Unlocking progress: Changing the culture and image of biobanking
Who knew?

- UK Biobank 10 years old
- 500,000 people genotyped
- 3,000 scientists registered users in 18 countries
- 100 scientific papers published
Central health records have poor public image

- Public frightened of loss/misuse of data
- Centralised data mistrusted
- Don’t trust ‘banks’

However, there is an appetite for ‘lifestyle’ data
Questions about commercial v public interest biobanks
Biobanks central to future of cancer research and treatment

What were considered to be one disease now revealed to be many different cancers

Graphic: Giuseppe Curigliano, European Institute of Oncology, Milan
Drugs work on some patients but not others

![Graph showing survival rates with different treatments](image)

- **Percent Alive**
- **Years**
- **combinations and sequencing**
- **a-PD-1/mpi**
- **PD-1 pathway blockade**
- **ipilimumab**
European Organisation for Research and Treatment of Cancer

- EORTC launched SPECTA to match patients to trials
- Collect tissue and liquid samples
- Make materials and data available to researchers
- Widen access to precision medicine for patients across geographical borders

SPECTA:
Screening Patients for Efficient Clinical Trials Access

A European vision for drug development and healthcare using longitudinal clinically annotated biobanks and molecular tumour profiling
In the public interest biobanks need to share better

“In the EORTC, we have banned this notion of ownership which I think is very detrimental. We ask: ‘Who is responsible for the chain of custodianship?’

“I feel more and more it is unethical for commercial silos to keep biological materials...

If a clinical trial is negative, the company will close the programme overnight and all the materials they have been collecting are difficult to access, if not impossible.”
Too many researchers keep butterfly collections

‘Butterfly collections decorate your room but that is it. And they fade away with time’

Denis Lacombe EORTC
“If we look at what we have done over the past two decades, it has been incredibly disappointing. It is very difficult to find the bio-markers for response or lack of response to the new drugs. The reason is that we never share results and put them in the public domain. It is a real nightmare and patients are totally unaware of this. They donate their material to science because they trust this will help future patients not in my view a particular company or investigator.”

Martine Piccart
Medical Director Jules Bordet Institute, Brussels
“Patients are often invited to sign a consent form about using their tissues for research.

“Most often a sample of tissue is stored in the hospital pathology lab and that is where it stays.

“A researcher can only track materials down if they can connect with patients who are sufficiently proactive.

“My experience suggests that, it takes strong determination on the part of the patient to make that happen.”

Jayne Bressington (PAWS-GIST tissue bank co-founder)
Good biobanks put patients first

Nurses at the Biobank for Translational Medicine in Milan spent time explaining why patients should allow tissue to be banked with clinical data. Patients are told about research outcomes.

Patient-run PATH biobank in Germany shares bio-material from 7 breast cancer centres.
Biobanks also help clinicians to recruit

Consultant George Pentheroudakis says liquid biobank will help him win back doctors who left Greece due to financial crisis.

Data will be shared across Hellenic Cooperative Oncology Group in 15 centres in Greece

“The way forward is to create a universal pan-European tissue bank.”
Some questions

• Can biobanks link their data and be more open with their materials?
• Are pan-European biobanks the way forward, and will they include post-Brexit UK?
• Can ethical biobanks enthuse the public about the benefits of storing and sharing materials and data?