Table of Contents

1. Welcome
2. Event information (including wi-fi login)
3. The Jury Questions
4. How we'll complete the jury task and planned schedule
5. Guidelines for Productive Conversations
6. Small Group Discussions
7. Simulation Exercise
8. Asking Good Questions
9. Preliminary thinking on questions - Worksheet
10. Day 3 Case Studies with Reflection Sheets
11. List of Expert Witnesses
12. Dr. Jon Fistein’s slides (on law)
13. Prof. Katherine Checkland’s slides (on patient records and referrals)
14. Helen McManus’s slides (on payment process)
15. Blank pages for notes

Electronic voting and questionnaires during the jury

We are using electronic surveys to let us collate your views more quickly. When asked, please use a smartphone or tablet to find the relevant survey form. Enter the weblink, fill in the survey and then press the “Done” button.

<table>
<thead>
<tr>
<th>Survey</th>
<th>Weblink to key in</th>
<th>QR code</th>
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<tbody>
<tr>
<td>Start-of-jury questionnaire</td>
<td><a href="https://www.surveymonkey.co.uk/r/NDG01">https://www.surveymonkey.co.uk/r/NDG01</a></td>
<td><img src="qr_code" alt="QR code" /></td>
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<tr>
<td>Daily participant feedback</td>
<td><a href="https://www.surveymonkey.co.uk/r/NDG02">https://www.surveymonkey.co.uk/r/NDG02</a></td>
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<td>Jury question voting with reasons</td>
<td><a href="https://www.surveymonkey.co.uk/r/NDG03">https://www.surveymonkey.co.uk/r/NDG03</a></td>
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<tr>
<td>End-of-jury questionnaire</td>
<td><a href="https://www.surveymonkey.co.uk/r/NDG04">https://www.surveymonkey.co.uk/r/NDG04</a></td>
<td><img src="qr_code" alt="QR code" /></td>
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If you have any difficulty, please ask for help from Mary, Chris or Malcolm.
Citizens’ Jury Event Information (including w-fi)

**Wi-fi network:** Friends-Wifi

**Wi-fi password:** welcome1

**Location:** The Upper Hall, Friends’ House, 6 Mount Street, Manchester, M2 5NS. For a map and directions, see http://www.meetinghousemanchester.co.uk/find-us/

**Time:** 09.30 – 17.15 for three days: Wednesday 17/1/18, Thursday 18/1/18, Friday 19/1/18. Please arrive by 09.15.

**Meals:** Lunch and drinks will be provided each day for all participants. Lunch will generally be from around 12.15 to 1pm, and there will be one tea/coffee break in the morning, and in the afternoon.

**Attire:** Dress comfortably. Please don’t wear clothing with messages or pictures that may be offensive to others.

**Questions:** Please email info@citizensjuries.org or ring Chris Barnes on 07790 634632 with any questions.

**PARTICIPANT CONDUCT**

**Respectful body language.** Please use respectful body language toward everyone. Match your body language with your intent of listening and learning, and be aware that eye rolling, crossing arms, or turning away from someone while they are speaking may send a message of disrespect.

**Respectful verbal language.** Do not use language that disrespects anyone’s religion, culture, racial group, appearance, etc.

**Avoid distracting behaviour.** Please keep all electronic devices including mobile phones turned off/silent during the sessions except where asked to use them.

**Attend all sessions and be attentive.** It is very important that participants hear all the information presented. There will be breaks to give you time to visit the toilet and/or take care of other needs and we ask you to remain in the room when the group is in session. To maintain the legitimacy and fairness of the process, anyone who misses a significant amount of time (i.e. 2 hours or more) will likely not be able to stay for the remainder of the jury process, even if their absence is due to a medical emergency.

**Emergency Contact.** During the jury session, you may have emergency calls directed to you through Chris Barnes. Phone: 07790 634632.
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 that:
   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 know
      Why?
   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”?
      - Yes
      - No
      - Don’t know
      Why?
   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 know
      Why?
   d) Dr Jones might discuss Anita’s case with Anita’s husband?
      - 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 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:
   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?
### How we’ll complete the Jury Task

<table>
<thead>
<tr>
<th>Day #1 &amp; 2</th>
<th>Day #3</th>
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</table>
| ![Image](#) Follow Anita’s treatment journey and consider what is reasonable to expect in multiple scenarios. | ![Image](#) - Identify reasons for judging what is reasonable.  
- Test these reasons with case studies. |

