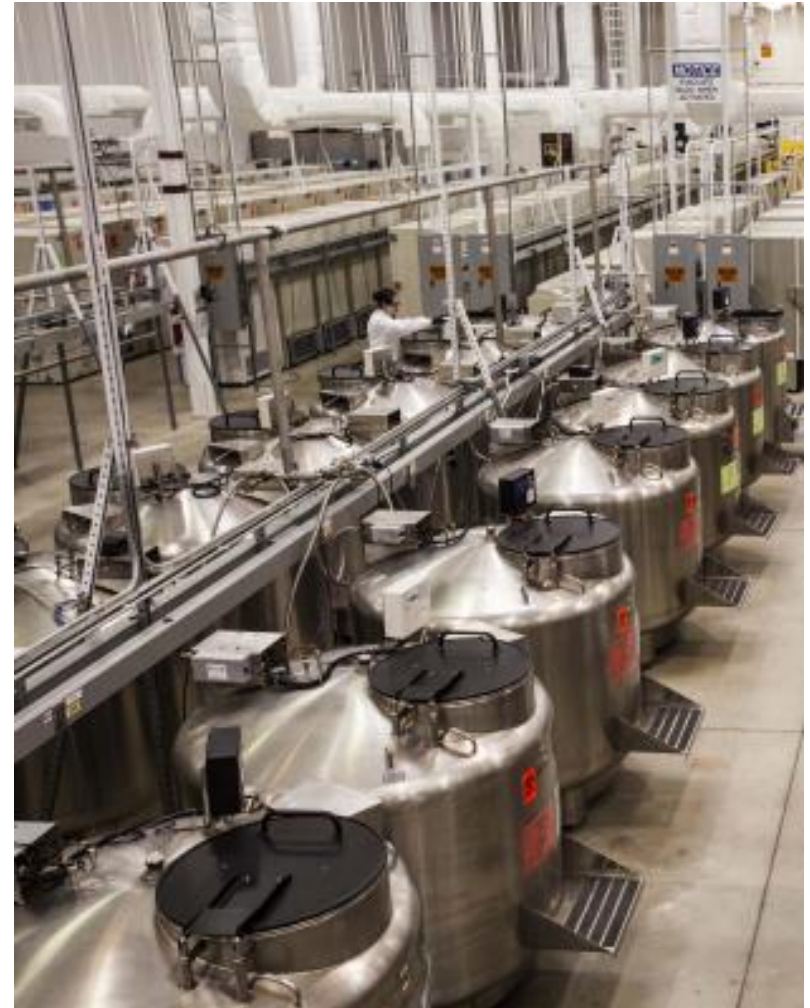


## Unlocking progress: Changing the culture and image of biobanking



Picture: ThermoFisher Scientific

## Who knew?

- UK Biobank 10 years old
- 500,000 people genotyped
- 3,000 scientists registered users in 18 countries
- 100 scientific papers published



**10**  
years of UK Biobank

**biobank**<sup>UK</sup>

Improving the health of future generations

UK BIOBANK PARTICIPANT NEWSLETTER October 2016

Welcome to the 2016 UK Biobank Newsletter. You have received this Newsletter because you are a participant in UK Biobank. Thank you for contributing to this exciting and pioneering study. You can follow UK Biobank in more detail by visiting our website.

**UK BIOBANK UNDERTAKES THE WORLD'S LARGEST IMAGING STUDY  
- AND WE NEED YOUR HELP TO MAKE IT A SUCCESS**

UK Biobank's imaging study is being rolled out across the country. This will give most UK Biobank participants the chance to participate in this exciting project.

Two new imaging centres are currently being developed – one in Reading and the other in Newcastle-upon-Tyne – to support the centre in Stockport, which has seen more than 10,000 participants scanned.

