Public attitudes to the use of patient data

Sept 2018 - Aug 2021

Understanding Patient Data

This deck lists the main research into UK public attitudes towards the use of health and patient data between Sept 2018 and Aug 2021.

Use this deck to find studies relevant to your work. We have included studies involving a qualitative or deliberative element. Let us know if there's something we should add by emailing hello@understandingpatientdata.org.uk.

Remember: there is no such thing as 'the public' and care should be taken when generalising about people's views. People's attitudes are rarely fixed and do not apply equally across different groups, times and contexts.

Data sharing in a pandemic
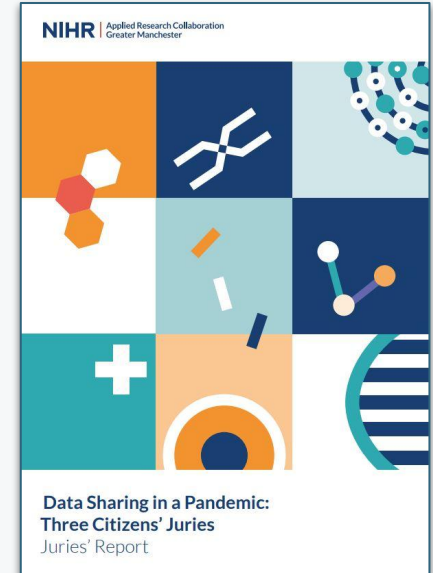## Three citizens' juries

What happened?
- ◦ Three online citizens' juries, with 18 people in each, discussed policy questions about data sharing initiatives introduced during the COVID-19 pandemic.
- ◦ They were primarily funded by the National Institute for Health Research Applied Research Collaboration Greater Manchester, with funds also provided by NHSX and the National Data Guardian.

What were the main issues covered?
- ◦ The Covid-19 Data Store, the OpenSAFELY platform, and the additional information added to the Summary Care Record
- ◦ Levels of support/opposition for each initiative
- ◦ Whether each initiative should continue, and why
- ◦ Who should make decisions about the future of these initiatives

Findings & next steps
- ◦ The findings are available online.

NIHR | Applied Research Collaboration Greater Manchester

Data Sharing in a Pandemic: Three Citizens' Juries
Juries' Report

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Putting good into practice

A public dialogue on making public benefit assessments when using health & care data
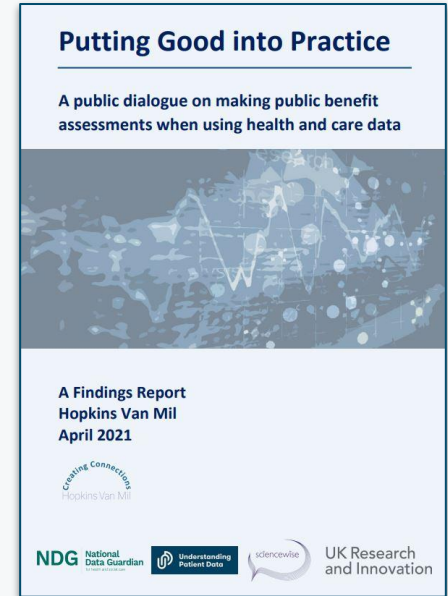
What happened?
- ◦ A public dialogue with more than 100 members of the public, to discuss how to make sure that health and care data is used to benefit people and society.
- ◦ It was co-funded by the National Data Guardian for Health and Social Care, Understanding Patient Data and Sciencewise.

What were the main issues covered?
- ◦ How to define public benefit
- ◦ What needs to be in place to ensure public benefit
- ◦ Scale of benefits and harms
- ◦ Type of data used
- ◦ Importance of equitable distribution of benefits, transparency, public involvement and ongoing assessment of public benefit

Findings & next steps
- ◦ The findings will be used by the National Data Guardian to produce guidance to help organisations making decisions about access to health and care data.

Putting Good into Practice

A public dialogue on making public benefit assessments when using health and care data

A Findings Report
Hopkins Van Mil
April 2021

Creating Connections
Hopkins Van Mil

NDG National Data Guardian   Understanding Patient Data   sciencewise   UK Research and Innovation

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Perceptions of anonymised data use and awareness of the NHS data opt-out
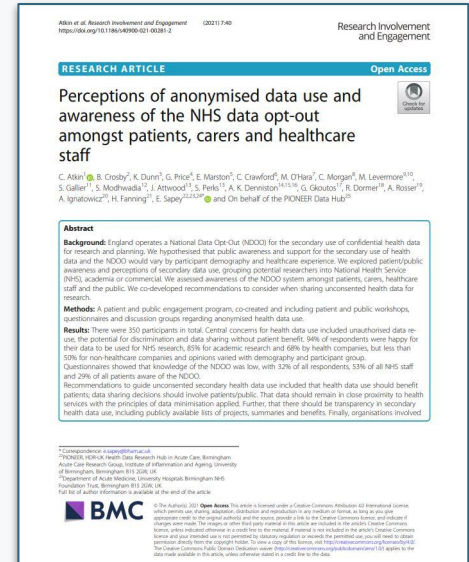
What happened?

