

THE ETHICAL ALLOCATION OF GAMETES DONATED FOR FERTILITY TREATMENT

by

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A thesis submitted to the University of Birmingham for the degree of
DOCTOR OF PHILOSOPHY

Medicine, Ethics, Society and History
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September 2013

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Abstract

This thesis is a discussion of the ethical issues surrounding the allocation of donated sperm and eggs to patients at fertility clinics. It adopts an empirical bioethics approach in which traditional philosophical analysis is combined with the collection and analysis of empirical data in order to ensure that the views of those involved in the field are represented.

Following the preliminary philosophical analysis, the second section of this thesis presents the results of a qualitative study, which was undertaken with fertility clinic staff and other relevant professionals such as academics and representatives of patient organisations. The views and ideas that emerged from these data were considered in light of the earlier philosophical analysis, and where relevant, initial conclusions were revised to account for these considerations.

The results suggest that the prioritisation of patients based on age, violent history, and health and health behaviours is justified, that allowing conditional and known donations may benefit all patients by increasing the number of donors, and that a national system of allocation may confer similar benefits, as well as being fairer than current, local allocation.

DEDICATION

To Morrissey.

Is life always like this, brother? Good for one side, bad for another.
-Twinkle

ACKNOWLEDGEMENTS

Given the multitude of people without whom this thesis wouldn't exist, I must apologise to anyone I have forgotten to acknowledge here.

I owe enormous thanks to my supervisors, Heather Draper, Sue Avery, and Jon Ives, for the countless hours they put into supervising me and this project. It has been a real pleasure, and I could not have asked for a better team. Heather's guidance and compassion helped me through many troubles, both academic and personal; Sue's warm enthusiasm and encouragement were a real source of support; and while I gratefully thank Jon for his rigour and commitment, I do not thank him for the squash-ball-shaped bruises on my legs and back.

I am grateful for the support of the Arts and Humanities Research Council, and of Birmingham Women's Hospital NHS Foundation Trust, in funding this project, and to those others who provided me with financial support during the course of my time here.

I'd also like to acknowledge the NIHR Clinical Research Network for their help with gaining permissions for the empirical aspects of the project. Regarding this empirical work, huge thanks to everyone who participated in my study, and for the hospitality shown to me by the various clinics I visited.

Thanks to the whole team in Medicine, Ethics, Society and History, particularly Angus Dawson, for advice and help along the way, and for providing a good community in which to work. The crew at 90 Vincent Drive also deserves a mention, given all the highs and lows (mostly of the temperature in the building) that we went through together. Thanks also to the Primary Care gang for being kind to a doe-eyed new PhD student.

I thank Greg Moorlock for giving me a taste for the following things: caffeine, making fun of people on tandem bicycles, and stealing Land Rovers. I have tried to treat Greg not merely as a means, but as the end that he truly is.

Thanks to my parents for bringing me into existence, and to all my siblings for making my existence so much more pleasurable.

Definitely worthy of a mention are: my old mate Chris Heard; Cat Armstrong and Rachael Heaven, for sorting my head out; Chris Robertson, for not talking about the kakapo as much as I was worried he would; Ray Steller, whose input into this thesis will no doubt harm me in some way; Nick Silverman, for letting me use his housemate's coffee machine; Simon Neville, for being a wild child; Michel Boissonnet, whom I like "allot"; Adrian Gheorghe, for being (mostly) so sensible; Tom Embury, for helping me rock the casbah; and Irene Alonso-Pérez, for being my vegan pal.

Final thanks to: Brad Hooker, Kent Hurtig, Rowan Cruft, Alan Millar, Adrian Haddock, Thomas Heyd, Jason Duffield, Chris Rogers, Ed Lacey, and McGregor.

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List of Statutes Referred to in this Thesis

Human Fertilisation and Embryology Act 1990

Human Fertilisation and Embryology Act 2008

Equality Act 2010

Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations
2004

Children Act 1989

1. INTRODUCTION

The need for a serious attempt to examine the ethics of the allocation of donated gametes arises from several considerations. First, gametes are a scarce resource: the National Gamete Donation Trust (NGDT) reports that 384 men donated sperm in 2008, when the number that was needed to treat all potential recipients was more than 500 (National Gamete Donation Trust, 2011). Their figures suggest an even greater shortfall for eggs; in the same year, 707 women donated eggs compared to a need for over 1200 donors to meet demand.¹ Insufficient supply means that decisions about gamete allocation, while bringing joy to some, will bring disappointment to others. This, in itself, provides a motivation for ensuring that we make allocation decisions fairly.

Even if we put aside questions of resource scarcity, however, there are other important reasons for thinking that gamete allocation warrants some ethical scrutiny. Even if there *were* enough gametes to treat every patient, we might think that there remain reasons to carefully consider how gametes are allocated. It could be that treatment is not deemed to be in the overall interests of the patient. Alternatively, it might be best to decline to treat a patient due to a very important feature of gamete allocation that differentiates it from other

¹ It is worth noting that these figures may be a little crude and simplified, as the way in which gametes can be said to be “available” to patients is not straightforward. Racial matching of gametes to recipients may mean that members of certain races perceive any shortage more keenly, as there may be fewer donors from the same background. Similarly, patients impose constraints on themselves where they ask for donors with certain characteristics, for example religious ones. Finally, donors can also set conditions on who can use their gametes, meaning that their gametes are not available across the board, exacerbating the problem for patients who do not fit the donor’s criteria. Regardless of these nuances, the data still show that there simply are not enough gametes available to satisfy every hopeful parent.

resource allocation scenarios; if used in treatment, gametes have the potential to develop into beings with interests of their own.

Thus it is not just the potential harms/benefits to the *patient* that must be considered; we might think that there are factors about the patient that may cause the resulting child to have an unacceptably unpleasant life (for example being so old or ill that their capacities as parents are questionable, or having a history of abusing children).

So we may not want to assist some people in becoming parents even if doing so does not deprive anyone else of the opportunity. There may also be some kinds of children that we do not want to bring into being, for example because they will suffer terrible health problems. Accordingly, there would be reasons to consider the ethics of gamete allocation even in a world where donated gametes were plentiful.

Of course, whether or not we are using *donated* gametes, concerns about child welfare or about risks to patients can still be relevant, and hence the ethical issues discussed in this thesis will allow for some crossover with concerns about assisted reproduction treatment in general. Donated gametes present additional challenges where resource scarcity means that the allocation of resources to one patient means that they cannot be allocated to another patient. On top of this is the ethical issue of using donors who are known to the recipient, and how this should affect a recipient's place on the waiting list. All of these issues gave rise to this project exploring gamete allocation.

1.1 Legal Context

The UK government acknowledged the need to regulate the use of reproductive technologies with The Human Fertilisation and Embryology Act 1990, which was amended in 2008 (hereafter the Act and amendments will simply be referred to as “the HFE Act”, except where it is specified that either the 1990 or 2008 Act are being referred to), informed by the findings presented in the Warnock report (Warnock, 1984). The HFE Act stipulates that those making treatment decisions must consider ‘the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), and of any other child who may be affected by the birth’ (HFE Act, 2008, section 14 (2)), and the Human Fertilisation and Embryology Authority (HFEA) Code of Practice indicates the kinds of factor that should be taken into account when making predictions about child welfare.

The provisions in the HFE Act, however, by no means address all of the ethical issues that can and do arise in fertility clinics. Many clinics use clinical ethics committees to give advice in difficult cases (Frith, 2009), suggesting that the HFE Act and its attendant guidance do not cover all eventualities. Moreover, what the HFE Act *does* cover, it covers quite broadly, with room for ambiguity and interpretation. For example, the Code of Practice requires treating clinicians to ‘take into account’ factors such as ‘mental or physical conditions’ and ‘drug or alcohol abuse’, in cases where these are ‘circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born’ (HFEA, 2009, section 8.10), but this guidance goes into no detail about *how* this is to be accounted for. When these factors are present, it is up to clinics to choose from a range of options that could all be described as “accounting for” these factors. These options include

excluding the patient from treatment, delaying their treatment, prioritising other patients who do not exhibit these factors, or offering them further counselling.

Clinical staff are also bound by the Equality Act (2010), which prohibits some kinds of discrimination: 'A person (A) discriminates against another (B) if, because of a protected characteristic, A treats B less favourably than A treats or would treat others' (Equality Act, 2010, section 13 (1)). The protected characteristics are age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex, and sexual orientation. The HFEA Code of Practice reflects this legislation, at least with regard to child welfare assessments: 'the assessment must be done in a non-discriminatory way. In particular, patients should not be discriminated against on grounds of gender, race, disability, sexual orientation, religious belief or age' (HFEA, 2009, section 8.7). It is safe to assume that "non-discriminatory" here is shorthand for *unjustified* discrimination, rather than discrimination of just any kind, as the purpose of performing welfare of the child assessments is to discriminate between parents who we can reasonably predict to provide an acceptable level of welfare for their children and those who we cannot. Indeed, one way of framing this project exploring the ethics of gamete allocation is to say that it sets out to establish which kinds of discrimination are justifiable and which are not.

This chapter has introduced the ethical issue at hand, and provided an overview of the legal context of the problem. The following chapter will consider some hypothetical clinical cases, to further describe some of the ethical complexities that can arise in gamete allocation.

2. EXAMPLES FROM PRACTICE

This section will highlight some of the ethical concerns that can arise for fertility clinics in allocating gametes. The following cases are all hypothetical:

2.1 Case One

Semen analysis has revealed that Bob has no sperm, and he and Betty have been presented with the possibility of treating Betty with donor sperm. During routine counselling at the fertility clinic, it transpired that Bob has been struggling with an alcohol problem, and has some anger issues that sometimes manifest themselves in the form of physical violence against Betty. Both Bob and Betty insist that the problems are the result of stress and frustration at their infertility situation, and claim that having a child together is what they need in order to achieve a harmonious family environment. The clinic now needs to decide whether to go ahead and allocate gametes to them.

2.1.1 Case One: Discussion

This case is more nuanced than it might seem at first glance. Perhaps the most obvious concern is how the child's life will go if the clinic does decide to go ahead and give Bob and Betty treatment. It is not certain that Bob and Betty are being completely honest in saying that they believe that having a child will create harmony in the family, and even if they are speaking in good faith, they might just be incorrect about how their lives will be if

they have a child. Thus, if problems do persist, there is a chance that this will interfere with their ability as parents, or that Bob will start to direct his violent behaviour towards the child. Another complication arises when we consider the fact that not all treatments or pregnancies are successful; the psychological impact of a failed pregnancy or treatment cycle might exacerbate the already-existing problems in Bob and Betty's relationship. At the same time, the clinic's revelation to Bob and Betty of a decision *not* to provide them with treatment may have a similar effect.

2.2 Case Two

Jim has poor sperm motility, so he and his wife Alice cannot conceive without assisted reproductive technology. Alice has Huntington's disease (HD), and while Jim does not and is not a carrier, Alice's condition is a dominant trait, so any child she has with one of her own eggs will have a 50% chance of inheriting the disease. Jim and Alice are aware of this, but would ideally like a child who is genetically related to at least one of them. There is the possibility of the clinic's using pre-implantation genetic diagnosis (PGD) to determine whether embryos created using Alice's eggs and donor sperm are affected before using them. Alice and Jim say that they cannot afford PGD, and that even if they could, they would be reluctant to use it, as they would value a child with HD as much as one who was unaffected.

Some staff members at the clinic have expressed concern about offering treatment where the child has a 50% chance of inheriting HD, particularly when PGD could be used to ensure that any child born from treatment would not be affected. Others agree with Jim and

Alice that an affected child would be just as valuable as any other, and that to select against HD would be offensive to the community of people with HD and undermine their place in society. Alice and Jim are open to the possibility of using a donor egg, as this seems to them to circumvent the discriminatory practice of selecting against HD. Staff at the clinic are reluctant to use a donor egg except as a last resort, as they are keen to avoid the complex psychological and social issues that they think can arise in families with donor-conceived children. Some also say they cannot understand why Alice and Jim are happier to use a donor egg than PGD, as they see both procedures as constituting selecting against HD. The clinic must now decide whether to treat Alice with a donor egg, or to artificially inseminate her with Jim's sperm using her own egg and accept that there is a 50% chance that the child will inherit HD.

2.2.1 Case Two: Discussion

The above case demonstrates different ethical issues to those in the first case. To begin with, there is the important question of whether Alice and Jim should have access to donor eggs when, arguably, the same result could be achieved by using PGD. Donated eggs are a scarce resource that could be used by somebody who has *no* eggs of their own, rather than by Alice who has eggs that could yield a healthy baby through the use of PGD. So, one reason speaking against treating Alice and Jim is that there are other people to whom we might prefer to give the gametes; this points to gamete allocation as a resource equity issue, unlike the case of Bob and Betty where the moral concern is not so much equity in resource distribution, but a desire to ensure positive consequences. We might say that the reasons

not to treat Bob and Betty are to do with Bob and Betty themselves (and their potential child), whereas with Alice and Jim we may have a reason to avoid treating them with donated gametes because of the effect that this will have on other potential recipients. When gametes are scarce, whatever is best for one patient may impact negatively on others. So now we are presented with an issue of fairness; it may be unfair to treat Alice with donor eggs instead of someone else for whom there are fewer alternatives available.

There may also be social reasons to avoid using a donor egg over another kind of treatment, if we think that the use of a donor egg may have a negative effect on relationships within the family or on the family's relationship with their community. Gamete donation creates non-standard family relationships, as donor-conceived children may have limited or no contact with one or both of their genetic parents throughout their lives. If this disadvantages anyone, then in some cases it may be best to avoid using donated gametes if other avenues are possible. Unlike Bob and Betty, Jim and Alice have a treatment option available to them that does not involve the use of donor gametes.

Another social question applying to this case is the question of the effect, if any, of selecting against a condition or disease on those living with that condition or disease. They may feel alienated or offended by the practice of selecting out future people on the basis that they may share this condition or disease. This raises the question of whether clinical staff should take such wider social issues into account.

The difference between the first case and the second can help to illuminate different ways of approaching gamete allocation. On the one hand, we might consider it a first come, first served system, where, barring any reasons militating against treatment, everyone gets treated in the order that they are referred to the clinic. Thus, everyone gets treated in turn,

except those problem cases like Bob and Betty, who are either delayed because they need further ethical consideration, or are refused entirely. On the other hand, we might consider each patient to be in competition with every other for donor gametes, which, given shortages, cannot be used to treat every patient who wants them. This would mean that clinics would have to take more into account than just whether or not there are any decisive reasons not to treat certain patients: they would have to assess the moral components of each case to decide which patient might be the best to treat.

Treating patients in order (except those patients who we wish never to receive treatment with donor gametes, like perhaps Bob and Betty) might be the most simplistic way of allocating gametes. A look at some other cases, however, might demonstrate some situations in which this system becomes problematic.

2.3 Case Three

Jane is infertile because she had radiotherapy treatment for cancer as a teenager. She and her husband Albert have been on a waiting list at their clinic for about six months, hoping to get treatment with donor eggs. During this time, they have made some friends on an internet forum. These friends say that when they received treatment at their local clinic, the time between being referred and receiving treatment was less than four months. Jane's local clinic has a policy of not treating women aged 50 or above, and at 49 she is concerned that if she is made to wait much longer, she will be excluded from the list altogether because of her age.

2.3.1 Case Three: Discussion

Jane's situation is that if she does not get treated soon, she may not be treated at all. As well as the decision whether to treat her at all, there is the question of *when* to treat her, given that her chances of having *successful* treatment diminish with time. Furthermore, there are increased obstetric risks as she gets older (including risks to the foetus). Thus, the longer she is kept waiting, the less likely she is to get the successful pregnancy she wants, with the possibility that she will never be treated. Perhaps, then, clinics should factor in the *age* of participants too, rather than just considering the time at which they arrived on the waiting list. This might help to ensure that patients do not get removed from the list by virtue of their being too old, which may seem unfair on older patients. However, there may be concerns that older patients make less suitable parents, as their shorter remaining lifespan may present problems for the child. Equally, favouring older patients in this way might be unfair on younger patients if they have been waiting longer.

This case also illuminates the problem of having different clinics operating at this degree of independence from each other. Jane and Albert seem to be waiting longer than some other people on waiting lists at different clinics. This could be due to a shortage of donors at their clinic, or a shortage of medical staff or facilities to provide treatment, or simply a greater demand for treatment at that clinic. This once again highlights the resource scarcity element of the issue, as the amount of funding or resources available may not be enough to meet demand. At any rate, Jane and Albert are left waiting while other people seem to be passing through the system much more quickly. In terms of their clinic's waiting list, people seem to be getting treatment in turn; however, on a *national* level, the situation

seems less fair. This might provide a motivation for creating a national allocation system or waiting list, so that people are not unfairly disadvantaged because of where in the country they live.

This next case will introduce some more complicating possibilities regarding patients' positions on waiting lists.

2.4 Case Four

Tess and Emily are a lesbian couple hoping to get treatment with donor sperm. Their mutual friend Robert had agreed to donate sperm to help them conceive, but changed his mind at the last minute, saying he was no longer comfortable with the idea. They joined the waiting list to receive sperm from an anonymous donor, but after they eventually reached the top of the list, it transpired that the donor they had been allocated had stipulated that he did not want his sperm to go to a lesbian couple. As there is a shortage of sperm donors, Tess and Emily now find themselves waiting for a suitable sperm donor to come along so that they can receive treatment.

2.4.1 Case Four: Discussion

In this case, Tess and Emily's position on the waiting list is not exactly clear. In one sense, they were top of the waiting list at one point, as they were ready to have treatment with Robert's sperm, and the clinic was willing to treat them, if only Robert had not changed his mind. They were not, however, really "waiting" at all – the fact that they knew someone

who was willing to donate sperm to them put them right to the top of the list, as Robert's sperm would only go to Tess and Emily, if anyone at all. Though we may sympathise with their disappointment at Robert's change of heart, it is not clear in the first place that it was entirely fair for them to get immediate treatment just because they knew someone who was willing to donate sperm only to them. We must ask why it is that Robert, or anyone else willing to donate sperm or eggs, should be allowed to choose the recipients of their gametes, or specify characteristics that the recipients must have.

On the one hand, we may have an intuition that gametes belong to a person, or are a part of their body, and so it is up to them (within certain constraints) what they do with them. However, donors might make different decisions about the recipients of their gametes that we find uncomfortable: someone might not want their gametes to go to same-sex couples, or to people of a certain race. A tension also arises when, although we want gamete allocation to reflect principles of fairness and non-discrimination, we may not want to deter people from donating gametes altogether by restricting people's control over what happens to their gametes once they have donated them. The homophobic or racist donor may choose not to donate at all if they cannot do so on their own terms. Allocation thus affects donation just as donation affects allocation.

It is not always the donors themselves that have such controversial views with regard to who is eligible to receive gametes, however. We saw in case three that there is an issue regarding age cut-offs for recipients, and relevant to case four there are discrepancies between clinics' treatment of same-sex couples, too: not all commissioning bodies will fund treatment for same-sex couples, meaning that they will have to travel elsewhere for

treatment where heterosexual couples would not have to do so. Such policies might be regarded as unjustly discriminatory against people of certain ages or sexualities.

Another argument might run the other way, suggesting that it is more unfair to treat same-sex couples than not to treat them. This comes from the idea that the individuals in such couples are not medically infertile – they could, if they wanted, find a partner of the opposite sex, and reproduce with them, but they choose not to do this. On the other hand, heterosexual individuals with medical infertility cannot reproduce regardless of with whom they try. The idea of a couple’s being infertile as a result of their own “choice”, rather than by unavoidable medical circumstances, then, may serve as a justification for treating heterosexual couples over same-sex ones.

2.5 Case Five

Rajkumar and Gulab are an Indian couple, and Rajkumar needs donor sperm if he and Gulab are to reproduce together. They have indicated that they would like to be treated with sperm from a white donor because they would like a child with fairer skin than they have. Some members of staff in the clinic have expressed concern about accommodating this preference, as this goes against their usual practice of allocating donors to recipients with similar physical characteristics, including ethnicity. Furthermore, some staff members have also expressed a concern that a mixed race child with two south Asian parents might look strange to other members of the community, and that this might have an impact on the family, especially the child. Rajkumar and Gulab have stated that they do not care how their

family is looked upon by society, and that it may in fact be a good thing to challenge prevailing expectations of how families should look.

2.5.1 Case Five Discussion

This case shows that patients may not want gametes from a donor with similar physical characteristics to them, raising the question of the extent to which clinics should account for the particular desires and preferences of patients. Our answer to this question may be influenced by the availability of the type of gametes being requested – if there is a preponderance of gametes from a certain type of donor, someone’s request for this may matter less than if someone requests gametes that are in low supply. We may question the claim that we have *any* more reason to allocate gametes to someone who matches the characteristics of the donor over someone who is less of a match.

There is also a putative welfare of the child concern in this case. In the above case, staff are worried that the family’s community may stigmatise them for having a child with a different ethnicity. This raises the question of whether this would actually occur, and if it would, whether it is the family’s choice to take the risk, or whether the clinic can legitimately insist that they choose gametes from a more closely matching donor. There are once again wider social issues, as we may consider the extent to which society’s potential expectations about families should be conformed to or challenged.

2.6 Summary Remarks

In all of the above cases, the couples concerned need assistance to reproduce; that is why they are involved with fertility clinics in the first place, and why staff have become aware of their situations. But although these individuals have fertility problems in common, the clinics' reasons for not offering treatment (and ultimately allowing these people to reproduce) are different in each situation. So, it is their infertility *in combination with* these various other factors about them that creates obstacles to them reproducing. In this sense, they are just unlucky: circumstances that would not prevent them from reproducing naturally (if they were physically able to) prevent them from reproducing with treatment. Outside of clinical settings, violent alcoholics, carriers of Huntington's disease, 50-year-olds, and those with diminished capacity all reproduce. Choosing one's reproductive partner is also the norm. There may be a motivation for attempting to treat patients as they would be treated "in the real world", i.e. to give them treatment that will bring them closer to how things would be if they did not have fertility problems. But for the people in the cases above, their need for clinical assistance means that in part, the decision rests with the clinical staff that choose whether or not to help them, raising the question of whether these staff members are obliged to help patients simulate a "normal" reproductive experience, or whether they have other obligations because of their involvement in the process.

This opens the door to many ethical issues: perhaps it is an infringement of people's liberty or autonomy to make decisions about whether or not people can reproduce based on judgements about their characters. Statutory obligations and professional codes of conduct may require staff to treat some patients regardless of whether they are comfortable doing

so. Certainly there is a legal responsibility, but this does not necessarily mean that there is an ethical responsibility.

This discussion may seem somewhat cursory; the issues discussed above will receive more detailed treatment later. These cases nevertheless illustrate some of the ethical issues that are at work in gamete allocation and that can face staff working in fertility clinics, and why there is a need to spend time considering them. These are the kinds of cases that can lead to disagreement between staff members, between staff members and patients themselves, or between these groups and entire sections of society.

Much that has been written in moral philosophy will have an indirect bearing on this issue, and this is considered in chapter four below. Some philosophers have also attempted to address the gamete allocation question directly. Pennings attempted to systematise the problem of allocating donated eggs (Pennings, 2001). This thesis' conclusions agree with Pennings that a priority or points system should be used for gamete (many of the ethical issues that apply to egg allocation apply also to sperm allocation, so this project will consider both of these issues together) allocation, but diverges from Pennings' view with regard to how criteria should be weighed into this system. Pattinson (2012) also discusses some putative criteria for gamete allocation, as part of a wider discussion of a national allocation system. This thesis considers these criteria in greater detail than Pattinson, exploring why they are valuable, and how they should be weighed.

3. METHODOLOGY

A project was designed and undertaken to help address the ethical issues outlined in the previous two chapters. This chapter describes this project in detail.

The overarching aim of this thesis is to generate a set of philosophically robust yet practically useful conclusions about how clinical staff should allocate gametes, including the use of known donation and a national allocation system.

3.1 Research Questions

1. What criteria are being used in the UK to allocate gametes donated for reproductive purposes – including criteria that are used to determine whether a potential recipient is accepted on to a waiting list?
2. What criteria ought to be used to allocate gametes for reproductive purposes? Should donors be permitted to influence the allocation process? Should known donors be used?
3. What are the ethical arguments for and against a national register of recipients and donors?
4. What are the ethical opinions of fertility clinic staff about gamete allocation, and how acceptable to them are the ethical conclusions relating to research questions 1-3 above?

3.2 Aims and Objectives

The overarching aim of the thesis was met by breaking it down into a series of smaller aims and objectives, the results of which address the overarching aim when taken together. These smaller aims were:

1. To explore what allocation criteria for donated gametes are being used by clinics in the UK, including those which govern admission to waiting lists.

Achieved by meeting the following objectives:

- i) A survey of publicly-available allocation criteria at UK fertility clinics.
- ii) Interviews with staff working in fertility clinics across the UK.

2. To determine what criteria ought to be used to allocate donated gametes.

Achieved by meeting the following objectives:

- iii) An ethical analysis of some of the potential criteria for allocating gametes.
- iv) An ethical evaluation of the use of known and conditional donors.
- v) An analysis of the ethical opinions of service providers, and of their reactions to the results of objectives iii) and iv)

3. To determine whether a national allocation system should be developed.

Achieved by meeting the following objectives:

- vi) An ethical analysis of the advantages and disadvantages of the national system, taking account of:
- vii) An analysis of the reactions of service providers to the arguments for and against a national register.

3.3 Project Design

The project was designed to draw conclusions and make suggestions that will be useful to fertility clinic staff, policy-makers, and those with influence over practice. To that end, serious efforts were made to determine and engage with the ethical views of these and other relevant stakeholders, so that their opinions could be considered alongside, and where appropriate integrated with, a more abstract theoretical analysis. This approach attempts to take seriously Mill's view that:

In the case of any person whose judgement is really deserving of confidence, how has it become so? [...] Because he has felt, that the only way in which a human being can make some approach to knowing the whole of a subject, is by hearing what can be said about it by persons of every variety of opinion, and studying all modes in which it can be looked at by every character of mind (Mill, 1991, p. 25)

The project is thus a combination of philosophical theory and empirical research, often referred to as empirical bioethics.

Before the empirical study was undertaken, the project involved a placement at a fertility clinic in the UK, providing the opportunity to engage with the kinds of staff members whose practice was to be considered in the project, and to observe laboratory work. The project also provided the opportunity to sit in on consultations with patients at a secondary clinic, where fertility patients who had seen their general practitioner (GP) would receive further care and examination before potentially being referred to a tertiary clinic for treatment. This provided an idea of how emotionally fraught the pursuit of fertility treatment can be. In addition, throughout the course of the project it was possible to observe the meetings of a fertility clinic ethics committee, which allowed exposure to real-life cases and ethical dilemmas occurring in fertility treatment. These experiences helped to ground the research in the real-life practices it aims to influence, and to foster understanding of the different perspectives at play, developing familiarity with the environment that the project was embedded in. It was important that this stage occurred prior to data collection, so that when the time came for data collection, some of the ethical issues that would be pertinent to explore with fertility clinic staff had already been identified.

3.3.1 Project Execution

Objective i) was completed by collecting data from the HFEA website, and, where they existed, the websites of clinics themselves. Data was also added from interviews in the first phase of the embedded study undertaken as part of this project, more details of which are described on pages 129-157. In addition to data on criteria listed on the HFEA website, the database also sought to include data on whether each clinic would offer treatment to

same-sex couples or single patients. These factors were of particular philosophical interest given their status as protected characteristics in the Equality Act (2010). In light of the emphasis on conditional and known donation as a research aim, the database also aimed to include information on this.

A philosophical exploration of gamete allocation was then undertaken. This considered some of the putative concerns and ethical issues arising. These issues were selected based on their salience in the philosophical literature, the statutes governing fertility treatment, and from observations made during the field placement. This philosophical analysis culminated in some tentative philosophical conclusions about gamete allocation ethics.

To meet the aim of ascertaining which criteria fertility staff employ in practice, how guidelines are interpreted, and how service providers would react to an ethical analysis, the project included an empirical study. This involved collecting qualitative data from professionals working in fertility clinics, academics with an interest in reproductive ethics, and representatives of relevant organisations, such as the HFEA (the organisation responsible for licensing fertility clinics in the UK) and the National Gamete Donation Trust (a charity providing information about gamete donation). This data comprises both practical information about what practitioners do and why, and information regarding their ethical opinions on current practice, for example the practices of which they approve or disapprove, and why. This data was then analysed in light of the earlier philosophical investigation, and the philosophical conclusions reassessed so as to accommodate the fact that the study's findings may indicate practical barriers to their implementation. These findings were then presented in a workshop, which itself was a phase of data collection (detailed descriptions of

the data collection phases are contained in chapter five). The conclusions then underwent final revisions in light of the workshop data. The project therefore used theory and data iteratively: preliminary philosophical exploration influenced the design and execution of the empirical study, which itself had a bearing on the theoretical elements of the project where philosophical conclusions were modified in light of the data. The next section will provide a detailed description of the relationship between philosophical theory and empirical data within this project.

3.3.2 Empirical Bioethics

The approach used in this project is referred to as “empirical bioethics”. The quotation from Mill above (see page 19) provides a good starting point in considering why this approach is appropriate – final conclusions will be strengthened if varied and opposing views have been considered and appropriately dealt with.

One reason to adopt an empirical bioethics approach in this project is that, as noted on page 20 above, seeking fertility treatment is a highly emotional endeavour. The empirical bioethics approach aims to take seriously the issue, as expressed by Ives and Draper, that ‘there is something lacking in an approach that appeals solely to abstract theoretical principles and rationality when the problems addressed are experienced in a particular context and arouse high emotion’ (Ives and Draper, 2009, p. 250). The emotional context in which gamete allocation decisions are made in practice is far removed from an ordinary academic context, and the need to adequately understand this emotional context gives rise

to the need for the project to include a more practical grounding than a straightforward philosophical thesis alone could provide.

The interests of stakeholders are even more acutely affected when ethical discussion has the potential to inform policy, as is the case with this project. Ives and Draper (2009) call this 'normative policy oriented bioethics (NPOB)' (p. 251). The heightened implications for such stakeholders in scenarios when ethics seeks to inform policy call for 'encounters with experience' to achieve 'contextual understanding' (Ives and Draper, 2009, p.251), where those engaged in ethical analysis immerse themselves in the experiences of others to the greatest tenable extent. The approach to this project thus attempts to give due concern to the experiences of those who are involved in the relevant processes of deciding how to allocate gametes.

The notion of sensitivity to emotional context is important, but so is the idea of context-sensitivity in general. In a discussion of context-sensitivity, Musschenga notes that empirical ethics 'takes seriously the intention of all practical ethics, not only to prescribe actions, but also to actually guide people in their behavior' (Musschenga, 2005, p. 468). This practical usefulness makes empirical ethics particularly advantageous in a project like this, which sets out to have high potential for impact on policy and practice. The result is a set of empirically informed ethical conclusions about gamete allocation practice, underpinned by robust philosophical justification. Note that the acknowledgement of the value of this context-sensitivity does not entail a commitment to the full-blown contextualism described by Musschenga, which 'rejects importing alien, external principles into a context' (Musschenga, 2005, p. 468). The next subsection will describe this thesis's theoretical approach, which includes the application of general principles to particular contexts.

Having now explained why an empirical approach is appropriate to this project, let us now turn to a discussion of the nature and structure of this approach. The iterative relationship between theory and data in the study has already been described, and this is key to understanding the manner in which ethical theory is integrated with empirical data in this project.

3.3.3 Relationship between Theory and Empirical Data

The project adopts a top-down approach to the relationship between theory and data, such that “upstream”, higher-order, theoretically justified conclusions will always be given priority over intuitions or opinions that are unaccompanied by robust argument. This means that the theoretical assumptions and starting points of the thesis (to be described in sections 4.1 and 4.2 below) are unlikely to be affected by the data, but rather, the data will be considered in the light of this theory. This is in line with Singer’s argument that ‘moral expertise would seem to be possible’ (Singer, 1972, p. 117), in that some credence is given to the value of ethical theory over the views of those with little or no experience in it.

This is not to say that theory can provide answers on all ethical questions. In the same piece, Singer is clear about the value of *information*: ‘to be moral experts, it would be necessary for moral philosophers to do some fact-finding on whatever issue they were considering’ (Singer, 1972, p. 117). This in itself provides a reason to collect empirical data. Applied to this project, information about how clinics currently allocate gametes may help us towards the goal of arriving at philosophical conclusions that are practically viable. Being aware of the status quo in how guidance and statutes are interpreted in practice may give a

clearer picture of what the next stage should be in terms of making conclusions about how to make practice more ethical. Further to this, exploring how acceptable staff find these conclusions will help create a picture of what kinds of conclusions might be realistically adopted into practice. Given that there is little existing data on clinical staff members' opinions about how to allocate gametes, a study collecting data directly from staff, regarding both their practices and their views, will provide useful facts in negotiating these questions.

In terms of how likely staff are to accept the conclusions made in this project, where the data shows that clinical staff have strong feelings about particular issues, this is taken seriously as a potential barrier to changes in policy or practice. This results in conclusions of different kinds, which diverge from each other: there will be "ideal world" conclusions that are recommended by philosophical theory, and pragmatic conclusions that strike a balance between what the theory being used would recommend, and what can reasonably be expected to actually occur in practice, given the strength of feeling of those who would be expected to act in the way suggested; as Huxtable puts it, '[d]iluting one's claims makes sound pragmatic sense when the likely alternative is the emptying of the whole draught' (Huxtable, 2013, p.132). This is somewhat oversimplified, as the *value* of potential outcomes needs to be considered as well as their likelihood. In some cases it may be better, on balance, to persist in arguing for a strong conclusion. The strong conclusion may be of enormous value, or the diluted one may be of too little value. At any rate, Huxtable is right in principle that compromise for the sake of practicality may sometimes be rational.

Let us consider the limitations of moral expertise outlined by Archard. Archard's argument is twofold: he begins by pointing to a flaw in the concept of moral expertise that renders it 'limited' (Archard, 2009, p. 125) at best, and then goes on to suggest that even if

fully-fledged moral expertise were possible, to acknowledge this in practice might have pernicious consequences. Both of these positions can be shown to be problematic.

Archard's argument that moral philosophers can have only 'limited' moral expertise rests on the premise that 'moral philosophers see themselves as required to construct moral theory on the foundations of common-sense morality[, which is] the set of moral maxims of which ordinary people have knowledge and of which they make use in their quotidian lives' (Archard, 2009, p. 123). This argument suggests that moral philosophers only deal with non-expert subjects, and that any expertise is in the 'systematization, clarification, disambiguation and – where necessary – modification of common-sense morality' (Archard, 2009, p. 125) rather than in normative judgements themselves. One need only deny this empirical claim about the practice of moral philosophers and the nature of moral theory to undermine Archard's argument against moral expertise. Indeed, this is one of the moves adopted by Gordon in his criticism of Archard's argument, who concludes that Archard's argument is 'unconvincing' (Gordon, 2012, p.4). It therefore seems that our acceptance of the possibility of moral expertise must rest on our ideas about the nature and purpose of moral reasoning; if we adopt the top-down approach, as is proposed in this thesis, there is room for moral expertise of a fuller kind than Archard allows.

Archard's second, consequentialist criticism of the notion of moral expertise is that to allow extra weight to the views of putative moral experts within the context of policy-making would be undemocratic: 'Exclusion from debates subverts the acquisition and strengthening of those traits, and consequently enervates democracy' (Archard, 2009, p. 127).

This thesis does not fall foul of democratic principles, as it does not seek to *exclude* anyone from debate.² Rather, the empirical approach hopes to add a variety of voices to the philosophical discussion, by inviting participants not just to disclose factual information, but to share and discuss their moral views on the topics at hand. This makes this project's philosophical analysis more democratic than would be the case with a non-empirical philosophical project. The top-down approach means that ethical theory is afforded a weightier vote, but voices are not excluded from the debate in the way that worries Archard – if the data suggests that there is enough support for, or opposition to, an idea, then the idea may be considered, regardless of whether it is supported by theory.

Beauchamp and Childress note that 'cases lead us to modify and refine embryonic theoretical claims, especially by pointing to inadequacies in or limitations of theories' (Beauchamp and Childress, 1989, p. 16). Whereas Hedgecoe (2004), and arguably Frith (2012), take this sentiment as support of a more data-driven approach, this thesis takes the view that not *all* moral theory should be considered "embryonic". In cases where moral theory is lacking, we can look to empirical data for help, but this does not make empirical data 'theory challenging' (Hedgecoe, 2004, p. 137) in the way that Hedgecoe would have it, because we must accept the conclusions to which a sufficiently robust theory leads. This thesis will subscribe to a paradigm of moral theory that affords greater weight to principles and their application than to considerations arising from individual instances of moral feeling. Data must thus go some way towards demonstrating where theory is flawed, rather than

² There is, however, the question of who is *included* in the debate, and decisions about *inclusion* may amount to decisions about *exclusion*. Chapter five of this thesis will describe the study's participants and the rationales for the inclusion criteria and sampling methods. Subsection 7.1.2 explains why patients were not directly included in the study.

just disagreeing with it. Preserving a unified, principled moral theory in this way provides a more appropriate backdrop for discussing questions of distributive justice, where distributions of resources must be justified to others. This means that data and lived experiences are examined and tested against moral theory, and at times can be used to revise it where it is already lacking, but they do not themselves put moral theory to the test.

As Borry et al. comment: '[e]mpirical research cannot by itself determine what is good or evil, right or wrong. The inductive approach runs the risk of lacking a critical attitude and assigning a sacred meaning to the facts without testing them against normative principles and theories' (Borry et al., 2004, pp. 48-49). The empirical bioethics approach in this project is thus something akin to that of Borry et al. Empirical data can help us to identify moral problems, and it can help us to evaluate them: 'empirical research can play a role in the description of the morally relevant facts. [...E]mpirical research plays a role in assessing the moral question [...and] in evaluating the decision-making process' (Borry et al., 2004, pp. 50-51). It is only in limited circumstances, however, afforded enough weight to influence theory – either those circumstances in which theory leaves questions open or unanswered, or when data suggests that theoretical conclusions are unlikely to be adopted into real-world practice.

Aside perhaps from placing this emphasis on the role of empirical data in the identification of moral problems, the approach being taken has parallels with Ives' "Reflexive Bioethics" approach to empirical bioethics, in that it includes a 'naive inquiry into the problem' (Ives, 2013, p.10) before in-depth analysis begins. In this case, the naive inquiry is the pre-empirical philosophical analysis. The final stage, 'reflexive balancing', is in this case

the integration of the philosophical analysis with the data. This process will be described in detail in subsection 5.4.3 below.

Now we have some idea of the relative weighting of theoretical conclusions compared to conclusions arising from the data. In general, there is little room for the empirical data to challenge any established and robust theory, though it can do so when the data suggests that the theory's conclusions are not pragmatically feasible, i.e. when a conclusion is expected to meet with so much opposition that it is unlikely to be adopted in practice. Now that the relationship between theory and data has been established, let us explore how this will be applied in this project.

Where the empirical data show that participants appear to agree with the conclusions in the philosophy chapter, they will require less discussion. This is not to assume that the participants' agreement ensures that the conclusions are correct, but it is at least helpful, pragmatically and perhaps theoretically, if there is some consensus, limited though it might be. In cases where the interview and workshop data show that participants have views that would oppose the recommendations in the philosophy chapter, then more in-depth analysis will be needed to establish whether the conclusions should be revised in light of their views if they are to be modified into conclusions that will be more likely to shape future policy and practice for the better.

These revisions could be needed for two reasons: the first is where the participants introduce theoretical considerations that had previously been given too little weight. In this case, the weightings may need to be reconsidered, which could result in different conclusions. This is consistent with the approach to empirical bioethics being used in this

thesis, where data can 'lead us to modify and refine embryonic theoretical claims' (Beauchamp and Childress, 1989, p. 16).

The second is that where there is opposition to one of the conclusions, the question arises of whether there is anything to be gained by making a recommendation that would most likely be rejected. For practical reasons it may thus be useful to try to strike such a compromise.

3.3.4 Theory within Context

Another feature that may cause us to modify theory is the legal context of gamete allocation. Much of the discussion to follow will thus consider moral factors in light of the broader legal context, as described above (pages 3-4). The philosophical work in this thesis may still suggest that the legal position is wrong, but moral theory that is to be of use to practitioners must account for the current legal situation, and offer guidance in accordance with it. This is not an example of data challenging theory *per se*, but rather an example of theory being sensitive to context in order for it to have practical application.

4. PHILOSOPHICAL CONSIDERATIONS IN GAMETE ALLOCATION

This chapter will define and categorise some of the different moral factors that may be relevant in gamete allocation scenarios, and consider *how* these factors can be used to assist in gamete allocation, and how they may interact and be weighed up against each other. It will also explore some technical matters regarding the relationship between philosophical theory and practical concerns.

This chapter is structured as follows: section 4.1 lays out some of the initial philosophical assumptions being made in this thesis. One of these, a conception of equality, is explicated in section 4.2. Section 4.3 outlines some considerations that may be valuable under the framework described in sections 4.1 and 4.2, and which thus potentially require us to deviate from the position of equality. Section 4.4 considers different characteristics to see how they relate to our commitments to the moral considerations identified in section 4.3, and how they interact with our commitment to equality. Sections 4.5 and 4.6 bring these considerations together and reflect on how they should be weighted. Section 4.7 discusses the concept of a national allocation system. Finally, section 4.8 tests the conclusions of this chapter using the hypothetical examples detailed in chapter two.

4.1 Moral Considerations

The moral dimensions of gamete allocation are so multitudinous that there will not be room to discuss them all. Some considerations, and some putative selection criteria for gamete receipt, will have to be omitted. Those moral issues that have been chosen are those

that seemed the most salient, based on the time spent in the field placement, and a survey of the philosophical and legal literature. These choices of what considerations to include have, therefore, both a theoretical and a practical underpinning, consistent with the empirical bioethics methodology being used here, and the intention that the project should produce practical conclusions. The work undertaken here is intended to provide a useful framework for considering similar moral questions in the future – the moral features of the considerations discussed may also apply to considerations not discussed.

Similarly, different moral theories could present totally different analyses of the situation, and it would be impossible to include a full discussion of every moral theory's implications for gamete allocation. This thesis has also been selective in terms of the moral framework used. While a context-independent case can be made for adopting the moral theory described below, there may also be contextual reasons that speak in favour of it. If we are selecting a theory with the intention of applying it to healthcare provision, then a theory that accords with some basic principles that tend to be applied within that context will speak in favour of using that theory. This is not to say that context is theory-challenging, as the issues therein have already been discussed (see page 27). It is merely to say that, when faced with a range of equally plausible higher-order moral theories, contextual applicability may speak in favour of choosing one theory over another.

To that end, one starting point of this thesis is the 'formal principle of justice' regarded by Beauchamp and Childress as one of *the* four principles for healthcare ethics: 'Equals must be treated equally, and unequals must be treated unequally' (Beauchamp and Childress, 2013, p. 250). According to this principle, discrimination requires justification: one must provide *reasons* for treating one person in a certain way and another person in a

different way in relevantly similar circumstances, on pain of acting in morally arbitrary ways. These reasons must appeal to defensible moral values in order to have legitimacy. These reasons must also go beyond mere favouritism; treating a person better because you like them is insufficient, particularly in healthcare settings where we expect benefits to be distributed according to less personal standards than this. It will therefore be presumed that we cannot distinguish between patients until a good reason is given to favour or disfavour anyone. Section 4.2 will therefore discuss considerations of equality, and what this might mean for gamete allocation decision-making.

Beyond this starting point of equality, this thesis will take a broadly consequentialist approach in determining how and whether to factor in other putative considerations. Again, while there are independent justifications for the general use of consequentialist theories of various types (see Bentham (1948); Mill (1998); Sidgwick (1901); Hare (1965 and 1981), Smart (in Smart and Williams 1973); Singer (1993); and Hooker (2000)), the kind of consequentialist theory described below is appropriate for our purposes here. Consequentialism as here defined serves only to distinguish the types of values that will be discussed in this thesis from retributive or desert-based values (except insofar as such values are useful from a consequentialist perspective).

This conception of consequentialism is roughly the “minimal consequentialism” advanced by Caws (1995). Caws rejects common descriptions of consequentialism that portray it as necessarily committed to certain theories of value or the imperative to maximise. He describes the following definition from Scheffler as an example of this common position: ‘Consequentialism in its purest and simplest form is a moral doctrine which says that the right act in any given situation is the one that will produce the best

overall outcome' (Caws, 1995, p. 318). Instead, Caws characterises the consequentialist view much more broadly: 'the rightness or otherwise of an act lies in its foreseeable consequences' (Caws, 1995, p. 317).

This broad notion of consequentialism is also explicated by Dreier, who describes 'strictly consequentialist theories' as 'those whose specification of relevant kinds of consequence make no reference, explicit or implicit, to times other than the time of the state of affairs that constitutes the consequence' (Dreier 1993, p. 23). Dreier also notes the way in which a plurality of values can be drawn into a consequentialist theory like this:

We merely take the features of an action that the theory considers to be relevant, and build them into the consequences. For example, if a theory says that promises are not to be broken, then we restate this requirement: that a promise has been broken is a bad consequence. Notice that the weighting is not yet specified. If the theory under consideration includes an absolute side constraint against promise-breaking, then we have the consequentialist version give a lexically prior negative weight to promise-breaking (Dreier 1993, p. 23).

Brown criticises this approach by suggesting that the assimilation of these values into consequentialism undermines consequentialism itself. It is beyond the scope of this thesis to consider Brown's argument in much detail, except to say that Brown's argument is problematic in that it commits the same mistake as the one that Caws attributes to Scheffler, where the most minimal form of consequentialism offered is one that erroneously describes maximisation as '[t]he non-negotiable core of consequentialism' (Brown, 2011, p. 751). This thesis sides with Caws in denying that consequentialism must be committed to maximisation.

At the same time, we should be conscious that there seems to be a prima facie reason to bring about more of a valuable thing. This is convincingly exemplified in this thought experiment from Mulgan:

Achilles knows that n is the number of people who are living below the poverty line. He also knows that, as soon as he enters a number into the computer, that number of people will be raised above the poverty line (at no cost to Achilles) [...]. Achilles enters a number (p) that, although fairly large, is significantly less than n . We ask him why he opted not to raise a further $n-p$ people above the poverty line. He replies that he is a Satisficing Consequentialist who thinks that saving p people from poverty in one day is 'good enough' (Mulgan, 2001, p. 131).

Mulgan thinks that Achilles obviously acts wrongly in this example. Even without entering into more detail about what exactly a "Satisficing Consequentialist" is, the point is clear: if we can do more good at no extra cost, we ought to do so. Hence, this thesis takes a pluralistic maximising approach.

A key question at this point is how "good" is to be conceived. The minimal version of consequentialism proposed could espouse a plurality of different values, including concepts typically not viewed as being consequentialist. For this reason, any mention of the welfare of stakeholders should be interpreted broadly, and could include concepts like happiness, interests, or autonomy. Minimal consequentialism could also involve mechanisms for negotiating these values not typically associated with consequentialism, like absolute constraints (of a deontological kind) on some actions.

The pragmatic, compromising approach (see page 25) that this thesis follows will also have some bearing on the theoretical choices made in this thesis. Given that the goal is to generate useful conclusions, the best move may be to adopt a pluralistic value theory, to

ensure that philosophical conclusions can plausibly impact the real world. We may also need to consider context to decide what theory of value to use here, as was a factor in the choice to adopt a (minimally) consequentialist theory in the first place.

Beauchamp and Childress's other principles of biomedical ethics can offer help here. The minimal consequentialist framework can employ autonomy and beneficence/non-maleficence principles (Beauchamp and Childress, 2013, pp. 101-241), so that we are operating with a theory of value that is not totally foreign to a healthcare setting. Much work can be done to flesh these principles out, but that is not the task of this thesis. It is sufficient at this stage to say that considerations of those types are values to be at least putatively considered. To align the discussion with the HFE Act, these values will be collectively considered as "welfare". This conception of welfare is broad, as it seeks to be open to a plurality of values – this thesis is not committed to a particular value theory, because exploring different ways of conceiving of value may be more palatable to policy-makers and practitioners than considering the question only under a narrow theory of value.

4.2 Equality

As has already been said, one starting standpoint in this thesis is a presumption in favour of equality. An allocation system that unjustifiably allows inequality may be described as an *unfair* one. Later sections will consider other morally relevant considerations, on the basis of which deviation from equality may be permissible, and in those cases it will be argued that our commitment to these other considerations ought to be taken to outweigh our commitment to equality. This section will examine the notion of equality, as well as

some of the arguments surrounding groups of people with different characteristics. We may want to preserve equality between certain groups when making decisions about gamete allocation, or we may think there *are* morally relevant differences that justify inequalities between these groups.

Clinical decisions must conform to legal standards of non-discrimination as laid out in the UK Equality Act 2010 (discussed above). Any discrimination must be justified not simply on features of a patient, but on considerations arising from these features. So for example, age can be a consideration, but it has to be shown that this is because it creates some other, attendant moral problem; for instance that efficacy is affected by age; that elderly parents cannot provide sufficient support for the child; or the presence of age-related health risks in pregnancy. In these cases, it is not strictly the patient's age that is our concern, but rather some problem associated with age. These may be risk factors common to specific younger women (for example, pregnancy risks associated with high blood pressure). Similarly, it is not the patient's age in itself that is the problem if we are concerned about sufficient parental support: perhaps the real issue may be more specific, for example how physically active the parent is, or how long they are expected to live.

There are two kinds of discrimination: direct and indirect. Direct discrimination is when someone is (dis)advantaged *simply on the basis of membership of a certain group* (like an age group). Indirect discrimination is where a policy³ or action with some *other* aim incidentally disadvantages members of a specific group: the policy 'applies to everyone but disadvantages a particular [group]' (Advisory, Conciliation and Arbitration Service, 2011, p.2). As an example, a fairground ride may have a policy requiring people to be at least 140cm tall

³ Both direct and indirect discrimination become systematic if they are made into policy.

if they are to ride it (and let us say that there is no explicit age restriction for this ride). This policy directly (though not necessarily unjustifiably) discriminates against those whose height is under 140cm, and *indirectly* discriminates against people on the basis of age, because (amongst children at least) there is a correlation between height and age, and so younger people are disadvantaged (albeit, in this case, for justified safety reasons).

The Equality Act includes an important clause that will in some cases allow indirect discrimination in relation to a protected characteristic. For this to be permissible, the discriminator must 'show it to be a proportionate means of achieving a legitimate aim' (Equality Act, 2010, section 19 (2)(d)). Lippert-Rasmussen echoes this: an act or policy is indirectly discriminatory against a group (in the moralised sense) only if the disadvantages to the group are 'disproportionate in the sense that the achievement of the goals promoted by such a requirement is not sufficiently important to justify the [...] effects on minorit[ies]' (Lippert-Rasmussen, 2011, p. 1).

This is crucial to the coming discussion, as it looks like pure equality between people of certain groups (defined as equal treatment irrespective of membership of such groups) gives way to other considerations. The goals of discriminatory practices, then, must be justified by balancing the loss and disadvantage to discriminated-against groups (not necessarily minorities as Lippert-Rasmussen would have it) against the advantages conferred by the discrimination. In the fairground ride case, the advantage (or legitimate aim) is safety, which outweighs the disadvantage of not being able to ride the ride. We now know what to consider if endorsing any practices that deviate from equality.

Being accurate about why discrimination is justified is key to avoiding the unjustified discrimination that may occur when some factors are over-generalised. Generalisation may,

however, be justified by an appeal to practicality when there is a high statistical likelihood of problems associated with membership of a group, even though the risk will not manifest in *every* case. It may not be possible to know who exactly will be affected, only that certain groups of people present higher risks than others. In effect, these generalisations are justified through our lack of knowledge – if we had perfect knowledge of the consequences of treating each individual patient, we would not need to generalise on the basis of other characteristics. Some of these characteristics will be considered more specifically in section 4.4. Even if these generalisations are being used, there can be provisions such that patients can still receive treatment if they can demonstrate their suitability in spite of being part of a group that is usually deemed ineligible.

It is thus important to discuss what reasons we may have to discriminate against some people, to make sure any generalisations we make are based on reasoned consideration. Now that we have a concept of when it is justifiable, in principle, to deviate from treating patients equally, we can go on to flesh out which aims count as legitimate, and which do not.⁴ The following section will consider different groups of people amongst whom we may discriminate when making allocation decisions, and consider whether our other moral commitments allow for this discrimination.

The commitment to equality is a decision-making principle, asking that deviations from equal treatment are properly justified. It is not a commitment to distributions that are egalitarian in terms of their outcome. If we think that egalitarian distributions may be of

⁴ It is worth noting that our moral commitments to equality may extend beyond the protected characteristics outlined in the Equality Act. The protected characteristics may only have been identified as needing such protection because they encompass the ways in which historically people have discriminated commonly and unfairly against others. Other forms of discrimination may similarly be unfair, even though they are not listed alongside these characteristics.

value, we must consider whether this value is sufficient to justify deviation from equal treatment.

4.3 Welfare

Our commitment to welfare may be a factor that justifies deviation from the principle of equality, however that equality is conceived. If different patients, or groups of patients, present different likelihoods for outcomes with regard to welfare, then it may be permissible for us to favour some patients over others based on the value of these outcomes. We must bear in mind, however, that ‘we need evidence to support the differential attribution of welfare to the different groups’ (Pennings, 1999, p. 1147). An evidential standard is important to justify any differential treatment, and pages 261-263 will discuss this standard further.

4.3.1 Global Welfare

Broome argues that ‘we must give up the idea that changes to the population are neutral. Adding to the population, or subtracting from it, may be either good or bad’ (Broome 2004: 207). Given the global community that is the modern world, the impact of adding one person could spread anywhere, and make things better or worse overall. The question of whether the addition of another life would be positive, negative, or neutral would require a calculation using a huge number of factors. Things like a person’s contribution to climate change, their patterns of consumption, and their employment

choices and contributions to the economy might all have a bearing on global welfare. The prediction looks very complex for clinics to make, and would likely have to be generalised: if clinics can make any judgement at all about whether a person will contribute positively or negatively to welfare, they will have to make relatively sweeping judgements about what people are *likely* to do, based on their membership of particular communities or societies. Such judgements may offer little help with gamete allocation. If UK citizens are said to be positive to welfare, so much the better for them, but this does not provide clinics with reasons to treat one patient over another if they are only choosing amongst UK citizens anyway.

If UK citizens are said to be *negative* for welfare, then this seems to speak against reproduction at all, assisted or otherwise. This seems to be a step further back from the starting point of this thesis. This thesis works within a framework that views assisted reproduction with donated gametes as being permissible at least some of the time, in order to consider what constitutes equitable allocation of gametes. This starting point is consistent with the HFEA's recommendation that '[t]here should be a presumption to provide treatment to all those who request it' (HFEA, 2005a, p. 3), although this thesis will conclude that there are many potential reasons *not* to treat a patient or couple.

Consequently, consideration that the practice of treating patients with donor gametes might be wrong in itself is a discussion for another time. At any rate, even if we think a practice is wrong in itself, there may be value in ensuring that it is done in the best way possible, if we expect the practice to continue. Hence, the discussion will proceed on the basis that providing fertility treatment to UK citizens, generally conceived, is at least neutral from a global welfare perspective.

This does not mean that *all* fertility treatments offered in the UK are at least neutral. It only commits us to saying that for the purposes of this thesis, we cannot condemn the treatment of UK citizens *per se*. This means that we will ignore factors that might speak against⁵ the treatment of all UK citizens, and only consider factors that help us distinguish between them.

This does not necessarily mean ignoring wider factors like environmental or economic ones, though. In some cases, clinicians may be able to make more specific judgements about groups of people within the UK context – for example, if there are differences in environmental impact between socioeconomic groups,⁶ rough judgements could be made on this basis. This may help us to choose between patients within the context of a UK fertility clinic.

Nevertheless, there is also the question of practicality with regard to considering multitudinous factors. Even if a system could be devised that would come up with strict guidelines about who or who not to treat based on information about certain groups' environmental, social, and economic impacts (or more specifically the impact of the *children* of members of these groups), and this system could be applied to clinics so that staff working there would not have to do any calculations of this sort for themselves, this would be an enormous and multi-faceted question that is beyond the scope of this thesis. Furthermore, a sophisticated, all-things-considered calculation of the relevant advantages and disadvantages may be beyond what we can reasonably and practically expect of clinics.

⁵ This chapter will make repeated mention of “factors speaking for/against treatment”, “reasons for treatment”, and “reasons to favour certain patients”. See pages 104-106 for further discussion of what terms like these should be taken to mean in this thesis.

⁶ See page 49 for a discussion of a narrower potential consideration regarding patients' socioeconomic status.

Hence, the discussion on welfare will be narrower in scope, and will be limited to stakeholders who clinical staff will be more accustomed to considering, and whose welfare is more easily predicted. These stakeholders are the children born of treatment themselves, and anyone else within the family unit who will be (relatively) directly affected by the birth.

The clinic's obligations towards some of these stakeholders are already enshrined in law – the HFE Act requires that account is taken of the welfare of any child born from treatment, or any other child who will be affected by this birth (HFE Act, 2008, section 14 (2)). For our purposes here we will take this to mean only other children within the same family. We can construe this broadly so as to include non-genetic family relations and other non-standard families, but the nuances of this will not affect the arguments made in this thesis – suffice it to say that we are simply excluding other children who will be affected in broader societal and global ways. To take account of child welfare, we must have a conception of the kinds of things that can influence a child's welfare. In the context of guidelines for treatment of patients, only things that can reliably be predicted before treatment occurs can be included. Accordingly, we are in the peculiar position of trying to determine a child's welfare before it is even conceived. It may not only be the child's welfare that needs to be considered, and in these calculations too we may find ourselves in similar difficulty in trying to make predictions about the welfare of the relevant stakeholders. The following subsections will come loosely in order of the level of difficulty they present when it comes to predicting the relevant factors, beginning with the most straightforward.

4.3.2 Welfare of the Child

As has already been mentioned (see page 3), clinical staff have statutory obligations to consider children's welfare. The Code of Practice splits child welfare considerations into two groups: 'past or current circumstances that may lead to any child mentioned above experiencing serious physical or psychological harm or neglect', and 'past or current circumstances that are likely to lead to an inability to care throughout childhood for any child who may be born, or that are already seriously impairing the care of any existing child of the family' (HFEA, 2009, section 8.10). These stipulations require clinical staff to consider a number of factors, many of which are mentioned explicitly in the Code.

This discussion will not follow in the way the Code splits up child welfare issues, as this introduces certain complications. To begin with, the Code places heritable medical conditions in the second group, rather than the first. Perhaps this is to avoid the complex issue of whether causing a child to exist can affect his/her welfare, when the alternative is his/her not existing at all (this issue will be discussed in greater detail on pages 51-56). But it seems odd to affiliate the wrongness of creating a child with a certain medical condition with his/her parents' inability to care for him/her, rather than grounding it in the child's suffering. Confusion is also introduced when "neglect" is mentioned in the first group, when it would seem more appropriate to associate neglect with the parents' (in)ability to care for the child. Perhaps the kind of neglect at play in the first group is of a more deliberate kind, so the second group is meant to deal with circumstances that are further beyond the parents' control.

Instead, this discussion will consider these issues in terms of how reliably clinical staff can make predictions based on them, beginning with the most straightforward. The class of factors for which clinical staff may be the most qualified to make predictions is health-related factors. Among these, heritable conditions are potentially the easiest to predict, as the likelihood of a child's inheriting a condition from its parents can be estimated as a function of the status of the parents, where known⁷, as carriers or sufferers of the condition and the status of the condition as a dominant or recessive trait. In spite of this, the severity of the condition may not be predicted as easily because an assessment of "severity" engages normative views about quality of life that are more subjective than calculations of percentage chances of risks manifesting.

4.3.2.1 Heritable Conditions

Allocating gametes to a couple or patient with a risk of passing on such a condition or disease can *reduce* the chances of any child born to that couple having it. Couples may seek treatment with donor gametes because they know that they are otherwise at risk of passing on a certain condition or disease to any child they have, and indeed the HFEA advised putative patients that a reason for using donor gametes could be that 'you have a high risk of passing on an inherited disease' (HFEA, 2013a). Donors are screened for heritable conditions⁸ so treatment with donor gametes will, if successful, result in a child without the condition or disease the couple are seeking to avoid. The use of donor gametes to avoid such

⁷ A discussion of whether it would be reasonable to instigate a battery of genetic tests for all patients prior to accepting them for treatment is beyond the scope of this thesis.

⁸ Though not all conditions can be tested for.

conditions complicates matters because a patient's having such a condition or being a carrier for one actually seems to speak in *favour* of treating them with donor gametes, rather than against.

Let us call the couple with the risk of passing on a heritable condition or disease "couple A", and another couple who are simply infertile "couple B". Let's also assume that there is an equal likelihood of success in both cases. At first glance, it seems that treating either couple will have the same result. If we treat couple A, then all other things being equal we have the same likelihood of a healthy child as couple B, and there are no grounds on which to distinguish between them.

A difference appears when we consider the potential consequences of the actions of those we *refuse* to treat. If we treat couple A, couple B will remain childless, unless they adopt. However, if we treat couple B, couple A may reproduce naturally and risk having a child with the heritable condition. If this possibility is undesirable, then there is a reason to avoid it and this may be a reason to favour couple A for treatment.

The wording of the HFE Act suggests that the responsibility of staff does not extend beyond their treatment decisions: it requires clinics to consider the welfare of children born *as the result of treatment*, rather than as a result of a failure to treat. The HFE Act only governs the creation and storage of embryos outside the body and their subsequent use, and the use and storage of gametes taken from the body. It is not designed to regulate unassisted reproduction however it arises, including as a result of decisions not to treatment.

Whether clinics should have some moral responsibility for reproductive behaviour subsequent to a refusal of treatment is unclear. As Savulescu asks (about the scope of medical practitioners' responsibility): 'Should doctors be influenced by reasons for action

which go beyond the welfare of the individual concerned? Should they be influenced by the welfare of others or political values?’ (Savulescu, 1999, p. 124). There may be good reasons to answer “no” to these questions: our faith in the integrity of the medical system may rely on, for example, doctors refraining from killing patients in order to give their organs to others, even where this means saving more lives overall (Harris, 1975). Savulescu agrees with this individualised approach to treating patients, with the important exception that ‘when no individual is harmed by promoting these other values, there is less reason to object to taking them into account’ (Savulescu, 1999, p. 124).

Applying this to the case of donated gametes and heritable diseases, the “other value” to promote is the avoidance of a child born with a heritable disease. We are now faced with the question of whether the clinic *harms* couple B (and “couple” can here substitute the “individual” of which Savulescu speaks) by choosing to treat couple A. If we think this, we are also committed to the converse – that by treating couple B, the clinic harms couple A. If we accept this claim that to de-prioritise a patient is to harm them, then harm does not give us a reason to distinguish between couple A and couple B, because in either case we harm someone. If a couple is to be harmed whatever we do, then Savulescu’s restriction on doctors accounting for other values is irrelevant, and we can legitimately take into account the risk of a child being born with a heritable disease. This means that all other things being equal, we should treat couple A, who risk creating such a child if they go untreated by the clinic, over couple B.

4.3.2.2 Substance Use

Of course, it is not only heritable health factors like these that will have an impact on the health of a child: features of a child's environment, both before and after birth, can affect their health. A good example of this is parental behaviour. Imagine that clinical staff have reason to believe that a woman will use potentially noxious substances⁹ during pregnancy that may adversely affect the developing foetus.¹⁰ This is not a *genetic* health concern, and is thus perhaps not *quite* as easy to predict, as we may be wrong in our estimation that the woman will continue these behaviours during pregnancy. If we think, however, that a woman is more *likely* than some other patient to use foetus-damaging substances during pregnancy, then an appeal to potential harm to the child might ground a reason to treat the non-substance-using patient over the substance-using one.

Such harms can extend beyond pregnancy: for example, being exposed to passive smoking increases one's risk of lung cancer (Taylor et al., 2007), sudden infant death syndrome (Tobacco Advisory Group of the Royal College of Physicians, 2010, p. 81), and respiratory illness (Tobacco Advisory Group of the Royal College of Physicians, 2010, p. 81-83). This may provide a reason for clinics not to treat patients with *any* smoking family members who can be expected regularly to smoke in the vicinity of the child in a closed environment. People with drug or alcohol problems are also more likely to neglect or abuse their children (Chaffin et al., 1996; Ammerman et al. 1999; Smith et al., 2007, p. 151;

⁹ I use this term loosely, to refer to the use of illegal drugs, harmful legal drugs, drinking alcohol, or smoking tobacco.

¹⁰ It is widely agreed that alcohol, tobacco, and certain drugs (the NHS names cannabis, ecstasy, cocaine, and heroin as examples) while pregnant can harm one's baby .See (National Health Service, 2014a) and (National Health Service, 2014b).

Appleyard et al., 2011). Given that a child with a substance-abusing parent is likely to be exposed to risks of various harms, then all other things being equal, we should treat a non-substance-abusing patient ahead of a substance-using one.

4.3.2.3 Violence

There are other parental behaviours that clinics can consider as indicating risks of harm for a child. It seems clear that treating a person with a history of violence could result in a child at greater risk of violence than treating a patient without such a history. Moreover, even indirect exposure to domestic violence (i.e. witnessing it) may lead to problems for children, at least of a psychosocial if not a physical nature (Hester et al., 2007, pp. 66-68; Kaufman et al., 2011). The case seems strong for favouring non-violent histories over violent ones.

This risk assessment may need to be sensitive to other indicators of an elevated potential for violence against children. The connection between substance use and child abuse has already been noted (pages 48-49 above). Controversially, both low socioeconomic status and having been a previous victim of child abuse (including physical abuse, sexual abuse, and neglect) are also both associated with a higher risk of abusing children (Glasser et al., 2001; Brown et al., 1998, p. 1066). Arguments might be made that someone's socioeconomic status should not be a barrier to their procreation, or that those who have been abused should not be doubly disadvantaged by having this count against them for fertility treatment.

These two arguments can be described as arguments from equality, and arguments from patient welfare, respectively. Section 4.6 below considers how equality should be weighed against commitments to child welfare, and it will be argued that child welfare must take priority. With regard to tensions between patient welfare and child welfare, again child welfare should be prioritised. This is because even if value at a more abstract level tells us that these individuals are all equally valuable, this does not mean that we must treat all of them the same. While a child may be just as valuable as an adult, the fact that a child is more at *risk* than an adult may offer us a reason, in decision-making and in practice, to act *as if* we are favouring the child rather than the adult. The target is actually to minimise the risk of something bad happening to this more vulnerable group of stakeholders, not to suggest that one group is any more valuable than the other. There is thus a practical reason to prioritise children's welfare. In the case of the previous victim of child abuse, the very reason that we sympathise with such a person is that they have been a victim of such abuse. This means that the argument about doubly disadvantaging patients itself marks out child welfare as of value. We must remember to be vigilant in preventing future instances of this, rather than giving dispensation to past victims. We should thus take a patient's history of abuse, either as perpetrator or as victim, as a reason against treating them.

4.3.2.4 Reasons for Procreating

One final consideration for clinics when assessing the prospective child's welfare is the parents' *reasons* for procreating in the first place. Lotz, for example, suggests that 'acceptable procreative reasons would be those other-referring reasons that augur a

parenting capacity that is at least compatible with and not contrary to, the good of any child who comes into existence' (Lotz, 2009, p. 4). As she notes, however: '[f]rom the limited empirical evidence that is available, [...] it would seem that we are not entitled to infer very much at all from procreative motivations to parenting capacity' (Lotz, 2009, p. 5). This is thus probably not something that can be accounted for in child welfare assessments. This conclusion is consistent with the HFEA consultation's finding that 'there was little appetite for clinics to continue to consider an individual's or couple's commitment to having children' (HFEA, 2005a, p. 7).

4.3.2.5 The Non-Identity Problem

The above discussion has painted a picture of some of the factors that clinics may reasonably consider in order to assess the welfare that a child can be expected to experience if it is brought into existence, comparing the different possible welfares of different potential children to arrive at solutions for deciding who to treat above whom.

Mulgan gives Tay-Sachs as an example of a disease that results in a life that 'contains nothing but suffering' (Mulgan, 2006, p. 5), such that anyone who would 'gratuitously' (Mulgan, 2006, p. 5) (though "intentionally" may be a better word) create such a child would be acting wrongly. His suggestion is not that the parents would be wrong to create the child with Tay-Sachs disease in the face of the possibility of creating a healthy child instead. Mulgan simply suggests that it would be wrong outright, because the overall balance of suffering and pleasure (should there be any of the latter) in the child's life tips so much in favour of suffering. In such circumstances, it may be wrong to allocate sperm or eggs to a

person *regardless* of whether these gametes could go to another patient to create a “better” child. The question this raises is whether it can ever be possible for a child to have been better off not living at all. Mulgan seems to think that it can.¹¹

The concept of someone’s being “better off not having been born” is controversial. It assumes that we can make statements about the welfare of non-existing, or not *yet* existing people. Making statements about potential people is conceptually difficult; of the potential Tay-Sachs child, we may intuit that “(s)he would be better off not being born”. If we rephrase this as a more typical conditional proposition, the problem is clearer: “if (s)he is not born, (s)he will be better off”. The problem is that the “(s)he” in this statement refers to what is at that time a non-existent entity. To speak of a non-existent child being “better off” than they would be if they were brought into existence strikes some as peculiar or conceptually impossible (Heyd 1992; Broome 1999; Herstein 2013).

Parfit describes a move to accommodate this peculiarity, calling it *The Person-Affecting View*. This is that ‘[i]t will be worse if people are affected for the worse’ (Parfit,

¹¹ Benatar argues for an even stronger claim that it is *always* better for someone not to have been brought into existence. This antinatalist position rests on an asymmetry between the *presence* of sensations and the *absence* of them: Benatar argues that while pleasure is good and pain bad, the absence of pain is good whereas the absence of pleasure is only “not bad” rather than bad. ‘[I]f the absence of pleasure [...] is ‘bad’ rather than ‘not bad’ then we should have to regret, for X’s sake, that X did not come into existence. But it is not regrettable’ (Benatar, 2006, pp. 38-39) Much of Benatar’s argument seems to rest on this last assumption that we should not regret a person’s non-existence. This assumption is, perhaps, made too swiftly. At any rate, if we accept Benatar’s conclusion as true, then we should consider the whole practice of assisted reproduction, and reproduction in general, morally wrong. As this thesis aims to negotiate the moral problem of the distribution of this resource under the assumption that *some* distribution is ethically permissible, an acceptance of Benatar’s view would shift the goalposts somewhat. Thus, the starting point of this thesis is a point at which we have already assumed Benatar’s view to be false, and consequently no further time will be devoted to it.

1984, p. 370). Mulgan's reformulation of this view may give it some clarity: he describes *The Person-Affecting Principle*, which goes like this: '[a]n action can be wrong only if there exists some particular person who is worse off after that action than they would have been if some other action had been performed instead' (Mulgan, 2006, p. 9). Both views incorporate the idea of particular, existing people being worse off, thus denying that actions or situations can be judged on the basis of how they "affect" people who would not exist if the action had not been performed, or if the situation had not been brought about.

Let us apply the idea of person-affectingness to the case of the child who will suffer from Tay-Sachs disease. We will start with Parfit's own formulation of person-affectingness: 'It will be worse if people are affected for the worse'. The question is whether creating a child with Tay-Sachs disease constitutes "affecting a person for the worse". Before the moment of conception, there was no one to affect. To speak of a non-existent person as being "affected" seems peculiar. If we think that this idea is unintelligible, then the Person-Affecting View allows us to say that the situation where the Tay-Sachs child exists is not worse than one where it does not.

