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Scientific Utilisations of Reproductive Tissues: “Good Eggs”, Women and Altruism

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

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2014
Author’s declaration

This thesis is my own work and does not incorporate, without acknowledgement, any material previously submitted for a degree or diploma in any university. It does not contain any material previously published or written by another person where due reference is not made in the text.

The following committees approved the collection of data discussed in this thesis: The University of Sydney’s Human Research Ethics Committee (HREC) and the Sydney West Area Health Service Human Research Ethics Committee, Westmead Campus (EC00152). The names of all research participants have been coded with pseudonyms to protect their anonymity.

Margaret Boulos

29 May 2014
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Abstract

The lack of available good eggs – fertile and mature oocytes – for the technique of Somatic Cell Nuclear Transfer (SCNT) poses interesting sociological questions regarding the conduct of promising science. This thesis examines current debates regarding whether women should donate oocytes or be paid. A payment system is expected to increase the number of oocyte providers by providing an impersonal rather than personal incentive: cheaper fertility treatment or interest in the therapeutic benefits of SCNT research. The contemplation of a payment system marks a shift from Titmuss’s model of altruistic tissue donation. However, this contemporary debate continues to insist that the ideal donor is disinterested in some way: by giving without economic or therapeutic recompense. In order to explore these issues, I report on empirical data collected through interviews and focus groups. Three cohorts were recruited: fertility patients, reproductive oocyte donors and ‘healthy’ donors. Interviews and focus groups were employed to provide insight into practical contexts of providing oocytes and embryos. I found that providing oocytes for SCNT research is unappealing because good eggs are essential to achieve one’s maternal aspirations and the process of oocyte extraction is perceived as requiring an extraordinary amount of physical and emotional discipline on the part of the donor. However, the results indicate that these concerns are mitigated when oocyte and embryo provision occurs for a personal incentive. This affective framework—the identification of a specified benefit or beneficiary—can change perceptions of effort, risk and reward. A woman may be transformed into a ‘good egg’ – a donor providing social benefit – if there are concrete, rather than abstract, dimensions to the process of scientific research. Hence, these findings indicate that connections between femininity and altruism are flexible and I sustain this claim by discussing the concept of discretionary reciprocity. Furthermore, I argue that concerns regarding payment reveal deep-seated cultural anxieties about donor autonomy and motivation. Money may be regarded as an impersonal incentive and its advocates recall the figure of the citizen who should behave as disinterested—detached from his or her personal benefit. However, for the participants in this study, payment represents an inappropriate motivation on which to base contributions in scientific research. I show that that contributions to science are interested and occur in relationship between an individual, the tissue and the collective the research claims to benefit.
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Glossary

**Allogeneic transplant:** the implantation of organs and tissues into the patient that are obtained from another person.

**Anonymous tissue provision:** this occurs when, **at the time** the tissue is provided, the donor and recipient(s) are unknown to each other. They may however, understand that their tissues are being provided to others in a specific geographical location.

**Autologous transplant:** the use of organs or tissue that are the patient’s own.

**Blastocyst:** A blastocyst is the name given to a fertilised oöcyte which develop in vitro for five to six days and divide into 70 to 100 cells.

**Cleavage embryos:** fertilised oöcytes which have divided into 6-8 cells.

**Cloned embryo:** the cell created through SCNT using a fertile oöcyte and adult cell.

**Embryo:** the cell resulting from the fusion of oöcyte and sperm.

**Gamete:** reproductive cells such as oöcytes and sperm.

**Identified tissue provision:** this occurs when, **at the time** the tissue is provided, the donor and recipient(s) are known to each other.

**Induced pluripotent stem cells (IPS cells):** adult cells which have been programmed to revert back to stem cells before reprogramming the stem cells to develop into a differentiated trajectory.

**Multipotent cells:** cells which have the potential to differentiate into **some** types of cells.

**Oöcyte:** female reproductive cell, sometimes referred to as ova (plural) or egg.

**Pluripotent stem cells:** cells which have the potential to differentiate into every type of cells.

**Reproductive oöcyte provision:** this involves the transfer of oöcytes from one woman to another in order to have a child/ren. This may be called therapeutic if infertility is considered a medical issue. This may occur within contexts of anonymous or identified provision.

**Scientific oöcyte provision:** for the purpose of the discussion contained in this thesis, this
term refers to the transfer of oöcytes from a woman to researchers who are undertaking research in SCNT. This may include non-profit, university-based or profit oriented research.

**Somatic Cell Nuclear Transfer (SCNT):** the technique of transferring an adult cell into a fertile oöcyte, reverting the cell into undifferentiated stem cells before programming the cells to develop a differentiated trajectory, including tissues and organs. The oöcyte cannot have been fertilised prior to this and its own DNA removed.

**Totipotent stem cells:** cells with the potential to differentiate into all types of cells including extra-embryonic tissue.

**A further note on style and word choice**

Occasionally, I have used the terms “succumb” and “disposition” to a) refer to process by which clinically-viable embryos are removed from storage, withheld from further use and allowed to expire and b) the choices made by individuals regarding “surplus” embryos after their own fertility treatment is finished. It may be argued these terms may appear emotive and more applicable to a human person, especially if the reader defines human life as beginning at birth, however, both terms are often used in the literature.

Throughout this thesis, I have used British-English rather than American-English spelling variations of words such as *organisation, recognise* and *behaviour*, except where I have directly quoted the latter versions.

I have consulted the following in my use of the author-date referencing system.
Chapter One

Somatic cell nuclear transfer (SCNT), sometimes referred to as therapeutic cloning, is a technique through which scientists can create a ‘cloned embryo’ by programming cells to return to a state where they have the potential to grow into any cell. Cloned embryos can be used to make patient-specific stem cell lines and tissues including whole organs like the heart, liver and kidney. The technique requires ‘good eggs’ – fertile and mature human oocytes – and their removal requires women to have medication and surgery.¹ Scientists believe that developing patient-specific stem cell lines on a large scale would enable widespread autologous organ transplant. If this proves correct, many of the current challenges associated with allogeneic organ transplant, such as a negative immunological response and organ shortages, may be avoided (Gearhart 1998). Pursuing SCNT may lead to other breakthroughs in the area of regenerative medicine including the treatment of spinal cord injury, Parkinson’s disease, Motor Neuron disease (MND) and diabetes (de Wert and Mummery 2003).

The conduct of SCNT research in Australia is strictly regulated. In 2006 The Prohibition of Human Cloning for Reproduction Act and The Regulation of Human Embryo Research Amendment Act, were passed in the Australian Federal Parliament with state and territory governments jointly agreeing to pass uniform regulations (National Health and Medical Research Council 2011). This legislation gives scientists permission to derive stem cells from cloned embryos but explicitly precludes the purchase of oocytes for such research, maintaining Australia’s strict adherence to the notion that the human body should remain outside commercial trade. According to the terms of the current Acts, oocytes may only be given within the established model of altruistic donation where reimbursement is offered for documented travel and childcare expenses, a premise which remains in place after the review of legislation in 2011 (Legislative Review Committee 2011). A payment system would resemble commercial exchanges of goods and services where financial remuneration is offered for oocytes and may include a free market model where the price is determined by demand or regulated by an overseeing body.

¹ While the primary focus of this thesis is the utilisation of oocytes for SCNT research, data was also collected in relation to perceptions and attitudes towards embryo donation. I draw on this information in a secondary way to highlight the utilisation of reproductive tissues is dependent on a number of different factors.
The model of altruistic donation is common to all forms of human tissue provision to scientific research in Australia. However, as with most jurisdictions in the Global North, Australia has witnessed a lack of oöcyte donation for SCNT research, leading to the closure of laboratories and a shift to alternatives (Braun and Schultz 2012). One notable example of this decline in research is the decision by prominent scientist Ian Wilmut to migrate into the field of induced pluripotent stem (IPS) cells in 2007. Wilmut’s expertise had been fundamental to the creation of Dolly the cloned sheep and thus to the establishment of SCNT as a successful technique in complex organisms (Franklin 2007). He attributed his migration from SCNT research to its inefficient use of “precious” human oöcytes and his perception that IPS cell research is more socially acceptable than SCNT (Highfield 2007). Wilmut’s changed research trajectory is but one consequence of the scarcity of good eggs that are needed for both research and reproductive purposes in a globalised economy in which the trade and movement of scientists, women providing or needing oöcytes is less subject to national or state regulations. In contrast, the altruistic donation of tissues such as blood, DNA, cancerous tissue and embryos does not pose quite the same problems of supply in Australia. Acquiring sufficient numbers of these tissues can often be complicated and difficult but researchers do not face the prospect of having to abandon entire research programs as a result.

Legislative responses to the general lack of oöcyte donation to SCNT research have varied around the world. Two jurisdictions, New York and the UK, have instituted a specific market mechanism designed to mobilise women, making it legal to pay up to $10,000 in New York (Nelson 2009) and £750 or cheaper fertility treatment in the UK (Haines, Taylor and Turkmendag 2012). These payments are given to women in exchange for their oöcytes, sometimes before they have been used for their own reproductive purposes. Such measures have achieved varied success in increasing supply of oöcytes for SCNT research, however and it has been reported that women do refuse to give their oöcytes in exchange for cheaper fertility treatment (Haines, Taylor and Turkmendag 2012). The altruistic donor model

2 There are exceptions of course. For instance the Indian government very recently banned gay couples from contracting Indian women as surrogates.
remains in place in the state of California, Canada, New Zealand and the European Union where it continues to be illegal to purchase oocytes for scientific research. There is little consensus that either model may sufficiently capture the complexities of oocyte provision to SCNT research. For instance, one basis for this debate is the fact that the oocyte is a basis for research and the development of stem cell lines, a patentable entity expected to yield commercial value (Waldby 2002; Dickenson 2006), rather than a tissue used for therapeutic purposes.

This thesis is concerned with this scientific utilisation of reproductive tissues and particularly debates regarding which economic models should be instituted for the provision of oocytes for SCNT research. This thesis regards the scientific utilisation of reproductive tissues as an indicator of socially and historically specific relationships between scientific institutions, the community as a whole and individuals within the community. I also consider what it means when women are central to the development of scientific knowledge. Untangling these relationships is complex because science is no ordinary social institution being a practical process by which to 'discover' the world, an integral ethos of modern Western society (Harvey 2007) and yet increasingly subject to scrutiny by new experts and lay people.

Aim

The aim of this thesis is to examine and analyse what the scientific utilisation of reproductive tissues (oocytes and embryos) can mean for women and develop a conceptual framework that can encompass the tensions and differences. Understanding these meanings is a valuable study for four reasons. Firstly, by situating the difference with reference to social norms regarding motherhood and family, we can contribute to knowledge about different donation rates. Secondly, we can assist in destabilising analytical boundaries between giving and altruism on the one hand and selling and instrumental relations on the other. Borrowed from gift giving scholarship, we generally understand that reciprocity is a universal part of gift giving. Providing reproductive tissues as a “free” gift (that is, without

---

3 In the US, regulations vary state by state. The government of California has invested significantly in stem cell research. While scientists in the state cannot purchase oocytes it has been reported that they have used donated oocytes which were legally purchased for reproductive purposes there (Braun and Schultz 2012).
reciprocity) creates and/or maintains unequal power relations between the donor and the recipient. Within the existing paradigm, giving without reciprocity is generally regarded as altruistic without potential for instrumental motivations and vice versa. The two models of behaviour can be regarded as reifying gift-giving as a static practice, largely enacted in the same way regardless of time and space. Thirdly, we can partially evaluate whether the introduction of a payment system will provide the incentive for women to provide their oocytes. Finally, we can consider the myriad ways that people contribute to scientific research without subjecting it to narrow expectations about political behaviour. This will have implications for our knowledge about the development of scientific research which relies on “the appropriate conduct of publics” (Irwin and Michael 2003, 37).

**Current fields of literature**

There is presently empirical research published on the scientific utilisations of oocytes and/or embryos (Haimes and Luce 2006; Svendsen 2007; Haimes et al. 2008; Svendsen and Koch 2008; Waldby and Carroll 2011; Braun and Schultz 2012; Haimes, Taylor and Turkmendag 2012). These examinations of attitudes, perceptions and practices of oocyte provision can be situated within “tissue economies” literature: inter-disciplinary work on the social aspects of giving reproductive tissues that is characterised by questions pertaining to tissue provision, property relations and donor equity. Underlying much of the current research (including this thesis to a degree) is the idea that experts determine current policies and in order to make tissue provision socially and ethically sustainable, the views of potential donors are essential.

However, this thesis departs from existing theoretical and empirical research in the following ways. Firstly, in contrast to principle-based approaches (Titmuss 1997 [1970]; Thompson 2007; George 2008; Dickenson and Alkorta Idiakez 2008; Ballantyne and de Lacey 2008; Skene 2009; Thompson 2009; Widdows 2009) it analyses concrete scenarios and connects individuals with their immediate social context where personal identity, social roles and institutions are all interconnected (Davidman 1999). Secondly, it does not situate these questions in an existential framework regarding timeless or absolute concepts of freedom and donor equity. Instead, this thesis considers the lack of oocytes for stem cell research as providing a wonderful opportunity to study the current status of relationships between
‘scientists’, ‘the public’ and the state which are always changing. The analysis is cognisant of asking what it means to pose these questions in 2013. In this way, parallels can be drawn between the development of my analysis and that found in some public understanding of science and technology (PUSET) literature, scholarship that is more explicitly engaged with the changing status of scientific knowledge (Irwin and Michael 2003). This paradigm explicitly engages with scientific knowledge as a heterogeneous institution, imagining possibilities of engagement beyond coercion and resistance to understand that trust and ambivalence always co-exist. However, I diverge from a PUSET approach in that my aim is to theorise how scientific research can proceed with specific tissues rather than evaluate the degree to which “the public” understands scientific discourse or if they employ their own explanations for phenomena.

Towards an analytic framework

The present study proceeds on three assumptions which form an eclectic framework. Firstly, I contend that the heated discussion about which economic model better manages oöcyte provision does not pay sufficient attention to the complex relationships between humans and their material world. Introducing money into the equation does not just increase women’s vulnerable social and economic positions vis-à-vis men but evokes social anxieties about being primarily motivated by a material substance. Without understanding that money-as-currency has a certain subjectivity, we cannot understand aversions to accepting it in particular circumstances.

Secondly, the scientific utilisation of reproductive tissues is not an “external” threat to women’s existential condition. Science is not a fixed category or monolithic institution but subject to its own economic and political pressures for legitimation. Thus, the “answer” to the scientific utilisation of reproductive tissues is not just resolved by the individual’s own moral authority through a enhanced process of informed consent or the implementation of new property relations but an analysis that addresses the fact that the social milieu in which individuals exist and is characterised by an ambivalent social status of scientists and scientific processes. This has implications for understanding oöcyte extraction as “risk”. I do not consider risk to be a universally understood, ‘fixed’ and necessarily minimised or avoided altogether but a social construction which individuals negotiate in relation to their
gendered, aged and cultural identities (Bunton, Crawshaw and Geen 2004). In this way, the risks of oöcyte extraction are not undertaken by women improperly informed or so vulnerable as to dismiss all danger but situated within narratives regarding the pursuit of motherhood for oneself or another.

Thirdly, my approach analyses aspects of the framework that effectively insists the best ‘donor’ is disinterested. I proceed from the view that this norm is itself a social construction which is based on a binary between reason and emotion that privileges the former. Existential questions about freedom and dignity that emerge regarding the scientific utilisation of reproductive tissues presuppose that freedom involves a detachment to the personal and specific and transcendence to the universal and abstract. However, we can consider that oöcytes and embryos exist in their own specific regimes of meaning. Giving these tissues away have different implications for women and realising their needs may not mean the same thing in both contexts.

**Statement clarifying relationship between PhD and ARC-funded project**

My candidature was part of a three-year research project funded by the Australian Research Council (ARC) called *Oöcytes for stem cell research: donation and regulation in Australia* (2008-2011); several people were involved in participant recruitment, ethics applications, data collection and interview transcriptions. Three principal investigators coordinated the project, Professor Catherine Waldby, Associate Professor Ian Kerridge and Professor Loane Skene. One postdoctoral fellow, Katherine Carroll, was also employed as the project coordinator and principal data collector. As a project based on the collection of empirical data gathered by qualitative methods, the principal investigators designed the research protocol in collaboration with a non-profit, fully-independent, fertility clinic attached to a major teaching hospital in Sydney. This clinic was considered the university-based project’s industry partner, hence the title of my candidature scholarship (Australian Postgraduate Award - Industry, or APA-I). Most of the study’s participants were recruited through this collaboration as we (the university-based researchers) were given limited access to the clinic’s patient database to maintain strict confidentiality.4

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4 As an industry partner, the fertility clinic provided cash and in-kind benefits to support the project. Funds were provided for research assistance, audio recording equipment, computers, qualitative data analytical
I began my candidature at the end of June 2008 with Professor Waldby and Associate Professor Kerridge as my dissertation supervisors. As a PhD candidate, my role during the three and a half years the project was funded was to assist in the development of participant information sheets, consent forms and interview schedules as well as collect and analyse data. The sample included three cohorts to determine the effect of specific lived experience on perceptions and attitudes towards providing oocytes for SCNT research in Australia. The cohorts were designated by experience and age: cohort one comprised of women treated for fertility issues, cohort two consisted of women who had donated oocytes for reproductive purposes and cohort three comprised of women aged between 18 and 30. This last cohort is often designated in biomedical literature as the “healthy donor” because these women are not being treated for fertility issues and their fertility is at its peak (Fiszbajn et al 2004).

In order to recruit this sample, the project submitted two ethics applications. The first was submitted to the Sydney West Area Health Service Human Research Ethics Committee – a document to which I contributed some basic information and helped to proofread. During face-to-face meetings or email correspondence, Professor Waldby, Dr Carroll and myself produced participant information sheets, consent forms and interview schedules. I was also in attendance at meetings with the fertility clinic staff updating them about the project’s progress and results. Professor Waldby usually chaired these meetings and minutes are available. Data collection did not begin until Sydney West Area Health Service Human Research Ethics Committee granted approval in late July 2009. In the temporary absence of Dr Carroll in August 2009 who was intended to be the principal data collector for cohorts one and two, I individually interviewed three women in cohort one and two women in cohort two.

In 2010, I independently organised the focus groups with cohort three. This involved coordinating the submission to the University of Sydney’s Human Research Ethics Committee (with input from Professor Waldby, Dr Carroll and Associate Professor software, travel costs associated with research meetings, costs associated with the recruitment and reimbursement of research participants, travel and venue hire expenses associated with the National Oocyte Donor Workshop and costs associated with the production and dissemination of the final Discussion Paper.

5 I hope that readers will recognise that using this label is necessary in order to engage in similar concepts and language that exist in the literature.
Kerridge), focus group information sheets, consent forms and the discussion schedule. From May to July 2010, I was responsible for advertising and liaising with potential participants by email (copies available) when they expressed interest in the study by providing them with an information sheet. In my ‘first-response’ email, I asked potential participants to be patient as I was ‘collecting’ as many expressions of interest as possible. In August 2010, I individually moderated three focus groups. I booked and set up the rooms (putting signs on doors), greeted participants, arranged seating, food, drink and paperwork. When all participants had arrived, I handed out the information sheets/consent forms they were required to read and sign. I then began the focus group by turning on the audio recorder and referring to the questions on the schedule.

A party external to the research team transcribed all interviews and focus groups which were then stored on a secure computer server. The data collected by myself and Dr Carroll was considered a common resource from which all researchers could draw. There were meetings in which data codes were discussed without necessarily reaching consensus. Ultimately, the responsibility to analyse the data in a coherent narrative was an individual one where my own assertions, validated by the evidence, were established. The analysis presented in this PhD dissertation is entirely my own. Please see Chapter Four for further discussion about my role within the project.

**Thesis outline**

This thesis is in three parts: background, results and synthesis. The following section outlines the significance of each chapter.

Part one develops the background knowledge of the research undertaken. It is made up of three chapters including the present one. The following chapter will provide technical information about stem cell research and SCNT and the current regulatory frameworks in the UK and Australia, describing important features of women’s reproductive capacity, common

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6 I think this is evident in the approach undertaken in this dissertation. I feel that as my candidature progressed, I became critical of many of the assumptions made by the existing scholarship, including the original research protocol, and sought to develop an approach that was more aligned with my understanding of sociological inquiry, please see the section titled ‘This Thesis is not a Sociological Study of Ethics’ in Chapter Four. Please also refer to Appendices O and P for a comprehensive list of publications arising from the common dataset including texts I have written or contributed to.
issues in the use of ARTs and the extraction of oöcytes. Chapter three will discuss the principle-based approaches to the issue of oöcyte provision. My examination of the bioethical literature will be complemented with reference to the “tissue economies” approach. This will include an in-depth examination of Titmuss’s (1997 [1970]) text on blood provision and the recent critique of its legacy.

Part two will develop a framework for the present study and describe the results of the research. Chapter four will draw out the implications of the current approaches to the issue and develop the trajectory of my own analysis. Chapter five will introduce elements of the research design, outlining a theoretical approach that seeks to draw new connections between conceptual ideas about gifts and the substantive issue of tissue provision. I will argue that a sociological approach can balance analytical models of understanding thus far advanced. I further discuss epistemological issues related to this research and will outline precisely how this study was undertaken and why methods such as interviews and focus groups were chosen to elicit data from participants.

Chapter six will discuss preferences about the utilisation of oöcytes and embryos. Broadly, I examine the utilisation of oöcytes and embryos within Robert’s (2007) framework which distinguishes between “kin” and “life” ethics. I move beyond this framework to understand these differences in relation to the maternal social role and the means by which oöcytes and embryos distinctly constitute this role. This chapter will also report attitudes towards donating oöcytes for SCNT research. I will describe perceptions of “ideal” conditions and the introduction of different incentive models including payment, compensation or egg sharing schemes.

Chapter seven will demonstrate that some instances of giving embryos and oöcytes occur within an affective framework – where the donor has identified a specific benefit or beneficiary. I examine the practice of oöcyte donation for reproductive purposes and explore the narratives of this specific cohort in order to understand how and why they came to make the decision to give their oöcytes to another woman. I argue that oöcyte donors act with both altruistic motives and instrumental concerns and these are oriented to the family they are helping to create, rather than themselves. I will contrast these responses with participants’ views about providing embryos for scientific research. This chapter shows that the affective
frameworks in which oöcytes are given is based on identifying a specific benefit or beneficiary while embryos are given in a spirit of embracing the “universal stranger”.

In Part three, I will synthesise the results of the research. I intend to draw the results together in order to discuss literature regarding women and altruism and the significance of gift giving and reciprocity for tissue contributions to scientific research. Chapter eight will introduce the concept of discretionary reciprocity in relation to arguments made about women as altruistic including their social roles as women, mothers and citizens. These social roles will be located within contemporary social and political contexts in order to discuss the tensions of living and contributing to scientific research within a society that has an ambiguous relationship to scientific institutions. I will argue that, contrary to ideals of citizens as acting impartially, their ‘passions’, which are directed at a specific benefit or beneficiary, are a significant determinant in the provision of reproductive tissues such as oöcytes and embryos. This is also evident in the issue of establishing a financial equivalent in exchange for oöcytes. I discuss participants’ distinctions between two forms of the same thing ‘payment’ and ‘compensation’ – money, as revealing deep-seated cultural anxieties about donor autonomy and motivation. My framework to understand this complexity draws on critical studies of materiality which provide an alternative narrative to arguments based on universal and rationally-derived principles about paying women for oöcyte provision to SCNT research. Chapter nine will conclude the thesis and point to potential policy implications and directions for future research.
Chapter Two: Regulatory Trajectories of SCNT Research

Introduction

Stem cell research is an umbrella term for a number of methods and processes. Producing stem cell lines from embryos became scientific fact in the late 1990s and was subject to a globalised debate between scientists, patients and their advocates and politicians. Despite the global dimensions of the debate, national contexts remain important in defining the parameters of scientific conduct. This largely descriptive chapter will provide important background information about regenerative medicine, of which SCNT research is part. I will define key terms and comprehensively examine the legislative trajectory of SCNT research in Australia and the UK. The information will demonstrate the social specificities in which stem cell research is conducted and provide the reader with accurate information about current developments in the science.
What are stem cells?

Stem cells can divide indefinitely, either continuing to replicate themselves (as stem cells) or differentiating into particular cells (Thomson et al. 1998; de Wert and Mummery 2003; Wallenfang and Matunis 2003). Stem cell research is part of the broader biomedical science of regenerative medicine, which focuses on utilising the potential of cells to be reprogrammed and manipulated in order to prevent or treat disease (Thomson et al. 1998). The science radically departs from traditionally linear perceptions of cells by destabilising the fixed trajectory along which cells travel—from inception to degeneration (Cooper 2006; Franklin 2006). Most somatic cells have a fixed trajectory and can only divide a limited number of times before beginning to degenerate. The capacity for infinite replication is called immortalisation and was once considered the distinctive feature of pathological or cancerous cells (Cooper 2006). The extent to which stem cells may be classified as either multipotent, pluripotent and totipotent is determined by their source (National Stem Cell Foundation 2010a).

Stem cell lines can be produced from embryos (including cloned embryos) and adult cells (de Wert and Mummery 2003). Embryonic stem cells (ESCs) are only found in embryos, tissue created through the fusion of oocyte and sperm. The fertilised oocyte produces an inner cell mass (ICM) and it is from this that stem cell line can be extracted (de Wert and Mummery 2003). While embryonic stem cells are pluripotent with the capacity to develop into any somatic cell (and perhaps gametes such as oocyte and sperm), they do not develop into ‘extra-embryonic’ tissue like the placenta or membranes, which are crucial for the growth of the foetus (de Wert and Mummery 2003; Couzin 2005; Vogel 2005; Ledford 2009). Adult stem cells are found in most tissues in the foetus and after birth, such as the brain, kidney, intestine, heart, connective tissue, skeletal muscle, bone marrow and umbilical cord blood (Waldby 2002; Dennis 2006; Holden 2007). These stem cells are defined as multipotent because they exhibit a high potential to develop into somatic tissues but are still more specialised than pluripotent stem cells (Waldby 2002; de Wert and Mummery 2003). Stem cells can also be produced in vitro by inducing genetic change in adult somatic cells. These cells are called Induced Pluripotent Stem (IPS) cells because their production involves
the reprogramming of differentiated (adult) cells to behave like embryonic stem cells but do not involve the use of embryos or oocytes (Cyranoski 2009).

The extraction of embryonic stem cell lines was first reported in 1998 by a team lead by James Thomson at the University of Wisconsin in the US, using fresh and frozen embryos donated from fertility patients (Gearhart 1998; Thomson et al. 1998; Cyranoski 2009). Prior to Thomson et al.’s (1998) research, scientists had only been able to derive stem cells from some mammalian species (Gearhart 1998). Since 1998, there have been many embryonic stem cell lines established around the world. The first UK stem cell lines were successfully derived in 2003 (Franklin 2006). Other developments have been made, including “insights into normal and pathological cellular biology, production and embryogenesis and the creation of disease models and systems for predicting toxicology and drug screening” (Kerridge and Bendorf 2010, 156). Currently, some beauty treatments utilise stem cells (Harvey 2011) and autologous stem cell therapy is used to treat osteoarthritis, psoriasis and multiple sclerosis in Australia (Macquarie Stem Cells 2013). In India and China, stem cells are used in clinical treatments for patients with spinal cord injury (Ryan et al. 2010).

**What is somatic cell nuclear transfer?**

Somatic cell nuclear transfer (SCNT) involves the creation of a cloned embryo. This occurs by inserting the nucleus of an adult somatic cell into an enucleated oocyte (an ovum that has had its own DNA removed). With manipulation, an enucleated oocyte has the capacity to ‘unpack’ the information of the adult cell or reprogram it to behave like embryonic stem cells. After this, a stem cell line may be extracted. SCNT is also known as cloning because the tissue and organs derived from the process and grown are expected to be the exact genetic match of the ‘donor’ adult cell (see figure 1 below). Research into SCNT requires fertile and unfertilised oocytes, rather than oocytes that have failed to fertilise and are termed “clinically unviable” (George 2008).

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7 By avoiding the use of these controversial and/or scarce tissues, IPS cell research has become a focus of intense scientific investigation worldwide (Baylis and McLeod 2007; Braun and Schultz 2012).
Figure 1, The technique of somatic cell nuclear transfer (SCNT) ⁸

As figure 1 indicates, a number of cells can be produced from a cloned embryo. While it may be argued that this figure is inappropriate because it depicts the process of SCNT using monkey-cells, the illustration nevertheless is a clear and straightforward depiction of the process. In particular, patient-specific stem cell lines are expected to contribute to the development of scientific knowledge and the management of chronic diseases largely affecting people in the developed world, such as diabetes, spinal cord injury and lesions, Parkinson's Disease, stroke, arthritis, multiple sclerosis and heart failure (de Wert and Mummery 2003). There are also predictions that transplant medicine is on the verge of an important transformation – one that will be able to deliver patient-specific (or autologous) tissues (Dennis 2006; Roberts and Throsby 2008). This means that the problems of allogeneic transplant, including the lack of donated organs and negative immunological responses, may be avoided by providing tissues from the actual patient (Scheper-Hughes 2007). It will be the patient's (healthy) somatic cell that will used to regress into stem cells before being directed to grow into a particular organ; this way, the cell's reintroduction⁹ will not generate resistance and the cell will not be attacked as a foreign object (Waldby 2002; Dennis 2006; Roberts and Throsby 2008). More generally, stem cell research is expected to relate to a variety of areas of scientific knowledge, including developmental biology, reproduction and ageing (Gearhart 1998; Thomson et al. 1998; Waldby 2002; Wallenfang and Matunis 2003; Dennis 2006). Creating cloned embryos is a complex and technically difficult procedure for scientists and to date, the existence of only one stem cell line has been verified. The company Stemagen (2008) announced that it had “become the first in the world

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⁸ [http://www.nature.com/nature/journal/v450/n7169/fig_tab/450485a_F1.html](http://www.nature.com/nature/journal/v450/n7169/fig_tab/450485a_F1.html) (accessed 14/12/2012).

⁹ Since the tissue is the patient’s own, the word transplant, while familiar, is technically incorrect.
to create – and meticulously document – a cloned human embryo using somatic cell nuclear transfer (SCNT)”. However, a stem cell line was not created (National Stem Cell Foundation 2010b).

**Female reproductive biology**

Oöcytes are female reproductive cells that carry the woman’s DNA. As noted above, oöcytes also have the ability to unpack and transform the adult cell, unlike a sperm cell which only carries DNA. In a ‘normal’ cycle, women ovulate one oöcyte per month that may either be fertilised or shed during menstruation. Biologically, men and women differ in terms of whether gametes are regenerative or not; sperm is a regenerative tissue, having no finite number, while the number of ova an individual has is limited in both number and lifespan; this means that the younger the oöcytes, the more fertile they tend to be. While sperm has no such ‘expiration date’, the viability of semen can be influenced by environmental factors (Oliva, Spira and Multigner 2001) but ultimately may be tested and known. In contrast, the fertility of oöcytes is largely unknown until fertilisation is attempted. If successful, an embryo is created; if not, oöcytes are designated as clinically unviable. Oöcytes are more fragile tissue than either sperm or embryos; they deteriorate by the hour (Braun and Schultz 2012) and are less successfully frozen and thawed.

In clinical fertility treatment, the maturation of a single oöcyte has been considered inefficient and it has been clinical protocol to stimulate the development of more than one ovum; this is called ovarian stimulation (Thompson 2005). This process involves the self-administration of injections and nasal sprays over a four to six week period. Initially drugs are used to stop the woman’s regular menstrual cycle (weeks one to two) before the injection of gonadotropins, which are used to simulate “the development of several egg-containing follicles” (Pearson 2006, 608). The final stage of medication involves hormones to mature the oöcytes. During this time, the patient will have blood tests and ultrasounds to monitor the development of follicles and at the end of the cycle, she will undergo a day-procedure requiring intravenous sedation and local anaesthetic. The oöcytes are aspirated through a large glass needle inserted into the ovary through the vaginal wall (Pearson 2006, 608).

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10 In reproductive medicine, fertilisation refers to the fusion of the oöcyte and the sperm while in SCNT research this would involve the insertion of the somatic cell.
Undertaking oocyte extraction may have short and long term health consequences. Reactions to medications vary between individuals and are impossible to predict. Yee, Hitkari and Greenblatt (2007, 2047) describe it as “a very physically invasive procedure” while Dickenson (2002) likens it to live kidney extraction. Common side effects may resemble symptoms women experience during their menstrual cycle, including fatigue, bloating, moodiness as well as cramps and breast tenderness. However, some women may develop ovarian hyperstimulation syndrome (OHSS). The symptoms of OHSS are much more pronounced and include “depression, short-term memory problems, insomnia, bleeding, hyperovulation stress syndrome [and] weight gain” (Ikemoto 2009, 770). Hospitalisation is usually necessary to treat OHSS. Little is understood about the long-term effects of oocyte extraction, as no studies have been conducted on women who undergo the process for themselves or others. Pearson (2006) suggests that few fertility clinics are eager to report cases of OHSS among their own patients or donors and this may impact on scientific knowledge about the effects of oocyte extraction.11

**Assisted Reproductive Technologies (ARTs) and stem cell research**

The emergence of ARTs, which use highly interventionist methods in comparison to other practices of fertility treatment (Haines 1993), is crucial to the advent of stem cell research. Both practices share a range of techniques as well as tissues for clinical and research purposes (Waldby 2002; Franklin 2006; Haines and Luce 2006; Parry 2006). Since the 1970s, scientists and medical doctors have attempted to treat infertility in a number of ways (Thompson 2005). One of the most significant developments to have emerged in this era was the creation of embryos in vitro (in glass). *In Vitro Fertilisation* (IVF) uses gametes extracted from potential parents12 and literally externalises fertilization by mixing extracted oocytes and sperm in a petri dish. The resulting embryo(s) is then implanted into the uterus of the patient who gestates the foetus. The development of IVF changed the nature of reproduction by involving a number of individuals, including parents, gamete donors,

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11 In Australia, the Fertility Society advises that clinics must advise patients and/or about the risks of OHSS and how to manage symptoms or seek assistance. The code of conduct does not stipulate that records must be kept (Fertility Society of Australia 2010).

12 I use this term loosely as gametes may be derived from people who do not intend to inhabit the social role of parent.
gestational surrogates as well as the doctors, nurses, counsellors and embryologists who perform these techniques (Sawicki 1991; Thompson 2005; Franklin 1997; Shaw 2007). The term IVF is commonly used to refer to fertility treatment generally, but it is just one technique among a myriad of others described under the umbrella of Assisted Reproductive Technology (ART). ARTs can include Gamete Intra-Fallopian Transfer (GIFT), which involves the injection of oöcytes and sperm directly into the woman’s fallopian tube for fertilisation to take place and Intra-Cytoplasmic Sperm Injection (ICSI), by which the sperm is directly injected into the oöcyte (Serono Symposia International 2004).

ARTs are used in many parts of the world and, while their use within Australia has grown steadily in the past decade, the first decline of 12.4% was reported in 2010 (Macaldowie et al. 2012, 49). In 2010, 30,558 women undertook approximately 56,489 treatment cycles from which 13,215 clinical pregnancies and 10,897 live births resulted. This indicates an overall success rate in relation to treatment cycles of 18.1%. More statistics collected about reproductive medicine in Australia and New Zealand show that most women being treated for infertility with ARTs used their own oöcytes (95%), with a clear majority (63%) having cycles using embryos which have not yet been frozen (“fresh embryos”) (Macaldowie et al. 2012).

Legislating stem cell research

The therapeutic promises of stem cell research are a major factor in its appeal (Rubin 2008); yet, it is legislated differently across the world in part because of its controversial use of embryos. When stem cell research was first debated, advocates of the methods argued that they will ultimately relieve untold patient suffering. The political implications of permitting stem cell research were two-fold: firstly, several governments considered that stem cell research may be a novel solution to the rising economic costs of chronic disease and ageing populations (Ehrich et al. 2012; Cooper 2006); secondly, as an increasingly industrialised endeavour, biomedicine is a significant part of some national or regional economies such as California, the European Union, Singapore and South Korea of which stem cell research is part (Jasanoff 2005; Gottweis, Salter and Waldby 2009). While the potential economic windfall and health management of its populations are appealing prospects to governments, there has not been a uniform response to the conduct of stem cell research. On the contrary,
regulatory frameworks are deeply reflective of national values and histories as well as economic and social factors in a globalising world (Jasanoff 2005; Franklin 2006; Gottweis, Salter and Waldby 2009). For instance, religious views and institutions such as the Catholic Church have been involved to a significant degree in the formation of policy (Isasi et al. 2004; Fink 2007). This does not suggest that religious views or institutions inevitably create scientific policy because the political power of, say, the Catholic Church varies nationally (Fink 2007). Indeed, it may even be used as a counterpoint. One interesting example of this is the way policy makers in Britain sought to assert themselves specifically in relation to the bioethical policies of the Europe Union which contended with the Catholic Church in a more explicit way (Jasanoff 2005).

The diverse regulatory frameworks that are in place and the debates that shaped them demonstrate that the therapeutic and economic possibilities of stem cell research are far from irresistible. In other words, stem cell research means many things to different groups in society and its status as a legitimate avenue of research is a matter of engaging with – and contesting – those meanings. The following section will examine the United Kingdom and Australia in-depth. These two countries have a shared cultural heritage and close economic, intellectual and political ties (Franklin, 2007), as well as significant (and changing) nationalised health services. However, as will be discussed, the development of regulations pertaining to SCNT research have been very different.

**The United Kingdom**

Its existing regulatory framework was one of the main reasons why the UK was the first country in the world to legalise stem cell research using embryos in 2001. While the passage of legislation was not uncontroversial, the UK’s history of cutting-edge reproductive science and medicine (it is the birthplace of the first IVF baby, Louise Brown as well as Dolly the sheep) was a key factor in its proactive and wide-ranging approach to the novel techniques (Gottweis, Salter and Waldby 2009). In the 1980s, the Thatcher government established the Warnock Committee to review ART practices, given their growing use. Among the committee's recommendations, reported in 1984 but not implemented until the early 1990s, was the establishment of the Human Fertilisation and Embryology Authority (HFEA). The HFEA is an independent statutory body which administers and licenses ART clinics and
research involving reproductive tissues for fertility purposes (Harvey 2008; Gottweis, Salter and Waldby 2009). The Human Fertilisation and Embryology Act of 1990 stipulated that embryos could be used for fertility research or as Jasanoff (2005) argues that the Committee permitted scientists use the pre-embryo. According to the Committee, the pre-embryo is characterised by the division of cells in contrast to the differentiated cells that characterise the embryo (evident from day 14 of fertilisation). The Committee argued that the ‘pre-embryo’ was an entity that existed prior to the development of the ‘primitive streak’ and was thus incapable of feeling pain (Gottweis, Salter and Waldby 2009). As Jasanoff (2005: 155) argues, the “ontological and political reality [of the pre-embryo] was not a product of biological knowledge alone but was created (or coproduced) out of a complex mix of pragmatism, empiricism, and trust in experts”.

The legacy of this legislative framework and regulatory environment played a significant part in Britain’s debates for stem cell research in the new millennium. Treading new but still familiar territory, Britain became the first country to permit embryonic stem cell research, the utilisation of animal oocytes and the method of SCNT with human oocytes. The latter stipulation was made explicitly on the basis that embryos created through SCNT were effectively the same as an embryo created through the fusion of sperm and oocyte and thus covered by existing HFEA regulations. This ruling was the result of court proceedings which ultimately ended when the House of Lords ruled against a campaign by pro-life organisation, the Pro-Life Alliance in 2003 (Jasanoff 2005). Britain is considered to have the most regulated – yet permissive – research culture in the world, what Jasanoff (2005, 9) considers to be a “relatively uncontested space for embryo research”. This was achieved after an organised campaign by government agencies, scientific societies and patient groups. In addition to this, the government considered that there was economic as well as scientific value in allowing such promising research to proceed and that the HFEA, a publicly trusted and internationally recognised body to oversee it, would allay some fears around the new science (Jasanoff 2005; Gottweis, Salter and Waldby 2009). Part of the legislative endorsement scientists received in order to proceed with the use of embryos for non-reproductive purposes, the practice of SCNT and animal oocytes to create stem cell lines, was the increasing scrutiny by researchers regarding the social impact and/or significance of the research (Franklin 2006).
Australia

In Australia, events such as the creation of Dolly the sheep or Thomson et al.’s (1998) research did not immediately propel the government into decisive action over stem cell research including SCNT, despite the fact that it had also enjoyed the reputation of once being at the forefront of ARTs (Franklin 2007). In 2002, federal legislation was first introduced in relation to the new methods and two paths were taken: embryonic stem cell research was allowed using embryos created during fertility treatment prior to April 5, 2002 but use of embryos subsequently created as well as the specific creation of embryos for research or through SCNT was prohibited (Harvey 2008). The administration of the new regulations was given over to a Licensing Committee, within the broader statutory body of the National Health and Medical Research Council (NHMRC). However, this licensing body was not given the same statutory weight or remit for public engagement as the HFEA in Britain. Such legislation was seen as a suitable compromise that allowed research to proceed during a time of exceptionally conservative government in Australia (Harvey 2008). The legislation was scheduled for review in 2005, during which time any developments in the science were to be considered along with “changes in community standards since 2002” (Ankeny and Dodds 2008, 221). The Lockhart Review was expected to be broader than the process involved in the initial legislation and to publicly consult the community. Apart from its specific recommendations, a principal function of the committee was to request that the NHMRC produce a working definition of the human embryo, as had occurred in Britain years earlier. As Harvey (2008) argues, this kept the debate focused on the technical dimensions of the embryo and was similar to those in the UK during the 1980s. This allowed the tissue to continue to have ‘special’ status whilst permitting experimentation.

The degree to which the Committee was able to capture the diversity of community views is controversial; as Ankeny and Dodds (2008) argue, the dissemination of the consultation process showed a prevalence of ‘expert’ views, well-organised institutions and religious groups. In his critical examination of the committee’s report, Parker (2009) asserts that the committee’s framework was based on a number of inconsistencies. Notably, that despite the fact that the committee professed the implementation of more ‘neutral’ imperatives such as ‘social justice’ and ‘human flourishing’ to assess the issue, a utilitarian framework was used.

13 Australia is also distinct from Britain because it is a federation of states that legislate their own laws.
Parker bases his claim on the fact that the recommendations of the committee ultimately privileged the potential benefit of embryonic stem cell research over the potential ‘harm’ to embryos or donors and those opponents were responsible for proving that the research should be banned.

In June 2007, the Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act came into law in the federal parliament of Australia, with all states and territories passing their own identical legislation (Kerridge and Bendorf 2011). This legislation brought Australia largely into line with Britain by permitting the conduct of SCNT research. One significant difference is the use of animal oöcytes, which Australia continues to ban in contrast to Britain (Harvey 2008). The Licensing Committee implementing the regulations has since only permitted research that utilises clinically unviable oöcytes. While experiments on such oöcytes will enable scientists to perform essential ‘practice’ work, mature and fertile oöcytes are essential for producing stem cells and ultimately patient-specific tissues (Klitzman and Sauer, 2009).

Oöocyte provision for SCNT research in a global context

Britain and Australia are similar in their approach to sourcing tissues required for stem cell research in principle. The commercial trade of human embryos and oöcytes, like other bodily tissues, is not permitted and are classified as gifts (Franklin 2006; Dickenson and Alkorta Idiacez 2008; Waldby 2008). Australia is not unique in its insistence of altruistic donor models; both Canada and New Zealand prohibit the buying and selling of human tissue (Shaw 2007; Yee, Hitkari and Greenblatt 2007). Recently, however, the UK has considerably widened interpretations of the gift ethos and has introduced egg-sharing and payment schemes. The Newcastle egg-sharing research scheme has had two iterations (Haimes, Taylor and Turkmendag 2012). Firstly, in 2005, researchers initially asked women to give two oöcytes if their clinicians had anticipated they would produce more than 12 oöcytes. Since the response to this was negligible, in 2007 the second development was licensed in which women “could be given a fees discount of £1500 for supplying half their fresh eggs retrieved during a treatment cycle” (Haimes, Taylor and Turkmendag 2012,

14 The reasons for this are unclear and the licensing committee does not undertake the same level of public engagement as the HFEA.
This discount for private IVF patients is funded by the Medical Research Council (Braun and Schultz 2012, 149). One rationale for the application was that egg-sharing for research should be treated in exactly the same manner as for fertility treatment. However, there were various conditions for the provision of oocytes to SCNT research; patients had to have experience of the IVF cycle, needed to volunteer themselves rather than be approached and undergo a consent process conducted by an independent research nurse. The number of oocytes retrieved before any could be given to research was reduced to six, “allocated one-by-one, immediately on retrieval, with no regard to quality; if they produced 5 or fewer eggs they would keep them all and still receive the discount” (Haimes, Taylor and Turkmendag 2012, 1201).

Since 2011, in addition to egg-sharing where in-kind benefits are exchanged, the HFEA has licensed the ‘compensation’ of women in Britain to provide oocytes for research purposes (Human Fertilisation and Embryology Authority 2012a). Currently, the amount is £750; prior to this, donors (of both semen and eggs) could claim travel expenses in addition to a maximum of £250 for loss of earnings, as is the custom with jury attendance (Human Fertilisation and Embryology Authority 2012a). In the late 1990s, donors were paid a token sum of £15 (Byrd, Sidebotham and Lieberman 2002, 175). The recently increased payment is available to both British citizens and non-permanent residents, although women in the latter category cannot “claim an excess to cover overseas travel expenses” (Human Fertilisation and Embryology Authority 2012b). The HFEA position now corresponds with the view of the Nuffield Council on Bioethics (2011, 11) that women should be paid to provide oocytes to research because they are undergoing significant discomfort, inconvenience and potential health risks “in order to contribute to the common good of research”. Since 2009, the state of New York has permitted the payment of up to $10,000 to women who provide oocytes to SCNT research (Nelson 2009). The publicly-funded

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15 The Council’s recommendation is made in light of its view that any non-altruist-focused interventions that are developed to increase supply of limited tissues “may need to be subject to closer scrutiny because of the threat they may pose to wider communal values” (2011, 8). The Council also makes a concomitant recommendation that may radically reconfigure the structural property relations that govern the provision of tissues to research: that “once donated for research purposes, bodily material should be regarded as a public good: researchers should make the most efficient use of it possible, and must be willing to share it on the basis of scientific merit” (2011, 12).
Hospital La Fé in Valencia Spain utilises oöcytes from fertility patients without any payment to the individual (Braun and Schultz 2012).

The IVF-Stem cell interface

The relationship between ARTs and stem cell research is complex. ARTs are the more established field of medicine and have played a vital part in the latter’s formation. ARTs maintain a monopoly of legitimacy over tissues such as oöcytes and embryos and stem cell research is yet to firmly establish a momentum of its own. This is evident in the fact that rates of oöcyte provision for stem cell research are much lower compared with reproductive oöcyte provision. In response to frustrations expressed by some scientists that embryos which could be potentially used in stem cell research were going to ‘waste’ because of bureaucratic inefficiency, the UK government instituted measures to ensure the safe and efficient transfer of reproductive tissue between fertility clinics and stem cell laboratories. Franklin (2006) labelled this the IVF-Stem cell interface. The interface developed with specific funding by the Medical Research Council to physically connect IVF clinics with stem cell research laboratories (Ehrich, Williams and Farsides 2010). However, the development of this interface is reported to be uneven.

Braun and Schultz (2012) argue the success of the IVF-Stem cell interface in procuring oöcytes is dependent on individual researchers implementing mechanisms to do so. This recent study demonstrates that research centres in Europe and California often utilise personal relationships and geographical proximity to IVF facilities in order to source oöcytes for their SCNT research. In each case, “the leading clinician at the facility where the oöcytes were obtained was also the researcher who led the respective SCNT project” (Braun and Schultz 2012, 144). However, scientists who were interested in SCNT research but worked in centres where no SCNT research was undertaken, reported that they practiced a form of self-censorship by refusing to ask women for oöcytes; this hesitancy was not necessarily due to regulations prohibiting the request, but a personal concern or fear of potential negative consequences and public scandal.

Attempts by the UK government to support stem cell research by funding the physical connection between fertility clinics and stem cell research laboratories has not resulted in a
uniform supply of embryos. Some attempts to ensure the supply of embryos to stem cell research are more successful than others. As Ehrich, Williams and Farsides (2010) report from their qualitative research in clinics/stem cell research laboratories, the classification of embryos in ‘normal’ contexts of IVF and those created in the context of pre-implantation genetic diagnosis (PGD) is very different. This research shows that in the context of “normal IVF”, embryologists and other fertility clinicians are often equivocal about the status of an embryo and there is often little agreement regarding the provision of ‘fresh’ clinically-unviable embryos to stem cell research. ‘Fresh’ embryos have not been cryopreserved and are unlikely to be implanted because of poor cell fragmentation. ‘Frozen’ embryos have been cryopreserved and stored with the intention of using them if earlier implantations are unsuccessful. There are different factors which converge in the embryologist’s decisions to classify embryos as viable or unviable. These factors can be technical, such as the number of cells into which the embryo has divided or they may be social details, such as the local authority’s funding of fresh cycles and patient narratives. In other words, classifying embryos involves human discretion rather than only biological properties (Ehrich, Williams and Farsides 2010).

In another iteration of the same data, Williams et al. (2008) report that stem cell scientists regard embryos that have been classified as affected with genetic disorders as ethically non-contentious tissue to use in stem cell research. In the context of fertility treatment using PGD, affected embryos are clinically unviable and will be discarded anyway. In contrast to the UK authorities, Australian policies are not similarly geared towards the development of the IVF-Stem cell interface. Oocytes used in stem cell research are clinically non-viable as stipulated by current NHMRC (National Health and Medical Research Council 2013) guidelines.

**Current knowledge regarding oocyte provision for SCNT research**

There is some published research into the attitudes and perceptions of oocyte providers to SCNT research, but it is relatively small in comparison with research into oocyte provision for reproductive purposes and other forms of tissue provision to scientific research. The dearth of information regarding oocyte provision to SCNT research is a consequence of its relative novelty. This section surveys the available studies regarding oocyte provision to
research. Without understanding the specificities of scientific oöcyte provision, designing a conceptual framework that may contribute to appropriate regulations will be ineffective.

While SCNT research is novel, researchers have been surveying women’s attitudes of oöcyte provision to research almost as long as reproductive technologies have allowed for the externalisation of oöcytes. For example, Kazem et al. (1995) report on attitudes towards reproductive and research provision in the UK. The researchers distributed their survey among women who had attended antenatal clinics, postnatal wards and fertility clinics as well as donors and recipients of oöcytes (the groups were largely defined as ‘fertile’ and ‘infertile’). Researchers also surveyed a selection of male partners in each cohort (n= 117). A total of 258 women were surveyed and the overwhelming majority (91.8%) thought that oöcytes should be used for therapeutic rather than research purposes, however, there were differences between each cohort. For instance, infertile women were more interested than fertile women in giving their oöcytes to research (although elaboration on what kind of research is absent).

Other scholars have found that openness to donation for research was found to be highly dependent on the participant’s fertility status with less-fertile women being more likely to donate their oöcytes for research purposes (Purewal & van den Akker 2009). Kazem et al. (1995) also reported a significant lack of approval in obtaining oöcytes for reproduction from other sources such as cadavers and aborted or miscarried foetuses; however, the authors do not note whether this same aversion would be applicable for research purposes. A study by Byrd, Sidebotham and Lieberman (2002) also surveyed reproductive oöcytes donors in the UK (n= 113) and found that 52% of participants would agree to provide oöcytes to research for a variety of reasons, including the benefit of research and minimising the waste of oöcytes.16

A recent survey in the US asked women who were providing oöcytes for reproductive purposes about their attitudes towards doing so for SCNT research. Klitzman and Sauer (2009) recruited women who were enrolled or participating in the Columbia University reproductive donor program (n=230) for which they received US$8000. The centre has

16 The authors do not differentiate between research.
screened over 1000 women in five years but has enrolled only 250 to become providers. While the majority of respondents were Caucasian (62%), other ethnic categories were also represented, including Hispanic (11%), Asian (10%) and African-American (11%) (2009) women. In this study, 40% of respondents did not state a preference about whether their oöocytes were given to research or reproductive purposes, although 51% preferred reproduction; 82% stated that they would be willing to provide oöocytes to medical research. 74% of respondents expected to be compensated the same amount of money to provide oöocytes for research or reproductive purposes while one third of the sample expected to be paid a minimum amount of US$8000 for research.

The studies cited above report attitudes and experiences of potential or actual donors as well as the general public. This scholarship remains descriptive, reporting in terms of tolerance or preferences towards the practice of oöocyte provision for research and speculating on the potential to increase the numbers of providers. In contrast, the discussion of the Newcastle egg-sharing research scheme (NESR) does conceptualise the practice of egg-sharing for SCNT research (Haimes, Taylor and Turkmendag 2012). This study into the NESR is one of the first to publish results regarding participants’ views on providing oöcytes and is an important reference for this thesis. The study involved two samples, interviewing women who had given their oöcytes for SCNT research (n = 29) and women who had given their oöcytes for reproductive purposes (n = 21). The authors focus on the issue of exploitation, providing qualitative data in relation to assertions made in the scholarly literature by Dickenson and Alkorta Idiakez (2008) and Roberts and Throsby (2008) regarding the NESR as structurally limiting women’s choices about utilising their oöcytes.

During interviews, participants did not, of their own volition, raise the issue of exploitation but neither did they express surprise at being asked questions in relation to the topic. Rather, participants responded in two ways: they either articulated, in a detached manner, that the NESR was potentially exploitative but did not acknowledge that exploitation had occurred, or they “refuted [the charge of exploitation] outright” (Haimes, Taylor and Turkmendag 2012, 1203). The authors (2012, 1208) suggest that “concerns about exploitation are not uppermost in women’s accounts of their experiences of the NESR,” demonstrating that participants expressed the ability to rationally consider the costs and benefits of the scheme. The researchers argue that many women ultimately refused to share their oöcytes with SCNT
researchers “despite their desperation” (2012, 1209) to have a baby. ‘Desperation’ refers to a construction of fertility patients common in both journalistic and social scientific literature. Presumably, in a context such as exists in the UK, where the National Health Service (NHS) restricts the provision of fertility treatment on the basis of age, whether the couple already have children and their residential location, the ‘desire’ to have a baby is hampered by bureaucratic regulations. The opportunity to partake in discounted fertility treatment is expected to be appealing. Underlying this scheme then is the presumption that because one cycle of IVF is rarely sufficient to produce a pregnancy or “live birth”, patients/participants should not focus on individual IVF cycles but the potential for many, ideally facilitated by discounted fertility treatment. Rapport (2003) believes that this broader social context is an important factor in the decisions of women and/or couples to participate in egg-sharing schemes. By saving money on individual treatments, women and/or couples can pay for more treatments. At the NESR clinic, staff observed a decline in the number of women agreeing to take part in their egg-sharing scheme and attributed this to recent increases in NHS funding for fertility treatment.

This recent study adds a novel dimension to the vigorous debate regarding the potentially exploitative nature of egg-sharing for research purposes. Examining the attitudes and experiences of participants in the NESR is an important contribution to knowledge for policy makers. The study draws attention to the importance of contextualising participants’ responses in specific temporal and geographical conditions. For example views regarding the state provision of fertility treatment are different from the UK of the 1980s and thus are different to Australia in 2013. The analysis provides important evidence regarding the degree to which women may choose to provide oöcytes at the same time as being treated as a fertility patient. Currently, there is a lack of data about women’s attitudes to stem cell research generally and SCNT in particular in the Australian context. We do not know whether Australian women agree that they should be paid to provide oöcytes for research purposes or if infertile women are more likely to provide their oöcytes for research than fertile women. Our knowledge regarding views of egg-sharing models during fertility treatment is also limited. More importantly, there is little conceptual analysis of why women in Australia and other parts of the Global North have thus far “failed” to donate their oöcytes to SCNT research. Current approaches will be discussed in the next chapter.
Conclusion

To advance the aims of this thesis, this chapter has provided important background information regarding technical aspects of stem cell and SCNT research and female reproductive biology. The conduct of stem cell research is subject to competing frameworks which are imposed by states as well as scientists. Thus, we can see that attending to specific national contexts remains important despite the global nature of scientific research where such boundaries are ostensibly less important. However, the development of the IVF-Stem cell interface also shows that expectations regarding the conduct of scientists exist within competing frameworks. In some cases, stem cell research may be legally permitted but scientists refrain from soliciting oocytes for their research. This dissonance is central to questions about the scientific utilisation of reproductive tissues and indicates the various tensions which characterise its conduct. Chapter three will address normative approaches to the question, first discussing principle-based approaches in the bioethical literature. I will then situate this debate within the “tissue economies” literature by examining the legacy of Titmuss’s (1997 [1970]) *The Gift Relationship.*
Chapter Three: Principle-Based Approaches Regarding the Scientific Utilisation of Women’s Reproductive Tissues

Introduction

This chapter has two sections. Firstly, I will review the substantive literature regarding oöcyte provision to stem cell research and largely focus on the debate by various scholars in the English-speaking world about the consequences of paying women (if they constitute healthy research subjects or tissue donors), the risks and benefits of the procedure and the efficacy of stem cell research. I organise this debate between scholars who advocate payment for women to provide oöcytes to SCNT research as a way of reconciling the importance of such research and recognition of its specific conditions, and scholars who are critical of women assuming the burden of experimental research. This chapter demonstrates that most scholarly literature is concerned with motivations and attitudes of potential or actual donors and does not conceptualise the practice in sociological terms by situating the discussion within specific temporal and geographic contexts.

