Citizens Jury Questionnaire Results

Jury 1

Prepared by Dr Sarah Clement

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 first jury.

Citizens Jury questionnaires – Jury 1

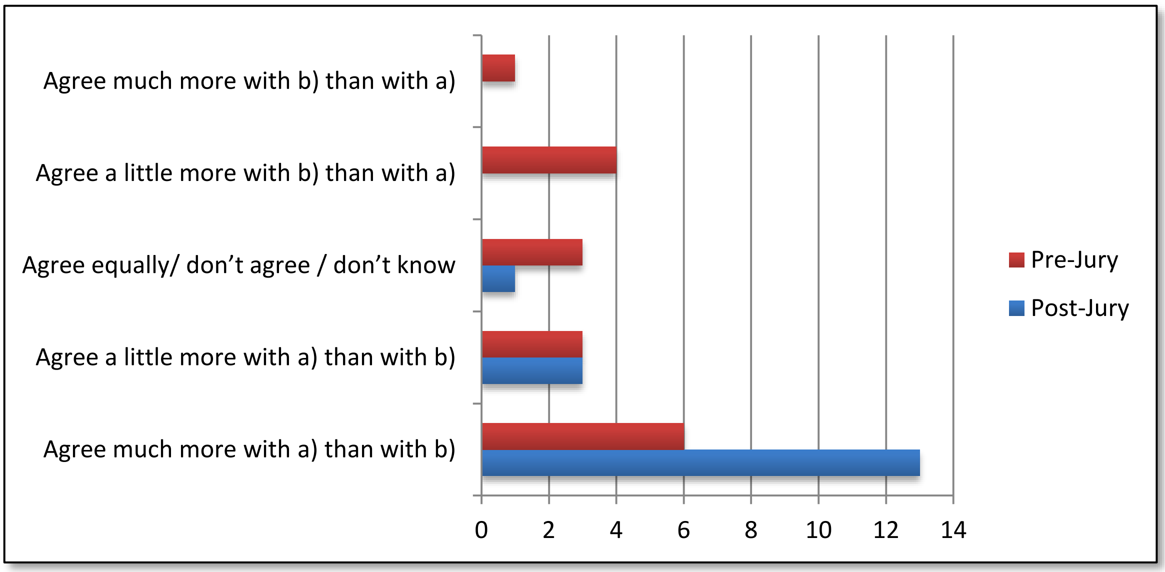
Privacy views question

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 Jurors' privacy views



<u>Changes in individual views</u>

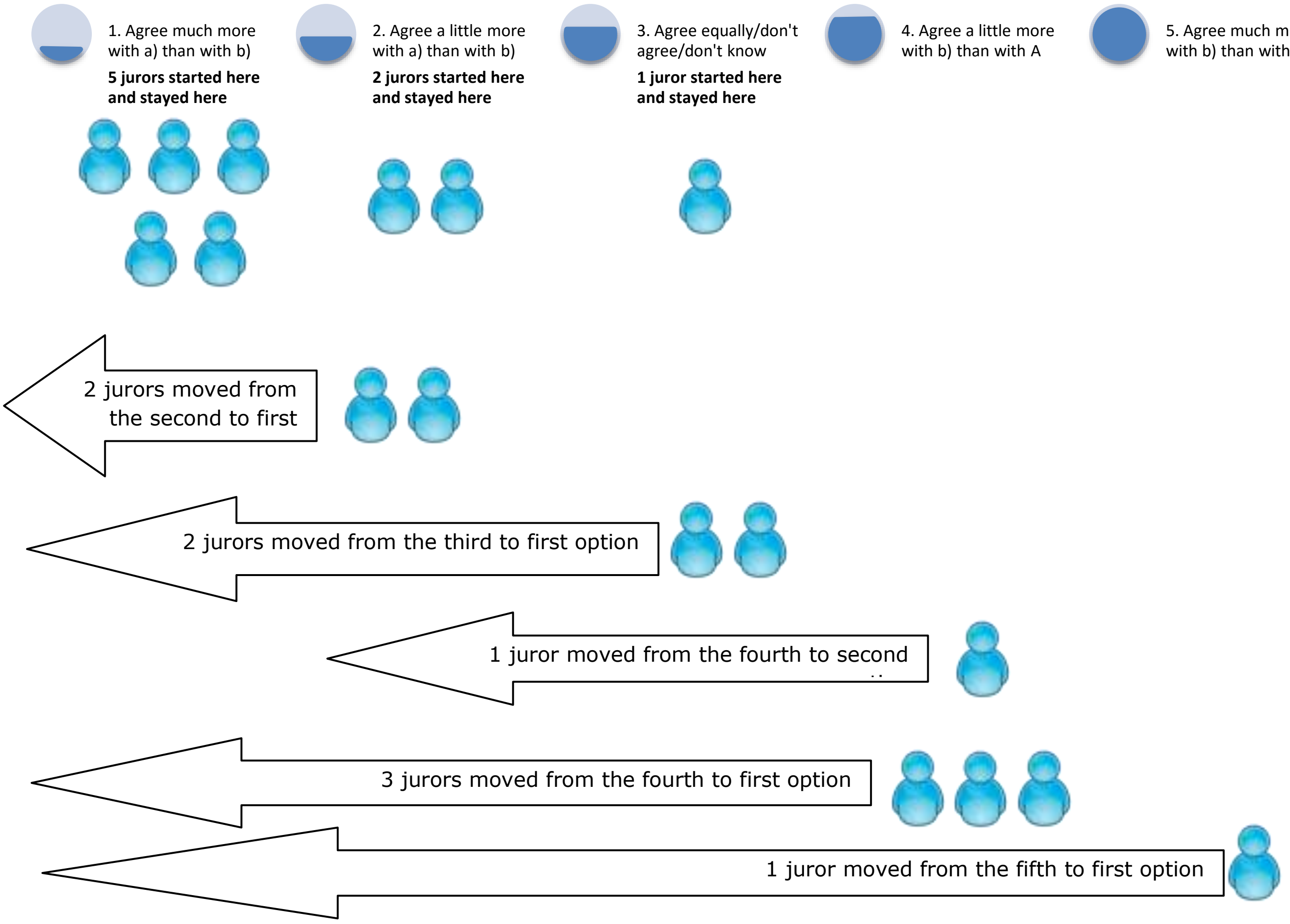
If we split the answers up into five categories:

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 jurors (53%) did change their view, with 7 of them (41%) making fairly large shifts in a way that favours public benefits over privacy (see diagram below).

Jury 1 results

Figure 2. Individual changes in juror views

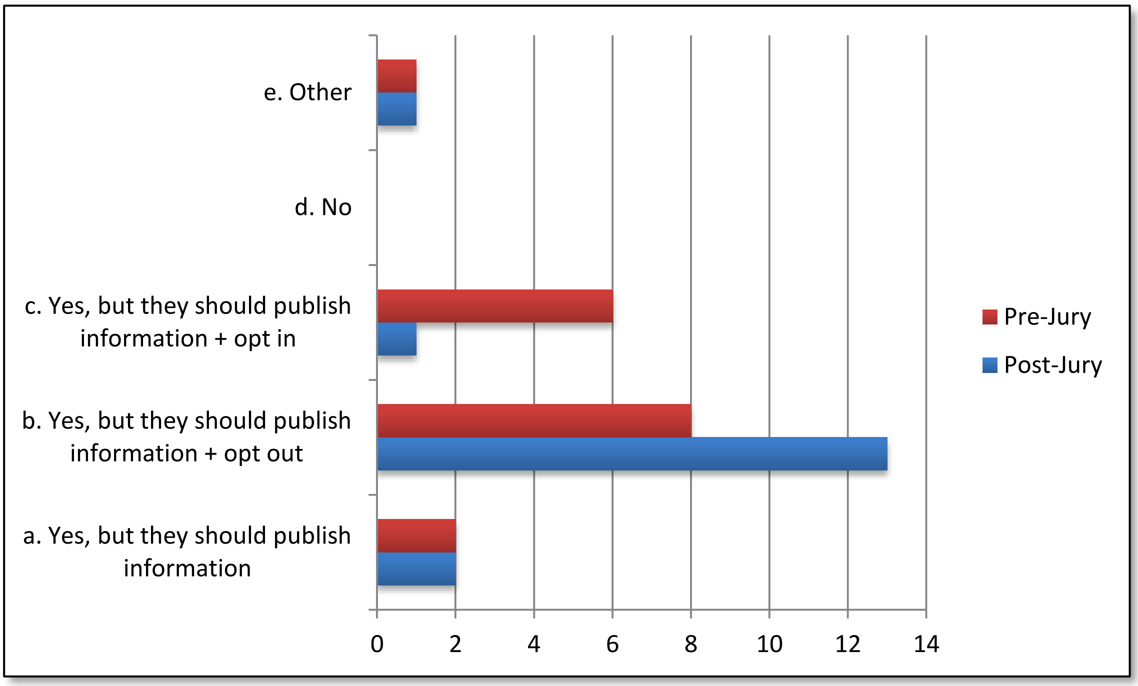


Jury 1 results

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?
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)



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.

