

Negotiating Socio-Technical Contracts
Anticipatory Governance and Reproductive Technologies

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ABSTRACT

This project develops the "socio-technical contract" concept, a notion that signifies the kinds of socio-technological assumptions and arrangements that characterize a particular domain of policy or practice. Socio-technical contracts, unlike their social contract counterparts in political theory, represent active negotiation and renegotiation of social contracts around emerging technologies, as opposed to the tacit social contracts of thinkers such as Locke. I use the socio-technical contract concept to analyze the governance of assisted reproductive technologies in the United Kingdom. For increasing numbers of people, reproduction is happening in a fundamentally different way. Conception outside of the womb became a reality with the 1978 birth of Louise Brown, the first baby born via in-vitro fertilization. Alongside Louise Brown's birth emerged new social and governance configurations around reproductive technologies, including, in the United Kingdom, the establishment of a national regulatory agency, the Human Fertilisation and Embryology Authority. The project applies the socio-technical contract concept in order to examine how distributed governance and socio-cultural processes in the British context worked over time to renegotiate fundamental ideas about families and kinship, the boundaries of "ethical" science, rules governing release of information, the "right to an identity," the role of the state in the reproductive choices of individuals, and general approaches to how to think about the roles and relationships of the child, parents, and the state in and around the introduction of these technologies. As these changes have occurred, policies, social understandings, and legal rights have been renegotiated and new governance capacities, what I call "anticipatory capacities," have come into existence to manage and coordinate change across complex social systems. In illuminating anticipatory capacities in each context, I explore the tools

deployed by government actors, scientists, stakeholders, and citizens in negotiating evolving socio-technical contracts around reproductive technologies.

DEDICATION

To my family for your constant love and support during this seven-year journey. To Oscar, for your encouragement and positivity. To my friends, for standing by me through the thick and the thin.

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CHAPTER 1

ANTICIPATORY GOVERNANCE AND SOCIO-TECHNICAL CONTRACTS

“In the technical realm we repeatedly enter into a series of social contracts, the terms of which are revealed only after the signing.” –Langdon Winner

Introduction

The idea that the pace of technological change has accelerated to an extremely rapid rate—and that society must race to catch up—pervades contemporary conversations about technologies. Today the idea of novelty is valorized, especially in science and technology. Social discourse abounds with anxiety about the unintended consequences of technological change, the failure of legal, policy, and ethical frameworks to keep up with new scientific advances, and thus the need to better govern new and emerging technologies. For example, the headline of a recent article in *MIT Technology Review* stated, “Laws and Ethics Can’t Keep Pace with Technology: Codes we live by, laws we follow, and computers that move too fast to care” (Wadhwa 2014). Similar headlines regarding fears of the implications of drones, NSA surveillance, social media, genetic modification, and other rapidly advancing areas of technology appear in the media on a daily basis. Younger generations—portraying themselves as more adept and adaptable—accuse their elders of being out of touch with new technologies like social media, smart phones, and computers and the modes of sociality they enable. Nations around the world worry about falling behind their neighbors in producing scientists, engineers, and technologically literate publics, as well as in the science and technology at the heart of the knowledge economy. The dominant narrative is one of a struggle to keep pace as technology hurtles forward.

These ideas—that there is a perennial lag in responding to technological change—are an illusion that we ourselves create. Discursive framings of the relationship

between the technical and the social postulate a technology independent of, external to, and ahead of attempts to regulate it, thereby creating the mirage (Johnson and Wetmore 2009). Technology does not, of course, advance by itself, independent of human action (Smith and Marx 1994). Technological change emerges out of a variety of social, political, and economic processes and arrangements (Hughes 1990). We know that people invent technologies in the laboratory. But even as technologies enter the market and use, they are still in the process of being made, their trajectories influenced by the decisions and actions of a multiplicity of social agents (Kline and Pinch 1996). Even the idea that technology shapes society is a fiction: technologies do not enter the world from the outside; rather, in putting new technological capabilities to work for social goals, people co-produce social and technological orders (Jasanoff 2004; 1996). Perhaps most importantly of all, there have always existed an array of capacities for thinking ahead about what new technologies might mean for anticipating social and technological change and for making choices about and governing those technologies. For example, the idea that visions of the future condition how societies envision and construct technologies, and put those technologies to work in fashioning social, economic, and political arrangements, is at the heart of the concept of socio-technical imaginaries (Jasanoff and Kim 2009). Just as engineers not only imagine potential social needs and are inspired by science fiction in creating new technologies (Berne 2006), societies also engage in anticipation when they develop cultural, legal, and social frameworks for integrating new technologies into society (Barben et al. 2008).

Today is an age of Frankenstein. Critics decry the rise of Frankenfoods and scientific chimera, genetically modified organisms that integrate hybrid DNA from other organisms, monsters created in the laboratory rather than from nature (Turney 1998). A recent headline in the *New York Daily Sun* proclaimed: “Frankenstein Babies Legalized

in the UK” (White 2013). Scientists, it turned out, had received approval in Britain to use a process of mitochondrial transfer via in-vitro fertilization to eliminate the possibility that the resulting child would inherit a genetic disease linked to their mother’s mitochondrial DNA. If carried out, however, the resulting child would effectively have three genetic parents. Yet, Mary Shelley’s novel *Frankenstein* was written two centuries ago. Not only was the novel, often celebrated as the “first modern work of science fiction,” itself an anticipatory exercise, but society subsequently created around the novel and its themes a repertoire of cultural understandings, motifs, and discourses for grappling with the implications of new and emerging technologies. A purpose of this dissertation is to begin to explore these capacities for anticipation.

Anticipatory Governance

The idea that society is unable to keep pace with technological development, or integrate societal concerns into the governance of technology, was famously captured by Winner (1986) in *The Whale and the Reactor*. Winner argues that society “sleepwalks” through the process of constructing socio-technical worlds in a state of “technological somnambulism.” By the time that society realizes the undesired consequences of new technologies and “wakes up,” Winner argues, society has already signed a social contract, the terms of which have been long set. By then, it is “too late” to go back and renegotiate. Society is stuck with technologies that have enormous social consequences but cannot be changed, a perspective also offered by David Collingridge (1980) in *The Social Control of Technology*.

More recently, the idea that society is responding too slowly to the rapid pace of technological change has been revitalized in the field of law. Gary Marchant, Douglas Sylvester, and Kenneth Abbott have argued, for example, that technology is “outpacing” the law, creating a “pacing problem” in which policy frameworks must race to catch up

with emerging technologies (Marchant et al. 2011). In this view, the law “features as the loser in the endless race against ‘technology’,” recalling the imagery of the tortoise and the hare, with the slow moving law representing the tortoise, forever trying to catch up with the quick and nimble technological hare (Moses 2011, 763-4).

I argue in this dissertation that this view—that society, law, and policy lag technology—is mistaken in important ways. My argument is rooted in the concept of anticipatory governance. Research on anticipatory governance maintains that society can actively and productively engage with new science and technology *as it is being built*, shaping both the trajectories of technological change and the ways in which technologies are taken up and integrated into social, economic, and political arrangements (Barben et al. 2008). To date, anticipatory governance has largely been viewed as a prospective exercise—that society needs to “build its muscles” for governing new and emerging technologies by cultivating the capabilities for governing in a forward-looking way (Guston 2014). Yet the idea that one must build one’s muscles presumes that one has muscles in the first place. Indeed, as scholars such as Ronald Kline and Trevor Pinch have demonstrated, society often plays a very powerful role in shaping technological trajectories, even as it reconfigures social, economic, and political arrangements in and around new and emerging technologies (Kline and Pinch 1996). Taking this idea as its starting place, this dissertation has been motivated by the question: Are there signs that we are actually not sleepwalking through socio-technical configurations? One such sign would be the identification of de facto anticipatory governance. Thus the dissertation asks, what capacities does society already have in place to exercise anticipatory governance?

To answer this question, the dissertation examines the history of the governance of assisted reproductive technologies (ART) in the United Kingdom over the course of

the twentieth century. In vitro fertilization and other areas of ART underwent extensive technological change in the second half of the twentieth century. The United Kingdom, in particular, stood at the epicenter of this change and in societal efforts to govern this suite of technologies, a result of the birth of Louise Brown, the world's first "test tube baby" in Oldham, UK, in 1978. Yet, even in my preliminary investigations, important anticipatory elements stood out in UK efforts to govern reproductive technologies. As early as the 1920s, British debates about infertility included speculative assessments of future technologies captured, for example, in J.B.S. Haldane's 1923 lecture, *Daedulus, or Science and the Future*, and Huxley's novel *Brave New World* (1932). UK media and institutions debated the concept of ART for decades prior to the birth of Louise Brown. Even regulatory institutions, such as the Human Fertilisation and Embryology Authority, while created after the birth of Louise Brown in 1990, were not simply reactive but rather took shape as part of a proactive, cultural effort to guide the future evolution of these technologies and the kinds of society Britain would create around them.

The analysis of these case studies illuminates several broadly distributed capacities for engaging in anticipatory governance. Following the lead of Barben et al. (2008), these capacities can be described in terms of foresight, integration, and engagement. The dissertation examines capacities for imagining future technologies and societies, via a variety of both formal and informal techniques of foresight. Other important anticipatory capacities explored include: frameworks for judging and evaluating the particular ways in which the social and the technical get integrated in the development and application of new technologies; capacities for engaging citizen stakeholders in renegotiating governance arrangements around ART, both through deliberations in the public sphere, as well as through the courts; capacities for establishing normative standards and for using those standards to draw and enforce

boundaries around the limits of legitimate technological development; and the responsive capacities of scientists within laboratory contexts to think and respond critically and proactively to developments and debates taking place in society.

In developing this argument, I build on and modify Winner's own idea of a social contract for technology to argue that anticipatory governance consists of an ongoing exercise in the making and remaking of *socio-technical contracts*: the coupled configurations of social and technological arrangements through which societies envision and organize the construction and application of new and emerging technologies. Understood in these terms, the dissertation examines how societies actively imagine, deliberate, apply, scrutinize, evaluate, and renegotiate these socio-technical contracts over time—in a forward-looking, anticipatory fashion—and the kinds of capacities they develop and exercise in so doing. Anticipatory governance thus represents the societally-embedded capacities opening up socio-technical contracts for reevaluation and reconfiguration, so as to “shap[e] things to come” (Barben et al. 2008, 993).

Governance and Anticipation

In the rest of this chapter, my goal is to introduce the concept of anticipatory governance as I define it in relationship to existing literatures. First, I introduce it in relation to the broader concept of governance in political theory and political science. I utilize Machiavelli's concepts of *fortuna* and *virtu* in order to situate anticipatory governance within the context of political theory, and the tradition of cultivating leaders who have appropriate capacities for dealing with an uncertain future. I then provide an overview of the concept of *governance*, distinguishing it from studies of *government*. Following recent work in policy studies, I define governance as extending beyond the formal institutions of government to include the full array of formal and informal

processes that policy action and the diverse actors (government institutions, stakeholders, NGOs, social movements, media, and cultural organizations) that contribute to them. Approaching governance in this way helps establish the significance and importance of anticipatory capacities distributed throughout society.

Second, I position my reading of anticipatory governance in relation to the existing literature on the concept, especially as it has been developed by scholars affiliated with the Center for Nanotechnology in Society at Arizona State University. I position the anticipatory governance framework as one component of the governance model discussed and defined within this chapter. Drawing from the work of scholars such as Guston and Sarewitz (2002) and Barben et al. (2008), this section provides an overview of foresight, engagement, and integration as key elements of anticipatory governance that the rest of the dissertation then explores in British efforts to govern ART.

Third, I introduce the notion of socio-technical contracts as my contribution to anticipatory governance. In doing so, I revisit Winner's concept of technological somnambulism and argue that anticipatory governance is a potential response to Winner's dilemma. This section develops the socio-technical contract concept as a tool for understanding the negotiation and renegotiation of socio-technical configurations. Drawing on Guston's (2000) writings on the social contract for science, which provides a basis for the key argument of the socio-technical contract concept, I argue that unlike traditional social contracts presented by thinkers such as Locke, socio-technical contracts are not tacit, rather, they are (and must be) actively engaged with.

The idea that governments should be proactive, rather than reactive, is not new. Arguably, all political theory, in its rich and complex tapestry, in some respect begins with a disposition towards the future, and concerns itself with the question: how

can we prepare for the unknown, for what comes next? While preparing for the unknown can be found as a motif in almost any of the writings of the great political theorists, it is particularly salient in the writings of Machiavelli. Machiavelli cautions leaders to be proactive in mitigating bad fortune. Rather than leaders attempting to “predict” the future through prophesy, oracles, and divination, he argues that there are other ways of preparing for the future. In *The Prince*, Machiavelli paints a picture of a world in which two predominant forces are at work, *fortuna* and *virtu*. *Fortuna* is like a raging river, unpredictable and volatile. All hope is not lost, however, Machiavelli argues. Leaders *can* mitigate the consequences of the unknown *fortuna*:

everything flies before it, all yield to its violence, without being able in any way to withstand it; and yet, though its nature be such, it does not follow therefore that men, when the weather becomes fair, shall not make provision, both with defences and barriers, in such a manner that, rising again, the waters may pass away by canal, and their force be neither so unrestrained nor so dangerous (1975, chapter xxv) .

It is through *virtu* that the forces of *fortuna* can be tamed. *Virtu* is a disposition that leaders must cultivate if they are to prepare for the unknown. A state’s leaders must embody *virtu*, in order to approach and handle “a diversity of temporal conditions” (Machiavelli 1989, 453). As James Pocock argues in his seminal work, *The Machiavellian Moment*, Machiavelli’s ideas of *fortuna* and *virtu* were taken up widely in the formation of new forms of government from the Renaissance to the Enlightenment, all grounded in the idea that government can act to tame the vicissitudes of history through proper planning and foresight (Pocock 1975, 517). It should also be noted that much of what Machiavelli argues for is about the work of techno-science, of controlling the volatile forces of nature through works of engineering. For Machiavelli, *virtu* is less about a broad disposition towards flexibility, and more about engaging in the techno-

scientific enterprise of, for example, engineering rivers in order to prevent them from ravaging the city-state. Machiavelli provides us with an illustration of the prototypical disposition of modernity to engage in the work of techno-science improve the human condition with a disposition and eye towards the future.

Where classic political theory focused principally on the problem of government, more recent scholarship has emphasized that the work of governing takes place in dialogue with a variety of actors outside the formal legislative arena. Classic works of public policy analysis offer competing perspectives for how policy comes to be; however a unifying feature of many of these theories is that that policy emerges out of the interaction of formal institutional frameworks with broader social and political processes. For example, John Dewey, writing in rebuttal to Walter Lipmann's *The Phantom Public* (1927), in *The Public and its Problems* (1954), offers an understanding of politics that suggests that government is broader and comprises more than just formal institutions. Dewey argues that the idea of government must include *both the public as well as its lawmakers* (27-28). Building on the idea that policy action emerges out of the work of both governmental institutions and other actors in society, Lasswell, Jones, Anderson, Brewer and deLeon developed the popular idea that policy is made in stages. This model divided the policy process into a series of discrete steps: agenda setting, policy formulation and legitimation, implementation, and evaluation. In each of these, governmental and non-governmental actors engage one another in a variety of activities and spaces to shape policy development (Sabatier 1999). An alternative to the stages model, the policy "streams" model, is best known from the work of John Kingdon who based his work on the "garbage can" model of organizational behavior (developed by Cohen, March, and Olsen 1972). Kingdon's (1984) work views the policy process as a confluence of three streams of actors and processes: a problem stream consisting of

data about various problems and the proponents of problem definitions, a policy stream involving the proponents of solutions to policy problems, and a politics stream consisting of elections and elected officials. These streams usually exist independently of each other, except when what he terms a “policy entrepreneur” can couple the various streams.

Others, such as Baumgartner and Jones (1993), assert that policy change arises in a “punctuated equilibrium.” The punctuated equilibrium framework frames policymaking as characterized by long periods of incremental change punctuated by brief periods of major policy change. Major change comes when political opponents can fashion new policy images and exploit the multiple policy venues characteristic of liberal democracies. Sabatier and Jenkins-Smith’s advocacy coalition framework (1988) focuses on the interaction of advocacy coalitions – each consisting of actors from a variety of institutions who share a set of policy beliefs, within a policy subsystem. Robert Dahl (2005) in *Who Governs?* argues that political parties, which form a bridge between government and citizens, are aggregations of diverse interest groups. The role of government is to act as a mediator of these different interests. Anthony Downs focuses on the role of the voter, asserting that government cares only for the *vote* of a citizen, not his welfare, “thus a return to *political economy*” (1957, 18, emphasis in original).

More recently, scholars in STS have argued for paying closer attention to knowledge and ideas in the policy process. The notion of *civic epistemologies* highlights the role of both state and non-state actors in shaping critical policy ideas, and thus aligns with Dewey’s argument that both governments and their publics are integral to determining the public good and imagining public futures. Civic epistemologies place the public, and public capacities for reflecting upon new knowledge claims, as a key space for negotiating visions of the public good. Civic epistemologies represent both

tacit and explicit, public and institutional, and formal and informal means of producing knowledge for public policy. Civic epistemologies signify “the set of institutions, norms and practices that govern the production, warranting, and use of knowledge for purposes of public policy making” (Bandhauer et al. 2005, 178). Within any society there exists shared understandings about what reliable claims consist of, what they should look like, how to present, articulate, and defend them. These understandings vary across cultures and countries, as they are “culturally specific, historically and politically grounded, public knowledge-ways” (Jasanoff 2005, 249).

Jasanoff (2005) defines civic epistemologies as the processes through which individuals examine and organize knowledge claims that become the foundation for making collective decisions. Each culture has established “folkways” that serve as traditional ways of providing a collective framework for viewing the world and social interactions, and that as cultures have progressed into the modern “technoscientific” era they have developed “tacit knowledge-ways through which they assess the rationality and robustness of claims that seek to order their lives.” Displays and arguments that do not meet these checks may be regarded as false or unfounded (Jasanoff 2005, 255).

Pulling together these ideas from public policy and STS, this dissertation defines governance in terms of the dynamics that comprise the policy-making sphere, reaching beyond (but also encompassing) formal policy-making institutions such as legislative bodies and the courts to also integrate the dynamics of broader political and policy deliberations scattered throughout society, such as those fostered by the media, the visual and literary arts, and the work of other informal and formal community groups and bodies (such as advocacy groups, societies, and informal networks of stakeholders). Governance is thus not the same as government; it goes beyond the boundaries of government to encompass not only the state, but also includes “actors such as

communities, businesses, and NGOs” (Lemos and Agrawal 2006, 298) and other participants who “contribute to the development of particular options for action” (Voss and Kemp 2005, 6). In this model, activities that might not traditionally be considered political, such as the processes of creating knowledge, determining who counts as an “expert,” and the basic processes of community building are in fact “deeply political exercises” and therefore part of the “broad sweep” of governance exercises that shape policy imagination, deliberation, implementation, and evaluation (Miller and Edwards 2001). The process of governance is thus an ongoing one, constantly in motion, distributed throughout society (Macnaghten et al. 2005, 270).

Anticipatory Governance Today

Anticipatory governance calls into question the notion that the modes by which new technologies emerge and disseminate throughout society are unknowable. Yet it is distinct from “predictive certainty.” Rather than attempting to predict every potential problem associated with a new technology, an anticipatory governance approach draws upon and emerges out of a “distributed collection of social and epistemological capacities” in an effort to increase preparedness in the face of uncertainty (Barben et al. 2008, 992). The current anticipatory governance approach maintains that mechanisms are needed for both lay and expert stakeholders, on an individual as well as institutional level, to imaginatively grapple with the challenges presented by new technologies prior to their development, deployment, and use (Barben et al. 2008, 993). Guston and Sarewitz (2002, 96) argue that technology assessment has not adopted an anticipatory approach due to the fear of those in the R&D sector of “untoward political interference” in the development of new technologies. The failure to “apply fully the tools of social science to the problem of enhancing the societal benefits of science and technology” was largely due to a perceived truth about how technologies emerge and disseminate

throughout society, that their trajectories are somehow predetermined, “largely unpredictable, and thus not subject to anticipatory governance” (Guston and Sarewitz 2002, 96).

Guston and Sarewitz (2002, 98) argue for a new form of technology assessment that is “embedded within the knowledge creation process itself” on the level of research and development (R&D). They seek to devise an approach by which to “anticipate how research and research-based technologies will interact with social systems” (96). The notion of “real-time technology assessment” (RTTA) builds off of an older concept of “constructive technology assessment” (CTA) that integrates societal aspects of science and technology into the innovation and design process. Guston and Sarewitz argue that a focus on the level of R&D for technologies is essential and must account for societal responses to innovation. Although the laboratory itself is the primary location for engaging in RTTA, Guston and Sarewitz (2002, 100) acknowledge the importance of the entire system, from the policy-making sphere to the research sphere, in building capacity in the face of an unpredictable future:

[T]he key to successfully grappling with unpredictability is to build a decision process that is continuously reflexive, so that the attributes of and relations between co-evolving components of the system become apparent, and informed incremental response is feasible.

Guston and Sarewitz (2002, 103) emphasize the importance of communication among various stakeholders, such as decision makers, researchers, the public, and the media. Such communication “significantly determines the complex societal relation with innovation.” They go on further to note that very little literature exists regarding communication between stakeholders at the *beginning* of a technology’s development (see, also, Wilsdon and Willis 2004), although there is plenty of literature regarding retrospective, “back end” communication once a technology has already hit the market.

Guston and Sarewitz argue for a “front end” anticipatory approach. They call their approach communication and early warning systems and advocate for content analysis of media sources about innovation, social judgment research, and public opinion polling efforts (Guston and Sarewitz 2002, 103). These activities then feed into technology assessment and choice, including assessment of the societal impacts of new and emerging technologies via foresight and forecasting, scenario development in order to foster deliberative processes regarding the trajectories of emerging technologies, and evaluating the role of RTTA itself on the research agenda (ibid., 104).

In their analysis of anticipatory governance, Barben et al. (2008, 983 & 993) likewise focus on incorporating societal concerns and perspectives into the R&D process at an early stage, arguing that an anticipatory governance approach necessitates and calls for a *society-wide distributed capacity* in “shaping things to come.” In this sense, anticipatory governance emerges as an integral aspect of the broader model of governance described above. Anticipatory governance is concerned with cultivating capacities for thinking about and governing technologies as they emerge over time. “Effective action” in crafting responsive policy, Barben et al. argue, is “based on more than sound analytical capacities and relevant empirical knowledge: *it also emerges out of a distributed collection of social and epistemological capacities, including collective self-criticism, imagination, and the disposition to learn from trial and error*” (Barben et al. 2008, 992, italics added).

Anticipatory governance aligns with the definition of governance presented in this chapter in that it presupposes a variety of “lay and expert stakeholders” participate in the process of policy-making via “an array of feedback mechanisms.” Through these mechanisms, anticipatory governance enables stakeholders to “collectively imagine, critique, and thereby shape the issues presented by emerging technologies before they

become reified in particular ways.” Barben et al. (2008) maintain that the process of cultivating these mechanisms for engagement with distributed sets of stakeholders gives rise to “a distributed capacity for learning and interaction stimulated into present action by reflection on imagined present and future sociotechnical outcomes” (992-993).

Extending this idea, Barben et al. suggest that anticipatory governance should also involve the *cultivation* and “*building [of] capacity* to more broadly anticipate and participate in shaping things to come” (Barben et al. 2008, 993, italics added). Guston (2008, 940) similarly argues that societies need to engage in “capacity building” for anticipatory governance. He analogizes anticipatory governance to going to the gym: taking steps to be prepared and build capacity for things to come, things that might be out of one’s control. When a person goes to the gym and builds up her strength, she does not only spend time working on her arms or legs. Instead she conditions and prepares her whole body for whatever might happen. No matter what the array of challenges that she might experience, the experience of exercise will help her deal with them. Being strong and healthy is useful in any number of circumstances, and by preparing as best as she can, she can mitigate the devastating effects of possible unknowns. In this sense, Guston suggests, so must societies continuously engage in exercises that enable broad-based capacity development.

The literature on anticipatory governance identifies three kinds of capacities of particular significance: foresight, engagement, and integration. Foresight emphasizes the building of knowledge and visions of the future that can guide pathways of technological development. Foresight includes diverse formal activities and methods for anticipating the future trajectories of emerging technologies, such as scenario development, but also encompasses the broader imaginative capacities of society. Foresight methods are distinct from efforts to “forecast the future” and other techniques

that seek to predict rather than anticipate. Forecasting holds an “allegiance to technological determinism” (Barben et al. 2008, 985) in that it presupposes that technologies follow pre-determined, fixed trajectories that can be precisely predicted. In contrast to forecasting and predictive modeling, which “address powerful industrial and governmental actors’ need for limiting uncertainty,” foresight approaches prefer to envision multiple possible futures, assume “intrinsic uncertainty,” and adopt more participatory methods, such as public deliberation and scenario building. Through such approaches, foresight endeavors to “enrich futures-in-the-making by encouraging and developing reflexivity in the system” (Barben et al. 2008, 985) through promoting greater awareness of divergent plausible technological trajectories early in the nascent developmental stages of new technologies (Rip and te Kulve 2008; Selin 2006). In addition to scenarios, foresight activities explore how stakeholders envision the future and the impact of stakeholder imaginings on technological trajectories (Selin 2007). Foresight thus engages a variety of methods for anticipating and deliberating the future that society is building.

The capacity for engagement emphasizes the involvement of publics in conversations regarding new and emerging technologies. Engagement goes beyond public opinion polling to include numerous sites and methods of involving publics in the deliberation of science and technology, such as science museums, consensus conferences, and deliberative forums. These strategies bring publics into the governance process at an early stage, Barben et al. argue, *before* the technology hits the market and only retroactive approaches are available (Barben et al. 2008, 987-988). Prominent examples of engagement include the National Citizens’ Technology Forums funded by the National Science Foundation and organized by the Center for Nanotechnology in Society at ASU (Hamlett and Cobb 2006, Guston 2014). These

forums were informed and inspired by the Danish Consensus Conferences, which bring together Danish citizens for the “purpose of advising Parliament about how to manage a specific technology” (Hamlett and Cobb 2006, 632-633). Other participatory exercises include public forums, such as those hosted by the Nanoscale Informal Science Education Network, the University of South Carolina, and the Center for Nanotechnology in Society at the University of California, Santa Barbara (Barben et al. 2008, 987-988). Indeed, arguably, engagement must include the full array of deliberative spaces distributed throughout society through which citizens discuss and debate science and technology (Dryzek 2010).

Finally, integration implies the bringing together of the technical and the social in amalgamated or hybrid packages (Latour 1993). For example, research on integration has explored methods for integrating social perspectives into the innovation process by placing humanists and social scientists into the laboratory where they can interact with scientists and engineers (see Fisher 2007, Schuurbiens and Fisher 2009). Of these laboratory studies, the Socio-Technical Integration Research (STIR) project, led by Fisher and Guston, is the largest and most ambitious to date. STIR investigates the “real-time effects of [integration] activities ... on scientific practices and decision making” with the aim of making decisions more reflexive by “broadening the scope” of what scientists take into account in their decision-making processes to include a variety of social considerations (Fisher 2007). More broadly, integration is about the hybridization of the social and technical: the bringing together of social, economic, political, and technical elements into socio-technical configurations or systems (Miller 2001).

Pulling all of these factors together, Barben et al. argue that anticipatory governance reflects a “distributed capacity” in society for learning, interaction, and action via foresight, engagement, and integration exercises (Barben et al. 2008, 993). The goal

of this dissertation is to identify and explore this capacity for anticipatory governance as it exists in society: the ability of various stakeholders, ranging from policymakers, to consumers and impacted populations, to scientists, to the general public through both individual efforts and an assortment of feedback mechanisms “to collectively imagine, critique, and thereby shape the issues presented by emerging technologies before they become reified in particular ways” (Barben et al. 2008, 992-993).

Anticipatory Governance and Technological Somnambulism: What Sort of Entities are Socio-technical Contracts?

To deepen this concept of anticipatory governance, I argue that it is useful to develop a notion of “socio-technical contracts” that are negotiated and renegotiated around technologies over time. In *The Whale and the Reactor*, Langdon Winner argues that social and technological change have become tightly coupled in modern societies. As a result, he argues, when society engages in the making of technologies it is also engaged in the process of making social worlds. The process of world-making is “the most important accomplishment of any new technology” (Winner 1986, 10) and occurs, Winner suggests, through the negotiation and acceptance of social contracts that arise because new technologies demand certain forms of social organization or otherwise impinge upon or shape the social, economic, and political possibilities available to a society that utilize them. For Winner, the terms of these social contracts are increasingly unpalatable and, far too frequently, signed “too late” for society to be able to make significant changes in technological trajectories and so avoid the construction of undesirable worlds. This, for Winner, is the consequence of “technological somnambulism”: sleepwalking through “[v]ast transformations” in the social, moral, and cultural fabric of society take place, yet, in the fashion of a sleepwalker not conscious of

his or her actions, such transformations “have been undertaken with little attention to what those alterations mean” (Winner 1986, 9).

Winner’s depiction of the social contracts surrounding technologies implies an inflexible contract, unable to adapt to change or to take new social and scientific conditions into account. “In the technical realm we repeatedly enter into a series of social contracts, the terms of which are revealed only after the signing” (Winner 1986, 9) and, therefore, one presumes, in Winner’s mind, unchangeable. Yet, it is unclear where precisely the signing of social contracts takes place in Winner’s model of technological change, nor precisely who signs them. Nor is it entirely clear what holds these contracts in place. Winner’s view leans, in this sense, as others have critiqued it, toward technological determinism: technology as an external causal force shaping society.

I argue in this dissertation that this perspective on social contracts is too rigid. As Button (2008, 3) notes, social contract theory has made one point abundantly clear: while the *making* of a promise is rather easy, the *keeping* of that promise is more difficult and demands ongoing reflection and work by society. “[P]romises stand to individuals as constitutions do to states: they are forms of precommitment that restrain and free us at once” (Button 2008, 3). Button illuminates the inherent tension/dilemma of the promises embedded in social contracts: how can promises, made by an earlier generation, retain their meaning and not become “petrified barriers to individual and collective development” as society evolves and new generations of actors emerge? In the cultivation of a contract, it in turn cultivates those who invoked it: the “institutional and cultural forms invoked by it must sponsor and cultivate the very beings who have ‘authored’ or ‘consented’ to the *pactio inter cives*” (Button 2008, 7). For Button and other theorists of social contracts, the social contract is a living promise that evolves alongside the people who continually remake it.

Building on this idea, I suggest an alternative approach to contracts from Winner's. Instead of contracts that are signed, once, and then remain immutable, I suggest that society engages in ongoing deliberation and reflection on the socio-technical configurations and worlds being made in the integration of technoscience into society. In the process of anticipatory governance, I argue, society continually negotiates and renegotiates its socio-technical arrangements or *socio-technical contracts*, opening them up for active reengagement and rethinking. The socio-technical contract concept serves as a metaphor for the thinking through and reworking of fundamental socio-technical questions in the emergence and use of novel technologies.

Is It "Too Late" for Anticipatory Governance?

The shift from Winner's fixed social contracts to continually renegotiated socio-technical contracts addresses an issue of temporality that confronts both the concept of technological somnambulism and law lag. Winner argues, for example, that society awakes from its technological somnambulism only after it is "too late." Yet, what does this mean? Why is it too late to change the way society relates to any given technology? Kline and Pinch, for example, observe that well after the automobile was introduced into society and the marketplace, rural communities were able to transform the automobile from the urban rich man's toy it began as into a working farm vehicle (Kline and Pinch 1996). Similarly, even as Winner was finalizing *The Whale and the Reactor*, which is, as much as anything, a critique of nuclear energy, US publics were in the process of fundamentally altering the socio-technical contracts surrounding nuclear power plants. For the next thirty years, the United States built no new nuclear power plants.

I distinguish my understanding of "too late" from Winner's sense of "too late." A reading of Winner suggests he means the term in the sense of it being too late to avoid unintended consequences, that the past cannot be undone. I suggest the possibility that

there are other interpretations of “too late,” and propose opening up a conversation around the politics of how we understand the idea. Too late for whom, or for what? In a world where we have certain freedoms, there will always be victims for whom the consequences of certain decisions are too late. I suggest that anticipatory governance is an attempt in thinking about minimizing the unintended consequences of technologies, and thinking through such issues sooner rather than later in a multiplicity of venues, from laboratories, to government agencies, to a variety of other formal and informal spaces where anticipatory governance can occur.

Therefore, this dissertation conceptualizes the notion of it being “too late” in a different sense than Winner’s, in part due to my conceptualization of socio-technical contracts. Socio-technical contracts are not generally actual contracts that get signed and enforced as written. Rather socio-technical contracts represent active negotiation and renegotiation of the legal and social norms and expectations surrounding technologies as they emerge and evolve in an ongoing process of change. Anticipatory governance provides a framework for the shaping of a “future to come” (Barben et al. 2008) that can be discussed and deliberated at any point in time. Indeed, the work of anticipatory governance will never be complete, as the “future to come” is always still to come.

While the idea of signing a contract works well as a metaphor for helping readers wrap their minds around complex socio-technical negotiations, it oversimplifies what happens in real cases. Indeed, even in cases where real contracts have actually been signed, including some that I describe in Chapter four, it is not necessarily “too late.” Societies often revisit and reconfigure their relationships to technologies over time in light of new social values or new evidence of problems in existing socio-technical arrangements. The metaphor of society “waking up” to discover itself bound to

unchangeable social contracts is equally problematic. Throughout my cases, I observe a steady and evolving flow of reflection and deliberation in public spaces around the responsible governance of new technologies. When we say that something is “too late,” it implies that some sort of line has been drawn. This work identifies the emergence of technology as a continuous process, from the germ of an idea to its dissemination and ongoing reconfiguration in society. Given this evolution, it is difficult to “draw a line” or identify something as “too late,” due to the evolving and continuous nature of both technological development and legislative frameworks. Neither is static.

Consider, for example, the case of the atomic bomb. There are those who might argue that, once Einstein had articulated the formula $E=mc^2$, it was too late; yet it would seem that, during World War II, German scientists did not pursue a bomb project, despite having much of the same scientific knowledge available to the United States. Or perhaps it was too late when a bomb was invented and tested; yet, even then, it is not clear that the world to be created around atomic weapons was pre-ordained. While the US did use its weapons in World War II on Japan, the Soviet Union never used its weapons during the Cold War, and the possibility of placing all atomic weapons under international control was seriously considered by US and Soviet diplomats in 1946. And, even after the US and Soviet Union built massive arsenals of weapons in the 1950s and 1960s, it was possible to shift course and, in the 1990s and 2000s, reduce those arsenals by 70%, with further reductions planned. All throughout this period, both societies were engaged in deep exercises of anticipatory governance, seeking to imagine, individually and together, what kinds of worlds were possible, given existing and future anticipated weapons technologies, which were desirable, and how the latter might be achieved. In light of the socio-technical contract concept and my reading of “too late,” which is distinct from Winner’s notion of the idea of “too late,” at no point was it too

late to engage in foresight, integration, or engagement activities that might inform how to govern the world of nuclear weapons today such that the world of tomorrow would be better.

Anticipatory governance also provides an answer to the problem of temporality in law lag. While the core argument of law lag is that the law and ethics are continually lagging behind technological developments, I argue that we might just as easily view the problem as one of conflict over anticipatory governance. When societies create laws, they anticipate the kinds of worlds—or, more narrowly, socio-technological arrangements—they desire to bring into being. Yet within those societies there may be or emerge groups with different conceptions of desirable worlds or socio-technological arrangements who may seek to force a renegotiation of socio-technical contracts. It is not that the law lagged new technology—the law actually preceded it—rather, there is a disagreement over what the law should be and how it should be applied to technologies. What appears as law lag, then, is actually an exercise in anticipatory governance, in which those involved in advancing new technologies are seeking to open up and renegotiate previously settled – if not always presciently worded – socio-technical contracts.

Social Contracts and Their Socio-Technical Cousins

My reading of socio-technical contracts follows a rich tradition of political theory around social contracts. Social contract theory, at its core, seeks to *justify* why individuals should *want* to enter into a contract, to legitimate certain orders over others. The aim of such thought is to grapple with the justification of particular political orders, individuals' relationships with each other, and with their government. The social contract is a long-standing theoretical tool in political thought and is best known from the works of Thomas Hobbes, John Locke, and Jean-Jacques Rousseau. Social contract theory is

helpful for grappling with *why* people would consent to leaving their present state of affairs, contracting with each other, and moving into an anticipated better, future condition. The contract is not established to benefit any one individual or group; instead, it is meant to elevate and benefit all members of society, helping individuals achieve communally what they could not achieve on their own.

The social contract provides a way of thinking about government that understands that trajectories of governance are not predetermined and immutable but instead frames trajectories of governance as having the potential to be opened up, made accessible to examination by members of society, and ultimately changed. Even the Hobbesian social contract, which has the explicit intention of *justifying* a strong sovereign authority, does not take the established modes of governing as fixed; rather Hobbes has to provide his case for why individuals should maintain their sovereign, knowing that revolution and change in government is precariously imminent.

In *Between Politics and Science*, Guston (2000, 41) takes this argument a step further with his concept of a “social contract for science” as a metaphor for the relationship between science and government. Guston illuminates an important distinction between traditional social contract thinking and the new “social contract for science.” Unlike the tacit and theoretical social contracts of Hobbes, Locke, and Rousseau, Guston argues that social contracts for science are real things that are being actively engaged in. As Guston (2000, 40) notes, “as a theoretical device the social contract is merely a hypothetical agreement. That is, arguments from a social contract hold its principles are valid not because actual people actually agreed to them, but because people [in a hypothetical ‘initial condition,’ or ‘state of nature,’] had they the opportunity to agree to them, would have.” Guston illuminates this by delving into Locke’s social contract. Locke’s social contract is renewed tacitly, each time an

individual partakes “of the material benefits of the state constituted by the social contract” (Guston 2000, 40). For Locke, simply by virtue of walking on the road, one is implicitly participating in the social contract.

By contrast, Guston posits that a social contract for science need not be tacit or hypothetical. Under the threat of Fascism, one could envision a scenario in which scientists and policymakers meet and agree that “the government would employ scientists to produce knowledge and instruments of war in order to secure the future of the free society that exists to their mutual benefit” (Guston 2000, 40). During the war, the social contract would be renewed each time a scientist accepted a contract from the government. After the war ends, the scientists and policymakers would come together once again to revisit the social contract in light of changed conditions. The new social contract would include not only national security but also broader considerations regarding the health, welfare, and economic security of the nation’s citizens. This new and broadened social contract would be renewed with each new grant from the government. The social contracts of traditional political theory comprise a variety of different types of constitutions. For example, Hobbes’s social contract is a contract amongst the people in order to set the sovereign above them, while Locke and Rousseau present social contracts that encompass joint agreements between the people and the government. Social contracts for science, argues Guston, are a “conjoint constitution,” representing an agreement between those that are governing and the people being governed. Scientists and policymakers are not giving up their freedom to a sovereign authority in order to benefit from the contract. The arrangement is conjoint because the entities that are subject to the contract are also the ones benefiting from it and agreeing to its terms (Guston 2000, 41).

Social contract frameworks for understanding the relationship between science and government must be “used strategically.” Because social contracts are implicit, there exist no “terms etched in stone to which the parties to this struggle can appeal” (Guston 2000, 42). Guston utilizes the social contract for science idea in order to explore the ways in which government trust in the integrity and productivity of science in the United States evolved and was reconstituted over time. Guston’s insights into social contracts, and the social contract for science, are key as this project develops the socio-technical contract concept, particularly in the sense that socio-technical contracts, when juxtaposed against their social contract counterparts in political theory, represent active negotiation and renegotiation of the social configurations in which emerging technologies get embedded, as opposed to the tacit social contracts of thinkers such as Locke. When social contracts are applied to the governance of new and emerging technologies, as Guston makes clear, there exist more mechanisms for collective action and active renegotiation of the terms of such contracts. Traditional social contracts are more tacit in this regard, and focus specifically on the relationship of the citizen to the sovereign.

Active Engagement in Social Contracts

If a social contract has to do with the relationship among citizens and between them and their government, then socio-technical contracts incorporate an additional element, the modes by which citizens contract with each other and their leaders on how to engage with technologies as they make present and future worlds. What makes these contracts legitimate, and how would we know if the contract has been broken? Just as Aristotle and Plato posed the question of the good life to the ancient Greeks, critically engaging with socio-technical contracts gives rise to this same question in contemporary societies: what is the good life, what kind of society do we want to

become, and how should we go about making the society that can provide us with the good life?

Winner's invocation of the social contract in the "technical realm" opens a new dimension for exploring anticipatory governance. Drawing from Winner's conceptual framework, I propose that the purpose of anticipatory governance is, as much as possible, to enable societal capacities to think through "socio-technical contracts," both creating such contracts up front, in the initial period of deliberation prior to and accompanying the development, marketing, and use of a new technology, and the renegotiation over time of that contract under changing social and/or technological conditions. Anticipatory governance represents the culturally specific, social capacities for making the terms of such contracts clear and open for negotiation. The anticipatory governance approach recognizes that as society integrates new technologies into its ways of life, the future is being built today. Rather than attempt to imagine exactly how the future is going to be, anticipatory governance opens up tracts for clearer negotiation. Anticipatory governance enables the social capacities and dispositions to think through socio-technical contracts up front and on an ongoing basis. In this sense, anticipatory governance is inevitably enmeshed within culturally differentiated *civic epistemologies*: the ways that political societies understand, reason through, and deploy knowledge within specific epistemic contexts (Miller 2008).

Is it possible to treat the writing of a socio-technical contract with the intentionality and deliberateness afforded to the founding of new political orders? Can questions of the relationship between technology and society be meditated upon and debated with the acknowledgment that new social orders are being developed as a result? That citizens are building the kind of world they want to live in, creating the future in the present? Can citizens critically consider what types of technological progress they want

to consent to? Social and political theories are largely silent on the questioning of technological progress—instead embracing such developments as necessary means to a better, more enlightened society. Technological development is a matter of progress. To question it is to halt it (Winner 1989). Anticipatory governance asks that we pause and seriously think about the role of technology in our lives, how we conceptualize the role of technology in our understandings of the future. It posits that it is possible to be intentional in the governance of technologies, and in the very construction of socio-technical contracts themselves.

In connecting socio-technical contracts with the anticipatory governance concept, I hypothesize that the terms of the contract can be made clear, and social considerations integrated, when operating under an anticipatory governance framework. This dissertation puts that claim to the test. It seeks to explore, empirically, what it might mean to talk about anticipatory governance as a wide-scale, distributed, proactive governance activity at the scale of a nation, proactively imagining and deliberating new and emerging technologies, creating the possibility of reflexivity from the earliest possible stages of technological development. If there were a perfect example of anticipatory governance, there would be little work to do in this area. Rather, like Plato's attempt to know the universal forms through studying particular objects, we must delve into particular, case-specific, attempts at anticipation, if we are to understand it.

Assisted Reproductive Technologies

This dissertation examines how British society has attempted, over the last two centuries, to actively deliberate the socio-technical contract for reproductive technologies and provide it with stewards, making it explicit, keeping it alive, open, interacting with various members of and stakeholders in society, and adaptable to technological change. These attempts are representative of an approach to managing socio-technical contracts

and evolving socio-political orders that attempts proactive governance, of attempts to actively build the future with a critical eye towards developing the society that we want to become, rather than allow the “building of the future” to progress without pause or consideration of the implications that the decisions (both tacit and conscientious) of the present have in shaping future worlds.

The following chapters explore the attempted formation of such anticipatory contracts, utilizing case studies of the governance of assisted reproductive technologies in the United Kingdom. The cases, covering nearly two centuries of governance dynamics, provide both a historical and ongoing perspective on the development and maintenance of the socio-technical contract.

Why focus on reproductive technologies? Reproductive technologies enable a deep exploration of the notion of the socio-technical contract as it relates to some of the most fundamental issues of our time: sex, contraception, marriage, abortion, embryo research, and genetic engineering, are just a few topics falling under the umbrella of these technologies. The concept of the “socio-technical contract” takes on a new dimension as we begin to explore the role of reproductive technologies in constructing social orders, opening up new avenues for building families, and pushing and reconfiguring the boundaries of ethical and responsible science and innovation. Political orders are continuously being constructed, critiqued, and renegotiated around large-scale technological enterprises such as reproductive technologies. Technologies falling into the realm of human reproductive science are widely debated, deployed, and contested in every human society and culture. Reproductive technologies are pervasive tools used at both the individual and societal level to control foundational aspects of human life. They fundamentally shape how people choose to lead their lives in relation to each other, their broader society, and in relation to future generations. The most

basic and fundamental of human institutions are built around reproduction: the institution of marriage legitimates who can have sex with who and legitimizes the enterprise of baby-making for those who are eligible to marry. Rights to citizenship are traditionally linked with birthplace, parentage, and marriage. Millennia-old notions of who can marry who are today forming fissures across societies, as some societies reinforce the institution of marriage between a man and a woman, and others, in light of shifting cultural norms and social circumstances, are broadening the definition to incorporate other lifestyles and sexual preferences. Even when legal definitions shift, and the institution of marriage (or legal partnerships) is expanded, reproduction and who can be called “parent” remains contested.

Birth control technologies are contested as “unnatural” and consequently, according to some religious communities, immoral, even when used in the confines of marriage or used to mitigate transmission of sexually transmitted diseases. The advent of in-vitro fertilization has raised questions and redefined parentage, kinship, and family. Such technologies are entangled in the most elemental issues of our age, the politics of life and death, questions of control and freedom, rights and responsibilities. Fundamentally, this suite of technologies is about the politics of how we order our lives and large-scale technological systems around sex and reproduction on a global level.

There are a number of rich case studies exploring the many facets of reproductive technologies. Charis Thompson’s *Making Parents: The Ontological Choreography of Reproductive Technologies* (2005) is one significant case study. Drawing on STS and gender-studies literatures to inform her analysis, Thompson conducted an ethnography of ART clinics, charting the “ontological choreography” within those clinics, as the activity of the clinic is normalized and naturalized, as both children and parents are “made” as technology and society co-produce in new and different

ways. Thompson develops the concept of “ontological choreography” to discuss the ways in which kinship, identity (of individual patients as well as the couple), gender, parenthood, and economic matters are negotiated and renegotiated over time within the fertility clinic. Thompson argues that in the case of assisted reproductive technologies, both babies and parents are simultaneously made. Thompson studies patterns of the “biomedical mode of reproduction,” as the social and natural worlds collide and reconfigure in new ways.

In *Born and Made* (2006), Franklin and Roberts also make substantial contributions to our understanding of the relationship between society and assisted reproductive technologies. Franklin and Roberts also take an ethnographic approach, delving into the regulation of preimplantation genetic diagnosis (PGD) technologies and unpacking the “designer baby” framing of the technologies. PGD technologies, as discussed in greater detail in other parts of this project, enable scientists and clinicians to biopsy a single cell from a human or animal embryo (created in-vitro), and through PCR (polymerase chain reaction) and genetic analysis techniques, determine certain genetic traits and genetic mutations within the embryo. Franklin and Roberts argue that, in some sense, we are all “born and made.” In one way this relates to the basic “facts of life,” and how technology has changed the dynamics of human reproduction: reproduction can now be achieved through technological means, and “particular types of reproduction can be deliberately chosen to a degree never witnessed before” (Franklin and Roberts 2006, xvi). The concept also “pits the view that biological identities are ‘given’ to us by our genetic origins against the opposite view—that we can, and sometimes have an obligation to, remake who we are by intervening in the basic biology of the beginning of life” (Franklin and Roberts 2006, xvi). The “born and made” theme is

a key component of their argument, that the born and made concepts are “an important new duality of the modern era” (Franklin and Roberts 2006, xvii).

Sociologist of science Michael Mulkey’s extensive body of work also grapples with the role of assisted reproductive technologies in society. Mulkey’s *The Embryo Research Debate: Science and the Politics of Reproduction* (1997) grapples with the social and ethical controversies associated with human embryo research. Mulkey provides an historical overview of key cases that preceded the 1984 publication of the Warnock report, including the thalidomide controversy and the abortion debates of the 1960s. These cases, and the resultant calls for better regulation, helped shape the British context into which Louise Brown was born. Mulkey provides insight into the complex regulatory terrain that makes up the governance of assisted reproductive technologies in Britain. Mulkey integrates the multiplicity of stakeholder groups and interests involved in the debates into his analysis. He illustrates the significant role that pressure groups played, and the ways in which various cultural myths played into the debates. Mulkey concludes his analysis of the British dynamics with a comparison to the U.S. context, noting the differences between the two contexts, and also strategies that might translate into the U.S. context.

As this brief literature review indicates, assisted reproductive technologies present “fertile” ground for exploration of the above issues in light of the socio-technical contract concept, and how such contracts are negotiated on multiple societal levels, from the immensely personal world of the bedroom, to the regulatory arena, to the highest courts in the nation. *This* is anticipatory governance – the messy, hard-to-define, complex processes ongoing in institutions formal and informal that comprise the questioning, reimagining, and critical evaluation of the role of technologies in society, as they relate to both present, future, and even past worlds. Thinking critically about the

role of technologies and the contracts that we enter into explicitly and tacitly, knowingly and unknowingly, is an essential aspect of anticipatory governance. The *how* and *why* of anticipatory governance as it occurs in various institutions, communities, and societies needs to be explored.

Assisted reproductive technologies are also significant in that they bridge societal capacities for anticipatory governance with capacities for anticipatory governance within government. ART manipulate, explore, and impact life in a variety of ways. The same can be said for a number of other emerging technologies, such as nanotechnology and biotechnology, that these technologies impact and alter our lives in a myriad of ways; however, ART is particularly unique because some countries, including the UK, have decided to address it by forming regulatory agencies. While the establishment of agencies to regulate a particular technology or set of technologies, is not novel or ground breaking, it nonetheless represents a significant socio-political act. Moreover, the decision to address ART in such a way is arguably an anticipatory act. The rationale behind creating these agencies was that because ART represents a controversial, important, and revolutionary suite of existing and future technologies that raise significant political, ethical, and cultural questions, the best mode of action would be to create agencies tasked specifically to answer those questions. The idea behind such agencies is to “get ahead” of the technology, via licensing and other regulatory activities, so that the benefits and promises of the technology can be fulfilled and the negative societal impacts can be mitigated as much as possible.

The history of ART in the UK provides a window into anticipatory governance. Following the birth of Louise Joy Brown, the first “test tube baby” and a new “social kind” (Star and Bowker 1999), the UK government established the Human Fertilisation and Embryology Authority (HFEA) as the first regulatory agency of its kind. Alongside the

creation of the HFEA, the UK also established new scientific kinds such as the “pre-embryo,” the classification of an embryo that is less than fourteen days old, which therefore created what was perceived as a more legitimate space for embryo research, since the object of study was not an embryo, but a “pre-embryo” (Jasanoff 2005). In addition to new scientific kinds, other new social kinds were born, particularly in the form of the “ethics expert,” Mary Warnock, who chaired the Committee of Inquiry into Human Fertilisation and Embryology (Jasanoff 2005). Both the complex history and present-day operations of the HFEA demonstrate that there is no easy answer to the governance of ART, and provide an example of an agency that was tasked with grappling with an emerging technology that, at the time, had no policy precedent. Inclusion of the HFEA in this study provides a case in which ART policy and regulation can be observed over a period of three decades, beginning with the birth of Louise Brown, the first in vitro fertilization baby, to the present day. It enables an opportunity to engage with and study an agency that has emerged and evolved alongside the ART science and technology. In others, it allows a historical and present-day lens into the evolving British socio-political orders as the technologies and the governance of them continues to evolve.

