

# Office for the National Data Guardian & Connected Health Cities Reasonable Expectations Report

A report of a citizens' jury designed to explore when it is reasonable for patients to expect patient data to be shared

April 2018



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# Introduction

On 17 January 2018, 18 people gathered at Friends' Meeting House in Manchester and began a three-day "[citizens' jury](#)". The task for these citizens was to tackle a set of [jury questions](#). The questions were designed to test a number of scenarios where patient data could be shared. In each case, the participants were asked to judge whether it was reasonable for a patient to expect the information to be shared, or whether it was reasonable for the patient to expect privacy.

Over the three days, the citizens heard from, and asked questions of, [expert witnesses](#), and worked in groups on the jury questions. They reached conclusions together, and were polled on their individual views. Together they identified reasons to expect information to be shared and reasons to expect privacy. Those reasons (effectively criteria) were then tested against two case studies.

This report explains [why](#) the jury was carried out, how it was [designed](#), what the [jurors did](#), and the jury results.

Further information about the jury can be found on the [Connected Health Cities](#) website.

## Why the citizens' jury was carried out

The National Data Guardian, Dame Fiona Caldicott, and her office have responsibility to provide guidance to the NHS and adult social care services, the public and other stakeholders about when it is acceptable to share information about patients and service users. One potential test of what is acceptable is whether a patient would reasonably expect confidential information to be shared. The Office of the National Data Guardian and Connected Health Cities want to better understand when a patient would expect information sharing, and when they would expect information to be kept private. A citizens' jury was chosen because the approach gives a cross-section of the public several days to understand and reach conclusions about a complicated public policy such as this. Over the three day jury, a variety of different information sharing scenarios could be tested on the public.

## Jury design

The citizens' jury was planned, designed and refined over a period of six months. There are many aspects to the jury design including:

- the [jury questions](#);
- the jury demographics and [recruitment](#) approach;
- the brief and selection of individuals to act as [expert witnesses](#);
- the brief and selection of individuals to act as members of the [oversight panel](#);
- the [programme of jury activities](#) across the three days; and
- the design of the [questionnaires](#) completed at the start and end of the jury.

The design documentation is available at the [Connected Health Cities](#) website.

Bias, both conscious and unconscious, is an important criticism of citizens' juries.[1] For example, it is very difficult to know what constitutes "impartial information" or balanced argument, and almost every design choice, even down to a bullet point on a presenter's slide, could be challenged on grounds that it might manipulate the citizens' jury towards one outcome or another.

Bias can be monitored and minimised but not eliminated. To monitor and minimise bias on this project, an [oversight panel](#) was appointed to review the jury design and materials, and report potential bias. The end of jury questionnaires also asked the jurors about bias. In these, 16 jurors reported no bias, and one juror thought that “perhaps occasionally” there was bias towards information sharing.

Other design controls used to monitor and minimise bias included:

