

# How NHS data could benefit us all and how to build the trust needed to make it happen

The pandemic has accelerated the data-sharing conversation and patients are increasingly receptive to sharing data, but missteps in this area could undermine public trust. This article outlines public concerns, lessons learned from previous unsuccessful activities, and the potential for secure data environments, which will be vital for the UK to maximise benefits for patients and the NHS.

## Introduction

The COVID-19 pandemic advanced the use of large healthcare datasets to develop and roll out treatments and vaccines across the UK and globally. Most cited is the impact of the Randomised Evaluation of COVID-19 Therapy (RECOVERY) trial, the results of which led to the prescribing of dexamethasone as treatment for severe COVID-19, estimated to have saved 1 million lives globally (NHS England, 2021). In the UK, NHS use of data to enable service delivery further highlighted the value of access to healthcare data to patients and the public. These successes were made possible through emergency legislation that resulted in more rapid access to data (NHS Digital, 2022a). Such benefits have led to calls for the continued use of the legislation or a similar mechanism to enable researchers working across public and commercial sectors to use NHS data and datasets to drive innovation to benefit patients and the NHS.

## NHS data and public concerns

The pandemic has accelerated the conversation about data sharing. Although patients and the public are increasingly receptive to sharing data given the benefits realised during this period, there is still a risk that missteps in this area could undermine public trust. The public raised valid concerns during the failed roll out of the GP Data for Planning and Research programme in 2022 (NHS Digital, 2022b) after NHS Digital undertook limited public engagement and failed to release adequate information. The impact of these errors was substantial: more than 1 million patients opted out of sharing their data (Jayanetti, 2021) and the programme has now been delayed indefinitely.

Lessons were learned from the failure of this programme and acknowledged in the government's Data Saves Lives white paper. To avoid future missteps, the white paper set out five principles (Department of Health and Social Care, 2022a) to ensure that the NHS and Department of Health and Social Care can demonstrate their role as trustworthy data guardians:

1. Secure data
2. Be transparent on how data are used
3. Ensure fair terms from data partnerships
4. Listen to public opinion on how data are used
5. Improve access for individuals to their health data.

However, there is still work to do to bring these principles into Department of Health and Social Care and NHS England's ways of working. More recently NHS England have published their own value sharing framework for NHS data partnerships (NHS England, 2023). This framework represents a positive first step, but more operational guidance needs to be developed given the growing interest and activity in this field. Meaningful patient and public engagement and input is crucial to any future use of NHS data and must be central to activities in this area. Initiatives such as the Imperial College Health Partners and Ipsos Mori OneLondon Citizen's Summit (OneLondon, 2022) offer a blueprint on how public consultations can be run and the invaluable information and insights they can generate.

Niki O'Brien<sup>1</sup>

Saira Ghafur<sup>1</sup>

Peter Howitt<sup>1</sup>

James O'Shaughnessy<sup>1</sup>

Ara Darzi<sup>1</sup>

Author details can be found at the end of this article

**Correspondence to:**

Niki O'Brien;  
n.obrien@imperial.ac.uk

### How to cite this article:

O'Brien N, Ghafur S, Howitt P, O'Shaughnessy J, Darzi A. How NHS data could benefit us all (and how to build the trust needed to make it happen). *Br J Hosp Med*. 2023. <https://doi.org/10.12968/hmed.2023.0191>

## Using the right technology to build public trust

There is an opportunity to increase public trust by focusing on building secure data environments (Department of Health and Social Care, 2022b) where data are stored and accessed on specially developed platforms with the highest levels of security and privacy. These enable users from across public and commercial research institutions and organisations to undertake analysis and research within this environment. No raw data can be extracted and processed data are only able to be extracted following a strict review and approvals procedure. If done well, including through co-design and effective communication with patients and the public, secure data environments can build confidence in healthcare data sharing and use in research, as they act as a safeguard for privacy and security.

## Maximising benefits from NHS data sharing

Patients and the NHS are the ultimate beneficiaries of healthcare data sharing when it is done right. The NHS alone cannot generate the potential breakthroughs and innovations possible through multi-sector participation and collaborations. Data sharing agreements with external organisations can provide health, social and financial value to invest further in population health and the NHS. Although there is increasing support for the sharing of healthcare data, mistrust towards sharing with the commercial sector remains a concern for patients and the public based on the potential for commercial gain trumping public benefit (Davis, 2021). It is critical that patients and the public have a strong voice in determining how the NHS works with external partners.

