

The UK Biobanking Time Bomb: Maintaining Strong Public Trust in Medical Research

Respect

Action: NHS data custodians to have visibility of consent given.

Why: There are no national mechanisms for checking consent. We should ensure the wishes of the donor are **respected** when deciding if access to data can be granted.

Recognise

Action: Validate biobanks to a standard that covers all activities

Why: If being a Biobank comes with a **recognised** level of capability (particularly with data) then decision making on data release should become easier.

Reward

Action: Find mechanisms to reward organisations that share samples

Why: Current academic metrics do not provide any **rewards** for sharing; they reward behaviour that discourages collaboration. We need to reward sharing.



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What are Biobanks?

There is no universally accepted definition of a Biobank



- Formal Biobanks have only really emerged post the human tissue act legislation across the UK
- The most liberal definition is any person or organisation that collects and stores human samples (and data) for future use in medical research
- It is not known how many Biobanks exist in the U.K:
 - In part because of the lack of a definition
 - The UKCRC Tissue Directory and Coordination Centre (<https://www.biobankinguk.org>) is developing a catalogue to answer this question

Why are Biobanks needed?

Research into human health cannot occur without access to samples and data



What have Biobanks supported?

- Core biological understanding, such as proteins and genes
- Development of now standard cancer therapies such as chemotherapy
- The concept of personalised medicine
- The delivery of personalised medicine
 - Genomics England

The Time bomb

Several factors are building that could pose a risk to the long term future of Biobanks

