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THE RACIAL MATCHING OF GAMETE DONORS IN UK FERTILITY CLINICS

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A thesis for title of PhD in Law

Kent Law School, University of Kent

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Abstract

Race is a deeply contested concept; however, race and related characteristics, including ethnicity and skin tone, are frequently provided with gamete donor information, implicating race in donor selection at UK fertility clinics. While existing literature shows that fertility professionals might sometimes seek a racial match between the donor and the patient(s), the role that race plays, if any, in donor selection has been relatively underexplored. By adopting a constructivist model of race and applying empirical evidence gathered through a series of in-depth semi-structured interviews with clinicians, counsellors and nurses, this thesis identifies if and how race plays a role in donor selection and whether patients and gamete donors are racially matched. It examines the nature and degree of involvement of fertility professionals in this matter and evaluates if a concern for race may be operationalised in ‘routine’ clinical practice or ‘problem’ cases where patients raise a query or challenge norms.

The findings demonstrate how race operates as a social construction where biological or essentialist notions of race are reproduced through racial matching and assumptions within the donor selection process. However, the construction of race is also observed to be linked to themes of privacy, identity and autonomy, presenting a complex and nuanced picture overall. Fertility professionals are seen to play an integral role in how race is deployed in donor selection. While assumptions around race-kinship congruity result from the problematising of racial mismatching, the findings also describe sensitive and meaningful interaction with patients’ understandings of kinship and the construction of relatedness. These findings raise important normative considerations for fertility practice and policy in this unique sphere of interaction between patient, donor and clinic.

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Glossary of acronyms

ARTs – assisted reproductive technologies

ASRM – the American Society for Reproductive Medicine

BAME – Black, Asian and minority ethnic

BICA – British Infertility Counselling Association

BSA – British Sociological Association

CMA – Competition and Markets Authority

CRT – critical race theory

DI – donor insemination

DNA – deoxyribonucleic acid

HFEA – Human Fertilisation and Embryology Authority

HRA – Health Research Authority

ICSI – intracytoplasmic sperm injection

IUI – intrauterine insemination

IVF – in vitro fertilisation

NICE - National Institute for health and Care Excellence

NHS – National Health Service

NKS – new kinship studies

PGD – pre-implantation genetic diagnosis

RCOG – Royal College of Obstetricians and Gynaecologists

SEED – the sperm, egg embryo donation report (HFEA)

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Any mistakes or inaccuracies contained in this thesis are entirely my own.

Introduction to the thesis

Race is a deeply contested and divisive concept, yet race – or some version of it – matters to patients who require the use of donated gametes (Fox, 2011:3; Fogg-Davis, 2002:13).¹ A number of reasons have been put forward to explain this situation: a desire for resemblance between parent and child (Becker et al, 2005:1301), welfare concerns for the child (Wainwright and Ridley, 2012:52), keeping the use of in vitro fertilisation (IVF) a secret or maintaining privacy (Smart, 2010; Hargreaves and Daniels, 2007:420), the desire to construct a ‘traditional’ family (Nordqvist, 2012:657), the forging of identity (Kramer, 2011) or the exercise of autonomous narrative building (Mohr, 2015). In each of these cases, race appears to play a role in gamete donor selection. Ideas of race feature in discussions around the selection of gamete donors and the occurrence of racial matching in fertility clinics has been reported by commentators examining donor conception (see Deomampo, 2019; Davda, 2018; Hudson, 2015; Nordqvist, 2012; Wade, 2012; Quiroga, 2007; Price, 1997). While patients’ ability to choose gamete (sperm or egg) donors based on their physical features at fertility clinics is still a very recent phenomenon in the UK (Pennings, 2000), donor traits that may be associated with race – including ethnicity, skin tone, height, age, eye and hair colour – are often listed on donor profiles. Gamete donors are asked to provide their race and/or ethnicity when donating, and donor catalogues often include race as a searchable characteristic. This thesis seeks to examine the role of race in donor selection by offering in-depth and fresh insights into the ways that race is deployed in the donor conception context from the perspective of the fertility

¹ The word ‘patient’ is used in this thesis to refer to the person seeking treatment and also their partner, if relevant, where treatment is being sought together regardless of the reason for infertility.

professionals involved. Its primary research question is therefore: what role, if any, does race play in donor selection, and how and why does it do so? The importance of race is also addressed as part of this evaluation; how it is discussed with fertility professionals and whether racial matching practices can be observed. However, a secondary research question emerges from this field, where relatively little is known about donor selection: how do patients choose a gamete donor and what is the nature of clinics involvement in this process? The findings of this thesis may have far-reaching implications for law and policy amid the ongoing challenge for legal frameworks to keep up with technological and social changes in the field of assisted reproduction.

1. Approaching race

As this thesis will demonstrate, references to the word 'race' itself – a key concept at the heart of this study – can be highly problematic. The validity of a biological basis for race has been significantly discredited by advances in biological and genetic science (see Sesardic, 2010). Instead, race has been reinterpreted through social and political constructivist theories as being deeply embedded in historical and social processes that have been used to classify and subjugate certain populations (Quiroga, 2007:144). It emerges from modern study not as an essential quality in the physical body, but a social or political construction (Roberts, 1996).

It is important at the outset of this thesis to address the difficult question of terminology and the problematic use of the word 'race' in this research, indeed used in the title for the thesis itself. In her work on terminology, Bradby rejects the use of the word 'race' in the sociology of health (but expressly not 'racism' or

‘racialisation’) preferring instead to use the term ‘ethnicity’ (1995:406). In response to assertions that a scientific version of race does not exist (discussed in Chapter one, section 2.i.a), Bradby explains that sociologists continued to use the phrase to represent an analytical concept or an ideological construct (1995:407). For Bradbury, use of the word race in health research carries ambiguities that further problematise the contentious debate between genetic, social and environmental determinants of health (1995:408). For the purposes of this study, which seeks to elucidate the complexities and the multitude of meanings that can operate around the use of the word race in donor selection, ‘race’ – both as an analytical concept and ideological construct – serves better than the word ethnicity. Ethnicity refers to the sense of belonging to a particular group on the basis of shared cultural or national traditions (Lexico, 2019b). In Bradby’s terms, ethnicity refers to the ‘common origins of a people with visions of a shared destiny’ and can be discerned through language, religion, work, diet or family patterns (Bradby, 1995:411). The focus of this research is on meanings and constructions that are potentially wider than this, which race better encompasses. Indeed, as discussed in Chapter 5, the use of the word race is associated with an array of meanings, only one of which is ethnicity.

There are certain terms that this thesis seeks to avoid using, however. Some respondents spoke about patients or donors as being ‘Caucasian’. While the word is commonly used as a synonym for ‘White’, it has also attracted controversy for inaccurately and incorrectly being used to refer to ‘White’ populations rather than its more accurate narrow reference to people native to the Caucasus (Khan, 2011). Furthermore, the use of the term ‘non-White’ has attracted criticism for its failure to appreciate a sense of belonging to a majority ethnicity (Bradby, 1995:414).

Indeed, in its advice on style and terminology, the ONS instructs users to avoid using the term ‘non-White’ (2015). It clarifies that ‘Defining groups in relation to the White majority was not well received in user testing and to define a group by what they are not, rather than what they are, can be confusing’ (ONS, 2015). As Bradby explains, it is important to distinguish between ethnic minorities, ethnic majorities and racialised minorities in contemporary Britain (1995). Instead of non-White, therefore, this thesis adopts the term ethnic minorities – the ‘minority’ being defined by ethnicity within an overall national population or region. (In the present study, White ethnicity was not defined at a level that identifies White minorities (ONS, 2015)).

If we wish to understand the role that race plays in donor conception, and to inform law and policy in this area, we must necessarily engage with its normative context and also the processes that underpin the construction of race. The analytical frameworks therefore provided by critical race theory, sociology and anthropology, particularly the literature that has examined race and kinship in the donor conception context, offer means through which these concepts and processes may be identified and spoken about. This thesis presents a socio-legal analysis of the concept of race and the practice of racial matching in the selection of egg and sperm donors by recipients at fertility clinics in the UK. It adopts the constructivist model of race as its central tenet. Using empirical evidence gathered through interviews it seeks to identify how concepts of race are used in the donor selection process and evaluates how the concepts and processes associated with race manifest in the assisted conception context.

By interviewing clinicians and fertility professionals who have experience of discussing donor selection with a wide range of patients, the thesis provides an original contribution to the deployment of race in this context. Fertility professionals can shed light on how a concern for race may be operationalised in ‘routine’ clinical practice and ‘problem’ cases where patients raise a query or challenge norms, or where things go wrong. Unlike much of the existing work on donor selection, which has focused on the perceptions of patients, this study offers an original contribution by identifying the attitudes of fertility professionals *about* the perceptions of patients, donor selection practices and the concept of race (the focus on fertility professionals is justified in Chapter Three). In this way, the interviews provide the opportunity to examine donor selection discussions, and the reference to race, in a relational and contextual environment. As this thesis will show, meanings around race are constructed through interaction with the clinic and donor services and this thesis seeks to articulate the nature and consequences of this interplay. Furthermore, fertility professionals have the ability to describe processes that fertility patients may not observe. Such an investigation may help open up broader discussions about patients’ interaction with reproductive technologies more generally, and how law, policy and practice can respond to the meanings generated in this unique sphere of interaction between patient, donor and clinic.

The Introduction sets up the central questions to which this thesis responds. It first offers a brief summary of the background and context of the provision of ARTs in the UK, such as is necessary to help understand the specific issues raised in the thesis. It then addresses some of the broad themes around the development of law and policy responses to certain regulatory challenges, before introducing the

donor conception process, outlining where and how patients select gamete donors and what is known about the role of race in this – setting the scene for the proceeding analysis.

2. The fertility sector in the UK

Infertility affects one in six couples in the UK; or around 3.5 million people (Fertility Fairness, n.d). Assisted conception includes the provision of in vitro fertilisation (IVF), intrauterine insemination (IUI) and other technologies that assist with human reproduction by helping patients reach a successful pregnancy. Commonly they are collectively termed assisted reproductive technologies (ARTs). ARTs cover an array of infertility procedures and complementary processes. IVF involves the removal of an egg from a woman's body, which is then fertilised with sperm in a laboratory. The fertilised egg is then implanted into a woman, with the hope it will lead to a successful pregnancy. In addition, patients may be offered intracytoplasmic sperm injection (ICSI). ICSI involves injecting sperm directly into an egg to fertilise it, before it is implanted into the woman's womb. Instead of fertilisation taking place in a dish, a single sperm cell is injected directly into each egg. The procedure means that even if sperm is obtained in low numbers, fertilisation is possible, assisting men with low sperm counts to use their own gametes. ICSI is often recommended where the male partner expresses fertility problems. Alternatively, patients may be offered intrauterine insemination (IUI), which simply involves placing sperm inside a woman's uterus. Other associated techniques include pre-implantation genetic diagnosis (PGD), comparative genomic hybridisation screening and mitochondrial DNA (deoxyribonucleic acid) techniques.

The fertility sector in the UK serves more than just those affected by degrees of infertility. Those unable to conceive naturally, including single women, homosexual couples, and couples with one or more partner who is of non-binary sex, can also sometimes access fertility treatment in the UK in order to conceive. Although some fertility techniques can be performed at home (for example, using home donor insemination kits), the technological interventions above must usually be performed in a clinical setting and by professionally trained staff. The range of techniques offered – and the number of people to whom they are offered – has generated a profitable (albeit regulated) industry. The number of women receiving IVF or ICSI has increased steady since the 1990s and the fertility sector in the UK is thought to be worth around £320 million per year in the UK (HFEA, 2018). As such, reproductive decision-making occurs in a commercial and professionalised context. The examination of race in donor conception is timely, not only since the non-medical use of donor conception may continue to rise, but also because law and policy reform around donor conception, including the removal of anonymity, continues to capture the media and political spotlight.

3. The social, legal and ethical context of gamete donation

The provision of fertility treatment invokes an array of complex legal, social and ethical issues in the use or manipulation of embryos, ex utero conception, and the new options thus created for biological and social parenthood. The use of gamete donors is but one broad practice within the wider engagement of patients with ARTs. As the practice allows children to be born to parents without a biological/genetic connection and facilitates the creation of families that challenge traditional models, the use of donor gametes raises specific ethical, legal and social issues. At the most general level, we are witnessing the collision of new

technology facilitating new forms of parenthood with traditional models of the ‘sexual family’ (McCandless and Sheldon, 2010:202). This fast-paced changing social environment challenges the law and policy to keep up.

The approach of law and policy makers towards ARTs and associated technologies is broadly speaking entrenched within a precautionary framework, which is in part underpinned by the debates that led up to the HFE Acts 1990 and 2008 (Eijkholt, 2011:100-101). Policy makers and other interested parties played an important (albeit complex) role informing and engaging in debates around the technical, social and ethical aspects of ARTs; an analysis of these discourses reveals a great deal about the social and political anxieties raised by assisted conception in relation to family, sexuality and reproduction (see, for example, Knight and Smith, 2013).

Donor selection must be considered within the interlocking themes surrounding IVF and ARTs that inform policy and practice in this area. The meaning of race in donor conception may therefore be influenced by overall trends in assisted conception in respect to patient mobilisation, involvement of third parties, clinical or commercial interests and considerations over the welfare of the intended child.

4. The provision of donor conception in the UK

Patients who require a gamete donor will generally choose to undergo donor insemination (DI), where fertilisation takes place inside the woman’s body, or IVF using donated gametes. Patients can choose to use a known gamete donor, or an unknown donor through a licensed fertility clinic. The gametes can be sourced from donors in the UK or imported from abroad. Many patients alternatively

choose to receive fertility treatment abroad, where different rules around donor anonymity, for example, operate. Donations made in the UK are provided anonymously to the patient, unless a known donor is used. These donors, if they donated at a licensed fertility clinic in the UK will have no legal responsibilities towards any resulting child, but any donor-conceived children are able to access identifying information about their donor (discussed in Chapter Two, section 2.ii.c).

Commercial organisations are often involved in provided gametes to patients through sperm or egg banks, although some patients will sometimes use the clinic's own donors. Commercial gamete banks and providers operate in the UK but also abroad, most notably in the United States (US) and Europe. The sector has witnessed an expansion in the commercial provision of gametes on a global level (see *The Economist*, 2017) – although the UK maintains a limit on payments to gamete donors of not more than reasonable expenses. This thesis considers the role of both external and internal gamete banks in donor selection.

A patient choosing a gamete donor is presented with a range of non-identifying information about the donor. Typically, the Human Fertilisation and Embryology Authority's (HFEA) donor information form contains information about the donor's medical conditions, the donor's ethnic group and that of their biological parents, and physical characteristics such as eye, hair and skin colour. It also gives information about the donor's religion, occupation, interests and skills and includes space for the donor to leave a message about themselves, known commonly as the 'pen portrait'. Sometimes gamete banks may provide further information – particularly those based outside the UK. For example, a gamete

bank in Europe includes donors' childhood photographs and a recording of their voice (Anon, f, n.d). The donor information provided to patients also includes ethnicity, with some gamete banks referring to 'race' specifically, and characteristics that may be associated with race (skin, hair and eye colour).² This thesis explores fertility professionals' perceptions of the kinds of information that matter to patients during donor selection. In particular, the interviews conducted as part of this thesis describe the various constructs of race that are raised in donor selection discussion and proceeds to identify not only if and how race is discussed, but the underpinning reasons for the modes of discussion encountered.

5. Donor matching and racial matching

Donor matching, including racial matching, has already been observed by a number of commentators to date (Deomampo, 2019; Davda, 2018; Hudson, 2015; Nordqvist, 2012; Wade, 2012; Quiroga, 2007; Price, 1997). The matching of patient and donors' physical characteristics including 'ethnic' matching was also previously recommended by the HFEA in its guidance to clinics (HFEA, 2003:32), but this has since been removed. Nevertheless, some clinics' websites still refer to matching – discussed in Chapter Two, section 4.iv. The thesis seeks therefore not only to explore the constructions of race and evaluate its importance and the role it plays in donor selection, but also seeks to demonstrate if – and why – matching practices are still prevalent in the fertility sector. Considerable literature examines the concept of race and kinship building in ARTs, but the specific role of race in donor selection is relatively underexplored. This thesis

² The UK is experiencing a disproportionate low number of gamete donors from ethnic minorities, with ethnic minorities also making up a significant minority of patients accessing ART (HFEA, 2019c).

seeks to examine fully this important question of the role of race using original empirical data and combining critical race and kinship analysis to draw conclusions for law and policy in this area.

6. Outline of the thesis

The literature review (Chapter One) outlines the existing literature that has examined the biological, philosophical and socio-cultural bases for race found in critical race theory (CRT) and ‘new kinship’ studies (NKS) in order to establish a theoretical framework for the analysis of race in donor selection. The CRT literature demonstrates that race is not only a social construction but has been politically constructed to enable those in power in society to perpetuate ideas of racial hegemony and to preserve the dominance of ‘White’ people over people of colour. CRT provides a set of analytical tools through which the replication of established idioms of racial hegemony and a framework through which nuanced and ordinary decision-making in donor conception can be examined.

CRT can be used to examine the extent to which race is routinised and operationalised in fertility clinics. It offers a social constructivist mode of race that enables scrutiny of how the concept of race functions to promote White privilege and replicates implicit forms of discrimination. While the chapter will also set out some reservations about the explanatory potential of this US literature (which mostly originates in the US) for the deployment of race in the UK clinical context, it will suggest that CRT nonetheless does provide a powerful framework to engage with normative ideas of race.

Acknowledging that race is not a biologically determined phenomenon but is socially constructed, the literature review observes that socially constructed ideas are no less 'real' than genetic 'facts' when it comes to lived experience of familial and cultural bonds. It proceeds to outline the key themes that have emerged from sociological and anthropological studies around the creation of kinship under NKS, including the importance of resemblance and the ways genetic information is understood and rendered meaningful within personal and familial narratives. ARTs generate unique and distinct meanings around genetic information through processes that are fluid and changing. Crucially, the meaning generated around kinship is personally, relationally and socially constructed; and is often constructed/deconstructed in contradictory and paradoxical ways. The literature presents a complex and multi-dimensional model of kinship that may capture a variety of nuanced uses of race in the donor selection context.

The NKS literature provides a theoretical framework better able to capture the complexity of race in the UK fertility context through a concentration on the relational interactions within families, which gives the approach real life significance. The analysis offers a range of useful insights and concepts which will help to frame the analysis that follows in subsequent chapters, including in particular, the idea of family resemblance, genetic ancestry and the importance of narratives.

CRT thus offers a framework through which any racialised assumptions around donor selection may be identified and interrogated. NKS, meanwhile, locates decisions of racial matching in a broader context of family-building using ARTs. The NKS literature focuses attention on the decisions or processes that revolve

around ideas of relatedness and resemblance given meaning in a relational or familial setting. Together, CRT and NKS offer complementary strands within an analytical framework through which race and donor selection can be thoroughly investigated.

Chapter Two outlines the legal framework in which gamete donor selection takes place, the available evidence of how donors are matched to patients in the UK, and the practices or policies commonplace across clinics. It also describes the donation process insofar as it is relevant to the donor matching process. Chapter Two first sets out the legislative framework presented by the Human Fertilisation and Embryology (HFE) Act 1990 (as amended) and the role and function of the HFEA, including how it regulates, its legal underpinnings and the development of the current regime.

Chapter Two then sets out the factual background to assisted conception and the use of gamete donors, outlining the procedures for donation, the information provided, and data specifically related to race. The chapter outlines and explains the framework for donor matching – what happens, who is involved and what sort of guidance is given or framework it is conducted in, insofar as is apparent from available literature. Doing so helps to identify the gaps that the current thesis can start to fill.

Chapter Two moves on to evaluate policy and guidance on donor matching, tracing the evolution of the HFEA's Code of Practice guidance on the matter, highlighting how an early version of the Code of Practice recommended that patients should not be permitted to select donors of a different ethnic origin for

‘social reasons alone’. Subsequent versions of the Code of Practice emphasised physical matching of donors to patients, until the removal of such provisions on the basis that the matching of donors and recipients was impractical and had a negative impact on donor treatment, as identified in the HFEA’s sperm, egg embryo donation (SEED) report. It also outlines the published guidance from fertility clinics and professional organisations.

Chapter Three discusses the methodology of this thesis, outlining the practical and theoretical justifications for the chosen method of data collection. The chapter discusses the need for conducting a systematic literature review (and how I went about it), and how a socio-legal approach is justified for this project. Furthermore, it explains the use of semi-structured interviews and the necessity of generating original empirical data. This includes identifying the functions of adopting a qualitative design, how the decision to use semi-structured interviewing best supported the research, how subjects were chosen and contacted, as well as the potential limitations of this approach, and the ethical issues encountered in the planning of the study and how these were addressed. I discuss how I compiled the questions and conducted the interviews, along with the practical hurdles I encountered, before providing a discussion of how I approached the analysis of the interview data.

Chapter Four draws on the interview data in order to address how patients select gamete donors and how this process is managed by fertility professionals in the UK. Drawing on interviews with a range of fertility professionals in the UK as well as the available academic literature, this chapter identifies what happens during gamete donor selection in fertility clinics. It explores how patients choose

sperm or egg donors and what the extent and nature is of the clinic's involvement in this process. Interviewees were asked to describe the donor selection process, giving their account of discussions between staff and patients, with whom these conversations take place and at what stage in the treatment process they occurred.

The interviews provide first-hand evidence about the extent of clinics' involvement in the donor selection process, revealing that clinics were often involved and do discuss donor selection – a finding that is perhaps not surprising but nonetheless significant given that such decisions are not necessarily ones that need to be, or indeed always are, made in clinics. The interviews show a wide variation in practice in the selection of gamete donors, ranging from 'paper-based' donor matching, with the clinic taking down the patient's characteristics and finding a match from donors available, to catalogues modelled on the Amazon.com shopping website (Counsellor A: 101-104), largely depending on the size of the clinic and whether an external sperm or egg bank was involved. Donor selection tended to be discussed early on in the patient's treatment cycle.

In addition, the interviews show that the range of topics potentially covered during the discussion of donor selection within clinics is broad, spanning not only the donor's physical and non-physical characteristics, but also procedural and practical issues regarding donor conception. Although the emphasis of the discussion varied according to each patient, it was evident that various fertility professionals and clinics viewed and conducted these discussions quite differently. Furthermore, some clinics tended to deal with perceived 'unusual' donor requests by patients at a team-discussion level. Overall, the data in this study shows that clinics were often heavily involved in donor selection

discussions, information which sets the scene for an analysis of what is perceived to be important to patients and how clinics manage donor selection in the next two chapters.

While Chapter Four explores process, Chapter Five moves on to the substantive content of donor selection discussions (including references to race and ethnicity), offering close consideration of the ways in which donor characteristics were seen to be discussed by patients, and which of these were considered to be important to patients. The interviews reveal that fertility professionals perceived physical characteristics as very important when selecting a donor, but that weight was given to non-physical characteristics giving rise to the idea that the ‘whole package’ represented by the donor information is used by patients in their selection decisions. Such references evoke certain impressions of biological heritage in the discussion of donor information. Furthermore, the interviews show there was a high degree of variation in the importance given to certain characteristics by different patients. While some patients expressed preferences for certain traits as being more desirable (for example, lighter skin tone), giving rise to questions over to extent to which donor selection decisions are racialised, the interviewees also reported highly individualised approaches by patients, who interpreted and constructed donor information in unique ways.

The chapter then turns to examine the importance attached to race specifically, including notions of ethnicity and racialised characteristics. The interviews show that many patients considered ‘race’ to be important in donor selection and that race was directly and indirectly discussed in gamete donor selection. However, a variety of concepts and phrases were used to discuss race, showing it to be a

complex and contested construct. Overall, patients were reported to often express a desire to achieve resemblance as part of the construction of relatedness.

Chapter Six explores why race was deemed important in donor selection. The central theme of resemblance is unpicked to identify a range of factors relevant to this, including concerns about maintaining privacy, the role of resemblance and race in the construction of kinship and relatedness, and also the connection to narrative building on the part of patients. Finally, this chapter explains how resemblance was also associated with welfare – in particular, the social and psychological effects physical dissimilarity would have on their child and family unit. The factors that underpin resemblance provide a range of perspectives on race and their interrelationship denotes the complexity of the various constructions of race at play in donor selection.

The conclusions to the thesis identify a complex and nuanced role for race in donor selection practices, raising questions for future policy over its positioning in donor information and the manner of its discussion. Normative questions are raised around the biologisation of race, the unconscious reproduction of social norms and the exercise of choice within a largely commercialised environment, which carry significant implications for wider issues of inequality, discrimination and racism in society. The thesis provides recommendations for policy and practice to mitigate these implications and to navigate the tensions expressed through the study findings.

Chapter One: Literature review

1. Introduction

The literature review outlines and combines two expansive bodies of literature – critical race theory (CRT) and ‘new kinship studies’ (NKS) – to establish a theoretical framework for the analysis of race in donor selection. It highlights the main contributions from the literature that may be particularly pertinent to an analysis of race and donor selection, including findings from relevant empirical studies, and helps to identify an original space for the theorisation and application of the empirical data collected in this thesis.

Any discussion of race invites engagement with a rich and fascinating body of scholarly literature referred to as CRT, compiled over a long and troubling history of racial segregation and discrimination in Europe, the US and elsewhere. CRT can be described as a multidisciplinary theory (or ‘coalition’ (Crenshaw et al, 1996)) concerned with the study of relationships between race or ethnicity and power within a broad social context (Delgado and Stefancic, 2012:3), allowing for an examination of the concept of race and its deployment in social interactions and institutions. The approach is grounded in the study of the use of race by those in power (generally those who are considered ‘White’) to categorise people within populations in such a way to subvert and marginalise certain groups – namely ‘Black’ and ethnic minorities (Roberts, 1996; Quiroga, 2007; Delgado and Stefancic, 2012, Crenshaw et al, 1996, Gotanda, 1991). Critical race theorists identify the use of race as a mechanism of control to serve political and social aims – namely to preserve racial (White) integrity and reaffirm in-built institutional prejudice towards minority communities – across various platforms,

such as advertising and education. Some critical race analysts focus on ‘real world’ interests of rights, discrimination, poverty, immigration and criminal justice, while others assess social discourse, observing how ordinary society constructs racism in basic ways (Delgado and Stefancic 2012:136). The latter approaches are more likely to examine the roles of thought, ideas and indirect or unconscious discrimination.

One of CRT’s primary contributions to the assessment of race in this study is therefore to provide a critical evaluation of the use of ‘race’ that focuses on the way it is spoken and thought about in everyday life. Such an approach is able to identify nuanced and unconscious expressions of race that can be distinguished from instances of more overt racial discrimination, which remains undoubtedly a significant societal problem in most Western states (see, for example, Devlin, 2018). CRT highlights the political implications of what may otherwise be seen as innocuous and neutral practices and questions notions of objectivity and neutrality around race. As such, it offers a set of tools which will allow this thesis to examine how race is discussed in donor selection conversations – an area particularly charged with notions of individual and community identity – as well as its positioning in donor information and associations made by patients and staff with other donor characteristics. CRT is able to expose assumptions made about race and racial matching, and questions the ordinary, daily practices that occur in fertility clinics.

CRT also argues that ‘race’ operates as a social and political construct rather than a biological fact (Lopez, 1994; Roberts, 1995). This understanding allows for a more complex assessment of how race is used in certain contexts, capturing the

social and political processes that underpin its expression and permits a more careful assessment of what is meant by race in the donor selection context. As a framework for assessing the role of race in donor selection, CRT can therefore highlight the implications that may directly or indirectly arise from decisions to choose gametes on the basis of race or ethnicity, and the way such concepts are used by clinical staff.

The application of CRT to donor conception in the UK is necessary to uncover the reasons why ‘race’, on the face of it, routinely plays a role in donor selection decisions. However, the use of race in the donor selection context has been relatively under-explored in the UK and the applicability of a body of literature mostly produced in the US to the UK context raises questions over potential historical and geo-social differences between the two jurisdictions. Furthermore, while race as a concept is relatively under-explored, many studies have examined donor conception and kinship-building in UK fertility clinics. The NKS (Carsten, 2000b:3; Franklin and McKinnon, 2001) examine the process of family-building facilitated by assisted reproductive technologies and attempts to identify the factors that feed into reproductive decision-making in families. When combined with CRT, the NKS literature therefore provides a theoretical framework able to capture the complexity of the ways in which ideas of race play out in the UK context through a concentration on the relational interactions within families. The NKS analysis offers a range of useful insights and concepts which will help to frame the analysis that follows in subsequent chapters, including in particular, the idea of ‘family resemblance’, genetic ancestry and the importance of narratives.

These two bodies of literature provide a unique and complementary framework through which race in donor selection can be thoroughly examined. While CRT uncovers assumptions around the use of race and subjects otherwise seemingly innocuous practices to close scrutiny, NKS identify how donor information can be understood in unique, diverse and sometimes paradoxical ways by patients, their families and fertility professionals alike. Discussions of race brings these perspectives into the forefront of analysis – as Nash observes, ‘the spectre of ‘race’ creates an uncomfortable tension between constructing the meaningfulness of genetic relatedness and tempering claims about its significance’ (2004:26). This literature review outlines these bodies of literature and attempts to mediate between the claims to create a unique framework through which to analyse race. The first section of this chapter will explore CRT and the second section draws on NKS.

2. Methodology for the literature review and background research

The first stage of the study involved thorough review of the literature relevant to the research questions to identify gaps and to establish the relevant academic fields and intellectual traditions (Marshall and Rossman, 2010:28). This work also provided a theoretical focus or framework from which the interview questions were devised and the data analysed (Prasad, 2017).

In undertaking the literature review, I adopted a traditional ‘narrative review’ (Bryman, 2015:91) to provide an overview and summary of the key contributions in critical race literature and also anthropological/sociological contributions that

have been grouped together and termed ‘new kinship studies’ (Carsten, 2000b:3; Franklin and McKinnon, 2001). I started by conducting desk-based and library-based academic research to identify key texts that could provide an overview and explanation of these areas, which helped me to comprehend essential terminology and concepts, as well as identifying prominent academic writings and traditions. Through access to the University of Kent’s library, I was able to identify writings that featured within the broad categories of anthropology, sociology and critical theory, which I scanned and placed in hierarchies according to usefulness for providing fundamental explanations and references to other key writings. I also conducted online searches using Google Scholar using key words like ‘critical race’, ‘critical race theory’ and ‘new kinship’, ‘kinship studies’, plus key concepts that had started emerging from my reading, such as ‘resemblance’ from kinship studies, and ‘race neutrality’ from CRT. I then combined these with subject definers, such as ‘fertility’, ‘gamete donor matching’ and ‘gamete donor selection’ to identify literature more specific to the topic of the thesis. I consulted relevant texts that were more difficult to locate from the British Library.

The inclusion criteria for the literature review covered empirical studies examining donor conception, including those from both patient and clinician perspectives, particularly on donor selection and matching; literature on race, including authority that introduces and explains critical race theory, the application of CRT to ART and in particular to donor conception; and studies examining kinship and the use of ART, particularly studies that have examined donor selection, matching and the relevance of race from such a perspective. Such was the breadth of the research topic it was also necessary to adopt exclusion criteria to streamline the research stage and ensure the literature review remained

relevant to the thesis questions. I decided to exclude CRT literature that applied in non-ART contexts, such as Hispanic relations in the USA or education. I also decided to exclude sociological and anthropological literature that explore the basis for kinship studies, except insofar as was necessary to explain the foundational concepts and trends relating to new kinship studies. Other areas were reviewed insofar as was necessary to support an assessment of the relevant background to donor selection prior to data analysis, including changes to rules of donor anonymity, the non-payment of gamete donors, statutory provisions relating to counselling and the welfare of the child. I returned to the literature searches once themes started emerging from the interviews and data analysis to further support the analytical discussion – for example, once it became apparent that fertility professionals were making connections between welfare and race, or that historical aspects of the broader regulatory regime were continued to be adopted by clinics, I returned to the literature on these topics to provide a robust basis for the analysis of the data. I conducted additional searches throughout the research to stay up to date and also following feedback during the viva, which highlighted suggested areas for further attention. Additional literature searches were conducted based on recommendations received during the viva and feedback.

An advantage of using online searches as well as the library search engine was that the results were prioritised according to relevance and popularity, which alerted me to key contemporary texts. I also sought out recommendations from my supervisor and academic colleagues working in related fields. For example, at one stage I contacted a key contributor to kinship studies who was able to recommend certain authors to read. I found these recommendations particularly helpful in helping me to hone my understanding and focus my research onto the

key debates and contributors to critical race and kinship studies. From these initial searches, I compiled a list of key texts and from these sources and using the bibliography, I identified literature that appeared particularly helpful and pertinent and sought this out – either texts or articles – adopting the same approach iteratively.