*Medical Record*
**Planned Schedule**
Wednesday 17 January to Friday 19 January, 9:30 am to 5:15 pm

### Wednesday

#### Morning
- Introductions
- Break
- Simulation exercise
- Anita sees the GP, part 1 with Kath Checkland and Jon Fistein

#### Afternoon
- Lunch
- Anita sees the GP, part 2
- Anita sees the GP, part 3
- Break
- Anita sees the GP, part 4
- Wrap-up & Daily Evaluation

### Thursday

#### Morning
- Re-gathering and introduction to the day
- Anita’s social worker pays a visit with Dave Clemmet
- Break
- Anita sees the consultant, part 1 with Rob Doran

#### Afternoon
- Lunch
- Anita sees the consultant, part 2
- Paying for Anita’s care with Helen McManus
- Break
- Anita’s scan is automatically processed by intelligent software with Niels Peek
- Wrap-up & Daily Evaluation

### Friday

#### Morning
- Re-gathering and introduction to day
- Compiling reasons that information might be shared
- Break
- Compiling reasons for privacy

#### Afternoon
- Lunch
- Identifying conditions that might increase acceptability of sharing
- Case study # 1
- Break
- Case study # 2
- Case study summary
- Report Review
- Wrap-up and final surveys
GUIDELINES FOR PRODUCTIVE CONVERSATION

STAY IN LEARNING MODE

Be open to new ideas and information, seeking to hear and understand a wide range of perspectives. Avoid “campaigning” for a specific position.

**Tips/Examples**
- Notice your beginning stance on an issue.
- Notice how your understanding changes as new information becomes available.

MAINTAIN A POSITIVE ATTITUDE

Assume good intent. If the intent of another party is not clear, ask questions and seek to clarify their meaning.

**Tips/Examples**
- “When you spoke, I interpreted what you said as _________. Is that what you intended to communicate?”
- “I’m curious why that’s important to you.”
- Smiling works!

LISTEN WITH CARE

Make a genuine effort to understand the perspectives of others, especially before trying to get them to understand your perspective. Limit interruptions.

**Tips/Examples**
- Bracket your own opinion(s) briefly in order to be ready to listen to others.
- Ask a question before responding, i.e. “what leads you to that conclusion?”
- Check for understanding, i.e. “I think I heard you say _______. Is that accurate?”

KEEP FOCUSED ON THE ISSUE

Pay attention to and focus on the most significant issues. Limit digressions and minimize stories unless they are pertinent to the issues being discussed. Focus on the issues, not on other people.

**Tips/Examples**
- Jot down points you want to make that are not related to the current discussion for later reference.
- Help each other, i.e. “Can you help me understand how this is related to the issue we’re discussing right now?”
<table>
<thead>
<tr>
<th>SPEAK CLEARLY &amp; CONCISELY</th>
<th>SHARE THE AIRTIME</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speak clearly and concisely. Time is precious, so limit discussion on an issue to as short a statement as possible. After you have had an opportunity to speak, wait for others to speak before contributing again.</td>
<td></td>
</tr>
<tr>
<td><strong>Tips/Examples</strong></td>
<td></td>
</tr>
<tr>
<td>• Jotting down what you want to say can help you be clear and concise.</td>
<td></td>
</tr>
<tr>
<td>• Check with and make room for people who may not have spoken as often as you.</td>
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<tr>
<th>PARTICIPATE FULLY</th>
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<tbody>
<tr>
<td>Participate and contribute to the discussion, but don’t dominate it by interrupting others or being long-winded. Don’t stay silent when your views differ from the current discussion—your perspective will enrich the conversation!</td>
</tr>
<tr>
<td><strong>Tips/Examples</strong></td>
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<tr>
<td>• Don’t dismiss your thoughts as unimportant if they differ from what others are saying.</td>
</tr>
<tr>
<td>• Let the group know if there is something that prevents you from participating fully (ex. you can’t see or hear, you’re missing a handout, etc.)</td>
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<tr>
<th>DISAGREE POSITIVELY</th>
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<tr>
<td>Express your views when you disagree, but do so in a positive way. Direct your energy toward the issues, not people. Be a problem-solver by suggesting alternative approaches or solutions.</td>
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<tr>
<td><strong>Tips/Examples</strong></td>
</tr>
<tr>
<td>• “I see that differently” or “I have a different conclusion,” rather than “you are wrong” or “I have a problem with that.”</td>
</tr>
<tr>
<td>• Inquire of others — “What leads you to this conclusion?”</td>
</tr>
<tr>
<td>• Be clear that you are speaking your position—“I understand it this way” rather than “this is the way it is.”</td>
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Small Group Discussions

Choose
(1) Someone to guide the group discussion
(2) Someone to record and report the group’s decisions.

