



# Connected Health Cities Citizens' Juries Report

**A report of two citizens' juries designed to explore whether the planned and potential uses of health data by Connected Health Cities are acceptable to the public**

**January 2017**



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# Foreword

Connected Health Cities take seriously the responsibilities associated with using health data. An important part of this responsibility is to demonstrate that we are using the data responsibly for the benefit of patients across the north of England, ensuring that we are trustworthy through transparent and open dialogue. The citizens' juries are one of a number of ways that the Connected Health Cities programme is working in partnership with the public to understand their views regarding the use of data to improve health services.

Connected Health Cities commissioned the citizens' juries to find out what people thought about some of our planned uses of health data. We chose this method of public involvement as it gave the jury members the time and opportunity to ask questions and deliberate about the range of evidence presented to them. This report tells us that, whereas the majority of people were supportive about our plans, others felt they had legitimate reasons to be concerned about whether there would be public benefit from those uses. In particular, their prior beliefs about how and why the NHS operates raised concerns about whether improving efficiency would lead to inequitable distribution or closure of services and whether the lack of funding or political will to implement new services would lead to increased public dissatisfaction due to expectations having been falsely raised.

Over the next six to twelve months Connected Health Cities will use the results of these juries to help inform the ways that we will provide information and engage in conversation with the people of the north of England.



Professor John Ainsworth  
Director, Connected Health Cities

January 2017

# Report on Connected Health Cities Citizens' Juries

On 2 November 2016, 18 people gathered at Friends' Meeting House in Manchester and began a "[citizens' jury](#)". A week later, a different cross-section of 18 citizens came together at the National Rail Museum in York for four days and went through the same process. The task for these 36 citizens was to tackle a set of [jury questions](#) (sometimes referred to as the "jury charge") about how [Connected Health Cities](#) (CHC) should protect and use health data, and to judge which planned and potential uses are acceptable. Over four days, the citizens heard from, and asked questions of, [expert witnesses](#), and carried out group exercises to explore the jury questions. They reached conclusions together, and were polled on their individual views at the start and end of the jury.

The people on the Manchester jury were drawn from two CHC regions (North West Coast and Greater Manchester) and the York jury was made up of people from the other two CHC regions: (Yorkshire and Humberside, and North East and Northern Cumbria).

This report explains [why](#) the two juries were held, how they were [designed](#), what the [jurors did](#), the [juries' findings](#), and the [results of the questionnaires](#) completed at the start and end of the juries. Further information about the juries can be found at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury)

## Why the citizens' juries were run

Connected Health Cities has three aims:

1. To develop a system that will continually improve care services and health. This system will make health care more efficient by providing information to health service managers that can be quickly implemented into standard practice. This system is known as a [Learning Health System](#).
2. To work with and gain the public's trust that we are using health data responsibly, safely and to improve services for the benefit of all patients.
3. To stimulate the UK's digital health economy by encouraging new technologies to be developed and new services to be created.

To meet these aims, CHC will be using anonymised data that have been derived from patient records held in general practices, hospitals and elsewhere. However, it is also important to protect an individual's privacy and their interests in keeping health information about them confidential. In order to understand better how the public balances these competing goals, and responds to CHC's planned and potential uses of data, CHC commissioned the two citizens' juries. It forms part of CHC's programme of work to meet the second aim above.

There is much to know and consider about how and why the CHC programme plans to protect and use anonymised data about patients. The citizens' jury method was chosen because it gives time for a broadly representative sample of citizens to learn about, and deliberate on, whether CHC's plans are acceptable.

## Planning and designing the CHC citizens' juries

The two juries were planned, designed and refined over a period of seven months. There are many aspects to the jury design including:

- the [jury questions](#);
- the jury demographics and [recruitment](#) approach;
- the brief and selection of individuals to act as [expert witnesses](#);
- the brief and selection of individuals to act as members of the [oversight panel](#);
- the [programme of jury activities](#) across the four days; and
- the design of the [questionnaires](#) completed at the start and end of the juries.

