

Globalisation and the ethics of transnational biobank networks

Lisa Dive, Paul Mason, Edwina Light, Ian Kerridge, Wendy Lipworth

Abstract

Biobanks are increasingly being linked together into global networks in order to maximise their capacity to identify causes of and treatments for disease. While there is great optimism about the potential of these biobank networks to contribute to personalised and data-driven medicine, there are also ethical concerns about, among other things, risks to personal privacy and exploitation of vulnerable populations. Concepts drawn from theories of globalisation can assist with the characterisation of the ethical implications of biobank networking across borders, which can, in turn, inform more ethically sophisticated responses. Using the China Kadoorie Biobank as a case study, we show how distinguishing between the subnational, transnational, supranational and extranational spheres of operation and influence can help researchers, institutions and regulators to understand and manage the ethical issues raised by the globalisation of biobanking.

Asian Bioethics Review, December 2017, 9(4):301-310

DOI: 10.1007/s41649-017-0034-8

Keywords: biobanks, ethics, globalisation, consent, privacy, trust

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Introduction

Biobanks, which can be defined as “structured collections of biological samples and associated data, stored for the purposes of present and future research” (Parodi 2015), are becoming increasingly important in scientific and medical research, and are believed to be an important foundation of genomic and personalised medicine. Advances in computational and information technology and data linkage platforms have greatly enhanced the potential of biobanks to identify biomarkers and develop new treatments.

Typically, biobanks have been housed within, or associated with, academic medical research institutions, governments, or commercial organisations (such as biotechnology or pharmaceutical companies). Increasingly, however, single institution biobanks are becoming unsustainable, both because they lack sufficient informational depth and also because they are operationally isolated. Biobanks are therefore frequently becoming part of national or international networks. This facilitates high powered molecular epidemiology—enabling researchers to make fine comparisons, to accommodate population heterogeneity, identify rare events, and develop predictive analytics (or “risk scores”) for treating individuals. In this way, biobank networking is closely intertwined with the promise of big data, and offers opportunities for collaboration and efficiencies of scale.

While globalisation affords biobanks enormous possibilities, the global networking of biobanks is associated with significant socio-cultural, ethical and regulatory challenges. These include challenges that arise in the context of local biobanking (including consent, privacy, return of research results, custodianship, commodification and exploitation), but which become increasingly complex as biobanks network, and also *new* issues created by the networking of biobanks. In this paper we outline some of the ways that biobanks can globalise, and elucidate some relevant concepts from theories of globalisation. Then, using the China Kadoorie Biobank as a case study, we show how concepts drawn from theories of globalisation can help to inform ethical approaches to issues that arise when biobanks network across international borders.

Modes of Biobank Globalisation

There is nothing new about biobanking (Hoeyer 2008). People have stored human biological materials and used them in research for decades. However in the 1990s, increasing attention turned to the ethical, social and legal consequences of biobanking. This was fomented by a number of forces such as the patient rights' movement, increasing commercialisation of medical research, and developments in genetics and data science. Moral attention was also drawn to the tension between the commodification and depersonalisation of human tissue on the one hand, and its residual biological personification and cultural identification on the other hand. The increasing capacity, reach and accessibility of genomic medicine has made it even more apparent that tissue retains its personal and cultural identity even when it becomes disembodied. The persisting personal and cultural identity that attaches to human tissue even when it is disembodied is increasingly recognised in the context of genomics. While relevant to individual biobanks, these issues become even more salient and challenging as biobanks globalise.

Biobanks can globalise in three principal ways. The first and most obvious way in is when a single biobank operates across international borders. An example of this is the for-profit incorporated company 23andMe which offers direct-to-consumer DNA analysis and retains saliva samples and/or genetic data from its customers. While the organisation's operations have been restricted in some jurisdictions,¹ it can accept saliva samples from anywhere in the world and retain the right to access and analyse customers' samples and data for future research.

A second way in which biobanks can globalise is that they can pool and/or centralise their resources across international boundaries. They can, for example, share facilities (e.g. "storage networks"), pool or centralise information technology platforms (e.g. "catalogue networks"), and/or form partnership networks to centralise and coordinate administration, including staffing, recruitment and other organisational functions.

