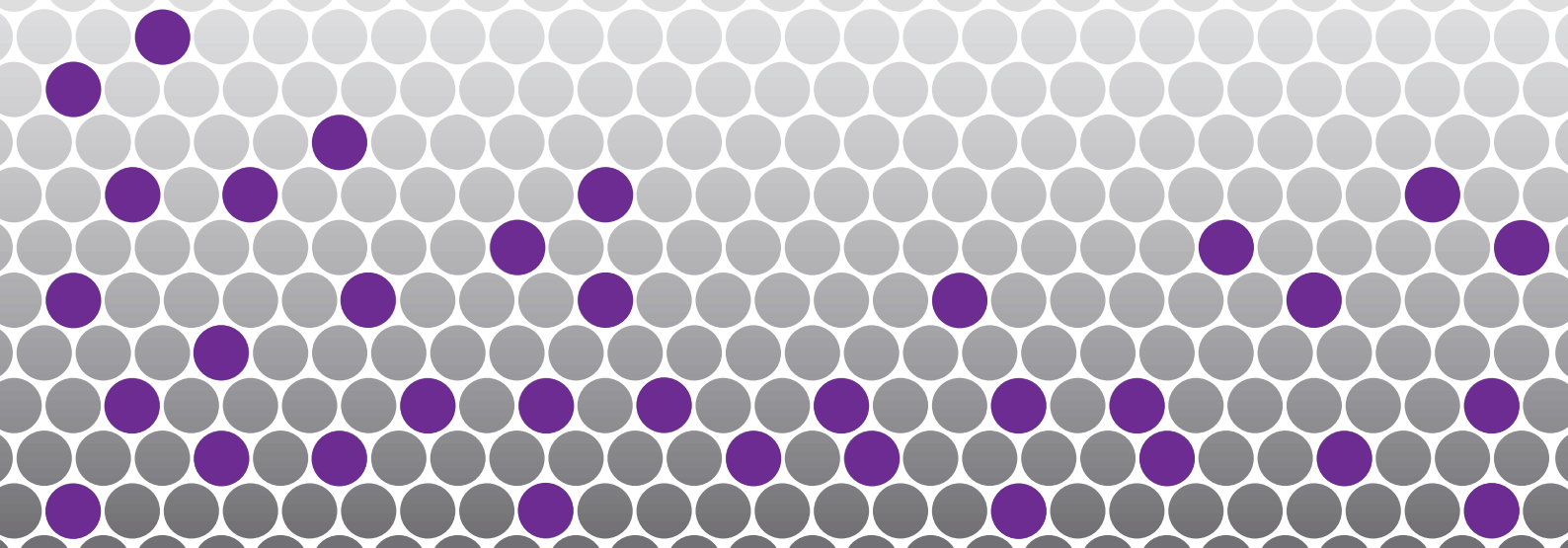
MANCHESTER 1824
The University of Manchester

Health Data on Trial

34 volunteers, 5 experts,
2 juries, 1 mission:

'To what extent should patients control access to patient records?'

The Citizens' Juries, January 2016



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THE CITIZENS' JURIES

REFERENCE MATERIAL

" I'm excited about taking part as this is completely different to what I do in my normal life"

Jason,
Juror, day 1

The jury mission

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)

" What attracted me first? Well the advert said you'd be paid for the three days so I thought that was good, then I read more and it said it would be a debate about public issues and I thought, I'd like to hear more about that"

Ryan,
Juror, day 1

Introduction

On 14 January 2016, 17 people gathered at Friends' Meeting House in Manchester and began a three-day "citizens jury". Their task was to tackle a public policy question on the extent to which patients should control access to patient records: the "jury mission" (sometimes referred to as the "jury charge"). Over three days, the citizens heard from, and asked questions of, expert witnesses, and carried out group exercises to explore the jury mission. They reached conclusions together, and were polled on their individual views at the start and end of the jury. A week later, a different cross-section of 17 citizens came together for three days and went through the same process.

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.herc.ac.uk/citizens-jury

Why the citizens' juries were run

The topic for the juries was chosen because it is one which:

- public authorities find challenging;
- requires competing values to be considered;
- can generate considerable public controversy, as was seen in 2014 with newspaper headlines about care.data and the "selling" of hospital records to private companies, and the subsequent inquiry by the Health Select Committee;[1]
- is of direct interest to the commissioners of the juries;
- and about which citizens' voices should be heard.

On the one hand, patient records can be used for everybody's benefit, for example in research to improve treatments. However, it is also important to protect an individual's privacy and their interests in keeping health information about them confidential. How should these competing aims be balanced? There have been many focus groups and surveys of public opinion about this subject, but few studies have aimed to inform participants about the policy question.[2] The citizens' jury method was chosen because it enables citizens to learn about, and deliberate on, this question, adding to knowledge of public attitudes on this subject. Very little similar research has been carried out (note though that in November 2015 NICE held a Citizens' Council meeting on a related topic and results will be published soon).[3]

The citizens' jury method was chosen because it enables citizens to learn about, and deliberate on, this question, adding to knowledge of public attitudes on this subject.

The research was also carried out to inform public authorities that must make value judgements on who should get access to what information in patient records and for what purposes. Value judgements are difficult for public bodies, and citizens' juries provide a means of informing those decisions.

" I think we will be expected to look at how medical information is used – I think anyway. I'm not really sure to be honest"

Jonathan,
Juror, day 1

CITIZENS' JURIES

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 budget, and the council is implementing virtually all of the jury's recommendations.[5]

" I don't think patient records should just be available to anyone, there should be controls...but...yet, some organisations help the public without detriment so, I guess I'm undecided about what I think"

Aeve,
Juror, day 1

The design of the citizens' juries

EXPERT WITNESSES

Expert witnesses were chosen to provide relevant information to the members of the jury to enable them to answer the two questions in the jury mission. Five experts gave presentations and then answered questions posed by the jurors.

