Imperial College London

A thorough interrogation into the egg sharing programme in the United Kingdom

Timothy Bracewell-Milnes MBBS BSc MRCOG
CID: 00331741

2016-2023

PhD Thesis

Supervisors: Dr Meen-Yau Thum and Professor Mark Johnson

Department of Metabolism, Digestion and Reproduction,
Imperial College London

PhD student

Timothy Bracewell-Milnes MBBS BSc MRCOG
Consultant Obstetrician and Gynaecologist
Sub-specialist in Reproductive Medicine
PhD Student at Imperial College London
Department of Metabolism, Digestion and Reproduction, Imperial College London
Chelsea and Westminster Hospital Campus
369 Fulham Road
London
SW10 9NH

Supervisors

Meen-Yau Thum
Fertility Specialist
Honorary Clinical Lecturer, Imperial College London
Lister Fertility Clinic
Chelsea Bridge Road
London
SW1W 8RH

Professor Mark Johnson
Professor in Obstetrics
Department of Metabolism, Digestion and Reproduction, Imperial College London
Chelsea and Westminster Hospital Campus
369 Fulham Road
London
SW10 9NH

Dedicated to my wife, Sarah…

No words can describe my gratitude to you for everything you have done in helping me through these last seven years

Acknowledgements

I would like to start by thanking my mother and late father, for all the guidance they have given me throughout my life. I am so fortunate to have had such a fantastic upbringing without which it would not have been possible to be where I am today.

I would like to offer a huge thanks to Professor Mark Johnson, for your help and support in supervising me during this project over the last seven years. I know there have been some hurdles to get to this point and I would like to thank you for putting me first, and being flexible with the PhD project. I am also very grateful for your help in switching my clinical activities during the PhD from the on call obstetrics and gynaecology rota, to working as a clinical fellow on the assisted conception unit at Chelsea and Westminster, which has helped me enormously in my career progression.

None of this would have been possible without my amazing wife, Sarah, who has held everything together while I have been working full time and also writing up a PhD thesis, which has been a trying task. We are also blessed with our beautiful three children: Annie, Cora and Sam. Thank you little ones for being you, you have been a welcome distraction and constantly remind me what is most important in life.

I would like to thank the fantastic egg donation team at the Lister Fertility Clinic. I am so lucky to now work alongside you, but you were so kind and helpful to me when I was there as a research fellow. The care you provide our patients is phenomenal and I hope reflected in some of the findings of this thesis.

My final thanks must go to my other PhD supervisor, Dr Yau Thum for all that you have done for me since we met, both academically and clinically. I know this thesis was not your initial plan, but I am so grateful to you for coming up with a plan B which you instigated so quickly, and has generated so much research output. I have always enjoyed our meetings immensely and am particularly grateful for your

passion, loyalty, humour and academic brain. There is no doubt in my mind that you have been the person who has had the most significant influence on me in my career, and all I can do is say thank you!

Declaration of originality

This work is submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

At Imperial College London

The work presented in this thesis is my own except where indicated.

I would also like to make clear that this thesis has generated 5 peer-review publications. Although the work submitted and published in these journals was entirely my own, following on from the advice of my supervisors due to Imperial's 'self-plagiarism' rule, great efforts have been made to change the wording from these publications. However, there may inevitably be some repetition in the methodology and results sections of these studies.

Copyright declaration

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Publications and presentations relevant to thesis

Peer review publications

March 2022: Does egg-sharing negatively impact on the chance of the donor or recipient achieving a live birth? **Bracewell-Milnes T**, Hossain A, Jones BP, Faris R, Parikh J, Nicopoullos J, Johnson M, Thum MY. Hum Fertil (Camb). 2022 Mar 25:1-10. doi: 10.1080/14647273.2022.2053213.

July 2021 Exploring the knowledge and attitudes of women of reproductive age from the general public towards egg donation and egg sharing: a UK-based study. **Bracewell-Milnes T**, Holland JC, Jones BP, Saso S, Almeida P, Maclaran K, Norman-Taylor J, Nikolaou D, Shah NM, Johnson M, Thum MY.Hum Reprod. 2021 Jul 19;36(8):2189-2201. doi: 10.1093/humrep/deab157.

April 2019 Investigating attitudes towards oocyte donation amongst potential donors and the general population: a systematic review. Platts S, **Bracewell-Milnes T**, Saso S, Jones B, Parikh R, Thum MY. Hum Fertil (Camb). 2019 Apr 15:1-13. doi: 10.1080/14647273.2019.1602736

March 2019 Investigating knowledge and perceptions of egg sharing among healthcare professionals in the United Kingdom. **Bracewell-Milnes T**, Rajendran S, Saso S, Jones B, Platts S, Cato S, Thum MY. Eur J Obstet Gynecol Reprod Biol. 2019 Mar 6;236:98-104.

May 2017 A systematic review investigating psychosocial aspects of egg sharing in the United Kingdom and their potential effects on egg donation numbers. **Bracewell-Milnes T**, Saso S, Abdalla H, Thum MY. Hum Fertil (Camb). 2017 May 26:1-11. doi: 10.1080/14647273.2017.1329554.

March 2016 Investigating psychosocial attitudes, motivations and experiences of oocyte donors, recipients and egg sharers: a systematic review. **Bracewell-Milnes T**, Saso S, Bora S, Ismail AM, Al-Memar M, Hamed AH, Abdalla H, Thum MY. **Human Reproduction Update**. 2016 Mar 24

Presentations at international conferences

January 2023 — Young oocyte donors do not negatively impact live birth rates in their recipients. **Bracewell-Milnes T**, Aziz S, Nicopoullos J, Bora S, Faris R, Parikh J, Thum M-Y. **Oral presentation** at British Fertility Society Conference, Belfast.

January 2022: — Investigating psychological attitudes, motivations and experiences of egg sharers and recipients. **Bracewell-Milnes T**, Wren M, Faris R, Parikh J, Nicopoullos J, Thum, M-Y. **Poster presentation** at British Fertility Society Conference, Virtual.

January 2022: — Comparison of knowledge and attitudes between fertility patients and the general public towards age-related fertility decline, egg donation and egg sharing. **Bracewell-Milnes T**, Wren M, Faris R, Parikh J, Nicopoullos J, Thum, M-Y. **Poster presentation** at British Fertility Society Conference, Virtual.

January 2022: — A systematic review investigating the psychosocial attitudes and disclosure decisions of oocyte recipients. **Bracewell-Milnes T**, Wren M, Faris R, Parikh J, Nicopoullos J, Thum, M-Y. **Poster presentation** at British Fertility Society Conference, Virtual.

January 2021 — Knowledge and attitudes towards egg donation and egg sharing among women in the UK general public. **Bracewell-Milnes T**, Holland J, Maclaran K, Norman-Taylor J, Nikolaou D, Thum MY. **Oral presentation** at British Fertility Society Conference, Virtual.

January 2021 — Does egg sharing compromise the chance of donors or recipients achieving a live birth? **Bracewell-Milnes T,** Hossain A, Faris R, Johnson M, Thum MY. **Poster presentation** at British Fertility Society Conference, Virtual.

January 2021 — Investigating psychological attitudes, motivations and experiences of oocyte donors and egg sharers. **Bracewell-Milnes T**, Inparaj S, Saso S, Jaya Parikh, Thum MY. **Poster presentation** at British Fertility Society Conference, Virtual.

June 2019	Does egg sharing during fertility treatment have any impact on live birth rates for the egg sharer or recipient? **Bracewell-Milnes T**, Parikh J, Saso S, Meen-Yau Thum. **Poster Presentation** at RCOG World Congress, London, UK
June 2019	Investigating the knowledge and attitudes of medical professionals towards egg sharing. **Bracewell-Milnes T**, Saso S, Cato S, Thum M-Y. **Poster Presentation** at RCOG World Congress, London, UK
June 2019	The psychological aspects, treatment experiences and disclosure decisions of recipients of donor oocytes: a systematic review. **Bracewell-Milnes T**, Saso S, Faris R, Jones B, Thum M-Y. **Poster Presentation** at RCOG World Congress, London, UK
January 2019	The impact of egg-sharing on live birth rates for the egg-share donor and recipient? **Bracewell-Milnes T**, Faris R, Wren M, Saso S, Jones B, Thum MY. **Poster presentation** at British Fertility Society Conference, Birmingham.
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January 2017	A systematic review investigating psychological aspects of egg sharing in the UK and its clinical implications. **Bracewell-Milnes T**, Saso S, Thum MY. **Poster presentation** at British Fertility Society Conference, Edinburgh.
January 2017	A systematic review investigating psychological attitudes, motivations and experiences of oocytes recipients. **Bracewell-Milnes T**, Saso S, Thum MY. **Poster presentation** at British Fertility Society Conference, Edinburgh.

Human Reproduction Update Advance Access published March 24, 2016
Human Reproduction Update, Vol.0, No.0 pp. 1–16, 2016
doi:10.1093/humupd/dmw006

human reproduction update

Investigating psychosocial attitudes, motivations and experiences of oocyte donors, recipients and egg sharers: a systematic review

Timothy Bracewell-Milnes[1,*], Srdjan Saso[2], Shabana Bora[3], Alaa M. Ismail[4], Maya Al-Memar[2], Ali Hasan Hamed[4], Hossam Abdalla[5], and Meen-Yau Thum[5]

[1]Division of Surgery and Cancer, Institute of Developmental Reproductive & Developmental Biology, Imperial College London, Chelsea and Westminster Hospital Campus, 369 Fulham Road, London, UK [2]Division of Surgery and Cancer, Institute of Reproductive & Developmental Biology, Imperial College London, Hammersmith Hospital Campus, Du Cane Road, London, UK [3]The Lister Hospital, Chelsea Bridge Road, London, UK [4]Obstetrics & Gynecology, Faculty of Medicine, Women's Health Centre, Assiut University, Assiut, Egypt [5]The Lister Hospital, Chelsea, London, UK

*Correspondence address. Division of Surgery and Cancer, Institute of Developmental Reproductive & Developmental Biology, Imperial College London, Chelsea and Westminster Hospital, London, UK and The Lister Fertility Centre, London, UK. E-mail: tjb101@doctors.org.uk

Submitted on June 30, 2015; resubmitted on January 25, 2016; accepted on February 15, 2016

HUMAN FERTILITY, 2017
https://doi.org/10.1080/14647273.2017.1329554

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REVIEW ARTICLE

Check for updates

A systematic review investigating psychosocial aspects of egg sharing in the United Kingdom and their potential effects on egg donation numbers

Timothy Bracewell-Milnes[a], Srdjan Saso[a], Hossam Abdalla[b] and Meen-Yau Thum[b]

[a]Division of Surgery and Cancer, Institute of Developmental Reproductive & Developmental Biology, Imperial College London, London, UK; [b]Fertility Specialist, The Lister Hospital, London, UK

European Journal of Obstetrics & Gynecology and Reproductive Biology 236 (2019) 98–104

Contents lists available at ScienceDirect

European Journal of Obstetrics & Gynecology and Reproductive Biology

journal homepage: www.elsevier.com/locate/ejogrb

Full length article

Investigating knowledge and perceptions of egg sharing among healthcare professionals in the United Kingdom

Timothy Bracewell-Milnes[a,*], Sara Rajendran[b], Srdjan Saso[b], Benjamin Jones[b], Sophie Platts[b], Sarah Cato[c], Meen-Yau Thum[d]

[a] Division of Surgery and Cancer, Institute of Developmental Reproductive & Developmental Biology, Imperial College London, Chelsea and Westminster Hospital Campus, 369 Fulham Rd, London, UK
[b] Division of Surgery and Cancer, Institute of Reproductive & Developmental Biology, Imperial College London, Hammersmith Hospital Campus, Du Cane Road, London, UK
[c] The Surgery, 20 Lee Road, Blackheath, London, SE3 9RT, UK
[d] The Lister Hospital, Chelsea, London, UK

HUMAN FERTILITY
https://doi.org/10.1080/14647273.2019.1602736

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ORIGINAL ARTICLE

Investigating attitudes towards oocyte donation amongst potential donors and the general population: a systematic review

Sophie Platts[a], Timothy Bracewell-Milnes[b], Srdjan Saso[b], Benjamin Jones[b], Riya Parikh[c] and Meen-Yau Thum[d]

[a]Imperial College Healthcare Trust, Hammersmith Hospital Campus, London, UK; [b]Division of Surgery and Cancer, Institute of Developmental Reproductive & Developmental Biology, Imperial College London, London, UK; [c]St Olave's Grammar School, Orpington, UK; [d]Lister Hospital, London, UK

Human Reproduction, pp. 1–13, 2021
doi:10.1093/humrep/deab157

human reproduction

ORIGINAL ARTICLE *Psychology and counselling*

Exploring the knowledge and attitudes of women of reproductive age from the general public towards egg donation and egg sharing: a UK-based study

Timothy Bracewell-Milnes [1,2,*], James C. Holland[2], Benjamin P. Jones [2], Srdjan Saso[2], Paula Almeida[1], Kate Maclaran[1], Julian Norman-Taylor[1], Dimitrios Nikolaou[1], Nishel M. Shah[2], Mark Johnson [2,3], and Meen-Yau Thum[2,3]

[1]Assisted Conception Unit, Chelsea and Westminster Hospital, London, UK [2]Division of Surgery and Cancer, Institute of Reproductive & Developmental Biology, Imperial College London, Hammersmith Hospital Campus, London, UK [3]The Lister Hospital, The Lister Fertility Clinic, London, UK

*Correspondence address. Assisted Conception Unit, Chelsea and Westminster, Hospital, 369 Fulham Rd, London SW10 9NH, UK. E-mail: timothy.bracewell@imperial.ac.uk https://orcid.org/0000-0001-9827-4816

Submitted on January 27, 2021; resubmitted on May 24, 2021; editorial decision on June 2, 2021

HUMAN FERTILITY
https://doi.org/10.1080/14647273.2022.2053213

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ORIGINAL ARTICLE

OPEN ACCESS Check for updates

Does egg-sharing negatively impact on the chance of the donor or recipient achieving a live birth?

Timothy Bracewell-Milnes[a,b], Aleena Hossain[a], Benjamin P. Jones[a], Raef Faris[b], Jaya Parikh[b], James Nicopoullos[b], Mark Johnson[a] and Meen-Yau Thum[a,b]

[a]Imperial College London, Department of Metabolism, Digestion and Reproduction, London, UK; [b]Assisted Conception Unit, The Lister Fertility Clinic, London, UK

Abbreviations

AMH	Anti-müllerian hormone
ANOVA	Analysis of variance
ART	Assisted reproductive technologies
ASRM	American society for reproductive medicine
BMA	British Medical Association
BMI	Body mass index
BFS	British fertility society
CBRC	Cross border reproductive care
CCG	Clinical Commissioning Group
CLBR	Cumulative live birth rate
CPR	Clinical pregnancy rate
DEDS	Donor eggs donor sperm
DEPS	Donor eggs partner sperm
DOH	Department of Health
DTC	Direct to consumer
ESHRE	European Society of Human Reproduction and Embryology
ET	Embryo transfer
EU	European Union
FSH	Follicle stimulating hormone
FR	Fertilisation rate
GP	General practitioner
HCA	Healthcare assistants
HCG	Human chorionic gonadotropin
HFE	Human Fertilisation and Embryology
HFEA	Human fertilisation and embryology authority
HIV	Human immunodeficiency virus

HMG	Human menopausal gonadotropin
IBM	International business machines corporation
ICSI	Intracytoplasmic sperm injection
IR	Implantation rate
IVF	In vitro fertilisation
LBR	Live birth rate
LFC	Lister Fertility Clinic
MR	Miscarriage rate
NGDT	National gamete donation trust
NICE	National Institute for Health and Care Excellence
NHS	National health service
OHSS	Ovarian hyperstimulation syndrome
PV	Per vagina
PR	Per rectum
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
RCOG	Royal college of obstetricians and gynaecologists
SD	Standard deviation
SEF	Social egg freezing
SPSS	Statistical package for the social sciences
UK	United Kingdom
UKDL	UK donor link database

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Abstract (Aims)

The aims of this thesis were to thoroughly explore all clinical aspects of egg sharing, to generate data that can be put forward to add to the long term ethical debate surrounding its practice. The thesis comprises five studies. The first component was to perform two systematic reviews to provide an up-to-date analysis of psychosocial factors surrounding egg sharing, from the point of view of the egg share donor and recipient. The motives, attitudes and treatment experiences of egg sharers and recipients will be investigated, as well as any issues about disclosure and non-anonymity. The second study examines the views and knowledge healthcare professionals in the UK have towards egg sharing, as well as the proportion of them who have actually referred a patient for egg sharing. The third study investigates oocyte donors and recipients who were treated at Lister Fertility Clinic between 2012-2019. The study aims to investigate their motivations, attitudes, and treatment experiences towards oocyte donation. The study will also investigate the issue of disclosure about the nature of their conception. Study IV examines whether egg sharing compromises the chance of the donor or their recipient having successful treatment, with a comparison also being made to the treatment outcomes of standard IVF patients and non-egg share recipients. Study V investigated the general public in the UK and their knowledge and perceptions of female fertility decline, as well as their knowledge and perceptions towards egg sharing. Both a systematic review and also a study to survey the general public will be performed. In conclusion, the work from this thesis has provided strong evidence in support of egg sharing, and its findings can be used to potentially increase the recruitment of egg sharers as well as improve the clinical care egg sharers and recipients receive.

Chapter 1:

Background on egg donation, egg sharing and donor anonymity

Background on egg donation, egg sharing and donor anonymity

1.1 In-vitro fertilisation

Infertility, defined as the failure to achieve a pregnancy after 12 months of regular unprotected intercourse, affects one in seven couples in the United Kingdom (UK) [1, 2]. While many fertility conditions will be treated with drug regimens, a significant number of patients will need to undergo in-vitro fertilisation (IVF). Data from the Human Fertilisation and Embryology Authority (HFEA) reports there were 74,375 fresh and frozen IVF cycles in the UK in 2018 [3]. After years of rapid growth in the number of treatment cycles performed by HFEA licensed fertility centres, these have now started to stabilise [3]. However, this figure means that 2% of all babies born in the UK are conceived through IVF [3].

1.1.1 Funding constraints for fertility patients in the UK

In the UK, the National Institute for Health and Care Excellence (NICE) recommend women under 40 years of age, who have been trying to conceive for more than 2 years, should have access to three full cycles of government funded IVF [2]. However, local clinical commissioning groups (CCGs) have ultimate control of treatment criteria in their area, and in the majority of cases they have chosen to significantly decrease IVF funding and tighten the criteria for couples accessing treatment [3-5]. The number of CCGs in England offering the NICE recommended three full cycles of IVF in women under 40 has halved in just five years, with 12% of CCGs now following NICE guidance, compared to 24% in 2013 [4]. In England in 2018, 61% of CCGs offered only one IVF cycle to couples, and 3% offered no fertility treatment to couples at all [4]. NICE also recommends women aged 40-42 years of age should be offered one full cycle of IVF, however 48% of CCGs offer no fertility treatment to this age group [2, 4]. These restrictions have resulted in a postcode lottery for couples trying to access government funded IVF in the UK.

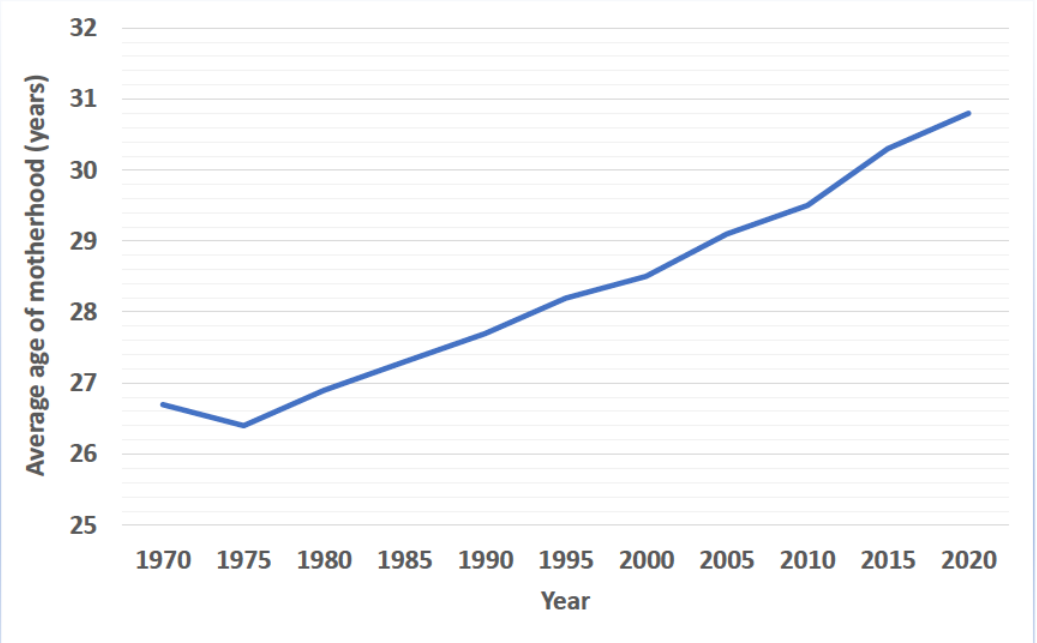
These restraints have meant that government funded IVF cycles now represent the minority of treatments in the UK, with just 41% of IVF cycles being National Health Service (NHS) funded [3].

This has resulted in the average amount of money a UK patient has to spend on fertility treatment being £11,378, with 10% of fertility patients spending > £30,000 [6]. Therefore, fertility patients in the UK are currently having additional financial pressures to the emotional burden of not falling pregnant. Furthermore, patients who cannot self-fund these expensive treatments and do not qualify for NHS funded IVF, will therefore not be able to access IVF.

1.1.2 Success rates based on female age

Live birth rates (LBR) from IVF have gradually improved over recent decades, with the average birth rate per embryo transfer being 23% in 2018 [3]. It is established that female age is the most important prognostic factor regarding IVF outcome [7]. HFEA data from 2018 reflects this, with women under 35 years having the highest birth rate per embryo transfer at 31%, compared to only 9% in 1991 [3]. In the UK in 2019, the mean age of motherhood reached an all-time high of 30.7 years, which is an increase of one year per decade since 1980, when the average age was 26.9 years (***figure 1.1***) [8]. This trend largely reflects positive societal change regarding women's improved education and career progression, and present obvious economic advantages, however the age-related fertility decline can pose a significant barrier to women trying to conceive later in life [9].

Figure 1.1: *Trend in the mean age of motherhood in the UK since 1970*



Regarding the most recent HFEA data, the average age of an IVF patient was 35.3 years [3]. In 2018, LBR per embryo transferred were 31.3% for women aged < 35 years; 24.6% for women aged 35-37 years; 18.7% for women aged 38-39 years; 11.3% for women aged 40-42 years; and 4.0% for women aged > 43 years ***(figure 1.2)*** [3]. In the UK, LBRs through IVF were three times higher than in 1991 [10]. Despite these substantial improvements in IVF success rates overall, this has not been reflected in women aged > 42 years, in whom success rates have remained very poor [9]. The reason for this is a significant increase in oocyte and resulting embryo aneuploidy with advancing maternal age. Indeed, aneuploidy in female oocytes rises very steadily from 25 years of age, with a significant increase in oocyte, and therefore embryo aneuploidy from age 36 years ***(figure 1.3)*** [11]. Despite the convincing clinical data, the molecular mechanisms causing this female reproductive ageing are still not completely understood [12]. Potential molecular issues have been proposed, including telomere shortening and dysfunctional DNA methylation [13-16].

Figure 1.2: *UK national IVF success rates based on female age*

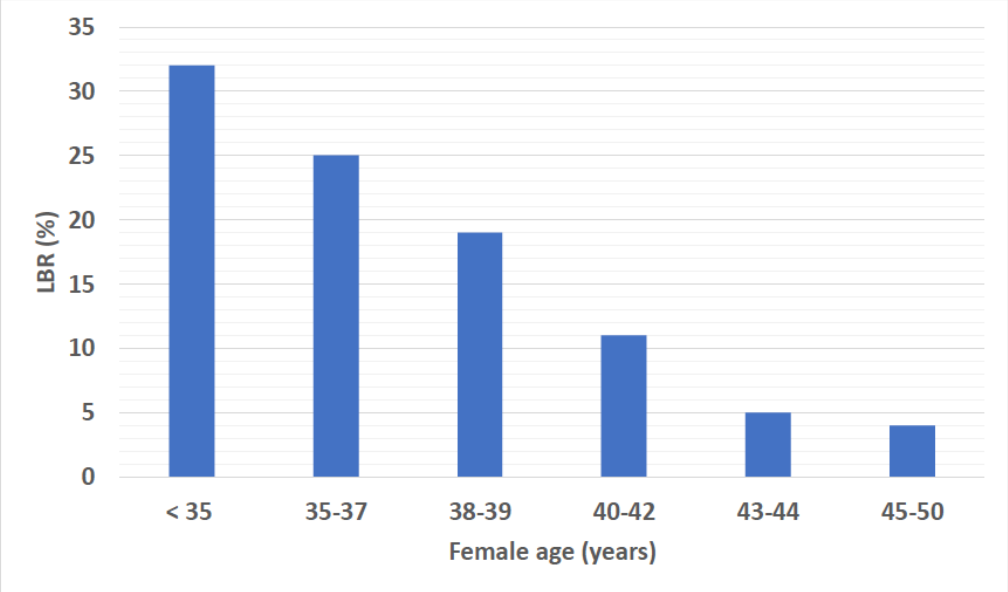
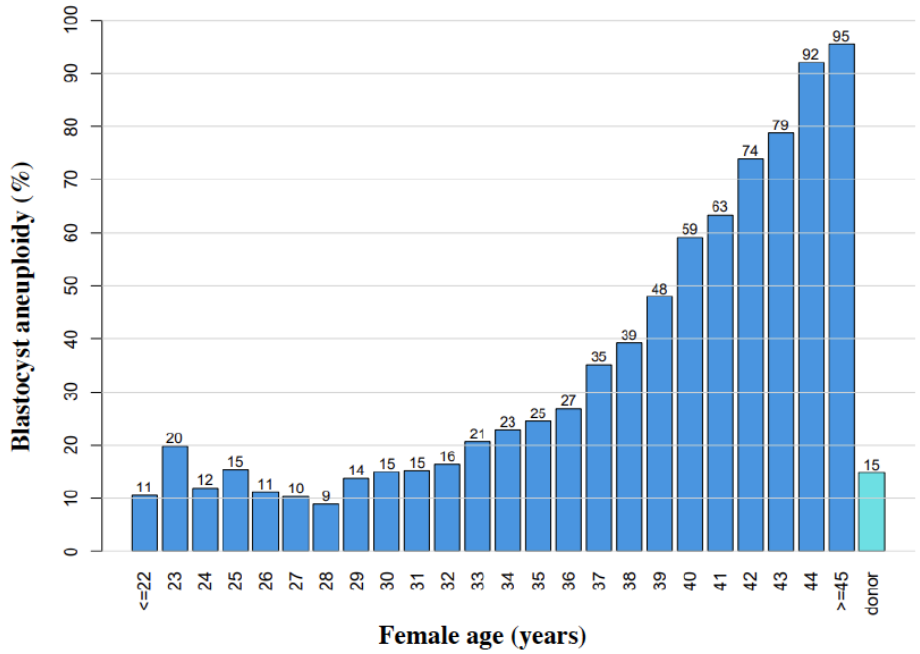


Figure 1.3: A comparison of blastocyst aneuploidy rate after pre-genetic testing for aneuploidy (PGT-A) with increasing female age



1.1.3 Public knowledge of female fertility decline and the risk of involuntary childlessness

With women delaying their age to first time motherhood, research has consistently highlighted a lack of knowledge amongst the general public regarding the significance of the female age-related fertility decline, even amongst well educated women [17]. This lack of knowledge, combines with the fact that women in developed countries, such as the UK, are having children at an older age, increases the risk of involuntary childlessness. Studies have consistently reported the significance of maternal age regarding natural conception, with the increased risk of infertility and miscarriage with advancing female age [18].

There are likely to be numerous reasons for this lack of knowledge in the population surrounding female age-related fertility decline, including a lack of education at school, and lack of information provided by primary and secondary healthcare. However, a likely precipitating factor is how the media are portraying older parenthood, especially surrounding coverage of celebrity pregnancies, with the likely need for fertility treatments barely being mentioned. This age illusion is predominantly created by the media and is likely to be a major contributing factor to the current lack of knowledge surrounding

female fertility and the biological clock. Misconceptions of older motherhood in the media, particularly surrounding celebrities, is sending the message that pregnancies well after 40 years of age is not only possible, but in fact normal. It is very likely that the vast majority of the celebrities achieving pregnancies in their late 40s and early 50s used fertility treatment to conceive, either through donor eggs, or having frozen their eggs at a much younger age [19, 20]. The vast majority of celebrities decide not to disclose the nature of their conception, which is of course their right. However, they often seek significant publicity surrounding the joy of their pregnancy and birth, and the resulting misinformation could be deceiving women into a false belief that achieving a pregnancy well into their 40s or even 50s is entirely realistic [19, 20]. Therefore, the implication is that high power female celebrities can simply reverse the female reproductive biological clock, resulting in an assumption that any woman who can afford fertility treatment can successfully have a child well into their 40s, or later. However, the reality of their conception, through prior egg freezing or egg donation is almost never mentioned. One study analysed 240 interviews with celebrities regarding how they conceived their pregnancy, and only 2 of these articles mentioned the need for fertility treatment, even though the majority of the celebrities in the articles studied were over 35 years [19]. This misconception could, at least in part, be further contributing to the increasing average age of motherhood in countries like the UK, with this issue escalating further unless this public health problem is addressed, with some couples currently 'sleepwalking into infertility' and involuntary childlessness [17, 18].

A systematic review on this topic reported contradictory findings regarding knowledge amongst the general public of age-related fertility decline [21]. Five studies found most women were aware of the female reproductive biological clock (51%-89.4%) [22-26]. However, one study found that only 45% of women understood the poor prospects of conceiving at age 45 years [25]. Stoop et al. (2011) surveyed 1049 Belgian women and reported only 14.3% of their study population had an accurate knowledge of the female age related fertility decline [27].

Importantly, sex education programmes in schools and primary care must be reformed to appropriately address this current problem. Family planning clinics provide women with numerous contraceptive

options, with an obvious and understandable emphasis on preventing pregnancy at that stage of their lives. However, such clinics have significant access to women of reproductive age, giving them the opportunity to ask about their future reproductive plans, and sharing knowledge of female age-related fertility decline. This discussion could enable healthcare professionals to provide key information about the options women have in terms of ovarian reserve testing and fertility preservation treatments.

This is a realistic concept in a family planning clinic and could also be part of a government funded scheme. A Danish group started a 'Fertility Assessment and Counselling Clinic', with the ultimate aim being to reduce future infertility and the need for fertility treatment in the future [28]. The average age of their 916 women seen in clinic was 33.4 years, indicating most women are being seen in the clinic at the correct age [28]. 99% of patients seen in this clinic found the appointment informative and useful, with the majority reporting a significant improvement in their knowledge of female fertility and the age-related decline [28]. 75% of this clinic population felt there was a need for better education surrounding infertility risk factors, most significantly related to female age [28]. The reassuring data generated from this study confirms the possibility for remodelling the current family planning process. Family planning services should of course concentrate on the importance of contraception, but also provide important information to women of reproductive age wanting to conceive in the future, hence aiding to reduce the risk of involuntary childlessness in the future, and the tremendous psychological burden this can place on women and couples.

1.2 Egg donation

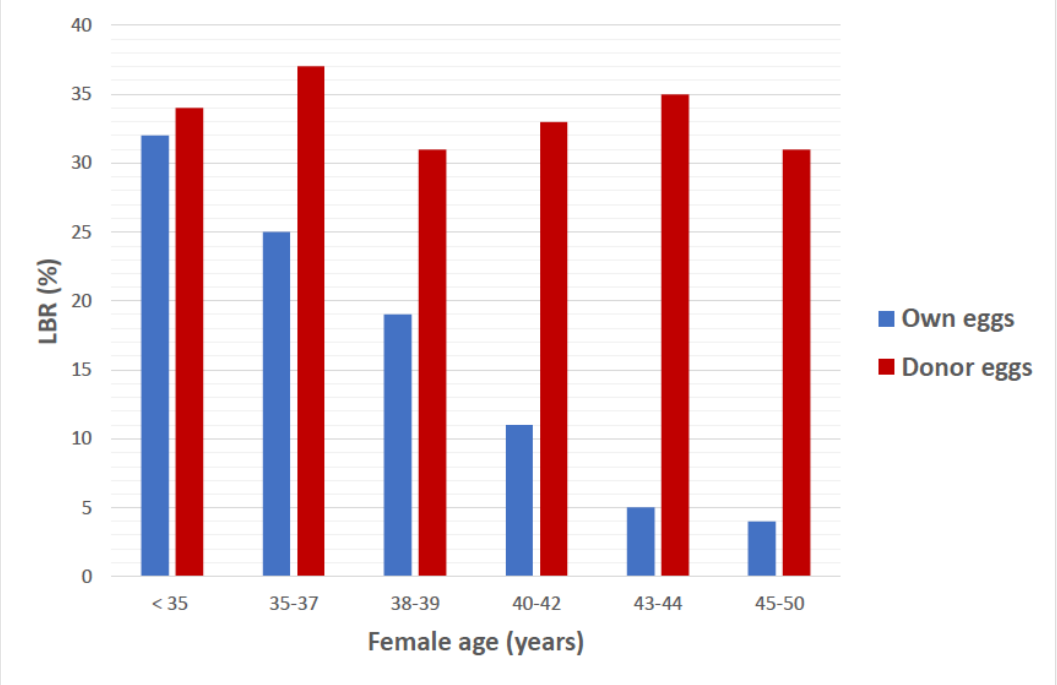
Egg donation was first performed in the early 1980s and was only a possibility due to the advent of IVF, with the first offspring conceived from a donor oocyte in Australia in 1984 [29, 30]. Fertility treatment using donor eggs was soon available in the UK, with the first live birth using donor oocytes achieved in 1987 [31, 32]. When donor oocytes are used to conceive there are two patient groups involved for the fertility clinic to care for: the donor herself, and the woman trying to conceive, the recipient. The use of donor eggs offers couples the chance to have their own child when treatment with their own eggs is unable or extremely unlikely to result in a successful outcome [33]. Before this option

was available many women who needed donor oocytes to conceive were unable to carry a pregnancy, and could only achieve parenthood through the adoption process, which carries its own significant logistical hurdles. The vast majority of women needing donor eggs to conceive are those who are over a certain age, or with a very poor ovarian reserve, meaning treatment with their own eggs carries a very poor chance of success [34]. Women with primary ovarian insufficiency (POI) will also require donor oocytes to conceive [35]. With ages of first-time motherhood consistently rising in western countries over recent decades, the demand for donor eggs has unsurprisingly also increased [8, 36]. More recently, an increasing number of homosexual male couples have been using donor oocytes and surrogacy as a means to have a genetic child [3].

Since 2011, the number of fertility patients using 'donor eggs and partner sperm (DEPS)' to conceive has increased by 49%, resulting in 5% of all IVF cycles in the UK using donor eggs, and 1% using both 'donor eggs and donor sperm' (DEDS) [3, 37]. The majority of DEPS cycles were undertaken in women over 40 years of age, who have a much poorer chance of success using their own eggs [3]. For example, when using their own eggs compared to donor eggs, women aged 38-39 years have a LBR of 19% vs 31%; those aged 40-42 years have a LBR of 11% vs 32%; those aged 43-44 years have a LBR of 5% vs 35%; and those aged > 44 years have a LBR of 3% vs 31% [3] **(*figure 1.4*).**

Clinical and legislative practices differ significantly between countries regarding egg donation. For example, in the United States of America (USA), women are offered significant payments for their donation [38], a process which is illegal in the UK, where any monetary payments are capped at £750 and termed 'compensatory' [39]. Those who participate in egg donation can be split into distinct groups: (i) known donors (the donor knows and donates directly to their recipient); (ii) anonymous donors who are either altruistic donors (donating for voluntary reasons) or commercial donors (accepting payment for donation); and (iii) 'egg share donors'(women donating a proportion of their oocytes from IVF treatment to a recipient, in exchange for free or subsidized fertility treatment).

Figure 1.4: *A comparison of IVF treatment outcomes of women using their own versus donor oocytes with increasing maternal age*



In contrast to donating sperm, the process of egg donation is far more invasive, with daily injections for ovarian stimulation, regular vaginal ultrasound scans, and a minor surgical procedure to collect the oocytes. Therefore, multiple visits to the fertility clinic are required, as well as an anaesthetic for the egg collection procedure. Unsurprisingly, studies have found that the majority of potential egg donors presenting to fertility centres do not then participate with the process, with one study reporting a 75% drop out rate [40]. Despite the increasing demand for donor eggs in recent years, the number of women registering as oocyte donors has remained quite stable at 1600 per year, which means supply for donor oocytes is currently falling short of demand in the UK [36, 37]. A potential resolution to the low number of donor eggs in the UK, where commercial payments are illegal, is the option of egg sharing.

1.2.1 Egg sharing

The egg sharing programme involves a fertility patient, who needs IVF for her own needs, donating a portion of her eggs (usually half) to a recipient who needs donor eggs to conceive, in exchange for heavily subsidized treatment. At the Lister Fertility Clinic (LFC), London (HCA, London), egg share donors are asked to pay an HFEA fee of £75 for their fertility treatment, whilst their recipient will pay

a standard fee for their fertility treatment. Any eggs collected from the sharer following ovarian stimulation are split equally between herself and her recipient. If less than eight eggs are collected from the sharer, she can either donate four eggs and use the remaining amount for her own treatment, or chose to keep all oocytes available and be charged a subsidized fee for her treatment. The practice of egg sharing has been regulated by the HFEA in the UK since 1998 [41, 42] and is now an option for fertility patients in many other countries, including Australia, Belgium, Denmark, Spain, Greece, Israel, and the USA [43, 44].

Since the first successful case of IVF using egg sharing was reported in 1992 from the Cromwell IVF and Fertility Centre [45], egg sharing has generated considerable ethical and policy debate, with many calling for it to be banned [46-48]. Indeed, shortly after it was introduced, the HFEA described egg sharing as an 'unacceptable' practice [42]. In 1998, having concluded that all payments for people donating gametes should be discontinued, the HFEA conducted a consultation to establish similar views among egg donation patients and healthcare professionals [42]. The responses the HFEA received to this consultation indicated a minority supported the withdrawal of egg sharing, and the HFEA concluded egg sharing should be 'regulated, not banned', since the data collected showed that egg sharers were motivated by the desire to have a baby, not by financial reasons [41]. Even then the HFEA were clear to caution that although they had allowed egg sharing to continue, they had not given the practice their ethical approval [49].

Since this statement, the egg sharing programme has continued to be analysed and discussed, clearly demonstrating the differences of opinion regarding this unique scheme [46-48], with some arguing that, other than IVF itself, no other assisted conception procedure has undergone such intense scrutiny [50]. More recently, in 2011 the HFEA revealed a significant revision in their attitudes towards egg sharing, evidenced by a growing ethical approval of the practice [39]. They therefore concluded that benefit-in-kind systems, like egg sharing, should continue to operate, since they widen access and have the potential to significantly alleviate current shortages in donor oocytes [39].

1.2.2 Benefits and concerns surrounding egg sharing

Egg sharing provides clear benefits for fertility patients using this treatment option. First, as the egg share donor needs to undergo treatment for her own needs, there is no third party enduring the relatively invasive process of ovarian stimulation and transvaginal egg collection [51]. Second, those who are ineligible for government funded IVF and cannot afford to self-fund are able to access much desired fertility treatment [47, 51]. NHS funding for fertility treatments has consistently fallen in recent years, meaning this benefit could be more significant in the UK than it was previously. Third, it gives the egg sharer a chance to help another fertility patient in a practical way, who would not be able to conceive without donor oocytes [52]. It is a completely unique type of egg donation since both the donor and recipient are connected in their simultaneous pursuit of conception.

However, as it is a controversial method of egg donation concerns have been raised. First, there is apprehension regarding the psychological adjustment of the egg sharer if her own fertility treatment is unsuccessful [53, 54]. With this issue potentially compounded by the possibility of her anonymously matched recipient's treatment being successful with the same batch of eggs [48]. Second, the theory has been proposed that the egg sharer is only participating so she can access fertility treatment she would otherwise have not been able to afford [55]. If this were true it would bring into question the validity of the egg sharer's consent to participate [55, 56]. Third, offering essentially free fertility treatment in exchange for donor oocytes could be viewed as contrary to the traditional societal preference for voluntary donation in the UK [54]. Fourth, there is a widespread belief that by splitting the donor oocytes 50:50 the treatment outcome of the egg sharer and her recipient could be negatively impacted [57]. Finally, concerns have been raised for the potential psychological impact on any resulting child from the recipient of egg sharing, who may discover their parents indirectly paid a fertility patient to donate their eggs [58].

The well-being of egg share donors psychologically is probably the most consistently raised concern regarding the egg sharing practice, with an obvious emphasis placed on those donor's whose own treatment cycle ended unsuccessfully. Experts theorize that egg share donors would bemoan their

decision to share their eggs, and feel their treatment would have been successful if they had not participated in the programme and retained all their oocytes for their own use. These feelings could obviously be worsened by discovering the anonymously matched recipient had conceived their genetic child with that batch of oocytes [59, 60]. Regarding this concern, there has been dialogue as to whether it is prudent for egg share donors to have the option of discovering the outcome of their recipient's fertility treatment [46-48]. Nonetheless, it must be noted that this debate is based on theory, rather than on evidence presented in the medical literature. Studies investigating this topic are very few, but both reported no difference in the psychological well-being of the egg sharer when her fertility treatment had been successful or unsuccessful [49, 60]. Indeed, one study reported that only 4.2% of egg sharers felt the programme was exploiting them, with the vast majority importantly reporting it offers a 'win-win' solution for the donor and her recipient [49].

The next most raised issue surrounding egg sharing is that both the donor and their recipient could be jeopardizing their chances of success because of the 50:50 split in oocytes [57, 58, 61]. It has also been suggested that fertility specialists would prescribe higher doses of gonadotrophins to egg share donors so to retrieve more oocytes, but significantly putting the donor at a higher risk of ovarian hyperstimulation syndrome (OHSS) [45]. There is also a concern that through egg sharing recipients are receiving oocytes from 'infertile' women, and the subsequent impact this could have on their own treatment outcome [62]. From the egg sharer perspective, they could also be concerned the fertility clinic would favor the recipient when it comes to the distribution of oocytes, since she is paying the clinic for her treatment [63].

Studies exploring the outcomes of fertility treatments involving egg share donors and their recipients have reported opposing findings, highlighting the importance of more research in this important area. The earliest studies to investigate this found recipients had higher pregnancy and live birth rates compared to their egg sharers [63, 64]. Following on from this, one study found no difference in pregnancy rates between egg share donors, standard IVF patients and their recipients [65]. Since then, other studies have also not reported an adverse pregnancy or live birth rate between recipients who used

an egg sharer and those who used a non-egg share donor [62, 66, 67]; although one of these studies reported recipients who used an egg share donor received significantly fewer oocytes [62]. One study also found that a high proportion of egg share donors did not have a fresh embryo transfer because of the increased risk of OHSS [67]. More recently Molhatra et al. (2013) reported lower pregnancy rates amongst egg share recipients in India [68]. The most recent study by Braga et al. (2020) reported egg share donors outcomes strongly predicted the pregnancy rates of their recipient, but differences between other outcomes were not reported [69]. Overall, these findings are contradictory and most significantly do not consistently report LBR.

1.3 Gamete donation and anonymity in the UK

1.3.1 The historical framework surrounding gamete donation in the UK

Donor insemination was first clinically used in England in the late 1930s, and was almost unanimously practised in secret [70]. The secrecy was because of a widespread condemnation of the practice, with reasons cited including religious beliefs, objections to masturbation, fears of the possible eugenic implications and its associations with the practice of agriculture [70]. Despite this opposition, the demand for donor insemination continued to grow and in 1968 it became available on the NHS on 'medical grounds' [71]. However, the process still occurred without central regulation, and medical records were usually not kept [71]. The husband of the woman also had no legal obligation for the resulting offspring, with the sperm donor considered the legal father [72]. Couples would usually enter false information by entering the husband on the birth certificate [72]. Thus the couple were being forced to commit an illegal offence, although it was unlikely to be discovered, with this illegality further contributing to couples desire for secrecy [72]. It was argued that donor anonymity would remove potential legal responsibilities for the donor, and allow the husband paternal rights [73]. The Warnock Committee was set up to address this issue in 1982, and advised 'The donor child should in law be treated as the legitimate child of its mother and her husband, where they have both consented to the treatment' [74, 75]. This resulted in a law change in 1987, permitting the husband to be written on the birth certificate as the father of the child [71]. The Warnock committee did also recommend the practice

of gamete donation should be anonymous to give legal protection to the donor, protect the husband's paternity rights and allow an increase in donor numbers [75].

In 1990, the Human Fertilisation and Embryology (HFE) Act was passed which enforced many of Warnock's recommendations into legislation [76]. The HFE Act (1990) clarified the legal status of the donor and recipient couple, specifically mentioning the couple did not have to keep the practice secret in order to falsify the birth certificate [76]. The Act stipulated that gamete donation should be anonymous, meaning the identity of the gamete donor could not be released to the couple receiving the gametes or the resulting offspring [76]. However, the identity of the donor was known to the authorities, with the HFEA keeping a confidential register of all donors and recipients of gametes [76]. The reasons for keeping this confidential register were: first, so the donor could be contacted and future donations prevented if the child was found to have an inherited disorder; second, if future attitudes were to change towards donor anonymity, identifying information would be available and allow the possibility of future access; and third, so the resulting offspring could discover if a prohibited relationship existed with their intended partner [77]. It was felt that by legislating this practice, the 1990 Act significantly influenced a growing acceptance of reproductive technologies, and the use of donor gametes to conceive [78]. Perhaps most significantly, in appreciating how attitudes towards anonymity could change over time, the Act put in place information gathering structures required if non-anonymous donation were to come into practice [71].

1.3.2 Calls for change to donor anonymity in the UK

Internationally, an increasing number of countries were allowing the child to find out donor identifying information upon reaching adulthood, including Sweden, Austria, Switzerland, Iceland, Australia and New Zealand [71]. It was in the context of changing international practices towards donor anonymity that in 2001, the Department of Health (DOH) launched a consultation to review the legislation governing access to information for those conceived through donor gametes [79].

A major argument for removing donor anonymity is the argument it is a human right to know our genetic origins [71]. Prior to the 2005 legislative change in the UK, donor offspring were the only group that were specifically prevented from learning the identity of their biological parents [71]. Experts argued that truth and openness were always preferrable to secrecy and deception, which could lead to significant stress within the family dynamic [80]. On the topic Warnock, who supported the passing of legislation for anonymous donation, said "I cannot argue that children who are told of their origins, if they are donor gamete children are necessarily happier, or better off in any way that can be estimated. But I do believe that if they are not told they are being wrongly treated" [74]. A second commonly raised argument is that being denied knowledge and access to our biological origins can be harmful to the offspring of donor gametes [71, 81], with the term 'genealogical bewilderment' created to represent this dilemma [82]. It has been claimed that offspring from gamete donation are curious about many aspects of their donor, including personality and medical history, and that uncertainty surrounding this knowledge could have a negative impact on the mental well-being of the resulting offspring [71]. Previously, donor records were often destroyed to guarantee their anonymity [83], which led to feelings of anger and frustration for the donor offspring about lack of access to important information, such as family medical history [80, 84]. However, most of the evidence gained on the harm caused by people not having access to their genetic origins comes from studies and knowledge surrounding adoption [85]. It must be noted that children born from gamete donation are in a very different situation within the family dynamic, compared to adoptive children. They have not been 'abandoned' by their genetic parents and are often genetically related to one of their parents. It is therefore perhaps premature to presume the conclusions from research on adoptive children will be similar to those conceived by gamete donation [86]. This lack of knowledge is compounded by the fact that anonymity was the legal position, so it was not possible to conduct adequate studies on the effect of disclosure and donor identity [87].

1.3.3 Arguments against removing donor anonymity

Prior to the 2005 legislative change, arguments were also made against the removal of donor anonymity. First, it was argued by some that it was in the best interests of the child to not know because of possible

stigma surrounding their nature of conception [88]. Concerns were raised that if extended family members found out it could negatively impact their relationship with the child [88]. These motives were to protect the non-genetically connected parent from the stigma of infertility, especially when male, and the concerns this knowledge could impact the child's relationship with that parent [70].

A second reason for not disclosing to the child is that the parents have their rights to privacy surrounding the nature of their conception, and if they chose to keep this secret then that is their choice [89]. Prior to the legislation being introduced in 2005 this position was corroborated by multiple studies supporting low levels of disclosure [71, 90-93]. One of these studies from Sweden, where loss of sperm donor anonymity was legislated in 1985, reported that 89% of parents had not informed their children of the nature of their conception [93]. Interestingly, one study compared views of heterosexual and homosexual couples towards donor anonymity, and found most homosexual couples planned to give details of the nature of conception, with 40% of them wanting the identity of the donor to be registered [94]. These studies highlight a major hurdle to those in favour of openness surrounding gamete donation: for a practice of non-anonymous gamete donation to have any relevance, the child must first be told of the nature of their conception [71]. Addressing this issue long before the donor anonymity issue reached parliament, The Warnock Report recommended that the parent who used donor gametes to conceive should have 'by donation' placed on the birth certificate next to their name [75]. However, this contentious suggestion was rejected by Parliament. No countries with legislation in favour of anonymous donation in place have any mechanism by which the child is told of the nature of their conception, other than relying on the parents disclosing it [71].

Finally, there was considerable concern that introducing non-anonymous gamete donation would significantly impact on the number of people coming forward to donate, potentially jeopardising the entire sperm and egg donation programme.

One of the most influential societies in the UK at the time, the British Fertility Society (BFS) and other major professional bodies, including the Royal College of Obstetricians and Gynaecologists (RCOG)

and the British Medical Association (BMA) were opposed to the loss of donor anonymity on the grounds of the anticipated significant negative impact this would have on donor supply [95]. In Sweden there was a significant decrease in gamete donors after donor anonymity was removed, however donor numbers did recover, although this took 10 years [96]. This pattern was mimicked in other countries with similar legislation, as well as numerous studies pointing towards a likely significant drop in donor numbers if anonymity were removed [90, 97-99]. It was also hypothesized that following the removal of donor anonymity, those still willing to donate may want to be overly involved with the family and resulting offspring [87]. It is important to realise that a donor has no right to information on the recipient couple or resulting child, so this potential concern would be unlikely to be a significant issue.

1.3.4.'Disclosure of Donor Identity' Legislation approved

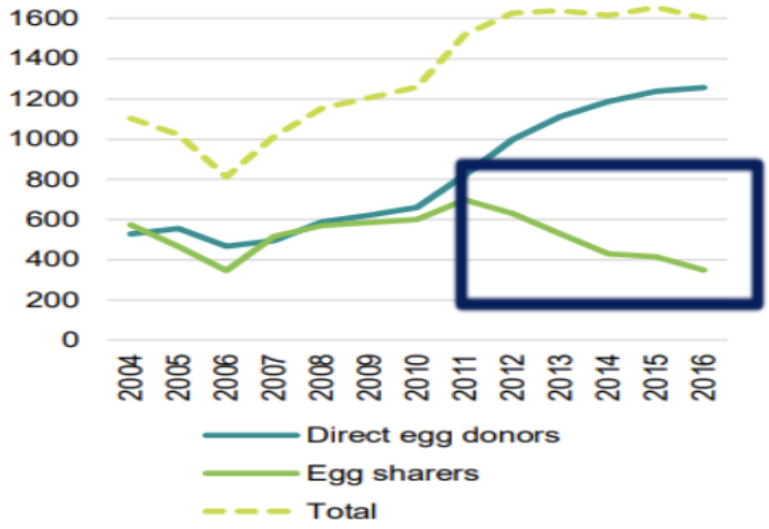
In February 2002, following the announcement that the legislation surrounding gamete donation and anonymity was to be reviewed, the DOH published a consultation paper, asking respondents what information should be available to offspring born as a result of gamete donation. The DOH published the responses they had received to the consultation document [100]. There was widespread agreement that an increased amount of non-identifiable information about the donor should be made available. Of the 211 responses they received, seven were from egg donors, nine sperm donors, and two embryo donors; and only 18 oocyte recipients responded [100]. Such a poor response rate raises concerns that the opinions of the major stakeholders had not been appropriately represented. When debated in Parliament the government supported the loss of donor anonymity, and in the UK, the 'Disclosure of Donor Identity' legislation meant that from 1st April 2005, all children born from treatment involving the donation of gametes or embryos have the right to learn the identity of the biological parent(s) on reaching the age of 18 [101]. These regulations allow offspring conceived as a result of gamete donation after April 2005 to request their donor's identity from the HFEA. The HFEA will inform the donor that the Authority has been contacted by a person conceived as a result of their donation with a request for information, but the HFEA will not provide the donor with any information about the offspring making the request. The regulation does not permit the donors or recipients to learn each other's identities, either at the time of donation or subsequently. It remains to be seen how efficient this process will be,

since the HFEA would be dependent on up-to-date demographic information of the donor, whose contact details and address would change over an 18-year period. However, with increasingly sophisticated telecommunications commonplace throughout the world, it is a much easier task to locate registered persons with limited demographic details.

1.3.5 Egg donation and egg sharing numbers following the 2005 legislation

This legislation was controversial because it was predicted to effectively end gamete donation in the UK [102, 103]. However, after an initial decline, egg donation figures have steadily risen over the last decade [104]. The HFEA also implemented changes during this time aimed at improving the numbers of new donors registering and maximizing the use of their gametes [39]. A significant change was the provision of egg donors with up to £750 compensation per cycle, replacing the previous limit of £250. HFEA figures after this legislative change showed the number of oocyte donors had steadily increased, with 815 donors registering in 2011, compared to 1103 in 2013 [104]. The number of egg donors newly registering at UK fertility clinics has remained consistent since 2013, at around 1600 per year. However, the HFEA policy change is not targeting egg share donors, and the HFEA did not discuss how recruitment of egg share donors could be optimized. This oversight could be explained partly by the contentious history of egg sharing and the limited knowledge available of the psychological well-being of patients after egg sharing. In 2016, 22% of newly registered egg donors were egg sharers, and 78% were direct egg donors [37]. In 2011, egg share donors comprised over 40% of the egg donation population in the UK [60]. Indeed in 2011, 698 of egg sharers participated as donors, compared to 348 in 2016, which is a 50.1% fall in numbers [37] **(*figure 1.5*).** The reason for this alarming drop in egg share numbers in the UK is complicated, multi-factorial and difficult to explain, requiring further in-depth research. The issue with an increasing demand and a plateau in oocyte donors means longer waiting lists and less choice for women.

