full analysis). However, there was a more even mix of male and female respondents in the online, drop in and stakeholder sessions.

Berwickshire locality

We received 85 responses from the survey in Berwickshire (e.g. Eyemouth, Duns, Coldstream) and two people attended the online and face to face sessions. In addition, a number of people who attended the stakeholder sessions lived in the Berwickshire area and their views are also reflected in this section.

From the survey the most important health and social care themes that were identified in this locality were focused on receiving care in a rural location including providing the right care at the right time.

The important key priorities from the survey for Berwickshire were reducing waiting times, timely access to GP and improving access to services.

What do you consider to be the gaps in health or social care services at the moment?

Top themes (Categories)		Most mentioned issues (Codes)	
Primary Care	21	Increase GP availability	11
Right care at the right time	12	Timely access to GP	7
Health in the community	9	Appropriate care locally	6

Seeing a local GP was stressed as important, avoiding having to travel to the BGH which is difficult to get to without your own transport. This issue emphasised the importance of local services.

“Being able to get a doctor’s appointment when you need one. It prolongs the wait and increases stress and having to try and manage your needs without medical advice”

“The distance to travel from Ayton to Melrose to access Borders Hospital services, especially in an emergency”

“Local services, within walking distance- bus services make it impossible to access services”

“The barriers to access the right person quickly - sometimes these are invisible barriers when services maybe try and slow down access to their part of the system due to the pressures they are facing”

Many of these themes were repeated in our follow up discussions.

What is working well?

- There were a **range of community activities** happening in the small rural towns and villages and good local supports in place
- We heard that the local pharmacy in Duns was accessible and provided early advice and help
- One new GP in the area was described as being accessible and having a different approach which was welcoming and inclusive

What doesn’t work so well?

- **Access to GPs** was a key theme – there appeared to be a specific challenge regarding recruitment of GPs following retirement which was impacting on the service provision
- Being able to contact your GP was a challenge. In order to get an appointment a call was needed at 8am, which was not always possible for people who were working. Some people would prefer more opportunities for face to face consultations.
- **Access to an NHS dentist** also appeared to be a challenge locally, with many people struggling to register with an NHS dentist when coming to live in the area. Many people had to register either a distance away or to pay for private care which some people could not afford. This was a particular challenge for people moving to Scotland to work from other countries

- Some **older people's housing** was viewed as being 'tired' and not necessarily adaptable to how people should and would want to live nowadays
- There were reports of a lack of **consistency in social care**, with different workers meaning that people were unfamiliar with who was working with or visiting them. There was concern that this had an impact on people's dignity
- The **pressures on home carers** means that they are spending less quality time with individuals and rushing from one visit to another. This can mean that people don't see a regular or familiar face sometimes or people's routine patterns in life are disrupted or not taken into account when care visits are made
- There was a sense that social care in a rural area is not the best for everyone, especially around mental health. Greater use of and improvements should be made to existing facilities and provision – ensuring that they are not institutional

How could things be improved?

In order to address these challenges in Berwickshire there were a number of specific suggestions

- **"More NHS community-based provision** e.g. X-ray service in Berwickshire / Eastern Borders area."
- Community Council could have a role in helping communication about what's available in areas
- **Transition management** could be better, making sure that there were better handovers between staff and services and that people receiving care or accessing services were informed and supported through changes
- A **place planning approach** could be taken which looks at the capacity of health and social care to cope with population expansion and growth in demand
- A number of people commented on the informal support in towns and villages in the area and felt that there could be increased use of volunteers to support people needing help such as shopping, gardening etc.
- "We [the public] need to help you move away from beds and buildings by becoming less attached to what are the traditional models of health and social care ... to perhaps hub/care village models seen elsewhere in the world at locations where our local population need support now and in the future."

Priorities

1. GP access and dentistry provision
2. Communication and engagement with the local community
3. Better monitoring of service provision in terms of availability and quality
4. Promotion of the Borders as a great place to live and work in to attract health and social care professionals to address staff shortages, impact of retiring professionals

Cheviot locality

There were 88 responses to the survey from the Cheviot area (e.g. Kelso, Jedburgh). Whilst only two people attended the online and face to face sessions, a number of comments were also made about local services in the stakeholder sessions which are included here.

From the survey the most important aspects of health and social care that were considered important were seeing a GP in person, access to specialist care and support in own home.

The most important changes in the area were identified as primary care, adequate staffing and services working together. There were a few suggestions to improve these areas including attracting more staff to the area and improving social care pay and conditions.

“Making roles in these areas more attractive so there is the staff to deliver”

“To have adequate NHS provision for social care, supporting people in their own homes at a level which gives a good quality of life and professional carers receive pay and conditions which reflect their value to the community”

As with other areas there was a suggestion that the nearby community hospital could be used to provide more local treatment and support.

“Open the local cottage hospitals to walk ins like an A&E dept for example Kelso cottage hospital”

What do you consider to be the gaps in health or social care services at the moment?

Most mentioned issues (Codes)		Top Themes (Categories)	
Adequate staffing	9	Specialist support	20
Dentistry	9	Staffing	13
Collaboration between health and social care	4	Services working together	9

There were a number of suggestions to address the staffing challenge which included:

“More use could be made of nurse practitioners to help with more proactive follow-up with patients to reduce pressure on GPs”

“Staffing crisis in both - remove agency workers / bank staff and offer permanent posts with appropriate salaries. Give staff a sense of belonging and get stability back into the workforce”

“The post-code lottery is a 'gap' even within the region. The stress and workloads on the professionals are leading to lack of warmth and empathy”

These comments were again reflected in the local discussions and stakeholder discussions.

What is working well?

- **Emergency services and care** were generally found to be **excellent**
- In social care the carers are good
- The **Community Hospital is good** but has limitations in beds and what it can do. The role of the hospital seems to be unclear to the public– is it A&E, recovery, hospice, specialist? Palliative care is good
- Generally people told us that the **treatment / operations at the BGH** and the referral processes were good

What doesn't work so well?

- Some people identified that bed blocking is a problem, with some unable to access care when it is needed and others being discharged too early
- In social care at times the linkages between carers and providers need to improve to address gaps in care and support
- Lack of communication about likely waiting times and then suddenly receiving an appointment for the BGH at short notice, which can cause practical problems

- There is a problem with follow up care after people leave hospital where there appears to be a disconnect

How could things be improved?

- Mention of the need for community first aiders and greater community resilience to take some of the burden away from front line services and provide greater preventative action
- More investment in digital to make systems more joined up and seamless, explore how technology can help people to stay independent in their homes for longer
- Access to primary medical care when you need it – reduced waiting times and more responsive services
- More frontline medical staff
- Slimline bureaucracy

Priorities

1. Access to good medical care when you need it, including through community nurses and consider opportunities for greater use of the community hospital
2. Closer integration between health and social care – particularly follow up care from hospital in the community
3. Local planning and developing services, so that the voice of lived experience is heard

Eildon locality

We received 261 responses from people living in the Eildon area (e.g. Galashiels, Selkirk, Melrose) and there were discussions with 14 people at the drop in venue and the online sessions for the area (including people attending the local craft group).

The most important areas of health and social care identified in the Eildon areas were improving access, timely access to GP and waiting times.