The third way that biobanks can globalise is by distributing and compartmentalising their operations. In these situations, different elements of the biobank's operations – including

¹ For example, until 2016, 23andMe was only permitted to provide ancestry information to US customers, and other countries have varying restrictions on the information that can be provided to customers.

financing, participant recruitment, sample collection, sample storage, data storage, analysis, governance oversight, etc. – are undertaken in different countries. Generally, operational components will be located in those countries with the most favourable ethical, regulatory and legal conditions, or where the relevant kind of expertise is located.

Conceptualisations of Globalisation

A number of scholars have developed theoretical frameworks and elucidated concepts for understanding social activities that occur both locally and across national borders. Key theories and concepts include Habermas's theory of postnational constellations (Habermas 2001), Appadurai's notion of global cultural flows (Appadurai 2010), and Harvey's concept of time-space compression (Harvey 1990). The concept of postnationalism, which is elaborated in all of these approaches, describes the reduction in the importance of the nation state and national identity in the face of internationalisation, the increasing plurality of actors involved in governance, both within and across nation states, and the challenges and opportunities to national structures afforded by subnational, transnational, and supranational formations.

At the *subnational* level – from the perspective of a single country – the increasing and intensifying movement of people across borders has led to more widespread diasporic communities and more multicultural societies. At the *transnational* level – that is, spanning across national borders – technologies of communication, travel and exchange have afforded new alliances. At the *supranational* level, globalisation has created organisations such as the World Health Organisation and the World Bank, whose operations and jurisdictions “sit above” national governance structures. Together, these formations displace, challenge and erode the authority, legitimacy and integrative capacities of the nation-state at multiple levels, thus creating and supporting postnational ideas and structures in which activities escape the jurisdiction of any particular nation and exist, either theoretically or tangibly, in extranational territory. This exemplifies the concept of postnationalism, the view that national citizenship is becoming decreasingly relevant as governments extend rights to people who are not their citizens. In this postnational context,

international organisations, such as the World Health Organisation, have become increasingly important in safeguarding human rights across borders (Jacobsen 1996).

Global biobank networks can be conceptualised as existing in this “extranational” space because they selectively and differentially share, transfer, transport and store material and data across national boundaries. This disrupts existing arrangements between peoples, institutions, and nations and remakes social, political, organisational, economic and regulatory relations along the way, subsuming local practices under the standards, structures and norms of international biomedical science. Concepts of globalisation can help to inform normative considerations and practical responses to the globalisation of biobanks because of the ways in which human biological samples are extracted multinationally; contributors and beneficiaries are distributed transnationally; and biobanks can be governed, and influence scientific practice, supranationally,

The China Kadoorie Biobank

The China Kadoorie Biobank (CKB) provides a model for examining the processes and implications of the globalisation of biobanks. The CKB was established to enable research into the genetic and environmental factors associated with common chronic diseases in China. Although initial funding for the project came from a Hong Kong-based charitable trust, from the start it was a collaborative project between the University of Oxford and Chinese researchers. This collaboration was partly motivated by researchers from Oxford’s Clinical Trials Service Unit experiencing difficult negotiations with the UK Biobank and seeking another large-scale biobank project to support prospective research into chronic disease prevention and treatment. It also followed on from decades of productive collaboration and trust between Oxford researchers and the Chinese Centre for Disease Control (Chen 2013). More than half a million participants from 10 geographical areas in China were recruited into the prospective cohort study between 2004 and 2008. All participants provided extensive data in addition to blood samples, with follow-up information gathered from 5% of participants (selected randomly) every four to five years (China Kadoorie Biobank 2017d). Sample and data collection for the CKB was undertaken by teams of qualified health researchers and relied heavily on the involvement of local health

and administrative (government) authorities in the selected communities (Chen 2013). All samples and associated data are stored in a central repository in Beijing, with cryopreserved plasma aliquots from each participant also sent to Oxford for further analysis and storage.

Although focused on the Chinese population, the study is being conducted and the biobank administered jointly by the University of Oxford's Clinical Trial Service Unit & Epidemiological Studies Unit, and the Chinese Academy of Medical Sciences. Funding for the biobank has been provided by a range of Chinese and UK funders. Initial financial support was provided by the Hong Kong government, with ongoing operations being supported by funders across the world including the Wellcome Trust, UK Medical Research Council, British Heart Foundation, Cancer Research UK, the Chinese Natural Science Foundation, and the Chinese Ministry of Science and Technology.

