

Citizens' Jury Questionnaire Results

Jury 2

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ABSTRACT

On 14-16 and 21-23 January 2016, two three-day “citizens’ juries” took place in Manchester, tackling policy questions related to the extent to which patients should control access to patient records. Over the course of the jury, the citizens heard from, and asked questions of, expert witnesses, and participated in group exercises to explore the jury mission. They reached conclusions together, and were surveyed on their individual views at the start and end of the jury. This document summarises the results from pre- and post-jury questionnaires for the second jury.

Citizens Jury questionnaires – July 2

Privacy views question

This question is taken from a national survey conducted by Ipsos Mori. It was used for pre-jury selection, and then measured again following the jury.

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"

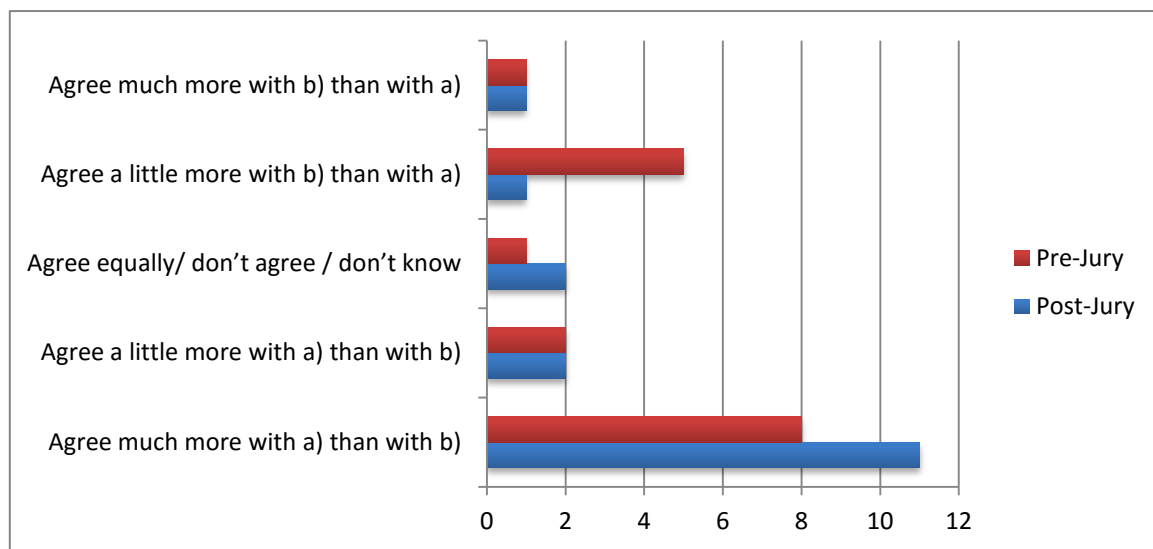


Figure 1 Pre-jury privacy views

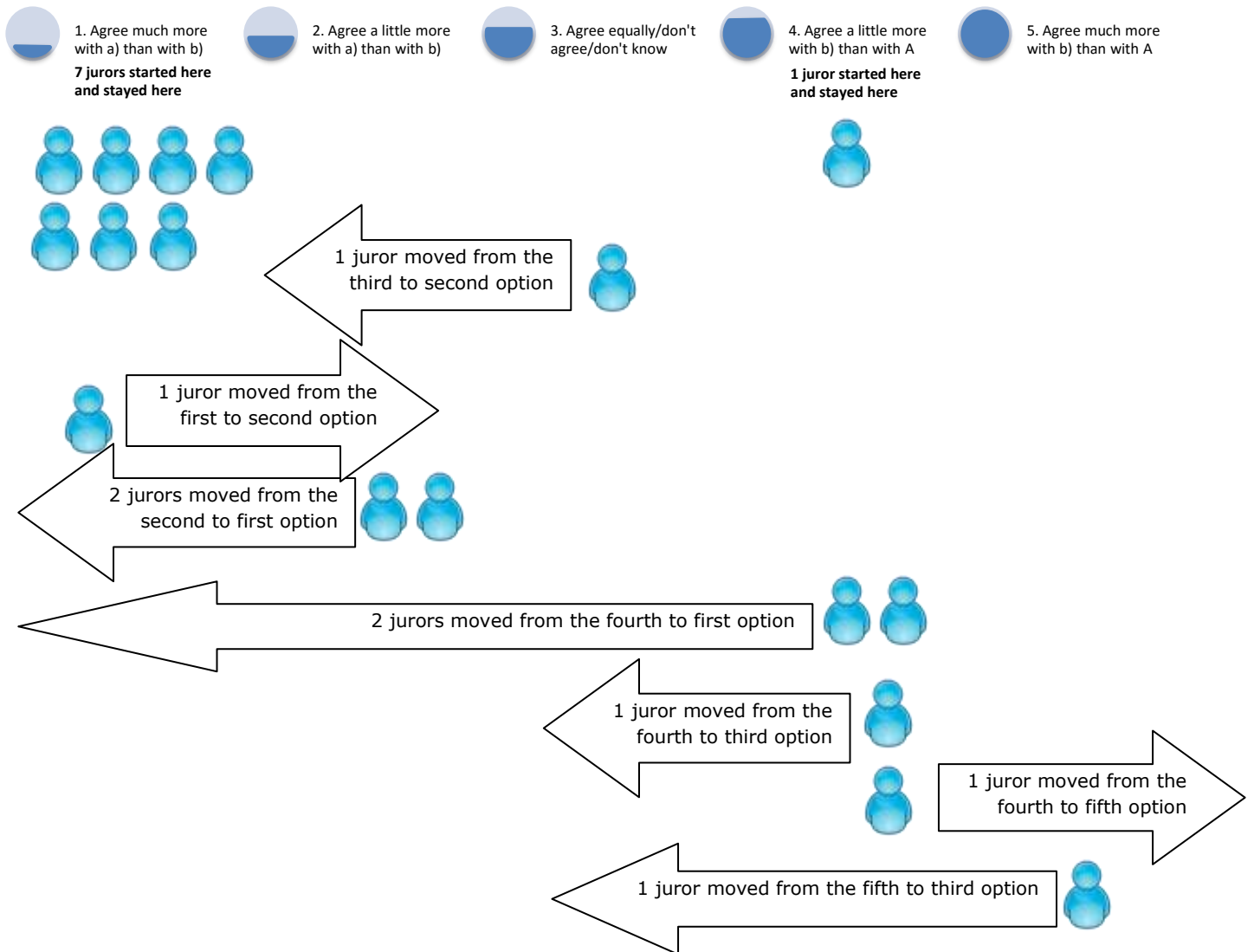
Individual changes in views for this privacy question