“Having a responsive health and social care service providing right care in right place, right time and of high quality”

Key issues that were highlighted locally were pressures on GP services particularly in the Newtown St Boswell areas which had not expanded in line with new housing in the area.

“GP Surgeries have not been open and many are no longer fit for purpose. I live in Newtown St Boswells and with the pandemic and ALL the additional residents now living here it can no longer manage. A new building and new Doctors etc. are badly needed now!”

Preventative services were also frequently highlighted as a gap.

“Ease of access and timely access to services. As a relatively healthy person I find it incredibly frustrating that the health and social care system can now only cope with extremes - those who are very physically unwell and those who need a significant level of social care services. We need to be focusing on preventative approaches, not just intervening when there is a crisis”

Key changes needed in the area included adequate staffing, access to GPs, improving systems and community healthcare.

What do you consider to be the gaps in health or social care services at the moment?

Most mentioned issues (Codes)	
Adequate staffing	33
Access to GP	14
Communication between services	12
Sufficient funding	12
Long waiting times	12

Top themes (Categories)	
Staffing	49
Specialist support	27
Health and care in the community	23

“Inpatient care is excellent. Outpatient care is shocking”

“Staffing levels are low, thereby putting too much strain on the people who are working, making them leave for similar paid jobs with less stress”

“Serious levels of short staffing in Nursing, Medical and Social work. Retention, Recruitment and succession planning needs to be core to address this workforce crisis”

What is working well?

There were several positive examples of things that had worked well for the people we talked to in the Eildon area including:

- **Crisis support**
- Dispensing GP practices works well

- Gastro service in the Borders General Hospital
- Breast service and role of breast cancer nurse was very supportive
- **Range of helplines** – e.g. Marie Curie and support from sympathetic and well informed nurses
- Day surgery avoids need for admission to a ward and helps people get home quickly

What doesn't work so well?

There were concerns raised in relation to some specific service areas including:

- MRI scanning service – too long to wait when you need results leading to anxiety
- In relation to the BGH, follow up from hospital needs to be improved
- Concerns about the condition and need for investment in the BGH along with improvements in the pharmacy in the BGH
- Although the BGH is in the Eildon area, greater centralisation and transport were reported as concerns – in outlying areas there was a lack of public transport to if you are unable to drive. e.g. if you live in Fountainhall or Herriot there is no public transport and the use of taxis is costly
- Timing (access and availability) – care provision is not available at certain times and changing in carers can be disruptive/unsettling for people – example provided of older person with hearing and sight loss
- The right support at the right time when people in their own home needed a quick response and is not available quickly
- Some of those we spoke to felt that responsibility often falls on the community who a) may not be available and b) are not experienced or qualified. This might result in a misdiagnosis or a delay in people receiving the care they need
- People (family and friends) often end up being carers by default and there is a very real need for **carer respite**
- **Volunteers** can help but shouldn't be a replacement for professional services, they should be part of a fully functioning system that people can easily understand, get information from and access
- Frustrations with automated telephone services (abandoning calls as a result). Personal conversations were important
- Recognition that although many people are now comfortable with technology, the infrastructure and interface still have to work
- Questions were raised as to how appointments for people with limited sight, memory or other conditions can work effectively for them
- People found it difficult to get past the GP reception to speak to a doctor in person and were uncomfortable sharing personal medical information with the receptionist rather than their GP

- Sense that some GPs are unwilling to carry out face to face appointments
- People stated that they often experienced waiting a long time for GP call backs, which was very difficult if they needed to go out or were working
- Too short a duration of appointments

How could things be improved?

- More use of volunteers e.g. for prescription collections
- Promote more self-care e.g. more access to fitness groups and support for costs of classes. Social Prescribing can play a key role
- Staff working differently e.g. more use of specialist advisors and nurse practitioners to help address staffing challenges
- Need to provide more face to face and longer appointments, where more consideration was given to the wider wellbeing of the individual.
- Staff sharing across facilities and changes to shift patterns
- Carers: provide more support and advice including access to carers allowance and respite services. The ability to juggle caring with life very difficult, not helped by having to travel and other caring responsibilities. Perception of staff shortages in care homes. Lack of support for carers with no carers allowance and no respite
- Access to information and support to find it and fill in forms etc.
- Communication: Important to know what exists, where and when it is available, not just in terms of services but also in the community
- An effective responder service which can release pressure on the BGH A&E service
- Need to see improvements in residential care and, when people want it, the focus should be on keeping people out of care settings and in their homes
- Improve on-site support in sheltered or supported housing
- Focus should be much more about support and prevention rather than crisis management, cheaper and better for people
- Could Borders benefit from something such as a **First Responder service**, which would relieve the pressures on family and friends who may not know what to do due to lack of medical skills and knowledge if a situation arises?

“A proper professional Responder Service. Such a service has operated for many decades now in Falkirk, Stirling and Clackmannan council areas - Former Central Region. My wife and I had experience of their excellent functioning in the Falkirk area over many years with both sets of parents.”

Priorities

1. Communication needs to be improved, with care and health services telling people what is happening and when. Also access to information about what's available in terms of support and keeping yourself well.
2. More preventative support – particular reference to a first responders service to take the burden off friends and family with no medical experience or knowledge
3. Develop support to carers, including through respite
4. Primary care – improved access to GPs and use of advanced nurse practitioners
5. Joined up care between different services and professionals

Teviot and Liddesdale locality

There were 90 responses to the survey from the Teviot locality (e.g. Hawick, Newcastleton) and seven people attended the local drop in and online sessions. In addition a number of local issues were also highlighted in the more specific stakeholders' sessions which are included here.

The important aspects of local health and social care identified in the survey for the Teviot locality were improving access, appropriate care locally and reducing waiting times.

Key changes required locally were identified as communication between services, community healthcare, and adequate staffing.

“Communication - knowing what help is available or know where to go to find out. Often there is help, but only if you know about it”

“Home carers should be more valued. Home Care packages be delivered with better co-ordination; I hear of carers criss-crossing in their own car at their own expense like poor imitations of Amazon delivery services”

“Better communication between agencies, even considering co-location of teams working with similar groups, i.e. children and families, Health, Education and Social Work services to promote team working”

What do you consider to be the gaps in health or social care services at the moment?

Most mentioned issues (Codes)	
Adequate staffing	11
Sufficient funding	5
Long waiting times	5
Adequate conditions for staff	5

Top themes (Categories)	
Staffing	20
Specialist support	12
Resources	7
Health and care in the community	7

“The largest gap is the recruitment crisis within health and social care staff, the local population is aging with an increasing demand on the services. Pay for front line staff is comparable with roles such as hospitality however the responsibility is much more. A local review of current pay may support in reducing the recruitment crisis”

“Lack of funding limiting the service that both are able to provide and clearly the NHS are under huge pressure to deliver with limited staff and resources. While this has been exacerbated by Covid the system was seriously stretched prior to the outbreak”

“Any type of mental health services. Due to lack of service in this area people who are in crisis are attending GPs and the BGH where they are not receiving the correct care (which is not the fault of the Hospital or GPs). Dedicated mental health services that are easier to access for people when they need them will give these people the correct care and then free up A&E and GPs”

What is working well?

