



Data saves lives: reshaping health and social care with data

Open letter from the Open Data Institute in response to the government's policy paper

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Summary

The Open Data Institute (ODI) is pleased that the government has published its draft health and social care data strategy for consultation '[Data saves lives: reshaping health and social care with data](#)'. As part of our response to the consultation, we are publishing this open letter to encourage the incoming Secretary of State for Health and Social Care to both recognise the scale of the opportunity and the task, and to commit to acting on them. After all, building half a bridge does not get you halfway to where you want to be; building half a bridge is simply an expensive way to get nowhere. Among the recommendations in this open letter are calls for the government to:

- not skimp on creating a trustworthy and trusted data sharing culture in the NHS and social care
- build a strong data infrastructure and ensure it is integrated into national strategy
- ensure that the strategy benefits those who are digitally excluded and does not compound bias or structural disadvantages
- recognise the challenges facing the quality of social care data and invest in the long term changes needed to improve data infrastructure in this area
- empower NHS staff, researchers, data infrastructure builders, developers and innovators both nationally and locally to use data effectively for public benefit.

We've structured this open letter to align with the 7 sections in the draft NHSX data strategy. We've also provided at the end a short list of relevant ODI resources in these areas.



Introduction

The ODI welcomes the government's proposed data strategy in the health and social care sector and its general focus on understanding how data is used, making sharing data the norm and building the right foundations. The Covid-19 pandemic has shown the importance of data in tackling societal challenges and catalysed developments in the use of data in the health system that should be built on.

As the new Secretary of State surveys his to-do list, we hope that he will draw on our wealth of experience and insight when it comes to his need to deliver on the data strategy. Our experience tells us that such a strategy will require dedication, attention and resources for it to be successfully implemented. To skimp on any of these aspects would be a mistake that could prove costly in the long run. After all, building half a bridge does not get you halfway to where you want to be; building half a bridge is simply an expensive way to get nowhere.

Delivering the aims of the data strategy will require building a strong [data infrastructure](#). While this will provide significant benefits in decision making and patient outcomes, the challenge should not be underestimated, given the size and complexity of the health and social care system. A strong data infrastructure is not just a technical issue. It includes the principles and practices that govern the handling and use of data and, most importantly, the people who collect, use and are affected by the data. Failure to fully understand and support all the relevant stakeholders will lead to failure in delivering the aims of the data strategy. We would draw particular attention to the role of private and third-sector care providers, and those who monitor and inform the public about the health system, both of which need to be supported through this strategy.

It should also be recognised that health and social care data does not exist in isolation from the rest of the economy and society. While it is frequently treated as a special case – given the highly sensitive nature of much of the information – the approach to health and social care data needs to be integrated into the government's wider strategies on data, in particular the [National Data Strategy](#) (NDS) and [AI Roadmap](#). Our experience is that drawing hard boundaries around data from different sectors is unhelpful: much of the potential value of data comes from sharing data across sectors, and a narrow focus on individual sectors is likely to miss opportunities for innovation and social value. We find that it is more helpful to take a challenge-focused approach to prioritising activities around data, aligned with government priorities. For example, linking health data with geospatial data could provide valuable insights into local health or environmental issues that would otherwise be hidden. Our [work with Wellcome around health data challenges](#) illustrates this approach.

Implementing the proposed health and social care data strategy will lead to a pronounced change in the way that data will be managed throughout the whole of the health and social care system. It will require a substantial change management programme and cultural shifts in the way that people work. If the full potential of the data is to be realised, it is vital that the government shows the necessary leadership to deliver this change and provide adequate

resources and funding to build capacity and data literacy. Part of this process will include clarifying the roles and responsibilities for all government departments and bodies that provide or use data about citizens' health and social care, to ensure that there is coherence between them.

Not all data that is relevant to improving people's health and wellbeing is personal data. However, data protection and trustworthy data practices will be critical to getting the best from data. As data protection legislation evolves post-Brexit, there will be risks and opportunities regarding how data is used and shared. Understanding individual and collective rights, benefits, harms and value exchanges associated with data from, or used by, the health and social care system will be vital, as will ensuring that the public is properly consulted and brought on the journey.

The remainder of this open letter provides comments on the individual sections of the draft strategy in more detail.

1. Bringing people closer to their data

We support the government's aims to deliver truly patient-centred care, empowering people by giving them access to their health records, and increasing their confidence in both their healthcare and the way in which data about them is used within the system.