Think: Consider your initial response.

Listen: Take turns sharing (or pass), in one or two sentences, your response. Listen with curiosity for new ideas and perspectives.

Discuss: Share what is important to you and inquire into the positions of others. Make sure that everyone gets the opportunity to speak.

Decide: Summarize the results of your discussion to report back to the large group.
Simulation Exercise

Baxter Walker is a well-known film producer. The popularity of his work has made him an occasional target for media attention and he is sometimes recognized by those he meets on the street. While recognizing that this publicity is an unavoidable result of his professional success, he does what he can to maintain his own privacy and is committed to keeping his family out of the public eye.

Baxter and his wife Abigail took a Sunday afternoon stroll with their one-year-old son, Connor, in a park near their home in a Manchester suburb.

A photographer in the park, unseen by the Walkers, recognized Baxter and took pictures of the family with a long range lens. The next day’s Evening News featured photographs of the family, including a clear picture of Connor seated in his covered pram.

Baxter and Abigail are very unhappy to find their son’s photo in the newspaper and feel their son has a right to privacy and that they should be able to go for a walk in the park without this happening.

Do you think it is reasonable for them expect this, or should the newspaper be allowed to publish the photo?
Asking good questions to get the answers we need

These are useful types of questions:

- **More Information**: What does it cost for...?
- **Clarification**: Can you help me understand...?
- **Verification**: What is the evidence for...?
- **Implications**: What would happen if...
- **Comparison**: What is the difference between...?
- **Outcomes**: What will the results be if...?
- **Trade-offs**: What are the costs and benefits of...?

These are not really questions:

- Don’t you think that...?
- Isn’t it true that...?
- Wouldn’t it be better to...?
- Isn’t the reality...?
- Shouldn’t we be...?

Some tips:

- Jot down questions while a speaker is talking. You may hear the answer later in the presentation or you’ll be ready to more prepared to ask it later.
- Think about what you actually want to know and design your question toward that.
- Avoid long introductory remarks.
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?

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”?

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?

d) Dr Jones might discuss Anita’s case with Anita’s husband?

Please use the space below for making notes or questions about what you hear from the expert witness, Prof Katherine Checkland, and her discussion with Dr Jon Fistein.

If you require more space, please continue overleaf.
Initial thinking on Questions 1a and 1b

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

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?
      • Yes
      • No
      • Don’t know

   Why? Note down your initial thinking below.

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

Q1. Is it reasonable for Anita to expect that:
   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”?
      • Yes
      • No
      • Don’t know

   Why? Note down your initial thinking below.

If you require more space, please continue overleaf.
Initial thinking on Questions 1c and 1d

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

Q1. Is it reasonable for Anita to expect that:
   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 know

   Why? Note down your initial thinking below.

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

Q1. Is it reasonable for Anita to expect that:
   d) Dr Jones might discuss Anita’s case with Anita’s husband?
      • Yes
      • No
      • Don’t know

   Why? Note down your initial thinking below.
Question 2 (Anita’s social worker) – Notes

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?

Please use the space below for making notes or questions about what you hear from the expert witness, Dave Clemmett, and his discussion with Dr Jon Fistein.

If you require more space, please continue overleaf.
Initial thinking on Question 2

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

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? Note down your initial thinking below.
Question 3 (The eye specialist) – Notes

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)?

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)?

Please use the space below for making notes or questions about what you hear from the expert witness, Dr Robert Doran, and his discussion with Dr Jon Fistein.

If you require more space, please continue overleaf.
Initial thinking on Questions 3a and 3b

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

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? Note down your initial thinking below.

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

Q3. Is it reasonable for Anita to expect that:

   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? Note down your initial thinking below.

If you require more space, please continue overleaf.
Question 4 (payment) – Notes

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?

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?

Please use the space below for making notes or questions about what you hear from the expert witness, Helen McManus, and her discussion with Dr Jon Fistein.

If you require more space, please continue overleaf.
Initial thinking on Questions 4a and 4b

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

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? Note down your initial thinking below.**

---

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

Q4. Is it reasonable for Anita to expect that:

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? Note down your initial thinking below.**

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*If you require more space, please continue overleaf.*
Question 5 (intelligent software) – Notes

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.