Overview

Utilizing the rich, complex, and controversial suite of assisted reproductive technologies as an exploratory tool in further developing and engaging the concept of anticipatory governance, this work explores how societies imagine the future, and grapple with the challenges of the present. It examines the negotiation, renegotiation, and maintenance of socio-technical contracts and political orders, as citizens attempt to realize the type of society that they want to become. Here I provide a brief conceptual overview of each chapter. Each chapter serves as an account of a particular case study in the governance of reproductive technologies in the UK (and in chapters four and

seven a comparative account including Canadian dynamics). While each case study has been informed by archival work, ethnographic research, and approximately eight months traveling to various sites of governance activity (including laboratories, workshops, agency meetings, conferences, and even trade shows), it was the personal narratives and stories that seized my attention: narratives of individuals struggling with infertility, same sex couples desperate for a child of their own, “genetic orphans” searching for their sperm-donor parents, and families looking to preimplantation genetic diagnosis as the miracle-technique for eliminating debilitating genetic diseases from their family line. It is these *human* stories, in which everyday people navigate socio-technical contracts and all that accompanies them—desperation and hope, politics and culture, despair and faith—that shaped the research foci and trajectory, and ultimately led to the conceptual exploration of anticipatory governance as a means of critically navigating, imagining, and opening socio-technical contracts.

Each chapter delves into a specific case study that explores the negotiation and renegotiation of socio-technical contracts over time and analyzes the capacities for anticipatory governance that emerge. The second chapter delves into the evolution of the imaginative capacities that have developed over the last two hundred years to shape contemporary approaches to the governance of assisted reproductive technologies. The chapter explores long-running conversations in British society that occurred prior to the 1978 birth of Louise Brown, demonstrating that the contemporary governance of reproductive technologies did not happen in a vacuum, rather that anticipatory governance is an ongoing societal activity distributed amongst a number of formal and informal societal capacities that evolve in tandem with emerging technologies. This chapter explores conversations around the biological sciences, fertility, and reproductive technologies as they emerge over time, highlighting the role that evolving societal

governance capacities have in shaping the conversations around such technologies. The first episode explored in this chapter cover dynamics surrounding an early emerging technology, galvanism, and the subsequent publication of Mary Shelley's *Frankenstein* in 1818. *Frankenstein* is widely considered to be the first modern work of science fiction and has been deployed as a metaphor for the dangers of science out of control. The second episode focuses on the publication of Aldous Huxley's *Brave New World*, and the ways in which it was used to frame conversations around new reproductive technologies. The third episode explores the dynamics leading up to the birth of Louise Brown, and the ways in which the stories, metaphors, and motifs generated by *Frankenstein* and *Brave New World* shaped the debates around the responsible innovation of reproductive technologies. I illustrate the evolving nature of anticipatory capacities over time, and paint a picture of anticipatory capacities as culturally embedded, distributed tools, or resources, for grappling with the possibilities and challenges presented by emerging technologies.

The third chapter begins with the birth of Louise Brown. It explores how the capacities elucidated in the second chapter are deployed within British dialogues around Robert Edwards and Patrick Steptoe's in-vitro fertilization breakthrough. Utilizing archival newspaper articles and other primary-source materials, the chapter traces the negotiation of the socio-technical contracts that resulted in the establishment of the Human Fertilisation and Embryology Authority in the UK. Specifically, the chapter delves into the atmosphere following the birth of Louise Brown, exploring public fears that science was careening out of control, calls for control, and the special capacity of experts within British society for reigning in "runaway social forces" (Jasanoff 2005). The primary governance capacity explored in this chapter is the capacities for judgment

embedded within the British experts tasked with negotiating the socio-technical contract around assisted reproductive technologies.

The fourth chapter explores two examples of the re-imagination and reassessment of the governance arrangements for donor conception technologies, and the legal and cultural shifts in British Columbia and the United Kingdom from frameworks of primarily anonymous donation to donor identification. Specifically, the chapter explores capacities for the *renegotiation* of socio-technical contracts. With advances in cryopreservation technologies in the early 1970s, donor sperm became more readily available, and donor conception became a popular option for couples experiencing infertility. Sperm donors in both Canada and the United Kingdom donated under a presumption of anonymity. As a result, thousands of children who were conceived through the process have grown up not knowing who their genetic fathers are. In the early 2000s, donor offspring plaintiffs claiming rights to identifying information on their donor challenged the right to anonymity, via court cases. This specific chapter utilizes the comparative method in order to illuminate national approaches to anticipatory governance and, especially, the possibility of renegotiating socio-technical contracts on an ongoing basis for a well established technology.

The fifth chapter delves into deliberative capacities for governance in the case of British approaches to embryo selection, also known as preimplantation genetic diagnosis (PGD), a technique in which embryos are created in-vitro (outside of the body), and are tested for genetic flaws. The implications of embryo selection are no longer the stuff of science fiction, e.g., movies such as *Gattaca* (1997), where embryos are selected for their superior genetic traits and lack of genetic diseases. In 2009, the first baby was born who had been tested for the BRCA 1 breast cancer gene as an embryo. This event was hearkened as a scientific miracle by supporters and as a case of “playing God” and

an era of new eugenics by critics. Alongside using preimplantation genetic diagnosis for analyzing the BRCA 1 and BRCA 2 genes, many laboratories around the world possess the capacity to test for other non-medical characteristics, such as gender, height, and eye color. This chapter explores how British society has navigated the issues presented by PGD technology in light of the deliberative capacities for negotiating socio-technical contracts.

The sixth chapter applies the socio-technical contract lens to the savior sibling controversies of early 2000's Britain. During this time, a new dynamic entered the PGD arena. It now was possible to apply HLA tissue-typing technology and PGD to in-vitro embryos, and create a perfectly matched donor for a sick relative. While families stated that they only wanted to utilize the stem cells in the umbilical cord in order to provide lifesaving treatment for their ill child, fears arose that the resulting baby would be viewed as a medical device or commodity, and would not have the ability to consent to any procedures utilizing his or her blood and other genetic materials. This chapter explores the role that policy language, specifically the "welfare of the child" policy language, played as a boundary-negotiating tool in shaping the regulatory terrain around "savior sibling" technology in the United Kingdom.

Chapter seven concludes the project by taking the socio-technical contract concept from the macro-level of national regulatory activity to the micro-level of the scientific research laboratory, and offers insight on how socio-technical contracts might be negotiated and navigated in the "midstream," at the level of R&D activity, in light of the anticipatory governance framework. The chapter includes ethnographic case studies from two genetics laboratories, one in Oxford, United Kingdom, and one in British Columbia, Canada, and specifically draws its methods from the integration sphere of the anticipatory governance framework to test and understand the capacities for thinking

about and reimagining socio-technical contracts in the places that emerging genetic and reproductive technologies emerge from – the laboratory context itself.

At the Nexus of Theory and Practice

This project operates at the nexus of theory and practice, drawing upon the fields of public policy, comparative politics, and political theory to build the conceptual framework for interrogating anticipatory governance as a distributed suite of societal capacities that contribute to national policymaking. Through the analysis of empirical cases studies at the level of national governance activity, the project seeks to provide a robust account of anticipatory governance as it operates within society. The socio-technical contract concept, an idea developed within the dissertation, contributes a new analytic tool to the anticipatory governance canon, providing a space in which anticipatory governance can be examined as an ongoing phenomenon, a series of societal negotiations and renegotiations, rather than specific moments in time that are determined to be anticipatory or not anticipatory. The empirical aspect of the dissertation provides an historical account of the governance of reproductive technologies that stands in contrast to the current scholarship on the subject, which tends to examine governance activity from the birth of Louise Brown onward. By examining historical governance capacities and negotiations around biology and the life sciences in the United Kingdom, the project situates the first “test tube” baby within a broader context of historical negotiations around this suite of technologies, providing practitioners and scholars alike with a new resource for thinking about anticipatory governance and how it can be activated within a variety of socio-cultural arenas.

CHAPTER 2

WAKING THE SLEEPWALKER: FRANKENSTEIN, BRAVE NEW WORLD, AND A

RABBIT IN A PASSENGER SEAT

“[T]he futuristic discourse of [technologies], as well as their fundamental technical and social uncertainties, requires the cultivation of a societal capacity for foresight, by which we mean not only formal methodologies but also *more generalized abilities to bridge the cognitive gap between present and future.*” (Barben et al. 2008 991, emphasis added)

“Surely acceptance of the beginning does not necessitate embracing undesirable ends?”
(Edwards and Steptoe 1981, 100-101)

Introduction

There exists a mythology around the birth of Louise Brown, that her 1978 birth suddenly shocked society out of its technological somnambulism, its sleepwalking stasis. That the convening of the Warnock Committee and the passage of the Human Fertilisation and Embryology Act were the first significant nodes of anticipatory activity around assisted reproductive technologies. A common theme in social discourse around technology is the notion that society tends to lag behind technological progress, and that it is constantly racing to catch up (e.g. Winner 1986). That new technologies are advanced with little attention given to their potential implications until it is too late. One predominate perspective is that “ethics and law have typically lagged far behind technological change,” and that if something is not done, technology will continue to outpace law and ethics, and if “we allow the lag time to increase, it will grow exponentially until both ethics and law will be realistically viewed as an irrelevant antique of a time long past and not fondly remembered” (French 2011, ix). The purpose of this chapter is to challenge this perspective, and to provide examples in which society is actively thinking about the implications of new and emerging technologies far before the technologies themselves came into existence. Specifically, the chapter explores the role

of imaginative capacities in stimulating reflective thinking about socio-technical futures and seeks to make an empirical case against the lag and technological somnambulism arguments. First, the chapter provides a conceptual overview of what I mean by “imaginative capacities.” Second, it delves into the societal conversations surrounding galvanism, and how it, in part, inspired Mary Shelley’s *Frankenstein* (1818), and gave birth to the monster motif. Third, the chapter explores the historical background that Aldous Huxley’s *Brave New World* (1932) was embedded in, and the societal dialogues around ectogenesis (or gestation of a fetus outside of the womb), embryo analysis, and government control of reproduction decades before Steptoe and Edwards’s first successful in vitro fertilization procedure. Finally, the chapter explores the societal conversations and governance activity leading up to the birth of Louise Brown and the ways in which the stories, myths, and motifs generated by Shelley and Huxley’s work served as tools for thinking about new reproductive technologies.

The anticipatory governance literature has proposed that it is indeed possible to remedy the lag between emerging technologies, ethics, and the law - that technological somnambulism is not an inevitable byproduct of technological advancement, and that with the proper tools and by establishing governance capacities throughout society it is possible to proactively govern and critically assess technological progress as it is happening, in real time. In further developing the anticipatory governance concept, this chapter advances the notion that anticipatory governance is an ongoing societal activity distributed amongst a number of formal and informal societal capacities that evolve in tandem with emerging technologies. Specifically, the chapter explores historical deliberative moments in the governance of biological and reproductive technologies, and the ways in which those moments indicate the cultivation of capacities for grappling with new and emerging technologies. It challenges the assumption that society is

sleepwalking (Winner 1986) through fundamental socio-technical configurations, that the issues are not well understood by society and that it is not well equipped to grapple with such issues. Rather, historical and contemporary capacities for anticipatory governance do exist, beyond entities such as the HFEA, and these capacities are rich and extensive in a way that perhaps seems surprising, especially when juxtaposed against commonly held assumptions that society is perennially lagging behind.

Barben et al. (1991, 2008) posit that “futuristic discourse” around technologies, and the accompanying societal considerations and uncertainties, calls for “the cultivation of a societal capacity for foresight” and “more generalized abilities to bridge the cognitive gap between present and future.” What are those “generalized abilities” for connecting the present with the future, and what are the modes by which societies cultivate their capacity for foresight? A reading of Barben et al. suggests that these capacities must be cultivated, and this chapter delves into anticipatory capacities as they evolve and are cultivated over time, utilizing Miller and Bennett’s (2008) work exploring the role of science fiction in the construction socio-technical futures.

Miller and Bennett’s work serves as an entry point for thinking about the ways that the imaginative capacities of society might also serve as important anticipatory capacities. Miller and Bennett argue that this approach is not “prediction.” Instead, “tools built on science fiction might serve as a means for building a reflexive capacity into the governance of technology: for helping individuals and communities to meaningfully deliberate technologies and to democratically construct technological futures” (Miller and Bennett 2008, 598). Miller and Bennett maintain that a major challenge for modern-day democracies is to “engage the public in questions about the future.” Miller and Bennett argue that integrating narratives of socio-technical futures into technology assessment practices might serve as a means of combating Winner’s problem of technological

somnambulism (Miller and Bennett 2008, 599). Miller and Bennett highlight Mary Shelley's *Frankenstein*, Aldous Huxley's *Brave New World*, and others have "cast indelible shadows over the meaning and imagination of science and technology in modern societies" (Miller and Bennett 2008, 599). Science fiction, they maintain, can provide a means for the public to "engage vitally with scientific and technological futures" (Miller and Bennett 2008, 605).

Another useful concept for thinking about the role of imagination as reflexive capacity is Jasanoff and Kim's (2009) sociotechnical imaginary concept. Jasanoff and Kim note that sociotechnical imaginaries are both "instrumental and futuristic." They "reside in the reservoir of norms and discourses, metaphors and cultural meanings out of which actors build their policy preferences." They "activate collective consciousnesses," deploy "visions of what is good, desirable, and worth attaining for a political community," and they also can serve as warnings of possible risks and implications of rapid scientific and technological development. Through imaginaries, people "create the political will or public resolve" to avoid or achieve them, deploying in the "understudied regions between imagination and action" (Jasanoff and Kim 2009, 122). This leads to the question, can imaginaries be created and deployed as anticipatory capacities for grappling with the implications of new and emerging technologies?

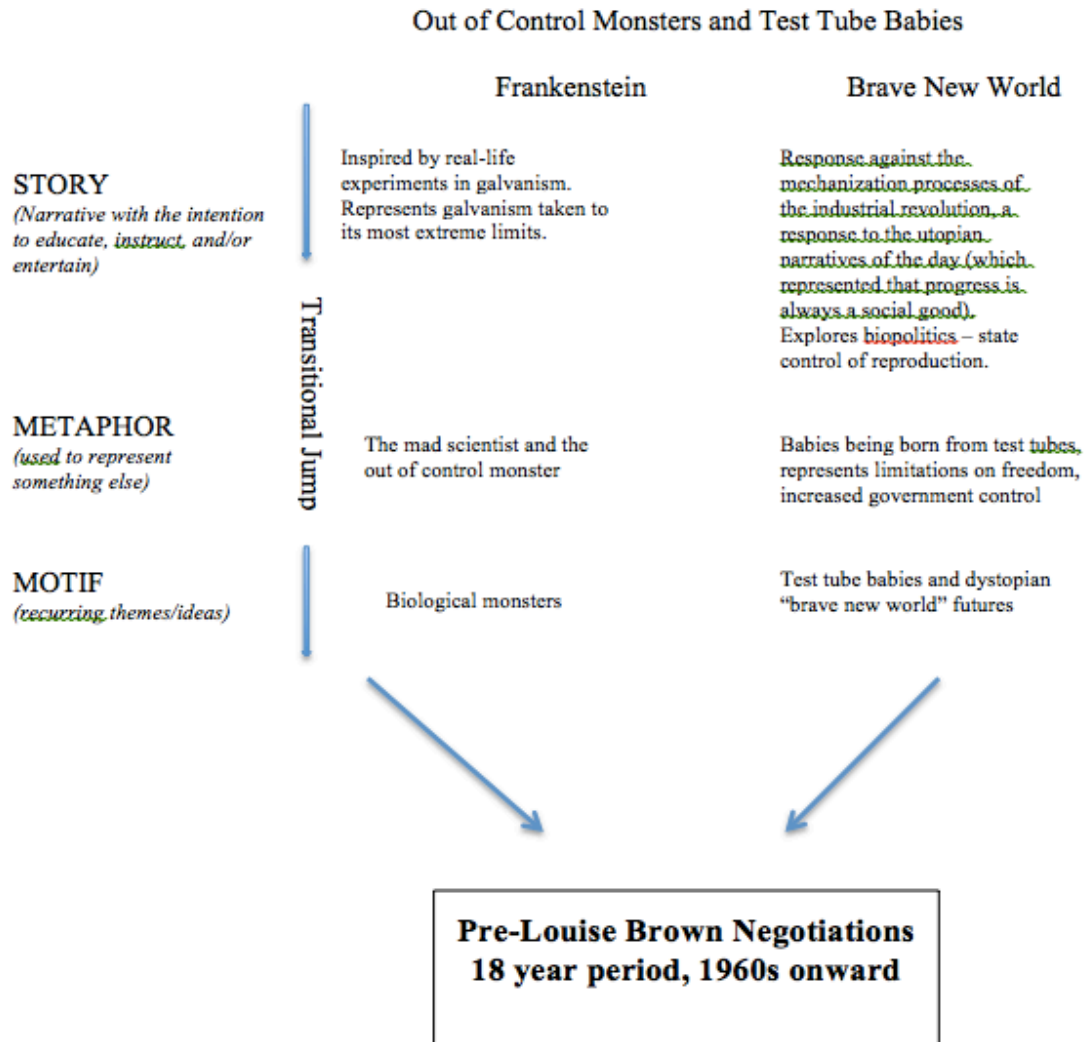
One area in which the socio-technical imaginary concept has not been fully explored is the ways that they are deployed and articulated in media materials and popular culture (Jasanoff and Kim 2009, 122). This chapter explores the role of science fiction narratives in shaping and negotiating societal debates around the use of reproductive technologies leading up to the birth of Louise Brown in 1978. Visions of what was socially desirable and not desirable were being deployed far before Louise's birth, as *Frankenstein* and *Brave New World* made the "transitional jump" from story to

metaphor to motif. As the stories evolved from stand-alone fictional accounts to serving as perennial motifs in the British social consciousness, they provided shared societal framings through which questions around the limitations and implications of reproductive technologies could be debated and discussed.

The chapter explores three periods in British history that gave shape to the contemporary socio-technical contracts that are the focus of this project: the Frankenstein period, the Brave New World period, and the pre-Louise Brown period. These periods center around three significant and interwoven eras in Britain around questions of the biological sciences, technology, and society. Each period focuses on the evolving set of cultural tools available to the British to make sense of and shape the relationship between emerging technologies and society. The periods in this chapter, as well as their transition and integration into the British socio-technical contract around reproductive technologies, are divided into three main sections. The below chart illustrates this transition and provides a broad outline of the flow of this chapter and the evolution of the stories that would ultimately be deployed as framing devices around emerging reproductive technologies in the 18 year period leading up to the birth of Louise Brown. I frame the evolutionary process of the stories as the transition from story to metaphor to motif. I define “story” as a narrative with the intention to educate, instruct or entertain. I define “metaphor” as an idea used to represent something else, such as the metaphor of the “mad scientist” representing the notion of science out of control. I define motif as a recurring theme or idea that progresses through time and embeds within a socio-cultural context. An example of an ongoing motif that emerged from *Frankenstein* is the idea of the biological monster, created through scientific ambition. A perennial motif that emerged from *Brave New World* was the idea of the “test tube baby”

– a term that continues to appear in headlines, television, and other media to the present day.

Figure 1:



The purpose of this chapter is to explore long-running conversations in British society that occurred prior to the 1978 birth of Louise Brown, the first baby born via in-vitro fertilization. Conception and gestation outside of the human body and the manipulation of sperm, eggs, and embryos have been intertwined in broader conversations about the role of technology in human life, questions of whether scientists

are “playing god,” and the limitations of scientific research that reach back centuries into the British social consciousness. Mary Shelley’s *Frankenstein; or, The Modern Prometheus*, published in 1818, and Aldous Huxley’s *Brave New World*, published in 1932, provide a lens into the framings, values, and perceptions of emerging technologies in the time period each work was embedded in. Both works, in their own right, served as metaphors for the socio-technical contract gone awry, and the potentially monstrous implications of human attempts to manipulate nature.

Frankenstein and *Brave New World* transcend beyond their specific time and place to be woven into an ongoing and uniquely British socio-technical contract, integrating into the large-scale sociotechnical imaginaries that frame, limit, and shape debates around the science of life itself. They do not only represent the era in which they were written, but are also tools in an evolving set of distributed capacities for thinking about and governing the British science-society relationship. The pre-Louise Brown negotiations explored in this chapter further illustrate this point, and provide an illustration of the transitional jump from story to myth to motif. As opposed to representing isolated instances, the modes in which societies grapple with the scientific issues of a particular day and age become woven into a broader socio-cultural fabric as metaphors and tools that frame how contemporary issues are perceived, understood, and tackled.

The Birth of a Monster

Imagine a scientist standing over a dead man. Metal rods, awaiting electrical impulses, are affixed to various places on the body, including face, torso, and appendages. The scientist and the body are not alone; encircling them is a crowd of onlookers, holding their breaths in a hush of fearful anticipation. *Will the dead man come back to life?* they wonder. The silence becomes even more palpable as the

scientist makes a motion to apply electricity to the metal rods. Electricity courses through the rods into the body of the deceased. The dead man begins to move.

The scene described above is not a scene from the latest TV science fiction drama, or the most recent of the summer blockbusters. The year was 1803, and the scientist was a real scientist, Giovanni Aldini, and the dead man was a real dead man – the body of convicted murderer George Forster. The most well known of Aldini's demonstrations was the one in which he used electricity to animate Forster's freshly executed body. In January 1803, at the Royal College of Surgeons, Aldini applied bimetallic electricity via metal rods to make Forster's body convulse and move as if it still had vestiges of life left in it (Parent 2004, 638). When electricity was applied to Foster's mouth and an ear via metal rods, "the jaw immediately began to quiver, the adjoining muscles were horribly contorted, and the left eye actually opened." When Aldini applied the rods to both ears, the entire face began to convulse, and "a motion of the head manifested." When Aldini also applied electricity to Forster's rectum, "such violent muscular contractions were excited, as almost to give the appearance of re-animation" (Aldini 1819, 80).

Aldini's experimental theater was the birthplace of the Frankenstein motif, an image that would ultimately come to represent the science as a runaway force, as innovation out of control. Aldini's gruesome experiments, part of an emerging field known as "galvanism," catalyzed early debates around the limitations of responsible science and whether scientists were overstepping their boundaries. The newspapers reported on the experiments in vivid detail over the course of the next few decades. The accounts illuminated the tension between whether the galvanists were controlling nature in order to raise the dead, or whether the research could provide important societal benefits, if appropriately regulated.

Even as early as 1800, the societal benefits of galvanism were being discussed in the public square. An article by William Pigram, writing for the *Observer* in 1800, provides one such example. The application of electricity to medicine had seen great successes, commented Pigram, “where the blind have been restored to their sight, the deaf to their hearing, and the palsied limb to vigour and health.” Despite the advances that had been made by trailblazers such as Benjamin Franklin, Pigram noted that the science was “yet in its infancy.” The new science of galvanism, remarked Pigram, has given insight into the properties of different metals, that some “have an influence on animals, and so powerful indeed, as to occasion their limbs to contract, and to evince other symptoms of life, even after the animal is dead!” Research in this area would not only be philosophically gratifying, stated Pigram, but could also “provide in the highest degree useful to mankind.”

Other commentators provided similar sentiments, that the extraordinary science had made great strides in manipulating life itself, that scientists had “succeeded in restoring animals, whose lives have been suspended by hanging and drawing” (*Observer* 1803). The galvanic experiments, “conducted on a large scale, and with a view to discovery, might produce results of the utmost importance to mankind” (*Manchester Guardian* 1823). Another commentator quipped that if galvanism was not “discredited by unskillful operators” it “promises to afford the most important services in its physical application [...]” (*Observer* 1803b).

Scientific Gratification

While Aldini was unable to restart the heart of a dead animal or human, he did travel through Europe demonstrating his experimentations in sending electrical currents through dead bodies in order to make them convulse and move as if alive. In one instance, Aldini used the bodies of decapitated kittens to demonstrate the power of

electrical current. By removing their spinal cords and replacing them with zinc and silver batteries, Aldini was able to start the hearts beating, and the bodies even “bounded around” for a short amount of time (Pilkington 2004).

An early newspaper account of Aldini’s experiments describes his experimental work to the British public in vivid detail. He captivated the attention and imagination of his audience by applying electricity to the body of a dead dog, whose head had been severed from its body, causing it to move as if vestiges of life were still present. Aldini’s display made such an impact that it elicited the suggestion that, out of curiosity, galvanism might be tested on the fresh body of a dead criminal:

Dr. Aldini, lately exhibited at the house of Mr. Hunter, some curious experiments on the body of a dog newly killed. The head of the animal was cut off. The head and the body were put beside each other, on a table rubbed with a solution of ammonia. Two wires, communicating with the Galvanic trough, were then applied, the one in the ear, and the other at the anus of the dead animal, when both head and body were thrown into the most animated muscular motion. The body started up with a movement, by which it passed over the side of the table: and the head moved; its lips and teeth grinning violently. A curiosity was expressed to have these experiments tried on a criminal newly executed. (Observer 1803c).

George Forster would have the unfortunate honor of serving as Aldini’s most well known human experimental subject.

Lectures and displays of galvanism garnered public attention and curiosity. In these demonstrations, galvanism was applied to the dismembered limbs of various animals, evincing both horror and fascination. Such demonstrations were so popular, that multiple events were planned to accommodate the large numbers of curious attendees. For instance, the *Observer* announced that there would be another demonstration following a particularly popular lecture by Mr. Hardie, noting that the event would provide the public with “an unusual opportunity of Scientific Gratification.”

In consequence of many Ladies and Gentlemen having been disappointed for want of room at his Lecture-Rooms, Somerset-street, Portman-Square. Mr. Hardie will repeat his interesting lecture upon his New Hypothesis of the Electric and Galvanic fluids, at the Large Theatre, Lyceum, To-morrow, Monday the 27th instant, when the surprising Effects of the Galvanic Influence upon the Muscular and Nervous System will be evinced, by exciting the Actions of crawling, kicking, leaping, &c. in the detached Limbs of dissected Animals. – The Functions of smelling, biting, chewing, swallowing, winking, and other voluntary motions, will be induced in the Head of a Sheep, Ox, or other large Animal, long after separation from the Body. –[...] the Public will have an unusual opportunity of Scientific Gratification.” (Observer 1804)

Reflections on the Darker Side

Other reflections on galvanism illuminated its darker side, speculating that the possibility of raising the dead could be a tangible reality. In January 1820, a commentary on galvanistic experiments labeled the practice as “horrible phenomena!” The experimentation, carried out by Dr. Ure on a murderer known as “Clydsdale” was labeled as “truly appalling.” In one of the experiments on the body of the dead murderer, electricity was applied to the neck of the corpse:

laborious breathing instantly commenced: the chest heaved and fell; the belly was protruded and collapsed, with the relaxing and retiring diaphragm; and it is thought, that but for the complete evacuation of the blood, pulsation might have occurred!! (Johnson 2007, *original quote from the Medical Repository 1820*)

Many people left the room over the course of the experimentations, and one person fainted, from “terror or sickness” (Johnson 2007). When electricity was applied to the nerves in the elbow, some of the spectators thought the criminal had come back to life, and the experimenter, Dr. Ure, felt that the body would have fully reanimated had the spine not been severed.

Emerging alongside the graphic descriptions of the effects of galvanism on dead bodies also surfaced accounts regarding the healing properties of galvanism – that it was “found beneficial in cases of blindness as well as deafness” (Observer 1803d). The technique was reported to have “great success” in combating paralysis of the optic nerve, and even cured a man of madness. The mad man, who had been bitten by a dog, had in his illness, suddenly become petrified by water and any object that shined. He was taken to Professor Rossi at Milan, where the application of galvanism led to an “astonishing cure”:

The patient suffered much during this operation, which, after several shocks, rendered him so weak, that he was unable to stand: being then extended on the floor, he was Galvanised with facility, the operation producing a copious perspiration. At two o'clock on the day succeeding, the process was repeated, and at six o'clock on the following morning, the man went alone to M. Rossi, to tell him he was perfectly cured, for he felt no pain; the inflammation in his throat had subsided, and he had entirely lost all aversion to water and other liquids. Some time after, he again submitted to the shock, and is now perfectly recovered. (Observer 1803e)

The *Observer* article that described the fantastic recovery of the man's hydrophobia also reflected that galvanism could “do much harm by misapplication.” However, if the technology was “judiciously-regulated” it could do a great deal of good “at the moment when any accidental cause has suspended the functions of the vital organs, [it] may preserve the lives of thousands” (Observer 1803e).

Other accounts surfaced of ill individuals who were “indebted [...] to the successful application of Galvanism,” such as Francis Cooke, a “poor blind sailor” whose sight was restored. Following examination by medical experts at Bath, it was declared that “the sight of one eye was perfectly recovered” (Observer 1804b).

Credible Science versus Swindle: Humphry Davy Calls for Debate and Educated Citizens

As galvanism emerged, so too did conversations regarding what comprised credible scientific work. The debate around legitimate versus illegitimate scientific practice was headed by chemist Sir Humphry Davy, a friend of Mary Shelley. He was considered a renowned and “eminent [British] chemist” (Manchester Guardian 1825). Davy was known for lecturing on galvanism and giving public demonstrations, and was a public critic of many practitioners of galvanism, arguing that many of the galvanists were pretenders masquerading as scientists. In one lecture, detailed in the *Observer*, Davy emphasized the importance of the history undergirding galvanism/electrical experimentation, remarking on the work of “illustrious characters” such as Benjamin Franklin in providing foundational knowledge of electricity (Observer 1811). Davy discussed the dangers of having an unformed public when it comes to issues of science and medicine. An uninformed public could easily be taken advantage of. Members of the public that could not understand the science were setting themselves up to be swindled:

Dr. D. in the course of his lecture, took notice of the various impositions which had been practiced by pretended applications of electricity to medical purposes; amongst these the most eminent were the metallic tractors. They were made of iron and brass; of all the metals which have been chosen, these possessed the least power of producing electricity from mutual action by contact. Their only real effect was that of drawing money from the pockets of the credulous. (Observer 1811)

Davy remarked that it was the duty of scientists to “pursue and disclose the truth,” that he would prefer to “be persecuted and die a martyr to its sacred cause, than live the slave of error, and be the parasite of false opinions” (Observer 1811).

Davy stated that there was a direct connection between the “progress of science” and “political freedom,” using the example of ancient Greece, known for the freedoms afforded to its citizens, where “science was cultivated with the greatest success.” He

argued for an atmosphere of “public freedom,” where the public can freely discuss the aims of science – in ancient Greece, due to the culture of freedom and discussion, the “mind was roused to energy.” Davy maintained that science is best cultivated in environments that value free and open discussion, rather than environments where freedom is stifled:

The ages of Greece most distinguished for heroism and freedom, were those in which science was cultivated with the greatest success. The mind was roused to energy by the cheering voice of public freedom and popular applause. The patronage of a tyrant might for a short period give a sickly encouragement to science, but it could only strike root and flourish with a vigour in a land where men enjoyed the power of free discussion, and were in possession of their civil and religious rights. (Observer 1811)

Although Mary Shelley was only a little girl at the time of Aldini’s famous demonstration at the Royal College of Surgeons, Davy recounted the experiments in vivid detail to her over a decade later.

Other accounts poked fun at the hype surrounding galvanism, which was viewed as a panacea for all sorts of ailments. “Galvanism in Piccadilly,” a cartoon by Robert Middleton (1800), satirically illustrates galvanism as a “cure all.” in the cartoon, a wealthy gentleman is hooked up to a galvanistic machine in an effort to cure his faltering libido. Upon being connected to the machine, the patient immediately sees a return to form, exclaiming, “Mercy on me, what a wonderful effect - bless me, theres a pretty girl over the way - I've a greate mind to run after her.” The operator treating the patient replies, “Dere mi - you Angloise - you no believe in galvanism - be gar two-dree shock more make you young again” (Middleton 1800). The Galvanism in Piccadilly illustration throws a comic light on the practice, inviting its viewers to question whether galvanism really can make the young old, and the old virile once again.

Figure 2:



In addition to comics and newspaper commentaries on the subject, Aldini's controversial experiments also informed one of the first works of science fiction. Mary Shelley's *Frankenstein*, first published in 1818, provides an early example of the "mad scientist" archetype, a figure that has been frequently deployed as a warning against unrestrained scientific activity since its inception onward. Widely considered to be the first modern work of science fiction, *Frankenstein* sparked the imaginative capacities of the British consciousness in grappling with the evolving relationships between human beings and technology, of the increasing capacities of scientific endeavors to control and manipulate human and animal life. The mad scientist archetype developed in *Frankenstein* became a cultural metaphor for "the ever present possibility that scientists, by the very nature of their activities, may get things disastrously wrong and that ordinary people may suffer as a result" (Mulkey 1996, 159). The story of *Frankenstein* has been called the "foundation-stone of the modern genre of science fiction" (Stableford 1995, 11) and the "first myth of modern times" (Hitchcock 2007, 4).

Shelley's family and social circle also shaped her intellectual environment and gave her insight into a number of competing philosophical and scientific perspectives. Her father was William Godwin, a utilitarian Enlightenment philosopher, and her mother was Mary Wollstonecraft, an early feminist known for writing the influential 1792 feminist treatise, *A Vindication of the Rights of Woman* (2004). In addition to her connections with British scientists, such as Humphry Davy, Shelley was also friends with a number of Romantic poets and philosophers, including Lord Byron, and would eventually marry Romantic poet Percy Shelley (Bright MacWilliams 2008, 16). Davy's descriptions of the Aldini experiments and discussions regarding "the nature of the principle of life" captured the imagination of Mary Shelley, who, one night was unable to sleep at all, and in her tossing and turning, a vivid imagery came to her:

My imagination, unbidden, possessed and guided me, gifting the successive images that arose in my mind with a vividness far beyond the usual bonds of reverie. I saw – with shut eyes, but acute mental vision, - I saw the pale student of unhallowed arts kneeling beside the thing he had put together. I saw the hideous phantasm of a man stretched out, and then, on the working of some powerful engine, show signs of life, and stir with an uneasy, half vital motion. (Hitchcock *quoting Mary Shelley* 2007, 38)

Scholars argue that Shelley was ideally situated to illuminate the underlying tensions and dynamics of emerging socio-technical configurations, of humanity's increasing understanding of and control over the basic mechanisms of life, and the oftentimes conflicting and competing values that such advances represented. Shelley was writing during a time of significant political shifts in Britain. As Bright MacWilliams (2008, 13) recounts, Napoleon had been recently defeated, with his defeat came widespread political changes, and a radicalized population of poor, a population that had grown larger due to the return of the military population back to civilian life following the Battle of Waterloo. There existed a backlash against the Enlightenment philosophies

that were closely associated with the French Revolution, such as a mechanistic, anti-religious view of nature promulgated by the scientific philosophies of the day (Bright MacWilliams 2008, 15).

Shelley wove the real life activities of Galvanism with the fictional account of a “monster” coming to life in such a way that would capture the public consciousness to the extent that it would continue to permeate public debate about the responsible conduct of science for almost two centuries, and is no less salient in the present day. *Frankenstein* exposed the reader to the internal discourses of the scientific realm, at once illuminating the immense potential of scientific discovery, the man-driven insights into the building blocks of nature itself, as well as the perils of extreme danger when well-intentioned science does not go as planned, when the results of the scientific enterprise do not line up with the real-life outcomes. As the novel’s young scientist Victor Frankenstein recounted, there seemed to be no downside to his work, he viewed himself as a benevolent creator, bringing new life into a “dark world”:

Life and death appeared to me ideal bounds, which I should first break through, and pour a torrent of light into our dark world. A new species would bless me as its creator and source; many happy and excellent natures would owe their being to me. No father could claim the gratitude of his child so completely as I should deserve theirs (Shelley 1818, ch. 4).

Shelley’s subtitle of the book, *The Modern Prometheus*, further signifies the dilemma of pushing science beyond its socially constructed (ethical, moral, social) limits. If we do not push the limitations, how are we to know what might be on the other side? On the other hand, if we do penetrate those limits, do we *really* want to know what exists on the other side? The book’s subtitle ties the modern myth of Frankenstein to the ancient myth of Prometheus, the “mythical technologist” and a Titan who defied the gods and gave humanity the gift of fire. Frankenstein, like Prometheus, pushed the boundaries of

convention making his way into the realm of the forbidden, going “beyond what has been done before and, entering forbidden territory, steals knowledge from the gods. He develops techniques for creating life, a secret and mysterious act previously known only to the gods” (Warrick 1980, 37).

A major theme represented in the book is the lack of foresight and ethical thinking exhibited by Frankenstein. The brilliant scientist’s creation soon turns into his worst nightmare, and he becomes enslaved by a fervent desire to destroy what he has created.

I had desired it with an ardour that far exceeded moderation; but now that I had finished, the beauty of the dream vanished, and breathless horror and disgust filled my heart. Unable to endure the aspect of the being I had created, I rushed out of the room[.] (Shelley 1818, ch. 5)

Frankenstein was published during the industrial revolution in Britain, a time of major social and technological reconfiguration. New ways of transferring knowledge and information were emerging, and with the increasing use of the copy machine (invented by James Watt in 1779), information was moving across Britain at increasingly rapid rates, and at lower cost. Frankenstein provided the lower segments of society with access to scientific ideas and debates that had previously been inaccessible to members of the middle and lower classes. Like Frankenstein’s creature itself, Mary Shelley’s novel was a first in many aspects, and as noted previously, it is considered by some to be the first “modern myth,” a scenario that envisions science taken to its farthest logical (and most fantastic) limits. In Shelley’s time, deceased human bodies moving about, powered by electrical currents, as Aldini’s decapitated kittens “bounded about,” appeared as if reanimation could be a possibility in the near future. The novel highlighted questions about the boundaries and limits of scientific practice in a salient way, the value conflicts presented by the industrial revolution, the French revolution,

Enlightenment ideas, and the immense potential and peril of science pushing the boundaries of convention.

Frankenstein, in tandem with new socio-technical configurations brought about by the Industrial Revolution, provided a new mode of sense-making for the British public, one that would become a historically embedded tool, evolving and deploying within the British cultural consciousness over time. Shelley's Doctor Frankenstein gave birth to what has become the perennial motif of the "monster" – the biological atrocity of man's own conscientious making. The unnamed creature, born of a scientist's dream to master nature and bring light to a "dark world," still lurks in the shadows of contemporary debates around responsible innovation and the appropriate limitations of scientific research. The metaphor of Frankenstein's monster has been deployed in a number of different arenas (such as the debates around the genetic engineering of food, e.g. "Frankenfood"), but has also served as a central motif in conversations around ectogenesis, embryo research, and advances in reproductive technologies (Mulkay 1996).

Critical Moments and Monstrous Motifs: Early Calls for Anticipatory Governance

Public newspaper documents detailing the practice of galvanism, and the reactions of both lay publics and the prominent scientists of the day, illustrate that concerns around the responsible boundaries and limitations of scientific practice reach far back in British history. The panacea-like qualities of galvanism that were highlighted in some accounts are reminiscent of the modern day promises of some emerging technological and scientific domains, such as nanotechnologies and stem-cell research. With promises to give sight to the blind and life to the dying, the societal benefits appeared endless. However, historical accounts of galvanism also illuminate ethical dilemmas and societal fears around the practice – that scientists were overstepping

ethical boundaries, tampering with life in unnatural ways, and manipulating life in such a way that should be left to God alone.

A critical anticipatory capacity, that of an informed and engaged public, was recognized as an important component in the cultivation of responsible scientific practices. The role of an informed and educated public was emphasized by Humphry Davy, as well as illuminated in satiric newspaper illustrations (such as “Galvanism in Picadilly”), in fostering a societal capacity for recognizing “credible” scientific claims from cheats and frauds that would claim expertise in order to make a profit. Davy’s call for an engaged public suggests that he recognized the value that every day citizens can contribute in the shaping of technological trajectories. Davy’s stance also indicates that the shaping of scientific practice rests beyond just those with scientific expertise – rather, an educated and engaged public contributes to an atmosphere of free, open, and public debate, which in turn cultivates more “truthful” scientific practices.

Why are the historically embedded practices of galvanism and the Frankenstein narrative significant to the anticipatory governance of assisted reproductive technologies in the United Kingdom? The era signifies a critical moment in which story and science merged together to produce the first “modern myth.” While it appears that there were indeed calls for responsible innovation in the realm of galvanism as far back as the 1800s, equally significant for the purposes of understanding anticipatory governance is the modes in which *Frankenstein* was deployed as an ongoing motif in shaping discourse around the responsible governance of assisted reproductive technologies. In a sense, *Frankenstein* evolved into an important “tool” in the societal tool belt for thinking about, grappling with, and governing emerging technologies. The ways in which this motif was woven in the social discourse of 1960s and 1970s Britain is at times quite subtle, and at other times quite clear. This era, and its accompanying scientific

controversies, and the societal tools for managing and conceptualizing such controversies will be explored in the third section of this chapter, the “pre-Louise Brown” negotiations.

Infertility is in the Air: An Increasing Focus on Fertility and Infertility

While Frankenstein’s monster was making its way into popular discourse, the British state, for the first time, began a national registry of births and deaths. The enterprise of tracking births and deaths can be traced back to epidemiologist William Farr, who “developed the first national vital statistics system and assured its use as a surveillance instrument” (Lilienfeld 2007, 985). An understanding of the population within its borders was important for the Britain of the 1800s, as statistics emerged, in part, because states wanted to count people, to know how many resources they had in order to fuel their armies. In his writings, Farr emphasized that increases in population corresponded with overall advancement of the state:

Great economic changes in land are wrought by human skill and labour. The land units and the human units go on improving together and increasing in value; and generally, the more people a land supports the more valuable are its acres, the more advanced are its inhabitants. (Farr 1877, 570)

At this point in British history, a fertile population was essential, as the “wealth and strength of a state depended strongly on the number and character of its subjects” (Porter 1995, 19).

Moving into the early 1900s, British government officials were becoming increasingly concerned with the declining birth rate. Coupled with people emigrating out of the country and the overall general poor health of the nation, health and fertility became a significant focal point. The British needed a robust workforce in order to remain an international industrial power. Additionally a strong military was perceived as

necessary, due to the tensions in Europe that threatened to become volatile (Census 1911: Fertility and Marriage).

Aldous Huxley's novel, *Brave New World*, was firmly nestled in the midst of a period in which fertility and population decline were an increasingly significant social issue for the British. The period of 1860-1940 represented a major decrease in British fertility. During this time, the amount of live births for each woman decreased from almost six per woman to approximately two (Szreter 1996, 1). Infertility was in the air, and while concerns about the quality of British reproduction reached back over a century, British population issues reached new heights in the aftermath of World War I. Millions died in the trenches as a result of the war, and the male population was particularly "decimated" (Bowley 1924). Population scholar A.L. Bowley chronicled the declining British birth rate: "The birth-rate per 1,000 women aged 20 to 45 was in 1911, 122, in 1921, 115, in 1922 about 105, and in 1923 only about 101." (Bowley 1924, 191).

In 1911 the British conducted a census that for the first time included a fertility component. In this year, the falling fertility rate was "placed on an entirely new footing of observational rigor," with the British government, for the first time, seeking to compile a full overview of "fertility patterns" for the entire nation (including England and Wales, but excluding Scotland) (Szreter 1996, 2). The results of the census were published in two reports, one in 1917 and one in 1923 – population reports – general register office (Farr is head of). In part, the explanation for the decline became one of birth control technologies – that the wealthier classes were utilizing new methods of birth control in order to limit pregnancies, and the lower classes were following suit.

The Wings of Daedalus: The Brave New World of the 1930s

Forty-six years prior to the birth of Louise Brown, the world's first "test tube baby," writers, journalists, scientists, and citizens were debating the consequences of

reproductive technologies that had not yet come into existence. At the time, as noted above, fertility was becoming a national issue for the British. Aldous Huxley's 1932 novel, *Brave New World*, provided citizens with a glimpse into a future in which reproduction extends beyond all current scientific and social conventions, where reproduction begins outside of the womb and human embryos are selected for based on their genetic characteristics. The term "brave new world" originates from Shakespeare's *The Tempest*, (Act V, Scene 1), and is uttered by Miranda when she first sees civilization:

"O wonder!

How many goodly creatures are there here!

How beauteous mankind is! O brave new world,

That has such people in't."

Some of the foundational ideas in Huxley's novel were likely influenced by his intellectual relationship with biochemist John Burdon Sanderson (JBS) Haldane, a prominent biologist who co-founded the *Journal of Experimental Biology* with Aldous's brother, Julian Huxley. Haldane was one of the first scientists to argue that ectogenesis, reproduction outside of the human body, was a distinct possibility in society's near-future, and he was the first to use the term in describing human reproduction outside of the body (Nicol 2007). In his *Daedalus; or, Science and the Future*, which was the text of a 1923 lecture that Haldane gave at the Cambridge Heretics Society, Haldane made a number of predictions about scientific advances, particularly in the realm of biology.

Haldane predicted that ectogenesis would become universal, and in the 1923 lecture, painted a future-earth that was at once as compelling as it was horrifying.

Haldane envisioned that the first ectogenic child would be produced by 1951, and that the practice would quickly begin to replace traditional reproduction:

Now that the technique is fully developed, we can take an ovary from a woman, and keep it growing in a suitable fluid for as long as twenty years, producing a fresh ovum each month, of which 90 per cent can be fertilized, and the embryos grown successfully for nine months, and then brought out into the air. [...] the news of [the] first success caused an unprecedented sensation throughout the entire world, for the birthrate was already less than the death rate in most civilised countries. France was the first country to adopt ectogenesis officially, and by 1968 was producing 60,000 children annually by this method. In most countries the opposition was far stronger, and was intensified by the Papal Bull ``Nunquam prius audito'', and by the similar fetwa of the Khalif, both of which appeared in 1960. (Haldane 1924)

In Haldane's near-future, less than thirty percent of children would be born from a woman, rather, they would be produced by ectogenesis. The separation of sex and love was "by no means wholly satisfactory" and traditional family life did have its benefits. In Haldane's future world, women could be induced to lactation by injection, "and thus conserve much of what was best in the former instinctive cycle." However, Haldane predicted that society would move towards a eugenic system of breeding, the benefits of which would compensate for lost familial love:

The small proportion of men and women who are selected as ancestors for the next generation are so undoubtedly superior to the average that the advance in each generation in any single respect, from the increased output of first-class music to the decreased convictions for theft, is very startling. Had it not been for ectogenesis there can be little doubt that civilisation would have collapsed within a measurable time owing to the greater fertility of the less desirable members of the population in almost all countries. (Haldane 1924)

Haldane closed the lecture with the haunting description of a scientist, working towards the new biological revolution, fully cognizant of its terrible beauty: "The scientific worker

of the future will more and more resemble the lonely figure of Daedalus as he becomes conscious of his ghastly mission, and proud of it.”

While neither Julian Huxley or JBS Haldane claimed credit for the scientific underpinnings of *Brave New World* (Nicol 2007), the parallels between Haldane’s visions of the impending biological revolution and Aldous Huxley’s dystopian World State are clear.

Huxley’s novel opens with a visual of the Central London Hatchery and Conditioning Centre. Despite the plainness of the “squat” thirty-four-story building, the ensuing description of what occurs inside is jarring. Here, the assembly-line concept pioneered by Henry Ford is applied to human reproduction. This center, and others like it scattered across major cities in the World State, is where ectogenesis occurs.

In Huxley’s future London, human reproduction has become completely automated, and human “viviparous” reproduction, by which mothers carry and give birth to live young, has been replaced by an assembly-line model of reproduction. Human sperm and eggs are mixed together in large vats, and the resulting embryos are classified into different castes. The ruling class of people, the Alpha and Beta castes, are born from embryos that are created via one unique egg and one unique sperm. The lower castes are reproduced by “Bokanovsky’s Process,” by which embryos “bud,” creating hundreds of genetically identical individuals. This process serves as “one of the major instruments of social stability,” enabling the speedy production of thousands of identical lower-caste embryos: “The principle of mass production at last applied to biology.” The developing embryos are predestined to both a caste and an occupation. As they make their way down the assembly line, they are “conditioned” to the characteristics of both their caste and their predestined occupation. For lower castes, embryos are kept in “below par” conditions, for example, being deprived of oxygen in

order to inhibit development of higher intellectual abilities: “The lower the caste [...] the shorter the oxygen.”

Huxley paints a world in which sex is not necessary for reproduction. Indeed, the vast majority of the World State’s population is engineered during fetal development to be infertile. The small minority of upper-caste women who do have functioning ovaries are conditioned to consistently take contraceptives (the practice of which is called the “Malthusian drill”), which are typically stored in a box attached to a “Malthusian belt.” The name of the belt is an allusion to Reverend Thomas Robert Malthus. Malthus, a late-18th century Englishman, proposed that long-term economic stability and the advancement of society towards utopia would be hindered by uncontrolled population growth. Malthus argued that population growth must be in line with available resources:

The happiness of a country does not depend, absolutely, upon its poverty, or its riches, upon its youth, or its age, upon its being thinly, or fully inhabited, but upon the rapidity with which it is increasing, upon the degree in which the yearly increase of food approaches to the yearly increase of an unrestricted population. (Malthus 2004, Chapter VII)

Huxley’s World State is predicated upon the notion that the collective happiness afforded by social stability is paramount. Indeed, the World State’s motto, “COMMUNITY, IDENTITY, STABILITY,” is emblazoned on the front of the Central London Hatchery and Conditioning Centre. The stability of the World State comes from precise population control and conditioning of human beings from their conception onward. In order to maintain stability, reproduction is solely in the hands of the government, and sexual relations serve as a means of pleasure only.

Brave New World Enters the Public Lexicon

“Mr. Aldous Huxley’s “Brave New World” is going to be fearfully and wonderingly read by everyone,” declared the Observer (Observer 1932). Huxley’s “Brave New

World” stands out as one of the novels of the year which linger persistently in the reader’s memory,” quipped another reviewer (Linford 1932). The novel was praised by the Observer as being one of the top four novels of 1932 (Observer 1933). While the novel received critical reception (a mixture of praise and luke-warm cynicism) upon its release, perhaps the Australian reception is the most perplexing. The book was banned in Australia, not allowed to pass through customs (Manchester Guardian 1933a). The British themselves were quite perplexed when talk of Australia banning the book hit the newsstands: “The author himself may not be surprised; he might quote this new ban as supporting the most appalling thesis of the book itself – that the absolute denial of liberty [...] Is Australia doing its best to bring that day nearer?” (Manchester Guardian 1933b).

A number of British reviews of the book praised it for its prophetic qualities. One reviewer commented that the “metabiological nightmare” that Huxley brought to life “might well be more prophetic than he imagined” and that the novel served as a provocative “deterrent [rather] than a summons to salvation by science” (Brown 1932). Another reviewer noted that Huxley’s “fanciful but compelling ingenuity” illustrated the world as it might be “if our present scientific control of nature were carried to its logical extreme” (Marriott 1932).