Figure 1.5: *HFEA data showing the fall in egg share numbers in the `UK over recent years*



1.4 Cross border reproductive care

Fertility treatments have increasingly become more global, with many patients travelling internationally to obtain their care. In the UK, this is particularly relevant for patients requiring egg donation, since the supply of donor oocytes falls far short of demand [105], causing long waiting lists and limited choices, especially among ethnic groups seeking egg donation [106]. In 2016 in the UK, the ethnicity of the majority of egg donors was white British (70%), followed by any other white background (14%) [37]. Those of Indian background (2%), black African background (2%), and mixed background (2%) comprised a significant minority [37]. This has led to some patients seeking treatment abroad to destinations where oocytes are more readily available, but where regulations may be less strict [107], a process known as cross-border reproductive care (CBRC).

As well as in the UK, the demand for donor oocytes is increasing significantly in Europe, with the use of donor oocytes growing from 6530 in 14 countries in the year 2000, to 40244 in 26 countries in the year 2013 [108, 109]. Within Europe, patients are allowed to travel for healthcare reasons. However, there are fundamental disparities between different European countries regarding legislation surrounding assisted reproductive technologies (ART), particularly with donor gametes [110]. This legal diversity, combined with regulations allowing the free movement of people within the European

Union (EU), creates the perfect background to use CBRC to evade laws and regulations in the patient's home country [110].

The European Society for Human Reproduction and Embryology (ESHRE) released a good practice guide for CBRC and recommended collaborations between doctors from different countries [111]. However, they did note in the same guideline that in certain countries this may not be possible where it is strictly forbidden for physicians to give information about alternatives, such as gamete donation, that are illegal in the country in which they are practicing [111]. The French Department of Health have threatened fertility clinics with a potential 5 year prison term and 75,000 Euros fine if they inform patients of the possibility of seeking ART using donor gametes abroad [110]. In Turkey, any doctor who helps couples go abroad for ART using donor gametes faces 1 to 3 years imprisonment [112].

With a significant improvement in vitrification techniques, human oocytes can now be frozen safely and used after thawing successfully in IVF cycles [113]. This has revolutionized fertility treatments using donor eggs, allowing oocyte donor banks to be created. This has significantly improved the access and flexibility of ART using donor oocytes [113, 114].

Oocyte banking does raise certain ethical considerations. First, the high demand for ART using donor oocytes, and the scarcity of donor oocytes in many western countries, manifests the ethical dilemma of how the available donor oocytes can be distributed fairly [115]. Second, apart from egg sharing, oocyte banking relies on healthy women donating, without any direct therapeutic benefit for themselves. In standard ART cycles, fertility specialists have the responsibility to the infertile patient, as well as any resulting children conceived [116]. In ART cycles using donor oocytes, this responsibility is also extended towards the welfare of the donor [116, 117]. Finally, the development of oocyte vitrification gives the possibility of donor oocytes being stored for long periods. This long-term storage of donor oocytes challenges current informed consent for donors and recipients [118].

1.5 Direct to consumer genetic testing

Within fertility clinics and healthcare systems, information about the donor is still kept securely to which only relevant clinic staff would be able to access. However, identifiable characteristics are now no longer only stored in regulated systems that healthcare organisations, professional bodies and/ or governments have control over. The recent proliferation of numerous medical diagnostic tests, including direct to consumer (DTC) genetic testing, enables the possibility for people to gain access to a wealth of medical and personal data on genetic relatives without going through previous necessary 'official' channels, that required navigating gatekeepers and regulatory structures [119].

Millions of people worldwide are accessing ancestry databases for DTC genetic testing, uploading their DNA results, and attempting to find out more information about their genetic origins [120]. Consumers send in DNA swabs, which are analysed and used to search for genetic relationships with other DNA profiles stored in the database [121]. These DTC genetic tests are mostly private funded. Currently, the vast majority of these tests are performed by people who are curious about their genetic ancestry and health, but such tests are now being increasingly utilized by the donor conceived community [119, 121]. This has caused some private companies to have donor conception sections, with the specific aim to find same-donor offspring or their donor [121].

1.5.1 The threat of direct to consumer genetic testing

Genetic testing is a potential threat to gamete donors, who donated under the assumption their donation was completely anonymous; to recipients who believed they could keep the nature of their conception a secret; and to the resulting offspring who may be unaware of the nature of their conception [122]. Donors and their resulting offspring can find each other through the genetic information stored in these databases, providing consumers with surnames of potential relatives. These potential candidates can then be narrowed down significantly by searching social media sites, such as Facebook or Instagram [123]. It is important to note that even donors and their conceived offspring that have not themselves registered on these genetic databases, can be traced through relatives who have used it for their own genetic curiosity [121]. Such matches could reveal half-siblings, cousins, aunts, uncles or grandparents, and by contacting these matches information about the donor could be accessed [121].

The chances of finding a relative are currently low, and estimated to be 12% in the USA [124], however with millions of people now profiled in ancestry databases and their use growing exponentially in recent years, this figure is likely to significantly increase [119]. Despite numerous groups mentioning this reality, and advising that all potential donors and recipients should be warned of the potential consequences of the growth of the DTC genetic testing market, there appears to be little awareness in fertility clinics about the implications of DTC genetic testing [125]. It is clear that the anonymity of donors, and unfortunately also their relatives, is no longer guaranteed, and it is therefore important healthcare professionals acknowledge this, and adapt to this new reality [126].

Indeed, some donors who have donated anonymously are using DTC genetic testing to share their genetic information online. One study from the USA reported that 40.6% of anonymous sperm donors had sent a DNA swab to a DTC genetic database, because they were willing to be identified as their donor offspring's biological parent [127]. However, it must be noted that contact with presumed genetic relatives could have far reaching consequences for all parties involved.

Very little is known about the effects on offspring, or parents, from contacting their anonymous donors. Studies investigating this involve donors who have changed their mind regarding anonymity and have demonstrated this by putting their details on voluntary registers [128-130]. These donors either have changed their mind about anonymity or did not mind about anonymity at the time of donation, but that was the rule at the time [123]. However, these numbers are small, evidenced by the small numbers of donors who are putting their details on voluntary registers [123]. A significant majority of anonymous donors do not want their donor status to be discovered, and do not want to be contacted [123]. Consequently, donors contacted as a result of genealogy searches may react with hostility to contact and refuse all contact [123]. This will likely lead to feelings of rejection and disappointment in their donor offspring [123].

1.5.2 Gamete donors utilising direct to consumer genetic testing

Certain donors may also take the initiative to search for their donor offspring. One study reported that gay men are in general more willing to be identified, and may be donating in a 'way of staking an identity claim to paternity if it is perceived that there are no other options available in this regard' [131]. Countries that have abolished donor anonymity still do not allow the release of the donor's personal details until the offspring have reached adulthood. This waiting period is important to protect the privacy of the family and allow them to establish stable relationships with their parents, as well as the privacy of the donor. However, some donors may wish to discover the identity of their resulting offspring at an earlier age, irrespective of whether the parents want this or whether the offspring have been informed of the nature of their conception [130]. This violates the rights of the parents and potentially invades their intimate family dynamic. This type of donor constitutes a significant threat to the recipient's family unit, made possible only by DTC genetic testing [130].

The majority of genetic databases are privately funded, however registries do exist that are government funded (UK DonorLink (UKDL)) database; Fiom, the Netherlands) and registries founded by donor-conceived offspring or their parents (Donor Sibling Registry, USA). The aim of these schemes are to aid donor-conceived offspring who are seeking mutually desired contact with those with whom they share genetic links. When these databases are run by government bodies, they provide support, including counselling sessions, for donor and their offspring, when contact is desired. In the UK, the UKDL database was set up in 2004 in response to the pending change in legislation surrounding donor anonymity. The motivations for donors to be registered were predominantly offspring orientated: to allow offspring to get information about their genetic past and family medical history; donors were also interested to know the outcome of their donation; and finally to gain information on the lives of their donor offspring [132].

1.5.3 Direct to consumer genetic testing and disclosure

Data is lacking regarding what percentage of parents disclose to their offspring that donor gametes were used in their conception. It is likely that a significant number, perhaps even the majority, do not disclose the nature of their conception [133]. There is also no evidence the legislative change in the UK in 2005

has led to an increase in parental disclosure. However, the exponential increase in genetic databases may well change this in the future, especially since these databases are likely to significantly expand in the future, for multiple reasons. First, there has been significant growth of government funded genomic programmes [134]. The Harvard Personal Genome Project aims to sequence and make publicly available the complete genomic profiles of 100,000 volunteers [135]. There are also initiatives in the UK, including the UK Biobank, which is linking genomic information with healthcare records of 500,000 patients [136]. Second, non-invasive prenatal testing, where a blood sample is taken from the mother in the first trimester to detect fetal aneuploidy, has the potential to be applied to all pregnant women [137]. As this technique becomes increasingly more widespread, it is not inconceivable that all children will be born with their genetic profile stored [137]. Third, there are efforts within the scientific community and society at large, to foster greater openness about sharing genetic information. This is evidenced by the exponential uptake of DTC genetic testing. These genetic advances are likely to have a profound influence on the anonymity surrounding gamete donation, regardless of the parent's decision surrounding disclosure.

Patients who use donor gametes in their treatment need to be informed that their child's DNA profile will reveal that they are not their biological offspring. They should therefore be encouraged to inform their children that donor gametes were used in their conception. If this is done early in the child's life, there is every likelihood that this information will not be perceived adversely by the child, and therefore not have a negative impact on the family dynamic [138]. Gamete donors also need to be informed, that if they are donating in a country where donor anonymity is protected or not, with DTC genetic testing, their anonymity cannot be guaranteed in the future. They should be informed that this also applies if a relative uses a database, and consideration also needs to be given to the donor's own children or potential children, as they may find out their parent was a donor and be exposed to genetic half-siblings in the future [119].

Overall, increasing DTC genetic testing and government funded genetic databases will make the anonymous donation of gametes and parental non-disclosure challenging. Fertility clinics will need to

develop robust guidelines and protocols informing patients of the issue surrounding genomic data into their current consent agreements. It is likely that genomic databases will change the way fertility clinics and the general public perceive the acceptability and realistic nature of non-disclosure surrounding gamete donation in the future.

Chapter 2: Study I

Investigating psychosocial attitudes, motivations and experiences of egg sharers (study Ia) and oocyte recipients (study Ib): a systematic review

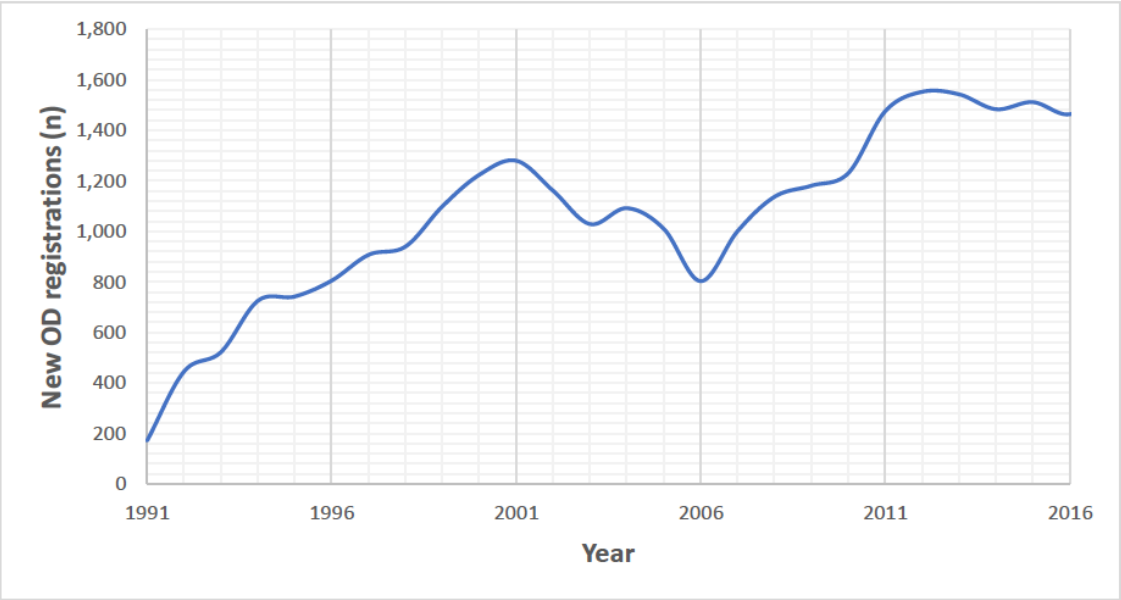
Study Ia: A systematic review investigating psychosocial aspects of egg sharing in the United Kingdom and their potential effects on egg donation numbers

2a.1 Introduction

Egg donation is a relatively intense process for the donor, involving multiple visits to the fertility clinic, ovarian stimulation with gonadotrophin injections, internal ultrasound scans and a surgical procedure to retrieve oocytes trans-vaginally. It is therefore unsurprising that the UK is currently suffering from a shortage of egg donors, with supply of donor oocytes falling short of demand, especially within ethnic minorities seeking egg donation treatment, resulting in long waiting lists for recipients [105, 106]. Recipients can avoid these long waiting lists by using a 'known' donor, usually a family member or close friend. Another option is to use egg share donors, a process where a fertility patient donates half her eggs to a recipient in exchange for heavily subsidized treatment.

Identifying the shortage of donor oocytes, the HFEA increased the compensatory payment donors could receive per cycle from £250 to £750 [139]. The most recent HFEA figures after this legislative change showed the number of oocyte donors had steadily increased, with 815 donors registering in 2011, which increased to 1593 in 2018 ***(figure 2a.1)*** [1]. This increase in numbers was attributed to the increase in compensatory payments, as well as improved awareness [104]. It must be noted that this policy change is not targeting egg share numbers, with the HFEA not making any changes in policy to optimize egg share donor recruitment. This oversight could be explained in part by the contentious history of egg sharing, as well as the still limited knowledge base for the psychological well-being of donors and recipients who have participated in egg sharing. Indeed, it is concerning to see the number of fertility patients participating in egg sharing in the UK has decreased from 708 in 2011 to 348 in 2016 ***(figure 1.5)*** [104]. This drop is concerning in the group that used to represent the majority of egg donors in the UK [139].

Figure 2a.1: *Egg donation registrations in the UK (1990-2016)*



2a.1.2 Aims

The egg sharing programme is undoubtedly an interesting practice, with significant psychosocial and ethical debate surrounding its practice [140, 141]. This systematic review is the first to exclusively analyse egg share donors. It aims to provide an up-to-date analysis of psychosocial factors surrounding egg sharing, from the point of view of the egg share donor. This knowledge aims to identify factors that could improve clinical practice as well as providing an improved understanding of potential reasons for the decline in egg sharer numbers, and how these numbers could be improved. Its secondary aims are to investigate the motives, attitudes and treatment experiences of egg sharers, as well as any issues about disclosure and non-anonymity.

2a.2 Methodology

2a.2.1 Search strategy

The systematic search followed 'preferred reporting items for systematic reviews and meta-analyses' (PRISMA) guidelines [142]. A bibliographic search of English language publications in four computerized databases (PubMed, Googlescholar, Science Direct and PsychINFO) was conducted. The search terms are listed in ***table 2a.1*** and were used in all possible combinations. The search was

augmented by identifying additional studies from references cited in primary sources and review manuscripts.

Table 2a.1 *Search and selection strategy for systematic review of psychological aspects of egg share donation.*

Databases searched	PubMed, Googlescholar, Science Direct, PsychINFO
Search keywords	Exposure: [oocyte donation OR egg donation OR gamete donation OR recipient OR oocyte sharer OR oocyte sharing OR patient sharer OR patient sharing OR egg sharing OR gamete sharing] AND [psychosocial OR psychological OR attitudes OR motivations OR beliefs OR reasons OR ethics OR experiences OR satisfaction] NOT [prospective OR potential]
Other sources	Additional studies were identified through references identified from included studies and reviews
Inclusion criteria	(1) Published in English in peer reviewed journals (no date cut off) (2) Studies focusing on ARTs only (3) Studies focusing on psychosocial well-being
Exclusion criteria	(1) Studies not in English (2) Full article not available (3) Studies not investigating psychosocial aspects of oocyte donation (4) Studies that focus on prospective oocyte donors, sperm donors, donor offspring, practitioners, researchers attitudes, fertility 'travellers'
Categories of studies	(1) Psychosocial aspects of oocyte donation in egg share donors (2) Psychosocial aspects of motherhood and parenting in egg share donors (3) Psychosocial aspects of disclosure decisions in egg share donors

2a.2.2 Study selection

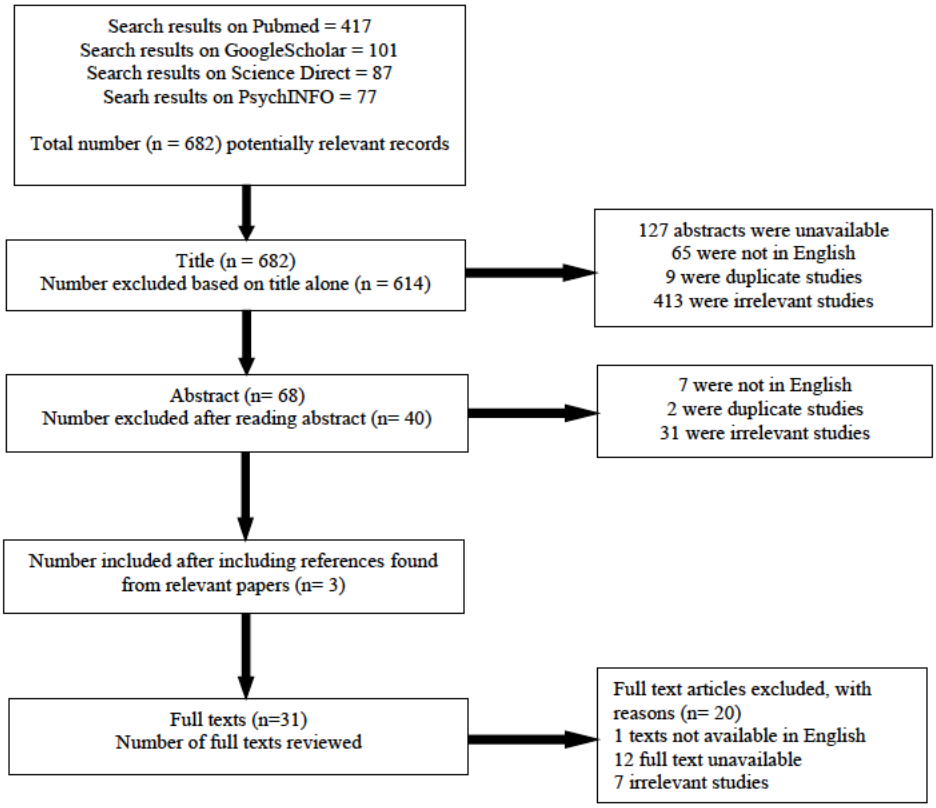
Given that oocyte donation is a relatively recent practice, there were no restrictions placed on publication date and inclusion. Only English language peer-reviewed studies that have examined the psychosocial aspects of oocyte donation on oocyte donors, sharers and recipients were included. This review aimed to synthesize all available data on the topic, so no studies were excluded based on study design. Because this review focused on patients directly involved in egg share donation, the following studies were excluded: (i) those that focused on potential oocyte donors; (ii) altruistic oocyte donors; (iii) anonymous oocyte donors; (iv) oocyte recipients other than egg share recipients; (v) sperm donors;

(vi) donor offspring; (vii) fertility 'travellers'; and (viii) attitudes of practitioners or researchers towards oocyte donation.

2a.2.3 Study screening

All manuscripts from the first search (n=682) were independently reviewed by the first author (T.B- M) based on the inclusion and exclusion criteria. Following an initial screen, 614 studies were excluded due to the title alone. After applying the exclusion criteria to these abstracts, 31 studies were evaluated for inclusion (***figure 2a.1***). An additional three studies were included from snowballing the references of studies identified. A total of 11 studies were included in this review. The screening process was cross-checked by the second author (S.S). Disagreements regarding extracted data were resolved by discussion and the final decision made by the senior author (M-Y.T)

Figure 2a.2: *PRISMA information flow diagram for the systematic review of psychosocial aspects of egg share donation*



2a.2.4 Data extraction

A data extraction spreadsheet was developed and agreed between the authors. The selected studies were comprehensively examined and relevant data was extracted from each paper and inputted to the spreadsheet by the first author (T.B-M) and crosschecked by the second author (S.S). Information selected included: (i) author details; (ii) year of publication; (iii) country of the study; (iv) study aim; (v) sample size; (vi) methodology; (vii) sample characteristics; (viii) outcome measures and (ix) summary of findings. Thematic analysis based on the methodology of Braun & Clarke was used to analyse the data and extrapolate key themes from the studies [143]. Disagreements regarding extracted data were resolved by discussion and the final decision made by the senior author (M-Y.T).

2a.3 Results

2a.3.1 General findings and demographics

Table 2a.2 summarises the study characteristics, sample size methods and aims. Of the 11 studies investigating egg share donation, seven only examined egg sharers and their recipients. Significant heterogeneity existed in the design and aims of the studies included. Eight studies used questionnaires while three used various interview techniques to obtain their data. All of the included studies collected their data after their participants had completed their donation. Two of the studies used qualitative interviews to evaluate donors' psychological experiences towards egg donation [48, 144] and one study used a previously recognized psychological interview tool [145]. The sample sizes range from 11 [145] to 144 egg sharers [51]. The study follow-up time ranged from 3 months [51] to 3 years from the point of donation [49, 52, 60]. There were significant differences found in the studies included, but despite this it was possible to pinpoint consistent issues that emerged. All of the included studies were UK based, as no studies fulfilling the inclusion criteria were identified from other countries. Regarding demographic data, of the 11 studies included, most egg sharers were married, nulliparous and over 30 years [48, 146, 147]. Very few demographic differences between donors and their recipients were reported in terms of their ethnicity, level of education, occupation, and religious beliefs [60, 146].

Table 2a.2: *Characteristics and aims of studies involving egg share donors*

[a]Unstandardised questionnaire with no reported measure of validity or reproducibility; [b]Unstandardised qualitative interview with no reported measure of validity or reproducibility; [c]Standardised questionnaire with a reported measure of validity or reproducibility; [d]Standardised qualitative interview with a reported measure of validity or reproducibility

Author, year and country	Sample	Method	Pre- or post-donation	Aim
Ahuja et al 1997 UK	49 oocyte share donors 46 recipients 12 volunteer oocyte donors	Questionnaire[a]	Post-donation	Examine attitudes of oocyte donors and recipients in regard to oocyte sharing and oocyte donation
Ahuja et al 1998 UK	114 oocyte share donors	Questionnaire[a]	Post-donation	Examine motives to participate in oocyte sharing, attitudes towards offspring of oocytes donated in oocyte sharing, reflection on donation experience
Blythe et al 2004 UK	22 oocyte share donors 18 husbands/partners	Explorative interview[b]	Post-donation	Investigate motives for oocyte sharing, experiences of treatment and attitudes towards oocyte sharing
Frith et al 2007 UK	75 gamete donors (12 oocyte share donors, 43 sperm donors)	Questionnaire[a]	Post-donation	Investigate patient attitude towards loss of donor anonymity
Gürtin et al 2012a UK	48 oocyte share donors 38 recipients	Questionnaire[a]	Post-donation	Investigate motives and anxieties about oocyte sharing, retrospective assessments and within group comparisons of donors and recipients
Gürtin et al 2012b UK	48 oocyte share donors 38 recipients	Questionnaire[a]	Post-donation	Reports on attitudes and feelings on consent, satisfaction and ethics of oocyte sharing
Gürtin et al 2012c UK	48 oocyte share donors 38 recipients	Questionnaire[a]	Post-donation	Reports on knowledge, motivations and anxieties of oocyte-sharing
Haimes et al 2013 UK	25 oocyte share donors	Explorative interview[b]	Pre-donation	Gain understanding of oocyte share participants perspectives and reasoning
Kirkland et al 1992 UK	15 oocyte share donors 20 volunteer donors 50 recipients	Questionnaire[a,c]	Post-donation	Examine attitudes involved in secrecy, anonymity, disclosure and payment issues in oocyte donation
Power et al 1990 UK	15 oocyte share donors 20 volunteer oocyte donors	Questionnaire[a]	Post-donation	Examine attitudes of oocyte sharer and volunteer donors towards donation, the recipient, the potential children conceived and experiences of medical treatment
Rapport et al 2003 UK	11 oocyte share donors	Interview[d] (van Manen's interpretive phenomenological analyses)	Pre-donation	Explore motivations, beliefs and experiences of oocyte share donors

However, egg sharers were significantly younger than their recipients [60, 146], with one study reporting a mean donor age of 33.7 years, compared to 44.7 years for recipients [60].

2a.3.2 Motivations and attitudes for egg share donation

Studies consistently found egg share donors citing altruistic motives and the importance of helping another infertile couple to have a child to be as significant a factor as having a child themselves [48, 51, 52, 144]. One study reported egg sharers to have a significant need to make their recipient 'happy' [60]. However, unsurprisingly studies have also shown accessing subsidized or free treatment was just as significant a motivation, with Gurtin et al. (2012c) finding 87% of their egg share donors citing this as an important reason to participate in egg sharing [52, 146]. One study found 64% of egg sharers preferred eggs to come from women already undergoing fertility treatment [49], and this was supported by a study reporting egg share donors felt sharing their eggs was a 'win-win' solution for both parties involved [48]. Gurtin et al. (2012c) found 27% of their egg sharers were in same sex relationships and already needing sperm from a donor for their own treatment, many also described a desire to help others achieve a pregnancy by donating their oocytes [52]. The same study also reported 54% of egg share donors would have strongly considered participating in the egg sharing programme if they had sufficient financial means to pay for their own treatment. Understandably a significant worry reported by both egg sharers and recipients was their treatment being unsuccessful [51, 60]. The main concerns reported by the recipients were the donor changing their mind or having insufficient eggs collected to donate [48, 52].

Studies consistently found most egg sharers wanted to find out the outcome of their recipient's fertility treatment [48, 60, 147]. One study reported a significant majority (79%) hoped their recipient had a successful outcome, and there was no statistically significant difference regarding this answer if their own treatment had been successful or unsuccessful [60]. The same study reported that 42% of egg sharers decided not to discover the outcome of their recipient's treatment, compared to 51% of egg recipients finding out about their donor's treatment, however this difference did not yield statistical significance [60]. Power et al. (1990) described egg sharers to be more 'detached' from their donation

treatment compared to purely altruistic donors, with 85% of altruistic donors wanting to find out the outcome of donation, compared to 40% of egg sharers. One study observed that 61% of their egg sharers thought about their recipient during treatment, with this figure decreasing significantly to 15% a year later, revealing the connection to be predominantly transient [60]. Another study reported that if the egg sharers own fertility treatment had worked, 68% would think about any potential offspring from their recipient's treatment [49].

2a.3.3 Egg sharers donation experience

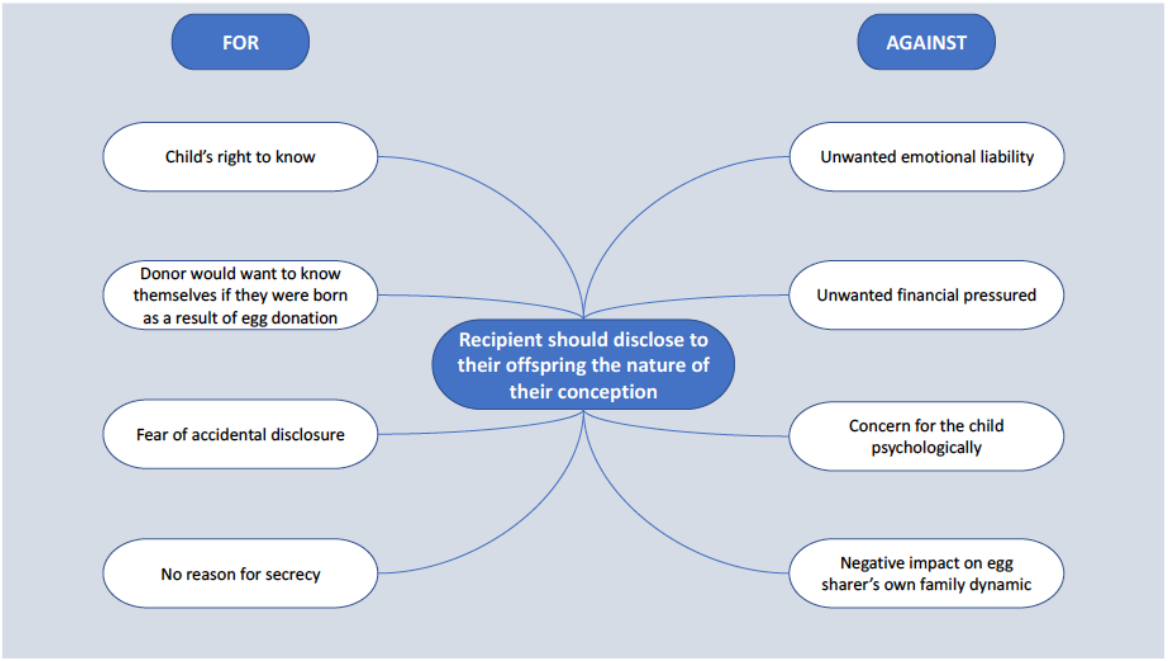
Ahuja et al. (1998) found the vast majority of their egg sharers whose treatment had been successful (89%) reported their treatment experience to have been positive, and this figure did not fall when the treatment outcome was unsuccessful (90%). This positive treatment experience was supported by another study, who reported 86% of their egg sharers not stating any regrets about participating, with 68% rating the experience 'extremely positively'. Ahuja et al. (1997) observed that 63% of their egg sharers would egg share again, with the same study also showing no negative feelings toward egg sharing from their family or close friends. Power et al. (1990) found the vast majority of egg sharers would donate again (90%), despite finding their egg sharers to be more 'removed' from the donation process compared to purely altruistic donors. Studies did find egg sharers consistently reporting reservations about losing half of their eggs, and whether this would impact the success of their own treatment [144, 145]. However, despite reporting this issue 100% of these respondents proceeded with egg sharing [144, 145]. Gurtin et al. (2012a) asked their egg sharers and recipients whether 'egg sharing is exploitative', with only 4.2% and 5.4% agreeing with this. Studies reported egg sharers to give a low importance to a genetic link to their recipient's offspring, with Ahuja et al. (1998) showing that 80% of egg sharers did not harbour any anxiety about their recipient's offspring being their genetic offspring, nor perceive them as their own child. Most egg sharers acquired their knowledge from the staff at their fertility clinic (44.1%), followed by personal research (29.8%), with a small minority coming from medical professionals, such as General Practitioners (GPs) or gynaecologists (4.3%) [52]. Gurtin et al. (2012c) found several of their egg sharers to have been frustrated to have not found out about the option of egg sharing from health care professionals earlier in their treatment journey. Regarding recipients,

the vast majority (81.6%) were glad they acquired their donor eggs through egg sharing, with only 5.3% voicing regret [49]. The same study found that 81.6% of recipients would take part in egg sharing again [49]. Both egg sharers and recipients found positive communication with their fertility clinic to be a significant factor [48], with one study finding 59% of both egg sharers and recipients stating good communication with clinical staff to be a vital factor in defining their overall treatment experience [52].

2a.3.4 Disclosure

Figure 2a.3 summarises egg sharers views on whether their recipient's offspring should be informed of the nature of their conception. The majority of studies reported egg sharers were in favour of recipient offspring being informed, with reasons for disclosure being the 'child's right to know', 'they would want to know themselves if they were born as a result of egg donation', and there being 'no reason for secrecy' [48, 51, 60, 146]. One study investigated egg sharers reflections and opinions on the change in legislation regarding donor anonymity [148]. The major issues raised by donors were unwanted financial accountability (10.8%), unwanted emotional responsibility (8.2%) and a negative effect on the child psychologically (7.6%) [148]. Studies reported between 74 and 94% of egg share donors informed family or friends about their participation in egg sharing [146, 147, 149]. Blyth (2004) reported that 66% of egg sharers did plan to disclose to their own child about the nature of their conception. A significant minority of egg sharers (42-47%) stated the recipient should ideally disclose to their child born through egg sharing of the nature of their conception, with only 5% believing the child did 'not have the right to know' [48, 60]. However, 54% felt it was their recipient's right to make the decision on whether to disclose or not [60]. Recipients' shared these opinions surrounding disclosure, with 86% intending to disclose in the future, and 78% feeling positive about potential future contact between the donor and their child [60]. One study found the majority of recipients would want to know if they had been conceived as a result of sperm or egg donation [149].

Figure 2a.3: *A diagram illustrating egg sharers reasons for and against disclosure to their recipient's offspring regarding the nature of their conception*



2a.4 Discussion

This systematic review explores the psychosocial aspects of the egg sharing programme, and investigates study participants motives, attitudes and treatment experiences of egg sharing as a donor or recipient. It also explores patients attitudes towards donor anonymity and disclosure. At the time this review was performed, there were only three other reviews [57, 150, 151] investigating similar aspects of egg donation and egg sharing. This is the first systematic review to study egg share donors and their recipients singularly and having identified 11 studies, makes it the most comprehensive review on this topic.

Egg sharing is an exception within the HFEA regulatory framework, which accentuates the concept that both sperm and egg donation should be cost neutral [101]. This is obviously far simpler to implement with sperm donation. Critics of egg sharing have focused on the potential issue that egg sharing could exploit women and couples who are otherwise unable to access fertility treatment; and that egg share donors could endure significant short- and long-term psychological sequelae if their own outcome is

unsuccessful, compared to standard IVF patients. This systematic review examined a large amount of qualitative data and has been able to address these concerns to a significant degree.

2a.4.1 Motivations, attitudes, and treatment experiences of egg sharing

The included studies consistently revealed the vast majority of recipients who secured their eggs through egg sharing reported positively about their treatment experience, and were also glad to have participated in the programme. However, recipients were anxious their egg share donor could change her mind or produce an insufficient number of oocytes during her treatment, when compared to recipients from known or altruistic donors [52]. Studies showed egg sharers motivations are multifactorial. They make a clear distinction between financial and treatment incentives when deciding to participate. A small majority of egg sharers would still partake regardless of their financial situation, showing they exhibit a broad attitude towards egg donation and the importance of reciprocity amongst couples seeking fertility treatment [146]. Importantly, there was no statistically significant difference in any study between egg sharers whose treatment was successful or unsuccessful regarding their feelings towards the recipient and any potential children born [60]. This systematic review revealed egg sharers to be educated and more than capable of addressing the key issues that arise from participating in egg sharing. They did not feel exploited by egg sharing, but instead stated a view that egg sharing provides the opportunity for a 'win-win' solution for themselves and their recipients. There was also reassuring data regarding the demographic profiles of the donors and recipients, which goes against concerns about more financially secure recipients indirectly taking advantage of 'poorer working class' donors [146]. Unsurprisingly there was a difference in age between egg sharers and their recipients, so it would be expected for recipients to be earning more than egg sharers, however, no studies investigated this. Relevant to the theoretical concern regarding exploitation of the egg share donor is the quality of her consent, since participating in the programme might be her only realistic chance of having her own child. Indeed, most of those forwarding arguments against egg sharing have placed this as one of their principal arguments [43, 55, 152, 153]. It is completely reasonable to postulate that egg sharing would be a morally unacceptable programme if women who would not potentially also donate for altruistic reasons were essentially forced to do so due to their own financial limitations [43]. The HFEA's Sperm,

Egg and Embryo Donation (SEED) report (2005) states *'If an egg provider's judgement were really obscured by the promise of free treatment, one might expect to find evidence of people complaining about this afterwards, or at least some egg providers later regret giving up their eggs'*. This review reports the vast majority of egg sharers to have been consistently happy to have taken part in the programme [48, 60, 63, 146], with one study reporting 83.3% of their participants would donate again, and only 2.1% regretted undergoing treatment as an egg sharer [60]. This data indicates egg sharers are well equipped to make the challenging decisions facing them, and therefore they are exhibiting adequate consent.

This review reports overwhelmingly encouraging data regarding the well-being of egg sharers and their recipients. However, it must be mentioned that the studies included in the review only included egg sharers and recipients who agreed to participate in research and therefore cannot be definitively extrapolated to an overall opinion of these patients towards the egg sharing programme [154]. Nonetheless, future ethical and moral debate should include this reassuring and extensive qualitative data presented, which could help to contribute to broaden evidence-based conversations on egg share donation in the future.

Gurtin et al. (2012c) was the only study reviewed to investigate how egg sharers and their recipient's acquired knowledge of egg sharing. The fertility centre was the main source of information for most participants, followed by their own personal research, with very little advice on this option obtained from GPs or gynaecologists. This is of potentially huge significance as these GPs and gynaecologists are a much more widely accessed source of medical information and options for couples trying to conceive. Indeed, Gurtin et al. (2012c) mentioned numerous participants were frustrated by the amount of time it took for them to learn of the option of egg sharing, with these women also stating significant disappointment that healthcare professionals they had spoken to earlier had not discussed egg sharing with them. This frustration is understandable as the period from initially seeing a GP to securing a referral to an IVF centre can be as long as 1-2 years in the UK. Furthermore, the nature of the

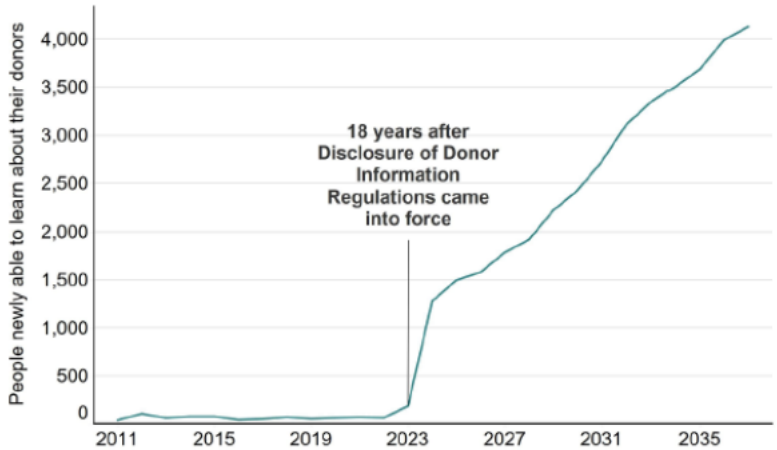
information being accessed is of concern, since it is known that personal research on the internet can contain a lot of inaccurate, unregulated, and biased information on the subject.

2a.4.2 Disclosure and anonymity issues

Studies consistently reported that both egg sharers and their recipients were predominantly in support of disclosure of the nature of their fertility treatment [60, 149]. In the UK, fertility clinics encourage patients towards disclosure in their counselling sessions during treatment, with this advice based on research from studies on the family dynamic of couples who adopted [155, 156], as well as studies of individuals conceived through egg and sperm donation themselves [80]. When the legislation surrounding donor anonymity was passed in the UK in April 2005, there was a notable decrease in sperm and oocyte donor numbers [104]. However, after this decline oocyte donor numbers then started to pick up significantly ***(figure 2a.4)*** [104]. In contrast, the number of women participating in egg sharing treatment has reduced in recent years in the UK ***(figure 1.5),*** which is a worrying trend, since they previously constituted the bulk of UK egg donors [104]. Four of the studies included in this systematic review were performed after the 2005 legislation, and these studies reported a significant minority of donors would not participate with oocyte donation due to the removal of their anonymity. The central and recurring explanations given for not donating without anonymity were concerns for any financial or legal responsibilities for any offspring born as a result of their donation, as well as the potential emotional impact of any surprise and unmediated contact [148]. The concerns surrounding financial and legal responsibility could be alleviated by fertility clinics improving information given and education of their patients, emphasizing to them that donors carry no such responsibilities to any offspring born. With regard to fears of unmediated contact, the British Fertility Society (BFS) has emphasized the need to offer and deliver counselling around times when couples disclose to their children how they were conceived or when contact is made between the donor and the child conceived by gamete donation [157], and there has been novel research work undertaken specifically to create ‘donor linking’ counselling [48]. Unfortunately, there has been no response from the UK government to any of these proposals, and there are currently no plans for any government funded counselling sessions for donor-conceived offspring around these key time points, such as those established in the

adoption services [158]. The obvious reason for this lack of urgency in launching these clinical services, was that when the donor anonymity legislation was passed in 2005, resulting offspring would not turn 18 years of age until earliest April 2023. However, this deadline has now passed and there remains no government funded counselling service for those involved in fertility treatment with donor gametes. In 2024 approximately 2300 donor-conceived people will be 18 years or over and therefore eligible to submit a request for identifiable information about their donor, such as their name, date of birth and last known postal address ***(figure 2a.4)*** [1]. Current HFEA data reveals that of those eligible donor-conceived people, 28 have already requested this identifying information from the HFEA [1]. Those conceived from a donor before April 2005 can only access identifiable information about their donor when they turn 18 years of age if their donor has contacted the HFEA and voluntarily removed their anonymity [1]. As of November 2022, 260 donors have taken this step and waived their anonymity [1]. Identifying the fact that donor conceived offspring and contact with their genetic parent is now a reality, Donor Conception Network are currently undertaking significant work to offer practical and psychological support to donors and their offspring. The knowledge that such services are available could encourage more potential donors and egg sharers to go ahead.

Figure 2a.4: *Figure showing donor-conceived people turning 18 born to identifiable donors, 2011-2037*



2a.4.3 Limitations of the systematic review

This was an extensive systematic review and the only review to exclusively examine egg sharers and their recipients. However, there were some methodological limitations identified in the studies included. First, the most significant issue was of potential sampling bias as the majority of included studies used questionnaires and interviews after treatment had taken place, with a response rate of approximately 30%. Patients with more positive or negative attitudes and experiences are more likely to be motivated to participate, thus leading to potentially significant publication bias [159]. Second, most of the included studies had relatively small sample sizes, and this was also true of the quantitative studies ***(table 2a.2)***. Third, the studies conducted their research only weeks or months following treatment, with a few following up to 3 years post-donation. Only one group has performed longitudinal studies on children born through gamete donation, and these patients were not egg sharers [133, 160]. In one of the published studies from this group, 87 children born from sperm or egg donation were compared to 54 natural conception families [160]. The study reported no difference in family dynamics between disclosing families and non-disclosing or natural conception families, however higher levels of adolescent well-being were found in those who had been informed of the nature of their conception before the age of 7 years [160]. The same research group reported that mothers who had not revealed the biological origins to their offspring exhibited greater levels of distress [133]. There is no longitudinal research undertaken on egg share donors or their recipients, and therefore there is no understanding of long-term psychosocial consequences within these families. Fourth, all the included studies are from the UK, which is surprising considering egg sharing is now in clinical practice around the world, with these countries not yet publishing their experience of the programme. This currently means the conclusions regarding a global issue are based on the attitudes of UK based egg sharers. Finally, all the studies recruited participants from a single fertility clinic. Egg sharing practice differs between clinics, and this could lead to a variation in the treatment experiences and even motivations of egg sharers.

2a.4.4 Suggestions for further research into egg sharing

This systematic review successfully investigated some significant psychosocial aspects of egg sharing and has led to some conclusions that we believe could impact future clinical practice and policy reform in the UK.

The first issue is surrounding the information provided into egg sharing, with patients stating significant frustrations they had not been informed about the possibility of egg sharing earlier by their GP or general gynaecologist, and the resulting delay this had on their fertility treatment. Currently an untapped resource in the UK regarding egg donation and sharing, these healthcare professionals are in a unique position as an early and consistent point of contact for patients trying to conceive. Fertility patients not being made aware of the option of egg sharing until late in their treatment is potentially having a significant impact on egg share donor numbers in the UK. A potential reason for this matter is doctors not specializing in reproductive medicine having a distinct lack of knowledge about the egg sharing programme. Fertility clinics that use egg sharing to access oocyte donors could address this issue by attempting to improve education of healthcare professionals that have the potential to refer patients for egg sharing. For example, by hosting regular educational events with GPs and general gynaecologists. While it is paramount potential egg donors or recipients do not feel pressured into egg sharing, it is also vital the current paucity of information is addressed. Studies investigating healthcare professionals' knowledge and attitudes towards egg donation and egg sharing have not been performed and would be very useful to confirm the findings of this systematic review.

Second, although this review reported egg sharers to be overwhelmingly positive about their experience, a consistent issue amongst donors was that donating a significant proportion of their oocytes would impact their own chances of a successful treatment outcome. There are very few studies that have investigated this topic, however one study reported no difference in pregnancy or live birth rates between egg share donors and standard IVF/ ICSI patients [65]. Fertility clinics could audit their own data and provide their own potential egg share donor patients on their success rates. Fertility clinics should be very open about treatment aspects of egg sharing that varies from standard IVF treatment,

and need to be aware of how significant the role of communication from clinical staff is for potential and actual egg share donors.

Finally, this systematic review generated a significant amount of reassuring psychological data regarding the egg share donor and their recipient. However, there were still relatively few studies investigating the psychosocial aspects of egg sharing. More studies involving larger numbers of patients would be valuable to further address this issue, and justify the continued existence of egg sharing, a programme that has been so heavily criticised and debated since its introduction. Nevertheless, the highly pertinent findings from this review should be considered for future policy discussions surrounding egg sharing in the UK.

2a.4.6 Conclusion

Currently in the UK, the number of donor oocytes available falls well short of demand, and in addition reduced government funding for fertility treatment means egg sharing provides a practical option for a greater number of patients to access IVF, whilst also providing more donor eggs. The psychosocial data presented in this review was reassuring for both egg sharers and recipients, but despite this the number of women participating in egg sharing have decreased in the UK. With greater awareness from improved education to healthcare professionals, there is the potential to recruit more egg share donors and meet the needs of more recipients currently, who are often on long waiting lists, under conditions that are beneficial to both sets of women.

Study Ib: A systematic review investigating psychosocial attitudes, motivations, treatment experiences and disclosure decisions of oocyte recipients

2b.1 Introduction

Egg donation treatment offers an answer for certain groups of patients to conceive, who would realistically have not been able to do this with their own oocytes. One of these groups of women are those with POI [35]. In addition to this, older women will often need donor eggs to conceive, due to the poor likelihood of success with their own oocytes [34]. In the UK in 2018, 67% of treatment cycles using DEPS were performed on women over 40 years [37]. Women aged 40-42 years have a 33.8% live birth rate, versus 11.3% with their own oocytes, and this gap increases further in women age 43-44 years (33.1% *vs.* 4.5%), and in women aged over 44 years (27.5% *vs.* 3.5%) ***(figure 1.4)*** [37]. The option recipients have of using donor eggs for their treatment allows them to experience pregnancy and childbirth, with DEPS cycles also allowing any resulting offspring to be genetically related to the recipient's partner [161].

2b.1.2 Aims

This systematic review aims to provide an up-to-date analysis of psychosocial factors surrounding oocyte donation from the point of view of the recipient. Its secondary aims are to investigate the motives, attitudes, and treatment experiences of recipients, as well as any issues about disclosure and non-anonymity.

2b.2 Methodology

2b.2.1 Search strategy

The systematic search followed PRISMA guidelines [142]. A bibliographic search of English language publications in four computerized databases (PubMed, Googlescholar, Science Direct and PsychINFO) was conducted. The search terms are listed in ***table 2b.1*** and were used in all possible combinations.

The search was augmented by identifying additional studies from references cited in primary sources and review manuscripts.

Table 2b.1 *Search and selection strategy for systematic review of psychological aspects of oocyte recipients*

Databases searched	PubMed, Googlescholar, Science Direct, PsychINFO
Search keywords	Exposure: [oocyte donation OR egg donation OR gamete donation OR recipient OR oocyte sharer OR oocyte sharing OR patient sharer OR patient sharing OR egg sharing OR gamete sharing] AND [psychosocial OR psychological OR attitudes OR motivations OR beliefs OR reasons OR ethics OR experiences OR satisfaction] NOT [prospective OR potential]
Other sources	Additional studies were identified through references identified from included studies and reviews
Inclusion criteria	Published in English in peer reviewed journals (no date cut off) Studies focusing on ARTs only Studies focusing on psychosocial well-being
Exclusion criteria	Studies not in English Full article not available Studies not investigating psychosocial aspects of oocyte donation Studies that focus on prospective oocyte donors, sperm donors, donor offspring, practitioners, researchers attitudes, fertility 'travellers'
Categories of studies	Psychosocial aspects of oocyte donation in oocyte donor recipients Psychosocial aspects of motherhood and parenting in oocyte recipients Psychological aspects of disclosure decisions in oocyte recipients

2b.2.2 Study selection

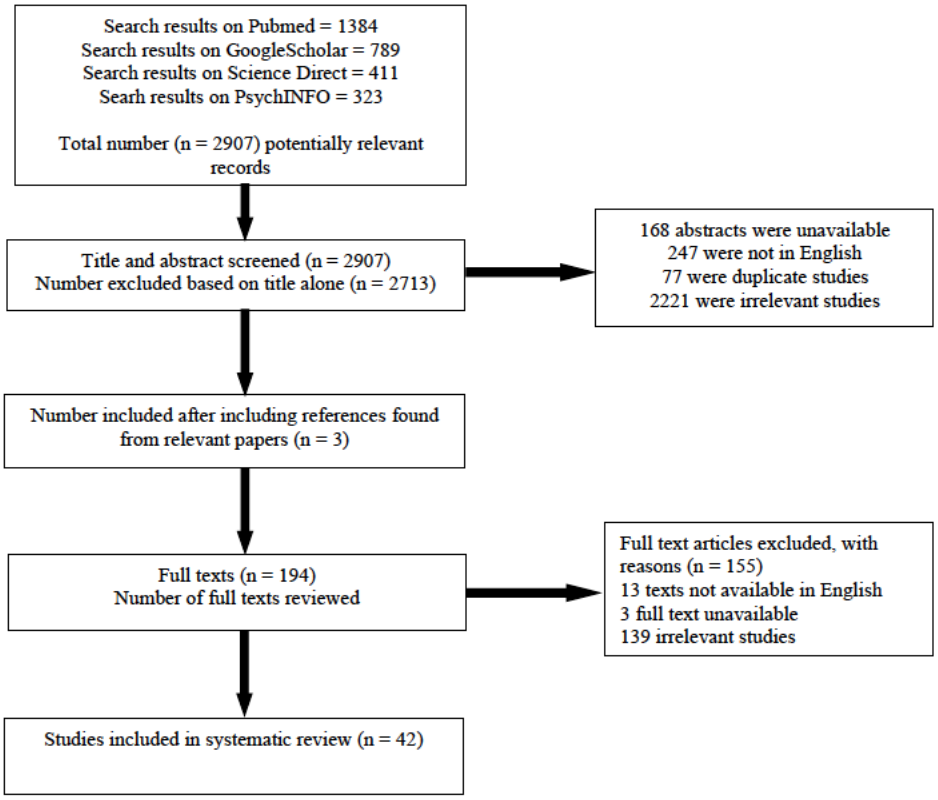
Given that oocyte donation is a relatively recent practice, there were no restrictions placed on publication date and inclusion. Studies were excluded when full-text articles were unavailable. Only English language peer-reviewed studies that have examined the psychosocial aspects of oocyte donation on recipients were included. This review aimed to synthesize all available data on the topic, so no studies were excluded based on study design. Because this review focused on confirmed oocyte recipients, the

following studies were excluded: (i) potential oocyte recipients; (ii) oocyte donors; (iii) sperm donors or recipients; (iv) gamete donors and recipients in general; (v) individuals undergoing cross-border reproductive care; and (vi) the attitudes of healthcare practitioners or researchers towards oocyte donation.

2b.2.3 Study screening

All manuscripts from the first search (n=2907) were independently reviewed by the first author (T.B-M) based on the inclusion and exclusion criteria (***figure 2b.1***). Following an initial screen, 2713 records were excluded based on title and abstract alone, leaving 194 articles for full-text evaluation. Additional studies (n=3) were added after screening of bibliographies of key relevant studies. A total of 42 studies were included in this review. The screening process was cross checked by the second author (S.P). Any disagreement was resolved by discussion between authors.

Figure 2b.1: PRISMA information flow diagram for the systematic review of studies exploring psychosocial aspects and disclosure decisions of oocyte recipients



2b.2.4 Data extraction and analysis

A data extraction spreadsheet was developed and agreed between the authors. The selected studies were comprehensively examined, and relevant data was extracted from each study and inputted to the spreadsheet by the first author (T.B-M) and crosschecked by the second author (S.P). Information selected included: (i) author details; (ii) year of publication; (iii) country of the study; (iv) study aim; (v) sample size; (vi) methodology; (vii) sample characteristics; (viii) outcome measures and (ix) summary of findings. Thematic analysis based on the methodology of Braun & Clarke was used to analyse the data and extrapolate key themes from the studies [143]. Disagreements regarding extracted data were resolved by discussion and the final decision made by the senior author (M-Y.T).

2b.3 Results

2b.3.1 General findings and demographics

The study characteristics, sample size, methods, and aims can be found in ***table 2b.2***. All studies used either questionnaires (n=19), qualitative interviews (n=17), or both (n=6). Sample sizes ranged from 8 [140] to 1168 [162]. Oocyte donation laws and regulations vary across different countries, and this will certainly impact on the studies' results and conclusions. Therefore, the country of origin of the study is of great significance. Of the 42 studies reviewed, the majority came from the USA (n=13) and the UK (n=11), with the remainder coming from Belgium (n=4), France (n=3), Sweden (n=3), Canada (n=3), Finland (n=2), Australia (n=1), and Iran (n=1). One study included participants from multiple countries (USA, UK, Australia, Canada and two European countries) [163]. 31 studies were conducted following oocyte donation, nine prior to the donation process and two studies involved participants pre- and post-donation treatment. 16 studies exclusively focused on oocyte recipients.

