

Change NHS

10 Year Health Plan for England

Open Data Institute response

December 2024

About the ODI

The Open Data Institute (ODI) is an independent, non-partisan, not-for-profit organisation founded by Sir Nigel Shadbolt and Sir Tim Berners-Lee in 2012. We have a mixed funding model and have received funding from multiple commercial organisations, philanthropic organisations, governments and intergovernmental organisations to carry out our work since 2012.

The ODI wants data to work for everyone: for people, organisations and communities to use data to make better decisions and be protected from any harmful impacts. We work with companies and governments to build an open, trustworthy data ecosystem. Our work includes:

- consultancy: working with organisations in the public, private and third sectors, building capacity, supporting innovation and providing advice
- research and development: identifying good practices, building the evidence base and creating tools, products and guidance to support change
- policy and advocacy: supporting policymakers to create an environment that supports an open, trustworthy data ecosystem

Our [5 year strategy](#) sets out what we think are the elements of an open and trustworthy data ecosystem for a world where data works for everyone. Our approach allows us to adjust our implementation and engagement as the world around us, and the organisations we work with, change. Our activities will be set out on an annual basis, mapped to the six principles that guide everything we do:

1. We believe that a strong data infrastructure is the foundation for building an open, trustworthy data ecosystem on a global scale and that this can help address our most pressing challenges.
2. Strong data infrastructure includes data across the spectrum, from open to shared to closed. But the best possible foundation is open data, supported and sustained as data infrastructure. Only with this foundation will people, businesses and governments be able to realise the potential of data infrastructure across society and the economy.
3. For data to work for everyone, it needs to work across borders – geographic, organisational, economic, cultural and political. For this to happen ethically and sustainably, there needs to be trust – trust in data and trust in those who share it.
4. There is greater need than ever for trusted, independent organisations to help people across all sectors, economies and societies to benefit from better data infrastructure.
5. For data to work for everyone, those collecting and using it need to be highly alert to inequalities, biases and power asymmetries. All organisations working in data must take proactive steps to ensure that they contribute fully and consciously to creating a diverse, equitable and inclusive data ecosystem.

6. The world needs a new cohort of data leaders – individuals who have data knowledge and skills and are equipped to understand the value, limitations and opportunities offered by data, data practices and data sharing.



The ODI's approach to this consultation

This document responds to the Department of Health and Social Care's consultation on the [Change NHS 10-Year Health Plan for England](#). As we outline in this response, we believe that NHS data infrastructure should be recognised as critical national infrastructure, requiring sustained investment and a comprehensive approach to governance, standards, and workforce development. This infrastructure underpins the transformation of healthcare delivery, supporting the shift from hospital to community, analogue to digital, and sickness to prevention.

Throughout our response, we emphasise five key messages that we think should inform the 10-Year Health Plan:

1. NHS data must be recognised as a national asset and remain in public ownership. Governance must remain within the public sector, overseen by those accountable to Parliament, with patients given a meaningful role in decision-making. Decentralised architectures that offer individuals direct access and control of their health data should be explored.
2. Data standards are fundamental building blocks, not mere technical specifications. The adoption of standards like FHIR, Croissant, OpenActive, and Open Referral UK is crucial for interoperability, AI readiness, and effective service delivery. Standards must be developed openly with stakeholder input to ensure they meet real-world needs and maintain public trust.
3. Secure data access, rather than data sharing, is key to innovation while protecting privacy. Initiatives like OpenSAFELY and the NHS's Secure Data Environment demonstrate how trusted research environments enable data-driven innovation while protecting patient privacy. Privacy-enhancing technologies (PETs) like federated learning offer great potential, allowing algorithms to access data without exchanging the underlying data itself.
4. Building and maintaining public trust is paramount. This requires transparent governance, clear communication, meaningful patient involvement, and robust privacy protections. The failure of past initiatives demonstrates how quickly trust can erode when these principles are not upheld. The participation of the private sector must be under public stewardship, with ultimate custodianship of the data remaining in the public sector's hands.
5. Social prescribing has the potential to transform healthcare delivery and generate substantial cost savings but requires robust data infrastructure to succeed. Integrating data standards like [OpenActive](#) and [Open Referral UK](#), alongside a commitment to building data capabilities within community organisations, will enable the successful implementation and scaling of social prescribing initiatives.

