Who has access to our health data? Local and national data systems

Introduction

This paper is prompted by the announcement by Barts Health NHS FT in November 2025 that it would be joining forces with other teaching Trusts in the capital to create a single data infrastructure, *Health Data for London (*HDfL). The announcement suggests that, currently, and unlike single-Trust cities like Oxford and Cambridge, the data held by London's teaching hospitals is fragmented, making London institutions less competitive. The HDfL initiative therefore aims to address this fragmentation and "cement London's status as a global player in the life sciences". [1]

There is no indication that HDfL will be used to provide direct patient care. However, this single data infrastructure' appears to be part of an increasingly complex network of data stores that offer access to our health data for research and development purposes. For example, HDfL builds on the existing Barts Health Data Platform:

> "a secure environment offering access to the electronic health records of an economically and ethnically diverse population of over three million individuals. Over a million new patient encounters are added every year, offering researchers an unrivalled repository of anonymised data to mine for insights and innovations." [2]

HDfL also appears to be part of the broader *London Health Data Strategy* (see below) and a growing number of national initiatives that aim to provide access to our health data.

These initiatives claim that innovation will lead to improved care, but the emphasis is largely on how our health data is needed for the growth and competitiveness of the life sciences. This trend, in which the innovation championed is often shorthand for market-driven research, raises questions of who is now gaining access to our health data, what is the relationship between different data stores, how accessible are they to the private sector, how secure is the data, what is the data being used for, and what are the implications for privacy and public trust.

This paper does not attempt to answer these questions. Instead, it aims to set out the complex infrastructure that is currently in place and that allows increasing access to our health data for non-direct care purposes. Finally, what began as an exploration of data sharing arrangements across London raised questions about how these related to national arrangements. This paper is therefore in two parts, the first using London as an example of local data systems, and the second looking at wider systems for storing and sharing data.

PART ONE: LONDON SYSTEMS

OneLondon

Created in 2018, OneLondon is a collaborative of London's Integrated Care Systems (ICSs) and the London Ambulance Service, supported by NHS England (London Region), the Greater London Authority (GLA) and London's three Health Innovation networks. It ostensibly focuses on "the delivery of data sharing between providers at the point of care to inform and support clinical decision making and inclusive patient access". In promoting One London, much is made of how the first step was to have a deep and genuine conversation with Londoners about how information would be used to improve care. What is given less prominence is that OneLondon is also part of" a digital innovation ecosystem for the capital, both for health providers and innovators.[3]

Board members of OneLondon include representatives from NHSE London, each of the ICSs, London Ambulance Service and 'other partners'.

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[1] https://www.bartshealth.nhs.uk/news/health-data-for-london-launch-18149#blg-cmt-frm

[2] ibid

[3] https://digitalhealth.london/one-london-local-health-and-care-record-exemplar-creating-the-data-sharing-ecosystem

Local Health and Care Record Exemplar

OneLondon is one of three areas chosen in 2018 by NHS England (NHSE) and the LGA to become Local Health and Care record exemplars.

The aims of the Local Health and Care Record programme at this time were to create an information sharing environment that

- helps to continually improve treatments
- tailors health and care needs to each individual, and
- "can empower people to look after themselves better and make informed choices about their own health and care".

Although the primary focus of Local Health and Care Record Exemplars is said to be on improving and coordinating individual care, they will also allow what are described as 'local communities' to use this information to

- support local health and care planning and management, and
- better understand the health and care needs of their local population.[4]

The Local Health and Care Record Exemplars also provide an opportunity "to make better use of information from people's health and care records",. This partly relates to individuals' care plans: the expectation over time was to be able to run algorithms between the record and the plan "to help people manage their health and their appointments". The Exemplars were also about supporting functions such as population health management and research as well as creating a set of national standards that all local health and care record initiatives across England will be required to follow.

Local Health and Care Record Exemplars: Use of information

Initially	Individual care	Real-time sharing of personally identifiable data: health care professionals will be able to access an individual's integrated care record to support delivery of care by other NHS and partner organisations, making use of clinical decision support systems.
	Individual care	Near real-time sharing of personally identifiable data: to support care planning, with the ability to support real time logic applied to populations and individuals to flag interventions
Later	Intelligence	Near real-time data availability of de-personalised data to understand population needs, monitor the effectiveness of health and care delivery and support the operation of the health and care system.
	Intelligence	Longer term studies of de-personalised data to review health and care service provision, identify relevant population cohorts to reduce inequalities, design new risk stratification approaches and identify future population care needs and services
Potential	Research	To support observational/real world evidence and interventional biomedical, clinical and applied studies (under the auspices of Digital Innovation hub).

