

## Connected Health Cities Citizens' Jury Design Specification

Jury name	Connected Health Cities using patient data – what is acceptable?
<p>Jury questions (i.e. the questions the juries will address over the 4 days - note that Q1 and Q5 will also be asked on the pre-jury questionnaire)</p>	<p>1. Which of the following uses of NHS data about patients (with identifiers like name and address removed) are acceptable?  <i>[Choose yes, no, or unsure]</i></p> <ul style="list-style-type: none"> <li>a. NHS staff working for Salford Royal Hospital get data from ambulances and hospitals. The purpose is to do research to help paramedics get better at spotting the signs of people who have had a stroke.</li> <li>b. University researchers in Leeds get data from hospitals, GPs and social care about frail elderly patients. The purpose is to help GPs identify individual patients needing extra care and follow up.</li> <li>c. University researchers in Liverpool get data from hospitals and GPs. The purpose is to provide information to doctors, nurses and ambulance staff about how to give more appropriate care to people suffering from alcohol-related problems.</li> <li>d. University researchers in Newcastle get data from hospital, GP and local authority records. The purpose is to plan future demand for A&amp;E services and meet the needs of special groups (e.g. people with dementia).</li> </ul> <p>Explain the most important factors affecting your choices (up to 300 words).</p> <p>2. Overall, are the rules over access to health data proposed by Connected Health Cities sufficient to allow these planned uses?  <i>[Choose only one]</i></p> <ul style="list-style-type: none"> <li>a. Certainly sufficient</li> <li>b. Probably sufficient</li> <li>c. Probably insufficient</li> <li>d. Certainly insufficient</li> </ul> <p>Explain the most important factors affecting your choice (up to 300 words).</p> <p>3. If you answered c. or d. to Q2, what else, if anything, would you want done before allowing these planned uses? (up to 300 words)</p> <p>4. Which of the following <b>potential</b> uses of NHS data about patients are acceptable?  <i>[Choose yes, no, or unsure]</i></p> <ul style="list-style-type: none"> <li>a. A pharmaceutical company requests general practice data about patients (with identifiers like name and address removed) including prescriptions, blood glucose measurements, and complications of diabetes patients. The purpose is to understand better what prescribing patterns get the best results for patients.</li> <li>b. A large computer software company seeks data about patients from hospital and general practices (with identifiers like name and address removed) including patient symptoms, diagnoses and outcomes. The purpose is to enable its intelligent software to “learn” and so be used</li> </ul>

	<p>to aid future diagnosis of sepsis, a life-threatening condition.</p> <p>c. A developer of an app, designed for a wearable device like a fitbit that tracks a person’s activity and measures key health indicators like blood pressure, seeks hospital data about patients (with identifiers like name and address removed). The purpose is to enable them to design the app to suggest safe fitness regimes tailored to each individual’s capability and characteristics (age, weight etc.).</p> <p>d. A health club chain seeks aggregated data (i.e. total numbers of patients) comparing levels of exercise, smoking history, alcohol consumption, body mass index, blood pressure for people who have had a heart attack with those who have not had a heart attack. The purpose is to understand and identify the type of club members who are most at risk of a heart attack and monitor them.</p> <p>Explain the most important factors affecting your choices (up to 300 words)</p> <p>5. Overall, are the rules over access to health data proposed by Connected Health Cities sufficient to justify the <i>potential</i> uses? [Choose only one]</p> <p>a. Certainly sufficient b. Probably sufficient c. Probably insufficient d. Certainly insufficient</p> <p>6. If you answered c. or d. to Q5, what else, if anything, would you want done before allowing these potential uses? (up to 300 words)</p>
Main jury outputs	<p>Signed consent forms from jurors</p> <p>Report of jury results (one per jury)</p> <p>Completed juror questionnaires from before and after four-day jury session</p> <p>Summary of questionnaire results</p> <p>Wordle of jury experiences</p> <p>A4 sheet about jury results?</p> <p>Jury video?</p>
Jury dates (4 days each)	<p>Jury 1: 2 – 5 November 2016</p> <p>Jury 2: 9 - 12 November 2016</p>
Venues for juries	<p>Jury 1: <a href="#">F12, F13 (Upper hall), Friends House, 6 Mount Street, Manchester, M2 5NS</a></p> <p>Jury 2: <a href="#">Mallard Suite, National Railway Museum, Leeman Road, York YO26 4XJ</a></p>
Number of jurors	<p>Jury 1: 18 jurors from West of the Pennines (plus 4 substitutes paid for day 1)</p> <p>Jury 2: 18 jurors from East of the Pennines (plus 4 substitutes paid for day 1)</p>
Jury method	As set out in the Jefferson Center's Citizens' Jury Handbook
Juror eligibility criteria <sup>1</sup>	<p>Resident in eligible area for 1 year minimum</p> <p>Over 18 years of age</p> <p>Has capacity to consent to participation in jury</p> <p>Has ability to contribute constructively to jury</p> <p>Fluent in English</p>
Juror exclusion criteria	<p>NHS healthcare professional (present or past)</p> <p>Special interest or conflict of interest in jury mission</p> <p>Should not know other jurors (other than by coincidence)</p>

<sup>1</sup> These criteria will be judged through a phone call with potential jurors after shortlisting.

