Understanding Patient Data response to the National Data Strategy consultation

About the consultation

The consultation was open from 9 September 2020 to 9 December 2020, in the format of an online form. Our responses are best read alongside the National Data Strategy. The Strategy is cross-sector and therefore much broader in scope than Understanding Patient Data's usual focus. We have therefore responded to a few specific questions, where we could draw on our evidence base and experience in health data to give comprehensive answers.

Q1. To what extent do you agree with the following statement: Taken as a whole, the missions and pillars of the National Data Strategy focus on the right priorities. Please explain your answer here, including any areas you think the government should explore in further depth.

Responsibility and permissiveness

- The Strategy rightly draws attention to infrastructure, skills and data accessibility in its pillars. However, the "responsible use" pillar is underspecified and could conflict with the intention to build on the "permissive approach" (s.2.3) to data use in light of the response to Covid-19. This phrasing suggests data accessibility will be prioritised over good outcomes arising from data use.

- Instead of permissiveness, the Strategy should focus on ensuring the intention to yield public benefits drives every use of data. This will be the only way to achieve a social license for the vision set out in the Strategy. Because 'public benefit' is a complex, value-based notion, by default there should be avenues for ongoing scrutiny and independent oversight, to ensure data use is trustworthy and trusted by the groups and communities it affects.

- In the health sector, use of the Control of Patient Information notices exemplifies a more permissive approach. These have enabled more health data to be used for the pandemic response but were designed for short term use as they override people's usual rights in relation to data about them. Although emergency measures and rapid decision-making on data use may have been necessary in the early stages of the crisis, it is vital that longer-term regulation and governance are set up in ways that respect and embed public views and values.

<u>Engagement</u>

- The Strategy proposes a "national engagement campaign" (s.7.1.2) about the benefits of data use. We strongly endorse the need for greater transparency and accessible, findable information for people about what data about them is being used, how and by whom, but disagree with the premise of a national approach. While it is important for messaging to be co-ordinated to provide consistency and clarity, engagement about data use needs to be embedded in and led from local regions. This can ensure the use cases, risks and benefits are relevant to local contexts and the things that people care about. Otherwise, 'data' feels abstract, dry and far removed from people's own lives.

- Engagement needs to be distinguished from communication. Communication is one-way and designed to inform. Engagement implies a dialogue, with the opportunity for people to ask questions, feed in ideas and for the systems of data use to be responsive to these. The Strategy should set out what it intends to communicate and whether there are opportunities for more meaningful engagement by citizens to develop and design accountable systems of data use.

<u>Communication</u>

- Communicating about data use at a high level without context and enough specific information can result in people's anxieties about data use being exacerbated, rather than alleviated. The aim should be for targeted interventions to inform people about data use that occur at a time that <u>people find these most useful</u> – and make sense in the context of, for example, their interactions with public services.

- Real examples are important to help people understand potential benefit.[1] Starting with 'the data' is abstract, confusing and leads to more concerns; starting with what people care about and how better use of data can/could help them in their own lives and interactions with public services has a greater chance of achieving the engagement objectives outlined.

- **Q4. We welcome any comments about the potential impact of the proposals outlined in this consultation on the UK across all areas, and any steps the government should take to ensure that they take account of regional inequalities and support the whole of the UK?**

<u>Addressing unequal research concentration</u>

- The UK Research and Development Roadmap <u>acknowledges the UK has an unequal concentration research and innovation activity</u>.[2] The National Data Strategy should address risks that investment in improving data quality and curation will accrue in areas that are already well-resourced, to the detriment of others. For example, in the health sector, areas with strong university research and teaching hospitals may be well-placed to invest in data quality and curation, and therefore capitalise on developments in

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[1] https://www.cancerresearchuk.org/sites/default/files/riccr_201609_amended.pdf
[2] https://www.gov.uk/government/publications/uk-research-and-development-roadmap p. 10)

data-driven technology. This will result in tools, products and services that are tailored to affluent areas and their population needs and demographics, while others miss out on innovation.

- This issue is reflected in public concerns. For example, in a health context, people want to see data use benefitting the whole system:

> *"If it* [health data partnership] *is of benefit to the NHS, it shouldn't just be Oxford or Sheffield. We all contribute to the NHS so we should all benefit from this research."*[3] (citizen juror)

- A nationally representative survey backed up this finding, with 81% responding that the benefits of data partnerships should be equitably shared across the NHS.[4]

Local vs. national approaches

Seeking equitable benefits requires data holders to have the right skill sets, guidance and support to understand how to pursue initiatives that are likely to accrue widespread public benefit. This is because they may need to navigate tensions between meeting immediate local needs (does this data project address a particular need within a community?) and considering wider and longer-term impacts (could there be negative impacts on others or greater costs downstream?)

- Balancing these local/national tensions is not a new problem. The UK Research & Develop Roadmap aims to "improve access to trusted data resources at a local level in to order to "build robust R&D ecosystems"[5]while the Centre for Improving Data Collaboration at NHSX has been formed to invest in local-level data holders, within the context of a national framework. We endorse this nationally-led, locally-delivered approach, which may require upfront investment but will generate better use cases and engagement opportunities in the longer-term.

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[3] https://understandingpatientdata.org.uk/sites/default/files/2020-03/Foundations%20of%20Fairness%20-%20Summary%20and%20Analysis.pdf (p. 11)
[4] https://understandingpatientdata.org.uk/what-do-people-think-about-third-parties-using-nhs-data
[5] https://www.gov.uk/government/publications/uk-research-and-development-roadmap (p. 38)