Table 2b.2: *Summary of the characteristics and aims of the studies reviewed*

Author, year and country	Sample	Method	Pre- or post-donation	Aim
Ahuja *et al.* 1997 UK	49 egg-sharing donors 46 oocyte recipients 12 volunteer oocyte donors	Questionnaire[a]	Post-donation	Examine motives to participate in oocyte sharing, attitudes towards offspring and reflections on donation experience
Applegarth *et al.* 1995 USA	49 oocyte donor recipient couples	Questionnaire[a]	Post-donation	Obtain preliminary follow-up information regarding the psychosocial well-being of families created through oocyte donation
Applegarth *et al.* 2016 USA	72 parents using oocyte donation	Questionnaire[a]	Post-donation	Explore if parents with children created through oocyte donation follow through with their original intentions regarding disclosure to their offspring
Baetens *et al.* 2000 Belgium	144 oocyte donor recipient couples 144 oocyte donors (known and anonymous)	Psychological interviews[b]	Pre-donation	Explore the motivations behind choice of donor and disclosure decisions to the offspring and community
Bartlett 1991 USA	16 known oocyte donors 14 recipients 16 infertile women undergoing IVF, not requiring exogenous gametes (control)	Psychological assessment (PSS + SCL-90)[c] & Psychological interviews[b]	Pre-donation	Examine the psychosocial, psychosexual, fertility and family history of known donors and recipients
Bertrand-Servais 1993 France	50 oocyte recipients	Psychological interviews[b]	Pre-donation and post-donation	Characterize the type of couple resorting to ART, and evaluate the repercussions of using ART on the couple's relationship
Blyth *et al.* 2012 Canada	15 known oocyte donors 18 known oocyte recipients	Psychological interviews[b]	Post-donation	Explore views of altruistic known donors and recipients on donor compensation
Blyth *et al*. 2013 Multiple countries	108 parents of children conceived following OD	Questionnaire[a]	Post-donation	Explore perspectives of parents of children conceived following OD
Craft *et al.* 2005 UK	165 oocyte donors 142 oocyte recipients	Questionnaire[a]	Post-donation	Explore oocyte donor and recipient attitudes towards loss of donor anonymity
de Melo-Martin et al, 2018 USA	28 oocyte donors 22 oocyte recipients	Psychological interviews[b]	Post-donation	Explore experiences with anonymity among oocyte donors and recipients who participated in an anonymous donor oocyte program
Golombok *et al.* 1999 UK	21 OD families (18 with anonymous donation, 3 with known donation) 45 donor insemination families 41 IVF families 55 surrogacy families	Questionnaires[c] (GRIMS, BDI, TAI, PSI/SF, Rutter "A" scale & PSPCSA), & psychological interviews[d]	Post-donation	Examine parents' emotional well-being, parenting quality, and childrens' socioemotional development in families with a child who is genetically unrelated to the mother or the father
Golombok *et al.* 2006 UK	41 OD families 41 donor insemination 34 surrogacy families 67 natural conception	Questionnaires[c] (GRIMS, BDI, TAI, EDS, PSI/SF & SDQ) & psychological interviews[d]	Post-donation	Examine parenting quality and psychological development of children in ART families where parents lack a genetic and/or gestational link with their child
Golombok *et al.* 2017 UK	32 donor insemination families 27 OD families 28 surrogacy families	Questionnaires[c] (IFR, PARQ, PCS, SDQ, Rosenberg Self-Esteem Scale & EPOCH), psychological interviews[d] & observational assessments	Post-donation	Establish whether children born through gamete donation were at risk of psychological problems following the transition to adolescence, and examine their nature and mechanisms

Greenfeld and Klock 2004 USA	157 oocyte recipients (70 with anonymous donors, 20 with known donors)	Questionnaire[a]	Post-donation	Compare anonymous and known donor mothers' demographics, knowledge about the donor, and disclosure attitudes.
Greenfeld *et al.* 1998 USA	90 oocyte recipients (64 used anonymous donation, 26 used known donation)	Psychological interview[b]	Pre-donation	Compare demographic and psychological characteristics of oocyte recipients and determine correlation between disclosure issues and choice of anonymous or known donor
Gurtin *et al.* 2012a UK	48 egg-sharing donors 38 egg-sharing recipients	Questionnaire[a]	Post-donation	Examine characteristics of egg-sharing participants and report views of egg-sharing donors and recipients on consent, exploitation and commodification
Gurtin *et al.* 2012b UK	48 egg-sharing donors 38 egg-sharing recipients	Questionnaire[a]	Post-donation	Examine thoughts and feelings of egg-sharing donors and recipients regarding the egg-sharing process, and attitudes towards disclosure of donor origins and future offspring-donor contact
Hadizadeh-Talasaz *et al.* 2015 Iran	11 OD recipient women/ couples 7 donor embryo recipient women/ couples 2 surrogacy and OD recipient women/ couples 3 surrogacy recipient women/ couples 5 healthcare professionals	Psychological interviews[b]	Pre-donation	Explore the experiences of disclosure to others encountered by infertile couples attempting ART donation
Hahn and Rosenberg. 2002 USA	31 OD recipient families	Psychological interviews[b] & questionnaires[c] (FES & SS-A)	Post-donation	Identify influences on disclosure decisions of parents who conceive using OD and compare these among disclosing, non-disclosing, and undecided families
Hershberger *et al.* 2007a USA	8 oocyte recipients	Psychological interviews[b]	Post-donation	Describe disclosure experiences of oocyte recipients, and identify significant decision-making factors
Hershberger. 2007b USA	8 oocyte recipients	Psychological interviews[b]	Post-donation	Describe lived experiences of pregnant women who used donor oocytes for conception
Indekeu *et al.* 2013 Belgium	5 oocyte recipient couples 5 donor sperm recipients	Psychological interviews[b]	Post-donation	Explore couples' experiences in the preconception phase of infertility treatment with donor gametes and its influence on the disclosure process to offspring and/or others.
Isaksson *et al.* 2011 Sweden	152 oocyte recipient couples 127 donor sperm recipient couples	Questionnaires[a]	Post-donation	Investigate recipient couples' attitudes and behaviour regarding disclosure and parenthood
Isaksson *et al.* 2012 Sweden	107 oocyte recipient women/ couples 107 sperm recipient women/ couples	Questionnaire[a,b] (ENRICH)	Post-donation	Investigate disclosure behaviour and intentions following gamete donation and study the association between agreement on disclosure to offspring and the couple's relationship satisfaction
Jadva *et al.* 2011 UK	9 oocyte recipients using intra-family donor	Psychological interviews[b]	Post-donation	Examine recipients' experiences of donation between sisters and sisters-in-law
Khamsi *et al.* Canada 1997	10 oocyte recipient couples with their known donors	Questionnaires[a]	Pre-donation	Explore motivations, and attitudes towards disclosure, anonymity and support systems, of oocyte recipient couples and their known donors
Kirkland *et al.* 1992 UK	20 altruistic oocyte donors 15 egg-sharing donors 50 oocyte recipients (47 used anonymous donation, 3 used known donation)	Questionnaires[a]	Post-donation	Examine attitudes involved in secrecy, anonymity, disclosure and payment issues in oocyte donation
Kirkman 2003 Australia	21 oocyte recipients (6 used anonymous donation, 15 used known donation) 3 embryo recipients 12 oocyte donors (6 anonymous, 6 known)	Psychological interviews[b]	Post-donation	Explore donor and recipient understanding of oocyte and embryo donation in relation to motherhood
Klock and Greenfeld. 2004 USA	62 oocyte recipient parents	Questionnaires[a]	Post-donation	Assess the information oocyte recipients received about their donors and their disclosure plans
Laruelle *et al.* 2011 Belgium	42 known oocyte donor recipients 45 anonymous oocyte donor recipients	Semi-structured counselling sessions	Pre-donation	Compares motivations, choices and attitudes of recipient couples in three types of donations: known donation, known-anonymous donation, and anonymous donation

Lindheim and Sauer 1998 USA	80 anonymous oocyte donor recipients	Questionnaire[a]	Pre-donation	Investigate expectations of oocyte recipients while waiting for their potential oocyte donor
Lindheim *et al.* 2000 USA	112 oocyte donors 132 oocyte recipients	Questionnaire[a]	Pre-donation	Investigate oocyte recipient and donor attitudes towards the importance of personal characteristics
Martin *et al.* 2019 UK	4 oocyte recipient women 3 oocyte recipient men (partners) 3 known oocyte donors	Psychological interview[b]	Post-donation	Examine lived experiences of known OD from donor and recipient couples' perspectives
Pettee and Weckstein 1993 USA	31 oocyte recipient parents (17 used known donors)	Questionnaires[a]	Post-donation	Explore experiences and recommendations of oocyte recipient parents
Raoul-Duval *et al.* 1992 France	32 oocyte donor/recipient couples	Questionnaires[a] And psychological interviews[b]	Pre and post-donation	Describe psychological profile of oocyte recipients
Snowdon 1994 UK	5 oocyte recipients 4 oocyte donors 4 undergoing gestational surrogacy	Psychological interview[b]	Post-donation	Examine the experiences of women involved in oocyte donation and surrogacy
Soderstrom-Anttila *et al.* 1998 FInland	49 oocyte recipients (8 used known donors, 41 used anonymous donors)	Questionnaire[a]	Post-donation	Investigate oocyte recipients' attitudes towards disclosure and oocyte donation
Soderstrom-Anttila *et al.* 2010 Finland	113 oocyte recipient mothers 100 oocyte recipient fathers	Questionnaire[a]	Post-donation	Investigate disclosure intentions and parents' attitudes and satisfaction following OD
Svanberg *et al.* 2016 Sweden	164 oocyte donors 213 oocyte recipients 89 sperm donors 487 sperm recipients 215 IVF patients	Questionnaire[a]	Post-donation	Investigate attitudes of gamete donors and couples undergoing ART towards aspects of gamete donation
Weil *et al.* 1994 France	69 oocyte recipients using known donation 31 recipients using anonymous donation	Psychological interviews[b]	Pre-donation	Compare attitudes towards confidentiality between known and anonymous oocyte donors
Wyverkens *et al.* 2016 Belgium	5 oocyte recipient couples	Psychological interviews[b]	Post-donation	Examine experiences of genetic ties in families with sisters as oocyte donors
Yee *et al.* 2011 Canada	15 altruistic known oocyte donors 18 oocyte recipients using known donation	Psychological interviews[b]	Post-donation	Explore oocyte donor and recipient views towards disclosure to offspring

[a]Unstandardised questionnaire with no reported measure of validity or reproducibility
[b]Unstandardised qualitative interview with no reported measure of validity or reproducibility.
[c]Standardised questionnaire with a reported measure of validity or reproducibility.
[d]Standardised qualitative interview with a reported measure of validity or reproducibility

PSS: Perceived Stress Scale; SCL-90: Hopkins Symptom Checklist-90; IFR: Index of Family Relationships; PARQ: Parental Acceptance Rejection Questionnaire; PCS: Parental Control Scale; SDQ: Strengths and Difficulties Questionnaire; EPOCH: Engagement, Perseverance, Optimism, Connectedness, and Happiness Measure of Adolescent Wellbeing; GRIMS: Golombok Rust Inventory of Marital State; BDI: Beck Depression Inventory; TAI: Trait Anxiety Inventory; PSI/SF: Parenting Stress Index (short form); PSPCSA: Pictorial Scale of Perceived Competence and Social Acceptance for Young Children; EDS: Edinburgh Depression Scale; FES: Family Environment Scale; ENRICH: Evaluating and Nurturing Relationship Issues, Communication, and Happiness;

2b.3.2 Motivations for choosing oocyte donation

Studies consistently reported the main motivating factors for undergoing fertility treatment with donor oocytes were the desire to experience pregnancy [140, 161, 164, 165] and the desire for the child to be genetically linked to their partner [140, 161, 164]. For many women, egg donation treatment offered

them a sense of hope and an opportunity to start a family [161]. A significant proportion of recipients also stated a 22% of recipients reported a mistrust of the adoption process, stating they felt 'more comfortable' with the option egg donation gave them [161].

2b.3.3 Type of donor selected

When studies compared recipient's choice of an anonymous or known oocyte donor, the majority of participants preferred anonymous donation [161, 165, 166]. Five studies investigated motivations for oocyte recipients preferring anonymous donation, with the primary theme being the maintenance of privacy and boundaries between themselves and the donor [163, 165, 167-169]. Specific concerns raised regarding known donation included the child having a constant reminder of their genetic origins, potential feelings of rejection by the recipient and being replaced as the mother figure by the donor, and potential legal and maternal claims to the child from the donor [167-171]. These feelings were ameliorated by the recipient using anonymous donation. Indeed, Laruelle et al. (2011) cited a desire to 'mark explicit boundaries and roles between the two parties involved' as the main motivation to choose anonymous donors. Multiple studies also reported that recipients decided to use anonymous donors due to the lack of access to known oocyte donors [163, 167-169]. Lindheim et al. (2001) examined the most significant characteristics requested by recipients and found (in order of decreasing significance) medical history (62%), race (49%), smoking/ alcohol/ narcotics use (44%), intelligence (39%) and physical appearance (29%) to be the most sought after. These were consistently the predominant characteristics requested in other studies [168, 172, 173]. Conversely, one study reported that 48% of recipients did not want any information regarding the oocyte donor [91].

Recipients who used known donors they were related to felt the physical resemblance and genetic link between the donor and the recipient was an important factor in their decision [168]. Additionally, recipients stated their known donors provided them with emotional reassurance during their treatment [174]. Having a strong personal relationship with the donor, knowledge of their personality and access to their medical history were also significant factors [168]. Lindheim et al. (2000) reported the most significant influencing factor for choosing their donor varied according to their age, with intelligence

being the most important donor characteristic for 80% of those over 50 years, and physical appearance being most significant for 75% of recipients under 45 years [175]. Three studies found that recipients would typically choose a close friend or relative to be their known donor, with only 14-20% of recipients stating they felt 'not close' to their donor [164, 167, 168].

2b.3.4 Recipients' attitudes towards oocyte donors

One study found that 14% of recipients of known donors expected to feel "grateful" to their donor [164], a feeling also reported by 75-81% of egg sharing recipients towards their egg-share donor [52, 60]. In contrast, some oocyte recipients reported feeling a "hostage" to their donor [176] or thought of their egg sharer as a potential "competitor" if her treatment was successful and hers was not [177]. One study demonstrated that recipients with unsuccessful treatment were significantly less likely to think of their egg sharer than recipients with successful outcomes [52].

Weil et al. (1994) reported that 80% of recipients using known donors, and 67% of recipients using anonymous donors considered the donated oocyte 'a gift', which has been similarly reported in other studies [52, 84, 176, 178]. Recipients also commonly considered the oocyte a 'means of giving life' or a 'favour' [178]. Others perceived the oocyte the same as any other type of organ donation [178].

Findings regarding recipients' views on payments to donors were contradictory. Recipients commonly reported a concern surrounding payments to donors could attract the 'wrong donors' for the 'wrong reasons' [146, 179]. A significant majority of recipients (64-66%) rejected the concept of monetary payments to donors in two studies [146, 149]. Some recipients raised concerns donor's would give inaccurate health information so they could still donate, if monetary payments were permitted [179]. One study also reported recipients feared treatment using donor eggs would become unaffordable if payments were made [179]. However, 36-55% of recipients in two studies approved of compensatory payments to donors, as they felt this could improve the number of women willing to donate [91, 146, 179]. Suggested payments ranged between £10-50 per oocyte to up to £2000 per round of ovarian stimulation [146], or solely for the reimbursement of expenses incurred from the donation [179].

Regarding the lack of a genetic link to the offspring, most recipients did not perceive this to be significant, with more value placed on the gestational link during pregnancy and delivery [170, 180]. A minority of recipients in one study questioned whether undergoing treatment with donor oocytes definitely makes the recipient of donated oocytes the mother of any resulting offspring [181]. The same study found that a genetic relationship with the offspring following sister-sister oocyte donation was equal to 'genetic motherhood' [181].

Studies show the majority of recipients support the 'Disclosure of Donor Information' Act in the UK [169, 179]. However, Craft et al. (2005) reported that a slight majority of recipients (53.5%) would not have undergone treatment with donor oocytes without donor anonymity. Another study revealed that only 12% of recipients felt that offspring should have the right to obtain donor identifying information [91].

2b.3.5 Recipients' treatment experiences

Overall, treatment experiences were positive, with the majority of recipients finding the process 'rewarding' and 'encouraging' [60, 91, 146]. 78.4% reported their lives were impacted positively [60], and 20% stated the treatment had a positive impact on their marital relationship [161]. Supporting this, 81.6% of recipients who had used egg sharers [60] and 72% of recipients using oocyte donors wanted to undergo further treatment [146].

More negative experiences of treatment were unsurprisingly unsuccessful embryo transfer procedures [91, 146]. However, anxiety surrounding treatment failure, the resulting child, and potential ethical concerns all but disappeared following birth [91, 146, 176, 182]. One study found that recipients' will to have a child was the key for them overcoming negative emotions following unsuccessful treatments and motivation to continue with egg donation cycles [91]. Another study described the importance of a support network and being realistic about their chances of success [176].

The importance of counselling in the oocyte donation process was consistently highlighted by multiple studies [146, 169, 177, 183, 184]. However, one study reported that 24% of recipients found the psychological support they were offered sufficient [182]. Another study reported counselling recommendations had no impact on their disclosure decisions [169].

2b.3.6 Recipients' disclosure decisions

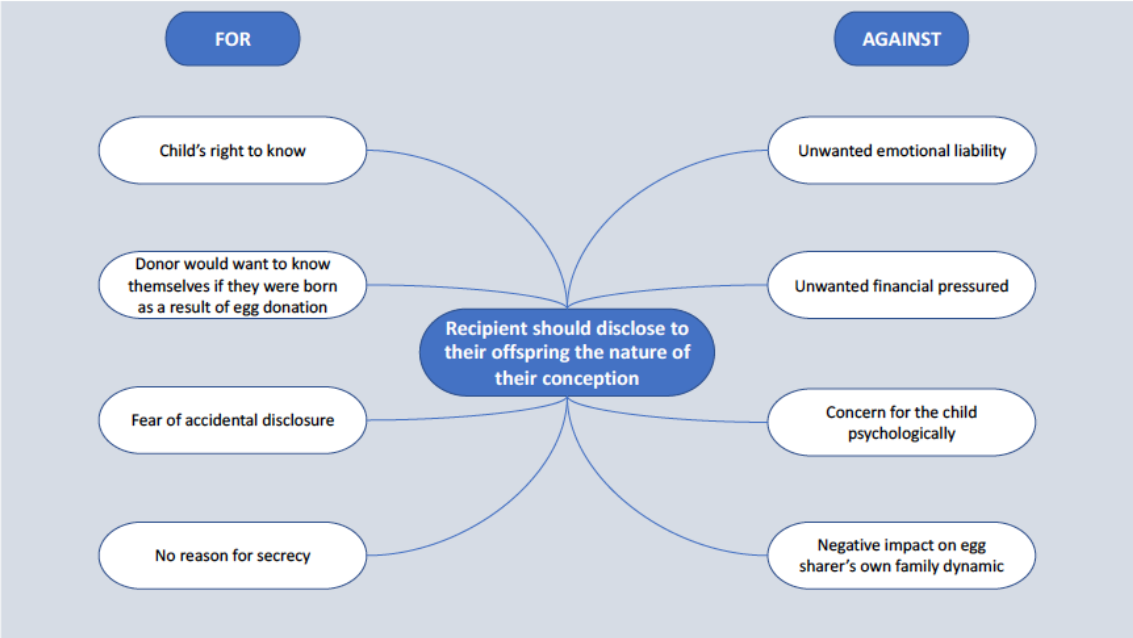
Disclosure decisions comprise informing the nature of conception to any resulting offspring, as well as to family and friends. Ten studies investigating disclosure found that 80% or more of recipients were open to disclosure [60, 149, 163, 180, 182, 184-188]. In contrast, only one small study involving 10 recipients, reported that 70% were against disclosure of the nature of their conception [189]. Studies also found higher disclosure intention rates amongst recipients who used known donors (88%) compared to anonymous (52%) [167, 174, 178]. Regarding recipients using known donors, their rates of disclosure were not impacted by whether or not they were in regular contact with the donor [140, 168, 169]. Some recipients liaised with their known donor to plan timelines regarding disclosure [84, 182]. Two studies reported disclosure rates to be higher in recipients in relationships with greater stability [168, 184].

Disclosure to their offspring

The main themes identified regarding reason for and against disclosure are summarised in ***figure 2b.2***. Studies consistently found the main reason for disclosing to their child was 'the child has a right to know about its origins', closely followed by 'openness and honesty in the family in preventing mistrust' [140, 146, 163, 168, 169, 171, 174, 180, 182-184, 186, 187, 190, 191]. Studies also reported fear of inadvertent disclosure to the child being a motivating factor for openness [140, 146, 187]. Studies consistently showed most recipients favoured disclosure to their child, with seven studies reporting no differences found between the type of donor and the choice of disclosure to any resulting offspring [60, 163, 168, 170, 182, 184, 186]. The most used planned disclosure strategies to offspring were using books or illustrations [84, 180, 182, 183, 192]. Only one study looked at the actual disclosure to the

child, and found a disclosure rate of 40% with the child aged 10 years, with a further 30% planning to tell the child over the next few years [190]. Longitudinal studies have shown an increasing openness towards disclosure, which may reflect both improving awareness of, and societal attitudes towards egg donation over recent years [182, 190, 193]. Two of the three longitudinal studies reported reassuring psychological adjustment between mothers and offspring after disclosure [182]. However, more recently Golombok et al. (2017) followed up donor-conceived offspring into adolescence and followed up 27 egg donation families and 28 surrogacy families. Oocyte recipient mothers reported more problems in family relationships, less positive relationships between mothers and adolescents compared to surrogacy families [193]. Reassuringly, there was no differences between family types for the adolescents themselves in terms of adjustment problems, psychological well-being and self-esteem [193].

Figure 2b.2: *A diagram illustrating recipients' reasons for and against disclosure to their offspring regarding the nature of their conception*



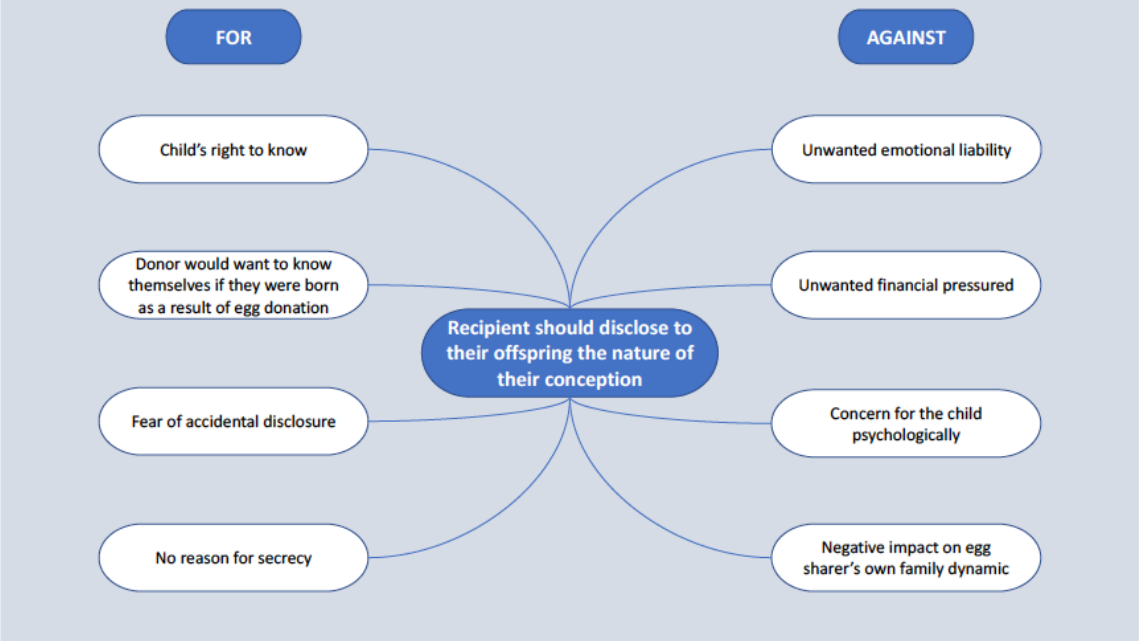
The commonest reasons for not intending to disclose to their child was there being 'no reason to tell' [168, 169, 171, 183-187]; 'concern for the child's well-being' [140, 161, 168, 169, 174, 190, 194]; and the 'fear of stigmatisation' [168, 177]. Some recipients delayed disclosure due to anxiety about how and when to disclose, and the potential consequences of the disclosure [163, 176, 184]. Less frequently

mentioned reasons for not disclosing include a lack of information about their donor, religious/ cultural reasons and trying to protect the donor and her family [168, 184-187].

Disclosure to family and friends

Studies were conflicting regarding recipients' intentions and motivations to disclose to their social environment. The main themes identified regarding reason for and against disclosure are summarised in **figure 2b.3.** The commonest reasons provided by studies to disclose to family and friends were that there was 'nothing to be ashamed about' and there being 'no reason for secrecy' [140, 168, 169, 191, 194]. The majority of recipients felt that honesty with their community would be beneficial for their child, and that any unexpected judgements from others would be insignificant to them [168, 169, 194].

Figure 2b.3: *A diagram illustrating recipients' reasons for and against disclosure to their community regarding the nature of their conception*



However, other studies reported over 50% of their recipients had significant concerns about a lack of understanding from their community [168, 177, 194]. Many studies reported a preference to share information to family members rather than friends, mainly due to lack of trust and a fear of disapproval [91, 140, 177, 180, 186, 190]. Studies also reported that recipients unsure about disclosing to their child

were unsurprisingly more secretive to their community [168, 182, 194]. In contrast, one small study found that four out of the five couples had already informed their family and friends but of those, only two planned to disclose the nature of their conception to their offspring [177]. One Iranian study, where the vast majority of recipients had decided against disclosing, reported fearing violent threats and harassment, and therefore avoiding disclosure to prevent trauma to themselves and their close family [194].

2b.4 Discussion

This systematic review reports the psychological aspects of egg donation treatment from the point of view of the recipient, and explores their motives, attitudes, treatment experiences and disclosure decisions. At the time of writing, only one other review [150] exclusively explored this group, and this is the only systematic review to examine oocyte recipients exclusively.

2b.4.1 Attitudes towards oocyte donation

Most studies reported that donor's genetic and medical background was more valued than intelligence and physical appearance. This could be explained by the fact recipients of anonymous donors partook in the treatment with the knowledge that access to information regarding physical appearance would be very limited, and therefore attributed importance to other characteristics they had more information about. Unsurprisingly, the principal motivation underpinning the decision to undertake egg donation across all the studies was the desire to achieve motherhood. Many recipients reported a feeling of optimism towards the process; however, a significant minority did report concerns about perceived social stigmatisation of using egg donation to overcome infertility. The process of egg donation treatment should be normalized by clinics as much as possible during consultations and counselling sessions. It may also be appropriate for clinics to mediate the meeting of prospective couples with patients who have undergone treatment with donor oocytes, successfully and unsuccessfully, to discuss their experiences and potentially alleviate potential concerns. The SEED Trust have produced short films providing personal insights from oocyte and sperm donors in an attempt to increase the number of people coming forward to donate [195]. Similar films involving women who underwent fertility

treatment with donor oocytes should be produced to give easily accessed accurate information, and potentially address anxieties prior to starting treatment. This could increase the willingness of both donors and recipients to undertake egg donation.

2b.4.2 Attitudes towards disclosure

Disclosure decisions among recipients to their offspring and community was a common theme investigated in the studies reviewed, which is unsurprising given the impact on future relationships and consequences for resulting offspring.

Regarding donation to their offspring, most recipients were open to disclosing the nature of conception to their child in the future. Numerous studies also confirmed that recipients stated they would want to know themselves if they had been born as a result of oocyte donation. Only one study found that more couples disclosed to family/ friends than to their offspring [177]. The fear of accidental disclosure considering the child may well be in regular contact with the donor, as well as the desire to establish clear boundaries may well account for higher disclosure rates amongst recipients who used known donors [167, 174, 178].

It is important to consider the potential implications of accidental disclosure on the parent-child relationship. Indeed, a significant minority of recipients chose not to disclose to their offspring, which is of concern since most recipients had confided to close family or friends of the nature of conception. This means multiple parties are involved in secrecy and inadvertent disclosure is a risk, which could significantly impact on long-term recipient-offspring relationships. Delayed disclosure to the child could also negatively impact their personal development. Detailed ongoing conversations from a young age (under 10 years) help the child to grow up understanding the nature of their conception and helps build openness and trust within the family unit [196]. Ongoing contact with a counsellor may alleviate feelings of being isolated and provide guidance on when and how to disclose. This also allows parents to involve their children in discussions in a supportive environment to strengthen the parent–child relationship.

The majority of studies supported the donor's giving identifiable information that any resulting child from their donation can access in the future. However, two studies reported most recipients were against the child accessing donor identifying information [91, 102]. The 'Disclosure of donor information Act' of 2005 in the UK removed donor anonymity, meaning donor-conceived children could request certain identifiable information about the donor from age 16 onwards. Evidently, some recipients do not want the child accessing information about its genetic origins due to the fear of an unfavourable response from the child and disruption to the family unit. After disclosure, the resulting support network was consistently cited as a reason for disclosure to a wider network [140, 168, 169, 177, 194].

Longitudinal studies are valuable to demonstrate whether the actual disclosure rate was the same as the intended disclosure. Reassuringly, longitudinal studies have shown an increasing openness towards disclosure, which may reflect both improving awareness of, and societal attitudes towards egg donation over recent years [182, 190, 193]. However, the most recent longitudinal study found egg donation mothers reported more problems in family relationships, less positive relationships between mothers and adolescents compared to surrogacy families [193]. Reassuringly, there was no differences between family types for the adolescents themselves in terms of adjustment problems, psychological well-being and self-esteem [193]. These findings suggest the absence of a genetic link between mothers and their children is associated with less positive maternal-adolescent relationships, whereas the absence of a gestational link has no adverse effect [193]. However, this follow up study is during adolescence, which is typically a strenuous time for parental-offspring relationships. More studies with longer term follow up are required before any significant conclusions can be drawn.

In contrast, an Iranian study reported the vast majority of women decided against disclosure [194]. This likely reflects a lack of awareness and acceptance surrounding IVF in general, but especially treatment involving donor gametes in Islamic countries, including Iran [197, 198]. In Iran, egg donation is permissible under Shi'a Islam but highly stigmatized [197, 198]. This clearly highlights how disclosure decisions are dictated by cultural views within a community. Such issues are more challenging to

address, but the growing acceptance regarding ART and egg donation treatment globally, can only help to improve de-stigmatization within these ethnic groups.

Regarding disclosure and potential future contact, the BFS has emphasized the need to deliver counselling around times of information sharing or contact with children conceived by gamete donation [157], and there has been innovative work undertaken specifically to create 'donor linking' counselling [48]. Unfortunately, at this time, none of these recommendations have been acted on and the UK government currently has no plans to fund counselling, such as those established in the adoption services [158]. Identifying the fact that donor conceived offspring and contact with their genetic parent is now a reality, Donor Conception Network are currently undertaking significant work to offer practical and psychological support to donors and their offspring. The knowledge that such services are available could encourage more potential donors and egg sharers to go ahead.

2b.4.3 Limitations of the systematic review

This is the most extensive systematic review solely investigating oocyte recipients, with 42 peer-reviewed studies included. However, there were some methodological limitations identified in the studies. First, most studies used post-donation questionnaires or interviews, with a response rate of 30%. Patients with positive attitudes and experiences are more likely to participate, thus leading to potentially significant publication bias [159]. Second, many of the studies had small sample sizes (***table 2b.2***). Third, research was usually conducted only weeks or months post-donation, with a few following up after 3 years. There were only three longitudinal studies on children born through gamete donation [182, 190, 193], with conflicting findings based on the follow-up time point. Fourth, there are very few studies investigating CBRC and the psychological impact and influence on disclosure decisions of patients who use these donor gametes abroad to conceive. One study found patients stated numerous reasons for seeking their fertility treatment abroad, including high costs in the UK, better success rates, more choice of donors, shorter waiting lists, dissatisfaction with previous UK treatment, and having treatment abroad being a less stressful environment [36]. Future studies should include a focus on the psychosocial

aspects of these patients using CBRC, their attitudes towards using egg donors from other countries, and implications for resulting children and their home country's healthcare systems.

Finally, multiple studies did not clearly or consistently differentiate between the type of oocyte donor used by recipients, such as known or anonymous. The choice of oocyte donor could significantly influence all aspects of oocyte donation, from attitudes and feelings towards the process, to current and future disclosure decisions, as well as future donor offspring contact. Consequently, each type of donation entails different psychological and social aspects for recipients to consider. Additionally, in some studies, with known oocyte donation, the interviews took place with the oocyte donor present, which may have compromised the validity of recipients' responses.

2b.4.4 Conclusion

This systematic review summarises the current literature surrounding the psychosocial attitudes of oocyte recipients towards oocyte donation. The psychological data presented in this review is largely reassuring for oocyte recipients. Whilst the uptake of oocyte donation and procedural disclosure appear to be increasing, oocyte recipients continue to be challenged by social stigmatisation, fears surrounding disclosure, and uncertainty regarding relationships with the donor. Counselling is invaluable at guiding oocyte recipients through the decision-making process, but longer term support is required, specifically following birth and around the time of disclosure to their offspring and community. Counselling sessions may be improved by incorporating the support of previous oocyte recipients, to provide prospective recipients with insight into the challenges through personal anecdotes. Consideration of specific boundaries to undergoing IVF with donated oocytes needs to be explored, including research amongst ethnic minorities where literature is lacking.

Chapter 3: Study II

Investigating the knowledge and attitudes of egg sharing among healthcare professionals based in the United Kingdom

Study II: Investigating the knowledge and attitudes of egg sharing among healthcare professionals based in the United Kingdom

3.1 Introduction

The number of women coming forward for treatment as egg sharers has declined over recent years in the UK. Indeed in 2011, 698 of egg sharers participated as donors, compared to 348 in 2016, which is a 50.1% fall in numbers ***(figure 1.5)*** [1]. As discussed in ***Chapter 2: Study I***, a possible reason for the decreasing number of egg sharers is that relevant healthcare professionals are not informing fertility patients of this option, when they seek fertility advice from them. One study investigated the treatment experience of egg sharers and found that only 4.3% of them were first informed of the option of egg sharing by their general practitioner (GP), and they reported this to be a significant frustration, due to the delay in them accessing this treatment [60]. This could be for numerous reasons, including lack of knowledge of egg sharing or disagreeing with it as a treatment option for couples. Due to the current situation with egg sharing numbers in the UK, it is particularly significant to uncover the reasons why healthcare professionals are not suggesting egg sharing to fertility patients, but despite this there has been no study investigating this issue.

3.1.2 Aims

Egg sharing is in widespread clinical practice throughout the world. However, healthcare professionals attitudes and knowledge towards egg sharing has not been previously studied. Therefore, this study aims to investigate the views and knowledge that healthcare professionals in the UK have regarding egg sharing, as well as the proportion of them who have actually referred a patient for egg sharing.

3.2 Materials and Methods

3.2.1 Study Design

An in-depth survey investigating healthcare professionals' attitudes and knowledge of egg sharing was designed. The questionnaire consisted of a series of simple questions, taking 15 minutes for participants to complete. The survey format was based on previously validated questionnaires from published studies investigating the attitudes towards face and uterine transplantation [199, 200]. The benefits and issues of egg sharing that participants were asked to consider were selected based on factors identified in previously performed systematic reviews by the same research group [57, 58, 151]. Feedback on the questionnaire was obtained by the transplant team who previously published a similar survey [199], and content validation on the questionnaire was performed by the egg donation team at LFC. The questionnaire was piloted on 20 fertility doctors, embryologists and nurses, who assessed whether the questionnaire asked what it should about egg sharing. The survey consisted of four main sections:

(i) Healthcare professional characteristics

(ii) Views on oocyte donation in general

(iii) Knowledge and views on egg sharing

(iv) Ranking various benefits and issues surrounding egg sharing.

3.2.2 Study participants

The three main target populations were GPs, obstetricians and gynaecologists and fertility specialists, although healthcare professionals from a variety of other fields were also included, as their responses were still of significant interest. Recruitment was performed by convenience and chain sampling. The questionnaires consisted of mainly closed-ended questions, but open-ended comment fields were also used, facilitating both quantitative and qualitative data to be obtained.

3.2.3 Data collection and analysis

The survey could be completed either on paper version or online format, using the Qualtrics survey tool. Paper responses were then manually inputted onto the Qualtrics platform. Statistical analysis of the quantitative data was performed using 'Statistical Product and Service Solutions' (SPSS). A comparison of views between medical professionals from different specialties was performed Fisher's exact test. Distribution of mean grades from the ranking of the benefits and issues of egg sharing were

checked with the Shapiro-Wilk test of normality, and then compared across medical fields using the Mann-Whitney *U* test.

3.2.4 Ethical approval

Ethical approval for this study was granted by 'London Riverside Research Ethics Committee', Research Ethics Committee (REC) reference: 17/LO/1491.

3.3 Results

Population characteristics are summarized in ***table 3.1***. A total of 324 healthcare professionals participated in the study. Of these, 20 were excluded due to insufficient completion of the questionnaire. In 48 of the 304 responses, one or more questions were unanswered, but these responses were still included. Most respondents were 25-34 years of age (43.6%) and female (73.3%). 14.6% of the healthcare professionals that responded had personal experience of infertility. 26.0% of participants had 5-10 years of experience working in their field, and 32.9% had more than 10 years of experience. Most of the responses received were from midwives (20.5%), followed by obstetricians and gynaecologists (19.5%), medical students (12.2%), GPs (9.9%), and those working inside a fertility unit (8.5%).

Table 3.1: *Population characteristics across the sample*

Characteristic (total no. of respondents)	% of respondents	
Age, y (n = 303)		
18 – 24	18.5	(n = 56)
25 – 34	43.6	(n = 132)
35 – 44	16.2	(n = 49)
45 – 54	13.2	(n = 40)
55 – 64	7.9	(n = 24)
> 65	0.7	(n = 2)
Sex (n = 304)		
Male	26.3	(n = 80)
Female	73.7	(n = 224)
Profession (n = 303)		
Midwife	20.5	(n = 62)
Obstetrician and gynaecologist	19.5	(n = 59)
Medical student	12.2	(n = 37)
General practitioner	9.9	(n = 30)
Hospital doctor	9.6	(n = 29)
Counsellor	6.3	(n = 19)
Staff nurse	5.0	(n = 15)
Fertility nurse	3.3	(n = 10)
Fertility specialist	2.6	(n = 8)
Embryologist	2.6	(n = 8)
Other	8.6	(n = 26)
Experience in the medical field, years (n = 304)		
< 1	3.6	(n = 11)
1 – 5	37.5	(n = 114)
5 – 10	26.0	(n = 79)
> 10	32.9	(n = 100)
Personal experience of infertility (n = 301)		
Yes	14.6	(n = 44)
No	85.4	(n = 257)

3.3.1 Knowledge of egg sharing and referral rates

Table 3.2 summarizes the responses received on numerous aspects of egg donation and egg sharing. Overall, there was significant support for egg donation, with 89.8% of healthcare professionals agreeing or strongly agreeing that it is a 'useful addition to the field of fertility', with only 2.3% of participants disagreeing with the use of oocyte donation in fertility treatment. Participants had a strong preference for altruistic oocyte donation over commercial donation. 45.2% 'strongly agreed or agreed' with the HFEA's £750 compensatory cap on payments to egg donors, with 26.4% 'disagreeing' and 28.4% 'undecided' (***table 3.2***). Interestingly, healthcare professionals who 'disagreed' or were 'undecided'

regarding oocyte donation did feel the £750 compensation was an insufficient sum to compensate an egg donor for the inconvenience and invasiveness of her treatment, compared to those in agreement with egg donation (Fisher's exact test, $p<0.05$).

Table 3.2: Summary of respondents' responses regarding oocyte donation and egg sharing
[a] n numbers vary due to incomplete questionnaires
[b] Questions on the "Disclosure of Donor Information' legislation were answered by females only
[c] This question was not applicable to 8 respondents, due to their advanced age

Opinion (total no. of respondents)[a]	% of respondents	
'Oocyte donation is a useful addition to the field of fertility' (n = 304)		
Agree	89.8	(n =273)
Disagree	2.3	(n = 7)
Undecided	7.9	(n = 24)
In agreement with the 'Disclosure of Donor Information' legislative change (n = 224)[b]		
Yes	60.7	(n =136)
No	13.8	(n = 31)
Undecided	25.5	(n = 57)
In agreement with £750 cap on compensation for oocyte donors in the UK (n = 303)		
Yes	45.2	(n =137)
No	26.4	(n = 80)
Undecided	28.4	(n = 86)
Extent of knowledge regarding the UK egg sharing programme (n = 298)		
A lot	15.4	(n = 46)
A fair amount	21.5	(n = 64)
Little to none	63.1	(n =188)
'Egg sharing presents a viable solution to the donor oocyte shortage' (n = 298)		
Yes	67.1	(n =200)
No	10.7	(n = 32)
Undecided	22.2	(n = 66)
'There is an ethical difference between egg sharing and commercial oocyte donation' (n= 295)		
Yes	63.4	(n =187)
No	28.8	(n = 85)
Undecided	7.8	(n = 23)
'Egg sharing should take place' (n = 298)		
Yes	78.2	(n = 233)
No	7.7	(n = 23)
Undecided	14.1	(n = 42)

Only female healthcare professionals were asked about their views on the 'Disclosure of Donor Information Regulations', since only female participants would themselves be able to donate oocytes. 60.7% were in support of the legislation, with 25.5% 'undecided' and only 13.8% 'disagreeing' with it (***table 3.2***). Most women (62.8%) also felt this change in legislature would not dissuade them from donating their eggs, with a small minority (16.3%) saying they would be dissuaded (***table 3.2***).

Study participants reported a consistent lack of knowledge of the option of egg sharing, with 63.1% of respondents knowing 'nothing or very little' about it. 21.5% knew 'a fair amount', with only 15.4% stating they have extensive knowledge of the egg sharing programme (***table 3.2***). Healthcare professionals were then provided with a short statement summarising egg sharing, and following this participants were then asked whether they felt the egg sharing programme potentially provided a viable solution to the shortage of donor eggs. 67.1% felt it could provide a solution, 10.7% stated they felt it did not, and 22.2% were undecided (***table 3.2***). Most healthcare professionals (63.4%) also felt egg sharing was ethically different to commercial payment for donor oocytes (***table 3.2***). The vast majority (78.2%) of healthcare professionals felt egg sharing should take place as a treatment (***table 3.2***). Although this is a significant majority, it should be mentioned the cohort reported less positively to egg sharing than egg donation in general (78.2% vs 89.8%).

It was important to differentiate how respondents from the fertility field responded (fertility specialists, fertility nurses, embryologists) compared to other healthcare professionals. A comparison of attitudes and knowledge of egg sharing between these different medical specialties is shown in ***table 3.3***. As expected, there was notable difference in the extent of knowledge of egg sharing depending on their medical field, with 100% of participants from the fertility field having at least a 'fair amount' of knowledge of egg sharing, compared to 30.9% of those answering from other medical fields (Fisher's exact test, $p<0.05$) (***table 3.3***). There was no difference in oocyte donation in general between the two groups, however acceptance of the egg sharing programme was higher amongst those from the fertility field (96.2%), when compared to other healthcare professionals (Fisher's exact test, $p<0.05$).

Table 3.3: Comparison of respondents' opinions of oocyte donation and egg sharing according to their field of practice.

Opinion	% of respondents from fertility field n = 26[a]	% of respondents from other fields n = 278[b]	Fisher's exact *p*
'Oocyte donation is a useful addition to the field of fertility'			NS
Agree	100.0 (n=26)	88.9 (n=247)	
Disagree	0.0 (n=0)	2.5 (n=7)	
Undecided	0.0 (n=0)	8.6 (n=24)	
Extent of knowledge regarding the UK egg sharing programme			<0.001
A lot	73.1 (n=19)	9.9 (n=27)	
A fair amount	26.9 (n=7)	21.0 (n=57)	
Little to none	0.0 (n=0)	69.1 (n=188)	
'Egg sharing should take place'			0.034
Yes	96.2 (n=25)	76.5 (n=208)	
No	3.9 (n=1)	8.1 (n=22)	
Undecided	0.0 (n=0)	15.4 (n=42)	

[a] Professions classed as part of the fertility field include fertility specialists, fertility nurses, and embryologists.
[b] n numbers may not total 278 due to incomplete responses.
NS = non-significant.

Healthcare professionals able to inform and refer fertility patients towards egg sharing (GPs, obstetricians and gynaecologists and fertility specialists) were asked whether they had referred such patients, and if not, their reasons why they had not. Overall, only 16.5% of respondents had referred a patient for egg sharing. The vast majority of those who had not referred, cited a significant lack of knowledge as the main reason for this. 76.6% of GPs were either unaware of the option of egg sharing or felt they did not know enough about it to refer a patient (***figure 3.1***). Perhaps unsurprisingly, 75% of fertility specialists had previously made an egg sharing referral, and none of the fertility specialists lacked knowledge of egg sharing (***figure 3.1***).

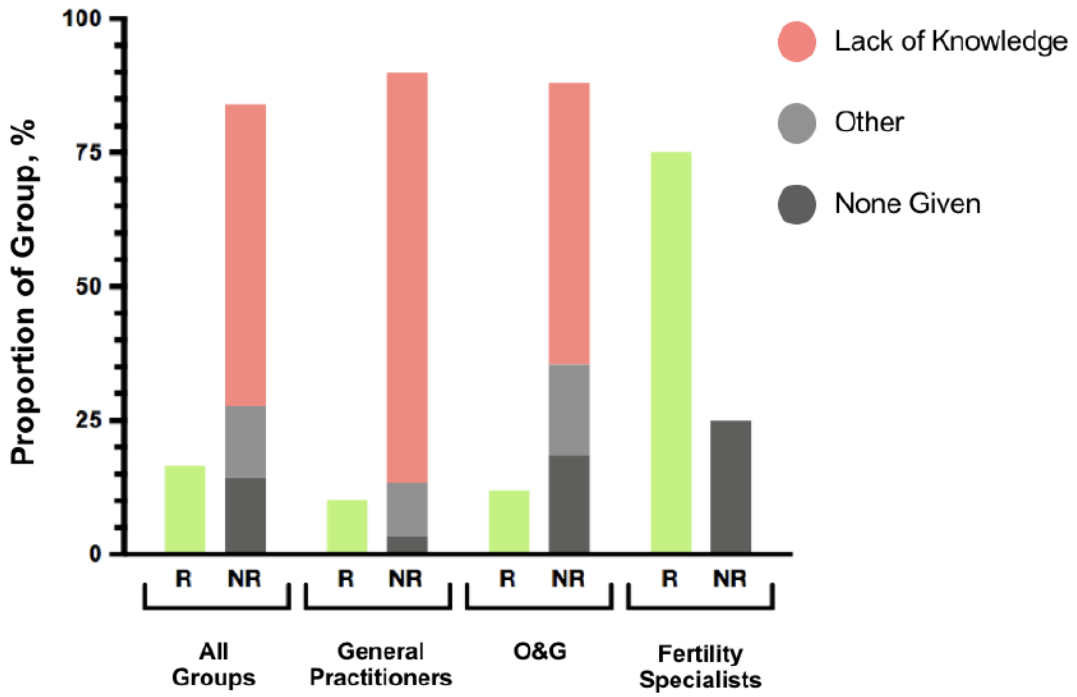


***Figure 3.1**: Proportions of all eligible professionals (n=97), general practitioners (n=30), obstetricians and gynaecologists (n=59) and fertility specialists (n=8) that have previously referred a patient for egg sharing, and reason given if no referral has been made. R = previous referral, NR = no previous referral, O&G = obstetricians and gynaecologists.*

3.3.2 Ranking of benefits and issues surrounding egg sharing

Participants were asked to grade the importance of eight issues commonly proposed as concerns surrounding egg sharing. Each issue was given a grade between 1 (least significant) and 5 (most significant), and the results are summarized in ***table 3.4***. The highest scoring issue (4.19) was the concern for the psychological well-being of a donor whose own IVF fails, especially as she can find out if her matched recipient's treatment was successful. The second highest mean scoring issue (3.78) was that a second stimulation cycle may be required to obtain enough eggs for the egg sharer and her recipient's treatment to be successful. The third highest mean score (3.66) was that the outcome of the egg sharer's treatment is negatively affected by giving up half of her collected oocytes. Other issues surrounding egg sharing which scored less highly were: 'the donor may have only agreed to share her eggs in order to gain access to fertility treatment' (3.60); 'potential adverse impact on the psychological well-being of the donor as the recipient is conceiving her genetic offspring' (3.59); 'the consent of the egg donor is questionable due to her desperation to conceive' (3.57); 'the act of donating oocytes in

exchange for subsidized treatment is contrary to a cultural preference for voluntary donation' (2.90); 'the recipient must pay for fertility treatment while the donor receives it for free' (2.62) (***table 3.4***).

Table 3.4: Average score given to potential issues surrounding egg sharing according to their significance. 1 = least significant, 5 = most significant. Mean calculated using only responses where all 8 issues were scored (n = 261).

Issues	Mean score
Potential adverse effect on the psychological well-being of the donor if her own treatment fails	4.19
The donor may require a repeat stimulation cycle and egg collection in order to obtain enough eggs for both herself and the recipient	3.78
The chances of the donor conceiving as a result of her fertility treatment could be reduced by the donation of half of her eggs	3.66
The donor may only have agreed to share her eggs in order to gain access to fertility treatment	3.60
Potential adverse effect on the psychological well-being of the donor as the recipient is conceiving her genetic offspring	3.59
The consent of the egg donor is questionable due to her desperation to conceive	3.57
The act of donating eggs in exchange for subsidised fertility treatment is contrary to a cultural preference for voluntary donation	2.90
The recipient must pay for fertility treatment while the donor receives it for free	2.82

Participants were also asked to grade the importance of five potential benefits of egg sharing. Each benefit was a given a grade between 1 (least significant) and 5 (most significant), and the results are summarised in ***table 3.5***. All of the potential benefits were given a mean score of more than 4, compared to the issues, whereas only the top ranked issue had a mean score of greater than 4. Enabling access to IVF for women who do not qualify for NHS funded treatment and cannot self-fund their treatment was considered the most important advantage (4.22), with the lack of third party involvement in their fertility treatment found to be nearly as significant (4.21). The other benefits which had a mean score above 4 were 'giving a woman suffering from infertility the opportunity to help someone in a similar situation' (4.11); 'has the potential to reduce the waiting list for donor oocytes' (4.11); and 'provides a viable solution to the acute shortage of oocyte donors' (4.04) ***(table 3.5)***.

Table 3.5: Mean grade given to 5 benefits of egg sharing according to their significance. 1 = least significant, 5 = most significant. Mean calculated using only responses where all 8 issues were scored (n = 261).

Issues	Mean score
Provides access to IVF for women who are not eligible for NHS-funded treatment and cannot afford to pay for IVF themselves	4.22
Eliminates the need for a third party to undergo an invasive oocyte collection proecdure	4.21
Gives a woman suffering from infertility the opportunity to help someone in a similar situation	4.11
Has the potential to reduce the waiting list for donor oocytes, and therefore the number of women going abroad to seek fertility treatment	4.11
Provides a viable solution to the acute shortage of oocyte donors	4.04

Fertility specialists and respondents from all other medical fields also differed in their assessments of the benefits and issues surrounding egg sharing (***figure 3.2***). Fertility specialists gave a significantly higher grade to the overall benefits of egg sharing than non-fertility field healthcare respondents (Mann-Whitney U test, $p<0.05$), while giving a lower significance to the issues (Mann-Whitney U test, $p<0.05$,).

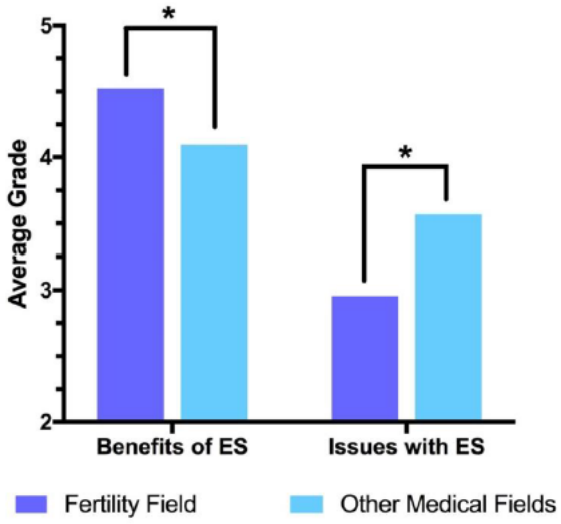


Figure 3.2: *Comparison of mean score given for benefits and issues with egg sharing by respondents from the fertility field and respondents from other medical fields. Average score calculated from individual scores given to 5 potential benefits and 8 potential issues by respondents from each group. Only responses where all benefits or all issues were scored were included in the calculation. Benefits: n = 26 for fertility field, n = 274 for other fields. Issues: n = 23 for fertility field, n = 261 for other fields. 1 = least significant, 5 = most significant. * p = 0.001, calculated with Mann-Whitney U test.*

3.4 Discussion

Overall, healthcare professionals who participated in this study appear to strongly support the process of egg donation in general, as well egg sharing. 89.8% of participants supported egg donation, and

78.2% believed egg sharing should take place. Therefore, although both egg donation and egg sharing are thought of in a positive light, there does appear to be higher acceptance amongst medical professionals of egg donation in general. Considering the controversy that has surrounded egg sharing since its introduction however, the fact that almost 4 out of 5 participants felt positively about the egg sharing is reassuring for the programme.

Healthcare professionals felt the biggest issue regarding egg sharing is a potential adverse psychological impact of the egg sharer if her own fertility treatment is unsuccessful. Three systematic reviews have reported on the psychological well-being of egg sharers [57, 58, 151], and reported that the data is overwhelmingly reassuring regarding the psychological well-being of both egg sharers and their recipients. Egg sharers did not feel exploited by the egg sharing process, but instead felt egg sharing represents a 'win-win' for both themselves and their recipients. Significantly, Ahuja et al. (1998) found that 89% of egg sharers whose treatment was successful reported their treatment experience positive, and when their treatment was unsuccessful 90% of egg sharers still reported a positive treatment experience [51]. Another study followed up egg sharers 3 to 5 years post-donation and reported that the egg sharer's treatment outcome had no effect on how frequently they thought about any children their recipient could have [60]. The same study also concluded that in the majority of cases where the egg sharer's treatment was unsuccessful and the recipient's was successful, the egg sharer felt positively about the recipient's outcome [60].

The issue with the second highest mean score was the concern that egg sharing could negatively impact the outcome of the egg share donor's own treatment. The largest study investigating this analysed treatment outcomes for 192 egg sharers, 274 recipients and 1098 standard IVF patients, and reported no significant difference in pregnancy or live birth rates between these three groups [65]. This is very important data for egg share donors, and it is important medical professionals are aware of the lack of impact egg sharing has on treatment outcome.

Another commonly raised concern about egg sharing is that it has potential to exploit desperate couples who cannot afford to self-fund their fertility treatment [47, 103]. Medical professionals answering this questionnaire raised concerns that egg sharers only agree to participate to gain access to fertility treatment, and questioned the validity of the consent of the donor, due to her desperation to conceive. Significantly, although healthcare professionals responding to this survey raised concerns, they also felt the most important benefit egg sharing provided was giving those same women the chance to access IVF and that it eliminates the need for a third party to undergo the invasive process of oocyte donation. Studies that have addressed some of these issues have provided largely reassuring data. One study found that more than 80% of the egg sharers they questioned disagreed that egg sharing was exploitative [49]. In the same study, 91.7% of egg sharers were glad they participated, and 83.3% would donate again [49]. Indeed, when their own treatment had been unsuccessful, most egg sharers did not express any regret in participating in the programme [49, 51]. The majority of egg sharers were at least partly motivated to share their eggs due to the free or discounted treatment they received [57, 60]. However, the majority reported they would have at least considered egg sharing even without any financial incentive [57, 60]. Although the concerns surrounding egg sharing are logical, it would be surprising for egg sharers to express such positive attitudes towards their experience if they felt they were pressured into taking part due to financial restraints. Even prior to the publication of these studies, the Sperm, Egg and Embryo Donation (SEED) report (2005) stated "if an egg provider's judgement were really obscured by the promise of free treatment, one might expect to find evidence of people complaining about this afterwards, or at least some egg providers later regret giving up their eggs' [58].

