

**To what extent should patients control access to patient records? 2 Citizens' juries  
Oversight panel bias questionnaire**

1. Having reviewed the jury design documentation, how satisfied are you that the two citizens' juries exploring the question "to what extent should patients control access to patient records?" have been designed with the *aim* of minimising bias?

fully satisfied

2. How satisfied are you that the two citizens' juries exploring the question "to what extent should patients control access to patient records?" were *successfully designed* to minimise bias?

fully satisfied

Comments and qualifications to your answers above

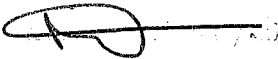
None.

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Your name      Mark Taylor

Organisation and role (optional) Senior Lecturer in Law, University of Sheffield

Signature



Date 19 February 16

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partially satisfied

Comments and qualifications to your answers above

There may be a slight bias in the materials as they relate to answering Q1 of the jury charge; in that more of the material presumes that creating the records in question is useful, necessary, and legal. For example, Ralph's presentation notes the benefits, Dawn's notes the creation of such records is legal, and Søren's presentation concludes the consent is not needed if regulatory safeguards are strong. The preamble to the charge also indicates the sharing will be "in good cause", which may not be helpful in getting jurors to think about the uses they are less comfortable with in principle. These aspects may make it difficult for jurors to consider a 'no' response to Q1. However, I think the role playing exercise will address some of this potential bias by getting jurors to think about both sides of these issues, and I think the changes to the crib sheets have largely minimised potential bias.

Regarding the partial witnesses, the witness supporting the charge has adopted a more moderate, nuanced argument, whereas the witness opposing the charge adopted a stronger position against the charge. This lack of balance between the partial witnesses may be a source of potential bias, although this could lead jurors further in either direction (eg the strong argument against the charge could be more compelling or more off-putting as compared to the more measured argument in favour). That said, this imbalance may also partially address the potential bias in favour of sharing noted above.

Regarding Q2, I have slight reservations about the mix between the "who" has access and the purpose of that access (ie "why"). Some jurors may find themselves more swayed by the who and some may be more focussed on the why, but the answers combine the two. It may be difficult to know which aspect has influenced their answers. I understand why this design decision was made, however, and again I think the role playing exercise will help jurors think about this distinction and the reasons they would support or oppose access. Deliberation during the citizens' jury exercise about the rationale behind the jury's response to the charge may also help jurors think about both aspects (ie who wants the data and why).

On balance, I am mostly satisfied that this bias has been minimised to the extent practicable within the confines of the project.

Your name Sarah Clement

Organisation and role (optional) Senior Policy Officer, Information Commissioner's Office

A handwritten signature in blue ink, appearing to read 'Sarah Clement', is centered within a light gray rectangular box.

Signature

Date 11/01/2016

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fully satisfied

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fully satisfied

Comments and qualifications to your answers above

I have selected 'fully satisfied' although I would prefer the option 'satisfied' (I don't think 'fully' or 'partially' are appropriate qualifiers here). I think I can be satisfied that the design is good; whether it is successful as a design must await its testing in practice (and it is difficult to say how successful it could be in 'minimising bias' without a sense of how low bias can be in practice, since the assumption is that it cannot be removed entirely). That said, I think the design is scrupulous and thoughtful and the comments of the oversight panel discussions were taken on board. On the strength of the materials considered in the second oversight panel discussion, I think those challenging extensions of data use may be at an argumentative disadvantage in the exercise, but this probably reflects an asymmetry in broader public debate, so would not constitute bias in that sense.

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Your name Peter Mills

Organisation and role (optional) Assistant Director, Nouffield Council on Bioethics

Signature



Date 1 February 2016