

Information sharing to improve care support: Summary of findings from regional forums

September 2023

About the National Care Service

The Scottish Government is working with people and organisations across the country to improve community health and social care support in Scotland.

We want everyone to have access to consistently high-quality local services across Scotland, whenever they might need them.

That's why we are introducing the National Care Service (NCS) and shaping it with the organisations and people who have experience of accessing and delivering community health and social care support.

Introduction

Throughout the summer of 2023, we held a series of regional events across different communities in Scotland as part of our on-going work to co-design the National Care Service. These took place in places from Stranraer to Shetland and were chosen to ensure we worked with both rural (mainland and island) areas as well as town and urban areas. We also ran online events for people who could not attend in person. This report is a summary of what we heard from people and what we will do next to continue co-designing the National Care Service with the people and organisations who need or deliver community health and social care support.

At each of these regional events we ran three co-design theme sessions as well as more informal drop-in lunchtime sessions. In some areas we also went out to local organisations to run additional events on their premises.

The sessions were all aimed at people:

- with lived experience of community health and social care support
- with lived experience of working (in a paid or an unpaid/carer capacity) or volunteering in community health and social care
- or who have an interest in community health and social care in Scotland

The total number of attendees at these events was 606.

The co-design sessions related to one of the five current co-design themes of the NCS:

- Information sharing
- Keeping care support local (part 1 local services and part 2 community health care)
- Making sure my voice is heard
- Valuing the workforce
- Realising rights and responsibilities

The first part of each session involved sharing our current understanding of:

- people's current experiences of health and social care
- where people felt the changes to community health and social care in the National Care Service should be focussed

We wanted to check with people if our understanding was right and if we had missed asking any important questions.

In the second part of each session we then asked people to share their ideas about how to solve the problems or make the changes we had discussed in the first part of the session.

This report is a summary of the key things that we heard from people. We will use the full detailed feedback we have gathered to develop further co-design work with people and organisations over the next 18 months, as we move towards the final decisions about the design of the National Care Service.

We will also run additional sessions targeted at children and young people, as well as at people from groups who we know are currently under-represented in this work. This is to ensure that the National Care Service reflects and meets the needs of all the different kinds of people who need to use and work in delivering (whether paid, unpaid carers or volunteers) community health and social care support.

About Information sharing to improve care support

This report relates to the feedback we have gathered from Information sharing to improve care support theme. This was collected at the events in:

- Stirling
- Dundee
- Stranraer
- Oban
- Strathpeffer
- Elgin

There was also an online event on this theme for people who could not attend an in-person event (for example due to ongoing concerns about Covid).

In total 97 people took part in Information sharing to improve care support sessions.

The theme focuses on three main areas requiring improvement. These are:

- the provision of care support information
- sharing of information between health and social care professionals as part of a person's care support
- people being able to easily access their own social care support information in order to be involved in decision making

The theme covers a person's journey from the first step of accessing information about what services are available, to receiving care. It also covers information about them potentially being shared between professions.

How we ran the sessions

People who attended took part in group discussions and completed group exercises. A week before each event, we sent participants a summary of the questions we would be asking during the session.

On the day, we explained the discussion topics and provided written information to make sure the questions were clear.

During the sessions the topics we covered were:

- information that people may want to share
- information people need to feel informed
- information they feel should be shared about them
- how they would like that information to be shared

We provided an example for how the Care Record could look and the types of information it could capture.

We wanted to find out what people understood about their rights and responsibilities around personal information, and how we can better explain this to them and others.

We also collected feedback about how people felt the session itself went at the end and used this information to improve how other sessions were planned.

This was to make the regional forums as accessible as possible for participants and to make sure we were asking the right questions. Because of this, the discussion questions changed slightly between the first regional forum and the last regional forum.

What we learned

We have gathered valuable feedback from the sessions.