The design documentation is available at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury)

Bias, both conscious and unconscious, is an important criticism of citizens' juries.[1] For example, it is very difficult to know what constitutes "impartial information" or balanced argument, and almost every design choice, even down to a bullet point on a presenter's slide, could be challenged on grounds that it might manipulate the citizens' jury towards one outcome or another.

Bias can be monitored and minimised but not eliminated. To monitor and minimise bias on this project, an [oversight panel](#) was appointed to review the jury design and materials, and report potential bias. The end of jury questionnaires also asked about bias. The maximum bias reported was by the York jury where three out of 18 jurors reported that witnesses on days 2 and 3 were biased either "perhaps occasionally" or "sometimes" in favour of information sharing.

Other design controls used to monitor and minimise bias included:

- The CHC [jury funders](#) were involved in setting the jury questions but were independent from the jury process and outcomes;
- The juries worked with facilitators to construct their own [reports of their findings](#); and
- The detailed jury design and results documentation being published.

## Jury recruitment

In total, 694 people applied to be a juror by completing an on-line survey. Shortlisted candidates had a brief telephone interview so that any ineligible candidates (e.g. healthcare professionals<sup>1</sup>) could be identified and excluded. Eighteen people (9 from two CHC regions) were recruited to provide a broadly representative sample of resident adults in North West England (for the Manchester jury). Similarly, there were 18 people (9 from Yorkshire and Humber, and 9 from North East and North Cumbria) on the York jury. Of the 36 jurors, 13 people were found through the Indeed jobs website, 10 through local newspaper advertisements, 5 by email, 5 by word of mouth, and 3 people by other means.

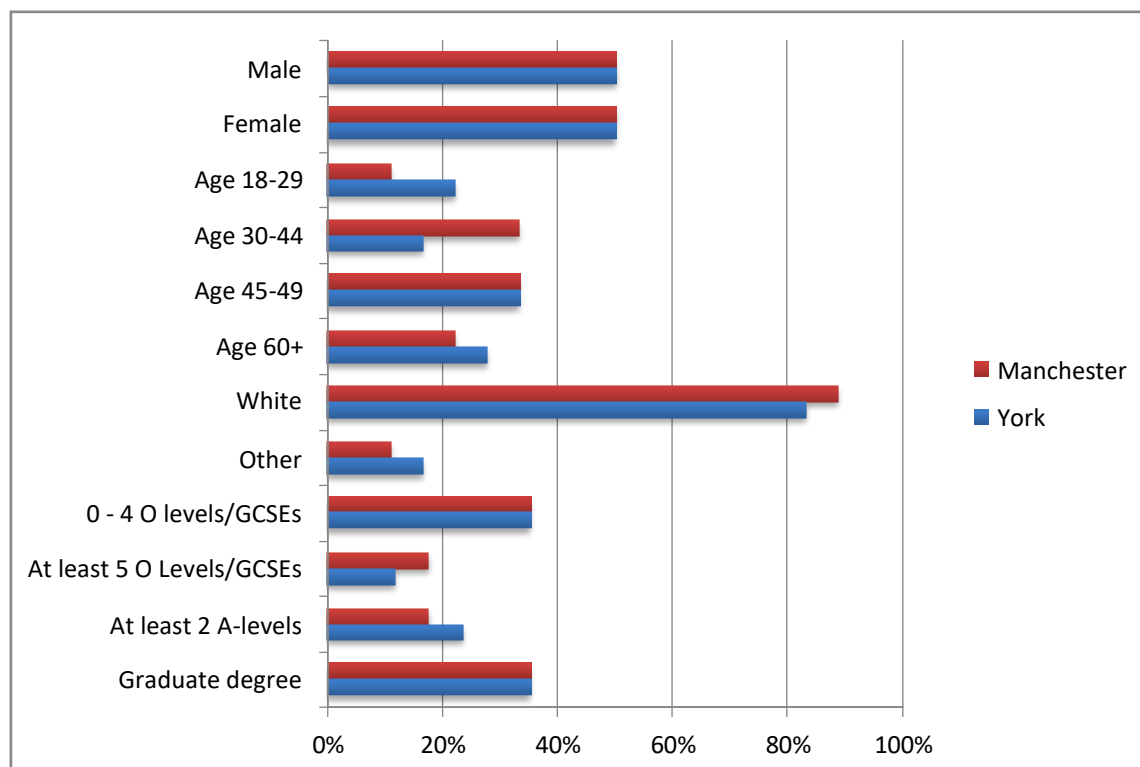
Each juror was paid £400 for four days plus an expense allowance which varied according to distance from their home to the venue. Seven reserve jurors were also recruited and paid to attend the morning of the first day. One reserve was needed to substitute for a jury member who did not attend the York jury.