Juror recruitment method	Primarily free web job recruitment site (Indeed) and local newspapers, but also emails to contact lists
Juror payment	£400 for 4 days per juror (to be paid into bank account after jury) Travel allowance of £0.40 per mile per juror and reserve juror (cash paid on day 1 and 3) £75 for substitute jurors for saving the 4 diary dates and turning up on day 1 (cash paid on day 1) Paid overnight accommodation for jurors living over 30 miles from venue
Jury sample controls (to represent adult residents of England)	Place of residence Sex Age Ethnicity Educational attainment Prior views on privacy of patient records
Target sample – place of residence	Jury 1: 7 – 11 from Greater Manchester, 7-11 from NW region (spread of postcodes) Jury 2: 7 – 11 from Yorkshire (spread of postcodes), 7 – 11 from NE region (spread of postcodes)
Target sample - Sex <sup>2</sup>	Females: 51% (NW+M/cr), 51% (NE&Yorks), 8 - 10 jurors per jury Males: 49%, (NW+M/cr), 49% (NE&Yorks), 8 - 10 jurors per jury
Target sample - Age <sup>3</sup>	Aged 18-29: 21%, 2 - 5 jurors per jury Aged 30-44: 26%, 3 - 6 jurors per jury Aged 45-59: 25%, 3 - 6 jurors per jury Aged 60+: 28%, 3 - 7 jurors per jury
Target sample – Ethnic group <sup>4</sup>	White: 90% (NW+M/cr), 92% (NE&Yorks), 15 - 17 jurors per jury Groups other than White: 10% (NW+M/cr), 8% (NE&Yorks), 1 - 3 jurors per jury, one of whom is Asian/British Asian
Target sample - Educational attainment <sup>5</sup>	Level 1 or no qualifications: 38% (NW&M/cr), 40% (NE&Yorks) 5 - 8 jurors per jury Level 2, level 3, apprenticeship & other qualifications: 37% (NW&M/cr), 38% (NE&Yorks) , 5 - 8 jurors per jury Level 4 qualifications and above: 24% (NW&M/cr), 23% (NE&Yorks ) 3 - 6 jurors per jury
Target sample – Privacy views <sup>6</sup>	How willing or unwilling would you be to allow your medical records to be used in a medical research study? The information given to researchers would not include your name, date of birth, address or any contact details.

<sup>2</sup> Target sample percentages based on Overview of the UK population: February 2016 from the Office for National Statistics at:

<http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/february2016#how-does-the-population-differ-across-the-uk>

<sup>3</sup> Target sample percentages based on 2011 UK Census Data for England from the Office for National Statistics

<sup>4</sup> Target sample percentages based on 2011 UK Census Data from the Office for National Statistics of Ethnicity across the English regions and Wales, available at:

[http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171776\\_290558.pdf](http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/dcp171776_290558.pdf)

<sup>5</sup> Target sample percentages based on 2011 Census: Key Statistics for England and Wales, March 2011, at:

<http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/2011censuskeystatisticsforenglandandwales/2012-12-11#qualifications>

<sup>6</sup> Target sample percentages based on “Wellcome Trust Monitor Report Wave 3” survey of a representative sample of 1524 UK adults aged over 18 by Ipsos Mori, 2 June to 1 Nov 2015, page 59, available at <https://wellcome.ac.uk/sites/default/files/monitor-wave3-full-wellcome-apr16.pdf>

	<p>a) Very willing  b) Fairly willing  c) Fairly unwilling  d) Very unwilling  e) Don't know</p> <p>a): 43%, 7-8 jurors per jury  b): 34%, 5-7 jurors per jury  c) + d): 21% (10%+11%), 3 – 4 jurors per jury  e): 3%, 0 – 1 jurors per jury</p>
Expert witnesses	<p>2 witnesses to inform jurors about:</p> <ol style="list-style-type: none"> <li>the information held in patient records, and the uses to which those records can be put, by whom, and for what purposes</li> <li>the law relating to health records and including rights patients currently have with respect to their records</li> </ol> <p>1 witness to set out CHC governance controls  1 witness to explain four CHC these planned uses of health data  1 witness to ask and answer questions so that a fair balance of information is provided to jury about CHC governance controls and planned uses  1 witness to put forward ethical arguments relating to jury questions (both for and against restricting/increasing access to health data).  1 witness to answer questions about potential uses  1 witness to ask and answer questions so that a fair balance of information is provided to the jury about potential uses</p>
Controls for bias	<p>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 questions).  Jury funders (Connected Health Cities) to influence jury questions but are independent from the jury process and outcomes.  Expert witnesses (days 1 and 2) briefed to be either impartial information givers or partial witnesses to argue for a particular viewpoint.  Jurors work with facilitators to construct the Report of Jury Results.  Oversight Panel and juries to complete questionnaires to identify signs of bias, and questionnaire results are published.  Jury to be run twice in two different cities with same facilitators and witnesses and jury process but with two different sets of jurors in order to validate outcomes.</p>