Access for everyone to their health and social care data is about more than just technology. It requires all aspects of the data ecosystem to be in place, including guidance, standards, procedures and legal requirements. In particular, there is a need for human-centred design of the data ecosystem that invests time and resources in understanding and engaging with all stakeholders that are impacted by the use of data. This includes family members, carers and healthcare professionals whose own activities can also be reflected in health records.

Not everyone is equally able to take advantage of access to data and services about their health and care. We support the commitment to reduce inequalities and improve health outcomes for minority ethnic populations in the UK; there also needs to be attention paid to the needs of children and families with disadvantaged socio-economic status, and to those without access, or limited access, to digital technologies. While data and related technologies can do much to reduce inequalities, there is a danger that they can also further ingrain existing biases in the system. Collecting data about who is accessing (and not accessing) health-related digital and data services is a vital first step and health professionals and service providers must be confident to do this securely and sensitively. The ODI's recent report on [inclusive data](#) provides valuable insights on how to address these issues and the report [Monitoring Equality in Digital Public Services](#) gives guidance on how digital services can adhere to legal requirements.

While it is not an explicit goal in the draft strategy, we strongly support the use of open data to keep the public informed about, and build trust in, the functioning of the health system in

general. Good examples are the coronavirus dashboards, which include data on testing and vaccination, and the publication of open data about prescriptions, which helps [highlight where there is the potential for cost savings](#) by switching to generic pharmaceuticals. In future versions of the strategy, we would like to see a more explicit goal around open data and transparency of the health and social care system, as highlighted for the government in general in [Lord Maude's Review](#).

Giving people confidence in the handling and use of personal data is a complex issue. The work of the Health and Care Information Governance Panel will be vital to build this trust. While we found the NHS to be one of the most [trusted organisations](#) around data, there is still work to be done: only 59% of people trust the NHS and healthcare providers to use data ethically. Lack of proactive engagement and communication about data use seriously undermines people's confidence. This has been demonstrated with the delay of the General Practice Data for Planning and Research (GPDPR) service over [concerns about why the data was being collected and kept safe](#).

Building a trustworthy data ecosystem requires starting from core ethical principles to ensure good practice around how data is collected, used and shared. We support the work done on updating the guidance to [good practice for digital and data-driven health technologies](#) in this respect. However, our [research on trustworthy data stewardship](#) highlights the need to actively assess, build and demonstrate trustworthiness, especially in an environment where capabilities, concerns and expectations have changed significantly over the last ten years.

We support the need for guidance for staff and look forward to the Information Governance Framework for Integrated Health and Care. But government must recognise, and properly fund, the time and resources needed to train and support staff. Data skills and literacy requires a holistic approach for all people who both collect data and use it to make decisions and deliver care. It should focus on building people's ability to think critically about data in different contexts and examine the impact of different approaches when collecting, using and sharing data and information. The ODI's [Data Skills Framework](#) illustrates this approach, showing how technical data skills must be balanced with other skills – such as service design, data innovation and change leadership – to ensure the best overall outcomes.

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

Having access to the right data is critical to the delivery of care but, as noted earlier, it is vital to understand the purpose(s) of data being collected and shared. In particular, it is essential to distinguish between sharing a patient record to support the care of that patient as they interact with different providers across the health and social care system, and sharing it to support medical research or to understand and improve the overall system.



We support the development of an Information Governance Portal as a single point of access to guidance. But the health and social care system is diverse and a ‘one-size-fits-all’ approach will be challenging. In addition, different parts of the system and even individual trusts will be at very different stages of their data transformation; this needs to be incorporated into the government’s commitments to information governance.

We support, in principle, the government’s commitment to introduce legislation to create a new duty to share data. Developing this legislation will provide clarity and an opportunity for a democratic debate about expectations around the sharing of health data. We believe data should be as open as possible, as expressed in the National Data Strategy, to unlock the value of data in the health and social care system and beyond. However, sharing data also introduces risks, and mandating a duty to share data – particularly sensitive patient data – could undermine trust in the system. Conflicts could arise between a duty to share data and health professionals’ duty of care to their patients; a number of GPs opted all of their patients out of GDPR because of concerns over the safe use of their data. Any duty to share data must be accompanied by a trustworthy data ecosystem that ensures data is handled with strict controls and accountability, along with careful public engagement to understand acceptability and potential unintended consequences.