QS Is it reasonable for Anita to expect that:

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

Please use the space below for making notes or questions about what you hear from the expert witness, Prof. Niels Peek, and his discussion with Dr Jon Fistein.

If you require more space, please continue overleaf.
Initial thinking on Question 5

<table>
<thead>
<tr>
<th>Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.</th>
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</thead>
</table>

Q5. Is it reasonable for Anita to expect that:

- Anita’s scan might be sent for processing by Anytown University so the intelligent software learns and improves?
  - Yes
  - No
  - Don’t know

**Why? Note down your initial thinking below.**
Case Study A (intelligent software) and Reflection Sheet

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. 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.

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.

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.

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. The company has to agree to protect the data and not to use it for other reasons. This data is used to test the technology on multiple occasions, until the software is approved and ready to be used.

Once the software is tested and operational, the technology company continues to hold this information from the hospital’s records. It receives updates with the records of new patients coming to the hospital. If any of the individuals contained in this database is admitted to hospital, any relevant information from this database will be sent to the doctor or nurse about previous treatment, as well as their current test results.

<table>
<thead>
<tr>
<th>Which of the criteria (reasons list) you identified apply in this case?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasons to expect information to be shared</td>
</tr>
</tbody>
</table>

Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

A. Would you judge that it is reasonable for patients to expect information about them to be shared in this way or kept private?
   - Shared
   - Kept private
   - Don’t know

   **Why? Note down your thinking below.**

If you require more space, please continue overleaf.
The NHS in England implements a scheme which will see six regional data hubs created. 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.

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.

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.

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.

<table>
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Please circle your answer (yes/no/don’t know) and then write notes explaining why in the box below.

B. Would you judge that it is reasonable for patients to expect information about them to be shared in this way or kept private?

- Shared
- Kept private
- Don’t know

**Why? Note down your thinking below.**

If you require more space, please continue overleaf.
## List of Expert Witnesses

<table>
<thead>
<tr>
<th>Day</th>
<th>Expert Witness</th>
<th>Slides?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day 1 &amp; 2</td>
<td>Dr. Jon Fistein</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>Trained as a medical doctor and barrister, now Associate Professor in Clinical Informatics at the University of Leeds.</td>
<td></td>
</tr>
<tr>
<td>Day 1 PM</td>
<td>Prof. Katherine Checkland</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>GP and Professor of Primary Care at the University of Manchester.</td>
<td></td>
</tr>
<tr>
<td>Day 2 AM</td>
<td>Mr. Dave Clemmett</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Trained social worker and Assistant Director of Social Services for Salford City Council prior to retirement.</td>
<td></td>
</tr>
<tr>
<td>Day 2</td>
<td>Dr. Robert Doran</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Consultant Ophthalmologist at Wye Valley NHS Trust in Hereford prior to retirement.</td>
<td></td>
</tr>
<tr>
<td>Day 2 PM</td>
<td>Ms Helen McManus</td>
<td>Yes</td>
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<tr>
<td></td>
<td>Business Intelligence Manager, Liverpool Clinical Commissioning Group.</td>
<td></td>
</tr>
<tr>
<td>Day 2 PM</td>
<td>Prof. Niels Peek</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Professor of Health Informatics at the University of Manchester, and President, Society for Artificial Intelligence in Medicine.</td>
<td></td>
</tr>
</tbody>
</table>
What you need to know about the law

- Although people talk about ‘their health records, the model is not one of ‘ownership’
- Legal, ethical and professional frameworks govern how data about people may be used e.g.
- The Data Protection Act (and soon GDPR):
  - requires ‘fair and lawful’ processing of personal data, via the data protection principles e.g. keep records securely, only use the minimum required for a particular purpose.
  - Allows ‘data subjects’ to know what data is held about them
- The common law of confidence and Human Rights Act:
  - Make clear health data about individuals is confidential and should be kept private, but can be shared with appropriate justification
  - One possible justification: when it is reasonable for the patient to expect the information to be shared
- We want to know from you: when is it reasonable?

How staff should use health data

- Members of the care team are expected to access and share relevant patient data to provide safe care
- They should abide by the law, only sharing health data that identifies an individual where the law allows
- All staff get training and sign employment contracts to say they will act lawfully, and treat information confidentially
  - They can be fired if they don’t
- Health and social care professionals (doctors, nurses, social workers etc.) can also be professionally sanctioned if they don’t
- But breaches do happen
Patient records

• **What is a patient record?**
• Why are patient records needed?
• Who makes patient records and where are they held?
• Does the record of a patient held in different places contain the same information?
Hospital records

• Look very similar
• Tend to only contain information about what happens to the patient in hospital, plus information contained in referral letters

Patient records

• What is a patient record?
• Why are patient records needed?
• Who makes patient records and where are they held?
• Does the record of a patient held in different places contain the same information?
Why are patient records needed?