From our drop in and online discussions there were a number of areas that people felt were working well for them:

- NHS 111 was felt to provide a useful service particularly the ability to book an appointment that same day
- The **What Matters Hub in Hawick** was very good, but would like to see it expanded beyond just a day a week
- **Dementia Café** is good and provides a valuable service to people with dementia and their carers
- **Local connections** – the neighbourliness, with a close-knit community at a local level, and very strong and supportive family connections
- Social care, health centre, family and the local chemist

What doesn't work so well?

- Recruitment and retention of care and professional medical staff is a problem, where people have walked away from care due to wages, pressures and role. This is creating a lack of professional carers, with providers drawing on a diminishing pool of trained and suitable staff
- The localities model was felt to be a problem, not recognising that people tend to self-identify as a community and there were “at least 50 separate communities in an around Hawick”
- There needs to be consideration of **'place'** and the physical environment, with things such as drop kerbs, pavements etc. (including quality and state of repair) should be thought of in health terms and part of the prevention agenda
- Day support - some people said they “feel like prisoners in their own homes because [day] services don't exist”. This also impacts on carers for people who are considered to have lesser needs who want someone to provide intermediate support, signposting or assisting people with basic support while they are out and about
- A lack of clarity on what the community hospital was used for, saying that it was often thought of as ‘a place to die’
- There were mixed views about idea of a care village, but agreement that care options in Hawick need to be improved

How could things be improved?

- Health and care support to be ‘fine-tuned’ to the individual or family
- Need to address the shortage of social workers and care workers
- Needs to be greater and clearer flexibility on personal budgets through Self-Directed Support (SDS), including an understanding from professionals on how and what they can be used for). SDS funding not always appropriate for what is needed
- A shift is needed from ‘person centred care’ to ‘person directed care’
- Considering dignity and respect as a fundamental part of independence
- Public transport links to health and social care, but also to support staff working in these areas
- Revitalising existing community assets and facilities to support health and social care e.g., libraries, leisure centres
- Better communication on waiting times and hospital discharges

Priorities

1. Need to focus on the growing demands around dementia, including treating people with dignity and respect, good quality day services, support for carers and training for staff
2. Improving the assessment process for health and social care – through skilled and knowledgeable staff
3. Changing to providing people with/preparing them for what they need before they need it. Prevention focus
4. Attracting and retaining health and care staff to address shortages and pressures
5. Developing the strategy in order that it influences and reads across to others – e.g. placemaking

Tweeddale locality

There were 188 responses to the survey from the Tweeddale area (e.g. Peebles, Innerleithen). Whilst only three people attended the drop in and online engagement sessions, a number of specific issues were also raised in the stakeholder sessions which are included in this section.

The three most important issues that were highlighted in Tweeddale by respondents were timely access to GPs, improving access to services and support, and reducing waiting times. When asked what the most important local change would be, the three top responses were GP availability, primary care in the local community, and improving staffing.

Some specific suggestions were made to address some of these challenges including people taking more control over their own health and support:

“As someone who regularly takes medication for high cholesterol and high blood pressure, I would like a sensible system for obtaining repeat prescriptions. The current practice of only being given a month’s supply of statins means that every 2 weeks I have to remember to submit a prescription creating work for Haylodge Medical Practice as well as Lloyd’s Pharmacy who are under a lot of pressure. Why can’t I have a couple of months’ worth each time?”

“Supported self-care – self-care is empowering, but when things aren’t going well, it’s important that the right support is available at the right time, including provision of specialist/specific health care in the community to support physical and mental health”

Having access to and improving services locally was also raised in our discussions – particularly using the local community hospital.

“Having the Peebles out of hours small hospital for minor ailments back again! Ridiculous to have to drive to Edinburgh or BGH”

What do you consider to be the gaps in health or social care services at the moment?

Most mentioned issues (Codes)	
Adequate staffing	22
Long waiting times	12
Access to GP	11

Top themes (Categories)	
Staffing	31
Health and care in the community	17
Right care at the right time	16

Some comments highlighted issues around joined up working and services working more closely together which could address some of the challenges.

“Because of the lack of affordable housing especially for care staff it is extremely difficult to provide care at home for the expanding elderly population and this is a serious problem in rural areas, of which there are many in the region!”

“Obviously waiting times for appointments and treatment. Poor provision of care at home and lack of coordinated planning for such. This seems worse for communities at the edge of the Borders region where Medical Practice and discharging hospital are in the neighbouring Health Board”

What is working well?

From the discussions there were some areas that had felt to have improved in the locality including:

- The ability for GP practices to contact people using IT and the opportunities this had brought for professionals too
- Whilst some GP practices provided good access it was felt the **variation between GPs** further highlighted the importance of the style and approach of the receptionist
- Progress in setting up ‘Dementia Friendly Tweeddale’ over recent months
- Dementia Café – twice a month in Peebles
- **Peer support in mental health** is good, looking at a more collaborative way of working with and supporting people
- Work done on creating an NHS Borders Wellbeing Point which detailed local mental health services was recognised, but this was hard for individuals to find on the web

What doesn't work so well?

- Mental health: there is a need for better communication between localities on what is available and where, including mapping of how things connect
- When speaking with services, there were suggestions of siloed working and lack of understanding across professional boundaries

“Nobody can describe or provide information on what other services were available or what they do”. “We are really poor at sharing what’s available”.

- People don't know what's available, how to access things, what will happen when they do and when it will happen. People are reaching crisis point before they access services
- Perceived pressure to get people out of care, resulting in individuals being **discharged too early** and not provided with ongoing support
- Concerns about how to change the system and the culture. There was a sense that some professionals believed their area of work was more important than others: **“it’s always worked this way, so why should it change?”**

There was reported to be a lack of services for people with dementia and their families.

- People with dementia are entitled to one year **post diagnostic support** but this is inconsistent (people with dementia need a consistent pattern of support). Additionally, “No support for people for people with dementia and their carers after one year of post diagnostic support”
- Disinvestment in services for people with dementia e.g., cognitive stimulation therapy which used to be for 1 – 2 hours with OT but now stopped. The Carers café had stopped because of Covid and has not yet restarted. Staff ‘seemed tired’ with a lot of turn-over, although one good Occupational Therapist (OT) in the team, who had the ability to connect with someone with dementia
- Day care at Firholm hospital has closed and although the provision of care was problematic it should have been improved providing more stimulation, socialisation and not closed with no alternatives provided. Important for people to be able to make friends with other people with dementia
- GP’s approach and understanding of support to people with dementia could be improved, for example there is no regular contact from GPs, unlike regular reviews for other long-term conditions
- Phone appointments do not work for people with dementia and services need to be more joined up.

“When I eventually managed to get GP appointment, it was over the phone which is no good for people with dementia. When eventually saw GP, referred back to Mental Health Older Adults team but no idea how long will have to wait for an appointment”

How could things be improved?

- Recognition of a need for a better relationship between professionals/services and people
- Need to get better evidence of impact of commissioned services and that they have worked before commissioning them again
- Scope for a model of social return on investment in commissioning
- Recognise that it's hard to gauge the impact of many things on a short-term basis; some outcomes may take years to be achieved but this doesn't mean progress isn't being made
- GPs to keep register of people with dementia and do annual reviews
- Training in dementia for GP practice staff including receptionists involved in triage
- Better communication about how long social work and/NHS waiting lists are
- Reinvest in local services – involve community (not online, telephone, centralised, institutionalised, ghettoised). Reference to good practice centre in Kirriemuir <https://www.kirrieconnections.com/meeting-centre>
- Using data and evidence for targeting and prioritisation of services and support.
- Wider contributions to health and social care – for example the Third Sector getting involved to support people.
- There needs to be more of a focus upon prevention, acknowledging the importance of the primary care team including physio services and other allied health professionals. However, waiting lists for these services were too long with some people waiting locally over six months.

