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A New National Purpose: Harnessing Data for Health

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Contents

Our Future of Britain initiative sets out a policy agenda for governing in the age of AI. This series focuses on how to deliver radical-yet-practical solutions for this new era of invention and innovation – concrete plans to reimagine the state for the 21st century, with technology as the driving force.

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01

Foreword

We are at a pivotal moment where the convergence of large health and biomedical data sets, artificial intelligence and advances in biotechnology is set to revolutionise health care, drive economic growth and improve the lives of citizens. And the UK has strengths in all three areas. The immense potential of the UK's health-data assets, from the NHS to biobanks and genomics initiatives, can unlock new diagnostics and treatments, deliver better and more personalised care, prevent disease and ultimately help people live longer, healthier lives.

However, realising this potential is not without its challenges. The complex and fragmented nature of the current health-data landscape, coupled with legitimate concerns around privacy and public trust, has made for slow progress. The UK has had a tendency to provide short-term funding across multiple initiatives, which has led to an array of individual projects – many of which have struggled to achieve long-term sustainability and deliver tangible benefits to patients.

To overcome these challenges, it will be necessary to be bold and imaginative. We must look for ways to leverage the unique strengths of the NHS, such as its nationwide reach and cradle-to-grave data coverage, to create a health-data ecosystem that is much more than the sum of its many parts. This will require us to think differently about how we collect, manage and utilise health data, and to create new partnerships and models of collaboration that break down traditional silos and barriers. It will mean treating data as a key health resource and managing it accordingly.

One model to do this is the proposed sovereign National Data Trust (NDT) – an endeavour to streamline access to and curation of the UK's valuable health-data assets. It would ensure a return on investment through access fees, quicker and more affordable access to innovative treatments, and value-added services such as data discovery, clinical trials and the analysis and facilitation of research. This would all be while maintaining public ownership and protection of the data, and never selling or transferring them to private interests. The NDT represents a fundamental shift in the approach to the governance and utilisation of health data, acknowledging its potential to improve lives and being clear about the necessity for a robust, transparent and sustainable framework to realise its benefits.

The NDT would serve as a catalyst for innovation within government. By providing a secure and trusted platform for data access and analysis, it would enable policymakers and public servants to experiment with new approaches, test hypotheses and make transparent, data-driven decisions that improve the efficiency and effectiveness of health-care services. It would be a way to determine which changes have worked and which have not. Giving access to innovators and entrepreneurs would enhance the discovery and implementation of the discoveries that will drive better disease prevention and health care, and a more sustainable model of delivery. This culture of innovation and public-private partnerships is essential if we are to tackle the complex challenges facing our society and deliver better outcomes for citizens.

At its core, the NDT should be about building and maintaining public trust and bringing benefits to all. Citizens must have confidence that their personal health information is being handled securely, used responsibly and protected against misuse. They also need to see clear evidence that the insights that could be gleaned from their data are being translated into better care, new treatments and improved health outcomes for everyone. It will require a governance model that has strong public oversight but works with the agility and expertise of industry partners. It will need robust safeguards and ethical frameworks to ensure that commercial interests never take precedence over the public good.

But alongside safeguards, we need innovation and experimentation, and this will require the involvement of the private sector. Realising the full potential of health data will mean taking calculated risks, exploring new avenues and learning from both successes and failures. Not every initiative will bear fruit, but by embracing a spirit of curiosity, collaboration and continuous learning, we can push the boundaries of what is possible and deliver meaningful benefits to patients and the public. This is how progress occurs.

During the Covid-19 pandemic the Vaccine Taskforce brought together the best of academia, industry and the NHS to develop and deploy life-saving vaccines at unprecedented speed, and it serves as a powerful example of what can be achieved through strategic collaboration and a shared sense of purpose.

The road ahead is not easy, but the stakes could not be higher. With bold leadership, a clear vision and an unwavering commitment to putting patients first, we can transform the lives of millions, build a more resilient and sustainable health system, and cement the UK's position as a global leader in life sciences. And the time to act is now. The National Data Trust is a critical first step on this journey to unlock the full potential of health data and create a future where every patient receives the right treatment at the right time, and where the UK leads the world in delivering cutting-edge care and pioneering new technologies for diagnosis, disease prevention and treatment.

Sir Patrick Vallance, Strategic Counsellor, TBI, and former Government Chief Scientific Adviser

02

Executive Summary

Britain's National Health Service (NHS) is the world's largest publicly funded health service. It is also the world's largest repository of health-care data. Yet these data are fragmented and underutilised. Making them accessible in one place would improve health and deliver wealth for the nation. Current efforts to improve data accessibility are held back by bureaucratic hurdles, short-term thinking and inadequate resources. This creates a vicious cycle that hinders the development of new treatments, diagnostics and innovations, ultimately impacting patient outcomes and economic growth.

To address these barriers and streamline access to health data for trusted researchers, we propose the creation of a National Data Trust (NDT). This would be majority-owned and controlled by the government and the NHS, together with investment from industry partners; it would connect NHS data and attract private investment in new medical discoveries. This initiative would bring the economic benefits of health innovation to citizens: if the NDT is fully integrated with clinical-trial services, it could drive an additional £2 billion in economic growth by 2030. It would accelerate the NHS's development of cutting-edge innovations, provide quicker access to these advancements at reduced costs, and generate a new funding source for the health-care system.