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[4] https://www.england.nhs.uk/wp-content/uploads/2018/05/local-health-and-care-record-exemplars-summary.pdf

As the table above indicates, one potential use of health and care records is to support research. "Working within the legal framework and fully meeting the strict parameters for sharing information and the security standards set out by the National Data Guardian", the Exemplars will provide data for research purposes to the Digital Innovation Hubs, described in the White Paper "*Industrial Strategy: building a Britain fit for the future*".[5] These Hubs will create controlled environments for

- real-world clinical studies;
- implementing new clinical trial methodologies; and
- analysing structured and unstructured multi-dimensional datasets (including imaging and, notably 'omics data[6] for the development of personalised medicine[7])

The London Care Record

Developed by OneLondon, the London Care Record (LCR) is "a single, aggregated record of patient health and care information over time and across organisations and geographies within London", enabled by a network of health information exchanges (HIEs) which combine data. [8]

The LCR allows frontline staff such as GPs, GP practice nurses, junior doctors, consultants, nurses, allied health professionals, pharmacists and social workers to view data about their patients and service users.

It provides a joined-up view of data from multiple settings, including primary care, acute services, mental health, community care and social care, although depending on development, the level of information varies across the Integrated Care Systems. The Record does not currently include local authority detail, ICU information or full mental health records. Staff are able to access the LCR from their native system and so no login credentials are required.

The London Health Data Strategy (LHDS)

OneLondon, Health Data Research UK and 'partners' have set out a London Health Data Strategy (LHDS). This aims to enable London to make better use of its rich data assets and position itself as the global location of choice for academic and industrial innovation regarding healthcare, so attracting inward investment while delivering benefits to patients and the NHS.[9] A key element of this is the London Secure Data Environment.

The London Secure Data Environment (LSDE)

The London SDE, due to be fully operational by April 2026, will create one of the largest data assets in the world. It is built on existing initiatives in the capital and stores London's health data on two separate platforms for privacy and security.[10]

1. A Patient-identifiable (PID) environment, **the London Data Service**, delivered by North East London (NEL) that provides a structured set of technologies to host and store identifiable information. The first phase of the programme store data from Primary Care (General Practice

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[5] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/664572/industrial-strategy-white-paper-print-ready-version.pdf

[6] 'Omics' refers to the branches of science such as genomics and proteomics.

[7] Personalised medicine, also known as precision medicine, tailors treatments and healthcare to individual patients based on their genetic make up and other personal characteristics. https://www.england.nhs.uk/wp-content/uploads/2016/09/improving-outcomes-personalised-medicine.pdf

[8] https://www.onelondon.online/wp-content/uploads/2020/10/London-Care-Record-Guidance-for-health-and-care-professionals.pdf

[9] https://www.onelondon.online/wp-content/uploads/2022/09/London-Health-Data-Strategy.pdf

[10] https://londonhealthdatastrategy.org/what-do-we-mean-when-we-talk-about-the-architecture-for-the-london-health-data-strategy/

since 2025), Secondary Care, Mental Health, and Community data from the Commissioning Data Set via the Secondary Use Service (SUS)[11]

This data environment is described as highly secure and divided into data stores for each of London's five Integrated Care Systems as well as a single environment for the whole of London.

NEL also provide the tools to support pseudonymisation, a process whereby PID data is anonymised but with a special token that enables the patient to be reidentified in the future.

As well as the above, NEL will deliver a terminology service for London. This aims to provide tools to ensure that information means 'the same thing, in the same way, all the time' so that all diagnoses, procedures, medication, and other important facets of the patient record are consistently identifiable. The management of terminologies will be "provided by a group of subject matter experts" on behalf of London.

2. An anonymised environment, **the Analytics Platform**, provided by Northwest London (NWL). Building on the Discover-NOW model in place since 2018, the Analytics Platform uses data from the London Data Service to

- support health and care staff in providing direct and proactive care
- help health and care organisations in the planning of services, and to assess and improve services
  help academics or 'industry partners' engaged in research and development.[12]

The NWL environment conforms to rules defined by Health Data Research-UK ensuring that people who access the data are appropriately vetted, that projects using the data are ethical, that technology environments are secure, that data is anonymised for the research project and outputs are controlled for the purposes of research.[13]

As the data moves between Northeast and Northwest London the data is anonymised and then staged within Northwest London for research use.

