Citizens' Jury Design Specification

Jury name	To what extent should patients control access to patient records?
Jury mission (i.e. the questions the jury must answer)	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. 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 Jurors to complete juror questionnaires before and after three-day jury session

	Video of jury proceedings Signed consent forms from jurors
Jury dates (3 days each)	Jury 1: 14-16 January 2016 Jury 2: 21-23 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[1]	Females: 51%, 8 - 10 jurors Males: 49%, 8 - 10 jurors
Target sample - Age[2]	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[3]	White: 85%, 14 - 17 jurors Groups other than White: 15%, 2 - 4 jurors
Target sample - Educational attainment[4]	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[5]	"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
[5] Target sample percentages based on "Perceptions of Data Sharing" survey of 506 GB adults aged 16-75 by Ipsos Mori, 23 – 25 June 2014, page 40, available at https://www.ipsos-mori.com/Assets/Docs/Publications/rss-privacy-and-data-sharing-tables-2014.pdf

	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. Funders' influence over jury design is controlled (main role is in articulating jury mission) 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.