If we split the answers up into five categories:

1. Agree much more with a) than with b)
2. Agree a little more with a) than with b)
3. Agree equally/ don't agree / don't know
4. Agree a little more with b) than with a)
5. Agree much more with b) than with a)

We can see that while 8 jurors didn't change their views at all, 9 (53%) jurors did change their view, although the shifts were not nearly as dramatic as for Jury 1. While 7 (41%) moved left on the spectrum 2 (12%) jurors moved more toward the privacy side of the spectrum (see diagram below).

Jury 2 Results



Jury charge: creation of records and opt-in / opt-out

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 to the stored records 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?

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

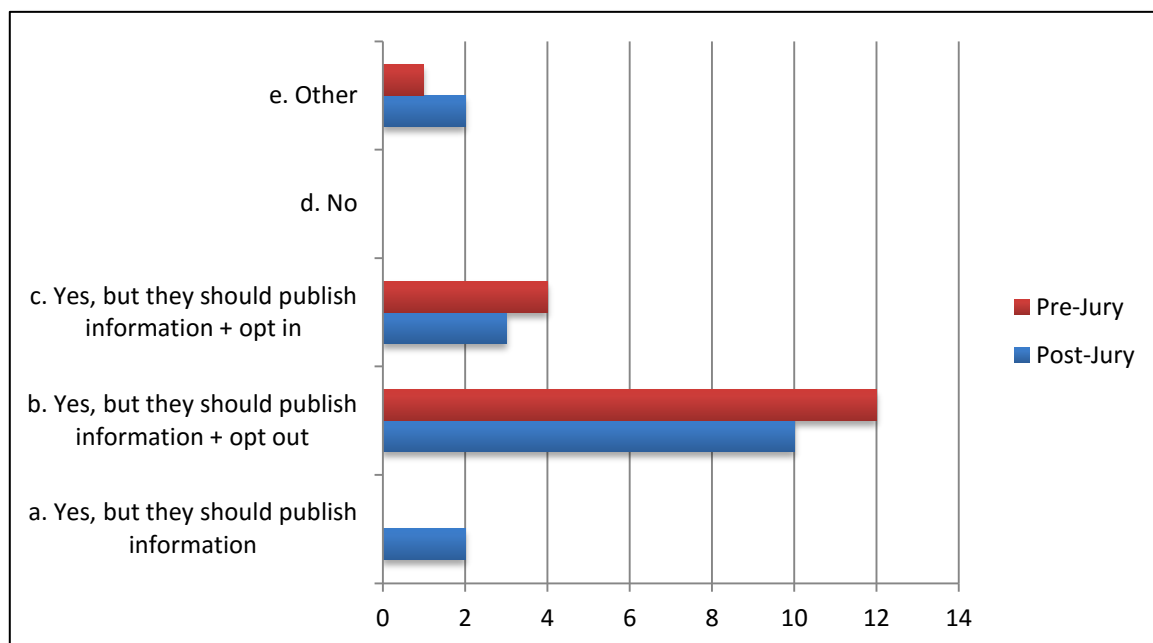


Figure 2. Pre- and post-jury views on creation of records

These results are for the pre-jury and post-jury questionnaires. Some people selected different answers in the questionnaire as compared to their vote during the jury.