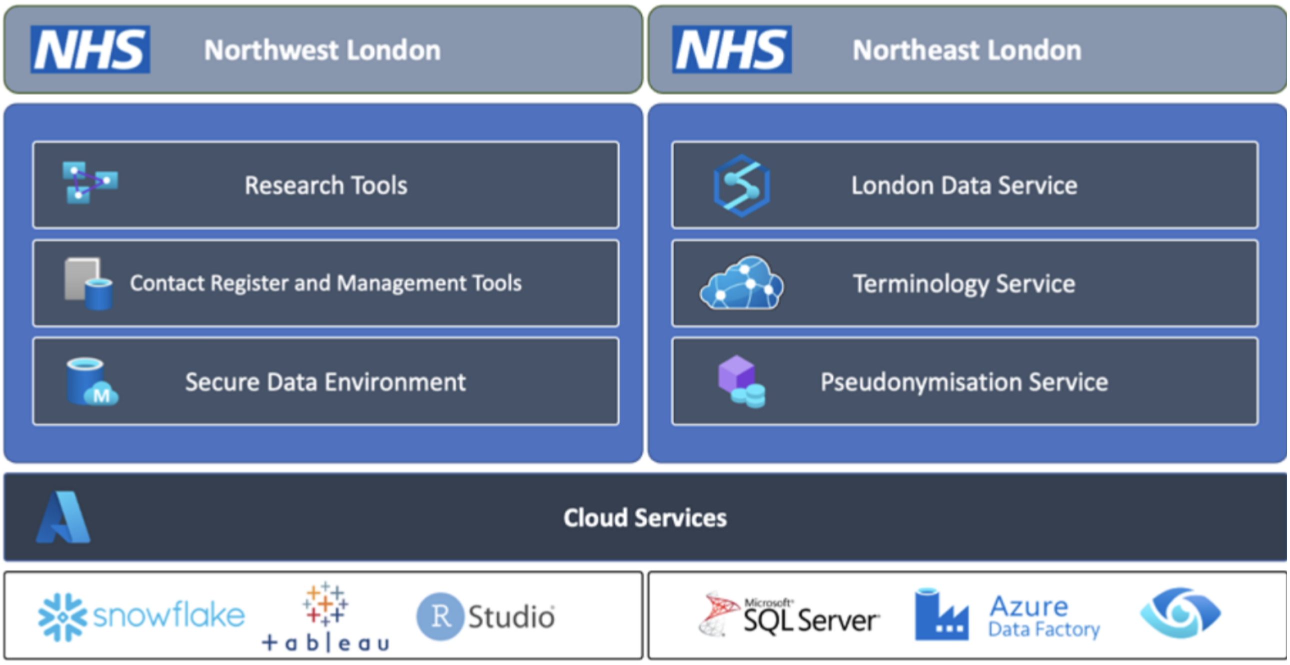

Diagram provides an overview of the technologies and capabilities that support the London Data Strategy

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[11] The Secondary Uses Service (SUS) is the single, comprehensive repository for healthcare data in England which enables a range of reporting and analyses to support the NHS in the delivery of healthcare services.

[12] https://www.onelondon.online/london-secure-data-environment/

[13] 'Research' now is often taken to mean commercial as well as academic enquiry.

These London-focused initiatives also exist in the context of national data sharing programmes such as the Health Data Research Service, the Federated Data Platform and the Single Patient Record.

PART TWO: NATIONAL SYSTEMS

The Federated Data Platform

In contrast to the HDRS, which primarily focuses on providing NHS data to external users for research and innovation, the NHS Federated Data Platform (FDP) is a government initiative to unify (and centralise) healthcare data across England and improve the use of existing shared care records to inform patient care and the operation of the NHS.[14] After piloting in 2022, the FDP was launched in 2023 with the aim of integrating (federating) patient, operational, and research data from various systems into one single 'ecosystem'.

