



# **Egg donation and having a baby in Australia**

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the degree of

**Doctor of Philosophy (Public Health)**

under the supervision of

Distinguished Professor Elizabeth Sullivan  
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## **CERTIFICATE OF ORIGINAL AUTHORSHIP**

I, Rosemarie Hogan declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy (Public Health), in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

This research is supported by the Australian Government Research Training Program.

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## **FORMAT OF THESIS**

This is a thesis by compilation. It is structured as a single manuscript and includes two published manuscripts and a further two manuscripts under peer review for consideration for publication. The manuscripts are included verbatim as accepted or submitted for publication. Copyright permission to reproduce the first two manuscripts has been obtained. The third manuscript has been peer reviewed and final revisions are being completed. The fourth manuscript is under review.

## LIST OF PUBLICATIONS ARISING FROM THIS WORK

### Peer-Reviewed Manuscripts Published (Chapters 4, 5 and 6)

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## **CONTRIBUTION OF AUTHORS**

**Rosemarie Hogan** is the author of this body of work. With the guidance and advice of all supervisors, she developed the research concepts and the design of the four studies undertaken during this candidature. Rosemarie is the primary author of all the publications and manuscripts included in this thesis.

**Distinguished Professor Elizabeth Sullivan** was the principle supervisor and contributed to the conception, design, writing, editing and proof reading of all manuscripts arising from the research findings.

**Associate Professor Alex Wang** was a co-supervisor and contributed to the conception, design, writing, editing and proof reading of all manuscripts arising from the research findings.

**Dr Jane Frawley** was a co-supervisor and contributed to the writing, editing and proof reading of the fourth manuscript arising from the research findings.

**Dr Karin Hammarberg** contributed to the editing and proof reading of all manuscripts arising from the research findings.

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## **ABBREVIATIONS**

AHR	adjusted hazard ratio
ANZARD	Australian and New Zealand Assisted Reproduction Database
AOR	adjusted odds ratio
ARR	adjusted relative risk
ART	assisted reproductive technology
BL	blastocyst
CI	confidence interval
CL	cleavage stage embryo
DET	double embryo transfer
FSA	Fertility Society of Australia
HR	hazard ratio
ICMART	International Committee Monitoring Assisted Reproductive Technologies
ICSI	intracytoplasmic sperm injection
IVF	in vitro fertilization
LBR	live birth rate
OR	odds ratio
RR	relative risk
RTAC	Reproductive Technology Accreditation Committee
SART	Society for Assisted Reproductive Technology
SD	standard deviation
SET	single embryo transfer
VARTA	Victorian Assisted Reproductive Treatment Authority

## **ABSTRACT**

**Background:** Egg donation is an essential component of assisted reproductive technology (ART) treatment. Studies indicate that when a woman or couple inquire about egg donation, they want to know if the treatment will result in a healthy baby. As yet, there is limited evidence comparing women receiving ART treatment with their own eggs, to women of a similar age using donor eggs. Also, there is little research on how donors and recipients experience the process of egg donation in Australia.

**Methods:** Mixed-methods research was conducted. Two population-based cohort studies investigated the impact of age on the cumulative live birth rate (CLBR) in egg donation cycles. Semi-structured interviews and thematic analysis were conducted with egg donors and recipients to examine the barriers and enablers for altruistic egg donation.

**Results:** Overall, the findings demonstrate that women in their 40s using donor eggs were five times more likely to have a baby than women using their own eggs. The evidence confirms that the age of the egg donor is critical. Women using eggs from donors under 35 years had a statistically significantly higher CLBR when compared with recipients using eggs from donors over 35 years. However, most women in their 40s undergoing ART used their own eggs despite the minimal chance of having a baby as a result. The qualitative findings report that women experience difficulties finding a donor while egg donors described

feeling undervalued. The egg donors wanted clinics to provide more person-centred care and emotional support.

**Conclusions:** The results of this study are timely and highly relevant to fertility clinics where egg donation is offered and to inform public health policy. This research is the first to evaluate the CLBR in women who have received donated eggs. The findings can be used when counselling women over 40 about their ART treatment options. The results lend support for the requirement to have an upper age limit for egg donors in Australia. Steps to improve women's experience of egg donation have been identified. Public health strategies such as national education campaigns on egg donation and the establishment of a public egg bank are recommended to increase donor recruitment and retention. Critically, better clinic follow-up care, including post-donation counselling, would significantly improve donors' experience of altruistic egg donation, which in turn may lead to egg donors being willing to donate more than once.

# **CHAPTER 1: INTRODUCTION**

## **1.1 BACKGROUND**

### ***Infertility***

One in six couples in Australia experience infertility (Australian Bureau of Statistics 2019). Infertility is defined as a disease characterized by the failure to establish a clinical pregnancy after 12 months of regular, unprotected sexual intercourse (Zegers-Hochschild et al. 2017). The cause of infertility may be unexplained or may relate to either the woman or her male partner, or both (Newman et al. 2019). While many women experiencing difficulty conceiving will be treated with medications, others will require assisted reproductive technology (ART) treatment.

### ***Assisted reproductive technology***

Over the last four decades, ART has evolved into a suite of mainstream medical interventions that have resulted in the birth of more than six million children worldwide (Adamson et al. 2018). ART treatment refers to all treatments or procedures that include the in vitro handling of both human eggs and sperm, or embryos, to establish a pregnancy (Zegers-Hochschild et al. 2017). This includes, but is not limited to, in vitro fertilisation (IVF) and embryo transfer, gamete and embryo cryopreservation, egg and embryo donation, and gestational surrogacy (Zegers-Hochschild et al. 2017).



## ***Assisted reproductive technology in Australia***

There is broad public acceptance of ART to treat infertility in Australia and utilisation rates are higher than in most other developed countries (Hammarberg, Johnson & Petrillo 2011). The most recent national estimates indicate that 4.3% of all women who gave birth in Australia in 2017 received some form of ART treatment (Australian Institute of Health and Welfare (AIHW) 2019). There are over 80 accredited fertility clinics offering ART treatments in Australia (Newman et al. 2019), the majority of which are privately operated.

Currently, there is no Commonwealth legislation that directly regulates ART in Australia. Instead, it is regulated by individual state and territory laws; the Federal government's National Health and Medical Research Council's (NHMRC) Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research (2017); and the Fertility Society of Australia's Reproductive Technology Accreditation Committee's (RTAC) Code of Practice (2017).

Australian Capital Territory	<b>No legislation directly regulates ART</b>
New South Wales	<i>Assisted Reproductive Technology Act 2007 &amp; Assisted Reproductive Technology Regulations 2014</i>
Northern Territory	No legislation directly regulates ART. Guided by South Australia.
Queensland	No legislation directly regulates ART
South Australia	<i>Assisted Reproductive Treatment Act 1988 &amp; Assisted Reproductive Treatment Regulations 2010</i>
Tasmania	No legislation directly regulates ART
Victoria	<i>Assisted Reproductive Treatment Act 2008; Assisted Reproductive Treatment Regulations 2009 &amp; Assisted Reproductive Treatment Amendment Act 2016</i>
Western Australia	<i>Human Reproductive Technology Act 1991 &amp; Human Reproductive Technology Act Directions 2004</i>

Source: NHMRC 2017

**Figure 1: Regulation of ART in Australian states and territories**

The Fertility Society of Australia (FSA) sets minimum standards for fertility clinics providing ART services and encourage continuous improvement in the quality of care provided. They conduct annual accreditation inspections of all clinics providing ART to ensure the clinics are adhering to the NHMRC Ethical Guidelines (2017) and the FSA Code of Practice (2015). The RTAC Code of Practice (2017) requires all ART clinics in Australia and New Zealand to provide treatment and pregnancy outcome data which are compiled by the AIHW National Perinatal Statistics Unit (AIHW NPSU) and published in an annual report (Newman et al. 2019).

In Australia, the financial cost of ART to couples is lower than in most other developed countries due to generous Medicare and the Pharmaceutical Benefit Schemes (PBS) rebates (Chambers et al. 2009). The out of pocket costs of ART will vary depending on the specific needs of the woman or couple but on average 50% to 60% of IVF costs can be covered by Medicare, with no cap on the number of cycles (<https://tinyurl.com/yb6rudx9>). Private health insurance may contribute a further rebate on ART costs especially with any hospital day surgery fees which are not covered by Medicare (<https://tinyurl.com/yajo9bk3>).

### ***Age related infertility***

In recent years, there has been a shift towards later childbearing with the birth rates for women aged 40 years and above at 12.9 births per 1,000 women in 2018, compared to 4.4 births in 1980 (Australian Bureau of Statistics 2019). Reasons cited for this trend include improved access to reliable contraception, women's greater participation in education, developing a career, and the erroneous belief that ART can extend the reproductive lifespan (Schmidt et al

2012; te Velde et al. 2012; Mills et al. 2011). The lack of a partner willing to commit to parenthood has been cited as another reason for delayed childbearing (Hammarberg et al. 2017). Also, an increasing number of divorces and second marriages have contributed to more women in their forties desiring children (Soderstrom-Anttila, Foudila & Hovatta 2001). Simultaneously, there has been an increase in the use of ART treatments by women 40 years and older. In Australia and New Zealand, almost a quarter (23.4%) of all ART treatment cycles in 2017 were undertaken by women aged 40 years and over compared to 16.1% in 2006 (Newman et al. 2019).

### ***Egg donation***

Women with fertility problems such as age-related infertility, recurrent pregnancy loss, hereditary disorders or premature menopause may be recommended to have ART treatment with donor eggs to increase their chance of having a baby (Blyth et al. 2011; Keenan, Gissler & Finger 2012). The donation of eggs is a technique that appeared in the early 1980s (Trounson et al. 1983) and has been made feasible as a result of IVF. There are two parties involved: the egg donor and the woman trying to achieve a pregnancy, the recipient.

### ***Own eggs or donor eggs***

Older women contemplating ART treatment face the reproductive dilemma of choosing between using their own (autologous) or donor eggs. Couples' motivations for using autologous eggs include a strong desire to have a biologically related child (Daniluk, Koert & Cheung 2012). However, in women 40 years and older, the risk of aneuploidy in their own eggs may exceed 60%, thereby significantly contributing to low embryo implantation rates and low

chances of a live birth (Meldrum 2013). To reduce the risk of aneuploidy and increase the likelihood of a live birth, women may be recommended to use eggs donated by a younger woman, ideally less than 35 years (Savasi et al. 2016).

### ***Shortage of donor eggs***

Since the birth of the world's first baby from a donated egg was reported in 1984 there has been a steady growth in the demand for egg donors globally (Lutjen et al. 1984). The most recent national estimates indicate that in Australia in 2017 there were 700 births resulting from donated eggs (Newman et al. 2019). Women in their late thirties and forties, with age related infertility, have contributed to the accelerated demand for donor eggs (Newman et al. 2019; Human Fertility and Embryology Authority (HFEA) 2019; Centers for Disease Control and Prevention (CDC) 2019). However, in Australia, the supply of donated eggs does not meet the demand as the number of women donating their eggs remains low. There are some reasons cited for this in the literature including the fact that egg donation is an invasive procedure for the donor which involves ovarian hormonal stimulation and transvaginal egg retrieval under mild general anaesthesia (Bracewell-Milnes et al. 2016). Kalfoglou and Gittelsohn (2000) and Yee, Hitkari & Greenblatt (2007) asserted that donors in their studies were willing to undergo egg donation only for a known recipient such as a relative or a close friend.

### ***Recruitment of egg donors***

Women in Australia predominantly receive a donated egg from someone known to them such as a family member or a friend (Hammarberg, Johnson & Petrillo 2011). Other women may find a local donor through online forums such as 'Egg Donation Australia' and 'Egg Donor Angels', or advertising in parenting

magazines such as 'Sydney's Child'. Advertising online is subject to legal restrictions. For example, in the state of Victoria, approval must be obtained from the Minister for Health before advertising (Victorian Assisted Reproductive Treatment Authority (VARTA) 2020). Because of the critical shortage of donor eggs in Australia, some clinics are now importing donor eggs from overseas. This is permitted if the supplier complies with Australian national and state laws. The World Egg Bank in the United States (US) for instance complies with the requirement for non-anonymous and non-commercial egg donation and export eggs to Australia (VARTA 2020). Due to the shortage of women who are willing to donate eggs, using a family member or a friend over 35 years of age as an egg donor may be the only alternative for some couples (Hammarberg, Johnson & Petrillio 2011).

### ***Age of the egg donor***

In Australia, where only altruistic egg donation is permitted and commercial donation (donation with monetary compensation other than "out of pocket" expenses) is prohibited, 36% of egg donors are 35 years of age or older (Newman et al. 2019). Ideally egg donors should be women in their 20's and early 30s, who are in good health and free from heritable conditions (Savasi et al. 2016; van Dorp et al. 2014), as women with younger donors have higher live birth rates than those with older donors (Wang, Farquhar & Sullivan 2012). In Australia, it is recommended that clinics do not use eggs provided by 'older' donors, though no upper age limit is specified (National Health and Medical Research Council 2017). However, because of the shortage of donors, most recipients use a willing friend or relative as their donor and ART clinics accept them irrespective of their age (Commonwealth of Australia 2017).

## ***Egg donation and success rates***

Whether using their own or donor eggs, the chance of having a baby is of fundamental interest to people who use ART. However, studies in Australia show that the quality of information on ART clinic websites, about the chance of having a baby as a result of ART, is poor (Wilkinson et al. 2019; Wilkinson, Roberts & Vail 2017). There are several different ways of presenting ART success rates with different authorities arguing for different approaches (Maheshwari, McLernon & Bhattacharya 2015; Abdalla, Bhattacharya & Khalaf 2010). ART success rates following egg donation are usually presented as 'outcome per embryo transfer' according to the donor's age (McLernon et al. 2016). However, Malizia and colleagues (2009) maintain that this statistic has limited value because it does not account for the additional chance of having a baby offered by the frozen embryos, which resulted from the same stimulated cycle. Instead, they advocate for the more comprehensive estimate of the 'cumulative live birth rate (CLBR)'. The CLBR is a more meaningful way of presenting the chance of having a baby for both patients and clinicians because it includes the added opportunity offered by all fresh and frozen embryos following one stimulated cycle (Chambers et al. 2017).

## ***Motivations and experiences of egg donors and recipients***

In Australia, the number of women donating their eggs remains low and the supply of donated eggs does not meet the demand. Incentives to increase the number of egg donors in Australia such as the introduction of financial compensation, is currently being debated (Gorton 2019). Previous studies have investigated the motivations of altruistic egg donors. In the UK, Byrd, Sidebotham,

& Lieberman (2002) conducted a survey of altruistic egg donors (n=113) and reported that the desire to help childless couples was the overwhelming motivation to donate. Pennings and colleagues (2014) surveyed egg donors (n=1,423) in eleven European countries (Belgium, Czech Republic, Finland, France, Greece, Poland, Portugal, Russia, Spain, Ukraine and the UK). In this study half of the donors were altruistic and donated their eggs to help others have a family (Pennings et al. 2014). Other motivating factors for altruistic egg donation cited in the literature include previous experience of fertility problems among friends or family (Bakker et al., 2017; Bracewell-Milnes et al. 2016; Svanberg et al. 2012; Purewal & van den Akker 2009). One qualitative study of 15 altruistic egg donors in Canada, who had donated eggs to a friend or a family member, investigated their relationship with the recipient. The authors concluded that the donors' positive relationship with their known recipient, played an influential role in their motivation to donate, as they would not otherwise have considered donating eggs (Yee, Blyth, & Tsang 2011). Little is known about the motivations and experiences of Australian egg donors. A better understanding of donors' experiences is important to inform clinics' recruitment strategies and provision of care.

For egg recipients, the decision to use donor eggs is complex and in Australia, finding a donor can be difficult. Individuals and couples pursuing egg donation often confront grief and disappointment about the loss associated with the realization that they cannot give birth to genetically related offspring (Applegarth et al. 2016). At each stage of the donation process the donor and recipient woman or couple need information and support (Martin et al. 2019). In Australia, the NHMRC (2017) recommends that parents disclose the use of donor gametes to

their children. The nature of future interactions between the child, the recipient and the donor should also be discussed in counselling prior to undergoing egg donation (Pasch 2018). Research examining the mother–infant relationship in egg donation families show that they are characterized by positive parenting and well-adjusted children (Imrie, Jadva & Golombok 2019). However, there is a paucity of studies exclusively examining the experience of donor egg recipients in Australia.

