

To what extent should patients control access to patient records?

2 Citizens' juries

Background

There will be 2 citizens' juries of 18 people. Each jury will meet for three days in Manchester. 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. 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. The two 3-day juries will be run by two skilled facilitators. The juries will be informed about the questions they are exploring, partly through expert witnesses who will make presentations and answer questions posed by the jurors. Jurors will also be given time to deliberate amongst themselves before reaching their conclusions, which will later be published. The jury proceedings will be filmed (subject to juror consent).

The above process, such as the choice of expert witnesses, is open to potential bias. It is not possible to completely eliminate bias, but it is important to try to identify and minimise it as far as possible before the juries take place. One way to try to achieve this is through asking an oversight panel who are independent from the process, and who have no conflicts of interest in the juries and their outcomes, to review the design of the juries.

Brief for oversight panel

The role of the oversight panel is to look for, and identify, bias that is evident in the plans and the design of the two citizens' juries, and the citizens' jury project more generally, so that the bias can be addressed prior to the two juries (being held in January 2016). The panel may also identify gaps in the documentation which could be sources of bias.

It is proposed that this is achieved through the following process:

- Jury design documentation (no more than 20 pages) is sent to oversight panel members for review in the week beginning 14 September 2015 (after the University of Manchester research ethics meeting on 14 September where ethics approval for the project will be sought);
- A two-hour teleconference is convened for the week beginning 21 September 2015 at which members of the oversight panel can discuss the design documentation, and identify areas of potential bias;
- In response to the feedback from the oversight panel, the citizens' jury project manager Malcolm Oswald amends the design documentation, and informs the panel of the amendments made prior to beginning of the process of recruiting jurors in October 2015;
- The above process is repeated in December 2015 in order to review prepared content for the sessions e.g. scenarios for the juries to explore (again, no more than 20 pages);
- Members of the oversight panel are asked to complete a short oversight panel bias questionnaire (see below), which will then be published.

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Oversight panel bias questionnaire**

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?

not satisfied

partially satisfied

fully satisfied

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?

not satisfied

partially satisfied

fully satisfied

Comments and qualifications to your answers above

Name

Organisation and role (optional)

Signature

Date
