

Consultation on the Data Saves Lives strategy

Written evidence submitted by the UK Pandemic Ethics Accelerator's Data-Use workstream



Executive summary

In this submission **we provide observations that may augment aspects of the Data Saves Lives (DSL) strategy from a data ethics perspective.** In doing so, we pay particular attention to the complexity and scales across which data in the health and social care sectors operates, and the social, institutional and governance contexts of data.

We welcome the ambition and timing of the strategy. Improved data quality, data flows and practices of data use are a necessary pre-condition of broader plans to improve health care and social care in England. Improved data infrastructures are also critical for continued covid-19 mitigation policies and for improving the health and well-being of people in the UK in the long-term.

DSL aims to bring a coherent data strategy to a large and diverse range of stakeholders across the health and care sectors, with very different levels of digital maturity. Each of these groups, organisations and institutions have different histories, cultures, practices, and obligations. Their goals are not always fully aligned, often for good reasons. For instance, patient groups, researchers, individual NHS Trusts, the Care Quality Commission (CQC), and the operators of care homes all benefit from quality data. But their needs for specific data, the condition of their digital infrastructures, their ability to finance the costs of data and to capture the value of data, as well as obligations and disincentives to share data all vary enormously.

DSL cannot itself solve these issues of heterogeneity across sectors – indeed, this diversity is valuable in many ways. Nevertheless, we argue that future iterations of the strategy will be strengthened if it can better acknowledge:

1. The complexity of the terrain over which health and social care data flows, and the need to map data flows across the entire system.
2. The issues that policymaking may encounter in building and connecting data infrastructure across this terrain.
3. The locations at which the trustworthiness of data infrastructure and of health and social care institutions need to be strengthened, and where more needs to be done to sustain public trust.

In this submission we identify some specific points at which interventions along these lines may be met with success or are particularly urgent. We believe by augmenting DSL with a map of the data terrain will enable the Department of Health and Social Care (DHSC) to better steer progress towards commonly identified goals in addition to accelerating towards promising directions of data innovation.

Key recommendations

1. A critical priority for Data Saves Lives should be **how to build public trust in the wider health and social care system while at the same time broadening data use**.
2. DSL needs to more clearly **distinguish between how different groups in society interact with health and social care data**, and experience data-informed decisions.
3. DSL should acknowledge that **different groups will benefit from data differently**. This influences how they value and trust data.
4. Urgent work is required to **understand the role the NHS App has assumed** for many people during the pandemic. It should not be presumed that everyone benefits from the expanded use of the App in the same way.
5. Concerns about the **General Practice Data for Planning and Research (GDPR) opt-outs show why issues of trust and public benefits are critical** for DSL. DSL should embrace and apply lessons from GDPR across the wider strategy. These include public engagement strategies as well as leading nuanced discussions distinguishing between different kinds of public data, such as individual data and aggregate data sets.
6. **Meanings and assumptions across health and social care systems need to be spelled out**. Data and the benefits of data cannot be taken to be the same in different parts of the health and social care systems. DSL should seek to more clearly identify the beneficiaries of proposed changes. These assumptions need to be justified and the potential for unforeseen rebound effects noted.

1. Public trust in data and trustworthiness of health and social care institutions

Summary point:

- A critical priority for Data Saves Lives should be **how to build public trust in the wider health and social care system while at the same time broadening data use**

Progress can be made by more clearly distinguishing between issues of trust and trustworthiness and mapping the social and technical factors that influence these.

By **trust** we mean people's willingness to assume that data about them will be used in ways they find acceptable. Work is required here to understanding the diverse social and contextual conditions that give rise to trust in different settings. For instance, on hospital wards, in care homes and amongst different communities.

By **trustworthiness** we mean the characteristics of the producers and processors of data – the organisations, institutions and infrastructures – that ensure that trust in them is well-placed. For instance, NHS England, NHS Digital, the CQC and the adult social care Capacity Tracker.

This issue is particularly salient now because **the context in which trust is established is changing** due to changes in long-term societal attitudes to data and because of more immediate shifts in how the public value health and social care due to the pandemic. Issues of trustworthiness have been influenced by the changing role of health and social care institutions and their use of data over the course of the pandemic.

An overarching priority of DSL should be locating and addressing tensions in building trust and trustworthiness. In particular, tensions around health and social care institutions and enabling much more extensive friction-free linkage within and between the health and social care sectors.

2. Distinguishing between different groups and how they benefit from data use

Summary points:

- Different groups will benefit from data differently. This influences how they value and trust data.
- DSL needs to more clearly distinguish between how different groups in society interact with health and social care data, and account for how experiences of data-driven decisions can radically differ from one group to the next.
- Urgent work is required to understand the expanded role the NHS App has assumed for many people during the pandemic. It should not be presumed that everyone benefits in the same way.

Willingness to trust and share data is influenced by prior experiences and perceived benefits and comes about differently in different social and institutional contexts. Because of this DSL needs to carefully distinguish between how different groups in society interact with health and social care data. The strategy should also seek to understand how experiences of data-driven decision making can radically differ from one group to the next. For instance, work needs to be done to understand how responses to automated instructions to self-isolate from the NHS COVID-19 APP differ across social groups.

This goes for groups of practitioners within the health and social care sector, for instance GPs, administrators, and workers in social care. It also applies to groups of patients and care-users who experience the impacts of data use in different ways across different settings, communities and regions.

We suggest that DSL learns from the work that the [Understanding Patient Data](#) project does to engage with stakeholders and patient groups and develop trusted approaches to data gathering and data use.