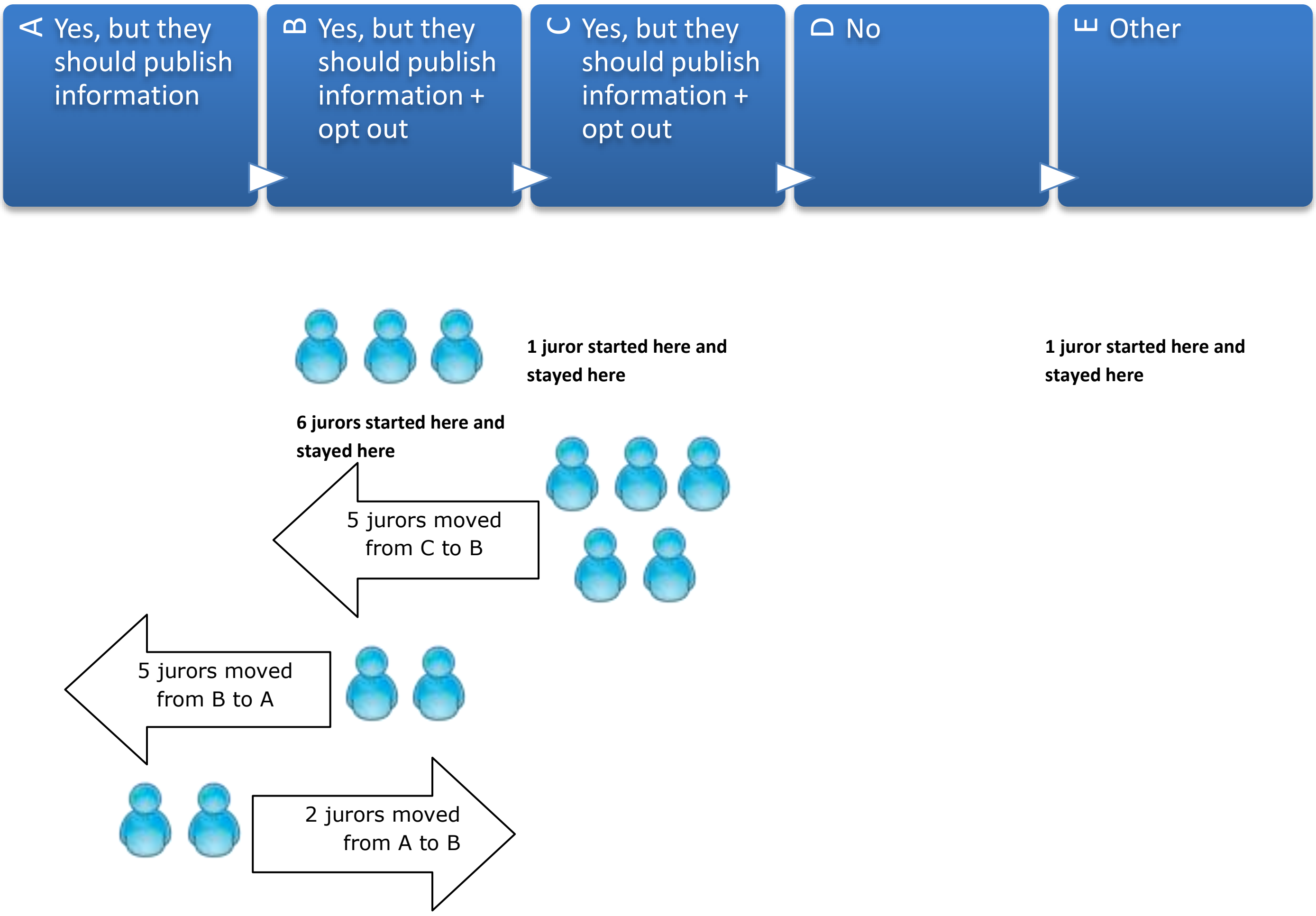
Change in jury views for Question 1
8 people did not change their view at all. 6 of these had selected option B. 1 had selected C and the other E.

As shown in Figure 3, 9 people changed their view by 1 category. Of these:
- 5 moved from C to B
- 2 moved from B to A
- 2 moved from A to B

This means that 41% moved toward a more “liberal” view in terms of data sharing, as framed in the jury charge.

Jury 1 results

Figure 3. Individual changes in views for Jury 1



Jury 1 results

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 whether they should begin research into a new drug for a genetic disease for which there is currently no treatment