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<sup>1</sup> For a full list of exclusion criteria, see the CHC Jury Specification at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury)

The sample chosen was controlled for gender, age range, ethnicity (in terms of white/other), and educational attainment (see chart below). The sample matched closely the demographics of people from the two geographical areas from which they were drawn<sup>2</sup>.

**Figure 1: Demographic make-up of Manchester and York juries**



Applicants also answered a question taken from a national survey to test their prior views on balancing privacy with health record sharing. [2] The range of views in each jury matched very closely those reported in the national survey.

## The jury process and juries' reports

The two juries in Manchester and York followed the same 4-day programme:

- [Pre-jury questionnaire](#) completed at the start of day 1
- Two facilitators: Kyle Bozentko of the Jefferson Center, and Victoria Chico, Lecturer in Law at the University of Sheffield;
- 9 [expert witnesses](#);
- [Ring binder of information](#);
- Group exercises and deliberation; and
- [End-of-jury questionnaire](#) completed at the end of day 4.

On day four of the Manchester and York jury proceedings, every member of the jury voted on the [jury questions](#). Jurors also suggested reasons for and against the options being considered, and voted on the most important of these reasons. Kyle Bozentko, the facilitator of the two juries from the [Jefferson Center](#), constructed the juries' report with each jury using the votes and ranked

<sup>2</sup> Based on 2011 and 2016 Census data. For full details, see CHC Jury Specification at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury)



reasons. The juries were led page-by-page through the jury report, which was displayed on a large projector screen, to gain the jurors' acceptance that it fairly represented their views. After each jury, the reports were sent to jury members so that any final changes could be made before the two [jury reports](#) were published.

## Jury questions and answers

The questions tackled and how the jurors voted are summarised below. "Before and after" results are shown where questions were also part of the pre-jury questionnaire. A spreadsheet containing the full set of jury questions and results is available at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury)

### Jury Question: are CHC planned uses of NHS data acceptable?

Which of the following **planned** uses of NHS data about patients (with identifiers like name and address removed) are acceptable?

[Choose yes, no, or unsure]

- 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.
- 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.
- 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.
- University researchers in Newcastle get data from hospital, GP and local authority records. The purpose is to plan future demand for A&E services and meet the needs of special groups (e.g. people with dementia).

**Figure 2: Manchester and York juror conclusions about planned uses**

Planned uses	Manchester (jury start)	Manchester (jury end)	York (jury start)	York (jury end)
<b>Use A. Strokes</b>				
Yes	15	17	15	18
Unsure	2	1	2	0
No	1	0	1	0
<b>Use B. Frailty</b>				
Yes	16	9	14	13
Unsure	2	3	1	3
No	0	6	3	2
<b>Use C. Alcoholism</b>				
Yes	12	13	11	16
Unsure	5	2	5	1
No	1	3	2	1
<b>Use D. A&amp;E</b>				
Yes	13	10	13	13
Unsure	4	3	2	1
No	1	5	3	4

The juries were also asked to “explain the most important factors affecting your choices (up to 300 words)”. The answers to these questions are provided in the two [jury reports](#).

The two most important reasons given for voting “yes” from each jury were that the planned use:

#### Manchester

- May lead to improved treatments, services, and care delivery and eventually to better health outcomes and more lives saved (Manchester jury - 24 votes<sup>3</sup>).
- Could strengthen research and help identify health trends, areas of concentrated positive or negative health conditions (“hot spots”), and special populations who are affected by different conditions or who have better than average health outcomes (Manchester jury - 15 votes).

