NHSX Data Strategy for Health and Care
Workshop Summary

This is a summary of the meeting held online on 13th July 2021 with Understanding Patient Data and the Ada Lovelace Institute in collaboration with The Open Data Institute. The aim was to gather the views of stakeholders across the patient data community, identifying common themes, concerns and aspirations.

Key Reflections for NHSX

This section outlines participants' views about what's needed in the strategy to respond to recent events.

→ **Respond to wider issues that drive distrust.** Participants across many disciplines felt strongly that the draft strategy needed to respond more comprehensively to wider issues of trust when it comes to the use of data and technology in society. In particular, it must take concerns about commercial organisations' involvement in the health service seriously.

→ **Commit to the Opt-Out system.** While the existing system may not be ideal, the Type 1 Opt-Out and the National Data Opt-Out have been used by millions of NHS patients. Given the prominence of both in communications around GP Data for Planning and Research (GPDPR), the strategy needs to outline its position on them.

→ **Improve the consultation.** A recent change of Secretary of State creates an opportunity to pause, reflect and establish an inclusive approach to the consultation. A formal consultation on the proposals in the strategy would better serve the interests of the NHS and the public and provide better avenues to explore solutions that respond to public attitudes and concerns.

→ **Shape the rules with people.** Many participants highlighted the lack of detail on the strategy's plans to involve people in decision-making about data use. NHSX needs to take building democratic accountability across the whole system seriously and see working with diverse members of the public as an enabler to achieve its aims, rather than a tick-box or problem to be dealt with.

→ **Clear communication.** Participants raised concerns about how the strategy envisions two-way communication with the public. The draft refers to 'citizen control' but mechanisms for this is not articulated. This risks misleading the public about how much choice and control they can and will exercise.

→ **Learning from GPDPR.** It was clear that NHS Digital need to work with clinicians to avoid extending the 'tech-lash' witnessed with the announcement of GPDPR. Several participants reflected on feelings of distrust of central government from the health and care workforce, particularly when it comes to sharing health data with other Government agencies.

→ **Be honest about the limitations of data.** Attendees reflected on the up-beat tone of the strategy, suggesting that focusing solely on the benefits of data use risks side-lining legitimate concerns about harms and how to mitigate them.

Background

NHSX published a [draft Data Strategy for Health & Social Care](#) in June 2021. In response, Understanding Patient Data and The Ada Lovelace Institute alongside The Open Data Institute brought together stakeholders for a closed session to discuss key aspects of the strategy. Participants represented a broad range of sectors and interests from academia, third sector and the health sector. This summary is not exhaustive but provides an overview of some of the key concerns and suggestions made by workshop participants. This note was collated by Tom Harrison & Iain Millar at Understanding Patient Data.

The meeting took place online, which served as a reminder of the prevailing impact of the Covid-19 pandemic. Participants reflected on the renewed salience and interest from the public in how health and care is used as well as recent programmes that have brought the issues into the media spotlight. In particular, participants reflected on the reaction to proposed changes to how NHS Digital collects data from primary care services. The announcement of the [GP Data for Planning and Research](#) programme in May 2021 has led to a two-fold increase in the numbers of National Data Opt-Outs being registered, representing approximately 5% of NHS patients in England.

The workshop was a welcome opportunity to exchange ideas and offer pragmatic suggestions to the proposals announced in the strategy. This was especially useful given the limited time (~4 weeks) permitted for members of the public to respond to the strategy.

The workshop was structured around 3 provocations, which were proposed by Understanding Patient Data, The Ada Lovelace Institute and The Open Data Institute respectively. This was to encourage deeper reflection on areas of the strategy that are critical to societal trust in data use but lacked detail.

Provocation 1: *Individual choice & control: what's changing in the strategy?*

Tom Harrison highlighted the rise in the number of Type 1 and National Data Opt-Outs being registered and reflected on the importance of choice and control to secure long-term public support for data sharing across health and care. Access the presentation [here](#).

Provocation 2: *Societal involvement and participation*

Reema Patel summarised recent research on public attitudes to date and called for the strategy to develop a meaningful and 'virtuous' cycle of participation in decisions about the health and care system use data – giving people real agency. Access the presentation [here](#).

Provocation 3: *When is more data better?*

Jeni Tennison questioned the rhetoric that often assumes that more data provides better results and asked where the strategy can focus more on data quantity and equity. Access the presentation [here](#).

Key themes

The breakout discussions responded to the provocations. Below we highlight the key themes that emerged from the discussion. For further detail please see appendices.

1. Choice and control

The rhetoric around the strategy focuses on citizens' control, but the strategy is largely silent on what mechanisms will be in place to support this for purposes beyond care. Following the announcement of GPDPR, the number of opt-outs has dramatically increased. Against this backdrop it was vital to reflect on how the strategy can better support people to have meaningful choice and control over how their data is used.

Key points raised included:

- **Position the opt-outs within the strategy**: Participants expressed concern that the strategy did not adequately engage with the existing opt-out system or outline how it could be improved. As a result, there is a risk that the number of opt-outs may continue to increase if these existing mechanisms of choice and control are not acknowledged and embedded in the strategy from the outset.