Public benefit and value of data. We welcome references to the findings of the National Data Guardian's *Putting Good into Practice* report on the public benefits of data, but at the same time it seems important for the strategy to do more to acknowledge that there may be disagreements about public benefit (particularly where data projects are led by commercial partners), and that determinations of public benefit need to be made in a way that maintains public trust.

DSL should recognise that data cannot benefit everyone in every instance. In order to consider how those left out or left behind out can be supported, it is therefore vital to understand who constitutes the public that *is* benefitting from data in each instance.

The NHS app. One specific area of focus should be the NHS App. DSL states that for many people, the NHS App is becoming their de-facto point of contact with the NHS. Further work is required to understand the ethical and social implications of this shift, and in particular any inequalities that may result from this. At the moment many people trust the App, and use it, but this trust cannot be taken for granted, especially given the rapid iteration of new functionality such as immunity certification. Of greater concern here is the expanded role the App might play in eroding trust in the wider NHS. The stakes for data management here are high.

It may be helpful for NHSX to partner with the ongoing Ada Lovelace and Health Foundation project on [data driven systems and health inequalities](#). This work becomes more urgent as more people experience the NHS App and the NHS Covid App seemingly curtail work, leisure and travel freedoms, through the integration of vaccine certification systems and NHS test and trace functionality respectively. No long-term research exists that shows how values towards the NHS may shift because of this.

3. Putting GDPR in the wider context of data use and the DSL strategy.

Summary points

- Concerns about GDPR opt-outs show why issues of trust and public benefits are critical for DSL
- DSL should embrace and apply lessons from GDPR across the wider strategy

We welcome the commitments on the GDPR programme from Secretary of State Jo Churchill in her [letter to GPs in England on 19 July](#). It might be useful to reflect on how we got to this point and apply lessons across DSL more broadly.

Concerns about GDPR opt-outs show why issues of trust and public benefits are critical for DSL. The chief concern raised by various stakeholders about this project was the limited communication and insufficient information about it in the public domain. This, compounded by the fact that the scheme was perceived to be rushed through during the pandemic, with a confusing opt-out procedure, has created public doubts about the trustworthiness of the exercise.

We agree with [Lord Bethel's comments to the Health and Social Care Select Committee](#) that the DHSC may have made a mistake in thinking about GDPR as an IT project rather than something that has to be engaging with GPs and the public more directly. To this end the proposed *Listening, Consultation, Demonstration, Delivery* framework is sensible, as are commitments to *Trusted Research Environments*.

GDPR also highlights opportunities for DSL to lead **more nuanced and careful interventions on the benefits of public health and social care data**. Across the health and social care systems it would be useful for DSL to distinguish between concerns about how value is created from: (i) the linking, sharing and use of individuals' data; (ii) how aggregate public data are used for research or other purposes and how these uses are valued by the public; (iii) the governance arrangements of existing and proposed public and private infrastructure and platforms designed to realise value from individual and aggregate data.

Media coverage of GDPR has focused on concerns about issue (i) and how individuals might assert control through opt-out mechanisms. But this is to miss broader concerns about how both

individual and aggregate data are valued by the public, and who is accountable for respective supporting infrastructures.

Also, much **more work is required to understand public attitudes to private sector involvement in data infrastructures**. GDPR has highlighted concerns about the sale of individual data to firms. But the issues are likely to be more complex and concerns more widespread. For instance Parliament's Public Accounts Committee has said that NHS Test and Trace must now "[wean itself off its persistent reliance on consultants](#)" and questioned whether "unimaginable" costs of these data infrastructure could be justified. It is likely that perceived failures of private sector involvement in pandemic data use, as well as successes, are influencing broad concerns on this issue.

In the public sector, **trust and trustworthiness often hinge around three key qualities: competence**, being seen to be **acting in the public's interest** and **openness and transparency**. In maintaining these three qualities, there will need to be openness and transparency about who data is being shared with and who is gaining financially, particularly when NHSX is partnering with the private sector to develop Apps. Given recent high-profile incidents with data sharing and security, as well as protests against developments such as the GP at Hand App, there is a significant risk that NHS data might be seen to be being used in ways that are not in the public interest. For instance, using public data from UK patients to *train* machine learning software for sale in overseas markets without a fair return to the UK public. Or being used to develop Apps that reduce patients' face-to-face access to services. This has the potential to undermine public trust in data but also the wider NHS.

Thinking through these questions will be a crucial part of public debates as the Centre for Improving Data Collaboration launches its Value Sharing Framework. We believe these are matters for public dialogue and that DSL is well placed to facilitate such dialogue.

About this evidence submission

This submission was supported by the UK Pandemic Ethics Accelerator, grant number AH/V013947/1. The submission was compiled by Dr Cian O'Donovan with contributions from Dr Melanie Smallman, Professor James Wilson, Nishtha Bharti and Steven Bow as part of the Accelerator's Data Use workstream. For further details contact Cian O'Donovan at the Department of Science and Technology Studies, UCL, Gower Street, London, WC1E 6BT. Email c.o'donovan@ucl.ac.uk.

The submission has been peer reviewed within the UK Pandemic Ethics Accelerator, a UKRI/AHRC-funded initiative that aims to bring UK ethics research expertise to bear on the multiple, ongoing ethical challenges arising during pandemics. We provide rapid evidence, guidance, and critical analysis to decision-makers across science, medicine, government and public health. We also support public debate on key ethical challenges. See <https://ukpandemicethics.org>.

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