Essentially, the FDP is not a SDE but a software platform providing NHS staff with access to patients' data through online dashboards, with access supervised by local data controllers, such as NHS Trusts or integrated care boards (ICBs) as well as NHS England. Built on cloud infrastructure (using Palantir's Foundry platform), the FDP's core purposes have expanded from building infrastructure and improving interoperability to include the provision of analytical tools, and pre-configured applications and tools (e.g. to focus on areas such as discharge planning or population segmentation and targeting).This expansion is said to have led to some confusion about the platform's core purpose and led to unrealistic expectations of what the FDP can achieve.[15]

Patients' personal data, necessary for direct care, is held in identifiable form within a trust's local system, although each healthcare professional can only see the data needed for their role in an individual's care. Personal identifiers are removed before the data is used for planning and improving services. However, although the FDP is being built with acute patient data, there are suggestions that it should not only add data from primary care but also incorporate local authority and policing data to build a 'citizen 360 degree view'.

The National Data Integration Tenant (NDIT) is a part of the FDP, described as "NHSE's secure platform for collecting and managing national health and care data", [16] replacing multiple systems by just one. The NDIT collects data
1) *for NHS analytics and planning*: data is pseudonymised and then passed to the national FDP;
2) f*or research purposes*: data is passed to the National Secure Data Environment for approved research projects and can then be provided in either identifiable or pseudonymised form, depending on research requirements and approval.

The National Data Opt-Out (NDOO) does not apply to NDIT processing because NHSE is legally required to process this data for national purposes. Nor does the NDOO apply to the FDP more generally because a) any confidential data used in a local FDP is only being used for direct patient care, and b) no confidential patient data is processed in the national FDP for purposes to which the NDOO would apply.

NHSE expects 85% of NHS Trusts to have adopted the FDP by March 2026, but providers have described challenges in adopting the platform.[17] In addition, concerns have been raised that the platform limits local innovation and that the FDP has become strongly associated with a single supplier

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[14] https://www.england.nhs.uk/digitaltechnology/nhs-federated-data-platform/fdp-faqs/#what-is-the-software-that-underpins-the-nhs-federated-data-platform-and-where-can-i-find-out-more

[15] https://publicpolicyprojects.com/wp-content/uploads/2025/06/Maiximising-the-impact-of-the-NHS-Federated-Data-Platform.pdf

[16] https://www.england.nhs.uk/digitaltechnology/nhs-federated-data-platform/security-privacy/the-nhss-safe-environment-for-national-data/

[17] https://publicpolicyprojects.com/wp-content/uploads/2025/06/Maiximising-the-impact-of-the-NHS-Federated-Data-Platform.pdf

(Palantir), limiting competition, to say nothing of whether such a notorious supplier should be embedded in the NHS.

In addition, the commercial contract to build and manage the FDP is for a period of around five years raising questions about what happens when the contract ends. For example, will the NHS be locked into high cost extensions, or will it have to rebuild or re-procure the system?

According to Public Policy Projects,[18] there are hopes that existing FDP infrastructure could help create the foundation for a single, unified patient record (SPR), leading to better coordination and insights across the health and care ecosystem. These are both very different in concept and purpose, with the FDP allowing the NHS (or those commissioned by the NHS) to access data for planning and population health planning purposes, and the SPR informing real-time clinical decision-making. Run in parallel, there is however significant overlap between the clinical and operational uses of the FDP and the SPR. The FDP does not make data available for research, although there are plans that the SPR may.

The Single Patient Record (SPR)

Proposals within the government's *Fit for the Future: 10 Year Health Plan for England*[19] include a new single patient record (SPR) that brings all of a patient's medical records into one place and will

> "wherever possible, build on and connect with existing systems – such as Electronic Patient Records, Shared Care Records, and the Federated Data Platform – rather than replacing them. Source systems will remain the clinical system of record."

A public engagement exercise began in early 2024 to consider the creation of a single patient record including data from across a range of health and care settings. Participants were also asked to consider the inclusion of general practitioner (GP) data beyond individual care, for planning NHS and care services and for research (referred to as 'secondary uses'). The programme to deliver the SPR entered its test and learn' phase in the autumn of 2025, at which point no decisions had been made on the system architecture or procurement approach.

The SPR, described ambiguously as "a patient passport", will be available to clinicians, while patients will be able to add their own data to it from clinically validated wearables. Over time, the SPR will also include "a personalised account of health risk" drawn from lifestyle, demographic and genomic data: this is "to help personalise the NHS's service offer and to support individual behaviour change".

