

The logo for the National Data Guardian, consisting of the letters 'NDG' in a bold, purple, sans-serif font.

**National
Data Guardian**
for health and social care

The National Data Guardian's response to the Department of Health and Social Care's consultation on its draft data strategy: 'Data saves lives: reshaping health and social care with data'

Published September 2021
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Introduction

This is the National Data Guardian's (NDG's) formal response to the Department of Health and Social Care's (DHSC) consultation on its draft data strategy – [Data Saves Lives: Reshaping health and social care with data](#).

I strongly support the appropriate use of data to improve health and social care and therefore commend the strategy's ambition to improve the nation's wellbeing through data use. There is much within this vision to inspire as potentially providing significant benefits to patients and staff. The feedback and advice I provide in this response is focused on highlighting:

- areas where further engagement to understand public perspectives will help to inform and strengthen the strategy's commitments
- areas where what is proposed has the potential to impact public and professional trust in a confidential health and care service, and where I believe further consideration is necessary

My considerations and suggested actions are intended to support the drafting of a clearer strategy that provides a more consistent commitment to:

- safeguarding patient confidentiality
- reinforcing the importance of building public trust
- ensuring that people understand how their data is used

1. Choice and control

What the strategy says

The strategy refers in the ministerial forward¹, and in its first priority², to a commitment to give the public control over how their data is used. The first priority states:

“Build understanding on how data is used and the potential for data-driven innovation, improving transparency so the public has control over how we are using their data.”

In explaining the priority, the strategy states:

¹ The minister states: *We want you to be in control*

² The first priority states: *first to build understanding on how data is used and the potential for data-driven innovation, improving transparency so the public has control over how we are using their data*

“The public’s data belongs to them so it’s important it is safely and securely only used in ways that benefit everyone using the health system.”

The commitments which the strategy makes to fulfil this priority reflect measures to increase the transparency of the use of health and social care data such as:

“Publish the first transparency statement setting out how health and care data has been used across the sector (2022).”

The NDG’s considerations

The creation of clinical record content is a shared endeavour involving a patient and their clinician, documenting the confidential information shared between them in the context of care.

As noted above, the concept of ‘giving control’ is primarily expressed in the strategy as a commitment to increasing transparency. The NDG welcomes the strategy’s commitment to increasing transparency in *setting out how health and social care has been used across the sector*. This commitment to increasing transparency will lead to greater awareness and understanding of data use.

The strategy should provide a clearer explanation of how people will be afforded increased control over their data. Being more transparent about data use does not equate to giving people greater control over the use of that data.

The strategy’s use of language regarding ownership requires clarification. The public owning their data implies a number of rights which are commensurate with ownership, which are not present with regard to health and social care data processed by health providers. The language of ownership does not seem to reflect the direction of the data strategy, which defines ‘control’ in terms of ‘rights of access’ as opposed to terms of ‘ownership’.

The narrative could more clearly outline the opportunities that people will have for increased control over their data. A key mechanism by which people can exercise genuine control is through having the choice to opt out of its use. The commitment to giving members of the public some control over their data would be significantly strengthened by including a reference to opt out mechanisms, including the national data opt out (NDOO). It is important that the strategy acknowledges and provides clear support for the principle of opt out choice if it is to speak meaningfully about individual control. Furthermore, I would like to see a commitment to improve how opt out mechanisms work in practice, engaging with the public to ensure choices are clear, coherent and simple to action; I would be keen to actively support this work, as aligned with my priorities in my recently published annual report.

Recommended actions

- include a commitment to the maintaining the choice to opt out, including the NDOO, and improving how opt out works in practice
- more closely consider the language used and its meanings, alongside giving clearer explanations: if people have control over their data, what are the mechanisms that enable this control? When data ownership is referenced, what does this mean in practical terms for patients and service users? Examples would be helpful

2. Transparency and equality

What the strategy says

Chapter 1 of the strategy commits to ‘bringing people closer to their data’. It will:

“Give citizens the ability to see what research their data has informed, and who has had access to their data, as soon as the technology allows (ongoing).”