Two witnesses were selected to provide impartial information:

- Dr. Ralph Sullivan, general practitioner and medical informatician, gave a presentation about patient records and how they are used; and
- Dawn Monaghan, Group Manager for Public Services at the Information Commissioner's Office, provided information about relevant law, and in particular the Data Protection Act 1998.

Three partial witnesses were chosen to provide arguments for and against greater use of patient records:

- Dr. John Ainsworth, Senior Research Fellow at The University of Manchester, argued in favour of using patient records in the public interest;
- Sam Smith, medConfidential Co-ordinator, presented the case for greater control of patient records;
- Prof. Søren Holm, Professor of Bioethics at The University of Manchester, identified ethical considerations both for patients sharing, and for patients controlling, patient records for uses other than direct patient care (such as research).

The expert witnesses were issued with a brief prior to preparing their presentations. It is published at www.herc.ac.uk/citizens-jury.

The juries were planned, designed and refined over a period of nine months. The design documentation was reviewed and approved by a University of Manchester research ethics committee in September 2015. This was followed by a day-long workshop with seven members of the public to test aspects of the jury design, including presentations by two of the expert witnesses, some of the planned jury activities, and the start and end of jury questionnaires. This highlighted a number of issues, leading to design changes.

A deliberate choice was made to give jury 1 (14-16 January 2016) and jury 2 (21-23 January) the same design. There are many aspects to the jury design including:

- the jury mission;
- 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 three days; and
- the design of the questionnaires completed at the start and end of the juries.

The design documentation is available at: www.herc.ac.uk/citizens-jury

Bias, both conscious and unconscious, is an important criticism of citizens' juries.[4] 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. On completion, each member of the panel completed a questionnaire about bias, published

" Yesterday, well...I found it was a bit too much information all at once and I went home feeling confused. Today has been clearer and I feel more confident about making a decision"

Lorraine,
Juror, day 2

To monitor and minimise bias on this project, an oversight panel was appointed to review the jury design and materials, and report potential bias.

at: www.herc.ac.uk/citizens-jury. Jurors were also asked to report bias in the end-of-jury questionnaire.

Other design controls used to monitor and minimise bias included:

- Jury commissioners (within The University of Manchester) were able to influence the jury mission but were independent from the jury process and outcomes;
- Expert witnesses were briefed to be either impartial information givers (day 1) or partial persuaders (day 2) but asked not to try to be both;
- Juries worked with facilitators to construct their own reports to address their mission;
- The jury process was run twice with same facilitators and witnesses and programme of activities but with two different sets of jurors in order to validate outcomes; and
- The detailed jury design and results documentation being published.

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 jury outcome, were:

- Dr. Sarah Clement, Information Commissioner's Office, Senior Policy Officer – Public Services;
- Dr. Peter Mills, Nuffield Council on Bioethics, Assistant Director; and
- Dr. Mark Taylor, University of Sheffield, Senior Lecturer in Law, and Confidentiality Advisory Group Chair.

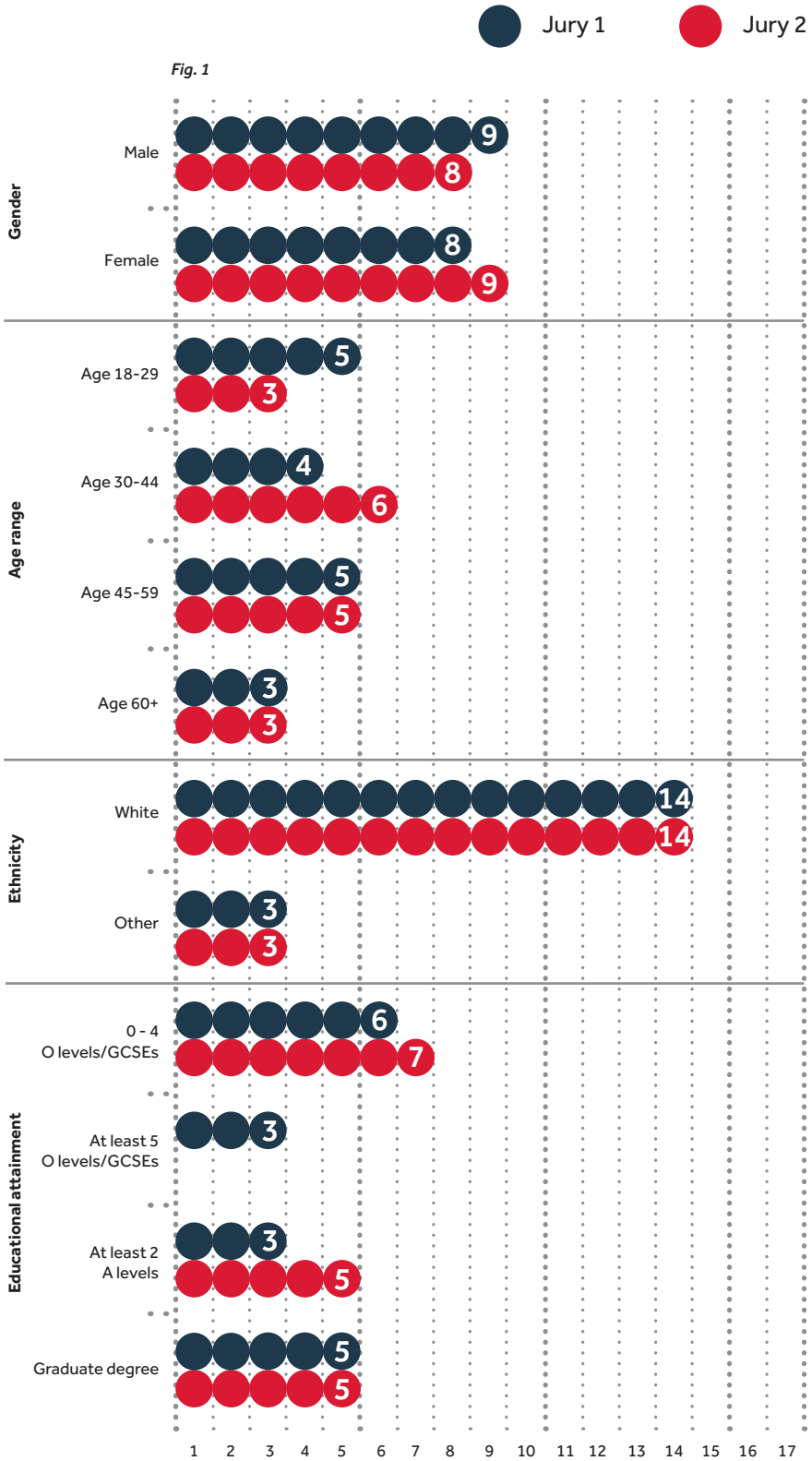
Each member of the panel completed a questionnaire about bias, published at: www.herc.ac.uk/citizens-jury. The brief for the oversight panel is published at the same site.