Any incentivisation for the donation of gametes will bring debate and controversy, and unsurprisingly different countries have different laws and legislation regarding this. The HFEA states that monetary payment for donation would 'contravene the principles of altruism and free choice', and therefore financial payment for egg donation in the UK is illegal, with any renumeration compensatory only and capped at £750 [39]. In contrast, commercial egg donation has been integrated into the USA healthcare system since the technique was in clinical practice, and the American Society for Reproductive Medicine (ASRM) have previously advised $5000-$10,000 as an appropriate payment for the 'time,

inconvenience, risks, and physical and emotional demands' involved in oocyte donation [201]. It must be noted this statement has been withdrawn following accusations of price fixing [201]. Interestingly, amongst the healthcare professionals surveyed in this study, concerns regarding incentivisation appeared to be a relatively minor issue. More than half of participants did not agree with the HFEA compensatory limit of £750, with many feeling this amount was insufficient recompense for the invasiveness and inconvenience associated with egg donation. Healthcare professionals surveyed also placed little significance to the traditional preference in the UK for voluntary donation, ranking it as seventh most significant of the eight potential issues. Some participants expressed positive attitudes towards commercial egg donation, feeling that increasing the £750 limit would encourage more donors to participate, thus decreasing the shortage of donor eggs in the UK. This attitude towards increasing monetary payments implies that concerns surrounding incentivization are not a significant barrier for healthcare professionals accepting egg sharing. Indeed, 64% of those surveyed did not see egg sharing as ethically equivalent to commercial donation, so negative attitudes towards the financial incentives that come with egg sharing seem not to apply.

It is important to note that despite attitudes amongst healthcare professionals towards egg sharing being slightly less favorable than for egg donation overall, 78.2% of healthcare professionals felt that egg sharing should take place, with 67.1% feeling it 'provided a potentially viable solution to the donor oocyte shortage'. Support for the programme amongst the medical community is further evidenced by the fact that they ranked all five potential benefits of egg sharing a mean score greater than four (maximum score five), whilst they only ranked one of the eight potential issues they were surveyed on a mean score greater than four.

Although most of the concerns raised by the medical community surveyed in this study regarding egg sharing have been addressed in the literature, most healthcare professionals have little or no awareness of this research. Indeed, 63.1% of participants had 'little or no knowledge' of egg sharing. This limited knowledge of the egg sharing programme almost certainly impacts on the number of referrals made to the programme. Indeed, over 75% of healthcare professionals surveyed in this study had never referred

a patient for egg sharing. This was particularly frequent among GPs, with 76.6% citing a lack of knowledge the main reason for them not having referred potentially appropriate fertility patients. GPs will almost universally be the first healthcare professionals couples trying to conceive will seek advice from, and this could therefore be having a significant impact on the amount of time it took for women to discover the option of egg sharing. Unsurprisingly, referral rates are significantly higher among fertility specialists than with GPs and obstetrician and gynaecologists. This finding is of potential significance, as fertility units will not accept women as egg share donors if they are over 35 years of age in the UK, so this delay could prevent women from participating as egg sharers.

It is likely there is a link between knowledge of egg sharing and approval. Unsurprisingly, fertility specialists were significantly better informed and more likely to believe egg sharing should take place than medical professionals from other fields. Fertility specialists also gave significantly more value to the benefits of egg sharing, and were less concerned with the potential issues. In addition, a significant proportion of respondents who were more indecisive or negative with their responses commented that they would need additional information to be able to support egg sharing. This study further supports other research that the legislative changes of 2005 regarding donor anonymity is not a major deterrent to participate as an oocyte donor [60, 190]. Most participants agreed this legislation was positive and would not personally dissuade them from hypothetically donating their eggs. Another study reported 65.1% of egg sharers would be happy with future contact with offspring conceived from their donation, with a further 14% neutral about this future contact [60].

Based on the findings of this study, it appears the drop in egg sharer numbers in the UK is more likely due to poor knowledge of the programme, rather than a disapproval of it. It would therefore be logical to hypothesize that by educating healthcare professionals about the option of egg sharing and the research relating to it may be instrumental in increasing the number of egg sharers in the UK. This would not only help to increase the awareness amongst fertility patients of egg sharing, but also allow healthcare professionals to address concerns patients may have that prevent them from potentially egg sharing, or even attending an assisted conception unit to discuss this option with a fertility

specialist. There is precedent to suggest that improved awareness of egg sharing could positively impact uptake, since the HFEA attributes the increase in altruistic oocyte donor registration to a heightened awareness as a result of increased marketing [39]. Implementing this strategy may benefit the egg sharing programme similarly, since currently less than 20% of egg sharers discover the option of egg sharing through advertising [58].

3.4.1 Limitations and recommendations for future research

This is the only study to assess the knowledge and views of the medical community regarding egg sharing. There were over 300 participants, allowing statistically significant qualitative data to be produced. However, this study did have some limitations. First, participants were recruited using convenience sampling, as this method allowed the greatest number of potential responses; however, this could have introduced sampling bias. Second, there was a discrepancy between the number of responses from healthcare professionals from certain professions and specialties, which again is a potential to introduce bias. Third, using a survey to obtain responses uses mainly close-ended questions, with a small proportion of questions not being answered, possibly due to confusion about a question's meaning. Other research methods, such as interviews, could allow a greater depth of qualitative data to be collected.

Fertility clinics experienced in egg sharing should present regularly at educational seminars and conferences to educate their peers about the option of egg sharing and potentially negate any of their concerns. Findings from this study imply that better education of certain healthcare professionals could improve their perceptions of egg sharing. A particular focus should be with GPs and obstetricians and gynaecologists, as these are the doctors' patients would usually see prior to being referred to a fertility clinic. These healthcare professionals should be specifically made aware of the lack of third-party involvement in oocyte donation and easy access to fertility treatment for couples who do not qualify for NHS funding, as these are the most consistently reported benefits identified by the medical community in this study.

Future studies could explore how the opinions regarding egg sharing of the medical community change depending on their familiarity with the programme, for example by performing interviews prior to and after an educational seminar. Future studies should concentrate on psychological aspects surrounding the egg sharer, as this was the most consistently raised issue from our study participants. Evidence from current studies is reassuring, but in small numbers and usually with small sample sizes. More studies with a larger number of participants and longer follow up time post-donation could help to further influence the negative view towards egg sharing that a minority of healthcare professionals hold.

3.4.2 Conclusions

This study has found there is an overwhelming lack of knowledge of egg sharing among key medical professionals that could both refer directly or inform fertility patients of this treatment option. The number of egg sharers registering and participating in the programme has reduced in recent years in the UK, and a lack of awareness amongst the medical community could be impacting these numbers. Overall, healthcare professionals voice significant support for egg donation and egg sharing, although when compared to purely altruistic donation, views of egg sharing were slightly less positive. The potential benefits of egg sharing ranked significantly higher than any potential issues surrounding the programme. The most consistently raised areas of concern were the potential negative psychological impact on the egg sharer if her treatment was unsuccessful, as well as the potential repercussions of donating half her eggs on her own treatment success. Published studies have shown these concerns to be far less significant than hypothesized, so educating the medical community about egg sharing and the research that supports it, could further improve healthcare professionals' attitudes of egg sharing and increase egg sharing numbers.

Chapter 4: Study III

Investigating attitudes, motivations, treatment experiences and disclosure decisions of egg share donors and their recipients

4.1 Introduction

Egg sharing programmes are a unique form of egg donation for two main reasons. First, both the donor and her anonymously matched recipient are engaged in the simultaneous pursuit of having a baby. Second, egg sharing schemes offer a benefit for the donor other than altruism. At LFC, egg share donors only pay the HFEA fee of £75 for their treatment, instead of the usual cost of IVF of over £5000. Therefore, fertility patients who do not qualify for government funded IVF and cannot afford to pay for their treatment gain valuable access to fertility services. The recipient pays the standard cost of her fertility care plus the HFEA fee. At LFC, the eggs produced by the donor are split equally between herself and the recipient. In the unlikely scenario that an egg sharer produces fewer than eight oocytes, then she has the option of either donating four oocytes and using the remainder for her own treatment, or retaining all her oocytes and paying a subsidized fee of £2000 for her treatment, which is a significantly cheaper sum than a standard IVF cycle.

As previously mentioned, there are also concerns raised surrounding egg sharing. First, it is theorised that the donor is only agreeing to donate to gain access to much desired treatment, which brings into question the egg share donor's quality of consent [55, 56]. Second, there is fear for the psychological well-being of egg share donors whose own treatment is not successful [53, 54]. Third, there is concern for the impact on the child psychologically if they were to discover that their parents indirectly paid a donor to contribute. Fourth, there is apprehension the treatment success of the egg share donor and recipient will be jeopardised by splitting the eggs between them. Finally, subsidised fertility treatment could be seen as contrary to a cultural preference for voluntary donation [54].

The systematic review performed in '***Chapter 2: Study I'*** revealed very few studies investigating the psychosocial issues surrounding egg sharing. However, those few studies reported largely reassuring data surrounding the programme. The egg sharing scheme has been one of the most debated areas in reproductive medicine, with some arguing that other than IVF itself, no other assisted conception procedure has undergone such intense scrutiny [50]. The concerns raised are theoretical and based on opinion, rather than empirical research. It is therefore vital that the psychological well-being of patients

who donate and receive oocytes through egg sharing is better studied. Obtaining increased psychosocial data on the topic would also enable improved counselling for our donor and recipient populations.

4.1.2. Aims

In this study oocyte donors and recipients who were treated at LFC between 2012-2019 will be surveyed. The study aims to investigate their motivations, attitudes, and treatment experiences towards oocyte donation. The study will also investigate the issue of disclosure about the nature of their conception. In the donation and recipient groups, participants were further divided into two groups: patients who have gone through treatment previously (retrospective patients), and patients who are currently undergoing treatment (prospective patients). Retrospective and prospective patients will be analysed to see how the time point the patients answered the questionnaire changed their responses. A comparison will also be made in their fertility journey between donors and recipients. The LFC has one of the largest cohorts of egg sharers in the UK, and conducts over 10% of the total egg share donor numbers in the UK. It is therefore an ideal centre to research this topic further.

We hypothesise the psychosocial aspects of the treatment for egg sharers and recipients will be positive in regard to the egg sharing scheme, regardless of the treatment outcome.

4.2 Methodology

4.2.1 Study design

Data for this study were gathered using a questionnaire. Patients were given the option to fill out the same questionnaire online, or on a traditional paper version. The content of the questionnaire was based on previously validated questionnaires [61, 199] and the knowledge gained from systematic reviews we have performed and published [57, 58]. The questionnaire was then tested and developed through extensive piloting within the fertility clinic. In the first stage the questionnaire was trialled on staff at LFC, feedback was obtained and appropriate changes were made. In the second stage the questionnaire

was trialled on a sample of egg donation patients at the LFC, feedback was received and appropriate changes were made.

Due to the differing nature of their treatments, there were four surveys, with subtle differences based on whether they were a donor or recipient, and a prospective or retrospective patient. The survey for all participants contained seven sections:

1. Background information
2. Information gathering surrounding egg donation
3. Motivations and concerns regarding egg donation
4. Treatment experiences of egg donation
5. Attitudes towards egg donation
6. Thoughts and feelings about the egg donor or recipient
7. Disclosure decisions surrounding the nature of conception

There were 83-96 questions in the survey, involving closed end and Linkert scale questions, allowing statistical analysis of quantitative data.

4.2.2. Sample

Selection criteria for the study were those who had participated in egg donation treatment between 2012-2018. Only patients who had agreed to participate in research during the consenting process of their treatment were sent an email invitation asking them to participate in the study, and if they preferred an electronic link to the questionnaire, or a paper questionnaire posted to them. Non-responders to the initial invite, were sent a reminder 2 weeks later. For the prospective patients, a similar process was performed. In addition, patients coming in for treatment at the fertility clinic were recruited for the study during their appointments at the clinic. If they agreed, they would be given the option of filling out a paper copy or to scan a QR code and fill out the questionnaire on their mobile device. The responses were anonymous, and the study team had no means of knowing which of the women had or had not completed the survey.

For retrospective groups 265 recipients and 394 donors were sent an email invite. Of these 176 recipients and 171 donors replied with consent to participate and were subsequently emailed with a link to the survey, or a paper copy posted to them. 14 of the retrospective recipients and 20 of the retrospective donors did not submit complete responses, and were excluded, leaving 162 retrospective recipients and 151 retrospective donors. This leaves a response rate of 61.1% for the recipients (162/265) and 38.3% for the donors (151/394), which is high considering the subject studied and the high number of questions. The prospective group had 30 recipients and 46 donors. 2 recipients and 11 donors submitted incomplete responses, leaving 28 prospective recipients and 35 prospective donors.

4.2.3. Data collection

After receiving the email link, respondents filled out the questionnaire online using the Qualtrics survey tool. The paper copies received were manually inputted by the research team onto Qualtrics. The questionnaire took on average 15-20 minutes for participants to complete.

4.2.4 Statistical analysis

Statistical analysis was performed using SPSS Statistics v27. Analysis was conducted using the χ^2, analysis of variance (ANOVA), Mann Whitney U test, and Fisher's exact test.

4.2.5 Ethics

Ethical approval for this study was provided by 'London Riverside Research Ethics Committee', Research Ethics Committee (REC) reference: 17/LO/1491.

4.3 Results

4.3.1 Demographic characteristics

Participant characteristics are shown in ***table 4.1***. Donors were significantly younger than recipients, with mean ages for the two groups 34.1 years and 43.9 years, respectively. The sample was predominantly Caucasian (87.1%), and there was no difference in ethnicity between donors and

recipients. There was also no significant difference between donors and recipients regarding religious background, and the level of religiosity. The majority of participants overall were not religious (41.2%) or Christian (50.5%). There was no difference between the two groups regarding employment status. However, recipients were significantly higher in educational level, with 75.3% of recipients having a university degree, compared to 58.1% of egg sharers (χ^2, $P<0.05$). This is mirrored by salary, with recipients earning significantly more money than egg share donors (χ^2, $P<0.05$). For example, 43.7% of recipients earnt > £100,000, whereas only 2.0% of egg share donors were in this category. The majority of egg sharers earnt < £30,000 (54.0%).

Table 4.1: *Demographic characteristics of egg sharers and recipients. (Significant p value < 0.05 calculated by: a= χ^2, b = Fishers extract test, c= ANOVA test, ns= non-significant)*

	Group				p-value
	Egg sharers (n=186)		Recipients (n=190)		Egg sharers v recipients
Characteristic	**%**	**n**	**%**	**n**	
Age (years)					
< 25	2.7	5	0.5	1	NS
25-34	50.5	94	5.3	10	<0.001[c]
35-44	46.8	87	43.2	82	NS
> 45	0.0	0	51.1	97	<0.001[c]
Ethnic group					
Caucasian	80.7	150	92.6	176	NS
Other	19.4	36	7.4	14	NS
Religious background					
None	45.2	84	37.4	71	NS
Christian	48.9	90	52.6	100	NS
Hindu	4.3	8	1.0	2	NS
Jewish	1.1	2	2.0	4	NS
Muslim	1.1	2	0.0	0	NS
Other	0.0	0	5.3	10	NS
How religious are you?					
Not	68.8	128	64.7	123	NS
Moderately	26.9	50	33.7	64	NS
Very	4.3	8	1.6	3	NS
Employment status					
Employed > 37 hours per week	58.1	108	61.1	116	NS
Employed < 37 hours per week	24.2	45	28.4	54	NS
Student	1.6	3	0.0	0	NS
Housewife	14.0	26	10.0	19	NS
Unemployed	2.2	4	0.5	1	NS
Educational level	19.4	36	5.8	11	<0.001[a]
GCSEs	16.7	31	9.5	18	<0.001[a]
A-levels	33.9	63	42.1	80	<0.001[a]
University degree	24.2	45	33.2	63	<0.001[a]
Post-graduate degree	5.9	11	9.5	18	NS
Other					
Annual salary					
< 30,000	52.2	97	11.1	21	<0.001[a]
30-50,000	35.5	66	13.7	26	<0.001[a]
50-100,000	10.2	19	33.2	63	<0.001[a]
> 100,000	2.2	4	42.1	80	<0.001[a]

As shown in ***table 4.2***, a higher proportion of egg share donors were single (13.4%), compared to recipients (7.9%), however this was not statistically significant. A greater proportion of recipients were married (71.6%), compared to egg sharers (48.9%) (χ^2, P<0.05). Regarding sexual orientation, the majority of egg sharers and recipients stated they were heterosexual. Slightly more egg sharers were homosexual or bisexual (25.3%), compared to recipients (16.3%), however this did not reach statistical significance. Perhaps unsurprisingly, the majority of both groups had no children. However, 90.4% of recipients had no children, compared to 72.0% of egg sharers, which was significant (χ^2, P<0.05).

Table 4.2: Relationship status and sexual orientation of egg sharers and recipients. (Significant p value < 0.05 calculated by: a= χ^2, ns= non-significant)

	Group				p-value
	Egg sharers (n=186)		Recipients (n=190)		Egg sharers v recipients
Characteristic	**%**	**n**	**%**	**n**	
Relationship status					
Single	13.4	25	15	7.9	NS
In a relationship (unmarried)	37.6	70	39	20.5	NS
Married	48.9	91	136	71.6	<0.001[a]
Sexual orientation					
Heterosexual	72.6	135	82.6	157	NS
Homosexual	16.1	30	12.1	23	NS
Bisexual	9.1	17	4.2	8	NS
Other	2.2	4	1.6	3	NS
Children before treatment					
None	134	72.0	170	90.4	<0.001[a]
One	40	21.5	17	9.0	NS
Two	7	3.8	3	1.6	NS
More than two	5	2.7	0	0.0	NS

4.3.2 Knowledge and information gathering surrounding egg sharing

Table 4.3 shows how the respondents first learnt about egg sharing, and their initial impression of the programme. The majority of egg sharers (37.1%) first heard about the programme from the internet, compared to only 14.2% of recipients (χ^2, P<0.05). Egg sharers found out about this option from family/ friends significantly more than recipients (19.4% vs 7.4%, χ^2, P<0.05); and social media (4.8% vs 0.5%, χ^2, P<0.05). It is unsurprising that recipients did not use social media as a source of information for egg sharing as they are on average 43.9 years of age, however with the use of social media so widespread among younger people, only 4.8% of egg sharers learnt about it from this source. The majority of recipients were first informed about the option of egg donation by their fertility specialist (51.6%), compared to only 7.0% of egg sharers (χ^2, P<0.05). This could be explained by the recipient having multiple failed cycles with her own eggs or being older with a poor ovarian reserve. In contrast, egg share donors would likely self-refer to the clinic, or could be referred by their gynaecologist or GP while trying to conceive naturally. It is therefore interesting to note that only 4.8% of egg sharers learnt of this option from their GP, and 15.1% from their gynaecologist, which was not statistically different from recipients.

Table 4.3: Information surrounding and first impressions of egg sharing. Values are proportion of study population (%) and n number, dashes (-) represent the question not being asked to that group. (Significant p value < 0.05 calculated by: a= χ^2, ns= non-significant).

	Group				p-value
	Egg sharers (n=186)		Recipients (n=190)		Egg sharers v recipients
Question	**%**	**n**	**%**	**n**	
How did you first find out about egg sharing?					
Internet	37.1	69	14.2	27	<0.001[a]
Newspaper/ magazine	3.8	7	1.1	2	NS
advert	5.9	11	0	0	<0.001[a]
Radio/ TV advert	4.8	9	0.5	1	<0.001[a]
Social media	19.4	36	7.4	14	<0.001[a]
Family/ friend	4.8	9	3.2	6	NS
GP	15.1	28	9.0	17	NS
Gynaecologist	7.0	13	51.6	98	<0.001[a]
Fertility clinic	2.2	4	12.6	24	<0.001[a]
Don't recall	0.0	0	0.5	1	NS
Other					
How long had you been trying to get pregnant before you heard about egg sharing?					
< 6 months	25.3	47	15.3	29	NS
6-12 months	8.6	16	7.9	15	NS
1-2 years	13.4	25	10.8	20	NS
> 2 years	52.7	98	67.7	126	<0.001[a]
How much research did you do into egg sharing before agreeing to take part?					
None	4.3	8	4.2	8	NS
< 1 hour	13.4	25	5.8	11	<0.001[a]
1-5 hours	41.4	77	22.1	42	<0.001[a]
> 5 hours	40.9	76	67.9	129	<0.001[a]
Did you have reservations regarding egg sharing?					
No reservations	46.2	86	20.5	39	<0.001[a]
Some reservations	44.1	82	54.7	104	NS
Definite reservations	9.7	18	24.7	47	<0.001[a]
What were your first impressions of egg sharing?					
A good idea	89.2	166	75.3	143	<0.001[a]
A bad idea	0	0	0.5	1	NS
Something I'd like to do	79.6	148	-	-	
A solution to a shortage of donors	70.4	131	73.7	140	NS
The only option I had to get pregnant	30.1	56	62.1	118	<0.001[a]
A chance to help someone while receiving treatment	84.4	157	-	-	

Most patients in both groups had been trying to conceive for more than two years, however this was truer for recipients compared to egg sharers (67.7% vs 52.7%, χ^2, P<0.05). As ***table 4.3*** shows, recipients undertook considerably more research compared to egg sharers. 67.9% of recipients undertook more than 5 hours of research, compared to 40.9% of egg sharers (χ^2, P<0.05). The majority of egg sharers researched the topic for between 1-5 hours, however 17.7% of egg sharers undertook less than one hour, or no research into the topic.

Respondents were asked their first impressions of egg sharing. They were initially asked if they had any reservations regarding participating in the egg sharing programme, and more egg sharers had 'no reservations' compared to recipients (46.2% vs 20.5%, χ^2, P<0.05). Therefore, unsurprisingly more recipients ticked 'definite reservations' compared to egg sharers (24.7% vs 9.7%, χ^2, P<0.05). Participants were then given various statements to tick if they agreed with regarding first impressions of egg sharing (***table 4.3***). When asked if it was a 'good idea' the responses were very positive from both groups, however a higher proportion of donors agreed compared to recipients (89.2% vs 75.3%, χ^2, P<0.05). Only one of the respondents in the whole study (a recipient) felt that egg sharing was a 'bad idea'. Unsurprisingly, more recipients felt that participating in egg donation was 'their only option to get pregnant', compared to egg sharers (62.1% vs 30.1%, χ^2, P<0.05). Both groups overwhelmingly reported egg sharing as an 'obvious solution to the shortage of donors' (70.4% vs 73.7%). Reassuringly, 79.6% of egg sharers ticked that it was 'something they would like to do' and 84.4% of them cited egg sharing as a 'chance to help someone while receiving fertility treatment'. It was interesting to note, that when analysing this further, a significantly higher proportion of retrospective egg sharers compared to prospective donors thought donating their eggs was 'something they would like to do' (89.7% vs 54.5%, fisher extract, p<0.05), and 'an obvious solution to the shortage of donors' (81.4% vs 39.4%, fisher extract, p<0.05).

4.3.3 Motivations and concerns surrounding egg sharing

Both donors and recipients were asked about their motivations for participating in the egg sharing programme. Perhaps unsurprisingly, for 94.9% of egg sharers and 96.4% of recipients, their main motivation was the desire to have a baby. Donors were also asked if they would have still considered participating in egg sharing if there was no direct financial benefit to them, with 35.2% answering 'yes', 34.7% saying 'no', and 30.1% 'unsure'. 52.6% of egg sharers would participate in the scheme regardless of their ability to pay, after hearing about the option of egg sharing. A slight minority would egg share if their eggs went to research (44.4%). There were no significant differences between retrospective and prospective groups regarding these findings (χ^2, p>0.05).

Patients were given a list of motivations and concerns about participating in egg sharing, and were asked to score each statement, with 1 being the least significant, and 5 being the most significant. They were then asked to state what was their single main motivating factor and concern. The motivations and concerns for egg sharers are shown in ***figure 4.1***. Altruistic reasons scored the highest mean scores, with the three highest scores being the 'desire to help someone else have a child' (4.2 +/- 1.1); the 'desire to make someone else happy' (4.0 +/- 1.2); and 'helping to solve the problem of a lack of donor oocytes' (3.9 +/- 1.1). The 'opportunity to obtain cheaper fertility treatment' ranked only fourth highest, with a mean score of 3.9 +/- 1.3. However, when asked to vote for the single most important motivating factor, 46.1% selected the 'opportunity to obtain cheaper fertility treatment', which was twice as popular as the next highest, the 'desire to help someone else have a child' (26.4%). The desire to 'avoid long NHS waiting lists' (2.2 +/- 1.2) and to 'have my fertility treatment in a private clinic' (2.4 +/- 1.4) ranked the lowest mean scores of the benefits surrounding egg sharing.

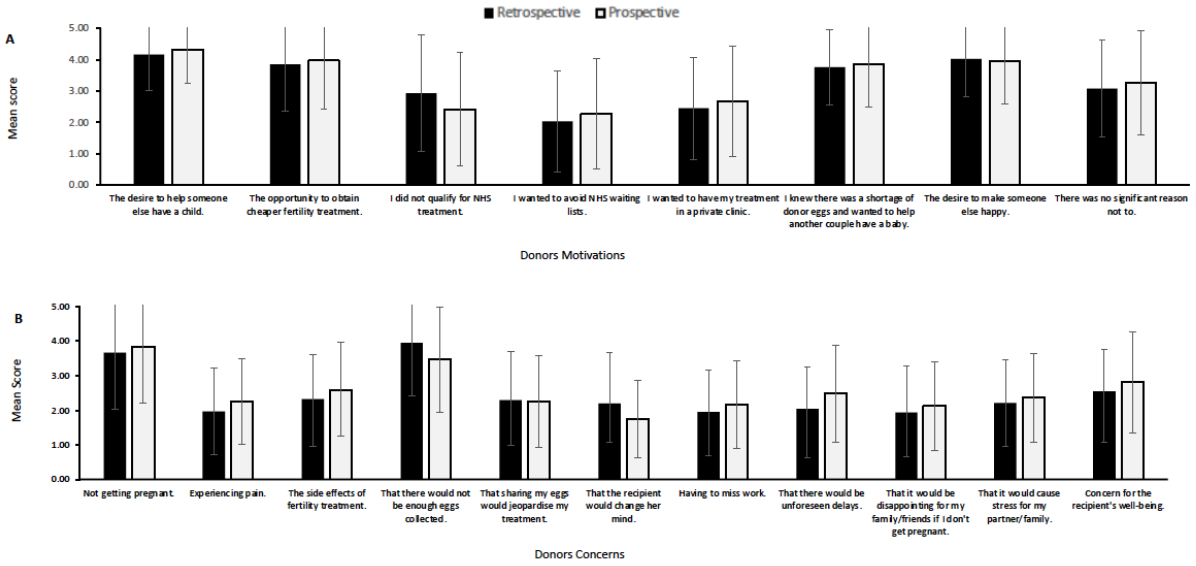


Figure 4.1: **The motivations and concerns of egg share donors, scored 1-5 (1=least significant 5=most significant).**
Patients were given a list of potential concerns and motivations and asked to score them. Patients are split into retrospective and prospective patients. Values displayed as Mean ± SD.
There were no significant differences between groups (Mann Whitney P>0.05)
A: Donors Motivations (Retrospective n=146 Prospective n=31)
B: Donors Concerns (Retrospective n=146 Prospective n=31)

The egg sharers ranked potential concerns lower than motivations (***figure 4.1***). The highest scoring concerns were 'not getting pregnant' (3.8 +/-1.1) and 'not enough eggs being collected' (3.7 +/- 1.5).

When asked to select their main concern, 40.7% of donors selected ‘not getting pregnant’, which was the highest concern.

Figure 4.2 reports on recipient’s motivations and concerns surrounding egg sharing. The highest ranking motivations reported by recipients were the ‘desire for my partner to have a genetic tie to the offspring’ (4.1 +/- 1.2) and the ‘desire to experience pregnancy’ (4.1 +/- 1.2). When asked what their main motivation was, 42.3% voted for ‘desire for my partner to have a genetic tie to the offspring’.

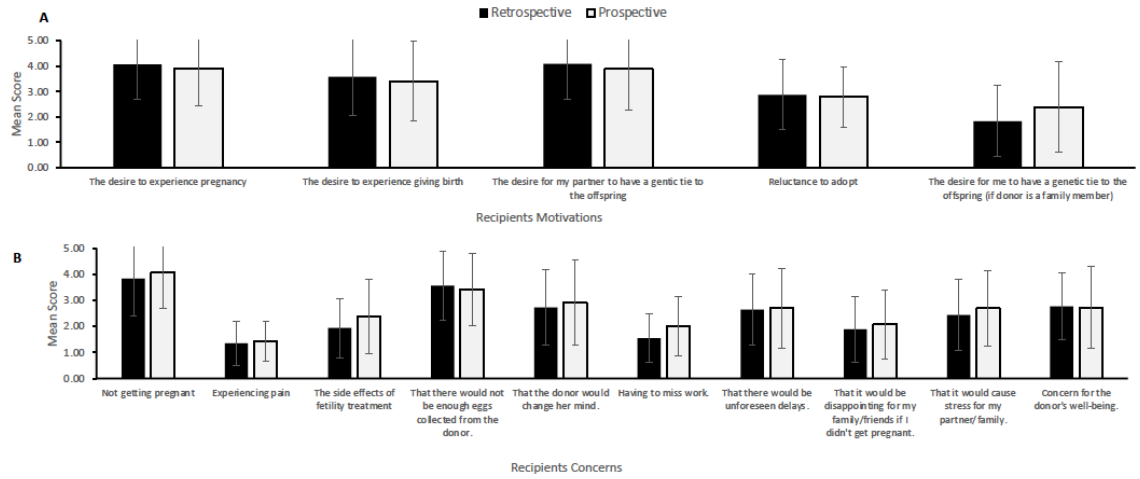


Figure 4.2: **The motivations and concerns of egg share recipients, scored 1-5 (1= least significant 5= most significant).**
Patients were given a list of potential concerns and motivations and asked to score them. Patients are split into retrospective and prospective patients. Values displayed as Mean ± SD. There were no significant differences between groups (Mann Whitney P>0.05)
A: Recipients Motivations (Retrospective n=161 Prospective n=27)
B: Recipeints Concerns (Retrospective n=161 Prospective n=27)

Recipients answered very similarly to egg sharers regarding concerns surrounding their treatment (***figure 4.2***). The highest rated concerns were ‘not getting pregnant’ (3.9 +/- 1.4) and ‘not enough eggs being collected’ (3.6 +/- 1.3). There was no statistical difference between donors and recipients responses to these concerns, when a comparison was possible (Mann Whitney U test, p>0.05). The next most consistently raised concerns for recipients were ‘the donor changing her mind’ (2.9 +/- 1.4), and ‘concern for the donor’s well-being’ (2.7 +/- 1.4). When asked to rank their single most significant concern, 60.3% selected ‘not getting pregnant’.

There was no significant difference between the responses from the retrospective and prospective groups regarding their motivations and concerns (***figures 4.1 & 4.2***).

4.3.4 Treatment experiences of egg sharing

Participants were asked about their treatment experiences of the egg sharing programme (***table 4.4***). Firstly, participants were asked to rate their treatment experience from very positive to very negative. Overall, the donors rated their treatment more positively than the recipients (85.7% 'very positive/ positive' vs 73.8% of recipients, χ^2, P<0.05). However, it must be noted the vast majority of both groups had a positive treatment experience. Overall, when combining the 'very positive/ positive' responses, there was no statistical difference in responses from egg sharers and recipients regarding the quality of medical care they had received. Indeed, the responses were overwhelmingly positive, with 92.6% of egg sharers and 83.7% of recipients positive about the medical care they received.

Table 4.4: *Treatment experiences of the egg sharing programme (Significant p value < 0.05 calculated by: a= χ^2, ns= non-significant).*

	Group				p-value
	Egg sharers		Recipients		Egg sharers v recipients
	%	n	%	n	
Overall how would you rate your treatment experience?					
Very positive	62.6	92	43.8	70	<0.001[a]
Positive	23.1	34	30.0	48	NS
Neither positive/ negative	10.9	16	13.1	21	NS
Negative	2.0	3	10.6	17	<0.001[a]
Very negative	1.5	2	2.5	4	NS
Overall how would you rate the medical care you received?					
Very positive	74.3	110	44.0	70	<0.001[a]
Positive	18.2	27	39.7	63	NS
Neither positive/ negative	4.7	7	8.2	13	NS
Negative	2.0	3	5.8	9	NS
Very negative	0.8	1	2.5	4	NS

Respondents were given a list of statements pertaining to their treatment experience and were asked if they agreed or disagreed with these statements (***table 4.5***). The vast majority of egg sharers (91.8%) and recipients (86.3%) were glad they took part in the programme, with no statistical difference between these groups. A significant majority of egg sharers (72.6%) and recipients (81.8%) would participate in egg sharing again in the future. There was also a very positive response when participants were asked if they 'would recommend friends or family who needed fertility treatment' using this programme, with 92.5% of egg sharers and 91.3% of recipients agreeing to this statement. More egg sharers felt well informed prior to starting their fertility treatment than recipients (90.5% vs 65.4%, χ^2, P<0.05). A

significantly higher proportion of donors also felt they had enough access to medical staff (87.2% vs 71.3%, χ^2, P<0.05), and had enough time with the counselling staff (90.5% vs 80.8%, χ^2, P<0.05) compared to recipients.

Table 4.5: *Prospective and retrospective egg donors and recipients' experiences of egg sharing. Statements are the proportion of respondents that agreed with the statement. Values are proportion of study population (%) and n number, dashes (-) represent the question not being asked to that group thus relative statistical test wasn't able to be performed. (Significant P value<0.05. a= calculated by χ^2, b=calculated by Fishers exact, ns=non-significant).*

	Groups								P value between groups		
Statement/Question	Retrospective Egg Donors (1) (n=147)		Prospective Egg Donors (2) (n=30)		Retrospective Egg Recipients (3) (n=160)		Prospective Egg Recipients (4) (n=28)		1v2	3v4	1+2v3+4
	%	*n*	%	*n*	%	*n*	%	*n*			
Statements											
Glad they took part	91.8	*134*	-	-	86.3	*138*	-	-	-	-	ns
Would still take part in the egg sharing scheme	87.6	*127*	-	-	90.6	*145*	-	-	-	-	ns
Would Participate in egg sharing again in the future	72.6	*106*	-	-	81.8	*130*	-	-	-	-	ns
Would Recommend egg sharing to a friend or family member who needs fertility treatment	92.5	*135*	93.9	*31*	91.3	*146*	-	-	ns	-	ns
Felt they were well informed prior to starting the egg sharing process?	90.5	*133*	93.9	*31*	76.9	*123*	65.4	*17*	ns	ns	<0.001[a]
Had enough time with medical staff	85.1	*126*	87.9	*29*	71.3	*114*	61.5	*16*	ns	ns	Ns
Had enough access with medical staff	87.2	*129*	-	-	71.3	*114*	-	-	-	-	<0.001[a]
had enough time with the counselling staff	90.5	*134*	-	-	76.7	*122*	80.8	*21*	ns	0.042[b]	<0.001[a]
had enough access with the counselling staff	89.2	*132*	-	-	77.4	*123*	-	-	-	-	ns
Do you feel you had enough support from the fertility clinic during your treatment?	94.6	*140*	-	-	71.1	*113*	-	-	-	-	<0.001[a]
Do you feel you had enough support from the fertility clinic after your treatment?	67.6	*100*	-	-	52.5	*83*	-	-	-	-	<0.001[a]

The retrospective groups were asked if they felt they had enough support from the clinic during and after their treatment. Egg sharers felt more supported than recipients both during (94.6% vs 71.1%, χ^2, P<0.05) and after their treatment (67.6% vs 52.5%, χ^2, P<0.05).

Experience based on treatment outcome

Patients were stratified into whether IVF treatment was successful or not (***figure 4.3***), with successful treatment being defined as a resulting live birth.

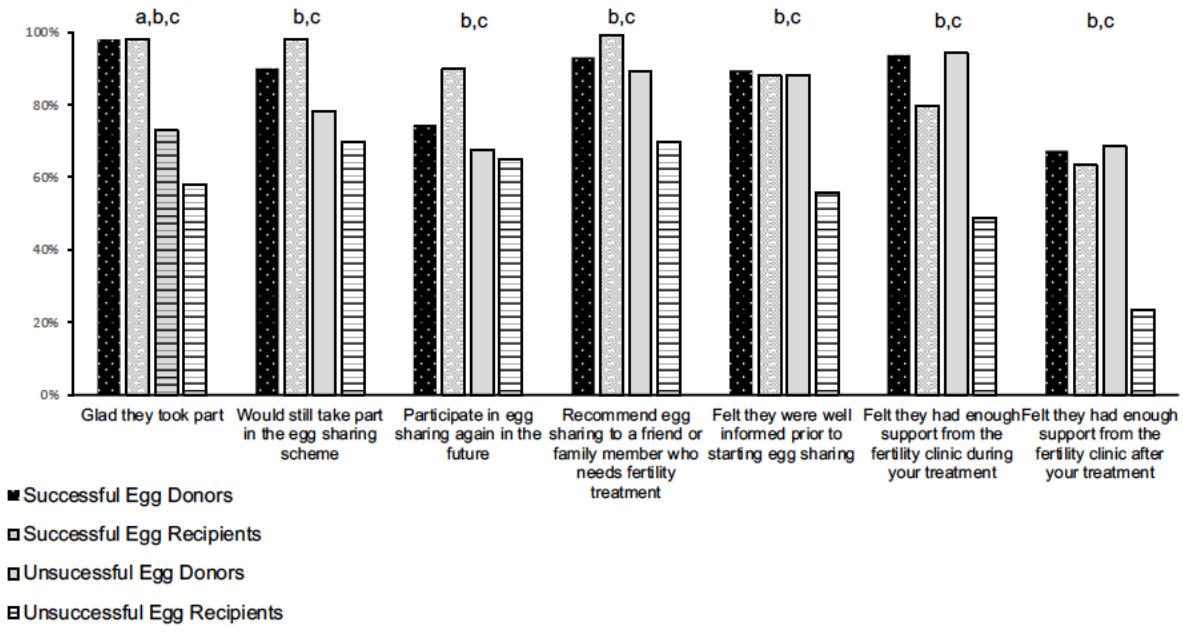


Figure 4.3: *The effect of outcome on treatment experience*
How experiences of egg sharing differed for donors and recipients depending on whether their treatment was successful or unsuccessful.
Participants indicated whether they agreed or disagreed with the statement (n=281)
'a' indicates a statistically significant difference between successful and unsuccessful donors (Fisher exact)
'b' indicates a statistically significant difference between successful and unsuccessful recipients (Fisher exact)
'c' indicates a statistically significant difference between successful donors + recipients unsuccessful donors + recipients (χ^2)

For egg sharers, there was no difference between positive or negative treatment outcome, and their responses to whether they: would participate in egg sharing again in the future; would recommend egg sharing to a friend or family member who needs fertility treatment; felt well informed of egg sharing; and felt they had sufficient support from the fertility clinic during and after treatment. The only answer that was statistically significant based on treatment outcome was when asked if they were 'glad they took part', with 99.4% of successful egg sharers answering yes, compared to 72.7% of unsuccessful egg sharers (Fishers exact, $p< 0.05$).

In contrast, for recipient's adverse treatment outcome negatively impacted all of their treatment experiences, with unsuccessful recipients answering the least positive for all of the four groups analysed. Recipients whose treatment was unsuccessful were less likely to recommend treatment to their family and friends (69.8% vs 99.1%, Fishers exact, $p<0.05$), and were less likely to undergo further fertility treatment (89.8% vs 65.1%, Fishers exact, $p<0.05$). Unsuccessful recipients felt they were less adequately informed before starting the process (55.8% vs 88.1%, Fishers exact, $p<0.05$). Unsuccessful recipients also felt less supported during their treatment (80.1% vs 50.1%, Fishers exact, $p<0.05$) and

afterwards (60.2% vs 21.4%, Fishers exact, $p<0.05$). Despite the statistical difference between the successful and unsuccessful recipient's treatment experiences, it is important to note that the majority of unsuccessful recipients still felt positively about their treatment experiences, just in lower proportions.

When grouping all successful patients (donors and recipients) with unsuccessful patients (donors and recipients), unsurprisingly successful patients were more likely to rate the egg sharing experience 'very positive' or 'positive' compared to unsuccessful patients (92.0% vs 44.6%, χ^2, $P<0.05$). The collated unsuccessful group were also less glad they took part (97.6% vs 65.0%, χ^2, $P<0.05$). It is again worth noting that although not statistically significant, nearly two thirds of the unsuccessfully treated patients were still glad they participated in the scheme.

4.3.5 Attitudes towards egg sharing

Patients' views on the ethics and regulation of egg sharing were elicited through a range of statements, to which they were asked to express their level of agreement or disagreement. The responses to these statements were analysed in 3 ways: (i) donors versus recipients, (ii) retrospective versus prospective patients, and (iii) successful versus unsuccessful patients. The statements and their responses are shown in ***table 4.6***.

Table 4.6: Attitudes towards egg sharing. *Prospective and retrospective egg sharers and recipients attitudes towards egg sharing. Values are proportion of study population (%) and n number that selected the response to each question. Significant p value < 0.05. a= χ^2, NS= non-significant*

	Groups								P value between groups		
Statement	Retrospective Egg Donors (1) (n=147)		Prospective Egg Donors (2) (n=33)		Retrospective Egg Recipients (3) (n=155)		Prospective Egg Recipients (4) (n=28)		1v2	3v4	1+2v3+4
	%	*n*	%	*n*	%	*n*	%	*n*			
1. I believe egg sharing is a good solution to a national shortage of donor eggs.											
Strongly agree	67.3	*99*	69.7	*23*	52.3	*81*	53.8	*14*			
Agree	28.6	*42*	27.3	*9*	33.5	*52*	34.6	*9*			
Neither agree nor disagree	3.4	*5*	3.0	*1*	11.6	*18*	11.5	*3*	NS	NS	p<0.001[a]
Disagree	0.0	*0*	0.0	*0*	1.9	*3*	0.0	*0*			
Strongly Disagree	0.7	*1*	0.0	*0*	0.6	*1*	0.0	*0*			
2. Egg sharing provides a 'win-win' solution for donors and recipients.											
Strongly agree	60.5	*89*	63.6	*21*	42.2	*65*	48.0	*12*			
Agree	26.5	*39*	27.3	*9*	37.0	*57*	36.0	*9*			
Neither agree nor disagree	9.5	*14*	6.1	*2*	13.0	*20*	16.0	*4*	NS	NS	p<0.001[a]
Disagree	2.7	*4*	3.0	*1*	7.1	*11*	0.0	*0*			
Strongly Disagree	0.7	*1*	0.0	*0*	0.6	*1*	0.0	*0*			
3. The egg sharing programme exploits women.											
Strongly agree	2.0	*3*	0.0	*0*	0.0	*0*	0.0	*0*			
Agree	7.5	*11*	3.1	*1*	5.2	*8*	7.7	*2*			
Neither agree nor disagree	7.5	*11*	9.4	*3*	20.0	*31*	11.5	*3*	NS	NS	p<0.001[a]
Disagree	26.5	*39*	37.5	*12*	36.8	*57*	30.8	*8*			
Strongly Disagree	56.5	*83*	50.0	*16*	38.1	*59*	50.0	*13*			
4. I prefer donor eggs to come from a woman who is already undergoing fertility treatment for her own needs, rather than from volunteer donors who would have to undergo an invasive procedure that they would not otherwise have needed.											
Strongly agree	9.5	*14*	12.5	*4*	16.1	*25*	20.0	*5*			
Agree	12.9	*19*	18.8	*6*	17.4	*27*	20.0	*5*			
Neither agree nor disagree	51.7	*76*	34.4	*11*	34.8	*54*	28.0	*7*	NS	NS	p<0.001[a]
Disagree	10.9	*16*	21.9	*7*	21.3	*33*	20.0	*5*			
Strongly Disagree	15.0	*22*	12.5	*4*	10.3	*16*	12.0	*3*			
5. I believe it is ethical to give women free or much cheaper fertility treatment in exchange for some of her eggs.											
Strongly agree	55.1	*81*	50.0	*16*	32.3	*50*	34.6	*9*			
Agree	32.7	*48*	43.8	*14*	43.2	*67*	38.5	*10*			
Neither agree nor disagree	8.2	*12*	6.3	*2*	18.7	*29*	19.2	*5*	NS	NS	p<0.001[a]
Disagree	2.0	*3*	0.0	*0*	5.2	*8*	7.7	*2*			
Strongly Disagree	2.0	*3*	0.0	*0*	0.6	*1*	0.0	*0*			

Overall, the majority of egg sharers and recipients agreed with statements 1-5 (***table 4.6***). However, egg sharers responses were statistically significantly more positive to statements 1,2,4,5 than recipients. When given the statement 'I believe egg sharing is a good solution to a national shortage of donor eggs', 95.9% of egg sharers agreed with this statement compared to 85.9% of recipients (χ^2, P<0.05). When asked if 'egg sharing provides a 'win-win' solution for donors and recipients', 87.0% of egg sharers agreed, compared to 79.2% of recipients (χ^2, P<0.05). Participants were then asked if 'egg sharing

exploits women', and 83.1% of egg sharers disagreed with this, compared to 74.9% of recipients (χ^2, $P<0.05$). Patients were then given the statement whether it is preferrable donor eggs come from women undergoing fertility treatment for her own needs, rather than from volunteer donors who would need to undergo invasive procedure they would otherwise not need. Statistically more recipients agreed with this statement (33.5%) compared to egg sharers (22.4%), implying recipients were morally connected to how they were acquiring their oocytes (χ^2, $P<0.001$). Finally, when given the statement that 'it is ethical to give women cheaper fertility treatment in exchange for a proportion of her eggs' 87.8% of egg sharers agreed with this, compared to 75.5% of recipients (χ^2, $P<0.05$).

Table 4.7 shows the attitudes towards monetary rewards and compensatory payments for donation. Responses were not statistically significantly different between donors or recipients, or between prospective or retrospective patients. The majority from both groups agreed that monetary payments for donation should not be permissible (χ^2, $P>0.05$). More recipients (87.8%) believed that egg donors should receive compensatory payments for their donation compared to egg sharers (79.8%), but this did not reach statistical significance (χ^2, $P>0.05$). A significant minority of both egg sharers (26.5%) and recipients (22.3%) felt monetary payments for their donations should be permitted, provided it is well regulated (χ^2, $P>0.05$).

Table 4.7: Attitudes towards monetary rewards and compensatory payments towards donation.
Prospective and retrospective egg sharers and recipients attitudes towards egg sharing. Values are proportion of study population (%) and n number that selected the response to each question.
(Significant p value < 0.05. a= χ^2, NS= non-significant)

	Groups								P value between groups		
Statement	Retrospective Egg Donors (1) (n=147)		Prospective Egg Donors (2) (n=33)		Retrospective Egg Recipients (3) (n=155)		Prospective Egg Recipients (4) (n=28)		1v2	3v4	1+2v3+4
	%	*n*	%	*n*	%	*n*	%	*n*			
1. Egg donors should not receive any payment for donating.											
Strongly agree	5.4	*8*	12.1	*4*	10.9	*17*	7.7	*2*			
Agree	10.2	*15*	18.2	*6*	20.5	*32*	0.0	*0*			
Neither agree nor disagree	37.4	*55*	30.3	*10*	32.1	*50*	34.6	*9*	NS	NS	NS
Disagree	34.7	*51*	21.2	*7*	26.3	*41*	50.0	*13*			
Strongly Disagree	12.2	*18*	18.2	*6*	10.3	*16*	7.7	*2*			
2. Egg donors should receive a compensatory payment to cover expenses and time off work for their donations.											
Strongly agree	37.4	*55*	39.4	*13*	48.1	*75*	30.8	*8*			
Agree	39.5	*58*	45.5	*15*	39.7	*62*	50.0	*13*			
Neither agree nor disagree	17.7	*26*	0.0	*0*	9.0	*14*	15.4	*4*	NS	NS	NS
Disagree	4.1	*6*	6.1	*2*	3.2	*5*	3.8	*1*			
Strongly Disagree	1.4	*2*	9.1	*3*	0.0	*0*	0.0	*0*			
3. Egg donors should receive a monetary payment for their donations, as long as it is well-regulated.											
Strongly agree	15.0	*22*	21.2	*7*	10.2	*16*	23.1	*6*			
Agree	26.5	*39*	30.3	*10*	22.3	*35*	38.5	*10*			
Neither agree nor disagree	42.2	*62*	30.3	*10*	35.7	*56*	26.9	*7*	NS	NS	NS
Disagree	12.2	*18*	6.1	*2*	25.5	*40*	7.7	*2*			
Strongly Disagree	4.1	*6*	12.1	*4*	6.4	*10*	3.8	*1*			

Analysis of these same 7 statements regarding the attitudes towards egg sharing were then made, depending on whether the patient's treatment had been successful or unsuccessful, with the results displayed in ***figure 4.4***. The only statement where treatment outcome had a significantly different response was 'egg sharing provides a 'win-win' solution for donors and recipients', with successful respondents agreeing to this statement in higher proportions (Fisher exact, $p<0.05$). It is significant to note that respondents disagreed that 'egg sharing exploits women', regardless of their treatment outcome.

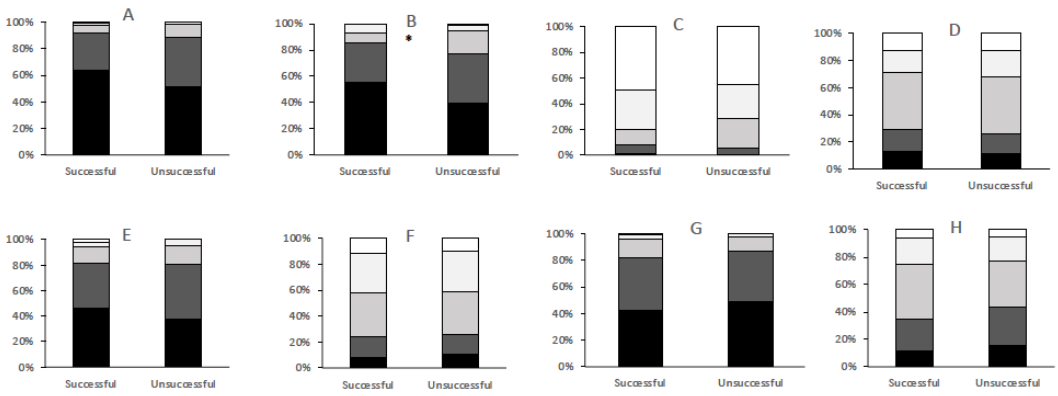


Figure 4.4: *The effect of treatment outcome on attitudes towards egg sharing*
The number of patients who strongly agreed, agreed, neither agreed nor disagreed, disagreed and strongly disagreed to the statements above (successful patients, n=200; unsuccessful patients, n=81).
* Indicates p value < 0.05 between successful and unsuccessful respondents.
A: I believe egg sharing is a good solution to a national donor egg shortage
B: Egg sharing provides a 'win win' solution for donors and recipients
C: The egg sharing programme exploits women
D: I prefer donor eggs to come from a woman who is already undergoing fertility treatment for her own needs, rather than a volunteer donor
E: I believe it is ethical to give women free or much cheaper fertility treatment in exchange for some of her eggs
F: Egg donors should not receive monetary payments for donating
G: Egg donors should receive a compensatory payment to cover expenses and time off work for their donations
H: Egg donors should receive a monetary payment for their donations, as long as it is well regulated

Egg sharers were asked how they would feel if their recipient's treatment was unsuccessful, and 79.5% of successful donors and 100% of unsuccessful donors felt empathy towards the recipient. Recipients were also asked how they would feel if their donor's treatment was unsuccessful, and 100% of successful recipients, compared to 29.1% of unsuccessful recipients felt empathy towards their egg sharer's treatment being unsuccessful (χ^2, $p<0.05$).

4.3.6 Thoughts and feelings about the egg donor or recipient

Participants were then asked how they felt about their donor or recipient (***table 4.8***). A higher proportion of recipients described feeling 'closer' to their egg sharer when compared to the donor (35.2% vs 28.9%, χ^2, $p<0.05$). Indeed, 96.5% of recipients said they felt gratitude towards their donor. More egg sharers answered agreement to 'not feeling anything about her' compared to recipients (12.6% vs 4.5%, χ^2, $p<0.05$). A higher proportion of egg sharers who had completed treatment agreed to 'not feeling anything about their recipient', compared to egg sharers who were undergoing treatment (12.6% vs 5.7%, χ^2, $p<0.05$). More recipients also reported feeling 'close to her' than egg sharers (34.5% vs 24.4%, χ^2, $p<0.05$). There was no difference between egg sharers or recipients when asked if they 'felt curious about her' (87.4% vs 81.6%, χ^2, $p>0.05$). There was also no difference between egg sharers and their

recipients when asked if they felt 'jealous of her' (2.2% vs 8.5%, χ^2, p>0.05). 97.8% of egg sharers hoped their recipient's treatment had been successful after they had completed their treatment, and this was significantly higher than egg sharers who responded to the survey during their treatment (97.8% vs 85.7%, χ^2, p<0.05). Retrospective egg sharers also felt more sympathy towards their recipient, compared to prospective egg sharers (82.2% vs 68.6%, χ^2, p<0.05). A higher proportion of donors wanted to 'make her happy' compared to recipients (85.9% vs 41.4%, χ^2, p<0.05).

