

# **A question for 2 citizens' juries: to what extent should patients control access to patient records?**

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FRIENDS MEETING HOUSE

MAKE US CHILDREN OF  
QUIETNESS, AND HEIRS  
TO PEACE.

Religious Society of Friends (Quaker)  
Friends' Meeting House  
Meetings for worship are held on:  
"Six Day" at 11.30 am, and 2.30 pm, 12.1.2017  
1.1.2017 and 1.1.2017 - 4.00 pm.  
All are welcome.

Friends Meeting House, Manchester

## Questions answered

- **What** were they doing?
- **Who** were they?
- **Why** should you be interested?
- **Why** might you temper your excitement?
- **What** was the outcome?

# What were they doing and **who** were they?



# What were they doing?... a citizens' jury

- “deliberative democracy”
- Jefferson Center method
- Born in the USA, alive and well e.g. in Australia
- 1 jury mission with 2 questions – you answered them

# What they did

- Over 3 days:
  - 5 witnesses
  - Deliberated together
  - Voted on mission questions
  - Joint conclusions
  - Polling
- Same process, facilitators, experts for both weeks – different jurors

# Who were they?

- (17+1) x 2
- 10 here today!
- Broadly representative mix (2011 census for England):
  - Age
  - Gender
  - Ethnicity
  - Educational attainment
- Also sampled on prior information sharing / privacy view: “initial question” (June 2014 IPSOS MORI survey)
- Recruited through various sources but mostly Indeed
- Paid £400

# Who else was involved?

- Facilitators: Kyle Bozentko, Amanda Hunn
- Expert witnesses:
  - Dr Ralph Sullivan, GP, on patient records
  - Dawn Monaghan, ICO, on relevant law
  - Dr John Ainsworth, researcher, arguing for information sharing for public benefit
  - Sam Smith, medConfidential, arguing for protecting privacy and individual patient choice
  - Prof Soren Holm, bioethicist, on ethical arguments
- Designed and project managed by me
- Data analysis by Dr. Sarah Clement, ICO
- Funded by HeRC and NIHR Greater Manchester PSTRC

**Why** should you be interested?



# **Why** should you be interested? Reason 1: **Juries increase legitimacy of public authority decisions**

- Law: what to do / not to do
- But “normative” policy decisions remain
- Rely on evidence AND values - few organisations state values
- NICE: an important exception
  - Researches social values
  - Publishes and applies contentious values
  - Red sheets
- Citizens’ juries/councils can inform and justify values and judgements

# Why should you be interested?

## Reason 2: Juries can tell us something different

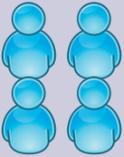
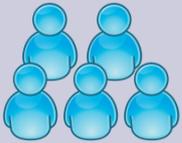
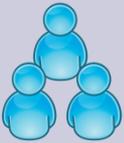
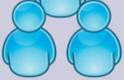
- Surveys and focus groups matter
- But policy is complex
- Citizens' juries can tell us what people think when more informed and able to talk to their peers
- People often change their minds

# People often change their minds

*Overall, which of the following statements is closest to your view?*

a) “We should share all the data we can because it benefits the services and me – as long as I can opt out if I choose”

b) “We should not share data as the risks to people’s privacy and security outweigh the benefits”

	Agree much more with a) than with b)	Agree a little more with a) than with b)	Don't agree / don't know	Agree a little more with b) than with a)	Agree much more with b) than with a)
N=7					
N=10					

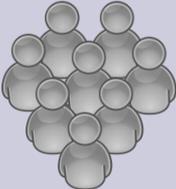
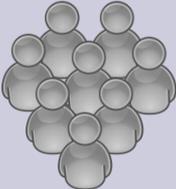
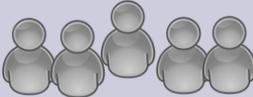
Jury 1

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	Agree much more with a) than with b)	Agree a little more with a) than with b)	Don't agree / don't know	Agree a little more with b) than with a)	Agree much more with b) than with a)
N=8					
N=9					

Jury 2

**Why** might you temper your excitement?



## Reasons for caution: an imperfect exercise

1. Small sample of people
2. Not perfectly representative
3. Potential for bias
  - Conscious, unconscious
  - Every little choice

## How bias was monitored and minimised

- Oversight Panel reviewed, reports on web
  - Dr Sarah Clement, ICO
  - Dr Pete Mills, Nuffield Council on Bioethics
  - Dr Mark Taylor, Confidentiality Advisory Group Chair
- Juror questionnaires: low levels of bias
- Funders independent from process
- Jurors' reports
- Same jury twice
- Transparency: website

Much more I could tell you...