To circumvent the constraints and short-term thinking that often hamper public-sector initiatives, the NDT could follow the BBC's model of combining public service with commercial success. The broadcaster provides a public service while also operating BBC Studios, a revenue-generating subsidiary that upholds public trust. Although the NDT's objectives could theoretically be achieved within the public sector, it would require a comprehensive overhaul of practices – from funding cycles to operational methods – which is an unrealistic undertaking given the immense scale of change required. Establishing the NDT as an independent entity, separate from the NHS, would shield it from the political pressures that have previously impeded efforts to create a coherent, modern data infrastructure. With autonomy, financial flexibility and the ability to attract specialised expertise, the NDT could more effectively tackle the complex challenges surrounding data accessibility and utilisation.

NDT could help in other areas too. Accelerated by artificial intelligence, new discoveries and the availability of data, biotechnology is offering new cures and treatments for many diseases, innovative approaches to biomanufacturing, and more personalised and effective health care. The previous report in the New National Purpose series highlighted the opportunity the United Kingdom has to build on its early advantages and lead this revolution. From pioneering scientific breakthroughs to being home to some of the frontier companies in biotech, the UK has the potential to play a leading part in one of humanity's most exciting endeavours. But in an increasingly competitive global environment, with countries such as France, Germany, Canada, Japan and the United Arab Emirates racing to build the industries of the future, and the US and China in the lead, the UK must be bold. Central to this will be unlocking the full potential of our health data.

The establishment of an NDT would be a transformative step, helping to drive innovation, improve patient outcomes and stimulate economic growth. This new body would connect together the access points of our fragmented data landscape, initially building on Secure Data Environments (SDEs). Over time, access to the Clinical Practice Research Datalink (CPRD), Genomics England (GEL) and UK Biobank would be streamlined and harmonised, overcoming the obstacles hindering efficient data access across the UK.

This “concierge” for data access for research and innovation would help to bolster the quality and sustainability of the NHS's data infrastructure and the integration of its research functions with its health-care-provision functions (contributing to wider effort to address data fragmentation and under-utilisation). The NDT would confer huge patient benefits, but also stimulate scientific discovery and the wider biotech and health-tech industry, especially in the AI era. Quicker access to a broader range of data via one system, plus shared services to investigate the data, will accelerate the development of new treatments and diagnostics, placing the UK in an enviable position compared with its peers.

Given the benefits to the private sector, partners will also support its creation, in the same way that they have significantly contributed to the growth and success of previous groundbreaking enterprises such as UK Biobank. At a minimum the NDT would aim to initially raise £150 million externally in additional funding, which would be critical at a time of tight public finances.

The trust would function as a professional commercial entity, with one of its primary aims being to provide an additional source of sustainable financing and well-curated, interoperable data to the NHS. In clinical trials alone, bringing NHS England and the National Institute for Health and Care Research (NIHR) together into a unified clinical-trials service would reignite the UK's reputation as an attractive site for global pharmaceutical research. Given such activities have dropped by 44 per cent since 2017, the revenue here alone could be significant – more than £250 million annually – while the wider benefits would amount to billions. With new forms of data also more readily available, the total annual value would be much higher. Building and maintaining public trust is critical and many will rightly raise the question of privacy. All data accessed through the NDT would be anonymised, with the body operating with high levels of transparency and robust data protection, particularly given the sensitive nature of personal health information. A coherent approach to opt-out rules – including making it easier to opt back in – will be necessary. This will require technical changes, including connecting diverse data systems and complying with complex regulatory requirements.

As AI changes the world around us, its impact on health and biology will be transformative. In the coming decades, we will live longer, healthier lives as science and technology drive the discovery of new drugs and diagnostics. Many of the most successful companies of the future will be in this area.

The UK's role in this future depends on its ability to utilise its rich array of data by treating them as a competitive asset. In its health data, the UK has one of the most potentially important resources of the AI era. Now is the time to make bold choices and realise this asset's full potential.

We propose:

1. **Setting up an NDT by 2026 as a company owned by the government and the NHS, with co-investment from industry**. To ensure its success, the NDT will be co-designed with the public and will aim to raise at least £150 million externally in additional funding to support its mission. It's important to recognise that the creation of the NDT and the development of the necessary technical infrastructure is a journey. While we propose establishing the NDT by 2026, it will take more than two years to fully build out the envisioned capabilities and achieve integration and interoperability across the health system.

2. **Consolidating other existing health-data access points**, starting with

SDEs and, over time, other data sources such as the CPRD (a government-owned research service that provides anonymised primary-care records for public-health research), GEL (a company set up and owned by the Department of Health and Social Care to deliver the 100,000 Genomes Project and sequence genomes from NHS patients) and UK Biobank (a large-scale biomedical database and research resource containing genetic and health information from half a million UK participants), under the NDT umbrella within two years of its establishment. This consolidation will end the high level of fragmentation and lack of interoperability that currently hinders access to UK health data, creating a more efficient and harmonised system and allowing organisations to focus on their core purpose.

3. **Creating a coherent clinical-trials service by integrating the efforts of the NIHR and NHS England**. The NIHR is the nation's largest funder of health-and-care research, working in partnership with the NHS, universities, local government, other research funders, patients and the public to improve the health and wealth of the nation. This unified service would enable commercial clients including large life-sciences companies, tech companies, start-ups, innovators and academic research organisations – companies that provide support to the pharmaceutical, biotechnology and medical-device industries in the form of research services – to utilise the NDT as the single, authoritative source of data for individuals enrolled in clinical trials.