Table 4.8: *Prospective and retrospective egg sharers and recipients thoughts and feelings towards each other. Values are proportion of study population (%) and n number that selected each answer. Respondents could select multiple answers. Dashes (-) represent the question not being asked to that group. Significant p value<0.05. a= calculated by χ^2, b=calculated by Fishers exact, NS=non-significant*

	Groups								P value between groups		
Question	Retrospective Egg Donors (1) (n=147)		Prospective Egg Donors (2) (n=33)		Retrospective Egg Recipients (3) (n=155)		Prospective Egg Recipients (4) (n=28)		1v2	3v4	1+2v3+4
	%	*n*	%	*n*	%	*n*	%	*n*			
How did you feel about your recipient while undergoing fertility treatment?											
I did not feel anything about her.	12.6	*17*	5.7	*2*	4.5	*7*	3.6	*1*	<0.001[b]	NS	<0.001[b]
I was curious about her.	87.4	*118*	84.8	*28*	81.6	*115*	85.7	*24*	NS	NS	NS
I was jealous of her.	2.2	*3*	8.6	*3*	8.5	*12*	0.0	*0*	NS	NS	NS
I felt close to her.	24.4	*33*	22.9	*8*	34.5	*49*	29.2	*7*	NS	NS	<0.05[a]
I felt we understood each other.	30.4	*41*	34.3	*12*	31.0	*44*	33.3	*8*	NS	NS	NS
I felt sympathetic to her.	82.2	*111*	68.6	*24*	-	-	-	-	<0.05[b]	-	-
I hoped her treatment would be successful.	97.8	*132*	85.7	*30*	-	-	-	-	<0.001[b]	-	-
I felt sorry for her.	38.5	*52*	34.3	*12*	-	-	-	-	NS	-	-
I wanted to make her happy.	85.9	*116*	57.1	*20*	41.4	*58*	41.7	*10*	<0.001[b]	NS	<0.001[a]
I felt grateful to her.	-	-	-	-	96.5	*137*	91.7	*22*	-	NS	-

4.3.7 Disclosure

Responses regarding the disclosure of the nature of their donation are shown in ***table 4.9***. The egg sharers and their recipients did answer with differing opinions on the majority of the questions asked surrounding disclosure. Overall, most recipients (89.0%) agreed that the child has a right to know of

the nature of their conception, compared to only 51.1% of egg sharers overall (χ^2, $p<0.05$). However, a significantly higher proportion of recipients also agreed with the statement 'they have a right not to tell their resulting offspring about the nature of their conception' compared to egg sharers (85.1% vs 33.3%, χ^2, $p<0.05$). Respondents were asked 'How would you feel if a child born from donated eggs contacted the donor as an adult?', 73.8% of egg sharers were happy with future contact compared to 42.9% of recipients (χ^2, $p<0.05$). Only 4.1% of egg sharers stated they would prefer no contact, compared to 17.5% of recipients (χ^2, $p<0.05$). When asked 'If a child born from egg donation has the right to learn the donor's identity as an adult' more retrospective egg sharers agreed with this, compared to prospective donors (69.0% vs 53.1%, χ^2, $p<0.05$). Interestingly, more recipients agreed with this statement compared to egg sharers, even though they were less keen in future contact with their child and their donor (79.9% vs 69.0%, χ^2, $p<0.05$). When asked if resulting offspring could be emotionally harmed by having future contact with their donor, more recipients agreed with this compared to donors, although it was still only a minority of respondents (14.2% versus 4.1%, χ^2, $p<0.05$). When asked if the recipient could be emotionally harmed by their child having future contact with their donor, there was no significant difference in responses, with 21.9% of recipients and 18.6% of egg sharers agreeing there could be emotional damage with this contact (χ^2, $p<0.05$).

Table 4.9: Prospective and retrospective egg sharers and recipients' opinions on disclosure. Values are proportion of study population (%) and n number that selected that response, dashes (-) represent the question not being asked to that group thus relative statistical test wasn't able to be performed. Significant P value<0.05. a= calculated by χ^2, NS= non-significant

	Groups								P value between groups		
	Retrospective Egg Donors (1) (n=147)		Prospective Egg Donors (2) (n=33)		Retrospective Egg Recipients (3) (n=155)		Prospective Egg Recipients (4) (n=28)		1v2	3v4	1+2v3+4
	%	*n*	%	*n*	%	*n*	%	*n*			
Do you believe that any children born by egg donation could be emotionally damaged if they inadvertently learn that they were born by egg donation?											
Agree	24.1	35	19.4	6	64.3	99	39.1	9			
Neutral	22.1	32	38.7	12	18.2	28	17.4	4	NS	<0.001[a]	<0.001[a]
Disagree	37.9	55	25.8	8	11.0	17	34.8	8			
No Opinion	15.9	23	16.1	5	6.5	10	8.7	2			
Do you believe that any children born egg donation have the right to know that they were conceived by egg donation?											
Agree	52.4	76	46.9	15	89.7	140	84.0	21			
Neutral	29.0	42	31.3	10	7.1	11	16.0	4	NS	NS	<0.001[a]
Disagree	2.8	4	3.1	1	0.6	1	0.0	0			
No Opinion	15.9	23	18.8	6	2.6	4	0.0	0			
Do you believe that the recipient of donated eggs has the right not to tell any resulting children about how they were conceived?											
Agree	33.8	49	25.0	8	85.3	133	84.0	21			
Neutral	31.0	45	43.8	14	9.6	15	4.0	1	NS	NS	<0.001[a]
Disagree	21.4	31	12.5	4	1.9	3	4.0	1			
No Opinion	13.8	20	18.8	6	3.2	5	8.0	2			
How would you feel if a child born from donated eggs contacted the donor as an adult?											
Happy	73.8	107	59.4	19	42.9	66	45.8	11			
Neither happy nor unhappy	6.2	9	18.8	6	9.7	15	16.7	4	NS	NS	<0.001
I would prefer no contact	4.1	6	6.3	2	17.5	27	12.5	3			
I don't know	15.9	23	15.6	5	29.9	46	25.0	6			
Do you believe that the child born by egg donation has the right to learn the donor's identity as an adult?											
Agree	69.0	100	53.1	17	79.9	123	70.8	17			
Neutral	21.4	31	40.6	13	12.3	19	16.7	4	<0.001[a]	NS	<0.05[a]
Disagree	2.8	4	3.1	1	3.9	6	8.3	2			
No Opinion	6.9	10	3.1	1	3.9	6	4.2	1			
Do you believe that the child born by egg donation could be emotionally harmed by having contact with the donor as an adult?											
Agree	4.1	*6*	3.1	*1*	14.2	*22*	8.3	*2*			
Neutral	31.0	*45*	46.9	*15*	41.3	*64*	50.0	*12*	<0.001[a]	NS	<0.001[a]
Disagree	49.0	*71*	31.3	*10*	33.5	*52*	41.7	*10*			
No Opinion	15.9	*23*	18.8	*6*	11.0	*17*	0.0	*0*			
Do you believe that the recipients of egg donation could be emotionally harmed by you the donor having future contact with their children?											
Agree	18.6	*27*	9.4	*3*	21.9	*34*	8.7	*2*			
Neutral	38.6	*56*	43.8	*14*	36.8	*57*	34.8	*8*	NS	NS	NS
Disagree	29.0	*42*	21.9	*7*	32.9	*51*	56.5	*13*			
No Opinion	13.8	*20*	25.0	*8*	8.4	*13*	0.0	*0*			

4.4 Discussion

This study provides an understanding of the psychosocial aspects of the egg sharing practice, from the aspect of both the recipient and their donor. It is only the second study to investigate this topic and the

largest to do so. This includes patients' motivations, knowledge, attitudes, treatment experience and disclosure decisions. The findings of this study are largely reassuring, consistent with previously published studies [49, 52, 60]. Importantly, patients did not find egg sharing exploitative, regardless of the outcome of their treatment. This data continues to support the HFEA's initial stance regarding egg sharing, namely that it should be regulated not banned [41].

4.4.1 Motivations and feelings about the egg sharing scheme

There is still considerable debate surrounding the motivations, particularly of egg donors, to participate in the egg sharing scheme, despite some studies reporting reassuring psychological data previously [49, 52, 60]. Egg share donors only ranked the opportunity to obtain cheap fertility treatment fourth overall, with the desire to help someone else have a child the number one motivating factor. 35.2% of donors stated they would still donate if there was no direct financial benefit to them, with 52.6% saying they would donate regardless of their ability to self-fund their fertility treatment. However, 35.2% of egg sharers agreed that egg sharing was their only option to get pregnant, implying they cannot afford IVF and therefore egg sharing is their only option if they want to have a child. This is a consistently raised concern of the scheme [55, 59]. To assess this key issue further, donors were grouped by their response to 'egg sharing was their only option to become pregnant (n=56) vs 'egg sharing was not their only option to fall pregnant' (n=117). They were then analysed based on their response to the question 'would you have considered participating in the egg sharing scheme regardless of your ability to pay for IVF?'. Respondents who answered that egg sharing was their only option to conceive were significantly less likely to take part if they could afford IVF (39.3% vs 59.0%, χ^2, $p<0.05$). This strongly implies some egg sharers are participating mainly for financial reasons, which is unsurprising. Interestingly, there was no difference in the annual incomes of these patients. These findings show that egg sharers motivations are multi-faceted and include financial considerations, and support findings from other studies regarding the co-existence of egg share donor's desire to help others but also themselves [48, 52, 145]. Despite this, it is important to note that the majority egg sharers highlighted their sense of empathy towards their recipient by ranking altruistic reasons higher than financial ones. Overall, they

clearly understood the scheme offered them a practical option, enabling them to address their financial concerns while helping someone else have a baby.

The recipients most significant motivation was the desire for their partner to have a genetic tie to the offspring, and their desire to experience pregnancy. Interestingly the concerns of the recipients scored lower than their motivations. This suggests the majority of patients who participated in the scheme found the positives significantly outweighed the negatives. As expected, the main concerns raised by both donors and recipients was not getting pregnant, as well as not having enough eggs collected. There were additional specific concerns raised by donors, such as concern for the well-being of the recipient, and for recipients, such as the donor changing their mind. Clear communication by clinical staff regarding whether a donor's and recipient's treatment is affected by egg sharing could alleviate these concerns. Indeed, participants should be made aware of the strong evidence that egg sharing does not have an impact on their treatment outcome [65, 202]. Increasing participants awareness of this could ease their concerns and potentially recruit more patients into the programme.

4.4.2 Knowledge and information gathering surrounding egg sharing

This study also revealed details of how donors and recipients came to acquire knowledge of egg sharing and what their first impressions were of it. Most egg sharers found out about the programme from the internet and personal research, in contrast to recipients who were informed of the option by their fertility specialist. Egg sharers can either self-refer to the fertility clinic after their own research, or be referred by their GP or gynaecologist. It is therefore interesting to note that only 4.8% of egg sharers learnt of this option from their GP, and 15.1% from their gynaecologist. This is very relevant as GPs particularly are a widely consulted source of advice and information for women trying for a baby. Additionally, although this study does not have detailed data on the nature of the information patients accessed on the internet, it is established that this source can often be inaccurate, bias, and unregulated. A study has reported egg sharers were frustrated not to have found out about the option of egg sharing earlier from their GP or gynaecologist, which implies these patients see these professionals as appropriate and reliable sources of information [52]. This frustration is understandable, as egg sharers need to be aged

35 years or under to be allowed to participate, as well as have an anti-müllerian hormone (AMH) level of 7 pmol/l or higher. The delay in them accessing egg sharing, with most egg sharers having tried to conceive for more than 2 years, could mean they are no longer eligible to participate as egg sharers. GPs are front line and the most easily accessible healthcare professional available to patients, and the vast majority of fertility patients will see their GP while trying to conceive prior to a fertility specialist. They are therefore in an excellent position to provide accurate and objective information to patients struggling to conceive, not only about the existence of the egg sharing programme, but also more generally about the various assisted reproductive treatments available to them. These findings are unsurprising as a study performed as part of this thesis (***Chapter 3: Study II***) investigated the knowledge and perceptions of egg sharing among healthcare professionals. Of the 304 healthcare professionals surveyed, 63.1% of respondents had little or no knowledge of egg sharing, although the majority supported the scheme once a short description was provided [61]. Only 16.5% of the GPs and Gynaecologists surveyed had previously referred a patient for egg sharing [61]. While it is obviously important not to pressurize potential egg sharers, it is also vital to tackle the paucity of information that is taking away the opportunities for some individuals to pursue these treatment options. Education of healthcare professionals about egg sharing and the research that supports it could improve their knowledge and perceptions of egg sharing, increasing referral rates and egg sharing numbers.

In contrast, most recipients found out about egg sharing from their fertility specialist, and this is likely explained by recipients having multiple failed attempts with their own eggs, or being older with a very poor chance of success. Recipients also undertook considerably more research on egg sharing and egg donation compared to their donors. 17.7% of egg share donors undertook less than an hour of personal research, exemplifying the importance of the role the fertility clinic and counselling service has with regard to giving egg sharers sufficient information to make an informed choice to participate in the scheme.

4.4.3 Attitudes towards egg sharing

In contrast to the other studies published, although there were key patterns of similarity in responses between donors and their recipients regarding their attitudes towards egg sharing, overall donors views were more positive when compared to recipients [49, 52, 60]. This is perhaps unsurprising as egg share donors are receiving their fertility treatment free of charge and will be the genetic mother of any child conceived, while the recipient is paying and will not have a genetic link to the child. However, it must be noted that the vast majority of recipients had positive attitudes towards the scheme, with 79.2% of recipients agreeing that egg sharing provides a 'win-win' solution for both parties. This is still a large majority but was significantly less than 87.0% of egg share donors when they were asked the same question. This data shows that both donors and recipients are, in the significant majority, glad to have participated in egg sharing and would still do so if they could make the decision retrospectively.

The majority of both groups also reported favourably regarding their opinions of the ethics and regulations surrounding egg sharing. The HFEA have previously published a report stating egg sharing's apparent exceptional status within UK regulations, which highlights the fundamental principle that gamete donation should be 'cost neutral' [101]. Therefore, concerns surrounding egg sharing have implied the financial incentives given to egg sharers, who would not otherwise be able to access IVF, act as an undue enticement which renders their consent invalid; as well as whether the egg sharing programme is allowing gametes to be turned into commodities. Critics of the programme have put compromised consent at the centre of their objections [54, 55, 59, 152, 153]. Couples who are desperate to conceive and need IVF, but do not qualify for government funded treatment or cannot afford to pay themselves, are a potentially vulnerable group that could be exploited. It would be morally unacceptable if a woman who would not donate for moral or psychological reasons is forced to reconsider this decision due to her financial situation [43]. Acting in this way against her previously held convictions suggests that a level of coercion exists, which threatens voluntary and informed consent [43]. This study directly explored this issue and the validity of the decisions they had made. The vast majority of egg sharers 'strongly disagreed' with the statement that egg sharing exploits women. 91.8% of egg sharers were glad to have taken part, 72.6% would participate in egg sharing again, 92.0% would recommend egg sharing to family or friends, and 92.6% of egg sharers felt positively about the medical care they

had received. This is consistent with another study that has investigated this issue [49]. It is also logical to assume that if an egg sharer's judgement was obscured by the offer of free IVF treatment, there would be evidence of people complaining about this afterwards, or at least expressing regret that they had taken part [101]. The data from this study provides strong evidence that they are not being exploited and that their consent is valid. Egg sharers are able to use their own judgements to form their own opinions on the issues surrounding this programme.

Supporters of egg sharing claim there is a significant difference between receiving monetary payments for donation and the egg sharing programme [48]. In this study, the vast majority of egg sharers and their recipients agreed that monetary payments for donation should not be permissible, however most did support a compensatory payment. There was no significant difference in how egg sharers and recipients responded. Prospective donors responded less positively to donors receiving a compensatory payment compared to retrospective donors. This could be explained by them underestimating how much time would need to be spent in the clinic, meaning time off work and travel costs, for which they should be compensated.

Regarding their feelings towards each other, the majority of egg sharers and their recipients responded positively, with the overall picture being one of goodwill in both directions. The vast majority of egg share donors wanted their recipient's treatment to be successful after completing treatment (97.8%). Interestingly, although 85.7% of donors surveyed during their treatment hoped their recipient's treatment was successful, this was statistically significantly less than retrospective responders. Both egg sharers and recipients responded overwhelmingly to feeling 'curious about her'. 96.5% of recipients felt gratitude towards their donor. While most donors and recipients thought about their egg sharing partner during their treatment, this fell significantly in respondents who had completed their treatment. A higher proportion of recipients did feel 'closer' to their donor compared to donors when considering their recipients, and although a minority of responders, more egg sharers reported 'not feeling anything about her' when compared to recipients. This is in contrast to a previous study which found no difference in responses between egg sharers and recipients [60]. These data suggests both egg share

donors and their recipients have an overwhelming feeling of good will towards one another, without being fixated, or thinking too much about each other. This is particularly true after treatment is completed.

4.4.4 Demographic differences between egg sharers and their recipients

There were some key demographic differences between egg sharers and their recipients which has not been reported previously. Both groups were predominantly Caucasian, not religious and employed full-time. The majority of both groups had no children, however more egg sharers had a child compared to recipients.

Although there was no difference in employment status, recipients were significantly higher in educational level, with most recipients having a higher university degree (75.27% vs 58.06%). This contrasts with a previous study, that reported no difference in educational level between egg sharers and their recipients [49]. There was a significant difference in age of donors and their recipients, with recipients on average 9.8 years older. This is unsurprising considering female age is directly related to positive prognosis of assisted reproduction, and that only women under 35 years are allowed to act as donors. Age is also related to annual income and career trajectory. It is therefore unsurprising that recipients earn significantly more money than their egg share donors. For example, 43.70% of recipients earnt > £100,000, compared to only 2.0% of egg sharers in this category. Most egg sharers earnt < £30,000 (54.0%). This is a significant finding and the first study to report this difference, with a previous study not including it as it was deemed inappropriate in piloting [49]. However, it does not mean that egg sharers are poor, desperate women who are forced to egg share against their own moral beliefs. When asked to vote for the single most important motivating factor, the highest selected answer was ‘opportunity to obtain cheaper fertility treatment’. However, a slight majority (52.6%) of egg sharers stated they would participate in the scheme regardless of their ability to pay. As reported above, they do not feel exploited. They also reported they were better informed of the process compared to recipients. Our data strongly suggests they are making an informed decision and taking pro-active steps

to participate in a scheme they rate very positively, rather than choosing to do so only because of a financial predicament.

There were differences in relationship status with significantly more recipients married (71.6% vs 48.9%), and significantly more egg sharers single (13.4% vs 7.9%). Most egg sharers and recipients were in heterosexual relationships, however more egg sharers were in same sex relationships (25.7%) compared to recipients (16.3%), however this was not statistically significant. There are three likely explanations for these findings. First, with numbers of women freezing their eggs for social reasons increasing exponentially in recent years, egg sharers have the option to undergo ovarian stimulation and then freeze any mature oocytes obtained for themselves for future use. Single egg sharers are 35 years and under, and it is likely that they are egg sharing for fertility preservation rather than embarking on single motherhood at that age, although this factor was not surveyed. Second, the number of women embarking on single motherhood by choice is growing, and women choosing to use this route to maternity are usually older women, and therefore requiring donor eggs to conceive [49]. It is worth noting that offspring born in this circumstance will be using DEDS to conceive, and therefore bear no genetic relationship to their parent. Third, lesbian women having IVF treatment are not infertile, and when presenting to fertility clinics at a young age are often ideal candidates to participate in egg sharing. There is the possibility, that lesbian women being over-represented in the egg sharing population could be explained by them being more willing to take part as egg donors in egg sharing schemes, compared to heterosexual women and if so, why would this be? One reason could be that lesbian women need donor sperm to conceive and are therefore more open to the idea of donating their own eggs to help another couple who require donor gametes to conceive, just like they did. These explanations are perhaps unsurprising but do demonstrate the changing landscape of patients accessing IVF, and the assumption that a patient attending for fertility treatment will be in a heterosexual relationship, having struggled to conceive naturally, to be completely outdated.

4.4.5 Experience based on treatment outcome

Concerns that egg share donors whose treatment was unsuccessful would be damaged psychologically were not supported from the findings of this study. In fact, there were very few significant differences between successful and unsuccessful egg share donors in their responses. Current HFEA guidelines allow fertility clinics to disclose to the egg share donor and their recipient about the outcome of each other's treatment [203]. This has been the case for some years now and is a recognition of the rights of gamete donors, including egg sharers. However, not all donors will want to find out this information. Regarding egg share donors in this study, the majority chose to find out whether the recipient's treatment had been successful or not (62.3%). Therefore, a significant minority are still making an active choice to ignore this information they are entitled to. This finding is consistent with the only other study to investigate this since the change in donor anonymity legislation [60]. It is the clinic's responsibility to clearly inform the egg sharer about what information they have access to regarding the recipient's treatment outcome, and also about the details of this information, such as when they can access it, and whether they will be informed about a change in the nature of this information. This could include the recipient having a miscarriage or still birth, as well as coming back for further treatment in the future if she was able to bank frozen embryos with the donor's eggs. This study has shown the heterogeneity in responses regarding an egg sharer's desire to access this information, and therefore it is essential these patients have a full understanding of what exact information is available and when.

For egg sharers whose treatment was unsuccessful, there was no significant difference between treatment outcome, and their responses to whether they would: participate in egg sharing again in the future; recommend egg sharing to a friend or family member who needs fertility treatment; felt well informed of egg sharing; and felt they had sufficient support from the fertility clinic during and after their treatment. However, when asked if they were 'glad they took part', 99.4% of successful egg sharers answered yes, compared to 72.7% of unsuccessful egg sharers, and this reached statistical significance. 14 unsuccessful donors found out their recipient's treatment was successful, and all reported they were happy for their recipients (100%), with the vast majority of this category stating they were glad they took part (85.7%). This category of women represents an important focus of interest, regarding the ethical debate surrounding egg sharing. Contrary to theoretical ethical debate, none of this group of

women express negative psychological feelings, and in fact all state they are happy for their recipient. Although the number in this group is small, it is higher than the only previously published study reporting similar findings [60].

In contrast when a comparison was made between successful and unsuccessful recipients, adverse treatment outcomes did impact negatively on their treatment experiences. Recipients whose treatment was unsuccessful were less likely to recommend treatment to their family and friends; less likely to undergo further fertility treatment; felt less supported by the clinic during their treatment, and afterwards. Despite these differences, it is important to note that the majority of recipients still felt positively about their treatment experiences, albeit in lower proportions. This finding is not a reflection on egg sharing, as the recipients would have almost certainly answered similarly regardless of how they sourced their donor eggs. It should be remembered that recipients have usually undergone multiple fertility treatments with their own eggs, and been told the most likely reason for failing to conceive is due to poor quality of their own oocytes. This is a difficult decision for a lot of couples to reach. It is therefore understandable they are expressing these feelings after unsuccessful treatment with donor eggs, and shows the importance of the emotional and psychological support a clinic offers them after a negative experience, such as ensuring easy access to clinical staff and counselling services after a negative outcome.

4.4.6 Attitudes towards disclosure

Supporting the findings from previous studies, a significant proportion of egg share donors were in favour of openness to children with regard to the nature of their conception, with the majority feeling it was the recipient's right to choose whether or not to disclose this to the child [48, 60]. This implies donors have trust in the parenting skills of their recipient, in contrast to another study which reported donors to be concerned of the parenting skills of the recipient couple [145].

With egg sharers donating with the knowledge of the lack of donor anonymity, it is reassuring that the vast majority of egg sharers were willing to meet their donor offspring in the future, with only 4.1%

preferring no future contact. This is reassuring for recipients and their offspring, who may have concerns regarding the reactions of their donor in the future if they wish to make contact. This raises a hypothetical issue of how the donor may feel in the future if they are not contacted. If they were anticipating and looking forward to future contact, this could bring feelings of disappointment. This issue should be addressed through counselling, where donors should be encouraged to understand their powerlessness regarding whether a child born as a result of their donation is informed of the nature of their conception, and if informed, whether that child would ever wish to make future contact with them.

Regarding recipients, the vast majority intended to disclose the nature of conception to their child, which is encouraging. This is in keeping with the general atmosphere surrounding disclosure and the advice patients are given by counsellors in the UK. It is of course important to understand the difference between actual disclosure rates and intentions to disclose, as it is possible women will change their minds in the future or may feel they haven't found the right time to disclose [204]. Regarding differences between donors and recipients and their responses, more recipients stated they had a right not to disclose the nature of their conception compared to donors. Recipients were also less happy with future contact with their donor and child. More recipients also felt that resulting offspring could be emotionally damaged with future contact, when compared to donors. These findings are in contrast with the only previous study to explore these issues, who reported no differences in responses from egg sharers and their recipients [60]. Counselling at the time of donation should provide realisation of the potential of their child having a same-aged genetic half-sibling, as well as the possibility of themselves, the recipient, or both parties not having children.

This study is the largest to explore the attitudes of egg sharers and their recipients towards disclosure and future contact with resulting offspring. Only longitudinal studies following up such family's years after treatment, will be able to offer conclusive data on actual disclosure rates and family dynamic of egg donor families. Since the legislative change towards donor anonymity from April 2005, the first children born from egg donation treatment will turn 18 in 2023. It will be interesting to see, as these

children turn 18 years of age, whether egg sharers and recipients maintain their attitudes towards openness, and any impact actual or anticipated contact has from both sides.

4.4.7 Strengths and limitations

This is the largest study to investigate the psychosocial issues surrounding the egg sharing scheme, with a total of 186 egg sharers and 190 recipients, leaving a total of 376 responses analysed. A significant proportion of patients were also prospective, in comparison to all previous studies which investigated egg sharers retrospectively only. The response rates were 38.3% of egg sharers and 61.1% of recipients which is high considering the length of the questionnaire and sensitive nature of the topic surveyed [205]. However, the first limitation was of potential sampling bias. Due to the nature of the questionnaire, patients with very positive or negative experiences are more likely to participate, thus leading to potentially significant publication bias [159]. This is further evidenced by 73% of respondents overall having conceived from egg donation, which is significantly higher than the clinic's average live birth rate figure of 54%. Second, all data accrued was from a single centre. The LFC is one of the largest egg sharing centres in the UK and has success rates above the national average [206]. Therefore, the data from this study may not be representative of the programme nationally or internationally. A third limitation relates to the study's methodology. Questionnaires are an efficient and effective way of collecting data from a large number of patients quickly. The questionnaire predominantly consisted of close-ended questions. Interviews with patients would have allowed a greater exploration of emerging themes and subjects of interest, as well as clearing up any inconsistencies. The data presented in this chapter gives significant weight to argue against a lot of concerns that are consistently raised about the egg sharing programme. Studies involving interviews would allow a much deeper exploration of key themes, potentially generating more detailed qualitative data. Finally, there was a lack of responses from minor ethnic groups. However, this is because they are currently donating in far smaller numbers, reflected in the egg donation demographic data of the clinic and nationally, and representing a limitation of the egg sharing scheme, not this study. The issues surrounding lack of donations from different ethnic groups is multi-factorial and outside the scope of this study. However, it is an interesting area of research to ultimately improve egg donation numbers

from these populations. Initial studies should focus on the general public and standard fertility patients from these different ethnicities.

4.4.8 Conclusion

This is the largest study to investigate the psychological issues surrounding egg sharing for donors and recipients. Overall, egg sharers and their recipients are similar groups of women, the majority of whom are pleased to have taken part in the programme. There were also much greater similarities between egg sharers whose treatment had been successful and unsuccessful. It is unsurprising that women who conceived were especially glad to have taken part, however the significant majority of unsuccessful donors were positive about the process, with only a very small minority expressing regret at taking part in treatment. Egg sharers are motivated by the desire to have a baby, obtain cheaper IVF, and to help other women to conceive. Therefore, while financial motives are important in their decision-making process, their motives are multifactorial with altruistic factors playing a similarly important role.

Chapter 5: Study IV

Does egg-sharing have a negative impact on live birth rates of the donor or her recipient?

5.1 Introduction

Healthcare professionals and potential egg share donors consistently report concern that by sharing their eggs they could be jeopardizing their chance of having a baby [57, 58, 61]. Some experts have also suggested that doctors administer gonadotrophins at higher doses to egg share donors to retrieve more oocytes, therefore increasing the risk of the donor suffering with ovarian hyperstimulation syndrome (OHSS) [45]. Alongside receiving fewer oocytes, egg share recipients also report not receiving sufficient eggs as one of their primary concerns, but also consistently mention a degree of apprehension about receiving eggs from infertile women, and that these factors could negatively impact their chances of having a live birth [62]. In addition, egg share donors and recipients could worry that the fertility clinic will provide preferential treatment to their counterpart during their care [63].

Existing studies that have investigated the outcomes from egg sharing have reported opposing findings, emphasising the need for more research into this question. Early studies reported better live birth rates with recipients when compared to their egg sharers [63, 64]. Check et al. (1992) evaluated 28 egg share donors and 22 recipients and reported a significant difference in pregnancy rates per embryo transfer (11.1% for egg share donors, compared to 32.3% for recipients). Miscarriage rates in this study were similar, with 25.0% of donors and 27.2% of recipients having a first trimester miscarriage [64]. This study therefore suggested the higher pregnancy rates amongst recipients cannot be explained by oocyte quality, but possibly due to a negative effect of hyperstimulation or an adverse endometrial environment of the donor [64]. This study did not present any data on hyperstimulation amongst its donors [64]. A study by Ahuja et al. (1996) also showed a significantly higher pregnancy and live birth rate among recipients (n=30) when compared to their egg share donors (n=25). Despite there being no difference in the number of eggs allocated, the fertilization rates, or mean number of embryos transferred, there were more live births in the recipient arm than with egg sharers (30.0% versus 20.0%) [63]. The outcomes of these studies are very low regarding LBRs for both donors and recipients, however this is due to the fact these studies were performed decades ago, when success rates were significantly poorer [63, 64]. Additionally, the number of patients was low in both studies, and the outcomes were also not compared to standard IVF patients [63, 64]. A subsequent study found no difference in live birth rates

between egg sharers, their recipients and standard IVF patients [65]. This study included significantly more patients, and included 192 egg share donors, 274 egg share recipients and 1098 non-egg-sharing standard IVF/ICSI cycles [65]. Supporting these findings, later studies found similar pregnancy and live birth rates between egg sharing and non-egg sharing recipients [62, 66, 67]. One of these studies did report recipients who used egg sharing as their source of donor oocytes, and they received fewer oocytes compared to other recipient sources [62]. Check et al. (2004) performed a retrospective analysis on outcomes of recipients using oocytes from paid donors (n=182) compared to those using egg share donors (n=238) [66]. They found a live birth rate of 48.9% with their paid donors versus 52.1% for their egg share donors [66]. Oyesanya et al. (2009) performed a prospective cohort study where recipients received oocytes from an egg sharer (n=220) or an altruistic donor (n=133). They reported no statistically significant difference in clinical pregnancy rates between egg sharers (28.2%) or altruistic donors (30.1%), although the clinical pregnancy rates were low in both groups. A subsequent study investigated whether egg sharers who donated half their eggs had an inferior outcome compared to IVF patients who were using all their oocytes [67]. This study reported no difference in pregnancy rates between the two groups. However, they found that more women who shared their eggs had to freeze their embryos and not have a fresh transfer due to a higher risk of OHSS, although they did not report rates of actual OHSS [67]. More recently, a study from India reported inferior pregnancy rates for recipients who used egg sharing [68]. A recent study found the outcome of the egg share donors treatment strongly predicted the pregnancy rates of their recipient, however disparities between other treatment outcomes were not investigated [69]. Overall, the findings of studies seem to contradict each other and frustratingly do not consistently report LBR, which is of course the most significant factor.

5.1.2 Aims

The primary aim of this study is to investigate whether egg sharing compromises the chance of the donor or their recipient having successful treatment, with a comparison also being made to the treatment outcomes of standard IVF patients and non-egg share recipients. Secondary aims are to compare cycle characteristics, and therefore fully update the current understanding of outcomes of egg sharers and recipients. LBR will be directly compared between the following groups of patients:

1. Egg-sharers and standard IVF patients
2. Egg-sharing recipients and non-egg-sharing recipients
3. Egg-sharers and egg-sharing recipients

5.2 Materials and methods

5.2.1 Study design

This was a large retrospective cohort analysis of egg share donors, their egg share recipients, other recipients and standard IVF patients undergoing IVF/ ICSI treatment cycles at the LFC (Chelsea, UK). The timeline for data collection was between January 2010 and December 2019.

Patients were therefore divided into four groups:

- Group 1: egg sharers
- Group 2: standard IVF patients
- Group 3: egg share recipients
- Group 4: non-egg share recipients.

Group 1: Egg share donors

All egg sharers who participated between 2010-2019 were included for analysis. To be eligible to participate in the egg sharing programme at the LFC patients must be aged < 35 years, have a body mass index (BMI) 18-29kg/m^2, and have an adequate egg reserve, with an AMH level of > 8 pmol/L. These patients require a negative blood screen (HIV, hepatitis B and C, cytomegalovirus, syphilis, cystic fibrosis and normal karyotype). Before they went ahead as egg sharers, the LFC insists all egg share donors had an assessment by a specialist fertility counsellor. The unit policy is to limit the number of cycles a patient can undergo while egg sharing to four cycles, although egg sharers could undergo more cycles than this on a case by case basis, after discussion in a multi-disciplinary team (MDT) setting. The aim is for the egg share donor and her recipient to have at least four eggs each for their fertility treatment. If an egg sharer produces fewer than eight oocytes, then she has the option of either donating

four oocytes and using the remainder for her own treatment, or retaining all her oocytes and paying a subsidized fee of £2000 for her treatment, which is a significantly cheaper sum than a standard IVF cycle.

Group 2: Standard IVF/ ICSI patients

The standard IVF patient group was retrieved by using women who did not participate in egg sharing and underwent treatment at the LFC in the same time period, therefore retaining all oocytes retrieved for their own treatment. These women were matched for age (< 35 years), BMI (18-29kg/m^2) and egg reserve (AMH > 8 pmol/L).

Groups 3 & 4: Egg-sharing and non-egg-sharing recipients

All women who used oocytes from egg-sharers (group 3) or non-egg-share donors (group 4) between 2010-2019 were included for analysis. Group 3 received a 50:50 share of the eggs available from their egg share donor, who was anonymously matched to them. Group 4 received all eggs from either a known or anonymous donor. Prior to their treatment, all recipients and their partners had a counselling session to go through potential future implications of using donor oocytes to conceive. Recipients had access to limited donor demographic and medical information, including physical appearance, medical history, family history and educational level. The egg donation team at the LFC would be provided with a close-up photograph of the donor and recipient and use this to provide a physical match with the egg share donor and her recipient. The egg donation coordinator at the LFC would attempt to find a suitable match according to the preferences set out by recipients. If the recipient had any issues with the egg donor the team proposed she could of course decline to have treatment using that donor. If a recipient were to decline three consecutive donors the oocyte donor had proposed, then the clinic policy is for the recipient to have another session with our fertility counsellors, to confirm she does want to proceed with fertility treatment using donor oocytes.

5.2.2 Stimulation protocols for egg share donors and standard IVF patients (Groups 1 & 2)

All patients underwent either the long protocol using nafarelin or buserelin mid-luteal pituitary down regulation, or the antagonist protocol. A gonadotrophin (recombinant FSH, HMG or urinary FSH) was administered for ovarian stimulation. 10,000IU of hCG was administered once follicles reached a pre-ovulatory size (18-22mm); 36 hours later, oocyte aspiration was conducted trans-vaginally with ultrasound guidance. Once embryos had cleaved, the best embryo(s) were selected for ET, conducted on day 3 or 5. All patients received pre-vaginal (PV) or per-rectal (PR) progesterone supplementation for two weeks, from the day before ET until the pregnancy test was conducted.

5.2.3 Hormonal replacement for recipients (Groups 3 & 4)

Women who still had ovarian function commenced the oral contraceptive pill from day 2 of the pre-treatment cycle to allow synchronisation with their egg sharer or other donor undergoing ovarian stimulation. A trans-vaginal ultrasound was performed on day 3 or 4 of their cycle, and if the ultrasound was satisfactory, oestradiol supplementation was commenced. A subsequent scan was then performed to confirm adequate endometrial thickness (> 7 mm). All patients received PV/PR progesterone supplementation from 4-6 days prior to embryo transfer, depending on the age of the embryo transferred, until the pregnancy test was conducted.

5.2.4 Outcome measures

The primary outcome measured was LBR. Secondary outcomes included the total dose of gonadotrophin given per stimulation cycle; the mean number of eggs collected; fertilization rate (FR); implantation rate (IR); clinical pregnancy rate (CPR) determined by a transvaginal scan confirming the presence of a gestational sac with a fetal heartbeat from 6 weeks of pregnancy; miscarriage rate (MR); LBR and cumulative LBR (CLBR).

5.2.5 Statistical Analysis

Statistical analysis was performed using Statistical Package for Social Sciences (SPSS version 26.0, IBM). Descriptive statistics including the mean and standard deviation (SD) were calculated for each

continuous variable, and the normal distribution was examined. Analysis of variance (ANOVA) was used to investigate the significance of differences in continuous variables, and Pearson's χ^2 analysis was performed to evaluate outcomes from categorical data. *P*-values <0.05 were considered statistically significant.

5.3 Results

Data was collected for the four groups between January 2010 and December 2019, and 4545 patients were included in the analysis (group 1, n= 670; group 2, n=2777; group 3, n= 765; group 4, n= 333). In total these selected patients underwent 5316 treatment cycles (group 1, n= 756; group 2, n=3293; group 3, n= 906; group 4, n= 361). ***Table 5.1*** shows the cycle characteristics and treatment outcomes of the four patient groups. No donors withdrew their consent to donate their oocytes during their treatment, meaning all allocated oocytes were available for the recipient. There was no difference in age ($p > 0.05$) between egg sharers and standard IVF patients (***table 5.1***). As expected, both groups of oocyte recipients (groups 3 & 4) were older than groups 1 & 2 ($p<0.001$) (***table 5.1***). There was no statistically significant difference in the duration of infertility between egg sharers and their clinically matched standard IVF patients (groups 1& 2) ($p > 0.05$), or between the two recipient groups (groups 3 & 4) ($p > 0.05$), however egg sharers had a significantly shorter duration of infertility when compared to their recipients ($p < 0.001$) (***table 5.1***).

Table 5.1: Treatment cycle characteristics and cycle outcomes

	Patient group				*p*–values between groups		
	1	2	3	4	1 v 2	3 v 4	1 v 3
Number of patients	670	2777	765	333	-	-	-
Number of stimulation cycles started	756	3293	906	361	-	-	-
Mean age (±SD)	31.44 (±3.43)	32.29 (±3.26)	43.04 (±3.17)	42.18 (±3.43)	0.121 (NS)[a]	0.318 (NS)[a]	p<0.001[a]
Duration of infertility (years) (±SD)	2.72 (±2.46)	2.40 (±1.79)	4.07 (±1.87)	3.98 (±2.03)	0.247 (NS)[a]	0.227 (NS)[a]	p<0.001[a]
Mean number of oocytes collected (±SD)	15.34 (±6.13)	14.17 (±6.21)	NA	NA	0.109 (NS)[a]	-	-
Mean number of oocytes donated (±SD)	7.37 (±2.92)	NA	NA	NA	-	-	-
Mean number of oocytes received	NA	NA	6.61 (±2.18)	9.31 (±2.98)	-	p<0.001[a]	-
Mean total gonadotrophin dose (IU) (±SD)	2560.29 (±1079.6)	2496.81 (±1187.2)	NA	NA	0.115 (NS)[a]	-	-
Mean days of stimulation (±SD)	11.95 (±2.32)	11.63 (±2.65)	NA	NA	0.414 (NS)[a]	-	-
Mean number of oocytes used in IVF (±SD)	6.87 (±3.27)	11.41 (±6.29)	NA	NA	p<0.001[a]	-	-
Mean number of day 3 embryos (±SD)	4.52 (±2.81)	7.43 (±4.84)	4.50 (±2.18)	6.20 (±3.45)	p<0.001[a]	p<0.001[a]	0.376 (NS)[a]
Mean number of embryos transferred (±SD)	1.25 (±0.71)	1.17 (±0.70)	1.38 (±0.89)	1.26 (±0.92)	0.347 (NS)[a]	0.107 (NS)[a]	0.111 (NS)[a]
Mean FR (%)	78.02	74.73	71.4	72.8	0.091 (NS)[b]	0.376 (NS)[b]	0.094 (NS)[b]
Mean IR (%)	44.32	43.94	44.7	45	0.459 (NS)[b]	0.289 (NS)[b]	0.314 (NS)[b]
CPR per ET (%)	63.61	60.51	57	59.7	0.114 (NS)[b]	0.385 (NS)[b]	0.092 (NS)[b]
MR per ET (%)	22.91	24.71	26.5	30.6	0.420 (NS)[b]	0.263 (NS)[b]	0.184 (NS)[b]
LBR per ET (%)	49.10	45.61	41.9	41.4	0.085 (NS)[b]	0.881 (NS)[b]	p<0.05[b]
CLBR per stimulation cycle (%)	51.72	55.60	51.3	62.7	p<0.05[b]	p<0.001[b]	0.844 (NS)[b]

Group 1= egg share donors; Group 2= standard IVF patients; Group 3= egg-sharing recipients; Group 4= non-egg-sharing recipients
SD= standard deviation; NA= not applicable; NS= not statistically significant (p>0.05); FR= fertilisation rate; IR= implantation rate; CPR= clinical pregnancy rate; MR= miscarriage rate; LBR= live birth rate; CLBR= cumulative live birth rate
[a]Statistically significant p value using ANOVA test
[b]Statistically significant p value using Pearson's χ^2test

There was no difference in number of oocytes collected between egg sharers (15.3 ± 6.1) or their clinically matched standard IVF patients (14.2 ± 6.2) (p > 0.05) (***figure 5.1(i)).*** There was also no difference in the mean number of days injecting gonadotrophins, or the total dose of gonadotrophin administered between the two groups of patients who had ovarian stimulation treatment. The mean number of oocytes egg share donors gave to their recipients was 7.4 ± 2.9 oocytes (***table 5.1***). Predictably, this meant standard IVF patients having 66% more eggs available to use in their treatment than egg sharers (11.4 ± 6.3 vs 6.9 ± 3.3) (p < 0.001) (***table 5.1***). This resulted in standard IVF patients having more day 3 embryos available for transfer (7.4 ± 4.8 vs 4.5 ± 2.8, p < 0.001) (***figure 5.1(ii)***). Group 3 (egg share recipients) also had significantly fewer eggs donated to them than group 4 (non-egg

sharing recipients) (6.6 ± 2.2 vs 9.3 ± 3.0, p < 0.001) (***table 5.1***); and less day 3 embryos available for transfer (4.5 ±2.2 vs 6.2 ± 3.5, p < 0.001) (***figure 5.1(ii)***). Therefore, on average non-egg sharing recipients used 37.3% more oocytes during their treatment and had 37.8% more day 3 embryos available to transfer compared to egg share recipients. When comparing egg sharers to their recipients (groups 1 & 3), there was no difference in the number of eggs allocated (6.9 ± 3.3 vs 6.6 ± 2.2, p=0.379) (***table 5.1***), or the number of day 3 embryos available for transfer (4.5 ± 2.8 vs 4.5 ± 2.2, p=0.376) (***figure 5.1(ii)***). There was no statistically significant difference in the number of embryos transferred between any of the four groups (***figure 5.1(iii)***).

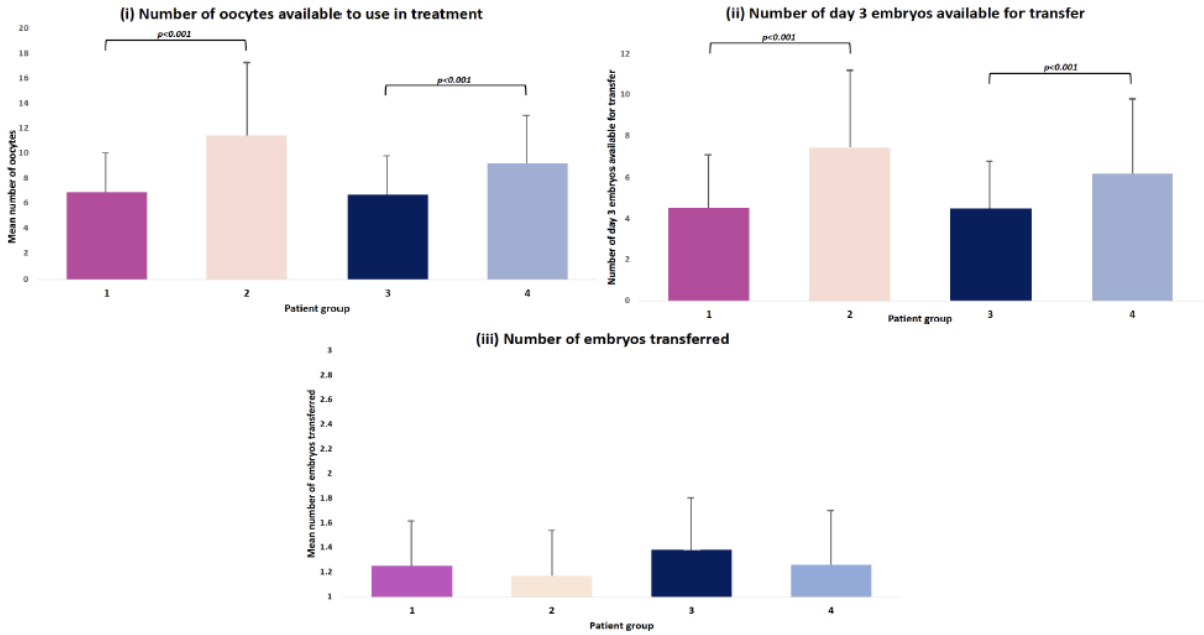


Figure 5.1*. Bar graphs comparing (i) the mean number of oocytes used in treatment; (ii) the mean number of day 3 embryos available for transfer; (iii) the number of embryos transferred. One-way ANOVA tests were conducted to investigate statistical significance. All data is presented as mean +/- SD bars*

There was no difference in FR or IR between all four groups (***figure 5.2***). ***Figure 5.3*** reports pregnancy outcomes for the different patient groups. There was no statistically significant difference in CPR, MR or LBR in egg share donors (group 1) compared to standard IVF patients (group 2) (***figure 5.3***). The CLBR was 3.9% higher in the clinically matched standard IVF patient group, compared to egg share donors, which reached statistical significance (55.6% vs 51.7%, p < 0.05) (***figure 5.3(iv)***). Similarly, there were no difference found in CPR, MR or LBR per fresh embryo transfer between egg sharing recipients (group 3) and non-egg sharing recipients (group 4) (***figure 5.3***). However, non-egg sharing

recipients had a higher CLBR when compared to egg share recipients which reached statistical significance (62.7% vs 51.3%, p < 0.001) (***figure 5.3(iv)***). Egg sharers had a statistically significant LBR (49.1% vs 41.9%, p < 0.01) per fresh embryo transfer compared to their recipients, while there was no difference in MR (p > 0.05) or CLBR (p > 0.05) (***figure 5.3***).

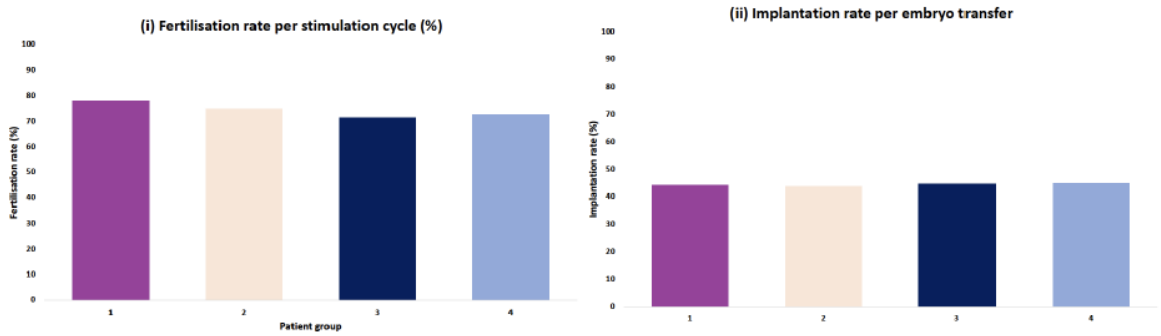


Figure 5.2. Graphs demonstrating the fertilization rate and implantation rate between the 4 groups. Analysis was performed using Pearson's chi-squared test. No comparisons reached statistical significance.

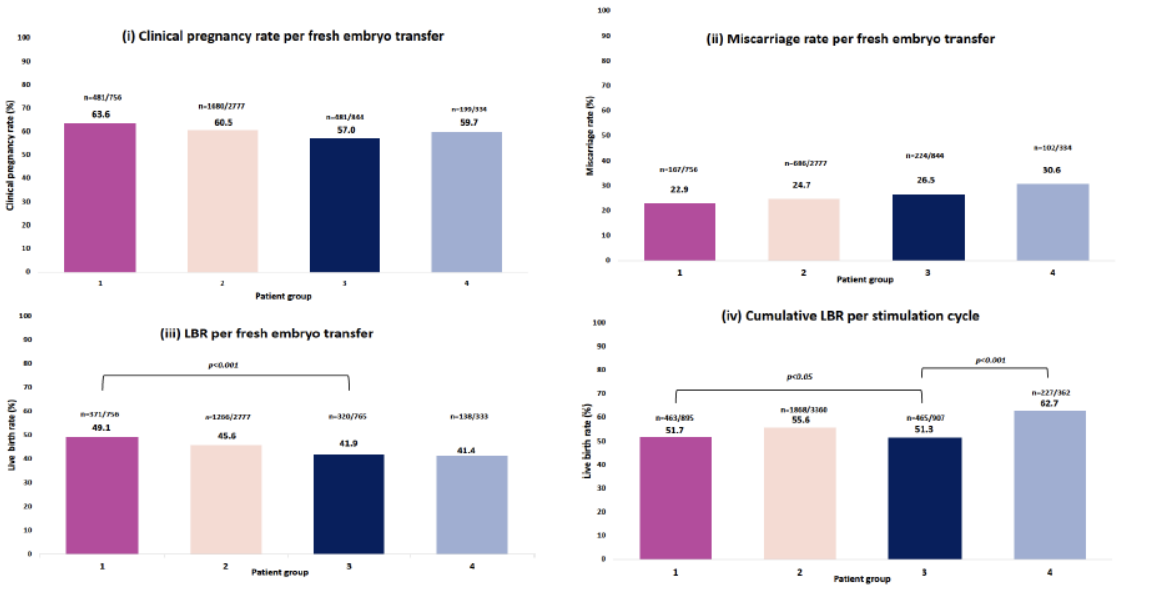


Figure 5.3. A series of graphs showing the different pregnancy outcomes between groups 1-4. Analysis was performed using Pearson's chi-squared test. Statistically different results were identified in LBR between groups 1 and 3 (p<0.001) and in CLBR between groups 1 and 3, and groups 3 and 4 (p<0.001).

5.4 Discussion

This study reports that egg sharing did not jeopardize the LBR per embryo transfer for egg share donors or their anonymously matched recipients, when compared to clinically matched standard IVF patients and non-egg sharing recipients. Nevertheless, it must be noted the CLBR was slightly lower in the egg sharers compared to standard IVF patients, meaning a small proportion of egg sharers will need to undergo further stimulation cycles to have a live birth. This is the first study to analyse these four patient groups together and is the largest to report on egg sharing outcomes, analysing a total of 5316 treatment cycles. The study findings for egg sharers and recipients will be discussed in detail below.

5.4.1 Egg sharer donors

Healthcare professionals have theorized that an egg sharer will likely decrease her chance of successful fertility treatment by giving away a proportion of her oocytes [47, 61]. However, data from this study revealed no statistically significant difference in FR, IR, CPR, MR or LBR between egg sharers and their clinically matched standard IVF patients. This study's findings corroborate other studies that reported no difference in LBR between the different patient groups [62, 65, 67]. Older studies with low patient numbers did show a reduced PR and LBR among egg sharers, when compared to their recipients [63, 64].

The number of day 3 embryos available for transfer however was less for egg share donors (group 1) when compared to their clinically matched standard IVF patients (group 2). This meant standard IVF patients had a higher CLBR of 55.60% compared to 51.72% for egg sharers, which reached statistical significance. This is unsurprising since a standard IVF patient has more eggs available to use in her fertility treatment, however this is the first study to report this finding regarding CLBR. It is debated that by increasing the number of eggs required for an egg share donor to be eligible to participate in egg sharing, the CLBR could be improved. One study compared the impact having two different policies regarding egg sharing would have on treatment outcome, with either ≥ 8 or ≥ 12 eggs needing to be retrieved for women to be permitted to participate in egg sharing [207]. This study found no significant difference in LBR between the ≥ 8 or ≥ 12 eggs groups, but there was significantly higher cancellation

rate of 29.7% in the policy where 12 oocytes were required, compared to 9.7% in the group requiring 8 eggs. The existing policy at LFC is that a minimum of 8 eggs are required, and are then shared equally between the egg sharer and recipient. Only 3.4% of egg share donors collected ≤ 8 oocytes in this study, meaning 96.6% of patients produced enough oocytes to egg share. If the number of eggs required to participate were increased to a minimum number of 12 or 15 eggs, then the potential cancellation rate would rise significantly to 29.5% and 54.4% respectively (***table 5.2***). Increasing this threshold would therefore substantially restrict a patient's accessibility to the egg sharing programme. This would also have a significant negative impact on the clinic's egg share numbers [207]. This study provides valuable data to allow fertility clinics to advise egg sharers that they have the same LBR per embryo transfer in comparison to clinically matched standard IVF patients, but have a 3.9% lesser CLBR, meaning a small proportion of them will require a further round of ovarian stimulation treatment, which they might not have needed if they did not participate in the egg sharing programme.

It therefore appears the current policy that a minimum of eight eggs is the ideal threshold for the egg sharing programme.

Table 5.2. *A table comparing the numbers of oocytes collected by egg-sharers in stimulation cycles (n=756), according to different minimum theoretical thresholds*

Minimum no. of oocytes	Proportion of stimulation cycles producing sufficient number of oocytes
<8	3.4% (26/756)
≥8	96.5% (730/756)
≥12	70.5% (533/756)
≥15	46.6% (352/756)

Critics of egg sharing have also suggested that to increase the number of eggs collected, fertility specialists will give inappropriately high doses of gonadotrophins, thus exposing their egg sharers to a higher risk of developing OHSS [55]. Data from this study found no difference in number of days of stimulation required, dose of gonadotrophin used, or number of oocytes collected, when egg sharers were directly compared to their clinically matched standard IVF patients. This corroborates the findings from other studies [65, 208]. This is encouraging data and reveals egg sharers are not given inappropriate drug regimens or hyperstimulated to produce more eggs, but instead put on the same

gonadotrophin dose as their clinically matched standard IVF patients, and therefore not put at higher risk of developing OHSS.

At LFC, all egg sharers and their recipients receive implication counselling prior to starting their fertility treatment, to help ensure their understanding of and commitment to the egg sharing programme. Egg sharers are aware they have the right to withdraw their consent from participating up until their recipient's eggs have been fertilized with sperm. If the egg sharer produces less than the minimum eight oocytes, she has two options. Firstly, she can donate four eggs and use the remaining oocytes for her own treatment. Secondly, she can use all the oocytes retrieved for her own fertility treatment. By choosing the second option, the patient would be leaving the egg sharing programme and become a standard IVF patient and be charged a fee for the treatment received. Between 2010-2019 only 3.4% of egg share donors faced this difficult clinical dilemma.

The subsidisation of costs egg sharing provides increases the number of patients who can access IVF, when cost is a significant issue for them, and due to increasingly stringent CCG restrictions regarding who qualifies for NHS funded IVF. Long NHS waiting lists and therefore time to access government funded treatment is another issue for a lot of patients, who may well have concerns regarding their 'ticking biological clock'. There are strong and understandable motivations for women to participate in egg sharing for their own needs [57, 58]. However, studies increasingly report altruistic motives to be as strong a reason for women to egg share as the financial motivations listed above [57, 58]. Consequently, despite this study reporting a 3.9% lower CLBR, patients who decided to egg share are likely to identify the overall benefits of the programme, considering any surplus embryos frozen from one round of stimulation a bonus, rather than an expectation.