The NDG’s considerations

The NDG supports the aim to increase people’s awareness, understanding and involvement in how health data is used.

The chapter sets out that the way in which people will be brought closer to their data is through ‘digital access’, ‘systems’ and ‘technology’. There is a wealth of evidence, such as the Office for National Statistics’ article [Exploring the UK’s Digital Divide](#), that indicates that those who are not engaging effectively with the digital world are at risk of being left behind. To demonstrate how the commitment to bringing people closer to their data applies to everyone, the strategy should also outline how it will provide opportunities to bring people closer to their data where people do not, or are unable to, engage with the digital world.

The commitment to inform people about how their data has been used would be strengthened by a clear plan for the implementation of the commitment: what tools will be available to inform people when their data has been used, by whom and for what purpose? The 2016 NDG [Review of Data Security, Consents and Opt Outs](#) recommended the development of an online tool that would allow people to see how sharing their data had benefited other people. Does the strategy intend to deliver on the commitment to enable people to use online services to see how their data has been used for purposes other than direct care?

Recommended actions

- provide a clearer explanation of how and when people will be provided with the ability to see what research and service planning their data has informed, and who has had access to their data, and whether this will be at individual or local population level
- provide additional information about how the strategy will strengthen digital inclusion and address digital exclusion, if appropriate signposting to existing or planned work if this is set out, or due to be set out, more clearly elsewhere (for example in the forthcoming Digital Transformation Plan, referenced in the Executive summary)

3. Clarifying proposals for legislative change

What the strategy says

Annex B outlines the ‘imperative for change’ in respect of existing legislation which inhibits the effective use of data.

The NDG’s considerations

The NDG understands the need to make changes to the law that might make it easier for health and social care staff to have the right information to do their jobs and deliver safe and effective care. The strategy explores this as a possibility in its proposals to a) develop primary legislation to share data that has been rendered anonymous, and b) secondary legislation to enable the sharing of information that could identify people.

It seems the aims of the proposed legislative changes are to:

- drive a culture of change that will strengthen the existing legal duty to share for direct care
- create a new duty on health and social care organisations to share anonymous data for the benefit of the system as a whole
- use secondary legislation to enable the proportionate sharing of personal data, where appropriate, to support the health and social care system

It is important to consider and address each of these aims in turn.

Drive a culture of change regarding the existing legal duty to share for direct care

The strategy suggests that the existing duty to share data for direct care does not apply to sharing between health and social care services.

The NDG suggests that section 251B (2) (b) *does* include a duty to share information between health and social care providers.

The section requires that information is disclosed to:

“Any other relevant health or adult social care commissioner or provider with whom the relevant person communicates about the individual.”

Given this, it seems that the commitment made in the strategy should be to effectively communicate the existing duty to share for direct care to all health and care staff caring for patients and service users.

I would welcome greater clarity about whether further legislative proposals are actually required here – and, if so, why the current legal duty in section 251B (2) (b), described above, is not sufficient to cover sharing for individual care across the health and social care system.

Create a new duty on health and care organisations to share anonymous data for the benefit of the system as a whole

The strategy commits to introducing a duty to share anonymous information (truly anonymous and de-identified) for the benefit of the system.

These proposals for primary legislative change are unclear on the crucial distinctions between data which does, and does not, identify individuals. For example, the use of the phrase “de-identified” infers data which has been through a process of pseudonymisation and may still be capable of identifying individuals.

While acknowledging that rendering data anonymous is privacy enhancing, the strategy does not adequately reflect on the legal and practical challenges of rendering data anonymous. Given the lack of clarity around the process of rendering data anonymous, this omission is significant and may hinder the aims of the strategy.

I would like to understand whether the legislation set out in the strategy will reflect the Information Commissioner’s Office (ICO) position on rendering data anonymous. The relationship to the ICO [‘Introduction to anonymisation: Draft anonymisation, pseudonymisation and privacy enhancing technologies guidance’](#) could helpfully be acknowledged in the strategy and there should be an explanation of how the standards of anonymisation will correspond with ICO guidance.

