

Editorial

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With the rapid expansion of medical technologies to preserve, store and use reproductive tissues, questions about the legitimacy of a market in eggs, embryos, ovarian tissue, umbilical cord blood and breast milk have captured the public imagination (Swanson 2014). As more people seek out these tissues to build their families, to ensure the future health of their children, and to contribute to scientific research, the ethical collection, distribution, and use of these materials must become a public priority. Exchange of reproductive tissues for research purposes, in particular, occurs within biobanks, either public or private. Tissues like umbilical cord blood, semen, ovarian tissue, and breast milk have long been collected and distributed this way. However, only recently have initiatives emerged for cryopreserved eggs and embryos, which have conventionally been allocated to research at the level of in vitro fertilisation (IVF) clinics working directly with scientists.

The purpose of this special issue is to interrogate the normative, ethical, and practical issues that arise from biobanking eggs and embryos for research. This topic involves three distinct but overlapping areas of research, each of increasing relevance due to emerging technologies and scientific discoveries about the human body: first, the growth of centralised *biobanks*, both real and virtual, containing human biological material; second, the growing amount of material and information derived from human reproduction, particularly *eggs and embryos* (but also cord blood and stem cell lines) in storage; and third, the growing propensity of that reproductive material to be used for non-reproductive *research* purposes. It is our

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contention that scholarly exploration of these three issues has been isolated and fragmented. The goal of this special issue is to bring them together, and to explore the various factors that affect biobanks for human eggs and embryos for research.

More specifically, this special issue is intended to promote critical thinking about the feasibility and desirability of biobanking of eggs and embryos, as well as of other reproductive tissues and fluids, for research. This means first evaluating the rich literature on biobanks themselves. Biobanks may be defined in any number of ways. However, we adopt the definition proffered by Baylis and Widdows in this special issue: 'Human biobanks are collections of human biological samples (such as, saliva, blood, urine, nail clippings, tumors) and information (about such things as health, family history, lifestyle, work, and memory) stored for research use; this may be health-related research or research involving heritage and ancestry tracing.' Agreeing on such a definition only poses further questions about what biobanks *should* do in practice. First and foremost, should we have biobanks for eggs, embryos, and other reproductive tissues? Are biobanks a feasible and desirable method of collecting, storing, and allocating eggs and embryos for research purposes? If so, what should the organizing ethical principles be? What role should the state play? In this vein, several articles in this special issue explore the institutional formation and architecture of existing (Capps; Haw; Hurlbut; Holm) and hypothetical (Stroud and O'Doherty) biobanks to determine which sets of rules are most likely to create a robust ethical framework, and to produce 'good governance' that is 'for the public good'.

Beyond biobanking generally, this special issue proceeds from the premise that *there is something unique about human reproductive material*, focusing largely on human eggs and embryos, but also including stem cells (adult and embryonic), cord blood, placenta, semen and seminal fluid, cervical mucous, and others. The limits of what we might consider reproductive tissues and fluids might lay less with the materials themselves than with the way in which they are regarded. The analogy of the sequoia put forward by political philosopher Michael Sandel, and quoted at length by Søren Holm in this issue, is instructive here: that we tend to give respect to regenerative human reproductive material not necessarily because it is intrinsically valuable or useful, but 'because we regard it as a natural wonder worthy of appreciation and awe' (Sandel 2004, p. 208). The respect afforded to reproductive tissues and fluids has two components. The first concerns the moral status of the embryo, and how it ought to affect clinical practice and the movement of the embryo from the clinic to the lab. Embryos, whatever else they may be, have human potentiality. But the 'appreciation and awe' also speaks to a second feature: the evolving literature on clinical labour, which explores the role of patients' bodies, particularly women's bodies, in the creation of eggs and embryos for reproduction, research, or both (Cooper and Waldby 2014). There are emerging concerns, as embryo research becomes normalised and routinised and as more women are encouraged to donate, that, in the words of Donna Dickenson (2006), 'the lady vanishes'. Several papers in this special issue (Baylis and Widdows; Haw; Haimes and Taylor; Cattapan and Snow) bring issues of women's clinical labour to the fore.

Exploring the role of patients and providers of reproductive material also highlights the importance of informed consent, which is especially important in the

context of research. As Stroud and O’Doherty (this special issue) note, biobanks of research material often use dynamic or other forms of consent, while the law concerning reproductive material, in Canada and other countries, relies on specific consent. This incongruity—between the rules that govern biobanks generally, and those that govern research on human eggs and embryos—illustrates the difficulty of establishing biobanks for eggs and embryos.

