

# Data Strategy for Health and Social Care

# **Executive Summary**





Date: February 2023

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Greater access, better insight, improved outcomes: a strategy for data-driven care in the digital age

#### Introduction

The Scottish Government, local government, NHS Scotland, and the social care sector recognise how essential good use of data is to delivering better services to people in Scotland. The pandemic showed us how much of an appetite there is for public use of healthcare data and statistics, and we know in wider society that there is a growing desire for people to be able to access, and use, their own data in a digital world.

For the first time, we are introducing a Data Strategy for Health and Social Care to help make better use of the data we have, to improve access to the data we hold, and to ensure a strong focus on addressing known gaps and weaknesses in how we collect, share and analyse data to improve health outcomes – in a secure, transparent and ethical manner.

This Executive Summary sets out the key priorities of our Data Strategy for Health and Social Care – those elements we need to address in order to deliver our ambition – and the reasons behind them. Please refer to the Data Strategy for the full details, particularly on the commitments we make and the annexes that set out how they will be delivered. The Data Strategy is a commitment of the wider <u>Care in the Digital Age strategy</u>, updated in October 2021, and its supporting <u>Delivery Plan</u>, published in November 2022. These documents also provide useful background and information.

The Data Strategy is the result of extensive stakeholder engagement and public consultation and will continue to develop and be updated over time as we maintain our dialogue with, and learning from, the public, our stakeholders and our shared experiences. It establishes a framework for the ethical, transparent use of data and identifies the first set of challenges we need to resolve in order to address more complex challenges in this area.

As members of the public, we all interact with health and social care throughout our lives, including funding it through taxes. The improved use of data means you will experience improved outcomes, and see a positive impact more broadly in population health.

#### **Our vision**

To improve the care and wellbeing of people in Scotland by making best use of data in the design and delivery of services.

We will achieve this by delivering three key ambitions:

 Empowering people in Scotland by giving individuals clear and easy access to their own health and social care data, and the ability to manage and contribute to it, where safe and appropriate

- Empowering staff providing health and social care support to have the ability and confidence to gather, use, and share data safely and securely to improve services and outcomes
- Ensuring fit for purpose data is accessible safely and securely for planning, research, and innovation; and used for the benefit and wellbeing of individuals and the public including development of new ways of working, new treatments and technologies, and improving care.

# What does the Data Strategy mean for you?

- As someone using health and social care services, improved use of data will mean that you and those who provide your care get appropriate access to your data and the ability to manage it, meaning better support, a better experience and improved outcomes
- As someone working in health and social care, improved use of data means access to the right information at the right time, supporting you in delivering the right care and support
- As a **researcher in health and social care**, improved use of data will mean secure access to the types of data that give insight into health and wellbeing and support the development of new treatments and models of support.

# Our shared challenge

We recognise the scale, complexity, and variation of Scotland's data landscape, and that delivering our ambitions can only be achieved as a shared endeavour that develops and improves over time. Therefore, this first iteration of the Data Strategy does not provide all the answers for everyone. Taking a step-by-step approach will allow us to learn, adapt and respond appropriately while establishing an agreed ethical and transparent approach that ensures public support and trust. Our work supports the aims of the NHS Recovery Plan and recognises the current challenges and requirements of the social care sector. By supporting the transformation of our health and social care system using data, we will be better able to identify and address gaps in data (for example, in relation to gender and ethnicity) and the challenges of data quality.

# **Key principles**

Public trust and the ethical use of data for the public good are central to this Data Strategy. We will maintain an inclusive approach, recognising the potential of data in helping us better understand inequalities, resulting in better targeting of support. We continue to work to the principles of Open Government as we define and publish ethically sound and trusted principles that support the unlocking of the social and economic value of public sector personal data in the service of people in Scotland. You can read about your individual data rights in the Data Strategy's annex.

We recognise that we must do more to develop the digital and data skills of our system leaders and deploy them where they can achieve impact and change, working with NHS Education for Scotland, the Local Government Digital Office, and the Scotlish Social Services Council. We must also develop the wider skills of our workforce and systems leadership through the confident and effective use of data.

The National Information Governance Programme will further provide a strong, future-proofed framework that will give assurance to the public and enable those managing and controlling data to work more effectively.

The call of the research and innovation community for access to more timely and validated data reminds us of the vital role data must play in delivering better and more equitable outcomes for people in Scotland, and in supporting our economic growth as a nation.

#### What we need to change

Our stakeholder engagement identified eight priority action areas for us to begin our work in order to achieve the Data Strategy's vision.



As we continue to build on the Strategy we will expand and refine these deliverable actions, and ensure they are aligned with the overall all Delivery Plan for Digital Health and Care. The priority action areas each have an aim as follows:

#### Ethical Approaches to Data

We want to embed an ethical, open, and human rights-based approach to the use of health and care data in Scotland that maintains public trust and confidence.

