Connected Health Cities: 2 Citizens' juries

Brief for expert witnesses

DRAFT

1. General briefing for all witnesses

You are asked to present to 2 citizens' juries of 18 people. Each jury will meet for four days. They will be charged with answering questions about how Connected Health Cities should protect health information and how such information should be shared.

The first jury will meet on 2, 3, 4, and 5 November 2016 in rooms F12, F13 (Upper hall), Friends House, 6 Mount Street, Manchester, M2 5NS. The second jury will meet on 9, 10, 11, and 12 November 2016 in Mallard Suite, National Railway Museum, Leeman Road, York YO26 4XJ. The two juries will be run by a skilled facilitator, Kyle Bozentko, Director of the Jefferson Center.

You will be asked to attend for either a half-day or full-day during each four-day jury period (see your witness brief below for your specific timings) and provide the jurors with the same presentation on both occasions.

Each jury will contain a cross section of adults. The people on the first jury will live in Manchester and North West England, and people on the second jury will live in Yorkshire and North East England. 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. Try to make your presentation as interesting and as clear as possible. Finish with a slide summarising your main points.

When drawing up your presentation, please be mindful of:

- Not trying to cover too much material, and repeat the main messages (e.g. say what you are going to say, say it, then say what you said)
- 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 each presentation is described below.

In addition to the presentation, some witnesses will engage in discussion with another witness (as described below). You are also asked to answer questions posed by the jurors. You should expect about as much time to be spent on answering questions from the jurors as on your presentation. If you wish, you can tell the jurors that you welcome questions during your presentation, but if you do, be careful to cover all your material in the time available. Some jurors may lack confidence, so...
please respond positively to any question you receive. You are recommended to take questions at the end; if you do take questions as you go, please make sure you cover your planned material.

The questions being posed to the jurors are not value-free, but are based on two normative assumptions:

1. The first is that patient records can be used for everybody’s benefit, for example in research, assessing the health needs of populations, monitoring and improving treatments, and improving health service efficiency, and that this is a good thing that we would want to pursue.
2. The second is that a health record about a patient is confidential, and that we should respect and protect an individual’s privacy and their interests in keeping their health information confidential.

It is assumed that almost everyone would agree that both aim 1 and aim 2 matter, and that this is considered to be common ground amongst people working in the field of access to patient records. There is much disagreement about the relative importance of these two aims. Furthermore, some people might support aim 1 but not accept sharing of health data with private companies even if it results in public as well as private benefit. Ultimately, the citizens’ juries are about exploring these issues with members of the public and asking how the two aims should be balanced in Connected Health Cities, a new initiative which will involve the sharing of health records across the North of England.

In general, please confine your presentation and answers to questions to matters of fact rather than values (note that this does not apply to the ethics witness). You should try to describe the world rather than judge it. Avoid making claims based on facts which are uncertain or disputed. As far as possible, try to choose what you say so as to give a balanced perspective. Please share your presentational material in advance with Malcolm Oswald to give him the opportunity to bring to your attention any material which he feels is not easy to understand or which might be considered biased. Your material will also be reviewed by an oversight panel of independent people who will review it for potential bias.

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 jury facilitator (Kyle Bozentko).

Please share your draft presentation material with Malcolm Oswald in advance (by 30 September 2016) so that it can be reviewed by Malcolm and by the Oversight Panel (which monitors bias).
2. **Specific briefing for each witness**

**Specific briefing for witness 1 on health records: Dr. Alan Hassey, GP and member of National Data Guardian Panel**

**Required on day 1 PM of the juries (2 Nov and 9 Nov)**

Approximate presentation time (excluding questions and discussion): 20 minutes

The presentation does not have to be structured in a particular way but it should finish with a summary slide and include information to address the following questions:

- what is a patient record?
- why are patient records needed?
- Who makes patient records and where are they held?
- What sort of information is contained within patient records, coded and non-coded?
- How might patient records be used in a simple patient journey? e.g. To a GP, then a referral to outpatients, and an out-patient appointment
- Outside of direct patient care, to what kinds of uses are patient records put?
- What does Connected Health Cities want to do with patient records?
- What does anonymisation of patient records involve, and does it eliminate risk?
- Could Connected Health Cities do what they want in some other way, without these records, or so there is no risk of identifying patients?

**Specific briefing for witness 2 on relevant law: Mark Taylor, Chair of Confidentiality Advisory Group**

**Required on day 1 PM of the juries (2 Nov and 9 Nov)**

Approximate presentation time (excluding questions and discussion): 20 minutes

The presentation does not have to be structured in a particular way but it should finish with a summary slide and include information to address the following questions:

- Where does a patient record fit within the law, including the Data Protection Act 1998, Human Rights Act and common law of confidence?
- How does the common law of confidence and Human Rights Act protect patients and patient records?
- When does the NHS believe it is reasonable to rely on the implicit consent of patients to disclose confidential information held in patient records, and when is explicit consent required?
- Which records are caught by the Data Protection Act 1998, and which are not, and how easy is it to determine?
- What rights do patients have under the Data Protection Act 1998 to access and control access to personal data in patient records?
- Under the Act, what are the main responsibilities of organisations that store and otherwise process patient records?
• How much effort should organisations make to tell patients what they are doing with patient records?
• In law, does anyone “own” the patient record?
• How will the law affect Connected Health Cities?
  o In restricting who can and cannot get hold of what data for what purpose?
  o In what is required of organisations responsible for the data?
  o In providing rights to affected patients?