We support the commitment to build a shared care record. This will again require a strong data ecosystem to ensure standards and practices are in place to enable interoperability of the data.

Reducing the burden of data collection is vital in the health and social care system, given its size and complexity and the need to focus on delivering better outcomes for patients and users. The Data Alliance Partnership’s remit contains good general principles but should focus on active engagement with frontline staff to understand the challenges they face and the type of data that needs to be collected.

3. Supporting local and national decision makers with data

We support the need to fully integrate all parts of the health and social care system and local systems that will be at the core of delivering services. We support the commitment to ensure that adult social care providers (where they have digitised records) are integrated with basic shared record solutions across health. But this must go further and government must commit to including all relevant parts of local health and care systems, which are at very different levels of resourcing and maturity, with support to digitalise where necessary.

Building communities of practice is an effective means of sharing knowledge, increasing skills and providing support to people. We have learned from doing this a number of times including for [startups](#), [open data leaders](#), [local authorities](#), and [data institutions](#). We support the commitment to grow the AnalystX community but stress the need to provide adequate funding for the community and to include support and stimulation from experts from the data and digital sectors. This will ensure that knowledge and guidance from those at the cutting edge of



developments gets fed into the health and social care system and will build greater recognition for data professionals working within the health system.

We fully support the commitment to make all new source code open and reusable. We encourage the government to extend this to the use of [open standards for data](#) and can provide support in the development of open standards (see section 7).

We fully support the commitment to use secondary legislation in due course to enable the proportionate sharing of data, and recognise the importance of people being able to exercise choice about data about data about them. We agree there is a need to ensure transparency and confidentiality and can support the government in their efforts to make data more accessible and interoperable (see section 7).

We support the commitment to improve data linkage – in transparent and trustworthy ways – across multiple departments and again highlight the need to recognise the fact that health data can be used in a much wider and integrated fashion to tackle many of the societal challenges that we face. In doing so, there will be a need for new types of [data institutions](#) and intermediaries who can facilitate and manage data access ethically and across sectors (see section 7).

4. Improving data for adult social care

NHS Digital research quoted in the draft health strategy on current levels of digitalisation and data ecosystems in adult social care reveals that the sector is starting from a very low base in many cases and the urgent need to raise the sector to an acceptable level where data can be used to improve outcomes for users. As [research from Future Care Capital](#) shows, the use of data in the social care sector falls well below that of the NHS and there is an urgent need to build all aspects of the data infrastructure in this sector. Part of the challenge will be to reconcile data from private social care providers with the public health and social care system and to align the data infrastructure and data governance processes in what is currently a very fragmented landscape.

The commitments made in terms of data collection, data sharing and improving the digital literacy of the social care workforce represent a reasonable direction of travel but do not appear to recognise the scale of the challenge. Much greater detail will be needed from the Department of Health and Social Care (DHSC) in practical terms regarding how the data infrastructure in social care will be improved, how the digital skills framework will be delivered and what funding and resourcing will be in place.

The proposed legislation to require adult social care providers to share information will be critical for driving change in the sector and in supporting the wider objectives of the NHSX Digitising Social Care Record programme to integrate it with the wider health system. However, as noted above, such a duty to share data can bring risks, both real and perceived, and must

include adequate engagement and support for the care professionals who will be required to share the data, as well as those representing the interests of people in care.

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

We fully agree with the aim of supporting the UK's health and clinical research sector and the importance of data to their work. We also agree that collaboration is imperative but would go further to emphasise the value of cross-sectoral, multi-disciplinary collaboration both in tackling health and social care challenges using data from other sectors, and in tackling a wider range of societal issues through the inclusion of health and social care data.

Data can provide a clearer picture of the needs of the most vulnerable groups in society but this may require non-digital as well as digital approaches. Measuring and demonstrating the success of secondary use of health data will be important, such as the ability to use data for sub-populations or rare diseases as discussed in our [White paper: EU policy on secondary use of health data](#).

We support the establishment of trusted research environments (TREs) and the commitments to build partnerships between researchers and healthcare professionals, and to clarify terminologies and legal definitions. Research hubs will be an important part of empowering the use of data in health research and we have been working with the [INSIGHT Health Data Research Hub](#), a hub for eye health funded through Health Data Research UK, to help them develop effective governance approaches around access to this data. We strongly encourage these organisations to recognise their role as data institutions and the responsibilities that this entails (see section 7), in particular in [building trust](#) with the public and identifying [sustainable funding models](#) to ensure longevity.