Jury demographics

The 18 people on each jury were recruited to provide a broadly representative sample of resident adults in England based on the 2011 census with respect to gender, age range, ethnicity (in terms of white/other), and lastly educational attainment (see fig 1 opposite). The characteristics fell within the target ranges which were set in advance as part of the jury design, based on 2011 census data for England. There was one exception: both juries were slightly beneath the target percentage for people over 60. In part, this was because one person over 60 from each jury left after the first day, leaving 17 people to complete the jury.

The characteristics fell within the target ranges which were set in advance as part of the jury design, based on 2011 census data for England.

Fig. 1



“ Today has highlighted how important it is that your information is kept within the boundaries of where and who you give it to”

Lorraine,
Juror, day 2

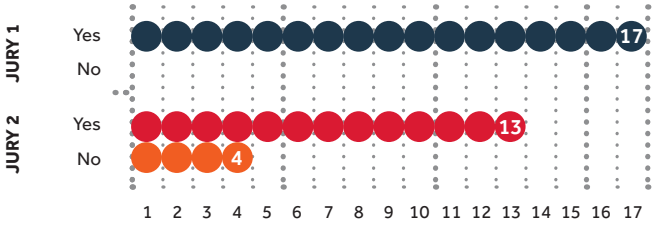
The juries' reports on their mission

Towards the end of the jury proceedings, Kyle Bozentko, the facilitator of the two juries from the Jefferson Center, constructed the juries' report with each jury. The two juries voted on both of the jury mission questions. Jurors also suggested reasons for and against the jury mission options, and the most important reasons given were chosen by juror voting. These votes and ranked reasons form the basis of the jury reports. On day 3, Kyle led the juries page-by-page through the jury report, which was displayed on a screen, and edited it with the jurors to gain their acceptance that it fairly represented their views.

Question 1 of the jury mission was broken down into three component parts, and jurors voted on each sub-question. They identified reasons for each of their choices, and then voted on which reasons were the most important. For brevity, the tables below show just the single most important reason for each option (as voted on by the jurors).

Q1a: Should the NHS body be allowed to create these records about you and other patients (yes or no)?

Fig. 2



Reason for option

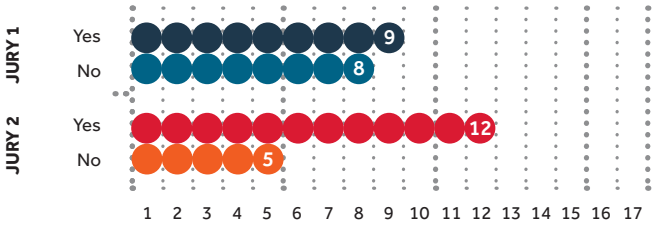
(Yes) "More detailed and complete data can produce more accurate evidence which can lead to more effective, more cost effective health care through NHS"

(Yes) "The more data available for analysis, the stronger and more reliable the evidence, results, and outcomes"

(No) "Without a clear understanding of who will be regulating the data and making decisions about access it is difficult to support the creation of new records"

Q1b: If such records were created should plans just be published or should patient input be allowed (yes or no)?

Fig. 3



Reason for option

(Yes) "People should be able to have control over their own data and records"

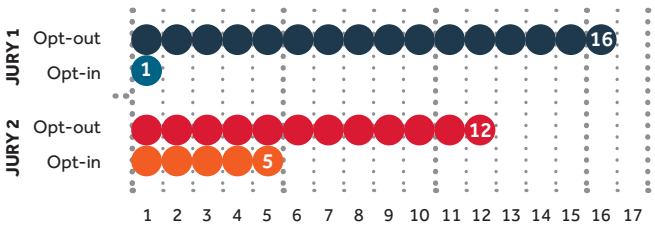
(No) "As part of a democratic process it is important for each person to have autonomy and freedom of choice when it comes to their own data or records"

(Yes) "This will ensure more accurate, complete data when all records are included"

(No) "Having a more complete data set will be a greater benefit to the population and would serve the greater good"

Q1c: If patient input is allowed, should individuals have the option to opt-out or opt-in?

Fig. 4



Reason for option

(Opt-out) "More people would be included in the data and this would lead to more accurate results and more representative samples of the population – this could lead to more effective research and better treatments"

(Opt-out) "More people would be automatically included in the database meaning more data for analysis"

(Opt-in) "This option would require the body or organisation to conduct an information campaign to educate the public"

Having voted on each sub-question, jurors then voted on the full question 1.