#### York

- May lead to better diagnoses of conditions, more effective treatments, and improved health outcomes for patients (York jury - 26 votes).
- Might allow NHS to more efficiently target the use of resources for particular conditions or communities which could allow more effective use of funds and resources (York jury - 14 votes).

The two most important reasons given for voting “no” from each jury were that the planned use:

#### Manchester

- May generate findings or research conclusions that are not supported with funding commitments so they may not lead to implementation (Manchester jury - 13 votes)
- May lead to an increase in geographic, community-based, and social stereotyping and stigmatization as well as inequitable distribution of resources (“postal code lottery”) (Manchester jury - 11 votes)

#### York

- Do not guarantee that general public will be aware of or support the use of their anonymised records for these purposes (York jury - 12 votes)
- Create the possibility for data breaches among partner organizations, especially in cases where medical and non-medical (social care) records are linked (York jury - 12 votes)

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<sup>3</sup> Note that each juror had 3 votes, and could attribute up to 2 votes on each reason. So 24 votes suggests that at least 6 of the 18 members of the jury attributed 2 votes to this reason.



### Jury Question: are CHC potential uses of NHS data acceptable?

Which of the following **potential** uses of NHS data about patients are acceptable?

[Choose yes, no, or unsure]

- 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.
- 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 to aid future diagnosis of sepsis, a life-threatening condition.
- 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.).
- e. 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.

**Figure 3: Manchester and York juror conclusions about potential uses**

Q2a potential uses	Manchester (jury start)	Manchester (jury end)	York (jury start)	York (jury end)
<b>Use A. Pharma</b>				
Yes	8	13	10	14
Unsure	5	1	3	0
No	5	4	5	4
<b>Use B. AI software</b>				
Yes	8	15	5	15
Unsure	5	2	9	1
No	5	1	4	2
<b>Use C. Fitness tracker app</b>				
Yes	2	1	5	1
Unsure	8	1	5	4
No	8	16	8	13
<b>Use D. Health club</b>				
Yes	5	0	4	0
Unsure	4	0	4	5
No	9	18	10	13

The two most important reasons given for voting “yes” from each jury were that the potential use:

#### Manchester

- May expedite research and development of new drugs, products, and services which could lead to decreased costs and improved services for consumers (Manchester jury - 17 votes)
- May help identify gaps that exist in health services, technologies, and drugs which could improve care outcomes, improve well-being, and, ultimately, save lives (York jury - 17 votes)

#### York

- Could lead to the development of efficient and cost-effective drugs, treatments and diagnosis programmes that might lower costs for NHS and patients (York jury - 25 votes)
- Might allow health professionals to recognise conditions earlier and improve the treatment of some conditions (York jury - 15 votes).

The two most important reasons given for voting “no” from each jury were that the potential use:

#### Manchester

- May not satisfactorily demonstrate that the goal for data usage is public benefit as opposed to simple commercial gain or profit for a company (Manchester jury - 25 votes)
- Do not always satisfy concerns about proper safeguards and data protection practices by private companies and other commercial interests (Manchester jury - 10 votes)

#### York

- Tend to be driven primarily by the need to increase or generate profit without ensuring a clear public benefit from the use of people’s personal health data (York jury - 25 votes)
- Can increase reliance on technology for identifying and diagnosing illness, leading to less clinical expertise for medical professionals and limiting the patient/doctor relationship (York jury - 12 votes).

### **Jury Question: are the safeguards sufficient for the planned and potential uses?**

During the four-day jury process, the information governance safeguards protecting health data used within CHC were explained to the juries. The juries were asked overall whether these rules over access were sufficient to allow the four planned uses, and whether sufficient to allow the four potential uses. These questions were asked only on the final day of the jury process so there are no “before and after” data. Juror voting on these safeguards is shown below.