The second section will evaluate current approaches to oöcyte provision for SCNT research in relation to “tissue economies” literature, a growing field of scholarly work that examines issues related to property and forms of exchange. This begins with an in depth discussion of Titmuss’s (1997 [1970]) The Gift Relationship focusing on his dichotomous portrayal of ‘donors’ and ‘vendors’ before a discussion of recent critiques from political-economy perspectives. I suggest that even though Titmuss’s approach has come under sustained critique and may now seem anachronistic, it continues to be an important reference point for more contemporary approaches in unexpected ways.
Bioethical debates regarding the provision of oöcytes to SCNT research

For feminist scholars, the scientific utilisation of women’s reproductive tissues poses significant questions about women’s social, civil and political status. These concerns have been channelled into a debate which has largely focused on whether altruistic or payment models can realise women’s rights to liberty. The payment system is advocated as a way of changing relationships between women and scientists in one of two ways; firstly, to economically recognise the labour of the women providing their oöcytes in a heavily commercialised field of scientific research and secondly, to transform social expectations that femininity is predicated on women being altruistic. However, payment systems are controversial for three reasons: firstly, because they undermine the notion that participation in scientific research should be autonomous and voluntary and occur without undue inducement. Secondly, paying women in particular provokes questions about specific forms of coercion based on a generalised vulnerability. Finally, a payment system commodifies things or social relations to which prices had not previously been attached. Whether scholars advocate a payment system or are critical of expectations that women contribute to scientific research, they are united in an assumption that an ethical decision is the outcome of calculating costs and benefits and the inclusion of money into this process is considered a way of mitigating the costs to women or increasing the risk that their bodies will be subject to commodification.

Citing the Belmont Report of 1975, Lo et al. (2004), Levens and de Cherney (2008) and Mertes and Pennings (2007) contend that oöcyte provision for SCNT research is simply another form of participation in scientific research. Mertes and Pennings (2007) recognise the “special status” of oöcyte providers as providers of material, rather than test subjects, but insist that this difference does not fundamentally change the broader framework in which they should be placed. For scholars who regard oöcyte provision for SCNT research as comparable to participation in clinical trials, the mechanism of informed consent is considered a sufficient means to ensure the autonomy of women (Haimes et al. 2013). However, what constitutes necessary information is heavily contested. Lo et al. (2004, 560) make the distinction between the provision of oöcytes and embryos, which should follow “explicit and specific” procedures of informed consent, and the use of cancerous tissues, which are removed during treatment. The information presented to oöcyte providers should
include knowledge about the use of embryos, including their destruction, the potential commercial value of the research and the sharing between researchers and institutions. Oöcyte providers in particular “need to understand that the resulting cells will be, except for mitochondrial DNA, genetically identical to the somatic cell donor and that they will not be used to create a pregnancy” (Lo et al. 2004).

Dickenson and Alkorta Idiakez (2008, 140) are not only critical of paying women to provide their oöcytes to SCNT research but argue that “conscientious researcher[s]” should not be asking women to provide oöcytes at all and they propose a moratorium on oöcyte provision for research until the risks are better understood. They questions whether women can fully consent if there is insufficient information about the procedure. Without “full disclosure”, potential donors cannot adequately calculate the risks and benefits of oöcyte extraction. The authors suggest that the long-term health and well-being effects of ovarian stimulation have not been definitively established and therefore, participants cannot be adequately informed and their consent is effectively hollow. George (2008) shares concerns that the process of informed consent cannot be considered a solution that reconciles the complexity of the issues at hand. Specifically, given the ‘speculative’ nature of SCNT research, oöcyte donors cannot be likened to kidney or liver lobe donors whose recipients usually stand to tangibly benefit from the donation; neither should oöcyte provision be compared with clinical trials because “there are [no] clear benefits for the indicated population” (George 2008, 288).

Clearly communicating the risks of any procedure is essential for the process of informed consent. However, within this sub-discipline, there is little consensus regarding the long or short-term risks of oöcyte extraction and the political implications of making such pronouncements are disputed. Scholars manage this uncertainty in specific ways; Levens and DeCherney (2008, 2175, emphasis added) rather optimistically state, “there is no conclusive evidence linking fertility drugs to breast, endometrial, or ovarian cancer risks”, yet they also suggest that there is a risk of OHSS which can be fatal in rare cases and a potential reduction in future fertility. Other scholars maintain an ambiguity in their own pronouncements by referring to both abstract and specific contexts. For instance, Mertes and Pennings (2007, 630 emphasis added) state that because “ovarian stimulation and oöcyte retrieval are common procedures in infertility treatment, and thus, accurate data are available on the immediate health risks for women…research into the long-term risks of ovarian stimulation
are still underway, and many of the existing studies present conflicting data”. At the same time, they also suggest that women should be informed of the uncertainties related to the effects of drugs and procedures of oöcyte extraction.

Other scholars insist that the medication and procedures used in the process of oöcyte extraction pose serious risks to women who undertake the process (Dickenson and Alkorta Idiakez 2008; Thompson 2009). George (2008, 289) argues that the risks of oöcyte provision for healthy donors and fertility patients are immense and cites clinical practices moving toward lower dose and more “natural/minimal stimulation IVF where fewer oöcytes are extracted than with standard IVF” as evidence that protocols seeking to maximise the number of oöcytes will automatically harm women. Mertes and Pennings (2007, 630) argue that OHSS is most likely in young donors with comorbidity factors, such as polycystic ovaries. Moreover, like George (2008), they suggest that to avoid OHSS, tempering the stimulation regime to more ‘natural’ levels of oöcyte maturation because the donor, unlike the fertility patient, is unlikely to benefit from the retrieval of high numbers of oöcytes. Thompson (2007) suggests mitigating risks of harm by using fertility clinics whose statistics show low rates of pregnancy and OHSS for providers, to oversee oöcyte extraction, arguing that less responsible clinics should not be used. This is the same view of the International Society for Stem Cell Research (cited in Haimes et al. 2013). However, the feasibility of this strategy is uncertain because as some researchers admit, clinicians may be reluctant to report if their patients or donors suffer from OHSS because of potentially adverse consequences such as bad publicity (Pearson 2006).

New empirical research has reported the medical effects of oöcyte extraction. Maxwell, Cholst and Rosenwaks (2008, 2166) undertook a retrospective analysis of donor charts at the New York Presbyterian Hospital-Weill Cornell Medical School between 1991 and 2007. The sample included donors (both anonymous and identified or directed) who participated in almost 1000 cycles ($n=587$). The research was designed to study the rate of both minor and serious complications related to oöcyte retrieval and found that the rate of serious complications was less than 1%. Serious complications include “moderate OHSS requiring hospitalization, ovarian torsion, infection, and a ruptured ovarian cyst” (Maxwell, Cholst and Rosenwaks 2008, 2169). The rate of minor complications was 8.5%; which was defined as mild or moderate symptoms of OHSS. Jayaprakasan et al. (2007) designed their study in
order to understand the potential risks of OHSS for the specific practice of oöcyte retrieval for research. The participants of the study included women undergoing fertility treatment at a NHS-funded centre in the UK (n=339), specifically those who developed a particular number of follicles after ovarian stimulation. The researchers reported that 14.5% of women required hospital admission to treat symptoms of OHSS, a figure Schneider (2008, 2016.e2) regards as “sizable”. Schneider draws attention to the fact that the studies related to short and long term risks of oöcyte retrieval have been based on the samples of women who have undertaken fertility treatment and is critical of assumptions that they may be translated to the ‘healthy’ oöcyte donor for stem cell research.

As the preceding discussion indicates, the risks associated with oöcyte extraction in the short and long term can be used as a basis for deciding which is the “best” oöcyte provider to SCNT research. These arguments are largely premised on the idea that justice should determine the selection of research participants. Just subject selection is a concern of the bioethical community that is critical of the recruitment of particular populations–usually prisoners or the economically disadvantaged – that are less capable of exercising their autonomy. This includes views regarding the consequences of introducing financial remuneration on different groups of women. For instance, Thompson (2007) argues that maintaining an altruistic system will inhibit the recruitment of “the healthiest possible donor” (women who are nonetheless inherently vulnerable in specific ways). The ‘healthy donor’ is not a fertility patient but a woman whose fertility is at its peak. According to Thompson, an altruistic system invariably puts pressure on women who are “vulnerable” because they are motivated by the potential outcomes of the research (i.e. women who are in someway closely related to prospective beneficiaries – those with diseases or genetic dispositions which SCNT research may help alleviate or cure). A payment system will alleviate the pressure on such women – those providing oöcytes in “specific” and “concrete” circumstances by giving women with no such motivation a reason to provide their own oöcytes (Thompson 2007; George 2008; Thompson 2009).

Introducing a payment system to ‘healthy donors’ to provide oöcytes for SCNT research is also expected to alleviate pressure on other potential donor populations, specifically women who are undergoing fertility treatment. Like Thompson (2007), this argument is based on the principle of just subject selection because paying healthy donors will increase the number of
oöcytes for research and distribute the risk across the society. Citing the IVF-Stem cell interface, Ballantyne and de Lacey argue that women undergoing fertility treatment are currently most vulnerable to becoming the population of providers by default. Fertility patients are unlike patients enrolled in randomized control trials (RCTs) because giving oöcytes to SCNT research does not represent any therapeutic benefit for their infertility.\textsuperscript{17} However, this cohort should only be approached to participate in research that specifically benefits them as fertility patients. The International Society for Stem Cell Research (Haimes et al. 2013, 288) regards the provision of some ‘reward’ to “women in fertility treatment programs…[as] ethically justifiable to compensate them for their willingness to accept added anxiety and some risk of reduced chances of pregnancy”. Ultimately, the view that ‘healthy donors’ rather than fertility patients are ideally approached corresponds with the positions taken by the Nuffield Council on Bioethics (2011) and Levens and DeCherney (2008, 2175) who argue “reasonable financial compensation is grounded in fairness to donors in exchange for the burden borne on behalf of the recipient or society in the case of donation for research”. However, it diverges from the suggestion made by Mertes and Pennings (2007, 631) that the benefit to providers should be increased by prioritising research into genetic research rather than “expensive tailor-made stem cell therapies”.

These views proceed from the desire to maintain respect for the human body and insist that paying providers does not automatically entail the commodification of human tissues. Scholars such as Thompson (2007), Isasi and Knoppers (2007) and Levens and de Cherney (2008) seek to temper their advocacy of payment by insisting that it should not be introduced in isolation. Other measures must be instituted in order to protect women who will be attracted to the financial compensation. This includes follow-up medical and/or psychological care for providers (Mertes and Pennings 2007; Thompson 2007). This is particularly apt in the context of the US and other jurisdictions that have minimal or restricted, rather than universal, provision for healthcare.\textsuperscript{18} Other scholars stipulate a number of conditions to mitigate the risks, including the number of oöcytes collected, regularly screening donors for medical problems, monitoring specifically for symptoms of OHSS,

\textsuperscript{17}Ballantyne and de Lacey (2008) do not discuss the fact that RCTs enroll patients who are given potentially new treatments (the experimental group) and others who may be treated with the established medicine or placebos (the control group).

\textsuperscript{18} In Australia, the Medicare system is comprehensive and covers emergency treatments and some non-essential healthcare.
restricting providers on the basis of age (minimum 25 years) and parity and allowing only two donations per woman (Thompson 2007). Levens and de Cherney (2008, 2174) recommend that oöcyte providers should be between 21 and 34 years of age (despite the legal age of consent being 18) and that they submit to psychological assessment in order to avoid potential long-term psychological effects, that have been reported by women who have provided oöcytes for reproductive (namely that they are not aware of the outcome).

Many scholars who advocate for payment to healthy donors insist that this constitutes neither coercion nor commodification (Thompson 2007; Skene 2009). For example, in their recommendations, the Committee for the International Society for Stem Cell Research (Haimes et al. 2013, 285) propose that any “compensation is not for the eggs, but rather for undergoing the processes involved in providing those eggs”. Isasi and Knoppers (2007, 42) argue “linking compensation to risk…preserves the essence of donation as a gift”. Commodification occurs if women are paid for the amount and quality of oöcytes they provide (i.e. providers would only be paid if they produced 15 fertile oöcytes). Payment is advocated on the basis that it is given for “the work of undergoing the donation procedure”, rather than the oöcytes provided that will commercialise “that which should be not be commercialized” (Thompson 2007, 209). Comparisons between other forms of onerous work and oöcyte donation should be made in order to determine the payment. Situating stem cell research in a more overt economic context, Ballantyne and de Lacey (2008, 160) argue that it is unjust to prohibit donors from receiving any monetary recompense for their efforts because the oöcytes are economically valuable and contend that “[c]ompulsory altruistic donation of eggs does not prevent the commodification of eggs; it simply prevents women from sharing in the financial benefits of the research”. Distinct from these approaches, the legal scholar Skene (2009, 28.4) argues that since oöcyte extraction is akin to ‘risky’ jobs such as film stunts or bridge construction, monetary payment is necessary to counteract the onerous “time [commitments] and invasiveness of the procedure”. Skene’s (2009) argument is based on the principle of autonomy and is critical of the state’s authority to regulate the decisions women can make about their bodies.

As the discipline of bioethics is heterogeneous, advocating for the introduction of a payment for healthy oöcyte donors is not without its detractors. Refuting Skene’s (2009) claim that payment does not automatically involve the commercialisation of oöcytes and human bodies,
Thompson (2009) argues that it is highly likely that providers will be poor if Australia legalises the payment of oöcyte provision to SCNT research. The basis of Thompson’s (2009, 29.1) claim is the idea that “a person uses her body and how she allows her body to be used are forms of self-expression that are intrinsically tied to her self-conception and the value she puts on her relationships with others”. This and other critical perspectives insist that any kind of payment is a form of undue coercion because it is likely to influence the individual to make a decision without proper consideration of the potential risks (Dickenson and Alkorta Idiakez 2008; Roberts and Throsby 2008; Widdows 2009).

Paying women to provide oöcytes for SCNT research does not necessarily relieve pressure from other potential donor populations; rather, given that women experience social and economic disadvantage in comparison with men, it would represent the potential for exploitation of women on a global scale, particularly those who live in nations where ethical oversight is often negligible (Dickenson 2002; Widdows 2009). In these countries, oöcyte provision for SCNT research will become a source of income (as is the case for some women in Romania) (Nahman 2008). In a similar vein, George (2008) does not believe it is possible that any form of oöcyte provision for SCNT research (paid or unpaid) can occur without harm to women and supports measures taken by the European Parliament to fund alternative research.

An important feature of these critical perspectives is a scepticism regarding the efficacy of SCNT research and thus the justification of bearing the risks of oöcyte extraction. Thompson (2009) asserts that the potential benefits of SCNT research should not be considered as a good in itself. Imperatives to improve healthcare and quality of life cannot be necessarily privileged at the expense of other social or ethical values. Similarly, Baylis and McLeod (2007) suggest that given the potential risks for women undergoing oöcyte extraction, scientists should focus on other viable and less socially controversial forms of stem cell research such as IPS cells. These approaches clearly resonate with community opposition to the HGDP discussed in chapter four; they demonstrate a cynicism about the benefits of scientific research and argue that the cost to women’s bodily and psychic integrity is too high.
Women and vulnerability

The commentators discussed in the preceding section acknowledge and address vulnerability in very different ways. Vulnerability is an intensely debated concept in bioethical literature and its meaning is contentious. Macklin (2003) surveys a number of examples and argues that defining exploitation is an important basis for determining vulnerability—whether individuals or groups have the ability to exercise protection of their own interest. Unequal power relations involve “wealthy or powerful individuals or agencies [taking] advantage of the poverty, powerlessness, or dependency of others by using the latter to serve their own ends…without adequate compensating benefits for the less powerful or disadvantaged” (Macklin 2003, 475). Macklin draws on two case studies: the testing of a drug for meningitis in Nigeria during an epidemic of the disease and the ‘importation’ of Estonian citizens as research subjects into Switzerland where few local people were enrolled in clinical trials. In addition, Macklin discusses the way in which religious and customary social contexts often create overt relations of gendered dominance. Macklin defines exploitation by calculating costs and benefits to the individual or group. This is distinct from Hurst’s (2008, 198) assertion that the potential vulnerability of research participants must be assessed in relation to specific wrongs that could eventuate from specific research projects. Hurst shifts the emphasis of vulnerability from being an essential trait in a particular social status such as gender, race, class or sexuality to an assessment of the potential harm a specific research protocol may pose.

Like Hurst, Luna (2009) is sceptical of approaches that simply use vulnerability as a label and dismissing the idea that vulnerability can be a natural fact, a part of the human condition. Instead, Luna constructs a dynamic and relational view of the concept and proposes that vulnerability be conceptualised as a layer, which can be placed on an individual within a particular context. A woman may or may not be vulnerable depending on the political and social context in which she exists and the rights that she can exercise. This approach is distinct from others that label specific populations or groups as vulnerable and render them a homogenous mass despite their complexity. It acknowledges that vulnerability is not a permanent state. Luna asserts that women have varying levels of social and economic capital that they may draw on in order to realise their interests.
The preceding discussion demonstrates that the concept of vulnerability is subject to specific debates regarding its meaning and application. The debate regarding oöcyte provision to SCNT research remains largely within the paradigm that a population is inherently vulnerable, with some attention to the specific context of oöcyte provision. For instance, even scholars advocating for the introduction of a payment system argue that it must be checked and balanced with other measures to mitigate the risk that women will sell their oöcytes because of the vulnerability caused by their economic and social deprivation. On the other hand, critiques of both payment and altruistic systems suggest that women are vulnerable to expectations of altruism and self-sacrifice because of conventional norms of femininity. This static view of women as vulnerable is also evident with regards to women and risks associated with oöcyte extraction, to be discussed further in chapter five.

**Tissue economies: the legacy of Titmuss’s *The Gift Relationship***

It is necessary to situate the foregoing discussion regarding the regulatory regime in which the scientific utilisation of oocytes can occur with reference to Richard Titmuss’s (1997 [1970]), *The Gift Relationship: From Human Blood to Social Policy*. This is because contemporary debates are seeking to change the status quo, and Titmuss’s altruistic-donor model for blood transfusions remains the template. As mentioned in chapter two, the altruistic donor model remains in place in Australia and many parts of the world. Efforts to introduce different models are always made in relation to Titmuss’s precursor even if this reference is implicit. For this thesis to progress, the arguments contained within *The Gift Relationship* must be discussed. I do not mean to suggest that blood and oocyte provision are biologically and technically analogous. However, I do wish to assert that by exploring Titmuss’s continuing legacy, we can examine the underlying social and political implications of specific models of tissue provision.

Titmuss was one of Britain’s important social thinkers of the post WWII period. His seminal work was written at a time of significant transition in British history. It was a period defined by the remnants of the empire, immigration from former colonies, the continuing legacy of the Second World War, the emergence of the European Common Market and the universalisation of access to healthcare and education (in policy at least), notwithstanding the entrenched social class system. The book was published during what is now considered
the nascent phase of economic de-regulation which would eventually result in the retreat from directly delivered state services. Titmuss's text was expected to act as a bulwark against the increasing encroachment of market forces into once sacrosanct social spheres (Waldby and Mitchell 2006).

It is important to recognise that Titmuss did not just discuss blood transfusion simply in terms of its medical benefits. His (1997 [1970]) analysis of competing economic models for therapeutic blood provision was an ethical and political statement not unlike the discussions made by feminist scholars regarding oocyte provision to SCNT research in the last decade. I sustain this claim on the basis that both refer to concepts such as liberty and rights. Titmuss’s analysis of blood provision services of the United States and the United Kingdom, with comparisons drawn from South Africa, the Soviet Union and Japan, treated the issue of therapeutic blood provision in economic language, discussing the creation of demand and supply. The basis of Titmuss’s argument is his discussion of the potential need of a substance that everyone has. Recipients were not extraordinary people; rather they were specific cases of a more general human vulnerability. One may need blood simply by coming face to face with fate and having an accident. In pregnancy and childbirth any woman may need blood. If the reader did not have a wife, daughter, sister, niece or aunt, they certainly had a mother. Need was based on medical criteria not social divisions such as class, ethnicity or gender (1997 [1970). In this way, Titmuss was using and encouraging the emergent human rights discourse.

To assert that blood donation systems were invariably healthier, more equitable and efficient than paid systems, Titmuss examined in depth the models of the US and UK. At that time and today, the UK was characterised as a donor system because neither recipient nor donor was required to pay or be paid for the contribution. The cursory discussion of British (English and Welsh) donors shows that Titmuss was keen to emphasise the representative nature of the donor pool, stating that there is near-equal participation of male and female donors. Titmuss does not examine in much depth the lifestyles of British donors, as they are considered so normal as to resist description. Taking into account “the possible effects of the age-incapacity and reproductive factors,” the study implies that donors are “regular”

19 Titmuss was almost certainly assuming a normative distinction between illicit and licit drugs.
Brits doing their bit, rather than the marginalised of society (1997 [1970], 186). Titmuss’s account shows that at the same time in the US, people gave blood under different circumstances and included donors and vendors to blood collected from an individual or their family because of their own use of blood, or those depositing blood for their individual use. Titmuss particularly focused on the selling of blood for monetary payment in the American context and drew on data showing that vendors were socially and economically deprived and that they sold their blood when they had no other means of income. His claim is sustained by studies showing that commercial blood was drawn precisely from this “skid-row” population – one that was more likely to have serum hepatitis than others in the general population. Titmuss offered little elaboration about the characteristics of these socially deprived individuals and their unhealthy bodies. Moreover, in surveying the overall demographics of vendors, Titmuss regularly emphasised the over-representation of “Negroes” but provided little evidence as to why these men in particular posed a medical risk to the population of blood recipients.20

**Titmuss’s gift and gift-exchange**

Titmuss’s analysis of the motives of vendors and donors clearly sought to establish a hierarchy of ethical conduct in the public sphere.21 This is shown through the connection he made between the transactional nature of the exchange with the idea that using money as a means to establish a supply of blood was not only morally wrong but therapeutically dangerous. In such transactions, Titmuss implied that neither the vendor nor procurer will make ethical decisions. On the one hand, vendors sell their blood when they need to, usually in a time of personal crisis or in order to obtain their next drug ‘hit’. These are personal circumstances.

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20 Titmuss may have been looking to highlight the endemic racial inequity in the US by suggesting that African-American men were barely able to experience their civil liberties but could sell their blood. However, the conflation of captive donors in Bantu communities in South Africa and "American Negroes" suggests that Titmuss (1997 [1970], 255) was prone to essentialising racial identities; for instance “like many American Negroes, [Bantus] are unlikely to internalize a wish to help the unseen stranger. The psychological processes of internalising values in adult life can only be nourished in association with self-respect and personal freedom”. However, given that the mere suggestion that African-American males are part of the blood vendor pool seems to be disturbing enough, something else is going on here. I would resist dismissing this racism (for lack of a better word) as simply anachronistic and instead suggest that Titmuss is imposing a particular meaning on these bodies – as symbolically threatening to the mainstream [white] population. Such concerns continue to exist in debates albeit in less overtly racist, sexist or homophobic terms.

21 Titmuss drew on ideas about moral weakness produced by poverty. This is certainly not a discourse that Titmuss himself created; as commodities became more available to the less wealthy (because high scale production made them cheaper), there were often debates as to how much these lower classes should have access to such objects in terms of their spiritual weakness (J. Shaw 2010).
reasons that do not take into account the ultimate destination of the blood and the unhealthy recipient. The vendor does not have any reason to be honest about the purity or health of his or her blood because the vendor has no relationship with the recipient. The exchange is transient and outside of ethical considerations because it is premised on blood for money rather than blood for health. On the other hand, Titmuss argued that due to the chronic shortage of blood, the principle of caveat emptor – let the buyer beware – is easily overlooked by procurers. The nature of the market transaction will inevitably distort the medical basis on which to distribute blood, forcing doctors to be expedient rather than cautious in order to treat their patients.

In designing a system to elicit altruistic behaviour, inter-personal anonymity was a central feature for Titmuss; a system in which donors and recipients could not identify one another made reciprocity logistically impossible. Both parties are forced to be in a quasi-relationship with each other in a more dignified way because it occurs for the benefit of another’s health and wellbeing, rather than for money or self-interest. More precisely, the altruistic donation of blood allowed donors to actively embrace the universal stranger and could thus have important implications for social cohesiveness generally. It allowed donors to find their inner ‘moral compass’ of empathy towards countless others whose only commonality is their basic human frailty. Titmuss’s appeal to embrace the ‘universal stranger’ through blood donation was built on connecting people through generic identification.

It might be argued that the inter-personally anonymous basis of blood donation is a bureaucratic response to the fact that blood can be banked and lots of it needed, not because of preferences at an institutional or personal level. However, my research of Titmuss’s texts indicates otherwise. My critique is not based on whether it is true that interpersonal anonymity will preclude cycles of reciprocity but rather the emphasis put on the biological/technical aspects of blood provision does not tell the story Titmuss intended. Titmuss asserted his claims in opposition to the analyses made by Mauss (2002 [1954]) and Levi-Strauss’s (1969) work on gift-exchange and generalized exchange respectively. Titmuss very clearly argued that inter-personal anonymity is a condition of altruism and without it reciprocity (in the immediate or long term future) will invariably prevail. I provide two quotes to sustain my claim:
In reference to Levi-Strauss’ claim that Christmas gift giving is one giant potlatch, Titmuss (1997 [1970] 277) asserts that “these examples…indicate that the personal gift and countergift, in which givers and receivers are known to each other, and personally communicate with each other, is characterised by a great variety of sentiments and purposes…Within all such gift transactions of a personal face-to-face nature lie embedded some elements of moral enforcement or bond. To give is to receive- to compel some return or create some obligation…No such gift is or can be utterly detached, disinterested or impersonal.

There is in all of these transactions an unspoken assumption of some form of gift-reciprocity; that those who give as members of a society to strangers will themselves (or their families) eventually benefit as members of that society. There is, nevertheless, a vague and general presumption of a return gift at some future date, but a gift that may not be deliberately sought or desired by the individual concerned – as with voluntary blood donors. (Titmuss 1997 [1970] 282)

As we can already see, Titmuss made his case for giving blood with reference to the *Essai sur le don* (translated as *The Gift: the form and reason for exchange in archaic societies*), first published in 1923 by French anthropologist Marcel Mauss (2002 [1954]). Mauss’s work sought to challenge common-sense ideas about the “free gift”: that people give out of spontaneous generosity and do not expect anything back (Douglas 2002 [1990]). Drawing on anthropological fieldwork from the Trobriand Islands and Indigenous groups in northwest Canada, Mauss asserted that self-interest and rivalry are the mechanics that drive the exchange of gifts in traditional societies (Frow 1997). Gifts actually create debt and act more as loans because they are always returned, oftentimes with interest (Waldby and Mitchell 2006). By insisting that donors and recipients in contemporary Britain could engage in anonymous, transient and obligation-free relationships, Titmuss conflated the language of gifts with the process of gift-exchange and thus the gift of blood was actually closer to the ideal of the free gift (Carrier 1995; Frow 1997).

22 Unlike many anthropologists, Mauss did not undertake research in the field but drew on the studies of others who had (Liebersohn 2011).
While Mauss (2002 [1954]) argued that obligations to give, receive and reciprocate were overt or latent motives behind the exchange of gifts and that this system is the basis for establishing and maintaining hierarchical social relations, Titmuss (1997 [1970]) radically insisted that giving could be free, that is spontaneous and democratic. The free gift was not a social fiction but rather an activity that had to be instituted and protected particularly under the condition of inter-personal anonymity. He also contended that people had as much “right to give” as they had “right to sell”. Even though the approaches taken by Mauss and Titmuss are different, both seem to suggest that gift giving within personally identified contexts is unlikely to be “altruistic”, that is “free” and that people known to each other will continue cycles of reciprocity.

**Challenging the altruistic-donor model**

Titmuss’s (1997 [1970]) legacy regarding gifts and tissue provision has come under sustained critique as anachronistic and bearing little relevance to the complex relationships that now characterise blood provision or the conduct of scientific research. The most sustained critique of the dichotomous assumptions made by Titmuss appears in *Tissue economies: blood, organs, and cell lines in late capitalism* (Waldby and Mitchell 2006), which charts developments in biomedical research and the utilisation of tissues by individuals, communities and companies. Waldby and Mitchell (2006) argue that the binary of commodity and gift and the social relations that Titmuss argued they engender, do not adequately capture the significant political, social and economic transformations that have occurred since he wrote his book. In contemporary society, Titmuss's legacy needs to be significantly re-assessed.

One critique posited in the book is that Titmuss’s model of altruistic [blood] donation has been erroneously applied to novel contexts of scientific research.23 Translating a model used

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23 Waldby and Mitchell’s (2006) assert that the altruistic-donor model has been erroneously applied to all forms of tissue provision regardless of whether it fits with their distinctive features. In light of this, some might argue that it is more appropriate to compare oocyte extraction with live organ donation. However, as already mentioned, Titmuss and the altruistic-donor model remains paradigmatic; I have used Titmuss’s work because of its centrality to the social scientific debate regarding tissue provision (there is a very clear lineage between contemporary bioethical and tissue economies literature and Titmuss’s work). I also think that the importance of Titmuss’s work was that it was intended to be a political statement based on the organisation of tissue provision in his society. He was not just talking about the transfusion of blood in a biological or technical fashion but the potential social relations that may organise it. Or rather, he took up the subject of blood
for a specific form of tissue implies that all tissues are the same regardless of their biological properties or social significance. Titmuss himself is unlikely to recognise the field of blood transfusion in the UK if he were alive today. Waldby and Mitchell (2006) demonstrate that since the 1970s, technological advancements have meant that blood can be fragmented to such a degree that whole blood transfusion is rare and one extraction will result in a multiplicity of recipients. These developments are claimed to undermine the relationship between the two strangers (mediated by medical professionals) that Titmuss regarded as emblematic of broader social relations. Furthermore, blood screening is now able to identify many diseases such as hepatitis C and HIV, thus removing some of the onus on providers to entirely tell the truth.

Another basis of critique by Waldby and Mitchell (2006) is that in Titmuss’s work there is little acknowledgement regarding the power relations that are attached to gift giving. They contend that there is a lack of critical awareness regarding property relations around donor paradigms. As biomedical research is increasingly industrialised tissues have become the material for the production of sophisticated technologies that are expected to be patented and recoup initial investments. These structures are upheld by government regulations and legal judgements and rely on specific understandings of labour and the legitimate forms of rights in property.

One example that is closely related to this thesis is the use of embryos for stem cell research. Patients who have undertaken fertility treatment may designate stored embryo(s) to be used for research purposes, for reproductive donation or to allow embryos to succumb. As Waldby and Mitchell (2006, 70) argue, regulatory bodies have consistently borrowed the

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24 The following is an example of the potential commercial value that stem cell research signifies; when the first stem cell line was created in 1998, the Wisconsin Alumni Research Foundation (WARF) applied for a patent on the method of deriving stem cell lines as well as “all mesodermal, endodermal and ectodermal hES cell lines, regardless of the way they were derived” (Gottweis, Salter and Waldby 2009, 39-40). WARF’s non-profit subsidiary was established to license use of its stem cell lines with the cost of a commercial research license requiring a $100,000 upfront fee and a further $25,000 to renew the license annually. Non-commercial research is licensed at $500 but must not result in commercial applications.

25 This is distinct from suggesting that tissues no longer have a therapeutic purpose without scientific mediation.

26 This involves the embryo being given to another woman or couple needing fertility treatment.
language of the gift for therapeutic tissue circulations but do not refer to the “gift of potential knowledge to a medical researcher”. However, the therapeutic paradigm is distinct because it involves the transfer of embryos to become children. The research paradigm involves the transfer of the embryo as research material and the relationship between donor and recipient is characterised by mutually exclusive property rights. Yet, the authors (2006) argue that this model of embryo provision to stem cell research is not just a means of conveying information to the donors but is a de facto contract. Consent forms include provisions for the donors to relinquish any property in the tissue and subsequent creations. This means that once the embryo is provided to the researchers, any potential stem cell lines and/or therapies are the property of the researchers and/or companies.

Critiques of tissue provision in contemporary society often reveal deep-seated assumptions about Western notions of property, labour, and the body. Contemporary scholars such as Ballantyne and de Lacey (2008) and Waldby and Mitchell (2006) regard Titmuss's model of the gift as incapable of justly serving individuals and society given the changes in economic, political and technological structures. However, it is not just Titmuss’s intellectual legacy that requires re-evaluation but fundamental premises on which contemporary social thought and legal practice is based. For example, the work of German philosopher Immanuel Kant is often drawn into debates regarding notions of human dignity. Kant’s democratic approach to dignity was radical for the 18th century because it dismissed the conventional structures that accorded dignity based on inherited status (Sullivan 1994). Kant (1976 [1949], 91) argued that rational beings engage with other rational beings on the basis of reason which has no other motive other than the “dignity of a rational being”. One consequence of this is that individuals should regard others as ends in themselves rather than means to an end. For Kant, “dignity” and “price” were mutually exclusive with the innate dignity of each rational being. On the one hand, those “things” which can be replaced and are utilised for “human inclinations and needs” have a price (which may be relative). On the other hand, unique “things” such as human beings have an inherent dignity and are “above all price, and therefore [admit] of no equivalent” (1976[1949], 92).27

27 This brief reference to Kant is intended to indicate that Titmuss’s ideas belong to a lineage within Western thought that encompasses philosophy, law, religion and economics. It is beyond the scope of this thesis to develop the point beyond this.
Labour and property rights: patent and the facilitation of knowledge production

Waldby and Mitchell’s critique may echo generally with approaches taken by critical theorists who argue that, within capitalist societies, ideological apparatuses are directly related to the mode of production and will obscure the latter's reality (Widdows 2009). While their analysis is crucial for understanding how the field is broadly constituted beyond the purview of most people’s understanding, they do not suggest, however, that private property is necessarily the basis of exploitative appropriation. Rather, Waldby and Mitchell emphasise that the structures in which tissue provision and biomedical research exist can be utilised differently by individuals and companies. They demonstrate that some community groups are able to use the language and artefacts of capitalism to their own advantage. One example is PXE International, a foundation established by Patrick and Sharon Terry after their children were diagnosed with the disease pseudoxanthoma elasticum (PXE). In collaboration with the University of Hawaii, the foundation funded research to isolate the gene that causes PXE and was subsequently patented. Since then, the foundation has used profits made by selling licenses to researchers around the world as a way to fund research which will contribute to curing PXE. The patent gives the foundation leverage to negotiate with companies that would otherwise avoid researching PXE for its lack of anticipated profitability. This example shows that forms of private property can be used as a means of generating research rather than as a basis of exclusive property rights that stifle research (Waldby and Mitchell 2006).

The contemporary bioethicist Dickenson (2007, 2006) has analysed the issue of oöcyte provision to SCNT research and argues that contract law, under which commercial exchanges of tissue would necessarily fall, is inadequate to capture the relationship between the ‘self’, the ‘person’ and their body. In common law, the self does not own its own property – the body – and therefore body parts cannot be sold. Drawing on the arguments of 17th century political philosopher John Locke, Dickenson argues that there continues to be differences between that which is created by humans (goods that can be sold) and that which is a naturally occurring entity (such as the body, which cannot be legally sold).

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28 The researchers who purchase a license may conduct their own research within a company or university.
The intellectual property rights that pertain to SCNT research are imbued with Western ideas of labour; intentionality and consciousness are privileged over the body, which is constructed as merely dumb matter (Waldby and Mitchell 2006; Dickenson 2007). Women are not considered *creators* of the oöcytes they provide for SCNT research. In the conventional model favoured by capitalist trade institutions, such as the Organisation for Economic Development (OECD), cognitive labour is considered crucial to creating something in which property rights may be vested. In this context, the oöcyte is the research material and the stem cell line into which it is transformed is the patent-able creation. With property rights vested only in stem cell line, research scientist and company, oöcytes becomes analogous to natural growing resources such as land and trees (Waldby and Mitchell 2006).

However, Dickenson (2006) is critical of the appropriation of biological tissue by capitalist organisations, which she argues is a contemporary form of enclosure, imitating the 16th century enclosures of pastures in the UK. Dickenson intends to counter this process of exclusion with an artefact which is also used as a means of exclusion: the contract, arguing that a technology that has often been used to undermine the autonomy of women can be made to adhere to feminist principles of social justice. Individuals providing human tissue for SCNT research should not be excluded from rights in the tissue once it is provided. One way this can be done is to recognise the labour involved in oöcyte extraction; women *labour* to produce more oöcytes than are usually matured through a natural menstrual cycle. This is similar to an argument made by Waldby and Cooper (2010) who argue that to extract oöcytes, which naturally remain *in vivo*, women must consciously adjust the chemical balance of their bodies with hormonal drugs prior to undergoing surgery.

In discussing oöcyte provision to SCNT research at the structural level, Waldby and Cooper (2010) and Dickenson (2006; 2007) uncover an inherent paradox: maintaining an altruistic-donor system is tantamount to enshrining the body beyond commerce. This formulation allows the products of the body to be used as the basis of commercial expansion but necessarily excludes the providers of the resource material. It also means maintaining a privileged space for property relations based on a particular definition of labour. The other

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29 As will be noted later in this chapter, between Titmuss and more contemporary, feminist-oriented scholars, there are fundamentally different conceptions of social justice and the individual.
side of the equation is that introducing a payment system is expected to invariably encourage contractual relations in all spheres of life. The ‘right to give’, that Titmuss (1997 [1970]) claimed to be based on the individual donor’s recognition of others’ universal human needs, will be increasingly subsumed by the ‘right to sell’. Yet, despite the structural focus, the solution is directed towards the individual in the short term, that is a payment for oöcyte providers, rather than provoking questions regarding the products of this scientific research in the long term. The individual’s ‘right’ to their moral authority subsumes the question of the ‘public good’ of scientific research.

Conceptualising the commercialisation of human beings as undignified, coupled with the increasing commercialisation of biomedical research, currently leaves the body as a free resource in which its vitality may be extracted and profited from without compensation. This novel situation offends contemporary sensibilities; indeed, the metaphor of a mine is often invoked. Yet, the inclusion of some economic benefit for oöcyte providers evokes the spectre of the contract and the situation Titmuss ultimately sought to avoid; a collection of individuals who associate with others on an instrumental basis and where transactors have neither relationship nor obligation to one another beyond the transaction. The paradox of the situation is evident in the legal structures under which this field may fall.

Conclusion

As examined in detail in this chapter oöcyte provision to SCNT research is usually discussed with a focus on whether women can participate as autonomous and free individuals or whether they are likely to be exploited by economic and social structures which undermine the importance of their labour. Yet the normative emphasis on existentialist questions such as freedom has so far restricted the scope of inquiry to whether payment will facilitate or inhibit women’s autonomy further and the kinds of risks that oöcyte extraction, particularly in the context of “healthy donation”. Consequently, this principle-based framework avoids three important questions. Firstly, does the scientific utilisation of reproductive tissues distinctly constitute women’s social roles and thus help us understand the different donation rates between embryos and oöcytes? Secondly, does the development and utilisation of novel

30 By transforming oöcyte providers into “labourers” in the emerging bioeconomy, capitalist property relations are left in place because the capitalist maintains property over the creations of the labour.
scientific methods in the biosciences say anything specific about sociological questions concerning the relationship between institutions and individuals in our specific historical or social context? Thirdly, how do values regarding political behaviour help to shape ideas about economic forms and thus questions of providing tissues to scientific research?

This thesis cannot answer these questions by identifying principles with which to guide the conduct of scientific research or women’s social roles but will explore them by drawing on empirical data from Australia. I intend to explore the gendered identities which may materialise by contributing to scientific research with tissues such as oöcytes and embryos. In doing so, I examine the way participants imagined their contributions and argue that this needs to be understood, acknowledged and accommodated within existing structures. I do not proceed a priori that the scientific utilisation of such tissues is based on or reproduces gendered inequality by referring to the relative social and economic disadvantage of women vis-à-vis men. Gendered social relations exist in all spheres of life but they are not evident in exactly the same way. Scientific research is an important social institution but it is not a monolithic entity without its own pressures for legitimation. Moreover, this exercise also involves destabilising assumptions that the best contributor to scientific research must possess certain attributes. Thus, this analysis does not just refer to the substantive issue of whether payment will or will not resolve the lack of oöcytes, but facilitates the development of a conceptual framework that connects gifts and giving, constructions of gender and contemporary scientific research.

In this chapter, I have drawn out the political and ethical aspects of Titmuss’s altruistic donor model, his critique of the ‘right to sell’ and how this might be contrasted with contemporary approaches regarding women’s right to their bodies and the effects on the ‘public good’. In the next chapter I will demonstrate that the specific limitations to Titmuss’s approach have not been fully dispensed with. Examining the contemporary debate regarding oöcyte provision in light of Titmuss’s text reveals values underlying the views regarding financial remuneration in exchange for oöcytes to SCNT research. I will show that there are points of convergence between Titmuss and contemporary scholars; while the contemporary debate generally involves the inversion of Titmuss’s concerns about paying providers, who he assumed would contaminate the blood supply, the problem of interested donors and the
introduction of monetary payment and the relationship to the ‘public good’ remains and is fundamental to the current impasse regarding future policy.

In addressing the limitations of the current framework, I develop my own approach, which is based on a sociological analysis of empirical data, not normative abstractions. This paradigm situates the ethical decisions made by individuals within a historically and socially specific context. This involves focusing attention on how participants perceive and ‘rationalise’ the risks of oocyte extraction and taking into account the specificity of the tissue, the procedure of its extraction and its effect on the donor. However, I do not simply seek to diverge from the emphasis of analytic knowledge regarding oocyte provision but intend to look more broadly at conceptions of women as political subjects, practices of gift giving and reciprocity. I suggest that understanding the scientific utilisation of reproductive tissue can, in part, be achieved by connecting the provider, the recipient, the tissue. We must understand the social roles women inhabit within a society that predominantly values scientific research and that sanctions those contributions it deems as ‘disinterested’.
Chapter Four: Towards a Framework for Analysis

This chapter develops an eclectic approach to assist in analysing the scientific utilisation of reproductive tissues and particularly debates regarding which economic models should be instituted for the provision of oöcytes for SCNT research. This approach is primarily informed by a sociological lens that contextualises social problems as historically and socially specific, postulating what they can reveal about contemporary values regarding the relationships between individuals, their tissues and social institutions. In its study of social life, sociology situates ethical practices within broader social relations particularly in relation to the context of modernity or post-modernity (Giddens 1991). Locating the individual in his or her immediate social context and highlighting connections between identity, social roles and institutions achieves this intention (Davidman 1999). Sociological approaches are distinct and can assist in shifting the creation of analytically-derived policies to take into account the social context in which ethical norms are formed and sometimes contradicted.

My reference to a sociological lens should not be taken as representing the discipline as homogenous; indeed, sociology is constituted by a variety of approaches, including (but not limited to) conflict theory, structural-functionalist and symbolic interactionism, each explaining social life in unique ways. There are also many diverse methodologies (Furze et al. 2012). Notwithstanding this multiplicity, my reference to a sociological lens echoes Mill’s (1959) concept of the “sociological imagination”. This approach connects an individual's biography with his or her historical moment, starting from questions regarding the kinds of human nature privileged in the social context and where that society stands in relation to its contemporaries and its past.

This chapter has three goals: firstly, to sketch an unfamiliar way of understanding gifts and giving; secondly, to develop a more nuanced account of science in/and society than currently exists in critical approaches to oocyte provision and thirdly, to critique an important

31 Without discussing the convoluted history of sociology, the discipline came into being and examined the nascent emergence of the modern period resulting from the “great transformation”. In Europe and the US in the 18th century, structural revolutions occurred in three distinct spheres: the political and the emergence of democracy with the French and American Revolutions; the economic and the emergence of capitalism with the Industrial Revolution in Britain; and the social with the development of the Scientific Revolution and urbanisation in Europe. Sociologists are interested in the attendant factors that shape social relations and public institutions that emerged from these shifts (Giddens 1991; Shilling 1993).
assumption about political behaviour upon which this debate is based: that there is one model for political activity which must involve the effacement of the specific and embrace of the general and abstract. In order to achieve these goals, the analysis must critically address the assumptions that inform the current frameworks’ approaches to the scientific utilisation of reproductive tissues. I begin with a discussion regarding gifts and commodities. I contend that the current literature tends to reiterate categorical binaries between these constructs and importantly refers to the material world as inanimate. I draw on critical ideas of materiality that do not privilege the social space as occurring between human individuals and groups (precisely that which sociology is meant to examine) but which also pays attention to the mutually constitutive relationship between humans and things. This is crucial in connecting the biological properties of the tissue and its social utilisations.

In order to develop a more fruitful account of the relationships involved in oocyte provision, I then turn my attention to events in South Korea, the only country to witness a sustained effort on the part of many women to donate their oocytes to SCNT research. Following this, I discuss feminist-informed analysis of this context and the legacy of feminist scholarship regarding women’s reproductive capacity. I argue that by emphasising the existential dimension to the scientific utilisation of reproductive tissues, this framework does not allow for the diverse and sometimes contradictory developments that have shaped the conduct of scientific research in recent decades. The next section will examine approaches to political behaviour. I assert that while the contemplation of a payment system ostensibly marks a shift from Titmuss’s (1997 [1970]) defence of altruistic blood donation, ultimately both bioethical and tissue economies literature are suspicious of those who may have personal interests and seek to organise political behaviour that is impersonally motivated.

**This thesis is not a sociological study of ethics.**

In order to substantiate my assertion that I am employing a sociological approach to the scientific utilisation of reproductive tissues, that is distinct from a ‘sociology of ethics’, it is necessary to briefly trace the trajectory of my PhD candidature. When I began my candidature, I had no prior knowledge of stem cell research and because I was overseas at the time, missed the debate regarding its legislation in Australia. I initially made sense of the literature by occupying myself with the sociology/ethics disciplinary borders debate (see
Shaw 2006). At this time, I constructed my dissertation as part of a recent, more explicit incursion of sociological scholarship into areas of bioethical concern such as the governance of medical knowledge and practices, including but not limited to emerging technologies, patient-practitioner relationships and health funding.32 This sociological literature often made critical reference to approaches and tenets of institutionalised bioethics, a discipline with an effective monopoly on questions regarding the conduct of medical and scientific research since the 1960s. The question posed by sociological scholarship to which I was then hoping to contribute, indeed as posed by Haimes (2002) herself is, ‘what can the social sciences contribute to the study of ethics?’ made me reconsider my own intentions and objectives, particularly whether I could or ought to contribute to this literature. In the article of that name, Haimes outlines the theoretical contributions of Weber, Foucault, Bauman and Giddens as well as examining recent empirical studies by Franklin (1997), Price (1992) and Edwards (1998). In particular, the empirical work quoted “reveals [for Haimes] how ethics are ‘done’ (identified, thought about, acted upon) in everyday life” (Haimes 2002, 99). Yet, as I read more widely, I began to challenge the idea that since the topic of oocyte provision to stem cell research had been hitherto discussed by ethicists, lawyers and scientific researchers, that my own contribution as a sociologist, necessarily needs to be a ‘sociology of ethics’, or in Haimes’s words “how ethics are done”. I will outline my reasons in the following section.

As a sociologist, I have often been intrigued by and rather dismissive of the apparently central question in bioethics. While it is a broad church, bioethics is predicated on identifying moral principles with which to guide clinical and scientific conduct, its central question being ‘how am I to proceed?’ (Komesaroff 1995). I wish to use it in order to elaborate why I did not choose to undertake a ‘sociology of ethics’. When I refer to my own understanding of sociology I am not so naïve as to want to repeat the same ‘sins’ I see in the discipline of bioethics. Furthermore, I am acutely aware that sociology is a heterogeneous discipline. How then to persuasively distinguish a sociological approach to the scientific utilisation of reproductive tissues without centralising the ethics that inform it?

32 In this construction, sociology has evolved as a discipline from a place where two of its foundational thinkers (Weber and Durkheim) rejected a normative approach to the study of society to an explicitly engaged one.
Firstly, to the question, ‘how am I to proceed?’; I make the critique that the ‘I’ asking the question is a social construct. I do not mean to suggest that the ‘I’ does not exist but rather that to ask the question in the first place requires a certain social context, a context in which there is always a potential to make choices. As sociologists who can make comparisons with other historical eras, we can ask basic questions about who is able to ask this question, what are the existing moral values that may shape the answers, are there any factors that may affect the answer? Are these based on biology (race, gender, age), sexual orientation, economic class or religious belief? We can also ask a different question, one that relates to the connection between individuals and institutions; what role does the person asking the question in the society hold? By looking at the role of the medical doctor in contemporary society, we can unpack the historical legacy of medical autonomy and its current manifestations. We will also need to look at what institutional structures exist in which these ‘ethical’ questions are asked. For instance, we need to look at the context of the Australian federal government’s funding of a universal system called Medicare, the hospitals that are largely funded by state governments, differences between urban and rural hospitals and the political infighting that affects the provision of healthcare (between political parties and members of the medical establishment). These institutional structures also exist within a specific social context in which ideas about health and wellbeing evolve. Again, in the Australian context, the introduction of a 30% rebate for private health insurance had an effect on the establishment and utilisation of complementary therapy (this of course is not the only reason why more people use CAMs) which may in turn have an effect on patient relations with medical doctors. The clinician asks a question about a particular scenario with numerous competing factors shaping the interaction between him/her, other staff, the patient and perhaps his or her family. Thus the ethics of the individual clinician are shaped and shape these institutional structures. The above is a primary level sociological insight into bioethical approaches. It is useful for getting first-year students to think critically about the objectivity of the social world and the so-called limitations of our freedom. Yet, it is a critical difference between the disciplinary paths that scholars may travel.

Secondly, I have made the assertion of ‘my own understanding of sociology’. As I am individual like any other and having argued such as I have above, how can I assert that I

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33 This was a key policy of the Howard government (1996-2007).
have created or used my own sociology? In fact, I do not make this claim. As a teacher of introductory sociology, social theory and sociological approaches to other subjects such as religion and the media, I have been exposed to a great deal of sociological thought and ideas. I understand that there is an objective dimension to the discipline of sociology, whether it is looking at the ‘three fathers’ – Marx, Weber and Durkheim – or theories on deviance, risk and modernity (there are more theorists and theories – too numerous to name here). However, I am lucky enough to know that I can relate to a specific part of the sociological pie. As a scholar, I need to ask how I shall conduct myself within the constraints of disciplinary/academic sociology. Is it enough to drop names like Weber, Giddens, Haines, Bauman, Waldby, Rose or Foucault? In order to move forward, I made specific decisions regarding the kind of scholar I intended to be. I began again from about 2011 with the data I helped to collect. I looked critically at the literature written on oocyte provision for stem cell research.

As I have argued, this literature is permeated by a focus on whether it is appropriate to pay women to provide their oocytes for stem cell research. I saw that there was a dissonance between what had been predicted and what has actually happened in the first ten years since SCNT research had been legalised in the UK and five in Australia. From reading literature on tissue provision more broadly, I knew there existed a number of examples where people do give their tissues. I was intrigued that the connection between oocytes, stem cell research and its apparent therapeutic benefits appeared to be so tenuous and unmotivating. I wanted to explain this dissonance, and the more I read and thought about it, another dissonance emerged: most of participants in the study tended to think quite positively about scientific research. In comparison with other nations too, Australian society has a relatively harmonious and positive relationship with ‘Science’, evident in little controversy about its legitimacy (with the exception of climate change since 2008 – yet even in this context, the public debate doesn’t focus on individual scientists or their “faulty” work but on how correctly we can predict something based on the facts to hand). In addition to this, what is the significance that these questions only relate to women? Could I think about these questions differently to the existing feminist literature, again given the dissonance between the predictions and the reality?
By doing so, I made the decision to disengage (by about 2012) from ‘existentialist’ questions that permeate the debate regarding oocyte provision to stem cell research: of whether women who accept or decline money for their oocytes as free, resisting, oppressed, self-sacrificing, deluded by therapeutic promises and misguided by naïve understandings of science. I made these decisions because I believe it is possible to refer to the existing literature and create a new direction for scholarly work to proceed; I do not have to respond to such questions with an empirical basis. For example as already mentioned Haimes, Taylor and Turkmendag (2012) present empirical evidence in relation to the Egg Sharing for Research Scheme at Newcastle, specifically in response to the criticism from authors such as Dickenson and Alkorta Idiacez (2008) and Roberts and Throsby (2008). The authors report that participants did not particularly feel exploited while simultaneously declaring that these decisions are made in a context not really of their own making. Such an analysis highlights a tension or conflict between the trends towards democratic or subjective knowledge (perhaps poststructuralist is the best shorthand) and the ongoing need as scholars to find an objective, indeed structuralist dimension when analysing social problems.

To reiterate, this thesis does not engage in a ‘sociology of ethics’ and it does not want to restrict itself to an analysis of institutional impacts on individuals. I agree with (Haimes 2002, 105) that “we have to engage in the detailed, contextualised dilemmas” but as social scientists, the data analysis we undertake does not have to be restricted to pre-existing questions about the existentialist nature of the actions or attitudes of the sample. We can expand the focus to look at many issues, not least the relationships between social institutions and communities within the context of social development. But we should not resort to simply reporting participant’s views. My aversion to such an analysis is based on my own scholarly interests and a conviction that such debates limit the potential for complex sociological analysis.

On a more personal note, I should also acknowledge that when writing was difficult and I was very unsure about my analysis, it was good for me to return to the scholarly work that inspired me. One example of this is Lawton (1998). There are no connections between Lawton’s work and my own. I came across the article as a teacher on an introductory sociology course in 2010 and cried as I read the article. More importantly, I wanted to
emulate Lawton’s sophisticated analysis. Lawton looked at patient care in palliative nursing homes but her analysis made the connection between everyday reactions to terminal cancer and Elias’s study tracing the historical developments of bodily functions in Western society. It reminded me of Weber’s analysis in the *Protestant Ethic and the Spirit of Capitalism*. Both of them are beautifully written but neither of them are primarily focused on existentialist questions (although it hard to ignore the implications of Weber’s analysis, particularly with the image of the iron cage with which he ended the book), but instead a empathic curiosity with everyday actions and the broad-sweep of social development contained therein.

**Giving gifts in real time**

At a very basic level, this thesis is interested in gift giving and tissue provision. The debate regarding oöcyte provision recalls fundamental ideas about different economic forms, divisions between giving and selling. For Titmuss (1997 [1970]), only the free gift was an ethical category, a deviation from Mauss’s rejection of the free gift among actors known to each other. From the proceeding chapters, it is clear that the ethical legitimacy of implementing a market mechanism to resolve the current lack of oöcytes for SCNT research is contentious. The current impasse is likely to remain unless we interpret divisions between gifts and commodities as suggestive of profound tensions about the human condition, the body and materiality, situating the “things” we circulate and how we circulate them in a much broader question of ethical life.

In order to develop my own analysis, it is important to recognise that the Maussian approach to gift exchange to which Titmuss inconsistently referred emphasised that reciprocity was a universal part of gift-giving where an equivalent object is returned when one is given out of obligation and social necessity. The Maussian approach to gift giving emphasises reciprocity that is based on an equivalent object given. Drawing on the work of anthropologist, Bronislaw Malinowski’s ethnography *Argonauts of the Western Pacific* in 1922, Mauss (2002 [1954], 29 original emphasis) describes the objects of the *kula* ritual involving tribal chiefs exchanging the following objects:
the *mwali*, which are beautiful bracelets, carved, polished, and placed in a shell…and the *soulava*, necklaces fashioned by the skilful craftsmen of Sinaketa in a pretty mother of pearl made from red spondylus.

Mauss’s (2002 [1954], 4 original emphasis) intention was to identify how the obligations to give, receive, and reciprocate are actually experienced and enacted and the central question of his study was: “*what power resides in the object given that causes its recipient to pay it back?*” His answer, addressed to a curious Western audience ‘imbued’ with secular rationality, was that there was something sacred in the objects that were exchanged on the Trobriand Islands during *kula*; they had a spirit of their own, an individualising force, and as such compelled the recipient to maintain its movement until it returned ‘home’. Thus, in contrast to Western society, everything, not just people are imbued with spirit:

> What imposes obligation in the present received and exchanged, is the fact that the thing received is not inactive…invested with life, often possessing individuality, it seeks to return to…its “place of origin” or to produce on behalf of the clan and the native soil from which it sprang (Mauss 2002 [1954], 15-16).  

Because the basis of gift-exchange is a spiritually active world where the objects are compelled to return to their initial place, Mauss’s analysis portrays the development of the money economy as the movement to detachment, objectification and disconnection between individuals and their material world. Another element of the analysis is that Malinowksi’s reporting of *kula* is characterised as if it were “a timeless, self-contained process” (Rosaldo 1993, 16), without specific reference to historical developments that contributed to the performance of the ritual. For instance, Mauss himself did not ponder how the equivalent between the objects was established. The two objects at the centre of the kula exchange were only discussed in relation to their vital properties. Mauss focused on the fact that these objects were traded without money and surmised that they were non-commodities or gifts—objects with special properties which circumvented their trade with money. I argue that Mauss theorised that the exchange of *kula* objects as a gift economy because it was devoid of currency. Indeed, Mauss (2002 [1954], 29) broadly defines the *mwali* and *soulava* as “a

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34 Here, Mauss borrows the concept of the “hau” from New Zealand Maori culture. The “hau” is a spirit which resides in things and is represented as needing to move towards its place of origin (Mauss, 2002 [1954], 15).
kind of money,” as these objects could also be used as a form of currency on the Islands. The probability that these objects do not have the same significance as the “government-backed legal tender” (Zelizer 2011, 89) that we know today, with its complex history of promissory notes and other transportable symbols of wealth, is not examined in any depth by Mauss and thus perhaps his own notions of currency as a trading counterpart were transposed on the kula system. The problem of establishing equivalency remains.