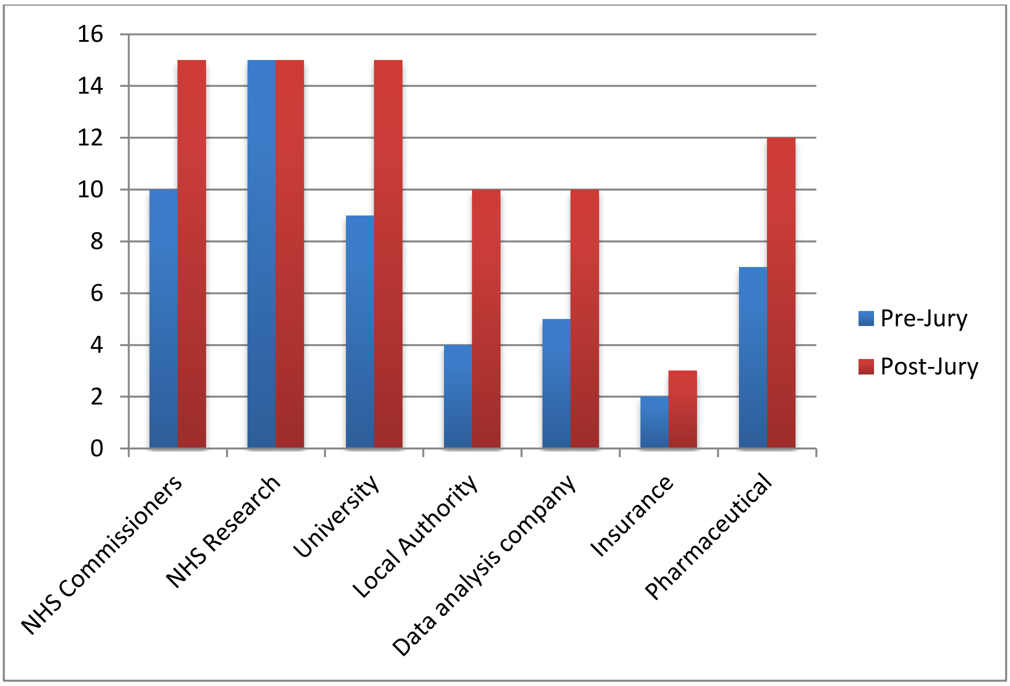


Figure 4. Pre- and post-survey views on who should access the records

<u>Changes in views for Question 2</u>

- 5 jurors changed their view regarding **NHS commissioners,** from denying access (pre-jury) to agreeing they should have access (post-jury).
- 4 jurors changed their minds about **NHS researchers**, with 2 agreeing to access pre-jury but not post jury. The other 2 agreed to allow access post-jury but not pre-jury
- 8 jurors changed their minds regarding **university researchers**, with 7 moving from denying access (pre-jury) to agreeing to access (post-jury). One went the opposite direction.
- 8 jurors changed their minds regarding **local authorities**, with 7 denying access (pre-jury) and then agreeing to access (post-jury). One went in the opposite direction.
- 5 jurors changed their minds regarding **data analysis companies**, with all five moving from denying access (pre-jury) to agreeing to access (post-jury)
- 3 jurors changed their minds regarding **insurance companies**, with 2 moving from denying access to agreeing to access (post-jury). One moved in the opposite direction.
- 5 jurors changed their minds regarding **pharmaceutical companies**, with all five moving from denying access (pre-jury) to agreeing to access (post-jury).

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[1]

