

Briefing Paper: Third Sector Data Strategy for Health and Social Care Background for an engagement session on 9th December 2021

Background

The recently published [Digital health and care strategy - gov.scot \(www.gov.scot\)](https://www.gov.scot/publications/digital-health-and-care-strategy/pages/introduction.aspx) commits to the development of Scotland's first ever dedicated Data Strategy for Health and Social Care.

Data Strategy for Health and Social Care – Our draft Vision

*“To ensure health and care data supports the delivery of health and care services.
To ensure it does so in a way that empowers the citizen and enables innovation and research.”*

Data is at the heart of our health and social care systems. Collecting, sharing and analysing data can help identify disease earlier, support independent living and make services more effective. But it is important that people are at the heart of any developments and that trust is built in how our data is stored and used.

What is meant by health and care data?

When we talk about health and care data it can mean information about many people: health and social care data can be made up of information taken from the health records of many different people that has been pooled together (“aggregated data”), for example to produce statistics.

Or it can be about one person (“individual level data”): health and social care data can be about individual people, whether they are identifiable from the data or not.

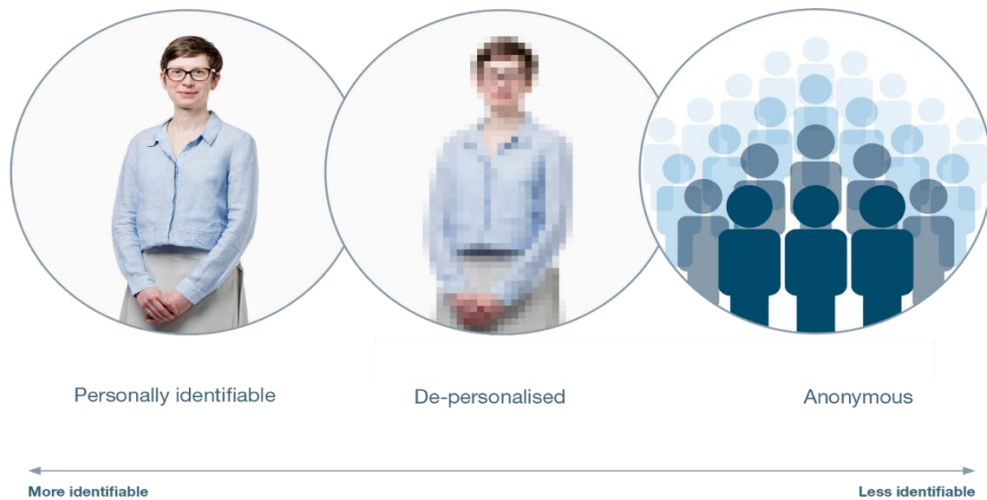
Individual data is data that relates to one person. It falls into three broad categories: demographic, administrative, and medical.

Confidential individual data is data that both identifies the person, and that the person does not want to share. This includes some information about their medical condition or treatment.

Personal data or personally identifiable data is data relating to a person who can be identified a) from those data, or b) from those data and other information which is in the possession of, or is likely to come into the possession of, the organisation in receipt of the data.

Anonymisation of data: The processing of personal data in such a manner that personal data cannot be attributed to a specific person.

Spectrum of identifiability



<p>Information that identifies a specific living individual (eg): CHI Number - 0101501294 Jo Green Female Age 31 Address 1 High Street, Anytown NT1 1AB Health COVID-19 Positive</p>	<p>Information that has been processed in such a way that the data can no longer be attributed to a specific data subject without the use of additional information (eg): CHI Number – Pseudonymised Ref ABCDE012345 Name –</p>	<p>All identifiers have been irreversibly removed and individuals are no longer identifiable in any way (eg): CHI Number – Name – Sex – Address Anytown Health COVID-19 Positive.</p>
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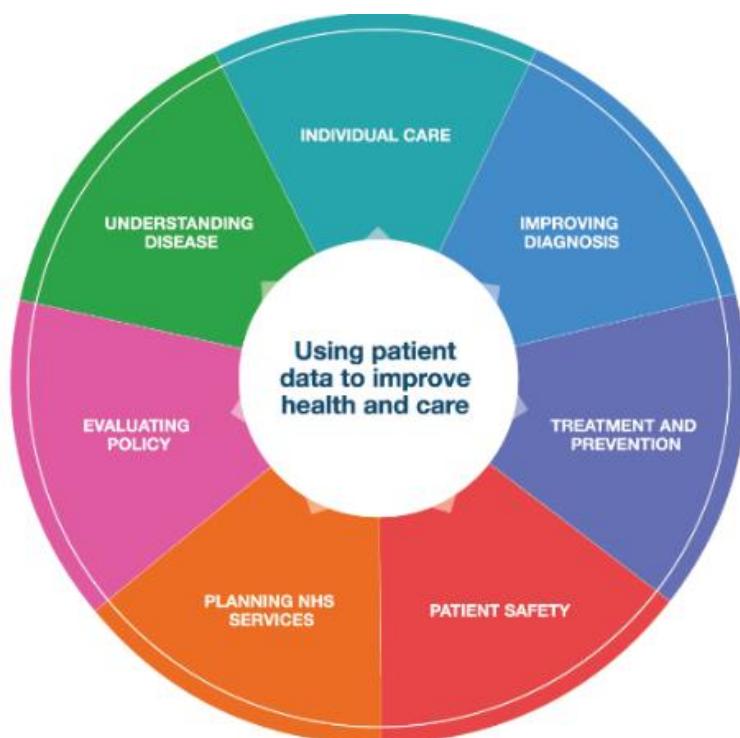
	Sex female Age 30 -50 Address Anytown Health COVID-19 Positive	
Use Case There is a need to update Jo Green's medical records to reflect he has COVID-19	Use Case There is a need to carry out research on whether there are differences in COVID 19 infection rates in Anytown due to factors such as age or sex	Use Case There is a need to compare COVID Infection Rates between towns e.g. Anytown has 15% and Old Town 20%