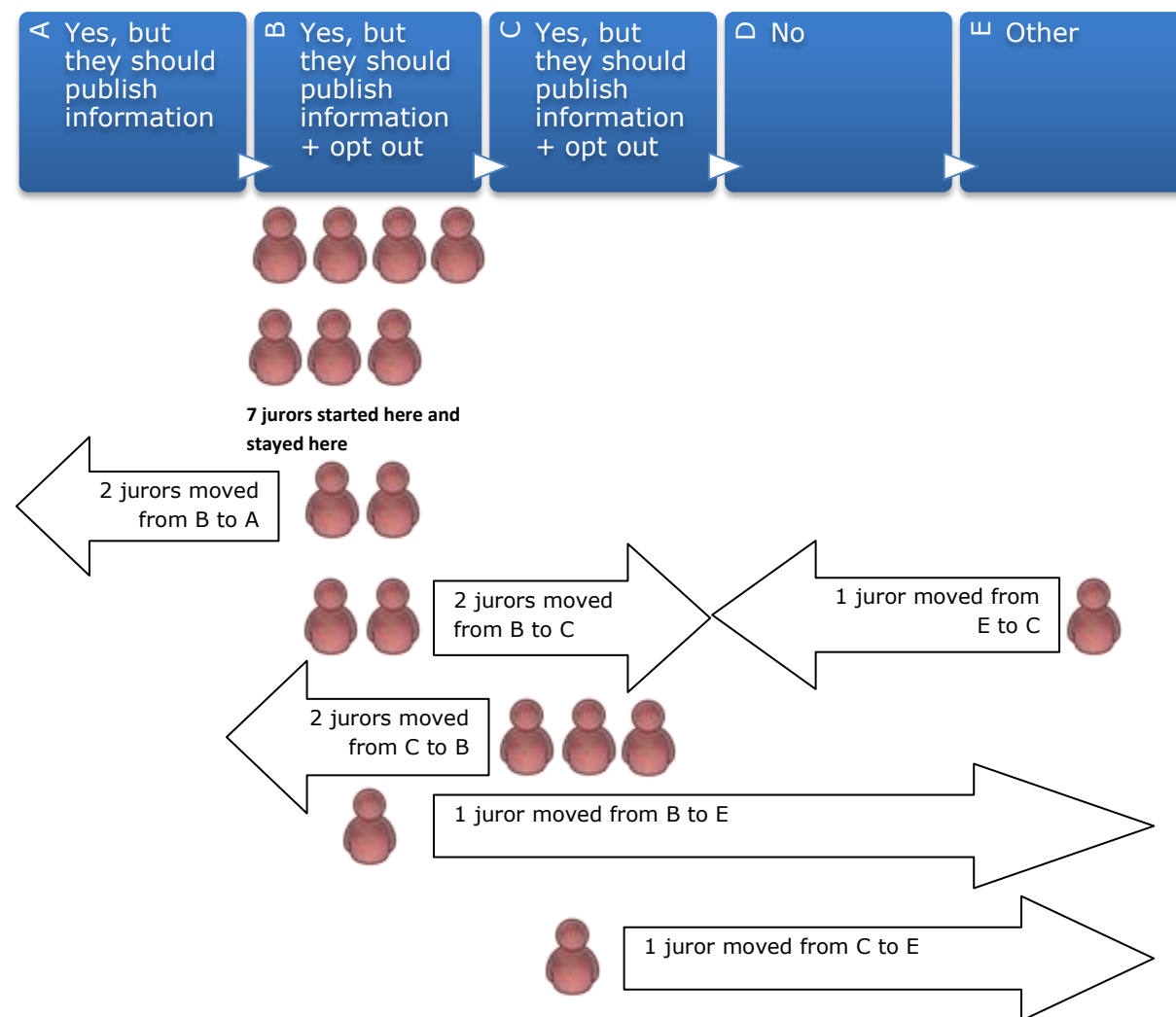
Individual changes in view for Question 1:

7 jurors did not change their mind. All of those who didn't change their mind had selected option b).