**Figure 4: Manchester and York juror conclusions about safeguards**

<b>Safeguards - planned uses</b>	<b>Manchester</b>	<b>York</b>
a) Certainly sufficient	4	9
b) Probably sufficient	14	7
c) Probably insufficient	0	2
d) Certainly insufficient	0	0
<b>Safeguards - potential uses</b>		
a) Certainly sufficient	1	2
b) Probably sufficient	5	6
c) Probably insufficient	12	8
d) Certainly insufficient	0	2

A follow-on jury question was: if you answered c. or d., what else, if anything, would you want done before allowing these planned/potential uses? A variety of answers were given (which are provided in full in the two [jury reports](#)), including:

- Additional safeguards will need to be put into place to protect the identities of racial and ethnic minorities in some of these planned uses as unique characteristics of individuals may be more identifiable given the smaller sample sizes (York juror);
- Regardless of the extent of safeguards applied to protect confidentiality when sharing and analysing anonymised data for commercial and research purposes, there may be cases where the ethical challenges presented by using data for commercial gain or profit means there is no justifiable use of patient data (Manchester juror);
- Trustworthiness and security within and among staff and personnel at commercial and private companies is more of a concern and this should mean that more strict safeguards should be applied to data usage and sharing among these groups (York juror).

### **Start and end of jury questionnaire results**

All 18 individuals from each jury completed a questionnaire both at the start and end of the jury. Some questions appeared in both questionnaires. The questionnaire design and the full results are available at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury).

One question, taken from an IPSOS MORI poll of the public commissioned by the Wellcome Trust [2], was asked in order to select a broadly representative sample in terms of balancing information sharing for public benefit and protecting privacy. The same question was asked in the post-jury questionnaire to gauge whether, and if so how, their views had changed by the end of the jury process.

*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.*

**Figure 5: Manchester and York juror conclusions about sharing information for public benefit**

How willing?	Manchester		York	
	Pre	Post	Pre	Post
Very willing	7	8	7	11
Fairly willing	6	10	6	4
Don't know	1	0	1	1
Fairly unwilling	2	0	2	1
Very unwilling	2	0	2	1

## Findings

### Discussion

The juries' voting on the planned and potential uses indicate that overall people tended to be a little more supportive of planned uses by the NHS and academic researchers than of potential commercial uses of CHC data. However, this was not always the case. For example, a total of 30 jurors supported the use of CHC data to develop artificial intelligence software to tackle sepsis (potential use B), whereas only 22 people supported the use of data for identifying frail elderly people who could be followed up for extra care (planned use B). Reasons given for not supporting the latter case suggest that some jurors were suspicious of, and unconvinced by, the need for this planned use and that this outweighed concerns about privacy risks. Jurors appeared to take into account not only the case made for each planned and potential use during the jury process but also their prior knowledge and views relevant to specific uses, such as how decisions are made about the planning, delivery and funding of health services.

The pre-jury and post-jury questionnaire results illustrate that individuals are liable to change their minds when they become more informed about a public policy problem, and have an opportunity to deliberate with their peers.

For example, people tended to move in their general attitudes in favour of greater sharing of information for public benefit, as illustrated by jurors' answers shown in table 5. This suggests that overall the jurors became more supportive in principle of information sharing for public / health benefit. Note, however, the voting on planned and potential uses (Figures 2 and 3) tells a different story. For some uses, citizens became more cautious about information sharing and for other uses they became less cautious; it depended entirely on the specific use under consideration.

### Key Findings

1. For all four of the CHC planned uses of health data considered, a majority of people in both juries were supportive.
2. A significant minority of jurors did not support the planned use B (frailty) and planned use D (A&E).
3. A majority of jurors supported the potential use A (pharmaceuticals) and potential use B (artificial intelligence), with support for these uses clearly increasing through the course of the

jury.

4. Only a small minority of jurors were supportive of potential uses C (fitness tracker app,) and D (fitness club chain), with support clearly decreasing through the course of the jury.
5. Jurors who voted against planned and potential uses often did so because they doubted that public benefit would result from the use.
6. Many members of the jury changed their view to become more supportive in general of sharing information for public benefit, even though they may have become less supportive of specific planned and potential uses considered.
7. There were strong similarities between the conclusions reached by the Manchester and York juries, although some of their reasoning differed.
8. Signs of bias were reported by a small number of jurors.