Paradoxically, Mauss’s analysis of the kula exchange between inhabitants of the Trobriand Islands challenges and supports what I shall term the ‘paradise lost’ thesis: the idea that commodity and gift economies are diametrically opposed as ethical categories and that the former superseded the latter in the development of civilisation. ‘Paradise’ represents a state of grace when individuals interacted with one another in less instrumental ways without the use of money (as currency) to arbitrate exchanges. This is evident in Cheal’s (1988, 4) statement, the “tension [between market relationships and personal relationships] is not found in the simplest societies, where an institutionalized market economy does not exist”. Each economy has its characteristics which are mutually exclusive. Therefore, in the market economy, things bought and sold in commercial transactions are “not linked in any significant, personal way to the transactors: it is an alienable and impersonal property” (Carrier 1995, 11). Commodification is characterised interchangeably as a process of monetization, when such things can become exchangeable for something as anonymous as money. One example of such a transaction involves a motorcar where “the buyer and the seller are identified without any ambiguity, so that property rights can be exchanged. As for the car, it is because it is free from any ties with other objects or human agents, that it can change ownership” (Callon 1998, 18). Market transactions are also voluntary and represent the individual’s best efforts to maximise their utility (Sandel 2012).

In contrast, gift-exchange involves obligatory reciprocity between parties. Moreover, gift-exchanges are the ‘natural’ state of social relations and objects (variously defined as created objects, people or their organs), connected or attached to their local environment and social setting (Callon 1998). The ‘paradise lost’ thesis relies on the idea that impersonal relations impose unnatural expectations over ‘natural’ social relations including the misappropriation of the producer’s labour and insistence that market transactions satisfy human needs and require no regulation, particularly from the state. This view is clearly evident in Titmuss’s
analysis which he intended to act as a protecting those parts of social life which had not yet been touched by the market.

Rather than define gift-exchanges as maintaining social relations and the monetised-exchanges as undermining them, I suggest that it is more fruitful to examine the significance in maintaining these distinctions, even if it is merely a matter of rearticulating that difference. I do so by drawing on critical materiality studies that critique preconceptions of the social sciences that social world is made in reference to the material world and instead examines the relationships between objects and humans as mutually constitutive. This view acknowledges that despite the prevalence of the money economy, the notion that Western societies uniformly regard mundane objects in rational ways has been destabilised to a degree (Gibson 2010; Miller 2003; 2005). Such a model can facilitate an adequate understanding regarding the choices made about different reproductive tissues, the relationship between the donor and recipient and how this may influence the donor’s decision to circulate the tissue in a gift or commercial relationship. In other words, I proceed from the assumption that the tissue (and by extension other ‘objects’) does not have an intrinsic quality of ‘commodity’ or ‘gift’ but that its meaning is relationally constructed. In asserting that it is necessary to examine the social significance of contributing to scientific research with one’s own tissues, examining the real time effect on different social roles, I challenge claims that commodification is effectively the same process everywhere for everything. For instance, slavery in ancient and modern times illustrates that being part of the human species did not automatically entail an individual to be considered a legal ‘person’ (Kopytoff 1988).

To elaborate on my own approach, I refer to the work of contemporary anthropologist Kopytoff (1988). Kopytoff’s framework adds a dynamism to establishing the equivalence of objects and may resolve limitations evident in Mauss’s (2002 [1954]) approach to gift giving. Drawing on anthropological data concerning the Tiv society of West Africa, Kopytoff (1988) argues that the circulation of things is hierarchically organised into separate universes of exchange value. The Tiv have three such spheres: subsistence items, prestige items and rights in people. Only objects within the same sphere may be traded for others. “Spheres of exchange” are dynamic and socially situated; for example, in times of hardship, objects from one sphere do become exchangeable with objects from another. Kopytoff’s
framework can be used to examine the designation of objects-as-gifts as a sociological fact rather than something having an inherent status.

Kopytoff’s (1988) argument has two important implications for this analysis. First, people interact with and circulate things in many different ways and designations of an object to a sphere of exchange do fluctuate. Second, classifications of value often involve a negotiation between individuals and others. What is priceless to the individual may be worthless on the market and vice versa. The central point I draw from Kopytoff’s framework is that everything is potentially tradeable but only in relation to those things that are designated as belonging to the same sphere of exchange. My analysis diverges from Mauss’s (2002 [1954]) dichotomy between things that are entangled (and given) because they are vital and things that can be commercial traded because they are disentangled from their ‘natural’ social environment. Rather than reify the object given as a gift because it is given in exchange for something other than money, it is possible to consider that the decisions made by participants about reciprocity and equivalence are an issue of transforming spheres of exchange.35 Returning to Mauss’s example of kula as gift-exchange, ‘things’ such as bracelets are designated as belonging to a particular sphere of exchange, equivalent objects to necklaces, and nothing else.

Within my framework, the analysis will inevitably involve looking at the meanings of oöcytes and embryos as the basis of decisions in giving them to scientific research. I do not focus on reasons to become or not become an oöcyte donor because simply paying attention to the reasons, while insightful, tends to treat the giving of oocytes in a rather abstract sense. There is often considerable time between making the decision and fulfilling it and there are a number of smaller parts that make up the whole process, including medication, medical and psychological appointments, communication between parties and of course oöcyte extraction (Kirkman 2003; Warren and Blood 2003; Shaw 2007, 2008a).36 How donors maintain their commitment is rarely examined. Furthermore, scant reference to whether the relationship between the donor and recipient is important, tells us too little about whether the recipient...
has specific characteristics or, following Titmuss (1997 [1970]), if he or she represents the “universal stranger”, an abstract concept which relies on the universalised and inherent need of fellow citizens. In other words, can giving be instrumentally as well as altruistically motivated? Understanding the specificities of giving oöcytes for different purposes can build nuanced knowledge regarding giving tissues in contemporary society. However, given that these undertakings do not occur in a social and historical vacuum, it is now necessary to turn attention to the scientific utilisation of reproductive tissues and the questions this may pose for women.

**Altruistic fervour in South Korea**

Across the Global North, altruistic donor models have not produced sufficient supplies of fertile and mature oöcytes for SCNT research. In contrast, significant numbers of women in South Korea expressed their desire to provide their oöcytes – or did in fact do so – in a context of altruistic donation. In 2004 and 2005, prominent South Korean stem cell scientist Hwang Woo Suk published claims in the prestigious journal *Science* that he had created patient-specific ESC lines from a cloned embryo through the process of SCNT (Hong 2008). The claim was of huge significance to the scientific community, which had been “waiting” for such news. However, the claims were later retracted after South Korean investigative journalists working on the television program, *PD Su-cheop*, uncovered inconsistencies in the research (Hong 2008). In addition to this, it was revealed that the practices surrounding the procurement of oöcytes used in the research had been misrepresented. According to *PD Su-cheop*, the number of oöcytes Hwang used was actually over 2200 instead of the 250 reported and two unpaid egg donors were members of Hwang’s own staff (Hong 2008). In addition to this, 66 out of 119 women had been paid to provide oöcytes, (Gottweis and Kim 2010) although it is claimed that Hwang was not aware of this (Cho, McGee and Magnus 2006).37

The South Korean community continued to support Hwang and his research despite revelations of his fabricating evidence. A significant number of women in South Korea continued to express their desire to donate their own oöcytes for Hwang’s stem cell research

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37 Other scholars (Leem and Park 2008, 11) report different numbers: 121 women supplied Hwang’s team with 2,221 oöcytes, 85 of which were paid and two of the 36 unpaid donors were part of the research team.
efforts (Parry 2005; Kim 2008). On December 6 2005, women rallied to show their support for Hwang’s research and declared the goal of finding 1000 donors. “The “one-thousandth woman” said “I finally made a decision to donate my eggs for my sister who suffered from leukemia. I hope many people participate in egg donations because it will help to save other people’s lives” (Yonhap News, 6 December 2006)” (Leem and Park 2008, 21). Moreover, public opinion continued to show support for Hwang, his research and procurement methods. Kim (2008, 40) reports that the monthly science magazine aimed at popular audiences Donga Science surveyed Koreans in an internet-based poll in November 2005, specifically asking questions related to their perceptions about the relationships between senior and junior scientists in Hwang’s team; 72% of respondents answered that the junior scientists had voluntarily provided their oocytes.

Initial efforts at analysing this unique situation emphasised the ethical failure of the regulatory environment (see Cho, McGee and Magnus 2006; Saunders and Savulescu 2008) or problems posed by an over-zealous state keen for the development of biotechnology. For instance, prior to his downfall, Hwang embodied the state’s ambitions to situate South Korea as a leader in regenerative medicine and was given considerable financial means to conduct his research (Hong 2008; Kim 2008). However, Leem and Park (2008, 18) argue that connecting South Korean nationalism with emergent biotechnology industries does not adequately address the gendered dimensions of the country’s “unique donation culture”. They develop a feminist analysis showing that many women who expressed a desire to donate their oöcytes to Hwang’s research regarded their decision as “natural” as being indicative of the paradoxical place of women in patriarchal South Korean culture; women and their bodies are both highly visible and invisible. This ambiguous situation is due to traditional expectations about women’s roles as mothers and developments in biomedical technology that are utilised to enhance women’s physical appearance and attain this role (reproductive medicine and cosmetic surgery).

According to Leem and Park (2008) motherhood is still the most privileged social role for women and the utilisation of reproductive medicine is attributed to the continuing primacy of the nuclear family. Fertility treatment is reported to be very common among married women.

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38 The authors cite this quote from a newspaper article dated 2006, however the article itself was dated 2005 and this earlier date corresponds with events in South Korea reported by Gottweis and Kim (2010).
after one year of marriage. However, since its emergence in the 1980s, the reproductive medicine industry has not been subject to much regulation because it was considered to belong to the private realm of the family. Similarly, the visibility of women’s bodies has also been evident in cosmetic surgery, which is another common practice among women. Through the augmentation of their physical features, women become “better commodities” (Leem and Park 2008, 20) in the marriage marketplace. Together, these technologies facilitate the fragmentation of women’s bodies into individual parts: oöcytes, breasts, nose, mouth/lips. SCNT research emerged within this culture and exploited the objectified status of women’s bodies.

Leem and Park’s analysis interprets the scientific utilisation of women’s reproductive tissues as based on and continuing of unequal power relations with a narrow focus on their reproductive capacity and the normative context in which it occurs, the family. Here, medical and scientific institutions constitute a powerful claim on women’s bodies. In such a paradigm, women’s desires to give their oöcytes are aligned with mechanical and alienating views of their body, discourses produced in the context of medical knowledge (Martin 1988). As the following discussion will show, women’s reproductive capacity and technology innovations in this field are an important area in feminist scholarship regarding women’s subjectivity. Situating Leem and Park’s analysis in this scholarship will assist in fully appreciating the assumptions which underpin feminist discussions of scientific utilisation of reproductive tissues in contemporary society.

**Feminist approaches to reproduction**

A hallmark of feminist social policies in the 20th century has been the establishment of women’s rights to decide if and when they bear children. 39 Medical technologies used to inhibit conception or pregnancy are still areas of contestation between politicians, women’s groups and religious conservatives in countries such as the US and Australia. That medical technology does not just inhibit conception but seeks to produce it, is more politically fertile ground for feminist scholarship. Reproduction occupies a deeply ambivalent space within feminist scholarly paradigms, as the literature has historically examined the connections

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39 Whether these are distinctly “political”, “social” or “civil” rights is complex; women’s rights can be expressed in laws which decriminalise abortion but that also provide access to contraceptive devices.
between ideals of femininity and practices of reproduction and has highlighted “motherhood” as a central feature of femininity. Constructions of womanhood involved not just the onus to be fertile and carry a child through pregnancy but to become the primary caregiver, making motherhood the only legitimate role for some women in society.40

Women’s reproductive capacity has been overlaid with negative connotations in both religious and secular Western traditions. In contrast to “male” spheres of life like production and labour, which are imbued with intention and consciousness, reproduction is seen as natural and unconscious. This rather negative view of reproduction was evident in feminist work that emerged in 1960s and 70s where women’s reproductive capacity was seen as a fundamental obstacle to achieving the full subjectivity enjoyed by men (Evans 1998). Largely derived from the analysis found in de Beauvoir’s The Second Sex (2010 [1949]), women’s reproductive capacity severely limits their capacity for active life projects. Political subjectivity required “freedom” from destiny and for women this meant that their reproductive roles had to be inhibited entirely or managed carefully to facilitate their ability to pursue their life projects (Evans 1998). Practically, this meant more freedom to manage fertility through contraception and abortion and the choice between a public role (a career) over the private one (motherhood). Given its reliance on a repressive power/subject model,41 these approaches inverted the value of such roles and women who continued to “choose” motherhood were assumed to be blindly adhering to traditional views of femininity and lacking conscious autonomy.

40 This caveat is necessary because while motherhood is probably an essential part of any traditional view of women, it is only within certain economic and racial categories that it became the role to the detriment of other possibilities. Poor black and white women have seldom had the opportunity to be full time mothers and indeed are often the targets of imposed fertility control (Takeshita 2012). This claim corresponds with that made by Pollack (2003), based on her research into reproductive oocyte provision in Massachusetts. Reporting on her own participant observation as an oocyte provider and in depth interviews with others, Pollack argues that oocyte donor recruitment agencies and fertility clinics construct the recipient woman as normatively feminine because she desires a family. In contrast, the oocyte provider’s selling of motherhood is effaced by the manufacture of “donor” altruism narratives by egg broking agencies. It should be noted as well that this study operationalised its aim to understand the practice of oocyte provision by narrowly focusing on the decision to be a provider while simultaneously discounting these as conforming to conventional femininity.

41 This term broadly refers to theories of power relations between individuals, others in the community or to the state. In opposition to liberal theories, including Marxism and liberal feminism, the philosopher Michel Foucault (2008 [1976]) argued that power is generative rather than repressive and that it functions by enabling behaviour rather than suppressing it. Individuals actually behave in relation to norms, not through force but through occupying subject positions where power operates by inciting desires and fulfilling real needs (Foucault 2008 [1976]; Sawicki 1991). Foucault’s model challenges the dichotomy between intentional agency and false consciousness where it is assumed that the status and behaviour of those considered powerless is a result of their conditioning and therefore freedom or truth exists outside the dominant discourse of the “powerful” (Foucault 2008 [1976]).
The American writer, Shulamith Firestone (1971) pursued a similar idea by arguing that the subordination of women as mothers was a natural extension of the biological process of gestation. In order to counter this, science and technology should be harnessed to remove the onus on women’s bodies to carry children. If neither sex had a monopoly on the bearing of children, the sexual division of labour would be fundamentally challenged and society could start from scratch in terms of gender roles (Firestone 1971). Clearly, both de Beauvoir and Firestone read reproduction and motherhood in one way with little appreciation of the experiences and subjectivities involved in its process; in effect, they rearticulated the Western tradition of negating “feminine” experiences and the body (Evans 1998). What is interesting about Firestone’s (1971) argument is that she viewed science and technology as liberating women from their social oppression, a view from which some feminist-oriented scholars discussing oöcyte provision to SCNT research such as George (2008) and Baylis (2009), diverge.

Both de Beauvoir (2010 [1949]) and Firestone (1971) were discussing traditional models of reproduction, centered on heterosexual intercourse before the development of ARTs as discussed in chapter two, which significantly changed the terrain of the debate. Novel questions emerged once medical technology sought to rationalise and manage conception. Feminist reactions to these new developments, while complex, were often non-celebratory despite Firestone’s utopian vision of rationalised reproduction. Perhaps due to the transforming perceptions of technoscience, some feminist scholarship examining ARTs tended to carry the weight of multiple strategies; they would encourage roles for women beyond motherhood while validating experiences of motherhood and they would explore the potential for specific feminine subjectivity while being critical of increasing medicalised management of female reproductive capacity.

The complexity of giving due consideration to the subjectivities engaged without losing sight of the inequitable social relations between men and women, patients (often female) and doctors (often male) and donors and recipients is evident in Corea’s The Mother Machine (1985) an example of critical approaches to ARTs. The book is centered on the idea that “the once unified biological processes of motherhood [being made] into separate functions [was] a dangerous degradation of motherhood” (cited in Sawicki 1991, 72). Women were being
dominated by [male] medical institutions who were appropriating the only space available for female subjectivity. While de Beauvoir (2010[1949]), Firestone (1971) and Corea (1985) saw the links between reproduction and politics very differently, they converged when discussing the roles of women involved. Women who desired motherhood to the extent of engaging in modern reproductive medicine did so at significant cost to their own freedom by continuing to adhere to patriarchal social expectations despite the space opened to them by feminist thought.

A shift has since occurred in feminist approaches to ARTs which counter Corea’s (1985) critical analysis. Employing a foucauldian framework, Sawicki (1991), asserted that the use of ARTs was likely to be enabling as well as limiting; by providing new ways of conceiving, new forms of motherhood and female subjectivity are engendered. For Sawicki (1991), despite the fact that women’s marginalisation from mainstream society has historically been based on their reproductive capacity, women who utilise medical science to become mothers are not necessarily naive or passive subjects of patriarchal control. An ethnography of ART clinics in the US in the 1990s also questioned rigid assumptions about human beings dominated by technology or women dominated by male medical authorities (Thompson 2005). As individuals become ART patients, they exhibit a particular agency which allows them to be subjected to ART specific treatment decisions and choices. Thompson (2005, 191) introduced the term ontological choreography to conceptualise the process by which patients “willingly accept the role of being the object of the medical gaze and in fact actively participate in it”. From this study, Thompson extrapolated about women’s experiences of ARTs and challenges distopiain views that reproductive technologies inevitably involve women’s objectification and commodification.

While it is clear that there has to some degree been a shift regarding the relationships between women and science in other fields of feminist inquiry, debates regarding oöcyte provision to SCNT research in particular tend to rearticulate views that science is an external imposition on women’s freedom by reproducing or exploiting unequal power relations (Martin 1988). The emphasis on autonomy evokes a virtually pre-social conception of individuals whose rights and obligations simply exist without reference to time and space. Women’s contributions to stem cell research cannot simply be examined by arguing whether they have an inalienable right to choose whether they provide their oöcytes (they do) but
understood as a practice which uses their reproductive capacities in novel ways while at the same time constituting that reproductive capacity in distinct ways. One way to discuss the utilisation of medical and scientific technologies is through the concept of risk. The risky nature of ovarian stimulation and oocyte extraction, in the context of SCNT research, where the provider does not expect to receive direct benefit from the process, is a major issue for both advocates and critics of a payment system.

Examining the assumptions about the physical side effects of oocyte extraction may help to illuminate the meanings that are shared in common amongst commentators in the field, particularly in relation to femininity and risk taking. Scholars such as Thompson (2007), Ballantyne and de Lacey (2008), Dickenson and Alkorta Idiakze (2008). Skene (2009) and Widdows (2009) take risk to be fixed and universal and advocate for risk minimisation or avoidance. For instance, if any risks of oocyte extraction exist, they can be mitigated by minimising the number of times an individual may undertake the process, providing post-extraction health care or monitoring each individual woman for long term health effects (Isasi and Knoppers 2007; Thompson 2007; Skene 2009). More “critical” commentators such as Widdows (2009), Dickenson and Alkorta Idiakze (2008) and George (2008) assert that oocyte provision for SCNT research should not occur under any of the current circumstances because the risks are likely to outweigh any potential personal benefit.

By constructing practices of tissue provision as a process of calculating risks and benefits, the parameters of the debate remain aligned to a positivist rendering of risk. That is individuals who undertake risk analysis and avoid risk are actually embodying modern constructions of the “rational” subject. Within a modernist framework, risk needs to be managed by projecting into the future and ascertaining what the present self might do to mitigate potential risks to the imagined ideal outcome (Giddens 1991). Social scientific approaches to risk unsettle this simplicity; risk is socially constructed rather than a neutral or natural category and thus reveals the boundaries, anxieties and values of a social order (Douglas and Wildavsky 1982). Examining risk in this way is itself a critical approach to social relations. For a number of scholars, the social construction of risk marks the shift from a traditional social order to a modern one. As Scott and Freeman (1995, 151) argue, risk management, particularly in relation to health, is a specifically modern preoccupation:
Risk is a relatively modern concept, to the extent that it is a product of a particular set of understandings of free will and decision-making as well as the result of an increasingly manipulated environment.

The relationship between gender and risk is a significant one but also requires elaboration in relation to age. Constructions of masculinity and femininity inherently involve a relationship between the individual and the external world and how he or she should negotiate unwanted events and risks. While young people in general are considered to take more risks and are “risky” in comparison to older people (Mitchell, Bunton and Green 2004), young masculinity is centered around the taking of risks while young women are “routinely warned to guard against risk, to keep themselves safe and to be cautious of strangers” (Green 2004, 57). However, the way people understand risk varies and research by Bunton, Crawshaw and Green (2004) has found that there are not always significant gender differences in taking risks but in the feelings associated with them.

Orthodox feminist views do not interrogate the idea that normative notions of femininity, particularly in relation to women’s reproductive capacities, regard that the best approach to risk is its minimisation or avoidance. By assuming that the only relationship between the rational subject and risk is one of minimisation, it does not acknowledge that definitions of risk are dynamic, contextual and whether “risky” actions can be rationalised within a specific narrative, such as gift giving. This is not to suggest that women undergoing ovarian stimulation and oöcyte extraction for research purposes should be uninformed about the procedure but rather, to point out that such an emphasis implicitly implies that risk is a fixed concept and that physical or emotional side effects of ovarian stimulation, in the short and long term, are risks which are themselves socially constructed. I suggest that understanding how and why women are motivated to undertake oöcyte extraction, particularly for another person, should be located within a context that admits risk is contextual and thus women do not necessarily need to avoid risk to be “rational” because this actually adheres to more conventional constructions of femininity.

Science in society
I have so far situated feminist-oriented interpretations of the scientific utilisation of reproductive tissues within a broader undertaking of feminist scholarship regarding women’s subjectivity and reproduction. Hopefully, this is an indication of the direction in which this theoretical framework is moving. I argue that it is important to be critical of assuming that the scientific utilisation of women’s tissues is reflective of women’s alienated experience wrought by powerful medical and scientific discourse (Martin 1988; Dickenson 2006; Leem and Park 2008; Waldby and Cooper 2010). These discourses and the institutions that produce them change as do meanings of freedom. In order to develop my own framework for analysis, it is necessary to sketch a more complex view of science as an institution than currently exists within the “tissue economies” literature. This involves a recognition that science is not an autonomous or monolithic entity and that is has significant power together with and separate from the state. I will attempt to capture the fact that science is not a static social institution but has been subject to major changes. These changes are diverse and at times paradoxical but ultimately they necessitate understanding that ‘science’ does not simply impose an external set of burdens on women from which they must be liberated.

Science is a distinct form of human conduct, subject to specific rules and its momentum is modeled on democratic collective endeavour. Unlike traditional social relations built on ‘natural’ hierarchies and where knowledge is embodied in a wise individual, is divinely bestowed or inherited, the scientific model of knowledge relies on the idea that it is transparent and can be transmitted between individuals with effort (Ezrahi 2004). There are also symbolic aspects that ‘science’ embodies the democratic spirit of modernity, distinct from the old claims of feudal and religious authority to which individuals had to submit, and thus the production of scientific knowledge is characterised as value-free (Smith Keller 1992).

As a social institution, science is a practical process by which to 'discover' the world and an integral ethos of modern Western society (Harvey 2007). However, its pre-eminent position as the default explanation of phenomena (Irwin and Michael 2003) has been increasingly destabilised in the post WWII period. These transformations shaping scientific conduct in the last part of the 20th century can be considered as an effect of science itself. According to Beck’s (1992) Risk Society thesis, science is no longer the unequivocal bearer of progress but “manufactures” risk too, ultimately undermining its own narrative that it can simply
remove or resolve humanity’s problems. “Manufactured” risks include the development of nuclear weapons or pollution from industrialised production and produce their own unintended consequences. For Lyotard (2001 [1984]) an erosion of trust in scientific narratives is emblematic of the postmodern condition. Lay people and other emergent experts such as feminists increasingly contest the truth claims made by scientists (usually those working within the natural sciences).

Scientific research has also been subject to more scrutiny in the second half of the 20th century despite the fact there have been many examples that it has progressed through unscrupulous means long before. The increasingly ambiguous epistemological position of science has unfolded in parallel with, or perhaps in reaction to, rationalising the conduct of scientific research. The earliest example is the Nuremburg Code of 1947 that emerged in light of Nazi atrocities. Other protocols include the Declaration of Helsinki (1964) and The Belmont Report (1975). These documents stipulated that, at the very least, scientific researchers should recruit their subjects and/or contributors only if they had been informed correctly and consented (Campbell, Gillet and Jones 2005).

From a Weberian (1948) perspective, efforts to counter these tendencies by governments, scholars and professional bodies, such as the World Medical Association, are indicative of a process of rationalisation that have transformed other areas of social and economic conduct in the modern period in similar ways. Rationalisation is “orientated exclusively toward the efficient maximization of practical goals” and involves the institution of universal norms over a certain field in order to become more economically efficient (Scaff 1998, 38). Ethical rationalisation may appear to be paradoxical given that ethics are the opposite of

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42 For example, as medical research became more competitive, medical scientists in 19th century Britain often paid grave-robbers to supply corpses (Lock 2001). Throughout the 20th century, questionable methods continued to be used under the auspices of national governments. Well-known examples are Nazi research experiments in which captured Jewish, homosexual and mentally-challenged individuals were subjected to extreme experiments (Rhodes 2010). Other state-sanctioned regimes, besides the Nazis, oversaw experiments and procedures which amounted to abuse and the violation of human rights as we know them today. Prisoners were often enrolled in phase-one clinical trials (Ballantyne and de Lacey 2008). During the 1980s, women in New Zealand were subject to the “unfortunate experiment”, in which treatment for ovarian cancer was withheld from patients (Campbell, Gillet and Jones 2005). More recently, it was revealed that researchers at a UK hospital had removed and stored the organs from the bodies of deceased children for future use in scientific research without the knowledge of their parents (Waldby and Mitchell 2006).
instrumental concerns but the ethical and economic rationalisation\textsuperscript{43} of scientific research have occurred in parallel with each other. These developments have generated new forms of ‘experts’ who act as intermediaries between the ‘scientists’ and the ‘public’. On the one hand, these new experts may assist in destabilising the autonomy of scientific conduct by subjecting it to the scrutiny of social and ethical norms but on the other hand maintain its privileged status by allaying the public’s concerns that scientists work within a regulated environment.

\textbf{“Houston, we do not have a problem”: politics and the conduct of scientific research}

Developments in broader social and political milieu have also contributed to destabilising the transcendent position of science in recent decades. I have already referred to feminist analyses of scientific and medical discourses that interpret them within the context of questions related to autonomy. In these paradigms, science stands accused of being partisan rather than neutral arbitrator among members of the community and the ‘public good’ of scientific research is challenged on the basis that rather than being an objective and neutral process, it is constituted by and helps to reproduce social inequalities. One issue in particular, prior to the emergence of stem cell research, is likely to have had an implicit – but strong – influence on the latter’s legislative and regulatory trajectory as well as its constructions by predominantly feminist scholars. I refer to the Human Genome Diversity Project (HGDP), which involved a number of genetic scientists in the 1990s proposing to collect tissue samples from people around the world “with a view of creating a database for the benefit of the scientific community” (Lock 2001, 78). The ostensibly benign endeavour to create a database of genetic material obtained through blood or saliva samples “to anchor understandings of human evolution” (Reddy 2007, 430) encountered strong resistance by some groups from which scientists sought samples. Members of indigenous groups around the world expressed concern about scientists’ lack of consultation and cultural insensitivity (Lock 2001). Some activists went further and interpreted the assumption of their involvement as evidence of their continually marginalised political status. For these groups, the HGDP was part of a long history of colonial dispossession and occupation. Scientific research that had accumulated and stored human tissue from indigenous people was another

\textsuperscript{43} Dickenson (2007), Waldby and Cooper (2010) and Baylis (2009) may refer to this more critically as commercialisation of scientific research.
means by which the oppression of indigenous peoples was achieved. This history involved but is not limited to the illegal or false removal of indigenous bodies and property as well as the development of scientific knowledge about racial hierarchies, which contributed further to their oppression (Lock 2001).

In the responses by indigenous people to the HGDP we see parallels with Leem and Park’s (2008) analysis of South Korea’s “donation culture”. The HGDP controversy was a powerful event that destabilised yet again the narrative of scientific research as a “public good” - universally applicable and beneficial. Importantly, the responses emerged from communities rather than experts. In light of the HGDP, more attention has since been paid to the social significance of scientific research as policy makers have sought to redress some of these issues by engaging with communities beyond the “deficit model”; that is, by taking their potential concerns, opposition or apathy seriously (Hoeyer 2006b). This development shows that the autonomy presumed by scientists is increasingly subject to questions that go beyond its epistemological merit, and indicates that to maintain its legitimacy science changes its relationship with its constituents.

These issues are evident in the experience of Reddy (2007), who was engaged in a mediatory capacity in a scientific project seeking blood/DNA samples from an Indian Gujarati community in Houston, Texas. In the wake of the HGDP controversy, policy makers and scientists expected to find similarly hostile views from the community. However, Reddy found that the project occurred in a straightforward and relatively non-confrontational manner. He encountered little hostility but much enthusiasm from blood/DNA sample providers regarding the claims of “public good” by researchers. In his account, Reddy refers to the dissonance between the expectations of researchers and policy makers regarding the community and the actual attitudes of the community. He reports that his researcher colleagues even queried “Why [he was telling them] all about what you have not found in Houston?” (2007, 455).

The extent to which similar concerns of exploitation and oppression characterise all novel scientific research cannot be assumed. Taken together, the development of new scientific

44 Public good may be used interchangeably with the term ‘common good’.
research methods, the changing status of science and scientists including more ethical and social oversight and a skepticism from other ‘experts’, science cannot easily be understood as a monolithic entity which exercises domination over women. Tilting the axis in the opposite direction and problematising all research as constituted by, and reproducing, unequal power relations is actually based on the same proposition that led to the HGDP controversy in the first place – that the scientific utilisation of tissues has the same meaning for all individuals or communities regardless of time and space (Irwin and Michael 2003).

By emphasising individual rights, current frameworks analysing oocyte provision to SCNT research perpetuate monolithic conceptions of ‘science’ and ‘the public’. According to Dixon-Woods et al. (2008, 72) this often reduces the complexity of the inter-subjective process within which people make sense of tissue provision and neglect the potential for “diverse ‘publics’ and ‘sciences’ [to] come together to form highly distinctive hybrid social worlds with their own norms, practices and logics”.

Given such complexity, the question of contributing one’s own tissue to scientific research cannot be exclusively examined by assessing whether the individual is participating in an autonomous and voluntary manner but by asking what scientific research can represent in an individual and collective sense. For instance, the lack of donated oocytes in the Global North clearly indicates an antipathy on the part of women but does not to explain the rates of embryo donation. We have not witnessed a similar assembly of women concerned about the scientific utilisation of their reproductive tissues; it has so far remained the concern of scholars. These factors indicate that the lack of donated oocytes is unlikely to be based on a view that the scientific utilisation of women’s reproductive tissue exploits women’s property or expectations of altruism. Clearly, women have specific relationships to scientific research and a discussion of their contributions must situate practices of giving within women’s experiences and social roles. Therefore, understanding broader narratives in which individuals may refer to scientific knowledge production is an important step to developing frameworks that can accommodate the scientific utilisation of tissues which are associated to a large degree with women’s social roles. This proceeds from understanding science as a dynamic institution, increasingly entrenched in complex economic, political and social bonds and thus is not a clearly delineated institution that can simply reproduce social inequality.
The Scientific Utilisation Of Reproductive Tissues as a “Public Good”: Individuals, Collectives and the ‘Ideal’ Donor.

I have already discussed feminist approaches to the scientific utilisation of reproductive tissues as being based on unequal social relations where science is characterised as a static institution which invariably hinders women’s autonomy. Yet this discussion perpetuates an emphasis on the individual as separate from their social milieu rather than being constituted by it. Here, questions regarding the exercise of freedom and rationality are posed at an individual level. However, it is necessary to develop another dimension of the framework regarding normative political behaviour – what should happen when individuals become a collective. Managing the ethical dimensions of science may be considered political theory in a different guise because it is prompts people in society to consider the “good” and how science fits into these questions. The ‘public good’ is a social construct and provokes discussion regarding the values, if any, that should ‘society’ affirm. In this section I develop a critique of the assumptions that are inherent in both Titmuss’s views on altruistic blood provision and current debates about oöcyte provision to SCNT research by asserting that political behaviour does not have to embrace the general and the abstract but that the specific and “passionate” are important considerations.

The ‘public good’ prompts reflection about the aim of political association, relationships which are usually contrasted with intimate relations based on kinship, as well as whether the “public good” is natural or the result of values being imposed by others whose interests have little public spirit. According to Frazer and Lacey (1993) and Yeatman (1994), the liberal tradition of political thought has a less than well-developed conception of the ‘public good’ because it is contrary to its chief principle regarding the moral authority of the individual and their liberty to exercise choices to achieve their happiness. Liberal premises regarding the importance of individual liberty might be averse to a view of the ‘public good’, which presumes a consensus about moral values, because the latter can be used to override an individual’s view of the good. The state should be a neutral mechanism between individuals and avoid imposing any of its own values on the citizenry (Frazer and Lacey 1993).

Titmuss’s (1997 [1970]) discussion of therapeutic blood provision clearly shows that he intended to formulate a comprehensive and explicit statement regarding the achievement of
the ‘public good’. The contest of interests between the individual, the collective and the role of the state is addressed by Titmuss who believed that a market mechanism or any commercialisation of blood provision would undermine the positive properties of transfusing blood. Titmuss’s defence of altruistic blood donation as the ‘right to give’ is complex because he invoked the model of the social contract. By doing so, he suggested that the social contract is dynamic and changes over time. This constituted a novel way of challenging the narrow focus of neoliberal thought, which increasingly threatened “positive” notions of liberty with its emphasis on “negative” ones. Berlin's (1969) distinction between the negative and positive dimensions of liberty is implicit in Titmuss’s work. Negative freedom is the absence of interference from engaging – or coercion to engage – in activities, and is aptly expressed in the libertarian view of liberty. In contrast, positive freedom is the ability to be “the instrument” of oneself and is a fuller expression of autonomy (1969, 131).

Titmuss (1997 [1970]) did not argue that individuals could be obliged to give blood, however, if they are likely to do so, it should be done under the auspices of the altruistic-donor model. The gift of blood was mutually constitutive of social relations: it would help to generate and reinforce fellow feeling between citizens (Waldby and Mitchell 2006). There were, however, individuals within the citizenry whose ability for altruism was compromised by their economic or social status and “to choose always their own freedom” should not take precedence over the therapeutic objective of blood transfusion (Titmuss 1997 [1970], 310). Because of this policy, blood donation in Britain and the US at that time was as much a question of exclusion as it was of inclusion. In the contest between individual rights and achieving a “public good”, Titmuss consistently argued that individuals whose personal interests could pose a threat to the “public good” needed to be excluded from giving blood.

Comparing approaches to the public good through oocytes and blood: problems of ‘technicity’

It is important to address the appropriateness of comparing oocyte provision for SCNT research and Titmuss’s views on blood donation. It may be argued that the basis for comparison is tenuous given that the biological properties and the technology involved in the extraction of each tissue is so different. Indeed, a comparison will show live organ transplant is much closer to the topic of oocyte provision. However, my analysis indicates that even
with biological and technological similarities between oocyte and live organ extraction, blood donation remains paradigmatic. It is my intention to argue that ethics councils and legislators do not doggedly adhere to Titmuss’s altruistic-donor model because they inadequately perceive the biological and technical features of the procedure but on the basis of the social relations the model was designed to promote.

Biological factors are intertwined with technical ones as a matter of *technicity*; that is, “the intersection of the material qualities of tissues – their location and function in the body; their durability, their immunological specificity – with the kinds of technology available to procure, potentiate, store, and distribute them” (Waldby and Mitchell 2006, 32). By looking at their material qualities, oocytes differ from blood in several ways: firstly, they are reproductive tissues, secondly, they do not regenerate. Thirdly, it is not possible to refer to the provision of oocytes for reproductive purposes as a transplant/transfusion per se: if transferred between one woman and another, the recipient woman does not ‘absorb’ the genetic problems contained in the oocyte’s DNA (the child might). Neither will this occur if using the oocyte to grow a stem cell line because the donor’s DNA is removed. Fourth, while oocytes and ovarian tissue can be frozen in advance of medical treatments such as chemotherapy, oocytes are generally not banked (for personal or research purposes) because their quality deteriorates by the hour (Braun and Schultz 2012). Cryopreserved oocytes (even if they are frozen within the first hour) do not have the same quality as ‘fresh’ ones. Finally, the technology used for oocyte extraction involves prolonged medication, surgery and perhaps prolonged recovery. In contrast, blood donors do not need to significantly prepare for the process (as will be discussed, being a blood donor is *enabled* by a healthy lifestyle). Blood provision as discussed by Titmuss is a therapeutic practice and can pose a threat of physical harm to the recipient. This is because blood is a biological substance that can become infected. Technologically during Titmuss’s time and now, the potential to cleanse infected blood is limited.

As discussed in chapter three, Skene (2009), Ballantyne and de Lacey (2008) and Thompson (2007) and the Nuffield Council of Bioethics (2011) advocate for the payment of women for

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45 Currently, the recipient would be the researcher(s). However, if a stem cell line was created from a cloned embryo and the ensuing patient-specific tissue was implanted into the patient, this person would be referred to as a recipient.
their oocyte provision to SCNT research based partially on the difficulty of the technological process. As outlined above, it is not difficult to dispute Titmuss’s altruistic-donor model on the basis of ‘technicity’ – no one can seriously suggest that the provision of oocyte is analogous to blood in biological and technological terms. But to retreat here and indeed treat the issue of oocyte provision for SCNT research simply as a question of ‘technicity’ is to miss fundamentally important and even interesting questions about the intersection between ‘technicity’ and social relations. It is here that I compare the implications of Titmuss’s ambivalent legacy with the ethical and political assumptions of oocyte provision to SCNT research.

For Titmuss, achieving the ‘public good’ had three interconnected physical (biological and technological) and symbolic dimensions. Firstly, the blood supply had to remain free from physical pollution by excluding ‘bad blood’. The connection between blood borne diseases and social deprivation and economic poverty is often self-evident and there is overwhelming evidence connecting poverty with vulnerability to disease and lack of resources to alleviate them. No doubt, Titmuss was both pragmatic and idealistic in maintaining a certain purity in the blood supply. Indeed, in the 1980s, the blood supply of Britain was contaminated because plasma obtained from paid vendors in other countries was imported (Waldby and Mitchell 2006). Secondly, a clean blood supply meant the “public good” had been cleansed of private interests. For Titmuss, because blood vendors were putting their own interests ahead of the recipients, individuals with limited economic and social integration into society could symbolically pollute the ‘public good’. Finally, paying people to provide blood transformed the process into transaction and undermined the social relationship between individuals by allowing the unfettered satisfaction of one’s own needs. In contrast, blood as a free gift invoked the individual who could discern the humanity of his or her fellow citizens, whose giving was not based on expectations of reciprocity and thus a sense of being interested in the gift or its return.

Titmuss drew on deep-seated values related to the division of ‘public’ and ‘private’ in social life. Private interests are a threat to the common good and need to be excluded as much as possible for the health of all by removing the inducement from the poor – money.

The literature related to blood provision in Australia and globally is vast. Given the scope of this thesis, the details given here are limited. I do not mean to suggest that there are no current problems in relation to it.
Ultimately, maintaining the traditional conflation between poverty and physical pollution and money, self-interest and symbolic pollution proved disastrous for blood donor systems in the 1980s with the emergence of new viruses, particularly the human immunodeficiency virus (HIV) and its association with more diverse parts of the population. For instance, in France, blood donors were venerated to such a degree that the risk of offending altruistic people contributed to the prevention or delay in implementing recommendations to verbally screen donors (Rabinow 1999). Titmuss himself, exhibited a similar sense of reverence for donors by conflating the symbolic (altruism) with physical purity (good health) and thus neglecting the fact that those who are altruistic can also have ‘bad blood’ and represent a risk to their recipients (Waldby and Mitchell 2006). Ultimately, it is evident that all bodies – not just those of the poor – are vulnerable to disease. More precisely, conflating poverty with moral ‘weakness’, that is being ‘selfish’, is logically tenuous, if not elitist.

With the benefit of hindsight, I cannot definitively claim what Titmuss would have made about the scientific utilisation of oocytes for stem cell research but I suspect he would support oocyte donation for three reasons. Firstly, his support for blood donation was based on the idea that certain things or processes should remain outside market exchange and that all human tissues should only be given. Secondly, there is some suggestion in The Gift Relationship that the same “right to give” upon which he based his argument for blood donation is akin to contributing to scientific research (although there is no discussion of what should happen if that research becomes commercialised). Thirdly, I think he would have adhered to his opposition that the individual has an inherent “right to sell”, especially if that right poses a danger to others. Titmuss may have suggested that there is a symbolic threat rather than a therapeutic one if oocyte provision was conducted as a commercial transaction.

Just as Titmuss (1997 [1970]) positioned blood provision within broader social relations, contemporary scholars debating oocyte provision to SCNT research do the same in two ways. Firstly, by contemplating a non-altruistic donor model, they imagine social relations in distinct ways. Secondly, they offer a different picture of the ‘public good’: they invert the premise of social relations on which it is based, dismissing the “right to give” and insisting that the rights of the woman-as-individual should take precedence over the collective. As

47 The effects of these new viruses as a result of social expectations regarding donors are not the responsibility of Titmuss.
previously intimated, the “political” implications of oöcyte provision relate to women’s social, economic and political status in society. The two economic models of tissue provision provoke questions about how the reproductive capacity of women is utilised in, or by, the ‘public sphere’. Whether scholars in the contemporary debate agree about instituting a market mechanism, they are held in common by a belief that in this context, the presence or absence of payment will affect the individual rather than the collective (Baylis and McLeod 2007; Dickenson 2007; Ballantyne and de Lacey 2008; George 2008; Skene 2009; Thompson 2009). The emphasis on individual rights and interests is partially due to the liberal understanding of the self and community that feminism has derived (Strathern 1988) and the classic liberal antagonism between the self and the state, in which the latter assumes too much power and subjects the individual to expectations that are not in her best interest (although in many feminist campaigns, the state is used as a means of ensuring women’s interests) (Cornwall and Molyneux 2008). Oöcyte provision for research purposes tend to focus on the effects to the donor and ask, is a woman doing something in her own best interest? The question of the “public good” is neglected because the individual’s own moral authority should be the basis for any decision to participate.

Introducing payment models in order for women to be motivated to provide oöcytes to SCNT research is not only reflective of a shift away from Titmuss paradigmatic model, but the relationship between the individual and the collective. The payment-for-oocytes model emphasises the vulnerability of the female individual and the potential exploitation and oppression paying her for oocytes may create or exacerbate. As noted in the earlier discussion regarding vulnerability, feminist-inspired views are predicated on a model of socialisation that presumes women’s integration into society is largely dependent on their embodying docile femininity in which their roles are defined in relation to men; for example women are not able to exercise their natural authority as moral beings because they are subject to expectations to conform to altruistic behaviour. The scientific utilisation of women’s reproductive tissues is an extension of these unequal power relations and thus

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48 This view is intimately connected to ideas regarding women’s reproductive capacity and its implications for their subjectivity as discussed in chapter three.

49 Although there are some references to economic and racial or ethnic divisions between women (Dickenson and Alkorta Idiakez 2008), attention remains on the abstract notion of the individual woman—the central figure in “mainstream” bioethics—and her relationship to the state and/or society.

50 This is distinct from arguing that feminism is a homogeneous monolith; I do acknowledge that there are many feminisms.
likely to be exploitative of women because women’s reproductive capacity is used as a basis of male power or capital accumulation. Although not explicitly referenced, Titmuss’s concept of the “right to give” is critiqued for its lack of attention to power relations and that women may be obliged to be self-sacrificing and other-oriented. In line with other contemporary debates regarding the payment of scientific research subjects, guinea pigging (Elliott 2008) and vulnerability, the focus has shifted to a more “sympathetic” one towards potentially exploitable individuals. This is clearly evident in the figures considered the most problematic providers of oöcytes to SCNT research in the current altruistic model: women who may give their oöcytes in order to help someone they know with a condition such as Parkinson’s Disease, diabetes or MND, or those who would exchange their oöcytes for reduced cost fertility treatment (Thompson 2007; George 2008). Giving oöcytes under these conditions does not constitute free and autonomous participation in scientific research because the woman is likely to be acting from pressure (subtle or overt); in other words, by directing one’s effort to a specific benefit or beneficiary, the act is concrete and passionate, rather than abstract and rational.

Differences between Titmuss’s approach to blood provision and contemporary debates regarding oöcyte provision to SCNT research are ultimately cosmetic. Despite the differences regarding the appropriateness of paying people, there is a similarity in the ideal donor or contributor in each context. This is the disinterested person who gives or contributes to an undifferentiated recipient and reaps benefits that are impersonal. This is more easily understood in the context of Titmuss’s blood donor: with the free gift, the donor exists outside cycles of reciprocity because the individual gives without expectation of a return. In the anonymous arrangement for which Titmuss argued, the recipient is undifferentiated, generalised and abstract: their need is not evaluated according to social status but their medical need. The donor gives without a specific beneficiary.51 In the context of oöcyte provision to SCNT research, ‘good eggs’ are women who provide their good eggs to SCNT research within the context of an abstract relationship between themselves, scientists and the accumulation of scientific knowledge. Remarkably, payment in this context serves as a means to exclude women who might give their oöcytes in an interested way: to obtain cheaper fertility treatment for themselves or to advance scientific research

51 Reference to specificity relates to the recipient’s personal or moral character rather than blood type.
which may help a specific beneficiary (Thompson 2007; Ballantyne and de Lacey 2008). For instance, Thompson (2007) argues that only monetary payment will attract the ‘healthy donor’. With sufficient numbers of ‘healthy donors’, women who have, or know someone who has, a disease that may be cured by SCNT research are likely to be relieved of pressure to provide their oocytes to a science they see as having little chance of progression without them. Receiving financial remuneration to give oocytes to SCNT research means that the recipient is undifferentiated and generalised; women are giving their oocytes to advance stem cell research without a specific benefit or beneficiary in mind.

**Constructing the Ideal Donor: Checking Passion at the Door**

Underlying much of these normative approaches to tissue provision in the context of therapy or scientific research, lies a suspicion of specific and interested motivations. In the context to SCNT research, giving oocytes to a specified benefit or beneficiary is not regarded as voluntary and autonomous participation in scientific research because it apparently relies on women as giving and altruistic. For scholars who advocate payment, the relationship between women, scientists and society will be transformed into a rational relationship based on calculating risks and benefits (Isasis and Knoppers 2007; Thompson 2007; Ballantyne and de Lacey 2008; Skene 2009). For scholars who caution against implementing a model which provides financial remuneration to resolve the lack of oocytes for SCNT research, relationships between women, scientists and society will continue to be based on the social disadvantage women experience vis-à-vis men (Baylis and McLeod 2007; George 2008; Thompson 2009, Widdows 2009).

It is important to note that advocating payment on the basis that it attracts the ‘right’ donor maintains ideal distinctions between ‘public citizens’ and ‘private individuals’ where exhibiting a generalised interest and impartiality is expected of the citizen *par excellence* (Voet 1998). Citizenship is a broad concept used to refer to political relationships, usually at the level of the nation-state. Citizenship presupposes a specific relationship between the self and other selves/citizens; it “can, in principle, be both the relationships between a state and an individual citizen and the political relationships between citizens themselves” (Voet 1998, 9). There is a substantial literature on the varied rights and duties that citizenship should entail as well as the exclusions that have applied (and in some cases continue to be) on the
basis of race, gender, religion, sexuality and age. My interest here is not to challenge the orientation of this literature but to argue that by constructing the "best" donor as rational – impartial to the outcomes of SCNT research – scholars in debating oocyte provision to SCNT research reinforce the idea that the “public good” is exclusively achieved when individuals relinquish their own interests, their “specificity” rather than embracing it (Thompson 2007; Ballantyne and de Lacey 2008). As citizens, individuals must be impartial, that is make decisions according to the needs of the general rather than the specific (themselves). As James (1992, 50) suggests. impartiality requires a virtual bifurcation of the self:

To speak impartially…is not to speak in one’s own voice, informed by one’s own particular interests and affections, but to speak from a more distant standpoint, as one person among others.

In historical terms, impartiality has been presumed to be the exclusive attribute of white, middle-class and heterosexual men. This is connected to constructions of male bodies as impermeable and stable and lacking the negative attributes associated with women’s bodies such as “personal receptivity, vulnerability, fluidity, and disintegration of the self” (Phelan 1999, 59). The insistence that women and other marginalised identities may also act impartially is a radical turn in theories which seek to encourage participation in the public space.

In political theory views about “passionate” and “rational” citizenship diverge. Beyond the expectation that only certain individuals may be impartial, the political theorist Phelan (1999, 63) argues that theorists of the Republic such as Pericles, Machiavelli or Theodore Roosevelt, are more likely than their liberal counterparts to accept their citizens’ feelings in the public sphere: “passions are important for liberals but are to be removed from the public sphere as much as possible”. The Civic Republic imagined by Republican theorists differs from view in the liberal political tradition by attempting to transform passions, such as love and hate, from an emotion directed at a specific individual to form the basis of a generalised and abstract relationship among the citizenry, not their exclusion. The emotion of love,

52 These labels do not refer to the major political parties in the contemporary US.
which is usually directed toward a specific individual, must be abstracted (although this may be a contradiction in terms) and directed towards a generalised recipient. Bonds between citizens are not due to any “personal virtue or qualities, but because they are fellow citizens” (Phelan 1999, 63 emphasis added). Importantly, for the purposes of this discussion, these political theorists fear that “preferences among citizens…may lead one to neglect one’s civic duty in order to protect or privilege loved ones” (Phelan 1999, 64). This transformation from the specific and passionate to the general and rational appears to be the only the basis for political relationships. When making political decisions, citizens also need to be detached from themselves and avoid acting in ways to benefit themselves personally. This returns us to an important tenet of ethical behaviour that connects Titmuss (1997 [1970]) and scholars regarding oocyte provision to SCNT research: the exclusion of donors who will participate on the basis that it will benefit specific people with whom they are emotionally connected rather than the “universal stranger” or the abstract notion of scientific progress.

The effect of privileging ‘rational’ contributions to scientific research is the denial that women may be positioned differently in relation to the outcomes of SCNT research simply because of their lived experience, that it may not be possible to remove or flatten these differences and ‘interested’ motivations can be integral to ethical decision-making. Critics of “passionate” donation do not doubt their assumption that women contribute to scientific research with the same attitudes and perceptions regardless of time and space. In this paradigm, there is one model of scientific research contribution: the rational approach which involves treating all potential subject-participants as a homogenous group as a way of protecting against harm. This model maintains the inter-personally anonymous and distant relationship between individuals and collectives that are analogous to the nation/citizen binary. Yet, like many efforts of rationalisation, the counter argument remains powerful: that rationalisation limits the capacity for human discretion and diversity and ignores the contextual and relational aspect of human life (Komesaroff 1995).

**Ideal donors in the context of live organ transplant**

Before closing this chapter, it is necessary to address another important issue. This relates to literature that has discussed the shift from anonymised organ donation to relational donation. Here, after a brief summary of literature regarding live organ donation, I argue that in spite
of operating on a similar logic oriented towards the construction of the ideal donor, the ideal donor is related and interested.

Traditionally, organs such as kidneys have been sourced from cadaveric donors. Increasingly, there has been a trend to increase the number of live donors where the donor is a healthy, living person (Ross, Glannon, Josephson and Thistlethwaite 2002; Truog 2005; Scheper-Hughes 2007). From a medical viewpoint, transplants from living donors are generally more successful than those from cadaveric ones (Hilhorst 2005). Like any tissue provider, the live organ donor must be in generally good health – although more flexible criteria with regards to age and health are increasingly considered by transplant centres and surgeons to expand the donor pool – and undergo medical and psychological testing (Reese, Caplan, Kesselheim and Bloom 2006; Scheper-Hughes 2007). Donors need to undergo rigorous medical testing in order to withstand the operation to remove the organ (Truog 2005). In most cases, the organ is not ‘matched’ to the recipient because he or she will take immuno-suppressant drugs to manage the effects of the transplanted organ. The recipient is on the waiting list for an organ transplant and in the case of kidney transplant, has probably been treated with dialysis for some years.

There are several types of living organ donors (Truog 2005).53 Firstly, there are donors who are known to the recipient through an existing – genetic or social – relationship. These donors can include parents, children, spouses and friends (Hilhorst 2005). Secondly, there are donors who are unknown to the recipient and who are characterised as volunteers. This second category may be further divided into two groups: firstly, donors who respond to public appeals for an organ (and therefore the recipient is identified) (Hilhorst 2005; Friedman and Friedman 2006) and secondly, donors who volunteer to give organs under the condition of inter-personal anonymity, renouncing a claim to direct their donation (Ross, Glannon, Josephson and Thistlethwaite 2002; Hilhorst 2005). All the types of donors listed above are subject to medical and psychological testing. All decisions to proceed with live organ donation (as with oocyte provision to SCNT research) are expected to be based on

53 This discussion cannot refer to the different regulatory frameworks that exist for live organ provision or organ sellers around the world. Here it is sufficient to refer to the fact that there is documented evidence that poor people in countries such as the Philippines sell their kidneys to medical tourists from first-world countries (the Philippines government instituted a ban on this practice in 2008). It is also illegal to sell such organs in the United States, the European Union and Australia. However, it is legal to sell one’s kidney in Iran (Scheper-Hughes 2007).
rational principles: that is, donors decide whether to donate (and medical staff should only proceed) when the benefits outweigh the risks of the operation and the effect of losing one kidney (Kahn and Matas 2002).

The following analysis highlights that scholarship regarding living organ donors treats them inversely to the scholarship regarding oocyte providers to SCNT research. The former are constructed as ideally interested (identifying a specific benefit or beneficiary) while the latter are expected to be disinterested. Typically, in the context of kidney donation, doctors in the American context have been suspicious of people who altruistically and anonymously donate a kidney, often dismissing them as psychopathological (Truog 2005). Here we can see a divergence from Titmuss’s altruistic-donor who was lauded for embracing the ‘universal stranger’. This is because the decision to be an anonymous altruist has been interpreted through the prism of self-interest (rather than Titmuss’s ‘right to give’). In this paradigm, human beings are inherently self-interested; any virtue such as altruism is finite and should only be directed at people inside the immediate social circle (Sandel 2012). Despite these misgivings, the anonymous altruist is increasingly used in transplant situations for two reasons: first, chronic shortages from cadaveric organ donors and better transplant outcomes in comparison with cadaveric organs (Ross, Glannon, Josephson and Thistlethwaite 2002; Truog 2005; Scheper-Hughes 2007).

The contrasting treatment of interested donors (those who are related to the recipient and therefore can identify a specific benefit and beneficiary) refers even more explicitly to the construction of an ideal donor in the context of oocyte provision. In the context of live organ donation, the motivations of the interested donor are generally interpreted in kinder terms. There are two reasons for this; firstly, in keeping with the self-interested paradigm discussed above, individuals are expected to behave altruistically to members of their social circle (Ross, Glannon, Josephson and Thistlethwaite 2002). Such behaviour is socially expected and acceptable. Secondly, returning to the issue as a rational cost/benefit analysis: the benefit of donating a kidney to their relation is considered to outweigh the cost because the benefits are concretely experienced: the recipient gains their longer term health and by extension, the donor’s own life is not significantly disrupted by the continued treatment of dialysis or the death of their loved one (Ross, Glannon, Josephson and Thistlethwaite 2002). Some scholars assert that these benefits do not concretely exist between an altruistic and anonymous kidney
donor and recipient (Kahn and Matas 2002; Ross, Glannon, Josephson and Thistlethwaite 2002). The condition of inter-personal anonymity does not permit the donor to direct their donation to a person of specific gender, race, age or medical history. These scholars interpret the condition of anonymity as meaning that the donor can only attach their action to an abstracted entity where the benefit of the donation is only an imagined experience not a lived one.54

Most of the scholars surveyed in this brief section view live organ donation between related individuals in positive ways, notwithstanding some concerns with the practice. For instance, there is concern expressed that donors may feel obliged or coerced into providing the organ to the relative. Generally, the testing process and counselling from hospital staff is considered sufficient to minimise this risk and if necessary, clinicians may invent a medical excuse to avoid putting a family member through the operation (Truog 2005; Scheper-Hughes 2007). Yet, scholars such as Ross, Glannon, Josephson and Thistlethwaite (2002) go so far as to argue that related donors will undergo more risk precisely because of their existing relationship with the recipient. This position is vehemently opposed by Scheper-Hughes (2007, 510) whose reference to ‘organ capture’ is indicative of her overall claim that live organ provision by a related donor is inherently exploitative and should be decreased. According to Scheper-Hughes this practice is inequitable for two reasons: firstly, that living donors are made invisible by the social expectation that gifts are not mentioned lest the recipient feel that the gift be reciprocated. Secondly, there is a documented bias between donors in terms of gender: women are more likely to be donors than recipients. Underlying this position is the ‘anthropological’ view regarding “families [which] are often violent and predatory, as inclined to abuse and exploit as to protect and nurture their members” (Scheper-Hughes 2007, 508).