4. **Amending legislation on data controllership within the NHS to move away from the current model, where general practitioners (GPs) are the sole controllers of a lot of patient data**. This shift will involve prioritising legislative changes to streamline the process of requesting access to data for research purposes (data-access requests), while ensuring robust safeguards for patient confidentiality.

The NDT can offer four distinct benefits for accessing health data for research and innovation, compared with both the current fragmented landscape and a centralised in-house model based within the NHS:

- Providing the ability to commit to longevity of intent and investments, avoiding the short-term funding cycles and merry-go-round of frequent structural changes that have held back progress in the past (see, for example, NHSX and NHS Digital, which were both absorbed into NHS England).
- Enabling funding to be carried forward from one year to the next, avoiding

the constraints of government budgeting processes and Treasury clawback of funding that make commercial ventures difficult.
- Taking external funding from industry, shifting investments off the public balance sheet at a time of limited fiscal headroom.
- Making it easier to attract talent, given greater flexibility in employment terms and conditions, enabling the NDT to compete with the private sector for scarce data-science and analytics skills.

While the NDT represents a critical step towards unlocking the transformative potential of the UK's health data to improve health outcomes, drive scientific discovery and spur economic growth, it is not a silver bullet for overcoming the fragmentation and underutilisation that currently hinder the system. Fully realising the bold vision of a streamlined, interoperable and innovation-friendly health-data landscape will require a commitment to building public trust through transparency and engagement, sustained investment and collaboration across the NHS, government and industry, and substantive legislative changes.

03

Introduction

The UK has a unique opportunity to become a world leader in the use of health data to drive research and innovation. With a national health-care system that covers the entire population from cradle to grave, the NHS holds an unparalleled health-data asset that could be used by researchers and innovators to drive ground-breaking medical discoveries, improve citizens' health and attract significant investment from the global life-sciences industry.

Realising these public benefits requires the NHS to collaborate with the right partners – public-sector organisations, non-profits, academia and private companies – without compromising its core principle that health care must remain free at the point of use.

The UK's current approach to access to health data is piecemeal, holding us back from realising their significant potential to accelerate medical discoveries. As a result, life-sciences companies are starting to vote with their feet and investment is leaving the UK. Clinical-trials activity dropped by 44 per cent between 2017–18 and 2021–22.[1]

Meanwhile, other countries are racing ahead. The EU has reached cross-national agreement on the secondary use of health-care data[2] and countries such as Germany have passed legislation to provide central access to their data.[3] Sweden, Finland, Denmark and Estonia are among the countries leading in the provision of quality, population-wide data, and are attracting top R&D companies as a result. In Finland, for example, Roche subsidiary Genentech and GSK have set up hubs to take advantage of the FinnGen research project's work on genomics. AstraZeneca has established a drug-development research centre in Sweden, in part to better leverage high-quality Nordic data.

If the UK fails to address the current challenges of accessing its health data for research and innovation, it risks severe long-term consequences for its health-care system. Innovative solutions are crucial for tackling the growing pressures of an ageing population and rising health-care costs. Without timely and cost-effective access to cutting-edge treatments and technologies, the NHS will struggle to provide high-quality, sustainable care, leading to poorer health outcomes and a widening gap between the UK and its peers.

Falling behind in the global race to attract life-sciences investment would further compound these challenges. The life-sciences industry is vital for developing new medicines, devices and diagnostic tools that revolutionise patient care and improve health-care efficiency. By failing to create an environment conducive to health-data research and innovation, the UK risks missing out on the substantial economic benefits of thriving life-sciences and academic sectors, such as job creation, scientific discovery, increased tax revenues and a highly skilled workforce.

Crucially, it should concern policymakers to see countries with smaller populations and less diverse data sets outpacing the UK in leveraging health data to improve citizens' health and wealth. The UK possesses a unique 60 million-person-strong data asset, combining a large population, a single-payer health-care system, diverse geographical differences and rich longitudinal data. Harnessing this asset effectively could drive medical breakthroughs, enhance patient outcomes and boost the economy. Failing to capitalise on this immense untapped potential at such a critical time would be a historic missed opportunity.

04

The UK's Broader Health-Data Infrastructure: Context and Challenges

By streamlining public-, charitable- and private-sector clients' access to health data for research and innovation, a National Data Trust (NDT) would advance the use of the UK's health-data asset for the benefit of the public. However, if this proposal is to succeed, several challenges to the UK's broader health-data infrastructure must be addressed.

First, data availability and quality for researchers must be improved by making the data consistently discoverable and accessible.

The complex and fragmented nature of the NHS, wherein thousands of individual organisations control different aspects of patient data,[4] makes it difficult for researchers to access and utilise this valuable resource effectively. The quality of recorded data varies and so do the rules to access them, creating barriers to research and innovation.

Second, public trust in data sharing must be gained and strengthened through engagement, transparency and robust data-protection measures.

A lack of public trust has historically been a major hurdle, with high national opt-out rates reflecting concerns about privacy and security. For instance, the care-data scheme, which aimed to extract and link data from GP practices to a central database, was suspended in 2016 after more than a million patients opted out amid concerns about how their data would be used and shared with third parties. Similarly, the General Practice Data for Planning and Research programme faced significant backlash in 2021, leading to a delay in its implementation, as patients and advocacy groups raised alarms about inadequate transparency and the potential for data misuse. While the Covid-19 pandemic and local public-engagement initiatives have demonstrated that these concerns can be overcome, building and maintaining public trust will require concerted effort at every step.

