

Citizens' Jury Specification

Jury name	NHS data sharing: what should patients reasonably expect?
Jury questions (i.e. the questions the jury must answer)	<p>Introduction</p> <p>Please read the following scenario about the experiences of Anita. You do not need to know her age or other personal details, except to say that she is a fairly average sort of person. You should assume that the only things that Anita is told about what will happen are those things mentioned in the scenario. The fictional scenario explains how information about Anita is shared as she is provided with care from different people and organisations. Your job is to decide when it is reasonable for someone like Anita to expect the information to be shared and when it should be kept private, and why.</p> <p>Anita sees the GP about her eyes</p> <p>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.</p> <p>Q1. Is it reasonable for Anita to expect that:</p> <p>a) Dr Jones might send information about Anita and her eye problems as part of the request to the local hospital?</p> <ul style="list-style-type: none"> • Yes • No • Don't know <p>Why?</p> <p>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"?</p> <ul style="list-style-type: none"> • Yes • No • Don't know <p>Why?</p> <p>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?</p> <ul style="list-style-type: none"> • Yes • No • Don't know <p>Why?</p> <p>d) Dr Jones might discuss Anita's case with Anita's husband?</p> <ul style="list-style-type: none"> • Yes

- No
 - Don't know
- Why?

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?

- Yes
- No
- Don't know

Why?

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
- No
- Don't know

Why?

- 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
- No
- Don't know

Why?

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
- No
- Don't know

Why?

- 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
- No
- Don't know

Why?

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

	<p>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.</p> <p>Q5 Is it reasonable for Anita to expect that:</p> <p style="padding-left: 40px;">Anita's scan might be sent for processing by Anytown University so the intelligent software learns and improves?</p> <ul style="list-style-type: none"> • Yes • No • Don't know <p>Why?</p> <p>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"?</p> <p>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?</p> <p>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?</p>
<p>Case studies for day 3 of jury to test answers to Q7 and Q8 above</p>	<p>Case study 1</p> <p>A large NHS hospital trust wants to help its doctors and nurses identify in-patients staying on their wards who have signs of developing acute kidney injury.</p> <p>This is a serious condition which normally happens as a complication of having another serious illness and can develop very quickly, over a few hours. It affects more than one in six in-patients and can lead to prolonged hospital stays, admission to critical care units and, in some cases, death.</p> <p>The hospital trust has teamed up with a technology company which thinks it can develop software that will process the results of tests much more quickly than the hospital's systems currently do and get alerts to doctors and nurses on their phones to let them know who is showing signs of being at risk of developing the condition.</p> <p>After some initial work, the company says it is ready to test out its technology and that it needs real medical records to see if the technology is safe and effective. They will use the medical records to test that the software can accurately pick out those patients who are at risk and not miss or misdiagnose cases of acute kidney injury. They will also check if the right information displays on the doctor's or nurse's phone and that it's easy for the care staff to use.</p> <p>The hospital and the company sign an agreement for the company to use the hospital records of 1.6 million patients. This includes all the patients who have been to the hospital over the last five years and the test results from patients who have been sent by their GP to the hospital for blood tests. In the signed agreement, the company has to agree to protect the data and not to use it for</p>

	<p>other reasons. This data is used to test the technology on multiple occasions, until the software is approved and ready to be used.</p> <p>Once the software is tested and operational, the technology company continues to hold this information from the hospital's records in a dedicated database. It receives updates with the records of new patients, and additional information about existing patients, coming to the hospital. When one of these patients is admitted to hospital, the software sends new test results and relevant medical details promptly to the phones of doctors and nurses treating the patient, and alerts them if the patient could be in danger of developing acute kidney infection.</p> <p><i>Is it reasonable for patients to expect that records about them are used in this way?</i></p> <p>Case study 2</p> <p>The NHS in England implements a scheme which will see six regional data hubs created.</p> <p>Across each region, records from GP practices, local authorities' social services departments, local hospitals, mental health services, and care homes are collected in one place and linked together, so that all the health and care information about each individual is connected.</p> <p>Once the system is operational, the records in the regional hub can be accessed by staff in the participating organisations who are providing care to individuals, including doctors, nurses, social workers, care managers, and administrative staff supporting professionals delivering care.</p> <p>Before the system goes live, information about the project is provided to people living in the region via posters in care settings, leaflets, web sites, local newsletters and newspaper adverts. The information leaflets explain that one of the key aims is that accurate information about patients will be available in all the different places an individual might receive care – the GP surgery, a hospital, a care home - enabling staff to understand patient needs, provide the right care, diagnoses, medicines and treatment. The hubs will also use anonymised copies of records for improving care through planning and research.</p> <p>Patients and service users can choose to opt out of having a record in the regional hub, either at the initial stage or at any later stage.</p> <p><i>Is it reasonable for patients to expect that records about them are used in this way?</i></p>
Other jury outputs	Jury report of conclusions Jurors to complete juror questionnaires before and after three-day jury session Word cloud of juror experience
Jury duration	Jury 1: 17-19 January 2018
Venue for juries	F12, F13 (Upper hall), Friends House, 6 Mount Street, Manchester, M2 5NS
Number of jurors	18 jurors (plus 4 substitutes paid to turn up on day 1)
Jury method	As practised by Jefferson Center (based on the Jefferson Center's Citizens' Jury