Overall, concerns raised by the utilisation of related and non-related living donors reveals a similar propensity to the literature on oocyte provision to stem cell research to construct an ideal donor. This propensity does not result in the same ideal donor. In the organ transplant context, the ideal donor is generally interested and their motivations and actions are least problematic because they are interpreted in relation to the public/private divide where

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54 It is necessary to clarify that the recipient does not becomes less than human if such particular markers are absent. I wish to thank Professor Michael for pointing this out.
private social relations are characterised by altruism rather than self-interest. In contrast, the altruistic anonymous donor is problematic because the cost/benefit calculation appears to be irrational (Kahn and Matas 2002; Ross, Glannon, Josephson and Thistlethwaite 2002).

For the majority of feminist scholars discussed in chapter two, specifically Thompson (2007), Ballantyne and de Lacey (2008) and Skene (2009) who advocate for the payment of women to provide oocytes in order to ‘relieve’ pressure from the related donor, the interested oocyte provider is acting from similar expectations about behaviour within the private sphere but these expectations are interpreted in largely negative ways (although there are explicit affinities with the approach taken by Scheper-Hughes 2007). Feminism critiques constructions of women’s behaviour as different from men and divorced from rationality. Within the context of cost/benefit analysis, there is little doubt that helping to progress scientific research (because the results cannot be immediate) is a cost without [rational] benefit. The oocyte provider who is motivated by impersonal [commercial] reasons – money – rather than emotional bonds or her own cheaper fertility treatment is the ideal donor because she is acting in the spirit of the public sphere, not necessarily for the public good. Thus, ideal donors are important in each context but each field of literature constructs its ideal donor differently.55

**Conclusion: research questions**

The scientific utilisation of human tissues varies considerably and it is an important political issue because it provokes questions about equality and representation as well as “public good” (and indeed there are questions about equal access to deciding the “public good” that cannot be addressed in this thesis). Current regulatory regimes, an effect of ethical rationalisation in recent decades, focus on the process of informed consent as a way a realising individual autonomy. This seems to be the means of deciding whether the conduct of scientific research is a “public good”, following the liberal conviction that the individual

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55 I do not wish to preempt my discussion of the results. However, I will note here that my overall argument is not necessarily undermined by the different constructions of the ideal donor in specific contexts. In chapter eight, I discuss other forms of tissue provision (cancer cells, blood, DNA) and the social contexts in which they are given – who does the donor imagine they are giving to and why? My argument that tissues are given to specific communities (inter-personally anonymous, national, international, abstract etc) captures the different forms of donor (not necessarily the constructions made by scholars about who is best). What is beyond the scope of this thesis is an understanding of how the kidney has become a tissue that can be given in two different contexts (specific and general).
is their own natural moral authority (Frazer and Lacey 1993). However, recent controversies such as the HGDP show that this question of the “public good” cannot simply be resolved with reference to individual autonomy because scientific research is part of broader political processes (Jasanoff 2005). What happens in the realm of science can reflect wider society and vice versa. One repercussion of the HGDP controversy should be the acknowledgement that different groups regard scientific research differently.

The approach undertaken here shifts the focus from gift-giving as self-contained and static rituals to reciprocal relationships enacted within specific social contexts. I have shown that it is important to depart from existing approaches to gift-giving practices, exploring their variations and situating them within a specific historical and social context. The latter view takes into account the object given or traded, the people involved and the motivations for giving. Drawing on critical approaches to materiality (Kopytoff 1988; Miller 2001, 2003; 2005 and 2008), the framework I employ analyses the diverse relationships which emerge from giving reproductive tissues that destabilise both the vital status of objects-given-as-gifts and the mechanistic meaning of money. In widening the net of analysis wider, my approach also refers to established feminist views regarding the relationship between science as a monolithic entity and women. “Tilting the scales” in the opposite direction and assuming that the scientific utilisation of oocytes and embryos can inevitably be regarded as similarly based on unequal power relations does not allow us to adequately understand the social significance of giving reproductive tissues to scientific research. I suggest that we can better understand giving reproductive tissues to stem cell research by allowing for a complex relationship between institutions of scientific research and women as members of the ‘lay’ community, for whom scientific research constitutes an important part of their everyday lives. The final dimension of my framework is a critical approach towards normative political or collective behaviour based on the inevitably suppression of specific and concrete concerns in preference for general and abstract ones.

Based on the preceding analysis and development of my own eclectic framework, the current study seeks to address substantive and theoretical dimensions pertaining to oocyte and embryo provision to stem cell research. This will be achieved by engaging with potential donors to understand their attitudes, perspectives and practices. The following research
questions are distinct from those the principal investigators devised in the original grant submitted to the ARC. 56

Firstly, the following empirical questions need to be answered:

1. What are the views of participants regarding oöcyte provision to SCNT research?
2. Are these views different to oöcyte provision for reproductive purposes? How?
3. What are the views of participants towards embryo provision to stem cell research?

Secondly, more conceptual questions need to be answered;

1. How does the ‘public good’ figure in preferences for providing oocytes and embryos to stem cell research?
2. How can we explain the scientific utilisation of reproductive tissues in relationship to citizenship and women without resorting to normative and ahistoric assumptions about autonomy and rationality?
3. Specifically, how does the empirical data relate to constructions of the ideal [disinterested] donor discussed in chapters three and four?
4. By using an approach that considers the relationships between objects and humans as mutually constitutive, as discussed in chapter four, how can preferences regarding payment models be understood?
5. How do preferences regarding oocyte provision for reproductive and research purposes reflect and challenge existing paradigms regarding gift-giving?

Chapter five will outline the research methods used and the means of recruitment to achieve the aim of this research; to develop a conceptual framework that better captures what the scientific utilisation of reproductive tissues means for women. I also examine specific epistemological concerns regarding the collection of data through research tools such as interviews and focus groups.

56 Appendix 2 contains an abstract of the original submission.
Chapter Five: Designing Research to Examine the Scientific Utilisation of Reproductive Tissues

Introduction

The preceding chapters have provided technical information about stem cell research, female reproductive biology and the properties of oöcytes that make them a valuable but fragile and difficult tissue to manipulate for research purposes. The preceding literature reviews focused on two fields of scholarship which proceed from a principle-based approach. Firstly, the debate regarding oöcyte provision to SCNT research with an emphasis on whether a payment system should be introduced to address the present shortage. Secondly, the field of tissue economies, with a focus on Titmuss’s (1997 [1970]) work sought to assert the validity of altruistic donation for blood provision. Despite differences in time periods, the biological and technical aspects of each tissue discussed, the appearance of immense philosophical differences between the field of scholars discussing oöcyte provision to SCNT research and Titmuss is only superficial. In both contexts the ‘ideal’ donor or contributor of human tissue is constructed a disinterested individual. His or her contribution is based on a generalised, rather than specific, benefit or beneficiary. The implication of this expectation is significant. It is my intention to discuss the idea that contributing human tissue to scientific research can be ‘interested’ and targeted towards a specific benefit or beneficiary.

As noted above, imposing a donor or payment system has so far emerged from a principle-based approach to the issue of contributing tissue to scientific research. An underlying assumption of such approach is that that contributing tissue to scientific research has one meaning for everyone in all contexts. However, an approach which collects data from potential donor populations is necessary to develop a conceptual framework that can capture the reproductive significance of oöcytes and embryos and the social roles women may create with their varying utilisations. This chapter will outline how I approach such complexity in my research design and collection of evidence. The rationale for this study will be discussed following an outline of the methods chosen; namely, participation selection and recruitment.
Outlining the research study

Looking at practical contexts of reproductive tissue provision relies on understanding the meanings people give to things and practices. Meaning-making is itself a complicated issue, and there are many debates about how different perspectives come to be produced and reproduced and how some rather than others become legitimated as self-evident knowledge. Sociologists working within paradigms such as Feminism, Marxism and Queer Studies are critical of the power relations that impact meaning-making and the ways in which some meanings become legitimated as morally right or scientifically objective, while others are dismissed or denigrated. While there is certainly a critical dimension of this thesis, I am primarily interested in the meanings of specific practices and perspectives rather than focusing on how some meanings are made more legitimate than others.

This research is situated within the interpretive research paradigm because it “combine[s] an empirical focus on the language and gestures of human interactions with a theoretical concern with their symbolic meanings and how the ongoing social order is negotiated and maintained” (Alford 1998, 42). As a social researcher, the significant question is that of precisely delineating the object of study. Is it enough to know what people do or what it means for them to do it? Interpretive research was chosen for this project because it allows for an in-depth and contextual examination of what constitutes an oocyte and what its utilisation means for different people. The interpretive paradigm is contrasted with the approaches that emphasise causal or historical explanations in the research process (Alford 1998). In the social scientific disciplines, the interpretive paradigm is related to hermeneutics, often contrasted with positivist sociological approaches borrowed from physical sciences such as biology. Bryman (2004, 13) argues that the key difference between the two traditions is that positivist approaches “seek to explain human behaviour while the latter seeks to understand it”. Human social life is considered much more complex than the physical world because “facts” are invested with meaning that are culturally and historically specific.

Knowing experience?
Undertaking social scientific research involving human subjects provokes questions about the authenticity of research participants’ perspectives. Many historians of marginalised groups and/or political movements, Scott (1991) argues, take the perspectives of their informants as unproblematic truth. Because these participants are designated as social others or deviants, they are expected to reveal the existence of oppressed identities and practices. This may resemble a naïve approach to Foucault’s concept of “subjugated knowledge”- that which is marginalised because it is perceived to be “unscientific”, “subjective” or “specific” (Foucault 2008). This concept is broadly situated within the Foucauldian paradigm of biopower, which provides a useful means for understanding specifically modern forms of political subjectivity (Sawicki 1991). In applying these ideas, Foucault suggests an “analytics of power from below” by looking at the subjective experience of individuals who occupy lay positions within discursive fields (Foucault 2008). Scott (1991) argues, however, that historians cannot simply reveal marginalised experiences as if they constitute a specific identity without questioning the social and historical specificity of subjectivity; indeed, “it is not individuals who have experience, but subjects who are constituted through experience. Experience in this definition then becomes not the origin of our explanation…but rather that which we seek to explain” (Scott 1991, 779-780). Scott thus emphasises that a Foucauldian approach analyses power to understand what identities, desires and behaviours are evoked on an individual subjective level.

Silverman (2007) contests the assertion that focus groups or interviews are ideal methods to gain insight into the diversity of human experience and advocates using data which is not manufactured such as ethnography or textual analysis with little or no direct questioning of participants. This is because people rarely “think” about what they do, rather people “act” and then produce coherent stories to explain them. The data gathered in focus groups and interviews is simply a record the individual’s version of events rather than an analysis of actual events. Silverman’s model is also based on social constructionism, but his approach “prioritises interaction over meaning and…prefers to look at what people do without any necessary reference to what they are thinking or feeling” (2005, 10). This “interactionist model” differs from the “emotionalist model” defined as the “study of perceptions, meanings and emotions” (Silverman 2005, 10). Such data is manufactured by directly talking to people as individuals or in groups in order to document and understand phenomena from the individual’s point of view. Silverman’s “interactionist model” appears to be rather positivist
because he treats the study of the social world as if it can correspond to the study of the physical world. For example, in asserting that asking people about their behaviour is likely to elicit a socially-appropriate narrative he dismisses an important dimension of what it is to be human: to report, narrate or perhaps even embellish various moments in our lives. Silverman’s approach can also be critiqued on the basis that it resembles other symbolic interactionist researchers who emphasise the episodic and dynamic nature of social life, while neglecting the importance of memory and social structures in sustaining relationships (Farganis 2008; Dillon 2010).

The points raised by Scott (1991) and Silverman (2005, 2007) are useful in helping to calibrate a view of social science research that assumes it is possible to reveal the participants’ insights or experiences as if they are indeed authentically their own. Although it is necessary to distinguish between the research framework and the methods used to implement it. For instance, talking to people individually or in groups does not necessarily presume that the researcher is seeking to reveal a hitherto oppressed truth; it is meant to reveal the lived experience of another human being and how it makes sense to her. While it is unlikely that the scientific utilisation of reproductive tissues will have the same meaning to women in the community, these are likely to differ to the principle-based approaches thus far discussed. My intention is to incorporate these responses into a conceptual framework that can express the tensions between the reproductive significance of oöcytes and embryos and the social roles women may create with their varying utilisations. In the process of understanding the social significance of contributing reproductive tissues to scientific research, concepts such as gifts, reciprocity, materiality and subjectivity will be drawn into the analysis.

**Data Collection**

In order to procure ARC-funding and prior to my participation in the research project, the principal investigators identified three broad aims. Firstly, to contribute to existing knowledge data from a small sample focusing on the attitudes of potential donors in Australia regarding the scientific utilisation of reproductive tissues. Secondly, to provide an empirical basis with which to engage key stakeholders such as stem cell researchers, fertility clinicians and policy makers such as the NHMRC. Finally, to produce an empirically based
submission to the federal government’s legislative review of The Prohibition of Human Cloning for Reproduction Act and The Regulation of Human Embryo Research Amendment Act scheduled for 2011. In addition to these aims, as a PhD candidate, I independently developed the aim of constructing a conceptual framework that captures the social significance of contributing to scientific research with one’s own tissues. This aim reflects my intention to move away from discussing the issue as if it were exclusively one of individual women’s autonomy.

Given that the project’s partner fertility clinic was not involved in stem cell research and did not ask any of its patients to provide their oocytes for their own or other research projects, the data are based on hypothetical scenarios and responses. This research may be used to further develop hypotheses for future projects. Yet I do not necessarily acknowledge the extent to which the hypothetical nature of this project and its small sample poses a significant limitation to the results and implications discussed herein. As discussed in chapter two, there are many published papers regarding attitudes towards oocyte provision for research purposes. Not all the participants in these publications had direct experience of fertility treatment or oocyte extraction for another’s purpose. I should also like to point out that the dataset from which my thesis draws has already been discussed in peer-reviewed journals without in-depth examination regarding the implications of the project’s hypothetical nature or small sample (see Waldby, Kerridge, Boulos and Carroll 2013 and Appendix P).

**Ethics**

No research was undertaken until approval was obtained from the South West Sydney Area Health Service in July 2009 and the University of Sydney Human Research Ethics Committee in November 2009. Further ethics approval was granted to provide payment to participants in the focus groups ($25) in July 2010. In consultation with Professor Waldby, I made the decision to seek permission from the University Human Research Ethics Committee to pay women to participate in focus groups. Prior to the offer of reimbursement, women did respond to the advertisements. However, given that these numbers were insufficient and we considered it important to maintain momentum, we offered reimbursement to add to the initial number of respondents to the advertisements.
Defining cohorts

As mentioned above, the ARC funded the project between 2008 and 2011; I began my candidature in June 2008. However, the South West Sydney Area Health Service took almost a year to approve the ethics application and thus data collection did not begin until August 2009. This research involved engaging directly with women who were not currently involved in the provision of oöcytes to SCNT research residing in the greater Sydney region of New South Wales (NSW), Australia between August 2009 and August 2010. As Table One indicates, there are a total of three cohorts in this sample. Fertility patients (cohort one) were the primary cohort because existing SCNT, human embryonic stem cell and fertility research utilises the oöcytes of women who are undergoing treatment for infertility issues (Franklin 2006; Parry 2006; Ballantyne and de Lacey 2008). This sample is expected to provide comparable evidence with other jurisdictions. We also included in our study women whose experience of oöcyte extraction occurs in different circumstances; for example, those who had undertaken the process of oöcyte extraction to help another woman become pregnant (cohort 2). The final cohort consisted of participants who represent the “healthy donor”, a label generated in biomedical literature pertaining to women who are not expected to have prior experience of fertility treatment, oöcyte extraction and who are between the ages of 18 and 30. The “healthy donor” label also refers to the biomedical perspective regarding women under 30 years of age being at their peak fertility with highly fertile oöcytes (oöcytes which are fertilisable). It might be argued that my use of this term is flawed, having been borrowed from medical literature to refer to individuals whose physical characteristics would qualify them to be considered as healthy donors by some clinicians and/or scientists. I use it because I think it succinctly sums up the women who participated in this cohort. After all, these participants cannot really be designated by any other common experience or feature except that they are “healthy donors” and were not being treated for fertility issues – notwithstanding further medical and psychological testing usually required of oocyte providers in paid and altruistic contexts (Bourne 2008; Almeling 2011). It is also interesting to note that the ‘healthy donor’ is particularly constructed in medical and social scientific literature as a direct contrast to the fertility patient who is undergoing medical

57 As noted above, the NHMRC has licensed the use of clinically unviable oocytes obtained within the context of fertility treatment (National Health and Medical Research Centre (2013).
treatment. Cohort three was further divided between women in the “general” population (3a) and women of the same age who have a family member or friend with a medical condition that may eventually be treated through such techniques as SCNT such as diabetes, Parkinson’s disease or spinal cord injury (3b). It was anticipated that the second group expected to be more likely to be disposed towards research donation outside an IVF setting, thus yielding valuable data about the extent to which close family or friendship relations shape perceptions of research donation. Cohorts one and two were largely based on experience – that is, having prior experience of fertility treatment and/or oöcyte extraction. Participants in cohort three were not expected to have had such experience.

Table 1 - outline of each cohort in the study

<table>
<thead>
<tr>
<th>Name</th>
<th>Participant type</th>
<th>Definition</th>
<th>Number of participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohort One</td>
<td>Fertility patients</td>
<td>Experience of fertility treatment for their own infertility (may be “female”, “male” factor or both)</td>
<td>20</td>
</tr>
<tr>
<td>Cohort Two</td>
<td>Reproductive oöcyte donors</td>
<td>Undertook oöcyte extraction for an infertile woman.</td>
<td>5</td>
</tr>
<tr>
<td>Cohort Three (A)</td>
<td>“Healthy donors” – general population</td>
<td>Women aged between 18 and 30, no prior experience of oöcyte extraction.</td>
<td>14</td>
</tr>
<tr>
<td>Cohort Three (B)</td>
<td>“Healthy donors” – related population</td>
<td>Women aged between 18 and 30, no prior experience of oöcyte extraction. Related to a family member with a diagnosed condition which may be helped by stem cell research.</td>
<td>4</td>
</tr>
</tbody>
</table>

The process of recruitment – cohorts one and two

Cohorts one and two were recruited through a fertility centre in metropolitan Sydney. The Australian Research Council Linkage grant involved a partnership between academics at the Universities of Sydney and Melbourne and a large fertility clinic based at a public hospital. The Postdoctoral Fellow, Dr Carroll coordinated the ethics application, designing the information sheets and consent forms with input from myself, Professor Waldby and Associate Professor Kerridge. Once ethics approval was obtained, clinic staff conducted a

58 These terms signify how clinicians sometimes referred to the source of infertility in either one or both patients.
search of the patient database to generate a list of women who had been treated for fertility issues in the previous two years but who were not actively engaged in treatment at the time of participation in the study. Clinic staff also identified participants they felt should be excluded from the study. The partnership between the clinic and researchers did not involve sharing the clinic’s patient database. Potential participants were invited to participate in the study. Dr Carroll and I mailed prospective participants a letter introducing the research project and an information sheet. The introductory letter was printed on the letterhead of the Fertility Clinic and signed by its director. Participants were invited to return the “consent for contact” letter directly to the university researcher whereupon Dr Carroll or myself would phone the respondent to arrange a time for the interview. It became clear during interviews that many participants in cohort one had taken a break from fertility treatment but considered the possibility of returning at some stage. The tables below show the selection period and how many potential participants were identified for cohorts one and two. Copies of the recruitment letter, information sheet and consent form are contained in Appendices A, E and F. Neither the researchers nor clinic staff kept a master copy of names to ascertain who did not respond. Appendix B shows the demographic information sheet participants were asked to complete. One participant’s data was lost due to equipment failure.

Table 2 - Fertility Clinic Recruitment (first and second rounds)

<table>
<thead>
<tr>
<th>Cohort</th>
<th>Selection Period</th>
<th>Total No. Potential Participants on database</th>
<th>No. Excluded (see Table 3)</th>
<th>No. Sent Invitation to participate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ex-IVF Patient</td>
<td>January 2008 – February 2010</td>
<td>585</td>
<td>68</td>
<td>517</td>
</tr>
<tr>
<td>Oöocyte donors</td>
<td>January 2008 – February 2010</td>
<td>35</td>
<td>2</td>
<td>33</td>
</tr>
</tbody>
</table>

Table 3: Reasons for exclusion from study for cohorts one and two (first and second rounds)

<table>
<thead>
<tr>
<th>Reasons for exclusion</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language Barrier (requires full interpreter service)</td>
<td>26 (IVF)</td>
</tr>
<tr>
<td>Rural home dwelling</td>
<td>42 (IVF)</td>
</tr>
<tr>
<td>---------------------</td>
<td>----------</td>
</tr>
<tr>
<td></td>
<td>2 (Donors)</td>
</tr>
<tr>
<td>Total</td>
<td>70</td>
</tr>
</tbody>
</table>

*The process of recruitment – cohort three*

Recruiting ‘healthy donors’ was also based on voluntary enrolment, involving some snowball sampling whereby participants volunteered to pass the information to interested friends or colleagues. My previous employment experience of organising focus groups taught me that obtaining an adequate number of participants to meet on the same day at the time involves a “process of attrition”. More participants than are needed to attend are still required to express an interest because the meeting time and day will not be suitable for everyone. Recruitment began in January 2010 and the primary advertising strategy throughout the Camperdown campus of the University of Sydney included A4 and post-card sized posters. These were placed in various lecture rooms, hallways, cafes and toilet doors. The research was also announced during brief speeches at the end of undergraduate lectures. Some effort was made to target faculties that can be female-dominated such as Nursing, Education and Arts and Social Sciences. By June 2010, it was evident that there was insufficient interest and the decision was made to apply for permission to pay participants. Further approval from the University of Sydney Human Research Ethics Committee was obtained in July 2010, in time for second semester. The research was further publicised in a student representative council (SRC) publication, *Honi Soit*, as well as newsletters emailed by the University to all staff and students. Both staff and student members of the Sydney University community were invited to participate. Participants were asked to express their interest by email after which an information sheet was sent. When I perceived that an adequate number of respondents had volunteered, I sent further emails to set the meeting time and day. Copies of the recruitment poster and advertisement, information sheet and consent form are contained in Appendices G, H, I and K. Appendix J shows the demographic information sheet participants were asked to complete.

The University of Sydney is largely populated with students from affluent areas of Sydney such as the north shore and eastern suburbs. Despite attempts by the university to diversify its student population, most students are at least the second generation to attend university
(University of Sydney 2013). In order to counter this “middle class bias”, attempts were made to recruit from the University of Western Sydney (UWS); specifically, the Bankstown campus), which accommodates students of the College of Arts and is likely to have a higher number of female students. Recruiting participants from this university would have provided further points of comparison between healthy donors of different ethnic, religious and socio-economic backgrounds. Most students attending UWS are from first-generation ESL backgrounds and are often the first in their family to attend tertiary education. While the Executive Dean of the College of Arts granted permission to recruit participants, advertising on campus proved difficult because maintaining the visibility of printed posters and advertising through University-hosted websites proved difficult. This strategy ultimately proved unsuccessful and was abandoned.

**Research methods**

The methods used in this study are focus groups and semi-structured interviews. Both tools were used to examine the practical contexts of providing reproductive tissues. This research project was designed to be iterative and sensitive to participants needs. One way to achieve this was by piloting both the interview and focus group. This strategy is used in the preliminary stages of research projects in order to detect inaccuracies or points of confusions (Bryman (2004). Pilot focus groups and interviews drew on informal networks of colleagues and were conducted in the same way as the actual interviews and focus groups.

**Focus groups**

Three focus groups were held on the campus of the University of Sydney in August 2010. The discussions lasted approximately two hours and involved introductions, signing consent forms, reading time and discussion. Tea, coffee and cake were served throughout. Participants were given descriptions of SCNT and oöcyte extraction and were asked if they needed clarification about what they had read. Participants in the healthy donor cohort were not expected to have prior experience of fertility treatment or oöcyte extraction. Participants were asked about their knowledge of, and level of support for, stem cell research. Participants in the cohort 3b with a friend or family member who may be helped by stem cell research discussed any specific caring responsibilities they have towards that person. Copies
of the focus group discussion schedule and visual prompts are contained in Appendices L and M.

Focus groups were chosen as the research method for the “healthy donor” cohort because the participants had no prior experience of fertility treatment or oöcyte extraction. This lack of experience meant that their attitudes towards oöcyte provision to SCNT research were mainly general and abstract. In order to draw out these attitudes, the focus group schedule was designed to elicit responses about oöcyte provision for SCNT research by comparing it to other forms of tissue provision such as blood and whole organs or oöcytes for reproductive purposes. Focus groups are often used in exploratory research where participants need no special qualifications to attend. They are used to elicit general social understandings about a particular topic rather than individualised narratives which emerge in interviews (Rice and Ezzy 2001).

Given the nature of their design, focus groups posed three issues for this research. Firstly, focus groups are a mixture of foreign and familiar social elements; strangers converging to discuss a topic may be an ideal of deliberative democracy but in practice, it can be influenced by factors such as domineering or submissive individuals and clumsy organisation. Rice and Ezzy (2001) argue that researchers must facilitate discussion with strategies designed to produce conversation such as open-ended questions. This shows that the idea of free-flowing conversation is in fact a case of good management and rests on a fine balance between allowing individuals to contribute to the discussion as they wish whilst ensuring that contributions are well distributed among the group. The researcher cannot expect the conversation to take its course smoothly without some direction.

Secondly, the dynamics created among many participants is a distinguishing feature of focus groups because participants are expected to interact with each other as much as possible. The moderator introduces subjects or topics through the use of visual or verbal aides and allows discussion to take place between participants rather than ask a series of questions to each participant (Rice and Ezzy 2001). This may correspond with Kitzinger’s claim that the aim of the focus group is to elicit a group perspective where consensus is built through complementary (“yeah…I agree because…”) or argumentative (“no, it's not that way for me…”) verbal interactions (cited in Bryman 2004, 357-58). In this way, focus groups allow
responses to be clarified or revised. As a predominantly peer-based interaction, more opportunities to “critically” examine participants’ responses are possible. Finally, focus group discussions will follow a certain plan in relation to the topics but because of their highly interactive nature will vary every time and are impossible to predict.

**Interviews**

Interviewing cohorts one and two began in August 2009. They were arranged individually, as contact-for-consent letters were returned in the mail and usually taking place in the participant’s home. The interviews generally lasted ninety minutes and were mainly conducted by both the post-doctoral fellow, Katherine Carroll (KC). I conducted five interviews in these two cohorts. Participants were asked if they read and understood the information sheets and to sign the consent forms; any questions were answered at the time. Interviews were tape-recorded and additional permission was asked prior to turning on the recorder. Before posing questions from the semi-structured interview schedule, I often asked why the participant had decided to participate in our study; this helped to “break the ice” and allow the interview to flow as a conversation. Participants were asked to recall their decisions to undergo fertility treatment or donate oöcytes and how they experienced the process.

Interviews normally involve two people: the interviewer and interviewee and can range from formal structured interviews involving a strictly adhered-to schedule to less formal semi-structured or in-depth interviews where the interviewee may be asked to narrate an experience and then be prompted to expand on their answers (Bryman 2004). More specifically, semi-structured interviews involve “a list of questions or fairly specific topics to be covered, often referred to as an interview guide, but the interviewee has a great deal of leeway in how to reply” (Bryman, 2004, 321). The purpose of semi-structured interviews is to engage the participant in responding to the topic in their own words. Researchers use semi-structured interviews when they have a clear focus to their research rather than a general interest in a topic (Rapley 2007).

Semi-structured interviews were chosen as the method for cohorts one and two because they had the experience of fertility treatment and oöcyte extraction and to maintain confidentiality
regarding personal stories. The interview schedule were designed to elicit information about the participant’s fertility treatment as well as their views on oöcyte and/or embryo provision for research. These women had no experience of providing oocytes to research and our information sheet made it clear that we were social researchers, only interested in their views. In contrast to focus groups, interviews allow responses to be developed because participants are not “competing” with each other to speak and there is more time to clarify uncertainty. Interviews are also private and do not expose intimate details of participants’ lives with strangers (other than the researcher). The power dynamics of interviews differ from focus groups in some respects: in a one-on-one situation, interviewers can be reluctant to highlight inconsistencies or ambiguities in the participant’s narrative (Willis 1980; Alvesson 2002). The sensitive nature of being treated for fertility with ARTs sometimes meant that women expressed themselves emotionally to which I usually responded with sympathetic phrases or by taking a break. Copies of interview schedules for cohorts one and two are contained in Appendices C and D.
Demographic Information

The following tables indicate the age range and educational attainment of participants by cohort.

Table 4 - Cohort One Age Distribution

Table 5 - Cohort One Education Attainment
Table 6 - Cohort Two Age Distribution

Table 7 - Cohort Two Educational Attainment
Table 8 - Cohort Three Age Distribution

![Bar chart showing age distribution]

Table 9 - Cohort Three Educational Attainment

![Bar chart showing educational attainment]

Data analysis

As stated in the introductory chapter, the design of research tools\textsuperscript{59} and collection of data was a group effort. Dr Carroll, Professor Waldby and I all contributed to the ethics application, the composition of interview schedules, consent forms and patient information

\textsuperscript{59} The principal investigators decided to use research tools such as interviews and focus groups.
sheets for cohorts one and two. I largely coordinated the same process in relation to focus groups for cohort three with some input and final approval by Professor Waldby. Transcription was outsourced to a professional company and a transcription of each interview was made as soon as it was completed. Audio files and transcriptions were stored on a password-protected university-based server to which immediate members of the project team had access. All data was held ‘in common’ by the immediate members of the project team and thus the five interviews I conducted in the absence of Dr Carroll were not “my property” and vice versa. Dr Carroll and Professor Waldby and myself (sometimes attended by the research assistant Brydan Lenne and Associate Professor Kerridge) discussed the data in relation to emerging themes and research being published overseas during face to face meetings. Dr Carroll and I produced coding reports in relation to our ‘respective cohorts’ and interests throughout 2010. These were distributed to other members of the team and largely acted as a quick reference guide to the data.

Discussing the data did not raise significant dissent between the immediate members of the project team. After all, there was little confusion about the data we had collected (participants were not keen to donate oocytes but would do so with embryos etc). This is because this information is rather unambiguous. Diversions in analysis appeared at a more conceptual or abstract level and this was due largely to each member’s interest. For instance, Professor Waldby was keen to use the data within the paradigm of feminist political economy approach, specifically the construction of oocyte providers as labourers in an emerging bioeconomy. As she was interested in organisational policies and procedures, Dr Carroll focused on the issue of informed consent. I sustain this claim with reference to the author’s respective publications – please see Appendix P. My own basis for analysis changed significantly between 2009 and 2013. I became increasingly aware that the feminist scholarship was imbued with a tone of “moral panic”, which the benefit of a decade since the introduction of SCNT seemed a largely unwarranted anxiety. At the same time, I was teaching and trying to understand ‘precisely’ what a sociological approach to such issues could be. As a lecturer designing my own course, I considered it more important to understand sociological concepts (modernity, risk, rationalism to name a few) in light of novel technologies rather than focus on ‘existentialist’ questions of freedom, power and oppression. This reason and the fascination generated by reading Miller and Kopytoff’s
scholarship on materiality led me to think deeply about the distinctions between ‘compensation’ and ‘payment’ made by participants. I also intuitively understood that oocyte provision for SCNT research could be considered a novel arena for ‘political’ theory where the intersection of gender, body tissue and novel social relations could be innovatively addressed.

I adopted a broad framework with which to analyse the collected data. The analysis was not structured in a specific way and borrowed features from various approaches such as grounded theory and thematic analysis (Dey 2007; Ezzy 2002). Grounded theory was not applied in its entirety because if followed closely, it expects the researcher to “enter” the field without preconceived ideas. However, the broad design of the research, established in order to obtain ARC-funding, explicitly made reference to debates, concepts and questions from existing literature. In this way, the data could be used comparatively with that of other projects. Approaches such as grounded theory also insist that research is not a linear process and that data collection and analysis should not be distinct phases of the research program. Instead, researchers should be reflexive, self-referential and follow unexpected leads. In line with dimensions of grounded theory, our early data collection and analysis did influence later stages (Dey 2007); for example, the issue of compulsory donor registers was explored with the healthy donor cohort because the law had come into effect the same year. Unfortunately, however, its relevance had not been fully appreciated during interviews with reproductive oocyte donors who were directly affected by the legislation.

Interviews and focus group discussions were transcribed and imported into the qualitative data software, NVivo as they were completed. A rigorous theoretical coding process was applied to the data (Flick 2006). Open codes were broadly applied during the initial stages where transcripts were read and re-read in an effort to comprehend the perspectives of participants (Ezzy 2002). Comparisons were made between my own codes and interpretations with existing literature. As Ezzy (2002, 81) argues, “qualitative research is demonstrably trustworthy and rigorous when the researcher demonstrates that he or she has worked to understand the situated nature of participants’ interpretations and meanings”. This includes listening to the diverse voices presented rather than effacing difference and representing the mainstream view; this is most evident in the analysis of Melissa’s
perceptions of oöcytes. Unfortunately, my own presentation of results may not satisfy Silverman (2007) who consistently laments the contemporary mainstream use and analysis of qualitative data collection through interviews and focus groups arguing that many sociologists resemble journalists because they do not comprehensively analyse their data, instead utilising a few quotes to support their arguments.
Conclusion

This chapter has discussed the methods which I will utilise to what the scientific utilisation of reproductive tissues means for women. This chapter has addressed the means by which the data was collected, including the definition and recruitment of cohorts and a description of the research tools used (interviews and focus groups). I have identified a significant rationale of this research: to specifically explore “lay” perspectives. I have then discussed two research tools that are considered appropriate for asking participants to construct a narrative: focus groups and interviews. Yet, in light of critical perspective regarding marginality and speech, I do not proceed from the assumption that these views are “authentic” simply because the narratives are more marginal than medical or policy discourses.

Part Two, comprising of chapters six and seven will present key findings from the data and address the research questions that ultimately seeks to achieve the aim of this thesis; namely, to discuss how oöcytes and embryos are used by women and how these various utilisations help constitute their intentions to become a mother.
Chapter Six: Reproductive Tissues, “Kin Ethics” and Preferences in Giving Oöcytes to SCNT Research

Introduction

Part one of this thesis has discussed the problem of altruistic donation of reproductive tissues to SCNT research, providing important background information and reviewing the substantive and theoretical literature regarding the practice. It has also introduced the reader to the guiding research questions and research methodology. The current chapter begins the discussion of findings; the first part addresses research questions regarding participants’ constructions of their reproductive tissues and their utilisation. I demonstrate that reproductive tissues are closely aligned or situated within a “kin ethics” framework (Roberts 2007). These meanings are determined by the biological properties of the tissues as well as the broader social meanings. I argue that most participants attempt to quantitatively manage their supply to counteract the qualitative unpredictability of their oöcytes. The second part of this chapter outlines more specific attitudes beyond the general disinclination to provide oöcytes to SCNT research. I demonstrate there was little consensus about the establishment of a financial equivalence for which oöcytes may be traded despite their shared perception that oöcyte extraction requires an inordinate amount of discipline and their preference that the recipient be a research company. This preference is based on an expectation that the recipient is capable of transforming the gift into something useful. Ultimately, many aversions to providing oöcytes to SCNT research are revised if the tissue is given within a context of a specified benefit or beneficiary. Based on this, I suggest that the tensions and ambiguities of oöcyte provision to SCNT research can be mitigated with the establishment of an affective framework.
Reproductive tissues and the “ethics of kin”

Discussing the attitudes and perceptions regarding oöcyte provision must make reference to other tissues. I will illustrate some of the complex meanings surrounding oöcytes and their potential utilisations with reference to another tissue discussed in detail in this study, the embryo. Attitudes towards oöcytes and embryos show that on one level, they are not analogous tissues even though they are both reproductive and necessary for having children. One way to understand this ambiguity is with reference to Roberts’s (2007) distinction between “life” and “kin” ethics. This binary was used as a conceptual framework to understand the fact that embryos are subject to competing moral frameworks. “Kin ethics” frames decisions about embryos in relation to their meanings as potential children, often privileging conventional notions of kinship based on biology such as the nuclear family. The opposing view, “life ethics,” emphasises that decisions about embryos must be made in relation to an inherent status as life and thus have an inherent right to existence; to ensure this life, embryos can and should be placed outside their original family. Roberts found that many of her participants preferred that their embryos succumb rather than provide them to other people for reproductive purposes. This was despite the fact that the couples were undergoing fertility treatment in Ecuador, a predominantly Catholic country. The Catholic Church is an institution that has consistently argued against the use of ARTs on the basis of its technical approach to reproduction, citing its grading systems, implantation of “good” embryos, the discarding of bad or old ones and the often indefinite storage of others.

For participants in our study, irrespective of cohort, oöcytes are not situated within the “life ethics” framework or considered as an entity with a moral status – a finding that concurs with research by Purewal and van den Akker (2010) and Haimes, Taylor and Turkmendag (2012). Yet, this lack of moral status does not help to easily position oöcytes within the “kin ethics” framework. For instance, participants perceive their oöcytes in predominantly functional terms, as a means to an end, and their value is derived from this function. The following participants, all of cohort one, compare the status and importance of their oöcytes with the embryo, which unambiguously fits within the “kin ethics” framework. This is because the reproductive potential of embryos remains after the patient has finalised his or her fertility treatment. Participants emphasise that the status of the embryo as a potential child in relation to an imagined family and echo similar sentiments expressed by those in
Haimes et al.’s (2008, 115) study who regarded the embryo much *closer* to a baby than an oöcyte despite the fact that “the embryo was [not] simply seen as the equivalence of a baby”.

**Atilia**: I can’t see the difference between an oöcyte and any other cell because an oöcyte…it can’t turn into a baby with sperm [sic] so I feel its [use in research is] alright…I think that the moment the oöcyte becomes human, when it’s fertilised, it’s a completely different story.

*(Undergoing fertility treatment)*

**Mandy**: Well, an embryo is just much closer to a possible baby. An oöcyte’s only one part of it; it’s only my part of it... I... Well, an embryo, life has already commenced, so that’s how I see it as different. The oöcyte is just potential; the embryo, life has already commenced, so that’s started already. So they’re quite different…to me.

*(Undergoing fertility treatment)*

**Caroline**: Because my oöcyte and Paul’s sperm together is our child. My oöcytes are just one half of a child. They’re not my child (sic). You know? Whereas an embryo would be ours; it is strange, I guess maybe in some ways it doesn’t make sense.

*(Undergoing fertility treatment)*

Irrespective of cohort, participants valued their oöcytes in relation to its reproductive function, as tissues with a significance derived from the capacity to help create children. When asked about potentially utilising their oöcytes in reproductive donation, participants responded that the biological properties of oöcytes – the transfer of DNA – situate their oöcytes within the “kin ethics” framework, although this may not be their own family.60

**Frances**: if it’s my genetic material, it should go to someone I trust t bring it up properly, because I don’t think it would be right to give half of my DNA (sic) to go towards a child that would be in a horrible family.

*(“Healthy donor”)*

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60This emphasis is particularly evident in the responses of reproductive oöcyte donors in this study, to be discussed in the next chapter.
Vanessa: I wouldn’t perceive it as my child, it’d just be my oocyte, someone else’s child.

(“Healthy donor”)

The connection between temporal and biological dimensions of oocytes and embryos are two factors which help to further demonstrate why embryos are less ambiguously situated within the “kin ethics” framework compared with oocytes despite the fact that without oocytes (and semen) embryos could not exist. The first factor is that the potential of the oocyte is future-oriented in that the capacity of particular oocytes to be fertile is unknowable until attempts at fertilisation occur. Prior to fertilisation, oocytes exist as an undifferentiated tissue; that is, they all have the potential for reproductive capacity. After fertilisation, oocytes become confirmed as fertile or infertile, an absolute status with no capacity for human discretion or intervention. However a woman decides to utilise her oocytes (for reproductive or SCNT research purposes), the decision must occur prior to fertilisation because these are mutually exclusive utilisations. The second factor in participants’ decisions is cryopreservation. While, there are many efforts to improve the success rate of oocyte cryopreservation, it remains relatively low, particularly compared to semen and embryos (Homburg, van der Veen, and Silber 2009). The cryopreservation of embryos is generally successful and may act as an “affordance point”, a material practice which immobilises the development of the embryo and allows couples the time to consider their potential utilisation outside more immediate moments of fertility treatment (Waldby and Carroll 2011). By generating time between the immediate context of fertility treatment, decisions about the further utilisation of the embryo are not characterised by the same sense of urgency or irrevocability.\(^{61}\)

Quantitative risk management and oocytes

So far I have suggested that oocytes are an initially undifferentiated tissue in that when they are removed from the ovaries they are all regarded as potentially fertile. It is the process of

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\(^{61}\) The existence of viable and frozen embryos and their potential uses are subject to intense public debate (Haimes and Taylor 2009). I shall discuss the various ways that embryos considered excessive to an individual’s fertility treatment may be used. This discussion will further elaborate on the differences between oocytes and viable embryos and show that questions of utilising the latter are based on retaining their status as potential children.
fertilisation that acts as a means of differentiation and classifies some oöcytes as fertile and others as infertile. These functional designations are the primary basis for the tissue’s ontology and it is from this functionality that oöcytes derive their value. This lack of moral status should not be taken as an indication that participants have no specific intentions for oöcytes. In fact, in almost all cases, they prefer to use their oöcytes for reproductive, rather than research, purposes. This finding is consistent with data reported by Haimes (2013). This preference is connected to the woman’s intention to become a mother. Irrespective of cohort or whether their intentions to become a mother figured in their immediate, medium or long term plans, participants suggest that giving away unfertilised oöcytes seriously jeopardises the opportunity to become a mother.

The specific biological properties of oöcytes help determine the way participants manage this tissue. Oöcyte management differs from managing the “health” of one’s own blood (discussed below) and embryos. As the fertility of oöcytes is a qualitative designation and impossible to determine, participants refer to quantitative strategies to manage their oöcytes. The number of oöcytes available for reproductive fertilisation must not be intentionally depleted with “extraneous” practices. Given the uncertain fertility of oöcytes, participants indicate that their form of risk management is to refuse giving their “good eggs” to SCNT research and keep them in order to fulfil their intentions to become a mother. Uncertainty regarding the fertility of oöcytes puts the onus on the individual to manage their supply in numerical terms, rather than in terms of its quality.

_Atilia:_ because you never know how many of my oöcytes will be fertilised, so I need as many oöcytes as I can have!

(Undergoing fertility treatment)

_Denise:_ Um, I’ve got to be selfish. I don’t have oöcytes, so [those] I do have, I’m keeping for myself.

_Interview (K.C.):_ Yeah. And what if you had, say, ten or fifteen oöcytes – would you still go, "Nope, these are my oöcytes?"

_Denise:_ Yep.

_Interview (K.C.):_ Yep. So you think it’s not worth the risk, or..?
Denise: Yeah, and especially if... If I was guaranteed to be getting the best quality out of that? Fair enough, I might consider it. But if I’m... the mix of the good and the bad, then no. I’ve got to put me first.

(Undergoing fertility treatment)

Rebecca: do you take that chance that that one live child might have gone to research?

(Undergoing fertility treatment)

Dominique: with embryos…I’ve taken what I need whereas with oöcytes you don’t know with them.

(Undergoing fertility treatment)

Isabel: But then I would have in the back of my mind, have they taken the ones that potentially would be fertilised?

(Undergoing fertility treatment)

The quantitative strategy women employ regarding their oöcytes is based on the relationship between the tissue’s biological properties and its social utilisation. Capturing the specific considerations involved in utilising oöcytes may be facilitated by discussing issues related to blood and its provision. As Valentine (2005) argues, donating blood in Australia continues to resonate with being a good citizen in a way that is implicit and explicit in debates about tissue provision for scientific research. In a society permeated with medical risk discourses, sharing the substance is an indication that the individual has been a good manager of their blood because they have avoided risk. According to Valentine (2005, 116), blood “bears the imprint of intimate practices – who we’ve had sex with and what that sex was, what drugs we’ve taken, what food we’ve eaten”. Thus, the act of providing blood is not just a matter of helping others but represents one’s status as having healthy blood. This issue is further explored in a publication by Waldby et al. (2004) showing the way blood serves to distinguish between people and the communities in which they may be included (and specifically focusing on interviews with people infected with the Hepatitis C virus).62 This group provides an opportunity to explore the connection between tissue and social identity

62 Waldby et al. (2004) and Valentine (2005) refer to the same dataset.
and was reported to have internalised the “risk” they pose to others and were self-regulating their exclusion from the donor pool.

The ability to share one’s bodily substances is subject to the tissue’s biological properties and its social meanings. In the context of blood provision, giving the substance is a positive sign of an individual’s generosity, health or status but in the context of oocyte provision, it is the sign of poorly managing a scarce resource. As long as the fertility of a particular oocyte cannot be predicted, hoarding the finite resource is one means of good management and evidence that the individual has ensured to some degree their chances of becoming pregnant.

I conceptualise participants’ refusal for egg provision as a quantitative-based strategy, which can be considered as a form of risk management. The classic form of risk management is the economic view of utility maximisation where the costs of giving oocytes to research are compared with the benefits of doing so. By referring to a risk management strategy, I evoke a sense that participants calculated the costs and benefits of egg provision to research. In this respect, Haimes’s (2013) perfunctory analysis of women’s decisions differs from my own.

Haimes (2013, 50) argues that few participants in her research project “engaged in detailed calculations of risk; most focused instead on their hope” and briefly draws ideas from Simmel63 and Gross (2012) to argue that non-information can be just as part of the deliberative process as rational calculation. However, I do not consider these to be mutually exclusive. Just because participants in the UK study expressed their hope that extra treatment might provide to their overall chances at pregnancy does not rule out a sense of rational calculation. Indeed, given the fact that fertility treatment is so unpredictable, it is reasonable to argue that such participants are engaging in rational calculation by situating one round of fertility treatment within many rather than focusing on the unlikely possibility that one treatment will suffice. Thus, the difference between the UK study and the one from which I refer is that participants in the latter considered one treatment cycle sufficient to result in a pregnancy.

63 No specific reference is cited for this author.
Egg-sharing for SCNT research

Egg-sharing involves the provision of “good eggs” by fertility patients rather than “healthy donors”. Egg-sharing schemes are regulated differently around the world and did not occur in the fertility clinic from which our sample was recruited. Participants in cohort one responded to the suggestion of egg-sharing schemes in overwhelmingly negative ways. This was partially based on the biological properties of oöcytes as fragile and unpredictable. Drawing on their experience of fertility treatment these participants considered egg-sharing as inherently exploitative, placing women in the difficult situation of choosing between their intentions of becoming a mother and the prospect of having to predominantly finance the process themselves.

Mandy: Well, I wouldn’t do it, but that’s only because having gone through IVF, I had twenty two oöcytes, and ended up with, over two cycles, four – like four embryos that could be used. So knowing how the numbers can drop so dramatically, when obviously I saw the number twenty two and was like “Wow! That’s so many! You know, I’ll be able to get ten cycles out of that if I have to!” So knowing that, I... I can’t see how that would be an incentive for people, but I’m not in other people’s shoes. I would never do that, for five hundred dollars...I wouldn’t do it if they said they were going to pay the whole IVF fee, so I don’t know how other people are motivated by money... Yeah, so that’s hard, not being in someone else’s shoes, so... No amount of money would compensate me for the possibility of me losing oöcytes that might lead to a pregnancy. (Undergoing fertility treatment)

Joanna: But to say that I have to give you this so I can afford IVF, because if it’s that expensive that people have to go down [that road] …you’re forcing people to do that. I think you should give people the choice, a proper choice, not a financial choice, because people with money don’t have to. (Undergoing fertility treatment)

Nadia: Oh, that’s bad! It’s good in, like, one [way], because she agrees to do that, but if you look at that, she’s going through so much stress, like having a baby and those things, and then because of the financial matters she has to agree, even if she doesn’t
like, she has to agree to do it. Maybe she doesn’t like it. Definitely (laughs) doesn’t like it, but still there’s no other option, so it’s more stressful for people to get what they want.

(Undergoing fertility treatment)

In the first study to evaluate the egg sharing scheme in Newcastle (NESR), considered controversial by scholars such as Dickenson and Alkorta Idiakez (2008) and Roberts and Throsby (2008), Haimes Taylor and Turkmendag (2012) and Haimes (2013) contend that the establishment of egg-sharing programs, even in the UK where fertility treatment is not as heavily subsidised as in Australia, women’s participation in such a scheme is not fait accompli. Participants from the UK study generally asserted that they would not consider clinically viable oocytes available for research and most of the patients at the fertility clinic did not opt for the discounted treatment in exchange for their oocytes because they needed “enough” to be able to consider the possibility of giving away 50% of oocytes removed. Women earning high incomes were active participants in the scheme (2013). Further, participants did not express a sense of exploitation because they felt they made their own decisions (indeed a condition of participating as an egg-sharer is that the woman must volunteer herself and not be approached). Ultimately, it is acknowledged that the subjective and objective dimensions of this issue might not be satisfactorily resolved, suggesting that while women may not perceive themselves as exploited, “these are not necessarily decisions made under circumstances wholly of their own choosing” (Haimes, Taylor and Turkmendag 2012, 9).

Studies looking at egg-sharing within the context of reproduction show that financial issues are very important in prompting providers. Blyth (2004, 157) reported on the experiences of women and their partners who had pursued or declined egg-sharing arrangements (n=38). The participants in the study could only access restricted NHS- fertility treatment and could not afford private services. The majority of respondents did not express their regret at partaking in egg-sharing and many agreed with the proposition that such regimes are mutually-beneficial to recipient and donor couples allowing each dyad to pursue their treatment. Donors were initially motivated to give their oöcytes for financial reasons, but empathy with the potential recipients became a significant motivating factor for egg-sharers. Blyth reports that participants in egg-sharing schemes who did not have enough oöcytes
retrieved to share them experienced feelings of sadness that the recipient may not have the opportunity to conceive.

More recent research undertaken by Gürtin, Ahuja and Golombok (2012) report that the overwhelming majority of women in their study (both donors and recipients of oöcytes for reproductive purposes) experienced egg-sharing as positive. This study drew on questionnaires returned by women (n=86) who had participated in the egg-sharing program at the London Women’s Clinic between 2007 and 2009. Participants had the opportunity to select words to describe their experience and the most commonly used were “rewarding”, “satisfying”, “happy”, “grateful” and “nervous” (2012, 703). The authors also note that most of the participants (specifically the donors) are educated to tertiary level and work in professions – a variable that may provide some convergence with the research undertaken in this study. A significant majority of donors in the study (87.5%) disagreed with the statement that "egg-sharing is exploitative" while 4.2% agreed. The authors do temper their findings to a degree by pointing out that their sample is over-representative of women who have successfully carried a pregnancy to term in comparison with the general population of patients at the clinic.

I suggest that differences between perceptions of egg-sharing schemes hinge on two factors. Firstly, the existing environment can influence participant’s expectations. For instance, the Australian health care system generates a sense of universal entitlement to fertility treatment by allowing heavy subsidies and not impose age, health or location restrictions on accessing the services means that patients do not have to necessarily ration the number of treatment they will access. Secondly, perceptions and decisions differ according to whether egg-sharing occurs for reproductive or research purposes. Helping others to have children provokes different sentiments than helping scientists produce new knowledge and/or therapeutic benefits.

**Giving oöcytes to SCNT research as waste management**

The preceding discussion has demonstrated that for most women undergoing fertility treatment in our study, oöcytes are not given to SCNT research on the basis of their unpredictable biological properties. Since oöcytes are just a means to an end, however, once
they have been defined as unviable through fertilisation (a functional and technical designation) they are often viewed by participants as appropriate material for scientific research. This shows that beyond their functional utility, oöcytes have little sentimental or moral value for participants who are primarily intent on using them to become a mother.

**Interviewer (M.B.):** Just say it was your next IVF cycle, would you donate any of those oöcytes from that batch to stem cell research?

**Caroline:** Only if they didn’t fertilise. And only if they were no good to me…I’m not going to put my body and emotion and time through that just to give it away. They’re too precious, when you’re going through IVF, to do that.

*(Undergoing fertility treatment)*

**Bridgit:** I would donate what was left over, because it’s such a waste, isn’t it? They just sort of get put down the gurgler and nothing gets done with them.

*(Undergoing fertility treatment)*

Distinctions of function influence whether oöcytes can be given to SCNT research. This last respondent specifically suggests that giving infertile oöcytes to scientific research is a form of waste management, a way of utilising oöcytes in a meaningful way if they prove to be clinically unviable. Infertile oöcytes are designated as waste in the process of fertility treatment by both clinicians and patients; for this reason, one might assume that giving infertile oöcytes to SCNT research would be uncontroversial. Giving away infertile oöcytes is possible because they do not undermine participants’ intentions to become a mother.

Designations of waste are specifically based on the tissue and the symbolic or physical significance to the individual. In a study of cancer patients and staff in an Australian hospital, Morrell et al. (2011, 80) show that the participants exhibited a decided willingness or indifference to the donation of their cancerous tissue, regarding “their tissue [as] “useless”, “waste”, and was intended to be thrown away”. The tissue is a symbol of the

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64 The NHMRC has issued a number of Australian research licenses that exclusively use clinically non-viable oöcytes and only one centre (attached to a private fertility clinic), Genea, is currently licensed to use such oöcytes for its SCNT research (National Health and Medical Research Council 2013).
illness from which they need and want to be separated. I argue that it is possible to see similarities between oocytes and other tissues that are categorised in relation to their biological utility rather than their social meanings. The removal of cancerous tissue in the therapeutic context is expected to bring the patient back to health. Moreover, given that the ‘regular’ self has been literally threatened by the presence of the tissue, removing the latter is expected to restore the ‘self’ to normality. In the context of oocyte provision to SCNT research, participants in cohort one can give their ‘waste’ tissue (infertile oocytes) without a significant impact on their therapeutic goals whilst maintaining some sort of donor identity, albeit a very limited one. In refusing to give good eggs to SCNT research, these participants protect their intentions to become a mother because they perceive that this social role cannot be obtained if they pursue oocyte provision for research.

**Oocyte provision for SCNT research: extraction, time and lifestyle**

Donating oocytes for research is perceived to affect one’s imagined future as a mother as well as the individual’s life as it currently is. This is based primarily on the idea that the participant already has commitments in her life that will be unsettled by the introduction of a new activity. ‘Time’ here is imagined as an entity that is possessed and spent in specific ways: in life, time is spent on various components such as employment, relationships and study. It is obvious that taking medication, undergoing ultrasounds and blood tests takes time but participants are not especially convinced that they have the time to undertake the process. Ideally, the intensity spent on regular activities is not expected to be reduced while the donor undertakes oocyte extraction. Most participants perceive that to undertake the process will dispossess the donor of time usually spent on her “ordinary life” and thus do not wish to accommodate oocyte provision because they are already busy.

**Grace**: it’s also, like, when in my life could I do this? Even for the money, I mean, when I’ve just got out of uni, maybe, when I get into a job. Once you have a job, once you have family commitments, who can just really take eight weeks out of your life?…It’s just a big commitment, and I’m not sure who has that space in their life for that commitment. Like I said, maybe when I’ve just finished uni, before I got into a set job, I would probably have that much time for that commitment, but that’s about it.
Then again, it’s probably when I’d most want to do it, because I’d have that damn HECS debt! (laughs).

(“Healthy donor”)

Interviewer (KC): And would you undergo an oöcyte collection cycle purely for donating oöcytes for research?
Sarah: No not now, no…Now that I’ve got two children; well, one on the way... You know, it’s such a difficult thing to manage. For eight weeks you have to be regimented that at twelve-hourly intervals you’re doing a medication thing. And it extremely affects your mood: you can’t work and manage the drugs and manage a family life and all the balance…it’s a very difficult thing to do… [Research oöcyte provision] would mean a commitment from women to actually go in and purposely go through the treatment [stimulation] to donate. And I’m not prepared to do that. Because one, I don’t have the time. Two, it’s very traumatic rationally.

(Undergoing fertility treatment)

Jenny: A couple of times we were away and I had to kind of take it [medications] all with me and do it wherever I was, so I guess yeah, just trying to stick to the routine with all the other demands of children and so on was a bit challenging.

(Reproductive oöcyte donor)

Julia: Yeah, it is kind of offputting. Like, I didn’t know anything about the process, how intense it is. It is kind of offputting. It’s not like, “Hey, have my eggs,” it’s actually six weeks of what could potentially be awful.