4.3.2.5.1 A Poor Solution

One route towards reconciling the conceptual difficulties of positing the welfare of non-existing people with the condemnation of the creation of such people is to suggest that person-affectingness is contingent on the time that judgements about welfare are made. This means that while a non-existing person is not better off not existing, an existing person *can* be said to be worse off existing, as they are in existence at that time. The difference

between these two cases is that the assessment of welfare applies in the first case to a non-existing person, and in the second case to an existing person.

Unfortunately, this does not solve the problem, but only serves as a complicating sidestep. The first case certainly posits the welfare of a non-existing person, if we conceive of a person who does not exist (but who we *could* bring into existence) and say that they are “better off” not existing. The problem, again, is that to say of a non-existing person that they are better off than anything seems odd, seeing as, by virtue of their not existing, they do not seem to be better or worse than anything at all. Now, the second case *seems* to be making a different move, but really it is not. We have before us the child with Tay-Sachs disease, and say of them that (s)he is “worse off”. The question here is: worse off than *whom*? This welfare assessment refers to an existing person (and let us call the thing, existing or not, to which a welfare assessment refers the “welfare referent”). What we must remember, however, is that assessments like “better off” and “worse off” are *comparative*. So to say that a person is better or worse off than someone or something else is not to posit one welfare referent, but rather, two¹². In this case, the first welfare referent is the child with Tay-Sachs disease. The second, hypothetical welfare referent is this same child “if (s)he did not exist”. The assessment is that the Tay-Sachs child is “worse off” than his/her non-existing counterpart, and to make such a comparative assessment, we must treat the non-existing person as a welfare referent, and this is exactly what the Person-Affecting View does not allow. Thus we once again come up against the problem of positing the welfare of a non-existing being.

¹² Remembering that a welfare referent can be something hypothetical.

4.3.2.5.2 A Practical Solution

Harris thinks that child welfare considerations *can* sometimes speak against bringing a child into existence, apparently in spite of the conceptual problems detailed above. He suggests, however, that the extent of this is overstated in the HFE Act. He notes that ‘unless the child’s condition and circumstances can be predicted to be so bad that it would not have a worthwhile life, a life worth living, then it will always be *in that child’s interests*, to be brought to being’ (Harris, 2000, p. 29). He goes on to say that ‘[w]herever that child’s life, despite any predictable sup-optimality’s [sic], will be thoroughly worth living, then it cannot be that child’s interests which justify any decisions or regulations which would deny it opportunities for existence’ (Harris, 2000, p. 33). The concern is that child welfare, considered in isolation from its wider impact on society or on anyone else but the child itself, seldom generates an injunction against creating that child altogether (because of the relative rarity of so-called “wrongful life” scenarios), yet the legislation suggests that it should.

The position on this matter taken by this thesis will echo that of Harris in that it aims at the practical rather than the theoretical. This may be theoretically unsatisfying, but it is at least practically useful with regard to the questions in this thesis. In effect, the problems of person-affectingness do not matter for the majority of gamete allocation cases. This is because most of these cases will involve comparisons between two different people, rather than comparisons between non-existing and existing people. For any couple generating child welfare concerns, there is likely to be another couple the treatment of whom does not generate these child welfare concerns and who could be treated instead – resulting in a child with a higher degree of welfare. We are thus rarely in the position of having to make the

conceptually bizarre comparisons identified by Heyd (1992), Broome (1999) and Herstein (2013). Instead of having to compare a potential child's welfare to its "welfare" were it not to be born, gamete allocation only requires that we compare a potential child's welfare with other potential children's welfare. The questions of this thesis are thus not affected by the non-identity problem. This means that we can consider heritable conditions as reasons against treating patients when patients without those conditions could be treated instead.

4.3.2.6 Final Remarks on Children Born from Treatment

We have now considered what kinds of things can affect the welfare of children born as a result of treatment. So far, we do not have many answers about the theoretical weighting of these considerations, and how far they legitimise deviation from the principle of equality. The more theoretical question of what *level* of welfare we ought to be seeking for children will be addressed in section 4.6.1.1. We have seen some of the issues that are at play, and some of the theoretical issues that underpin them. Given the nature of the gamete allocation decision as necessarily taking place before the existence of any child, many of these issues revolve around factors surrounding the patients themselves. As we have seen, these range from heritable conditions that can have a direct bearing on the wellbeing of the child, to issues with substance abuse and violence that may call into question the suitability of the patients as parents. Before we can make any firm judgements about how these considerations must factor into decision-making, however, there may be other factors to consider.

4.3.2.7 Other Children

There are more stakeholders involved in gamete allocation decisions than just the children born from the gametes. The HFE Act tells fertility clinics that they must account for ‘the welfare of any child who may be born as a result of the treatment (including the need of that child for supportive parenting), *and of any other child who may be affected by the birth*’ (HFEA, 2008, section 14 (2), my emphasis). It is doubtful that a literal reading of “any” is intended here.¹³ Parliament probably had in mind here other children within the same family unit, allowing clinical staff to decide against gamete allocations where siblings might be disadvantaged. The disadvantages of the arrival of a sibling include the potential to be deprived of a number of resources, like time, money, or even affection. It may be impossible or impractical to try to judge whether parents have sufficient affection to care for another child. Other, more material resources, however, might be taken into account, such that if fertility clinic staff have reason to believe that the arrival of another child may cause parents to struggle to provide for an existing child’s material or chronic health needs, this could count as a reason against treating them.

Outside of this, we might reasonably assume that a sibling will *improve* the lot of an existing child, from an emotional/social perspective.¹⁴ This might be taken as a reason to treat patients with existing children ahead of those without. We will see later, however, that

¹³ See section 4.3.1

¹⁴ There is also the possibility that an existing child’s life could be improved if the potential new child could act as a saviour sibling. Given the rarity of this in gamete donation cases, however, this issue will be set aside here.

there are overriding reasons not to do so (see pages 88-90 for this discussion of the relevance of parental status).

The previous subsection considered situations where a parent has been known to cause harm or be neglectful to existing children. This has implications for the welfare of existing children as well as for any new child that is added to the family; if an existing child is already being harmed or neglected, the addition of a new child may exacerbate this problem by providing the parents with additional burdens and therefore increase stressors that may escalate their violent reactions. It thus appears that considerations of the welfare of children born from treatment carry over to welfare considerations for pre-existing children within the family, too. Thus, many of the same risks apply, and so if we have reason to believe that a new child will increase the likelihood of an existing child's being the victim of physical or emotional abuse, or neglect (which might include parents' inability to provide for them), then this is a reason against treating them.

4.3.2.8 Final Remarks on Child Welfare

A recent study found widespread concern for child welfare amongst those working in fertility clinics but also that, in practice, very few patients were denied treatment on this basis (Lee et al., 2012). While we must be open to the possibility that child welfare issues are simply not very common, we must also acknowledge the possibility that child welfare issues may be going undetected or are insufficiently weighted in decisions about treatment.

4.3.3 Welfare of Recipients

Another thing to consider is the welfare of (putative) parents themselves. If it is the case that both parents want treatment to occur (i.e. there is no coercion), then there is a welfare presumption (and this could be fleshed out in terms of psychological benefit, or in terms of satisfying reproductive autonomy – the distinction is not important for us here) in favour of treating. It is conceivable, however, that we think a person's welfare rests on more than just their desire to have treatment, and so it is possible that other welfare considerations about the parents might outweigh their desire to have a child.

One example is obstetric risk. A woman may have pre-existing conditions such that any pregnancy she undertakes has a higher risk than normal of complications. Such risk is something that could speak against treatment. Related to this is another child welfare concern, as obstetric complication can impact upon the welfare of both the child(ren) in utero and any existing children of the patient. It is also reasonable to assume that harm to one member of the couple in a loving relationship will have a negative impact on the other member. The patient's welfare is valuable both in itself, and instrumentally insofar as it affects child welfare and that of their partner.

In a sense, all pregnancies are risky given the possibility of complications that may harm or even kill the mother, even though these risks have been reduced by modern medicine.¹⁵ Unless we are to condemn donor gamete treatment altogether, a move we have already rejected, then we need to accept that these risks are simply par for the course when

¹⁵ See (Centre for Maternal and Child Enquiries (CMACE), 2011).

it comes to pregnancy. This means that we are theoretically committed to saying that the goods, for a patient, of having treatment, can outweigh *some* risk to their health. The important question now is how much of a risk we can accept.

The scarcity of resources will give us an answer to this question. We know that not every patient can be treated so that, effectively, treating one patient means refusing another. If two patients are equal in *every* way except one of them presents a higher risk to their own health if they are treated (ignoring child welfare risks for the moment), then the better option is clearly to treat the one with the lowest risk. Again, this provides a higher level of expected welfare overall.

4.3.3.1 Efficacy

There is yet another dimension to consider. Some patients' desires are easier to fulfil than others, by virtue of the fact that some patients are more likely to have successful treatment than others. Hence, the risk of embarking on treatment must be weighed against the likelihood of the treatment being successful. This likelihood can be described as the *efficacy* of the proposed treatment. In the context of prioritisation of health resources, the value of efficacy is rooted in the welfare of patients, as taking it into account can help to ensure that more patients get the *successful* treatment that they want. All other things being equal, someone with a 25% chance of their next cycle being successful should be given priority over someone with a 15% chance, because in the case of the patient with the 25% chance, the cost-benefit analysis works out more favourably. The fact that resources are scarce adds another dimension to these efficacy considerations. One patient's treatment

may come at the expense (or at least delay) of another patient's treatment. Hence, we are not only weighing efficacy against the risk of patient harm (an *intra*-patient calculation); we are also weighing up each patient's efficacy/risk ratio with the efficacy/risk ratios of other patients (an *inter*-patient calculation).

This concern for efficacy must be weighed against equality, because favouring patients with a better prognosis (assuming the other patients still have *some* chance of success) constitutes unequal treatment, and a form of discrimination. For the time being, it is sufficient merely to note that efficacy is a value that should be accounted for. Efficacy will be considered in greater detail later, particularly with regard to patients' age (pages 73-85), and we will also consider the extent to which efficacy is important when compared to equality (pages 115-118).

4.3.4 Welfare of Donors

This chapter has said little so far about the gamete donors themselves. While donor welfare is an important consideration (particularly when we are considering intrusive procedures like egg collection), this project is concerned with gamete *allocation*, and thus is only concerned with donors insofar as they pertain to this question. The most interesting and relevant question regarding donors and allocation is thus whether donors should have any *choice* about how their gametes are allocated.

A gamete donor might make all kinds of stipulations, like directing their donation to a particular person,¹⁶ or not wanting their gametes to go to people of a certain race, or sexuality, or marital status. This latter kind of gamete donation will henceforth be referred to as “conditional donation”, in line with the terminology used by the HFEA (HFEA Ethics and Law Advisory Committee, 2011).

It may be good for clinics to honour donors’ wishes, if they have a right to use their gametes as they wish (with certain limitations), and if this improves their welfare. Importantly, it may also increase the number of gamete donors, if those whose stipulations are refused will simply not donate their gametes at all. This is likely to be the case for known donors.

Also, since donor anonymity was lifted in the UK (as of 2005 (HFEA, 2004)), once a donor-conceived person reaches the age of 18, they will have access to identifying information about their donor. This means that a great many more donor-conceived children will now be able to form relationships with those who donated gametes for their parents’ use. The UK’s new system means that donors’ involvement in the parental project has the potential to extend far beyond the process of donation. A donor’s desire to enter into such a relationship with their donor-conceived child may provide a reason for us to respect their wishes with regard to with whom their gametes are used for treatment, if we regard the fulfilment of these desires as a good thing – we might build this into our conception of

¹⁶ “Known donors” are donors who are known to the recipient, and who donate on the presumption that their gametes go only to that recipient. In a straightforward case, a man may donate sperm to a friend or relative whose own sperm are not suitable, or who has no sperm. Similarly, a man may donate sperm to a lesbian couple known to him. As for eggs, a woman may also donate them for a female friend or relative, or a male couple known to her.

welfare either by saying that desire-fulfilment is good in itself, or that it conduces to psychological wellbeing.

One possible argument against respecting donor choice in these circumstances is that clinical staff may be uncomfortable with doing so. They may feel unhappy (in such a way that diminishes their welfare) about, for example, prioritising a heterosexual couple over a lesbian couple to fulfil the sperm donor's wishes. If donors' wishes should be respected because it makes them better off, then perhaps those of clinical staff must be respected too, for the same reason. This leads to a conflict when these wishes are not compatible.

We might resolve such conflicts, however, by finding a way of prioritising the wish fulfilment of one or other of the parties. For example, in spite of their direct involvement with the assisted reproduction process, we may feel that it is the job of clinical staff to perform procedures whether or not they are comfortable with them, and not to question donors' wishes if certain kinds of wishes have already been pre-established as worthy of respect (by, for example, legislation).

The possibility of unjust discrimination may be a factor here. Allowing certain kinds of discrimination in fertility clinics may undermine the principle of equality being used in this thesis, particularly if donors are allowed to have a say in gamete allocation. If equality has this value, this provides a reason to refuse the gametes of a potential donor who wants to discriminate on the basis of things like race, age, or sexuality. This would also appear to be in line with the Equality Act (2010), which prohibits discrimination by public institutions on the basis of these and other 'protected characteristics' (Equality Act, 2010, section 4).

There is, however, an issue that complicates this matter. We may also think that we do not want to discriminate against people on the basis of certain beliefs, either. One of the

protected characteristics in the Equality Act is 'religion or belief'. If respecting this protected characteristic involves respecting beliefs (which may themselves be religious) about gamete donation, then a conflict arises in cases where such beliefs seem to violate other protected characteristics. The clinic, then, faces a dilemma, where respecting the donors' beliefs seems to violate commitments to equality between recipients, but *refusing* to respect their beliefs seems to violate the commitment to ensuring that donors are not discriminated against due to their beliefs.

Discrimination is, however, not necessarily bad. Certainly there seems to be a reason not to discriminate against certain people just because of their beliefs. But if those beliefs are in themselves unfairly discriminatory, then perhaps it better serves the cause of non-discrimination to actually discriminate against those with such beliefs in the context of conditional gamete donation. Discrimination is therefore permissible when what we are discriminating against is discrimination itself. If so, then arguably it is the would-be donor who attempts to introduce discrimination into the equation, so that a policy amongst clinics *not* to respect such requests is one that stops unjustifiable discrimination by permitting justifiable discrimination. This might mean that we should not accept stipulations on donations.

This philosophical position above is reflected in the Equality and Human Rights Commission's proviso, stated in the Code of Practice on services, public functions and associations, that the belief 'must be worthy of respect in a democratic society, not incompatible with human dignity and not conflict with the fundamental rights of others' (Equality and Human Rights Commission, 2011, p. 36). The example they give of a belief that

fails to meet these criteria is of a person who has a belief about racial superiority. This may suggest that such stipulations from donor gametes cannot lawfully be allowed.

The protected characteristics represent criteria on which it is widely acknowledged to be wrong to discriminate against people. Moving away from these protected characteristics, however, we face some questions about the limits of the value of equality. Equality between people of certain ages, races and the like seems to be valuable, but there are may be other inequalities that should be considered. Conditional and known donor cases are examples of this: with conditional donation, the fact that a patient is a member of a group that a donor favours generates an inequality between that patient and other patients who are not members of that group. For known donation, the fact that a patient knows their donor generates an inequality between them and those who do not know someone who is willing to donate gametes for them.

If we are unwilling to allow discrimination based on features like the protected characteristics detailed in the Equality Act, perhaps we should be similarly unwilling to allow donors to discriminate by donating only to those they know. After all, the problem of discriminating unfairly on the basis of the protected characteristics comes from the fact that such protected characteristics do not, in themselves, provide adequate reasons for discriminating. We do not want someone to suffer, or be treated worse, *just because* they are a certain type of person. Discrimination because a person knows or does not know a certain other person may be an example of this.

So far, it looks as though permitting donors to make stipulations may cause problems in that it will, at least in some cases, undermine principles that we hold to be more important. However, if we are to champion equality instead of donors' welfare (and the

added welfare that this brings by increasing the pool of donated gametes), this must be done consistently. We need a reason to value equality between people with regard to the protected characteristics without similarly ensuring equality between people with regard to other characteristics, for example between those with brown eyes and those with blue eyes. Conditional and known donation cannot guarantee that the exclusion of anyone from treatment is the result of considered moral deliberation based on true and relevant facts. This is true even if there are legal limits to the kinds of specifications that donors can make.

It is clear that allowing donors to choose who can receive their gametes opens the door to deviations from equality that are potentially unjustifiable. Pennings appears to agree, and his response is to argue that gamete donors should be allowed to make choices about recipients only based on pre-set categories and criteria derived from 'categories judged important by the different moral communities' (Pennings, 1995, p. 2740). This is a restrictive version of allowing donor stipulations, which gives donors choices while echoing the Equality Act's requirement that certain groups are not subjected to unjust discrimination.

It is important to remember, however, that whilst it may be wrong of the donor to make certain stipulations, it may be acceptable for clinicians to accept their donations nonetheless. After all, there is something to be gained from doing so, because if these donors' stipulations really are *conditions*, and not just *preferences*, such that they will only donate if the stipulation is respected, then in fact nobody is disadvantaged by that donation being allowed. A patient who gets discriminated against by a stipulating donor may not have access to that donor's gametes, but adding gametes to the pool removes some competition on the waiting list, making that patient better off than they would be if the donation was refused. Moorlock considers this feature with regard to conditional organ donation,

describing it as ‘negative loss; that is a loss of benefit for somebody without a corresponding increase in benefit for somebody else’ (Moorlock, 2012, p. 117). Ideally, we might wish that everyone would just donate without making stipulations so that we can use the donation as we wish, but if this is not the case, we may as well take what we can get in order to benefit everyone on the list. This notion of serving equality by *removing* resources (or the opportunity to attain resources) from the better-off instead of by *providing* the resources (or the opportunity to attain them) is known as “levelling down”. Raz notes that ‘often the only way to avoid violating [egalitarian principles] is to create or allow waste’ (Raz 1986: 227). If waste is something we should avoid (and the resource scarcity angle of this project assumes that it is), then this method of serving equality is not to be allowed. Temkin’s classic example provides a forceful argument against levelling down (the *Levelling Down Objection*):

[I]magine that C is a world where half are blind, D a world where all are. One *could* always transform C into D by putting out the eyes of the sighted. However, many find the view that this would improve the situation in even one respect *more* than incomprehensible; they find it abominable. That D is more equal than C gives one *no reason at all*, they think, to transform C into D; and only a hardened misanthrope, or someone motivated by the basest form of envy, could think otherwise. After all, they ask, how *could* D’s greater equality make it better in *any* respect, if there is *no one* for whom it *is* better? (Temkin, 1993, pp. 247-248)

Temkin later summarises the intuition thus: ‘[g]reater equality is only desirable when it *benefits* the worse-off, not when it results from levelling down the better-off!’ (Temkin, 2002, p. 132). This discussion will proceed on the basis that levelling down is a problematic way of securing equality, but that the Levelling Down Objection does not present a knock-

down case against the promotion of equality in all cases. It is consistent with the approach adopted in this thesis that equality is merely one value among many.

Accepting known and conditional donations avoids the problem of levelling down.¹⁷

This may suggest that there is a moral objection to applying the Equality Act when it asks us to level down. There is, however, the question of whether the Equality Act really asks this. The Equality Act asks that nobody be treated 'less favourably' (Equality Act, 2010, section 13 (1)) because of a protected characteristic. If refusing these donations would be levelling down, then by definition, accepting them means that nobody is treated less favourably. Hence, the Equality Act arguably does not actually prohibit conditional donation. The HFEA may support this interpretation of the Equality Act:

When deciding whether or not to recruit donors who place conditions on the use of their gametes or embryos, the centre should judge whether this will result in less favourable treatment because of a protected characteristic (eg, if it will reduce the choice of donors for a particular person by virtue of a protected characteristic) (HFEA, 2013b, section 11.20).

The example of choice-reduction seems carefully chosen, as it speaks to the notion of levelling down described above – if the conditional donation is accepted, choice is not limited if the alternative is to not have that donation at all.

The potential benefits of allowing conditional and known donation are thus quite weighty, and the Levelling Down Objection provides a reason to deviate from the principle of

¹⁷ Those distinguishing between acts and omissions will point out that this does not constitute a true example of levelling down. They would argue that there is a distinction between those who are *made worse off* (true levelling down) and the people in this scenario, who are instead *denied the opportunity to become better off*.), We will not give credence to this distinction here.

equality in this case. This means that we should allow conditional and known donation across the board, regardless of whether or not they apply to pre-set categories, as suggested by Pennings. The legal situation is complex, but the Equality Act may not actually prohibit the permission of all conditions in the way suggested.

4.3.4.1 Rewarding Donors

The previous discussion argued that donors should be allowed to set conditions on the use of their gametes, as this does not disadvantage anyone. Pennings advances a donation system in which donors are *rewarded* for donating, by being prioritised for the *receipt* of gametes. This leads to a 'mirror exchange' (Pennings, 2005, p. 2990) system wherein a person's donation of sperm gives them priority in receiving eggs (i.e. for their partner), and a person's donation of eggs gives them priority in receiving sperm (again for their partner's use).

Pennings draws on a basic principle of reciprocity, suggesting that those who use gametes in the donation system should repay into the system if they are able (there are provisions for those who are unable to contribute, such as those of a certain age or those with heritable conditions). Framed in terms of gamete allocation, then, Pennings' argument is that a patient's or a patient's partner's willingness to donate gametes should count in favour of that patient's receiving treatment. He considers this mutually beneficial, describing '[a] win-win system in which contributors have a mutual advantage' (Pennings, 2005, p. 2991). The system confers advantage by introducing additional gametes into the system, and any disadvantage to donors is redressed by the reward they receive in the form of

prioritisation. It may be objected that the separateness of sperm and egg waiting lists renders this untrue: a patient's use of donor sperm does nothing for others waiting for sperm if all she has contributed is eggs. Given, however, that such a system would overall also include a mirrored system for those contributing sperm and using eggs, this does not constitute a problem. Even if the shortfall for sperm is different from the shortfall for eggs (the figures given on page 1 would suggest that this was the case at least as recently as 2008), all patients seeking gametes will still be better off than they would be without the system, if the system encourages more people to donate gametes overall. Such a system would continue to confer benefit until there was *no* shortfall for either sperm or eggs.

Given the benefits of the use of such a system, it might be suggested that it could be extended, such that a person could recruit *anyone* to donate on their behalf, rather than only their partner. As an example, a single woman might recruit a friend (male or female) to donate gametes to the general pool, in exchange for treatment with donor eggs from another donor who is unknown to her. This is close to known donation, in that the recipient gets priority for treatment by bringing in someone they know to donate gametes. The only difference is that the recipient is not ultimately treated with that person's gametes.

Such a donor does not even really need to be "known" to the patient who brings them in. A person may recruit any donor who is willing to donate in order to give them priority for treatment. This improves the waiting list situation in the same way, by alleviating the scarcity of gametes.

This system might be said to place more emphasis on the fact that it confers advantage on everyone than on any principle of reciprocity – it might be argued that if a patient can avoid their obligation to donate gametes by just recruiting someone to donate

on their behalf, then they themselves are no longer paying into the system, and so the reciprocity element is lost.

Given the importance of improving the welfare of patients, the idea that the reciprocal element of the system may be compromised by a person's gaining points by recruiting someone else to the system is not problematic, as long as overall benefit is created for those seeking treatment with donor gametes. With this in mind, then for the purposes of this thesis, reciprocity might better be conceived as considering who benefits rather than who pays – if a person is generating benefit for the system (by bringing in a donor), we should not be concerned that *they personally* are not the ones paying into the system, as long as, just like in any case of known donation, adequate safeguards are in place to ensure that the donor is not being coerced or exploited. The most important fact is that, were it not for them, that benefit would not exist, and so this should be incentivised. Second, it is not obvious that someone who recruits a donor is not, in fact, paying into the system – they are at least doing some work in recruiting, which the clinic would otherwise have to do themselves, so the reciprocal element is at least partly preserved.

It is thus the conclusion of this section that anyone who is able to alleviate the pressure on the waiting list should be given priority for doing so. This process removes that patient from the waiting list and does not diminish the overall number of gametes available to others.

4.3.5 Summary of Welfare Subsections

This concludes the discussion of welfare. To summarise: when we are considering the welfare of other children within the family, our assessments look similar to those for the welfare of the child to be born from treatment, such that we must consider whether the welfare problems are weighty enough for us to deviate from our standpoint of equality, according to which we want to avoid discriminating against certain groups of people. In considering the welfare of the parents themselves, however, this thesis presumes that treatment is a good thing, and so we are here weighing up desire-related concerns with welfare concerns. It is assumed that it is good for the parents to have a child simply because they want one, but it may be the case that continuing with treatment will be too risky from a medical perspective, such that their desires to be treated are outweighed by other concerns for their welfare. Further to this, welfare concerns for patients are related to concerns about the efficacy of treatment, as the risks of treatment and pregnancy must be justified by a sufficient chance that it will be successful. Finally, given resource scarcity, efficacy concerns can have an impact on how many patients get what they desire. This means that one patient's efficacy affects *all* patients hoping for treatment, rather than just the patient in question.

Similarly to the discussion of child welfare above, there is the issue of how seriously we are to take welfare concerns surrounding putative parents. This section has acknowledged that their interests must be taken into account. Hence, there needs to be a serious reason for us to deny treatment to any patient.

So far, we have surveyed the landscape of welfare considerations, paying particular attention to child welfare, but also considering the welfare of other members of the family and how this might be factored in. It is clear that there are many factors that can affect both the welfare of children and the welfare of patients, and that taking these into account may give rise to differential treatment between patients. The next section will consider whether there are any particular groups of people who may pose greater risks with regard to these factors than others.

4.4 Characteristics

This section will consider whether there are certain groups in society, the treatment of whose members presents elevated risks with regard to the considerations discussed above. In such cases, it may be justifiable to have blanket policies of withholding treatment from certain groups. Consideration of these factors can form the basis of gamete allocation criteria for clinics.

4.4.1 Age

This subsection will consider whether a patient's age should have a bearing on the consideration they get for treatment. As with the previous subsections, we should be concerned to preserve equality between groups unless there are good reasons to allow for inequalities. So let us now look at what some of the differences are between patients of different ages that may give us reason to treat them differently.

Many studies have shown that older¹⁸ women receiving fertility treatment are less likely to conceive and successfully carry a pregnancy to term (Schwartz and Mayaux, 1982; Padilla and Garcia, 1989; Piette et al., 1990; Stovall et al., 1991; van Noord-Zaadstra et al., 1991; Tan et al., 1992; Scott et al., 1995; Dor et al., 1996; Hull et al., 1996). The Royal College of Obstetricians and Gynaecologists (RCOG) accepts this conclusion, stating that '[d]elay in childbirth is associated with worsening reproductive outcomes', with 'more infertility' first on their list (Bewley, Ledger and Nikolaou, 2009, p. 353). It also states that '[a]ssisted reproductive technologies, including *in vitro* fertilisation (IVF) with the woman's own fresh oocytes, cannot compensate for the effect of reproductive ageing' (Bewley, Ledger and Nikolaou, 2009, p. 353). The HFEA reports a 32.2% success rate for women under 35, decreasing to 20.8% for women aged 38-39, down to only 5.0% for women aged over 43-44 (HFEA, 2013c). Note that the rate of decline itself also increases with age (Leridon, 2004; HFEA, 2008), so that the difference in success rate between the ages of 40 and 45 is much greater than the difference in success rate between the ages of 35 and 40. Age is therefore a determinant of treatment efficacy.

The use of donor eggs, however, may circumvent these age-related efficacy concerns, with studies tending to find that where donor eggs are used, recipient age no longer has an effect on delivery rates (Navot et al., 1994; Sauer, Paulson and Lobo, 1996; Abdalla et al., 1997; Paulson, Hatch, Lobo and Sauer, 1999; Noyes et al., 2001). This is also consistent with the HFEA's more recent data on donor egg efficacy rates (HFEA, 2008). While there is

¹⁸ This thesis will make use of the terms "older" and "younger" to denote relative ages of patients. It should be assumed that "younger" means a patient that does not yet present risks associated with older age, but who is old enough that they do not present risk associated with being *too* young for treatment.

evidence pointing in both directions regarding this, the majority of evidence suggests that donor eggs align success rates for older women with those of younger women, and therefore we have insufficient justification for differential treatment between patients of different ages in cases where donor eggs are used. The following discussion of age and efficacy should therefore be taken to refer only to sperm donation where the gestational mother's own eggs are used.

In the case of donor sperm, there may be arguments for age discrimination from a resource perspective: as has been established, sperm are a scarce resource, and it may be better to allocate them to someone who has a better chance of a successful pregnancy, rather than using them in a potentially less effective way on someone with the lower chances of success associated with increased age. We might refer to these suboptimally effective treatments as gamete "wastage" – this is not to say that the use of these gametes does not do *some* good, only that they could be used to greater effect elsewhere. Even though this represents unequal treatment between age groups, it seems to maximise the chances that *somebody* gets what they want from the whole process, and this maximisation justifies the deviation from equality.

The risk of failure also gives rise to a psychological consideration. It may be worse for a patient to proceed with treatment, potentially raising their hopes, only to meet with disappointment later when the treatment fails, than not to be treated at all. Admittedly, however, this must be balanced with the possibility that failed treatment is psychologically beneficial where it may make the patient feel like they have done all they could to have a

baby¹⁹ – so perhaps these psychological considerations cannot weigh in here. At any rate, the fact that prioritising based on efficacy will lead to more people having babies gives us a reason to treat women with a greater chance of success. If older women have a reduced chance of success, this gives us a reason to favour the treatment of younger women.

Treatment efficacy necessarily has value in a system whose aim is to provide effective treatment. The benefit of prioritising patients based on efficacy is that it will generally maximise the number of successful treatments. It is important, however, to note that this is not necessarily the case. It seems intuitive to say that if clinical staff always aim to treat whoever on the waiting list has the best chance of a successful pregnancy, this will generate the largest number of successful births. This, however, is not always true.

Suppose there are two patients on the waiting list, one who is 23, and another who is 39. Imagine that we know that we will only ever be able to treat *one* of these patients (let us imagine that gamete donation is to be outlawed tomorrow and this is the last treatment of the day). They are exactly alike in every other respect – imagine that they both arrived on the waiting list at the same time, or perhaps more realistically, that their records were somehow muddled or destroyed and it is unknown who got there first (this serves to remove any argument based on one patient's having waited longer than the other). Clearly, if we are in the business of providing effective treatments, then in this instance we should treat the 23 year old, to maximise the chances of *someone* getting the treatment they were after. This idea of treating younger patients to maximise the number of births was advanced by Canada's Royal Commission on New Reproductive Technologies (1993).

¹⁹ This argument was presented by a member of the ethics committee at one of the meetings observed as part of the project's preliminary "fieldwork".

The situation is not as simple as this, however. Given the strict choice between treating one patient or the other, it seems clear that we must treat the one with the best outlook for success, all other things being equal. But the reality of the waiting lists is somewhat different, as we can reasonably expect more gametes to become available at some point or another. This expectation, while it might be positive in that it increases the overall likelihood of *both* patients going away with what they wanted, makes the whole situation a little trickier for decision-makers. For if we treat the 23 year old patient, then by the time another donor comes along, it may be too late for the 39 year old: she may grow too old to be on the waiting list (based on efficacy concerns); and we know that her chances of success decrease with age, so even if she does come to be treated, by this time it may be too late and it may be unsuccessful where, had we treated her beforehand (i.e. instead of the 23 year old), she may have been successful (though obviously we could never know this for sure).

If we treat the 39 year old instead, this lessens the problem somewhat. Certainly it could be the case that the next donor takes so long to appear that the 23 year old is similarly too old to receive treatment, and the same occurs. But if we have some (reasonable) expectation that a sperm donor will appear before that time, we have a complex problem on our hands. If we want to maximise the success using *one particular gamete*, then it is obvious that we should just treat the 23 year old. But if we want to maximise the chances of success for both patients, it looks like there might be a reason to treat the older woman first. After all, she is a more urgent case in that she requires treatment sooner if she is to get it at all.

Real life waiting lists are not quite like this – they have more than two people, and a (perhaps) more reliable inflow of gametes. In reality, then, we may need more information about waiting lists. An important empirical question that would impact our ideas about how to maximise births is what the age distribution is across waiting lists. Let us simplify this by assuming that there are only two categories of patient: young and old. The young patients present a better option for treatment efficacy. At first glance, then, we ought to just treat them. The problem, though, as illustrated above, is that once we have treated all of them, then unless the waiting list is constantly replenished with young patients to claim the next sets of gametes, we must then move onto the older patients (unless we are going to exclude them entirely – in which case, we should just be honest about this from the outset. Now, by the time we have treated all of these young patients, the older patients will, of course, have aged. The problem lies in the fact, as mentioned above, that treatment efficacy may diminish *at a greater rate* for the older patients than it does for the younger patients. Hence, the difference between, say, age 39 and age 40, is likely to be *greater*, in terms of treatment efficacy, than the difference between age 23 and age 24. Hence, if we know that we are going to move on to treating the older patients *at some point*, we have a reason to treat them *now*, because our strategy for maximising births demands that we account for their more rapidly diminishing fertility.

Let us consider this numerically, using the tables below. Let us say that a 23 year old has a fertility score of 20, and a 39 year old has a fertility score of 10. These scores represent the chance of treatment being successful – a higher score means a higher chance. Hence, this scoring system serves to convert the value of efficacy (and the disvalue of inefficacy) into integers. Now, to represent the faster rate of decline for older patients, let us say that

for the older patients, their score declines by 2 points a year, whereas for the younger patients, it only declines by 1 point a year. Let us say there are 2 young patients and 2 older ones on the list, and that it takes a year to treat each patient and move to the next.

Table 1 – Effect of Prioritising Younger Patients When Older Patients Will Be Treated Afterwards

Year	Patients				Total points
	Young patient A	Young patient B	Old patient A	Old patient B	
0	20	20	10	10	60
1	20	19	8	8	55
2	20	19	6	6	51
3	20	19	6	4	49

Table 2 – Effect of Prioritising Older Patients When Younger Patients Will Be Treated Afterwards

Year	Patients				Total points
	Young patient A	Young patient B	Old patient A	Old patient B	
0	20	20	10	10	60
1	19	19	10	8	56
2	18	18	10	8	54
3	18	17	10	8	53

The green bars represent the point at which that patient has been treated. The “total points” column on the right represents the total efficacy score of all the patients put together – because we cannot treat them all at once, the score diminishes with time,

corresponding with the patients' declining fertility. The red cell demonstrates the final number of points achieved in each scenario – this number corresponds to the total efficacy of the four patients put together. Table 1 represents a scenario in which we treat younger patients first, and table 2 one in which we treat older patients first. We can see that we have a higher overall efficacy score in scenario 2. This is because scenario 2 more quickly deals with those patients whose fertility is more rapidly declining, thus avoiding greater point losses through time.

The examples in the tables are simplified, as fertility may decline more or less rapidly from patient to patient. The basic idea, however, can be mapped onto real life waiting lists. The message is that if there are so few young patients on the list that we will end up treating the older ones anyway, then we have a reason to treat the *older* patients first to maximise births. If we have so *many* young patients on the list that we will *never* end up treating the older ones, we must question why we put those older patients on the list anyway – they are effectively excluded.

The above discussion has simplified matters somewhat. For a start, there will be numerous patients, of varying ages, on the list. In the above example it was clear that treating the older patients first would maximise the number of successful treatments. But in other cases this would not be so. If there are so many older patients that we end up treating them to the detriment of younger patients who are potentially very valuable (in terms of “efficacy points” that is), then we may be failing to maximise. Effectively what the system comes down to is that older patients must only be treated if they would be treated *anyway* (but later), and younger patients must otherwise be prioritised.

It may be, then, that the question of whether to prioritise younger patients, or whether to prioritise older ones, is dependent on the age distribution on the waiting list, and how many people are on the list. This will require both detailed knowledge of the waiting list, and for some predictions to be made about how many patients will be treated. Given that this may vary throughout time and from clinic to clinic, it may be necessary for staff to periodically review their waiting lists, in conjunction with data about how many gametes are expected to be available, in order to establish which patients to prioritise. It is worth pointing out here that this may speak in favour of having a national waiting list. If the age distribution on the waiting list is a factor in determining how prioritisation should work, then this may differ from waiting list to waiting list. Having a national waiting list would mean that only one calculation about this age distribution would need to be made, and this could be done centrally, alleviating the workload overall. The idea of a national waiting list will be considered in more detail below (pages 118-120).

Given the fact that egg donation can be used to circumvent these age-related efficacy concerns to the extent that delivery rates for older women are comparable to those of younger women, the discussion of age as a relevant criterion for decision-making will only apply to cases using donor sperm rather than donor eggs. As was mentioned in case three in chapter two, however, there are increased obstetric risks associated with pregnancy at a later age (Cnattingius et al., 1992; Jolly et al., 2000; Caplan and Patrizio, 2010), which may not be avoided by the use of donor eggs (Sauer, Paulson and Lobo, 1996; Vasireddy and Bewley, 2013). These risks threaten not only the woman, but the child. This may also provide a reason to discriminate against women who are older in favour of those who are younger,

derived from both child welfare considerations, and considerations about the welfare of the patient.

There may thus be both patient and child welfare considerations if we are concerned that obstetric issues and pregnancy complications may affect the health of the child. An additional consideration is that the older the parent, the younger the age at which the child can be expected to experience the death of that parent. If we think that it is worse for someone to lose a parent at a younger age, then this too may speak in favour of treating younger patients. But this is only true to an extent – there will be an age at which a patient is so young that their difficulties in being a parent will outweigh the potential difficulties of their child’s loss of a parent. The increased obstetric risks and the potential social difficulties are reasons to refuse to treat minors.

The non-obstetric reasons for disfavouring older patients do not only apply to the patients themselves – they may apply to either member of the couple,²⁰ too, whether or not that person has a biological or genetic connection with the child. Consider a woman who wishes to be treated with donor sperm. Her partner will not be biologically or genetically related to the child that will result from this treatment (if it is successful). But we may have reason to consider the age of this partner, if the partner’s presence is considered part of the

²⁰ It should be noted that it is not always clear who the patient is in fertility treatment. Consider a case of an infertile man going for treatment with his female partner. While *he* is the one with the medical issue, *she* is the one who will ultimately go to theatre and be inseminated. For simplicity’s sake, this chapter will use the word “patient” to refer to the woman hoping to carry a child as the result of treatment.

child's "supportive parenting", and if this partner's early death would cause added distress for the child when compared with a later death.²¹

There seem, then, to be a variety of reasons for which it may be legitimate to discriminate against older patients. This discrimination is indirect; people are not being discriminated against *just* because they are older, but because their being older means that they have a statistically greater likelihood of presenting problems in the future, with a patient's capacity for raising children and the amount of time they can be expected to remain alive being the primary concerns. This latter point would also require us to regard those with life-limiting illnesses as worse candidates for treatment. This, however, would depend on the nature of the illness and its effect on parenting capacity, whether there were someone else who could parent the child in the event of one parent's death, and the actual impact for children of parental death.

The relationship between child welfare and maternal age is, however, unclear. Although there are increased obstetric risks and risks of foetal abnormalities, there is some evidence suggesting that children are better off with slightly older mothers (Sutcliffe et al., 2012). The Sutcliffe et al. study found that children born to older mothers had 'better language, and fewer social and emotional difficulties' (Sutcliffe et al., 2012, p. 4). It only considered children up to the age of 5, however, so the issue of early maternal death is still relevant. The Sutcliffe et al. study also considered some health-related issues, finding that children born to older mothers had fewer hospital admissions and greater levels of

²¹ There could be a way to minimise this distress if we think that there are ways to make children less attached to their parents. But this might have the side effect of creating social issues. Without getting into this debate, then, this chapter will assume that parents should still attempt to be the best parents they can.

immunisation, whereas the risks we are concerned about when treating older patients are chromosomal abnormalities and other health problems at birth. It also ought to be noted once more that some of the child welfare risks are associated with egg age rather than maternal age, making matters more complicated in that donor eggs virtually eliminate these risks. Age-based criteria may need to be sensitive to these nuances.

There is no cut and dried way to say that congenital conditions are better or worse for children than health problems resulting from having younger mothers, such as lower immunisation levels, or more hospital admissions (as suggested by the Sutcliffe et al. study). Some congenital conditions will be more severe than others, and some hospitalisations will be more severe than others. The Sutcliffe et al. study did not record the severity of hospital admissions. It may be possible to pool data on the average severity of congenital conditions and compare this with the average severity of hospital admissions. This comparison would also need to evaluate the dangers of having fewer immunisations, and various other factors. This may provide an answer to the question of whether it is older or younger patients who pose greater health risks to their children. It is unfortunately beyond the scope of this thesis to synthesise and evaluate all of this data. For the moment, we must make do with the tentative conclusion that congenital conditions speak against the treatment of older women using their own eggs (but not for those using donor eggs), and that there may be social benefits to having older mothers (up to a certain age at least – there may be a point at which these benefits would not manifest themselves). Child welfare considerations thus seem to lead to the conclusion that in some cases we should favour older patients, and in other cases, younger patients.

One objection to the notion of prioritising the young, however, is that it may leave the old without opportunities for treatment at all. If a waiting list comprises enough young patients, then efficacy considerations may require that *all* gametes go to the young, leaving the old by the wayside. This is true only if we incorrectly assume that the desideratum at play in fertility treatment is to have an opportunity for treatment, rather than to take home a baby to parent. We could offer treatment to everyone regardless of the likely efficacy of the treatment, but this, too, would leave people by the wayside, in that fewer babies would be taken home overall. It might *look* like everyone is being offered something, but in actual fact the patients on the waiting list would be worse off overall. This issue of opportunity versus efficacy will be revisited in greater detail later on (pages 115-118).

In summary, the age of patients raises many significant issues. The decline in efficacy provides a motivation to treat younger patients instead of older ones, except in cases where older patients will be among those treated anyway, in which case, they should be treated first so as to best account for the fact that their chances of success decline faster. This will ensure the best use of scarce gametes. Obstetric risks associated with age provide further reasons to prioritise younger patients. Child welfare considerations are more complicated, as this is more to do with the age of the eggs used, so that in cases where donor eggs are being used, the problem is circumvented. The problem may still arise in cases where an older patient uses her own eggs and donor sperm, however. There is little to suggest any social reason not to treat older patients, but otherwise there is much that speaks against their treatment if younger patients can be treated instead.

4.4.2 Primary and Secondary Infertility

According to the NHS, a person who has fertility problems after they have already had a child is regarded as having “secondary infertility” whereas someone who has fertility problems and has *never* had a child is someone with “primary infertility” (National Health Service, 2013). If the difference between primary and secondary infertility is not morally relevant, then this should not be considered in decision-making, and people with primary and secondary infertility should be treated equally.

As argued on page 39, however, there are different ways of conceiving of equality. Treating groups differently may be justified in order to redress the inequality that appears when some people can have children and some cannot.²² The starting point was to insist that justification is offered for all unequal treatment. But treating primary and secondary infertility cases differently may result in more egalitarian distributions, where giving priority to those without children already means that more people have a chance to have children at some point.

Unfortunately, cases surrounding primary and secondary fertility can become quite complicated. They are most straightforward in cases where the couples either both have no children, or have both previously had children together. Slightly more complicated are cases in which both members of a couple have children, but have not had children together. More complicated still are cases where only one partner has children from a previous relationship. A further dimension is which member of the couple is infertile in such cases, and whether it

²² Another way to redress this inequality would be to *stop* certain people from having children. This would be another example of levelling down, though, and again is too much of a welfare sacrifice to be allowed.

matters whether the partner with children is the one with the fertility problem. Table 3 shows the sixteen possible combinations of previous parenthood and infertility for any couple. The final four, in which both members of the couple are fertile, could apply in cases of genetic conditions, or in same-sex couples.

We should also consider another distinction that can arise in cases where one partner has existing children: a person's relationship with their (or their partner's) children may range from one mirroring "normal" parenthood, with years of close, intimate contact and cohabitation, to no parental involvement whatsoever. In these latter cases, it cannot be said that the person already has children, in either a social sense, or a genetic sense (as they are the *partner's* children). So childlessness is not a discrete property – it has various modes, and so it is not clear whether or how the parental status of individual members of a couple should be accounted for.

Table 3 – Combinations of Infertility and Previous Parenthood

	Partner 1 infertile	Partner 2 infertile	Partner 1 previous children	Partner 2 previous children
Combinations	Yes	Yes	Yes	Yes
	Yes	Yes	Yes	No
	Yes	Yes	No	Yes
	Yes	Yes	No	No
	Yes	No	Yes	Yes
	Yes	No	Yes	No
	Yes	No	No	Yes
	Yes	No	No	No
	No	Yes	Yes	Yes
	No	Yes	Yes	No
	No	Yes	No	Yes
	No	Yes	No	No
	No	No	Yes	Yes
	No	No	Yes	No
	No	No	No	Yes
	No	No	No	No

4.4.2.1 A More Accurate Distinction: Parents and Childless People

At this stage, we must shift the terminology slightly, from primary versus secondary infertility to childlessness versus having a child. This is because in the case of couples, infertility status does not necessarily correspond to parental status, as it may be the fertile member of the couple who has no previous children.²³ Given that it is effectively the couple together who are being treated, the question of whether it is the infertile partner or the

²³ A single patient seeking fertility treatment may also be fertile.

fertile one who is childless is irrelevant to the ultimate decision not to prioritise a couple (one member of which is childless and one of which is not).

Fortunately, the minimalist consequentialism with which we are working will not be sensitive to these different conceptions of parenthood and childlessness. This framework asks that we only account for future harms and benefits. Unless it can be shown that patients having their first child stand to benefit more than patients having an additional child, taking into account a person's current status as a parent seems to be one of these latter considerations.

There may be an argument for this, from the perspective of psychological distress. Greil et al. note that 'many studies have treated women with infertility as a monolithic group, thus missing important distinctions among women with different types of infertility (primary or secondary)' (Greil et al., 2011, p. 2101). Consequently, there is only a small body of data on the psychological differences between these two groups (Epstein and Rosenberg, 2005; Greil et al., 2011). These studies, however, supported the hypothesis that 'women with primary infertility would have higher levels of FSD [fertility-specific distress] than women with secondary infertility' (Greil et al., 2011, p. 2102 and 2109).

This gives us a reason to think that there is a greater psychological difference between having one's first child and having subsequent children, and may justify giving priority to childless couples. It may also suggest that couples, one member of which is childless, should get second priority, with couples, both of whom have children (either together or apart) at the bottom in terms of this criterion.

This is not to deny Robertson's point that '[the denial of] reproduction and the parenting that accompanies it [...] is experienced as a great loss, even if one has already had

children' Robertson, 1994, p. 24). All of the above groups might experience their infertility as a great loss, as Robertson says. Some groups, however, may experience it as a greater loss than others, and parental status seems like a case where this can be accounted for.

There are still complications, as the studies did not consider the relationship that these people had with their children. Greil et al.'s study defined the difference between primary and secondary infertility as whether the woman had 'experienced prior pregnanc[y]', and they combined the initially separate groups of 'prior pregnancy but no live birth' and 'live birth' (Greil et al., 2011, p. 2104). This means that any women who had miscarried, or women who had had no relationship with the children to whom they had given birth, would have been grouped together with women who had ongoing relationships with their children. Their study was not sensitive to the parenting experience in this way, so while it offers us a justification for distinguishing between women based on their previous parenthood, it does not help us to flesh out this concept.

In this case it would probably be best to consider that the distress caused to the secondarily infertile women was due to a lack of parenting experience, rather than not having conceived (as Greil et al.'s study might suggest at first glance). Given the scalar nature of parenting experiences that are available, this provides a mandate for clinical staff to consider the parenting experiences of patients individually, and establish a cut-off point for what counts as a suitable degree of parenting experience for the patient to no longer be described as "childless". The conclusion of this subsection is thus that a patient's parental status can be taken into account in deciding whether or not to treat them, such that those who have not already experienced parenting should be given priority, all other things being equal, over those who have.

4.4.3 Same-Sex Couples and Single Patients

The 2008 amendment to the HFE Act suggests that doubts over the preference for heterosexual couples over single women and same-sex couples have already been raised. While the HFE Act previously asked for the clinic to consider ‘the need of [the] child for a father’ (HFEA, 1990, section 13 (5)), the legal requirement is now less specific, detailing ‘supportive parenting’ (HFE Act, 2008, section 14 (2)) instead. The debate leading up to this change, documented in the Hansard, illuminates some of the relevant issues. Evan Harris complained about Iain Duncan Smith’s proposal to legislate such that clinics must consider “the need for a father and a mother”, describing this move as unjustified:

On the European convention on human rights [sic], the House is advised by the Joint Committee on Human Rights [...]. In a unanimous report, the Committee stated that “Without justification, such distinctions” [...] “may be in breach of the right to respect for private life without discrimination”. The report continued: “Similarly, the Convention prohibits unjustified discrimination” [...] “between married and unmarried parents for the purposes of recognition of parental responsibility, or wider family law decisions on access and custody.” (HC Deb 20 May 2008, vol 476, col 172)

The suggestion is that Duncan Smith’s proposal would discriminate against single people or same-sex parents, and that this would be an unjustifiable breach of principles (and indeed laws) governing equality. Harris argued that a child does not specifically need a *father* in order to enjoy an adequate degree of welfare, nor specifically a mother, but that

parenting can be adequately supportive in the absence of either of these. This would make room for more non-standard family arrangements, such as families with single mothers, or same-sex couples, where a legal requirement to account for the “need for a father” could deny treatment to such people.

The proposal to specify a child’s need for a father and mother was eventually defeated, so that the HFE Act as amended reflects the idea that single parents and same-sex parents are capable of providing supportive parenting to children. There is evidence to support the view that same-sex parents are able to provide such supportive parenting to the same degree as heterosexual parents. The body of evidence includes longitudinal studies, measuring child welfare outcomes across a range of measures, including school outcomes, psychosocial adjustment, peer relations, romantic relationships, sexual functioning, delinquency, and substance use (for example Golombok et al., 1997; Golombok, 2000; Stacey and Biblarz, 2001; Golombok, et al., 2004; Wainright, Russell and Patterson, 2004; Wainright and Patterson, 2006; Golombok and Badger, 2010; and Perrin, 2002). Thus there seems to be no reason to discriminate against same-sex parents in gamete allocation.

The case for single parents is similar with regard to child welfare. Golombok and Badger note the evidence suggesting that children’s welfare is compromised when they are raised by single mothers, but point out that:

[T]hese outcomes cannot necessarily be generalized to children born to single mothers by donor insemination. The situation of these mothers is different from that of single mothers who have separated or divorced, or who became pregnant unintentionally, in that they are generally financially secure with good social support, and the children have not been exposed to parental conflict or family disruption (Golombok and Badger, 2010, p. 151).

This distinction is crucial to the discussion here, because in the context of gamete allocation, the situation of children raised by single mothers *generally* is largely irrelevant – we should only consider the evidence about those who become single mothers through donor insemination. Golombok’s series of studies is sensitive to this distinction, and shows that children born to single mothers from donor insemination tend to fare as well as those born to two-parent families (Golombok et al., 1997; Golombok et al., 2004; Golombok and Badger, 2010). Golombok and Badger point out the relevance of this finding to the HFE Act.

From a child welfare perspective, there thus appears to be no reason to distinguish between two-parent families and single women. The question of single *fathers* in this context remains unknown and under-researched, with the concept of treating single men virtually unmentioned in fertility treatment literature. This may be due to a small number of single men seeking, or being accepted for, treatment at fertility clinics. In the absence of sufficient evidence that single men becoming fathers as a result of infertility treatment gives rise to children with lower welfare, it seems we do not yet have a reason to justify differential treatment of single men either. This move is based on the starting presumption that differential treatment requires justification, and so the absence of evidence as a form of this justification forbids us from discriminating.

So far it looks as though single patients should be able to access treatment just as easily as couples, given that there seem to be no differences between these groups with regard to child welfare. From a *patient* welfare perspective, however, there may be a crucial difference that militates against the treatment of single patients: there is only one of them.

The discussion above (pages 59-59) acknowledged that patient welfare has some value, and that there is a prima facie reason to offer treatment to patients for the patient's own sake. If there are two potential parents, then this reason is likely to be strengthened, as there are more people on whom to confer benefit. Even if the joy of having a wanted child is *shared* somewhat between couples, it is unlikely that an argument that it is *halved* could get off the ground. Treating couples therefore generates more welfare per treatment, and for this reason, couples should be prioritised over single patients, all other things being equal. This line of argument may also provide a reason to prioritise patients with a third "parent" (for example a donor who will play a role in parenting), if this third person will gain from this arrangement without detracting from the benefit of the other parents or the child. This consideration may iterate to four parents and beyond, but the diminishing likelihood of these arrangements means we need not go into further detail about them.

This chapter has so far considered some values that may give us reasons to discriminate between patients and thus depart from our initial standpoint of equality. The current section has been a consideration of which groups might legitimately be discriminated against, on the basis that membership of such groups generally indicates a heightened risk with regard to the aforementioned values. Now, the discussion will turn to exactly how these values should be weighed up, and attempt to cash out whether and to what extent these values can cause us to deviate from equality, and in which situations our standpoint of equality should be maintained in spite of the risk that these values may be partly compromised.

4.5 Weighing Considerations

Sections 4.1 to 4.4 of this chapter provided a broad brush stroke look at some of the ethical issues that can confront clinical staff when deciding who to treat with donor gametes. So far, these ethical issues have been taken in isolation from each other, giving little indication about how they interact. Each moral consideration was discussed in its own right, its value considered under “all other things being equal” conditions. The following section will discuss some of the facets of this technical issue, and may provide us with a clearer picture of what to do with all of the sometimes conflicting moral demands that seem to all be in operation at the same time.

4.5.1 Two Potential Relationships between Moral Considerations

Broadly, there seem to be two main ways of describing this relationship between moral considerations of potentially varying significance and weight. The best way to describe these is by way of example. Imagine a tournament, where competitors take part in different events. For each event, one competitor receives a gold medal, one a silver medal, and another a bronze medal. At the end of the tournament, we want to establish a hierarchy to determine everyone’s position and declare a winner.

A lexical ordering model takes the highest-ranked medals (the gold ones) and counts them up. If one competitor has more gold medals than anyone else, they are the winner. If there is a tie, and there are multiple competitors with the same number of gold medals, then we count up the number of silver medals each competitor has, and then bronze until a

winner emerges. In this way, medals “trump” other medals lower on the list, and anyone holding more medals that are higher up the list than another competitor is ranked higher than that competitor, *regardless* of how many medals from lower down the list that competitor has. As Rawls puts it, ‘serial [lexical] ordering avoids, then, having to balance principles at all; those earlier in the ordering have an absolute weight, so to speak, with respect to later ones, and hold without exception’ (Rawls, 1972, p. 43).

The second method, which we will call the “non-absolute model” (by way of contrasting it with the lexical ordering model), however, still assigns some value to medals lower down the list, even if another player has more medals of a type higher up the list. So, under this kind of model, we might assign a value of 10 points to a gold medal, 5 to a silver medal, and 1 to a bronze medal and total up the number of points a competitor has to determine the winner. Now, we might expect results to be similar to the results under the lexical ordering model. Certainly it is still advantageous to have as many gold medals as possible. However, it is theoretically possible, under this model, to win without having any gold or silver medals at all, even if another competitor has some. Table 4 below demonstrates the lexical ordering model. We start by looking at the gold medals – player 2 clearly has more than player 1, so player 2 wins on this basis alone. Table 5 below shows how we get different winners from the same medals when we use the non-absolute model. The bracketed numbers show the total points gained for medals of that type. Unlike in the lexical ordering case, the vast number of bronze medals accrued by player 1 are counted, and that they ultimately give player 1 a bigger score.

Table 4 – The Lexical Ordering Model

Medals	Players	
	Player 1	Player 2
Gold	0	50
Silver	0	10
Bronze	1,000	0

Table 5 – The Non-absolute Model

Medals	Players	
	Player 1	Player 2
Gold	0	50 (500)
Silver	0	10 (50)
Bronze	1,000	0
Total	1,000	550

4.5.2 Challenges for the Models

Both of these models can present challenges in certain circumstances. The value of the lexical ordering model might be in its simplicity: once we have established what our hierarchy of considerations is, we need only consider the values of the most important consideration, unless these are equal. If they are equal, we consider our *second* most important consideration. If *these* are equal, we consider our *third* most important consideration, and so on until we find an inequality in people's scores, or run out of considerations that are relevant to our decision-making.

This model, however, seems to fail to account for the weight of all these considerations, and in practice, this may not look particularly appealing. These problems are best expressed if we move on from medals and apply these models to gamete allocation. Consider a simplified example, with patients A and B. The considerations at play are age, and history of substance abuse. Patient A has a substance abuse problem and patient B does not, but patient A is considerably younger than patient B. Let us assume that the history of substance abuse consideration is more important than the age one. Under lexical ordering, this means that the substance abuse consideration is “lexically prior” to the age consideration. Now, if we are using this model, then as patient B has no substance abuse problem, and patient A does (and as having such a problem speaks against treatment), we should treat patient B over patient A.

Substance use and age, however, are not discrete variables. There is more to the story than just whether someone can be called a substance user or not. In reality, substance use can come in degrees, and so of course can age. Perhaps patient A’s history of substance use is that they smoked cannabis ten years previously. Let us also assume that patient B is in her mid fifties, such that treating her would be unlikely to succeed. The lexical ordering model means that patient A’s rather minor substance abuse history trumps the age considerations, even though the age considerations appear rather weighty.

Treating these considerations as discrete variables, like the lexical ordering model does, ignores the range of different values that these considerations can actually have. First, it has the potential to ignore the difference between a heroin addict and a one-time cannabis user. This problem can be solved, however, by refining terms and splitting them into different variables. For example, instead of considering all heroin addicts and one-time

cannabis users to be positive substance abusers, we could take these as different variables, deciding individually whether someone is a heroin addict or not, then deciding in isolation from that whether they have ever used cannabis, and consider their status as heroin addict lexically prior to their status as one-time cannabis user in our weighing up process. This slightly finer-grained approach helps to deal with the problem of being ignorant to the weight of these considerations, as it does not exclude considerations on the basis that they are lexically inferior. This may come at some practical cost as it would require more details to be recorded and assigned a place in the lexical ordering system.

We are still presented with the problem, however, that in the lexical ordering model, any consideration for which a patient scores more highly than another will trump all the considerations further down the list. This means that even if we use our refined system for negotiating the heroin/cannabis distinction, if patient A still loses based on one of these criteria, then the difference between a young woman and a much older one (in terms of treatment outcomes) is totally ignored. It seems that this model, then, can place too much emphasis on its lexically prior considerations (gold medals) at the expense of the huge (and theoretically infinite) other considerations (like silver and bronze medals). In the lexical ordering model, overriding considerations trump others and negate their value entirely, whereas in the non-absolute model, the value of considerations lower down the list is preserved and accounted for.

4.5.3 Ranking and Points

Notice that the non-absolute model works by assigning numerical weighting to the medals as a way of demonstrating their relative value, thus allowing us to rank them in order. This model is therefore aligned with the ranking system for oocyte allocation proposed by Pennings, which is '[a] point system which gives credit points to the morally relevant features of the prospective recipients' (Pennings, 2001, p. 57). This can be extended to cover sperm allocation. What this means for the moral considerations explored in chapter 4 above is that, where it was concluded that a factor (for example, having children already) was morally relevant "all other things being equal", such a factor either adds or subtracts points to a patient's overall "score", to provide them with a final ranking.

The conclusions of this thesis will not include a detailed value system that defines the appropriate number of points that should be awarded for each moral consideration. Instead, this thesis is concerned with the prior task of establishing those moral considerations that should be included in such a points system, and whether they would be used to add or subtract points to a patient's score. The lack of statutory guidance on these considerations in gamete allocation, as described above (page 3), speaks to the importance of establishing which criteria are morally relevant before attempting to determine the extent or weight of that moral relevance. Hence, this thesis will propose a ranking system for patients, detailing some of the criteria that should be used to rank them, but will not propose the exact weightings of these criteria.

One of Pennings' justifications of the use of moral considerations in a ranking system is the following: 'it allows us to take into account more than one relevant factor

simultaneously in the allocation procedure' (Pennings, 2001, p. 57). Pennings' point is related to the concern about trumping in the previous paragraph – trumping and lexical ordering often force us to ignore factors that may be morally relevant. Furthermore, he argues that '[a] point system is the ideal solution to prevent arbitrary selection and prejudices. The criteria for ranking candidate recipients are determined in advance and create an open and verifiable list' (Pennings, 2007, p. 189). There is thus the added benefit of transparency and a diminished possibility of manipulation and personal selection.

Still, the non-absolute model also presents problems. While it is theoretically appealing in that, unlike the lexical ordering model, it assigns *some* value to *all* our considerations, it is much more difficult to use in practice. This is because much more calculation needs to be done. The earlier example assigned numerical values to gold, silver, and bronze medals, and then simply added them all up. This was not too onerous a task in this context, but was still more time-consuming than simply adding up the gold medals. In gamete allocation, there may be a greater number of things to consider, and accounting for them all may put inordinate strain on the time of clinical staff in making these decisions. Pennings himself is aware of this problem of unwieldiness, noting that '[o]ne should be careful not to include too many factors in order to obtain a practical system which is not too cumbersome for the clinic to maintain and which is transparent for the patients' (Pennings, 2005, p. 2992)

Furthermore, counting up medals is simpler than measuring criteria like substance use, or age, or potential for violence, over which there may be less consensus. One more issue is that time may be wasted weighing up considerations if we know that one consideration weighs very heavily. In terms of the medal example, if player 1 has a million

gold medals and player 2 has zero, we may think that it is pointless to count up the other medals, given the clear advantage that player 1 already has at this stage of the calculation. This may be contingent on information we have about other medals – perhaps there is an upper limit, and no player may have more than a million of any medal, in which case player 2 cannot win. In terms of gamete allocation, a patient may have a long history of abusing children, and this may count so heavily against them that we think it unlikely that any other patient would be ranked below them. The aim of the following subsection will be to outline some proposals that will allow us to use a stripped-down version of the non-absolute model that deals with these concerns.

4.5.4 Prioritisation and Exclusion

Pennings describes a three-stage process for selecting patients. Given that this project primarily aims to provide tools for tertiary clinical staff to use in their decision-making, we will ignore Pennings' comments surrounding the first stage, which is referral for treatment, as this occurs before patients arrive at the kinds of clinics described in this project. Pennings rightly notes that 'the crucial player at this point is the general practitioner' (57) and examination of this is beyond the scope of this project.²⁴ The question of which barriers confront patients at those early stages of their fertility journey is certainly an interesting one, but takes place at a level of decision-making prior to that under discussion here.

²⁴ A similar project to the one undertaken in this thesis, discussing this stage and gathering the views of GPs, could be of use, and is in fact being planned as a continuation of this work.

The second two stages, however, are of interest to us here. They are “admission to the waiting list”, and “selection from the waiting list”. For Pennings, certain criteria should be used to govern admission to the waiting list, and if a patient fails based on these criteria they do not get included at all. Once patients are on the list, other criteria can be used to “rank” them and decide who gets treatment first. The approach to patient management in this thesis will reflect the ranking system suggested by Pennings. The criteria discussed above can be used to prioritise patients over others, challenging the view that patients should be treated in the order in which they arrive on the list. This priority system takes seriously the notion that there are other morally relevant factors that determine to whom it is best to offer treatment. Thus, where this thesis refers to moral factors that “speak for” or “speak against” treating a patient (or similar terms), these terms should be taken to mean that the factor in question gives us a reason to treat or not to treat (respectively) that patient. This reason is not absolute – a factor that speaks against treating a patient does not necessarily mean that they will be excluded, as other patients may have factors speaking more heavily against them. As a theoretical example, someone may be de-prioritised for being a smoker, but they may not be excluded if the other people on the list are convicted child abusers.

At the same time, , there are also patients who we might not want to treat at all, irrespective of whether there are others seeking treatment. This was discussed in the introduction to this thesis (page 1). An example might be a case where treatment would be particularly threatening to a patient’s health. In situations such as these, patients can be excluded outright, without reference to who else might be treated instead. In other cases, we may exclude patients for practical reasons. There may be little point in continuing to

assess and consider a patient for treatment, if we can be reasonably certain that, based on the priority system, other patients will be treated ahead of them. This level of certainty will depend on how many other patients are on the list. To follow the above example: if there are a great number of patients on the list, it may be very unlikely that they are *all* to be given lower priority than someone who is de-prioritised for being a smoker. Hence, this person may be “effectively excluded”.

Given the suitability of the non-absolute model over the lexical ordering model for negotiating the use of moral considerations in prioritising patients, most of the conclusions about moral considerations in this thesis should be taken as referring to ways of prioritising patients rather than reasons to exclude them outright. Exclusions can only occur in two circumstances:

- a) the moral consideration in question suggests that the patient(s) themselves are not expected to benefit from the treatment, and
- b) the moral consideration in question weighs so heavily against the patient that, given the profiles of the other patients on the list, the patient is expected never to be treated. This is the effective exclusion described above.

In cases of type a), the outcome will be a matter of clinical judgement. For type b), the outcome will depend on the suitability of other patients on the list.

Effective exclusions as described by type b) cases, however, will occur much less often if the amount of time that the patient has been waiting is accounted for – if a patient’s time waiting is taken as a reason to give them priority, most patients will eventually be

treated once this consideration becomes weighty enough. This is true in all cases except those involving other considerations that also change with time, such as age. The following subsection will now consider waiting time as a moral consideration.

4.5.5 One More Putative Consideration: Time Waiting

So far, this approach more or less mirrors Pennings' view. We diverge, however, where he argues that the time the patient has spent waiting is morally relevant. Taking patients' waiting time into account would mean that patients would no longer be excluded by having very low scores, as would happen to (among others) the older patients who are on lists with many young patients. This criterion is one that Pennings describes as 'neutral' (Pennings, 2001, p. 60). Pennings rightly suggests that this cannot be the *sole* consideration, as there are other morally relevant considerations at play also. A "first come, first served" system will thus be inadequate as it fails to account for all of the relevant considerations.

Still, Pennings thinks that time spent waiting counts for something. His argument for this is twofold. He notes that it is 'a way equally to distribute the opportunity of trying' (Pennings, 2001, p. 60). The idea of distributing this opportunity equally has already been discussed and the problems therein exposed (see pages 115-118). Pennings' second point is the 'psychological effects of being put on a list', with reference to 'powerlessness', 'uncertainty', and 'stress' (Pennings, 2001, p. 60).

The psychological burden, however, might be mitigated if there is no expectation that patients will eventually receive treatment, and the practice of simply excluding patients who are likely to never receive treatment might remove this sense of expectation. At any

rate, the burden of being placed on such a list needs to be demonstrated, so the picture is thus unclear regarding the psychological issues of being on a waiting list.

The proposal being made here is that patients do not get extra priority based on how long they have been waiting, as this is at best a backward-looking consideration that does not fit with the consequentialist framework being adopted here. This means that under the model being proposed here, a patient can be excluded if the list includes so many patients who score more highly than them in the priority system that they are unlikely to ever receive treatment. An example of this would be an older patient on a waiting list populated largely by younger patients.

A more palatable way of conceiving of this denial of the moral relevance of waiting time is to recognise that under the priority and exclusion system being proposed, there is not really a “waiting list” at all. In reality, patients would be assessed for their suitability based on the criteria discussed in chapter four, and allocated points as a result of this assessment. They would thus be on a list of sorts, but not a *waiting* list. The patients with the most points would receive treatment, and the number of patients treated would correspond to the availability of gametes at that time. With all of the gametes allocated to the most suitable patients, those less suitable would not join any list, and be declined treatment straight away. We can refer to this as an “effective” or “de facto” exclusion – patients are not excluded because they are unsuitable for treatment, but rather because other patients who are *more* suitable are given priority.

This gives rise to a kind of “temporal unfairness” by which patients may or may not receive treatment based on what the composition of the waiting list happens to be like when they are referred to the clinic. This may be likened to the postcode lottery, where

patients are (dis)advantaged because of where they live. The temporal unfairness issue seems insurmountable, however; it seems hugely impractical to maintain temporal fairness in a system that is perpetually and unpredictably changing, as in this case where there is no way of knowing how many and which donors and recipients will join the list. For this reason, we will have to put the temporal unfairness point to one side.

This section has discussed some possible ways of interpreting the moral considerations that can arise in gamete allocation scenarios, favouring a non-absolute model over a lexical ordering model so as to ensure that morally relevant factors are sufficiently accounted for. The non-absolute model suggests that clinical staff should exclude patients, the treatment of whom will not be in the patient's own interests, and then use a priority system to decide which of the remaining patients are most suitable for treatment. As many of the most suitable patients should be treated as resources allow, with the remaining patients being "effectively excluded" due to a combination of their lesser suitability for treatment, and the shortage of gametes.

4.6 Weightings

We now turn to the crucial question of how the welfare considerations described in section 4.3 are to be weighed up against our commitment to the principle of equality described in section 4.2, and how far we are required to secure welfare before this interferes impermissibly with equality. First we will consider how the more abstract philosophical values weigh together, for example equality and efficacy. For reasons of space

and scope, this thesis will not enter into detail about how all of the considerations in section 4.3 should weigh against each other, for example how a patient's substance abuse weighs against a violent history. The thesis argues that these factors should be afforded some weight, but how much weight each should have relative to every other factor would require more discussion than there is room for here.

4.6.1 Weightings of Theories

The following two subsections will comment on the existing philosophical debate about how some of these commitments to different theories should be weighed up. First, we will consider how far child welfare concerns allow us to deviate from equality, and second, we will consider how far considerations about treatment efficacy allow us to deviate from this. Child welfare, equality, and treatment efficacy are all concepts that have been highlighted as important in this chapter.

4.6.1.1 Equality and Child Welfare

Pennings' discussion of measuring child welfare implicitly considers its status with regard to other commitments, one of which is equality. He considers a range of principles to guide our conduct with regard to child welfare: the maximum welfare principle, the minimum threshold principle, and the reasonable welfare principle. According to Pennings, '[t]he maximum welfare principle implies that one should not knowingly and intentionally bring a child into the world in less than ideal circumstances'. Of the person-affectingness

problem described above, Pennings suggests that it 'does not prevent us from comparing the quality of life of different children born in different settings' (Pennings, 1999, p. 1146). The analysis of the non-identity problem above (pages 51-56) was in agreement with this. This means that in gamete allocation, the *maximum welfare principle* requires us to consider all the children that could be created with the donors and recipients that we have available, and create the set of children with the highest predicted level of welfare. Perhaps unsurprisingly, this accords most with maximising versions of consequentialism.

Next is the *minimum threshold principle*, which suggests that it is permissible to create any child as long as some minimum standard of its welfare is met. Pennings suggests that the wrongful life standard is 'one of the most frequently used minimum thresholds', and states that '[a]ccording to this principle, the child is only harmed if it is brought into existence with a life not worth living' (Pennings, 1999, p. 1148).

The third and final putative principle that Pennings suggests is the *reasonable welfare principle*. He defines this as "intermediate" relative to the other two principles, and formulates it thus: 'The provision of medical assistance in procreation is acceptable when the child born as a result of the treatment will have a reasonably happy life' (Pennings, 1999, p. 1148).

Strictly speaking, these principles are all interchangeable. We can render the maximum welfare and minimum threshold principles the same by stipulating that the minimum threshold *is* maximum welfare. We can similarly render the maximum welfare and reasonable welfare principles the same by stipulating that reasonable welfare *is* maximum welfare. The minimum threshold principle and reasonable welfare principles require even less manipulation when we consider that the minimum threshold might be considered

reasonable. Nevertheless, we can take the maximum welfare, minimum threshold, and reasonable welfare principles to (respectively) require maximum welfare, a very low level of welfare, and somewhere in between.