**Specific briefing for witness 3 on ethics: Soren Holm, Prof. of Bioethics, University of Manchester**

**Required on day 2 AM of the juries (3 Nov and 10 Nov)**

Approximate presentation time (excluding questions and discussion): 20 minutes

You are expected to present normative reasoning about:

• the questions that lie behind the jury questions (see Appendix A), and
• the two normative assumptions which are considered common ground (see page 1 above) and the ethical problems in reconciling these two aims.

Other than this, there are no specific questions that must be addressed. You should aim to provide a balanced perspective, bringing out important ethical arguments in favour of using patient records for the public good, and those for empowering patients to control access to records and protect privacy. You should focus on the ethical claims for and against the kind of planned and potential uses (see Appendix) by Connected Health Cities using anonymised data (where there is still a very small risk of re-identification).

**Specific briefing for witness 4 on Connected Health Cities planned data uses: Prof. John Ainsworth, Director of Connected Health Cities Hub**

**Required on day 2 of the juries, from 11am (3 Nov and 10 Nov)**

Approximate presentation time (excluding questions and discussion):

• 5-10 minute introduction, you should end with a summary slide, and address the following questions:
  o Why do such planned uses of health data matter?
  o What examples are there of benefits coming from similar uses of health data in the past?
  o Why are data from patient records necessary for such work?
• 20 minutes: questions and answers from jurors, joint with witness 4
• 5-10 minutes presentation on each planned use, each time followed by open discussion with witness 5 (see below) for approx. 10 minutes, and by questions and answers from jury
You are being asked to present to the jury four planned uses of data by Connected Health Cities. For each planned use, you should explain:

- the purpose of this use;
- what data will be needed, about which individuals;
- whether there will be an opt out (Witness 6 cover will this but good to introduce it here);
- who will get access to the data and how;
- why do it – what public and private benefits it could bring.

Other than this, there are no specific questions that must be addressed. You are expected to provide information rather making a strong case in favour of these planned uses. The “balancing witness 5” should raise questions and points to counter-balance as necessary the information you provide (including potential reasons against these planned uses) so that jurors are provided with a fair picture of these planned uses.

**Specific briefing for “balancing witness” 5: Dr. Jon Fistein, University of Leeds**

**Required on day 2 from 11AM, and on day 3 AM of the juries (3-4 Nov and 10-11 Nov)**

Approximate presentation time (excluding questions and discussion):

- 5-10 minutes: introduction about planned uses. In this brief presentation, you should finish with a summary slide, and explain why people might be cautious about such planned uses, addressing the following questions:
  - What are the potential risks?
  - Have there been incidents when such record sharing has gone wrong in the past?
  - Are there other issues the jury should consider about such uses?
- 20 minutes: questions and answers from jurors, joint with witness 4
- After each presentation on a planned use from witness 4, ask questions of, and have open discussion with, witness 4 for approx. 10 minutes, followed by questions and answers from jury

On day 3, after the presentation by witness 6, ask questions of, and have open discussion with, witness 6 for approx. 15 minutes, followed by questions and answers to you both from jury.

You should contribute to the discussions in such a way that the jury is provided with a balanced perspective, bringing out important questions for witness 4 and witness 6, and arguments that you feel need to be made so that the jurors are presented with a fair picture of Connected Health Cities governance and the four planned data uses.

**Specific briefing for witness 6 on Connected Health Cities information governance: Clare Sanderson, Connected Health Cities Information Governance Lead**

**Required on day 3 AM of the juries (4 Nov and 11 Nov)**

Approximate presentation time (excluding questions and discussion): 20 minutes. Followed by open discussion with “balancing witness 5” of approximately 15 minutes and Q&A with jury.
Drawing on the privacy impact assessment for Connected Health Cities, your presentation should finish with a summary slide and address the following questions:

- What sort of data will Connected Health Cities require?
- Will that be anonymised or identifying (explain if anonymised in law but > 0 risk)?
- Who will use the data and for what purposes?
- What are the risks?
- Can all the risks be eliminated?
- Who will decide on who gets the data?
- How will the data be protected?
- What will the public be told and how?
- What choices, if any, will the public have to restrict data sharing?

Other than this, there are no specific questions that must be addressed. You are expected to provide information rather making a strong case in favour of the planned governance. The “balancing witness 5” should raise questions and points to counter-balance as necessary the information you provide (including potential information governance weaknesses) so that jurors are provided with a fair picture of Connected Health Cities risks and controls.

