

# To what extent should patients control access to patient records?

## 2 Citizens' juries

### Brief for expert witnesses

#### General briefing for all witnesses

You are asked to present to 2 citizens' juries of 18 people. Each jury will meet for three days in rooms F12, F13 (Upper hall), Friends House, 6 Mount Street, Manchester, M2 5NS. The first jury will meet on Thu 14, Fri 15 and Sat 16 January 2016. The second jury will meet on Thu 21, Fri 22 and Sat 23 January 2016. The two juries will be run by two skilled facilitators. Impartial witnesses will be asked to attend for the afternoon session of day one (i.e. both the 14th Jan pm and 21st Jan pm) and partial witnesses will be asked to attend the morning session of day two (i.e. both the 15th Jan am and the 22nd Jan am) and provide the jurors with the same presentation on both occasions.

Each jury will contain a cross section of adult residents of Greater Manchester. They will be selected to include a mix of people in terms of age, gender, ethnic group, educational attainment and attitudes to privacy of health records. As the jury will have people with different levels of educational attainment, including people with no educational qualifications and people with university degrees, it is important that you try to explain things as simply as you can, and that you avoid acronyms and do not assume that the audience has any prior knowledge of your subject. Try to make your presentation as interesting and as clear as possible. 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.

In addition to the presentation, you are also asked to answer questions posed by the jurors. You should expect more time to be spent on answering questions from the jurors than on your presentation. If you wish, you can tell the jurors that you welcome questions during your presentation. Some jurors may lack confidence, so please respond positively to any question you receive.

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. Ultimately, the citizens' juries are about asking members of the public how these two aims should be balanced.

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 to one of the two jury facilitators (Kyle Bozentko and Amanda Hunn).

Please share your draft presentation material with Malcolm Oswald in advance (by 21 December 2015) so that it can be reviewed by the Oversight Panel (which monitors bias).

### **Briefing for impartial witnesses**

If you have been asked to be an impartial expert witness, please confine your presentation and answers to questions to matters of fact rather than values. You should try to describe the world rather than judge it. 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.

Two impartial witnesses will present on day 1 of the juries (14 Jan 16 and 21 Jan 16). Your presentations and question and answers session are expected to be required after the day 1 lunch break. You may wish to come for the whole day.

#### **Specific briefing for impartial witness 1: Ralph Sullivan, GP and health informatician**

Approximate presentation time (excluding questions and discussion): 25 minutes

The presentation does not have to be structured in a particular way but should 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 the patient record, 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 sorts of organisations use patient records for these other uses, and how do they get the records?
- Are these records totally anonymous, or do they identify individuals (or something in between)?

- What would be the consequences for the NHS and for patients if patient records weren't available for such uses?
- Would it be possible to do all these things using information from records where there is no risk of identifying patients?

**Specific briefing for impartial witness 2: Dawn Monaghan, Group Manager for Public Services, Information Commissioner's Office**

Approximate presentation time (excluding questions and discussion): 25 minutes

The presentation does not have to be structured in a particular way but should 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?
- 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? How well would the Data Protection Act protect individuals affected by the scenario being considered by the jury?
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- 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?
- In law, does it matter who wants the data, for example healthcare professional or non healthcare professional, NHS organisation or university or private company?
- In law, does anyone "own" the patient record?

**Briefing for partial witnesses**

If you have been asked to be a partial expert witness, you will be expected to make the case for a particular viewpoint or viewpoints. Please try to illustrate your case by using example(s) of how an individual may be harmed, may benefit or be otherwise affected by access to patient records. Your arguments may be based on both facts and values. However, avoid making claims based on facts which are uncertain or disputed. In terms of presenting a balanced perspective, the role of impartial witness 1 differs from partial witnesses 2 and 3; see the specific briefings below.

The three partial witnesses will present on day 2 of the juries (15 Jan 16 and 22 Jan 16). Your presentations and question and answer session will be needed sometime in the morning of day 2, and you will be advised on approximate timings later. Ideally, you will come for the whole of the morning session, and you may wish to come for the whole day.

**Specific briefing for partial witness 1: Soren Holm, University of Manchester and President of the International Association of Bioethics**

Approximate presentation time (excluding questions and discussion): 30 minutes

You are expected to present normative reasoning about:

- the questions that lie behind the juries charge, 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.

**Specific briefing for partial witness 2: John Ainsworth, University of Manchester and Health e-Research Centre**

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

You are being asked to make a particular case, and your arguments may draw on facts as well as values. Your arguments should:

- stress the importance of the first assumption i.e. 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; and
- how in your view, given the importance of this assumption, the jury should respond to its charge.

Other than this, there are no specific questions that must be addressed. You are not expected to provide a balanced perspective but make a strong case in favour of using patient records for public (and potentially private) benefit.

**Specific briefing for partial witness 3: Sam Smith, medconfidential**

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

You are being asked to make a particular case, and your arguments may draw on facts as well as values. Your arguments should:

- stress the importance of the second assumption i.e. 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;
- how in your view, given the importance of this assumption, the jury should respond to its charge.

Other than this, there are no specific questions that must be addressed. You are not expected to provide a balanced perspective but make a strong case in favour of protecting individual privacy in general and the confidentiality of patent records specifically.

## Appendix A: Jury's Charge

Suppose an NHS body wants to create new records from the patient records stored by your general practice and by hospitals that have treated you. They want to use them for purposes other than your direct patient care, like research about better treatments, and for checking that patients are receiving safe and effective health care. These records would be held securely and would not contain your name, address and other identifiers. Despite this, there is a small risk that the records might still identify you, because they would contain lots of detailed information about the care you receive from your GP and from different hospitals. The NHS body would also review requests from other public and private organisations, granting access only where they believed it was lawful and in a good cause.

1. (i) Should the NHS body be allowed to create these records about you and other patients?  
*[Choose only one of the following]*
  - a. Yes, but they should publish information about what they plan to do
  - b. Yes, but patients should be told in advance and be able to opt out
  - c. Yes, but only for patients who have given permission (i.e. opt in)
  - d. No
  - e. Other (explain in less than 30 words)
- (ii) Give reasons for your answer (in less than 300 words)
2. (i) Given your answer to question 1, who should be allowed to access and extract data from the records created?  
*[Choose as many of the following examples that apply]*
  - a. NHS staff who decide which health services should (and should not) be funded
  - b. NHS staff doing approved research into the safety of prescribed medicines
  - c. University staff doing approved research into the safety of prescribed medicines
  - d. Staff employed by local authorities planning the future need for residential care homes
  - e. Staff employed by a private company being paid by a hospital NHS trust to compare the number of people dying after surgery with other hospitals
  - f. Staff employed by an insurance company aiming to set health insurance premiums accurately
  - g. Staff employed by a pharmaceutical company investigating whether they should begin research into a new drug for a genetic disease for which there is currently no treatment
- (ii) Give reasons for your answer (in less than 400 words)