The phrase “brave new world” almost immediately was integrated into the British vernacular. The term implied the lofty intentions of scientific progress going completely and horrifically wrong (e.g. see *A Brave New World?* 1932, Manchester Guardian). British newspaper commentaries discussing scientific, political, or social developments readily seized the idiom. A review of British newspaper articles before and after 1932, the year that “Brave New World” was published, illustrate use of the phrase corresponding with the book’s publication. Prior to 1932, the phrase was virtually absent

within the public lexicon.¹ One commentary discussed the shift towards mass production and labor-saving measures and employed the vision of a “brave new world” in illustrating this transition to mechanized labor processes, which, in turn, would strip people of their individuality:

All the work of the world will be done by a few brains which will be highly paid and kept in moral safes and a few executants, the function of whom will be the maintenance of the necessary machinery. Without even adventuring oneself into a brave new world, human effort, all around us, is steadily being made impossible by the withdrawal not only of the big necessities but of the little things which occupied our minds and our hands. Even the flowers will soon be sent home ready arranged. (Manchester Guardian 1932c)

“Brave New World” was often mentioned in popular discourse regarding the potentials and pitfalls of scientific development, and the role/responsibility of scientists themselves in the application of their research. In a newspaper review of a collection of essays entitled “The Frustration of Science,” for example, the “brave new world” of scientific advancement was described as a balancing act between “what science might do for the world if we would only let it” versus the potential undesired implications of scientific advancement. Essays such as “The Invention of Sterility” and “Bacterial Warfare” set the stage for this balancing act, that “neither science nor fascistic reactions against science can save us” (Manchester Guardian 1935). Some scientist-writers in the book grappled with the results of scientific discovery being turned into “instrument[s] of warfare”: “The scientific investigator has no control over the uses to which his work is put, and one aim of this volume is to call the attention of scientific workers to their responsibility for such uses” (Desch 1935, 558).

¹ Based on a search using ProQuest Historical Newspapers research database: The Guardian (1821-2003) and The Observer (1791-2003).

The “Frustration of Science” was not alone in exploring the “brave new world” of the future, however. “The Book of the Future,” by Ritchie Calder, sought to translate cutting-edge scientific research for lay readers. Calder visited a number of prestigious laboratories, whose research he recounted in the book, in an effort to “explain to the common man (so far as explanation is possible) how science is getting on, and what it is aiming at” (Observer 1934). Calder, in the style of Huxley’s “Brave New World,” attempted to give readers an idea of how scientific research endeavors of the present would affect the future, for better or for worse. He predicted that

We shall have television and harnessed tides, and euthanasia and a stabilized birth-rate, and there will be ‘very different views’ on the subject of divorce. Men and women will be some two inches taller, much less liable to disease, and will be bred, more or less, ‘according to plan.’ (Observer 1934)

Calder was “not entirely happy” about the future scenario that he illustrated in the book. He feared that advances in science and technology would be accompanied by a mechanization of human life, where industry would subsume everything else.

The Social Significance of Infertility in Britain

The period between the publication of Huxley and Haldane’s work and the 1978 birth of Louise Brown was a time of transition. The advent of World War II signified a transformation from “how big are your armies” to “how big are your bombs”. The pre-World War II conversation, with its focus on fertility and the declining population, was different from the conversation that evolved after the war. There was a line being drawn between what Haldane and Huxley raised concerns over (babies being born without mothers), and the evolving post-WWII framing of research on human reproduction. In the 1960s, with news that researchers were attempting to grow humans outside of the womb, it seemed as if Haldane and Huxley’s fears could soon become reality – that modern scientists might become real-life Doctor Franksteins and create monstrosities

born through ectogenesis. Frankensteins and Brave New Worlds would continue shaping and framing the debates around human reproduction, but the predominant societal framings around research on human reproduction would evolve again, to focus on the tensions between helping infertile couples have children and the responsible limitations around fertility research, as Patrick Steptoe and Robert Edwards took center stage, accompanied by a rabbit in the passenger seat.

An Unconventional Passenger

In 1970s England, it was not uncommon for gynecologist Patrick Steptoe to be seen driving from Oldham to Cambridge with a rabbit in the passenger seat (Doyle 1978). Steptoe's unconventional driving companion served as an ideal incubator for human eggs, which he would remove from women during gynecological surgery and house in the womb of the rabbit for the road trip. Once the eggs successfully arrived in Cambridge, physiologist Robert Edwards would mix human sperm with the eggs in an attempt to create *in-vitro* embryos, or embryos conceived outside of the human body (Doyle 1978). Fertilization had been successfully achieved with hamster and mouse eggs, but consistent, successful *in-vitro* fertilization of human eggs was proving to be a greater challenge, both technically and ethically (Tucker 1969).

Societal hackles were raised early on when in 1961, Italian embryologist Daniele Petrucci claimed to have achieved successful fertilization of a human egg in a "test tube," destroying the embryo after 29 days of development, "because it had become monstrous and was about to outgrow its glass cell" (The Miami News 1961). The Vatican condemned the activity, stating that creating human life outside of its "natural conditions" would have "monstrous consequences" (Guardian 1961). Reflecting on the moral implications of his research, Petrucci said that he did nothing that went against his Catholic faith. He did say that researchers should proceed carefully "from the moral or

practical point of view, we must be very careful [...] Since we don't know when God sends the soul into the body, we must not try anything that would separate them [...]" (CBC 1961). Petrucci did not publish his results in a scientific journal, which caused members of the research community to doubt his statements.

A few years later, Petrucci claimed to have created forty embryos through IVF in a device he called a "biological cradle" (Quebec Chronicle-Telegraph 1964), but again, rather than publishing his results in a scientific journal, made his announcements through the popular press. Lacking support from Italy and most of Western Europe and the United States, Petrucci moved to the Soviet Union, where he and Moscow scientists claimed to have developed artificial wombs to keep embryos alive and growing. They even claimed to have kept a fetus alive for six months outside of the womb before it died (Henig 2004, 32-33). Petrucci's claims stirred up dystopian images of cheapened human life and mechanized baby factories:

Petrucci's account to an Evening Standard reporter of his work at Bologna reads like something out of Aldous Huxley's *Brave New World*. The artificial conception in the "biological cradle" takes place between chamois leather disks to simulate the natural site of implantation. Plasma from other pregnant women is dropped in and the temperature carefully controlled. (Quebec Chronicle – Telegraph 1964).

Unlike Petrucci, Edwards was not interested in keeping embryos alive outside of the womb for an extended period of time. However, he would regularly get quizzical looks from gynecologists when he would ask them to provide him ripe eggs removed as a result of surgery. They would look at him as if he was crazy, and would quickly try to change the subject (Doyle 1978):

Trying to persuade other UK gynaecologists to donate [...] pieces of ovary removed for surgical reasons had usually been a dismal failure. Those consultants had narrowed their eyes, withdrew instinctively when the word embryo was mentioned, then suddenly discovered an urgent

appointment that demanded their immediate departure.
(Edwards 2003, 353)

Edwards expected similar attitudes when in 1965 he traveled to Johns Hopkins Hospital, Baltimore, to search for “slivers of ovaries” from gynecological surgeries, so he could study the maturation of human eggs, and to also attempt to produce human embryos. During this six-week visit, he met Georgeanna and Howard Jones, an endocrinologist and gynecologist, respectively. Edwards began collaborating with the Joneses, and managed to create human eggs with pronuclei in-vitro. Edwards hesitated calling the experiment a true in-vitro fertilization, because while the sperm had successfully entered the egg, it had not yet fully fused (Edwards 2003, 352-353). Following publication of Edwards’s write-up of the experiment in the *Lancet*, a British scientific publication, he read about his own research in the *Sunday Times*: “I noticed the headline on the other side of the front page. BIRTHS MAY BE PROXY. Underneath it my own name featured in a story about ‘experiments reminiscent of Aldous Huxley’s *Brave New World*’” (Edwards and Steptoe 1981, 57).

Steptoe and Edwards began collaborating after they met at the 1968 meeting of the Endocrinological and Gynaecological section of the Royal Society of Medicine. Edwards was impressed with Steptoe’s use of laparoscopy in order to diagnose gynecological conditions. The procedure was minimally invasive, with the slender instrument working to provide clear images of the internal organs in the abdomen. Steptoe showed vivid pictures of a patient’s ovaries at the meeting, prompting Edwards to ask Steptoe about using laparoscopy to remove eggs from the ovaries (Steptoe and Edwards 1981). Steptoe, the “world’s master of the method” (Edwards 2001, 1092), was able to use laparoscopy to successfully remove eggs from the ovaries of some of his infertility patients, providing Edwards with access to far more eggs than he had

previously (de Melo-Martin 1998, 51). Edwards and Steptoe discussed the safety of their methods, as well as the potential ethical ramifications: “We agreed to work together as equals, pursue our work carefully, and stop if any danger emerged to patients or children, but not for vague religious or political reasons” (Edwards 2001, 1092). For Steptoe, the collaboration presented a “unique opportunity” to help people: “He was a scientist, I was a doctor. We both wanted to help people who had seemingly insoluble infertility problems. So why not?” (Steptoe and Edwards 1981).

New Hope for the Childless

In 1969, *The Guardian* announced a “startling discovery” in Cambridge. Patrick Steptoe and his team had been successful in fertilizing a human egg with human sperm outside of the human body. They had produced a fertilized embryo, but destroyed it over the course of experimenting on it. The nightly news piece that originally covered the story reported that the nascent technology could go “even further,” by “continu[ing] to develop the fertilised egg artificially and perhaps even produce a human baby without using the mother’s body again at all” (Guardian 1969). *The Guardian* also quoted a *Nature* commentary, praising the potentialities of the emerging technology:

The day of the test tube baby is not here yet, and the advantages of this work are clear. These are not perverted men in white coats doing nasty experiments on human beings, but reasonable scientists carrying out perfectly justifiable research. One of the possible benefits of this research could be the treatment of some forms of infertility, probably in older women, who are thought to produce a high proportion of abnormal embryos which fail to develop. (Guardian 1969)

In this account, the author is arguing that Steptoe and Edwards are very different from the “perverted” Frankenstein-esque Dr. Petrucci, trying to create monsters in test tubes. Rather, these “reasonable scientists” are working for the betterment of society, helping families suffering from infertility. The *Nature* and *Guardian* commentaries signify a shift

in societal conversations around the nature of research around human reproduction. Steptoe and Edwards are framed as helpers of the infertile, working to solve a national health issue, rather than renegade scientists seeking to push the boundaries of nature. Despite the shift indicated in these commentaries, the tensions between, on one hand, the solving of health/infertility issues, and on the other hand, scientists “playing god,” would continue to permeate and shape social debates.

Out of Control Monsters

The February 15th, 1969 issue of the *Guardian* featured a cartoon of a scientist clad in a white laboratory coat placing sperm into a test tube containing an egg (Tucker 1969). As the cartoon progressed, the scientist looked at the test tube in happy anticipation, and a baby emerged from it. The next frame showed the scientist standing next to the baby, patting him on the head. The baby then began to grow quickly...very quickly. Before the scientist knows it, the baby is taller than him, and begins to turn into a grotesque monster. The baby-monster is soon much larger than the scientist, and is now patting the *scientist* on the head. The last two frames illustrate the out-of-control monster stuffing the scientist into a test tube. The final visual that readers are left with is the scientist, squished inside a test tube, shouting “Son! Let me out son. Listen to me son. Son!!!”

Figure 3:



The accompanying article to the comic, authored by *Guardian* Science Correspondent Anthony Tucker, advised readers to not jump to conclusions, however. That while it might be a distant possibility that an embryo could be developed to full term within a laboratory, as the Italian scientist Petrucci claimed to have achieved, “tinged with horror and hedged round with all manner of moral, ethical and legal problems,” that the “potential human value of being able to manipulate fertilisation outside of the body” should not be disregarded. Hereditary diseases and genetic conditions could be avoided using the technique. Lady Summerskill, an “ardent campaigner for women’s rights,” stated that these new developments could eventually make it so that “no woman need ever be without a baby if she wants one.” However, in the same statement, she also advocated for control over access to the technologies, expressing her concern with the “need to improve human stock” – in an overpopulated world where people with “mental defectives” and people “irrespective of genetical health” can “produce anything they like.”

Tucker wrote that while dystopian human selective breeding programs were likely not right around the corner, the responsibility would rest on society to ensure such a future does not come into existence:

What society makes of advances in biological or other knowledge is not under the control of scientists but of society itself. [...] What is possible and what is permissible are very different things, but society now has to face up squarely to new and potentially disturbing possibilities and decide unequivocally what is permissible. (Tucker 1969)

Sylvia Allen: A “Step Nearer to Test Tube Baby”

In 1970, after experimenting with fertilizing donated human eggs with donated human sperm outside of the body (always having destroyed the fertilized eggs following the experiments), Edwards and Steptoe took a new step in their research, illustrating to

the professional gynecological community that their experiments have “practical application” to issues of infertility. The February 4th, 1970 issue of *The Guardian* reported that Robert Edwards had successfully fertilized a woman’s egg with her husband’s sperm in-vitro. Thirty-four-year-old Sylvia Allen, from Lancashire, had blocked fallopian tubes and was unable to become pregnant. She hoped to produce “the world’s first test-tube baby,” and was willing to take on the risks presented by the implantation operation (Guardian 1970). Allen volunteered to take part in the experiment after watching a TV program featuring Patrick Steptoe and his research. Allen had already undergone four separate operations to remove eggs from her ovaries. While two eggs had been fertilized with her husband’s sperm, neither was suitable for implantation.

After the announcement, leadership in the Church of England and the Roman Catholic Church were vocal about their concerns regarding the moral and ethical consequences of the new technologies (Guardian 1970). The Church of England stated that

The use of this particular development in scientific technique will need to be assessed carefully on moral, social, and legal grounds. Because it may prove technically possible does not mean that it should be done. (Guardian 1970).

Catholic Cardinal Gordon Joseph Gray issued a warning, advocating for vigilance in the face of new scientific developments:

I certainly feel that these developments need very careful examination. I think we have to look beyond this particular case. [...] As anyone will realize, the possible effects of developments in longterm ‘biological engineering’ are frightening. I am all for genuine scientific research, but society, for its own good, must be constantly vigilant on where the developments are taking us. (Guardian 1970)

A representative of the Methodist Church, Reverend Leslie Marsh, expressed concern over the decisionmaking of the individual scientists involved in the experiment:

The doctor who is to produce the first test-tube baby says it is not for him but for society to say whether he is right or wrong. How can we have confidence in such a doctor? The moral responsibility is on the doctor's shoulders. He cannot put the blame on society. [...] The doctor may be able to link the chemistry of the body, but the secret of the relationship between chemistry, consciousness, and personality has not yet been opened to scientists. Until more is known of the things that really matter, is the doctor justified in experimenting with human lives? (Guardian 1970)

Members of the medical community also expressed their concern. Dr. Douglas Bevis from Sheffield University's department of obstetrics and gynecology was worried about the psychological and emotional implications of the procedure on hopeful patients: "I am terrified about the number of patients who are going to come up and are just going to be disappointed." Other doctors advocated that Steptoe's experimentation should be halted in its tracks until guidelines could be issued by the Royal College of Obstetricians and Gynaecologists. The British Medical Association also acknowledged that the technology presents new ethical concerns, and that the "public would need reassurance on a number of points" (Guardian 1970).

While Sylvia Allen had expressed her hope that the successfully fertilized eggs would be implanted in her within a few weeks, the implantation was never performed (Wilson 1996, 125).

Around this time, Edwards became increasingly frustrated with media portrayals of his work, declining to participate in a BBC documentary on the "increasing control over early life," including cloning. Edwards declined the interview, and when the program aired, was glad that he did not participate:

Terrible Brave-New-World visions such as those we had just viewed irritated me. They still do. They are based on the pessimistic assumption that the worst will happen. The whole edifice of their argument is fragile – that nuclear physics led inevitably to the atom bomb, electricity to the

electric chair, civil engineering to the gas-chambers. Surely acceptance of the beginning does not necessitate embracing undesirable ends? (Edwards and Steptoe 1981, 100-101)

Steptoe and Edwards "Ride [out the] storm in a test tube"

In October 1971, Edwards participated in a public debate with leading scientists and theologians (Auerbach 1971). In the debate, titled "Fabricated Babies: the Ethics of the New Technology in Beginning Life," Edwards was urged to halt his work. James Watson, biologist who co-discovered the molecular double-helix structure of DNA, warned Edwards that his research could have immensely undesirable consequences, and that careful thought would be necessary before moving forward: "You can only go ahead if you accept the necessity of infanticide. [...] There are going to be a lot of mistakes, what are we going to do with the mistakes? We have to think about some things we refuse to think about." Paul Ramsey, a Princeton theologian and specialist in medical ethics, and Leon Kass, with the National Academy of Sciences, joined Watson in his criticism of Edwards. They called for Edwards to consider the welfare of the potential resulting child, that there was no way of knowing how such experimentation would affect the development of the child, that it could do "irreparable damage" to the baby, and that the "slightest lapse or mistake would be disastrous to a future possible human being" (Auerbach 1971).

Edwards said that the attacks on the research were influenced by dogma, and were "ultra-conservative" and "unacceptable," that the benefits of the work (in the form of hope for infertile couples) were being ignored. Edwards was not alone in his defense of his work. Dr. Howard Jones, Edwards's American collaborator from John Hopkins University, compared the attacks made on Edwards to the "tribulations of Galileo." Jones stated that it was "unthinkable that there should be any area of scientific investigation set off limits." When it was suggested to Edwards that he and Steptoe stop

their work until an international body reviewed it, Edwards stated, “We will do our transplants and go on with our work as we decide, not as anyone else decides” (Auerbach 1971).

Despite his outwardly maverick attitude about doing research on his own terms, Edwards exercised caution with moving forward with implanting an embryo into a volunteer. In 1973, Steptoe and Edwards were “reasonably sure” that the “incidence of abnormality in any developing foetus would be no higher than is normal throughout the population.” However, of the dozen embryos that Steptoe and Edwards attempted to implant, none were successful. Other researchers were also moving from the laboratory into the clinic, and were attempting to achieve a successful pregnancy using the “external” fertilization technique. All of the attempts resulted in failure (Doyle 1974).

The First “Test Tube Babies”?

In January 1972, Dr. Douglas Bevis, a leading researcher at Jessop Hospital in Sheffield announced that he was ready to move ahead with implanting an embryo in a human womb. He stated that it had to be the right patient, however. “When I find her I am in a position to go ahead. It could be as soon as next week or much longer” (Guardian 1972). Bevis, apparently found the right patients in 1974, when he claimed to have successfully implanted embryos in women who gave birth nine months later (Parkin 1974). The gaunt and unassuming gynecologist made this announcement at the annual meeting of the British Medical Association, and said that he had learned of the three births in casual conversation with colleagues (Bakalar 2011). Without fanfare, Bevis passed out a press release of this news prior to presenting a paper on embryo research. Following the announcement, Bevis was hounded by the media for the names of the mothers and their babies. It was reported that he was offered £30,000 for the rights to the story. Bevis refused to divulge the names of his patients. He cloistered

himself in St. James's Hospital, and would not take calls or talk to reporters. A hospital spokesperson announced that Bevis needed time, as he "want[ed] to think of the implications of what he has said" (Hildrew 1974).

The introverted Bevis was "bewildered" and frustrated with the constant barrage of media attention, and announced on July 18th, 1974 that he was giving up research on in-vitro fertilization. On the same day that Bevis announced that he refused to do further research in the field, the *New Law Journal* published a feature that called for the Government to investigate the issue: "The rights of the child thus born, and the rights and duties of the parents and of society raise fundamental matters of morality and of practical law" (Parkin 1974).

Doubts regarding the validity of Bevis's claim began to quickly emerge. Bevis was criticized for his secrecy and for not providing verifiable evidence of a successful birth. Patrick Steptoe announced his harsh criticism of Bevis, for "making claims unsupported by scientific evidence." Steptoe stated that he was "astounded that Professor Bevis would have made this statement. [...] As far as I know, no one in this country or anywhere else has yet succeeded in this technique." Not documenting his successes, Steptoe argued, was "a very unethical way to behave" (Hildrew 1974). Others believed Bevis, that he would usher in a new era of "brave new bab[ies]" despite his lack of evidentiary support (Rorvik 1974). Whether Bevis was telling the truth, or not, the shocking announcement of "test tube" births opened the floodgates of debate. Questions of what might become of the "first man" to allegedly "transplant an entire human life" plastered newspaper headlines for a brief period (Rorvik 1974). However, Bevis faded back into obscurity, passing away in 1994, never having revealed the names of his patients (Dewhurst 1994).

A Cross Between a Virgin Birth and a Frankenstein? Anticipatory Activity Four Years Prior to the Birth of Louise Brown

In 1971, the British Association for the Advancement of Science formed an interdisciplinary study group to examine emerging issues associated with new reproductive technologies, such as laboratory fertilization, sperm banks, and artificial insemination. The British Association viewed itself as playing the “special role” of an “intermediary body” by providing linkages between scientists and society, “educating the public on the one hand and ensuring consideration for the state of science and its social implications by leaders in all walks of life on the other” (British Association 1974, 3). The aims of the study group, which was known as the Committee on Social Concern and Biological Advances, were as follows:

- 1) to educate the public by presenting the state of scientific knowledge and research;
- 2) to foster contacts between scientists and Members of Parliament, government officials, the press, theologians, community leaders, and others;
- 3) to explain to Members of Parliament and others developments in science where these advances have important social, ethical, and legal ramifications;
- 4) to produce at intervals reports on scientific issues of social significance;
- 5) to anticipate needs for information about developments in science before publicity, which, if sensationalized, could distort issues and give rise to unnecessarily emotional public response.
- 6) to organize meetings and symposia. (British Association 1974, 3)

The report of the study group, entitled “Social Concern and Biological Advances,” stated that social issues were increasingly being seen as involving issues of science. Additionally, the report noted, “scientific advances themselves often cause difficulties for society.” (British Association 1974, 3) The study group, comprised of scientists, including Robert Edwards, church representatives, politicians, journalists, and legal

professionals, called for urgent overhauls of existing law and “entirely new measures for control” (Tucker 1974).

The report stated that while in-vitro fertilization, once “perfected,” would have many implications similar to that of anonymous sperm donation, it would also have additional unique issues, in part because a woman would be able to give birth to a child that she had no genetic relation to. The safety of a child conceived through the process should be paramount, contended the report. It noted that animal research indicated that chances of abnormality from in-vitro fertilization would be no higher than that of natural conception. Despite this, it “in no way detracts from the ethical question of whether or not it is justifiable to use a procedure with human beings which, in view of the lack of full knowledge, is in some degree experimental.” (British Association 1974, 8).

Another ethical problem raised was that of the destruction and disposal of human embryos used in the in-vitro fertilization process, especially at the current stage in the technology, because in-vitro embryos had yet to be successfully implanted in a human womb, thus all embryos used in the process were ultimately discarded/destroyed. Among the issues raised in this vein was the continuing one of “when human life could be said to begin.” (British Association 1974, 8)

At present 24 weeks is the maximum gestation period during which an abortion can legitimately be induced. How does this precedent relate to the controversy concerning research on *in vitro* fertilization? How is medical knowledge to be obtained and in what circumstances is it justifiable to attempt to obtain it. Research on *in vitro* fertilization has contributed to a better understanding of human embryology, and it could lead to improved methods of contraception. But if it can be argued that the life of a man or woman begins *in vitro* (i.e. in laboratory glassware), then difficult problems are posed. (British Association 1974, 8)

The Committee argued that IVF would likely not contribute to overpopulation issues, as “its use will always be limited.” Additionally, the low numbers of babies up for

adoption in the UK provided a “good reason for instituting other ways of providing children for some infertile couples.” If IVF were to be limited to “husband and wife couples,” many of the issues associated with anonymous sperm donation could be avoided. The Committee cautioned against abuse of IVF technology by women who would want to hire “hosts” to carry their child for them. However, a “host” carrier could be a “legitimate recourse” for a woman who has an “absent or damaged” womb.

While caution was urged by the study group, researchers, such as Anne McLaren, an Edinburgh scientist, argued that an IVF birth would have greater chances for “normality” than a regular birth: “There will be a public tendency to regard the unfortunate child born in this way as a cross between the virgin birth and Frankenstein[... however] the chances would actually be lower with an egg transfer than with a normal conception because the baby is going to be monitored the whole time” (Guardian 1974).

The media quickly picked up the report, with Anthony Tucker writing that such changes were necessary and “urgently needed” British society was to “cope successfully with the problems posed by sperm banks, artificial insemination, and laboratory fertilisation of human eggs.” The recommendations put forth by the report to proactively grapple with the emerging issues, included special “specifically targeted meetings” between stakeholders (community leaders, politicians, and scientists) to address emerging issues, “public dangers,” and a course of action. Other recommendations included: legally defining the status of children born through donor conception, regulating sperm banks, and creating a framework that outlines procedures for the procuring of sperm.

While the report recommended that research on laboratory fertilization techniques should move forward, the government and scientists “must be prepared to

set quickly to 'prevent abuse,' and that there must be a continuing review of advances in research on genetic engineering so as to foresee 'implications and social consequences'" (Tucker 1974).

1975– The First IVF Pregnancy

Dozens of attempted embryo implantations failed between 1973 and 1975. While on vacation in the summer of 1975, Edwards received a frantic telegram from Steptoe: "Pregnancy test positive. Ring me urgently. Patrick" (Le Fanu 2002, 143-144). Steptoe and Edwards attempted to reimplant an embryo into a patient experiencing infertility from impaired tubal function. Following implantation of the embryo into the patient's uterus, the pregnancy appeared to progress normally fourteen days in. Seven weeks into the pregnancy, an ultrasound showed "an enlarged uterus, approximately nine weeks in size, with identifiable fetal parts." However, the next week, the patient began to experience mild pelvic pain. At the ten-week point, the patient's pelvic pain increased. The ultrasound showed lack of fetal movement and lack of a fetal head. The patient's pregnancy tests turned negative. Laparoscopy showed that the pregnancy was ectopic, meaning that rather than the embryo implanting in the uterus, it implanted in the fallopian tube. Following thirteen weeks of gestation, the embryo was removed. While the embryo could not be carried to term, Edwards and Steptoe's work served as the "first documented evidence that human embryos cultured for four and a quarter days are capable of implantation" (Steptoe and Edwards 1976, 880 – 882).

Despite the breakthrough in achieving an actual implantation, Edwards reflected that this period was a difficult time for his patients, both mentally and physically. The patients "who realized how close [Steptoe and Edwards] were to helping them" had to endure "a long slow haul" including the long hospital weights, the intensive hormone

treatments, the laparoscopic removal of their ripened eggs, and more hormone treatments in preparation for the implantation.

And after all that, and after the tests to see if they were pregnant, the going home to a house generally without children's voices in it, going back from where they had set out and returned in disappointment and with the taste of nothing on the tongue. [...] New and drastic departures from our routine were obviously needed. (Edwards and Steptoe 1981, 133)

Sea-Change: Imaginative Capacities

Anticipatory governance is more than a formalized process - something that resides only within specialized institutions such as the Human Fertilisation and Embryology Authority. Rather, it is also embedded within a diverse array of social institutions, including fairly traditional and also less conventional institutions that are struggling to make sense of ongoing socio-technical reconfigurations. Such institutions include the courts (explored in Chapter 4), the media, and the stories and narratives embedded within a particular political culture.

The episodes represented in this chapter are relevant to an understanding of anticipatory governance because they represent evolving capacities for thinking about and engaging in the governance of emerging technologies. They illustrate the capacity of society to participate in anticipatory negotiations of socio-technical contracts – far before the technologies themselves come into existence. In each era, socio-technical reconfiguration is ongoing, and accompanying each reconfiguration existed debates about how that reconfiguration should happen. In this chapter, the capacities for negotiating socio-technical reconfigurations are reflected in the ongoing stories, metaphors, and motifs that shape and engage societal perceptions and debates around new and emerging technologies, specifically, in this case, the biological sciences and reproductive technologies.

Socio-technical imaginaries emerge at moments of co-production. The episodes explored within this chapter each represent moments of co-production, moments in which technological orders and narrative arcs coalesce around evolving sociotechnical configurations. The imaginaries deployed by stories such as *Frankenstein* and *Brave New World* can illustrate what are both attainable and desirable futures for a society, but they can also provide visions of what is not desirable, and the possibly dangerous wrong turns that socio-technical trajectories can take. While socio-technical imaginaries typically do not emanate from one individual (instead usually emerging from governments and other bodies and institutions), in the episodes presented in this chapter, socio-technical imaginaries emerged from a confluence of activity: technological development, imaginative dystopian narratives, and lively public dialogues around the issues, together, setting the framework for a robust deliberative capacity for creatively grappling with present and future socio-technical configurations.

The capacities explored in this chapter generate a sense of the issues that existed within each specific time frame, and the ways in which citizens were reflecting upon them. Debates about socio-technical configurations and reconfigurations are not embedded within just one locus of activity, rather the historical capacities represented here support the idea that debates are distributed across society in an ongoing manner. Imaginative capacities open up conversations, and are also simultaneously capacities about judgment – how society judges at what point it becomes necessary to rethink socio-technical contracts.

The rabbit in the passenger seat represents more than just the mildly amusing, unexpected, and ultimately jarring image of Patrick Steptoe driving on narrow, winding roads through England's rainy countryside, with a rabbit packed full of human eggs seated next to him. It represents what would soon become a fundamental shift in

technological capacities for human reproduction. The rabbit in the passenger seat is indicative of a sea-change in the conversations around reproductive technologies. In-vitro fertilization of human embryos would no longer be the stuff of speculation, science fiction, and heated debates. It was on the cusp of realization, and Louise Brown, the first IVF baby, in her own process of becoming, would herald in changing socio-technical configurations.

CHAPTER 3

“STOPPING ‘BRAVE NEW WORLD’”: THE BIRTH OF LOUISE BROWN, THE ESTABLISHMENT OF THE HFEA, AND THE ROLE OF BRITISH EXPERTS IN NEGOTIATING THE SOCIO-TECHNICAL CONTRACT

“Society’s views on the new techniques were divided between pride in the technological achievement, pleasure at the new-found means to relieve, at least for some, the unhappiness of infertility, and unease at the apparently uncontrolled advance of science, bringing with it new possibilities for manipulating the early stages of human development.” (Warnock 1984, 4)

Capacities for Judgment: Reigning in Runaway Social Forces

The United Kingdom’s Human Fertilisation and Embryology Authority (HFEA) is viewed as an exemplar of anticipatory governance, of how countries might proactively govern assisted reproductive technologies, and other new and emerging technologies. Established in 1990 with the passage of the Human Fertilisation and Embryology Act, the authority is delegated with writing and managing national policy regarding the use of human gametes (eggs and sperm) for scientific research and clinical practice. The 1990 Human Fertilisation and Embryology (HFE) Act was both novel and revolutionary in that it established the first national agency for regulating assisted reproductive technologies. Much of the HFE Act, and resulting establishment of a licensing authority, was based on recommendations from a government appointed Royal Commission, known as the “Warnock Committee,” named after its chair, Oxford philosopher and Baroness Mary Warnock.

This chapter examines the period spanning from the birth of Louise Brown, the first “test tube baby,” to the establishment of the HFEA and the ways in which the British negotiated the emerging socio-technical contract around assisted reproductive technologies. Specifically, this chapter explores *capacities for judgment*. How would the

socio-technical contract be negotiated? Who would negotiate this transition? In what groups or people is this capacity located? Following the birth of Louise Brown, what mechanisms were present that enabled British society to make judgments about *how* new reproductive technologies should be governed? While the chapter seeks to provide a historical overview of the period from Louise Brown's birth to the establishment of the HFEA, it focuses specifically on two areas of inquiry. The first focuses on the public atmosphere following Louise Brown's 1978 birth, and the overarching public sentiment that the birth represented the potential for reproductive science, if unregulated, to careen out of control, that the new modes of creating life would lead to a breakdown in social order. This section sets the stage for an examination of how the British negotiated the runaway forces, a threat to public order, into a controlled governance framework, and the role of the expertise-laden Warnock Committee in "Stopping [a] 'Brave New World'."

The second focuses on the establishment and structure of the Warnock Committee, of the capacity for integrating lay concerns into expert processes, and the special role of experts within British society in facilitating the negotiation of socio-technical contracts. This chapter raises a number of questions in relation to the role of experts, specifically, the ways in which British experts were pulled in to reign in and provide order to what was perceived as science out of control. Jasanoff (2005) provides an insightful and informative analysis of the role of British experts in the demarcation of the "pre-embryo" from the fourteen-day-old embryo proper, with a specific focus on the period of Parliamentary debate following the publication of the Warnock report. While this chapter includes the timeframe that Jasanoff delves into, and the timeframe leading up to the establishment of the HFEA within it, the main focus is examining the period prior to it - the "out of control" atmosphere following Louise Brown's birth, and the role of Warnock and her committee in facilitating "dissent without disaster" (Shapin 1994) and

serving as negotiators of the new socio-technical configuration around reproductive technologies in Britain.

Experts are “indispensable to the politics of knowledge societies” (Jasanoff 2005). They quell the knowledge insecurity that is common to contemporary society. Individuals are bombarded on all sides with new information, issues, and questions – their understandings are incomplete (as no one can know everything) and their environments can impact their knowledge perceptions. Jasanoff asks “how can governments ever know enough to act wisely or publics be persuaded that their governments are behaving responsibly?” She poetically states that “the unknown threatens continually to engulf the known,” and individuals and policymakers are unable to act unless “ground rules” are set down for what types of evidence lends to authoritative knowledge. The responsibility ultimately rests on the shoulders of experts who must “satisfy society’s twinned needs for knowledge and reassurance under conditions of uncertainty” (Jasanoff 2005). Given this focus, the chapter delves into a number of questions: What was the role in the experts that constituted the Warnock Committee in negotiating the socio-technical contract around assisted reproductive technologies? What is the meaning of “expertise” in light of the British historical context? Who counts as an expert and why? What are the tensions and pressures put on the notion of expertise in such a context? In the context of governing assisted reproductive technologies in the UK, how does one *become an expert* and have either a formal or informal role in governance activities? For historical purposes and to provide further context for the following chapters, this chapter also chronicles the period following the publication of the Warnock Report, including initial public response to the report and the debates leading up to the 1990 Human Fertilisation and Embryology Act and the establishment of the HFEA.

England, 1978

For the British, the 1970s were a time of change and unrest, where declining relations between the government and unions led to strikes, resulting in the most basic services, such as electricity and hospital care, coming to a grinding halt. New industrial technologies developed in the 1960s made some jobs obsolete, and others required new training for workers with outdated skills(The National Archives). For many, the decade is remembered as “the decade of strikes, electricity shortages, and piles of rotting rubbish on the street” (BBC News 2007b). Rolling blackouts and industrial strikes made the activities of everyday life a challenge. University students had to write essays by candlelight. Children wore bright yellow bands on their coat sleeves so they could be seen in the darkness. In the cold of winter, students in science class huddled around Bunsen burners for warmth. Families were forced to get by on miniscule amounts of water. Even the hallowed hallmarks of British pride and identity fell victim to the strikes, with Trafalgar Square transformed into a “mountain of black garbage bags twitching with rats” (BBC News 2007b). Others recall that the tumultuous decade gave rise to a new generation of politically active young people with a decidedly “anti-authoritarian” streak. Youth would gather in large cities and small towns, debating British politics and the plight of third world countries, galvanized by the protest music of Bob Dylan and other artists (BBC News 2007a). Fervor surrounding the election of Prime Minister Margaret Thatcher with her promises of reigning in out-of-control union activity were promising to many, giving British citizens hope that tumult of the decade were coming to an end.

This Britain, a Britain full of hope yet trepidation in the face of an uncertain future, was the Britain that Louise Brown was born into. Louise Brown, famously known as the first “test tube baby,” was the proof-of-concept for John Edwards and Patrick Steptoe’s in-vitro fertilization (known colloquially at the time as an “embryo transfer” or “test tube

baby”) technique. The baby, conceived in a petri dish and subsequently transplanted into Lesley Brown’s womb as an embryo, elicited in the British public equal parts hope and horror. In one sense, Louise Brown served as a human manifestation of the out-of-control atmosphere present in 1978 Britain, in another sense, she also represented the potential for the British to negotiate chaos into order, to bring structure and regulation to what otherwise might be an unruly social kind, the “test tube” baby.

The “First Test Tube Baby”: “All Hell Will Break Loose”?

After trying to become pregnant for nine years, Lesley and John Brown arrived in Patrick Steptoe’s office in 1976. Steptoe and Edwards felt that the Browns were an ideal couple for treatment. They had tried a multitude of other treatments ranging from hormones to surgery. Despite these many failed attempts, the Browns remained positive and determined. The IVF team warned the Browns that the embryo implantation treatment could fail, but the Browns were willing to take the plunge (Maienschein 2003). In April 1978, the *Guardian* dubbed the Steptoe and Edwards duo “test tube men” and reported that they were remaining tight-lipped regarding Lesley Brown’s pregnancy, and would not confirm with the media whether the first test tube birth would soon be a reality. Edwards stated that the team would play by its own rules if and when it announced a successful IVF birth, and said “When the time comes, if the time comes, we will make our own statement in our own way. Until then, everything is speculation” (Anonymous1978, 3).

Two months following Edwards’s statement, Dr. Ronald Barnes, a researcher who had been performing embryonic research on mice and rabbits at the Middlesex Clinical Research Centre, called for a moratorium on “test tube” baby research, until it could be proven that the technique was safe. Barnes published his warning in the medical journal *Pulse*, stating that he had abandoned his research on mouse and rabbit

embryos because of “adverse results” (i.e. “malformed embryos”) in the course of in-vitro fertilization experiments. Barnes was also head of the sub-division of Embryology and Foetal Development at the Clinical Research Centre, which was part of the Medical Research Council, an entity funded by the British government. Four years previously, the Council had been asked to fund research on in vitro fertilization, but had refused given that animal studies had resulted in abnormal embryos. Barnes expressed concern regarding the unknown risks to the mother and baby, such as the effects of hormone-induced superovulation (which stimulates a woman to produce more eggs than she naturally would). Animal research had demonstrated that higher than usual amounts of hormones resulted in a “direct relation” to abnormal embryonic development. Other concerns centered on potential increases in chromosomal abnormalities in in-vitro human embryos, as experiments on in-vitro mouse embryos produced much higher rates of chromosomal abnormality when compared to those conceived naturally. Until IVF was confirmed to be safe in animal studies, maintained Barnes, it should not be attempted in humans “until the risk is eliminated.” Steptoe and Edwards had no comment on Barnes’s remarks (Deeley 1978, 3).

Media inquiries and speculation regarding the first test tube baby came to a roiling boil in the late weeks of June and early July. On July 12th, the *Guardian* named the unborn baby the “£325,000 test tube child,” due to the newspaper bids for the exclusive story with the family. After a “gigantic international auction,” the *Daily Mail* won the rights to the story. The Browns had entered into the contract on Steptoe’s advice. Steptoe stated that there was a “double purpose” to the deal – it would “take the pressure off the parents; and secondly to secure a financial future for their child.” The massive price tag attached to the exclusive rights for the story of the first test tube baby, and the role of hospital officials in facilitating the deal raised concerns regarding the

appropriateness of such a deal in the face of such a groundbreaking event. One hospital administrator commented that the flurry of media activity around the birth was causing interference with normal hospital operations: "it is having great difficulty in maintaining normal services in that part of the hospital because of the enormous numbers of press, radio, and television reporters who are seeking admission" (A Staff Reporter 1978, 22).

While the media jostled for the best vantage point of the impending birth, others expressed concern over the possible future implications of the new embryo transfer technology. Christine Doyle postulated that the new technology could lend itself to an assisted insemination by donor "in reverse." Legal and ethical problems could arise if a woman who had healthy eggs, but was unable to carry a baby, solicited another woman to carry the baby for her. Doyle called this a "modern form of 'wetnursing.'" Doyle also noted that there was a "warning in the background." That while use of and desire for cloning and genetic engineering on humans was "'light years' away" from becoming a reality, that the creation of an embryo outside of the human body was the first step to such a possibility, which "cannot be ignored" (Doyle 1978, 2).

As the birth of the baby crept closer, Members of Parliament expressed their unease over potential risks related to the Steptoe and Edwards embryo transfer technique. Labor MP Leo Abse called the technique "exciting but perilous" (Dunn 1978, 2). He requested that Shirley Williams, the Secretary for Education and Science consult the advisory committee on "genetic manipulation research into the fertilizing of a human egg by a sperm in a laboratory." Abse wanted the committee to explore what sorts of control would be necessary in the emerging field and requested that the committee be expanded in order to the "ethical and social aspects" of the research. Abse stated:

It is the hope of all of us that a safe delivery will be given to the eager parents of the first test tube baby, but the very

success of the transplant will bring nearer the fulfilment of the prophecy of some biologists a few years ago that a woman would soon be able to buy a tiny frozen embryo, take it to a doctor, have it implanted into her uterus, carry it for nine months and then give birth to it as though it had been conceived in her body.

We are now moving to a time when an embryo could be sold in effect with a guarantee that the resulting baby would be free of genetic defect and the purchaser could select in advance the colour of the baby's eyes and hair, its sex, its probable size of maturity, and its probable IQ.(Dunn 1978, 2)

While some doctors, such as Dr. Barnes, voiced concerns regarding the speed at which IVF technology was developing, others could not understand why the birth was being made into a media spectacle. The impending birth was "regarded with equanimity" by the British Medical Association. The secretary of its central ethical committee, Dr. John Dawson, stated "This is a non-starter as far as medical ethics are concerned." Dawson further commented that "All you are talking about is medical intervention; the doctor is not involving anyone outside the family unit. Medical ethics are concerned with trying to do what is best for your immediate patient. What Mr. Steptoe is doing is within our guidelines" (Anonymous1978a, 1).

On July 25th, shortly after midnight, the Brown's baby was delivered via a planned caesarian section procedure. The birth was about a week premature, as it was discovered that Mrs. Brown had toxemia, a condition that is characterized by blood poisoning. While the doctors knew the sex of the baby prior to its birth, the Browns opted to keep it a surprise. It was reported that Mrs. Brown, known as the "Test Tube Mother," had a girl (Beresford 1978, 1).

Pictures of the baby girl, named Louise Joy Brown, were immediately plastered across newspapers around the world. Patrick Steptoe stated that the baby was born "crying its head off and in a very good state, a beautifully normal baby"(Anonymous1978,

22). The media marveled at her apparent normalcy, with articles announcing in their headlines observations such as “Test-tube baby can cry”(Anonymous1978b, 1). Steptoe and Edwards described the birth in a letter to the *Lancet*, entitled “Birth after the reimplantation of a human embryo”(Steptoe and Edwards 1978, 366-366). In their letter, Steptoe and Edwards announced the successful birth, stating: “We wish to report that one of our patients, a 30-year-old nulliparous (never having previously borne a child) married woman, was safely delivered by Caesarean section on July 25, 1978, of a normal healthy infant girl.”

Steptoe and Edwards emphasized that they were only trying to help along a natural process and that they were not interested in “doing anything other than helping infertile couples.” However, despite Edwards and Steptoe’s claims that their work was ethically neutral, in the hours following the baby’s birth, mixed viewpoints emerged on the new technique from religious communities. Pope Pius XII of the Roman Catholic Church emphasized that the artificial creation of human life – “artificial fertilisation of any kind” went against church teachings and “violated the law of nature and was contrary to the right of marriage and morality.” Others in the Catholic community came out in defense of the new treatment, such as Bishop Augustine Harris, who stated that the technology can help married couples with a “deep desire for children” to conceive. Harris argued that in these types of situations, science is “support[ing] the loving and natural ambitions of the couple to produce a new life.” Scottish Cardinal Gordon Gray, the Archbishop of St. Andrews, stated that he had “grave misgivings” over Louise Brown’s Birth. Giles Eccleston, of the Church of England’s Board for Social Responsibility, welcomed the technological advances, arguing that it was a step through “which man had taken responsibility for shaping the conditions of his life”(Morris 1978, 22)

The sentiment of Dr. Dawson of the BMA, that the first IVF birth was a “non starter,” was starkly juxtaposed against the voices of others in the scientific community. In an article written two days after Louise Brown’s birth, entitled “Brave New World of Test Tube Babies,” Anthony Tucker reported that “Baby Brown” made “reverberations throughout the Western world.” The article reflected on James Watson’s prediction that “All hell will break loose” upon the birth of the first artificially conceived baby (specifically the ethical and moral dilemmas that would accompany the baby). However, the article incredulously reported, there was little outrage to be found. Rather, it stated, gynecologists from around the world saw the test tube birth as “a great boon to the tiny percentage of infertile women to whom it may be of value, and you can almost hear the cash registers ringing with joy” (Tucker 1978, 11).

While some lamented the commercialization of Louise Brown’s birth, others expressed concern over the frenzied attempts of the media to get a sighting of “young Miss In Vitro” and her family: “May she later escape the morbid attentions of the daily Press and the film crews who clamour even now to get in on her arrival in a world she did not ask to join, and will doubtless regret she ever did.” The article, entitled “Birth Frights,” stated that by comparison, the birth of Jesus Christ in Bethlehem was less frenzied:

This has been a pretty nasty story. Childbirth is humanity’s most wonderful phenomenon; it is sad to see it demeaned into the Steptoe Sideshow. Poor Baby Brown. There was less vulgarity about a birth in Bethlehem 1978 years ago. But then the spectators were Wise Men, not reporters. (Anonymous 1978, 10)

Calls for Control

Alongside the excitement over Louise Brown’s birth, also emerged new perturbations in existing social and legal frameworks around reproduction and the family. In some aspects, the nascent technology presented new complexities that were

presently unaddressed by the law. Tucker's "Brave New World" emphasized that the "unsavory" implications of the technology was being masked by the joy of Louise Brown's birth (Tucker 1978, 11). The article expressed concerns regarding a lack of control of the emerging technology. The knowledge in the wrong hands, he warned, could be disastrous. Once Steptoe and Edwards published their technique, Tucker contended, there was currently no way of reigning in the potentially unsavory uses of the technology, both in Britain and on a global scale. Tucker painted a dystopian portrait of what the world could potentially look like once Steptoe and Edwards published their work, and unleashed it into an unprepared society that lacked the necessary regulation and governance.

But what happens after the full publication of their [Steptoe and Edwards's] techniques, when a full spectrum of the medical and biochemical professions can practise on mice and then have a go? How can you control that, worldwide?

Tucker reasoned that one of the most frightening possibilities of Edwards' and Steptoe's work was the potential emergence of an underground market of women hiring themselves out as surrogates – surrogate mothers who would carry an IVF embryo created with a couple's egg and sperm to full term. The egg would come from another woman rather than the surrogate herself.

[After] all, if you can pop an undamaged blastocyst – fertilised and nurtured through its first cell divisions in the laboratory – back into its mum's womb and bring it happily to full term, you can probably bring it to full term in somebody else's womb.

Tucker predicted that the "surrogate mums" for hire could make a "decent living for a decade or so." The surrogate mother enterprise would not come without a plethora of social and legal issues. Such a practice, noted Tucker, would "worry our administrators" (Tucker 1978, 11).

Tucker also raised concerns regarding the lack of regulation of embryos created for scientific purposes. With the new technical knowledge from Steptoe and Edwards' successful work, the prospect of creating human embryos en masse for a variety of scientific research projects seemed like a distinct possibility:

Chick embryos are a crucial component of many research and pharmaceutical operations, but there are a vast range of research areas in which human embryos would be preferable. Many disease organisms, for example, will not grow satisfactorily in culture – but they will grow in an embryo. And if you want to test a substance for its effect on the growing foetus, why not do it in batches in the laboratory?

Surely, given the technique which blessed us with Baby Brown, we can put this enormous wastage [of unused sperm and eggs] to important use? In the clinical and anonymous isolation of the laboratory any sense of personal attachment is lost: and since no "life" is created (the life resides in the oocyte and spermatozoa) and no additional humans result (experimental animals are disposed of at the end of an experiment) there appear to be great advantages.

Frightening scenarios of distant futures of human cloning were not needed for citizens to "begin to get worried" stated Tucker. The scientific breakthroughs presented new implications that should not be pushed aside in the excitement of Louise Brown's birth:

Today's cheers and congratulations, however warm and appropriate, have little to do with implications. As Dr James Watson said, all hell will break loose, politically and morally, in a world already grossly overcrowded, it is not easy to understand the joy. Perhaps that is because knowledge and wisdom are far from synonymous. (Tucker 1978, 11)

Tucker was not the only writer to express concerns regarding the ethical and legal implications of the emerging technology born alongside Louise Brown. Jill Tweedie wrote that while IVF was presently not a panacea to resolve all issues of infertility, the

implications of Louise Brown's birth should be delved into: "It is the implications behind this breakthrough that interest me and ought to preoccupy us" (Tweedie 1978, 11).

Tweedie voiced concerns similar to Tucker's, that the technology could open ethically and legally ambiguous realms that had previously been nonexistent. Tweedie also shared the example of surrogate motherhood as an area where no regulation existed, yet possible negative implications were imminent. She recounted a story of a British prostitute who was paid by a couple to carry the husband's child, since his wife was unable to. The surrogate mother decided to keep the baby. The legal arena would become even grayer, suggested Tweedie, if surrogate mothers carried offspring that were not at all genetically related to them:

Recently a childless couple paid a prostitute to have the husband's child that his own wife could not carry. Obviously, the next step now is to pay women to bring to full term in their own wombs an implanted egg donated by another woman and fertilised by her husband's sperm.

The practice of implanting an embryo created with a male sperm and the egg of another female into a separate female to carry was not an outlandish notion, as the practice was routinely used in the process of livestock breeding, with the embryo of one species even being temporarily carried by another species:

Already this process is used by stockbreeders. A fertilised egg from a strain of cattle is implanted in a rabbit and the rabbit is then shipped overseas, where the buyer gets the egg removed and implanted again in a cow, thus saving on transport costs, since it is a lot cheaper to cart rabbits about than pregnant cows. A practice for which I feel a certain distaste on behalf of the rabbit.

But is the same sort of thing equally distasteful in consenting human beings? A spokesman for the Roman Catholic Archdiocese of New York thinks so – he has already pronounced upon test tube babies by saying: "It turns the marital bed into a chemistry(*sic*) set," which seems to me a fairly irrelevant statement since many a

woman, by the end of an ordinary pregnancy, has had so many tests and probings of various kinds that she feels like a chemistry set as it is.

[The] first breakthrough obviously puts the next very much on the cards, particularly in view of the extreme shortage of babies reported by all adoption agencies.

The questions were numerous, and the answers uncertain, with Tweedie's concerns specifically resting with the complexities presented by utilizing IVF technology in surrogacy arrangements.

If a woman carries to term in her own body a baby that is not genetically hers, how much less is she the mother of that child than a woman who puts her genetic offspring up for adoption? The prostitute who gave birth to a man's child for him in lieu of his wife changed her mind and held on to it after birth – would she have done so if no part of her own genes had been involved?

Tweedie argued that the issue should be examined in a different light, focusing not only on the adult parties involved, but also on the resulting children and the impact that such arrangements might have on their emotional and psychological development. She drew from the experiences of adopted individuals, and children who had primarily been raised by nannies to elucidate her point that genetic ties might not be the only factor in determining whether a child feels attached to an adult figure. Thus, a child that is carried in the womb of a woman that is not genetically related to that woman might still desire a connection with her.

Perhaps the whole problem should be stood on its head. We usually think in terms of the parents when we discuss parenting but the children's reactions deserve consideration too. Children who had devoted nannies felt as strongly about them as they would have felt about their own mothers, had they been raised by them. That and the love adopted children feel for their foster parents is the argument for long-term mothering.

But adopted children often also want to meet their real mothers later on. Do they only want to find out about their own inherited characteristics or would they feel the same about a woman who had simply given them birth?

Tweedie also highlighted the possible implications on the surrogates themselves, using the term “rentawombs” to describe women who are hired as surrogates. While the IVF technology was new and presented unique challenges, it also hearkened back to historical exploitation of poor and disadvantaged women over the centuries, who have resorted to livelihoods such as prostitution because they are unable to make an income any other way.

