Introduction

The Academy of Medical Sciences promotes advances in biomedical and health research and supports efforts to translate these advances into healthcare benefits for society. Our response is informed on the principles and public dialogue from the Academy's *Our data-driven future in healthcare* working group project as well as our wider work in the health data policy space.[1,2]

Public engagement, involvement and trust

1.1 **Public trust is fragile, and there is a significant risk of a high proportion of the public opting out from their data being collected and/or accessed beyond their direct care.**[3] If this were to transpire, the usefulness of health data sets would be dramatically impacted, in terms of their ability to inform service improvement, to enable new biomedical and health innovations, and to provide any economic return to the NHS and wider society. This cannot be allowed to happen, as once a 'point of no return' is reached, building trust back would be hugely challenging. There is an additional risk that rate of opt-outs will vary across different demographics, with some communities already having a lower trust of the healthcare system than others.[4,5] This will not only harm the quality of data sets, but also reduce the ability of data-driven approaches to narrow health inequalities as the evidence-based interventions that are derived from them may not be appropriate for all sectors of the UK population.

1.2 In addition, **not all types of health data are viewed in the same way by patients and the public,** even if de-identified or anonymised. For example, data relating to mental ill health is viewed as especially sensitive and may therefore need greater protections and reassurance than other types of data. It is therefore vital that people with experience of mental ill health are involved in oversight and decision making around these types of data. The Clinical Record Interactive Search from the NIHR Maudsley Biomedical Research Centre is an example of a system that included people with experience of mental ill health in its planning, implementation and oversight.[6] Similar approaches should be taken with other types of data considered more sensitive, such as data pertaining to sexual health.

1.3 In general, **there is a 'diameter of trust' amongst the public and patients, with local providers and services being trusted more than larger national bodies.** As such, it may be inherently more difficult to build trust for national programmes compared to local solutions irrespective of the quality of engagement and communication. One potential solution to this is to consider where national combined data sets legitimately add value, and where smaller, local data sets that sit within diameters of trust might be sufficient for certain uses. This may be especially

[1] Academy of Medical Sciences (2018). *Our data-driven future in healthcare* https://acmedsci.ac.uk/file-download/74634438

[2] Academy of Medical Sciences and Ipsos MORI (2018). *Future data-driven technologies and the implications for use of patient data* https://acmedsci.ac.uk/file-download/6616969

[3] https://digital.nhs.uk/data-and-information/publications/statistical/national-data-opt-out/july-2021

[4] https://yougov.co.uk/topics/politics/articles-reports/2021/03/17/who-do-bame-britons-trust-when-it-comes-covid-19

[5] Public Health England (2020). Beyond the data: Understanding the impact of COVID-19 on BAME groups https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

[6] https://www.slam.nhs.uk/quality-and-research/clinical-record-interactive-search-cris/

true when data are being used for local service planning and improvement, or research that does not require millions of records to provide useful insights.

1.4 **Building and maintaining trust is a process that requires concerted, long-term commitments to dialogue, engagement, involvement and transparency.** Ideally, the Data Strategy and policies, processes and structures that emerge from it will be tested with the public and patients prior to any commitments being carried out to avoid any unseen risks to trust, and to demonstrate a willingness to adapt and iterate according to what works best for patients and the public. Where possible, this engagement could go further to consist of real co-creation with patients, the public and clinical staff. Of particular short-term concern is ensuring that models for anonymisation and data access are communicated effectively. The recent postponement of the plans for the launch of the GP Data for Planning and Research database is a response to this sensitivity.[7] However, it is far better to address these issues from the beginning rather than resort to later revisions, delays or postponements, by which time irreparable damage to trust might have already been done.

1.5 In addition to being involved in the co-creation of processes, and before any action is taken, **the goals of the Strategy should involve patients and the public at every step of the data life cycle, from generation and curation, through to stewardship and sharing and then to its legacy.** This is vital for several reasons. Firstly, public and patient views are ever evolving, and given the timeframes involved in developing and implementing some processes there is a risk that the end product does not reflect current views. Secondly, it is rare for processes to look the same at implementation as they do at the planning stages, and so input and scrutiny is needed throughout to ensure any changes made are appropriate. Finally, all steps of process development and implementation concerning health data would benefit from the input of patients and the public.

1.6 **The trust of clinical staff is equally important, given that they are the gatekeepers to patients** and will be integral both to conversations with patients about their health data, and in the collection of data itself. Clinical staff need to be included in dialogues and co-creation processes, and transparency processes tailored to ensure clinical staff are informed and confident about how the data they are responsible for collecting is held and used.

Training for staff

2.1 While simplifying information governance for front-line staff is a positive step towards ensuring data is captured routinely and is of high quality, training for staff needs to also include a broader set of skills related to health data collection, access and use. **Staff need to be supported to have conversations with patients about how data about them will be collected, who will have access to the data, and how the data might be used both by NHS organisations and by third parties.** It has been shown that the public and patients have greater confidence in the use of health data when these processes are clear and transparent and where the benefits of using health data are clearly communicated.[8] Given that NHS staff are already stretched, both by long-term service pressures and new pressures created by the COVID-19 pandemic, there is a risk that staff will not have the time nor motivation to have these conversations unless given the right support to do so.

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[7] https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research/secretary-of-state-letter-to-general-practice
[8] OneLondon LHCRE, Ipsos MORI and The King's Fund (2020). *Public deliberation in the use of health and care data* https://www.onelondon.online/wp-content/uploads/2020/06/Public-deliberation-in-the-use-of-health-and-care-data.pdf

2.2 Data could also be an enabler of greater shared decision making, as demonstrated by new guidance from NICE. **Empowering patients to take part in shared decision making requires staff to themselves be supported in understanding the uses and limitations of health data in decision making about care**, as well as specific training in working with patients to make shared decision making meaningful and genuine. While in the long term digitalisation may free up staff time to spend more time with patients, it has been shown that in the short term digitalisation may actually lengthen processes or make them less efficient (for example the phenomenon of 'alert fatigue'). Simplifying information governance processes may go some way to alleviating this, but ultimately additional resourcing and investment in staff roles with data and informatics expertise may be required to alleviate the burden on other front-line staff.