## **1.2 RATIONALE OF THESIS**

Egg donation brings with it medical, psychosocial, ethical, legal and monetary considerations for both the donors and recipients. In Australia in recent years, there has been a shift towards later childbearing and simultaneously, there has been an increase in the use of ART treatments by women 40 years and older. Older women contemplating ART treatment face the reproductive dilemma of choosing between using their own (autologous) or donor eggs. The chance of having a baby is high with donor eggs received from a woman who is aged 35 years or less but the decision to use donor eggs is complex and in Australia, finding a donor can be difficult. In Australia ART treatments including egg donation have been facing public scrutiny over the issue of success rates and the cost to the tax payer in Medicare rebates (Gorton 2019; ABC News 2015). For example, cost saving proposals suggest that Medicare should apply a limit on the number of ART cycles and enforce an upper age limit for egg donors (Chambers et al. 2012). It is argued that the CLBR should be used when counselling clients on the chances of egg donation success. The CLBR is more meaningful for egg recipients because it accounts for the potential need for multiple cycles to achieve



a live birth by using the fresh and frozen embryos from one stimulated cycle (Maheshwari, McLernon & Bhattacharya 2015).

Central to the delivery of an effective clinical service, is an understanding of the client's experience. Currently, there is a lack of evidence-based literature on the motivations and experiences of altruistic egg donors and recipients. There are inadequacies and missed opportunities to enhance clinicians' understandings in this area, develop patient-centred services and facilitate strategies to improve the experiences of women in egg donation programs and enhance the recruitment of egg donors in Australia.

### **1.3 THESIS STRUCTURE**

This thesis is submitted as a thesis by compilation and includes manuscripts that have been published or submitted for publication (Table 1). Therefore, some chapters are presented in the format in which the manuscripts were published. Due to the individual journal requirements, in-text citation and reference styles vary in the chapters containing publications. The thesis is structured into a total of eight chapters, including this chapter, *Introduction* (**Chapter 1**).

**Chapter 2:** In chapter two, a thorough review of the literature underpinning the study is presented and provides background information regarding the history, types and utilisation of ART treatments. It includes a detailed discussion of altruistic egg donation in Australia currently, including the relevant legislation.

**Chapter 3:** This chapter outlines the research design and methods used in this thesis.

**Chapter 4:** Study 1, *Having a baby in your 40s with ART: the reproductive dilemma of autologous versus donor oocytes*, investigated the cumulative live birth rate for women aged 40 years and above undergoing ART in Victoria, Australia, using their own eggs compared to women of similar age using donor eggs.

**Chapter 5:** Study 2, *Oocyte donor age has a significant impact on oocyte recipients' cumulative live-birth rate: a population-based cohort study*, investigated the effect of the egg donor's and recipient's age on the CLBR in egg donation cycles of women undergoing ART in Victoria, Australia

**Chapter 6:** Study 3, *'Battery hens' or 'nuggets of gold': a qualitative study on the barriers and enablers for altruistic egg donation*, reported on the experiences of altruistic egg donors in Australia.

**Chapter 7:** Study 4, *Recipients' experience of altruistic egg donation in Australia*, reported the findings of women's experiences of receiving altruistically donated eggs.

**Chapter 8:** *Discussion and conclusions* summarises the findings from the four studies and describes how the findings meet the overall objectives of the thesis. The thesis concludes with suggested strategies to improve the experiences of women in egg donation programs and the recruitment of egg donors in Australia. Proposed directions for further research on egg donation is also discussed.

## **1.4 RESEARCHER'S POSITION AND MOTIVATION**

Based on my experience as a registered midwife and given the growing use of egg donation as a family-building option, I recognised the importance of needing

to understand more about how women navigate, understand and experience altruistic egg donation in Australia. I also identified the need to investigate how a woman's chances of having a baby through egg donation can be optimised. As a researcher, I have positioned myself as an observer, rather than a clinician. The academic process and this thesis have provided opportunity to take part in a scientific, peer reviewed international conversation. My aim is to inform the care of women and couples who have ART with donated eggs and contribute to the development of strategies to increase egg donor recruitment.

## **1.5 CONCLUSION**

This investigation into the factors for success in egg donation programs in Australia is timely and highly relevant to fertility clinics where egg donation is offered. This research will be the first to evaluate the CLBR in women who have receive donated eggs. It is anticipated that the findings, generated through a mixed methods approach, will apply to women, clinicians and policy makers and the knowledge gained can be transferred into a change in practice to improve women's experience of egg donation. The dissemination of the findings should also raise awareness of this public health concern and inform public health policy.

Table 1: Thesis structure and publications

Details		Title, authorship and reference
Chapter 1		Introduction
Chapter 2		Literature review
Chapter 3		Research design, methodology and methods
Chapter 4	Paper 1	<b>Having a baby in your 40s with ART: the reproductive dilemma of autologous versus donor oocytes.</b>
	Authors:	Hogan, R.G., Wang, A.Y., Li, Z., Hammarberg, K. Johnson, L., Mol, B.W. & Sullivan, E.A.
	Journal:	<i>Australian and New Zealand Journal of Obstetrics and Gynaecology</i>
	Date of Publication	18 May 2020; <a href="https://doi.org/10.1111/ajo.13179">https://doi.org/10.1111/ajo.13179</a>
Chapter 5	Paper 2	<b>Oocyte donor age has a significant impact on oocyte recipients' cumulative live birth rate: a population-based cohort study.</b>
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Chapter 6	Paper 3	<b>'Battery hens' or 'nuggets of gold': a qualitative study on the barriers and enablers for altruistic egg donation</b>
	Authors:	Hogan, R.G., Hammarberg, K., Wang, A.Y. & Sullivan, E.A.
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Chapter 7	Paper 4	<b><i>Recipients' experiences of altruistic egg donation in Australia</i></b>
	Authors:	Hogan, R.G., Hammarberg, K., Frawley, J., Wang, A.Y. & Sullivan, E.A.
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	Date of Submitted	20 May 2020
Chapter 8		Discussion, recommendations and conclusion

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## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

A woman's reproductive lifespan, previously shaped by nature, can now be artificially extended through the use of assisted reproductive technologies (ART) such as cryopreserved oocytes (eggs), in vitro fertilisation (IVF) and egg donation (Sauer 2013). The positive outcomes of ART are evident in increased live birth rates in an otherwise infertile population (Newman et al. 2019). However, infertility remains an important public health issue as it brings with it medical, psychosocial, ethical, legal and monetary considerations (Klitzman 2017).

#### **2.1.1 Infertility and Subfertility**

Infertility affects approximately 15% of women of reproductive age at any given time (World Health Organization 2010). The Oxford English Dictionary (2017) defines 'infertile' as 'not able to have babies or produce young', which implies a state of sterility rather than 'difficulty in conceiving' or subfertility. The common medical definition of 'infertility' is the failure to achieve a clinical pregnancy after 12 or more months of regular unprotected sexual intercourse (Zegers-Hochschild et al. 2017). Infertile couples are recognised as those who do not achieve a pregnancy within two years, and they include the sterile members of the population, for whom there is no possibility of natural pregnancy, and the remainder who are subfertile (Sauer 2013). The term sterile may refer to either the male or the female, whereas the term subfertile refers to the couple (European Society of Human Reproduction and Embryology (ESHRE) Capri Workshop Group 2015). Social infertility is defined as 'the inability to have children because of social factors, rather than medical reasons, for example

same-sex relationships, single individuals' (National Health and Medical Research Council (NHMRC) 2017).

Infertility is the source of much personal suffering to millions around the world and is increasingly being overcome through advancements in fertility treatment, in particular, ART (Klitzman 2017). The most recent national estimates indicate that 4.7% of all women who gave birth in Australia in 2017 received some form of ART treatment (Australian Institute of Health and Welfare (AIHW) 2019). ART has evolved over the last four decades into a suite of mainstream medical interventions that have resulted in the birth of more than six million children worldwide (Adamson et al. 2018).

## **2.2 ASSISTED REPRODUCTIVE TECHNOLOGY (ART)**

ART offers those who are affected by infertility an opportunity to have children. In Australia, most women regardless of their sexual orientation or marital status have access to ART services including egg donation (Human Rights Law Centre 2017).

ART is defined as all treatments or procedures that include the in vitro handling of both human eggs and sperm, or embryos, to establish a pregnancy (Zegers-Hochschild et al. 2017). This includes, but is not limited to, in vitro fertilisation and embryo transfer, intrafallopian gamete transfer, zygote intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, egg and embryo donation, and gestational surrogacy.

Australia has one of the highest utilisation rates for ART in the world largely due to the affordability of treatment (Chambers et al. 2012). Latest estimates indicate

that 14.8 cycles per 1,000 women of reproductive age in 2017 are undertaken in Australia (Newman et al. 2019) compared with 3.0 cycles in 2015 in the United States (Centers for Disease Control and Prevention (CDC) 2017) and 5.1 cycles in 2017 in the United Kingdom (Human Fertility and Embryology Authority 2019). In Australian fertility clinics in 2017, 13,944 babies were born following ART treatment. Eight in ten babies (80.2%) were full-term singletons of normal birthweight. The majority of women being treated for infertility with ART use their own eggs (95%), with 25.1% of autologous cycles undertaken by women aged 40 or older (Newman et al. 2019).

Treatments with ART are physically demanding, at least for the woman, and accompanied by successive feelings of hope and despair, which is exacerbated when several treatment cycles are undertaken. Psychological distress is compounded by uncertainty about treatment success and the low chance of a live birth (Rowe, Fisher & Hammarberg 2017).

### **2.2.1 Cost Implications of ART**

Globally, ART is not universally available and, if available, the cost is prohibitive to most couples in resource-constrained countries. In Australia since 1990, ART treatments are partially subsidised through Medicare, the Australian public health insurance scheme. Associated drug therapies are funded under the Pharmaceutical Benefits Scheme (PBS) (Australian Government Department of Health 2020). Medicare allows access to out-of-hospital medical care and treatment in public hospitals. There is a cap of 80% for reimbursement of services once an annual threshold expenditure is met. In addition to Medicare, private health insurance schemes can be purchased to reduce the financial cost of private hospital care. Eligibility for Medicare rebates is restricted to people who

have a diagnosis of medical infertility. Without such a diagnosis, the cost of treatment is not eligible for any public reimbursement and the person receiving treatment must pay all expenses out of pocket.

Australia provides public funding for an unlimited number of ART cycles for women eligible to receive benefits under Medicare. The burden of the cost of ART, therefore, falls more heavily on the Australian Government than in most other countries (Chambers et al. 2012). However, currently, this is under review. The Australian Government Department of Health has established 'The Medicare Benefits Schedule (MBS) Review Taskforce' which is considering how the items on the MBS can be aligned with contemporary clinical evidence and practice and improve health outcomes for patients (Australian Government Department of Health 2020). As part of this taskforce the 'Assisted Reproductive Technology Working Group' has been formed to provide advice on the evidence for ART services, appropriateness, best practice options, levels and frequency of support through the MBS (Australian Government Department of Health 2020).

### **2.2.2 Regulation of ART in Australia**

There is currently no Commonwealth legislation that directly regulates ART in Australia. Instead, it is regulated by individual state and territory laws; the Federal government's NHMRC Ethical Guidelines on the Use of ART in Clinical Practice and Research (2017); and the Fertility Society of Australia's Reproductive Technology Accreditation Committee's (RTAC) Code of Practice (2017) (*Refer Figure 1: Regulation of ART in Australian states and territories*).

The Fertility Society of Australia (FSA) sets minimum standards for fertility clinics providing ART services and encourage continuous improvement in the quality of

care provided. They conduct annual accreditation inspections of all clinics providing ART to ensure the clinics are adhering to the NHMRC Ethical Guidelines (2017) and the FSA Code of Practice (2015).

The RTAC Code of Practice (2017) requires all ART clinics in Australia and New Zealand to provide detailed information to the AIHW National Perinatal Statistics Unit (AIHW NPSU) about the number and type of treatment cycles performed and the number of pregnancies and births resulting from treatment. Treatment and pregnancy outcome data are compiled by the AIHW NPSU and published in an annual report (Newman et al. 2019).

### **2.2.3 Regulation of ART in Victoria**

The Victorian Assisted Reproductive Treatment Authority (VARTA) is the statutory authority responsible for regulating ART activities in Victoria according to the NHMRC Ethical Guidelines (2017), the RTAC Code of Practice (2017), and the Victorian Assisted Reproductive Treatment Act 2008. VARTA's responsibilities include:

- regulating access to information about ART procedures
- promoting research into the incidence, causes and prevention of infertility
- maintaining donors' conception registers (VARTA 2020).

The Assisted Reproductive Treatment Act (2008) in Victoria is accompanied by the Assisted Reproductive Treatment Regulations (2009) which outlines requirements for counselling, consent, expenses that may be reimbursed, information that must be recorded by clinics and with donor registers (VARTA 2020).

The Assisted Reproductive Treatment Amendment Act (2016) amends the 2008 Act to give all donor conceived people, no matter when they were born, the right to know their genetic heritage. As a result, donors will no longer have the ability to veto the release of their identifying information to their donor offspring but will be able to determine how – or if – they have contact with an applicant (VARTA 2020).

## **2.3 EGG DONATION**

Australia has a long history of involvement in egg donation programs, and since the world's first successful live birth using donated eggs in Australia in 1984 (Lutjen et al. 1984), the number of egg donation cycles has grown considerably. In Australia, egg donation represents 5.1% of all ART cycles (Newman et al. 2019), while in Europe it accounts for approximately 4.5% (Kupka et al. 2014) and 12% in the United States (CDC 2017). Globally, egg donation has led to the birth of more than 200,000 children (Woodriff, Sauer & Klitzman 2014).

### **2.3.1 Regulation and Egg Donation**

In Australia, only altruistic egg or non-commercial donation is permissible. Apart from compensation for expenses incurred as a result of donating eggs, a donor cannot receive any payment or another inducement (VARTA 2020). Individual State laws, the NHMRC Ethical Guidelines (2017) and the FSA Code of Practice (2015) also stipulate that:

- Potential donors must undergo screening for infectious diseases.
- Recipients are entitled to access information about the donor's medical history, physical characteristics, and the number and sex of children born from eggs donated by the same donor.



- Children born as a result of egg donation have the right to access information about the donor, including identifying information.
- The donor does not bear legal responsibilities for and is presumed not to be the parent of a child born as a result of his or her donation.
- A maximum number of families can be created with a donor's gametes.
- Legislation introduced in Victoria in 2010 requires eligible women and their partners (if they have one) to undergo criminal record and child protection order checks before treatment. Victoria is believed to be the first jurisdiction in the world to implement such rigorous checks (VARTA 2020).
- Counselling is mandatory before proceeding with egg donation, and that potential donors and recipients must receive adequate information about the medical, social, psychological and legal implications of donor procedures.

In a prospective longitudinal survey of 72 donors and recipients in Victoria, the majority perceived the counselling they received before undergoing donor procedures significantly more helpful than anticipated (Hammerberg et al. 2008). The authors also reported that attitudes among parents are changing towards increased willingness to tell children about the way they were conceived with 77% of those considering using a donor to conceive stated that they felt positive about disclosing the use of a donor to the child. There are many reasons why a couple or an individual may decide to create a family through egg donation.

### **2.3.2 Indications for Egg Donation**

The need for donor eggs may arise where ovarian failure or declining ovarian function is the cause of infertility, poor egg quality has been identified, or the woman is a carrier of a heritable genetic condition (Sauer 2013). Women who experience repeated fertility treatment failure may be advised that their chance of having a baby are higher if they use donor eggs. Personal circumstances may lead others to opt for egg donation and may appear as the only way they may have a family. For example, some may be women in their 40's or 50's with age related infertility, women who find a partner later in life, older couples in second long-term relationships, or those who have experienced the loss of a child. Others will be single or in a same-sex relationship. Whether egg donation represents a good investment of health resources has been debated in Australia for some time (Chambers et al. 2012).

### **2.3.3 Finding an Egg Donor in Australia**

A shortage of egg donors has been reported in many countries (Bracewell-Milnes et al. 2016), including Australia (Rodino, Goedeke & Nowoweiski 2014). Demand for donated eggs continues to rise, without a corresponding increase in the supply of donors (Gorton 2019). Sourcing eggs maybe even more acute for people from diverse ethnic groups, who seek donors with a shared ethnic background (Goedeke, Shepherd & Rodino 2020).

Studies report that recipients in countries which legislate for altruistic egg donation only, like Australia, choose their donor from their immediate family or social circle (Laruelle et al. 2011; van Berkel et al. 2007; Yee et al. 2007; Baetens et al. 2000). Occasionally egg donors are recruited by ART clinics and are unknown to the recipient couple. When couples have difficulties finding a donor, advertising in parenting magazines, or joining an online egg donation forum may

offer them additional opportunities. Laruelle and colleagues found that the recipients who selected an unknown donor did so because they had been unable to find a known donor (Laruelle et al. 2011).