Women’s biology, they used to say, was our destiny. Will biology, in the future, become a way of earning a living, hiring ourselves out as rentawombs? Women today are prostitutes because there is a market in catering to male sexual needs and many women are unable to make a reasonable living in other ways. The same principle may soon apply to women carrying other people’s children. Shall we regard this as exploitation, another unacceptable use of the female sex or will we think of it as just another job?

Tweedie concluded by expressing her fears that the same economically disadvantaged women who “once wet-nursed and cared for rich women’s children,” were now going to give birth to them as well. “It seems to me extremely likely...” she postulated, and finished her article by posing a question to her readers: “What do you think?” (Tweedie 1978,11).

The first wave of articles surrounding Louise Brown’s birth created flurry of reader feedback (Anonymous1978, 10). *Guardian* readers from across Britain wrote in, sharing their thoughts, hopes, and fears regarding the breakthrough and its implications. Reader Maire Davis took issue with Tucker’s article, arguing that in his writing, he forgot one key component of surrogacy arrangements – the women. Davis argued that Tucker objectified women as incubators: “Women are people, not incubators.” Davis argued

that it was difficult to imagine that most women would be able to easily part with a baby that she carried, even if it was not genetically hers, given the complex emotional and psychological issues that would manifest from a surrogacy arrangement:

It is unlikely that many women could carry a baby for nine months, feel it move, give birth to it, perhaps even suckle it, and then calmly part with it. The evidence so far points the other way – for example the prostitute surrogate mother who kept her baby despite being “highly paid” to hand it over. Many thousands of adoptive mothers are deeply attached to children who are not even their own to this extent.

Davis felt that Tucker as well as the scientific community were making incorrect assumptions when they speculated that such surrogacy arrangements would be likely. Davis argued that women would seek other ways of making a living, rather than subject themselves to a painful (physically and emotionally) surrogacy arrangement when there are “less painful and time consuming methods of earning a living.” She issued the challenge: “What makes all these eager scientists so sure that women will cooperate in their megalomaniac schemes?” (Anonymous1978, 10).

Other letter writers provided alternative views on the subject, sharing their own experiences of infertility, and sought to defend the progress of the rapidly evolving science of reproductive technologies. Helene Neal wrote to the *Guardian* describing her personal story of infertility, a life filled with “anguish and despair, [...] longing and inadequacy.” She described her struggle as a constant up and down battle of hope and loss of hope: “The months of sobbing; every month the hope – then despair – then regained hope.” Helene felt that time had run out for her, and felt that at the age of 38, she would no longer be a suitable candidate for infertility treatment:

The years go by: time runs out. I am now 38. An infertility clinic in London recently wrote to me offering me an appointment to try something new. It was for a year

ahead! Time *has* run out for me. I replied that someone younger should have the appointment.

In a society dedicated to “the family with regulation two-four children,” Helene asserted that infertile women are “made to feel different by the people who share our lives.” The “frustration and sadness” of Helene’s infertility was only exacerbated by comments from friends, such as “Don’t they want any?” and “They’d better hurry up...”

Helene asked her readers who were “blessed with children not take them so much for granted and think of us [infertile women] occasionally.” With “hopes dashed” and marriages “teetering on the brink,” infertile couples struggled to “make something of that which was ‘primarily ordained for the procreation of children.’” Helene concluded that infertility should be treated as any other medical issue:

We all benefit from the enterprise and success of brilliant scientists: kidney transplants, radiotherapy, hip-joint replacements, spectacles – the list is endless. Why should the problems of infertility be any different?

Ms. M. Williams also wrote in, echoing Helene Neal’s concerns that the article writers were being “unthinking and insensitive” in how they were framing the issue. Williams stated that the article writers did not “seem to understand the unhappiness of people who cannot have children.” She argued that the stance that “human beings shouldn’t tamper with nature” was “profoundly reactionary.” Scientific breakthroughs that benefit humanity tend to be “unnatural,” she quipped, such as airplanes and modern medical technology that saves lives (Anonymous1978, 10).

Concerned citizens wrote in response to Tweedie’s article. Many felt that the technological advances were moving far too quickly, and that the future implications would be dire (Anonymous1978, 10). Dystopian narratives such as *A Brave New World* and *1984* were alluded to. Michele Richman of London expressed fears that a 1984-esq scenario could be around the corner, if women had to be evaluated by a panel of social

workers, doctors, and psychiatrists in order to determine whether she was mentally fit to carry a “test tube embryo.” Such a notion would “give rise to a new and sinister connotation of the word ‘babysitting,’” argued Richman. Others, such as Theresa Doughty of Surrey and Rory Fenton of London, expressed fears that surrogate mothers would be little more than “breeding cow[s],” and that the wealthy would be able to “buy their way out of” childbearing by employing surrogates. Fenton was “filled with disgust and dismay” at the prospect. She asked, “Are we people whose primary purpose is to develop our humanity, or are we animals whose primary purpose is the propagation of the species by all and any means?” (Anonymous 1978, 9).

Others expressed agitation that money and resources were being poured into developing technology to help infertile couples, that there was such an emphasis on having “children of our own bodies,” while “the world is over populated and thousands of children in homes are deprived of a loving family.” Rather than putting that money towards creating “test-tube” babies, Maureen Ambrose of Sunderland argued that it should be put towards education and social services programs to help children that already exist and need looking after. Susan Seager of London stated that if she were infertile, she would “prefer to offer a loving home to a child who exists here and now and is in urgent need of love and care rather than go to extreme lengths merely to propagate my own and my husband’s flesh and blood” (Anonymous 1978, 9).

Res Mitchelmore of London expressed trepidation over the prospect of sex selection of embryos. She argued that advanced infertility treatments could, “in a few years, be the final weapon that is needed to control women completely.” A Brave New World was in the realm of imaginable futures, but in this Brave New World, women would be rendered near obsolete:

If it comes to sex selection of babies before birth – a matter
of one or two years – how many parents will choose to

have boy children instead of girls? When it comes to population control, hitherto left to the chancey affair of men and women getting together and hitting it off, who will decide how many children are born into a Brave New World of imitation placentas and sex selection?"

Huxley naively allowed the girls to have as much chance as the boys in his version of the future. But 40 years later we are still nowhere near real equality, so what indication is there that men will create equal numbers of presumably obsolete women and equal opportunity when they have systematically excluded us from every arena of power and decisionmaking – not to mention the arts – for the past few thousand years? (Anonymous 1978, 9)

"Panic Stricken Reactions": "There is a difficult line to draw"

"There is a difficult line to draw," stated the author of "The Making of Baby Brown" (Hawkes 1978, 9). While growing a baby from conception to birth in a test tube would perhaps satisfy the curiosities of a few scientists, it would "clearly be offensive" and furthermore would be "medically pointless." The article grappled with the distinction between the embryo transfer technique that facilitated the birth of Louise Brown, and the use of other, more seemingly mundane, techniques for helping infertile women, such as ovary-stimulating drugs and surgery to clear blocked Fallopian Tubes. These techniques are "unnatural," but also "cause little fuss." If the embryo transfer technique could be "demonstrated to be safe, reliable and free of complications" it would likely join the arsenal of existing tools in treating infertility. Complications would arise, however, if babies born as a result of the technique had a higher chance of abnormality. If there was a high risk of abnormalities, "the balancing of risk against benefit would then become extremely difficult, with individual parents making different judgments from the mass of the medical profession." Like abortion in years past, infertility treatment might be "forced underground."

Considerations like these may have been behind the decision of the Medical Research Council some years ago not to support Dr Edwards's work, and the opinions

expressed by some doctors and scientists that the work should stop. Committees, of course, are not always right; Jenner would probably never have been allowed to invent vaccination against smallpox if he had to seek approval from an 18th century MRC.

[...]So we already know that society is able to resist ideas which it finds offensive and we need not necessarily assume that whatever is scientifically possible will be done. It is good to discuss these things, since only by public discussion will the necessary social guidelines be drawn up; but panic-stricken reactions are neither necessary or helpful. (Hawkes 1978, 9)

Birth of the Blues

As the media eagerly followed every move of Louise and her family, ranging from Louise's growth progress to her trip to Japan in March 1979 (Anonymous1979, 1), hundreds of hopeful women signed up for waiting lists as the first IVF clinics prepared to open their doors (Anonymous1979, 7). In Cambridge itself, however, two years after Louise Brown's birth, it seemed as if Steptoe and Edwards' goal of opening a clinic in Bourn Hall (a British mansion that the doctors intended to retrofit) was at a standstill. As the *Guardian* reported in "Birth of the Blues" in March 1980, a "deathly hush" had fallen over Bourn Hall and Steptoe and Edwards' IVF program. "Nearly two years have been wasted," the article lamented, "two years that may have done something to dim the 'hope and joy of thousands of childless couples'" (Anonymous1980, 17).

Steptoe and Edwards continued performing their embryo implantation procedure, despite the lack of their own clinic, and by 1979, had performed the procedure thirty-two times, with four of those implantations leading to pregnancy. One of those pregnancies had resulted in Louise Brown, and another had resulted in the Glasgow birth of Alastair Montgomery. In July of 1980, tides appeared to be turning, as reports emerged that Steptoe and Edwards had officially purchased Bourn Hall from Associated Newspapers (Rusbridger 1981, 1). In preparation for the opening of the clinic, Steptoe and Edwards

sent the Department of Health and Human Services a draft code of conduct that they had developed for the clinic. The purpose of the code was to “safeguard patients against any possible abuses of their work.” The code prohibited use of surrogate mothers, a policy that was different from comments Steptoe had expressed the year prior, in which he stated that “fertilised eggs might be placed in stand-in mothers, if the real mother was unable to carry the baby to term.”

While clinics, such as that of Steptoe and Edwards, were making progress in producing self-imposed guidelines of responsible practice, concerns about the welfare and rights of children produced through the new methods were being discussed in citizen organizations and in the media. The National Association for the Childless called for a focus on rights. It advocated for a Royal Commission to further grapple with the policy and legal implications associated with the new technology. The Royal Commission, it argued, could make decisions regarding issues of legitimacy and parental rights (Hills 1978, 9).

Bringing in the “Great and Good” Warnock: “The Queen’s Government Must Go On”

In 1982, Dame Mary Warnock was appointed chairwoman of a Committee of Inquiry to examine the societal, legal, and ethical implications of ART. Wilson (2010) provides an excellent overview of the internal processes within the Departments of Education and Science (DES) and Health and Social Services (DHSS) that resulted in Warnock’s selection as chair. Wilson (2010) writes that ministers of Parliament called for a government inquiry because they did not feel that the professional consultations (primarily from the medical community) that had been conducted accurately reflected public opinion on the subject. Norman Fowler, the Secretary of State for Health and Social Security, made efforts to distance the government inquiry from the inquiries that had already been conducted by the medical community. The ministers wanted a diverse

committee, with varying religious and professional backgrounds, and they wanted someone from outside of the medical profession to lead it. Warnock was the top choice on a short list of individuals that might lead the committee, and was considered to be “very well qualified for the job” by civil servants within DES and DHSS. Even more important than Warnock’s “outsider” perspective as a philosopher, argues Wilson, was her reputation as one of the “great and good” of Britain: “She had led a previous committee, was known for her organizational skills, and was typical of the well connected, Oxbridge educated figures that civil servants looked to when selecting committee members.” Warnock agreed to serve as chair of the inquiry in June of 1982 (Wilson 2011, 121-141).

Mary Warnock was born Mary Wilson on April 14, 1924, in Winchester England. Although her father died while her mother was still pregnant, the family remained financially well-off, as her grandfather was a wealthy banker. Mary attended highly regarded schools as a youth, and following an education at St. Swithin’s School in her hometown, attended St. Prior’s School. Julian and Aldous Huxley were among the school’s alumni, and the school was originally founded by the Huxley family. She then attended Oxford, where she studied philosophy and met her husband, Geoffrey Warnock (Wilson 2011, 121-141).

An article profiling the “Good Woman” from Oxford highlighted Warnock’s zeal for public service and public engagement, her good character, and “composure and aplomb”(Anonymous1984, 7). An “Oxford philosophy don,” declared the next Mistress of Girton in Cambridge, “also a well-seasoned warrior in the regiment of the great and good who fight honourable battles in the committees and quangos of British public life.”In the profile, the “sagacious” Dame Warnock stated that she was “prone to say yes to anything” related to public service, because she did not want to “get too walled up in

school.” The article illuminated perceptions of Warnock’s excellent reputation and her ability to multitask several important responsibilities at once, having served on a number of commissions, including the Royal Commission for Environmental Pollution, the UK National Commission for UNESCO, the Economic Social Research Council, serving as chair of the Oxford Committee on the Disabled,“ and also fits journalism and the (annual) awarding of Harkness fellowships into her prodigious workload” (Anonymous 1984, 7).

Due to this proclivity for service and involvement, the article noted that Warnock “is perhaps in danger of taking on too much, spreading herself too thinly,” that she was “fashionable committee’s first choice.” However, citizens should not worry, as Warnock “has a reputation for not accepting anything unless she can do it properly.” Warnock was considered adventurous with her commitments, as well: “She will plunge into areas of which she knows nothing, but she is a quick student and what a colleague called ‘a good examinee.’” That same colleague also stated that there was a “trace of playing God” embedded within Warnock’s “deep sense of public duty,” quipping that “I think she actually believes that the Queen’s Government must go on.” Despite her many commitments “in her conscientious to British Public life she has forfeited nothing,” and perhaps even “gained – in personal charm.” In terms of her personality and physical presentation, “She has a beautiful voice; wears good clothes; is welcomed for the humour and sharpness, as well as the intellectual rigour, clarity and force, she brings to the toughest debate. She also likes a drink.”

Warnock is an individual, “her own person” noted a Tory junior Minister. She is a valuable public servant: “her reports are her own: and that’s what makes her so valuable to government.” Warnock made it a point and a “habit” when on a committee to “declare her own views and prejudices straight away, so that colleagues can jump on her if she

gets too 'bossy and schoolmistressy.': clearly, in her case, both a more attractive and a more effective device than a poker face" (Anonymous 1984, 7).

The profile described the issue of reproductive technologies as incredibly complex, a subject "not for the squeamish." "Two British Women, hired through an agency for surrogate mothers, are now expecting babies they will exchange for cash at birth. Two frozen 'orphan embryos' are alive in a tank of liquid nitrogen in Melbourne, Australia, while their millionaire American parents have been killed in an air crash. An eminent French scientist has predicted it may soon be possible for a man to become pregnant." Mary Warnock, however, was up for the challenge. "Dame Mary is not squeamish [...] and she has found the philosophical questions raised by this inquiry very much to her taste. She has made no secret of her own views, notably her distaste for surrogacy; but nothing she has learnt or looked at with this committee has stirred the repugnance she has felt in walking through certain laboratories as chairman of the Advisory Committee on Animal Experiments" (Anonymous 1984, 7).

As Wilson (2010) recounts, Warnock, in collaboration with Norman Fowler and a team of civil servants, went to work recruiting an array of the "great and good" of Britain to serve on the committee. The committee Warnock recruited comprised a number of different professional and religious backgrounds. The committee was consisted of seven individuals from the medical/scientific field, and eight from other fields, including social workers, an executive from the Immigrant's Advice Service, theologians, a court recorder, and solicitors (Wilson 2011, 121-141). In her note to Norman Fowler and other government officials at the beginning of the report, Warnock wrote that the "professional expertise" of members of the committee, in addition to their diverse religious backgrounds, "enhanced the report" (Warnock 1984). The below chart details the composition of the committee as it appears in the final report (Warnock 1984):

Table 1:

Dame Mary Warnock DBE MA B Phil(Chairman)	Mistress of Girton College, Cambridge; Senior Research Fellow, St Hugh's College, Oxford.
Mr Q S Anisuddin MA	Legal Executive; Vice-President, UK Immigrants Advisory Service.
Mr T S G Baker QC	Recorder of the Crown Court.
Dame Josephine Barnes DBE FRCP FRCS FRCOG	Consulting Obstetrician and Gynaecologist, Charing Cross Hospital.
Mrs M McCarriline MA	Social Worker; Former Vice-Chairman of British Agencies for Adoption and Fostering.
Dr D Davies MA PhD	Samuel Ferguson Professor of Social and Pastoral Theology, University of Manchester.
Mrs N L Edwards OBE J P B L SRN SCM	Chairman of Gwynedd Health Authority.
Dr W Greengross MB BS D Obst RCOG	General Practitioner; Chairman of Sexual and Personal Relations of the Disabled.
Professor W G Irwin MB BChir BAO MD FRCGP D Obst RCOG	Head of Department of General Practice, Queens University Belfast.
Professor J Marshall DSc MD FRCP (London) FRCP (Edin) DPM	Professor of Clinical Neurology, Institute of Neurology Queen Square, London.
Professor M C Macnaughton MD FRCP (Glas) FRCOG FRSE	Professor of Obstetrics and Gynaecology, University of Glasgow.
Dr A McLaren MA DPhil FRS	Director, Medical Research Council Mammalian Development Unit.
Mr D J McNeil WS	Solicitor, Edinburgh.
Professor K Eawnsley CBE MB ChB FRCPsych FRCP DPM	Professor of Psychological Medicine, Welsh National School of Medicine.
Mrs MJ Walker JP MA APSW	Psychiatric social worker, former student counselor at Cambridge University.

The decision of the government to appoint an expert advisory group - the Royal Commission – to explore the social, legal, and ethical issues presented by advances in reproductive technologies was underscored by overarching themes in British

policymaking, such as faith in the state and, by extension, the law in reigning in “runaway social forces” (Jasanoff 2005). Tied to this perspective is the value placed in empirical evidence and trustworthy experts in synthesizing that evidence to provide wise policy recommendations in the face of uncertain technological futures (Jasanoff 2005).

Beyond Professional Expertise

Warnock’s inquiry was comprised of a group of sixteen individuals that, as the final report notes, had “professional expertise” (Warnock 1984). While the notion of British professional expertise does place high importance on experience in one’s profession, it goes beyond an individual’s membership in a particular professional body and is rooted within the British aristocratic context – a historical context that places high value on individual excellence, one that ties expertise to *individuals* as opposed to professions (e.g., being a barrister does not necessarily equate to being an expert of law, one must have demonstrated character, experience, and good judgment in order to provide expert advice). The British expert must demonstrate both *aristos*, excellence, in their field, and also *kratos* – the demonstrated capacity to engage in wise governance. It is through the British expert’s character, experience, and achievements that enables him or her to “possess the transcendental capacity for discernment” (Jasanoff 2005). As Jasanoff notes, it is the British expert’s “function” to not only apply his or her technical skill and knowledge to problem solving, but to also “discern the public’s needs and to define the public good” (Warnock 1984). Indeed, the Committee viewed its role as “discover[ing] the public good,” noting in the forward, “it was our task to attempt to discover the public good, in the widest sense, and to make recommendations in the light of that” (Warnock 1984).

The Report of the Committee of Inquiry into Human Fertilisation and Embryology: The Warnock Report

Warnock and her committee were assigned the following task:

"To consider recent and potential developments in medicine and science related to human fertilisation and embryology; to consider what policies and safeguards should be applied, including consideration of the social, ethical and legal implications of these developments; and to make recommendations." (Warnock 1984)

The Report of the Committee of Inquiry into Human Fertilisation and Embryology (1984), widely known as the "Warnock Report," was developed following consultation of the Royal Commission with a variety of individuals and groups, including religious bodies, scientists, professional associations. The report opened with a reflection on the concept of ethics, and noted that for the committee's purposes, the concept would need to extend beyond notions of proper, or "acceptable," professional practice, to foundational questions related to the underlying principles upon which regulation and law "would rest" (Warnock 1984). Thus, the committee was "obliged" to operate under a "less restrictive" understanding of ethics in order to conduct its inquiry. Furthermore, the report argued, that in dealing with the matters at hand, "reason and sentiment" are not necessarily contradictory. However, because "moral indignation, or acute uneasiness, may often take the place of argument," the report presented the arguments for the committee's recommendations, and also counterarguments as well. The committee emphasized presenting both sides of each argument because it believed its task was to, as noted above "to discover the public good" (Warnock 1984).

The report noted that the main commonality linking the developments within the "still developing, and rapidly changing" "sphere of activity" that it was studying was "the anxiety they generated in the public mind" (Warnock 1984). The report, in discussing the establishment of the committee, described the public atmosphere at the time of its establishment. The "new horizons" that Louise Brown's birth opened up also created new public anxieties and trepidation:

It was now possible to observe the very earliest stages of human development, and with these discoveries came the hope of remedying defects at this very early stage. However there were also anxieties. There was a sense that events were moving too fast for their implications to be assimilated. Society's views on the new techniques were divided between pride in the technological achievement, pleasure at the new-found means to relieve, at least for some, the unhappiness of infertility, and unease at the apparently uncontrolled advance of science, bringing with it new possibilities for manipulating the early stages of human development. (Warnock 1984)

The report sought to make “practical proposals, capable of implementation” (Warnock 1984). It made sixty-three recommendations regarding ART. It recommended that commercial surrogate motherhood be made illegal. The report allowed research on spare and deliberately created embryos until the fourteenth day of the embryo’s development. According to bioethicist Albert Jonsen (2005), the Warnock Report stands as a “bioethical milestone,” principally for its support of the fourteen-day research limit on developing embryos. It recommended the establishment of a regulatory body that would regulate both ART research and practice, arguing that of all of the recommendations that it made, the establishment of a statutory body, “within whose powers would fall the licensing and monitoring of provision for infertility treatment and of research on the human embryo,” would be the most critical. The committee recommended that the body comprise professional representatives from the medical and scientific communities, but that it also integrate members of the lay public in its representation: “None of our other recommendations can have any practical impact until such a body is set up” (Warnock 1984).

Expert Capacities: Identifying Trustworthy Agents

The appointment of Mary Warnock as chairman of the Committee of Inquiry signifies a specific capacity for negotiating socio-technical contracts, specifically, that of

expert capacities, and the modes by which societies identify trustworthy agents to navigate complex and ethically nebulous socio-technical configurations. Social stability has traditionally been maintained in Britain through an aristocracy, an assembly of individuals that through good reputation, lineage, and character possess the capacity for judgment. In 16th century France, the term “aristocracy” made its first appearance in Europe. It was derived from the Greek *aristokratia*, meaning that the best citizens, the most excellent (*aristos*), govern (*kratos*). The term embodied one of Aristotle’s ideal forms of government – rule by the wise and educated citizenry. Because of their wealth, these citizens had the time and energy to cultivate their wisdom through education and to focus on the “general welfare of the rest of society” (James 2010). Steven Shapin, in *A Social History of Truth*, provides historical context and insight into the role of the British aristocracy in establishing public trust and maintaining social order. Trust, argues Shapin, can be viewed as a “device for reducing social complexity” (Shapin 1994). Good-decision making was embodied in the British gentleman: “He was accounted to be such a man as had no inducement to misrepresent the case, no forces working on him that would shift his utterances out of correspondence with reality.” It requires the mobilization of certain kinds of people:

“These traditions suggest that the fabric of our social relations is made of knowledge – not just knowledge of other people, but also knowledge of what the world is like – and similarly, that our knowledge of what the world is like draws on knowledge about other people – what they are like as sources of testimony, whether and in what circumstances they may be trusted. Accordingly, the making of knowledge in general takes place on a moral field and mobilizes particular appreciations of the virtues and characteristics of types of people.” (Shapin 1994)

Historically, public trust in British policymaking has been established through “embodiment in trustworthy people” (Jasanoff 1997, 221-232). Epstein (1998) also illuminates this tension. He notes that both the lay public and the scientific community

often find themselves assessing claims of authority or knowledge, and “asking who or what they should trust and believe.” However, the issue, contends Epstein, is that assessments of credibility can only be made indirectly, “through the scrutiny of external markers of credibility” (Epstein 1998).

The aristocracy served as mediators in reigning in social forces. This can be observed in the aristocracy’s historical involvement in cultivating and regulating religious practice, for example. Religion served as essential social glue and also served as a way of organizing political power. Differing religious beliefs and practices could lead to conflict or unrest and threaten the stability of society. The term “nonconformist” comes from this era in English history – when those who did not conform to Anglican doctrine were considered threats to established order.² In 1662, for instance, Parliament sought to resolve conflicts between competing Protestant sects by passing the Act of Uniformity, which established national standards for religious practice in England. When social activity appeared to be out of control, England looked to the aristocracy to assert its wisdom and reign in and regulate the social threat. Throughout British history, the aristocracy was a primary force in reigning in out of control social movements. Given the ongoing British motif of reigning in forces that are perceived as threats to the realm, it is not farfetched to see why British leaders would react so strongly to the birth of Louise Brown, and why they would turn to Britain’s *aristos*, i.e. its most excellent citizens, for guidance.

In light of these historical British sensibilities in reigning in perceived out-of-control forces, the way in which the British responded to the birth of Louise Brown, framing the meaning of the birth as science potentially out-of-control and calls for government control, is not necessarily a stretch. Within this context, the “test tube

² See Edmund Calamy “The nonconformist’s memorial”

baby,” a new, unusual social kind, could be viewed as a threat to traditional social forces. Bringing in Warnock as a negotiator of the socio-technical configurations associated with ART indicates a slightly broadened notion of the “great and the good” concept of the traditional guardian of the realm. Warnock serves as an illustration of larger dynamics about how governments managed transitions and deal with novelty – especially how they deal with perceived threats and runaway social forces. In Britain, the issue is addressed by pulling together a certain kind of people, the “great and the good” to negotiate the transition. In the context of Warnock, there exists a motif of science out of control, and a sense that the state feels obligated to address a radical new technology invented within its borders. The solution is to bring the Great and Good together.

Jasanoff (1997) provides further insight into the role of the Great and Good, and the important role of advisory bodies (and the composition and leadership of such bodies) in British policymaking. She notes that in British policymaking, “personal integrity and public influence walk hand in hand.” One must demonstrate character before one can exert influence:

It is no accident that difficult policy choices are so often committed to advisory bodies of the ‘great and the good’—to people, that is, who couple power with virtue, whose capacity for governance has been tested in gradually widening spheres of action until they are seen as reliable, discreet and worthy of public trust. [...]They do, however, presume a relationship between a society and its ‘great and good’ representatives—a relationship founded on shared values and deference to expertise [...]. (Jasanoff 1997, 221-232)

Warnock illustrates that British expertise is not *strictly* contained within professional expertise. In British policy advising, “It is enough to show that the best people were selected to evaluate the situation and to draw the appropriate conclusions. Their collective judgment could not be bettered by inserting other, less experienced people in

their places” (Jasanoff 1997, 221-232). While an entirely separate discipline of bioethics had to emerge for in the United States in order for philosophers to engage in conversations related to advances in the life sciences, for example, in the British context, Mary Warnock represents a great deal more. Within this context, the expectation exists that someone like Warnock would be appointed in leading these socio-technical negotiations. The British are not hiring an abstract set of expertise, rather, it is embodied within the individual.

Initial Response to Warnock

The completed Warnock Report was made public without delay. The report received both praise and criticism immediately following its publication. Mary Warnock acknowledged that criticism of the reports conclusions would be “inevitable,” however, she believed that the report made two significant contributions: “a reasoned discussion of the issues which should help a high standard of public debate; and a coherent set of proposals for how public policy, rather than the individual conscience, should tackle developments in the field”(Wainwright 1984, 4)

An editorial in the *Guardian* praised the report for its “calm and balanced” assessment of the current state and future of reproductive technologies. The Warnock Report, which “itself has spent so much obvious anguish over its conclusions,” provided an opportunity for society to engage with the implications of a set of emerging technologies before it outpaced efforts to regulate it:

Recent history is littered with examples, of which the Bomb is the most dramatic: technology races ahead, fired by its own particular imperatives; society’s response lingers far behind. Moral and political implications are left largely unexplored until sever years, and many anguished headlines, later. Nowhere are the issues more sensitive and disturbing than in human reproduction, touching as they do the deepest religious and human instincts and

triggering hair-raising fears of a brave new world of genetic engineering.

The editorial argued that the report provided a blueprint for public debate, a debate in which emotions can easily overwhelm rational argument: “As a text for the political debate which is to follow, Warnock could hardly have been improved upon” (Anonymous1984, 12).

Others were critical of the report, such as Lord Denning, who argued to the House of Lords that the Warnock Report’s recommendations were “potentially most dangerous to our society.” Denning took issue with the report’s policy recommendations regarding embryo research, and speaking in the Lords debate on the Warnock Report stated that embryos should be afforded the same rights that all other people have: “that the only logical point at which the law could start is the moment of conception” (Anonymous 1984, 6).

In its letters to the editor section, the *Guardian* provided space for public comments on the report. The write in section was titled “Why Warnock’s offspring will dismay women” (Anonymous 1984, 10). Accompanying the section was a cartoon illustrating a pregnant woman, who had a “strange urge” to eat the “unpalatable” Warnock Report:

Figure 4:



Deborah Cameron of London wrote in, contending that the Warnock Report was unfair to single women and lesbians who wanted to become mothers: “It remains entirely mysterious why this cost-conscious government did not just pick 20 people off the streets to write it, since it embodies every kind of irrationality and popular prejudice scientists are supposed to be above. [...] What is the evidence that single women and lesbians make inadequate mothers?” Cameron alleged that the Warnock Report intended to reaffirm traditional family structures, a “traditional and sentimental stereotype of motherhood, taking for granted heterosexuality, marriage, the sexual double standard and ‘natural’ maternal instinct” (Anonymous 1984, 10).

Joealyn Selson from London also wrote in, expressing her concerns regarding sperm donor anonymity. Little has been discussed, she lamented, about the “‘right’ of the child when born to know its true parents.” Warnock, she argued, was ignoring the potential psychological issues that could manifest when donor-conceived individuals are denied knowledge of their biological origins. She drew a parallel to the experiences of adopted children, but noted that donor-conceived children might be in a worse predicament: “A group of children seems likely to be created who are going to have enormous identity problems, already difficult for those who have been adopted, but they

at least have a choice now of being able to find out who their parents are.” John Ling, from Evangelicals for LIFE, also wrote in, and advocated for adoption rather than infertility treatment: “Surely a better way to ‘escape’ infertility is by adoption. Sad to say, our aborting of more than two million unborn children since 1967 has largely meant that this way is now virtually a cul-de-sac for infertile couples. Two wrongs still do not make a right” (Anonymous 1984, 10).

Others, such as the Bishop of Chelmsford, John Trillo, called for immediate action upon the Warnock Committee’s recommendations, such as the ban on commercial surrogacy: “Womb-leasing” is “unacceptable, and undermines the dignity of women and child-bearing and the family.” In opposition to Trillo’s calls for immediate action, Lord Glenarthur, the junior health minister, cautioned against moving too quickly, and that it was important to provide space and time for debate: “The Government had published the report without delay, believing a period of consultation to be appropriate. There would not be a consensus view on all the more than 60 recommendations, as the committee itself was divided on some of them, he said” (Anonymous 1984, 6).

Calls to Legislate

Four years after the Warnock Committee’s report, little progress had been made in the way of legislation. Parliamentary progress had been slow in determining whether experimentation on embryos should be completely banned or adhere to the fourteen day time limitation that the Warnock report had recommended. Pro-life MP, Bernard Braine, advocated for legislation banning all experiments on human embryos, no matter how many days old they were. Bernard stated that he and the pro-life group of MPs he led were “determined to protect the human embryo from being used as a guinea pig” (Veitch 1984, 3).

An article titled “Time to Legislate” emerged shortly after the tenth birthday of Louise Brown, calling the delays “quite disgraceful,” leaving a number of stakeholders in limbo.

Decisions on Warnock may look to ministers like a low priority, fit for the back of the queue, but for others - doctors and researchers at the frontiers of medical advance, childless couples who feel their time may be running out, and people for whom the very thought of experiments with embryos is full of horror and repugnance – these are matters of very great urgency, far transcending the bulk of the legislation which the Government plans for next session. (Anonymous 1988, 18)

The urgency of the matter was underscored by alternative bills that were being proposed by members of Parliament to “fill the vacuum which Government inaction had created.” In the 84-85 session of Parliament, Enoch Powell had introduced a bill banning all research on human embryos, and required infertile couples to seek permission from the government to move forward with treatment (Anonymous 1988, 18).

A 1985 editorial in the *Guardian* pleaded that “Warnock have a hearing.” It argued that Powell and his backers were moving too fast: “But the fact remains that they are moving too fast. The one thing that is clear about public opinion on infertility is that it is not clear” (Anonymous 1985, 12). The widespread confusion and conflict on these issues should give policymakers pause, argued the article. It contended that the Warnock Report should be given a fair hearing: “Honest and sincere people approaching these debates find themselves troubled and torn by the conflicting issues. And it was precisely for that reason that Warnock was asked to take a comprehensive look at the whole interface between medical science and human fertility.” The editorial attributed the delay in giving the Warnock Report a full hearing to fundamentalism on all sides of the issue – no one group was pleased with the Warnock recommendations because it was ultimately a compromise:

The Warnock report has been with us only since July. In that time, there has been a period of initial general response, a single parliamentary run round the course [...]. It does not add up to the necessary gestation before decisive legislative action. To the fundamentalists on all sides this does not seem to matter. For the, Warnock is a Weasel compromise and a moral dereliction. For many church people (mainly, but not exclusively, Catholics), for the experiment at-all-costs Frankensteins, and for some feminists, Warnock is a sell-out from the start. The churches, being the best organised of these lobbies, have got their retaliation in first in the shape of Mr Powell's bill. This selects one part of the report, albeit an important part, and lays down rules which will effectively kill off embryo research of all kinds.

This is undesirable for several reasons. For one thing, it pre-empts the full discussion of Warnock which we, along with the health minister, Mr Kenneth Clarke, have urged before any bill comes to parliament. For another, the very strictness of the bill proscribes any effective role for research on the fertilised embryo. And it is this moral absolutism which is the deeper charge against both the bill and its precipitate introduction. The Warnock report is a morally serious document which still requires considerable discussion and reflection from those who approach it from certain and uncertain standpoints alike. It should not be subjected to Mr Powell's legislative abortion. (Anonymous 1985, 12)

Robert Edwards also criticized Powell's bill, calling it inhumane, and a violation of human rights, stating, "I don't know of any other government in the world, including dictatorships, that has ever imposed such a regulation" (Chorlton 1985, 3).

That it failed to become law had little to do with the merits of the case. Kept alive in its later stages by the procedural guile of its authors, it was finally brought down by a matching procedural sleight of hand on the part of its opponents. Attempts to resurrect the bill in later sessions also collapsed, but for want of time, not for want of support. (Chorlton 1985, 3)

Powell's bill failed for another reason. Members of Parliament had been "begged" to not vote for a private bill, having been promised by Minister of Health Kenneth Clarke that official government legislation was on the near horizon. However, the article surmised, it was likely that another year would pass without government action, and members of Parliament would begin to doubt the government's promises. Another private member would put forth an alternative bill, the article hypothesized, and it could very well pass, given the continued government inaction: "It's not time but will that is lacking. The Government could act on Warnock if it chose. It just thinks it more important to privatise water" (Toynbee 1986, 10).

In 1987, speaking to Europe's top IVF specialists in Cambridge, Mary Warnock emphasized the need for government legislation on embryo research. Although she felt the Pope was "wrong to condemn all research on embryos," legislation was indeed needed in order to delineate at what stage in an embryo's development scientific experimentation should stop. The medical community that Warnock was speaking to was fearful that all research on human embryos would be halted, and that infertility treatment would be extremely limited. The medical community was concerned due to the strong pro-life lobby and pro-life "backbenchers" across the span of political parties (Veitch 1987, 5).

In 1989, health secretary Kenneth Clarke successfully received support from Parliamentary leadership (known as Whips) to introduce a bill that would implement the recommendations of the Warnock Report (Hencke 1989, 6). Clarke's push for a bill was welcome, but the tension caused by the government delay was palatable. The Voluntary Licensing Authority that was in place modified its name to the Interim Licensing Authority "in protest" of the Government delay (Ballantyne 1989, 28). Writing for the *Guardian*, Aileen Ballantyne announced that "The rights and wrongs of scientific research will

shortly be removed from cool analysts in the laboratory to the emotive and prejudiced floor of the House of Commons.” The bill was expected to be announced in the Queen’s speech in November 1989, and MPs would have a choice of voting for one of two options. The first option was that all embryo research would become a crime. The second option was for the permitting of research within the existing fourteen-day time limit, if regulated by a licensing body such as the one proposed in the Warnock Report (Ballantyne 1989, 28).

Mary Warnock herself expressed her displeasure at the legislative delays, stating that it was illogical for the embryo research legislation to be conflated with abortion legislation, and that government plans to attach an abortion clause to embryo research bill would only serve to further confuse two separate issues:

The Government plan to attach an abortion clause to a Bill concerned with embryos *in vitro* denies this difference. It presupposes some identity between two different kinds of entity, the cells in the test tube and the foetus in the womb, and between two kinds of procedure, carried out for quite different purposes. It cannot be in the interests of clarity to consider both in one piece of legislation. (Warnock 1989, 59)

The use of human embryos for ART was a heated topic of political debate in the United Kingdom, and the anti-abortion movement strongly objected to ART practices and embryo research (Jackson 2001). Towards the beginning of the embryo research debates, the anti-research lobby was well-organized and seemingly had both the public and Parliament on its side, and if not for delays in Parliament almost all ART and embryo research would be illegal. The first Parliamentary debate on the Report was quite heated, and a number of Members called for a moratorium on ART research (Blank 2004, 125). However, between 1985 and 1990 the pro-research lobby, including scientists and medical practitioners, swayed opinion in Parliament (183). The victory of

the English pro-research lobby was due to a number of factors (Mulkey 1997). These factors included the creation of a Voluntary Licensing Authority (VLA), which served as an example to policymakers that scientists were willing to co-operate with a monitoring authority and that embryo research could be regulated by a statutory agency as stipulated by the Warnock Report. Additionally, success of the research lobby could be attributed to the images and stories that infertility clinics and scientists presented to the media – coupling “moving personal narrative” with “expert scientific testimony.” The unified efforts of the pro-research lobby stood in clear contrast to the anti-research lobby, which “relied heavily on constant repetition of the abstract moral arguments taken over from the anti-abortion movement” (Mulkey 1997).

Another factor contributing to the victory of the pro-research movement was the successful demarcation of the “pre-embryo” from the embryo proper. Initially, most members of Parliament stated that embryo research was wrong based on moral grounds. Pro-research interests were successful in moving the debate away from moral arguments towards one of demarcating an appropriate space and time period for embryo research. Jasanoff (2005) discusses this demarcation. Embryos that are less than fourteen days old are considered “pre-embryos,” and in the eyes of the law, stand apart from and are distinctive to the embryo proper. By demarcating the pre-embryo from the embryo, a new research space was created in which research could continue on the pre-embryo, which was devoid of the human characteristics associated with the term “embryo” and its accompanying controversies. This creation of a new scientific reality was only possible with the enlistment of the state as a biopolitical agent: “The splitting of the developing human embryo into two distinctive legal and biosocial entities was feasible only with the full mobilization of the state as an agent of biopolitics” (Jasanoff 2005).

The HFE Act and the Establishment of the HFEA

The Human Fertilisation and Embryology Act brought before Parliament in 1990 dealt with the issues illuminated in the Warnock Report. It has been called a “milestone in biomedical regulation” and “the first attempt in English law to provide a comprehensive framework for making medical science democratically accountable” (Montgomery 1991, 524-534). Topics primarily centered around human embryos created outside of the body for scientific research. The Human Fertilisation and Embryology Act of 1990 created a regulatory structure for ART and embryo research. It requires that research and practices falling within the act, including the creation, use, handling, and storage of human embryos only occur in licensed facilities. The main component of the Act is the establishment of HFEA, a regulatory body that works via committees to license, monitor, and inspect facilities, review human embryo research protocols, and “make policy when faced with novel issues” (Knowles and Kaebnick 2007). The HFE Act requires that the chairperson of the HFEA be a layperson (someone not from the medical community), furthermore, it requires that more than one-third but less than one-half of the HFEA members be from the medical community (Anonymous 1990). The HFEA would be tasked with not only adhering to standards issued by Parliament, but it would also required to develop standards for appropriate practice as well (Montgomery 1991, 524-534). A key designation to the HFEA by the 1990 Act was that it keep abreast of new innovations and research in the field, so it could provide advice to the government:

keep under review information about embryos and any subsequent development of embryos and about the provision of treatment services and activities governed by this Act, and advise the Secretary of State, if he asks it to do so, about those matters [...](Anonymous 1990)

The 1990 Act also granted the new authority the ability to establish license committees, which would carry out the day-to-day and case-by-case approval, varying, or revocation

of licenses for research and clinical institutions working with human gametes. It would also license specific forms of treatment, as well (Anonymous 1990).

The Act delegated to the authority the directive of creating and updating a code of practice that would evolve on an iterative basis. The purpose of the code of practice was to provide guidance on “proper conduct” of work done under the authority’s licensing scheme. It was also to provide guidance to practitioners regarding the “welfare of children who may be born as a result of treatment services (including a child’s need for a father), and of other children who may be affected by such births.” The code could also provide direction “about the use of any technique” regarding “the placing of sperm and eggs in a woman.” The code was to be reviewed and revised “from time to time.” If licensed entities violated the code of practice, the licensing committee had the power to revoke licenses (Anonymous 1990).

In 2008, the HFE Act was updated to include a ban on sex selection for social reasons, removing the requirement that clinics take account of a child’s “need for a father,” and allowing same sex partners and unmarried couples to apply to be treated as the parents of a child born via a surrogate, among other amended items (Anonymous 2008). As a regulator, under the Human Fertilisation and Embryology Acts of 1990 and 2008, the HFEA’s responsibilities include mandates to license and monitor clinics engaging in in-vitro fertilization and donor conception practices; to license institutions engaging in embryo research; regulate entities that store sperm, eggs, and embryos, and keep a registry of all entities licensed for ART practice, research, and gamete storage (Anonymous 2008).

Negotiating Socio-technical Contracts

What does the narrative of Louise Brown, Warnock, and the HFEA mean, then, for furthering our understanding of socio-technical contracts, and of anticipatory

governance as a mode through which those socio-technical contracts can be “opened up”? What capacities for negotiating socio-technical contracts emerge in this case? As explored in the first section of this chapter, the British policy community was fundamentally under fire from the media and members of the general the public for being consistently behind scientific advances, having to race to catch up. It appeared to be a quintessential example of Langdon Winner’s technological somnambulism, in which society “sleepwalks” through technological configurations and by the time society wakes up or action is taken, it is too late. However, as the latter half of chapter two and the first section of this chapter demonstrate, there was a fairly healthy public dialogue about the implications of new reproductive technologies, before the technologies themselves even existed. Professional bodies such as the BMA also sought to examine the issues and provide voluntary guidelines. Despite what appeared to be a robust public dialogue and the establishment of voluntary guidelines for practitioners, there was little movement on the British government’s end until the birth of Louise Brown in 1978. Was Louise Brown’s birth the catalyst that “awoke” the government from its technological somnambulism?

This trajectory, in one sense, suggests that socio-technical contracts are not static, and that the British socio-technical contract around ART was built with the notion of flexibility and adaptability in mind. The HFEA’s ongoing and evolving code of practice is one example. That the HFE Act was updated to ban sex selection and remove the requirement that a child created through ART have a father is another example of a socio-technical contract that is flexible enough to adapt to changing social perspectives, new information, and new innovations, without having to be completely renegotiated or rebuilt. The mechanisms present in the HFEA’s structure enable it to proactively engage with and keep an eye on advances in reproductive technologies. The HFEA’s directive

to monitor research and advancements in the field, and to either adapt its code of practice, or advise the Secretary of State in light of these changes, is also a critical foresight mechanism that enables the authority to stay abreast of and adapt policy to emerging issues.

Perhaps the most salient capacity illuminated in this specific narrative is that of expert capacities. The way in which experts are perceived and deployed varies in light of a nation's social, cultural, and historical context (Jasanoff 2005). In Britain, as explored in the above section, trustworthy agents are rooted within historical understandings of the aristocracy as possessing wisdom, reputation, and character necessary for the pursuit of good judgment. As the appointment of Mary Warnock as chairman of the Committee of Inquiry demonstrates, capacities for judgment, and the capacity for negotiating controversial, ethically contentious socio-technical issues, rests, in one sense, with Britain's Great and Good.

Significant challenges also exist with this model, however, as the "mad cow disease" (bovine spongiform encephalopathy) scare in Britain demonstrates. Due to a lack of understanding about the disease, the gap between the lay public and experts was diminished, resulting in a "civic dislocation" (Jasanoff 1997). Public trust in the government's ability to make good decisions vanished, and citizens felt they could no longer depend on the government's experts for advice. Due to the immense uncertainty and lack of knowledge about mad cow disease, Jasanoff (1997) argues that the general, non-expert public was in almost on equal footing with government experts in making decisions on how to handle with the issue. British experts "capacity to reassure" diminished, and the government fell short as it was not able to engage the public or bring lay voices into decision-making in a meaningful way. The following chapters illuminate

the tension and assumed “dichotomy between lay judgment and expert knowledge” (Brown 2009), as the HFEA, in some cases, struggled to listen to the voices of lay individuals directly affected by its policy, including donor conceived individuals petitioning for a right to know their anonymous sperm donor biological father, and prospective parents hoping to create a “savior sibling” of a sick existing through preimplantation genetic diagnosis and tissue typing techniques. The role of the courts becomes significant in renegotiating the socio-technical contract then, as impacted individuals in such cases resorted to the court system in order to give voice to their concerns.

CHAPTER 4

GENETIC ORPHANS: RENEGOTIATING THE RIGHTS OF DONOR CONCEIVED CHILDREN IN CANADA AND THE UNITED KINGDOM

Introduction

The following case studies explore two examples of the reimagination and revisitation of the governance arrangements of one suite of assisted reproductive technologies – donor conception technologies, and the legal and cultural shifts in British Columbia and the United Kingdom from frameworks of primarily anonymous donation to donor identification. With advances in cryopreservation technologies in the early 1970s, donor sperm became more readily available, and donor conception became a popular option for couples experiencing infertility. Sperm donors, in both Canada and the United Kingdom, donated under the auspices of anonymity. As a result, thousands of children who were conceived through the process have grown up not knowing who their genetic fathers are. In the early 2000s, donor offspring plaintiffs claiming rights to identifying information on their donor challenged the right to anonymity, via court cases.

I utilize the Canadian and British contexts to explore the systems change around these evolving socio-technical configurations. The chapter examines how governance processes in the two contexts worked over time to renegotiate fundamental ideas about families and kinship, rules governing release of information, the “right to an identity,” and general approaches to how to think about the roles and relationships of the child, parents, and the state in and around the introduction of this technology. As these changes have occurred, policies, social understandings, and legal rights have been renegotiated and new governance capacities have come into existence. This chapter does four things. First, it provides a narrative lens into the “right to an identity” versus “right of anonymity” debate by chronicling the experiences of two donor conceived

individuals, British Joanna Rose and Canadian Olivia Pratten, as they navigated the court systems in their respective countries in an effort to renegotiate the socio-technical contract around donor conception. This narrative account is woven and integrated throughout the chapter. Second, the chapter delves into historical practices of secrecy and maintaining legitimacy in donor conception and contextualizes these practices within the British and Canadian contexts. Third, the chapter compares the approaches of the Canadian Royal Commission on New Reproductive Technologies (often referred to as the “Baird Commission,” which produced its advisory report in 1993, and the British Committee of Inquiry into Human Fertilisation and Embryology (often referred to as the “Warnock Committee”), which produced its report and final policy recommendations in 1984. Finally, I reflect on the capacities in each context that enabled reflection on and renegotiation of the socio-technical contract around donor conception practices.

Joanna Rose – United Kingdom

Joanna Rose was born in Reading, England in 1972. Conceived through a process of donor insemination, her parents told her about her unconventional conception when she was eight years old. As Joanna grew up, she involved herself in the donor-conceived community, going to workshops and conferences for donor conceived people and their families. Not content to sit and listen, Joanna began speaking openly about her experiences as a donor-conceived person, emphasizing the role of communication and openness in families with donor-conceived children. She was invited to speak about communication within families at a conference on donor insemination, one in which donor-conceived people, families, and sperm donors were present (Cronin and Jones 2000).

As Joanna was speaking at the conference, she realized, mid-presentation, that there was more to being donor-conceived than she had originally believed. There was

another party involved in her conception – the donor. While Joanna had understood from a young age that about half of her genes came from a sperm donor, the idea that her biological father was a real person was a new concept to her. She had an entire biological family that she knew nothing about:

I nearly passed out because I just suddenly realised that there was more to this and that that meant that I had a biological father and a whole biological family that I'd never thought of before and I really thought I was going to pass out in front of a few hundred people on a stage (Cronin and Jones 2000).

Joanna went back to her seat, with the new realization that her biological father could be one of the thousands of men she brushed up against every day in the London Underground, or the bus, or the elevator. As she sat back down, she looked over to a donor sitting next to her. Joanna leaned over and whispered a joke about how he could be her father. Although she was trying to make light of the situation with humor, the reality of the joke dawned on both of them. Joanna and the donor almost fell off their chairs (Cronin and Jones 2000).

Olivia Pratten – British Columbia, Canada

Across the pond in British Columbia, Canada, another little girl was staring at a family tree that was only half filled in. Olivia Pratten looked at her hand-drawn family tree, perplexed by the task that her fifth grade teacher had presented to her. She was able complete her mother's side of the tree in without issue, but when it came time to fill in the vacant branches on the other side, the paternal side, Olivia, understanding that she was donor-conceived, did not know how to proceed (Skelton 2006).

Growing up in the verdant, rainy Canadian province of British Columbia, Olivia had a loving family. She was a happy child, but her emotional journey of grappling with her donor-conceived status began when she was only five, when she posed the question

that parents universally dread: Where do babies come from? Olivia's mother explained (as best as she could to the five year old) that the man she knew as her father was not biologically related to her.

Olivia was perplexed by the family tree assignment – her parents had divorced, and she felt a sense of emptiness when she realized that, unlike her classmates, who could trace their family trees back generations, her tree was only half-full. Olivia had no idea who the inhabitants of the empty half of her tree might be, what they were like, what their hobbies or favorite dessert might be. The empty branches peered back at Olivia, as she tried to make sense of the illustration. The inhabitants of those empty branches were ethereal specters to her – she knew they existed, but they were as intangible as ghosts (Skelton 2006). Who were they?

Joanna's Search

The donor at the conference was not Joanna Rose's biological father, but the new perspective she gained at the conference catalyzed her interest in searching for him. Joanna met with a number of men who could have potentially been her father. While some donors preferred to remain anonymous, others, such as those Joanna spoke with, were intentional in their efforts to connect with their genetic kin. All of these men were sperm donors when they were younger, and although they had donated their sperm under the auspices of anonymity, each wanted to connect with his genetic offspring. At one point Joanna thought she had found her biological father, a man who had donated at the same clinic she was conceived in. The man, now a doctor, believed that he had fathered between 100 and 200 biological children, and that she could potentially be his daughter. The two had similar health issues, such as arthritis and psoriasis. A test showed that they had the same blood type, but upon further genetic testing, it was determined that they were not related (Cronin and Jones 2000).

Throughout this process, Joanna felt emotional turmoil, stigma, and stifling uncertainty (Rose 2006).

The notion that she could have anywhere from 100 to 200 half-brothers and sisters overwhelmed her. That hundreds of her half-siblings could be any of the anonymous faces she encountered on a daily basis caused Joanna to question the intentions of the medical community and the British government. She did not understand how a situation such as hers could be sanctioned by the state. It seemed as if profits were the primary concern, with the well being of the people resulting from the procedure (the donor-conceived) coming along as an afterthought. She was frustrated that there were not mechanisms in place to protect “people like [her]” from “people making profit.” Joanna saw herself as the result of a social experiment: “I’ve always felt like a social guinea pig, an experimental guinea pig” (Cronin and Jones 2000).