At the ODI, we have extensive experience working on data infrastructure and governance initiatives in the healthcare sector, including collaborations with Moorfields Eye Hospital, Roche,

and various social prescribing initiatives. We are also actively involved in developing and promoting data standards like Croissant and OpenActive. This experience has informed our recommendations for how data can be a foundation and driver of a more effective, efficient, and equitable health service in the decade ahead. Our work with [Frontier Economics on social prescribing](#) highlights the potential for data-driven approaches to divert millions of GP appointments annually, demonstrating the tangible benefits of investing in community-based care.

Finally, civil society must play a vital role in shaping the future of healthcare data. We advocate for involving diverse stakeholders, including patients, clinicians, community organisations, and researchers, in developing and stewarding data infrastructure and governance frameworks. This will ensure that the 10-Year Health Plan reflects the needs and perspectives of all those who rely on and contribute to the NHS.

Q1. What does your organisation want to see included in the 10-Year Health Plan and why?

At the Open Data Institute (ODI), we envision a National Health Service that leverages the transformative power of data to enhance patient outcomes, drive efficiency, and foster innovation. With the NHS involved in nearly every citizen's most personal moments from cradle to grave, data underpins every interaction, justifies clinical decisions, and enables patients to understand their conditions through digital services like the NHS app.

NHS data is about people, it relates to them and their taxes paid to create it, so it must remain in public ownership. The 10-Year Health Plan should focus on building a better future for the NHS with data and AI that creates public value for public good while maintaining public trust. This requires a collective commitment to ethical, transparent and innovative data practices, ensuring public trust is not sold out for private gain.

The plan should recognise that public sector health data represents a significant national asset that requires careful stewardship. While this data offers immense potential for improving healthcare delivery through new technologies like AI, its governance must remain within the public sector, overseen by those accountable to parliament, while giving patients a meaningful role in decision-making. Rather than centralisation, decentralised architectures that offer individuals direct access and control of their health data should be explored. This data—widely regarded as some of the most consistent in the world—requires governance frameworks that maintain public trust while enabling innovation for public benefit.

NHS data may benefit from a wholesale reassessment of data as a public asset, both in terms of its value in training AI models and for use in other emerging technologies, as well as a means of accessing—and having the right and ability to—treat UK patients or conduct clinical trials.

Three core priorities

To support the government's vision of transforming healthcare delivery from this consultation—from hospital to community, analogue to digital, sickness to prevention—the ODI recommends three key priorities:

1. Establish NHS data infrastructure as critical national infrastructure

The NHS should recognise and invest in data infrastructure as critical national infrastructure. The ODI's work with Moorfields Eye Hospital through the [INSIGHT](#) Health Data Research Hub demonstrates how well-designed data infrastructure enables secure analysis of patient data while maintaining privacy and trust. This infrastructure has supported groundbreaking research in eye disease diagnosis and treatment while protecting patient data through robust governance frameworks.

The cost of poor data infrastructure is significant. The government [estimates](#) that NHS staff spend 140k hours annually manually transferring information between systems—representing both a clinical burden and economic inefficiency. By investing in proper data infrastructure, these resources can be redirected to patient care while improving health outcomes.

The [UK Biobank](#)'s vast datasets and potentially also the [National Data Library](#) (into which the ODI has inputted design ideas through the ODI's response to the Invest 2035 consultation and the AI Action Plan) — encompassing genetic information, lifestyle factors, and health outcomes—offers a unique opportunity to enhance early disease detection while maintaining public stewardship. By linking the public sector and the biobank data with health data held more locally, for example by GPs, more accurate risk prediction models can be designed. It also becomes possible to identify individuals who may benefit from targeted screening or preventative interventions—including those that can benefit from physical activity such as that promised by social prescribing.

2. Implement robust, interoperable data standards

Healthcare data standards must be treated as fundamental building blocks rather than mere technical specifications. For example:

- Adoption of FHIR ([Fast Healthcare Interoperability Resources](#)) would enable standardised health data exchange across the UK health sector
- Implementation of standardised metadata formats like [Croissant](#), that the ODI is working on would make healthcare data AI-ready while reducing administrative burden
- Integration of the [Community Service Data Standard](#) would support preventative care initiatives.

