

**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.

Timings	Agenda items	Lead
10.00	Tea/coffee and registration	
10:30 – 10:40	Welcome and Introductions	Dawn Monaghan, Group Manager, ICO
10:40 - 10:55	Keynote from the ICO Understanding key information rights issues from the public's perspective	Christopher Graham, Information Commissioner
10:55 – 11:15	Presentation from the Wellcome Trust Key findings from deliberative consultation into public attitudes of private sector use of health records	Natalie Banner, Policy Officer, Wellcome Trust
11.15 – 11.25	Questions for Christopher Graham and Natalie Banner	Dawn Monaghan, Group Manager, ICO
11.25 – 11:40	Interactive Exercise Discovering views of participants on questions tackled by 2 citizens' juries	Malcolm Oswald, Honorary Research Fellow, University of Manchester
11.40 – 12.00	Tea / coffee	
12:00 – 12:30	Outcomes from 2 Citizens' Juries Overview of findings of 2 citizens' juries investigating the extent to which patients should control access to patient records, and experiences of jurors	Malcolm Oswald, and 2 citizen jurors: - Francesca Costello (jury 1) - Paul Walton (jury 2)
12.30 – 12:45	Office of the National Data Guardian Priority areas for the NDG relating to consent and control of patient records in health and social care	Dame Fiona Caldicott, National Data Guardian
12.50 –	Questions for Malcolm Oswald, the	Dawn Monaghan,

13.10	citizen jurors, and Dame Fiona Caldicott	Group Manager, ICO
13.10 - 13.15	Introduction to break-out session	Sarah Clement, Senior Policy Officer – Strategic Liaison, ICO
13.15– 13:50	Lunch A sandwich lunch will be provided	
13:50 – 14:45	Break out session Discuss in small groups: 1. Organisations and value judgements a. Does your organisation make judgements that rely on values as well as evidence? b. How does your organisation learn about the public’s values and priorities? 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? 2. Risks of a public debate 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? b. Is this a good reason not to engage in a public debate? c. What can be done to address this risk?	Small group work
14:45 – 15:00	Discussion of feedback from break out session Discussion in plenary of results of the break out session	Sarah Clement
15:00 – 15:20	Open forum Comments from participants, actions and take-home messages for organisations and individuals	Dawn Monaghan, Group Manager, ICO
15.20 – 15.30	Closing remarks	Dawn Monaghan, Group Manager, ICO and Dr. John Ainsworth, Senior Research Fellow, University of Manchester