At the age of nineteen, Joanna moved to Brisbane, Australia for college. The move was an effort to distance herself from the dissonance she was experiencing. She was determined to “gain the space and time [she] needed to understand [herself] better” (Rose 2006). She was grateful for the geographical distance put between herself and her parents in the United Kingdom, as she tried to figure out why she was “so uncomfortable” with herself and work through her bulimia and depression (Rose 2006).

Olivia: Trying to Fill the Missing Branches

Olivia Pratten, now a Toronto journalist, was born in 1982, conceived through a process of donor insemination in Dr. Gerald Korn’s Vancouver clinic. As she matured into an adult, she continued to wonder about her biological father, and what role his genes played in developing her identity, both biologically and socially. Did he also have thick, dark hair and porcelain skin? Was he an American or a Canadian? Did he ever wonder about his biological children resulting from the sperm he donated? Olivia had

the head and heart of a journalist, full of natural inquiry and a passion for finding answers to the “tough questions” facing contemporary society. Did her donor also have this zeal for discovery? Knowing that he existed, and having no means of contacting or learning more about him, agonized Olivia (Pratten 2009).

When Olivia was born, she was born into a world where donors were... donors. Their role in the process of conceiving a child was limited to the sperm donation itself. Donors never met the people hoping to use their sperm to create a child. Most of the donors at Korn’s clinic had been medical students at the local university, and like all donors, they were guaranteed that their names and personal information would not be disclosed. Whether a donor did or did not want to reveal his identity at a later date was irrelevant to the guarantee, which promised anonymity, but also prohibited identification of donors.

When Olivia was nineteen, she journeyed back to the clinic where she was conceived. Here, Dr. Korn performed the donor insemination procedure on Olivia’s mother, Shirley. Nervous, palms sweaty with anticipation, but full of hope, Olivia sat in the waiting room enveloped in the bright hue of the overhead fluorescent lights, praying that Dr. Korn would provide her with the information she needed in order to contact her donor (Pratten v. British Columbia 2011; Pratten 2006). Finally, she might be able to put branches on the other half of her tree.

Secrecy in Context

The secrecy surrounding Joanna Rose and Olivia Pratten’s conceptions was not a new phenomenon. Historically, secrecy has been a basic practice in donor insemination going back to the 1800s. With the exception of advances in cryopreservation (enabling sperm to be frozen and stored almost indefinitely), the technological aspects of assisted insemination have remained fairly unchanging. Most

discussions of the genesis of gamete donation center on a narrative set in 1800s Philadelphia. Although donor insemination practices are rumored to date back as far as 1700s France, the first recorded case of donor insemination occurred almost a century before Joanna and Olivia's conceptions, in 1884 Philadelphia, when Professor William Pancoast used a rubber syringe to inseminate an anesthetized Quaker woman with donor sperm from his "best looking" medical student. The woman was not aware that the sperm came from a donor rather than her infertile husband. Nine months after the procedure, a healthy male baby was born. Fearing the mother's reaction to knowledge of being inseminated by sperm other than her husband's, Pancoast instructed the husband to never tell his wife. One of Pancoast's former students, Addison Hard, recorded the secret operation in a 1909 issue of *Medical World*, an American medical journal. Hard, breaking his "vow of silence" on the matter, writes,

Neither the man nor the woman knew the nature of what had been done at the time, but subsequently the Professor repented on his action, and explained the whole matter to the husband. Strange as it may seem, the man was delighted with the idea, and conspired with the Professor in keeping from the lady the actual way in which her impregnation was brought about [...] (Horn 1997, 147)

Hard had also traveled to New York to meet the son of the Quaker couple, who was now a young businessman, and shake his hand. It has been widely speculated that Hard was the sperm donor (Daniels 1998, 78). Either consciously or unwittingly, Professor Pancoast, Addison Hard, and Pancoast's other students set in motion a practice of secrecy and non-disclosure that would continue for the next century. If Hard really was the sperm donor, though, his desire to meet the young man conceived from his sperm throws an interesting light onto the narrative – despite the intentional secrecy of the entire endeavor, secrecy that Hard was complicit in and supportive of, he still met with

the boy. What his intentions were in wanting to meet his genetic offspring, despite his commitment to secrecy, we can never be certain of.

Debates around Donor Insemination, Adultery, and Secrecy in the Twentieth Century

Secrecy remained common practice throughout the 1900s, and perhaps not surprisingly so, given the continuing public debates over whether the practice of donor insemination consisted of adultery. Debates on both the spiritual and legal legitimacy of the practice came to life in the experiences of couples such as Scottish Ronald MacLennan and his wife Margaret. A 1958 *Time Magazine* article reports that the couple separated in 1954. Margaret moved to the United States and Ronald stayed in Scotland. Ronald filed for divorce, believing that Margaret committed adultery, since she gave birth to a baby over a year after he had last seen her. Margaret said that the baby was born as a result of donor insemination; therefore she had not committed adultery. Ronald's lawyer argued, "[T]he essence of adultery is not how it is accomplished, but 'the surrender of a woman's reproductive organs to another man.'" Lord Wheatley, the Scottish judge hearing the case, ruled that Margaret's actions were not "adultery in its legal meaning," noting that a person cannot "have intercourse with only one person present" (Time 1958).

Following the ruling, British theologians, both from the Catholic community and from the Church of England, issued public critiques of donor insemination. Responding to Wheatley's ruling, Roman Catholic spokesman Father Paul Crane retorted that artificial insemination puts humans on the same level as animals: "Human beings are not cattle to be bred by test tubes. Only a pagan world would treat them as such" (Time 1958). Representatives from the Church of England also made their thoughts known. The Archbishop of Canterbury, Geoffrey Fisher, stated that donor insemination is a violation of the marriage compact, and is rooted in deception. A few years prior to the

MacLennan case, Fisher headed a church inquiry that recommended that the practice be criminalized. The report, entitled *Artificial Human Insemination*, concluded that while assisted insemination practices using the husband's sperm was morally permissible, use of the sperm of another man entailed adultery for both the woman and the sperm donor (Creighton 2009, 64).

Canadian theological inquiries reacted more favorably to the practice. In 1977, the Anglican Church of Canada issued a report on the ethics of donor insemination, *Artificial Insemination by Donor: a Study of Ethics, Medicine, and Law in Our Technological Society*. The fifteen-member task force concluded that donor insemination was morally permissible when used within the confines of marriage. Phyllis Creighton, author of the report, recounts that the majority of members in the task force felt that donor insemination was

a humane, moral response of marital love faithful to God's will, the desire and need legitimate, children a blessing for the couple and society, and, where responsibly undertaken by the pair, the donation of sperm humane and responsible. (Creighton 2009, 65)

A minority of the ACC task force expressed reservations, believing that viewing donor insemination as a technological remedy to infertility ignores the "human dimensions" – "the anonymous biological father and the partial genetic otherness of the child." The Task Force also grappled with the implications of donor anonymity, drawing parallels to the adoption experience, and citing the research of adoption experts regarding the damaging effects of secrecy and the importance of adopted children in learning about their genetic origins (Creighton 2009, 66). These early dialogues drawing parallels to the adoption experience would continue to permeate contemporary Canadian ethical and legal debates over the issue of genetic identity and anonymity.

An Aura of Secrecy: Legitimacy

As use of donor sperm became more prevalent in the 1970s, as it could now be cryopreserved, it was common practice for British parents undergoing donor conception to be told by their clinician to forget about the procedure, that “no-one ever need know” that they underwent gamete donation (House of Commons Science and Technology Committee 2005, 42) and that they “don’t need to tell anybody” (Warnock 2002, 65).

The birth of Louise Brown in 1978 caused a resurgence of interest in reproductive technologies, with the practice of donor insemination (two decades after the MacLennan case) making its way back to the forefront of the debate. As one British scientist noted, renewed interest in the potential implications of new reproductive technologies began after British scientists Patrick Steptoe and Bob Edwards “begat Louise Brown – with a little help from Mr and Mrs Brown” (McLaren 1990, 209). The role of individuals *other* than Mom and Dad in the process of babymaking was seen as novel, and a new scientific venture that gave rise to new kinds of people – IVF babies.

In 1984, one hundred years after Pancoast’s successful donor insemination experiment, and four years after the birth of Louise Brown, the British Committee of Inquiry into Human Fertilisation and Embryology generated the *Report of the Committee of Inquiry into Human Fertilisation and Embryology*. The report provided recommendations regarding the governance of fertility treatments and research involving the manipulation of human gametes (for full detail and history of the Warnock Committee, please see the previous chapter). While donor insemination was a not a new technological phenomenon the committee dedicated a significant portion of the report to researching and providing recommendations on next steps. Since donor insemination had been practiced for decades in Britain, predominately under the auspices of anonymity and secrecy, the committee had the challenge of evaluating those practices in light of both legal and social contexts. On one hand, the MacLennan case

made it clear in 1958 that donor insemination does not comprise adultery in the legal sense, and on the other, British social and political order was rooted within a context that historically, placed a great deal of emphasis on producing legitimate heirs. Therefore, the committee had to navigate those two contexts, and ultimately, renegotiate the notion of familial legitimacy in contemporary Britain.

The Warnock Report was explicit in its discussions around the notion of legitimacy. The committee grappled with the issue of legitimacy under the law, and legitimacy within the family and society. The report noted that while assisted insemination is not unlawful, whether the sperm is from the mother's husband or a donor, there exists a question of legitimacy when the sperm comes from a donor, while the child conceived via donor semen is considered "illegitimate," which is considered a "disadvantage[d] status":

A child born to a married couple as a result of AIH is the legitimate child of that couple. A child born as a result of AID, on the other hand, is illegitimate, and so is liable to suffer all the disadvantages associated with that status. In theory the husband of the woman who bears an AID child has no parental rights and duties in law with regard to that child; these in principle lie with the donor, who could be made liable to pay maintenance, and who could apply to a court for access or custody. (Department of Health and Social Security 1984, 20)

The emphasis on legitimacy and ensuring that donor-conceived children were viewed as legitimate was embedded within a broader historical dialogue surrounding legitimacy of birth, where sons and daughters are heirs as much as they are individuals. This preoccupation with heirs is particularly apparent in the context of the British monarchy, where the blood linkages from father to son have served as the means by which order has been restored to British political society. Legitimate heirs are essential in maintaining legitimate political power within family lines.

Family ties, and the ability to trace those ties, served as an important facet of British political order. Historically, British society has been maintained by aristocracy. Edmund Burke praised the British aristocracy as embodying public virtue, a virtue that the Marquess of Curzon noted to the House of Lords was “genetically transmitted” (James 2010, 2). Burke noted that the deep connection of the members of the aristocracy to past, present, and future generations – the dead, the living, and still-to-be-born family members – was the essence of aristocracy. The family was the “most fundamental unit of upper class existence” (Cannadine 1994, 1). Thus, maintaining the appearance of legitimacy, of genetic lineage, within the British family, particularly the aristocratic class, was of the utmost importance. Given this context, there is the sense that British children are heirs to part of a larger society by virtue of their birth, of their genetic linkages. To be illegitimate is to be disadvantaged, and to lack the social advantages that one would otherwise have, if one was legitimate.

Warnock, in her reflections on the work of the Committee, reflected that a common social view of families created with the help of a third party (i.e. a donor) is that such families are “artificial,” implying that these families are not legitimate or not real, as opposed to “wholly beneficial” treatments that only involved the gametes of the husband and wife:

The general public, and members of the Committee, began to have moral hesitations when participation of a third party, not one of the infertile couple, is involved in the remedy for infertility, as is the case with artificial insemination by donor (AID), egg donation, and surrogacy of the form most usually considered where the mother who carries the child is its genetic mother. [...]Some people are prepared to argue that such remedies for infertility are intrinsically wrong, since the family ought to consist of mother, father, and the genetically related children, and that deliberate deviation from this pattern is contrary to the moral law. Such arguments would make AID and surrogacy into forms of adultery. But even short of so extreme a view, many people feel doubts about the status

of the child in such "artificial" families, within which the relation of parents to child is asymmetrical, and where the child is often brought up deceived about his true origins. His position is bound to be ambiguous, both emotionally and legally. So it is argued. (Warnock 1985, 507)

The language that frames families created with the help of donor gametes as "artificial" families puts such families in opposition to other families – families comprised of *real* genetic ties. One can imagine that the introduction of a third party into the process of babymaking would be especially disruptive in a society that views its children as heirs. This concern is evident in how the Warnock report framed the sperm donor – a third party who can suddenly appear and demand custody, a third party who is the legitimate father under the law. The very presence of a third person in the British historical memory creates a disaster in thinking about inheritance. One only needs to take a quick glance at British history to see that monarchies are contested, primarily on questions of biological legitimacy.

Co-Production: Using Legitimate Treatments to Create Social Legitimacy

The introduction of the third party, the donor, presented a fundamental challenge to the Warnock Committee to reconcile legitimacy with traditional cultural understandings of the British family. The committee noted that the donor could potentially be a threat to a couple's relationship, since the wife would be carrying another man's genetic offspring.

And it could even be viewed as adulterous:

it is also seen as a threat to the relationship and to the family which is based on it. The threat arises because the child would be biologically the wife's and the donor's, and the husband would have played no physical part in its procreation. Some go so far as to suggest that the introduction of a third party into the marriage means that AID is in fact comparable to adultery, in that it violates the exclusive physical union of man and wife, and represents a break in the marriage vows. (Department of Health and Social Security 1984, 20)

While acknowledging why, socially, a child conceived through donor gametes might be viewed as illegitimate, or “artificial,” the committee made extensive effort in trying to show that donor conception is *distinct* from other unconventional forms of family-building. This technology and the use of donor gametes do not comprise adultery, contended the report – indeed, use of donor insemination can actually make a couple’s relationship stronger:

However, in law AID does not constitute adultery and in practice there are several distinctions. AID involves no personal relationship between the mother and the donor at all, and the identity of the true father of the AID child will normally be unknown to the mother, and unascertainable by her. In most cases it can be assumed that the mother’s husband is willing from the start to treat any resulting child as his own and not merely as an accepted “child of the family”.³ It will often be true that AID with the consent of the husband is a mark of stability in a marriage while an act of adultery may well be the opposite. (Department of Health and Social Services 1984, 20)

The committee noted that if children discovered that they were conceived via donor insemination, there could be harmful psychological implications, but the impact would be equally harmful if they accidentally learned that they were illegitimate or adopted. “However, while we agree that it is wrong to deceive children about their origins, we regard this as an argument against current attitudes, not against AID in itself” (Ibid, 21).

Donor insemination enables a couple to bring up a child “as their own,” with the child at least being “biologically the wife’s” (Ibid, 22). Indeed, unlike adoption, the committee stated that the couple is able to “share the experience of pregnancy, in the same way as any other couple does” – this in turn “may strengthen their relationships as joint parents” (Ibid, 23). The committee then affirmed its view that donor insemination is

³ This phrase was traditionally used in England and Wales for a child that is not biologically related to one or both of a couple. Stepchildren could be considered children of the family.

a “legitimate form of treatment” for infertile couples, and should “be available as a treatment for the alleviation of infertility.” Furthermore, it recommended that the husband be listed on the birth certificate as the father of the child conceived through donor insemination.

As matters stand at present there is a temptation for the couple to conceal the true situation when a child is conceived as a result of AID, in order to hide the fact that the husband is infertile and to avoid unfavourable reactions among relatives and friends. Therefore the couple may, in registering the birth, state that the husband is the father, thus committing an offence. Where the mother is married and the husband consents to AID (4.17) we recommend that the law should be ch[a]nged so as to permit the husband to be registered as the father.

The committee noted that it could be criticized for “legislating a fiction”:

We are fully aware that this can be criticised as legislating for a fiction since the husband of a woman who has conceived by AID will not be the genetic father of the child and the register of births has always been envisaged as a true genetic record. Nevertheless it would in our view be consistent with the husband's assuming all parental rights and duties with regard to the child. (Department of Health and Social Security 1984, 26)

While the 1984 report of the committee states that detailed information about a donor should not be released, in order to discourage parents from seeking to give birth to a “particular type of child” (Ibid, 24) (e.g. a child with brown hair and brown eyes, or a child with blonde hair and blue eyes), the committee recommended that donor-offspring be able to access more detailed information on their donors upon turning eighteen, such as the donor’s ethnic background and health record. The report noted, however, that such legislation “should not be retrospective,” so any donor-conceived individuals born before the legislation went into effect would not be able to access any information on their donor (Ibid, 26).

A second concern relates to the role of the donor as a third party, an identifiable real person, and the potential emotional impact such information could have on families, in addition to what the interjection of a third parent might have on the identity development on donor-conceived children. Despite recommending that donor conceived individuals have some access to limited information on their donor-parent, the Warnock Committee was reluctant to expand access to specific identifying information. The report argues for the “absolute anonymity of the donor” based on fears that a known donor could potentially be an “inva[sive]... third party” to a familial situation.

The other fear of the Commission was that a system in which donors were *not* anonymous would dissuade people from donating out of fear of being asked to take monetary or other responsibility for any resulting offspring. The report reads:

Without anonymity, men would, it is argued, be less likely to become donors in view of the risk that they might subsequently be identified and forced to accept parental responsibility for an AID child, by payment of maintenance or otherwise. Clearly in view of our recommendation (4.17) that the AID child should for all purposes be treated as the legitimate child of the couple who have benefited from successful treatment, the donor should have no responsibilities towards the child. **We therefore recommend a change in the law so that the semen donor will have no parental rights or duties in relation to the child.** We recognise that one consequence of this provision would be that AID children, even if informed about the circumstances of their conception would never be entitled to know the identity of their genetic fathers. (Ibid, 25)⁴

Despite acknowledging the consequences of such a recommendation, that donor-conceived individuals would have no right to know the identity of their donor-parents, the committee ultimately felt that a steady sperm supply would be put in jeopardy if a scenario in which donor-anonymity was abolished were to come to fruition. Although the committee mentioned little else regarding the need to maintain anonymity

⁴ Corrected for spelling errors.

for the sake of maintaining a supply of donors, that it cited this problem as a reason for keeping anonymity is significant. Why the committee argued that abolishment of anonymity would lead to a drop in donors, and why such drop would be unacceptable, can be viewed a few different ways.

I argue that one could view it as an issue maintaining the health of the British population. If there is not a supply of sperm to meet the demand of infertile couples, it would be more difficult to serve the health of those couples. It could also potentially be interpreted in light of a British need for population growth, as the Warnock report was generated shortly after what is known as the “years of zero growth,” when, in the 1970s, dropping birthrates began to demand public notice. In this decade, the population only increased by .03 percent. With a population that was getting older, and not reproducing, “plans for schools, roads, jobs, hospitals, early retirement, and social services would have to be reevaluated, and, in many cases, scrapped” (Soloway 1995, 358). Another interpretation of the committee’s preoccupation with the sperm supply goes back to the conceptualization of the British family in terms of parents and heirs. Giving birth to an heir would be a culturally meaningful event. Having a supply of sperm would then ensure that infertile couples could produce an heir.

New Routes to Legitimacy

By creating legal fictions, the Warnock committee established a new route to legitimacy. It renegotiated tacit social contracts so that legitimacy is no longer just biological. The committee acknowledged that it could be perceived as creating a legal fiction, where a child who might be perceived as illegitimate, through the construction of legal regimes, is converted into a legitimate child. This was done by eliminating the donor, an “invasive third party,” out of the family dynamics. By legally obscuring the donor, and listing the mother’s husband as the legal father, a normal couple and their

baby is all that is left. Note that the child resulting from donor conception is, throughout the report, explicitly labeled as an “AID child,” although the family is never referred to as an “AID family.” The committee sets out to renegotiate these different categories, or “kinds” of people, and normalize them (see Hacking 1999, 36). In Britain, there is no such thing as an “AID family.” Thus, the committee fits what might have been an unruly social kind, the AID child, back into traditional institutions of social and political life, and the British are ultimately left with only one kind of family – a legitimate family.

Canadian Dynamics

The approach of the Canadian government was contextualized by a different set of dynamics, largely leaving the medical community to regulate itself, with the private market dictating payments for donors, and each clinic crafting its own forms and verbiage regarding guarantees of anonymity (Pratten v. British Columbia 2011, 71). While the birth of Louise Brown in Manchester, UK had become deeply seated within British consciousness, the Canadian context did not parallel the British experience, particularly in relation to Britain’s rapid response to establishing an inquiry and creating a policy framework. The fervor following the birth of the first IVF baby was widespread and longstanding in Britain, while the impact on the Canadian public consciousness is more debatable. The different levels of national coverage help illustrate the varying levels of national awareness, and why Britain might move quickly in addressing policy around reproductive technologies.

In an overview of news articles on “Louise Brown” and “IVF,” in the Canadian *Toronto Star* and the British *Guardian*, the terms appear in three articles in the *Toronto Star* between 2006 and 2010, whereas in the *Guardian*, there are fifty articles mentioning the terms between 1985 and 2011. When a search is conducted for just the term “IVF,” the *Toronto Star* generates a total of 201 news articles between 1986 and

2011, with eighteen articles in the period of 1986 and 1989. A search of the *Guardian*, on the other hand, generates a total of 1000 news articles on IVF between 1984 and 2011, with 73 articles falling within the 1984 and 1989 time periods. The levels of newspaper coverage of Louise Brown's birth and of IVF technologies in Canada and Britain demonstrates that while there was a peak in coverage in both nations, the peak in Britain was spread out over time, as opposed to in Canada, where coverage was less prevalent and died off after the 1980s. The dynamics and timetables of governance in Canada are different from the British response to the technologies. Such dynamics are embedded in ongoing Canadian national identity formation – of what it means to be a Canadian, the tensions of a federal state navigating the relationship between the national government and the provinces, and the role of the state in relation to the concerns of its citizens (Brooks 1996, 40-50).⁵

In the absence of federal regulation and frameworks for reproductive technologies, small groups of Canadian citizens comprised of activists and academics began petitioning the government to explore the potential implications of the technologies. The Canadian approach to governing reproductive technologies is situated within a number of influencing factors, including an inherent tension between the provincial and federal governments, and also with a powerful configuration of citizen lobbyists, who brought a “particular feminist discourse” to the national stage (Mavis and Salter 2010, 421). Throughout the 1980s, the vocal feminist lobby was led by lawyer

⁵ These tensions, in part, can be tied back to the notions of court and country, concepts that illustrate the historical Canadian dilemma of the state and its power as it relates to the various societal groups that make up the citizenry. The court perspective represents a “powerful legislature, centralized political power, strong executive, and traditional prerogatives of the crown.” Country, on the other hand, was and is a perspective opposed to strong executive power, favoring a powerful legislature more in tune with social needs and individual liberties, one that emphasizes individual liberties and a check on the powers of the executive (Brooks 1996, 52).

Maureen McTeer and educator Margrit Eichler (Gray 1991, 1371). The feminist lobby was primarily concerned with issues related to the commoditization of the human body and payment for tissues such as sperm and eggs (Jones and Salter 2010, 321). In 1987, the lobbyists officially established themselves as the Canadian Coalition for a Royal Commission on New Reproductive Technologies.

The dialogue around rights, reproductive technologies and their role in society emerged alongside the Constitution Act of 1982, a year after Olivia Pratten was conceived, which provided a formal amendment process for the Canadian Constitution. Up until this point, the Canadian Constitution did not incorporate notions of civil rights/liberties. Prior to the Act, civil rights had not been formally protected by the Constitution, rather, an evolving patchwork of statutes served as the primary reference to Canadian civil liberties. Indeed, the groundwork for debates in the late 1980s had been laid years earlier, when Canadian Prime Minister Pierre Trudeau catalyzed what was deemed the Homecoming of the Canadian Constitution (i.e. patriation of the Canadian Constitution from Britain) (Jones and Salter 2010, 424). Patriation would provide for an amendment process for the Canadian Constitution, absolving British Parliament of any responsibility in stewarding the Canadian Constitution, which was, until 1982 a component of British law and could only be amended by an act of British Parliament. Debates over patriation from the 1960s onward primarily focused on “virtually all attempts to achieve recognition and equality within Canadian society. Aboriginal peoples, multicultural communities, women’s groups, the disabled, the gay community, low-income Canadians, unions, and others all sought express mention within the constitution, and when successful (and even when not), tried to vindicate their rights before the courts” (Webber 1994, 92). Following patriation in 1982, which included

a Charter of Rights and Freedoms, the provinces were given a three-year period to conform to the new provisions.

During this time, a group of primarily female lawyers led a campaign to focused on equality rights in Section 15 of the Charter. They wanted guaranteed equality rights that could not be overridden by any other section of the charter. “They were successful; rights to protection of the law free from discrimination based on “race, national or ethnic origin, colour, religion, sex, age or mental or physical disability” are enshrined in the Charter as it stands today, and guaranteed by the “notwithstanding clause,” Section 28 (Government of Canada, Department of Justice, 2004). These events had far-reaching effects which began to emerge throughout the remainder of the 1980s” (Jones and Salter 2010, 423).

The Baird Commission: Medicalization and the Women’s Movement

The Baird Commission was established in 1989 and generated its report “Proceed With Care” in 1993. Two ideas emerged from the Baird Commission’s work on donor insemination that diverged from the writings of the Warnock Committee. The first is the idea of the child and his or her welfare as an independent entity apart from the family. The second is the focus on the psychological constitution of the family as opposed to patrilineal constitution. In its emphasis on the psychological aspects of familial constitution, the Baird Commission viewed the family as a functioning social unit that has the potential to have healthy or unhealthy dynamics.

In its investigation of assisted insemination and donor insemination, the commission stated that the technology and its accompanying social implications deserved more attention than had been paid to it previously (Baird 2003, 425). Although many clinics kept records on patients undergoing donor insemination beyond the minimal requirements set forth by provincial law, there was no guarantee to patients that

the records would continue to be preserved. The Commission noted that assisted insemination practices had primarily been self-regulated by the medical community, ranging from issues related to access, confidentiality, and record keeping:

[T]he medicalization of AI has also created a situation in which medical practitioners are the gatekeepers of DI in particular, enforcing what they perceive to be community standards about family formation by establishing access criteria to it. There were also concerns that despite being viewed as within the medical sphere, some aspects of DI are in fact under-controlled and not monitored, so that the procedure is not as safe as it should be. (Baird 1993, 430)

While professional guidelines were established for assisted insemination practices, they were entirely voluntary, and originated from the medical community itself. A number of Canadian medical organizations published voluntary guidelines for “every step of the process,” with the first guidelines published by Health and Welfare Canada in 1981, but these guidelines continued to be completely voluntary, “not uniformly adhered to,” with some clinicians “not even aware of them” (Baird 1993, 431).

The Commission declared that the lack of consistent record keeping and monitoring of the practice would make it “impossible to [meet the] future needs of AI children and their families for information.” Families created with the help of donor sperm were characterized as living in a “legal vacuum” in most Canadian provinces, given the “haphazard” means of recording DI births, and patient and donor information (Baird 2003, 441).

The language of the Baird Commission around the “gatekeeping” role of the medical community mirrors broader dialogues around the women’s movement in the United States and Canada, which argued that health is “about much more than particular reproductive organs and secondary sex characteristics,” rather, it is embedded within social, environmental, and psychological contexts, and is therefore “a social issue and a

social contract rather than simply a medical and technical problem to be addressed by experts” (Morrow et. al. 2007, 36). Alongside the women’s health movement in Canada, national policy frameworks were being developed that integrated broader social contexts into the health sphere, “recogniz[ing] the role of social justice and equity as prerequisites for health.” This perspective became formalized in the 1986 Ottawa Charter for Health Promotion, which defines health as embedded within broader social contexts, not just the medical community itself:

Health promotion is the process of enabling people to increase control over, and to improve, their health. [...] Health is a positive concept emphasizing social and personal resources, as well as physical capacities. Therefore, health promotion is not just the responsibility of the health sector, but goes beyond healthy lifestyles to well-being. (World Health Organization 1986, 1)

Concerns about the moral and social implications of the medicalization of infertility in relation to emerging reproductive technologies shaped the women’s movement of the 1980s. With a self-regulating medical community, doctors ultimately became the gatekeepers to fertility treatments, including treatments such as artificial insemination. Access to these treatments for non-traditional families, such as lesbian couples and single women, was solely the discretion of individual medical practitioners (Morrow et. al. 2007, 44).

The Baird Commission’s extensive report spends seventy pages exclusively dealing with the topic of assisted and donor insemination and its impact on families and children. Language focusing around the implications of assisted and donor insemination on “offspring and families” is prevalent throughout the chapter. The commission, in its introduction on the topic, states that

the lack of enforceable regulation and inadequate monitoring of the practice of AI have the potential to endanger the health of AI recipients, their partners, and

their children; [...] inadequate record keeping is making it impossible to meet the current and future needs of AI children and their families for information; [...] families formed through assisted insemination exist in a legal vacuum in most provinces, with the potential for conflict and distress if disputes over a child's parentage, custody, or inheritance arise. (Baird 2003, 425)

The commission's concerns about custody and other legal issues around the use of reproductive technologies in Canada coincides with the new challenges around custody that American courts were forced to grapple with. Jasanoff (1995, 176-178) highlights the complexities that arose in the late 1980s when donor insemination was coupled with surrogate motherhood. The story of "Baby M," where a custody battle raged over whether the surrogate mother had legal parental rights to the child, illustrates one such complexity. That the Baird Commission identified a "legal vacuum" in this area is not an accident.

The report emphasized the negative implications of secrecy on both individual families and broader Canadian society. It stressed the importance of counseling in helping families deal with "the strong psychosocial implications of DI." "People need the opportunity to discuss and weigh their options with a qualified counsellor" (Baird 1993, 461). Although "not everyone wants counselling [...] perhaps to help maintain secrecy about their involvement and appear as close to a 'normal' family as possible," the Commission advocated that "patients would benefit significantly from counselling before, during, and after treatment, and from discussing their situation and the options before them" (Baird 1993, 462).

Secrecy in Canada

"New social dilemmas" emerge from the complexities of donor insemination, noted the Commission, both at the individual and societal levels. Secrecy at the individual level can lead to conflicts within the "DI family," and at the broader social level,

secrecy can lead to “gaps in relevant research, legal direction, and record keeping,” therefore leaving it difficult to address the needs of DI families via law and policy (Baird 1993, 463). Secrecy, additionally, implies that there is “something to be ashamed of,” which is reinforced when practitioners suggest to patients that they keep the DI procedure secret, “even from the child, to preserve the appearance that the family does not differ from most other families.”

The Baird Commission’s proposition that secrecy suggests something to be ashamed of runs counter to the understandings of secrecy found in the Warnock Committee’s report. In the Warnock Report, secrecy is not an implication that there is nothing to be ashamed of, but a strategy of ensuring that there is nothing to be ashamed of. Indeed, in having a “government obsessed by secrecy” and even an Official Secrets Act, there is nothing contrary to British values in holding secrets (Knightley 1987). Shapin notes that there was even such a concept as “virtuous” secrecy, with British writers encouraging gentlemen to be wary of being too open about private matters: “Precisely because certain things that a person knew could decisively tip the balance of advantage in social transactions, one’s statements in those transactions had carefully to be gauged according to the complex calculations of interest, trust, and the principles of virtuous action” (Shapin 1994, 105). The Baird Commission, conversely, maintained that secrecy contradicts Canadian social values, noting that “our society values honesty and openness in personal relationships,” (Baird 1993, 463) although parents are encouraged to keep the procedure a secret by Canadian laws and medical institutions (Baird 1993, 464). Secrecy, although it might seem “easy to maintain [...] on the surface,” it “places great strains on families.” Mothers and fathers must “always be on guard” to not give away the secret (Baird 1993, 464).

Further diverging from the Warnock Committee, the Baird Commission did not downplay the role of the donor, rather the Commission recognized the donor as a key actor – an actor that has psychological and emotional needs that had largely been ignored. The commission acknowledged the role of the donor by stating that donor insemination “begins with the donor,” yet donors have been largely absent from studies on donor insemination (Baird 1993, 441). The donor’s interests and role should not be ignored, wrote the Commission, because the donor, anonymity, and the practices of clinics “have implications for the donor’s health and psychological well-being, as well as that of the recipient and her child” (Ibid). Here again, we can observe the focus on the health and well-being of the parties involved in the donor insemination process.

Learning from the Adoption Experience: DI Families and DI Children

The Commission argued that the DI family was, in some legal areas, not fully covered by existing family law, and, given the special nature of how these families were created, required special policy to remedy the gaps: “Reforms in Canadian family law are needed to define the roles and responsibilities of DI participants and to avoid further confusion in this area” (Baird 1993, 466). Unlike the Warnock Committee, which goes to great lengths to “legislate a fiction” so that donor conceived children and their families are viewed as no different from any other British family, the Baird Commission sets donor conceived children and their families apart as a separate kind of child and family that need to be acknowledged as different from conventional families, so their emotional and psychological well being can be accounted for. DI families and children need additional measures to ensure their well being, such as improved recordkeeping measures. The “haphazard” or lack of record keeping on DI practices could be a threat to the “psychological needs” of DI children and their families (Baird 1993, 469). Improved

recordkeeping practices would afford “peace of mind” to DI participants (Baird 1993, 470).

While DI families and adoptive families “are different,” the Commission noted that the adoption experience can shed light and guidance in developing a framework for DI policy, particularly in relation to disclosure of donor information (Baird 1993, 468). Here, the Baird Commission diverges from the approach of the Warnock Committee again. While the Warnock approach views the adoption experience as fundamentally different from donor insemination (noting that unlike adoption, parents can share in the experience of pregnancy and forge stronger parental bonds as a result), the Baird Commission views the adoption and donor conception experiences as having some underlying similarities. The report described the adoption recordkeeping framework as being based on the “best interests of the child,” and noted that DI practices “should have similar goals,” particularly in caring for the emotional well being of the child:

All jurisdictions have some means of providing for the release of non-identifying information about birth parents to adoptive families, in recognition of its importance to the emotional well-being of adoptees. (Baird 1993, 470)

The commission considered three different options regarding information disclosure to donor-offspring. The first option was full disclosure. With full disclosure, donors would be informed that their donation would not be anonymous and that patients and the resulting children would have access to the donor’s identifying information. The commission asserted that the issue is not as “straightforward” as it might first seem, and full disclosure might actually work against the interests of the resulting child by impeding on and “threatening” the development of family bonds, could “encourage secrecy” and discourage parents from disclosing a child’s true origins to them (Baird 1993, 443-444). Here, the divergent viewpoints between the Baird Commission and the Warnock

Committee can be observed. The Baird Commission frames the issue of full disclosure as being an issue of the well being of the child – full disclosure could actually harm the well being of the child. The Warnock Committee, on the other hand, frames full disclosure as potentially harmful in that it opens the door to an “invasive third party” (the donor) to interrupt what is otherwise a legitimate family.

An additional justification for rejecting the option of full disclosure is that donor-offspring are not the only Canadians who might not know who their father is:

It has been estimated that the birth certificates of between 6 and 10 percent of children born in Canada do not contain an entry for the father. Even in Cases where paternity is presumed, children born as a result of extra-marital affairs or relationships that broke up before the current union are often raised thinking they are biologically linked to both their parents – society does not demand disclosure in these instances. (Baird 1993, 443)

This perspective would become a major arguing point in the resulting British Columbia court case that Olivia Pratten would bring forth, decades later. The committee’s final reason for rejecting full disclosure was the fear that it would lead to a drop in donors. The report cites 1985 Sweden as a case study, where after abolishing anonymity, the country saw a drop in donors.

The commission also considered a “dual system” in which donors could choose whether they wanted to have identifying information, including their name, released or to remain anonymous. Patients could then choose an anonymous or identifiable donor, as is the case in situations of adoption in some provinces. The offspring could then access the identifying information when reaching eighteen. The commission re-emphasized that it understood “DI families” to be different from families that adopt, since in adoption, neither adopted parent is genetically related to the child, and in DI families, one parent is genetically related to the child. Additionally, adoption occurs when the biological parents

are unable to care for the child, and donor-conception is deliberate, with “the intent of nurturing and raising [the child].” Such a system would also create two classes of individuals, one group of people who would have information on their donors, and one group who would not have access. Finally, the commission argued that a donor might not feel the same way about disclosure in eighteen years, when the offspring would access the information: “it is unrealistic to believe that a donor’s feelings and beliefs about his role are unchanging” (Baird 1993, 445).

The final option that the Commission considered, and ultimately endorsed, was disclosure of *non*-identifying information. It recommended the practice of collecting of identifying information (by a national authority) that would be stored for 100 years after the last child was born from a donor’s sperm. In extreme, “extraordinary,” medical circumstances, the authority would have the power to disclose identifying information. In all other circumstances, families and offspring would be able to access non-identifying genetic, social, and health information on their donor. The committee asserted that this system was the most balanced and respectful of the needs of donors, children, and families:

It is a system that acknowledges the need of individuals for social, genetic, and medical information about their biological parent, but it also acknowledges the need for DI families to flourish and form a strong unit if the best interests of the child are to be served. (Baird 1993, 445)

The Commission concluded that its recommendations would help “protect the integrity of families” formed by the technology (Baird 1993, 489). Although the Baird Commission ultimately rejected full disclosure, by drawing parallels to the adoption experience and focusing on the well being of the child, it was laying the groundwork for an argument to be made in favor of it.

Canada – a Culture of Recognition

The Baird Commission's report does not shy away from viewing (and embracing) donor conceived children and their families as different (alternating between referring to them as "AI" children and families and "DI" children and families). Such a perspective is consistent with broader Canadian governmental policies and social understandings. In 1947 Canadians were left to forge their own national identity with the Citizenship Act, which legally made British subjects residing in Canada into Canadian citizens (Government of Canada 2009). Canadian identity was no longer explicitly tied to British citizenship, and Canadians had to now articulate what it meant to be Canadian. Canada is a country that is built and sustained on difference. In line with Canadian multiculturalism policies, people with different backgrounds are "seen as assets rather than burdens, as crucial contributors to Canada-building rather than a national liability, and as fully fledged members rather than outsiders in need of control or return" (Fleras 2009, 190). Differences are celebrated, rather than homogenized.

Joanna Rose: Legitimacy Versus the Right to Know

In the year 2000, British-born Joanna Rose entered the legal arena. In 2000, Joanna brought her case to the English High Court, arguing that the lack of access to information on her donor violated her rights in the 1950 European Convention on Human Rights and Fundamental Freedoms, specifically Article 8, which "guarantees respect for private and family life, including the right to form a personal identity" (Mail Online). The European Convention was proposed after World War II, an era that served as a catalyst in raising questions regarding the most basic rights of individuals. Eighteen months prior to the hearing of the cases, the European Convention was integrated into English law as the Human Rights Act, with Article 8 serving as a major cornerstone of the document (Davis 2003, 22). The integration of the Act brought about new questions regarding the rights of donor offspring to know their genetic heritage. How would the very meaning of

“identity” change in light of the Human Rights Act? What new spheres of rights would be constructed regarding genetic identity and access to information regarding one’s genetic ties, in light of the exceptional suite of circumstances that gamete donation gives rise to?

At the time of the court case, the identity of donors was completely anonymous, although upon turning eighteen, donor-conceived individuals could access limited information on their donor if they were born after 1991, when the HFEA was established. Joanna Rose, twenty-nine at the time, was not able to access any information about her donor, since she was born before the 1990 Human Fertilisation and Embryology Act, which states that donor-conceived individuals can access basic information about their donor once they turn eighteen, including race, hair color, eye color, and height. Rose and an anonymous donor-conceived child, “EM” (represented by her mother), sought judicial review of the Secretary of State’s denial of Rose’s request for information about her donor, review of the denial of EM’s family’s request for non-identifying information about EM’s donor, in addition to the creation of a donor contact register. The Barrister for the case, Monica Carss-Frisk, said that EM’s parents sought to get as much information possible about her donor prior to her turning eighteen, so they would be able to answer the inevitable questions their daughter would have as she turned older (BBC News 2002). Rose was specifically challenging the Department of Health’s decision to not provide any non-identifying donor information to people born before 1991. After 1991, the HFEA collected donor information from clinics, who were obligated to provide such information. The cases were supported by Liberty, a civil rights group. Liberty emphasized that the ultimate aim of the cases was not to identify the donors, but to make more non-identifying donor information available to donor-conceived offspring and to have the HFEA gather and preserve pre-1991 donor information. The cases also

sought to establish a voluntary registry where willing donors and offspring could get in touch with each other (Dyer 2002).

The Secretary of State denied Joanna and EM's requests, but did say that there would be a government consultation regarding the issues associated with donor anonymity (Med. Law Review 2003, 139).

Joanna suffered a major emotional blow when she discovered that her records had been destroyed, but wanted to continue with the case based on principle, to "give others more rights than she had."

The United Kingdom: A shift from "unnecessary intrusion" to welfare of the child

In the early 2000s, accompanying integration of the Human Rights Act, there was a clear shift in British legal and policy dialogues about donor anonymity. In the past, claimants such as Joanna Rose lacked legal footing, as the unwritten British constitution provided no guarantees of a right to an identity, however, broader legal shifts in facilitating Britain's integration into the European Union created space for new dialogues around donor conception. Paralleling the changing legal dynamics was a shift in the thinking of Baroness Warnock herself. In 2002, shortly after the integration of the Human Rights Act, Warnock stated that she was absolutely convinced that the law regarding donor anonymity needed to be changed, arguing that "It is undermining to any relationship between two people if one knows a salient fact about the other which is not divulged" (Warnock 2002, 65-66). Members of the British media have deemed Warnock's change of opinion as a "complete reversal" of her former mindset (BBC News 2002). Warnock called it "absolutely deplorable" that donor-conceived children not "know what other children know" (BBC News 2002), and that "such deception is evil" (Warnock 2002, 66). Although the common practice in 1984 was that parents not tell their children that they were donor-conceived, Warnock stated that such children were being raised in

a “cloud of deceit,” and if they discovered their genetic origins, it tended to be in “a rather brutal way” (BBC News 2002). Warnock warned against the use of the 1984 report as justification for the status quo, noting that the argument was two decades old (BBC News 2002).

With the integration of the Human Rights Act, new court cases on DNA testing and paternity began to emerge that decided in favor of the rights and wellbeing of the child. Joanna looked to an earlier High Court case where a mother’s objections to a DNA test to determine her seven-year-old-boy’s true paternity were overrode based on Article 8. The judge stated that the boy had a right to access his “true roots and identity” (Dyer 2002). Although the judge stated that he was “sympathetic” to the mother’s perspective, in which she wanted to preserve the fiction that her husband was the boy’s biological father, he concluded that, when considering the boy and balancing his mother and her husband’s interests, DNA testing “ought to take place” (Re: T Approved Judgment 2001). After considering English domestic law and Article 8 of the Human Rights Act, the judge felt “entirely satisfied” after balancing the interests and rights of the adults and child, that the child’s rights were “weightiest,” and “that he should have the possibility of knowing, perhaps with certainty, his true roots and identity [...] a knowledge which would accompany him throughout his life” (Ibid). The 2001 case is significant, because rather than going the historically traditional route of preserving the “legitimacy” of the family structure by keeping the boy’s true paternity a secret, the court instead “interpret[ed] the rights of the child as a need to know” (Dyer 2001).

In addition to arguing that Article 8 was applicable to Rose and EM’s case, the legal team also invoked Article 14 of the Human Rights Act. Article 14 is concerned with freedom from discrimination:

[...] the current system is discriminatory *vis-à-vis* DI offspring and adoptees; and between DI offspring such as

JR (born before the current system came under force under the Human Fertilisation and Embryology act 1990) and those born thereafter, such as EM.

The plaintiffs claimed that the state had an obligation to collect, protect, and make available to DI offspring and their parents. They also argued for the establishment of a voluntary contact register, much like the adoption register (Med. Law Review 2003, 139). In 2002, Justice Scott-Baker of the High Court judge determined that donor-offspring were entitled, under new the Human Rights Act, to ask the courts for more information about their biological fathers. The Human Rights Act integrated the European convention on human rights into English law in October 2002. Scott-Baker ruled that Article 8 served as a basis for donor-conceived offspring to request access to their donor-parents' non-identifying information. The ruling stated, "an AID child is entitled to establish a picture of his identity as much as anyone else" (Med. Law Review 2003, 141).

Joanna expressed her relief at the outcome of the case and stated that it served as a "legal foothold" towards establishing donor-conceived individuals' "rights and identities": "This is an important and heartening event on a long road to recognition of us as people – just like everyone else, with social and genetic roots – rather than as products" (Liberty 2002).

An Act of Parliament and New HFEA Policy

On April 1st, 2005, under new HFEA regulations established by a 2004 Act of Parliament, gamete donors in the UK could no longer donate anonymously. With the change in law, donor offspring, upon turning eighteen years of age, can request their donor's identifying information. This rule is not retrospective, however, so individuals conceived via gamete donation prior to the law going into effect (such as Joanna Rose) will not have the opportunity to access identifying information. In the place of an official

government system for these individuals to contact their donors, more informal, voluntary networks (supported in part by government funds) have arisen, such as the UK DonorLink Initiative. The UK DonorLink Initiative is a voluntary register funded by a 2003 Department of Health grant. It is based off of an organization experienced in post-adoption consultation, After Adoption Yorkshire. The registry is specifically for people who were conceived via donor sperm or were donors in the UK before the Human Fertilization and Embryology Act became law.

BRITTONS: WE WANT YOUR SPERM

At the time of the law's enactment, many commentators feared that it would increase reproductive tourism to other countries where the laws about gamete donation are not as strict or that individuals seeking a child would go to unregulated "backstreet clinics" in an effort to become pregnant (BBC News 2005). However, after the implementation of the 2005 law, there were no permanent drops in the number of donors. A BBC report stated that sperm donations were actually on the rise, up six percent. In the twelve months following the new law, 265 new sperm donors registered with the HFEA (Henderson 2007). These numbers were actually higher than the year before the law came into effect, with only 250 new registrations the year prior. However, regardless of the anonymity law, sperm donations have been falling since the 1990s, when donors peaked at 459 (BBC News 2007). The HFEA has noted that overall demand has also decreased, however, as new fertility treatments offer other options to couples experiencing infertility (Curtis 2006). The six percent rise was surprising to many, since most fertility doctors expected the law to seriously impact the number of men willing to donate sperm, however the figures indicate that the change did "not adversely affect[...] the number of men prepared to donate sperm" (Henderson 2007). However, the change has led to a major shift in who is actually willing to donate sperm.

One of the major sources of donations in the past, “students keen to earn cash[...] all but disappeared,” with older donors, with what some consider more altruistic motivations, taking their place (Curtis 2006).

Since these changes have taken effect, the British National Gamete Donation Trust, a government-funded charity, has undertaken a campaign to recruit more sperm donors (giveatoss.com). The “Give a Toss”⁶ campaign frames sperm donation as an act of serving one’s country. The young blonde woman on the front page of the campaign’s website strikes an “Uncle Sam” pose, pointing her finger at potential donors visiting the sight. Her tight white t-shirt proclaims “WE WANT YOUR SPERM” in blue capital letters. The red text beside the picture reads, “BRITONS: WE WANT YOUR SPERM.” While the website uses humor to its advantage (for example, the loading page reads “We’re coming as fast as we can!”), the underlying tone is also one of patriotism and civic duty.

Olivia Pratten

Despite the work of the Baird Commission in laying a record-keeping framework for future donor-conceived individuals, donor-conceived Canadian Olivia Pratten still felt like she was stuck in the metaphorical “legal vacuum.” Doctor Gerald Korn, the doctor who performed the donor insemination procedure on Olivia’s mother, would only reveal to Olivia her biological father’s height, hair color, eye color, blood type, and that he was a “healthy” Caucasian medical student (Arvay 2008, 3). Doctor Korn refused to reveal the donor’s identity because, he asserted, the donor had the expectation that he would remain anonymous. Although Korn still had the gamete donor records in his possession, he would not provide Olivia with any guarantee that he would preserve them, as the College of Physicians and Surgeons of British Columbia, (under Rule 13 of the Medical Practitioners Act, R.S.B.C 1996, c. 285), only required that the records be preserved for

⁶ According to urbandictionary.com, in the UK, to “give a toss” is slang for masturbation. It also can mean to care about something or “give a hoot.”

six years. The rule does not specifically address donor conception and any issues that might be related to it; rather, it is a general rule regarding the handling of all patient records in the province. Donor-conceptions and the resulting records were not afforded any special status or specificity. Clinicians, such as Dr. Korn, discussed the anonymous nature of the procedure both in verbal conversations between the doctor and his patient, and also provided a written form articulating anonymity. The format and specific wording changed over the years, but the expectation of anonymity remained the same (Pratten v. British Columbia 2011, 53).

When a teenage Olivia wrote to the College requesting that her records be protected, she was informed that after the six-year time “retention period,” the records could be incinerated (Arvay 2008, 3). Although Olivia petitioned the College to take custody of Korn’s records, it refused to do so, since the six-year retention period was long since past.

Olivia had hope, though. She was aware that the Baird Commission had recommended that the records be preserved and protected for 100 years. Olivia and her mother were under the impression that once formed, the long-awaited agency would handle the collection of all donor records and would be able to seize and protect past records. During the time that the AHR legislation was being developed, many conferences were occurring, hosted by various groups, ranging from Infertility Network to Health Canada. In one conference, a patient advocate spoke about the donor records, stating that they could not set up a new system for the future without taking care of the past. A spokesperson from Health Canada assured the donor-offspring advocates that the new agency would be able to deal with the issue. The advocates later discovered that the agency legally could not handle the issue of past donor records, and when the national AHR legislation was finally approved, a mandate for Assisted Human

Reproduction Canada to collect past donor conception records was absent. In 2008, four years after the AHR legislation became law, Olivia was told that AHRC had no legal jurisdiction to protect past donor records (Pratten 2009). With their other options exhausted, Olivia and her mother decided to go through the legal system in hopes of learning her father's identity and changing the way that gamete-donation records are handled in British Columbia. Patients have noted that even if AHRC were to immediately begin collecting donor information and if donor anonymity was immediately abolished, it would not be just, because past donor records could still be destroyed. Olivia is the first donor-conceived person in Canada to file a case seeking the identity of her donor parent (CBC News 2008). The Prattens viewed the lawsuit as a "last resort." A source close to Olivia stated that "you can't put it right only for the future [individuals who might be affected]. Citing the example of asbestos, she said, "You can't ignore the past. You can't just say sorry, your records will be destroyed."

Olivia's lawyers, based out of the Arvay Finley law firm located in Vancouver, had a reputation for being the "bulldogs" of the Canadian legal world, willing to take on complex, controversial cases that other lawyers shy away from. The Prattens approached Joe Arvay, a specialist in human rights and constitutional law who was instrumental in the Canadian gay rights movement, when they felt that they had exhausted all other options. They believed they had done everything possible and the issue "wasn't moving." From the Prattens' perspective, the human rights of donor-conceived offspring were being sacrificed. Although the Prattens had approached the situation focused on *human* rights, the legal team decided that approaching the issue from an *equal* rights approach, versus a human rights approach, would be the best way to attack the issue, since Arvay could then argue that donor-conceived individuals were being denied rights to access records that adopted individuals have.

