Citizens’ Jury Design Specification

<table>
<thead>
<tr>
<th>Jury name</th>
<th>To what extent should patients control access to patient records?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jury mission (i.e. the questions the jury must answer)</td>
<td>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.</td>
</tr>
</tbody>
</table>

1. (i) Should the NHS body be allowed to create these records about you and other patients?  
   [Choose 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) Give reasons for your answer (in less than 300 words)  

2. (i) Given your answer to question 1, who should be allowed to access and extract data from the records created?  
   [Choose 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) Give reasons for your answer (in less than 400 words)  

| Other jury outputs | Jury report of conclusions  
|---------------------|--------------------------------------------------------|
| Video of jury proceedings  
Signed consent forms from jurors |
|-----------------------------|
| Jury dates (3 days each)  
Jury 1: 14-16 January 2016  
| Venue for juries  
F12, F13 (Upper hall), Friends House, 6 Mount Street, Manchester, M2 5NS |
| Number of jurors  
Jury 1: 18 jurors (plus 5 substitutes paid to turn up on day 1)  
Jury 2: 18 jurors (plus 5 substitutes paid to turn up on day 1)  
Note: No juror can participate in both juries |
| Jury method  
As set out in the Jefferson Center’s Citizens’ Jury Handbook |
| Juror eligibility criteria  
Resident in Greater Manchester for 1 year minimum  
Over 18 years of age  
Has mental capacity to consent to participation in jury  
Fluent in English |
| Juror exclusion criteria  
NHS healthcare professional (present or past)  
Special interest or conflict of interest in jury mission  
Should not know other jurors (other than by coincidence) |
| Juror recruitment method  
Various, such as face-to-face, emailing groups (disinterested in jury mission), web job recruitment site. Will not involve cold phone calling. |
| Juror payment  
£375 for 3 days including expenses per juror (to be paid at end of day 3)  
£25 per juror for saving the 3 diary dates and turning up on day 1 (cash paid on day 1)  
£75 for five reserve jurors for saving the 3 diary dates and turning up on day 1 (cash paid on day 1) |
| Jury sample controls (to represent adult residents of England)  
Sex  
Age  
Ethnicity  
Educational attainment  
Prior views on privacy of patient records |
| Target sample - Sex  
Females: 51%, 8 - 10 jurors  
Males: 49%, 8 - 10 jurors |
| Target sample - Age  
Aged 18-29: 21%, 2 - 5 jurors  
Aged 30-44: 26%, 3 - 6 jurors  
Aged 45-59: 25%, 3 - 6 jurors  
Aged 60+: 28%, 4 - 7 jurors |
| Target sample – Ethnic group  
White: 85%, 14 - 17 jurors  
Groups other than White: 15%, 2 - 4 jurors |
| Target sample - Educational attainment  
Level 1 or no qualifications: 36%, 5 - 8 jurors  
Level 2, level 3, apprenticeship & other qualifications: 37%, 5 - 8 jurors  
Level 4 qualifications and above: 27%, 4 - 6 jurors |
| Target sample – Privacy views  
“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 this information should be shared within government. Data sharing can bring benefits, such as finding more effective |

1 Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics  
2 Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics  
3 Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics  
4 Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics  
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”

Agree more with a than b: 52%, 7 - 11 jurors
Agree more with b than with a: 34%, 5-7 jurors
Agree equally with both / don’t agree with either/don’t know: 14%, 1 - 4 jurors

| Expert witnesses | 2 witnesses on day 1 to inform jurors about:
|--------------------|---------------------------------------------------|
| a. the information held in patient records, and the uses to which those records can be put, by whom, and for what purposes
| b. the rights patients currently have with respect to their records, and how they are used
| 3 witnesses on day 2 to put forward arguments relating to jury mission (both for and against patients controlling access to patient records). |

| Controls for bias | Oversight Panel to review jury specification and jury materials. Oversight panel to contain a minimum of three people with no conflict of interest in the jury outcomes (though they may have a special interest in the jury mission). Jury funders (University of Manchester) may influence jury mission but are independent from the jury process and outcomes. Expert witnesses briefed to be either impartial information givers (day 1) or partial persuaders (day 2) but not both. Jurors work with facilitators to construct the statements that address their mission. Post-jury questionnaires ask jurors to identify signs of bias, and questionnaire results are published. Jury process is filmed and made available on request for research. Jury to be run twice with same facilitators and witnesses and jury process but with two different sets of jurors in order to validate outcomes. |