Questions of informed consent also reveal another issue: the dichotomy between eggs and embryos to be used for *reproduction* on the one hand, and for *research* on the other. As at least two contributions (Haimés and Taylor; Cattapan and Snow) demonstrate, the providers of reproductive material, the processes by which they engage in clinical labour, and the ethical considerations that must be taken into account are often identical regardless of whether those eggs and embryos are used for reproductive or research purposes. And yet, both in clinical practice and in the literature, these two issues are often treated as discursively and conceptually distinct. Concerns about the relationship between informed consent and the use of reproductive tissues also emerge in Jennie Haw’s work on private cord blood banking in Canada (this special issue) which highlights how cord blood is ‘made meaningful’ and given promissory value by divorcing it from its reproductive context. Moreover, in his study of the RENEW biobank at Stanford university, J. Benjamin Hurlbut (this special issue) quotes one of the biobank’s architects in saying that for a researcher, ‘the process of acquiring embryos is “like taking a book out of the library”’. This example shows the formal institutionalisation of the divide between reproduction and research *par excellence*.

Is this distinction between research and reproduction something that ought to concern bioethicists? Or alternatively, if proper consent mechanisms and legislative provisions regarding patients’ bodies are in place, can biobanks act as valuable and efficient mechanisms for embryo research? These questions do not have easy answers. There are certainly examples of providers’ experiences being lost in the discourse, as demonstrated by Haimés and Taylor’s description of egg providers in the UK (this special issue). At the same time, some might claim that a properly organised and functioning biobank could potentially create the best of both worlds: a robust ethical framework that ensures gamete providers’ best interests are taken into account, combined with an efficient structure to best allocate reproductive materials to satisfy research demand and reduce information asymmetries.

The issue begins with three contributions (and two commentaries) that apply ideas about the general governance of biobanks to the specific issue of biobanking eggs and embryos for research. Benjamin Capps examines the differences between two biobanks: deCODE’s population-based biobank in Iceland, and the UK Biobank. Capps demonstrates that formal institutions, rules, and governance matter: while both biobanks purport to do their work for the public interest, the UK Biobank is better able to actually provide concrete benefits to the UK population. By contrast, deCODE Genetics’ biobank has been rife with problems from the beginning, as its ‘methods (and perhaps ongoing interests) belie its status as “for the public good”’ (2015). Through his evaluation of the two banks, Capps’ article encapsulates many of the debates present throughout this volume, including the role of informed consent, the importance of true public deliberation, and the potential

pitfalls of commercialised research. In his commentary on Capps' article, Einar Árnason extends the analysis and examines the specific ways in which deCODE's governance structure led to numerous failings. For Árnason, deCODE is a 'prime example of how public goods can be hijacked by private individuals who disregard public interest for their relentless pursuit of financial profit' (2015). Lessons for future biobanks abound.

Søren Holm shifts the focus slightly, focusing on embryonic stem cell banks, which hold and distribute stem cell lines. Drawing on the examples of the UK Stem Cell Bank, the Spanish Banco Nacional de Lineas Celulares and the US National Stem Cell Bank, Holm identifies three arguments that policymakers use to create and maintain support for biobanks. The first two, which he identifies as 'ethical' arguments, are the protection of the embryo itself and the protection of gamete and embryo providers. Such ethical arguments mirror concerns identified above related to moral status and clinical labour. However, Holm identifies a third argument used to justify stem cell banks, which he terms an 'efficiency' argument: that stem cell banks can more efficiently and effectively facilitate high-quality research. Interestingly, Holm notes that while 'protection of the embryo' and 'efficiency' arguments are typically used to justify the creation and continued existence of stem cell banks, concerns regarding protection of gamete providers tend to be absent. Like other contributors to this issue, Holm shows how the clinical labour of providers, particularly women, has been of secondary concern to those stakeholders most involved in the creation and maintenance of stem cell banks (2015).

How biobanking governance should occur is also the primary consideration for Karla Stroud and Kieran O'Doherty, who apply a previously developed deliberative approach to governance (O'Doherty et al. 2011) to address the feasibility and desirability of a research biobank for eggs and embryos in Canada. Drawing from Canadian law on reproductive biotechnologies, they highlight a potential snag: while much of the literature on biobanks relies on models of consent such as 'dynamic consent' and 'open consent', Canadian law quite clearly requires 'specific consent'. Under Canada's *Assisted Human Reproduction Act*, obtaining consent for future-oriented research projects in which biobanks specialise will be difficult. By identifying principles that should inform the governance structure of any research biobank for human eggs and embryos, the authors also highlight the need to consult multiple stakeholders—particularly gamete providers, often left out of governance structures for embryo policy in Canada—'[b]ecause of the potentially controversial and sensitive nature of the materials' (2015). In her commentary on their article, Katharine Browne interrogates how the principles of good governance articulated by Stroud and O'Doherty can be put into action (2015). In addition to difficulties related to informed consent, Browne highlights potential problems with public deliberation, and calls for an 'appeal to principles of ethics' to address biobank governance.

