

# Data Strategy for Health and Social Care

## Tell us what you think



**Tell us what you think**



1. Do you think the idea is a good one?

Yes

No

Not sure



## Why are having a consultation?



**Data** is facts, figures and information.

The Scottish Government wants the people who get health and social care services to be at the centre of the decisions about health and social care data.



We want to know what you think about how data should be gathered, stored and used.

These views will help us develop Scotland's first Data Strategy for health and social care.

It will be published in 2022.

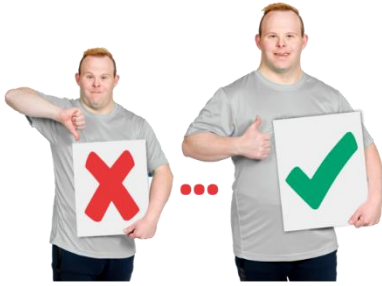
Data can be used to help the people of Scotland.

This includes:

- the delivery of better services
- finding new ideas and new ways of doing things
- supporting research – looking at information to develop new treatments, machines, equipment and information



## Why are we developing a Data Strategy?



There are still many areas where we do not have enough data to make health and social care services better.

We want to improve:

- how data is used
- how people can get their data



The Data Strategy will support organisations to work together to stop people having to give the same information to many different people and services.

It will make sure there are ways to include people who do not or cannot use online services.

## What work have we done so far



In 2019 we looked at what people in Scotland thought about using and sharing health and social care data.

This information is online here:

<https://datadialogues.nesta.org.uk/>

In November 2021 we asked people [what they needed from a Data Strategy](#).

The answers have helped us decide what to ask in this consultation.



## Our Vision – what we want to see happen



We want the Strategy to:

- have ways to use data to improve the health and **wellbeing** of people in Scotland.

**Wellbeing** means feeling comfortable, healthy and happy.

To help us do this we have 3 aims – things we want to see happen:



- **for the people of Scotland:**

to have greater access to their own health and social care data and greater control of it.



- **for staff and organisations that provide health and social care services:**

to give them ways to record and share information to make good decisions in time and have better services.



- **for innovators and researchers**

to make sure data is used to develop new and better treatments and new ways of working.

**Innovators** are people who come up with new ideas or ways of working.



**Researchers** are people who look closely at facts, figures and information.

## Giving people power



When we asked people what they thought in the [National Care Service consultation](#) most people and organisations agreed there should be a Scottish social care and health record that is online and accessible.



Giving people more access and control over their data will help them to trust health and social care services.

People will know they have been treated fairly.



Data must be presented in a way that is accessible and understandable to everyone.



The Data Strategy must have ways to include people who cannot use online services.

## Your health and social care data rights



The Data Strategy must explain the importance of:

- the rights people have to their information

This must include when someone's age or ability to make their own decisions could make this difficult.



- how people can have a greater say in how their data is shared
- the legal reasons for collecting the data
- how and why their data will be used and shared
- how someone can change their data

## **How do I take part in the consultation?**

**There are 3 parts in the survey:**

- Part 1: people of Scotland - page 7
- Part 2: staff delivering health and social care services - page 11
- Part 3: researchers and innovators - page 16

**We all fit into one or more of these groups.**

**Please complete as many sections as you feel comfortable with.**

**You do not have to answer a question if you do not want to.**

**Click on the box of the answer you agree with and a tick will appear.**

**If you change your mind you can click on it again to untick it.**

**If you have more to say type in the 'Type your answer here' spaces.**

**The space will grow as you type.**

## Part 1 – the people of Scotland



Health and social care data could be things like results from a blood test, how it has been decided what your illness is, or information communicated to a health and social care service.

**1. What does ‘your health and social care data’ mean to you?**

Type your answer here:



**2a. Think about accessing your own health and social care data.**

**What would be the most important data for you to have access to and more control over?**

Type your answer here:



**2b. If a person cannot access or understand their own data would it be right to give access to a guardian, carer or a person they trust?**

Yes

? I am not sure

No



If you answered 'yes', what would make sure this is done safely? Type your answer here:



**Ethical** means knowing the rules about what is right and wrong.





It means for example treating people the way you would like to be treated.

**3a. What information would make it clear how your data is used in an ethical way?**

Type your answer here:



**3b. How important is it to collect data so health and social care services know if they are giving a good service to people with protected characteristics?**

-  very important
-  important
-  I am not sure
-  not important





Think about health and social care staff seeing and using your health and social care data.

**3c. What more could be done to make sure you trust how they would do this?**

Type your answer here:



**4a. Are there any times when you would not be comfortable with your data being shared?**

Type your answer here:



**4b. The law says your health and social care data can be shared for direct care - ways that prevent, look into and treat your illness.**

**Would you be comfortable with your data being shared with health and social care organisations for other reasons?**



**✓** Yes

**?** I am not sure

**✗** No

Please tell us more. Type your answer here:



More people are using devices to track their own health.