	Handbook)
Juror eligibility criteria	Resident in UK for 1 year minimum Over 18 years of age Has capacity to consent to participation in jury Has capability to contribute constructively to jury Fluent in English
Juror exclusion criteria ¹	NHS healthcare professional (present or past) Special interest or conflict of interest in jury questions Should not know other jurors (other than by coincidence)
Juror recruitment method	Email previously unsuccessful applicants (who consented to further contact) Indeed job recruitment website
Juror payment	£300 for 3 days including expenses per juror (cheque to be given at end of day 3) £25 for travelling expenses (cash to be paid on day 1) £75 for 4 reserve jurors for saving the 3 diary dates and turning up and staying till lunchtime on day 1 (cash paid on day 1)
Jury sample controls (to represent adult residents of England)	Sex Age Ethnicity Educational attainment Employment status Prior views on privacy of patient records
Target sample - Sex ²	Females: 51%, 8 - 10 jurors Males: 49%, 8 - 10 jurors
Target sample - Age ³	Aged 18-29: 21%, 2 - 5 jurors Aged 30-44: 26%, 3 - 6 jurors Aged 45-59: 25%, 3 - 6 jurors Aged 60+: 28%, 4 - 7 jurors
Target sample – Ethnic group ⁴	White: 85%, 14 - 16 jurors Groups other than White: 15%, 2 - 4 jurors
Target sample - Educational attainment ⁵	Level 1 or no qualifications: 36%, 5 - 8 jurors Level 2, level 3, apprenticeship & other qualifications: 37%, 5 - 8 jurors Level 4 qualifications and above: 27%, 4 - 6 jurors
Target sample – employment status ⁶	Employed or self-employed: 75% of 16-64 year olds, 7-12 jurors
Target sample – Privacy views ⁷	How willing or unwilling would you be to allow your medical records to be used in a medical research study? The information given to researchers would not include your name, date of birth, address or any contact details. a) Very willing b) Fairly willing

¹ These criteria will be judged through a phone call with potential jurors after shortlisting.

² Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

³ Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

⁴ Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

⁵ Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

⁶ Target sample percentages based on UK employment rate, September 2017

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes>

⁷ Target sample percentages based on “Wellcome Trust Monitor Report Wave 3” survey of a representative sample of 1524 UK adults aged over 18 by Ipsos Mori, 2 June to 1 Nov 2015, page 59, available at <https://wellcome.ac.uk/sites/default/files/monitor-wave3-full-wellcome-apr16.pdf>

	<p>c) Fairly unwilling d) Very unwilling e) Don't know</p> <p>a): 43%, 7-8 jurors per jury b): 34%, 5-7 jurors per jury c) + d): 21% (10%+11%), 3 – 4 jurors per jury e): 3%, 0 – 1 jurors per jury</p>
Witnesses	<p>Prof. Katherine Checkland (GP) Dr Jon Fistein (trained barrister, doctor) David Clemmett (retired Director of Social Work) Dr Robert Doran (retired consultant ophthalmologist) Helen McManus (Clinical commissioning group business intelligence manager) Prof. Niels Peek (Professor of Health Informatics)</p>
Controls for bias	<p>Oversight Panel to review jury specification and jury materials. Oversight panel to contain a minimum of three people with no conflict of interest in the jury outcomes (though they may have a special interest in the jury questions). Jury funders (National Data Guardian's Office and University of Manchester) to influence jury questions but are independent from the jury process and outcomes. Expert witnesses briefed to be either impartial information givers or partial persuaders but not both. Jurors work with facilitators during the jury process to construct the report of jury results. Oversight Panel and juries to complete questionnaires to identify signs of bias, and questionnaire results are published. All products from the jury process are published.</p>