(“Healthy donor”)

Participants in our study suggest that oöcyte extraction requires a high level of effort that displaces other features of “normal” non-donor life because it reorders their life around the specific moments of ovarian stimulation. This indicates that potential donors assess the “social side effects” of the medical regime in addition to the physical ones. Combined, these

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65 HECS stands for Higher Education Contribution Scheme, introduced by the Australian federal government in 1989. Students were charged tuition fees for tertiary education but were able to defer repayment until their salaries reached a minimum amount.
effects render the process of extraction as something akin to a job to which allows little flexibility to engage with other activities. However, as will be discussed below, the social and physical discipline does not equate to employment.

The discussion of accommodating oöcyte extraction into the individual’s life is an infrequent subject of discussion in the literature (Kazem et al. 1995; Byrd, Sidebotham and Lieberman 2002; Purewal & van den Akker 2009; Klitzman and Sauer 2009; Haimes, Taylor and Turkmendag 2012). Yet such an analysis is important in providing a more nuanced understanding regarding the dearth of oöcytes for research purposes. This discussion goes beyond reports that many women are likely to decline giving oöcytes once they have been informed of the procedure (Murray and Golombok 2000) by showing that the decision to decline to give oöcytes is based on how it affects the individual’s day-to-day life and long term future.

**Self-exclusion and hierarchies of emotional effort**

Participants irrespective of cohort, regarded the temporal demands required for oöcyte extraction to be extraordinary: that they exist outside ordinary life and for this are unlikely to be accommodated. In contrast, constructions of the emotional dimensions of oocyte extraction are more flexibly and dependent on the participant’s experience. Here it is necessary to point out that these constructions involve projecting certain characteristics onto groups to which one does not belong. For example, participants in cohort one considered oöcyte extraction as emotionally demanding and especially emphasise the emotional aspects of producing oöcytes in the context of trying to become pregnant. Participants in cohort one characterised the extraction of oöcytes, the result of weeks of medication, bloods tests and ultrasounds, as a moment of intense pressure because the number of oöcytes retrieved for that time is finite; the only way to get more oöcytes is to undergo another round of medication and surgery. The removal of oöcytes is always coupled with the outcome – having or not having a child.

**Lisa:** for us, [patients] it’s a case of “Do we or don’t we get a child at the end of it?”

*Undergoing fertility treatment*

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66 I am specifically referring to ovarian stimulation and oöcyte removal.
Interviewer (KC): And what do you think are the main aspects you’d want communicated to this young group of women about becoming an oöcyte donor?

Dominique: The emotional aspect of it, definitely. It’s very up and down, and because the drugs escalate that as well…I guess if you’re just going through the process of giving your oöcytes up at oöcyte collection, then you don’t then have the – are they going to fertilise? Am I pregnant? So you don’t have all that which, certainly for me, was the worst part of it.

(Undergoing fertility treatment)

In the context of fertility treatment, oocyte extraction is always a means to an end, not an end in itself. Within this context, oöcyte extraction is a symbolically potent signal of the patient’s fertility and the subsequent course of her treatment. The high emotional cost of the process is endured because it is a step to achieving one’s intention to become a mother. Outside the context of one’s own fertility treatment, oocyte extraction becomes an end in itself. Without the goal of getting pregnant, the emotional aspects become ‘traumatic’ and are thus used by respondents as a basis for refusing to give oocytes outside of fertility treatment. These responses diverge from studies which found that “less-fertile” women were more likely than fertile ones to provide their oöcytes for research (Kazem et al. 1995; Purewal and van den Akker’s 2009).

Participants in cohort one contextualise their experience of oöcyte provision within the precarious and unpredictable journey of trying to become pregnant and construct it as emotionally traumatic. Yet, the same participants often represent undertaking oöcyte extraction for SCNT research as lacking any of this intensity or meaning. Indeed, the “healthy donor” is presented as ideal for their social characteristics as much as their biological ones. An important dimension to this construction is that oöcyte providers to SCNT research are represented as undertaking the process in a perfunctory manner, devoid of emotional attachment or impact on the individual, precisely because she is assumed to have less at stake.

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67 It is not clear whether the women in these studies were more likely to give their unviable oöcytes and to what degree the timing of the donation mattered.
Mira: if…you’re doing it purely for research…they might think, "Oh, this is easy!" because they’ve got no emotional strings attached to it, whereas if I go through oöcyte retrieval, there’s a lot of emotion and, you know, feeling towards it”.

(Undergoing fertility treatment)

Sarah: it’s not that overwhelming, it’s just more when you’re in a position where this is the be-all and end-all: to have your child, then it’s completely consuming. If you’re going in for a totally different purpose, then you’re trying to assist others. It’s a totally different approach.

(Undergoing fertility treatment)

Participants in other cohorts share perceptions that research and reproductive oöcyte provision are different. These differences relate to the donor’s motivation and relational outcomes and expectations – to whom they will provide their oöcytes, its result and whether they will consider undertaking the process with or without payment. In contrast to the assumptions made by participants in cohort one, participants in cohorts two and three do not think that oöcyte provision for SCNT research can be undertaken in a detached way simply because one’s immediate fertility future is not at stake. It is, however, a process that does not attach them to other people in the immediate or long-term future. As the responses quoted below indicate giving oöcytes to SCNT research is different than its reproductive counterpart precisely because it does not create a new relational figure (a child) and it is acknowledged as a temporally delimited process, that is, it has a beginning, middle and an end. If the individual is willing to accommodate oöcyte provision, it is only for the duration of physical process rather than indefinitely, as is potentially the case in reproductive oöcyte provision, where children born from donor gametes may seek to contact that person once they turn 18 years old.

Julia: I’d probably feel differently about donating oöcytes for research as opposed to donating oöcytes for reproduction. Strangely enough, I think I’d feel happy about donating oöcytes for research rather than for reproduction, because I just personally don’t want to have a half-child out there and not know them.

(“Healthy donor”)
Mathilde: Well, just the same reason – if it’s to reproduce, then it has the potential that it might have my kid somewhere on earth, and just that feeling might disturb me. But research – nothing’s going to happen at the end. It’s just for the sake of science. (“Healthy donor”)

Reciprocity and oöcyte provision for SCNT research: unresolved tensions

Differences between reproductive and research provision are also evident in the expectations for reciprocity. At first glance, scientific oöcyte provision appears to lend itself to a commercial transaction in contrast to giving oöcytes for reproductive purposes which participants insist should prelude monetary payment (this will be discussed in more detail in chapter seven). These views are rationalised in two broad ways; on the one hand, some participants argued that oöcyte provision to research is analogous to other forms of participation and contribution in scientific research such as clinical trials or surveys that, in the popular imagination, are usually based on commercial transactions. On the other hand, participants situated the expectation for reciprocity within the broader structural context in which scientific research is conducted. Without some form of net benefit, the individual is potentially being exploited for their generosity if companies will stand to benefit enormously from provided tissue. It is noteworthy that participants, quoted below, could not precisely articulate the basis of this difference but suggested that these invisible boundaries should not be breached.

Rose: I don’t like the idea of payment for oöcytes for reproductive or other, really...especially reproductive. I don’t know why it’s different, but it feels different! (“Healthy donor”)

Lisa: You know what? For some reason, I don’t really have a problem with people being paid by a research company to donate it [oöcytes] to research. I really don’t have a problem with that. I have a problem with it being to donate for reproductive purposes...because I mean now we pay people...doing weird study like injecting themselves with things...I can’t articulate why [I have a problem with payment for reproductive oöcyte provision]. (Undergoing fertility treatment)
Donna: for stem cell research...I'd probably feel better about it if I got some form of compensation...when I donate to a couple it's the great joy that what's going to happen but for research I definitely think I wouldn't say no to it.

(Reproductive oöcyte donor)

Grace: Yes. I have less of an issue with [payment for] research than for reproduction. I actually don’t know why! (laughs) I just do! Like, for research, it seems more like they should pay me for it, because you pay when you do research. You pay for things. You pay for materials, you pay study subjects to do focus groups with you...! (laughs) So it just seems more fitting for there to be payment for research than it does for there to be payment for [reproduction].

(“Healthy donor”)

Raphaelle: Yeah, sort of or more from a line of, what you’re giving for free is contributing to their research which is going to make them a few billion dollars, so it’s kind of unethical for them to not, not even compensate, but not provide an equitable exchange.

(“Healthy donor”)

The responses are similar to the results from Klitzman and Sauer’s (2009) survey of women, who overwhelmingly considered that research and reproductive oöcyte provision should be “compensated” with the same amount of money (US$8000). However, the degree to which these two studies may corroborate the other’s evidence is limited. Participants in Klitzman and Sauer’s study undertook the process in the US where reproductive oöcyte provision regularly occurs within a payment system. This institutional framework has significant repercussions for which is presumed “normal”.

Despite the fact that the procedure is the same for reproductive and research oöcyte provision, the perception remained that they are distinct undertakings. No participant expressed the idea that they would give their fertile oöcytes to research without some form of reciprocity. In part, the responses from our study suggest that individuals do not perceive contributing to scientific research as rewarding in itself. Moreover, the original claim that
reciprocity is more appropriate for oöcyte provision for research than for reproduction becomes on closer inspection a more fragile sentiment. In its own right, the introduction of payment produces anxiety not about the appropriateness of receiving money but rather being primarily motivated by it. If money is to be included in the relationship between individual donor and recipient, it should be peripheral rather than central to it.

**Interviewer (K.C.):** And what do you think the right reasons [to provide oöcytes for SCNT research] are?

**Denise:** To help someone else, whether it be for reproduction or research, you should be doing this, not because you’re going to profit from it.

*(Undergoing fertility treatment)*

**Alicia:** Because if you’re genuinely willing to do it, and go, “I get paid so that’s a bonus well that’s great, but I think if you offered to pay someone for donating their oöcytes, it would just get into too much of a risky business. People would be donating not because they wanted to, for the research, but because they need the money, and I don’t think that’s a good reason.

*(“Healthy donor”)*

The responses from our participants reveal visceral reactions that are rather nebulous and they do not provide a rational basis for such responses. Instead the responses may point to norms about receiving money in exchange for a "gift" no matter how onerous the process for the donor.

**Yvette:** For me, I wouldn’t want, I wouldn’t want to be paid for it, because I would feel uneasy about that, but I don’t know how I would feel about it being legal for people to be paid, or if people were paid for it. I just know, myself, I would want to do it because I’d feel that that’s a good thing to do.

*(“Healthy donor”)*

**Mona:** It’s a really difficult decision, because it kind of takes...I feel it takes a bit out of the whole donating and giving and stuff, if you’re expecting to be paid for your
services, then it’s just another...I don’t know. I think I’d have a lot of issues. If I’m getting reimbursed so I’m not losing anything other than the oocyte that I’m donating.

(“Healthy donor”)

**Delia:** Yeah. I have the same feeling with the money. Like, I don’t know why, because you think, “OK, I’m providing them with something they need; why shouldn’t I get paid?” but when you introduce money into it, in some way it almost taints it, and I don’t know why that is.

(“Healthy donor”)

The data depart from Titmuss’s (1997 [1970]) views in particular on the vendors of human tissue such as blood. Participants do not necessarily regard oocytes vendors as morally dubious characters although these claims too are contentious. Many participants in cohort one rejected the possibility that they would accept money or discounted fertility treatment but often expressed the view that women who fit the “healthy donor” category are ideal ‘donors’ for social as well as medical reasons. That the “healthy donor” is invariably young and youth often involves the often-irresponsible pursuit of material possessions and/or money, the ‘healthy donor’ became a convenient counterpoint to the experiences and choices of the fertility patient. As indicated from the discussion regarding the emotional dimensions of oocyte extraction, the figure of the young woman is often constructed in opposition to the fertility patient. Young women have plenty of eggs to offer, their fertility is robust and if not infinite then as close as possible to it.

In some contexts of tissue provision, the connection between moral identity and providing blood for money continues to be a concern and means of hierarchically organising “donors”. In her study of Australians’ attitudes towards blood donors Valentine (2005, 118) found that blood donors are perceived as actually doing something everyone has the capacity to do but often refrain from doing; as such they are “discussed...in language invoking moral superiority [and] are seen as more caring, compassionate, and generous than non-donors”. This perception is contrasted with that of potential vendors of blood and the question of whether payment for blood should be introduced in Australia. Participants in Valentine’s study assumed that if blood was saleable, socio-economic hardship and drug addiction would be the primary motivators of vendors. Participants constructed paid blood providers as
dangerous to recipients and “the moral valuing of the donor as a compassionate and more generous citizen than normal is reversed in assessments of the potential paid donor…because they may indulge in riskier practices [and be] willing to expose other people to harm” (Valentine 2005, 123).

Compensating ‘healthy’ donors

The process of establishing a financial equivalent for oöcytes in the context of SCNT research is further complicated by the concept of compensation. The term compensation was discussed by participants in all cohorts and referred as a separate option to paying women in an unregulated market. It was made clear to participants that compensation involved the provision of oöcytes for money but they determined its precise amount. For some participants, the difference between ‘payment’ and ‘compensation’ can be a simple question regarding the sum of money that constitutes both categories.

**Interviewer (M.B):** Does anyone want to talk about a number or does anyone want to talk about the idea of compensation versus payment?

**Julia:** I think five grand would be compensation and ten grand would be payment! That’s what comes to me.

(“Healthy donor”)

Compensation was overwhelmingly considered an appropriate form of recognition and reciprocity for oöcyte providers to SCNT research with these responses indicating an interest in distinguishing between “payment” and “compensation”. Participants expect recognition for their effort through compensation and that is likely to be monetary. It also shows that donors make careful evaluations about the research to which they may contribute and assess recipients on the basis of whether they can deliver on therapeutic promises.

**Naomi:** I like the compensation model. I’m not really comfortable with the idea of paying for oöcytes, but if someone was really desperate for oöcytes for some kind of disease in particular, then I would be comfortable with paying women.

(“Healthy donor”)

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Giselle: Yeah. You should be compensated, because obviously you’re going out of your way, and there’s other things...you don’t want to be, like, at a loss in terms of emotional impact as well as financial and whatever other impacts come into it, but yeah, payment is anything above that, kind of thing.

(“Healthy donor”)

Rose: I agree, even though I was the one who brought up the “I want to be paid for it!” Like, I wasn’t thinking exorbitant amounts of cash. I was thinking more something along the lines of something that was more fitting with what you’d taken out of your time and everything to do, I guess. Like, ten thousand dollars sounds ridiculous to me...I was thinking a few hundred.

(“Healthy donor”)

So far, analogies to work convey the idea that the data corresponds closely to arguments made Waldby and Cooper (2008) and Dickenson (2006) that the process of oöcyte extraction is a form of production in an economic sense because it requires an embodied effort as well as extensive self-management. However, wider acceptance of a compensation model may indicate that strict analogies between work, effort and labour are too rigid. For instance, if these participants know that individuals are ‘paid’ for labour and not ‘compensated’, then rejecting ‘payment’ makes little sense. This also implies that participants do not want to maximise the profit that may be gained by undertaking oöcyte extraction for SCNT research. It suggests, on the one hand, that oöcyte extraction is laborious and the discipline needed to undertake it should not belittled but on the other hand, it is imprecise to categorise the process as ‘labour’ which should be treated as a regular commercial transaction where labour and products would be sold. This indicates that while participants do expect some monetary reward, they do not want to be ‘paid’ for their contributions.

Views of stem cell research

So far in my discussion of the meanings of reproductive tissues within the framework of “kin ethics”, I have already indicated that participants are most likely to give their oöcytes to SCNT research once fertilisation decides the oöcyte’s reproductive potential. The discussion focused on the tissue’s biological properties and the process of extraction as important
factors in their provision to stem cell research. I also examined the ambiguities of establishing a monetary equivalent for oöcytes given the context of commercialised scientific research. This analysis does not tell the entire story regarding the scientific utilisation of reproductive tissues because the issue gets reduced to a biological matter. Giving or not giving away one’s oöcytes is essentially a relational issue which in the case of donating oöcytes to SCNT research, women become involved in a relationship between science, researchers, companies, contemporary patients and future generations. In order to understand the circumstances in which women can give even their “good eggs” away, I will turn address views related to scientific research, values and disclosure.

As discussed in chapter four, literature pertaining to the public understanding of science or utilisation of human tissues demonstrates that people do not always explain the world with scientific meanings or consider the production of scientific knowledge as a “public good” which can benefit everyone in the community (Lock 2001; Irwin and Michael 2003; Reddy 2007). The HGDP is but one example of scientific controversy involving incompatibility of world views regarding scientific research. It is sociologically important because it galvanised an opposition to scientific research that could not be ignored or dismissed for its religious conservatism or Ludditism and provoked questions regarding the “politics” of science.

In the public debates regarding the development of stem cell research, opposition predominantly concerned the utilisation of embryos. Within scholarly literature, particularly from feminist-oriented perspectives concerns were focused on the lack of comment regarding the supply of reproductive tissues needed for the research (Dickenson 2006). As I argued in chapter four, views regarding the provision of oöcytes to stem cell research tend to be based on underlying assumptions about the “public benefit” of scientific knowledge and applications. The regulatory environment based on informed consent cleanses different views regarding stem cell research by facilitating the decisions to be made on an individual level.

Further discussion of participants’ attitudes towards providing their oöcytes to SCNT research must be examined in relation to their vies regarding the research generally. Here we can develop a deeper understanding of their views, moving away from biological factors. Stem cell research figured quite positively in the participants’ imaginations. Participants
generally approved of scientific research and occasionally situated it within a nationalistic
discourse regarding Australia’s capacities and standing in a global order.

**Interviewer (K. C.):** And do you have any professional, spiritual or religious views that influence your attitude to stem cell research?

**Paola:** I am Christian. I believe God put us all here for a reason. And whether that reason is to do the stem cell research and to find cures, or to be part of that by donating your eggs to stem cell research...We’ve got some of the best scientific models in the world in Australia. I don’t see why we can’t be leaders in the world in this.

*(Reproductive Oöcyte Donor)*

**Raja:** Yeah. If we’ve got the funds, yeah. Why not? I think the more countries that are involved with it, and the different researchers, the better the outcomes are going to be, and maybe we’ll find things faster that we can do. The more countries, the better.

*(Reproductive Oöcyte Donor)*

**Raphaelle:** I would probably wait till after I’d had my own children to do it, because of any risks involved for me personally. I wouldn’t want to risk my own ability to have children by doing it. But I would have no problem donating my eggs for stem cell research.

*(“Healthy donor”)*

The conduct of stem cell research was an important issue for Australian identity. Nationalistic under- or overtones are commonly attached to scientific research. Governments fund scientific research through competitive grants or secure funding in national interests such as The Manhattan Project which developed the atomic bomb in the 1940s. As discussed in chapter four, South Korean authorities fostered an economic and social environment which encouraged stem cell research as a key factor in the country’s modernisation platform (Hong 2008; Kim 2008).

**Interviewer (K. C.):** Do you think Australia should be involved in stem cell research?

**Joanna:** Definitely. Definitely. Definitely. I think any western country should, especially now America’s involved! (laughs)
Francesca: Australia is a western country. We’re one of the countries that is fortunate to have what we have and we have in the past been successful with research and been the first country to discover other things, so why not? We could be the first country that’s successful with stem cell research, and that would be fantastic!

Melissa: I just think it’s a shame that the whole medical research framework is looking at intervention at the other end of the spectrum. I can’t be black and white with that. I’m very grateful that they invented Oroxine, because that keeps me alive in terms of my thyroid not producing the hormones that it should be producing… I think it’s easy to put science on a pedestal and say, “Isn’t this amazing! We should be doing all these wonderful things because we can get some cures for some horrible things, and I’m very grateful that my children haven’t got any horrible genetic conditions, so I can be a bit more purist in my thinking,” but yeah, it just comes back to thinking, well, I’m doing things now – hopefully preventative – that will lessen the chance of my kids getting Type 1 diabetes or other things which are increasing in Australia…And as I said before, I just worry that there’s not a lot done in terms of preventative health. I look at my own family and friends, and thinking, well, the choices that you’re making with lifestyle aren’t good for you, you’re likely to end up with heart disease and other things, but that’s a choice that they’ve made, so why should we be doing all this other stuff with…and I know for some people there isn’t any choice, and horrible things
happen in terms of spinal cord trauma and genetically being predisposed to things…it’s terrible, and I don’t want to say that’s *not* terrible for them, but it’s just at what cost does a cure come, and is that OK?

*(Undergoing fertility treatment)*

**Kali:** I thought about when I was thinking about whether I would – not so much “donate”, but whether I had issues with [stem cell research]. But…I came to the view that their life with whatever condition they had was the same value as that embryo, and so I wasn’t going to mess with that.

*(“Healthy donor”)*

The small amount of variety in responses indicate that while there are dissenting views regarding the conduct of scientific research as a “good” in and of itself, the consensus reflects a commitment to scientific research as a value and an essential way of organising explanations about human life and society in contrast to custom or religion (Irwin and Michael 2003; Harvey 2007). These views also concur with research by Allen and McNamara (2009) regarding the level of trust Australians invest in scientific institutions as being relatively high, particularly in comparison with the UK where trust in scientific authorities has dropped to “critically” low levels.

The decided unwillingness to donate “good eggs” to stem cell research suggests a specific orientation towards scientific research. It indicates that there is a significant difference in declaring support for scientific research and actually contributing to its development. This is evident in the fact that many participants expressed strong interest and support in the nature of the stem cell research, whilst also insisting that they be given the opportunity to evaluate the research to which they would be expected to contribute. Participants expected their personal values coincide with the merits of the research which would be communicated directly to them. Although supportive of scientific research, scientists may not automatically lay claim to an individual’s oöcytes but must actively convince them of the meritorious nature.

**Raphaelle:** If I was going to do it I'd want to know specifically what research my eggs were contributing to. I wouldn't just go, "alright, you need this? That's cool, do your
science”. I’d want to know exactly what they were doing with [it], what the research is, what level they're at with it, what stage they're at with it...so I'd want to know exactly what it was going to do before.

(“Healthy donor”)

Grace: Part of the question is: should you be made aware of it? And I think we should, because it would play a part in the decision, as far as I’m concerned.

(“Healthy donor”)

As indicated by the quotes above, the process of informed consent was considered the mechanism through which problematic structural issues pertaining to the outcome of and funding of research could be assessed by potential participants and resolved according to their personal values. In this way, the imperfect marriage between commerce and science can be mitigated at an individual level. Participants across all cohorts expressed confidence that the full disclosure by researchers was an effective means of ethical oversight because the individual could decide to proceed with her contribution based on the information.

Cara: I think all you need, my opinion, if it’s informed consent, then wherever you come from, I mean, there may be undue influence in this case, but I think that informed consent is the only bar to anything.

(“Healthy donor”)

Sketches of an affective framework

Participants in the healthy donor cohort show a distinct preference for a specified beneficiary or benefit. The small number of healthy donors in cohort 3b suggested that although they could identify a specified beneficiary, there was currently no specified benefit. This may indicate that like reproductive oocyte donors, these respondents are keen to find worthy recipients and they do so mainly through their existing social relationships; namely, family (blood or marriage) or friends. Healthy donors feel that the risk oocyte extraction poses to their reproductive hopes and/or health could be “worth it” if it is undertaken for a specified benefit or beneficiary:
**Olive:** I think it would have to be a very good cause, though. So, say – I don’t know, if I knew someone, or if my partner had a spinal injury, and the possibility of me donating my oöcytes after I’d had children would possibly find a cure for him, then yes, of course I’d do it, but it has to be a very good cause or a very personal cause, as opposed to just any old research.

(“Healthy donor”)

In addition to this, women in this study showed an inclination to give oöcytes for research in ways that actually resembles current forms of blood provision or organ transplant, in that it should have an immediate therapeutic benefit. These responses express a disinclination to follow the model currently in place for oöcyte provision to SCNT research in the Global North, in which the main objective is for scientists to do research and accumulate knowledge before creating therapeutic applications. While respondents do not dismiss the merit of research, they suggest that this is not a sufficient reason *in itself* to undergo the process of oöcyte extraction. Participants in the healthy donor cohort, quoted below, perceive donation as the opportunity to actualise their values by contributing to scientific research with which they agree.

**Giselle:** Also, at this stage, it’s kind of like you need oöcytes to do the research, but it’s not particularly specific in terms of what they need them for… So it’s kind of like – it’s not justified as well as I would like it to be, to go through all of that for it. And obviously if you knew someone…if there’s a personal element to it, it would colour how you thought of doing it.

(“Healthy donor”)

**Kali:** Well, if it got to the stage where stem cell research – like, it was actually having a really practical, positive and tangible impact on people, then it would kind of be at the level of donating blood. If you go and donate blood, you don’t really need – no-one really asks, “Where’s my blood going?” and stuff like that, because they know it’s working.

(“Healthy donor”)

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Julia: If it [therapeutic application] wasn’t imminent, then I would have my children, then I would donate. If it was (sic) imminent, I would consider donating and then having children, yeah.

(“Healthy donor”)

Yvette: I think I would be a lot less hesitant if the research was closer to being, “Yes, this is working,” that sort of thing yeah I think it would be important.

(“Healthy donor”)

Alicia: Well, it’s research as opposed to actual medical application.

(“Healthy donor”)

These findings may diverge to those produced in Purewal and van den Akker’s (2010) study of participants who completed online questionnaires (n= 253), targeting women with an interest in reproductive health who were referred via internet search engines and reproductive health websites. The results indicated that approximately 38% of the sample would donate in the future and within in this group, “70% would consider donating their oocytes to find a cure for illnesses and diseases, 72% would donate to research trying to improve fertility treatment” (2010: 1084).

As discussed in chapter three, scientific research has been increasingly subject to commercial principles relating to profitability and scholars such as Waldby and Mitchell (2006) and Ballantyne and de Lacey (2008) argue that this has important consequences for the structure of the relationship between the provider of oocytes and the recipients of researchers. Tissue providers are obstructed from economically benefiting from their tissues despite the fact that companies are increasingly able to reap their own economic rewards. While the public’s perception of this is little understood, one recent study examined public perceptions of the commercialisation of research specifically related to HESCR and therapeutic cloning (Chritchley and Nicol 2011). The survey was undertaken as part of the annual Swinburne [University] National Technology and Society Monitor and was generated from a representative sample of the Australian population (n=1000). The research found that “Australian respondents were particularly uncomfortable with research being undertaken in private companies” (2011, 361), showing that the broader structural organisation of research
is an issue of concern for the public. This study did not ask whether participating in such studies would be conditional on the funding source or if they agree whether universities or research companies could claim exclusive property rights to the materials they created.

In contrast to the respondents in Critchley and Nicol’s (2011) study, our participants do not hold uncompromising assumptions about the nature of scientific research in contemporary society. The commercialisation of scientific research is not considered a significant factor in deciding to whom a donor may potentially give her oocytes. Indeed, participants perceive companies, compared to non-profit outfits, to be better situated to make the best of the resource because they have the means to do so. This may suggest that the obligation of the recipient (in this case, the company) seems to centre on the capacity to transform the gift into something else. The gift may be wasted if idealistic considerations, such as a principled stance against commercialised research, rather than pragmatic ones are prioritised. It is better to transform the gift into a practical application (participants, irrespective of cohort, did not doubt that the research would advance to therapeutic applications) than let it be potentially wasted because the recipient is deemed to be more virtuous in principle. Participants make distinctions between those who can or cannot realise the aims of research and the benefactors of the research in the long-term.

**Cara:** But how does...wouldn’t you think that if you’re going to donate it, let’s give it to the best chance, therefore go for a profit organisation?

(“Healthy donor”)

**Mona:** I personally wouldn’t feel like I was doing a bad thing by doing that. Like, I’m still helping some people, and yes, it is the privileged few who could afford it, but if it came down to that or nothing, and not donating, then I’d still donate.

(“Healthy donor”)

**Erica:** Because my opinion would be, you know...obviously, having informed consent and knowing that it is going to a profiting company, then that is very important, but whether that will affect my decision on whether I want to donate oocytes or not, I don’t think it will, just because, like, as you [Cara] were saying, it’s still going to a
good cause, it’s still helping to develop technology, possibly at a faster rate in comparison to non-profit organisations, where they’ve always had issues with funding. (‘Healthy donor’)

Umeko: I agree with that, because I personally feel that even if it is a profit organisation, if there’s the chance that it’s going to go out to more people, and it’s going to help more people, than that, ethically, appeals to me more. (‘Healthy donor’)

Overall, participants show a preference for giving to worthy recipients. In the context of oöcyte provision to SCNT research, companies are worthier recipients compared with non-profit organisations because they are most capable of transforming the gift. Participants in the healthy donor cohort perceive that companies are likely to translate experimental research into clinical benefits more quickly. This may be considered the fulfilment of the obligation to reciprocate the initial gift of oöcytes and may not necessarily mean that such companies are obliged to share the benefits with countless others. The point is to transform the oöcytes and research into something of value. What is evident here is the implicit assumption that companies have the obligation to make sure the aims of the research are realised.

These results suggest that donors make careful evaluations about the research to which they may contribute and assess recipients on the basis of whether they can deliver on therapeutic promises. In the context of oöcyte provision to SCNT research, relationships between the donor, recipient and reward – economic or otherwise – are more complex and ambiguous than they first suggest. Initially, participants perceive that they may navigate the process of oöcyte provision for SCNT research with relatively more ease than its reproductive counterpart because it does not result in a new being with whom the individual may have a relationship. This is a sentiment that was particularly appealing to participants in the healthy donor cohort. However, this negation ultimately undermines the development of a concrete motivation to give oöcytes to SCNT research in the here and now. Close inspection of the data shows that the reasons to contribute resemble the desire expressed by reproductive oöcyte donors in this study; that is, to do so in contexts of a specified beneficiary or benefit
for non-reproductive benefit. In both contexts, the participants express the desire to be clear about what the ‘gift’ will achieve.

**Conclusion**

This chapter has demonstrated that the way women utilise their oöcytes relates to their intentions to become a mother. This has included an analysis of how participants construct oöcyte provision to SCNT research.

The following results were discussed:
1. Oöcytes are important for their functional utility and there is a significant difference between fertile and infertile oöcytes. Participants, particularly in cohort one, perceive that the latter can be given to SCNT research because they are not required to become mothers.
2. The majority of participants seek to ‘efficiently’ manage their oöcytes in quantitative terms because their qualitative dimension–their fertility–is unknowable until fertilisation is attempted.
3. Most participants construed oöcyte extraction as an onerous process that required the donor to sacrifice much of her time and identity (including work and social life). Participants in the fertility patient cohort imagined that the process undertaken for research would be devoid of the emotional labour they experience themselves;
4. Participants may ‘risk’ their reproductive future for a specified beneficiary or benefit;
5. If asked to consider donating to research, participants expect to evaluate the merits of the research of their own accord and contend that informed consent is a mechanism through which the individual’s personal values and the efficacy of the research can be negotiated;
6. Participants in all cohorts expect some form of economic benefit as reciprocity and prefer ‘compensation’ rather than ‘payment’ for this;
7. (In the cohort one) imagined oöcyte sharing similar to that instituted in the NESR, to be highly exploitative
8. Participants, irrespective of cohort, did not suggest that if women were asked to provide oocytes in exchange for monetary payment were morally corrupt or put others in danger.
By comparing oocytes and embryos, this analysis demonstrated that there is a specific logic to whether participants are likely to provide their reproductive tissues to research. I used Roberts’s (2007) framework as an important reference for understanding the broad categories in which reproductive tissues are placed. Oöcytes and embryos are both reproductive tissues but the symbolic regime in which oöcytes exist emphasise their functional value more than their status as children as is the case with embryos. My analysis built on this framework to demonstrate that the biological properties and social meanings of tissues cannot be easily separated. This is why I emphasised that in order to understand why women keep their “good eggs”, it is necessary to discuss their responses in light of their aspirations for motherhood. I did not neglect the biological properties of the tissue and technological mechanisms used to achieve social identity. Thus, one factor was the improbability of clinicians (and by extension patients) being able to definitively predict which oocyte would fertilise. Another factor discussed was the potential to freeze and subsequently thaw oocytes and embryos for use at a later date. An implication of this comparative analysis is that we can shift from assuming that the same tissue can be given away in the same process and for the same reasons.

The results do not just shed light on the biological/technological differences between tissues or the ethical categories in which they can be placed; they also highlight broader social aspects of oocyte provision with reference to science. This is evident in the discussion of participants’ views regarding stem cell research. It was noted that there was a small variation in views regarding stem cell research with only a minority of participants across all cohorts expressing “negative” views about the research and/or its use of embryos. Therefore, I make my contribution by pointing out that the disinclination to provide oocytes to SCNT research must be understood with reference to the ‘paradox’ that the majority of participants supported stem cell research but excluded their own ‘good eggs’ from such use. By sketching an affective framework, we can begin to better understand those circumstances in which participants would give their oöcytes to SCNT research. This was evident in the clear preference to provide their oöcytes for a specified benefit or beneficiary rather than the abstract accumulation of scientific knowledge.

These results indicate the different expectations that shape decisions about providing oöcytes to research. It is clear that participants’ preferences cannot be easily accommodated within
the paradigm of the rational donor discussed in chapter four because no participant indicated that they would accept money in exchange for their oocytes. The rational donor model which relies on an exchange of money for tissue neglects to acknowledge the different personal investments in the conduct of scientific research. Ironically, while remaining sceptical of the public good of science, these rationalisations effectively flatten the social terrain and insist that there should be one form of tissue provision (the disinterested donor).

It is clear that most participants privilege the reproductive utilisation of their oocytes despite the fact that most are supportive of scientific research. However, the decisions of oocyte donors in this study complicates simple connections between this utilisation and the reproductive future they are expected to create. In the next chapter, I will examine more empirical data to understand how oocyte donors in our study undertook the donation process. Reproductive oocyte donors maintain the reproductive utilisation of their oocytes while disconnecting the tissue from their own intentions to become a mother. Despite this, they continue to privilege the reproductive utilisation of oocytes. I will also discuss views regarding the provision of embryos to research. I examine these different responses and suggest that their commonality is based on an affective framework – the identification of a specific benefit or beneficiary. This element is precisely what is absent from oocyte provision to SCNT research.
Chapter Seven: Giving Reproductive Tissues Within Affective Frameworks

Introduction

Chapter six addressed data related to the meanings and preferred utilisations of oöcytes. I have claimed that participants categorise their oöcytes in predominantly functional ways and decisions about their use are made in relation to their reproductive capacity. Oöcytes are a means to an end and once they can no longer fulfil their reproductive potential, they are considered appropriate material for SCNT research. However, these findings do not entirely represent the complexity of the dataset and it is now necessary to explore contexts where reproductive tissues are given away. This refers to the cohort of oöcyte donors who do give away such “precious” tissues. In this chapter I examine the narratives of oöcyte donors and argue that oöcytes are given away in contexts where a specific benefit has been identified. The following analysis demonstrates that the recipient is an important figure in the decision to donate. Indeed, I claim that donor’s decisions reflect a mixture of altruistic and instrumental concerns; donors do not expect reciprocity but they select their recipients on the basis that they are “good” parents. This challenges the idea that gift giving in known contexts inevitably leads to cycles of reciprocity. Subsequently, I consider responses related to embryo provision for research and reproductive purposes. I show that embryos are given without the identification of a specified benefit or beneficiary. Whether embryos are given for research or reproductive purposes, the recipient is generalised and abstract. Embryo donors assume that the recipient’s needs are important without personally identifying them. I suggest that this relationship is built on the donor’s own fertility treatment, an experience that provides membership into a community of other fertility patients (in the past, present and future) from whom the donor feels they have received benefit.
Reproductive oöcyte provision: an overview

Reproductive oöcyte donation remains a marginal practice in Australia and New Zealand, accounting for 5% of all treatment cycles (Wang et al. 2011). In Australia, the practice occurs on the basis of donation, that is women may only be reimbursed for documented travel and childcare costs expenses. If a woman presents to a fertility clinic and her oöcyte “quality” is deemed to be poor, the clinician may suggest using donor oöcytes. Oöcyte donation usually involves the transfer of oöcytes from a younger woman whose fertility has been proven through previous pregnancy. The age of donors, however, is a point of some controversy: in the UK donors should not be over the age of 36 (Human Fertilisation and Embryology Authority 2012a) while in Australia these decisions are made by the clinic. Recent research from the Australian Institute of Health and Welfare (AIHW) indicates that women over the age of 40 did donate their oöcytes. The median age of women who donate oöcytes was 33 years while the average age of women receiving donated oöcytes or embryos was 40.9 years (Macaldowie et al. 2012).

The sample under discussion includes five donors. Of the sample, three donors (Jenny, Paola and Donna) gave oöcytes to women they knew outside the context of donation: Jenny to a couple in her extended social network and who were not considered to be “great friends”, with sporadic contact over the year; Paola to a work colleague in her late 40s who had started a relationship with a new partner and Donna to a close friend. Two donors, Raja and Agnes had thought about donation prior to instigating a search for a recipient: Raja found an advertisement in the local newspaper and Agnes responded to a number of advertisements about oöcyte donation before selecting her recipient. Not all donation attempts were successful: of the sample, pregnancy ensued for the recipients of Raja, Agnes and Donna. Both Raja and Jenny undertook the process of extraction twice while other donors did so once.

‘Disembodied’ motherhood

In chapter six, I argued that participants, irrespective of cohort, valued their oöcytes for their functional capacity and did not perceive them as having an inherent moral status. Their oöcytes’ position within the “kin ethics” framework was ambiguous however, particularly in
comparison with embryos whose status as kin was clear for participants in cohort one. The oöcytes’ capacity as a reproductive tissue was the basis of participants’ refusals to give their “good eggs” to SCNT research – a potential threat to their intention to become a mother. Given that participants, irrespective of cohort, predominantly refused to give away their oöcytes, it may be unclear how and why participants in the donor cohort gave their oöcytes to other women to utilise for reproductive purposes. There were two significant factors in decisions to donate oöcytes for reproductive purposes: the donor’s own intentions to become a mother and a perception that the genetic attributes of the tissue does not create a social relationship between the woman and the child.

Firstly, the decisions to donate are made in light of broader choices around personal fertility. Participants in cohort two either have no plans to have children, have children prior to donation or they have some reassurance that it will not affect their future fertility. Donors relied on different means to understand the effect of oöcyte extraction on their future fertility; for instance, Donna relied on medical knowledge while Agnes’ assurance came from a belief in not being punished (unable to bear children in the future) for doing a good deed.

**Donna:** I wasn’t going to tell the people I wanted to donate to until I was happy enough that I’d be comfortable to do it, so I kind of got some background info, um... And it was very, you know, like a zero, zero point nine per cent chance, but I don’t know, for some reason that was my worst fear. So I just had to clear my mind of that, and then um, yeah I just really wanted to do it

**Agnes:** I’ve had three different psychics tell me I’m having twins...Even with the limited knowledge I had of the side effects [like] “What if something happens? You should only do it after you had your own (children)…” and I’m like, “It’s not...I’m doing it for a good cause. God’s not going to punish me and make me infertile for doing something good! [Its about generating] Good karma!”

Donors also made the decision to give their oöcytes away by distinguishing between the reproductive capacity of their oöcytes and the expectation that that capacity be used
exclusively for their own intentions to become a mother. One way donors do so is by dismissing the idea that because the oocyte bears DNA, that this inevitably results in a social relationship with the child they intend to help create. Unlike mainstream social sentiments, kinship – in this case – does not depend on a biological connection. To reinforce the disconnection between DNA and kin, reproductive oocyte donors (quoted below) emphasise gestation and rearing as the constitutive elements of motherhood:

**Donna:** And some people don’t really understand it’s just an oocyte; but a lot of people think “well, that’s almost like that’s your child as well?” and it’s not. Because I’ve seen it grow in somebody else, and it’s all their child – so for some people it’s a bit…“oh, that’s a bit weird!”

**Raja:** I explained to him [donor’s partner] I don’t consider from the moment I was doing it that these are my children, they’ve got my DNA but that’s as far as it goes.

**Agnes:** I never see it as “my child” or “half my child”, I guess it’s all just perspective. It’s in her. She’s going to be pregnant, she’s going to give birth to her.

**Jenny:** it’s hard to know [what] the relationships [between donor and recipient would entail]…what if there had been a child and they’d been parenting in a way I didn’t agree with? Is it my place to say something? Not really. It’s their child.

Participants in this cohort rarely falter in their conviction that they are not “mothers” to the oocytes they provide to other women. They often construct their contribution as virtually insignificant, despite the fact that without it, no pregnancy could ensue. This resonates with results from a large-scale survey conducted in Sweden. Skoog Svanberg et al. (2003a and b) report on a study with a sample of random participants (n=1000 men and women respectively) aged between 25 and 40 years. Women who were more likely to donate oocytes for reproductive purposes did not place too much importance on the genetic basis of motherhood; however, they did expect children born from gamete donation to be told of their origins.
In the following extract, the participant explicitly contends with potential issues that may arise related precisely to the “common-sense” connection between biology and kinship. This occurs on the basis that the donor and Angela (the recipient woman) are phenotypically very different and the donor, Paola, presumes that this may cause attachment problems between Angela and the child. Paola resolves this issue by drawing on biological ideas about dominant and recessive genes and suggests that in this scenario, the problem she briefly imagined will ultimately be avoided because the dominant genes of John (Angela’s partner) would also overwhelm those of Angela. Paola is not suggesting that she and Angela are interchangeable but that her potentially problematic presence (looking too much like the child) may be rendered less so by the fact that the child will not look like its “mother” in any case:

Paola: When I met John [recipient’s partner] he’s got brown eyes, I’ve got brown eyes, he’s got brown hair, I’ve got brown hair…and Angela’s [recipient] blond hair, blue eyes, so the child would definitely look like John, it wouldn’t look like me.

(Reproductive oöcyte donor)

Practices of assisted conception can disrupt the contemporary norm of the nuclear family where children are expected to have one mother and father from whom the child is given their genetic heritage. However, the practice of reproductive oöcyte provision represents a fundamental challenge to social ideas and legal definitions of motherhood in a way that semen donation does not. This, as Jackson (2006) argues, is because within English common law (from which Australian law is derived), the attribution of maternity, prior to the use of ARTs, has been an uncontested fact while the attribution of paternity has always technically been a legal fiction; this is based on historic modes of reproduction during which oöcytes remained in vivo while semen was always externalised. In our study, participants highlight the tissue as providing DNA but reject it is the basis of social relationships.

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68 In NSW, legislation that covers practices of Assisted reproduction includes the Status of Children Act 1996 No 76 and the Assisted Reproductive Technology Act 2007 (2009); parentage is defined as:

3) If a woman (whether married or unmarried) becomes pregnant by means of a fertilisation procedure using an ovum obtained from another woman, that other woman is presumed not to be the mother of any child born as a result of the pregnancy.
It is important to recognise that the views of oocyte and semen donors can diverge as Almeling’s (2011) research demonstrates. In Almeling’s study, male donors did consider themselves the fathers of the children they help to create while oocyte providers did not consider themselves the mothers. According to Almeling (2011), the basis of this difference are traditional cultural representations of paternity which considers semen the most important aspect of reproduction rather than women’s own tissues, DNA or the gestation process. Yet, it does not appear that Almeling sufficiently accounts for the legal aspects of paternity and maternity in that the former is always a legal fiction which must be established through trust or technical means (a paternity test) but it is only with the development of ARTs that involve the removal of oocytes from the woman’s body, that genetics and gestation can be separated.

**Suspending reciprocity in identified reproductive oöcyte provision**

The social relationships created through oöcyte provision not only adhere and challenge ideas about motherhood but gift giving as well. As we can recall, Titmuss (1997 [1970]) insisted that anonymity be a key feature of maintaining the provision of blood as a free gift. The premise of inter-personal anonymity was based on the presumption that gift giving in contexts where donor and recipients are known to each other will inevitably lead to cycles of reciprocity, where the pressure to return gifts will be immense. In contrast to Titmuss’s model and most arrangements around the world, Australian clinics do not act as brokers and by encouraging patients to find donors through their own social networks or by advertising in community publications such as Sydney’s Child, are informally helping to establish contexts of known oöcyte donation. This results in the formation of a relationship between donor and recipient that is largely self-regulated and as we shall see, does not necessarily lead to the establishment of a social relationship involving reciprocity.

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Donating oöcytes takes a lot of time and effort for both the donor and recipient woman who must also undergo an IVF cycle to prepare her uterus to implant potential embryos. In Australia, if the donor and recipient are unknown to each other, initial contact will involve phone conversations or email exchange during which both parties make personal assessments about the suitability of the other before meeting each other in person. Oöcyte donors must undergo detailed medical, social and family history examinations and be tested for venereal disease, Hepatitis B and C, HIV antibodies as well as traits for sickle cell and Thalassemia Minor (Bourne 2011). Legally, the oöcytes and any resulting embryos will belong to the recipient woman and/or her partner and donors do not have any legal rights or duties towards the child born. Recipients and donors both partake in counselling sessions at the fertility clinic during which the social and legal implications of gamete assistance are discussed (Fertility Society of Australia 2010). Also discussed are the relationship between the donor, recipient and donor-conceived child, the level of disclosure about gamete-assisted conception and having a child who is not the genetic relation of one parent (Bourne 2011).

Australia’s rather relaxed approach to the relationship between oöcyte donors and recipients is unique in a global context. Anecdotal evidence indicates that fertility clinics wish to cultivate a culture of openness between donors, recipients and children in addition to avoiding the cost of maintaining a database of potential donors. In contrast, countries like Sweden and the UK can restrict knowledge between donors and recipients at the time of donation (Skoog Svanberg 2003a; Human Fertilisation and Embryology Authority 2012b); in Spain, even if a patient brings her own provider to the clinic, these oöcytes will not be used but exchanged for those of another [anonymous] provider (Orobitg & Salazar, 2005). In her study of the nascent formation of the Human Fertilisation and Embryology Act in the UK, Haimes (1993) examined the attitudes members held regarding the provision of semen and oöcytes and argued that while it essentially involves the genetic contribution of a “third party”, its symbolic representation is gender specific. As the following excerpt shows, the Warnock Commission placed significant emphasis on the principle of anonymity in gamete assisted conception but emphasised this more so in relation to semen donors (who were

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70 I am uncertain if any provisions which stipulate that the partner must be male.
71 The code of practice by the Fertility Society of Australia stipulates that all clinics must appoint a senior counsellor.
72 The same clinic may have different policy regarding semen: for instance, on its website IVF Australia states that it does not keep database of oöcyte providers but does recruit semen providers.
perceived as more threatening to the family) in comparison with oöcyte donors, particularly known donors (who were represented as much more innocent). Haimes (1993: 91) writes:

“Semen donation is presented [in relation to] inappropriate sexuality, such as masturbation, adultery and illegitimacy…egg donation on the other hand, is presented as a new and complex procedure…is firmly located in a clinical setting and is essentially asexual…the egg donor apparently runs the risk of physical damage through her participation in the practice which serves only to enhance the view that her motives must be altruistic.”

These claims correspond with studies of public perceptions in the UK around the same time and the US more recently. Bolton et al. (1991, 221) designed their study “to examine whether or not differences exist in attitudes towards egg donation compared with sperm donation”. Four groups ($n=399$) were surveyed about their attitudes toward each form of gamete transfer: one group patients using donated eggs; another group receiving donor insemination, one group of potential oöcyte donors and the general population people with no reported history of fertility problems. The results indicated that while there was little difference in approval for semen donation and oöcyte donation for fertility patients, anonymity was perceived to be of greater importance for semen donors; 59% of semen recipients wanting to maintain anonymity of the donor. In her study reporting on both semen and oöcyte provision in the US, Almeling (2009) contends that organisational structures similar to those reported by Haimes (1993) are embedded in the recruitment process of gamete providers; while oöcyte providers and recipients do not meet, the providers are identified by their physical traits and personality, as well as names, photographs and personal essays. In contrast, semen providers are identified with numbers and “under no circumstances are sperm recipients allowed to meet donors” (Almeling, 2009, 50).

As this brief review indicates, anonymity in gamete provision has been strictly regulated around the world and this may or may not be applied in a ‘gender-blind’ way. Notwithstanding the broader social implications of embracing the universal stranger, for Titmuss, anonymity meant that cycles of reciprocity were unlikely to develop as they would

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73 The women were receiving treatment for infertility and were asked of their attitude toward donating excess oöcytes (Bolton et al. 1991).
in contexts of known donation. Titmuss’s model of the [inter-personally anonymous] free gift is compromised as the data collected shows that most participants in this study preferred to donate their reproductive tissues in identified contexts. Irrespective of cohort, participants report that they are more inclined to give oocytes when the information to imagine the future family is available.

Agnes: Um…I’d like to say “yes”, but I don’t know if I would…In one way, like, I did want to meet them. I want to, sort of, know that my oocytes are going at least to someone who’s worthy of them, in a sense. I don’t know if that sounds bad or not.

(Reproductive oocyte donor)

Atilia: If I knew them [the couple] and if I’m really sure that everything will be alright with their baby, then yes I can do it but to an unknown couple, I wouldn’t donate.

(Undergoing fertility treatment)

Grace: If somebody is raising a child with half of my DNA…I’d probably want to know they’re going to a good home.

(“Healthy donor”)

It is possible to argue that the desire to know the recipient conveyed by our participants, may be based on the biological and symbolic properties of the oocyte in creating a sentient being. This suggestion both concurs and diverges from other research. For instance, two studies reported that donors usually give their oocytes to their own sister or close friend (Warren and Blood 2003; Yee, Hitkari and Greenblatt 2007). In contrast, Skoog Svanberg et al.’s (2003a) survey of women in Sweden showed that one in six respondents indicated that they would consider donating oocytes anonymously in the future.

For oocyte donors in this study, preferences for identified donation may be incompatible with their earlier insistence that a social relationship does not inevitably emerge between themselves and the children created from their oocytes. However, their preference for known donation relates to the donors’ desire to select the recipients of their oocytes rather than the establishment of long-term social relationships and the attendant cycles of reciprocity Titmuss anticipated. As one donor, Raja, articulated, the children (twins) she helped to create

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are not her own “kin” and she does not speculate about them as individuals. At the same time Raja is keen to draw boundaries around the family she has helped to create and spurns significant involvement in the children’s upbringing. The importance of the family-as-nuclear is evident for the donor. Titmuss’s worry that cycles of reciprocity are a natural part of gift giving in known contexts is unfounded in the context of oöcyte provision because the context in which oöcytes are given shape the expectations of reciprocity.

**Interviewer (M.B.):** did you discuss that beforehand…What kind of contact there would be?

**Raja:** Yeah. The lady said that she would like contact and to be friends afterwards and everything, and I said, “OK, look, I don’t want to be a second mum or anything, but if you give me photos or an update every year or whatever, I’d be happy with that, just to see that everything’s OK.”

(Reproductive oöcyte donor)

Choosing ‘good’ parents

Identifying one’s recipient is an important issue for donors in this study and I suggest that it has at two effects. Firstly, a certain intimacy characterises the relationships between donors and recipients as individuals while distance is maintained regarding the family. Secondly, the donor is able to evaluate and select their ideal recipient: people who adhere to social norms regarding suitable parenting styles.

The largely self-regulated nature of oöcyte provision in Australia is one reason why intimate relationships, however transient, between donors and recipients emerge. By intimate, I refer to “a complex sphere of ‘inmost’ relationships with self and others [that are] not usually minor or incidental (although they may be transitory), and they usually touch the personal world very deeply” (Plummer 2003, 13). Although the degree to which intimacy characterises the relationships between donors and recipients in this study varied, some sort of identification is evident. The following quotes show a high level of identification between the donor and the recipient.
**Agnes:** And after, we met up, I had a dream on the same night that she [the recipient] had a dream, that because of this process she had a baby girl. And she emailed me on Monday, “I had a dream on Saturday!” and I was like, “Oh, my god, no. I had a dream on Saturday that you had a baby girl.” And it was just bizarre. She was like a forty-three year old version of me. Like…it was very interesting; the same personality, temperament…we’re both nerds; we sit at home, reading a million books, mm, very nice.

(Reproductive oocyte donor)

I do not wish to suggest that all relationships between donors and recipients in our study exhibited a similar level of identification between the two parties, but it is interesting to note that such identification was an important necessary part of the process for Agnes and cannot be dismissed as contingently related to her match. In these self-regulated settings, donors do not have any other cues with which to evaluate the recipient. While there are varying levels of intimacy between donors and recipient(s) in our study, it is evident that the idea of a specified beneficiary and benefit is at the forefront of the donor’s intentions and contributes to their motivation to complete the process. This may be because the relationship is largely self-regulated, beginning *outside* the ART clinic. Even in cases where the donor and recipient are not known to one another previously, the relationship is initiated and established by individuals before they attend the clinic. I suggest that the clinic is a *facilitator* of technical aspects such as medical care and provides important legal and psychological oversight but does not define who is a good parent or worthy recipient and thus avoids operating as a moral gatekeeper. Private individuals deal with the relationship and all its effects – good and bad. Meeting recipients on a number of occasions ensures that some sort of relationship exists with both formal and informal aspects. This includes initial meetings and negotiations occurring privately and mandatory counselling sessions at the recipients’ fertility clinic. The resident counsellor facilitates these sessions and imposes a peculiar kind of intimacy as each party is subject to scrutiny that may not have emerged without their presence.

The relationship between donors in our study and their recipients has another function. As the following participants suggest, the inter-personal dimension helps to psychologically sustain the donor until the goal of pregnancy is (hopefully) reached.
**Raja:** The first time…none of them [embryos] took, and she asked me if I would go through again, and I said, “Of course, until either you cannot have children, or you have a child.” And the second time…both of them took, and they’re twin boys now…I think what made it easier was that the couple was really nice. That made it a lot easier. If it had been just an anonymous donation, and having that similar experience, I don’t think I would have gone through with that. I think I would have stopped. But it’s just because the couple were really nice.

*(Reproductive oöcyte donor)*

In these accounts, the donor is primarily focused on the recipient with whose needs and desires she can empathise. While the processes of ovarian stimulation and oöcyte extraction are necessary parts of the process, in this context they might be considered merely the technical elements to a much broader, more affectively-oriented undertaking.

**Donna:** And then the first time I got ten oöcytes …but I didn’t realise how unsuccessful – like ten oöcytes, they only really got three [embryos] from it…from what they were able to get for me, they actually didn’t get a lot of success from that… I thought, a couple died, then when you freeze them, then they defrost, a few more die. So they tried once or twice, and it was unsuccessful. And then they had like two left in the freezer, so to speak, and I said, “Oh, because you haven’t really had much of a go, how about we have another go of it?

*(Reproductive oöcyte donor)*

Assertions made here about the importance of a specific beneficiary with oöcyte provision develop claims made in other research. A recent Canadian study conducted by Yee, Hitkari and Greenblatt (2007) reports that since laws prohibiting the sale of any gamete were introduced in 2004, known donation has become the default option. The authors studied oöcyte provision that had occurred between January 2000 and December 2005 between known parties (n= 13) who were largely a combination of sisters and close friends. The authors (2007) report that donors were largely motivated by a desire to help others they consider to be struggling with fertility treatment and most of the participants said that the decision to donate oöcytes was not especially difficult. The results from our study show that
oöcyte provision between women known to each other outside the context of donation can occur within the framework of altruistic donation. In identifying a specified beneficiary connection, the donor undertakes the process within an affective framework.

The identification of recipients is an important part of the process of giving away oöcytes for reproductive purposes. While donors are not particularly interested in ongoing relationships with the child, the care taken to find such recipients demonstrates that they are interested in the long-term consequences of their decision in a specific way. As we saw in chapter six in reference to choosing recipients in the scientific context, potential donors wanted to choose worthy recipients. Such recipients are those who are likely to transform the gift of the oöcytes into something valuable. For participants, it is better to choose the recipient on this basis rather than adhere to an ideological principle which separates private and public property and profit. I argue that a comparable process of identifying worthy recipients occurs in the reproductive sphere as donors attempt to find ‘good parents’.

These assertions develop claims made by Rhonda Shaw (2007, 2008a and 2010) who has undertaken much research regarding what she terms ‘bodily gifting practices’ within New Zealand. Shaw (2008a) argues that reproductive oöcyte provision is a complex process that rarely resembles the gift ideology proffered by fertility clinics and government organisations. She contends that while the New Zealand jurisdiction prohibits the selling of oöocytes for reproduction, this does not necessarily mean that the women who do provide their oöcytes are simply altruistic. Thus, while monetary payment is absent, altruism is seldom the only motivation in the process of giving to others.

On the one hand, the narratives of donors in this study echo Shaw’s (2008a, 16) definition of altruism as a feeling or behaviour “which…seeks to increase or enhance another’s welfare, life chances or pleasure, not one’s own [it is] voluntary [and] expects no external reward or reciprocation”. On the other hand, the considerable care exercised in selecting an appropriately worthy recipient indicates that altruism and more instrumental concerns are not mutually exclusive. This indicates that although they are being altruistic by sharing their oöcytes, they do not view ‘the infertile’ as an undifferentiated mass, all deserving of the ‘gift’. Vetting potential parents and making value judgments about their suitability, in some ways, resembles a less regulated version of the assessment involved in adoption. Participants
in our study tended to represent their recipient as ‘deserving’ because their donation would redress a sense of imbalance in the recipient’s life. In some cases, they also implied that recipients who had not ‘struggled’ (to conceive) or did not display the required desperation may be less deserving of their help. In this respect, donors represented their chosen recipients in terms of their need; the more needy the recipient and the greater the obstacles that they have faced, the more appropriate the gift. This may relate to choosing childless couples over those who wish to add to their family. It may also be based on knowledge that recipients have been unsuccessful through their own attempts at becoming parents. The more needy the recipient seems and the obstacles they have faced, the more appropriate the gift of the donor.