Some of the most common issues that were raised across the sessions include:

- keeping people's information safe and secure
- giving people a say in who their information is shared with
- how sharing my information could improve people's experience of accessing social care support

In-person sessions

These are some headline themes which have emerged from the in-person co-design sessions. They are based on feedback on the 'about me' information, which people will be able to add and manage within their own Care Record.

'About me' information aims to include information about someone's life, what is important to them, and will provide context for the planning of their support and care. This will not include the information which is already shared between health professionals.

People want to be informed about information sharing

We heard that:

- people want to understand what is shared about them and with who
- there is a lack of confidence and understanding around GDPR and rights amongst general public in relation to viewing data and records

We need to build trust around information sharing

We heard that:

- building trust around information use is key to information sharing
- there are concerns about who has access to personal information and the consent around information sharing
- the experience of digital exclusion or lower levels of digital capability can affect people's attitudes towards information sharing
- some are open to sharing their information without barriers if they trust that it can bring benefits

The use of the Care Record needs to be person-centred

We heard that:

- people want to be respected and supported to make their own decisions about care
- people want to be able to manage how information is shared
 - people feel they should be able to decide who they don't want to share 'About me' information with
 - people want the ability to update how their information is shared
- people want to be able to manage what information is shared
 - people want the ability to update what information is shared
 - people want greater clarity around their rights to sharing information
 - some people want to be able to create a Care Record prior to any social care support being needed, to allow for future planning
- personal decisions about what information to share and who the information is shared with depend on circumstances and can change

- deciding on who from someone's support network should have access to their information is complex and unique to the individual
- sometimes personal information can be deliberately left out of a record by choice – for example, distressing information that can potentially retraumatise the supported person

Information sharing practices need to keep people safe

We heard that:

- there should be clarity around the types of information people can input into their Care Record and how this will be used so that it doesn't hold unnecessary information
- sometimes information needs to be shared with people or services for safeguarding reasons
- there needs to be a process for an emergency use of information to ensure that someone is safe
- there needs to be a process for handling the sensitive information held on a Care Record
- support is sometimes needed to help the supported person share their information

The Care Record and information sharing can make a difference to people's support and care experience

We heard that:

- the Care Record can relieve the emotional burden of information sharing, such as the negative effects of having to repeat your story
- the Care Record can be used as a tool to enable person-centred support
- the Care Record can help care and support to focus on outcomes
- the Care Record can help make people's experiences more joined up across different services
- flexibility of care delivery and faster responses to change are needed to deliver the care people need. This includes quick changes to information
- access to information about services can help or cause barriers to care and support

The workforce needs to be supported to share information more effectively

We heard that:

- information being shared properly and securely by health and social care support staff is key, and the responsibility for information sharing should not lie solely with the supported person
- understanding and implementing effective GDPR practices by the workforce is key for effective information sharing and are sometimes perceived as a barrier
- access to training around how staff should capture and share information is a challenge

- there are concerns about how organisations are sharing information differently
- the existing information sharing and decision-making culture between and within services should be improved
- concerns around staff not using the information they have access to, to make care and support person-centred
- social care support staff feel undervalued and workforce fear increasing information sharing means taking on additional work
- workforce hierarchy affects frontline staff's access to information and the perceived credibility associated with what they share with other professionals
- effective information sharing is also vital in keeping staff safe, for example flagging if a supported person should be visited with at least two members of staff
- information sharing should be supported beyond community health and social care support services for example, in schools, prison services, police

How the Care Record will fit into existing information sharing practices

We heard about the importance of:

- co-ordinating with existing initiatives for information sharing (including single shared assessment, anticipatory care plans, health passport, red bag)
- recognising that personal relationships remain vital in sharing and understanding information between the supported person and professionals

Testing the Care Record

From testing an example of how the Care Record could look in the in-person sessions, we also gained a better understanding:

- of the top four information priorities for people:
 - 'how I communicate and how to communicate with me'
 - 'what is most important to me'
 - 'people who are important to me'
 - 'how and when to support'
- that there are differences in priority for how professionals and supported people want information to be ordered in their view of the Care Record
- people want their care record to capture positive and broad information about themselves – for example, 'my wellness' and 'my hopes, goals, aspirations', and not just the things that they cannot do and need support with
- recording more information about people within a Care Record that the things they need support with and why could help support independent living and be a way for people to self-advocate for their choices

Online session

The following points were gathered in the online information sharing session.