This ‘snowball’ approach (Edwards and Holland, 2008:6) to compiling relevant sources had the distinct advantage of allowing the time and space to familiarise myself with the vocabulary, key academic contributors and conceptual framings of bodies of literature to which I was previously unfamiliar. For example, Petra Nordqvist, Carol Smart, Jennifer Mason, Nicky Hudson, Dorothy Roberts, Seline Quiroga and Dov Fox, to name just a few, quickly emerged as key contributors and I was able to then find and read their other publications relevant to the research questions.

These investigations also alerted me to particular journals that could be searched independently, and using these key words I came across the occasional special issue dedicated to topics relevant to my research (such as *Hypatia*’s special issue on ‘The Reproduction of Whiteness: Race and the Regulation of the Gendered Body’ (Hypatia, 2007) or conference outputs. I also presented a related paper at a conference in the later stages of the research where I was fortunate to speak to Dr Nordqvist, whose work had featured prominently in the literature review (BSA, 2016). Doing so not only gave me the opportunity to consolidate my understanding of their contributions, but also to ask questions and speak about the themes with the expert directly and others in attendance. These events provided extensive material on related subjects and identified contemporary themes and

debates that I incorporated into the review. Through direct, active participation and discussion with academics whose work was relevant to the thesis, I developed more quickly familiarity with a subject area with which I was not previously familiar.

Once these key actors and concepts were identified, it became easier to conduct more specific searches and stay up to date. For example, I set up email alerts using the keywords on specific journals that had so far been useful, and often revisited relevant sources and used productive search terms, like ‘donor insemination’. I would make notes from each reading and store these as separate documents, from which I would later compile a draft of the literature review.

For the background research for the second chapter that outlined the current framework for fertility regulation and any past or present policy statements on donor matching, I again took desk-based approach and looked at industry-produced material as well as academic literature. Most of this involved research using online materials. Notably, the HFEA’s website includes archive material that contains the minutes of Authority meetings (HFEA, n.d.h.). As well as being able to trace the previous versions of the Code of Practice to search for any reference to race, ethnicity or donor matching, from the minutes it was possible to identify when and where matching was discussed and to locate a change in policy in the aftermath of the SEED review (HFEA, 2005). Minutes from the meeting concerning this review evidenced the rationale that went behind the policy change to remove a clause that encourages clinics to match donors to patients (described in Chapter Two). My previous role as legal editor at *BioNews*, published by the Progress Educational Trust, helped me to keep abreast of legal and scientific

developments in assisted conception, and also gave me first-hand experience with the research required to find authoritative information on donor conception.

I also sought out information on donor matching from clinics' own websites, searching express policies on donor matching. While some of these websites were difficult to navigate for such specific information, a Google search using keywords ('race', 'matching', 'fertility clinics') revealed some NHS-affiliated clinic policies on matching (discussed in Chapter Two). It became apparent the NHS clinics published such information more often than did private clinics, and this finding confirmed the need for interviews to examine the question of how donor matching occurs in more detail. I therefore asked the interview participants if their clinic had a policy on donor matching in either current or previous practice, or if they were aware of any such policies (even if the answer was 'no' or 'I don't know'). It was extremely rare for clinics to have a published matching policy on their website.

3. Race and donor conception

As discussed in detail in the next chapter (Chapter Two, section 4.ii), the word 'race' is observed in both the provision of donor information and also discussion about donor selection by patients in UK clinics. While it may be difficult to assess the extent of its importance, race does appear to play some role – ethnicity is included in the HFEA's donor information form and many gamete banks include race as a searchable characteristic (for example, Anon, g, n.d). However, race is a highly contested concept and the uses of the word, as well as its validity, require extensive critical examination. Indeed, it has been said that there is no such thing as race (see Chow-White and Green, 2013; Sussman, 2014a and b). The

invocation of ‘race’ in the donor conception context therefore invites discussion of its definition, including the processes and constructs that it entails. It is thus necessary first to identify the origins of the manner of the usage and definitions of race in donor selection, before proceeding to explore the meanings associated with its usage in this context.

i) What is the concept of ‘race’?

The noun ‘race’ has been defined, historically, as referring to distinct groups in mankind having certain physical features (Lexico, 2019a). According to this definition, race is used to signify divisions between major groups of people and hence serves to categorise people according to phenotypic (or physical) characteristics. However, this definition of race is highly contested and is associated with a long history of social and political abuses, from mass slavery to segregation and discrimination. The idea that populations can be separated by physical characteristics has received substantial criticism and the purported biological basis of race does not accord with current scientific and genetic understandings of the human body and brain.

a) Debunking the biological basis to race

As set out by its early and influential practitioners, the biological view of race, portrayed as fact and ostensibly backed by evidence, entails the opinion that race is reducible to a visually detectable set of characteristics (Bender, 2003:56). Such thinking can be traced back to the 1700s, when Swedish physician Carl Linnaeus’s work on taxonomy subdivided the human species into the four known regions of the world, assigning each a set of physical – but also cultural and social – traits (Roberts, 2011:29). Europeans were described physically as ‘muscular’

and 'blond', Native Americans as having 'black hair' and 'wide nostrils' and being 'beardless', Asians as having 'black hair, dark eyes' and Africans as having 'black kinky hair', 'silky skin', 'flat nose[s]', and 'fat lips'. The four regions were colour-coded red, white, yellow and black. Such categories formed the basis of typology of race.

This essentialist view of race as constituting fixed and biological entities began to take hold in the first half of the nineteenth century (Richards, 2008). These ideas became infused with the notion of heritability upon the onset of emerging understanding of human genetics during the late nineteenth and early twentieth centuries (Bender, 2003). At the time, genetics was used by some to give legitimacy to the 'science of race' and biological demarcations of race (Roberts, 2011). As knowledge of genetics progressed, this perception of race began to be challenged by the emerging realisation that the genetic variance seen in humans meant that people do not fit a 'zoological definition of race' (Roberts, 2011). Even in the early 1900s, it was remarked that there is no possible scientific division of race (see Lopez, 1994:11) but it was not until understanding of genetics developed more fully that the implausibility of the biological definition of race was refuted itself by biological understanding of variation.³

During the 1950s, population geneticists gained a consensus of accord within the social and natural sciences that race was a social construct. This was reflected by the UNESCO Statements on Race in 1950 and 1951 (Gannett, 2001). The 1950 Statement (UNESCO, 1969), compiled by leading anthropologists and scientists

³ A more critical approach to race continued in the 1950s in the response to state eugenic practices during World War II and elsewhere following the realisation that the state abuse orchestrated by the Nazis and others drew on biological understandings of race (Lopez, 1994).

under an anti-racialised agenda (Hazard, 2011) and representing an attempt to counter previous attempts to by state governments to use racial demarcations (Reardon, 2005), declared that human populations were not separated into fixed and distinct phenotypic groups but instead overlapped in physical and genetic traits (Hazard, 2011:178). Reardon highlights that the UNESCO Statements maintained that race did not have any fixed social meaning, and not – as has been since interpreted – that race has no biological basis (2005:7). As such, the UNESCO discussions were more of an attempt to prevent race from being used to achieve political aims rather than an authoritative deconstruction of the biological basis of race.

Subsequently, the Human Genome Project, an international research project to sequence human DNA, confirmed there was such a degree of genetic variance across previously categorised race groups that it no longer made sense to adhere to arbitrary groupings based on race (Brown and Aremlagos, 2001). It helped affirm that the previous demarcations of racial groups by phenotypic traits such as skin and hair colour were not consistent with genetic evidence (Owens and King, 1999:453). More recently, the view of race as a social construct has been bolstered by modern-day epidemiologists, who contend that racial disparities in health can be explained by environmental factors (Hartigan, 2008:165), and understandings of genetics highlighting the variability between persons falling into what were previously considered racial categories (Hartigan, 2008:178). Indeed, upon the completion of the draft Human Genome Project in 2000, Craig Venter, chief executive officer of Celera, a gene sequencing and biotechnology company which ran a parallel privately-funded sequencing venture alongside the

Human Genome Project (see Chial, 2008b), declared that race had no ‘genetic or scientific basis’ (Hartigan, 2008:168; *New York Times*, 2000).

b) Race as a social and political construction

The notion that race is a social construct rather than a biological fact is central to CRT (Roberts, 1995; Quiroga, 2007:144). This idea began to gain traction following the work of Franz Boas in 1912 and Du Bois in 1915 who both challenged the biological categorisation of race (Hartigan, 2008:165). The debunking of the biological myth of race brought social understandings of race to the fore, revealing that race can only be social rather than scientific in origin (Lopez, 1994:13). The social understanding of race allows for a broader set of attitudes and cultural views to influence its deployment, presenting it as a complex and wide-reaching concept. Race becomes a product of the collective consciousness of generations of people across societies, whereby cultural values partially shape biomedical views, which in turn reproduce ideology, inequality and power relations (Quiroga, 2007:146; Roberts, 1997:937; Lock and Kaufert, 1998:4-5). Biological categorisations of race have contributed to certain views on heritability, which although evidentially unsustainable in light of more recent scientific understanding remain ingrained in popular understandings of genetics. For example, both Whiteness and race as social constructions cannot be inherited as such, the merging of the boundaries between a person’s phenotype and genotype (an individual’s collection of genes contained in each cell) have led to the implicit assumption that Whiteness is heritable (Quiroga, 2007:144).

The malleable nature of race and its construction therefore becomes vulnerable to pernicious political aims. ‘Race’ has been used a tool to segregate and stratify

people based on crude classification of physical characteristics (Davda, 2018; Quiroga, 2007:144): once the biological basis is removed, the political purposes behind such moves is exposed. Racial categories were created for political purposes and used to serve ideological ends, particularly enforcing the view, in Roberts' summary, that, 'Blacks were biologically destined to be slaves, and Whites were destined to be their masters' (Roberts, 1995:225). The representation of the 'Self and the 'Other' – where the 'other' denotes other races – allows for racism to be reproduced (Duncan, 2003:149). This renders the 'Other' controllable, allowing power-holders in the state to exercise control over certain populations. Race therefore continues to serve a distinct political function, with real-life consequences for people's health, wealth and social status (Roberts, 2011:5; West, 2001).

The political construction of race can be traced to the origins of CRT, which lie in part in the emergence of civil rights discourse in the US in the early 1900s, where challenges began to then-established views and attitudes around race (Crenshaw et al, 1996). This set the activist foundations of CRT, in which theorists sought to change societal thinking and approaches to race, rather than merely document them. CRT demonstrates how race is constructed to oppress and subjugate; a central tenet of CRT holds that the use of race by institutions and in social practice recreates power imbalances in society and serves to subjugate marginalised communities (Roberts, 1996; Quiroga, 2007; Gotanda, 1991).

While CRT predominantly seeks to expose overt power imbalances and the exercise of control through the concept of race, it also sets out to identify more implicit and nuanced versions of discriminatory practices that may, superficially,

appear neutral. CRT took a departure from the civil rights movement in the 1960s and 1970s when CRT scholars expressed dissatisfaction with the traditional civil rights discourse (see Brown, 2004; Wing, 2002) and its campaign for equal treatment. One of the primary concerns of CRT scholars was that the construction of racism as intentional and conscious wrongdoing prevented the critical examination of apparently neutral ways to distribute jobs, power and wealth. Some theorists have argued that there was an assumption in mainstream civil rights discourse that when once-irrational bases of race were removed from race consciousness, everybody would be treated equally; however, many CRT thinkers remained unconvinced. Although the liberal response to social inequality was largely to evoke the idea of colour-blindedness (Crenshaw et al, 1996), which was embraced in mainstream and legal thought, many critical race theorists continued to see race exercised in the 'race-neutral' policies of US institutions and ostensibly innocuous daily interactions between citizens: if racism was solely identified with outright exclusion of ethnic minorities, institutional or non-direct forms of racism would pass by unnoticed. Policies appeared to become immunised from critical reproach following the removal of race, whereas many saw those policies as indirectly perpetuating or by-products of racialised norms. The removal of race thus restricted the ability of the civil rights campaigners to evoke position change (Crenshaw et al, 1996), since without an idea of 'race', the ability to examine supposedly neutral institutions that deal with jobs, wealth, education and power was severely curtailed. Some critical race theorists went even further and observed that arguments for equality actually *helped* those with power in American society to maintain their superiority on their own terms.

CRT therefore rejects the position that the law and policy can ever be neutral or objective or written about from an objective or detached manner (Crenshaw et al, 1996) and instead views race as a persistent factor. So-called colour-blinded policies placed advocates of affirmative action on the defensive; they actively *required* the use of race as a socially meaningful category – something which could not be acknowledged under colour-blinded policies (Crenshaw et al, 1996). CRT therefore adopted a position of race-consciousness as a means of examining the ethnic character of US institutions, which were otherwise deemed racially and culturally neutral (Crenshaw et al, 1996). An important theme to CRT therefore involves a re-examination of race-consciousness as a tool for discovering and analysing the relevance of race and racism in institutional policies as well as ‘the ordinary’ or mundane, where they might be largely invisible. CRT is tasked to ‘make visible, thematise and problematise that which has largely remained invisible, unremarkable and ‘normal’’ (Cross, 2010:416).

The expression of race through ordinary and mundane daily actions as a focus of analysis points to a more nuanced conception of race and race-based practices that fits in neatly with the social construction model discussed above. The social construction of race also served to depolarise its characterisation as an ‘essentialist thing’ or something that is devoid of content. Through its expression in everyday behaviour, race is observed to become a multi-faceted and complex concept. For example, in an ethnographic study of lay understanding of race and genetics, Tyler explained that as a social anthropologist, she seeks to analyse laypeople’s understandings of race and genetics without adopting ‘utopian or dystopian’ positions (2009:38). She explores a research strategy that provides a language for analysis that neither condemns laypeople as ‘racist devils that

reproduce essentialist models of racial and biological difference', nor over-determines them as 'anti-fascist angels for challenging that construction' (Tyler, 2009:38). Such polarisation of the 'race debate' obscures its common usage. Tyler observes that people behave as 'reflexive actors who mobilise their cultural world-views' (2009:38), with some White people tending to screen out the meaning and significance of the colonial past within everyday racialised discourses and practice (see Bergmann, 2011:287). Solutions to these social observations lie broadly in recognising and changing the way meaning is attached to words used by others (Delgado and Stefancic, 2012:34).

The political implications of the constructivist model of race should not lead to the conclusion that race as a concept should be devalued or neutralised, however. Although race is not an essentialist thing, neither is it an illusion (Lopez, 1994:7). Rather than burying race with its biological definition, Lopez argues that it is a 'powerful social phenomen[on]' (1994:19). Beyond a construct of people's misguided beliefs or pernicious political aims, as a category it is seen as signifying people linked together by complex, historical and social elements. According to Lopez, race is a '*sui generis* social phenomenon in which contested systems of meaning serve as the connections between physical features, races, and personal characteristics' (1994:7). Furthermore, Fogg-Davis points out that race can and 'should be' a source of self-identification, and to some extent group identification. Individuals, for example, need to be able to navigate between the racial categories ascribed to them and their own racial self-identification (Fogg-Davis, 2002). Nevertheless, she argues for 'racial navigation' to guide interpersonal conduct in the market for human gametes, which recognises 'the practical need to acknowledge the social and political weight of racial categories,

while urging individuals to resist passively absorbing these expectations into their self-concepts' (2002:14). Evidently, within the construction of race there lie possible tensions between those who self-identify in part using racial categories, and the political or normative ramifications of the use of race of daily life.

Race therefore continues to be an important concept in modern-day society, and a key component in the understanding of identity. Nevertheless, it remains difficult to pin down what race is or on what basis it can be understood, if not biological. Revealing the complexity of its underpinning conception, Lopez defines race as an 'ongoing, contradictory, self-reinforcing process subject to the macro forces of social and political struggle and the micro effects of daily decisions' (Lopez 1994:7). Race is not seen as a 'thing' as such, but more of a 'process', or a set of processes. This understanding allows for an examination of what those processes are that underpin uses of race.

The constructivist model of race is relevant to an evaluation of donor selection for it serves as a framework through which the manner in which patients and fertility staff talk about race (or not) can be analysed in greater detail. It captures the wider social and political influences and implications of the use of race in a way, as will be seen, that both complements sociological analysis and also adds to it. Both CRT and NKS reflect constructivist approaches that seek to explain social phenomena through the processes that underpin the concept of race, but CRT arguably contributes a stronger normative assessment of the implications of references to race. By identifying the broader social and historical processes that influence how race is constructed, CRT not only debunks the biological basis for race discussions in donor selection, but accounts for race in a way that exposes

assumptions and seemingly mundane practices to scrutiny. The constructivist model adds weight to the argument that discussions of race invite an awareness (or even responsibility) of the potential for replicating outdated values and hierarchy (see Fox, 2011:6).

c) Application of CRT outside the US 'race' context

The origins of CRT in its focus on Black histories in the US arguably presents specific geo-political limitations in terms of its applicability to the UK and generalisation to race as a concept. By many accounts, CRT includes as part of its political mission an activist arm in the US, which responds to perceived failures by both liberal and conservative movements to address racial inequality and discrimination (West, 2001; Crenshaw et al, 1996; Gotanda, 1991). Cornel West, an American philosopher and high-profile public figure in the US, explains that CRT is a historically situated scholarly and politically committed movement in law (West, 2001; see also Crenshaw et al, 1996) – although today it is also relevant to education, psychology, cultural studies, political science and philosophy (see Crenshaw, 2010:1256). These facts root CRT's origins firmly as residing within – and critically responding to – the civil rights movement across US law schools.

CRT is by no means limited to 'Black' history in the US, however, and has focused on other oppressed minorities including Hispanic communities (Delgado and Stefancic, 2012). CRT has also branched into Whiteness studies, which examines the formation of White ethnic and racial identities (Delgado and Stefancic, 2012:86; see Nayak, 2007). According to Nayak, critical 'Whiteness' studies are underpinned by the belief that Whiteness is a modern invention and

social norm ‘chained to an index of unspoken privileges’, reflecting much of the critical race approach (2007:738). However, he recognises that new attention has been given to the question of White ethnicity. Whiteness studies is said to be an attempt to redress the ‘asymmetry’ of critical race work. As defined by Delgado and Stefancic, White privilege corresponds to a ‘myriad of social advantages, benefits and courtesies that come with being a member of a dominant race’ (2012:87). Documenting such advantages, McIntosh has identified 46 privileges that pertain to people perceived to have White skin (McIntosh, 1988; cited in Delgado and Stefancic, 2012:88) – including, for example, ‘I can go shopping alone most of the time, fairly well assured that I will not be followed or harassed by store detectives’. These ‘privileges’ are by no means unique to the populations in the US.

The legal definition of Whiteness in the US took place in the context of immigration law (Delgado and Stefancic, 2012:85) and was defined in opposition to ‘non-Whiteness’, which marked a boundary between the privileged and ‘Other’. Groups have moved in and out of Whiteness over time, coming in and out of privilege and status. For example, the Irish, Jews and Italians were once considered ‘non-White’ (a contested term discussed in the Introduction) but though joining unions, political parties and acquiring wealth, they earned the ‘prerogatives and social standing’ of Whites (Delgado and Stefancic, 2012:86). Drawing similarities with the constructivist model of race above, according to Shome, Whiteness is not just about bodies and skin colour, but ‘rather more about the discursive practices that, because of colonialism and neocolonialism, privilege and sustain the global dominance of White imperial subjects and Eurocentric worldviews’ (Shome, 1999:108; see also Cross, 2001). This European viewpoint

provides a more useful notion of Whiteness that applies to the UK context.

According to Cross, 'Whiteness is certainly associated with the legacy of White European colonial power and is manifested not only in racist acts of physical or verbal violence' (2001:417). It is observed when particular 'unspoken assumptions and unconscious prejudices associated with the colonial legacy inform representations of the world and of human beings' (Cross, 2001:417).

The observations around Whiteness have particular resonance for contexts in which 'race' is less frequently discussed or cited as an issue. Within 'White' community discourse, race is not often expressly discussed and 'White people' do not explain success on the grounds of their ethnic identity (Tyler, 2009:41; see also Dyer, 1997). In Western societies, Whiteness is generally constructed as the norm and race is less expressly discussed. So once again although the concept of race may be expressly absent from social discourse, that does not mean it is not present or unimportant.

Whiteness, argues Cross, has the status of a 'racialised norm' in Britain, to a much greater extent than in the US (2001:427). This view is enforced by Tyler, whose ethnographic work on Whiteness and class in Leicester highlighted the role played by the 'Empire' and colonialism in the characterisation of 'others' (2012). In her attempt to examine the reproduction of White power and privilege through a postcolonial perspective, Tyler draws on the perceived importance of 'imperial histories' to place postcolonial peoples in the 'history of Englishness' and also within contemporary expressions of nation (2012:1). She refers to the ways that legacies of Empire, and ideas of race, nation and place, are mobilised in this field. The process of 'normalisation' around ideas of race that may be grounded in

problematic histories is elaborated further in this thesis, but discussions around genealogy clearly resonate with these ideas.

ii) Racial identity

Race can have powerful meanings for a person's identity. Some critical race theorists in the US have emphasised the importance of using race to build a narrative through which a person can explain their history – giving a voice to marginalised groups and examining how race can be identified in America (Delgado and Stefancic, 2012). For example, both Bell uses stories drawn from a history stemming back to slavery to reveal the true conditions of race experiences. The use of storytelling or narrative helps others consider the narrators' experiences and can bridge divides between people of different backgrounds (Bell, 1987). In addition, storytelling can be used to counter pernicious narratives or beliefs by reinstalling a perspective that aligns with the narrator's own view of their 'race' and its significance (or otherwise) in their lives (Delgado and Stefancic, 2012:49).

The relationship between race and identity is complex, however, and takes many forms. According to Ung et al 'racial identity is embedded within multiple complex systems, and thus is heavily influenced by race, ethnicity and culture, which are informed by social and political contexts' (2012:77). For example, Ung et al identify a number of forms of racial identity that highlight a multi-dimensional model. In respect to social self-identity, they identify what they term 'cognitive racial identity' – what a person thinks and/or knows her or himself to be – as a means to represent the internalised product of an interaction between persona and the environment (2012:79). A related concept, 'visual race identity',

refers to the colour one sees one's own skin to be (2012:80). Ung et al's model of social self-identity helps to explain the underpinning force of narrative for the construction of identity. Three broad themes emerge from the literature on race and identity that may be pertinent to an examination of donor selection.

First, the notion of racial identity is heavily influenced by the environment but the relationship between the two is a complex one. Ung et al identify 'feeling racial identity': one's subjective experience (e.g. feeling 'White') that is heavily influenced by the immediate community (2012:74; see also Hudson and Culley (2009 and 2014) for a perspective on relatedness in British South Asian communities). As such, the identification of socio-cultural forces such as power and racism are but one factor that impacts on racial identity – much depends on what the individual 'feels', on how they perceive their own race and their relationship to surrounding racial politics.

As such, according to Ung et al, racial identity can be viewed as a 'multi-dimensional construct that evolves as a result of an interactive and reciprocal relationship between a person and his or her social, cultural and political environment' (2012:74). It is defined by the 'transactional processes between the internal and subjective awareness of the individual and their external and environmental experiences' (Ung et al, 2012:74). Crucially, it is a construction that is not necessarily rendered meaningful by external rationale and biological understanding, but by relational processes of interaction within families and communities.

The placing of the self within a community by reference to race or ethnicity is not merely an abstract cognition of one's self, but also has very real and practical consequences, including within the kinds of family and community spaces that pertain to conception. Racial identity can affect the ability of a person to deal with racism. For example, the perceived ability of a child to deal with racism was found to be an important factor in transracial adoption: Wainwright and Ridley make clear that ethnic matching needs to consider how well a child could deal with racism they might experience (and that Black, Asian and minority ethnic (BAME) adoptive parents were able to nurture this resilience) (2012:58). They cite Thoburn et al (2000), who concluded that ethnic matching has had a positive effect on Black identity within BAME children and their wellbeing. On the other hand, some studies have found no relationship between self-esteem and ethnic identity (Wainwright and Ridley, 2012:5). There is evidence to suggest that transracial adoptions are successful in terms of placement success, psychosocial outcomes and dealing with racism (Thoburn et al, 2000).

It seems likely that such concerns arise because of social attitudes towards race rather than because of a disruption of racial identity, as such. Helms argues that racism and oppression are 'states of being', the social conflicts of which must be managed (1995; cited in Ung et al, 2012). This view may negate the direct impact of the environment on the development of racial identity and highlights the complexity of the development of identity (Helms, 1995). As Ung et al outline, Helms concludes that: 'racial identity remains a process defined by the individual's intra-psychic ability to cope with the socially constructed meaning of race' (Ung et al, 2012:75), thus expressing the complexity of an individual's navigation of the construction of race above. If one's ability to deal with racism is

largely affected by one's understanding of where one 'comes from' (either geographically or biologically), then this factor would also have significant effects on self-esteem and self-image – arguably individualistic self-identity. In short, the social situation whereby racism exists forces some people to adopt certain notions of racial identity, which in the absence of social pressures, may otherwise not necessarily arise.

Second, race may represent a visual identifier that ties a person to their culture, and efforts to preserve racial signifiers may in fact represent an effort to preserve and protect cultural identity. Quinton (2012:3) has put forward a 'moral and ethical' argument that ethnic minority communities have a right to maintain their own culture and bring up their children within these cultures. The connection between race and culture here may represent a slippage of terminology between race and ethnicity, in which the physical characteristics associated with race come to represent the more cultural notions of ethnicity. However, once again such congruence between race and ethnicity is not necessarily based in fact, with the possibility that people of different races might share cultural and ethnic characteristics.

Drawing on kinship studies in her ethnographic study of minority communities' experiences of IVF, Tyler also notes that a feeling of ancestral relatedness to slavery enables members of interracial families to confront racism (2012:17). She explains how people of colour draw upon genealogy and their ancestry (including affiliation to slave pasts and histories) to 'self-fashion an identity that is neither fixed or endlessly fluid' (Tyler, 2012:17; see also Nash, 2002:49). As Tyler states in her study: 'knowledge of the slave past becomes entwined with each woman's

sense of identity, understanding of racism, becoming and a member of the Black community in Leicester and the wider diaspora' (2012:201).

Third, disruption of racial identity can potentially affect a person's sense of identity and relationship with their parent and family. A child's ability to reconcile their own sense of self-identity with their biological parent manifests not only in a series of character and personality traits, but also in life values and racial identity. Coming back to the example of transracial adoption, Ung et al argue that 'accurate information about one's heredity lays the foundation on which racial identity is built', the absence of which can 'strip the transracially adopted person of a sense of legitimacy and authority about who they are as a racial being' (Ung et al, 2012:78). This can be exemplified by the importance placed on a child's racial identity in transracial adoption policies, where ethnic matching is sometimes (but not always) encouraged (Barn and Kirton, 2012). In one study, Thoburn points to a significant result of the additional challenges in relation to ethnic identity presented by transracial adoption: 'placement with a family of a different ethnic background . . . should be unusual and should be clearly linked to specific reasons in individual cases' (Thoburn et al, 2000; see also Barn and Kirton, 2012). One rationale behind matching practices in adoption policies has been a concern over fracturing of a child's sense of religious or cultural identity, linked in this particular case to racial inheritance, and how this might in fact lead to a degree of psychological harm (for example, see Lee, 2019). In *Re JK (Transracial Placement)* [1990] 1 FCR 891 a local authority attempted to move a child born to a Sikh birth mother from the 'White' English foster family to an Asian family (although not Sikh) (discussed in Jivraj and Herman, 2009). The local authority had an ethnic matching policy and refused the foster parents'

application for adoption. Evidence from social workers indicated their concern about the child's adolescent years when she may become 'more aware of her own racial background'. Sir Stephen Brown decided for the foster family, however, on the basis that removing the child from a family in which she had become comfortable (though of different racial identity) would cause psychological damage. Nevertheless, the basis for the local authority's arguments in this case, as well as the judge's reference to the foster family's efforts to maintain contact with the child's 'own background' ([1990] 1 FCR 891 at p898; cited in Jivraj and Herman, 2009:12), reveals a certain significance placed on racial heritage. Commenting on this case, Jivraj and Herman observed that in this case the 'child's religious identity is inextricably linked to her genetic/racial inheritance' (2009:12). They observe that religious practices become 'ethicised' to be shared as traditions by others in the same racial community.

Although Wainwright and Ridley's study of adoption staff revealed that adoption service providers did not consider themselves to be too rigid about ethnic matching ('The goal was to achieve a holistic match rather than one based solely on ethnicity' (2012:54)), culture was a factor seen to be relevant in determining the child's needs. Many adoption clinics encouraged prospective parents to be flexible but where there was not an ethnic or religious match then the most important criterion was whether the prospective parents possessed the religious and culture sensitivity to raise the child to understand their own birth ethnicity and religion (Wainwright and Ridley, 2012:55). This demonstrates how the observations of environmental factors and visual indicators above interact to produce, at least as seen in interracial adoption, a set of considerations that are linked to ideas of wellbeing and the successful formation of identity. This set of

observations can be linked to donor conception, which focuses attention on genetic relatedness. Returning to Tyler's study, two interviewees explained that crucial to their own sense of identity and understanding motherhood is the importance of learning about Black history and its significance for the formation of both their own and their children's identities (2012:175, 188). The notion of genetic connection, as denoting a cultural code of identity and belonging, is therefore intimately tied up in notions of identity more generally.

iii) Race and gamete donation

CRT provides a useful set of tools for scrutinising the deployment of race in the gamete donation context and as a technique for revealing the power dynamics and cultural realities that may underpin the provision of treatment (Fox, 2009:33). A number of critical race theorists have applied the critique of race to its use in ARTs and donor conception, focusing on access, and the ability to 'control' reproduction through the selection of gamete donors (Roberts, 1996; Bailey and Zita, 2007; Deomampo, 2019; for a study in the UK context, see Davda, 2018); by additionally considering notions of patriarchy, these theorists further understand the control of reproduction as something that male-dominated systems can apply to women's bodies (Quiroga, 2007:144). The technical ability to control human reproduction and introduce choice in the process of selecting gametes has, for some, allowed for the manipulation of ARTs to introduce power relationships that congregate around the use of ARTs (Morgan, 1996:223; Lock and Kaufert, 1998; Quiroga, 2007; Roberts, 1996). Some critical race theorists perceive that ARTs rely upon technologies of power, control and manipulation that allows those in power (typically White males) to maintain racial (and other forms of) supremacy through race-based definitions of kinship (Bailey and Zita, 2007) and emphasised

through the notion of a genetic tie (Roberts, 1996). Fertility techniques that help people have genetically related children can be said to promote the importance of the genetic connection which, from a CRT perspective, is a mostly ‘White’ phenomenon and is absent from many other communities (Roberts, 1995). Bailey and Zita explain that a ‘White anxiety’ about racial purity has manifested as interests in reproduction, sex and desire; the ability to control – and dominate – these social phenomena has fused with this ‘obsession’ for racial purity (Bailey and Zita, 2007:9). From this perspective, ARTs have contributed to the subjugation of people of colour and of certain socio-economic groups by helping to preserve the notion of racial boundaries and ‘White’ lines of inheritance.

Furthermore, it has been argued in areas of feminist literature that ARTs reveal the influential presence of patriarchy in the reproductive context (see Rothman, 1990). Since ARTs have the potential to disrupt existing kinship arrangements through the use of donor sperm or eggs that introduces ‘other’ genetic material, it presents a challenge to men as the non-genetic fathers of offspring (Roberts, 1996). It can also present a threat to the essentialist notion of Whiteness since sperm and eggs itself are themselves ‘colourless’ (Quiroga, 2007:150). As such, Quiroga has argued that sperm banks ‘manage the subversion of patriarchy and racial purity’ through classifying donors according to physical characteristics and attempts to ensure the matching of the donor’s physical characteristics to that of the male partner or social parent (2007:150; see also Wahlberg, 2018). In this way, the man’s perceived role in the family remains unchallenged and aspects of continuation of bloodline recreate reproductive bonds that may otherwise have been generated through natural conception. Relatedly, ARTs have been accused of complicity in the oppression of women through the commodification of the

human body and the furtherance of pronatalist attitudes. Feminist critiques of ARTs (for example, Corea, 1985; Rothman, 1990), which view the technologies as a means of gender oppression, intersect with CRT leading to the observation that women of colour are most vulnerable to attempts at control (Roberts, 1996). However, as will be seen, these arguments can be potentially countered by examining the issue from the perspective of privacy and respect of individual autonomy.

a) Access to ARTs

A number of features of the fertility sector in the US give some weight and illustration to the claims above. First, the sector is characterised by high costs, little regulation and socio-economic and racial disparities among users (Roberts, 1996:940); costs per IVF cycle can be \$10,000 or more and payments to gamete donors are largely unregulated.⁴ Importantly, there is no ceiling for payments to donors or fees paid by customers, with provision of IVF and donor selection processes mostly operating within a free market. In terms of access, few medical insurance plans provide for ARTs, and racial and class disparities are evident: middle- and upper-income White families are twice as likely to access fertility services as African American or Latino / Latinx (Roberts, 1996; Daniels and Golden, 2004). A recent review of data on race and ethnicity in the US suggests that significant racial/ethnic disparities remain in IVF, but that less than 65% of reported cycles include race/ethnicity recommend that information about race/ethnicity should be available for all reported cycles (Wellons et al, 2012).