The lack of egg donors has led to an increase in cross-border reproductive care as recipients seek donors in other countries (Rodino, Goedeke & Nowoweiski 2014). Common are Czech Republic, Greece, South Africa and Spain where donors must be <35 years, anonymous and compensated for their time (Pennings et al. 2014). Cross-border reproductive care continues to raise ethical concerns about the commodification of the human body, plus the need for appropriate care and compensation for the egg donors (Inhorn & Gurtin 2011).

However, recipients can import donated eggs to Australia if they comply with state laws and national regulations. For example only non-commercial donation is permissible, counselling is mandatory and the donor's identity must be registered in the state in which the recipient resides so that any potential child or children can trace the donor once reaching eighteen years (Hammarberg et al. 2011). In Victoria, prior approval must be obtained from VARTA before importing donor eggs (VARTA 2020). One overseas source of donor eggs is The World Egg Bank which has been operating since 2004 and will ship eggs directly to the recipient's ART clinic in Australia (The World Egg Bank 2020). The World Egg Bank donors comply with Australian state laws and national regulations (VARTA 2020).

Nonetheless, the increasing gap between donor supply and the needs of recipients suggests that current recruitment systems do not seem to attract sufficient donors to meet the rising needs of patients of donor-assisted conception

(Gorton 2019; Pennings et al. 2014). As an incentive to increase the number of egg donors in Australia, the introduction of financial compensation for the risk and personal time invested in the donation process, similar to the UK model, is currently being debated (Gorton, 2019). In the UK egg donors receive a fixed sum of £750 per donation cycle to cover expenses. This payment was introduced by the Human Fertilisation and Embryology Authority (HFEA) in 2012 and has reportedly resulted in an increase in the recruitment of egg donors (HFEA 2019). A similar compensation structure exists in other countries e.g. Denmark and Greece (Pennings et al. 2014). In Australia, a donor can be reimbursed by the recipient for reasonable expenses, incurred as a result of donating eggs, such as travel and accommodation costs within Australia (Commonwealth of Australia 2017). However, the term 'reasonable expenses' is not defined. A recent study conducted by Goedeke, Shepherd & Rodino (2020) in Australia and New Zealand with key stakeholders involved in donor-assisted conception, indicate support for the reimbursement of expenses for donors but payment constituting financial advantage was regarded less favourably.

#### **2.3.4 Egg donation process**

Ideally, donors should be aged between 25-36 years, have completed their own family and be free from any medical or inheritable disorders (VARTA 2020). In keeping with the legislation, once a woman agrees to donate her eggs, all involved parties will have counselling and medical screening. A typical egg donation cycle involves the following steps (Figure 2):

1. The egg donor undergoes controlled hormonal ovarian stimulation;
2. Oocyte pick-up (OPU) where mature eggs are aspirated from ovarian follicles;

3. Endometrial preparation of the recipient;
4. Fertilisation of the collected eggs using the recipient's partner or donor sperm;
5. Embryo maturation to cleavage (2-4 days) or blastocyst (5-6 days) stage;
6. Transfer of one or more fresh embryos into recipient woman's uterus in order to achieve pregnancy;
7. Cryopreservation and storage of remaining eggs or embryos for potential future use (Newman et al. 2019).

### **2.3.5 Cost Implications of Egg Donation**

Currently, egg donation programs are partially subsidised through the Australian public health insurance scheme, Medicare. Medicare rebates (Figure 2) for donor programs are dependent on the presence of a medical reason for treatment and are not available if there is no medical reason identified. If treatment is approved, there is a cap of 80% for reimbursement of services once an annual threshold expenditure is met. Unlike other countries, Australia currently provides public funding for an unlimited number of ART cycles for eligible women, and there is no upper age limit on the age of eggs used in donor conception (Chambers et al. 2012). The burden of the cost of ART, therefore, falls more heavily on the Australian Government than in most other countries. Health expenditure in Australia has increased which has prompted the current government to set up a taskforce to review funding, including support for egg donation programs. It is anticipated that the taskforce will report to the government in 2020 (Australian Government Department of Health 2020).

<b>Commonly associated fees for ART</b>		
<b>Procedure</b>	<b>Treatment cost</b>	<b>Estimated out of pocket costs (1<sup>st</sup> cycle in a calendar year – safety net not reached)</b>
IVF treatment cycle	\$9,828	\$4,991
Preparation of known egg donor		\$865
Egg donor cycle planning fee		\$400
<b>Total</b>	<b>\$9,828</b>	<b>\$6,256</b>

Source: Australian Government Department of Health, Medicare Benefits Schedule

Figure 2: Average cost of treatment using donated eggs (costs correct at 1 May 2020)

### 2.3.6 Success after Egg Donation

Success rates after egg donation are generally among the highest of all ART treatments (Pennings et al. 2014). However, as with all pregnancies the healthier the woman – both donor and recipient, the increased chance of having a positive outcome and reaching the goal of taking home a baby (Stoop et al. 2012). Adequate screening and health education before commencement of an egg donation program is imperative, e.g. improving lifestyle factors such as exercise, excluding alcohol and smoking (Savasi et al. 2016; van Dorp et al. 2014). Age is the main factor identified with donor success (Wang, Farquhar & Sullivan 2012) while recipient characteristics include BMI, age and reproductive health (van Dorp et al. 2014).

Cohort studies report one of the most important factors in determining the success of egg donation programmes is the age of the egg donor (Wang, Farquhar & Sullivan 2012). Optimal egg donors are young (<35 years old), in good health and free from heritable conditions because the risk of an abnormality

occurring in the neonate increases with the advancing age of the donor (Sauer 2013).

The age limit for women donating eggs varies throughout the world. Considering older women, using eggs from younger donors, have a very real chance of success, most centres have a 35-year age limit (Pennings et al. 2014). In Australia, it is recommended that clinics should not use gametes provided by older donors (NHMRC 2017) though there is no upper age limit specified. This raises legal and ethical issues for couples, clinicians and policy makers alike concerning the upper age limits for egg donors (Chambers et al. 2012).

Factors unique to the recipient have also been studied. Research on the recipient's age demonstrate that age may play a role in ART success (Soares 2008). A retrospective cohort study of 27,959 donor egg cycles found that recipients have stable rates of pregnancy outcomes before age 45, after which there is a statistically significant decline implantation, clinical pregnancy and live birth rates, and this decrease persisted after controlling for a variety of potential confounders (Yeh et al. 2014). In an Australian study by Chambers and colleagues (2017), the probability of a live birth for women aged 30-34 years, using their own eggs, after three full cycles of treatment, was between 64% and 74%, and after six cycles between 69% and 88%. For women aged 40-44, on the other hand, the probability after six cycles was in the range 21-34%. Few women, approximately 4%, over 44 years of age after five cycles conceived using their own eggs (Chambers et al. 2017).

Other recipient factors such as body mass index, uterine receptivity and well-synchronised replacement of good-quality embryos have been shown to impact

successful clinical outcomes of egg donation programs. Rittenberg et al. (2011) concluded in their systematic review that obese women using ART had higher rates of spontaneous abortions and exhibited lower clinical pregnancy rates. The findings on the impact of uterine receptivity indicate that clinical pregnancy rates and live birth rates trend toward greater success when the endometrial thickness is greater than 9 mm (Stoop et al. 2012). The overall quality of the egg and eventually the embryo is also important for a successful pregnancy (Noyes et al. 2001). A high-quality embryo, those with at least five cells and minimal blastomere fragmentation on day 3, led to the highest clinical pregnancy (63 %), live birth (54 %), and implantation (36 %) rates (Noyes et al. 2001).

Poorer outcomes have been demonstrated especially for twin pregnancies and are associated with the development of obstetrical complications (Malchau et al. 2013). In a large retrospective study from 2004–2008, of 50,328 births in Australia and New Zealand following ART treatment, single embryo transfer was associated with significantly lower rates of fetal and neonatal mortality compared with double embryo transfers (Sullivan et al. 2013). Australia leads the world in the proportion of ART cycles culminating in a single embryo transfer (SET). In 2002 the Reproductive Technology Accreditation Committee in their guidelines recommended the use of single embryo transfers (SET) (RTAC 2002). Sullivan et al. (2013) endorse that SETs should be adopted as best practice in the overall interests of society, where the costs of treatment, pregnancy, neonatal care and subsequent upbringing of the child are a responsibility of the state.

The success rates of ART are generally reported as the number of clinical pregnancies or live births per single fresh or frozen/thaw cycle (Newman et al. 2019). The need to move to reporting of cumulative live birth rates (CLBR) based



on individual patient data, rather than live birth rates only, has been highlighted (Maheshwari, McLernon, & Bhattacharya 2015; Malizia, Hacker & Penzias 2009). The CLBR is defined as the number of births, resulting from one initiated ART cycle, including the transfer of all fresh and/or frozen embryos, until one live birth occurs or until all embryos are used, whichever comes first (Zegers-Hochschild et al. 2017). Cumulative live birth rates account for the shift in routine clinical practice to cryopreservation of embryos and encourage single embryo transfer (SBT) by removing the emphasis on single cycle success (McLernon et al. 2016).

### **2.3.7 Egg Donation and cumulative live birth rate (CLBR)**

When a woman or couple enquire about egg donation, they want to know if the treatment will result in a baby (Malizia, Hacker & Penzias 2009). Traditionally, ART success rates following egg donation are presented as outcome per single cycle or embryo transfer according to maternal age (Malizia, Hacker & Penzias 2009). However, single cycle-based studies provide limited information for couples who undergo multiple ART cycles (Stern et al. 2010). Instead, it is argued that the CLBR provides a more accurate estimate of the chance of success with continued treatment (McLernon et al. 2016). Nonetheless, there is limited research on the CLBR in egg donation cycles. For example, to date no research has been done comparing CLBR outcomes of ART treatment with autologous versus donor eggs in women  $\geq 40$  years; or on the effect of the egg donor's and recipient's age on the CLBR. This research aims to fill these gaps.

### **2.3.8 Egg Donor's Motivation and Experiences**

With an acute shortage of egg donors the motivation behind egg donation is important to understand (Bracewell-Milnes et al. 2016). It has been claimed that research has tended to focus on the recipients' perspective and largely neglect

to explore the experiences of egg donors (Acharya et al. 2016; Hershberger et al. 2007). However, egg donation has the potential for psychological impact on the donor and therefore worthy of research.

Altruistic motivation is the predominant motive expressed by volunteer donors who tend to be married, have completed their own family and are professionally educated (Bakker et al. 2017; Pennings et al. 2014; Yee et al. 2007; Byrd et al. 2002; Kalfoglou & Gittelsohn 2000). This is consistent with Platts et al. (2019) findings that altruism is the primary motivator for egg donors. Having good family support and a stable relationship are cited as important factors in helping egg donors cope with the emotional aspects of donation (Acharya et al. 2016). Experiencing fertility problems within their family or close social circle is also cited as a motivator for altruistic egg donors (Bakker et al. 2017; Purewal & van den Akker 2009; Byrd et al. 2002). Interestingly, Bakker and colleagues (2017) found a substantial number of donors in their study had a background in healthcare. This was supported by Soderstrom-Anttila's study in 1995 (Soderstrom-Anttila & Hovatta 1995).

A Swedish study (Isaksson et al. 2012) reported that 65% of identity-release egg donors surveyed five to eight years after donating were positive towards being contacted by offspring once they reached the age of 18, with a further 17% being neutral towards this prospect, and only 2% stating that they did not want to meet a child conceived through their donation. The nature of the relationship and the amount of contact desired by the donor varies with the majority reporting positive experiences; unhappy experiences included contact being severed by the donor-conceived child's mother (Jadva et al. 2011).

There is a paucity of studies reporting egg donors' experience of the medical care they received during the egg donation process. In Soderstrom-Anttila and colleagues study (2016) most donors were satisfied with the medical care and support offered to them, some (9%) emphasised that they were unprepared for the physical side-effects during and after the cycle and would have liked more information. Furthermore, egg donors wanted more feedback on the quality of their eggs and knowledge of the outcome of the recipient's treatment (Soderstrom-Anttila et al. 2016).

Given the limited evidence on egg donors psychosocial needs, this research aims to understand their motivations for donation and experiences of the process preceding, during and post egg donation.

### **2.3.9 Recipient's Experiences of Egg Donation**

It has been recognised that the decision to use donor gametes is commonly experienced as stressful, time consuming and emotionally exhausting (Baetens et al. 2000). Recipients in a study by Applegarth et al. (2016) experienced grief and disappointment about being unable to have a genetically related child. Reasons for choosing treatment with donor eggs include the desire to experience a pregnancy and to have a child who has a genetic link to at least one parent (Bracewell-Milnes et al. 2016).

Once recipients come to terms with egg donation as the only way to have a baby, they face the dilemma of finding an egg donor, particularly in countries like Australia where only altruistic donation is permitted (Rodino et al. 2014). Studies report that recipients in countries which legislate for altruistic egg donation only, choose their donor from their immediate family or social circle (Laruelle et al.

2011; van Berkel et al. 2007; Yee et al. 2007; Baetens et al. 2000), with a minority not acquainted with the donor, having met for the purpose of the donation (Laruelle et al. 2011; Greenfeld & Klock 2004; Baetens et al. 2000). When couples have difficulties finding a donor, advertising or joining an online egg donation forum may offer them additional opportunities. Nowoweiski, Matic & Foster (2011) explored the experiences of people's attempts to recruit an egg donor through advertising in Victoria. Regardless of whether respondents recruited an egg donor or not, most reported that the process of writing the advertisement was stressful and their main concern was whether they would receive any responses (Nowoweiski, Matic & Foster 2011). Laruelle and colleagues found that the recipients who selected an unknown donor did so because they had been unable to find a known donor (Laruelle et al. 2011).

During recent years, the attitude towards disclosure in gamete donation has shifted from secrecy to openness. Women found counselling invaluable particularly in helping them make disclosure decisions (Yee et al. 2007). Studies have shown that early disclosure to children about the way they were conceived is associated with positive outcomes on family relationships (Golombok et al. 2013; Jadva et al. 2009).

In studies with women who had children through egg donation, some highlighted complex feelings of not being "real" mothers and that these feelings were rooted partly in the lack of genetic relationship with their child (Kirkman 2008). However, a UK survey of women who had conceived through egg donation found that only 4% reported that they had felt concerned prior to birth about bonding with their baby, and nearly half stated that they had not felt concerned (Hertz & Nelson 2016). Similarly a qualitative study by Stuart-Smith and colleagues (2012) with

egg recipients reported concerns during their pregnancy about whether they would feel like the child's "real mother" but once the baby was born these fears were not realized. Pregnancy, birth and the ease with which they had bonded with their newborn contributed to their sense of identity as the baby's mother (Stuart-Smith et al. 2012). These findings are supported by a recent qualitative study where 85 recipients reported that most felt secure and confident in their position as the child's mother by the end of the first year (Imrie et al. 2020). The authors assert that their findings may prove reassuring to other women who are pregnant or are considering treatment with donor eggs (Imrie et al. 2020).

There is substantial evidence that infertility and ART are emotionally demanding experiences, particularly for women. However, there is a paucity of studies exploring women's experiences of receiving donated eggs in a jurisdiction where only altruistic gamete donation is permitted. Given the growing use of egg donation as a family-building option (Imrie et al. 2019), it is vital to explore how recipient women navigate, understand, and experience egg donation, to inform the care of women and couples who use donated eggs. This research aims to fill this gap.

## **2.4 SUMMARY**

A woman's reproductive lifespan can now be artificially extended through the use of ART including egg donation. The most recent national estimates indicate that 4.8% of all women who gave birth in Australia in 2017 received some form of ART treatment (AIHW 2019), with 5.1% of these women using donated eggs. There is currently no national legislation that directly regulates ART including egg donation in Australia. Instead, it is regulated by individual state and territory laws, the

Federal government's NHMRC Ethical Guidelines on ART (2017), and the RTAC Code of Practice (2017). In Australia, since 1990, ART treatments are partially subsidised through Medicare. As a couple's primary concern is the chance of a live birth, it is argued that the CLBR should be used to estimate the outcome of the entire course of treatment (Maheshwari et al. 2015), following egg donation. The CLBR is more meaningful for egg recipients as it accounts for all cycles from one initiated ART cycle until a live birth occurs or until all the embryos are used, whichever occurs first. However, there is limited population-based studies on the outcome for women aged  $\geq 40$  years having ART treatment with autologous eggs compared to donor eggs; or on the effect of the donor's and recipient's age on the CLBR. Egg donation brings with it medical, psychosocial, ethical, legal and monetary considerations for both the donors and recipients. There is limited research studying the motivations and experiences of egg donors and recipients.