While the Baird Commission drew parallels between the experiences of donor conceived and adopted individuals, but stopped short of saying that both groups should have the same access to information, Arvay took the argument one step further and argued that since adoption and gamete donation are both activities regulated by the province, individuals conceived through donor gametes should have the same access to their biological parents' identities as adopted children do. Adoption policies in British Columbia ensure that information relating to the social and medical history of an adoptee's biological parents is recorded and preserved. This information is available if needed for medical reasons, and is provided to the adoptee when they turn 19 years of age. Additionally, the identities of the biological parents are preserved, and are provided upon request to the adoptee, in which case they can make contact with their biological parents if they so choose. Adopted individuals also have the right to access their biological parent's identities to verify that they are not related to a potential sexual partner (Arvay 2008, 4). Under the equality provision of the Canadian Charter of Rights and Freedoms (section fifteen), Pratten's attorneys argued that the denial of access to donor-conceived individuals' records is discrimination by mode of conception, and denying donor-conceived individuals access to their medical history has been argued to be a violation of the right to personal security in section seven of the charter. The inconsistency between preservation and access to adoption records versus gamete donor records was the fulcrum upon which Pratten's case was based. The filing of the lawsuit against the Attorney General of British Columbia and the College of Physicians and Surgeons of British Columbia and on October 24, 2008 was the "ultimate empowerment" for Olivia, who had up until then felt as if she was powerless, that "her self-worth had been negated by the government and medical profession" (Pratten 2009).

On October 28, 2008, Chief Justice Donald Brenner of the Supreme Court of British Columbia approved an interim interlocutory injunction, ordering that all gamete donor records be preserved; including documents regarding the donor's medical history, social history, and identity, in addition to documents identifying DI patients and any resulting children. The injunction prohibited the "destruction, disposal, redaction or transfer out of British Columbia of Gamete Donor Records" (Gerow 2008, 2). Although it had been served, there was no representative of the College of Physicians and Surgeons at the hearing. The order instructed that the College inform all of its member clinics of the requirements of the mandatory injunction.

In May 2011, Madam Justice Elaine Adair, writing for the B.C. Supreme Court, ruled in favor of Olivia Pratten. Justice Adair found that British Columbia's adoption laws were discriminatory toward donor-conceived individuals. Adair agreed with the Baird Commission that

there is much to learn from the adoption experience in considering the needs, circumstances, and best interests of donor offspring, that there are many points of similarity between the two groups, that donor offspring share with adoptees many of the same social, psychological and medical needs for information about biological parents, and that, even if well intentioned, serious harm can be caused by cutting off a child from his or her biological roots. (Pratten v. British Columbia 2011, 71)

The Court also concluded that the adoption experience can teach "valuable lessons [...] with a goal [...] of creating and preserving records in the best interests of the child" (Pratten v. British Columbia 2011, 71). The Court also found that because parts of the *Assisted Human Reproduction Act*, such as the sections regarding donor offspring, had not yet come into force, donor conceived people were "no better off." The Court also noted that the actions of the private sector alone were not enough to protect the interests of donor conceived people, that the market "cannot provide an adequate substitute for

government protection and regulation” (Pratten v. British Columbia 2011, 72). Based on the evidence collected, the Court determined that “assisted reproduction using an anonymous gamete donor is harmful to the child, and it is not in the best interests of donor offspring” (Pratten v. British Columbia 2011, 73).

The judge found that the *Adoption Act* and *Adoption Regulation* create a distinction between people who were adopted versus those who were donor conceived:

In my view, excluding donor offspring from the benefits and protections of the ***Adoption Act*** and ***Adoption Regulation*** creates a distinction between adoptees and donor offspring. Furthermore, the distinction is based on an analogous ground, namely manner of conception, and, specifically, conception by anonymous gamete donation. Like race, this is a personal characteristic that is immutable. (Pratten v. British Columbia 2011, 78)

The Attorney General of British Columbia argued that adopted and donor conceived people are different because adopted people do not know their biological origins at all, whereas donor-conceived people have access to half of their genetic ties (having one known biological parent). However, the Court found that whether a person knew only one, or neither, of their biological parents, the situation could be equally harmful.

The evidence in this case, including the evidence of current practices that are designed to avoid cutting off donor offspring from their roots, compels me to the conclusion that cutting off a child from half of his or her biological origins is not in that child’s best interests. (Pratten v. British Columbia 2011, 86)

Having concluded that the omission of donor offspring from the *Adoption Act* and *Adoption Regulation* discriminated against donor offspring and violated Section 15 of the *Charter*, the Court ordered the province to “draft and enact” new legislation to bridge the gap between adopted and donor conceived individuals (Pratten v. British Columbia 2011, 107).

Shortly following the decision, the Attorney General filed an appeal with the federal Supreme Court. However, if the decision is upheld on the federal level, all Canadian provinces “will be compelled to prohibit donor anonymity” (Blyth 2011).

Conclusion: Renegotiating Socio-Technical Contracts

The processes by which reconsiderations of the governance frameworks surrounding donor anonymity took place in the Canadian and British contexts are both similar and different. One issue that spans both contexts focuses on the idea of donor-conceived versus adoptee rights, and the notion that donor-conceived babies ought to be understood in the same way that adoptees are. That if the state is regulating adoption practices and providing means for adopted persons to access information regarding their genetic origins, then the state, which also regulates donor conception, should provide means for donor-conceived persons to access the same information. Both the *Rose* and *Pratten* cases highlight the similar wishes of donor-conceived individuals to know information relevant to their genetic health and also their personal identity.

While *Rose* and *Pratten* might have resulted in similar outcomes, they are different in terms of temporality and context. In the Canadian case, there is a national constitution that has to be upheld, but it is the responsibility of the provinces to do so. In the United Kingdom, there is no constitutional guarantee to a right to an identity, however, renegotiations occurred because the United Kingdom is part of an emerging transnational governance context, and with the integration of the Human Rights Act into British law, new legal spaces for deliberation and renegotiation provided a foothold for Joanna Rose to move her case forward.

The discourses around donor conception within the United Kingdom and Canada were also specific to each context. The Warnock Committee’s report established new

routes to legitimacy other than that of biological legitimacy. It created “legal fictions” in order to renegotiate traditional notions of what it means to be legitimate versus illegitimate. The “AID child” was folded back into traditional British family institutions. Canadian discourses were distinctly different in this regard. Rather than attempting to fit donor-conceived individuals and their families into existing frameworks, the Canadian experience took a different route. The Baird Commission’s report recognizes donor-conceived children and families as unique and different, therefore requiring special policies and treatment in order to establish and promote the emotional well-being of donor conceived children and their families.

The responsibility assumed by the state is also unique to both contexts. On one hand, the British experience highlights a context in which the state assumed responsibility for the regulation of the practices of assisted reproductive technologies almost from the very beginning, with the establishment of the Warnock Committee and the rapid implementation of the Warnock Committee’s recommendations. Clinics were tightly controlled by the Human Fertilisation and Embryology Authority, and information and data was maintained by the government. In Canada, the government was relatively slow to act, with regulation and practices largely being left to the private sector. When Assisted Human Reproduction Canada was finally established, it was immediately contested by the province of Quebec on issues of constitutionality, thus leaving donor-conceived regulation and practices in a continued state of limbo.

The Canadian experience demonstrates that capacities for renegotiation can occur within the private sector itself, specifically in regards to evolving ideas around “known ID” patients, where clinics provide families with the option to select a known donor. However, capacities are also lodged within democratically constituted Canadian officials (such as judges). It is the democratic *office* (as opposed to any one individual)

that has certain rights and responsibilities to respond to what is going on in the market. For example, Canadian Judge Adair goes to pains to observe that even though the private sector was beginning to move forward with a remedy, it was not enough. There was a constitutional issue that the government had to remedy. Whereas in the United Kingdom, the capacity of rethinking and the locus of where ideas evolve is more centered in the government, and in particular within “great and good” individuals with embodied expertise where it can actually make a difference. Expertise is embodied in individuals, as opposed to governmental offices (Jasanoff 2005). In the United Kingdom, the fact that Baroness Warnock changes her mind on the issue of donor-conception matters. One of the places that the capacity for rethinking and reimagination is embedded in people like the Baroness. This also signifies, within the British context, that when decisions are made, they are not necessarily forever. Those with embodied expertise observe, potentially change their minds, and muddle through.

The renegotiation of governance practices around donor conception practices highlight important bottom-up governance capacities at the level of individual experiences and families. In each case, individuals and their families utilized the governance tools at their disposal (specifically the court systems) in an attempt to open up a space for renegotiation of socio-technical contracts that had become static decades prior. However, in each context, the courts have different roles. In Canada, the role of the courts is potentially much more significant in renegotiation and reimagination precisely because there is a founding constitutional document that makes it possible to declare things that the government has done as unconstitutional. In the United Kingdom, on the other hand, with its uncodified constitution, the *Rose* case was not a constitutional claim, rather, it was about two laws in conflict. This again signifies that while there might have been similar outcomes in terms of moving towards governance

schemes that focus on banning anonymous donation, the process by which such socio-technical contracts have been renegotiated is contingent upon specific national and cultural contexts that consist of a multiplicity of capacities at various levels, ranging from individuals and their families, to government commissions, to the private sector, to government commissions.

CHAPTER 5

DELIBERATIVE CAPACITIES: THE GOVERNANCE OF PRE-IMPLANTATION GENETIC DIAGNOSIS TECHNOLOGY IN THE UNITED KINGDOM FROM 1993-2001⁷ *PGD and Socio-technical Contracts*

This chapter explores the deliberative capacities within the United Kingdom that gave shape to British approaches to pre-implantation genetic diagnosis (PGD), and the tensions between the Human Fertilisation and Embryology Authority (HFEA), which is the body responsible for regulating PGD, and the various British publics that attempt to engage and shape PGD policy.

The governance of the ethically nebulous suite of pre-implantation genetic diagnosis technologies in the United Kingdom serves as an exploratory lens into British approaches to anticipatory governance. PGD technology enables prospective parents to select for (or against) certain genetic traits in an embryo created in-vitro. PGD has a “distinctive historical profile” in the various countries in which it is used (Franklin and Roberts 2006, 73). Its historical and social deployment is intertwined with the modes by which it is governed. Its controversial and evolving nature and sensationalized appearances in the media make it a useful case study for exploring the negotiation and renegotiation of socio-technical contracts as they have evolved over time, in tandem with developing technological capacities.

As genetic analysis technology continues to evolve, societies are posed with the question of what PGD should be permitted for – by what standards should governance processes allow or disallow regulation? Should the *severity* of a particular disorder be the measure by which testing is permitted or prohibited? At what point in the development of the technology is it appropriate to intervene, and in what ways? It is in

⁷ The majority of this chapter was originally submitted as a chapter for the *Yearbook of Nanotechnology in Society: Nanotechnology and Democracy*

these blurred regulatory boundaries that robust capacities for navigating socio-technical contracts become essential.

How do societies navigate the complex governance issues accompanying PGD and other emerging technologies in an anticipatory way? How are socio-technical contracts negotiated amongst a multiplicity of stakeholders and competing societal values? The national regulation of PGD provides an empirical lens by which fundamental negotiations around *what kinds of people should be born* can be examined in light of emerging technological capacities that were previously non-existent.⁸ The United Kingdom's Human Fertilisation and Embryology Authority (HFEA) is the body tasked with providing guidance and governance around assisted reproductive technologies, including PGD technologies.

As illustrations of the socio-technical contract concept, I focus on the role that the HFEA and other formal and informal societal institutions played in negotiating the ongoing socio-technical contract that emerged alongside the evolving suite of PGD technologies in the seven-year period from 1993-2001. While even today, PGD still resonates with many as a "new" technology, the HFEA began consulting with the British public on PGD twenty years ago, in 1993, when the technology was still in its nascent stages. However, it is a mistake to think about anticipatory governance as something that *only* resides within the HFEA. The chapter also illuminates other anticipatory capacities, fairly traditional elements of democratic society that struggle to make sense of and negotiate around the emerging technology, such as the role of the media, community groups, and other formal and informal institutions. These multiple societal elements, elements that a healthy democracy is dependent upon (Brown 2009), when

⁸ In "Confessions of a Bioterrorist," Charis Thompson (1999) presents a fascinating fictional narrative grappling with the idea of human-animal hybrid pregnancies. Within this account, she too delves into the question of "what kinds of people should be born?"

observed as a functioning whole, serve as a window into the societal deliberations around PGD. In providing an overview of the role that lay participants, advisory bodies, citizen activists, and citizen engagement efforts played in the governance of PGD from 1993-2001, the chapter aims to illuminate these elements as important deliberative capacities for anticipatory governance.

A “Brave New World Society”? Reopening the Socio-technical Contract

Following the 1978 birth of Louise Brown, the first baby conceived via in-vitro fertilization, the British government established an advisory committee chaired by philosopher Mary Warnock. The “Warnock Committee,” as it became known, convened in 1982 and was tasked with grappling with the implications of the evolving suite of new assisted reproductive technologies, and providing advice for responsibly governing the new area. The 1990 Human Fertilisation and Embryology Act was based on recommendations from the Warnock Committee’s report, and provided the framework for the establishment of the Human Fertilisation and Embryology Authority (HFEA), the statutory body responsible for the regulation of assisted reproductive technologies and embryo research. The HFEA’s tenure as independent regulator officially began in July 1991.

Although the capacity for analyzing the genetic traits of human embryos was virtually nonexistent at the time of the Warnock Report, published in 1984, it discussed, in a few small sections, the possible issues associated with future genetic analysis technologies and the accompanying societal concerns regarding social and ethical impacts. One section of the report specifically focused on the use of assisted reproductive technologies in preventing genetic defects, and although PGD on human embryos was not yet a reality, the report did allude to the possibility of creating “normal” embryos by technological means:

12.15 If it should become possible to identify at a very early stage of embryonic development certain genetic defects; and to insert a replacement gene which will remedy the defect, a genetically normal embryo could be created. It is argued that this would provide the means to prevent certain genetic diseases.

The report tied the issue of “normal” embryo creation to historically embedded societal fears around the issue of eugenics and selective breeding.

12.16 Public anxiety about these techniques centres, not so much on their possible therapeutic use, but on the idea of the deliberate creation of human beings with specific characteristics. This has overtones of selective breeding. We regard such techniques as purely speculative but believe that any developments in these fields are precluded by the controls we have already recommended. We would however go further. **We recommend that the proposed licensing body promulgates guidance on what types of research, apart from those precluded by law, would be unlikely to be considered ethically acceptable in any circumstances and therefore would not be licensed.** We envisage this guidance being reviewed from time to time to take account of both changes in scientific knowledge and changes in public attitudes. (Warnock 1985, 74)

The 1990 Human Fertilisation and Embryology Act (the act of the British Parliament establishing the HFEA) also does not directly address the regulation of pre-implantation genetic diagnosis or prenatal diagnosis. However, dating back to as early as 1993, the HFEA has held public consultations in an effort to gauge patient, public, clinical, and scientific sentiment and to provide guidance on the issue, as originally advised in the Warnock Report. In 1993, PGD would make its way into the British public consciousness on the waves of concern accompanying a much older issue – the desire of parents to have a baby of a specific sex.

In January 1993, *The Guardian* announced that the HFEA was calling for a public debate “over whether Britain wants a Brave New World Society in which people can choose the sex of their babies” (Mihill 1993). The HFEA debates were in part ignited by

and coincided with the activities of two doctors, offering sex selection for £650 a time, catalyzed the British debates around PGD for social sex selection. Doctor Alan Rose, a chemical pathologist, aged sixty-six and retired from the National Health Service, and Doctor Pete Liu, a thirty-nine-year-old biochemist from Imperial College, opened the London Gender Clinic in North London. The doctors stated that they were providing a service that gave couples “a choice they should be allowed to make.” While their stated goal was to help couples “balance” their families, Rose and Liu did admit that about two-thirds of the 200 women they had treated up to that point were Asian and expressed a desire for male babies. Most of the other couples they treated expressed a preference for a girl (Mihill 1993).

Fearing that Rose and Liu’s work could lead to babies being “sold like hamburgers,” Members of Parliament called for a ban on clinics that were providing sex selection services. Conservative MP for Harlow, Jerry Hayes, stated that Rose and Liu were operating off of a “principle whereby you’re franchising babies.” Tory MP for Basildon, David Amess, said that it was “arrogant beyond belief” for scientists to “play God,” further noting that “Commercial exploitation of the desire of parents to have a child of a particular sex is grubby beyond belief” (Mihill 1994a).

At a press conference, Rose stated that his clinic had already interviewed approximately 500 couples for treatment. *The Guardian* reported that telephones had been ringing “continually” at the clinic, as more couples expressed interest in bringing “balance” to their family (Mihill 1994a).

The newspaper accounts made it clear: the desire for sex selection was not isolated to one or two couples. Hundreds of couples were interested in pursuing the treatment, and with the issue’s increasing notoriety in the media, even more people were outreaching to Rose and Liu for their assistance in balancing their family. Coupled with

the concerns voiced by Members of Parliament, the new statutory body was at a significant crossroads. Was the two-year-old HFEA prepared to confront the task of navigating public fears and crafting public policy in light of the concerns illuminated by Rose and Liu's practices? Did the young HFEA have the capacity to navigate the social and political transition from the present governance framework into a future one?

The HFEA Consultation on Sex Selection

The HFEA did not have power to regulate Rose and Liu's sex selection practice, since they were only using the sperm of the male partner, and were not using donated sperm. The HFEA would only have remit to regulate if Rose and Liu were using donated sperm. However, in response to Rose and Liu's new center, Colin Campbell, then chairman of the HFEA, stated, "This is a matter of serious public concern which should be fully debated before decisions are made." The HFEA had already been working on a consultation document regarding the ethics of PGD sex selection technology, and, following the opening of the London Gender Clinic, brought the document forward for consultation with the public (Mihill 1993).

The HFEA's 1993 consultation grappled with the issue of limits and the responsible use of increasing technological capacities around PGD and provided overviews of pro and con arguments around the social, ethical, and medical implications of its use, specifically in relation to sex selection. PGD for sex selection was the primary focus of the consultation, as only one inherited disease, cystic fibrosis, could be "unequivocally identified" via PGD at the time (HFEA 1993, 7). The public response to the consultation document also came out "strongly against" social sex selection, with sixty-seven percent of public respondents opposed. One major concern expressed by public respondents regarded "reinforcing sexual stereotypes to the disadvantage of women," and "lead[ing] to a widespread preference for male children." Another prominent theme in public

feedback focused around fears of “the start of a ‘slippery slope’ towards selecting the ‘perfect child.’” Public responses also indicated concerns regarding the impact of social sex selection on the family, such as psychological effects on the child. Other concerns centered around the disparate impact on certain ethnic communities, and that social sex selection was “not a proper use of medical resources, skills, and time.”

The HFEA, in sharing its views with the Department of Health, recommended that PGD for sex selection “in principle” be allowed for medical reasons when there is a risk of a “life threatening sex-linked disease.” The Authority did not recommend techniques such as sperm sorting be used for medical reasons, due to limited data regarding successful outcomes. The HFEA emphasized that the public supported its views: “Accordingly, while the arguments on this issue are complex, the view of the Authority on sex selection for social reasons is strongly supported by the public who responded to our consultation exercise.”

The outcome of the 1993 consultation resulted in the 5th edition of the HFEA’s Code of Practice being updated to not license social sex selection of embryos, but it would license PGD for sex selection on medical grounds. The HFEA recognized that the issue was not a stagnant one, and would likely be subject to ongoing review in light of changing scientific and social developments. The socio-technical contract would need to stay flexible and open for renegotiation given the evolving and rapidly changing nature of the technology:

This may be an issue which we shall need to return to in the future. Technological advances are constantly being made. We shall, therefore, be keeping the matter under review in the light of any new information or changes in public opinion.” (Appendix B, Outcome of the 1993 Consultation – Letter to the Undersecretary of State).

The HFEA's 1993 consultation indicates a reopening of the socio-technical contract around reproductive technologies in Britain. While the Warnock Report originally discussed genetic analysis technologies and their implications to a limited extent, the 1993 consultation served as the first major engagement of the British public regarding the governance of PGD technologies.

The 1993 consultation illustrates the role of the HFEA as being both backward-looking and forward-looking, backward looking in that it is responsible for taking account of and managing the current state of scientific development in the realm of reproductive technologies (e.g. the licensing of clinics performing PGD and the enforcement of the law as it currently stands), but it is also a forward-looking entity in that has made efforts to actively engage the British public around issues of genetics, reproduction, and technology in an ongoing way through public consultations, advisory committees, and a code of practice that evolves in light of feedback from engagement exercises and evolving technological capacities. Here, we can observe an administrative agency attempting to look forward in an anticipatory way as it navigates, negotiates, and renegotiates fundamental policy issues centered around the earliest stages of human life.

1999 Consultation: The Disability Community Emerges as a Vocal Critic

The HFEA kept the issue of PGD under review, and six years after its original consultation on sex-selection, it again took the issue to the public in 1999, a move that signified that the "gene screening debate [went] public" in the UK (BBC 1999). It was now possible to accurately test for other genetic conditions, beyond those that were sex-specific. With these new capacities came a new set of considerations for British society. The HFEA "anticipat[ed] a future where much more will be possible in genetic screening and there will be increasing demand for it. There are difficult ethical issues to be tackled

before it becomes more widespread” (Boseley 1999). While the HFEA had been reviewing and consulting the public on issues of PGD since 1993, increasing knowledge of and capacity to test for genetic conditions at the embryonic stage gave it reason to bring the issues to the public sphere via another public consultation. Ruth Deech, then chairman of the HFEA felt that it was “time the public had a say,” stating that “New scientific and medical advances, especially in the field of genetics, often cause public unease and present us with complex social, ethical and regulatory questions” (Boseley 1999).

The HFEA in conjunction with the Advisory Committee on Genetic Testing (ACGT) (later subsumed by the Human Genetics Commission) established a joint working party (JWP) in order to review the HFEA’s interim PGD licensing guidelines (HFEA 2001, 9). The JWP conducted a public consultation and integrated the feedback garnered from the consultation in providing its final recommendations, and while overall it felt that the licensing structure was effective, recommended “developments in a number of areas” based on public response. Recommendations included: expanding the array of peer reviewers consulted in the licensing application process to include “clinical geneticists, molecular geneticists, cytogeneticists, and genetic counsellors” (HFEA 2001, 2); that clinics should provide a paragraph “describing in lay terms” the condition as well as the experiences and impact on individuals affected with the condition (HFEA 2001, 3); that there be a multidisciplinary team in place to provide service to patients at all licensed clinics, including “reproductive specialists, embryologists, clinical geneticists, genetic counsellors, cytogeneticists, and molecular biologists” (HFEA 2001, 3).

The JWP also indicated in its recommendations that the *perception* of the seriousness/risk level of a condition by the prospective parents seeking PGD should also

be considered in the decision-making process. As advocated for by respondents in the consultation, in order to assist patients in making an informed decision, the JWP recommended that the information provided should include information “provided by disabled people and their families about their experiences living with disability” (HFEA 2001, 7). While the 1999 consultation did provide the opportunity for various segments of the public to respond, some groups felt that disabled communities were not being properly integrated into the process. Some felt that it was simply too little too late, and others believed that any use of PGD equaled to discrimination against disabled people. For example, the anti-abortion group, Life, rallied against use of PGD, contending that new capacities for detecting genetic defects would only push the country towards a culture of greater discriminatory practices (BBC 1999). Angela Corless, the spokeswoman for Life, stated that genetic testing, in concert with other reproductive technologies, is “done in order to search out and destroy less than able babies and so it is discrimination against disabled people before birth” (BBC 1999).

When the HFEA consulted the public about embryo screening in 1999, members of the disabled community asserted that the “real experts” – disabled persons – were not being consulted by the HFEA about the use and regulation of PGD technology. Tom Shakespeare, a member of the disabled community, argued against Juliet Tizzard, then the director of the Progress Educational Trust (Shakespeare and Tizzard 1999). Shakespeare and Tizzard engaged in a debate, via letters that they had written to each other, that were published in the Guardian as an illustration to the public of the perspectives of advocates and critics of PGD.

Shakespeare stated that the HFEA consultation was a waste of time, and that consultation of the public at this policy juncture “seem[ed] rather tokenistic.” Shakespeare noted that there appeared to be a widespread perception that disability

was synonymous with tragedy: “Society in general – and doctors in particular – tend to think that disability invariably equals tragedy. But many of us lead happy and successful lives.”

Shakespeare commented that the part of the issue was one of framing:

At face value, we seem to be asking the public whether the technique should be used to help couples with serious genetic disorders have healthy babies. Few are going to disagree with this proposition. But if you asked people ‘Do you think we should take another step towards designer babies?’ they might give a different answer.

Tizzard critiqued Shakespeare, stating that the issue was one of definition and use of the term “designer baby,” arguing that Shakespeare does not “explain what this mythical ‘designer baby’ is” or how PGD is further enabling its creation: “Embryo screening has been with us for nearly a decade: can you point to anyone who has used it frivolously?” Tizzard argued that reproductive technologies have been subject to democratic scrutiny since 1989, when they were being debated in Parliament. “Ethics and regulation are not lagging behind genetic science. They’re very much ahead of the game.” PGD is already subject to “strict controls,” argued Tizzard, and with the consultation and subsequent licensing framework processes, it will be even further regulated. “The process is already subject to strict controls.” “But I don’t believe they should decide who gets PGD and who doesn’t. We are all quite responsible enough to make our own reproductive decisions. The trouble starts not when we have reproductive choice, but when politicians and regulators stop trusting us to exercise it responsibly.”

Shakespeare challenged Tizzard’s view that the decision to use PGD should be a solely individual choice within a “reproductive free market,” and that PGD could be used to prevent “severe disability”:

Who decides what “severe disability” is? Why don't we listen to those who live with impairment, and often have very successful lives despite it? Public fear and ignorance about disability offers an alibi to those who seek to intervene in pregnancy. The best solution to the problem of disability would be to remove discrimination and prejudice, not to remove disabled people. Where do we draw the line? What about behavioural traits? And will screening be offered only to families already affected by genetic conditions, or are all people who use IVF going to be offered it? [...] PS What if someone like me, with restricted growth – or someone who was deaf – wanted to use screening to have a baby who shared their condition? Would support for parental choice go this far?

Shakespeare argued that it seemed as if medical experts have dominated the discussion and the public was not being involved in the way it should be. “Many don't have that trust [of medical experts], and don't see these developments as progress.” Shakespeare felt that the current path of permissiveness was leading society to a dark place: “What can be done has been done” in reproductive medicine up to the present. “This is the road that leads to genetic cleansing.”

Tizzard responded that her perspective was realistic. PGD provides a resource for people “who feel they can't leave things to chance anymore,” because of family history, genetic disease, multiple abortions, and risk of serious impairment. Accessibility to PGD technology is not the road to genetic cleansing, she argued, rather, “This is the road that leads to them having what the rest of us take for granted: a healthy child.”

The issue of designer babies and whether society was enabling their creation did not wane in the public eye following the 1999 consultation and Shakespeare and Tizzard's debate. The issue continued to grab headlines, and newspapers were peppered with sensational headlines such as the February 2000 headline: “Who Would Deny Us This? Embryo Screening has Sparked a Furious Ethical Debate” (Atkins 2000). This particular article chronicled the experiences of a couple, Susie and Kevin Duce, seeking to have a baby free of spinal muscular atrophy (SMA), a disorder that they both

carried the recessive gene for. Susie commented that “PGD is only about having a ‘designer baby’ if ‘designer’ means one that lives.”

The article argued that PGD was not about creating designer babies, rather, bringing healthy babies into the world when there is a high chance they will inherit a serious genetic condition:

Concern about genetic manipulation is understandable. A couple of years ago we were panicking about cloned sheep and posthumous fathering. Last week, there was the furore over the news that women’s eggs can now legally be frozen then defrosted for use years later. But PGD isn’t about creating a blue-eyed super race. It is currently only used – in Britain, at least – to screen out specific, highly disabling (and usually lethal) disorders like SMA, cystic fibrosis and haemophilia.

While some people will never agree with embryo screening, such as those who believe that life begins at conception, or those who disagree with it for ethical reasons, “those who fear future abuse of these advances probably needn’t worry” because the HFEA had already prohibited non-medical uses. “Furthermore, HFEA is currently circulating a document to ask us – the public – what we think of PGD” (Atkins 2000).

In her reflections on embryo screening in *The Guardian*, PDG patient Leah Wild contended that debates around designer babies are ultimately a debate of who society does and does not want to be born, of what disabilities and diseases society is prepared to allow screening for, versus those it is not (Wild 2000). From Wild’s perspective, “designer babies” are a good thing, but also something that will have major implications for society, as the technology provides the capacity to determine who we *do* and *do not* want to be born (Wild 2000). Wild had a condition known as a “balanced translocation,” in which fragments from two of her chromosomes broke off and traded places. While the condition had no implications for Wild’s health, the chances were very high that her

resulting child would inherit the translocations, leading either to a miscarriage or early death.

I am hoping to have a designer baby. Any offspring of mine will not be God's gift: I fully intend to exploit the latest medical advances to ensure my child is as perfect as possible. This involves selecting some embryos and eliminating others. He or she will be chosen according to how good their genes are.

That same week, it had been announced that the sequencing of the human genome was near completion. Wild acknowledged that the progress with the human genome will make PGD easier and more accessible. "For despite Bill Clinton's claim that 'our children's children will know the term cancer only as a constellation of stars', human genetic engineering is not, in the short term, at least, about preventing and curing disease. It's about whom we want to be born" (Wild 2000).

Wild labeled herself, and others in similar shoes, 'genetically disadvantaged,' noting that her choices are different from others of normal reproductive health. "I either make this genetic selection, or risk further multiple miscarriages and accept infertility. I would prefer not to have to. No one in her right mind would opt for the procedure of PGD instead of what is quaintly called 'the old fashioned method.'"

Wild posed the question of limits. What sorts of limits should there be "in this brave new world of human genome sequencing"? What sorts of conditions should be tested for? When should they be tested for and under what circumstances?

From where I'm lying – feet up in stirrups – this is not an abstract philosophical debate. Nor is it a merely a matter of enabling people to benefit from medical advances. As with the choices being made about testing for Down's syndrome, these are not medical but political matters. It is up to us, with the knowledge given to us by the scientists, to decide.

We must begin to vigorously debate the limits of acceptable genocidal. To pretend that the human genome is all about saving, rather than destroying, lives is

to be blind to the brutal truth about our very human, flawed condition (Wild 2000).

Even with many serious conditions, those that Wild calls “genetically disadvantaged” can live fulfilled lives with preventative treatment (take for example the BRCA 1 and 2 breast cancer mutations – just because someone has the mutation does not make having it a “death sentence”). Thus, what is an acceptably severe condition that PGD would then be permitted for? Who decides?

The perspectives illuminated in Shakespeare and Tizzard’s debate, and Wild’s article, indicate a “democratized public sphere” in which multiple minority viewpoints come to the table where British negotiations around the use of PGD technologies are shaped (Chambers 204, 2000). They represent the deliberative nature of negotiations around PGD in the United Kingdom, and what Chambers (204, 2000) calls the “talk-centric” approach to governance (in contrast to a voting-centric approach) – where the focus shifts from the voting booth and majority-rules as the primary means of expression of public preferences, to an expansion of the public sphere, where multiple perspectives, especially minority viewpoints, such as the viewpoints of the disability community, or of PGD patients such as Wild, can be voiced and give shape to broader social deliberations on decision-making. It signifies a capacity for multiple voices, including marginalized groups, to “participate in shaping, influencing, and criticizing public opinion” (Chambers 204, 2000).

The question of *what kind of society do we want to live in* thus becomes much more complex than the one originally confronted by the HFEA. The perspectives voiced by other aspects of society brought up additional complexities but also indicate robust deliberative capacities in negotiations around PGD. Dryzek defines deliberative capacity as “the extent to which a political system possesses structures to host deliberation that is

authentic, inclusive, and consequential” (Dryzek 2009, 1382). The disability community played a significant role in critiquing majority views on PGD and added a unique perspective into the public deliberations on the subject. The critique, as Shakespeare’s comments suggest, highlighted that the ramifications of PGD might be larger than many might perceive. That while it might seem relatively straightforward that social selection sex is wrong, and that the medical field ought to alleviate genetic diseases, the critique points out that the issue is more complicated, and that the established framework might not integrate disabled voices in the way that it should. Instead, the critique indicates that the perception that the disabled community is bad off is a fiction that society has manufactured. That idea that society might want to eliminate babies that might be born disabled, would be as offensive as the idea that society might want to eliminate people of a certain race. To the disability community, the idea was equivalent. The question of what kind of future society wants to deal with then becomes a radically different one.

Are Socio-technical Contracts People-driven or Institution-driven?

Other voices advocated that the HFEA take a much more individualized and flexible approach to licensing, even in terms of selecting embryos for social reasons. Alan and Louise Masterton had four sons, and wanted to use PGD to have a girl. They had tried to have a girl for fifteen years, and were finally successful, in producing a daughter, Nicole. Nicole was three years old when she died from a bonfire accident. She had suffered 90% burns over her body and died shortly after. Louise Masterton had a tubal ligation performed years prior, so IVF would be the only way she would be able to produce another child.

The Mastertons wrote a letter to the HFEA, asking that the licensing body allow them to move forward with PGD for sex selection. They included a picture of Nicole, stating, “This is our precious daughter Nicole. The joy and happiness she brought into

our lives, her spirit and her place in our family and our hearts are the driving force behind [t]his appeal” (Wilkinson 375, 2008) The HFEA’s licensing framework strictly ruled out social sex selection, only allowing it for sex-linked genetic conditions. Given the HFEA’s policy on the matter, the Mastertons considered launching a court case against the Authority under the European Convention on Human Rights, which “guarantees a fair hearing from public authorities” (Scott 2000).

The couple stated that they were not seeking to replace their daughter who had died, “but had a deep psychological need for a girl in the family.” In order for the HFEA to even consider the Masterton’s case, they needed to submit an application through a British IVF clinic. They stated that they were turned down each time, due to the clinics not wanting to go against HFEA policy (Scott 2000).

Simon Fishall, the director of the Centre for Assisted Reproduction at the Park Hospital in Nottingham, “painted a Kafkaesque picture of the plight of the Mastertons, caught in a maze of buck-passing ethical bodies” (Meek 2000). Fishall’s statements illustrated the “growing dissatisfaction” amongst clinicians at “the caution and long decisionmaking processes at the HFEA” and that the HFEA was receiving pressure from “several fronts” (Meek 2000).

A former HFEA board member, Richard Holloway (the Bishop of Edinburgh), stated that the case should be considered: “I think, in this case, [the HFEA] probably ought to look hard at it because, while you could probably make a case for a general regulation that sex selection is a bad thing, there must be exceptional circumstances. I would think this one probably was, and I hope they can get a centre to send an application to the HFEA.” Others disagreed with the Bishop. Ken Mason, a professor at Edinburgh University felt that the case crossed boundaries, and that it teetered on the “point of absurdity” and would open the door to other sorts of social selection, and was

opening up Pandora's box (Scott 2000). Ultimately the Mastertons decided to circumvent HFEA policy and went to Italy in order receive the PGD sex-selection procedure, however, they were unable to produce a female embryo. The Mastertons chose to "give away" the male embryo they produced while undergoing the IVF and PGD procedure in Italy. They placed it in cold storage in a Rome clinic, until a "suitable recipient" could be found. While the Masterton case did not lead to any direct changes in policy, it did bring about a revisitation of the sex selection issue in the public sphere, and also, within the HFEA. Following the case, in 2001, the British government requested that the HFEA revisit its stance on sex selection (HFEA 1, n.d.).

The Masterton case illustrates a significant question in relation to the socio-technical contract concept, that is, are socio-technical contracts primarily institution-driven or people-driven? In the case of PGD is the HFEA the primary crafter of the socio-technical contract, or are individual stakeholders (such as the Mastertons and Wild) and communities (such as the disability community) equally present in the ongoing negotiations around the issue? The tensions that arise between the HFEA and the multiple communities engaging both the HFEA and the broader public on the issue suggest that the HFEA is not the only platform for engaging the British socio-technical contract around PGD – that socio-technical negotiations emerge as a result of the interplay of formal institutions such as the HFEA with other elements of society, such as the narratives, metaphors, and motifs explored in chapter two. The Masterton case also illustrates the non-static nature of this particular socio-technical contract. While it appeared as if the issue of sex selection had been settled as a result of the 1993 consultation and policy framework, the high-profile Masterton case brought the issue back to the to the forefront of debates around reproductive technologies – so much so

that the government requested that the HFEA revisit sex selection six years after its original consultation on the topic.

Conclusions: Societal Capacities

The HFEA, then, in conjunction with the various publics that critique and engage with it, is tasked with negotiating the transition; one in which it must craft a governance framework that adequately transitions the present society into the future one in light of ongoing societal deliberations around the issue of PGD and what it represents more broadly in terms of the new socio-technical orders that are being created. It must assess the present state of PGD technologies, as well as grapple with what the technology *could* be doing in the future, in addition to having to evaluate whether the technology is being used responsibly. The entrance of voices such as the disability community and the Mastertons into the debate reiterated the notion that despite the seemingly “objective” realities that science provides regarding the physical world, such as the detection of cancer genes in an embryo, or the use of donated sperm or eggs to achieve pregnancy, society is often left with more questions than answers, such as: Should parents have the right to choose the genetic traits of their child? Who decides? Lori Andrews (2004, 106) notes that “Twelve percent of potential parents, for example, say that they would abort a fetus with a genetic propensity toward obesity.” Broader and more complex questions continue to emerge as technological capacity increases. For example, if embryos with obesity genes can be eliminated, why would an entity such as the National Health Service pay for people suffering from issues related to obesity? The same goes for those with breast cancer (BRCA) mutations, and so on.

Thus, as technological capacities continue to increase, and social and ethical issues emerge, it becomes increasingly important that societies be equipped with the tools to grapple with the potential complexities that emerging technologies such as PGD

might present. The issue is not simply about who is going to be parents that is at stake, but it is about what kind of parental rights one has, and in particular, what kinds of parental complaints justify medical intervention in the resulting child, whether the intervention is PGD, in-vitro fertilization, etc. In a sense, the matter evolves into one of parental consent, in tandem with policies crafted by bodies such as the HFEA and critiques voiced by advocates, activists, and proponents. It becomes a complex negotiation of the unbinding and rebinding of traditional sensibilities of how babies and children come to be in the world.

When the concept of capacities is meditated upon in these terms, the question at hand becomes *what kind of future do we want to live in*, and how well equipped is society for grappling with these questions? What kinds of debates are emerging versus the kinds that an anticipatory governance approach would demand? What might suggest that societal capacities are robust, and that a society is managing transitions into new socio-technical arrangements well? Some indications might be the particular kinds of issues that get discussed, also, whether they get a full hearing and by whom, and the degree to which social processes make judgments that enable socio-technical contracts to be held in place.

In the case of PGD, is the HFEA ahead of the game or behind the curb in helping judge what kinds of PGD should be permitted? It is clear that the HFEA struggles with an inability to control what happens in genetics research laboratories outside of its remit of regulation. It cannot, in a sense, fix the socio-technical contract because laboratories are constantly bringing about new possibilities for what is possible and what can be done in terms of genetic analysis. The HFEA has not been able to stabilize a particular framework in grappling with PGD. It started developing a framework in 1993 with the notion that social sex selection should be banned, however as new cases arose, the

boundary broke down to what comprises social selection versus medical. The question becomes one of severity, and it the question of what conditions are severe enough to permit PGD for remains in flux. In part, the question remains due to the strength of the “talk-centric” public sphere, where a diversity of viewpoints on the issue juxtapose against each other, from the advocacy and critique from members of the disability community, such as Shakespeare, to the patient advocates, such as Wild, who just want to have a “normal baby.” Thus what might seem like incapability on the HFEA’s part to stabilize a particular framework might also be due to its attempt to continually reevaluate and revisit the socio-technical contract.

PGD presents a classic case of a technology that can fundamentally transform the nature of society. The cases explored in this chapter represent the negotiation of a principal question in light of an emerging and transformative technology, that is, what kind of society do we want to live in? What kinds of people will society permit to be born? Therefore, the question of what kinds of capacities we might want to create or further support in regards to anticipatory governance is an important one, as societies continue to grapple with the complexities presented by new and emerging technologies as they navigate from the present to future society. With technologies such as PGD, that have a potential for deep social transformation, the renegotiation of the socio-technical contract is likely to be lengthy and intense, as evidenced by the examples presented in this chapter. While the HFEA attempted to do the best that it could in terms of managing the negotiation of this socio-technical contract, as explored in the next chapter, it would again be challenged to engage stakeholders, re-interpret policy, and make sensitive, difficult decisions as a new technology entered the PGD arena – HLA tissue typing, which enabled clinics to create a perfectly matched “savior sibling” from an in vitro embryo, in order to help cure a sick relative.

CHAPTER 6

THE PERFECT EMBRYO: NAVIGATING THE POLICY DISCOURSE OF PRE- IMPLANTATION GENETIC DIAGNOSIS IN THE UNITED KINGDOM ⁹

Introduction: Socio-Technical Contracts and Savior Siblings

This chapter further explores and develops the socio-technical contract concept and applies it as a lens to an empirical case study of the “savior sibling” controversies in early 2000s Britain. The paper seeks to do three things: provide an overview of the socio-technical contract concept and illustrate its utility in the study of historical governance efforts of emerging technologies, apply it to the negotiations that arose around the application of pre-implantation genetic diagnosis (PGD) technology for creating a “perfectly matched” donor sibling for an existing older sick sibling, and analyze the modes in which the “welfare of the child” policy language was deployed in negotiating boundaries around acceptable and unacceptable uses of the technology.

The governance of PGD provides a salient case study for illuminating the socio-technical contract concept. The dynamic tensions of PGD set it apart from other technologies, due to its perceived eugenic capacities. The capacities of the technology to select for genetic traits in embryos, coupled with the wariness of traveling down a path that some critics contend will lead back to Nazi Germany, present unique governance issues for contemporary nation-states. Debates on the moral and ethical implications of PGD continue to rage as states grapple with the moral dichotomies of the technologies. On one hand, the technologies are promoted as being a medical revolution, a force of good for families struggling with devastating genetic diseases. PGD is framed as a technology that can bring hope, health, and a future to those families. On the other hand, critics contend that the technology poses too many moral dangers to be permitted.

⁹ Most of this chapter was originally submitted as a manuscript to *Medical History*.

They argue that no matter the good intentions of reproductive scientists, it is a slippery slope to a new eugenics. Popular dystopian narratives, such as *A Brave New World* and *Gattaca* speak to societal fears regarding the capacity of reproductive technologies that enable scientists to “play God.”

In the early 2000s, with advances made in tissue typing technology, a new and highly controversial dynamic entered the embryo screening arena, that of the “savior sibling.” Utilizing tissue typing technology, along with PGD and IVF, it was now possible to create a “perfectly matched” donor sibling for children suffering from certain life threatening diseases, such as some forms of leukemia and anemia. Stem cells from the resulting sibling’s umbilical cord could be transplanted into the sick older sibling, providing the possibility for a much better quality of life and a potential cure. Jodi Picoult’s 2003 fictional novel, *My Sister’s Keeper*, was inspired by and grapples with these issues. In the novel, a thirteen-year-old American donor sibling (who was selected as an embryo) sues her parents for rights to her own body.

A number of stakeholders and groups took issue with the controversial application of tissue typing technology, ranging from pro-life campaigners to Lord Winston, an eminent British scientist who pioneered and perfected PGD technology in humans. Fears centered around a multiplicity of issues, primarily focused around commoditization of human life – with the primary purpose of the donor sibling serving as a medical product. Another concern was whether the donor sibling would be forced into continuing to provide donations if the original transplant did not work. On one hand, how can one blame desperate parents for seeking out any sort of cure possible? On the other hand, what about the welfare of the resulting child? Given its controversial and highly publicized nature, PGD, or “savior sibling,” technology provides a useful case study for analyzing the negotiation and renegotiation of socio-technical contracts.

The paper explores how the concept of the *welfare of the child* served as both a guiding principle for the Human Fertilisation and Embryology Authority and as a means by which policy boundaries and the limits of acceptable medical practice can be renegotiated in light of new technological capacities and medical applications. The HFEA is the British agency established in 1990 charged with managing and writing policy regarding the use of human eggs and sperm in medical clinics and scientific laboratories. The use of the welfare of the child language signifies more than a debate over terminology and regulatory language; it also provided a space in which the epistemological and imaginative aspects of the debate could be deliberated and renegotiated. The HFEA utilized the principle of the welfare of the child in an effort to grapple with and negotiate boundaries around controversial applications that were previously non-existent, and even unfathomable (such as tissue typing embryos to create a donor sibling). The *welfare of the child* language originates from the 1990 Human Fertilisation and Embryology Act (the Act of Parliament establishing the HFEA), which states that the welfare of the resulting child must be accounted for as a primary consideration when licensing treatment:

Section 13 (5): A woman shall not be provided with treatment services unless account has been taken of the *welfare of any child who may be born as a result of the treatment* (including the need of that child for supportive parenting), and of any other child who may be affected by the birth.

Section 2 (1) ... “treatment services” means medical, surgical or obstetric services provided to the public or a section of the public for the purpose of assisting women to carry children. (italics added)

The welfare of the child became particularly important as a framing device and guide as the HFEA received license requests for HLA tissue typing in order to create a “savior

sibling” for an ill older brother or sister who needed a perfectly matched tissue donor. Whose welfare should be considered? That of the existing sick child? That of the donor sibling-to-be? The HFEA had to negotiate these difficult issues as it determined what was acceptable versus non-acceptable use of tissue typing technology in the cases of the Hashmi and Whitaker families.

A Brief History of PGD

While the cases in this article focus on the renegotiation of the socio-technical contract around PGD and its application to humans, PGD research originated from experimentation on farm animals. The first known PGD was performed by Edwards and Gardner in 1968, who demonstrated that it was possible to determine the sex of rabbit embryos in vitro when they biopsied and sexed rabbit embryos at the blastocyst stage (Harper et al. 2001) and checked for the presence or absence of sex chromatin (Edwards 2005, xiii). The embryos were subsequently placed into adult female rabbits and were carried to term. The resulting sex of the offspring corresponded with the initial sexing in Edwards and Gardner’s analysis (Gardner and Edwards 1968, 346-348). After successful application to rabbits, PGD was next applied to cattle and sheep. The use of PGD in farm animals, particularly cattle, was considered valuable because it provided commercial advantage, specifically in controlling the numbers of male and female cattle produced (Theodosiou and Johnson 2011). The Edwards-Gardner method was attempted, and failed, on human embryos three years later in 1971. Robert Edwards would later go on to collaborate with Patrick Steptoe and develop the in-vitro fertilization technique in which an embryo could be fertilized outside of the human body. The Steptoe and Edwards IVF technique became successful in 1978, and resulted in the birth of Louise Joy Brown, the first “test tube baby.”

In 1985, scientists began discussing the potential of biopsying a single cell from a human embryo. At this point, it was thought that the genetics of an embryo could not be analyzed with a solitary cell, and that the single cell would have to be cultured to have enough material to analyze (Harper 2009). PCR (Polymerase Chain Reaction) technique, developed in 1983, provided new avenues for researchers to pursue. PCR enables the “copying and pasting” of segments of DNA, versus the “cutting and pasting” method of traditional recombinant DNA engineering. PCR requires very little genetic material to work, as little as one molecule of DNA, and is an essential component in virtually any “DNA analysis” performed today. While PCR has revolutionized areas such as the forensic investigation of crime scenes, in which there is typically very little genetic material to work with, it also had far reaching impact in propelling PGD into a tangible reality.

Little attention was allotted to PGD in the 1984 *Report of the Committee of Inquiry into Human Fertilisation and Embryology*, a report authored by the Warnock Committee, a group convened by the British Government and chaired by Oxford philosopher Mary Warnock. The Warnock Committee was tasked with assessing the current state of reproductive technologies, the potential present and future social and ethical implications, and providing recommendations to the government regarding their governance. The Warnock Committee’s recommendations included the establishment of a regulatory body. The framework of the regulatory body would be established in the 1990 Human Fertilisation and Embryology (HFE) Act. The potential societal implications of PGD were discussed in only two parts of the Warnock Report, and was not directly mentioned in the subsequent 1990 HFE Act. One of the sections focused on the use of reproductive technologies as a means of preventing genetic defects in embryos and creating “normal” embryos through technology:

12.15 If it should become possible to identify at a very early stage of embryonic development certain genetic defects; and to insert a replacement gene which will remedy the defect, a genetically normal embryo could be created. It is argued that this would provide the means to prevent certain genetic diseases.

The report noted that the genetic analysis of embryos ties into public anxiety regarding concerns around selective breeding and eugenics. However, the report stated that such techniques were “purely speculative” at the time of its writing, and that the issue would need to be reviewed in light of new advances, and subsequent recommendations and policy would need to be crafted in light of new developments:

12.16 Public anxiety about these techniques centres, not so much on their possible therapeutic use, but on the idea of the deliberate creation of human beings with specific characteristics. This has overtones of selective breeding. We regard such techniques as purely speculative but believe that any developments in these fields are precluded by the controls we have already recommended. We would however go further. **We recommend that the proposed licensing body promulgates guidance on what types of research, apart from those precluded by law, would be unlikely to be considered ethically acceptable in any circumstances and therefore would not be licensed.** We envisage this guidance being reviewed from time to time to take account of both changes in scientific knowledge and changes in public attitudes.

In 1990, the same year that the HFEA was established, over two decades after it was first applied to farm animals, PGD was used in a clinical setting on human patients (Theodosiou and Johnson 2011). Initially, PGD was only applied to “pre-existing Mendelian diseases,” including cystic fibrosis, but was not widely applied until 1993-1994, when it was coupled with fluorescence *in situ* hybridization (FISH) analysis (Edwards 2005, ix). The first use of PGD in a clinical setting is attributed to Handyside et al., who diagnosed the sex of embryos in couples who were at risk to transmit

recessive X chromosome linked diseases. By using PCR to amplify a sequence on the Y chromosome, the researchers were able to determine the sex of the embryo depending on the presence or absence of the “Y-specific band” on a gel (Harper et al. 2001, 195).

In 2000, HLA (human leucocyte antigen) tissue typing was introduced as an option in the PGD process. HLA, when coupled with PGD, offered “a new method for treating (older) siblings with congenital or acquired bone marrow diseases.” This process is colloquially referred to as creating a “savior sibling” for an older affected brother or sister. In cases where a donor sibling was born, cord blood would be collected at delivery, which was utilized in stem cell transplantation for the older sibling (Edwards 2005, x).

The Age of the Savior Sibling

Before delving into the Hashmi and Whitaker cases, it is important to understand their context by reviewing their American precursor, the case of Adam Nash, which presented an unprecedented case that now needed to be considered within the emerging British regulatory system around PGD and tissue typing technologies. American baby Adam Nash was born into a web of controversy. Adam’s parents, Lisa and Jack, underwent IVF and PGD in order to select the embryo that could serve as a perfect match for his sister, Molly, who suffered from Fanconi anemia, a genetic condition that typically leads to acute myelogenous leukemia and early death. That embryo would eventually become Adam, who would be free from Fanconi anemia himself, and whose tissue was matched to his sister’s so that his umbilical cord blood would provide the stem cells necessary for her bone marrow transplant. With the transplant, doctors predicted that six-year-old Molly’s chances of recovery would increase to 85-90% (BBC 2000). When news of the Nash case was unveiled at a

scientific conference earlier that summer, “the hall echoed with the sound of stunned scientists gasping” (Browne and McKie 2000).

Across the pond, concerns were immediately raised about how the HFEA would handle such a case. Vivienne Nathanson, head of ethics and policy for the British Medical Association, stated that the technique would likely not be allowed in the UK because the child would be seen as a “medical product.” “You obviously have sympathy with the family,” Nathanson commented in a BBC interview, “but we have to have concern about the second child. We would have very serious concerns that he is a commodity rather than a person” (BBC 2000).