⁴ Gamete donation is regulated by the FDA and CDC; and the ASRM establishes guidelines for clinics – however, the focus of these organisations is on communicable disease (Daniels and Golden, 2004), with the ASRM having a residual ethical remit. The ASRM had issued guidance on compensation and selection practices recommending limits on egg donor compensation that it should not exceed \$10,000 in 2009 but these were removed following the settlement of a class action brought by egg donors that claimed the guideline violated antitrust laws (see Low, 2016).

Wellons et al recommend that information about race/ethnicity should be available for all reported cycles (Wellons et al, 2012:406).

The high cost of ARTs and limited means of access have been observed to favour 'White' users above other ethnicities (Roberts, 1996). The high cost of treatment supports a system of 'class and race stratified reproduction', where some groups are empowered to reproduce and others are disempowered (Quiroga, 2007:149; see also Colen, 1995). Colen defines the concept of stratified reproduction as 'physical and social reproductive tasks [that] are accomplished differently according to the inequalities [...] based on hierarchies or class, race, ethnicity... and that are structured by social, economic and political forces' (Colen, 1995:78). On the subject of assisted reproduction, Darling writes that as technologies are being developed capable of eugenically controlling low-income people and women of colour, reproductive enhancement options are simultaneously reserved by 'economically and racially privileged women' (Roberts, 2009:784, citing Darling, 2004). In this way ARTs support the affluent and privileged to have children of a certain genetic type (Quiroga, 2007:144, 149, citing Sherwin, 1992), while suppressing the less affluent and privileged. More widely, the reproduction of racial purity is said to have been enhanced in the US through the commercialisation of IVF (Quiroga, 2007:148).

The observation that 'White' users dominate ARTs is also true in the UK, with costs of up to £5,000 per cycle (NHS, 2018) and where Black and other ethnic minorities make up a notable minority of ART users and donors. Recent data from the HFEA shows that 19% of patients in 2018 identified as BAME (HFEA, 2019c). While donors can only be paid according to limits set by the HFEA, IVF

and donor conception remains costly for patients. Restrictions on publicly funded IVF on the National Health Service (NHS) mean that not everyone has equal access to fertility treatment in the UK and its provision is patchy (Brazier, 1999:177; West et al, 2003; Fertility Fairness, n.d.a).

b) The classification of donor information, including race

Important questions arise over the way that the concept of race is used in the classification of donor information by clinics and gamete providers. Classification relates to the sorting of information into differentiated categories. As described above, race has been used to stratify people based on the classification of physical characteristics (Quiroga, 2007:144; Davda, 2018). Applied to the donor conception context, the presentation of donor information in donor catalogues and/or in clinics – including race and ethnicity – therefore raises normative questions about the extent to which such practices may operate to stratify and subjugate certain populations. Davda's ethnographic study exploring egg donation matches in two fertility clinics in South East England, examines how clinicians classify donors and recipients; how clinicians allocate donors to recipients; and how recipients express preferences about donors in choosing to accept or decline them (2018). The study finds that clinicians categorised donors and recipients by social and physical characteristics, revealing the socially constructed nature of race and, in particular, a degree of racialisation of donor information in this process (2018:305). The construction of race according to discernible physical traits can be seen as a racialised process that promotes artificial categorisation.

A further example of this concern is seen in the advertising of donor gametes, particularly in the US where donors can be paid for their gametes. In her

examination of gamete banks in the US, Thompson explains that skin tone is one of the categories that donor databases use to categorise their donors (2009:134). For example, terms such as ‘fair’, ‘medium’, ‘olive’ and ‘black’ are used. Such labels convey more than their description alone suggests and connections between skin colour, nation, ethnicity, religion and race are all commonly made (Thompson, 2009). Thompson’s conclusion on this matter is striking: ‘I have yet to find a US egg donor database or sperm catalogue that does not classify donors/specimens by nation, race and or ethnicity in one form or another’ (Thompson, 2009). Where price is based on desirability, and desirability is linked to skin tone, the financial value placed on gametes is fundamentally linked to the perceived social value, based on assumptions made on their skin-tone, that the future child will one day have (see Deomampo, 2019:624).

Thompson’s analysis of a large gamete bank in the US highlights that the sperm catalogue includes information about a donor’s height, weight, education, occupation, religion, ethnic origin, facial features, eye colour, hair colour, hair texture, skin tone and race (Fox, 2009).⁵ At 21 May 2013, most donors on the registry were in the categories of 5’9’–5’11’ in height, with brown eyes and brown straight hair, and professing Christianity. The least numerous categories were 5’8’ and below in height, with grey/black eyes, or red curly hair. Sperm vials are sorted used colour caps to indicate the donors’ races under its quality assurance program. African-Americans are given black caps, Asian American donors have yellow caps and Caucasian donors White caps. Red caps refer to ‘unique ancestry donors’, such as Latin or American Indian (Quiroga, 2007:150).

⁵ It also offers a ‘donor look-a-like’ service that compares donors with known celebrities. Additional information, such as baby photos, handwriting samples, audio tapes and personality assessments, can be obtained for an extra fee (Fox, 2009) (see Plotz, 2006)

As Quiroga explains, '[u]sing red to mark donors whose race cannot be categorised as 'pure' reinforces the notion that other donors' races are somehow pure' (2007:150). A large gamete bank in the US also offers donor matching consultation options, which includes a matching consultation request where customers list key physical characteristics required or preferred in a donor (Anon, e, n.d). The advertising and access to gamete donors in the US therefore illustrates both the cost-access implications for ethnic minority populations and the problematic positioning of race through the exercise of donor selection.

The role of fertility professionals in the classification of donor information and the reproduction of racialised boundaries requires critical attention. Deomampo's interviews with fertility clinic staff in New York, Los Angeles and Honolulu investigating how race is constructed, categorised and marketed around gamete donation, concludes that staff play a crucial role in shaping constructs of race, which is observed to be 'resintantiated as a biogenetic category in various ways' (2019: 629). This thesis will seek to examine to what extent similar observations may hold true in the UK donor selection context, although studies already conducted have implicated clinicians in the classification of race. For example, Davda concludes: 'Clinicians' classification of patients' characteristics illustrated how clinicians foregrounded their *own perceptions* of skin tone and genetic inheritance to categorise individuals into different "ethnic" categories and to "mark" the ethnic classification of some patients (particularly white and mixed ethnicity patients)' (2018:325, my emphasis added). Indeed, the technology of reproduction, as seen by assisted conception provided by fertility clinics, raises the question of the extent of clinicians' roles in determining what is 'natural' or 'unnatural', 'normal' or 'abnormal' (Quiroga, 2007; see also Morgan, 1996).

c) Patients' donor selection decisions and the exercise of choice

Another area illustrating the application of CRT to donor conception is an examination of the donor selection decision by patients themselves and the process and context by which this occurs. As Hudson has observed, the selection of donors according to racialised physical characteristics raises important questions over the re-legitimation of problematic and contested concepts of race (2015:3). The decisions made by patients and the involvement of fertility professionals therefore raise questions over how such decisions may perpetuate certain assumptions of race and racialised family models. According to CRT, reproductive decision-making is inextricably linked to traditional family forms and social norms. Quiroga argues that assisted reproduction 'developed in ways that adhered to the contours of the American kinship mode,' which is rooted in biology via blood and genetics (2007:145; see also Schneider, 1980). In the UK egg donation context, Davda observes that matching practices constitute a 'biomedicalisation of kinship' that serves to reproduce normative families (Davda, 2018: 321). In assisted conception, such ideas of family form merge with technology and science (where cultural values partially shape biomedical views) which in turn reproduce ideology, inequality and power relations (Quiroga, 2007; Lock and Kaufert, 1998). Consequently, choice within the ART context may ultimately be shaped by ideological pressures and confining social structures (Quiroga, 2007:148) – a phenomenon that has also been observed in sociological studies of the use of donor conception (Nordqvist, 2012). However, these connections or assumptions are not always expressed in the same way. Tober observes that, 'donor selection plays into individual, variable, and imprecise notions of what is genetically valuable' (2018:72). The result is that race may be

prioritised in this context in different ways, making it necessary to examine closely how social norms may be challenged. Nevertheless, the exercise of choice itself in donor selection – or the expression of preference – raises questions that reflect many of the concerns of CRT scholars that race is being reproduced as a biological category (see Deomampo, 2019:629-630).

d) The racial matching of donors to patients

Relatedly, the matching of gamete donors to patients and/or their partners has been observed in the literature (Deomampo, 2019; Davda, 2018; Zadeh et al, 2016b; Nordqvist, 2012). This observation has been extended to racial matching specifically (Davda, 2018; Hudson, 2015). The extent to which matching practices can be evidenced in the regulatory guidance and clinics' own published practices is explored in Chapter Two, but it is important to highlight at this stage of the discussion that matching, including racial matching, immediately raises significant normative questions around race.

The practice of racial matching underpins a certain reinstatement of donor information as being heritable (on the assumption that the resulting child will bear the traits sought through matching) (see Davda, 2018:256). The practice of donor matching also prioritises the normative view that there *should* be resemblance between parent and child. The importance of resemblance to kinship is discussed in the next section, but in cases of racial matching, resemblance implies that families should display the same race, or at least share resemblance (Wade, 2015:122). Applied in the context of the access to ART discussed above where the majority users of donor conception identify as 'White', then racial

matching is implicated in the reproduction of race congruity and certain normative family models (Davda, 2018:26).

Clarifying the reasons that fertility professionals seek to match donors to patients requires in-depth analysis. Davda observes that clinicians view racial matching as integral to the protection of the social welfare of children born through egg donation (2018:307). Maintaining secrecy has also been identified as a motivation being donor matching (Daniels and Taylor, 1993; Richards, 2014, discussed further in Chapter Two). The use of donor conception has in more recent times also emphasised the privacy of the patient's decision to use donated gametes. While donor matching may be premised on notions of racial heritability, it also reveals the complex social identities inherent in race which complicate how the concept is operationalised in the donor conception context (Hudson, 2015:3).

The controversies and sensitivities around racial matching have been illustrated by a range of sperm mix-up incidents in fertility clinics both in the US and the UK (see Blackburn-Starza, 2015; Bender, 2003). In the US, a recent case discussed below involving the wrong sperm sample being given to a same-sex ('White') female couple, which resulted in a 'mixed-race' child (discussed below) attracted attention from critical race theorists for the legal claim that was filed by the parents (Starza-Allen, 2014). Commenting on the case, Williams argue that the claimants seemed 'engulfed by the same race panic that has put the bodies of other children at risk' and the rhetoric of the litigants implied that the child 'dispossesses her mother by being born, taking the space of a more qualified, more desired White candidate... a neighborhood defiled as well as a family disappointed' (2014). Elsewhere, McKnight wrote that by 'equating race with

‘genetic traits,’ [the claimant] is claiming that race is a biological fact’ and that the claim for damages ‘tacitly condones the hierarchy in this country that determines the relative worth of one life over another’ (2014). These comments reveal how donor selection decisions based on race – which are brought to the forefront when mistakes arise – point to wider concerns about social hierarchy based on race as identified above, while also reintroducing contested understandings of race as a biological fact. The mix-up cases reveal concerns about racial mixing and the privileging of white kinship (Hudson, 2015:3; Quiroga, 2007), as they do assumptions about biological heritability of race (Hudson, 2015:3).

In Northern Ireland, a different mistake in the provision of donor sperm resulted in a child born of noticeably darker skin tone to that of the parents (Starza-Allen, 2010; also discussed below at Chapter Six, section 5) and significant distress to the family (see Sheldon, 2011).⁶ What is noticeable about the Northern Ireland and Cramblett cases is that they both concerned the mixing up of donor gametes, which distinguishes them from other mix-up cases, such as *Leeds* (discussed at fn 6 and Chapter Six, section 5 below), where a donor was used *instead of* the intended father’s sperm – thereby fragmenting biological parenthood. In the Northern Ireland and Cramblett cases the complaint therefore centred around the notion of the ‘wrong donor’ – specifically, a donor without the requested set of racialised characteristics.⁷ From a CRT perspective, as Duggan and McCandless

⁶ Another example of a sperm-mix up involving a White couple being incorrectly provided with sperm from a ‘non-White’ donor, resulting in mixed-race children, was seen in *Leeds Teaching Hospitals NHS Trust v A and Others* [2003] EWHC 259. Although the case centered on the issue of the donor’s biological (and legal) parentage (and the loss of biological connection with the social father), the couple affected spoke about the distress resulting from a difference in skin tone between their children and themselves (see Horsey, 2006).

⁷ Families from ethnic minorities have also been affected by sperm mix-ups (see BioNews, 2004b).

point out, the underpinning assumption that the children were entitled to inherit their parents' Whiteness raises questions over the 'power and privilege associated with the intersection of perceived racial characteristics and family structure' (2015:3) – although the authors proceed to address the courts' 'colour blind' approach to the issue and its failure to consider the harm caused by 'identity-based persecution' (2015:7; see also Bender, 2003). These cases raise important questions about the use of, reliance on and assumptions made around race, heritability and desirability in the ART context. Simultaneously, they also reveal the complexity of the relationship between personal and political considerations, in addition to illustrating deeply embedded constructions of kinship and relational identity (Hudson, 2015:4).

e) The commercialisation of fertility services

The broader context of the commercialisation of fertility services gives rise to considerations of how an attention of profits may influence the operation of race in donor selection. In the US context, where gamete donors are often paid beyond reasonable expenses, the commercial element to donor selection is particularly pertinent. Fox argues that by engaging in racial selection of gamete donors, consumers are involved in the potentially discriminatory practices linked to race-conscious designed donor catalogues (2009:12); furthermore, clinics or sperm banks who categorise donors by race are equally engaging in a 'pernicious practice' that sends a message that single-race families are preferable to multi-racial ones (Fox, 2011:6; for an examination of the social, cultural and political processes underpinning the routinisation of sperm banking in China see Wahlberg, 2018). Although Fox acknowledges that there is little evidence to suggest that racial prejudice comes before commercial profiteering to account for

why sperm banks sort sperm donors by race, this does not preclude a careful consideration of how reproductive decision making might accentuate racial preferences (2011:10-11; see also Deomampo, 2019:623).

Due to the limitations imposed on the financial reimbursement for gamete donation in the UK, the type of market-access described above has limited resonance in this jurisdiction. Although, as explained, IVF and donor conception remain costly when not funded by the NHS and the HFEA's data indicates a limited uptake of ARTs among ethnic minorities. Furthermore, the display of donor information, including race, through online profiles is also a feature of UK donor banks (Pennings, 2000). The choice of donors presented to fertility patients in the UK, and the manner in which this information is presented and used, therefore engages similar critiques of the use of race, as identified in the US by Thompson, Quiroga and Fox above.

iv) Conclusions from CRT

From one perspective, then, race is not only a social construction, but is also *politically* constructed to enable those in power in society to perpetuate ideas of racial hegemony and to preserve the dominance of 'White' people over people of colour. In this view, ARTs facilitate this subjugation by reinforcing White patriarchal ideals of family. CRT raises important questions over the intersection of race and donor conception that expose issues of access to donor gametes, the presentation of donor information, the substantive and procedural aspects of decision making and choice, along with the broader context of the provision of commercial services. These issues are linked to observations from CRT concerning the use of race to pursue and maintain certain social and political

assumptions of race and embedded racialised stratification within society and institutions.

Such arguments about race are powerfully charged and their relevance arguably rests upon empirical observations of racialised practices – although CRT also acknowledges that racist attitudes are not always manifested explicitly but are often expressed unconsciously or behind race-neutrality. This may or may not be evidenced in the UK fertility sector; CRT is, in some accounts, a product of its geospatial origins and may operate differently where civil rights concerns are high on the political agenda. While CRT scholars openly embrace a specifically political mission not just to expose racism but also to challenge it and thereby change society, the purpose of this thesis is not only to explore the application of CRT to the UK context of donor conception, but to explore and give language to the ways that race is being used. While the ‘White over colour subversion’ may not be overtly evident in the UK fertility context, as opposed to that of the US, CRT gives us the tools to explore the extent to which participants in the system may replicate established idioms of racial hegemony. CRT offers a framework through which nuanced and ordinary decision-making in ARTs can be seen open to examination. It also challenges notions of colour-blindedness or race neutralisation. The empirical data collection in this thesis will be used to explore how these concepts and ideas may play out in the UK context. As this thesis will set out, the UK’s fertility sector can be differentiated from that of the US by the presence of statutory regulation and a regulatory body that specifically observes binding legal obligations on fertility clinics. In the UK, the provision of fertility treatment can be partially funded by the NHS, creating a somewhat different environment to the arguably more commercialised model in the US. Nevertheless,

CRT will be employed to examine the assumptions about race that may lie behind donor selection in the UK and expose what may otherwise be viewed as innocuous, mundane or ordinary practices. This not only raises crucial normative considerations that may inform law and policy in this area, but the constructivist model of race adopted by CRT may also elucidate the complex meanings and processes that underpin its use in donor selection. It is by building on these perspectives that this thesis seeks to make an original contribution.

4. New Kinship Studies

While the deployment of race in UK clinics has been relatively under explored, a great deal of literature studies the way that ARTs are used in family formation. This literature review now proceeds to outline the key themes that emerge from sociological and anthropological studies around the creation of kinship, including the importance of resemblance and the ways genetic information is understood and rendered meaningful within personal and familial narratives. These understandings can at times seem to be paradoxical and fluid (Franklin, 2013), as they are caught up in construction processes around kinship, but which – as will be seen – are nonetheless significant and unique in their constitution.

i) Introducing the ‘new kinship studies’

Assisted reproductive technologies, including donor conception, enable family-building where this was previously impossible because of biological or social infertility (e.g. same-sex couples). Procedures such as IVF and donor conception have enabled people affected by infertility or subfertility, single women and homosexual couples to have children who are genetically related to one or both of

their parents or have been brought to term by the biological mother.⁸ The provision of these techniques therefore produces at least two significant social phenomena: first, the creation of new family models and the ‘reconfiguration of kinship’ (Tyler, 2005:478); and second, the presentation of choice in reproductive decision-making. Both of these factors are often, but not always, facilitated by professional third-party intervention in the form of fertility clinics. A significant body of literature referred to as new kinship studies (NKS) (Carsten, 2000b:3; Franklin and McKinnon, 2001) – a subset of kinship studies – looks specifically at the creation of families through ARTs.

In helping create new family forms, assisted conception has challenged traditional family models by enabling the creation of kin relationships outside of a hetero-patriarchal ‘nuclear’ family model based on blood ties or genetic connections (Butler, 2002:37, see Logan, 2013; Herrmann and Kroløkke, 2018:31). The use of ARTs can threaten common assumptions within families around ideas of relatedness and stability (Hargreaves, 2006:261) and challenge what may previously be considered as families that are ‘fixed by nature’ (Mason, 2008:30). As these common assumptions and traditional models are dismantled, patients using ARTs become involved (wittingly or not) in processes of reconstruction. As Franklin highlights, this situation has not only changed understandings of biology, evolution, inheritance and genealogy, but has altered what ‘biological’ can ‘do, and mean’ (2013:66).

ARTs arguably present fertility patients with a high degree of choice through which they can choose how to build their families. At the point of donor selection,

⁸ Single men are now also able to utilise ART coupled with surrogacy, as written into the HFE Act 2008 section 54A.

patients will often be presented with a range of donors from which their child's progenitor genetic material can be selected. To a certain extent this allows patients to 'pick and choose' their donor although, as will be seen, in reality the choices may often be quite limited (for example, if a donor egg as opposed to sperm is needed). The availability, or more accurately, the exercise of choice means that a unique set of processes take hold around reproductive decision-making that are facilitated or mediated in the context of fertility clinics. This phenomenon provides a unique point of investigation for how ARTs and the meaning generated around these reproductive processes are understood and this thesis seeks to interrogate how clinicians understand (how patients, parents and families understand) these processes.

Despite a strong body of evidence about the effect that gamete donation has on kinship (Nordqvist, 2010, 2011, 2012 and 2014; Nordqvist and Smart, 2014; Mason, 2008; Smart, 2007), many of these studies (with some important exceptions, discussed below) have not given explicit attention to the role of race in the UK and how the concept is deployed through processes around donor selection in fertility clinics. Furthermore, many of the existing studies on kinship have focussed on the views of patients, whereas this study examines the views of fertility professionals. As discussed in Chapter Three, this approach provides a unique perspective through which race can be critically examined.

On donor information, numerous studies have enquired into the removal of donor anonymity: in particular, work produced by the Centre for Family Research and Golombok's interviews of children born following donor conception into new family forms (Golombok, 2015). These studies are relevant to the broader context

of this thesis, but do not explicitly address the role of race or ethnicity in donor matching. More specifically on race, Tyler has conducted ethnographic research in Leicester to explore how people think about biological and cultural aspects that make up racial identity in interracial families (2005). Similarly, Culley and Hudson conducted focus groups to examine public understandings of gamete donation among British South Asian communities (2009). Again, however, little empirical work in the UK looks at race from the perspective of professionals and in the donor-matching context specifically.

In the US, Almeling (2007) and Fox (2011) have both examined the role or positioning of race in donor catalogues but this work, while important to the framing of the analysis of empirical data in this thesis, does not provide empirical evidence of how fertility professionals view the role of race or its role in donor matching more generally. From the perspective of clinics, both Thompson (2005) and Franklin (2013) have engaged in ethnographic work with fertility professionals but this work has not isolated the issue of donor matching and the role of race itself. The empirical work presented in this thesis therefore occupies an original space in a wealth of related literature.

Notable exceptions, among many, are found in the work of Hudson (2015), Davda (2018), Deomampo (2019) and Moll (2019). Hudson examines the concept of race and perceptions of heritability in the gamete donation context. She raises the normative implications associated with references to race and ARTs (2015:1), while also discussing the complexity in the way in which race ‘mediates the formulation of racial identities and the construction of kinship’ (2015:4). In addition, Hudson acknowledges the limited existence of empirical research

examining how views of race and heritability are operationalised in clinical practices (2015:4) – an area to which this thesis seeks to make an original contribution to.

Kinship literature contributes empirically derived observations on the importance of ‘connectedness’ to personal life, or relatedness (Culley et al, 2009; Nordqvist, 2019) and the meaning of wider family networks (Nordqvist, 2014:269; Smart, 2007). A few central themes emerge from the literature, which are of specific relevance to this thesis: resemblance; social construction; fluidity, change and paradox; and the use of narrative.

ii) **Resemblance within families**

According to the empirical studies in this area achieving resemblance between a child and the parent using ARTs has emerged as an express motivation for patients’ selection of gametes (see Nordqvist and Smart, 2014; Pennings, 2000). An underpinning notion is that resemblance denotes a genetic connection or bloodline (even if that does not truly exist), which in turn supports kin connections between family members, or that the transmission of genetic material underpins kinship (Strathern, 1992:5; Davda, 2018: 256-7). Upon this view, kinship can be understood as a ‘fact of society rooted in the facts of nature’, where kin relatives are divided between blood line relations and those bounded by marriage (Strathern, 1992:16). The role of genetics and notions of the bloodline can be seen as a defining feature of the ‘family’ (McLaughlin, 2004; see Jivraj and Herman, 2009:10-11) but, of course, in donor conception this genetic connection to the child is absent for at least one of the parents (in fact, the use of donor gametes ‘creates the biological parent as a separate entity’ (Strathern,

1992:20)). Nonetheless, families where one or more parent does not have a genetic connection to their children have been observed to use physical resemblance to construct notions of relatedness (Nordqvist and Smart, 2014:132; Hargreaves, 2006:269). Interviewees in one study conducted by Nordqvist demonstrate that families were able to identify resemblances between child and the family even in the absence of a genetic connection; doing so allowed them to 'construct links' between the children, parent and wider family (Nordqvist and Smart, 2014:133). Nordqvist and Smart observe that the 'mapping' of resemblance is an important strategy undertaken by parents to deal with the absence of a genetic connection and to reclaim a sense of genetic connectedness with the child. The importance given to genetic connectedness has undergone critical examination (Horsey, 2010; McCandless and Sheldon, 2010), but the notion of genetic relatedness remains prominent in social and legal discourse, even when it is technically absent.

The importance of physical resemblance between the child and parents can be explained in part by the idea that it suggests (from the outside) a biological linkage between the non-genetic parent and child. For some heterosexual couples, this may help to keep their use of donor conception a secret (Nordqvist and Smart, 2014). Sometimes this is desired because of personal or cultural reasons (Culley and Hudson, 2009), but it is also tied to a parental desire for how their relationship with their children is perceived by others, i.e. that the child is their biological own. Some users of donor conception may want to do this in order to appear 'normal' or because of concerns over questions around the child's 'legitimacy' or even privacy (Sheldon, 2010). While it may be one thing to be open with friends

and family about donor conception, this does not necessarily mean that donor gamete users are happy to share this with the wider community or strangers.

As the couple affected by the clinical sperm-mix up in Northern Ireland (discussed above at section 2.iii) have claimed, a perceived difference in resemblance between parent and child can give rise to concerns about infidelity. Speaking after the incident came to light, the father affected explained: ‘This mistake has devastated our family and almost destroyed our marriage. We can’t go out together because people openly stare at us. My wife has been asked if she’s had an affair with an Indian man on holiday’ (cited in Sheldon, 2011:4).⁹ It is important to note that the population in Northern Ireland is predominantly White (98.2% identified as ‘White’ in the 2011 census (NISRA, 2012:15)), giving some context to the parents’ expressed distress and highlighting also how the experience of race and identity perception, including by the children involved in this case, is very much influenced by interactions with social environment.

The idea of a ‘normal’ family or legitimate family structure is heavily present in discussions around resemblance. Becker, drawing on interviews with 148 couples who had used donor gametes to have a child, reported that some participants voiced fears that a medical error could result in a child of a different racial or ethnic group (Becker et al, 2005). The interviewees’ concerns were significant: ‘For parents of children conceived with donor eggs or sperm, resemblance talk represents the on-going threat that comments about physical appearance could stigmatise their children or cast doubt on the legitimacy of their family structure’

⁹ A similar complaint was expressed by the parents involved in *Leeds Teaching Hospitals NHS Trust v A and Others* [2003] EWHC 259 who spoke about their children being asked why their skin tone differed to that of their parents (Horsey, 2006). Marital breakdowns partly attributed to sperm mix-ups have also been reported (Everett, 2019).

(Becker et al, 2005:1300). Davda explains the concern expressed by recipients is one over 'relational stigma' arising from their relationship with their child, rather than in relation to a particular attribute (2018:257). The idea of 'legitimacy' here is one constructed from the traditional model of the nuclear family; as such, ideas of 'matching' and physical resemblances can be seen to 'rehearse hetero-normative ideas of family recognition' (Marre and Bestard, 2009).

Whether concerns about legitimacy can be upheld in a modern society where ARTs are widely accepted and donor conception is openly discussed is unclear. Genetic relatedness and bloodline kinship have permeated social discourse and influences contemporary understandings of family to the extent that visibly non-traditional families have also been observed to attempt to adhere to traditional family models. For example, Nordqvist has found that finding a matching donor is a long-standing strategy amongst same-sex female couples (Nordqvist, 2012:648). Furthermore, Nordqvist found same-sex couples wanting to become parents feel the pressures of conventional patterns of intimate life (Nordqvist, 2012:658). Same-sex female couples in her study sought to select donors whose physical characteristics were similar to those of the mothers, mirroring established practices in heterosexual donation (Nordqvist, 2011:118).¹⁰ While the practice of visibly different family structures adhering to conventional family models raises important questions about the pressures of conformity in kinship arrangements, it also demonstrates a more constructivist definition of the family unit where notions of resemblance are redeployed amid personal, familial and social norms.

¹⁰ Resemblance in this context has meaning for family relationships and social identification (Nordqvist, 2010:1131).

Another version of the 'family', sitting in contrast to one of shared genes and the bloodline is to view the family as 'the collection, sharing and passing on of memory, stories and the legacy of history' (McLaughlin, 2014:626). In this view, narrative building becomes important to the formation and maintenance of the family – the sharing of stories passed down across generations. The importance of narrative is discussed as a key theme below, but for the present purposes it underpins a more reflexive and constructed model of the family.

Resemblance therefore ties in with a broader concept of legitimacy premised on socially constructed ideas of relatedness – or within the broader theme of kinship 'imagined by social arrangements' (Strathern, 2002:3). Families in which a genetic connection is visibly absent may still strive to display conventionality, thereby separating the social construction of relatedness from the strict idea of the bloodline. According to Nordqvist, perceived physical resemblance can confirm family connectedness and can establish families as socially 'legitimate' (Nordqvist, 2010:1132). This broader view of legitimacy encapsulates the social dimensions of resemblance and what it means to 'fit in', revealing the complexity of these themes.

Resemblance is not limited to parent-child relationships and has been observed across family units. Becker et al observe that some parents were concerned about their child's resemblance to other relatives, such as grandparents (2005). When this connection was lost by non-resemblance, these parents expressed the view that the child's appearance prevented a relationship with that family member from taking hold (Becker et al, 2005:1304). Indeed, regardless of using a donor, parents

have noted pressure to have a child that looked like other family members (Becker et al, 2005:1303).

The need to resemble family members – or to have children who resemble certain individuals or common perceived traits within a family – can reflect desires for relatedness and fitting in on a relational and familial level (Marre and Bestard, 2009; Becker et al, 2005:1307). The legitimacy of the family can be achieved through external recognition by presentation of perceptible physical resemblances – the family unit looks like a family. Finch observes that families must undertake ‘display work’ to show themselves as family units (Finch, 2007; see Nordqvist, 2010). For a family, resemblance can be about establishing family ties between family members, offering a lens through which family members are viewed and highlighting the relational bonds between them (Marre and Bestard, 2009). It is important to note that resemblance is not limited to physical features, but extends to aptitudes and personality (Almeling, 2007). Being ‘sporty’ or ‘musical’, for example, are qualities that may be sought by parents (Nordqvist, 2014:74). Constructions of resemblance can therefore involve both the physical and non-physical attributes of the child.

The idea of familial identity is a strong one and families as a unit may engage in narrative building as much as individuals do. The act of changing a name or surname to avoid a negatively viewed past, for example, can silence undesirable social factors. It seems, therefore, that the ability to fashion one’s identity by past, present and future is not limited to each individual member of a family but can be orchestrated by a family as a unit (McLaughlin and Clavering, 2012; McLaughlin, 2014). However, the perceived legitimacy of a family may also rely on internal

factors with notions of relatedness helping to promote kin connections between members themselves. For example, the construct of race as a set of inheritable physical characteristics that differentiates kinship can lead people to seek resemblance through racial matching in an attempt to construct family connectedness (Nordqvist, 2012). In this way, 'resemblance talk' legitimises the child as part of the family and is part of the process of constructing the child's identity within the family' (Becker et al, 2005:1301).

The idea that families construct relatedness within their own units supports the observation that resemblance is caught up in the way that families think about and perceive themselves. Resemblance thus plays a role in our 'cultural imagination' about family bonds and ties and serve to signify belonging (Strathern, 1992:34). It also emphasises the relational context in which decisions about ARTs are made and highlights how an overly individualistic approach cannot adequately capture the relational position of people within their familial setting.

Resemblance can therefore be perceived to be a multi-dimensional concept that engages aspects of biological, familial and social norms. Ideas of biological relatedness interplay with the construction of relatedness within families using the prism of resemblance. As Nash observes in her work on genealogy, the 'dynamic and performative sense of relatedness' is often overshadowed by the primacy given to genetics and biology as the basis for identity (Nash, 2004:5). While notions of heritability, the bloodline and genetic connections may remain dominant in discourses around relatedness, there lies a background set of processes around the social construction of relatedness. Discussions of resemblance, both physical and non-physical, can be said to underpin both

biological and social constructions of relatedness. Helping to explain this phenomenon, Nash also observes that conventional social practices and structures, including the ‘nuclear family’, are naturalised by genetics, such that discussions of genealogy can slip into genetic essentialism and biological determinism (2002:31). According to Strathern, ‘natural facts’ are themselves social constructions (1992:17; see Franklin, 1991). The relationship between biological fact and social construction of relatedness therefore provides for a unique way of understanding how resemblance is understood by families and its role in kinship building. Indeed, Nash presents the idea of ‘genetic kinship’ as a mode of understanding relatedness through a ‘new alliance of already hybrid discourses’ (2004:5). This landscape of inter-lapping and coexisting themes of biological, social, individualistic and relational understandings of largescale concepts, such as the family and relatedness, will now be explored further as a framework through which donor information, including race, can be perceived.

iii) The construction of kinship

As has been seen above, discussions of resemblance cannot be entirely isolated from the social context in which these conversations take place. As such, the words or phrases used to discuss resemblance and the heritability of genetics or phenotypic traits, for example, can themselves carry socially determined meaning; NKS provide a fresh perspective to biological or genetic ‘facts’, rendering them open to multiple interpretations.