**Donna:** Um, I think because they were so great to kids anyway. And I know they’d been trying – they were so good to my first, my Benjamin, my son; and I thought, “God! You’d make great parents.” And they’re just so caring, and they give to everybody else – I was like, “Oh well, it’s time that you got something back.” And they’ve been trying as well.

*(Reproductive oöcyte donor)*

**Jenny:** I remember just feeling very intensely that if I could help them, I would like to, because it’s something that she wanted so much, and I just thought myself how awful it would be, having had two children, to feel that I couldn’t have fulfilled being a parent, because it’s important to me and it was obviously very important to her as well.

*(Reproductive oöcyte donor)*

Donors have their own qualifications about who they consider to be a ‘good parent’. Importantly, as the excerpt from Agnes’s interviews suggests, recipients who placed conditions on the donor they sought disqualified themselves by not appearing to be unconditionally grateful.

**Agnes:** And a lot of the ads – it was quite funny. They were very specific.

**Interviewer (MB):** In what way?

**Agnes:** You have to be a non-smoker. You have to have fit (sic)– like, I know they recommend to have your own children first before donating oöcytes, but a lot of them
were very specific in regards to that. You have to be Asian, or you have to be over – no, you have to be under 25, and...I’m like, woah! But completed your own family! I’m just, like, “Alright. You’re a bit too fussy!” Then there were some other ads where they’d had their first child but wanted a second one, and I was, like, “No, I don’t want to go for them, because they’ve at least got one. I want to go for someone who hasn’t.”

(Reproductive oöcyte donor)

Other elements that figure in decisions about the right recipients are more socially-defined traits such as financial status, relationship stability, and personality. These attributes represent Australian norms about ‘good’ parents that reflect some of the diversity of contemporary society. For example, as the excerpt from Raja’s interview shows, sexual orientation is not a basis to exclude people, but donors in our study ultimately remain committed to an idealised version of relationships as long term and child-focused.

Raja: I wouldn’t just donate and not know...I sort of need to know the couple’s financially secure and that their marriage, or relationship – I don’t care if they’re gay or whatever – that their relationship is strong. They’re really two important factors for me.

(Reproductive oöcyte donor)

In the excerpt below, Paola represents the recipient, Angela, as a ‘good parent’ precisely because she already had children. Paola uses the evidence of Angela’s previous mothering experience as a basis for her claim that Angela will make a ‘good parent’. Thus, in contrast to Agnes above, a ‘good parent’ can be constructed by wanting more children.

Paola: I’ve known Angela for a while, I’ve met her husband, I’ve met all her children…and I know for a fact that Angela would be a good parent…She’s quite strict with her children. If she’d been my mum, I might have finished school, you know? Very strict. So any kid having that kind of parent would be a good child.

(Reproductive oöcyte donor)
These responses show that, for our participants, donating eggs in identified contexts enables them to select a specific recipient among the undifferentiated mass of infertile individuals or couples. These attitudes return us to the initial discussion regarding the social relationship between the child derived of their oöcytes and the donor. While donors do not recognise the intended child as their own, they do not simply ‘abandon’ but rather entrust the children to ‘good parents’. These findings correspond with others studies showing that donors make distinctions between the offspring of donated oöcytes and their ‘own’ children whom they have or will gestate (Kirkman 2003; Nahman 2008). These narratives suggest that when women give their oöcytes for reproductive purposes based on an altruistic concern to help another person, they also evaluate their recipients according to social norms about “good” parents. Altruistic and instrumental motivations are coupled together to ensure the child is raised in the right family.

**The reward of family**

As discussed in chapter six, participants in this study are easily able to articulate the difference between providing oöcytes for reproductive and research purposes; one leads to the creation of a child, the other leads to the production of scientific knowledge. Reproductive oöcyte donors insist that despite being emotionally taxing and onerous, donation is nonetheless a rewarding process. Reward is based on being able to witness the transformation of an infertile couple into a happy family. Furthermore, while these participants do not dismiss the idea that SCNT oöcyte provision has a dimension of the ‘greater good’, it is perceived as less rewarding than its reproductive counterpart because the recipient and the outcome are not as personally constituted.

**Interviewer:** Okay. Would you ever donate oöcytes for research into infertility?

**Donna:** Probably once I’d got to the point that I’ve done enough for family reproduction, then, you know, maybe in another few years, before my oöcytes stop, I probably would…I think, yeah, even though I know the research is going to be a fantastic effect down the track, that’s an initial understanding with a couple, that you know you’re doing it for them... The little bit more of a personal – I think that there’s such a more personal connection with what you’re doing, and you can see, see it instantly? And you go, “God, the joy that I’m giving to them is enough for me?” So,
when you give it to sort of anonymous, big bad – well it might not be bad, but the big world of science! – you kind of go, “Well, who knows where it’s going to end up? And thanks for coming.” Maybe it’s that whole, “This is a huge process for me!” and because it's somebody you don’t know on the other side, who’s just going to take them and do what they need to do, it may not be the same... personal recognition, maybe? Yeah, because it’s a pretty invasive thing!...Where giving to science – it could in the long run help somebody, you know, be healed from an actual disease, but there’s no direct link; I don’t get a direct reward from that…I don’t get to see the direct results, as I would for the couple. That’s probably the only difference – not saying I wouldn’t do it, but I think my priority is trying to help someone have a child, because they’ve been wanting to do it for years.

(Reproductive oöcyte donor)

Raja: because I think you don’t get the satisfaction of knowing that – you can’t see the outcome of your work as such. Having seen the twins, I can sort of see something, whereas for research, you’re not really…

(Reproductive oöcyte donor)

The difficulty of establishing an equivalent for oöcytes in the scientific context, discussed in chapter six, does not appear in the case of reproductive oöcyte provision. What is apparent is an affective framework that involves the identification of a specified beneficiary. Knowing the donor facilitates the construction of an affective framework through which the extensive medical procedures can be experienced and tolerated. The medical procedures outlined above are a means to an end, not the end in itself. Helping a woman become a mother is the end. This data indicate that cycles of reciprocity are not the inevitable consequence of gift giving in known contexts. This suspension of social norms is based on two factors: firstly, when recipients have been identified as incapable of becoming parents without donor-assistance and as a consequence are expected to accept the donor’s gift. Secondly, because it is more important to maintain the family as nuclear where the child born from donor-assisted conception effectively has one mother and father.

Mobilising reproductive oöcyte donors for SCNT research
Speculating about whether reproductive oöcyte donors in this study are likely to represent a relatively uncontroversial population of donors to SCNT research is complex. Donors are constituted by the fact that they give some of their reproductive capacity (their oöcytes) away for other women to use.\footnote{The term “constituted” is not meant to mislead the reader and suggest that these women are essentially donors.} This decision distinguishes them from other participants in our study who do not want to jeopardise their maternal aspirations by giving away their own oöcytes. However, all participants, irrespective of cohort, do not consider their oöcytes to exist with the “life ethics” framework and were imagined as more closely aligned with the “kin ethics” framework. Donors went further and regularly referred to the oöcytes as simply carriers of DNA and not the basis of a social relationship between themselves and the child. These references indicate that giving away one’s oöcytes pose a challenge to many things, not least conventional family structures. In the context of reproductive provision, the tissue’s value remains functional but is detached from the individual’s intention to become a mother. This occurs by investing in the maternal aspirations of another woman and situating oöcyte extraction within the affective framework. Thus, despite the fact that oöcyte donation is an ambiguous process simply translating the physical act of oöcyte extraction from one context to another is not straightforward. This analysis shows that just because reproductive oöcyte donors are not undertaking the process for themselves, they are undertaking the process in a detached manner.

This analysis has so far sought to explore some of the ambiguities involved in reproductive oöcyte donation as it is practiced in Australia, where the donor is neither entirely disinterested in the recipient or expects to be reciprocated. I have demonstrated that relationships between women in the oöcyte donor cohort and their recipients do have instrumental components to them, although these are centered on child-friendly and ‘family’ values. Overall, however, the practice is overlaid with affective elements and a ‘feeling’ of reward in undertaking the process.

**Embryo provision: an overview**

The primary focus of this thesis is to elucidate the perceptions and attitudes of oöcyte provision to SCNT research. To achieve this aim, I have drawn comparisons with other
tissues; namely blood and embryos. I now wish to discuss the latter in more detail. Oöcytes and embryos are both reproductive tissues but exist under different regulatory and symbolic regimes. In the following section, I examine how women undertaking fertility treatment imagine the provision of embryos and I show how the experience of fertility treatment and the context of the nuclear family differently impacts their choices. I show that while reproductive oöcyte donation may be considered an example of disembodied motherhood, which for most women is problematic, there are certain parallels between the ways in which fertility patients regarded giving away their embryos.

For the purposes of this dissertation, it is necessary to clarify whether the embryos to which our respondents referred were ‘fresh’ or ‘frozen’ (Ehrich, Williams and Farsides 2010). ‘Fresh’ embryos have recently fertilised; they have not been cryopreserved. These embryos will vary in quality, from poorly fragmented to well fragmented. The level of cell fragmentation may change if the embryo is cultured to a blastocyst (Scott et al. 2012). “Frozen” embryos have been cryopreserved and stored with the intention of using them if earlier implantations are unsuccessful. Clinic policies vary in whether they will freeze embryos that cannot be implanted (those that have been deemed to be of good quality) (Haimes and Taylor 2009; Scott et al. 2012). The clinic with which this study is associated did freeze patients’ embryos (those which had divided to an acceptable degree) and had a policy of implanting all frozen embryos in succession before women would be allowed to undergo another round of ovarian stimulation and oöcyte extraction. Our participants are referring to those embryos that are frozen but will not be used by them because they do not want more children.

Thus, this discussion diverges from the implications of Scott et al.’s (2012) assertions regarding the process of informed consent when requesting “fresh” embryos. Examining the legal implications of requesting “fresh” (recently fertilised) embryos for stem cell research in the UK, the authors argue that the process should be subject to three levels of consent: firstly an embryo’s disuse in clinical treatment, secondly, its use in research and thirdly that the patients consent to further ART treatment. This contention is based on the contingent factors that assess embryos as excessive to treatment. These factors include the difficulty,

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75 The article draws on the same data reported by Ehrich, Williams and Farsides (2010) and Ehrich et al. (2012) hitherto discussed in this dissertation.
even ‘art’ of grading embryos and clinical methods that may impact on this ‘grading’ such as culturing embryos to blastocyst stage before their implantation as well as the clinic’s freezing policies, (often implemented prior to the conduct of stem cell research in that facility). As freezing is not a uniform practice in UK fertility clinics, patients may be unaware or unable to keep viable embryos which invariably go to research. Some clinics insist that a specific numerical threshold must be reached before any embryo is frozen or embryos are frozen at a specific day which can affect their subsequent utilisation. Typically “less than 70% of day three cleavage stage (non-blastocyst) embryos survive thawing, although the survival rate typically increases to near 90% if blastocysts have been frozen” and subsequently implanted (Scott et al. 2012, 262). Another factor is that patients are considered the ‘owners’ of embryos and embryologists do consider the views of patients and will inevitably yield to patients’ wishes to freeze embryos.

**Embryo provision to research: keeping the family nuclear**

The following discussion will include meanings of the tissue and their implications for the individual’s sense of self and social relations. Continuing the reference to Robert’s (2007) “kin ethics” framework, I suggest that even once treatment stops, participants continue to perceive the embryo as a potential child and make decisions about their use in relation to this meaning. While, data from this study concurs with that of de Lacey (2007), whose South Australian participants discussed disposition choices about embryos, the conclusions I draw are different. De Lacey explored decisions around providing “surplus” embryos to another’s reproductive path or the research path and found that women were more inclined to give embryos to scientific research rather than be implanted in another woman who would gestate the foetus and raise the child. Participants took this position even though giving embryos to research technically involved the destruction of the tissue because they regarded the embryo as too similar to a potential child. De Lacey (2007, 1755) argues that the decision to discard or give to scientific research and not donate for reproduction on the basis that the embryo is too similar to a potential child is irrational because the embryo is effectively destroyed. The following quotes from women in cohort one captures what de Lacey calls a paradox about providing the embryo to scientific research: that these decisions are not based on reducing the embryo to a technical entity but precisely the opposite–embryos are too child-like to be given to another family:
Caroline: Again, because…and it’s kind of contradictory, in a way. A fertilised embryo [sic]⁷⁶ is our child, and I just…I don’t know. I wouldn’t want our child being with someone else. It’s ours. Perversely, I suppose, I wouldn’t mind the embryo being used for medical purposes to enhance knowledge and make things better in the future, even though it would obviously mean destroying the embryo! (laughs) So I suppose it’s a bit perverse, but.

(Undergoing fertility treatment)

Eva: Because it [scientific research] wouldn’t be creating a human being. It would just be helping the technology, or helping somebody else become pregnant, [through research] or maybe even – if it wasn’t working for me, helping me, at some point down the line, become pregnant.

(Undergoing fertility treatment)

De Lacey’s (2007) ‘paradox’ may make more sense when the context in which embryos are created and exist is taken into consideration. Drawing on Robert’s distinction between either “kin” or “life” ethics discussed in chapter six, I suggest that many participants in this study favoured giving their embryos to scientific research because it avoids the issue of having ‘their’ children grow up in another family, particularly in anonymous circumstances.⁷⁷ Many participants expressed the idea of not knowing what could happen to the child as they grew up in another family and the ‘inevitable knock on the door eighteen years time’. Participants from the fertility patient cohort (quoted below) have trouble envisioning their embryos as existing outside the boundaries of the nuclear family.

Joanna: I wouldn’t want to know them [prospective parents]! (laughs) I wouldn’t want to know because I might take it – “Give it back”! Yeah, it’d be in my head like where do they live. Are they treating him or her right?

(Undergoing fertility treatment)

Interviewer (K.C.): So, would you ever donate embryos to another couple?

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⁷⁶ The correct term is fertilised oocyte
⁷⁷ It is important to reiterate that the participants were making hypothetical statements.
Sarah: I’d feel really strange about having my own offspring given to somebody else. Effectively that’s what it is. I’m happy for others to do it! (laughs) But I don’t know if I’d be comfortable with doing it myself. Sharing my own embryos.

(Undergoing fertility treatment)

Bridgit: [No] because it’s basically giving your child away. Like, it’s genetically your child, and the thought of having someone that’s genetically mine, that’s exactly a genetic match – not a genetic match, but like a full brother or sister to my children.

(Undergoing fertility treatment)

Some respondents in this cohort suggest that the decision to provide embryos to scientific research is a way of recognising the value of their embryos while guaranteeing its immediate reproductive potential (as a child) will be disabled. Embryos are not given to scientific research because they are “waste” material, that is, because they are clinically unviable. Embryos are given to scientific research because they remain within the framework of “kin ethics” (Roberts 2007): their reproductive capacity does not change. This shows an important difference between embryos and oocytes where the latter are valued in more functional terms and are given to scientific research once this function no longer exists. With some qualifications, this also diverges from the assertions made by Williams et al. (2008, 8) regarding embryos tested prior to implantation for diseases. Pre-implantation genetic diagnosis (PGD) involves testing embryos for “serious genetic conditions” by testing one or two cells; embryos which do not indicate the presence of genetic disorders will be implanted into the patient’s uterus. Usually, in the practice of PGD, embryos which test positive for genetic diseases will be discarded, however, scientists working in human embryonic stem cells and PGD perceived that the emerging field of hESC research could “partially [disable] the destruction of a number of these embryos as waste” (2008, 15).

My own analysis suggests that traditional ideas about biology and kinship influence participants’ decisions to provide their embryos to scientific research. I again refer to Roberts’s (2007) framework distinguishing between kin and life ethics. Giving embryos to scientific research preserves the notion that the embryo is akin to a child but importantly it

78 This study did not discuss the process of PGD with any of the participants.
also refers to the social entity in which the child should exist: the nuclear family. Giving embryos to another woman or couple in order to enable pregnancy would profoundly challenge traditional notions that connect parenthood and biology. It may also pose a threat to their intentions to become a mother in a conventional sense because another woman will gestate the embryo. The embryo, like the oocyte, is used to serve the needs of the individual self and their trajectory in biological and symbolic ways. The lack of oocytes challenges the possibility of biologically becoming pregnant while embryos (usually ‘spare’ because fertility desires have been fulfilled) challenge the individual to consider disconnecting biology and kinship as it is legally and socially most legitimate in contemporary Australian society. The reproductive identity of these participants is intimately linked to notions of the nuclear family as a bounded structure.

Embryos and a commons of (in)fertility

I have demonstrated that oocyte provision occurs and is likely to occur within a context where a specific benefit or beneficiary has been identified. Reproductive oocyte donation allows the donor to remedy the fertility problem of an individual couple and literally witness the result of their effort in a concrete and tangible way. When speculating on the conditions under which they may provide their oocytes to scientific research, the participants in this study do not show a strong inclination to use oocytes as a means to accumulate scientific knowledge but rather to realise their reproductive capacity. In contrast, for participants (hypothetically) considering the disposition of ‘spare’ embryos, these sentiments are not especially important. Most participants refuse to give embryos away for reproductive purposes, preferring instead to give them to research. As I have explained above, this maintains a traditional biological basis of kinship. The decision to donate for research or reproductive purposes, for a small number of participants in cohort one, also occurs on the basis of identifying with recipients in a general and abstract way. This is the most significant difference between the provision of oocytes and embryos; the former is preferably given to the specific benefit or beneficiary while the latter is given to the generic or abstract recipient.

In early drafts of my analysis, I applied the term ‘fertility patient’ in a broad way without realising that the label implied something about my perceptions of the cohort. The term is not just descriptive but designates women who had fertility treatment as if this experience is
the totality of their identity rather than acknowledging the fact that it is only one social role. However, on further reflection I also suggest that it is precisely this limited dimension of their identity and experience that came to bear on their responses to interview questions. Women who experience fertility treatment become generalised and *identify* as fertility patients and with a community of people with similar experiences. Participants inhabit the generalised category of ‘fertility patient’ through the process of seeking fertility treatment. For instance, clinicians will often discuss treatment options with reference to statistics that are based on aggregate data of past treatments in a local or global context. Patients will eventually contribute to these statistics with their own decisions for treatment. I argue that the experience of being treated for fertility helps the individual to identify with other real but also inter-personally anonymous people in the same context.

Thus, giving embryos to research can also be constructed as a way of enabling families in a mediated form. Participants who expressed a preference for (hypothetically) giving their embryos to research do so with an acute understanding and knowledge of the presence of other fertility patients. The women in cohort one are fully cognisant of the fact that having treatment involving ARTs draws on a vast array of research from the past involving people who have donated their gametes or embryos. Even though these women have not met everyone who has required fertility treatment in Australia or overseas, they will have a sense of their physical or virtual presence as they sit in waiting rooms, hear of specialists’ long waiting lists or peruse their views on internet-based forums or in other publications. Treatment creates a discrete community to which the individual belongs by virtue of seeking treatment. I suggest that research is material practice that can connect the patient self and the community of infertile people. Their experiences, treatment outcomes and embryos may be legitimately situated within this common space by clinicians and researchers who publicise research findings and treatment outcomes.

**Francesca**: The last thing we would do is just dispose of the oocytes and not do anything with them, because I’m strongly...the research that’s brought IVF to Australia is the research that’s given us this child.

(Undergoing fertility treatment)

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79 It is why I use the less efficient label “women undergoing fertility treatment”.

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Mandy: [providing oocytes] for infertility [research], it would – if I felt that it was helping someone who was going through, or future people, who were going through something similar to what I was going through, in regards to having children.  
(Undergoing fertility treatment)

Eva: Because it [scientific research] wouldn’t be creating a human being. It would just be helping the technology, or helping somebody else become pregnant, or maybe even – if it wasn’t working for me, helping me, at some point down the line, become pregnant… 
(Undergoing fertility treatment)

Mandy: for infertility, it would – if I felt that it was helping someone who was going through, or future people, who were going through something similar to what I was going through, in regards to having children, which is what the eggs are all about, then I might consider it.  
(Undergoing fertility treatment)

These responses may resemble the notion of imagined community, borrowed from Anderson’s theory of the nation-state (1983). In contrast to other forms of political organisations such as monarchy, the nation-state is impersonal and abstract and it is highly unlikely that an individual will meet all of their fellow citizens. Anderson (1983, 31) argued that despite the intangibility of the modern political association, even if it is based upon territory, there are means through which individuals “know” of their fellow inhabitants such as those that involve national narratives such as reading the paper whereby the individual is reminded of “their steady, anonymous, simultaneous” presence.

Embryos for reproductive purposes: the abstract recipient

Giving embryos to research is expected to make fertility treatment better but it is not intended to alleviate the infertility of anyone specific. In contrast, a subset of participants in cohort one do consider giving their embryos directly to infertile couples. Rebecca, characterises research into fertility as completely negative suggesting that it does not create
anything. What she means is that research disables the immediate reproductive capacity of the embryo and shifts it to more diffuse and generic ‘products’ such as knowledge and therapy. From Rebecca’s perspective, embryos are like oöcytes and their use is meant to be reproductive in a strict sense. Both women quoted below express the sentiments usually offered by reproductive oöcyte donors who consider the tissues to be reproductive but may be more flexible about the circumstances in which this potential may be realised.

**Rebecca**: Well, to me our embryos – we don’t need them for ourselves anymore, our embryos, so I’m happy to give them away…obviously they can’t become anything if they’re just donated to research compared to if they were given to another couple. There is the chance they could become a human being, as beautiful as our two beautiful children! And you know giving them to another couple, we just think that would be incredible.

(Undergoing fertility treatment)

**Interview (KC)**: Would you consider donating spare embryos to a more general scientific research program that wasn’t attached to fertility?

**Lisa**: if I had no need for them and it’s going to help somebody else down the track, and no-one else needs them, then sure. I think I’d rather offer them to someone, and any leftovers could then go to research. That would be my way of thinking for anything. And research, to me, is research. Be it into infertility or whatever, it’s research.

(Undergoing fertility treatment)

**Francesca**: well, everyone deserves the right to have a child, especially a couple going through this. You don’t go through this unless you desperately want children. It’s not something you do light-heartedy. So yeah, that’s what we decided we would do…If it’s a couple we knew that needed it and was willing to accept it, we’d be happy to do that – especially if it was a sibling or something along those lines. …I’m happy to donate to a couple that’s not necessarily someone we know either. We feel it’s important to give another couple the opportunity that we were lucky enough to have,
because not every couple can produce oocytes like I can (laughs). If we can give one couple the gift of a child, why not?

(Undergoing fertility treatment)

Francesca’s perspective in particular echoes strongly with those of reproductive oocyte donors because it presupposes a specific and deserving recipient. Women who have had fertility treatment see similar distinctions regarding their embryos, differing in means but ending in the same way; whether they provide their embryos to research or reproduction, they perceive it as helping to create children and families. In relation to stem cell research (not SCNT), many participants expressed hope that the therapies derived from provision could benefit individuals they know. I suggest that embryos are much more likely to be perceived as a tissue ‘in common’ and thus the theoretical leap from specific (fertility) research to more general (stem cell) research is not particularly problematic.

Eva: Just knowing that someday it might create…even if it doesn’t grow a kidney,\textsuperscript{80} then maybe it could help with something – who knows what our children will get, or something that could help my family.

(Undergoing fertility treatment)

Isabel: Yes – I’m not necessarily more just for fertility [research]. Again, for me, then, if they’re [embryos] going to be donated for research… I actually think that in this day and age it’s something that I think is needed, because we’re an aging population, so more and more people are coming down with particular conditions that they need to find cures for, or ways to make people’s quality of life that little bit better than what they would have to go through before. If stem cell research can help that, I’d like to know that I was able to assist in some way.

(Undergoing fertility treatment)

As demonstrated, women perceive embryos in complex ways and are not unanimous in their hypothetical decisions about ‘spare’

\textsuperscript{80} Eva’s husband had a kidney transplant in his early twenties from a kidney donated by his father; Eva describes it as a “63 year old kidney”. It is likely her husband will need another kidney transplant in the future.
embryos. These results show that the consequences for the maternal social role are different when the individual is giving embryos. On the one hand, refusing to give embryos to others who are also experiencing infertility maintains the ‘natural’ connection between biology and kinship because the embryo remains within their biologically related family. On the other hand, donating embryos for reproductive purposes can also help to “reproduce” the idea of family outside the (potential) donor’s own experience. Whether the provision of embryos is “direct” or “indirect”, both forms of embryo provision rely on the generalised and abstract, rather than the specific, donor and recipient.

**Conclusion**

This chapter addressed a number of research questions including what is involved in the decision making process of oöcyte and embryo provision for reproductive and research purposes and presented the following results:

The oöcyte donors in our study:

1. Prefer to donate oöcytes to recipients they can identify but do not expect long-term relationship with their recipients and/or the children their donation helps to create
2. Seek to find ‘good parents’ for their oöcytes that are largely defined as having economic, social and personal stability.
3. Experience the process as rewarding because they personally witness the outcome of the process
4. Do not perceive oöcyte provision to SCNT research as similarly rewarding, suggesting the benefits are too impersonal.

Participants in cohort one who discussed embryo provision for research or reproductive purposes in a hypothetical manner:

1. At times regard the provision of embryos – entities which they consider to be their children – to research as a means of disabling that reproductive capacity, thereby maintaining a symbolic and tangible link between biology and kinship.
2. Understand the provision of embryos as a means of relating to the ‘imagined community’ of other fertility patients from whom their own treatment is derived.

These results show that women utilise their reproductive tissues for themselves or others and that these differences have specific consequences for their intentions to become a mother. For instance, most participants, irrespective of cohort, do not want to give their oöcytes to SCNT research because this will undermine their intention to become a mother. Where the donor has identified a specific benefit or beneficiary, the process of oöcyte extraction is placed within an affective framework. This framework can change perceptions of effort, risk and reward. A woman may be transformed into a “good egg” if there are concrete, rather than abstract, dimensions to undertaking oöcyte extraction. This framework also changes expectations of reciprocity. Without necessarily having a prior relationship with the recipient, the donor undertakes to correct a perceived imbalance for the recipient and this contributes to the suspension of obligations of reciprocity, where gift and counter-gift must be offered.

I have explained the potential provision of embryos to research in two broad ways. Firstly, as a way of keeping the family nuclear. Because their provision has different consequences for women’s intentions to become a mother, most women in cohort one will given their embryos to stem cell research because their intentions to become, and be, a mother specifically means that this should occur within the nuclear family. Secondly, embryo provision to research is a consequence of one’s experience of fertility treatment. Embryos are given to a community of other fertility patients but these people only share a generic quality – their fertility treatment. Giving to such a community does not involve a thorough evaluation of their characters or personalities. In this way, the logic underlying the provision of embryo is different to the logic underlying oocyte provision: the embryo is given to the generic and abstract beneficiary and benefit.

So far, these chapters have sketched out the ways in which reproductive tissue provision is contextual and differs in relation to the donor, the recipient and its social and historic specificity. Giving reproductive tissues can occur in two ways, by identifying a specific or generic benefit or beneficiary. The relationships that are created by doing so do not always adhere to expectations of reciprocity. These findings will be discussed in more depth in
chapter eight, which will address research questions in relation to gift-giving in Australia and the connections between gender, altruism and political associations in a “scientific” society.
Chapter Eight: Scientific Utilisations Of Reproductive Tissues in Australia: Recognising Discretionary Reciprocity and Passionate Dimensions

Summary

This thesis is concerned with the issue of oöcyte provision to SCNT research, a novel technique that may transform the nature of transplant medicine. So far in the Global North very few women have provided oöcytes within the context of altruistic-donation, the paradigmatic model of tissue provision for therapeutic and research purposes. Scientific researchers, bioethicists and policy makers charged with its ethical oversight have thus far examined the issue within analytical frameworks, discussing the risks of oöcyte extraction and the benefits of scientific research. It has been suggested that the introduction of a payment system will increase the number of providers generally and these new providers are likely to be motivated by impersonal incentives like money and/or an abstract interest in science. These providers are contrasted with 'passionate' donors, women who have personal stakes in the research or may exchange their oöcytes for cheaper fertility treatment. Overall, the introduction of a payment system has been controversial because it is expected to target the vulnerability of women.

Chapter Two examined the regulation of SCNT research in two countries, the UK and Australia, arguing that while these have common political and social heritage, each jurisdiction has approached SCNT research differently. Australia allowed SCNT research from 2007 but continues to ban the use of animal oöcytes and payment to individuals. In contrast, the UK permitted the research from 2001 and owing to the low levels of donated oöcytes it began compensating donors (in the amount of £750) in 2011.

In Chapter Three, I surveyed the literature regarding oöcyte provision to SCNT research, paying close attention to the debate about the necessity of instituting a payment system and whether this will constitute an undue inducement, undermining the principle of free and autonomous participation in scientific research. I then discussed Titmuss’s (1997 [1970])

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81 Scholars such as Skene has had an advisory role as the Deputy-Chair of the Lockhart Committee and was its spokesperson after the Chair, Justice Lockhart suddenly died.
account of blood provision for therapeutic purposes because the tissue economies literature continues to debate the implications of his work. Titmuss advocated an anonymous blood-donor model that avoided payment of any kind in order to exclude potential blood vendors who would put their own interests before the common good. Titmuss wanted to encourage altruism on a national scale where individuals could embrace the ‘universal stranger’ rather than direct their gift towards specific recipients.

In chapter four, I developed my own eclectic framework for analysis. I critiqued the current approach on the basis that it remains too close to static binaries of gifts and commodities, it persists in constructing a conflict or division between a monolithic category of science and individuals and continues to uphold the idea that the ideal donor is motivated by rational means and gives to research as an abstract good directed to general – rather than specific – recipients. From this analysis, I generated research questions about the practical contexts of giving reproductive tissues and their sociological constructions by potential donors. In chapter five, I discussed the epistemological rationale for the current research achieving a dynamic understanding of gift giving as a relational process between donor, recipients and the broader institutional context in which it takes place. I presented the research design and outlined the means of recruiting the sample and the research methods utilised to achieve the study’s aim.

Chapters six and seven reported the results of the research, organised in a thematic way by drawing on responses from cohorts to various questions. The results indicate that there is a general consensus among participants that they would not provide their good eggs for SCNT research. Participants in this study perceive oocytes as a tissue whose significance is based on their reproductive function; it is a fragile reproductive tissue that must be managed and protected carefully. The results show that the majority of respondents are more inclined to provide infertile/clinically unviable oocytes than fertile ones. The provision of infertile oocytes to SCNT research may be considered a strategy of waste management, which enables further use of infertile eggs in a meaningful way.

In examining the narratives of reproductive oocyte donors, I sought to demonstrate that the affective overtones – namely the identification of a specified beneficiary or benefit – are a
crucial motivating factor in the process of oocyte extraction and provision.\textsuperscript{82} Even if the oocyte has a predominantly functional rather than moral significance, reproductive oocyte donors are enabling the creation of sentient beings who need ‘good parents’. Based on this, I argued that the relationship between donor and recipient was an important element in undergoing the process of oocyte extraction and argued that the technical and medical elements of oocyte extraction are perceived as a means to an end, not an end in themselves. The provision of embryos created within the context of fertility treatment was also shown to vary. Viable, stored embryos, those which were considered surplus to the individual’s family size, were often considered appropriate for scientific research. Using Roberts’ kin ethics framework, I suggested that this is an important strategy for maintaining the biological foundations of kinship. From this data, I argued that whether participants wished to provide embryos ‘directly’ to others for reproductive purposes or to give embryos to fertility research, they were interacting with other fertility patients and their treatment had generated a specific identity in relation to the embryo.

In discussions about providing oocytes to SCNT research, most participants preferred to give in circumstances of a specified benefit or beneficiary. In the absence of these conditions (these do not currently exist), there was some confidence expressed that for-profit companies are more capable of transforming the initial gift into a clinical benefit, rather than non-profit researchers. The reciprocal relationship between the oocyte provider and the research recipient is complex; on the one hand, some form of reciprocity is expected in recognition of the high level of commitment oocyte extraction requires and the fact that companies will make a profit out of their research; on the other hand, the precise level of economic benefit is elusive and participants distinguished between two forms of money, ‘payment’ and ‘compensation’. Participants who were undergoing fertility treatment consistently argued that egg-sharing models are potentially the most exploitative of women like themselves, because these models do not offer ‘true’ choice to women who may not have the financial resources to pursue fertility research. Instead, egg-sharing was perceived to prey on women

\textsuperscript{82} As noted in chapter five, attempts at analysing the data changed between 2009 and 2013. Initially I tried to reconcile the data with existing literature on reproductive oocyte donation. However, I found this to be predominantly situated within a feminist discourse that was hostile to the process by assuming that it was based on inherent exploitation of women’s reproductive (biological) or social capacities. Eventually, I decided to use these narratives as a way of understanding what was different about oocyte provision to SCNT research. Prior to my candidature, I thought very little about oocyte provision for research and reproductive purposes and do not believe I was particularly ‘surprised’ by the results.
with little financial resources to utilise ARTs. Based on the data, I suggested that oocyte provision to SCNT research was not considered rewarding in itself and it requires an affective dimension such as a specific benefit or beneficiary in order for it to be undertaken in an altruistic-donor context.

In the following chapter, I intend to discuss the diverse attitudes, perceptions and practices regarding reproductive tissue provision for research and reproductive purposes in order to examine the significance that intending to become a mother may have. I first discuss the connection between gender and altruism, asserting that these are not as inflexibly connected as is often claimed by feminist scholars debating this issue. I sustain this claim by discussing the concept of discretionary reciprocity. This concept is derived from evidence showing that the specific social contexts in which gifts are given can determine the level of reciprocity in the relationship between the donor and recipient. Moreover, the construction of the recipient’s needs is crucial to the donor’s expectations of reciprocity. I contend discretionary reciprocity can account for practices of giving in known contexts that do not institute reciprocal relationships.

I further discuss whether reciprocity for oocyte provision to SCNT research is invariably a fairer system by looking closely at the difficulty of finding an equivalent for oocytes, evident in the need by participants to distinguish between ‘compensation’ and ‘payment’. I do so by critically discussing Mauss’s approach to gift-exchange that insisted that objects had an inherent gift status because they were spiritually vital. I refer to the claim made in chapter four that the kula ritual to which Mauss based his claim of gift-giving-as-exchange does not actually reflect on how these objects came to be equivalents at all. It is important to understand this point in order to understand how some gifts can be constituted as ‘free’ – outside cycles of reciprocity. I then explore the implications of this point for contemporary debates regarding the institution of a payment model in Australia. Drawing on critical approaches to materiality discussed in chapter four, I argue that the object of money (as currency) is constituted in two ways; as ‘compensation’ or ‘payment’. Rather than being an inert object, money becomes vital once it passes a symbolic threshold. This can explain the ethical differences between the two forms and the concerns that participants and some scholars express about the institution of a payment system.
In spite of a weakened position as the only valid or pre-eminent means of explanation, scientific research continues to be an important part of contemporary society in an economic, social and cultural sense. Principle-based approaches may differ as to whether individuals should be paid to provide oocytes to SCNT research but are united in the belief that the ideal donor is “rational”, that is disinterested in their own needs and will be motivated by abstract principles such as the advancement of scientific knowledge. As there are many ways people may enact the social role of contributor to science, I argue that the rationalised approach does not actually capture the ways which many people make sense of their contributions to scientific research. I do not claim that passionate and rational imperatives are mutually exclusive but that it is important to acknowledge that contributions to scientific research have passionate aspects. I use the term passionate to claim that people who give tissues are not abstract individuals but members of a community and they understand that giving (or withholding) their tissues can be connected to past efforts of donors and scientists. I refer to Levi-Strauss’s concept of generalized exchange. The current generation make their decisions about tissue provision in relation to the experiences of past members of the community because their identities are an effect of these practices. In the studies I draw upon, the abstract principle of accumulating scientific knowledge is present in the background but science effectively operates as a mediator between members of a community who enact a form of generalized-exchange. Thus, I claim that the momentum of scientific research is based on a relationship between individuals and specific identities, the tissue and the collective the research claims to benefit. Current appeals for women-in-general to provide their ‘good’ eggs to SCNT research does not evoke a specific social role such as mother, daughter, niece or aunt and thus remains too abstract to motivate one to undertake the process of oocyte extraction.
Gifts, anonymity and reciprocity

The results from this study demonstrate that gift-giving practices are variable, even with the same tissue and in identified contexts. This challenges Titmuss’s (1997 [1970]) central claim that blood provision for therapeutic purposes can be a ‘free’ gift based simply on altruism. If blood provision is donated under conditions of anonymity, the relationship does not constitute a gift-exchange. The act of blood donation permits individuals to embrace the universal stranger and view their blood as a therapeutic connection rather than a basis for social divisions. At this level of analysis, Titmuss appears to diverge from Mauss’s (2002 [1954]) analysis of the free gift as a social fiction, insisting that it can work despite much empirical research of contemporary gifting practices (Cheal 1988; Komter 2005; Shaw 2008b, 2011). From this research it is evident that reciprocity is rarely enacted in precisely equivalent terms but that ultimately, the “failure to return a gift, or say thank you for that matter, symbolizes a refusal to cement the social and moral bond” (Shaw 2011, 299). However, I suggest that Titmuss and Mauss are not entirely opposed in their approaches regarding gift giving and that the former sought to structurally manage the imposition of a free gift system. Titmuss did not deny that gift giving would probably inevitably lead to gift-exchange (the establishment of cycles of reciprocity) and thus insisted that the only way to avoid this was inter-personal anonymity. Hence, despite the differences between Mauss and Titmuss, they appear to converge regarding the universal nature of reciprocity between people inter-personally known to each other.

The relationships between donors and their recipients in this study is a mixture of motivations and intentions and their altruism is not devoid of more practical concerns. As discussed in chapter seven, Australian fertility clinics do not act as oöcyte ‘brokers’ and have instead instituted an informal process of oöcyte donor recruitment between individuals. Fertility clinics actively encourage their patients to find their own donors through their social networks or by advertising. After finding a donor, the recipient is expected to attend a fertility clinic with her donor in order to undergo a series of medical and psychological tests and mandatory counselling sessions prior to formalisation of the agreement with informed consent. The sense of intimacy that emerges between the donor and recipient is formed between the donor and recipient is formed

83 The company IVF Australia which has offices in NSW, Victoria, and Queensland does recruit semen providers.
outside of the clinic because the clinic does not undertake brokerage duties. As a consequence, the clinic mediates the technical aspects of oöcyte extraction and formally recognises the relationship between the donor and recipient with legal documents. Outside the context of oöcyte donation, the site is of little consequence to the donor.

There are ‘instrumental’ elements in the process of providing oöcytes, even in the context of altruistic and inter-personally identified donation. Part of a narrative donors construct about their recipients is that they have been chosen precisely because they represent a ‘good parent’. Designating the recipient as a ‘good parent’ provides further basis for the donor to argue that she found someone whose needs are urgent and justified. The donor constructs herself as correcting a significant imbalance in the recipient’s life and returning it to equilibrium—achieving parenthood. Donors themselves retreat from cycles of reciprocity in two ways; they decline the importance of financial reward claiming they are rewarded by having helped another person and they insist that they do not wish to pursue long-term relationships with the recipients or children born from their donated oöcytes. Indeed, for some participants in our cohorts, particularly those in healthy donor cohort and women who had ‘spare’ embryos, the prospect of being identified as a donor was perceived as disturbing familial boundaries. Women who donated their oöcytes maintain that they are satisfied with choices made at the time of donation about the suitability of recipients and do not attempt to ensure that the recipients will live up to their expectations to behave as ‘good parents’.

In the context of reproductive oöcyte donation Titmuss’s idea of the gift is compromised because it occurs as a form of identified tissue provision, that is, individuals are known to each other and the tissue is directed at a specific recipient rather than the universal stranger. By all accounts, it should involve the inevitable formation of reciprocal relationships. However, the consequences are surprising. The data indicate that establishing and/or maintaining social relations through gift giving is dependent on the context in which this occurs. Participants in our study do not always seek to maintain relationships with their recipients because the gift given can effectively act to undermine the biological basis of kinship. In seeking to help recipients become ‘good parents’, they maintain the nuclear family. Cycles of reciprocity involving recognition of the donor would further threaten the recipient woman’s ability in particular to be the child’s “authentic” mother because traditionally, the mother has been the figure who has contributed her DNA and gestated the
child (Jackson 2006).\textsuperscript{84} The decisions made about reciprocity are connected to legal structures and social norms that privilege a particular definition of the family in which gift giving must be situated. Gift giving does not necessarily create gift-exchange because it does not occur in a social vacuum. In this context, the institution of the family comes to bear on the practice of gift giving. The idea of the family as nuclear, comprised of children with one biologically-related mother and father, helps to shape the role of the donor and the cycles of reciprocity that may be appropriate.

Using anonymous donor systems to circulate blood and other tissues has broader implications for society. It can have a radical effect on society by establishing the inherent right to health, a condition to be objectively determined by medical authorities. A system where blood was given for specific races or castes reproduced systemic social divisions. Titmuss’s (1997 [1970]) call for individual to embrace the ‘universal stranger’ through anonymous blood donation corresponds with other representations regarding donor’s selection of recipients. For instance, Bauman’s perspective quoted below suggests that recipients should be seen as an undifferentiated mass of needy people. Gift giving should not involve the evaluation of the recipient

[I]n the case of the gift...the needs and the rights of others are the main - perhaps the only - motive for action...The goods are given away, the services are extended merely because the other person needs them and, being the person it is, has the rights for the needs to be respected (Bauman 1990, 90).

In contrast, reproductive oöcyte donors demonstrate that they do not understand parenthood to be a universal expectation or ‘right’ to be granted simply because one wishes it; rather, some recipients are more ‘deserving’ than others. Reproductive oöcyte donors in our study do not regard fertility patients as a homogenous group of undifferentiated people in need. Instead, the ‘good parent’ has struggled with his or her fertility but also adheres to social norms about economic stability and child-centered parenting styles. While donors do not exclude people based on common social divisions such as race, sexuality or age, they nevertheless favoured couples whose parenting abilities were reinforced by their economic

\textsuperscript{84} There is also much evidence to suggest that these issues occur within assisted insemination donation (Daniels 1998; Hargreaves 2006; Grace, Daniels and Gillet. 2008).
status and the hardship of struggling infertility. Their strategies to select recipients indicate at least two things about families in contemporary Australian society: first, individuals expect to be able to make moral decisions about the creation of families without interference from government regulation and conservative social norms. Second, only some efforts to access healthcare are regarded as reasonable, that is parenthood is not a universal right. These strategies indicate that in some contexts, donors will not necessarily assess their recipients as worthy (indeed, there are legal restraints about this). Titmuss argued in the case of blood donation that the recipient has an inherent right to receive its therapeutic benefit. However, in the case of reproductive oöcyte provision, some recipients are more deserving than others because they represent ‘good’ parents. The evaluation practices in which our donors engaged reflect enduring social norms about ‘good parents’. Overall, gift giving in identified contexts does not inevitably lead to cycles of reciprocity because the recipient’s needs are situated in the broader social context.

**Discretionary reciprocity**

In contrast to reproductive oöcyte provision, participants do not consider the recipient of scientific oöcyte provision should be excluded from the obligations of reciprocity. This expectation of reciprocity is related to the fact that their decisions to donate are related to distinguishing which recipient is best situated to transform the gift into something tangible and ultimately useful. The scientific recipient is not characterised as deficient and thus the donor can argue they are addressing an important – but not a desperate – need. This especially relates to ‘for-profit’ research organisations because they can match the commitment to pursue ‘bench’ research with the material resources required to translate it into therapeutic applications. Thus, it may be argued that the industrialisation of scientific research, to some degree, contributes to expectations of reciprocity by potential donors (Ballantyne and de Lacey 2008; Dickenson and Alkorta Idiakez 2008). In this context of giving oöcytes, recipients are expected to recognise the effort of the donor in some way, perhaps as further acknowledgement that the donor has chosen wisely and given to the

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85 This does not neglect the fact that fertility treatment can still be limited or entirely denied to people who are not heterosexual and/or married. Also, this study did not actively seek to interview people whose sexual orientation or marital status impacted on their fertility treatment. In South Australia and Victoria, there are legislative restrictions imposed on same-sex attracted couples seeking fertility treatment including the use of donor gametes and in the state of Victoria, all prospective IVF patients are expected to undergo a police background check (Betts 2010).
‘right’ recipient. This is different from the basis of reproductive oöcyte donation where the recipients are identified as deficient in their capacity to be fertile. Despite the donation occurring between identified parties, norms of reciprocity are suspended. The gift resembles an act of charity, designed to restore the recipient to a point of equilibrium and, importantly, reciprocity is imagined to be superfluous to the donor's effort because she does not perceive the process to be a drain on her emotional and physical resources.

It is beneficial to situate these different orientations regarding the provision of oöcytes within broad frameworks of gifts, giving and reciprocity defined by Titmuss (1997 [1970]) and Mauss (2002 [1954]). I refer to results that show participants’ evaluation of potential recipients consequently determines the type of relationships into which the parties enter, rather than an inevitable desire to give to others. The findings presented in this dissertation strongly indicate that participants’ expectations of reciprocity are contextual. I refer to this variability as discretionary reciprocity. When asked about receiving something in return for oocytes, participants in this study expect those recipients, such as a commercial research company, who can reciprocate to do so, while others, such a people using oöcytes for reproductive purposes are excluded from cycles of reciprocity. Gifts of oöcytes for reproductive purposes are restrained in their uni-directional form by social norms that inhibit ongoing relationships between donors and recipients. By using the term discretionary reciprocity, I contend that practices of giving oöcytes are largely determined by the donor’s perception of whether the recipient is capable of reciprocating their gift. That is, gift giving does not necessarily lead to gift-exchange.

The concept of discretionary reciprocity may appear to be redundant given that any object can be used to reciprocate the gift and research shows that it is rarely symmetrical (Komter 2005; Shaw 2011). But my point relates to the idea that it is not the nature of the returned gift that is important but whether the gift should be returned at all. For instance, reproductive oöcyte donors do not need to be given oöcytes or a child in order to be reciprocated, anything may constitute a return gift. As I have demonstrated, the donor constructs the reproductive oöcyte recipient in a specific way, as incapable of fulfilling her own intentions for motherhood. In comparison with research companies, these women/couples are running their own “deficit”. This is why I suggest that despite all that reproductive oöcyte donors
give, the participants in our study rarely represented themselves at a loss of time or oöcytes. Hence, this claim diverges from conceptualisations of reciprocity as a universal part of gift giving (gift-exchange) where the parties are known to each other (Mauss 2002 [1954]; Titmuss 1997 [1970]).

The term discretionary reciprocity may, to a degree, correspond with Testart’s (1998) critique of Mauss’s (2002 [1954]) conceptualisation of reciprocity as a universal part of gift giving. Testart demonstrates that in many contexts in which contemporary Western people give to others, such as change to homeless people on the street or invitations to dinner, the obligation of reciprocity is not reinforced by any legal sanction. In contrast, the chiefs partaking in potlatch ceremonies of Northwest Canada, to which Mauss referred, must reciprocate by destroying more of their wealth because “it is indeed the honour and the prestige of the chiefs that is at stake in the obligation to reciprocate” (Testart 1998, 99). Furthermore, the potlatch was an institutional and broader social event between groups rather than individuals. Thus if the tribal chief refused to partake in the potlatch in the prescribed way, his and others’ social roles may be jeopardised. However, distinguishing between legal and social sanctions does not sufficiently account for the fact of giving in the first instance and feelings of gratitude or potential offense if the gift is not reciprocated. In my own analysis of giving oöcytes in two different contexts, the term discretionary reciprocity indicates that the donor does not always give with the expectation that the gift will be reciprocated. Whether oöcytes are given without expectations of reciprocity is determined by the donor’s perceptions of the recipient and the reasons for giving oöcytes. This does not just refer to whether oöcytes are given with altruistic or instrumental intention but the outcome the donor hopes to achieve.

**Destablising the connection between altruism and femininity**

This analysis of oöcyte provision also diverges from predominantly feminist-oriented scholarship of the practice for predominantly reproductive purposes (Pollack 2003; Almeling 2006, 2009; Shaw 2007, 2008a; Nahman 2008). Analysing the donor narrative, rather than isolating the reasons that contribute to their decisions, indicates that they have instrumental and altruistic concerns despite the fact that they cannot and do not expect to be financially remunerated for their actions. I argue that these two strands of motivation are the basis for
suspending norms of reciprocity and can account for the donor’s commitment throughout the relatively long process. This is not to dismiss scholarship that shows how assumptions about feminine and masculine behaviour can have material affects on policies and their implementation (Almeling 2009, 2011). Rather, it points to the limiting and one-dimensional assumptions about behaviour as either altruistic or instrumental, not both. For instance, in the context of the US, Spain and now the UK, rhetorics of altruism continue to be applied to oöcyte donation rather than semen, despite the fact that oöcyte donors are financially remunerated for their effort.

As previously cited, Almeling (2011) argues that gift rhetoric persists in the context of providing eggs even when it is essentially a commercial aspect (money is traded for eggs) because ultimately it is the family that is for sale. Family life has long been considered a non-market space and thus egg selling “is a more direct violation of the cultural distinction between market and family than is paid sperm donation” (2011, 88). According to Almeling’s own approach, to consider the organisational and personal experiences of egg provision, maintaining the sanctity of the family may be considered a cultural imperative and thus is the organising principle of the entire process of commercial egg provision in the US. However, Almeling does not thoroughly speculate on the consequences of breaking such a taboo except to say women who are considered to be career egg providers or display too much interest in the financial aspects are either encouraged to downplay this or are rejected from the process. These exclusionary tactics are also reported by Pollack (2003).

Feminist assumptions that the “powerful stereotype of female self-sacrifice [would create] in the minds of some women…an expectation that they surrender their own interests and assume the risks of egg extraction” (George 2008, 290) is comparable with similar assumptions on the part of scientists, such as Ian Wilmut, who appeal to women to donate oöcytes. The UK newspaper, The Guardian, quoted Wilmut saying:

I have never doubted that women would donate if they thought we were helping people to have treatment. Our hope and belief is that women who have seen the devastating effect of [motor neurone] disease will be prepared to make such a donation (Sample and McLeod 2005).
Wilmut suggests that women could be motivated by the prospect of helping people with severe disabilities or diseases, now or in the future, and makes seamless the trajectory between women’s contributions, scientific research and therapeutic application. He “banks” on the currency of science, through which human society benefits from the conduct of scientific research. Both views contend that women can be referred to in an abstract and universal sense, as a category that is not socially and historically specific. This relies on a specific construction of the individual as being in tension with other individuals or the broader society and culture (Martin 1988; Strathern 1988). Gender is analysed in such a way as to deny the possibility of diversity or multiplicity; the conclusion is that women will feel obliged to give because it is an expression of femininity or women will sell their oocytes because they are socially and economically vulnerable vis-à-vis men. In both instances, giving and/or providing is a consequence of patriarchal and capitalist power relations. The argument is circular: to be a woman in contemporary society is to give and/or provide and to give and/or provide is to be a woman. These views do not recognise the diversity of decisions made about oocyte provision and ambiguities related to the conduct of scientific research.

The data from this study suggests that a general anxiety about women being exploited for their socially defined roles as altruists and a distorted sense of self-sacrifice is largely unfounded, and that it is necessary, to revise the basis of this premise. Most participants, particularly those with experience of fertility treatment, emphatically reject the idea that they would give their ‘good’ eggs to SCNT research. This is contrary to the view of Ballantyne and de Lacey (2008) and Roberts and Throsby (2008) that such women will become oocyte suppliers by default. In part, this is because participants experience and construct their oocytes as a fragile resource in the pursuit of their intention to become mothers. In order to achieve their maternal aspirations, women intend to keep all oocytes until they have been differentiated through the process of fertilisation. Once this designation has been made, women will consider providing infertile/clinically unviable oocytes to SCNT research. I contend that this finding provides important insight into the general lack of altruistic donation of oocytes to SCNT research in the Global North and indicates that pressures women face to be ‘generous’ are not inevitable. As much as I would like it, this statement does not have universal resonance but it does echo Haimes’s (2013) findings that women in
the UK do not inevitably provide their oocytes for research even when they are “paid to share” (Roberts and Throsby 2008) and that those who did partake in the scheme had high incomes. The general lack of good eggs for SCNT research demonstrates that expectations of femininity-as-altruistic may be less powerful than social norms about motherhood and kinship structures. It suggests that while giving is generally considered an unqualified good, it occurs in relation to other intentions or narratives that the individual may intend to pursue, between which there may be tension or conflict.

**Reproductive tissue and the politics of motherhood**

At this stage, I want to connect this discussion to ideas about the citizen emerging in the 18th century, with which feminist and other liberal theorists in contemporary society continue to grapple. I suggest that ideas about the citizen are central to understanding the current lack of oocytes and attempts to solve the problem. Historically, women have been excluded from enjoying the full rights of citizens, often refused recognition as independent political subjects, without the right to vote, own property or self-determination (Dickenson 1997). In the modern era, while the universality of equality was being promoted, the division between the feminine private sphere and the masculine public sphere was partially attributed to the nature of the sexes (Phelan 1999); for example, according to the 18th century political philosopher Jean-Jacques Rousseau, women could not sustain the kind of abstract thought needed to engage in democracy, whereas men could be rational and objective (Phelan 1999). The private sphere of the home was seen as an important counter to the cold and calculating public sphere. Passions belonged in the private sphere and specific and private interests could be privileged over the universal and common good. These ideas continue to shape perceptions about feminine and masculine behaviour and are central to the discussion of oocyte provision for SCNT research. I want to suggest that divisions between public and private spheres and expectations of altruism persist and are at the heart of the paradox of assumptions that women would altruistically give their oocytes for SCNT research and the fact that so far, societies of the Global North have not witnessed significant demonstrations to do so.\(^86\)

\(^86\) I do not mean to suggest that by looking only at oocyte provision to SCNT research will deconstruct ideologies of altruism, or that other forms of tissue provision such as blood and organs do not grapple with similarly low rates of donors. However, I do think it is important to acknowledge that the emergence of stem
The political scholar Pateman (1992) argues that women have had a specific role within the public sphere that the state has largely been able to define and regulate. Pateman (1992, 19-20) explores the capacity of women to make a ‘political contribution’ in a society divided between public and private spheres, arguing that it “rests on a major paradox: [women] have been excluded and included on the basis of the very same capacities and attributes”. What she means by this is that motherhood, which has been perceived as the ultimate expression of subjective feeling and the most intimate of relationships, has a political dimension to it (Voet 1998). This is distinct from other approaches which have defined political status and duty in narrow terms such as voting. According to Pateman (1992, 19-20), the political dimensions of the maternal role has its origins in political philosophy regarding republics. Modern republican polities were based on an actively engaged citizenry. In this gendered political order, men were expected to express their duty militarily, as defenders of the territory, while women expressed their duty as breeders of future citizens. As Pateman (1992, 29) points out, men’s duty to protect the state has transformed from serving in war to being economically productive but for women “motherhood and citizenship remain intimately linked”. Most recently in Australia, the idea of ‘citizen mother’ has been explicitly expressed by the federal Treasurer of Australia, Peter Costello who in 2004, urged women to increase their individual fertility rate by having three children; one each for dad, mum and country (Waldby and Cooper 2008). It is also evident in ongoing debates in Australia about women’s participation in employment, access to superannuation and adequate childcare facilities. The implications of maternal citizenship – as an expression of duty to others within a defined territory or in service to an ideological principle – are central to questions about oocyte provision for SCNT research because it effectively provides a novel expression of women’s reproductive capacity, their own subjectivity and relationship with the polity. In utilising female gametes and relying on embryos that require significant female labour to produce, regenerative medicine can be considered a novel form of the political or “public” use of women’s reproductive capacity. This is related to the “public cell research was greeted with a lot of scholarship based on assumptions about women’s “inherent” vulnerability and the inevitable imposition that scientific utilisations of reproductive tissues will generate.

87 This idea is also different from de Beauvoir’s existential analysis of motherhood which are situated at the level of the individual.

88 In contemporary societies, these divisions are of course blurring with participation in the workforce increasingly becoming the central duty and status symbol of citizens despite the difficult faced by minorities (Aapola, Gonick and Harris, 2005).
good” of scientific research and attempts by successive governments around the world to utilise its discoveries to improve health and control populations. Women’s bodies give to the polity through the production of scientific knowledge.

Giving oöcytes to SCNT research could represent a distinct manifestation of female citizenship where the traditional utilisation of the oöcyte for kinship purposes is transformed into material for the universal stranger and an anonymised polity. This Titmuss-esque sentiment was encapsulated in Ian Wilmut’s appeal to women to provide oöcytes for his SCNT research discussed earlier. However, the novel tension between ‘mother’ and ‘citizen’ manifests differently regarding decisions about embryo provision to research. The kinds of relationships on which reproductive tissues should be based remains unexamined. At this stage, I simply wish to focus on the fact that the choice of motherhood instead of the provision of oöcytes to SCNT research does, to some degree, reinforce the idea that women’s reproduction does not have a Political\(^9\) dimension such as the interests of the state. In choosing to utilise their fertile oöcytes as reproductive tissues in the traditional sense and achieve aspirations to become mothers,\(^9\) participants in our study prioritise relationships that are ostensibly absent from the public sphere and exist in the private sphere, as intimate relations. Women’s altruism then is normative in specific contexts rather than an essential dimension of femininity.