Of the 10 jurors who changed their mind:

- 2 changed from b) to a).
- 2 changed from b) to c).
- 3 changed from c) to b).
- 1 changed from b) to e).
- 1 changed from c) to e).
- 1 changed from e) to c).

Figure 3. Individual changes in juror views



Jury charge: who should access

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

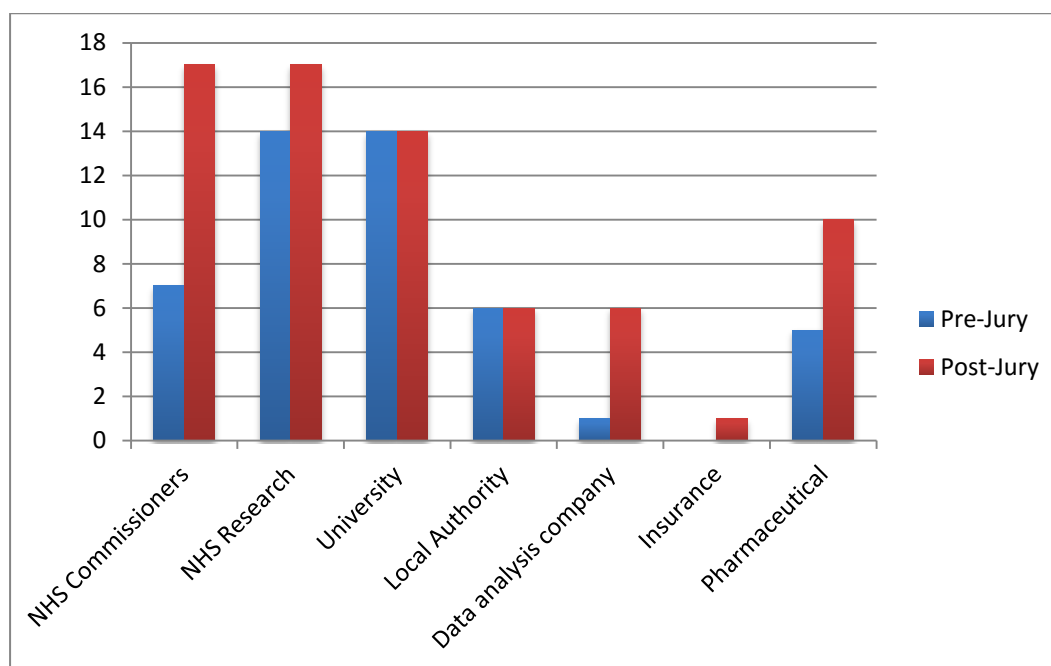


Figure 4. Pre- and post-survey views on who should access the records

Jury 2 Results

Changes in views for Question 2

- 10 jurors changed their views to agree that **NHS commissioners** should have access (post-jury).
- 3 jurors changed their views to agree **NHS researchers** should have access.
- 6 jurors changed their view regarding **university researchers**, with three moving from denying to allowing access and the other three moving in the opposite direction.
- 6 people changed their views regarding **local authorities**, with 3 moving from denying access (pre-jury) and to allowing access (post-jury) and the other 3 moving in the opposite direction.
- 5 people changed their views regarding **data analysis companies**, with all of them moving from denying access (pre-jury) to allowing access (post-jury)
- 1 person changed their view regarding **insurance companies** to allow access (post-jury)
- 7 people changed their view regarding **pharmaceutical companies**, with 6 moving from denying access (pre-jury) to allowing access (post jury) and 1 juror moving in the opposite direction.