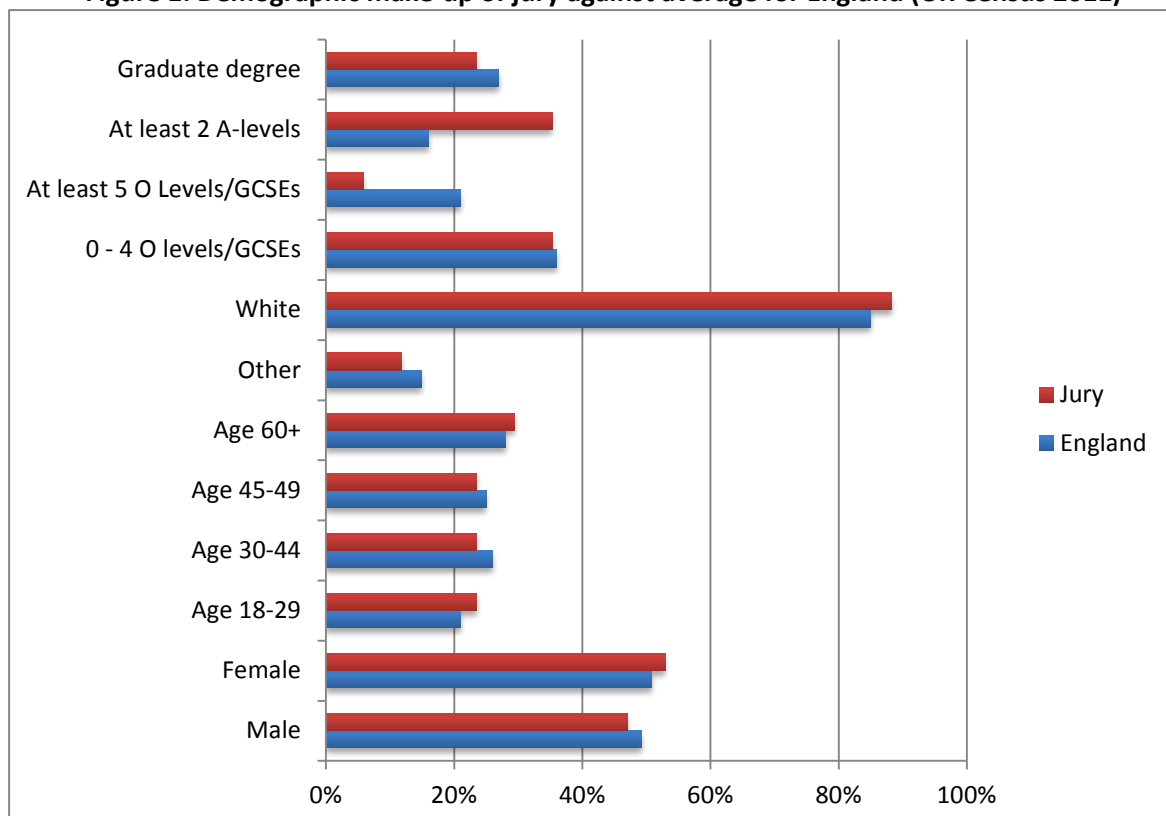
- The [jury funders](#) were involved in setting the jury questions but were independent from the jury process and outcomes;
- The jury worked with facilitators to construct their own [report of their findings](#); and
- The detailed jury design and results documentation being published.

## Jury recruitment

### Jury recruitment

In total, 481 people applied to be a juror by completing an on-line survey. Shortlisted candidates had a brief telephone interview so that any ineligible candidates (e.g. healthcare professionals) could be identified and excluded. Eighteen people were recruited. One member of the jury came from Leeds; the other jurors came from in and around Manchester. The sample chosen was controlled for gender, age range, ethnicity (in terms of white/other), and educational attainment (see chart below). The percentage mix of these control categories matched closely the demographics of people in England (as recorded in the UK Census 2011). 17 people completed the three-day event (one leaving after day 1 for personal reasons). The table below shows the demographics of those 17 people.

**Figure 1: Demographic make-up of jury against average for England (UK Census 2011)**



Applicants also answered a question taken from a national survey to test their prior views on balancing privacy with health record sharing.[1, p. 59] The range of views in the jury matched very closely those reported in the national survey.

Of the 17 jurors, 5 people were found through the Indeed jobs website, 10 through an email sent to those on the database of market research company Research Opinions, and two through an email sent by Citizens Juries CIC to people who had applied unsuccessfully to a previous jury. Each juror was paid £300 for three days plus a £25 expense allowance. Two “reserve jurors” came until lunch on day 1 and were paid £75 each (and one reserve took the place of a person who did not attend on day 1).

## The jury process and jury report

The 3-day jury programme:

- Began with a pre-jury questionnaire at the start of day 1;
- Was facilitated by Kyle Bozentko, Executive Director of the Jefferson Center, and Rachel Hassey, NHS Management Trainee;
- Included evidence presented by 6 [expert witnesses](#), who answered questioned posed by the jurors and by a “balancing witness”, Dr Jon Fistein, whose role was to enable the jury to hear reasons why it might be reasonable to expect data sharing and to expect privacy;
- Engaged jurors in group exercises and deliberation;
- Ended with an end-of-jury questionnaire the end of day 3.

On day three of the jury proceedings, every member of the jury voted on the [jury questions](#). The jury together identified a set of potential reasons to expect privacy and reasons to expect data sharing, and then each juror selected up to two of these reasons to explain their answer to each jury question. Where six people voted for the same reason, the reason appears in the jurors’ report (and the “Jury Questions and Answers” section below). Minority views chosen by fewer than six people were recorded and are available at the [Connected Health Cities](#) website.

