DESIGN A BIOBANKING ECOSYSTEM

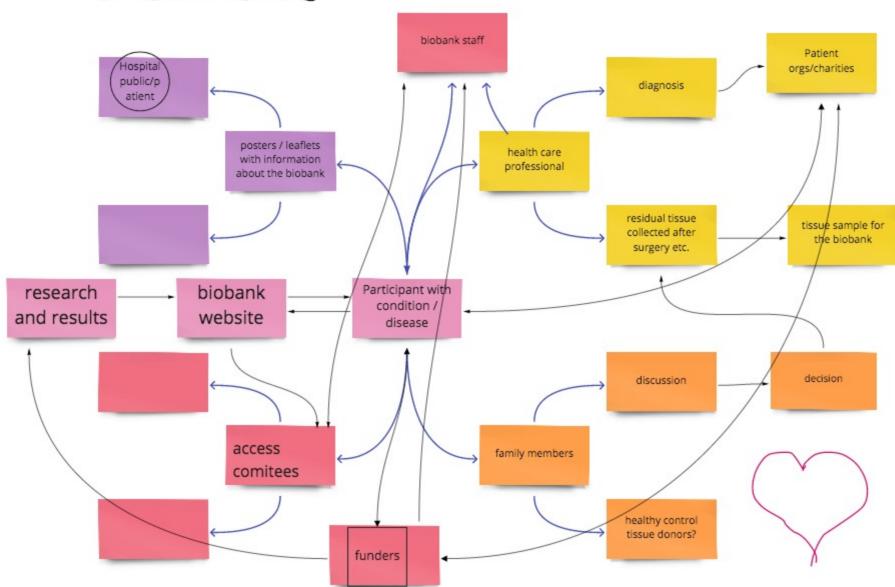
If we were starting from a blank canvas, how would we design the biobanking ecosystem in the UK? What features would we want to allow fair access for all? How would the landscape work for patients, biobanks and researchers? What would sample collection, consent and access look like if redesigned? Who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



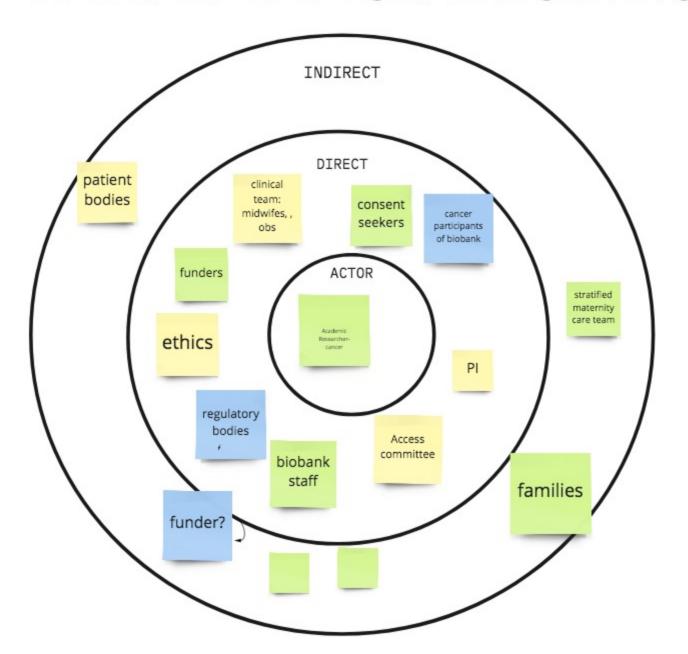
DONOR



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



Academic researcher: cancer

- -quality and reproduuible 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

University /NHS lead

Initial scoping - will collections be of use?

Patient PPI groups

Finance

education of research community

Governance

Consent broad and tiered?

Material/Data Transfer Agreement

Storage facility

certified biobank?/lab?

