Information sharing to make care support better

Easy Read version





Introduction



The Scottish Government is working to make health and social care support better in Scotland. They are working with people and organisations across the country.



We want everyone to have access to high-quality local services across Scotland. People should get them when they need them.



We held events across Scotland in the summer of 2023 as part of our work to make a National Care Service. These happened in places all over Scotland.





We worked with people in towns and cities. We also worked with people in the countryside and island communities.

What we learned about information sharing



We got feedback from the events. Some of the common things people said were:



 People want their information kept safe and secure.



 People want a say in who their information is shared with.



 People want to know how sharing their information could help them.

In-person sessions



There were some main themes that came from the events. They are about the 'about me' information people can add to their Care Record.



'About me' information is about someone's life and what is important to them. This will help in planning their support and care.

People want to be told about information sharing



People told us they do not know enough about Data Protection laws. They want to know more about their rights to see information and records.

We need to build trust around information sharing



People told us they are worried about who can see their personal information.



Some people are not confident when using computers or the internet. This can make them worried about information sharing.



Some people said they would be happy for their information to be shared if they know it will help them.

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



People want to be respected and supported to make decisions about care.



People want to be able to manage what information about them is shared. They want to be able to decide who can see it.



People want to be able to update what information is shared.



Some people want to have a Care Record to fill in before any social care support is needed. This will help with future planning.



People can change their minds about who their information is shared with. Everyone has different reasons for choosing who can see their information.



Sometimes information can be left out of a record by choice. This might be because it could be upsetting for the person.

Information sharing needs to keep people safe



People need to know what kind of information they should put in their Care Record. They need to know how this will be used.



Sometimes information needs to be shared with people or services in an emergency. This should only happen if it is to keep someone safe.



Some people might need support to help them share their information.

The Care Record and information sharing



People said the Care Record can help make things easier for people. It can save them from having to tell their story again.



The Care Record can be part of person-centred support. It can help make sure a person gets the care that is right for them.



The Care Record can help people to have the same experiences across different services.

Good and fast information sharing can mean a person gets better care and support.

Staff need to be supported to share information



People told us that it is important for information to be shared properly and securely by health and social care support staff.



Staff need to know the laws about Data Protection. This will help them to share information in the right ways.



It can be hard for staff to get training about Data Protection. Different organisations share information in different ways.



Some people say staff do not use the information to make care and support better. Some worry that information sharing will mean more work. Sharing information properly is important for keeping staff safe.



Some staff do not feel valued.



Information sharing is not only important for health and social care services.

Online session



The following points are what we learned from people in the online session.

The Care Record



People said the National Care Service and the Care Record needs to be social care focussed.



Some people said there should be more focus on supporting, enabling, and empowering people to live the life they want.

Awareness



People said that what the Care Record is used for by staff and people accessing social care support should be clear.



People should know that their Care Record will not only have health information. It will also be about their lives and the things that are important to them.

Trust



People said that having more choice about how information is shared would help them to trust services.



Having information gives people more say about the support they get.

Sharing



People said they needed to know what information is collected and who it is shared with.



People want the Care Record to make it easier for staff to share information across services.

Next steps

What's next for information sharing



What people told us will help us understand what the Care Record should do.



We will keep working with the people who use social care services.



Staff have concerns about lack of training and support. We will talk to them more.



People said they want to see care planning information in their Care Record. This would help them get better support. We will work with staff on how we can do this.

What is next for the National Care Service





The Scottish Government wants the National Care Service by 2026. We are now working to improve the social care system.



Events will help us to make the National Care System, its policies, and the National Care Service (Scotland) Bill better.



A Bill is a proposed law that needs to be passed by the Parliament before it could become a law. The Scottish Parliament will vote on the National Care Service (Scotland) Bill in January 2024.



Over the next 18 months we will continue designing the National Care Service.



We will involve people who have accessed social care support. We will also involve groups of people whose voices currently are not being heard.



We will keep improving the social care sector for the already existing staff and to make it a good profession to work for.

Getting involved



We want to hear from you to as we develop the new National Care Service. If you would like to share your experiences you can join our <u>Lived</u> <u>Experience Expert Panel</u>.



If you join the panel, you will be invited to take part in different things like:

- surveys
- interviews
- discussions

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



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