• For day to day patient care
• To help health professionals communicate with one another
• To make sure that health care professionals are providing good care - by allowing oversight and audit
• To collect information for payment
• To help understand patterns of disease and treatment in the population

For day to day patient care
To make sure healthcare professionals are providing good quality care

To collect information for payment
Who makes records?

- Each organisation has their own
- These records can often talk to one another – eg I can look at hospital system to see test results, hospital can see summary of GP record
- GP record is the most complete – it contains almost all information about your care, including letters from hospital etc (exceptions might include information re sexual health, or information that is missed/lost in transfer)
Anita’s records

- What sort of information might be contained in Anita’s GP record, coded and non-coded?
- How might Anita’s records be used in the scenario you have just seen?
  - Before the consultation?
  - During the consultation?
  - After the consultation?
- What might Anita’s referral look like?
- Can the GP assume that the hospital already has information about Anita?
- How will the referral get to the hospital’s eye department?
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Anita’s records

- What sort of information might be contained in Anita’s GP record, coded and non-coded?
- How might Anita’s records be used in the scenario you have just seen?
  - Before the consultation?
  - During the consultation?
  - After the consultation?
- What might Anita’s referral look like?
- Can the GP assume that the hospital already has information about Anita? - no
- How will the referral get to the hospital’s eye department? – by email
Information Flow for paying Hospitals

- Patient sees Dr in Hospital
- Dr records diagnosis and procedures manually on patient notes
- Patient notes shared with coders to be coded on the hospital system
- Hospital sends invoice to the CCG responsible for the patient
- CCG validates invoice against other systems/data**
- Is the CCG’s Patient? Is the care costed correctly?
- CCG pays the hospital or challenges the payment

*Clinical Commissioning Group: Organisations responsible for paying health care providers, ensuring they are meeting standards and improving health. Organised in geographies e.g. Manchester, Liverpool, Birmingham

** Other Systems/datasets can be checked against the invoice data to see which CCG a patient belongs to and/or what diagnosis, procedures happened in the care

NB: GPs are paid via a different system

Example Invoice

- This is an invoice from Anytown Hospital Trust for several patients care
- Invoice total: £210,802.00
- This invoice includes Anitas episode of care
- Backing data is provided with details of the care (next slide)
Invoice Process

- Invoice is sent from hospital with 'backing data' below containing:
  - NHS number
  - Dates of care
  - Registered GP practice
  - Price
  - HRG/Clinical code describing the care

- Backing data is checked by the finance administrator:
  - Against a national system - to check the patient is registered in a GP practice within Anytown Clinical Commissioning group
  - Against the national Tariff – to check the tariff was prices correctly

<table>
<thead>
<tr>
<th>NHS Number</th>
<th>Date</th>
<th>GP Code</th>
<th>Price</th>
<th>HRG Code</th>
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<td>4802</td>
<td>FZ36G</td>
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<td>N82097</td>
<td>508</td>
<td>HC32K</td>
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<td>1243526171</td>
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<td>6690</td>
<td>HE11A</td>
<td>Hip Fracture with Multiple Interventions, with CC Score 8+, NHS number OK on OE. Price OK on LT.</td>
</tr>
</tbody>
</table>

Invoice Credit - example

<table>
<thead>
<tr>
<th>SL #</th>
<th>NCA QT2 2017/18 - DATA TO FOLLOW DICE SAFE HAVEN ADDRESS IS CONFIRMED - END TO</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>NCA QT2 2017/18 - DATA TO FOLLOW DICE SAFE HAVEN ADDRESS IS CONFIRMED - END TO</td>
</tr>
</tbody>
</table>

Inv number 368151 refers
Why?

The main reason is to:-
A) save money and
B) because of data quality

Data Quality, some examples:-
- Hospitals may not have assigned the correct patient to a CCG within their hospital system
- A general practices’ patients could be consistently coded to the incorrect CCG
- Hospital may not have assigned an NHS number
- There could be duplicate records in the invoice for the same patient
- The incorrect tariff/cost may have been assigned by the hospital finance department