3. Enable secure data access for research and innovation

Initiatives like [OpenSAFELY](#) and the NHS's [Secure Data Environment](#) demonstrate how well-designed systems enable secure analysis while protecting privacy. This [trusted research environment](#) approach, where algorithms go to the data rather than data being shared, provides a proven model for expanding data-driven innovation while protecting patient privacy. Federated learning (FL) has great potential in the health service, allowing - as it does - algorithms to access data from multiple local datasets without exchanging the underlying data. Oxford University's [CURIAL-Federated platform](#) has shown promising results—this platform developed a COVID-19 screening test by training data across four NHS Trusts, with hospitals retaining data custody.

By implementing "data access" rather than "data sharing" approaches, where data is not shared, but models are trained on data in their local settings to extract insights, data-driven innovation can be expanded while maintaining public trust.

To illustrate how this might work in practice, consider the implementation of consent management systems that put patients in control of their data. Drawing inspiration from emerging international practices, such as India's Digital Personal Data Protection Act 2023, the NHS could establish a framework where healthcare providers act as "consent managers" for their patients. These consent managers could serve as trusted intermediaries, helping patients give, manage, review, and withdraw consent for their data use through accessible, transparent platforms.

For example, your GP could serve as your consent manager for decisions about your health data, using pre-formulated data usage terms that clearly explain how data might be used for research or service improvement. This approach would allow for explicit consent - when needed for sensitive data - and implicit consent - for routine care delivery - all while maintaining public ownership and control of the data.

Supporting social prescribing through data infrastructure

The NHS Long Term Plan commits to 900k social prescribing referrals by 2023/24. Evidence shows this could transform healthcare delivery while generating substantial cost savings:

- Physical inactivity alone [costs the UK economy £20 billion](#) annually, with £0.9 billion in direct NHS costs
- Research indicates that 20% of GP consultations are primarily for social problems
- ODI [research](#) with Frontier Economics suggests that social prescribing could potentially divert 3.2-8 million GP appointments annually

To support this scale of delivery, the ODI recommends:

Integrating proven data standards

Data standards must be developed and implemented under public stewardship while enabling innovation. Two complementary standards demonstrate how this can work in practice:

- The [OpenActive](#) Standard - currently enables 500k+ activity opportunities to be published weekly across 4k providers
- [Open Referral UK](#) - provides standardised data about community services
- These complementary standards enable prescribers to connect patients with appropriate non-medical interventions quickly and have the potential to be significantly scaled to benefit more patients across the UK

Building on existing success

The ODI's [2021 report on social prescribing data](#), accompanied by an interactive mapping tool, demonstrates how combining open datasets can enable better service planning and deployment. This tool helps policymakers identify where social prescribing would have the

most impact. Research from the [Royal College of General Practitioners](#), [National Academy for Social Prescribing](#) and [Sheffield Hallam University](#), among others, highlights a lack of knowledge and awareness of local community services as one of the key barriers to effective social prescribing practice. The network of experienced interested parties in social prescribing should be supported in the ten-year plan to avoid loss of expertise and replication costs if it's later revisited.

Implementation challenges

Three key challenges must be addressed while maintaining public trust and ownership:

1. Data integration

- Current systems operate in silos - the NHS holds vast amounts of data, often in siloed IT systems, making it hard to use across the health service ecosystem. Over 180 NHS trusts collect patient data through different electronic health record (EHR) systems, complicating data sharing and access. Although digital transformation is changing this, it should be sped up
- NHS Digital's [SNOMED CT codes](#) need integration with community data sources to create a common language between clinical and community settings. This integration is essential because SNOMED CT serves as the NHS's standardised clinical terminology, used across all healthcare settings. Without connecting these clinical codes to community service data, it becomes less possible to track patient journeys between healthcare and community settings or measure the effectiveness of all prescribing interventions (including social prescribing).
- Standards must be developed openly with stakeholder input to ensure they meet real-world needs and are trusted. This means actively involving healthcare professionals, community organisations, and patients in their development. Standards developed without proper stakeholder engagement could fail to address practical challenges or may create new barriers to effective care delivery. By involving those who will use and be affected by these standards in their development, their support for - rather than objections to - care delivery can be ensured while maintaining appropriate governance and public trust.