Given that a suite of future ICO guidance is also anticipated, DHSC should work closely with the ICO during the implementation of the strategy proposals for primary legislation on the sharing of anonymous data to ensure the alignment of standards on anonymisation.

Setting out clear standards on rendering data anonymous is necessary for the strategy's commitment to making sure that data is handled in line with the UK's data protection legislation.

Co-operation between the health and social care sector and the ICO to lead to clear standards on legal bases for data use and rendering data anonymous will also provide much needed reassurance to the health and social care workforce, and correspondingly for patients and the public.

Use secondary legislation to enable the proportionate sharing of personal data where appropriate to support the health and social care system

The government's commitment to use secondary legislation to enable the proportionate sharing of personal data where appropriate to support the health and social care system, introduces potential risks for patient confidentiality.

Any duty which allows the sharing of personal data must clearly articulate why sharing is appropriate and proportionate. It also needs to detail the safeguards. The wider sharing of patient information that can identify individuals must also reflect public expectations.

We would like to understand the measures that the strategy will put in place to ensure patient confidentiality is protected, and both public and professionals are engaged to raise awareness and understanding of the data uses that this secondary legislation will enable.

In the commitment to creating secondary legislation, the strategy will:

“Work closely with stakeholders and the public to make sure that these changes are implemented transparently and that appropriate safeguards are in place.”

It would be helpful for the strategy to outline at which points in the legislative process there will be wider engagement with stakeholders and the public, and to explain what form this engagement will take.

With regards to the proposed change to secondary legislation relating to the use of personal information, I think it would be helpful to see at this stage a description of the scope of any proposed modification to the duty of confidence. This should include an explanation of why the secondary legislation proposed should establish a mechanism other than that which exists under Regulation 5 of the Control of Patient Information Regulations (COPI) 2002 and Confidentiality Advisory Group Support under Section 251 NHS Act 2006.

Currently the NDOO would apply to such processing under Regulation 2 and Regulation 5. If the secondary legislation covers uses of data which the NDOO would currently apply to, the strategy should acknowledge and consider how the ability to opt out will continue to be protected.

Recommended actions

- provide clarity on the application of existing legal obligations to share information for direct care for health and social care
- address the practicalities of new legal concepts such as sharing anonymous information and the standards which will need to be met
- provide a clear plan for public engagement where secondary legislation intended to facilitate sharing confidential information
- provide a description of the scope of proposed modifications to the duty of confidence
- explain how the NDOO will continue to be protected

4. Public expectations of data sharing across government

What the strategy says

Chapter 3 *Supporting local and national decision makers with data* includes a commitment to:

“Work across central government, including colleagues in MHCLG, DfE, the Cabinet Office, MoJ, DWP and across devolved administrations to improve appropriate data linkage to support people’s health and wellbeing.”

The NDG’s considerations

The strategy does not fully explain the scope of its commitment to link data across central government, and how this will be achieved in practice.

The sharing of health data across non-health providing government organisations that do not provide health and care services would be a significant development.

Whilst some data sharing across departments might be envisaged to confer public benefit, this development has the potential to negatively affect public trust in how the health and social care system safeguards confidential health data. Any diminution of the boundary around confidential health and care data risks people choosing to disclose less, or inaccurate, information to health and care professionals due to concern its use may negatively impact either themselves or members of their community. It would seem reasonable to assume this potential loss of trust is most likely to occur in already disadvantaged groups, who historically may have more complicated relationships with non-health government organisations. If such a loss of trust in its use occurs, in addition to its negative impact on health seeking behaviour, it would

also be to the detriment of data quality both for the safety and effectiveness of individual care, and wider system intelligence for planning and research.

The strategy should demonstrate that it has considered how sharing with DWP, MOJ, DfE and other government departments might affect public trust and discourage people from providing full and accurate information, or even seeking treatment.

Given its potential for considerable impact, the plan to share data across central government should be given further consideration and coverage in the strategy. A more detailed explanation of the legal basis for this sharing is needed. As are clear descriptions of how it is anticipated this information will be used: what sort of actions will be taken, or decisions made about people, based on this shared information?