- ○ PIONEER data hub ran a series of public engagement exercises in Birmingham.
- ○ It involved patients, public and staff, in total around 350 people, and included workshops, discussion groups and a questionnaire.

What were the main issues covered?

- ○ Use of depersonalised health data for research and planning
- ○ Access to data by different types of organisations: academic, pharma, tech etc.
- ○ Awareness of the National Data Opt-Out
- ○ How the system should be improved, with recommendations co-developed with patients & public

Findings & next steps

- ○ The findings were published in Research Involvement and Engagement.

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Public deliberation in the use of health care

What happened?
- ◦ 100 Londoners came together to debate how the city's health and care system should join up and use data.
- ◦ The Citizen's Summit was run by OneLondon, the Local Health and Care Record Exemplar for the city.

What were the main issues covered?
- ◦ Joining up health and social care data
- ◦ Access and control in health and care data
- ◦ Use of de-personalised data for individual care
- ◦ Use of de-personalised data for health and care planning/ improvement
- ◦ Use of de-personalised data for research and development
- ◦ Governance and oversight

Findings & next steps
- ◦ The findings will be used to develop a single set of policies for London.
- ◦ The materials used to run the deliberation are openly available for anyone to reuse.

Public deliberation in the use **of health and care data**

Delivered by ONE LONDON ipsos The Kings Fund

Supported by LONDON COUNCILS MAYOR OF LONDON NHS

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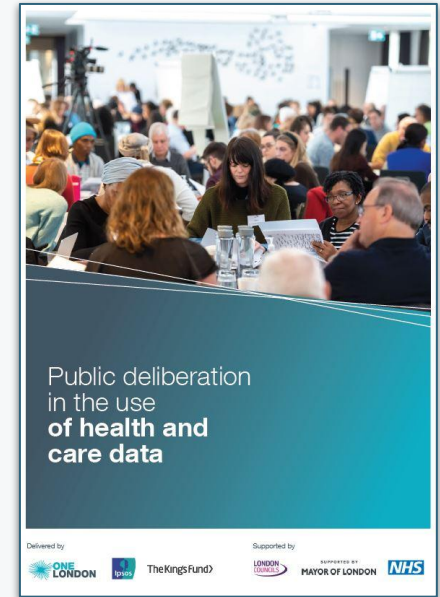
Confidence in a Crisis?
Building public trust in a contact tracing app

What happened?
- ◦ The Ada Lovelace Institute, Traverse, Involve and Bang the Table ran a rapid online discussion with 28 members of the public to explore attitudes to the use of technology to manage Covid-19.
- ◦ The work aimed to answer the question: 'Under what circumstances do citizens think that technological solutions like the Covid-19 contact tracing app are appropriate?'

What were the main issues covered?
- ◦ Transparency and evidence for the use of a Covid-19 app
- ◦ The need for independent review
- ◦ Boundaries for data use, and rights and responsibilities
- ◦ Addressing the needs of vulnerable groups

Findings & next steps
- ◦ The findings were published alongside this blog post in August 2020.
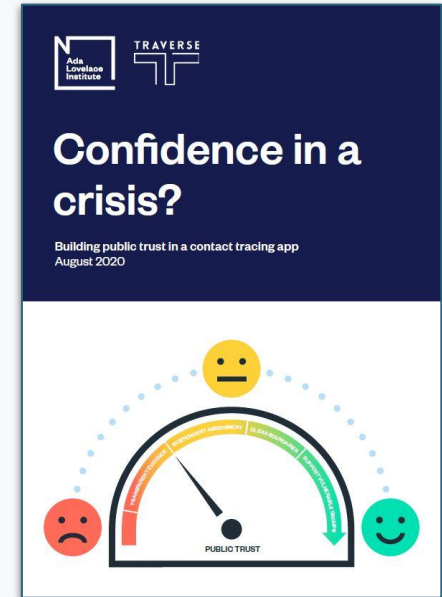
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Foundations of Fairness

Where next for health data partnerships?

What happened?
- ◦ Understanding Patient Data commissioned research to find out what the public thinks about third-party access to NHS data.
- ◦ This mixed-methods, deliberative research included: discussions with patient advocacy groups, 3 citizens' juries, and a survey of over 2,000 people.

