Strategy Paper: Data saves lives: reshaping health and social care with data, July 2022

Summary response from use MY data

Background to our response

Following the publication of the new NHS data strategy for England; “Data saves lives: reshaping health and social care with data”, we collated views from our Members, before running a Members’ education session on how the strategy matched patient expectations.

The summary is presented here, which also relates to our previous submissions to the initial draft strategy in 2021, our submission to the Goldacre Review in 2021 and our complimentary Position Paper on the final Goldacre Review, which we published in 2022.

How does the vision of the Strategy contrast with that of use MY data?

Our initial reflection is that there is a striking similarity between the vision as stated in the Strategy and our own **use MY data** vision. The Strategy says:

> “Our vision: the public have confidence in how their data will be handled, and are happy for their data to be used to improve the care that they and others receive”.

The vision of **use MY data** says:

> “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”.

It is encouraging to see such similarities between the two and that key elements from our own vision are now being adopted as national policy.

Key points from use MY data Members

We welcome the publication of “Data saves lives: reshaping health and social care with data” [the Strategy], which comes at a time, post pandemic, when there is a clear need for an ambitious, transparent and inclusive approach to the uses of health data for patient benefit.

These are use MY data’s top ten points on the Strategy, which have come direct from our Members.

1. The seven sections of the Strategy are logically themed and presented, but for a strategy about patient data, the delivery needs a greater emphasis on patient involvement and not just engagement

As with preceding strategies, there is a limited focus on involvement of patients in delivery.

Whilst being something of a crude assessment, a simple word-search in the document showed: “PPIE” appears once, “involvement” appears 4 times (including in a sentence about involvement in crime), “engagement” appears 31 times. It may be unfair to draw simplistic conclusions, but it is not easy to ignore.

When considered as a whole, the Strategy seems to emphasise engagement over involvement. This needs to be addressed during the delivery.

2. We welcome the commitment to develop a new Data Pact between the public and the health and care system

Commitment 102 says “We will work with the public to establish, for the first time, a data pact that will set out how we will use health and care data, and what the public has the right to expect”, with a planned completion date of December 2022.

This is a very positive step which we strongly support.

We already have a series of Position Statements developed by our Members which will readily feed into this work. Our Position Statements include:

- Our expectations of organisations which use our patient data
- Acknowledging and raising awareness of patient data
- Highlighting the benefits of using patient data
- Recognising the use of patient data - The Patient Data Citation
- Realising the benefits of a truly National Health Record

3. We are deeply frustrated about the lack of urgency in giving people better access to their own data

Both sections 1 & 2 make references to access to your own health data. But the focus seems to be primarily on shared care record access by organisations, and not by patients themselves. The commitment to extend the record beyond primary care data is not due until December 2025 and is subject to Treasury approval.

Whilst the Strategy says it will give people "better access to their own data through shared care records and the NHS App", there is no clarity about what this means in practice. The delivery of access to connected social care data is not clear, and progress will therefore be difficult to measure.

We set out our case clearly in our Call to Action, "My Access to My Health Records", which we published in July 2021.

Whilst the Strategy seeks to establish simplified, more transparent and safer ways for patient data to be shared, the only group that still won't have access to patient data are the patients themselves. This is not a balanced approach.

We also noted that the draft strategy talked about a national data layer facilitating a National Health Record and a National Research and Planning Repository. The published wording appears confused between whether we are heading for a National Health Record or a spread of rival, incompatible, local health records. This is not in the interests of patients.

4. Transparency is still being talked about as something you do, rather than a culture that you adopt

Commitment 103 – to be completed by December 2022, says "We will co-design a transparency statement, as part of a regularly updated online hub, setting out how publicly held health and care data is used across the sector."

The Strategy very much talks of "doing" transparency by, for instance, publishing a statement on transparency. There is little in the Strategy to demonstrate that transparency is being adopted as a culture.

5. The conversation about "value of data" needs to develop, to ensure good intentions in the Strategy are realised and that patients' expectations are met

We welcome the commitment (108) to publish the value sharing framework, which will support the health system to deliver good data partnerships. However, this framework needs to be developed with patients, and clearly communicated, if it is to provide the anticipated assurances.

We note and welcome the principle about NHS organisations not entering into any exclusive arrangements about data. However, we would also note that all arrangements should be transparent and available for scrutiny.

6. It remains to be seen whether some of the more ambitious challenges laid down in the Goldacre Review are to be taken up

One of the challenging recommendations in the Goldacre Review (rec 25), was to address the unnecessary replication and decision making around access to health data, and to reconsider the potential for national data controllership. Whilst the Strategy identifies the potential for national data controllership, it then says "while this recommendation is not addressed in the data strategy commitments, the recommendation may be considered as part of wider work on the development of secure data environments".

Whilst this would be a challenging recommendation to implement, we would like to see this given serious consideration, by working with patients.

7. A change in emphasis from Trusted Research Environments to Secure Data Environments

We welcome the commitment to the use of Secure Data Environments, as we also welcomed the recommendation to use Trusted Research Environments highlighted in the Goldacre Review.

The use of the term Secure Data Environments (rather than just Trusted Research Environments) makes sense.

We have a concern that the Goldacre Review recommended a very restricted number of health planning and research environments, while the Strategy appears to accept we will have multiple ones – national and regional, for analysis and research.

SDEs offer a unique opportunity to address the data requirements of rare diseases, which need national and international data, though SDE links to international data are unclear. Patient registries do not exist for every disease type, and there is no national approach to collecting this data. If we were to identify the research that should be prioritised for each disease area, SDEs could be the place to collate this data for researchers to work with. Crucially, this needs a national approach.

An additional concern is the lack of detail on common access processes/ committees to speed access. Given that this is a critical problem for research, this is an unwelcome omission.

We also note the commitment (502) which is to “work with expert partners and the public to implement secure data environments as a default across the NHS”. We see the role of use MY data as being one of these expert partners.

8. There is a golden opportunity to radically rethink the scrutiny of national data by embedding patient voices

“Insanity is doing the same thing over and over again and expecting different results” [Albert Einstein]

Organisational change, with the planned merger of NHS Digital into NHS England in 2023, brings a unique opportunity to do things differently.

The creation by NHS England of a statutory safe haven for health and care data in NHS England, its use of data, including how it shares data externally, will be subject to independent scrutiny. We would like to see a radically different appetite to involvement, transparency and scrutiny, as part of the core service, and not just as an add-on.

9. Addressing the mistrust in health professionals about the uses of health data

The Strategy references a report by the National Data Guardian to highlight that the NHS is trusted more highly (in the way it manages data) than most organisations.

However, the same report, citing a survey about likelihood to opt-out of their data being used for research, also suggests a lower degree of trust amongst NHS staff than in the general public:

“After being told about the opt-out, 25% said they were likely to opt-out……. Among those working in health and care, likelihood to opt-out remains much higher – it was 46% in July 2020.”
https://www.gov.uk/government/news/polling-indicates-growing-public-understanding-about-importance-of-using-health-and-care-data

If this is true, do we need to think about tackling why the NHS staff trust the NHS less than the public trust it?

10. Simplifying the National Data Opt-out

The Strategy makes a clear intention “to simplify the opt-out process so that it is accessible, simple to action and easily explained”.

The related commitment to “in-depth engagement with the public and professionals”, through focus groups and large-scale public engagement is welcome.

But this is a complex, lengthy and potentially costly piece of work. We are unclear how this will be designed with patients, how this will be delivered and by whom.