Health inequalities and diversity

3.1 **Health data and the innovations derived from them have the potential to both narrow health inequalities and, if care is not taken, potentially widen them or create new inequalities.** COVID-19 has shown the impact that non-health factors can have in driving health inequalities, and it is known that data sets can be biased by a lack of data from individuals from certain demographics, including protected characteristics.[9] As such, research and innovations derived from biased data sets are likely to incorporate the biases within them.[10,11] Biased data sets could be generated by a number a factors, including: heterogeneity of digitalisation across the healthcare system, bias imparted during data collection and recording and variation in engagement with the healthcare system across different demographics. Ideally these three factors would be addressed such that health data sets do not have inherent bias that would affect their use for research and innovation.

3.2 In addition, digital exclusion continues to be a concern, and **while 'digital by default' can provide significant advantages both for patients, NHS staff and for health data collection, some groups, such as older people or those from disadvantaged backgrounds may not realise these benefits in the same way**. This could especially be a concern if health services and decision making begin to incorporate app, wearable or home-technology derived data, which are systems likely to have varied engagement across different demographics. In addition, the data collected through these new services may lack diversity and therefore lead to datasets with inherent bias.

A 'fair return to the NHS'

4.1 The Strategy aims to support 'researchers' and 'innovators' in accessing health data sets for the purposes of providing new insights and innovations that could improve the health of the nation. **A significant stakeholder within these two groups are private companies, which operate for profit and for which access to NHS held data sets could be highly valued in the development of new products.** Access by these companies necessitates data-access agreements with the NHS. Public dialogues commissioned or run by the Academy, Understanding Patient Data and the Ada Lovelace Institute, OneLondon LHCRE and the National Data Guardian have made it clear that the public support the use of data for public benefit but this

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[9] Nuffield Trust and the NHS Race and Health Observatory (2021). *Ethnicity coding in English health service datasets* https://www.nuffieldtrust.org.uk/files/2021-06/1622731816_nuffield-trust-ethnicity-coding-web.pdf
[10] NHSX (2019). *Artificial Intelligence: How to get it right* https://www.nhsx.nhs.uk/media/documents/NHSX_AI_report.pdf
[11] Centre for Data Ethics and Innovation (2020). *Review into bias in algorithmic decision-making* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/957259/Review_into_bias_in_algorithmic_decision-making.pdf

benefit needs to be demonstrable and shared equitably.[12,13,14,15] In these dialogues, the types of 'public benefit' that are considered most acceptable are those that have the potential to lead to improvement in health, whether via research, system improvement or public health measures. It is also important to note that, while patients and the public perceive the NHS as a single body, it is a collection of organisations, and the actions of individual NHS bodies may reflect on the entire NHS. However, the term 'fair return', if not well defined, could encompass a range of other types of public benefit which may be less acceptable to the public and patients. It is vital that data-access agreements are informed by and respect the views of these and other dialogues with the public and patients.

4.2 While we are pleased to see the Strategy commit to 'a fair return to the NHS', and highlight the development of the Value Sharing Framework, **it is not yet clear what these data-access agreements will look like and how they will be developed and evaluated.** Clearer guidance on what the Framework will encompass and what influence it will have on NHS bodies in forming data-access agreements with private companies will be invaluable to providing confidence to the sector that data-access agreements that harm the reputation of the NHS are unlikely to take place. As these models are likely to come under a significant amount of public scrutiny, it is essential that the public and patients have a say in what acceptable agreements look like prior to any being formed.

4.3 **What constitutes 'a fair return' and 'public benefit' should be decided in a process that involves patients and the public as equal partners.** Such processes would need to be transparent and open to scrutiny if they are to engender trust in wider society, and should be careful to avoid 'tokenism'.

Mechanisms and processes for data sharing

5.1 While there is much focus on scrutiny of data access by third parties, **it is essential that access across the NHS and between the NHS and Government departments or arm's length bodies, while supported where beneficial, are held to the same high standards.** The Strategy would benefit from making clear whether sharing across the NHS and with and between Government departments or arms lengths bodies will be subject to the same approval processes and transparency requirements as that for third parties, and if not what the differences in these requirements will be.

This response was prepared by Dr James Squires, FORUM Policy Manager and informed by members of the Academy's Fellowship and previous policy work in this area. For further information, please contact Dr James Squires (james.squires@acmedsci.ac.uk; +44(0)20 3141 3227)

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[12] Academy of Medical Sciences and Ipsos MORI (2018). *Future data-driven technologies and the implications for use of patient data* https://acmedsci.ac.uk/file-download/6616969
[13] Understanding Patient Data and the Ada Lovelace Institute (2020). *Foundations of Fairness* https://understandingpatientdata.org.uk/sites/default/files/2020-03/Foundations%20of%20Fairness%20-%20Summary%20and%20Analysis.pdf
[14] OneLondon LHCRE, Ipsos MORI and The King's Fund (2020). *Public deliberation in the use of health and care data* https://www.onelondon.online/wp-content/uploads/2020/06/Public-deliberation-in-the-use-of-health-and-care-data.pdf
[15] National Data Guardian, Understanding Patient Data, ScienceWise and UK Research and Innovation (2021). *Putting Good into Practice* https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/977737/PGiP_Report_FINAL_1304.pdf