Better people to listen to...

# What was the outcome?

EXPERT # 1: THINGS TO REMEMBER \*MOST IMP

Dr. SULLIVAN

Didn't realise how important your information was to the big picture of medical statistics didn't know how they got all the relevant information.

Ability to target particular illnesses  
Research re treatments - how effective

Data is used to collect information for different parts of the country.

RECORDING DATA CAN BE BENEFICIAL FOR OUR DIRECT CARE.

How sharing patient info could influence future treatments.  
Always have access to medical records

Data can be used to identify bigger health problems (eg swine flu)  
Doctors can then doctor to prescribe correct medicine

Data has to be passed between GPs, hospitals etc, and it is difficult to keep the info under control + confidential.

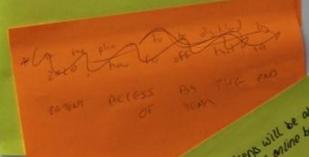
KEEPS COMING UP WHAT CAN BE DONE WITH THE INFORMATION IN MY MEDICAL RECORDS: COMING PROBABLY FINANCIALLY

You can check your own medical record ON LINE BY THE END OF THE YEAR

Patients have access to their own records.

How patients will be able to view their medical record online by the end of the year.

Commercial organisations want to use patient records.



# Francesca Costello: citizen from jury 1

- In my day job...



## My thoughts on the citizens' jury process

- Never taken part in anything like this before – not even heard of citizens' juries
- Had no previous knowledge of health records; like many others taking part, assumed there was already 'joined-up' thinking and sharing of information
- Plenty of time for discussion
- Opportunities to ask questions of 'expert witnesses' to become more informed
- Different opinions from a cross-section of people

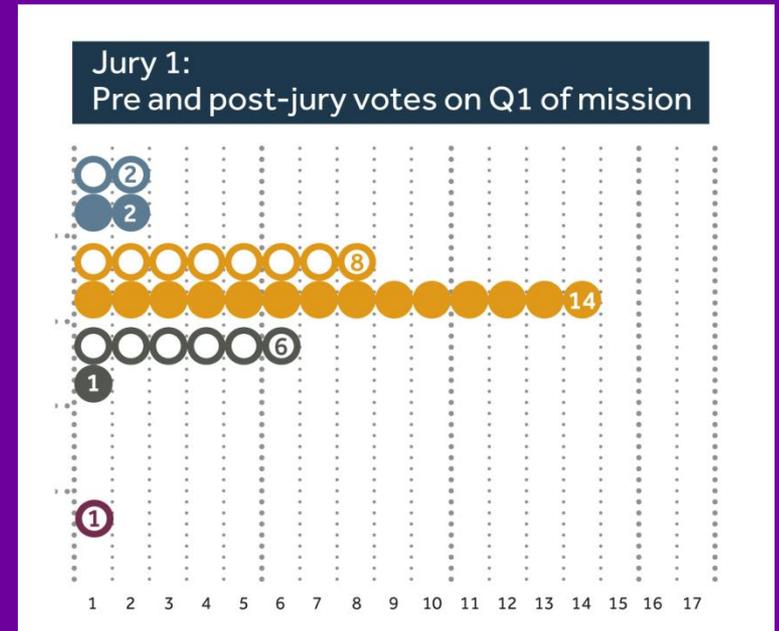
## Question 1 from the jury mission

- Question 1 was broken down into component parts
- We voted on each component, identified reasons for our choices, and ranked our reasons
- We then voted on question 1 overall...

