2. Ensuring Public Support For Biobank Cooperation With Industry

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Published on March 4, 2019

This article starts by considering what past studies have shown about public attitudes to biobank cooperation with industry. The lack of public awareness about biobanking itself is highlighted and the article concludes by explaining why education and transparency are vital for ensuring public support for biobank cooperation with industry.

Public Attitudes to Biobank Cooperation With Industry

The general finding from studies in North America and Europe is that the level of public trust in, or support for, biobanking research, tends to be lower if industry is involved in either funding or conducting the research. This section gives a factual account of a few key studies from North America and Europe that describe public attitudes to industry access to biosamples and associated data.

A publication entitled '**Biobanking, Consent, and Control: A Survey of Albertans on Key Research Ethics Issues**', Caulfield, Rachul and Nelson described the results of a telephone survey of members of the public in Alberta, Canada.

TABLE 3. PUBLIC TRUST IN INDIVIDUALS OR INSTITUTIONS INVOLVED IN BIOBANKING RESEARCH

Person or institution	*A great deal*	*Somewhat*	*Not at all*
Insurance industry	7.1%	46.4%	46.5%
Provincial government	18.7%	60.4%	20.8%
For-profit industry	6.0%	31.4%	62.6%
Data collection organizations	33.6%	54.4%	12.0%
Disease-based foundation	40.0%	50.2%	9.8%
University researchers funded by gov't	45.1%	48.7%	6.2%
University researchers funded by industry	19.5%	53.6%	26.9%
Hospitals	46.9%	46.6%	6.5%
Doctors	60.7%	34.8%	4.5%

The survey asked about level of trust in a variety of individuals and institutions that may care for and use confidential health information. The results provided in this table show that the insurance and for-profit industries were the least trusted, whereas doctors and hospitals were the most trusted.

Please note these results are not 'all or nothing'. Even doctors who are the most trusted group, are only somewhat trusted by 34.8% and not at all trusted by 4.5%.

The article '**A systematic literature review of individuals' perspectives on broad consent and data sharing in the United States**' by Garrison et al (2016) reported on a number of studies concerning the attitudes toward biobanking, broad consent, and data sharing. Regarding the willingness to share with commercial enterprises, their overall summary was that: 'The majority of participants were willing to share with pharmaceutical company researchers, but the percentage was generally less than the percentage willing to share with academic researchers.'

A 2013 study by Lewis et al entitled '**Public views on the donation and use of human biological samples in biomedical research: a mixed methods study**' provides evidence from both a quantitative survey of the UK population as well as from focus group discussions.

From the survey they report that 'Most survey responders were willing to donate human biosamples to National Health Service hospitals (84%), medical research charities (79%), universities (68%), diagnostic companies (63%) and pharmaceutical companies (56%).

It should be noted that willingness to donate is related to trust, but is not the same thing.

From the focus group discussions they report, 'Some initial negativity was found in relation to pharmaceutical companies conducting research because of their commercial, profit-making nature and concerns that they 'exploit patients'. However, such concerns were often addressed by other members of the group who acknowledged that commercialisation of research was 'a fact of life' and that pharmaceutical companies 'need to make money to keep their research going'.

In May 2017, a UK study commissioned by the Health Research Authority (HRA) and the Human Tissue Authority (HTA) undertook a public dialogue with 75 selected volunteers from across the UK, to explore views of consent to use patient data linked to human tissue in health research. This was entitled '**Consent to use human tissue and linked health data in health research**'.

In focus group discussions about consent, '*participants' most common red lines were no access for commercial companies like insurance companies or marketing companies using data to sell a product. There were some who did not want pharmaceutical companies to have access to their data, but after their role in research was explained, almost all felt less strongly about this*'.

The study found that: '*Few participants had heard of biobanks before, but there was a great deal of interest in what purpose they serve, and how they operate*'.

The Need For Public Education About Biobanks

As just mentioned, not many participants in the 2017 UK study had heard of biobanks before. This is despite the existence and outstanding success of the UK Biobank - a project involving 0.5 million volunteers!

This is not completely unexpected. In '**Winds of Change?**' a 2010 report by Gaskell et al to the European Commission's Directorate-General for Research, described findings of the Eurobarometer 73.1 survey on the Life Sciences and Biotechnology. The survey found that many European citizens are unaware of biobanks. Two thirds of respondents had not heard about biobanks before they were interviewed.

Here are a few points relating to this limited public awareness of biobanks:

- It may not be very useful to examine public attitudes on matters relating to biobanks, without first educating participants about what a biobank is. For this reason, focus group studies, where participants are able to discuss, question, learn and develop their opinions, may be more informative than simple questionnaires and surveys.

- Any effort to ensure public support for biobank cooperation with industry will need to involve education. One obvious place for this education is during the informed consent process, when potential donors can be informed about why industry needs to access biosamples and the benefits that may arise in terms of developing new drug and diagnostic products. This seems obvious, but is probably not a routine part of informed consent for biobanking in many centres.
- As scientists, technologists and healthcare professionals, we have a good understanding of why the pharma, diagnostics and biotech industries need to have access to human biosamples. We need to explain to the general public, so they understand why it is important to be supportive.

The Need For Biobank Transparency

We live in "The Age of Transparency". All of us are accustomed to finding information on the internet with great ease, so when we can't find information it is harder than ever to accept. Linked to this, we have a growing expectation that institutions and companies should be transparent. Here is a nice quote to illustrate the importance of transparency!

'A lack of transparency results in distrust and a deep sense of insecurity'. Dalai Lama

So to ensure public support for biobank cooperation with industry, biobanks need to be transparent, particularly on the way they distribute biosamples.

This starts with the informed consent process, where there is a trend towards greater transparency. The revised US Common Rule (2017) requires that contributors who provide informed consent must be told whether contributor biospecimens could be used "for commercial profit" and whether contributors will share in such profit themselves. **Federal Policy for the Protection of Human Subjects. Final rule.** Fed Regist. 2017;82(12):7149–274.

To provide a European example, the UK MRC guidelines on '**Human Tissue and Biological Samples for Use in Research**' (2014) states the following (in section 7B):

It is important that there is clarity of arrangements for allowing commercial access to human biological material originally donated for research projects funded by the public or charity sectors. Where possible, participants should know when their sample or products derived from it may be used by the commercial sector, and the potential benefits of this access. It is also important to let the participant know they will not be entitled to a share of any profits that might ensue, as is also the case for IP rights generated from sample use in the academic sector.'

Another way in which biobanks can be transparent, not just to donors, but to all stakeholders, is by giving annual reports on how they distribute biosamples. For example, the **UKCRC Tissue Directory and Coordination Centre** has asked all UK biobanks to make this detail publicly accessible. Here are two examples:

- **United Kingdom Collaborative Trial of Ovarian Cancer Screening (UKCTOCS)**
- **Scottish Human Papillomavirus Archive**

Conclusion

To sum up, previous studies have shown that members of the public are less trusting of industry research on biosamples (as compared with university research on biosamples). However, when the benefits of this industry research are explained it does make them more supportive. At least in Europe, there is limited public awareness about biobanks, and public education is certainly needed to explain why biobanks need to cooperate with industry (in order to support development of new drug and diagnostic products). Most importantly, biobanks need to be transparent about how they distribute biosamples, in order to maintain public trust. This trust will help to ensure support for biobank cooperation with industry.

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