The set of potential reasons was tested against two case studies. Kyle Bozentko, the facilitator of the jury from the [Jefferson Center](#), then constructed the jury’s report from their votes and reasons. The jurors were led page-by-page through the jury’s report, which was displayed on a large projector screen, to gain the jurors’ acceptance that it fairly represented their views. The next section “Jury Questions and Answers” is taken directly from the jurors’ report.

## Jury Questions and Answers

The questions tackled and how the jurors voted are summarised below. “Before and after” results are shown where questions were also part of the pre-jury questionnaire. The full set of jury questions and results, including reasons which were supported by fewer than 6 votes (excluded below), are available at the [Connected Health Cities](#) website.

### 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?**

Reasons to expect sharing:

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?**

Reasons to expect sharing:

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?**

Jury answers: [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?**

Reasons to expect privacy:

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)?**

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

**Why?**

Reasons to expect sharing:

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)?**

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

**Why?**

Reasons to expect sharing:

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?**



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

**Why?**

Reasons to expect sharing:

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?***

Jury answers: [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?***

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

**Why?**

Reasons to expect sharing

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”?**

Reasons are shown below where at least 6 people said “no”.

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

**Start and end of jury questionnaire results**

18 jury members and two reserves completed the start-of-jury questionnaire at the beginning of day 1, and the 17 members of the jury completed the end-of-jury questionnaire at the end of day 3. This section shows results for the 17 jurors who completed both questionnaires. The questionnaire design and the full results are available at the [Connected Health Cities](#) website.

One question, taken from a 2016 Ipsos MORI poll of the public commissioned by the Wellcome Trust [2], was asked in order to select a broadly representative sample of jury members in terms of balancing information sharing for public benefit and protecting privacy. This question was asked when jurors applied to participate in the jury, and then again in the end-of-jury questionnaire so as to gauge whether, and if so how, their views had changed by the end of the jury process. The question, and the answers given by the 17 jury members, are shown in the table below.

Ipsos MORI survey question: *“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.”*

**Figure 5: Summary of juror answers**

How willing or unwilling?	Pre-jury questionnaire	End-of-jury questionnaire
Very willing	6	11
Fairly willing	7	4
Don't know	0	0
Fairly unwilling	2	1
Very unwilling	2	1

In the start-of-jury questionnaire, the members of the jury were asked individually most of the [jury questions](#) that they were to go on and tackle together over the three following days. The table below summarises how the answers they gave in the questionnaire to questions 1 to 5 compares to their votes on day three. The figures separated by commas are those that said “yes”, “no” and “don’t know” respectively.

Question	Brief jury question description	Start of jury (day 1): Reasonable to expect sharing? (yes, no, don't know)	End of jury (day 3): Reasonable to expect sharing? (yes, no, don't know)
Q1a	GP to hospital referral data	17,0,0	16,1,0
Q1b	Access by hospital doctor to prioritise referral	16,1,0	15,2,0
Q1c	Hospital administrator organising patient's out-patient appointment	12,2,2	10,7,0
Q1d	GP discussion with patient's husband	5,11,1	5,11,1
Q2	Social worker accessing GP to hospital referral	13,2,2	16,1,0
Q3a	Multi-disciplinary team discussing patient's case	13,3,1	17,0,0
Q3b	Patient data sent to assist diagnosis of another patient	11,4,2	12,5,0

Q4a	Hospital administrator coding patient episode	11,2,4	15,2,0
Q4b	Commissioner administrator validating invoice for patient	7,7,3	11,6,0
Q5	Hospital sending patient data to enable university to develop AI software	11,2,4	14,2,1

Note that all but three of the jurors changed their minds on at least three of the ten jury questions above over the course of the three-day event. Even for Q1d, where the total “before and after” results are the same, five people gave a different answer on day 1 than on day 3.

# Appendix 1: further information about the jury

## The Citizens' Jury Method

Like much public policy, balancing privacy and information sharing is a complex area with a lot of information and many arguments to consider. Surveys and focus groups provide useful information about what the public thinks, but they are not mechanisms to inform people. A citizens' jury can tell policymakers what members of the public think once they become more informed about a policy problem. In a citizens' jury, a broadly representative sample of citizens are selected to come together for a period of days, hear expert evidence, deliberate together, and reach conclusions about questions they have been set.