Collaborating institutions include universities and research centres in Australia, Sweden, France, Finland and China. Researchers from around the world can apply to gain access to the data in the CKB, although access to biological samples is strictly controlled due to the small volume of biomaterials collected from each participant in the study. Researchers can also apply for access to baseline data, follow-up prospective data and from 2018 they will be able to access genotype datasets. The CKB's Data Access and Sample Sharing Policy (China Kadoorie Biobank 2017c) requires researchers to demonstrate that they are employees of a recognised institution that has policies and procedures in place to ensure the appropriate and responsible use of the dataset. The CKB policy aligns with the Data Access and Sharing Policy of the Nuffield Department of Population Health. An Independent Access Committee oversees data access for the CKB, providing guidance and reviewing applications that raise specific issues.

Ethical Responses to Global Biobank Networking

When biobanks network their operations across international borders, the ethical issues of local relevance to specific biobanks become increasingly complex. Here we will focus on the following issues: consent, participant privacy and confidentiality, benefit sharing and trust. These particular issues have been chosen both because of their centrality to biobanking ethics generally, but also because they become more complex when biobanks network

globally. We will give a brief overview of each of these issues, explain how they become more complex in the context of global networking, and then use the example of the China Kadoorie Biobank to show how a postnational understanding of globalisation can practically enhance ethical responses to these issues.

Consent

Consent is an important issue in biobanking, because the kind of consent that a donor gives will determine how their tissue sample and its associated data can be used. Donors might consent only to a single, specific use of their sample. Project-specific consent, however, significantly limits the utility of a sample for research purposes. For this reason, broad rather than specific informed consent is usually sought as this provides for long-term storage and unspecified or unknown future research use. Alternative models of consent provide for both broad and specific consent. Dynamic consent, for example, uses technology platforms to engage donors in an ongoing way, in decisions about what kind of research they wish their information to be used for.

When a biobank shares samples or data in an international networking arrangement, the connection between the original donor and the researchers using their sample becomes increasingly distant. This disconnection can have implications for the control that a donor can exercise over their sample, and the extent to which the networked biobank partners are required to uphold the original biobank's obligation to donors. As global biobank networks operate on a *transnational* scale, they may not be bound by the (*subnational*) laws of a single jurisdiction's legislative and regulatory requirements with respect to their obligations to donors. Consent requirements can vary substantially between countries. Furthermore, different countries can take different approaches to how stringently they enforce their regulations relating to consent. Similarly, if global biobank networks operate in an *extranational* space, then there is a risk that donors' rights in relation to the consent that they granted when giving their sample could be overturned or no longer relevant in another jurisdiction. Therefore it is essential that when biobanks globalise, clear arrangements are made for how consent obligations to donors will be upheld.

In the context of the China Kadoorie Biobank, regulatory challenges related to consent were addressed by ensuring that the project adhered to the more stringent standards of

regulation that governed the UK partners in the project. In a 2013 multi-method empirical study, Scott (Scott et al. 2012) noted how the study's central coordinating centres placed significant emphasis on the importance of obtaining informed consent, and that regional staff in various operational branches were urged to follow prescribed processes for obtaining broad consent.

However, interviews and focus group feedback identified some misunderstandings among donors. Participation in the CKB was often understood to be a means of accessing free health examinations. Indeed, the benefit of free physical examinations was one of the two main reasons reported as motivating people to participate in the study, with the other being the public good of advancing scientific and medical research. These misunderstandings potentially undermine the legitimacy of consent to participation in the CKB, and the use of samples of data both locally and internationally.

Issues surrounding consent in the context of the globalisation of biobanks are made more complex by differences in values across different cultures. For example, an analysis of consent forms in East Asia found that they performed a broader social and communicative function than comparable documents from genomic research projects in Europe, the UK and Africa (Yoshizawa et al. 2017). This reflects earlier findings that in East Asian countries, informed consent is more of a collective process than an individual one (Yoshizawa et al. 2014), with significant involvement of participants' family and community members in the decision making process. Collective consent processes were involved in the CKB case, as local community members—both administrative and medical—played a significant role in recruiting participants for the study. This locally distributed decision-making then underwent a shift as CKB moved out of the *subnational* context—with its emphasis on family and community—and adopted UK standards for participant consent, which is a more individualistic approach to informed consent. The decision by the CKB to adhere to *transnational* (UK and European) standards in relation to consent demonstrates a commitment to seek and implement more stringent standards for the benefit of participants. However, this approach contrasts with the recruitment methods for the study, which depended on the active involvement of local community networks.

