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Biobank Economics and the “Commercialization Problem”

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Abstract

The economics of biobanking are intertwined with its social and scientific aspects. In this article, we illustrate this interrelationship and describe two problems that structure the discussion about the economics of biobanking. First, there is a ‘sustainability problem’ about how to maintain biobanks in the long term. Second, and representing a partial response to the first problem, there is a ‘commercialization problem’ about how to deal with the voluntary, altruistic relationship between biobanks and their participants, on the one hand, and the potential commercial relationships that a biobank may form, on the other. We agree with those social scientists who have argued that the commercialization problem is inadequate as a way to construct the multiple tensions that biobanks must negotiate. Turning to alternative accounts of bioeconomy, we suggest that contemporary consideration of the economics of biobanking primarily in terms of participants and their bodily tissue may reproduce the very commodification of science that these scholars critique. We suggest that an alternative conception of the economics of biobanking, one which goes beyond the logics of commodification, may thereby allow broader questions about the social and economic conditions and consequences of biobanks to be posed.

1. Introduction

Biobanks are a “collection of biological material and the associated data and information stored in

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an organized system, for a population or a large subset of a population” (OECD 2007). Contemporary biobanks can include collections of specific tissue, as well as large prospective population-based data. In their broadest conception, contemporary biobanks serve a range of clinical and research purposes, from blood banking to the genetic epidemiology of common complex diseases. In what follows, we are concerned with issues related to prospective population-based biobanks. These can be understood as an attempt to create research infrastructure, and (at least) promise to create new forms of scientific, social and economic value (Meijer, Molas-Gallart, and Mattsson 2012).

Bioethicists and sociologists have taken an interest in biobanking as a phenomenon and many (mostly ethico-legal) scholars have become active in the establishment and governance of biobanks and the international collaborative organizations that support their coordinated development (eg. P3G², BBMRI³, ISBER⁴). Biobanks must recruit participants who are expected to provide biological material and other health data. In return, biobanks are expected to manage these samples and data in socially, ethically and legally legitimate ways. This raises normative questions about precisely what counts as “legitimate” and descriptive questions about how biobanks negotiate the tensions involved in conducting research and commercial activities with these data. Indeed, most who write about this field use very similar concepts to structure these debates including: consent, ownership, privacy, commercialization, trust, and governance (For example, see the systematic review: Budimir et al. 2011; or other reviews such as Tutton 2010; Hoeyer 2008).

According to Meijer and colleagues, biobanks exist at the “interface between sample donors and biomedical researchers, in an academic or pharmaceutical setting” (Meijer, Molas-Gallart, and Mattsson 2012, 492), where the economics of biobanking are intertwined with the social and scientific aspects. Biobanks are caught directly between the values and rights of the participants and the potential commercial and scientific value of the samples and data, and, at the same time, have to construct a business model that will ensure the long- term sustainability of the biobank. We describe these tensions below and demonstrate how this characterization of biobanks produces a narrowly conceived economics.

Two distinct problems, which we discuss in turn, structure the discussion of the economic aspects of these tensions. The first is the “sustainability problem”, about how to maintain biobanks in the

² <www.p3g.org>

³ <www.bbmri.eu>

⁴ <www.isber.org>

long term. The second problem, which represents a partial response to the first, is the “commercialization problem”, about how to deal with the voluntary, altruistic relationship between participants and biobanks, on the one hand, and the potential commercial relationships that the biobank may form, on the other. Finally, turning to alternative accounts of bioeconomy, we suggest that contemporary consideration of the economics of biobanking primarily in terms of participants and their bodily tissues may reproduce the very commodification of science that these scholars critique. Following Birch (2012; and Birch and Tyfield 2012), we suggest that an alternative conception of the economics of biobanking, one which goes beyond the logic of commodification, may thereby allow broader questions about the social and economic conditions and consequences of biobanks to be posed.

2. The sustainability problem

University or hospital based biobanks are often characterized as not being financially secure, because they rely on mixed, short-term or per-project funding streams (Vaught, Kelly, and Hewitt 2009; Meijer, Molas-Gallart, and Mattsson 2012; Winickoff and Winickoff 2003; Diaferia, Biunno, and DeBlasio 2011). For example, biobanks---oriented as both for- and non-profit---may be partially supported by a variety of sources, such as: government agencies, universities, hospitals, charities, private pharmaceutical investment, or venture capital.

