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Manchester Citizens' Jury on Reasonable Expectations

*Commissioned by the Office of the National Data Guardian and Connected Health
Cities (CHC)*

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Introduction

This is a general overview of proceedings of Manchester Citizens' Jury on Reasonable Expectations convened from 17 January through to 19 January 2018 at the Friends Meeting House in Manchester, UK.

Overview of Proceedings

Jury Mission and Goals

A group of 17 jurors representing a broad cross-section of the public living in and around Greater Manchester worked together to respond to a series of questions related to when it is reasonable for a patient to expect health information about them to be shared, and when it is reasonable for a patient to expect information to be kept private. Reasons for these judgements were identified, and tested against two case studies.

The Citizens' Jury was asked to:

- Learn about:
 - A variety of scenarios involving a fictional patient - Anita - where information about Anita was shared as part of, or as a result of, providing health and social care to Anita.
- For each scenario:
 - Vote on whether it would be reasonable for Anita to expect the information to be shared
 - Report the reasons that inform the votes
- Where at least 6 jurors voted that information should not be shared, identify what (if anything) could be done to make the information sharing acceptable
- Reflect on the reasons behind the votes to identify criteria: by identifying the types of circumstances when it is reasonable for a patient like Anita to expect information can be shared and when kept private
- Test the criteria using two case studies.

Statement from participants

To our friends, neighbours, health professionals, the public

Through this process we learned from experts, deliberated and learned with and from one another, developed a better understanding of data sharing protocols and guidelines, and carefully considered the potential benefits, risks, and trade-offs about sharing health data in different situations. We hope that regardless of whether you are a health professional, policy-maker, or member of the public like us you are able to more fully understand the concerns we have about the potential challenges we see in sharing our health data, recognise the places where

we've changed our minds about data sharing, and identify the possible benefits that exist from sharing this information. We hope that decisions about how, why, and with whom health information is shared are made with a long-term perspective even when developing short-term solutions.

We recognise an opportunity for everyone to be more informed about this topic – the general public as well as health professionals who have been working in the field for years. We have a deeper appreciation for the complexity of day-to-day decisions in healthcare and policymaking, along with a better understanding for the potential benefits and potential negative impact of sharing health data and hope this report helps in the development of future guidelines.

We want people to know that processes such as citizens' juries exist to inform the public and that sponsoring bodies are open to considering and learning from people like us. We hope others will benefit from our ideas, take the opportunity to review their own records when available, and be better informed about this topic as a result of our work.

Jury Questions and Answers

Anita sees the GP about her eyes

Anita goes to her GP, Dr Jones, because she's been having problems with her eyesight. They agree that Anita should be referred to Dr Crooks, an eye specialist at the local hospital in Anytown. The GP tells Anita to expect an appointment letter from the hospital soon. After Anita leaves, the GP sends the hospital a referral with relevant details about Anita and her symptoms. The next day, a doctor in the hospital's eye department reviews the referral, and marks it as urgent. A hospital administrator reads relevant information in the referral, makes an appointment for Anita with Dr Crooks, and sends Anita a letter with details of the appointment. That evening, Dr Jones meets Anita's husband (who is also her patient) on her way home from work. Anita's husband asks if it's important for Anita to see the hospital consultant very soon. Dr. Jones replies that Anita's eye problem is fairly urgent and that she expects Anita will receive an appointment letter soon.

Q1. Is it reasonable for Anita to expect that:

- a) *Dr Jones might send information about Anita and her eye problems as part of the request to the local hospital?*

Jury answers: [YES: 16 // NO: 1 // UNSURE: 0]

Why?

1. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare (9 votes)
 2. Promotes Informed and accurate decision-making by doctors and care team (9 votes)
 3. Improves timeliness of treatments and interventions, avoiding repetition and unnecessary treatments, procedures (5 votes)
- b) *Before Anita's appointment, a doctor (other than Dr Crooks) might read the referral and the information it contains about Anita, before marking the referral as "urgent"?*

Jury answers: [YES: 15 // NO: 2 // UNSURE: 0]

Why?

1. Improves timeliness of treatments and interventions, avoiding repetition and unnecessary treatments, procedures (8 votes)
 2. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare (7 votes)
 3. Promotes informed and accurate decision-making by doctors and care team (6 votes)
- c) *An administrator working at the local hospital might read the referral information, make an appointment for Anita with Dr Crooks, and write to Anita?*
[YES: 10 // NO: 7 // UNSURE: 0]

Why?

