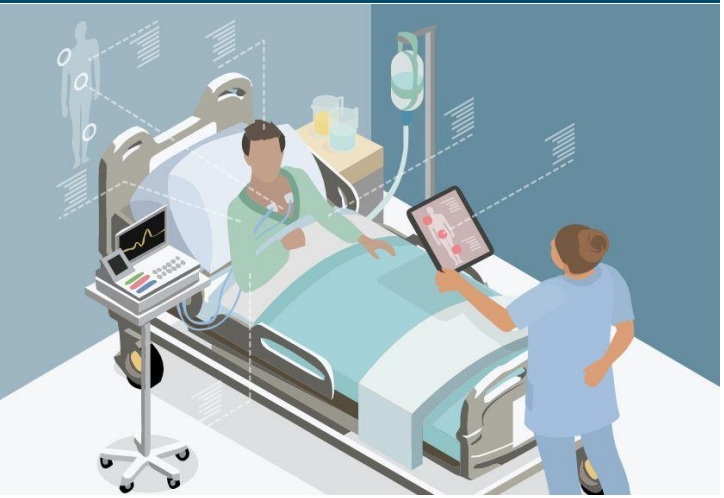
Understanding Patient Data



Patient Data in the Pandemic – why we need to talk about trust

NHS R&D Forum Symposium
9th December 2020

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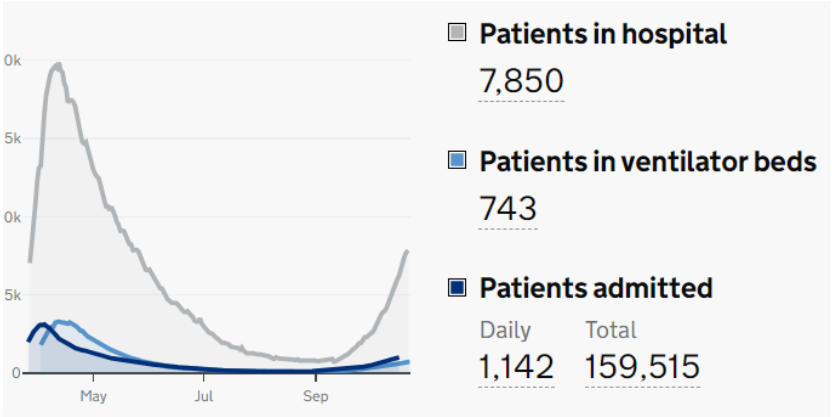
The Context of Covid-19

UK's covid R number drops to between 1.2 and 1.4



Filling in the gaps: smart use of health data lies behind the RECOVERY trial's success

Calls for government to invest in local data sharing to recover from Covid

Disparities in the risk and outcomes of COVID-19

Privacy advocates demand clarity over Covid-19 datastore

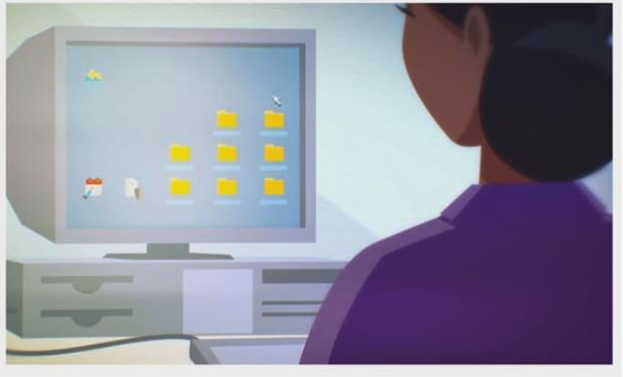
Covid contact-tracing app not sharing data with police

The Context of Covid-19

- 3rd party partnerships set up rapidly in crisis period

  - NHSX Datastore, Test & Trace, Covid-19 app, JoinZoe *etc*

- Control of Patient Information Notices have enhanced data use and sharing
  - currently until end March 2021



Taking a long view

- Policies, regulations, infrastructures, norms and partnerships established now may have a long shelf life
- National Data Strategy aims to build on ‘permissive’ data environment enabled during the pandemic

Counting what counts

- Analyses highlight issues of data quality, completeness and representativeness
  - OpenSAFELY study: 26% health records lacked ethnicity category

White	10,866,411 (62.9)
Mixed	169,697 (1.0)
South Asian	1,022,130 (5.9)
Black	339,909 (2.0)
Other	320,132 (1.9)
Missing	4,560,113 (26.4)

Source: Williamson, E.J., Walker, A.J., Bhaskaran, K. *et al.* Factors associated with COVID-19-related death using OpenSAFELY. *Nature* **584,** 430–436 (2020).