Fair processing

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

- 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

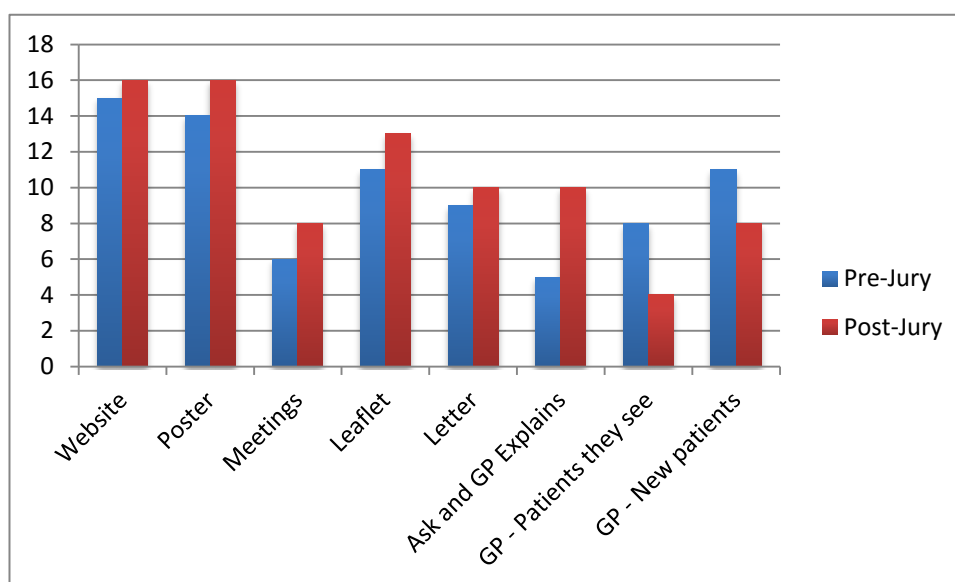


Figure 5. How should this be communicated with patients?

4a) It's my record and so I should decide what happens to it

Likert scale – strongly disagree to strongly agree

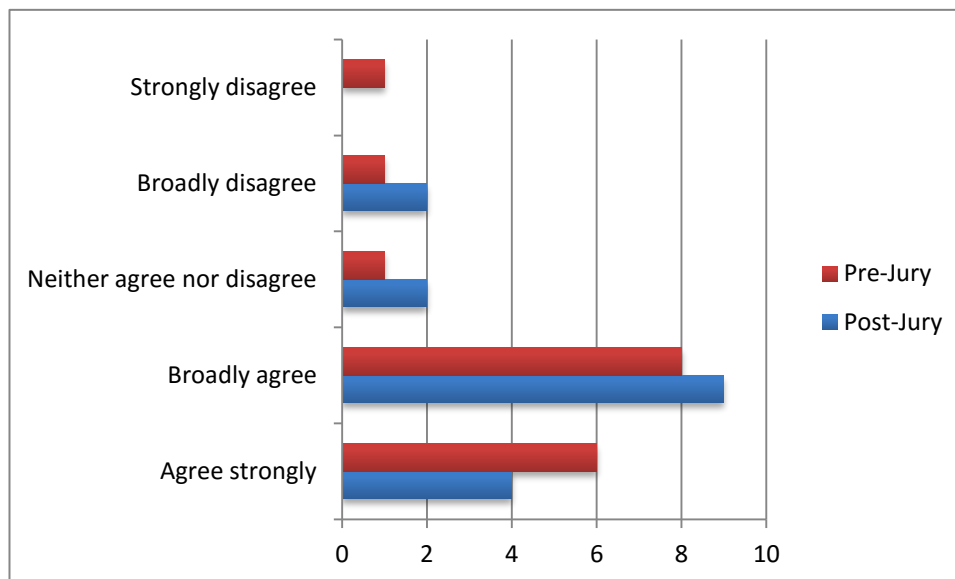
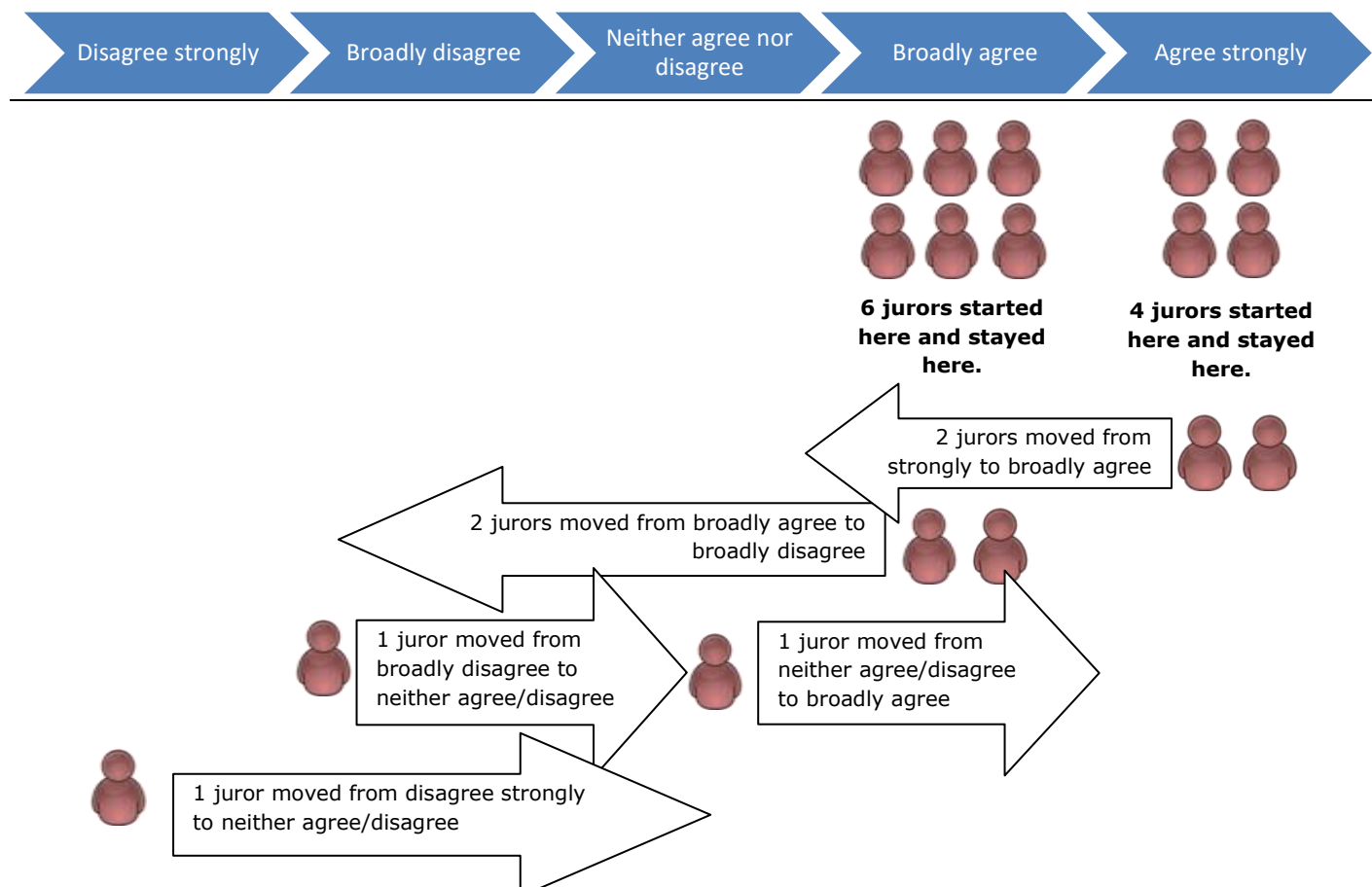