High quality (and therefore scientifically useful) biobanking facilities are costly, both in terms of infrastructure and expertise (Vaught, Kelly, and Hewitt 2009; Winickoff and Winickoff 2003; Diaferia, Biunno, and DeBlasio 2011; Gottweis and Lauss 2012), but they offer minimal short-term returns (Kozlakidis, Mant, and Cason 2012). In order to manage these costs, as McDonald et al observe, “increasingly biobanks must operate as business enterprises as well as scientific laboratories” (2012, 422). Winickoff and Winickoff (2003), and others (Diaferia, Biunno, and DeBlasio 2011), have therefore noted a trend for these smaller university- or hospital-based biobanks to outsource their collections to larger private biobanks that specialize in providing expertise and infrastructure but are still able to take advantage of economies of scale. Indeed, Anderlik (2003, 203) argues that for-profit commercial biobanks have “assumed a leading role” in biobanking sample and data management.

In addition to outsourcing collections to larger private biobanks, Meijer et al (2012) argue that there is an “economic logic” driving biobanks to become larger, or to become more closely networked and share data with other biobanks, thereby creating much larger “virtual” biobanks (see also: De Souza and Greenspan 2013). Indeed, they recommend growth as a viable “development path” in

order to allow biobanks to become more sustainable: the key advantage is that growth can turn them into a platform for commercially valuable research (Meijer, Molas-Gallart, and Mattsson 2012). This introduces at least two ethical tensions however.

First, and to anticipate the commercialization problem which we discuss below, a commercial focus may put the biobank at odds with the values of the participants. Second, investment in biobanking (whatever the funding source) comes with an economic and a social opportunity cost. As Foster and Sharp state: “investments made today in prospective cohorts and biobanks that are projected to be used (and funded) for decades to come will have significant consequences for determining both the opportunities and limits of future research” (2005a, 120). As a consequence, some observers have worried about the kinds of research that infrastructural and collaboration decisions may lock biobanks into. Foster and Sharp (2005b; 2005a) discuss the fairness of investments in infrastructure that could either (1) maximize returns for the most people (ie. allow the most broadly generalizable science to be conducted), or (2) maximize returns in specific populations that do not benefit the wider populations (ie. choosing to focus on a particular population sub-group on the basis of age, ethnicity). Of course, opportunity costs may also include government spending lost to other areas, since public funding invested for one purpose is therefore not available for use elsewhere. For example, Mitchell and Waldby express the concern that biobanking infrastructure has been positioned in a way that caters “in very direct ways to the research needs of the pharmaceutical industry” (2010, 338) rather than to public health.

An additional way that biobanks have been described as addressing the sustainability problem, aside from outsourcing, or growth and commercialization, is by offering research services (Vaught et al. 2011; Kozlakidis, Mant, and Cason 2012) or charging fees for access to the biobank's resources (Pathmasiri et al. 2011). Vaught et al note that there are a number of services that biobanks are uniquely positioned to offer, such as: “customised processing services”, “managed collections”, and “centre of excellence training” (2011, fig. 4). The operation of such mechanisms, however, are context and phenomena dependent; biobanks of differing size and funding structures will use differing sustainability mechanisms. For example, whether a private biobank is in a position to manage collections from the pathology departments of local hospitals depends on its own capabilities, as well as the regulatory environment within the healthcare system in which it operates.

3. The commercialization problem

One way to address the sustainability problem is to leverage the potential commercial value of a

biobank's samples and data. However, in social and ethico-legal literature, this is seen as presenting two problems for biobanks. First, commercializing a biobank's resources (samples and health related information) introduces tensions in the values and aims of biobanks by threatening to undermine both the notion of altruistic donation and the notion that biobanks serve the scientific and public good (Waldby 2009; Nicol and Critchley 2012; Pullman et al. 2012; Gottweis, Gaskell, and Starkbaum 2011). For example Nicol and Critchley note the impact that commercialization might have on a participant's trust, claiming that "commercial involvement in biobanking will cause some potential participants to question their motivation, because it will be seen by them as introducing a profit motive into what is otherwise a public good activity" (Nicol and Critchley 2012). Similarly Waldby describes a public biobanking project in Singapore, where reference to notions of citizenship and public good, given as justification for the project, creates tensions "between populations as bioeconomic resources and as rights-bearing citizens" (2009, 268). There are few empirical studies of participant concerns about commercialization; interestingly, in one of these studies participants were not found to be concerned about commercialization per se but rather about issues of fairness and the maintenance of human dignity (Steinsbekk et al. 2011).