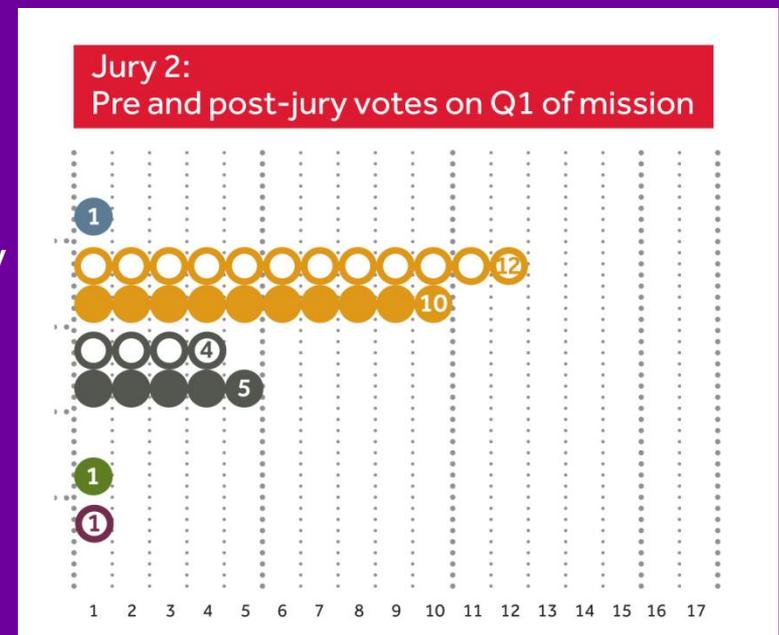
# Question 1 – start of jury questionnaire and jury vote

	Pre-jury	Post-jury
a) Yes, but they should publish information	<input type="radio"/>	<input checked="" type="radio"/>
b) Yes, but they should publish information + opt-out	<input type="radio"/>	<input checked="" type="radio"/>
c) Yes, but they should publish information + opt-in	<input type="radio"/>	<input checked="" type="radio"/>
d) No	<input type="radio"/>	<input checked="" type="radio"/>
e) Other	<input type="radio"/>	<input checked="" type="radio"/>

Jury 1



Jury 2



## **Jury 1 favoured opt out - most important reasons**

- 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 (13 votes)
- This could be more time effective and cost effective as it is an easier, more convenient option for individuals (12 votes)

# Paul Walton - citizen from jury 2

- In my day job...



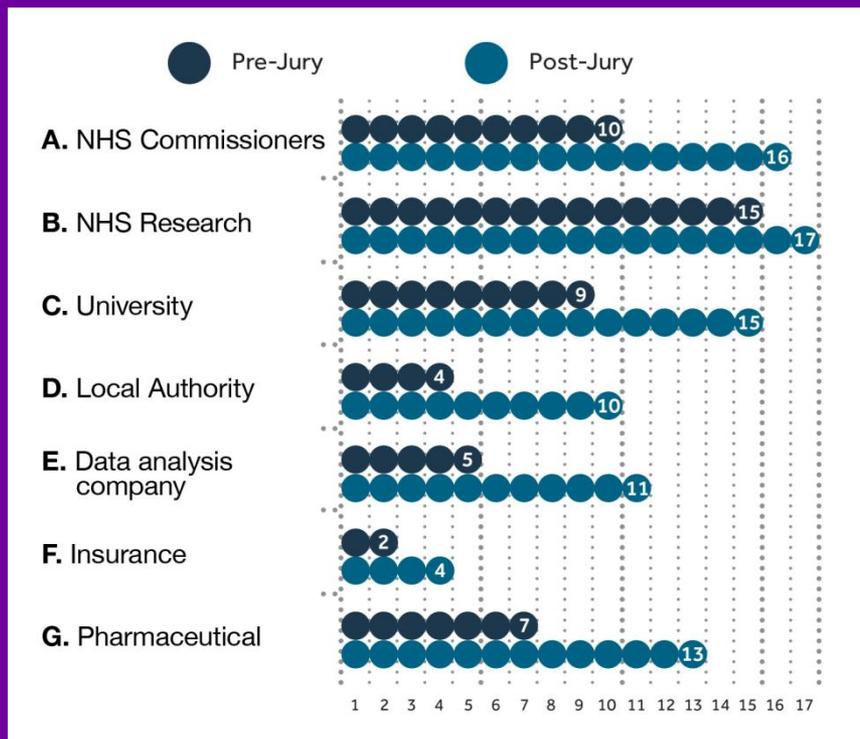
# My personal thoughts on the citizens' jury process