QUESTION 1 : SHOULD THE NHS BODY BE ALLOWED TO CREATE THESE RECORDS ABOUT YOU AND OTHER PATIENTS?

Having voted on each sub-question, jurors then voted on the full question 1. These voting results, which show the conclusions reached towards the end of the jury proceedings, are shown as "post-jury votes" in fig. 5 & fig. 6. The "pre-jury" votes are taken from the start-of-jury questionnaire, completed at the very start of day 1. Some jurors voted differently on a component question than on the full question 1. Most notably, of the eight people from jury 1 who voted for no patient input on Q1b, only two went on to vote for option A in the full question 1.

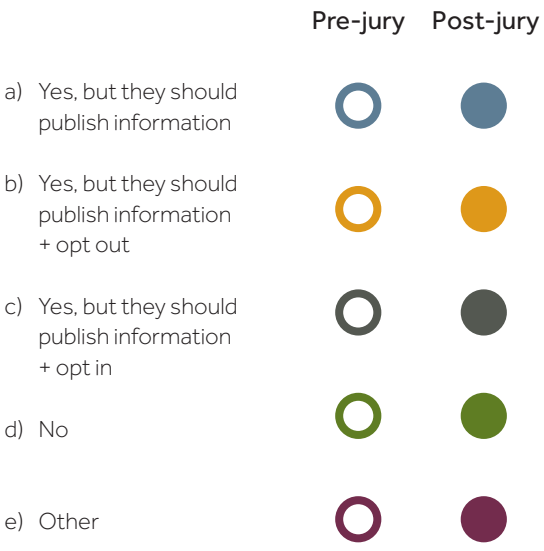


Fig. 5
Jury 1: pre and post-jury votes on Q1 of mission

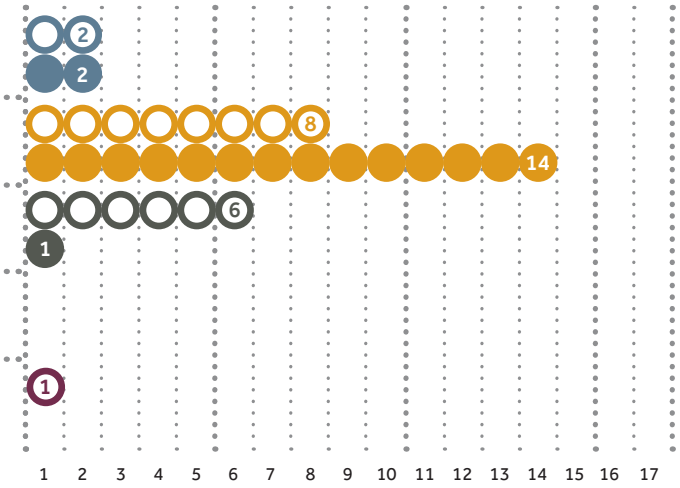
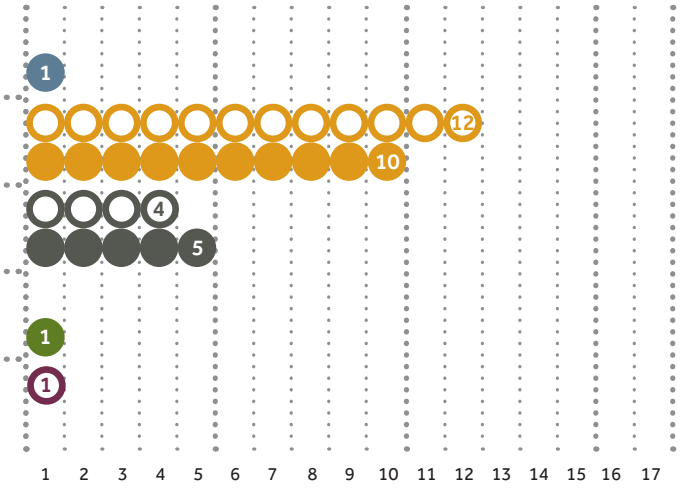


Fig. 6
Jury 2: pre and post-jury votes on Q1 of mission



QUESTION 2: WHO SHOULD BE ALLOWED TO ACCESS AND EXTRACT DATA FROM THE RECORDS CREATED?

Given your answer to question 1, who should be allowed to access and extract data from the records created? [Tick 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

Both jury 1 and jury 2 concluded that organisations and individuals who should be granted access to these records tend to demonstrate certain similar characteristics.

The juries' conclusions on question 2, based on voting during day 3, are shown below as "post-jury". The same question was asked in the start-of-jury questionnaire on day 1; the results from that questionnaire are shown below as "pre-jury".