Sarah Nathan, a member of the HFEA’s ethics committee posed the question of whether it was “ever ethical to use one child to save another, and more especially to create one child to help another” (Nathan 2000). Nathan found it difficult to see the negatives in the Nash’s specific case, noting that “It saves a life, relieves suffering and is not likely to make baby Adam less loved and appreciated than he would have had he been randomly, naturally conceived.” Thus, Nathan felt that it would be hard to condemn the Nash parents and the doctors involved for what they did.

She noted that the issue, however, of the slippery slope continues. Will these techniques lead to designer babies, “genetically manipulated at the parents’ whim to be taller, blonder, cleverer or more athletic than their peers”? The slippery slope argument was debatable, because PGD is not a walk in the park, contended Nathan. “It is certainly not something you would undertake lightly, or for trivial reasons [...] you need a good, compelling reason such as infertility to undergo all that.” At the time Nathan was writing, no one had approached the HFEA wanting to do a procedure like the Nash family had done (Nathan 2000).

The “touching” photos showing the Nash family and their new addition “prompted not delight but panic,” reported *The Guardian*. In an editorial entitled “Grave Moral Dilemmas: Nash case shows the need for pragmatism,” *The Guardian* explored public concern over the technologies, reflecting that a great deal of the alarm around the Nash case relates to the slippery slope argument.

This response is about fear of the future and the uncontrollability of this technology. It is not about the moral dilemmas thrown up by the Nash story, none of which are in fact new. The fear is that Adam Nash will be followed by a generation of genetically selected, athletic, six-foot blond haired blue-eyed ‘Genrich’. These are issues for concern, not panic. In reality it is unlikely that we will ever be able to identify accurately the genes for intelligence and beauty. Furthermore, the expense of genetic selection and the scarcity of donor eggs will limit access to the procedure. Besides, guidelines can be used to regulate genetic selection just as the HFEA has regulated embryology. (The Guardian 2000)

Accompanying these fears, commented *The Guardian*, is a desire for “an era of moral certainties.” A time when institutions (church, state, community) provided black and white guidance as to what was moral and what was not.

The moral maps with which many of us were raised are ill-equipped to negotiate the kinds of dilemmas thrown up by dramatic developments in medical technology. Many of our oldest philosophical concepts – like what fate means in an age of genetic selection – are redundant. Philosophy should be on the curriculum; today’s children will need its reasoning skills. We also need a system similar to that in the Netherlands where local panels draw on legal, medical, ethical and lay opinion to help the morally bewildered and take the case-by-case approach required. Blanket principles in this brave new world of contemporary medicine will be of no help. The worst option is that these decisions end up in an adversarial courts system determined by narrow legal definitions as we witnessed in the case of the conjoined twins last month.

One week after news of the Nash case hit national headlines, the October 2000

announcement that a British doctor, Paul Serbal, intended to perform the first PGD in Britain to eradicate a specific cancer from a family line “could not have come at a more inflammatory time” (Browne and McKie 2000). Writing for *The Observer* in an article entitled “We’ll Have That One – It’s Perfect,” Anthony Browne and Robin McKie reported that Serbal was using PGD to eliminate familial polyposis, a bowel cancer, from a family that had suffered from it for generations. Critics argued that familial polyposis is not necessarily a death sentence, and that doctors were crossing the line of what was ethical: “We are plunging into a brave new world of designer babies, said the pundits. We have created a realm, they claimed, in which parents can use the slightest excuse to discard ‘tainted’ embryos or have children genetically selected as organ factories for other family members.” Eliminating embryos with the faulty gene was not necessary, argued Serbal’s critics. If caught early, those with the mutation can “simply have their colons removed before the disease has a chance to manifest itself.” Serbal was not persuaded by his critics, however, and argued that he was helping parents have a healthy child and “peace of mind.” “All I am doing is ensuring the birth of a child that will be unaffected by cancer in 40 years and will not need major surgery. I am giving parents, and their offspring, peace of mind.”

The question on the minds of those following the US Nash case, and the subsequent ongoing dynamics in the UK, was, “So what will happen when it arrives in Britain? Will there be an even greater outcry?” Answers to these questions were not easily found, and the questions continued to compound as new cases and ethical dilemmas emerged, such as when the individual in need of a transplant is not a sibling, but a parent. “Will people have a baby to cure themselves?” asked Brown and McKie. Serbal announced plans to perform PGD for the inherited blood disorder thalassemia, in which the baby would be born free of the disease and the umbilical cord blood would be

used to help the father. Serbal did not “see a problem,” rather, he argued, “It is just an added bonus to having a healthy child.” Others, such as Alastair Kent, representing the Genetic Interest Group, agreed with Serbal, seeing it as a humane solution that would help both the resulting child and his or her family (Browne and McKie 2000).

As PGD is used more frequently for an increasing array of diverse conditions, Browne and McKie imagined that it could become a routine part of the process of having a genetically healthy baby, “just as it is routine now to test newborn babies for certain conditions.” Sarah Nathan (of the HFEA’s ethics committee) disagreed, remarking that she did not think that women would routinely screen for genetic disorders via PGD in the future. However the recent PGD cases might pan out, as scientific frontiers continue to expand, Browne and McKie commented that “as we enter this brave new world” ethical frameworks will not remain stagnant, and are “likely to evolve.” “What seems shocking now may seem ethical in the future.”

The UK’s “First Designer Baby Lab”

In December 2001, news emerged that the “UK’s first designer baby lab [was] under way” (Blackstock 2001). Egyptian-born Mohammad Taranissi was establishing the laboratory in London in order to help families with ill children the opportunity to “select genetically designed embryos.” Taranissi said he was going to go ahead with the laboratory even if the HFEA refused to permit it. Taranissi, one of the UK’s top fertility experts, with the best IVF success record in the country, was not a stranger to controversy, having bumped heads with the HFEA in court multiple times.

The news of Taranissi’s laboratory elicited feedback from critics such as Lord Winston, one of the scientists who invented embryo screening techniques. Winston, in an interview with BBC’s *Newsnight*, stated that a line needed to be drawn: “It really troubles me that some of my colleagues are prepared to consider a child as a

commodity ... I think that's fundamentally wrong and I think it's fundamentally dangerous. There is a principle at stake here." The issue, Winston, argued, is that children are being treated as commodities. "Just as we do not allow these techniques for the choosing of the sex of a child because that child might be a commodity for the same reason we should not be choosing its genetics as a commodity because that is truly the beginning of a slippery slope and I hope the HFEA recognizes that and do not go down that route" (Blackstock 2001).

Taranissi, who wanted to use the Nash technique for a British mother and her son, who had the same condition as Molly Nash, disagreed with Winston, arguing that the baby would not be a commodity and that it would be "loved and cherished on its own merit." It would not be simply "produced as a spare part" and "once we have taken the cord blood it's not going to be killed or dumped somewhere." Peter Millis, the HFEA's policy manager, told Newsnight that the Nash procedure had never been used before in the UK, and that the "huge ethical issues" that emerge "vary from case to case" (Blackstock 2001).

The Case of Zain Hashmi: Negotiating Acceptable Uses

A few short months after the announcement of Taranissi's impending "designer baby lab," in February 2001, the HFEA announced that it was prepared to allow certain savior sibling PGD techniques, "subject to the merits of each case." The HFEA's decision was "triggered" by a Nottinghamshire fertility clinic, which submitted an application for Shahana and Raj Hashmi, a Leeds couple, to carry out PGD for thalassemia as well as tissue typing, to ensure that the baby would be able to provide umbilical cord blood for a "perfectly matched bone marrow transplant" for his or her brother, two-year-old Zain Hashmi, who was suffering from the blood disorder and would

die without the transplant. The Hashmis saw the procedure as their only option. Neither parent and none of their other five children were a match for Zain (Boseley 2003b).

Discussing the decision to approve the license request, the Chair of the HFEA, Ruth Deech, stated that the authority had considered the issues and “implications of this treatment very carefully indeed.” In cases in which PGD was *already* being undergone to prevent a new child from inheriting a genetic disease, the HFEA could “see how the use of tissue typing to save the life of a sibling could be justified.” Deech noted that this sort of situation would happen in the rarest of circumstances. While the HFEA allowed the harvesting of umbilical cord blood cells for transplant into Zain, it would not allow for doctors to take the new baby’s bone marrow for transplant if the umbilical cord blood did not work (Boseley 2003b). Zain’s brother or sister-to-be was called the “first officially sanctioned ‘designer baby’ in British history” (Meek 2002).

The week previously, a baby girl who had been selected as an embryo to be a match for her brother, suffering from leukemia, was born in a British hospital. The anonymous family had completed the genetic screening in the United States, and therefore was not subject to HFEA policy. Peter Garrett, representing Life, asked whether it was appropriate to create a child for such purposes: “Should we allow a child to be manufactured in order to serve the medical needs of an older brother? Whilst the term ‘designer baby’ is often overused, it is all too appropriate in this case.” The Hashmis and the anonymous family stated that they were not “designing.” Speaking with ITV, Mrs. Hashmi said that they were only asking for a “helping hand by the scientists. [...] This baby is going to be given to us by nature, but all the scientists are doing is making sure we get the one we want. They’re not going to design anything (Meek 2002).”

A few months later, in the summer of 2001, Zain's parents had produced fourteen IVF embryos, but none of them had been a match for him. At that same time, in a report on the regulation of genetics and embryology, Members of Parliament from the House of Commons select committee on science and technology criticized the HFEA for its decision in the Hashmi case, with a main criticism being that the HFEA had failed to consult the public. The committee argued that the 1990 Human Fertilisation and Embryology Act should be rewritten in order to "reconnect the act with modern science." The committee was particularly inflamed by a comment made by Ruth Deech (Chair of the HFEA until that past April), who had stated that by making decisions such as the Hashmi case, the HFEA "protects members of parliament from direct involvement in that sort of thing." The committee, in its report, stated that "Parliament does not need protecting and democracy is not served by unelected quangos taking decisions on behalf of parliament." Maureen Dalziel, Chief Executive of the HFEA agreed that the law needed to change: "New, clearer legislation is desperately needed that takes into account the massive scientific advances that have taken place since the last act. [...The HFEA must also change] to keep pace with scientific and medical advances, make its operating procedures easier and quicker" (Boseley 2003b).

The Case of Charlie Whitaker: Negotiating Limits

In July 2002 the HFEA rejected a license application for embryonic tissue typing. Working with Dr. Taranissi, Michelle and Jayson Whitaker submitted an application in hopes of saving their three-year-old son Charlie, who suffered from Diamond Blackfan anemia (DBA), an extremely rare blood condition. A bone marrow transplant from a perfectly matched donor would potentially give Charlie a chance at long-term survival. Charlie's condition required that he participate in constant medical procedures, such as "day-long blood transfusions and daily injections of life-saving drugs" (Allison 2002).

The HFEA ruled that it would be unable to accept the Whitaker's application because the resulting child would not be at risk of inheriting the disease, as opposed to a case like the Hashmi's, through which PGD would ensure the resulting child would be born free of the disease. If the Whitakers were to have another child naturally, chances were that the resulting child would not have DBA, in fact it would be almost impossible, as Charlie's condition was non-hereditary. Charlie's future brother or sister "was at no extra risk of contracting the disease Charlie had by virtue of being his sibling" (Dodd and al Yafal 2002). Therefore, embryos matching Charlie's tissue type would be selected over other healthy embryos that did not. An HFEA spokeswoman stated, "Every member of the authority on the committee had enormous sympathy for Charlie Whitaker and his parents, but they were unable to approve the licence" (Allison 2002).

The Whitakers said that they were "absolutely devastated" by the HFEA decision, and it was reported that they were making plans to travel to the US for treatment. They argued that they were not trying to create a designer baby, "as they are not choosing the baby's sex, intelligence, or skin colour." Taranissi said that he was unsurprised by the HFEA's decision, but felt that it was "unfair," and was "not a decision based on the ethics." He argued that there was a "political element" to the outcome. Taranissi stated that it was impossible to create a designer baby, and the public's perception was incorrect. "There is no such thing" as a designer baby, he said. "We do not have the technology to change embryos in the lab. All we do is test the embryo for specific problems" (Allison 2002).

While the HFEA, scientists and clinicians, and the impacted families had served as the primary voices in the renegotiation of the socio-technical contract, some were now calling for the issue to be subjected to democratic Parliamentary debate. In response to the HFEA's decision the health spokesperson for the Liberal Democrats

stated that the twelve-year-old authority was “creaking under the strain of new medical developments”:

From the patient’s point of view it is difficult to justify a distinction between the use of embryo screening to save the life of a child with an inherited disease, as with the Hashmis, but not save the life of an equally sick child like Charlie Whitaker simply because the condition is not hereditary. It’s high time the government allowed parliament to address these issues. (Allison 2002)

Tom Shakespeare, a prominent disability rights advocate, disagreed with the HFEA’s decision, commenting that he felt that “the HFEA are being too tough in this case.” To Shakespeare, the distinction between the Hashmis and the Whitakers did not seem significant enough to give one license approval, and deny the other one. “In the Hashmi case the family would have used PGD anyway, in this case they wouldn’t. It sounds like they are quibbling over a minor distinction.” Others criticized the HFEA for its heavy bureaucracy, blaming the issue on bureaucratic red tape rather than actual ethical issues (Dodd and al Yafal 2002).

The pro-life community praised the HFEA’s decision, however. The Society for the Protection of the Unborn Child said that it found itself in the surprising and “unfamiliar” position of agreeing with the HFEA, noting that “Usually we think they are doing the wrong thing.” The Human Genetics Alert also supported the decision, stating that embryo screening “turns embryos and children into tools, as a means to an end” (Dodd and al Yafal 2002).

Renegotiating the Scope of HFEA Powers: the Courts Step In

Four days before Christmas 2002, High Court Justice Maurice Kay ruled that the HFEA did not have legal power to authorize the Hashmis’ treatment. Kay said that the Human Fertilisation and Embryology Act was “tightly drawn” to “restrict the potential for misuse of science and technology.” Pro-life advocate Josephine Quintavalle, a member

of the pressure group Comment on Reproductive Ethics (CORE), brought forth the case in an effort to put a halt to the “ethically objectionable” practice of screening embryos for the purpose of creating a perfect donor match for an ill family member (Dyer and Boseley 2002). In the one-day hearing on the issue, Quintavalle stated that allowing it would open the door to “designer babies” (The Telegraph 2002). “With social sex selection around the corner and innumerable other designer baby possibilities on the horizon, today’s judgment is particularly timely. These vital issues involve the very essence of what it is to be human.” Quintavalle stated that the ruling was a “victory for the supremacy of parliament... We are adamant that it is not for the HFEA, a small unelected quango, to make these decisions” (Boseley 2003a).

Despite the High Court ruling, Suzi Leather, Chair of the HFEA, felt that the HFEA had made the right decision in approving the Hashmis’ license application: “It is important to recognise that what is at stake is not only the future of these families, but many other families that suffer from serious genetic conditions” (Boseley 2003a).

Clare Dyer reflected that “technology and ethics [were] collid[ing], and that debates over the ethical use of embryos would begin seeping into the court system in increasing numbers. The defiant Taranissi stated that in his mind, the HFEA did not have power to regulate embryo screening. Because of the HFEA ruling on the Whitaker case, he had to circumvent HFEA policy by collaborating with a Chicago clinic in order to conduct testing of the Whitaker embryos. At the time of the High Court ruling, Michelle Whitaker was ten weeks pregnant.

Because of the court ruling, the Hashmis spent £25,000 on testing in the United States. After two attempts in the US, they were still unsuccessful in producing a match for Zain, and began a fundraising campaign in order to raise money to attempt a third round. They had also made the decision to terminate a naturally conceived pregnancy

at fifteen weeks because tests had shown that the fetus had the same disease as Zain (Dyer 2003). Zain's father, Raj Hashmi said that the decision to terminate was "heart-breaking." "We had to take the heart-breaking decision to terminate the pregnancy. We are against abortion. It is the most heart-rending decision we have ever made in our lives" (Boseley 2003a).

The Hashmis' British embryologist, Simon Fishel, painted a dire picture for Zain if he were to continue without transplant treatment. "He might live til he's 40 with a very difficult quality of life. He might die next year. It can all change overnight. It's a stark contrast between a normal quality of life and a miserable quality of life with an unknown demise at any stage." Fishel contrasted embryo screening against couples attempting to conceive naturally in an attempt to have a child that would be a tissue match. A likely outcome would be termination of pregnancy, having additional children with the condition, or having "lots more children and never reaching the tissue type they want" (Dyer 2003).

While the Hashmis were seeking out other screening avenues in the United States, their case was also moving towards the appeals court. Zain's mother Shahana stated that his case would not be "fought in vain." "We'll take it to the highest level. We should never had to go along this road to where we are today. We should have been given the treatment to make sure his suffering is ended" (Boseley 2003a). She begged the public to understand that they were not trying to make a designer baby, that the donor cells would be coming from the umbilical cord, not the new baby itself. "We are not designing, we are not cloning, we are making use of waste." The cells from the umbilical cord would have been discarded, otherwise. "We will love this baby just as much. At the end of the day all we wanted to do was save our son from this horrible fate" (Dyer 2003).

The Hashmi's hopes were answered in January 2003, when the appeals court overturned Justice Kay's decision that the HFEA's regulatory powers were "limited to helping women with fertility problems bear children." The justices gave the Hashmi's permission to move forward immediately with their medical efforts. The "ecstatic" Hashmis were thrilled with the outcome. Shahana Hashmi commented that the couple had done everything within their power in an effort to save their son's life. "Now we all have new hope," she said. Zain's father, Raj, said when he got home from work after hearing the news, "the main thing was Zain running towards me and giving me a massive hug and saying: 'Dad, dad, well done! You've done it. I can get better now.'"

The Chair of the HFEA, Suzi Leather, expressed her approval of the judgment, noting that "clearly clinicians cannot always prevent diseases but if they are able to and also save the life of a sibling, then this is a *legitimate* use of these new techniques" (emphasis added) (Dyer and Wainwright 2003).

James Whitaker is Born

In June 2003, newspapers announced that Britain's "first designer baby" was born. The Whitaker's travels to undergo IVF and tissue typing in Chicago had paid off, in the birth of their son Jamie (James Harry) in a Sheffield hospital. Jamie was called "the first baby born in the UK to be genetically matched while still an IVF embryo." Mr. Whitaker emphasized that Jamie was not selected for social reasons: "All we did was change the odds from a one-in-four chance of a tissue match to a 98% chance. There was no selection on the basis of colour of eyes or hair or sex" (Blackstock 2003).

Jamie's arrival brought forth waves of both praise and criticism. Vivienne Nathanson, head of ethics with the British Medical Association, supported the Whitakers in their decision: "As doctors we believe that where technology exists that could help a dying or seriously ill child, without involving major risks for others, then it can only be

right that it is used for this purpose [...] The welfare of the child born as a result of the treatment is of crucial importance. But in our view this is not incompatible with allowing selection of embryos on the basis of tissue type. We would like to wish the Whitakers well.” Others still felt that the HFEA’s original decision to not approve the Whitaker’s license application was wrong. Dr. Taranissi said the decision was illogical. Others, however, were not so elated with Jamie’s birth and the reasons that he was brought into the world. Lord Winston expressed concern over the development, noting that Jamie, as a baby would not be able to provide informed consent: “Can you think of any other medical treatment which you would expect anybody to undergo without informed consent for somebody else’s benefit? [...] This child has the spectre of being born for somebody else’s benefit throughout his whole life. I find it incredible that the law might be changed.” What would happen if the transplant didn’t work? Lord Winston asked. Would Jamie then be expected to provide additional donations? What about later in life? What if Charlie needed a kidney? Would he be expected to give a kidney? (Boseley 2003b).

Others called for a review of the Human Fertilisation and Embryology Act, arguing that the science was outpacing policy efforts, and that the Act was outdated: “Clinical advances are overtaking the initial principles on which the HFEA was set up 13 years ago. It is time the Act was independently reviewed” (The Guardian 2003). Still others said that genetics had “outgrown” the legislative framework meant to reign in and place limits around it, but that ultimately, fears of creating “designer babies” was preventing “humanitarian” uses of it, and policy was becoming a hindrance rather than a help:

New techniques offer great hopes but also raise ethical dilemmas, particularly in the emotive field of fertility. Is it right to bring a child into the world with a predetermined genetic make-up to offer hope of a lifesaving cure for an

existing child? And if so, is it also right for would-be-parents to choose characteristics –blue eyes, say – of an unborn child; the so-called ‘designer’ baby? Commonsense makes us welcome the first but oppose the second. Yet a fear of appearing to sanction ‘designer babies’ is preventing a humanitarian answer to families desperate to save their children.

The HFEA has served us well till now, earning respect for its application of principle and logic to difficult ethical questions. But it should not give in to the ‘slippery slope’ argument. There is all the difference in the world between selecting an embryo to save a child and trying to predetermine hair or eye colour. We must not be frightened to proceed rationally, case by case.

No parents should have to nurse a dying infant knowing a technique exists to save their child. (The Observer 2003)

Concluding Remarks: The Contours of the Contract

While the Hashmis were not able to produce a successful match for Zain, their case paved the way for other families seeking treatment in the UK. The Hashmi and Whitaker cases provide an example of the negotiation of a socio-technical contract, one in which questions around who ought to be born, and for what reasons, were grappled with by the HFEA, the courts, families, doctors, and the public. The Hashmi and Whitaker cases illuminate a key question embedded within the socio-technical contract concept, that is, who are the actors that are actually participating in and shaping the renegotiation of socio-technical contracts? While traditional policy studies might focus on the regulatory institution itself as the primary actor in shaping the “rules of the road” around a certain technology, the cases discussed in this paper illuminate the role that other actors might also play in shaping socio-technical contracts. As explored in the Hashmi and Whitaker examples, parents and families served as both advocates and spokespeople for the licensing of PGD and tissue typing technology to create a matched sibling. They brought the issue to the media, and also into the court system, where

debates about the appropriateness of the savior sibling technique took place far beyond the walls of the HFEA.

The idea of the “welfare of the child,” and which child’s welfare should be taken into account, served as an important boundary-negotiating tool through which the lines of acceptable versus non-acceptable uses of the “savior sibling” technique were drawn. The term “designer baby” served as another boundary-negotiating tool around the ethical and non-ethical use of PGD and tissue typing technology. While the term “designer babies” was a contested concept, it also served as a constant throughout debates on embryo screening. For example, there are a number of “first designer babies” and “first designer baby clinics” in the history of assisted reproductive technologies. Does one create a designer baby when selecting for certain phenotypical traits? In the case of the Hashmis and the Whitakers, the debate was more about process than intention. Both families were very explicit in their intention to not select the sex, height, eye color, and other physical features of their child. But they were also adamant in finding the “perfect match” in order to help their older child. These cases transcend the issue of eugenics, or trying to create a superior race, and struggle with the moral entanglements of the law and the limitations of medicine and healing. That the term has continued to be used but has also been redefined and renegotiated in light of new technologies indicates its fluidity as contexts change and time passes.

The idea of love is also being negotiated in these cases. The families and their doctors were adamant that the physical trait of perfectly matched umbilical cord stem cells would not be a factor in how love was given to the resulting child. However, as one can observe in the Hashmi case, despite the rhetoric of loving a second child no matter what, the Hashmi parents did terminate a pregnancy when the fetus was not a match for Zain, and also had the same disease. Despite the emphasis on love, the overarching

goal was to not just create any child to love, but to create a *perfect* child for an *imperfect* first child.

Finally, the notion of consent is also being negotiated. The socio-technical contract concept engages the notion of consent, and illuminates the tacit and explicit terms that society and individuals are consenting to upon entering socio-technical arrangements. These arrangements and the very meaning of consent becomes increasingly complex in the world of assisted reproductive technologies, where the welfare of parents, existing children, sperm and egg donors becomes juxtaposed against the welfare of those who are not yet born. Whose welfare comes first? What happens when the welfare of the potential child does not align with the interests of parents and existing siblings?

The Hashmi and Whitaker cases highlight the complex and ever-evolving nature of the governance of assisted reproductive technologies, and illuminate questions that governance arrangements struggle to answer, such as, should parents have the right to choose the genetic traits of their child? Who decides? Is it ever acceptable to select a “perfect” embryo in order to save an ill family member? It is in this complex and gray terrain that robust governance capacities for negotiating socio-technical contracts becomes essential.

CHAPTER 7

ASSESSING RESPONSIVE CAPACITY: NEGOTIATING SOCIO-TECHNICAL CONTRACTS AT THE MIDSTREAM

Introduction

This final chapter draws upon my research as an “embedded humanist” in genetics laboratories in British Columbia and Oxford. In this chapter, I argue that that integration exercises can serve a vital role in rendering socio-technical contracts within the midstream more visible to participants and in opening them up to reflection. A key theme within each of the previous chapters in this project has been unearthing existing capacities for engaging in anticipatory governance. This chapter also explores capacities for negotiating socio-technical contracts, but on the level of the laboratory, or in the “midstream” of technological development activity, when research mandates, funding, and policies have already been established, but before research products enter the market or results are published (Fisher 2007). Specifically, rather than exploring *existing and historical capacities* for engaging in anticipatory governance, this chapter takes a different angle on the idea of capacity building, and drawing from the integration sphere of anticipatory governance, delves into the ways in which *capacities for anticipatory governance are currently being built* within the R&D sphere.

Before jumping into the case studies, it is important to define capacity for renegotiating socio-technical contracts within the laboratory context. Fisher (2007) explains the “capacity of laboratory decisions,” or more broadly “the responsive capacity” of scientists and their practices to respond to the societal needs, values, and concerns related to their work. Furthermore, responsive capacity also concerns “the conditions for negotiations [in scientific work] to arise and open up in the first place” (Fisher 2008, 5). A key component of integration studies, in assessing responsive capacity, also includes

assessment of “the extent to which human and social scientists can participate in the processes of framing and closure that they chronicle” (Fisher 2008, 5).

This chapter delves into how socio-technical contracts were renegotiated within the laboratories during the duration of the studies. First, in order to provide a broader context of the external policy mandates on the laboratories, I will provide an overview of policy dialogues around “responsible innovation” in Canada and the United Kingdom. I follow this by providing an overview and definition of socio-technical integration. Then, I will provide an overview of three key areas that enabled my participation in the renegotiation of socio-technical contracts and assessment of responsive capacity within the laboratory setting. These areas include: *the price of integration*, *participating in material practices*, and *responsible innovation*. Then, I utilize these three areas to structure discussion of my case studies. Over the span of these two studies in the spring/summer and fall/winter of 2009, I participated in structured and unstructured interactions with my geneticist collaborators on topics ranging from research decision-making to responsible innovation. Throughout the course of the collaborations, I transitioned from a laboratory outsider to a valued team member, assisting with and performing my own experiments, transferring laboratory techniques, and stimulating changes in laboratory patient engagement practices.

The Policy Language of Responsible Innovation

In his January 2001 response to the Speech from the Throne, Canadian Prime Minister Jean Chrétien remarked that, “In the 21st century, our economic and social goals must be pursued hand-in-hand. Let the world see in Canada a society marked by innovation and inclusion, by excellence and justice” (Government of Canada 2001a). This theme of social and innovation goals and values as intertwined entities was echoed in the Canadian government’s 2001 Innovation Strategy: “Achieving Excellence.” The

report emphasized the importance of fostering an “innovation environment” in which “public [...] confidence challenges are addressed before they develop” (Government of Canada 2001b, 11). Issues of science and technology permeate the social discourse, noted the report:

There are few areas of policy where science and technology do not play a role either as a source of public concern or as a potential solution to pressing problems. Innovation extends our capabilities and allows us to do things we have never been able to do before. Ensuring that we use these capabilities wisely, safely, and equitably is the role of good stewardship (2001b, 64).

Canadian commentators have highlighted the apparent contradiction between the democratization of science and the specialized expert knowledge that accompanies the practice of science, posing the question, “how do you democratize expertise? Is it not a contradiction in terms to make special knowledge everyone’s business?” (Saner 2009).

Policy discourse around innovation in Britain has followed similar language, focusing on the connections between innovation, economic growth, and “societal wellbeing” (Excellence with Impact 2012). In Britain, the life sciences employ 165,000 people and brings in £50 (\$77) billion a year, making it one of the leading industries in the country (Moran 2012, 125). The focus on the broader impacts of scientific research can be observed in British funding bodies such as Research Councils UK, which comprise over eighty percent of the British science budget, and the expectations it sets out for its grantees (United Kingdom 2006, 23), in which it expects researchers to “demonstrate an awareness of the wider environment and context” of their research, “demonstrate an awareness of the social and ethical implications of their research, beyond usual research conduct considerations, and take account of public attitudes towards those issues,” and “identify potential benefits and beneficiaries from the outset,

and through the full life cycle of the project” (Statement of Expectation on Economic and Societal Impact 2012).

The United Kingdom’s Science and Innovation Investment Framework highlighted the importance of fostering public trust in science by considering the potential implications of technologies early on, rather than when new developments are about to be disseminated into society:

In pushing forward the boundaries of science and breaking new ground in technological progress, the public needs to have confidence in the ethical and regulatory framework within which these advancements are being made [...] the Government promotes public understanding of and engagement with the science base and stresses the need for regulatory and ethical issues to be considered at the emerging stages of new science, when action can be taken to address them head on” (United Kingdom 2004, 15).

Similarly, the Government Office for Science published the Universal Ethical Code for Scientists (United Kingdom 2007), which seeks to foster a “continually renewed relationship between scientists and society” by encouraging scientists to actively reflect “on the implications and impacts of the work,” and to “seek to discuss the issues that science raises for society.”

Developing a capacity to render “expert” scientific practices more responsive to social goals and values may seem paradoxical, and yet it is a central task if nations such as Canada and the United Kingdom are to live up to their commitments for responsible innovation. *Integration* activities between social and natural scientists represent one effort to build such a capacity. Collaborations between social scientists and geneticists are already ongoing in the province of British Columbia in projects such as Genome BC, a large scale endeavor that seeks to make British Columbia a leader in “selected ethical, legal and societal issues related to genomics” (Mission and Objectives, Genome BC). One aspect of Genome BC employs the work of social scientists, who observe the

activities of scientists to see if they correspond with social goals. Genome BC is primarily funded by the province of British Columbia and the Canadian government.

The goal of integration is to feed back insights from public engagement, critical reflections and anticipatory exercises into R&D processes themselves with the purpose of engaging such processes in the social implications of scientific research. Integration activities are located within the “mid-stream” of scientific research, *after* public research goals and mandates have been set, but before research results are published and products enter the market (Fisher 2007). In the spirit of the ongoing Canadian and British dialogues and activities calling for increased reflection on the implications of scientific research, integration activities emphasize collaborations between social and natural scientists and engineers with the goal of increasing responsive capacity, the ability to link and engage with social and technical issues “in tandem,” within the sphere of R&D activities (Fisher and Lightner 2009). These capacities were explored by Fisher (2007) in a collaborative three-year engagement with a nanotechnology research laboratory at University of Colorado Boulder. The results of this initial study indicate that collaborations between social and natural scientists have value both in exploring the science-society interface in a hands-on manner and in increasing reflexive capacity within laboratory decision-making processes.

In order to fully immerse themselves in the laboratory environment, embedded researchers building on Fisher’s work utilize ethnographic sensibilities, but also engage in an “extended” form of ethnography, via weekly interviews with scientific researchers, using a decisionmaking protocol that explores the various considerations that scientific researchers currently integrate and could integrate into their research. Such considerations can range from material considerations, social considerations, to legal considerations. The weekly interviews serve as a venue for the social scientist to

provide constant feedback to researchers, focusing on researchers' decisions and how the considerations taken into account for material, social, and political practices might be broadened and productively re-shaped. Interviews using the decision protocol serve as a unique opportunity for social scientists and natural scientists to engage about decisionmaking, as it should be noted that the social scientist does not tell the natural scientist to think about social, legal, or ethical considerations, rather the social scientist seeks to serve as a reflexive tool for thinking deeper about such issues.

Fisher's intervention-oriented work provides the basis for the ethnographic assessment of reflexive capacity in two genetics laboratories. One laboratory is located in Vancouver, British Columbia, the other is located in Oxford, United Kingdom. The Canadian portion of the study spanned May through August 2009, and the British segment spanned October through December 2009. The remainder of this chapter explores three broad themes that emanated from the laboratory engagement project.

The first theme focuses on the *price of integration* in the project's attempt to bridge the "two cultures" of the social and natural sciences. As I experienced firsthand as an embedded social scientist, integration is two-way, and there was a toll (emotional and mental) in opening myself and my own (intellectual and national) culture to the cultures of the laboratories. Culture, in the sense of the social scientist/natural scientist dichotomy, and also of the American/Canadian and American/British dichotomy. Through this process, the social and natural scientists step outside of their comfort zones in order to learn each other's "languages" and establish trading zones.

Paying the price of integration was an important, and perhaps essential, component in establishing the relationships necessary to engage in the next theme, *participating in material practices*. In both laboratories, I was invited to participate in the material culture of the laboratory by performing my own experiments and assisting my

collaborators with their work. I was also able to transfer a material practice from the Vancouver laboratory to the Oxford laboratory. Stepping into the shoes of my collaborators and donning a lab coat enabled new modes of engaging in dialogue and establishing trading zones at the laboratory bench itself.

The new perspective afforded by participating in the material culture of the laboratory provided a space in which laboratory members and I grappled with the third theme, the meaning of *responsible innovation*. This theme is situated in dialogue around responsible research practices, and resulted in two distinct outcomes. In Vancouver, dialogues around responsible innovation resulted in laboratory changes in patient engagement practices. In the United Kingdom, the micro-level bench-side dialogues that I engaged in with a laboratory post-doc equipped me with the necessary insight to actively participate and provide critical feedback to senior scientists and policymakers at a policy workshop on preimplantation genetic diagnosis licensing schemes.

The Laboratories

The Canadian period of the study (May-August 2009) occurred in a genetics laboratory in Vancouver, at the University of British Columbia. The laboratory director, Alice Williamson,¹⁰ focused primarily on reproductive genetics, with her laboratory staff tackling a number of different projects, including novel prenatal diagnosis techniques, genetic causes of premature infertility, and research on chromosomal abnormalities, epigenetic changes, and disorders that are linked to the placenta. The laboratory is adjacent to a research hospital from which the laboratory receives many of its samples. Although patients who donate the samples are in close proximity, there is little interaction between patients and laboratory members. In addition to Alice, the laboratory had two PhD students, one post-doctoral researcher, one lab manager, one lab tech,

¹⁰ All names have been changed to protect the identity of the participants.

one masters student, an undergrad, and a research coordinator. In total, there were three males in lab, and the other six are female.

The British portion of the study (October 2009 – December 2009) took place in a genetics laboratory at a research institute based at the University of Oxford. Directed by Edward Jones, the laboratory's research focused on researching the genetic causes of cranio-facial malformations, the connection between genetically based diseases and increased paternal age linked to tumors in testes, and research exploring genetic mutations potentially implicated in autism disorder. Edward Jones spent a great deal of time (sometimes up to half his work-week) with patients in the clinic at the adjacent hospital as part of an interdisciplinary team comprised of clinicians and geneticists. In addition to Edward, the laboratory had two doctoral (DPhil) students, four post-doctoral researchers (two relatively new, two at 10+ years), and one lab tech. The laboratory had five males and three female staff members at the time of the project.

The Price of Integration

The Two Cultures

On the first day of the Vancouver laboratory engagement in May 2009, I met with the laboratory's director, Alice Williamson. Alice, who is an established and well-regarded researcher in fertility and genetics, provided an overview of the laboratory and briefly introduced me to her management style. Having conducted a small ethnography herself in high school, Alice understood the basics of the project, such as regularly spending time in the laboratory, making observations, and talking with researchers. Despite her understanding of the mechanics of ethnographies and other social science activities, her wariness of the social sciences was evident. "It's like we're talking two different languages," she immediately stated. She had collaborated with a psychology student in the past, utilizing surveys in order to garner perspectives on fertility issues.

The collaboration provided some useful insights for presentations, “but,” she added, “ultimately that is soft science. It’s good because you can point to it [as evidence]. It [social science] was fun, but not something I would want to do again.” This comment was at once disorienting and intimidating, causing me to question whether collaboration would even be possible in such a context. Clear allusions to the two cultures were not something that I expected to encounter in the first meeting, however, there was a distinct parallel between Alice’s comments on speaking two different languages, and my discussion with Oxford laboratory director Edward Jones.

After arriving in Oxford in October 2009, Edward and I met at least an hour, and discussed the overall laboratory format, Edward’s leadership style, and his take on each laboratory member and how they fit into the larger picture. Compared to the tightlipped and quiet nature of the overall culture of the Jones’ laboratory, Edward was forthcoming and candid in expressing his opinions. At one point, he bluntly commented (although in good humor) that he understood about “one tenth” of what I “actually do,” although he was willing and ready to learn, and stated that he would be interested in me emailing him some of my papers. “We come from two different cultures, two different worlds,” Edward stated.

Although, in Edward’s words, he only understood “one tenth” of my work, he hoped that I could help translate the laboratory’s work for a broader audience. Edward gave me a task, stating that it was my “first job” as the laboratory’s visiting social scientist. The task was to review a media release written by the Wellcome Trust regarding the laboratory’s most recent *Nature Genetics* piece. Edward felt that the release needed to be reworked from both a technical and readability standpoint. While he would be editing and rewriting most of the piece himself, he wanted a “new pair of eyes” to review it and provide recommendations on how the article could be less jargon-

heavy, and more tangible for a broader public audience, of scientists and non-scientists alike.

Alexi, one of the Jones laboratory's senior post-docs, voiced a similar sentiment – that social scientists and natural scientists speak “different languages,” and it was “unclear” to her what a social scientist could bring to a functioning laboratory that already has a “steady dynamic,” unless there was “a situation of crisis” that needed to be addressed.

I have no idea what you could bring in. I'm sure there is something, I just can't see it. Would it only be during a situation of crisis? Would it be before the crisis occurred? ...I do strongly believe there is a lot to do with interdisciplinary study, but that requires knowledge, and interest, and it is very difficult to do that because people don't speak the same language.

John, another post-doc in the Jones laboratory, also expressed that he was unsure what role social scientists could play, as he felt that the governance of science should be left to senior scientists with experience and knowledge.

C.P. Snow's writings on the two cultures, the divide between the humanities and natural sciences, although archaic and perhaps no longer completely descriptive of the complex and dynamic relationship between the natural and human sciences, fit surprisingly appropriately in the initial phases of each laboratory engagement project. Snow, reflecting on his personal experiences moving between the realms of the human and natural sciences states that he felt as if he were “moving among two groups [...] who had almost ceased to communicate at all, who in intellectual, moral and psychological climate had so little in common that instead of going from Burlington House or south Kensington to Chelsea, one might have crossed an ocean” (1993, 2).

The initial conversations with the senior scientists in the two laboratories indicated a certain cultural understanding of the relationship between the social and

natural sciences, that the two cultures do not come together unless there is a specific issue that needs to be addressed, and the relationship, if there is to be one, is one of utility. In Alice's reflections, the "soft science" of ethnographies and surveys was useful because she could use it as evidence and context to further buttress her scientific findings on young women's perspectives on fertility. While Alice noted that there was utility in her social science forays, collaboration with social scientists did not fit into her day-to-day laboratory life. Edward also saw a specific utility in collaborating with a social scientist on the back-end of research projects, in that following publication in a scientific journal, the social scientist could "translate" his research for a broader public audience. In this regard, the social scientist would serve as an ambassador of the laboratory to the general public. Alexi, too, viewed interdisciplinary collaboration as a primarily need-only relationship, e.g. the laboratory might call in social scientists to assist with a crisis situation, such as a public relations crisis or serious ethical quandaries.

In all of these perspectives, the social scientist is viewed as having one set of expertise (ethics and public relations/engagement), and the natural scientist has another (empirical insights into the natural world). The two only come together for short bouts of time to address specific issues related to specific events. In this model, social scientist intervention or collaboration occurs in the downstream of scientific research, after research agendas have already been set, experiments are undertaken, and articles are authored. The laboratory, the locus and "midstream" of research and development activity, has traditionally not been viewed as a place for governance of research. Such activity would occur either upstream, where research mandates and policies are set, or downstream, when research results are published, applied commercially, or applied to new projects. By this time, it is often too late to augment research and technological trajectories. Fisher et al. (2006, 491) note that it is not surprising that the laboratory

context “remains largely conceptualized as the instrument of promotion, with control almost by definition seen as externally orchestrated, even when scientists and engineers themselves initiate or devise it.” However, engagement within the laboratory context itself, the midstream, potentially enables proactive engagement with issues *before* the crises that Alexi alluded to occur.

The laboratory engagement model developed by Fisher (2007) and undertaken in this project seeks to engage social and natural scientists in the midstream itself, to explore the capacities for reflexivity, reflection, and responsiveness to societal considerations within the laboratory context. In order to move beyond a punctuated equilibrium of collaboration, where social and natural scientists only sporadically come together to retroactively address an issue, the siloed social science and natural science actors must be able to come to some sort of grasp of each other’s languages and cultures. The following sections of this paper explore this process in-depth, highlighting that such immersion does not only entail the learning of languages, but also comprises a complex tapestry of social, cultural, and political contexts that the embedded social scientist must navigate.

A Journalist or a Psychologist? Initial Distrust and Hesitation

One such complexity that I encountered was the initial hesitation and distrust that many of the laboratory members had regarding my presence in their space. While each laboratory had its own unique dynamic, there were a number of similarities in terms of how my role was initially perceived by the researchers. Members of both laboratories asked me if I was spending time in the laboratory in order to “dig up dirt” on them. There were also fears that I would give away privileged laboratory information, either accidentally or intentionally, therefore jeopardizing the laboratory’s ability to publish. Vancouver laboratory members asked me if I was secretly an embedded journalist,

intent on finding the wrongdoing in their daily activities. While the “journalist” framing was predominant in Vancouver, one particular laboratory member in Oxford, Seamus, asked me if the purpose of my study was to “psychoanalyze” the laboratory members. Seamus’ unease would manifest most saliently when one of the Oxford laboratory members and I would leave for an interview. “Have fun getting psychoanalyzed!” was a common comment that Seamus would call out.

The initial distrust exhibited by many of the laboratory members slowly subsided over the first few weeks, as some inquisitive individuals began to ask me basic questions about the social sciences. One such example came early on in the Oxford engagement. My space in the Jones laboratory was close to the workspace of Lavender, one of the DPhil students in the Jones laboratory. Lavender turned to me. “So what research will you be working on in the laboratory?” she inquired. I responded that I was broadly interested in how scientific researchers grapple with and think about the social and ethical aspects of their research, in light of various considerations. “So are you a scientist?” she asked.

“Not in your traditional sense,” I said. I explained that my background was in political science, and that I focus on the connections between science, technology and policy, and that I was hoping to explore those relationships further during my time in the laboratory.

“What is political science?” she shot back. “I don’t think that there is anything that my research has to do with politics or policies. I just do science!” I sensed that her questioning was born out of interest and curiosity, and her posture and body language, despite her lack of sleep and pending poster presentation, conveyed that she was willing to listen. Rather than give her a textbook answer, I told her that just as she examines complex biological relationships, I unpack the relationships between the material and the

social. I then pointed to various materials around the laboratory and used them to illustrate how they might be embedded in a complex policy discourse. I pointed to the refrigerators that held various types of biological samples, both human and animal, and noted the system of consent that patients have to go through before providing samples, a practice rooted in historical rationale and concepts of human rights and dignity, after the abuses of Nazi scientists and incidents such as the Tuskegee syphilis experiment. “Interesting,” she said. “I didn’t think we had anything in common.”

Accounts of British and Canadian Culture

My first chance to meet the Williamson laboratory as a whole was at the laboratory meeting. Coupled with my lack of knowledge of genetics, the challenge of finding common ground seemed to become even more insurmountable at that meeting, where a conversation on the differences between Canadian and American genetics conferences gave way to some laboratory members discussing the perceived cultural divide between Canada and America. Being the social scientist from America, the odd woman out in more ways than one, my outsider status was highlighted as Alice, who had spent a large portion of her life in America, and the other lab members highlighted the communal spirit of Canadians, noting that Canadians tend to care more about their communities and each other than Americans and making statements such as “Canadians are friendlier and care more about their country” and “Socialism isn’t a bad word here.” I had the distinct impression that they were discussing this for my benefit, and perhaps did not realize the unintended impact this comparison would have on me. The tone of the conversation further strengthened my feelings of otherness. I felt categorized with the rest of America as unfriendly, individualistic, and uncaring. Although I laughed it off, and joked about it at the time, I silently agonized over it.

The Oxford experience was different in this regard. Throughout the engagement, few overt references were made by laboratory members regarding nationality or British versus American culture. One of the few conversations that touched on this topic was with Alexi, who was an international researcher. She noted that Oxford was a “very strange place,” a separate “reality” which strives to keep a certain mystique. “There is a mystique about it,” she said, “but I don’t *really* appreciate it because I’m not British...I don’t really care, for me...it’s just a place to work.” She said that the Oxford mystique was particularly salient for English people: “There’s an aristocracy of intellectual development...and that’s what Oxford does to any English person.[...]We do fabricate these worlds, and the value is cultural, and also personal.” She also commented on the differences between European and American university experiences:

You probably haven’t met many undergrads here, but there is this terrible pressure of being first at Oxford...students are very rarely happy here, which is very different from an American campus. Why do people do that to themselves? Why does it have to be painful to be valuable? We do this as a human species, but much less Americans than other people. Loads of Americans are there to have a good time. But as Europeans there is this idea that to have a valuable experience, it has to be tough, and you have got to suffer...

Reflecting on the quiet and more reserved nature of the Jones laboratory, Alexi commented that “People respect each other’s boundaries, which is a very English thing to do[...]The laboratory used to be very international, but it has become very British.” She then highlighted her perceptions on American versus British laboratories:

In general, it’s kind of a cliché but the American people are very outgoing at first, but it doesn’t go much deeper than that. It tends to not go that much further...the British personality is hard to crack that first step, but they are actually very caring. It’s not indifferent. Once you know them, there is no difference. But it’s not a naturally outgoing culture. [Historically] they’ve had to put up with a lot of crap. I think that Americans tend to complain too easily.

During a casual lunch conversation with Michael, a researcher from another laboratory, I learned that the Jones laboratory was perceived by other laboratories as particularly “British.” Michael, an international researcher himself, commented that I would likely notice the differences between his laboratory and the Jones laboratory. “They’re a very British laboratory,” he stated. “You’ll notice that many of the other labs are much more international. Sometimes it can be harder for a non-British person to be part of the group. It takes a lot of work to break that thick British skin.” Later in the day, John mentioned that I was the latest “talk of the town,” as Michael’s lab had been talking about me – the Jones’s laboratory’s American “social scientist.”

Fertility and Aging: Laboratory Level Bio-Politics

In addition to the challenges of navigating Canadian and British culture within the laboratories, I was also exposed to “culture shock” of a different kind. During my encounters with Frank, the post-doctoral researcher, and other laboratory members in Vancouver, I sensed a trend regarding laboratory members’ perspectives on fertility and aging. While Frank was providing me with basic overviews of molecular genetics, he asked me how old I was. After I responded, he turned back to the computer screen. “Well take a look at this,” he said. He pointed to a graphic representing various ages and corresponding fertility. “See how egg quality and overall fertility decline more rapidly as you enter into your late twenties and thirties? And how drastic the decline is as you approach your forties?” I was speechless. It took me some time before I could respond to him.

This was not the first discussion regarding age and fertility, however. In my first meeting with Alice, I was advised, “Have babies before you turn thirty.” She offered me this advice because of the increased issues and risks associated with trying to have a baby as one becomes older, a statement that was supported by her research. Although

one might imagine this as a somewhat comedic situation, underneath the humor is an undercurrent of seriousness. A number of laboratory projects are dedicated to understanding the relationship between aging and fertility. In fact, at least one laboratory member has undergone in vitro fertilization (IVF) in the past and subsequently gave birth to a healthy baby. When asked if her experiences with IVF influenced her research interests, the laboratory member responded that it was “the other way around.” She noted that the decision was influenced by her participation as a scientist in fertility research. Given that many of her colleagues were IVF researchers and practitioners, her own research on genetics and fertility, and a scientific curiosity regarding IVF, the researcher decided to try the procedure.

The research coordinator, Jackie, had her thirtieth birthday fast approaching. The laboratory community, in typical fashion, wanted to put together a card to let her know that she was appreciated. The lab opted against a placenta-replica birthday cake for Jackie, although they excitedly showed me pictures of previous placenta-shaped cakes from other celebrations. I asked one member how old the “birthday girl” would be. They responded “thirty,” and jokingly said that I shouldn’t mention the specific age the birthday girl was turning, since the turning thirty signified that her fertility was beginning to decline faster. “Shhh,” the researcher teasingly stated, “we don’t want to upset her.”

Although the lab members are able to joke about their fellows’ fertility, these casual conversations and the unsettling effects they had on me served to illustrate the researchers’ perspectives on science and self. Clearly, the ongoing scientific work that researchers engage in permeates and shapes laboratory culture and social life, in addition to interactions with outsiders. The mantra of “have babies before you turn thirty” that was expressed to me multiple times continued to impact how I perceived my body and my fertility choices. Typical birthday jokes might address aging or going “over the

hill,” but most do not reference the reproductive side of aging (for the obvious reason that most people would not take kindly to their reproductive health being referenced in a joke). There are exceptions, however. Discussing fertility is not taboo in the Williamson laboratory. It is the exact opposite, since human fertility in this setting is literally under the microscope.

Such micro-level dynamics associate with the scientists’ perspectives and publications on fertility and ageing impact the macro-level dynamics of how society and individuals view fertility and aging, in personal choices, the media, and in the policy realms. In North America and Europe, the multiple births rate from IVF is twenty to thirty percent, whereas in “naturally conceived” pregnancies, the rate is only one percent (Baylis 2009). A thirty-five year old woman might opt against the safer single-embryo transfer while undergoing IVF and choose to transfer multiple embryos because she perceives herself as being less fertile due to her age. The popular media romances the notion of multiple births through reality shows such as “John and Kate Plus Eight,” and pays little heed to the health risks associated with multiple births, for both mother and children. Most Canadian provinces do not fund IVF procedures; therefore many women want to save money by transferring multiple embryos at a time, in hopes that more embryos transferred will lead to a successful pregnancy.

There were a number of occasions where I witnessed the powerful and emotionally charged nature of fertility research, such as when Alice and Rosa came close to tears when recalling working with samples from terminated pregnancies. At the same time, I felt that Alice was trying to retain the objective and impersonality commonly associated with scientific research, but despite those attempts, it was evident that she too was strongly impacted by the experience. Given the above considerations and examples, fertility research is quite different from other areas of research. Decisions in

the areas of other emerging technologies are arguably and perhaps debatably much less personal and intimate than the decision of when and how to have a child, a decision that is increasingly being affected and influenced by scientific and policy realms.

The philosophy of the Williamson laboratory, where researchers are encouraged to have children earlier in their careers, rather than later, was different from what Alexi (in the Jones laboratory) had experienced in her career. When I approached Alexi and asked if she would be willing to do an interview with me on issues related to science and society, she started laughing and joked that her opinion would depend on what day of the month it is. She segued into talking about the challenges and difficulties of being a woman in a scientific field. “They don’t get it,” she stated, referring to the unanticipated hardships associated with having children while doing research or trying to finish school.

A few weeks later, Alexi sat down with me for a formal interview. She had studied and worked at a number of top universities before coming to the Jones laboratory, where she had been working as a senior post-doc for the last eight years. Prior to coming to the Jones laboratory, she had secured a post-doc in London. During this post-doc, she became pregnant. “People don’t tend to very much like it when you take maternity leave on a short term contract...it’s an issue...so basically, I got fired.”