(Diagram from Understanding Patient Data, licensed under [CC BY.](#))

Why is health and care data important?

Health and care data is used:

- To help people get the best individual care. Good quality information is essential to inform their care. A person's whole care team, whether in a GP practice, a hospital, a care home or at home, needs to have access to up-to-date information to inform their treatment, and to provide the best care possible.
- To improve health, care and services through research and planning (improving diagnosis, treatment and prevention, patient safety, planning services, evaluating policy, understanding disease).



(from Understanding Patient Data, licensed under [CC BY.](#))

Who uses our health and care data?

- The public uses health data, for example during the Covid-19 pandemic many people used the Public Health Scotland dashboard to inform their personal choices about movement and activity.
- Service providers and commissioners who use data to monitor trends and patterns in population health, hospital and care activity, to assess how care is provided, and to support local service planning.
- University researchers who use data to understand more about the causes of disease, to develop new ways of diagnosing illness or to identify ways to develop new treatments.
- Charities who use data to evaluate services, advocate for patient communities and identify ways to improve care.
- Companies who use data for many reasons, for example if they are partnering with the NHS or other service providers, developing drugs or providing services.

This jargon-free introductory film made by the Alliance explains how our data is used in healthcare - [Health and Care Data - Bing video](#)

How does the health and care system protect data?

Each organisation holding health or care data – for example, a hospital, a GP surgery or a local authority – has responsibility for the data it collects and stores and has a legal obligation to keep confidential information stored securely. Only a health professional directly involved in the care of the patient has permission to access the relevant health data, unless the patient gives consent for records to be shared. Further, the confidentiality of personal information such as medical records is protected by data protection laws such as the General Data Protection Regulation (EU) 2016/679 (GDPR) and the Data Protection Act 2018, as well as the Freedom of Information Act 2000.

Health and care data can be used for research professionals, but only under strict conditions that protect confidentiality. This is often facilitated by placing data in a data safe haven, where it can only be accessed by authorised individuals after the research project has been signed off by a panel of information governance experts.

Previous public/citizen engagement has highlighted the following themes in relation to public attitudes to health and care data:

1. Access to and control over data (transparency and accountability)
2. Safeguarding of data and the risks involved in using/not using data
3. Equality issues and data

The Digital Health and Care Directorate commissioned NESTA to undertake an eighteen-month long dialogue with Scottish citizens to better understand their opinions and ideas for the use and sharing of health and care data. The full report on that dialogue can be accessed here: [Data Dialogues Summary Report](#). There is

also an interactive website that provides an innovative way of presenting the dialogue findings: [Data Dialogues \(nesta.org.uk\)](http://www.nesta.org.uk).

For further information about the development of the Data Strategy for Health and Social Care: [Digital Health and Care Data Strategy Working Group - gov.scot \(www.gov.scot\)](http://www.gov.scot)

What we want to know

Our engagement session will gather your information and views to help shape a draft Data Strategy for Health and Social Care. This will then be formally consulted on. The following questions are those we will discuss with you at the engagement session.

Data Standards

1. Research shows that people increasingly demand, and expect, more control over their health and care record. What are the equality implications of this shift in direction?
2. Data is used for many reasons from developing new medicine through research, using your medical records to provide you with health and care services to planning services and providing tailored care. Are there specific equality-related issues that need to be considered or addressed as we develop the strategy in relation to data sharing?

Technology/Platform

1. What are the benefits to your stakeholders of using technology to access health and care data?
2. What are the challenges faced by your stakeholder groups of using technology to access to health and care data?

Data Skills

1. What needs to be done to improve the confidence and skills of your stakeholders to access and share their own health and care data?