- The jury process was carried out in a constructive and cooperative way with everyone given ample, and equal opportunity to contribute and question the expert witnesses
- By having Kyle facilitate the jury I didn't feel there was any 'axe to grind'. He was only interested in the jury process and not putting any particular spin on the results
- I personally did not agree with all the findings of the Jury, but agree with the process to get to a collective outcome and support it 100%
- I found the whole jury process thoroughly rewarding and I have to confess quite empowering
- Coming to the process without much prior knowledge on medical records and how they are shared, I now feel much more educated and informed

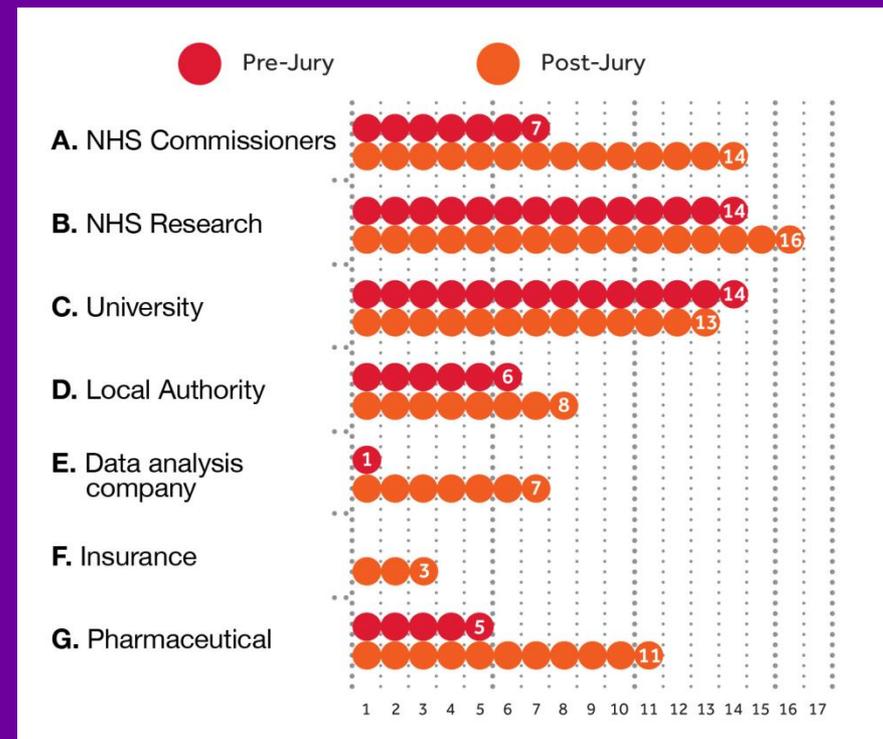
# Question 2: start of jury questionnaire and jury vote

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

July 1



July 2



## Question 2: Jury 2's agreed reasoning

- Typically, organisations that should gain access:
  - 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

## Key messages from the juries

- Citizens' juries are a valid and valuable method of understanding more about what citizens think about a policy problem
- People often change their minds as they become more informed
- Citizens' juries provide a means to inform the many value judgements public authorities must make – an important addition
- 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.

## Key findings from the juries

- 33 out of 34 jurors voted in support of the scenario to create the new records, with 24 favouring opt-out , 6 favouring opt-in, 3 no choice.
- Many jurors changed their opinion, with more people supporting wider information sharing by the end of day 3
- When considering who should get access to the new records, the two juries had very similar reasons for their decisions - public benefit was important to both juries
- There were differences in the conclusions drawn by the 2 juries:
  - jury 1 was more strongly supportive of sharing patient records for public benefit
  - jury 2 sought to give patients more control over patient records
- Signs of bias were reported by a small number of jurors



Thank you