

Citizens' jury

Brief for expert witnesses

1. General briefing for all witnesses

You are asked to present to 2 citizens' juries of 18 people. The jury will meet for three days: on 17, 18 and 19 January 2018 in rooms [F12, F13 \(Upper hall\), Friends House, 6 Mount Street, Manchester, M2 5NS](#). They will be charged with answering questions about when it is reasonable for a patient to expect health data about them to be shared and when it is reasonable for a patient to expect it to be kept private.

The two juries will be run by a skilled facilitator, Kyle Bozentko, Director of the [Jefferson Center](#) with support from a second facilitator, Rachel Hassey.

You are asked to attend part of the three-day jury period (see your witness brief in section 3 below for your specific timings).

Each jury will contain a cross-section of adults from in and around Greater Manchester. They will be selected to include a mix of people in terms of age, gender, ethnic group, educational attainment and attitudes to privacy of health records. As the jury will have people with different levels of educational attainment, including people with no educational qualifications and people with university degrees, it is important that you try to explain things as simply as you can, and that you avoid acronyms and do not assume that the audience has any prior knowledge of your subject. When answering questions, please try to make your answers clear and concise, and if you do not know the answer to a question, please say so.

Each witness will engage in discussion with another witness (as described below); the “balancing witness” will aim to ask questions that enable the jury to think about why it might be reasonable for health data about Anita to be shared, and why it might be reasonable for Anita to expect it to be kept private. His role is not to “catch you out”.

You are also asked to answer questions posed by the jurors. Some jurors may lack confidence, so please respond positively to any question you receive.

The questions that the jury is charged with answering are not value-free. The citizens' jury process is set up to encourage the citizens to explore and express their values. Please try to confine what you say to the jury to matters of fact rather than values. You should try to describe the world rather than judge it. Avoid making claims based on facts which are uncertain or disputed. **In particular, avoid suggesting whether or not it is reasonable for Anita to expect information to be shared/kept private as that is the question posed to the jury.** As far as possible, try to choose what you say so as to give a balanced perspective.

If you have any doubts about your role prior to the juries, please speak to Malcolm Oswald. During the jury sessions themselves, you may speak to Malcolm or the lead jury facilitator (Kyle Bozentko).

For witnesses presenting with slides (i.e. Jon Fistein, Kath Checkland and Helen McManus)

For witnesses using slides, try to make your presentation as interesting and as clear as possible.

You will be provided with draft slides. Please amend these in discussion with Malcolm Oswald. The slides and other presentational material will also be reviewed by an oversight panel of independent people who will review it for potential bias. They will be sent for this review just before Christmas.

When drawing up your presentation, please be mindful of:

- Not trying to cover too much material
- Relating what you say explicitly to the jury's charge (see Appendix A);
- Illustrating your points with examples e.g. by saying how it may affect an individual; and
- what the other expert witnesses will be covering (as set out in this briefing).

A digital projector will be available on site but please use any visual aids or other devices you think will help you explain things more clearly. The time allotted for your presentation is described below.

Please complete and send your draft presentation material to Malcolm Oswald by 20 December 2017.

2. Specific briefing for each witness

Specific briefing for witness 1: Dr. Kath Checkland, GP

Required on the afternoon of day 1 of the jury (17 January 2018) between approximately 11.30 and 14.30.

Approximate time for presentation on health records (excluding questions and discussion): 15 minutes

Jon Fistein (the “balancing witness”), and members of the jury will ask you about question 1a-1d, and the text in the Anita scenario that directly precedes it.

Jon’s questions may include, for example:

- Why does the health data about Anita need to be sent from Dr Jones (the GP) to the hospital?
- Is all the referral information relevant?
- Why doesn’t Dr. Crooks (the eye specialist) read and prioritise the referral by the GP? In the NHS, is this “triage” always done by a hospital doctor (but not necessarily the “right doctor”)?
- Could the doctor who reviews the referral also do the appointment letter? Does it need to involve an extra person: the administrator?
- What do you think is Dr. Jones’s aim when she speaks to Anita’s husband?