4.6.1.1.1 Pennings and Maximising Welfare

Pennings criticises the first two principles and advocates the third. Broadly, his criticism of the first principle, maximising welfare, has two parts, one theoretical and one practical. The simpler, practical issue is that actually accounting for all of the elements that can affect a child's welfare is too complex: '[t]he concrete circumscription of all dimensions of the child welfare proves almost impossible' (Pennings, 1999, p. 1147). Given that this project aims to have practical applications for clinical staff, we should take this concern seriously, and it may be unrealistic to require or expect clinics to take so many factors into account. This, however, does not mean that *some* factors cannot be considered, so there still remains some room for making *some* child welfare assessments. Furthermore, there is a legal requirement that clinics do this, so unless we wish to challenge the law, this must be done.

The theoretical problem is that maximising leads to the conclusion that '[p]eople who are poor, unemployed, handicapped, obese, workaholics, and/or old should all be rejected as potential parents since the child they will have would have had a better life had it been

born to other parents'²⁵ (Pennings, 1999, p. 1147), and he considers this to be a 'bias against some groups'. While it is not explicit, we can perhaps take Pennings to be appealing to considerations of equality as detailed in the previous section. Pennings is rightly resistant to courses of action that appear to discriminate against certain groups, but his defence of this kind of equality is not absolute: he points out that 'we need evidence to support the differential attribution of welfare to different groups' (Pennings, 1999, p. 1147). While Pennings seems to condemn the practice of discriminating against these groups in order to maximise child welfare, his final move in this section is to suggest that differential treatment among these groups could be justified as long as there is sufficient evidence. Hence, it is not clear how far his commitment to equality among these groups stretches. Certainly we can all agree that there is no way to justify arbitrary discrimination among these groups, but what is on the table here is *not* arbitrary discrimination – it is discrimination with a view to maximising child welfare. At any rate, we can take Pennings as arguing that child welfare is not the only important consideration, and that maximisation of child welfare will compromise our commitments to equality to too great an extent.

4.6.1.1.2 Pennings and Minimum Welfare

For Pennings, the minimum threshold principle makes the opposite mistake. He rejects this view on the basis that it would permit the creation of children 'whose prospects and opportunities are awful' (Pennings, 1999, p. 1148). Pennings suggests that this is

²⁵ Of course, a child born to different parents is in many senses a different child altogether, but this is not important here. As we learned from the analysis above (pages 51-56), we can still sensibly make comparisons between different potential people in this way.

intuitively unappealing, but perhaps the intuitive force of this is diminished once we consider that Pennings uses “awful” here in a linguistically unfamiliar way, to mean “low but still higher than zero”. Indeed, the awfulness of this situation is very much contingent on where we place this minimum threshold, but we can take Pennings to mean that this threshold is a very low one. This kind of intuition is one he shares with Parfit, where Parfit rejects the ‘repugnant conclusion’ (Parfit, 1984, pp. 387-388), arguing that a world populated with very many people, all with very low but higher than zero welfare, would be extremely undesirable. The rejection of a minimum welfare principle is consistent with the maximising approach being taken in this thesis (see pages 35-35): if we can improve child welfare at no extra cost to some other value or principle, we ought to do it.

4.6.1.1.3 Pennings and Reasonable Welfare

Pennings thinks that our decisions in these situations should promote a certain level of child welfare that is more than minimally above zero, but that above some point, the effort for welfare must be limited:

We can reject procreation in alternative settings because the welfare level of the existing child is lower than the expected welfare level of another possible child that would have been born in (what we consider as) ideal circumstances. The existing child is harmed to the extent that it could have had a better life. This is an extremely strong standard. When we take the time to scrutinize the consistent application of this rule, we will soon find out that this standard would exclude the overwhelming majority of the population from procreation (Pennings, 1999, pp. 1146-1147)

Importantly, given that Pennings' discussion takes place within the context of fertility treatment, the word 'population' here has the narrow definition of referring to the population of people seeking fertility treatment. This has implications for the notion that 'the overwhelming majority' of people would be excluded, because in fact if we are using the maximum welfare principle to decide amongst patients as Pennings describes, we are still treating the same *number* of patients than if we were using some other principle. The difference is *who* gets treated, not *how many* are treated. It would thus be wrong to read Pennings' complaint as being that fewer patients would be treated. Rather, his concern is the resulting 'bias against some groups' (Pennings, 1999, p. 1147) that the application of this principle would involve. For Pennings, the maximum welfare principle interferes to too great an extent with our commitment to secure equal treatment amongst patient groups.

Unfortunately, Pennings does not give us much information about what is the right level of child welfare to seek. Beyond describing it as "reasonable", he cites a few examples of things that could compromise child welfare unjustifiably, such that deviations from our principle of equality are permitted:

[A]n individual has a decent welfare level when he has the abilities and opportunities to realize those dimensions and goals that in general make human lives valuable. *All* those conditions and defects which obstruct the pursuit of the normal human interests should be considered as harm to the person' (Pennings, 1999, p. 1148, emphasis added).

If we take Pennings' use of "all" in the preceding quotation seriously, then the child welfare standard is quite high, as the set of things that can constitute such an obstruction has many members. On the other hand, Pennings probably meant to use "obstruct" as a threshold

concept here, such that a condition must affect a child *to a certain extent*, rather than just obstruct it minimally. This is evidenced by his desire to find a middle ground between the maximum welfare and minimum threshold principles, and by his implicit endorsement of the fact that '[i]n reality we only criticise parents when they pursue their own goals although this has disastrous consequences for children' (Pennings, 1999, p. 1148).

Pennings continues: '[t]he deviations which cause the welfare level of the child to fall significantly below this baseline comparison state are sufficient reason to refuse treatment' (Pennings, 1999, p. 1148). This claim raises the obvious question of what counts as "significantly" below his baseline comparison, and in the absence of this being fleshed out, all we can get from this statement is that welfare considerations do not take absolute priority over equality ones.

Pennings' argument against maximum welfare affords a different status to the principle of equality and justice that was our starting point. For Pennings, equality considerations serve to temper child welfare considerations. For this thesis, however, the commitment to equality is a starting point, but it is not a principle that has weight when compared to other considerations. This thesis is considering factors that can justify deviation from the equal treatment of patients, but we cannot argue that a factor is morally relevant such that it provides justification from deviation up to a certain point and no further – to do so would be arbitrary. Either child welfare is morally relevant or it is not, and, like in the case of Achilles described above (page 35), we are not justified in considering something "good enough" if we could do more at no cost to some other value. Equality is not a candidate for such a value.

4.6.1.2 – Equality and Efficacy

The debate between Savulescu and Harris considers the relationship between equality and treatment efficacy, and their insights will provide a useful foil for considering this relationship in gamete allocation. This discussion is with reference to healthcare in general, not specifically applying to fertility treatment (though it is mentioned). As Savulescu points out, the debate tracks the wider philosophical issue of the value of goodness versus the value of fairness, discussed, for example, by Broome (1998). We will now consider this problem in more detail.

Savulescu details an allocation system incorporating what he calls ‘a plateau (submaximising) threshold relationship’ (Savulescu, 1998a, p. 235). He contends that “Man C”, whose chance of success is $1/1,000,000$, has less reason for wanting treatment than “Man A”, whose chance of success is $1/50$, and that we can thus prioritise Man A on the basis of his better prognosis. So far this looks like a purely welfarist picture, but further considerations come into the picture that make this framework more egalitarian: Savulescu thinks that ‘[a]t some point, the probabilities are so close that any difference is not relevant to the old man’s reasons in this situation’ (Savulescu, 1998a, p. 232), and that this intuition is borne out when we consider the difference between people with a $1/50$ chance and a $1/51$ chance.

Savulescu sells his theory short here, as there is more to the story than just intuition. The irrelevance of reasons between cases with similar (but not equal) chances is based on Savulescu’s reasons-based theory of value, where he advocates a ‘threshold view of rationality’ (Savulescu, 1998b, 234). This is based on Slote’s satisficing view, which allows

that 'an act might qualify as morally right through having good enough consequences, even though better consequences could have been produced in the circumstances' (Slote and Pettit, 1984, p. 140). In Savulescu's words this means 'the state of affairs promoted must have an expected value which is *good enough* relative to other available alternatives' (Savulescu, 1998a, p. 228, emphasis added). As with Pennings' reasonableness criterion above (pp. 100-101), this gives rise to the use of thresholds. However, Savulescu's thresholds are not absolute – they are relative to the alternatives. The relative threshold view means that 'reasons are not so fine grained as to be sensitive to small changes in expected value' (Savulescu, 1998a, p. 232). Incorporating thresholds that are relative to available alternatives is in effect the same as merely having a coarse-grained view that disregards small differences between outcomes. This means that there can be a difference between 1/50 chances and 1/1,000,000 chances, but not between 1/50 and 1/51. The upshot of this is that patients with similar chances of success are not ranked against each other, but patients with vastly different chances are.

Harris's ideas about allocation are in contrast to this. Savulescu notes that '[o]ne consequence of [the] utilitarian decision procedure is what Harris calls *de facto discrimination*' (Savulescu 1998: 215). This is the same as indirect discrimination as described above (pages 37-38). While Savulescu's allocation system may incidentally arrive upon more egalitarian treatment decisions than a strict maximising model in that it does not allow for fine-grained distinctions between those with similar prognoses, this still does not give enough weight to equality to satisfy Harris:

I am not claiming that equal opportunities for health care are either intrinsic or instrumental goods, they are *both and more* [...]. A denial of equal opportunities is a slap in the face; it is an existential rejection disproportionate to the value of the good or welfare that the opportunity might have afforded. So it is not the case that the opportunity is valuable only for what it is an opportunity to do or to be, nor is it merely valuable in itself. [...Equal opportunities] are important because the denial of them is a rejection of equality and therefore an affront to human dignity (Harris, 1999, pp. 399-400).

Harris here claims that the “existential rejection” created by denying equal opportunities outweighs the value of the welfare being generated. If such an existential rejection always trumps the welfare being distributed, this means that where welfare considerations would require deviations from the distribution that respects equality of opportunity as Harris asks, they should be ignored. Where welfare considerations happen to *accord* with Harris’s equal opportunities (this could be rare because it would mean that the best distribution in terms of welfare happens to be the same as the one that distributes opportunities equally), then they can be satisfied, but note that this does not really afford any value to welfare at all; in this instance, commitments to welfare are only fulfilled because they incidentally coincide with prior commitments to equality. Harris’s insistence on equality of opportunity as opposed to equal distribution of the resource puts welfare on an even lower pedestal. This is because Harris’s affording equality of opportunity lexically prior status allows no room whatsoever for deviation based on considerations like welfare, except in unlikely cases where equality of opportunity considerations are equal. This offers us no help, as one starting point of this thesis was open-mindedness to the view that some considerations could permit deviations from equality. Hence, Harris’s view about the absolute importance of equality without regard for any other moral considerations is too

much of a hard line for what is being discussed here, as this thesis aims to be more pluralistic than this.

Harris is unabashedly concerned with equal opportunities, apparently at any cost to welfare. Savulescu's theory, on the other hand, is welfarist but pays some incidental heed to equality by ignoring small differences in welfare. While Savulescu's claim is only convincing if we are convinced by Slote in the first place, it is more appealing for our purposes here in that it at least patronises a pluralistic value theory. While it may not place any theoretical value on equality, it is at least pragmatically palatable to those who have an interest in securing equality. Hence, we will proceed on the basis that Savulescu's coarse-grained welfarist theory is the right one.

4.7 National Allocation

Pattinson notes that '[t]he absence of a body empowered to nationally coordinate the system of gamete donation means that approaches to the recruitment of gamete donors for treatment and research, and the allocation of donated gametes for treatment, vary between clinics' (Pattinson, 2012, p. 577). He then goes on to describe the national allocation system used for organs and blood, and claims that '[t]he idea of adopting such a system for gamete donation, at least for treatment, has widespread support' (Pattinson, 2012, p. 578), though without further description of or evidence for this support. Examples of this support, however, might be the HFEA's 'Sperm, Egg and Embryo Donation (SEED)' review survey, which reported clinical staff's 'suggestions to centralize gamete provision in form of a national recruitment program or a central donor bank' (HFEA, 2004, p.5), or the

British Fertility Society (BFS)'s report calling for 'a national framework of sperm donation services [...], based on a 'hub and spoke' model' (BFS, 2008). Importantly, this idea was advanced as a means of increasing the number of sperm donors, by making the system of donor recruitment more efficient. The system could also be used to increase the number of egg donors. If this would be the result, it is a strong reason in favour of having such a system, as it would confer additional benefit on patients.

Pattinson's arguments in favour of a national donation/allocation system are twofold: the first is that 'it could remove the significant regional variations and inequalities of access that currently beset the use of donor gametes in fertility treatment and it could enable centralised support for research uses of gametes'. This, he notes, is born from considerations of 'justice, transparency, and equality' (Pattinson, 2012, p. 593). Indeed, a national system may make it easier to implement standardised access criteria for treatment with donor gametes, so that whatever is deemed the best model for allocating gametes can be used across the country.²⁶

The second argument is slightly problematic. Pattinson says that 'the national coordination of gamete donation [and allocation] would also enable the implementation of other methods of encouraging gamete donation' (Pattinson, 2012, p. 594). He then goes on to describe mirror exchange schemes as outlined by Pennings (discussed above, pages 69-71). The problem with this suggestion is that while it would indeed speak in favour of a national system if it facilitated the mirror scheme (see pages 69-71), it is not clear that the national system would make the mirror scheme any more viable, as such a scheme could be

²⁶ It is worth noting recent moves in Scottish legislation to standardise access criteria for fertility treatment (Scottish Government, 2013).

employed by individual clinics, as long as they were large enough. Still, the national system has in its favour that it may be fairer, more transparent, and less admitting of the personal biases about which Pennings is worried, assuming that the same democratic principles as espoused in this thesis are used.

One consideration with regard to the implementation of such a system is the Levelling Down Objection. As Pattinson notes, a national system may reduce variation between clinics, and this may make the system fairer in the sense of providing more egalitarian outcomes. If, however, this comes at a cost, we would need to consider whether the benefits in fairness, and in potentially increased numbers of donors, are worth these costs, bearing in mind the Levelling Down Objection. This may depend on the nature of these costs, and whether they are borne by patients (perhaps financial resources would be diverted from elsewhere, ultimately resulting in fewer treatments).

The ethical status of the national system seems to rest on empirical data about the practicalities of implementing it, and what its effects would be. It seems to be something that may be worth considering further in light of participants' views in the empirical study.

4.8 Guidelines and Test Cases

This section will outline the conclusions that this chapter makes with regard to allocating gametes. This section will also include some discussion of how these guidelines might work in practice, using the cases from chapter two above as examples.

4.8.1 Guidelines

While the current system merely asks for certain thresholds to be satisfied before a patient is eligible for treatment, there is some room for comparisons between patients, such that certain patients should be prioritised over others, for reasons other than just the amount of time that they have been waiting on the list.

The rationale for this idea of prioritising recipients comes partly from the scarcity of gamete donors. Given that the demand for gamete donors can be expected to remain high (in spite of the recently increased compensation for donation²⁷), clinics can make stringent decisions about who can receive gametes without fear of wasting them, as there will likely be somebody else who is more suitable for treatment. This gives rise to the following conclusions:

- 1) There should not be a presumption that patients will simply be treated in the order in which they arrive at the clinic or on the waiting list. A priority system should be adopted to ensure that as many morally relevant factors as is pragmatically viable are taken into account.

Many of the remaining conclusions will relate to this first one, as they will describe which factors can legitimately be factored into the priority system. These factors should at least take the following into account:

²⁷ As of April 1st 2012, sperm donors can be compensated up to £35 per clinic visit and egg donors can be compensated up to £750 per donation cycle. See HFEA (2013e) and (2013f).

First, child welfare and its high importance leads to the conclusion that:

- 2) If any patient, any patient's partner, or any person who is expected to have a significant role in rearing a child born of treatment, is revealed to have a continuing problem with substance use (including smoking), alcoholism, violence or domestic discord, this should be taken as a reason against further consideration of this patient for treatment.

Currently, clinics are only required to "account for" such factors in their child welfare assessments, and there is no explicit suggestion that the presence of such factors should operate as a factor that completely excludes potential recipients (an "excluder"). It may be the case that clinics are risk-averse with regard to child welfare in practice (this could be either for their own sake, for the child's, or for that of the patient) and so do regard these factors as excluders. This seemed like an important empirical issue to explore in the interviews.

These conclusions go further than the current HFEA Code of Practice. The 'substance use' criterion should be taken to also include smoking behaviour. There are good reasons for clinical staff to acknowledge that parents who are expected to smoke in the vicinity of children have the potential to cause harm to those children just as parents who use other substances do. Excessive use of alcohol or illegal drugs may be more likely to lead to additional neglect, but the direct harm caused by smoking should not be ignored.

As a coverall for other potential scenarios that may affect child welfare, the following conclusion is made:

- 3) Any other factors that call into question (supported by evidence) the expected welfare of children affected by treatment, including the potential recipient's ability to parent the child, should be seriously considered as reasons against treatment unless they can adequately demonstrate that such factors do not present a risk to child welfare.

Similar child welfare issues bear on cases where parents risk passing on heritable diseases to their children, leading to the following conclusion:

- 4) Patients who can reproduce without donor gametes, but who can only do so at the risk of passing on diseases, should be given some priority on this basis.

This is based on the idea from Savulescu that, other things being equal, clinicians can take wider societal concerns into account.

Given the scarcity of resources, it makes sense to treat those who have the most to gain from treatment with regard to efficacy, and the least to lose with regard to their own welfare.

- 5) Patients should be prioritised based on the chance of the treatment being successful, and the risks to their health of undergoing treatment, with those with higher chances and lower risks the higher priority.

Clinics should not prioritise patients solely on the basis of their age, but age is a marker for other issues. Given that, in the case of sperm, these resources can be used with varying chances of success depending on the age of the patient, and that obstetric risks rise as patients get older it is recommended, as an application of recommendation 5), that:

6) Younger patients should take priority over older ones, except in cases where there are so few younger patients that older patients are expected to be treated anyway. In such cases, the older patients should take priority.

The exact application of this rule will depend on the number and age of the patients on the waiting list. The concept of exceptions for when “older patients are expected to be treated anyway” gives rise to one of the ramifications of this guideline: that there may be situations in which older patients, given the prioritisation of younger patients, are *not* expected to be treated anyway. It is true that in such cases, these patients are effectively excluded, and so in cases where there is genuinely no expectation that they will receive treatment, they should be told this straight away, rather than put on a list where they will never reach the top.

Finally, while the wider commitments of health services (public and private) to equality and fairness might suggest that patients should not be refused treatment on the basis of arbitrary factors, conditional and known donation actually benefits everybody by removing competition from the waiting list. This gives rise to the next recommendation:

- 6) Gametes can be allocated on the basis of conditions set by the gamete donors, including conditions based on the protected characteristics in the Equality Act.

Further to this, and as a result of the further advantages that can be gained with a mirror exchange scheme, the following is recommended:

- 7) Patients who can recruit donors to donate to them, or to the general pool, should be given some priority.

Given the possibility of increased psychological distress amongst those who are childless, the following recommendation is made:

- 8) Parental status should be accounted for in prioritising patients, so that patients who have had less experience of parenting are prioritised over those who have had more experience of parenting.

It is not having children *per se* that is important here, so this conclusion is sensitive to the good of the parenting experience (as opposed to, say, just having a genetically-related child but having no relationship with them).

There is a lack of evidence to justify distinguishing between patients based on their membership of same-sex couples. This gives rise to:

- 9) Patients should not be prioritised or de-prioritised based on their sexual orientation.

Next, given the commitments to maximising the value of scarce resources, the following conclusion is made on the basis that it will generate more welfare per treatment:

- 10) Staff should give priority to parenting arrangements involving greater numbers of parents.

Finally, the following is suggested as a possibility for increasing the number of gamete donors, and as a way of making the system fairer:

- 11) A national allocation system should be considered (and is a candidate for further exploration in interviews).

4.8.2 Test Cases

Let us now consider what bearing these conclusions would have on the hypothetical cases presented in the prologue to this chapter. The solution to case one, Bob and Betty, is probably obvious. The history of violent discord between this couple and the fact that Bob has an alcohol problem would each count as an excluder on their own, derived from child welfare considerations.

Case two, Jim and Alice, is more complicated. This is because they are a couple who do not need donor gametes in order to reproduce. Certainly they need assistance, but this does not need to be in the form of the donor egg that Jim and Alice would prefer over PGD. Treatment with an egg from Alice and sperm from Jim could be achieved, but this is not an

option because of the potential for the child to have Huntington's disease, and our commitment to ensure the best outcome. While we need to give some weight to the fact that they would prefer treatment with a donor egg to PGD, the fact that this would be a use of gametes that could go to someone else when they could use Alice's eggs and have PGD rules this out – the scarcity of gametes overrides individual considerations about Jim and Alice's preferences in this instance, as the welfare of others must also be considered. Thus, given that there is another option available to Jim and Alice that will allow them to have a child without HD, they should not be treated with donor gametes if somebody else could be treated instead.

The situation for Jane and Albert in case three is similar. Even though waiting much longer may compromise their ability to ever have children together, both the risk of gamete wastage through ineffective treatment and the increased obstetric risks speak for treating someone with a better chance of success.

The discussion of known donors has shown that Tess and Emily, of case four, should be given some priority, given the benefit that this creates. For the same reasons, the anonymous donor ought to be able to make stipulations. Finally, with little evidence to support the idea that matching physical characteristics confers any benefit on a child or that failing to match causes welfare issues, it seems that Rajkumar and Gulab should have the gametes they prefer, if they are available.

This concludes the philosophical analysis of gamete allocation ethics. The remainder of this project will comprise a description of the methods for the empirical work, a description of the results of the empirical work, and finally a discussion of these results in light of this philosophical discussion. This will culminate in a final list of conclusions about

ethical gamete allocation, based on and shaped by the themes identified in the existing philosophical literature and in the empirical study.

5. METHOD USED FOR EMPIRICAL STUDY

5.1 Introduction

This section will outline the protocol for the empirical element of the project, beginning with a description of the compilation of the publicly available access criteria for treatment, and then providing a detailed description of the qualitative study. One of the aims of the project was to determine how fertility clinic staff actually use and interpret statute and guidelines in practice. As a preliminary way of achieving this, publicly available information was sought from the HFEA website, and from individual clinics' websites, and a database of selection criteria compiled (see pages 160-188).

5.2 The Qualitative Study

5.2.1 Rationale

Following this, an empirical study was undertaken (see pages 17-30 for the detailed rationale for this). It was necessary to communicate directly with clinical staff for two reasons. First, given that the first aim of the project was to ascertain what allocation criteria are actually used in practice (pages 18-19 for aims and objectives), it was necessary to explore how practitioners *interpreted* the relevant regulation and guidance. For this reason, merely consulting the documentation itself would be insufficient. Second, the project aimed to gain an understanding of the potentially complex ethical reasoning used by fertility clinic

staff, to establish how and why decisions are made about gamete allocation. This speaks to the first aim of the project (to establish how gametes are allocated) but also to the second: how gametes *ought* to be allocated, in that an account of the ethical views of clinical staff may help to establish what allocation practice should be.

These aims gave rise to the need for a study that could paint a picture of the experiences of relevant informants, including staff members of fertility clinics, but also other relevant professionals, such as philosophers, policy-makers, and representatives of patient groups. Qualitative methods facilitate access to an understanding of the nuances and depths of participants' experiences and ethical opinions, 'in a depth which addresses the rich context that is the substance of their meanings' (Jones, 1985, p. 46)²⁸. This depth comes at the cost of breadth: the small sample sizes, and the non-random sampling methods, in each of the three data collection phases (described in detail below) mean that the results cannot be generalised to any larger population. They will, however, serve to provide a useful snapshot of some of the views of professionals whose roles are relevant to the research aims. This will help to ensure that the final conclusions made in this project are not purely abstract (Ives and Draper 2009), but have some relevance to real-world practitioners, especially given the workshop phase, where 'stakeholders are involved in the process of reflection and analysis' (Widdershoven et al. 2009, p. 236). This helps to achieve the project's second aim of determining how to allocate gametes, as it will mean that the conclusions have, to some extent, undergone the scrutiny of the kinds of people they will affect.

²⁸ Jones is referring to interviews here, but the point applies to qualitative methods generally.

5.2.2 Overview

Figure 1 – Relationship between Theory and Data

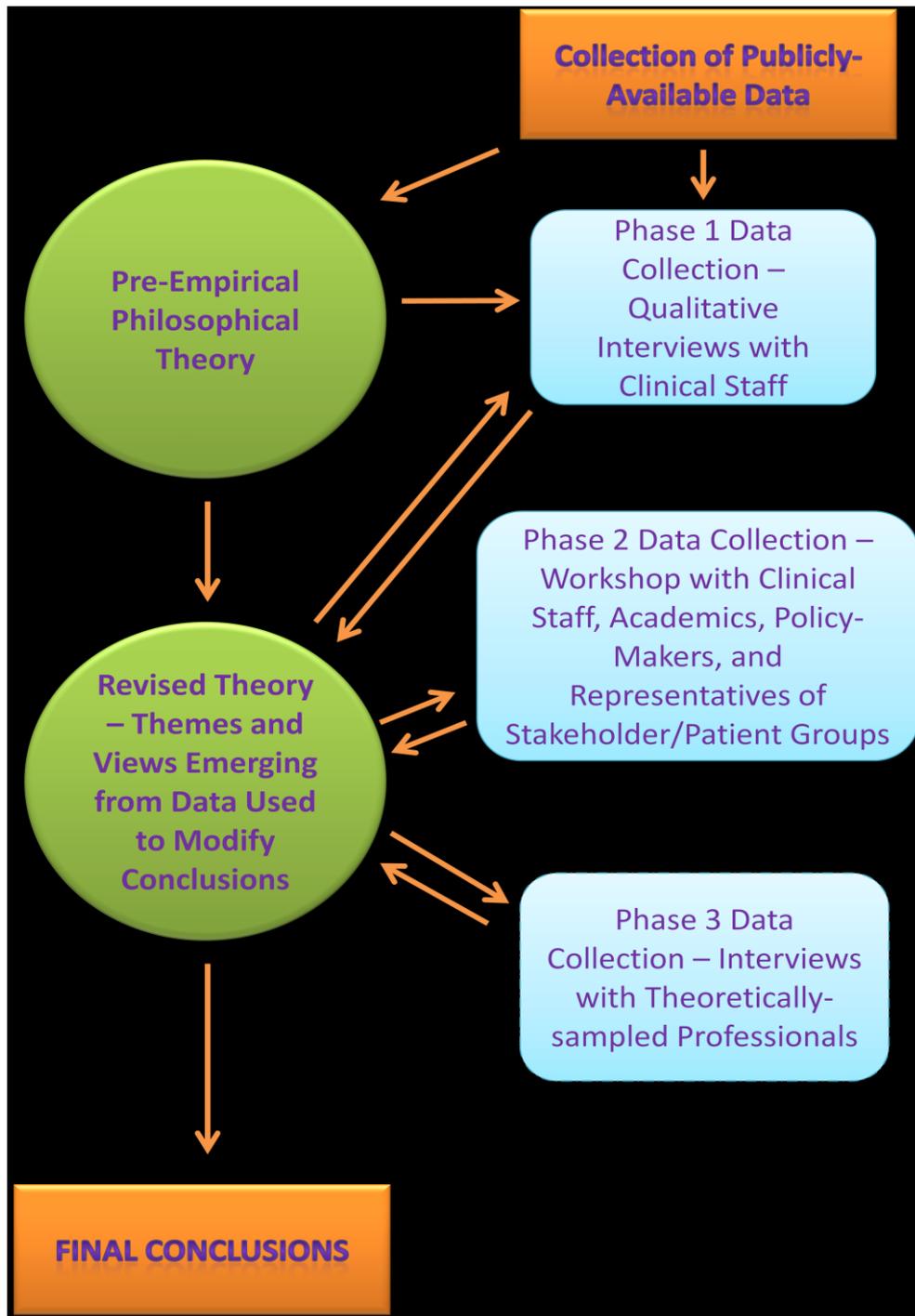


Figure 1 above shows the data collection phases and how they occurred alongside philosophical theory. The arrows show which stages of the project influenced which. The preliminary philosophical analysis influenced the design of the first data collection phase. The results of this phase were then used to modify the conclusions of this theory, resulting in empirically-informed revised theory. This revised theory itself influenced phase 1 data collection, where later interviews probed concepts that previous participants had raised.

Once phase one data collection was complete, the themes that had been identified by both the philosophical analysis and the data were made into a set of philosophical conclusions, which were presented at the workshop at phase 2. Emerging themes and discussion were then used to revise the conclusions further. Where these discussions seemed incomplete, participants were invited to participate in phase three interviews, so that further elements of these concepts could be explored in greater depth. The data from phase three was then used to fine-tune the philosophical conclusions, resulting in the final set of conclusions shown in chapter seven.

5.3 Philosophical Stance and Method

The overarching aim of this thesis to generate a set of philosophically robust yet practically useful conclusions for clinical staff provides a reason for designing a study that will generate tangible, useful data. This makes the *critical theory* paradigm, as described by Guba and Lincoln, an appropriate approach because the thesis partly needs to provide ‘the *critique and transformation* of the [...] structures that constrain and exploit humankind’

(Guba and Lincoln, 1994, p. 113) in relation to gamete donation. The overarching notion of aiming at change and reform make this an appropriate paradigm for the project.

The *epistemological* position to be adopted in this study, however, is one that falls slightly further to one side of Guba and Lincoln's spectrum, nearer to the positivist/postpositivist position. More specifically, a brand of positivism known as "weak verification", put forth by Ayer, is employed in the study. Ayer's verification suggests that propositions can only be true if they are at least conceptually verifiable. This means that we need to be able to conceive of a situation in which the statement under scrutiny could be verified as true, but not that we need to be in a position to carry this out. Ayer presents the following example to demonstrate this principle of conceptual verification:

No rocket has yet been invented which would enable me to go and look at the farther side of the moon, so that I am unable to decide the matter by actual observation. But I do know what observations would decide it for me, as is theoretically conceivable, I were once in a position to make them. And therefore I say that the proposition is verifiable in principle, if not in practice, and is accordingly significant (Ayer, 2001, p. 36).

For the purposes of the empirical study, it is thus taken that propositions about what clinicians both do in practice and about how they feel about such practice are verifiable. Happily, they are verifiable in practice as well as in principle, as long as it is accepted that participants' reports are mostly reliable.

Verification can take two forms, strong and weak. Both are discussed by Ayer. He distinguishes them thus: 'the question that must be asked about any putative statement of fact is not, *Would any observations make its truth or falsehood logically certain?* [strong

verification], but simply, *Would any observations be relevant to the determination of its truth or falsehood?*²⁹ (Ayer, 2001, p. 38) This means that we arrive at truth in a probabilistic fashion, such that if evidence can be mounted in support of a proposition, this gives us a reason (albeit a reason that could be outweighed by countervailing evidence) for believing it. Soames paraphrases Ayer's view thus: 'a statement that can play a role in explaining or predicting observations must be meaningful' (Soames, 2003, p. 284).

The chosen method in the study will not allow for generalisations to be made to wider populations of fertility clinic staff, but this epistemological stance can still apply to the study population, and still reflects (and is crucial to) the manner in which data was analysed in the project. Weak verification only asks for evidence to *support* conclusions, rather than for evidence that creates certainty about conclusions.³⁰ This allows room for interpretation, such that if there is uncertainty about data (for example, what a participant's statement is meant to mean), we can still make inferences and come to conclusions as long as that data goes some of the way towards a certain conclusion.

The purpose of taking this particular epistemological stance is to maximise the data's usefulness in practice. An approach to knowledge like this, which 'assume[s] an objective external reality upon which inquiry can converge', and 'enables the investigator to determine "how things really are" and "how things really work"' (Guba and Lincoln, 1994, p. 111) will allow us to make bolder claims from the data about what staff do and what they believe, and gives a better foundation from which to create conclusions that can affect how things are and how things work in the future, compared with more relativist or constructivist

²⁹ Ayer introduces some further complications to this principle but they should not trouble us here.

³⁰ Indeed, the principle of weak verification is compatible with the denial of the possibility of certainty.

paradigms that take a more fluid and skeptical approach to what can be known (see for example Dunn and Ives, (2009)). Of course, as with any claim, there always exists the possibility that the study's data is in some way inaccurate. The probabilistic approach to knowledge adopted here acknowledges this possibility, but nevertheless this positivistic position allows us to assume the truth of the data in order to develop useful conclusions.

5.4 Study Execution

Phase one was an interview phase undertaken with staff at fertility clinics, the purpose of which was to determine how legal and clinical guidance was interpreted in practice, and the ethical opinions of practitioners about this practice. Asking practitioners directly offered deeper insight into the complexities of and reasoning behind their practices and opinions.

Phase two was a workshop involving practitioners, academics, policy-makers, representatives of patient groups, and other relevant professionals. The purpose of this was to present preliminary findings to professionals. These findings comprised an ethical discussion which took phase one data into account. This process sought these professionals' input on the acceptability and practicality of the philosophical conclusions, so that these conclusions could be revised and strengthened for greater philosophical rigour, but also impact and practical use.

Phase three data collection appears as a cut-out in figure 1 to show that its occurrence was contingent on whether it was deemed necessary based on the analysis of phase one and phase two data. This was a final interview phase to discuss particular relevant

issues in greater detail, either with individuals who had attended previous data collection phases and who appeared to be able to offer greater insight, or with individuals who had not been able to attend previous phases but whose input was considered to add value to the project and its findings. This helped to strengthen conclusions relating to areas of discussion at the workshop that had been identified as requiring further empirical input.

5.4.1 Sampling and Recruitment

5.4.1.1 Phase One

5.4.1.1.1 Sampling

This interview phase made use of purposive sampling for maximum variation so that a broad range of clinics could be represented, in the spirit of the project's aims with regard to the quotation from Mill above (page 19). Clinics were selected from those on the HFEA website, which lists all of the HFEA-licensed clinics. Sampling was based on finding clinics that, between them, had all of the following characteristics:

- Located in England
- Located in Wales
- Located in Scotland
- Located in Northern Ireland
- Treats same-sex couples
- Does not treat same sex couples
- Offers NHS-funded treatment
- Does not offer NHS-funded treatment (private)

- Allows “known donor” donation
- Does not allow “known donor” donation

Unfortunately, information about some of the above criteria was not readily available publicly, not being published on the HFEA website, nor on clinics’ individual websites. Given the increased difficulty in obtaining information about whether a clinic would offer treatment to same-sex couples, it was decided that this criterion should no longer form part of the sampling process, and that the interviews themselves may reveal information about clinical practice in these cases.

Fifteen clinics were originally selected so that each interview could be undertaken at a different clinic, ranging across the criteria above (excluding the criteria about same-sex couples). Some clinics, however, declined to take part, and so alternative clinics needed to be approached. Because of this, and given the small number of clinics that, according to the HFEA website, did not allow known donation, it was not possible to recruit a clinic from this category.

In addition, Research and Development (R&D) permissions were required for each NHS clinic (because each clinic was in a different Trust – a consequence of gaining the desired geographical spread), and management permissions were required for private clinics. In some cases this process was so lengthy that alternative clinics were approached in order to expedite the process of recruitment and data collection, to ensure that the project would finish on time. This meant that there was an element of chance involved in selection, where clinics that were more willing to take part and/or had more efficient R&D processes were more likely to be involved in the study. It also meant that for the sake of ease and

convenience, multiple interviews were sometimes undertaken at the same clinic (up to a maximum of three from each clinic), where the original intention was to interview fifteen participants from fifteen different clinics. This results in less diversity of clinics, but different perspectives on the same clinic were gained. Seven of these permissions were ultimately gained in total, in order to interview at seven different clinics – there were two clinics for which the process was begun but abandoned. Table 6 below shows the total number of clinics approached, their locations, the services offered at each (with regard to the criteria described on the previous page, and whether the R&D process was begun at the relevant Trust for that clinic.

Table 6 – Clinics Approached for the Study

Number	Name	Location	Services Offered			Status
			Offers NHS-funded treatment	Treats same-sex couples	Accepts known donors	
1	Birmingham Women's Hospital	Birmingham	✓	✓	✓	R&D permissions attained
2	London Women's Clinic	London	✓	?	✓	Approached
3	Glasgow Centre for Reproductive Medicine	Glasgow	X	?	✓	Management permissions attained

4	Regional Fertility Centre	Belfast	✓	?	✓	R&D permissions begun but not attained
5	Leicester Fertility Centre	Leicester	✓	X	✓	R&D permissions attained
6	The Bridge Centre	London	✓	?	✓	Approached
7	IVF Wales	Cardiff	✓	?	✓	R&D permissions attained
8	Edinburgh Assisted Conception Unit	Edinburgh	✓	?	X	Approached
9	Origin Fertility Care	Belfast	X	?	✓	Approached
10	Bourn Hall Clinic	Cambridge	✓	?	✓	Management permissions attained
11	Bath Fertility Centre	Bath	✓	?	✓	R&D permissions begun but not attained
12	Centre for Reproductive and Genetic Health	Camden, London	✓	?	✓	Approached
13	Aberdeen Fertility Centre	Aberdeen	✓	?	✓	R&D permissions attained
14	Glasgow Royal Infirmary	Glasgow	✓	?	✓	R&D permissions attained
15	Centre for Reproduction and Gynaecology Wales	Llantrisant	✓	?	X	Approached
16	Brentwood	Essex	?	?	✓	Approached
17	Herts and Essex Fertility Centre	Cheshunt (near Enfield)	✓	?	✓	Approached
18	Oxford Fertility Unit	Oxford	✓	?	✓	Approached
19	Midland Fertility Services	Aldridge, West Midlands	✓	?	✓	Approached
20	Peninsular Centre for Reproductive Medicine	Exeter	✓	?	✓	Approached
21	Newcastle Fertility Centre at Life	Newcastle	✓	?	✓	Approached
22	The Leeds Centre for Reproductive Medicine	Leeds	✓	?	✓	Approached
23	Arrowe Park Fertility Clinic	Wirral	✓	?		Approached

24	Ninewells Hospital	Dundee	✓	?	✓	Approached
25	Ayrshire Fertility Unit	Kilmarnock	✓	?	✓	Approached
26	Manchester Fertility Services Ltd	Manchester	✓	?	✓	Approached
27	The James Cook University Hospital	Middlesbrough	✓	?	✓	Approached
28	Reproductive Medicine Clinic	Bristol	✓	?	X	Approached

A limited snowballing approach (Bryman, 2012, p.202) to recruitment was also used. When being invited to the study, staff members were encouraged to pass on recruitment information to relevant colleagues. This means that clinics as a whole may have engaged in self-selection of individual participants within them.

5.4.1.1.2 Inclusion Criteria

The inclusion criteria for participation in phase one were: donor coordinators and those whose occupational role gave them significant influence in the gamete allocation process, including those who had such influence over admission to waiting lists. This could include the directors of the clinics or other clinical staff. These people were considered to be the group with the greatest knowledge and first-hand experience of how allocation decisions are made.

5.4.1.1.3 Exclusion Criteria

Only those who were unwilling to participate, those with whom a suitable time for interview could not be arranged, or those working at clinics where R&D permissions could not be obtained, were excluded from participation in the study.

5.4.1.1.4 Recruitment

Initial contact was made with potential participants by post (Appendices 1, 2, and 3). Separate letters were sent to directors of clinics and to donor coordinators – those responsible for managing donors. These individuals were invited to assist with the snowball sampling described above (page 140). If no response was received after two weeks, they were sent a reminder letter (see Appendix 6) by post. If there was no reply to this, they were not contacted again.

5.4.1.2 Phase Two

5.4.1.2.1 Sampling

Participants were purposively sampled to ensure that the workshop included representatives of fields, disciplines, and organisations that would give the analysis the benefit of the scrutiny of philosophers, bioethicists, sociologists, healthcare practitioners, policy-makers, and those representing stakeholder/patient groups (see the Limitations

section on pages 256-260 for a discussion of why individual patients were not included). We aimed to recruit approximately thirty participants to the workshop. The number of participants was constrained by the available budget (the study paid for participants' travel expenses), but it was also judged that thirty participants would suffice to include the desired range of disciplinary and professional perspectives, and to explore the philosophical conclusions and the theory from which they were derived, so that they could be modified and refined in the way that Beauchamp and Childress suggest (as was discussed on page 27 above).

5.4.1.2.2 Inclusion Criteria

Inclusion criteria were broader for phase two than for phase one. Eligibility was limited to anyone with a professional (not necessarily clinical) role connected to the allocation of gametes in practice, or as a concept, from the perspective of policy, or representatives relevant stakeholder organisations, in particular support groups for patients. This included those involved in forming policy, and academics. In addition, all participants from phase one were invited to participate in phase two (eight of whom attended) as a form of respondent validation where phase one participants were able to comment on the presentation of the themes that had arisen in the interviews. The purpose of this was to 'seek confirmation that the researcher's findings and impressions [were] congruent with the views of those on whom the research was conducted' (Bryman, 2012, p. 391). This confers some credibility on the results, as it provided these participants with the opportunity to

challenge the interpretation of the data if they thought their views were being misrepresented.

5.4.1.2.3 Exclusion Criteria

Nobody fitting the above description was excluded, except for those who chose not to participate, or were unable to participate for practical reasons.

5.4.1.2.4 Recruitment

Participants who had left contact details at phase one and agreed to further contact at phase two were contacted in the manner that they had expressed preference for (for example email, phone, or text message). Other potential participants were invited by post (see Appendices 8 and 9). If no response was received after two weeks, they were sent a reminder letter (see Appendix 6) by post. If there was no reply to this, they were not contacted again.

5.4.1.3 Phase Three

5.4.1.3.1 Sampling

This data collection phase made use of purposive and theoretical sampling. One of the participants was somebody who was unable to attend the workshop. This participant

was purposively sampled because they were a representative of a patient group. They were considered to potentially have interesting and relevant opinions, and to be able to add to the patient representation among the participant group. The other two participants had participated in the workshop, and were theoretically sampled on the basis that their views were of particular interest, or presented particular challenges that required further detailed exploration.

5.4.1.3.2 Inclusion Criteria

Inclusion criteria for this phase were narrow. Following the workshop, the research team met and discussed their preliminary impressions of the data. Participants were selected on the basis that they would add more detail and rigour to the arguments that the research team thought, on the basis of this meeting, were emerging in the data as being important.

5.4.1.3.3 Exclusion Criteria

Nobody fitting the above description was excluded, except for those who chose not to participate, or were unable to participate for practical reasons.

5.4.1.3.4 Recruitment

Participants in phase three were all contacted by email, as they had all agreed to this method of contact after having been approached previously with regard to participation in other phases.

5.4.2 Data Collection

5.4.2.1 Phase One

The interviews were audio recorded and transcribed verbatim. Interviews were semi-structured to allow participants to speak about practices or concerns that they themselves found relevant and interesting, but simultaneously to allow the interviewer to ensure that the interview considered each of the research questions in enough depth (Taylor 2005: 40). A topic guide (Appendix 7) was used, which included a list of prompts and was divided into three sections, so that the interviewer could ensure that all the relevant subjects were covered. The topic guide assumed that the interviews would last approximately one hour.

The topic guide included questions designed to address key topics that the study aimed to explore. In particular, the topic guide was constructed so that where possible, the interview sections began with simple information-gathering questions, leaving more sensitive questions until later as a means of easing the participant into the interview and allowing them to relax (Fontana and Frey, 1994, p. 371; Taylor, 2005, p. 45). The first question on the topic guide was 'how does the clinic decide who to put on the waiting list for

donated gametes?', whereas the last was a more specific question that asked for an opinion: 'what do you think about the idea of a national waiting list for donors and recipients?' All questions on the topic guide were very open ended, allowing participants to interpret and answer the questions in whatever way they felt to be most appropriate. The loose structure of the interviews allowed the interviewing researcher to probe areas of interest that the participant had mentioned, but ensured that participants could steer the interview towards issues they felt pertinent. Allowing the participant to raise issues themselves is consistent with the approach to empirical bioethics proposed by Borry et al. being used in this thesis (as discussed above on page 28), which suggests that one of the principal purposes of the data is to help *identify* moral problems.

The interviews were structured in a way that would reflect the theory-driven nature of the relationship between theory and data, as described above (pages 24-30). The questions posed by the interviewer were theoretically underpinned in two ways. First, the preliminary review of literature and philosophical work gave rise to certain theoretical areas of interest that the research team felt it pertinent to explore. A particular example of this is the theme of child welfare. The statutory obligations for those providing fertility treatment place great emphasis on securing child welfare, and as such there is a wealth of philosophical literature about this concept. As a result, this question was sometimes directly posed to interview participants if they had not mentioned it already. This was also true of other issues that had arisen in the theoretical, pre-empirical part of the project.

Second, an iterative theoretical approach was used in some cases to generate interview questions. Where concepts arose from the data as being pertinent and interesting, these were sometimes used as prompts in later interviews. Bryman defines a prompt as

occurring ‘when the interviewer suggests a possible answer to a question’ (Bryman, 2012, p. 224). This helped to generate rich data with regard to the concepts that had arisen in earlier interviews, and in establishing whether those earlier views would be held by many other participants, or whether they would be outliers. As an example, as the issue of age cut-offs became increasingly prevalent in earlier interviews, participants in later interviews were sometimes asked about this issue specifically. These prompts, however, were used only after each participant had been given the chance to identify concepts that they themselves found salient.

The iterative approach thus applied not only *between* the three data collection phases (as exemplified in figure 1 above), but also *within* the first phase, where interview questions were altered in light of previously collected data from the same phase. This iterative approach also created the added practical advantage of allowing the later interviews to take place concurrently with the analysis of earlier ones.

5.4.2.2 Phase Two

The purpose of the workshop was to generate feedback and critical comment on the preliminary philosophical conclusions of the project, so that they could be revisited, modified, and strengthened. The workshop³¹ began with a warm up exercise, during which participants were asked to rank some hypothetical gamete allocation cases in the order in which they felt they should be treated. This exercise served a number of purposes. To begin

³¹ The workshop programme and warm up exercise are contained in the workshop summary document (Appendix 18).

with, it helped familiarise participants with the kinds of issues that would arise throughout the day. Second, the results of it were also used later to elucidate the differences between how participants would prioritise patients, and how the philosophical analysis presented above argued that they should be prioritised. These differences are considered in the discussion of the results (pages 256-318).

The workshop then featured a presentation³² of the study's initial results, to gauge the feedback of the participants to the preliminary philosophical conclusions (in line with objective v) above (page 18)). In accordance with the Millian idea above (page 19) of including a variety of voices to the debate, this was followed by three presentations from invited speakers, who had been sent a summary of the main presentation and invited to respond from a specific perspective, with one participant speaking as a philosopher and HFEA member, another speaking as a patient group representative, and another speaking as a policy-maker. The audience was invited to ask questions and raise concerns throughout the event, and they participated in facilitated breakout group sessions in order to interact in smaller numbers and discuss certain elements of the debate in greater detail. These were similar to focus groups, giving participants the opportunity to speak in a different environment that they may have found more comfortable than the larger group discussions. This is consistent with Morgan's idea, considered by Bryman, that small groups like this are appropriate 'when topics are controversial or complex and when gleaning participants' personal accounts is a major goal' (Bryman, 2012, p. 507). These discussions were led by facilitators either from the research team or the same department as the research team, so that they could make use of probing and prompting (Bryman, 2012, pp. 223-224) in order to

³² Slides from this presentation are appended (Appendix 19).

stimulate discussion. The facilitators met prior to the meeting so that less informed members could be briefed about the project and so that an agreed strategy could be outlined and followed to give some unanimity to the groups. These breakout groups were semi-structured to strike a balance between allowing participants to lead the debate (Taylor, 2005, p. 40) and ensuring that discussion remained relevant (McCracken, 1988, p. 22) with facilitators and participants guided by prompt slips³³ containing four questions for the participants to focus on.

Each breakout group was asked to focus its attentions on a particular question in the first instance, to avoid each group focusing on the same issue and neglecting others.

All of the presentations and discussions were audio recorded. This includes the breakout groups, which were each recorded individually. These audio data were then all transcribed verbatim, so that they could undergo thematic analysis to identify critical or supporting comments on the preliminary suggestions for allocation criteria.

5.4.2.3 Phase Three

The questions for the two participants who had attended the workshop at phase two were constructed largely on the basis of comments that they had made at the workshop. Similar to the reason for having breakout groups in the workshop, this allowed participants to go into greater detail and complexity in their criticisms and comments of specific issues relating to gamete allocation. In this way, the data collection at phase three also took the iterative approach, using data from previous phases to inform data collection in later phases.

³³ See Appendix 20.

It was deemed necessary to provide a platform that would allow further elaboration than the workshop would allow, so interview questions for the third participant were slightly more general given that (s)he had not participated in the study previously. The questions were still directed at topics that had arisen from the data, with a view to refining and modifying the philosophical conclusions that had been drawn relating to those topics. The interviews in phase three were thus more theoretically oriented than phase one interviews – a brief set of questions was drawn up for each interview, with questions and comments written specifically for each participant (see Appendix 19). These interviews were audio recorded and transcribed as with phases one and two. This is with the exception of one participant, who requested to be emailed a list of questions to which (s)he provided a written response. For the sake of convenience, this phase will still be referred to as an interview phase.

5.4.3 Analysis

5.4.3.1 Phase One

Transcripts were coded using NVivo software. Qualitative analysis software ‘serves to facilitate an accurate and transparent data analysis process whilst also providing a quick and simple way of counting who said what and when, which in turn, provides a reliable, general picture of the data’ (Welsh, 2002, p. 3). We might modify this slightly to “accounting for” for a more accurate picture, as there was no “counting” as such in the analysis undertaken here. This is more in line with the goals of this study in establishing concepts themselves rather

than how many people subscribe or agree to those concepts. As McCracken puts it, '[t]he purpose of the qualitative interview is not to discover how many, and what kinds of, people share a certain characteristic. It is to gain access to the cultural categories and assumptions according to which one culture construes the world' (McCracken, 1988, p. 17). We are therefore not interested in counting.

The data underwent thematic analysis closely mapping the process described by Braun and Clarke. Braun and Clarke suggest that their method is aligned with 'constructionist paradigms' (Braun and Clarke, 2006, p. 78). While this may seem slightly at odds with the positivistic outlook being adopted in this thesis, the element of 'theoretical freedom' (Braun and Clarke, 2006, p. 78) that this provides actually facilitated an important goal of the project. This was to allow the data to provide themes not previously identified, independently of theory, so that participants' own views on which moral issues in gamete allocation are salient could be represented. The emphasis on a primary purpose of data as being theme identification reflects the fact that this project follows Borry et al. in terms of its use of empirical data, as discussed above (page 28). Here, the data helped to identify, shape, and assess the moral questions at hand.

This method of analysis included the following steps: familiarisation with the data through transcription, re-reading and annotation of transcripts with initial ideas; generation of codes and themes; and finally, generation of visual thematic maps to demonstrate the relationships between themes.

The thematic analysis did not include hypotheses or presuppositions about what the participants' views would be about each theme, nor which themes they would introduce or focus on. It was, however, partly driven by the philosophical discussion undertaken in

chapter four, which meant that the identification of codes was guided by the themes that had been identified by the philosophical analysis, both directly in terms of the thematic analysis, and indirectly as the topic guide was influenced by the philosophical analysis. This means that the data analysis took a combined approach, in part using directed analysis in that theory-driven themes were identified, and in part using conventional analysis in that space was given for themes to arise from the data (Hsieh and Shannon, 2005).

Participants' responses were categorised to fit within the broader ethical categories defined in the philosophy chapter. For example, if a participant suggested that a certain practice was "unfair" because it favoured one type of person over another, this might have been categorised as a consideration relating to equality as defined in the philosophy chapter. In this way, the philosophical theory provided a pre-existing ethical framework in which participants' views could be placed. This relates to Frith's claim that 'ethical theory is a body of knowledge that can be brought to bear on different issues and used as an analytic tool' (Frith, 2012, p. 202).

The method of integrating the data with the philosophical analysis was to identify themes and categories, and then consider each of them in terms of their coherence with the theories and conclusions laid out in the philosophical analysis. This process of searching for coherence between data and theory, and modifying either if necessary to achieve coherence, follows the reflexive balancing approach described by Ives (2013). In some cases, the principles offered by participants were slightly ambiguous, and could be interpreted such that they achieved sufficient coherence with the philosophical analysis. In other cases, principles were rejected by virtue of being unable to achieve this coherence. Finally, in cases where there was high dissonance between the general participant view and the

philosophical analysis, the philosophical conclusions were supplemented or altered in order to account for these views. Normally, this was for the pragmatic reason that any conclusion likely to face a high level of opposition may have little practical value (as per the discussion of Huxtable on page 25 above). The conclusions of this integrative process formed the preliminary conclusions that were presented at the workshop in phase two.

Participants sometimes seemed surprised by some of the questions in the interview. While the topic guide was provided for participants to read in advance, the invitation to do so did not make sufficiently clear that it would be useful for them to consider the questions in advance. Owing to this, analysis of data in these instances took on a more hermeneutic flavour than was originally intended, as it was not always clear what the participants' justifications were. This meant that sometimes it was necessary to make an interpretive judgement about what the ethical underpinning of a participant's view might be, as they were sometimes unable to articulate this themselves or consider the subject at this more abstract level. This aligns the analysis with the "interpretive reading" approach to qualitative analysis described by Mason: 'An interpretive reading will involve you in constructing or documenting a version of what you think the data mean or represent, or what you think you can infer from them. [...]ou will be involved in *reading through or beyond* the data in some way' (Mason, 1996, p. 149). This fits with the epistemological approach being taken here, where data is seen as providing support for conclusions in a probabilistic manner (pages 132-135).

Two of the coded transcripts were independently checked by members of the supervisory team in order to check that all theoretically relevant themes were being identified. Additionally, the research team met and discussed the themes emerging from the

data as this analysis progressed. Once again, as interviews took place concurrently with these discussions, the process of interviews and analysis was iterative, with the analysis of some interviews affecting what might be explored in others. The data analysis was thus both theoretically- and data-driven.

5.4.3.2 Phase Two

Phase two data analysis was similar to that for phase one, though with some differences. It was much more theory-driven than that of phase one. Themes and important issues were by this stage already established, both by the philosophical analysis and by the analysis of data at phase one. By this stage the aim was not to introduce or identify new themes, but to focus on fine-tuning particular concepts, so the process of coding took a more directed approach. An example of this is child welfare. Child welfare had already emerged as a theme, both from the philosophical analysis (which identified this as important in part due to the legal requirement to consider child welfare in the HFE Act), and from the interviews at phase one. Phase two considered this concept in greater detail, discussing the moral weighting of this concept, for example whether child welfare should be considered “paramount” and whether paramountcy meant it was a trumping consideration, or just a heavily weighted one. In this way, the themes that arose in phase two were interrogated for agreement with the earlier philosophical conclusions, and where possible, interpreted in ways that made them cohere with these conclusions. Analysis for phase two was thus focussed on developing and examining the content and meaning of themes that had already

been identified. This is consistent with the aims of phase two as strengthening and scrutinising the initial philosophical recommendations that were presented at this stage.

5.4.3.3 Phase Three

Phase three analysis was again not concerned with identifying any new themes, and was thus purely theory-driven. This phase aimed to discuss previously-identified themes and concepts in further detail if it was felt that participants would have something to add. This means that the analysis for this phase followed a similar process as described for phase one, but omitted the preliminary theme-identifying stage, and only included the reflexive balancing part in which data and theory were modified for coherence.

5.4.4 Consent

5.4.4.1 Phase One

Participants were given information sheets (Appendix 4) at least 24 hours prior to interview, and were given the opportunity to ask any questions about the interview or the study before beginning the interview. All participants gave written consent (Appendix 5) to take part, following this consent interview with the researcher. On giving their consent to phase one, participants were also invited to consent to being contacted about phases two and three. It was made clear on the consent form that consenting to earlier phases did not commit them to consenting in later phases.

5.4.4.2 Phase Two

Participants were given information sheets (Appendix 11) at least 24 hours prior to the workshop, and were given the opportunity to ask any questions about the workshop or the study prior to arrival. All participants gave written consent (see Appendix 12) on arrival at the workshop venue. On giving their consent to phase two, participants were also invited to consent to being contacted about phase three.

5.4.4.3 Phase Three

Participants were given information sheets (Appendix 13) at least 24 hours prior to interview, and were given the opportunity to ask any questions about the interview or the study before beginning the interview. All participants then gave written consent (see Appendix 14).

5.4.5 Ethical review and local R&D

A favourable opinion (reference 11/WM/0099) for the study was obtained from a Research Ethics Committee in the West Midlands. R&D permissions were also obtained from each of the Trusts governing the clinics at which interviews took place. Management permissions were obtained from private clinics. Evidence of the favourable opinion and of these approvals can be found appended to this thesis (Appendices 20 and 21).

This concludes the description of the empirical study, and the justification of the methodology used.

6. RESULTS

6.1 Tables of Publicly-Available Access Criteria

The tables below contain publicly-available information on access criteria for fertility treatment in the UK, collected to meet objective i) described on page 18. These data relate to actual access criteria at individual clinics, which may differ from funding criteria as stipulated by the Clinical Commissioning Group (CCG) that manages funding for that clinic. All data is from the HFEA, except where otherwise specified in brackets. Bracketed numbers refer to interview participants. A “?” means the data could not be found in the public domain. In some cases there is apparently conflicting data, though this may be due to different, unspecified definitions. For example, where a clinic website contradicts information from the HFEA, this may be because one source refers to NHS funding and the other to self-funding criteria. Data was collected up to and including July 2012. The first table shows specific access criteria, and the second table shows additional comments for some of the clinics.

The tables show that information on the treatment of same-sex couples and single patients, and information on conditional donation, was not accessible online in most cases. Another point to note from the table is that the criteria on the HFEA website did not refer exclusively to treatment with donor gametes, only treatment generally. For example, while some clinics had general upper age limits, some had different age limits for treatment with donor gametes, but the HFEA’s published data was not sensitive to differences such as these. The database thus only provides an approximation of criteria for donor gamete treatment in

different clinics. It still, however, serves to show that access criteria for fertility treatment are variable from clinic to clinic (the so-called “postcode lottery”).

Two conclusions can be drawn from the exercise of compiling this database: 1) some information about clinical selection criteria is not readily available online. For example, information about whether clinics will treat same-sex couples was almost always unavailable from clinic websites. 2) In some cases, the information on the HFEA website contradicted the information given on the clinic’s own website. This occurred most often with regard to the upper age limit for treatment. The clinic websites should probably be considered more likely to be accurate, as these tend to be operated by the clinics themselves, who will probably be more aware of their own criteria than the HFEA website, which has to maintain a database of nearly two hundred clinics and satellite centres.

Table 7 – Clinics’ Access Criteria

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Aberdeen Fertility Centre	Aberdeen	Over 44	Y (3 & 5)	Y (3, 4 & 5)	Y	Y	Y (HFEA & 3, 4, & 5)	Y (5)	35
Andrology Solutions	Central London	None	?	?	N	Y	Y	?	None
Assisted Conception Unit Leigh Infirmary	Leigh, Lancashire	None	?	?	Y	N	N	?	35
Assisted Conception Unit Queen Mary's Hospital	London SW15	None	?	?	Y	N	N	?	None
Assisted Conception Unit, King's College Hospital	SE5 9RS	40-42	Y (only women?) (clinic site)	Y	Y	Y	Y	?	30 (35 for self-funding)
Assisted Reproduction and Gynaecology Centre	London W1G 6LP	Over 44	?	?	N	Y	N	?	None
Ayrshire Fertility Unit	Kilmarnock	None	?	?	Y	N	Y	?	35

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Barts and The London Centre for Reproductive Medicine	London EC1A	Over 44	?	?	Y	Y	Y	?	19 - 30
Bath Fertility Centre	Bath	Over 44	?	?	Y	Y	Y	?	30 for NHS funding
Berkshire Independent Hospital	Reading		?	?	?	?	?	?	?
Beski Women's Care Ltd	NW5		?	?	?	?	?	?	?
Birmingham Heartlands Hospital	Birmingham		?	?	?	?	?	?	?

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Birmingham Women's Hospital	Birmingham	Over 44; over 45 for own eggs (7); over 50 for donor eggs (6 & 7)	Y (1, 6, & 7) but not if male (6)	Y(6 & 7)	Y	Y	Y (HFEA & 1, 6, & 7)	Y (1 & 6)	35 for self-funding patients needing IVF or ICSI. 30 for NHS funded patients according to PCT criteria' - HFEA
BMI Chelsfield Park ACU	Orpington, Kent	Over 44	?	?	Y	Y	N	?	37 (NHS)
BMI Priory Hospital	Edgbaston, Birmingham	Over 44	?	?	Y	Y	Y	?	30 (NHS)

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
BMI The Beaumont Hospital	Bolton		?	?	?	?	?	?	?
BMI The Chaucer Hospital	Canterbury, Kent	40-42	?	?	Y	Y	Y	?	19-29 for NHS, 34 for private
BMI The Hampshire Clinic	Basingstoke	N	?	?	N	Y	N	?	19-35
BMI The Saxon Clinic	Milton Keynes	?	?	?	?	?	?	?	
Bourn Hall	Cambridgeshire	Over 44; (43 own eggs and 50 donor eggs according to 9 (HFEA stipulation?); over 50 for donor eggs (10)	Yes (8 & 9) but not men (10)	Yes (8)	Y	Y	Y	Y (8)	30
Bourn Hall	Colchester	Over 44	?	?	Y	Y	Y	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Bradford Teaching Hospitals NHS Foundation Trust	Bradford		?	?	?	?	?	?	?
Brentwood Fertility Centre	Essex	43-44	?	?	N	Y	Y	?	Yes according to HFEA site (but doesn't say what)
Bridge Centre	London	Over 44	?	?	Y	?	?	?	Depends on individual cases'
Brighton Fertility Associates	Brighton	?	?	?	Y	Y	Y	?	?

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Bristol Centre for Reproductive Medicine	Bristol	Over 44	?	?	Y	Y	Y	?	35 but usually 30 for NHS-funded patients
Burton Hospitals NHS Trust	Burton Upon Trent	Over 44	?	?	Y	Y	Y	?	NHS Patients - As per commissioning Primary Care Trust criteria Private patients - BMI limit of 35'

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Calderdale Royal Infirmary	Halifax	45 (clinic site)	?	?	?	Y (clinic site)	Y	?	?
Cambridge IVF	Cambridge	Over 44	Y (clinic site)	Y (clinic site)	N	Y	?	?	N
Cambridge University Hospitals NHS Foundation Trust	Cambridge	?	?	?	?	?	?	?	?
CARE Boston	Lincs	?	?	?	?	?	?	?	?
CARE Leicester	Leicester	?	?	?	?	?	?	?	?
CARE Manchester	Manchester	Over 44	Y (female only?) (clinic site)	Y (clinic site)	N	Y	Y	?	N
CARE Mansfield	Notts	?	?	?	?	?	?	?	?
CARE Northampton	Northampton	Over 44	?	?	Y	Y	Y	?	35
CARE Nottingham	Nottingham	Over 44	Y (female only?) (clinic site)	Y	Y	Y	Y	?	35

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
CARE Peterborough	Peterborough	?	?	?	?	?	?	?	?
CARE Sheffield	Sheffield	Over 44	Y (female only?) (clinic site)	Y	Y	Y	Y	?	Between 19 and 30 for NHS, up to 35 for Private Patients
Central Middlesex Hospital	Park Royal, NW London	?	?	?	?	?	?	?	?
Centre for Reproduction & Gynaecology Wales (CRGW)	Llantrisant	None	?	?	Y	Y	N	?	None
Centre for Reproductive and Genetic Health	Camden, London	Over 44	?	?	Y	Y	Y	?	19-30
Centre for Reproductive Medicine	Coventry	Over 44	?	?	Y	Y	Y	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Centre for Reproductive Medicine and Fertility	Sheffield	Over 44	Y (clinic site)	Y (clinic site)	Y	Y	Y	?	19 - 29 for NHS patients . 19-35 for self-funded patients
Chapel Cottage	Hampshire	?	?	?	?	?	?	?	?
Chelsea & Westminster Hospital	SW10	46+ for self-funded. Suggests they follow NICE guideline for NHS-funded (clinic site)	?	?	Y	Y	?	?	35 - clinic site
Chichester Nuffield Hospital	Chichester	?	?	?	?	?	?	?	?
Chiltern Hospital Fertility Services Unit	Bucks	Over 44	?	?	Y	Y	Y	?	30
Complete Fertility Centre Southampton	Southampton	40-42	Y	Y	Y	Y	Y	?	36

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Conceive International		?	Y (clinic site)	Y	?	?	?	?	?
Concept Fertility	Mitcham, Surrey	?	?	?	?	Y	?	?	?
Cornwall Centre for Reproductive Medicine	Truro	23-39 (clinic site)	?	?	Y	?	?	?	19-29.9 (clinic site)
Cotswold Fertility Centre	?	?	?	?	?	?	?	?	?
Cotswold Fertility Unit (Cheltenham)	Cheltenham	?	?	Y	Y	Y	?	?	?
Countess of Chester Hospital	Chester	Over 44	Y - lesbians (clinic site)	Y (clinic site)	Y	Y	N	?	30 for NHS, 35 self-funded

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
County Durham ACU	Bishop Auckland	?	?	?	Y	?	?	?	?
Craigavon Area Hospital	Craigavon	N	?	?	Y	N	N	?	35
CREATE Centre for Reproduction and Advanced Technology	SW20 8NJ	Over 44	Y (but emphasis on sperm so presumably just women (clinic site))	Y	Y	Y	Y	?	35
Create Health Clinic	W1G 6AJ								
CRM London	NW8 7JL	Over 44	?	?	Y	Y	Y	?	35
Dr Amanda Tozer	London	?	?	?	?	?	Y	?	?
Dumfries and Galloway Royal Infirmary	Dumfries	N	?	?	Y	N	N	?	N
Ealing Hospital NHS Trust	UB1 3HW?	?	?	?	?	?	?	?	?
Edinburgh Assisted Conception Unit	Edinburgh	Over 44	?	?	Y	Y	N	?	32

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Epsom and St Helier NHS Trust	Surrey	?	?	?	?	?	?	?	?
Fertility Unit Barking, Havering and Redbridge Hospitals Trust	Romford, Essex	38-39	?	?	Y	N	N	?	18-30
Gateshead Fertility Unit	Tyne & Wear	43-44	?	?	Y	Y	N	?	Preferably below 35
Glasgow Centre for Reproductive Medicine	Glasgow	Over 44; over 55 for donor eggs (11 & 12); over 45 for own eggs (12)	Y (11)	Y (11)	No	Y	Y	Y (12)	None
Glasgow Nuffield Hospital	Glasgow	43-44	?	?	N	Y	Y	?	35
Glasgow Royal Infirmary	Glasgow	Over 44	?	?	Y	Y	Y		35
Good Hope Hospital NHS Trust	Sutton Coldfield, Birmingham	23-40	?	?	Y	N	Y	?	30 or below

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Guys Hospital	SE1 9RT	Over 44	?	?	Y	Y	Y	?	30 (HFEA site); 35 (clinic site)
Hartlepool General Hospital	TS24 9AH	Over 44	?	?	Y	Y	Y	?	29
Herts and Essex Fertility Centre	Cheshunt (nr Enfield)	Over 44	?	?	Yes	Y	Y	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
IVF Wales	Cardiff	Over 44 - HFEA; IVF, ICSI, or DI cycle should start before patient's 40th birthday (clinic site)	Y (clinic site)	Y (clinic site)	Y	Yes - HFEA	Y	?	Lower BMI limit of 19 - upper BMI range of 30 for NHS patients as set by the Welsh Health Specialised Services Committee
James Cook University Hospital	Middlesbrough	Over 44	Y	Y	Y	Y	Y	Y (clinic site)	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Leeds Centre for Reproductive Medicine	Leeds	Over 44	?	?	Y	Y	Y	?	35
Leicester Fertility Centre	Leicester	No limit (HFEA) BUT clinic website says women must be 49 or under for donor eggs	Y (2) (and on clinic site it says lesbians)	Y (clinic site)	Y	Y	Y (2)	N (2)	NHS patients - Depends on PCT funding criteria Upper limit 30 Lower limit 19'
London Women's Clinic	London	Over 44 - HFEA	Y (clinic site)	Y (clinic site)	Y	Y	Y		Depends on individual cases'
Manchester Fertility Services	Manchester	None	Y (clinic site)	Y (clinic site)	Y	Y	Y	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Midland Fertility Services	Aldridge, West Midlands	Over 44	?	?	Y	Y	Y	?	Approximately 30'
Newcastle Fertility Centre at Life	Newcastle	Over 44	?	?	Y	Y	Y	?	30
Ninewells Hospital	Dundee	40-42	?	?	Y	Y	Y	?	35
Origin Fertility Care	Belfast	No limit (HFEA)	?	?	N	Y	Y	?	33
Oxford Fertility Unit	Oxford	Over 44	?	?	Y	Y	Y	?	N
Peninsular Centre for Reproductive Medicine	Exeter	Over 44	?	?	Y	Y	Y	?	19 to 30
Regional Fertility Centre	Belfast	Over 44 - HFEA (website says female must be under 40 for NHS)	? 'There must be a medical cause of infertility' for NHS funding (clinic site)	? 'There must be a medical cause of infertility' for NHS funding (clinic site)	Y	Y	Y	?	None
The Agora Gynaecology and Fertility Centre	Hove	Over 44	Y (clinic website)	Y (clinic site)	Y	Y	Y	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Hewitt Centre for Reproductive Medicine	Liverpool	Over 44 (HFEA site) (must be before 40th birthday according to clinic site)	?	?	Y	Y	Y	?	According to PCT criteria. Available on request' - HFEA; between 19 and 29 or NHS funding (clinic site)
Hexham General Hospital	Northumberland	N	?	?	Y	Y	Y	?	30 for NHS funding
Homerton Fertility Centre	E9 6SR	Over 44	Y	Y	Y	Y	Y	?	30
Hull IVF Unit	Hull	Over 44 HFEA		Y (clinic site)	Y	Y	Y		35 (30 for NHS)

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
IVF Hammersmith	W12 0HS	Over 44 HFEA site	Y (clinic site)	?	Y	Y	Y	?	N
IVF Scotland	Edinburgh	N	Y (clinic site)	Y	N	Y	Y	?	N
Lanarkshire Acute Hospital NHS Trust	Airdrie	?	?	?	Y	N	?	?	?
Lister Fertility Clinic	SW1W 8RH	Over 44 - HFEA site (but clinic site says up to 50) 'We also treat older women up to the age of 50' http://www.ivf.org.uk/egg-donation/	?	?	N	Y	Y	?	30
London Female and Male Fertility Centre	N6 4DJ	Over 44	?	?	N	Y	Y	?	30
London Fertility Centre	W1B 1QJ	Over 44	?	Y (clinic site)	Y	Y	Y	?	35

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
London Women's Clinic, Cardiff	Cardiff	Over 44	? (but maybe as they offer booklets about lesbian parenting and gay dads?)	?	N	Y	Y		35 and >35 on individual basis
London Women's Clinic, Darlington	Durham	N	? (as above with leaflets)	?	N	Y	Y	?	preferably below 30'
London Women's Clinic, Swansea	Swansea	Over 44	? (as above with leaflets)	?	N	Y	N	?	35
Luton And Dunstable NHS Trust Hospital	Luton	?	?	?	?	?	?	?	?
NewLife Fertility Centre	Epsom, Surrey	N	?	?	N	Y	N	?	N
North Middlesex University Hospital (Reproductive Medicines Unit)	Edmonton, London	N	?	?	Y	N	Y	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Know n donor s	Donor stipulations	BMI limit
Nuffield Health Woking Hospital	Woking	Over 44	?	?	Y	Y	N	?	34.9
NURTURE	Nottingham	Over 44	?	?	Y	Y	N	?	N

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Portsmouth Fertility Centre	Portsmouth	43-44 (document says younger though)	Y (but only if "sub fertile")	Y (but only if subfertile)	Y	Y	N	?	BMI 19-30 for NHS patients having IVF as per SHA criteria; will see and advise regarding lifestyle those outside this range, and can treat privately when BMI greater than 30 if appropriate to clinical needs.'