The social construction of kinship was observed before contemporary practices of donor conception became commonplace. Schneider argues that kinship should be treated as a distinctive set of social relations and argued that references to biology

in the discussions of family and relatives had no necessary connection to biology as a natural process (Schneider, 1972:45, cited in Levine, 2008:376). The NKS question the assumption of substance in such claims of blood kinship by demonstrating that blood connections are socially constituted in biological terms (Kramer, 2011:381; Nash, 2004) and that kin relations are cultural (Levine, 2008:376).

Individuals using donor conception socially construct 'natural' or biological fact, as Thompson has observed, rendering it meaningful in many different ways (2009). Findings from a qualitative study conducted by Hargreaves identified how families conceiving using DI in New Zealand 'strategically established themselves' as the 'sole parents' of their children by drawing on the power of social and biological connection (2006:261). The process of kinship utilises environmental and external information, such as genetic information. As a construction, new kinship allows for biological fact to be reinterpreted and rendered meaningful in the kinship-making process. For Strathern, kinship is a 'social system rooted in constructions of both nature and society' (1992, cited in Nordqvist, 2014:271). 'Natural facts' are socially constructed, which in turn reveals these 'facts' themselves to be social constructions (Hargreaves, 2006:262-263; Strathern, 1992).

By disconnecting from ascertainable natural 'truths' (Strathern, 1992), the meanings generated around ARTs become less fixed and constant, and more complex, nuanced discussions of resemblance can be described. Indeed, the whole process of undergoing fertility treatment has been described as socially embedded: 'The most important decisions that people make – to define themselves as

infertile, to seek treatment (or not) ... are all part of a fundamentally social process' (Culley and Hudson, 2009:5). The contribution of the social constructivist approach therefore not only allows for multiple meanings but also helps situate discussions of resemblance in a relational and social context. This makes for a particularly amorphous and fluid landscape in which these processes occur.

iv) Definitions of kinship - fluidity, change and paradoxes

Another defining contribution made by the NKS literature is the dynamic and fluid definition of kinship it offers. Mason observes how kinship involves 'active creation' in everyday life, providing a framework of relatedness that is 'worked through, defined and known within and through everyday life, rather than something given' (Mason, 2008; Nordqvist, 2014:269). The capacity of kinship discourse to 'fold and stretch into different shapes' (Nordqvist, 2014:280) allows for meanings given to genetic information and biological material involved in ARTs to be captured without being fixed in form. 'Much like clay,' Nordqvist summarises, 'it emerges as something that can be manufactured into numerous meaningful shapes and forms, and yet still be recognised as the same thing, i.e. kinship relationality' (Nordqvist, 2014:280). This provides a perspective or language through which to speak about kinship as it is constructed by each family using ARTs – a strong 'real life resonance' that helps understand the kin relations that people 'really engage in' (Mason, 2008:31). It emphasises how kinship can be understood more as a process and gives the construction model above real-life application.

Central to the kinship analysis is the notion that ARTs can both alter kinship structures around reproduction while at the same time keeping those very structures intact (Thompson, 2005; Franklin, 2013:6). This notion of ‘turning back’ meanings onto themselves (see Strathern, 1992) captures the apparently paradoxical meanings attached to genetic information (Franklin, 2013:6-7) whereby, for example, a person might attach significance to biological inheritance of eye colour while simultaneously dismantling other instances of inheritance. According to the new kinship approach, rather than being flawed or the reasoning being anomalous, such contradictions are an integral part of this process of kinship making.

Mason’s discussion of ‘affinities’ neatly captures the amorphous construction of meaning around kinship and sets out a framework to understand the creative work around genetic information, discussed next. In an attempt to explain the apparent importance placed on genetic heritage by some people, Mason presents the idea of ‘tangible affinities’ to explain the fascination seen in the general public with the notion of kinship – itself a contested concept (Mason, 2008). For Mason, these affinities – fixed, negotiated, ethereal and sensory – represent different ways of imagining and practising relatedness (Mason, 2008). They capture the interchangeability and complexity of kinship processes.

According to Mason, ‘fixed’ affinities are those that are given or considered as made (see Carston, 2004). While not necessarily biological in basis, it is a connection that is ‘non-electively *there*’ whether we choose it or not (Mason, 2008:33). Perceived resemblance may be one example of a fixed affinity – albeit not unequivocally – and notions of heritability that rely on biological

understandings (Mason, 2008:34; see also Mason, 2018). This version of affinities echoes the discussion of resemblance and relatedness, and this importance of physical traits, above. However, Mason also points that in their engagement with biology, people sometimes view these fixed connections (e.g. resemblance) in ‘visual, sensory, tangible, “real life” experiential ways’ (2008:34). To explain these non-fixed perspectives, Mason proposes, negotiated or creative affinities – the moral and material dimensions of family responsibilities that are negotiated interactively (2008:36); ethereal affinities – something magical and fascinating, beyond rational explanation, part of the everyday (e.g. a photograph that captures non-visible resemblance) (38); and sensory affinities – the idea of connections between people, how we think about nature and biology (40).

A number of important conceptual tools that emerge from this analysis. First, Mason’s affinities emphasise the fluidity of concepts of kinship. The affinities are not fixed, she claims, but operate as ‘axes around which kinship rotates and is negotiated’ (2008:32-33). This viewpoint provides a useful analytical framework to delineate the complex and overlapping yet conceptually distinguishable constructions of genetic or biological information. It demonstrates how kinship does not carry any fixed definitions but rather these four affinities can be thought of as dimensions within or across which kinship is achieved and defined.

Second, Mason’s analysis demonstrates how ideas of kinship can at the same time replicate substantive fact but also be creative, acting in a complementary rather an opposite manner. For example, ‘ethereal affinities’ are mysterious, magical, psychic, metaphysical, spiritual and ethereal – matters considered beyond rational explanation, between and beyond persons and gestures (Mason, 2008:37). This

notion complements, 'fixed affinities' which are things that are 'given' and that interplay with 'what is made' (Mason, 2008:33). The fixity, not just the creativity, of kinship has the power to fascinate, says Mason, as without notions of fixity then the power of genealogy becomes lost (2008:35-36). Mason's analysis identifies the subtle interaction between biological fact and creative imagining when it comes to genetic identity, a sort of suspension of disbelief that people intentionally recraft to make sense of their own feelings of identity and place.

Third, Mason's 'ethereal affinity' allows for the inclusion of that what cannot be easily codified and objectively validated but which can form an important part of one's understanding and preferences in family building (2008:37). This is an important aspect to kinship that gives weight to a substantive value perhaps overlooked by more formalist frameworks. Furthermore, Mason's 'fixed affinities' do not rely on biological fact that is externally validated. Rather they are explicable from a personal perspective, being a product of one's own outlook of genealogy and rendered meaningful by different people in different ways. Arguing that '[a] part of kinship is non-electively *there*, whether we choose it or not' (Mason, 2008:33), and concludes that fixed affinities may even sometimes have no connection with 'biological' ties (35).

Overall, the discussion of affinities captures the fluid and paradoxical understandings of kinship and component concepts such as resemblance, within which donor information can be situated. This approach is particularly apt for donor conception which, as Nordqvist explains, 'transgresses taken-for-granted cultural idioms of blood and relatedness' (2014:269). Mason's affinities therefore present a language and set of concepts to articulate what may lie behind, or be

involved in, discussions of heritability and donor information, including race – to reveal the multiple of different and shifting ways ‘connectedness’ is known (Nordqvist, 2014:269).

v) The use of narrative in kinship construction

A further theme that emerges particularly clearly from NKS is how people using ARTs engage in ‘telling stories’ about their donor or using donor information. This has already been discussed in the context of resemblance and constructing relatedness above (McLaughlin, 2014) and the concept of creative affinities and the ‘real life’ fascination of kinship (Mason, 2008) but the notion deserves further expansion as a stand-alone concept.

Kinship and relatedness have been said to constitute ‘creative’ identity work (Lawler, 2008; cited in Kramer, 2011:381), where the biological information that *symbolises* genetic relatedness is used to build kin relations. An example of the use of narrative can be seen in Hertz’s study of single women who have used sperm donors to have children. Hertz observed that, not wanting to break with tradition, the ‘single middle-class women’ she interviewed sometimes separate genetic and social families by constructing the male genetic contributor using the information there is available about the donor (Hertz, 2002). This process of ‘rebuilding’ can entail the use of ‘fantasy images’ (Hertz, 2002:8) or stories that serve a range of purposes. For example, from partial information about donors, women construct the ‘fantasy father’ to tell their children about, to ‘buffer’ the child’s feelings of ‘rejection’ by an unavailable genetic father (reinforcing the patriarchal model of need for *a* father) (Hertz, 2002:8).

A number of different features are associated with storytelling. The use of storytelling in 'creative identity work' is clearly connected with the construction of personal and familial identity. Interviewees in Carsten's study emphasised the positive value of 'knowing where you've come from' (2000a). Knowing 'where you come from' is not so much an epistemological question but one about self-conception and the 'completeness of knowing' ourselves (Carsten, 2000a:687). Parents may also have very real concerns about how infertility may have an impact on their own 'genetic identity' or, at least, the preservation of it. Such ideas can be closely connected to notions of loss and compensation associated with the psychosocial effects of infertility but through a focus on genetic identity we can see how ideas of genetic lineage as a distinct concept may influence a patient's donor gamete selection. For example, a patient from a particular cultural or ethnic background may well select a gamete donor upon the characteristic of 'race' in an attempt to preserve the culture or ethnic heritage that has been disrupted through the use of donated gametes.

The process of making the past relevant to a contemporary construction of the self entails the crucial idea that development of the self does not begin at birth but with one's ancestors (Lawler, 2008:42, cited in Kramer, 2011:382). A good example of how kinship building can involve stories about the past, present and future is how knowledge of genealogical information about ancestry is connected to notions of identity.

Kramer's work on genealogy establishes that for some people personal identification with the past can help them build their own identity (Kramer, 2011). Genealogical information enables a person to personalise the past – allowing

people to establish ‘continuities in their own lives between past, present and future’ (Carsten, 2000b:689). It is very much an abstract process, however. Genealogy signifies existence and provides meaning while ‘allowing the self to connect beyond and of itself’ (Basu, 2005, cited in Kramer, 2011:380). This transcendental inquiry may also have material implications for some people if genealogical information is considered important for ‘self-making, self-exploration and self-understanding’ (Kramer 2011:380). Furthermore, an interest in genealogy may be accompanied by grieving or loss and used to manage grief. It allows people to work through the grief and loss of dead kin by making creative meaning of their pain and reworking the past (Kramer, 2011:385).

Another feature of the use of storytelling is that building a narrative can function as a tool to ameliorate emotional and psychological difficulties associated with using, or the need to use, ARTs. Reproduction (or procreation) can be seen as fundamental to a person’s identity and life goals (Johnson and Fledderjohann, 2012) and for many, reproduction represents an important functional capacity. There are several studies that emphasise the impact of infertility in psychosocial functioning (Daniels, 1999). For example, Mazor (1992, cited in Daniels, 1999:57) identifies how fertility patients often feel ‘damaged, defective and “bad”’, with the use of a gamete donor closely associated with negative feelings of loss and worries about sexual function, which may also be connected to feelings of physical attractiveness, performance and productivity in other areas. As such, the clinical diagnosis of infertility itself can impact adversely on a woman’s (and presumably a man’s) self-identity (Olshansky, 1987; cited in Johnson and Fledderjohann, 2012:884) beyond feelings of stress or depression.

Such feelings can be reinforced by pronatalist attitudes within the patient's social environment which may alter how they perceive themselves (Daniels, 1999). For example, Johnson and Fledderjohann find that women with traditional attitudes to childbearing may be more greatly affected by infertility and consider it as a threat to their identity (2012:885). Non-traditional families – lesbian women, gay men and single parents – may also encounter related identity problems, perhaps associated with their dissonance with the traditional family model promoted by pronatalist societies. For example, Lawler has shown that in non-conventional family models, identity is described as 'fractured' or 'partial' leading to an identity crisis (Kramer, 2011:382; citing Lawler, 2008). Therefore, biological or social infertility can have profound implications for how a patient – or their partner – understands their own identity that goes beyond immediate physiological stress factors. Identity building for a patient may also be viewed as the redeployment of socially constructed ideals around reproduction (Thompson, 2005:10) and draw on already established frameworks around social and biological relatedness (Culley and Hudson, 2009:262).

Additionally, the notion of narrative building is closely allied with the principle of autonomy in that it promotes an individual's ability to live a life according to his or her own choices and wishes. Thompson's analysis of patients undergoing donor gamete conception shows how key concepts of control and empowerment surround a patient's interaction with ARTs in response to the uncertainty created around infertility (2009). For some clinics, the unpredictability of genetics itself may conflict with the patient's understandings or at the very least frustrate their believe in identity building.

Narrative building may also be associated with the psychological impact of infertility. As Marre and Bestard (2009) highlight, a degree of uncertainty lies in biological reproduction, which contrasts with a feeling of ‘certainty’ of kinship. The decision to use donated gametes thus represents a perceived method of avoiding ‘uncertainty’, while at the same time replicating the reality of biological reproduction: ‘the choice of assisted reproductive techniques is based on the uncertainty of biological reproduction, while adoption is based on the certainty of social filiation’ (Marre and Bestard, 2009:77). Such a view suggests that control is a key feature in relational views of resemblance to continue or preserve, or re-instantiate, the familial bonds.

Although meanings around genetic information through the kinship lens presents a unique process of storytelling, subjectivity and personal decision-making, the effect of the broader social and political environment on this process remains discernible. An illustration of the use of narratives in the donor gamete context is the reconstruction of traditional family norms by ‘non-traditional’ families.

Studies demonstrate that some lesbian women have indicated a need to construct a family according to traditional values (Nordqvist, 2012:650, 653). As Nordqvist shows, female same-sex couples frequently socially construct a genetic relationship between both women and the child: ‘At times, the accounts suggested that the women felt constrained in their actions, and unable to be creative and innovative in their practices. But more often, the couples mobilised conventional family values to account for their own practices, ambitions and values, thus asserting traditional intimate values’ (Nordqvist, 2012:657). Nordqvist found that couples often asserted traditional intimate values, rather than ‘turning them on their head’ (2012:657). Donovan and Wilson have similarly established how the

‘two-parent relationship’ became the defining feature of same-sex families undergoing donor conception (2008:662). In both studies, participants revealed their commitment to becoming parents and a willingness to tolerate heterosexist assumptions to have a child, adding a further dimension to the redefining of meaning discussed by Franklin (2013) and others, outlined above.

vi) The socio-cultural context

The discussion so far clearly indicates that the individual or couple’s socio-cultural context influences the way that they will think about gamete donation and infertility in general. The meanings associated with infertility and the requirement to use gamete donors may play out differently across various ethnic minority backgrounds (Culley, 2009a:251). Wider social networks, which could include friends or colleagues, may also have such an impact (Hampshire et al, 2012).

One study exploring infertility among British Pakistani Muslims in Teesside identified dimensions of infertility to include childlessness; having enough children; having large family; having children at the right time; the right kind of children (‘e.g. son preference’); and becoming childless (through death or estrangement) (Hampshire et al, 2012). Some of these notions were clearly influenced by certain community expectations about fitting in. Another study of British Indian, Bangladeshi and Pakistani communities in three cities in England revealed that while infertility was viewed as a major personal and social catastrophe and a medical problem that required intervention, the use of donated gametes from a third party was considered to be highly problematic (Culley, 2009a:261). The use of donated sperm, in particular, was considered especially risky, presenting a social and cultural threat (2009a:263).

Culley and Hudson outline the experiences of minority or marginalised communities in the UK which demonstrate the importance of the socio-cultural context of fertility treatment (2009a; 2009b). They highlight interrelationships between individuals and the communities in which they live, revealing a complex and nuanced picture. Indeed, the ‘community’ often fails to be clearly definable. However, they claim that ‘while the idea of a fixed culture is challenged, people are still cultural beings’ (Culley et al, 2009b:5).

This theme is echoed by earlier research carried out by Twine in which one (Black) interviewee, asked about her views on White women parenting children of African-descent, responded: ‘I don’t think White mothers have that understanding of what it means to be Black ... Sometimes they haven’t dealt with their own racism’ (Twine, 2000:84, see Tyler, 2005:477). This extract suggests two things – the perception that ‘White’ parents carry some ingrained or implicit racial prejudice but also, crucially, that with being ‘part’ of a ‘race’ necessarily brings with it a sense of understanding. Twine further notes that some White mothers had agreed that racial difference was capable of disrupting their maternal bond with their children (although others said the mother-child bond transcends race) (Twine, 2000:104, cited in Tyler, 2005:477).

Another study observed that, when thinking about gamete donation, participants drew on pre-established frameworks of relatedness in families; the way participants drew on ‘common knowledge’ of relatedness demonstrate the difference or uniqueness to couples within socio-cultural contexts (Culley and Hudson, 2009a:262). This common knowledge – sociocultural specific

understandings of relatedness – is seen to feed into narratives around gamete donation (Culley and Hudson, 2009a:262). This observation demonstrates how the process of narrative discussed above can vary according both to the socio-cultural context in which the narrator and the wider family, even community, is positioned.

vii) Conclusions from NKS

Several conclusions can be drawn from this literature review on NKS. First, ARTs generate unique and distinct meanings around genetic information. People's 'creative' engagement with kinship emphasises the subjectivity of meanings attached to genetic information and materials used in ARTs. The NKS literature offers a framework for departure from objectively ascertainable notions of biological or genetic information, and instead emphasises that understandings of these phenomena are constructed by processes engaged in by individual in different ways – and not always in the same way. As Strathern summarises, 'Choices are made about whether biogenetic kin connectedness is rendered meaningful or not' (Nordqvist, 2014:271; citing Strathern, 1992). This demonstrates how meaning might be negotiated rather than given (Nordqvist, 2014). This notion of kinship is vastly complex, operating across diverse personal and cultural contexts, but commonly involves construction processes that drawn on biological and social frameworks. Ideas of kinship interrelate with broader ideas of family. These meanings are complex, nuanced and highly personal, albeit impacted by social contexts. Donor matching processes may therefore be understood as an arena of the artificially created genetic bonding, but also the conscious reconstruction of the *signifiers* of genetic ties, fulfilling a role in identity-building for parents and children

Second, meaning is generated through processes that are fluid and changing. The thought processes leading to gamete donation have been described by Donovan and Wilson as ‘reflexive’ (2008:662) – how families are imagined and then reimagined when engaged in construction – presenting a picture of a very fluid idea of kinship. This ‘active’ kinship work (Mason, 2008) presents a dynamic model of kinship.

Third, meaning is personally, relationally and socially constructed, an observation which offers a multi-dimensional model of kinship, within which the different areas of influence inter-relate and overlap with one another. This leads to the fourth conclusion; meaning is constructed/deconstructed, contradictory and paradoxical. Decisions of patients in the selection of a donor, for example, are caught up in complex processes of meaning-construction which may not follow clear logical steps. Moreover, the way people speak about genetic information, donor characteristics and so on may not be consistent, and may indeed be paradoxical. Rather, more complex and nuanced models are required for understanding participants’ statements.

Finally, an awareness of social, historical and political traditions is extremely important. As the literature demonstrates, such discussions cannot ignore the influences that affect the way patients speak about genetic information and the social/ political climate around which these decisions are made.

5. Positioning the thesis within the existing literature

The above literature demonstrates that within the studies of kinship and the application of critical race to the provision of fertility treatment, including donor conception, there has been relatively little attention given to the views of fertility professionals and their accounts of donor selection practices specifically and the broader area of law and policy (with recent notable exceptions, see Davda, 2018 in the UK and Deomampo, 2019; Thompson, 2009; and Almeling, 2007 elsewhere). This thesis seeks to provide an important contribution to the existing literature on gamete donation by offering an original insight into how fertility professionals understand and account for the concept of race and its deployment in the donor selection context, in addition to how race may be operationalised in clinical practice.

6. Conclusions from the literature review

This chapter has outlined two broad fields of literature that combine to form a unique analytical framework to examine donor selection. While a discussion of ‘race’ in donor selection may invoke an array of important policy considerations around the position of race, racial matching policies and the scrutiny of race-based decisions, the meanings that are attached to donor information and notions of kinship are nuanced and highly personal.

CRT allows for the examination of relationships between race or ethnicity and power within a broad social context (Delgado and Stefancic, 2012:3) and can be characterised by its strong political critique of the use of race by those ‘in power’ over marginalised groups and to subvert racial minorities. Through its application

to question the purported racial neutrality of modern US institutions, it provides a useful tool for discovering and analysing the relevance of race in ‘the ordinary’ or mundane, in situations where they might be largely invisible. This aspect of CRT identifies assumptions around the use of ‘race’ and ethnicity that maps their usage onto social, political and historical processes.

Through this framework any racialised assumptions around donor selection may be identified and interrogated, shedding a critical light on what may at first glance appear to be an ordinary or implicit assumption of the relevance of race in donor selection discussions. It also debunks express views of race that may be raised in decision making but which lack scientific validity, which may instead operate as complex social or political constructions (Roberts, 1995; Quiroga, 2007).

NKS, on the other hand, locate decisions of racial matching in a broader context of family-building using ARTs, which involves decisions or processes that revolve around ideas of relatedness and resemblance given meaning in a relational or familial setting. The exercise of these notions relies upon a form of constructivism similar to that seen in CRT, but which makes use of or translates biological and genetic understandings in unique ways that are meaningful (subjectively) for each family. Sociological and anthropological studies of kinship address how assisted reproduction including gamete donation affect traditional models of family life and kinship. NKS address to what extent kin relations fall inside or outside existing kinship groups or forms and how new family models challenge ideas of what is ‘fixed by nature’ (Mason, 2008:30). The literature presents a framework that is particularly apt to donor conception, which challenges traditional notions of kinship by enabling the creation of kin

relationships outside of a hetero-patriarchal family model based on blood ties or genetic connection.

Together, CRT and NKS produce a complementary analytical framework through which race and donor selection can be thoroughly investigated. They can be deployed concurrently to develop a rich and complex constructivist model of race, invoking an array of social and political processes. The CRT constructivist model of race complements NKS observations of the individualistic, interpersonal, familial and social background to infertility. The theoretical framework presented by the construction model allows for multiple meanings around the use of the word or concept of 'race' to be spoken about, while also permitting space for 'abductive' reasoning from the empirical data to generate new theories or conclusions (Timmermans and Tavroy, 2012). Race as a construct is affected by the relational processes that surround gamete donation and the use of ART such that, as M'Charek observes, it is not a singular object but a relational entity and one that may be simultaneously factual *and* fictional (2013:421).

Furthermore, CRT and NKS can each work to interrogate the implicit premises of the other, offering a unique solution to apparent limitations. Turning first to NKS, the concentration on family-building provides an alternative perspective to the consideration of the implications of the very processes and practices involved. However, the two cannot be neatly separated – as Donovan and Wilson, in addition to Nordqvist, observe above, the formation of kinship has been observed to replicate traditional family models and ideas of relatedness, but other considerations are also at play (see also Kroløkke et al, 2016; Deomampo, 2019:625). For example, a decision or preference for physical resemblance may

be said to perpetuate a model of familial hegemony, but – perhaps even at the same time – it also represents a key component of personal and familial identity and narrative. With notable exceptions (Bender, 2003; Nordqvist, 2014; Wade, 2014; Hudson, 2015; Kroløkke et al, 2016; Deomampo, 2016 and 2019; Davda, 2018; Moll, 2019), the NKS have spent relatively little attention to the concept of race and the normative implications of kinship building. CRT brings forward the question of race and adds a critical dimension to the individual and family constructions observed in NKS that have meaning beyond ensuring resemblance and (visual) relatedness. CRT allows for these very bases for understandings to be questioned and provides a response to charges of replication of social injustice through the exercise (and respect for) individual agency associated with kinship building. CRT provides a framework to consider the implications of ‘newly constructed genetic kinship for social relations’ and how genetics may be implicated in ideas of identity, personhood, cultural belonging and the community (Nash, 2004:15). For example, in her study of genealogy, Nash has observed how as the language of genetic identity slips from the individual and family to wider notions of ‘collective identity, origins and communities of descent’, it meets a racialised version of difference and belonging (2004:26). The work of Kroløkke et al (2016) Deomampo (2016, 2019) and Davda (2018) considers the intersection of kinship and critical race, raising observations of stratified reproduction in the reproductive tourism, surrogacy and egg donation contexts.

On the other hand, the CRT framework can be charged operating within a very specific normative context around race in the post-civil rights era and its main proponents are based in the US, posing questions regarding its application to the UK fertility context. The NKS approach is grounded in the relevant context and

provides a language to discuss family-building in a way that captures wider meanings constructed by those involved that lie apart from social and political processes. It highlights how people's reproductive decisions are meaningful from the personal perspective and are constructed by families in an attempt to exercise core beliefs or themes around family building, adding degrees of nuance and complexity to how race as a concept is caught up in kinship processes associated with donor selection.

Overall, the literature provides a framework that has both interrogated and reinvigorated biological notions of race, emphasising the social and political construction of the concept, and enforcing the multi-dimensional perspectives on race that coalesce around a patient's decision or clinic's policy to racially match patient to donor. It is these dimensions of race that this thesis attempts to uncover. The interviews will provide the opportunity to examine how race is involved in the creation of kinship and personal or familial identities, whether its usage 're-legitimises' discredited notions of race, and whether it has been operationalised in donor selection (Hudson, 2015) – considering also the significance of this for both kinship construction and normative implications about the use of race.

Chapter Two: Fertility treatment, donor IVF and donor matching in the UK

1. Introduction

The fertility sector in the UK operates within a unique framework of law and policy, as governed by the Human Fertilisation and Embryology (HFE) Acts 1990 and 2008, under the oversight of the HFEA, which imposes additional requirements to the general regulation of fertility services through its licensing powers. The need for this level of regulatory attention can be in part explained by the observation that reproductive technologies, including donor conception, raise complex ethical and social issues that are largely influenced by a changing landscape of social attitudes and political culture.¹¹ The result is that, in practice, assisted reproduction in the UK is a sector characterised by high levels of legal regulation (at least in part, see Brazier, 1999) and bureaucratic administration (English, 2006:3048). This chapter sets out this regulatory context, highlighting aspects that are pertinent to the analysis of donor selection.

As a fertility technique, DI has been practised since the late 1800s. However, it was not until the development of IVF in 1978 that donor conception services began to be commercialised through fertility clinics and gamete donor selection was mediated by professional third parties and payment for services (see Richards, 2016). It is around this time that the sector began to attract high levels of regulatory – and academic – attention. Professional healthcare standards in fertility practice in respect to selecting patients, donors and the provision of

¹¹ See, for example, the debate on IVF at 40 years old in the House of Lords (Hansard, 2018)

counselling developed in the 1970s (Richards, 2016:26) and were largely put on a statutory footing following the Warnock Report in 1984, the recommendations of which led to the establishment of the HFEA and the passing of the HFE Act 1990 (a voluntary licensing authority established by those working in the field operated after the Warnock Report and prior to the HFEA). Today, as evidenced by the HFEA's Code of Practice, which helps clinics to meet statutory compliance standards, the obligations on UK fertility clinics are extensive. They include the provision of counselling, consent requirements, strategies to reduce multiple births, obligations to consider the welfare of the child, specific requirements regarding embryo testing, donation and surrogacy, as well as provision for research and training and administrative issues.

Of equal or greater significance is the commercialisation of the fertility sector, which is estimated to be worth £320 million per year in the UK (HFEA, 2018). The provision of professional donor conception services is dominated by the private sector – although importantly, not solely – and patients are also able to source sperm and eggs from both outside agencies in the UK and overseas.¹² The fertility sector is therefore characterised by high levels of regulation and commercialisation, where clinics' legal and ethical obligations in the provision of fertility services are integrated with the need to attract and retain business in the UK and the medical ethics of healthcare provision. It is within this context that donor selection decisions take place.

This chapter first outlines the legal framework for the provision of assisted conception in the UK, before explaining its historical backdrop. The chapter then

¹² This includes the option of importing gametes from overseas or travelling abroad in order to receive treatment.

proceeds to identify key features of the UK's regulation of assisted conception that may be pertinent to the analysis of donor matching. There are certain features around counselling, the welfare of the child assessment, the removal of donor anonymity, limits on the payment to gamete donors and the commercialisation of the IVF sector that all may impact on donor selection or matching policies. These key features of the regulation not only affect access to treatment, but also the conditions in which donor conception is offered and the attitudes or expectations of patients, clinicians and others. As such, fertility treatment continues to be regulated differently from other healthcare interventions, with the reasons for its specific regulatory regime embedded in historical social and political processes. Identifying these themes is crucial to understanding the context in which donor matching takes place.

The chapter then explains how patients arrive at donor conception. Section three outlines the provision of information to patients and degree of clinical involvement in the treatment of fertility from start to finish. The chapter finishes by outlining how donor conception, specifically, is offered in the UK, including how and where patients can obtain donated gametes, the type of information that is collected and made available about donors, data on ethnicity or race of donors, and any identifiable matching policies in the guidance provided by the HFEA and also expressed by clinics themselves.

2. The legal framework for the provision of fertility treatment in the UK

The UK has implemented a unique legal framework to govern the provision of IVF and other fertility techniques, as well as associated technologies, such as pre-implantation genetic diagnosis (PGD) and mitochondrial donation techniques. The legal framework is grounded in primary legislation – the HFE Act 1990 (as amended). The HFE Act 1990 establishes the HFEA, which both regulates and licenses clinics that offer fertility treatments. Every provider of fertility treatment in the UK that involves donor gametes or the ex utero creation of embryos (therefore including IVF, ICSI, IUI) must possess a licence issued by the HFEA. The HFEA also issues licences for the storage and testing of gametes and embryos, as well as research licences to laboratories for work on human embryos (HFEA, n.d.a).

The HFEA publishes a periodically updated Code of Practice to ‘help clinicians understand and comply with [...] legal requirements as a licensed centre’ (HFEA, 2019d). The principles of the Code of Practice reflect the ‘key regulatory priorities’ of the HFE Acts and the current version is in the ninth edition, published in January 2019 (HFEA, 2019b). Through its licensing powers, the HFEA has the power to direct clinical practice through its policy decision-making within the broader framework of the HFE Act 1990, even where the legislation does not specifically address a given issue. Practitioners must also be accredited by the relevant professional bodies. Fertility doctors are accredited by the Royal College of Obstetricians and Gynaecologists (RCOG), while other clinical staff included nurses, embryologists, counsellors and allied roles are accredited by the relevant professional body, e.g. the British Infertility Counselling Association

(BICA). Furthermore, health professionals working in this area are subject to the same provisions of general health regulation – including criminal and civil law, as well as professional norms – as governs all health practice.

The UK regulatory framework is therefore a mix of general and specific legislation, guidance and ‘soft law’ as directed by the HFEA and relevant professional bodies, where applicable. Notably, the UK’s regulation of assisted conception is that it is regulated by legislation to a greater extent than other healthcare interventions (see Harris, 2010), despite its increasing widespread use and acceptance across society. In other jurisdictions, such as in the US, fertility treatment is ‘unregulated’ in the sense that it falls under the provision of general healthcare or professional bodies (the American Society for Reproductive Medicine (ASRM)) rather than being governed by specific legislation.

When the proposed disbanding of the HFEA was considered in 2010 (see Smart, M. 2010) many came out in support of the need to retain the HFEA and its functions under the remit of one special regulatory agency, rather than divide them under general healthcare regulation or the extension of other bodies, such as the Human Tissue Authority (HTA) (see Parsons and Savvas, 2010). The case for dedicated regulation was robustly put forward by the HFEA and many fertility professionals (Parsons and Savvas, 2010; Cutting, 2012; see Smart, M. 2010). The need for public confidence in science is put forward as one reason why special legislation is needed for embryo research, primarily, but also for fertility treatment (Parsons and Savvas, 2010). Without public support, the UK may not be able to stay abreast of scientific developments and maintain its edge in technological innovation. Relatedly, the HFEA plays a role in the public understanding of

science, conducting a number of public consultations that seek to gauge public opinion about a topic and explain the science and ethical issues involved. The HFEA also plays an increasingly important data collection role (Parsons and Savvas, 2010), which assists patients in making decisions about their treatment and which clinic to attend.

However, the observation remains that assisted conception is more heavily regulated than other healthcare interventions. A prime example of this is the inclusion of what is known as the so-called ‘need for a father’ clause, section 13(5), in the HFE Act 1990.¹³ The clause represents the application of a welfare principle that applies to parents wanting to conceive through fertility treatment – a level of external scrutiny that does not apply to those who conceive through natural sexual intercourse (Jackson, 2002:177). Several key themes emerge from the sector that may explain the difference in approach – but first, it is necessary to place the regulation of assisted conception within the broader historical and political context at the time.

i) [Historical background to the regulation of assisted conception](#)

The idea of assisted conception today may, for some, evoke images of lab coats, petri dishes and clinical environments,¹⁴ but the practice of artificial insemination in humans dates back to a time where assisted conception was often subsumed within marital practices. For example, in the late 1700s, a surgeon known as John Hunter instructed a London clothier with severe hypospadias on how to perform donor insemination with his wife while ‘still under the influence of coitus’

¹³ Later amended by the Human Fertilisation and Embryology (HFE) Act 2008 section 14(2) to substitute ‘father’ with ‘supportive parenting’.

