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# Data saves lives: reshaping health and social care with data

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## Commentary

The government's long-awaited data strategy - ['Data saves lives: reshaping health and social care with data'](#) - was published today, following a raft of previous initiatives designed to harness and capitalise on the NHS's rich store of patient data. Tentatively published in draft form, with an emphasis on the rigorous and wide engagement with the sector and the public to come over the summer months, it arrives amidst a growing and increasingly familiar dispute over data handling and privacy.

Post-pandemic, it is now better understood than ever that the among developed health systems the NHS has a particular opportunity to realise value from its vast stores of patient data. In a single payer system, data can - in theory - be accessed centrally and at scale, enabling AI and deep learning capabilities to be deployed en masse without the fragmentation and legal obstacles that arise from a system with multiple payers, or with providers operating under legally separate organisations. Coupled with the size and heterogeneity of the population in England, that makes NHS data a highly valuable asset.

Historically, that opportunity was primarily understood as being about the development of new therapies, tools and pathways, with access to data enabling researchers and clinicians to develop products at pace and scale. Yet COVID has shown that that opportunity can also be operational, with the huge advances in planning and central management - such as the [COVID-19 NHS Data Store](#) - pointing to the wider advances in system efficiency and operational management that a more comprehensive and better integrated data architecture could bring about. This new strategy from the Department of Health and Social Care seeks to realise both these opportunities - aiming to 'bottle the spirit' seen during COVID and deploy those advances and capabilities to meet the future challenges ahead for the system.

There is much in the strategy that is radical yet uncontroversial, and will be broadly welcomed:

- Commitments to combined individual health and – critically – social care records and sovereign personal data stores, with simplified access to these data for clinical staff delivering direct care;
- Simplification and strengthening of information governance, and support for the greater use of privacy enhancing technologies that enable data analysis without compromising security;
- A commitment to openness, with plans to publish the first transparency statement in 2022, setting out how health and care data has been used across the sector;
- Reduction of data collection burdens and more investment in automated data collection and coding;
- Investments in staff training and expertise, with a particular focus on the c.10,000 coding and data analytics personnel already working in the NHS; and,
- Investment in better data architecture and the promotion of open standards, code and APIs to promote interoperability and void vendor capture, with the data and application layers being separated.

There are two very significant areas, however, where the Government can expect a more rocky road ahead, and they both involve the use of NHS data by third parties. As we have noted, the NHS has been an active participant in sharing data for clinical research for decades, and yet this activity still attracts controversy. The recent delay to, and review of, the [GP Dataset for Planning and Research](#) initiative showed that without extensive patient engagement in data sharing activities trust can be lost and the data opportunity reduced. While the Strategy is keen to emphasise that the NHS must become a more proactive partner for data-led innovation – pointing to initiatives like the [NHSX Centre for Improving Data Collaboration](#), the [NHS AI Lab](#) and the successful [Digi-Trials](#) programme, which ran the world-leading RECOVERY trial – many of the anticipated policy changes on health data research will not be revealed until the publication of the Goldacre Review later in the summer.

If this represents a debate delayed, then the Strategy has ploughed headlong into a major argument about its plans to create a duty to share data between health and care organisations. As the Health Service Journal pointed out:

*“The strategy also says the government will use “secondary legislation in due course” to enable data-sharing for activities such as invoicing, commissioning, planning, analysis, policy development, audit and risk stratification without breaching the common law duty of confidentiality.”*

Critically, this would seem to cover information over which patients currently have an opt-out. The DHSC believes that the current definition of secondary usage, which covers both operational planning and research, is too broad, and that in some circumstances

confidential personal information should be easily accessible for planning purposes as well as for direct care. Privacy campaigners are, predictably, up in arms, with MedConfidential commenting:

*“Does this Government really believe it can use “secondary legislation” to overturn the millennia-long trusted principle of doctor–patient confidentiality that lies at the very heart of healthcare?”*

Winning this argument with the public and clinicians will be critical to the success of this strategy.

Although the strategy is a fairly high level document, it is nonetheless ambitious. Ministers are determined to capture what they see as the progress on data-sharing made during the pandemic, yet this will require on-going political commitment and sustained focus to bring it to fruition. If achieved, the effect on the sector will be significant. After a period of consultation, legislation to bring these policies into effect is envisaged later this year, either through the upcoming Bill or via secondary legislation. As ever, legislation and regulation are only half the battle; the public must be brought along too, as do the NHS and its staff, and it would be a mistake for policymakers to take this for granted. Peacetime attitudes often differ from wartime ones, and Ministers will need to demonstrate that the data-sharing approach that was helped us to fight COVID can have an equally transformative effect on the rest of the NHS.

## **Main proposals**

The draft Health & Care Data Strategy sets out a high-level framework across seven key themes of reform, with policy ambitions that will be operationalised through secondary legislation later this year, and then passed to the NHS’s agencies and delivery structures to be shepherded to fruition. Those seven themes are:

### **1. Bringing the public closer to their data**

The first theme, and perhaps the most important, is public confidence in how their data is used. The golden thread running through this strategy, and the core opportunity of the NHS’s wider shift to population health, is an engaged and empowered community of citizens that can share responsibility for their health with the system. To that effect, the strategy sets out an intention for the NHS to enable every patient across England to have access to their own health data, for much broader use and engagement with the NHS app, and for stronger protections and rights over where and how the NHS uses the public’s health data. We can shortly expect an Information Governance Framework for Integrated Health and Care, which will establish a clear set of rules and standards under which staff and patients can access and deploy their data.