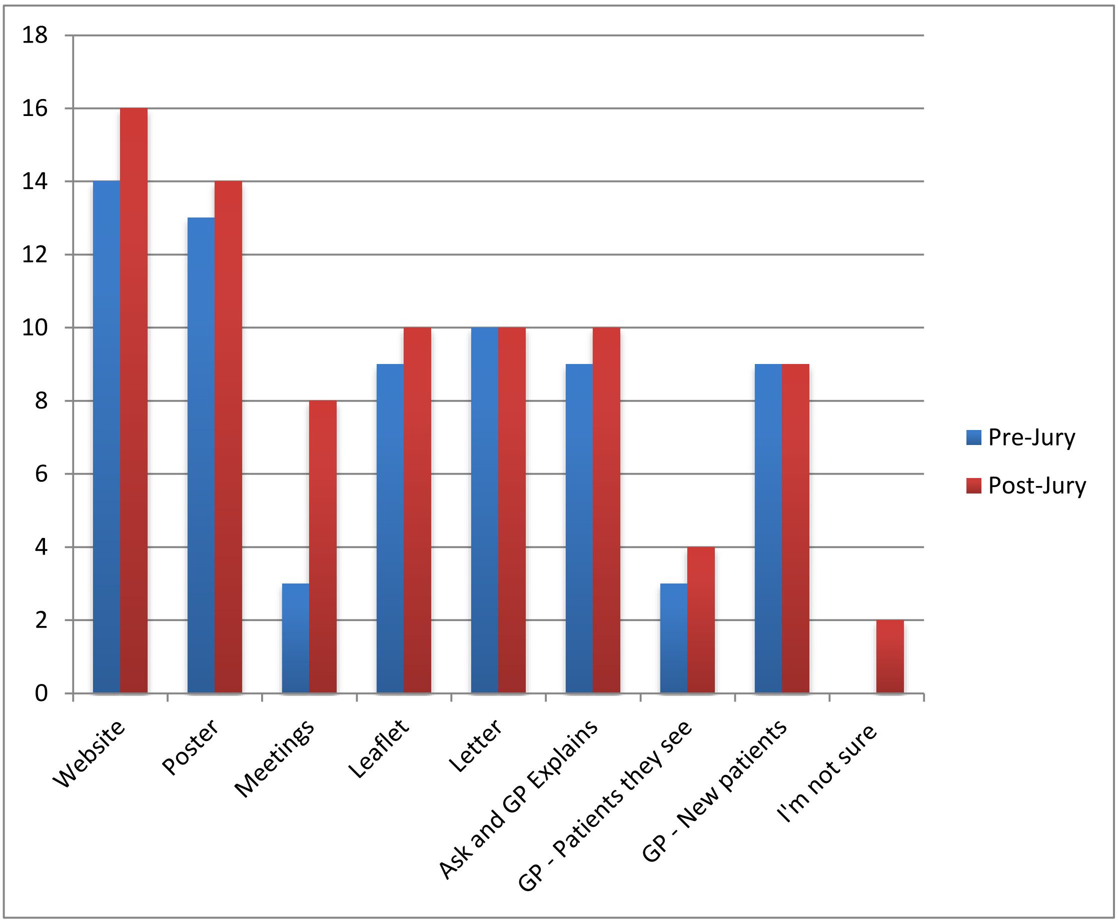


Figure 5. How should this be communicated with patients?

---

[1] One participant selected all options plus "I'm not sure".

Jury 1 results

Patient control