¹⁴ The majority of pictures returned on the first page of a Google Images search for ‘assisted conception’ include such images.

(Richards, 2014:22; Ombelet and Robays, 2015:138). However, not until the 1930s did artificial insemination become established in Britain as a clinical procedure for male infertility (Richards, 2014:22), after the technique was developed for applications in animals and farming, and human donor sperm became more widely available (Ombelet and Robays, 2015:139). Following the development of IVF in the late 1970s, semen preparation techniques were developed making the use of artificial insemination – either using the male partner or donor sperm – safer and more effective (Ombelet and Robays, 2015:140). Artificial inseminations can also now be used in conjunction with IVF, thereby completing its transition from a fertilisation technique more associated with intra-marital intercourse to a clinical intervention for the treatment of infertility.

Indeed, in some cases, great lengths were taken to prevent the use of assisted conception to threaten marital relations. Reports of one of the first applications of artificial insemination to produce a child were attributed to a doctor in the US called William Pancoast in the late 1800s (Kramer, 2016; Yuko, 2016). Pancoast attracted controversy for reportedly performing the procedure using donor sperm on one of his patients under anaesthesia without her knowledge. Instead of using her husband's sperm (which had so far been unsuccessful), he used sperm donated by one of his students (when Pancoast later told the woman's husband, they reportedly both decided to keep the matter a secret). These examples illustrate how artificial insemination was initially assimilated within the hetero-patriarchal family model and sexual intercourse (and also how the procedure – or at least the method of application and those performing the technique – invited moral scrutiny and raised questions of medical ethics early on). The procedure was seen as a threat to the patriarchal model prevalent in society at the time; a model which still

influences kinship today – especially up until donor anonymity was removed in 2005. Paradoxically, such incidents can be seen as attempts to avoid the potential of fragmentation of kinship presented by the involvement of genetic material from outside the marriage, while at the same time (by maintaining secrecy) enabling reproduction that seemingly preserves the blood line – as well as notions of the traditional family and marriage.

While the early practice of artificial insemination mostly used the husband's sperm (Richards, 2014:22), there were some reported cases using donor sperm. The technique had also been applied for 'social' infertility, such as for woman who had lost husbands in the First World War or single women (Richards, 2014:22). Assisted conception was thus entwined from the beginning both in models of kinship and in socio-political processes (for example, the fall in birth rate following WW1); its history affords one means of tracing changing social attitudes and standards of morality. However, it took a while for artificial insemination and, later, IVF to become more widely accepted following more widespread use of the techniques.

Social attitudes towards early assisted conception were largely negative. In the 1940s, concerns over the procedure were expressed in society, the medical profession and the Church (Richards, 2014:23), leading to early attempts to prohibitively regulate and discourage it. Indeed, the Catholic Church objected to any departure from natural conception within marriage and had as early as the 1800s declared its opposition to the procedure by issuing an edict that it was 'non licere' (not allowed) (Richards, 2016:15). The Anglican church had its own concerns, and a commission to look into assisted conception was set up by

William Temple, Archbishop of Canterbury in 1946 and chaired by the Bishop of London, William Wand (Richards, 2016:24). The resulting report, the Wand Report 1948, called for the criminalisation of donor conception on the basis that it was ‘wrong in principle and contrary to Christian standards’ (Wand, 1948:58, cited in Richards, 2014:24), a demand which was not taken up by the Government at the time – or since. The Wand Report condemned the use of donor sperm, equating the practice with adultery, being both immoral and also grounds for divorce (Wand, 1948:41, cited in Richards, 2016). The Report alleged that DI ‘violates the exclusive union set up between husband and wife’ and ‘defrauds the child begotten’, while deceiving the child’s ‘putative kinsmen’ and wider society (Wand, 1948:58, cited in Richards, 2014:24).

The ethical sensitivities and concerns over the disruption of traditional kinship models, as well as marriage, resulted in attempts to keep its early use a secret (Richards, 2016:16). Doctors in the first half of the twentieth century tried to avoid the legal and ethical problems raised by using donor sperm by mixing it with the husband’s, or sperm from other donors, and/or encouraging marital intercourse during treatment (Richards, 2016:18). Some fertility doctors also pursued matching practices in an attempt to prevent the child from standing out because of a ‘lack of familial resemblance’ and to avoid the dissolution of marriage (Richards, 2016:18-19). DI was sometimes kept secret so to protect children’s welfare, keep the husband’s sterility private, and avoid emotional and legal complications by reducing the chances of discovery of the child’s ‘illegitimate’ status. In fact, the Medical Defence Union’s guidance for doctors in the 1940s (produced in an appendix to the Wand Report) covered the avoidance of negligence by appropriate screening of the donor and selecting characteristics and

the face of the donor to those of the husband (Richards, 2016:18). Negative attitudes around donor conception continued into the 1960s, when the Feversham Committee (chaired by Lord Feversham) discouraged the practice but stopped short of recommending that it be prohibited (Richards, 2016:20; see also Davis, 2017). The Feversham Committee thought that the medical professions' solution of keeping donor conception a secret was harmful to the child and wider society, preferring instead to abandon the practice altogether (Haimes, 1998:58). Richards says one of its major concerns was the 'unwitting incestuous marriage of donor half-siblings' (2016:22) – concerns which have been voiced in recent times in relation to calls to limit the number of offspring from a sperm donor (Freeman et al, 2006). In the UK, the HFEA imposes a limit to the number of 'families' that can be created using donated sperm from a single donor to ten (HFEA, n.d.a). Elsewhere, stories of prolific use of sperm by individual donors have been reported. For example, one donor in the Netherlands was estimated to have fathered 200 children (Usborne, 2018).

The early history of assisted conception is characterised therefore by concerns over the threat it posed to traditional family models, the institution of marriage and wider social mores around reproduction and kinship. This began to change with the introduction of IVF in 1978. By the 1970s donor conception was already becoming the subject of professional panels at science, law and ethics conferences and in 1973, the British Medical Association accepted DI as an appropriate medical practice, advocating its inclusion on the NHS (Richards, 2016:25). Professional reports published in the 1970s began to establish standards for the selection of donors and patients, as well as the need for counselling (Richards, 2016:26). The modern regulation of the fertility sector in the UK has its roots in

establishment of the Warnock Committee in 1982. Its remit was to ‘consider recent and potential developments in medicine and science related to human fertilisation and embryology’ and ‘to consider what policies and safeguards should be applied, including consideration of the social, ethical, and legal implications of these developments’ (BMJ, 1984).

The Warnock Report was published in July 1984. While society had by this time become somewhat more accepting of assisted conception (Franklin, 2013:60; see Henig, 2006, cited in Franklin, 2013:313), the Warnock Report reflected that the Committee felt that there remained ‘anxieties’ around assisted conception and that some felt developments in the technique were ‘moving too fast’ (Warnock Report, 1984:4. Para 1.1). The Committee acknowledged the increasing prevalence of fertility techniques and endorsed the treatment of infertility (1984:10. Para 2.4) but also took the view that artificial insemination was not yet ‘universally accepted ethically’ (1984:5. Para 1.3). In particular, one issue the Committee remained concerned about was prospective parents’ uses of donor conception. Its Report (1984:24, para 4.21) recommended that donor information should be restricted to ‘basic facts’ to discourage parents from seeking donors with specific characteristics (Warnock, 1984:24; cited in Richards, 2016:29; see Pennings, 2000:509-510). Of note to this thesis, the Report includes ‘ethnic group’ alongside genetic health as such a ‘basic fact’, which is described as ‘sufficient relevant information for their assurance’ (Warnock, 1984:24). The fact that the Warnock Committee felt that access to information should be restricted to ethnicity and health – features the Committee felt the children should have a ‘right’ to access upon reaching 18 (Warnock Report, 1984:25) – demonstrates that the relevance of race may have been taken to be self-evident by the Committee. Against a

backdrop of lower uptake of ARTs among ethnic minority communities (Roberts, 1996; Moss, 2019), the Warnock Committee was arguably ahead of its time in recognising that people from ethnic minorities would use assisted conception

The Committee also engaged with the issue of the moral status of the embryo. It highlighted the ‘special status’ (1984:63, para 11.17) of the embryo and proposed a regulatory body to oversee activity in this area. Prior to the establishment of a statutory body (the HFEA) an Interim (Voluntary) Licensing Authority was formed to regulate based on the recommendations in the Warnock Report. Shortly after the Warnock Report was published, the Government at the time drew upon Warnock’s recommendations in a White Paper in 1987 (Cm 259; see also Horsey, 2015:3), which led to the passing of the HFE Act 1990. The Act came into force in 1991, with the HFEA starting work on 1 August of that year. The Warnock Report facilitated the introduction of permissive regulation of ARTs in the UK, allowing the country to remain at the forefront of scientific research and fertility development (Horsey, 2019).

A number of Regulations were passed in the 1990s to extend periods for storing eggs and sperm (Jackson, 2016), and to make more detailed provision for consent and parental orders in surrogacy cases (Human Fertilisation and Embryology (Statutory Storage Period) Regulations 1991). Further legislation was passed in 2001, making human reproductive cloning illegal (Human Reproductive Cloning Act 2001¹⁵), while research around stem cells and cell nuclear replacement remained permitted. In 2004, Regulations were passed to remove donor anonymity, permitting details about egg and sperm donors registered after 1 April

¹⁵ Now repealed. The prohibition on human reproductive cloning is now covered by section 3(2)(a) HFE Act 1990 (as amended by the HFE Act 2008).

2005 to be passed on to the offspring when they reached the age of majority (Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004/1511).

After these years of operation, the legislation became subject to further wide-ranging review in 2005 and a White Paper followed in 2006 (Cm 6989), leading to the Human Fertilisation and Embryology Bill in 2007, which ultimately amended parts of the HFE Act 1990, and offered a substantial new section on parenthood provisions – although some commentators have argued that amending the HFE Act 1990 (rather than introducing a new legislative framework) was a missed opportunity to re-think the governing legislation of fertility treatment more generally (Fox, M. 2009). The introduction of civil partnerships in 2005 (The Civil Partnership Act 2004) also necessitated reform of the HFE Act 1990. The Human Fertilisation and Embryology Act 2008 (HFE Act 2008) came into force in a few phases in April and October 2009, and April 2010. In the meantime, Regulations to give force to the European Tissue and Cells Directive in UK law had also been introduced in 2007.

A historical view of the regulation of assisted conception demonstrates a transition from a prohibitive to a more progressive stance on the procedure and other technologies (for example, the use of statutory powers under the HFE 1990 Act, as amended, to permit the use of mitochondrial donation techniques to prevent the transmission of mitochondrial disease (The Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015 No. 572)), in part reflecting changing social and medical attitudes, as well as wider economic-political considerations around the development of the fertility sector and access

to fertility treatment. However, the regulation remains to some extent consistently rooted in an attempt to navigate complex and sometimes contrasting attitudes towards the technology and its application. The ethical sensitives and moral pluralism around the procedure that were acknowledged in the Warnock Report 1984, and which characterised the development of the procedure in the twentieth and early twenty-first centuries, arguably remain relevant today. Indeed, they continue to underpin the basis for regulatory intervention in reproductive autonomy and family creation. In 2012, proposals to disband the HFEA and merge its functions under two general healthcare regulatory and research agencies, the Care Quality Commission and the Health Research Agency, or to merge the HFEA with the HTA (McDonagh, 2013), put the question of the need for dedicated regulation of fertility treatment back on the agenda. Both proposals were eventually abandoned by the UK Government following the outcome of a public consultation, in which many respondents, including the Wellcome Trust, the British Medical Association and the Academy of Medical Sciences, favoured maintaining the HFEA's independence (Petchey, 2013). Furthermore, an independent review conducted by Justin McCracken endorsed the HFEA's crucial role in maintaining public confidence in 'complex, sensitive, and dynamic areas' regulated by the HFEA, which would be put at risk if it was to be merged with the HFEA (McCracken Review, 2013:5; see McDonagh, 2013). Performing fertility techniques and embryo research within a regulated environment, with oversight by the HFEA, instils confidence in the public that scientists are not running away with technologies, such as cloning.

The case for dedicated regulation of assisted conception therefore has a long history and its justifications remain debated today. It is important to note,

however, that the scope of regulation under the HFE Acts 1990 and 2008, and the remit of the HFEA, is very wide, covering research on embryos, the keeping of records for donation and assisted conception (as emphasised by the McCracken Review (2013:20), and IVF-related procedures, such as mitochondrial donation. Therefore, the justifications for special regulation are also varied and cannot be solely linked to donor conception per se. Concerns over ‘designer babies’, genetic engineering and embryo research, rather than IVF itself, as well as a concern over the prospect of such technologies falling into the wrong hands, underscore public anxiety in this area. Whether the provision of DI and IVF requires dedicated regulation therefore remains pertinent, but the presence of complex regulation based in part on perceived sensitivities is a fundamental point of reference to discuss donor selection and the approaches taken by clinics to this. There are certain features of the regulation that may be particularly relevant to this analysis and that may influence how donor selection decisions are made. These include the provision of counselling to fertility patients, the requirement to consider the welfare of the child, the removal of donor anonymity and the non-commercialisation of gamete donation.

ii) Key features of the UK’s regulation of assisted conception and donation

a) Counselling

Under its licence conditions, a clinic must not provide a woman with treatment using embryos or donated gametes unless she and any person who is to be treated with them is provided with a ‘suitable opportunity to receive proper counselling’ about the implications of being provided with treatment (s13(6) HFE Act 1990 (as

amended)). Section 13(6) of the HFE Act 1990 requires clinics to provide ‘proper’ counselling about the ‘implications’ of providing treatment and that the woman has been provided with ‘such relevant information as is proper’. For patients using donated gametes, the Code of Practice 9th edition (HFEA, 2019b:28, para 3.3) recommends that patients receive implications counselling about ‘treatment with donated material’ separately from the implications of treatment in general and before treatment starts – reinforcing the view discussed above about the special ethical considerations raised by donor conception, or the added complexity of the associated implications.

The Code of Practice does not define what is meant by ‘proper’ and what entails ‘implications’ but it does state that the counsellor should be both qualified and accredited (HFEA, 2019b:22, para 2.14). Some further guidance can be taken from the professional association for infertility counsellors, BICA, which offers accreditation recognised by the HFEA. BICA says that counselling offers patients a way of understanding the meaning and implications of any choice of action they may take and explains that infertility counsellors are trained to help others cope with the emotional and social issues associated with infertility (BICA, n.d.). The HFEA is evidently supportive of therapeutic aspects of counselling, with information available acknowledging the depression or anxiety that can be triggered by infertility and providing information about the support options available (HFEA, n.d.c). It has also included a provision in the latest Code of Practice requiring clinics to develop a ‘patient support policy’ to ensure patients and others receive ‘appropriate psychosocial support from *all* staff’ (my emphasis), which includes but is not limited to the provision of counselling (HFEA, 2019b:30, para 3.14). The support provided by clinics should be ‘patient-

centred' and should include details of patient support events organised by the clinic or others (HFEA, 2019b:30, para 3.14). Furthermore, counselling offers another means for clinics to ensure that patients are appropriately informed when giving consent to treatment or storage about matters such as storage limits (HFEA, 2019b:34, para 4.2).

Fertility clinics also detail the nature of counselling offered to their patients. For example, one clinic offers patients implications, support and therapeutic counselling, both in person and available over Skype (Anon, d, n.d.). Implications counselling aims to cover the patient's treatment plans, wider family and any child conceived following treatment or donation, while therapeutic counselling assists patients in 'coming to terms' with treatment and support counselling explores coping strategies and practical issues (Anon, d, n.d.b). A similar set of services is provided by another large clinic in the UK, which posts information of its website detailing the types of counselling provided (Anon, b, 2018).

In practice, clinics have been observed to expect that patients – particularly those using donated gametes – would routinely see a counsellor (Anon, d, n.d.b). In fact, one study conducted by Lee et al found that some clinics viewed the provision of counselling as mandatory (Lee et al (2015b:38)). This observation raises concerns, especially when considering Lee et al's finding that counsellors sometimes play a 'gatekeeper' role to treatment on the grounds of welfare of the child (2015:73), blurring the lines between welfare and counselling – notwithstanding the recommendation in the Code of Practice that welfare considerations are conducted separately from counselling (2019b:28, para 3.3). The role of counsellors in donor selection is explored in Chapter Four.

b) Welfare of the child

A controversial provision contained in the original HFE Act 1990 (now amended) imposed an obligation of fertility clinics in the UK to consider the welfare of the child including, in the provision's original wording, 'the need of that child for a father' before providing treatment to the patient (section 13(5) HFE Act 1990). This was later amended to replace the need for a father with the need for 'supportive parenting', following criticism of the clause for appearing to discriminate against single women and lesbian couples (Lee et al, 2015:73; see Jackson, 2002).¹⁶ Guidance for clinicians in how to interpret this phrase is provided under the HFEA's Code of Practice, which sets out a range of considerations including, for example, previous convictions relating to harming children (2019:8.14-15). The Code of Practice also states that where no risk factors are identified, then clinicians should presume that prospective patients (and parents) would offer 'supportive parenting' under section 13(5) (2019:8.15).

Notwithstanding this presumption in favour of treatment, it has been observed that the effect of section 13(5) has been to instil a sense of 'responsibility' to consider the welfare of the child (Lee et al, 2015:73). Not only is this a level of oversight to which those who conceive naturally are not subjected (Jackson, 2002:178), but it seems rather odd since clinicians would typically not have access to information needed to assess a patient's parenting abilities nor the skills to do so (Jackson, 2002:194). The extent to which clinic staff express a sense of responsibility towards future children is something that is discussed by interviewees and examined in detail in Chapters Four and Six.

¹⁶ Amended by section 14(2) HFE Act 2008.

c) Removal of donor anonymity

Historically, gamete donation in the UK was anonymous and many jurisdictions still offer the option of anonymous sperm and egg donation.¹⁷ Indeed, the Warnock Report endorsed gamete donation but recommended that it should be anonymous between patient and donor (1984:15, para 3.2). Subsequently, in the early 2000s, growing calls for the removal of donor anonymity in the UK, based in part on considerations regarding the rights of children to know their genetic origins and the benefits of doing so, and also following consultations with the public and fertility clinics, culminated in a change in the law in 2005. The agenda for reform was influenced by the Rose case (*R v Secretary of State for Health, ex parte Rose* (2002) EWHC 1593), discussed below, which was instrumental in achieving policy change in this area. Rose and others have since contributed to debates around donor anonymity and she continues to advocate for the right of donor-conceived people to access full and complete information about their donor (for example, see Udoh, 2015). Under the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004, anyone who donated at a licensed UK fertility clinic after 1 April 2005 is identifiable on the request of any person born as a result of the donation. The donor-conceived child can access the donor's name and last known address once they become 18, including a 'pen portrait' offering a personalised description of their donor, including interests and hobbies. Crucially, though, this right pertains only if they are aware of their donor-conceived origins, and there is no legal obligation to

¹⁷ Spain is one such example, although this policy is currently up for consideration (Euro Weekly News, 2019).

disclose this to children. Those who donated before 1 April 2005 can remain anonymous unless they choose to voluntarily register to become identifiable.

The broad themes that emerge from the debates around the removal of anonymity are discussed in the Introduction to this thesis, but two strands are specifically relevant to the racial matching of gamete donors and the policy in this area – the welfare approach to anonymity and the rights-based approach. First, practical considerations about the potential harmful effect of maintaining secrecy around the use of IVF and/or gamete donors has been given as a primary reason for removing donor anonymity. Indeed, this argument was put forward by Rose in her case above. The right to know ‘the truth’ of one’s genetic inheritance is associated with the view that secrecy can cause stress and anxiety. In this approach, being denied knowledge about one’s biological origins can be harmful to donor-conceived children (Frith, 2001:821, citing Snowden and Mitchell, 1981) or, more specifically, the keeping of secrets involved in non-disclosure may result in family tension (Blyth et al, 2004:2623).

However, the evidence basis for the harm caused by not knowing one’s genetic origins is unclear; indeed, there is much to be said about the rise in public understandings and knowledge of genetics and how this has contributed to these debates. Some studies indicate only a neutral to moderate benefit to families in knowing such information (Scheib et al, 2003:1124) and some commentators have argued it may never be shown beyond doubt whether disclosure or non-disclosure actually causes a participant harm (Pennings, 2007:2842). Many arguments for disclosure based on avoiding harm have been drawn from literature on adoption. Recounting arguments made in adoption literature, Blyth points out that it has

been argued that a child's identity is built on openness and trust (Blyth et al, 2004:2620). However, there are crucial differences between the two fields. Adoption involves the placement of an existing child that has arguably already encountered some form of 'harm' of disruption, whereas ARTs involve the creation of a much-wanted child from conception. Therefore, it can also be said to be 'unwarranted' to assume that conclusions from adoption apply in the same way to donor conception (Frith, 2001:821). Indeed, as noted above, recent studies have shown that children born through assisted conception fare as well as, or even slightly better, than those who have been conceived naturally (Golombok, 2015; 2017).

It might therefore be difficult to demonstrate the harm of denying a child knowledge of their genetic origins; nonetheless, the keeping of secrets in a family can potentially be destructive (Blyth et al, 2004:2620) and policy has appeared to proceed on the basis that avoiding late disclosure, and subsequent disruption to family life, is the best way forward. In fact, recent data from the University of Cambridge supports the view that children should be told of the means of their conception at an early stage: anecdotal evidence suggests it may be emotionally harmful for children to be informed in late adolescence (Golombok, 2015; Nordqvist and Smart, 2014). It seems common-sense that keeping secrets from a child, at least in some cases, could cause hurt and upset when the true information is disclosed – but the evidence to support the basis for harm by non-disclosure in this area is varied. Arguments based on harm caused by non-disclosure sit in clear tension with the perceived notion of matching as avoiding physical dissimilarity that *may* expose the parents receiving IVF as having used a donor gamete (although, of course, dissemblance can occur through natural conception also). It

therefore remains to be seen what impact, if any, discourses around knowledge of one's genetic origins has on donor matching practices or policies.

The second theme pertinent to donor matching is the ethical case for removing donor anonymity based on the autonomous interests of the donor conceived. The ethical case for removing donor anonymity has been supported by observations that, at least for some donor-conceived people, knowledge of one's own biological origins and even a relationship with one's biological parents is associated with the formation of self-knowledge and social identity (see Nuffield, 2013:89-90). Consideration of these interests – or in some accounts, a right to know one's biological origins – have been successfully deployed to justifying arguments for a change in the law. Indeed, the legal basis for anonymous donation was put under review in the case of *Rose* (EWHC 1593), where the court held that Article 8 European Convention on Human Rights (ECHR) was engaged by the question of whether non-identifying information about the donor should be made available to donor-conceived people. The questions of whether Article 8 had been breached ultimately did not arise, as a public consultation on the matter had already been promised at the time the case was heard, after which the Department of Health had announced its intention to change the law.

The attention given to the rights or interests of donor-conceived individuals represents, to some extent, a move away from a concern with the autonomous interests of the parents (or at the least a rebalancing of supposedly competing interests) and marks a possible encroachment into the private life of the family and parents themselves (see Starza-Allen, 2013). The spotlight on the previously under-considered interests of donor-conceived people should be welcomed,

especially when one considers the need to review human rights implications of modern technologies. Yet there remain important questions whether other rights have been de-prioritised in this process – namely those of the donor and would-be parents.

Turkmendag et al argue that the views of people who intended not to disclose to the resulting child were not heard in the debate over the removal of anonymity (Turkmendag et al, 2008:302). The authors observe that when the Government's position was scrutinised by those calling for the restoration of anonymity for sperm donors, no would-be parent joined the discussion (2008:292). If this is the case, this is a significant omission. As Professor Sir Colin Campbell wrote to the *The Times*, the interests of a person yet to be conceived should not necessarily take priority over the legitimate interests of existing would-be parents (cited in Turkmendag et al, 2008:303).

One of the concerns expressed in Campbell's letter was that anonymity would lead to a shortage of donors creating an impediment for those wanting to have IVF using donated gametes (Turkmendag et al, 2008:303). Such arguments about the effect of removing donor anonymity on the availability of gametes were made frequently in the run up to the change in the law (see BioNews, 2004a).

Nevertheless, while data from the HFEA showed a decline in the number of newly registered donors immediately afterwards the change in law in 2005 (see BioNews, 2005), the figure soon increased (HFEA 2019a) – perhaps in part due to greater publicity and the improved recruitment of donors, as well as a documented shift in the general profile of donors from male medical studies to older men mostly signing up for altruistic reasons (Elmhirst, 2014).

However, the concerns of would-be parents were not limited to their interest in accessing available gametes but extended also to fundamental questions about their own privacy and how to assess child welfare, and from whose perspective. Turkmendag et al argue that parents are more concerned with securing their child's welfare by protecting them against the potential harm of knowing the truth rather than giving them greater autonomy (2008:302). As they write: 'Openness in the parent-child relationship is not always thought to be best for the child's interest, and legislative initiatives have no significant impact on parents' assessment of their child's welfare' (2008:302). Proponents of anonymity might point out that this discussion indeed supports telling children early on about their donor-conceived origins, but the point remains that if parents are often tasked as decision makers for their children, then why should this be removed for donor-conception? Arguably, the restriction of parental autonomy and decision making by the courts in cases of child welfare in other areas tends to be justified on avoiding serious and largely undisputed considerations of harm.

While this point speaks to the observed difficulty of assessing welfare discussed above, it also raises an important point of ethics in that the prioritisation of the donor-conceived child's autonomy could be given too much attention, with paternalism on the other hand, too easily refuted. Still, as Turkmendag et al point out, parenthood itself is inherently paternalistic in the sense that 'all parents treat their children as a person of lesser capacity (at least) until they reach a certain age' (2008:302). Most parents consider what is best for their children (Turkmendag et al, 2008:302) and so making decisions on behalf of children, and the consideration of their best interests, is therefore something that is inherent in

many decisions as a parent. It may therefore seem rather odd that donor conception is marked out as an exception or at least worthy of special attention, especially given that doing so involves the pre-conception consideration of welfare.

Finally, the observation that policy in this area provides for disclosure deserves closer attention not only given the variation in the construction of welfare and limited value of the rights-based approaches, but also when one considers the complexity of the social norms and context in which disclosure operates.

Historically, secrecy around heritability has been used to preserve the legitimacy of the male father, reflective of the pro-natalist views in society that fertility in men has been associated with sexuality and virility (Daniels and Taylor 1993:157). Indeed, as discussed above (Chapter Two, section 2.i), in the 1950s, sometimes women would ask doctors to not inform their husbands that DI had taken place (Daniels and Taylor 1993:157, citing Fletcher, 1954) – although for egg donation, the practice of secrecy operates differently indicating that carrying the pregnancy emphasises the importance of gestational motherhood. The curtailment of parental autonomy seen in the debate around donor anonymity is therefore partly justified by the perceived harm caused by maintaining secrets. However, not only are there issues about evidencing any such harm (as discussed above), the study of family secrets involves a complex array of considerations and cannot be reduced to simply the provision of incorrect factual accounts.

According to Smart, family secrets form part of the construction of the family and reveal the complex relationships between personal, social and cultural norms and practices (2011:549). Smart argues that secrets, particularly those concerning reproduction, have the power to ‘reconfigure’ families in their navigation of

memory making, identify construction and the wider governance of family life (2011:551).

Examining the concept of secrecy in the donor conception context, Frith et al's study emphasises the socio-cultural context of keeping secrets around donor conception. For some families, according to the specific time and location, it was important for them to display biogenetic relationships, where anomalous aspects were concealed and kept hidden (2018:199). This had implications for the extended family and the way it was seen – although keeping secrets that sought to maintain a particular biogenetic model was 'often experienced as harmful' (2018:199). According to Frith et al, it is the socio-cultural context that grounds such secrets that gives them meaning, but also determines how significant deception can be perceived to be (2018:200).

The debates and reforms around donor anonymity highlight a number of important features of the UK's regulatory and wider system of policy governance over assisted conception. While a rights-based discourse has clearly afforded great attention to the children both through donor conception, and a careful consideration of their interests, there remain vital debates around evidencing welfare, the weight given to the interests or rights of all concerned and the complexity of family social practices and discourses.

Notwithstanding the 2005 reforms, it remains the case that many parents opt not to tell their children about their genetic origins, meaning that in reality a number of children born using donated gametes would not think to check the donor register unless they have reason to believe there are not genetically related to their

parents. Although there may be a greater trend towards openness, donor-conceived children will only be able to access identifying information about their donor from the donor register if they are informed of their donor conception origins. The policy to date has been not to mandate disclosure, although there have been calls for this, but to encourage it. For example, on its website, the HFEA tells users: ‘Of course the decision of whether to talk to your child about their origins is completely up to you. However, family secrets can undermine trust and lead to conflict and stress’ (HFEA, n.d.e; see DCN, 2018). The embracing of a culture of openness and the nudges to disclosure, as well as the rights and welfare arguments around the importance of knowing one’s genetic identity, may therefore impact on donor matching practices. This thesis will seek to ascertain such an impact, if any.

d) Non-payment of gamete donors and altruism

Donation in the UK can be characterised by the absence of a commercial element (in so far that payments are prohibited by law), which mirrors other areas of ARTs, including surrogacy. The payment of donors in the UK is prohibited but donors may receive compensation to reasonably cover any financial loss (e.g. travel expenses) incurred as a result of the donation. As of 2019 this was up to £35 per clinic visit for sperm donors and up to £750 per cycle of donation for egg donors. This distinguishes the UK from other jurisdictions where payments may be legal, such as the US. UK policymakers have framed the donation of human material and tissue, including gametes, as a gift that is often given altruistically (Nuffield, 2011:5 para 18,11:46). The HFEA says on its website: ‘Choosing to donate your eggs to someone in need is an amazing, selfless act that gives hope to the thousands of women who are unable to conceive naturally’ (HFEA, n.d.f).

Taken together with the removal of donor anonymity, the ban on payments beyond reasonable compensation to gamete donors underpins the altruistic and relational aspects of donation. As a result of the changes noted above, donor profiles seem to be changing; where once these might have been caricatured as students donating for beer money, now there is a greater presence of men and women wishing to help other people alleviate fertility obstacles, and who are prepared to be contacted in the future by their donor offspring (see Elmhirst, 2014).

e) The commercialisation of IVF

The fertility sector in the UK operates on a partly private and partly publicly funded basis, through the NHS. Most fertility treatment in the UK is provided through private fertility clinics (HFEA, 2018). IVF can be provided in the NHS and the National Institute for health and Care Excellence (NICE) recommends that eligible patients receive up to three cycles of publicly funded IVF (NICE Fertility Guideline). However, many CCGs do not provide the recommended number of cycles to patient, with some providing just one or even no cycles at all (Fertility Fairness, 2017), and, where they do, with stringent eligibility restrictions. Consequently, the RCOG estimates that six in ten cycles of IVF are funded by patients themselves (RCOG, 2018).

When it comes to the use of gamete donors, NHS funding for DI again depends on each CCG but patients have the option of purchasing gametes from commercial gamete banks – although as discussed above (Chapter Two, section 2.ii.e), it is illegal to pay a donor anything beyond reasonable expenses.

One cycle of IVF can cost up to £5,000 (Lindsay, 2018), depending on the treatment options made available. There has been recent debate about the value for money associated with the private provision of IVF, particularly around the marketing of add-ons to treatment (see, for example, Zotow, 2018). However, the HFEA has no remit over price and the fertility sector is allowed to set its own prices for treatment.

Private fertility clinics operate on a profit-making basis and therefore have a vested interest in the expansion of their business (Brazier, 1999:192). The sector is worth an estimated £320 million per year and the market is growing at around 3% per year (HFEA, 2018). The commercialisation of the fertility sector in the UK remains a much-debated issue (see, for example, Luik, 2015). While the pros and cons of the commercial model of IVF is outside the scope of this study, a potential focus on profit-making and the concomitant handling of patients as consumers also, could impact on how the selection of donors and donor matching is managed. It is possible, therefore, that patients' wishes and satisfaction could become a top priority, for example – although one must remember the welfare obligations imposed on clinics under the current legislation, discussed above.

3. Treatment pathways involving donor conception

The standard treatment pathway for fertility patients moves from concerns regarding a failure to conceive, to diagnosis, to treatment and – if all goes well – to pregnancy. This pathway is well documented on the websites of both NHS and private clinics, patient support organisations, and also by NICE, which makes recommendations for fertility treatment on the NHS. NICE recommends that

information and advice regarding care and treatment options is given to people who are concerned with delays in conception early on in the treatment process, including exploring the range of reasons that can contribute to infertility (NICE 2013). In particular, when considering the psychological effects of infertility, it recommends that counselling should be offered to patients before, as well as during and after, its investigation and treatment. NICE suggests that information and counselling is offered once indications for the need for donor gametes is established, followed by the screening of donors, tests offered to the patient, discussion of the type of insemination prior to unstimulated DI (NICE 2013).