At the heart of this aspect of the commercialization problem is the idea that biobanks are positioned in relation to two distinct clusters of economic and ethical rationales (see for example: Martin, Brown, and Turner 2008, Table 1). Public funding of biobanks suggest notions of biobanking for the common good, scientific and public health benefit and values of sharing and trust, whereas notions of profit, private interest, economic benefit and mistrust cluster around privately funded biobanks (Onisto, Ananian, and Caenazzo 2011). Precisely how biobanks configure themselves is a process of sociotechnical network formation in which the intertwining of social, ethical and economic aspects, and public and private values must be negotiated (Bunton and Jones 2010).

Second, commercialization raises ethico-legal issues about consent, intellectual property and ownership (Petrini 2012; Martin and Kaye 2000). For example, participants may not want their samples to be used for commercial research; the patenting of genes may lead to expensive therapies and diagnostic tests, which undermine the equity of biobank's benefits; or that fear of litigation may stifle innovation (Andrews 2005; see also: Pathmasiri et al. 2011). These issues are illustrated by prominent legal cases, such as *Greenberg v Miami Children's Hospital Research Institute*; *Moore v Regents of the University of California*; and *Washington University v Catalona* (see: Petrini 2012; Anderlik 2003; Tutton 2010).

It is not clear with respect to either of these cases whether the objection is to commercialization as

such, or whether the problem is merely one of how to mitigate possible unjust or exploitative consequences of a biobank's commercialization strategies. The literature is equivocal as to whether the response to issues raised by commercialization should be principled or pragmatic. Petrini notes that both the EU Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine, and the UN Universal Declaration on the Human Genome and Human Rights take the position against commercialization, stating that it is impermissible to commercialize or profit from human material (Petrini 2012, 90). More pragmatically, the ethico-legal problems of commercialization have been constructed as questions about "what social and legal norms will shape and constrain the commercial activity" (Anderlik 2003, 206; see also: Martin and Kaye 2000). Conley (2012) describes two broad approaches that have been proposed in response to the dangers of commercialization: (1) redefining notions of consent and refining regulation, as illustrated by shifts to "open" or "broad" consent and ethical oversight by IRBs (Institutional Review Boards) (Greely 2007; Greely 1999; Caulfield, Upshur, and Daar 2003; Merz et al. 2002; Rothstein 2002), or (2) the creation of innovative ethico-legal frameworks for benefit sharing, which re-imagine the relationship between biobanks, participant and commercial activity; examples of which include a "charitable trust model" (Winickoff and Winickoff 2003; see also: Otten, Wyle, and Phelps 2004; Winickoff and Winickoff 2004), a "trade secret model" (Conley et al. 2012), and a "stewardship model" (Fullerton et al. 2010).

As a consequence, the descriptive accuracy and analytical power of a simple dichotomy between public and private interests has been questioned as a way to understand the dynamics of commercialisation (Mitchell and Waldby 2010; Onisto, Ananian, and Caenazzo 2011; Bunton and Jones 2010), partly because of the practical difficulty of disentangling the two (Martin and Kaye 2000, 169). Mitchell and Waldby claim instead that there is "considerable continuity between national biobanks and commercial biobanks... [and] donor (sic) participation in biobanks contributes simultaneously to state and pharmaceutical interests, public and private value." (Mitchell and Waldby 2010, 336). Moreover, they suggest that since participants are expected to be available for follow-up over an extended period, participation should be thought of as a kind of "clinical labor", rather than a simple gift. Indeed, unlike other biotechnologies, such as cell-lines, the samples and data in biobanks depend on the on-going work of participants for their value; because population biobanks are oriented towards the discovery (and commercialization) of risk factors, which requires longitudinal collection of the samples and data. Mitchell and Waldby therefore argue that the work of participants is crucial in order for biobanks to establish the data necessary to create therapies or tests targeted at health risks, rather than disease.

Mitchell and Waldby do not attempt to solve the commercialization problem; instead, they want to show that it is inadequate as a framework by which to illustrate the multiple tensions that biobanks must negotiate. We agree that the commercialization problem is inadequate but so too is the argument that the biobanking economy is solely about commodifying participant labour or its latent value, as is implicit in Waldby and Mitchell's argument. Participants "labour," as do the range of scientists and others involved in the production of bioknowledge and its attendant, or anticipated, value. For large population biobanking projects, which position data as central to the production of value, and as the "fundamental unit of exchange" (Murtagh et al. 2012, 243) additional (likely multiple) forms of value and labouring arguably exist.