Establishing a coherent approach to opt-out rules (including making it easier to opt back in) and adequate legal safeguards should be an urgent priority, regardless of the development of an NDT. Learning lessons from Covid-19 and striking the right balance between not stifling access to data and legitimate concerns about privacy and transparency will be essential and require strong public engagement.

Third, sustained and reliable funding needs to be secured to support long-term research and innovation programmes. Structural issues within the health-care system pose additional challenges.

One of the most fundamental weaknesses of the UK's health sector is its approach to funding health-data initiatives. It is characterised by small, short-term grants from multiple sources and frequent reinvention of programmes, in part as a response to a political desire to announce new initiatives. This leads to a fragmented landscape of competing programmes that rarely achieve commercial viability or scalability, in contrast with other leading countries in this space. Nordic countries have had more comprehensive and well-funded data strategies for many decades; these established data systems meant that countries were able to quickly harness these data to better support patient care and recruitment of trial participants during the Covid-19 pandemic. Investment in data infrastructure and analytical capability is a core component of large US health-care systems. Mayo Clinic, for example, is able to conduct large-scale research within its own system using the longitudinal records it holds on its patients.

Alongside the fragmentation of funding, the structural separation of NHS England and the NIHR is not helping matters. The NIHR's research focus has primarily been on achieving academic excellence, which, while undeniably important, has sometimes taken priority over demonstrating the immediate practical utility of research findings for NHS organisations, including being responsive to the health system's needs and enhancing the translation of research into practice. This is particularly crucial when funding is scarce and making the right allocative decisions is vital to maximise the impact on health care. Research is therefore often seen as a nice-to-have, especially at a time when the NHS is under significant operational and fiscal pressure.

Progress is being made in these areas. NHS England's Data for R&D Programme is creating a strong foundation of data infrastructure and fostering public trust at national and local levels through Secure Data Environments (SDEs). These specialised data platforms act as "reading libraries" designed to ensure the secure handling and processing of sensitive information, thus enabling ease of access to data by accredited researchers in a privacy-preserving manner. The Health Data Research (HDR) Innovation Gateway enables data to be discoverable centrally from varying data sets across the UK, collated from a wide range of sources. Without the Gateway, researchers would have to know what data existed and where to find them – this resource saves a huge amount of time identifying relevant data sets.

Lord O'Shaughnessy's 2023 review of UK commercial clinical trials has provided a comprehensive blueprint for creating an end-to-end clinical-trials environment that can significantly increase the UK's ambition and reverse the recent decline in this field. At the Review's recommendation, the government has already begun to put in place networks for research delivery and clinical trials. A promising development in strengthening public trust is the NHS App, which serves as a powerful platform for proactively informing and recruiting patients for clinical trials at a national level.

05

A Radical Solution to the Data-Access Problem

Amid these complex challenges – improving data availability and quality, strengthening public trust and securing reliable funding – lies a significant opportunity for the UK to take a meaningful step forward by addressing one critical piece of the health-data-infrastructure puzzle: streamlining access to health data for research and innovation.

Creating a more efficient and harmonised system for accessing health data would already improve the UK's ability to leverage its unique data assets. This would accelerate scientific discovery, attract investment and ultimately deliver better health outcomes for the public.

Despite the progress made so far, a lack of long-term political commitment and sustained financial investment is already hindering the UK's ability to realise the value of this national data asset to improve the NHS and increase health innovation by fully integrating its health-data infrastructure (and improving its integration with clinical-trial infrastructure), enhancing data quality and creating compelling services for data access. Funding cuts and a lack of clarity around future budgets further add to the uncertainty. Many detailed questions about the commercial model, pricing, and the exact scale and scope of services are still to be agreed upon, and vital legislative changes to speed up data access have not yet been passed into law.

To truly streamline data access, two radical actions should be taken to alter the UK's existing approach.

The first action is to create a single interface for accessing data. Despite there being a single "front door" for discovering data assets (the HDR Innovation Gateway), there isn't a single "concierge service" to follow this up with the tools that clients need to understand and make use of the data. The NDT would fill this gap. This includes joining up the data-access service with the service for setting up clinical trials.

A considerable amount of data – local and national – is already discoverable centrally through the HDR Innovation Gateway. The Gateway hosts data from across the UK’s four nations, spanning varying disciplines, and drawn from primary-, secondary-, acute- and palliative-care settings, as well as biobanks and research cohorts. And the core design principle of the SDE programme, which has both a central and local layer, is that data sets should be collaborative and federated with one another. There is also work underway to harmonise data-access processes and bring down lead times between requesting and receiving access to less than a month, which would be a great step forward.

However, this should be taken one important step further: there is scope to simplify exactly how the SDE programme’s data-set federation will work and streamline the number of access points there will be among the SDE family. High demand for the relevant commercial expertise and analytical skills – which are currently in short supply in an increasingly competitive market – further strengthens the argument for centralisation.

Similarly, pricing and commercial models for the SDEs currently vary across the country, as do the range of the service offer and scale of resources, creating huge inefficiencies for data users.