Reasons to expect sharing:

1. Improves timeliness of treatments and interventions, avoiding repetition and unnecessary treatments, procedures (7 votes)
2. Creates best value and most effective use of resources, services for providers, patients, and payers (5 votes)

Reasons to expect privacy:

1. Uncertain whether sharing is relevant, necessary or desirable to improve patient care or to contribute to future research, etc., (6 votes)
2. Cannot determine potential risk of sharing beyond initial transfer of data or future uses of data (3 votes)

- d) *Dr Jones might discuss Anita's case with Anita's husband?*
Jury answers: [YES: 5 // NO: 11 // UNSURE: 1]

Why?

1. Patient may be unaware of giving consent and unclear what their consent applies to beyond the initial use (5 votes)
2. Uncertain whether sharing is relevant, necessary or desirable to improve patient care or to contribute to future research, etc., (4 votes)
3. Trust and dignity of patients and doctor/patient relationships (4 votes)

Anita's social worker pays a visit

The following week, Anita's social worker from the council visits Anita at her flat, as agreed 4 weeks before. Anita wants some adjustments made to her home so that she can get her wheelchair through her door more easily. In Anita's city, all referrals across health and social care can be viewed by the patient's GP, social worker, and other people involved in the patient's care and treatment. So, when reviewing Anita's case before they meet, her social worker is able to see that Anita has been referred to the hospital consultant because of her eye problems, and can discuss it with Anita.

Q2 *Is it reasonable for Anita to expect that:*

Her social worker might see the information about the referral?

Jury answers: [YES: 16 // NO: 1 // UNSURE: 0]

Why?

1. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare (12 votes)
2. Promotes informed and accurate decision-making by doctors and care team (9 votes)
3. Sharing between experts to improve care of patients and to safeguard against inaccuracies and misdiagnoses/improper treatments (6 votes)

Anita sees the consultant

Before Anita's appointment at Anytown Hospital NHS Trust, Dr Crooks reads the referral and other information the hospital holds about Anita. At her appointment, Dr Crooks examines Anita. She has an unusual mark on her face, beside her eye. Dr Crooks asks Anita if he can take a photograph of the mark beside her eye, and takes a scan of Anita's eye and says that he will examine it closely. It would be possible to identify Anita from the photograph, as the mark is so distinctive. Dr Crooks says he will be able to explain what he finds to Anita in two weeks, and asks Anita to make an appointment with the receptionist on the way out.

On examining the scan, Dr Crooks thinks that Anita may have a very rare eye condition. In order to confirm his diagnosis, Dr Crooks presents Anita's case, with the scan and photo to the next multi-disciplinary team meeting with a wide range of doctors and other healthcare professionals involved in the care of eye patients at the hospital. Anita's case, her suspected diagnosis, and what care plan she should receive, are discussed at the meeting (in addition to the cases of the other patients considered by the multi-disciplinary team).

The next day, Dr Crooks travels to London for an annual conference of eye doctors. There he gets talking to Dr Keen, a doctor based in a hospital in another city. Dr Keen explains he is treating a patient with a lesion and he is a bit stumped by the case. It sounds to Dr Crooks that it might be the same rare condition that Anita has.

Dr Crooks and Dr Keen arrange a telephone call the next day to discuss the cases. Dr Crooks sends the eye scan, the photo, and relevant medical details about Anita to Dr Keen before the call. These prove very useful to Dr Keen in diagnosing his patient.

Q3. *Is it reasonable for Anita to expect that:*

- a) *A wide range of health care professionals might discuss Anita's case prior to Anita's follow up appointment with Dr Crooks (as happens at the multi-disciplinary team meeting)?*

[YES: 17 // NO: 0 // UNSURE: 0]

Why?

1. Sharing between experts to improve care of patients and to safeguard against inaccuracies and misdiagnoses/improper treatments (11 votes)
2. Promotes informed and accurate decision-making by doctors and care team (7 votes)

3. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare (6 votes)
- b) *Dr Crooks might send the identifying photograph, the scan and other relevant details about Anita to help the diagnosis of another patient (like Dr Keen's patient)?*

[YES: 12 // NO: 5 // UNSURE: 0]

Why?