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Princess Of Wales Hospital (ABM University Health Board)	Bridgend	?	?	?	?	?	?	?	?
Queen Mary's Hospital	Kent	43-44	?	?	Y	Y	N	?	35
Queens Medical Centre Fertility Unit	Nottingham	43-44	?	?	Y	Y	Y	?	N
Reproductive Genetics Institute	London W1G 7BX	Over 44	?	? (though clinic site refers to "couples")	N	Y	N	?	N
Reproductive Medicine Clinic, Bristol	Bristol	N	?	?	Y	N	N	?	30
Reproductive Medicine Unit	London, NW1 2BU	38-39	?	? (though clinic site refers to "couples")	Y	N	N	?	N

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Royal Derby Hospital	Derby	N	?	?	Y	Y	N	?	To access NHS-funded treatment: upper limit of 30 for females and 35 for males
Salisbury Fertility Centre	Salisbury	43-44	?	? (though clinic site refers to "couples")	Y	Y	N	Y (clinic site)	?
Shirley Oaks Hospital	Croydon	43-44	?	?	N	Y	N	?	N
Shropshire and Mid-Wales Fertility Centre	Shrewsbury, Shropshire	Over 44	?	? (though clinic site refers to "couples")	Y	Y	Y	?	30 or lower
South East Fertility Clinic	Tunbridge Wells, Kent	Over 44	Y (lesbians only?) (clinic site)	Y (clinic site)	Y	Y	Y	?	N

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
South West Centre for Reproductive Medicine	Plymouth	Over 44	?	?	Y	Y	Y	?	NHS funding - 29.9 Other - 35
Spire Bristol Hospital	Bristol	?	?	?	?	?	?	?	No donor eggs, only sperm
St Jude's Women's Hospital	Wolverhampton	Over 44 (site says Over 52 for egg recipients) (http://www.stjudeclinic.com/eggdonation-recipient.htm)	Y but possibly only female (clinic site)	?	Y	Y	N	?	30
St Mary's Hospital	Manchester	38-39	?	?(though clinic site refers to "couples")	N	Y	Y	?	19-30
Sunderland Fertility Centre	Sunderland	40-42	?	?	Y	Y	N	?	30

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Sussex Downs Fertility Centre	Eastbourne, East Sussex	Over 44	?	?	Y	Y	N	?	30
Swansea Reproduction Unit	Swansea	40-42	?	?	Y	N	N	?	30
Torbay Hospital	Torquay	N	?	?	Y	N	N	?	N

Name	Location	Age limit	Same sex couples	Single women	NHS-funded patients	Private patients	Known donors	Donor stipulations	BMI limit
Wessex Fertility Limited	Southampton	Over 44	Y but possibly lesbians only (clinic site)	Y (clinic site)	Y	Y	Y	?	35
West Middlesex University Hospital	Isleworth, Middlesex	N	?	?	Y	N	N	?	40
Whittington Hospital Fertility Unit	London, N19 5NF	N	?	?	Y	N	N	?	19-30
Winterbourne Hospital	Dorchester	Over 44	?	?	Y	Y	Y	?	No limit for private patients. For NHS - specific to PCT
Women's Unit, Cwm Taff NHS Trust	Llantrisant, Rhondda Cynon Taff, Wales	N	?	?	Y	N	N	?	30

Table 8 – Additional Comments on Clinics’ Access Criteria

Name	Additional Comments
Assisted Conception Unit Leigh Infirmary	Unclear which donor services available
Assisted Conception Unit Queen Mary's Hospital	Unclear which donor services available
Berkshire Independent Hospital	Seems to only offer gynaecological care, may not be suitable
Beski Women's Care Ltd	No info available
Birmingham Heartlands Hospital	No info available
BMI The Beaumont Hospital	Site suggests DI and egg donation occur at clinic but no further info
BMI The Saxon Clinic	Site suggests no fertility treatment here
Bourn Hall	Partner clinic of Bourn Hall, Cambridgeshire. Extent to which policies linked to those of Cambridge clinic unclear
Bradford Teaching Hospitals NHS Foundation Trust	No info available
Bridge Centre	We do not apply any selection criteria to the patients we treat' (clinic site)
Brighton Fertility Associates	Information unavailable on HFEA site, link to clinic's site broken

Name	Additional Comments
CARE Leicester	Consultations, daily monitoring and injection training are available at CARE Leicester with patients travelling to CARE Nottingham only for egg collection and embryo transfer.'
Central Middlesex Hospital	May only offer gynaecological services
Create Health Clinic	Same as clinic above for all
Epsom and St Helier NHS Trust	Unclear whether offers treatment or only workup
Good Hope Hospital NHS Trust	No children from previous relationships
Guys Hospital	No previous parenting experience by either partner. No previous NHS funded treatment (and/or no more than two previous cycles of treatment) (clinic site)
IVF Wales	Must both be non-smoking; '•For couples – there are no children (biological or adopted) living with the couple and one of the partners has never had a biological or adopted child. For single women – that the woman has never had a biological or adopted child.' (IVF or ICSI); '•Post code in Wales' (DI)
Ninewells Hospital	No children living in the home; unexplained infertility of at least 4 years' duration (Tayside), 3 years for Forth Valley (clinic site)

Name	Additional Comments
Origin Fertility Care	In addition, there are further eligibility criteria in Northern Ireland; for example, priority is currently given to couples without children (whether in their current, or in previous relationships). ¹ - (clinic site)
Hewitt Centre for Reproductive Medicine	Neither partner must have any living children, from either the current or previous ; Sub-fertility must not be the direct result of a sterilisation procedure in either partner (this does not include conditions where sterilisation occurs as a result of another medical problem). Couples who have undertaken a reversal of their sterilisation procedure are not eligible for treatment.
London Women's Clinic, Cardiff	May treat same-sex couples as offers booklets about lesbian parenting and gay fathers (clinic site)

6.2 The Qualitative Study

The interviews and workshop generated data both about the *criteria* that are used to decide how to allocate gametes (for example, age limits and body mass index (BMI) restrictions), and the decision-making *processes* that are used (for example deferring to directors of clinics, or the use of ethics committees). Given that the aim of the study was to determine the basis on which staff allocate gametes between patients, the data presented in this chapter focus on the allocation criteria rather than the decision-making processes. This latter part of the data was explored in an undergraduate dissertation project undertaken by Helen Cartwright, and supervised by myself. The data are presented to reflect the way in which themes arose in the interviews, beginning with basic criteria and then exploring the ethical underpinnings of those criteria. Where appropriate, the relevance of these themes to the broader ethical issues presented in the philosophy chapter (for example, welfare) will be highlighted.

In phase one, the shortest interview was 43 minutes, and the longest was 1 hour and 8 minutes. The median interview time was 56 minutes. In phase three, only two interviews took place, the shorter being 39 minutes, and the longer 48 minutes.

6.2.1 Participants – Phase One

Eighteen interviews were undertaken, because after fifteen, interviews had not yet taken place with participants at a clinic in Wales. Given that the R&D process had been completed for a clinic in Wales, extra interviews were not inconvenient to undertake, and

this allowed for a better geographical spread of clinics. These interviews took place in seven different fertility clinics, rather than the fifteen that were originally planned. Three of the clinics were located in Scotland, three in England, and one in Wales; the difficulty of obtaining timely Research and Development permissions in some Trusts meant that it proved too impractical to include a clinic in Northern Ireland. Five of the clinics were NHS and two were private.³⁴ One of the private clinics was in England and the other in Scotland. Furthermore, one of the clinics in Northern Ireland raised a concern about incomplete anonymisation given the few fertility clinics in Northern Ireland. For this reason, the analysis plan changed so that participants would no longer be identified by geographic region. Ultimately, however, this Northern Irish clinic was not included in the study, as Research and Development permissions could not be obtained within a suitable timeframe.

Not all clinics had particular members of staff with clearly defined roles for allocating gametes, like “egg donor co-ordinator” or “sperm donor co-ordinator”. The participant group comprised the following categories of staff:

Three egg donor co-ordinators

Three nursing staff members

Two sperm donor co-ordinators

Two medical directors

³⁴ In reality, the situation is more complicated than there being discrete NHS and private clinics. Much of the time, privately-operated clinics will treat (a certain number of) NHS patients, and NHS-operated clinics (i.e. ones managed by NHS Trusts) will treat self-funded (i.e. private) patients too. For the sake of simplicity, the thesis will continue to speak of “NHS” and “private” clinics, and this should be taken as a distinction between clinics operated by NHS Trusts and other clinics, rather than saying anything about where the funding of individual treatments comes from.

Two counsellors

Two gynaecologists

One embryologist

One clinical midwife

Two other clinical staff

Fourteen of the staff were female, and four were male.

6.2.2 Participants – Phase Two

There were twenty participants at the workshop, plus seven facilitators. As well as eleven fertility clinic staff members (eight of whom had participated in phase one), the participant group comprised representatives of the following organisations: the HFEA (two participants), the National Gamete Donation Trust (NGDT), Progress Educational Trust, the Donor Conception Network (DCN), and the British Medical Association Ethics Committee. The final three participants were academics from bioethics and social science backgrounds. Seventeen of the participants were female, and nine were male.

6.2.3 Participants – Phase Three

There were three participants in this phase, out of three who were invited. Two were participants from the workshop, and one was a participant who had been invited to the workshop but had been unable to come. The small number of participants in this phase is

explained by its theoretical nature – only those who had been hand-picked as having potentially detailed and important points on particular matters were included, so that '[t]he process of data collection [was] *controlled* by the emerging theory' (Glaser and Strauss, 1967, p. 45). Two of these participants were interviewed by telephone, with each telephone interview lasting approximately half an hour.

6.3 Themes

The philosophical analysis selected allocation criteria that were salient in the legal literature, the philosophical literature, and in the fieldwork undertaken at the beginning of this project. This analysis was in part influenced by practice and informed the topic guide exploring practice. It is perhaps unsurprising, therefore, that many of the themes that arose from the data mirrored those that were discussed in chapter four. Some of the participants' views, however, were quite different to the conclusions in the philosophical analysis: there was disagreement about how age and parental status should be accounted for, and some opposition to a priority system in general with strong support for waiting time to influence selection, as well as opposition to a national waiting list (especially amongst phase one participants). As a visual complement to this chapter, mind maps detailing themes and their justifications are provided below. The mind map for gamete allocation criteria and that for the national waiting list are shown below. A mind map for themes relating to known donors was considered, but there were not enough themes arising relating to this concept for a mind map to be necessary.

Figure 2 – Mind Map (Allocation Criteria)

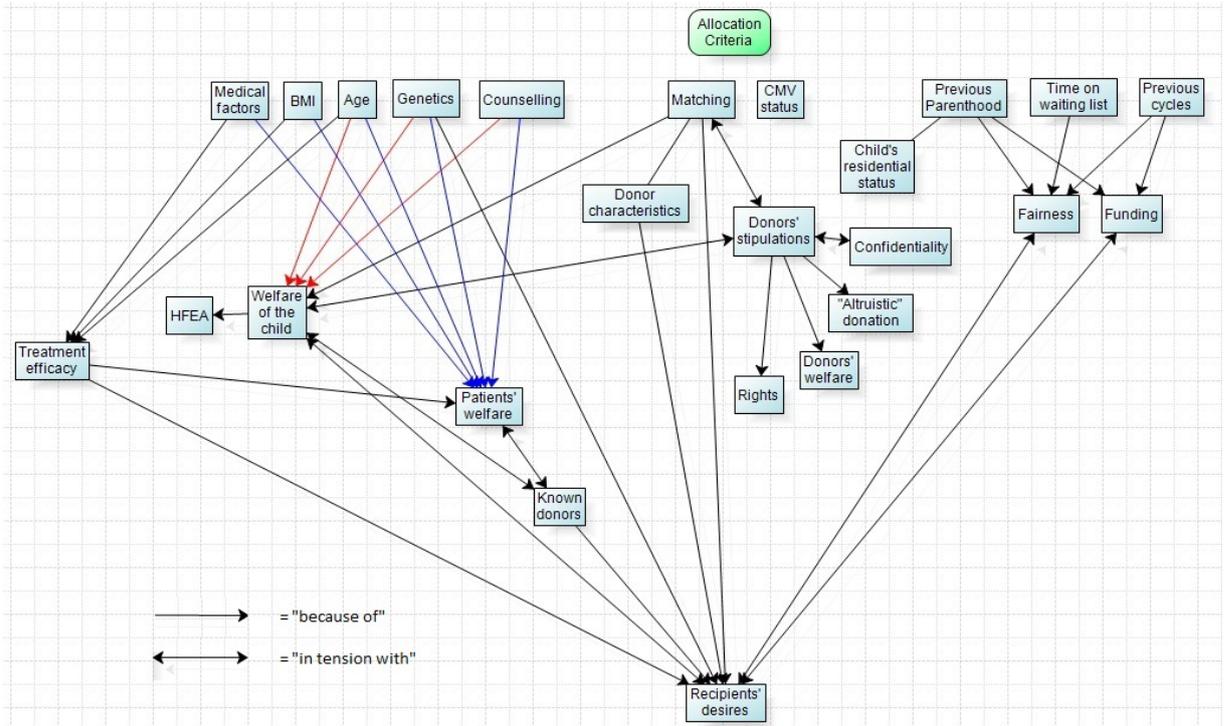
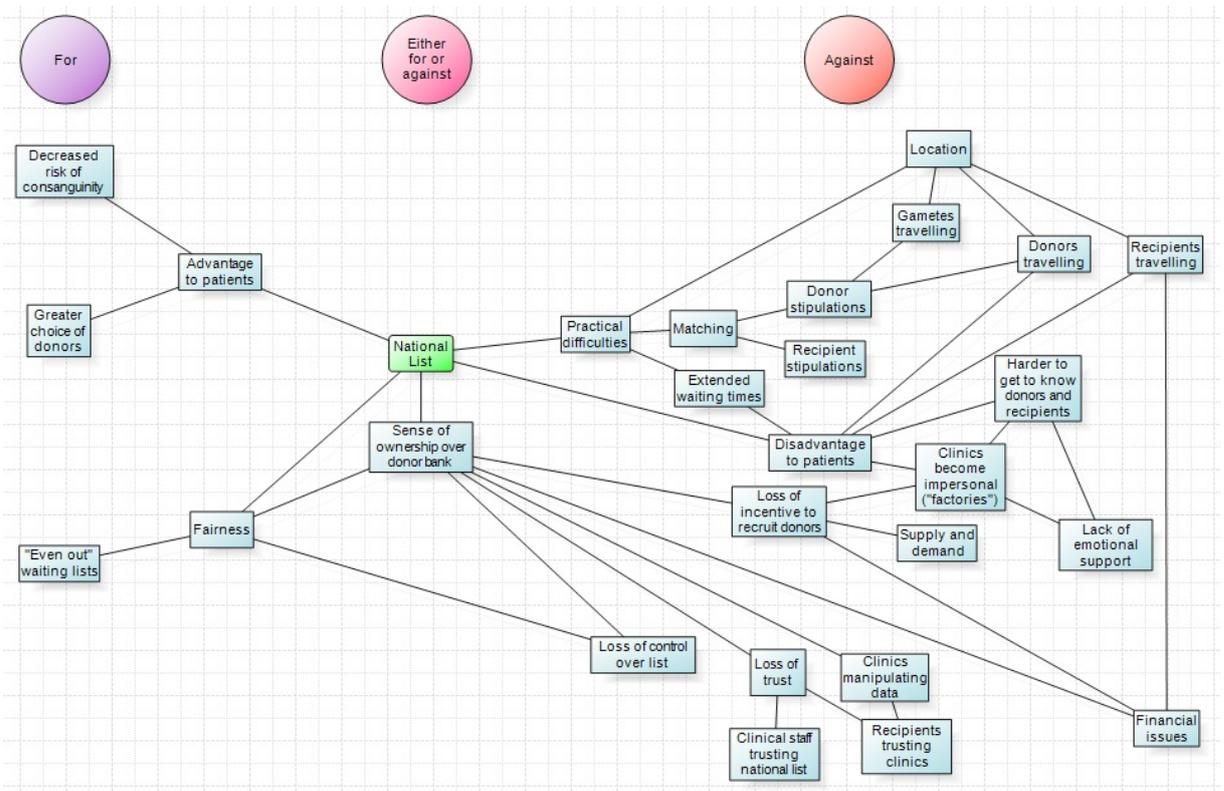


Figure 3 – Mind Map (National Allocation System)



Themes arising included age, body mass index, substance use, time on waiting list, parental status, refusing to treat patients, welfare, violence, same-sex couples, single patients, patient choice (both that of donors and of recipients, including some discussion of matching), known donors, the national waiting list, and the prioritisation system. These findings will now be presented before discussion in the following chapter. As a brief note on style: shorter quotations will be embedded within paragraphs, whereas longer ones will be separated from the main text body.

6.3.1 Age

Most of the participants mentioned age as a criterion for being allocated gametes. In most of these cases, they raised this theme themselves without being prompted. Some participants reported that their clinics imposed an upper age limit, and this often differed according to whether the patient was using donor eggs or was self-funding:

45 for, uh their own eggs, and well it's 44 now actually, and and 50, 50 for donor gametes is generally, most people find that's acceptable (participant 06, phase one)

I think there is an age limit for funded treatment (participant 01, phase one)

One justification for applying an age limit was the importance of protecting the welfare of any child resulting from treatment, with some participants expressing a concern that treatment of older women could result in children with poorer health:

[Y]ou just don't see people being pregnant over the age of really realistically 43 [...I]n your back of your mind you're wondering what will happen in, you know when they are actually pregnant when they get to their antenatal appointments the likelihood of getting a good outcome is slim, you know? I send them away thinking "gosh I hope that baby's not Down's" (participant 07, phase one)

[T]he pregnancy in a woman of age 42 has got associated risks, with uh chromosomal abnormalities (participant 03, phase one)

It is worth noting that these particular welfare of the child concerns would only apply to situations in which a patient's own egg is used, as conditions like Down's syndrome and other chromosomal abnormalities are linked to the age of the egg rather than the age of the recipient. An older patient using her own eggs with donor sperm, however, would still face these risks.

Another participant noted the potential stigma attached to being an older parent, or being a child with (an) older parent(s). Ultimately, however, the participant thought that the decision whether to risk suffering a degree of stigmatisation was the patients' decision to make, so this did not ultimately factor into the *clinic's* decision about whether or not to treat:

Uh, I think if you're fit and well and you go through all the pros and cons of these things, by and large you should be allowed to do as long as it's not illegal, you should be allowed to do what you want to do [I: ok] um. That's my personal view, [I: sure], um. There's the yuck factor of course, you know you're, you're 55 and picking up a, a kid at the school gates, and everyone thinks you're the gran, when in fact you're the mother [I: yeah], there's that but you know society's changing (participant 11, phase one)

In the more general discussion of child welfare that will occur later in this chapter, we will see that there was some discomfort in general about the idea of such social factors being taken into account.

Some of the participants considered yet another reasons for age restrictions:

[T]here are natural pregnancies 48, possibly 47 48, so I think 50 is a, a good time to stop. [...]t's the natural age for your fertility, years of fertility ending anyway' (participant 06, phase one)

This suggests that for this participant, one justification for an upper age limit is to mirror 'natural'³⁵ reproduction rather than to ensure a minimum chance of treatment success.

Another justification offered for an upper age limit was the increased risks associated with pregnancy at older ages: *'[A]s good as we all look these days, you're still 42 years old your organs are still 42 years old, so a pregnancy can be slightly more challenging than if you're 32 years old'* (participant 03, phase one).

Another reason cited for the age limit was the efficacy of treatment:

[T]he age limit has to be linked to the efficacy of the treatment (participant 03, phase one)

³⁵ This might involve "unnatural" processes but still aims at making fertility treatment as close as possible to reproduction outside the clinic.

I think it's more to do with, um, thinking how the patient's likely to respond if they respond better within those [l: right] those kind of age limits (participant 14, phase one)

Participant 03 suggested that providing treatments with a low chance of success could be a 'waste of time', but did not elaborate on this or say anything about *whose* time it would be wasting:

[W]e put guidelines in place for age, BMI, and they are based you'll find evidence as to why you should stop at 42 or 40 or 38, you you will find evidence wherever you go, it's what's your threshold is is 10% a good outcome for a, um, a patient trying to become pregnant? Is 20% that's 10% is it a waste of time? (participant 03, phase one)

One participant felt that the reason for the age limit for NHS funding was to alleviate pressure on the waiting list, and was concerned about the balance between fairness and treatment efficacy:

The older ones have got less chance of conceiving, but if you treat all the older ones the younger ones'll be older by the time they come through [...] so do you target the younger ones with the better success a better chance? [...] for years we treated the same patients again and again, [...] they just kept going, [...] using up all these cycles [...] and the younger ones were gonna be too old by the time they came through. So they brought in the blanket this is the age and the waiting list. They tried, like sort of took quite a bit off the waiting list but there isn't a fair system (participant 12, phase one)

Part of the problem for this participant seemed to be that treating older patients first would be unfair on younger patients.

Participants in the workshop did not appear to object to using age as a criterion for prioritising or de-prioritising patients, except where they were uncomfortable with prioritising patients in general. The age criterion was not a common topic at the workshop, in spite of the fact that it was mentioned specifically in the presentation as something that was a justifiable basis for prioritisation. In the discussion following the main presentation, the presenter commented *'if the waiting list is so short that you would eventually end up treating [all the patients] anyway, then you want to kind of hurry through the older patients'*. Participant 07 (who participated in phases one and two) responded *'older patients, that's right'*, and perhaps this can be interpreted as acquiescence to a prioritisation system that takes age into account for efficacy reasons.

In some cases, interview participants suggested that an older patient could actually be advantaged by her age:

When they're near the upper age limit we'll always try and find them a donor sooner [I: ok] so they might jump the queue [...] because they're, otherwise they would not get treated at all (participant 09, phase one)

The justification for this seemed to be that providing someone with an opportunity to have a child was more important than keeping a strictly "first come, first served" waiting list. This idea was echoed almost exactly by another participant:

Participant 10 (phase one): *We won't automatically put somebody like that at the top of at the top of the waiting list, uh but we would perhaps if, if faced with a similar situation somebody a similar length of time on the waiting list, 32 is is 49 we*

Interviewer: *might give preference to the 49 year old because she only has one opportunity left.*
Yep. Ok. Um, so can you say a bit about what the kind of uh rationale for that is?

Participant 10: *Well purely the fact that um, that she wouldn't have time or the opportunity to have further treatment.*

This participant also said that a patient would not be allowed to queue-jump in this way until they were already at a point where they would receive treatment in the next 6 months. This was the most detailed prioritisation “system” mentioned by any participant.

The prioritisation of older patients was not universally reported or endorsed. Participants suggested that this would justifiably cause annoyance to those patients who were disadvantaged by it: *'I think it's very unfair if you've come to me, put your name on the waiting list, and you've been waiting for 12 months, 16 months, and then somebody else has come on the list and gets treatment before you'* (participant 13, phase one). As the reason given for being uncomfortable with prioritisation was to do with fairness, the participant was pressed by the interviewer with the suggestion that being fair to patients on the waiting list in this sense might compromise fairness in another sense if older women were denied the opportunity to ever have children. The response was:

I would have to say to her that unfortunately because we've got the clinic policy, because I've got a long waiting list I've a lot of people who've been waiting before, the only way she could come to the top of the list was to recruit a donor who would donate to somebody else and she could move to the top (participant 13, phase one)

As the question is about whether the policy is correct, it may be inconsistent to hold the view that a policy against prioritisation is justified in terms of fairness and simultaneously say that any unfairness the policy causes is justified simply because it is policy. This inconsistency demonstrates the complexity of the problems at play here, and the deference to policy may be a strategy for managing these problems.

The response also suggests that fast-tracking can occur if someone brings in their own donor. This will be discussed under the “known donors” heading below (pages 242-248).

Some other participants were similarly unhappy about the idea of prioritising for older age:

Um, no, that wouldn't be fair. Sometimes you know circumstances are really um, hard, you know perhaps they've met late in life, they've had a miscarriage, and there's a lot of extenuating circumstances, um, but we can't move people up, up the list, ... sometimes it's really very hard to, to sit ... with someone and say, I'm sorry but I can't, I cannot move you up the list, um, I know your age I know the history, but um everyone else is, everyone else has a history behind them, and feels it just as important, so I don't think they should be moved up the list because of their age (participant 04, phase one)

This participant also cited fairness as an argument against prioritisation, suggesting that while someone may have a case in favour of their treatment because of older age, other patients had their own histories and cases for treatment too, such that age should not be taken into account.

A different participant was less against the idea of prioritisation, but seemed somewhat conflicted about it. Initially the participant felt that older patients could be

blamed for waiting too long before seeking medical assistance with fertility and thus should not be fast-tracked, as this could be unfair on those beneath them on the list:

[W]hy should someone who's already waited two years be bumped because they didn't go to their GP sooner? Because, people do, some people put off amazing amounts of time before going to the doctor, so really why should they be fast-tracked? Um, but if you had a cancer you'd be fast-tracked. [...] It's a difficult unless they've just met the man, but you know they've put off, and I think part of that is because the way you read or listen to the news, you think clinics can do everything, um, and we can put off all of this and uh, then they'll put it right for us if it doesn't work in the next few years (participant 05, phase one)

When the participant then went on to give reasons for why patients might wait too long, however, this seemed to shift the responsibility away from the patient: *'I think their expectations are wrong. Uh, misled, but again, not really their fault. Uh because the news would make you think that it doesn't matter how old you are'* (participant 05, phase one).

The participant seems to think that considering a patient's responsibility for their circumstances was important, but was unclear as to how this would work.

Participant 06 (phase one) did not seem to like the idea of fast-tracking a gamete recipient because of her age, but would consider it if based on the age of the surrogate being used:

Participant 06: *[C]urrently I wouldn't be looking at fast-tracking anybody, and I haven't done previously [I: right] for those reasons. Not for age anyway.*

Interviewer: *Ok. So there are other reasons that you might fast-track someone.*

Participant 06: *Um, now they did have somebody that we fast-tracked, um, we considered fast-tracking somebody whose mother was going to be, she was going to have donor eggs and whose mother was going to be the surrogate, but the mother was be too old to be a surrogate if we left it too long. This particular patient never came through for treatment in the end anyway.*

Participant 11 (phase one) was against the idea of prioritising as (s)he thought it was unfair on those lower down the list.

[Y]ou're disadvantaging the person who was above you. Directly above you. But in fact, every woman above you you're disadvantaging 'cos you've been fast-tracked. Um, but that's, so no we don't have a fast-track policy. As in as in we won't fast-track. [...] I don't think it's fairer. That's fine, 'cos somebody's been disadvantaged, there's the maleficence side of things (participant 11, phase one)

The participant's mention of '*maleficence*' could be a reference to Beauchamp and Childress's four principles of biomedical ethics, and the participant's interpretation of maleficence is broad enough to include disadvantaging someone by making them wait longer for treatment.

A participant from another clinic also noted an example of someone getting special treatment for being older, though in this case they were not necessarily prioritised over other patients, but rather given an opportunity for treatment even though they had gone over the age limit:

[T]he age criteria, yes we have gone up gone above it very slightly, so we have given somebody who'd hit their 46th birthday, who'd been on my waiting list, a shot at treatment [I: right] with agreement from the director. [...W]hat can you say to somebody who has waited and gone over that magic 46th birthday? (participant 07, phase one).³⁶

In summary, age was a prominent theme in interview discussions of gamete allocation criteria, but participants' views on what the upper age limits should be, and on the precise role age should play in allocation decisions, were mixed. Whilst all participants seemed comfortable with a policy of an upper age limit, there was variation in the cut off age used, and also a variety of different opinions in how flexible those age limits should be. Some participants were happy with the practice of fast-tracking older patients, justifying this judgement on the basis that older patients would miss out on the opportunity to have children at all unless they were fast-tracked. None of the participants mentioned a lower age limit at any point, and although the HFEA Code of Practice states that '[g]ametes for the treatment of others should not be taken from anyone under the age of 18' (HFEA, 2009, section 5.33), there is no reference in the legislation to a lower age cut off for gamete *recipients*, though lack of capacity to consent, and not yet having reached puberty, would be legal and physical (respectively) barriers to treatment of the very young. All of the clinics had a specified upper age limit for treatment. Where participants made the distinction, the upper age limit for the use of donor eggs was usually higher than for treatments using the

³⁶ It is not clear whether this patient was being treated using donor gametes or not. The participant's mention of '*that magic 46th birthday*', combined with her statement that the cut off for treatment with donor eggs is 50, suggests that this treatment was with the patient's own eggs, though she may still have been using donor sperm.

recipient's own eggs, which reflects the fact that the likelihood of success is based in part on the age of the egg rather than the age of the recipient. In terms of the workshop, age was not the focus of much discussion, and nobody took issue with upper age limits themselves, though some concern was expressed about the idea of prioritising patients in general, whether that be for age or any other reason.

6.3.2 Body Mass Index (BMI)

Many participants reported a clearly defined BMI range into which patients needed to fall in order to be considered for treatment. Where this was raised, it was usually raised by participants themselves. This was not discussed in the philosophical analysis, but participants linked it with efficacy: '*BMI is based on success rates*' (participant 07, phase one). This means that the philosophical analysis may still provide direction on this matter, and that it should be added to the list of considerations.

Two phase one interview participants (08 and 11) noted that there were only BMI requirements for patients seeking NHS-funded treatment (both of these clinics treated self-funded patients too). This was likely due to the National Institute for Clinical Excellence (NICE)³⁷ guideline, which states that '(w)omen should be informed that female body mass index should ideally be in the range 19–30' (National Institute for Clinical Excellence, 2004,

³⁷ The acronym "NICE" will be used to cover all incarnations of the organization, and will not distinguish between the National Institute for Clinical Excellence, the National Institute for Health and Clinical Excellence, or the National Institute for Health and Care Excellence.

paragraph 1.10.7.1).³⁸ The BMI requirement was very similar to the age requirement, both in terms of the justifications offered (relating to treatment efficacy and patient welfare), and staff members' attitudes towards flexibility in this requirement, where they would only waive the requirement to be within a certain range if it was a borderline case, and if it represented the patient's last chance for treatment.

The following quotations show that some participants seemed to think that treatment efficacy was an important reason for having BMI restrictions.

[L]ooking at the, the kind of higher, uh body mass index, it's been research that has shown that um, having body mass index greater than 35 um, affects how you're likely to respond to treatment. You're not likely to respond so well, it's a bit more, um, difficult when we're doing, the, um, scanning, and it's also a bit more difficult on the day that you're having eggs retrieved as well, um, it can affect I know it's, it's slightly different when it's donor eggs, um, because the embryos are going back but it can affect the kind of pregnancy side of things as well (participant 14, phase one)

Risks to patients themselves were also noted here where participant 07 mentions 'safety in pregnancy' and 'medical health':

BMI is based on success rates, and also NHS funding, which might be an issue for the patients, they might not want to self-fund treatment, so if they can't afford to don't wish to are only seeking NHS funding, they have to go with the NHS guidelines, which are obviously stricter than the general clinic guidelines, but they're based on success rates for fertility treatment, um, and that is, a partly there is an element of safety in pregnancy, but it's more about success rates for treatment, and there is the things to

³⁸ The 2004 guideline is cited here because these participants were interviewed before the 2013 guideline was published.

do with obviously medical health and having an anaesthetic they're all sort of filtered in to the sort of guidelines that we have (participant 07, phase one)

I think it's more for the surgery side of things, I'd imagine rather than trying to promote a healthy family and things like that, I think it's more for the anaesthetist type kind of things (participant 08, phase one)

As the discussion went on, however, participant 08 (phase one) suggested that perhaps social factors *should* be taken into account:

Interviewer: *[D]o you think there should be an element of promoting healthy families?*

Participant 08 (phase one): *I think probably it needs to move that way, but then at the end of the day I don't know whether is that the responsibility of the clinic? [...] Well I think you're going into the realms then of saying to a patient "oh you can't have treatment because you don't exercise", I don't know if that's morally correct. [I]f two very overlarge people could just get pregnant naturally without our interventioning [sic], they could probably have a healthy baby*

Here we see a tension between the participant's idea that social factors should be considered, and his/her reluctance to refuse treatment on this basis. (S)he also considers the fact that overweight people could reproduce without fertility treatment, reflecting the idea voiced by participant 06, in relation to age, that fertility treatment should mirror reproduction outside the clinic.

This participant suggested that patients would be advised to lose weight in order to improve their chances of successful treatment. (S)he thought that it was good to be flexible with the BMI restrictions, especially if a patient was about to become too old to receive treatment:

If their weight was sort of above the 40 BMI then you've got to be medically you've got to be, but if it's sort of within 35-40, people out there get pregnant anyway at high BMI, so I don't see why I can say no we can't treat you, and be unrealistic about getting their weight down, but obviously I discuss it with other people yes we have BMI limits but if it's somebody's last chance, and they're not gonna lose that weight before they come out of the criteria for age, then we have to be a bit flexible about it (participant 06, phase one)

Here we see an interesting relationship between the age cut off and other criteria: where the age limit is strictly applied, it provides a motivation, for some participants, for allowing treatments that are sub-optimal according to other criteria.

Finally, one participant noted that there was scope for flexibility seemingly regardless of BMI:

[T]here is the odd patient who has been successful and whose weight is very high um, so, occasionally there, there have been agreements to let patients whose BMI has been outside the criteria proceed, but not with fresh treatment, only with frozen treatments (participant 07, phase one)

The significance of flexibility being allowed only for 'frozen treatments' seems to be to do with the availability of gametes. The participant said 'we have recently allowed a patient

whose BMI we wouldn't like to have treatment, but only because, because she has frozen embryos, because it's very clear that she had received treatment in the past' (participant 07, phase one), and so treating a patient who falls outside of the BMI restrictions in these cases does not disadvantage anyone else. In most cases this would likely be with the patient's own gametes.

Overall, then, participants thought that BMI restrictions were mostly related to treatment efficacy, but there was also an emphasis on patient welfare. There was a minor suggestion that creating "unhealthy" families was an issue, but this seemed to be trumped by a general reluctance to tell someone that they are too overweight to have a family.

6.3.3 Substance Use

Another recurring theme in discussion of allocation criteria was substance use and abuse. It was again usually the participants that raised this criterion. Participants' attitudes towards the use of different substances varied. Some thought that anyone known to be using '*recreational drugs*'³⁹ (participant 14, phase one) would not be offered fertility treatment:

[I]f people were, were using recreational drugs and had told us about it then again we would be looking for them to have stopped that before they were going through any treatment. [...] And they would be checking with their GP to see if that had happened and there would be some checks done on that (participant 14, phase one)

³⁹ It is assumed that participants' use of the word '*drugs*' means illegal drugs, and is separate from alcohol and smoking.

[W]e write to the GP to try and get as much information if patients are on um, if indicated they are referred for drug addictions and this is locally, and they have to be clean of urine for one year before they will be accepted (participant 15, phase one)

Other participants reported that drug use might not exclude a patient, but it would be a spur to investigate that patient further. Consequently, being a substance user did not lead to automatic exclusion from treatment, but might lead to more intensive scrutiny by clinic staff.

[I]f any one member of staff feels there's a real reason to call into question treatment, they can call a meeting and ask for it all to be discussed. The final decision might not go their way. But at least it's been broadened it's been examined. To take things to that length we would ask for GPs' input, perhaps even depending if there'd been violence past social work input, if there'd been drugs in the past you know we'd ask for more input [I: yep] before we made any dramatic final decisions, either to treat them or to not treat them (participant 05, phase one)

I think if the doctors had seen the patients and I don't know they've got they were both heroin addicts or something and they had declared it or it's picked up, it gets sent to the ethics committee for discussion and they would decide. You'd like to think that you'd say "oh no, you can't" you can't I don't think you, you like, you can't speak to the patients and say "you're both alcoholics, we're not gonna treat you we can't give you a baby" 'cos you don't know what goes on in their lives, I don't know you'd ever know the facts to be able to make that decision (participant 05, phase one)

[W]e acknowledge that people do take drugs but in fact even someone being a habitual drug user doesn't necessarily mean that you feel that they have a welfare of the child issue (participant 07, phase one)

Excessive alcohol use was noted by some participants as something that could give cause for concern, but was never described as an exclusion criterion, and a strict definition of “excessive” was not offered. Instead there was again a notion that each case would be considered individually, with some participants mentioning that GPs would be consulted. If there were serious alcohol problems reported (such as alcoholism), this would give cause for concern:

I don't think the smoking and the drinking would be so much of a problem, unless it had been reported to us it was, it was excessive, or you know if somebody was um, arriving in to have a scan in the morning and they were, they were finding out that you know they weren't, they weren't quite compos mentis⁴⁰ (participant 14, phase one)

The majority of participants, however, felt that welfare of the child was the main reason for being concerned about substance use, though they did not elaborate on whether the concerns were to do with children's physical or psychological welfare, or both:

[T]hey may be on drugs. Uh, various issues which would make it not in the welfare of the child to be, uh, of the a child born to them (participant 09, phase one)

Similar to drug abuse but certainly alcoholism um would also be a significant welfare of the child concern (participant 10, phase one)

⁴⁰ “Compos mentis” in this context can reasonably be taken to mean not under the influence of drugs or alcohol, rather than anything to do with having capacity.

[A]lcohol abuse drug abuse so anything like that that may impact upon lifestyle and having children (participant 13, phase one)

Participants only occasionally cited pregnancy complications and medical issues (sometimes relating to treatment efficacy) as the reason for concern about substance use, and in some cases this was linked to child welfare anyway:

[I]f the recipients are smoking um, then there is the risk to their own health that you want to reduce as much as possible. And you can't force people to give up smoking. But there's also you know issues surrounding um, children, you want to make them aware, you know, that it's, it's, you shouldn't really be smoking round about children, and you know there might well be a link to asthma in childhood, um, being exposed to, to smoke, so you want to make them aware of that. If they um, were drinking to excess then obviously that could affect them carrying a baby. Um, so you would want to make them aware of that and that would be an issue in that regard, not only regard that they smoked and they drank it was the fact that you know how could it affect their outcome and how could it affect the welfare of the child in the future? (participant 14, phase one)

I would say smoking does affect health, isn't it and if the patients can't help themselves, why should somebody else help them? That's one. Smoking does affect fertility. Yeah. And if they don't want to stop it and help themselves, um, why should you fund a treatment which will be less accessible⁴¹, because of their smoking? (participant 16, phase one)

⁴¹ Participant 16 may have meant “effective” instead of “accessible”.

While many participants acknowledged the welfare of the child-, patient health-, and treatment efficacy-related reasons counting against treatment, this was not considered to be reason enough for automatic exclusion.

Smoking had a similar status, but also occasionally represented an exception, as some participants noted that smoking would automatically exclude someone from receiving NHS-funded treatment:

I think if they're coming um, through the NHS, um I think there might be I think they're, they're not allowed to smoke (participant 08, phase one)

It's really the NHS-funded patients that are disqualified because of that (participant 10, phase one)

Participant 16 (phase one): *Um, say like, if you are a smoker, you're not eligible for treatment. And we might not have come to know about it when they were put on the waiting list.*

Interviewer: *Ok. And is that all treatments or just NHS-funded treatment or?*

Participant 16: *Yeah NHS treatment.*

Like the BMI restrictions, this again may come from NICE guidelines, which state that '[c]ouples should be informed that maternal and paternal smoking can adversely affect the success rates of assisted reproduction procedures' (NICE, 2004, paragraph 1.10.6.2).

NICE guidelines speak against drugs as well as against alcohol: 'A number of prescription, over-the-counter and recreational drugs interfere with male and female

fertility, and therefore a specific enquiry about these should be made to people who are concerned about their fertility and appropriate advice should be offered' (NICE, 2004, paragraph 1.1.9.1). This might suggest that smoking was more of a disqualifier than these drugs, as smoking could be a barrier to receiving NHS funding in cases, where in the case of drugs, only advice is suggested. Given the participants' emphasis on NHS funding here, it is worth noting that being a non-smoker is in some instances only a condition for meeting *funding* criteria, rather than receiving treatment *per se* – a smoker could still self-fund and receive treatment. However, if smoking presents concerns for the welfare of the child, consistency and equality dictate that this should apply to patients regardless of their funding.

Many participants were keen to stress that welfare of the child concerns relating to substance use cut across not just NHS- and self-funded patients, but also patients looking for treatment with donor gametes and those able to use their own gametes, and that there were no differences between their clinic's treatment of these two groups in this regard. Hence, while such lifestyles could potentially create a barrier for patients looking to receive treatment, this would not be specific to treatment with donor gametes. These concerns could apply both to the patient seeking treatment, and to that patient's partner. Treatment efficacy concerns could also apply to the partner, for example in cases where smoking or drug use could damage sperm.

In summary, substance use was often linked to welfare of the child concerns, but participants did not tend to elaborate on what kind of welfare they thought would be at risk (physical or psychological). Some participants were concerned about the effect that substance abuse would have on treatment efficacy.

6.3.4 Time Waiting

Support for waiting time to be considered as a factor in any gamete allocation system was unanimous amongst phase one interview participants. While most workshop participants did not address this question directly, and none of the phase three participants did, those in the workshop that did held the same view as the phase one participants. This means that there is peculiarly little to report on this theme from the data. This concept often arose from the participants themselves, particularly in cases where the waiting list was a simple “first come, first served” system. Whenever this concept arose, participants supported the idea that it should be included as a factor in prioritisation: *‘Waiting time is a legitimate basis’* (participant 19, phase two). Those opposed to prioritisation based on other criteria tended to be in favour of this being used as the *only* relevant factor for allocation: *‘Whatever comes down I will just decide first in that order. I never put one to the top of the pile and think “oh I’ll do this one or that one”, never. As they come down I just decide, I just see everyone exactly the same’* (participant 08, phase one). This general opposition to prioritisation based on other factors will be reported further in section 6.3.13 below.

6.3.5 Parental Status

Another general theme to arise was parental status, sometimes from participants and sometimes after prompting, and the extent to which already having children could count against treatment. Central to these discussions were participants’ individual views on how

“parenthood” is defined, and their perceptions of what the fundamental “goods” of parenthood are.

One participant was adamant that previous children were only morally relevant if they were the children of both members of the couple. For this participant, even if a couple had a child living with them who was born from either member’s previous relationship, this would not count against treatment:

Their own child. And as a couple together, the child. If for example my partner has had children before is fairly irrelevant to me. It’s either their own child, children before, or them as a couple. But not the male partner’s previous children it’s irrelevant. And that’s quite often the situation if there is previous children, um where it will be the male partner’s previous children. Second most common scenario would be that they as a couple together would have had one child perhaps before. I think maybe the female urge to have children is perhaps a bit stronger. I would give preference to that. Or that they want to have children together (participant 10, phase one)

This suggests a view that a woman should be given greater weight than a man, all other things being equal. This would mean that in cases where clinic staff are choosing between treating a couple where the man has previous children, or a couple where the woman has previous children, they should treat the first couple. It is also worth noting that this participant seems to be suggesting that the existing child’s age or place of residence (i.e. whether the child lived with the couple or was an adult that had moved away) is irrelevant.

It is not clear whether this participant meant that the child needed to be genetically related to them, or whether a child born from gamete donation would count as ‘*their own child*’. If genetic relatedness is the driving factor here, then not having a genetically-related

child would be an irrelevant prioritising factor for gamete donation since this treatment would not alter their position of being without a child of their own.

At the workshop, one participant suggested that patients could be allocated different numbers of prioritisation “points” based on how many members of the couple had previous children. So, in cases where there were no children, they would get the highest number of points. In cases where one member has a child and the other does not, they would get fewer points. In cases where they both had children, but not necessarily together as it were, fewer points still. While the participant did not say anything about residential status or how to conceive of parenthood *per se*, his/her ideas represent a system for implementing the consideration of previous parenthood into gamete allocation decision-making.

Like participant 10 above, participant 03 went into some detail about how parenthood was defined:

[F]or couples that don't have their own genetic child, to be denied at least one go at NHS-funded treatment is quite harsh. The way it is at the moment the no child in the home, it's just ludicrous, because you have people say no well but, they'll go and stay with their mother for half the time and, so then where is the child resident? [...W]e've had an example a chap that's had, frozen sperm, prior to chemotherapy but is now sterile, because of the chemotherapy, we've frozen the sample so we can use it for treatment but they have to self-fund it. Because they have a child. That's quite harsh. Because in fact he's sterile (participant 03, phase one)

This participant felt that there were difficulties in assessing what was meant by a child ‘*in the home*’, and that some of the results of this criterion, for example refusing treatment to a sterile person, rendered this criterion ‘*ludicrous*’.

Some participants felt that a genetic connection would not be enough to count as

parenthood, citing sperm donors as an example:

I think we have to keep that quite separate. You, you're thinking of a sperm donor that then goes on to have their own family (participant 03, phase one)

[B]y the letter of the law [the sperm donor] hasn't fathered a child (participant 05, phase one)

There was some agreement at the workshop that it would be '*completely iniquitous*' (participant 26, phase two) to discount patients whose child had died. When pressed, some participants agreed that this suggested that the parenting experience was more important than biological processes like pregnancy or giving birth.

One participant stressed that previous parenthood was only a factor if age was too:

[With younger patients] we wouldn't even look at the children [...] I think if 2 couples, both old age. So if they're both equal in terms of age [I: yeah] but the one has children other one hasn't we will give preference to the one who didn't have, has [I: ok] not had children (participant 10, phase one)

The fact that previous children are only considered if a patient is above a certain age makes this model similar to that detailed by participant 06 above in relation to BMI restrictions being loosened if a patient is older. This might suggest that these participants felt that there was something morally significant about allowing someone the chance to have children before it is too late.

Another participant described the situation in similar terms: *[I]f we don't fast-track [an older patient] she may not get a chance to have a baby at all* (participant 09, phase one); (s)he then went on to say that such a patient would not be entitled to such fast-tracking if they already had children:

[I]f she's come so, she's already got 3 or 4 children, and she's only doing it because she's found a younger, new husband, I will not fast-track at all [...H]er need to have another child is not as high as that of somebody who hasn't got any children (participant 09, phase one)

It is not clear what the significance of the husband's being '*younger*' here is, or whether any previous children of *his* would be taken into account. The '*somebody*' in the next sentence thus seems like it applies to the next patient on the waiting list, suggesting that for this participant, it may only be women's parenthood that is accounted for.

Participant 08 did not seem to think that such fast-tracking applied at all:

I won't prioritise them that. I mean it might I don't know I don't even I think even if we had a sperm shortage I still don't think we'd think oh well they've had children, oh we'll put them to the bottom of the pile, that would just never happen (participant 08, phase one)

With regard to NHS-funded treatment, previous parenthood seemed to present more of an obstacle to receiving treatment. Whilst NICE guidelines do not address 'social criteria for treatment (for example, whether it is single women or same-sex couples who are seeking treatment, or whether either partner in a couple already has children)' (NICE, 2004, section 2,

p. 34), the recommendations from the Expert Advisory Group on Infertility Services in Scotland (EAGISS) *do* address such criteria, stating as a criterion for eligibility for assisted conception ‘No child living with the couple in their home’ (EAGISS, 1999, p. 5). One participant did not see this as relevant:

[I]f it's a partnership that's got together, and one of the partners has children by a previous relationship then, some, primary care trusts won't fund that.' [... M]y thought, that would occur to me, why won't you let if a couple already have a child by a previous marriage why won't you pay for them to have another one? Because the health service is short of money and you've already got one. So we'd prefer to put the money into some that's the way I would see it, into something, more important (participant 01, phase one)

When asked what might be more important, the participant's response was:

I don't know. Treatments for uh, and things that can't be avoided that are not a choice. I think. [...] Cancer treatments, X-ray things that are. If you want a child and you can't have one, it's your choice whether you try for IVF or whether you pay for it or it's funded. If you get cancer, you've gotta have the treatment [I: yeah], no choice, that kind of, that's the way my mind sees it (participant 01, phase one)

Some participants reported that there was a guideline stating that patients could only be treated if they had no children living with them in their home, with one participant (apparently using “slightly” without irony) describing this requirement as ‘*the slightly contentious one*’ (participant 03, phase one).

Overall, the participants accepted the idea of treating patients who already had children, but importantly they were more reluctant in the case of donated eggs (due to the

scarcity).

Some participants felt that previous parenthood should not be accounted for in allocation decisions, and this was often grounded in the idea that all patients should be treated equally in this regard because they all share a *desire* for treatment:

I don't think it matters if you've got one or two kids, if you want one more that's my experience (participant 02, phase one)

I have to respect their wishes, because I'm, um, you, if you saw that someone had a child, you can't say well they've got a child, ah well we'll take this one behind them that hasn't got a child, you can't do that [I: ok], 'cos everyone's on that waiting list for different reasons, maybe a second relationship, it may be that having a second child is just as important if not more important than having a first child, or what however many children (participant 04, phase one)

I don't make any judgement about whether somebody has one child or 10 children, um, it's it's done on their desire. And I don't think it's right to judge whether we should allow patients to potentially have one, two or more children (participant 06, phase one)

One participant raised some specific concerns about the '*child in the home*' requirement, one of which was that this could encourage people to leave their children in order to receive treatment:

[I]f she's had a 17 year old and he's away, there's no child in the home so they get treatment. If she's had a child and given it away to her ex-partner, there's no child in the home. If they've come over from Poland and they've left the children behind,

there's no child in the home, and that definitely seems wrong to me that you've left your child somewhere (participant 05, phase one)

This suggests that this requirement might unintentionally generate tension with clinics' welfare of the child obligations. Alongside his/her concerns about the fairness of this guideline, however, the participant acknowledged that there was a resource scarcity element to it too: *[T]here are some of the guidelines that I know are unfair but I also know there's not the money to treat all these people* (participant 05, phase one).

Another participant thought it should not be the case that a couple whose child had left home could receive treatment when others with a child in the home could not. (S)he stated that given funding restrictions (s)he would prefer a broader conception of previous parenthood that would exclude from treatment those who already have children; resident, genetically related, or otherwise:

[I]f you have a, a couple has a child living with them, no matter how the child came about, if that's a criteria, even if child has left the home [...] I would not want to offer them, 'cos they have enjoyed bringing up a child. [...] So they've had that experience. ... It's better to give that opportunity to someone else who's never had that experience (participant 15, phase one)

This participant thought it would be better if the excluding factor were something like "having previously raised children", which would be more exclusive than the existing '*no child in the home*' criterion. It should be noted that conceiving of the parenthood criterion as "having already raised children" would need slight modification, as it suggests a full parenting cycle, where one can say that the parenting experience has been completed. It

would thus need to be slightly amended, to reflect a present tense “is already raising children”.

The workshop participants had a similarly broad range of views about whether previous parenthood should be taken into account at all, or if it should, how it should be conceived of. Some participants felt that it was legitimate to discriminate on these grounds as a way of negotiating the problem of finite resources. One participant raised the point that someone with previous children was making a more informed decision about whether they wanted to have another one than someone deciding about whether to have a first child, as the latter may have an idealised understanding of what parenthood is like. If the degree of information a patient has is to be considered in weighing up which patients should be more likely to receive treatment, then patients with children have a *pro tanto* advantage over patients without them.

A related link was created between previous parenthood and child welfare when a participant noted that many welfare of the child assessments consider the status of a patient’s existing children (for example, if there has been involvement from social services), and that in this sense, previous parenthood could be used to assess the potential welfare of a future child.

Another point raised by a participant at the workshop was whether it is preferable to be an only child or to grow up with siblings, and that it might be better to give a family another child rather than to create yet another family with only one child. As with participant 05 above, this frames the question of previous parenthood in terms of child welfare (both for the existing child *and* for the as yet unborn child) rather than in terms of patients’ interests. It would provide a reason to favour those who *already have children*,

over those who do not. Hence, the participants' comments show that even if we *can* account for previous parenthood, it is not clear whether it should count in favour of or against prioritisation.

Another important and perhaps more factual point that arose in the workshop is that a patient who has already had children using donor gametes could have more children with the same donor's gametes without necessarily depriving someone else of the opportunity to start a family or to have additional children. There is a limit to how many *families* can be created from one donor (ten) but not on the number of children within those families. Adding more children to an existing family therefore neither precludes another patient from using this same donor to add children to their family, nor does it preclude new patients from using this donor up to the maximum permitted. Accordingly, and particularly in relation to sperm, it can be new donors, rather than gametes, that are in short supply. This is not strictly accurate, as even if this sperm is "assigned"⁴² to a recipient, it may not actually be used. At any rate, when this happens the donor is partially "used up" in the sense that they can only be assigned ten times. The problem of donors being assigned to recipients and their sperm never actually used is a question of logistics and communication between clinics, and these inefficiencies in the system may be a separate question from the ones being considered in this thesis.

In summary, there were mixed feelings between participants, both in the interviews and at the workshop, about how previous parenthood should be interpreted, or whether this should be used at all in deciding which patients should receive treatment. Participants

⁴² Given the HFEA's upper limit of ten families per donor, sperm can be assigned to a maximum of ten different recipients. Such an assignment is sometimes referred to as a "pregnancy slot".

tended to be unhappy with the idea that a child's residential status should be taken into account, especially given the possibility of this conflicting with another child's welfare (if it results in parents abandoning children, for example). Some participants felt that previous parenthood should not be accounted for at all.

6.3.6 Refusing to Treat

The philosophical analysis explored the suggestion that welfare of the child concerns could mean that clinics should take into account what may happen if they *refuse* to treat patients, rather than just what may happens when they *do* treat patients. This was usually raised by the researcher, though one participant raised this issue during a discussion of why clinics would treat lesbian couples or single women. The participant felt that situations where such people were refused could be problematic if they went on to attempt to conceive without the help of a clinic. The participant asked '*is that in the best interests of anybody, not least the bloke who's been duped into being a sperm donor? [...] I'd feel very bad for the bloke*' (participant 11). So, the participant considered that there was potential for patients to deceive others if they perceived this to be their only option for conception. While the participant said that '*we don't have a responsibility for it*' and '*I feel no compunction to stop them doing it if they want to do that*', his/her view was unclear overall, because upon being asked '*is that a kind of contributing factor in the in the sort of desire if you like to treat lesbian couples, to avoid that kind of thing from happening these kind of private arrangements?*', the participant's response was '*I would say that probably is a factor in it*'.

The participant added that there is another reason to treat such couples: '*[T]here's also the safety factor, you go sleep with [have sex with] somebody, you might get Chlamydia, you might give him Chlamydia*'. The participant's concerns were thus twofold in such cases: first, it is not ideal to conceive a child with an unwilling or unknowing man, and second, there are health risks associated with casual sexual encounters. After some probing, (s)he stated that this also applied to heritable diseases: '*[I]f it's an inheritable thing, oh quite definitely yeah, and they're driven by that they don't want to pass on Huntington's or whatever, yeah absolutely of course that would be a motivation*' (participant 11, phase one).

The notion that clinics ought to consider what patients will do if the clinic refuses to treat them was raised at the workshop by a member of the research team. The idea was met with disapproval, on the basis that this responsibility lay with patients, not clinics: '*Patients have got to take responsibility for their own actions*' (participant 22, phase two).

In summary, only one participant in the interviews thought that clinics should consider what might happen as a result of their *refusal* to treat somebody. This participant drew on the problem of genetic diseases, but also the possibility of people making private arrangements to conceive that could result in disease or unwanted (by some parties) pregnancy. Workshop participants disagreed that clinics should take this into account, given the disadvantage to other patients, and because they believed that clinical responsibility did not stretch to encompass *everything* that a patient might do when turned away.

6.3.7 Welfare

The welfare of the child was a consideration with respect to age, BMI, and substance abuse. It was, however, also a concern in its own right, in both interview phases and in the workshop, including how the welfare of children weighed against the welfare of others.

Concern for the welfare of the child was a common theme, occurring repeatedly in all interviews in various contexts, and usually this was raised by the participants themselves. This is unsurprising given its prominence in the HFE Act, which gives clinics a legal obligation to make the welfare of the child a consideration in all treatment decisions. There was thus widespread support for child welfare to be considered, with one interview participant stating that *'procreators owe a duty to the future child to be reasonably assured any such child will have a minimally decent life. I do not think there are insuperable problems in estimating whether any future child will have a life so bad that it should not be conceived'* (participant 32, phase three).

There was, however, disagreement about *how* to account for child welfare. Some participants described the welfare of children as "paramount", which goes further than the HFE Act and echoes the Children Act 1989. The latter specifies how court decisions about the upbringing of children should be decided: *'the child's welfare shall be the court's paramount consideration'* (Children Act, 1989, section 1 (1) (a)). Some participants, however, saw their primary concern being the welfare of the gamete recipients:

[E]mbryo transfers and egg collections could be complicated by pelvic infection, septicaemia and they could end up in death, if a fulminating infection so if you are intervening, and putting a person's life at risk, to get the best benefit then you have

to make sure that the circumstances are justifiable [. ...] I cannot stand and defend myself, having authorised intervention when I knew that the risks are gonna be higher' (participant 18, phase one)

Some hinted that already-existing people (namely patients themselves) were more important than those not yet born or conceived:

[Our specialist obstetricians] also advised us we shouldn't, you know after 40, blood pressure, fibroid, variety of things all plenty of things, postpartum haemorrhage, all that increases so that, that is a bigger concern for us. I think although in the back of mind we have 'older mother how is she going to cope and how much time is she going to get?' You're not going to see them, you know once they're out from here, although that concern is there we're not facing it if you like. So, the welfare of the mother during pregnancy, it's a bigger concern. In the short term (participant 15, phase one)

The addition of 'in the short term', however, makes it unclear as to whether this participant thought that issues in the near future were more important than long-term child welfare issues. This may support the idea their obligations to future and existing children are not clear to staff.

Perhaps contrary to this, participants did not tend to prioritise existing children over potential children. When asked which of the two was more important, one participant commented: *'I would put importance on both of them. I don't spend my life thinking which one's more important than the other'* (participant 05, phase one).

Given the prominence of welfare of the child considerations both in the legislation and in the interviews, it was a subject that was raised at the workshop, both in my own presentation and in discussion groups. Participants were specifically asked about their views

on paramountcy, in order to clarify what weight it should be given. Some participants were clear in their view that paramountcy meant that welfare of the child considerations should be dealt with first, and that once they had been satisfied to a certain (not necessarily maximal) extent, other considerations could come into play. This would suggest that welfare of the child considerations are lexically prior to other considerations.

Some workshop participants were concerned that the welfare of the child stipulation in the HFE Act was being used wrongly. Participant 19 suggested that welfare of the child should only be used to avoid the births of children with severe disabilities or diseases, and should not be used to justify judgements about things like which people would make better parents. The participant disagreed that welfare of the child should be considered paramount in the above way, stating that '*the logical conclusion is unacceptable*' (participant 19, phase two).

This participant argued that patients presenting with other child welfare issues should be treated anyway, and that social services could be contacted later. Many of the other participants appeared to disagree with this, with one describing it as '*totally irresponsible*' (participant 26, phase two). Either these participants felt that such patients should be excluded outright, or that social services should be contacted earlier to prevent the problem rather than clearing up the mess afterwards.

Participant 26's concerns about the use of welfare of the child considerations were, however, echoed by some, who felt that even if there was evidence to suggest that welfare of the child is better secured by some parents rather than others, we may not want to prioritise treatment on that basis. The most popular illustration used in relation to this argument was the patients' financial situation. Whilst there is evidence to suggest that the

financial status of parents could have an impact on a child's welfare, most participants thought that this should not be taken into account when allocating gametes. At the workshop, participant 30's comment summarises this view: *'[T]here's lots of statistically significant features of parents, which may have a big impact statistically on kids' welfare, but would nonetheless be morally repugnant reasons to prioritise people.'* Clearly, for the participants who took this line, other considerations competed with child welfare for paramourcy.

A related concern voiced by one workshop participant was that child welfare as an argument against treatment is used in a way that is *'highly selective'* (participant 29). This participant commented that:

[W]e're going to check lesbians while in fact all the evidence indicates that lesbians are no problem whatsoever, but we never check into the sexual history of all the child abuse of the parents, while in fact we know that there is at least a very high risk that they are going to abuse their own children [...W]hy are we looking at a certain number of things? Because we do not like them. [...]if you're concerned that welfare of the child is indeed paramount then explain to me why these people should have treatment (participant 29, phase two)

The participant's overall point here was that welfare of the child considerations are invoked in some cases and not in others, and that this distinction does not reflect the actual body of evidence about what factors can affect child welfare, but rather reflects the personal preferences of clinical staff.

Hence, the discussions on child welfare created widespread disagreement, both in the interviews and at the workshop. There was disagreement about how welfare of the child

principle should be implemented in general, and disagreement on its bearing in relation to gamete allocation. The data collected presented little evidence that participants thought that already-existing people should be prioritised over those yet to exist, and participants also seemed to think that the welfare of children born of treatment, and the welfare of those affected by the birth, were on equal footing.

6.3.8 Violence

Some participants discussed whether a patient's history of violence could count against their having treatment. Participants tended to raise this themselves. One interview participant cited a case where a patient who had been previously imprisoned for assaulting a child, was given treatment:

[W]e have the welfare of the child of any potential child you know if somebody's already had a history of that, and the people that that spoke against it were very clear that, um, that they felt that he'd done it once and he could do it again [...]. It was a reasoned discussion, as opposed to well I just don't believe that's right, um, on any level. They were involved in all the discussion and they could make a reasoned argument [...] so I think there is a difference from an outright "no" (participant 03, phase one)

In this case there was disagreement in the clinic about whether this patient should be treated. The participant's final statement appears to suggest that an automatic exclusion is not the best way to deal with things, and that each case must be assessed individually.

Another participant at the same clinic referred to ‘*the exclusion criteria of violence*’ and when asked ‘*why do they exclude people based on these things that you’ve mentioned?*’ the response was:

Welfare of the child [...W]e have to take in account, as we’re asked to by the HFEA, the welfare of the child and of any existing children, so you really want to know that if you’re going to these great lengths to help a couple have a child, that that child will have a relatively healthy and safe upbringing. To take things to that length we would ask for GPs’ input, perhaps even depending if there’d been violence past social work input, if there’d been drugs in the past you know we’d ask for more input [I: yep] before we made any dramatic final decisions, either to treat them or to not treat them (participant 05, phase one)

It looks as though for these participants, violence requires concrete evidence if it is to act as an excluder.

At another clinic, a participant mentioned violence but did not go so far as to say how it operated in terms of excluding or counting against patients:

There’s things that are looked at but, but not I mean, you know you’ve got to be realistic about how people live their lives and it isn’t our job per se to intrude on them beyond ensuring that they’re, uh to the best of our ability, that they’re not likely to abuse the you know, abuse their children. [...] And that they’re not violent and they’re not in a discordant you know, or their children or their wife or anything else like that so once you’ve covered that, that’s, that’s as far as it goes (participant 07, phase one)

The participant mentioned, then, that the clinic would try to ensure that people were not likely to abuse the child.

One participant from a private clinic noted that a criminal record for domestic violence (they did not specify whether in the partner or the patient themselves) would definitely exclude a patient:

Domestic violence, um, I think if someone has, if there's if there's significant violence that causes somebody to have a criminal record I think that would be a definitely a, um, disqualifying factor but I think that's probably unlikely, I'm more talking about um, domestic violence and, and um issues of safety of previous children under their care perhaps (participant 10, phase one)

While there seemed to be a difference between clinics about how seriously they took histories of violence, it was at least clear from most participants that concern about violence was predominantly a welfare of the child issue, summed up neatly by participant 02: [W]e don't want to provide another football to get kicked round the family home (participant 02, phase one)

Violence, then, was something that staff generally took quite seriously. In terms of what steps should be taken to discover violence, some participants, questioned how appropriate it was to “intrude” into the lives of patients to try to discover histories of violence.

6.3.9 Same-Sex Couples and Single Patients

There was some uncertainty and perhaps disagreement regarding funding for single women. This was sometimes raised by the participants, and sometimes by the interviewer.

None of the participants reported that their clinic would exclude a patient on the basis that they have come in for treatment as a single woman:

[S]ingle women or same-sex, they're, why should they not be treated? There has to be a very good reason not to treat (participant 05, phase one)

[L]ive and let live [laughs], the if you're a single woman or if you're a lesbian woman and you want a baby, speak to [name], our counsellor, about the implications of these things, and yes we will treat you because the alternative is you go and find somebody on a Friday night and shag them and you don't know what you're gonna get and everything else, you know, so we'll treat you, yeah [note that this response is related to the comment above about clinics taking into account the consequences of their refusal to treat] (participant 11, phase one)

One participant noted a practical difficulty, in that sperm matching was problematic in cases of single women and same-sex couples:

[T]hey're treated um, exactly the same, but in point of view of my donor sperm and everything, um, if anything they're more tricky to um, assign donor sperm because with the um, and the same-sex couples 'cos with heterosexual couples I try and match the um, man's characteristics, um, whereas with the same-sex couple and single women, it's more difficult to assign, because I'm not really sure what they're after, or [l: mmm] not not maybe sure if they know so that's why it's good to give them two choices to consider and think about height, eyes, and hair and so I find that more difficult to assign than the heterosexual couples (participant 08, phase one)

In terms of funding, one participant commented: *[S]ingle women, they're kinda. I don't think they do get treated on the NHS (participant 12, phase one)*. While this clinic might not have a policy of excluding single patients, they might still be excluded from NHS funding

(if this participant is correct about the situation), much like in the case of smoking detailed above. This will depend on local eligibility criteria, and how they interpret infertility (some Trusts interpret infertility as failing to conceive after having regular unprotected sex for a certain time period, which may exclude single women – see (University Hospitals of Leicester NHS Trust, 2011)), because as has previously been mentioned, the NICE guidelines do not comment on social factors such as these. It is interesting to note that this participant was not certain about the funding situation for single women – this suggests that some staff may be uncertain about what the criteria for funding are.

A slightly different funding issue was mentioned by another phase one participant at a different clinic:

Interviewer: *[A]re you saying that single women can't get NHS funding here?*
Participant 14: *Uh, that, I think they now can get NHS funding. I can't tell you for definite if we've had anybody through yet, um but I think they can get NHS funding.*
Interviewer: *Oh ok, right.*
Participant 14: *Um. But I think they still need to pay for their donor sperm*

According to this participant, it may be the case that while these patients can get NHS-funded treatment, they still need to pay for donor sperm, which women in couples may not need to do.

Another participant presented a different view:

Under NHS funding, single women are not eligible [I: right], and the same would apply to gamete donation. Um. And, because I'm a pure NHS employee, I haven't really given a thought to it. Because I've always worked within that constraint that single women are not eligible (participant 15, phase one)

Another participant suggested that there could be a welfare of the child issue at play in treating single women:

Of course I mean you have to look at the stable relationship as one factor, uh if it's a single woman seeking treatment is the child growing or going to grow up in an environment that is, because the child, the Code of Practice, as it evolved, one of the things that the child should grow in a satisfactory environment including the, the need for a father figure in the environment, I mean that was one of the issues, that was in one of the code of conduct, sorry Code of Practice uh documents (participant 18, phase one)

The participant should perhaps be taken as referring to the historical context of the legislation, given the 2008 amendment to the HFE Act that removed the requirement to consider a child's need for a father, or indeed the fact that the NICE guidelines explicitly state that they are not intended to make any comment on single women. Still, this quotation also demonstrates the staff's uncertainty, and that their interpretation of statutory criteria and funding criteria by both clinics and individuals within those clinics can present hurdles for patients.

Most participants considered the treatment of same-sex couples in much the same light as they did the treatment of single women, or of anyone else:

[S]ame-sex couples, not an issue. They would be treated the same as any other couple (participant 03, phase one)

Again if they're covered for welfare of the child, no problems (participant 13, phase one)

It's the same. Just the same for everybody going through (participant 01, phase one)

I'm not aware of any clinic that discriminates people because they are same-sex or single. I thought all clinics [inaudible]. To the best of my knowledge I think most almost every clinic in this country treats everybody (participant 09, phase one)

It is unclear whether participants who referred to “same-sex couples”, meant only same-sex *female* couples. One participant commented that his/her clinic excluded same-sex male couples:

[W]e have something we call a welfare of the child assessment, so unless there is a problem there, we would allow them access, um, the exception to that at this stage in our clinic is um same-sex male couples. [...]it's our policy not to treat them (participant 10, phase one)

While this participant initially separated the exclusion of same-sex male couples from the welfare of the child assessment, his explanation of this exclusion was very much rooted in welfare of the child considerations:

I feel that the presence of a mother is absolutely essential. The presence of a father is not that essential it's preferable, but I don't feel it's essential, [...] so, our policy clinic, uh our clinic policy is not to treat same-sex male couples. [...]his is not a practical problem as in difficulty obtaining. There obviously there would be difficulty like in any donor egg treatment there's always difficulty in obtaining eggs, or and obtaining surrogates, but that is not the reason why we decline the treatment to them. It is more an uh ethical concern than a practical concern (participant 10, phase one)

A participant at another clinic shared a similar view about the effect on child welfare, though it was not merely restricted to same-sex *male* couples:

[W]hat we accept in this society as a norm, there is a mother and a father. And both have their place in child's upbringing. Children I feel, they need their mother more when they're young, I think. But paternal influence is equally important. And I don't quite know how these children cope with, I don't know what happens to them when they go to school. How do they face that? How the other children react to them (participant 15, phase one)

The participant acknowledged that patients could receive treatment with donor gametes as same-sex couples, but expressed concern that a child needs both a mother and a father in order to have a normal upbringing and avoid social stigma.

This theme barely arose at the workshop, in spite of being included in the main presentation. The participants in the interviews often considered same-sex couples and single patients together, and one workshop participant commented that these groups should be treated as distinct groups in discussions about gamete allocation because the concerns surrounding each group are different. While the discussion in the philosophical analysis ultimately concluded that child welfare worries were not sufficiently supported by the evidence for either group, it was argued in the philosophical analysis that patient welfare is an issue that divides single patients and same-sex couples. We thus have both theoretical and data-led reasons to distinguish between these groups.

In summary, there were varying opinions about providing treatment to single patients and same-sex couples. There were some minority concerns that children need both maternal and paternal influences in its early life, and as such it seemed like such participants would favour heterosexual couples, who could provide both of these influences.

6.3.10 Patient Choice

Patient choice was a common theme. Where the philosophical analysis considered this predominantly from the perspective of the gamete donors, the study participants tended to focus on gamete recipients (for simplicity's sake, we will characterise both recipients and donors as patients). This was usually raised by the participants. Many participants emphasised the importance of allowing patients to make their own decisions, and suggested that the role of clinical staff was to advise and inform, not to dictate what patients should do. For one participant, there was a greater emphasis on choice when recipients were paying for their own treatment:

[I]f we said "you should definitely only have 1 back because you're 23 and blah blah blah", people would just be like "I'm paying money here so how can you tell me what I should do?" [I: yeah] whereas if you take a sort of more rounded approach to it you can usually get people to understand the reasoning why you're saying it and it's for their own good and not because you're being mean (participant 13, phase one)

This participant's notion of a 'rounded approach' to advising patients is something that came up in multiple interviews. For some participants, there seemed to be a tension between giving patients the freedom to choose, and the participant's desire to steer patients away from choices that they thought were ill-advised/imprudent. Such a choice was characterised by this participant as one with a low chance of a successful outcome:

[I]t's very sad, some people get really angry if you don't treat them, and make complaints against the clinic, when really you know you're saying that your chances

are so low, you know this is hence the reason why we're, you know perhaps we're not treating you, but donated gametes, that's sort of really the last stop, and if it's their turn, if it's their time to come through, although their chance is maybe low, again who are we to say "no, we're not gonna give you that chance to go ahead with an egg donor"? Because maybe it's that you know a donated egg'll make all the difference (participant 04, phase one)

The above quotation suggests that in some cases a patient would be refused because of a low chance of a positive outcome, but also that it is not the place of staff to refuse people. This further demonstrates the tension between allowing a patient to choose for themselves, and the staff member's desire for the patient to make a certain choice. Participant 13 said '*I don't think it's good to tell people what to do, but you kind of hope*', and this seemed to be the overall response to such tensions: staff would make recommendations to patients, but usually they would ultimately defer to the patients' choices. It is not clear whether there was a distinction between self-funded or NHS-funded patients in this respect.