The UK’s clinical-trials infrastructure also remains fragmented. For example, the latest version of the NHS App gives citizens a way to opt into research opportunities nationally, but this remains underdeveloped and not adequately interconnected with other elements of NHS infrastructure, such as the clinical-trials hub DigiTrials.

The second action is to make a bold choice about where the concierge service for access to data sits. Both nationally and globally, existing data assets’ organisational forms vary (see Annex for a list of relevant examples). While different approaches have their merits, setting up the NDT outside the NHS as an external commercial entity would enable the commercial edge and sustainability that it needs to succeed.

At the same time, having the government and the NHS as majority-controlling owners will be vital to build and maintain public trust, and to ensure acting in the public interest remains the key driver of the NDT’s mission.

06

Setting Up the National Data Trust for Success

The NDT should be set up outside the NHS for the following reasons:

1. To Avoid NHS Short-Termism and the Risk of Politicisation

Establishing a coherent and modern data infrastructure is highly complex and takes time and money, especially given that the UK was an early adopter of digital technology and as such has a large number of legacy systems. Connecting data across these systems is very difficult and requires a stable funding and policy environment, as well as better use of the NHS's market power to enforce a set of common standards.

This cannot be achieved from within government as it currently operates. Short-term thinking and political pressure are deeply entrenched within NHS culture. Clinicians are primarily focused on immediate patient care, while the NHS itself is subject to shifting priorities and reorganisations driven by an electoral cycle every five years. This limited foresight and constant upheaval have resulted in the absorption of initiatives like NHSX – a government policy unit formed in 2019 to enable the NHS's digital transformation – into the broader NHS England structure, undermining their intended impact through a lack of longevity.

The Centre for Improving Data Collaboration (CIDC), which aimed to access NHS data for research and innovation purposes – akin to the NDT's mission – met a similar fate.

These entities deserved dedicated resourcing and autonomy to realise their full potential. They serve as evidence that establishing the NDT outside government is essential in order to insulate it from these cyclical pressures and ensure its longevity. That said, maintaining a high degree of political engagement to secure buy-in remains crucial.

2. To Circumvent Fiscal Constraints

The UK state's current fiscal architecture does not provide the right incentives for commercialisation from within government. Balance sheets of public-sector organisations are prone to financial clawbacks. For example, an NHS trust generating a fiscal surplus from efficiency measures at year-end is likely to find its budget reduced the following year, disincentivising investment in cost-saving measures or revenue-generating initiatives. Most NHS organisations also can't carry forward money from one year to the next, with unspent budget being transferred back to the Department of Health and Social Care (DHSC).

This fundamentally undermines the incentives for commercialising data access from within the NHS.

Establishing the NDT outside government would therefore enable longer-term focus and financial flexibility, akin to that of a private company. With appropriate Treasury oversight, the NDT could retain, ringfence and reinvest its revenues into key NHS projects over sustained periods of time, rather than having surpluses absorbed into the general government coffers.

3. To Enable the NDT to Raise and Hold External Funding

Establishing the NDT as a private entity with greater fiscal agility would enable it to raise and hold external funding from industry and other sources. At a time of limited fiscal headroom, this helps shift investments off the public balance sheet.

4. To Attract Industry Expertise

The public sector's rigid pay scales and job structures make it challenging to attract and retain the specialised data-science, engineering and leadership expertise required to drive digital transformation.

Operating outside the NHS and DHSC frameworks would allow the NDT to offer competitive employment terms and remuneration packages, enabling the recruitment of top talent from industry, research and academia into critical management and technical roles.

07

Overview of the National Data Trust: A Radical Yet Practical Proposal That Benefits the Public

In addition to generating revenue that can be reinvested into the NHS (therefore helping the UK to secure its place at the global innovation frontier), realising the value of the UK's health-data asset through an NDT would also deliver for citizens.

As a model for public and private entities to access health data, the NDT represents a bold new approach. It would operate as an independent commercial entity with majority ownership by the government and the NHS, and a proposed public-private ownership ratio of 70:30. Working with investors and partners where appropriate and necessary, the NDT's explicit aim would be to generate direct benefit to patients, the NHS and the wider economy.

The NDT could be modelled on the BBC's approach of blending public service with commercial viability. The broadcaster operates a revenue-generating commercial subsidiary, BBC Studios, while maintaining its public-service mission and commitment to trust. The NDT would act as a one-stop shop providing centralised access to health data from various sources and data-related services, with a secure accreditation-to-access process.

More importantly, the single front door would include services such as data discovery, direct data access, basic analytical support, facilitation of feasibility studies and patient recruitment for clinical trials. It would enable quicker, easier access to data, and support both industry and the NHS in making the most out of those data. Most critically, the NDT would be built on the SDE programme, which guarantees the highest standards of security for data access, enabling patients and the wider public to have ultimate control over who accesses their data.

GEL demonstrates how a public-private partnership can attract industry investment, with partners providing upfront investment at a 5 per cent rate to support the use of health data for research and innovation. However, its experience also highlights the need for a clear commercialisation strategy and a more significant level of private investment from the outset to effectively generate returns and support its broader mission. The model for Our Future Health, the UK's largest-ever health-research programme, which collects and analyses data from millions of volunteers to develop new ways to prevent, detect and treat diseases, illustrates the willingness of industry to invest upfront to support the development and operation of essential health-data infrastructure.