Priorities

1. Improving communication (and understanding) between services and with communities and those accessing services
2. Provide longer-term support for those with mental health challenges and support for people with dementia and their families
3. Working better together, improving access to services and increasing professional and support capacity
4. Prevention, not intervention



Stakeholder engagement

We engaged with **eleven groups of stakeholders** to listen to views from people with protected characteristics/from different equality groups to enable us to be inclusive.

In the sessions (some face to face, some online) we encouraged people to share their experiences and views on **what is working well** and **what needs improving** – as well as their **top priorities for the Strategic Plan**. It was important for each group to shape and feel comfortable with the discussion so the structure and topics covered varied between groups. For example some groups would focus on one or two key issues for them (e.g. accessing GP services) and share stories of good and poor experiences. Others covered a wider range of issues and priorities for the Strategic Plan.

We complemented the findings from the stakeholder engagement sessions with open text comments from the survey, analysed by stakeholder groups, and other recent relevant engagement reports (e.g. Carers Survey). These conversations and comments echo many of the consistent issues raised in the survey and the locality sessions while bringing out the ways in which they affected specific groups of individuals. They also raised some issues that were particular to a certain group.

1. Physical Disability Group (PDG)

An online meeting of 12 members of the PDG raised the following key issues as examples of what works well – and what needs improving – from members' experiences.

What is working well?

- **Having a strong user/carer voice**
The PDG grew out of the co-production of the initial Physical Disability Strategy and has since been involved in several updates. It also feeds into the Ability Borders Access Panel. Several members thought that being on the PDG and knowing more about the NHS made it easier to access GP and other services.

- **Role of the Third Sector**

The Third sector plays a crucial role in preventative services and quality of life. E.g. Ability Borders, RVS and Red Cross – which all have user groups for the voice of people with lived experience. The Third sector took a lead role during Covid and was well placed to respond as it was less prescriptive or bureaucratic than the public sector.

What needs improving?

- **Consistent access to GP services**

GP services are crucial as the first point of contact for people with long term conditions but experience is very variable. People on the PDG gave some **good examples of how GPs and Borders General Hospital continued to respond to health issues during Covid** and of GP practices where, during lockdown, arranging appointments and phone conversations with GPs worked well.

“Patients who phone the practice [in X] get an appointment – face to face if masked – and if tests are required, they are sent for tests at the hospital promptly”

Other people voiced **concerns about poor communication about/from GPs** including with follow up (e.g. after tests) and about routes to see a GP (e.g. triage system, options), **delays in seeing a GP and waiting for test results** and being uncomfortable talking to a GP receptionist about a medical condition.

“[In Y] you have to ring up at 8 am, when you eventually get through you are grilled by receptionist who says there are no appointments – it’s impossible to see a GP”

- **Accessing and communicating with social care**

There was also a range of experiences with adult social care. Some people were **complimentary about the support** they had received saying:

“It was very inclusive, very professional but personal. They kept in contact with us”

Others had **problems accessing social care** and in receiving consistent, ongoing care and support they required when living at home with long term conditions. They **recognised that staff shortages were causing delays** but felt communication should be improved

- **Joined-up/preventative services for ‘Living a good life’**

If health and social care provision only works in a crisis because of lack of staff, this affects people’s quality of life. E.g. the transition of young disabled people from school to adult services, who can get stuck in the

system without appropriate support; people who have to give up their job to care for a relative because no paid care at home is available, affecting income levels and health inequalities.

Top three priorities for the Strategic Plan

- **Address variation in GP services** – learn from good practice that exists. Improve and communicate the triage system/role of GP receptionists
- **Address staff shortages in social care and improve communication and consistency**
- **Join up** services to take a preventative, partnership approach in which the Third Sector has a key role, as shown during Covid

The session with the Physical Disability Group echoed the analysis of the **45 responses from people with physical impairments to the Strategic Plan Survey**. These focused on:

- **Better information about services** with suggestions of a directory and/ or a person who can be a single point of contact /provide liaison between service users and services
- **Access to appropriate, affordable housing** e.g. bungalows or ground floor housing
- Receiving care locally or via video call/telephone

“I have a disability and need someone to take me to my appointments which is hard work for me and a strain on time for my husband who takes me as he’s self-employed. Travelling from Peebles to BGH to have a conversation with a consultant is not a good use of anyone’s time and expense”

“Ensuring that there are centres in all towns and some larger villages where health and social care advice and support are made available”

2. See/Hear Group

We met with 12 attendees of the See/Hear group for an engagement meeting to hear about what’s working well and what could be improved in health and social care services.

What is working well?

- ECHO services for carers and people with sight loss are offering practical and emotional support and information - but they need to be publicised more
- Joined up approach to audiology and sensory services

- Technology is improving e.g. using technology more for follow ups and more support in people's own homes - but need to remember that [audio] technology doesn't work for everyone e.g. deaf people and those who use British Sign Language (BSL)

What needs improving?

- Waiting lists for audiology – these are getting longer so 'going in the wrong direction'
- Staffing shortages – often due to difficulties recruiting staff
- Need to use multiple formats and ways to engage people – some people prefer face to face contact which can conflict with professionals finding technology a better use of their time.

3. Mental Health Forum

We met with eight members of the Mental Health Forum at the end of August to hear about what was working well and what could be improved.

What is working well?

- Good example of **multi-agency response** to a person whose mental health was deteriorating. This approach showed what's possible, with key positives being: an easy to access GP, good communication between professionals and good clear communication by all. The individual then knew what was going to happen, timescales and who was going to get involved

“There was a speedy response and good communication from the GP to the mental health team and good links with the Distress Brief Interventions team”

- **Local Area Co-ordinators (LAC) workers** providing lower-level support and helping people to access community resources and activities
- **Mental health awareness training/** suicide prevention information being offered in sports venues, particularly rugby clubs
- **Input into service design and delivery** through co-production charter, people with lived experience on recruitment panels and involvement of Galashiels Resource Centre service redesign

What needs improving

- **Waiting lists** – for mental health but particularly for autism diagnosis

“For less severe cases [of autism] the impact on the family is still great. In one case it has taken two and a half years to get a diagnosis and then support in place”

- Need for **more joined up peer support** – between the different organisations providing it e.g. Breathing Space
- Lack of **engagement network for people from ethnic minorities**
- **Gaps in some services- e.g.** no specific services for people with eating disorders or gambling addiction
- Lack of services/ support for **people with borderline personality disorders**

Work has already been completed by Borders Care Voice to inform the **Mental Health Improvement and Suicide Prevention Action Plan**. Twenty-seven people with lived experience took part in this.