Other participants were less concerned about patients making choices that may not be in their best interests, and seemed happier to defer to patient choice without feeling this tension. Participant 01 felt that giving patients the choice was the priority, regardless of whether these resulted in interventions with very low chances of success: '*The fact that 2% it's not really a good odds, if they want to basically what I'm thinking is if they want to waste their money, it's their choice. [...]t's up to up to every individual what they do with their own earnings*' (participant 01, phase one).

On a similar note, however, another participant had the opposing view that it would be wrong to take money from patients if their chances were low: '*I don't agree with some that go on and treat people again and again and again, taking their money*' (participant 05)

One participant raised a practical concern with regard to gamete recipients making choices about who their donor would be:

[W]e have 2 red-headed donors, and we can't, they're not very popular [I: right], and so there might be wastage from them but that's, that's, you know we've taken them on, they're good donors, nice people, but that's patients don't choose them. You could say that's wastage (participant 12, phase one)

Overall, then, while some staff may have felt slightly uncomfortable (both for reasons of treatment efficacy and for practical reasons) and attempted to suggest patients take a particular course of action, the choice was usually in the hands of the patient.

This was often the case for gamete donors also: '*[C]ertain, stipulations are fine, um, if they say no same-sex couples, um, no Italians, no Indians whatever. Little stipulations like that you can cope with'* (participant 01, phase one). This participant was happy to allow donors to make *some* stipulations about who could receive their gametes, but expressed concerns that sometimes this made matching too complicated:

But when you get onto got to be married got to have a university degree got to, and it's a little bit too much so, in a way if you get too much leeway. But because donors are so hard to come by, it's basically you gratefully accept what you can get to be honest (participant 01, phase one)

While the participant suggested that donors were allowed too much freedom to make stipulations, (s)he noted that it was necessary to allow this due to the shortage of donors.

In contrast to this, participant 02 (phase one) stated that their clinic would not accept donors' stipulations, but rather take donors in for counselling until they no longer wanted to make such stipulations about the use of their gametes. The participant offered several reasons for this. One issue was that this could have an effect on the child born of treatment. The participant gave an example of a donor who had been refused after requesting that his sperm did not go to a lesbian couple: *'I wanted him to think very carefully about what the effect would be on any potential children who were born, who read that, um, if they themselves particularly did turn out to be gay'* (participant 02, phase one) For this participant there were welfare of the child concerns associated with accepting donor stipulations.

Another concern that this participant voiced was that it might be practically difficult to honour the stipulations, and cited the consequences of a mistake as a serious problem: *'[T]he potential for it going wrong, the potential for it sort of what if we did let slip. Um, oh shit we've let a lesbian couple use this, what do we do about it then?'* (participant 02, phase one).

6.3.10.1 Matching

Related to the concept of patient choice is that of patient matching, which is the process in which clinical staff attempt to allocate gametes to patients who have similar characteristics to the donor. The matching of gamete recipients to donors with regard to characteristics such as ethnicity and hair/eye colour was sometimes the very first thing that participants mentioned when asked about how gametes were allocated in their clinic In some cases, interview participants suggested that this occurred at the request of the

recipients. For example, the comment that red-headed donors are '*not very popular*' (participant 12, phase one), and thus do not get used up even when they are readily available. There are, however, examples to the contrary in the data: '*They have to state on the well they state on the form what they are and I just take yeah the presumption that they will want the same or as close as possible*' (participant 08, phase one). This participant suggested, though, that this was not mandatory, and that recipients could choose if they wanted: '*[A]s long as it was written all on a form I would assign the characteristics they wanted*'. This means that matching was presumed but not compulsory.

To summarise this section on patient choice, attitudes towards *recipient* choice were quite different to attitudes towards *donor* choice. While some participants had some qualms about allowing unfettered patient choice for fear of their making decisions with poor chances of a successful outcome, they felt in general that it was important to respect what the patient wanted. There were mixed views about donors making stipulations, however, and this was sometimes rooted in child welfare, but sometimes in practical views regarding the management of these stipulations within the clinic. With regard to matching, there was sometimes a presumption that recipients would want gametes from people with similar characteristics to them, but it seemed like patients could request otherwise if they desired.

6.3.11 Known Donors

During each interview, participants were asked about their views on the use of known donors. The following is typical of the responses:

[I]t would save them a long wait. We do do that, we do have some cases like that, um, fine, not a problem [...]No problem with it I think the more that could do that, um, would be, probably a good thing. I can't see any reason, anything that's wrong with it
(participant 01, phase one)

One participant drew a distinction between the limitations placed by known donors on who receives their gametes and other stipulations about recipients:

[I]t's ok to say "I just want my family, my my friend to just use this donor sperm." I think there's a very sort of clear distinction between that, um I think there's a big difference from someone saying "oh I'll I only I don't want same sex couples using my sperm" (participant 08, phase one)

This distinction was echoed at the workshop and the nature of the relationship was given as a justification. There was some concern that donors excluding certain groups of recipients could cause offence, particularly to the child who is born, and that this thus represented a welfare of the child concern.

The workshop also suggested that a distinction should be made between donors who are known to a patient and donate *to that patient* (i.e. directly to them or their partner), and donors that are known to a patient and who donate *on behalf of that patient* to another patient on the list, so that the patient they know benefits. This benefit may take the form of

either by receiving gametes from another donor straight away, or by being moved higher up the list.

Another participant felt that allowing known donors could only provide benefits, with no disadvantages to anyone: *'[y]ou know so it is a bit of a win-win if they, if they're on the waiting list and they don't recruit somebody, then you're stood where you are, but if they've recruited the donor you actually move up'* (participant 03, phase one).

Some participants, however, highlighted potential problems with known donation, one of which was to do with social stigma and perception:

[T]here is something perceptual in, in a sister helping a sister, that feels different to a brother being a sperm donor. [I]t is to do with the way that you get sperm, as opposed to the way that you get eggs. [...] I could understand that somebody would quite happily say my sister donated an egg to me, and I think people would, you know that you can't just you know the egg doesn't magically get fertilised in some ways, whereas it comes down to the sperm donation where it is, you know it is possible isn't it, to get pregnant (participant 07, phase one)

The participant seemed to be suggesting that there is a difference between the social perception of a woman using donor sperm from a family member, and the social perception of a woman using a donor egg from a family member. This may stem from the fact that "donor sperm" (of a sort) could be attained outside a clinic through sex (perhaps with connotations of incest if it were a blood relative, or with connotations of one's brother having sex with one's partner), whereas this could not be the case for donor eggs. Such a situation is unlikely but perhaps symbolically compelling for this participant.

Participant 02 (phase one) raised the issue of how known donation would affect families, with the question: *'what's the family dynamics gonna be if it's within the family?'*, though this only slightly hints at what a potential problem might be.

Another participant asked more or less the same question with regard to non-familial known donation: *'they need to be well informed about the possible long term psychological problems, because it's not anonymous and it's not in the family [...] What is the dynamics gonna be between the friends?'* (participant 10, phase one).

Another participant expressed some concern that known donation may not be fully voluntary:

I think a direct donation has a place. I'm particularly happy with that if it's in the family. So a sister to sister donation of egg for example. If it's somebody that was recruited and a direct donation I'm slightly more uncomfortable with that, 'cos there might be some degree of um, what's the right word, um, coercion? Involved there. Um, but we wouldn't, we wouldn't refuse to treat somebody on a direct donation basis with the, with their own recruited donor. But I would want counselling involved very early on (participant 10, phase one)

This participant seemed to think that coercion was less likely with family donation than with donating to strangers.

One participant even cited a case that seemed more like exploitation than coercion:

I have a feeling looking at everything that donor has probably taken undue advantage or, I don't know whether I should use the word "blackmail" but, you know I'm doing this for you, so this donor, I think this recipient broke her bank balance completely because the donor, her children everybody else, every time came she had to put them up in a hotel accommodation, so I have reservations about it (participant 15, phase one)

While these participants were perhaps a little more apprehensive than some others, they would still accept such donations, at least in certain circumstances. The same view came across at the workshop – participants felt that social issues might indicate a need for counselling, or extra counselling specifically targeted at things like identity issues, but in general the participants seemed to think that such arrangements were permissible if these issues were adequately addressed.

In contrast to this, there was one participant who was uncomfortable with the practice of known donation full stop:

I think it is like opening a can of worms or as they say. Um, you know for future of the baby. At least with the anonymous donor, although they can trace, uh the father at age 18, they at least grow up as a donor child, whereas with the known donor I don't know how it works...My concerns. I don't know, it sounds very complicated for me you know. Um, even if he has just provided the sperm and gone away, what the woman is going to tell the child, etc. Mmm, I don't know. [...] I think it's about what relation has this woman got with the man [I: ok] and how it is going to affect the baby (participant 16, phase one)

Another participant also voiced child welfare concerns:

I sit with a couple, and say um, you know, you might have a great relationship with your younger sister now but in 10 years' time but in a fit of pique 'cos you fall out she says that's not your daughter that's mine, genetically that's true, um how do you think the child's gonna feel? And you've gotta be open with the child' (participant 11, phase one)

These concerns seemed to be justified with reference to the welfare of the child principle, due to worries about what the relationship between the child and the donor would be like (assuming it is known to the child that they are donor-conceived in the first place). It is not clear, however, given the last comment about openness, how much these concerns are intrinsic to known donation, or how much they are dependent on the idea of telling the child about their genetic heritage and the problems of secrecy. Secrecy was also mentioned by participant 03, who considered that there could be problems where family members neglect to tell each other about known donation arrangements: *'we all know secrets are very dangerous in families'*. This participant, however, went on to say that *'patients have never come back and said do you know what happened it all fell apart'* (participant 03, phase one), suggesting that, at least in this their experience, these putative problems have never actually manifested themselves.

Participants across all phases were not particularly concerned that using known donors was unfair in any way, and one participant strove to make the distinction between known donors and more general conditional donation: *'I think conditional donation is ethically permissible only so long as it consistent with broadly construed principles of equality and non-discrimination (i.e. I would not allow donation only to a designated ethnic group)'* (participant 32, phase three).

Another participant argued in the context of a stipulation against same-sex couples that the conditional donation could create child welfare issues where the child might be offended: *'there's potential for problems between people regarding welfare of the child stuff [...]What if the child was gay?'* (participant 02, phase two).

Concerns about known donors tended to be about social issues, like the stigma of a woman using her partner's brother's sperm, or about the relationship between the child and the donor. There was also concern about coercion in some circumstances, as in the example of the recruited donor, or the patient who was "blackmailed".

6.3.12 National Allocation System

As with known donors, the concept of a national allocation system was raised (in the interviews) by direct questioning rather than by participants. It was left up to the participants to consider what a national system would look like, but when some of them asked for further information, it was explained to them that it could be a way of equalising waiting times across the country to prevent unfairness in this regard. At the workshop, it was suggested to the participants that a national system could improve fairness for patients.

In the interviews, the idea of a national system for gamete donors and recipients was met with universal disapproval, though some participants were more amenable to the idea than others. The disapproval broadly took two forms, both of which are prominent in the interview data.

The first was practical. Some participants, particularly those who seemed to have more involvement with matching donors and recipients, were concerned that matching was difficult enough on the relatively small-scale basis within one clinic, and so doing this on a larger scale would be logistically difficult, expensive and untenable:

[T]he logistics would be a nightmare (participant 01, phase one)

[I]t would be a huge task [...] I think it would be quite a difficult one to, to manage, and quite big (participant 03, phase one)

Absolutely not, when I see the waiting list I've got here, and matching characteristics with what we've got, it's a minefield (participant 13, phase one)

[T]he expense involved in having this kind of national system (participant 07, phase one)

The second concern was about clinics gaining access to gametes. Participants had a sense that, seeing as they had put in effort to recruit donors, it would be unfair to then reallocate those donors to recipients in other clinics:

[W]e've got enough to supply our own needs [I: yeah] thank you. We haven't got enough eggs but nowhere's got enough eggs. Um, we work damned hard getting eggs as well, um. Will people make as much effort, do you think, if it's a national thing? (participant 02, phase one)

There was a sense of ownership over the donor banks, such that staff did not want to relinquish control over the gametes of the donors that they had put the time into recruiting:

[W]hy should I send my you know we've worked bloody hard, we've put hours into these which is really mean, and small-minded, and I know all this, but you know [...]. Am I gonna hand those nice lads off to [other clinic] who can't be bloody arsed? And anyway, who are making shedloads more money than we are out of the whole deal. Um, 'cos we want to keep our prices down. They don't bother about that, and they're gonna waltz off with my donors? Bugger off. It's mine (participant 02, phase one)

Participant 05 was ambivalent, but ultimately came down on the same side as participant 02:

I don't think I would like it, but equally I don't like the postcode lottery that you can get something one place and not something anywhere else, but that said patients we do very well by our patients here in [name of city] they get 8 cycles of treatment, but we put a lot of work into getting our donors, so I suppose I wouldn't like the idea that nationally I was told I could only give them less treatment, when actually we put a lot of resource into supplying the donors, so I don't think I'd be comfortable relinquishing that, you don't like using the word control but I suppose that's what it is (participant 05, phase one)

There was also a concern that staff liked to get to know their donors, and that this would be more difficult if the waiting list was nationalised:

[W]e've always been very proactive at sperm recruitment and we're also very fussy about donors. [...] We want to get to know them and we want them to get to know us, so yeah we sort of look after them, and because we've got a good relationship going with the current donors, [...] and if I don't like 'em if I can't take to them I'll go on and on and on and on until I know what I'm happy with. [...] I justify that by saying that's my bit of welfare of the child. I have a duty with regard to the welfare of the child if there's something about somebody that puts me off (participant 02, phase one)

It is not clear from the above quotation how this more personalised way of screening donors would impact on child welfare, but the concept of getting to know donors more personally came up often at the workshop. One idea was that staff wanted to personally ensure that if a donor-conceived person (upon reaching 18 years of age) went to meet their donor, the donor would treat them well. Hence, staff members suggested that they wanted to maintain a system where they could personally meet donors, so that if they thought that a donor

might compromise child welfare that far down the line, they could reconsider accepting them as donors.

The idea of a national system generated a great deal of discussion at the workshop. Participants went into more detail regarding the concern about “freeriding” clinics – those that do not make as many efforts to recruit donors benefiting from the efforts of others. There was a suggestion at the workshop that the sharing of gamete donors would require a ‘*cooperative element*’ (participant 26, phase two) that could not exist because of the proportion of donor gamete treatments that are performed privately, by clinics that would be less likely to cooperate with each other.

Workshop participants also expanded on the idea from the interviews about ensuring that donors were ‘*good*’. This was with particular reference to children, as staff seemed to want to be able to personally ensure that if a child went to meet the donor, that donor would act in a certain way.

Practical difficulties were considered too, with some expressing concern about who would take responsibility for regulating the national system, and how this would be funded. The point about difficulty in matching also recurred, and another practical concern came up which pointed out that sperm would be easier to nationalise than eggs, because unlike eggs, sperm can be frozen without efficacy being compromised. This means that sperm can be readily transported around the country, whereas a national egg bank might require moving the donors themselves around (to enable ‘fresh’ donation), which could be costly and inconvenient, for clinics or for donors.

One of the participants in phase three presented a comprehensive strategy for how (s)he thought a national allocation system could work. This participant addressed the

concerns about some clinics freeriding on others and about the inconvenience of moving egg donors around the country. His/her solution to the freeriding issue was to introduce an endorsement scheme, whereby clinics that were good at recruiting donors (and who would supply other clinics with gametes) would gain official recognition for this, and that this recognition could be used to recruit more donors (those seeking to donate would be referred to these centres over other centres). This would encourage clinics to share gametes between them, and may result in the added benefit of recruiting a higher overall number of donors into the system.

[W]e're going to develop donor centres of excellence [...T]he way we try to sell the concept to the clinics is that it will benefit them that they are part of the donor centre of excellence scheme [...!f we get ten people on board who will see their recruitment streamlined and with relatively little effort from themselves see their number of donors go up, [...] other clinics will come on board as well. Admittedly, that's not really ethical for clinics but their motive is commercial (participant 31, phase three)

This participant's suggestion is that clinics are provided with an incentive for successfully recruiting donors, and for passing these donors onto other clinics. If this incentive is sufficient to make clinics share donors, an allocation system could be implemented where donors are allocated to recipients nationally rather than locally.

This same participant suggested that if the practice of freezing eggs were adopted more widely in the UK, this would eradicate the need to move egg donors around the country to allocate them to recipients in different localities:

[W]hat would be an idea is an egg bank. The principle of an egg bank is a very good one. It's been done in some countries. At the moment, the technology or the skills

available in the UK aren't good enough. [...] typically the freezing of the eggs is a problem and the thawing of the eggs (participant 31, phase three)

Freezing the eggs in this way would mean that the eggs could be transported, rather than the egg donors.

In summary, there was very little support for a national waiting list, with most participants expressing concern that it would present practical difficulties. Some participants also expressed concerns about fairness to those who put most effort into recruiting donors, only to lose the resulting gains to other clinics. One participant in phase three, was in favour of a national allocation system, and attempted to respond to the objections put forward by other participants after seeing these objections described and discussed at the workshop.

6.3.13 Prioritisation and Exclusion

Many phase one participants were asked directly about the prioritisation system, though some others mentioned fast-tracking independently of prompting. Some interview participants tended to be unhappy with the idea of prioritising, whereas others noted that certain factors could allow for fast-tracking (as noted, for example, in section 6.3.1 on age). At the workshop, the idea that gametes should be allocated according to a priority system was presented. The workshop generated some discussion about which criteria should be used to exclude patients from treatment altogether, and which should be used to prioritise them. One view was that child welfare should act only as an excluder, so that someone

presenting with child welfare issues should either be excluded if they are sufficiently bad, or otherwise allowed onto the list without this acting against them for allocation purposes.

There were mixed opinions about the prioritisation system in general. Some agreed that it could be acceptable in principle: *'It seems to be unproblematic so long as the criteria for prioritisation are defensible'* (participant 32, phase three).

Others were uncomfortable with considering differences between patients in this way:

[W]ell I think everyone's sort of equal, just because we feel they've got a lower chance than someone that's 25 coming through when who's probably gonna get pregnant first time I don't think we can say they can't use them, I mean everyone should be entitled to use them equally (participant 08, phase one)

I find it difficult when you're saying about prioritising by age and having specifics that you would be excluded people from other than welfare of the child issues (participant 04, phase two)

Workshop participant 04 felt that the *only* reason that someone could be excluded from treatment was for child welfare reasons.

Other participants were more amenable to the idea of prioritisation, with one saying (in the context of treatment efficacy): *'I'm not going to say everyone is entitled to every treatment come what may. I think that's a bit stupid'* (participant 18, phase one). This suggests that this participant may have been in support of excluding for efficacy reasons.

It was suggested at the workshop that patients would not understand why other criteria were being accounted for, but that they *would* understand referral date as a criterion: *'I think patients understand the principle of referral date. They understand "referred on this date", put on the list, then get treated'* (participant 22, phase two).

6.4 Summary

This chapter represents a description and exposition of the findings of the empirical study in three phases, with contextual information provided by a survey of criteria found on websites. In general there seem to be some real discrepancies, both between the policies noted by participants, and in their views about them. Participants reported varying degrees of willingness to consider treating patients other than on a "first come, first served" basis, and different clinics seemed to have different policies on fast-tracking patients who were approaching the upper age limit. Indeed, clinics appeared to have different age limits for treatment, different ways of accounting for child welfare, and different policies regarding factors such as smoking, parental status, and same-sex couples. The attitudes among participants towards these various policies were similarly wide-ranging. The following chapter will consider how these results interact with the conclusions in the philosophy chapter, for example whether there is sufficient rigour in any view to warrant the modification of the theory proposed in the philosophical analysis, or whether there is sufficient strength of feeling to warrant a revision of the conclusions for pragmatic purposes.

7. DISCUSSION

This chapter will discuss the empirical results and assess the extent to which they influenced the philosophical analysis. First, however, it will highlight some of the potential limitations of the empirical study, which must be considered when the data is used to inform ethical theorising.

7.1 Limitations

7.1.1 Other Barriers to Access to Gametes

The study addressed questions of access criteria for fertility treatment at the tertiary level – fertility clinics to which a patient has already been referred, either from a GP at primary care level, or from a secondary care clinic. As Pennings suggested and as was noted above (page 102), the fact that a patient must pass through the system at these levels before reaching the fertility clinic means that they may be selected out or excluded from treatment at earlier stages than this study investigated. A more comprehensive study would have collected data from GPs and staff at secondary level, as they are also potential gatekeepers (i.e. people with some degree of influence over a patient’s eventual access to treatment – this could be in the role of helpers as well as of hinderers⁴³). This is relevant to Pennings’ discussion of the distribution of eggs, where he considers ‘referral for the

⁴³ A GP might help a patient by recommending that the clinic offers them treatment, or hinder them by furnishing the clinic with information that may obstruct their treatment, for example child welfare-related issues.

treatment' as the first of three 'selective steps or stages'. He goes on to say that '[v]ery little is known about the first stage. The crucial player at this point is the general practitioner [...] whose evaluation of the patient as a potential recipient will be decisive' (Pennings, 2001, pp. 56-57). The omission of GPs and secondary care practitioners from the participant group is a relevant limitation of the study's scope. This more limited scope did not have a great deal of impact on the philosophical analysis, however, which in most cases would apply broadly regardless of who the decision-maker is. At the same time, the emphasis on child welfare was derived from the presence of that concept in the HFE Act, which only applies to clinics that are licensed by the HFEA.

The conclusions may have a bearing on policy, which raises a vital point in support of the choice to collect data from tertiary clinicians rather than primary or secondary ones: much of the policy at play in questions relating to gamete allocation will apply more directly to staff at fertility clinics than to GPs or secondary clinicians. The HFE Act, for example, applies only to HFEA-licensed clinics offering treatment. This provides an additional justification for focussing on how tertiary practitioners operate, and what they think. Of course, GPs may *consider* the HFE Act in their decision-making, but they are not legally bound by it as they are not the ones providing fertility treatment under licence from the HFEA. Given time and budgetary constraints (not least of which related to protracted R&D processes) and the discussion of gamete allocation within a particular context (fertility clinics), it made more sense to focus on the group that is more directly affected by this legislation. A study that had also gathered data on how GPs make referral decisions would have provided a more comprehensive account of barriers to fertility treatment requiring donor gametes, but this study had to focus on access to treatment once patients have

already progressed to tertiary level. Research is needed that investigates GPs' and other non-tertiary practitioners' gatekeeping roles more specifically.

7.1.2 Patient Representation

This study did not gather data from patients. The research team decided not to interview patients or invite them to participate in the workshop. This was because given that one aim of the project (and indeed part of the justification for the interview methods used) was to uncover the ethical considerations around certain policies and practices, as identified by clinical staff, it was felt that given the emotional nature of involuntary childlessness, the patient voice may have constrained debate by making interviewers and other participants feel unable to challenge points for fear of causing offence or distress. It was therefore decided that patient representatives would be invited to participate in the workshop and to interviews at phase three, such that some patient views were considered, albeit in a limited way. In the end, the workshop was attended by a representative of the NGDT, and the DCN. Phase three interviews were undertaken with a representative of the NGDT, and one from Infertility Network UK. This allowed patient advocates to advance a generalised patient perspective. It is acknowledged, however, that more patient representation in the design and execution of the study, for example through the use of a steering group, would have strengthened the patient representation in the study, but the interrogative methods necessary to elicit the kind of data this project required made it inappropriate to speak to patients directly.

7.1.3 Further Limitations

Sometimes, interview participants were unable to offer considered responses to the researcher's questions (as noted on page 153 above). This may have affected the quality of their answers, as during an interview there is little time to consider the question, or the reply, in much detail. While attempts were made to anticipate this phenomenon by offering participants the opportunity to read the topic guide ahead of the interview, only one participant accepted this offer. With hindsight, it would have been better to have been more specific and asked the participants to read and consider the questions in advance.

A further limitation is the structure and time constraints of the workshop. Financial constraints only allowed for a one-day workshop, and several presentations needed to be compressed into a single day, the timing of which also needed to permit participants time to travel. Discussions in between presentations sometimes felt rushed, and not every view from every participant may have been explored to its fullest. The workshop groups and phase three interviews served to mitigate this somewhat, but there may still have been participants whose voices were too drowned out even for their views to be heard in the breakout groups or selected for further consideration in phase three.

This chapter will now consider the conclusions from the philosophy chapter in light of the results of the data collection: the two phases of qualitative interviews, and the workshop. The opinions given by the participants are considered in light of the existing literature. Finally this chapter will assess whether and how the conclusions from the philosophy chapter need revision in the light of this comparison.

The structure of the discussion also reflects the move from a general reporting of the results to a more philosophical discussion of what they mean for the final ethical conclusions. It will begin with some discussions about general concepts that connected across all of the themes presented in the results, before moving onto some specific discussion of the themes themselves. Given that one of the major philosophical conclusions to arise from the analysis in chapter four was that a priority system should be introduced, much of the discussion below will consider the themes arising from the interviews in light of the proposed priority system, rather than the more general discussion of each of the themes that was reported in the results (chapter six).

7.2 Fears and Concerns

Despite the fact that participants were not asked to consider and formulate their views ahead of the interview, thereby enabling them to provide more robust and considered responses, the data encouragingly shows that the majority of participants had concerns about at least some of the issues with which they dealt, demonstrating a degree of ethical engagement with their work: they worried about things like child welfare, fairness to patients, and the distribution of scarce resources. This section will discuss the weight that we should attach to the ethical concepts that the practitioners had such strong feelings about, and will ultimately argue that while it can be beneficial to have practitioners who are ethically conscientious, their fears need to have evidential support if they are to be acted on.

The participants' concerns did not always have such support. A good example of this issue is one workshop participant's concern about the use of welfare of the child

considerations being '*selective*' (see page 229). (S)he used lesbians as an example of a patient group that is scrutinised for child welfare issues, while those who have been abused as children are not considered risks to future children by clinical staff, in spite of the evidence that those who abuse children are more likely than not to have been abused themselves (Brown et al., 1998, p. 1066).

The participant's example of lesbians may not be the most appropriate in light of the data in this study, which did not suggest that much discrimination was occurring against lesbian couples. As noted on pages 91-93, however, the issue of lesbian couples' parenting ability was given considerable attention in Parliament in the debate surrounding the 2008 amendments to the HFE Act, supporting the workshop participant's concerns that child welfare concerns in cases of lesbian couples are given undue attention.

The participants may have been appealing to something akin to the precautionary principle (PP) with these concerns. This principle places the burden of proof on agents proposing action, requiring them to demonstrate that a proposed (new) action will *not* cause harm. It is thus a principle of risk-aversion. The acceptance of the PP would relieve clinical staff of the burden of having to demonstrate child welfare concerns – under this principle, a *lack* of demonstrated child welfare concerns for certain patient groups would be sufficient for them to refuse treatment.

There are some problems with this. First, with regard to certain patient groups, there *is* evidence that there are no child welfare concerns. To remain with the example of lesbians, Golombok's studies, as described in the philosophical analysis, did not uncover greater or increased child welfare issues relating to children raised by lesbian mothers. The PP should not, therefore, be used to justify discrimination against them.

In the philosophical analysis, however, it was also suggested that we might extrapolate this data to include same-sex *male* couples, and similarly extrapolate data about single mothers to include single fathers. The PP may not allow this, as there remains the possibility that child welfare would be compromised.

The PP, however, is internally problematic. Holm and Harris, with presumably deliberate irony, recommend that the principle 'be treated with caution'. They note that it 'instructs us to change [the] normal balance by giving evidence pointing in one direction more importance than evidence pointing in the other direction' (Holm and Harris, 1999). Holm and Harris thus point out that the precautionary principle requires us to skew our cost-benefit analyses to avoid risk, and in doing so we forgo potential benefits: 'the PP will block the development of any technology if there is the slightest theoretical possibility of harm', and they rightly describe this as a 'fatal weakness' (Holm and Harris, 1999). By definition, the PP leads to a loss of potential benefits that is disproportionate to the avoidance of potential harm, so it seems irrational to follow this principle.

Another problem with the PP is that it breaches the principle of equality and justice that was a starting point of the philosophical analysis (see pages 32-33). This principle requires that all patients are treated equally until reason is given to do otherwise. The PP would suggest that clinical staff's worries, unsupported by evidence though they may be, could constitute such a reason. To give staff's unjustified worries such weight would be in serious tension with the theory-driven approach to empirical data being adopted in this thesis (see pages 27-28), where participants' views can modify theory but cannot make such drastic revisions to it. The PP must thus be rejected.

This means that there are no theoretical reasons to subscribe to the risk-averse approach that seems to be favoured by some of the study's participants. Pragmatic reasons to consider staff's fears and concerns might persist even in spite of these theoretical shortcomings. It may be the case, however, that once made sufficiently aware of the evidential situation with regard to the specific fears that they have, staff members would be willing to revise their views in line with this evidence. This need for information provides support for evidence-based policy such as the recommendations being made in this thesis.

The PP would require that the concerns of those like the participants in the study are given weight in spite of the lack of evidence supporting those concerns. We have seen that the PP is problematic in itself, and also in serious tension with the principle of equality being employed in this thesis. The argument against the PP thus gives general strength to the conclusions in the philosophy chapter, which considered the ethical status of putative allocation criteria in light of the available evidence regarding those criteria.

7.3 Time Waiting

There was strong support amongst the participants for factoring in the time that patients had spent waiting for treatment. Participants rarely considered what it would be like to have a priority system that took into account multiple factors of which time on the waiting list was one. Where participants opposed the prioritisation system, they felt that a straightforward "first come, first served" system should be used instead, which in effect is a priority system that only accounts for one factor: waiting time. Waiting time was hence the most universally supported criterion for allocation emerging from the data. There exists the

alternative possibility that dispensing with the idea of a waiting list entirely, so that there is no list *per se* but rather a group of people seeking treatment, some of whom will be treated and some of whom will not, may mitigate the feelings of unfairness that some staff experience when faced with the idea of what they see as a “queue-jumping” system. Given the strength of feeling in the data about waiting time, however, it would be unreasonable to assume that clinical staff would be satisfied with this. Further to this, the philosophical literature on gamete allocation supports waiting time as a criterion for gamete allocation: Pennings argues that longer waiting times create psychological difficulties for patients, and represents a way to distribute opportunities equally, though philosophical analysis demonstrated problems with both of these arguments.

Indeed, one of the starting points of this thesis is that a first come, first served system may not account for all of the morally relevant considerations, and section 4.5.5 (pages 105-107) struggled to come up with a justification why time on the waiting list should be accounted for. Characterising it as a fair or egalitarian system was shown to rely on a faulty and incoherent conception of equality, in spite of a strong and possibly culturally-ingrained intuition that treating people in turn is fair. While there may be an argument that having to wait longer prolongs the psychological suffering associated with childlessness, this is undermined by the fact that *all* patients are undergoing this suffering, and so treating someone merely because they have been suffering longer does nothing to reduce suffering in the future, unless of course the suffering of being on the waiting list increases with time. Adding points based on waiting time may then be an unjustified way of making sure that everyone gets a chance at treatment, regardless of how many other factors speak against treating them.

At the very least, this presents waiting time as a candidate for the kind of compromise considered above (page 25), which would re-align the proposed system in this thesis with something more akin to a waiting list rather than an out-and-out priority and exclusion system. Philosophically we might conclude that waiting time is irrelevant, and while the analysis in chapter four presented good reasons for doing this, this may be of no practical use if there is such opposition to excluding it from consideration. A practical recommendation would therefore be that waiting time is included in the priority system, if this makes the priority system more palatable to those who would otherwise oppose such a system entirely. Furthermore, unless two patients are referred to the clinic at the exact same time, accounting for waiting time provides an answer in tie-break situations where an exhaustive examination of all the morally relevant criteria relating to a patient does not give any reason to distinguish between patients. The inclusion of waiting time as a criterion may have an impact on the “effective exclusion” of patients as discussed above (page 106). This is because a patient’s effective exclusion will no longer be as obvious, as even patients who are less suitable than others based on other criteria may receive treatment on account of having waited longer. Nevertheless, these effective exclusions will still be maintained if a patient is given such low priority, based on other factors, that the priority they receive for waiting a long time can never override this. The waiting time criterion will mean that every patient will be ultimately eligible for treatment, but that some will never be treated because by the time they have waited long enough to receive treatment, they will be too old to do so.⁴⁴

⁴⁴ It is worth noting that, if patients are de-prioritised as they age, waiting time would need to be weighted more heavily than age in order to have any effect.

7.4 Prioritisation and Exclusion

One of the major conclusions suggested to participants at the workshop was that clinical staff should prioritise patients based on factors *other* than the time at which they are placed on a waiting list. Much of the discussion below will consider the interview themes in light of the proposed priority system, rather than the more general discussion of the themes that was reported in the results chapter.

In many instances the various criteria that clinical staff can consider when deciding who to treat with donor gametes included some consideration of whether and how patients can be prioritised based on these criteria. Given the acceptance of prioritisation, the discussions of the various criteria in the sections below are directed to answering the following two questions:

- 1) In light of the data collected from the study, is the criterion in question morally relevant such that patients should be prioritised on the basis of it?
- 2) If the answer to question 1) is “yes”, what weight should be given to this criterion, and how is it to be used for prioritisation?

There is, however, a prior question. Before going into the specific criteria and discussing *whether* (question 1 above) and *how* (question 2 above) they should each be used in gamete allocation decisions, it is necessary to consider the argument, put forth by some participants (predominantly in the interviews but also at the workshop), that patients should not be prioritised in this way at all, but rather that clinical staff should make use of *exclusion* only,

but in a specific, limited way. The concepts of exclusion and prioritisation map onto the concepts of access to the waiting list, and treatment once *on* the waiting list: if you are excluded, this means you (at least temporarily) are not listed. Prioritisation is the means of deciding who to treat amongst those who *are* “listed”, i.e. those who have not been excluded. A patient may gain access to the list and then be excluded if new information emerges, but this does not have any substantive effect on the distinction being made here. A common view among participants, both in the interviews and workshop, was that it was legitimate to deny patients access to the waiting list altogether (exclusion), but that once they were on the list, it would be wrong to consider any factors other than how long the patients had been waiting for treatment (prioritisation).

It was suggested in the results chapter that many participants in the interviews and workshop were uncomfortable with the finer-grained prioritisation approach being proposed in the philosophical analysis. This discomfort was based on a desire to treat patients “equally” irrespective of factors other than their time of arrival on the list. Hence, we can fairly interpret this as a suggestion that treating patients on a “first come, first served” basis was not considered by these participants as being a violation of some principle of equality, whereas they would consider prioritisation based on other factors as constituting such a violation. As we saw in chapter four, Pennings and Pattinson *do* consider other factors than waiting time these things to be relevant factors, such that we have a moral obligation to account for them. Given that things like the welfare of children and the effectiveness of treatments have obvious moral value, we must take these things into account.

We do not have to characterise the participants who held this view as ignoring or denying the moral relevance of these other factors altogether. They may think that they

have some moral relevance, but that they are lexically inferior to considerations of equality, so that when these equality considerations are present (perhaps they have to be extreme), they trump whichever other factors might have otherwise been at play, and exclude the participant. There is a tension between equality defined as treating all patients the same regardless of other factors influencing welfare, (the participants' view) and equality taken as a starting point from which we can deviate if given reason to (the view supported in the philosophical analysis).

The participants' invocation of equality as an argument against the prioritisation of patients on the list runs into two problems. The first is an issue of consistency with regard to the reasons for excluding patients. Participants were concerned that everyone should have equal access to treatment, but when it came to factors on the basis of which they were happy to exclude patients, this notion of equal access seemed to lose some of its force. If equality has the trumping status that these participants seemed to afford it in the case of prioritisation, then some justification is needed to explain why equality considerations do not apply when patients are being excluded from treatment altogether (i.e. denied access to the list). The inconsistency lies in the fact that patients are treated differently with regard to their position on the waiting list, seemingly without reason.

For consistency's sake we would need to do one of three things: a) invoke equality in the exclusion cases too, such that we must offer treatment to *everyone* without exception; b) allow that some factors can be taken into account to prioritise just as they can be taken into account to exclude, and that this is true regardless of how far along their fertility journey the patient is, or c) provide a reason to explain why equality considerations trump in some cases but not in others.

Option a) is unacceptable, given that we have already established that there are circumstances in which patients should be excluded (see pages 104-105. Option c) would provide a justification for holding the distinction between getting onto the waiting list and being treated once on the list, but it seems that this difference has no moral relevance that would ground such a distinction. Considerations like welfare or efficacy must apply on either side of this line. Hence, option b), allowing for prioritisation, is the most favourable.

The parallel between this scenario and that of end of life care will help to draw out why there is no morally relevant difference between accounting for criteria before a patient is on the list, and once a patient is on the list. We can consider refusing to put a patient on the list as analogous with withholding treatment, and considering access criteria (with the potential to effectively exclude someone from treatment) once they are on the list as analogous with withdrawing treatment. Vincent, for instance, argues that there is 'no ethical difference' between withdrawing and withholding, because '[i]n both cases, the doctor decides whether to apply the treatment [...] for the next few hours, minutes, or even seconds, regardless of whether the therapy is already applied at the time of the decision' (Vincent, 2001, p. N52). One of Vincent's arguments is that what has happened up to the time of decision-making is irrelevant, and this is consistent with the rejection of backward-looking principles being applied in this thesis. Similarly, it is irrelevant whether a patient seeking donor gametes has already been placed on a list. As long as the system is transparent such that a patient is aware that changing circumstances may affect their place on the list, the moral dimensions of the situation are the same. Indeed, the General Medical Council's most recent guidance on this does not draw a distinction between these two things, as when it considers 'withdrawing or not starting a treatment' (General Medical Council,

2010, p. 9), it places the two in the same category without distinguishing between them. This line of argument acknowledges that whether treatment has yet begun is not relevant to whether there should be treatment or further treatment in the future.

Another option would be not to count equality as a trumping consideration, but to count it as a very weighty one. This might temper the counter-intuitive conclusion above that consistency might require us to treat *everyone*, with no exclusions. Equality might be the primary concern, but if other considerations weigh in heavily enough, they may alter the obligation. For example, a patient may be an avowed child abuser who promises to abuse any child they gain access to. In this instance, welfare of the child considerations may outweigh equality ones.

This is the kind of weighing up system that was proposed in the chapter four, and the only difference between this system and that proposed in chapter four is its emphasis on equality as a particularly weighty consideration. The philosophical analysis established that the welfare of the child is a weightier consideration than equality, so there is no need to repeat those arguments here. It is sufficient to say that the participants in this project's empirical study did not provide any arguments for *why* equality was so important that could challenge the analysis already undertaken, so there is no argument for a modification of the weightings of equality and child welfare that operated in the philosophical analysis. Furthermore, some of the participants accepted the idea of a prioritisation system, so it does not seem that we have a pragmatic reason to compromise in this case either: the opposition to the philosophical analysis's conclusion is present, but may not be sufficient for us to conclude that advocating such a system is unlikely to lead to any change in policy or practice. This response to the data is consistent with the theory-driven approach being adopted here,

in which data must at least illuminate flaws or limitations of the theory if it is to influence it – it is insufficient that contrary opinion simply disagrees with it.

The second issue with the participants' view on equality is that it is not clear whether prioritisation even counts as a violation of equality considerations. This speaks to the discussion in the philosophical analysis about how we ought to conceive of equality in a fertility treatment scenario. For this discussion, let us temporarily disregard the issue that excluding some patients might create inequalities between those who are excluded and those who are not. Hence, for now we will limit our discussion of equality to a discussion of equality *amongst those who make it onto the list*, ignoring those who are excluded altogether.

In this case, it is hard to configure a conception of equality that makes a “first come, first served” system the most equal system. A move like defining a system as equal if it treats everyone in the order in which they arrived would be question-begging. In order to show this, let us consider some of the other ways of conceiving of equality.

We might define equality as every patient having an equal *chance of receiving treatment*. This would mean that from the time that they get put on the list, they are treated just the same as everybody else (for now we will discount other factors like the potentially fluctuating availability of gametes). A “first come, first served” system will not satisfy this notion of equality, because some patients will have a worse chance than others of receiving treatment, for example older patients. This is true given age cut-offs imposed by the clinics, but even if such cut-offs were not in place, the “natural” cut off of age-related decline in fertility means that older patients' chances are worse.

As the philosophical analysis suggests, however, there are more ways to conceive of equality than this, and indeed, this may not be the best one to employ in this circumstance. Giving everyone an equal chance of having treatment preserves equality in one respect, but the actual desideratum for patients is not just to have treatment, but to become parents. Giving everyone an equal chance to become parents would look very different to giving everyone an equal chance to have treatment, as it would have to take into account each patient's prognosis for successful conception, implantation and bringing to term of a pregnancy. For example, imagine there are two patients, one of whom (if treated) is twice as likely to successfully have a baby as the other, and only one of these patients can be treated. Tossing a coin would give them an equal chance of receiving treatment. It would not, however, give them an equal chance of becoming a parent – one patient's chances would still be twice as good as those of the other. To equalise the chances of having a baby, the coin toss would need to be weighted in favour of the patient with the worst prognosis, to factor in the fact that she is less likely to be successful in her treatment.

The weighted coin toss conception of equality is less blunt than the first one described above: treating people equally, irrespective of their prognoses. It is at least sensitive to the value of egalitarian outcomes, and sensitive to chances of success, albeit in the wrong way. The philosophical analysis suggested, contra Harris and based roughly on (though also somewhat divergent from) ideas from Savulescu, that these conceptions of equality are flawed, and that we still have a reason to consider a patient's higher chance of success as a reason for prioritising them, not for *de*-prioritising them. One participant agreed, directly opposing Harris's idea that treatment should be given to all regardless of prognosis: *'I'm not going to say everyone is entitled to every treatment come what may. I think that's a*

bit stupid' (participant 18, phase one – see page 254). The participant thus suggested that failing to account for efficacy, at least to an extent, appears absurd.

The argument from equality thus fails on two counts. First, equality amongst patients must be considered only as one factor among many other important factors. Second, even if equality *is* considered to be the dominant consideration for fertility clinic staff, the most appropriate conception of equality still speaks in favour of prioritising, in order to give everyone on the list an equal chance of having a baby. This means that all of the more specific features of patients that feed into efficacy (for example whether a patient smokes, their age, or their BMI), could be legitimately used to prioritise, *even if* equality (appropriately conceived) was our only concern. Thus, it is not possible to use equality considerations to argue against prioritising amongst patients on the list, without using an implausible definition of “equality”.

A second reason was given for clinical staff’s reluctance to adopt a prioritisation system. This idea emerged quite distinctly in the workshop, and was a more practical rather than theoretical issue, based on the fact that there are certain criteria that medical staff are not qualified to assess and therefore to take into account. This is borne out in the fact that the participants stated a greater willingness to make decisions that one could interpret as being clinical and medical (for example, decisions based on treatment efficacy), and suggested that factors about patients that fed into *these* types of considerations (for example a patient’s age) were ones they could take into account, as they were qualified to make reasonable judgements in this area. Indeed, age is objectively verifiable (or at least more easily so) than many other putative allocation criteria, which may explain the participants’ greater degree of comfort in using it to exclude patients. On the other hand,

participants tended to view decision-making based on things like *social* concerns with suspicion, and some phase one participants felt that meeting a threshold with regard to *medical* concerns was the extent of their remit. This leaves scope for accepting that there could be a threshold for excluding or de-prioritising patients based on social factors, but that they would not, as things stand, feel qualified to apply the criteria. Equally, this argument does not rule out efficacy considerations being incorporated into a prioritisation system, and hence it does not rule out prioritisation once listed.

The fact that medical staff are not qualified to make some of the decisions that should feed into prioritisation does not necessarily address the fact that participants seemed to accept that some patients could be excluded from the list altogether. It could be argued that exclusion criteria and thresholds that the participants might be willing to apply are so extreme that less specialised skill is needed to exclude patients who meet them. For example, one might not feel that it is necessary to be a qualified and experienced social worker in order to judge that the patient who has a history of child abuse and who vows to abuse any child in her care should not be treated. Prioritising one patient over another may, however, be a more nuanced task than excluding individuals who meet extreme criteria. Hence, it is not necessarily the case that if clinical staff are not qualified to prioritise based on social factors, then they are not qualified to exclude using them either.

It is admirable that there was a culture of reluctance amongst the participants to make judgements that fell outside their areas of competence. At the same time, it is not obvious that, when faced with the prospect of making the wrong decision due to incomplete information or lack of adequate/relevant training, it is best to default to a position of doing *nothing* with this information. Given the presumption to treat mandated by the HFEA, it

looks like this would effectively result in patients being automatically treated in cases where staff felt unqualified to make a decision.

The idea that more qualified staff, such as social services should be consulted in advance of listing decisions may have received implicit support at the workshop, where some participants offered this as an alternative to allowing social services to deal with problems once the child has been born. This is consistent with the HFEA's recommendation, in the report of their consultation on child welfare, that:

[Clinics] should collect detailed medical and social information from the patients themselves and they should make enquiries to any individual, agency or authority (such as a GP, social services or the probation service) if the clinic has concerns about information provided by the patient (HFEA, 2005a, p. 11)

This seems like it would secure an adequate balance between ensuring that child welfare standards are met, and avoiding the requirement for clinical staff to act in ways in which they do not feel qualified to act.

This section has suggested that the arguments against prioritisation put forward in the interviews and workshop are not sufficient to justify ignoring considerations that may indeed be relevant. Largely, participants' views reflected those of Harris, when he argues that equality considerations require that every patient gets an equal chance of being treated. Ignoring questions of efficacy in a situation of resource scarcity (as is the case with gametes), however, is not justifiable because to do so will likely lead to a distribution that fails to make the best use of the scarce resource. So even if equality were as weighty as the participants

seemed to think, some limited prioritisation would be justifiable. Either way, there are other considerations outside of equality that are sufficient to motivate prioritisation.

Now that it has been shown that the priority system is at least sometimes justifiable (in spite of the concerns of some of the study participants), the following sections will look at the participants' views on the potential factors that could be fed into a prioritisation system, and consider just how they should fit into it, i.e. *whether* and *how* participants can be prioritised based on these factors.

7.5 Age

The philosophical analysis suggested that it would be justifiable to consider the age of patients as a reason to treat some patients ahead of others, based mostly on considerations of treatment efficacy, and risks to the health of the patients themselves. Some child welfare factors were also considered. In the philosophical analysis it was noted that these considerations were mostly medical; with regard to *social* factors relating to age, it was concluded that there was only limited evidence to justify their inclusion. The idea that older patients should be prioritised because they may not have another chance of treatment was considered to have some intuitive force, particularly in cases where the patient has no previous children. It was concluded, however, that while it may appear that refusing to treat such a patient would be to deprive her of something profound, treating a patient with a worse prognosis than another patient would actually result in more deprivations of the same kind (in situations of resource scarcity). While it may seem, on the face of it, insensitive to refuse treatment to such a patient, more patients may be enabled to become parents if

efficacy is the primary consideration. It was noted, however, that this is in part dependent on the length of the list and the ages of the patients on the list.

In the interviews and workshop, participants' concerns about treating older patients were often grounded in treatment efficacy, which is in line with the work of chapter four. Participants often cited the consideration of treatment efficacy as being important for avoiding the disappointment arising from unsuccessful treatment. In this sense, the participants' views were only partly in agreement with the philosophical literature. Caplan and Patrizio, for example, describe one concern as 'the safety of pregnancy for older women' (Caplan and Patrizio, 2010, p. 281), and while their concern is likely more to do with direct obstetric risks for older women in pregnancy, it is on one level similar to the participants' concerns in that it has the welfare of the mother in mind first and foremost. In sum, while the nature of the risks described by the participants is different to that described by Caplan and Patrizio (with participants describing psychological risk and Caplan and Patrizio describing physical risk), the participants found common ground with these authors in marking out the patient as an important stakeholder, perhaps unsurprisingly given their professional obligations, to 'make the care of [their] patient [their] first concern' (General Medical Council, 2013). The participants were interested in patient welfare issues insofar as they could manifest themselves either during treatment, pregnancy, or after failed treatment. The participants did not express many opinions about age-related ethical issues that might appear after the birth of a child.

One participant (participant 11), however, was concerned about social factors such as stigmatisation amongst older parents, describing the '*yuck factor*' (see page 195) that might be an issue in other people's perception of such parents. This is one of the few

instances in the data of a participant suggesting that the age of the patient may be a *social* determinant of child welfare. Even though this participant raised this as a potential issue, (s)he did not think it was something clinical staff should use as a reason to disfavour older patients in their decision-making. The notion that such issues should not count against older patients is in line with chapter four's conclusion about social factors concerning older parents: while Sutcliffe et al. found that children born to older mothers actually had '*fewer* social and emotional difficulties' (Sutcliffe et al., 2012, p. 4, emphasis added), this study did not account for children over five, for whom other problems may arise, so it was concluded that the data on social difficulties and age provides little, if any, reason against (or for) treatment.

The interview participant felt that the risk of patients or their children facing stigma as a consequence of being an older parent was a risk that parents should be allowed to choose to take, rather than having clinics decide for them. As one need only operate with a bare bones notion of the value of respecting autonomy to think that allowing people to run the risk of minor stigmatisation is their choice to make, the participant's view seems tenable.

As we saw in the results chapter, some participants at the workshop objected to social factors being taken into account *at all*. As this discussion diverges from the issue of age that is currently under consideration, we will consider that problem later in a more general discussion of child welfare (pages 302-309). While Sutcliffe et al. pull us in the direction of ignoring *social* factors when it comes to older parents, their study cannot support the notion that there are no child welfare issues at all in treating older patients, as social issues are not the whole picture. There might still be child welfare risks related to age if we consider obstetric risks to be risks for children too.

With regard to medical concerns relating to age that might compromise or affect child welfare, participants considered conditions like Down's syndrome and chromosomal abnormalities. Again it is important to note that these problems are, strictly, associated with egg age rather than maternal age, and so in terms of gamete donation, they would only arise in cases of donated sperm rather than donated eggs (for simplicity's sake the discussion will not consider the possibility of recruiting older egg donors). The possibility of children being born with such conditions raises questions about the obligations that we have regarding which children we create, and these worries have been voiced by (among others) Savulescu, Mulgan, Pennings, and in a more theoretical way by Parfit.

Participants did not articulate Savulescu's view that there is an obligation to create the *best* children, but many gave the impression that they supported the position that some conditions were worth taking steps to avoid: '*procreators owe a duty to the future child to be reasonably assured any such child will have a minimally decent life*' (participant 32, phase three (see page 226)). In their explanation of the reason for upper age limits, participants suggested that treating older patients (again, with their own eggs) presents a higher risk of babies being born with conditions or diseases; and the implied conclusion is that these conditions or diseases should be avoided. Also, in the discussion about whether clinics should consider treating patients with *genetic* diseases or conditions in order to circumvent the transmission of these to their offspring, one participant agreed that this would be a motivation (see page 225), though others did not think this was a reason to prioritise such patients over others.

This suggests that some participants were agreed that there are, at least in some circumstances, obligations to choose courses of action that will result in healthier children.

They only spoke about diseases or conditions as negative factors, though, and did not enter into any discussion about whether the *best* children should be created, and rather only considered that some types of children should *not* be created.

This is possibly in tension with the conclusion in the philosophical analysis:

4) Patients who can reproduce without donor gametes, but who can only do so at the risk of passing on diseases, should be given some priority on this basis.

Most participants were happy to exclude patients on the basis that they did not meet a minimum standard of child welfare (medically conceived), for example in the Huntington's case mentioned by participant 11. Participants suggested that they would be happy to treat patients with a lower than average outlook for child welfare, as long as they were not *too* low. The conclusion from the philosophical analysis was that fertility treatment should deprioritise patients whose are likely to be born with *any* genetic condition, whereas the dataset suggests that staff may only be comfortable to exclude in order to prevent or circumvent only conditions or diseases that meet a minimum threshold of seriousness. The level of opposition amongst staff here suggests that it may be unlikely for such a recommendation to effect any change in policy or practice. There is thus some divergence between what is philosophically recommended by this thesis, and what is unlikely to actually be implemented in practice, so a more pragmatic set of recommendations might include only a watered down version of conclusion 4), where only the severest diseases are taken into consideration.

Returning to considerations that may be related to age, conclusion 6) was that:

6) Younger patients should take priority over older ones, except in cases where there are so few younger patients that older patients are expected to be treated anyway. In such cases, the older patients should take priority.

Unlike conclusion 4), the impact of the interview and workshop data on this conclusion is less clear. The justification for this conclusion was twofold: first, that older patients have lower chances of successful pregnancy than younger patients, leading to potential gamete/donor wastage, and second, that older patients are themselves under increased physical risk during pregnancy. Let us now consider the participants' views on these ideas.

Participants were moderately concerned about obstetric risks to patients. Their main concern, however, seemed to be the chances of successful pregnancy, but none of the participants felt that the reason for this being problematic was gamete wastage. Rather, and once again likely due to professional obligations, they were more concerned about the psychological welfare of the patient, and the idea that it might be a waste of patients' time and efforts to undergo such treatments if they were unlikely to give the patients what they desired. In case of self-funded treatment, they were also concerned that patients may be wasting their money, and that it would be wrong for the clinic to take money from patients when the chances of success were so low. Hence, the participants' reasons for thinking that efficacy was important were characterised differently to those in the philosophical analysis. The participants' views on this matter can be regarded as somewhat individualistic – they felt that in cases of poor prognosis, patients could be psychologically harmed if treatment

was offered. The philosophical analysis was more ambivalent to the weight given to disappointment, given the possibility that patients may gain the psychological benefit from unsuccessful treatment of having exhausted all possibilities. We do not therefore know whether it is harmful on balance, so as long as any risk of harm is explained to patients, this risk is no reason to deny treatment.

The question of *physical* harm raised by participants was more in line with the philosophical analysis, where phase one participants made it clear that risks to patients would be taken very seriously (pages 151-152). Not all treatments with donated gametes will involve use of the procedures mentioned by participant 18 above, so this may not apply to gamete donation scenarios across the board. As an example, donor insemination does not necessarily require embryo transfer or egg collection, drawing a distinction between procedures associated with egg and sperm donation and receipt. Nevertheless, it remains the case that some procedures are risky and where accompanied with low chances of success for specific patients may result in greater risks of harm than opportunities for benefit, suggesting that they may not, on balance, serve those patients' interests.

While the health risks to patients were acknowledged in the philosophical analysis, the reasons given there for considering efficacy important were more global – the idea was that in order to maximise the number of patients who are enabled to take home a baby, people who have a greater chance of doing so when using the same resources should be prioritised for treatment. Although unfortunate for those with poor chances, the welfare principles being employed in this project require that we satisfy the most people rather than distribute resources equally without regard to each person's ability to use those resources to gain benefit.

The philosophical analysis did not dispute that individual patient welfare is important, and hence the health risks still counted for *something*. This means that the philosophical analysis and the participants' views accorded with each other insofar as they both accepted that harm and benefit to patients is something to account for.

In general there was support amongst the interview participants for the view that efficacy was important. Given the clear connection between patient age and efficacy, then, the data can be interpreted as broadly in support of taking age into account in gamete allocation decisions. Indeed, this is one of the proposed criteria with which the interview participants tended to agree. In terms of the workshop, efficacy was a theme that received a lot less attention, in spite of the fact that the workshop presentation placed emphasis on it in line with the philosophical analysis. Even so, some workshop participants agreed that efficacy was an important consideration.

So far the importance of efficacy, both in itself and as a measure of other important things we should secure (namely the safety of the patient and the child) has been considered, and the conclusion drawn that we should prioritise younger patients in some cases, but not always. Two of the participants in phase one, however, felt that there were other reasons to prioritise older patients, independently of efficacy: '*we might give preference to the 49 year old because she only has one opportunity left*' (participant 09, phase one (see page 198)). We can consider this to be an argument for a different kind of prioritisation based on age, and one that draws upon different values such as the disbenefit of being involuntarily childless. We must now investigate whether concerns regarding these values are sufficient to override the efficacy (and related) concerns that are present when older women are treated.

The view that older patients should be prioritised was echoed by multiple participants, usually by appeal to the fact that this would be the patient's only remaining opportunity to have a child. This would be a good argument if prioritising an older patient with only one opportunity left did not also present a lost opportunity for another patient, who would likely have a better chance of success. This thesis has already argued that, for this reason, younger patients should be prioritised, at least when we expect older patients on the same list never to receive treatment, and this argument about the patient's last chance is in tension with this argument.

There is thus a perception that declining to treat an older patient whose last chance it is for treatment is to deny them a child. In the system being proposed in this thesis, however, age is not a special case, because many people would be denied treatment on the basis that other patients are prioritised ahead of them. The "last opportunity" line of argument effectively suggests that everyone should be given a chance to have treatment. We have already seen the problems with this line of argument, in the discussion of Harris and equality above (pages 115-118). To accept that everyone should get a chance to have treatment would be to unjustifiably disregard all of the other morally relevant factors that are at play.

In conclusion, while some participants in the interviews felt that patients who were approaching their "last opportunity" to receive treatment should be prioritised, the discussion of equality that has pervaded this thesis so far has shown that this argument does not withstand philosophical scrutiny. The main considerations with regard to age, then, are treatment efficacy and obstetric risks. The latter are rooted in the welfare of both the child and the patients themselves. These considerations mean that younger patients should be

prioritised in most cases, except in those cases where treating the older patients first will actually result in a more effective range of treatments (see tables 1 and 2 on page 79).

7.6 Substance Use

Another candidate for prioritisation was the patient's status as a substance user. The priority system would allow for choosing patients based on their status as substance users, to the extent that this status increased the likelihood that they would present welfare of the child or efficacy problems. Hence, much of the discussion from the previous section of this chapter will apply here, and as such there is no need to repeat it. (This also applies to factors like body mass index and smoking.) As noted in the previous chapter, participants' concerns about substance use were based both on welfare of the child and treatment efficacy grounds. The welfare of the child concerns with regard to substance use could have been about either psychological or physical issues. The participants' concerns were broadly in accord with those described in the philosophical analysis, though there was some difference in opinion regarding how seriously these concerns should be taken. Stringent welfare of the child standards were proposed in the philosophical analysis, whereas some of the study participants argued for more lenient standards. With regard to substance use in particular, opinion was quite polarised, so it does not seem like there would be so much opposition that the substance abuse recommendation should be abandoned for pragmatic reasons.

One line of thought from the interview participants was that substance use could not be accounted for, at least with regard to alcoholism: *'[Y]ou can't speak to the patients and say "you're both alcoholics, we're not gonna treat you we can't give you a baby" 'cos you*

don't know what goes on in their lives' (participant 05, phase one (see page 209). The participant's comment about knowing what is going on in the patients' lives may reflect the value of being non-judgmental in lieu of concrete evidence. The suggestion that we should not make judgements on the basis of incomplete information is troubling – arguably we must do the best we can with the information we have. As described in the philosophical analysis, the information that a person has an alcohol problem (we can fairly take the participants' comment to apply to substance abuse too) creates some serious implications for what the child welfare and treatment efficacy situation will be like. Hence, substance use problems cannot be so easily ignored.

The final proposal regarding substance use thus remains the same: we should remain mindful of the potential problems relating to parental substance use, and be willing to take them into account when deciding who to treat. This is consistent with participant 07's view, (page 209), that *'[E]ven someone being a habitual drug user doesn't necessarily mean that you feel that they have a welfare of the child issue'* (participant 07, phase one), as we can acknowledge that such habits do not *necessarily* mean welfare of the child issues, but still consider the fact that they can increase the likelihood of such issues as a reason to de-prioritise a patient.

7.7 Parental Status

Parental status proved to be one of the most complicated and divisive concepts, with little, if any, concordance emerging from the interviews with clinical staff in interviews, or as a result of interaction between participants at the workshop. Where some participants felt

that '*[H]er need to have another child is not as high as that of somebody who hasn't got any children*' (participant 09, phase one (see page 218)), others felt that '*it may be that having a second child is just as important if not more important than having a first child, or what however many children*' (participant 04, phase one (see page 220)). Thus there was disagreement about whether having a first child was more significant than having subsequent children.

One participant went some of the way towards offering a justification for making such a distinction: '*[E]ven if child has left the home [...] I would not want to offer them, 'cos they have enjoyed bringing up a child. [...] It's better to give that opportunity to someone else who's never had that experience*' (participant 15, phase one (see page 221)). This participant offers a reason for prioritising a couple that has not had any children in the past. The assertion made by the participant may hint at the distress-related reason for prioritising childless patients, detailed in the philosophical analysis.

The results chapter reported a potential tension between parental status considerations and securing the welfare of the child. One participant's concern was that the requirement that patients have '*no child in the home*' might encourage parents to leave their children with other relatives, potentially in different countries, in order to qualify for NHS funding for treatment. If this is a welfare of the child issue, and the '*child in the home*' criterion encourages this behaviour, then there is a tension occurring between de-prioritising based on previous parenthood in this way and the duty to secure child welfare. Hence, there is potentially a welfare of the child-related reason to *ignore* parental status in this context.

There may also, however, be such a reason to prioritise based on previous parenthood. Welfare of the child assessments can take into consideration a patient's track record regarding other, already-existing children, such that if a child has been removed from the patient by social services, this may count against the patient's getting treatment. Indeed, some participants suggested that any record of violence to children, regardless of their relationship to the patient, could count against or exclude a patient. If it is the case that a *bad* track record with children can count *against* a patient for treatment, perhaps then a *good* track record should count *in favour of* a patient for treatment. Parental status may be a marker for parenting capacity. This project is challenging the presumption that all patients should be treated solely based on their time on a waiting list, until they give staff a reason to delay or refuse treatment. The project is open to and takes seriously Savulescu's idea that staff have an obligation, in some cases, to do more good than they otherwise could, rather than taking a sufficientarian approach. Welfare of the child considerations thus offer us mixed messages about whether to take parental status into account.

The child welfare issues of the previous parenthood criterion could be dealt with by operating with a different version of it that does not account for a child's residential status. In addition, there is an asymmetry with regard to the track record issue – a person's having a history of child abuse speaks against them, in comparison to other patients, in a way that a person's having a history of being a good parent does not speak for them, in comparison to other patients. This is because in the latter case, those who have not had children have not yet had the chance to prove themselves as parents. There is no evidence that those with children already will make better parents than those who have not yet had this chance.

While opinion on this matter was very much polarised amongst participants in the interviews and workshop, in light of the evidence, provided by Epstein and Rosenberg, 2005 and Greil et al., 2011, that having a first child is psychologically more important than having another child, we should distinguish between patients on this basis. In terms of how parental status should be conceived, it looks as though defining it based on the residential status of the child (i.e. whether they live with the parents) may give rise to child welfare issues, which is a possibility that may need to be investigated further in determining how to conceive of parenthood in this context. Given the earlier discussion that established that the desideratum in fertility treatment is not merely genetic/biological reproduction, but to take home a baby and ultimately have a parenting experience, those who have never had the opportunity to parent should be prioritised, with those with existing relationships with their children given lower priority. The spectrum of relationships with children is large, so clinicians would need to operate using coarse-grained thresholds for practical purposes. This could be determined based on the approximate level of involvement that the parents have with their children, for example how much contact they have with them. Further research could help to determine a consensus as to how close the relationship between a parent and child needs to be before a patient is de-prioritised on this basis, but we can still conclude that, all other things being equal, patients who have enjoyed less experience of parenting should be given priority over those who have enjoyed more.

7.8 Same-Sex Couples and Single Patients

The philosophical analysis concluded that the research into whether children born to single women and same-sex couples are disadvantaged as a result when compared to children born to heterosexual couples could find no evidence of disadvantage. Not only is it crucial to an impartial ethical framework that we do not discriminate against anyone without a morally relevant reason for doing so, it is made explicit in the HFEA Code of Practice: '[i]t is presumed that all prospective parents will be supportive parents, in the absence of any reasonable cause for concern that any child who may be born, or any other child, may be at risk of significant harm or neglect' (HFEA, 2009, section 8.11). In light of the lack of evidence about a child's need for two opposite-sex parents (see pages 91-93), it does not seem that the participants' views constituted the reasonable cause for concern required by the HFEA.

Participant 10 (phase one)'s statement that his/her clinic would not treat same-sex male couples may at first come across as discriminatory based on sexuality, but the participant's explication of this shows that this policy actually discriminates based on *sex*. While the concept of *single* male patients was never mentioned, the ethical justification of the policy offered by the participant was that children need a mother.⁴⁵ Hence, the clinic would presumably refuse to treat single males, too. Similarly, the participant singled out same-sex *male* couples, implying that they would treat lesbian couples. This participant's comment suggests the additional consideration that the sex of putative parents is morally

⁴⁵ Given that the term "mother" was used as a justification for refusing to treat any male couples, we can reasonably assume that it is a term meaning "female parent" rather than referring to a kind of parenting role.

relevant. This bears on both single patients *and* same-sex patients, but not in cases where a female will raise the child. The concept of the relevance of the sex of patients thus falls under the theme of “same-sex couples and single parents” because only members of these groups could be affected. Not *all* members of these groups would, however, be affected – it is actually men in general who would be discriminated against by the policy outlined by this participant, rather than just gay men.

It may be that the view about children’s need for a mother was partly influenced by the 2008 change in legislation. Where the 1990 HFE Act states that staff must account for ‘the need for a father’ (HFEA, 1990, section 13 (5)), this was changed in 2008 to ‘supportive parenting’ (HFEA, 2008, section 14 (2)), acknowledging that previous legislation had discriminated against lesbians and single women without justification. In short, the need for a father (or a male parent) had been assumed rather than demonstrated. The idea that the sex of parents is relevant may lead to a perception that a *mother* is the essential factor in parenting, rather than a father, suggesting a potential misinterpretation of the rationale for the change in legislation. In light of the evidence on same-sex parenting, this perception also seems to rest on an assumption.

There are social reasons to be explored here as well, though. If a father is more likely to become absent than a mother, then this may give rise to specific legislation for clinics to consider this as a possibility, rather than suggesting that a father is more important than a mother. Similarly, given the technical difficulties in treating single men or same-sex male couples (as they require a surrogate), and the relative infrequency of surrogacy arrangements in 1990 compared to today, it may have been unnecessary to legislate for the child’s need for a mother, as in the vast majority of cases treatment would be being given to

a woman. Regardless of how notion of a child's needing a mother came about, the evidence does not support this view, as would be required both by a suitably impartial and non-discriminatory ethical framework, and by the Code of Practice.

Most of the other interview and workshop participants had no problems with the idea of treating same-sex couples or single patients, though it is possible that they did not consider single men. Participants in any phase were not asked specifically about conclusion 11, which suggested that couples should be prioritised over single patients. This was based on the argument that it provides greater patient welfare by helping two patients rather than one. Given the general willingness to avoid discriminating against single patients, however, we can imagine that there would be initial opposition to this conclusion. In addition to this, the recent change in legislation, removing the stipulation for the need for a father, better accommodates single women (alongside lesbian couples). During the parliamentary debate surrounding this change, one of the arguments for it, advanced by Emily Thornberry, was that it would make clearer that these groups should not be discriminated against:

If there is a lack of clarity in the current law, we have an opportunity to sort it out today. If we were to confirm the need for a father, [...] there would be increased confusion – or worse, no clear law at all. Many hospitals would have eligibility criteria for IVF treatment as explicit as that published in Birmingham (HC Deb 20 May 2008, vol 476, col 176)

This may make it unlikely that the suggestion that single patients should not be treated will be implemented in practice. At any rate, the conclusion has theoretical justification, independently of these arguments based on non-discrimination, in terms of its providing additional welfare benefits for use of the same gametes, so while it is included in the final

conclusion set, it is not expected to gain any practical ground, though some may be amenable to the idea that patient welfare is improved by offering treatment more parents rather than fewer.

In conclusion, somebody's status as a member of a same-sex couple does not provide enough of a reason to distinguish between them in terms of the priority system, as is required by the principle of equality being used here. This means that this is not a criterion that staff should take into account in their decision-making. The reasoning that has led to this conclusion will have some bearing on the arguments on known donors (below), as we will once again fall back on the line of argument that without sufficient reason to discriminate against a certain group or forbid a certain action, we should not do so. The argument against treating single patients remains philosophically supported.

7.9 Patient Choice

7.9.1 Matching and Recipient Choice

Participants rarely considered matching an ethical issue in its own right. Instead, it tended to arise in the context of other discussions. For example, participants sometimes cited the difficulty of matching as a problem associated with the treatment of same-sex couples, or as an argument against the introduction of a national waiting list. It is unclear from the data whether the staff operated under the presumption that matching these physical characteristics was desirable (such that its importance outweighed the benefits of

such things as a national list), or whether matching occurred at the request of patients themselves.

The presumption of matching physical characteristics was formerly recommended by the HFEA in the Code of Practice, but was removed after the 6th edition (HFEA, 2003, p. 32). The HFEA later stated that '[t]here is little evidence available about the value or effectiveness of donor-recipient matching, particularly in relation to the welfare of resulting children' (HFEA, 2005b, page 8), so if there is a presumption to match in clinics today, it is something of a "hangover" from guidance that no longer exists. If clinics automatically match patients based on physical characteristics, this could be ethically problematic, as they may disadvantage certain patients by assuming that they should have a certain kind of donor. For example, if gametes from black people are rare, a black couple may be disadvantaged if they are made to wait for sperm from a black man, on the presumption that they would not or should not use sperm from a man with an ethnicity that would make the child look ethnically different from his/her parents.

Some participants suggested that matching at least sometimes occurred at the request of the recipients, for example stating that red-headed donors were '*not very popular*' (see page 240). In such cases, matching is less morally problematic, because patients create the disadvantage⁴⁶ for themselves by making stipulations, rather than having disadvantage imposed on them by the clinic's allocation system. There was, however, one case where matching would be automatic unless the patient requested otherwise (see page 242). If a

⁴⁶ Of course, a patient may not view this as disadvantage if they do not want gametes of a particular kind. For convenience's sake, however, this discussion will continue to speak of this as "disadvantage" from the perspective of their attempt to access treatment.

patient is unaware that this matching is taking place, then they could be disadvantaged if the gametes relating to their ethnicity are rare. It is thus appropriate to ensure that those on the waiting list are given sufficient opportunity to express their desires with regard to matching, so that they are not unduly disadvantaged in this way.

The suggestion of this section is thus that the presumption of matching should be done away with altogether. It is unclear that children or their families are worse off in cases where children do not look ethnically similar to their parents. If recipients *want* donors who are matched to them, this may provide a reason to seek ethnic matching, but otherwise there seems to be no justification for doing this. It should thus not be assumed that patients want donors whose characteristics physically match their own. Instead, they should have these options discussed with them in the name of transparency.

7.9.2 Donor Choice

The participants in this study expressed two concerns about donor choice in the interviews. The first was a practical one, regarding the increased difficulty of finding suitable recipients for a donor's gametes if the donor chose to place stipulations on who could receive their gametes. This practical concern is not addressed in Pennings' argument, but should be taken into account if it exists.

The second issue, raised by participant 02 (phase one – though (s)he discussed it again during phase two), was one regarding the welfare of the child to be born as the result of treatment. This participant was concerned that if a donor decided to exclude, say, lesbian parents from being recipients of his sperm and the resulting child turned out to be gay or a

lesbian, the donor's stipulation, if discovered, might cause the child some upset and distress. We can generalise this case and say that the concern is that if a child turns out to be a member of any group against which the donor has discriminated, that child may experience distress at being the genetic offspring of somebody who would discriminate against people of the same type as them.

