Citizens’ Juries on the reuse of health data

Dr Mary Tully
Director of Public Engagement, CHC
University of Manchester
Outline

• Why is public engagement different for big data?
• What happens if you don’t engage
• Citizens’ juries
  • Method
  • Findings
• What we can learn
Public Engagement for Data Use

• Purpose of public engagement for data use:
  • to reflect public values, interests or concerns & ensure public trust through making the data science initiative trustworthy
  • To raise awareness of what the data science initiative is doing and hence to create public trust
Difference for engagement in data use/linkage

• Scale of research “participants”
• Distance between data scientists and data subjects
• Distance between data subjects and “their” data
• Lack of instrumental rationale
• Need for social license
NHS England scraps controversial Care.data programme

Insurance bosses buy medical records of all NHS hospital patients

By Laura Donnelly, Health Correspondent

THE medical records of every NHS hospital patient in the country have been sold to insurance bosses, a major organisation for UK insurers revealed last night.

Chris Sorensen, principal of the Staple Inn Actuarial Society – a trade association for UK insurers – said that details of how the information was sold had been handed.
Google given access to healthcare data of up to 1.6 million patients

Artificial intelligence firm DeepMind provided with patient information as part of agreement with Royal Free NHS trust

A company owned by Google has been given access to the healthcare data of up to 1.6 million patients from three hospitals run by a major London NHS trust.

Google's DeepMind shouldn't suck up our NHS records in secret
Randeep Ramesh

The revelation that 1.6 million patients' records are being used by the company's artificial intelligence arm rings alarm bells
Methods of Engagement

• Informing
  • E.g. Presentations, podcasts, blogs

• Consulting
  • E.g. Panels & user groups, surveys & interviews

• Collaborating
  • E.g. Citizen Science, public as employed researchers, ‘expert patient’ on research team, citizens’ juries
What is a citizens’ jury?

• “deliberative democracy”
• “based on the premise that, given enough time, opportunity, support and resources, members of the public are quite capable of arriving at decisions about complex matters”
• Citizens chosen, given information and questions to answer over 2+ days
• Jefferson Center method
The Citizens' Assembly on Brexit is taking place over two weekends in September, bringing people together and broadly representing the electorate of the United Kingdom. The Citizens' Assembly on Brexit allows members to engage in detailed, reflective and informed discussions about what the UK's post-Brexit relations with the European Union should be. The project is led by the Constitution Unit at UCL, supported by a range of partners and funders listed below.

The members, who were selected to reflect the diversity of the UK's electorate, are...
Who were the citizens?

- 18 per jury, 9 from across North of England
- Broadly representative mix (2011 census for England):
  - Age
  - Gender
  - Ethnicity
  - Educational attainment
  - Geographical spread
- Also sampled on prior health record sharing/privacy view (2015 Wellcome IPSOS MORI survey-1524 adults)
- Recruited through various sources including recruitment website Indeed
- Paid £100 per day + expenses
What did the juries do?

• Over 4 days:
  • 7 expert witnesses
  • Group exercises and deliberations
  • Voted on jury questions
  • Joint conclusions
  • Polling
  • Developed a jury report in situ with facilitator

• Same process, facilitators, experts for both Manchester and York – different jurors
Video of citizens juries

• [https://www.connectedhealthcities.org/get-inv](https://www.connectedhealthcities.org/get-inv)

*Jury members share their thoughts on the use of health data for purposes beyond their direct care.*
Key findings

- Many jurors changed their view to become more supportive in general of sharing information for public benefit, even though they may have become less supportive of specific planned and potential uses considered.
How willing or unwilling would you be to allow your medical records to be used in a medical research study? The information given to researchers would not include your name, date of birth, address or any contact details.

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<tr>
<th>Very willing</th>
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People often change their minds

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Manchester Jury
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York Jury
Which of the following planned uses of NHS data about patients (with identifiers like name and address removed) are acceptable?

[Choose yes, no, or unsure]

A. NHS staff get data from ambulances and hospitals, to do research to help paramedics get better at spotting signs of a stroke.

D. University researchers get data from hospital, GP and local authority records, to plan future demand for A&E services and meet the needs of special groups.

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What can we learn from this?

• Plans that produced explicit public benefit more acceptable than those that improved “efficiency”
• Particularly concerned about:
  • whether improving efficiency would (once again) lead to inequitable distribution or closure of services
  • whether the lack of funding or political will to implement new services would lead to dissatisfaction due to expectations having been falsely raised
Questions deliberated on by juries

• Which of the following potential uses of NHS data about patients (with identifiers like name and address removed) are acceptable?

[Choose yes, no, or unsure]

A. A pharmaceutical company requests general practice data to understand better what prescribing patterns get the best results for patients with diabetes.

D. A health club chain seeks aggregated data about people who have or have not had a heart attack to understand and identify the type of members who are most at risk of a heart attack and monitor them.

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What can we learn from this?

• Potential uses should clearly communicate the possibility for improvements in drugs, treatments, and other healthcare at lower costs for NHS

• Some jurors became more accepting of commercial uses as they understood them better

• Commercial uses that did not produce actual health benefits were unacceptable, regardless of data safeguards

• Commercial gain should be secondary to public benefit
Some conclusions...

- Juries elicit more informed judgement from citizens and can add legitimacy to public authority decision-making
- People will often change their minds
- People tend to be more accepting of health data sharing to both private and public sector after the jury process
- But only where they see a public interest in the data sharing
- People bring their prior understanding e.g. of A&E services to the process
Thank you and any questions?