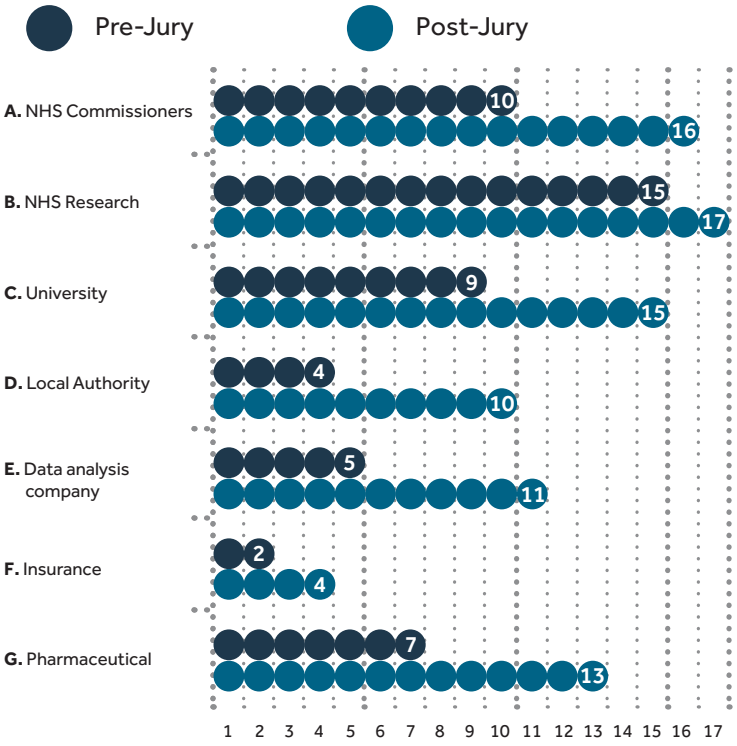
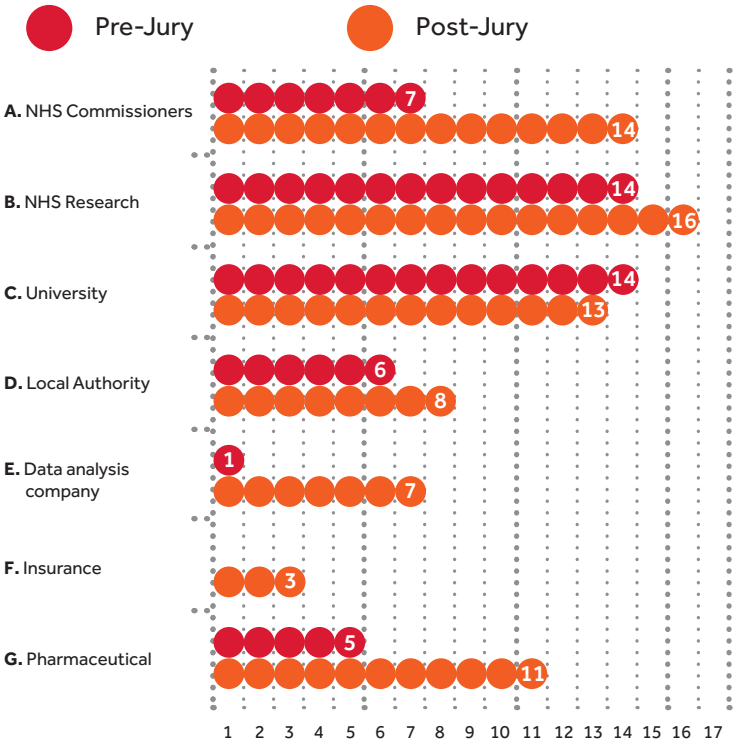


Fig. 7 Jury 1 (above and Jury 2 (below): pre- and post-jury views on access



> **" For me, it's a 100% yes for data sharing The more the information is shared the better things will be for the future"**
>
> **Jason,**
> Juror, day 2

Both jury 1 and jury 2 concluded that organisations and individuals who should be granted access to these records tend to demonstrate certain similar characteristics. The two groups identified, and ranked through voting, a set of different, but very similar, reasons shown below.

Q2: Who should be allowed to access and extract data from the records created? Reasoning

Jury 1 reasoning

Typically access should be given to organisations which:

- Make a clear and compelling case for why they need these patient records
- Provide clear justification for how and why the data will be used, why it is relevant to their efforts, with whom it will be shared, and only access records they need to perform their data analysis and have explored other options (such as other data sets)
- Have a track record of protecting data and records and can be trusted to maintain control of data without sharing or have controls in place to safeguard against internal misuse
- Clearly demonstrate that the primary goal for using the data is for public benefit such as improved medical care and treatments, improved public health, or management of public funds.

Jury 2 reasoning

Typically access should be given to organisations which:

- Are conducting analysis that aims to produce a clear public benefit
- Can be trusted to properly secure the data and have adequate safeguards in place in the event of misuse
- Demonstrate a clear connection between their needs (research, analysis, etc.,) and the information contained in the data or records and can not get adequate data from other sources
- Show a clear, relevant connection between the issues they are addressing and the information contained in these records
- Need access to the data to conduct urgent and/or timely analysis.