The preceding argument regarding the sustained preference to use oöcytes as traditional reproductive tissues remains inadequate in relation to the (hypothetical) provision of embryos for patients who have undertaken fertility treatment. In fact, the inverse seems to be applicable here; many participants give their embryos to research (fertility or stem cell) precisely because they are reproductive material–potential children. If they are surplus to the individual family’s requirements, they are not usually given to another family to raise as their child. The embryo being a fusion of oöcyte and sperm, it carries the DNA of both ‘parents’ and, on a practical level, this means that the decision to donate them is a joint one. It may also indicate a specific protection of the male’s offspring, one not afforded to oöcytes,

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\(^9\) I use the capitalised term to denote the traditional and non-feminist sense which separates the individual self, society and the state.

\(^9\) It is important to note that motherhood is not a uniform identity but for the purposes of this argument must be seen as a role that can be pursued.
and this connects to normative constructions of femininity. Yet, such patriarchal reasoning does not adequately explain responses regarding embryo provision to research; here, intentions to become a mother lead to different outcomes and decisions regarding the scientific utilisation of embryos.

Giving away embryos to scientific research has the opportunity to disable their immediate reproductive potential and inevitably invokes the individuals’ experience of fertility treatment, without which the embryos cannot exist. Importantly, it usually occurs once the woman has become a mother rather than before or during the process. In the context of embryo provision specifically to scientific research, motherhood is not undermined; in fact, it may actually reinforce norms about motherhood that existed prior to the development of ARTs. This occurs because they want the biological and social basis of motherhood to remain intact. Participants do not want other women to gestate the foetus and for other families to raise the child to whom they are genetically related. Thus, intentions to become a mother in this context actually signify becoming a mother within the context of the nuclear family, where children have one mother and father from whom they have inherited their genetic makeup. Thus, we have a concrete framework for understanding the ‘conflict’ that is inherent in the question of women providing oöcytes to SCNT research; the role of ‘mother’ is not easily reconciled with ‘research oöcyte provider’, although we have seen that ‘mother’ may be reconciled with ‘embryo provider’. Based on these findings, I assert that intentions to become a mother manifest differently in the case of oöcyte and embryo provision.

The different utilisations of reproductive tissue have compelling implications for discussions of risk in relation to femininity and reproduction. Risk is not a universal concept and its understanding and management vary on the basis of gender, age and class (Bunton, Crawshaw and Green 2004). Participants in our study, particularly those in cohort one, employ a specific strategy that imposes a quantitative plan to counteract the qualitative opaqueness of oöcytes. In this context, good eggs must not be lost and because the fertility of oöcytes is unknown prior to fertilisation, all oöcytes are potentially ‘good eggs’. Each utilisation runs in parallel to the other, that is utilising oöcytes for research annuls the

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91 As shown in chapter six, one participant in cohort one, Caroline, articulated this by suggesting: Because “my oöcyte and Paul’s sperm together is our child.” I also refer to the fact that clinical guidelines will expect any disposition questions to be resolved by both patients.
possibility of using them for reproductive purposes and vice versa. In contrast, for participants in cohort one, the frozen embryo can be utilised for both reproductive and research purposes. Having “finished their families” giving embryos to stem cell research maintained the connections between biology and kinship; indeed for some participants and scientists, stem cell research is an extension of its traditional reproductive capacity (Franklin 2006; Parry 2006). Thus, the biological properties of each tissue have different implications for the individual’s intention to become a mother and oöcytes and embryos are utilised differently to achieve this.

**Forms of money and problems of equivalency**

So far I have suggested that oöcyte and embryo provision to research must be understood by paying close attention to the relationships between the tissue, the donor and recipient as well as broader institutional contexts in which these practices occur. I discussed the term discretionary reciprocity to refer to evidence showing that donors perceive the merits of recipients distinctly and this contributes to different expectations of reciprocity. In this section I discuss further the complexities of gift giving in the scientific context and the problems related to establishing a financial equivalent for oöcytes. I will examine how the same object–money (as currency)–can exist in two different forms. I argue that the form of ‘compensation’ is more palatable to participants because it may not influence their decisions to provide oöcytes for SCNT research in the same way as ‘payment’. I sustain this claim by drawing on critical approaches to materiality discussed in chapter four.

An oöcyte can be a unique example of such an object in the ‘rationalised’ Western society; as the bearer of the donor’s DNA, it can be considered quite literally to carry the individual’s essence. DNA has special resonance in contemporary society, replacing blood as a signifier of the individual’s status in society. Genetic testing can be used to augur some events in an individual’s biography; in contrast, blood tends to tell the story in reverse and reflect the risks an individual has or has not taken (Valentine 2005). Yet giving oöcytes, particularly for reproductive purposes, can be quite a paradoxical process because the very substance donors are giving could undermine the broader implications of the undertaking; helping others to create a family while undermining the chances of having their own. As reported by other scholars such as Kirkman (2003), Orobitg and Salazar (2005) and Haylett (2012), the data
collected in this study reflects the efforts of donors to minimise the possibility that the oöcyte can represent a social relationship between themselves and the potential offspring. If the conventional connection between biology and kinship is emphasised, it is likely to undermine the donor’s attempts to give the recipient woman an authentic sense of motherhood, not just a child.

The individualising force of an oöcyte is less important than its functional capacity. Therefore, once this functionality is proven, infertile oöcytes are moved from the reproductive sphere to research. These latter oöcytes no longer represent a reproductive tissue and their claim to the reproductive sphere is lost. In contrast, giving embryos for reproductive purposes has the potential to maintain this individualising force. How the fertility patient feels about this will determine if the embryos is shifted from the sphere of reproduction to research. The embryo is never devoid of its individualising force but neither can this be entirely separated from the broader basis of biological function–namely, the kinship the embryo signifies.

Understanding this broader context of oöcyte provision to SCNT and the multidimensional social space in which objects are located is necessary but may not fully explain why it is difficult for participants in our study to define an appropriate form of reciprocity in exchange for oöcytes. Advocates of a payment system in particular have not sufficiently examined specific moral issues which emerge with monetisation, that is participants felt that being motivated primarily by money provoked questions about one’s ability to maintain a sense of autonomy. However, this does not mean it is necessary to reiterate arguments regarding the inherent ‘evil’ of money; instead, it is important to distinguish between two forms of money–‘compensation’ and ‘payment’ – and examine their symbolic dimensions in relation to donor motivation.

For our participants, there remained considerable ambiguity about a financial equivalent to providing oöcytes to SCNT research. This issue draws attention to some inadequacies in advocating for women to be paid on the basis of an impersonal motivation, rather than the personal motivation of helping a sick family member or friend by advancing research related to their disease (Isasi and Knoppers 2007; Thompson 2007; Ballantyne and de Lacey 2008
and Skene 2009; Nuffield Council on Bioethics 2011; Haimes et al. 2013). Economic remuneration is expected to motivate women on an impersonal basis and relieve pressure on women to provide oöcytes on a personal basis. On another level, these scholars recognise that oöcyte extraction is a long and onerous process for women, though Skene (2009) is most explicit in claiming that payment would align oöcyte extraction for SCNT research with other ‘risky’ forms of labour. Based on the analogy of work, the expectation of economic remuneration is likely. Participants in this study do consider oöcyte provision to be hard work requiring more discipline than other forms of tissue provision such as blood. However, they did not conflate this discipline with labour, which is a form of activity that is exchanged for economic remuneration. The anxiety generated by ‘payment’ might evoke the spectre of undertaking oöcyte extraction as an income source.

So far, I have argued that the functional capacity of oöcytes generally inhibits the movement of ‘good eggs’ from one sphere to another but identifying a good parent may actually ‘shift’ oöcytes to be used for another woman’s intentions to become a mother rather than one’s own. If money is to be given in exchange for oöcytes, this amount must be quantified. Finding an equivalent for oöcytes given to scientific research is complex; I illustrate this by examining results that show that the same object in a different form provokes specific reactions. This evidence unsettles simplistic assumptions about the monetisation of equivalency because not all money is the same. I argue that money can be more animated than usually allowed and this has important consequences for potential donors. The significance of the form with which donors are comfortable demonstrates that contrary to prevalent scholarly thought in this debate, money is not an instrumental mechanism that will automatically increase the supply of good eggs.

The participants in our study did not reach a consensus about the appropriate remuneration for oöcyte provision for SCNT research. One consensus they did reach was their preference for being ‘compensated’ rather than accepting ‘payment’ for their efforts. I consider this distinction to be an important finding of this research. Preferences for ‘compensation’ over ‘payment’ signify that perceptions of gift giving not only involve the recipient and what they may reciprocate, but suggests a specific moral deed on the part of the donor. Here I develop

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92 This distinction is also evident in institutional practices which maintain distinctions between compensation and payment.
the claim that the object of money (as-currency) takes two forms: ‘payment’ and ‘compensation’. Being ‘paid’ to provide oocytes for SCNT research generates anxieties about being motivated entirely or primarily by an impersonal incentive. One basis for this assertion is that there is likely to be no real difference in the sum of money women receive in ‘payment’ or ‘compensation’ to provide oocytes for SCNT research. As the example of oocyte provision in Romania demonstrates, women who are ostensibly ‘compensated’ are given a sum of money that is so generous by local standards that it can be a basis for women to undertake oocyte extraction as an independent income source (Nahman 2008).

Thus, it is imperative to recognise and reflect on the oppositional meanings and feelings, these two words evoke. As the participants in our study actually rejected the idea of being ‘paid’ with money, I claim that ‘payment’ can be interpreted as a sum of money that not only counterbalances the effort involved in oocyte extraction but, more importantly, it is a sum of money that transforms the decision to provide oocytes into one that is based primarily on an impersonal incentive. ‘Payment’ shifts the reasons for providing oocytes to the donor’s own benefit rather in relation to a specified beneficiary or benefit. In contrast, ‘compensation’ is a sum of money that recognises the significant effort of the donor but is insufficient enough that it remains peripheral to the decision to provide oocytes. ‘Compensation’ does not eclipse other motivations the donor may have and thus it is offers an ethical basis for providing oocytes. The different feelings towards being ‘paid’ and ‘compensated’ suggest that the problem per se is not the exchange of money for oocytes. This unsettles Titmuss’s strict binary between money and selling on the one hand and donation and altruism on the other. These results indicate that expectations of reciprocity is quite a different process to establishing an appropriate equivalent for an object, even in the context of industrialised science where oocyte provision for SCNT research occurs.

As Wearing (1996, 130) states, “symbols are powerful tools, and can be used effectively to control and influence our own behaviours and beliefs”.

Sandel (2012) can be considered an update of Titmuss’s (1997 [1970]) critique of the encroachment of market norms that have created a market society rather than simply a market economy. Sandel considers many examples where a market exchange has been introduced or come to dominate practices or areas of life where, until recently, none existed. One example among many is that lobby groups can hire people to stand in lines for important congressional meetings until the meeting begins and they take their place in the meeting. Without this line-standing service, the lobbyist would not be able to attend the meeting without sacrificing his or her own time. Although this is not related explicitly to my topic of the scientific utilisation of eggs, I reflect on this point to some degree to show that Sandel’s (2012) approach while never predictable or simple does tend to involve the challenge to market logic on the basis of two principles: fairness and corruption. Sandel’s discussion of blood provision follows this line of thought. Based on his rejection of an economist view that
The ambiguous division between ‘compensation’ and ‘payment’ shows that some manifestations of reciprocity may actually threaten a certain perception that the donor has of herself. I do not regard this a matter of potentially becoming further indebted, but that of having her motivation and, most importantly, her ‘existential certainty’ questioned. What I mean by this is that in most analyses of gift giving, a delicate balance is evident. Based on recent research into gift giving in The Netherlands, Komter (2005) argues that the ‘original’ gift given by the donor must be so that the recipient returns the gift with interest without too much imposition. The original gift cannot be so much that the recipient feels or is incapable of reciprocating. Mauss (2002 [1954]) discussed potlatch ceremonies of Northwest Canada as contests of honour. Here, tribal chiefs competed with their counterparts in destroying their wealth by hurling it into the sea or burning it. Mauss argued that the intention of the ritual was to shame others for their lack of generosity to their god(s). In the context of oöcyte provision to SCNT research, it is possible to assume giving oöcytes creates an imbalance for the donor herself, because the process of oöcyte extraction can take a significant toll on her. Maintaining a disdain for payment could be construed as an effort to ‘shame’ recipients for their inadequacies. However, this interpretation is not sufficient for two reasons: first, the reproductive donors in our study saw the process of oöcyte extraction as a means to an end and did not consider themselves to become deficient by it; in fact, the recipient’s own deficit was restored by the donation. Second, in this context the donor would be ‘shamed’ if she is given more money than was sufficient because it would indicate that her intentions are instrumental more than anything else.

My claims about the existential threat ‘payment’ poses are sustained by the lack of consensus regarding what constituted an appropriate equivalent. While it was consistently argued by participants that in the context of oöcyte provision for SCNT research, the recipient should reciprocate in some way, the impersonal equivalent of ‘payment’ could be interpreted in a negative way, appearing to primarily motivate the donor. In other words,

market transactions have no impact on the thing traded, Sandel argues that once blood provision is made a commercial transaction, the act of non-commercial (altruistic) blood provision may then be considered a way of depriving the blood seller of their income. Another counter-argument to economist view of altruistic blood provision is that it relies on the idea that altruism, like other virtues, is naturally in short supply and presumably the state and/or society should not expect individuals to deplete such resources. Interestingly, acting in such virtuous ways with families and friends is considered normal and needs to be protected.
despite its lack of specified benefit or beneficiary, participants believe that giving oocytes to
SCNT research should not be entirely instrumental.\textsuperscript{95} This helps to construct, to a degree,
oocyte provision as free and beyond reciprocity. Ultimately, however, the picture is more
complicated than this. If the donor is ‘compensated’ her real intentions remain clear and
untarnished; she simply has had her hard work recognised. ‘Payment’ not only takes on the
character of coercion but undermines the intention of the donor to help.

This returns us to the spirit of the contemporary debate in surprising ways. Titmuss wanted
to foster support for the universal stranger on the basis of his or her inherent humanity, not
because the donor would stand to gain by helping. His discussion of this is a construction of
a dichotomy between self-oriented \textit{vendors} and other-oriented \textit{donors}. However, more
recently Thompson (2007) and Ballantyne and de Lacey (2008) argue that payment is the
only effective means to avoid the problem of other-oriented donors; ‘payment’ creates the
opportunity for self-oriented \textit{vendors} to sell their oocytes and relieve pressure from women
who are other-oriented and whose incentives are personal. As ‘payment’ raises more
questions about the donor’s ethical behaviour than does ‘compensation’, these results
indicate that providing oocytes for SCNT research on an entirely impersonal basis is
existentially suspect.\textsuperscript{96}

\textbf{Payment and freedom}

Paying women to provide oocytes to SCNT research with money can be seen as a
continuation of depersonalising relationships that characterise contemporary society. This
would create the scenario Titmuss hoped to avoid: a social world of individuals who
contracted with others as instrumental means. Titmuss’s model of blood donation was as
much about exclusion as it was about inclusion; keeping the right people in and the wrong
people out. However, in this representation, money appears to be irresistible for those whom
fate has reduced to poverty. By selling their blood, the needs of the poor are met despite the
potential danger to others. In contemporary approaches to the question of exchanging
oocytes for money, it is a rational outcome of the calculation between the potential donor’s

\textsuperscript{95} This was not a view shared by women undertaking fertility patients regarding other potential oocyte
providers who they often constructed as money-hungry, poor and solely motivated by pecuniary interests.
\textsuperscript{96} Assumptions that there is a specifically feminine form of ethical reasoning are not supported by the
following discussion.
own effort to provide oocytes and the commercial profit research with the oocytes is likely to provide (Ballantyne and de Lacey 2008; Waldby and Cooper 2010). Accepting money should be largely uncontroversial. However, as I have already suggested, ‘payment’ provoked an anxiety that ‘compensation’ did not. If these are essentially two forms of the same thing, it is necessary to employ an alternative narrative to the rational arguments so far provided.

It is immediately apparent that the these distinctions are nebulous. Participants in our study found it difficult to quantify ‘compensation’ versus ‘payment’ because the threshold between the two is subjective and contextual; it will mean something different to individual who must contend with the local costs of living. As oocyte provision in a global context illustrates, one woman’s token payment is another’s annual wage (Nahman 2008; Almeling 2009). For the purposes of this discussion, I will explore further the latent meanings of money—whether it is regarded as ‘compensation’ or ‘payment’—as a means of remunerating the individual provider financially. Participants in our study demonstrate a clear lack of seeking to capitalise on their resources – this includes the opportunity to receive reduced-cost, or free fertility treatment. This cannot simply be explained by gendered norms related to self-sacrifice, the importance of achieving motherhood or the honour of giving in greater capacity than the recipient. I argue that ultimately the difference between ‘compensation’ and ‘payment’ is related to latent meanings of the object of money (as-currency) in Western societies. Drawing on critical approaches to materiality, I argue that the object considered to be entirely anonymised and inanimate is actually the reverse.

Western philosophical traditions encompass two broad schools of thought regarding money; one in which money can be morally fraught and one in which money can liberate (Bloch and Parry 1989). In recent history, establishing equivalences is regarded as having a unidirectional trajectory. Indeed, the social theorist Georg Simmel (1950) argued that money is the very essence of modernity. What Simmel meant by this is that the predominance of the money economy is part of the modern West’s radical break with traditional society. The modern era is based on urbanisation, industrialization and new forms of personal conduct and social relations. In particular, urbanisation draws together people who have no ‘natural’ connection between each other in addition to creating significant distance between producers
and consumers. Individuals interact with mediators, such as the retailer, and this relationship is instrumental. The qualitative dimensions of ‘things’ diminish in importance and are eclipsed by quantitative considerations. Simmel (1950, 330) argued that the most important question for the individual in the metropolis is “how much?”

Simmel represented the predominance of the money economy as a fait accompli—that more and more ‘things’ will be reduced to their quantitative dimensions. However, he also maintained that such an economy produces a new level of freedom unprecedented in history. Simmel (1990 [1900], 286) contrasted the social and property hierarchies within the feudal and modern eras to argue that individuals are given more autonomy to conduct their affairs through the increasing use of money:

The lord of the manor who can demand a quantity of beer or poultry or honey from a serf thereby determines the activity of the latter in a certain direction. But the moment he imposes merely a money levy the peasant is free, in so far as he can decided whether to keep bees or cattle or anything else.

A transaction with money changes the relationship between the transactors and provides a level of anonymity and flexibility. Trade with money releases one individual in the relationship from having to adhere to narrow definitions of conduct and products. Simmel’s semi-optimistic perspective on money is different to the other branch of philosophical and religious approaches in the Western tradition. For example, in Ancient Greek society, Aristotle (cited in Bloch and Parry 1989, 2) wrote that the finite needs of humans could be satisfied by home-based production and any “[p]rofit-oriented exchange is…unnatural; and is destructive of the bonds between households…Money as a tool intended only to facilitate exchange is naturally barren, and, of all the ways of getting wealth, lend at interest – where money is made to yield a ‘crop’ or ‘litter’ – is ‘the most contrary to nature’.”

While the approaches of Simmel or Aristotle may appear oppositional, I claim that they are based on the same principle: the object of money, has inherent qualities that may transform people and relationships at a personal and structural level. As currency has existed for

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97 It is difficult to ignore a similar sense in this narrative of once naturally entangled objects (in this case humans) and the detachment and disassociation that the monetised modern period has brought (Callon 1998).
centuries (Miller 2002), I do not claim that it is money per se which provokes anxiety for participants. Indeed, my argument is that money-as-currency is not the problem because participants would ultimately accept a material equivalent for their oöcytes but preferred compensation over payment; this demonstrates that money-as-currency is "dangerous" only when it surpasses a certain amount. This threshold, however, is largely symbolic. I argue that the issue of offering money for women to provide oöcytes for SCNT research evokes the promise to which Simmel referred—the potential for freedom—and yet also raises significant ethical questions about that behaviour. To imply that ‘money’ is the focus of an individual’s motivation is to upset the perception of the donor as motivated by more noble ambitions. My claim is based on the anxieties evident in our participants. This evidence suggests that money-as-currency is not an inert and innocuous object—a thing, as Waldby & Mitchell (2006, 68) label it, of “pure exchange value without use value of its own [circulating] anonymously, changing from hand to hand, indefinitely substitutable for itself”. Rather money in the form of ‘payment’ is represented as having a vitality of its own that may undermine the existential certainty of the donor. I would suggest that money is not simply a thing onto which the individual may project their own meanings but has its own subjectivity. In different amounts, it can change its ability to compel people to change their minds, particularly in contexts where a desired behaviour is lacking—such as the provision of oöcytes for SCNT research. Thompson (2007), Skene, (2009), George (2008) and Thompson (2009) each wield the prospect of giving money to women who provide oöcytes to SCNT research as a powerful structural change. While I do not suggest that money is a sentient being—indeed, there may be objections to using the term ‘subjectivity’ because it is usually used to refer to a vital being with the capacity to make decisions—I do suggest that the disdain for ‘payment’ reveals a hesitation on the part of our participants to give their oöcytes for an impersonal motivation. This suggests that doing something for an entirely instrumental reason will create a certain existential anxiety about the donor’s own sense of freedom.

To reinforce this argument, I draw on Miller’s scholarship, which provides a nuanced view of human subjectivity, the material world and the relationship between the two (Miller 2001; 2002; 2003; 2005 and 2008). Miller (2008, 287) critically examines assumptions evident in scholarly approaches towards the animated social world and its inanimate material counterpart, arguing that “[w]hatever a person does, whether cooking or moving from one
room to another, the order of things in time and space reinforces their basic beliefs about the natural order of the world”. The social world does not just include the relationships between human individuals and groups (precisely that which sociology is meant to examine) but the objects that populate physical spaces. Objects are a crucial means of relating to others and ourselves and contribute to individual subjectivity.

The relationship between humans and objects are usually regarded as operating in a single direction. Objects such as furniture or machines are produced by humans and exist *merely in relation* to the human, not in and of themselves. Another view posits that objects and humans are mutually constitutive, that objects be as vital as humans. As Miller (2008, 287) argues “people exist for us in and through their material presence”. On the one hand, he means that it is on the basis of consuming certain ‘paraphernalia’ throughout their lives that people become ‘subjects’; ‘things’ such as books, music, food, cars, clothes, houses are part of a process of subjectification. This view differs from scholarship which studies the economic implications of being able to consume things. A common lament from scholars and lay people is that in contemporary society, people identify themselves and others through ‘things’, not through more traditional forms of identity such as place or family (J. Shaw 2010). On the other hand, Miller (2008) goes on to argue that ‘things’ have their own agency and exist in social spaces; they have their own intrinsic meaning that must be negotiated. Humans have common understandings of things and how to use them; we don’t eat on chairs, we sit on them; we do not cook in cars, we drive them. It is this meaning that I wish to draw on in relation to money and to illustrate with an anecdote from the anthropologist Bloch, describing an incident that occurred on his leaving fieldwork in Madagascar. Handed a wad of bills from his host, Bloch (1989, 165 emphasis added) remembers the shameful feelings on its presentation “without even a decontaminating envelope”.

Critical approaches to materiality are distinct because they dissolve the dichotomy between the inanimate world of the West and the vital objects of ‘archaic’ gift-exchange societies to which Mauss (2002 [1954]) referred. From this study, we have seen that the gift giving does not necessarily involve a gift with an individualising force and other factors contribute to the

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98 This tends to ignore the fact that before the advent of consumer society, one’s access to objects also indicated their social status (see Bauman 1991).
movement between spheres of exchange. On the other hand, the object that is usually referred to as having the least differentiation and vitality (notwithstanding Zelizer’s (2011) research on “pin-money”) can unsettle its recipient. As Bloch recalls, money that had no ornamentation to hide it provoked disturbing feelings about pollution and by default its other-purity. The wish for the gift of cash to be obscured by the another object (the envelope) appears to suggest that the problem is not money-as-currency per se but its exposure and, by extension, that of the recipient. Bloch’s situation recalls paying women to provide oöcyte to SCNT research because money-as-currency is the centre of the relationship and may transform the transaction into an entirely instrumental one.

The results from our study show two forms of the same object provoking different reactions. Other research suggests that reciprocity is rarely symmetrical (Komter 2005) or “tit-for-tat” (Shaw 2011, 298); Young (1997) argues that to return a gift with the same object is not giving (or rather generous) at all. However, my analysis is distinct because it illustrates that in this context there is no difference in the object given (money-as-currency) but in the significance of the amount: the difference between accepting ‘enough’ and ‘too much’ money. Thus, the same object provokes different reactions because it will refer to and perhaps undermine the donor’s original intentions. ‘Compensation’ is perceived to recognise the effort of the donor while ‘payment’ will suggest she has no other motives than instrumental ones. One’s personal identity hinges on this rather fragile and symbolic separation between being motivated by impersonal incentives and personal ones. This analysis reveals that there is something beyond the analytical understanding of oöcyte provision to SCNT research and these different perceptions must be taken seriously in order to effectively address the shortage of good eggs. Relationships between people, animals and objects, made and found, constitute the social world. Having money or other economic wealth is usually regarded as a status symbol and its increase can signify good management. In this context, however, if money is considered ‘payment’ rather than ‘compensation’ it will change the moral status of the individual in a negative way.

The preceding discussion has sought to elaborate on some difficulties in establishing and quantifying an equivalent for women to provide oöcytes to SNCT research. Based on data I have argued that participants find it difficult to accept ‘payment’ because it is regarded as
too impersonal an incentive and this is why they preferred to be ‘compensated’. As both of these terms represent money-as-currency, I speculated on the symbolic differences between the two. I argued that ‘payment’ represents a virtually vital object with the capacity to compel individuals to make decisions they ordinarily would not make. This analysis connects latent views of money-as-currency, individual independence and donor motivation. In doing so, the debate regarding oöcyte provision for SCNT research is critically reframed as privileging a rationalist conception of materiality rather than capturing the complex relationship between humans, their bodies and human-made objects such as money. Including these latter perspectives will contribute to more holistic explanations of participant’s resistance to payment or providing oöcytes to SCNT research in the first instance.

**Checking passion at the door: rationally finding the ‘public good’**

I have thus far discussed the results of this study within a framework that draws on anthropological and sociological understandings of social life and that counters more rationalised representations of human and material subjectivity. SCNT research asks women to utilise their oöcytes in the ‘public sphere’ of scientific research rather than their traditional reproductive utilisation in the ‘private sphere’ – to create children. I have demonstrated that it is difficult for women to become ‘good eggs’ – donors providing social benefit – because the reproductive capacity of their good eggs is mutually exclusive with SCNT research. In contrast, stem cell research does not undermine the reproductive capacity of excess-to-treatment embryos. These differences relate to the individual’s intention to become a mother. The following analysis attempts to capture the relational dynamism between citizens and scientific research. My analysis will examine the current lack of oöcyte provision for SCNT research and the solution of paying women in reference to the specific place of scientific research in an ostensibly scientific society.

Increasing the number of rational providers is the anticipated result of introducing economic remuneration in exchange for ‘good eggs’ (Thompson 2007; Ballantyne and de Lacey 2008; Skene 2009). These women are contrasted with those who are interested in the potential outcomes of SCNT research or those who are being treated for [in]fertility – the latter representing at best, a sample of convenience or at worst, coercion and debts of gratitude.
(Ballantyne and de Lacey 2008; Scully et al. 2012). For these scholars, motivation by payment is the lesser evil in this scenario and represents the main difference with Titmuss’s blood donor model. These arguments are based on technical aspects of the process of extraction and the ultimate use of the tissue; drawing blood is not especially painful and sharing the substance is a signifier of good health or risk management (Valentine 2005). Giving good eggs to SCNT research is an onerous process requiring self-discipline and may involve adverse reactions to the medication. In contrast to semen, the fertility of oöcytes is not dependent on the lifestyle and genetic identity of the provider (Oliva et al. 2001; Dickenson 2006). Payment is considered to bear no relationship to the individual’s moral character but rather the inequitable structure of scientific research.

Ultimately, however, the payment model is not very dissimilar from the donor model advocated by Titmuss, who was anxious to exclude those people who privileged their ‘private’ interests over the common good.99 While superficially distinct, Titmuss and the inheritors of his legacy remain committed to the idea that the best kind of donor is one whose motivation occurs on an impersonal basis and whose intentions are directed at the general, rather than specific, benefit or beneficiary. In this case, the progress of scientific research should be considered a good in itself. Titmuss advocated for citizens to give blood in a similarly abstract way; that is, to give to the generic recipient and to do so without personal benefit. His approach is based on ‘rational’ rather than ‘passionate’ associations because it does not allow donors to pick and choose their recipient on personal preference (or vice versa).

Efforts by scholars and lay people to dismantle divisions between the public and private spheres and the assumptions on which they are based have not permeated the discussion of oöcyte provision to SCNT research. Predictions that women will act altruistically in the public sphere are carried over from expectations of their behaviour in the private. The scientific utilisation of women’s reproductive capacity moves that reproductive capacity into the public sphere in a more obvious way than having children. So far this request has been made on the basis of altruism which invokes the woman of the “private” sphere. “Payment”

99 I do not claim that disinterestedness is a specifically Western approach to ethics or politics: as Reddy (2007) shows there are Sanskrit origins to embracing humanity in a universal manner.
transforms the exchange into an impartial transaction where specific interests are again effaced or precluded. Advocating that oöcyte provision to SCNT research should be paid because it will encourage the impartial contributor (Thompson 2007; Ballantyne and de Lacey 2008) remains committed to the view that citizenship is awarded based on the ability to exercise impartiality (here manifest in the eschewing of emotional interest in SCNT research) despite being generally critical of traditional approaches to gender roles and public life where women could not be considered as citizens with civil, political and social rights because they were considered incapable of transcending the specificity of their worldview or experience.

Participants, particularly in the ‘healthy donor’ cohort, showed distinct preferences for oöcyte provision in contexts of a specified beneficiary or benefit. This condition produced the least amount of anxiety or concern about undertaking the process, including the loss of potentially fertile oöocytes, and is the difference between simply supporting this scientific research and contributing to its progress. Within such an affective framework, participants can reconcile a number of problems pertaining to oöcyte extraction for SCNT research, including property relations and the process of extraction. While ‘passionate’ associations, based on specificity, describe the provision of tissues more accurately, this does not mean that “rational” and “passionate” contributions are mutually exclusive. “Passionate” contributors to scientific research can also recognise the rational dimensions of the act. For instance, science is an endeavour based on rational principles: scientists converge to discover universal knowledge and their associations are built on merit rather than personal preference. Based on the principle of evidence, science is also democratic and scientists are not expected to adhere to previous knowledge if evidence to the contrary is found. Science is conducted in rational ways and it also represents rationality – reason based on evidence. All of these principles are evident in scientific research but they are not the only factors which motivate people to contribute to its advancement. For lay contributors, they are latent: present but are usually in the background.

In asserting that participants seek to provide to research with a specific beneficiary or benefit, my analysis corresponds with other research regarding various forms of donation in the Australian community where people are most likely to give in scenarios where they can identify a specified benefit or beneficiary (Lyons, McGregor-Lowndes and O’Donoghue
2006). This finding poses yet another problem for scholars examining the issue because it undermines advocacy for impartial donors who are expected to be motivated by an immediate economic benefit to themselves. However, my claim helps to further elucidate the problem of ‘payment’ by showing that donors identify with specified (although not necessarily interpersonally known) others and situate their tissue or the process of giving within this framework. In contrast to approaches that seek to minimise the intrusion of the passionate over the rational which is the only way the common good will be achieved, I argue that rational imperatives of scientific research can be achieved through passionate means. I will discuss this further in relation to scholarly debate and then examine how people actually provide their tissues, rather than how they ought to.

**Inter-personal anonymity and generalized exchange**

Contrary to approaches which discuss tissue provision to scientific research as a contest between the individual’s rights and the ‘public good’, I assert that contributing to scientific research is implicated in the specific social roles and relationships that are related to an individual's family or national/international communities. Tissue provision is not simply a ‘gift’ made to the institution of science, in the hope of progressing scientific research in an abstract or universal way; rather, science can be a means of connecting people together (as fertility patients) or can have implications for existing social relationships and identities (such as indigenous people). For some of our participants contemplating embryo donation to research, their own treatment was due, to some extent, to the donations of previous fertility patients. This indicates that science has had a real effect on these individuals in relation to their reproductive tissues and their decisions to donate embryos are made within this context. Participants situate their contributions within the experience of fertility treatment. They express gratitude towards previous donors and propel their gratitude forward rather than backward. Patients do not attempt to identify specific donors or researchers. I suggest that their relationship with other fertility patients is built on the donor’s own fertility treatment, an experience that provides membership into a community of other fertility patients (in the past, present and future) from whom the donor feels they have received benefit. These participants situate themselves in a continuum of research and treatment. My assertions correspond, to some degree, with claims made by Scully et al. (2012) about gratitude, serial reciprocity and embryo provision. The authors argue that it is unlikely that their sample of
fertility patients perceive treatment as a gift because it operates under the auspices of UK’s National Health Service (NHS) and is considered a medical service. Nevertheless, participants situated their decisions to provide their embryos within a broader community of previous donors and future patients. To analyse the motivations of donors, Scully et al. draw on the concept of serial reciprocity, which refers to gifts reciprocated from unknown individuals.

In anthropological literature, serial reciprocity is usually referred to as generalized exchange (Levi-Strauss 1969). I argue that this term captures the ways in which people understand their contributions to scientific research as instances of gift-exchange occurring between individuals who are not inter-personally identified but who are nonetheless connected in some way. Diverging from Mauss’s examples of identified and intimate gift-exchange in the kula, Levi-Strauss argued that cycles of reciprocity are evident even when the same person or group to whom it is presented do not reciprocate the gift given. Generalized exchange can be used in relation to contemporary Western societies that have experienced mass migration and industrialisation, where kinships are no longer the only significant social reference point for individuals. In the absence of strictly face-to-face relationships, Levi-Strauss (1969, 265) argued that “generalized exchange establishes a system of operations conducted ‘on credit’ [and participants must have] the confidence that the cycle will close again…The belief is the basis of trust and confidence opens up credit. In the final analysis, the whole system exists only because the group adopting it is prepared, in the broadest meaning of the term, to speculate”. The concept of generalized exchange enables a sociality through which individuals can make sense of their identities and relationships over time and on a number of different levels to encompass those that are inter-personally anonymous but nevertheless remain identified in some way (Svendsen 2007).

So far my use of the concept of generalized exchange is broad and I argue that it is more relevant for participants in cohort one and a more appropriate form of circulation for embryos than oöcytes. Whether the embryo is given for reproductive or research purposes, its donation draws on the individual’s experience of treatment as a fertility patient and

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100 This point may diverge from my earlier claim regarding oöcyte donor’s perceptions that having children is not a universal right and must only be bestowed upon “good parents”.
101 Titmuss (1997 [1970], 278-279) was critical of Levi-Strauss’s adherence to Mauss’s insight that gift-giving had to have instrumental dimensions to it.
involves a vague understanding that ‘people like me’ need the embryo. The ‘me’ which is referred to here emerges from a specific experience – fertility treatment. Embryo donation relies on a generalised and anonymous recipient both in terms of bureaucracy and individual preferences. Participants in our study expressed no desire to meet potential recipients, trusting in their worthiness. This belief could be considered as a projection of one’s own experience – including emotions, dreams, hopes and disappointments – onto the recipient who ‘becomes’ the generic fertility patient. I argued in chapter seven that this is largely due to the fact that the donor herself has become a generic fertility patient, incorporated into the history of reproductive medicine, becoming ‘another statistic’ and adding to its knowledge in some minor way.

It is not possible to precisely distinguish between the passionate motivations and rational imperatives that are involved in embryo donation. Instead, the act of donation is a mixture of both; science creates the community of contemporary fertility patients and acts as a meeting ground between its members. Embryo donors can be confident in the achievements of scientific research because they have experienced its tangible outcomes (without necessarily being a success story of reproductive medicine). However, their motivations are also passionate because they are targeting the donation towards specific individuals—other fertility patients. This proposition highlights the degree to which decisions about tissue provision are made in relation to the individual’s everyday experience, thus shifting the emphasis of giving tissue from whether the individual is simply free or exploited to questions about the role science plays in that everyday life. In the context of fertility treatment, scientific research mediates between individuals who need the treatment in a direct or indirect way.

My reading of tissue provision as having a significant affective dimension diverges from models of the social contract where science and society exist separately by recognising that tissue provision involves a person who is embedded in a very real social and historical context, whose rights and obligations do not simply exist in the present and without reference to others but those who came before them and those who are not yet born. This view corresponds with findings from studies around the world that highlight the social context of tissue provision (Lock 2001; Hoeyer 2003, 2006a and 2006b; Hoeyer and Lynøe
2006; Reddy 2007; Svendsen 2007; Dixon-Woods et al. 2008). Together, this empirical research illustrates that contributing to scientific research is implicated in a number of relational possibilities in which individuals are situated such as their families, their national or international communities or their identity as an indigenous person for whom modern political institutions (including science) often provide a precarious form of recognition and respect. They also demonstrate that the abstract good of scientific research may be reinforced or destabilised in relation to a specific identity and contributions to scientific research may occur in a number of different ways, from acquiescence and welcome to hostility and refusal.

Positive orientations: the self and the welfare state

The work of Svendsen (2007) and Hoeyer (2003; 2006a and 2006b) expand discussions about the contextual nature of moral choices made about tissue provision to biomedical research and take into account political relationships between state and citizens and citizens themselves. In his study of a Swedish biobank, Hoeyer (2003; 2006a and 2006b) studies perceptions of individuals who provided blood or tissue samples to a database of genetic material. Hoeyer (2006b, 217) argues that participants in his study situated their decisions and the genetic research in broader social, political and economic contexts and were concerned “with the equal distribution of research results, eugenic uses of science”. In a separate explication of the same work, Hoeyer and Lynöe (2006, 17) show that people have limited interest in the information sheets they are required to read before consent is taken challenging the idea that individuals decide to participate or contribute to scientific research exclusively on the basis of the information they read. People expressed their motivation to contribute their tissues “in general terms about the benefits for society and about a shared responsibility for advancing medicine”.

102 Participants in the study perceived giving their tissue samples within the specific context of the Swedish welfare state, where the comprehensive public provision of healthcare is deeply entrenched. Moreover, they contended that the state has a responsibility to ensure access to healthcare and the subsequent results of research remain available to the public. These sentiments evoke the

102 Participants also expressed general concern about the trajectory of scientific research but were not especially confident in declaring the “good” of genetic research and the biobank to which they were contributing (Hoeyer 2003).
idea of a ‘social contract’ between participants, researchers and the state that funds research. These participants do consider that providing their blood and/or DNA is a broader political act because they situate their overall health within their own model of the social contract—that is, the welfare state.

Svendsen’s work on embryo donation to stem cell research in Denmark, a Scandinavian country with a similarly comprehensive health system to Sweden, has many resonances with the results of my study. The research explores the perceptions and attitudes of couples who had situated their decisions within a continuum of their fertility treatment which is provided by the state. Svendsen notes that for participants, undergoing fertility treatment virtually marks their reproductive tissue as ‘public’ because it has involved with the assistance of state-sponsored clinicians. This is not to suggest that ownership of the embryos was assumed by the clinic, and the mechanism of informed consent was employed to make this handover clear. Rather, individuals undergoing fertility treatment are contemporaneously “patient and citizen [which] makes them become embryo donors” (Svendsen 2007, 37).

I would suggest, however, that the term ‘patient’ is only a arbitrary marker of citizenship, as some states provide comprehensive healthcare for their citizens while other states vary in their provision. Nonetheless, Svendsen (2007) provides key insight into the specificities that may characterise such associations and points to reasons for cultural differences with Australian women in this study. That Danish couples in Svendsen’s study expressed their decision to provide embryos to state-financed hES cell research as self-evident (although not coerced) demonstrates that they connect the activities of the public health care institutions that handle embryo donation with hES cell research and their fertility treatment. The national context of Denmark was a significant contributor to both the production of embryos and embryonic stem cell research conducted there and they both may be considered to be part of national ‘commons’. In contrast, the women undertaking fertility treatment in our study did not connect their embryos to their specific fertility clinic. As mentioned in chapter seven, this cohort were treated at a non-profit fertility clinic, heavily underwritten by the federal government’s system of universal healthcare called Medicare, which funds to varying degrees medical treatment, pharmaceuticals and the unrestricted use of ARTs). Preferences to give to other fertility patients may best resemble Titmuss’s universal stranger because their only defining feature was health-related. Nationality, ethnicity, class or religion did not
differentiate the other members of the community. Our cohort may be considered embryo providers in the globalised context of research.

Drawing on two studies, I have so far argued that tissue provision to scientific research does not necessarily sit outside the remit of the social contract, probably because the social contract is a dynamic process rather than a static entity. However, beyond this basic point, the notion of the citizen relies on an abstraction by connecting unrelated individuals on the basis of living, working and being born in a specific geographical territory. Citizenship is an objective reality, it is not personally constituted; that is an individual cannot exclusively declare what features of citizenship to which they are entitled and will adhere. While contributions of embryos in Denmark and blood/DNA in Sweden were made in the context of the nation–as citizens–and were thus rational, they were also passionate because they were directed at specific recipients who share the donor’s attribute of national citizenship. Even if we move away from nationalised contexts to examine further the connections between social role, tissue and its circulation, we find similar ‘passionate’ contributions to scientific research. Here, I draw on the study by Dixon-Woods et al. (2008) about the provision of cancerous tissue from paediatric cancer patients in the UK, a study that resonates with Australian data about providing cancerous tissue for scientific research (Morell et al. 2011). Dixon-Woods et al. (2008, 67) found that many participants did not place significant ontological value on the tissue once it had been removed. Many “identified the tumour material as being ‘external’ to the child and having an intruder status” or considered it waste and most, if not all participants were likely to consent to the provision of tissue for scientific research. The authors connect the largely enthusiastic provision of such tissue within the context of belonging to the childhood-cancer community. The community is a ‘tangible’ entity characterised by a process of generalised reciprocity involving gifts of the past (or present) helping to contribute to the treatments of today (or future). Dixon-Woods et al. (2008, 72) argue that their “data suggest that participants see themselves as belonging to a distinctive community united by a sense of common purpose, in which values are shared and members of the community are to be trusted”.

So far I have discussed largely positive connections between individuals and the provision of their tissue to scientific research. Positive orientations toward scientific research are based
on one of two experiences: the individual has received some form of benefit, such as state-sponsored healthcare, or the experience of illness has resulted in the specific tissue becoming a point of convergence between the donor and the community of people with the same illness. These imagined communities operate on the principle of generalized-exchange and can refer to past and future members. On the one hand, these are rational contributions and associations because the members are generic and their personalities matter less than their nationality or illness experience. On the other hand, these contributions are also passionate because they are directed towards a specific community or outcome. This research shows that, strictly, there are no obligations or sanctions if the individual does not contribute their own tissue, but the current generation often follows the behaviour of previous generations of citizens and/or ancestors because their own experiences and narratives are a culmination of these effects.

**Marginal identities and scientific research**

Here, I want to develop my claim that contributing to scientific research invokes a perception of science-as-benefactor. Science is not universally regarded in positive ways and is perceived and experienced as science, involving practices which are controlled by commercial or political interests (Harvey 2007). Harvey argued that despite the many public scandals which had occurred in the UK, most people included in his research observations were committed to fundamental scientific principles. Yet, it appears that this commitment to science is based on experiencing it as a benevolent institution. Individuals or groups who identify as a marginalised polity may regard science with hostility because historically it has been a means of that marginalisation. Withholding tissues from scientific research constitutes a form of resistance to science.

I return to the example of the HGDP and the opposition some communities expressed (Lock 2001; Reddy 2007). This scenario shows that that relationships between scientists, scientific production and “the public” can be dysfunctional and acrimonious, with people suspicious of and hostile to the use of their bodily tissue, despite its “grand vision”. As discussed in chapter two, the HGDP evoked the spectre of former oppression and dispossession because colonial powers had utilised scientific research to rationalise unfair and violent social divisions. Scientific research continues to be considered a means of marginalisation. This
oppositional posture may be due to the fact that the post-colonial identity involves not just a separation from imperial governance but the social and cultural institutions and/or values with which the imperial power has historically been aligned. This point corresponds to a similar assertion made by Rabeharisoa and Callon (2002), who report that in the United States, some African-American people diagnosed with sickle-cell anaemia have refused to “cooperate” with researchers or clinicians and remain politically disorganised, viewing the organisation of a “patient group” as a mechanism of novel stigmatisation that may continue the history of scientifically-derived racial oppression.

In both of these contexts, science is not perceived as the benign benefactor of *humanity* but as invested in the political aspirations of oppressive people or processes. Contributing to its production is perceived as assisting in the creation of further rationales on which to base prejudice. This orientation challenges the generality of Harvey’s (2007) approach, insisting that those who embrace science may have nothing to fear from it and do so on the basis that it has supported rather than oppressed a specific conception of their identity (for example, the rational European). As I argued in chapter four, in the wake of the HGDP controversy, scientific research has been situated within broader political transformations between nation-states and/or colonisers and indigenous populations where it is labelled as ‘Western’ or neo-imperialist rather than the universal and apolitical institution it purports to be. However, precisely drawing a line between the former colonisers who ‘identify’ positively with science (Caucasian Europeans) and the formerly colonised who ‘identify negatively with science is scientifically implausible. This is evident from Reddy’s (2007) research with Indian Gujaratis in Houston, Texas. Collecting blood samples to construct a Haplotype Map, in the wake of the HGDP, was not quite the ethical or political minefield anticipated by Reddy, his collaborators or ethical review boards. Rather, many members of the community identified positively with the ‘goods’ that were expected to emerge and were “realistic about risks and misuses, placing responsibility for monitoring and reporting with the brokers of the transaction” (2007, 454).

Examples of negative orientations towards science are also passionate because they connect scientific research with specific outcomes and groups. Scientific research is not imagined as an impersonal endeavour to which an individual can democratically and autonomously contribute. Rather, based on the past, some members of indigenous communities continue to
believe that science is a mechanism for their oppression. This demonstrates that individuals and/or communities can be positioned differently in relation to the conduct of scientific research, which has also had variable effects on different communities. From the research cited, the experience of some indigenous groups destabilises the assumption that scientific research and knowledge inevitably achieves an abstract or concrete good. Scientific researchers are real and imperfect people whose quest for knowledge may directly or indirectly contribute to social divisions. Flattening the terrain and declaring that there can only be one ideal donor whose interest in science is general and abstract does not sufficiently capture the diversity of experiences.

**Women as a general category**

Finally, I return to the question of oocyte provision to SCNT research. Earlier in this chapter, I briefly discussed the eminent UK scientist Ian Wilmut’s attempt to mobilise women to provide oocytes for his research into Motor Neuron disease using the technique of SCNT. I argued that Wilmut’s claims were based on a number of abstract and universal categories, including the homogenous groups of ‘women’, ‘scientists’ and ‘patients’ and the therapeutic benefit of scientific research. Notwithstanding the brevity of his plea, Wilmut’s assertions effaces the complexity of processes such as oocyte extraction, funding needed for long-term research including trials and the accumulation and translation of scientific knowledge into clinical practice. However, it also relies on having a bird’s-eye view regarding the scientific process. From Wilmut’s position, these separate elements contribute to the whole, situating the process of oocyte extraction in a context of universal healthcare. This may seem disingenuous given that from its outset, stem cell research was conducted to achieve certain therapeutic and economic benefits (Baylis 2009). What is interesting is that Wilmut’s representation helps potential donors identify a specific benefit and beneficiary but the donor remains general and undifferentiated. My analysis of the results of this research show that invoking the role of ‘women’ in its general and ahistoric sense does not provide enough motivation to give good eggs. The relationship between women, scientists and MND sufferers has failed to materialise because it only exists in a rational way rather than having a passionate dimension. I contend that women (people who are anatomically female) will give

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103 The different relationships between communities and social movements is a common feature of PUSET literature but unfortunately there is only scope to discuss issues related to medical science.
their oöcytes when it is also passionate: that is, once they can connect that beneficiary or benefit to a specific part of their own identity.

The findings of this research suggest that hostility or scepticism does not characterise the relationships between women and Science. Problematising women’s contributions to SCNT research as evident of unequal power relations (Dickenson 2006; George 2008; Baylis 2009) recalls some feminist opposition to medicine, or ARTs in particular, as a unique form of medicalised surveillance (Corea 1985). Yet, participants do not frame their lack of enthusiasm to provide oöcytes for SCNT research by referring to themselves as “women” – the inferior category in patriarchal and capitalist social relations – and thus as a form of resistance to or subversion of patriarchal capitalism. The term “woman” is too broad a social category to reconcile with the diverse experiences of participants. Without identifying a specified benefit or beneficiary, they cannot muster the motivation to undergo the process of oöcyte extraction. If participants can connect the process with a real person, concrete experience or outcome, they are more likely to consider undertaking oöcyte extraction. Furthermore, it is likely that their roles as ‘daughters’, ‘sisters’, ‘mothers’ or ‘nieces’ will be at the forefront of any serious contemplation to give their oöcytes to SCNT research. These relationships resemble those experienced between reproductive oöcyte donors in our study and their recipients. While the relationships donors formed with their recipients may have been transient, the relational context placed the process of oöcyte extraction within an affective framework. Donors were invested in the happiness of their recipient and the technical aspects of undergoing oöcyte extraction, as intense and risky as they were, became a means to an end. In our study, women want to provide their oöcytes to research that will have similarly tangible benefits for people they know. They are committed to scientific research in a rational way but ultimately their contributions need to have a passionate dimension. The difference in perceptions illustrates the difficulty of instituting the rational form of contributing to science and the need to acknowledge that women may have varying ‘passionate’ interests in the conduct of SCNT research. Other research indicates that when these two forms of engagement are connected, participants are motivated to contribute to research.

The responses from this study indicate clearly that a specific benefit or beneficiary is at the centre of oocyte provision. Scientific research may be a fundamental social and cultural
value of Western society, (Harvey 2007) it may also be subject to more hostile scrutiny from novel experts and lay members of the community but ultimately positive orientations towards scientific progress are rarely evoked in an abstract way; rather, science operates as a mediator between people who are connected on the basis of belonging to a national group, their lack of it – as is the case with indigenous people whose acceptance into settler societies continues to provoke questions about identity and authenticity – or an experience with illness that has incorporated them into a sub-group. It may help transform emotions for specific beneficiaries into knowledge for everyone, but it must begin with this. By contributing to scientific research, individuals recognise themselves as part of a community in the same or future temporal space; they may also identify with others at different political levels, such as helping people of the same race, nation or simply the human species (Reddy 2007). Some sort of relationship is evoked through the provision of tissue, rather than the abstract and isolated human individual for whom tissue provision means the rational deliberation of costs and benefits.

To answer a central question from Titmuss’s (1997 [1970]) work on blood provision, ‘who is my stranger?’, I have responded with heterogeneity. The answer is that the donor’s stranger depends on the donor in a specific social and historic context. The relationships in which individuals exist may all compete to lay claim to their tissues; however, it is often through some experience through which tissues are produced that help determine their trajectory. To embrace the universal stranger and recognise the humanity of every individual is ideal but it does not necessarily motivate contributions to scientific research, particularly if those contributions involve an extraordinary commitment on the donor’s part. Nor does such an approach acknowledge that individuals and communities are situated differently to science. Effacing these differences and insisting that the best donor is rational does not necessarily lead to more contributions to scientific research. I have argued that this universality is difficult to sustain in contemporary society where the individual is implicated in many social roles and relationships in his or her life.
Chapter Nine: Conclusions and Directions for Future Research

The aim of this thesis was to develop a framework that could connect a scientific utilisation of reproductive tissues with women’s intentions to become a mother and examined practical contexts of giving such tissues and the sociological constructions around these. My discussion has examined tensions in the current regulatory environment, focusing on the issue of introducing a payment system in exchange for "good eggs", mature and fertile oöcytes, and the ostensible shift from Titmuss’s (19970 [1970]) donor model this view signals. I have argued that despite the polarised stances this issue generates, they are based on the same imperative to rationalise scientific research with the imposition of universal principles. Not surprisingly, at the heart of this rationalisation is the rational donor or contributor to science who makes decisions autonomously, voluntarily and without a specific interest in their outcomes. This model flattens the social terrain, the different investments individuals or groups may have in scientific research and certain tissues and insists that ‘passionate’ contributions are inherently based on coercion and exploitation.

The analysis contained in this thesis draws on primary data collected within the context of a three-year ARC project (2008-2011), specifically the period between July 2009 and August 2010. There were three cohorts in this study: women had experience of fertility treatment for themselves (cohort one), women had given their oöcyte for reproductive purposes (cohort two) and women who are regarded as the ‘healthy donor’ as they are at an age where their fertility is at its peak and they are unlikely to be engaged in fertility treatment (cohort three). The research implemented two methods to collect data, semi-structured interviews (cohorts one and two) and focus groups (cohort three). The data collected potential donors’ perceptions and attitudes towards giving their oöcytes and embryos for research or reproductive purposes. The specific experiences of each cohort were discussed in order to contextualise their responses; for instance, participants in cohort one were asked about their fertility treatment, participants in cohort two were asked about their decisions to donate oöcytes for reproductive purposes and participants in cohort three were asked about other

104 As mentioned in chapters one and five, the ARC funded the project from 2008 to 2011. We collected data between 2009 and 2010 when the specific ethics committees granted approval.
forms of tissue donation. All cohorts were asked about their attitudes towards scientific research generally and stem cell research specifically.

**Principal Findings**

The data from this sample provide important insights into the biological and social factors that have thus far inhibited the altruistic donation of oöcytes to SCNT research. The lack of donated oöcytes to SCNT research is not based on a hostile or unfavourable view of stem cell research generally. Many women expressed positive attitudes towards the conduct of stem cell research and considered that other women’s participation was sufficient for its progress. I contend, based on these findings that the primary reason for the lack of oöcytes donated to SCNT research is that oöcytes are essential for women who intend to become a mother in the immediate, short or long term future. Given that the biological properties of oöcytes means that utilisation for research or reproductive purposes is a mutually exclusive option, women prefer to keep their oöcytes to offset the possibility that the oöcytes they are left with are infertile. Giving infertile oöcytes to research may represent a form of waste management. Oöcytes are essential first-steps to realise one’s intention to become a mother, however, the biological and social properties of embryos relate to the maternal social role differently and thus giving these tissues to research is based on a different logic. Embryos relate more specifically to questions of biology and kinship. For many participants in cohort one, giving embryos for reproductive purposes hypothetically represents a destabilisation of the family as nuclear (where children are raised by one mother and father to whom they are biologically related).

Analysis of the contexts in which reproductive tissues are given (in actual or hypothetical situations) provide important insights into the issue of oöcyte provision for SCNT research. Following Levi-Strauss’s (1969) model of generalized-exchange, donors connect with a specific recipient (who may be inter-personally anonymous) and/or experience the benefit of scientific research themselves. I demonstrated that oöcytes and embryos are given away within an affective framework which varies between the identification of specific (sometimes inter-personally identified) recipients and generalised ones. In relation to oöcytes, narratives of participants in cohort two show donors’ preferences to identify a
specific recipient whom they have *evaluated* as ‘good parents’. With the identification of a specific beneficiary the donor validates the desire for parenthood with reference to social and personal markers of “good parents” and by default demonstrate that all people who need oöcytes for reproductive purpose are not deemed worthy. This indicates that the donor’s altruism – concern for the other – also has an instrumental basis. In contrast, participants spoke about hypothetical situations of embryo provision in the Titmuss-esque spirit of embracing the “universal stranger”, that is a recipient who was not inter-personally identifiable to the donor but whose needs, nonetheless, are recognised by the donor as valid.

I interpreted participants’ hypothetical discussions of embryo provision for research or reproductive purposes within the context of generalized-exchange where donors and recipients were known to each other in generic ways. I argued that the experience of fertility treatment had generated a new identity for the individual and membership into a community of fertility patients whose experience of fertility treatment was constituted by the previous donations of fertility patients. Within this largely “imagined community” (Anderson 1983), the embryo connected the donor with other people who also wanted to have children in an indirect or direct way. Research was an indirect relationship between the donor and recipient(s) while reproduction was a direct way that the donor and recipient could connect.

I identified the affective framework – the identification of a specific benefit or beneficiary as an important factor in giving away reproductive tissues. The affective framework is present in the way participants from other studies have imagined giving away their tissues such as embryos, blood and DNA. However, I have shown that the affective framework is absent from the context of oöcyte provision to SCNT research. Here, the donor is referred to in such general terms that there is little connection between potential benefits or beneficiaries. For instance, the potential donors of oöcytes can simply be referred to as “women”, an abstract category, undifferentiated by personal relationships, experience or interests in scientific research.