Moving from Canada to the United States, J. Benjamin Hurlbut highlights how America's history of assisted reproduction has helped frame IVF as as '(private) medical intervention rather than an experimental practice that should be subject to (public) ethical oversight' (2015). Hurlbut examines Stanford University's RENEW biobank and the privatisation discourse it employs to suggest that biobanks are an

increasingly popular option among researchers insofar as they have ‘ethical efficiency’: that is, they primarily ‘serve as infrastructures for enhancing the efficiency of research’ (2015). While the standardisation and centralisation that such biobanks offer provide reliability and control, attempts to engage in ‘ethical efficiency’ have served to disconnect gamete providers from researchers, and removed hitherto available avenues for ethical deliberation and reflection. Through its promise of renewing ‘valueless waste’, RENEW, like other biobanks, purports to offer much in terms of scientific progress. Hurlbut’s piece raises flags concerning how ‘opportunities for ethical deliberation’ have been relegated to the periphery.

Commercialised research and research efficiency are also at issue in Jennie Haw’s exploration of private cord blood banking in Canada. Through her interviews with clients and employees of Canadian cord blood banks, Haw shows how such banks differ from other biobanks by offering clients the opportunity to save ‘one’s own body tissue for potential future use as a form of individualised health security’ (2015). Haw uses her case study to examine how cord blood fits into contemporary discussions of ‘biovalue’ (Waldby 2002), and how biological material that was previously considered ‘waste’ becomes inscribed with meaning by various social actors. Whereas women who pay money to bank their cord blood do so on the basis of its future-oriented, ‘promissory’ value, private banks are incentivised to view cord blood solely in terms of its ‘profit value’. Like Capps and Árnason (above), Haw’s work highlights the dangers of creating a market in human biological material, suggesting that the private framework incentivises banks to overstate a unit’s promissory value, and ‘places women at a disadvantage in relation to banks’ (2015).

Françoise Baylis and Heather Widdows explore unique ethical dilemmas posed by biobanking eggs and embryos. In particular, they explicate the concept of ‘genetic relatedness’ and note two potential issues that regenerative reproductive materials raise. First, because genetic information is shared, it challenges traditional individualistic notions of informed consent. Second, because biological samples are identifying, banking them poses additional hurdles for protecting provider confidentiality and preventing identification. Baylis and Widdows also highlight how ‘real and imagined kinship’ tends to result in greater emotional attachment from egg and embryo providers to their tissues. In another reference to the uniqueness of human reproductive material, they conclude that the ‘future use of reproductive tissues as compared with other bodily tissues is significant’ (2015). The ‘assumed potential’ of reproductive tissues further complicates the biobanking process.

Erica Haimes and Kenneth Taylor examine a small but growing subset of gamete providers: egg providers for mitochondrial disease in the United Kingdom. They analyse four sources—the Nuffield Council on Bioethics, the Human Fertilisation and Embryology Authority, the Department of Health and Parliamentary debates—to determine how the discourse surrounding the UK’s legal change, implemented in 2015, functioned to permit certain clinics to use genetically-manipulated eggs for therapeutic purposes. They find that women’s clinical labour has been deliberately diminished in the discourse to such a degree that the ‘level of commitment and involvement in producing eggs for research is rarely acknowledged’ (2015). The

instrumentalisation of women and minimisation of their contribution in this new field of research is an unfortunate and troublesome continuation of trends found elsewhere in the use of assisted reproductive technologies.

Policymaking discourse is also of interest to Alana Cattapan and Dave Snow who analyse the way in which embryo ‘research’ has been theorised in Canada since the 1980s. They demonstrate that a linguistic dichotomy has emerged to such an extent that Canadian law has instantiated a sharp—and, in their view, artificial—distinction between embryos to be used for reproduction, and embryos to be used for research. They argue that this distinction is problematic for two reasons: First, this distinction does not map onto how patients view their own reproductive material. Second, by formalising this distinction in law, Canada has provided incentives for clinicians and researchers to allocate embryos for ‘improving’ or ‘providing instruction for’ assisted reproductive technologies to potentially avoid government oversight. Like Haimes and Taylor, they contend that ‘discursive categorisation matters’, as the language used by experts can make its way into legislation and affect clinical practice. They end by recommending that as the policy evolves and amendments are considered, policymakers in Canada and elsewhere begin from the premise that it is ‘impossible to disentangle material designated for the improvement of assisted reproduction from clinical research’ (2015).

Finally, Natalie Ram reviews Kara Swanson’s *Banking on the body: The market in blood, milk, and sperm in modern America* (2015), which chronicles the growth of biobanks in the United States. Ram notes how the book challenges many of our assumptions concerning the establishment and maintenance of biobanks, particularly the role played by payment, gender, and race. Although Ram notes that the book could say more about the ‘banking of human tissue for research purposes’, it provides an important launching pad for scholars—including all of those who have contributed to this special issue—to do so.

Collectively, the contributions to this special issue cross disciplinary lines, bringing together bioethics, law, political science, sociology, and medicine. Although the focus is primarily on the British, American and Canadian cases, the contributions to this special issue provide a comparative and interdisciplinary framework that will provide scholars, researchers, and practitioners around the world with a better context from which to address the normative and ethical questions raised by the biobanking of eggs and embryos for research.

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