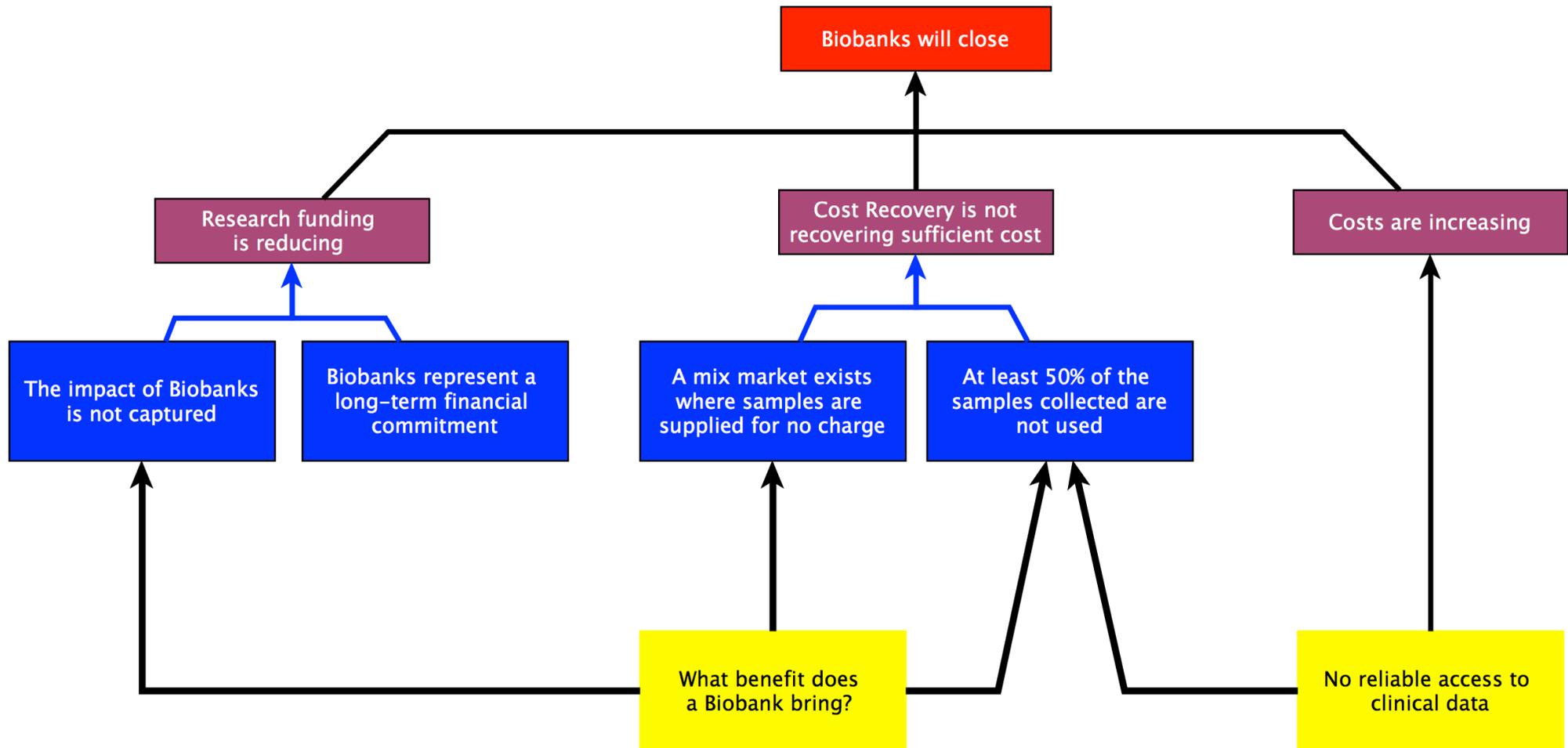


- **Research grants are reducing**, how Biobanks are funded is changing, meaning, Biobanks no longer enjoy funding that underpin all of their activities. Many have to seek cost-recovery models to be sustainable.
- **Cost recovery is not recovering cost**, the costs are calculated on a per-sample basis, but, the number of samples used is low. We would estimate somewhere in the region of 50%-75% of samples are **not** used resulting in a significant proportion of the costs not being recovered. Confounding this issue is that some Biobanks can still supply samples at no cost, sometimes in exchange for a co-authorship on publications.
- **Costs are increasing**, to operate a Biobank has always been a costly exercise requiring long-term investment. As an example, data is the vital commodity, without data the samples have a significantly reduced benefit. The level of data required is increasing, yet, most will employ staff to read and transcribe the medical records for the Biobank. Clearly not a sustainable, reliable or cost-effective mechanism – but very few credible alternative approaches currently exist.

The Time bomb

There are underlying factors driving these challenges that we wish to change

- ***What benefit does a Biobank bring?*** There is currently no way to derive the impact of a Biobank. Most academic markers of success are derived from the research undertaken by an individual researcher and then collated to a University. A Biobank in contrast should be providing the samples as a service to researchers internationally. Two equally undesirable outcomes come from this situation. **(1)** Biobanks that provide the samples as a service and operate in line with best-practice are not seen as generating valuable output. The consequence, a funder or a host University can see the costs of operation but cannot see the benefit. **(2)** The system currently rewards those that restrict access to the samples to their own collaborative projects, to ensure co-authorship and joint funding applications, therefore recognition.
- ***No reliable access to clinical data.*** Medical research is in an exciting time of development and new insights into diseases are delivering benefits to patients. With this increasing understanding of disease comes an increasing requirement to have more clinical data from the people that have donated samples. Without data, the samples are almost unusable. Yet, the process to collect data is basic, usually requiring a member of staff to read patient records and then retype that data into a Biobank database. Clearly not cost-effective but also prone to error. The two underlying factors drive each other. If you are an academic that has invested significant effort into collecting the data - would you be willing to hand that across to others, to receive no recognition? That only reinforces the undesirable behaviour of (2).



Public Trust?

The person has consented for their samples and data to be used to further medical research and to prevent the others from suffering

We need to **respect** their wishes

We need to **recognise** what is a Biobank

We need to **reward** those that share

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Further Information

Advanced Data Analysis Centre, University of Nottingham:
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UKCRC Tissue Directory and Coordination Centre
contact@biobankinguk.org
<https://www.biobankinguk.org>



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Want more?



UK Biobanking Showcase

16th November 2016

9.00 to 16.30

The Oval, London

<https://www.biobankinguk.org/uk-biobanking-showcase/>