

23 July 2021

## Data saves lives: reshaping health and social care with data

### Summary of Royal Society response to the NHSX Data Strategy

#### Introduction

The Royal Society is the National Academy of Science for the UK. It is a Fellowship of many of the world's most distinguished scientists working across a broad range of disciplines in academia and industry. The Society draws on the expertise of its Fellows and Foreign Members to provide independent and authoritative scientific advice to UK, European and international decision makers.

This note sets out the comments made as part of the Royal Society's response to DHSC's online survey consultation on the NHSX Data Strategy, which the Royal Society welcomes. It draws from the Royal Society's recent reports and statements relating to well-governed access to data, as listed in the text below. The subheadings in this note relate to the sections of NHSX's online consultation.

#### Data saves lives: vision of the Strategy

Safe and rapid use of data and digital technology can bring significant benefits for individual and public health and care. This vision is welcome in setting out a strategy to make good use of data and digital technologies.

The Royal Society, with the British Academy, has established as a principle that 'human flourishing' should be at the heart of data use. Therefore, we agree that people – patients, their families, those delivering health and social care and ultimately wider society – should be at the heart of this strategy. Better use of data can create efficiency in systems and deliver new insights, but these must be with a focus on supporting peoples' flourishing.

The challenges in achieving this include needing open and transparent ways of negotiating the potential tensions between the rights and interests of individuals, communities and wider society. There is potential tension between public health needs which can be better understood with the right data, and the needs and interests of individuals. There are potential tensions between individuals having choice and control of the data about them but feeling like they have less choice about data for public health. Implementing the strategy will require public and patient engagement to navigate these important negotiations between uses and interests. (See: [Data management and use: governance in the 21st century \(royalsociety.org\)](https://royalsocietypublishing.org/doi/10.1098/rsos.200200))

The challenges also involve achieving *meaningful* choice and control for patients. To understand the degree of patient choice depends very much on the kinds of choices, and the kinds of data involved – and so broad commitments in the strategy will need to be developed in more detail. Achieving transparency and explainability of data use is also potentially challenging – digital technologies can use data in ways that are complex and not always transparent, and understanding what kinds of explanation a patient needs, for what purpose and how that can be achieved is important. (See: [Explainable AI: the basics \(royalsociety.org\)](https://royalsocietypublishing.org/doi/10.1098/rsos.200200))

It is also essential to understand the rights and controls that individuals have over data. While it is intuitive to say that health data 'belongs' to the patient, the idea of data 'ownership' is challenging and it is important to be clear on the actual rights and controls patients will have – and it is important to consider the role of collective rights and controls and the role of stewardship to enable those. (See [data-ownership-rights-and-controls-October-2018.pdf \(royalsociety.org\)](https://royalsocietypublishing.org/doi/10.1098/rsos.200200))

The COVID-19 pandemic has shown how important it is to have quality, timely data available to decision makers. Understanding the nature of the data needed is important – for example, whether it is aggregated or disaggregated. Lack of detail within the data can obscure inequalities or issues that relate to specific groups; while in contrast disaggregated data may be more sensitive.

For researchers to be able to make the best use of data for public benefit, the following are essential: systematic data collection; to deliver data that is timely and of good quality; based on standards enabling interoperability between data systems and connection of different data; to enable access to data in a timely way; and good data governance to ensure that data is accessed and used by researchers in a trustworthy way. (See [National academies response to the National Data Strategy \(royalsociety.org\)](#))

### **Priorities**

The use and appropriate sharing of data across the health system is of high importance. Its effectiveness will essentially depend on secure and interoperable data infrastructure. It also depends on the having the right skills for the use and management of data.

Technological foundations are important and the uptake of privacy enhancing technologies highlighted by the strategy is welcome, given the potential of these technologies to enable use of detailed data while protecting data subjects. However, technology must be used alongside good governance to ensure that data is used while protecting the privacy of data subjects and ensuring that the processing of data is fair and equitable. (See [Protecting privacy in practice \(royalsociety.org\)](#))

### **Commitments**

All of the commitments made in the NHSX Data Strategy are important. The pandemic showed how important data is for decision makers, in supporting research to understand how best to treat and prevent disease, and to inform and support health professionals, but access to both health data and data relating to everyday interactions was challenging during the pandemic. The Royal Society's RAMP and DELVE initiatives found that timely access to data has been the greatest barrier to providing the best possible scientific advice and has frustrated exploiting the UK's extraordinary data science capability to fully support the response to the pandemic. However, significant strides by bodies such as ONS and HDRUK have improved the situation significantly, and the lessons of these approaches need to be taken on board to continue to build data systems for policy, public health and patient care.

The Strategy sets out important commitments to supporting secure and privacy-preserving access to data for research – examples like OpenSafely of how technologies can enable the use of data for research without needing direct access to data. This is a further example of how there is a great deal to be learned from the pandemic and the systems that were established in response to it.

### **What are the three most important things that will help to deliver the strategy?**

- Building the right data infrastructure: this involves creating standards for data quality and interoperability in order to connect data across the health and care system
- Data skills: skills at all levels to use and manage data and the guidance to do this with confidence
- Trust: good data governance to ensure that the collection and use of health and care data is trustworthy, and engagement with the public and patients to ensure that it is trusted. Both are key to carefully manage tensions between the interests, right and responsibilities of data subjects and those who generate, collect and use that data. Also of great value is careful stewardship of data, and the role of the National Data Guardian is important in that regard.

**What are the three most significant challenges that could prevent delivery of the strategy**

- Funding: data infrastructure requires investment, as do the computing systems used to collect and analyse it.
- Accessing data skills: in terms of higher-level skills, there is significant competition for people with data engineering and data science skills and it is essential to attract and retain those skills. The steps already outlined in the strategy to build an analytic profession and to support collaboration and best practice are important and should be maintained.
- Loss of trust: if there is not sufficient investment in good governance and public engagement there is a risk that essential trust will be lost, risking the benefits of safe and rapid use of data.

**For further information contact: [public.affairs@royalsociety.org](mailto:public.affairs@royalsociety.org)**