- Data isn't telling the full story of what matters
  - Lived experience, long-Covid, social and financial factors impacting on health…

Public trust and data use

- Recent polling by the National Data Guardian found 70% of people believe data sharing rules should return to what they were before Covid-19[1].

- 'High trust in NHS' mantra cannot be assumed – evidence of low trust in health system by those from minoritized communities[2].

1. https://www.gov.uk/government/news/polling-indicates-growing-public-understanding-about-importance-of-using-health-and-care-data
2. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

Public trust and data use

- Data is suddenly everywhere – a great chance to engage

- But it looks confusing to many – *lies, damned lies and statistics*

- Trust can't be assumed – it is influenced by so much beyond data use in the health system

So what does a **trustworthy** system look like for health data?

Foundations of Fairness research

What does a "fair" partnership between NHS and third parties using NHS-held data looks like?

- Discussions with patient advocacy groups to shape the research
- Three citizens' juries
- Nationally representative survey >2,000 people

1. Equity matters to people

All data partnerships between the NHS & third parties must aim to improve health and care for everyone, across the country.

> If it 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.
>
> Citizens jury participant, Taunton

2. Commercial exploitation is a concern

People do not believe NHS bodies are well set up to negotiate good terms and won't get a fair return for access to data

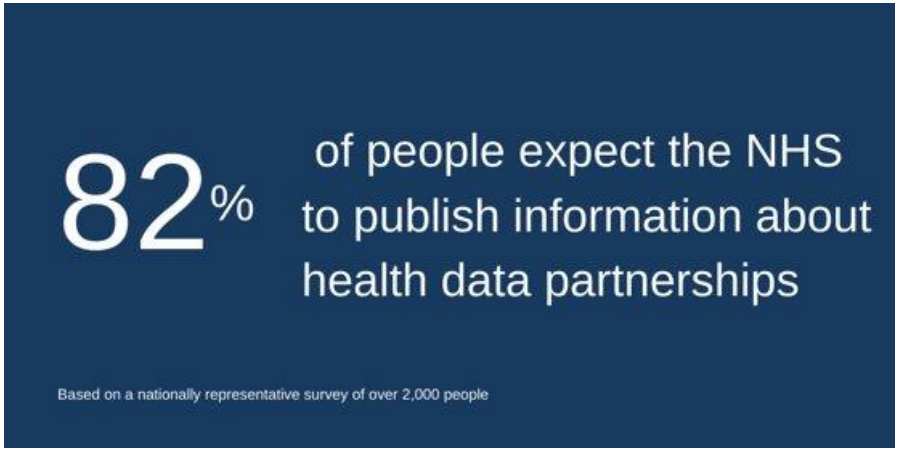
> There's a danger of exploitation of the NHS. We don't think the NHS is very savvy, business-wise so we don't trust it out there with the big bad wolves of business.
>
> Citizens jury participant, Leeds

3. Earning trust requires good governance

High standards of:

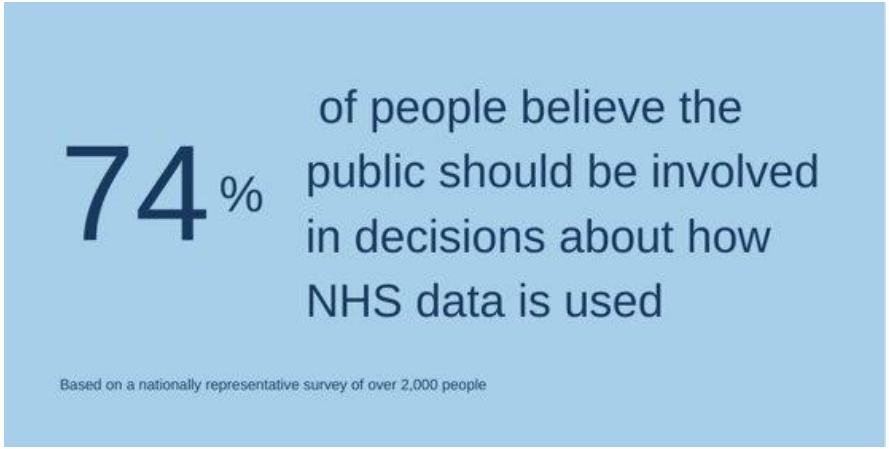
- public accountability;
- robust governance;
- transparency;

if public confidence is to be built (especially when commercial interests are involved)



4. People want a say in decision-making

Data comes from people; they care and have a stake in how it is used.
Different views, values and perspectives need to be voiced.



Three lessons from 2020 for health data

1. **Trust in data use is fragile and needs to be re-earned**

2. **There is a growing appetite for learning about how and why health data can be used as a public good**

3. **Embedding public involvement into decision-making builds trustworthiness and accountability: it's win-win.**

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Thank you

www.understandingpatientdata.org.uk