Design a Biobanking Ecosystem

If we were starting from a blank canvas, how would we design the biobanking ecosystem in the UK? What features would we want to allow fair access for all? How would the landscape work for patients, biobanks and researchers? What would sample collection, consent and access look like if redesigned? Who collects and how? How do we decide who gets the samples?

In this exercise, breakout groups decided how the ecosystem would be organised from the point of view of a given actor:

- sample donor
- academic researcher
- biobank
- commercial researcher
- funder
DONOR

What do we think?
- Good that they have key points of communication
- Good that the healthcare staff and biobank are independent from each other
- Seems messy but they are mostly interacting with a few actors
Academic researcher: cancer

- quality and reproducible research- fitness for intended purpose
- Funding
- sourcing
- lack of harmonised systems
- lack of harmonised pricing
- affect on quality Vs. value for money
- Customer relations and understanding the market that the BB serves.
- Issues with agreements/contractual requirements/IP ownership
- funders requirements introduced early on may encourage best practise, enable equality of use.
- funders enabling formal networks for better use, better expenditure
- post- funding- where will the samples be located? business plans?
- access to smaller disease groups: -visibility
- 'hogging' of material locally?
**BIOBANK**

- Bioresource bio-bank
- Governance
- Education of research community
- Consent - broad and tiered?
- Material/Data Transfer Agreement
- Quality Management System
- Processing Lab
- Sample types and storage
- BIMS
- Provenance info of sample -> quality check/SOPs
- GDPR and ELSI rules - metadata publication

**University/NHS lead**

- Initial scoping - will collections be of use?

**Finance**

- Data harmonization from several diagnosis - MI

**Access and Sharing rules**

- Requestor of samples/data from public

**Patient groups**

- PPI
- Storage facility
- Certified biobank?/lab?

**Negotiation process between biobank and requestor**
Funder

Indirect Influence

Direct Influence

- ROI in forms of advertising (i.e., citations) & monetization
- IP & patent co-ownership
- Final price of the product
- Time pressure
- Research type
- Donor demographics

Funder

Small independent, commercially driven funder

Market's demand

Government / Law

Popularity of the topic

Medical research seen as part of the NHS - part of our health care

Funded centrally by the Government but controlled independently

Collecting % from taxpayers and allocating to non-trending research projects