

**Workshop on Patients' Control over Patient Records  
ICO and University of Manchester  
Thursday 10 March 2016, 10.00am to 15.30pm  
Committee Rooms 1-3  
Stockport Town Hall SK1 3XE**

**Aim:** To disseminate the findings of the recent citizens' juries and panels to key stakeholders in organisations using patient data and consider how these findings should inform their decision-making.

<b>Timings</b>	<b>Agenda and Outputs</b>	<b>Lead</b>
10.00	<b>Tea/coffee and registration</b>	
10:30 – 10:40	<b>Welcome and Tribute to Karen Thomson</b>	Dawn Monaghan, Group Manager, ICO; Malcolm Oswald, Honorary Research Fellow, University of Manchester
10:40 - 10:55	<b>Keynote from the ICO</b> Christopher Graham gave a presentation (without slides) on understanding key information rights issues from the public's perspective	Christopher Graham, Information Commissioner
10:55 – 11:15	<b>Presentation from the Wellcome Trust</b> Natalie Banner presented key findings from deliberative consultation into public attitudes of private sector use of health records  Output: Natalie Banner Slides 10 March 2016 available at: <a href="http://www.herc.ac.uk/citizens-jury">www.herc.ac.uk/citizens-jury</a>	Natalie Banner, Policy Officer, Wellcome Trust
11.15 – 11.25	<b>Questions for Christopher Graham and Natalie Banner</b>  The two speakers answered a variety of questions from workshop participants.	Dawn Monaghan, Group Manager, ICO

11.25 – 11:40	<p><b>Interactive Exercise</b> Discovering views of participants on questions tackled by 2 citizens’ juries Malcolm Oswald asked the audience to vote using their smart phones on three questions, and displayed the results through the data projector.</p> <p>Output: Results from the interactive exercise morning session on 10 March, available at: <a href="http://www.herc.ac.uk/citizens-jury">www.herc.ac.uk/citizens-jury</a></p>	Malcolm Oswald, Honorary Research Fellow, University of Manchester
11.40 – 12.00	<b>Tea / coffee</b>	
12:00 – 12:30	<p><b>Outcomes from 2 Citizens’ Juries</b> The three presenters explained the design and findings of 2 citizens’ juries investigating the extent to which patients should control access to patient records, and experiences of jurors</p> <p>Output: Malcolm Oswald and Jurors slides 10 March 2016 available at: <a href="http://www.herc.ac.uk/citizens-jury">www.herc.ac.uk/citizens-jury</a></p>	Malcolm Oswald, and 2 citizen jurors: - Francesca Costello (jury 1) - Paul Walton (jury 2)
12.30 – 12:45	<p><b>The National Data Guardian’s Review</b> Dame Fiona discussed her current review, and in particular the priority areas for the NDG relating to consent and control of patient records in health and social care.</p> <p>Output: Dame Fiona slides 10 March 2016 available at: <a href="http://www.herc.ac.uk/citizens-jury">www.herc.ac.uk/citizens-jury</a></p>	Dame Fiona Caldicott, National Data Guardian
12.50 – 13.10	<p><b>Questions for Malcolm Oswald, the citizen jurors, and Dame Fiona Caldicott</b></p> <p>The speakers answered a variety of questions from workshop participants.</p>	Dawn Monaghan, Group Manager, ICO
13.10 – 13.15	<p><b>Introduction to break-out session</b></p> <p>Sarah Clement explained to participants that they had been assigned to tables for group work in the afternoon and that each table would discuss either issue 1 or issue 2 (see below). Each table had a chair and a scribe.</p>	Sarah Clement, Senior Policy Officer – Strategic Liaison, ICO
13.15– 13:50	<p><b>Lunch</b> A sandwich lunch will be provided</p>	
13:50 – 14:45	<p><b>Break out session</b> 3 tables discussed the following issue, voting on 1a and 1b, with the scribe summarising the points from 1c. 1. Organisations and value judgements</p>	Small group work

	<ul style="list-style-type: none"> <li>a. Does your organisation make judgements that rely on values as well as evidence?</li> <li>b. How does your organisation learn about the public's values and priorities?</li> <li>c. Can you use what you heard this morning from the citizens' juries and the Wellcome Trust research to inform your decisions, and if so how?</li> </ul> <p>4 tables discussed the following issue, voting on 2a and 2b, with the scribe summarising the points from 2c.</p> <p>2. Risks of a public debate</p> <ul style="list-style-type: none"> <li>a. Is there a risk that when the public hears more about sharing health records, they will get more concerned about the risks of sharing?</li> <li>b. Is this a good reason not to engage in a public debate?</li> <li>c. What can be done to address this risk?</li> </ul> <p>Outputs: Voting on 1a, 1b, 2a, 2b and notes from the discussion of the open questions 1c and 2c (as entered by the table scribes), are provided in March 10 group work results, available at:  <a href="http://www.herc.ac.uk/citizens-jury">www.herc.ac.uk/citizens-jury</a></p>	
14:45 – 15:00	<p><b>Discussion of feedback from break out session</b></p> <p>Sarah Clement walked through the groups' online voting and notes from 1c and 2c (with some difficulty because of a poor internet connection).</p>	Sarah Clement
15:00 – 15:20	<p><b>Open forum</b></p> <p>Participants made some final comments about the day.</p>	Dawn Monaghan, Group Manager, ICO
15.20 – 15.30	<p><b>Closing remarks</b></p> <p>Dawn Monaghan and John Ainsworth made some final comments and thanked the speakers and everyone else for attending.</p>	Dawn Monaghan, Group Manager, ICO and Dr. John Ainsworth, Senior Research Fellow, University of Manchester