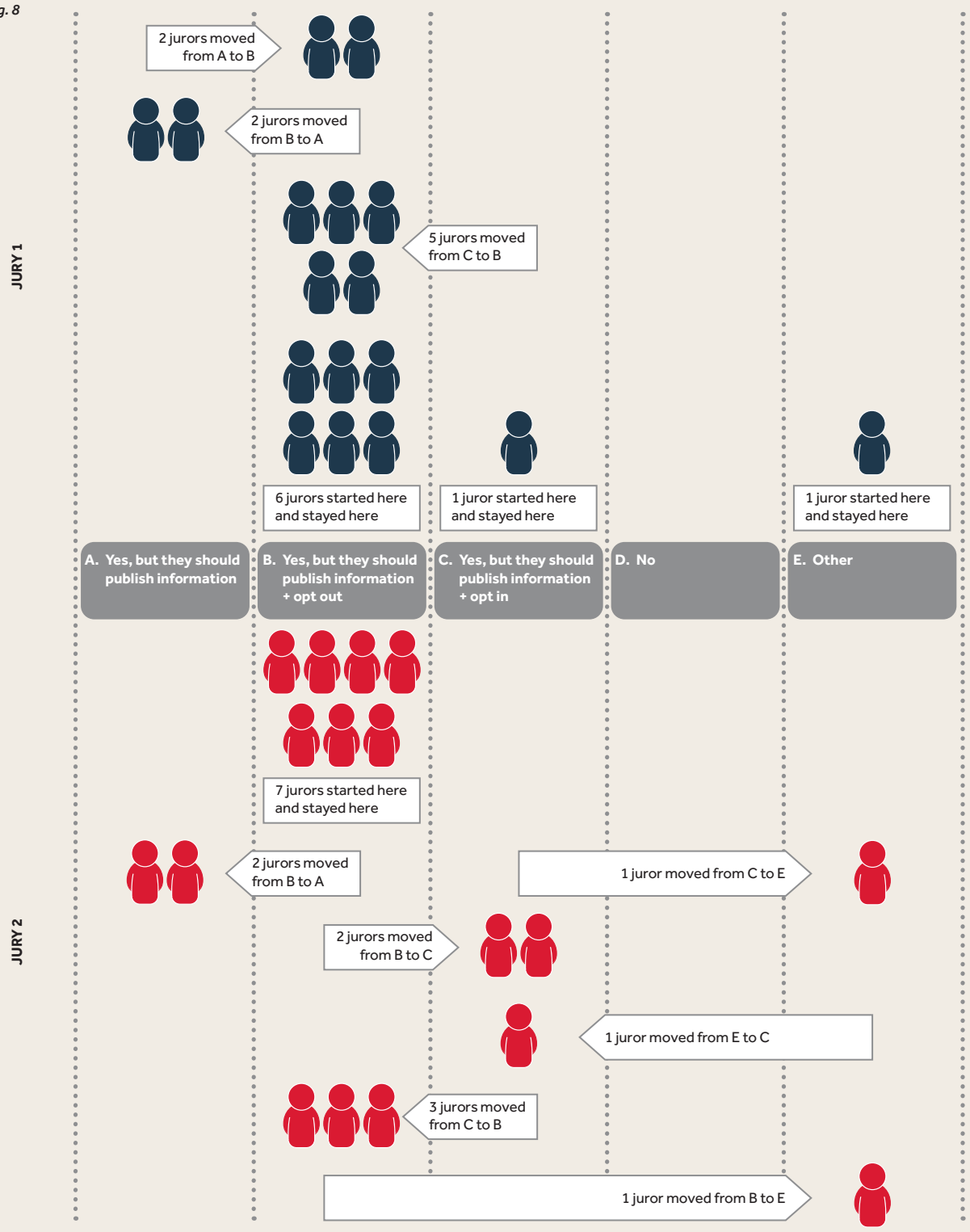
The full reports produced by the two juries are available at: www.herc.ac.uk/citizens-jury

Questionnaire results

All 17 individuals from each jury completed questionnaires 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.herc.ac.uk/citizens-jury. Key findings are summarised below. These 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, on question 1 of the jury mission, over half the jurors changed their minds:

Fig. 8



> **" Yes I think this is an important issue, it's a matter of life and death isn't it?"**
>
> **Kevin,**
> Juror, day 2

The questionnaire results suggest that over the course of three days a few people moved towards more patient control over patient records, but overall more people moved towards enabling greater sharing of information for public benefit. This is illustrated in the answers to the following question which was asked before the juries began and then again in the end-of-jury questionnaire:

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 of this information should be shared within government. Data sharing can bring benefits, such as finding more effective 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"

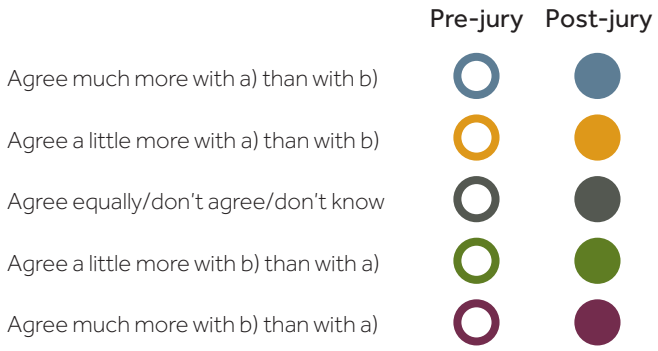


Fig. 9 Jury 1: pre and post-jury privacy views

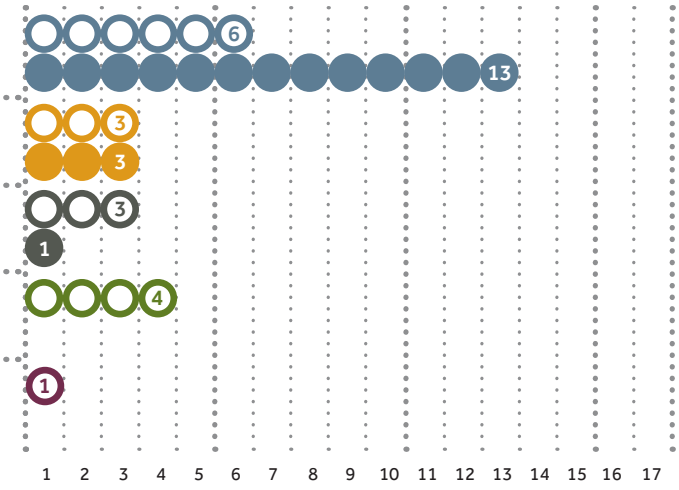
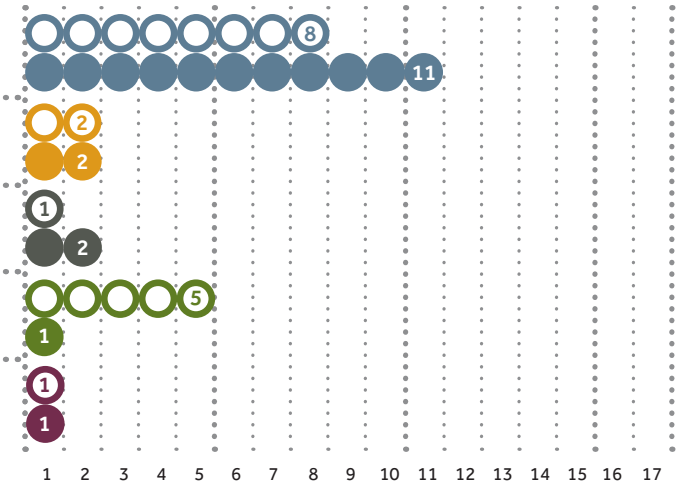


Fig. 10 Jury 2: pre and post-jury privacy views



Citizens' jury project team and funders

The project manager and main researcher was 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. Sarah Clement from the Information Commissioner's Office carried out the analysis of the questionnaire data.