5.4.2 Egg share recipients

With a consistent trend towards postponing first time motherhood since the 1950s in the UK, more women are not able to have a child using their own eggs and require an egg donor to conceive [209]. Supply for donor oocytes falls far short of demand in most developed countries, including the UK. The

egg sharing programme provides a viable solution to this shortage, where monetary payments for donors are illegal and financial payments are significantly restricted [210]. Studies have consistently found oocyte recipients to be skeptical about receiving oocytes from egg share donors, as they are concerned that receiving only a proportion of a donor's oocytes could negatively impact their own treatment outcome [62, 211].

One concern raised by experts regarding egg sharing, is that a fertility clinic will prioritize the recipient, who is paying for her treatment, over the egg share donor during the allocation of the oocytes retrieved. Data from this study revealed no difference in the number of oocytes allocated, FR, IR, CPR, and MR were no different between the egg share donor and their recipient. Egg share recipients did have a significantly inferior LBR per embryo transfer compared to their egg sharer, which was an unanticipated finding (49.10% vs 41.90%, $p < 0.05$). Oocytes retrieved from egg sharing are allocated at random, as it is not possible to accurately assess egg quality immediately after oocyte retrieval, meaning this theoretical concern of preferential treatment regarding allocation of eggs is not only unlikely, but not practically possible. Of note, there was no difference in CLBR between egg sharers and their recipients (51.72 vs 51.30, $p > 0.05$). The data from this study is in contrast to earlier studies who reported better LBR for recipients compared to their egg share donors [63, 64, 212].

Another issue surrounding egg sharing that is regularly raised is that egg share recipients feel they will receive poorer quality eggs from egg share donors as they are infertile with no proven fertility, compared to recipients using purely altruistic donors [62, 213]. Egg share recipients received fewer eggs when compared to other recipients (6.61 vs 9.31, $p < 0.001$), which meant they had fewer day 3 embryos available for potential transfer (4.50 vs 6.20, $p < 0.001$). This resulted in egg share recipients having a lower CLBR (51.3% vs 62.7%, $p < 0.001$). This data reveals that egg share recipients are at no disadvantage per embryo transferred, but as they have fewer eggs compared to other recipients they may need to undergo further treatment, which of course increases emotional and financial burdens. This issue should be weighed against the obvious advantages of the egg sharing programme, which include the potential to address a significant supply issue, lowering waiting times to access donor eggs and

minimising the need for non-patient donors to undergo unnecessarily invasive treatment. Additionally, egg donor banks will often choose to divide eggs collected from their donors between two recipients, with this strategy showing no negative impact on success per embryo transfer, supported by this study [208, 213, 214]. This practice with altruistic donors, similar to egg sharing for recipients, maximizes treatment efficacy, decreases oocyte donor shortages and avoids the potential non-usage of donor oocytes [214]. However, it is significant to mention that these studies did not report CLBR.

Summarising, egg share recipients should be informed of an overall high LBR per embryo transfer of 41.9% and a CLBR of 51.3%. It would seem that as egg share donors are highly selected for age and adequate egg reserve, the reduced number of oocytes available for their recipient are still enough to offer excellent outcomes for both the egg share donor and her recipient.

5.4.3 Conclusion

The number of egg donors falls far short of demand in the UK, and the egg sharing programme has the potential to decrease this deficit and increase the pool of oocyte donors. This study shows egg sharing does not reduce the chances of the egg share donor or their recipient having a baby from a treatment cycle. However, egg sharers may require additional ovarian stimulation cycles to have a positive outcome. With government funding for fertility treatment continually declining in the UK, the egg sharing programme gives more patients the chance to access fertility treatment, while not putting themselves through the small risk of complications, that is relevant to purely altruistic donors. The data presented from this study should provide reassurance to potential egg share donors and egg share recipients, as well as to GPs and general gynaecologists who have the potential to refer fertility patients towards egg sharing. Egg sharing is currently the most efficient way fertility clinics have of maximising the use of the very precious resource of donor oocytes.

Chapter 6: Study V

Investigating attitudes towards oocyte donation amongst the general public: a systematic review (study Va) and survey of the general public (study Vb)

Study Va: Investigating attitudes towards oocyte donation amongst potential donors and the general population: a systematic review

6a.1 Introduction

Countries have very different legislation and regulation regarding sperm and egg donation. In the UK, financial payments for donation are illegal, with women who donate their eggs given a compensatory payment to cover their travel costs and time missed at work, with this capped at £750 [104]. Some countries, such as the USA, allow significant monetary payments to women who agree to donate their eggs [38]. Some countries, such as China and Israel, only allow donation of oocytes that are considered surplus from women already having IVF treatment. In general terms, Islamic countries do not allow any form of gamete donation for their fertility patients [197].

Oocyte donation and the associated psychological issues egg donation patients endure have been analysed in several studies. This thesis has performed two systematic reviews of the literature on this topic (***Chapter 2: Study I***). However, it is also important to understand the general public's views, as well as potential donors. This will allow a knowledge of a much wider viewpoint surrounding this heavily debated area of reproductive medicine.

6a.1.2 Aims

This systematic review aims to define psychosocial aspects of the general public and potential oocyte donors which includes their motivations, concerns, and attitudes towards oocyte donation. Additionally, this systematic review explores potential donor's views surrounding donor anonymity. An improved understanding of these psychosocial aspects has the potential to assist fertility units in increasing their oocyte donor numbers and improve patient experience. It is the only systematic review to exclusively explore the general public and potential oocyte donors.

6a.2 Methodology

6a.2.1 Search strategy

A systematic search was performed using PRISMA guidelines [142]. Three computerized databases were systematically searched for peer-reviewed journals published in English language (PubMed, EMBASE and PsychINFO). The search and selection strategy are presented in ***table 6a.1***, with the search terms used in all possible combinations. The search was enhanced by identifying additional studies referenced in studies that were reviewed during the search process.

Table 6a.1: Search and selection strategy for systematic review of psychological aspects of potential egg donors.

Databases searched	PubMed, EMBASE, PsychINFO
Search keywords	Exposure: [oocyte donation OR egg donation OR gamete donation] AND [prospective OR potential] AND [psychosocial OR psychological OR attitudes OR motivations OR beliefs OR reasons OR ethics] NOT [recipient OR oocyte sharer OR oocyte sharing OR patient sharer OR gamete sharing OR known donor OR volunteer donor OR anonymous donor OR commercial donor]
Other sources	Additional studies were identified through references identified from included studies and reviews
Inclusion criteria	(1) Published in English in peer reviewed journals (no date cut off) (2) Studies focusing on ARTs only (3) Studies focusing on psychosocial well-being
Exclusion criteria	(1) Studies not in English (2) Full article not available (3) Studies not investigating psychosocial aspects of oocyte donation. Studies that focus on prospective oocyte donors, sperm donors, donor offspring, practitioners, researchers attitudes and fertility 'travellers'
Categories of studies	(1) Psychosocial aspects of potential oocyte donors from patient population (2) Psychosocial aspects of potential oocyte donors from non-patient populations

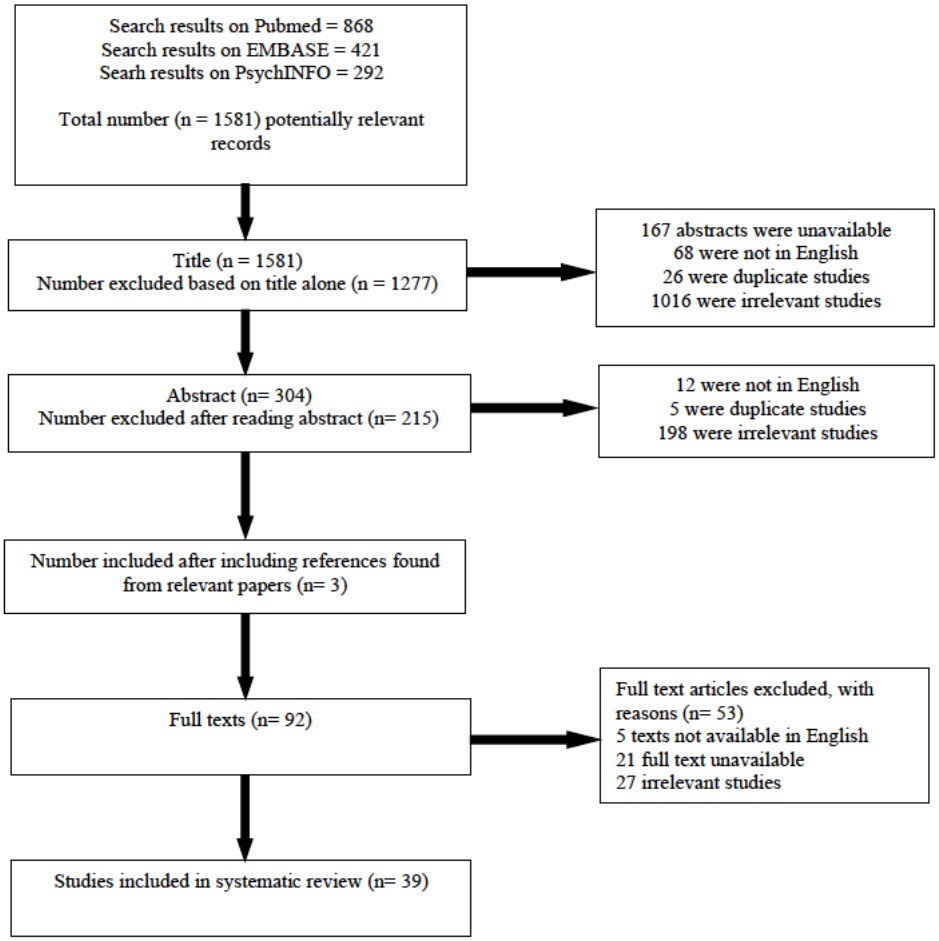
6a.2.2 Study selection

Egg donation is a relatively recent treatment, so no time restrictions were placed on date of publication and inclusion. This systematic review aimed to analyse all available data on the subject, meaning no studies were excluded based on study design. Only peer-reviewed studies published in English were included for analysis. This review focused on the general public and potential egg donors, meaning the following studies were excluded: (i) those that studied actual egg donors; (ii) sperm donors; (iii) donor offspring, (iv) fertility 'travellers'; (v) and attitudes of healthcare professionals or researchers towards egg donation.

6a.2.3 Study screening

All manuscripts identified following the initial search (n=1581) were independently reviewed by two authors based on the agreed inclusion and exclusion criteria. After applying the inclusion and exclusion criteria to the title alone, 1277 studies were excluded. The abstracts were then screened, with 92 studies deemed suitable for further evaluation for inclusion (***figure 6a.1***). An additional three studies were identified from the references of studies reviewed for inclusion. After full screening by two authors independently, a total of 39 studies were included in this systematic review. Any disagreement regarding the study screening was settled by discussion. The study screening procedure was cross-checked by the senior author (M-Y.T).

Figure 6a.1: PRISMA information flow diagram for the systematic review of psychosocial aspects of potential oocyte donors



6a.2.4 Data extraction

A data extraction spreadsheet was designed by S.P and T.B-M and agreed between the authors. The selected studies were extensively reviewed, with relevant data extracted from each study and inputted into the spreadsheet. Information collected included: (i) author details; (ii) publication year (iii) country of origin; (iv) study aim(s); (v) sample size; (vi) methodology used; (vii) sample characteristics; (viii) outcome measures and (ix) summary of findings. Any disagreements regarding the data extraction process were resolved by discussion, with the final decision made by the senior author (M-Y.T). Data were analysed using thematic analysis to extrapolate central issues [143].

6a.3 Results

6a.3.1 General findings and demographics

The study sample, country of origin, methods and aims can be found in ***table 6a.2*** (summarising studies on potential patient and potential non-patient oocyte donors) and ***table 6a.3*** (summarising studies on potential non-patient oocyte donors only). The findings from individual studies are discussed in detail in this section and are therefore not included in ***table 6a.3*** or ***table 6a.3***.

39 studies were identified which investigated patient and non-patient populations psychosocial attitudes towards oocyte donation, with sample sizes ranging from n=8 to n=2110 respondents. A total of 29 studies used questionnaires and 10 studies used interviews to collect their data. Eight studies used validated or pre-existing interview or questionnaires. The majority of these studies were performed in the UK (n=13) and the USA (n=8). Other countries who investigated this topic were Sweden (4), Australia (2), Brazil (2), Greece (2), Turkey (2), Argentina (1), Belgium (1), Germany (1), Netherlands (1), India (1), Iran (1), Iran and UK (1).

Thematic analysis was performed and identified several themes including knowledge, motivations, deterring influences, demographic differences in views towards donation, and attitudes on disclosure and donor anonymity.

Table 6a2: *Characteristics of studies with potential donors.*
[a]Unstandardised questionnaire with no reported measure of validity or reproducibility; [b]Qualitative interview with no reported measure of validity or reproducibility; [c]Data analyses did not distinguish between different oocyte donor groups; [d]Using pre-existing interview or questionnaire tool.

Study	Country	Sample	Method	Research question
Adsuar et al. (2005)	USA	122 potential anonymous oocyte donors	Interviews[b]	To assess wishes regarding disposition of oocytes and embryo management relating to possible clinical scenarios
Bakker et al. (2017)	Netherlands	92 potential oocyte donors approaching IVF clinic to donate	Interviews[d]	Demographic characteristics and donation motivations in women approaching IVF clinic to donate
Baluch et al. (1994)	UK & Iran	100 Iranian women (50 fertile and 50 infertile) and 75 British women (25 infertile and 50 fertile)	Questionnaires[a]	Investigate how fertile and infertile British and Iranian women regard third party involvement in fertility treatment
Baykal et al. (2008)	Turkey	368 infertile women	Questionnaires[a]	Investigate infertile population attitudes towards gamete donation and surrogacy
Bharadwaj (2003)	India	43 infertile patients and clinicians	Interviews[b]	Explore the experiences of infertility treatment for Indian fertile populations
Bolton et al. (1991)	UK	53 infertile patients receiving oocyte donation; 134 infertile patients receiving donor insemination; 168 potential patient donors; and 44 general	Questionnaires[a]	Investigate differences in fertile and infertile population attitudes towards oocyte donation

		population (290 women and 190 men, unknown gender ratio in each group)		
Gezinski et al. (2016)	USA	92 potential oocyte donors	Questionnaires[a]	Explore women's motivations to donate eggs, assess awareness and knowledge of egg donation prior to entry into the egg donation programme and explore attitudes towards egg donation
Gezinski et al. (2016)	USA	40 potential oocyte donors	Questionnaires[a]	To assess how potential egg donors market themselves to intended parents
Kan et al. (1998)	UK	501 women: 356 women who did not donate ('non-donors') and 145 women who donated their oocytes ('donors')	Questionnaires[a]	Explore demographics and reasons why potential oocyte donors did not donate
Kazem et al. (1995)	UK	258 women (97 fertile; 113 infertile; 20 recipient mothers; and 28 oocyte donors) (and 117 men)	Questionnaires[a,c]	Investigate differences in fertile and infertile, men and women's attitudes towards oocyte donation
Lindheim et al. (2001)	USA	537 prospective oocyte donors (380 who later received 2500 USD and 157 oocyte donors who later received 5000 USD)	Questionnaires[a]	Investigate the motivations of potential oocyte donors entering an assisted reproduction programme-comparing altruistic and financial incentives in two groups receiving 2500 and 5000 USD
Lyall et al. (1995)	UK	870 women attending a family planning centre, 160 women attending an abortion clinic and 180 women attending a fertility clinic	Questionnaires[a]	Investigate infertile and fertile population attitudes towards donated eggs and ovarian tissue from donors, cadavers and fetuses
Oskarsson et al. (1991)	UK	222 infertile couples undergoing IVF	Questionnaires[a]	Attitudes towards gamete donation amongst infertile couples

Svanberg et al. (2012)	Sweden	181 potential oocyte donors (and 119 sperm donors) prior to donation	Questionnaires[d]	To study motives and ambivalence towards donation prior to donation
Straehl et al. (2017)	Brazil	69 infertile women undergoing fertility treatment	Questionnaires[a]	To assess the views of infertile women towards oocyte donation and ART
Urdapilleta et al. (2001)	Argentina	55 infertile patients on waiting list for oocyte donation; 35 infertile patients who can use their own oocytes; and 67 fertile women	Questionnaires[a]	Investigate fertile and infertile population attitudes towards oocyte donation
Waldby and Carroll (2012)	Australia	20 IVF patients and 5 patients who had previously donated oocytes	Interviews[b]	To understand IVF patients' and reproductive donors' perceptions of oocyte donation for stem cell research
Waldby et al. (2013)	Australia	43 potential donors: 20 IVF patients, 5 reproductive oocyte donors and 18 nonpatient women	Interviews[b]	To assess understanding and ideas of altruistic, reimbursed, subsidized, compensated and paid donation for both reproductive and research eggs
Westlander et al. (1998)	Sweden	50 IVF patients; 62 patients under investigation for infertility; 50 attending maternity unit after delivery; 50 attending family clinic for therapeutic termination; and 44 patients with Turner syndrome	Questionnaires[a]	Investigate fertile and infertile population attitudes towards oocyte donation
Zweifel et al. (2006)	USA	32 anonymous oocyte donors pre- and post-donation	Questionnaires[a]	Explore attitudes regarding disposition of oocyte and embryo before donation (and post donation)

Table 6a3: *Characteristics of studies from the general population.*
[a]Unstandardised questionnaire with no reported measure of validity or reproducibility; [b]Qualitative interview with no reported measure of validity or reproducibility; [c]Data analyses did not distinguish between different oocyte donor groups; [d]Using pre-existing interview or questionnaire tool.

Study	Country	Sample	Method	Research question
Brett et al. (2008)	UK	143 females from	Questionnaires[a]	Investigate the impact of removal of donor anonymity on willingness to donate
Culley et al. (2007)	UK	67 women (and 10 men) from British South Asian background	Focus groups (using thematic analysis)	Explore the meaning of infertility for British South Asians
Chliaoutakis et al. (2002)	Greece	185 females (and 180 males) from general population	Interviews[b]	Investigate population attitudes and intentions towards oocyte donation and surrogacy
Chliaoutakis et al. (2002)	Greece	185 females (and 180 males) from general population	Interviews[b]	Investigate population attitudes and intentions towards oocyte donation and surrogacy
Espirito Santo et al. (2013)	Brazil	1565 general population: 1284 women (and 281 men)	Questionnaires[a]	To assess the opinions of the Brazilian population about incentives for oocyte donation
Isikoglu et al. (2006)	Turkey	232 females (and 168 males) from general population	Questionnaires[d]	Investigate population attitudes towards oocyte donation amongst Muslim population

Kailasam et al. (2001)	UK	428 women (and men) from the general population	Questionnaires[a]	Investigate population attitudes towards gamete donation
Khalili et al. (2006)	Iran	200 women and men from general population (100 Christians and 100 Muslims)	Questionnaires[a]	Investigate ethnic differences in attitudes towards oocyte donation
Lee et al. (2017)	USA	1427 women (and men) from general population	Questionnaires[a]	To determine public opinion on gamete donor compensation
Lessor et al. (1990)	USA	501 women (and men) from general population	Questionnaires[a]	Investigate public attitudes towards oocyte donation between sisters
Purewal and van den Akker (2006)	UK	101 women from general population	Questionnaires[d]	Investigate ethnic differences in the importance of altruism and willingness to donate
Purewal and van den Akker (2009a)	UK	349 women from general population	Questionnaires[d]	Investigate population attitudes towards oocyte donation and examine the link between oocyte donation intentions and reasons for parenthood
Purewal and van den Akker (2009b)	UK	8 fertile parous and nulliparous women from White and South Asian backgrounds	Interviews[b]	Assess the meaning of oocytes and oocyte donation for treatment and research among non-patient women in the UK
Purewal and van den Akker (2010)	UK	253 women from general population	Questionnaires[d]	To investigate non-patients attitudes and intentions to donate oocytes for research

Svanberg et al. (2003a)	Sweden	724 women from general population	Questionnaires[a]	To explore attitudes towards oocyte donation and factors affecting willingness to donate
Svanberg et al. (2003b)	Sweden	729 women (and 556 men) from the general population	Questionnaires[a]	Investigate population attitudes towards oocyte donation
Stevens and Hayes (2010)	USA	330 female undergraduates	Questionnaires[a]	To evaluate the perceptions of young female students regarding oocyte donation
Stobel-Richter et al. (2009)	Germany	2110 women (and men) from general population	Intterviews[d]	To determine opinions and attitudes of the German general population towards the treatment methods of reproductive medicine: egg donation, surrogate mothering, and reproductive cloning and opinions regarding disclosure
Stoop et al. (2011)	Belgium	1914 women from general population	Questionnaires[d]	To assess public attitudes and intentions towards considering undergoing oocyte cryopreservation and subsequent donation

6a.3.2 Knowledge of egg donation

Perhaps unsurprisingly, even early studies reported the majority of their participants have at least heard of assisted reproductive techniques [215-217].

Several studies have investigated both fertility patient's and the general public's awareness and knowledge regarding egg donation treatment. However, studies have illustrated that perceived knowledge of egg donation treatment is often poor [218-223], particularly among those without fertility issues [224]. Isokoglu et al. (2006) reported less than one-third of their Turkish population had any knowledge pertaining to oocyte donation. Interestingly, knowledge about the option of oocyte donation was poor amongst infertile couples undergoing IVF treatment [220]. Stevens et al. (2010) found that 38% of women undergoing IVF treatment had 'very little knowledge' regarding egg donation treatment. A recent study also reported 6% of their fertility patients had 'never heard' about oocyte donation [222]. However, a relatively limited knowledge of oocyte donation does not appear to hinder an individual's hypothetical intention to donate eggs [219], nor their willingness to give their opinions on the subject [215, 221, 225].

Views on egg donation

Studies largely reported positive views towards egg donation, particularly amongst the general public who had no fertility issues, with 50.8–91.8% of non-patient participants reporting generally positive views regarding egg donation [201, 215, 217, 220, 224, 226-231]. However, it must be mentioned that total opposition to egg donation was reported by a significant minority of participants (11-40%) in four studies [220, 227, 228, 230]. Concerns towards egg donation were also raised by respondents in several other studies, with some consistent issues towards egg donation discussed below [221, 223, 231-233].

6a.3.3 Motivations to consider donation

Several studies explored what circumstances would potentially motivate women to donate their eggs. The two most consistently raised motives were altruism and financial gain, with other motivations identified including personal experience of fertility issues through family or friends, passing on their

genetic material to offspring and the significance of a potential relationship with an infertile woman or couple.

Altruism

Reassuringly, studies investigating women who were considering donation reported largely altruistic motivations, with 82-98% of study participants stating altruism as their main reason to donate their eggs [116, 221, 231, 232, 234-238]. Purewal et al. (2010) divided their participants into groups of 'probable', 'possible', and 'non-donors' and reported altruism was not a significant factor for being in the 'probable' or 'possible' group.

Financial

Monetary payments were widely discussed and considered a significant motivation for potential egg donors in a number of studies, however this differed significantly depending on the country the study was performed in [221, 232, 239, 240]. Gezinski et al. (2016) found financial need was the second most common reason to donate, with 48% of respondents reporting this motivating factor. However, participants rarely reported financial compensation as their primary motivating factor [232]. A study from Brazil found the general population felt a lack of payment was responsible for the lack of egg donors in their country, and that financial incentives could improve egg donor numbers [239].

In contrast, many studies from Europe and other parts of the world have reported ambivalence towards payment for donor eggs [116, 216, 217, 224, 229, 232, 241]. Waldby et al. (2013) reported the majority of their Australian population were against introducing payments for the donation of gametes, with the majority reporting only those willing to donate altruistically should be permitted [241]. Westlander et al. (1998) found most of their respondents felt donors should have their medication cost and loss of income compensated, rather than receive payment for their donation. Another study reported that only 3 out of 222 potential egg donors thought donors should receive payments [229]. In contrast, a recent study from 1427 men and women from the general public in USA reported 90% to be in favour of paying egg donors [201]. 46% of participants from the same study felt a limit on donor payments was

appropriate, with the majority believing this limit should be less than $10,000 [201]. The most commonly reported concern regarding monetary payments of gamete donors was that it could lead to them withholding important aspects of their personal and family medical history [201].

Motivation depending on oocyte recipient

Studies were contradictory regarding whether knowing the recipient would have a positive impact on their motivation to donate. Oskarsson et al. (1991) reported couples undergoing IVF treatment would prefer a relative (27%) or friend (29%) to receive their oocytes, with other studies finding the motivation to donate eggs increased if the recipient was a close relative [215, 217]. However, a Greek study suggested their population were more inclined to donate to an anonymous recipient [219]. Lessor et al. (1990) specifically studied sister to sister donation and their willingness to donate, and amongst their 501 responses there was reported to be a high level of acceptance for this type of donation [215].

Other motivating factors for oocyte donation

A personal experience of infertility, or through friends and family was consistently cited as an important factor that would motivate women to donate [116, 217, 232, 234, 237, 242]. One study reported approximately 20% of those motivated by altruism had been exposed to a friend or member of the family who had struggled to conceive [232]. Less commonly identified motives were the importance of a potential relationship with an infertile couple [232, 234] and passing on their genetic information [231, 232, 234].

Concerns regarding donation

Consistently raised concerns which deterred potential donors from donating included the time commitment involved, concerns about potential complications from the procedure, and distance from the fertility unit [231, 233]. One study reported 55-67% of participants stated inherent risks they felt were connected with egg donation, including medical and procedural risks (33%), poor knowledge (30%), and ethical and religious reasons (24%) [232]. Another study suggested these concerns could be

addressed if potential oocyte donors could speak to women who had already gone through the process [231].

6a.3.4 Attitudes towards oocyte donation

Participants thoughts and concerns regarding oocyte donation, and their likelihood of donating depended on the study population's fertility status, parity, ethnicity, and religion.

The impact of fertility status on the attitudes towards oocyte donation

Numerous studies reported a higher acceptance of oocyte donation amongst infertile women and a greater likelihood to donate compared to fertile patients [217, 224, 226, 229]. Straehl et al. (2017) investigated reasons for donating among their study population of 69 infertile women, and found 54% were willing to donate eggs to another couple. In contrast, Baluch et al. (1994) reported that fertile British and Iranian women felt more positively towards egg donation than infertile patients, however, there was a significant age difference between the fertile and infertile women. Supporting this, Isikoglu et al. (2006) studied rates of approval of egg donation between fertile and infertile individuals, and found no significant difference however, the sample size of infertile women was low.

The impact of parity on the attitudes towards oocyte donation

Gezinski et al. (2016) reported that 92.9% of mothers mentioned the pleasure of having their own child as their main motivation. Another study found that already having their own children increased their likelihood to donate [231]. In contrast, an Iranian study from their general population reported that having children of their own made them have a less positive attitude towards donation [220].

The impact of ethnicity on the attitudes towards oocyte donation

A study investigating views on infertility amongst South East Asian communities in the UK reported the use of donor gametes to be comprehensively socially unacceptable [225]; and that if infertile couples in their community were 'desperate enough' to use this option, then they would certainly not disclose to their community or child as to the nature of their conception [225]. An Indian study investigated

attitudes towards sperm and egg donation amongst the Indian general public and found a similar lack of acceptance [243]. The same study's infertile population were against egg donation, mainly on religious grounds, but it was still considered an acceptable way to achieve parenthood, as long the nature of conception was not disclosed [243]. One study looking at differing attitudes between different ethnicities in the same country found that British Caucasian women were more likely to potentially donate than British Asian women [242].

The impact of religious background on the attitudes towards oocyte donation

A study involving the general public in the US reported 14% of the 295 respondents indicated that ethical or religious reasons were significant issues that would potentially prevent them from donating their oocytes [221]. A Greek study found that those who reported being more religious were then less likely to agree to donate their gametes [219]. However, other studies reported no influence on the degree of religiosity and their decision to donate [222, 229]. One study from Iran compared Muslim and Christian responses and found their Muslim population were more against egg donation compared to Christians [228]. Baluch et al. (1994) reported Muslim respondents regarded their infertility as 'God's will' [244]. However, some countries where Islam is the main religion have reported couples having quite positive attitudes towards egg donation in principle [218, 228].

Attitudes towards donation for research

One study reported 90% of their infertile couples were willing to donate oocytes for research [224], with another study reporting a difference in attitudes between fertile and infertile women, with infertile women more in favour of using donor oocytes for research [229]. Another study investigated IVF patients thoughts on the use of donor oocytes for stem cell research and found the majority unwilling to donate their viable oocytes for this research, however couples with surplus frozen embryos were significantly more willing to donate these for human embryonic stem cell research [245]. Purewal et al. (2010) found that 68% of their potential oocyte donors had no preference whether they were donating for research or to an infertile couple [235]. One study investigated attitudes towards financial compensation for oocyte donation and found that their participants were more accepting of paying

oocyte donors for research than for clinical donation [241]. Another study of the general public found that those more interested in social egg freezing were also more open to the principle of donating their oocytes for research [27].

Attitudes towards donation to same-sex couples

A few of the included studies reported on attitudes towards donating to same sex couples [227, 246, 247]. Kailasam et al. (2001) investigated their general population and reported 40.7% of them supported the provision of donor oocytes to lesbian couples, with 32.9% disagreeing. Another study was far more positive, with 100% of their participants in favour of donation to female same-sex couples, and 97% in favour to male same-sex couples [246]. Adsuar et al. (2005) questioned potential donors' views on the distribution of oocytes and embryos (in an anonymous OD programme) relating to potential clinical situations, including donating to same-sex couples. The study did report ambivalence amongst the majority of prospective oocyte donors about their donation and unwillingness in some to proceed [247].

Attitudes towards disclosure

Most studies reported that participants should disclose to offspring born from egg donation treatment how they were conceived [223, 226, 229, 248]. In contrast to this, studies conducted in Iran and Turkey found the general public did not feel the child should be informed [220, 228]. Findings were mixed regarding donor anonymity and potential future contact with resulting children. One study reported half of their participants felt information should be given to offspring if they requested it, with a third disagreeing with this [231]. Another study found that 38% of participants from the general public felt children had the right to know their genetic parents, with parents answering consistently more against this compared to those without children [230]. A study from the USA found their respondents were in overwhelming agreement 'the recipient should receive some information about the donor' [232]. The response depended on the parental status of their participants, with 33% of those with children disagreeing with this statement, compared to 60% of those without children [232]. Studies have consistently shown a significant proportion of participants (34-41%) questioned were willing to donate non-anonymously [151, 217, 229, 249].

6a.4 Discussion

This was the first systematic review to explore the attitudes and motivations towards donation of potential donors, as well as the general public exclusively. Thematic analysis was used to identify key motivating factors and concerns surrounding donation, and has illustrated demographic differences in attitudes.

6a.4.1 Motivations and attitudes towards donation

Data from this review consistently reported altruism as the primary motivating factor, although monetary compensation was also a significant factor. It is important to note that motivations will be multi-factorial [232]. Gezinski et al (2016) emphasize that most participants will cite multiple motivations rather than a single factor [232]. Although financial gain was mentioned as a motivating factor in some studies, the majority reported a generally negative attitude towards monetary payment for donation. It is more difficult to review whether financial gain would be a motivator to donate eggs in countries where legislation prohibits or caps payment, such as the UK. A study compared the motivations of a group who could potentially be paid $2500 to one that could receive $5000 [240]. Financial motives were greater in those being paid $5000 (68%) compared to $2500 (39%). Supporting this, monetary payments are not widely reported in countries where payment for donation is capped, such as the UK [250]. In countries prohibiting any compensatory payments for donation, the number of women donating is significantly less, showing the likely importance of compensation to encourage donation. Payment for donor oocytes has been avidly debated over the years due to the concern that some women may be at risk of exploitation based on their financial needs [251]. These ethical concerns have led to many countries, including the UK, introducing legislation regarding financial renumeration.

There are variations in motivations and attitudes towards egg donation depending on demographic differences. Studies reported a higher acceptance of egg donation amongst infertile women and a greater likelihood for them to donate, compared to the fertile population. This is understandable, as infertile

women are more likely to empathize with the significant psychological impact of infertility, making them potentially more likely to donate altruistically to other women struggling to conceive. This confirms that fertility patients are a potential valuable source of donor oocytes, such as in the egg sharing programme.

This review highlights the differences in attitudes towards egg donation across different countries, ethnicities, and religions. This issue appears to be multifaceted and is likely to be impacted, at least in part, by different nation's policy and legislation surrounding gamete donation. These issues are poorly studied, and specifically exploring issues surrounding egg donation within these differing populations and cultures will allow clinicians to explore potential solutions to improving donor acceptance and therefore recruitment in these different communities.

6a.4.2 Donor anonymity

Changes have been made to legislation surrounding donor anonymity in many countries, with a change in position to increased favourability towards donor identifiable information being made available to recipient's offspring when they reach adulthood. This move towards identity release has largely resulted from the recognition that access to the donor's identity could be of importance to the donor offspring [252]. These legislative changes were controversial and caused considerable concern in countries where such changes have been made, mainly the likely impact on increasing challenges in recruiting egg donors. However, the attitudes of the general public, potential donors and patient donors have not been widely studied following this legislative change. Despite this loss of donor anonymity, this review found a significant proportion of women would still consider donating their eggs non-anonymously. This is supported by UK data, where after an initial decline in women donating their eggs, numbers have steadily risen over the last decade [104]. Therefore, it appears this legislation has not impacted donor numbers nearly as significantly as predicted, whilst also giving access to medical history and their genetic origins for the recipient's offspring. In the UK in 2023, the first offspring conceived from donor gametes will be able to access information surrounding their genetic parent's identity. Researching the longitudinal outcomes of egg donation, including psychological aspects following donation and the

happiness of the family dynamic will provide useful data to potentially reassure both donors and recipients, therefore aiding future donor recruitment.

6a.4.3 Study limitations

This review successfully explored the important psychosocial aspects of egg sharing amongst the general public and potential egg sharers and has led to several conclusions that we believe could impact on future clinical practice and policy reform. Nevertheless, there were some methodological limitations identified in the studies.

First, the use of psychological interviews and questionnaires to establish motivating and deterring factors is potentially problematic. Potential egg donors could purposefully over emphasize their altruistic motives to donate to present themselves in a more favourable light to fertility clinics. However, it must be emphasized the questionnaires were anonymous and included no patient identifiable data. This review also includes both patient and non-patient populations, and by including the general public's responses the potential impact of this limitation is significantly reduced. Second, the majority of studies involved western populations only, meaning there is a significant lack of data involving other ethnicities. It is also important to consider the impact of social stigma towards egg donation on the uptake of certain ethnicities participation. Third, those agreeing to participate in the studies included in this review could have strong beliefs on egg donation, be it positive or negative, leading to participation bias. Finally, some studies included were from countries where data collection was performed prior to legislation changes on donor anonymity in that country. Attitudes and motivations to potentially donate may well have changed significantly since this legislative change, however this review included all egg donation studies, regardless of the year of study.

6a.4.4 Future research

The only solution to address the imbalance between supply and demand of donor eggs in the UK is to recruit more altruistic donors willing donate non-anonymously. Future studies should focus on the following areas: first, studies must continue to identify more about the 'typical' egg donor, their

demographic background, their motives to go ahead with donation, and any issues which prevent them from participating. Additionally, studies must focus on exploring specific patient populations in greater detail, especially ethnic and religious minorities, where the use of donor oocytes appears less accepted, but donor eggs are in higher demand. Second, the deterring factors identified was an important finding of this systematic review and it is imperative fertility specialists are aware of these. Fertility services should attempt to improve education and awareness of egg donation amongst both the general public and their fertility patients. Educating the general public and patients on public health issues is a complicated task, but options include patient support groups, online free educational webinars on topics such as egg freezing and egg sharing, access to speak to patients who have participated in egg donation, and more targeted advertising campaigns. Improved access to counsellors, rather than a one-off mandatory counselling appointment could also help women make more informed decisions regarding the process. Finally, in the UK there are few fertility clinics with access to egg donor banks, which leads to logistical difficulties for patients, such as lengthy travel times to other fertility clinics. Studies should investigate this issue, and if it is identified as a consistent barrier to treatment, fertility clinics would be more pressured to enforce changes to make egg donation treatment more accessible.

6a.4.5 Conclusion

This systematic review is the first to exclusively analyse potential oocyte donors and provides an important summary of the key findings regarding the shifting attitudes and motivations which may influence their decision to donate. Although this review has identified progressive information to guide current clinical practice, gaps in the literature were identified regarding psychosocial aspects of potential egg donors. More studies exploring these psychological issues could improve clinical care further, and potentially lead to an increased number of women from the general public deciding to donate.

Study Vb: A survey investigating the knowledge and attitudes towards egg donation and egg sharing amongst the general public from the United Kingdom

6b.1 Introduction

The general population have been found to have quite a poor knowledge of egg donation from the few studies that have investigated this topic [218, 221, 222]. Studies that investigated infertile couples who are having IVF treatment interestingly also reported their knowledge surrounding oocyte donation to be poor, with many patients stating they had 'very little knowledge' of egg donation [221, 222]. However, this relatively limited knowledge of egg donation did not seem to hamper a woman's hypothetical donation intentions, nor their ability to convey their opinions on the subject [219, 225]. The public from western societies gave generally positive views on egg donation [201, 220]. However, this appeared to be in contrast to other studies from different ethnic and religious populations, such as Asian and Islamic backgrounds, where most reported the use of donor sperm or oocytes to be unacceptable on social and religious grounds [221, 225, 235, 243]. One UK based study also specifically found that their British Caucasian participants were far more likely to agree to egg donation compared to their British Asian counterparts [242]

There has been no study investigating the attitudes and knowledge towards egg donation and egg sharing amongst the general public in the UK. This is highly relevant as these women of course are representative of potential egg donors, and if better informed and encouraged to participate, could go some way to helping to solve the oocyte supply issue in the UK.

This study aims to investigate the knowledge and perceptions of female fertility decline, as well as the knowledge and attitudes towards egg donation and egg sharing amongst women from the UK. Secondary aims were to investigate the opinion of UK women of the 2005 legislative change towards donor anonymity. Knowledge provided by this study could help to provide potential ways of increasing the number of women coming forward for egg donation or agreeing to participate in egg sharing.

Women in developed countries are continuing to delay the age of first time motherhood, and are therefore increasingly needing fertility treatment to conceive. This means more women from the general public may potentially become egg donors, egg sharers or recipients to conceive in the future, making the findings from this study to be potentially highly significant.

6b.2 Material and methods

6b.2.1 Study design

A detailed questionnaire investigating the public's knowledge and perceptions of egg donation and egg sharing was formulated. The format and content of the survey was based on previously validated and published studies investigating the attitudes towards either face or womb transplantation, as well as a questionnaire on healthcare professionals attitudes towards egg donation, which was published by the same group [61, 199, 200]. These surveys were altered to evaluate the knowledge and perceptions of female fertility decline, egg donation and egg sharing among women of the general public in the UK. The questions respondents were asked to answer were selected based on their identification in previous published systematic reviews that the same authors performed [57, 58, 253]. The questionnaire was then piloted on fertility consultants, fertility nurses and fertility counsellors within the egg donation team at LFC, as well as ten fertility patients during their fertility treatment. The feedback received was noted and minor revisions to the questionnaire were made accordingly, namely medical jargon and questions deemed unnecessary for the aims of the questionnaire.

6b.2.2 Study participants

The inclusion criteria for participants to be eligible were to be female, over 18 years and resident in the UK. This was the initial question of the survey, with only those meeting the above criteria able to participate. The questionnaire consisted of 46 close-ended questions that took a total 15 minutes to complete. The questionnaire was disseminated online using the Qualtrics survey programme. A link to the questionnaire, as well as a brief statement summarising the purpose of the study, was posted on

social media community groups who were based throughout the UK. These community groups had absolutely no link to fertility issues or fertility groups or fertility networks. The posts were only made after the group administrator approved it. Responses were received on a purely voluntary basis, with no financial or other incentives offered to potential respondents. The survey consisted of five sections: (i) demographic and personal information; (ii) knowledge of female fertility; (iii) egg donation; (iv) egg sharing; (v) UK legislation.

6b.2.3 Data collection and analysis

Data was collected over a 45-day period between15th March 2020 to 29th April 2020. Data was collected using the Qualtrics survey tool, with statistical analysis of the generated quantitative data exported into and performed using SPSS. Comparisons between the categorical data collected was analysed using Pearson's Chi-squared test. Distributions of mean grades from the ranking of benefits and issues of egg sharing were assessed using Mann-Whitney U testing. Statistical significance was given a 'p value' of $p<0.05$.

6b.2.4 Ethical approval

Ethical approval for this study was provided by 'London Riverside Research Ethics Committee', Research Ethics Committee (REC) reference: 17/LO/1491.

6b.3 Results

The demographic details of respondents are summarized in ***table 6b.1***. In total 635 women responded and participated in the study. 523 respondents completed all of the survey questions meaning 134 of the responses received had one or more question unanswered. These incomplete responses were not excluded from the study analysis. All participants were female, with most aged 18-25 years (35.8%), although there was a quite an even distribution among the different age groups overall (***table 6b.1***). A significant majority of participants were Caucasian (91.0%), with most stating they were 'not religious' (52.1%). There was quite an even spread regarding relationship status, with 26.5% single, 35.3% 'in a relationship' and 38.2% married. Regarding sexual orientation, 91.8% of participants were

heterosexual. Most respondents reported their level of education to be a 'university degree' (42.6%), worked full-time (49.5%) and earned an annual salary of < £30,000 (70.3%).

Table 6b.1 Sample population demographics

	%	n
Age, y (657)		
18-25	35.8	235
26-30	12.8	84
31-35	10.1	66
36-40	13.2	87
41-45	10.7	70
> 45	17.5	2
Ethnicity (657)		
White British	83.7	550
With other	7.3	48
Mixed ethnicity White/ Black	1.8	12
Mixed ethnicity White/ Asian	1.5	10
Mixed ethnicity Other	0.6	4
Asian Indian/ Pakistani/ Bangledeshi	1.9	13
Asian Chinese	0.4	3
Asian Other	0.3	2
Black African/ Carribean	1.3	9
Arabic	0.2	1
Other Ethnicity	0.8	5
Relationship status (657)		
Single	26.5	174
In a relationship unmarried	35.3	232
Married	38.2	251
Sexual orientation (657)		
Heterosexual	91.5	601
Homosexual	2.3	15
Bisexual	5.8	38
Other	0.5	3
Existing children (657)		
Yes	48.7	320
No	51.3	337
Religious background (657)		
None	52.1	342
Christian	43.8	288
Muslim	1.2	8
Jewish	0.6	4
Hindu	0.9	6
Other	1.4	9
Education level (657)		
GCSEs	12.6	83
A-levels	14.2	93
College diploma/ apprenticeship	14.2	93
University degree	42.6	280
Postgraduate degree	16.4	108
Employment status (657)		
Full time	49.5	325
Part time	18.7	123
Student	23.9	157
Housewife/ Housework	5.3	35
Unemployed	2.6	17
Annual salary (657)		
< £30,000	70.3	462
£30- 50,000	23.6	155
£50- 100,000	5.2	34
> £100,000	0.9	6

6b.3.1 Knowledge of female fertility

The summary of respondents' answers about female fertility can be found in ***table 6b.2***. Participants were asked how frequently they thought about the decline of female fertility with age, with responses split quite equally between 'frequently' (22.9%), 'occasionally' (36.4%), 'rarely' (21.6%), and 'never' (19.2%). Respondents were also asked about the decline of female fertility with age, and 33.1% thought

the decline started age 30-34 years and 40.6% answered 34-39 years. A significant minority of respondents' felt female fertility did not decline until > 40 years (16.5%). Survey participants were also asked about the age they ideally wanted to start a family and 9.9% responded they did not want to have children. Of those wanting children, 84.9% stated they would have ideally done this before 35 years of age. Only 0.7% of women wanted to ideally have a child after 40 years of age. Women were asked the average LBR per embryo transfer at age 40 years for women undergoing IVF, and were realistic with their responses, with 19.1% stating < 10% pregnancy rates, 30.4% answering 10-20%, and 29.6% stating pregnancy rates 20-30%.

Table 6b.2 Summary of respondents' answers about female fertility

Characteristic (total no. of respondents, n)	%	n
Do you regularly think about female fertility decline with age? (n = 608)		
Frequently	22.9	139
Occasionally	36.4	221
Rarely	21.6	131
Never	19.2	117
At what age do you believe female fertility starts to significantly decline? (n = 608)		
20-24 years	1.5	9
25-29 years	8.4	51
30-34 years	33.1	201
35-39 years	40.6	247
40-44 years	13.5	82
> 45 years	3.0	18
At what age would you like to ideally start a family? (n = 608)		
Do not want to have children	9.9	60
< 20 years	2.1	13
20-24 years	15.1	92
25-29 years	39.3	239
30-34 years	28.3	172
35-39 years	4.6	28
40-44 years	0.7	4
> 45 years	0.0	0
What is the average pregnancy rate per embryo transfer at age 40 years?		
0-10%	19.1	116
10-20%	30.4	185
20-30%	29.6	180
30-40%	14.8	90
40-50%	3.8	23
> 50%	2.3	14

6b.3.2 Knowledge and attitudes towards egg donation

Prior to completing the questionnaire, most respondents had 'little' or 'no knowledge' of egg donation (56.4%), with only 8.8% of participants answering they had 'significant knowledge' on the subject (***table 6b.3***). Participants were then provided with an impartial statement explaining the egg donation programme, and following this information 86.0% said they 'strongly agreed' or 'agreed' with egg

donation, with a very small minority (3.2%) disagreeing with the donation programme (***table 6b.3***). Interestingly, participants who had prior knowledge of egg donation did not answer more or less favourably towards it (χ^2, p=0.660). However, women aged 18-30 years were more likely to agree with egg donation compared to those aged over 30 years and this was statistically significant (χ^2, p<0.05).

Table 6b.3 Summary of respondents' answers about egg donation

Characteristic (total no. of respondents, n = 591)	Percent	n
Knowledge about egg donation prior to answering the questionnaire		
No knowledge	15.4	91
Little knowledge	41.0	242
Some knowledge	34.9	206
Significant knowledge	8.8	52
Do you agree with the principle of egg donation?		
Yes	86.0	508
No	3.2	19
Unsure	10.8	64
Would you consider donating your eggs altruistically as an anonymous donor?		
Yes	35.9	212
No	36.7	217
Unsure	27.4	162
Would you consider donating your eggs to a close friend or relative as a known donor?	49.8	294
Yes	27.2	161
No	23.0	136
Unsure		
If you were to donate your eggs hypothetically, what would be your main motivation?	29.0	171
Altruism	7.7	46
Financial	58.8	348
Family/ friend having fertility problems	1.4	8
Passing on my genetic material	3.2	18
Developing a relationship with an infertile couple		
If you were to donate your eggs hypothetically, what would be your main concern?		
Medical procedures	43.3	213
Potential future contact with child	34.2	168
Recipient may be too old	0.6	3
Recipient may be in a same-sex relationship	1.0	5
The donation not working	16.5	81
Taking time off work	3.5	17
Religious reasons	1.0	5
If you were unable to have a child and your only realistic option to conceive was through an egg donor, would you pursue egg donation?		
Yes	56.0	331
No	17.8	105
Unsure	26.2	155

Despite the majority of participants agreeing with the principle of egg donation, only 35.8% stated they would even consider egg donation as a voluntary donor. However, 49.8% of participants would consider donating their eggs as a known donor to a friend of family member. When presented with the hypothetical scenario of what would motivate them to donate their eggs, the vast majority answered 'to help family/ friend having fertility problems' (58.8%), with altruism (7.7%) and financial reasons

(7.7%) being the other most answered motivating factors (***table 6b.3***). The most commonly cited hypothetical concerns raised were the medical procedures they would endure (43.39%), potential future contact with resulting children (34.3%) and the donation treatment being unsuccessful (16.5%) (***table 6b.3***). When asked if when trying to conceive they were informed they would only be able to conceive using donor oocytes, 56.0% said they would pursue this option, with 17.8% saying they would not (***table 6b.3***).

6b.3.3 Knowledge and attitudes towards egg sharing

Perhaps unsurprisingly, most participants had 'little' or 'no knowledge' of egg sharing (80.7%) (***table 6b.4***). Participants were then provided with an impartial statement explaining the egg sharing programme, and following this information, respondents were asked if they agreed with the egg sharing programme taking place; 70.4% agreed, 9.1% disagreed, and 17.5% answered unsure (***table 6b.4***). A significant majority (60.6%) felt egg sharing could provide a viable solution to the shortage of donor oocytes in the UK and worldwide (***table 6b.4***). The majority reported an ethical disparity between egg share donors who receive significantly subsidized fertility treatment and a woman being paid a significant monetary sum to donate as a commercial donor, however 22.0% felt there was no difference (***table 6b.4***). Those who answered favourably towards egg donation were more likely to approve the practice of egg sharing, with this difference reaching statistical significance (χ^2, $p<0.05$).

Table 6b.4 Summary of respondents' answers about egg sharing

Characteristic (total no. of respondents, n)	Percent	n
Knowledge about egg sharing prior to answering the questionnaire (571)		
No knowledge	54.6	312
Little knowledge	25.0	143
Some knowledge	14.2	81
Significant knowledge	6.1	35
Do you agree with the principle of egg sharing? (571)		
Yes	73.4	419
No	9.1	52
Unsure	17.5	100
Do you believe egg sharing could be a viable solution to the worldwide shortage of donor eggs? (571)		
Yes	60.6	346
No	12.6	71
Unsure	26.8	153
Do you see an ethical difference between egg sharers receiving free fertility treatment and a commercial donor being paid to donate? (523)		
Yes	56.8	297
No	22.0	115
Unsure	21.2	111
Hypothetically, if you needed IVF to have a child would you consider egg sharing? (523)		
Yes	56.8	297
No	21.9	115
Unsure	21.2	111

Participants graded the significance of five potential benefits egg sharing provided. Each of these benefits was ranked between 1 (least significant) to 5 (most significant), with the mean scores respondents gave to these benefits summarized in ***table 6b.5***. For all five of the potential benefits participants were questioned on, the modal rating was 5. Four of the potential benefits were given a mean score >4, other than benefit (v) 'egg sharing provides a realistic solution to an acute shortage of eggs', with this benefit recording a mean score of 3.95. The general public rated the benefit of allowing access to IVF to couples who were not entitled to NHS funded fertility treatment and could not otherwise afford to pay for their treatment as the most significant benefit. The mean score of the benefits of the egg sharing programme were then stratified by the response to the question as to whether they felt egg sharing should take place. Perhaps unsurprisingly, those in favour of egg sharing gave a higher mean ranking to the benefits of egg sharing compared with those against the practice, and this reached statistical significance (***figure 6b.1***, Mann-Whitney U test, $p<0.001$).

Table 6b.5 *Mean scores given to benefits surrounding egg sharing according to their significance. 1 = least significance, 5 = most significance. Mean and standard deviation (SD) calculated using only responses where all benefits were scored (n = 523)*

Benefits	Mean score +/- SD
Those without access to NHS (government) funded IVF who cannot afford to pay for their treatment get fertility treatment they would otherwise have not been able to access	4.15 +/- 1.04
It allows a person suffering with infertility to help a person in a similar situation	4.15 +/- 1.05
Unlike with volunteer egg donors, with egg sharing no third party needs to go through invasive procedures, such as egg collection, since the donor needs to undergo these procedures anyway for her own fertility treatment	4.01 +/- 1.03
Currently, due to long waiting lists for donor eggs in the UK women are seeking fertility treatment abroad in often unregulated clinics, egg sharing could reduce women seeking treatment abroad	4.00 +/- 1.11
It provides a realistic solution to an acute shortage of eggs	3.95 +/- 1.09

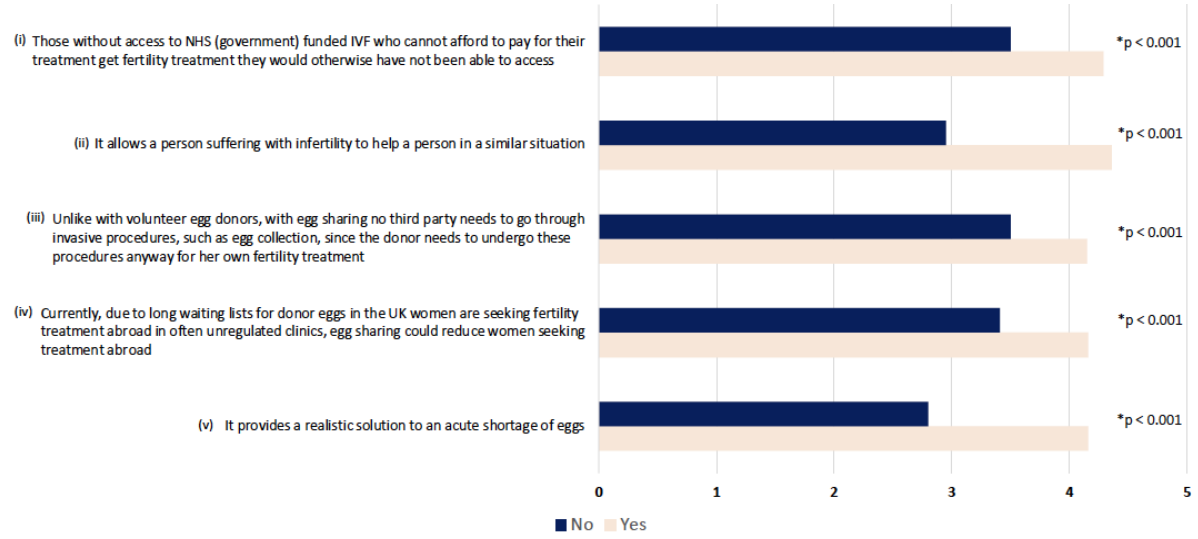


Figure 6b.1: *Bar charts representing the distributions of significance ratings for each benefit of egg sharing, where '1' = 'Not significant' and '5' = 'Very significant', stratified by answering 'Yes' [n=336] or 'No' [n=53] to the question "In your opinion, should egg sharing take place?". Statistically significant differences in 'significance rating' distributions between those answering 'Yes' or 'No' upon Mann Whitney-U testing are shown, with '*' representing a p-value < 0.001.*

Respondents also graded the significance of five potential issues surrounding the egg sharing programme. Each of these concerns was given a score between 1 (least significant) and 5 (most significant), with the outcomes summarised in ***table 6b.6***. 'Concern for the psychological well-being of egg share donors whose own treatment is unsuccessful' and 'concern that egg sharing could reduce the chances of the donor conceiving as she is donating half her eggs' were the only concerns respondents gave a mean score of > 4. The mean score of the issues surrounding egg sharing were then stratified by response to the question as to whether they felt egg sharing should take place. Again, perhaps

unsurprisingly, those who answered unfavourably towards egg sharing gave higher mean scores to the potential issues surrounding the programme, with this reaching statistical significance for question (i) and (iii) (***figure 6b.2***, Mann-Whitney U test, $p<0.05$).