Specific briefing for “balancing witness” 2: Jon Fistein

Required from approximately 11.30 on day 1 (17 January on the afternoon of day 1 of the jury (17 January 2018) to 5pm on day 2 (18 January)

Approximate presentation time (excluding questions and discussion) on relevant law: 10 minutes

In addition to the brief presentation on law, your role is to ask witnesses relevant questions about the Anita scenario and associated jury questions. The aim is to bring out information to allow the jurors to judge whether it is reasonable for Anita to expect information sharing or information to be kept private. In general, the questions should be about why information flows and whether it might be done differently. Examples of questions are shown against the brief for each witness.

Specific briefing for witness 3: Dave Clemmett, Social Work Director (retired)

Required on the morning of day 2 of the jury (18 January 2018) between approximately 09.30 and 11.15.

Jon Fistein (the “balancing witness”), and members of the jury will ask you about question 2, and the text in the Anita scenario that directly precedes it.

Jon’s questions may include, for example:

- Why might it be useful to the social worker to see Anita’s referral to the eye specialist before the assessment in her flat? Couldn’t the social worker just ask Anita about her health?
- Do social workers generally get to see information in patient records? Does the NHS generally share referrals with social workers?
- Who else at the council will be able to see Anita’s referral?

Specific briefing for witness 4: Rob Doran, consultant ophthalmologist (retired)

Required on day 2 (18 January 2018) between approximately 11 and 1pm

Jon Fistein (the “balancing witness”), and members of the jury will ask you about question 3a and b, and the text in the Anita scenario that directly precedes it.

Jon’s questions may include, for example:

- What role do multi-disciplinary teams play, and why they are arranged?
- Are all of the people in the multi-disciplinary team likely to be relevant to the discussion about Anita?
- How would Dr Keen seeing details from Anita’s patient record help him in diagnosing his own patient? Does this kind of discussion about the patient of a doctor from a different hospital happen often?

Specific briefing for witness 5: Helen McManus, Clinical Commissioning Group Business Intelligence Manager

Required on day 2 (18 January 2018) between approximately 1.30pm and 3.30pm

Please present and explain two slides to the jury:

- One with a chart of the process e.g. showing data coming from the clinical record, being coded, going on to an invoice, sent to the CCG, checked by the CCG, queried back to the hospital trust
- One with an example of an invoice showing the data about Anita that might be sent to the CCG.

Jon Fistein (the “balancing witness”), and members of the jury will then ask you about question 4a and b, and the text in the Anita scenario that directly precedes it. Jon’s questions may include, for example:

- Why is clinical coding required? Why isn’t it done by Dr Crooks?

- Does the clinical coder need to see all the details about Anita and her treatment?
- Why does Anytown Hospital Trust have to invoice another NHS organisation to get paid?
- How does Anytown Hospital Trust know how much to charge Anytown Clinical Commissioning Group?
- Why does Anytown Clinical Commissioning Group have to be told about all the patients who have been treated? Couldn't they trust the hospital to ask for the right money? Or do an audit every now and again?
- Why does Anytown Clinical Commissioning Group need Anita's NHS Number?

Specific briefing for witness 6: Prof. Niels Peek, Professor of Health Informatics and until recently, President of the Society for Artificial Intelligence in Medicine

Required on day 2 (18 January 2018) between approximately 2.30pm and 4.30pm

Jon Fistein (the "balancing witness"), and members of the jury will then ask you about question 5, and the text in the Anita scenario that directly precedes it. Jon's questions may include, for example:

- What is "artificial intelligence software"?
- Can it really diagnose eye conditions using scans of people's retinas? Accurately?
- If the software already works, why does Anita's scan need to be sent to the university?
- Why not ask Anita whether she wants her scan sent to the university?

Appendix A: Jury Questions (note – still subject to minor changes)

NHS data sharing: what should patients reasonably expect?

Introduction

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.

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:

- a) Dr Jones might send information about Anita and her eye problems as part of the request to the local hospital?
 - Yes
 - No
 - Don't knowWhy?
- b) Before Anita's appointment, that a doctor (other than Dr Crooks) might read the referral and the information it contains about Anita, before marking the referral as "urgent"?
 - Yes
 - No
 - Don't knowWhy?
- 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
 - No
 - Don't knowWhy?
- d) Dr Jones might discuss Anita's case with Anita's husband?
 - Yes
 - No
 - Don't knowWhy?

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:

a) That 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) That 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:

a) That 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) That 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 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:

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

- Yes
- No

- Don't know
Why?

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"?

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?

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?