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# **CHAPTER 3: RESEARCH DESIGN, METHODOLOGY AND METHODS**

## **3.1 INTRODUCTION**

The current body of literature demonstrates the need to understand more about how women navigate, understand, and experience altruistic egg donation in Australia and how women's chances of having a baby through egg donation can be optimised. However, the current body of literature is still scarce and the need for further research in this area was demonstrated in Chapter 2. This chapter outlines the design and methods used in this thesis. Some of the methods are repeated in Chapters 4 – 7 that follow as each is a stand-alone publication.

## **3.2 RESEARCH AIMS AND OBJECTIVES**

The overarching aim of this thesis is to inform infertile women, clinicians and health policymakers of the factors that contribute to a woman's chance of having a baby through egg donation in Australia.

The specific objectives are:

1. To compare the cumulative live birth rate (CLBR) for women aged 40 years and above undergoing assisted reproductive technology (ART) using their own eggs and women of similar age using donor eggs.
2. To investigate the impact of the donor's and recipient's age on the CLBR in egg donation cycles.
3. To investigate egg donors' motivations and experiences of egg donation in Australia.

4. To investigate the motivations and experiences of Australian women who received donated eggs.

### **3.3 RESEARCH DESIGN AND METHODOLOGY**

This thesis used a mixed methods approach, to explore and gain a better understanding of the factors that contribute to the success of egg donation programs and the experience of altruistic egg donors and recipients in Australia. The methods used in this research were predetermined based on the research questions, and were planned at the beginning of the research process. Both quantitative and qualitative methods were used as four distinct studies in which the data collection and analysis were conducted separately for each study (Creswell & Plano Clark 2011).

#### **3.3.1 Mixed Methods Research**

Mixed-methods research is the integration of qualitative and quantitative approaches into one program of research in order to provide a more comprehensive and complete understanding of a research problem (Creswell 2014). The mixed-methods approach is supported as a powerful tool for the investigation of complex processes in health care (Fetters, Curry & Creswell 2013). While quantitative research addresses questions about relationships of association, causality, generalisability, or the magnitude of effect, qualitative research seeks to arrive at an understanding of a particular phenomenon from the perspectives of those experiencing it (Fetters, Curry & Creswell 2013). The use of mixed-methods was justified as little was known about the impact of the donor's and recipient's age on the CLBR in egg donation cycles or the experiences of Australian egg donors and recipients. In addition, the research



questions directed the need for different methods that enabled each of the research questions to be adequately answered (Creswell 2014).

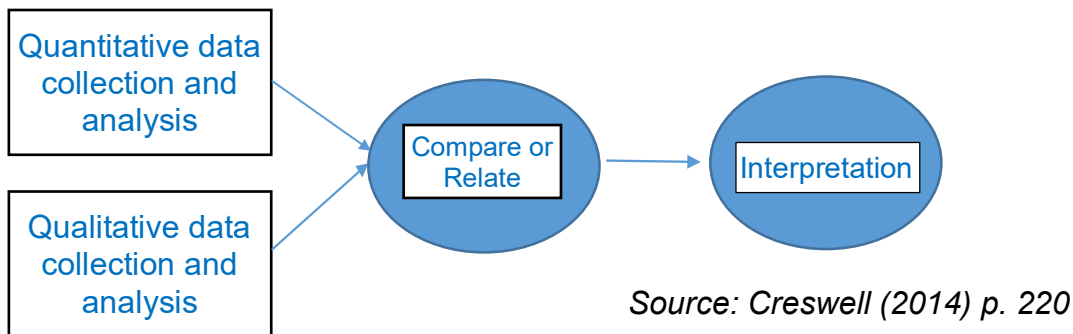
### **3.3.2 Philosophical Pragmatism**

The philosophical stance appropriate to underpin this mixed method study is identified as pragmatism. Mixed methods research is generally recognised as the 'third' research paradigm alongside quantitative and qualitative research paradigms (Johnson & Turner 2010) with a unique methodological orientation including its own worldview, vocabulary and techniques (Tashakkori & Teddlie 2010). Mixed methods approaches are characterised by the use of quantitative and qualitative methods in the same research project and the use of pragmatism as the philosophical underpinning of the research (Creswell 2014; Creswell & Plano Clark 2011; Tashakkori & Teddlie 2010). The purpose of research from a pragmatic perspective is to find solutions to real-world problems in a manner that is generalisable, and to see the knowledge gained through research, transferred into a change in practice (Creswell 2014). In this context, philosophical pragmatism is identified as appropriate to underpin this mixed method study.

### **3.3.3 Convergent Mixed Methods**

A well-known approach in mixed methods research is the convergent mixed methods research design. It involves the collection and analysis of both quantitative and qualitative data, drawing on the strengths of both approaches, and connecting the studies by integrated analysis (Creswell 2014; Creswell & Plano Clark 2011) (Figure 3). The idea is to pull together the respective strengths and non-overlapping limitations of quantitative methods, such as large sample sizes and the ability to generalize, with those of qualitative methods, such as

small samples and enriched meaning (Kettles, Creswell & Zhang 2011). This is considered useful for understanding the contextual and environmental factors that influence behaviour, health, policies and programs, in order to fully understand the research problem (Fetters, Curry & Creswell 2013).



**Figure 3: Convergent Mixed Methods**

Integration of this mixed methods study occurred at a study design level through the convergent mixed methods design. By using the convergent design the intent was to merge the phases in order that the quantitative and qualitative results could be compared. The quantitative and qualitative data collection occurred in parallel and the analysis for integration occurred after the data collection process was completed. The two forms of data were analysed separately and then merged. This study design gives equal emphasis given to quantitative and qualitative data forms, facilitates corroboration and elaboration in both data analysis and interpretation phases of the study, illuminating deeper meanings and processes, an aim according to Fetters et al. (2013) that is essential for health disparities research. Mixing of the research data in this current study occurs at the end of the project.

The strength of the chosen research design is that it provides a comprehensive design to answer the research questions of this thesis. A mixed methods approach addresses questions that qualitative or quantitative methods alone are not able to answer, offsetting the weaknesses of any single study method. It is recognised, however, that this is not an easy method, requiring a longer project time-line and knowledge of both forms of data collection, analyses and interpretation (Fetters et al., 2013). Nevertheless, the methods chosen allowed extensive investigation of this topic, offering new insights on a health.

The two phases in this research project were aligned with the requirements of a convergent mixed methods research approach and were linked by a common theoretical construct: they each examined aspects of the concept of egg donation and the factors for success. While the studies were published separately, the results of each were considered together in the discussion chapter of the thesis (Chapter 8). Tashakkori & Teddlie (2010) agree that integration can occur through writing about the data in a discussion where the separate results of the quantitative and qualitative studies are discussed together.

### **3.4 OVERVIEW OF RESEARCH STUDIES**

Based on the gaps in the current body of literature two phases were designed for this research thesis as follows:

#### **Phase 1 (quantitative)**

- Study 1: a quantitative investigation comparing the CLBR in autologous and recipient women aged 40 years and above;

- Study 2: a quantitative investigation of the impact of egg donors' age on recipients' CLBR.

### **Phase 2 (qualitative)**

- Study 3: a qualitative exploration of donors' motivations and experiences of egg donation in Australia; and
- Study 4: a qualitative exploration of the experiences of Australian donor egg recipients.

The research methods and data collection for each phase are described below and depicted in Table 2. Some of this detail is also included in Chapters 4 – 7 as each individual manuscript contains a methods section.

Table 2: Overview of Research Studies

PHASE 1			
RESEARCH AIM		DATA COLLECTION METHOD	SAMPLE/ PARTICIPANTS
<b>Study 1</b>	To compare the CLBR* for women ≥40 years undergoing ART** using their own eggs with women of similar age using donor eggs.	<ul style="list-style-type: none"> <li>Quantitative</li> <li>Victorian state-wide</li> <li>Retrospective population-based cohort study</li> <li>Discrete-time survival model</li> </ul>	All women aged ≥40 years undergoing ART** with donated (n=987) or own eggs (n=19,170) between 2009 and 2016.
<b>Study 2</b>	To study the impact of the donor's and recipient's age on the CLBR* in egg donation cycles.	<ul style="list-style-type: none"> <li>Quantitative</li> <li>Victorian state-wide</li> <li>Retrospective population-based cohort study</li> <li>Multivariate Cox proportional hazard regression</li> </ul>	All women undergoing ART** with donor eggs (n = 1,490) between 2009 and 2015.
PHASE 2			
RESEARCH AIM		DATA COLLECTION METHOD	SAMPLE/ PARTICIPANTS
<b>Study 3</b>	To explore the experiences of altruistic egg donors in Australia, and identify potential enablers or barriers to altruistic egg donation.	<ul style="list-style-type: none"> <li>Qualitative</li> <li>Australia wide</li> <li>Semi-structured interviews</li> <li>Thematic analysis</li> </ul>	18 women who had donated eggs altruistically in Australia within the last three years.
<b>Study 4</b>	To explore women's experiences of receiving altruistically donated eggs.	<ul style="list-style-type: none"> <li>Qualitative</li> <li>Australia wide</li> <li>Semi-structured interviews</li> <li>Thematic analysis</li> </ul>	17 women who were recipients of altruistically donated eggs in Australia within the last three years.

\*Cumulative live birth rate

\*\*Assisted reproductive technology

### **3.4.1 Phase 1 (quantitative)**

This phase addresses objectives 1 and 2 of the thesis:

- To compare the cumulative live birth rate (CLBR) for women aged 40 years and above undergoing assisted reproductive technology (ART) using their own eggs and women of similar age using donor eggs.
- To investigate the impact of the donor's and recipient's age on the CLBR in egg donation cycles.

#### **Study design**

Two population-based retrospective cohort studies were used to address the objectives. Study 1 examined the data from all women aged  $\geq 40$  years undergoing ART with donated ( $n=987$ ) or autologous oocytes ( $n=19,170$ ) in Victoria, Australia between 2009 and 2016. A discrete-time survival model was used to evaluate the CLBR following ART with donor or autologous oocytes.

Study 2 examined the data from all women ( $n = 1,490$ ), undergoing ART with donated oocytes in Victoria, Australia between 2009 and 2015. This included women since 2013, who obtained donor oocytes from The World Egg Bank in the United States. The association between the donor's and recipient's age and CLBR was modelled by multivariate Cox proportional hazard regression.

#### **Data collection**

The data was obtained from the Victorian Assisted Reproductive Treatment Authority (VARTA). Approximately 30% of all ART treatment cycles undertaken in Australia are performed in Victoria (Newman et al. 2019). VARTA is a statutory authority which records details of all initiated ART treatments undertaken in

Victoria, including demographic characteristics, type of ART treatment and resulting pregnancy and birth outcomes (VARTA 2020).

From 2009, upgrades to the VARTA dataset enabled successive treatment cycles undertaken by one woman, to be identified via two data items in the dataset: the patient unique identifier and the statistical linkage key (SLK). The patient unique identifier is assigned by the clinic. The SLK is a combination of the first two letters of the woman's first name, the first two letters of her surname and her date of birth. The combination of the patient unique identifier and the SLK allows the tracking of women's treatments and resulting outcomes within and between clinics.

The demographic details in the dataset include the woman's and her partner's age at the time of treatment, the cause of infertility and previous pregnancies of  $\geq 20$  weeks gestation. ART treatment factors consist of the number of oocytes retrieved, source of sperm, method of fertilization, number of embryos transferred, the stage of embryo development (cleavage stage embryo/blastocysts), and method of embryo cryopreservation and subsequent uses. The outcome measurements include clinical pregnancy, early pregnancy loss (ectopic pregnancy, termination and miscarriage), the method of birth, gestational age, birthweight, congenital abnormality and perinatal mortality.

### **Data management and analysis**

Descriptive statistics were used in Studies 1 and 2 for data on women's age, male partner age, history of previous pregnancy of  $\geq 20$  weeks gestation, fertilisation procedure, stage of embryo development and the number of embryos

transferred. Descriptive statistical analysis was performed using SPSS 25 (Armonk, NY, USA: IBM Corp.).

In Study 1, a discrete-time survival model was used to evaluate the CLBR following ART with donor or autologous eggs (oocytes). The odds ratio, adjusted for woman's age; male age; parity; cause of infertility; and the associated 95% confidence intervals (CI), were calculated. The numbers needed-to-be-exposed (NNEs) were calculated from the adjusted odds ratio (AOR) and the CLBR in the autologous group.

In Study 2, the association between the donor's and recipient's age and CLBR was modelled by multivariate Cox proportional hazard regression with the following covariates adjusted for: male partner's age, recipient parity and cause of infertility. Donor age was grouped as <30, 30-34, 35-37, 38-40 and ≥41 years, and recipient age as <35, 35-37, 38-40, 41-42, 43-44 and ≥45 years.

## **Ethics**

Ethics approval for Phase 1 was granted by the Human Research Ethics Committee of the University of Technology Sydney, Australia (UTS HREC REF NO. ETH16-0800). Access to the VARTA data was granted by VARTA.

### **3.4.2 Phase 2 (qualitative)**

This phase addresses objectives 3 and 4 of the thesis:

- To investigate egg donors' motivations and experiences of egg donation in Australia.
- To investigate the motivations and experiences of Australian women who received donated eggs.



## **Study design**

Qualitative methods were used to answer questions about motivation, experience and expectations with egg donors and recipients. Two studies (Studies 3 and 4) were conducted using individual semi-structured interviews.

## **Participants and recruitment**

Women who had donated or received eggs in Australia within the last three years were included in this study. Participants responded to a targeted advertisement (see Appendix 1) placed in the Victorian Assisted Reproduction Treatment Authority's (VARTA) March 2019 newsletter. VARTA is a statutory authority in the state of Victoria, Australia. One of its roles is to provide independent information and support for individuals, couples and health professionals on fertility and issues related to ART, including donor-conception. VARTA's website is the main platform for dissemination of information and a monthly newsletter is emailed to subscribers. Interested participants who responded to the advertisement were followed up via email or telephone and sent a 'Participant Information Sheet' (see Appendix 2 & 3) and consent form (see Appendix 4 & 5).

## **Data collection**

Women who were willing to be interviewed were given the option of a face-to-face or telephone interview if they lived in the greater Sydney metropolitan area. Those living in other parts of the country were only offered a telephone interview. The interviews were conducted between March and July 2019 using an interview guide. The interview guides (see Appendix 6 & 7) were developed based on findings from published research and included questions about participants' experience of egg donation; the perceived quality of the clinical care; and views about whether their needs were met and ways in which care could be improved.

All questions were open-ended and framed as invitations for participants to describe their experiences in their own words, with follow-up prompts inviting elaboration when needed. Interviews were audio-recorded with the permission of the participants and lasted between 40 and 60 minutes (mean 45 minutes).

### **Data management and analysis**

In total, 18 women who were egg donors (Study 3) and 17 women who had received eggs (Study 4) were interviewed. All interviews were audio-recorded, transcribed verbatim and coded electronically using the NVivo qualitative data analysis software Version 12 (QSR International Pty Ltd Burlington, MA, USA). The transcripts were analysed using the established technique of Braun & Clarke's (2019) approach of reflexive thematic analysis. The purpose of reflexive thematic analysis is to identify patterns of meaning across a dataset that provide an answer to the research question being addressed (Braun & Clarke 2019). Patterns are identified through a rigorous process of data familiarisation, data coding, and theme development and revision. According to Braun & Clarke (2019), analysis is necessary to judge whether the information generated by participants offers something new or not.

The six specific steps of reflexive thematic analysis outlined by Braun & Clarke (2019) were followed:

(1) Becoming familiar with the data. This phase involved reading and re-reading the data, to become immersed and intimately familiar with its contents. This included listening to the audio data, reading/re-reading the transcripts and making notes about individual data items, as well as the whole dataset.

(2) Generating codes. To identify important features of the data that are relevant to answering the research questions, succinct labels or codes were generated. Data was organised around similar meanings and the content reduced into collated chunks of text. This involved coding the entire dataset which was followed by the collation of all the codes and all the relevant data extracts, together for later stages of the analysis.

(3) Identifying themes. This phase involved examining the codes and collated data to identify significant broader patterns of meaning or potential themes. Following the Braun & Clarke (2019) approach, similar codes were collated, together with associated data, into coherent clusters or meaning that told a stories about particular aspects of the dataset. In this way the move was made from developing codes to constructing candidate themes. In this phase the researcher found thematic mapping generated through NVivo useful as a process to visually explore the potential themes and subthemes, and the connections between them.

(4) Reviewing themes. During this phase all of the coded data for each of the candidate themes were compiled and reviewed to develop a clear sense of how each theme related to the others. Themes were refined which involved them being split, combined or discarded.

(5) Defining and naming themes. Following the review of the themes, a detailed analysis of each theme took place in order to work out the scope and focus of each theme. Again during this phase the thematic map was useful to visualise how the themes fitted together, to ensure that the themes did not overlap and that they told the overall story of the data.

(6) Selecting quotes that best illustrate the themes were identified.