*The centres will create the world's biggest collection of scans of internal organs which will transform health*



## The Telegraph

HOME » NEWS » HEALTH » HEALTH NEWS

Patients' medical records go online without consent

## INDEPENDENT

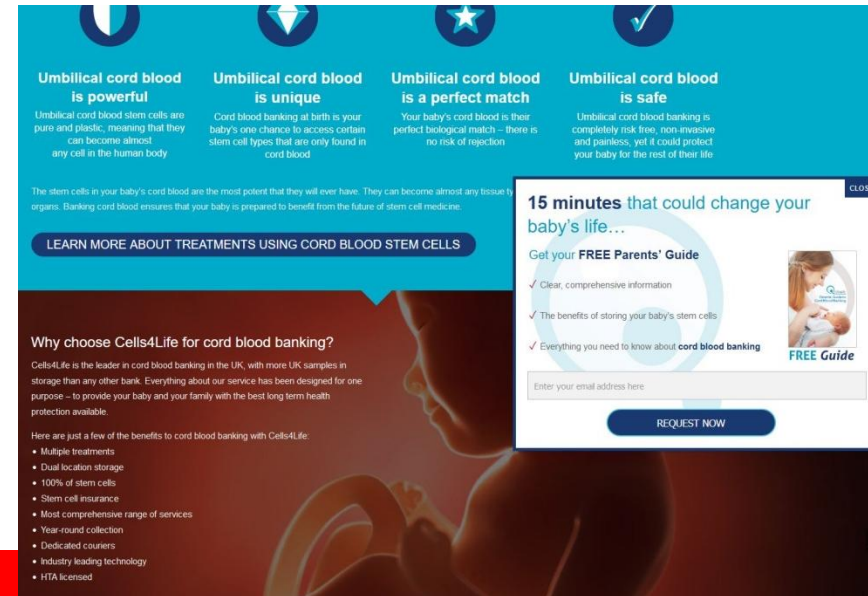
Lifestyle » Health & Families » Health News

Controversial mega-database of medical records scrapped over privacy concerns

- However, there is an appetite for 'lifestyle' data
- Questions about commercial v public interest biobanks

## Central health records have poor public image

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



The advertisement features four columns of benefits:

- Umbilical cord blood is powerful:** Umbilical cord blood stem cells are pure and plastic, meaning that they can become almost any cell in the human body.
- Umbilical cord blood is unique:** Cord blood banking at birth is your baby's one chance to access certain stem cell types that are only found in cord blood.
- Umbilical cord blood is a perfect match:** Your baby's cord blood is their perfect biological match – there is no risk of rejection.
- Umbilical cord blood is safe:** Umbilical cord blood banking is completely risk free, non-invasive and painless, yet it could protect your baby for the rest of their life.

Below these columns, a text block states: "The stem cells in your baby's cord blood are the most potent that they will ever have. They can become almost any tissue type in your body. Banking cord blood ensures that your baby is prepared to benefit from the future of stem cell medicine."

A call to action button reads: "LEARN MORE ABOUT TREATMENTS USING CORD BLOOD STEM CELLS"

The main heading for the ad is: "15 minutes that could change your baby's life..."

Below this, it says: "Get your FREE Parents' Guide"

- ✓ Clear, comprehensive information
- ✓ The benefits of storing your baby's stem cells
- ✓ Everything you need to know about cord blood banking

There is a "FREE Guide" icon showing a parent and child. Below the list is a form: "Enter your email address here" and a "REQUEST NOW" button.

At the bottom, it asks: "Why choose Cells4Life for cord blood banking?"

Cells4Life is the leader in cord blood banking in the UK, with more UK samples in storage than any other bank. Everything about our service has been designed for one purpose – to provide your baby and your family with the best long term health protection available.