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

Likert scale – strongly disagree to strongly agree

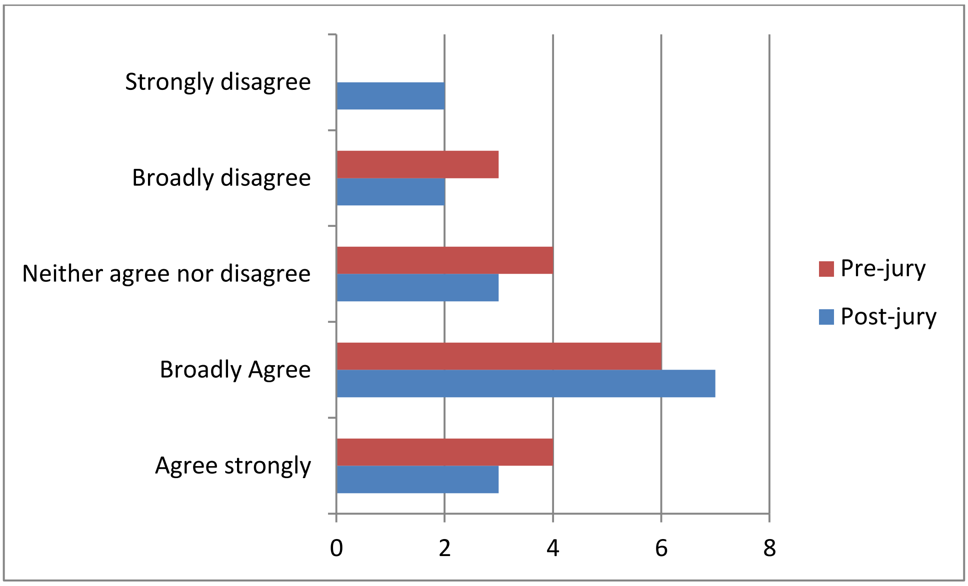
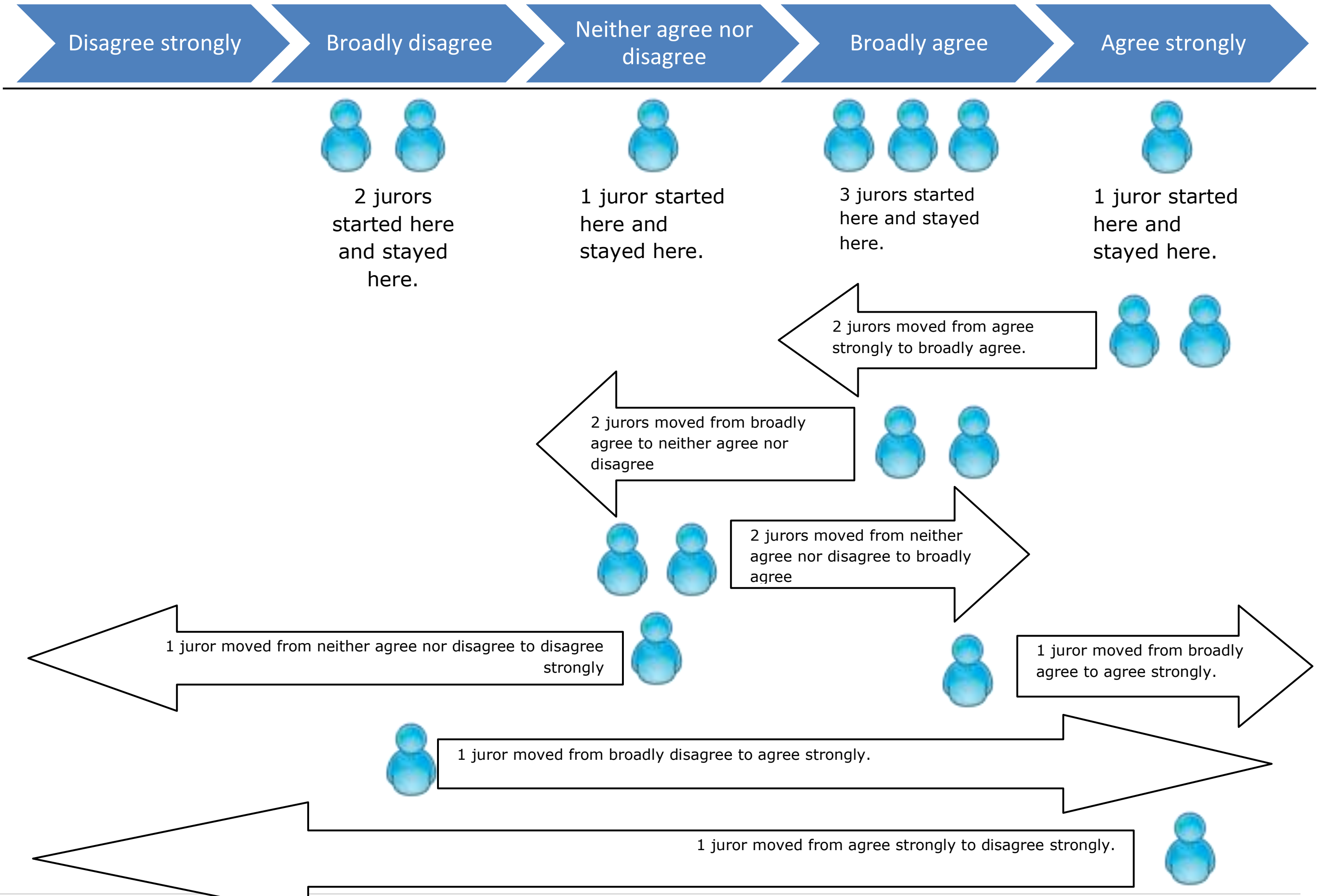