1. Benefits future research and increased knowledge of health professionals (7 votes)
2. Demonstrates potential for greater good and public benefit beyond the individual patient (6 votes)
3. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare (3 votes)
4. Sharing between experts to improve care of patients and to safeguard against inaccuracies and misdiagnoses/improper treatments (3 votes)

Paying for Anita's care

In the weeks that follow, Anita receives treatment for her eye condition from Anytown Hospital NHS Trust until she is discharged by Dr Crooks. The discharge is marked on Anita's hospital records, and Dr Crooks sends a discharge letter to Dr Jones, Anita's GP. A specially-trained administrator at the hospital reviews Anita's hospital records, and assigns a set of codes to her records, which classify the kind of treatment she has received, and therefore the amount that the hospital can receive for the treatment. An invoice for Anita's treatment is then sent to Anytown Clinical Commissioning Group, the NHS organisation that is responsible for paying the hospital for the care that it provides to Anita and other patients in its area. The invoice includes Anita's NHS number, a description of the treatment she received and the associated payment codes assigned by the hospital administrator. As this is an unusual case, an administrator at Anytown Clinical Commissioning Group queries the case with the hospital before approving the invoice for payment.

Q4. Is it reasonable for Anita to expect that:

- a) *A trained administrator at the hospital might read Anita's treatment records so payment codes can be assigned?*

[YES: 15 // NO: 2 // UNSURE: 0]

Why?

1. Creates best value and most effective use of resources, services for providers, patients, and payers (15 votes)
 2. Improves timeliness of treatments and interventions, avoiding repetition and unnecessary treatments, procedures (5 votes)
- b) *An administrator at Anytown Clinical Commissioning Group might receive information that could potentially identify Anita and some details of her treatment and uses it to verify the invoice?*

[YES: 10 // NO: 6 // UNSURE: 1]

Why?

Reasons to expect sharing:

1. Creates best value and most effective use of resources, services for providers, patients, and payers (10 votes)
2. Benefits future research and increased knowledge of health professionals (3 votes)

Reasons to expect privacy:

1. Uncertain whether sharing is relevant, necessary or desirable to improve patient care or to contribute to future research, etc., (5 votes)
2. Cannot determine proper conditions for data management, storage, and/or access (such as tiered access, flexible platforms for relevant/necessary access, or other data security issues) (2 votes)

Anita's scan is automatically processed by intelligent software

Anytown Hospital NHS Trust is working with Anytown University to develop intelligent software (i.e. a computer program) that helps to diagnose eye problems using digital eye scans. All digital eye scans produced in Anytown Hospital NHS Trust are automatically processed by the software. In this way, the software "learns" and continually improves by processing thousands of real scans with suspected diagnoses. This enables the software to spot patterns and identify potential problems that an eye specialist might miss. One department in the hospital (not Dr Crooks' department) is already using the intelligent software to assist with diagnosis. Anita's scan, and relevant details about Anita and her eye condition, are automatically fed through to Anytown University for processing by the intelligent software.

Q5 Is it reasonable for Anita to expect that:

- a) *Anita's scan might be sent for processing by Anytown University so the intelligent software learns and improves?*

[YES: 14 // NO: 2 // UNSURE: 1]

Why?

1. Benefits future research and increased knowledge of health professionals (13 votes)
2. Demonstrates potential for greater good and public benefit beyond the individual patient (7 votes)
3. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare (3 votes)
4. Promotes Informed and accurate decision-making by doctors and care team (3 votes)

Q6 If you said "no" to one or more of the questions above, what if anything could have been done by the doctors or others in the scenario to make you say "yes"?

Q1c: For this scenario (a hospital administrator managing and scheduling appointments), those who expressed a reasonable expectation of privacy indicated that they were not convinced that only necessary or relevant information for scheduling appointments was shared. The following constitutes necessary information:

- Contact details (identification and NHS number)
- Appointment Date
- Level of urgency
- Instructions for the patient
- Department of appointment with hospital
- Whether or not there is special considerations (disability, allergies, etc.,) or vulnerability

If this condition is met, all participants feel this scenario would be reasonable to expect sharing of information.

Q1d: For this scenario (a doctor discussing a patient with that patient's husband in a public environment), those who expressed a reasonable expectation of privacy indicated they were not convinced that only relevant or necessary information was shared and that it was not clear whether or not informed consent had been given to share any information. Several possibilities were offered for how to address these concerns:

- Had the discussion taken place within a clinic or formal medical context (3 votes)
- Since the discussion did not include disclosure of any medical information (diagnosis, treatment, etc.,) but rather administrative or practical aspects of a patient (3 votes)
- Had the patient been present during the discussion (4 votes)
- Had consent been expressly given by the patient (6 votes)
- If the spouse/husband had power of attorney or was/is designated carer (8 votes)

Of the conditions above, a number of participants indicated that individual conditions would satisfy their concerns (corresponding to the vote total after each point above). Of the 11 who originally voted for a reasonable expectation of privacy, 8 indicated that the presence of the final three points would satisfy their concerns. A total of 3 participants indicated that there is no circumstance or condition that would alleviate their concerns with this scenario and it is reasonable to expect privacy under any conditions.