They are a form of “deliberative democracy”, based on the idea that individuals from different backgrounds and with no special prior knowledge or expertise can come together and tackle a public policy question. A citizens' jury is a particularly relevant method for informing public bodies making value judgements. Some organisations have used citizens' juries to *make* policy decisions, even though members of juries are not elected and cannot be made accountable for decisions. For example, Melbourne City Council has appointed a citizens' jury to determine how to allocate its A\$5 billion budget, and the council is implementing virtually all of the jury's recommendations.[3] A [Citizens' Council in Ireland](#) is currently considering many important questions. Its first topic was whether to change the Irish Constitution on abortion, where its advice to a parliamentary committee has led to a national referendum.

## Expert witnesses

Six expert witnesses were chosen to provide relevant information to the members of the jury to enable them to answer the jury questions. Each witness answered questions posed by the jurors. Some presented slides (see table below). One witness (Dr. Jon Fistein) was asked to be a “balancing witness”, engaging in dialogue with the other witnesses so as to enable the jury to consider both reasons for a patient to expect information to be sharing and reasons to expect privacy.

The expert witnesses were issued with a brief prior to preparing their presentations. It is published at the [Connected Health Cities](#) website.

The following table was provided (in ring binders) to jurors about each witness.

Day	Expert Witness		Slides?
Day 1 & 2	Dr Jon Fistein	Trained as a medical doctor and barrister, now Associate Professor in Clinical Informatics at the University of Leeds.	Yes
Day 1 PM	Prof. Katherine Checkland	GP and Professor of Primary Care at the University of Manchester.	Yes
Day 2 AM	Mr. Dave Clemmett	Trained social worker and Assistant Director of Social Services for Salford City Council prior to retirement.	No
Day 2	Dr. Robert Doran	Consultant Ophthalmologist at Wye Valley NHS Trust in Hereford prior to retirement.	No
Day 2 PM	Ms. Helen McManus	Business Intelligence Manager, Liverpool Clinical Commissioning Group.	Yes

Day 2 PM	Prof. Niels Peek	Professor of Health Informatics at the University of Manchester, and President, Society for Artificial Intelligence in Medicine.	No
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## The oversight panel

The oversight panel was appointed to help monitor and minimise bias. The panel reviewed the citizens’ jury questions and design, and much of the detailed jury documentation, including the jury questionnaires and the slides from the presentations by the impartial expert witnesses, resulting in some changes to these materials. The oversight panel members, chosen for their knowledge of the topic and lack of conflict of interest in any particular jury outcome, were:

- Mr. Chris Carrigan, Chair of NHS Digital’s Independent Group Advising on the Release of Data (IGARD)
- Ms. Amanda Hunn, Joint Head of Policy at the Health Research Authority;
- Mr. Jacob Lant, Head of Policy and Public Affairs at Healthwatch England.

The brief for the oversight panel is available at the [Connected Health Cities](#) website. Each member of the panel completed a questionnaire about bias, which are published at the same site. Two of the three panel members were “completely satisfied” that the jury was designed to minimise bias. The third panel member did not complete the survey.

## Citizens’ jury project team and funders

The citizens’ jury and survey were jointly funded by the Office of the National Data Guardian (NDG) and Connected Health Cities (CHC). The lead commissioners of the work for these organizations were Jenny Westaway, Head of the Office of the NDG, and Dr. Mary Tully, Director of Public Engagement for CHC.

The project manager of the citizens’ jury was Dr. Malcolm Oswald, Director of Citizens Juries CIC and an Honorary Research Fellow in Law at The University of Manchester. Chris Barnes and Amanda Stevens from Citizens Juries CIC recruited and supported the jurors, and jury process. The lead jury facilitator was Kyle Bozentko, Executive Director of the [Jefferson Center](#) in the USA. Kyle, with support from his colleague Larry Pennings, worked closely with Malcolm to design the jury, and in particular the three-day jury activity programme. Kyle then facilitated the jury with Rachel Hassey, an NHS Management Trainee.

## The citizens’ jury programme of activities

The activities were designed primarily by the Jefferson Center in line with their citizens’ jury method [4] and managed by the two facilitators. The jury ran Wednesday 17 January to Friday 19 January, 9:30 am to 5:00 pm. There was lunch, plus a tea/coffee break in the morning and afternoon.

### 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 Clemmett
- 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



## Appendix 2: Bibliography

1. Armour, A., *The citizens' jury model of public participation: a critical evaluation*, in *Fairness and competence in citizen participation*. 1995, Springer. p.175-187.
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