Unifying Health Data in the UK: the Sudlow Review

7 July 2023

Introduction

In June 2023 the UK Government commissioned an independent review to map and assess the flows of health-relevant data across the four nations of the UK.

The review, 'Unifying Health Data in the UK', also referred to as 'the Sudlow Review', will evaluate how data can be better managed to improve public health while maintaining privacy and trust.

We noted the invitation to contribute to the review by 5pm, Friday 7th July 2023.

This is a significant document and of interest to Members of use MY data. The Secretariat sought the views of Members of use MY data and their direct views have been collated into this summary response.

The response has been submitted directly using the online web form. The contents of our submitted review are also shown in this document below, to make it more readily accessible and referenceable to our Members and other readers.

Responses on the four questions in the consultation

We have listed each of the four questions in the consultation (shown in blue), together with the direct responses of use MY data Members (shown below each question).

Note that all the contents are taken directly from the responses of our Members, so there may be a contrasting range of views in each question.

What are your views of the use of health data in research and healthcare as it stands today?

Access to data is overly slow, which is frustrating for patients who are involved with research groups.

Too many time-consuming and delaying barriers between legitimate researchers and data. The barriers are inconsistent between different data holders and prevent good research which will save lives and drive forward UK plc. Having a national health service, we should be world leaders in enabling holistic research across all aspects of patients' demographics, conditions and care.

The current situation is sub optimal, given the large amounts of patient health data that sit in primary and secondary care silos. Many patients, particularly those with chronic conditions managed by GPs and reviewed by specialist secondary care clinicians, are frustrated that their data is not joined up.

Researchers are frustrated that accessing data from across the UK and from primary and secondary care is so difficult.

In contrast, one Member noted:

Lack of proper oversight as to the quality of research proposals seeking to access data. It seems that almost anyone with some form of academic or health related association can access data regardless of how poorly formulated their research proposal.

What are the barriers to uniting health data in the UK?

Needs good communications to patients and public – too many previous "data programme" failures from which we never seem to learn. And these failures have had a very negative impact.

Risk averse and risk negligent behaviour about data sharing – anticipated benefits need to be balanced against the potential risk.

The regulatory barriers of multiple data controllers across primary care, secondary care and four different UK national health systems need critical review, as well as the silo-mentality and the risk-averse culture of denying or delaying access that the Byzantine structure of approvals has created.

There is also a risk of negligent data access control with data access committees etc., failing to check the credentials of those asking to access patient data.

As well as the bureaucratic barriers, and despite having had a National Health Service for 75 years, we do not have a national health record for patients or even a definition of a target data model for a national health record, so data is inconsistent across the country.

What are the solutions for unlocking these barriers and realising the potential of health data in the UK?

From a patient perspective, the fundamental problem isn't about lack of data, nor about lack of technology, nor about analysts/data scientists, nor even about money (so it seems). The fundamental problem is that there is never any emphasis put on communications to, and involvement of, patients and the public. How does the comms budget stack up against the tech budget?

It's difficult to get any clarity about industry/commercial uses of data, despite these being high up the list of public concerns. Ducking the issue, and not being totally clear, is damaging trust. Almost every announcement about or performance measure used in the NHS is based on data – number of patients waiting for treatment, target times for pathways, even the number of people who have a specific condition. NHS and others need to keep reminding us that this is how data is used.

It is likely that top-down UK wide regulatory change is needed notwithstanding the devolved nature of healthcare. Or, at the very least an agreement to share data between UK nations brokered across the devolved administrations.

Urgent progress needs to be made on health data strategies such as NHSE's data saves lives. We also need a more conscious and constant effort to tell the good news stories, especially around industry/commercial use of data – not trials (for which we volunteer) but routine healthcare data.

With regard to the above, there needs to be more care taken regarding who is accessing the data and how they will analyse it. There need to be more checks on the methodological rigour of studies seeking to access patient data.

We should define a national health data model and over time ensure that all providers move towards that data model (e.g., every system's investment should be tested against whether it helps move to that model and only in exceptional circumstances should investments be funded which do not move towards it).

There should be a National Health Data Controller with a remit to facilitate legitimate research whilst ensuring that effective safeguards are in place. This would not only ensure consistent standards and faster access to data for life-saving research but would also free the time of doctors and other providers from acting as data controllers (which is not why they joined the NHS) to get on with doctoring.

Perhaps what is needed is a sort of Data Passport for researchers, so that once they have a set of (standardised) approvals it would then cover most other data holders - much as we now have standardised contracts for running clinical trials at different sites, for example.

Perhaps the passport idea would help with checking credentials of researchers.

Should we be recommending patient/public reps on every access committee, alongside academic methodologists? It's not only our data, but perhaps we patients are likely to ask the important questions rather than get bogged down in box-ticking?

The development of Secure Data Environments (SDEs) brings the potential for more robust, auditable and accessible means for appropriate uses of health data, for patient and public benefit. It is essential that the development takes place with significantly improved inclusion and transparency, then has been the case for some national patient data developments.

But we see significant confusion about the overall plans for national health data infrastructure. The relationships between national SDEs, regional SDEs and the Federated Data Platform are poorly and/or barely described. Without simple clarity about how patient data will be used, it is not possible to engender public interest, support or trust. This is a serious omission.

What types of data should be prioritised now to be made available to support research and healthcare?

A key gap in patient data is the lack of integration of data from primary and secondary care. The issues around lack of access to (and linkage with) GP data must be resolved. That is very much a problem of hearts and minds, not technology.

What needs prioritising is not a type of data, it is the need to speed up access and linkages for research.

Additional comments

The whole subject of health data exploitation for the benefit of patient care and health research needs addressing at the highest political level in the four UK nations to provide direction and impetus to change and unblock the flow of health data for ethically approved and regulated research.

The remit of the National Data Guardian should be changed from being a guardian (& thus having a negative focus towards innovative research) to being a responsible enabler of legitimate data-driven research.

We hope our comments are useful and would encourage these to be raised with the Secretary of State, to remind him what he stands to gain.

Our vision

Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously.

Our mission statement

- use MY data is a movement of patients, carers and relatives.
- use MY data endeavours to highlight the many benefits that appropriate usage of healthcare data can make, to save lives and improve care for all.
- use MY data supports and promotes the protection of individual choice, freedom and privacy in the sharing of healthcare data to improve patient treatments and outcomes.
- use MY data aims to educate and harness the patient voice to understand aspirations and concerns around the use of data in healthcare delivery, in service improvement and in research, aimed at improving patient decision making, treatment and experience.

What we do

- We promote the benefits of collecting and using patient data to improve patient outcomes with sensible safeguards against misuse.
- We work to bring a patient voice to all conversations about patient data.
- We have developed the Patient Data Citation, which acknowledges that patients are the source of the data. Details are available here.
- We act as a sounding board for patient concerns and aspirations over the sharing and using of data in healthcare and health research.
- We provide learning resources for patient advocates on patient data issues, including:
  - Hosting events for patients and the public, focussing on patient data topics
  - a library of resources of data security, consent
  - narratives from individuals about the value of collecting and using patient data.
- We advocate public policy that supports the effective use of patient data within appropriate frameworks of consent, security and privacy, and with the aim of providing benefit to patients and their health care services.