Another point on this matter is the question of how seriously this compromises the child's welfare. There are two elements to this point: first, there is the question of whether such stipulations compromise child welfare so much that the child should not exist. Importantly, child welfare considerations arising from donor stipulations are unlike other child welfare considerations, because in these cases we are not comparing the welfare of that child with another child that could be born in its place. If these are true stipulations, then we are to imagine that the donor will not donate unless (s)he is satisfied that they will be upheld. This means that the child either comes to be, or no child does.

Now we are in a win-win situation, because even if, for theoretical reasons, we cannot make a comparison between a person's life if they were to exist and their life if they were not to exist, so much the better: we cannot say it would be better for the child not to exist, so the stipulation can go ahead. If we *can* make this distinction, then it is unlikely that a child who is offended by the stipulations of their donor would have such a low quality of life that they would be better off not existing. Both of these conclusions suggest that we should just accept the donor's stipulation.

The second element regarding the claim that donor stipulations might affect child welfare is a less theoretical, empirical one: we do not have any evidence that such stipulations compromise children's welfare. Among the studies on the views of donor-

conceived people about their mode of conception (for example Turner and Coyle, 2000; Scheib et al., 2005; Jadva et al., 2009; Mahlstedt et al., 2010), there is no evidence available regarding what donor-conceived people think about stipulations that their genetic, donor parent may have made, or indeed the extent to which social parents disclose information about such stipulations to their children.

Pennings has tried to be careful about the donor stipulation situation by only allowing discrimination against certain groups, and the nature of these groups must be pre-ratified with respect and regard for certain 'moral communities' (Pennings, 1995, p. 2738). This system could work if certain groups are more sensitive to this discrimination than others – we can say that the most sensitive groups are protected from such discrimination. The sexual orientation groups seem like they would fall into this sensitive category; participant 02 (phases one and two)'s example derives its force from positing a gay or lesbian person who is offended, upset, or distressed by the discovery that their genetic parents (whatever their relationship, if any, with them) chose to discriminate against gay or lesbian patients when choosing who could receive their gametes. Pennings' argument implicitly suggests that there are groups of people who would be less offended to learn that their donor had chosen to discriminate against people of their group. I take this suggestion as implicit because it is the logical corollary of stating that some groups can be discriminated against by gamete donors and others cannot, if what is at stake is the welfare of the potential child.

This, however, is also an empirical claim, and will fall foul of the same lack of evidence problem as the more general claim that donor stipulations harm children. Let us consider a hypothetical example. Say a person, Fred, learns that he was conceived through the use of a donor, and the donor specifically requested that his or her gametes do not go to

consequentialists. Fred's parents, as devout deontologists, were allocated this donor, and he was born. Now, let us say that Fred grew up to be an avowed consequentialist before learning this truth about his donor parent. The question at hand is whether it would cause Fred any less upset to learn about his donor's stipulation than it would cause upset to the gay or lesbian person (potentially a child) to learn that their donor had discriminated against gay or lesbian people. For Pennings' view to be tenable, some work needs to be done to show that, and explain why, certain groups are more vulnerable to this offence than others, such that we can drive a wedge between these groups, permitting discrimination against some but forbidding discrimination against others. Until this work is done, we have no reason to allow certain kinds of donor stipulations and not others on the basis of some being more or less offensive than others.

We now know that we cannot sensibly draw a distinction between discriminating against some groups and discriminating against others, or indeed summon sufficient evidence that donor stipulations compromise child welfare. Given the benefits that stipulations may bring in terms of increasing the donor pool, however, they should be permitted.

7.9.3 Known Donors

One of the project's aims is to analyse the ethics of the use of known donors. Participants were asked what they thought about the use of known donors in all of the interviews, and this topic was also discussed during the workshop. The philosophical analysis described some potential problems with known donors, but concluded that given the

general advantage that their use confers with regard to speeding up the waiting list, they should be accepted.

As noted in the results, all of the participants thought the use of known donors was morally permissible, at least in some circumstances. That is to say that nobody thought it was *conceptually wrong*. Some participants expressed concerns about social issues, such as the identity of the child, the child's relationship to the donor, or the issue of growing up in a non-standard family environment, for example where a child's biological (genetic) father is his/her social grandfather (as would be the case where a man donates sperm on behalf of his son). Many of these issues are related to child welfare, but could also affect patients. Some participants also expressed concern about the possibility of people being coerced into donating their gametes. Participants were satisfied, however, that these possibilities could be investigated, and that there could be situations in which their concerns about them would be sufficiently dispelled to warrant going ahead with treatment. The discussion below (page 312) will consider how staff should consider evidence for and against treating a given patient.

If social problems for children, patients, or families, were generated from the use of known donors, perhaps these should speak against this practice, providing these problems were sufficiently bad and insurmountable. Avoiding them might not mean refusing treatment, however – perhaps those who perceive problems are prejudiced against non-standard families and should change their views. The question that would need answering first, however, is whether these problems actually exist. These social problems are rather nebulous, but let us spend some time looking into whether the participants considered what

the content of them might actually be, and whether this gives us any reason to be concerned about them without evidence of their presence.

No participant cited any actual cases of anything ever going awry in a social sense in these known donation cases, but they may have just been unaware of it. This problem could be analogous with the same-sex couple and single patient cases, which might suggest that we need to be offered more serious reasons for refusing to perform a certain action, and thus that in the absence of those reasons, it is permissible to perform the action. The same-sex and single patient cases may appear to have slightly different content, because in those cases it is clear that we are considering reasons for discriminating between groups of people. In the case of known donation, it looks as though we are not discriminating between groups of people *per se*, but rather deciding whether a certain type of donation should be allowed. This can be reframed, however, to mirror the language of discrimination in the same-sex and single patient cases. We can say that to forbid known donation is to discriminate against those who bring in their own donors. This is not to say that they are being disadvantaged, but just that they are being denied the opportunity to benefit from their circumstances.

It seems, then, that if we cannot discriminate against same-sex couples or single patients without good reason, then we cannot similarly discriminate against the hopeful recipients of gametes from a known donor, either. We need sufficient reason to forbid or condemn such activities, and mere speculation about potential harm should not be considered sufficient, though actual evidence of harm might be. Concern about social issues provides insufficient justification for denying patients the option of coming in with known donors.

Coercion, on the other hand, is perhaps a possibility that requires less empirical work to justify our fears about. Whilst the *social* problems associated with known gamete donation are vague, we can easily conceive of a situation where somebody is coerced into donating gametes for a friend or relative. This could be problematic, as known donations more readily open the door to coercion or exploitation than anonymous donations. These problems may be remedied by taking measures to ensure that donations are undertaken voluntarily.

This discussion has raised the complex question of how risk, or perceived risk, should be managed. It has been argued that risk needs to be demonstrated rather than simply feared if it is going to be used as a justification for restricting action or forming policy. This demonstration need not be comprehensive, but there needs to be more than just a feeling of concern that a problem might exist, because as we have seen in the same-sex couple and single patient scenarios, sometimes this risk can be overstated, where staff worry about problems that the evidence shows do not exist.

The analysis suggests that there is at least nothing theoretically wrong with the use of known donors, then. As has been shown, a commitment to patient choice allowing donors to stipulate their gamete recipients more generally must, in order to be consistent, also motivate a commitment to allowing donors to direct their gametes to particular individuals. There may indeed be risks of coercion and the like in instances like these, but those risks do not present insurmountable ethical obstacles to some forms of known donor treatments being used. Given the overall benefits generated by donor stipulations, they should be accepted.

7.10 Welfare of the Child

Participants also spoke more generally about child welfare, and this discussion sometimes became more abstract, moving away from ideas about how particular putative decision-making criteria (for example age and substance use) affected welfare of the child. Instead, the discussion was sometimes theoretical, with some patients explaining why welfare of the child was important at all, or how it weighed up against the welfare of others, for example other existing children or the patients themselves. This discussion may help us to consider how seriously we should take welfare of the child considerations as reasons for and against treatment in our consideration of the particular criteria with which we have so far been concerned. In short, this section will consider whether the emphasis on the importance of child welfare is supported by what the participants said in the interviews. If it is not, we will need to reconsider whether welfare of the child should have pride of place in our ethical decision-making, as I have so far argued that it should.

As noted in the results (see page 227), while one participant suggested that *'the welfare of the mother during pregnancy, it's a bigger concern'* (participant 15, phase one), the participant effectively undermined this statement by adding *'in the short term'*. This participant did not articulate his/her views about the relative importance of patient welfare and child welfare. Hence, this statement offers us nothing in our considerations of how to weigh these things up.

Participant 05 (phase one) was asked about the importance of child welfare between the children born from treatment, and other children affected by the birth (in line with the stipulations in the HFE Act). The participant suggested that they were both important, and

then commented that '*I don't spend my life thinking which one's more important than the other*' (participant 05, phase one). Perhaps we can infer from this that this participant felt that these groups were equally important, and any difference would be so negligible as to be not worth considering.

Within a framework where impartiality dictates that we should be reluctant to deviate from a standpoint of equality when it comes to considering who/what to value, the participants' reluctance to attribute greater value to any one group over another is laudable. As the philosophical analysis showed (page 50), however, the fact that children are at increased risk of undergoing harm suggests that in practice, their welfare should be considered a priority over the welfare of others.

We have now considered, in light of the study data, how child welfare is to be weighed against the welfare of other stakeholders. Let us now consider how it weighs against considerations regarding the specific groups and characteristics discussed in the philosophical analysis. Recall that some participants felt that total reliance on child welfare as a prioritisation criterion for gametes could result in patients being prioritised based on '*morally repugnant*' (participant 30, phase two – see page 229) reasons. The question that this raises is *why* these prioritisations would be morally repugnant. If a prioritisation system satisfies requirements of child welfare but still produces morally repugnant results, then some principle *other* than child welfare must be appealed to in order to demonstrate the repugnance of such a system. Indeed, the philosophical analysis did not suggest that child welfare was the *only* consideration, and much attention was paid there to the potential tensions between considerations of equality and considerations like welfare (of which child welfare is obviously a part). The philosophical analysis did, however, suggest that child

welfare was more important than (i.e. weightier than but not able to trump) other considerations, and it seems that some of the workshop participants felt differently about this, given their view that in some situations, even large returns in child welfare should be foregone for the sake of other considerations.

One participant at the workshop gave an example of this (see page 229). (S)he argued that it would be morally repugnant to prioritise patients based on their sexuality, regardless of whether there was evidence about trends in child welfare between families with same-sex parents and those with heterosexual parents. It is important to note that this is not an empirical question about the effects of these factors on child welfare. Rather, it is a theoretical question about the value of child welfare versus the value of avoiding discrimination on intuitively repugnant grounds. This is not only a concern for those who would *maximise* outcomes for children, but for anyone who thinks there is a point at which child welfare would be so low that it would be wrong to bring that child into existence (this would include Mulgan, Pennings, and Harris). Furthermore, a consideration like parental financial status would not definitively demonstrate a particular level of child welfare – it can only give us an indication.

There are far-reaching historical and political reasons why people find it unsavoury to discriminate based on certain factors like these. Discrimination (in the non-moral sense) based on sexual orientation, race, or sex is uncomfortable because people of certain sexual orientations, races or sexes have historically been systematically disfavoured and discriminated against, often solely on the basis of their membership of groups relating to these characteristics. Discomfort about discrimination based on financial status may come from a sense that certain rights are universal and should not be more easily accessible for

the financially privileged. Reproductive rights would be a good candidate for such a right, if any. Further, there may be a concern with NHS-funded treatment that the prioritisation of wealthy patients would be an unfair way of distributing funds that people from a more diverse set of socioeconomic backgrounds pay into. This may depend, however, on more general ideas about how such resources should be distributed: Draper and Sorell note that a welfare state is 'justified by the belief that a decent society ought to use what resources it can to support the weakest and poorest' (Draper and Sorell, 2002, p. 344). While it seems at first glance that prioritising the wealthy would be to confer benefit on those who need it least, we must remember that the reason for this is to ensure a greater level of *child* welfare. Hence, the fact that it helps the wealthy is only a by-product of its maximising the benefits experienced by 'the weakest and poorest' – the child to be born from treatment. There is thus a general reluctance to discriminate on these grounds.

The philosophical analysis has already considered that while it may be worthwhile being wary about such discrimination, the fact that many of them have historical contexts does not make them special, in the sense that it may be just as wrong to discriminate on the basis of arbitrary characteristics that do not have such a history. Thus it is not clear that there must be an absolute constraint about discriminating based on certain characteristics, if membership of certain groups relating to these characteristics is associated with moral considerations that we wish to take seriously, for example child welfare.

One participant raised a concern about the "selective" use of child welfare as a means of disproportionately discriminating against certain groups for which there was actually no evidence base. The concern was that child welfare was often invoked as a justification for refusing to treat same-sex couples or single women, but that the same child

welfare principle would apply more seriously to others such as those who had been the victims of abuse when they themselves were children, and was ignored in such cases. This selective use of child welfare is a serious concern, but it can also cut the other way. We can legitimately invoke equality considerations in some contexts if we are concerned about one group being systematically discriminated against, but if we are to do so then we must be willing to invoke them wherever they apply, at the risk of being inconsistent. If we think that equality considerations apply between certain groups and not to others, justification needs to be offered for this. It is not clear that the characteristics on whose basis we usually want to secure equality are more important than some others. As has been argued, equality considerations are certainly important, but the vulnerability of children means that their welfare must take priority, and hence if it is true that certain groups are able to secure better levels of welfare, they should be treated first.

This relies on the argument in the philosophical analysis that concluded that a good allocation system for gametes also needs to take seriously Savulescu's principle of Procreative Beneficence (PB), where there is an obligation to create the best child possible. The interview data suggest that clinical staff were often not in agreement with this idea. They tended to report a preference for *exclusion* rather than *prioritisation*, in the sense that they were happy to exclude patients altogether in extreme cases, but not to prioritise one non-excluded patient over another in cases that were more similar. This suggests that they did not subscribe to PB, but rather adopted a threshold view where only a minimum, "good enough" standard of child welfare was required. This could be regarded as a kind of *sufficientarianism* with regard to child welfare, though we might consider that it is perhaps more nuanced than that.

If we are talking solely about efficacy outcomes, this sufficientarianism is in line with Savulescu's comment that a good approach 'allow[s] that patients with lower but reasonable prognosis should have a share of public resources' (Savulescu 1998: 212). When it comes to child welfare, however, Savulescu argues that the principle of Procreative Beneficence applies, creating an obligation to create the best child possible. The conclusions of the philosophical analysis were in agreement with this latter principle from Savulescu, but not the former; indeed, some justification is needed if maximisation is obligatory in one circumstance (child welfare) and not in another (efficacy). The philosophical analysis concluded that considerations of equality, as defended by Harris and Savulescu, were not sufficient to ground this difference, and that clinical staff should adopt a maximising, rather than sufficientarian, approach to both child welfare *and* efficacy, with only limited exceptions for the sake of practicality in terms of managing waiting lists. The approach taken by many of the staff in the interviews does not fall foul of the consistency problem, as by and large they were sufficientarians across *both* camps. Their views diverge from the recommendations of the philosophical analysis, then, as their acceptance of exclusion but reluctance to prioritise means that they would favour a system that permits suboptimal treatments, whether the suboptimality refers to child welfare or efficacy outcomes.

There is evidence in the data, both from the workshop and from the interviews, that speaks directly to these two categories of suboptimality and the idea that at least some participants are in agreement with them. As discussed previously (see page 254), participant 08 (phase one) felt that considerations of equality were what gave rise to allowing people with poorer prognoses to have treatment: *'everyone's sort of equal, just because we feel they've got a lower chance than [someone else] I don't think we can say they can't use them,*

I mean everyone should be entitled to use them equally' (participant 08, phase one). This speaks to the debate between Savulescu and Harris about equality versus outcomes, in which Harris argues for equal treatment *regardless* of outcomes, and Savulescu argues for equal treatment amongst patients but with a cut-off point for efficacy, below which a patient should be excluded for treatment. The participants' views were sometimes in line with Savulescu's view that there is a lower cut-off for efficacy below which someone should be denied treatment, and many participants took this approach with regard to child welfare, too. This is in line with the view advocated in the philosophical analysis, though in this case it seems to be a concession to equality whereas the philosophical justification for not recommending that staff aim for maximally healthy children was due to pragmatism. Given the problematic nature of equality as discussed previously in this chapter, the participants' deference to equality at the expense of child welfare and efficacy, both of which were deemed to be more important than equality, cannot be viewed as legitimate. At any rate, the conclusion is the same, and staff would thus be permitted to make decisions where suboptimal children are created. The location of the threshold still needs to be cashed out, though the emphasis on child welfare and the problems with equality detailed in this thesis might suggest that at present, staff are operating with too low a threshold (i.e. they are not excluding often enough) than is justifiable. Within the context of a priority system, staff could effectively exclude patients if child welfare considerations are weighted so heavily that patients cannot expect ever to receive treatment.

This section has teased out some of the more general and theoretical ideas about welfare as they appeared in the interview and workshop data. It has been shown that we must still consider child welfare to be an important consideration, both with regard to the

welfare of other stakeholders, and other potential values such as equality. Child welfare considerations can therefore be considered as reasons to prioritise or de-prioritise patients.

7.11 National Allocation

Pattinson states that gamete allocation could be variable between clinics (Pattinson, 2012, p. 577), and this was supported by the interview data. Pattinson then describes support for a national system, and the HFEA's SEED review suggested that this might be the case (see page 118). The interview results, however, do not indicate that the participants were in support of this idea. Two practical reasons for this were that participants felt that there would be difficulties with matching donors on a bigger list, and that they were concerned with the cost of implementing a national system.

It is unclear how matching would be much, if at all, more difficult with a national list than with the individual clinic lists. Complexities may arise in matching when a clinic attempts to match in such a way as to maximise the usage of its donors. Let us consider an example of matching following a recipient's stipulation: imagine there are two recipients, one of whom specifies their desire for, say, a university-educated sperm donor. The other recipient has made no stipulations and does not mind about the education level of their donor. Now, if a group of donors comes in, one of whom is university-educated, it of course makes sense to use this donor with the recipient who has made the stipulation, because even though this donor could be used with others, the recipient may only be used with him.

Financial costs could be an issue. On the basis that the argument for a national list comes from the standpoint of fairness to recipients (re: the postcode lottery issue), and

fairness is less important than maximising effective treatments (as argued above), then an increase in financial costs at the expense of the number of treatments that can be offered would suggest that we should dispense with the idea of a national system.

Part of the strength of this objection to the national allocation system would depend on the source and nature of funding. Without going into this complicated question here, it would be good to consider first whether such a system would indeed cost more, and if so to consider means of funding for such a system and whether its implementation would really be detrimental to patient outcomes. Only once this costing work has actually been done can we legitimately consider letting go of the idea of a national system. Until then, it remains on the table as a viable and justifiable system by virtue of its increased fairness and transparency.

Another argument against the national list was the complaint that people at each clinic worked hard to recruit donors (see pages 249-250), and that they would consequently not want to see donors used at other clinics that might gain financial benefits from their work and efforts, and this idea also received attention at the workshop. It is understandable that a staff member may be concerned about this, but this does not represent a decisive argument against a national allocation system, as a national system does not necessarily mean that the fruits of staff members' labour will be redistributed in this way. A perhaps straightforward way around this may be to also nationalise recruitment (though the concern about cost may reappear here). This was part of the system advanced by one of the participants in phase three (see pages 251-253). This would alleviate the problem of staff members feeling that the benefits of their work were disappearing elsewhere. It is worth

noting that organ and blood donation functions using a system of local recruitment and national allocation.

The conclusion regarding the national waiting list, then, is a tentative one. This discussion has tried to establish that the objection, raised by the interview participants, that a national system would be too cumbersome in terms of matching, cannot be considered decisive until more thought has been put into the logistics of it, and the burden of proof would be on the detractors to explain why matching would become untenably difficult under a national system when it is functional under a local system. The cost issue is perhaps more pressing, but the same principle applies: the national system would have benefits, in terms of potentially increasing the number of donors, and in terms of fairness, where criteria would be more standardised. Importantly, it may provide a better platform for implementing the best allocation criteria, ensuring better practice nationwide. These advantages need to be weighed up against the disadvantages (i.e. cost) of implementing a national system. We must not simply assume that this cost would be too great. The participants' concern that the distribution of costs and benefits to themselves with regard to recruitment and allocation would become unfair is yet another issue that needs further consideration, but it appears that there are solutions on the table regarding this. We should therefore take factual details into account about alternative arrangements for the national list, before any firm conclusions can be reached.

8. CONCLUSIONS FOR GAMETE ALLOCATION

Before moving onto the final conclusions for gamete allocation, it is necessary to comment on how they ought to be used. Many of the final conclusions that will be made in this chapter relate to information about patients. For example, conclusion 2) suggests that any patient's substance use and/or domestic violence problem should be taken into account. This raises the question of how clinical staff will come to know this information, and how sure they can be of its veracity. It is suggested, consistently with the concept of using probability to establish approximations of truth as outlined in section 5.2, that staff consider the probability that a patient presents such a problem, rather than there being an expectation of cast-iron evidence, which may render the relevant conclusions useless if clinical staff cannot gain full access to information. There must, however, still be a requirement for *some* evidence – a staff member's fears or intuitions are not enough to speak against treating a patient, as this too readily allows the expression of prejudice.

The final conclusions for gamete allocation are shown in a list below, before some brief explication. It is hoped that the application of these conclusions will be adopted in future practice.

- 1) There must not be a presumption that patients will simply be treated in the order in which they arrive at the clinic or on the waiting list. A priority system should be adopted to ensure that as many morally relevant factors as is pragmatically viable are taken into account.

Much work has been done to show the justifiability of conclusion 1), in light of the plurality of moral factors that are relevant and may be being ignored under a “first come, first served” system (see page 100). This first conclusion will influence the way that following conclusions are used.

- 2) If any patient, any patient’s partner, or any person who is expected to have a significant role in rearing a child born of treatment, is revealed to have a continuing problem with substance use (including smoking), alcoholism, violence or domestic discord, this should be taken as a reason against further consideration of this patient for treatment.

Conclusion 2) is relatively uncontroversial, as the participants’ views in the data were broadly in agreement with it. The importance of considering child welfare has been argued for extensively in this thesis, and is also supported in the HFE Act. Furthermore, the relevance of the above factors to child welfare has been linked to empirical evidence. This discussion can be found on pages 44-58, and pages 302-309.

- 3) Any other factors that call into question the expected welfare of children affected by treatment, including the potential recipient’s ability to parent the child, should be seriously considered as reasons against treatment unless they can adequately demonstrate that such factors do not present a risk to child welfare. The relationship between these factors and child welfare issues must be supported by empirical evidence.

Conclusion 3) will be more controversial given the extra weight that some participants seemed to want to give to equality considerations. The relationship between welfare and equality has been discussed in this thesis, however, and it has been concluded that child welfare is a legitimate basis on which to treat patients unequally (pages 108-114). The amendment to this conclusion aims to be sensitive to the concern that welfare of the child issues may sometimes be used “selectively” (see page 229).

- 4) Patients who can reproduce without donor gametes, but who can only do so at the risk of passing on diseases, should be given some priority on this basis.

Conclusion 4) was met with widespread disagreement amongst most participants. The justification for this conclusion is based on child welfare. The discussion (pages 45-47) took seriously Savulescu’s argument that practitioners should account for wider societal concerns, in cases where no harm will be done by so doing. This thesis argued that the avoidance of children with heritable conditions constitutes a legitimate wider concern, and that prioritising patients for this reason would not cause harm. Given the participants’ disagreement with this conclusion, however, it is deemed that while it is a point of future philosophical interest, it is unlikely to make any ground in practical terms.

- 5) Patients should be prioritised based on the chance of the treatment being successful, and the risks to their health of undergoing treatment, with those with higher chances and lower risks the higher priority.

Conclusion 5) is one of the most important conclusions, and many considerations will be relevant to these ideas of efficacy and risk (see pages 60-61 for discussion), which are predominantly grounded in the welfare of patients. This conclusion will ensure that gametes are used in a way that confers the most benefit to patients.

- 6) Younger patients should take priority over older ones, except in cases where there are so few younger patients that older patients are expected to be treated anyway. In such cases, the older patients should take priority.

Conclusion 6) will do the same, and relates to conclusion 5) insofar as, in the case of donor sperm, age is a good yardstick for treatment efficacy. The application of this conclusion will depend on the size and population of the waiting list in question.

- 7) Gametes can be allocated on the basis of conditions set by the gamete donors, including conditions based on the protected characteristics in the Equality Act.

Conclusion 7) is based on the fact that conditions will increase the number of donors, increasing the numbers of gametes available and thus allowing more patients to be treated. The discussion on pages 61-71 suggested that this may not constitute a breach of the Equality Act, as no individual is disadvantaged by it.

- 8) Patients who can recruit donors to donate to them, or to the general pool, should be given some priority.

Conclusion 8) acknowledges the points advanced by Pennings and Pattinson regarding the benefits of a mirror exchange system in increasing numbers of donors. As with conclusion 7), this is grounded in patient welfare as it allows more patients to be treated.

- 9) Parental status should be accounted for in prioritising patients, so that patients with less parenting experience are prioritised over those with more parenting experience. Staff may wish to generate some discrete cut-off points to negotiate the fact that the spectrum of parenting experience is very broad.

Conclusion 9) reflects the fact that there is evidence of psychological differences between primary and secondary infertility patients (see pages 88-90), so that parental status is included in the priority system.

- 10) Staff should not base their decisions on the sexual orientation of patients.

Conclusion 10) aims to make explicit that certain criteria are morally irrelevant to this decision-making and thus should not be accounted for. Evidence was presented showing that same-sex parenting has no deleterious effects on child welfare (see pages 91-93). Recommending against decisions based on sexual orientation and relationship status reflects the legal status quo, but staff should be wary of indirect ways that these groups can be discriminated against.

11) Staff should give priority to parenting arrangements involving greater numbers of parents.

Like conclusion 4), it is not expected that conclusion 11) will gain any practical ground, but it remains a philosophically interesting problem nonetheless, and is based on the idea that it is better to help more people where possible. If parenting is seen as a good for patients, then it makes sense to provide this opportunity to as many patients as possible with the same resources.

12) A national allocation system should be adopted, unless it proves to be so costly as to disadvantage patients.

Conclusion 12) has been tempered slightly to account for the fact that many of the study participants opposed the national allocation system. The national system still remains a potentially good way of ensuring fairer allocation, and increasing donor numbers. This reflects the discussion of Pattinson (2012) above (pages 118-120).

13) Patients whose BMI would pose risks to their health if treated, or whose treatment might be less effective due to their BMI, should be de-prioritised on this basis.

BMI was not originally considered in the philosophical discussion, on the grounds that the ethical issues associated with it would be discussed with relation to other putative criteria. Indeed, ethical issues pertaining to BMI include patient welfare and efficacy, both of which

have been discussed extensively so far (see pages 59-61). Nevertheless, participants identified BMI as significant, giving rise to conclusion 13).

- 14) There should not be a presumption that recipients should be matched to donors with matching physical characteristics. If there is, patients should be able to opt out of this system and request gametes from a non-matching donor. This option should be made explicit to them at an early stage.

Conclusion 14) has been added in light of the fact that matching arose as a theme in the empirical study (as reported on pages 241-242), and out of concern for the fact that patients may be disadvantaged if it is presumed that they want donors with matching physical characteristics.

- 15) Patients should be prioritised based on how long they have been waiting for gametes.

Finally, conclusion 15) is totally at odds with the suggestions of the philosophical analysis, but the data showed overwhelming support for the idea that waiting time should be accounted for, as reported on page 214 above. In order for the priority system in general to be more palatable to staff, it is thus recommended that waiting time be accounted for. This acknowledges the importance of compromise as outlined by Huxtable (2013) and discussed above (page 25).

8.1 Summary

This discussion has tried to take seriously the views of participants in the interviews and in the workshop, and consider the extent to which they should impact upon the conclusions drawn from the philosophical analysis. An overarching theme in this discussion has been an emphasis on equality and fairness from participants, which has been shown to be somewhat difficult to defend, given the peculiarities of accepting some conceptions of equality in this context. With the difficulties of relying too heavily on equality in mind, it has tended to be the case that the original recommendations can withstand many of the criticisms and concerns raised by the participants.

The discussion calls for a revision of our evaluation of the relationship between equality considerations and welfare considerations in the healthcare setting. This chapter has argued that equality considerations are often given too much weight, and that once this concern is taken seriously, intuitive anxieties about priority systems lose their bite. Serious consideration of child welfare issues means that clinical staff must be readier to exclude those who pose a risk to children, either through their own behaviour or by passing on conditions or diseases.

Finally, while it may not be ideal for donors to make stipulations about their gametes, the fact of the matter is that this may confer advantage on some patients without disadvantaging anyone. So, while we may feel an intuition or principled response against allowing people to make stipulations if we think they might be repugnant, autonomy considerations in combination with the problem of levelling down based on such principles

(which again represents an overemphasis on equality) mean that we must allow such stipulations to occur.

9. FINAL COMMENTS

9.1 Reflexivity

The question of how my own personal views and biases may have entered into the project is a complicated one, given the philosophical nature of the project, and the overarching philosophical questions about whether ethical viewpoints can ever be more than matters of opinion or reflections of personal desires. I have attempted to offer justifications for every argument I have advanced, but one problem is that the ethical principles on which those justifications are founded may also be matters of personal preference.

I make no secret of my allegiance to consequentialist moral theory, and my choice to take a consequentialist approach in this thesis is a reflection of that. Undoubtedly a Kantian approach to the same question could yield vastly different results and conclusions. This, however, is where the strength of the empirical aspect of the study arises – to test these ideas against those of others in the field. Where appropriate, conclusions that were obviously consequentialist and potentially at odds with other ways of thinking were suggested tentatively.

Another avenue for reflexivity regards my own *personal* experiences of (in)fertility and the world of reproduction, assisted or otherwise – I have none. I have no plans to have children at any stage in my life, and I have tried to allow this to give me a more objective vantage point from which to discuss these issues. Part of the rationale for the fieldwork and empirical elements of this project was that it would allow me to avoid the charge of having

written this thesis without a true understanding of the plight of the involuntarily childless, and I think this thesis gives adequate weight to the suffering associated with that plight.

9.2 Conclusion

The overarching aim of this thesis was a list of philosophically robust conclusions about how gametes ought to be allocated, including whether to allow known donors, and whether a national waiting list of donors and recipients should be used. This was achieved by a survey of the philosophical literature and the legal context surrounding the allocation of donor gametes to fertility patients. These conclusions were then considered against the responses of participants in an in-depth empirical study. The study also aimed to gain an understanding of the current status quo of gamete allocation practice. This understanding was facilitated by the compilation of publicly-available information regarding gamete allocation criteria, collected from the HFEA's website, and from the websites of individual clinics themselves. The collection of this publicly-available data helped to identify some of the salient ethical aspects of gamete allocation, for discussion in the philosophical analysis.

An empirical bioethics methodology was deemed appropriate for the study, given its aim of establishing ethical conclusions that accounted for the views and practices of real-world service providers. The thesis devoted considerable time to explicating the complex relationship between the data collected in this study and the philosophical analysis undergone beforehand, aiming to strike a balance between theoretical rigour and practical applicability. The thesis is original in that it represents, to date, the most in-depth investigation of both the ethical dimensions of some of the putative criteria for gamete

allocation, and the views of clinical staff with regard to the question of gamete allocation. As a result, this thesis has produced a set of fifteen empirically-informed philosophical conclusions about how gametes donated for human reproductive purposes should be allocated. These conclusions may now be put forward as guidelines for future clinical practice.

10. APPENDICES

10.1 Appendix 1 – Participant Invitation Letter (Phase One - Coordinators)



UNIVERSITY OF
BIRMINGHAM

Primary Care Clinical Sciences
School of Health and Population Sciences
College of Medical and Dental Sciences
University of Birmingham
Birmingham B15 2TT

[Date]

[Recipient address]

Dear [name],

The ethical allocation of gametes donated for the purpose of fertility treatment

My name is Simon Jenkins, and I am a PhD student at the Centre for Biomedical Ethics at the University of Birmingham. Enclosed is an information sheet about my doctoral research study, in which I hope you will be interested in participating. My research is about how gametes are allocated in fertility clinics in the UK. I am writing to you because in your role as sperm/egg donor coordinator, you are likely to be in a position to make decisions about such allocation.

Dr Sue Avery, director of the Fertility Centre at Birmingham Women's Hospital, is part of my supervisory team, and I enclose a covering letter from her. The enclosed Participant Information Sheet will give you more information. If you would like to participate in this study, please complete the enclosed reply slip and return it to me. You can also contact me by telephone, text or email. If you do not want to participate in the study, just disregard this letter. You will be sent a reminder letter about this study in approximately two weeks. If you do not wish to receive this reminder, please tick the appropriate box on the reply slip and return it to me. Alternatively, if you disregard this letter and the reminder letter, we will not contact you about this study again.

No one from the research team will tell anyone from your place of work about any interest you show in the study, and your personal information will be kept strictly confidential.

If you wish to contact me by email or phone, details are as follows:

Email: sji029@bham.ac.uk

Phone: 0121 414 7483

Alternatively you can contact me using the stamped and addressed envelope enclosed with this letter.

Thank you for taking the time to read this, and I hope you will consider participating. Also, if you know of anyone else who you think may be suitable for the study and is interested in participating, please do not hesitate to pass this information on to them.

Yours sincerely,

Simon Jenkins

10.2 Appendix 2 – Participant Invitation Letter (Phase One - Directors)



UNIVERSITY OF
BIRMINGHAM

Primary Care Clinical Sciences
School of Health and Population Sciences
College of Medical and Dental Sciences
University of Birmingham
Birmingham B15 2TT
[Date]

[Recipient address]

Dear [name],

The ethical allocation of gametes donated for the purpose of fertility treatment

My name is Simon Jenkins, and I am a PhD student at the Centre for Biomedical Ethics at the University of Birmingham. Enclosed is an information sheet about my doctoral research study, in which I hope you will be interested in participating. My research is about how gametes are allocated in fertility clinics in the UK. I am writing to you because in your role as director of a fertility clinic, you may be in a position to make decisions about such allocation. Whether or not you are in this position yourself, it would be helpful if you could circulate this information to those in your clinic who are.

Dr Sue Avery, director of the Fertility Centre at Birmingham Women's Hospital, is part of my supervisory team, and I enclose a covering letter from her. The enclosed Participant Information Sheet will give you more information. If you would like to participate in this study, please complete the enclosed reply slip and return it to me. You can also contact me by telephone, text or email. If you do not want to participate in the study, just disregard this letter. You will be sent a reminder letter about this study in approximately two weeks. If you do not wish to receive this reminder, please tick the appropriate box on the reply slip and return it to me. Alternatively, if you disregard this letter and the reminder letter, we will not contact you about this study again.

No one from the research team will tell anyone from your place of work about any interest you show in the study, and your personal information will be kept strictly confidential.

If you wish to contact me by email or phone, details are as follows:

Email: spj029@bham.ac.uk

Phone: 0121 414 7483

Alternatively you can contact me using the stamped and addressed envelope enclosed with this letter.

Thank you for taking the time to read this, and I hope you will consider participating. Also, if you know of anyone else who you think may be suitable for the study and is interested in participating, please do not hesitate to pass this information on to them.

Yours sincerely,

Simon Jenkins

10.3 Appendix 3 – Covering Letter from Sue Avery



Dr Sue Avery
Fertility Centre
Birmingham Women's Hospital
Metchley Park Road
Edgbaston
Birmingham B15 2TG
[date]

[address]

Dear [name],

The ethical allocation of gametes donated for the purpose of fertility treatment

I am currently supervising a PhD project that seeks to explore how gametes are currently allocated in fertility centres and what ethical issues (if any) arise from those allocation procedures. The student, Simon Jenkins, is hoping to interview staff at fertility clinics across the UK to get an idea of how decisions about gamete allocation are made. It would be very helpful if you could participate in this research, or pass this information on to anyone who has a role in decision-making regarding access to waiting lists or gamete allocation in your clinic (for example, directors of clinics or donor coordinators). Please find the relevant documents enclosed, and thank you for your time.

Yours sincerely,

Dr Sue Avery
Director
Fertility Centre
Birmingham Women's Hospital

10.4 Appendix 4 – Participant Information Sheet (Phase One)



The ethical allocation of gametes donated for the purpose of fertility treatment

Chief Investigator: Simon Jenkins, PhD student, University of Birmingham

Supervisors:

Lead supervisor: Professor Heather Draper, University of Birmingham

Dr Sue Avery, Fertility Centre, Birmingham Women's Hospital

Dr Jonathan Ives, University of Birmingham

We would like to invite you to take part in our research study. Before you decide, it's important for you to understand why we're doing this research, and what participation would involve for you. Please take the time to read this information sheet carefully, and feel free to speak to others about the study if you wish. If you would like more information on any aspect of the study, or if there is anything in this information sheet that you don't understand, then please ask us.

What is the purpose of the research?

The study aims to find out how staff at fertility clinics in the UK make decisions about which patients to treat with donated eggs and sperm. The information you give us will become part of a larger project looking at the best way to allocate eggs and sperm. The purpose of this study is to explore the ethics of the allocation of donated eggs and sperm, and to identify best practice.

Why have I been invited?

We're trying to find out how people make decisions about how to allocate donated gametes. Because of your role in the fertility clinic as a decision-maker, we imagine that you have a significant level of influence in this process. We're hoping to interview between twelve and fifteen people like you from selected clinics across the UK so that we can see if there are any similarities or differences in people's approaches to allocation.

Do I have to take part?

You do not have to participate in this study if you don't want to. It is entirely up to you whether or not you do so. Once you've read this information sheet and had time to think, you can contact us to take the process further. We'll ask you to sign a consent form to show that you've agreed to take part. Even after signing the consent form, you'll be free to withdraw from the study at any time up until 48 hours after your interview has finished, without giving any reason. Withdrawing from the study won't affect your job in any way – we won't tell anyone you work with about your participation in the study or any interest you show in it.

What will happen to me if I take part?

If you do decide to participate, you'll be asked to attend an interview lasting about an hour, during which you'll be asked some questions about how you decide which patients receive treatment with donated eggs and sperm. We'll record and transcribe the interview so that we can analyse your responses and compare them to what other people say. We'll try to make the interview as convenient as possible for you by arranging for it to take place where you work, so you don't have to travel. You won't get any money for participating but you might find it interesting and helpful to talk about issues that arise in your daily working life.

You can also choose to attend a workshop in 2012 (date to be confirmed), and you may choose to participate in a second interview after the workshop. At this workshop we will present the findings from the first interview phase, and you'll have the chance to contribute your views in a group setting. You do not have to take part in either of these if you do not want to, and you can use the last page of this form to let me know if you do not want to be contacted about them.

What will happen to my details and the information that I give?

Your personal details will be kept confidential, and anything you say during the interview will be anonymised. We'll follow legal and ethical practice so that all information about you is handled in confidence, and so no one but the research team will be able to find out that you've participated in the study unless you tell them yourself. Your contact details will be stored on a respondent database on a password-protected personal University of Birmingham computer, in an office that is only accessible through two swipe-card-secured doors. Interviews and the workshop will be audio recorded using a portable audio recording device, transferred to the University computer at the earliest available opportunity, and then deleted from the original recording device. The recordings will then be transcribed, and stored on the University computer. The recording of the interview needs to be kept because

the study is being written up for a PhD thesis. The transcriptions will be anonymised, and a key for the purpose of linking personal details to individual recordings/transcripts will be kept in a different location on the same computer. All electronic files will be backed up on a firewall-protected University server. Paper files (for example reply slips and consent forms) will be stored in a locked filing cabinet in the same office as the computer. Personal details and audio recordings will be destroyed after the PhD project has been examined. Transcripts and consent forms will be kept and securely stored for ten years before being destroyed.

The research team will talk about the findings of the study as a whole, and the results will be published. Sometimes we will use word-for-word quotations, but we'll never identify you by name, and any other information that might identify you will be removed. Once the study is complete, you'll be allowed to see a summary of the results, if you wish to.

Will I get any money for taking part?

You won't be paid for participating in this study. As the interview will take place in your usual place of work, you won't incur any extra travel expenses.

What are the possible risks and disadvantages of taking part?

The interview should not be burdensome, and does not carry significant risk. However, we understand that some of the questions we'll be asking in the interview might cause a bit of discomfort, as we are asking questions about how you do your job and how you justify the decisions you make. If you do find the interview uncomfortable you are free to withdraw at any time during the interview or for up to 48 hours afterwards, and you don't have to give any reason for this.

Who is organising and funding the study?

Simon Jenkins, a PhD student at the University of Birmingham, is organising the study. Professor Heather Draper and Dr Jonathan Ives from the Centre for Biomedical Ethics at the University of Birmingham will supervise the study, along with Dr Sue Avery from the Fertility Centre at Birmingham Women's Hospital. The Arts and Humanities Research Council is funding the research.

What if I have a complaint?

If you have any concerns about any aspect of the study, you should ask to speak to the researcher who will do his best to answer any questions you have. If you wish to complain formally, you can contact Professor Heather Draper with the following information:

Professor Heather Draper
Centre for Biomedical Ethics
Primary Care Clinical Sciences Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT, UK
0121 414 6941
h.draper@bham.ac.uk

What do I do if I want to participate or find out more?

For questions about the study, this document, or to participate in the study, please contact Simon Jenkins: sji029@bham.ac.uk 0121 414 7483

You can also contact Dr Sue Avery, Director of the Fertility Centre at Birmingham Women's Hospital, with the following information:

Dr Sue Avery
Birmingham Women's NHS Foundation Trust
Metchley Park Road, Edgbaston
Birmingham B15 2TG
0121 627 2797

We may also want to contact you about future phases of the study. We are planning to host a workshop to which people will be invited hear our findings so far and contribute their views. There may also be another interview session after this to explore people's views further. The reply slip will give you an opportunity to tell us whether you're happy for us to contact you about these events. You can still participate in this first interview even if you don't want to come to the workshop or do the second interview.

Reply Slip:

Return this slip to Simon Jenkins at the University of Birmingham in the stamped and addressed envelope provided.

Name:	
Preferred contact address:	
Home Telephone at preferred address:	
Mobile:	
Email address:	
<p>I'd like to take part in this interview: <input type="checkbox"/></p> <p>I don't want to take part. Please don't contact me again: <input type="checkbox"/></p> <p>I'm happy for you to contact me about other study phases, like the workshop and second interview: <input type="checkbox"/></p> <p>If you're happy to take part, please tick your preferred means of contact:</p> <p>Phone call <input type="checkbox"/> Email <input type="checkbox"/></p> <p>Post <input type="checkbox"/> Text message <input type="checkbox"/></p>	

Please use this space to let us know if there are any times that are particularly convenient or inconvenient to contact you. We will do our best to be flexible and arrange an interview time that suits you.

10.5 Appendix 5 – Consent Form (Phase One)

Appendix 5 - Participant Consent Form (Phase 1) – Version 1.5 – 9.5.11



UNIVERSITY OF
BIRMINGHAM

The ethical allocation of gametes donated for the purpose of fertility treatment

Researcher: Simon Jenkins, PhD student, University of Birmingham

Lead supervisor: Professor Heather Draper. Other supervisors: Dr Sue Avery; Dr Jonathan Ives

Please
initial
box

1. I confirm that I have read and understand the information sheet dated 14.3.11 (version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time up to 48 hours after the interview has taken place without giving any reason, without my legal rights being affected.
3. I understand that my interview will be audio recorded.
4. I would like to receive a summary of the results of this research.
(Please initial one box only) By email By post I do not want a summary
5. I give permission for the research team to contact me asking for feedback regarding the research summary.
6. I also give permission for my contact details to be used to send me information about the workshop and second interview planned for the future. I understand that this agreement does not constitute consent to future participation.
7. I agree to take part in the above study.

Name of participant:

Signature: Date:

Name of person taking consent:

Signature: Date:

NRES ref number: 11/WM/0099 R&D ref number: 11/BWH/PO26

10.6 Appendix 6 – Participant Reminder Letter



UNIVERSITY OF
BIRMINGHAM

Primary Care Clinical Sciences
School of Health and Population Sciences
College of Medical and Dental Sciences
University of Birmingham
Birmingham B15 2TT
[Date]

[Recipient address]

Dear [name],

The ethical allocation of gametes donated for the purpose of fertility treatment

My name is Simon Jenkins, and I am a PhD student at the Centre for Biomedical Ethics at the University of Birmingham. About two weeks ago we contacted you inviting you to participate in a research study. This letter is a polite reminder to offer you another chance to involve yourself in the study, should you want to. The information sheet about the study is enclosed again in case you have mislaid the first one. If you do not respond to this letter, we will not contact you about the study again.

Yours sincerely,

Simon Jenkins

10.7 Appendix 7 – Topic Guide

The ethical allocation of gametes donated for the purpose of fertility treatment

This guide comprises a list of topics and instructions that the researcher can use to generate discussion in interviews and to keep the discussion on track. The researcher will not necessarily use all of them in each interview – this will depend on the extent to which the participant answers the research questions without being prompted.

Guidance for interviewer:

- *Begin by introducing yourself and try to ensure that the participant is relaxed. Explain that the interview will go on for about an hour. Loosely describe the 3 parts of the interview, in particular emphasising that you want to know about waiting list access and gamete allocation amongst those already on waiting lists (otherwise the questions may seem repetitive and confusing).*

Section 1 – Patients' Access to Waiting Lists

- Clinics' decision-making – A general picture of how the participant perceives how the clinic decides who gets onto waiting lists for gametes. Prompt: *How does the clinic decide who to put on the waiting list for donated gametes?*
- Official or agreed policy at clinic. Prompt: *What official or agreed guidelines or policy are there at your clinic for deciding how patients gain entry onto waiting lists for gametes?*
- Ethical considerations that underlie current policy/decision-making. Prompt: *Which ethical considerations appear to underlie guidelines, policy or decision-making at the clinic?* (N.B. if the participant states that there are guidelines already then ask about this. If not then ask about decision-making more generally.)
- Participant's opinion about these considerations. Prompt: *What do you think about these considerations?*
- Any problems associated with these considerations. Prompt: *To what extent do these considerations pose problems?*

- Occurrence of deviation from agreed practice/policy. Prompt: *To what extent does deviation from guidelines/policy occur?* (N.B. this question is only relevant if the participant states that there are guidelines.)

Section 2 – Allocation of Gametes

- Clinics' decision-making – A general picture of how the participant perceives how the clinic decides who finally gets treatment with donated gametes. Prompt: *How does the clinic decide how to allocate gametes?*
- Official or agreed policy at clinic. Prompt: *What official or agreed guidelines or policy are there at your clinic for deciding how gametes are allocated?*
- Ethical considerations that underlie current policy/decision-making. Prompt: *Which ethical considerations appear to underlie such guidelines/policy?* (N.B. if the participant states that there are guidelines already then ask about this. If not then ask about decision-making more generally.)
- Participant's opinion about these. Prompt: *What do you think about these considerations?*
- Any problems associated with these. Prompt: *To what extent do these considerations pose problems?*
- Occurrence of deviation from agreed practice/policy. Prompt: *To what extent does deviation from the guidelines/policy occur?* (N.B. this question is only relevant if the participant states that there are guidelines.)

Section 3 – Known Donors and National Waiting List

- Opinion on known donors. (A known donor is somebody known to the recipient, who donates their gametes for the exclusive use of that particular recipient.) Prompt: *What do you think of the idea of using known donors?*
- Patients "shopping around". Prompt: *To what extent do you think patients to "shop around" at different clinics to get the treatment they want?*

- Opinion on a national register. Prompt: *What do you think about the idea of a national waiting list for donors and recipients?*

10.8 Appendix 8 – Participant Invitation Letter (Phase Two – Previous Participants)



UNIVERSITY OF
BIRMINGHAM

Primary Care Clinical Sciences
School of Health and Population Sciences
College of Medical and Dental Sciences
University of Birmingham
Birmingham B15 2TT

[Date]

[Recipient address]

Dear [name],

The ethical allocation of gametes donated for the purpose of fertility treatment

Thank you once again for your participation in the interview for my research study. When we recorded your consent on that occasion, you kindly agreed for me to contact you again regarding future phases of the study. I would like to invite you to take part in the next phase of the study, which is a workshop at Birmingham Women's Hospital.

The enclosed Participant Information Sheet will give you more information. If you would like to participate in this workshop, please complete the enclosed reply slip and return it to me. You can also contact me by telephone, text or email. If you do not want to participate in the workshop, just disregard this letter. You will be sent a reminder letter about this workshop in approximately two weeks. If you do not wish to receive this reminder, please tick the appropriate box on the reply slip and return it to me. Alternatively, if you disregard this letter and the reminder letter, we will not contact you about this study again.

If you wish to contact me by email or phone, details are as follows:

[Redacted contact details]

[Redacted contact details]

Alternatively you can contact me using the stamped and addressed envelope enclosed.

Thank you for taking the time to read this, and I hope you will consider participating. Also, if you know of anyone else who you think may be suitable for the study and is interested in participating, please do not hesitate to pass this information on to them.

Yours sincerely,

Simon Jenkins

10.9 Appendix 9 – Participant Invitation Letter (Phase Two – New Participants)



UNIVERSITY OF
BIRMINGHAM

Primary Care Clinical Sciences
School of Health and Population Sciences
College of Medical and Dental Sciences
University of Birmingham
Birmingham B15 2TT
[Date]

[Recipient address]

Dear [name],

The ethical allocation of gametes donated for the purpose of fertility treatment

My name is Simon Jenkins, and I am a PhD student at the Centre for Biomedical Ethics at the University of Birmingham. I would like to invite you to take part in a research study. My research is about how gametes are allocated in fertility clinics in the UK. We have conducted interviews with practitioners on this subject, and also looked at the ethical implications of a range of allocation methods. We would like to present our initial findings to get a picture of what people think.

[Personalised section – this paragraph will contain information about why the particular person is being invited, and will differ depending on their professional or public role]

The enclosed Participant Information Sheet will give you more information. If you would like to participate in this workshop, please complete the enclosed reply slip and return it to me. You can also contact me by telephone, text or email. If you do not want to participate in the workshop, just disregard this letter. You will be sent a reminder letter about this workshop in approximately two weeks. If you do not wish to receive this reminder, please tick the appropriate box on the reply slip and return it to me. Alternatively, if you disregard this letter and the reminder letter, we will not contact you about this study again.

If you wish to contact me by email or phone, details are as follows:

[Redacted contact details]

Alternatively you can contact me using the stamped and addressed envelope enclosed.

Thank you for taking the time to read this, and I hope you will consider participating. Also, if you know of anyone else who you think may be suitable for the study and is interested in participating, please do not hesitate to pass this information on to them.

Yours sincerely,

Simon Jenkins

Gamete Allocation Workshop

Friday October 19th 2012, Birmingham Women's Hospital

Volunteers wanted to participate in workshop for research study:

How should fertility clinics allocate donated sperm and eggs? This workshop is your chance to hear professionals' views and discuss your own opinions



Simon Jenkins
University of Birmingham
'The Ethical Allocation of Gametes
Donated for Fertility Treatment'

Professor David Archard
Queen's University Belfast
'Regulating gamete allocation: ethics, law and policy'

Laura Witjens
National Gamete Donation Trust

Dr Evan Harris

Is your work related to this?

Are you involved in an organisation or support group related to this?

If so, please get in touch!

This is a **free event**

We will provide **lunch** and reimburse **travel expenses**

Event will run from 10am to 3.30pm





The ethical allocation of gametes donated for the purpose of fertility treatment

Chief Investigator: Simon Jenkins, PhD Student, University of Birmingham

Supervisors:

Lead supervisor: Professor Heather Draper, University of Birmingham

Dr Sue Avery, Fertility Centre, Birmingham Women's Hospital

Dr Jonathan Ives, University of Birmingham

We are holding a workshop, to which you are invited. The study aims to find out how staff at fertility clinics in the UK make decisions about which patients to treat with donated eggs and sperm. The purpose of the workshop is to present the initial findings of the study, so that we can find out what people think about them, and to generate some discussion around the ethical issues that arise. So far we have conducted interviews with clinical staff and performed an ethical analysis using these, and considered the implications of different models that staff could use when making gamete allocation decisions. We'd now like to invite people to come and contribute to a discussion about these guidelines.

If you choose to participate, we'll follow legal and ethical practice so that all personal information about you is handled in confidence. Your contact details will be stored on a respondent database on a password-protected personal University of Birmingham computer, in an office that is only accessible through two swipecard-secured doors. The workshop will be audio recorded using a portable audio recording device, transferred to the University computer at the earliest available opportunity, and then deleted from the original recording device. The recording will then be transcribed, and stored on the University computer. The recording of the workshop needs to be kept because the study is being written up for a PhD thesis. The transcription will be anonymised. All electronic files will be backed up on a firewall-protected University server. Paper files (for example reply slips with your contact details on them and consent forms) will be stored in a locked filing cabinet in the same office as the computer. Personal details and audio recordings will be destroyed after the PhD project has been examined. The transcript and consent forms will be kept and securely stored for ten years before being destroyed.

Please be aware that the meeting will be audio recorded. If you are not willing to be recorded, you will not be able to participate in the workshop.

If you wish to take part, there is a reply slip enclosed for you to return using the stamped addressed envelope provided. I have also enclosed a flyer about the workshop, which will give you some more information about the programme for the day and other practical information. You may wish to display this in staff areas at your organisation to help us recruit for the workshop. If you have any concerns or questions about the workshop or any aspect of the study, you should ask to speak to the researcher who will do his best to answer any questions you have. For questions about the study, this document, or to participate in the study, please contact Simon Jenkins:

[REDACTED]

The workshop will be phase 2 of a study with 3 phases. On the reply slip you can indicate whether or not you're happy for us to contact you to invite you to phase 3, which will be a one-to-one interview, in which we'll explore people's views in a bit more depth. If you do not want to do an interview, you are still allowed to participate in the workshop.

What if I have a complaint?

If you have any concerns about any aspect of the study, you should ask to speak to the researcher who will do his best to answer any questions you have. If you wish to complain formally, you can contact Professor Heather Draper with the following information:

Professor Heather Draper
Centre for Biomedical Ethics
Primary Care Clinical Sciences Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT, UK

[REDACTED]

[REDACTED]

You can also contact Dr Sue Avery, Director of the Fertility Centre at Birmingham Women's Hospital, with the following information:

Dr Sue Avery
Birmingham Women's NHS Foundation Trust
Metchley Park Road, Edgbaston
Birmingham B15 2TG

[REDACTED]

Reply Slip:

Return this slip to Simon Jenkins at the University of Birmingham in the stamped and addressed envelope provided.

Name:	
Preferred contact address:	
Home or mobile telephone (in the unlikely event of the workshop's being cancelled at short notice):	
Email address:	
<p>I'd like to take part in this workshop. Please reserve me a place: <input type="checkbox"/></p> <p>I don't want to take part. Please don't contact me again: <input type="checkbox"/></p> <p>I'm happy for you to contact me about phase 3, the interview: <input type="checkbox"/></p> <p>If you're happy to take part, please tick your preferred means of contact:</p> <p>Phone call <input type="checkbox"/> Email <input type="checkbox"/></p> <p>Post <input type="checkbox"/> Text message <input type="checkbox"/></p>	

10.12 Appendix 12 – Consent Form (Phase Two)

Appendix 12 - Participant Consent Form (Phase 2) – Version 1.5 – 9.5.11



UNIVERSITY OF
BIRMINGHAM

The ethical allocation of gametes donated for the purpose of fertility treatment

Researcher: Simon Jenkins, PhD student, University of Birmingham

Lead supervisor: Professor Heather Draper. Other supervisors: Dr Sue Avery; Dr Jonathan Ives

Please
initial
box

1. I confirm that I have read and understand the information sheet dated 14.3.11 (version 1.5) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time before or during the workshop, without giving any reason, without my legal rights being affected. I understand that if I withdraw during the workshop, my anonymised comments may still be used in analysis.
3. I understand that the event will be audio recorded.
4. I would like to receive a summary of the results of this research.
(Please initial one box only) By email By post I do not want a summary
5. I give permission for the research team to contact me asking for feedback regarding the research summary.
6. I also give permission for my contact details to be used to send me information about interviews planned for the future. I understand that this agreement does not constitute consent to future participation, and that my participation may not be required.
7. I agree to take part in the above study.

Name of participant:

Signature: Date:

Name of person taking consent:

Signature: Date:

NRES ref number: 11/WM/0099 R&D ref number: 11/BWH/PO26



The ethical allocation of gametes donated for the purpose of fertility treatment

Chief Investigator: Simon Jenkins, PhD student, University of Birmingham

Supervisors:

Lead supervisor: Professor Heather Draper, University of Birmingham

Dr Sue Avery, Fertility Centre, Birmingham Women's Hospital

Dr Jonathan Ives, University of Birmingham

We would like to invite you to take part in our research study. Before you decide, it's important for you to understand why we're doing this research, and what participation would involve for you. Please take the time to read this information sheet carefully, and feel free to speak to others about the study if you wish. If you would like more information on any aspect of the study, or if there is anything in this information sheet that you don't understand, then please ask us.

What is the purpose of the research?

The study aims to find out how staff at fertility clinics in the UK make decisions about which patients to treat with donated eggs and sperm. The data collection for the study will take place in 3 phases, and this information sheet is about the third and final phase. Thus the information we want to collect now will become part of a larger project looking at the best way to allocate eggs and sperm. The purpose of this study is to explore the ethics of the allocation of donated eggs and sperm, and to identify best practice. We have already conducted interviews with practitioners and hosted a workshop to discuss our findings so far. A summary of the research so far and of the workshop is enclosed.

Why have I been invited?

We're trying to find out how people ought to make decisions about how to allocate donated gametes, and see how people feel about the idea of a national register of donors and recipients. You have been invited either because you attended our workshop at phase 2 of the study, or because you are someone whose views we think will be valuable to our study because of your professional or public role.

Do I have to take part?

You do not have to participate in this study if you don't want to. It is entirely up to you whether or not you do so. Once you've read this information sheet and had time to think, you can contact us to take the process further. We'll ask you to sign a consent form to show that you've agreed to take part. Even after signing the consent form, you'll be free to withdraw from the study at any time up until 48 hours after your interview has finished, without giving any reason. Withdrawing from the study won't affect your job in any way – we won't tell anyone you work with about your participation in the study or any interest you show in it.

What will happen to me if I take part?

If you do decide to participate, you'll be asked to attend an interview lasting about an hour, during which you'll be asked some questions about the allocation of eggs and sperm, with particular regard views that you expressed at the workshop if you attended, or to your views on the enclosed summary of the workshop. We'll record and transcribe the interview so that we can analyse your responses.

We'll try to make the interview as convenient as possible for you by arranging it to take place where you work, so you don't have to travel. If this isn't convenient for you then we can arrange something else, and reimburse you for travel expenses too. You won't get any money for participating but you might find it interesting and helpful to talk about ethical issues.

What will happen to my details and the information that I give?

Your personal details will be kept confidential, and anything you say during the interview will be anonymised. We'll follow legal and ethical practice so that all information about you is handled in confidence, and so no one but the research team will be able to find out that you've participated in the study unless you tell them yourself. Your contact details will be stored on a respondent database on a password-protected personal University of Birmingham computer, in an office that is only accessible through two swipecard-secured doors. Interviews and the workshop will be audio recorded using a portable audio recording device, transferred to the University computer at the earliest available opportunity, and then deleted from the original recording device. The recordings will then be transcribed, and stored on the University computer. The recording of the interview needs to be kept because the study is being written up for a PhD thesis. The transcriptions will be anonymised, and a key for the purpose of linking personal details to individual recordings/transcripts will be

kept in a different location on the same computer. All electronic files will be backed up on a firewall-protected University server. Paper files (for example reply slips and consent forms) will be stored in a locked filing cabinet in the same office as the computer. Personal details and audio recordings will be destroyed after the PhD project has been examined. Transcripts and consent forms will be kept and securely stored for ten years before being destroyed.

The research team will talk about the findings of the study as a whole, and the results will be published. Sometimes we will use word-for-word quotations, but we'll never identify you by name, and any other information that might identify you will be removed. Once the study is complete, you'll be allowed to see a summary of the results, if you like.

Will I get any money for taking part?

You won't be paid for participating in this study. As the interview will take place in your usual place of work, you won't incur any extra travel expenses.

What are the possible risks and disadvantages of taking part?

The interview should not be too burdensome, and does not carry significant risk. However, we understand that some of the questions we'll be asking in the interview might cause a bit of discomfort, as we are asking personal questions about ethical viewpoints. If you do find the interview uncomfortable you are free to withdraw at any time during the interview or for up to 48 hours afterwards, and you don't have to give any reason for this.

Who is organising and funding the study?

Simon Jenkins, a PhD student at the University of Birmingham, is organising the study. Professor Heather Draper and Dr Jonathan Ives from the Centre for Biomedical Ethics at the University of Birmingham will supervise the study, along with Dr Sue Avery from the Fertility Centre at Birmingham Women's Hospital. The Arts and Humanities Research Council is funding the research.

What if I have a complaint?

If you have any concerns about any aspect of the study, you should ask to speak to the researcher who will do his best to answer any questions you have. If you wish to complain formally, you can contact Professor Heather Draper with the following information:

Professor Heather Draper

Centre for Biomedical Ethics
Primary Care Clinical Sciences Building
University of Birmingham
Edgbaston
Birmingham
B15 2TT, UK

[REDACTED]

[REDACTED]

What do I do if I want to participate or find out more?

For questions about the study, this document, or to participate in the study, please contact Simon Jenkins: [REDACTED]

You can also contact Dr Sue Avery, Director of the Fertility Centre at Birmingham Women's Hospital, with the following information:

Dr Sue Avery
Birmingham Women's NHS Foundation Trust
Metchley Park Road, Edgbaston
Birmingham B15 2TG

[REDACTED]

Reply Slip:

Return this slip to Simon Jenkins at the University of Birmingham in the stamped and addressed envelope provided.

Name:	
Preferred contact address:	
Home Telephone at preferred address:	
Mobile:	
Email address:	
<p>I'd like to take part in this interview: <input type="checkbox"/></p> <p>I don't want to take part. Please don't contact me again: <input type="checkbox"/></p> <p>If you're happy to take part, please tick your preferred means of contact:</p> <p>Phone call <input type="checkbox"/> Email <input type="checkbox"/></p> <p>Post <input type="checkbox"/> Text message <input type="checkbox"/></p>	

Please use this space to let us know if there are any times that are particularly convenient or inconvenient to contact you. We will do our best to be flexible and arrange an interview time that suits you.

10.14 Appendix 14 – Consent Form (Phase Three)

Appendix 14 - Participant Consent Form (Phase 3) – Version 1.6 – 9.5.11

**UNIVERSITY OF
BIRMINGHAM**

The ethical allocation of gametes donated for the purpose of fertility treatment

Researcher: Simon Jenkins, PhD student, University of Birmingham

Lead supervisor: Professor Heather Draper. Other supervisors: Dr Sue Avery; Dr Jonathan Ives

Please
initial
box

1. I confirm that I have read and understand the information sheet dated 14.3.11 (version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time up to 48 hours after the interview has taken place without giving any reason, without my legal rights being affected.
3. I understand that my interview will be audio recorded.
4. I would like to receive a summary of the results of this research.
(Please initial one box only) By email By post I do not want a summary
5. I give permission for the research team to contact me asking for feedback regarding the research summary.
6. I agree to take part in the above study.

Name of participant:

Signature: Date:

Name of person taking consent:

Signature: Date:

10.15 Appendix 15 – Sample of Coded Transcript

11: Um, we are a private clinic [I: mmmhmm] and the patient decides, if she, we base well we're talking eggs, if we're talking eggs first of all [I: sure, yeah] and then we'll deal with sperm [I: yeah]. Um, eggs point of view it's based on her past history what's called her ovarian reserve and her age, so these things we'll say look, really you need donor eggs, and then what we do is we say, we have 2 options, one is our in-house donor programme, the waiting times are about 16 months, um, we don't know how that's gonna change come April the 1st and that might come out in other questions, um and then we have a link with Valencia in Spain, and 90% of our patients go to Valencia, because it's quicker, from signing consent forms to going out is about 10 weeks.

I: Ok.

11: And success rates are fantastic 'cos they're mostly students who've been the donors [I: right], um, so, so, we send 8 or 9 patients a month to Valencia.

I: Right, ok.

11: So.

I: Ok.

11: So now from sperm, obviously then it's a case of um, azoospermic or there's a major sperm problem, um, therefore you need donor sperm, and again there are 2 options from our point of view, we have an in-house programme, it's not huge, we've only got 4 donors on the list at the minute. And we bring a lot of sperm in from the European Sperm Bank to um, for couples who need donor sperm [I: mmm], or single women or lesbian women.

I: Yep.

11: Yeah.

I: Ok, um so you've mentioned quite a few different things that I'd like to um, sort of tease out um, so you mentioned kind of, if I can sort of categorise things into two groups there's kind of medical considerations and ethical ones [I: yeah] right. So I'm sort of particularly interested in the kind of ethical [I: yeah, sure] considerations. Um, so you mentioned age [I: yeah] as, so can you say a bit more about how a patient's age affects whether they go on the waiting list?

11: Um, we have uh, Valencia will treat patients up to age 50. They will treat patients older than that provided they're not diabetic, they're not hypertensive, that kind of thing. We pretty much have the criteria although in fact our ethics committee which is made up of, so the chairman is a retired lawyer there's a OK on the committee, a journalist somebody from INEIK uh, and who's the other

Single parents

Anonymity

yuck factor

Parenthood

cancer

Mental capacity

liberty

Bottom of list

Non-judgemental

Honesty

Smoking

NHS

Family dynamics

Known donors

Height

Harm

Finances

natural

waiting time

Work vs. personal opinion

Efficacy of treatment

Patients' wellbeing

Law

Responsibility

Spain

Same-sex couples

Family donation

Decision-r

Medical re

BMI

genetic issue

Patient choice

coercion

Non-NHS clinics

Queue-jump

Other clinics

Policies

Ethics con

Counselling

Waiting list

Welfare of the child

Age

Coding Density



**Birmingham Women's NHS
Foundation Trust Charities**
Registered Charity No.1089035

The Ethical Allocation of Gametes Donated for Fertility Treatment

An empirically-informed philosophical analysis of gamete allocation

Briefing Summary
for the
Gamete Allocation Workshop
at
Birmingham Women's Hospital
19th October 2012

Simon Jenkins
Doctoral Researcher

Medicine, Ethics, Society & History
University of Birmingham

Supervisors
Lead: Professor Heather Draper
Dr Sue Avery
Dr Jonathan Ives

How should staff at UK fertility clinics decide who to treat with donated sperm and eggs?

Background

The need for a serious examination of the ethics of the allocation of donated gametes arises in part because gametes are a scarce resource. The National Gamete Donation Trust reports that 384 men donated sperm in 2008, when the number that was needed to treat all the hopeful recipients was more than 500¹. Their figures suggest an even greater shortfall for eggs: in the same year, 707 women donated eggs compared to a need for over 1200 donors to meet demand.² Insufficient supply means that decisions about gamete allocation, while bringing joy to some, will bring disappointment to others. This provides a motivation for ensuring that we make allocation decisions correctly. Such scarcities lie at the heart of many ethical problems. Sometimes these centre on tangible goods like gametes, at other times they concern more abstract things like happiness or welfare. Aside from the scarcity of gametes themselves, there may be reasons to withhold treatment from certain patients altogether.

Aims

The overall aims of the project are to determine what allocation criteria for donated gametes are being used by clinics in the UK (including those which govern admission to waiting lists), and to determine what criteria should be used for this allocation, with particular emphasis on the ethical status of known donation and a national waiting list.

The aim of this workshop is to present some recommendations for gamete allocation and get feedback on them from relevant professionals, service providers and stakeholders. The responses and comments of attendees will be recorded, analysed and integrated with these recommendations to account for the views expressed at the workshop.

Methodology

The project takes an iterative approach to integrating philosophical theory with empirical data. It began with pre-empirical theoretical work, which was then revised in light of the Phase 1 of the data collection - qualitative interviews with clinical staff (see below). Phase 2 of the data collection is this workshop. Phase 3 will be a second set of one-to-one interviews aimed at investigating ideas that arose in the workshop in greater detail. Figure 1 demonstrates the relationship between theory and data collection in the project.

¹ National Gamete Donation Trust (2012), 'Becoming a Sperm Donor', available at: <http://www.ngdt.co.uk/downloads/Becoming%20a%20Sperm%20Donor%20V10.pdf>, accessed 12.9.12

² National Gamete Donation Trust (2012), 'Becoming an Egg Donor', available at: <http://www.ngdt.co.uk/downloads/Becoming%20a%20Egg%20Donor%20V6.pdf>, accessed 12.9.12

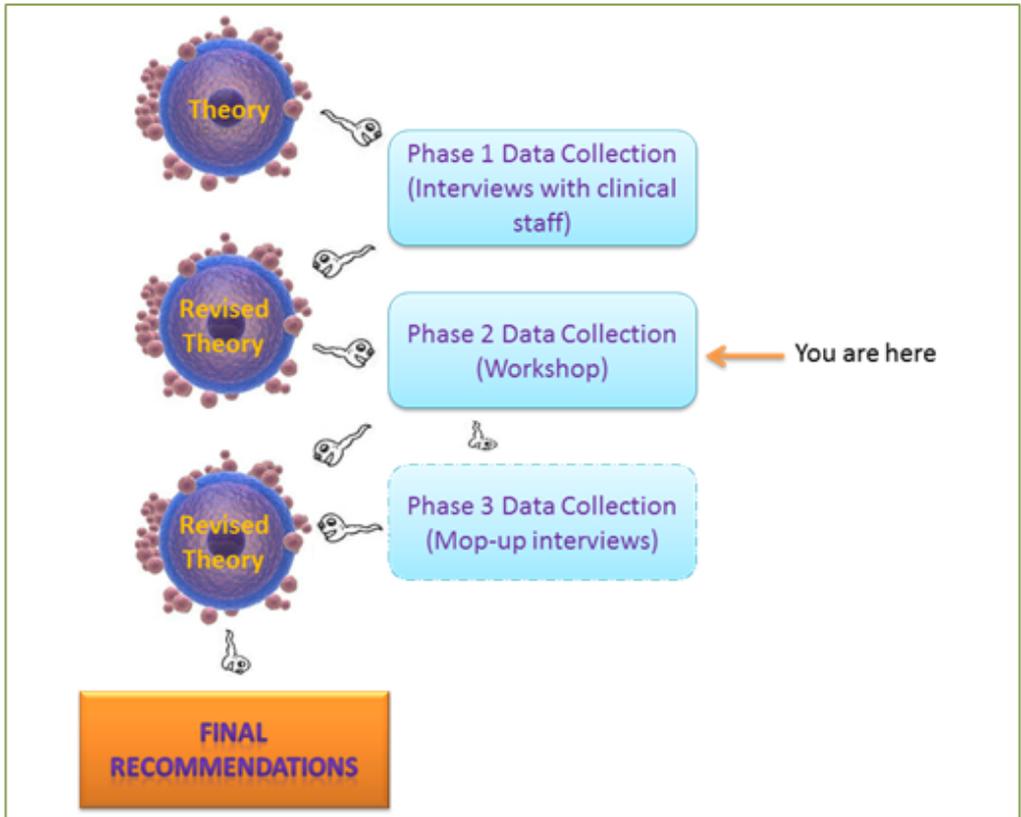


Figure 1

Data Collection Phase 1
Purposive/snowball sampling
 Phase 1 data collected using face-to-face interviews
 Data analysed using content analysis of verbatim interview transcriptions

Clinic profiles (n= 7)	Participant profiles (n=18)
5 NHS, 2 private 3 in Scotland 3 in England 1 in Wales	14 female, 4 male 3 egg donor co-ordinators 3 nursing staff members 2 sperm donor co-ordinators 2 medical directors 2 counsellors 1 embryologist 2 gynaecologists 1 clinical midwife 2 other clinical staff

Emerging Recommendations

Priority System

- Order of arrival at a clinic is not the only morally relevant consideration.
- Patients' "scores" should be based on other considerations: age, body mass index, genetic diseases, patients' substance use (including smoking), violent history, and previous parenthood.
- Status as single patients or same-sex couples is irrelevant.
- Consideration of age depends on the size of the waiting list to ensure maximum efficacy:
 - short lists: older patients will eventually receive treatment anyway, so should be prioritised for maximum efficacy;
 - long lists: older patients should be excluded as younger patients more effective to treat.