The success of the NHS DigiTrials RECOVERY Trial demonstrates the potential of large clinical trials to improve the treatment of patients and deliver better care. However, Covid-19 was a unique case in terms of its public profile and the urgency of finding treatments. Few other cases will be as well-known to the public and more needs to be done to reverse the trend of declining recruitment and retention of participation in clinical trials if the commitment to build on platforms such as NHS DigiTrials is to be realised. In particular, the government needs to improve its communication with the public on the value of participation to tackle specific health issues and provide confidence that their data will be used confidentially and securely, for public benefit.

6. Helping colleagues develop the right technical infrastructure

A strong [data infrastructure](#) will be essential to build an ecosystem that supports and enables data to flow appropriately between the people, devices and organisations that make up the health and social care system. Technical infrastructure is only one part of this data

infrastructure, which also includes the data assets along with the human resources, policies and processes that underpin it. We agree that data is a shared asset and that the data ecosystem must be built on strong foundations if it is to deliver the most value to the system.

Building the data ecosystem on solid foundations will ensure that the data will be high-quality, and its use trustworthy and accountable. The foundations will be the same as those for data ecosystems across government and the wider economy and should follow the principles being set out in the NDS and related policies such as the AI Roadmap and upcoming Digital Strategy.

Covid-19 has shown the need for a strong data infrastructure and a coordinated approach to the use of data. Our work on [Covid-19: Building an open and trustworthy data ecosystem](#) highlighted a range of issues including publishing data in times of crisis, sharing models, anonymising data and ethics, that have arisen during the pandemic.

In general, the ODI has a number of tools and guidance that can assist organisations at all levels in understanding and developing their data infrastructure:

- [The ODI Data Landscape Playbook](#) – this supports organisations working on data access initiatives, helping them tackle common challenges by conducting a ‘data landscape review’ to understand how their data is being accessed, used and shared.
- [Open Data Maturity Model](#) – this assesses how well an organisation publishes and consumes open data, and identifies actions for improvement. It includes data management processes, skills, user support and engagement, investment and financial performance and strategic oversight.
- [Data Ethics Canvas](#) – this specifically helps identify and manage ethical issues, asking questions on the primary purpose for collecting and sharing data, and who could be negatively affected by the use of data.
- [Anonymisation and synthetic data](#) – this addresses the challenges associated with sharing sensitive data in a way that safeguards privacy and maintains trust while enabling the creation of value from data.

We support the need to promote and develop data and technical standards and the commitments to produce a standards and interoperability strategy (including a standards roadmap), supported by legislation, to mandate the use of standards. As noted in the policy paper, collaboration is an essential part of developing data standards and the ODI has in-depth experience of working with organisations in this area that could provide valuable insights and support, such as in our [open standards for data guidebook](#).

It is important to recognise that many of the organisations that make up the health and social care system will assume the role of data stewards and intermediaries. Our work on [data institutions](#), and [Applying new models of data stewardship to health and social care data](#), highlights the various roles and responsibilities that this will entail in terms of the data organisations hold, making the data accessible and interoperable, and maintaining common data infrastructure. Covid-19 has demonstrated the importance of data intermediaries as

highlighted in our work [Matchmakers of the data world: how 'data intermediaries' can bring decision makers and data together to help combat Covid-19.](#)

7. Helping developers and innovators to improve health and care

We agree that innovation in the private sector and civil society will play a significant role in improving patient outcomes and driving economic growth. Greater access to data will be vital to enable more [open innovation](#), which in turn will promote fresh perspectives, access to new talent and creativity, increased capacity, and reduced costs. It will also lower the barriers to participation for otherwise disadvantaged communities and ensure innovation reflects their needs. We support the commitments to produce a digital playbook and to ensure that grants for research follow open data principles. This will rely on the development of a strong data infrastructure as discussed in the previous section and it is important that developers and innovators are fully engaged in this process, particularly in terms of developing open standards and ensuring the trustworthy use of data.