Table 6b.6 *Mean scores given to issues surrounding egg sharing according to their significance. 1 = least significance, 5 = most significance. Mean and standard deviation (SD) calculated using only responses where all issues were scored (n = 523)*

Issues	Mean score +/- SD
Concern for the psychological well-being of egg share donors whose own treatment is unsuccessful	4.14 +/- 0.99
Concern that egg sharing could reduce the chances of the donor conceiving as she is donating half her eggs	4.14 +/- 0.99
The egg share donor might need to undergo repeated IVF cycles and egg collections to collect enough eggs for her and the recipient	3.95 +/- 0.97
The donor is only agreeing to share her eggs to gain access to fertility treatment	3.57 +/- 1.27
The recipient of the donor eggs having to pay for treatment when the donor receives treatment for free	3.57 +/- 1.27

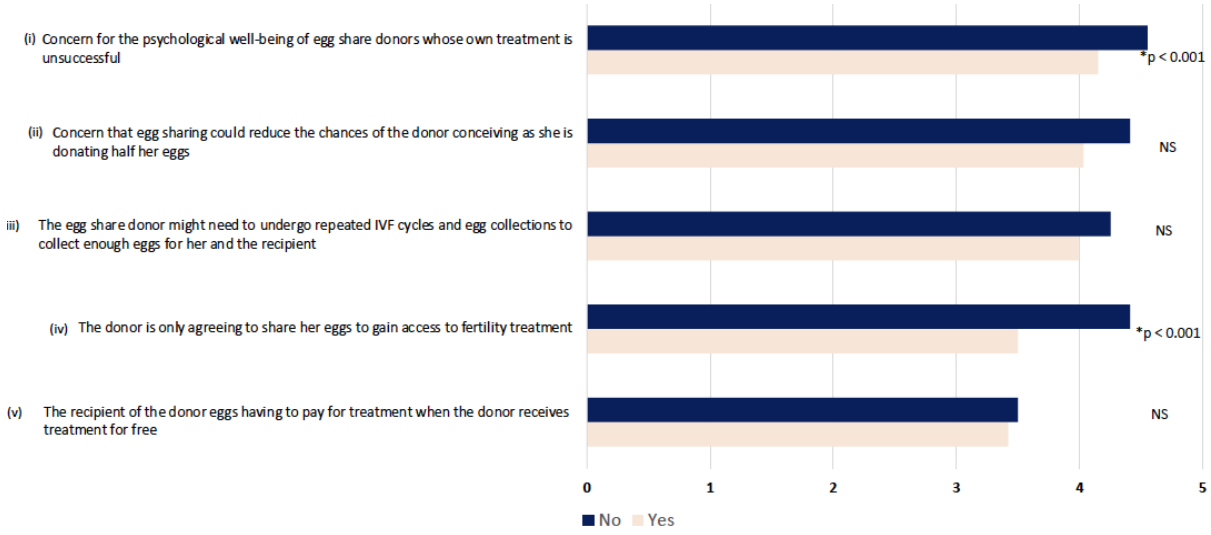


Figure 6b.2: *Bar charts representing the distributions of significance ratings for each concern with egg sharing, where '1' = 'Not significant' and '5' = 'Very significant', stratified by answering 'Yes' (a) [n=336] or 'No' (b) [n=53] to the question "In your opinion, should egg sharing take place?". Statistically significant differences in 'significance rating' distributions between those answering 'Yes' or 'No' upon Mann-Whitney U testing are shown, with '*' representing a p-value < 0.001 and 'NS' representing no statistical significance.*

With regard to the option of fertility preservation, respondents were asked whether they were aware they had the option of participating in egg sharing to freeze their eggs for social reasons, and 80.1% of participants were not aware they had this option (***figure 6b.3***). When questioned as to whether they felt

being able to potentially freeze their eggs and therefore preserve their fertility whilst sharing their eggs, and accessing this treatment essentially for free was a good option, 63.3% answered 'yes', 15.1% answered 'no' and 21.7% were 'unsure' (***figure 6b.3***).

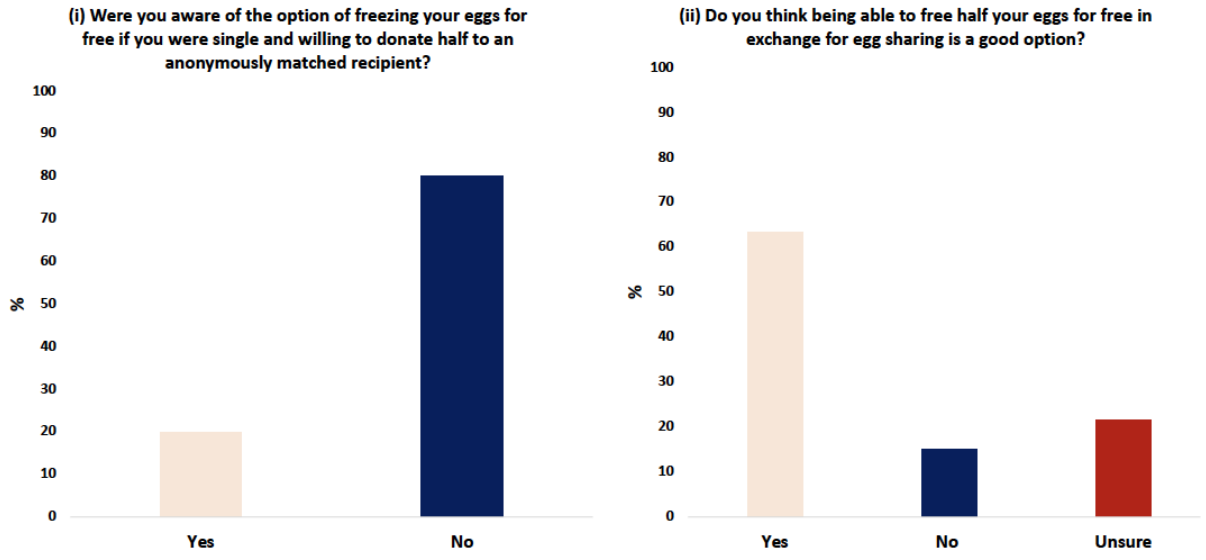


Figure 6b.3: *The general public's views on potentially using the egg sharing programme to access fertility preservation (n=523)*

6b.3.4 Attitudes towards UK legislation and compensatory caps

Participants were asked whether they thought the £750 compensatory payment for donating oocytes was enough, and the majority answered 'no' (46.9%), 31.3% answered 'yes' and 21.8% were 'unsure' (***figure 6b.4***). However, if the compensatory payment was increased, 52.6% stated they would be no more motivated to donate their oocytes, with 32.5% saying they would be more willing (***figure 6b.4***). Attitudes towards the level of compensation available for donors had no association with the respondent's annual income (χ^2, $p=0.41$). Younger participants (< 30 years) felt the compensatory cap was insufficient (χ^2, $p<0.05$), and would be more motivated to consider donation if the payment was higher (χ^2, $p<0.05$), when compared to those over 30 years of age.

Most participants (65.3%) thought that couples who needed to use donor oocytes to conceive should have their fertility treatment government funded, with only 16.1% answering against this viewpoint (***figure 6b.4***). Participants who had previously answered against the process of egg donation were

significantly less likely to agree that fertility treatment using donor eggs should be NHS funded, when compared to those who had answered favourably towards the practice of egg donation (χ^2, $p<0.05$).

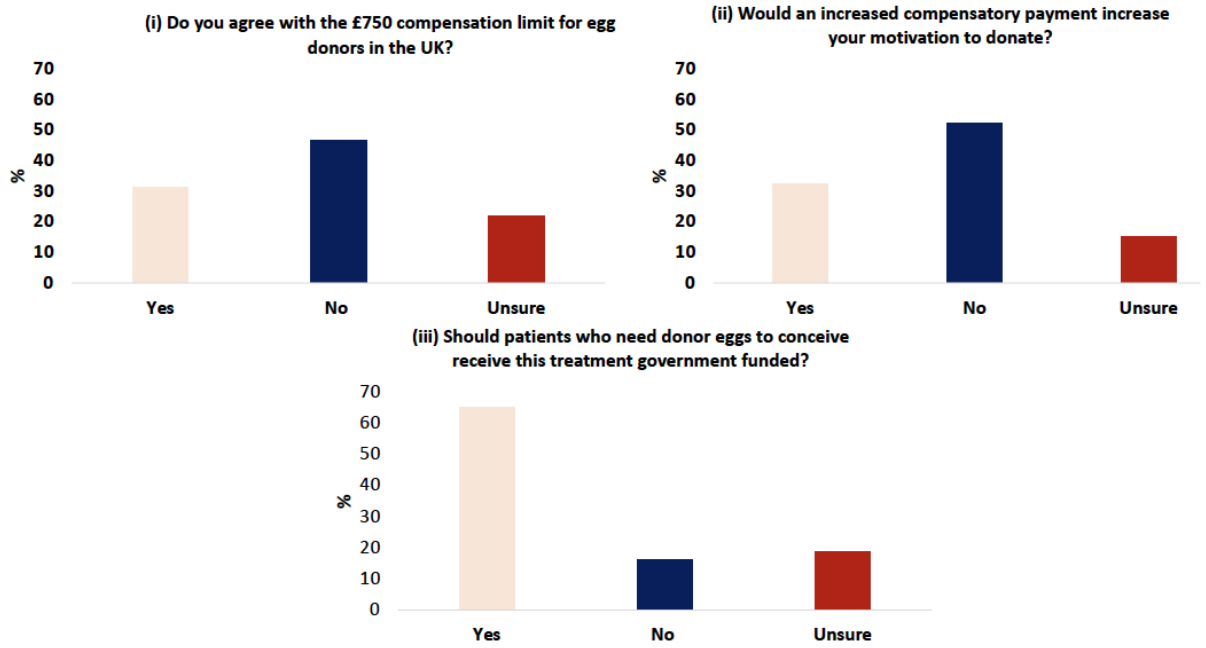


Figure 6b.4: *Attitudes of the general public towards compensatory payments and government funding of egg donation cycles*

Participants were then given a description and explanation of the 2005 'Disclosure of donor information' legislation, with 55.8% then agreeing with this regulation, 19.1% disagreeing and 25.0% answering 'unsure' (***table 6b.7***). Most respondents (59.2%) felt this legislature surrounding donor anonymity would not dissuade them from donating their eggs in the future. Unsurprisingly, those who disagreed were significantly less likely to donate because of the change in legislation (χ^2, $p<0.05$). Answers were very split regarding future contact with the women to whom they donated their oocytes, with 25.0% answering 'yes', 31.6% saying 'no', with the majority 'unsure' (43.3%) (**table 6b.7**). There were similar findings regarding future contact with any resulting children, with 23.0% answering 'yes', 31.6% saying 'no', with the majority again 'unsure' (45.4%) (**table 6b.7**).

Table 6b.7 Summary of respondents' attitudes towards disclosure and potential future contact with donor offspring

Characteristic (total no. of respondents =591)	Percent	n
Do you agree with the 2005 'Disclosure of Donor Information' legislation		
Yes	55.8	330
No	19.1	113
Unsure	25.0	148
Would the 2005 'Disclosure of Donor Information' legislation stop you from donating eggs?		
Yes	20.6	122
No	59.2	350
Unsure	20.1	119
Hypothetically if you donated your eggs, would you want future contact with the couple you donated to?		
Yes	25.0	148
No	31.6	187
Unsure	43.3	256
Hypothetically if you donated your eggs, would you want future contact from any children resulting from the donation?		
Yes	23.0	136
No	31.6	187
Unsure	45.4	268

6b.4 Discussion

This is the first study to investigate the general public's knowledge and attitudes towards the practice of egg sharing. This study also investigated the knowledge and attitudes towards egg donation amongst the general public, and the issues surrounding removal of donor anonymity.

6b.4.1 Fertility knowledge

This study has shown that the general public appear to have a generally accurate understanding of female age-related fertility decline. It is accepted the beginning of fertility decline occurs in the early 30s, with a more significant drop in fertility from age 35 years [254, 255]. Studies report contradictory findings regarding knowledge of age-related fertility decline. Seven studies have previously shown poor knowledge of female fertility decline among the general population [22, 25, 27, 256-259]. Hickman et al reported that only 15% of women understood the likelihood of infertility at age 45 years [25]. Another study from Belgium reported similar findings, with 14.3% of respondents having realistic knowledge of female fertility decline. Interestingly, Garcia et al (2017) reported poor knowledge of fertility decline among healthcare professionals, with physicians outside the field of gynaecology reporting on average 77.3% spontaneous pregnancy rates in women over 40 years [260]. Our respondents had a relatively

accurate knowledge, with 40.6% answering a significant fertility decline aged 35-40 years, and 33.1% answering 30-34 years. This is supported by other studies who also reported realistic knowledge regarding female fertility in their cohort (51-89.4%) [23, 24, 26, 261-264]. Milman et al. (2017) found that in their survey of 1000 women, 40% were considered 'fertility knowledgeable' by correctly answering four of six questions assessing general reproduction and age-related fertility decline [265]. Nevertheless, 16.5% of our cohort reported female fertility to decline only >40 years, which although a minority of respondents, could still lead to a significant minority of women in the general public over-estimating their fertility potential in their later reproductive years.

Respondents also appeared to have realistic family planning intentions, with 67.6% ideally planning on starting a family between 25 and 35 years of age, with only 5.3% answering >35 years. Study participants also had good knowledge of the success rates per embryo transfer based on female age, with 49.5% correctly stating success rates < 20% in the 40-42 year old age group. HFEA data reports success rates of 9.6% with fresh embryos and 15.6% with frozen embryos in this age group [266]. However, a significant minority of our participants did significantly over-estimate IVF success rates in this age group, with 20.9% estimating success rates of IVF treatment to be >30% per embryo transfer.

6b.4.2 Egg donation

The general public's knowledge surrounding egg donation was quite poor, with 56.4% of study participants stating 'little or no knowledge' of egg donation, which is consistent with the findings from other published studies [218-220, 222, 223]. Isikoglu et al. (2006) investigated the general public from Turkey, and found that less than one third had any knowledge of the egg donation process, nor its potentially significant role in fertility treatments to help couples have children [220]. However, after being provided with a concise explanation 86.0% agreed with egg donation taking place. In addition, 35.9% said they would consider using donor oocytes for their own treatment if required, providing it were anonymous [220]. A significant proportion of their participants (49.8%) also said they would strongly consider donating their oocytes to a friend or family member [220]. The findings from this

study are interesting, as it contrasts starkly with other studies of Asian and Islamic populations, where these couples stated using donor gametes to conceive was 'socially unacceptable' [221, 225, 235, 243].

The vast majority of our study participants cited 'altruistic' motivations or the desire to help a 'family member or friend having fertility problems', with only 7.7% stating financial motivations. This is probably expected as the study took place in the UK, where financial payments for donor gametes are not permitted, and capped as a compensatory payment. However, our study cohort were not informed of the illegality of payments when they were asked this question, implying a possible societal apprehension towards financial payments for egg donation in the UK. Altruistic motives are consistently reported in other studies in participants from the general public, or those considering participating in egg donation, with 82-98% of potential donors citing altruism as their predominant motivating factor [116, 221, 232, 235, 237].

Most other studies investigating this topic found relatively negative attitudes towards monetary payments to secure egg donors [216, 217, 224, 229, 241, 250, 267]. This could be, at least in part, due to the difficulties in ascertaining financial motives in countries where respondents are aware payments are illegal, such as the UK. One study investigated the motivations of potential egg donors in 11 countries in Europe, and found financial motives to be significantly less important for participants in countries where payment was not an option, compared to those where payments are permitted [250]. Some studies did find participants reported strong financial motives for them to consider potentially donating, with most of such studies coming from the general public in the USA [201, 221, 232, 240]. Lee et al. (2017) found that 90% of their study cohort supported donors being paid, with the appropriate amount not exceeding $10,000 [201]. Another study investigated women who were considering donation, with similar background demographics, and compared responses from those who would be given $2500 or $5000 to donate respectively [240]. The financial motivations were more significant in those who would be given $5000 (68%) compared to $2500 (39%) [240]. Further evidence to potential bias regarding country of study and motivations is given indirectly, as in countries where financial

payments are illegal there are less egg donors, implying financial incentives are potentially more significant in certain countries, than our study cohort implied [253].

The predominant issue surrounding egg donation in our study was the invasive medical process involved (43.29%). This finding agrees with other studies which reported 33-67% of respondents from the general public had concerns regarding the invasiveness of the medical treatment and the risks of the stimulation process and egg collection procedure [221, 231-233]. Svanberg et al. (2003) found their study cohort were more likely to potentially donate if they could speak to patients who had already donated oocytes [231]. Characteristics such as advanced maternal age and recipients being in same-sex relationships were not an issue for our study cohort, with only 0.6% and 1.0% citing these as an issue respectively. This is in keeping with another study who reported 100% of their participants were positive about donating to female same-sex couples, and 97% to male same-sex couples [246].

6b.4.3 Egg sharing

There is a distinct lack of knowledge of egg sharing in the UK, with 80.7% of our cohort having 'little or no knowledge' of the process. This finding was anticipated, since as reported in '***Chapter 3: Study II***' 63.1% of healthcare professionals had 'little or no knowledge' of the egg sharing programme [61]. This meant only 16.5% of those healthcare professionals surveyed, who could refer a patient for egg sharing, had done so [61]. When given a concise description and explanation of egg sharing, 73.4% of the general public agreed with the practice, and almost two thirds felt egg sharing could provide a viable solution to the significant global shortage of donor oocytes. Our study cohort from the general public gave a similar level of support for egg sharing as healthcare professionals did (73.4% vs 78.2%) [61]. The combined lack of knowledge amongst the general public and healthcare professionals with regard to egg sharing means there will be a poor patient self-referral and clinician referral rate to clinics for egg sharing, which is likely to be significantly hampering the number of women currently participating as egg sharers. This is an especially valid theory when the high approval ratings towards the egg sharing scheme are considered.

Our study cohort gave all of the benefits of egg sharing a high ranking, with 'allowing those access to fertility treatment who otherwise would not be able to access it', and 'the lack of a third party undergoing invasive procedures to donate', the highest scores, which is consistent with other studies in this area [57, 58, 61, 151]. The issues surrounding egg sharing that respondents rated highest were 'fears of egg sharing reducing the chance of success for the egg sharer', and 'concern for the psychological well-being of the egg sharer if her own treatment was unsuccessful', with the knowledge the recipient she donated to could have conceived. These concerns about egg sharing have been theorised previously as expert opinion [46, 47, 54], and also in '***Chapter 3: Study II'*** in a survey of healthcare professionals [61]. Therefore, our study cohort answering this survey had a good understanding of the concept of egg sharing, as they cited similar benefits and concerns surrounding the process as healthcare professionals and other experts in the field. Unsurprisingly, our study participants who were in favour of egg sharing gave these issues a lower score than those against egg sharing.

Regarding the potential impact egg sharing has on the success rates of treatment, we reported no difference in LBR between egg sharers and age matched standard IVF patients (***Chapter 5: Study IV***). Most other studies have also reported no difference in LBR in patients who egg share [62, 65, 67]. Studies have also investigated the psychological adjustment of egg sharers who participated, and reported generally positive attitudes towards their overall experience, with low levels of regret, even when their own fertility treatment was not successful [57, 58].

Despite some of the concerns our study participants raised, only a minority (21.9%) answered 'no' to considering egg sharing if they were to need it for their own treatment in the future, which implies the benefits of egg sharing generally outweigh the issues for the majority of women. Regarding the use of egg sharing for women to access fertility preservation treatment and social egg freezing (SEF), only 19.9% of study participants knew this was an option to be available, and only 15.1% felt this was not a good option for them. Indeed, other studies have consistently found the financial cost to be the most significant barrier for them to go ahead with SEF [24, 26, 268]. Other studies have found that 71-73% of women would likely chose to undergo SEF if the cost were paid for by their employer or subsidized

by the government [23, 269, 270]. With financial constraints being one of the most consistent barriers to women accessing SEF, egg sharing provides a different option to government or employer subsidization. The age women reaching first time motherhood has increased steadily in the UK over the last 70 years [8]. Allowing more women to potentially access SEF could directly decrease the number of women and couples suffering with infertility and involuntarily childlessness in the future, and those requiring a donor egg to conceive.

6b.4.4 Legislation surrounding egg donation

The passing of the 'Disclosure of Donor Identity' legislation in 2005 in the UK was feared to end anonymous egg donation in the UK, as it was hypothesized numbers would drop so dramatically. Most of our study cohort agreed with this legislation, with 19.1% 'disagreeing' with it, and only 20.6% answering this regulation would stop them from potentially donating their oocytes. The data from this study's participants is supported by two systematic reviews on the attitudes towards donor anonymity, with most supporting donor identity release (***Chapter 2: Study I; Chapter 6: Study Va***) [57, 253]. It must be noted that when this legislation was passed in 2005, there was an initial steep decline in donor numbers. However, there has been a steady increase in the number of altruistic egg donors in recent years in the UK [5]. Despite this recent increase and willingness to donate non-anonymously, the slight majority of our study cohort would not want contact with the recipient couple or resulting offspring in a hypothetical scenario, which is again consistent with other studies (***Chapter 6: Study Va***) [253]. This suggests that although our study cohort agree with the principal of non-anonymous gamete donation, the thought of future contact with their potential recipient or resulting children remains quite overwhelming. In 2023, the first children conceived from donor gametes after legislative changes will start to be able to obtain identifiable information of their donor, and therefore make contact. Longitudinal research into the psychological outcomes of egg donors and recipients years after their treatment, as well as reporting on the family dynamic will be vital, and could aid in reassuring future potential egg donors, presuming this psychological data acquired will be positive.

Regarding the general public's views on the amount of compensation oocyte donors are currently paid (£750), most of our study participants were 'against' or 'undecided', and it is significant that these views were not linked to the annual income of the respondent. However, despite this it was interesting that the majority of our study cohort would not be more motivated to donate if this compensatory limit were increased, with very few answering financial gain being the main motivation for them to donate. These findings show that most respondents feel egg donors are being inadequately compensated, but as an increase in the amount of compensation provided would not increase their motivation to donate, we must conclude that increasing the compensation limit would not significantly increase the uptake of donors. Our findings regarding attitudes towards monetary payments are consistent with other studies performed in countries where commercial payment for donor eggs is illegal [216, 224, 229, 241]. It must be emphasized that the impact on recruitment rates should not be the sole consideration countries should have regarding the ethics of financial payments. However, the fact it seems unlikely increasing this payment would result in an increase in women donating their eggs in the UK is an interesting finding.

Most respondents felt women needing donor eggs to conceive should have their fertility treatment funded by the government. In the UK, there is a huge discrepancy in NHS funding for fertility treatment, dictated by the CCG in which the couple live. The vast majority of CCGs do not fund donor egg treatment in the UK, especially in women aged over 40 years.

6b.4.5 Limitations and recommendations for future research

This is the first study to investigate the general public's knowledge and attitudes towards egg sharing. There were over 600 study participants producing statistically significant qualitative data. This has allowed for improved awareness into numerous potential factors that could be negatively impacting egg donor and egg sharing recruitment. Additionally, the questionnaire used for this study was modified from a previously validated survey that has been used in other studies that have been published in peer-review journals [61, 199, 200].

Despite this, there were some limitations to this study. First, we used convenience sampling to access participants, and while this permitted many women to be recruited to the study, this methodology could have introduced sampling bias. Second, our study cohort was not a true reflection of the UK population overall, with most respondents Caucasian, heterosexual and holding a university degree. Third, the study is also open to participation bias, since those with good knowledge, or very positive or negative thoughts on the subject being surveyed are potentially more likely to participate. Fourth, survey based research is limited as closed questions are used to permit the generation of quantitative data and statistical analysis. This does not give study participants the option of giving a justification of their answers, or going into more detail, which limits the depth of analysis that can be performed. For example, most of our study cohort were in favour of ED, and said they would consider donating, however we know this does translate into the vast majority of them going on to donate.

It would be valuable for future studies to focus on performing interviews with the general public. This would give the interviewer the opportunity to investigate interesting answers and topics in greater detail, enabling more in-depth analysis of certain complex issues. Interviews would also give the opportunity to clarify unclear responses, allowing a reduction in missing data or misinterpretation. Additionally, there should be a greater drive to discover the knowledge and attitudes of women from different religions and ethnic minorities, as well as more same-sex couples.

6b.4.5 Conclusions

It has been previously reported that healthcare workers have very poor knowledge of the egg donation and egg sharing process. As expected, this study reports even worse knowledge among the general public in the UK. Low numbers of women coming forward for egg donation and egg sharing mean that supply is currently falling far short of demand for donor oocytes. The reasons for this are likely to be multiple, but this lack of knowledge could be a significant contributor to the current shortfall, especially when considering the positive attitudes our study cohort had towards egg donation and sharing.

With studies consistently revealing positive attitudes for egg donation and sharing from healthcare workers and the general public in the UK, an increased weight should be placed on education and marketing campaigns to allow more women to know about their options, particularly egg sharing, allowing them to make more informed choice about their treatment options. This approach could lead to egg share numbers returning to their previous levels in the UK, which would provide direct benefit to these patients as well as women who need more choice for donor eggs.

Chapter 7:

Summary of findings and conclusions

Summary of findings and conclusions

Currently the number of donor eggs available for women in the UK does not meet the demand. Egg sharing traditionally constituted a significant number of egg donors in the UK, however the number of women coming forward for egg sharing has dropped in recent years [266]. The explanation for the low egg numbers and dropping egg share numbers in the UK are not immediately obvious, but are certainly multi-factorial and warrant careful consideration.

Since egg sharing was introduced, it has generated considerable ethical and policy debate, with many calling for it to be banned [46-48]. Egg sharing is an exception within the HFEA regulatory framework, which accentuates the concept that both sperm and egg donation should be cost neutral [101]. Even after allowing egg sharing to continue in the UK, the HFEA were clear to caution that although they had allowed egg sharing to continue, they had not given the practice their ethical approval [49]. Since this statement, the egg sharing programme has continued to be analysed and discussed, clearly demonstrating the differences of opinion regarding this unique scheme [46-48], with some arguing that, other than IVF itself, no other assisted conception procedure has undergone such intense scrutiny [50].

This thesis has thoroughly interrogated all clinical aspects of egg sharing in the UK. First, a systematic review was performed of all existing literature on this topic to ensure all available information on the topic was synthesized to aid in formulating the other studies that were performed (***Study I***). Second, a survey of healthcare professionals was undertaken to ascertain their knowledge and views on egg donation and egg sharing (***Study II***). Third, patients who had donated or utilized donor oocytes through egg sharing were extensively surveyed regarding their motivations, attitudes, treatment experiences and views on donor anonymity (***Study III***). Fourth, outcome data from egg share donors and recipients was analyzed (***Study IV***). Finally, the general public's views on egg donation and egg sharing was investigated (***Study V***). The data generated from this research will be summarised below, with points on how the research findings could be utilized clinically, as well as likely reasons for the falling egg share numbers in the UK.

7.1 Study I

Two systematic reviews were performed. Study Ia was titled 'A systematic review investigating psychosocial aspects of egg sharing in the United Kingdom and their potential effects on egg donation numbers'. Study Ib was titled 'A systematic review investigating psychosocial attitudes, motivations, treatment experiences and disclosure decisions of oocyte recipients'. These systematic reviews aim to provide an up-to-date analysis of psychosocial factors surrounding egg sharing, from the point of view of the egg share donor and recipient. Its secondary aims are to investigate the motives, attitudes and treatment experiences of egg sharers and recipients, as well as any issues about disclosure and non-anonymity.

7.1.1 Study Ia

The included studies consistently revealed the vast majority of recipients who secured their eggs through egg sharing reported positively about their treatment experience, and were also glad to have participated in the programme. Studies showed egg sharers motivations are multifactorial. They make a clear distinction between financial and treatment incentives when deciding to participate. A small majority of egg sharers would still partake regardless of their financial situation, showing they exhibit a broad attitude towards egg donation and the importance of reciprocity amongst couples seeking fertility treatment [146]. This systematic review revealed egg sharers to be educated and more than capable of addressing the key issues that arise from participating in egg sharing. They did not feel exploited by egg sharing, but instead stated a view that egg sharing provides the opportunity for a 'win-win' solution for themselves and their recipients. Unsurprisingly there was a difference in age between egg sharers and their recipients, so it would be expected for recipients to be earning more than egg sharers, however, no studies investigated this. This review reports the vast majority of egg sharers to have been consistently happy to have taken part in the programme [48, 60, 63, 146], with one study reporting 83.3% of their participants would donate again, and only 2.1% regretted undergoing treatment as an egg sharer [60]. This data indicates egg sharers are well equipped to make the challenging decisions facing them, and therefore they are exhibiting adequate consent. Gurtin et al. (2012c) was the

only study reviewed to investigate how egg sharers and their recipient's acquired knowledge of egg sharing. The fertility centre was the main source of information for most participants, followed by their own personal research, with very little advice on this option obtained from GPs or gynaecologists. This is of potentially huge significance as these GPs and gynaecologists are a much more widely accessed source of medical information and options for couples trying to conceive. Indeed, Gurtin et al. (2012c) mentioned numerous participants were frustrated by the amount of time it took for them to learn of the option of egg sharing, with these women also stating significant disappointment that healthcare professionals they had spoken to earlier had not discussed egg sharing with them. This frustration is understandable as the period from initially seeing a GP to securing a referral to an IVF centre can be as long as 1-2 years in the UK. Furthermore, the nature of the information being accessed is of concern, since it is known that personal research on the internet can contain a lot of inaccurate, unregulated, and biased information on the subject.

Studies consistently reported that both egg sharers and their recipients were predominantly in support of disclosure of the nature of their fertility treatment [60, 149]. In the UK, fertility clinics encourage patients towards disclosure in their counselling sessions during treatment, with this advice based on research from studies on the family dynamic of couples who adopted [155, 156], as well as studies of individuals conceived through egg and sperm donation themselves [80]. The central and recurring explanations given for not donating without anonymity were concerns for any financial or legal responsibilities for any offspring born as a result of their donation, as well as the potential emotional impact of any surprise and unmediated contact [148]. The concerns surrounding financial and legal responsibility could be alleviated by fertility clinics improving information given and education of their patients, emphasizing to them that donors carry no such responsibilities to any offspring born. With regard to fears of unmediated contact, the BFS has emphasized the need to offer and deliver counselling around times when couples disclose to their children how they were conceived or when contact is made between the donor and the child conceived by gamete donation [157], and there has been novel research work undertaken specifically to create 'donor linking' counselling [48]. Unfortunately, there has been no response from the UK government to any of these proposals, and there are currently no plans for any

government funded counselling sessions for donor-conceived offspring around these key time points, such as those established in the adoption services [158]. The obvious reason for this lack of urgency in launching these clinical services, was that when the donor anonymity legislation was passed in 2005, resulting offspring would not turn 18 years of age until earliest April 2023. However, this deadline has now passed and there remains no government funded counselling service for those involved in fertility treatment with donor gametes. In 2024 approximately 2300 donor-conceived people will be 18 years or over and therefore eligible to submit a request for identifiable information about their donor, such as their name, date of birth and last known postal address ***(figure 2a.4)*** [1]. Current HFEA data reveals that of those eligible donor-conceived people, 28 have already requested this identifying information from the HFEA [1]. Those conceived from a donor before April 2005 can only access identifiable information about their donor when they turn 18 years of age if their donor has contacted the HFEA and voluntarily removed their anonymity [1]. As of November 2022, 260 donors have taken this step and waived their anonymity [1]. Identifying the fact that donor conceived offspring and contact with their genetic parent is now a reality, Donor Conception Network are currently undertaking significant work to offer practical and psychological support to donors and their offspring. The knowledge that such services are available could encourage more potential donors and egg sharers to go ahead.

7.1.2 Study Ib

Unsurprisingly, the principal motivation underpinning the decision for recipients to use donor eggs to conceive across all the studies was the desire to achieve motherhood. Many recipients reported a feeling of optimism towards the process; however, a significant minority did report concerns about perceived social stigmatisation of using egg donation to overcome infertility. The process of egg donation treatment should be normalized by clinics as much as possible during consultations and counselling sessions. It may also be appropriate for clinics to mediate the meeting of prospective couples with patients who have undergone treatment with donor oocytes, successfully and unsuccessfully, to discuss their experiences and potentially alleviate potential concerns. The SEED Trust have produced short films providing personal insights from oocyte and sperm donors in an attempt to increase the number of people coming forward to donate [195]. Similar films involving women who underwent fertility

treatment with donor oocytes should be produced to give easily accessed accurate information, and potentially address anxieties prior to starting treatment. This could increase the willingness of both donors and recipients to undertake egg donation, as well as have a positive impact on treatment experience.

Regarding donation to their offspring, most recipients were open to disclosing the nature of conception to their child in the future. Numerous studies also confirmed that recipients stated they would want to know themselves if they had been born as a result of oocyte donation. Only one study found that more couples disclosed to family/ friends than to their offspring [177]. The fear of accidental disclosure considering the child may well be in regular contact with the donor, as well as the desire to establish clear boundaries may well account for higher disclosure rates amongst recipients who used known donors [167, 174, 178].

It is important to consider the potential implications of accidental disclosure on the parent-child relationship. Indeed, a significant minority of recipients chose not to disclose to their offspring, which is of concern since most recipients had confided to close family or friends of the nature of conception. This means multiple parties are involved in secrecy and inadvertent disclosure is a risk, which could significantly impact on long-term recipient-offspring relationships. Delayed disclosure to the child could also negatively impact their personal development. Detailed ongoing conversations from a young age help the child to grow up understanding the nature of their conception and helps build openness and trust within the family unit [196]. Ongoing contact with a counsellor may alleviate feelings of being isolated and provide guidance on when and how to disclose. This also allows parents to involve their children in discussions in a supportive environment to strengthen the parent–child relationship.

The majority of studies supported the donor's giving identifiable information that any resulting child from their donation can access in the future. However, two studies reported most recipients were against the child accessing donor identifying information [91, 102]. The 'Disclosure of donor information Act' of 2005 in the UK removed donor anonymity, meaning donor-conceived children could request certain

identifiable information about the donor from age 16 onwards. Evidently, some recipients do not want the child accessing information about its genetic origins due to the fear of an unfavourable response from the child and disruption to the family unit. After disclosure, the resulting support network was consistently cited as a reason for disclosure to a wider network [140, 168, 169, 177, 194].

This systematic review summarises the current literature surrounding the psychosocial attitudes of oocyte recipients towards oocyte donation. The psychological data presented in this review is largely reassuring for oocyte recipients. Whilst the uptake of oocyte donation and procedural disclosure appear to be increasing, oocyte recipients continue to be challenged by social stigmatisation, fears surrounding disclosure, and uncertainty regarding relationships with the donor. Counselling is invaluable at guiding oocyte recipients through the decision-making process, but longer term support is required, specifically following birth and around the time of disclosure to their offspring and community. Counselling sessions may be improved by incorporating the support of previous oocyte recipients, to provide prospective recipients with insight into the challenges through personal anecdotes. Consideration of specific boundaries to undergoing IVF with donated oocytes needs to be explored, including research amongst ethnic minorities where literature is lacking.

7.2 Study II

The systematic review performed (***Chapter 2: Study I***) identified poor knowledge and referral rates for fertility patients regarding egg sharing, particularly from GPs and general gynaecologists. A possible reason for the decreasing number of egg sharers is that relevant healthcare professionals are not informing fertility patients of this option when they seek fertility advice from them. This could be for numerous reasons, including lack of knowledge of egg sharing or disagreeing with it as a treatment option for couples. Healthcare professionals attitudes and knowledge towards egg sharing has not been previously studied. Therefore, this study aims to investigate the views and knowledge that healthcare professionals in the UK have regarding egg sharing, as well as the proportion of them who have actually referred a patient for egg sharing.

Overall, healthcare professionals who participated in this study appear to strongly support the process of egg donation in general, as well egg sharing. 89.8% of participants supported egg donation, and 78.2% believed egg sharing should take place. Therefore, although both egg donation and egg sharing are thought of in a positive light, there does appear to be higher acceptance amongst medical professionals of egg donation in general. Overall, only 16.5% of respondents had referred a patient for egg sharing that were in a position to do this (GPs or gynaecologists). The vast majority of those who had not referred, cited a significant lack of knowledge as the main reason for this. 76.6% of GPs were either unaware of the option of egg sharing or felt they did not know enough about it to refer a patient. Healthcare professionals felt the biggest issue regarding egg sharing is a potential adverse psychological impact of the egg sharer if her own fertility treatment is unsuccessful. The issue with the second highest mean score was the concern that egg sharing could negatively impact the outcome of the egg share donor's own treatment.

This study has found there is an overwhelming lack of knowledge of egg sharing among key medical professionals that could both refer directly or inform fertility patients of this treatment option. The number of egg sharers registering and participating in the programme has reduced in recent years in the UK, and a lack of awareness amongst the medical community could be impacting these numbers. Overall, healthcare professionals voice significant support for egg donation and egg sharing, although when compared to purely altruistic donation, views of egg sharing were slightly less positive. The potential benefits of egg sharing ranked significantly higher than any potential issues surrounding the programme. The most consistently raised areas of concern were the potential negative psychological impact on the egg sharer if her treatment was unsuccessful, as well as the potential repercussions of donating half her eggs on her own treatment success. Published studies have shown these concerns to be far less significant than hypothesized, so educating the medical community about egg sharing and the research that supports it, could further improve healthcare professionals' attitudes of egg sharing and increase egg sharing numbers.

7.3 Study III

The systematic review performed in ***Study I*** revealed very few studies investigating the psychosocial issues surrounding egg sharing. However, those few studies reported largely reassuring data surrounding the programme. The concerns raised surrounding egg sharing are theoretical and based on opinion, rather than empirical research. It is therefore vital that the psychological well-being of patients who donate and receive oocytes through egg sharing is better studied. Obtaining increased psychosocial data on the topic would also enable improved counselling for our donor and recipient populations. In this study oocyte donors and recipients who were treated at the LFC between 2012-2019 were surveyed. The study aimed to investigate their motivations, attitudes, and treatment experiences towards oocyte donation. The study also investigated the issue of disclosure about the nature of their conception. In the donation and recipient groups, participants were further divided into two groups: patients who have gone through treatment previously (retrospective patients), and patients who are currently undergoing treatment (prospective patients). Retrospective and prospective patients were analysed to see how the time point the patients answered the questionnaire changed their responses. A comparison was also made between donors and recipients. It is only the second study to investigate this topic and the largest to do so.

7.3.1 Motivations and feelings about the egg sharing scheme

Egg share donors only ranked the opportunity to obtain cheap fertility treatment fourth overall, with the desire to help someone else have a child the number one motivating factor. 35.2% of donors stated they would still donate if there was no direct financial benefit to them, with 52.6% saying they would donate regardless of their ability to self-fund their fertility treatment. However, 35.2% of egg sharers agreed that egg sharing was their only option to get pregnant, implying they cannot afford IVF and therefore egg sharing is their only option if they want to have a child. This is a consistently raised concern of the scheme [55, 59]. Respondents who answered that egg sharing was their only option to conceive were significantly less likely to take part if they could afford IVF (39.3% vs 59.0%, χ^2, $p<0.05$). This strongly implies some egg sharers are participating mainly for financial reasons, which is unsurprising. Interestingly, there was no difference in the annual incomes of these patients. These findings show that egg sharers motivations are multi-faceted and include financial considerations, and support findings

from other studies regarding the co-existence of egg share donor's desire to help others but also themselves [48, 52, 145]. Despite this, it is important to note that the majority of egg sharers highlighted their sense of empathy towards their recipient by ranking altruistic reasons higher than financial ones. Overall, they clearly understood the scheme offered them a practical option, enabling them to address their financial concerns while helping someone else have a baby.

The recipients most significant motivation was the desire for their partner to have a genetic tie to the offspring, and their desire to experience pregnancy. Interestingly the concerns of the recipients scored lower than their motivations. This suggests the majority of patients who participated in the scheme found the positives significantly outweighed the negatives. As expected, the main concern raised by both donors and recipients was not getting pregnant, as well as not having enough eggs collected. There were additional specific concerns raised by donors, such as concern for the well-being of the recipient, and for recipients, such as the donor changing their mind.

7.3.2 Knowledge and information gathering surrounding egg sharing

Most egg sharers found out about the programme from the internet and personal research, in contrast to recipients who were informed of the option by their fertility specialist. Egg sharers can either self-refer to the fertility clinic after their own research, or be referred by their GP or gynaecologist. It is therefore interesting to note that only 4.8% of egg sharers learnt of this option from their GP. This is very relevant as GPs particularly are a widely consulted source of advice and information for women trying for a baby. Egg sharers need to be aged 35 years or under to be allowed to participate, as well as have an anti-müllerian hormone (AMH) level of 7 pmol/l or higher. The delay in them accessing egg sharing, with most egg sharers having tried to conceive for more than 2 years, could mean they are no longer eligible to participate as egg sharers. GPs are front line and the most easily accessible healthcare professional available to patients, and the vast majority of fertility patients will see their GP while trying to conceive prior to a fertility specialist. They are therefore in an excellent position to provide accurate and objective information to patients struggling to conceive, not only about the existence of the egg sharing programme, but also more generally about the various assisted reproductive treatments

available to them. These findings are unsurprising as a study performed as part of this thesis (***Study II***) reported that 63.1% of healthcare professionals surveyed had little or no knowledge of egg sharing [61]. Only 16.5% of the GPs and Gynaecologists surveyed had previously referred a patient for egg sharing [61]. While it is obviously important not to pressurize potential egg sharers, it is also vital to tackle the paucity of information that is taking away the opportunities for some individuals to pursue these treatment options.

In contrast, most recipients found out about egg sharing from their fertility specialist, and this is likely explained by recipients having multiple failed attempts with their own eggs, or being older with a very poor chance of success. Recipients also undertook considerably more research on egg sharing and egg donation compared to their donors. 17.7% of egg share donors undertook less than an hour of personal research, exemplifying the importance of the role the fertility clinic and counselling service has with regard to giving egg sharers sufficient information to make an informed choice to participate in the scheme.

7.3.3 Attitudes towards egg sharing

In contrast to the other studies published, regarding their attitudes towards egg sharing, overall donor's views were more positive when compared to recipients. This is perhaps unsurprising as egg share donors are receiving their fertility treatment free of charge and will be the genetic mother of any child conceived, while the recipient is paying and will not have a genetic link to the child. However, it must be noted that the vast majority of recipients had positive attitudes towards the scheme.

The majority of both groups also reported favourably regarding their opinions of the ethics and regulations surrounding egg sharing. Critics of the programme have put compromised consent at the centre of their objections [54, 55, 59, 152, 153]. Couples who are desperate to conceive and need IVF, but do not qualify for government funded treatment or cannot afford to pay themselves, are a potentially vulnerable group that could be exploited. It would be morally unacceptable if a woman who would not donate for moral or psychological reasons is forced to reconsider this decision due to her financial

situation [43]. This study directly explored this issue and the validity of the decisions they had made. The vast majority of egg sharers 'strongly disagreed' with the statement that egg sharing exploits women. 91.8% of egg sharers were glad to have taken part, 72.6% would participate in egg sharing again, 92.0% would recommend egg sharing to family or friends, and 92.6% of egg sharers felt positively about the medical care they had received. It is also logical to assume that if an egg sharer's judgement was obscured by the offer of free IVF treatment, there would be evidence of people complaining about this afterwards, or at least expressing regret that they had taken part [101]. The data from this study provides strong evidence that they are not being exploited and that their consent is valid.

7.3.4 Demographic differences between egg sharers and their recipients

There were some key demographic differences between egg sharers and their recipients which has not been reported previously. Although there was no difference in employment status, recipients were significantly higher in educational level, with most recipients having a higher university degree (75.27% vs 58.06%). This contrasts with a previous study, that reported no difference in educational level between egg sharers and their recipients [49]. There was a significant difference in age of donors and their recipients, with recipients on average 9.8 years older. This is unsurprising considering female age is directly related to positive prognosis of assisted reproduction, and that only women under 35 years are allowed to act as donors. Age is also related to annual income and career trajectory. It is therefore unsurprising that recipients earn significantly more money than their egg share donors. For example, 43.70% of recipients earnt > £100,000, compared to only 2.0% of egg sharers in this category. Most egg sharers earnt < £30,000 (54.0%). This is a significant finding and the first study to report this difference, with a previous study not including it as it was deemed inappropriate in piloting [49]. However, it does not mean that egg sharers are poor, desperate women who are forced to egg share against their own moral beliefs. When asked to vote for the single most important motivating factor, the highest selected answer was 'opportunity to obtain cheaper fertility treatment'. However, a slight majority (52.6%) of egg sharers stated they would participate in the scheme regardless of their ability to pay. As reported above, they do not feel exploited. They also reported they were better informed of the process compared to recipients.

There were differences in relationship status with significantly more recipients married (71.59% vs 48.92%), and significantly more egg sharers single (13.44% vs 7.89%). Most egg sharers and recipients were in heterosexual relationships, however more egg sharers were in same sex relationships (25.70%) compared to recipients (16.32%), although this was not statistically significant. There are three likely explanations for these findings. First, with numbers of women freezing their eggs for social reasons increasing exponentially in recent years, egg sharers have the option to undergo ovarian stimulation and then freeze any mature oocytes obtained for themselves for future use. Single egg sharers are 35 years and under, and it is likely that they are egg sharing for fertility preservation rather than embarking on single motherhood at that age, although this factor was not surveyed. Second, the number of women embarking on single motherhood by choice is growing, and women choosing to use this route to maternity are usually older women, and therefore requiring donor eggs to conceive [49]. It is worth noting that offspring born in this circumstance will be using DEDS to conceive, and therefore bear no genetic relationship to their parent. Third, lesbian women having IVF treatment are not infertile, and when presenting to fertility clinics at a young age are often ideal candidates to participate in egg sharing. There is the possibility, that lesbian women being over-represented in the egg sharing population could be explained by them being more willing to take part as egg donors in egg sharing schemes, compared to heterosexual women and if so, why would this be? One reason could be that lesbian women need donor sperm to conceive and are therefore more open to the idea of donating their own eggs to help another couple who require donor gametes to conceive, just like they did. These explanations are perhaps unsurprising but do demonstrate the changing landscape of patients accessing IVF, and the assumption that a patient attending for fertility treatment will be in a heterosexual relationship, having struggled to conceive naturally, to be completely outdated.

7.3.5 Experience based on treatment outcome

Concerns that egg share donors whose treatment was unsuccessful would be damaged psychologically were not supported from the findings of this study. For egg sharers whose treatment was unsuccessful, there was no significant difference between treatment outcome, and their responses to whether they

would: participate in egg sharing again in the future; recommend egg sharing to a friend or family member who needs fertility treatment; felt well informed of egg sharing; and felt they had sufficient support from the fertility clinic during and after their treatment. However, when asked if they were 'glad they took part', 99.4% of successful egg sharers answered yes, compared to 72.7% of unsuccessful egg sharers, and this reached statistical significance. 14 unsuccessful donors found out their recipient's treatment was successful, and all reported they were happy for their recipients (100%), with the vast majority of this category stating they were glad they took part (85.7%). This category of women represents an important focus of interest, regarding the ethical debate surrounding egg sharing. Contrary to theoretical ethical debate, none of this group of women express negative psychological feelings, and in fact all state they are happy for their recipient. Although the number in this group is small, it is higher than the only previously published study reporting similar findings [60].

In contrast when a comparison was made between successful and unsuccessful recipients, adverse treatment outcomes did impact negatively on their treatment experiences. Recipients whose treatment was unsuccessful were less likely to recommend treatment to their family and friends; less likely to undergo further fertility treatment; felt less supported by the clinic during their treatment, and afterwards. Despite these differences, it is important to note that the majority of recipients still felt positively about their treatment experiences, albeit in lower proportions. This finding is not a reflection on egg sharing, as the recipients would have almost certainly answered similarly regardless of how they sourced their donor eggs. It should be remembered that recipients have usually undergone multiple fertility treatments with their own eggs, and been told the most likely reason for failing to conceive is due to poor quality of their own oocytes. This is a difficult decision for a lot of couples to reach. It is therefore understandable they are expressing these feelings after unsuccessful treatment with donor eggs, and shows the importance of the emotional and psychological support a clinic offers them after a negative experience, such as ensuring easy access to clinical staff and counselling services after a negative outcome.

7.3.5 Attitudes towards disclosure

Supporting the findings from previous studies, a significant proportion of egg share donors were in favour of openness to children with regard to the nature of their conception, with the majority feeling it was the recipient's right to choose whether or not to disclose this to the child [48, 60]. This implies donors have trust in the parenting skills of their recipient.

With egg sharers donating with the knowledge of the lack of donor anonymity, it is reassuring that the vast majority of egg sharers were willing to meet their donor offspring in the future, with only 4.1% preferring no future contact. This is reassuring for recipients and their offspring, who may have concerns regarding the reactions of their donor in the future if they wish to make contact. This raises a hypothetical issue of how the donor may feel in the future if they are not contacted. If they were anticipating and looking forward to future contact, this could bring feelings of disappointment. This issue should be addressed through counselling, where donors should be encouraged to understand their powerlessness regarding whether a child born as a result of their donation is informed of the nature of their conception, and if informed, whether that child would ever wish to make future contact with them.

Regarding recipients, the vast majority intended to disclose the nature of conception to their child, which is encouraging. This is in keeping with the general atmosphere surrounding disclosure and the advice patients are given by counsellors in the UK. It is of course important to understand the difference between actual disclosure rates and intentions to disclose, as it is possible women will change their minds in the future or may feel they haven't found the right time to disclose [204].

Regarding differences between donors and recipients and their responses, more recipients stated they had a right not to disclose the nature of their conception compared to donors. Recipients were also less happy with future contact with their donor and child. More recipients also felt that resulting offspring could be emotionally damaged with future contact, when compared to donors. These findings are in contrast with the only previous study to explore these issues, who reported no differences in responses from egg sharers and their recipients [60]. Counselling at the time of donation should provide realisation

of the potential of their child having a same-aged genetic half-sibling, as well as the possibility of themselves, the recipient, or both parties not having children.

This is the largest study to investigate the psychological issues surrounding egg sharing for donors and recipients. Overall, egg sharers and their recipients are similar groups of women, the majority of whom are pleased to have taken part in the programme. There were also much greater similarities between egg sharers whose treatment had been successful and unsuccessful. It is unsurprising that women who conceived were especially glad to have taken part, however the significant majority of unsuccessful donors were positive about the process, with only a very small minority expressing regret at taking part in treatment. Egg sharers are motivated by the desire to have a baby, obtain cheaper IVF, and to help other women to conceive. Therefore, while financial motives are important in their decision-making process, their motives are multifactorial with altruistic factors playing a similarly important role.

7.4 Study IV

Healthcare professionals (***Chapter 2: Study I)*** and potential egg share donors (***Chapter 3: Study II; Chapter 4: Study III***) consistently report concern that by sharing their eggs they could be jeopardizing their chance of having a baby [57, 58, 61]. Some experts have also suggested that doctors administer gonadotrophins at higher doses to egg share donors to retrieve more oocytes, therefore increasing the risk of the donor suffering with OHSS. Alongside receiving fewer oocytes, egg share recipients also report not receiving sufficient eggs as one of their primary concerns, but also consistently mention a degree of apprehension about receiving eggs from infertile women, and that these factors could negatively impact their chances of having a live birth [62]. In addition, egg share donors and recipients could worry that the fertility clinic will provide preferential treatment to their counterpart during their care [63].

The primary aim of this study was to investigate whether egg sharing compromises the chance of the donor or their recipient having successful treatment, with a comparison also being made to the treatment outcomes of standard IVF patients and non-egg share recipients. Secondary aims are to compare cycle

characteristics, and therefore fully update the current understanding of outcomes of egg sharers and recipients.

7.4.1 Egg sharer donors

Data from this study revealed no statistically significant difference in FR, IR, CPR, MR or LBR between egg sharers and their clinically matched standard IVF patients. This study's findings corroborate other studies that reported no difference in LBR between the different patient groups [62, 65, 67].

The number of day 3 embryos available for transfer however was less for egg share donors when compared to their clinically matched standard IVF patients. This meant standard IVF patients had a higher CLBR of 55.60% compared to 51.72% for egg sharers, which reached statistical significance. This is unsurprising since a standard IVF patient has more eggs available to use in her fertility treatment, however this is the first study to report this finding regarding CLBR. It is debated that by increasing the number of eggs required for an egg share donor to be eligible to participate in egg sharing, the CLBR could be improved. The existing policy at LFC is that a minimum of 8 oocytes are required, and are then shared equally between the egg sharer and recipient. Only 3.4% of egg share donors collected ≤ 8 oocytes in this study, meaning 96.6% of patients produced enough oocytes to egg share. If the number of eggs required to participate were increased to a minimum number of 12 or 15 eggs, then the potential cancellation rate would rise significantly to 29.5% and 54.4% respectively. Increasing this threshold would therefore substantially restrict a patient's accessibility to the egg sharing programme. This study provides valuable data to allow fertility clinics to advise egg sharers that they have the same LBR per embryo transfer in comparison to clinically matched standard IVF patients, but have a 3.9% lesser CLBR, meaning a small proportion of them will require a further round of ovarian stimulation treatment, which they might not have needed if they did not participate in the egg sharing programme.

Critics of egg sharing have also suggested that to increase the number of eggs collected, fertility specialists will give inappropriately high doses of gonadotrophins, thus exposing their egg sharers to a higher risk of developing OHSS [55]. Data from this study found no difference in number of days of

stimulation required, dose of gonadotrophin used, or number of oocytes collected, when egg sharers were directly compared to their clinically matched standard IVF patients. This is encouraging data and reveals egg sharers are not given inappropriate drug regimens or hyperstimulated to produce more eggs, but instead put on the same gonadotrophin dose as their clinically matched standard IVF patients, and therefore not put at higher risk of developing OHSS.

At LFC, all egg sharers and their recipients receive implication counselling prior to starting their fertility treatment, to help ensure their understanding of and commitment to the egg sharing programme. Egg sharers are aware they have the right to withdraw their consent from participating up until their recipient's eggs have been fertilized with sperm. If the egg sharer produces less than the minimum eight oocytes, she has two options. Firstly, she can donate four eggs and use the remaining oocytes for her own treatment. Secondly, she can use all the oocytes retrieved for her own fertility treatment. By choosing the second option, the patient would be leaving the egg sharing programme and become a standard IVF patient and be charged a fee for the treatment received. Between 2010-2019 only 3.4% of egg share donors faced this difficult clinical dilemma.

7.4.2 Egg share recipients

One concern raised by experts regarding egg sharing, is that a fertility clinic will prioritize the recipient, who is paying for her treatment, over the egg share donor during the allocation of the oocytes retrieved. Data from this study revealed no difference in the number of oocytes allocated, FR, IR, CPR, and MR were no different between the egg share donor and their recipient. Egg share recipients did have a significantly inferior LBR per embryo transfer compared to their egg sharer, which was an unanticipated finding (49.10% vs 41.90%, $p < 0.05$). Oocytes retrieved from egg sharing are allocated at random, as it is not possible to accurately assess egg quality immediately after oocyte retrieval, meaning this theoretical concern of preferential treatment regarding allocation of eggs is not only unlikely, but not practically possible. Of note, there was no difference in CLBR between egg sharers and their recipients (51.72 vs 51.30, $p > 0.05$). The data from this study is in contrast to earlier studies who reported better LBR for recipients compared to their egg share donors [63, 64, 212].

