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Manchester Citizens' Jury on Patient Health Records

Citizens' Jury #2 - Initial Report



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Scenario

Suppose an NHS body wants to create new records from the patient records stored by your general practice and by hospitals that have treated you. They want to use them for purposes other than your direct patient care, like research about better treatments, and for checking that patients are receiving safe and effective health care. These records would be held securely and would not contain your name, address and other identifiers. Despite this, there is a small risk that the records might still identify you, because they would contain lots of detailed information about the care you receive from your GP and from different hospitals. The NHS body would also review requests from other public and private organisations, granting access only where they believed it was lawful and in a good cause.

Question 1 (full): Should the NHS body be allowed to create these records about you and other patients? (select one option)

- A. Yes, but they should publish information about what they plan to do (1 vote)
- B. Yes, but they should publish information about what they plan to do and patients should be able to opt out (10 votes)
- C. Yes, but they should publish information about what they plan to do, and only create records for patients who opt in (5 vote)
- D. No (1 votes)
- E. Other (explain in less than 30 words) (0 votes)

Question 1a: Should the NHS body be allowed to create these records about you and other patients (yes or no)?

YES: 13 votes /// NO: 4 votes

Please provide reasons for this decision (150 words maximum)

Reasons selected by participants who voted "yes" to create and share new patient records

- A. The more data available for analysis, the stronger and more reliable the evidence, results, and outcomes
 - a. Projections and estimates will be more accurate if organisations are able to utilize a single dataset for their analyses (11 votes)
- B. More records included in datasets will allow better monitoring of treatments and prescription drugs, increasing patient safety (10 votes)

- C. Creating and sharing a record created from GP and other records will be more cost-effective for organisations and potentially reduce duplication of records, increasing the quality of data available for analysis (8 votes)

Reasons selected by participants who voted “no” to create and share new patient records

- D. Without a clear understanding of who will be regulating the data and making decisions about access it is difficult to support the creation of new records (4 votes)
- E. Despite safeguards, data and records may not be secure and may be accessed by individuals and/or organisations who don’t have proper permission or legal authority (2 votes)

Question 1b: If such records were created should it be published or allow patient input (yes or no)?

Publish only: 5 votes /// Patient option: 12 votes

Provide reasons for your decision (75 words maximum)

Reasons chosen by those who voted for publication only

- A. Having a more complete data set will be a greater benefit to the population and would serve the greater good (4 votes)
- B. Based on the time and expense for providing an option for patients to participate, this approach will save time and money and improve results (3 votes)

Reasons chosen by those who voted for a patient option (either opt in or opt out)

- A. As part of a democratic process it is important for each person to have autonomy and freedom of choice when it comes to their own data or records (11 votes)
- B. Individuals should have a choice as to whether or not their record is included because it pertains to their own, personal information (9 votes)

Question 1c: Should individuals have the option to opt-in or opt-out?

Opt-in: 5 votes /// Opt-out: 12 votes

Please provide reasons for your decision (75 word maximum)

Reasons for those who selected “opt-in”

- A. This option would require the body or organisation to conduct an information campaign to educate the public (4 votes)
- B. An opt-in option will ensure that individuals whose data are used in analysis make the intentional decision to be included (3 votes)

Reasons for those who selected “opt-out”

- A. More people would be automatically included in the database meaning more data for analysis (12 votes)
- B. The process of adequately providing individuals the chance to “opt-in” would be hugely expensive and time consuming. It would take an enormous effort and may still not properly provide the opportunity to every individual to make an informed decision (10 votes)

Question 2: Which organisations should be granted access to these records? (Select all that apply and provide rationale)

Organisations that should be granted access to these records:

- A. NHS clinicians and administrators who decide which health services should (and should not) be funded (14 votes)
- B. NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately (16 votes)
- C. University staff doing approved research into whether doctors are prescribing medicines appropriately (13 votes)
- D. Staff employed by a pharmaceutical company investigating whether they should begin research into a new drug for a genetic disease for which there is currently no treatment (11 votes)

Reasons these organisations should be granted access to these records:

We have determined that organisations and individuals who should be granted access to these records tend to demonstrate similar characteristics. Typically, these organisations:

- Are conducting analysis that aims to produce a clear public benefit
- Can be trusted to properly secure the data and have adequate safeguards in place in the event of misuse
- Demonstrate a clear connection between their needs (research, analysis, etc.,) and the information contained in the data or records and can not get adequate data from other sources
- Show a clear, relevant connection between the issues they are addressing and the information contained in these records
- Need access to the data to conduct urgent and/or timely analysis

Organisations that should not be granted access to these records:

- A. Staff employed by local authorities planning the future need for residential care homes (8 votes)
- B. Staff employed by a private company being paid by a hospital NHS trust to compare the number of people dying after surgery with other hospitals (7 votes)
- C. Staff employed by an insurance company aiming to set health insurance premiums accurately (3 votes)

Reasons these organisations should not be granted access to these records:

- These organisations do not present a clear, compelling case that the information contained in these records is directly relevant to their analysis
- These organisations can not necessarily be trusted to use the data for direct public benefit as opposed to increasing profits or for personal gain
- These organizations do not always have a trusted track record for securing data and may be more likely to share or sell the data or findings to other sources for financial gain