Figure 6. Patient view re: control of records about them

<u>Changes in individual views for Question 4a</u>
Individual views changed quite a bit for this question, with 10 jurors changing their views and 7 staying the same. The shifts were in both directions, as depicted in the diagram below.



2 jurors started here and stayed here.

1 juror started here and stayed here.

3 jurors started here and stayed here.

1 juror started here and stayed here.

2 jurors moved from agree strongly to broadly agree.

2 jurors moved from broadly agree to neither agree nor disagree

2 jurors moved from neither agree nor disagree to broadly agree

1 juror moved from neither agree nor disagree to disagree strongly

1 juror moved from broadly agree to agree strongly.

1 juror moved from broadly disagree to agree strongly.

1 juror moved from agree strongly to disagree strongly.

Patient trust

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

Likert scale – strongly disagree to strongly agree

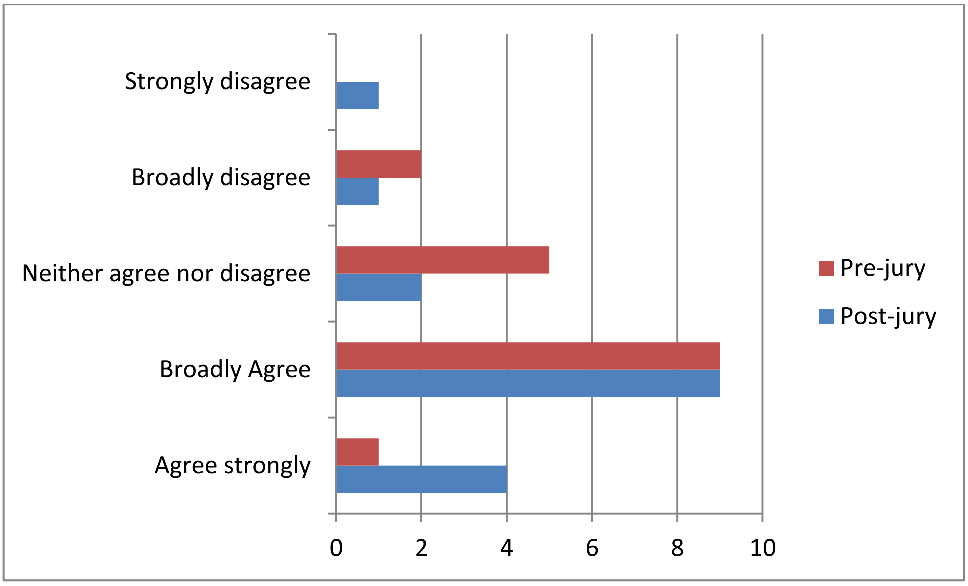


Figure 7. Participants' trust in the NHS to protect patient records

Prioritising public benefit

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

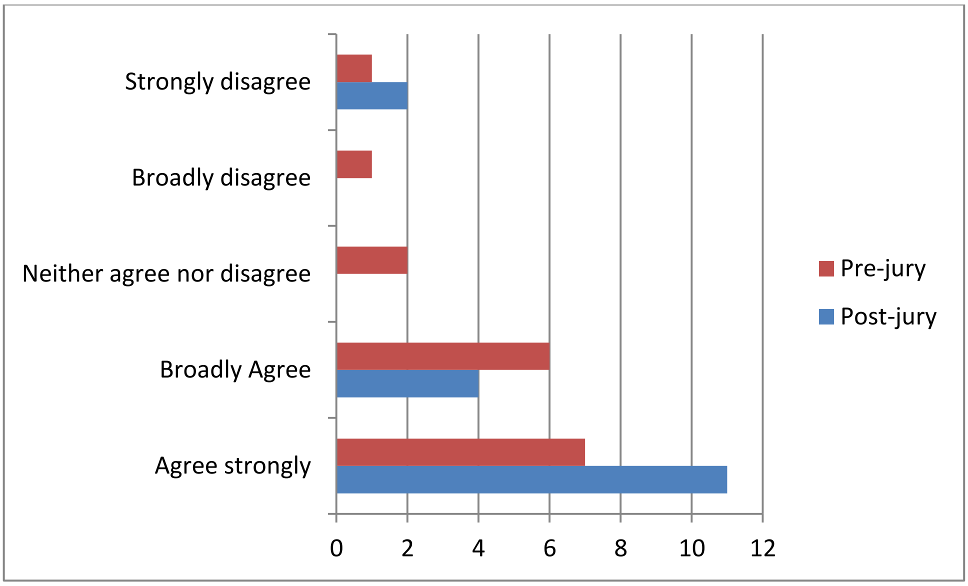


Figure 8. Participant view on whether NHS should prioritise the use of patient records to maximise public benefit