Initial deliberation exercises have demonstrated that the public have clear ‘red lines’ for healthcare data sharing, which led to the formulation of conditions by OneLondon Citizen’s Summit (OneLondon, 2022) that should be considered when agreements are being made. These include:

1. Access to data should be controlled and not be exclusive. Decisions about data access should be made by an independent group including (but not only) the public
2. Investment should be made in health and care organisations developing commercial skills so that the NHS gets a fair deal
3. A range of benefits should be considered without limiting this to financial benefits, although it is important that financial benefits are realised to (at a minimum) cover the costs of collecting and storing data
4. The charging model for access should be tiered to ensure fairness, consistency and inclusivity in research activities.

These conditions represent the beginning of what must be a continued engagement and collaboration between the NHS and the public on data sharing. To ensure the NHS is in the best possible position to do this, and to make sure that value-sharing agreements between NHS data controllers and third parties are fair and transparent, a clear framework that delivers high minimum standards for such data licencing agreements would be of significant value.

## Conclusions

Maximising the UK’s use of NHS data has the potential to provide substantial benefits back to patients and the NHS. Following the successful vaccines and treatments developed through data sharing during the COVID-19 pandemic, the UK is in a strong position to further deliver ground-breaking research and innovation. However, the NHS and Department for Health and Social Care must learn from previous failures by listening to public concerns and actively engaging patients and the public in developing an ecosystem for healthcare data sharing in the UK. It is only by working together that future benefits from NHS data can be realised.

### Author details

<sup>1</sup>Institute of Global Health Innovation, Imperial College London, London, UK

## Key points

- The NHS alone cannot generate the potential breakthroughs and innovations possible through multi-sector participation and collaborations.
- Patients and the NHS will be the ultimate beneficiaries of healthcare data sharing done successfully and at scale in the UK.
- Successful sharing of healthcare data during the COVID-19 pandemic has led to calls for permanent mechanisms to be put in place to use NHS data and datasets to drive innovation to benefit patients and the NHS.
- Although patients and the public are increasingly receptive to the sharing of healthcare data, missteps could undermine public trust.
- There is an opportunity to increase public trust through a focus on building secure data environments with the highest levels of security and privacy.
- Initial deliberation exercises have demonstrated that the public have clear 'red lines' for healthcare data sharing, particularly with the commercial sector, which has led to the formulation of conditions that should be considered when agreements are being made.

## References

- Davis J. People's COVID inquiry: profiteering from the people's health? 2021. <https://blogs.bmj.com/bmj/2021/09/06/peoples-covid-inquiry-profiteering-from-the-peoples-health/> (accessed 3 August 2023)
- Department of Health and Social Care. Data saves lives: reshaping health and social care with data. 2022a. <https://www.gov.uk/government/publications/data-saves-lives-reshaping-health-and-social-care-with-data/data-saves-lives-reshaping-health-and-social-care-with-data> (accessed 3 August 2023)
- Department of Health and Social Care. Secure data environment for NHS health and social care data - policy guidelines. 2022b. <https://www.gov.uk/government/publications/secure-data-environment-policy-guidelines/secure-data-environment-for-nhs-health-and-social-care-data-policy-guidelines> (accessed 3 August 2023)
- Jayanetti C. NHS data grab on hold as millions opt out. 2021. <https://www.theguardian.com/society/2021/aug/22/nhs-data-grab-on-hold-as-millions-opt-out> (accessed 3 August 2023)
- NHS Digital. Control of patient information (COPI) notice. 2022a. <https://digital.nhs.uk/coronavirus/coronavirus-covid-19-response-information-governance-hub/control-of-patient-information-copi-notice> (accessed 3 August 2023)
- NHS Digital. General practice data for planning and research (GDPR). 2022b. <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/general-practice-data-for-planning-and-research> (accessed 3 August 2023)
- NHS England. COVID treatment developed in the NHS saves a million lives. 2021. <https://www.england.nhs.uk/2021/03/covid-treatment-developed-in-the-nhs-saves-a-million-lives/> (accessed 3 August 2023)
- NHS England. Value Sharing Framework for NHS data partnerships. 2023. <https://transform.england.nhs.uk/key-tools-and-info/centre-improving-data-collaboration/value-sharing-framework-for-nhs-data-partnerships/> (accessed 11 August 2023)
- OneLondon. Public deliberation in the use of health and care data. 2022. <https://www.onelondon.online/wp-content/uploads/2022/09/Public-deliberation-in-the-use-of-health-and-care-data.pdf> (accessed 3 August 2023)