The **key themes** that were identified, which could feed into **priorities for the Strategic Plan** are:

- **Access to local groups** – physical activities/ social/ creative/ peer support
- Need for some form of **directory of services/ activities** available in Borders and local promotion of this
- **Awareness raising of mental health** in general with more focus on prevention of self-harm and suicide. Education around mental health from early age e.g. schools
- **Training on mental health and suicide prevention** available to a wider audience
- **Addressing low confidence and self-esteem** - perhaps through a buddy system
- **Peer support options**, local groups, Borders wide - online and face to face
- **Knowledge of what support is available** for a mental health crisis
- **Funding to support services** longer term. Existing and new and creative approaches

Other points to consider in the Strategic Plan are:

- Need to **combat stigma** and lack of understanding around mental health
- More **focus on prevention** – and the need to keep people out of hospital
- Better **information and support to carers**
- Importance of **people with lived experience influencing** at strategic level and service level
- Improve **consistency and communication** from [paid] carers

“Note the impact of other issues [on people with mental health issues] e.g. staffing, notably the shortage of home carers, money pressures etc. People with mental health also have additional stresses of caring for other family members and get further stressed when carers not available or there is poor communication. [We] need to know who is coming in and when”

The session with the Mental Health Forum echoed the analysis of the **70 responses from people with mental health conditions to the Strategic Plan Survey**. These focused on:

- **Better access to mental health services**

“Right now it's access to mental health services or any kind of NHS service. The waiting lists are so long & it's not ok”

“Help and guidance with anxiety and other mental health issues, especially for under 16-year-old as there is nothing available, according to our doctor”

- **Better communication from mental health practitioners**

“The way you're spoken to by members of staff, in particular mental health outpatient teams and inpatient”

“Social care / social work services being less risk averse and more willing to be creative and respond to what people say would make a difference to them (e.g. with SDS payment use)”

4. Self-Directed Support (SDS) Group

We met with five members of the Self-Directed Support Group (SDS) in September 2022

What is working well?

- **In a crisis, services do respond well** generally– one person gave an example of following a fall, the ambulance responded within an hour and moved person to hospital

What needs improving?

- **Access to GPs** –although this varied between and within localities
- **Communication** – about what GP and other services do and don't offer, what services are available and from whom, and with clarity and transparency about changes e.g. GPs are not doing ear syringing and small procedures, which leads to more pressure on BGH outpatients but on a positive note more pharmacies are offering medication reviews over the phone
- **Access and follow up by NHS dentists**
- **Out of hours services** - for things that are not urgent and for people with chronic conditions – if a wheelchair breaks down, there are no services at weekends leaving an individual unable to move/ get around
- **Anticipatory care plans** – currently not in place leading to crises occurring

- **Self-Directed Support** – works well for some but the main issue is recruitment of staff/ carers. The values and principles of SDS e.g. importance of choice and control are still not featuring in some social care assessments.
- There is a pre-assessment worker who can offer advice to people waiting for a social care assessment but there has been no training for SDS over the last three years for front line staff – although there is some discussion of this restarting. Need an approach to the patient / person with a **whole team approach and holistic plan**
- **Support and respite for carers** – need a discussion about day centres as family/unpaid carers giving support at home need to get some space – but there is a lack of suitable respite placements, which are often out of area and not able to cope with complex care

“Carers get forgotten- do people actually understand what it is to be a carer?”

Key priorities for the Strategic Plan

- Staff recruitment and training - including training to use equipment
- Communication – through a range of methods (too much reliance on internet to find information) and having a central source of information available

5. People with Learning Disabilities

We spoke with 13 people at two online meetings in September 2022. These included people with learning disabilities, family carers and facilitators.

What is working well?

- **Having a voice** – two people at the sessions were/had been Chairs of their **Local Citizens Panel (LCP)** and others appreciated the LCPs as a way of “finding out who to talk to [for information about services and support]” and feeding into service providers. There are around 60 people currently involved in the LCPs although there are concerns that “some people don’t know about them”. Members of the LCPs have also been involved in recruitment panels, developing good practice and new service developments
- **Community support** – In addition to **peer support** through the LCPs, people said that the Local Area Co-ordination (LAC) team is helpful and valued support from **Borders Care Voice** for family carers. One person mentioned the Kathryn Elliot Centre (KEC)

- **Involvement in community activities** such as walking groups and a gym for disabled people at Kelso High School. Engaging in stimulating activities with their carers or buddies

“Buddies are good but you have to find the right buddy who likes doing the same things, has the same interests”

- **Hospital liaison service** – including the ‘**Helping hands initiative**’, where a clock is placed above the bed in BGH when a person needs help - now adopted across Scotland

What needs improving?

- **Consistent use and better awareness of learning disability markers/alerts.** While there were some good examples of GPs, BGH and opticians using learning disability markers in people’s notes to enable a positive experience for people with learning disabilities, there were several examples where these were not available and/or not used by practitioners leading to frustration and miscommunication. In addition, people with learning disabilities and their families often don’t know about the marker/alert scheme so can’t ask for services to use it

“My son had a very good experience when having some teeth out at BGH. A Liaison Nurse from the LD service gave us a ‘passport’ to fill in which was then given to hospital staff. It was brilliant – but I didn’t know this existed; there’s a lack of communication about what’s available”

“When R went to the doctor at BGH outpatient, there was nothing on his notes about his hidden learning disability. Luckily, he went with his mum and dad so they could explain “but there should be something on my notes. There was when I had day surgery at BGH”

- **Transport for independence.** People with a learning disability often have difficulties using public transport – exacerbated if staying in a rural area. Particular issues mentioned included accessing transport without a carer/buddy and getting used to the PINGO bus (which can be crowded and noisy for people with autism). There are also problems if support services cannot get out to people living in rural areas and family carers cannot drive or worry about when they will no longer be able to

“I can only go to places with my carer, except for very local on my pushbike. So I just count rabbits and crows!”

“What’s important to me is getting out and about – I need someone to help me do this”

- **Social care support** – which can work well, but not for everyone. Staff need to have right approach and understanding. Carers don't have enough time to spend with people. Strict eligibility criteria mean that some people only get services when there is an identified crisis– but not preventative support – or sufficient support for complex needs

“R had a social worker but then they moved on. He was told he didn't need one but would like to know why “You get stuff done with a social worker – they get the ball rolling”

- **Day support services** - Some people are happier coming out of day services but still need activities and stimulation. Some day-centres have closed but a new service is being commissioned and family carers have been involved in this, although this needs to be communicated more widely

“People want to know what's happening with Day Centres. There's a review going on. A range of support is important but people with 'critical and substantial needs' need something physical in each locality”

- **Carer support and respite** – some carers would welcome additional respite support to give people time away from caring responsibilities but with more good experiences for people e.g. Jumbulance holidays where people have a good holiday with activities
- **Communication** – it's often a problem knowing who makes decisions and who to go to for information about services, particularly during Covid and about what's happening in the community

“I asked for a Social Work structure chart but didn't receive one. How does the system work? Nobody knows – it's like M15!”

- **Volunteering and work opportunities** – which are really important for people with a learning disability for independence and self-esteem. One person volunteers weekly at a local club for people with learning disabilities but others faced barriers to participating in volunteering or paid employment because of lack of transport, support or information

6. Dementia Working Group

Borders Care Voice and the Dementia Working Group (DWG) held a **dementia voices film launch** – ‘Living Well with Dementia’ in September 2022. We attended the film launch, which showed people talking about their experiences of dementia, and which was attended by 40 interested individuals, people with lived experience and their carers, third sector representatives and professionals.