Privacy and confidentiality

When an individual donates a sample to a biobank and allows it to be used in health and medical research, there are both moral standards and regulatory requirements with respect to the individual's privacy and confidentiality. These generally aim to enable research (a public good) while also respecting an individual donor's right to privacy and protecting them from harm arising from use of their data (Dove et al. 2014). While at one time donors could be given assurances that their data would remain private and secure, advances in genomic technologies and big data, and the imperative to make data accessible, means that an individual's privacy can no longer be guaranteed (Lunshof et al. 2008).

When biobanks enter into networking arrangements, particularly across international borders, it becomes exponentially more difficult to maintain donors' privacy and confidentiality. (Chadwick and O'Connor 2016). Furthermore, as with consent, when a donor's tissue or data are shared with institutions in other jurisdictions, that institution might be bound by different legal and regulatory frameworks to those that applied in the jurisdiction in which the donor gave their tissue. This means that donors might not be protected by their own country's privacy legislation when their sample or data is used in another jurisdiction.

When the CKB began, it did not share its data as baseline measurements were collected and aggregated. However, since 2016 researchers from around the world in any reputable research organisation (including commercial organisations) have been able to apply to have access to the samples and data held in the CKB. Available datasets include the baseline survey data, follow-up and resurvey data, as well as blood-based SNP (single nucleotide polymorphism) genotyping datasets (China Kadoorie Biobank 2017b). In the case of the CKB, this kind of *transnationality* has led to the adoption of higher standards of privacy protection than would usually exist in China, which lacks robust national mechanisms for governing biomedical research (Chen 2013). This arrangement not only offers research participants greater technological and regulatory protection but also creates data management resources that are beneficial to Chinese and overseas researchers. However, *transnationality* does not necessarily always work to protect research participants as collaborating countries might also have less rigorous and more lenient ethical and regulatory standards and so work to undermine participant protection. Indeed, some would

argue that genetic researchers can no longer guarantee the privacy of participants (Lunshof et al 2008). This could be exacerbated if a biobank network actively engages in regulatory arbitrage and seeks to locate its data storage functions in the jurisdictions with less onerous privacy regulations. Another consideration is that the imposition of UK standards for safeguarding patient data leads to a more individualistic emphasis on participant rights. This does not necessarily align with the tendency of East Asian countries to emphasise the broader societal benefits of participating in genomic research (Yoshizawa et al. 2017).

Benefit sharing

A significant ethical consideration, particularly when different countries become involved in a biobanking research project, is how to ensure the equitable distribution of the benefits of research. While individual countries have different *subnational* regulations about the obligations of researchers to research participants, when samples are collected in one country and sent to another for analysis, the research project is operating in a *transnational* context and hence these obligations become less clear. Chadwick and O'Connor (Chadwick and O'Connor 2016) point out that benefit sharing between countries involved in biobanking research is especially pertinent when there are economic disparities between the countries involved. The primary concern they identify is that comparatively disadvantaged communities will donate samples for medical research – bearing the burden of risks that research participation entails – and the benefits resulting from the research – either monetary or in terms of healthcare advances – tend to accrue to the wealthier, more advantaged countries whose medical research institutes obtain the samples and conduct the research. As early as 2000, the Human Genome Organization (HUGO) clarified that benefit sharing goes beyond obligations not to harm research participants (Knoppers et al. 2000). HUGO encouraged researchers to consider how benefits of research such as direct healthcare, provision of technologies, and contributions to broader community infrastructure can be distributed to communities that contribute to medical research. They also recommended that any profit-making entities engaged in medical research donate a percentage of profits to improving healthcare infrastructure or supporting humanitarian efforts in communities that have contributed to their research.

The CKB currently releases datasets to CKB researchers first, then allows limited access for other researchers in China only for a period of three to six months. Researchers who access CKB data are required to publish their findings and return them to CKB, both for the benefit of future research and for the public good (China Kadoorie Biobank 2017a). Beyond that, publicly available CKB documentation does not indicate any further requirements for benefit sharing with donors to the study from researchers who use the samples or data.

Empirical examination of the motivations of donors to the CKB (Chen 2013) found that they participated in the hope that they would obtain some benefit, either for themselves or their communities. As described above, a key reason for participating in the CKB was that donors wanted to access the physical examinations that were conducted as part of the project.