Welfare of the Child

- Children's vulnerability requires that their welfare be treated as a paramount consideration.
- Serious child welfare concerns include dependence on non-therapeutic drugs or alcohol and violence.
- As well as counting against patients in the priority system, these considerations may result in outright exclusion from treatment.

Known Donors and Donor Stipulations

- Use of known donors disadvantages no one – recipient gets faster treatment, others unaffected.
- Donor stipulations similar except for potential harm to offended parties (donor-conceived people might be unhappy to learn of their donors' views), but the benefits are still worth the risk.

National Waiting List

- Fairer as time on waiting list not affected by patient's location.
- Potentially costly but costs should be properly explored.
- Could help to standardise treatment criteria.

How should the following be prioritised?

Pre-workshop exercise: put the following four cases in the order in which you think they should be treated.

Bob and Betty have been trying for a baby for many months but to no avail. Semen analysis has revealed that Bob has no sperm, and they have been presented with the possibility of treating Betty with donor sperm in order to allow her to conceive. After referral to a fertility clinic, they underwent some routine counselling during which it transpired that Bob has been struggling with an alcohol problem, and has some anger issues that sometimes manifest themselves in the form of physical violence against Betty. Both Bob and Betty, however, insist that the problems are the result of stress and frustration at their infertility situation, and claim that having a child together is what they need in order to achieve a harmonious family environment. The clinic now needs to decide whether to go ahead and give them the treatment that they want.

Jim is infertile. His wife Alice is deaf, and while Jim is not deaf and is not a carrier, Alice's deafness is a dominant trait, so any child she and Jim have will have a 50% chance of inheriting her deafness. Jim and Alice are informed but still want fertility treatment. They cannot afford PGD, and at any rate they are ideologically opposed to its use in the case of deafness. Staff at the clinic are concerned about replacing embryos with a 50% chance of inheriting deafness, particularly when PGD could prevent this.

Alice and Jim are willing to using a donor egg to conceive but concerned about the waiting time so prefer to use Alice's eggs.

The clinic must now decide whether to treat Alice with a donor egg and sperm, or to artificially inseminate her with donor sperm using her own egg (with a 50% chance that the child will be deaf).

Jane had radiotherapy treatment for cancer when she was younger, and because of this she can no longer produce eggs of her own. She and her husband Albert have been on a waiting list at their clinic for about six months, hoping to get treatment with donor eggs. Jane's local clinic has a policy of not treating women aged 50 or above, and as she is nearly 50, she is concerned that if she is made to wait much longer, she will be excluded from the list altogether because of her age. The clinic needs to consider whether to jump her to the top of their waiting list.

Tess and Emily are a lesbian couple hoping to get treatment with donor sperm. Their mutual friend Robert had agreed to donate sperm to help them conceive, but changed his mind at the last minute, saying he was no longer comfortable with the idea. Eventually they find another donor, Ed, who does not want his sperm to go to a lesbian couple but is willing to donate to the clinic so that Tess and Emily can be treated as quickly as they would have been using a known donor. The clinic needs to decide whether to put Tess and Emily at the top of the waiting list in exchange for Ed's sperm.

Use the tear-off slip below to rank these four cases according to the order in which you think they should be treated (with a "1" for first and so on). Give the tear off-off slip to one of our friendly helpers.

Bob and Betty	Jim and Alice	Jane and Albert	Tess and Emily

Programme

09.30 – Arrival and registration (+ tea and coffee)

10.00 – Introduction from Sue Avery

10.10 – Simon Jenkins: 'The ethical allocation of gametes donated for fertility treatment'

10.50 – Questions for SJ

11.05 – David Archard: 'Regulating gamete allocation: ethics, law and policy'

11.25 – Laura Witjens

11.45 – Questions for DA and LW

12.00 – Comfort break

12.10 – Breakout groups*

13.30 – Back together for discussion

14.30 – Evan Harris

14.50 – Questions for EH

15.00 – Suggestions for recommendation revision from SJ

15.30 – Close

*A light buffet lunch will be served during the group sessions.

The Ethical Allocation of Gametes Donated for Fertility Treatment

Simon Jenkins
Medicine, Ethics, Society and History
(MESH)
spj029@bham.ac.uk

Professor Heather Draper
Dr Sue Avery
Dr Jonathan Ives



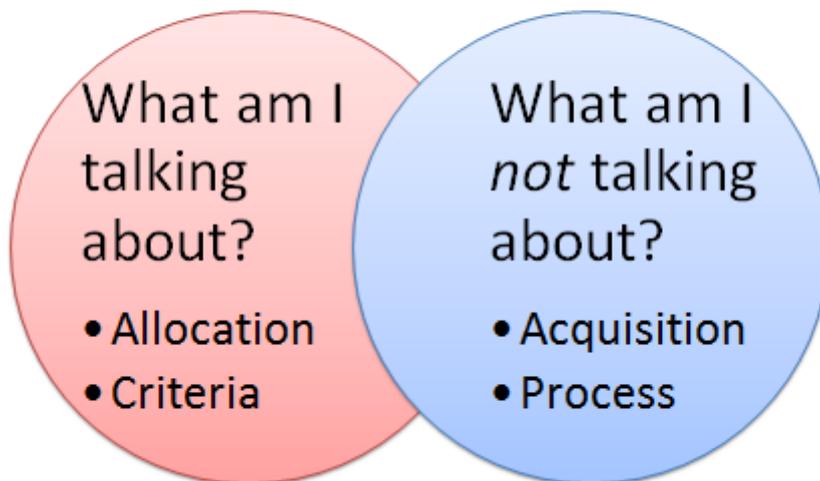
Birmingham Women's NHS
Foundation Trust Charities
Registered Charity No.1089035

1

Overview



1



3

Key recommendations



4

prioritisation root

Can we do better than just treating people in the order they arrive at the clinic?

Is "I got here first" a morally relevant factor?

If there was *no other basis* on which to make a judgement, a "first come, first served" system might be ok. But aren't there other bases?

Pragmatism

'One should be careful not to include too many factors in order to obtain a practical system which is not too cumbersome for the clinic to maintain and which is transparent for the patients'

- Pennings (2005)

7

A purely practical system might look like a "first come, first served" system. But of course there are practical difficulties with all sorts of things – welfare of the child assessments could be an example. Would we be justified in dispensing with these for purely practical reasons?

There can be moral reasons to do things even if they are practically inconvenient

8

How impractical is too impractical?

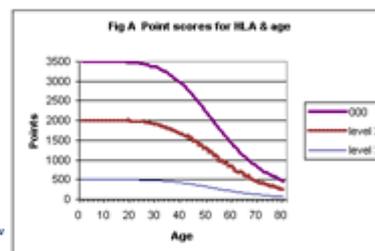
- We should be wary of failing to account for morally relevant considerations on the basis that they are practically inconvenient
- This is especially true if other, similar systems are already in place for the allocation of other resources and seem to be working fine...

9

Algorithm for Kidney Transplants

- This scheme is based on five Tiers:
- 000 mismatched paediatric patients - highly sensitised* or HLA-DR homozygous
- 000 mismatched paediatric patients - crosssensitised* or HLA-DR homozygous
- 000 mismatched adult patients - highly
- 000 mismatched adult patients - others & favourably matched paediatric patients (100, 010, 110 mismatches)
- All other eligible patients
- * $\geq 25\%$ calculated reaction frequency (based on comparison with pool of 10,000 donor HLA types on national database)
- Paediatric patients in Tiers A and B are prioritised according to waiting time. In the remaining Tiers, patients are prioritised according to a points score based on:

- Waiting time (1)
- HLA match & age combined (2)
- Donor-recipient age difference (3)
- Location of patient relative to donor (4)
- HLA-DR homozygosity (5)
- HLA-B homozygosity (6)
- Blood group match (7)
- Points scores are calculated as shown:
- (1) Waiting time points = number of days of waiting time accrued (see definitions)
- (2) HLA match & age points combined are defined as:
 $\text{points} = 3500 / (1 + (\text{age} / 55)^5)$ if level 1 mismatch
 $2000 / (1 + (\text{age} / 55)^5)$ if level 2 mismatch
 $500 / (1 + (\text{age} / 55)^5)$ if level 3 mismatch
 Points scores are illustrated in Figure A and mismatch levels are shown in Table C below



- (3) Age difference points = $-1/2$ (donor-recipient age difference)²
- (4) Location points =
- 900 for patients at the same centre as the donor
- 750 for patients at another centre within the local area as defined below:
 Area A - Bristol, Cardiff, London (Guy's, Royal Free, Royal London, St George's and the West London Renal Transplant Centre), Oxford, Plymouth and Portsmouth
 Area B - Belfast, Birmingham, Coventry, Cambridge, Leicester, Nottingham and Sheffield
 Area C - Edinburgh, Glasgow, Leeds, Liverpool, Manchester and Newcastle
- (5) HLA-DR homozygous points = 500 for all HLA-DR homozygous patients (where HLA level > 1)
- (6) HLA-B homozygous points = 100 for all HLA-B homozygous patients (where HLA level > 1)
- (7) Blood group points = -1000 for blood group B patients when the donor is group O (Tiers D and E only)

10

Exclusion

As hinted at earlier, there are some situations in which we won't want to treat a couple/patient at all. These people can (in some cases) be excluded outright and won't make it onto the waiting list

[W]e don't want to provide another football to get kicked round the family home - participant 02

11

Criteria

Age

12

Why discriminate based on age?

- Welfare of the child
 - Physical risk?
 - Social risk?
- Safety of patient
 - vs. autonomy?
- Treatment efficacy
 - Gamete wastage
 - Disappointment for patient?

13

Welfare of Child (re: age)

‘Increasing maternal age was associated with improved health and development for children up to 5 years of age’

- Sutcliffe et al (2012)

N.B. this doesn't account for the potential problem (for the children) of early parental death

14

1. AGE – all clinics had (a) defined upper age limit(s).

Most common reason **efficacy**

[T]he age limit has to be linked to the efficacy of the treatment - participant 03

Sometimes **efficacy linked to child welfare:**

[Y]ou just don't see people being pregnant over the age of really realistically 43 [...I]n your back of your mind you're wondering what will happen in, you know when they are actually pregnant when they get to their antenatal appointments the likelihood of getting a good outcome is slim, you know? I send them away thinking "gosh I hope that baby's not Down's". - participant 07

13

Such **risks increase continuously with age**. Support for priority system rather than discrete cut offs?

Next comment cites age cutoff as being not due to efficacy per se, but to do with mirroring pregnancies outside the fertility clinic:

[T]here are natural pregnancies 48, possibly 47 48, so I think 50 is a, a good time to stop - participant 06

16

Participants thought that discrete age cutoffs (i.e. refusing to put patients on the waiting list outright) were permissible but (usually) felt that it was unfair and thus *impermissible* to move people around once on the waiting list

17

- In some cases, participants reported that an older patient could actually be advantaged by their age (this runs contrary to the recommendation I had made about prioritising younger patients):

When they're near the upper age limit we'll always try and find them a donor sooner so they might jump the queue, because otherwise they would not get treated at all

- participant 09

18

Other participants felt differently, however:

'I think it's very unfair if you've come to me, put your name on the waiting list, and you've been waiting for 12 months, 16 months, and then somebody else has come on the list and gets treatment before you' – participant 13

19

Discussion

- Inconsistent to say that it is unfair to discriminate against people because of their age when some people are excluded outright on this basis
- Always prioritising the young, however, does **not** maximise the efficacy of gametes

20

Substance Use

21

Recommendation

While it is certainly true that someone's being a substance user (recreational drugs, alcoholic, smoker) does not necessarily mean welfare of the child problems, it increases the likelihood, and so clinical staff should be wary of this and willing to disqualify on these grounds

22

2. SUBSTANCE USE

Disparity between participants' reports about how serious a consideration this was treated as:

'[I]f people were using recreational drugs and had told us about it then again we would be looking for them to have stopped that before they were going through any treatment. - participant 14

[E]ven someone being a habitual drug user doesn't necessarily mean that you feel that they have a welfare of the child issue
- participant 07

[Y]ou can't speak to the patients and say "you're both alcoholics, we're not gonna treat you we can't give you a baby" 'cos you don't know what goes on in their lives - participant 08

23

Parental Status



24

Discussion

Is a patient's need for their first child more important than their need for a second?

Do the patients need children at all or do they just want them, and does this distinction help us to negotiate different patients' claims?

How does the resource scarcity issue factor into this?

23

[H]er need to have another child is not as high as that of somebody who hasn't got any children - participant 09

[T]he health service is short of money and you've already got one. So we'd prefer to put the money into some that's the way I would see it, into something, more important

- participant 01

[E]veryone's on that waiting list for different reasons, maybe a second relationship, it may be that having a second child is just as important if not more important than having a first child, or what however many children - participant 04

25

Parental status - recommendation

- Previous parental status should be accounted for

But potential theoretical issues
(difficulty/impossibility of weighing up
desires/needs to reproduce)

Practical issues: child abandonment?

27

SINGLE PATIENTS AND SAME-SEX COUPLES

28

Discussion

No evidence that the presence of a mother is essential, so no justification for discriminating against men

No evidence that children raised by same-sex couples encounter extra problems as a result of this, so no justification for discriminating here, either

Research supports the view that same-sex parents are able to provide such supportive parenting to the same degree as heterosexual parents. See for example (Stacey and Biblarz 2001); (Wainright et al. 2004); (Wainright and Patterson 2006)

29

[S]ingle women or same-sex, they're, why should they not be treated? There has to be a very good reason not to treat - participant 05

I feel that the presence of a mother is absolutely essential. The presence of a father is not that essential it's preferable, but I don't feel it's essential ,[...] so, our policy clinic, uh our clinic policy is not to treat same-sex male couples. [...]his is not a practical problem as in difficulty obtaining. There obviously there would be difficulty like in any donor egg treatment there's always difficulty in obtaining eggs, or and obtaining surrogates, but that is not the reason why we decline the treatment to them. It is more an uh ethical concern than a practical concern. – participant 10

30

[W]hat we accept in this society as a norm, there is a mother and a father. And both have their place in child's upbringing. Children I feel, they need their mother more when they're young, I think. But paternal influence is equally important. And I don't quite know how these children cope with, I don't know what happens to them when they go to school. How do they face that? How the other children react to them. - participant 15

31

5. WELFARE OF THE CHILD

Importance:

[Welfare of the child considerations are] all paramount 'cos I, I mean it's the child that's at the centre of it all - participant 03

[T]he HFEA guidance is to do what's right for the unborn child. You know if you're really reading into theirs that would be their paramount, um and it certainly is ours but you also have to do right by the couple - participant 05

[T]here can be welfare of child issues even when there's no physical welfare of the patient issues. But the other way round when there's welfare of the patient issues almost invariably there'll be uh implication the welfare of the child - participant 09

32

WELFARE OF THE CHILD (continued)

Timing of assessment:

[I]n our clinic we do welfare of the child at the first visit for everyone

- participant 05

[T]he way we do it is when we see patients to discuss treatment which is when they're well up the waiting list, welfare of the child issues issues will be discussed at that point. - participant 06

[I]f we have made a mistake in assessing their eligibility if we have told them, you will be treated, we will still treat. 'Cos there may be cases when they have a child living with them which is another reason why they shouldn't have NHS treatment, and this has only come out later, if we have promised that we will treat, they will be treated. I think we are probably afraid of patients complaining. Yeah, we want to stick to our promises. We don't want to go back and say "oh sorry", um. "There was [a] mistake". - participant 16

33

Timing of assessment (discussion)

Early assessment: could save time to deal with automatic excluders straight away. But if waiting times are several months/years, something could come up in the interim

Late assessment: waste of time to do workup only to find they are excluded anyway

Recommendation: early assessment with regular re-checks in the interim

34

Welfare of the child

- Violence, substance use, alcohol problems and smoking should all be taken seriously
- Financial factors can be accounted for
- Staff should consider what might happen if they *refuse* to treat. Consider:

Couple A: Carrier of hereditary disease; fertile

Couple B: Carrier of hereditary disease; *infertile*

We should prioritise couple A

35

KNOWN DONORS

36

Discussion – known donors

It is indeed unfair that some patients get the benefit of known donation while others do not.

But banning it doesn't improve the situation for anyone, so perhaps it should still be allowed (in some forms?)

Same *could* apply to donor stipulations, but there is more scope for harm here (offence?)

37

[W]hy can't people bring their own donors in? Why can't people do that? No reason why not. - participant 02

You know so it is a bit of a win-win if they, if they're on the waiting list and they don't recruit somebody, then you're stood where you are, but if they've recruited the donor you actually move up. - participant 03

[I]t's ok to say "I just want my family, my my friend to just use this donor sperm." I think there's a very sort of clear distinction between that, um I think there's a big difference from someone saying "oh I'll I only I don't want same sex couples using my sperm" - participant 08

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NATIONAL WAITING LIST

39

Everyone was against it!

Absolutely not, when I see the waiting list I've got here, and matching characteristics with what we've got, it's a minefield

- participant 13

[T]he expense involved in having this kind of national system - participant 07

40

[W]hy should I send my you know we've worked bloody hard, we've put hours into these which is really mean, and small-minded, and I know all this, but you know [...]. Am I gonna hand those nice lads off to [other clinic] who can't be bloody arsed? And anyway, who are makin' shedloads more money than we are out of the whole deal. Um, 'cos we want to keep our prices down. They don't bother about that, and they're gonna waltz off with my donors? Bugger off. It's mine.

- participant 02

41

Discussion

Is matching really that difficult? Less complicated than tissue matching

Expense could be prohibitive. No point making things fairer if it just makes things worse for everyone overall

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Summary of Recommendations

- A priority system is favourable as it can provide better treatment outcomes and help secure WofC to a reasonable degree. This could account for age, BMI, genetic diseases, substance use, people with children already, and violence, but *not* for same-sex couples or single patients
- Staff should also be more willing to exclude outright for WofC reasons
- Known donors and donor stipulations permissible
- National waiting list could be tenable but we should be wary of cost

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Close and Bibliography

- Aglioni, S. and Harris, J. (2020) Should the foundation of families be regulated? *CRISPR and Family Law Quarterly*, 13 (1), 191-211.

- Anderson, H.F. and Cook, D.B. (1997) Postconception and sudden infant death syndrome: review of the epidemiological evidence. *Thromb. Haem.* 77 (11), 1023-1029.

- Appleton, C., Berlin, L., Kessler, G., et al. (2011) Preventing Birth Defect Medication: Implications from a Longitudinal Study of Maternal Abuse History, Substance Use Problems, and Offspring Malformation. *Prenatal Diagnosis*, 31 (2), 139-149.

- Basuluma, T. (2007) *Principles of Health Care Ethics*. John Wiley & Sons.

- Basuluma, T. and Chikara, J. (2021) *Principles of Biomedical Ethics*. 20th Oxford Oxford University Press.

- Bender, D. (1998) The Undesirable Effects of Bringing into Being. *Journal of Applied Philosophy*, 15 (1), 173-182.

- Bender, D. (2000) Better Never to Have Been: The Harm of Coming into Existence. *Clarendon Press*.

- Braker, M. and Cox, B. (2007) Medicine, patients and the law. *Penguin Books*.

- CDC. (2009) *Underpinning of Clinical Ethics committees: An interdisciplinary qualitative study*. *Clinical Ethics*, 4 (2), 91-97.

- Brooks, John (2020) *Slipping into New York*. Oxford University Press.

- Busch, David. (2020) *Moral Dimensions of the Stem Cell Research of Pluripotency*. Available at <https://www.gutenberg.org/files/59999/59999-h/59999-h.htm>

- Culy, David B. and Bartlett, Lisa (2010) *Natural versus Assisted Reproduction in South Africa*. In *Studies in Ethics, Law and Technology*, 1 (1).

- Dunbar-Walters, Christened Leela. *New York*.

- Ford, Philipp (2021) *The Fragments of Creation and the Decline of Double Effect*. In *Virtues and Vices*. New York: CUP

- Gill, B. (2020) *Morality, the Future and Justification*. Oxford University Press, 120.

- Human Fertilisation and Embryology Act (1990) (London). [Accessed 10/8/22]

- Jolly, M., Sakre, N., Harris, J., Robinson, David Page. (2020) The role associated with pregnancy in women aged 40 years and over. In *Human Reproduction*, 35 (11), pp 2189-2197

- Kaplan, Shaly (1998) *The Limits of Morality*. Oxford Oxford University Press

- Kaufman, Jay et al. (2011) Characteristics of Young Children Born to Mothers Who Self-Identify as Gay. In *Journal of Interpersonal Violence*, vol. 26, no. 10, pp. 2011-2021

- Lippert-Rasmussen, Susan (2011) *Moral Discrimination: Some Points, available at www.le.ac.uk/lrc/teaching/moral_discrimination.doc*

- Lutz, Maria (2020) *Preventive Parental Paternalism: On the Moral Significance of Who We Have Children*. In *Bioethics*

- Mink, Jon M., Mink, David B., Fessler, Alan J. and Brubaker, Alan (2020) Single Parents, Working Mothers, and the Educational Achievement of School Children. In *Journal of Education*, vol. 29, pp. 111-138

- Nagel, Tom (2000) *Justice for All*. New York: Oxford University Press

- Parfit, Derek (1984) *Persons and Passions*. New York: Oxford University Press

- Patterson, D. (2011) *The Value of Body Material: Acquiring and Misusing Human Genes*. *Medical Law Review*

- Penning, B. (2002) *Genetic Screening in context: an interdisciplinary approach*. *Human Reproduction*, 17 (11), 2190-2193.

- Parfit, David (2000) *The Reasons of Morality*. New York: Oxford University Press

- Rawls, John (1971) *A Theory of Justice*. Cambridge: Oxford University Press

- Rawls, John (1993) *The Morality of Freedom*. New York: Oxford University Press

- Robertson, John D. (1990) *Children of Choice: Freedom and the Ethics of Reproductive Technologies*. Chichester: Friesen University Press

- Savelle, Julian (1999) *Should Doctors Infinitely Devalue the Dead?* In *Journal of Medical Ethics*, 13

- Savelle, Julian (2001) *Preventive Parental Paternalism: Who We Should Save: The Bad Children*. In *Bioethics*, 15 (2), 210.

- Savelle, Julian and Kilgus, Ben (2009) *The Moral Obligation to Create Children with the Best Chances at the Best Life*. In *Bioethics*, 23 (2), pp 171-180

- Smart, Judith and Williams, Bernard (1975) *Utilitarianism: For and Against*. Cambridge: Cambridge University Press

- Zamy, Judith and Kilgus, Ben (2011) *Who Deserves the Best? Orientation of Parents Matter*. In *American Bioethics*, vol. 25, no. 2, pp. 119-122

- Zeman and Cass (1987) *Parental smoking and lower respiratory illness in infancy and early childhood*. In *Thorax*, 41, pp. 802-814

- Zuffante, S.B., Barnes, J., Belsky, J., et al. (2011) *Workload and Development of children born to older mothers in the United Kingdom: observational study using longitudinal infant data*. *BMJ*, 343 (7812).

- Taylor, et al. (2007) *Morality of studies of passive smoking and lung cancer: ethics of study (passive smoking)*. In *International Journal of Epidemiology*, 36, 1019-1028

- Tomlin, Larry J. (1990) *Inequality*. New York: Oxford University Press

- Tomlin, Larry J. (2000) *Equality, Priority and the Leading Down Option*. In *The Quest for Justice*, ed. by Matthew Clayton and Andrew Williams. Basingstoke: Macmillan, pp. 110-121

- Thomson, Judith (1980) *Taking, Letting Die and the Trolley Problem: In Rights, Preferences, and Fairness in Moral Theory*, ed. by W. Parfit. Cambridge: Harvard University Press

- Van Oosterhout, D. and Pines, C. (2021) *Environmental Ethics & Public Health*. Thomson: Nelson Aulick

- Wang, Jennifer et al. (2020) *Preventive Paternalism, Defiant Children, and Parental Relationships of Adolescents with Gender Parents*. In *CRISPR Development*, vol. 73, no. 2, p. 1220

- Wang, Jennifer and Patterson, Charles R. (2020) *Discrimination and substance use among adolescents with female same-sex parents*. In *Journal of Family Psychology*, vol. 34, no. 2, pp. 210-218

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Questions

1. To what extent do you agree that child welfare should be the paramount consideration? What do you take “paramount” to mean in this context?
2. To what extent do you agree that a patient's previous parenthood should be taken into account, and for what reasons? What do you think counts as previous parenthood, and if there are different ways of conceiving of parenthood, should they count differently (i.e. have different weight)?
3. To what extent do you agree that the use of known donors disadvantages no one? What do you think are the risks of allowing donors to stipulate who can use their gametes?
4. To what extent do you agree that a national waiting list would be fairer? What do you think the costs of such a system would be?

10.19 Appendix 19 – Phase Three Topic Guides

Participant 32

1. What do you think about clinics allowing donors to make stipulations about who can receive their gametes?
2. What do you think are the issues surrounding safeguarding child welfare when the child in question is yet to be conceived?
3. What do you think of the idea of prioritising patients rather than treating them on a “first come, first served” basis?
4. How do you think the HFEA would view the prioritisation scheme, and the ideas presented at the workshop about what criteria should be used? What practical difficulties do you foresee for the proposals, both personally and from the perspective of the HFEA?

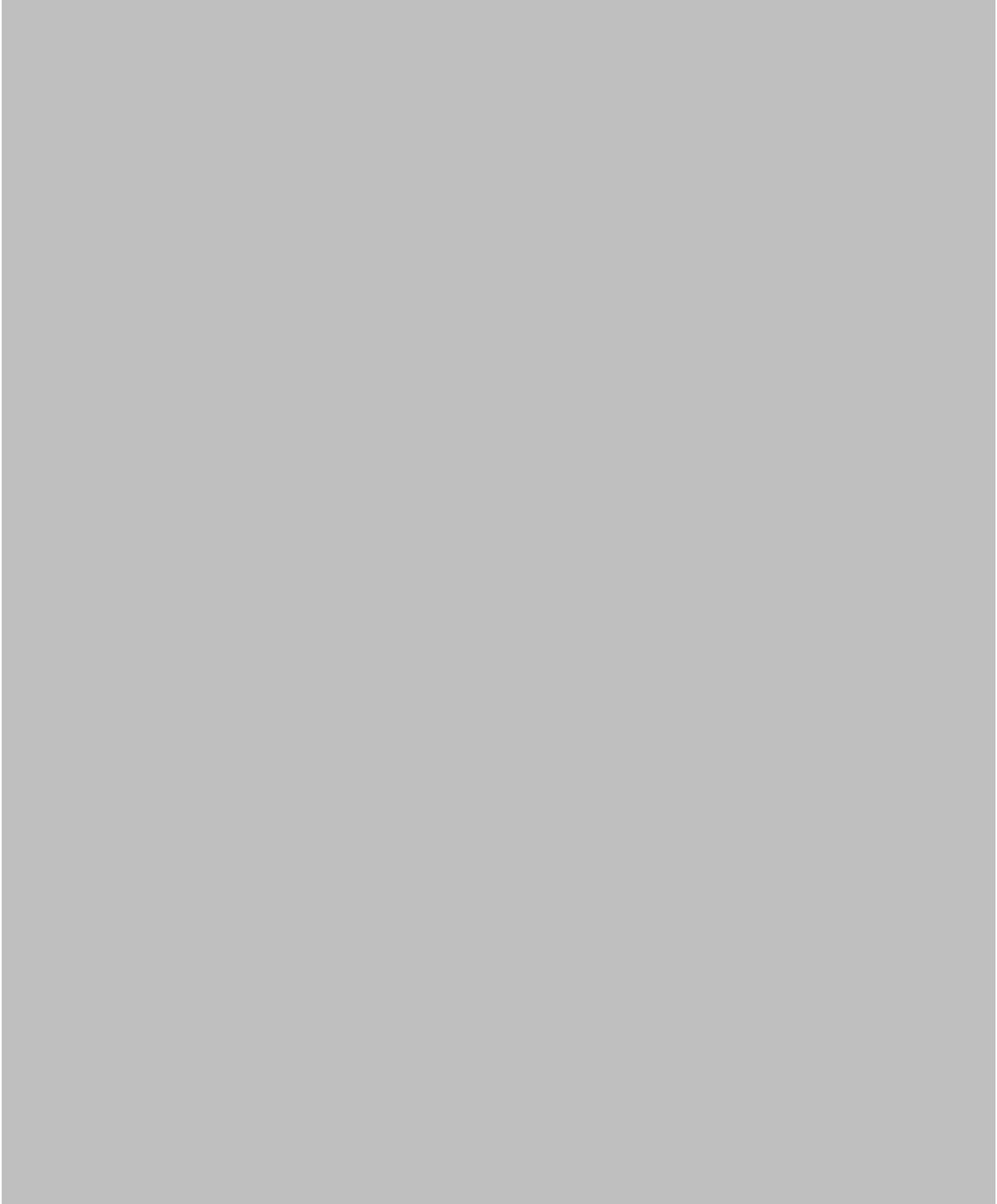
Participant 31

1. What do you think is the solution to the freeriding issue that arose with regard to having national waiting lists for donated gametes? (This was the issue that some clinics would not see the benefit of the recruitment that they themselves undertook).
2. How do you think efficiency could be improved to meet scarcity issues?
3. How do you think welfare of the child should be assessed, if at all?

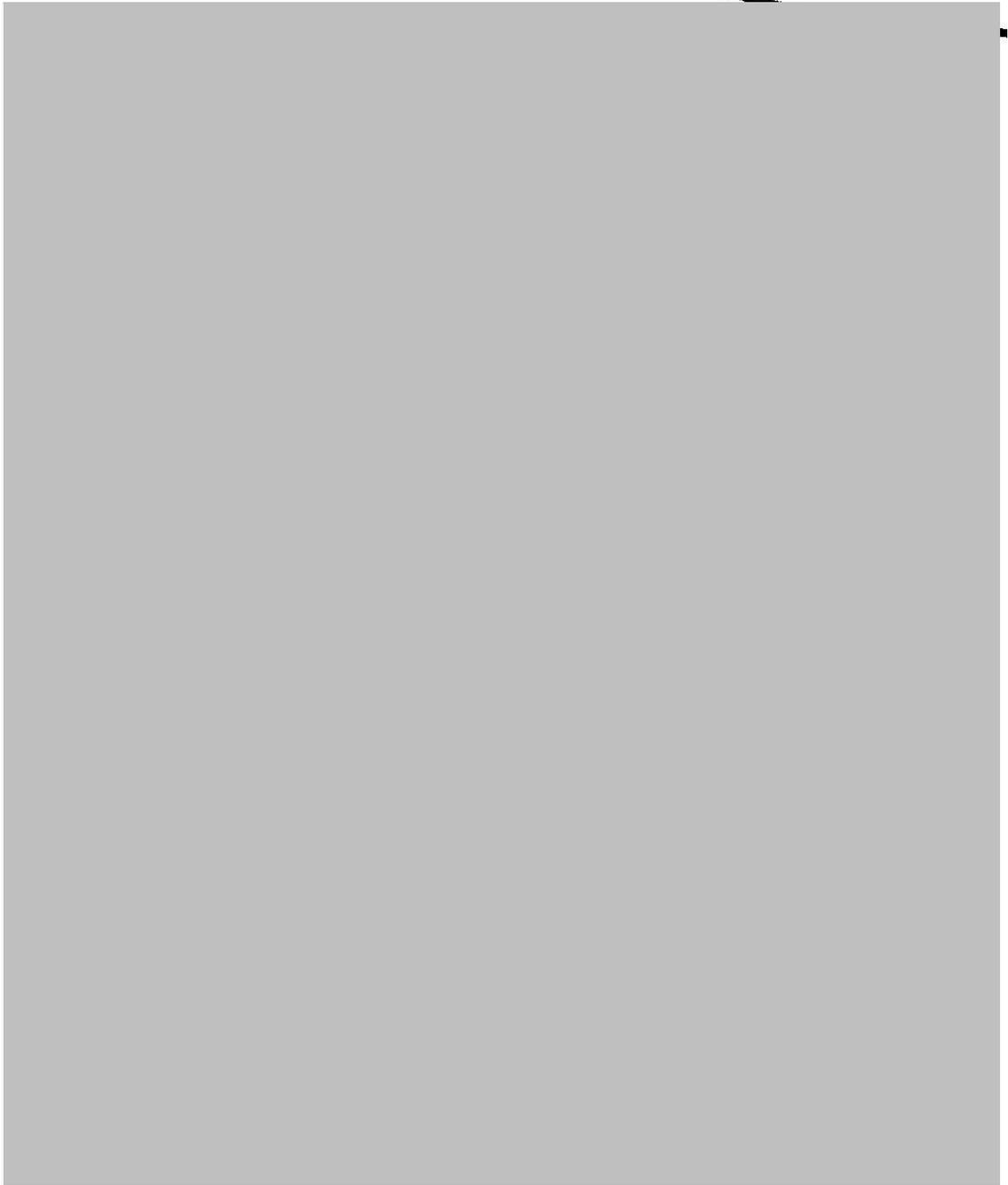
Participant 38

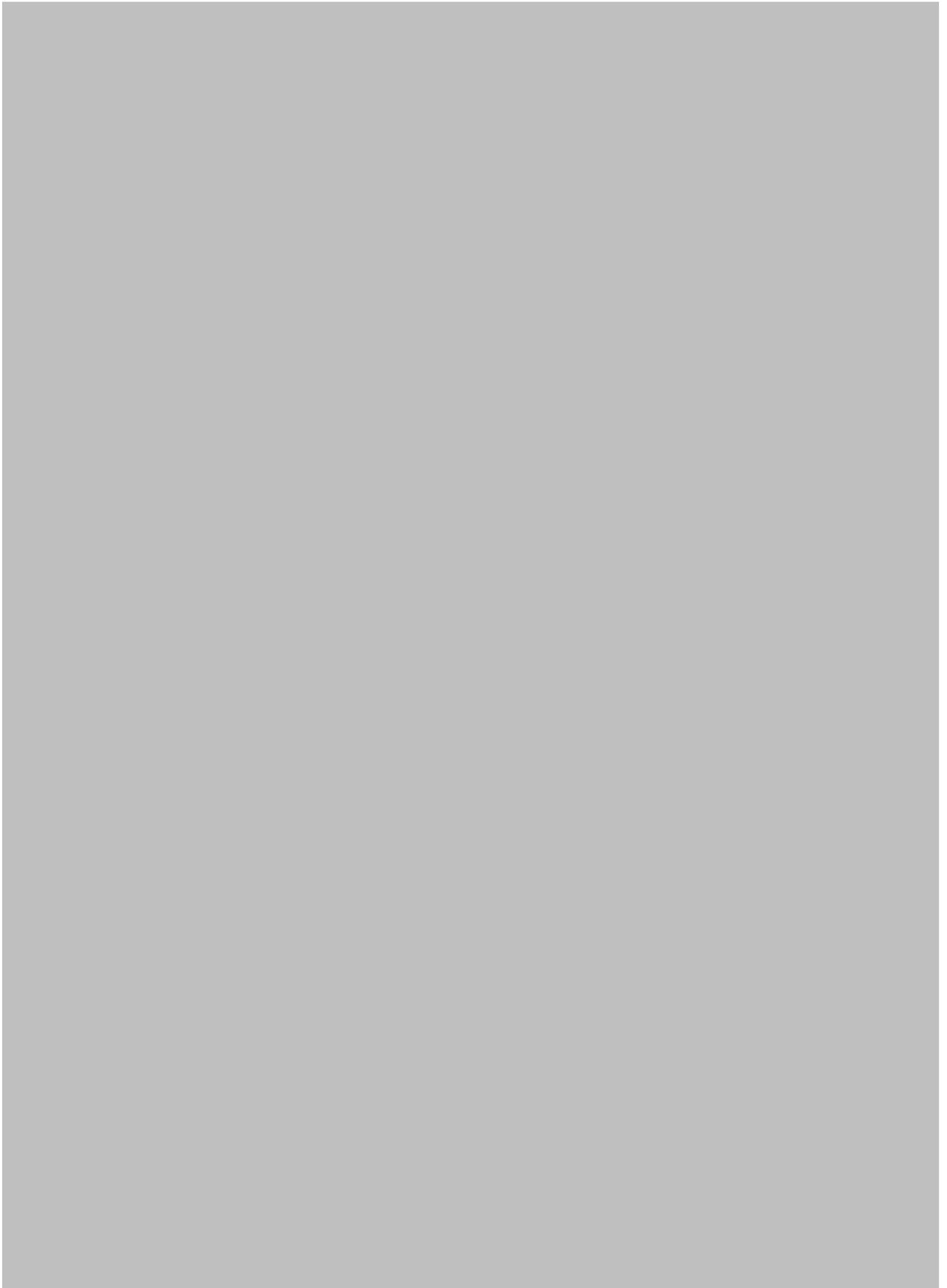
1. How do you think welfare of the child should be assessed, if at all?
2. What do you think about the idea of a priority system where patients are not treated on just a first come, first served basis? (This would mean that other factors are considered, such as the patient’s age, whether they smoke, or whether they already have children, and these factors would be used to create a treatment “score” that would determine the order in which patients get treated.)
3. What do you think of the idea of a national waiting list for donors and recipients of gametes, so that instead of clinics each having their own lists, all patients would wait on one larger national list?

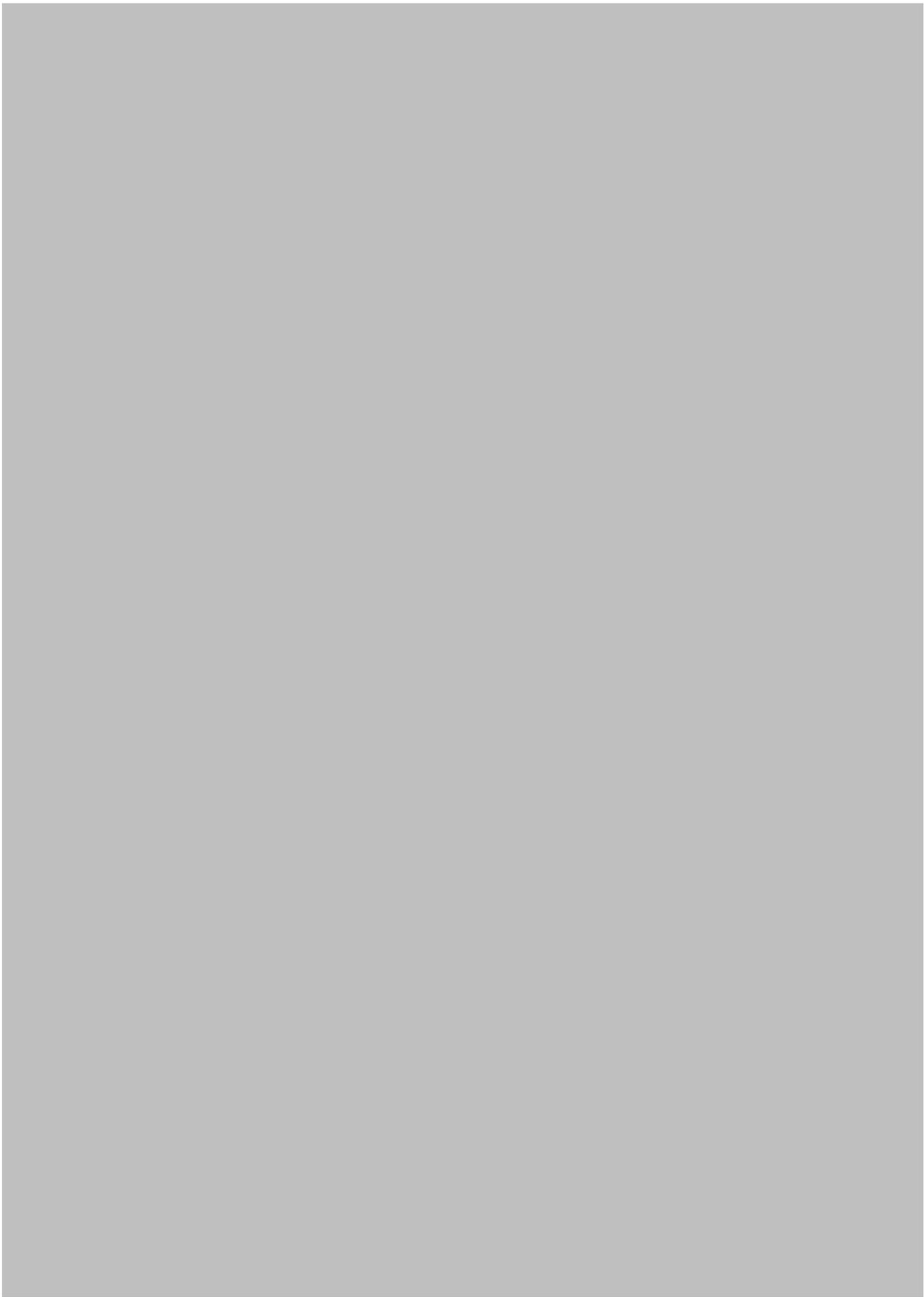
10.20 Appendix 20 – Research Ethics Committee Favourable Opinion Letter and Other Correspondence