**Specific briefing for witness 7 on Connected Health Cities potential data uses: John McGovern, Director of Quaenam**

**Required on day 3 of the juries (4 Nov and 11 Nov)**

Approximate presentation time (excluding questions and discussion):

- 5-10 minutes introductory presentation (see below) followed by 20 minutes questions and answers to you and “balancing witness 8” (see below)
- After video of each potential use is played to the jury, there will each time be 10 questions and answers from jury to you and “balancing witness 8”.

You are being asked to give a brief introductory presentation on why organisations other than the NHS and universities (like commercial companies) need access to patient data for uses like the four potential uses being considered, and then to answer questions from the jury about videos of the four potential uses of Connected Health Cities data, and have open discussion with “balancing witness” 8.

In the 5-10 minute introduction, you should end with a summary slide, and address the following questions:

- Why do such potential uses of health data matter?
- What examples are there of benefits coming from similar uses of health data in the past?
- Why are data from patient records necessary for such work?

Other than this, there are no specific questions that must be addressed. You are expected to provide information rather making a strong case in favour of these potential uses. The “balancing witness” 8 should raise questions and points to counter-balance as necessary the information you provide.
(including reasons against these potential uses) so that jurors are provided with a fair picture of these potential uses.

**Specific briefing for “balancing witness” 8: Alexander Martin, journalist for “The Register”**

**Required on day 3 of the juries (4 Nov and 11 Nov)**

Approximate presentation time (excluding questions and discussion):

- 5-10 minutes introductory presentation (see below) followed by 20 minutes questions and answers to you and witness 7 (see above)
- After video of each potential use is played to the jury, there will each time be 10 questions and answers from jury to you and witness 7.

Before the juries, you are asked to interview those speaking on behalf of the four potential uses of health data that could be accessed through Connected Health Cities’ data. The interviews will be filmed and played to the juries. In the interviews, you should ask interviewees to explain what data they seek, for what purpose, and for what potential benefit (to the company, patients and others). You should aim to give the potential use a fair hearing, but also raise questions about potential risks of sharing data outside the NHS and universities (e.g. with commercial companies).

During the juries, you are asked to give a brief introductory presentation on reasons to be cautious about organisations outside the NHS and universities accessing patient data. In the brief presentation, you should finish with a summary slide, and explain why people might be cautious about such potential uses, addressing the following questions:

- what are the potential risks?
- Have there been incidents when such record sharing has gone wrong in the past?
- what does the public think about such sharing?

You should contribute in such a way that the jury is provided with a balanced perspective, bringing out important questions for the other witnesses, and arguments that you feel need to be made so that the jurors are presented with a fair picture of Connected Health Cities governance and the four potential data uses.
### Appendix A: Jury Questions (note – still subject to change)

1. Which of the following uses\(^1\) of data about patients (with identifiers like name and address removed) are acceptable?

   [Choose yes, no, or don’t know]

   a. NHS staff working for Salford Royal Hospital get data from ambulances and hospitals to do research to help paramedics get better at spotting people who have had a stroke

   b. University researchers in Bradford get data from hospitals, GPs and social care about frail elderly patients to help GPs identify those patients needing extra care and follow up

   c. University researchers in Liverpool get data from hospitals and GPs to provide information to doctors, nurses and ambulance staff to help them give more appropriate care to people suffering from alcohol-related problems

   d. Planned use 4 (TBC, from North East CHC)

Explain the most important factors affecting your choices (up to 300 words).

2. Overall, are the rules over access to health data proposed by Connected Health Cities sufficient to allow these planned uses?

   [Choose only one]

   a. Certainly sufficient

   b. Probably sufficient

   c. Probably insufficient

   d. Certainly insufficient

Explain the most important factors affecting your choice (up to 300 words).

3. If you answered c. or d. to Q2, what else, if anything, would you want done before allowing these planned uses? (up to 300 words)

4. Which of the following potential uses\(^2\) of health data about patients (with identifiers like name and address removed) are acceptable?

   [Choose yes, no, or don’t know]

---

\(^1\) These 4 uses should be supplied by the 4 CHC regions prior to the juries

\(^2\) These potential uses to be gathered prior to the juries commencing from consulting with private companies about uses to which they would like to put health data that might be available through Connected Health Cities
a. Pharmaceutical company requests data about prescriptions, blood glucose measurements, and complications of diabetes patients to understand better what prescribing patterns get the best results for patients

b. Large computer software company seeks data about patient symptoms, diagnoses and outcomes so the intelligent software can “learn” and so aid future diagnosis

c. Potential use 3 (TBC, but likely to be about sharing data with app development company capturing data through a device like a fitbit)

d. Potential use 4 (TBC, from private company 4)

Explain the most important factors affecting your choices (up to 300 words)

5. Overall, are the rules over access to health data proposed by Connected Health Cities sufficient to justify the potential uses?

[Choose only one]

   a. Certainly sufficient

   b. Probably sufficient

   c. Probably insufficient

   d. Certainly insufficient

6. If you answered c. or d. to Q5, what else, if anything, would you want done before allowing these potential uses? (up to 300 words)