Figure 6. Patient view re: control of records about them

Individual changes in views for Question 4a

There were fewer jurors who changed in July 2 than in July 1 for this question. 10 jurors did not change their views. Of the 7 who did, they moved in both directions, as depicted below.



Patient trust

4b) I trust the NHS to protect and use these records appropriately

Likert scale – strongly disagree to strongly agree

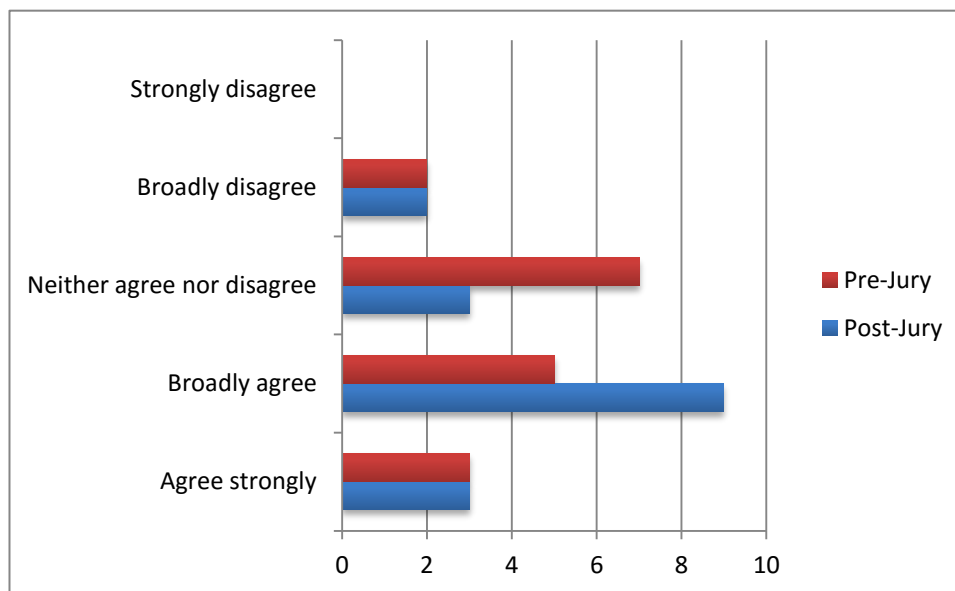


Figure 7. Participants' trust in the NHS to protect patient records

Prioritising public benefit

4c) The priority should be for the NHS to use patient records to provide as much public benefit as possible.

