

Citizens' Jury Specification

<i>Item</i>	<i>Description</i>
Jury name	Pandemic Data Sharing Juries
Jury questions (i.e. the questions the jury must answer)	<p>The three citizens' juries will all consider the same questions. The juries will consider three pandemic data initiatives which were introduced or substantially changed in response to Covid-19::</p> <ul style="list-style-type: none"> • Summary Care Record (which was extended to include more data about patients during the pandemic) • NHS Covid-19 Data Store (which was created in response to the pandemic) • OpenSAFELY (which uses primary care data for research). <p>For each initiative, the jury will address the following questions:</p> <ol style="list-style-type: none"> 1. a) How supportive are you of the decision to introduce this data sharing initiative in 2020 as part of tackling the COVID-19 outbreak? Very much in support/ Broadly supportive/ Neutral/ Broadly opposed/ Very much opposed b) "What are the most important reasons to be supportive?" c) "What are the most important reasons to oppose the initiative?" 2. What should the future of the data sharing initiative be? <ol style="list-style-type: none"> a) For how long should the initiative continue <ol style="list-style-type: none"> i. As short a time as possible ii. Only as long as the Covid pandemic continues and emergency powers¹ are in place iii. As long as it is valuable (potentially beyond the pandemic and for Covid and non-Covid uses) iv. Something else b) By whom should these decisions be made? <ol style="list-style-type: none"> i. An independent advisory group of experts and lay people ii. The minister or organisation accountable for the data initiative iii. Parliament iv. Someone else c) How could or should the initiative and its uses be usefully changed in the future (if at all)? d) What actions, if any, could be taken to engender greater public trust in the initiative? e) What are the main reasons for these answers? <p>[Note that there are many questions above, each for several case studies, and to fit the process design into the time available may require that some or all of the</p>

¹ Emergency powers are in place to deal with the pandemic, see:
<https://www.instituteforgovernment.org.uk/explainers/emergency-powers>

	<p>answers to Q2c), d) and e) will be given by individuals rather than by the jury as a group.]</p> <p>At the end of each jury, the jury will be asked:</p> <p>3. What lessons can we learn from how these pandemic data initiatives were introduced</p> <ul style="list-style-type: none"> ○ which could be useful for future pandemics? ○ which could be useful outside of pandemics? <p>Following discussions with NHS England and NHS X, two “sub-case studies” will be added to the NHS Covid-19 Data Store for the jury to consider. These are systems reliant on the Data Store:</p> <ul style="list-style-type: none"> ● The Early Warning System ● The Immunisation and Vaccination Management (I&V) Capability. <p>The juries will answer two of the above questions about each of these sub-case studies: 1 a) and 2a).</p>
Other jury outputs	<p>Jurors’ reports (developed during the jury process using the jurors’ own words)</p> <ul style="list-style-type: none"> - 1 for Manchester jury - 1 for rural Sussex jury - 1 for National jury <p>Juries’ Report</p> <p>End-of-jury questionnaires – 1 per juror</p> <p>Word cloud of juror experiences</p> <p>Video</p> <p>Colour brochure about juries</p> <p>Post-jury workshop</p> <p>Policy paper</p>
Jury duration and venues	<p>Three juries, each equivalent to 5 full days duration, but running over a two-week period, with 8 days of online sessions of approximately 4.5 hours each with a break in the middle.</p> <p>The dates for the three juries are:</p> <ul style="list-style-type: none"> - Jury 1, National jury: 16-19, 22-25 March; - Jury 2, Greater Manchester jury: 6-9 April, 12-15 April; - Jury 3, Sussex jury (primarily rural): 27-30 April, 3-6 May.
Number of jurors	18 jurors (plus up to 3 substitutes paid to participate in day 1) per jury
Jury method	As practised by Jefferson Center (based on the Jefferson Center’s Citizens’ Jury Handbook)
Juror eligibility criteria ²	<p>Resident in UK for 1 year minimum</p> <p>Over 18 years of age</p> <p>Has capacity to consent to participation in jury</p> <p>Has capability to contribute constructively to jury</p> <p>Fluent in English</p>
Juror exclusion criterion ³	Special interest or conflict of interest (e.g. health researcher) in jury questions
Juror recruitment	Indeed job recruitment website, volunteer websites, Healthwatch

² These criteria will be judged through a phone call with potential jurors after shortlisting.

³ This criterion will be judged through a phone call with potential jurors after shortlisting.

method	
Juror payment	£480 per juror for participation in full event. £80 each for 3 reserve jurors per jury for saving all the diary dates and for participation in first 4.5 hour session on day 1. All paid by electronic bank transfer.
Jury sample controls (to represent adult residents of England)	Gender (as chosen by applicant) Age range Ethnicity Educational attainment Employment status Prior views on attitudes to data sharing in a pandemic (see below) For national jury, a broad geographical spread across England will also be sought
Target sample - Gender ⁴	Females: 51%, 8 - 10 jurors Males: 49%, 8 - 10 jurors Other: 0 - 1 jurors
Target sample - Age ⁵	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 ⁶	White: 85%, 14 - 16 jurors Groups other than White: 15%, 2 - 4 jurors [Black / African / Caribbean / Black British (0-1 jurors); Mixed / Multiple ethnic groups (0-1 jurors); Asian/ British Asian (0-2 jurors); Other (0-1 jurors)]
Target sample - Educational attainment ⁷	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 – employment status ⁸	Employed or self-employed: 75% of 16-64 year olds, 8-14 jurors
Target sample – Prior views ⁹	Q: Thinking about your confidential NHS and social care information, please indicate how concerned you are about ...: Data being shared unlawfully or accidentally with organisations outside of the NHS and care system. a) I don't know/I haven't really thought about this b) I am very concerned about this c) I am quite concerned about this d) I am not really concerned about this

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

⁵ Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

⁶ Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

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⁸ Target sample percentages based on UK employment rate, September 2017

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes>

⁹ Target sample percentages based on TG30 (Column C) of online survey of a representative sample of 2114 GB adults aged over 16 commissioned by National Data Guardian's Office and carried out by Kantar in August 2020. It is available from Jenny Westaway and publicised at <https://www.gov.uk/government/news/polling-indicates-growing-public-understanding-about-importance-of-using-health-and-care-data>

	<p>a)18%, 2 - 4 jurors per jury b): 36%, 6 - 7 jurors per jury c): 32%: 5-7 jurors per jury d): 13% 2 – 3 jurors per jury</p>
Oversight Panel	<p>Rachel Thomson, Swansea University Katherine Wright, Nuffield Council on Bioethics Christine Patch, Caldicott Guardian for Genomics England</p>
Controls for bias	<p>Oversight Panel to review jury specification, design 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 questions). Jury funders to set jury questions but not determine the jury process and outcomes. Expert witnesses briefed to be either impartial information givers or partial persuaders but not both. Jurors work with facilitators during the jury process to construct the report of jury results. Oversight Panel and juries to complete questionnaires to identify signs of bias, and questionnaire results are published. All non-proprietary products from the jury process are published.</p>