The Word “Masturbation”

Unlike the Williamson laboratory, which focused on the relationship between maternal age and genetic disorders, much of the Jones laboratory’s recent research has focused on the relationship between *paternal* aging and resultant sperm mutations and certain congenital disorders. In order to explore the relationship between paternal age and certain mutations, researchers engaged in “massively parallel sequencing” sperm DNA. Performing research on sperm DNA requires sperm, and therefore sperm donors. Alexi stated that while one might think that procuring semen donations would be easier

than getting blood donations, since it does not include a needle, it is actually much more difficult: "Masturbation is one big taboo." She noted that men tend to be split on the issue, and that their willingness to donate is largely dependent on culture, with Catholic cultures being particularly difficult to procure samples in.

I have found over the years that people really offer to give it, or they will not even consider doing it. It's very simple, you cannot convince anybody. It's either not a problem (and I think it has to do with education and culture)...I think some people even have a real taboo about the word masturbation. It's very common, so it's all about how you produce a sample. You know, that's for the men to decide, it has nothing to do with me, really. But if you think about it, practically, it's much less invasive than taking blood. It's a taboo, and a cultural taboo. It's very clear.

Like the Williamson laboratory, the Jones laboratory also had its inside humor, although, the jokes tended to come as more of a shock to me, given the quieter and more serious nature of the Jones laboratory. For example, when grabbing coffee with Sonny and Lavender, the two DPhil students in the laboratory, they began discussing the latest happenings at the research institute. A random (and apparently used) pair of men's underwear had been found in one of the men's bathrooms at the institute. The two laughed and immediately quipped, "It's probably Alexi telling someone to drop their pants and give her a sample!"

I was also in for quite a surprise when Lavender opened her desk drawer and took out a pair of preserved testes, which she was in the process of cutting into extremely thin slices so she could examine them under a powerful microscope. Lavender's work focused on identifying tumors in the testes, which laboratory research indicates produce the mutant sperm. "Since we've been talking about them so much, I wanted to show you my testes!" Lavender exclaimed. Later, when Lavender and I were talking with John, I told him what Lavender had shown me. He laughed, and informed me, "Lavender never showed me her testes before!"

I reflected with John on the patterns of humor I was beginning to notice in the laboratory. John stated “We’re a bunch of leg twitching antisocial dorks. We never see the sun.” “So, English, essentially,” I joked back. “English to the extreme,” he noted.

Engaging in Material Practices

Material Practices - Vancouver

During the first two weeks of the Vancouver laboratory engagement, I despaired ever coming to a real understanding of what the researchers did in their daily practices. I would stare, mystified, at the large machines that surrounded my workspace. I would hear conversations regarding “snips.” *What is a snip?* I desperately scanned the Internet in an effort to find answers. However, I was not able to find a clue to the mysterious “snip” entity that seemed to be so popular in laboratory discussions.

I decided that, despite the potential embarrassment it might cause me, I would broach the topic of the “snip” in my interviews with the researchers. My weekly interviews with Joy and Zhi served as a primary source of information for me, particularly when it came to learning the language of genetics. The primary reason that I could not solve the mystery of the “snip” is that although the term is pronounced as “snip” it is actually an acronym: “SNP,” which stands for “single nucleotide polymorphism.” These SNPs occur when one “letter” (the nucleotides represented by the letters A,C,T,G) in the genetic code gets switched out for another letter. Depending on where these SNPs occur, they can either be harmless or are considered a genetic mutation, having a vast impact on human development and health.

Although conducting interviews and spending time in the laboratory was important in establishing rapport and trust relationships, spending time, in and of itself, does not necessarily translate to gaining competence or understanding. Each day spent at the laboratory meant being surrounded by strange equipment that I only vaguely

recognized as being important for DNA analysis from forensic television programs. Researchers would spend hours hunched over their benches, using slender instruments to draw liquid from one set of tubes and deposit it into other sets of tubes. This ritual was simultaneously hypnotizing and perplexing.

During my weekly interviews with Joy and Zhi, two PhD students in the lab, terms such as “PCR,” “sequencing,” and “SNP” were used quite frequently, and I was coming to have a nebulous grasp of what the terms meant, yet the discourse, at this point, was far divorced from an understanding of practice. I could engage in conversation about scientific practices, and could even string the words “polymerase chain reaction” together, yet I could not connect the concept with the practice. Discussing SNPs and PCRs was akin to talking about fairytales and swords in stones. I could attempt to imagine them situated in scientific practice, but had never witnessed or experienced them firsthand. I could have a conversation about a PCR, but I still could not understand how it was actually done. We might talk about ethidium bromide agarose gel in multiple conversations, yet a cognitive dissonance would remain. I could not connect the idea of the gel to the actual practices of the laboratory. The researchers would patiently explain concepts to me in our interviews, but without an understanding of material, physical practices that I could anchor them to, the concepts continued to remain empty and meaningless to me. Understanding the concept was not enough; I needed to understand how the concept operated in practice (see Rabinow’s “Making PCR: A Story of Biotechnology” for a history of the PCR, from concept to technique).

The opportunity to move from engaging with the concept to engaging with the technique came in my interactions with Frank, the post-doctoral researcher in the Williamson laboratory. My work area was right next to his workbench. Frank’s hands were constantly busy preparing and executing experiments. While working, he typically

carried on one or more conversations on a wide array of topics with me and his lab mates, topics ranging from music to food to science. Approximately three weeks into the project, I asked Frank if I could watch him “do a PCR.” That same day, my bench-side friend transformed into my key informant. My guide readily agreed to let me watch him “do the PCR,” but he actually did much more than just let me watch. Having taught courses at his former university, he pulled up the PowerPoint slides (which were in Spanish) and began the process of teaching me about genetics. He realized that we would have to start with the basics when he asked me if I knew what a PCR was. Rather than pretend to know something I did not, I admitted that I hardly understood it, with only a vague understanding from popular television shows such as CSI.

Frank described to me how all genetics research depends on DNA amplification. For a geneticist to study a particular gene or region of DNA, the tiny fragment must be amplified. The PCR, or as I came to learn, “polymerase chain reaction,” is both a process and an entity, which explained some of my earlier confusion. The process includes putting together a complex combination of liquids to create a reaction. The reaction only happens under a series of intense heat exposures, which are carried out in a PCR machine. So when a researcher says that he or she “has to go do a PCR,” the expression encompasses both the PCR process of mixing liquids and the machine itself. Put simply, the purpose of the PCR is to amplify particular regions of DNA. The regions to be amplified depend on what the researcher wants to study, and he or she will put together a specific and customized mixture of primers, enzyme, and nucleotides that will bind to and amplify the specific regions to be studied. The “chain reaction,” the process of DNA amplification, only happens when specific temperatures are applied to the mixture inside of the PCR machine. I was struck by how simple the process was – there was basically no difference between it and cooking: one must add the proper ingredients

and use the proper temperatures to achieve the desired product. A good PCR requires both experience and skill. A novice can stumble through, but the old adage that “practice makes perfect” holds true for PCRs; the steady hand and experienced eye of a veteran typically results in a more consistent PCR reaction.

By this point, about four weeks in, I was interacting with the researchers in casual social situations on a daily basis. During coffee breaks and lab outings to lunch, the researchers would provide me with updates on their projects. Frank and I would discuss when he would start and end his experiments, confirming timetables so I would be sure to be there when he received new information and breakthroughs. When I arrived at the lab each day, he would provide me with an update of the ongoing saga of successful PCRs, failed PCRs, and the latest sequencing successes and challenges. At this point, I was not only interviewing researchers about their work, I was becoming an invested participant – almost like I was part of a family.

About nine weeks into the project, laboratory members and I were regularly engaging in lab social events, such as lunch, coffee, and after-work outings. Around this time, Frank showed me that he had re-designed the laboratory member’s pictures and biographies on the door to include my own picture and blurb. Laboratory members and I were also connected on the social networking website Facebook. On Facebook, I signaled my intention to audit a molecular genetics course in order to deepen my understanding of some of the laboratory’s experiments. I was confronted by Zhi, who had learned of my expressed interest. “Why would you want to do that?” he demanded. After I explained my motives, Frank, also present, asked if I had “done a PCR.” When I responded that I had not, my collaborators immediately suggested that I try my hand at one. Within a matter of days, donning a lab coat and rubber gloves, and armed with a pipette, I was doing my own PCR, no longer “benchside,” but at the bench itself. The

researchers found it novel, humorous, and exciting that I was rolling up my sleeves and engaging in the physical, material aspects of their work. When Pearl, the technician, saw me working, she exclaimed, “Wow, I can’t believe my eyes!” Pearl and some of the other researchers excitedly snapped pictures of me holding a tray of samples and using a pipette.

The experience was a vital learning exercise, providing me with insight into scientific practice that I would not have had otherwise. For example, when pipetting my PCR product into the ethidium bromide agarose gel wells, I realized that my blood sugar had dropped quite low (I had not eaten that morning), since my hands were shaking, and I was beginning to feel slightly lightheaded. When I expressed how unsteady my hands had suddenly become, the undergraduate student, Tsai, showed me a way to hold the pipette with both hands that helped me steady my grip. If I had not been performing the delicate pipetting task, I never would have noticed that something as seemingly trivial as skipping breakfast could have an impact on the physical aspects of a scientist’s work. Knowing that I would be doing more work with Frank, I changed my eating habits and began to eat breakfast. Despite my shaky hands, I managed to successfully pipette the rest of the PCR product into the wells, and a few hours later, after the completed gel electrophoresis, Frank found my PCR results to be so exemplary that he ran to the copy machine and made a copy, to use as an example of a “good PCR result” in his future lectures on the topic. Such lectures would include guest lectures, and genetics courses that he will teach in Vancouver and his home country.

Material Practices - Oxford

The opportunity to engage in material practices in the Oxford laboratory came early on, indeed, the very first day of the engagement. I accompanied John, one of the laboratory’s post-docs, on a brief trip to the lab to put some samples into the freezer. I

commented to him how familiar the laboratory seemed, despite Canada and the UK being separated by an ocean. I gestured to various familiar instruments, such as pipettes, stating how I had used them while preparing PCR product and doing experiments in the Vancouver laboratory. John's eyes lit up when I mentioned that I had experience, and noted that that he had hundreds of samples and PCRs to "do," so it would be great to have my assistance and another pair of hands.

Two weeks into the Oxford engagement, I was wearing a lab coat, assisting John with the preparation of gels, pipetting PCR product into hundreds of little wells. I would regularly assist John with his experiments, typically spending two or three days out of the week, either at the lab bench, working alongside John, or accompanying him to the "mouse house" – checking on the genetically modified mice that he used for some of his research. John expressed his admiration of the work that I had been doing, and even called me a "PCR god," stating that "pipetting one hundred wells and making a gel is a good day's work for anyone."

Oxford – a Mini Turing Test

During lunchtime, the scientists at the institute would convene and talk shop. Early on, I spoke with Michael, a researcher at the institute about to receive his doctoral degree. We discussed his work on blood disorders, and he was surprised to discover that I was not a natural scientist. All of the researchers outside of the Jones laboratory that I met and talked with assumed that I was a scientific researcher, based on my ability to engage them in the more technical aspects of their work. It was always a surprise to my interlocutor when the conversation would turn to my own research, and they would learn that I was not a scientist at all and had no formal training or scientific background.

Oxford – Transferring Material and Knowledge Practices

During my time in the Oxford laboratory, I came to know a DPhil student named Sonny. Sonny was having issues achieving successful PCRs. Before I met Sonny, I learned about his PCR challenges in my first conversation with Edward Jones, the laboratory's director. Part of our conversation centered around trying to understand each others' "cultures." When Edward expressed to me that he understood only about "one tenth" of what I do, I told him that I was also still trying to understand his world, as well. I explained that I had been engaging in some material practices in my last laboratory engagement, and had some basic understanding of genetics from a practitioner's perspective, but that there was still a great deal to learn. I showed him results from a PCR that I had done in the Vancouver laboratory. "You are probably equal to or farther along in your understanding of genetics as Sonny is, who has been here for months, and still can't manage to do a PCR," Edward stated.

Edward's comment, that I was equally competent or surpassing in understanding material practices as one of his doctoral students, was an unanticipated acknowledgment of my increasing capacities for material competence and understanding. The day following my conversation with Edward, Sonny and I were casually chatting in the lab, and he expressed his frustration with his PCRs to date. We sat down at his workspace, and Sonny showed me his PCR notebook. Most of the researchers in the laboratory used large red notebooks to record their experiments and notes. The sturdy red covers ensured that they could withstand wear and tear, and could be referred to years later. Despite spending hours at his bench preparing his PCRs, they always ended in failure. The bands signifying the presence or absence of specific DNA mutations were non-existent, or very faint at best. Despite Sonny's poised and secure attitude, I could sense that he was becoming frustrated at his lack of success. The ability to complete a PCR is a basic skill necessary for a geneticist to be

competent in before he or she can do anything else, and Sonny's futile attempts, after four months of trying, were preventing him from going any further in his research endeavors.

Disconcerted at Sonny's distress, I reached for my folder containing my notes and PCR results from the Canadian laboratory. "Maybe we could compare PCRs," I said. I pulled out the PCR sheet and results that I had completed in my last laboratory engagement.

"Where did you get this?" Sonny asked.

"It's from my laboratory engagement this past summer," I said. "This is one of the PCRs that I did."

"*You* did this?" Sonny asked.

I responded that it was my very first attempt at a PCR. Sonny commented that he was very impressed that it was my first try. "The bands look so nice!" he exclaimed. "Bloody good. Goes to show that you don't need a scientific background to do a PCR." Sonny then took a closer look at the PCR "sheet," a rubric that Frank, the post-doc in the Canadian lab, had designed. The sheet listed all of the basic ingredients for a PCR, and allowed the researcher to fill in all of the specific amounts of the necessary materials. It was a useful tool for both seasoned veterans and new researchers alike to keep track of exactly what was going into their PCR solution. Sonny found the PCR sheet design to be both elegant and useful. He had been writing everything down in his notebook, and he noted that without the PCR sheet, it makes it more likely that the researcher could omit something or make an error. Sonny asked if I could provide him with a copy of the PCR sheet so he could use it and employ some of its characteristics in his own note-taking and PCR practices. I contacted Frank from the Canadian lab, and asked him if

Sonny could have a digital copy of his PCR sheet design. Frank was happy to oblige, and was excited that someone was interested in using his PCR sheet.

Interactional Competence – Going Beyond Linguistic Engagement to Material Engagement

How can natural scientists and social scientists create a shared space for collaboration? Peter Galison (1997) grappled with this dilemma and proposed the idea of trading zones as a way of surmounting the barriers of different disciplinary languages, paradigms, and epistemic cultures: “distinct groups, with their different approaches to instruments and their characteristic forms of argumentation, can nonetheless coordinate their approaches around specific practices” (1997, 806). In this collaborative space, the actors develop a shared language, or creole. While Galison explored trading zones amongst different scientific disciplines, Collins, Evans, and Gorman (2010) have tested the idea in collaborations between natural scientists and social scientists, developing the notion of interactional expertise.

Collins (2004, 125) defines interactional expertise as the “ability to converse expertly about a practical skill or expertise, but without being able to practice it, learned through linguistic socialization among the practitioners.” At a specific point along the way, in the Vancouver-Oxford laboratory engagements, there was a shift from conversing with the researchers about their experiments to actively participating in their material practices alongside them. Collins (2004, 128) saliently highlights this transition, from the “painful period” of ignorance, to being able to “join in” and even transfer knowledge amongst scientists, to the point where the social scientist can coherently engage with his or her scientist collaborators:

the sociologist of scientific knowledge entering a new domain initially understands neither the banter nor the technical terms pertaining to some new piece of science being investigated. After a painful period, the inferences in

others' conversations start to become clear and eventually it becomes possible to begin [to] join in.[...] Eventually the scientists will become interested in what you know, not as a scientist in your own right, but as a person who is able to convey the scientific thought and activities of others. If you have just come from visiting scientist X you may be able to tell scientist Y something of *the science* that X is doing, and tell it in a way that is convincing enough to enable Y to be sure they have learned something.

While learning how to converse about the domain of research, I was also engaging in the practice of it. In Vancouver, as the shift of moving away from only dialogue to participating in material practices while engaging in dialogue occurred, laboratory dynamics also shifted. In Vancouver, my name and picture were placed on the door alongside the names of the other laboratory members – I was no longer perceived as the outsider keen on “digging up dirt,” rather, I was another member of the laboratory, an invested participant.

The process of gaining interactional expertise while also participating in the material practices of the laboratory culture poses what some scholars might perceive as serious risks to the integrity of ethnographic research. The transitional experiences from laboratory outsider to laboratory insider highlight an important aspect of ethnographic research, that is, the risks associated with “going native,” of blurring the distinction between the observer and the observed, of participating *too much* in the culture that one is observing. Ethnographers are warned that feeling too “at home” is a danger: “there always must remain some part held back, some social and intellectual ‘distance’”. For it is in the space created by this distance that the analytic work of the ethnographer gets done” (Hammersley and Atkinson 2007, 90). While there is the risk that the ethnographer might lose his or her objective ethnographic gaze by actively breaking down the boundaries between the Self and the Other, there are also advantages to conscientiously going native. In the case of the Vancouver and Oxford studies, going

native by engaging in material and other cultural practices of the laboratory served as a strategy to foster diverse modes of engagement and discourse.

In Oxford, following the Vancouver study, I “hit the ground running,” and shortly after my arrival, began participating in material practices on an almost daily basis. Unless they already knew of me as the “Jones laboratory’s American social scientist,” other researchers at the Oxford research facility assumed that I was also a geneticist, based on my growing capacity to fluently converse with them, and also empathize with their day-to-day challenges. If their PCR was not turning out, or they were feeling overwhelmed by the amount of pipetting they had to do, I could empathize, and even offer advice in some circumstances. I was able to empathize with the struggles of the Oxford DPhil student, Sonny, identify a specific issue in terms of how he was recording his PCRs, and identify something that might help him by transferring the Vancouver PCR protocol over to him. Sonny was willing to take my advice and attempt doing things differently because I could not only dialogue about PCRs with him, I was able to show him an artifact (the PCR sheet and pictures of a successful PCR) of my firsthand experience that served as evidence of competence in the domain.

For the purposes of the Vancouver and Oxford projects, “going native” served as a strategy in establishing and building trust relationships that would make further dialogue, engagement, and even changes in laboratory practices tangible. Learning about and engaging in the material/procedural aspects of laboratory work illustrated to laboratory members that I was eager to “walk in their shoes” and engage in their daily work activities alongside them. Engagement is a two-way process, and as the social scientist demonstrates that she is willing to expand or step outside of her comfort zone, and as demonstrated in the following sections, her collaborators will begin to step outside of their comfort zones, as well.

Responsible Innovation: Public Engagement, Reflexive Awareness, and Integrating Across Scientific and Policy Domains

Puzzling over Responsible Innovation in the Laboratory

Throughout the laboratory engagements, I engaged in dialogues with laboratory researchers on their own perspectives on responsible innovation. Joy, one of the PhD students in the Williamson laboratory, and I had ongoing conversations on the topic, starting with her very first interview, about the role of the laboratory in thinking about social and ethical considerations. While Joy felt that the laboratory was taking important ethical issues such as patient confidentiality seriously, when prompted for her thoughts on areas that could be enhanced, she acknowledged that there is always room for improvement, particularly in the realm of patient engagement efforts. She informed me that the laboratory was presently not participating in any particular engagement efforts. She noted that inaction on the part of researchers to engage with patients was not confined to her laboratory, however. It is a condition that pervades many studies that incorporate patient samples: With many human studies, the “findings or implications for whatever disease, disorder, or condition you’re studying is never actively reported back.” Unless patients proactively pursue this information, “they won’t actually know what sort of progress is being made.” Rather than continuing in the vein of the status quo, in which the only laboratory-patient communication happens in the beginning recruitment stage, Joy preferred to see an iterative system where the laboratory could potentially contact patients throughout the research process and update them on the project’s progress. “Because if they participated in the first place then obviously they have a

vested interest. They would probably be curious, not necessarily about individual findings, but just overall how the research is going.”¹¹

Shannon: [Ideally you would want to] show [the patients] the whole, the big picture of what their small contribution is going towards.

Joy: I know the Smith lab across the hall, they work with Huntington’s, and they have a lot of interaction with Huntington’s patients. They hold conferences to give them updates and things like that. I think it’s a cool way to engage public interest, other than just having posters and recruiting patients, following up with some of the important [information].

Shannon: Do you think in the future you’d be able to do something like that?

Joy: “Potentially. Someone would have to head it up and take responsibility for it. I don’t really know what sort of ethical considerations should be taken into account when approaching that kind of thing. I think you wouldn’t want to cross any lines with privacy.

Shannon: So respecting individual confidentiality while at the same time conveying the big picture.

Joy: Yeah.

The conversation on patient-engagement, a conversation from our first interview, served as my primary introduction into how Joy thought about social considerations in her day-to-day research. Social considerations, from her perspective, revolve mainly around the patient. Her response to me indicated that she had already been thinking about the issue of engagement and how current practices might be improved. The interview format provided a venue in which we could collaboratively explore such issues further, and think about various ways in which those considerations could be implemented in a concrete fashion.

¹¹ Exact question asked: “Do you think there’s any room for improvement, or do you think the system is already doing what it *should* be doing?”

Joy's and my conversations on responsible innovation led to us exchanging articles that the other might find interesting. In the days following a conversation regarding the limits and boundaries responsible scientific practice, she searched for a Bill Joy piece that had a particularly strong impact on her thinking about science and boundaries. Once she found it, she made sure to tell me the moment I walked into the laboratory, and had already placed it at my workspace with a post-it note saying, "Shannon, I found that article!" Due to her enthusiasm and willingness to dialogue with me on the topic, I provided her with a selection of articles about integration and anticipatory governance, and included an explanation of how the articles could help inform and illuminate aspects of the Bill Joy article, as well as issues that we had covered in our "benchside" conversations. Little did I know that I would be given the opportunity to feed Joy's insights on responsible innovation into the larger group weeks later.

That opportunity occurred about eight weeks into the engagement when I was invited to give a lab talk. Frank approached me and asked if I would be willing to give a talk on responsible innovation. Rather than attempt to give a lecture on the topic, it seemed best to simply guide the conversation in the style of a seminar. Since a main topic of the workshop was responsible innovation, the question "what does responsible innovation mean to you?" was presented to the researchers.

Alice, the laboratory director, discussed her trouble with reviewing grants. She used the example of experiments that use monkeys as animal subjects. She noted while reviewing a particular grant that she had sincere difficulty grappling with the consequences of particular experimentation on monkeys. "What is my role in this?" she asked. "Can I reject the grant because of the ethical issues that I see, or do I have to make my judgment based solely on the science"? She said that reviewers do not have a

specific mandate to review the ethical implications of projects. She stated, “We can adhere to all of it [the guidelines] but are the benefits/cruelty really worth the risk?” She used another example of an experiment in which mice are starved to death, paradigmatic of experiments where the pain and suffering of the animal is obvious, and the social benefits much less so. These points led to more discussions about science and ethics, concluding with the question of “where does ethics end and science begin?”

The conversation also touched on issues of lab safety, training, confidentiality, and patient consent. Laboratory members brought up the notion that “informed consent is a process, not a document” – something that can be forgotten in the day-to-day grind of scientific research. At the same time, there is a fine balance that must be struck – lab members reflected that it would probably be *irresponsible* to unnecessarily contact patients that provided miscarriage samples. In these cases, minimal contact might be better than too much contact, given the sensitive and emotional nature of such a case. Contacting patients in such a case might cause more harm than good. This led to more philosophical questions, such as the idea of doing research for the “common good.” Rosa, the laboratory manager, inquired into the notion of the common good – “What is the common good?” “What is good for who?” “Is the majority what rules? Is whatever is good for the majority good for society?”

Over the course of the conversation, I was able to present my own contextual notion of responsible innovation. I made comments about the patient-centeredness of the laboratory culture, making references to past conversations about lab members’ passion for helping patients. I noted that when and prompted to think about responsible innovation in the context of the laboratory, I immediately connected responsible innovation with patient engagement. I referenced my first interview with Joy, who was

out of town for this particular lab meeting. “Can this lab do something like the Smith lab is doing?” I inquired.

“Well, I’m not sure about what the other labs are doing in terms of patient outreach,” said Alice, “But I have wanted to put out a newsletter to our patients for quite a while.” She claimed that the major setback was that she wanted to design it herself (having created many of the graphics on recruitment brochures, etc.), and did not have the time to get the newsletter underway. Enthusiasm had been sparked in the conversation, and we continued talking about the possibility of an iterative patient newsletter, touching on topics such as format. This prompted Alice to jump out of her chair and run to her office to grab a newsletter that had been sent to her house. She particularly liked the format of this newsletter, and wanted to show it to the group, since it was close to her vision of what a patient update newsletter might look like.

Shortly following this interchange, the discussion came to a close, as there were other items on the meeting agenda to address. The discussion afforded an opportunity to explore laboratory members’ thoughts and concerns regarding responsible innovation and how they understand it. It provided a venue for the sharing of stories and ideas that are not typically discussed in the everyday laboratory setting, and importantly, served as an opportunity for the scientists themselves to raise concerns regarding patient engagement, where it was lacking, and where it might be possible to make it better. Such concerns relate back to the notion of enhancing accountability and democratizing scientific expertise making it “everybody’s business” to know what goes on in the context of the laboratory.

A roundtable discussion such as the above example, in which scientists’ own insights and perspectives are fed back into the larger group, provides an opportunity in which junior scientists’ own tacit knowledges or tacit expertise can play a role in

enhancing the reflexive awareness and capacities of laboratory leadership and the laboratory itself. As the facilitator of the discussion, I tapped into my ongoing conversations with laboratory members and presented some general insights to the larger group. The insights that were presented to the larger group all stemmed from the laboratory members themselves, what integration provided was an opportunity to discuss their ideas and insights via the interview protocol, which would not otherwise have been accessed and fed back. While immediate changes in practice might not occur, or even need to occur, such interactive roundtable venues serve as a perturbation in the everyday fabric of laboratory culture, and by their very nature of “bringing up things that are not normally discussed [in lab meetings]” and revisiting issues that have “sat on the backburner” for years, change the laboratory culture itself.

It appeared that the newsletter idea had been set on the backburner once again, until the very last lab meeting. In this meeting Alice said that she was planning on moving forward with the newsletter, and told her researchers that she wanted each one to work on a lay summary of their research. The process would become a part of laboratory culture: “When someone publishes a paper, they should write a lay version.” She went on to discuss the merits of the newsletter: “[It will be] great for people to be involved in the process and know the progress of it.”

That the newsletter appeared to be in the process of implementation as a laboratory practice less than a month after it had been discussed as a method of patient engagement in the responsible innovation conversation was an unexpected and exciting turn of events. Laboratory members have indicated that the responsible innovation conversation played a role in the various dynamics that led to the newsletter’s implementation. In the final interview with Joy, we were discussing the various activities that the laboratory is doing in terms of actively integrating social and ethical

considerations into its work. I brought up the newsletter as one way that the laboratory was actively pursuing integration, and she asked, “Was that your idea?” “No,” I responded, “It was yours!” I told her that I had fed her earlier thoughts regarding patient engagement back into the larger group while she was out of town, therefore, the feedback and our earlier conversation on patient engagement had provided an important foundation for later conversations and action on the topic. Fisher (2007, 163), encountered a similar experience, where a change in material practices was not triggered by an external mandate or policy, but rather by the participant’s own “latent concerns.” As Fisher notes, “the engagement may have influenced practice, but to do so required the practitioner’s desire to remedy a perceived deficiency.”

Oxford/London – Responsible Innovation, Micro and Macro

Most of the material work that I participated in within the Jones laboratory was for John’s projects. One of his projects focused on exploring the underlying genetic factors related to autism, a neurological developmental disorder affecting 1/150 children (Zimmerman 2008, 3). Contemporary estimates for diagnoses of autism *spectrum* disorders, which can range from mild to severe symptoms, put the numbers at 1/88 children (Carey 2012). While symptoms range in severity, individuals along the autism spectrum can have difficulties in socialization, communicating, and might also have issues with intellectual development. However, children that are diagnosed and begin treatment can see improvement in symptoms over time. John hoped that his research could assist with early diagnosis and better therapy. As my work relationship with John deepened, we would dialogue about the nature of his research, and I learned that autism was a particularly challenging area in genetic research because of its extreme variability from individual to individual, and to date, no single genetic mutation or combination of mutations can account for the complex symptoms that comprise autism disorder.

During a discussion with John, I mentioned that I was in the process of learning about preimplantation genetic diagnosis. Preimplantation genetic diagnosis (PGD) is a technique that enables genetic analysis of in-vitro embryos before they are implanted into the womb. In order to detect genetic abnormalities that might indicate predisposition to a particular disease, a single cell is biopsied from the embryo. The technique has been utilized for a number of different conditions, including the genetic mutations associated with particular forms of breast cancer (the BRCA 1 and 2 mutations). In 2009, clinicians in the United Kingdom made headlines around the world when they performed PGD for a couple in which the father's family line had a predisposition to breast cancer. The clinicians created a number of embryos in-vitro, and selected the embryos that did not have the BRCA 1 and 2 mutations, therefore enabling the couple to have a baby without the genetic predisposition to breast cancer. It has been lauded by supporters as a miracle technique, because it can enable couples who might be carriers for certain devastating genetic conditions to have healthy babies. It has also been criticized as a harbinger of a new eugenics, of scientists "playing God" as other genetic predispositions unrelated to disease, such as sex, eye color, height, and other characteristics could be tested for. The practice has been critiqued by some religious groups as well, because any unused embryos, or embryos with undesired genetic predispositions are discarded. Additionally, having certain genetic mutations such as BRCA does not guarantee that an individual will get the disease, rather, in the case of BRCA, they have a higher chance (50 to 80 percent) of getting breast cancer at some point. Some states, such as Italy and Germany, ban the practice. The double-edged sword of PGD is a highly regulated practice in the United Kingdom by the Human Fertilisation and Embryology Authority (HFEA).

Early on, I made a mental connection between John's autism research and the potential implications in embryo screening. I asked John for his thoughts on PGD and autism. "What if your research on autism genetics was applied to diagnosis of embryos?" I inquired. "If your project is successful and the research published, there exists the potential that the genetic markers that you identify could be used to screen embryos for this condition. Are you comfortable with the results of your research being used in such a way?"

"I have honestly never thought about this issue before," responded John. "I would hope that the research results would not get used in that way. I want my research to go towards helping people. Autism isn't a death sentence – individuals with autism can lead fulfilling lives, and can benefit greatly from therapeutic measures. I hope that the research can be applied to helping diagnose individuals earlier so they can get better treatment."

During the Oxford study, I would also travel to London every few weeks in an effort to understand the broader ongoing policy dynamics underpinning genetics and new reproductive technologies. During one such visit to London, I participated in a stakeholder workshop on British PGD licensing policy, hosted by the HFEA. The vast majority of the participants at the workshop were primarily scientists, stakeholders, or policymakers.

Clinics must be licensed by the HFEA to carry out PGD, and once licensed they can carry out PGD for any condition previously approved by the HFEA. Two conditions do not follow this licensing category, however, and the HFEA licensing committee considered the approval of testing on a case-by-case basis. The two conditions are "lower penetrance," where not everyone who has the mutation will get the disease, and "later age of onset" conditions, which carry with them the possibility for preventative

surgery. BRCA is considered a later age of onset condition, and therefore would fall into the second category. A number of the clinicians at the workshop noted that the licensing application and case-by-case approval process was so lengthy (sometimes over the course of multiple years), that many couples would give up, especially couples experiencing a potentially short reproductive lifespan, either because they are older couples, or would have to undergo treatment, such as chemotherapy, mastectomy, etc. that could affect reproductive health.

For part of the workshop, participants were divided into breakout groups. The participants at the table, with the exception of myself, were well-established scientists and clinicians in the area of reproductive technologies. The table was grappling with the question of whether lower penetrance and later age of onset conditions PGD should continue to be licensed on a case-by-case basis, or whether a blanket licensing scheme would be appropriate in some circumstances (i.e. once a clinic was approved to test for a certain condition, they would not need to reapply for a new license for that condition each time). One clinician mentioned that she had been approached by a couple who wanted to carry out PGD for autism. The couple had two sons already, and both were affected by the condition. They hoped that the same mutations that were detected in both sons could be detected via PGD. She implied that the couple gave up due to the lengthy licensing and approval process.

While the couple ultimately did not end up moving forward with PGD, the clinician's brief comment reminded me of John's work, and the highly variable nature of autism, and his comment that autism is not a "death sentence" – some individuals with autism can benefit greatly from therapy. I relayed these thoughts back to the larger table, noting my experience working with John on the autism project. While the clinicians had been complaining about the hindrance of lengthy case-by-case review

process for low penetrance conditions, I noted that certain conditions, such as autism and other genetic disorders might merit closer scrutiny because they are so variable. I also noted autism, unlike BRCA, for example, has a number of genes that could potentially be implicated in the condition, therefore making a blanket licensing policy difficult and laden with ethical ramifications. The clinician who had originally raised the autism example commented that the points I raised about the unique and variable nature of autism were important issues, and while she had brought up the example to show why the current case-by-case licensing policy was unwieldy and unnecessary, the additional insights I shared provided a space for her to further reflect on the issue, and she in turn adjusted her viewpoint. She and the rest of the scientists at the table agreed that some conditions might still merit a case-by-case licensing approach (they felt that BRCA should be blanket licensed, because the mother might have a short reproductive lifespan), but other cases that might fall along a spectrum, such as autism, should remain case-by-case. The group relayed this feedback and the autism example back to the HFEA Head of Policy. The Head of Policy stated that the feedback would be taken into consideration, as it illustrated that the HFEA should not take an all or nothing approach to licensing and making all conditions blanket licensed.

Integration Agents: Engaging Inside and Outside the Lab

The two above vignettes illustrate two ways that an embedded social scientist can critically interface with scientists both inside and outside the laboratory. Te Kulve and Rip (2011, 704) call for “engagement agents” – individuals who can traverse the multiple “streams” and “work at more than one level” of innovation processes. Such actors can serve as “linking pins” amongst the multiple levels that comprise a particular scientific and policy domain (Te Kulve and Rip 2011, 704). Integration work presents one way of developing interactionally competent engagement agents. The trading zones

that embedded social scientists develop with their scientist collaborators within the context of the laboratory are not necessarily confined to the four walls of the laboratory. Rather, as the collaboration strengthens over time, and the social scientist becomes more familiar with the technical aspects of the scientists' work, and also becomes more comfortable asking questions at the confluence of the socio-technical, they consequently can take their newfound perspectives, knowledge, and critical insight to other levels, or streams, within the innovation system.

Tennyson (2005), recounting the journeys of Odysseus, writes, "I am a part of all that I have met." Similarly, the embedded social scientist carries his or her experiences both inside and outside of the laboratory with them, moving between the laboratory and other domains of scientific, policy, and socio-cultural practices. The embedded social scientist becomes a mobile trading zone, in a sense, capable of directly engaging with laboratory cultural and material practices, while also being able to dialogue and provide critical insight into those same practices that she is actively participating in. In the Vancouver case, this dialogue and feedback provided the laboratory a venue in which the laboratory director decided to change laboratory practices around patient engagement. In Oxford, my experiences assisting John with his project, and our resulting dialogues, enabled me to "render [...] visible" to him the "unperceived contexts" of embryo analysis that his work might influence (Fisher and Miller 2009, 371). These laboratory-level interactions further equipped me with the tools necessary to engage outside of the laboratory, and when the topic of licensing PGD for autism entered the conversation, I was able to provide modest insight from both the laboratory *and* the policy realms, and raise issues related to PGD licensing that neither the scientists nor the policymakers had discussed.

Discussion: Engaging Responsive Capacities

The cases explored in the three themes of *the price of integration*, *participating in material practices*, and *responsible innovation* suggest that laboratories are not isolated silos, as a traditional understanding of the two cultures might imply. Rather, laboratories are nested within broader socio-technical dynamics and specific cultural contexts. These multiple layers of culture intersect at the level of the laboratory, giving shape to both the formalized and “tacit knowledge-ways” (Jasanoff 2007) that inform decision-making within the midstream. The ongoing engagement in socio-technical contracts (as opposed to sporadic interdisciplinary collaboration) that integration affords enables social and natural scientists to reflect on the broader dynamics of scientific research, establishing collaborative trading zones in which “latent concerns” of the researchers themselves can be unearthed (Fisher 2007, 163; Gorman 2002).

As the work of Fisher (2007) and the examples explored in this chapter indicate, engaging the reflexive capacities of scientific researchers through consistent structured and unstructured interactions can in turn catalyze their own responsive capacities, in which the researchers themselves initiate laboratory-level change in response to broader social contexts and issues related to their research. Furthermore, with new modes of engagement come new ways of understanding, and just as integration equips natural scientists with new tools for thinking about the broader context of their research, integration also furnishes the embedded social scientist with new perspectives and understandings cultivated through bench-side dialogue, and even, in some cases, participating first-hand in material practices. Such experiences enable social scientists to become mobile trading zones, effective integration agents capable of engaging across the multiple levels of both practice and policy within a particular scientific domain, rendering socio-technical contracts more visible, and reflecting upon how they might be productively renegotiated with practitioners. This collaborative configuration does not

happen automatically, though. Integration is the study of what is possible when scientists and social scientists take the time to listen to each other, step outside of their comfort zones in order to establish trading zones, and learn each other's "languages" by stepping into the shoes (or in this case the lab coat) of the other. Therefore, while the "price" of integration might be a high one, it is well worth the cost.

CONCLUSION

TECHNOLOGICAL SOMNAMBULISM IS NOT INEVITABLE: REPRODUCTIVE TECHNOLOGIES, ANTICIPATORY GOVERNANCE, AND SOCIO-TECHNICAL CONTRACTS

The anticipatory governance literature advocates for the creation of tools to assist in developing “distributed capacities” for various stakeholders to engage in the governance of technologies. This project has explored the anticipatory capacities that exist within governance arrangements for thinking through and bringing about significant changes in what I describe as “socio technical contracts” – or the kinds of socio-technological assumptions and arrangements that characterize a particular domain of policy or practice. This work has focused on the question of anticipation, and the modes by which societies engage in the proactive governance of emerging technologies. The project explored the concept in tandem with the rapid scientific and technological evolution of the last century, where it often seems as if technological development and scientific breakthroughs outpace societal attempts to govern them.

As argued earlier, however, this is not always the case – it is possible for society to “get ahead” of the curve and proactively grapple with the implications of new and emerging technologies – before it is “too late.” And when it does seem to be “too late,” and that the socio-technical contract has already been “written,” that is possible to renegotiate, rethink, and rewrite the terms of the contract (see, for example in chapter four, which focuses on donor conception technology). While there exists a rich literature in Science and Technology Studies, Feminist Studies, and Policy Studies on reproductive technologies (such as the work of Jasanoff, Thompson, Mulkay, Franklin and Roberts, and others) I sought to bring a new perspective to this literature by bringing reproductive technologies together in conversation with existing literature on anticipatory

governance, and utilize the case studies as a way of putting anticipatory governance in conversation with the socio-technical contract framework. Drawing from Guston's (2007) work on the social contract for science, the empirical material in this project also helped illuminate another aspect of social contracts as they relate to the governance of emerging technologies, that is, socio-technical contracts diverge from the traditional social contracts of thinkers such as Locke, Rousseau, and Rawls in the sense that rather than being tacit agreements, they are dynamic negotiations that are actively being renegotiated and deliberated upon.

The case studies in the governance of assisted reproductive technologies explored within this project illustrate the process of active negotiations of socio-technical contracts. Society does not sleepwalk through every technological configuration. Citizens and stakeholders, in these case studies, were not necessarily being blindsided by advances in reproductive technologies, rather, as the case studies illustrate, questions were being raised about the implications of reproductive technologies far before the technologies themselves actually existed. One aspect of the empirical work that comprises this project that I sought to illuminate was the critical role that individual citizens, various government entities, and other informal entities can play in combatting the "lag" that is commonly attributed to the relationship between technology and ethics/policy by taking an active role in negotiating and renegotiating socio-technical contracts. The remainder of this conclusion situates the capacities described within the project within the foresight, engagement, and integration spheres of anticipatory governance, and provides thoughts and questions regarding future areas for research.

The Governance of Assisted Reproductive Technologies and Foresight, Engagement, and Integration

The foresight, engagement, and integration spheres are foundational to the concept of anticipatory governance. As Barben et al. (2008) emphasize, anticipatory governance comprises distributed and societally embedded capacities for shaping things to come, and these shaping mechanisms are framed within Barben et al. 2008 as foresight, engagement, and integration. Therefore, how do the capacities explored in this project fit into these three key spheres? In the following section, I discuss the distributed capacities illuminated in this project as they relate to the foresight, engagement, and integration concepts, illustrating how the anticipatory governance framework overlays with large-scale, governance dynamics and capacities for proactively shaping things to come.

The *imaginative capacities* explored in the second chapter align with the *foresight* and *engagement spheres* of anticipatory governance. Within this chapter I drew from Miller and Bennett's work on science fiction in constructing socio-technical futures, and Jasanoff and Kim's work on sociotechnical imaginaries in order to reflect on and contribute new ideas regarding the imaginative capacities of society, and the role of story, metaphor, and motif in shaping and catalyzing debates around the future implications of new and emerging technologies. I illustrated that there were ongoing debates and dialogues about the responsible practice of science reaching to before the time of Shelley's *Frankenstein*, when concerns about the responsible use of galvanism were being deliberated and the importance of citizen participation in the scientific enterprise was being discussed in the public sphere. *Frankenstein*, widely considered to be the first modern work of science fiction, served as a reflection on the practices of galvanism taken to the extreme limits of the imagination. Shelley's motif of the monster, born from a scientist's desire to "play god" by controlling the powers of life itself, continued to be an important framing device for stimulating dialogue about responsible

innovation all the way to the birth of Louise Brown and beyond. Huxley's *Brave New World* similarly captured the societal imagination during the time that it was published, serving as a reflection on the role of government in society and, taking the idea of government control to its extremes, reflecting on government control of all aspects of human activity, including reproduction. In the third part of the chapter, I drew from archival sources to illustrate how (sometimes in subtle ways, and sometimes in quite blatant ways) the two works of science fiction served as ongoing motifs in conversations around reproductive technologies. Before Louise Brown was born, and before PGD technology was a possibility, the chapter reflected that citizens, stakeholder groups, and independent and government advisory bodies were actively deliberating upon the future trajectories of these technologies and engaging in societally embedded foresight activities.

In the third chapter, I chronicled the governance dynamics in the UK from the birth of Louise Brown to the establishment of the Human Fertilisation and Embryology Authority. This chapter explored *capacities for judgment*, chronicling the “out of control” atmosphere following the 1978 birth of Louise Brown, and delving into the role of Britain’s trustworthy experts, the “great and good,” in reigning in those perceived out of control forces and giving shape to the new socio-technical contract that would provide the foundations (embodied within the Warnock Report and the Human Fertilisation and Embryology Act of 1990) for how the British would engage with reproductive technologies from that point onward. One significant capacity for judgment was embedded within the expertise-laden Warnock Committee, who was tasked with negotiating the perceived chaos into order and “Stopping [a] ‘Brave New World’.” This chapter aligns with both the *foresight* and *integration* spheres of anticipatory governance. It aligns with the foresight sphere in the sense that the Warnock

Committee, though the report it generated, engaged in an anticipatory exercise in providing recommendations that could not only encompass the nascent, current state of reproductive technologies, but that could also evolve with the technology as it transitioned from an experimental technique to a widely distributed medical treatment. It aligns with the integration sphere in the sense that the Warnock Committee was not only integrated in terms of bringing together an array of experts from the social, humanistic, and natural sciences, but it also brought together the social and technical elements of new reproductive technologies and packaged them together, creating new types of socio-technical hybrids as a result, such as the “pre-embryo” or the “legitimate” donor-conceived child (as discussed in chapter four).

Chapter four focused on capacities for *renegotiating* socio-technical contracts, and specifically delved into the role of individual stakeholders and traditional legal institutions, such as the courts, in reimagining the rights of citizens. The dynamics explored within this chapter align with the *engagement sphere* of anticipatory governance in the sense that the courts provided a new space for donor conceived individuals to engage with existing policy and shape future policy dynamics. Chronicling the experiences of Canadian Olivia Pratten and British Joanna Rose, both donor-conceived individuals seeking information about their biological sperm donor fathers, this chapter contrasted with Winner’s notion that once a social contract has been written, it cannot be rewritten. It explored the experiences of donor-conceived individuals in Canada and the United Kingdom as they attempted to rewrite the terms of the socio-technical contract in light of new societal considerations regarding the “right to an identity.” The chapter also falls into the *integration sphere* in terms of the work of the Warnock Committee in renegotiating the donor-conceived child from what might be considered an unruly social kind, the “DI child” back into the traditional, “legitimate”

British family. The foresight sphere appears again here, as reading of the Warnock Report, with particular attention to the sections on donor-conceived children illustrates the parallels between *Brave New World*, and the world Warnock was seeking to avoid (e.g. babies being born outside of a family context, avoiding the commodification of babies, and avoiding the design of children). The Warnock Committee was clear that it wanted children embedded in families, not wards of the state. *Brave New World* was a future it wanted to avoid.

Chapter five also falls into the *engagement sphere*, as it explored the *deliberative capacities* within the United Kingdom for actively negotiating socio-technical contracts around PGD policy. The chapter recounted societal debates around whether allowing PGD for limited medical uses would open the door to giving couples the opportunity to select for “designer babies.” The HFEA was tasked with navigating and simultaneously providing a space for public discourse around the controversial topic, with vocal stakeholders from the disability community arguing that allowing PGD would be akin to new era of eugenics. On the other hand, patient advocates argued that they simply wanted a “normal” baby, free of severe inherited disease. Although the HFEA started developing a framework for PGD regulation in 1993, it has been unable to stabilize a framework for PGD, as the question of what medical conditions are severe enough to allow PGD continues to be an ongoing debate. As I argued in the chapter, rather than viewing the lack of a stable framework as a negative, it could be seen as a positive, due to the strength of the “talk centric” public sphere in the United Kingdom, and the HFEA’s efforts to continually rethink and revisit the socio-technical contract around PGD.

Chapter six ties into the *foresight sphere* of anticipatory governance. Specifically, the chapter focused on the *capacity of existing HFEA policy for addressing new and controversial issues*. This chapter explores how the foresight exercises (and

resulting policy language) of the past shape present-day policy decisions. Specifically, the chapter attends to the “welfare of the child language” within the HFE Act, and the ways in which it acted as a boundary-negotiating tool in helping the HFEA determine what would be appropriate versus inappropriate use of PGD and HLA tissue-typing technology. Using the case studies of the Hashmi and Whitaker families, the chapter further addressed the societal debates and dialogues around PGD, in light of the new technological capacity of HLA tissue typing, which, when coupled with PGD, enables for the creation of a “savior sibling” – a perfectly matched donor whose umbilical cord stem cells could provide relief and even a cure to an ill older sibling or other family member. The line between right and wrong becomes even murkier, however, since the donor sibling would also be a perfect match for other biological materials, such as kidneys. The chapter also explored the negotiation of the meanings of love and of perfection, as families struggled with a severely ill child – seeking to create a *perfect* younger sibling to cure an *imperfect* older sibling.

And finally, chapter seven approached the negotiation of socio-technical contracts at a different level of analysis, at the level of the laboratory. Chapter seven falls into the *integration sphere* of anticipatory governance, and comprised two case studies of genetics laboratories in Canada and the United Kingdom, and explored the *responsive capacity* of laboratories to integrate societal considerations into daily decisionmaking processes. Drawing from Fisher’s (2007) work, the integration sphere of anticipatory governance argues that the laboratory, or the “midstream” of the R&D process, is an overlooked but important sight for governance, and as I argue within the chapter, a key arena for the negotiation and renegotiation of socio-technical contracts. This chapter is distinct from the others in one other key way: while the previous chapters explored existing capacities for anticipatory governance and the negotiation of socio-

technical contracts, chapter seven illustrated another key aspect of anticipatory governance – that *capacities for anticipatory governance can be actively and intentionally built*.

While I began this study with the intention of primarily focusing on the HFEA as an agent of anticipatory governance, my time spent both in the field and immersed in archives led to an augmentation of the scope of analysis. As Barben et al. (2008) note, anticipatory governance should not be limited to any one entity, rather, anticipatory governance can be thought of as a “society-wide distributed capacity for shaping things to come.” Indeed, this project was not solely a study of *government*, but instead tackles the topic from the perspective of *governance*. The case studies discussed above reflect the broader notion of governance – there is no one specific entity engaging in the negotiation of socio-technical contracts. Instead, the capacity resides in many different parts of society, from formal institutions such as the HFEA, to plaintiffs in court cases, to dialogues at the laboratory bench, to conversations about these issues in coffee shops and pubs. The foresight, engagement, and integration tools in the societal tool belt for anticipatory governance are broad and diverse in nature. Thus, technological somnambulism is not the inevitable trap that Winner had originally posited.

Questions for Future Research and Proposed Next Steps

This project sought to lay groundwork for new directions for research in anticipatory governance. It argues that the policy process is broader than legislation alone, that there are capacities being cultivated within society for anticipatory governance, and therefore presents a different way of looking at the world from what Winner lays out. A number of questions for future research then arise. For example, what does anticipatory governance look like in different national contexts? One key question and new direction for research relates to *what anticipatory capacities look like*

in different socio-cultural contexts. In what ways are capacities distributed in similar and dissimilar arrangements? What is the *process for cultivating capacities* in the British and other contexts? How does one measure and evaluate capacities? What are the means for determining whether they are effective or ineffective? In what ways do these anticipatory capacities help British society construct a better future? What sorts of capacities for anticipatory governance need to be pursued and cultivated moving forward? These questions cannot be answered here, but I raise them because in order to have a more robust understanding of how anticipatory governance operates within different contexts, they need to be answered.

While this work focused primarily on British capacities for negotiating socio-technical contracts, the next phase of my research plan includes integrating a comparative Canadian component. I propose to utilize the comparative method, comparative institutional histories, and archival work to examine historical anticipatory capacities in the British and Canadian governance of reproductive technologies. Comparative case studies enable the researcher to parse out activities that are context-specific, and those that are not. There are a number of similarities between British and Canadian societies which make governance activity within these contexts solid comparisons, including a parliamentary system of government, shared legal traditions, a similar language, shared histories, and additionally, they are two of the only countries that have created national licensing agencies to govern assisted reproductive technologies. Despite their similarities, however, my initial research into British and Canadian approaches to the governance of anonymous sperm donation indicates that there are also significant distinctions in British and Canadian approaches to governing assisted reproductive technologies. A comparison between the UK and Canada provides the opportunity to focus on a study of historically embedded anticipatory

capacities that emerge in both cases, as well as those capacities that might be specific to each context.

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To: Erik Fisher
SS

From: Mark Roosa, Chair
Soc Beh IRB

Date: 11/07/2008

Committee Action: **Exemption Granted**

IRB Action Date: 11/07/2008

IRB Protocol #: 0811003431

Study Title: STIR: Socio-technical Integration Research

The above-referenced protocol is considered exempt after review by the Institutional Review Board pursuant to Federal regulations, 45 CFR Part 46.101(b)(2) .

This part of the federal regulations requires that the information be recorded by investigators in such a manner that subjects cannot be identified, directly or through identifiers linked to the subjects. It is necessary that the information obtained not be such that if disclosed outside the research, it could reasonably place the subjects at risk of criminal or civil liability, or be damaging to the subjects' financial standing, employability, or reputation.

You should retain a copy of this letter for your records.