#### Data Access

We want to empower individuals and professionals to make better informed decisions by providing access to the right data at the right time.

#### Talent and Culture

We want to attract, develop, support, and retain a workforce that is confident and competent in the use of data, including all staff having essential data skills that help us all to better manage the information we all depend upon; and advanced data skills that help us to create more insight from data.

#### Protecting and Sharing Data

We want to improve the efficiency, consistency and transparency of how our IG practices are evaluated, with an increased focus on public engagement.

We want to keep health and social care data safe and secure, and maintain public confidence and trust in our management of data.

#### Technology and Infrastructure

We want to make sure that we have the technology and infrastructure in place to equip us to better collect, store and use data. This includes structured data held within databases; unstructured data and information held in paper records; real-time data from sensors; and the Internet of Things.

#### Information Standards and Interoperability

We want to improve the quality of our health and social care data, and drive up interoperability through using common standards, making it easier to reuse data.

#### Creating Insights from Data

We want to work in partnership with health and social care to adopt a wholesystem approach to creating insights from data that allow us to improve services. This includes the creation of insights to inform communities and policy, target interventions and support, improve services, and improve partnership working.

### • Supporting Research and Innovation

We want to support research and innovation by facilitating safe access to health and social care data for researchers, innovators, and industry so that we can work together to develop better ways of working, better treatments and models of support, new medicines, and improved services for care in Scotland.

# **Examples of positive impact**

Ultimately, the delivery of the Data Strategy's aims supports improved experiences for everyone who needs to use, or who would benefit from using, data to improve health and wellbeing in Scotland. Here are a few examples.

I use, or may need to use, health and social care services and support, and this means I will:

- benefit from greater transparency through having greater access to my own health and care information, as well as access to wider public health and care information
- be able to see clearly and manage the data that is held about me, where it is appropriate. This will help me to better understand my health and care needs and my data rights, and feel more able to actively manage my care
- no longer have to repeat my story to each new person involved in my care, I
  can choose to share my data with family, friends and people who support me,
  so they can quickly understand my health and wellbeing needs which will
  enhance the support for me
- have the confidence that my data is up-to-date, and it is being handled in a safe and secure way
- understand how my data is used by researchers to improve health and social care services in Scotland.

#### I am an unpaid carer, and this means I will:

- have access to individual care information, subject to appropriate permission, so that I can provide the best support to them
- with consent, be able to keep track of appointments with health and social care professionals, who was involved, and what the next steps will be
- have access to user-friendly and up-to-date information about services in my area that provide respite care and support for me.

#### I am a member of health and social care staff, and this means I will:

- have secure and easy access to the right data about people I support, even if they have been or are being supported elsewhere
- spend less time looking for and capturing information that has already been captured elsewhere, so I can spend more time with the individuals I help support
- be able to more easily communicate with other professionals or unpaid carers supporting individuals, so that I understand the full story and can have the right conversations with them
- have up-to-date and complete data to support proactive care, smoother transitions between services and support providers, and to plan and oversee future services
- have confidence about when and how I should access information, giving me the assurance that I am respecting data privacy and supporting better outcomes for people
- have the confidence and capability to use the most suitable technology to gather, safely use, plan, commission and share data to ensure outcomes are being met to support the individual and sustainably improve services
- have confidence that I can make the right decisions in a timely manner based on improved access to relevant information.

#### I am a researcher, and this means I will:

- have better understanding as to what data is available and how it can be accessed
- have quicker access to quality data that is complete, up to date and better represents the people in Scotland
- have confidence that I am using this data in a safe and secure manner that will allow me to explore hypotheses or identify and pursue new areas for research and innovation, ultimately delivering new insights, improved care and support, treatments and better outcomes for people
- be able to quickly and easily access data from a universal system that will support my research and innovation studies in areas such as developing new treatments, vaccines or diagnostic tools to support better outcomes for people
- have easy to follow guidance explaining what I need to do to access data.

You can see more detailed examples of how the improved use of data can have a positive impact at the <u>Digital Health and Care Innovation Centre</u> website.

# How we will deliver the Strategy's aims

You will see in the full Strategy document that each section sets out a number of commitments, supported by Annexes setting out the key deliverables and timescales for each, and who will lead on them. You may find it useful also to refer to the overall Digital Health and Care <u>Delivery Plan</u>, which will be updated in May 2023.

#### **Next steps**

From the Data Strategy's publication, we will begin a programme of focused engagement with key stakeholders that will also set out and explore supporting areas of work such as the National Information Governance Programme, the Digital Inclusion Programme, and the Digital Front Door. You can participate, keep up to date with developments, and share your views at <a href="mailto:our Digital Health and Care">our Digital Health and Care</a> website and on <a href="mailto:Twitter at our twitter handle @DigiCare4Scot">Twitter at our twitter handle @DigiCare4Scot</a> or by email at: <a href="mailto:HSCDatastrategy@gov.scot">HSCDatastrategy@gov.scot</a>.



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