Opinion **UK business & economy**

The public must have more clarity on government plans for NHS data

We need greater detail about how this immensely valuable information might be used to prevent patients from opting out

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The NHS has a poor record of maintaining patient privacy when negotiating data partnerships © Ron Lavine/Stone/Getty Images

Naomi Lee YESTERDAY

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The UK Department of Health and Social Care released its draft strategy on NHS patient data last week. It is an ambitious vision to facilitate access to data for patients and clinicians alike. But recent proposals around the use of patient data for improving care or research, rather than direct clinical care, have been controversial. Much of the debate has turned on whether NHS data should be used for these purposes. But this risks playing into the hands of those who see data only as a commodity to be traded without recognising the shared value of this asset.

I have seen first-hand how poor access to health record data initially held back our understanding of Covid-19. By the end of May 2020, there were nearly 6.2m confirmed cases globally, but the best information on the outcome of Covid-19 in people with cancer was from data manually collected to inform two studies of under 1,000 people each. Throughout the past year, advances in health data have been made. Many major Covid-19 studies have been underpinned by large electronic health record data sets, including the first nationwide study of vaccination from Israel, the UK Recovery trial on the role of steroids in reducing mortality and OpenSAFELY, which used primary care data from 40 per cent of the UK population to understand the risk factors.

It is unsurprising that the UK government, and many in research and healthcare, want to expand the use of NHS data further. As a nationally representative, large data set, embedded as part of a universal healthcare system, it is unparalleled. The potential it offers for improving care in the UK population cannot be overstated. But there is also potential to place the country ahead in health research, and healthcare innovation, particularly in digital health technology or artificial intelligence.

UK NHS data is already being used for secondary purposes: the Clinical Practice Research Datalink has generated over 2,800 research papers. However, the accusations that the government is making a data grab under the cover of a pandemic are not unjustified. According to survey data, 50 per cent of UK patients would share their anonymised personal health data with a research institute. Only 12.2 per cent would share it with a tech company, even for the purposes of improving healthcare, and just 3.5 per cent for a commercial purpose. The draft strategy gives no assurances on how data access by commercial companies would be governed or what the logistical or financial arrangements might be.

That draft strategy is also light on detail when it comes to data security and privacy, saying they are looking to the development of new technological advances. These details are of critical importance. The UK public must be able to understand and scrutinise the arrangements being made with their data. The NHS has a poor record of maintaining patient privacy when negotiating data partnerships.

The public have until July 23 to comment on the draft, and September to opt out from the primary care data scheme. This opportunity must be used to press the government for details on the commercial arrangements and privacy safeguards. Without providing this clarity, the government risks reducing the value of the entire enterprise. Not only would a loss of faith in the system mean individuals opting out on a large scale, therefore decreasing the size and representativeness of the data, its key asset, but it could also mean a loss of faith in research generated from the data.

The outcome of the NHS data strategy will have implications for similar regional and national projects beyond the UK, for example the European Health Dataspace currently being created. Patient data sets are a shared resource where the value is collective. Decisions on who benefits from them require transparency and public debate. The future of healthcare is inseparable from these discussions.

The writer is an editor on The Lancet