By following this process the researcher was to look at the emerging themes and identify patterns. Furthermore, as this process of reflexive thematic analysis was continuous and iterative, it provided the researcher with the ability to move backwards and forwards across the data, which helped them to become more familiar with and immerse themselves in it (Smith et al. 2011), ultimately leading to a better understanding of the perceptions and experiences' of the study's participants. This approach provided the researcher with a systematic and flexible structure to manage and analyse the data, enabling the development and maintenance of a transparent audit trail.

Once the thematic structure was finalised and its meaning interpreted through discussion among the researchers, representative quotations were selected to reflect thematic interpretation and diversity of experience. Each respondent was anonymised and referred to with a pseudonym.

### **Reflexivity**

Reflexivity is described as the process of reflecting critically on the self, and of analysing and noting personal values that could affect data collection and interpretation thereby improving the rigour of the research (Shaw 2016). These practices include critical self-reflection on one's personal biases, preconceived notions, assumptions, theoretical predispositions, and ideological commitments (Sandelowski & Barrosa 2002).

In phase 2 of this research project, to reduce the effects of researcher influence, a sound research design was utilised, and experienced academics supervised all aspects of the research. This included open discussions with academic

supervisors regarding the intentions for conducting the research and the use of a journal throughout the entire study for self-reflection.

## **Ethics**

Ethics approval for Phase 2 was granted by the Human Research Ethics Committee of the University of Technology Sydney, Australia (UTS HREC REF NO. ETH18-2264 and 2270). All participants in the two studies participated voluntarily and gave informed consent.

## **3.5 DATA STORAGE**

Data from this research project are currently stored according to the guidelines of the Australian National Health and Medical Research Council (<https://www.nhmrc.gov.au/>). Paper-based consent forms are stored in a locked cabinet in the Faculty of Health, University of Technology Sydney (UTS). The data files from transcribed digital recordings are stored in a password-protected secure cloud storage database owned by UTS to which only the researcher (RH) has access. Data are archived for a minimum period of 5 years from the publication of results as per the UTS data management policy. After this time, data will be destroyed in a secure manner such as shredding of paper documents and erasure of computer-generated data.

## **3.6 CHAPTER CONCLUSION**

The mixed methods research design described in this chapter provides a comprehensive approach to answer the research questions of this thesis. The following chapters will provide details of each study undertaken, including background, aims, methods and results in manuscript form, with a discussion of

the significance and implications of findings for infertile women, clinicians and health policymakers, of the factors that contribute to a woman's chance of having a baby through egg donation in Australia.

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## CHAPTER 4: STUDY 1

This chapter appears as the following published paper in the *Australian and New Zealand Journal of Obstetrics and Gynaecology*:

**Hogan, R.G.**, Wang, A.Y., Li, Z., Hammarberg, K. Johnson, L., Mol, B.W. & Sullivan, E.A. 2020, 'Having a baby in your 40s with ART: the reproductive dilemma of autologous versus donor oocytes', *Australian and New Zealand Journal of Obstetrics and Gynaecology*, published online 18 May 2020, <<https://doi.org/10.1111/ajo.13179>>.

<b>Declaration of the authors' and role in the study</b> (signatures can be provided on request)
<b>Rosemarie Hogan</b> – drafted manuscript, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Alex Y. Wang</b> – designed the study, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Zhuoyang Li</b> – carried out the statistical analyses, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Karin Hammarberg</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Louise Johnson</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Ben Mol</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Elizabeth Sullivan</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript

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## 4.1 ABSTRACT

**Background:** Increasing numbers of women  $\geq 40$  years are accessing assisted reproductive technology (ART) due to age-related infertility. There is limited population-based evidence about the impact on the cumulative live birth rate (CLBR) of women aged  $\geq 40$  years using their own oocytes, compared to women of a similar age, using donor oocytes.

**Aims:** Compare the CLBR for women  $\geq 40$  years undergoing ART using autologous oocytes and women of similar age using donor oocytes.

**Materials and Methods:** This population-based retrospective cohort study used data from all women aged  $\geq 40$  years undergoing ART with donated ( $n=987$ ) or autologous oocytes ( $n=19\ 170$ ) in Victoria, Australia between 2009 and 2016. A discrete-time survival model was used to evaluate the CLBR following ART with donor or autologous oocytes. The odds ratio, adjusted for woman's age; male age; parity; cause of infertility; and the associated 95% confidence intervals (CI), were calculated. The numbers needed-to-be-exposed (NNEs) were calculated from the adjusted odds ratio (AOR) and the CLBR in the autologous group.

**Results:** The CLBR ranged from 28.6% to 42.5% in the donor group and from 1.4% to 12.5% in the autologous group. The discrete-time survival analysis with 95% CI demonstrated significant AOR on CLBR across all ages (range AOR: 2.56, 95% CI: 1.62–4.01 to AOR: 15.40, 95% CI: 9.10–26.04).

**Conclusions:** Women aged  $\geq 40$  years, using donor oocytes had a significantly higher CLBR than women using autologous oocytes. The findings can be used when counselling women  $\geq 40$  years about their ART treatment options and to inform public policy.

## CHAPTER 5: STUDY 2

This chapter appears as the following published paper in *Fertility and Sterility*:

**Hogan, R.G.**, Wang, A.Y., Li, Z., Hammarberg, K., Johnson, L., Mol, B.W. & Sullivan, 'Oocyte donor age has a significant impact on oocyte recipients' cumulative live birth rate: a population-based cohort study', *Fertility and Sterility*, vol. 112(4), pp. 724-730, <<https://doi.org/10.1016/j.fertnstert.2019.05.012>>.

<b>Declaration of the authors' and role in the study</b> (signatures can be provided on request)
<b>Rosemarie Hogan</b> – drafted manuscript, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Alex Y. Wang</b> – designed the study, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Zhuoyang Li</b> – carried out the statistical analyses, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Karin Hammarberg</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Louise Johnson</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Ben Mol</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Elizabeth Sullivan</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript

## 5.1 ABSTRACT

**Objective:** To study the impact of the donor's and recipient's age on the cumulative live birth rate (CLBR) in oocyte donation cycles?

**Design:** A population-based retrospective cohort study

**Setting:** Data obtained from the Victorian Assisted Reproductive Treatment Authority (VARTA) in Victoria, Australia.

**Patient(s):** All women using donated oocytes (n = 1,490) in Victoria, Australia between 2009 and 2015 were included.

**Intervention(s):** None

**Main Outcome Measure(s):** The association between the donor's and recipient's age and CLBR was modelled by multivariate Cox proportional hazard regression with the following covariates adjusted for: male partner's age, recipient parity and cause of infertility. Donor age was grouped as <30, 30-34, 35-37, 38-40 and ≥41 years, and recipient age as <35, 35-37, 38-40, 41-42, 43-44 and ≥45 years.

**Results:** The mean age of the oocyte donors was 33.7 years (range 21 to 45 years) with 49% aged 35 years and over. The mean age of the oocyte recipients was 41.4 years (range 19 to 53 years) with 25.4% aged ≥45 years. There was a significant relationship between the donor's age and the CLBR. The CLBR for recipients with donors aged <30 years and 30-34 years was 44.7% and 43.3% respectively. This decreased to 33.6% in donors aged 35-37 years, 22.6% in donors aged 38-40 years and 5.1% in donors aged ≥41 years. Compared with recipients with donors aged <30 years, recipients with donors aged 38-40 years had 40% less chance of achieving a live birth (AHR 0.60, 95% CI 0.43-0.86) and

recipients with donors aged  $\geq 41$  years had 86% less chance of achieving a live birth (AHR 0.14, 0.04–0.44). The multivariate analysis showed no significant effect of the recipient's age on CLBR.

**Conclusion:** We demonstrate that the age of the oocyte donor is critical to the CLBR and is independent of the recipient woman's age. Recipients using oocytes from donors aged  $\geq 35$  years had a significantly lower CLBR when compared to recipients using oocytes from donors aged  $< 35$  years.

**Key Words:** oocyte donor, oocyte recipient, cumulative live birth rate, donor age, assisted reproductive technology

## 5.2 INTRODUCTION

Since the world's first live birth using donated oocytes was reported in 1984 (Lutjen et al. 1984) the number of oocyte donation cycles has grown considerably. Currently, in Australia, oocyte donation represents 5.6% of all assisted reproductive treatment (ART) cycles (Fitzgerald et al. 2018), while in Europe and the United States it accounts for approximately 4.5% (Kupta et al. 2014) and 12% (Centres for Disease Control 2014) respectively. Oocyte donation is an important component of ART particularly for women with age-related infertility, poor ovarian reserve, and for women who carry genetic abnormalities (Sauer 2013).

In Australia, only altruistic gamete donation is permitted. Altruistic donors are usually parous and cohabiting or married, unlike the majority of compensated donors who are nulliparous and single (Purewal & van den Akker 2009). This may partly explain why altruistic donors are on average older than compensated donors. The average age of women donating oocytes in Australia in 2016 was 32.6 years, with 40.8% of cycles involving donors aged 35 or older (Fitzgerald et al. 2018). Apart from compensation for expenses incurred as a result of donating oocytes, a donor cannot receive any payment or other inducement as per the Prohibition of Cloning Act 2002 (Commonwealth of Australia 2017). Furthermore, the Australian National Health and Medical Research Council (NHMRC) Ethical Guidelines (2017) and the Fertility Society of Australia Reproductive Technology Accreditation Committee (RTAC) Code of Practice (2015) stipulate that children born as a result of oocyte donation have the right to access information about the donor when they reach the age of 18.

Cycle-based evidence shows that live birth rates with oocyte donation are dependent on the age of the donor, where recipients with younger donors have a higher live birth rate than those with older donors (Wang, Farquhar & Sullivan 2012). There is also evidence showing a relationship between ART outcomes and uterine receptivity in older oocyte recipient women. In 2002, Toner and colleagues performed a retrospective analysis of oocyte donation data gathered by the Society for Assisted Reproductive Technology (SART) registry (2002). They found ART outcomes declined in recipients >45 years and declined further in recipients >50 years. Similarly, Yeh and colleagues found that recipients on the SART database between 2008 and 2010 had stable rates of pregnancy outcomes <45 years but this declined in recipients >45 years (Yeh et al. 2014). They conclude that there is relationship between ART outcomes, oocyte donor age and uterine receptivity in older women.

However, there is no international agreement on “how old is too old”. It is known that women over 35 years have a higher aneuploidy rate and fewer oocytes retrieved following hormonal stimulation than younger women (Pennings et al. 2014). Therefore, ideally oocyte donors are women in their 20’s and early 30s, who are in good health and free from heritable conditions (Savasi et al. 2016; van Dorp et al. 2014). In Australia, it is recommended that clinics do not use oocytes provided by ‘older’ donors, though no upper age limit is specified (NHMRC 2017). However, because of the shortage of donors, most recipients use a willing friend or relative as their donor and ART clinics accept them irrespective of their age (Commonwealth of Australia 2017). Hence, women older than 35 years are accepted when they donate to a specific recipient, who has been counselled about the implications of the donor’s age. Similarly in countries in Europe, where

commercial donation is prohibited, the upper age limits of oocyte donors may be interpreted flexibly in cases of direct donation because there is a great scarcity of donors and thus no alternative (Pennings et al. 2014).

When a woman or couple enquire about oocyte donation they want to know if the treatment will result in a healthy baby (Malizia, Hacker & Penzias 2009). Artificial reproductive technology success rates following oocyte donation are usually presented as outcome per cycle or embryo transfer according to donor's age (McLernon et al. 2016). However, Malizia and colleagues (2009) maintain that this statistic has limited value because it does not account for the additional chance offered by frozen embryos resulting from a stimulated cycle. It is argued that the CLBR has more significance for recipients and clinicians because it provides an overall estimate of the chance of having a baby following one stimulated cycle (Maheshwari, McLernon & Bhattacharya 2015). The purpose of this population-based cohort study is to provide population statistics on the effect of the oocyte donor's and recipient's age on the CLBR in oocyte donation cycles.

## **5.3 MATERIALS AND METHODS**

### **Data**

In the state of Victoria in Australia, only registered ART providers can offer ART. Data used in this study are collected from all registered ART providers in Victoria by the Victorian Assisted Reproductive Treatment Authority (VARTA) and the University of Technology Sydney (UTS). VARTA is a statutory authority funded by the Victorian Department of Health and Human Services in Victoria. Among its obligations, VARTA is responsible for monitoring and reporting on all ART procedures carried out in registered clinics.



All women using donated oocytes (n = 1,490) in Victoria, Australia between 2009 and 2015 were included. This included women since 2013, who obtained donor oocytes from The World Egg Bank in the United States.

Data collected for oocyte recipient cycles include age, parity, cause of infertility, number of oocytes donated and received, fertilization procedure (IVF or ICSI), stage of embryo at transfer, and number of fresh and thawed embryos created and transferred. Data on the outcomes of resulting pregnancies and births, including birth status, gestational age, birth weight and congenital anomalies, are also collected.

Data on fresh and frozen embryo transfers following oocyte donation undertaken from 1 July 2009 to 30 June 2016, or until a live birth was achieved, and resulting pregnancy and birth outcomes were extracted from the VARTA database and are included in this study.

### **Study factors**

The donors' ages were calculated in completed years at the time of oocyte donation and classified into five groups: <30, 30-34, 35-37, 38-40, and  $\geq 41$  years. The recipients' ages were calculated at the time of first transfer and categorized into six groups: <35, 35-37, 38-40, 41-42, 43-44, and  $\geq 45$  years. The cause of infertility was classified as male factor infertility, female factor infertility, combined male-female factor infertility, unexplained infertility and not stated.

Previous pregnancy of  $\geq 20$  weeks gestation was grouped as yes, no and not stated. Fertilisation procedure was either IVF or ICSI. Stage of embryo development was grouped into cleavage or blastocyst stages. The number of embryos transferred in each cycle was grouped as one or two embryos.

## **Main outcome measure**

The primary outcome was the cumulative live birth rate (CLBR), defined as at least one live birth following one oocyte donation, including fresh and any associated frozen embryo transfers. A live birth was defined as a baby showing signs of life with gestational age  $\geq$  20 weeks or birthweight  $\geq$  400 grams. The observed CLBR was reported using the conservative assumption that women who did not return for treatment did not have a pregnancy resulting in a live birth.

## **Statistical analysis**

Chi-squared test was used for categorical variables. Cox regression was used to model the association between the donor's and recipient's age and CLBR. The adjusted hazard ratio (AHR) and 95% confidence intervals (CI) were calculated. Adjustment was made for the male partner's age, recipient parity (nulliparous/parous) and, cause of infertility (male only/female only/combined male-female/unexplained). A p-value  $<0.05$  was considered statistically significant. All statistical analysis was performed using SPSS 24.0 software (Armonk, NY, USA: IBM Corp.).

## **Ethics**

Ethics approval for this study was granted by the Human Research Ethics Committee of the University of Technology Sydney, Australia (UTS HREC REF NO. ETH16-0800). Access to the VARTA data was granted by VARTA.

## **5.4 RESULTS**

In all 1490 oocyte recipients had 2919 fresh and frozen embryo transfer cycles. Characteristics of donors and recipients are shown in Table 9. The mean age of the oocyte donors was 33.7 years (range 21 to 45 years) with 50.4% aged  $<35$

years. The mean age of the oocyte recipients was 41.4 years (range 19 to 53 years) with one quarter (25.4%) aged  $\geq 45$  years. Overall one in five recipients (21.9%) had a history of a previous pregnancy  $\geq 20$  weeks. The mean number of oocytes received was 11.93 (range 11.28 to 12.51) and was similar across all recipient age groups.

The proportion of blastocyst transfer observed in cycles of recipients aged  $< 35$  years (50.2%) was not significant when compared to older recipients (45.2%). Double embryo transfer accounted for 23.4% of all embryo transfers and was most common in recipients in the 35-37 years age group (29.9%) (Table 10). There were 44 twin births, of which 38 (86.4%) occurred following double embryo transfers. We observed that the age of the oocyte donor did not have an effect on the number of embryos that were transferred to the recipient (Table 11).

The CLBR ranged from 31.7% among recipients aged 38-40 years to 41.4% among recipients aged  $< 35$  years. The multivariate analysis showed no significant differences in the success by recipient's age (Table 12). The CLBR by cycle is provided in the Supplementary Tables.

There was a significant association between the donor's age and CLBR. The CLBR for recipients with donors aged  $< 30$  years and 30-34 years was 44.7% and 43.3% respectively. This decreased to 33.6% in donors aged 35-37 years, 22.6% in donors aged 38-40 years and 5.1% in donors aged  $\geq 41$  years. Compared with recipients with donors aged  $< 30$  years, recipients with donors aged 38-40 years had 40% less chance of achieving a live birth (AHR 0.60, 95% CI 0.43–0.86) and recipients with donors aged  $\geq 41$  years had 86% less chance of achieving a live birth (AHR 0.14, 0.04–0.44) (Table 12).