The lead jury facilitator was Kyle Bozentko, Executive Director of the Jefferson Center in the USA. Kyle, with support from his colleague Larry Pennings, designed much of the three-day jury activity programme. He was deploying the citizens' jury method developed by Jefferson Center founder Dr. Ned Crosby in the 1970s. It was the first time the Jefferson Center had run a citizens' jury outside North America. Kyle facilitated the two juries with Amanda Hunn, Engagement and Policy Manager at the Health Research Authority.

The juries were commissioned and funded through two centres led by The University of Manchester: the Health e-Research Centre (HeRC), and the NIHR Greater Manchester Primary Care Patient Safety Translational Research Centre (Greater Manchester PSTRC). Four people from these two bodies commissioned and oversaw the research: Mary Tully, Reader in Pharmacy Practice; Niels Peek, Reader in Health Informatics; Lamiece Hassan, Patient and Public Involvement & Governance Research Officer; and Ruth Norris, Research Programme Manager. As both HeRC and Greater Manchester PSTRC have a direct interest in the use of patient records for research, they were involved in articulating the questions for the juries (the jury mission), but were not involved in many other aspects of jury design so as to reduce the risk of bias.

The two juries were made up of a broadly representative group of citizens.

The citizens' jury programme of activities

The two three-day juries followed the same programme. The activities were designed primarily by the Jefferson Center in line with their citizens' jury method[6] and managed by two facilitators:

DAY 1:

- participants complete the start-of-jury questionnaire and consent form
- introduction to the event
- group work simulation exercise (about allocation of ambulance services)
- presentation and questions with expert witness on patient records (Ralph Sullivan), and group work to identify key learning points
- presentation and questions with expert witness on the law (Dawn Monaghan), and group work to identify key learning points

DAY 2:

- presentation and questions with expert witness arguing for greater use of patient records in the public interest (John Ainsworth), and group work to identify key learning points
- presentation and questions with expert witness arguing for protection and patient control of patient records (Sam Smith), and group work to identify key learning points
- presentation and questions with expert witness identifying ethical considerations (Søren Holm), and group work to identify key learning points
- group work to identify, discuss and rank reasons for and against the different components of question 1 of the jury mission
- juror voting on question 1

DAY 3:

- group work with prepared crib sheets to develop the case for and against different parties gaining access to records, as set out in question 2 of the jury mission
- group work to identify, discuss and rank reasons for and against the different parties identified in question 2 of the jury mission
- juror voting on question 2
- participants complete the end-of-jury questionnaire

Some of the participants in jury 1 were interviewed on film about their views of the process on each of the three days. Quotes from these interviews are used throughout this report to illustrate the experience of the jurors.

Jury recruitment

Jurors were recruited through various methods, including email to a community choir, a presentation at a block of retirement flats, and a university research volunteer website. However, over 80% of the jurors recruited had responded to a free advertisement on a jobs website.

Shortlisted candidates were interviewed by telephone to check eligibility, namely: over 18; fluency in English and the capacity to contribute to jury discussions; not a health care professional; at least a year as a resident of Greater Manchester; and no special knowledge, interest or conflict of interest in the jury mission. 18 jurors and four reserves were selected for each jury. Jurors were paid £400 for three days, and reserves were paid £75 to stay until lunchtime on day 1 (unless needed as a juror, when they were paid £400). One person withdrew from each jury after day one, and was not replaced, leaving 17 people to complete the jury.

Jurors were chosen on demographics, and also according to their prior views on an IPSOS MORI survey question which involved balancing privacy against information sharing for public benefit.

" At first, I was for opt-in and was dubious about whether there should even be health records but now, I think there should definitely be shared records and that the public should have to opt-out"

Ryan,
Juror, day 3

" The public should have some autonomy and control over what happens to their records. It should be transparent and the public should be able to say "No, I don't want my details in the database.""

Aeve,
Juror, day 3

Reports of Bias

After reviewing the jury design and documentation, oversight panel members completed a questionnaire about bias, published at: www.herc.ac.uk/citizens-jury. The questionnaires suggest that the panel members were fully satisfied that the juries had been designed with the aim of minimising bias, and mostly satisfied that this had been achieved.

Jurors were also asked to report bias in the end-of-jury questionnaire, and on day 1 and day 2 in feedback forms. The most notable signs of potential bias reported related to the impartial expert witnesses. One free-text comment suggested Ralph Sullivan had a pro-privacy bias but conversely two comments suggested he had a pro-information sharing bias:

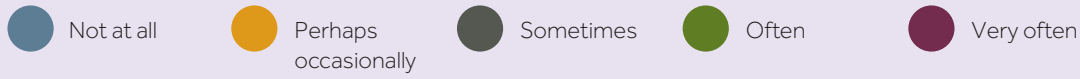


Fig. 11 Expert witness bias: Jury 1

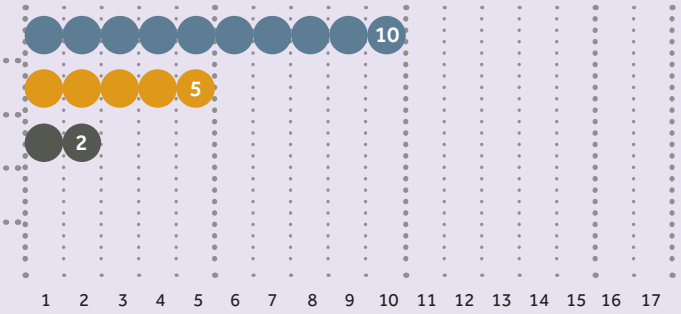
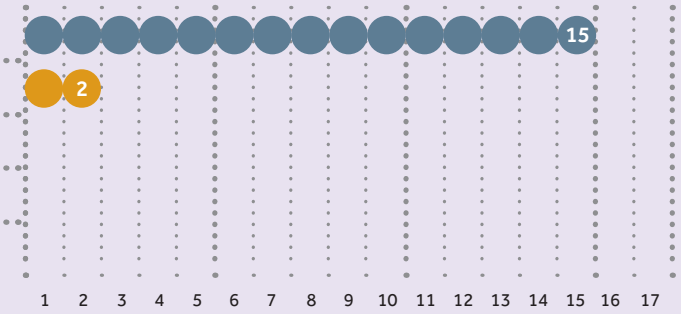


Fig. 12 Expert witness bias: Jury 2



Jurors reported lower levels of bias in relation to the jury facilitators, and towards other people involved in the jury process. One person from each jury commented that the "crib sheet" materials used to inform question 2 of the jury mission were weighted towards justifying the need for information sharing, with less weight given to challenging their need for the information. More detailed results can be found at: www.herc.ac.uk/citizens-jury

Jurors were chosen on demographics, and also according to their prior views on an IPSOS MORI survey question which involved balancing privacy against information sharing for public benefit. The prior views of the jurors on this survey question (see fig. 9 and fig. 10) broadly matched the distribution of views expressed by a sample of 506 British adults in June 2014.[7] However, the targets set in advance and reviewed by the oversight panel did not take account of the strength of view expressed, only whether people were more in favour of information sharing, or more in favour of protecting privacy. Unintentionally, of the actual sample of jurors chosen, a disproportionate number of those in favour of information sharing held that view strongly. This creates a potential bias.

However, pulling in the opposite direction, the sample of 366 people who applied to be part of the citizens' juries had a significantly higher percentage of people with pro-information sharing views compared to IPSOS MORI survey of 506 British adults (52% in the IPSOS MORI survey; 66% in the 366 jury applicants). This could have a number of causes. For example, it could be that the views of people from Greater Manchester who applied to take part in the juries are not representative of UK citizens, and/or it may be that the public's views have changed since the date of the IPSOS MORI survey (June 2014, which was a time of newspaper headlines about the risks posed by care.data and the "sale" of hospital records).

Public bodies making value judgements

Administrative law, such as the Health and Social Care Act 2012, determines and constrains what public bodies are constituted to do. Many other laws, such as the Data Protection Act 1998, further constrain the actions of public authorities. Nevertheless, many difficult public policy choices remain. Public authorities rely heavily on evidence to make such decisions. It is important to use evidence, but evidence alone rarely answers a public policy question: they are invariably "normative" questions. In other words, they are ethical questions that require value judgements about what is the right thing to do.[8]

Public authorities often find these value judgements particularly difficult, and hard to justify to the public. Many authorities will publish the evidence backing up their decisions, but few publish the values on which they were based. One important exception is the National Institute for Health and Care Excellence (NICE). Amongst other things, it is charged with making life-and-death decisions: which new medicines should be funded by the NHS, and which should not. Its published method on technology appraisal sets out the main basis for its rationing decisions: that a year of healthy human life is generally worth £20,000 - £30,000 spending. This method is also based on the assertion that providing a few months of extra life for people who are soon to die is worth more than the same life extension for people with many years to live. In publishing these "social values", NICE allows people to disagree (and many do).[9]

One means by which NICE lays claim to the legitimacy of its values is the NICE Citizens' Council. This body of 30 citizens who together largely reflect the demographic characteristics of the UK, tackle important social value questions relevant to NICE, typically over a two-day period.[10] By linking its published values to the published reports of its Citizens' Council, NICE can justify its values to citizens.

" I think health records should be shared because they can help people with specific conditions. They can save lives"

Gareth,
Juror, day 3

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KEY FINDINGS

1. 33 out of 34 jurors voted in support of the scenario to allow an NHS body to create new records for uses other than patient care (such as research), with 24 wanting individuals to be able to opt-out and 6 favouring opt-in.

2. Many jurors changed their opinion about who should get access to these records, with more people supporting wider information sharing by the end of day 3.

3. When considering who should get access to the new records, the two juries had very similar reasons for their decisions. Both juries thought that public benefit was one necessary justification for access.

4. There were differences in the conclusions drawn by the two juries, and jury 1 was more strongly supportive of sharing patient records for public benefit, whilst jury 2 was more cautious and sought to give patients more control over patient records.

5. Bias was reported by a small number of jurors, particularly regarding the impartiality of information from expert witnesses.

KEY MESSAGES ABOUT CITIZENS' JURIES

A. Citizens' juries are a form of deliberative democracy, based on the idea that people from a variety of backgrounds with no special knowledge or experience can come together and tackle complex public policy problems.

B. Citizens' juries are a valid and valuable method of understanding more about what citizens think about a policy problem, and illustrate that people often change their minds as they become more informed, and talk to their peers.

C. Citizens' juries provide a means to inform the many value judgements public authorities must make.

D. Citizens' juries are imperfect, reflecting the views of a very small sample of citizens, and subject to bias which can be monitored and minimised but not eliminated.

Further information

About the project and citizens' juries:
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