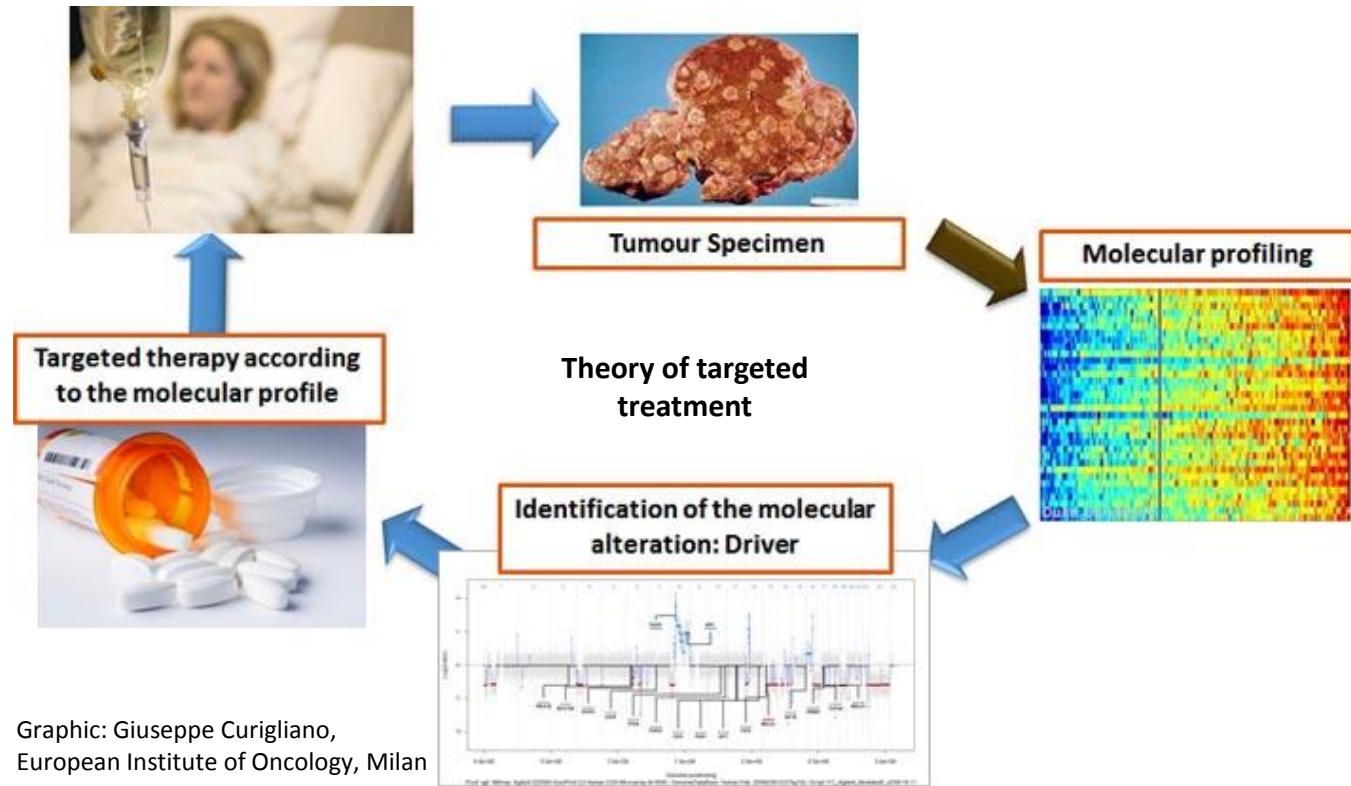
Here are just a few of the benefits to cord blood banking with Cells4Life:

- Multiple treatments
- Dual location storage
- 100% of stem cells
- Stem cell insurance
- Most comprehensive range of services
- Year-round collection
- Dedicated couriers
- Industry leading technology
- HTA licensed