What were the main issues covered?
- ◦ Use of NHS patient and operational data by industry, charities and academics
- ◦ Ensuring public benefit
- ◦ Defining fair value for the NHS, including different financial models
- ◦ Public involvement in decisions
- ◦ Governance, transparency and accountability

Findings & next steps
- ◦ We're working to bring the findings to the attention of policy makers and initiatives involving health data partnerships, including the NHSX Centre for Expertise, the Local Health and Care Record Exemplars and the HDR-UK Health Data Hubs.

Foundations of Fairness

Where next for NHS health data partnerships?

March 2020

Understanding Patient Data

Ada Lovelace Institute

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Joined Up Yorkshire and Humber

What happened?
- ◦ The Yorkshire and Humber Local Health and Care Record Exemplar (YHCR) commissioned research to explore people's beliefs about how their health and care records should be used.
- ◦ The research was mixed methods, based on a survey, focus groups, case studies and workshops. Nearly 2,000 people took part.

What were the main issues covered?
- ◦ What is considered an appropriate use of health data?
- ◦ When should data be shared?
- ◦ Levels of trust in different organisations
- ◦ Concerns about data and rules that could help reduce them

Findings & next steps
- ◦ The findings were used to inform the development of the YHCR.
- ◦ The findings include a set of challenges for the YHCR to address to reassure people about how their data will be used.

Yorkshire & Humber Care Record

Joined Up
Yorkshire & Humber

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Commissioned by
Rebecca Nichells
Yorkshire & Humber Care Record
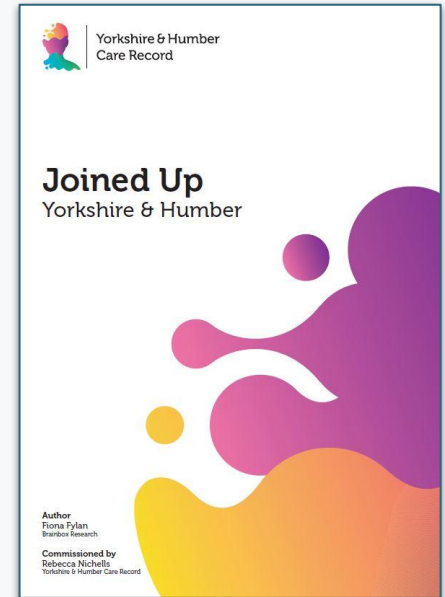
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Giving something back

A systematic review and ethical enquiry into public views on the use of patient data for research

What happened?

- A systematic review of 20 public attitudes studies, to understand public views on the use of patient data for research
- It found that there is widespread willingness to share health records for research for the common good. But this support is conditional, and the public evaluates the trustworthiness of research organisations by assessing their competence in data-handling and motivation for accessing the data.

What were the main issues covered?

- Knowledge and awareness of electronic health records
- Willingness to share data for secondary purposes like research and planning
- Privacy and trust
- De-identification and consent preferences
- Demographic differences (age, education, socioeconomic status and ethnicity)

Findings & next steps

- The findings were published in Wellcome Open Research.

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Public views on sharing anonymised patient-level data where there is a mixed public & private benefit

What happened?
- ◦ The Health Research Authority and University of Sheffield held workshops with patients and members of the public, to understand people's attitudes to the use of 'anonymised' data.
- ◦ The workshops were attended by 55 people, representative of the UK population.

What were the main issues covered?
- ◦ Views on different organisations' use of 'anonymised' data, and how that changed by the end of the workshops
- ◦ Commercial access to data
- ◦ Factors that influence perceptions (e.g. risks, NHS endorsement, regulation)
- ◦ Factors that influence attitudes to commercial involvement

Findings & next steps
- ◦ The findings are available online.

The University Of Sheffield.

NHS Health Research Authority

Public views on sharing anonymised patient-level data where there is a mixed public and private benefit

September 2019

Victoria Chico
Amanda Hunn
Mark Taylor

Supported jointly by:
Health Research Authority
University of Sheffield School of Law
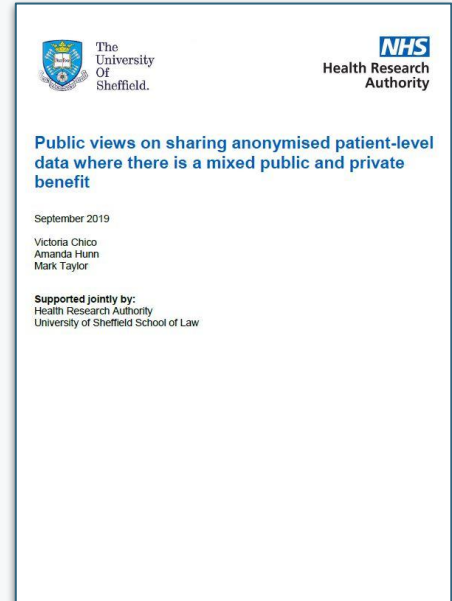
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Patients' and public views and attitudes towards the sharing of health data for research

What happened?
- A narrative review of publications on public views and attitudes towards the use of health data for research purposes.
- This included literature in PubMed (MEDLINE), Embase, Scopus and Google Scholar in April 2019.
- Twenty-seven papers were reviewed, including both qualitative and quantitative studies and systematic reviews.

