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Manchester Citizens' Jury on Patient Health Records

Commissioned on behalf of Connected Health Cities (CHC)



Citizens Juries c.i.c. & Jefferson Center

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COMMISSIONED ON BEHALF OF CONNECTED HEALTH CITIES (CHC)

Executive Summary and Overview

General overview of proceedings of Manchester Citizens' Jury on Patient Health Records convened during November 2, 2016 through November 5, 2016 at the Friends Meeting House in Manchester, UK.

Overview of Proceedings

Jury Mission and Goals

A group of 18 jurors representing a broad cross-section of Greater Manchester worked together to respond to a series of questions related to planned uses of data through the Connected Health Cities (CHC) project, potential uses by commercial and other actors, to determine whether or not existing safeguards and controls are sufficient for protecting patient health records, and draft rationale supporting their decisions.

The Citizens Jury was asked to:

- Learn about:
 - 4 uses of anonymised health records planned by Connected Health Cities (CHC)
 - 4 potential uses of anonymised health records by commercial entities
 - Existing safeguards to protect patient privacy
- Vote, regarding each use:
 - Whether or not it is an acceptable use
 - If safeguards are sufficient to allow the use (if not, suggest what else could be done)
- Report regarding the reasons that inform the votes

Jury Questions

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

[Choose yes, no, or unsure]

- a. NHS staff working for Salford Royal Hospital get data from ambulances and hospitals. The purpose is to do research to help paramedics get better at spotting the signs of people who have had a stroke. [YES: 17 // NO: 0 // UNSURE: 1]
- b. University researchers in Leeds get data from hospitals, GPs and social care about frail elderly patients. The purpose is to help GPs identify individual patients needing extra care and follow up. [YES: 9 // NO: 6 // UNSURE: 3]
- c. University researchers in Liverpool get data from hospitals and GPs. The purpose is to

provide information to doctors, nurses and ambulance staff about how to give more appropriate care to people suffering from alcohol-related problems. [YES: 13 // NO: 3 // UNSURE: 2]

- d. University researchers in Newcastle get data from hospital, GP and local authority records. The purpose is to plan future demand for A&E services and meet the needs of special groups (e.g. people with dementia). [YES: 10 // NO: 5 // UNSURE: 3]

Explain the most important factors affecting your choices (up to 300 words).

The strongest, most compelling arguments that highlight the potential benefits of the planned uses of anonymised data proposed by Connected Health Cities have a few important themes.

They have the potential of benefitting the public through improving care and saving lives and are likely to have multiple benefits or lead to a ripple effect where one finding may generate other improvements later. The strongest arguments in support of these planned uses value the principles of the NHS and the treatment of individuals over and above cost savings or financial benefits while maintaining the possibility of achieving cost savings and efficiencies in care delivery eventually. Finally, they focus on investments we can make today with the potential of improving care, research, training, and services well into the future.

These planned uses:

- 1) may lead to improved treatments, services, and care delivery and eventually to better health outcomes and more lives saved (24 votes¹)
- 2) could strengthen research and help identify health trends, areas of concentrated positive or negative health conditions ("hot spots"), and special populations who are affected by different conditions or who have better than average health outcomes (15 votes)

The strongest, most compelling arguments that highlight potential drawbacks of the planned uses of anonymised data by Connected Health Cities have a few important themes.

They highlight the risks and challenges of collecting, maintaining, and analysing data properly throughout the entire course of the research process from start to finish when multiple agencies or organisations handle the data. They emphasise the risks of people's data being accessed inappropriately, for people being identified in the data, and having their confidentiality broken. Additionally, they highlight the challenges of developing and maintaining public support and confidence, especially if people grant consent for their data to be used and there is little or no follow up or implementation after the data have been used or if this leads to negative outcomes and/or stigmatization.

These planned uses:

- 1) may generate findings or research conclusions that are not supported with funding commitments so they may not lead to implementation (13 votes)

¹ Note that each juror had 3 votes, and could attribute up to 2 votes on each reason. So 24 votes suggests that at least 6 of the 18 members of the jury attributed 2 votes to this reason.

- 2) may lead to an increase in geographic, community-based, and social stereotyping and stigmatization as well as inequitable distribution of resources (“postal code lottery”) (11 votes)

2. Overall, are the rules over access to health data proposed by Connected Health Cities sufficient to allow these planned uses?

[Choose only one]

- a. Certainly sufficient [4 votes]
- b. Probably sufficient [14 votes]
- c. Probably insufficient [0 votes]
- d. Certainly insufficient [0 votes]

Explain the most important factors affecting your choice (up to 300 words).

Top rationale for determining that safeguards for protecting data in CHC planned uses:

1. National rules and regulations (such as the Data Protection Act and Common Law) will apply to data collected, managed, and shared (16 votes)
2. Contractors and organisations who use CHC data will be properly vetted and approved before they are able to access and use the data (14 votes)
3. NHS structures for data management and protection are already in place and will be followed for the CHC planned uses (8 votes)
4. Mechanisms such as incidence (breach of confidentiality) and Advisory Groups will be in place which will help ensure integrity (5 votes)
5. There will be a strong emphasis on training staff to use and manage the data properly (5 votes)
6. Data sharing contracts will be utilised and since these can be audited it will be possible to ensure that standards are met and followed (4 votes)

Top rationale for determining that safeguards are insufficient for protecting data in CHC planned uses:

1. It is unclear if public communication and awareness building efforts will be effective and whether or not the general public will agree with these uses of data if they are aware (14 votes)
2. Data quality cannot be adequately guaranteed by the safeguards currently in place (13 votes)

3. If you answered c. or d. to Q2, what else, if anything, would you want done before allowing these planned uses? (up to 300 words)

--- Not Applicable because no member of the jury answered c. or d. ---

4. Which of the following potential uses of NHS data about patients are acceptable?

[Choose yes, no, or unsure]

- a. A pharmaceutical company requests general practice data about patients (with identifiers like name and address removed) including prescriptions, blood glucose measurements, and complications of diabetes patients. The purpose is to understand better what prescribing patterns get the best results for patients. [YES: 13 // NO: 4 // UNSURE: 1]

- b. A large computer software company seeks data about patients from hospital and general practices (with identifiers like name and address removed) including patient symptoms, diagnoses and outcomes. The purpose is to enable its intelligent software to “learn” and so be used to aid future diagnosis of sepsis, a life-threatening condition. [YES: 15 // NO: 1 // UNSURE: 2]
- c. A developer of an app, designed for a wearable device like a fitbit that tracks a person’s activity and measures key health indicators like blood pressure, seeks hospital data about patients (with identifiers like name and address removed). The purpose is to enable them to design the app to suggest safe fitness regimes tailored to each individual’s capability and characteristics (age, weight etc.). [YES: 1 // NO: 16 // UNSURE: 1]
- d. A health club chain seeks aggregated data (i.e. total numbers of patients) comparing levels of exercise, smoking history, alcohol consumption, body mass index, blood pressure for people who have had a heart attack with those who have not had a heart attack. The purpose is to understand and identify the type of club members who are most at risk of a heart attack and monitor them. [YES: 0 // NO: 18 // UNSURE: 0]

Explain the most important factors affecting your choices (up to 300 words)

The strongest, most compelling arguments that highlight the potential benefits of the potential uses of anonymised data proposed in the Citizen’s Jury demonstrate some common characteristics.

The use of data for the potential uses may sometimes be justified if both a private and a public benefit can be adequately demonstrated. In some defined circumstances commercial gain and saving lives could go hand in hand. The kinds of public benefit possibly flowing from private gain might be a proactive approach to streamlining and targeting health services which would reduce costs and improve treatment. Additionally, commercial organisations being more invested in the production of health products or services and commercial organisations behaving in a more ethical manner because they accept and adopt the NHS principles would also be a benefit.

These potential uses:

- 1) may expedite research and development of new drugs, products, and services which could lead to decreased costs and improved services for consumers (17 votes)
- 2) may help identify gaps that exist in health services, technologies, and drugs which could improve care outcomes, improve well-being, and, ultimately, save lives (17 votes)

The strongest, most compelling arguments that highlight potential drawbacks of the potential uses of anonymised data proposed in the Citizen’s Jury demonstrate some common characteristics.

The biggest draw back to the use of data in the potential uses is the fact that commercial gain (financial, reputational) seems to be the priority. Commercial gain is not a sufficient reason for using anonymised patient data. We should expect to see a significant public gain from use of data and the public gains anticipated from the potential uses were not sufficiently clear. The lack of evidence of the effectiveness of the potential uses in terms of benefitting health is also a concern. Stringent regulation of a particular commercial health product/service or endorsement by the NHS based on clear evidence of effectiveness might help allay worries.

These potential uses:

- 1) may not satisfactorily demonstrate that the goal for data usage is public benefit as opposed to simple commercial gain or profit for a company (25 votes)
- 2) do not always satisfy concerns about proper safeguards and data protection practices by private companies and other commercial interests (10 votes)

5. Overall, are the rules over access to health data proposed by Connected Health Cities sufficient to justify the potential uses?

[Choose only one]

- a. Certainly sufficient [1 votes]
- b. Probably sufficient [5 votes]
- c. Probably insufficient [12 votes]
- d. Certainly insufficient [0 votes]

Explain the most important factors affecting your choice (up to 300 words).

Top rationale for determining that safeguards are sufficient for protecting data in potential uses:

1. Analysis of the data will take place at Connected Health Cities (CHC). Organisations and individuals will not be allowed to download the data. This limits potential misuse. (21 votes)
2. The use of aggregated data requires less safeguarding because the risks of identification are so low. (14 votes)

Top rationale for determining that safeguards are insufficient for protecting data in potential uses:

1. Because there is an ethical dimension to the use of data for potential uses which no amount of safeguarding can overcome. (21 votes)
2. There is a lack of evidence for the product or service that the commercial organization expects to provide upon analysing the data. This could cause corresponding damage to the NHS's reputation. (14 votes)
3. We are not convinced about the ability of the particular commercial sector to collect, store and use health data securely because using, collecting and storing sensitive data is not a usual part of their business. (11 votes)

If you answered c. or d. to Q5, what else, if anything, would you want done before allowing these potential uses? (up to 300 words)

- Development, testing, and enforcement of standardised quality and data management guidelines, staff and personnel training, and ongoing monitoring of data safeguarding practices among private and commercial organizations and corporations.
- All prospective companies should be vetted and approved by NHS England and CHC for suitability, proposed use and future benefit in order to gain access to anonymised data.
- Regardless of the extent of safeguards applied to protect confidentiality when sharing and analysing anonymised data for commercial and research purposes, there may be cases where the ethical challenges presented by using data for commercial gain or profit means there is no justifiable use of patient data.