2. Service coordination

- Maintaining accurate service directories requires sustained investment
- Data about service accessibility and safeguarding needs to be standardised to enable interoperability

3. Resource allocation

- Clear methodologies are needed for valuing NHS data assets. Recognising data as an intangible asset would enable a more robust evaluation of the long-term impacts of public investments. For example, assigning an economic value to NHS data would support strategic decisions about funding, access, and its role in fostering innovation. These measurable outcomes would demonstrate how investments in data

governance and infrastructure translate into tangible benefits such as increased accessibility, improved data quality, and enhanced public trust

- To ensure the utility of data as an intangible asset, consistent methodologies are needed to quantify economic impact, and sustained investment in data infrastructure maintenance will be essential.

Expected benefits

Taken together, the ODI believes that the steps outlined above would deliver substantial benefits through:

- Reduced pressure on primary care
- Improved population health outcomes through better access to community activities for prescribers and patients
- Increased workforce productivity through reduced absenteeism
- Higher quality-adjusted life years (QALYs) through preventative interventions
- More efficient resource allocation through data-informed decision-making
- Greater public trust in - and satisfaction with - the NHS

Q2. What does your organisation see as the biggest challenges and enablers to move more care from hospitals to communities?

Successfully moving healthcare delivery from hospitals into community settings requires robust data infrastructure that connects healthcare providers with community services while maintaining privacy and security. Drawing from the ODI's experience working with both healthcare providers and community organisations, there are several critical challenges and opportunities in enabling this transition.

Key challenges in community care transition

Integration of community and clinical data

Moving care into communities creates an urgent need to connect previously separate data ecosystems. While hospitals maintain sophisticated electronic health records, community organisations often lack comparable digital infrastructure. This disparity creates significant barriers to coordinated care delivery. Moreover, community organisations frequently operate with limited technical capacity and resources, making it difficult for them to participate fully in digital health initiatives.

A technical divide can lead to fragmented patient journeys, with vital information about community-based interventions failing to flow back to primary care providers. This missing feedback loop makes it difficult to evaluate the effectiveness of community care and adjust interventions accordingly.

Service discovery and navigation

A fundamental challenge in community-based care is helping both healthcare professionals and patients find appropriate local services. Community provision is inherently hyperlocal, making it difficult to maintain comprehensive, up-to-date information about available services. The ODI's [research](#) into social prescribing has revealed that healthcare professionals often lack visibility of community service availability including capacity, and waiting times, hampering their ability to make effective referrals.

The [Open Referral UK](#) standard provides a consistent framework for service information, but its adoption remains limited. Without standardised ways of describing and discovering services, community care options remain unnecessarily difficult to access and coordinate.

Privacy and data governance

Moving care into communities introduces new complexities in data protection and governance. Community organisations need access to relevant patient information to deliver appropriate care, but may lack the infrastructure and expertise to handle sensitive health data securely. Meanwhile, healthcare providers need assurance that community partners can maintain appropriate data protection standards.

Initiatives like [OpenSAFELY](#) demonstrate that privacy-preserving approaches to data access are possible, but implementing these solutions at scale across diverse community settings presents significant technical and operational challenges. [Privacy-Enhancing Technologies \(PETs\)](#), including [Federated Learning](#), [Multi-party Computation](#) and personal data stores like [Solid](#), offer promising solutions for enabling secure data access without compromising privacy or security.

Enablers for community care transition

Standardised service information

The foundation for successful community care delivery is standardised, accessible information about available services. The Open Referral UK standard, already adopted by several local authorities and NHS organisations, provides a proven framework for sharing service information. When combined with activity data from platforms like OpenActive, which currently publishes over 500k opportunities for physical activity and leisure weekly, these standards enable apps and services to be built that can enable healthcare providers to identify and refer patients to appropriate community services quickly.

Digital service coordination

The NHS framework emphasises "safe referrals," but maintaining accurate service directories is challenging. Social Prescribing Link Workers need real-time information about community service availability and capacity to make appropriate referrals. Digital platforms

that connect healthcare providers with community services can significantly improve care coordination. When supported by appropriate digital infrastructure, link workers can more effectively match patients with community services and monitor outcomes. These platforms need to be designed with community organisations' limited technical capacity in mind, making it easy for them to maintain service information and provide updates on patient engagement.