Quality

Management

System

BIMS

provenance info of sample -> quality

data harmonization from several diagnosis - MI

> GDPR and ELSI rules metadata publication

requestor of samples/data from public

negotiation process between

biobank and requestor

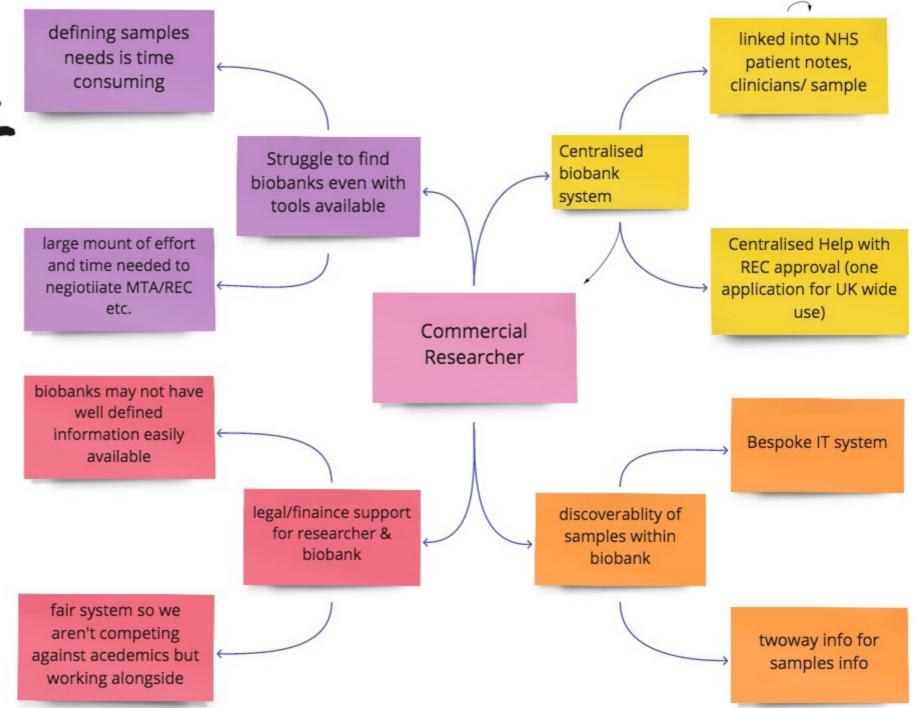
Access and Sharing rules

Processing Lab

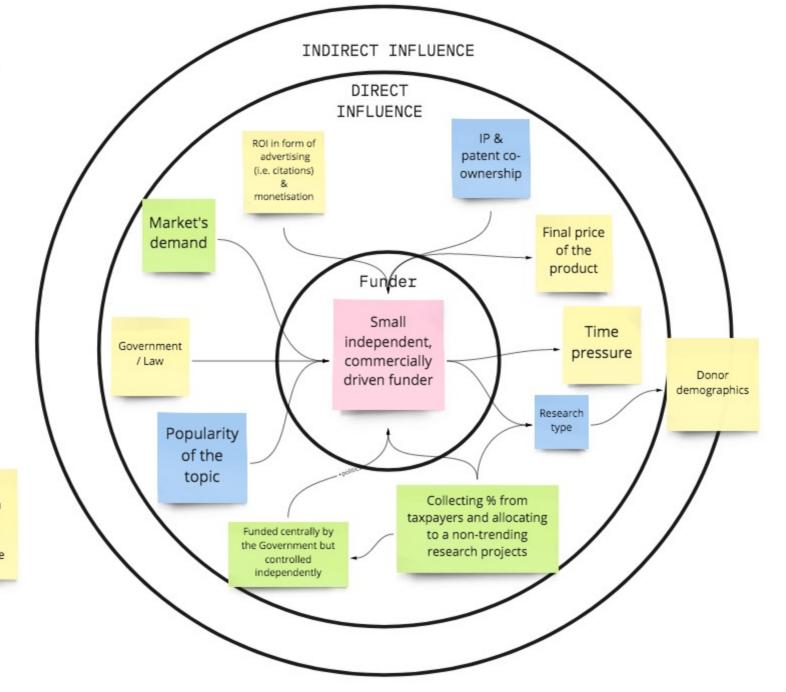
Sample types and storage

check/SOPs

COMMERCIAL RESEARCHER



FUNDER



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