

**EUROPE
BIOBANK
WEEK**

SEPTEMBER 13-16, 2016
VIENNA - AUSTRIA

**Marianne Talbot (University of Oxford, UK):
"Biobanking from a donor perspective"**



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BIOBANKING FROM A DONOR'S PERSPECTIVE

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13TH SEPTEMBER 2016

**I am a
donor to
Biobank
UK**

biobank^{uk}

Improving the health of future generations

Annual Meeting 2016



Annual Meeting 13 June 2016

@uk_biobank #UKBAM16



Biobanks and Trust

**Without donor trust
biobanks would founder**

**What might cause me to
lose trust in Biobank UK?**

**Interpreting
consent too
generously**

**At the Annual Meeting Biobank UK
said it might come back to donors
for additional consent**

Two reasons were mentioned:

- **use of tissue from tumours
etc;**
- **link to HMRC to get
financial information**

Interpreting consent too generously

One way Biobank could lose the trust of donors is by interpreting the initial consent too generously.

Donors do *not* see themselves as having:

- **given consent to the collection of *any* information**
- **consented to the collections of samples other than those given to biobank during the initial donation.**

Donors disagree on where the limits are.

But that there are limits is clear.

Interpreting
consent too
generously



Interpreting
consent too
generously

The Human Tissue Act 2004



Human Tissue Act 2004 logo

Interpreting
consent too
generously

The Human Tissue Act 2004

**Biobanks would be well-advised
to interpret donors' initial
consent austerely**

**Of course returning to donors
for further consent will cost
money**

**But given the *catastrophic*
consequences of loss of trust, it
seems worth it**

Human Tissue Act 2004 logo

Donor withdrawal

- 1. no further contact – UK Biobank wouldn't be able to contact me in future but could still use my information and samples even in future;**
- 2. no further access – UK Biobank would still be able to use past samples and information but couldn't collect more, or even contact me, in future;**
- 3. no further use – UK Biobank must withdraw my information and destroy my samples.**

I have concentrated on what sort of thing might make me insist that Biobank UK withdraw my information and destroy my samples

I shall also concentrate on a real and present danger

The danger I will concentrate on is the fear of the loss of confidentiality

“Insurance companies and employers will not be given any individual’s information, samples or test results, and nor will we allow access to the police, security services, relatives or lawyers, unless forced to do so by the courts”

(UK Biobank Information Leaflet p. 9).

Breaching Data Confidentiality

Courts *have* forced the release of such information.

- **The murderer of Anna Lindh (the Swedish Foreign Minister) would never have been caught if police hadn't matched DNA found at the crime scene with details found on the killer's Guthrie card.**
- **Detective Gary Fraser from Perth, Australia would never have convicted a man for incest if he hadn't proven the man was the father of his daughters' children by accessing the DNA on the man's Guthrie card.**
- **Stephen Kelly would never have been prosecuted for knowingly passing on HIV to his partner if police hadn't accessed samples collected by researchers whilst Kelly was in prison.**

Breaching Data Confidentiality

Even if I am sanguine about *legal* use of my information, I might still be worried about the *illegal* use of my information

Breaching Data Confidentiality

I more worried about the theft of my medical data than my financial data.

- **medical data is far more valuable on the black market in fact it is *ten* times more valuable - stolen patient health records can fetch as much as \$363 per record!**
- **I am likely to remain in blissful ignorance for months, or even years**
- **so much more can be *done* with my medical data, especially if it contains information on my DNA – e.g. thieves could use the data to blackmail me**

Breaching Data Confidentiality

UK Biobank assures me that “the risk to participants of a breach of confidentiality is considered very low”.

This is because:

- **“security is in place to block unauthorised access”;**
- **“once the data are provided they are separated from participant details”;**
- **“researchers are not sent the identifying information”;**
- **staff who *do* have access to identifying information are trained, monitored and aware that they will be sacked if they breach confidentiality**

But how good *is* the security that blocks unauthorised access?

No doubt Anthem Health Care Systems believed they had such security in place in 2014.

But then they discovered that Chinese hackers had been operating within their network for months

These hackers harvested the details of *over 78m people* who had taken out insurance plans

In the UK our NHS health care records seem more at risk from carelessness than from hacking.

In 2015 the UK Information Commissioner imposed fines of £1.3 million on NHS trusts for their lax security.

Brighton and Sussex University Hospital, for example, was fined £325,000

69,000 patient records were found on hard disk drives being offered for sale on an internet auction site

I hope that the security at the UK Biobank is better!

I wonder if they test the security of it regularly?

I also hope that UK Biobank staff with access to identifying information are taking their training to heart

I hope too that they aren't too disaffected when they leave Biobank!

Breaching Data

Confidentiality

I'd hate to discover that my records had been encrypted onto discs, but with the passwords allowing access taped to the side when they were found abandoned in a skip.

This happened to the medical records of 6000 prisoners from a Lancashire prison

I am also not totally convinced that the separation of my identifying details from the data collected from me will do the trick.

William Weld, Governor of Massachusetts in the mid-1990s was confident that such 'pseudonymisation' would work when he released the health records for all his state employees to researchers.

Then Professor Latanya Sweeney from Harvard University handed him his own health records.

She had combined the health data in his record with data from the electoral roll and motor vehicle records.

It took her \$20 and 24 hours to re-identify his medical records as his.

Breaching Data

Confidentiality

Professor George Church, the Harvard Professor of Genetics who runs the Personal Genome Project was also embarrassed

Professor Sweeney named 42% of the supposedly anonymous participants of the project

Biobank requires data that is not fully anonymised, but only *pseudonymised*

Pseudonymised data admits of re-identification whenever that data can be combined with other data sources in such a way as to generate uniqueness.

Could *you* be uniquely identified, for example, from the combination of your birthdate, gender and post-code?

I am a trusting soul,

**I have not withdrawn from the UK
Biobank.**

But reflection on all this *does* worry me.

**All we need is one seriously big scandal
and the success of biobanks could be
seriously compromised.**

**I believe that biobanks are important and
I want to see them do well.**

Don't put me
in a position
where I want
to withdraw

***Please don't interpret my
consent too generously!***

***Please take the security of
my data seriously!***

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