Another issue surrounding egg sharing that is regularly raised is that egg share recipients feel they will receive poorer quality eggs from egg share donors as they are infertile with no proven fertility, compared to recipients using purely altruistic donors [62, 213]. Egg share recipients received fewer eggs when compared to other recipients (6.61 vs 9.31, $p < 0.001$), which meant they had fewer day 3 embryos available for potential transfer (4.50 vs 6.20, $p < 0.001$). This resulted in egg share recipients having a lower CLBR (51.3% vs 62.7%, $p < 0.001$). This data reveals that egg share recipients are at no disadvantage per embryo transferred, but as they have fewer eggs compared to other recipients, they may need to undergo further treatment, which of course increases emotional and financial burdens. This issue should be weighed against the obvious advantages of the egg sharing programme, which include the potential to address a significant supply issue, lowering waiting times to access donor eggs and minimising the need for non-patient donors to undergo unnecessarily invasive treatment.

Summarising, egg share recipients should be informed of an overall high LBR per embryo transfer of 41.9% and a CLBR of 51.3%. It would seem that as egg share donors are highly selected for age and adequate egg reserve, the reduced number of oocytes available for their recipient are still enough to offer excellent outcomes for both the egg share donor and her recipient.

7.5 Study V

Oocyte donation and the associated psychological issues egg donation patients endure have been analysed in several studies. This thesis has performed two systematic reviews of the literature on this topic (***Chapter 2: Study I***), as well as surveying healthcare professionals (***Chapter 3: Study II***), and egg share donors and recipients from LFC (***Chapter 4: Study III***). However, it is also important to understand the general public's views, as well as potential donors, which will allow a knowledge of a much wider viewpoint. To achieve this, there were two aspects to ***Study V***. First a systematic review was performed with the aim of defining psychosocial aspects of the general public and potential oocyte donors, which includes their motivations, concerns, and attitudes towards oocyte donation (***Study Va***).

Additionally, the systematic review explores potential donor's views surrounding donor anonymity. This is the only systematic review to exclusively explore the general public and potential oocyte donors.

There has been no study investigating the attitudes and knowledge towards egg donation and egg sharing amongst the general public in the UK. This is highly relevant as these women of course are representative of potential egg donors, and if better informed and encouraged to participate, could go some way in helping to solve the oocyte supply issue in the UK. ***Study Vb*** aims to investigate the knowledge and perceptions of female fertility decline, as well as the knowledge and attitudes towards egg donation and egg sharing amongst women from the UK. Secondary aims were to investigate the opinion of UK women of the 2005 legislative change towards donor anonymity.

7.5.2 Study Va

Data from this review consistently reported altruism as the primary motivating factor, although monetary compensation was also significant. It is important to note that motivations will be multi-factorial [232]. In countries prohibiting any compensatory payments for donation, the number of women donating is significantly less, showing the likely importance of compensation to encourage donation. Studies reported a higher acceptance of egg donation amongst infertile women and a greater likelihood for them to donate, compared to the fertile population. This is understandable, as infertile women are more likely to empathize with the significant psychological impact of infertility, making them potentially more likely to donate altruistically to other women struggling to conceive. This confirms that fertility patients are a potential valuable source of donor oocytes, such as in the egg sharing programme.

Changes have been made to legislation surrounding donor anonymity in many countries, with a change in position to increased favourability towards donor identifiable information being made available to recipient's offspring when they reach adulthood. Despite this loss of donor anonymity, this review found a significant proportion of women would still consider donating their eggs non-anonymously.

This is supported by UK data, where after an initial decline in women donating their eggs, numbers have steadily risen over the last decade [104].

7.5.2 Study Vb

Fertility knowledge

Respondents had a relatively accurate knowledge of female fertility decline, with 40.6% answering a significant fertility decline aged 35-40 years, and 33.1% answering 30-34 years. Nevertheless, 16.5% reported female fertility to decline only >40 years, which although a minority of respondents, could still lead to a significant minority of women in the general public over-estimating their fertility potential in their later reproductive years.

Study participants also had good knowledge of the success rates per embryo transfer based on female age, with 49.5% correctly stating success rates < 20% in the 40-42 year old age group. HFEA data reports success rates of 9.6% with fresh embryos and 15.6% with frozen embryos in this age group [266]. However, a significant minority of our participants did significantly over-estimate IVF success rates in this age group, with 20.9% estimating success rates of IVF treatment to be >30% per embryo transfer.

Egg donation

The general public's knowledge surrounding egg donation was quite poor, with 56.4% of study participants stating 'little or no knowledge' of egg donation, which is consistent with the findings from other published studies [218-220, 222, 223]. However, after being provided with a concise explanation 86.0% agreed with egg donation taking place. The vast majority of our study participants cited 'altruistic' motivations or the desire to help a 'family member or friend having fertility problems', with only 7.7% stating financial motivations. This is probably expected as the study took place in the UK, where financial payments for donor gametes are not permitted, and capped as a compensatory payment. However, our study cohort were not informed of the illegality of payments when they were asked this

question, implying a possible societal apprehension towards financial payments for egg donation in the UK.

The predominant issue surrounding egg donation in our study was the invasive medical process involved (43.29%). This finding agrees with other studies which reported 33-67% of respondents from the general public had concerns regarding the invasiveness of the medical treatment and the risks of the stimulation process and egg collection procedure [221, 231-233].

Egg sharing

There is a distinct lack of knowledge of egg sharing in the UK, with 80.7% of our cohort having 'little or no knowledge' of the process. This finding was anticipated, since as reported in '***Chapter 3: Study II***' 63.1% of healthcare professionals had 'little or no knowledge' of the egg sharing programme [61]. When given a concise description and explanation of egg sharing, 73.4% of the general public agreed with the practice, and almost two thirds felt egg sharing could provide a viable solution to the significant global shortage of donor oocytes. Our study cohort from the general public gave a similar level of support for egg sharing as healthcare professionals did (73.4% vs 78.2%) [61].

Our study cohort gave all of the benefits of egg sharing a high ranking, with 'allowing those access to fertility treatment who otherwise would not be able to access it', and 'the lack of a third party undergoing invasive procedures to donate', the highest scores, which is consistent with other studies in this area [57, 58, 61, 151]. The issues surrounding egg sharing that respondents rated highest were 'fears of egg sharing reducing the chance of success for the egg sharer', and 'concern for the psychological well-being of the egg sharer if her own treatment was unsuccessful', with the knowledge the recipient she donated to could have conceived.

Regarding the use of egg sharing for women to access fertility preservation treatment and social egg freezing (SEF), only 19.9% of study participants knew this was an available option, and only 15.1%

felt this was not a good option for them. Indeed, other studies have consistently found the financial cost to be the most significant barrier for them to go ahead with SEF [24, 26, 268].

Legislation surrounding egg donation

The passing of the 'Disclosure of Donor Identity' legislation in 2005 in the UK was feared to end anonymous egg donation in the UK. Most of our study cohort agreed with this legislation, with 19.1% 'disagreeing' with it, and only 20.6% answering this regulation would stop them from potentially donating their oocytes. The data from this study's participants is supported by three systematic reviews on the attitudes towards donor anonymity, with most supporting donor identity release (***Chapter 2: Study I; Chapter 6: Study Va***) [57, 253]. Despite this recent increase and willingness to donate non-anonymously, the slight majority of our study cohort would not want contact with the recipient couple or resulting offspring in a hypothetical scenario, which is again consistent with other studies (***Chapter 6: Study Va***) [253].

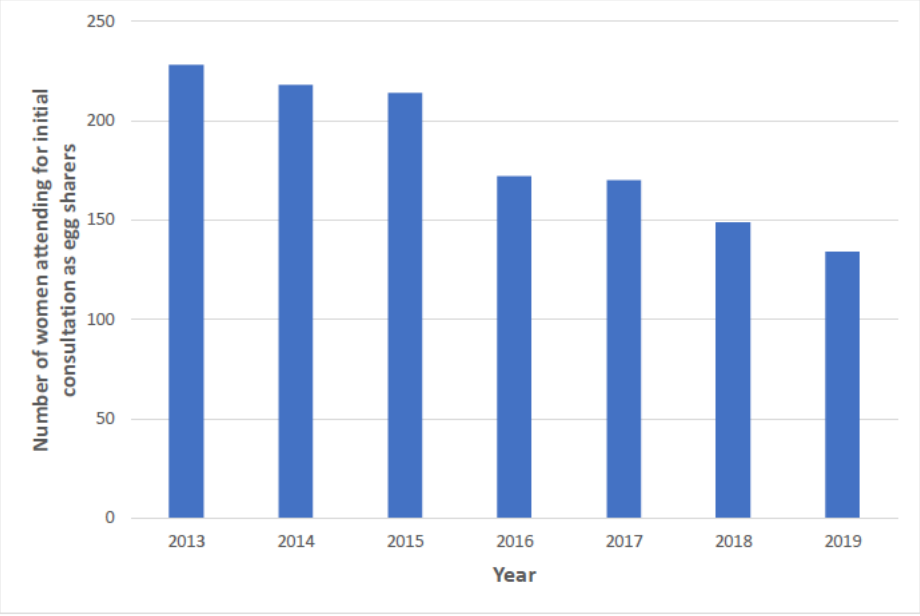
Regarding the general public's views on the amount of compensation oocyte donors are currently paid (£750), most of our study participants were 'against' or 'undecided', and it is significant that these views were not linked to the annual income of the respondent. However, despite this it was interesting that the majority of our study cohort would not be more motivated to donate if this compensatory limit were increased, with very few answering financial gain being the main motivation for them to donate. These findings show that most respondents feel egg donors are being inadequately compensated, but as an increase in the amount of compensation provided would not increase their motivation to donate, we must conclude that increasing the compensation limit would not significantly increase the uptake of donors. The fact it seems unlikely increasing this payment would result in an increase in women donating their eggs in the UK is an interesting finding.

7.6 Current egg sharing numbers in the UK and potential clinical utilization of this research

This thesis has demonstrated that healthcare professionals (***Chapter 3: Study II***); patients who had fertility treatment as egg sharers (***Chapter 4: Study III***); and the general public (***Chapter 6: Study V***)

all reported consistently positive attitudes towards the egg sharing scheme. Despite this reassuring research, there has been a decrease in the number of fertility patients participating in egg sharing, which has fallen from 698 in 2011 to 348 in 2016 [37]. This national fall is mirrored by the egg share numbers at LFC, where this research was performed. ***Figure 7.1*** shows the number of women attending for initial consultation at LFC as potential egg sharers, with 228 attending in 2013, decreasing to 134 in 2019. A likely contributing factor is poor knowledge of the existence of egg sharing in the general public, but also amongst healthcare workers, as shown by data presented in this thesis. For example, 63.1% of healthcare professionals surveyed had no knowledge of the option of egg sharing, which resulted in only 16.5% of GPs, gynaecologists and fertility specialists, who could have referred a patient to a fertility clinic for egg sharing, having done so, with a significant majority of them stating their lack of knowledge about the egg sharing process was the reason they had not referred [61].

Figure 7.1: *Graph showing the number of women attending for initial consultation at Lister Fertility Clinic, Chelsea*



Another study investigated how egg sharers and recipients discovered the option of egg sharing to achieve a pregnancy; with the fertility clinic the principle information source, followed by personal online research, with very little knowledge learned from GPs and their gynaecologists [52]. This is important as GPs and gynaecologists are the most widely consulted healthcare professionals fertility

patients will see whilst trying to conceive. This is a source of frustration for fertility patients, who expressed disappointment they had not been informed of the option of egg sharing by doctors they had consulted earlier in their fertility journey [52]. This frustration is understandable, as our research found that egg sharers had been trying to conceive for an average of two years prior to having their fertility treatment. Egg sharers must be 35 years of age or under and have a good egg reserve, so this time delay could have prevented some women from participating in the programme. Additionally, the accuracy of the content women are accessing during their personal research is of potential concern, as the internet contains a lot of inaccurate and biased information for patients.

In addition, the general public have been found to have very poor knowledge of egg sharing (***Chapter 6; Study V***); however, when an explanation was given, 70.4% approved of the practice. This poor knowledge amongst the general public, fertility patients and healthcare professionals is likely to be contributing significantly to falling numbers of egg sharers. LFC has posted adverts over the years with marketing campaigns using social media posts and radio adverts promoting and informing women of the option of egg sharing to conceive. An example of one such social media post is shown in ***figure 7.2***. Since 2019, LFC has performed no marketing campaigns regarding egg sharing, which has caused the clinic to see a significant drop off in egg share donors coming forward, with only 53 egg share donors booking consultations in 2022, which is 23.2% of the number of patients egg sharing during the clinic's peak egg sharing figures. However, it must be noted that this drop in the number of egg sharers had already started prior to the decrease in advertising, with only 58.8% of the number of egg sharers booking appointments in 2019 compared to 2013, with the same marketing budget (***figure 7.1***). The proportion of women at LFC who book an initial consultation and then progress through for fertility treatment as egg sharers is consistently between 85-90%, showing that the vast majority of egg sharers who book these initial consultations are very serious about participating. The issue is therefore the drop in the number of women attending fertility clinic's as potential egg sharers, not egg sharers who subsequently drop out of treatment after being seen in the fertility clinic.

Figure 7.2: *A typical advert posted on social media as part of Lister Fertility Clinic's marketing campaign for egg sharing*

Another likely reason for the drop in numbers is the increasing number of fertility patients travelling abroad from the UK to receive their treatment [271]. Their main motivations to seek CBRC are cheaper treatments, long waiting lists in their home country, improved success rates, and societal and cultural concerns [111, 271-273]. Many government funded healthcare systems, including the UK, consider fertility treatment a relatively low medical priority, meaning funding is limited. One of the most basic concepts of economic theory is that people usually act in a rational manner to maximize their welfare at the lowest possible cost [271]. Therefore, if fertility patients cannot access government funded treatment in their own country, they will often look for the most economically viable treatment abroad [271]. With the increasing demand of infertile patients to have children and the expanding supply of fertility services in many countries, the global CBRC industry has steadily developed in recent years [271, 274]. A significant proportion of women choosing CBRC for predominantly financial reasons may well have pursued egg sharing if they were aware of this option. The issues surrounding CBRC include unclear regulations, insufficient information provision, increased multiple pregnancy rates with increased costs for the healthcare system of the home country, and the shifting of medical resources from the public to private sector in the destination country [271, 274-276]. Women requiring fertility

treatment may still prefer to pursue CBRC, however they should be aware of the option of egg sharing before they make this decision.

Additionally, the development of the vitrification technique for cryopreserving oocytes has given recipients more options to pursue egg donation treatment abroad, due to the increasing evidence that outcomes using frozen or fresh oocytes are now comparable [277]. If the eggs are already stored, then recipients will be able to decide how many oocytes to purchase, and do not need to synchronize their own fertility treatment with their egg donor, as the eggs are already stored. Recipients who participate in egg sharing treatment, will not know how many oocytes they will have for their own treatment until the donor has had her oocyte retrieval procedure. At LFC, recipients who use an egg sharer to conceive are given a minimum of four oocytes, but may of course receive more than this. The disadvantage of using oocytes from abroad is that these clinics will not be regulated by the HFEA. For example, many countries still allow anonymous donation, meaning any resulting offspring will be denied access to information about their biological mother. This may be appealing to some recipients, however our research found the majority of recipients preferred non-anonymous oocyte donation (***Chapter 4: Study III***).

7.7 Potential clinical utilization of this research

With these issues in mind, fertility clinics should focus on providing relevant healthcare workers with educational meetings, presentations, and webinars, which would give them the knowledge and confidence to then mention this option to their patients and refer more appropriately. The current lack of referrals could be preventing women from accessing the egg sharing scheme in a timely manner. An increased referral rate would allow patients to seek advice from a fertility specialist with appropriate expertise, to help them make an informed decision about whether this is the right option for them. An emphasis should also be placed on public education regarding the option of egg sharing, which would empower women and couples to self-refer to a clinic for further advice. Improved public education is long overdue regarding egg reserve testing, the female biological clock, and the options available for them to preserve their fertility. Particular focus should also be placed on identifying and contesting

common misconceptions that exist currently regarding infertility, and especially female infertility, as well as the options of egg donation and egg sharing. The current confusions and lack of knowledge may lead to a reluctance to seek help or to donate.

There is good evidence to show that by improving public awareness of egg donation and egg sharing, more women may come forward to donate, as the HFEA themselves attribute an increase in altruistic donor registration to improved awareness after several marketing campaigns [139]. One such campaign was led by the National Gamete Donation trust (NGDT) in 2005, and saw a 500% increase in potential donors coming forward with enquiries in the following 6 months [278]. Similar advertising campaigns could have a similar positive effect on the number of women coming forward for egg sharing, as currently less than 20% of women are finding out about this option through marketing [58]. The drastically increasing popularity and use of social media platforms over the last decade may allow for greater viewership of online advertising campaigns, thus giving the potential to replicate or surpass the success of these marketing strategies.

Improved education and knowledge of egg sharing could also help to alleviate concerns surrounding egg sharing, namely the potential neutral impact egg sharing has on treatment outcome, and for the psychological well-being of the donor if her own treatment was unsuccessful. ***Chapter 3: Study II*** reported that although 78.2% of healthcare professionals supported egg sharing, this was significantly lower than the 89.8% who supported egg donation in general, and these above concerns are likely to explain this difference. Healthcare professionals should be made aware of the strong evidence presented in this thesis (***Chapter 5: Study IV***) and other studies that egg sharing does not have an impact on patient's treatment outcome [65, 202]. Increasing participants awareness of this could ease their concerns and potentially recruit more patients into the programme. Regarding the psychological well-being of the egg share donor if her own treatment was unsuccessful, data presented in this thesis showed the vast majority were still pleased to have participated and hoped their recipient's treatment was successful (***Chapter 4: Study III***). This is very reassuring psychological data and its dissemination to a wider audience could have a positive impact on egg share numbers in the UK.

7.7.1 Concluding paragraph

Egg sharing is far from a perfect solution to the shortage of egg donors worldwide, however it does provide a practical option for a greater number of patients to access IVF, whilst also providing more donor oocytes into the donor pool. Since its introduction is has been debated and criticized more than perhaps any other aspect of reproductive medicine. These criticisms were predominantly based on expert theory, rather than findings from empirical research. This thesis has performed five studies that have thoroughly interrogated all clinical aspects of egg sharing in the UK, and it is the largest to do this worldwide. The findings from this research overwhelmingly supports the egg sharing programme and rebukes the majority of the concerns surrounding its practice.

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Appendix A: ethical approval for the study

Health Research Authority

London - Riverside Research Ethics Committee
Level 3 Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 02071048044

11 October 2017

Mr Timothy Bracewell-Milnes MBBS BSc MRCOG
Clinical Research Fellow
Division of Surgery and Cancer
Institute of Developmental Reproductive & Developmental Biology
Imperial College London
Chelsea and Westminster Hospital Campus
369 Fulham Rd, London SW10 9NH

Dear Mr Bracewell-Milnes

Study title:	**Investigating the psychological attitudes, motivations and experiences of oocyte donors and recipients**
REC reference:	**17/LO/1491**
Protocol number:	**n/a**
IRAS project ID:	**216136**

Thank you for your letter of 27th September 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Covering letter on headed paper		
Covering letter on headed paper		10 August 2017
Covering letter on headed paper	2	27 September 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Imperial insurance]	1	24 July 2017
IRAS Application Form [IRAS_Form_05102017]		05 October 2017
IRAS Application Form XML file [IRAS_Form_05102017]		05 October 2017
IRAS Checklist XML [Checklist_05102017]		05 October 2017
Letter from sponsor [Sponsor letter]	1	07 August 2017
Letters of invitation to participant [Invite letter]	1	28 June 2017
Non-validated questionnaire [HCP questionnaire]	1	10 January 2017
Other [PIS- prospective donors/ recipients]	3	10 June 2017
Other [Info sheet HCP]	1	01 July 2017
Other [ED recipient questionnaire 1 and 3 years post-donation]	1	01 May 2017
Other [Recipient pre-treatment questionnaire]	1	01 May 2017
Other [Recipient retrospective questionnaire]	1	01 May 2017
Other [Donors questionnaire 1 and 3 years post-donation]	1	01 May 2017
Other [Donor pre-treatment questionnaire]	1	01 May 2017
Other [Donor retrospective questionnaire]	1	01 May 2017
Other [Email invite letter]	1	16 August 2017
Other [PIS- prospective donors/ recipients]	4	27 September 2017
Participant consent form [Consent form- prospective]	3	10 June 2017
Participant information sheet (PIS) [PIS]	3	27 September 2017
Referee's report or other scientific critique report [Imperial College Peer review Assessment]		21 April 2017
Research protocol or project proposal [Study protocol]	3	27 September 2017

Summary CV for Chief Investigator (CI) [CV]		03 July 2017
Summary CV for student [Student CV]		03 July 2017
Summary CV for supervisor (student research) [Supervisor CV]		03 April 2017

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/1491	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

Pp

Dr Margaret Jones
Chair

Email: nrescommittee.london-riverside@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Miss Becky Ward*
Mr Timothy Bracewell-Milnes, Imperial College London

Appendix B: Research and development approval for the study

HCAHealthcare UK

17 Dec 2018

Dr Timothy Brawell-Milnes
The Lister Fertility Clinic
Chelsea Bridge Road
London
SW1W 8RH

Dear Dr Brawell-Milnes,

Re: Research Governance Approval (R&D Approval)

Study Title: Investigating the psychological attitudes, motivations and experiences of oocyte donors and recipients

REC Reference number: 17/LO/1491
R&D Reference number: R&D/18/025
Site: The Lister Fertility Clinic

Confirmation of approval

On behalf of HCA International Ltd, I am pleased to confirm permission / approval for the above research. This has been granted on the basis described in the application, supporting documentation* and the Clinical Trial Agreement.

This approval/ permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, applicable UK Regulations and all general conditions of R&D policies and procedures.

Permission is only granted for the activities for which a favorable opinion has been granted by the REC and which have been authorized by the MHRA

Below are listed final approved documents including the MHRA and REC approval letters:

Document	Version	Date
R&D Trial Proposal Form (Part A and B)		10Dec2018
REC Approval Letter		11Oct2017
Data Access Agreement between Imperial College – HCA [01Nov 2018 – 31 Nov 2021]		12Nov2018
Imperial College Indemnity[01Aug18 –31July19]		27Jul2018
Mr Timothy Bracewell-Mines - PI GCP		13Nov2018
Mr Timothy Bracewell-Mines - PI CV		03Jul2018
Protocol	3	27Sept2017

HCAHealthcare UK

PIS/ICF	3	27Sept2017
Patient Consent Form[Consent Form – prospective]	3	10June2017
PIS – Prospective donor/prospective	4	27Sept2017
Letter of Invitation to Participant	1	28June2017
Letter from Sponsor	1	07Aug2017
Imperial Sponsorship letter		07Aug2017
ED recipient questionnaire 1 and 3 years post-donation	1	01May2017
Recipient pre-treatment questionnaire	1	01May2017
Recipient retrospective questionnaire	1	01May2017
Donors questionnaire 1 and 3 years post-donation	1	01May2017
Donor pre-treatment questionnaire	1	01May2017
Donor retrospective questionnaire	1	01May2017
Email Invite Letter	1	16Aug2017

Specific Conditions of approval (if applicable)

Not applicable.

Amendments
Please ensure that all amendments are submitted to the R&D department for approval in line with guidance available on IRAS. Please submit the following documents electronically in order for an amendment to be approved:

- EU Notification of Substantial Amendment Form
- REC letter of amendment approval
- All listed REC approval documentation
- MHRA approval (if applicable)
- mCTA amendment (if applicable)

GCP Training

- All staff involved in the conduct of the trial must undertake a GCP refresher training every two years.

Insurance certificate

- A renewed copy must be sent to R&D upon expiry.

Annual Progress Report

- A progress report should be submitted to the REC which gave the favourable opinion 12 months after the date on which the favourable opinion was given. Annual progress report should be submitted thereafter until the end of the study- A copy of the progress report should be forwarded to R&D.

End of study

HCAHealthcare UK

- A copy of the end of the trial notification submitted to the REC which gave a favourable opinion should be submitted to R&D within 90 days of the end of the study or within 15 days if the study is terminated early.

Please ensure that R&D department is notified of any changes in status of the study and any urgent safety measures enacted.

.

Kind Regards,

Usha Annadurai
R&D Coordinator

*Supporting document confirming that the research team is appropriately experienced & that supporting services have the capability and the capacity to deliver the study as planned.

Appendix C: Study II survey
Health care professionals survey: views on egg sharing

1. What is your medical profession?

Obstetrician/ Gynaecologist □
Fertility specialist □
General practitioner □
Hospital doctor □
Fertility nurse □
Paediatrician □
Psychiatrist □
Counselor □
Staff Nurse □
Midwife □
Health care assistant □
Medical Student □
Others, please specify ……...

2. Please indicate your age and gender

Age …… Gender ……

3. **Please indicate the length of time that you have been working/studying within the medical field**

Less than 1 year □
Between 1 and 5 years □
Between 5 and 10 years □
More than 10 years □

4. Have you ever experienced any personal issues with infertility?

Yes □ No □ Declined to comment □

5. Do you know anyone (woman or a couple) who has experienced problems with conceiving i.e. infertility?

Yes □ No □

6. Prior to today, how much have you known about the UK egg sharing programme?

A lot □ A fair amount □ Heard it discussed only a few times □
Nothing □

The UK egg sharing programme is a scheme whereby an IVF patient gives a portion of her eggs to an anonymously matched recipient in exchange for subsidized or free fertility treatment

7. How interesting do you find the concept of egg sharing?

A lot □ A fair amount □ Not that much □ No interest whatsoever □

8. I understand the benefits of egg sharing

Strongly agree □ Agree □ Undecided □ Disagree □ Strongly Disagree □
If disagree/strongly disagree, why?
……..…….

9. I would recommend egg sharing to a friend/ family member who was struggling to conceive?
Strongly agree □ Agree □ Undecided □ Disagree □ Strongly Disagree □
If disagree/strongly disagree, why?
……..……

10. I believe that the egg sharing programme is a useful and welcome addition to the field of fertility
Strongly agree □ Agree □ Undecided □ Disagree □ Strongly Disagree □
If disagree/strongly disagree, why?
……..……

11. Do you believe egg sharing is a viable solution to solving the worldwide shortage of donor eggs?
Yes □ No □ Not sure? □
If not sure, why?
……..
If no, why not?
……..

12. Do you see an ethical difference between egg share donors receiving free fertility treatment and a commercial donor being paid by fertility clinics to donate their eggs?
Yes □ No □ Not sure? □
If not sure, why?
……..
If no, why not?
……..

13. In your opinion should egg sharing take place?
Yes □ No □ Not sure? □
If not sure, why?
……..
If no, why not?
……..

14. Hypothetically, if you were a single female in the UK and wanted to have children in the future were you aware of the option of freezing your eggs for free for potential future use, if you donated half to a recipient?
Yes □ No □

15. Do you think this is a good option?
Yes □ No □ Not sure? □
If not sure, why?
……..

If no, why not?

……..

16. If you are a medical practitioner, have you ever referred a patient to a fertility specialist for egg sharing?

Yes □ No □ Not applicable □

17. If no, why not?

Do not know enough about it □

Ethical grounds □

Other

……..

Benefits surrounding egg sharing

Please GRADE the following potential benefits of egg sharing according to how important you feel they are in relation to each other

Grade from 1-10 where 1=least important and 10=most important

Benefits can be given the same grade

1. Unlike with volunteer egg donors, with egg sharing no third party needs to go through
   ……
   invasive procedures, such as egg collection since the donor needs to undergo these procedures anyway for her own fertility treatments
2. Those without access to NHS IVF who cannot self fund get fertility treatments
   ……
   they otherwise would not be able to access
3. It allows a person suffering with infertility to help a person in a similar situation
   ……
4. It provides a realistic solution to an acute shortage of egg donors
   ……

Issues surrounding egg sharing

Please GRADE the following potential issues according of egg sharing according to how important you feel they are in relation to each other

Grade from 1-10 where 1=least important and 10=most important

Issues can be given the same grade

Egg share donation issues

1. The donor is only agreeing to share eggs to gain access to fertility treatment ……
2. The consent of the egg share donor is questionable since she is desperate to ……
   conceive herself
3. The psychological well being of egg share donors whose own treatment is unsuccessful ……
4. Issues for the donor surrounding the recipient conceiving their genetic offspring
5. The donor may need to undergo a repeat stimulation cycle and egg collection to collect ……
   enough eggs for her and the recipient
6. Egg sharing to gain subsidized fertility treatment is contrary to a cultural …… preference for voluntary egg donation
7. The recipient having to pay for treatment when the donor receives treatment for free ……
8. Concern for the psychological impact on the child learning their parents indirectly ……
   paid a donor to contribute

Appendix D: Study III retrospective survey
Egg donation questionnaire

Section 1: Background information

1. **How old are you?** **……**

2. **What is your ethnicity?**

   White:
   White British □ White Irish □ White other (please specify) ……
   Mixed ethnicity:
   White/ Black Caribbean □ White/ Black African □ White/ Asian □
   Other mixed ethnicity (please specify) ……
   Asian/ Asian British:
   Indian □ Pakistani □ Bangladeshi □ Chinese □
   Other Asian background (please specify) ……
   Black/ African/ Caribbean/ Black British
   African □ Caribbean □
   Any other Black/ African/ Caribbean background (please specify) ……
   Other ethnic group
   Arab □ Any other ethnic group (please specify)

3. **What is your relationship status?**
   Single □ In a relationship (unmarried) □ Married □

4. **What best describes your sexual orientation?**
   Heterosexual □ Homosexual □ Bisexual □ Other □

5. **How many children did you have before donating your eggs?**
   None □ One □ Two □ Three □ More than three □

6. **How many siblings do you have?**
   None □ One □ Two □ Three □ More than three □

7. **What is your religious background?**
   None □ Christian □ Muslim □ Jewish □ Hindu □
   Other (please specify) ……

8. **How religious are you?**

Not religious □ Moderately religious □ Very religious □

9. What is your employment status?

Employed > 37 hours per week □ Employed < 37 hours per week □

Student □ Housewife □

Unemployed □

10. What occupational category best describes you?

Architecture and engineering □ Healthcare professional □

Arts, design, media □ Housewife □

Business and finance □ Legal □

Cleaning and maintenance □ Management □

Computing □ Office and administrative support □

Construction, installation, and repair occupations □ Personal care and service □

Education and training □ Sales and related occupations □

Farming, fishing and forestry □ Transportation □

Food preparation and related occupations □ Other (please specifiy)……..

11. What is your educational level?

GCSEs □ A-levels □ University degree □ Post-graduate degree □

Other (please specify) ……..

12. What is your annual salary?

< £30,000 □ £30-50,000 □ £50-100,000 □ > £100,000 □

Section 2: Information surrounding egg sharing

1. **How did you first find out about egg sharing?**
   Internet □ Newspaper/ magazine advert □ Radio/ TV advert □
   Social media □ Family/ friend □ GP □
   Gynaecologist □ Fertility clinic □ IVF seminar □
   Don't recall □ Other (please specify)……

2. **How long had you been trying to get pregnant before you heard about egg sharing?**
   Less than 6 months □ 6 months to 1 year □ One to two years □
   More than 2 years □

3. **How much research did you do into egg sharing before agreeing to take part?**
   More than 5 hours □ 1-5 hours □ Less than 1 hour □
   None □

4. **Initially, did you have any reservations regarding egg sharing?**
   Definite reservations □ Some reservations □ No reservations □

5. **What were your first impressions of the egg sharing scheme?**
   Good idea
   Yes □ No □ Unsure □

   Bad idea

Yes ☐ No ☐ Unsure ☐

Something I'd like to do
Yes ☐ No ☐ Unsure ☐

An obvious solution to a shortage of donor eggs
Yes ☐ No ☐ Unsure ☐

Only option I had
Yes ☐ No ☐ Unsure ☐

Chance to do something special for someone else while receiving treatment
Yes ☐ No ☐ Unsure ☐

Other (please specify)
……

6. **Were you using donor sperm for your IVF treatment**
   Yes ☐ No ☐

7. **Do you already have a child through egg sharing?**
   Yes ☐ No ☐

8. **How many egg share cycles did you do?**
   One ☐ Two ☐ Three ☐ More than three ☐

Section 3: Motivations and concerns regarding egg sharing

1. **Would you have considered participating in the egg sharing scheme if there was no direct benefit for you (i.e. free or reduced cost IVF treatment offered)?**
   Yes □ No □ Unsure □

2. **Would you have considered participating in egg sharing regardless of your ability to pay for IVF?**
   Yes □ No □ Unsure □

3. **Would you have considered participating in egg sharing if your eggs were donated to research, rather than a recipient?**
   Yes □ No □ Unsure □

4. **Other than having a child, what motivated you to participate in egg sharing?**

   A The desire to help someone else have a child
   Yes □ No □ Unsure □

   B To obtain cheaper fertility treatment
   Yes □ No □ Unsure □

   C I did not qualify for NHS treatment

Yes ☐ No ☐ Unsure ☐

D I wanted to avoid NHS waiting lists
Yes ☐ No ☐ Unsure ☐

E I wanted to have my treatment in a private clinic
Yes ☐ No ☐ Unsure ☐

F I knew there was a shortage of donor eggs and wanted to help another couple have a baby
Yes ☐ No ☐ Unsure ☐

G The desire to make someone else happy
Yes ☐ No ☐ Unsure ☐

H There was no significant reason not to
Yes ☐ No ☐ Unsure ☐

Other (please specify)……

5. Of the above, which was your main motivating factor?

A ☐ B ☐ C ☐ D ☐

E ☐ F ☐ G ☐ H ☐

6. **What were your concerns during egg sharing?**

A Not getting pregnant
Yes ☐ No ☐ Unsure ☐

B Experiencing pain
Yes ☐ No ☐ Unsure

C Side effects of fertility treatment
Yes ☐ No ☐ Unsure ☐

D That there would not be enough eggs collected
Yes ☐ No ☐ Unsure ☐

E Sharing my eggs would jeopardise my treatment
Yes ☐ No ☐ Unsure ☐

F The recipient changing her mind
Yes ☐ No ☐ Unsure ☐

G Missing time off work
Yes ☐ No ☐ Unsure ☐

H Unforeseen delays
Yes □ No □ Unsure □

I Disappointing my family/ friends if I didn't get pregnant
Yes □ No □ Unsure □

J Stress for my partner/ family
Yes □ No □ Unsure □

K Concern for the recipient's well being
Yes □ No □ Unsure □

7. Of the above, which was your main concern?

A □ B □ C □ D □

E □ F □ G □ H □
I □ J □ K □

Section 4: Experience of egg sharing

1. What was the outcome of your egg sharing?
Livebirth □ Miscarriage □ Unsuccessful □

2. How would you rate overall the egg sharing experience?
Very positive □ Positive □ Neither positive or negative □
Negative □ Very negative □

3. Are you glad you took part in the egg sharing scheme?
Yes □ No □ Unsure □

4. With the benefit of hindsight would you still take part in egg sharing?
Yes □ No □ Unsure □

5. **Would you participate in egg sharing again for future fertility treatment?**
   Yes □ No □ Unsure □

6. **Would you recommend egg sharing to a friend or family member who needs fertility treatment?**
   Yes □ No □ Unsure □

7. **Did you feel your best interests were always the primary concern of the medical staff?**
   Yes □ No □ Unsure □

8. **Now you have gone through the process, do you feel that you were well informed prior to starting the egg sharing process?**
   Yes □ No □ Unsure □

9. **Do you feel you had enough time with the medical staff (nurses and doctors)?**
   Yes □ No □ Unsure □

10. **Do you feel you had enough access to the medical staff (nurses and doctors)?**
    Yes □ No □ Unsure □

11. **Overall how would you rate the medical care you received?**
    Very positive □ Positive □ Neither positive or negative □
    Negative □ Very negative □

12. **Do you feel you had enough time with the counselling staff?**
    Yes □ No □ Unsure □

13. **Do you feel you had enough access to the counseling staff?**
    Yes □ No □ Unsure □

14. **Overall how would you rate the counselling session at the clinic?**
    Very positive □ Positive □ Neither positive or negative □
    Negative □ Very negative □

15. **Do you feel you had enough support from the fertility clinic during your treatment?**
    Yes □ No □ Unsure □

16. **Do you feel you had enough support from the fertility clinic after your treatment?**
    Yes □ No □ Unsure □

17. **Please provide any comments on your experience you feel the fertility clinic would benefit from?**
    ……
    ……
    ……
    ……

Section 5: Attitudes towards egg sharing

Regarding egg sharing

1. **I believe egg sharing is a good solution to a national donor egg shortage**
    Strongly agree □ Agree □ Neither agree nor disagree □
    Disagree □ Strongly disagree □

2. **Egg sharing provides a 'win win' solution for donors and recipients**
    Strongly agree □ Agree □ Neither agree nor disagree □
    Disagree □ Strongly disagree □

3. **The egg sharing programme exploits women**
   Strongly agree □ Agree □ Neither agree nor disagree □
   Disagree □ Strongly disagree □

4. **I prefer donor eggs to come from a woman who is already undergoing fertility treatment for her own fertility needs, rather than volunteer donors who would undergo invasive procedure they would not otherwise have needed**
   Strongly agree □ Agree □ Neither agree nor disagree □
   Disagree □ Strongly disagree □

5. **I believe it is ethical to give women free or much cheaper fertility treatment in exchange for some of her eggs?**
   Strongly agree □ Agree □ Neither agree nor disagree □
   Disagree □ Strongly disagree □

Regarding egg donation in general (i.e. donors who give their eggs to women they know or on a voluntary basis)

6. **Egg donors should not receive any payment for donating?**
   Strongly agree □ Agree □ Neither agree nor disagree □
   Disagree □ Strongly disagree □

7. **Egg donors should receive a compensatory payment to cover expenses and time off work for their donations**
   Strongly agree □ Agree □ Neither agree nor disagree □
   Disagree □ Strongly disagree □

8. **Egg donors should receive a monetary payment for their donations, as long as it is well regulated**
   Strongly agree □ Agree □ Neither agree nor disagree □
   Disagree □ Strongly disagree □
   If strongly agree or agree, what should this payment be in? £_____

9. **What information do you feel comfortable sharing with your recipient prior to them agreeing to participate in the egg share scheme? (please tick the boxes that you are happy to disclose)**

Characetristics:	Age	□	Race □
	Hair colour	□	Eye colour □
	Skin tone	□	Height □
	Weight	□	Religion □
	Occupation	□	Area where you live □
	Educational background	□	Criminal convictions □
	Sexual orientation	□	
Medical history:	Medical conditions	□	Psychiatric history □
	Smoking status	□	Alcohol intake □

Section 6: Thoughts and feelings about the recipient

1. **How did you feel about your recipient while undergoing fertility treatment?**
   I did not feel anything about my recipient
   Yes □ No □ Unsure □

   I was curious about her
   Yes □ No □ Unsure □

   I was jealous of her
   Yes □ No □ Unsure □

   I felt close to my recipient
   Yes □ No □ Unsure □

   I felt we understood each other
   Yes □ No □ Unsure □

   I felt sympathetic towards her
   Yes □ No □ Unsure □

   I hoped her treatment would be successful
   Yes □ No □ Unsure □

   I felt sorry for her
   Yes □ No □ Unsure □

   I wanted to make her happy
   Yes □ No □ Unsure □

   Other (please specify)……..

2. **How often did you think about your recipient during your fertility treatment?**
   All the time or often □ Sometimes □ Rarely or never □

3. **How often do you think about the recipient now?**
   All the time or often □ Sometimes □ Rarely or never □

4. **What was the outcome of your egg donation?**
   She had a baby □ She did not get pregnant □ I do not know □

5. **How do you feel about the outcome of the recipient's fertility treatment? (Please fill out A, B, or C)?**

A **Successful donation:**

Happy for her to know □ Neutral □ Unhappy □ Unhappy □

B **Unsuccessful donation:**

Upset for her □ Neutral □ Pleased □ Unhappy to know □

C **I decided not to find out my egg donor's treatment outcome** □

6. **Would you rather not have the option of knowing the outcome of the recipient's treatment?**

Yes I don't want the option □ No I would like to know □ Not sure □

7. **Regarding the recipients fertility treatment outcome**

I was hoping that the recipient would become pregnant

Yes □ No □ Unsure □

I was hoping that the recipient would not become pregnant

Yes □ No □ Unsure □

I was hoping that the recipient would become pregnant when I knew the outcome of my treatment

Yes □ No □ Unsure □

I was hoping that the recipient would not become pregnant when I knew the outcome of my treatment

Yes □ No □ Unsure □

8. **How often do you think about any children that may have resulted from your donation?**

All the time or often □ Sometimes □

Rarely or never □ Not applicable (she didn't get pregnant) □

9. **If the person who received your eggs had any of the following characteristics, would you be unhappy donating to them? (please tick all that apply)**

Age > 40 □ BMI > 40 (severely overweight) □

Age >45 □ Single □

Age > 50 □ Same sex couple □

10. Would you feel responsible for any potential children born as a result of your donation if anything happened to their parents?

Yes □ No □ Unsure □

11. Do you think more or less positively about egg sharing now than you did before and around the time of your fertility treatment?

Yes □ No □ Unsure □

12. Do you think about the person you donated your eggs to more or less now compared to around the time of your fertility treatment?

Yes □ No □ Unsure □

Section 7: Disclosure

Regarding who you discussed your egg sharing with

1. **Who did you discuss egg sharing with prior to taking part in it? (please tick all relevant boxes)**

Nobody	□	Partner	□	IVF doctor	□	Counsellor	□
GP	□	Support group	□	Mother	□	Father	□
Brother	□	Sister	□	Other family	□	Closest friend	□
Friends	□	Colleagues	□	Partner's family	□		

Other (please specify)…….

2. **Who did you tell that you went ahead with egg sharing? (please tick all relevant boxes)**

Nobody	□	Partner	□	GP	□	Support group	□
Brother	□	Sister	□	Other family	□	Closest friend	□
Friends	□	Colleagues	□	Partner's family	□		

Other (please specify)…….

3. **If you have not yet told anybody that you donated your eggs, who do you plan to tell in the future? (please tick all relevant boxes)**

Nobody	□	Partner	□	GP	□	Support group	□
Brother	□	Sister	□	Other family	□	Closest friend	□
Friends	□	Colleagues	□	Partner's family	□		

Other (please specify)…….

4. **If your own fertility treatment was successful, do you plan to tell any children from your treatment that you participated in egg sharing?**
   Yes □ No □ Unsure □

Regarding the person you donated your eggs to (whether their own treatment was successful or not)

5. **Do you believe any children born by the person you donated your eggs to should be told about how they were conceived?**
   Yes, it is their right to know □
   No, they should not be told □
   It is up to their parents □

6. **Do you believe any children born by the person you donated your eggs to could be emotionally damaged if they learn they were born by egg donation inadvertently?**
   Agree □ Neutral □ Disagree □ No opinion □

7. **Do you believe any children born by the person you donated your eggs to have the right to know they were conceived by egg donation?**
   Agree □ Neutral □ Disagree □ No opinion □

8. **Do you believe the person you donated your eggs to has the right not to tell any resulting children about how they were conceived?**
   Agree □ Neutral □ Disagree □ No opinion □

Regarding future contact with a potential child from your donation (please answer hypothetically, whether their own treatment was successful or not)

9. **How would you feel if a child born by the person you donated your eggs to contacted you (as an adult)?**
   I don't know how I'd feel □
   I would be happy to be contacted □
   I would be neither happy nor unhappy to be contacted □
   I would prefer not to be contacted □

10. **Do you believe the child born by the person you donated your eggs to should have the right to learn your identity (as an adult)?**
    Agree □ Neutral □ Disagree □ No opinion □

11. **Do you believe the child born by the person you donated your eggs to could be emotionally harmed by having contact with you (as an adult)**
    Agree □ Neutral □ Disagree □ No opinion □

12. **Do you believe the parents that you donated your eggs to could be emotionally harmed by you having future contact with their child?**
    Agree □ Neutral □ Disagree □ No opinion □

13. **Do you believe having contact with the child born as a result of your donation (as an adult) could be harmful to you or your partner?**
    Agree □ Neutral □ Disagree □ No opinion □

14. **Do you believe having contact with the child born as a result of your donation (as an adult) could be harmful to your children?**
    Agree □ Neutral □ Disagree □ No opinion □

15. **In general, have your views on disclosure to offspring born by egg donation changed now compared to around the time of donation?**
    Yes □ No □ Unsure □

Thank you very much indeed for taking the time to fill out the questionnaire. Finally, if there is anything you feel that is relevant that has not been mentioned in the form and could help us improve our service, please say below

.....

.....

.....

.....

Appendix E: patient email for consent to participate in survey

Dear (insert patient FIRST NAME ONLY)

We are contacting you because you participated in the egg donation programme at The Lister Fertility Clinic, and have given your consent to participate in research. Dr Yau Thum (the head of the egg donation department) is carrying out a research project with Imperial College London on patients' attitudes, motivations, experiences and disclosure decisions surrounding the egg donation process.

We have designed a completely anonymised questionnaire with no identifiable data requested. Your participation only involves answering this questionnaire, which should take 10-15 minutes to complete. We will use the results to better understand patients views and experiences as a donor/ recipient of donor eggs, aiming to improve the quality of our service and patient care in the future. This research will also be published to help the egg donation process globally.

Please kindly reply with your consent if you wish to participate and please let us know if you'd prefer to complete the questionnaire online (you will be sent a link by email) or a paper questionnaire (you will be sent a questionnaire by post with a pre-paid postage envelope to send back to us, please provide your current U.K address in your reply email).

Thank you in advance if you agree to participate.

Yours sincerely

The Lister Fertility Clinic Egg Donation Team

Appendix F: Study V survey
General Public's Views on Egg Donation and Egg Sharing

Part 1 – Background

1. **How old are you?**
   - 18-25 ☐
   - 26-30 ☐
   - 31-35 ☐
   - 36-40 ☐
   - 41-45 ☐
   - >45 ☐

2. **What is your ethnicity?**

   White:
   White British ☐ White Irish ☐ White other ☐

   Mixed Ethnicity:
   White/Black Caribbean ☐ White/Black African ☐ White/Asian ☐
   Other Mixed ethnicity (please specify) _____

   Asian/Asian British:
   Indian ☐ Pakistani ☐ Bangladeshi ☐ Chinese ☐
   Other Asian ethnicity (please specify) _____

   Black:
   African ☐ Caribbean ☐ Black British ☐
   Other Black ethnicity (please specify) _____

   Other ethnic group:
   Arab ☐
   Other ethnic group (please specify) _____

3. **What is your relationship status?**
   Single ☐ In a relationship (unmarried) ☐ Married ☐

4. **What best describes your sexual orientation?**
   Heterosexual ☐ Homosexual ☐ Bisexual ☐ Other ☐

5. **What is your religious background?**
   None ☐ Christian ☐ Muslim ☐ Jewish ☐ Hindu ☐
   Other (please specify) _____

6. **What is your employment status?**
   Employed full time ☐ Employed part-time ☐
   Student ☐ House-wife ☐

Unemployed ☐

7. What occupational category best describes you?

Architecture and engineering	☐	Healthcare professional	☐
Arts, design and media	☐	House-wife/husband	☐
Business and finance	☐	Legal	☐
Cleaning and maintenance	☐	Management	☐
Computing	☐	Office and administrative support	☐
Construction, installation and repair	☐	Personal care and service	☐
Education and training	☐	Sales and related	☐
Farming, fishing and forestry	☐	Transportation	☐
Food preparation and related	☐	Other (please specify) _____	

8. What is your educational level?

GCSEs ☐ A-Levels ☐
College diploma/apprenticeship ☐ University degree ☐
Post-graduate degree ☐

9. What is your annual salary before deductions?

< £30,000 ☐ £30,000-£49,999 ☐ £50,000-£99,999 ☐ >£100,000 ☐

Part 2 – Fertility intentions and knowledge

10. Please rate each of the following goals 1-5 (1 = not important, 5 = very important) that you would CURRENTLY consider to be important to you.

Career	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Education	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Travel	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Meeting a partner	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Starting a family	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

11. Please rate each of the following goals 1-5 (1 = not important, 5 = very important) that you would consider to be important to you IN THE FUTURE.

Career	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Education	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Travel	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Meeting a partner	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
Starting a family	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

12. Have you thought about the decline of fertility with age?

Yes, frequently ☐
Yes, occasionally ☐
Rarely ☐
Not at all ☐

13. At what age do you believe female fertility starts to significantly decline?

20-24 years ☐
25-29 years ☐
30-34 years ☐
35-39 years ☐
>40 years ☐

14. At what age would you ideally want to start a family?

I do not want to have children	☐	31-35	☐
<20	☐	36-40	☐
20-25	☐	41-45	☐
26-30	☐	>45	☐

15. What would you estimate the UK national average IVF pregnancy rate to be per embryo transfer at the age of 40?

0-10% ☐
10-20% ☐
20-30% ☐

30-40% ☐
40-50% ☐
>50% ☐

Part 3: Regarding egg (oocyte) donation

Egg donation is a process by which a woman donates her eggs to another woman who cannot have a child with her own eggs.

In the United Kingdom (UK) egg donors can be either altruistic donors (a volunteer who donates eggs to an unknown recipient without financial reward) or known donors (donates eggs to a known recipient). Financial payments for egg donation in the UK are illegal.

The process of egg donation involves daily hormone injections to stimulate the ovaries to produce multiple eggs, and then a minor surgical procedure to collect the eggs.

16. **Prior to answering this questionnaire how much knowledge did you have regarding the egg donation programme?**
    No knowledge ☐ Little knowledge ☐
    Some knowledge ☐ Significant knowledge ☐

17. **Do you agree with the principle of egg donation?**
    Yes ☐ No ☐ Unsure ☐

18. **Would you consider donating your eggs altruistically as an anonymous donor?**
    Yes ☐ No ☐ Unsure ☐

19. **Would you consider donating your eggs to a close friend or relative as a known donor?**
    Yes ☐ No ☐ Unsure ☐

20. **Hypothetically if you were to donate your eggs, what would be your main motivation (select one)?**
    Altruism ☐
    Financial ☐
    Family/ friend have had fertility problems ☐
    Passing on my genetic material ☐
    To develop a relationship with an infertile couple ☐
    None of the above ☐

21. **Hypothetically if you were to donate your eggs, what would be your main concern (select one)?**
    The medical procedures I would need to go through ☐
    Potential future contact with the child ☐

The woman receiving my eggs would be too old ☐
The woman receiving my eggs might be in a same-sex relationship ☐
The egg donation not working ☐
Taking time off work ☐
Religious reasons ☐
None of the above ☐

22. In the UK in 2004 legislative changes meant a child born as a result of egg donation could find out the identity of the egg donor when they reach 18 years of age. Do you agree with this?

Yes ☐ No ☐ Unsure ☐

23. Would this legislative change stop you from donating your eggs?

Yes ☐ No ☐ Unsure ☐

24. Hypothetically if you donated your eggs would you want future contact with the couple you donated to?

Yes ☐ No ☐ Unsure ☐

25. Hypothetically if you donated your eggs would you want future contact with any children resulting from your donation?

Yes ☐ No ☐ Unsure ☐

26. If you were unable to conceive and you were advised your only realistic chance of a child was with an egg donor, would you pursue this option?

Yes ☐ No ☐ Unsure ☐

27. There is currently a significant shortage of volunteer egg donors in the UK. The UK caps compensatory payments for egg donation at £750 (travel costs, child care etc), whilst in countries such as the USA financial reward for egg donation can be as high as $10,000. Do you agree with the compensatory limit of £750 in the UK?

Yes ☐ No ☐ Unsure ☐

28. Currently to avoid long waiting lists for donor eggs, a significant proportion of couples from the UK are seeking fertility treatment with donor eggs abroad. Do you consider this to be a significant issue?

Yes ☐ No ☐ Unsure ☐

29. Should patients requiring donor eggs as part of their IVF treatment have this available to them on the NHS?

Yes ☐ No ☐ Unsure ☐

Part 4: Regarding egg sharing

The UK egg sharing programme is a scheme whereby a patient undergoing IVF for her own needs gives a proportion of her eggs to an anonymously matched recipient in exchange for subsidized or free fertility treatment

30. Prior to answering this questionnaire how much did you know of the egg sharing programme?

No knowledge ☐ Little knowledge ☐
Some knowledge ☐ Significant knowledge ☐

31. Do you believe egg sharing is a useful and welcome addition to the field of fertility?

Yes ☐ No ☐ Unsure ☐

32. Do you believe egg sharing is a viable solution to solving the worldwide shortage of donor eggs?

Yes ☐ No ☐ Unsure ☐

33. Do you see an ethical difference between egg share donors receiving free fertility treatment and a commercial donor being paid by fertility clinics to donate their eggs?

Yes ☐ No ☐ Unsure ☐

34. In your opinion should egg sharing take place?

Yes ☐ No ☐ Unsure ☐

35. Hypothetically, if you needed IVF to have a child would you consider egg sharing?

6Yes ☐ No ☐ Unsure ☐

36. Hypothetically, if you were a single female in the UK and wanted to have children in the future, you could freeze your eggs for free for potential future use if you donated half to an anonymous recipient. Were you aware of this option?

Yes ☐ No ☐

37. Do you think this is a good option?

Yes ☐ No ☐ Unsure ☐

38. Benefits surrounding egg sharing

Please GRADE the following potential benefits of egg sharing according to how significant you feel they are

Grade from 1-5 where 1= INSIGNIFICANT and 5= VERY SIGNIFICANT

Benefits can be given the same grade

A. Unlike with volunteer egg donors, with egg sharing no third party needs to go through invasive procedures, such as egg collection, since the donor needs to undergo these procedures anyway for her own fertility treatment

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

B. Those without access to NHS (government) funded IVF who cannot afford to pay for their treatment get fertility treatment they would otherwise have not been able to access

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

C. It allows a person suffering with infertility to help a person in a similar situation

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

D. It provides a realistic solution to an acute shortage of eggs

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

E. Currently, due to long waiting lists for donor eggs in the UK women are seeking fertility treatment abroad in often unregulated clinics, egg sharing could reduce women seeking treatment abroad

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

39. Issues surrounding egg sharing

Please GRADE the following potential issues of egg sharing according to how significant you feel they are

Grade from 1-5 where 1= INSIGNIFICANT and 5= VERY SIGNIFICANT

Issues can be given the same grade

A. The donor is only agreeing to share her eggs to gain access to fertility treatment
1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

B. Concern for the psychological well-being of egg share donors whose own treatment is unsuccessful
1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

C. The egg share donor might need to undergo repeated IVF cycles and egg collections to collect enough eggs for her and the recipient
1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

D. Concern that egg sharing could reduce the chances of the donor conceiving as she is donating half her eggs
1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐

E. The recipient of the donor eggs having to pay for treatment when the donor receives treatment for free
1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