Community data capability building

Successful community care delivery requires investment in building data capabilities within community organisations. This includes technical infrastructure for secure data handling, training in data protection and governance, support for adopting and maintaining service information standards, and resources for tracking and reporting outcomes.

Moving care from hospitals to communities represents a fundamental transformation in healthcare delivery. Success requires treating community data infrastructure as essential public infrastructure, worthy of sustained investment and support. The economic and social returns on such investment - through reduced hospital admissions, improved population health, greater patient and citizen satisfaction with the NHS, and more efficient resource allocation—will far outweigh the upfront costs and should be seen as an investment decision to reduce future costs.

Q3. What does your organisation see as the biggest challenges and enablers to making better use of technology in health and care?

The ODI recognises the transformative potential of technology in healthcare. However, realising this potential requires robust data foundations alongside careful consideration of governance and trust. The ODI's experience working with healthcare organisations has shown that successful technology adoption fundamentally depends on getting the underlying data infrastructure right.

The technological opportunity

Healthcare technology is already demonstrating significant impact. The [NHS AI Lab](#) has shown promising results in disease prediction and risk stratification, while tools like '[C the Signs](#)' have markedly improved cancer detection rates. To build on these successes and scale technological innovation across the health service, several foundational challenges must be addressed:

Core challenge

Data quality and accessibility

The effectiveness of healthcare technologies fundamentally depends on the quality and accessibility of their underlying data. The ODI's work with Moorfields Eye Hospital through [INSIGHT](#) demonstrates how proper data infrastructure enables innovation whilst protecting patient privacy. This initiative has helped develop new diagnostic tools for eye disease by ensuring researchers can access high-quality imaging data through secure, governed routes.

However, many healthcare organisations struggle with fragmented and inconsistent data. When data sits in disparate systems or lacks standardisation, developing and deploying technologies effectively becomes nearly impossible. The BMJ [found in a survey](#) this year of NHS trusts that 88% of trusts now have electronic patient records, 7 trusts are still only using paper records, 130 trusts are mixed and just 45 trusts are fully electronic. NHS staff resorting to manual data entry or even mixed entry across multiple systems creates inefficiencies and increases the risk of errors despite the initial personal ease of reaching for a pen and paper.

Technical infrastructure and integration

Healthcare technologies must integrate seamlessly with existing systems and workflows. Legacy systems within NHS trusts create integration challenges with modern digital solutions. Achieving interoperability requires technical standards and governance frameworks. This technical debt creates significant barriers to technology adoption.

The challenge extends beyond individual organisations. As demonstrated through the ODI's [work with Roche](#) mapping European health data ecosystems, achieving interoperability across different healthcare providers requires both technical standards and governance frameworks that enable safe data flows whilst protecting privacy.

Trust and adoption

Public trust is paramount for adoption of healthcare technology. The [2021 GP Data for Planning and Research](#) (GDPR) programme demonstrated how quickly trust can erode when data governance concerns are not adequately addressed. Patient opt-outs [nearly doubled](#) during this period, highlighting the critical importance of transparent governance and clear communication about how patient data will be used.

ODI [research](#) looking at the secondary use of health data found that, without a foundation of trust, individuals are hesitant to participate in data-sharing initiatives, potentially hindering the development of the large datasets crucial for advancing medical research and public health strategies. If the private sector is involved, it must be under public stewardship, and the ultimate custodianship of the data must remain in public sector hands.

Healthcare professionals also need confidence in new technologies. ODI research has shown that clinicians are more likely to adopt technologies when they understand how they work and trust their underlying data. This requires both technical reliability and clear frameworks for accountability.

Key enablers

Standards and interoperability

Standardised data collection and access approaches create the foundation for effective technology deployment. The [FAIR](#) principles (Findable, Accessible, Interoperable, and

Reusable) provide a valuable framework. When data follows these principles, developing and scaling technological solutions becomes significantly easier.

Privacy-enhancing technologies

Advanced privacy-enhancing technologies (PETs) offer new ways to analyse healthcare data whilst maintaining security. The success of OpenSAFELY during the pandemic demonstrated how federated approaches, where algorithms travel to the data rather than data being centralised, can enable rapid research and innovation whilst protecting patient privacy.