- **Consider collective choice and control:** Participants noted that choice and control take place at a collective level as well as at the individual level. Many called for the strategy to consider how choice and control can be exercised at a more collective level, recognising that because some of the impacts of data use for planning and research are about group risks/harms or benefits, exercising choice at the individual level is not always sufficient to protect and promote people's right and interests.

- **Communicate choice and control:** Participants expressed concern that the existing dual system of type one and national data opt-outs is poorly communicated and challenging to understand. The strategy should be including proposals to better communicate with the public about their options for choice and control, including and potentially beyond the current opt out system. It equally needs to be up front about any limits to these options which may be necessary (for example, as has been the case during the pandemic).

2. Societal oversight and involvement

Recent findings from [Citizens' Juries on Health Data Sharing in a Pandemic](#), led by the University of Manchester, confirmed that the public want to have a say in decisions about how their health data is used and shared. We asked participants to reflect on how the strategy could act as a catalyst for increasing public involvement, and what steps may have to be taken to enable this.

Key points included:

- **Fully embed public involvement:** Participants noted that the strategy represents an opportunity to embed concrete mechanisms of public involvement into decisions about data use. The strategy should not view public involvement as a one-off – in order to build a trustworthy health data system public involvement needs to be at the heart of decision making.

- **Translate outputs to outcomes:** Participants noted that lots of positive public engagement work has taken place in the past, but this does not always translate to substantial improvements in how decisions about health data use are made. The strategy should ensure that recommendations from public involvement are prioritised in the decision-making process. Otherwise, there is a risk that public trust will be undermined if their engagement outputs have few visible impacts.

- **Reference public involvement authentically**: While participants welcomed references in the strategy to previous engagement work, they stressed that this work must be reflected fully and authentically. This means the strategy should acknowledge not only the evidence where the public supports data use and sharing, but it should openly acknowledge any caveats and concerns which the public have also raised.

3. Data quality

Data quality is closely linked to how trustworthy a system is perceived to be. It determines whether individuals and groups feel accurately represented in the data and in turn the quality of decisions being made about them. We asked participants to reflect on what "good" quality data looks like and how the strategy could aim to improve data quality in order to address inequalities.

Key points included:

- **More data is not always better data:** While volume and accuracy of data records can lead to better health outcomes (e.g. for rare genetic disorders), the strategy needs to acknowledge that volume of data alone is not the solution. Often qualitative insights coupled with good quality data can lead to improved outcomes, meaning that *quality*, and not quantity should be NHSX's focus.

- **Limitations of data:** The strategy needs to acknowledge the limitations and biases in large existing datasets. For example, in a [study](#) from OpenSAFELY across millions of primary care records, 26% lacked data on ethnicity. This should be openly acknowledged and mechanisms to improve the accuracy of data should be developed.

- **Practical considerations:** Attendees stressed that the strategy should not forget the practical considerations related to data quality. This includes greater focus on training professionals who are inputting the data as well as upgrading the technical infrastructure so that data recording is more user friendly and less time consuming.

4. Effective communication

While not a predetermined theme of our workshop, it became clear during the event that communication around data use is a vital foundation for the strategy as a whole.

Key points included:

- **Communicate risks:** The strategy communicates well the promise of improved data use for health outcomes, but it could do more to highlight the risks or value judgements that need to be made. Being open and honest with the public about the trade-offs and risks associated with wider data use is a critical step in making health data use more trustworthy.

- **Be consistent:** A consistent approach to language and definitions around data use is needed. For example, consent should not be confused with opt-outs, and language around data ownership needs to be consistent and more nuanced. Consider developing clear definitions and 'talking points' for those in Government and the NHS working on and with the data strategy as it moves forward.

- **Effective communication is not a silver bullet:** It is important to stress that a clear communications strategy is not a solution to some of the concerns with the draft strategy. Effective communication is strengthened and underpinned by meaningful mechanisms of public and health professional engagement embedded in the strategy.

Appendix: Breakout group discussions

This section outlines in greater detail participants reflections within the breakout groups.

Individual choice & control

*"The system is conveying choice in the way **it** thinks, and not in the way **patients** think"*

Across the breakouts, there was a majority view that the way choice and control is expressed in the strategy, and in wider debates about health and care data has been misleading at best. There were several calls from attendees across disciplines for a greater clarity of message and a definition of purpose when it comes to the opt-outs in particular.

While the opt-outs were referenced as an important factor in some people's support of data sharing around the health system - the limitations were clearly articulated. Many participants sought to focus attention on seeking to achieve more collective forms of control, with some participants suggesting that ultimate control through greater public ownership of health data infrastructure.

In terms of how to define choice and control, conversations weighed heavily on the need for good quality information as a prerequisite. As it stands, the current system for collecting and using data across health and care is poorly understood. This means people working in health and care as well as patients and service are unlikely to feel they have meaningful control of how data is used. For some, this perceived lack of control, coupled with high profile concerns about commercial exploration, explained the significant rise in National Data Opt-Out and Type 1 opt-outs being registered since the announcement of the GP Data for Planning and Research programme.