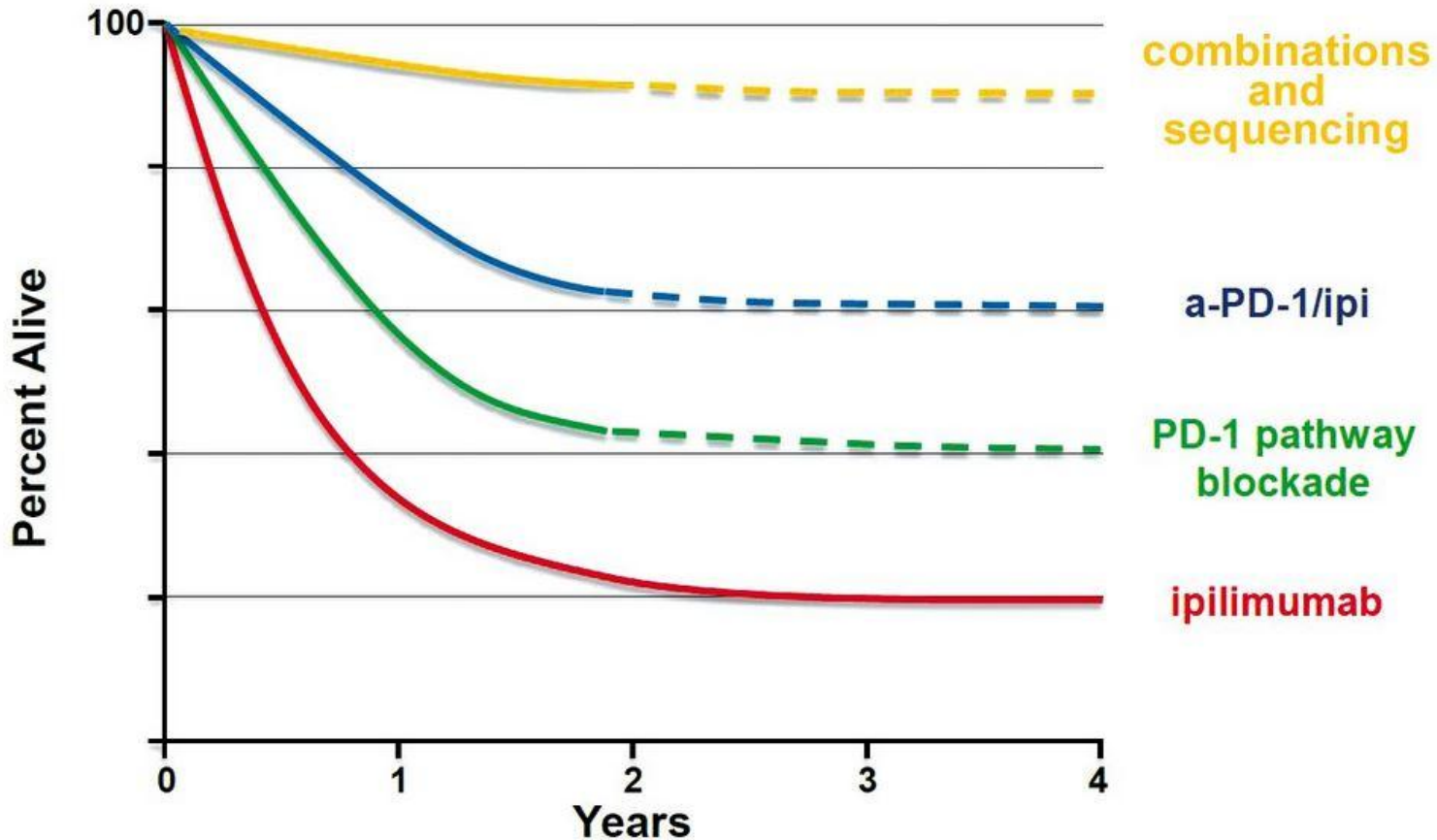


## Biobanks central to future of cancer research and treatment

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



Drugs work on some patients but not others



## 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



**Denis Lacombe**  
**Director General EORTC**  
European Organisation for  
Research and Treatment of Cancer

## 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 are 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)



**Patient advocate Jayne Bressington**  
one of the founders of the PAWS-GIST  
tissue bank

## 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.



Top: Translational Medicine Biobank, European Institute of Oncology Milan

Left: Ulla Ohlms, co-founder of the PATH biobank in Germany

## 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?