The news provider *ditgtalhealth,*[20] drawing on a leaked report from the Data and Technology working group[21] that advised on the Ten Year Health Plan, suggested that "The single patient record will be available to researchers by default", with opt-out only available by exception. However there is no mention in the published 10 Year Health Plan that the SPR will make data available to researchers. (The universal national record giving access to researchers that the working group called for may have emerged as the Health Data Research Service – see below).

The SPR will require new legislation that places a duty on every health and care provider "to make the information they record about a patient accessible to that patient", and ensure patients have access to their SPR via the NHS App. This is not the first time that increasing access to health data has been sold to patients on the basis that they can access their data by default – as it is often put, be 'in control' of their data.

In addition, the legal framework governing the use of routinely collected patient data for research, planning and population health will be amended "to improve the NHS and for research that benefits its patients - including through the Health Data Research Service announced by the Prime Minister in April 2025".

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[18] Public Policy Projects, founded by former Conservative Secretary of State for Health, Steven Dorrell, specialises in "facilitate discussions between private and public sector providers to find improvements to the delivery of public policy in the health and life sciences sectors."

[19] https://www.england.nhs.uk/long-term-plan/

[20] https://www.digitalhealth.net/2025/02/single-patient-record-planned-across-health-and-social-care/

[21] Notably, the working group included Dr Charlotte Refsum, director of health policy at the Tony Blair Institute.

The Health Data Research Service (HDR Service)

Announced in August 2025 after mention in the 10 Year Health Plan, and following the Sudlow Review,[22] the HDR Service aims to create a single gateway to health and care data for academic and commercial research purposes, with a view to speeding developments, such as precision medicine.

After "extensive stakeholder engagement"[23] between June and October 2025 with patients, health practitioners and researchers across the UK, the HDR Service is due to go live at the end of 2026 and be fully operational by 2030. Set up with around £600 million of government and Wellcome Trust funding, it is now approved as a government company to provide care providers and 'approved users' with a single access point to various national datasets for the first time, for example, to speed up clinical trials. [24] This will include access to de-identified data, already available to care providers from the Single Patient Record.

Still under discussion, the core capabilities of the HDRS are likely to be:

- Access to linked primary care, hospital, prescribing and mortality data at national scale, providing researchers with a complete picture of patient journeys through the health system.
- Access to research-ready datasets holding data from participants in major research studies
- Access to diagnostic images, laboratory results and genomic data,
- Integration of health data with the platforms that researchers use to help conduct clinical trials,
- Standardised agreements and approvals processes and secure research environments.
- The ability to link health data with information from other sectors – like environmental or social data – will offer richer understanding of factors that affect our health.[25]

The new service will be housed at the Wellcome Genome Campus in Cambridgeshire, where Wellcome is building new R&D laboratory and office spaces "to expand the current campus's capacity for innovative genomics and biodata companies".[26]

Why is all this important?

To begin with, this Labour government is unashamedly pro-business and 'innovation', and sees access to NHS data as vital to economic growth. Consequently, although new data sharing systems are usually announced with the assurance that they will "maintain the highest standards of data protection", the priority is fast becoming to slash 'red tape' so that the economic potential of our health and care data can be unlocked. [27]

We can see this in recent legislation, the Data (Use and Access) Act (2025), which, for example, redefines 'scientific research' to include commercial activities. It also allows patients' consent to the

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[22] The Sudlow Review called for health data to be removed, that it should be seen as critical national infrastructure "that can underpin the health of the nation" and barriers to access should be removed. https://www.hdruk.ac.uk/helping-with-health-data/the-sudlow-review/

[23] Notably, the National Institute of Health and Care Research defines public engagement as "the many ways in which the activity and benefits of an organisation or research can be shared with the public. Engagement is a two-way process, involving interaction and listening with the goal of generating mutual benefit", while public involvement means that "activities and research are carried out 'with' or 'by' members of the public, rather than 'to' or 'for' them,

[24] At the same time, the Wellcome has commissioned Emrys Health to conduct a landscape analysis of exiting digital technology supporting health data research. https://wellcome.org/research-funding/funding-portfolio/major-initiatives/health-data-research-service#when-will-the-health-data-research-service-be-ready-for-researchers-to-use?-3c55