**5a. Do you collect your own health data, for example measuring activity, sleep patterns or heart rate through a mobile phone or watch?**

- yes
- no



**5b. If you answered 'yes' would you want to share this data with health and social care professionals, and for them to use it to make services better?**

- yes
- no

## Part 2 – Staff delivering Health and Social Care services



We need to give staff who deliver health and social care services:

- skills and training
- guidance to understand data language
- guidance to understand the rules about recording and sharing data
- machines and equipment
- ways to easily gather, record and share data
- one system so all staff can share information quickly and easily
- templates – ways to make sure all staff are recording information in the same way



Sharing data between different services would make sure staff have all the information in a person's health and social care record.



**6a. What are the top skills and training gaps in data in Scotland's health and social care services?**



Data visualisation

Understanding and use of management information by managers

Understanding of what data there is and where to find it

Knowing how to access data

Confidence in using data

Understanding of governance – who is in charge and what they are responsible for

Other. Tell us what:



**6b. How can these gaps in skills and training be addressed?**

Write your answer here:



**6c. What is the most important work to be done to make sure people have access to health and social care data they can understand and use?**

Type your answer here:



**7a. What 3 things are needed to make the data used by health and social care services better and more accessible?**

Type your answer here:



**7b. If you are answering on behalf of an organisation - what can your organisation do to make the data used by health and social care services better and more accessible?**

Type your answer here:



**7c. What other data could be made available to health and social care staff to make health and social care services better?**

Type your answer here:



**8a. Do you agree that the Scottish Government should decide the rules and standards for gathering, storing, and accessing data at a national level?**

I agree

? I am not sure

I do not agree



**8b. What data standards should we have?**

Type your answer here:



**9a. Will more sharing of a person's data between health and social care organisations mean there are better services?**

Yes

I am not sure

No



**9b. If you are a clinician – how could we make patient safety better through better sharing of data and information?**

Type your answer here:



**10a. What are the most important pieces of management information needed, that are not available now to provide better health and social care services?**

Type your answer here:



**10b. What is needed to develop an end-to-end system for business intelligence for health and social care organisations in Scotland?**

Type your answer here:



**11. What data sets and data points should be used across health and social care to stop information being added more than once and stop people having to tell their story many times?**

Type your answer here:

### Part 3 - Supporting industry, innovators and researchers



People are worried about sharing data:

- for it to be used for marketing
- for people to make money from it
- in case it is given to private companies

We want to have ways of using data that are open and honest and that people can trust.



The Scottish Government wants to use **Artificial Intelligence (AI)**.

**AI** uses computers and machines to copy how the human mind solves problems and makes decisions.

AI analyses data and finds patterns and answers that humans could not find on their own.

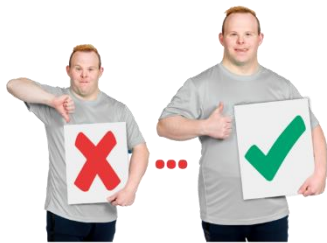
AI is making big changes to the way healthcare services are being delivered.



## Sharing Scottish data with the rest of the UK



Sharing Scotland's health and social care data and working with our partners across the four nations of the United Kingdom can help us improve health and social care services across the United Kingdom.



**12a. How do you think health and social care data should be used by industry and innovators to make health and social care services better?**

Type your answer here:



**12b. How can industry and innovators keep the trust and confidence of the people of Scotland when using their health and social care data for research purposes?**

Type your answer here:



**12c. How should Scotland's health and social care data not be used by industry, innovators, and researchers?**

Type your answer here:



**12d. How should industry, innovators and researchers be honest and open about why they are accessing health and social care data and why they want to use it?**

Type your answer here:



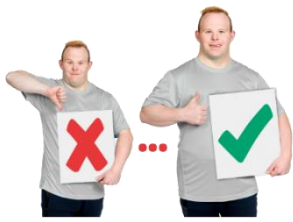
**13a. How should the Scottish Government store and share health and social care data for research in a way that it is easy to access but is still safe and secure?**

Type your answer here:



**13b. What health and social care data does industry, innovators, and researchers need but not have?**

Type your answer here:



**14a. What are the good things about using Artificial Intelligence to make health and social care services better?**

Type your answer here:



**14b. What will make sure using Artificial Intelligence is done safely?**

Type your answer here:

## **Send us your answers**



Send us your answers before 12 August 2022.

## **Respondent Information Form**



Please fill in the Respondent Information Form and send it to us along with your completed consultation.

Post the form and consultation to:



Digital Health and Care  
Strategy & Policy Unit  
Scottish Government, Basement Rear,  
St. Andrews House  
Edinburgh EH1 3DG

or email: [HSCDatastrategy@gov.scot](mailto:HSCDatastrategy@gov.scot)



To find out how we handle your personal data, please see our [webpage](#) on privacy policy.

## What happens next?

Answers to the consultation will be published on [Citizen Space](#) if people have said that is ok.

We will look at all the answers and make a report.

Your answers will help us decide what should be in the Data Strategy for Health and Social Care.

The first part of the Strategy will be published by the end of 2022.

More parts will be published as we keep working on the Data Strategy.



## Comments and complaints



If you have any comments or complaints about how we have done this consultation send them to:

Digital Health and Care  
Strategy & Policy Unit  
Scottish Government, Basement Rear,  
St. Andrews House  
Edinburgh EH1 3DG



or email: [HSCDatastrategy@gov.scot](mailto:HSCDatastrategy@gov.scot)



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