While operating as a business, the NDT by statute would be firmly committed to generating positive outcomes for patients, the NHS and the wider economy. The benefits are threefold.

First, patients receive better care in research-active health-care organisations.[5] By driving more research activity, the NDT would therefore help to deliver better patient outcomes. Institutions that are active in research can better attract and retain top medical talent, and more effectively maintain both their early access to innovative treatments and technologies, and their adherence to the latest clinical guidelines and best practices. Moreover, research participation often provides patients with additional monitoring and support, leading to better disease management and reduced complications.

Building on the benefits of health-care organisations that are active in research, the NDT would also play a crucial role in making the NHS more active in clinical trials, which is essential for attracting cutting-edge trials to the UK, such as the recent NHS-Galleri collaboration to assess health-care company GRAIL's new cancer-detection test. Covid-19 demonstrated the importance of rapid discovery: the RECOVERY trial, which was set up in only six weeks,[6] delivered one of the world's first treatment options, dexamethasone, estimated to have saved one million lives worldwide.

Second, the benefits of access to high-quality data will also enable the development of wider digital health solutions powered by artificial intelligence. These innovative solutions are not only essential for improving patient outcomes but also for generating significant cost savings for the NHS.[7] For example, AI-powered diagnostic tools can help detect diseases at an earlier stage, when they are more treatable and less costly to manage. Similarly, personalised treatments tailored to an individual's genetic profile and medical history can be more effective and efficient than one-size-fits-all approaches, particularly in areas such as cancer and cardiovascular diseases.

By enabling prevention, early diagnosis and targeted interventions, these solutions can reduce both overall treatment costs and future demand on the health-care system. Patients can benefit from earlier, tailored and more effective interventions, leading to better health outcomes and quality of life. Access to data for start-ups and other innovative companies would also allow a far greater opportunity for innovation and support a new ecosystem in the UK.

Third, the NDT can generate additional resources for the NHS, which is stretched for resources and financing. While a world-class service, its current ability to provide treatment for people who need it is at breaking point, with patients left waiting for extended periods of time, and staff facing burnout and real-wage decreases for their efforts. Providing the NHS with an additional funding source beyond public taxation and new approaches to gain earlier access to new products at reduced cost would help to address some of these issues, build innovation in the NHS and ultimately provide patients with the care they need and deserve.

The economic benefits that the NDT can help unlock, particularly by improving the UK's clinical-trials infrastructure, are substantial. The global clinical-trials market, currently worth £67.6 billion, is projected to grow to £98.6 billion by 2030.[8] If the UK can restore its market share from the current 3.8 per cent to its previous high of 6.8 per cent, it could generate an additional £1 billion in revenue by 2024 and £4.1 billion per year by 2030.[9] In terms of gross value added (GVA), regaining the 6.8 per cent market share could drive an additional £2 billion in GVA, based on inflation-adjusted figures from 2014–15 when the UK's share was at its peak.[10]

When the case for benefit is strong, the right security measures and guardrails are in place and the public is well informed, people are generally willing to share their health information for the improvement of health care for others. This is evident from the thousands of people who donate blood for life-saving transfusions and the millions who have signed up for data schemes such as Our Future Health. The appetite to donate data for research is strong, especially when there are concrete benefits that are clear to the public.

The NDT should therefore build on the momentum and public interest in health-data sharing demonstrated during the pandemic by clearly communicating the public benefits, ensuring robust security measures and providing individuals with greater control over their data. During the pandemic, we witnessed people taking a deep interest in their own health and that of the nation (this demonstrates that when the public understands the importance and potential benefits of sharing health data, it is more likely to support such initiatives). Alongside this increased awareness, Control of Patient Information (COPI) notices were issued to improve the flow of patient information for research; in addition, the DHSC indemnified GPs for the risk associated with data sharing.

08

Target Operating Model for the National Data Trust

STRUCTURE AND GOVERNANCE

Operational independence of the NDT is vital to ensuring longevity of intent and funding, as well as institutional stability. In turn, these aspects are crucial for creating enduring, high-quality data infrastructure and overcoming the stop-start funding cycles and frequent structural changes that have hampered progress in the past.

The design of the NDT's governance structure will need to ensure public interests are met, as well as enabling the interests of investors and other key stakeholders and aligning with the mission of the organisation.

Securing public trust, which has been a major challenge in previous data-sharing initiatives, will be paramount, particularly given the co-investment from industry. Meaningful involvement of citizens in the governance structure should therefore be considered either by having them directly represented on the board or through a citizens advisory group – a model that has worked well in London.[11]

The board of the NDT would have the necessary autonomy to pursue the organisation's commercial and wider interests set out above, including the pursuit of discovery. This operational independence is critical to avoid the bureaucratic constraints and short-term political considerations that have often hindered the agility and effectiveness of public-sector data initiatives. However, it is essential to note that the board's primary and non-negotiable duty would be to prioritise the interests of the NHS and the public benefit, keeping them at the forefront of all decision-making processes.

DATA ACCESS AND SERVICES

The NDT will not hold the actual data, which remains the prerogative of individual data controllers through a federated data-access model. Instead, it would provide seamless access to a range of data assets, starting with centrally available NHS data – such as the national SDE and remaining Health

Data Research UK (HDR UK) data-hub infrastructure – before linking into the sub-national SDEs locally. This approach addresses the challenge of data fragmentation and inconsistency by providing a unified platform for data discovery and access. However, this is also the most challenging aspect of the NDT and will take time to develop. Starting small and expanding over time will be an important principle.

