Biobank Showcase

Building public confidence in sharing tissue and data for research

Amanda Hunn - 18 October 2017
Joint Head of Policy
Joint HRA/HTA public dialogue to understand better what and how we should ask consent for sharing patient data to be linked with donated tissue
The Health Research Authority (HRA)

To protect patients in health research
Approve health research studies

The Human Tissue Authority (HTA)

Provides guidance and sets standards for the removal, storage, and use of human tissue and organs

Sciencewise

Ipsos MORI team
Improvisers
Experts
Independent Evaluator
Talking to the public

- General public invited to attend two deliberative workshops
- 3 locations across England
- 25 people in each group
- Members of general public recruited in the street according to a quota
- Experts invited to debate issues with the public
Context

• Tissue of little value without patient data

• Lack of adequate consent at time that tissue sample is taken

• Lack of adequate guidance on consent for sharing future patient data in relation to tissue

• What happens when tissue becomes data?
The big question

How should researchers seek permission to link patient data with human tissue for health-related research?

• What is the most trustworthy way?

• What are the best ways, to reduce delays and extra costs?

• What exactly do people ‘consent’ to?
Three areas of discussion

- Biobanks & broad consent
- Genomics England consent
- Dynamic consent
Some early findings

- Public support the notion of data sharing with tissue donation for research. They clearly understand the public benefit but have some concerns about commercial gain.

- Public are in the main supportive of research, and welcome opportunities for their genetic data to be used.

- Public support consent for unlimited future use of data as well as past
• Would like to have ability to opt out of consent for some types of research or researchers

• Room for improvement for current consent forms and need to ensure greater clarity

• Support for notion of dynamic consent but appreciate the costs of setting up

• Strong views on the access committee
An access committee can include...

- Ethicists
- Biobank experts
- Doctors
- Patient representatives
- Biobank participants
How will we use the results

- Results of public debate will feed into joint HRA/HTA guidance on consent for sharing patient data linked to tissue
- Inform the work of Genomics England
- Building on work already carried out by Wellcome and others on patient data
Thank you

Any questions?

Please send comments suggestions to amanda.hunn@nhs.net