



Understanding
Patient Data

What's next for health data partnerships?

*APPG on Data Analytics & APPG on Health
symposium
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Understanding Patient Data

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Understanding Patient Data aims to make
the use of patient data more visible,
understandable and trustworthy

The Context of Covid-19

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

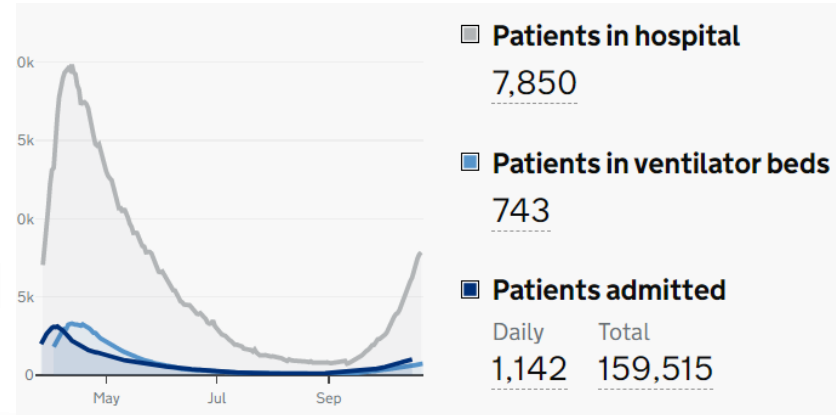
Filling in the gaps: smart use of health data lies behind the RECOVERY trial's success

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

Privacy advocates demand clarity over Covid-19 datastore

Disparities in the risk and outcomes of COVID-19

Covid contact-tracing app not sharing data with police



Data, data everywhere

- Analyses highlight issues of data quality, completeness and representativeness
 - OpenSAFELY study: 26% health records lacked ethnicity category
- Are we counting all that counts?
 - Lived experience, long-Covid, social and financial factors impacting on health

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).

Taking a long view

- 3rd party partnerships set up rapidly in crisis period
 - NHSX Datastore, Test & Trace, Covid-19 app, JoinZoe *etc*
- Policies, regulations, infrastructures, norms and partnerships established now may have a long shelf life
- National Data Strategy aims to build on ‘permissive’ data environment

We sought to answer the question:

What does the public think a “fair”
partnership between NHS and third
parties using NHS-held data looks like?

Foundations of Fairness research

- 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)

82%

of people expect the NHS to publish information about health data partnerships

Based on a nationally representative survey of over 2,000 people

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.

74% of people believe the
public should be involved
in decisions about how
NHS data is used

Based on a nationally representative survey of over 2,000 people

Three lessons from 2020 for health data partnerships

- 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