What were the main issues covered?
- Willingness to share data for research
- Motivations to share data
- Perceived benefits of data sharing
- Perceived risks of data sharing
- Factors affecting willingness to share data (e.g. age, region)
- Conditions for sharing (e.g. value, privacy, transparency)

Findings & next steps
- The findings are available online.

Future data-driven technologies and the implications for use of patient data

What happened?
- ◦ The Academy of Medical Sciences commissioned Ipsos Mori to carry out a series of dialogue workshops with the public, patients and health care professionals on awareness, aspirations, and concerns around uses of patient data in future technologies.

What were the main issues covered?
- ◦ Expectations and awareness of the use of patient data for new technologies
- ◦ The NHS ethos, including public benefit and clinician-patient relationship
- ◦ Response to specific new types of data gathering, analysis and delivery
- ◦ Education of the public of new technologies in healthcare

Findings & next steps
- ◦ The findings from the dialogue workshops are published online, alongside policy reports informed by this research.

Future data-driven technologies and the implications for use of patient data

Dialogue with public, patients and healthcare professionals

Sarah Castell, Louise Robinson, Heather Ashford

November 2018
Report prepared for the Academy of Medical Sciences by Ipsos MORI

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Who benefits and how?

Public expectations of public benefits from data-intensive health research
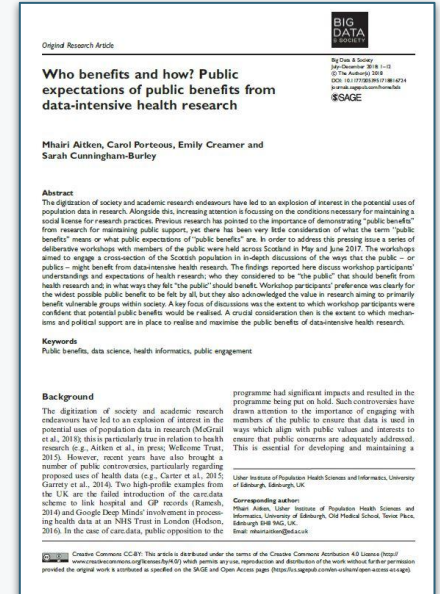
What happened?
- Deliberative workshops were held with Scottish participants from a cross-section of the population to discuss public benefit from research using patient data.
- Around 70 people were involved, from a mixture of regions and demographics.

What were the main issues covered?
- Understanding and expectations of health research
- Who 'the public' are
- Who should benefit from research and how
- Value of research focused on vulnerable groups
- Levels of confidence as to whether potential benefits would be realised

Findings & next steps
- The findings were published in Big Data & Society.

Investigating the extent to which patients should control access to patient records for research

What happened?
- ○ Two citizens' juries of 17 people each were held over three days, to find out what control people want over the use of health records for research.
- ○ Jurors heard from expert witnesses, held discussions amongst themselves, and were opinion-polled.

What were the main issues covered?
- ○ Linking of NHS records
- ○ Patient choice and control
- ○ Who get access to data and why
- ○ How to balance individual privacy and public benefit

Findings & next steps
- ○ The findings are available online.
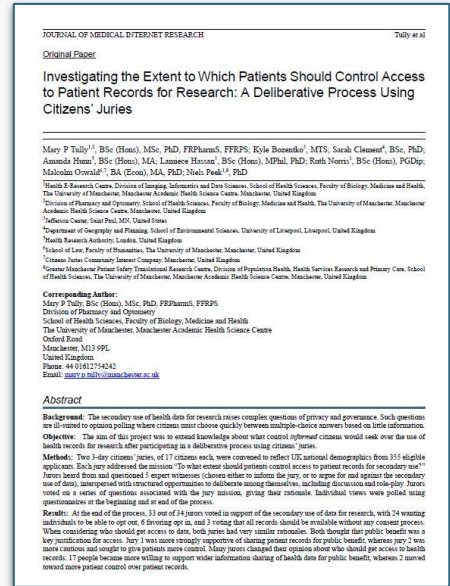
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Think there's something we should add?

Write to us at hello@understandingpatientdata.org.uk

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