**Limitations**

All research benefits from hindsight and care is needed in interpreting these claims. SCNT research is a novel method and this research study was designed to be exploratory in order to
capture in-depth and context-specific account of perceptions and attitudes towards the scientific utilisation of reproduction tissues. It did not use an experiment to produce findings. The findings and claims may be limited in several ways. First, the research methods used were focus groups and interviews and the sample of 43 women generated an enormous amount of data. However, given the small number of participants recruited, it is unable to provide a basis for generalisations based on causal relationships between variables. Second, the data are based on hypothetical situations. Like much research conducted on the same subject around the world, (refs), this dataset is an important means of gauging public opinion. However, it is important to remember that the clinic from which our participants were recruited did not engage in stem cell research and did not ask their patients to provide oocytes for reproductive or research purposes. Therefore, the participants’ views, with the exception of cohort two, are not based on real-life experience of providing tissues to stem cell research. Thirdly, it is not entirely known whether reproductive oocyte donors in this study were the beneficiaries of some sort of reciprocity despite their own claims that this was the case. Finally, the findings of this study are not inevitable and changes are likely to reflect changing dynamics in society, gender norms and technological advances in both SCNT research and reproductive biology. For example, if oöcyte vitrification becomes a more stable and less experimental procedure, allowing women to rationally manage their fertility, perceptions of oöcyte use for scientific research will likely change, as well as individuals’ willingness to donate. Finally, these results may show a bias towards women whose first language is English and are highly educated (almost 52% had received a tertiary education while a further 40% of the sample had obtained some education beyond high school).

Nevertheless, these findings are consistent with emerging research that has also examined women’s decisions, particularly those who undertake fertility treatment, to provide their reproductive tissues to stem cell research. For instance, Klitzman and Sauer (2009) also report that women are unlikely to provide oöcytes for SCNT research in order to protect their intentions to become a mother. Haimes, Taylor and Turkmendag (2012) and Haimes (2013) show that in spite of measures designed to source more good eggs such as egg-sharing, women do not inevitably jettison their intentions to become a mother. While research in this area is sparse mainly because the field of regenerative medicine has grown substantially in the last 20 years, this emerging field of scholarship demonstrates that oöcyte provision for SCNT research must be researched further in order to elucidate the specificities of the issue.
Interconnections between findings and theory

The current study has important implications for scholarly fields related to both substantive and theoretical issues. At an empirical level, this research elaborates on our understanding of gift giving practices. By approaching gift giving as a practice it is revealed to be anchored in a specific social context resulting in variable expectations of reciprocity between donors and recipients, even in known situations. For instance, Titmuss (1997 [1970]) insisted that for blood provision to be a “free gift”, it had to be anonymous. However, from this research we know that donors can be motivated by both altruistic and instrumental concerns and giving in known contexts does not have to compel the recipient to reciprocate. I argued that different expectations of reciprocity can be understood with reference to the concept of discretionary reciprocity. This concept recognises that the obligation to reciprocate depends on the donor’s perceptions of the recipient and the reasons why they are giving the tissue in the first place. The concept of discretionary reciprocity facilitates a shift from an inextricable connection between women’s gift giving and restrictive perceptions of femininity because it recognises that the different circumstances in which oocytes and embryos are given can facilitate distinct identities for women. In the context of oocyte donation for reproductive purposes, the context of helping another to produce a family can over-ride the imperative for reciprocity in known contexts. In contexts of scientific oocyte provision, the recipient is chosen because they have the ability to transform the gift into something substantial. Yet, expectations of reciprocity can become mired in the complexity of establishing a financial equivalent for oocytes.

This research shows that approaches regarding the commodification of objects do not refer to the social consequences of giving away tissue, that is, how the donor is affected by their gift. As discussed above, whether reproductive tissues may progress to the state of disentanglement (albeit always incomplete) depends on the social consequences for women. Giving reproductive tissues constitutes the maternal social role in two distinct ways: giving oocytes might jeopardise the intention to become a mother while giving embryos helps to

I refer to Mauss’s (2002 [1954]) own language regarding reciprocity. In this paradigm where reciprocity is a universal part of gift giving, the obligation to reciprocate is invariably felt by the recipient. However, I have tried to separate the two parties and the objects given in the process and insist that the donor can contribute to decisions about whether the recipient should reciprocate.
maintain the biological basis of conventional kinships. This research also assists in destabilising the assumption that gift giving inevitably involves the circulation of ‘vital’ objects while commercial transactions presuppose inanimate things, evident in Mauss (2002 [1954]) work on gifts. Rather than assume that commodities are those things which have been “decontextualized, disassociated and detached” (Callon’s 1998, 19), I argue that reproductive tissues defy this binary in surprising ways. Objects that are circulated as gifts do not have an inherently vital status, this is evident in the fact that oöcytes were the tissues which were viewed in functional terms, without a moral status in and of themselves. In contrast, embryos were situated within the framework of “kin ethics”, perceived as siblings of children born through their parents’ use of ARTs. Their provision to research rested precisely on the premise that they were children who could not be given to another family.

At another theoretical level, the examination of oöcyte donation for SCNT research facilitates speculation about the degree to which scientific research represents both a “public good” itself and the means of realising it. Whether institutions pay people to provide tissues or rely on donors relates to questions about the basis of political associations, the moral authority of the individual and the potential for the “public good”. Distinct from questions about inclusion in the public sphere and the process by which the “public good” is decided, the ideal of political associations are that they are “rational”, a polity constituted by features common to all members, such as being born (including recent ancestors) or working in the same geographical territory rather than “passionate” which are feelings shared between at individuals in an idiosyncratic way. The ideal citizen should be “rational” by detaching him or herself from his or her own interests and considering the implications of their decisions for the “public good”. In this paradigm, human tissues are provided to scientific research simply on the basis that scientific research is a “public good” and posing a benefit in the immediate or distant future and distinguishing the “modern West” from its religious and theoretical past. In contrast to the ideal of “rational” contributions to scientific research, I contend that it is important to recognise that there are passionate dimensions to people’s decisions. Passionate tissue contributions do not have to be directed at one person who is known to the donor, but they involve the identification of a specific beneficiary who is exists in relationship to the donor as fellow citizens, through an experience such as fertility treatment or other medical treatment provided by a nationalised health service.
To understand the complexity of the scientific utilisation of human tissues, analysis should consider moving beyond models based on abstracted views of individuals and the social space they inhabit. That people actually give their tissues in “passionate” circumstances – where they have been able to identify a specified benefit or beneficiary – shows that many theorists who dismiss passion as a basis of political association do not adequately capture human experience. Insisting that tissue provision must be rational and motivated by impersonal incentives does not sufficiently recognise the different relationships and experiences individuals and communities can have with scientific research in contemporary Australian society. The examples I draw on illustrate that when tissues are given to scientific research, they often draw on relationships the individual has with others (Lock 2001; Hoeyer 2003; 2006a and 2006b; Hoeyer and Lynøe 2006; Svendsen 2007; Reddy 2007; Dixon-Woods et al. 2008).

**Implications**

The ARC project of which my candidature was part undertook community engagement in two broad ways. Firstly, the immediate project team authored a public submission to the federal government’s Legislative Review Committee in 2011 (as stated in the dissertation, this review was foreshadowed in the original Parliamentary Acts of 2006). Secondly, Professor Waldby and Associate Professor Kerridge chaired the National Oocyte Donor Workshop at the University of Sydney in 2011. This workshop was intended to disseminate results to the attendees and generate further discussion for policy initiatives. I contributed to both of these. So far this thesis has contributed to policy discussion in the Australian context through the publication of articles (listed in appendix O). It is hoped that once the revisions of this thesis are accepted, I will publish more sole-authored articles. These publications will be directed to policy-makers as well as the academic community.

By insisting that contributions to scientific research must adhere to the criteria of the “rational” contributor, the hitherto lack of donated oöcytes is likely to be understood as revealing an oppositional or apathetic attitude towards the progress of scientific research. From the current analysis, we know that factors thus far inhibiting the altruistic donation of oöcytes to SCNT research are based on the relatively long period of medication and surgery...
required for oocyte extraction and the lack of an affective framework. The day-to-day process of taking medication, culminating in surgery is unlikely to be sustained on the basis of generalised and abstract exchange. Neither does the inclusion of money automatically transform the relationship a potential donor’s motivation into a concrete one. Rather, there is a symbolic threshold between ‘compensation’ and ‘payment’. Being “paid” rather than “compensated” may also provoke moral dilemmas for individuals who insist that financial concerns should be peripheral to the decision to contribute to scientific research. This is not to suggest that the decision to give oocytes under different circumstances cannot be made – the fact that many women around the world sell their oocytes attests to this – however, I remain committed to the assertion that without this specificity the donor will ultimately ‘float’ losing interest in the process or feel exploited.

Tissue provision to scientific research resonates deeply with individuals at an everyday level, connecting them with different experiences of political subjectivity and healthcare. Policy-makers in Australia may find that the following points have important implications for general guidelines related to tissue provision for scientific research. First, my work suggests that tissues must be recognised as a heterogeneous category because they have different moral and social dimensions that affect their provision. Reproductive tissues such as oocytes and embryos uniquely constitute the maternal social role and are given to research in specific circumstances and for different reasons. Secondly, the examination of oocyte provision to SCNT research shows that donor perspectives themselves must be recognised as heterogeneous: there is not one donor perspective but many. Furthermore, the relationships between potential donor groups must be managed carefully; for instance in this dataset some participants in cohort one sought to construct “healthy donors” as “ideal” while simultaneously excluding themselves – these constructions are not mutually beneficial and must be treated with care. Thirdly, attitudes about scientific research must be understood in their specificity: problematising scientific research as constituting unequal social relations simply universalises attitudes towards scientific research in reverse. Finally, maintaining a focus on whether women should or should not be paid to provide oocytes for SCNT research will simply reiterate a critique of scientific utilisation of human tissue as based on unequal social relations – a contest between the moral authority of the individual and the “public good” – as if these are not mutually constitutive.
This last point is an important means of shifting the parameters of the debate from one that currently focuses on whether paying women to provide oocyte to SCNT research is a means of freedom or coercion to one that meaningfully addresses the degree to which the conduct of scientific research is a “public good” in the immediate and long-term future. Governments focusing on the immediate prospects of establishing a bioeconomy consequently adopt a capitalist model of property relations without attention to future consequences of these decisions. In the context of healthcare, the implications are serious because potentially life-saving technology is likely to be prohibitively expensive for governments and individuals. As discussed in chapter four, the response to these structures may be to pay women to provide oocytes in order to be recognised as the ‘labourers’ they are. Yet with adequate financial recognition of this ‘labour’, structural capitalist property relations remain in place and the capitalist maintains ownership of the products of labour. In the absence of adequate attention to the long term consequences of maintaining this capitalist structure in the context of healthcare, the questions which emerge with the provision of tissues is unlikely to be resolved to the satisfaction of scientists, corporate interests and different sections of the ‘lay’ community. 106

Towards future research

Some questions go beyond the remit of the current framework and it would be fruitful to use some of the conceptual insights gained from this study as the basis for further research. In relation to gift giving literature, this may include examining my claim that reciprocity can be a discretionary part of contemporary gift giving practices, rather than a universal one. Studies can examine in what contexts is reciprocity expected, from which recipients? Another area of potential research relates to the claim I have made that rational political associations – community based on generic attributes of members – and the ends it seeks to

106 Ethical practice in the Australian context needs to take into account the implications of scientific research in a long-term context. I believe from the data contained in this dissertation and a critical reading of the literature that an emphasis on individuals does not effectively take into account the social implications of scientific research. We should not simply rely on existentialist questions of autonomy and construct a contest between the community and individual rights. As a scholar, I would like to see the development of policy that carefully draws on insight from individuals and leadership about meeting needs of the community. Sociological research that conceptualises, rather than simply reporting data and perfunctorily engage with theoretical concepts such as risk can make an important contribution to debates.
achieve can also have “passionate” dimensions, where giving occurs with the identification of specific benefits or beneficiaries. One way to elaborate on this claim would be research into the kind of community that is commensurate with oöcyte provision to SCNT research. What might make the process of oöcyte extraction a part of the relationship in an interpersonally anonymous context, that is the national community in the medium, long or distant future? This may involve collaboration with scientists interested in, or actually conducting, SCNT research. Beyond this, two issues with which this research project could only briefly touch upon suggest themselves; namely, taking full advantage of Australia’s cultural and religious diversity to develop further a nuanced account of the Australian communities perceptions about scientific research and doing a comparative study between other kinds of tissue provision to scientific research.

Another worthwhile direction for future research is to develop a more explicit dialogue between ‘tissue economies’ and ‘public understandings of science and technology’ literature. This undertaking could involve examining the data in relation to theories about ‘publics’ and ‘experts’ in a comprehensive way. Rather than simply evaluating whether the lack of oöcytes for SCNT research indicates a low level of trust in the latter, it is possible to develop a nuanced account of trust in impersonal systems that acknowledges the ‘passionate’ dimensions that continue to shape our everyday lives. The ramifications for social theories about risk societies and individual risk strategies could be interesting to witness (Lyotard 2001 [1984]; Giddens 1991: Beck 1992; Beck, Giddens and Lash 1994). Future research can also examine the extent to which scientific institutions, autonomously and together with the state, must engage with its constituents in order to progress and maintain a sense of legitimacy.
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Appendix A: Letter and information to patients and donors of X Fertility Centre, including consent for contact form (version: December 2008).

Dear IVF Patient,

We are writing to you as someone who may be interested in taking part in a research project about egg donation in Australia. The research study is being run by The University of Sydney with the support of X IVF.

The research project is called “Human Oocytes for Stem Cell Research: Donation and Regulation in Australia”. It is jointly funded by the Australian Research Council and X IVF clinic. The research team is especially interested in women’s attitudes about the issues of donating oocytes (human eggs) for stem cell research purposes. The researchers believe that the perceptions and insights of women who have actually experienced the procedure of egg collection through IVF cycles are very important in developing guidelines that will ensure ethically sound and safe egg donation procedures in Australia.

You are invited to take part in an interview that will focus on your experiences and perceptions of IVF treatment. You will also be asked about your attitudes to egg donation for both reproduction and stem cell research. These questions will only be hypothetical; the research team is not asking you to donate eggs now or in the future.

The hour-long interview would occur at a time and place which is convenient to you. The interview is strictly confidential and will be conducted by a female researcher (Katherine Carroll or Margaret Boulos) from Sydney University. The researchers are independent from X IVF clinic. X IVF staff will have no knowledge of your decision to participate in the study. Your participation in this study is entirely voluntary, you are free to withdraw from the study at any time, and your decision to participate will not affect your access to current or future treatment at X IVF clinic.

If you agree to take part in this research, the researcher would ask you a series of interview questions. The interview would be recorded so that the questions and answers can be transcribed for analysis. The transcribed interview will not name you, and we will take out any features that could identify you. The research study has been approved by NSW Health Human Research Ethics Committee (approval number HREC/09/WESTMEAD/15)

If you would like to participate in the study, please follow the following steps:

(i) Read the “participant information form” that has been included in this letter. This document will tell you more about the study.
(ii) Complete the “consent for contact” form that has been included with this letter. Please note your preferred contact time and number for us to call you on in order to arrange an interview.
(iii) Return the “consent for contact form” to us using the reply-paid envelope.

If you have any further questions about the research, please feel free to telephone or email Katherine Carroll a member of the Sydney University research team. Her contact details are listed below:

Ph: 9036 7994  email: katherine.carroll@usyd.edu.au

We thank you for your time and should you choose to be involved in this research, the research team look forward to meeting you and hearing your experiences.

Kind Regards,

N.B. signature of clinician removed to protect confidentiality.
Consent for Contact Form

I have read and understood the participant information form and I consent to be contacted by a member of the research team to arrange a time for an interview at my convenience.

NAME (PRINTED):

SIGNATURE: __________________________________________

DATE: __________________________________________

Preferred contact number: ________________________________

Preferred contact time: ________________________________

Please leave a message if I do not answer the phone: YES / NO

Please ensure all questions are completed and then place this form in the reply-paid envelope and send to:

Katherine Carroll
A-26 RC-Mills Building
School of Sociology and Social Policy
University of Sydney 2006

On behalf of the Sydney University Research Team we thank you for your time and look forward to meeting you!
Appendix B: Cohorts one and two Demographic Information form (version: February 2009)

Demographic Information

Postcode of residential address _______________

Age Range (Please circle)

1. 21-25
2. 26-30
3. 31-35
4. 36-40
5. 41-45
6. 46-50
7. 51-55

Occupation _____________________________

Highest Educational Qualification (please circle)

1. Postgraduate Degree Level
2. Graduate Diploma and Graduate Certificate Level
3. Bachelor Degree Level
4. Advanced Diploma and Diploma Level
5. Certificate Level
6. Secondary Education
7. Primary Education
8. Pre-primary Education
9. Other Education

Relationship Status ________________________

Number of Children _______________________

First IVF cycle: Month ____ Year ____
Last IVF cycle: Month ____ Year ____

Are you continuing your IVF treatment now or in near future: yes / no

RESEARCHER USE ONLY:

Participant Code Number _________________
Appendix C: Women undergoing fertility treatment – interview schedule

Oocyte donation and regulation in Australia for Stem Cell Research: IVF patient interview schedule

1. Introduction

Researcher introduces self, the research topic and expected outcomes

Interview Preamble –

In this interview we are seeking your insights and understandings of egg and embryo donation for stem cell research. We wish to interview you about this topic because you have personal experience of IVF and/or egg donation to assist other women to have a child. We understand that you yourself have not donated for stem cell research. However during the interview we will explain to you different aspects of donation for stem cell research, and ask for your opinions and feelings about it. We feel that, as someone who has been through IVF, you have unique insights into this topic, and we wish to draw on your experience to improve the process for women who will donate and embryos for stem cell research in the future. We are social researchers and our interview is not intended to persuade you to donate yourself, now or in the future. We are only interested in your opinions and feelings about the subject. We will use this information to formulate recommendations for the ethical regulation of oocyte donation for stem cell research in Australia.

Discuss role and rights of participant, the consent process, and confidentiality
Ask participant if has any questions
Provide participant with demographic survey to fill in
Reconfirm consent to record, and test recording.

2. Introductory Discussion

How did you come to choose X IVF as a clinic for you?
What has your experience been at X IVF?
Is this your first time with IVF? How has your experience been of IVF?
3. Embryo Donation in ART

When you have ART you have several options about your embryos. You can use some for your treatment cycle, you can dispose of the ones you don’t want for treatment, and freeze the rest to use later if the cycle, doesn’t work. You can donate them for research or to another couple.

Would you donate to another couple/woman?

Anonymous donation or to a known person?

Would you consider donating embryos for research into infertility? Why/why not?

Would you consider donating embryos for commercial research e.g. genetics? Why/why not?

In each of these cases (if yes) – how would decide when to donate them (e.g. once achieved pregnancy, after having several unsuccessful cycles, once embryos had been kept for a particular amount of time?)

4. Egg donation in ART

Now let’s talk about egg donation – X IVF doesn’t ask women in ART to donate eggs, so I am just asking for you opinion and ideas.

Bear in mind that eggs can’t be kept because they don’t freeze well. So you are thinking about donating your fresh eggs while you are going through a treatment cycle.

Would you consider donating eggs for research into infertility? Why/why not?

Would you consider donating eggs for commercial research e.g. genetics? Why/why not?
Would you donate to another couple/woman?

Anonymous donation or to a known person?

If answer is different from embryo donation, what is the difference for you?

Who would you discuss donation of embryos or eggs with? Partner, family, friends, anybody?

5. Patients with (or seeking) their own egg donors [skip if not applicable or if short of time]

How did you find out you needed an egg donor?

How are you looking for an egg donor / how did you find an egg donor? Why are they donating for you? How would you describe your relationship with them?

Do you have Family / Friends who have donated / received donated eggs to assist conception?

Were you involved in helping them decide? What things did you discuss?

6. Donation for Stem Cell Science

Have you heard of stem cell research? Where did you hear about it? What is your understanding of stem cell research? Why is it important?

Have you heard of SCNT (therapeutic cloning)?

If yes, What is your understanding of the potential benefits of SCNT and stem cell research?

[interviewer to give simple explanation of need for embryos and eggs and potential benefits and that it is experimental research] on separate attachment
Do you have any family or friends with conditions that might be helped by stem cell research in the future? E.g. diabetes, MS, spinal cord injury, Parkinson’s disease, stroke, heart or kidney disease

If yes, how does this make you feel about stem cell research?

6a. Embryos for SCNT

Would you consider donating embryos for stem cell research? Why/why not?

How would you decide when you would donate them? (e.g. once achieved pregnancy, after having several unsuccessful cycles, once embryos had been frozen for a particular amount of time?)

6b. Eggs for SCNT

Would you consider donating eggs for stem cell research? [remind that they must be diverted from treatment and can’t be stored] Why/why not? If yes, how would you decide which ones to donate?

Is there any difference for you between donating eggs to another couple and donating to stem cell research? What is it?

Now that you have gone through IVF have your feelings about your eggs changed? If yes, in what way have your feelings changed? If no, why not?

(If pregnancy was achieved) Do you think the pregnancy from IVF has influenced your feelings about your eggs?

(If pregnancy not achieved) Have the unsuccessful cycles of IVF influenced your feelings about your eggs?
The ideal egg donor for stem cell research (medically speaking) is a young woman (18-30) with high fertility, who would not be attending an ART clinic.

Do you think that this group of women should be asked to donate for stem cell research?

What kind of information should they be given before they agree to donate?

7. Payment and Incentives

Different countries use different approaches to encourage women to donate eggs for stem cell research and to assist other women’s reproduction. I’d like to know what you think of these different approaches.

In the UK women can get discounted IVF fees and compensation of expenses up to £250 (check) if they donate eggs for stem cell research – this is called ‘egg sharing’. This may involve donating viable eggs that could be used to make embryos. IVF treatment in the UK is more expensive than Australia.

In the UK women who are not IVF patients can also donate eggs for stem cell research. They are not paid but they can receive up to £250 (about $500) as compensation for expenses.

In the USA women can sell their eggs on an open market, and young white women with university degrees can charge very high prices (up to $100,000 per cycle, but usually around $15,000 - $20,000). Women can also sell eggs for research purposes, but the fees are not as high as for reproduction. (around $4000)

Some women in other countries are paid to provide eggs for couples having IVF - they can be young students in America or Spain, or mothers and/or poor working women in Romania or India. These eggs may also be used for stem cell research. Do you have any thoughts/feelings about this?
In Australia no payment is given to egg donors. “Reasonable” costs to the donor are reimbursed by the recipient. These may include immediate medical and travel expenses, and babysitting. Is this fair?

Do you think Australian egg donors should be paid?

In some cases donated eggs may be used for research that generates profits. In light of this, what do you think about payment for research eggs?

Do you have any professional, religious or spiritual views that influence your decisions and opinions about egg donation for stem cell research?

8. Policy

Should women be asked to donate eggs for stem cell research?

Should Australia be involved in stem cell research?

What information should women be given if they agree to donate eggs for research? How could it be most effectively delivered?

What do you think are necessary protections for women who choose to donate eggs for research?

9. Closure

Is there anything else you would like to add that you think is important?

Would you like to be sent a report on the findings from this study?

Would you be prepared for us to contact you for a follow-up interview in 6 months time?
Appendix D: Reproductive oöcyte donors – interview schedule

1. Introduction

Researcher introduces self, the research topic and expected outcomes

Interview Preamble –

In this interview we are seeking your insights and understandings of egg donation for stem cell research. We wish to interview you about this topic because you have personal experience of IVF and/or egg donation to assist other women to have a child. We understand that you yourself have not donated eggs for stem cell research. However during the interview we will explain to you different aspects of egg donation for stem cell research, and ask for your opinions and feelings about it. We feel that, as someone who has been through IVF, you have unique insights into this topic, and we wish to draw on your experience to improve the process for women who will donate eggs for stem cell research in the future. We are social researchers and our interview is not intended to persuade you to donate yourself, now or in the future. We are only interested in your opinions and feelings about the subject. We will use this information to formulate recommendations for the ethical regulation of egg donation for stem cell research in Australia.

Discuss role and rights of participant, the consent process, and confidentiality
Ask participant if has any questions
Provide participant with demographic survey to fill in
Reconfirm consent to record, and test recording.

2. Personal Donation Decision

How did you become an egg donor? Would you tell me your donation story?
How did you come to your decision?
Did you discuss the decision with others? Who?
[If donor has a partner - prompt for her perceptions of partner’s belief]
What was their opinion?
What were the factors that influenced your decision?
Did your decision waver over time?
How do you feel about your decision now?

If and when you told people about your decision to be an egg donor, what kind of reactions did you experience/expect? What kinds of reactions did you actually get?

Do you have Family / Friends who have donated / received donated eggs to assist conception?
Were you involved in helping them decide? What things did you discuss?

3. Donation Experience

Is this your first time donating? How has your donation experience been?

[If not first time] – how was this experience compare to other IVF experiences?

How were the staff involved in your donation process? Can you describe the process? (e.g. Who did you interact with and at what moments in the process?)

What kinds of issues did the staff discuss with you when you agreed to donate?
Was the experience of donation different to what you were expecting? How?
Can you tell me about the consent process?
Would you change the consent process?
If yes, in what way? If no, why not?

Legally, once your donated eggs are combined with the sperm (from the recipient’s male partner or sperm donor), the egg belongs to the recipient. What are your feelings about that?
4. Other kinds of egg donation

You have donated eggs to a woman who you know. I want to ask you about some other donation options.

Would you consider donating eggs anonymously? i.e. to someone you don’t know, decided by the clinic? Why/why not?

Is there any type of person you would not donate to?

Would you consider donating eggs for research into infertility? Why/why not?

Would you consider donating eggs for commercial research e.g. genetics? Why/why not?

5. Donation for Stem Cell Science

Have you heard of stem cell research? Where did you hear about it? What is your understanding of stem cell research? Why is it important?

Have you heard of SCNT (therapeutic cloning)?

If yes, What is your understanding of the potential benefits of SCNT and stem cell research?

[interviewer to give simple explanation of need for embryos and eggs and potential benefits and that it is experimental research] on separate attachment

Do you have any family or friends with conditions that might be helped by stem cell research in the future? E.g. diabetes, MS, spinal cord injury, Parkinson’s disease, stroke, heart or kidney disease

If yes, how does this make you feel about stem cell research?
Would you consider donating eggs for stem cell research? Why/why not?

Is there any difference for you between donating eggs to another couple and donating to stem cell research? What is it?

Now that you have gone through egg donation have your feelings about your eggs changed? If yes, in what way have your feelings changed? If no, why not?

The ideal egg donor for stem cell research (medically speaking) is a young women (18-30) with high fertility, who would not be attending an ART clinic.

Do you think that this group of women should be asked to donate for stem cell research?

What kind of information should they be given before they agree to donate?

6. Payment and Incentives

Different countries use different approaches to encourage women to donate eggs for stem cell research and to assist other women’s reproduction. I’d like to know what you think of these different approaches.

In the UK women can get discounted IVF fees and compensation of expenses up to £250 (check) if they donate eggs for stem cell research – this is called ‘egg sharing’. This may involve donating viable eggs that could be used to make embryos. IVF treatment in the UK is more expensive than Australia.

In the UK women who are not IVF patients can also donate eggs for stem cell research. They are not paid but they can receive up to £250 (about $500) as compensation for expenses.
In the USA women can sell their eggs on an open market, and young white women with university degrees can charge very high prices (up to $100,000 per cycle, but usually around $15,000 - $20,000). Women can also sell eggs for research purposes, but the fees are not as high as for reproduction. (around $4000)

Some women in other countries are paid to provide eggs for couples having IVF - they can be young students in America or Spain, or mothers and/or poor working women in Romania or India. These eggs may also be used for stem cell research. Do you have any thoughts/feelings about this?

In Australia no payment is given to egg donors. “Reasonable” costs to the donor are reimbursed by the recipient. These may include immediate medical and travel expenses, and babysitting. Is this fair?

Do you think Australian egg donors should be paid?

In some cases donated eggs may be used for research that generates profits. In light of this, what do you think about payment for research eggs?

Do you have any professional, religious or spiritual views that influence your decisions and opinions about egg donation for stem cell research?

7. Policy

Should Australia be involved in stem cell research?

Should women be asked to donate eggs for stem cell research?

What information should women be given if they agree to donate eggs for research? How could it be most effectively delivered?
What do you think are necessary protections for women who choose to donate eggs for research?

8. Closure
Is there anything else you would like to add that you think is important?
Would you like to be sent a report on the findings from this study?
Would you be prepared for us to contact you for a follow-up interview in 6 months time?
Appendix E: Cohorts One and Two Participant Information (version: July 2009)

PARTICIPANT INFORMATION (IVF Patient)

Study Title: Human Oocytes for Stem Cell Research: Donation and Regulation in Australia
Short Title: Human Oocytes for Stem Cell Research

Chief Investigator: A/Prof Catherine Walby
Catherine.Waldby@usyd.edu.au
Department of Sociology and Social Policy
University of Sydney

Principal Investigator: A/Prof Ian Kerridge

Researchers: Katherine Carroll and Margaret Boulos

What is the purpose of the study?

This study will explore the meaning of oocyte (egg) donation for women, scientists, IVF clinicians, ethicists and policy makers. In particular, the focus of this study is on the social and ethical issues raised by donated eggs that are used for stem cell research. The information collected from this study will contribute to the development of ethical guidelines and practices for Australian stem cell research. It will contribute to the protection of women’s health and autonomy through the design of sound donation practices and support services.

Who will be invited to enter the study?

You have been invited to enter the study because you have undergone egg collection. If you are a woman who has undergone egg collection or IVF treatment at X Fertility Clinic (“the Clinic”) you have been identified through the Clinic’s database as someone who might be interested in taking part in the study. Because of your experiences of egg collection and/or IVF, you may be able to provide special insights and perceptions about the issues that surround choosing to donate eggs. If you are interested, you need to give us permission to contact you via telephone to request a face-to-face interview.

What will happen on the study?

If you choose to take part, this would involve a one-hour interview with a female member of the Sydney University research team. The interview would be conducted at X IVF Clinic at a time that is convenient to you. The interview would involve talking about attitudes and feelings regarding egg donation for both reproduction and research purposes. You do not need to have actually donated eggs – we are interested to talk to women who have general experience with egg collection or IVF.
This research study is not about asking you to donate oocytes now, or in the future. The researcher will discuss with you any ideas that you may have about appropriate consent and protection procedures for women undertaking egg donation for research. The researcher will also ask you about your perceptions of stem cell research and your understandings of the potential benefits that eggs may provide stem cell research. You do not need to understand the science to help us with our research.

If you are at the beginning of your IVF treatment you may also be asked to be part of a smaller longitudinal (across time) component of this research project. This would involve up to three separate hour-long interviews across a two-year period to understand how your experiences and perceptions of egg donation may change over time. You will be given the choice as to whether you would like to be contacted for a further interview between today’s date and 2011.

The interview(s) is/are confidential and are you will not be identified. The interview will be recorded for research purposes only. Once anonymously transcribed, the recorded interview will be kept as a password protected file on a password access only computer. This computer is kept in a locked office by the chief investigator (Catherine Waldby) for the duration of the research project. Upon completion of the project, the interview files will then be destroyed after seven years.

**The anonymised transcripts of your interview may be used for academic papers, reports and presentations. Any participants in this study will have their identity concealed and your identity of any identifying features will not be disclosed to anyone in publications or presentations.**

Are there any risks?

There are no likely physical or psychological risks as a result of taking part in this study. As we will be discussing your experiences, perceptions and decision-making processes associated with IVF or egg donation there may be a small possibility that you find discussing some personal issues uncomfortable. If you feel any anxiety or distress during the interview a trained counsellor will be made available to you, should you request it.

Are there any benefits?

Your participation in this research provides you with the direct benefit of being able to discuss your experiences with independent researchers. Participating in this research also enables you to contribute to the wider community of women who are using IVF treatment and who are also considering egg donation in the future.

Confidentiality / Privacy

All aspects of this study, including results, will be strictly confidential and only the researchers from the University of Sydney will have access to your personal information. Any publication of the results from this study will use only de-identified information.

Do you have a choice?
Yes. Your participation in this study is entirely voluntary. You can choose the day and time of your interview, and it should be convenient for you and your family. If you choose not to join the study, or you wish to withdraw from it at any time, your medical care now and in the future will not be affected.

**Complaints**

If you have any concerns about the conduct of the study, or your rights as a study participant, you may contact

X Hospital Patient Representative: name removed to protect confidentiality
Telephone No:

**Contact details**

If you have any problems while on the study, please contact

Name removed to protect fertility Centre’s confidentiality
Telephone No:

Fertility Centre Counsellor
Telephone No:

Katherine Carroll (Post-doctoral Research Fellow, University of Sydney)
Telephone No: (BH) 90367994 (AH) 0403 974 013

A/Prof Ian Kerridge (Principal Investigator)
Telephone No: 9036 3405
Appendix F: Cohorts One and Two Consent form (version: July 2009)

The University of Sydney

CONSENT TO PARTICIPATE IN RESEARCH

Study Title: Human Oocytes for Stem Cell Research: Donation and Regulation in Australia

Name of Researchers: Catherine Waldby, Katherine Carroll, Margaret Boulos

I understand that the researcher will conduct this study in a manner conforming with ethical and scientific principles set out by the National Health and Medical Research Council of Australia and the Good Clinical Research Practice Guidelines of the Therapeutic Goods Administration.

I acknowledge that I have read, or have had read to me the Participant Information Sheet relating to this study. I acknowledge that I understand the Participant Information Sheet. I acknowledge that the general purposes, methods, demands and possible risks and inconveniences which may occur to me during the study have been explained to me by __________________________ (“the researcher”) and I, being over the age of 16 years acknowledge that I understand the general purposes, methods, demands and possible risks and inconveniences which may occur during the study.

I acknowledge that I have been given time to consider the information and to seek other advice.

I acknowledge that refusal to take part in this study will not affect the usual treatment of my condition.

I acknowledge that I am volunteering to take part in this study and I may withdraw at any time.

6. I acknowledge that this research has been approved by the Sydney West Area Health Service Human Research Ethics Committee.

7. I acknowledge that I have received a copy of this form and the Participant Information Sheet, which I have signed.

8. I acknowledge that any regulatory authorities may have access to my medical records to monitor the research in which I am agreeing to participate. However, I understand my identity will not be disclosed to anyone else or in publications or presentations.

Before signing, please read ‘IMPORTANT NOTE’ following.

Name of participant ________________________________
Date of Birth ________________________________

Address of participant
Name of parent or person responsible (where applicable) _______________________________________

Address of parent or person responsible (where applicable) _______________________________________

Signature of participant ______________________________________ Date: ______________________

Signature of parent or person responsible (where applicable) ____________________________ Date: ________________

Signature of researcher ______________________________________ Date: ______________________

Signature of witness ______________________________________ Date: ______________________

IMPORTANT NOTE
This consent should only be signed as follows:
Where a participant is over the age of 16 years, then by the participant personally.
Where a participant is between the age of 14 and 16 years, it should be signed by the participant and by a parent or person responsible.
Where a participant is under the age of 14 years, then the parent or person responsible only should sign the consent form.
Where a participant has impaired capacity, intellectual disability or is unconscious, then specific approval for the process for obtaining consent must be sought from the Human Research Ethics Committee.

WITNESS:
I, __________________________________ (name of witness) hereby certify as follows:

1. I was present when ______________________________ (the ‘participant’) appeared to read or had read to him/her a Participant Information Sheet comprising (____ pages); or was told by ____________________________ the participant that he/she had read the Participant Information Sheet (delete as applicable).

I was present when ______________________________ (the ‘researcher’) explained the general purposes, methods, demands and the possible risks and inconveniences of participating in the study to the participant. I asked the participant whether he/she had understood the Participant Information Sheet and understood what he/she had been told and he/she told me that he/she did understand.

I observed the participant sign the consent to participate in research and he/she appeared to me to be signing the document freely and without duress.
The participant showed me a form of identification which satisfied me as to his/her identity.

I am not involved in any way as a researcher in this project.

(Delete this clause if not applicable) I was present when _________________________ (the ‘interpreter’) read the Participant Information Sheet to the participant in the _________________________ (insert appropriate language) language. I certify that when the researcher explained the general purposes, methods, demands and possible risks and inconveniences of participating in the study that what was said by both the researcher and the participant was translated by the interpreter from the English language into the above language and vice versa. When I spoke to the participant, what I said and what the participant said was translated by the interpreter from the English language into the above language and vice versa.

Name of witness _________________________ Relationship to participant _________________________

Address of witness __________________________________________________________

Signature of witness _________________________ Date: _________________________

Name of interpreter (if applicable) _________________________

Signature of Interpreter (if applicable) _________________________ Date: _________________________
STEM CELL RESEARCH

FOCUS GROUP PARTICIPANTS NEEDED!

ARE YOU A WOMAN AGED BETWEEN 18 AND 30?

Researchers at the University of Sydney are holding focus groups with young women to hear their views about egg donation for stem cell research.

We are only interested in your thoughts and feelings about egg donation and you won’t be asked to donate by us now or in the future.

Focus groups will be held on campus during semester. Discussions will last about 2 hours.

You will be reimbursed for your time.

Contact Margaret Boulos: margaret.boulos@sydney.edu.au

The University of Sydney
STEM CELL RESEARCH
FOCUS GROUP PARTICIPANTS NEEDED!

ARE YOU A WOMAN AGED BETWEEN 18 AND 30?

DO YOU HAVE A RELATIVE OR CLOSE FRIEND WITH A CHRONIC HEALTH PROBLEM LIKE DIABETES, PARKINSON’S DISEASE, SPINAL CORD INJURY OR BRAIN DISEASE?

RESEARCHERS AT THE UNIVERSITY OF SYDNEY ARE HOLDING FOCUS GROUPS WITH YOUNG WOMEN TO HEAR THEIR VIEWS ABOUT EGG DONATION FOR STEM CELL RESEARCH.

WE ARE ONLY INTERESTED IN YOUR THOUGHTS AND FEELINGS ABOUT EGG DONATION AND YOU WON’T BE ASKED TO DONATE BY US NOW OR IN THE FUTURE.

FOCUS GROUPS WILL BE HELD ON CAMPUS DURING SEMESTER. DISCUSSIONS WILL LAST ABOUT 2 HOURS.

YOU WILL BE REIMBURSED FOR YOUR TIME.

CONTACT MARGARET BOULOS: margaret.boulos@sydney.edu.au

The University of Sydney
Appendix H: Cohorts Three A and B – *Honi Soit* advertisement for (28 July 2010)

SHARE YOUR VIEWS ABOUT DONATING EGGS FOR STEM CELL RESEARCH

Researchers in the Department of Sociology and Social Policy are holding focus groups with women about their attitudes towards egg donation for stem cell research.

∞ If you are a young woman aged between 18 and 30,
∞ And may also have a relative or close friend with a health problem like diabetes, Parkinson’s disease, spinal cord injury or brain disease, contact Margaret Boulos for further information by email: margaret.boulos@sydney.edu.au.

Staff and students are welcome to participate and you will be reimbursed for your time. Discussions will run for approximately two hours.

Please note that the researchers are only interested in your thoughts and feelings about egg donation and they will not ask you to donate, now or in the future.

The University of Sydney
FOCUS GROUP PARTICIPANT INFORMATION STATEMENT
Research Project

Title: Human Oocytes for Stem Cell Research: Donation and Regulation in Australia

(1) What is the study about?
This study is interested in young women’s attitudes to egg donation for stem cell research.

You have been invited to participate in the study because you are a member of one of the following groups of women:

(iv) You are a woman aged between 18 and 30 years

b) You are a woman aged between 18 and 30 years with a family member or friend diagnosed with a health condition that stem cell research may be able to treat in the future, such as diabetes, Parkinson’s disease or spinal cord injury.

(2) Who is carrying out the study?
The research team is from the University of Sydney. One of the researchers, Margaret Boulos, is undertaking this research to meet the requirements for a PhD degree under the supervision of Associate Professor Catherine Waldby (02 9036 7206) of the School of Social and Political Sciences at the University of Sydney.

(3) What does the study involve?
This study will involve attending one two-hour focus group with approximately 8 to 12 other young women to discuss issues surrounding oocyte (egg) donation for stem cell research.

During the discussion we will also ask you about your attitudes towards organ donation, stem cell research egg donation for research.

You do not need to know a lot about stem cell research. We will provide you with information about this topic.

The focus group will be audio-recorded and written down for analysis.

You will not be asked to donate egg, organs or other tissues by our research team now or at any time in the future nor will your name be given to any organisation which may contact you to donate eggs, organs or other tissues now or in the future.

(4) How much time will the study take?
The focus groups will run for about two hours.

(5) Can I withdraw from the study?
Being in this study is completely voluntary - you are not under any obligation to consent and - if you do consent - you can withdraw at any time without affecting your relationship with the University of Sydney.

While you may leave the focus group at any time if you do not wish to continue, any contributions you have made to the discussion may still be included in data analysis.

(6) Will anyone else know the results?
Everyone in the study will be given false names (pseudonyms) so you will not be able to be identified in any publications or reports. Results will also be published in peer-reviewed academic journals and through presentations at national and international conferences. The results of this research will also contribute to a PhD thesis. Individual participants will not be identifiable in any of these publications.

(7) Confidentiality/Privacy
All aspects of the study, including results, will be strictly confidential and only the researchers will have access to information on participants. A code-name will be applied so that your responses can not be identified. Personal information will be kept separate from research data and kept in lockable storage. The data (transcripts and digital recordings) will be kept for 7 years after the research is completed in a locked filing cabinet to which only Associate Professor Catherine Waldby has key access. After this time, these files will be destroyed.

(8) What are the benefits and risks?
This research does not provide you with any direct benefits. However, participation in this research may enable you to contribute to the development of policies on egg donation for stem cell research.

As recognition for your time, we would like to offer you a payment of $25 cash.
There are no physical or psychological risks associated with this research. However, as you may discuss issues raised by a family member or friend’s illness, there is a small possibility you may experience some distress.

If you find this to be the case, the researchers will ensure that you obtain counselling or other psychological support.

(9) Can I tell other people about the study? 
You can tell others about the study but we ask that you respect the privacy and confidentiality of other participants by not revealing their personal information in the future.

(10) What if I require further information? 
When you have read this information, Margaret Boulos or Katherine Carroll will discuss it with you further and answer any questions you may have. If you would like to know more at any stage, please feel free to contact Associate Professor Catherine Waldby, on 9036 7206.

(11) What if I have a complaint or concerns?

*Any person with concerns or complaints about the conduct of a research study can contact the Deputy Manager, Human Ethics Administration, University of Sydney on (02) 8627 8176 (Telephone); (02) 8627 8177 (Facsimile) or human.ethics@usyd.edu.au (Email).*

This information sheet is for you to keep
Appendix J: Cohorts Three A and B – Demographic Information form
(version: September 2009)

The University of Sydney

Demographic Information

* This information is required

* Postcode of residential address _______________

* Age Range (Please circle)
1. 18-21
2. 22-25
3. 26-30

* Highest Educational Qualification (please circle)
1 Postgraduate Degree Level
2 Graduate Diploma and Graduate Certificate Level
3 Bachelor Degree Level
4 Advanced Diploma and Diploma Level
5 Certificate Level
6 Secondary Education
7 Primary Education
8 Pre-primary Education
9 Other Education

* Your area of study/ occupation______________________________

Parents’/Guardian occupation______________________________

Income (approximate range only)___________________________

Number of Children ____________________________

* Have you ever had treatment for fertility issues? Yes/ No

RESEARCHER USE ONLY:

Participant Code Number ________________
Appendix K: Cohorts Three A and B – Consent Form, including revocation of consent (version: September 2009)

Department of Sociology and Social Policy
School of Social and Political Sciences
Faculty of Arts

ABN 15 211 513 464

CHIEF INVESTIGATOR: ASSOCIATE PROFESSOR CATHERINE WALDBY

Room 167
RC MILLS A26
University of Sydney NSW 2006
AUSTRALIA
Telephone: +61 2 9036 7206
Facsimile: +61 2 9036 9380
Email: catherine.waldby@usyd.edu.au
Web: www.usyd.edu.au/

FOCUS GROUP PARTICIPANT CONSENT FORM

I, .............................................................................................[PRINT NAME], give consent to my participation in the research project

TITLE: Human oöcytes for stem cell research: donation and regulation in Australia

In giving my consent I acknowledge that:

1. The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

2. I have read the Participant Information Statement and have been given the opportunity to discuss the information and my involvement in the project with the researcher/s.

3. I understand that I can withdraw from the study at any time, without affecting my relationship with the researcher(s) or the University of Sydney now or in the future.

4. I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

5. I understand that being in this study is completely voluntary – I am not under any obligation to consent.
6. I understand that I can leave the focus groups at any time if I do not wish to continue, however, my contributions to the audio recording will still be used in the study.

7. I consent to: –
   i) Audio-taping YES NO
   
   iii) Receiving Feedback YES NO
   If you answered YES to the “Receiving Feedback Question (iii)”, please provide your details i.e. mailing address, email address.

Feedback Option

Address: ____________________________________________
________________________________________

Email: ____________________________________________

Signed:

Name:

Date:
Revocation of Consent

Project Title: Human Oocytes for stem cell in research: donation and regulation in Australia.

I wish to advise that I no longer wish to participate in the study Human oocytes for stem cell in research: donation and regulation in Australia.

I understand that any contributions I have made prior to withdrawal from the study may be referred to in analysis and dissemination of findings but my name or any other identifying information will not be included.

I understand that my relationships with the researchers and the University of Sydney will not be adversely affected in any way.

Signed:

Name:

Date:
Appendix L: Cohorts Three A and B – Focus group visual materials

Somatic Cell Nuclear Transfer

Egg + Sperm = Natural Embryo

Egg + nucleus + Somatic cell = SCNT Embryo

SOMATIC CELL NUCLEAR TRANSFER

DONATELIFE

SUMMER BLOOD CHALLENGE

There are some wishes you can’t keep to yourself.

YEAR OF THE BLOOD DONOR

Current blood stocks are dangerously low. Click here to learn how you can make a difference.
Appendix M: Cohorts Three A and B – Focus group schedule including information on embryonic stem cell research and description of oöcyte extraction (version: September 2009)

Focus Group Schedule

Bonding Question – why did you decide to come to focus group?

General discussion of knowledge about stem cell research (groups 1 and 2)

Provide information regarding stem cell research and SCNT to be used as basis for discussion – emphasise that participants are not being tested on their knowledge.

Embryonic Stem Cell Research

Stem cells are cells that generate or regenerate tissue. They are undifferentiated cells that can renew themselves and give rise to one or more specialized cell types with specific functions in the body, for example heat muscle, skin cells or kidney cells. Stem cells exist during early development of the baby in the womb but also occur in the adult body. The most medically useful type of stem cell is ‘pluripotent’, meaning that it has the capacity to develop into almost all of the body’s tissue types. Recent research suggests that it may be possible to produce large numbers of pluripotent stem cells that differentiate on demand, providing an unlimited supply of transplantable tissue. Medical researchers think stem cells may be very useful in treating currently untreatable medical conditions – Parkinson’s disease, Alzheimer’s disease, stroke, spinal cord injuries, and arthritis – and also provide new therapies for common conditions like diabetes. The cells may act as substitutes for organ donation, repairing an existing heart or kidney rather than replacing it. It may also be possible to produce stem cell lines that are genetically the same as the patient, avoiding the problem of organ rejection found in organ transplants.

Human embryos (the name for the earliest period of development of the baby in the womb, between 0-8 weeks) are a key source of pluripotent stem cell lines. Stem cell scientists all over the world are asking women in IVF treatment to donate embryos that they do not want for pregnancy, so that these embryos can be used for research and eventually treatments. This has been controversial because the research prevents the embryo from developing into a child, although in fact most embryos not used for IVF treatment are discarded. A particular type of Stem Cell research, called Somatic Cell Nuclear Transfer, needs human eggs as well as embryos. This is the special area of research aimed at producing compatible organs for patients.

Embryonic stem cell research is only experimental at this stage. So far, only one clinical trial has been conducted, to test embryonic stem cells as a treatment for people with spinal cord injury. Other clinical trials are planned.
Egg Donation (description based on IVF Australia Patient information for reproductive egg donors)

Before becoming an egg donor a woman is required to:

- undergo a medical assessment
- undertake psychosocial counselling to discuss the social and psychological aspects of becoming an egg donor. If they are married or in a de-facto relationship, their spouse is also required to attend.
- undergo brief genetic counselling by telephone
- undergo blood tests to ensure (as far as possible) that they are free of any serious infectious diseases or genetic disorder that may be passed on to any child conceived from her eggs.
- complete the consent forms and a confidential donor questionnaire. If the donor is married or in a de-facto relationship, their spouse is also required to give their consent to donation.

Donation Process

- Egg donors undergo an IVF cycle. Hormonal medications are given to induce the ovaries to produce and mature multiple eggs so that a good number of embryos can be created and the recipient has the best chance of a pregnancy.
- The medication is given for approximately 12 days by subcutaneous injection, which is an injection into the skin, not a vein. Donors and/or their partner are taught how to give these simple injections so that the time required at the clinic is kept to a minimum.
- Blood tests and ultrasound scans will determine when the eggs are mature enough to be collected. On average, this is done 12 to 14 days after starting the injections.
- The egg collection is done in day surgery under light sedation and the donor can choose to be awake or asleep during the procedure. The procedure takes approximately half an hour and, on waking, there aren't the usual groggy side effects of a general anaesthetic. Nausea and vomiting is unusual and you are usually able to go home around lunchtime.
- After egg recovery, it is not unusual to feel quite tired and slightly bloated for several days, due to the combined effects of the drugs and the anaesthetic. Generally, you are able to return to work or normal activities the day after egg collection.
- Your menstrual period is expected approximately 8-12 days after the egg collection. Periods may be more irregular for 1 to 2 months after the IVF cycle but will return to normal.

Short term side effects of the drugs

The reaction to the drugs varies for each individual but common side effects include tiredness, abdominal distension, tender ovaries and breasts, vagueness and mood swings. In approximately 5% of women, in the second half of the cycle (after the eggs have been collected), the symptoms can become more severe and medical treatment is required. This condition is called "ovarian hyperstimulation syndrome" (OHSS).

Future Fertility

Provided there are no complications during the egg donation cycle, there should be no effect on the future fertility of the donor. There is, however, a very rare complication where infection can occur following egg collection, and reduced future fertility may be a consequence if an infection occurs.

Long term side effects of the drugs

Currently studies don't indicate any long-term increased risk of breast or ovarian cancer.

Having established some basic knowledge about the procedure of oocyte extraction and stem cell research, the discussion will now turn to talking
about perceptions of the issues.

Probes

What is your understanding of stem cell research?
Where did you hear about it?
Was it different to this information we’ve given you?

Have you heard of SCNT?
What is your understanding of SCNT?

Views and perceptions of bodily tissues (groups 1 and 2)
Provide examples of advertisements/leaflets for organ, blood and egg donation – through projected images or shared enlarged copies.

Probes

Who has thought about signing the organ donor registry?
Donating blood?
Donating eggs for stem cell research?
For reproductive purposes?

Is there any difference in these donations? What kind of differences?
Does this effect whether you would be prepared to donate? Why /why not?

Views and feelings about personal fertility (groups 1 and 2)

Who has thought about having children and what is considered an ideal age to do so? Why?
Do you think about issues around fertility? What issues tend to come up? Have you had any experiences with women you know that have made you think differently?
Do you think feelings about your fertility will change much when you’re older, say at 35?

Given what’s been said about fertility, how does that make you feel about egg donation for stem cell research?

Issues surrounding relational responsibilities (group 2)

Discussion of responsibilities toward family member/friend
Are you/diagnosed person involved in contributing to scientific research? How so?
Have you ever thought about participating in stem cell research by donating tissues, embryos, eggs?

Given that there is a general egg donor shortage, does that change things for you?

Scenarios (groups 1 and 2)

The purpose of the scenarios is to present hypothetical situations (drawn from real life as much as possible) to further understanding of the circumstances in which egg extraction can happen. While emphasising that there are no right or wrong answers, the point is to facilitate discussion.

<table>
<thead>
<tr>
<th>Scenarios</th>
<th>Probes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kelly is a 22 year old woman living in San Francisco. She has graduated</td>
<td>How would you describe Kelly’s situation compared to Nadia’s?</td>
</tr>
<tr>
<td>from college with a Design degree and now works as an Assistant in</td>
<td>What difference does it make that she’s paid much more than Nadia?</td>
</tr>
<tr>
<td>an architecture company.</td>
<td></td>
</tr>
<tr>
<td>Kelly has a significant student loan debt from attending university.</td>
<td></td>
</tr>
<tr>
<td>She lives independently from her parents in a share house. She doesn’t</td>
<td></td>
</tr>
<tr>
<td>have any children.</td>
<td></td>
</tr>
<tr>
<td>Kelly has blonde hair and blue eyes and because she is a</td>
<td></td>
</tr>
</tbody>
</table>
A college graduate with good athletic ability, she considers signing up to an egg donor agency that will organise the extraction of her eggs and give them to IVF patients. She will be paid approximately $80,000 for a cycle of egg extraction.

Advertisements appearing in Sydney’s Child Classifieds under the Egg Donors section

A baby from U to ME
At the age where I am still blessed of fertility, I am wasting time for a marriage to work out with the wrong man. I finally woke up, moved on and met a husband that I never dared to dream. A husband that truly loves me and we want a child of our own. The saddest part, I am not that so blessed of fertility anymore. So please help us, if you are under the age of 28 and have children of your own.

A Child
I’m hoping to meet an exceptionally kind woman (under 35 years) who would help me create a much wanted child. All expenses paid. Please call Theresa.

In Australia, it’s illegal to offer money for eggs for reproductive purposes (i.e. making a baby); what do you think of that in comparison to the U.S. and Romania?

If it were legal to sell eggs for reproductive purposes, would you consider doing so? Why/why not?

Under what circumstances do you think you it’s okay to provide eggs for reproductive purposes?

Would you prefer to donate to someone you know or anonymously?

Theresa is a 30 year old child care worker who has heard a lot about stem cell research on the news on TV and the internet. Theresa reads a newspaper article where scientists talk about needing women’s eggs to be able to use in experiments to grow stem cell lines for therapeutic research. It sounds like that stem cell research could produce cures for lots of different conditions like diabetes, heart disease and spinal cord injury. She contacts the Research Centre where the scientists work to volunteer her eggs. She is given some money to cover her travel expenses and the time off work.

The researchers are part of a company that is trying to develop therapies for diabetes. They will try and patent the therapy and charge hospitals or governments to use it with patients. Should Theresa have been made aware of this? Does that change the situation for you? Would you be more inclined to donate to a non-profit organisation rather than a for-profit company?

This is an advertisement from research company in U.S.A.

Research team seeks women aged 21 to 35 with at least one child to donate eggs for stem cell research; compensation for time, travel and child care expenses provided.

In Australia, it’s illegal to offer money for eggs for research purposes, what do you think of that?

If it were legal to sell eggs for research purposes, would you consider it? Why/why not?

Under what circumstances do you think you may sell eggs for research purposes?

So Yeon lives in South Korea. She is in her final year of a Medical Science degree and works part time on an embryonic stem cell research project at a university research department in Seoul. She is hoping to continue her research career when she has graduated.

At team meetings, senior researchers often complain that there is a significant egg shortage because IVF patients are not sharing them. The scientists say that they can’t do the

Do you think this is a situation of voluntary egg donation for stem cell research? Why/Why not?
kind of research they would like without a regular supply of eggs. These researchers are often men. Because of this, So Yeon is thinking about donating her eggs to her research team, like other women at the centre even though they have not been directly asked. So Yeon doesn’t have any children but she has some idea that long term effects on fertility from egg extraction are unknown.

| Leslie is 22 and her older sister, Melanie (26) suffers from a permanent spinal cord injury. Melanie and Leslie’s family are very much engaged in learning about what can be done for spinal cord injury and keep up to date with research findings and new possibilities. Leslie thinks about donating her eggs to a research team in Brisbane who are working on curing spinal cord injury. | What do you think of scientists engaged in stem cell research focusing their attention on people whose family members have a diagnosed condition? Is this fair? Why/Why not? Would Leslie’s relationship to Melanie be a factor in this situation? |

Wrap up conversation and thank participants.
### Appendix N: Selected demographic information for cohorts one, two and three (a & b)

<table>
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<tr>
<th>Participant ID</th>
<th>Pseudonym</th>
<th>Age Range</th>
<th>Highest Educational Qualification</th>
<th>No. Of Children</th>
<th>Continue IVF?</th>
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<th>Occupation*</th>
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Appendix O: Publications I have authored or contributed to arising from the common dataset


This chapter uses data regarding reproductive oöcytes reported in this thesis. It discusses the notion of reciprocity and the lack of inter-personal anonymity that characterises reproductive oöcyte donation in Australia in comparison with Europe and the US.


This article examines the issue of payment from the perspective of the entire sample in this dataset. I contributed information regarding the recruitment of focus group participants and its methodological rationale. I also contributed parts of my thesis in relation to the distinctions some participants made about ‘payment’ and ‘compensation’.


This early conference presentation discussed data from the reproductive oöcyte donor cohort in this dataset. Much of it is the subsequent basis for the chapter regarding donors and their ambivalent or paradoxical relationships to the families they are helping to create; here I discuss in relation to predominantly feminist literature related to assisted reproductive technologies and donors.
Appendix P: Publications List using common dataset (submitted to ARC)

Books:

Journal articles:

Book Chapters

Journal articles in preparation or under review:
- Carroll, K., and C. Waldby. 'Informed consent and fresh egg-donation for stem cell research: the case for incorporating embodied knowledge into ethical decision-making' submitted to Journal of Bioethical Inquiry.
Journal article—non-refereed article:

Conference Proceedings:
- Waldby, C. (2011). ‘Deliberation and preservation: the role of tissue banking in the decision to donate eggs and embryos for stem cell research’, Bringing Regenerative Medicine to the Clinic: Trials and Tribulations in Europe and Beyond, University of the Basque Country, Bilbao, Spain, April 18-19 2011.