# Appendix 1: further information about the juries

## The Citizens' Jury Method

Like much public policy, balancing privacy and information sharing is a complex area with a lot of information and many arguments to consider. Surveys and focus groups provide useful information about what the public thinks, but they are not mechanisms to inform people. A citizens' jury can tell policymakers what members of the public think once they become more informed about a policy problem. In a citizens' jury, a broadly representative sample of citizens are selected to come together for a period of days, hear expert evidence, deliberate together, and reach conclusions about questions they have been set.

They are a form of “deliberative democracy”, based on the idea that individuals from different backgrounds and with no special prior knowledge or expertise can come together and tackle a public policy question. A citizens' jury is a particularly relevant method for informing public bodies making value judgements. Some organisations have used citizens' juries to *make* policy decisions, even though members of juries are not elected and cannot be made accountable for decisions. For example, Melbourne City Council has appointed a citizens' jury to determine how to allocate its A\$5 billion budget, and the council is implementing virtually all of the jury's recommendations.[3] A [Citizens' Council in Ireland](#) is currently considering many important questions, including whether to change the Irish Constitution on abortion, advising a parliamentary committee.

## Expert witnesses

Expert witnesses were chosen to provide relevant information to the members of the jury to enable them to answer the jury questions. Each witness gave a presentation and then answered questions posed by the jurors. One witness (Dr. Jon Fistein) was asked to be a “balancing witness”, engaging in dialogue with another witness (firstly John Ainsworth, then again with Clare Sanderson) and identifying points that might challenge the statements they had made.

The expert witnesses were issued with a brief prior to preparing their presentations. It is published at [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury)

The following is the information provided (in ring binders) to jurors about each witness.

### Day 1 Expert Witnesses

**Dr Mary Tully** is Director of Public Engagement for Connected Health Cities. She is here to explain what Connected Health Cities is, and why the citizens' juries have been commissioned.

**Dr. Alan Hassey**, a GP and former chair of the Data Access Advisory Group which is a national committee that assesses who can get access to detailed data about patients admitted to and visiting hospitals. He also works for the Office of the National Data Guardian. He is here to provide information about patient records.

**Dr. Mark Taylor**, a senior lecturer in law at the University of Sheffield, and Chair of the Confidentiality Advisory Group which advises the Secretary of State for Health. He is here to provide information regarding the laws regarding patient health records.



## Day 2 Expert Witnesses

**Prof. John Ainsworth** is a researcher at the University of Manchester, and the Director of Connected Health Cities, the body that will use health records across the North of England to try to help improve the health and prosperity of the population. He is here to explain how records are planned to be used within Connected Health Cities, and why such uses are important.

**Dr. Jon Fistein** is a medical doctor and barrister, and has worked for many years in the area of health records and protecting patient confidentiality. He is here to raise questions and challenges that might be associated with using health records in these ways.

## Day 3 Expert Witnesses

**Clare Sanderson** is an independent consultant working for Connected Health Cities and specialises in “information governance” – which is about protecting health records.

**Dr. John Fistein** (see text above)

**John McGovern** is here to explain why private organisations seek to use health records. John has a history of working in and around the NHS, especially around uses of health data. He is now Chief Intelligence Officer of a consultancy company.

**Alexander Martin** is a journalist who works for an online magazine called *The Register* and who has reported in the past on large-scale uses of health data. He is here to explain the possible risks associated with commercial use of health records.

## The oversight panel

The oversight panel was appointed to help monitor and minimise bias. The panel reviewed the citizens’ jury design, and much of the detailed jury documentation, including the jury questionnaires and the slides from the presentations by the impartial expert witnesses, resulting in some changes to these materials. The oversight panel members, chosen for their knowledge of the topic and lack of conflict of interest in any particular jury outcome, were:

- Dr. Joanne Bailey, GP and Chair of the Data Access Advisory Group
- Mr. Ian Inman, Group Manager Strategic Liaison - Public Services at the Information Commissioner's Office;
- Dr. Murat Soncul, Head of Information Governance at South London and Maudsley NHS Foundation Trust and Confidentiality Advisory Group member.

The brief for the oversight panel is available at: [www.bit.ly/CHCjury](http://www.bit.ly/CHCjury). Each member of the panel completed a questionnaire about bias, which are published at the same site. All three panel members were “completely satisfied” that the two juries were designed with the aim of minimising bias. Two panel members were “mostly satisfied” that this aim was achieved, and one member was “completely satisfied” it was achieved.