As such, some participants expressed disappointment that the strategy mentioned neither of the data opt-outs and no plan to strengthen or even review how these work. Several participants suggested the opt-outs should be more granular with the ability to be more specific about which purpose and under which circumstances that data access from individual health records could be used. In some cases, this view led to a discussion about how the government's rhetoric around citizen control of data and references to data 'ownership' have been unhelpful in setting up unrealistic expectations of choice and control.

From all the breakouts, it was clear that the draft strategy was an opportunity to build trust in the system, and that the future of an effective health and care service relies on good quality, appropriately used data. There was broad support for much of the ambition, particularly around securing patient record access and enabling interoperability. But this was accompanied by a widely held view that the proposals cannot be delivered without recognising public concerns and will incur costs. For instance, one attendee observed that patient record access will drive up interest and the need for more clinicians to have meaningful conversation with patients about the quality of their records - as well as what choices they can have about their contents.

Societal oversight & involvement

"You need to use engagement methods as ongoing monitoring of the strategy – not as a one off. Engagement can't just be a comms exercise".

Throughout the workshop, participants stressed the need for more robust societal oversight, involvement and engagement. While the strategy contains important ambitions to give people greater access to their health data, as well as increased transparency about how their data is used, it was clear that access and transparency are only one part of a broader framework for societal involvement.

Instead, participants called for the strategy to go further in its ambitions for societal oversight and involvement. This should involve building in concrete and long term mechanisms for societal and public involvement in decisions about how their data is used. This could follow successful models such as the OneLondon public dialogue, or it could learn from alternative models proposed, such as Learning Data Governance. It was so acknowledged that NHS organisations need adequate resources and equipped with skills to undertake meaningful engagement.

Participants noted that rather than viewing societal oversight and involvement as a one-off, or as a method to be drawn on during times of controversy, instead we should view societal oversight and involvement as a 'virtuous cycle of participation'. Crucially, this cycle should involve reporting back to the public about the impact from their involvement. It should also consider more critically which public voices are being heard, and actively engage with seldom-heard voices to better ensure that societal involvement is representative.

Moreover, it was stressed that public involvement should be outcome-centred. While research into public attitudes is vital, the impact of this research is limited if there is no meaningful mechanism for public views to feed into policy decisions. If we are to build a truly trustworthy system of health data, then outputs from public engagement work must translate to tangible policy outcomes.

While participants stressed that communication about data use was only one part of the picture, it was noted that good communication with the public was a vital foundation for good public involvement and oversight to be built upon. The strategy should learn from good practice in this area, for example OpenSAFELY's public facing resources.

Finally, breakout groups noted that it was important to engage with healthcare workers and professionals working with health data to build their views and practical needs into the strategy going forward. It was particularly important to ensure that healthcare workers and those inputting health data into the system can do so easily and quickly. Otherwise, there was a risk that data quality could be impacted due to rushed inputting of data or cumbersome IT systems.

Data quality and inequalities

"If you think about it from an individual perspective, concerns about data quality lead us to feeling heard or unheard, to feeling seen or unseen".

Participants responded to the provocation *'when is more data better?'* to underline that it was important for the strategy to put more emphasis on *how* health data is used, rather than *how much* data is used. Participants wanted the strategy to commit to developing better data use practices across the health and care system which examine and tackle the *cause* of poor data quality more comprehensively. Rather than thinking solely in terms of 'data quality', it was suggested that 'data maturity' may be a better aim for NHS organisations to reach in order to drive improvements in their analytical capability and ability to use patient data in an equitable way.

Several participants argued that the strategy focused too heavily on quantitative data, suggesting instead that qualitative insights grounded in patient experience improve patient care and treatment. It would also be more likely to be welcomed by patient groups. In general, there was a desire from participants for the strategy to be more nuanced about data quality whilst recognising that in many cases, such as in initiatives like MBBRACE-UK, data quantity is critical.

When discussing how best to improve data quality, NHSX was urged to consider the practical context in which health data is gathered. There was agreement the strategy was right to aim to improve the ease in which health care workers can input data, but that in order for this to happen, widespread engagement with healthcare workers is required, both to ensure that they are confident in the health data available to them, and that they are able to accurately record data about an individual.

Participants also recognised that data collection in healthcare settings places demands on clinician's time and that this has a direct cost on the NHS. Several attendees highlighted that the ambitions to further develop the technical infrastructure outlined in the strategy is an opportunity to improve data quality but had an unrealistic time frame for completion.

Finally, participants stressed that it was important to recognise and be open about the current limits of health data. There was significant concern that the current health data system is missing data on ethnicity. For example, OpenSAFELY analysis has found that approximately 20% of UK health records lack information on ethnicity. This lack of data has the potential to translate to a lack of insight into health outcomes and lead to concerning disparities in health outcomes if left unaddressed.