The Care Record

We heard that:

- there should be more focus on the integration of health and social care support in how the National Care Service (NCS) and the Care Record are being presented, as currently people feel it is too health-focused
- there is fear around the use of the word 'care' in isolation without the context of 'social care and support'. This is because 'care' has associated health connotations when not all people in receipt of social care support require a health intervention.
- some people recommended that there is a focus on the social model of disability in the presentation of the Care Record as opposed to a medical model

Awareness

We heard that:

- the purpose of the Care Record (for the workforce and for people accessing social care support) should be clear for everyone
- messaging around the Care Record will be key in helping people understand that their Care Record will include not only health and social care support information but things that support them to live and important things they would like people who support them to be aware of– for example hobbies, aspirations, goals and communication needs

Trust

We heard that:

- there is a lack of trust of the current social care support service landscape and having meaningful choice around how information is shared about them would help people build trust around the services they use
- having control over their personal information is seen as important for establishing a good balance of power between people who access and people who deliver social care support

Sharing

We heard that:

- there is a need for transparency about what information is collected and who it is shared with
- people want the Care Record to make accessing and sharing information more equitable across the workforce in all the community health and social care services people get support from.

Next steps

What's next for Information sharing to improve care support

The insights from the information sharing sessions will be used to further develop the understanding of what the Care Record needs to do and inform potential policy changes required to make improvements to information sharing.

The findings will also be used to inform the creation of an example Care Record that can be tested with those who will use it.

This work will continue to be co-designed and tested with the people who access and the people who deliver community health and social care services.

The insights we gathered in these sessions also highlighted differences between those delivering care and those receiving care in terms of what information is important to them. We will look at this in more detail with people delivering care support to understand:

- what information is priority for them (by profession or role) to help them carry out their work
- what information should potentially not be shared with the person in receipt of care
- approaches to how best to provide information

We also found that there are issues and concerns with information sharing between professionals in terms of:

- access to information
- knowledge of information security and rights
- lack of support and training

We will also discuss this in more detail with those delivering care support.

People have also told us that they expect to see some care planning information in their Care Record, and that the Care Record can play a role in enabling person-centred care and support. Further co-design work with the workforce will help us explore the links between the Care Record, the care assessment, and the care plan.

What's next for the National Care Service

The Scottish Government remains committed to delivering a National Care Service to improve quality, fairness and consistency of provision that meets individuals' needs. We are also working to make improvements to the social care system now.

What we have learned during the summer events will inform these early improvements, as well as the future structures and policies of the NCS, including the National Care Service (Scotland) Bill.

The Bill is currently in Committee stage in the Scottish Parliament. In January 2024, MSPs will take their first vote on the general principle of the Bill. This is called Stage 1.

Over the next 18 months we will continue to co-design with people who have experience of accessing and delivering social care support to design the National Care Service.

We will be doing additional work with people from groups we know are currently underrepresented in our work so far.

In the meantime, we will continue to drive forward improvements across the social care sector, including improving terms and conditions for our valued workforce - making it an attractive profession and bringing even more talent into the sector.

Getting involved

We want to hear from as many voices as possible as we shape and develop the new National Care Service (NCS). If you'd like to share your experience or views, you can join our [Lived Experience Expert Panel](#). If you join the panel, you'll be invited to take part in different things like:

- surveys
- interviews
- helping come up with ideas about what the NCS could look like
- helping us understand what our research is telling us
- helping us make sure we're designing the NCS to meet everyone's needs

For more information about the National Care Service, visit gov.scot/ncs.



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