## Citizens' jury project team and funders

The juries were paid for by CHC, and commissioned by a project board of people from the CHC hub and regions. CHC is a £20 million pilot programme, funded by the Department of Health.

The project manager was Dr. Malcolm Oswald, an Honorary Research Fellow in Law at The University of Manchester. He received advice and support from many people, including the jury funders, the jury facilitators, [oversight panel](#), and [expert witnesses](#). Chris Barnes and Amanda Stevens recruited and supported the jurors, and jury process.

The lead jury facilitator was Kyle Bozentko, Executive Director of the [Jefferson Center](#) in the USA. Kyle, with support from his colleague Larry Pennings, worked closely with Malcolm to design the jury, and in particular the four-day jury activity programme. Kyle was deploying the citizens' jury method developed by Jefferson Center founder Dr. Ned Crosby in the 1970s. He facilitated the two juries with Dr. Vicky Chico, Lecturer in Law at the University of Sheffield.

## The citizens' jury programme of activities

The two four-day juries followed the same programme. The activities were designed primarily by the Jefferson Center in line with their citizens' jury method [4] and managed by the two facilitators. Jurors were asked to arrive by 09.30 to begin the jury at 09.45. The day ended by 17.15. There was lunch, plus a tea/coffee break in the morning and afternoon.

When	Main content	Expert Witnesses involved
Day 1, AM	<ul style="list-style-type: none"><li>• Consent forms</li><li>• Introductions</li><li>• Pre-jury questionnaire</li><li>• Why are we here?</li><li>• Brief introduction to Connected Health Cities (CHC)</li><li>• Jury simulation exercise</li></ul>	Dr. Mary Tully, Public Engagement Lead at CHC on introduction to CHC
Day 1, PM	<ul style="list-style-type: none"><li>• Witness on health records, Q&amp;A, jury deliberation</li><li>• Witness on relevant law, Q&amp;A, jury deliberation</li><li>• Jury exercise: anonymising a health record</li></ul>	Dr Alan Hassey, GP and National Data Guardian Panel member (on health records)  Dr Mark Taylor, Confidentiality Advisory Group Chair (on law)
Day 2, AM	<ul style="list-style-type: none"><li>• Witness on relevant ethics (for and against record sharing), jury deliberation</li><li>• Introductory presentations on reasons to allow planned uses, and reasons to be cautious</li></ul>	Prof. Soren Holm (on ethics)  Prof. John Ainsworth, Director of CHC hub (on planned uses)  Dr Jon Fistein, Leeds University (balancing witness)
Day 2, PM	<ul style="list-style-type: none"><li>• Witness on CHC 4 planned uses (one per region), Q&amp;A with "balancing witness", jury Q&amp;A and deliberation</li></ul>	Prof. John Ainsworth  Dr Jon Fistein

Day 3, AM	<ul style="list-style-type: none"> <li>• Witness on CHC information governance, Q&amp;A with “balancing witness”, jury Q&amp;A and deliberation</li> <li>• Introductory presentations on reasons to allow potential uses, and reasons to be cautious</li> </ul>	<p>Clare Sanderson (on CHC IG)</p> <p>Dr Jon Fistein (balancing witness)</p> <p>John McGovern (Quaenam and private sector use representative)</p> <p>Alexander Martin, journalist of “The Register” (balancing witness)</p>
Day 3, PM	<ul style="list-style-type: none"> <li>• 4 Filmed interviews between private companies with potential uses and journalist</li> <li>• Jury Q&amp;A with one private sector use representative and journalist, jury deliberation</li> </ul>	<p>John McGovern</p> <p>Alexander Martin</p>
Day 4, AM	<ul style="list-style-type: none"> <li>• Jury deliberation on jury questions</li> <li>• Jury voting on questions</li> </ul>	None
Day 4, PM	<ul style="list-style-type: none"> <li>• Jury report preparation</li> <li>• End of jury questionnaire</li> </ul>	None

## Appendix 2: Bibliography

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