When oocyte recipient and donor ages were combined the highest cumulative live birth rate was in recipients aged 35-39 years with donors aged <30 years (51.1%). The lowest cumulative live birth rate was in recipients aged ≥45 years and donors aged ≥40 years (5.3%) (Table 13).

## **5.5 DISCUSSION**

This population-based cohort study, on outcomes of oocyte donation, found that recipients with donors aged 35 years or older had a significantly lower CLBR, regardless of the recipient's age. To the best of our knowledge, there are no other studies that have evaluated the CLBR in women who have received donated oocytes.

The mean age of the oocyte donors in this study was 33.7 years. This is significantly older than the average age of donors in European (Pennings et al. 2014) and United States (Kawwass et al. 2013) studies of 27.4 years and 28 years respectively. In Australia, only altruistic gamete and embryo donation is permissible but there are no regulations that set an age limit for oocyte donation (NHMRC 2017; FSA 2015). Artificial reproductive technology clinics accept older donors because the demand for donated oocytes exceeds supply (Commonwealth of Australia 2017). This may in part explain the finding that almost half (49%) of the oocyte donors in this study were 35 years of age or older. This is similar in the United Kingdom where only altruistic oocyte donation is permitted and the upper age limit of women donating oocytes may be interpreted flexibly because of the scarcity of donors (Pennings et al. 2014).

The mean age of the oocyte recipients in this study was similar to the ages of recipients reported in studies in the United States (Kawwass et al. 2013) and the

United Kingdom (Pennings et al. 2014). A range of circumstances can lead women of advanced reproductive age to request oocyte donation to overcome age-related infertility such as having experienced repeated fertility treatment failure, being single or finding a partner later in life, being in a second long-term relationship, or having experienced the loss of a child (ASRM 2016; Sauer 2013). Younger women may also need oocyte donation if their fertility has been compromised by gonadotoxic agents (for example due to chemotherapy) or if they have a genetic inheritable disorder or primary ovarian insufficiency (Yeh et al. 2014).

In the current study we were not able to confirm if the women donating oocytes were known to the recipients because this information is not collected by VARTA. As Australian women must rely on altruistic egg donors, the donors are often family members, close friends, or colleagues who may be closer in age to the recipients than compensated donors might have been (Hammarberg, Johnson & Petrillo 2011). Additional to local donation, patients in Victoria have legally been able to recruit oocyte donors from The World Egg Bank since 2013.

Intrafamily donation is not uncommon and generally regarded positively. One of the first studies to report on this was by Sauer and colleagues (Sauer et al. 1988) who surveyed a small group of couples undergoing IVF with donated oocytes. They concluded that the acceptability of using a sister for gamete donation is high among couples desiring oocyte donation. More recent studies also demonstrate that women prefer sisters as their donors because they value the genetic connection with the child (Jadva et al. 2011; Laruelle et al. 2011). A recent survey of more than 2000 United States residents by Bortoletto et al. (2018), reported that oocyte donation from a family member was viewed favourably by 86% of the

respondents as it made access to oocytes a reality for infertile individuals or couples.

### **Oocyte Ageing**

Previous studies on oocyte donation have indicated that oocyte ageing makes a much larger contribution than uterine deterioration to the age-related decline of fecundity and that oocytes from younger donors markedly improves the chances of pregnancy in women of advanced reproductive age (Wang, Farquhar & Sullivan 2012; Noyes et al. 2001; Stolwijk et al. 1997). This is supported by the findings of the current study: when the oocyte recipients' and donors' ages were combined, (i) the highest CLBR was in recipients aged 35-39 years with donors aged <30 years (51.1%), and (ii) the lowest CLBR was in recipients aged  $\geq 45$  years with donors aged  $\geq 40$  years (5.3%). However, if a recipient woman aged  $\geq 40$  years received oocytes from a donor  $\leq 34$  years, they had a similar chance of having a live birth as a younger recipient with a young donor. In order to eliminate the possibility of a confounder, we adjusted for both the age of the donor and the age of the recipient and there was no similarity found between their ages.

When looking at the donor's age alone, the CLBR was 5.1% for recipients with donors aged over 41 years. The latest Australian and New Zealand Assisted Reproductive Data report shows that the cycle specific live birth rate for women aged 40-44 years using their own eggs was 4.9% after the fourth cycle and 3.9% after eighth cycle (Fitzgerald et al. 2018). This indicates that the age of oocyte is a critical factor and lends support to the requirement for an upper age limit for oocyte donors. Recipients with donors aged 40 or younger can succeed one live birth per every five oocyte donation/recipient arrangements.

The need to move to reporting CLBR based on individual patient data, rather than live birth rates per cycle, has been highlighted (Maheshwari, McLernon & Bhattacharya 2015; Malizia, Hacker & Penzias 2009). Currently, the success rate of ART is generally reported as the number of clinical pregnancies or live births per single fresh or frozen/thaw embryo transfer. McLernon and colleagues (2016) agree that the CLBR is more meaningful to women/couples and clinicians than cycle-based success rates making the results of this study relevant for clinicians and patients.

### **Study Limitations**

A limitation of this population-based study is the lack of information available on clinic-specific protocols and processes for ART and the potential impact of these on clinical outcomes. The management of both female gametes (such as oocyte degeneration and choice of ICSI timing) and male gametes (such as DNA fragmentation) may affect the efficacy of ART treatments (Rubino et al. 2016). Further studies are required to evaluate the influence of these kinds of technical aspects on clinical outcomes. Demographic confounders including obesity and cigarette smoking, medical complications and other residual confounders, which may have affected the findings of this study, are not recorded in the VARTA dataset. In addition, information about the cause of infertility was not recorded in around one third of cases. While judged as unlikely, these missing data may have influenced the study findings.

### **Conclusion**

In conclusion, this study suggests that the age of the oocyte donor is critical to the CLBR and is independent of the recipient woman's age. The cumulative success rates derived from the present data can be used in the counselling of

couples at the start of treatment or when making decisions about treatment continuation, if one or more cycles have been unsuccessful. The findings of this study lend support to the requirement for an upper age limit for oocyte donors. From a public health perspective, there is justification for advocating oocyte donors, ideally  $\leq 35$  years but under 41 years, with the aim to reach above 20% CLBR.

### **Author's roles**

All authors contributed to the conceptualisation of the study. A.Y.W. designed the study; Z.L. carried out the statistical analyses; and R.H. drafted the manuscript. All authors contributed to the interpretation of the data and critically revised and approved the final manuscript.

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### **Funding**

No funding was received for this study

### **Conflict of interest**

None



## 5.6 REFERENCES

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**Table 9: Selected demographics of participants in oocyte donor/recipient cycles**

	Oocyte recipients' age group (years)						All ages (n=1,490)
	<35 (n=191)	35-37 (n=171)	38-40 (n=246)	41-42 (n=234)	43-44 (n=270)	≥45 (n=378)	
<b>Donors' age group(years)</b>							
Mean (yr)	32.8	33.9	34.9	33.9	33.5	33.2	33.7
< 30	44(23.1)	31(18.2)	26(10.6)	40(17.1)	59(21.9)	93(24.6)	293(19.7)
30-34	80(41.9)	53(31.0)	75(30.5)	69(29.5)	73(27.0)	107(28.3)	457(30.7)
35-37	42(22.0)	57(33.3)	81(32.9)	72(30.8)	68(25.2)	94(24.9)	414(27.8)
38-40	23(12.0)	25(14.6)	46(18.7)	39(16.6)	51(18.9)	50(13.2)	234(15.7)
≥41	2(1.0)	4(2.3)	16(6.5)	12(5.1)	17(6.3)	27(7.1)	78(5.2)
Unknown	0(0)	1(0.6)	2(0.8)	2(0.9)	2(0.7)	7(1.9)	14(0.9)
All	<b>191(100)</b>	<b>171(100)</b>	<b>246(100)</b>	<b>234(100)</b>	<b>270(100)</b>	<b>378(100)</b>	<b>1490(100)</b>
<b>Infertility diagnosis (%)</b>							
Male factor	22(11.5)	24(14.0)	29(11.8)	26(11.1)	37(13.7)	45(11.9)	183(12.3)
Female factor	54(28.3)	40(23.4)	59(24.0)	46(19.7)	63(23.3)	101(26.7)	363(24.4)
Combined male/female	33(17.3)	34(19.9)	38(15.4)	44(18.8)	37(13.7)	61(16.1)	247(16.6)
Unexplained	18(9.4)	16(9.4)	27(11.0)	23(9.8)	27(10.0)	45(11.9)	156(10.5)
Not stated	64(33.5)	57(33.3)	93(37.8)	95(40.6)	106(39.3)	126(33.3)	541(36.3)
<b>Previous pregnancy of ≥20 weeks gestation</b>							
	27(14.1)	35(20.5)	55(22.4)	54(23.1)	50(18.5)	106(28.0)	327(21.9)

**Table 10: Treatment factors of embryo transfer cycles**

	Oocyte recipient's age group (years)						All ages (n=1,490)
	<35 (n=191)	35-37 (n=171)	38-40 (n=246)	41-42 (n=234)	43-44 (n=270)	≥45 (n=378)	
<b>Fertilization procedure</b>							
ICSI <sup>a</sup>	227(83.2)	212(83.5)	342(89.8)	328(90.4)	393(88.1)	590(87.3)	2092(87.4)
<b>Stage of embryo development</b>							
Blastocyst	137(50.2)	117(46.1)	174(45.7)	159(43.8)	194(43.5)	316(46.7)	1097(45.8)
<b>Number of embryos transferred</b>							
1	207(75.8)	178(70.1)	289(75.9)	278(76.6)	333(74.7)	574(80.9)	1832(76.6)
2	66(24.2)	76(29.9)	92(24.1)	85(23.4)	113(25.3)	129(19.1)	561(23.4)
<b>Total</b>	<b>273</b>	<b>254</b>	<b>381</b>	<b>363</b>	<b>446</b>	<b>676</b>	<b>2393</b>

<sup>a</sup>Intracytoplasmic Sperm Injection

**Table 11: Cumulative live birth rates in oocyte recipient cycles by age of recipients and donors**

	Cumulative Live birth		
	Rate (%)	HR hazard ratio	AHR adjusted hazard ratio
<b>Recipient's age (years)<sup>a</sup></b>			
<35	41.4%	Ref	Ref
35-37	38.0%	0.93(0.67,1.29)	1.07(0.73,1.56)
38-40	31.7%	0.71(0.52,0.97)	0.90(0.62,1.30)
41-42	32.9%	0.77(0.56,1.06)	0.88(0.59,1.30)
43-44	37.8%	0.88(0.65,1.17)	1.06(0.73,1.54)
≥45	33.3%	0.74(0.56,0.98)	0.92(0.63,1.33)
<b>Donor's age (years)</b>			
<30	44.7%	Ref	
30-34	43.3%	1.01(0.81,1.26)	1.07(0.84,1.36)
35-37	33.6%	0.75(0.59,0.96)	0.80(0.61,1.03)
38-40	22.6%	0.55(0.40,0.75)	0.60(0.43,0.86)
≥41	5.1%	0.13(0.05,0.36)	0.14(0.04,0.44)

<sup>a</sup>Adjustment was made for male age, parity and cause of infertility

**Table 12: Cumulative live birth rate by recipient and donor ages**

Donor age	Recipient age				
	<35	35-39	40-44	≥45	All
<30	50.0%	51.1%	40.4%	44.1%	44.7%
30-34	46.3%	42.4%	47.2%	35.5%	43.3%
35-39	28.8%	30.7%	30.3%	33.8%	31.0%
≥40	37.5%	10.0%	10.4%	5.3%	10.5%
All	41.4%	35.3%	34.8%	33.3%	35.4%

## CHAPTER 6: STUDY 3

This chapter is a paper which has been submitted to *Human Fertility* and revisions are being finalised:

**Hogan, R.G.**, Hammarberg, K., Wang, A.Y. & Sullivan, E.A. 2020, 'Battery hens' or 'nuggets of gold': a qualitative study on the barriers and enablers for altruistic egg donation', *Human Fertility*, under review, finalising revisions.

<b>Declaration of the authors' and role in the study</b> (signatures can be provided on request)
<b>Rosemarie Hogan</b> – drafted manuscript, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Karin Hammarberg</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Alex Y. Wang</b> – designed the study, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Elizabeth Sullivan</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript

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## **6.1 ABSTRACT**

The demand for donated eggs outstrips supply in countries such as Australia where only altruistic egg donation is permitted. We conducted semi-structured interviews with women ( $n = 18$ ), who had donated eggs in Australia in the last three years, to identify barriers and enablers for altruistic egg donation. Women reported difficulties in accessing trusted information on all aspects of egg donation and limited public awareness about the need for donor eggs. They generally had a good experience of pre-donation counselling and of the care provided by the fertility clinic staff. However, post-donation follow-up was deemed inadequate. Participants offered suggestions for how public education campaigns could enhance awareness about egg donation and how clinics could improve the post-donation experience. The findings indicate that the availability of independent, easily accessible, evidence-based information on egg donation; improved public awareness about the need for donor eggs; and proactive recruitment of donors may increase the local supply of donor eggs. Better clinic follow-up care, including post-donation counselling, would improve donors' experience of altruistic egg donation.

### **KEYWORDS:**

egg donation / altruistic / qualitative research / experience / motivation / recruitment

## CHAPTER 7: STUDY 4

This chapter is a paper which has been submitted to *Reproductive BioMedicine Online* and is being considered for publication.

**Hogan, R.G.**, Hammarberg, K., Frawley, J., Wang, A.Y. & Sullivan, E.A. 2020, 'Recipients' experiences of altruistic egg donation in Australia', *Reproductive BioMedicine Online*, under review.

<b>Declaration of the authors' and role in the study</b> (signatures can be provided on request)
<b>Rosemarie Hogan</b> – drafted manuscript, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Karin Hammarberg</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Jane Frawley</b> - contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Alex Y. Wang</b> – designed the study, contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript
<b>Elizabeth Sullivan</b> - contributed to conceptualisation of study, contributed to the interpretation of the data, critically revised and approved the final manuscript

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## **7.1 ABSTRACT**

### **Research question:**

What are the experiences of women who receive altruistically donated eggs?

### **Design:**

Semi-structured interviews were conducted with 17 women, who had received altruistically donated eggs in Australia in the last three years, to explore their experiences of egg donation. Interview transcripts were analysed thematically.

### **Results:**

Four overarching themes emerged from the interviews: “Navigating the egg donation process”; “Becoming a mother”; “Donor relationship”; and “Disclosure: deciding whom to tell and how to tell”. Among the many challenges women identified, finding an altruistic egg donor was particularly difficult. Women also described grief about being unable to have a genetically related child and ambivalence regarding whom to tell about the way they had conceived. Counselling was seen as helpful to manage these emotions.

### **Conclusions:**

In Australia, where only altruistic donation is permitted, the demand for donor eggs outstrips supply. Public health campaigns to raise community awareness of the need for donor eggs and the establishment of a national body to facilitate connections between altruistic donors and recipients may increase the availability of donor eggs. Counselling plays an essential role in helping women manage the emotional aspects of donor conception. The findings of this study can be used to guide future research, improve the standard of care for recipients, and inform public health policy.

## **CHAPTER 8: DISCUSSION AND CONCLUSION**

### **8.1 INTRODUCTION**

This thesis explored the factors that contribute to a woman's chance of having a baby, with assisted reproductive technology (ART) using donor eggs. Globally, in recent years, there has been a shift towards later childbearing. In Australia, the birth rates for women  $\geq 40$  years are 12.9 births per 1,000 women in 2017, compared to 4.4 births in 1980 (Australian Bureau of Statistics 2018). Reasons cited for this trend include improved access to reliable contraception, women's greater participation in education, developing a career, and the erroneous belief that ART can extend the reproductive lifespan (Schmidt et al. 2012; te Velde et al. 2012; Mills et al. 2011). The lack of a partner willing to commit to parenthood has also been cited as a reason for delayed childbearing (Hammarberg et al. 2017). Simultaneously, there has been an increase in the use of ART treatments by women  $\geq 40$  years. In Australia and New Zealand, almost a quarter (23.4%) of all ART treatment cycles in 2017 were undertaken by women aged  $\geq 40$  years compared to 16.1% in 2007 (Newman et al. 2019).

Considering more women in Australia  $\geq 40$  years are accessing ART, and are likely to continue to do so, the findings of this body of work are timely. The four studies undertaken, and reported in Chapters 4 to 7, provide new information for clinicians, health policymakers and infertile women, on their chances of having a baby through egg donation. During the process of data integration, the research questions and objectives raised in this thesis were answered, providing a deeper understanding of egg donation. Mixing the data enabled the development of a

series of recommendations to improve the clinical care for women who donate their eggs and for the recipients of donated eggs.