A great deal of information for patients concerned about fertility is provided by the HFEA, including details of the full range of treatment options. The HFEA's website informs prospective and current patients about the law on assisted reproduction (HFEA, n.d.b) and also more practical matters, such as finding a clinic (HFEA, n.d.g). In addition, the NHS website provides information on becoming pregnant and the provision of IVF and other fertility techniques (NHS, 2017). This level of information exposure can result, in some cases, in patients being highly informed at the outset about their course of treatment, even prior to any specialist intervention. While information is provided by organisations, such as the Donor Conception Network, there are a number of information sources online that offer less reliable information.

Furthermore, by the time a patient is considered for treatment at a fertility clinic, they will have already been through a highly medicalised set of investigations and consultations. Once a patient has been identified as infertile, they would then see a specialist consultant to discuss their options for attempting conception, further

assessment or possible treatment. For NHS patients, this initial investigation stage is conducted by the GP prior to a referral to the NHS fertility clinic or obstetrics and gynaecology consultant. Once the secondary care investigation phase is completed, including further testing and diagnosis, the treatment stage begins. This is typically offered by the IVF/ICSI tertiary fertility services provider. In the private sector, clinics might conduct the full range of procedures from initial set of investigations or the provision of treatment, and subsequent monitoring. DI, or egg donation, is considered once indications for the need for donor gametes is established. Therefore, fertility treatment typically follows a lengthy process of diagnostic tests, consultations and interventions, with one IVF cycle alone taking four to six weeks. The medical landscape of the pathways to fertility treatment lays the ground for a great deal of interaction between clinics, their staff and patients, as information, treatment and advice provider-recipients. These interactions may have relational consequences in how the doctor-patient relationship is characterised.

While early feminist analysis of women's experiences of IVF has claimed that women expected to be objectified by success-orientated doctors (Franklin, 2013:206), in more recent years, commentators have observed a growing emergence of a more complex, interactive relationship between patient and clinic. Franklin argues that the concept of 'biosociality' (Rabinow, 1992, cited in Franklin, 2013:219) – the reconstruction of biological ties through technical processes and the deconstruction of human biology (see also Rabinow and Rose, 2006) – applies as much to the IVF context as genetics, albeit with an additional feature of 'ambivalence' expressed by patients towards reproductive technologies (Franklin, 2013:219). Her description of patient's experiences of IVF in the UK as

‘a way of life’ encapsulates the heavy integration of lifestyle, engagement and information between patient and clinic, as evidenced by the treatment pathways described by NICE. The data collected for this study also casts some light upon the nature of the relationship between clinics and patients, albeit exclusively from the perspective of clinic staff, as will be seen in Chapters Four, Five and Six below.

4. IVF using donated gametes and donor matching in the UK

There are two forms of assisted conception that involve the use of a gamete donor. DI covers treatment using donor sperm where the fertilisation takes place inside the woman’s body; IVF involves the use of gametes provided by the man or woman receiving treatment, or donated eggs and/or sperm. For lesbian and gay couples and single women a gamete donor is, of course, necessary.

According to the latest data from the HFEA, the use of donated gametes in fertility treatment has been increasing each year (HFEA, 2019a, d), with the use of IVF accounts for much of this increase. The number of patients receiving DI (where sperm is inserted directly into the woman) is decreasing (HFEA, 2019a:18). This decline may reflect improvements in fertility treatments, allowing infertile couples to use their own gametes, such as the development of ICSI (where a sperm cell is placed directly into an egg cell) used for male factor infertility – the use of ICSI has increased until 2014 (HFEA, 2019a:18; see also Bhattacharya, 2019 on reports that ICSI is being offered unnecessarily to some

patients). In contrast, the number of single women and homosexual couples receiving treatment is increasing (HFEA, 2019a:3).

i) Sourcing gametes in the UK

There are two avenues for donating sperm or eggs in the UK: through licensed fertility clinics and sperm banks, and, for sperm at least, in informal or private arrangements (see Jackson, 2015; Sundram, 2013). The latter are unregulated in the UK, but the former falls under the regulatory capture of the HFE Acts and the HFEA. Sperm, eggs or embryos can be stored by cryopreservation either by vitrification or freezing techniques and used at a later date. The donor must sign the relevant consent forms.

If donating at a licensed fertility clinic or bank, then donors are not legally responsible for any children born following the donation. The donor will not be named on the birth certificate, he or she will have no say about how the children are brought up and will not be required to pay child support. However, if a donor provides sperm for use in conception outside a licensed UK fertility clinic, as part of a private arrangement, then he or she may be considered in law to be the child's legal parent. There may also be risks associated with unscreened sperm and the absence of imposed limits to donor offspring (Jackson, 2015), as well as controversies around the use of so-called 'connection' websites (see Ravelingien et al, 2016).

In the UK, commercial entities offer customers a wide selection of donors. Often these banks are connected to fertility clinics and typically tend to supply patients at their associated clinic (Anon, g, n.d.). Although many respondents in the

present study explained that this type of arrangement continues to date, it also emerged that fertility patients were using sperm or eggs obtained from outside their own clinic or its associated banks. Alternatively, many patients source and import their gametes from overseas or travel to receive treatment abroad. In many cases, particularly in the US, patients receive more information about the donor than they might otherwise do in the UK (see Daniels and Heidt-Forsythe, 2012). In other cases, patients might travel abroad – for example, to Spain – because they prefer to seek anonymity (Marre et al, 2018).

ii) Donor information

When donating at a licensed fertility clinic, all egg and sperm donors are requested to complete a donor information form or registry form. The HFEA's donor information form contains information about the donor's medical conditions (each donor should have been screened¹⁸), the donor's ethnic group and that of their biological parents, and physical characteristics such as eye, hair and skin colour. It also asks about religion, occupation, interests and skills and includes space for the donor to leave a message about themselves, known commonly as the 'pen portrait'. The completion of the donor information form is mandatory for all donations in the UK and also for donor conception using gametes imported from abroad. The HFEA states that non-identifying information from the donor information form may be given to patients by fertility clinics.

In addition to the information required by the HFEA, gamete banks may provide further non-identifying information about the donor. For example, a gamete bank will typically state the race, ethnic origin, eye and hair colour, skin tone, weight

¹⁸ See fn20.

and height of their donors, along the line of the HFEA donor information form (for example, Anon, g, n.d). However, each donor also has a more extensive profile page of their own which includes a longer list of donor attributes including qualifications, occupation and religion, text about the agency's 'impression' of the donor (e.g. 'He is a fairly relaxed and easy going person with a cheerful disposition'), medical information such as blood type and allergies, and also information about the donor's personality, including their interests and hobbies and skills. One gamete bank offers a similar set of information about their donors – although for both banks, each profile may be different (Anon, g, n.d). Pennings attributes the expansion of information about the donor provided to patients to the growing commercialisation of gamete banks, particularly those in the US (2000:508). Indeed, he points out previous guidance was that patients would not choose their own donor, noting the Warnock Committee's concern to limit the amount of information made available to patients, discussed above (2008:508).

Most sperm and egg donors (as newly registered) are domiciled in the UK (76% sperm donors in 2010 and 95% of egg donors). All donors, whether UK-based or overseas, must provide the same information to the HFEA and are subject to the same screening requirements.¹⁹

Patients receiving treatment abroad receive highly variable levels of information about donors. In the US, for example, it is not uncommon for patients to be

¹⁹ The screening requirements are set out in section 13(9) HFE Act 1990 (as amended) and under the licence conditions (HFEA, n.d.k:T52 and T55), as detailed in the Code of Practice (HFEA 2009b:112-115; 117-18). The Code of Practice (9th edition) also recommends that the recruiting centre should take a donor's medical and family history before accepting gamete donation (2009b:117). This may include testing for chromosomal abnormalities, including for sickle-cell disease if the donor is from an African or Afro-Caribbean background, or cystic fibrosis if the donor is European, for example (HFEA, n.d.l).

provided with childhood photographs of their donor. In Europe, one gamete bank provides ‘extended profiles’ of ‘up to 8-10 pages of personal information’ about their sperm donors, including much of the above, childhood photographs, a handwritten greeting, a recording of their voice and an EQ profile indicating their ‘emotional intelligence’) (Anon, f, n.d).

iii) Gamete donation and race

As indicated above, donors are required to include their ‘ethnic group’ and their mother and father’s ethnic group on the HFEA’s donor information form (as well as skin, hair and eye colour). According to the latest data published by the HFEA (2019a), 70% of egg donors were ‘White British’, with a further 14% identifying as being from other White backgrounds. Only 2% of egg donors identified as Indian and 2% as Black African, with 3% ‘other White European’ and 2% any other mixed background (ethnicities that made up less than 1% were not stated). The figures are similar for sperm donors: 71% White British, 12% ‘other White background’, and 2% for Indian, Black African and Chinese and white Irish, respectively (HFEA, 2019a) – again, only the most common ethnicities were stated. These figures can be compared with the latest data on ethnicity on those undergoing IVF – out of over 55,000 patients in 2018, 66% identified as White, while only 19% identified as either Asian, Black, Mixed or Other (HFEA, 2019c). While the relevant data set shows an increase in the number of patients from Asian, Black and Mixed ethnicities since 2013, 2018 saw a slight fall in the number of patients from Black and Mixed backgrounds. The data evidence a comparatively low uptake of IVF from people from ethnic minorities in the UK compared with patients identifying as White, and that also gametes from ethnic

minorities are scarce, suggesting that demand outstrips supply. Indeed, anecdotal evidence from clinics points to a shortage of ethnic donors (see Packham, 2018).

This apparent shortage of gamete donors from ethnic minority populations and the disproportionately low number of people from ethnic minorities may reflect some of the CRT concerns about access to IVF technologies by ethnic minority populations, discussed in Chapter One (for example, Roberts, 1996; Daniels and Golden, 2004). It may also reflect the view that the use of gamete donation is associated with stigma in certain communities (Agarwal, 2019; Daniels and Taylor, 1993). Commenting on data showing ethnicity disparity in the use of IVF in the UK, Sally Cheshire, Chair of the HFEA, said: ‘We know that some patients from an ethnic minority background face unique cultural and sometimes religious challenges when they struggle to conceive’ (HFEA, 2019c). Hudson argues that race is reconstructed through these debates, where ‘particular minoritised groups are represented as unwilling donors’ (2015:3). She continues to say that ‘shortages of particular types of gametes are mapped onto the willingness or otherwise of particular social groups to donate their gametes for the use of infertile couples and subsequently reinforce ideas about the biological heritability of a homogenous racial identity’ (2015:3; see also Deomampo, 2019:625). How race may be reconstructed in donor matching in light of such attitudes and the disproportionately low number patients and donors from ethnic minorities, along with gamete availability, is explored further in this thesis.

iv) Donor selection and matching

The existing literature contains only limited discussion of precisely how donors are selected by patients or matched by clinics and this was thus one of the central

areas for investigation of this thesis. While these processes are specific to each clinic, below I outline some general observations from the literature available.

The existing literature often does not make clear which clinic staff are involved in the donor-selection process (a question which is discussed in Chapter Four) but some clinics do apparently employ donor coordinators who work with patients in selecting donors, and counsellors may also discuss the matter with patients. A patient requiring the use of donated gametes may choose to use a known donor (either through the clinic or as an informal donation, falling outside the remit of the HFE Acts), or may choose a donor who donates anonymous (to the patient) at a licensed fertility clinic. A patient will often be asked to choose from a range of sperm or egg donors, from which they can choose. As discussed in section three of this chapter, patients using gamete donors will also usually be provided with counselling. Once a donor is chosen, the gametes may then be ‘reserved’ for the patients (to also monitor the number of offspring resulting from the donation), who have the option of securing that donor for their future use, so that future children conceived in this way could be genetic siblings (HFEA, n.d).²⁰

Due to the lower number of egg donors (which may in part be explained by the more invasive procedures required for egg extraction), patients may not be given such a wide choice of donors. Sperm donations are, however, comparatively numerous and patients will have more of a selection. As outlined above, the ‘shortage’ of egg donors may become particularly problematic for patients seeking egg donors with particular characteristics, such as a certain ethnicity, and

²⁰ Indeed, there are reports in the US and in the UK that some donor conceived people are actively seeking out their genetic siblings conceived from the same gamete donor (see, for example, the Donor Sibling Registry (n.d.). Some parents of donor conceived children have also sought contact with the donor and other offspring (Freeman et al, 2009).

the impact of this on donor-matching practices is something that will be explored in Chapter Five.

a) HFEA guidance

As outlined above, the HFEA's Code of Practice helps clinics understand how to meet statutory requirements and it has previously provided guidance on matching donors to intending parents, although there have been variations to this provision across its successive iterations. The first four editions provided as follows:

3.20 When selecting donated gametes for treatment, centres should take into account each prospective parent's preferences in relation to the general physical characteristics of the donor which can be matched in accordance with good clinical practice. Clients should be advised that the result of any attempt at matching physical characteristics cannot be guaranteed. (HFEA, 1991:3.vi, Code of Practice, first edition)

This language was amended in the fifth edition of the Code of Practice, which stated:

3.18: When selecting donated gametes for treatment, *centres should take into account each prospective parent's preferences* in relation to the general physical characteristics of the person providing gametes for donation. *This does not allow the prospective parents to choose, for social reasons alone, a donor of different ethnic origins(s) from themselves.*

People seeking treatment with donated gametes should be advised that the result of any attempt at matching physical characteristics cannot be

guaranteed. (HFEA, 2001:17, Code of Practice, fifth edition; my emphasis)

Changes to paragraph 3.18 were made in the HFEA's sixth Code of Practice. In the period in between the fifth and sixth codes of practices, the HFEA was embroiled in a row over 'designer babies' after it had been criticised for allowing the Hashmi family in 2001 to try to select an embryo that would be a genetic match for their son, Zain, who suffered from beta thalassaemia (see Allison, 2002). The decision led to a judicial review, which was ultimately unsuccessful in the House of Lords,²¹ with the HFEA changing its policy subsequent legislation was passed to permit the technique.²² Prior to this, however, the HFEA had rejected a similar application in 2002 from the parents of Charlie Whitaker, who was suffering from a rare blood disorder, to use tissue-typing technique, amid accusations it was permitting the creation of 'designer babies' (see Allison, 2002). The provision in the fifth Code of Practice that patient's 'preferences' should be taken into account may therefore have been viewed by the HFEA to be in tension with ethical concerns around parents choosing embryos on the basis of genetics. In the sixth Code of Practice, reference to taking into account patient preferences was removed and the negative wording advising against allowing patients to choose a donor from a different ethical origin for 'social reasons alone' was bolstered to a positive guideline that clinics should seek to match the donor to the patient. The section now read:

²¹ *Quintavalle (on behalf of Comment on Reproductive Ethics) v. Human Fertilisation and Embryology Authority* [2005] UKHL 28

²² The Human Fertilisation and Embryology Act 2008, schedule 2 para 1za

3.18 Where treatment is provided for a man and woman together, *treatment centres are expected to strive as far as possible to match the physical characteristics and ethnic background of the donor to those of the infertile partner, or in the case of embryo donation, to both partners, unless there are good reasons for departing from this procedure.*

3.19 When discussing the selection of potential donors, treatment centres are expected to be sensitive to the wishes of those seeking treatment for information, whilst avoiding the possibility that this information could be used to select a donor possessing certain characteristics for reasons that are incompatible with or not relevant to the welfare of the child. For example, *those seeking treatment are expected not to be treated with gametes provided by a donor of different physical characteristics unless there are compelling reasons for doing so.* Those seeking treatment with donated gametes (or embryos) are expected to be advised that no guarantees can be given where an attempt is made to match physical characteristics. (HFEA, 2003:13, Code of Practice, sixth edition; my emphasis)

Patients were also told in the HFEA's Guide to Infertility: 'Your clinic can provide details about the physical characteristics of donors available. They will attempt to match donor and patient characteristics. But just as with naturally conceived children, there is no guarantee that your baby will closely resemble the donor' (2007:29). Previous guidance from the RCOG to some extent replicated the matching clause in the HFEA's Code of Practice (HFEA, 2003). The RCOG has previously advised clinics to match sperm donor and husband on the criteria of eye colour, hair colour and blood type (height and body build are in practice

taken into account) – an observation that Price argues was part of the culture of concealment (Price, 1997:222, citing RCOG ethics guidance in 1983). The same guidance advocated donor anonymity (Price, 1997:221). However, it has not been possible to find reference to matching in current RCOG guidance. Indeed, NICE makes no reference to matching in its fertility guideline CG156 (2013). Other professional bodies are more ambivalent about the practice, with BICA saying that those involved in donation should be given additional information on the matching of donors, among other things (BICA, 2012; 2019), without specifying what such advice entails.

Notably, the ‘matching clauses’ in the Codes of Practice have now been removed following the sperm, egg embryo donation (SEED) report (SEED Report 2005), based on a consultation by the HFEA with fertility clinics on the policy and regulation of gamete donation following the removal of donor anonymity (BioNews, 2005). The SEED report detailed responses from the clinics that said the matching of donors and recipients was impractical and had a negative impact on donor treatment, and there was little evidence that donor matching was of relevance to the resulting welfare of the child (2005:8, para 2.1). In particular, the SEED report highlighted that the evidence and submissions received made clear that: Any general requirement to match donors and recipients closely would drastically reduce the availability of treatment; no reliable evidence existed about the value of donor-recipient matching in relation to the welfare of the donor-conceived child; and concerns remained about using gametes of a donor from a different ethnic group to the recipient (2005:8, para 2.2).

The authors reasoned that little evidence supports the value or effectiveness of donor–recipient matching and that, in any case, a donor’s appearance will give little information about what characteristics an offspring might inherit (2005:9, para 2.5). The SEED Report concluded that the ‘most appropriate approach is to offer those seeking treatment advice or counselling’ and to discuss the implications of using third party gametes, highlighting the value of openness and also providing accurate information about the genetic inheritance of physical and other characteristics (2005:9, para 2.6). The Report also referenced the value of ‘openness’ about donor conception, an argument that contributed to the removal of donor anonymity (discussed above in section 2.ii.c). It is therefore likely that matching clauses were considered to be in tension with trends towards promoting greater openness. The Report concluded that there should be ‘no prescriptive guidance from the HFEA on the selection of donors for treatment of a particular recipient’ but that the HFEA should produce guidance on issues to be taken into account (2005:9, para 2.6). Indeed, in the eighth (HFEA, 2009) and also the latest version of the Code of Practice (ninth edition, HFEA, 2019b), it states:²³

11.16 Centres are *not expected to match the ethnic background of the recipient to that of the donor*. Where a prospective recipient is happy to accept a donor from a different ethnic background, the centre can offer treatment, subject to the normal welfare of the child assessment. (HFEA, 2019b:118; my emphasis)

It therefore appears that the HFEA’s position of ethnic matching has gone full circle from no specific reference in the first edition of the Code of Practice, to

²³ It was not possible to locate the seventh Code of Practice online as it has now been archived.

guidance avoiding non-matching requests, to recommendations that clinics positively match patients and donors, to removing the provisions altogether. The reasons for this, as documented in the SEED Report, are varied but involve practical considerations regarding the availability of gametes and the limited evidence of donor-recipient matching impacting on the welfare of the child. Regarding gamete availability, the SEED Report was published at a time of expressed concerns about the impact the removal of donor anonymity would have on the numbers of people willing to donate gametes (see discussion above). Data from the HFEA has showed an initial drop in the number of donors, but this figure has increased since. However, anecdotal concerns regarding the availability of gametes (see, for example, Mundy, 2010), particularly those from ethnic minority communities, arguably have remained.

Wade observes that the official policy of racial matching in UK fertility clinics was once part of an inclusive anti-racist strategy ‘enumerating race for inclusion’, which, following adoption policy, took the view that placing a child in a racially matched household would be in their best interests when faced with the threat of racism in wider society and considering also the formation of identity (Wade, 2015:122; see also, Sheldon, 2011). Studies examining transracial adoption placements have identified additional challenges that non-matching presents around identity, cultural heritage and dealing with racism (Barn and Kirton, 2012:28). The core tenet of racial or ethnic matching policies in adoption, explain Barn and Kirton, is that ‘ethnicity ‘matters’ and should be reflected in matching preferences’ (2012:28). They explain that it is difficult to argue that ethnic matching is ‘racist’, in terms of having a detrimental impact on children, given the studies that show that ethnicity matters (2012:30) – although when rigidly applied

they could result in children not being placed for adoption. Barn and Kirton claim that in order to address inequalities it is ‘necessary to identify, measure and understand them’ and that, on balance, ethnic matching does more to combat racism than it does to embed it (2012:32).

Notwithstanding the difficulties of applying conclusions from adoption literature to assisted conception, outlined above (section 2.ii.c; see also Frith, 2001; Blyth et al, 2004), this sort of race-conscious approach has arguably given way to colour-blindedness. Wade observes that the HFEA’s abandoning of a racial matching policy was probably influenced a desire to avoid being seen to promote policies that might be viewed as eugenic (2012:86), in addition to the controversial character of racial matching in adoption policy and the view that the HFEA should not be regulating such matters (2015:123). For Wade, the abandoning of the matching policy in the HFEA Codes of Practice represented a move towards colour-blindedness (2015:122). However, as the debates around the removal of donor anonymity show, such race-based policies are likely to have operated alongside policies of openness and also the practical context of a limited supply of gamete donors to contribute to a move away from official matching policies recommended by the HFEA.

b) Fertility clinics and common practice

Some clinics have adopted their own practices on matching that may have continued since the HFEA guidance changed. It is established clinical practice in heterosexual couple conception to match physical characteristics of the donor with those of the non-parent (Nordqvist 2012:649; 2010:1129). The practice of matching has also been observed in same-sex couples seeking fertility treatment.

According to the respondents in one study, clinic staff commonly advised same-sex patients to use donors with ‘matching’ physical characteristics – although patients who arranged donor conception themselves were also observed to find a donor that ‘matched’ (Nordqvist, 2010:1133). Other studies that have largely examined the patient’s perspective and decision making have shown the importance that the donor matches the non-biological partner (Frith et al, 2012:716).

An online search of various clinics’ websites show that many do indeed seek to match physical characteristics.²⁴ For example, one clinic advises would-be patients: ‘We try to match donor and recipient physical characteristics as closely as possible; however, we advise that the results of this cannot be guaranteed’ (Anon,a, nd.). Another, meanwhile, states: ‘Egg recipients are matched with a donor who has similar characteristics to them, e.g. hair colour, eye colour and build’; and for sperm donation it says that: ‘A donor can be chosen whose physical characteristics match those of the parent’ (Anon, b, 2018). Other clinics are more ambiguous about the features that they match. A further clinic, for example, says: ‘Our Donation Team will provide you with a choice of sperm donors that match your preferences’ (Anon, c, n.d). While some other clinics make no reference to matching, they instead emphasise the range of options available: ‘[The clinic] understands the importance of choosing a donor who is right for each individual patient. That’s why specialist donor recruiters aim to provide a wide range of donors from a variety of different backgrounds’ (Anon, d, n.d.c).

²⁴ The search was conducted using key words such as ‘donor matching’ and ‘race’ or ‘ethnicity’. A sample of findings is presented here insofar as it is necessary to demonstrate more broadly that such policies do exist in clinical practice.

Several fertility clinic websites show a wide variation in stated practice regarding donor matching. Although donor matching is no longer encouraged in the HFEA Code of Practice (ninth edition), it nevertheless appears to remain an advertised policy at least in some clinics. Donor matching clearly takes place in fertility clinics, but the details of practices regarding the matching for race and ethnicity between patient and donor are a little more elusive. Donors provide more information than just their race and ethnicity, including a ‘pen portrait’ and the matching process is likely to be done on a wider basis than race or ethnicity alone. Race as a signifier for physical resemblance, though, can be implicated within general physical matching. On the other hand, for some patients, race may present unique considerations.

5. Conclusion

This chapter has set out the regulatory framework within which fertility treatment is provided in the UK, highlighting certain themes that are particularly pertinent to donor conception and the role that race and ethnicity play in donor selection. It has outlined the treatment pathways for fertility services and donor conception, including how and where donors are sourced. It also identified what is known about donor selection and matching in the context of licensed treatments, demonstrating that there is evidence in policy and practice that matching occurs. Finally, it outlined what is known about the donor information that may be important to patients. This discussion sets the scene for the empirical data collection in this study. It demonstrates that there are important questions to be asked about donor matching – the extent to which this occurs in contemporary clinical practice; how practice varies across the sector; how matching is discussed;

and who are the key actors in this process. Equally, it shows that comparatively little is known about donor selection processes in UK fertility clinics. Moreover, where donor matching practices are identified, these in turn raise important questions about the motivations that underpin them. The next chapter outlines the methodology for the exploration of these questions in this study.

Chapter Three: Methodology

1. Introduction

This thesis aims to investigate a previously underexplored issue in UK fertility practice: what, if any, is the role of race in the selection of donor gametes and how do fertility clinics manage the process of selection? Drawing from newly gathered empirical data, this study produces original findings regarding both the staff–patient discussion process that takes place during donor selection and identifies the policies and procedures that may be applied in clinics. This study examines the perspectives, interpretations and understandings of fertility professionals pertaining to this question. The study also presents an opportunity to document how donors are selected by patients (i.e. what is discussed and with whom). It thereby helps to address the paucity of information about donor selection processes in UK fertility clinics. By drawing on in-depth, semi-structured interviews with a range of fertility professionals who have experience of the gamete donor matching process, the thesis provides an original account of the donor matching process itself, as well as advancing an evaluation of whether, and to what extent, race ‘matters’ in the fertility context.

This chapter outlines the methodological framework for the empirical data collection and reflects on the methods of the thesis generally. It discusses both the approach to and the rationale for a systematic literature review and justifies a socio-legal approach for this research project. Further, it explains the necessity for generating original empirical data, the justification of the decision to conduct interviews with clinic staff, and also clarifies the use of the ‘semi-structured interview’ for doing so. The latter method includes identifying the functions of

adopting a qualitative design, explaining how semi-structured interviewing best supports the research and how subjects were chosen and contacted; it also acknowledges the potential limitations of this approach, the ethical issues encountered in the planning of the study and how these were both addressed. The chapter discusses how the questions were compiled and the interviews conducted, detailing some practical hurdles that were encountered. It then discusses the initial analysis of the interview data.

2. Socio-legal methodology

Given the complexity of the thesis topic and exploratory nature of the research, I approached the thesis questions from legal, sociological and anthropological perspectives, combining empirical data collection with socio-legal analysis.

Although the primary subject area of this thesis is law and it seeks to produce recommendations for law and policy around donor conception, a purely doctrinal approach to the topic was not favoured. Legal studies can be described as lending themselves towards more rigid, formal study of legal norms (Banakar, 2005:7), suitable for existing doctrines or legal frameworks. Due to the absence of specific legal rules and policies on donor selection and matching, an assessment of donor-matching practices from a legal perspective alone would be somewhat limited.

The question for this thesis was therefore not to analyse any specific rule or legal principle in itself, but to identify and examine the social discourse, norms of behaviour and attitudes that may be found in fertility clinics. Observations and conclusions on this target of analysis can best inform how and why the law and policy should respond, if at all, to a specific area of fertility practice that is characterised by novel social phenomena.

The particular methodological approach adopted in this research can be described as sociological and empirical. Such an approach is justified by two important methodological considerations. First, it is warranted by the need to conduct empirical research to support and illustrate analysis of the research question. Empirical research entails gaining knowledge through observations rather than by theorising. The data gathered then in turn be analysed qualitatively or quantitatively – with the qualitative approach described below. The collection of empirical data was considered appropriate since this thesis explores processes and practices that have not been previously examined. Following an empirical approach, therefore, before existing law and policy are addressed, the priority was to identify and isolate the subject matter and ask what happened during donor selection – what was said, to whom, and how clinics managed this process and responded to requests. Such questions could most comprehensively be addressed by speaking to those involved through the use of semi-structured interviews (the qualitative approach is discussed in the section below). An empirical examination of this social phenomenon is therefore a necessary prerequisite to any subsequent formulation of law and policy. It also allows for an examination of the ways in which the limited law and guidance that exists around donor matching can permeate norms of professional practice.

Second, to the extent that a sociological approach allowed for a highly analytical and careful documentation of the subject matter, the data collection and analysis was firmly grounded in the methods of sociological enquiry. Sociology can be broadly characterised as concerned with obtaining ‘knowledge’ about the world, ‘looking beyond what is given’ and seeking to capture the complexity and diversity of social life (Banakar, 2005:10-11). A sociological approach

encompasses both a positivist and constructivist focus, whereby the positivist observations that seek to describe social reality can be complemented with a constructivist focus on how human interaction and relationships create social reality (Marvasti, 2011:2-5). Both approaches have a common focus on empirical observation in the production of knowledge (Marvasti, 2011:7). The disciplinary perspectives of sociology were particularly helpful in unpacking some of the concepts referred to in the interviews including ‘race’, ‘ethnicity’ and ‘donor matching’ or ‘donor selection’. As an analytical framework, therefore, sociology provides insights into and documents the complexity of the social phenomenon under examination, resisting any narrowing down or conceptual limiting of the issues before the empirical data is interpreted. It attempts to ‘explain and understand social reality’ (Banakar, 2005:11) – in this case, the actual discussions and interactions between clinic and patient – in a more open manner than a purely legal focus on normative rules and institutions. This approach helped to explain the complex narratives offered on race in the interviews and provided a useful interpretive framework that invited an empirical investigation of the research questions (Cotterrell, 1998:183).

The contribution of sociology to legal studies has been documented in a rich and diverse body of literature linked together by a methodological approach termed ‘socio-legal studies’ or sociology of law, whereby legal phenomena are studied through a sociological lens. Law is a particularly apt subject for sociological examination as, notwithstanding positivist proponents of legal theory, law (including policy and other forms of regulation) can be seen both as the product of social, political and economic processes and also as an influencer on these processes themselves. A socio-legal approach therefore exposes these historical

and social processes that shape law and policy (Cotterrell, 1998: 173), documenting and describing according to the sociological approach. Socio-legal examination has the potential to identify the relationship between the social and law. In the donor selection context, this enables an identification of the attitudes, assumptions and social norms that lie behind the application of the HFE 1990 and HFEA guidance in relation to donor selection, as well as clinic practices and policies on donor selection and donor matching. Such an analysis will support an examination of how fertility professionals understand their statutory obligations under the HFE Act 1990 and regulatory guidance from the HFEA.

A sociological approach also entails the recognition that law and policy in the fertility context is also an aspect of society (see Cotterrell, 1998:182), as much as the people and institutions to deliver it. Law is itself a social phenomenon that regulates and organises individual and communal relationships (Cotterrell, 1998:185). Such a perspective allows for an examination of how law and policy can shape and embody social discourse and attitudes, in this case the views of fertility professionals and clinics' approaches to donor selection.

An empirical approach supports both the etiological and consequential focuses of sociology. It becomes necessary to examine the way legal doctrines are shaped and applied from an empirical perspective that documents how law and policy is understood, expressed and experienced (Cotterrell, 1998:186). Specifically, empirical legal research can explain the practices and procedures of legal systems and the impact of these systems on social institutions, businesses and individuals (Genn, Partington, Wheeler, 2006:1). Applied to fertility clinics, the empirical questions outlined above (what was said, to whom, and how clinics managed this

process and responded to requests) will ground both an assessment of the origins and consequential influence of the operation of law and policy on social and clinical discourse in this area.

A further advantage of the sociological approach is that it is able to generate results that are complimentary to the important normative questions that this thesis also seeks to engage in. As described in Chapter One, race is a contested concept. Uses of race in institutional settings such as fertility clinics raise important questions about the extent to which the policies and practices that will be examined and identified play a role in perpetuating assumptions about race that reproduce traditional models of kinship. Understanding law as a social and political phenomenon can therefore help us to understand society better (Genn, Partington, Wheeler, 2006:1) and by evaluating empirical observations about how race is understood and influenced by fertility professionals operating within an environment of law and policy, a more persuasive account can be produced of donor selection practices in UK fertility clinics.

I also drew on anthropological literature that has traced and described the social effects of assisted conception on kinship arrangements, most notably in recent decades (Strathern, 1992; Franklin, 2013). As discussed in Chapter One, it was decided necessary to review anthropological literature on donor conception after reading a number of core theories involving sociological examination of donor conception (for example, Nordqvist and Smart, 2014). These in turn pointed towards the underpinning anthropological framework set out by Strathern (1992). Combining sociology with anthropology was necessary to properly investigate the role of race in donor conception, since race does not simply present as a social

phenomenon to document, but also implicates complex social interactions and kin relations between patients, their family and broader society. Anthropology – the study of human culture and their development – captures the formation of kinship within communities and the ongoing role of race in this process, whereas sociology – the study of human society – describes the connections between patients and others, and the relevance of race to these constructions. It was necessary to understand how these kin relations could be described and formed to identify such manifestations in the interview data.