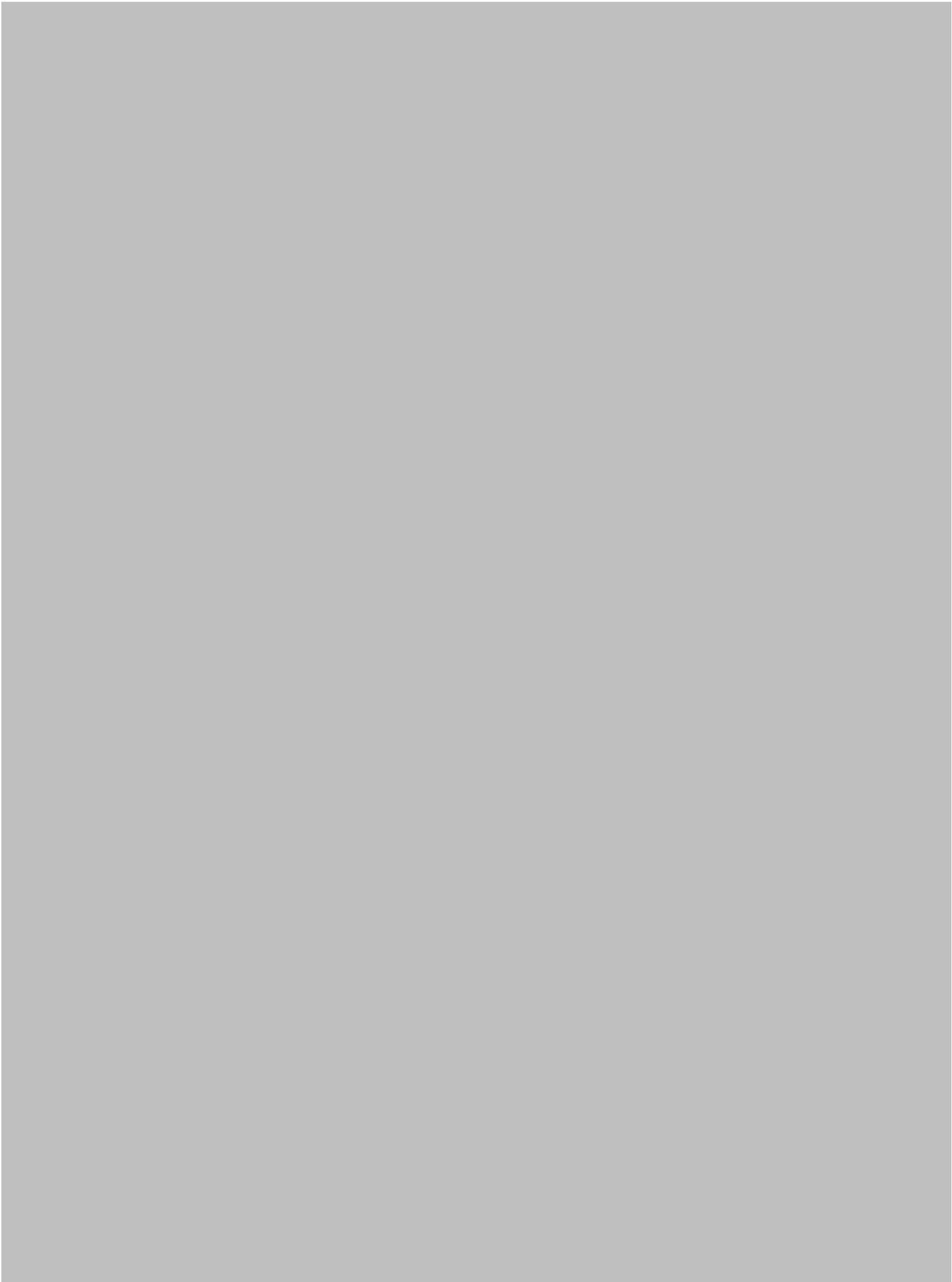




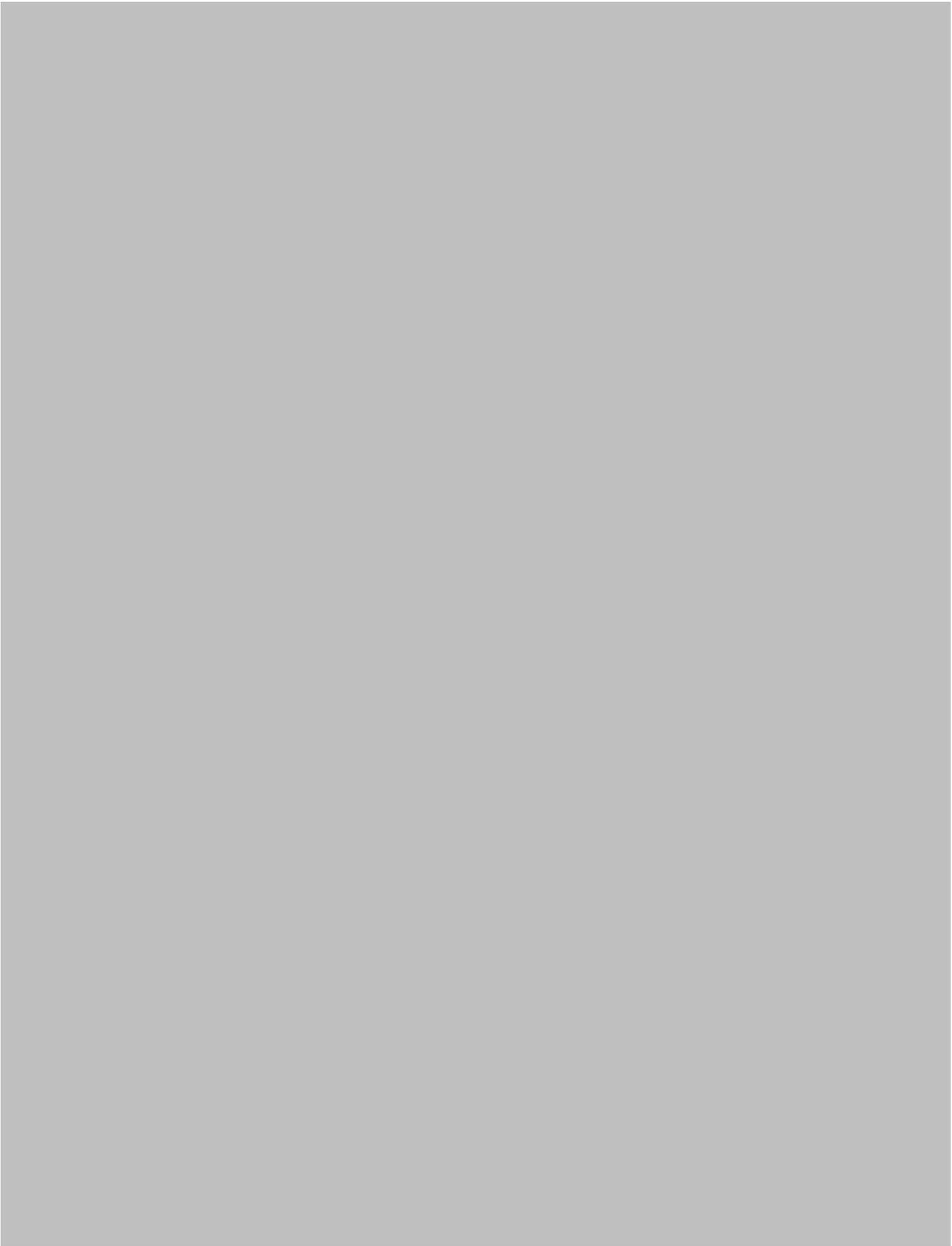








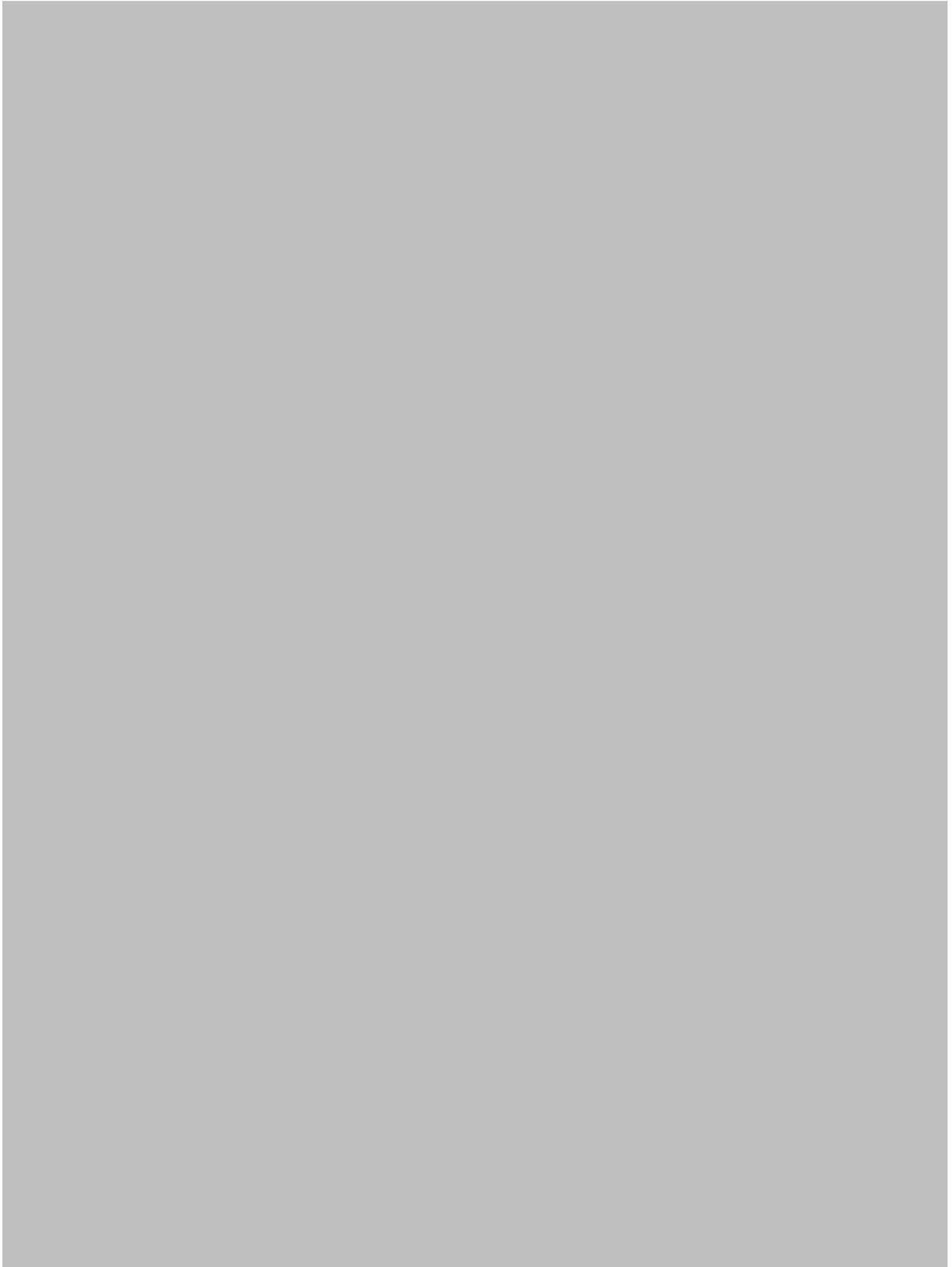






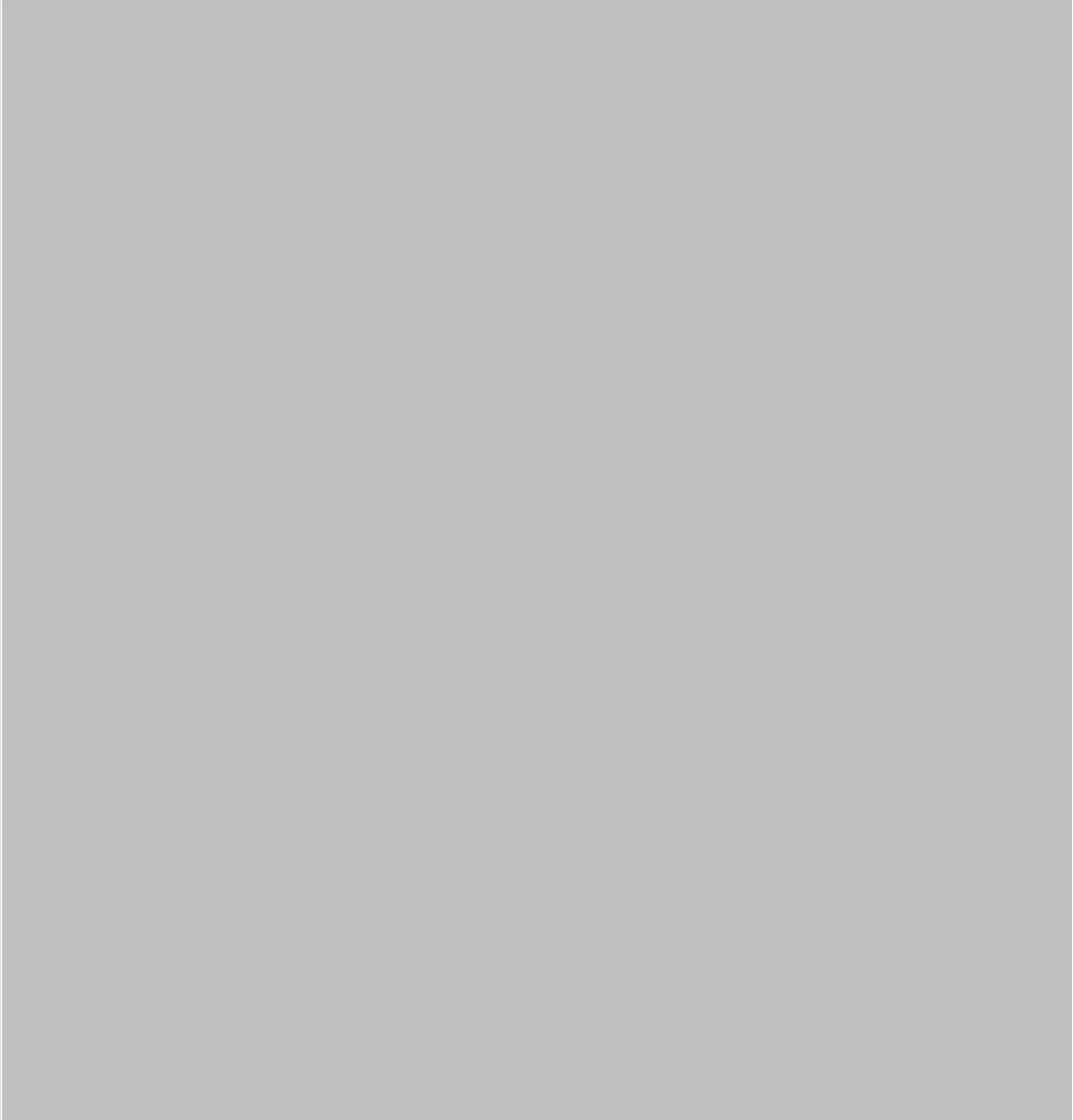


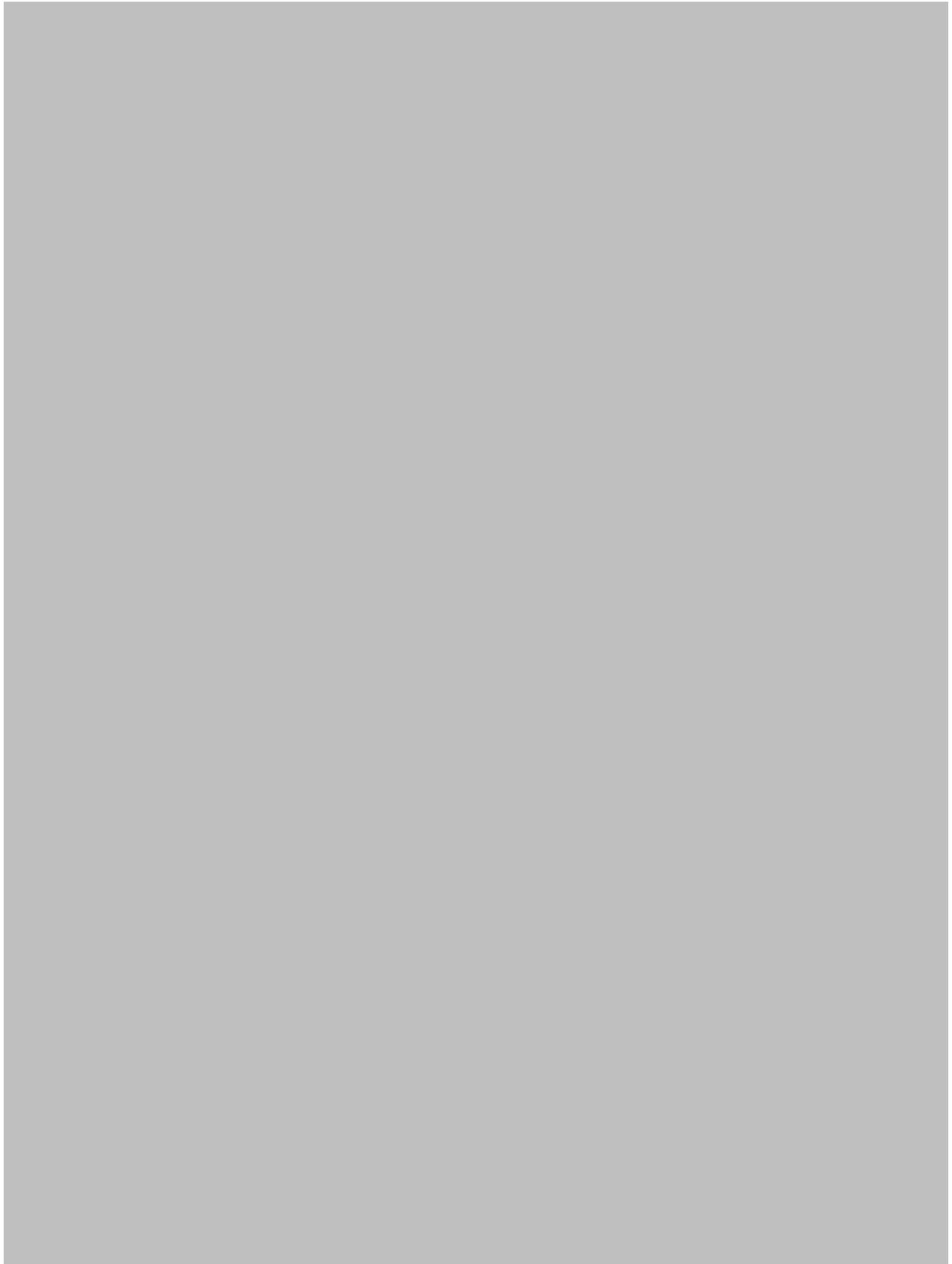




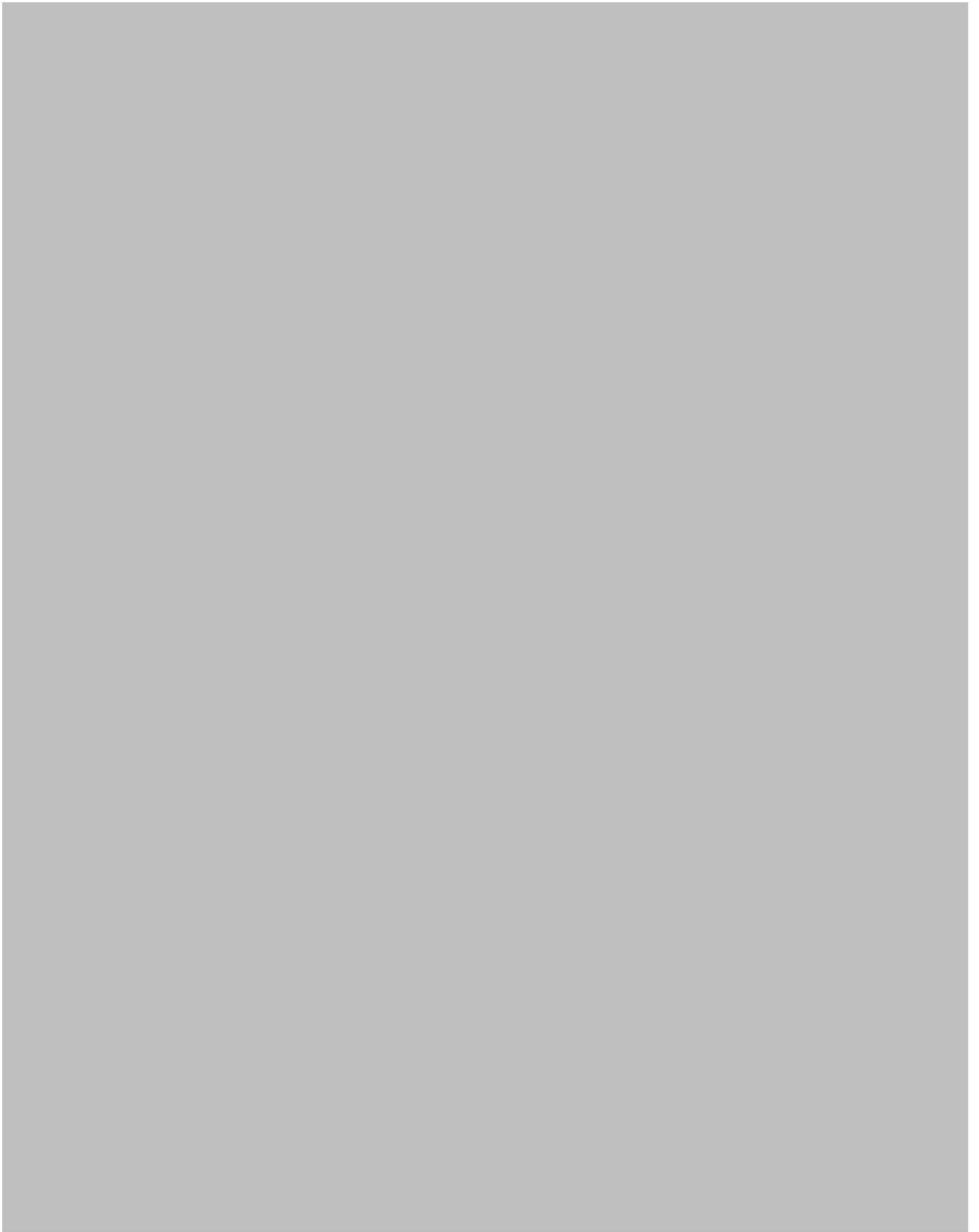




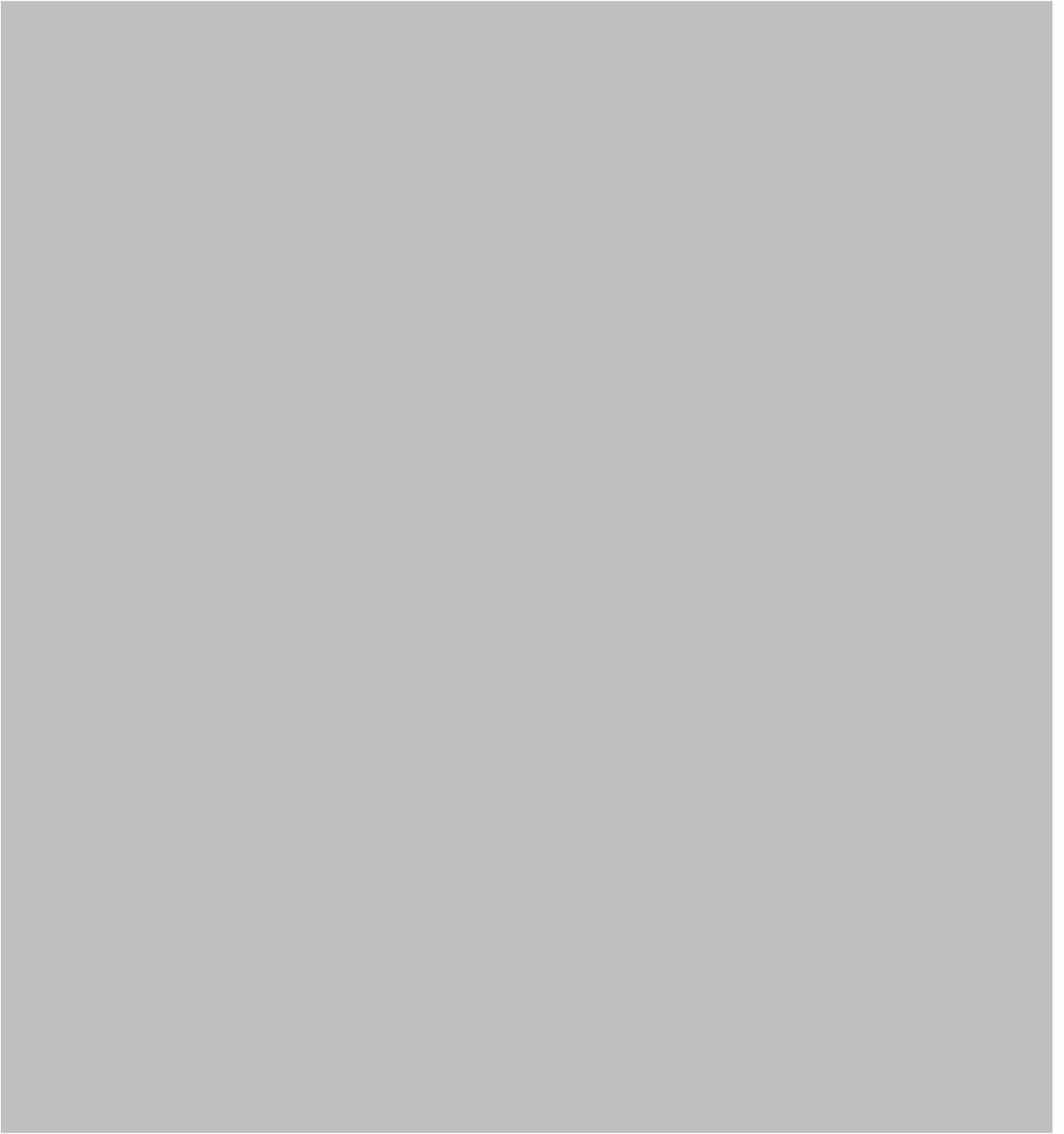


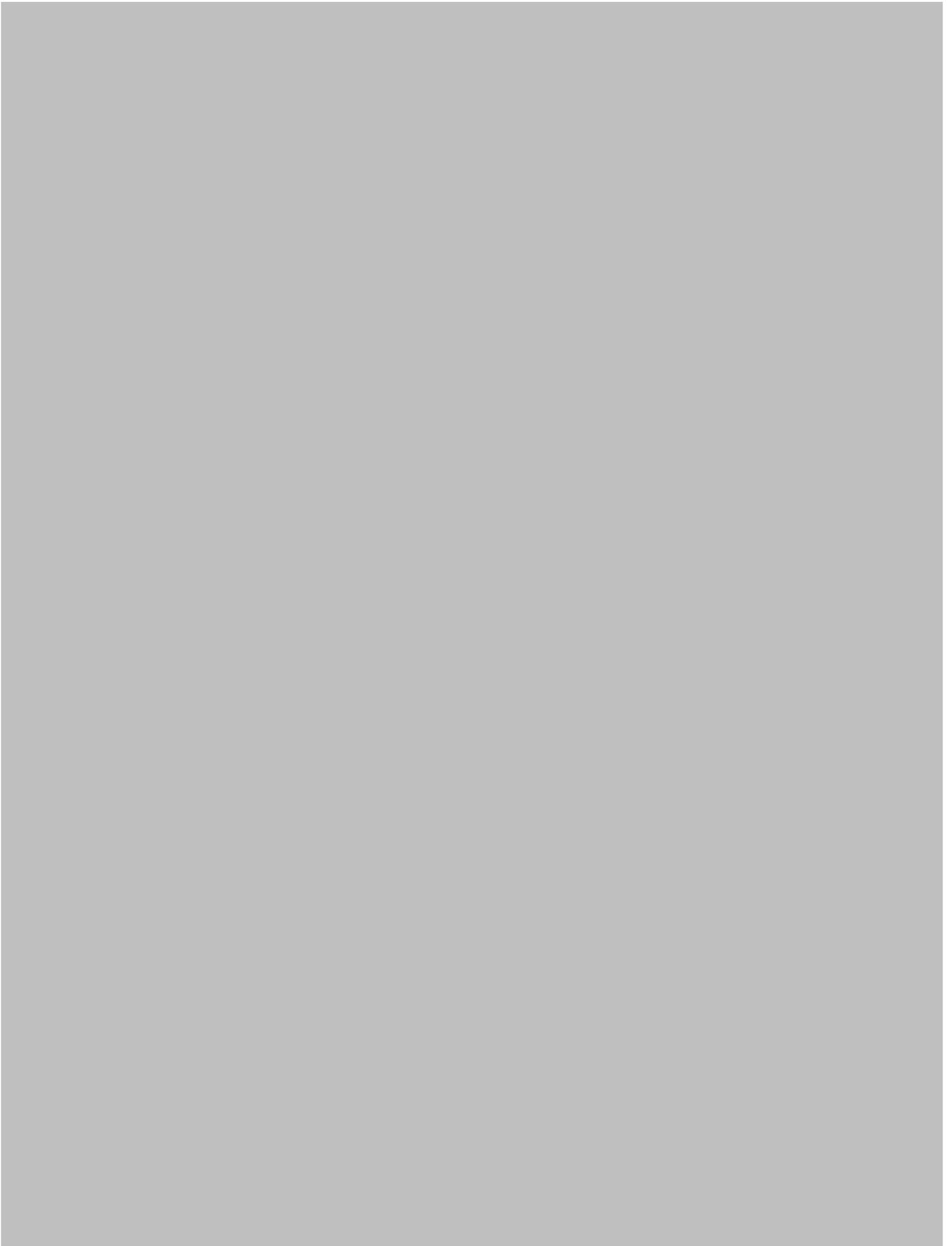


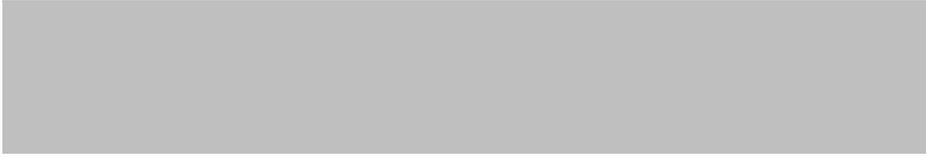


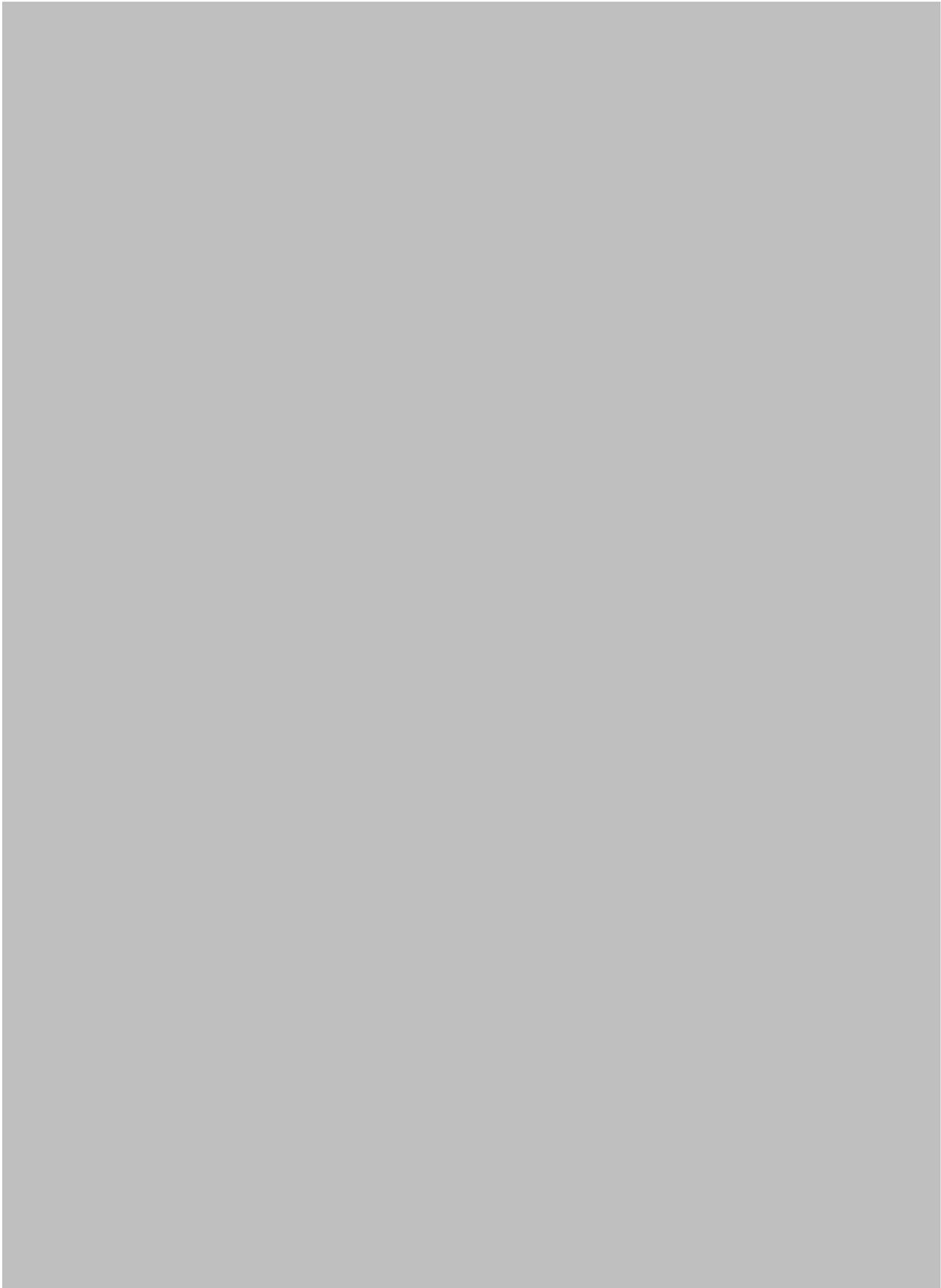


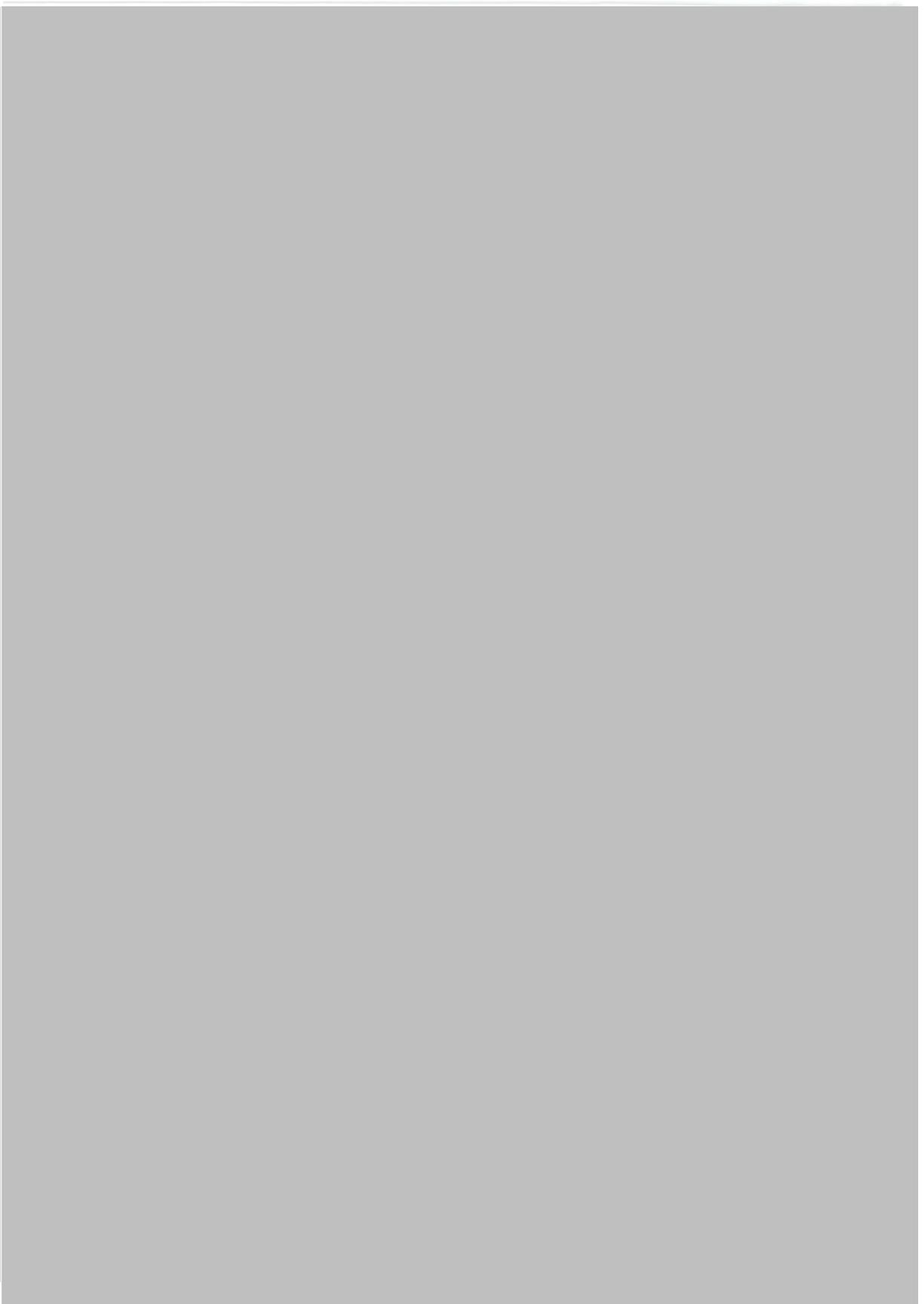


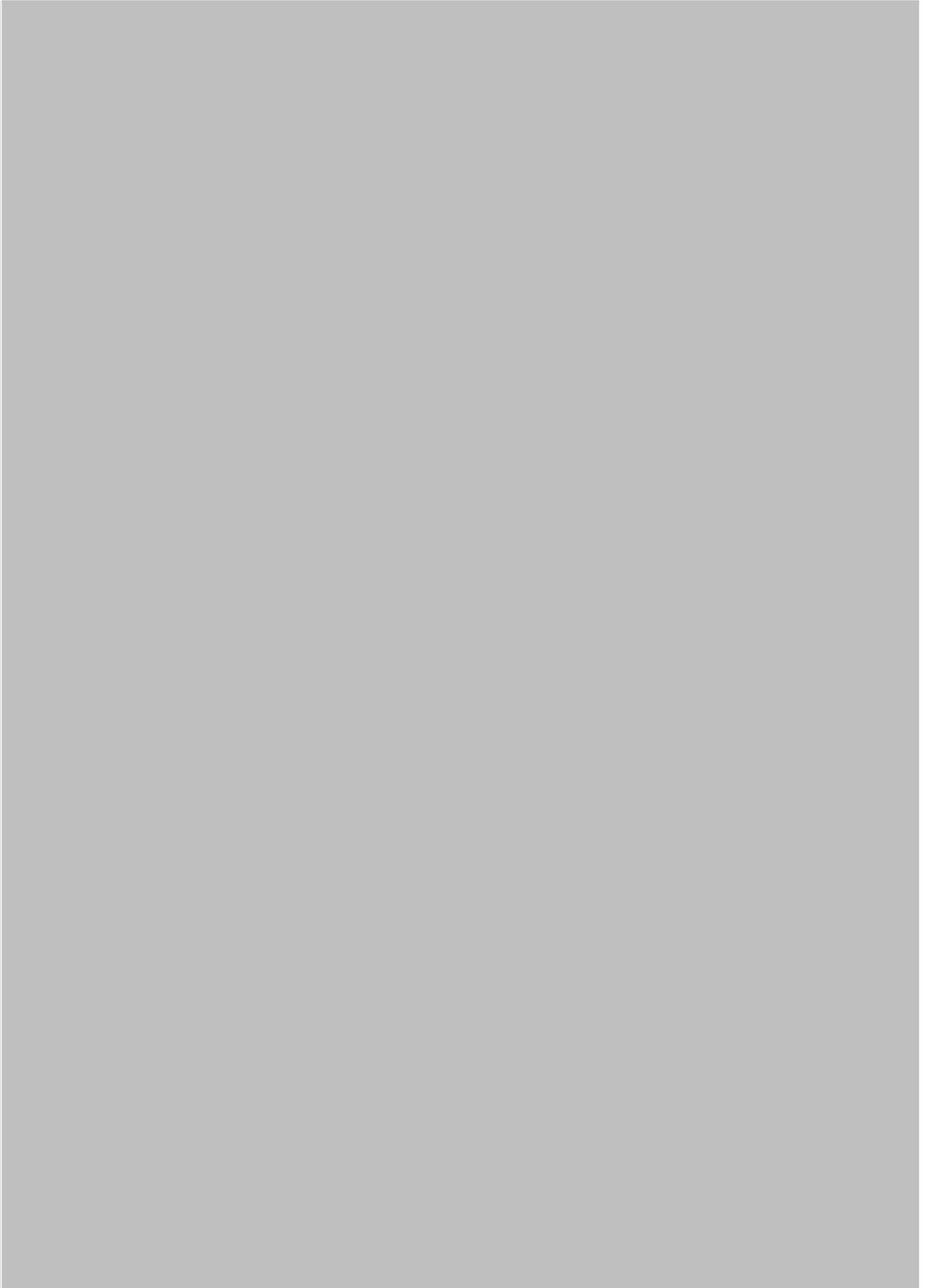


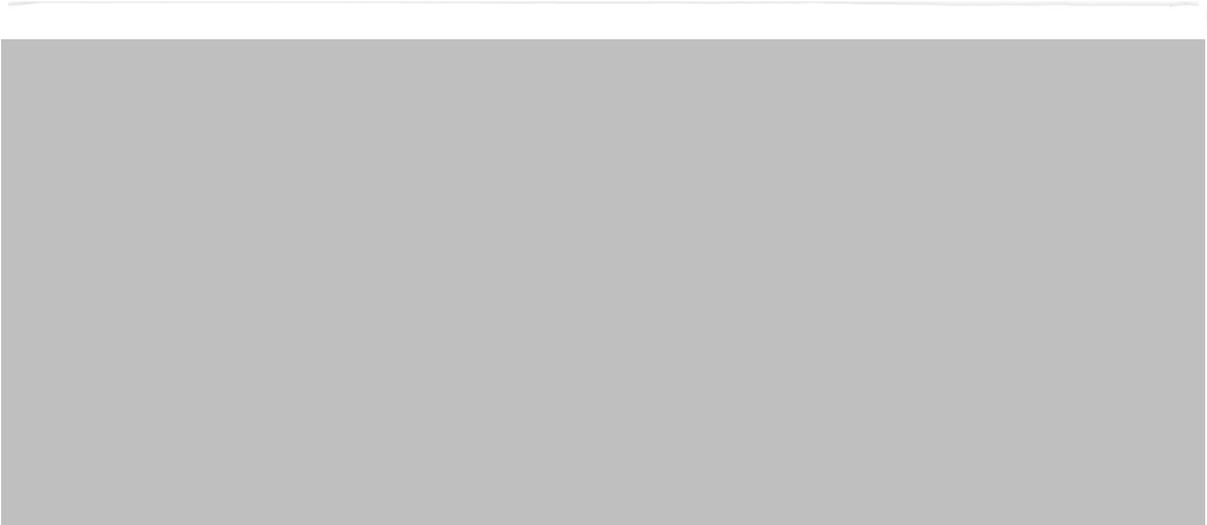


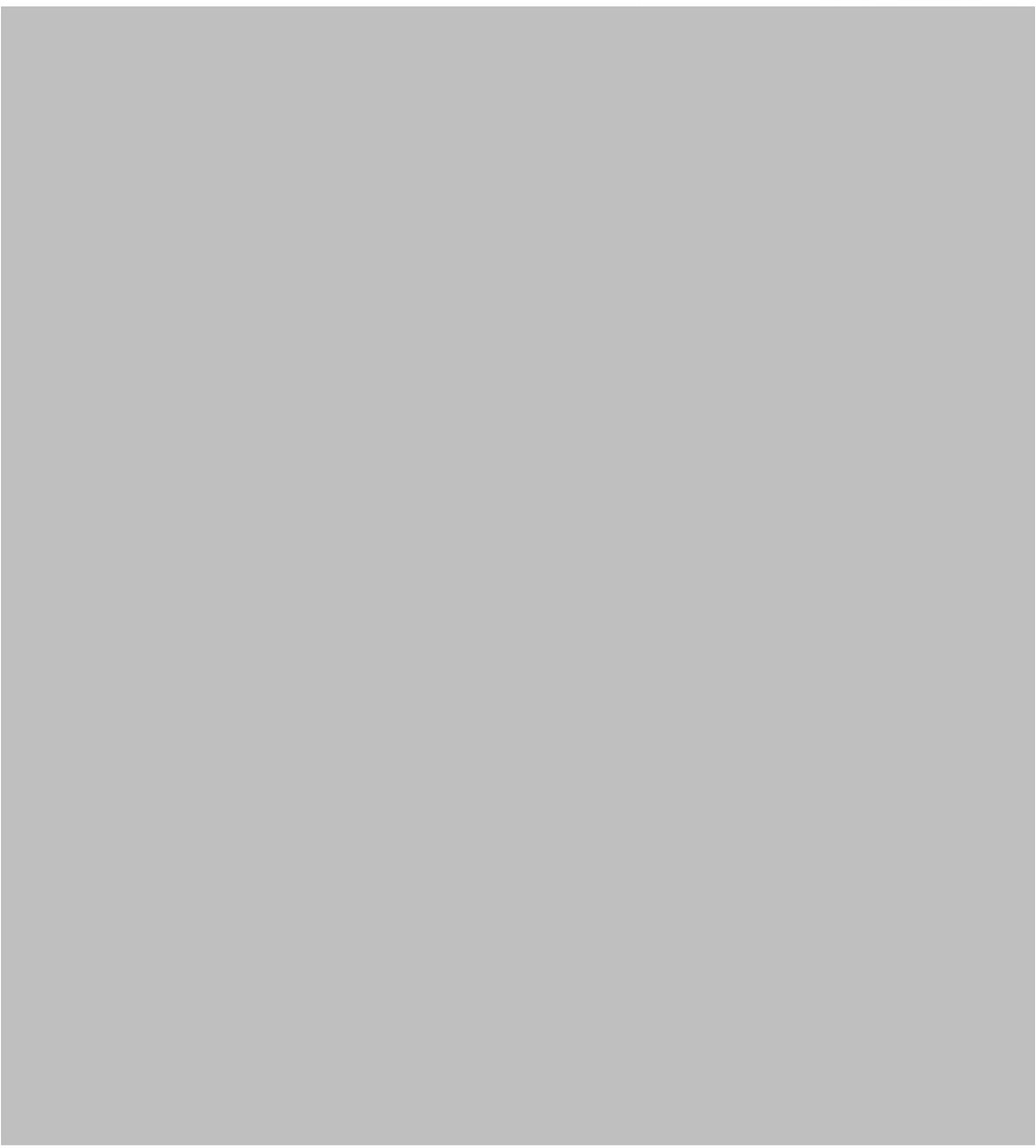










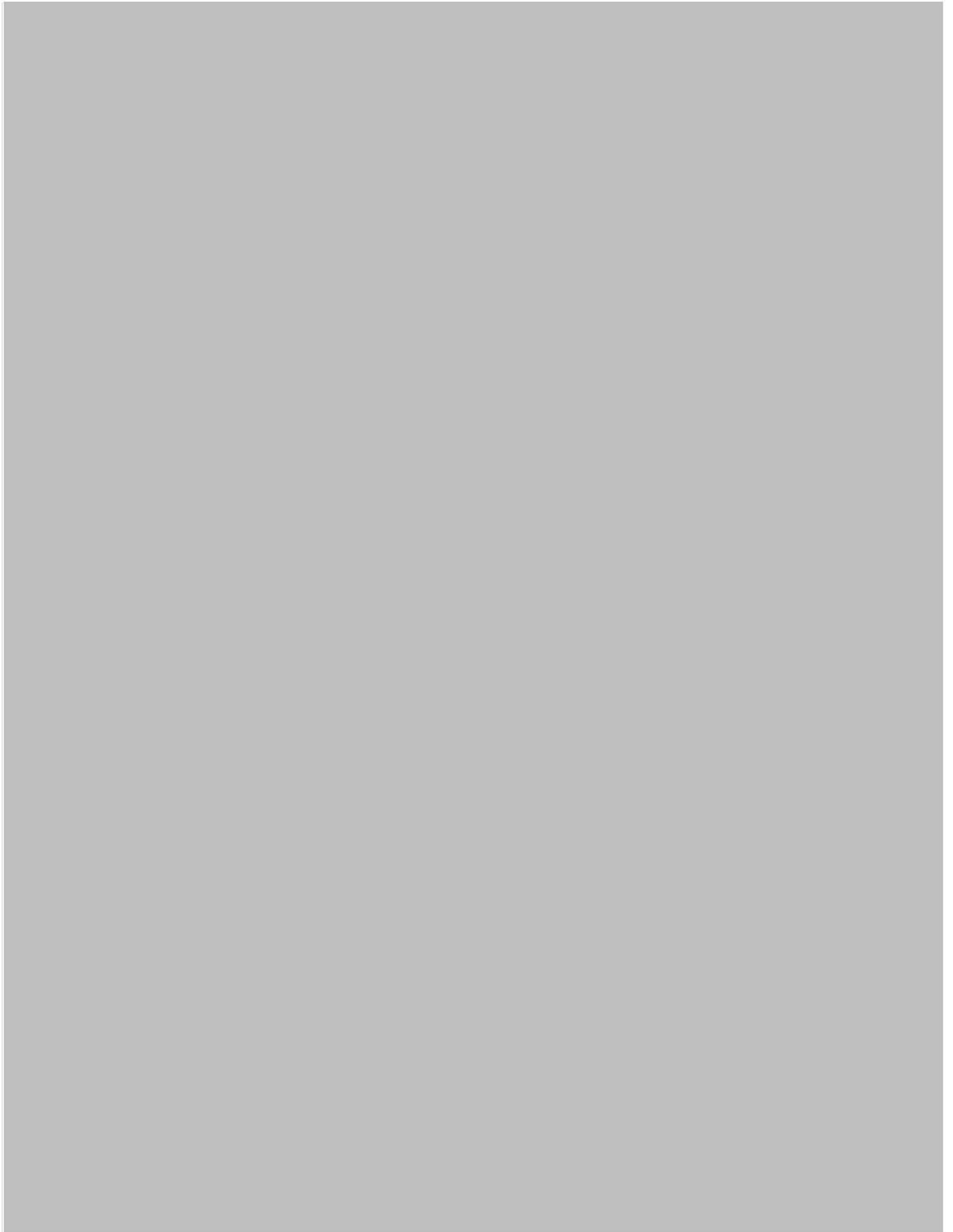


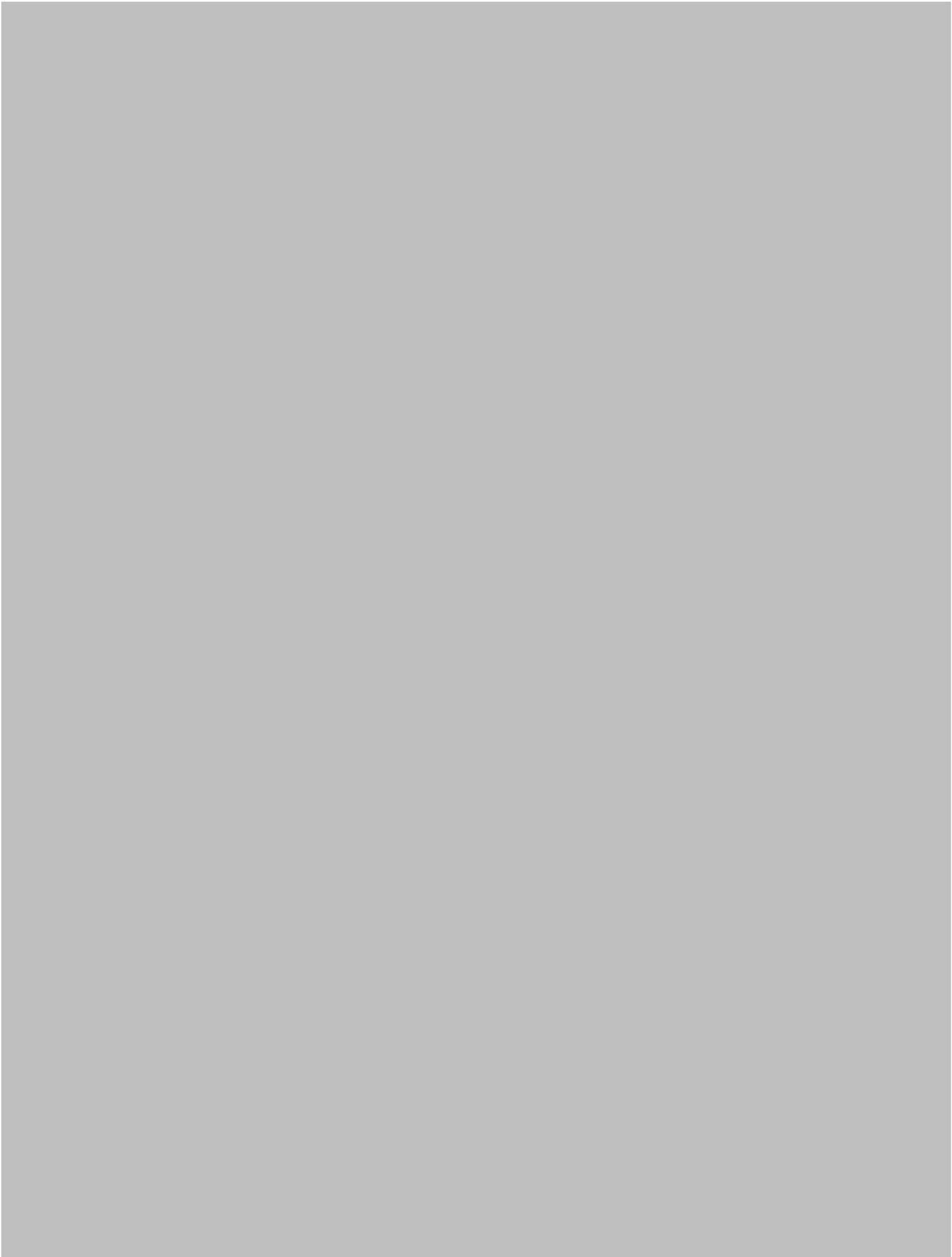


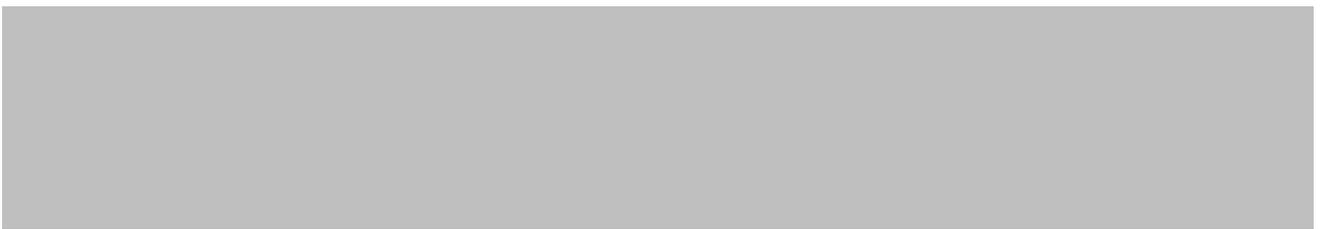
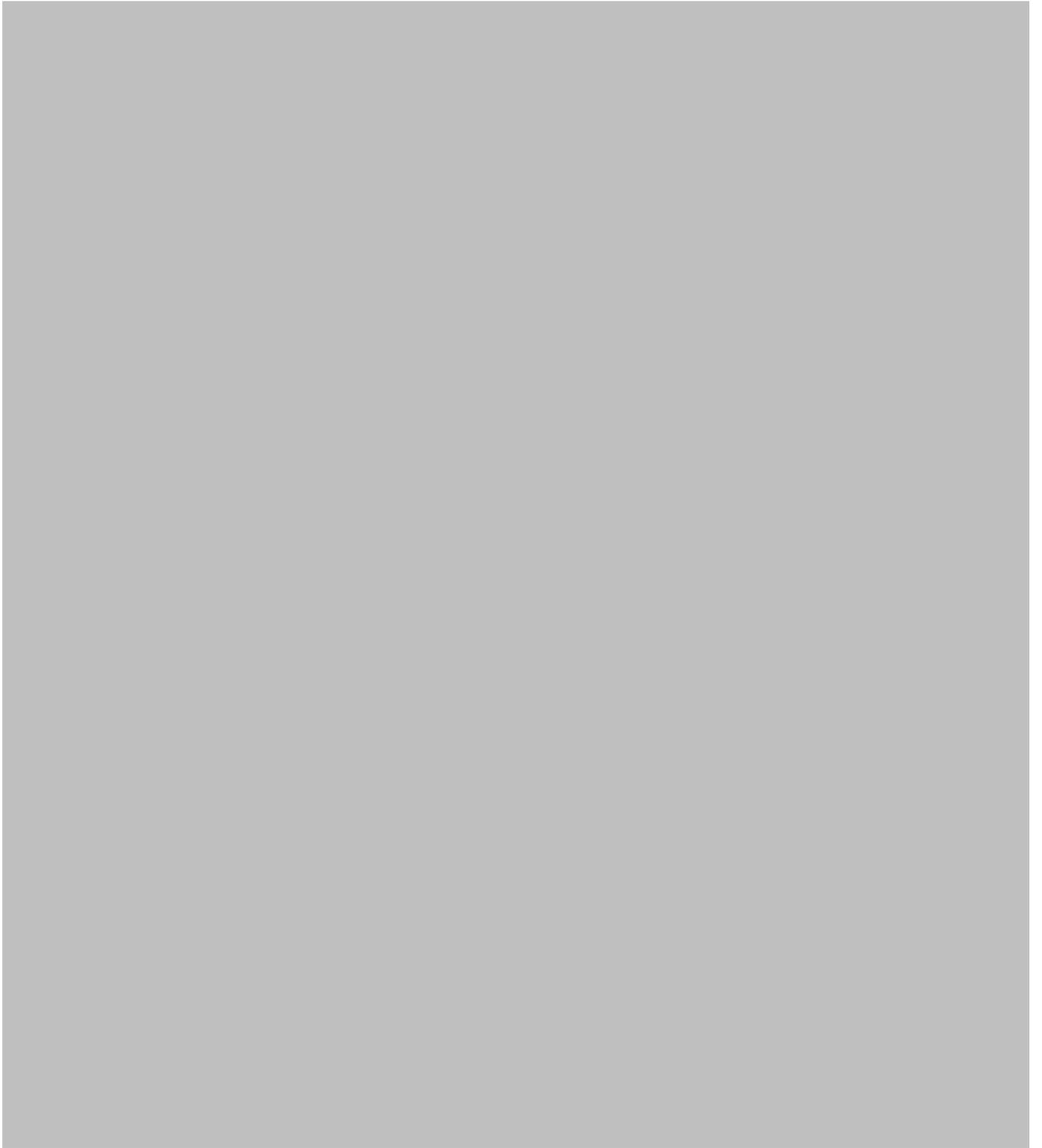


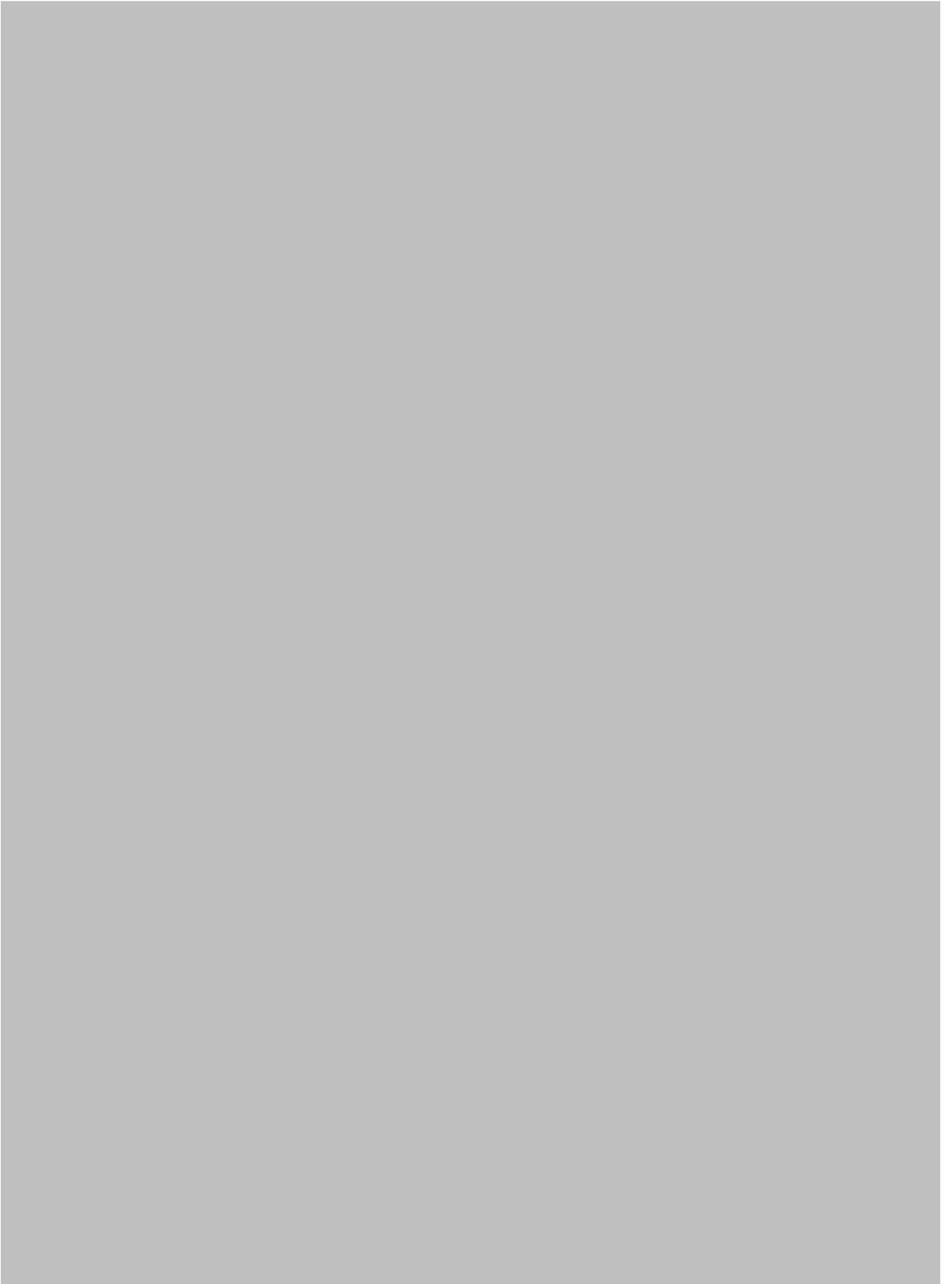


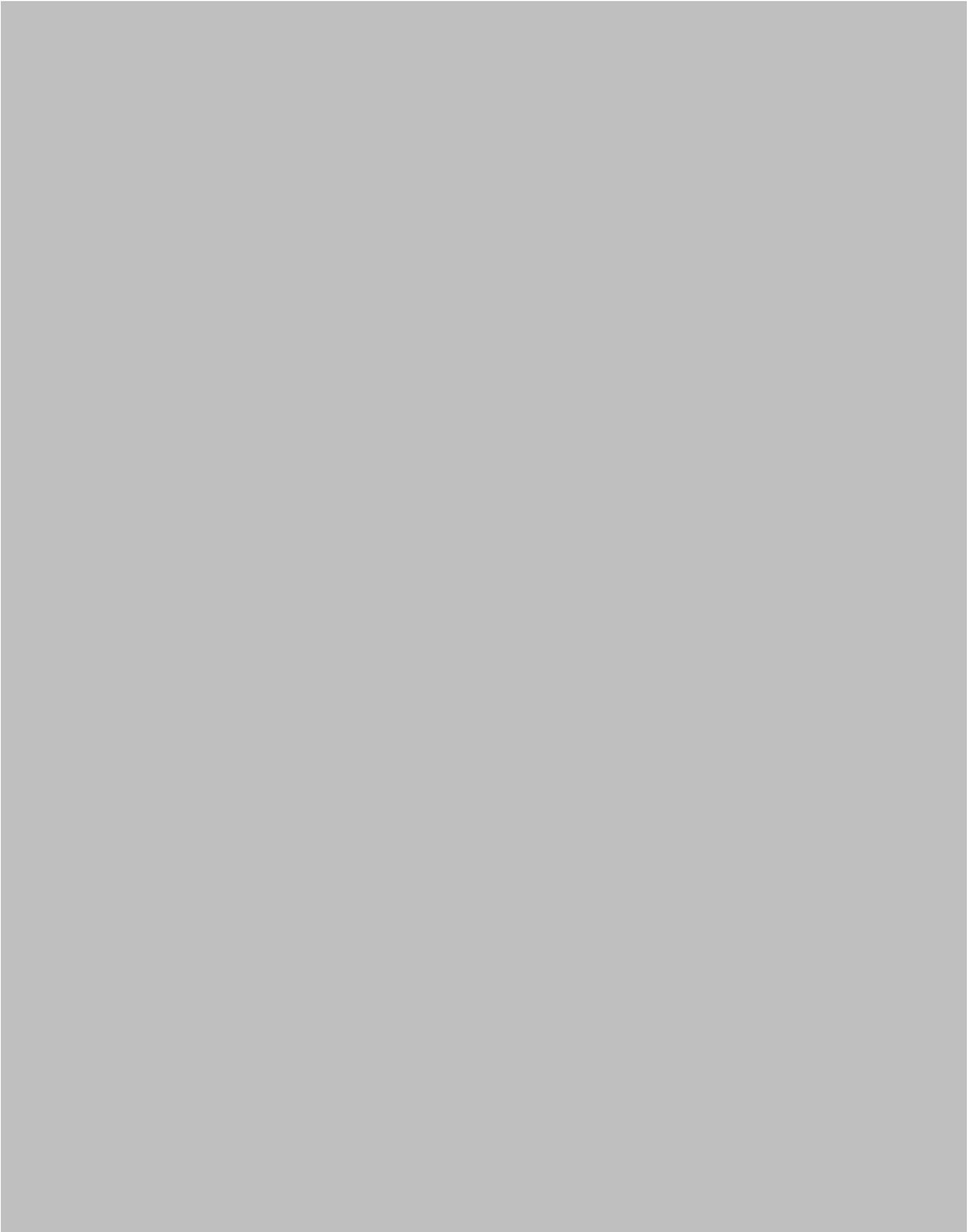




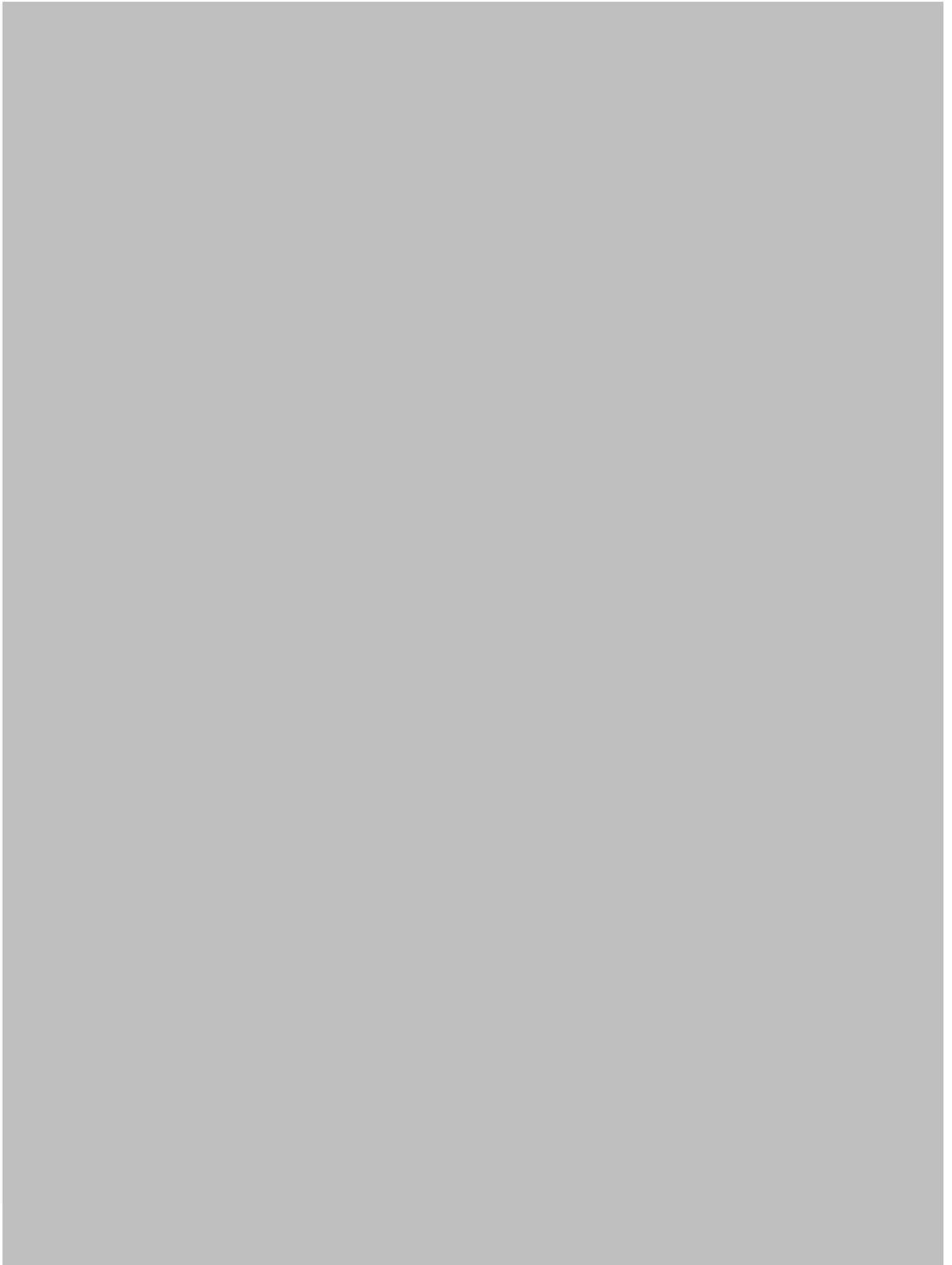
















11. BIBLIOGRAPHY

- Advisory, Conciliation and Arbitration Service, (2011) **The Equality Act – What’s new for employers?** [online]. Available from: <http://www.acas.org.uk/CHttpHandler.ashx?id=2833&p=0> [Accessed 28 February 13]
- Ammerman, R. T., Kolko, D. J., Kirisci, L., Blackson, T. C. and Dawes, M. A. (1999) Child abuse potential in parents with histories of substance use disorder. **Child Abuse & Neglect**, 23(12), pp. 1225-1238
- Anderson, H. and Cook, D. (1997) Passive smoking and sudden infant death syndrome: review of the epidemiological evidence. **Thorax**, 52(11), pp. 1003-1009
- Appleyard, K. Berlin, L., Rosenbalm, K. and Dodge, K. (2011) Preventing Early Child Maltreatment: Implications from a Longitudinal Study of Maternal Abuse History, Substance Use Problems, and Offspring Victimization. **Prevention Science**, 12(2), pp. 139-149
- Archard, D. (2009) Why Moral Philosophers Are Not and Should Not Be Moral Experts. **Bioethics**, 25(3), pp. 119-127
- Ayer, A. J. (2001) **Language, Truth and Logic**. London: Penguin
- Beauchamp, T. and Childress, J. (1989) **Principles of Biomedical Ethics**, 2nd edn., New York: Oxford University Press
- Beauchamp, T. and Childress, J. (2013) **Principles of biomedical ethics**, 7th edn, Oxford: Oxford University Press
- Becker, H.S. (1996) “The Epistemology of Qualitative Research”, in **Ethnography and Human Development: Context and Meaning in Human Enquiry**, ed. by Richard Jessor, Anne Colby, and Richard A. Schweder. Chicago: The University of Chicago Press
- Benatar, D. (2006) **Better Never to Have Been: The Harm of Coming into Existence**. New York: Oxford University Press
- Bentham, J. (1948) **An Introduction to the Principles of Morals and Legislation**. New York: Hafner
- Bewley, S., Ledger, W. and Nikolaou, D. (eds.) (2009) **Consensus views arising from the 56th Study Group: Reproductive Ageing**. London: Royal College of Obstetricians and Gynaecologists Press, pp. 353-356
- Borry, P., Schotsmans, P. and Dierickx, K. (2004) What is the role of empirical research in bioethical reflection and decision-making? An ethical analysis. **Medicine, Health Care and Philosophy**, 7, pp. 41-53

Boyle, R. J. and Savulescu, J. (2001) Ethics of using preimplantation genetic diagnosis to select a stem cell donor for an existing person. **BMJ**, 323(7323), pp. 1240-1243

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. **Qualitative Research in Psychology**, 3(2), pp. 77-101

British Fertility Society (2008). **British Fertility Society calls for national infrastructure to improve sperm donor recruitment in the UK** [online]. Available from: http://www.fertility.org.uk/news/pressrelease/08_11-DonorRecruitment.html [Accessed 27 September 2013]

Broome, J. (1998) Good, Fairness and QALYs. **Royal Institute of Philosophy Lecture Series**, 23, pp. 57-73

Broome, J. (1999) **Ethics out of Economics**. Cambridge: Cambridge University Press

Broome, J. (2004) **Weighing Lives**. Oxford: Oxford University Press

Brown, C. (2011) Consequentialize This. **Ethics**, 121(4), pp. 749-771

Brown, J., Cohen, P., Johnson, J. G. and Salzinger, S. (1998) A longitudinal analysis of risk factors for child maltreatment: findings of a 17-year prospective study of officially recorded and self-reported child abuse and neglect. **Child Abuse & Neglect**, 22(11), pp. 1065-1078

Bryman, A. (2012) **Social Research Methods**, 4th edn, Oxford: Oxford University Press

Caplan, A. L. and Patrizio, P. (2010) Are you ever too old to have a baby? The ethical challenges of older women using infertility services. **Seminars in Reproductive Medicine**, 28(4), pp. 281-286

Caws, P. (1995) Minimal Consequentialism. **Philosophy**, 70(273), pp. 313-339

Centre for Maternal and Child Enquiries (CMACE) (2011). Saving Mothers' Lives: reviewing maternal death to make motherhood safer: 2006-08. The Eighth Report on Confidential Enquiries into Maternal Deaths in the United Kingdom. **British Journal of Obstetrics & Gynaecology**, 118 (Suppl. 1), pp. 1-203

Chaffin, M., Kelleher, K. and Hollenberg, J. (1996) Onset of physical abuse and neglect: Psychiatric, substance abuse, and social risk factors from prospective community data. **Child Abuse & Neglect**, 20(3), pp. 191-203

Children Act (1989) [online]. Available from: <http://www.legislation.gov.uk/ukpga/1989/41/section/1> [Accessed 31 August 2012]

Cochrane, A. (2009) Undignified Bioethics. **Bioethics**, 24(5), pp. 234-241

Cohen, A., Lindheim, S. R. and Sauer, M. V. (1999). Donor age is paramount to success in oocyte donation. **Human Reproduction**, 14(11), pp. 2755-2758

Cnattingius, S., Forman, M.R., Berendes, H. and Isotalo, L. (1992). Delayed childbearing and risk of adverse perinatal outcome. A population-based study. **Journal of the American Medical Association**, 268(7), pp. 886-90

Dancy, J. (1982) Intuitionism in Meta-Epistemology. **Philosophical Studies**, 42(3), pp. 395-408

Dancy, J. (2004) **Ethics Without Principles**. Oxford: Oxford University Press

Darby, H. and Hamm, D. (2011) **Donating sperm and eggs. Have your say...** [online]. Available from http://www.hfea.gov.uk/docs/Authority_presentation_FINAL.pdf [Accessed 2 August 2013]

Dor, J., Seidman, D.S., Ben-Shlomo, I., Levran, D., Ben-Rafael, Z. and Mashiach, S. (1996). Cumulative pregnancy rate following in-vitro fertilization: the significance of age and infertility aetiology. **Human Reproduction**, 11(2), pp. 425-428

Draper, H. and Sorell, T. (2002) Patients' Responsibilities in Medical Ethics. **Bioethics**, 16(4), pp. 335-352

Dreier, J. (1993) Structures of Normative Theories. **The Monist**, 76(1), pp. 22-40

Dunn, M. and Ives, J. Methodology, epistemology, and empirical bioethics research: a constructive/ist commentary. **The American Journal of Bioethics**, 9(6-7), pp. 93-95

Epstein, Y. M. and Rosenberg, H. S. (2005). Depression in primary versus secondary infertility egg recipients. **Fertility and Sterility**, 83(6), pp. 1882-1884

Equality Act (2010) [online]. Available from: <http://www.legislation.gov.uk/ukpga/2010/15/contents> [Accessed 29 July 2013]

Equality and Human Rights Commission (2011) **Services, public functions and associations: Statutory Code of Practice** [online]. Available from http://www.equalityhumanrights.com/uploaded_files/EqualityAct/servicescode.pdf [Accessed 3 August 2013]

Expert Advisory Group on Infertility Services in Scotland (1999) **Evidence & Equity: A National Service Framework for the Care of Infertile Couples in Scotland** [online]. Available from: <http://www.show.scot.nhs.uk/publications/me/eagiss.pdf> [Accessed 6 August 2013]

Fontana, A. and Frey, J. H. (1994) "The Art of Science". In Denzin, N. K., and Lincoln, Y.S. (eds.) **Handbook of Qualitative Research**. Thousand Oaks: Sage

Foot, P. (1978). **Virtues and Vices**. Berkeley and Los Angeles: University of California Press

Frith, L. (2009) Use or ornament? Clinical ethics committees in infertility units: a qualitative study. **Clinical Ethics**, 4(2), pp. 91-97

Frith, L. (2012) Symbiotic Empirical Ethics: A Practical Methodology. **Bioethics**, 26(4), pp. 198-206

General Medical Council (2010) **Treatment and care towards the end of life: good practice in decision making** [online]. Available from [http://www.gmc-uk.org/Treatment and care towards the end of life English 0513.pdf](http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life_English_0513.pdf) [48902105.pdf](http://www.gmc-uk.org/Treatment_and_care_towards_the_end_of_life_English_0513.pdf) [Accessed 21 August 2013]

General Medical Council (2013) **Good medical practice** [online]. Available from: http://www.gmc-uk.org/static/documents/content/GMP_2013.pdf [51447599.pdf](http://www.gmc-uk.org/static/documents/content/GMP_2013.pdf) [Accessed 27 September 2013]

Gert, B. (2005) **Morality: Its Nature and Justification**. Oxford University Press, USA

Glaser, B. G., and Strauss, A. L. (1967) **The Discovery of Grounded Theory: Strategies for Qualitative Research**, Chicago: Aldine

Glasser, M., Kolvin, I., Campbell, D., Glasser, A., Leitch, I. And Farrelly, S. (2001) Cycle of child sexual abuse: links between being a victim and becoming a perpetrator. **British Journal of Psychiatry**, 179, pp. 482-494

Golombok, S. (2000) **Parenting: What Really Counts?** Hove: Routledge

Golombok, S., and Badger, S. (2010) Children raised in mother-headed families from infancy: a follow-up of children of lesbian and single heterosexual mothers, at early adulthood. **Human Reproduction**, 25(1), p. 150-157

Golombok, S., and MacCallum, F. (2004) Children raised in fatherless families from infancy: A follow-up of children of lesbian and single heterosexual mothers at early adolescence. **Journal of Child Psychology and Psychiatry**, 45, pp. 1407-1419

Golombok, S., Tasker, F. and Murray, C. (1997) Children raised in fatherless families from infancy: family relationships and the socioemotional development of children of lesbian and single heterosexual mothers. **Journal of Child Psychology and Psychiatry**, 38, pp. 783-792

Gordon, J. (2012) Moral Philosophers Are Moral Experts! A Reply to David Archard. **Bioethics** [online]. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1467-8519.2012.02004.x/pdf> [Accessed 31 July 2013]

- Greil, A. L., Shreffler, K. M., Schmidt, L. and McQuillan, J. (2011) Variation in distress among women with infertility: evidence from a population-based sample. **Human Reproduction**, 26(8), pp. 2101-2112
- Guba, E. G. and Lincoln, Y. S. (1994) "Competing paradigms in qualitative research". In: Denzin, N. K. and Lincoln, Y. S. (eds.) **Handbook of Qualitative Research**. Thousand Oaks: Sage
- Haidt, J. (2001) The emotional dog and its rational tail: A social intuitionist approach to moral judgement. **Psychological Review**, 108(4), pp. 814-834
- Hare, R. M. (1965) **Freedom and Reason**. Oxford: Oxford University Press
- Hare, R. M. (1981) **Moral Thinking: Its Levels, Method, and Point**. Oxford: Clarendon
- Harris, E. (2008) **House of Commons Hansard Debates**, column 172 [online]. Available from: <http://www.publications.parliament.uk/pa/cm200708/cmhansrd/cm080520/debtext/80520-0005.htm> [Accessed 21 July 2013]
- Harris, J. (1975) The Survival Lottery. **Philosophy**, 50(191), pp. 81-87
- Harris, J. (1999) Justice and Equal Opportunities in Health Care. **Bioethics**, 13(5), pp. 392-404
- Harris, J. (2000) The Welfare of the Child. **Health Care Analysis**, 8, pp. 27-34
- HC Deb 20 May 2008, vol 476, col 172
- Hedgecoe, A. M. (2004). Critical Bioethics: Beyond the Social Science Critique of Applied Ethics. **Bioethics**, 18(2), pp. 120-143
- Herstein, O. J. (2013) Why 'Nonexistent People' Do Not Have Zero Wellbeing but No Wellbeing at All'. **Journal of Applied Philosophy**, 30(2), pp. 136-145
- Hester, M., Pearson, C., Harwin, N. and Abrahams, H. (2007) **Making an Impact: Children and Domestic Violence**, 2nd edition. London: Jessica Kingsley
- Heyd, D. (1992) **Genethics: Moral Issues in the Creation of People**. Berkeley, CA: University of California Press
- Holm, S., and Harris, J. (1999) Precautionary principle stifles discovery. **Nature** 400, p. 398
- Hooker, B. (2000). **Ideal Code, Real World: A Rule-Consequentialist Theory of Morality**. Oxford: Clarendon Press

Hsieh, H.F. and Shannon, S. E. (2005) "Three Approaches to Qualitative Content Analysis", in **Qualitative Health Research**, 15(9), pp. 1277-1288

Hull, M.G., Fleming, C.F., Hughes, A.O. and McDermott, A. The age-related decline in female fecundity: a quantitative controlled study of implanting capacity and survival of individual embryos after in vitro fertilization. **Fertility and Sterility**, 65(4), pp. 783-90

Human Fertilisation and Embryology Act (1990), section 13 (5) [online]. Available from: <http://www.legislation.gov.uk/ukpga/1990/37/section/13> [Accessed 21 July 2013]

Human Fertilisation and Embryology Act (2008) [online]. Available from: <http://www.legislation.gov.uk/ukpga/2008/22/contents> [Accessed 26 July 2013]

Human Fertilisation and Embryology Authority (2003) **Code of Practice**, 6th edn. [online]. Available from http://www.hfea.gov.uk/docs/Code_of_Practice_Sixth_Edition.pdf [Accessed 22 August 2013]

Human Fertilisation and Embryology Authority (2004) **Sperm, Egg, and Embryo Donation (SEED) policy review. Findings of the clinic survey** [online]. Available from http://www.hfea.gov.uk/docs/Clinics_survey_Seed_review.pdf [Accessed 25 September 2013]

Human Fertilisation and Embryology Authority (2005a) **Tomorrow's Children: Report of the policy review of welfare of the child assessments in licensed assisted conception clinics** [online]. Available from: http://www.hfea.gov.uk/docs/TomorrowsChildren_report.pdf [Accessed 16 July 2013]

Human Fertilisation and Embryology Authority (2005b) **SEED Report: A report on the Human Fertilisation Embryology Authority's review of sperm, egg and embryo donation in the United Kingdom** [online]. Available from <http://www.hfea.gov.uk/docs/SEEDReport05.pdf> [Accessed 28 September 2013]

Human Fertilisation and Embryology Authority (2008). **A long term analysis of the HFEA Register data (1991-2006)** [online]. Available from: [http://www.hfea.gov.uk/docs/Latest_long_term_data_analysis_report_91-06.pdf\(1\).pdf](http://www.hfea.gov.uk/docs/Latest_long_term_data_analysis_report_91-06.pdf(1).pdf) [Accessed 10 January 2014]

Human Fertilisation and Embryology Authority (2009) **Code of Practice**, 8th edn. [online]. Available from: http://www.hfea.gov.uk/docs/8th_Code_of_Practice.pdf [Accessed 16 May 2013]

Human Fertilisation and Embryology Authority (2013a) [online]. Available from: <http://www.hfea.gov.uk/76.html> [Accessed 19 August 2013]

Human Fertilisation and Embryology Authority (2013b) [online]. Available from: <http://www.hfea.gov.uk/498.html> [Accessed 3 August 2013]

Human Fertilisation and Embryology Authority (2013c) [online]. Available from: <http://www.hfea.gov.uk/ivf-figures-2006.html#1280> [Accessed 12 September 2013]

Human Fertilisation and Embryology Authority (2013d) [online]. Available from: <http://www.hfea.gov.uk/2587.html> [Accessed 25 September 2013]

Human Fertilisation and Embryology Authority (2013e) [online]. Available from: <http://www.hfea.gov.uk/7091.html> [Accessed 10 July 2013]

Human Fertilisation and Embryology Authority (2013f) [online]. Available from: <http://www.hfea.gov.uk/500.html> [Accessed 10 July 2013]

Human Fertilisation and Embryology Authority Ethics and Law Advisory Committee (2011) **Donation Review – Conditional Donation** [online]. Available from: http://www.hfea.gov.uk/docs/2011-06-08_ELAC_paper_-_conditional_donation.pdf [Accessed 24 June 2013]

Huxtable, R. (2013) **Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?** Abingdon: Routledge

Ives, J. (2013) A method of Reflexive Balancing in a Pragmatic, Interdisciplinary and Reflexive Bioethics. **Bioethics** [online]. Available from <http://onlinelibrary.wiley.com/doi/10.1111/bioe.12018/full#bioe12018-note-0001> [Accessed 22 August 2013]

Ives, J., and Draper, H. (2009) Appropriate Methodologies for Empirical Bioethics: It's All Relative. **Bioethics**, 23(4), pp. 249-258

Jadva, V., Freeman, T., Kramer, W., and Golombok, S. (2009) The experiences of adolescents and adults conceived by sperm donation: comparisons by age of disclosure and family type. **Human Reproduction**, 24(8), pp. 1909-1919

Jolly, M., Sebire, N., Harris, J., Robinson, S. and Regan, L. (2000) The risks associated with pregnancy in women aged 35 years or older. **Human Reproduction**, 15(11), pp. 2433-7

Jones, S. (1985) "Depth Interviewing". In R. Walker (ed.) **Applied Qualitative Research**. Aldershot: Gower

Kaufman, J.S., Ortega, S., Schewe, P.A., Kracke, K. and Safe Start Demonstration Project Communities. (2011) Characteristics of young children exposed to violence: the safe start demonstration project. **Journal of Interpersonal Violence**, 26(10), pp. 2042-2072

Lee, E., Macvarish, J. and Sheldon, S. (2012) **Assessing Child Welfare: Under the Human Fertilisation and Embryology Act: The New Law** [online]. Available from http://kar.kent.ac.uk/32881/1/Summary_Assessing-Child-Welfare-final.pdf [Accessed 3 June 2013]

Leridon, H. (2004) Can assisted reproduction technology compensate for the natural decline in fertility with age? A model assessment. **Human Reproduction**, 19(7), pp. 1548-1553

Lippert-Rasmussen, K. (2011) **Indirect Discrimination: Some Puzzles** [online]. Paper given at Society for Applied Philosophy Conference. Available from: cesem.ku.dk/papers/Indirect_Discrimination.doc [Accessed 19 July 2013]

Lotz, M. (2009) Procreative Reasons-Relevance: On the Moral Significance of *Why We Have Children*. **Bioethics**, 23(5), pp. 291-299

Mahlstedt, P. P., LaBounty, K. and Kennedy, W.T. (2010) The views of adult offspring of sperm donation: essential feedback for the development of ethical guidelines within the practice of assisted reproductive technology in the United States. **Fertility and Sterility**, 93(7), pp. 2236-2246

Malizia, B. A., Hacker, M. R. and Penzias, A.S. (2009) Cumulative Live-Birth Rates after In Vitro Fertilization. **The New England Journal of Medicine**, 360, pp. 236-243

Mason, J. (1996) **Qualitative Researching**. London: Sage

McCracken, G. (1988) **The Long Interview**, Newbury Park: Sage

Mill, J. S. (1991). **On Liberty and Other Essays**. Oxford: Oxford University Press

Mill, J. S. (1998) **Utilitarianism**. Oxford: Oxford University Press

Milne, A. M., Myers, D. E., Rosenthal, A. S. and Ginsburg, A. (1986) Single Parents, Working Mothers, and the Educational Achievement of School Children. **Sociology of Education**, 59(3), pp. 125-139

Moorlock, G. (2012) **An Empirically Informed Ethical Analysis of Conditional and Directed Deceased Organ Donation** [a thesis submitted to the University of Birmingham for the degree of Doctor of Philosophy]

Mulgan, T. (2001) **The Demands of Consequentialism**. Oxford: Oxford University Press

Mulgan, T. (2006) **Future People**. Oxford: Oxford University Press

Musschenga, A. W. (2005). Empirical Ethics, Context-Sensitivity, and Contextualism. **Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine** 30(5), pp. 467-490

National Gamete Donation Trust (2011) **Becoming a Sperm Donor** [online]. Available from: <http://www.ngdt.co.uk/downloads/Becoming%20a%20Sperm%20Donor%20V10.pdf> [Accessed 12 September 2012]

National Gamete Donation Trust (2011) **Becoming an Egg Donor** [online]. Available from: <http://www.ngdt.co.uk/downloads/Becoming%20an%20Egg%20Donor%20V8.pdf> [Accessed 12 September 2012]

National Health Service (2013) **Infertility** [online]. Available from <http://www.nhs.uk/conditions/infertility/Pages/Introduction.aspx> [Accessed 8 January 2013]

National Health Service (2014a) **Alcohol and drugs during pregnancy** [online]. Available from <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/alcohol-medicines-drugs-pregnant.aspx#close> [Accessed 10 January 2014]

National Health Service (2014b) **Stop smoking in pregnancy** [online]. Available from <http://www.nhs.uk/conditions/pregnancy-and-baby/pages/smoking-pregnant.aspx#close> [Accessed 10 January 2014]

National Institute for Clinical Excellence (2004) **Fertility: assessment and treatment for people with fertility problems** [online]. Available from: <http://www.nice.org.uk/nicemedia/pdf/CG011niceguideline.pdf> [Accessed 19 July 2013]

Noyes, N., Hampton, B. S., Berkeley, A., Licciardi, F., Grifo, J. and Krey, L. (2001). Factors useful in predicting the success of oocyte donation: a 3-year retrospective analysis. **Fertility and Sterility**, 76(1), pp. 92-97

Padilla, S.L. and Garcia, J.E. (1989). Effect of maternal age and number of in vitro fertilization procedures on pregnancy outcome. **Fertility and Sterility**, 52, pp. 270-273

Parfit, D. (1984) **Reasons and Persons**. Oxford: Oxford University Press

Pattinson, S.D. (2012) The Value of Bodily Material: Acquiring and Allocating Human Gametes. **Medical Law Review**, 20(4), pp. 576-603

Paulson, R.J., Hatch, I.E., Lobo, R.A. and Sauer, M.V. (1997) Cumulative conception and live birth rates after oocyte donation: implications regarding endometrial receptivity. **Human Reproduction**, 12(4), pp.835-839

Pennings, G. (1995) Should donors have the right to decide who receives their gametes? **Human Reproduction**, 10(10), pp. 2736-2740

- Pennings, G. (1999) Measuring the child welfare: in search of the appropriate evaluation principle. **Human Reproduction**, 14(55), pp. 1146-1150
- Pennings, G. (2001) Distributive Justice in the Allocation of Donor Oocytes. **Journal of Assisted Reproduction and Genetics**, 18(2): 56-63
- Pennings, G. (2004) Saviour siblings: using preimplantation genetic diagnosis for tissue typing. **International Congress Series**, 1266, pp. 311-317
- Pennings, G. (2005) Gamete donation in a system of need-adjusted reciprocity. **Human Reproduction**, 20(11), pp. 2990-2993
- Pennings, G. (2007). Mirror gametes donation. **Journal of Psychosomatic Obstetrics & Gynecology**, 28(4), pp. 187-191
- Perrin, E. C. and the Committee on Psychosocial Aspects of Child and Family Health (2002). Technical Report: Coparent or Second-Parent Adoption by Same-Sex Parents. **Pediatrics**, 109, pp. 341-344
- Piette, C, de Mouzon, J, Bachelot, A. and Spira, A (1990). In-vitro fertilization: influence of women's age on pregnancy rates. **Human Reproduction**, 5(1), pp. 56-9
- Rachels, J. (1975) Active and Passive Euthanasia. **The New England Journal of Medicine**, 292, pp. 78-80
- Rawls, J. (2005) **A Theory of Justice**. Cambridge, Massachusetts: Belknap Press
- Raz, J. (1986) **The Morality of Freedom**. Oxford: Clarendon
- Ross, W.D. (2002) **The Right and the Good**. Oxford: Oxford University Press
- Robertson, John. A. (1994) **Children of Choice: Freedom and the New Reproductive Technologies**. Princeton: Princeton University Press
- Royal Commission on New Reproductive Technologies (1993) **Proceed With Care**. Ottawa: Ministry of Government Services Canada
- Sandelowski, M. (2010) What's in a name? Qualitative description revisited. **Research in Nursing & Health**, 33(1), pp. 77-84
- Sauer, M. V., Paulson, R.J. and Lobo, R.A. (1996). Oocyte donation to women of advanced reproductive age: pregnancy results and obstetrical outcomes in patients 45 years and older. **Human Reproduction**, 11(11), pp. 2540-2543

- Savulescu, J. (1998a) Consequentialism, Reasons, Value and Justice. **Bioethics**, 12(3), pp. 212-235
- Savulescu, J. (1998b) The present-aim theory: a submaximizing theory of reasons?. **Australasian Journal of Philosophy**, 76(2), pp. 229-243
- Savulescu, J. (1999) Should doctors intentionally do less than the best? **Journal of Medical Ethics**, 25, pp. 121-126
- Scheffler, S. (1982) **The Rejection of Consequentialism**. Oxford: Oxford University Press
- Scheffler, S. (ed.) (1988) **Consequentialism and its critics**. Oxford: Oxford University Press
- Scheib, J. E., Riordan, M. and Rubin, S. (2005) Adolescents with open-identity sperm donors: reports from 12-17 year olds. **Human Reproduction**, 20, pp. 239-252
- Schwartz, D and Mayaux, M.J. (1982). Female fecundity as a function of age: results of artificial insemination in 2193 nulliparous women with azoospermic husbands. **The New England Journal of Medicine**, 306, pp. 404-406
- Scott, R.T., Opsahl, M.S., Leonardi, M.R., Neall, G.S., Illions, E.H and Navot, D. (1995). Infertility: Life table analysis of pregnancy rates in a general infertility population relative to ovarian reserve and patient age. **Human Reproduction**, 10(7), pp. 1706-1710
- Scottish Government (2013). **NHS IVF services to be fairer and faster** [online]. Available from <http://www.scotland.gov.uk/News/Releases/2013/05/IVFservices15052013> [Accessed 28 September 2013]
- Sheldon, S. and Wilkinson, S. (2004a) Hashmi and Whitaker: An Unjustifiable and Misguided Distinction? **Medical Law Review**, 12, pp. 137-163
- Sheldon, S. and Wilkinson, S. (2004b) Should selecting saviour siblings be banned? **Journal of Medical Ethics**, 30, pp. 533-537
- Sidgwick, H. (1901) **The Methods of Ethics**. London: MacMillan
- Singer, P. (1972) Moral Experts. **Analysis**, 32(4), pp.115-117
- Singer, P. (1993) **Practical Ethics**, 2nd ed. Cambridge: Cambridge University Press
- Slote, M. and Pettit, P. (1984) Satisficing Consequentialism. **Proceedings of the Aristotelian Society, Supplementary Volumes**, 58, pp. 139-163+165-176
- Smart, J. J. C., and Williams, B. (1973) **Utilitarianism: For and Against**. Cambridge: Cambridge University Press

Smith, D. K., Johnson, A. B., Pears, K.C., Fisher, P. A., and DeGarmo, D. S. (2007) Child Maltreatment and Foster Care: Unpacking the Effects of Prenatal and Postnatal Parental Substance Use. **Child Maltreatment**, 12(2), pp. 150-160

Soames, S. (2003). **Philosophical Analysis in the Twentieth Century, volume 1**. Princeton: Princeton University Press

Stacey, J., and Biblarz, Timothy J. (2001) (How) Does the Sexual Orientation of Parents Matter? **American Sociological Review**, 66(2), pp. 159-183

Steinbock, B. (1986) The Logical Case for 'Wrongful Life'. **Hastings Center Report**, 16(2), pp. 15-20

Stovall, D., Toma, S., Hammond, M. and Talbert, L. (1991). The effect of age on female fecundity. **Obstetrics and Gynecology**, 77(1), pp. 33-6

Strachan, D. and Cook, D. (1997) Health effects of passive smoking. 1. Parental smoking and lower respiratory illness in infancy and early childhood. **Thorax**, 52(10), pp. 905-914

Sutcliffe, A. G., Barnes, J, Belsky, J., Gardiner, J. and Melhuish, E. (2012). The health and development of children born to older mothers in the United Kingdom: observational study using longitudinal cohort data. **BMJ**, 345:e5116

Tan, S.L., Royston, P., Campbell, S., Jacobs, H.S., Betts, J., Mason, B. and Edwards, R.G. (1992). Cumulative conception and livebirth rates after in-vitro fertilization. **The Lancet**, 339(8806), pp. 1390-1394

Taylor, M. C. (2005) "Interviewing". In Holloway, I. (ed.) **Qualitative Research in Health Care**. New York: Open University Press

Taylor, R., Najafi, F. and Dobson, A. (2007) Meta-analysis of studies of passive smoking and lung cancer: effects of study type and continent. **International Journal of Epidemiology**, 36(5), pp. 1048-1059

Temkin, L. (1993) **Inequality**. Oxford: Oxford University Press

Temkin, L. (2002) "Equality, Priority, and the Levelling Down Objection". In Clayton, M. and Williams, A. (eds.) **The Ideal of Equality**. Basingstoke: Palgrave MacMillan

Thornberry, E. (2008) **House of Commons Hansard Debates**, column 176 [online]. Available from:

<http://www.publications.parliament.uk/pa/cm200708/cmhansrd/cm080520/debtext/80520-0006.htm> [Accessed 18 September 2013]

Tobacco Advisory Group of the Royal College of Physicians (2010). **Passive smoking and children** [online]. Available from <http://www.rcplondon.ac.uk/sites/default/files/documents/passive-smoking-and-children.pdf> [Accessed 19 July 2013]

Turner, A. J and Coyle, A. (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. **Human Reproduction**, 15(9), pp. 2041-2051

University Hospitals of Leicester NHS Trust (2011) **NHS Funding for Assisted Conception Treatment: A Guide for Patients** [online]. Available from: <http://www.leicesterfertilitycentre.org.uk/userfiles/patient-information/NHSFundingInfo-WPS010-1007334.doc> [Accessed 7 December 2012]

Vaismoradi, M., Turunen, H., and Bondas, T. (2013) Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. **Nursing and Health Sciences** (online only)

van Noord-Zaadstra, B. M., Looman, C. W. N., Alsbach, H., Habbema, J. D. F., te Velde, E. R. and Karbaat, J. (1991) Delaying childbearing: effect of age on fecundity and outcome of pregnancy. **BMJ**, 302, pp. 1361-1365

VanDeVeer, D. and Pierce, C. (2003) **Environmental Ethics & Policy Book**, 3rd ed., Belmont: Thomson/Wadsworth

Vasireddy, A., and Bewley, S. (2013). IVF is safe over 50 if it is not fatal. **American Journal of Perinatology**, 30(10), pp. 881-882

Vincent, J. (2001). Cultural differences in end-of-life care. **Critical Care Medicine**, 29(suppl), pp. N52-N55

Wainright, J. L., and Patterson, C.J. (2006). Delinquency, victimization, and drug, tobacco, and alcohol use among adolescents with female same-sex parents. **Journal of Family Psychology**, 20, pp. 526-530

Wainright, J. L., Russell, S. T., and Patterson, C. J. (2004). Psychosocial adjustment, school outcomes, and romantic attractions of adolescents with same-sex parents. **Child Development**, 75, pp. 1886-1898

Warnock, M. (1984) **Report of the Committee of Inquiry into Human Fertilisation and Embryology** [online]. Available from: http://www.hfea.gov.uk/docs/Warnock_Report_of_the_Committee_of_Inquiry_into_Human_Fertilisation_and_Embryology_1984.pdf [Accessed 26 July 2013]

Welsh, E. (2002). Dealing with Data: Using NVivo in the Qualitative Data Analysis Process. **Forum: Qualitative Social Research**, 3(2), art. 26

Widdershoven, G., Abma, T. and Molewijk, B. (2009). Empirical Ethics as Dialogical Practice. **Bioethics**, 23(4), pp. 236-248