

Ethics: Forensic access to research banks ^{5,6}



Murder of Anna Lindh

In 2003, Swedish police accessed a hospital biobank while investigating the murder of Swedish Foreign minister Anna Lindh. The bank was set up for medical treatment and academia, but the samples obtained by the police were used to build a DNA profile which played a significant role in identifying the murderer.

Conviction of Stephen Kelly

In a separate example, Stephen Kelly, a Glaswegian male suspected of recklessly spreading HIV through sexual intercourse, was convicted using biological samples from a academic biobank. Kelly had provided a sample to a study investigating the spread of HIV through needle-sharing. By matching his sample to that of his girlfriend's, the police were able to prove that she had contracted it from him.

Forensic branches of the police possess their own biobanks, which are used to store the large quantity of biological samples and data they collect during their investigations. However, there have also been a number of cases in which police have accessed research biobanks in order to obtain information.

Ethical Considerations



- Donors to biobanks are rarely, if ever, told that authorities may be able to access their samples – how does this affect their ability to give **informed consent**?
- Most countries do not yet have regulations relating to police access to biobanks. Without appropriate scrutiny, the **consequences** of misuse could be severe, as samples could be used to plant or manipulate evidence

- Incidences like these could undermine **public trust** in the academic community
- Donors can have good reason for wanting their data to remain anonymous (even if they **have not committed a crime**) because research can cover very sensitive issues
- Kelly's samples were collected using a **police warrant**. Deciding to compromise privacy in favour of a conviction under exceptional circumstances is not a new concept
- Failure to assist a police investigation may **also harm the public's view** of the academic community
- Both Lindh's murderer and Stephen Kelly were guilty of very serious crimes: some might consider an invasion of privacy a **proportional response**



What is a biobank? ^{1,4,5}

Biobanks come in many shapes and sizes. Simply put, a biobank is an organised collection of biological samples and/or their associated data. Some are small, used in academia or hospitals, while others are much larger (such as the UK Biobank collection, containing data from half a million individuals).

Biobanks have many different applications, including medical and academic research, clinical studies, biotechnology, and judicial purposes. By their very nature, they raise complex ethical questions, such as those regarding the rights of donors and informed consent.



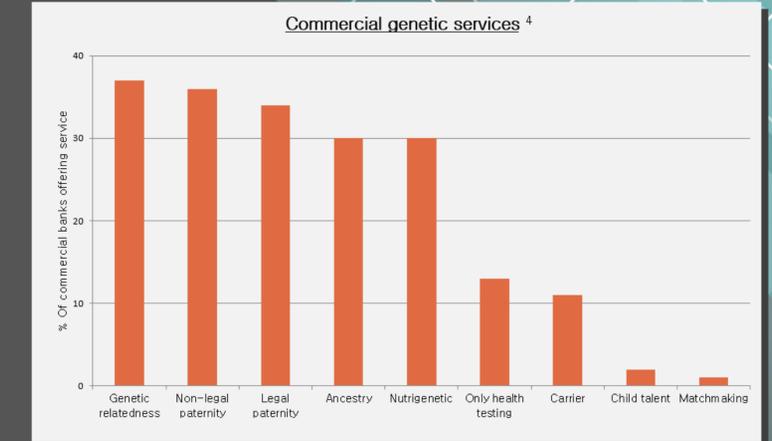
BIOBANKS

Why are they on the rise? ^{1,2,3,4}

A major factor contributing the rise of biobanks are advances in computing. When the human genome was first sequenced in 2001, it cost **\$100m** (£67m) and the resources of multiple laboratories. In January of this year, it was sequenced on a handheld device costing just **\$1,000** (£700). With sequencing now available at such a low price, it is accessible to more researchers and organisations than ever before.



A number of **commercial** biobanks have also emerged, such as those operated by 23andMe. These companies offer genetic services to the general public, raising the demand for biobanks further.



Ethics: Direct-to-consumer banks ^{4,7,8,9}

Direct to consumer (DTC) biobanks offer genetic services to the general public. For a fee, the companies provide consumers with an analysis of their biological samples. This analysis can cover a wide range of topics (see chart), both medical and non-medical, and most will also contribute to academic research. This will either be through studies run by the company itself, or by distributing data to third parties.

Examples of DTC biobanks include 23andMe, Gene by Gene, and AncestryDNA. Some have already attracted a large following, with the latter acquiring more than a million customers in three years.



Ethical Considerations

- There are questions over the **validity** of the tests. Very few companies offer full genome sequencing, so the analysis provided is limited. Services such as nutrigenetics (diet advice), analysis of 'child talent', and 'matchmaking' do not have sufficient evidence to show they are valid. There is a real possibility that, in some cases, people are paying for useless information
- Some tests use samples taken from **minors** (e.g. child talent tests). Can a child give meaningful consent to such tests? How could the outcome impact their autonomy?
- The literature generally shows that donors are unaware their samples could be used in **research** in addition to the tests they paid for. Companies often do a very poor job of conveying this. How does this affect consent?
- Donors are usually asked to collect the samples themselves, at home. There are concerns that this system is too open to **tampering or contamination**, particularly where issues such as paternity are involved
- DTC genetics has the **potential to do great good**. Tests for carriers of genetic conditions could be invaluable to couples who are considering having children. Other services can help provide personalised medicine, offering more effective treatment for patients and possibly saving money in the process
- Tests of paternity and genetic relatedness can offer a means for **resolving family disputes**
- The samples stored could be used to greatly accelerate **medical research**. The argument has been made that withholding them, even on the grounds of privacy, is itself unethical