Workforce development

Successfully deploying healthcare technology requires a workforce that can effectively use it. Investment in data literacy and technical skills is essential. Technology adoption and diffusion improves significantly when staff receive appropriate training and support—meeting the joint issues of both digital literacy and avoiding digital exclusion.

Practical steps forward

To enable better use of technology in health and care, the ODI recommends focusing on:

- Establishing clear data standards and governance frameworks that enable safe technology deployment
- Investing in technical infrastructure that supports interoperability and data quality
- Building public trust through transparent communication and robust privacy protections
- Developing workforce capabilities in data and technology

Success requires viewing data infrastructure as fundamental to technology adoption. By addressing these foundational elements, it's possible to create an environment where healthcare technology can deliver on its promise to improve patient outcomes and system efficiency.

Q4. What does your organisation see as the biggest challenges and enablers to spotting illnesses earlier and tackling the causes of ill health?

Effective early disease detection and prevention requires a sophisticated data ecosystem that can identify emerging health risks whilst supporting targeted interventions. Working with healthcare organisations, the ODI has identified several critical factors that influence the NHS's ability to shift towards more preventative care.

Understanding the data challenge

The foundation for early intervention lies in connecting different types of health information. When clinicians can see a complete picture—incorporating medical history, social determinants, and lifestyle factors provided it is shared with consent given by the patients or those with delegated responsibility for care—they can identify emerging health risks more effectively. However, this comprehensive view remains difficult to achieve because vital information is currently fragmented across multiple systems and organisations.

The ODI's [work with Roche on European health data ecosystems](#) demonstrated how this fragmentation directly impacts patient care. When information exists in separate systems—whether in GP surgeries, hospitals, or local authorities—healthcare providers cannot identify early warning signs that might be visible from a more complete dataset. For example, combining data about housing conditions with primary care records could help identify respiratory health risks before they lead to serious illness.

Evidence of impact

The potential of connected health data is already being demonstrated through several pioneering projects. The UK leads in health data reuse through initiatives like [INSIGHT](#), which enables early detection of eye diseases by allowing secure analysis of retinal imaging data. Similarly, the [NHS AI Lab](#) has shown how machine learning can predict disease progression and identify high-risk patients when given access to appropriate data. These successes demonstrate how proper data infrastructure enables both immediate care improvements and long-term innovation in preventative medicine.

The analytics advantage

Analytics capabilities built on this data foundation can drive system-wide improvements in early detection. The ODI's early work on prescribing patterns demonstrated how data analysis could identify opportunities for both cost savings and improved patient care. In this instance, ODI data analysis showed [the NHS could save £200mn annually](#) by changing the prescribing of statins. This same analytical approach, applied to early detection, could help identify emerging health trends and target interventions more effectively.

Core challenges

However, realising these benefits requires addressing several interconnected challenges. The first is technical: healthcare data often resides in separate systems that cannot easily share information. This separation particularly affects understanding of social determinants of health, which typically remain disconnected from clinical records despite their crucial role in prevention. The second challenge involves privacy and security: early detection often requires analysing sensitive patient data across multiple sources. While privacy-enhancing technologies like those used in OpenSAFELY can enable secure analysis, implementing these solutions at scale requires significant infrastructure investment.

Resource and capability requirements

Resource constraints compound these challenges. Many healthcare organisations lack the analytical capabilities needed to effectively utilise their data for preventative purposes. This includes both technical infrastructure and staff with appropriate data literacy skills. These limitations particularly affect smaller organisations, creating inequities in prevention capabilities across the healthcare system.

Building for success

Strong foundations must first be established through standardised approaches to data collection and sharing to enable earlier intervention. The [FAIR](#) principles provide a valuable framework, ensuring health data is findable, accessible, interoperable, and reusable. Building on these principles, secure data access mechanisms can be implemented that enable necessary analysis while maintaining privacy protections.

The path forward

Success in early detection and prevention requires treating health data infrastructure as a critical national asset. This means developing comprehensive standards for health data sharing, building robust frameworks for measuring data quality, investing in analytical capabilities across the healthcare system, and supporting stronger integration between healthcare and community services. By addressing these fundamental infrastructure needs, a healthcare system better equipped to identify and address health issues before they become severe can be created.