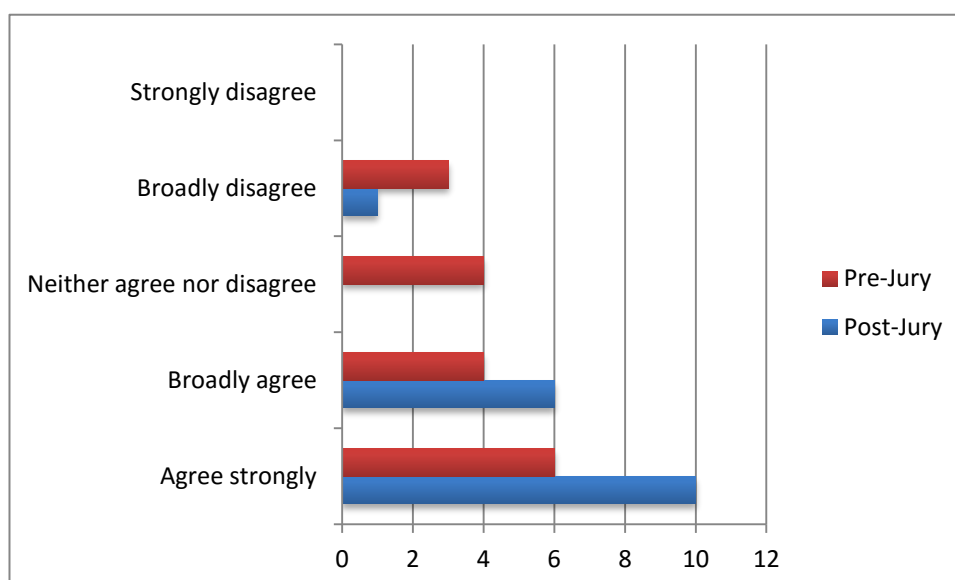


Figure 8. Participant view on whether NHS should prioritise the use of patient records to maximise public benefit

4d) Protecting privacy and using patient records for public benefit are both important