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

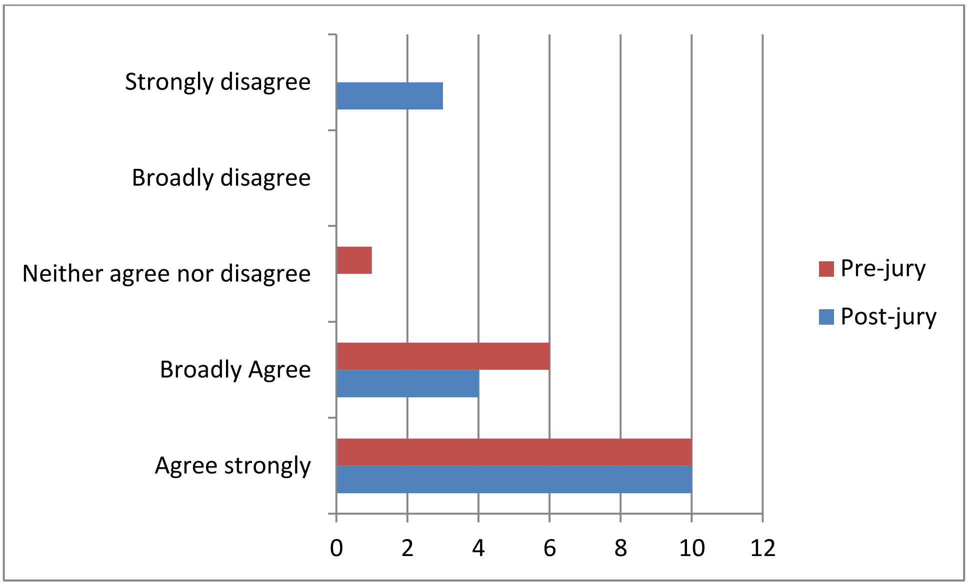


Figure 9. Participant views on privacy vs public benefit

4e) This issue is important to me

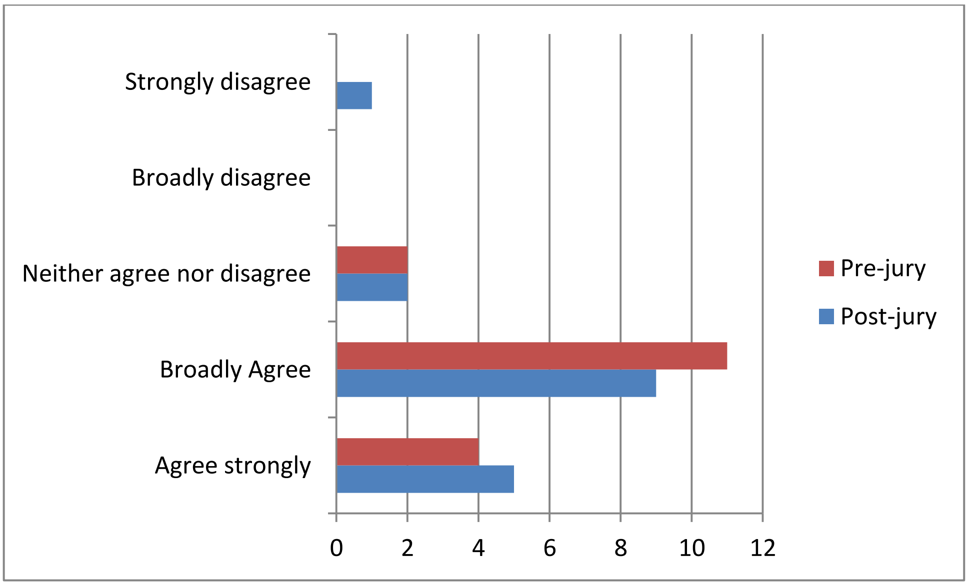


Figure 10. Participant view on importance of the issue

Jury 1 results

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".

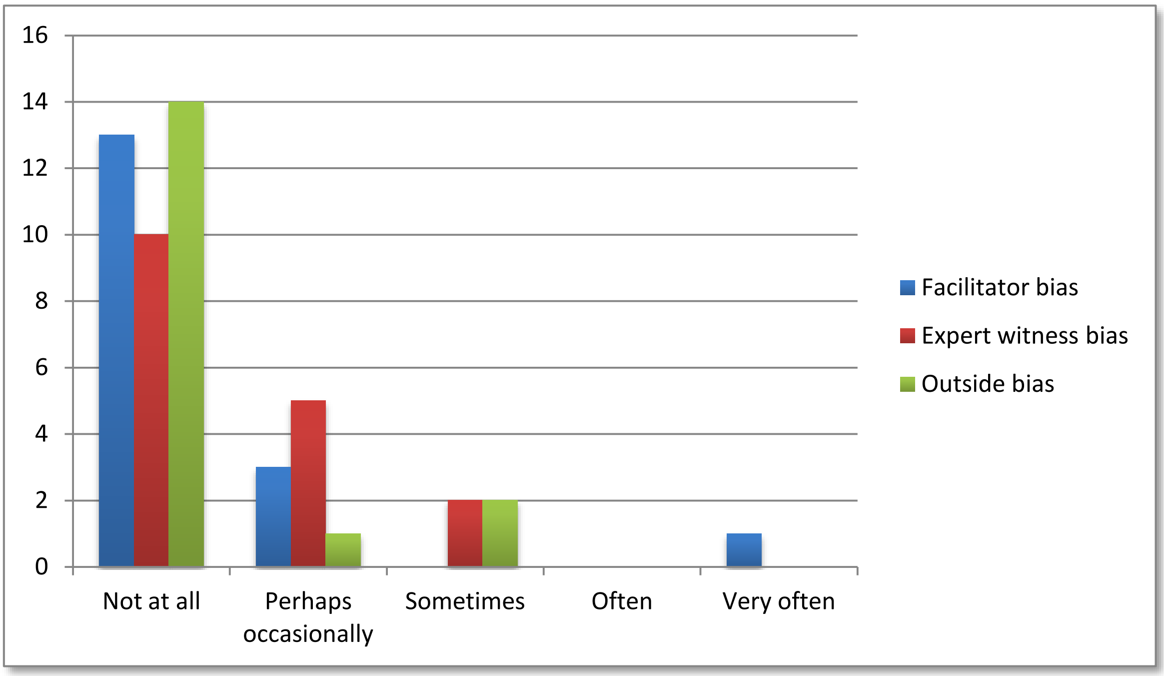


Figure 11. Participant views on bias in the jury process

Open-ended responses relating to facilitator bias (Q8)

"I didn't feel that Amanda the faciliatator should have asked for words to be changed on the final draft. This should have been left entirely to the jury."

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

"Ralph was positive about sharing the data for the good of all."

"Ralph the expert witness advocated privacy."

"The roles of the expert witnesses made them naturally inclined to imply certain things, although nothing was explicitly said to persuade us."

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

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

Two jurors indicated that they had other concerns about bias. One of these did not elaborate with a comment. The other said:

"Some questions were multiple choice and others were done by vote - results varied massively."

Another who replied no said:

"Replied no but did feel Sam presented his arguments in a slightly biased way. (didn't change my opinion)"