Q5. Please use this box to share specific policy ideas for change. Please include how you would prioritise these and what timeframe you would expect to see this delivered in, for example: • Quick to do, that is in the next year or so • In the middle, that is in the next 2 to 5 years • Long term change, that will take more than 5 years

For a better future for the NHS, a collective commitment to ethical, transparent and innovative data practices is needed. In the work of building and developing NHS digital and data infrastructure, it's important not to sell out public trust for private gain. The UK's public sector health data is a significant national asset - it relates to UK citizens; its collection and stewardship is paid for by taxpayers. It is also extremely sensitive and should not be made available to the private sector without proper governance; governance that must remain inside the public sector, overseen by those who have people's best interests at heart and giving patients themselves a role in decision-making

Without this structure, too few people will remain unconvinced that the benefits of data sharing outweigh the risks. At a time when fewer than just one in four of us is satisfied with the way the NHS is running, an approach that does not recognise the significant role of public trust in health data sharing risks undermining the trust needed to enable it (and any economic or social value that might be derived from it).

Instead of centralisation, new decentralised architectures that offer individuals direct access and control of health data about them should be explored. Strong data infrastructure must be built, especially in the era of wider AI adoption.

Immediate priorities (within 12 months)

Sustainable funding for data infrastructure

The NHS should recognise and invest in data infrastructure as essential national infrastructure, requiring sustained investment. At the upcoming Spring Spending Review, the ODI recommends establishing dedicated long-term funding mechanisms for maintaining and developing critical data standards. This would help prevent the erosion of existing data infrastructure while enabling continuous improvement to meet evolving healthcare needs.

Strengthen data governance

Building on lessons from initiatives like OpenSAFELY, the ODI advocates implementing robust data governance frameworks that balance innovation with privacy protection. Patients and citizens should be at the heart of service delivery and have agency over the decisions that are made. Frameworks should include:

- Clear protocols for secure data access

- Accountability measures for data use
- Transparent processes for monitoring compliance
- Patient involvement in decision-making over data about them
- If there is involvement of the private sector, it must be under public stewardship and the ultimate custodianship of the data must remain in public sector hands too

Standardise core data requirements

Healthcare providers should adopt standardised approaches to data collection and sharing, focusing initially on areas where fragmentation most impacts care delivery. The [INSIGHT](#) project demonstrates how standardisation enables both immediate care improvements and future innovation.

Medium-term development (2-5 years)

Build integrated data access systems

Rather than creating centralised data repositories, federated systems that enable secure data access while maintaining local control are recommended. This approach, proven successful through initiatives like [OpenSAFELY](#), allows authorised researchers and clinicians to analyse data across different NHS systems while adhering to strict privacy controls.

Enhance community healthcare data integration

Building on [Open Referral UK](#) and [OpenActive](#) standards, develop comprehensive frameworks for integrating access to community health data with NHS systems. This integration is crucial for supporting the shift toward preventative care and community-based services.

Develop workforce capabilities

Implement comprehensive data literacy programmes across the NHS, ensuring staff at all levels can effectively use data tools and understand data governance requirements. This should include:

- Technical training for data specialists
- Basic data literacy for all healthcare staff
- Leadership development in data strategy

Long-term transformation (beyond 5 years)

Enable privacy-enhancing technological innovation

Invest in developing and implementing privacy-enhancing technologies that allow sophisticated data analysis while maintaining robust protection of patient information. This

builds on existing work in the health sector, including deployments of Federated Learning and secure computing environments.

Create sustainable data ecosystems

Establish frameworks for long-term sustainability of healthcare data infrastructure, including:

- Professional standards for data stewardship
- Sustainable funding models
- Clear metrics for measuring impact
- Mechanisms for continuous improvement

Build public trust through transparency

Develop comprehensive approaches to maintaining public trust in NHS data use through:

- Clear communication about data practices
- Meaningful patient involvement in decision-making
- Regular public reporting on outcomes
- Transparent governance processes

Measuring Success

Implementation success should be evaluated through clear metrics including:

- Adoption rates of data standards
- Improvements in service accessibility
- Maintained levels of public trust
- Demonstrated impact on health outcomes
- Economic benefits realised and measured against an updated valuation of data assets