## **8.2 PRIMARY FINDINGS**

### **8.2.1 Phase 1: quantitative data**

Women  $\geq 40$  years accessing assisted reproductive technology (ART) due to age-related infertility face the dilemma of deciding between using their own eggs or donor eggs. However, there is limited population-based evidence available to guide them or their fertility specialists.

The aim of Study 1 (Chapter 4) was to compare the cumulative live birth rate (CLBR) of women aged  $\geq 40$  years using their own oocytes, to women of a similar age, using donor oocytes. The CLBR is advocated as a more useful way of presenting the chance of success for both patients and clinicians because it includes the added opportunity offered by both fresh and frozen embryos, and provides an overall estimate of the possibility of having a baby following one stimulated cycle (Chambers et al. 2017). A population-based retrospective cohort study was used to compare the data from all women aged  $\geq 40$  years undergoing ART with donated ( $n=987$ ) or autologous ( $n=19\ 170$ ) oocytes in Victoria, Australia between 2009 and 2016.

Across all age groups, women in the donor group were five times more likely to have a baby than women in the autologous group. The cumulative live birth rate (CLBR) ranged from 28.6% - 42.5% in the donor group, compared to 1.4% - 12.5% in the autologous group. The discrete-time survival analysis with 95% CI demonstrated significant AOR on CLBR across all ages (range AOR: 2.56, 95% CI: 1.62–4.01 to AOR: 15.40, 95% CI: 9.10–26.04). This study demonstrated that

women aged  $\geq 40$  years, using donor oocytes had a significantly higher CLBR than women using autologous oocytes.

The purpose of Study 2 (Chapter 5) was to further explore the impact of the donor's and recipient's age on the CLBR in egg donation cycles. For this population-based cohort study, the data was obtained from all the ART clinics in Victoria, Australia with permission from VARTA. All women using donated oocytes ( $n=1,490$ ) between 2009 and 2015 were included. The association between the donor's and recipient's age and CLBR was modelled by multivariate Cox proportional hazard regression with the following covariates adjusted for: male partner's age, recipient parity and cause of infertility.

We found that there was a significant relationship between the donor's age and the CLBR. The CLBR for recipients with donors aged  $<30$  years and 30-34 years was 44.7% and 43.3% respectively. This decreased to 33.6% in donors aged 35-37 years, 22.6% in donors aged 38-40 years and 5.1% in donors aged  $\geq 41$  years. Recipients with donors aged 38-40 years had 40% less chance of achieving a live birth (AHR 0.60, 95% CI 0.43-0.86) compared to recipients with donors aged  $<30$  years. Recipients with donors aged  $\geq 41$  years had 86% less chance of achieving a live birth (AHR 0.14, 0.04-0.44). The multivariate analysis showed no significant effect of the recipient's age on CLBR.

In summary, we demonstrated that the age of the egg donor is critical to the CLBR and is independent of the recipient woman's age. Recipients using eggs from donors aged  $\geq 35$  years had a significantly lower CLBR when compared to recipients using oocytes from donors aged  $<35$  years. This is in keeping with previous cycle based studies (Wang, Farquhar & Sullivan 2012), which shows

that the age of the egg donor at the time of donation is critical for the chance of success.

### **8.2.2 Phase 2: qualitative data**

After analysing the findings from Phase 1 of this thesis, it was evident that a high proportion of Australian women in their 40s, who access ART, use their own eggs despite the minimal chance of having a baby as a result. The shortage of donated eggs in Australia may partly explain this trend. Kalfoglou and Gittelsohn (2000) suggest that improved donor satisfaction is likely to improve donor recruitment and retention. However, little is known about the experiences of altruistic egg donors in Australia.

The aim of Study 3 (Chapter 6) was to explore the experiences and motivations of altruistic egg donors in Australia, and identify potential enablers or barriers to altruistic donation. A targeted advertisement was placed in the VARTA March 2019 newsletter inviting women who had donated eggs altruistically in Australia within the last three years to participate in this study. In total 18 women who fitted the criteria were interviewed using a semi-structured interview guide between March and July 2019. All questions were open-ended and framed as invitations for participants to describe their experiences in their own words, with follow-up prompts inviting elaboration when needed. Three overarching themes emerged from the interviews: “Awareness of egg donation”, “Motivation for egg donation”, and “Experience of egg donation”.

Throughout participants’ accounts, it was apparent that their knowledge and awareness of egg donation was limited or non-existent before they encountered someone with fertility problems or accidentally came across the topic of egg

donation in the media. This finding has highlighted an unmet need for independent, easily accessible, evidence-based information on egg donation.

Participants identified a number of factors that motivated them to donate their eggs such as their desire to help others experience motherhood. However, they also identified a number of barriers for egg donors such as feeling undervalued and receiving limited emotional support. These findings highlight the need to enhance the overall donor experience including follow-up care for egg donors. This is in line with Soderstrom-Anttila and colleagues' (2016) study of altruistic egg donors, which found that donors want more psychosocial support and discussion after the donation procedure.

As the trend towards delayed parenthood is on the rise, the demand for ART with egg donation is growing (Newman et al 2019). However, finding an egg donor can be difficult in Australia where only altruistic donation is permitted. Thus the need for donated eggs outstrips supply (Gorton, 2019). The aim of Study 4 (Chapter 7) was to explore how recipient women navigate, understand, and experience the process of egg donation.

Data was collected using semi-structured interviews with 17 women throughout Australia who had received altruistically donated eggs in the last three years. Participants responded to a targeted advertisement placed in the VARTA March 2019 newsletter. All interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis.

Consistent with other studies on women who have ART with donor eggs, most participants were in their 40s and well educated (Newman et al. 2019; Bracewell-Milnes et al 2016). The main reason cited for having ART with donor eggs was

repeated failure with their own eggs. This is in keeping with the findings from Study 1, which showed that most women in their 40's undergoing ART use their own eggs despite the minimal chance of having a baby as a result (Hogan et al., 2020). This may reflect a preference for biologically related children and societal expectations of family formation (Sylvest et al. 2018; Vassard et al. 2016; Pennings et al. 2014; Hammarberg et al. 2013; Schmidt et al. 2012).

However, women also reported that finding an altruistic egg donor was particularly difficult. Most participants sourced the donor eggs themselves from either relatives or friends, through friends of friends, or from an online egg donation forum. This serious shortage of donor eggs results in treatment choice constraints for women who might have a better chance of success with donor eggs (Gorton 2019).

Women suggested the establishment of an independent body to proactively recruit donors and to facilitate the connection between donors and recipients making it easier for them to find a donor. This is in line with the Gorton (2019) report which found that there is insufficient emphasis on public education about egg donation in Australia and advocates for recruitment campaigns to increase the number of egg donors.

Women described experiencing grief about being unable to have a genetically related child. Kirkman (2008) reported similar findings of grief and a sense of failure among egg recipients. Other experiences described by women in our study included ambivalence around disclosure of donor conception for fear of being stigmatised. Little is known about recipients' experiences of telling others about using donor eggs (Indekeu et al. 2013). Counselling played an essential role in helping women in our study manage the emotional aspects of donor

conception. Martin and colleagues (2019) in their qualitative study highlighted the need for counselling prior to egg donation to give both donors and recipients the opportunity to explore the impact of donation. The findings of this study contribute to the limited research on women who receive altruistic donor eggs in Australia and can be used to improve the standard of care for recipients.

## **8.3 IMPLICATIONS OF FINDINGS**

### **8.3.1 Implications for women**

A key message for women resulting from this body of work is that female fertility declines with increasing age and that ART cannot reliably compensate for the associated decline in fecundity. For older women contemplating ART, they often face the reproductive dilemma of choosing between using their own (autologous) or donor eggs. In the first population-based cohort study of this body of research the CLBR ranged from 28.6 to 42.5% in the donor group compared to 1.4% to 12.5% in the autologous group. These results demonstrate that women  $\geq 40$  years using donor eggs are five times more likely to have a live birth than women using their own eggs.

A second key message for women contemplating ART with donor eggs is that they should have an egg donor who is  $\leq 37$  years but ideally  $\leq 35$  years as the age of the donor egg is critical to success. The second population-based cohort study in this body of research provided statistics on the effect of the egg donor's age on the cumulative live-birth rate (CLBR), defined as at least one live birth after one stimulated oocyte donation cycle, including fresh and any associated frozen embryo transfers. The study demonstrated an association between the donor's age and CLBR. Women with donors aged  $\geq 35$  years had a statistically



significantly lower CLBR, regardless of the recipient woman's age. However, recipient women aged  $\geq 40$  years who received eggs from a donor  $\leq 34$  years, had a similar chance of having a live birth as a younger recipient with a young donor.

While previous cycle-based evidence demonstrated that live birth rates with oocyte donation are dependent on the age of the donor (Wang, Farquhar & Sullivan 2012), this was the first study to have evaluated the CLBR in women who have received donated oocytes. It is argued that the CLBR has more significance for recipients because it provides an overall estimate of the chance of having a baby after one stimulated donation cycle, which includes fresh and any associated frozen embryo transfers.

However, this research shows that most women in their 40s who access ART use their own eggs despite the minimal chance of having a baby as a result. A possible explanation for this is the acute shortage of donor eggs in Australia, where legislation only allows altruistic gamete donation. This results in treatment choice constraints for women who might have a better chance of success with donor eggs (Gorton 2019). The qualitative findings in this thesis highlighted that women experience difficulties finding an egg donor. While some were able to source eggs from women in their family or from women they knew, others had success seeking out 'unknown' donors through online forums or advertising in local newspapers. However, currently in Australia, these informal channels are unregulated and lack screening processes, so it is recommended that women use caution when advertising for an egg donor.

Recipient women interviewed as part of this body of research spoke positively about their counselling experience and its role in helping them manage the emotional aspects of donor conception. It is recommended that women

communicate with their fertility doctor, nurses and counsellors as they navigate the egg donation process to assist them with their treatment decisions and emotions.

### **8.3.2 Implications for clinicians**

Findings reported in this thesis show that women  $\geq 40$  years using donor oocytes were five times more likely to have a live birth than women using autologous oocytes. However, the results suggest that the age of the oocyte donor is critical to the CLBR and is independent of the recipient woman's age. The findings lend support to the requirement for an upper age limit for oocyte donors. Therefore, it is recommended to inform women that the donor should ideally be  $< 40$  years or for an even better chance of success, younger than 35 years.

The cumulative success rates derived from the research can be used when counselling women or couples making treatment decisions such as using donor eggs, or undergoing treatment continuation if one or more cycles have been unsuccessful. It is recommended to move to reporting CLBR based on individual patient data, rather than live birth rates per cycle. Currently, the success rate of ART is generally reported as the number of clinical pregnancies or live births per single fresh or frozen/thaw embryo transfer. McLernon and colleagues (2016) and Maheshwari and colleagues among others agree that the CLBR is more meaningful to women/couples and clinicians than cycle-based success rates making the results of this study relevant for clinicians and patients.

In light of the current shortage of donor eggs in Australia, clinics can take a number of steps, as identified in this thesis, to improve donor satisfaction and to improve donor recruitment and retention. The egg donors interviewed in this

research reported feeling undervalued which is a problem for recruitment of donors. In particular they reported the need for more open, clear, timely, and consistent communication and continuity of care. Williams and Machin (2018) found these aspects of care to be critical for optimal donor satisfaction. In Victoria, the recent review of ART services (Gorton 2019) also found that donors feel unappreciated which is a problem for the recruitment of donors. To increase the number of donors it is recommended that clinics provide person-centred care and emotional and mental health support for egg donors (Gorton, 2019). There is also a recognised need to enhance follow-up care for egg donors to improve their experience. This is in line with Soderstrom-Anttila and colleagues' (2016) study of altruistic egg donors, which found that donors want more psychosocial support and discussion after the donation procedure.

Our findings suggest that women who receive donor eggs are satisfied overall with their health care experience. In particular, recipients reported that counselling was very important to help them with the emotional aspects of egg donation and with establishing positive donor/recipient relationships. In light of this, it is even more important that clinicians encourage women to attend counselling sessions.

### **8.3.3 Implications for health policy makers**

In Australia there is an increasing number of women over 40 years having babies (Newman et al 2019). This is concerning as there is reliable evidence of the negative effects of increasing maternal age on fertility and obstetric outcomes (Biro et al. 2012; Schmidt et al. 2012; De Graff et al. 2011). Targeted national education campaigns are required to promote awareness of the factors that influence fertility and to encourage childbearing when the chance of spontaneous

conception is greatest. Our data shows that the majority women in their 40s undergoing ART use their own eggs despite the minimal chance of having a baby as a result. Considering that a woman's age is the most important factor determining the chance of conception, increasing young people's awareness especially on the effects of age on fertility is essential to allow them to make informed decisions about the timing of family formation. Prior et al. (2018) found in their study of Australian University students that most people want and expect to have children but lack of awareness about the biological limits of fertility which may reduce their chance of achieving their parenthood goals. It is recommended that priority is given to public fertility education to help women and men understand the impact of age on fertility so they can make fully informed choices and decisions.

To reduce the conflicts young people might face between family formation and other life goals such as study and career aspirations, there are a number of social policies which could be strengthened in Australia, such as policies that make provision of flexible working hours for people with young children mandatory rather than optional and increased government support for access to high quality and affordable childcare. Such policies may give both men and women confidence to start their families at a younger age and in turn increase the likelihood that they will fulfil their reproductive goals.

Women using eggs from donors in our research were five times more likely to have a baby than women using their own eggs. This evidence confirms that the age of the egg donor is critical and lends support for the requirement of an upper age limit for egg donors in Australia. There is a need to improve education about fertility to counter a growing perception that ART is a reliable 'safety net' for

women who may seek to become pregnant in their late 30s or early 40s. It is important that women and men are provided with verbal and written information about the range of physical and emotional impacts of infertility and ART and the value of supportive counselling in assisting them to manage these.

The few available studies on access to ART suggest that affordability is a powerful determinant of whether couples pursue treatment (Connolly, Hoorens & Chamber 2010; Chambers et al 2009). It is recommended that an upper age limit and funding limits for ART treatment are imposed on women who wish to use their own eggs. Better and more transparent information on the full costs of ART treatment and success rates would enable people to make more informed choices especially if they are considering or receiving ART.

The qualitative findings indicate that women have difficulties finding an egg donor and there is a lack of public awareness about the need for donor eggs. Public health strategies such as e campaigns to improve community awareness of egg donation, are required to increase the recruitment of egg donors in Australia. An independent public body like an egg bank should be considered as it may also serve this purpose (Gorton 2019). An egg bank that is operated by health professionals could also facilitate matching between recipients and donors, thereby alleviating some of the delays and frustrations experienced by recipients.

## **8.4 SUGGESTIONS FOR FUTURE RESEARCH**

Future research is essential to improve outcomes and the provision of care for egg donors and recipients. Further studies are required to evaluate the influence of clinic-specific protocols and processes for ART (such as the assessment of

oocyte quality and ICSI timing) as these types of technical aspects may impact clinical outcomes.

It is critical to further develop the findings in this thesis and further explore women's experiences of egg donation. For example, little is known about recipients' experiences of telling others about using donor eggs and about public perceptions of gamete recipient families (Indekeu et al. 2013). Further research is needed to explore the experiences of women who cannot find a local egg donor or are unsuccessful when they use donor eggs. In addition, further research in the form of a discrete time experiment could be designed to supplement the qualitative data and investigate the extent to which women and their partners will go to in order to have a baby.

## **8.5 LIMITATIONS**

A limitation of the quantitative studies was the disparity between the large numbers of women in the autologous groups compared to the donor group. In addition, a small proportion of women (less than 2%), were counted in both the donor and autologous groups as they were treated with autologous oocytes before being treated with donor oocytes. While judged as unlikely due to the small numbers, this may have influenced the study findings. The lack of information available on clinic-specific protocols and processes for ART (such as the assessment of oocyte quality and ICSI timing) may also potentially have an impact on clinical outcomes (Rubino et al. 2016). Demographic confounders, including obesity and cigarette smoking, medical conditions and other residual confounders, which may have affected the findings of this study, are not recorded in the VARTA dataset.

Due to the online recruitment method, there is a potential bias towards respondents of higher, rather than lower socioeconomic status which may limit the study findings. Another limitation is that only women for whom egg donation was successful participated in the study. The experiences of women who are unsuccessful when they use donor eggs may differ from those who achieve the desired outcome. Further research is needed to explore the experiences of women who are unsuccessful.