We support exploring how AI and machine learning could provide significant benefits in the delivery of health and social care, and highlight the importance of data to their development. However, it is important to ensure that the outcomes match the promises with innovations targeted to where they are most needed. Evaluation is key and we support the government's commitments to enable the independent evaluation of algorithms and a robust evaluation method for their practical deployment. In particular, this should evaluate any potential differential impacts on groups of users such as those with protected characteristics. We note that designing for robust evaluation includes consideration of what data needs to be collected for that evaluation up front, as highlighted in [our research with the Health Foundation](#). Transparency, [open models](#), and the ability to explain the AI algorithms will be critical to building trust, as discussed in our work on [AI and algorithmic accountability](#). [Open AI business models](#) should also encourage fairer competition and equitable outcomes.

Creating fair returns in data partnerships is essential and we support, in general, the principles set out in the policy paper, particularly the need for clarity on the purpose for any use of data and recognition that data is an important shared resource. Although the principles are explicit in terms of protecting the value of the data being shared, they should also be clear about the associated risks and how these will be shared in any partnership.

Conclusion

There is a long history in government of ambitious departmental digital and data strategies that promise a great deal, including better services and cost savings, but don't always deliver. This has been highlighted in recent reports from the National Audit Office on [data in government](#), [digital technology in the NHS](#), and [digitalisation in government](#). We would encourage the Department of Health and Social Care and NHSX to learn from these previous experiences. In particular, the draft strategy provides a long-term vision; it will require strategic prioritisation and

a long-term commitment to achieve an outcome that delivers value for money and has longevity.

Achieving the goals of the draft data strategy for health and social care will require capacity building and improvements, and data literacy across the health and social care system. The diversity of needs and capabilities across the system calls for flexibility to support basic infrastructural improvements within organisations with little digitalisation or significant legacy systems, while enabling those who are further along the digital journey to innovate in responsible and trustworthy ways. Leadership is needed at all levels to make the vision a reality.

Finally, for the full benefits of data to be felt not only in the health and social care system but in the wider economy and society, the strategy needs to be effectively aligned with other data efforts across government. There are substantial benefits to be found not just in bringing non-health-sector data to bear on issues in health and social care, but in data from the health and social care system to bring insights on broader societal challenges.

For reference – recent relevant projects by ODI

- [Report from a workshop](#) about the draft NHSX data strategy (with the Ada Lovelace Institute and Understanding Patient Data)
- [Research project](#) on public attitudes to data rights and the responsibilities around them (with Luminata and the RSA)
- Approaches to [inclusive data and data practices](#), including a resource guide of research, toolkits, and relevant projects (with the Ada Lovelace Institute and the Centre for Public Data)
- How [Covid-19 symptom tracker apps](#) can collate health-surveillance data for early diagnostics, without exposing personal health data (funded by Luminata).
- The [role data intermediaries can play](#) in protecting the privacy of health data while also making anonymised, aggregated health data available for scientific research.
- The opportunity of secondary use of health data to [open new markets in physical activity businesses](#), which in turn generate greater preventative health opportunities for local populations (with SportEngland).
- How competitive industry stakeholders are able to collaborate and share clinical trial data on [global health challenges such as antimicrobial resistance](#), while still protecting their commercial advantage (commissioned by Wellcome Trust)
- Summary of the global data governance environment, including current debates on health data as a global public good, and current maturity of data governance globally and emerging best practices, created as [pre-reads for the WHO Data Governance Summit](#), held on 30 June 2021.
- An [analysis of existing European health data policies](#), gaps and opportunities, and data [mapping of health data standards](#) in Europe (commissioned by Roche).



About the Open Data Institute

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.

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:

- **pilots and practice:** working as a critical friend 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

We believe that our six manifesto points will help us to achieve our vision:

- **Infrastructure:** Sectors and societies must invest in and protect the data infrastructure they rely on. Open data is the foundation of this emerging vital infrastructure.
- **Capability:** Everyone must have the opportunity to understand how data can be and is being used. We need data literacy for all, data science skills, and experience using data to help solve problems.
- **Innovation:** Data must inspire and fuel innovation. It can enable businesses, startups, governments, individuals and communities to create products and services, fuelling economic growth and productivity.
- **Equity:** Everyone must benefit fairly from data. Access to data and information promotes fair competition and informed markets, and empowers people as consumers, creators and citizens.
- **Ethics:** People and organisations must use data ethically. The choices made about what data is collected and how it is used should not be unjust, discriminatory or deceptive.
- **Engagement:** Everyone must be able to take part in making data work for us all. Organisations and communities should collaborate on how data is used and accessed to help solve their problems.

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.