Additional information in the strategy on the below points would aid clarity:

- whether a legislative change is required, if so, this should be explained in Annex B
- the terms on which data will be accessible need to be clear to avoid any unintended adverse consequences, such as people providing incomplete or inaccurate information or not seeking the care they need, through fear of how it may impact on themselves or others they care about

Recommended actions

- Clearly explain the legal basis for sharing information between agencies, what decisions may be made using this information, and how this may affect people

5. Strengthening trustworthiness

The NDG's considerations

The first priority seeks to build understanding on how data is used. The NDG wholeheartedly supports this, and to achieve this, a culture of continued communication and engagement with the public needs to be established. To be successful in building this culture, all of the organisations that use health and social care data need to explore how their systems for ongoing communication and engagement can be developed and improved.

Organisations may wish to reflect upon how they can demonstrate why they should be considered trustworthy in relation to their use of health and social care data. Within this context it is important to be mindful that some

organisations are more likely to be perceived as trustworthy than others. The strategy states that:

“The NHS is one of the most trusted organisations in the UK.”

Whilst this may be true in a general sense, there have been circumstances where this trust has not been reflected in the public response, such as people’s recent reaction to the proposed collection of patient data held by GPs by the GP Data for Planning and Research programme (GPDPR), evidenced by the rise in opt out rates. This response suggests an erosion of trust, which this strategy provides an opportunity to address.

The strategy makes a further commitment to increase the amount of data collected. There needs to be a greater consideration of how the plans to implement the strategy’s commitments to facilitate greater access to, and usage of, health and social care data will earn and maintain public and professional trust and confidence, and how concerns will be engaged with and addressed.

Presenting an authentic position on the balance of benefits and risks of data use is an important aspect of demonstrating trustworthiness. People are aware that there are privacy and other risks associated with data sharing and if this is not acknowledged, people may naturally question motives as to why. Only presenting benefits therefore runs the risk of diminishing trust. Human nature is such that risk concerns often weigh heavier for us than potential benefits, even if these may be significant. Being open about risks and their mitigations provides an opportunity to meaningfully engage the public and build confidence in the system.

Similar openness is also advised about the use of data by commercial companies and the role that they play in enabling advancements in health and care. We know from public attitudes research that people have concerns about the use of their data by profit-making third parties. We also know when the facts, benefits and safeguards are explained, this can help to address these concerns.

I feel that the strategy could do more to surface, and address, the matter of commercial involvement. For example, it refers to ‘innovators’ as a group who the government is committed to supporting through access to health and social care data. The term lacks clarity and specificity, and therefore a clear explanation of what is meant by ‘innovators’ should be provided within the document. The fact that some of these innovators are commercial organisations could be more clearly drawn out, accompanied by a confident explanation of the role that commercial organisations may play in improving health and care through access to data, including, most significantly, the safeguards that would accompany any access. The upcoming publication of our public benefit guidance will assist organisations who need to make a public benefit assessment of any

proposed commercial access. The guidance recommends transparency and active public involvement in processes for making public benefit evaluations as key components of such assessments.

The use of case studies to explain the benefits of data use is helpful. However, there is an overreliance on examples from the pandemic response. While this showcases how integral data use is to protect the population, there is a risk that this over reliance on data use during a time in which special measures are in place impacts the ability of the strategy to remain relevant in the future. The case for data use is not static: it should be assessed and made continuously as a dynamic process, in the light of the ever-changing landscape of evolving risks and opportunities.

Recommended actions

- provide further, more specific information about how the strategy will build and maintain public trust
- present a more balanced view of the benefits and risks of data use and how these will be addressed
- use clear, unambiguous language and explain what unfamiliar terms mean
- include additional case studies to demonstrate the benefits of data use that are not pandemic response specific

In conclusion

I welcome the publication of the draft strategy and the extended period for consultation as an opportunity to gather feedback to strengthen it further. From the informal engagement I and my panel have had thus far with the strategy team, I am confident this response will be received in a spirit of constructive challenge as part of that process and look forward to further discussion where this may be helpful on the specific areas outlined above.