Over time, the NDT aims to provide a consolidated front door to all health-care data discoverable via the HDR Innovation Gateway, amalgamating commercial access to currently separately accessed data assets like CPRD, GEL and UK Biobank. By bringing access to these resources together under a single umbrella, the NDT would create a more efficient and harmonised system – or "concierge service" – for researchers and innovators to access the wealth of UK health data.

Given the vital importance of clinical trials to revenue generation, the NDT would integrate, where appropriate, with the NIHR clinical-trial infrastructure, building on the NHS DigiTrials approach. This integration would involve the NDT providing access to relevant health data to support clinical trials, working in conjunction with the NIHR's existing clinical-trial infrastructure and expertise. This integration is crucial for streamlining the clinical-trials process, enabling faster and more efficient recruitment of participants, and ultimately attracting more life-sciences investment to the UK.

Access to data alone is not enough to create a compelling proposition: to truly unlock the potential of the UK's health data, the NDT must offer a comprehensive range of services to trusted researchers. This would include data discovery, direct access to health-care data for accredited parties, basic descriptive and automated search functionality, feasibility studies for trials, trial recruitment, provision of data about individuals from a single source for locally recruited trials, health economics and analytical services, and the ability to validate and develop machine-learning algorithms. By offering this comprehensive suite of services, the NDT aims to become a one-stop shop for health-data research and innovation in the UK.

Access to data would be governed by a pre-accreditation licensing system, with substantial use of patient-level de-identified data via a streamlined data-access-committee process. This approach addresses the current challenges of inconsistent and lengthy data-access processes across different organisations. Legislative changes should be prioritised to enable central sign-off and access within weeks rather than months, removing a significant barrier to the timely and efficient use of health data for research.

It is important to note that the NDT's development would be a gradual process, with the full scope of services and data assets being integrated over several years. Building the requisite technical infrastructure, including the integration of federated SDEs and the creation of a robust, interoperable data platform, would be a complex undertaking that would extend beyond the initial two-year timeframe for establishing the NDT. Existing progress would continue and there would be no "big bang" switch-over moment. This iterative approach allows for continuous improvement and adaptation based on evolving needs and technological advancements, ensuring that the NDT remains a flexible and future-proof solution for the UK's health-data ecosystem.

COMMERCIAL MODEL AND REVENUE GENERATION

The NDT would be tasked with generating revenue on behalf of the taxpayer for the benefit of the NHS, increasing the fiscal headroom of the taxpayer-funded health system while fostering knowledge generation. As the central point of access for commercially funded research, the NDT would eventually serve as the sole entrance point for accessing all centrally funded health-data assets (the SDEs). While locally developed and funded data assets (e.g., those held by universities or tertiary institutions) would not be obligated to use the NDT as the "concierge", they would be encouraged to do so in order to benefit from its scale, expertise and streamlined processes on a non-exclusive, fee-for-service basis. The NDT aims to offer such a compelling service that it naturally attracts the broadest-possible range of stakeholders in the health-data ecosystem, without the need for a mandate.

This focus on commercialisation is critical to ensuring the long-term sustainability of the NDT, reducing reliance on grant funding and short-term government investments and maximising returns for the public. It would also accelerate the development of groundbreaking technologies within the NHS – and improve access to these innovations at lower costs.

A range of wider fiscal and societal benefits will accompany revenue generation, including faster and cheaper access to novel treatments, and general spillover effects such as job creation and increased GVA.[12]

Any surplus generated would be reinvested into services and infrastructure or distributed among owners and data contributors, guided by principles co-designed with the public, investors and data controllers. This approach ensures that the benefits of data commercialisation are shared equitably and transparently, building trust and support among key stakeholders.

The redistribution model would consider the relative risk taken by contributors, balance return on initial investment with future development, and tie revenue to actual data use to incentivise high-quality data provision.

Revenue could also be ringfenced for specific purposes, such as prevention, public health or the overall research budget, providing incentives for the NHS and R&D community to prioritise commercialisation of access to data. This targeted reinvestment of funds could help to address the structural separation between NHS England and NIHR, fostering a more integrated and collaborative approach to health-data research and innovation.

This would address the current lack of incentives for capturing high-quality data at the point of care; at present, the use of data for research purposes is not adequately rewarded or recognised. Of course, it is likely to take significant time before a surplus can be realised given the infrastructure investment required.

The NDT would have a transparent pricing model informed by public engagement, market intelligence and the experience of existing organisations in this space. Public consultation has shown support for commercialising health-care data, particularly when there is a strong public benefit, and favours a tiered pricing model based on location and ability to pay.[13] This approach ensures that the NDT's commercial strategy is aligned with public values and expectations, helping to build and maintain trust in the use of health data for research and innovation.

FUNDING AND INVESTMENT

The NDT aims to become financially self-sustaining in the medium term, allowing funds currently invested in creating research capacity and capability to be redirected to front-line service provision. However, achieving sustainability will require further initial investment from government and external sources, given the significant upfront costs of developing the necessary technical infrastructure and service offerings. Government funding should come from broader economic growth agenda, rather than relying solely on the health department's budget.

