



THE NEXT CHAPTER FOR HEALTHCARE: PATIENT DATA AT THE CENTRE

The rise of healthcare data

The use of data in healthcare was already on the rise prior to the pandemic, increasing nearly 900% between 2016 and 2019¹, but its importance has been further recognised over this past year, leading to changes in the way that healthcare providers are connecting with their patients.

Focusing on patient data at the centre is now seen as an increasingly important strategy in supporting health economy transformation. According to the 2020 Dell Technologies Digital Transformation Index², 96% of digital leaders say their ability to collect, analyse and act on data has made it easier to adapt and survive over the past 12 months.

Healthcare analytics and data can be used to help understand more about disease risk and causes, improve diagnosis, develop new treatments and improve wellness and preventative health.

With technologies such as AI and Machine Learning, it is now easier to not only collect data but also to convert this information into critical insights that can then be used by caregivers to help provide better outcomes for their patients³. Healthcare analytics and data can be used to⁴ help understand more about disease risk and causes, improve diagnosis, develop new treatments and improve wellness and preventative health. This will help to plan NHS services, increase patient safety and evaluate efficacy of healthcare policy.

But although it has a clear and important role in the digital transformation of healthcare, the increase of data presents challenges around how patients' confidential information is protected and used⁵.

Data's role in pandemic response

Data has been utilised by the NHS during the pandemic to solve challenges across the board. At a national level, data was captured to help understand the scale of the pandemic and co-ordinate measures to try and minimise the impact on healthcare services.

¹ <https://www.delltechnologies.com/en-gb/data-protection/gdpr/index.htm> ² <https://www.delltechnologies.com/en-us/perspectives/digital-transformation-index.htm#scroll=off>
³ <https://ieeexplore.ieee.org/document/9351494> ⁴ <https://understandingpatientdata.org.uk/why> ⁵ <https://www.htworld.co.uk/news/how-healthcare-organisations-can-protect-data/> ⁶ <https://www.gov.scot/publications/coronavirus-covid-19-ppe-distribution-statistics/>

At a local level PPE stock levels came under high demand and national co-ordination was required to understand where it was needed most. This was distributed⁶ appropriately, to a point where a secure data store of patient information on a national level was established.

The NHS COVID-19 Data Store⁷ provides more accurate visibility into the impact of COVID-19 response, and allowed clinicians and researchers to identify how and where the virus was spreading, and patient groups who may be more severely impacted.

The use of data today is benefitting the roll-out of the vaccination programme⁸, with a data system that enables patients to be offered and book the vaccine based on their age and health status, providing a birds-eye view on areas where people may not be getting access – thus ensuring the correct number of dosages are deployed to areas that may need them the most.

Data is now being used to drive decisions in the NHS, in a way that they never had been before. But so far, this has been driven by necessity and the urgency of the pandemic. Data has long sat in silos across the NHS system and so if you are trying to access multiple datasets, it can often be difficult because the quality of data is so variable. During the pandemic, NHS trusts have collaborated and shared data allowing for better distribution, analysis and outcomes.

And so, how do we ensure that we continue to advance the collaborative use of data versus returning to data sharing prior to the pandemic?

Data sharing that works for patients

The Government is responsible for the National Data Strategy⁹, which seeks to free organisations to keep using data as they have during the pandemic, to innovate, experiment and drive a new era of growth. It also seeks to harness the power of data to boost productivity, create jobs, improve public services and position the UK as the forerunner of the next wave of innovation.

To successfully maintain wholesale digital transformation across health and social care, it is crucial that patients are involved in decisions about what data is held about them.

The Government's health and social care white paper¹⁰, published in February, outlines the legislative proposals that will enable the innovations accelerated by the pandemic to become permanent.



⁷ <https://www.england.nhs.uk/contact-us/privacy-notice/how-we-use-your-information/covid-19-response/nhs-covid-19-data-store/> ⁸ <https://digital.nhs.uk/coronavirus/nhs-digital-coronavirus-programme-updates/programme-updates-13-october-2020/support-delivery-of-vaccinations> ⁹ <https://www.gov.uk/government/publications/uk-national-data-strategy/national-data-strategy> ¹⁰ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/960548/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-web-version.pdf



To successfully maintain wholesale digital transformation across health and social care, it is crucial that patients are involved in decisions about what data is held about them. It is important that lessons are learnt to ensure patients understand the benefits that can be derived and there is full transparency about how their data can be used in the future.

One of these advantages is care continuity. The rise of patient portals and NHS Digital enables people to access records, results, prescriptions, appointments¹¹ and even manage their care through a PC or an app¹². This allows clinicians to engage with patients outside of hospital, so they do not feel disconnected.

This care continuity can also be seen in patients with chronic illnesses such as long-term heart disease management. The benefit they gain from data sharing is that all medical professionals they see will know their basic background and clinicians will be less reliant on the patients themselves having to relay information.

The sharing of data has also improved the provision of care delivered by providers and reduced the overlap and wasted services caused by duplication when patients move from hospital to hospital.

The expectations coming from patients is that they should see the same level of care wherever they go, but this is not possible without greater sharing of data. There is inconsistency in the sharing and utilisation of data across healthcare regions. Where there is a common record across providers, there has been greater transformation in the pathways of care.

There is a gap between those whose local NHS trusts are equipped well in new technologies – where they have large datasets – and regions that have seen less funding, less technology and therefore, less diverse and representative datasets¹³. Part of the long-term healthcare digital transformation strategy has to be engaging regions that have traditionally been slow to embrace technological progression.

Driving value and better regulation

An important distinction has to be made between data for research and care, versus data for commercial outcomes – with different regulation needed for each. Patients tend to be more willing to share their private information for the former, because they can more easily grasp how it will directly benefit them.

The sensitivity of this data however makes it the most commercially valuable, as the outcomes it derives for use in research or medicine development, in turn will drive profits.

It will be important for regulation to evolve, to ensure it is reflective of the demands of today's healthcare system.

¹¹ <https://digital.nhs.uk/services/nhs-login> ¹² <https://www.nhs.uk/nhs-services/online-services/nhs-app/> ¹³ <https://blogs.bmj.com/bmj/2020/09/01/covid-19-is-magnifying-the-digital-divide/> ¹⁴ <https://dcms.shorthandstories.com/Our-Ten-Tech-Priorities/index.html>

Regulation is no doubt a hurdle to work through for data sharing to be efficient and successful, but we must also consider that it has been designed to protect our privacy and preventing the unlimited or inappropriate use of patient data for commercial reasons.

It will be important for regulation to evolve, to ensure it is reflective of the demands of today's healthcare system. This must be led by the healthcare industry itself, with the engagement and contribution of citizens. The Government should also play its part, and has committed to unlocking the power of data through the Department for Digital, Culture, Media & Sport's 10 tech priorities¹⁴, which will aim to remove barriers to responsible data sharing, so that the UK becomes the world's number one data destination.

There is a role for the private sector and commercialised data in the wider progress of health and social care – not least in training and empowering NHS staff to scale their use of data – but it has to be ethical and transparent. As with the vaccine roll-out, public confidence in the system will be as crucial to the efficacy of the data itself.