

## End-of-jury Questionnaire

*Please complete and return before leaving. Any information that you give us here will not be passed on to any of the facilitators or witnesses, other than in a general and anonymous way.*

The information collected will be stored securely and destroyed after 5 years.

Juror Number:

### Questionnaire about your views after the jury

1. 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.

(i) Should the NHS body be allowed to create these records about you and other patients?

***[Tick only one of the following]***

- ☐ a. Yes, but they should publish information about what they plan to do
- ☐ b. Yes, but they should publish information about what they plan to do and patients should be able to opt out
- ☐ c. Yes, but they should publish information about what they plan to do, and only create records for patients who opt in
- ☐ d. No
- ☐ e. Other (explain in less than 30 words)

(ii) Comment (optional)

2. (i) Given your answer to question 1, who should be allowed to access and extract data from the records created?

***[Tick as many of the following examples that apply]***

- ☐ a. NHS clinicians and administrators who decide which health services should (and should not) be funded
- ☐ b. NHS clinicians and administrators doing approved research into whether doctors are prescribing medicines appropriately
- ☐ c. University staff doing approved research into whether doctors are prescribing medicines appropriately
- ☐ 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) Comment (optional)

3. What should be done to try to make people aware of these new records, their proposed uses, and their options for participating/not participating?

***[Tick as many of the following that apply]***

- ☐ a. There should be publicity material on a website
- ☐ b. There should be posters in GP surgeries
- ☐ c. There should be public meetings about it
- ☐ d. A leaflet should be delivered to every household
- ☐ e. GPs should send a letter to every patient
- ☐ f. GPs should explain the scheme to any patient who asks about it
- ☐ g. GPs should explain the scheme to every patient who they see in surgery
- ☐ h. GP practices should explain the scheme to every new patient who registers
- ☐ i. I'm not sure

(ii) Comment (optional)

4. (i) For each of the following, please tick a box to show whether you agree the statement.

a) It's my record and so I should decide what happens to it

☐ Agree strongly    ☐ Broadly agree    ☐ Neither agree nor disagree    ☐ Broadly disagree    ☐ Strongly disagree

b) I trust the NHS to protect and use these records appropriately

☐ Agree strongly    ☐ Broadly agree    ☐ Neither agree nor disagree    ☐ Broadly disagree    ☐ Strongly disagree

c) The priority should be for the NHS to use patient records to provide as much public benefit as possible

☐ Agree strongly    ☐ Broadly agree    ☐ Neither agree nor disagree    ☐ Broadly disagree    ☐ Strongly disagree

d) Protecting privacy and using patient records for public benefit are both important

☐ Agree strongly    ☐ Broadly agree    ☐ Neither agree nor disagree    ☐ Broadly disagree    ☐ Strongly disagree

e) This issue is important to me

☐ Agree strongly    ☐ Broadly agree    ☐ Neither agree nor disagree    ☐ Broadly disagree    ☐ Strongly disagree

(ii) Comment (optional)

5. As you may know, different government departments and services collect data about individuals, for example your tax records and health records. People have different views on how much of this information should be shared within government. Data sharing can bring benefits, such as finding more effective medical treatments, using information about local communities to plan local schools or roads etc. But some people worry that data sharing will be a risk to their privacy and security, by linking different types of data together and potentially allowing them to be identified.

Overall, which of the following statements is closest to your view?

- a) "We should share all the data we can because it benefits the services and me – as long as I can opt out if I choose"
- b) "We should not share data as the risks to people's privacy and security outweigh the benefits"

***[Tick only one of the following]***

- |   |   |   |   |   |
|---|---|---|---|---|
| <input type="checkbox"/> Agree much more with a) than with b) | <input type="checkbox"/> Agree a little more with a) than with b) | <input type="checkbox"/> Agree equally / don't agree / don't know | <input type="checkbox"/> Agree a little more with b) than with a) | <input type="checkbox"/> Agree much more with b) than with a) |
|---|---|---|---|---|

6. How interesting did you find the jury process?

- |   |   |   |                                      |                                    |
|---|---|---|--------------------------------------|------------------------------------|
| <input type="checkbox"/> Very interesting | <input type="checkbox"/> Mostly interesting | <input type="checkbox"/> Neither interesting nor dull | <input type="checkbox"/> Mostly dull | <input type="checkbox"/> Very dull |
|---|---|---|--------------------------------------|------------------------------------|

7. If other citizens' juries were run on different topics, would you be interested in being asked about taking part?

☐ Yes

☐ No

*If you need more space for comments, please write them below*

## Questionnaire about whether the jury process was fair

8. Did you ever feel that the jury facilitators tried to influence you towards particular conclusions?

☐ Not at all

☐ Perhaps  
occasionally

☐ Sometimes

☐ Often

☐ Very often

If you did feel you were influenced, please explain:

9. Did you ever feel that the expert witnesses on **day 1** (Ralph Sullivan and Dawn Monaghan) tried to influence you towards particular conclusions?

☐ Not at all

☐ Perhaps  
occasionally

☐ Sometimes

☐ Often

☐ Very often

If you did feel you were influenced, please explain:

10. Did you ever feel that anyone else outside the jury tried to influence you towards particular conclusions?

☐ Not at all

☐ Perhaps  
occasionally

☐ Sometimes

☐ Often

☐ Very often

If you did feel you were influenced, please explain:

11. Did you have any other concerns that the process was biased?

☐ Yes

☐ No

If yes, please explain: