



Public dialogue on consent for tissue and linked patient data

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Joint Health Research Authority and Human Tissue Authority project on sharing patient data with tissue



Issues:

- Tissue is of little value without patient data
- Shift in public concern from focus on tissue alone to when tissue becomes data
- How can we link patient data to tissue on an ongoing basis so that new diagnoses and treatments are included?



Public dialogue

- Invite approx. 75 members of general public invited to attend deliberative workshops
- 3 locations across England
- Reconvened meetings a week or two later
- Demographically representative of local area
- Experts attended every group including expert patients



Key questions to address:

- What happens when tissue becomes data
- Broad consent
- Ongoing dynamic consent

Funding now agreed by Sciencewise



Workshops planned for Sept 2017



Any questions?

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