Key themes from the films

- Importance of clear communication – to be given correct information and not false promises
- Impact of dementia in terms of a spatial perspective - confusion can be alleviated by use of different colours e.g. dark toilet seats.
- Importance of support from friends and family but also from sharing experiences with other people going through the same process.
- Post diagnosis support is not available “The doctors did nothing to help”
- Services have not restarted since COVID
- Concerns about people with dementia who live alone – what support do they get with no family locally?
- Dementia cafes are helpful but carers also need have some time to get a break. They need respite care/social activities for people with dementia where personal care can be provided (e.g. going to the toilet so the carer does not have to be there)
- Important for people with dementia to be understood and to be yourself

We also joined in the **group discussions and spoke to some individuals** with dementia and their carers, who raised the following:

- Need for **carer support** for carers to have a break – with stimulating activities also available for the person with dementia
- Lack of social carers due to recruitment issues so Self-Directed Support feels like it puts the onus back on the families
- There is work in Peebles to develop a Dementia Friendly Communities and set up meeting places which could be taken forward in other areas across the Borders
- Alzheimer’s Scotland has two workers but there is a need for more support for carers through day supports and personal care for people living with dementia at home

One carer at the event sent a letter describing her journey as a three-legged race:

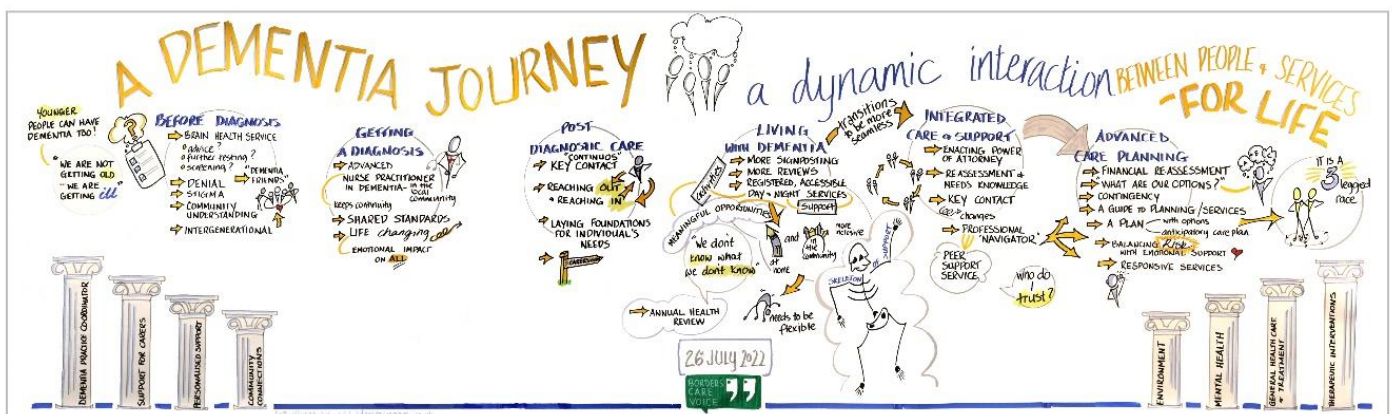
“I want to remain at the heart of the team of my husband and I both living with his dementia. I don’t want to find myself one day confessing to hitting him in desperate frustration because I’ve run out of reserves or failed to rebalance myself when the 3-legged yoke yanked me over. I want to talk about the frustration and exhaustion and feelings of inadequacy (the times I shout and am then ashamed – some of the ‘poo’ of our lives) and have it heard – not just with sympathy, but with action - with services designed for both partners in this unequal partnership to manage to keep going. And with those of us actually living this life – running this 3-legged race - being included at the core and the start of every planning team (including plans to cut/reshape services)”

Priorities for the Strategic Plan

Key priorities identified in recent work by the Dementia Working Group (DWG) reflect the support and services needed throughout the dementia journey. These include important elements needed at each part of the journey:

- Before diagnosis- good advice and screening services
- Getting a diagnosis- recognising the emotional impact on all involved
- Post diagnostic care - key contacts, consistent support and information
- Living with dementia including more support from registered day and night support services: support for carers and meaningful activities for the cared for person
- Integrated care and support- professional navigators, reassessment and reviews
- Advanced care planning – including financial advice and future care planning and crisis plan

An infographic showing the journey has been created by people with a dementia diagnosis and carers.



7. Carers

So as not to duplicate the HSCP's recent survey of unpaid carers, we did not hold a separate engagement session with carers, although we have referenced comments from carers who attended other stakeholder groups. We have also analysed the 206 responses from carers to our Strategic Plan survey - and used the findings from the carers' survey from the report 'Needs Assessment of Unpaid Carers in the Scottish Borders 2022' - to inform the questions we have been asking stakeholders to feed into the Strategic Plan.

a) Analysis of Carers' responses to Strategic Plan survey

We asked people 'Thinking about your health and/or social care, what is the single thing that matters to you most and why?' Carers' response was:

Most mentioned issues (Codes)		Top themes (Categories)	
Timely access to GP	26	Right care at the right time	43
Improving access	23	Primary care	39
Reducing waiting times	14	Specialist support	24

The open text responses to this question focused on **the need for support to carers and the people they care for**. Typical comments were:

“Improving support to carers especially unpaid carers such as spouses, partners, children, parents, etc... As this seems to be the prominent issue that often falls between the gaps”

“Provision of day services for older adults in the community. It keeps them active which improves physical and mental health, it addresses loneliness and social isolation and it gives elderly spouses with their own health issues opportunities to rest (which supports them to continue caring) while cared for spouse gets positive effects noted above”

“That unpaid carers, particularly those caring 24/7, have regular respite across a variety of options. Stressed burnt out carers mean 2 people require health and social care input instead of 1”

b) Needs Assessment of Unpaid Carers in the Scottish Borders 2022

What works well?

- **Support from organisations in relation to their caring role** – including from Borders Carers Centre, Meeting of Minds, BANG (Borders Additional Needs Group), Social Work teams and Mental Health teams (MHOAS and CAMHS), Dementia Cafe and Macmillan amongst others

What works less well and needs to be improved?

- **Carers' own health and wellbeing affected by their caring role** due to increased anxiety, exhaustion, time and unable to leave those they care for alone.
- **Support from GP practices in relation to their caring role** – e.g. support from Practice Managers or Practice Nurses

- **Time out for carers** – with a lack of appropriate services being the biggest barriers to time out for carers. Other barriers included a lack of choice and flexibility, a lack of paid carers with appropriate skills and an insufficient personal budget
- **Better information** – suggestions included a centralised website, clear signposting at an early stage, improved communication between linked services, locality specific information, regular email communications and updates, more face-to-face support groups in the evenings and at weekends to support working carers, and more information displayed in GP surgeries, schools and hospitals, including information booklets to take away

8. Borders Older People's Partnership

We met with four people from Borders Older People's Partnership (BOPP) in August 2022

What is working well?

- **Working with Department of Works and Pensions (DWP) and partnership working** more generally, for sharing information and intervening early to avoid crises
- **Community responding and community resilience groups stepping up during the pandemic** – important not to lose that capacity
- **Use of technology** for people to keep in touch during the pandemic and ongoing. This helped address isolation and enabled people to attend meetings with support to access devices provided. Borders Care Voice offer free training for informal carers and others – need to publicise this more

What needs improving?