The NKS literature neatly complements the approach provided by CRT to form an overall analytical framework (see Chapter One, section 4). Broadly speaking, CRT enables the questioning of assumptions and existing practices (Bronner, 2011:2). Whereas both critical theory and more specific CRT both involve elements of activism – changing how things should be (Bronner, 2011:2) – as a methodology it provides insights that may not necessarily be arrived at through sociological or anthropological analysis. For example, while a sociological approach can be silent on the normative discussion of the role of race in fertility clinics, CRT presents thought-provoking questions about appropriate discussion points during donor selection. On the other hand, CRT – which is embedded in the US context and has a specific set of normative commitments – does not necessarily capture the full range of meanings that fertility professionals attached to constructs of race, as explained below. This study therefore considered the wider implications and underpinning assumptions of the descriptive observations made in the interviews through sociological and anthropological examination, to present sensitive and socially informed conclusions for law and policy.

Overall, the issues raised by donor conception are implicated in broader social, ethical and political issues that affect the individual, the family and the state, while discussions of race invoke highly contested concepts of biological inheritance, identity and underpinning political tensions. As such, the research topic itself is inherently complex and an empirically-grounded, socio-legal study was the preferred approach to produce significant observations that can and should inform law and policy in donor conception. As a field, assisted reproduction is heavily associated with the ways that changing social norms and attitudes around reproduction interact with technological and medical developments to present novel regulatory challenges for law and policy. Legal norms must be informed by an appreciation of the social (and political) processes that operate through the way people use (and how clinics offer) reproductive technologies. For example, the professional third-party intervention in the reproductive capabilities of same-sex or single parents raises many questions about how social attitudes towards such groups of people has influenced the rules that determine access and the normative debates around whether such access should be facilitated. It therefore makes sense to support the analysis of the empirical data findings in this thesis with literature from disciplines outside of law, as embodied in the literature review. As such, the scope and nature of enquiry necessitated the adoption of sociological and anthropological techniques and concepts in an attempt to capture and describe the process of donor selection and any involvement of race.

3. A qualitative approach and the use of semi-structured interviews

The desk-based literature review identified a range of interesting questions for further study and revealed significant gaps in current knowledge regarding how donor matching is practised in clinics and the extent to which ideas of race are deployed in this practice. To attempt to answer these questions and address this gap, semi-structured interviews were used to collect the empirical data and a qualitative approach was chosen as the method for analysis. As a methodology, qualitative analysis can be defined as a set of interpretive practices that seek to make sense of or interpret phenomena and the meanings that people may bring to them (Davies and Hughes, 2014:9). The qualitative approach entails a belief that a researcher can generate meaningful data by talking to people and analysing their responses (Mason, 2002:64). Interviews with fertility professionals allowed me not only to find out what happens during donor-matching procedures – the descriptive contribution, part of what Marshall and Rossman term documenting ‘issues of interest’ (2010:41) – but provided empirical data that was intrinsically valuable in providing evidence of how constructs of race are deployed and rendered meaningful within this process. Through the way that race was discussed, experienced, interpreted and understood by fertility professionals, I was able to identify certain themes and assumptions around the importance of these constructs (Bernard and Ryan, 2009:8), as well as seeing first-hand how such definitions were incorporated or translated into the donor conception context. As a method of data collection, in-depth interviewing therefore allowed for both an exploratory and explanatory approach (Marshall and Rossman, 2010:41), investigating the under-researched issues around race, and providing an explanation of the factors that may be causally implicated in their construction.

The 'semi-structured' approach to interviewing enabled a carefully designed schedule to direct the discussion to the research questions in a flexible and dynamic manner (Taylor et al, 2016:102), discussed further below.

The decision to take a qualitative approach was also justified by the complexity of the research topic. As social, political and personal constructions, notions of race are inherently unstable and open to a range of interpretations. It was therefore imperative to listen to what fertility professionals had to say about race in donor matching to explore the complexity of meanings associated with these constructs. A decision was therefore made to use semi-structured interviews over questionnaires, which would have generated a greater number of responses, precisely because of the difficulties in reducing an exploratory thesis into a series of discrete questions regarding the importance of race. The research questions did not lend themselves to 'yes or no' answers, and the use of open questions in questionnaires would not have produced the same quality of information as a face-to-face interview, nor would they allow me to guide or prompt the discussion. The qualitative interviewing method therefore captured the complexity of the data, offering in-depth and nuanced material to examine the construction of social explanations and arguments regarding, in this case, race (Mason, 2002:64; Taylor et al, 2016:102).

4. The pre-interview stage: Sampling

Fertility clinics employ a wide range of professional and support staff. A look at a typical UK fertility clinic's 'meet the team' webpage will list consultants (fertility and gynaecology), nurses, embryologists and support staff. Some clinics employ counsellors directly, while others will have arrangements with private fertility

counsellors or other clinics. Some clinics also have staff dedicated to running and coordinating donation programmes. Other professional roles in fertility clinics include sonographers, urological surgeons, and clinical geneticists; some clinics also provide specialists in alternative treatments. A clinic's staff profile is largely determined by its size and type of treatments offered but it is clear a wide range of clinical and support staff are typically employed.

In this study, four main staff positions were interviewed: clinicians, embryologists, nurses and counsellors. Although the study did not seek to make findings representative of the full range of staff profiles across clinics in the UK, the categories of staff interviewed, as well as the fact that small-to-large clinics were interviewed, gave a clear indication of whom within the clinic donor selection was discussed. Due to the limited size of the study an ethnic representation across the interviewees was not sought, nor were interviewees asked to identify as any given race or ethnicity (although this would have been considered in a larger study format).

i) The rationale for interviewing fertility professionals

The first crucial decision that was made as part of the research design was to interview fertility professionals rather than patients. The decision was made to interview fertility professionals with views on and experience in donor matching, past or present, because they are in the best position to explain the donor matching process and comment on standard practices employed by clinics. The interviewees were able to discuss how and if donors were matched to patients, when, why, and (to some extent) what was discussed. They also reported whether their clinic – or previous clinics they had worked in – had, or did have in the past, a policy or

protocol on donor matching. The perspective of fertility professionals was therefore vital to gaining insight into these processes and practices. Only staff directly or indirectly involved could explain how the process worked in their clinic or previous clinics they had worked in.

Furthermore, fertility staff were well-placed to provide evidence that could support an analysis of the role of race. Interviews with fertility professionals offered significant insight into donor selection practices deemed ‘normal’ or ‘routine’ and also those cases where donor matching went ‘wrong’ or where the patients raised ‘unusual requests’. These instances shed light on the possible assumptions regarding race or reveal previously underexplored aspects concerning family building as expressed through kinship studies. The accounts of fertility professionals will allow for an examination of how race and racial matching may be operationalised in donor selection (Hudson, 2015), while also providing insight into how clinics are involved in kinship processes that may underpin donor selection.

A focus on fertility professionals therefore represented concentrated access to specialist knowledge: interviewing a relatively small number of people (important due to the time and resource constraints of the PhD) gave access to a large body of experience regarding the donor matching process. Interviewing patients to obtain this sort of information would have also presented more onerous NHS REC approval. The recruitment process would have been excessively time-consuming and expensive within the constraints of the project.

The focus on fertility professionals and the use of second-hand information about how patients select gamete donors is a potential limitation to this study. The data produced will not provide unmediated access to the views of patients and so therefore their accounts can only be partially informative about what patients think. In any event, the reports of fertility professionals may not necessarily be a reliable reflection of what patients think and feel. However, for the reasons outlined above, the views of fertility professionals are important phenomena in themselves and provide original and valuable data regarding a wide range of patients and practices.

ii) Identifying clinics and respondents

During the data collection stage, I interviewed 21 fertility professionals including counsellors, doctors, embryologists and nurses across 12 clinics, amounting to 20 interviews in total (one respondent was interviewed twice and on another occasion three respondents were interviewed in one interview). All the respondents worked in fertility clinics that offered treatments both on a private and NHS basis. The interviews were conducted both in person and over the telephone. All interviewees bar one was interviewed once. The interviews were recorded and later transcribed.

Table one

Interviews:	20	Clinics	12	Participants:	21
		interviewed:			
Total time (hrs):	15.6	In person:	15	Telephone:	7
Location of clinics:					
<i>London</i>	<i>South East</i>	<i>South West</i>	<i>Midlands</i>	<i>North East</i>	<i>North West</i>
8	1	1	1	0	1
Clinic size (cycles):					
<i>Large (>1000)</i>	<i>Medium</i>	<i>Small (<450)</i>	<i>No data</i>		
	<i>(450<1000)</i>				
7	3	1	1		
Staff position:					
<i>Counsellor</i>	<i>Clinician</i>	<i>Embryologist</i>	<i>Nurse</i>		
5	6	6	5		

The first task was to put together a list of fertility clinics to approach. I created a spreadsheet of fertility clinics which offered donor conception, using information from the HFEA's 'Fertility Clinic Search' webpage that lists all the UK fertility clinics in a format searchable by location, treatments offered and whether it saw patients who were privately funded or NHS funded, or both (HFEA, n.d.i). I searched by region for clinics that offered IVF or ICSI with donor eggs, sperm and embryos, compiling a list of these clinics, their location and contact details. The HFEA's website (HFEA, n.d.i) provided details about the licence holder and person responsible (the person who ensures compliance with the HFE Act and Code of Practice), as well as other information likely to be of relevance and interest to patients, such as waiting times for donation. The clinic's profile also included their main contact telephone number, email address and link to their

website. I entered this information into an Excel spreadsheet, which I could then easily navigate to track the interview contact process.

Several factors contributed to the initial clinic selection: the location of clinics; the size of clinics; the range of services offered; private and NHS provision; the relative ease of gaining access. I sought to generate data from a range of practices on the hypothesis that practices might vary according to these factors. All the clinics I interviewed were based in England, with eight clinics in London and one clinic from each region in the South East, South West, Midlands and the North West (I did not interview any clinics in the North East of England, nor did I consider any clinics in Scotland, Wales or Northern Ireland). I decided to focus on clinics situated in London and the surrounding area because the majority of fertility clinics are based in this region: around one-third of UK clinics offering treatment with donated gametes are in London or the South East (HFEA, 2013:11). Since I was based in London, interviewing clinics that were accessible was also more realistic given the time and financial constraints of the study.

While the high concentration of fertility clinics in the South of England meant that this approach did not appear to restrict my selection in any significant way, I carefully considered the methodological implications of the geographical location of the clinics. For example, clinics across the country treat different proportions of ethnic groups, with some more ethnically diverse than others. This could have affected the empirical study insofar as donor selection might operate differently in different communities, reflecting different social norms and beliefs. It could also affect the ability of clinics to match patients to donors given that there remains a lack of available donors from ethnic minority populations, discussed above. To this extent, I did attempt to make contact with clinics located in areas shown to be

ethnically diverse, particularly urban areas. I used data provided by the Office for National Statistics that identifies London as the most ethnically diverse area across England and Wales and the ‘lowest proportion of the White ethnic group at 59.8 percent in 2011’ (ONS, 2012). Ultimately, however, this thesis does not seek to collect data regarding the ethnic representation of fertility patients across clinics but instead identifies evidence of how ethnicity might impact on the selection of donors.

I also sought to interview staff at large clinics who, through their experience with large numbers of patients and patients from a range of backgrounds, would contribute most usefully to the interview data. Using information provided by the HFEA in its clinic inspection reports and also its own description of the clinic, it was possible to estimate the size of each clinic by reference to the treatment cycles carried out. I attempted therefore to contact large clinics (as described by the HFEA or those that provided over 1,000 treatment cycles per year). The large clinics tended to also be located in London. Of the 12 clinics interviewed, I categorised seven as large (over 1,000 IVF cycles in a year), three as medium (between 450 and 1000 treatment cycles) and one as small (under 450 treatment cycles) [one clinic provided no data] – see table one above. Between them, they represent around 10,000 fertility cycles per year, and taking into account the many years they have been in operation, these 12 clinics thus present a cumulative wealth of expertise.

Large clinics were more likely to offer a full range of fertility services, most importantly donor conception services. Using the HFEA website, it was possible to ascertain what services each fertility clinic offered. Typically, the private

clinics in and around London tended to offer all types of treatment and so the prospect of a limited range or no donor provision was not a significant methodological issue. However, when I proceeded to interview staff at NHS-based fertility clinics, it was apparent that many hospital fertility services did not provide donor conception services. It was therefore important to identify which clinics under each Trust did provide donor conception services and I did this once I was in initial contact with the Trust before taking the research ethics application with them any further. At this stage of the research, it was not crucial to approach every NHS fertility clinic systematically, as I had already collected the data needed for analysis.

Since the NHS only funds a comparatively smaller proportion of fertility treatments using donated gametes than private clinics (HFEA, 2019e), I decided early on to focus initially on privately-run clinics in order to initiate the interview stage of the thesis. Given the range of treatments and size associated with privately run clinic, this seemed to be a practical starting point while waiting for NHS research ethics approval to be obtained.

I was conscious of the potential methodological limitations of having an over-representation of private clinics in the data, since it was possible that patients' profiles could be linked to socio-economic status, availability of donors/treatments, patient expectation and clinic staff attitudes towards patient/acceptability of treatment. In respect to patients' expectations and staff attitudes, self-funded patients may come to the clinic with different expectations and clinics may in turn be more amenable to their requests (in order to attract and keep their business). However, since most clinics that offered donor conception

are private, such a weighting could be methodologically justified. Any preliminary conclusions that pointed to the potential differences in approach between NHS and private clinics present themselves as an opportunity for further research for more wide-ranging studies, in which a fully representative sample of clinics are interviewed. Furthermore, due to the mixed nature of NHS/privately funded fertility treatment (almost all clinics engage in both), many of the interviewees at private-based clinics would be able to comment on the practice in the fertility sector as a whole. I decided to include NHS clinics during the empirical data collection to secure the fullest possible range of views within the confines of a project with a necessarily limited scale.

Despite the limitations of conducting a small, qualitative study, the interviews do point to a wide range of views within the fertility sector, while also highlighting questions for future research. In order to promote the quality and reliability of the empirical data, I responded to the above methodological limitations associated with identifying clinics at the outset wherever possible.

iii) [Narrowing down the sample and contacting potential participants](#)

The initial list of private clinics included over 25 clinics, with almost 20 clinics both private and NHS operating in London. Using the spreadsheet, I then devised an appropriate order in which to contact the clinics. I found it particularly helpful to speak to people who had previously conducted empirical research with fertility clinics to get a sense of who to approach and how best to do so. I spoke with Jan Macvarish at the University of Kent who, with Ellie Lee and my supervisor Sally Sheldon, had specific experience contacting UK fertility clinics as part of their study (Lee et al, 2014).

In total, I contacted 21 privately-run clinics from my initial selection with a further ten NHS-run clinics after obtaining NHS REC ethics approval. Of the first 21, I received 12 positive replies and conducted interviews at nine of the clinics. From the NHS clinics, I received two positive replies and interviewed both clinics. There was less success with securing a positive response from within the NHS, but since many of the interviewees I spoke to worked across both the NHS and private sectors, this reduced any limitation presented by an under representation of NHS clinics.

Contrary to my expectations, many busy fertility professionals were willing to give up their time to contribute to a student's doctoral research.²⁵ Responses were invariably friendly, positive and supportive. Yet fertility clinics are indeed notoriously busy, a fact which constituted the major obstacle to completing the interviews within the initial envisaged time span. I learned through experience to be more conservative in planning the interview stage; I revised the completion date for the interviews several times throughout the course of the research.

Email enquiries proved the most effective means of soliciting interviewees. In the absence of a contact name, I would email or call a clinic's main enquiry line.

Direct approaches to individuals were often more successful than general enquiries: some clinics did not respond or rejected my request when contacted through the generic enquiry line or email address. (One notable exception invited me to conduct interviews with a range of staff.) Of the 12 positive replies to my first round of queries, 11 derived from direct contact with a named person

²⁵ Lee et al (2015) also speak about the challenges in conducting empirical research at UK fertility clinics in a large study.

directly. Of the two NHS clinics that responded positively, I contacted one directly and the other responded to my general enquiry.

Following each interview, I asked those interviewed to recommend someone else who might be interested to take part. This can be termed ‘snowball’ sampling (Bryman 2015:410). This method was by and large successful, but less so than the initial direct contact. I had to be prepared to follow up on requests, keeping track of people I was in contact with using a spreadsheet and setting reminders to follow up at appropriate intervals (without being too ‘pushy’) – up to around three or four attempts. Fortunately, I had a clear idea of the range of professionals that I wanted to interview from the outset and so worked actively to generate interviews with the professionals underrepresented in my sample after the initial series of interviews.

iv) Deciding how many people to interview

While the size of a sample in qualitative research should be determined at the end rather than the outset (Taylor et al, 2016:106), I started the research with a rough assumption that I would aim to carry out around 15 in depth interviews. This helped me to timetable the empirical data collection stage and to help determine how many clinics I would need to start approaching. However, authorities suggest there is no conclusive answer on ‘how many’ interviews a researcher should conduct, with much depending on the practicalities and nature of the project (Edwards and Holland, 2013:66-67) and I continued to interview until the data reached ‘saturation point’ – defined as the stage at which the data supports a ‘convincing analytical narrative’ based on ‘richness, complexity and detail’ (Baker and Edwards, 2012:5). Themes started to emerge concerning patient

autonomy and the welfare of the child shortly after the first eight or so interviews. I continued interviewing until it was clear that no new data was being produced, which occurred after around interview 16 or 17 (I stopped interviewing at interview 20).

The core sample had to be sufficient in size to include a range of participants that would allow me to explore different experiences and responses to the research question (Davies and Hughes, 2014). I interviewed five counsellors, six clinicians, six embryologists and five nurses (see table one above). The interviewees also often spoke about their previous positions so, for example, sometimes managers would talk about their previous clinical experience. The range of staff interviewed represented the core provision of fertility services and presented a roughly balanced weight.

Overall, this approach represents a mixture of ‘convenience sampling’ (taking what you can get from where you can most easily get it) and ‘purposive sampling’ (identifying individuals believed to be typical of the population being studied) (Davies and Hughes, 2014) in the recruitment of interview participants. I started with the most obvious places I could contact potential interviewees while also strategically selecting the study participants from a finite, defined population, who may most likely allow the research questions to be answered (Bryman, 2015:410). For example, I sought to interview counsellors who had probably discussed the selection of donors with patients and those fertility staff involved in the selection process, and also donor coordinators. It was a natural decision in carrying out the empirical stage of the thesis to seek to interview those with specific experiences of gamete donation. It was also important to interview a number of people from

the key job titles that I had identified to ensure that a meaningful range of views was obtained, and to also observe any commonalities in opinion, subject to the limitations about representation discussed above.

While there is no 'recipe' or rule of thumb which sets out how sampling should be done in every project (Mason, 2002; Bryman, 2015:408), I maintained in so far that it was practical a strategic approach so to avoid unintended bias and to obtain valid and relevant answers to the research question (Davies and Hughes, 2014).

The convenience approach I took to sampling was justified given the time and resource constraints of the project and was suitable to the goals of the research. As far as practicably possible, I sought to ensure that the sampling included members of all key fertility profession, a range of clinic sizes and both private and NHS clinics, to sufficiently ground the findings of the thesis and generate a range of views.

5. The pre-interview stage: Setting the questions and preparing for the interviews

i) Pre-interview information and consent-taking

Each interview participant was contacted directly prior to interview to confirm if they were happy to proceed. A time and location convenient to the participant was then arranged – which, if to be conducted in-person, was almost in all cases the fertility clinic – although in three cases I conducted the interviews in person off-site.

In compliance with the ethics approval for the study (see below) and to promote informed consent, each participant was provided with a sheet of basic information about the thesis and a copy of a consent form prior to the interview (see Appendices B and C). The information sheet informed the participants who I was and why I was interviewing them, the level and extent of participation required, and an outline of the thesis objectives and research questions. It also informed them about the possible dissemination of material and the research, along with data protection and confidentiality assurances (Edwards and Holland, 2013:67). The consent form informed participants of their right to withdraw from the study within three weeks of the interview (see Appendix C). Although I provided my contact details for possible questions, I was not contacted at any stage. For the NHS REC approval, the Health Research Authority (HRA) asked me to expand the information sheet to create a 'participant information sheet' in compliance with its approvals process (see Appendix C). This included statements that the transcription and audio files would be stored on a password-protected computer and that any personal details about patients would not be disclosed in the presentation of the thesis findings. It also clarified why I was interviewing them, a written request that the interviews be recorded, an indication of the length and what I would expect them to do – e.g. sign a consent form. I also gave participants to opportunity to conduct the interview over the telephone or Skype, if this was more convenient. At the interview, each participant was asked to sign the consent form or return a signed copy by email (see Appendix B). I filed a copy of each consent form that was signed. I used a different consent form in the interviews of NHS clinics, as required by the HRA (described below; see Appendix B).

ii) Designing the interview questions

The interview questions were designed so that interviewees were asked a similar set of questions but allowed for flexibility to respond to the direction in which the interviewees took the discussion (Bryman, 2015:466-468; Bernard and Ryan, 2009; Taylor et al, 2016:102). In fact, as Bryman points out, ‘rambling and going off at tangents’ can be encouraged as it gives insight into what the interviewee sees as relevant (2015:466). The interview questions themselves were therefore not so specific to close down alternative avenues of enquiry that may arise during the course of interviewing (Bryman, 2015:470), but a clear focus was taken from the outset to help ensure relevance of the lines of questioning.

To achieve this goal, I created an interview guide containing a series of broad questions that each participant was asked that generated responses to the research questions and instigated discussion more generally around the topics (see Appendix A). Questions were chosen to give the interviewee the freedom and scope to choose how to respond which both elicited descriptive content and also the personal views of the interviewee.

The questions were roughly divided into two parts, which I explained to the interviewees. First of all, the questions were designed to provide responses that outlined how patients choose donors and the processes involved in this. The second group of questions was designed to provoke more in-depth responses about the meanings of race and reasons that underpin donor matching. I tended to start by asking the more descriptive questions (although in some interviews the issues surrounding ‘race’ were addressed early on). Descriptive questions included such questions as ‘Can you explain your role in the clinic?’, ‘How do

patients select a sperm or egg donor?’, ‘Does the clinic have a [donor matching] policy?’. These questions seek to respond to the secondary research question in this thesis which is about how donor matching takes place in practice.

On questioning about the potential role of race, interviewees were asked initially open questions that generated a range of opinions. Doing so helped avoid the risk of interviewer bias and also predetermining responses. For example, in order to draw out the interviewees’ views on the role of race in donor matching, they were asked ‘what’ role does race play, ‘if any’. Their response would then usually go on to cover the interviewees’ own views on the use of race in donor matching and their opinions about the process – whether race should be available to patients and whether they thought it is meaningful to patients, or not, and why.

The interviewees were also asked ‘Have patients raised any unusual requests?’, which was designed in the first instance to obtain narrative accounts of donor matching but also was a prompt to further discuss why the interviewee or others felt that the situation was unusual (Taylor et al, 2016:120-121). Additionally, I asked interviewees a very open question about their opinion on the donor-matching process and if any aspects of it could be changed or improved. This broad, open-ended question was included to capture any previously unidentified themes that are pertinent to the research and was also a convenient way to draw the interview to a close.

Occasional silence was an interviewing challenge during data collection. In anticipation of this, the interview questions were divided into eight central questions, with a number of prompts under each question designed to steer the

discussion forward. I could then add to these or adjust them as the interviews progressed.

Interview questions were informed but not guided by the literature review so that the questions avoided presupposing responses, narrowing down the responses or setting out to prove specific hypotheses. This followed a qualitative design in leaving a theory open rather than using empirical data to support a theory already formulated (Corbetta, 2003:12). The interview questions were as such not too specific (Bryman, 2015), and I refrained from asking interviewees the research questions themselves (Davies and Hughes, 2014:170) or leading questions (Bryman, 2015).

Two pilot interviews were conducted initially to assess the interview questions and adjust if necessary. I conducted these at a large fertility clinic with two interviewees with whom I also discussed the scope of the research questions and confirmed the lines of enquiry as being of interest. The interviews produced interesting and pertinent information. They also helped me appreciate early on the value of story-telling and the recounting of patient decisions by interviewees for producing information relevant to the thesis question. I therefore included in my interview questions a prompt to encourage interviewees to give specific examples of where donor requests were considered ‘unusual’ and to ask how the clinic dealt with such requests. The pilots were recorded and feature in the subsequent analysis.

6. The interviewing stage

i) Conducting the interviews

I began each interview by introducing myself and explaining the research questions, as well as the reasons for conducting empirical research (Davies and Hughes, 2014; Edwards and Holland, 2008:71). I spoke briefly about my teaching and research interests, and how far I had progressed with the PhD study. Not only was this a good ice-breaker to the interview, but also helped promote the participant's informed consent to the project (as I explain later, this information was provided prior to the interview). In this initial introduction stage, I was able to initiate some rapport with the interviewee, which helped promote in-depth discussion of the interview questions by creating a more relaxed atmosphere.

When conducting the interview questioning itself, I broadly followed the interview question sheet (see Appendix A). The interview questions provided a certain order that I could follow so that the topics covered flowed and linked together. I ensured that each interview had a clear beginning, middle and an end (Davies and Hughes, 2014), and to this extent I prepared questions that would naturally break up the interview in such a way. For example, the first interview question would invariably be asking the interviewee to state their role and explain their daily activities and involvement in gamete donation, if any (Taylor et al, 2016:116). I found this approach to be a good transition into the substantive matters for discussion. Ending the interview was sometimes difficult and in the early stages of interviewing was sometimes too abrupt, so I then included a final question as standard, asking what the interviewee's personal opinion was on the gamete donor process and what could be improved. I found this more effective to wrap up the discussion than simply asking if there was anything else they wished

to add, which was generally met with a 'no', and it often ended up generating further discussion on the primary research questions.

The 'middle' of the interview, which contained the substantive questions, was divided roughly into two. Usually, I would start by asking more descriptive questions about the processes and practices involved in gamete donor selection, and then would proceed to ask more specifically about what patients look for, whether race was discussed and questions eliciting why the participant thought this was so or was important. I spoke about the practices and processes first, to get the interviewee used to discussing the subject matter, before asking the more difficult or complex questions about race and patient requests. However, I was also prepared to change the ordering during the interview if this facilitated the discussion in a way that responded better to the research questions (Bryman, 2015:470). At times, some interviewees were keen to discuss race very early on, and where this happened I facilitated the discussion, letting the interview run its natural course. I would mark certain questions to come back to. I was prepared to engage and contribute to the discussion in more ways than simple questioning (Davies and Hughes, 2014), such as acknowledging what people were saying with a nod or a smile – although it was important to maintain the balance between achieving impartiality as far as practicable and encouraging interviewees to respond and discuss issues in a natural way. Asking interviewees about unusual requests and what patients looked for in gamete donors also signified parts of the interview that drew out more in-depth discussion. Overall, this represented a thematic, topic-centred approach, while also allowing for a fluid and flexible structure (Mason, 2002:62; Taylor et al 2016:102).

The interviews lasted approximately one hour, although some ended earlier if the interviewee was particularly busy. The interviews ranged between 31 and 80 minutes in length (excluding one interview that was cut short), with an average length of around 48 minutes. Those over the telephone tended to be shorter (at an average 38 min in length) compared to in person (an average 51 min in length). I conducted 13 in person, and seven over the telephone.

It was preferable to see the interviewee in person as it helped facilitate the discussion, especially when asking about issues the interviewee had perhaps not recently thought about regarding race and donor conception. Interviewees also appeared to respond more positively in person, often showing a genuine interest in the research topic, whereas over the telephone or Skype, the interviewee's level of interest was more difficult to ascertain. The conversations online and over the telephone also felt more formal and they presented more of a challenge to record. The sound quality was better for in-person interviews than it was over the telephone (which needed to be done via the loudspeaker function) but it was sufficiently clear for transcription. As well as enabling word-for-word transcription of the interviews, the recording allowed me to listen and respond appropriately in the interviews themselves (Edwards and Holland, 2008:69).

ii) Reflexivity

Carrying out an empirical investigation entails a degree of reflexivity on the part of the researcher that requires consideration of their own role in documenting and interpreting the social phenomena under investigation (Dvora and Schwartz-Shea, 2016:1; Mason, 2002:64). The analysis of the thesis data itself is a reflexive activity, such that the data analysis should not be seen as the final stage of the

investigation but as part of the research design and data collection (Coffey and Atkinson, 1996:6). The interpretive analysis involved in understanding and representing the views of interviewees can be influenced by the researcher's own assumptions and values (Smith and McGannon, 2018:104). This required addressing some aspects of my own profession, gender, class, race and ethnicity and how this could potentially affect how I designed and carried out the research.

The term reflexivity refers to the concept of turning something back upon itself. In the context of social science, reflexivity has tended to refer to the practice of the individual researcher consciously seeking their own position in the social world. It requires the researcher to ascertain what they know and how they know it to avoid producing over-generalised knowledge (Wilkinson, 2016:395-6). Key considerations for me as the researcher were therefore how I viewed my own ethnicity and my attitudes towards this, if any. Speaking personally, I do not have a conscious projection of my own ethnicity beyond assuming that others may perceive me to be 'White European'. One striking observation that occurred to me whilst carrying out this research is that before engagement with critical race, I had rarely discussed race in reference to my own identity. My experience accords with the critical race observation that race is not often expressly discussed within 'White' community discourse (Tyler, 2009:41; see also Dyer, 1997). When interpreting the interview data, it was therefore important not to overlook what may initially have appeared to be ordinary and to ensure that searching questions were asked during the interviews. This avoided the potential consequence of missing the racialised significance of normalised practices. A reflexive consideration of the researcher's own race or ethnicity is an important part of the methodology since otherwise race, class and gender hierarchies in the UK may be

overlooked. I sought to guard against any potential assumptions that I could otherwise unconsciously introduce into the research through the application of a robust analytical framework and careful research design.

Beyond a consideration of my own race and ethnicity, reflexivity also involves engaging with ‘local interpretations and understandings’ of the social phenomena under consideration (Wilkinson, 2016:396). My academic and professional research interests lie in fertility law and I have attended many events and conferences where the views of patients, fertility professionals and others were expressed. Such experience could manifest in the thesis design and analysis through self-selecting questions or emphasising certain themes of analysis according to normative values that I personally and professionally advocate. In response to this methodological challenge, I followed a careful, guided approach to the data collection and analysis supported by authorities on methodology (such as that set out by Braun and Clarke, 2006; Bryman, 2015; Bernard and Ryan, 2009, among others). My professional involvement in the field may also have helped me to set up the interviews as sometimes respondents would appear willing to speak to me about the subject following their familiarity with organisations that I was associated with, such as my study and teaching institutions. An explanation of my own research interests also helped set the exploratory tone of the interviews, during which I found respondents expressed genuine interest in the subject as being worthwhile to examine.

Beyond considering my own position, the need for reflexivity can also extend to guard against ‘social and intellectual unconscious’ bias in analysis (Oren, 2016: 315). Qualitative research poses a potential risk that the researcher may

unconsciously influence the focus and formulation of questions and the conduct of interviews. In my own research, this could mean introducing bias in the questioning of participants by asking certain questions or omitting others or being selective in their transcription or analysis.

To respond to these concerns, I thought very carefully about how I came across, the questions I was asking and how I facilitated the interview to avoid or minimise (or at least acknowledge) my own potential influence on the data gathering. To respond adequately to such potential risks, I considered my role carefully and designed the study in such a way as to consciously account for the reflexive questions above. In designing the interview questions, I opted for mainly open questions that would allow the interviewee to direct the conversation on the topics and areas that were relevant to the thesis. I also allowed them freedom and time to speak in the interviews, even if they were moving off at a tangent, and refrained from offering my opinion on the issues under examination. Since every researcher will inevitably conduct and examine their research from a position that may be implicated by social phenomena like gender, race, education or their own previous experience, by spending time considering my own role in the research I hoped to ensure careful design to support the justification that my data is nevertheless valid and reliable.

7. The post-interviewing stage

After each interview was completed, the audio recording was transcribed and added to the empirical data set. The transcription took longer than expected and produced a lot of interview data. I did not wait until the end of the interviews to begin the analysis and I started to code the data after around ten interviews had

been transcribed. I transcribed the interviews word-for-word using app-based software called 'Transcriptions' (version 1.2), inserting symbols to indicate where I could not hear what was said. The use of software was essential to slow the speed of the audio file down and to conveniently pause and replay. After transcribing the first five interviews, I started to use a reputable transcription service recommended by colleagues (and with whom confidentiality was ensured). This saved me time and also allowed me to read through the transcript and audio together with a fresh mind, thinking about the themes for analysis.