They were also motivated by an interest in contributing to scientific research, which reflects a general trend observed in East Asian countries, where researchers have been observed to have a tendency to emphasise the virtue of participating in medical research for the purpose of advancing medical and scientific knowledge (Yoshizawa et al. 2017). The ethical issue here is how the *transnational* activities of biobanks such as the CKB flow to the *subnational* realm. For instance, what tangible benefits drawn from the research findings (or profits derived from them) could be distributed to the donor communities, such as health infrastructure, improved medical care, and so on? It is therefore crucial that, as banks like the CKB enable research in many countries, donor communities remain connected with the benefits of the research that their samples make possible.

Trust

Trust is a central issue that underpins many of the ethical and regulatory challenges in biobanking, not least because without trust people are unlikely to volunteer their biological samples and data for research use. In order to agree to relinquish control of one's tissue sample and its associated data, a typical person would require some degree of trust that the institution conducting the research will not misuse their sample or information in a way that could harm them (or others). The trust on which such arrangements are usually entered into are often based on the donor's perception of the institution or individuals involved with the research as trustworthy, either by virtue of their institutional reputation or by some other kind of interpersonal trust grounded in a relationship with the individual/s.

This trust is often transitive: when a person trusts their doctor and the hospital they attend, then by virtue of that trust they also trust the laboratory technician and the researcher analysing their sample, and so on, even though they do not have a direct relationship with the latter professionals or specific knowledge of their credentials. It is likely that the transitivity of trust is placed under tension when it stretches across international borders. If a person in a rural village in China agrees to participate in a research study on the urging of their local community doctor, they would likely do so on the basis of the trustworthiness that they attribute to the doctor. While the donor likely understands that the doctor will not retain personal control over their sample and data, she probably does not realise that teams of researchers in Oxford – and indeed, years later, researchers in other countries who have paid for access to the CKB samples – can use her tissue and associated data for research purposes.

In the case of the CKB, community members' trust in their local authorities and doctors was a significant factor in the establishment of the biobank and the recruitment of participants. Village administration bodies and street communities, for example, played a crucial role in promoting involvement with the project (Chen 2013). Trusted local community members such as doctors from community health centres went door-knocking among their constituents, encouraging them to donate to the biobank. The trustworthiness of local doctors was also – significantly – transitive, in the sense that community members' trust in local doctors led them to agree to participate in a study run by central coordinating authorities in both Beijing and Oxford.

Trust is subject to the dynamics of globalisation. The initial relationship that encouraged participation in the CKB – that is the perceived trustworthiness of local doctors and authorities – is geographically local (i.e. is *subnational*). However participants need to understand and accept that they are participating in a *transnational* project with *supranational* arrangements. Sutrop explores the nature of trust required by participants in human genetic databases, distinguishing between trust in individuals and in institutions (Sutrop 2007). The trust that individual participants have in their local doctors and authorities is, to some extent, transferable in that it extends from trust in individuals to trust in organisations with which those individuals are associated. However this interpersonal dimension of trust also means that as participants become further removed

from the researchers working with their data, the trust relationship could weaken. In this way, the globalisation of biobanks could have the effect of diluting participants' trust in researchers as biobanks aggregate transnationally.

The application of local (*subnational*) governance standards described above, therefore, impacts not only on consent and privacy protection but also on trust. O'Neill (O'Neill 2002) explains that "trustworthiness is expressed through institutions, practices and actions". This means that partnering with trustworthy institutions from other jurisdictions can be a way of improving trust. While individual donors might not be concerned with the data access policies that the CKB has adapted from various UK and European institutions, their local doctors or others higher up the "trust chain" might feel more justified in promoting the initiative locally if they have confidence in the governing institutions of the wider project. Conversely, trust might be threatened if the CKB partners with institutions in countries with less rigorous governance arrangements.

Conclusion

We have argued that concepts drawn from theories of globalisation theories can help us to understand and make sense of the ethical issues that arise when biobanks globalise. The China Kadoorie Biobank provides a good illustration of the issues that are at stake, because it is an example of a biobanking project that has shifted from a *subnational* to a *transnational* context, with *supranational* oversight. An awareness of these dynamics will support the development of ethically robust postnational responses to globalisation of biobank networks.

Acknowledgements

Research related to this paper has been funded by the National Health and Medical Research Council of Australia (APP1083980).

The authors gratefully acknowledge the other investigators on this project: Cameron Stewart, Robert Cumming, Simon Easteal, Emma Kowal, Catherine Waldby, Christine Critchley, Warwick Anderson, and Paula Marlton.

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