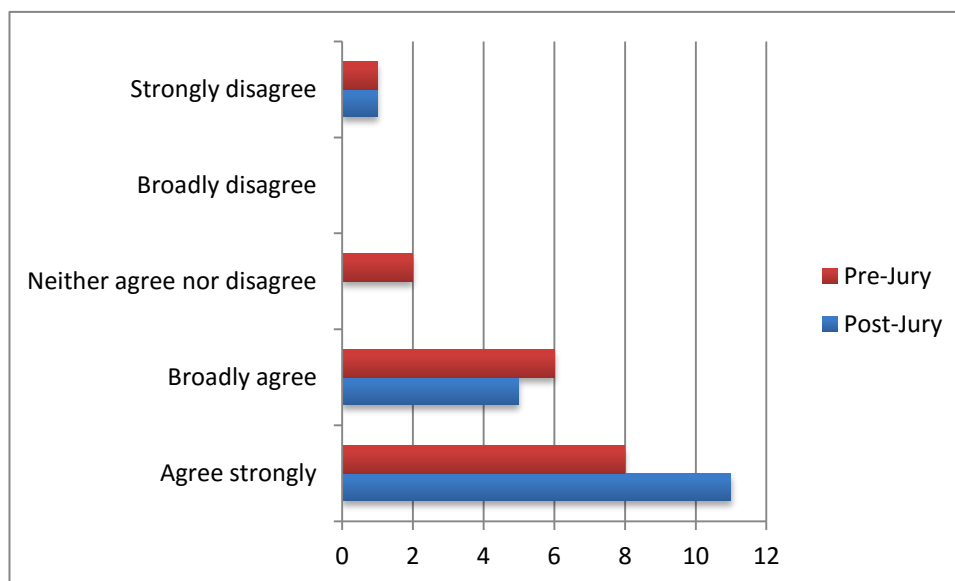


Figure 9. Participant views on privacy vs public benefit

4e) This issue is important to me

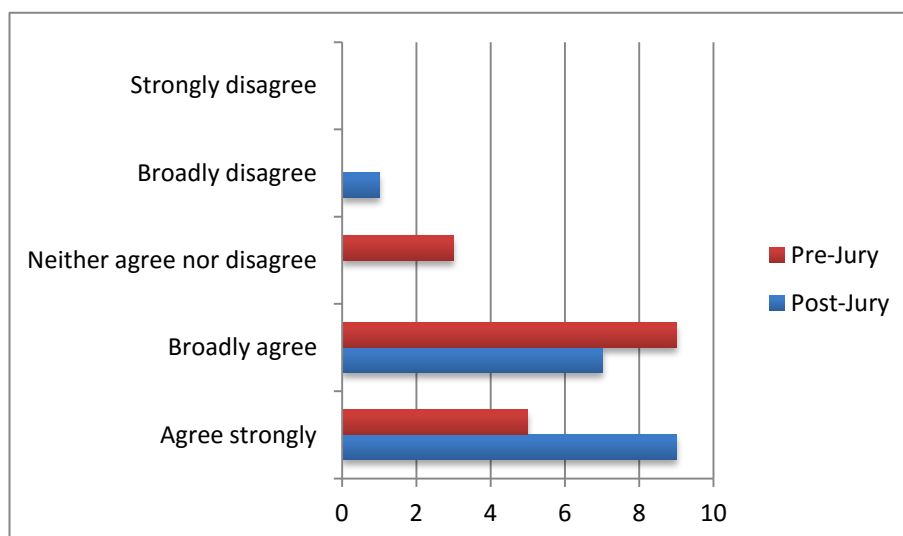


Figure 10. Participant view on importance of the issue

Bias in the jury process

Three questions were included in the post-jury questionnaire about bias in the jury process. Figure 11 depicts the answers to each of these questions.

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

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

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

Likert scale from "not at all" to "very often".

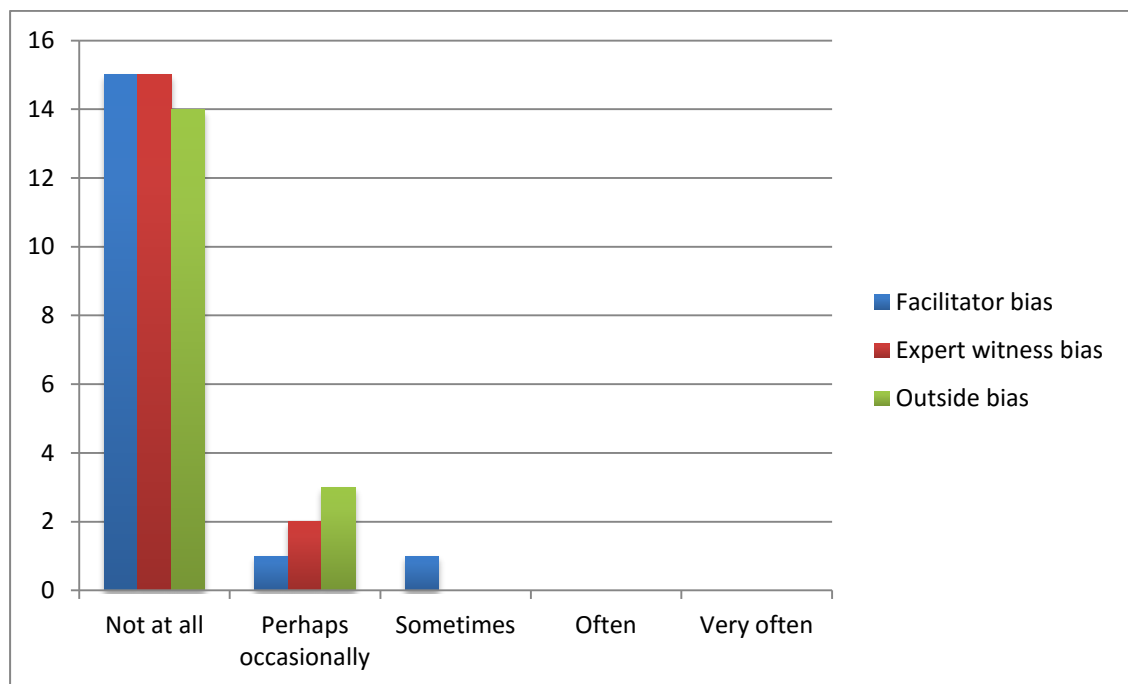


Figure 11. Participant views on facilitator bias¹

¹ No jurors selected often or very often.

Open-ended responses relating to facilitator bias question (Q8)

"Final section, the worksheet had the arguments FOR already written out. I believe unbiased way would be to have no suggestions or to have AGAINST written out as well (not as questions as they beg an answer, rather than stand alone as?..... Also I was unsure AGAINST arguments were not recorded on several occasions."

"Facilitators did not influence directly but witness 'for' the case much stronger than witness against."

Open-ended responses relating to expert witness bias question (Q9)

Although only two participants felt there was some bias, three jurors provided comment on this question. The first response was from a juror who selected 'not at all' on the questionnaire.

"Dr Sullivan had been using data from electronic records for some time. He seemed in favour of bringing this information together"

"Dr S had a preference that was noticeable."

"I think they inadvertently let their opinion slip out but not intentionally"

Open-ended responses related to the question about outside bias (Q10):

"Sam Smith but that is what he was supposed to do."

There was a fourth question about bias, i.e. Q11:

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

One juror indicated that he/she had other concerns about bias.

"As mentioned the case against sharing medical data was not presented well."

Another who replied no said:

"I think everyone had strong opinions and was respectful of each other"