4. Discussion

To be set-up and maintained, prospective population biobanks require significant economic resources. Once operating, they face a sustainability problem that can be addressed in multiple ways: commercially, for example, by offering research services or collaboration and commercialization agreements with private companies; through public funding, from governments and research agencies; or some combination of funding streams. Insofar as commercialization represents a (partial) solution to the sustainability problem, it may also be thought to pose its own ethico-legal problems. Most notably, through a line of argument that pits commercial and private interests against the public good aims and values of biobanks. As described above, many authors have noted the descriptive and analytical problems with this line of argument, in order to argue that commercialisation is may not necessarily be problematic. Indeed as Pathmasiri et al state, regarding commercialization and intellectual property arrangements, "what is in the best interests of the public in the context of publicly funded biobanks is far from obvious" (Pathmasiri et al. 2011, 322). Notwithstanding this range of views, some large publicly funded biobanks in the UK have taken the view, undoubtedly in response to the perceived problems of commercialization, that their samples and data will not be used for commercial purposes. The 1958 Birth Cohort Study, for example, includes a clause in its consent form that directly precludes use of data and samples by commercial interests⁵. Other biobanks accept commercial interest in their collections but explicitly preclude commercial practices that would constrain shared knowledge production: UK Biobank "reserve[s] the right to take [legal] action when patents are generated as a result of using the Resource that hold up other research or are unreasonably restrictive in other ways"⁶.

Birch (2012) and Birch and Tyfield (2012) have argued that, while being attentive to objects (such

⁵ <www2.le.ac.uk/projects/birthcohort/1958BC-About/commercial-use-of-the-1958bc-resource>

⁶ <www.ukbiobank.ac.uk/faqs/what-happens-if-a-researcher-makes-a-profit-from-using-the-resource>

genes and tissue fragments) and people (participants, donors, and researchers), existing social scientific analyses of the economic aspects of biobanking, have given less attention to knowledge production (Birch 2012, 184). Birch and Tyfield put forward a strong criticism of existing social science analysis for its inappropriate and vague quasi-economic concepts, such as “biovalue.” They state: “in using terms such as value, capital, surplus, and so on, current STS conceptualisations of the bioeconomy not only misappropriate such concepts in their discussion of capitalist relations but also misrepresent modern bioscience and biotechnology” (Birch and Tyfield 2012, 15). More positively, they argue that value is realized by the application of knowledge (constituted in intellectual property) derived from biobanking science, not through “fetishizing” biological material using concepts such as “vitality” and “biovalue.”

Birch (2012) and Birch and Tyfield (2012) are therefore able to reframe the commercialization problem as a “modern-day enclosures movement” which takes publicly funded knowledge and locks it into “an international IP regime” (Birch 2012, 184). Thus the commercialization problem is better thought of as the “apparent contradiction between open cooperation in knowledge production and privatized control and exploitation” (Birch 2012, 184). This suggests an alternative framework for empirical investigation of the economics of biobanking, one focusing on how these contradictions are navigated and resolved across contexts, and, if open cooperation is the rubric, includes examination of how scientists' interests converge (or don't) within this IP regime.

We agree with this shift in focus from tissues and data, to knowledge, and from treatments and tests, to IP. First, the social scientific literature explicitly frames the output of biobanking science as treatments and tests. This is how, for example, Mitchell and Waldby are able to construct their notion of “ontologizing” risk within diagnostic tests (Mitchell and Waldby 2010, 346). On the contrary, we claim that public health outputs---structural or behavioural interventions, for instance---are an equally plausible application of the knowledge derived from biobanking science. The key point is that once we remove the conceptual focus on commodities, we open up new ways to realize the value of knowledge derived from biobanks. For example, this permits us to view commercialization as being aligned with public health interests, rather than as eroding trust. Notwithstanding this, second, there is no reason to collapse the epistemic and temporal distance between biobanking projects now and their imagined future outputs. The “commercialization problem,” however it is conceived, may fail to be a genuine problem because of the remote and speculative nature of the outputs, commercial or otherwise, from biobanking science. Furthermore, any recasting of the commercialization problem should reflect on the way that it reconstructs these “sociotechnical futures,” for example, through the putative alignment of commercial and public health interests.

We conclude by noting the scope and potential for a more sustained analysis of the economic aspects of biobanking. The social scientific literature has moved beyond the simple opposition of public and private interests as a way to understand the dynamics of biobank sustainability and commercial activity. There is clearly a place, however, for more sophisticated and nuanced understanding the of the data, knowledge and IP economies of biobanking.

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