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York 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 York Citizens' Jury on Patient Health Records convened during November 9, 2016 through November 12, 2016 at the National Railway Museum in York, UK.

Overview of Proceedings

Jury Mission and Goals

The jurors 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 will—

- 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: 18 // NO: 0 // UNSURE: 0]

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: 13 // NO: 2 // 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: 16 // NO: 1 // UNSURE: 1]

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: 13 // NO: 4 // UNSURE: 1]

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.

These arguments emphasise how uses of patient data can improve treatments and diagnoses, improve health outcomes, and ultimately improve the quality of life of many patients. They demonstrate the potential for more targeted use of resources and possible cost savings for the NHS and for residents. Additionally, they highlight how the use of patient data can help patients to become more informed about their care and be more involved in their healthcare and medical decisions. They also show how these uses can lead to a broad public benefit, how training and professional development can be improved for medical staff, and the ways that research can support new ideas and treatments in unforeseen ways.

These uses:

1. May lead to better diagnoses of conditions, more effective treatments, and improved health outcomes for patients (26 votes)[1]
2. Might allow NHS to more efficiently target the use of resources for particular conditions or communities which could allow more effective use of funds and resources (14 votes)
3. Could lead to patients being better informed about their healthcare options which would give them more control over their care and choice in medical decisions (11 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.

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[1] Note that each juror had 3 votes, and could attribute up to 2 votes on each reason.

These arguments emphasise the risk of the public being unaware about how and under what circumstances their data will be used and that the public may be unwilling to allow their health data to be used for purposes beyond personal care. They identify the potential for data breaches and risking individuals' confidentiality when non-NHS organisations or groups collect, manage, and share data. Additionally, they highlight that while research may identify new treatments or programmes, the funding to implement or carry out these discoveries is not currently guaranteed which could lead to lack of follow-through and increased public dissatisfaction. Finally, they recognise the human element of medical care and the potential stigmatisation and stereotyping of communities.

These uses:

1. Do not guarantee that general public will be aware of or support the use of their anonymised records for these purposes (12 votes)
2. Create the possibility for data breaches among partner organizations, especially in cases where medical and non-medical (social care) records are linked (12 votes)
3. Do not have guaranteed or committed funding for implementation so might end up being abandoned and wasting resources (7 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 (9 votes)
b. Probably sufficient (7 votes)
c. Probably insufficient (2 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 CHC planned uses:

1. Pre-existing safety guidelines are already in place and will apply to data sharing and management and there are sanctions that will apply if breaches occur (16 votes)
2. Access to CHC data for planned uses will be restricted to organisations or individuals who are vetted and approved and they will only be able to access data justifiably relevant to their research (14 votes)
3. A public awareness campaign will be conducted to inform the public of data use and sharing and hold CHC partners accountable to ensuring people's privacy (8 votes)
4. Data is only available for these purposes via NHS Digital (6 votes)
5. No one organisation or researcher has access to all data, security keys are distributed among various actors, and backups are in place (4 votes)

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

1. Data protection in this system still relies on human honesty to appropriately and accurately access and protect data (18 votes)
2. There will be a need to continuously update data protection protocols in order to maintain security in response to the evolving tactics of hackers and others who want to access the data improperly (11 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)

Additional safeguards will need to be put into place to protect the identities of racial and ethnic minorities in some of these planned uses as unique characteristics of individuals may be more identifiable given the smaller sample sizes (particularly if postcode data is more specific).

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: 14 // NO: 4 // UNSURE: 0]
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: 2 // UNSURE: 1]
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: 13 // UNSURE: 4]
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: 13 // UNSURE: 5]

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

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

These clearly communicate the possibility for improvements in drugs, treatments, and other healthcare as well as how these improvements could lower costs for the NHS. They emphasise how uses of data can generate new technologies and drugs that improve health outcomes for patients. They also highlight the role that data can play in expediting and advancing research which might lead to decreased costs down the line. The strongest arguments in favour of these uses also emphasise how the use of data for commercial purposes may lead to direct benefits to the NHS.

These uses:

1. Could lead to the development of efficient and cost-effective drugs, treatments and diagnosis programmes that might lower costs for NHS and patients (25 votes)
2. Might allow health professionals to recognise conditions earlier and improve the treatment of some conditions (15 votes)
3. Could lead to the development of technologies or approaches for one condition that might be beneficial to others, creating a spill-over effect (12 votes)

The strongest, most compelling arguments that highlight possible drawbacks of the potential uses of anonymised data proposed in the Citizens' Jury demonstrate some common characteristics.

We are deeply concerned about using patient data for reasons which prioritise generating profit for private organisations over public benefit. The lack of regulation of some areas of the private sector raises concerns about the quality of the particular use and the safety of the disclosed health data. If products are not valuable, or the data which underpins them is not reliable, the end result might not be worth the risk of misuse of the health data. If the product is valuable, profit driven pricing might lead to exclusive access. Allowing algorithms to replace health professional/patient interaction could be harmful.

These uses:

1. Tend to be driven primarily by the need to increase or generate profit without ensuring a clear public benefit from the use of people's personal health data (25 votes)
2. Can increase reliance on technology for identifying and diagnosing illness, leading to less clinical expertise for medical professionals and limiting the patient/doctor relationship 12 votes)
3. Could lead to the development of products that are not used by individuals or communities who might need them most due to price or other accessibility obstacles (7 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 (2 votes)
b. Probably sufficient (6 votes)
c. Probably insufficient (8 votes)

    d.   Certainly insufficient (2 votes)

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

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

1. Where there is a potential public benefit that we can all subscribe to, we are content to accept more risk (23 votes)
2. Access to CHC data for planned uses will be restricted to organisations or individuals who are vetted and approved and they will only be able to access data justifiably relevant to their research (14 votes)
3. Data is only available for these purposes via NHS Digital (5 votes)
4. There is an organisational and institutional culture that emphasises safety as a clear priority among CHC staff and partners (5 votes)
5. Pre-existing safety guidelines are already in place and will apply to data sharing and management and there are sanctions that will apply if breaches occur (5 votes)

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

1. Perceived trustworthiness of particular commercial organisations affects willingness to determine sufficiency of safeguards (21 votes)
2. Data protection in this system still relies on human honesty to appropriately and accurately access and protect data (16 votes)
3. It is unclear if data will be secured properly beyond initial 3-year CHC pilot (6 votes)
4. Lack of clear public benefits mean we are less willing to take risks about data security and safeguards (4 votes)
5. If a breach occurs, it is not always possible to recall or reclaim data from those who access it inappropriately (3 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)

- We feel that the safeguards are likely sufficient and appropriate for all potential uses, but that potential uses A and B demonstrate a satisfactory level of public benefit in addition to their likely private commercial benefit. We do not feel this is the case for potential uses C and D and therefore while the safeguards may be sufficient to protect confidentiality and ensure data security in these scenarios, would not want to grant permission for these strictly commercial uses unless they could clearly demonstrate the possibility of public benefit.
- Trustworthiness and security within and among staff and personnel at commercial and private companies is more of a concern and this should mean that more strict safeguards should be applied to data usage and sharing among these groups.
- We would want further assurance that those who allow access to commercial or private organisations would apply very stringent contractual vetting and approval to all those seeking to use and analyse the data.