The NDT would hold funding to invest in data-for-research infrastructure, aggregating existing funding and raising additional external funding to provide scale and longevity. Over the next two to three years, an estimated minimum of £200 million would be required to develop the full functionality of the SDE data asset, operationalise full federation, and cover the core operating costs of the NDT before revenue becomes sufficient. This minimum level of investment is necessary to create a truly world-class health-data infrastructure that can compete on the global stage.

The NDT would therefore aim to raise between £200 million and £300 million initially, with the government retaining a majority stake, implying an external target of £100 million to £150 million. To help meet this funding goal, the government should consider utilising part of the £400 million investment programme of the 2024 voluntary scheme for branded medicines pricing, access and growth (VPAG).

In addition, industry may wish to provide further contributions. No exclusive access to data would be granted in return for investment; instead, external investors would be offered preferential access rates where appropriate. This approach ensures that the NDT remains a public asset, focused on generating benefit for patients, the NHS and the wider economy, rather than serving narrow commercial interests.

As clinical trials are the most lucrative market, the NDT's return would rely on significant growth in clinical trials alongside wider data-access activity – for the development of digital-health interventions and AI, for example. In 2018–19, the total estimated income for the NHS from delivering commercial clinical trials was £355 million. The wider benefits from clinical trials are substantial, with an estimated £2.7 billion in gross value added to the UK economy and 47,500 full-time equivalent jobs. In addition, the total estimated cost saving for the NHS was £28.6 million (where trial drugs were used in place of standard ones).[14]

By streamlining and centralising access to health data and clinical trials, the NDT has the potential to significantly increase these figures, driving economic growth and job creation across the country.

RISKS

Establishing the NDT outside the public sector (as an entity owned by the government and the NHS, with co-investment from the industry) on top of the current data infrastructure has a number of clear benefits, as set out above. However, to fully harness the potential of the UK's health data for research, innovation and patient benefit, the following issues must be addressed in parallel with the creation of the NDT:

1. Broader existing technical and operational challenges need to be addressed. This involves tackling the fragmentation of data across multiple systems and organisations, and improving data quality and standardisation. While the NDT alone cannot solve these issues, its establishment may generate the necessary fiscal longevity and focus to make significant progress in these areas.
2. A compelling offering for industry co-investment must be developed. This entails providing high-quality data access, analytics and clinical-trial services, as well as demonstrating the ability to commercialise these services and generate revenue. The NDT's success in attracting industry investment will depend on the strength and scope of its service offering.
3. Meaningful public engagement must be prioritised from the start. Building and maintaining a high level of public trust, as well as involving the public in key decisions and governance processes, is essential. Significant public involvement is required from the outset to ensure the NDT's success and long-term viability.

While addressing these broader issues is essential for the NDT to achieve its full potential, the initiative itself also carries specific risks that must be carefully managed:

1. Public concerns about a private company commercialising access to sensitive health data, which could undermine trust and support for the initiative. To mitigate this risk, strong and meaningful public engagement that addresses these concerns from the start is vital.
2. The separation of services and investment from delivery capacity, which could make it harder to direct resources and priorities at the local level. To address this challenge, the NHS front line and data controllers must feel the benefits of commercialising data, in terms of both financial return and better data infrastructure for various use cases.
3. The potential for a single point of failure if the NDT does not provide an

efficient, user-centric service, which could damage the UK's reputation and attractiveness as a destination for health-data research and innovation. The NDT's organisational design and structure are key to mitigating this risk, enabling it to have sufficient autonomy and distance from public-sector bureaucracy, and to operate as a commercially minded entity that is responsive to market needs and customer demands.

LEGAL AND POLICY CHANGES

To enable the NDT to function effectively, two urgent legal changes should be prioritised:

1. Enabling a single sign-off process for access to all de-identified data, bringing multiple integrated care boards (statutory NHS organisations responsible for planning and commissioning health-care services for their local populations) under a single data-access-committee process. This change would streamline the currently fragmented and inconsistent data-access landscape, reducing delays and administrative burdens for researchers and innovators.
2. Addressing data controllership, potentially by establishing joint controllership between NHS England and individual data controllers, as is the case in Scotland. This shift would help to clarify roles and responsibilities, reduce the risks and liabilities faced by individual data controllers, and facilitate a more coordinated and strategic approach to data sharing and commercialisation.

A clear roadmap should be developed across all current public investments into health-care data to consolidate commercial access and functions, within a reasonable transition period. This roadmap should set out a phased approach to migrating existing data assets and services into the NDT, ensuring a smooth and orderly transition that minimises disruption to ongoing research and innovation activities.

09

Conclusion

The National Data Trust represents a bold and ambitious approach to unlocking the value of the UK's health-data asset, driving innovation and improving patient outcomes. By providing a streamlined, transparent and commercially viable platform for data access, shared services and clinical trials, the NDT has the potential to transform the UK's health-data landscape and cement its position as a global leader in life-sciences research and innovation.

The real value of the NDT lies in its ability to lock the UK into a long-term strategy with business discipline. As such, it takes the management of this critical asset away from short-term political considerations.

At its most fundamental, the NDT can offer distinct advantages in ensuring the longevity of investments, enabling funding to be carried forward, allowing external investment and attracting top talent. By bringing together the best of the public and private sectors, leveraging the unique strengths of the NHS and prioritising public trust and engagement, the NDT offers a compelling vision for a new era of health-data research and innovation in the UK.

Download the full technical annex.

Lead image: Getty

Endnotes

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