Q4b: For this scenario (a Clinical Commissioning Group (CCG) administrator verifying an invoice), those who expressed a reasonable expectation of privacy indicated that they were not convinced that only necessary or relevant information for verifying an invoice was shared. The following constitutes necessary information:

- Coded identifiable information (such as NHS number)
- Treatment and other information in coded format only

If this condition is met, all participants feel this scenario would be reasonable to expect sharing of information in this scenario.

Q7 Considering all of your answers above, can you identify types of circumstances when it is reasonable for patients to expect confidential information to be shared?

Individual patient

1. Provides broader understanding of individual patient and possible care options, leading to improved quality of care, patient safety, and patient welfare
2. Promotes informed and accurate decision-making by doctors and care team

Procedural efficiency and effectiveness

3. Improves timeliness of treatments and interventions, avoiding repetition and unnecessary treatments, procedures
4. Sharing between experts to improve care of patients and to safeguard against inaccuracies and misdiagnoses/improper treatments

Greater good and public benefit

5. Demonstrates potential for greater good and public benefit beyond the individual patient
6. Benefits future research and increased knowledge of health professionals

Administrative, financial, industry benefit

7. Creates best value and most effective use of resources, services for providers, patients, and payers

Q8 Considering all of your answers above, can you identify types of circumstances when it is reasonable for patients to expect confidential information to be kept private?

Relevant, necessary, and desirable

1. Uncertain whether sharing is relevant, necessary or desirable to improve patient care or to contribute to future research, etc.,

Consent and informed consent

2. Patient may be unaware of giving consent and unclear what their consent applies to beyond the initial use
3. Minors & vulnerable people have special considerations for permission and consent

Preventing confirmation bias & prejudice

4. Difficult to assess the potential impact of inaccurate and/or irrelevant data on patient care and confirm need of input from multiple sources

Safeguarding patient information against misuse

5. Trust and dignity of patients and doctor/patient relationships
6. Cannot determine potential risk of sharing beyond initial transfer of data or future uses of data
7. Cannot determine proper conditions for data management, storage, and/or access (such as tiered access, flexible platforms for relevant/necessary access, or other data security issues)

Conditions for sharing data and expectations of privacy/confidentiality

8. May not satisfy ethical requirements of data protection and sharing
9. May not satisfy legal requirements for sharing data and information

Case Studies

After the jury had answered all of the questions above, the citizens' jury was asked to:

- Consider two case studies:
 - Case study A concerning a hospital providing patient data to a company that was developing intelligent software to help spot patients developing acute kidney failure

- Case study B involving the establishment of six regional data hubs across England to provide patient data to a variety of professionals providing health and social care to patients
- For each case study:
 - Identify which of the jury’s criteria apply
 - **CASE STUDY A**

Reasons to expect information to be shared	Tally	Reasons to expect information to be kept private	Tally
1	2,1,0 =3	1	1,2,0=3
2	0,0,1=1	2	3,1,2=6
3	0,0,2=2	3	0,0,0=0
4	1,1,3=5	4	0,0,1=1
5	4,1,0=5	5	0,0,0=0
6	3,2,2=7	6	1,2,0=3
7	2,1,4=7	7	2,2,0=4
8	0,0,0,=0	8	0,2,0=2
		9	3,2,4=9
TOTAL	12,6,12=30	TOTAL	10,11,7 = 28

□ **CASE STUDY B**

Reasons to expect information to be shared	Tally	Reasons to expect information to be kept private	Tally
1	5,4,2 =11	1	3,0,0 =3
2	0,3,0 =3	2	1,0,1=2
3	0,4,3=7	3	2,0,2=4
4	5,5,2=12	4	0,1,1=2
5	1,0,2=3	5	0,0,1=1
6	0,0,4=4	6	3,1,1=5
7	1,0,1=1	7	0,2,1=3
		8	0,1,2=3
		9	0,0,2=2
TOTAL	12,16,14 = 42	TOTAL	9,5,11 =25

- Vote on whether or not it is reasonable for patients to expect information about them to be shared as done in the case study
 [Case study A: YES: 13 // NO: 4 // UNSURE: 0]
 [Case study B: YES: 16 // NO: 0 // UNSURE: 1]
- Consider whether the case studies highlight the need for any changes to the jury’s criteria

No changes to the jury’s criteria (answers to Q7 above) are necessary.