- **Issues about volunteering** – e.g. Food Train struggling to get volunteers
- Concerns about the **cost of living crisis** – many older people are retired and now needing to use their savings to manage increased fuel bills etc. This - and the pandemic - has an **impact on mental health and social isolation** that need to be addressed
- Need to provide more **information** e.g. pension credit needs to be publicised
- Concerns about **staffing and recruitment leading to waiting times**
- Importance of **working together** between all agencies and communities e.g. greater use of pharmacists, advanced nurse practitioners - but people not always aware of these options

Key priorities for the Strategic Plan

- Provide good information and advice about what is happening and support at local level – this helps with prevention

- Continue to develop technology – this can address social isolation for those who are housebound
- Providing the right care, at the right time and in the right place
- Providers need to work together to provide support

9. People from Ethnic Minorities

We attended a face-to-face meeting facilitated by Farne Salmon, based in Duns which was attended by 18 employees from Ukraine, Poland, China and Portugal to discuss their experiences of health and social care. This was a younger group of people, some with young families, than most of the other stakeholder groups we spoke with.

What is working well?

- Pharmacy in Duns offering consultations and support – and relieves pressure on GP services
- Free prescriptions
- Booking an online consultation with a GP (example from across the Border)
- Ambulance response times have been good when needed

What needs improving?

- **Access to primary care** including greater consistency to see a family **GP and NHS dentist**. There were stories of difficulties and/or long waits to see a GP (mainly in the Duns area) and long waits/travel times to for an NHS dentist. Longer opening hours for GPs would help those working

“You need to ring at 8am to get an appointment – but you’re not able to do that when working – so people then go to A & E when it’s not an emergency and end up with long waits [there]”

- **Transport – direct public transport is** not available to BGH – one man we spoke to drove over an hour to reach A&E with a broken wrist
- **Communication** – information in **people’s own languages** needs to be more readily available. Translators can be found but sometime people have to rely on staff in the hospital or rely on friends or colleagues to translate. This can be problematic especially when talking about medical issues e.g. cancer or very personal details.
- **Information about how to volunteer** to help others, which is much more common in people’s home countries. but in order to get involved, people need to know how they can help and how to go about it
- More use of **technology**
- **Improved access to mental health** services/support

Priorities for the Strategic Plan

- Better access to GPs
- Recruitment of health and social care staff – technology may help
- Availability of NHS dentists

10. People in the LGBT community

We were supported to circulate the key engagement questions through the LGBT networks and received written feedback to our questions from 13 contacts in the LGBTQ community. The summary of responses is shown below.

What is working well?

- **Good experiences with GPs – for some people.** Comments included “Excellent GP where I live”, “My GP is good, BGH handy, pharmacy poor”, “Good GP access”
- **Access to free travel**
- **Local support – from services** including home visits from medical professionals and visits from a person’s housing association. Peer support **through friendship and voluntary work** was also valued

“Great support network and lots of friends”

“Cafe Polari [once a month alcohol-free drop in cafe for LGBT people and friends]”

A number of people said nothing or very little was working well for them especially following Covid.

What needs improving?

- **Recognition of LGBT rights and needs** and **LGBT Equalities training** for Health and Social care staff for a better understanding of LGBT people. There were concerns that ‘using protected characteristics being under a total Equalities umbrella’ allows people to ignore specific LGBT rights and needs

“GPs being ignorant of trans/queer people” and “We have little visibility within the community”

“Communication, confidentiality, and trust between patient and professional needs to be improved”

- **Reassurance on safety for LGBT people** for personal choice and dignity when accessing health and social care resources. Better communication and more publicly available information to provide reassurance

“[I’ve] not spent much time in hospital for physical health but recently had a cystoscopy at BGH and felt humiliated at the procedure. They had to fill my bladder with water then drain it and then immediately after without my legs being dried or body appropriately covered I had to walk from the procedure room past the public waiting room to the changing room”

- **Mental health services** – appointments are hard to get, GPs lacking understanding of LGBT people with mental health issues and often only attempting to help people through medication, lack of communication resulting in stress. More investment needed including in suicide prevention through meeting spaces and activities
- **Invisibility of older people** and improvement of health and social support for this age group

“I’ve noticed that when someone reaches a certain age they are invisible to GP and the medical profession. Any aches or pains put down to old age”

“The elderly needing care get ignored unless there is an emergency. Why do they not get an annual health check and meds review? Things change for them as for anyone else in the community”

- **Access to primary care** – although some people had good experiences with GPs, others had difficulty in getting face to face appointments with GPs (even after telephone screening). There were also **transport and communication barriers** to getting access to community nurses or health and social care workers in rural areas out with the main centres of population, sometimes resulting in poor outcomes, such as through late cancer diagnoses

“[We need] good transport links, good internet, access to carers, access to services (particularly mobile services for rural communities), better publicity about what is available to people”

- **Local and community support** – through **GP practices and visiting practitioners offering more in-house/local care** e.g. physiotherapy, chiropody, counselling, OT, which would improve access and reduce hospital waiting lists. **Support to reduce social isolation** (exacerbated by Covid) especially for older people – and through more opportunities for physical and social activities like walking and cycling
- **More meaningful consultation and involvement of LGBT people** - as they were thought to be invisible within the Strategic Plan. This needs funding for a platform (and other support for premises, link worker etc.) for LGBT people to speak up about their experiences and be involved in planning,

designing and delivering services to LGBTQ+ people (beyond the strict medical model of provision)

“How do you as an organisation monitor any issues raised by LGBT community, and how likely is it that someone who has a bad experience will have the confidence to raise it and with whom?”

11. Homelessness – Housing Strategy engagement

We attended an online Homelessness workshop in August 2022, held as part of Adair Consultancy’s work to develop the Local Housing Strategy (LHS) 2023-2028. Unfortunately no formerly homeless people participated in the workshop, even though 400 people with previous lived experience of homelessness were invited. Instead, we discussed with the consultants their **Housing Issues Paper on Homelessness**. This is based on progress made on the previous LHS (2017 – 2022) and feedback from an **early engagement survey** carried out in Oct – Nov 2021. Relevant information to the Strategic Plan is as follows.

What is working well? Progress on current LHS

- **Adoption of new outcomes in current LHS:** “Promote independent living & tenancy sustainment through effective delivery of housing support duty” with linked strategic action to: “Improve access to health and social care services for homeless people, particularly for those with complex needs by working with integration partners”
- A **Borders Homelessness and Health Strategic Partnership** was established during 2018/19
- **Housing First** (2021–23 pilot) is a first response for people with complex needs and facing multiple disadvantages. It will work in collaboration with the HSCP, and other relevant services, to ensure tenancies are supported and sustained

What needs improving? Findings from Early Engagement Survey

Although health, care and wellbeing did not appear in survey respondents’ top three priorities, there were findings about what needs improving (with illustrative quotes from the Housing Issues paper):

- **Shortages in local housing provision - people have to move away from support networks**

“There has to be some recognition of locality for homeless people. I have come across people forced to move from Peebles to Kelso as they are only entitled to one offer and if they refuse this then the Homeless service won’t assist them further. The Borders is a huge area and this cuts people off from their social supports”