Finally, it is recognised as a limitation that the women who had ART using donor eggs in Victoria, Australia, may have had a different experience to women elsewhere in the country as Victoria has particularly rigorous ART regulation around donor conception. This could be expected to have an impact on the attitudes or experiences of some women involved in the thesis studies. In particular, this regulation required Victorian women to seek and receive Ministerial approval before advertising for egg donors and to undergo police checks before being given access to ART (though this was repealed in June 2020 after the interviews had taken place).

## **8.6 SUMMARY**

In conclusion, the research findings demonstrate that most women in their forties who access ART use their own eggs despite the minimal chance of success. We found that, across all age groups, women  $\geq 40$  years using donor oocytes were five times more likely to have a live birth than women using autologous oocytes. These findings can be used when counselling women  $\geq 40$  years to help them make informed decisions about ART and whether to use their own or donor oocytes.

The results demonstrate that the age of the egg donor is critical and thus lends support for the requirement to have an upper age limit for egg donors in Australia. Women should be informed during counselling that the donor should ideally be <40 years or for an even better chance of success, younger than 35 years.

The qualitative findings report that women experience difficulties finding an egg donor. Public health strategies such as national education campaigns on egg donation and the establishment of a public egg bank are recommended to increase donor recruitment and retention. Critically, better clinic follow-up care, including post-donation counselling, would significantly improve donors' experience of altruistic egg donation, which in turn may lead to egg donors being willing to donate more than once. Overall, the findings from this thesis contribute to the currently limited research on altruistic egg donation in Australia.



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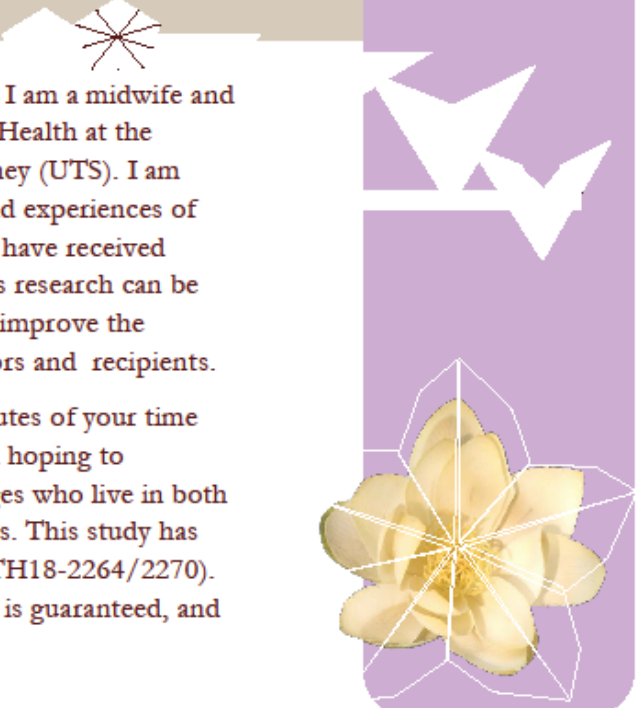
# APPENDICES

## APPENDIX 1: ADVERTISEMENT FLYER

Are you an egg donor or have you received  
donated eggs?

### Research help needed

Here is your opportunity  
to speak about your experience



My name is Rosemarie Hogan. I am a midwife and PhD student in the Faculty of Health at the University of Technology Sydney (UTS). I am researching the motivations and experiences of women who are egg donors or have received donated eggs. Insight from this research can be used by fertility clinics to help improve the experience for future egg donors and recipients.

I would need about 20-30 minutes of your time for a telephone interview. I am hoping to interview women of various ages who live in both metropolitan and regional areas. This study has ethics approval from UTS (ETH18-2264/2270). Anonymity and confidentiality is guaranteed, and you can withdraw at any time.

If you are interested in participating, I would be very grateful if you could contact me  
Rosemarie Hogan  
email: [rosemarie.hogan@student.uts.edu.au](mailto:rosemarie.hogan@student.uts.edu.au)  
or phone (02) 9451 4588

## APPENDIX 2: PARTICIPANT INFORMATION SHEET (Donor)

### Investigating the motivations and experiences women who donate eggs (oocytes)

#### **WHO IS DOING THE RESEARCH?**

My name is Rosemarie Hogan and I am a doctoral student at UTS. My supervisors are Distinguished Professor Elizabeth Sullivan ([Elizabeth.Sullivan@uts.edu.au](mailto:Elizabeth.Sullivan@uts.edu.au)) and Associate Professor Alex Wang ([Alex.Wang@uts.edu.au](mailto:Alex.Wang@uts.edu.au)), Australian Centre for Public and Population Health Research, Faculty of Health, University of Technology Sydney.

#### **WHAT IS THIS RESEARCH ABOUT?**

This research is being conducted to find out about the motivations and experience of women who donate their eggs (oocytes) in Australia where an altruistic model of donation exists. There is a lack of in-depth research exploring the donors' perspective. Insight from this research can be used by fertility clinics to identify and prioritize targets for patient-centered quality improvement projects to help improve the experience for oocyte donors in Australia.

#### **FUNDING**

No funding has been received for this project.

#### **WHY HAVE I BEEN ASKED?**

You have been invited to participate in this study because you have been identified as a woman who has volunteered to donate eggs to another woman/couple to help her/them have a baby.

#### **IF I SAY YES, WHAT WILL IT INVOLVE?**

If you decide to participate, I would like to interview you (for about 40 - 50 minutes) about your motivations and experience of egg (oocyte) donation. I will telephone or email you in advance to arrange a mutually suitable time and date. The interview will be conducted by telephone. The interview will be audio recorded and transcribed with your permission. At all times this information will be treated confidentially.

#### **ARE THERE ANY RISKS/INCONVENIENCE?**

Yes, there are some risks/inconvenience. For example, you may be asked sensitive questions and you will be required to allocate time for the interview. Should you become uncomfortable or distressed while discussing any topic during the interview, the following actions will be taken by the interviewer:

1. The researcher will suggest that it is appropriate for the interview be terminated.
2. If you wish this to happen, the interview will be ceased.
3. A recommendation will be made that you speak to your GP or a counselling professional to discuss your concerns. The contact details for *beyondblue* are **1300 22 4636 or Lifeline 13 11 14**.
4. A follow-up phone call will be made by the interviewer the following day to ensure that you are well and to determine feasibility of a follow up interview if one is planned.

#### **DO I HAVE TO SAY YES?**

Participation in this study is voluntary. It is completely up to you whether or not you decide to take part.

#### **WHAT WILL HAPPEN IF I SAY NO?**

If you decide not to participate, it will not affect your relationship with the researchers or the University of Technology Sydney. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Rosemarie Hogan: ([Rosemarie.Hogan@student.edu.au](mailto:Rosemarie.Hogan@student.edu.au)). If you withdraw from the study, the transcripts will be destroyed.

#### **CONFIDENTIALITY**

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. I plan to use the results in my doctoral thesis, publish the results in academic journals and discuss at fertility or nursing/midwifery conferences. In any publication, information will be provided in such a way that you cannot be identified.

#### **WHAT IF I HAVE CONCERNS OR A COMPLAINT?**

If you have concerns about the research, please feel free to contact me on email: [Rosemarie.Hogan@student.edu.au](mailto:Rosemarie.Hogan@student.edu.au). Alternatively, you can also contact my supervisor Associate Professor Alex Wang to discuss this research on email: [Alex.Wang@uts.edu.au](mailto:Alex.Wang@uts.edu.au).

#### **NOTE:**

This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC ETH18-2264]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: +61 2 9514 2478 or email: [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au) and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

## **APPENDIX 3: PARTICIPANT INFORMATION SHEET (Recipient)**

### **Investigating the motivations and experiences of Australian women who obtain donated eggs (oocytes)**

#### **WHO IS DOING THE RESEARCH?**

My name is Rosemarie Hogan and I am a doctoral student at UTS. My supervisors are Distinguished Professor Elizabeth Sullivan ([Elizabeth.Sullivan@uts.edu.au](mailto:Elizabeth.Sullivan@uts.edu.au)) and Associate Professor Alex Wang ([Alex.Wang@uts.edu.au](mailto:Alex.Wang@uts.edu.au)), Australian Centre for Public and Population Health Research, Faculty of Health, University of Technology Sydney.

#### **WHAT IS THIS RESEARCH ABOUT?**

This research being conducted to find out about the motivations and experience of women in Australia who obtain eggs (oocytes) from a donor. There is a need for further studies that can help enlighten women considering embarking on obtaining donated eggs (oocyte) as well as informing health professionals in the field.

#### **FUNDING**

No funding has been received for this project.

#### **WHY HAVE I BEEN ASKED?**

You have been invited to participate in this study because you have self-identified as a recipient of donated eggs (oocytes) by responding to the advertisement asking for participants in this study.

#### **IF I SAY YES, WHAT WILL IT INVOLVE?**

If you decide to participate, I would like to interview you (for about 40-50 minutes) about your motivations and experience of obtaining donated eggs (oocytes). I will telephone or email you in advance to arrange a mutually suitable time, date and place. The interview will be audio recorded and transcribed with your permission.

#### **ARE THERE ANY RISKS/INCONVENIENCE?**

Yes, there are some risks/inconvenience. For example, you may be asked sensitive questions or may experience emotional fatigue. You will be required to allocate time for the interview.

#### **DO I HAVE TO SAY YES?**

Participation in this study is voluntary. It is completely up to you whether you decide to take part.

#### **WHAT WILL HAPPEN IF I SAY NO?**

If you decide not to participate, it will not affect your relationship with the researchers or the University of Technology Sydney. If you wish to withdraw from the study once it has started, you can do so at any time without having to give a reason, by contacting Rosemarie Hogan ([Rosemarie.Hogan@student.edu.au](mailto:Rosemarie.Hogan@student.edu.au)) or Associate Professor Alex Wang ([Alex.Wang@uts.edu.au](mailto:Alex.Wang@uts.edu.au)). If you withdraw from the study, the transcripts will be destroyed.

#### **CONFIDENTIALITY**

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. All this information will be treated confidentially. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law. I plan to use the results in my doctoral thesis, publish the results in academic journals and discuss at fertility or nursing/midwifery conferences. In any publication, information will be provided in such a way that you cannot be identified.

#### **WHAT IF I HAVE CONCERNS OR A COMPLAINT?**

If you have concerns about the research that you think I can help you with, please feel free to contact me on email: [Rosemarie.Hogan@student.edu.au](mailto:Rosemarie.Hogan@student.edu.au) or 02 9514 4588. Alternatively, you can also contact my supervisor Associate Professor Alex Wang to discuss this research on email: [Alex.Wang@uts.edu.au](mailto:Alex.Wang@uts.edu.au) or telephone: 02 9514 4578. You will be given a copy of this form to keep.

#### **NOTE:**

This study has been approved by the University of Technology Sydney Human Research Ethics Committee [UTS HREC ETH18-2270]. If you have any concerns or complaints about any aspect of the conduct of this research, please contact the Ethics Secretariat on ph.: 02 9514 2478 or [Research.Ethics@uts.edu.au](mailto:Research.Ethics@uts.edu.au) and quote the UTS HREC reference number. Any matter raised will be treated confidentially, investigated and you will be informed of the outcome.

## APPENDIX 4: CONSENT FORM (Donor)

### CONSENT FORM

Investigating the motivations and experiences women who donate eggs (oocytes) in Australia

[UTS HREC ETH18-2264]

I \_\_\_\_\_ agree to participate in the research project 'Investigating the motivations and experiences women who donate eggs (oocytes) in Australia' [UTS HREC ETH18-2264] being conducted by Rosemarie Hogan, Faculty of Health, UTS.

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.

I agree to be:

Audio recorded

I agree that the research data gathered from this project may be published in a form that:

Does not identify me in any way

I am aware that I can contact Rosemarie Hogan if I have any concerns about the research.

\_\_\_\_\_  
Name and Signature [participant]

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Date

\_\_\_\_\_  
Name and Signature [researcher or delegate]

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Date

#### \* Witness to the consent process

If the participant, or if their legally acceptable representative, is not able to read this document, this form must be witnessed by an independent person over the age of 18. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. By signing the consent form, the witness attests that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the participant (or representative) and that informed consent was freely given by the participant (or representative)



## APPENDIX 5: CONSENT FORM (Recipient)

### CONSENT FORM

**Investigating the motivations and experiences of Australian women who obtain donated eggs (oocytes)**

[UTS HREC APPROVAL NUMBER: ETH18-2270]

I \_\_\_\_\_ agree to participate in the research project 'Investigating the motivations and experiences of Australian women who obtain donated eggs (oocytes)' [UTS HREC ETH18-2270] being conducted by Rosemarie Hogan, Faculty of Health, University of Technology Sydney.

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research as described in the Participant Information Sheet.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time without affecting my relationship with the researchers or the University of Technology Sydney.

I understand that I will be given a signed copy of this document to keep.  
I agree to be:

Audio recorded

I agree that the research data gathered from this project may be published in a form that:

Does not identify me in any way

I am aware that I can contact Rosemarie Hogan if I have any concerns about the research.

\_\_\_\_\_  
Name and Signature [participant]

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Date

\_\_\_\_\_  
Name and Signature [researcher or delegate]

\_\_\_\_/\_\_\_\_/\_\_\_\_  
Date

**\* Witness to the consent process**

If the participant, or if their legally acceptable representative, is not able to read this document, this form must be witnessed by an independent person over the age of 18. In the event that an interpreter is used, the interpreter may not act as a witness to the consent process. By signing the consent form, the witness attests that the information in the consent form and any other written information was accurately explained to, and apparently understood by, the participant (or representative) and that informed consent was freely given by the participant (or representative).

## **APPENDIX 6: INTERVIEW GUIDE (Donor)**

### **INTERVIEW GUIDE**

#### **Investigating the motivations and experiences women who DONATE eggs**

- Thank you for your time today
- Aim of the interview is to explore your experience as an egg donor
- Introduction – self
- Confidentiality
- Assurance that participant can ask for clarification of questions, can decline to answer a question(s) at any time, take a break or stop the interview at any time.

#### **1. Why did you choose to donate your eggs?**

Probe: Where did you first learn about egg donation?

Probe: Why did it interest you?

Probe: Did you know anything about the recipient(s)?

#### **2. What is your experience of egg donation?**

Probe: Tell me about any meetings you had with a counsellor

Probe: Tell me about getting the injections and the retrieval

Probe: What was your experience like with the clinic staff?

Probe: Tell me about the follow-up care?

#### **3. What information was especially important to you?**

Probe: What information do you have about what became of your eggs?

Probe: Tell me about your desire to have contact with any donor children?

#### **4. Tell me how you think the experience for future egg donors can be improved....**

#### **5. Tell me why you would or would not do this again.**

#### **6. What would you tell a friend who was considering being an egg donor?**

#### **7. Who have you discussed your donation with and what was their reaction?**

Probe: mother, spouse/significant other, family, extended family, friends?

#### **8. Why do you think there is a shortage of egg donors in Australia?**

Probe: What do you think about the concept of having a Donor egg bank in Australia?

Probe: What are your views on monetary compensation for egg donors?

**Is there anything else you would like to add?**

## **APPENDIX 7: INTERVIEW GUIDE (Recipient)**

### **Investigating the motivations and experiences of RECIPIENTS of donor eggs**

- Thank you for your time today
- Aim of the interview is to explore your experience as a recipient of donated eggs
- Introduction – self
- Confidentiality and consent to audio recording?
- Assurance that participant can ask for clarification of questions, can decline to answer a question(s) at any time, take a break or stop the interview at any time.

#### **1. Why did you choose to obtain donated eggs?**

Probe: Where did you first learn about egg donation?

Probe: Were you able to obtain eggs in Australia or overseas?

Probe: Did you know anything about the donor?

#### **2. What is your experience of egg donation?**

Probe: Tell me about any meetings you had with a psychologist or counsellor

Probe: Tell me about the medical screening process

Probe: Tell me about the implantation process

#### **3. Tell me about the relationship you had with the IVF clinic staff.**

Probe: Did you have the opportunity to have all your questions answered?

Probe: What information was especially important to you?

#### **4. Did you become pregnant? (If the answer is YES – probe. If the answer is NO proceed to question 6)**

Probe: – how was the pregnancy?

Probe: - Type of birth, baby's gender, weeks' gestation and health status?

#### **5. What are your arrangements for telling your child?**

#### **6. Have you used all of the oocytes/embryos?**

#### **7. Tell me why you would or would not do this again.**

Probe: What would you tell a friend who was considering donated eggs?

#### **8. Who have you discussed your donation with and what was their reaction?**

Probe: mother, spouse/significant other, family, extended family, friends?

#### **9. Why do you think there is a shortage of egg donors in Australia?**

Probe: what do you think we can do to encourage more egg donors?

#### **10. Is there anything else you would like to add?**