[25] https://www.england.nhs.uk/blog/health-data-research-service-unlocking-the-potential-of-health-and-care-data-to-transform-lives/

[26] https://www.gov.uk/government/news/prime-minister-turbocharges-medical-research

[27] For example, https://www.england.nhs.uk/blog/health-data-research-service-unlocking-the-potential-of-health-and-care-data-to-transform-lives/

use of their data for one research project to be taken as consent for its use in future studies, even if the purpose of these is unknown at the time.[28]

Similarly, updated guidance for the NHS on intellectual property (IP)[29] shifts the way that IP ownership is viewed: now, "commercial partners are often best placed to develop and scale new products".[30] Historically, NHS Trusts have kept ownership of IP arising from the data it contributes to collaborations with other parties, with the aim of ensuring a return on public investment. Now, however, the priority is the speed of innovation, rather than keeping important NHS assets.

Moreover, the view of who 'owns' NHS data itself is shifting. For instance, when answering the question of whether the FDP will sell patients' data, NHS England has said that "Patients can have confidence that data in the NHS Federated Data Platform will always remain in the full control and protection of the NHS". However it qualified this by saying "it will not give access to confidential patient data for marketing or insurance purposes",[31] leaving open the possibility that it may sell NHS data for research and development purposes.

But even if data held by the FDP will be restricted to informing patient care and the operation of the NHS, there is already talk about marketing data stored by the Health Data Research Service. A joint statement by the Department of Health and Social Care, the Department for Science, Innovation and Technology, and Dr Zubir Ahmed [32] says that, with the HDRS,

> "Researchers will only analyse data in controlled environments where every action is monitored, and the data does not need to leave secure systems. They will only have access to the specific data they need to answer their research question."[33]

However, according to Zubir Ahmed, in addition to accelerating the discovery of new treatments for NHS patients, the UK should "leverage" the Health Data Research Service commercially "for the benefit of the Treasury coffers". [34]

Use of the word 'leverage' was duplicitous: the reference to Treasury coffers suggests that 'sale' would be a more accurate term. Until now, researchers have paid for *access* to anonymised NHS data on a cost-recovery basis. However, according to the Financial Times,[35] the pricing of health data will raise public concerns about profiteering from personal information. Moreover, Minister Ahmed as saying that the HDRS's Chair and CEO should have the autonomy to decide what they charge and to whom. Notably, the Chair of the HDRS is Baroness Nicola Blackwood[36] and its CEO is Dr Melanie Ivarsson,[37] both of whom have been recruited from industry.

What will this mean for the ownership or control of data? Who owns data is widely contested but doesn't sale (as opposed to cost recovery) imply the transfer of ownership? And if external parties can claim to own our data, doesn't that mean such data can be removed from the control of the data store?

And finally, broader and faster access (with uncertainties about security and control), or the prospect of data selling, have implications for public trust, with loss of trust having consequences for the extent to which patients will feel confident in providing personal data, and subsequently for the accuracy and comprehensiveness of the data held by the NHS.

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[28] https://keepournhspublic.com/five-things-you-should-know-about-the-new-data-use-and-access-bill/

[29] https://www.gov.uk/government/publications/intellectual-property-ip-guidance-for-the-nhs-in-england/intellectual-property-ip-guidance-for-the-nhs-in-england

[30] https://www.lexology.com/library/detail.aspx?g=3b7d69d7-6953-4e22-af7b-e008879b80ac

[31] https://www.england.nhs.uk/digitaltechnology/nhs-federated-data-platform/fdp-faqs/#will-the-nhs-sell-my-data

[32] Here described as an MP but elsewhere as Minister for Health Innovation.

[33] https://www.gov.uk/government/news/visionary-leader-appointed-for-health-data-research-service

[34] https://www.digitalhealth.net/2025/12/uk-should-make-money-from-nhs-patient-data-says-health-minister/

[35] https://www.ft.com/content/0531e76b-a800-450f-8a10-ac5ada1b2695

[36] Baroness Blackwood is Chair of Oxford University Innovation and Genomics England and also serves0on the boards of biotechnology company BioNTech and investment fund RTW Biotech Opportunities.

[37] Dr Ivarsson's background is in health care innovation and industry: she has had senior roles at pharmaceutical companies Eli Lilly, Pfizer and Tadeda, and led trials into Covid-19 vaccines at Moderna.