It is hoped that patients can access their own medical information, procedures and care plans, as well as manage prescriptions, appointments and communicate with health staff. As well as the obvious benefits to patient experience and health outcomes, over time this can also help patients to understand how their data is being deployed and improve public trust in the process.

## **2. Giving health and care professionals the data they need to provide the best possible care**

Greater integration of digital tools and data should release time for NHS staff to care for patients, but often it means the opposite. Staff bear the responsibility of collecting and inputting patient data into complex IT systems, but also the challenge of accessing multiple complex – often distinct – IT systems in real time. The strategy seeks to reduce that burden, with a new ‘Data Alliance Partnership’, made up of organisations from across health and social care, empowered to oversee and incrementally manage down the burden of data collection and input on healthcare workers across the system.

Yet for patients, there is an equally significant opportunity on the upside. Too often, clinicians have to work around cumbersome and sometimes contradictory rules to access and share patient details across care settings. The strategy seeks to accelerate the shift to ‘Shared Care Records’ with consistent and clear standards across primary and secondary care, overseen by the Integrated Care System (ICS). Each ICS is set a target of a basic shared care record to be in place by September this year.

Underpinning all these initiatives will be a new duty to share data – including confidential personal information – for both direct care and operational planning purposes. This is intended to overcome the many unnecessary obstacles that can impede data sharing between different settings, often negatively impacting on the quality of care, but it is the inclusion of a legal basis beyond direct care which will prove most controversial when this comes to fruition.

## **3. Supporting local and national decision makers with data**

The NHS is entering a new era of commissioning, based around integration and collaboration instead of targets and incentives, with ICSs at the vanguard of that shift. The more digitised, data rich NHS envisaged in this strategy can give those structures the tools they need to deliver that more sophisticated form of planning, procurement and partnership with external suppliers. Yet this will require, in many ways, a rethinking and a retooling of the NHS’s existing data analysis capability.

The strategy seeks to build the workforce that can deliver that, building on the partnership with industry and academia that was seen in COVID to embed an expanded

data science capability in the NHS. There are new training programmes, a new ‘analyst workforce observatory’ to support professional development, and new competency frameworks to help align and orientate training and educational institutions towards the expanded NHS market. In the long term, this expanded capability will build the sophistication within the NHS to support that new form of commissioning – one focused on data and innovation, measured patient outcomes and early intervention.

The strategy also recommits itself to the focus on interoperability, with a new role for ICSs in driving this. The array of clinical settings coming under the banner of the ICS gives it particular locus to drive this consistent approach. Yet it also implies a much more co-ordinated approach to procurement and purchasing of digital tools across a footprint than many had thought likely. The long unchallenged incumbency of large digital service providers in primary care may find the market rapidly shifting if purchasing and procurement is now subject to a wider array of stakeholders.

#### **4. Improving data for adult social care**

The strategy seeks to take on the challenge of data collection and use in the highly atomised adult social care sector. Meaningful integration with NHS services will not be possible without the development of a meaningful digital and data architecture in that sector, but as so often before, the highly fragmented provider base may well constrain any real advances towards that.

The strategy includes a new framework for data collection in adult social care and an extension of GP connect to include staff in social care settings. There will also be a new programme of partnership with local authorities – as significant providers in the market – to collect more robust and more granular data. Yet with the starting point in social care so low, concerted focus, investment and clear standards will be needed from the regulators and agencies operating in the sector.

#### **5. Empowering researchers with the data they need to develop life-changing treatments, models of care and insights**

A core part of the strategy is improving patient engagement and participation with new research studies on areas such as developing new treatments, vaccines or diagnostic tools, but in doing so, to capitalise on the array of data available from the proliferation of new digital and self-care tools.

The work of the Goldacre Review, yet to be published, will also inform that ambition. New digital platforms, such as NHS DigiTrials will enable much faster identification of suitable participants for clinical trials, along with new efforts to standardise clinical

trials protocols across the G7, will hugely accelerate and expand the scope of data available for researchers.

## **6. Developing the technical infrastructure**

There is an ambitious plan to separate patient data out of the commercial EPR data system, with a new set of 'structured care records' stored independently the cloud. This, it is hoped, will enable much faster data deployment as well as broader access and understanding, both for the system and for patients. It also sets out a major upgrade of the NHS's cyber defenses, with new standards for local providers and systems to follow, and new programmes for training and development of the digital infrastructure across the system.

## **7. Helping developers and innovators to improve health and care**

The role of AI and digital providers in health care has already hugely accelerated, but the NHS still has not fully leveraged the capabilities it could at the core of its model of care. The strategy sets out a commitment to support 100 companies through the AI in Health and Care Awards, as well as a new independently way to independently validate AI technologies for screening. Regulation will be improved to make it consistent and harmonised and give much greater clarity for suppliers of the rules of the NHS market they seek to enter.