- **Shortage of safe homeless accommodation for vulnerable groups of people**

“There is an acknowledged lack of safe homeless availability for adults and young people at risk who are also vulnerable. There is also a shortage of local supported housing for younger adults with disability, mental health, addiction or other support needs”

- **Joined up approach for individuals with mental health problems**

“There needs to be better communication between the IJB and housing to ensure individuals within our communities are receiving the correct level of support to ensure tenancy sustainability. Private landlords must be held more accountable regarding stock condition and affordability. After the pandemic more people are suffering from mental health problems so investment must be prioritised for more supported accommodation”

- **Lack of affordable housing for key workers in NHS and social care**
Raised by the consultants as a housing issue (rather than homelessness specifically) that affects health and social care through contributing to staff shortages



Summary and conclusions

Consistent themes from the engagement sessions

The face-to-face and online engagement sessions reinforced the survey findings about the **important principles** of:

- **Maintaining independence** – staying in your own home, in your existing community.
- **Effective communication** - between services and you, knowing what's happening, when and how and between different parts of the health and social care system.
- **Living a good life** – helping you stay well, with opportunity for employment, meaningful activities, maintaining health and happiness

The discussions about 'what is working well', 'where are the gaps and what needs to be improved' and the 'Priorities for the Strategic Plan' differed between the locality and stakeholder groups as detailed in the previous sections and illustrated by specific examples – but there are **clear consistent themes and key messages** from across the groups.

What is working well?

- **Strategic involvement of some groups** in developing strategies and service redesign– e.g. People with Learning Disabilities via Citizen's Panels who are part of recruitment panels; Physical Disability Group involved in the development of the Physical Disability Strategy
- **Crisis intervention.** An emergency response was there when needed for most people and many people reported positive experiences of in-patient care at the BGH.
- **Role of Third Sector for community support.** This came to the fore during Covid and needs to be built on to harness community assets and expertise. There are strong communities in the Borders who are keen to work together with the Council and NHS
- **Peer Support** services in mental health are welcomed along with the recent additional investment in this service together with the Local Area Co-ordination services helping people to access community supports. The

Dementia Working Group provides support for people with dementia and their families supported by Borders Care Voice

- **The range of community and third sector groups that engaged** in this exercise and enable people with diverse lived experience to have a voice about services in local communities e.g. Dementia Working Group, Citizen's Panels

Where are the gaps – what needs improving?

- **Consistency of access to GPs** - some good experiences but also real difficulties with seeing a GP, particularly in Berwickshire and for people with long term conditions
- **Workforce challenges and staff shortages in NHS and social care.** People were aware of these and the impact of this on waiting times and access to services. There was discussion about recruitment and retention of staff as well as the need for staff training and support.
- **More support for family/unpaid carers.** Whilst there were some welcome local support initiatives such as dementia café's more local support services were needed especially when caring for people with complex care needs through home care, specialist day services and respite.
- **Post-diagnostic support for people with dementia** – with the lack of this means there is a gap in GP and other support between a diagnosis and 24-hour care and support.
- **Access to NHS dentistry** – which has worsened following the pandemic
- **Better links between services** and more joined up service responses e.g. Housing, Transport, DWP with Health and Social Care – so that there is access to services which takes account of individual needs and reduces barriers.
- **Better communication** – keeping people informed about waiting times, clearer more up to date information about what is available - where to get what, when needed. Greater awareness of rights (LGBT people) and better training about how to communicate with particular groups e.g. people with learning disabilities (use of markers), multiple formats for people with sensory impairments, and communication
- **Engagement that involves people with lived experience** at an early stage of planning and designing services e.g. LGBT people, people with learning disabilities
- **Access to local health and social care services** – many people felt that there needed to be more local health and social care services and that

existing facilities such as community hospitals could offer more to provide local care. This would help to address the **lack of transport** which is also a barrier than when accessing central services, particularly for people in very rural areas and with physical disabilities and/or learning disabilities.

How can people and the community get involved?

There were a number of key areas which people and communities themselves identified could help maintain and improve their own health and care. This included accessing local community activities and participating in community sports and social activities to keep as fit and well as possible. People spoke of being able to provide peer support and befriending opportunities and also were keen for opportunities to be involved in employment opportunities and volunteering.

Some individuals were already taking these opportunities but there is scope for improving information about them as well supporting all groups of people to participate in them.

Priorities for the Strategic Plan

The locality and stakeholder groups discussed their priorities for the new Health and Social Care Strategic Plan. There was a high degree of consistency in the emerging priorities, albeit with specific details and nuances for particular groups. The top priorities, chosen by five or more groups are as follows:

- **Communication** about how services can be accessed when needed, likely waiting times for appointments and test results, and information available in different media and formats. New technology has an important part to play but recognising there is still a need for some in person meetings and consultations
- **Engagement of local communities and stakeholder groups** so people with diverse lived experience can participate in service planning, design and monitoring.
- **Consistent access to primary care.** Including to GPs, NHS dentists and community nursing services, especially for ongoing support for people with long-term conditions
- **Workforce planning and addressing staff shortages** - with suggestions for promotion of the Borders as an attractive place to live and work, and looking at improving access to transport and affordable housing for health and care workers

- **Integration and joint working between services.** To improve person-centred approach. This is needed between health and social care but also better links with transport, housing, employment support etc.
- **Improved access to social care and support** to improve access to social care to support people to live at home and to address the interrelated issues of waiting times for assessment, eligibility and Self-Directed Support
- **Support to carers.** Especially but not exclusively for carers of people with dementia including through respite care to provide socialisation and stimulation for people with dementia and/or other disabilities and respite for carers
- **Preventative approach.** To reduce the need for crisis responses and pressure on acute services. Enabling early intervention and holistic, community-based support to improve people's quality of life
- Reflecting the rural nature of the Border more access to **local health and care services and improved transport** to access appointments

Key messages from Community Engagement

The people of the Scottish Borders have engaged openly and actively around the HSCP Strategy, welcoming the opportunity to input, inform and shape decisions around services and support available in their localities.

In many cases, people described the quality of services that they had received from health and care staff as good or even exceptional. Concerns tended to be about systems, communication and accessing services.

Whilst the availability of resources is an important factor in the determination of priorities in the Strategic Plan, a number of the improvements and ideas that are summarised in this report could be viewed as ones that may not require significant resources; rather they require a shift in approach, thinking or ways of working.

There appears to be a gap between what is known by services and what is known by the community itself. There is sufficient evidence - albeit often anecdotal - that professionals who have worked in and with a community for a period of time, get a sense and knowledge of that community, both its needs and its assets. Equally, community facilities and activities are often available, but not known about by professionals, creating missed opportunities to join up statutory services and community supports in a person-centred approach.

This community involvement in health and social care – in its widest sense – is vital. It ranges from participation in planning and service design, monitoring and

giving feedback on services, setting up local groups and activities, and volunteering and providing peer support.

Listening to the voice of local people to inform the development of the Health and Social Care Strategic Plan 2023-26 is the first step in genuine engagement, involvement and participation in the co-production of services.

This co-production is based on the active involvement of those accessing or needing supports, bringing their lived and diverse experience to designing services, being part of the decision-making process and having opportunity to get involved in provision.

This engagement exercise for the Health and Social Care Strategic Plan is a good platform on which the HSCP can build by creating an ongoing partnership with local people and communities as well as with a wide range of services and stakeholder organisations.