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Manchester Citizens' Jury on Patient Health Records

Citizens' Jury #1 - 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 (2 votes)
- B. Yes, but they should publish information about what they plan to do and patients should be able to opt out (14 votes)
- C. Yes, but they should publish information about what they plan to do, and only create records for patients who opt in (1 vote)
- D. No (0 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: 17 votes /// NO: 0 votes

Please provide reasons for this decision (150 words maximum)

- A. More detailed and complete data can produce more accurate evidence which can lead to more effective, more cost effective health care through NHS (16 votes – 32%)
 - Including more records and information produces more reliable data
 - Utilizing more data can improve healthcare for a larger share of the population
 - Improved health care delivery would serve NHS in improving the public good and public health
- B. Personalized medicine and treatments can only be discovered and utilized effectively through use of more complete data and records (12 votes – 24%)

- C. The data already exists in our current personal health records and consolidating would make it easier to access and use for research (9 votes – 18%)
- D. Creating new records and sharing records can help identify ineffective drugs and treatments sooner so that they can be removed from use (8 votes – 16%)

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

Publish only: 8 votes /// Patient option: 9 votes

Provide reasons for your decision (75 words maximum)

Reasons chosen by those who voted for publication only

- A. This will ensure more accurate, complete data when all records are included (8 votes)
- B. This will save time and money through a much more streamlined, efficient process (6 votes)

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

- A. People should be able to have control over their own data and records (7 votes)
- B. This will allow greater transparency in how records are used and shared (7 votes)
- C. An option will allow individuals to maintain their confidence in doctors and other healthcare settings where trust is critical (5 votes)

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

Opt-in: 1 vote /// Opt-out: 16 votes

Please provide reasons for your decision (75 word maximum)

- A. More people would be included in the data and this would lead to more accurate results and more representative samples of the population – this could lead to more effective research and better treatments (13 votes)
- B. This could be more time effective and cost effective as it is an easier, more convenient option for individuals (12 votes)
- C. It is easier to include individuals in a data set if they are included as a default option (7 votes)
- D. This option allows those who may simply be undecided (not opposed) to still contribute to research and improvements in healthcare (6 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 (16 votes)
- B. NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately (17 votes)
- C. University staff doing approved research into whether doctors are prescribing medicines appropriately (15 votes)
- D. Staff employed by local authorities planning the future need for residential care homes (10 votes)
- E. 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 (11 votes)
- F. 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 (13 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:

- Make a clear and compelling case for why they need these patient records
- Provide clear justification for how and why the data will be used, why it is relevant to their efforts, with whom it will be shared, and only access records they need to perform their data analysis and have explored other options (such as other data sets)
- Have a track record of protecting data and records and can be trusted to maintain control of data without sharing or have controls in place to safeguard against internal misuse
- Clearly demonstrate that the primary goal for using the data is for public benefit such as improved medical care and treatments, improved public health, or management of public funds

Organisations that should not be granted access to these records:

- A. Staff employed by an insurance company aiming to set health insurance premiums accurately (4 votes)

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

- Do not clearly indicate that the primary use of the data is for public benefit and may use the data solely for private gain or commercial profit
- Can not provide evidence that they will access only the data or records that they need
- May not have a record for protecting data or transparent safeguards for protecting against misuse
- May use the data to exploit or manipulate individuals or populations or may manipulate the data to support their own agenda