

The full health and care data strategy must address its shortcomings

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- Josh Keith

On 22 June, NHSX published their [draft data strategy for health and social care](#). This strategy could not have come at a more crucial time. Population health was already suffering before the pandemic, through stalled improvements in life expectancy and widening health inequalities. Now the NHS faces renewed and unprecedented pressure, with a growing backlog of care ([4 million fewer people completed elective care in 2020 than in 2019](#)), and the long-term health burden of the pandemic still unknown.

The past 18 months have highlighted the opportunities, with data being used to track outbreaks, identify those who should shield, develop treatments, and target and monitor vaccine rollout. The challenges have also been clear: [the loss of 16,000 coronavirus test results](#) (a problem of data infrastructure), and the absence of national data to identify care home residents, for example. More recently, plans to overhaul the collection and sharing of GP data have provoked controversy, along with calls for greater transparency and better engagement with the public around how data are collected, shared and used – and the start date for that programme [has been pushed back further](#). It is for exactly these reasons that the strategy should be welcomed.

What do we need from a strategy to deliver effective and responsible use of data to improve health?

To really underpin transformation in the use of data in health and social care the strategy needs to address many issues. There are at least three areas of need.

Firstly, better data – more timely, granular, accurate and higher quality – on the health and health needs of the population. This information is needed to inform public debate, decision making at

a local and national level, design and delivery of health-improving activity, and to understand inequalities and monitor progress against them. Clinical audit and registry data need to be integrated with electronic health record systems. There must be improved measuring of outcomes, shifting from a focus on simply measuring activity and costs. Social care must not be forgotten either: the sector [still trails far behind when it comes to its use of data](#) – which was exposed during the pandemic.

Secondly, we need a system that can routinely develop and deploy data-driven solutions at scale and do so safely and equitably – reducing, not exacerbating, health inequalities. We must overcome the barriers that are preventing data-driven innovations from being implemented (both those developed within the health and social care system, and those from industry). These include technical and regulatory issues, evaluation challenges, wider implementation challenges, and lack of capacity and freedom within NHS analytical teams to drive innovation. [Creating a culture of sharing and reproducibility](#) will help ensure that data science innovations developed in one place can be rapidly spread elsewhere – making best use of limited resources.

Finally, perhaps most importantly of all, we need to recognise how important the trust of patients, the public and the workforce is. Meaningful and transparent engagement that ensures the public can influence decisions about how we use health data is central to building and maintaining trust. This is particularly important given the recent concerns raised about the GP data for planning and research programme. We are not starting from a blank slate here – there are [examples of good practice](#) springing up around the system showing just how this engagement can be done.

Will the data strategy enable the transformation needed?

There is much to be positive about in the NHSX data strategy. It is an important statement of intent, signalling the government is serious about unlocking the potential of data for health and social care. The core priorities are welcome: building understanding and transparency, making appropriate data sharing the norm, and building the right foundations to enable this.

The strategy's recognition of the importance of the health and social care analytical workforce is a welcome step forward – highlighting the need to ensure they get the recognition, professional status and support needed to be able to put their skills to use. Our [Advancing Applied Analytics programme](#) is one initiative that has been trying to address just this. Also welcome are commitments to supporting open and reproducible analytics, addressing the data deficiencies in social care, and acknowledging the importance of federated analytics, something the Health Foundation's [Networked Data Lab](#) is deploying to analyse linked datasets.

But there are some important areas in which the draft strategy perhaps falls short and which the final version (expected before the end of the year) must address.

The strategy doesn't go far enough on the complex relationship between data and inequalities. Data are critical to measuring inequalities, understanding their drivers and monitoring progress towards reducing them. But there are big risks. Using data or data-driven tools without a critical assessment of the context in which the data were generated [risks reinforcing existing structural inequalities](#) – such as unequal access to health care services. Furthermore, efforts to increase patients' access to their own data could lead to inequalities between those with the digital access and skills needed and those without. The final strategy should have a bigger focus on addressing inequalities, and clear commitments. The Health Foundation and the NHS AI Lab are funding [research](#) aimed at addressing one part of this – advancing the use of artificial intelligence for the benefit of minority ethnic communities. Other actions could include improving the diversity of the analytical workforce, at all levels of seniority.

Recognition of the specific challenges in social care is encouraging and much needed. But we need bigger and bolder action, in collaboration with the sector, to address the challenges which include variable levels of digitisation among care providers and a fragile provider landscape that produces [conflicting motives when it comes to data sharing](#). Collection of client-level data is welcome, but given the pressures providers are under, the data collection burden must not become too great.

The issues related to the GP data collection and sharing programme, described earlier, raise concerns that the lessons about the importance of communicating and engaging with the public from the care.data scheme [have not been learned](#). While the strategy includes commitments to increasing transparency, building trust will require a conversation through which the public can influence decisions about how their data are used, by who and under what conditions. Health care professionals – among [the professions most trusted by the British public](#) – must also be engaged in the development and implementation of the strategy.

Finally, of course, the strategy alone cannot guarantee change – this will be driven by how the commitments are implemented. In some areas these commitments are light on detail. The final strategy has an opportunity to address this, building confidence that it is backed-up with a clear plan for delivery. It remains to be seen whether we are about to witness a long-awaited step-change in how data are used for everyone's benefit.

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