After the interview, the interviewee was not required to participate any further and was not routinely provided with a copy of the transcript or a summary of the study findings, unless requested. The data validation method of 'member checking' (whereby the interviewees are provided with a copy of the transcript and/or results) was not routinely applied (Smith and McGannon, 2018:103) for practical reasons due to the constraints of the study. However, I took into account that this was not the only relevant method of data validation and that it does not in itself ensure the trustworthiness of qualitative research results (Smith and McGannon, 2018:117). Although I did offer interviewees the opportunity to request the transcripts, I did not receive any requests during the period in which the study was conducted.

8. Research ethics

The empirical data collection stage of the thesis required ethics approval from the University of Kent and, since some interviews were conducted with NHS staff on NHS premises, the NHS HRA.

i) University of Kent

Ethics approval was obtained from the University of Kent to conduct interviews with human subjects (See Appendix: D). This required me to state the purpose of the project, location of the research and make a declaration if the research involved any vulnerable groups, such as children, which it did not. I was also required to demonstrate how informed consent and confidentiality were ensured. I needed to renew the ethical approval to cover the duration of the study.

ii) NHS HRA approval

When I commenced the empirical data collection, since the study was only interviewing NHS staff and not patients, local research and development (R&D) approval was sufficient. Each NHS Trust or organisation, including Higher Education institutions, have their own – or sometimes joint – R&D departments that are responsible for ensuring all relevant approvals are in place (NIHR, n.d). However, by the time I was starting to contact NHS fertility clinics, the NHS approvals process had changed. Since March 2016, HRA approval has been required for all project-based research in the NHS in England. This involved making an application through the Integrated Research Application System (IRAS) (NHS HRA, 2019) which I did in December 2016.

I made the initial application after receiving preliminary agreement to interview someone at a fertility clinic that operated on NHS grounds and the local NHS R&D office requested that I submit an IRAS application in order to obtain HRA approval. I started the application in Autumn 2016 and it was submitted a few months later, in part due to the length and complexity of the form, which I was learning to complete for the first time. Further documentation and specific formats

for items including the consent form and participant information sheet were later requested, and the final HRA approval was granted in June 2017.

Once approval was granted, the HRA then contacted NHS Trusts in England on my behalf to invite them to participate in the study. Although this was useful in maximising the potential reach of the study, I soon found that some NHS Trusts who responded did not, in fact, house fertility services that provided donor conception (indeed most NHS clinics do not). I often found myself identifying and contacting the relevant fertility services *after* their NHS Trust R&D department had been in contact. Furthermore, even if the clinic did provide donor conception services, it was sometimes quite difficult to get into conversation with the relevant person within that clinic who oversaw the research operations. A few potential interviews were lost in the coordination stage. In the end, the administration of logging, responding and acting on emails from NHS Trusts, and the subsequent liaising with the fertility services, took much of my research time between June and August 2017.

One notable aspect of the NHS approval process was that it uses one standard format for all research submissions. Many of the questions were therefore not relevant to my small-scale project that involved interviews with staff, but the IRAS form did request a full methodology, including a clear statement of the reasons for conducting the project and why interviews were necessary. I was also requested to set out step-by-step how I would conduct the interviews and the predicted involvement of participants, so that the time commitment and any associated costs of the project could be measured prior to approval.

Another hurdle I encountered was that it was necessary to obtain a ‘letter of access’, also known as a research passport, to conduct interviews on NHS premises (which was not required for telephone interviews). This research passport required confirmation of my student status from the University of Kent HR department and needed signing off by the NHS Trust’s central R&D department, before presenting to the clinic on arrival to conduct the interviews.

I applied for HRA clearance to conduct an interview at one NHS location with the view to add others at a later stage – I had already provisionally been in contact with possible interviewees at NHS clinics. Ultimately, however, during the course of obtaining NHS research approval the number of interviews at private clinics took me towards the saturation point. It is important to note that several interviewees working at private clinics also spoke about past or present NHS experience.

iii) Ethical considerations raised by the study

The use of interviews raises a number of methodological challenges, but the research conducted for this thesis did not present any obvious ethical issues beyond those ordinarily raised by interviewing human subjects. All the interviewees were adults and employed in professional positions, the capacity in which they were being interviewed. The interviews were conducted at the interviewee’s place of work and arranged directly with them. The project did raise some general issues associated with the sensitivities of discussing patient donor selection and the possibility of disclosing clinic practices and policies in a commercially competitive, ethically sensitive and media-alert environment. During the interviews, participants spoke about particular selection decisions that

were made. Such decisions made by patients to choose a particular donor are private, and therefore it was important to maintain the confidentiality of both clinic staff and clinic patients. These less obvious, 'highly situational' (Bryman, 2015:71) potential infringements presented a risk of 'harm' to the research participants in the form of breach of confidentiality or not proceeding with properly informed consent (Bryman, 2015:127; Erikson, 1967).

The subject matter of racial matching or selection based of 'race' did also raise some distinct ethical issues and sensitivities. Interviewees were asked to comment on when they thought decisions were 'unusual' or 'odd', which could reveal the participant's own personal views on race, if any, or where they may feel accused of racism, for example. The interviews did reveal a possible awkwardness when discussing race or associated characteristics, such as skin tone, where respondents might on one hand deny any discussion of race, but later indicated that it was discussed in donor selection. The political and personal sensitivities of topics closely linked to past and present discriminatory practices and pernicious attitudes, as well as negative perceptions about essentialising race and portraying race as a biological fact, could nonetheless make the participant feel uncomfortable in their discussion. Furthermore, speaking in their professional capacity, interviewees spoke about their clinic's practices or policies (or lack of), which if construed negatively and linked back to the particular clinic, could result in adverse publicity. In response to this potential ethical consideration, I ensured that interviewees were informed of the right to withdraw after the interview so that if anything was said that they later felt uncomfortable with then they could request for the transcript or part of the transcript to be deleted. The interviewees were conducted sensitively (they were informal and relaxed), and respondents

were given space to discuss what they wanted in their own chosen terms as the questions were drafted in a sufficiently opened-ended way and attempted to avoid excessively leading the discussion.

Ultimately, however, given that all the participants were professionals and their confidentiality was ensured, as well as the subject matter of the thesis being communicated clearly prior to interviewing, the risk of increased harm to participants was minimal. Nonetheless, I took seriously the need to protect confidentiality in the data analysis, presentation and publication with these specific issues in mind. I took every step to protect anonymity and reduce the risk of identification, which remained minimal. Significant weight was also placed on the need to ensure fully informed consent.

iv) Anonymity, confidentiality and data protection

All ethical codes and guidelines state the need to preserve the confidentiality of research participants (Allen and Wiles, 2016:150; Wiles et al, 2008:422; Scott, 2005:244). Participant records must be kept confidential and, in the absence of their consent to their identity being made known, participants should not be identified or identifiable in the presentation of findings (Bryman, 2015:127). In particular, the British Sociological Association statement of ethical practice states that: ‘Where appropriate and practicable, methods for preserving anonymity should be used including the removal of identifiers, the use of pseudonyms and other technical means for breaking the link between data and identifiable individuals’ (2002, para 36).

However, a difference has been drawn between conferring ‘anonymity’ – whereby the name and the location of sources remain unknown – and confidentiality, where the researcher undertakes not to reveal the participant’s identity (Scott, 2005:247; Allen and Wiles, 2016:151). This study adopted anonymity in the presentation of the data (although the identity of the participants was known to the researcher) and sought to preserve confidentiality through the use of pseudonyms (Wiles et al, 2008:422; see also Taylor et al, 2016:110). Accordingly, all data discussed in this thesis and any related publications was ‘pseudonymised’. This means that participant names were replaced with artificial identifiers, such as ‘Counsellor A’. Likewise, in those cases where patients were discussed – for example, if their names were disclosed in the interview (which did not in fact occur) – this information was not used in the analysis or recorded in the transcript. The data in its original form was not shared with other members of staff, institutions or third parties.

To protect confidentiality, I used identifier codes on data files, such as the interview recordings and transcripts, and stored the list of participants names and details in a separate, password protected file (Holmes, 2012:88-90). The original transcripts were then pseudonymised for data analysis. To the extent that the interviews contained personal information as defined under the Data Protection Acts (Bryman, 2015:128), I ensured that such data was processed for limited purposes, as necessary and no more than for the research project itself. Interviews were recorded and stored on a password-protected computer to which I had sole access. All transcription word-processed files were similarly protected. I also sought agreement from the transcriber to sign an undertaking to preserve the confidentiality of the people discussed in the interviews.

Nevertheless, maintaining confidentiality can be problematic in the course of qualitative research (Wiles et al, 2008:422), especially where the research seeks to produce sufficiently nuanced and ‘thick’ data (Allen and Wiles, 2016:151) – for example, in this study, through the use of in-depth interviews. My research posed a small risk of identification from the pseudonymised data since the population being studied was relatively small and operated in a specific sector with a set of key clinic operators (Allen and Wiles, 2016:151; Bickford and Nisker, 2015:277). Since many of the clinics I interviewed were based in and around London, this further limited the pool from which people were recruited. Furthermore, the use of anecdotes and narratives in interviews presented an increased risk of identification (Scott, 2005:249). To guard against this, I only included only what was pertinent and necessary to address the research questions in the final thesis. For example, if a clinic’s location was not necessary for data analysis (as I was not seeking to draw conclusions about nationwide clinic practices in part because of the small data set) then I would not routinely include it. However, since an interviewee’s job title was relevant to data analysis then I did include the staff position – with the proviso that due to the representation limitations discussed above, only tentative conclusions could be drawn.

In addition to attempting to minimise the risk of identification, I also informed participants of such a risk before they gave their consent to participate in the study. The information sheet and consent form (see Appendices B and C) informed participants that confidentiality would be maintained through the use of pseudonyms but highlighted the risk of re-identification using external

information, such as that held by the HFEA on the clinic, and the small number of participants taking part (Scott, 2005:253).

v) Informed consent

In line with general research protocols (Bryman, 2015:129), as well as guidance provided by the British Sociological Association (BSA, 2017) and the Economic and Social Research Council (ESRC, 2015), I sought as far as possible to ensure that interview participants had enough information to make an informed decision about whether to participate in the study. This included ensuring that each participant was able to give their informed consent to all aspects of their participation in the study, the possible dissemination of findings and also the minimal risk of re-identification. The BSA Statement of Ethical Practice emphasises that it is the responsibility of the researcher to explain in appropriate detail and in terms that are meaningful to the participants what the research is about, who is undertaking it, why it is being done and how the findings might be disseminated and used (2017:5, para 18). To help achieve this I emailed copies of consent forms and information sheets to potential interviewees at least two working days before each interview, reiterating their right to withdraw at any stage.

The information sheet included an outline of the thesis and research questions. It also stated the purpose of the interview study and how it is needed to answer the research questions (see Appendix C). The consent forms highlighted the possibility of identification (discussed above) and the opportunity to withdraw from the study within three weeks of the interview taking place. This time limit was considered appropriate given the timescale of the study and the tasks of

transcription and initial data analysis. Interviewees thus had the opportunity to make their own informed assessment of the risk of harm.

9. Data analysis

I started the interview data analysis once I had completed ten interviews, by which stage I had already noticed particular commonalities beginning to emerge (although, as Braun and Clarke (2006:7) point out, it is important to avoid providing a passive account of the analysis and the active role in identifying themes should be addressed. Starting the analysis at an early stage also fitted in with the open, qualitative design for the study and presented the option of returning to the interview questions if necessary.

The first stage of data analysis (after transcription – during which I became familiarised with the data, itself a preliminary stage of analysis (Braun and Clarke, 2006:17)) was to produce a set of initial codes that I could apply to the interview data. I read through a sample of materials and began coding, giving names to portions of text. The initial set of codes largely that broadly reflected the questions that I had in mind, but that ultimately differed from the final themes (Braun and Clarke, 2006:18). I also began to draw up codes to organise ‘explanatory responses’ to the key questions interviewees were asked, from which as many potential themes or patterns were identified (Braun and Clarke, 2006:19). A theme is defined as capturing something important about the data relevant to the research question that presents as a pattern or meaningful response (Braun and Clarke, 2006:10). I then tested this draft framework by marking up pseudonymised and collated transcripts with the initial codes looking out for repetitions (Bernard and Ryan, 2009). I did this using Microsoft Word, marking key phrases using the comment, search and highlight functions. It was helpful to

think of the coding stage of analysis as breaking down the data into component parts, ascribing names – using coding as a device to label and organise the data. This allowed me to start compartmentalising longhand text in such a way that could be searched, identified and used to ground the thematic analysis.

After I coded the first three interviews, I then began revising the initial coding framework. It was quickly apparent that the initial codes were too broad (e.g. ‘The extent of the clinic’s involvement’) and did not capture the full range of responses to these issues. I then devised subcodes within major codes to categories specific themes and answers to broader questions. For example, code A dealt with ‘How do patients select a donor?’ but within code A were 13 subcodes to capture responses such as ‘Use of a catalogue’ or ‘Use of external UK sperm banks’ (see Appendix E). In developing the codes into themes, I searched for common elements, writing summaries of the codes and began to give names or labels to themes and subthemes (Bryman, 2015:585). By looking for repetitions, topics that recur again, and also exploring how interviewees discussed a topic in different ways, it was possible to look for subthemes or codes that underpinned others. This stage of analysis is what Braun and Clarke term ‘searching for themes’, where the analysis re-focusses on the broader level themes rather than codes, with codes sorted into potential themes and how the codes may combine to form overarching themes (2006:19).

In the next stage of coding, I sought to review and refine the themes, first by reconsidering the codes and whether they fit a coherent pattern, and then considering the validity of the themes in accurately reflecting the meanings evident in relation to the data set as a whole (Braun and Clarke, 2006:20-21). I

looked for ‘key words in context’ (Bernard and Ryan, 2009:65) using Word to find all the instances of these words in the interview transcripts. As such, my approach to establishing the themes was not only to draw on the data that was presented but also to bring my prior knowledge of the topic (such as the relevance of patient autonomy and welfare of the child considerations) in an attempt to isolate the evidenced themes (Bernard and Ryan, 2009:56).

I found the theoretical and practical guidance in the literature review helped me to take a structured approach to the empirical data analysis and identify themes and patterns in the donor-matching context. For example, I searched the files for phrases such as ‘welfare’, ‘autonomy’, and ‘HFEA’. My literature review also helped me to link the research questions into broader theoretical frameworks or policy issues, highlighting issues of wider significance (Marshall and Rossman, 2010:7). Insofar that the research questions presumed the hypothesis that race plays a role in gamete donor matching, the analytical induction approach was appropriate to see if the interview data provided any answers or explanation for such a hypothesis. It provided a framework, or a key set of issues, concepts and questions, that was used for further interrogation of the interview data, including: how race matters, what race means, how people use assisted conception to build a family, and what factors are important in this process. These themes were central to the codes that were developed to analyse the interview data and how this information was read and understood in the analysis.

I then coded the entire data set, again using the functions in Word, which proved easy and convenient. Although I could have used software, such as Nvivo, to perform some of these functions, I came to the conclusion that the primary

purpose of coding (to collate and highlight parts of text) could be done more expeditiously by myself using a familiar, if basic, platform. This conclusion proved correct in turning out the key themes and highlighting relevant quotations, but one drawback from using Word was having to manually count recurrences of the themes, such as ‘how many responses indicated yes’ etc. Since the thesis is not presenting quantitatively significant findings representative of fertility practice across the UK, this was not the priority for coding. Furthermore, at 100,000 words, the data set was relatively small.

Having coded the interview data for the purposes of this study, the second stage was to organise the themes and relevant quotations into coherent structures for the data analysis chapters. It was at this point that I engaged with Braun and Clarke’s fifth stage of analysis by defining and naming the themes (Braun and Clarke, 2006:22). I cut and sorted the key themes that emerged as significant into quotations, arranging these into lists that appeared to fit together (Bernard and Ryan, 2009). This formed the basis of two data analysis chapters. From here, it was possible to derive a structure to each chapter and consider the logical progression of the points emerging from the data and conclusions that could be drawn. The content and structure of the two chapters to follow thus emerged organically from the data.

Having produced these chapter outlines, the third stage was to write up the findings – the final step of Braun and Clarke’s guide for thematic analysis (2006:23). The writing up stage involved documenting these insights and building a ‘compelling narrative’ about the data (Bryman, 2015) or the ‘story’ the data tells within and across themes (Braun and Clarke, 2006: 23). The analysis was

supported by evidence in the literature review and invited further specific assessment of the particular themes that emerged from the interview data – some of which were novel, while others had already been documented elsewhere.

10. Evaluating quality

The methodology for this thesis was ultimately designed to produce interview data that is both reliable and valid. Whereas there is some debate over the validity of these criteria for qualitative research (Bryman, 2015:383) – not least because such research does not require adherence to representation and statistical validity that comes with quantitative studies – reliability and validity remain important in establishing the quality of qualitative studies (Bryman, 2015:383). Due to the practical limitations associated with conducting doctoral research, certain measures of quality outlined by Smith and McGannon (2018) such as ‘member checking’ (discussed above) and ‘investigator triangulation’ (involving two or more researchers interpreting data independently) were not adopted – although my supervisors, friends and colleagues who commented on my research did serve as ‘critical friends’ by challenging my interpretations of the data (Smith and McGannon, 2018: 113). In order to promote rigour, I sought to demonstrate a number of ‘universal’ hallmarks of research quality discussed by Smith and McGannon (2018). Relying on the work of Tracy (2010), the authors explain that open-ended criteria are used to judge the quality of qualitative work (2018:116). These criteria consist eight ‘universal’ hallmarks, including a worthy topic, rich rigour, sincerity, credibility, resonance, significant contribution, ethics (discussed in section nine) and meaningful coherence (Smith and McGannon, 2018:114) – all of which must be used if Tracy’s approach is used to demonstrate rigour (Smith and McGannon, 2018:118).

In regard to the worthiness of this research topic, as explained above an examination of race in donor selection is timely and relevant (in light of the increased use of donor gametes in the UK and elsewhere) but also seeks to question assumptions and challenge ideas (Tracy, 2010:840), such as around race. I have sought to demonstrate rigour above through evidencing sufficient research data and exhibiting care in data collection and analysis (Tracy, 2010:841). In designing the methodology, I sought to demonstrate that I am ‘observing, identifying, or “measuring”’ what I say I am (Mason, 1996:24) by presenting carefully constructed research design and linkage between the research questions, literature review and data analysis. As Tracy explains, ‘a researcher with a head full of theories, and a case full of abundant data, is best prepared to see nuance and complexity’ (Tracy, 2010:841). The ‘sincerity’ of the research I hope is demonstrated by the process of self-reflexivity, described above, which is one of the primary indicators of honesty and authenticity (Tracy, 2010:842). I also outline the limitations of the methodology and the thesis more generally below and in Chapter Seven.

Creditability refers to the trustworthiness and plausibility of the research findings (Tracy, 2010:842). To achieve a degree of trustworthiness and validity of the data, the methodology was designed to evidence dependability (by showing an audit trail of the research) and conformity (producing an objective account and ensuring my own views do not take hold) (Lincoln and Guba, 1985) – although due to the exploratory and small-scale nature of the study, the latter aspect of validity was less important.

Lincoln and Guba (1985) also argue for the authenticity of qualitative data by seeking fairness in the representation of different viewpoints, as well as ontological and educational authenticity to assist in better understanding of the research topic and helping others appreciate perspectives of those in their social group. The analysis of the interviews seeks to offer a ‘thick description’ of the areas of study by offering in depth detail and explanation (Tracy, 2010:842).

The latter is linked to what Tracy terms ‘transferability’, where readers transfer the research into their own action, a method to help demonstrate the resonance of the research (2010:845). Indeed, some respondents commented on the discussion as having made them think harder about their involvement in donor selection. To this extent, I hope the findings will be of relevance – and use – to the fertility and wider academic communities, a factor that supports the ‘significant contribution’ of the research (Tracy, 2010:846).

Overall, by outlining the socio-legal, empirical methodologies to explore the constructions of race in the institutional fertility context, this chapter seeks to demonstrate the ‘meaningful coherence’ of the research through an interconnection of the research design, data collection and analysis methods with the theoretical framework and goals (Tracy, 2010:848).

11. Limitations

Acknowledging limitations is a necessary part of quality research (Taylor et al, 2016:131). There may be relevant limitations associated with the overall methodology adopted, the constraints of the research and the researcher, and the

subject matter under examination. Addressing and responding to these limitations helps promote rigour through honesty.

Qualitative research methodology entails several limitations. First, during interviews, respondents may not say what they believe or explain what they do (Taylor et al, 2016:105). This limitation could become particularly significant given the commercial and ethical sensitivities around race and donor selection, discussed in section 9 above. Not only did I consider this from a research ethics perspective, but (as outlined in section 7 of this chapter) in conducting the interviews I sought to ensure that respondents were given sufficient time and freedom to provide their responses. I would allow interviewees to talk freely without interruption and allowed the interviews to run until the discussion had come to a natural conclusion. This provided in-depth interviewing that is able to respond to these limitations (Taylor et al, 2016:106). The findings are also expressly explained as resting on a constructivist logic, whereby meaning is constructed not discovered (James and Busher, 2009:7). In the generation of knowledge, this research entwines the philosophical epistemological assumptions of phenomenology, which holds that the responses in the interviews can demonstrate how the respondents interpret the world, and symbolic interactionism, which refers to the process of interpretation of meaning (James and Busher, 2009:8). It is through these philosophical perspectives that this thesis seeks to produce new knowledge, rather than portraying the interviews as demonstrating ostensible fact. This is an important qualification to the understanding of the findings of this thesis.

An associated limitation is that for reasons of confidentiality it was not possible to observe interviewees in the actual context of discussing donor selection with patients (see Taylor et al, 2016:105). Furthermore, interviews as a methodology also entail inherent limitations in not being entirely neutral and susceptible to providing partial accounts or accounts where the interviewee is silent about a particular topic (Chew-Graham et al, 2002:289). I therefore had to rely on respondents' potentially incomplete and impartial accounts of this process, but once again the in-depth interviewing model gave respondents time and opportunity to explore these contexts with me.

This research project was also limited by time and financial constraints. It was not possible to interview every fertility clinic in the UK or a sufficiently large number of clinics across different regions to achieve a representative sample (discussed in section 5 above). However, it is not necessary to achieve representation in qualitative research as it is in statistical analysis, providing that rigour is maintained. The sampling method that was adopted and described above was therefore appropriate to produce quality data within the practical constraints of the thesis.

Further possible limitations include those associated with my own role in the research, which I sought to address by considering reflexivity (discussed in section 7 above). There may also be limitations resulting from the subject matter itself, if respondents felt uneasy discussing race and clinical practices. I sought to address these limitations through the in-depth interview design and how I conducted the interviews discussed in section 7 above.

12. Conclusions

This chapter has outlined the practical and theoretical justifications for the methodology of this thesis. The adoption of a socio-legal framework through which the empirical data collected by the use of semi-structured interviews with fertility professionals can be constructed and interpreted is necessary in order to respond in a meaningful, in-depth way to the research questions – *how* and *to what extent* constructs of race are discussed in donor matching procedures.

In addressing the potential limitations presented by the nature of the study, this chapter has sought to highlight the validity and reliability (Bryman, 2015:383) of the empirical data. Furthermore, by presenting a carefully constructed research design and linkage between the research questions, literature review and data analysis, I have attempted to demonstrate that I am ‘observing, identifying, or “measuring” what I say I am’ (Mason, 1996:24) – helping establish the validity of conclusions that flow from the interview data. However, the chapter has also acknowledged the limitations of what is a relatively small study, based on interviews only with professionals and not with patients seeking treatment. A number of potentially profitable avenues of future research could be explored through a systematic large-scale study, which included patients within its sample. Nevertheless, this smaller scale project does seek to make an original contribution to the literature by raising some important issues that are poorly explored in the existing literature, contributing new empirical data on them, and – it is hoped – serving as an impetus for further work in this area.

Chapter Four: Donor selection and matching in UK

fertility clinics

1. Introduction

Relatively little is known about how patients select gamete donors and how this process is managed by fertility professionals in the UK. Many studies have explored the motivations for donation, particularly around the removal of anonymity (see, for example, Frith et al, 2007) and the implications of donor conception for families (for example, Golombok, 2015). The motivations for donation have tended to identify factors around altruism and financial incentives (Freeman et al, 2016:2083), although in the UK compensation is limited by law. A number of studies have also explored donor selection decisions and patient narratives in detail (Lingiardi et al, 2016; Chabot and Ames, 2004) including, most notably in the UK context, Nordqvist's studies of same-sex couples (2012; 2014), as well as Zadeh et al's study of single mothers (2016a) and Zadeh et al's study on patient perspectives on donor information (2016b). These studies, however, did not focus on donor selection processes (how decisions are made, by and with whom) in the clinics specifically. For example, in Nordqvist's study, although many of the respondents had conceived or were trying to conceive through NHS and private fertility clinics (2012:647), some of them had also obtained their sperm informally outside clinics or at clinics through known donors (2014). Chabot and Ames study of lesbian couples choosing to become parents through donor conception did look at how such decisions were made but mostly examined known donation (where the donor is known to the recipient) and the use of external sources (such as group forums, friends, the internet and books) as key

sources of information (2004:352) – again, it was not clear how many respondents underwent DI at a fertility clinic.

Literature from the US has explored how staff organise gamete donation in donor agencies and banks (Almeling, 2007), but not all arrangements were conducted through clinics (with many people using donor agencies and inseminating at home); furthermore, these studies were (understandably) not focussed on the UK fertility sector. In many of these studies therefore, the input of clinic staff and the selection process itself was not a primary focus of the research (notable exceptions include, Deomampo, 2019 and Davda, 2018).

Moreover, less attention has generally been given to heterosexual couples needing donor conception (with the notable exception of Becker et al, 2005). Nordqvist explored how same-sex female couples engaged in planning and becoming a family through donor conceptions, including the routes to conception and their motivations (Nordqvist, 2014:272) and Zadeh et al examined how single mothers represent the donor and the impact of anonymous donation (2016a:118).

Nevertheless, it remains unclear how donor selection processes differ for heterosexual and homosexual couples or single women except that in the treatment of heterosexual couples the need for the use of a gamete donor may arise later on in the treatment/consultation process once infertility is diagnosed.

Although the existing literature, outlined in detail in Chapter One of this thesis, does not directly address how UK clinics manage the selection process with patients, some of it does provide evidence that such decisions are made in clinics (see also Becker et al, 2005:1303). For example, studies have shown that

established clinical practice in heterosexual couple conception is to match the donor's physical characteristics with those of the non-genetic parent (Zadeh et al, 2016b; Nordqvist, 2012:649, citing Becker, 2000). According to respondents in one study, clinical staff commonly advised patients to use donors with 'matching' physical characteristics (Nordqvist, 2010:1133). As outlined in Chapter Two, some clinics' websites make it clear that a number of clinics seek to match physical characteristics. There is also evidence of staff participation in selection decisions in clinics in the US and in sperm banks and at agencies in the UK.

Nevertheless, various questions remain largely underexplored, including: how patients choose their gamete donors when they are receiving treatment at a clinic; what happens during this process; which clinical and non-clinical staff are involved; what information or guidance is provided by the clinic; and what happens when someone makes an 'unusual' request. This thesis aims to make a contribution to this gap in our knowledge.

This chapter begins by discussing what the interviews revealed about when in the treatment pathway donor selection is raised, how donors are selected, and the nature of the clinics' involvement in these discussions, before turning to an analysis of the extent of involvement and the reasons for this. The chapter then proceeds to discuss donor matching and racial matching, specifically, before ending with a discussion of the practices and policies around matching that transpired from the interviews.

2. The medical context of donor selection

Donor selection occurs within a unique context of ordinary healthcare provision (as part of a standard medical procedure – DI – or coupled with IVF) and highly customised regulation and bureaucracy, amid the public (NHS) and private provision of services. The options available to patients in selecting donors, including how, where and when to source them, may be significantly influenced by these broad spheres of operation.

As outlined in Chapter Two, prior to the use of gamete donation, the typical fertility patient will have already been exposed to a large amount of information about their treatment and donor options, as well as having undergone numerous consultations with medical staff either inside or outside their treating clinic. NICE recommends the early provision of advice and information to patients concerned with delays in conception (NICE, n.d). Patients typically proceed through initial indications of infertility by their GP and secondary care diagnosis and testing, prior to the provision of treatment by private fertility clinics or tertiary NHS services. In the private sector, clinics might conduct the full range of investigations from the start to finish. By the time a patient starts to discuss treatment options, including donor conception, they will in many cases have already undergone a lengthy process of diagnostic tests, consultations and interventions. Clinics will first meet new patients at various stages in their fertility investigations – following immediate diagnosis of infertility and the requirement to use donated gametes, after a number of failed cycles or after having received treatment at another clinic.

However, while donor selection operates within a highly medicalised environment of interventions, consultations and advisory services, little is known outside the sector about how clinics discuss donor selection. The discussion of gamete donor selection is not specifically mentioned in the standard pathways to fertility treatment (although information provision and informed consent is a central part of the process), nor is it entirely clear from published material how and at what stage of the treatment process it typically takes place.

Reflecting the early provision of information evidenced in the treatment pathways, respondents in this study highlighted that the discussion of sperm or egg donor selection would typically occur early on in the patient's treatment, with selection taking place in advance of any further medical intervention (once the need for donated gametes had been established):

It's before anything else that goes on, the patient, the couple, have to have a donor set up. We don't do anything else unless they have decided.

(Embryologist A: 621)

This makes practical sense, since there are several issues regarding gamete donation requiring discussion, including various options for sourcing gametes, that may well determine the course or timing of subsequent treatment. However, some respondents also pointed out that patients could benefit from being given sufficient time to consider their use of donor conception:

What strikes us is that they find it very quick, once they have seen the doctor and the doctors says yes, you are eligible for gamete donation and

your bloods are screened and now go and choose a donor – that's when they halt. (Embryologist A: 621)

In addition to being practically significant, discussing donor selection early on reflects the psychological complexity of requiring the use of a gamete donor. The distress associated with infertility and the psychological implications of using a donor have been well documented already in existing literature (Johnson and Fledderjohann, 2012). Early discussion could most likely help patients and their partners come to terms with its use, and also reduce the likelihood that the patient backs out of treatment later down the line. Respondents indicated that in some cases, patients were given considerable time to decide, with some patients waiting for months for a suitable donor (although primarily because of limited donor availability). This finding indicates that issues surrounding selection can often delay the start of treatment. As one respondent said:

They [patients] need to understand [the donor conception process] before they make any form of decision. Some patients do not want to go there until they get their head around the idea. Then they come back to discuss how to find the donor and how we match a donor. How we plan the treatment ... but very few patients want to go into details until they address the idea [of using a donor in the first place]. (Clinician D: 7708)

Evidently, there is not necessarily a fixed time to discuss gamete donor selection in the treatment process and these discussions might occur at different points depending on the patient and the clinic. Yet some clinics are keenly aware of the

complexities surrounding the use of donor conception and build time into the decision-making process to adequately deal with this.

Questions of whether, how and when to discuss donor selection largely fall under each clinic's own informal practices. Clinics in the UK are given considerable discretion in clinical practice on certain matters. The HFEA regulates the UK's fertility sector through its Code of Practice, but each clinic is given a wide margin to implement measures to meet their statutory obligations. While the obligations around the taking of consents and the safety of treatment, governed by the Care Quality Commission and healthcare regulators, are robust, clinics remain free to manage their own practices and policies in how they deliver their treatment services, including what services are provided and how patients access them. As this thesis will show, the interviews in this study support such an assessment and paint a picture of significant variation in practice around the selection of gamete donors, ranging from the use of in-house donor banks to external banks either elsewhere in the UK or overseas.

3. The methods of donor selection

All interviewees were asked to describe the process by which patients select sperm and egg donors. In answering this question, some respondents discussed how their clinic (or previous clinics they had worked at) used to carry out donor selection and how this has changed in recent times. What emerged was a picture of donor selection previously conducted by 'pen and paper' giving way to the use of donor catalogues and, in some cases, external gamete banks.

A number of clinics did – and still do – conduct donor selection between the patient and clinic in person. One respondent explained how the previous selection process was conducted mostly using pen and paper:

Until our donor catalogues went online it was very much a couple of people sat in the office with A4 folders who would offer a donor to a recipient based on their physical characteristics. And that's how it used to work. (Counsellor A: 26)

List-keeping was a practice that other respondents reported too:

We literally have a list. The person at the top of the list is the person who I would consider first when I get a donor become available. So, I would keep it in a very strict fairness order. Most of the time I would contact that patient – the person at the top of the list – and say, I've got this donor, these are the characteristics. (Nurse A: 4551)

This position was also reflected by a respondent from another clinic:

Normally, to be honest we have very few donors here. What would tend to happen is when a donor comes into the system, I'd see who's at the top of the queue and look at the characteristics. (Nurse E: 10987)

The interviews illustrate how donor selection – at least in some clinics – was once predominantly informal in nature, involving personal and direct discussion with fertility professionals, with patients being offered a selection from a highly

limited number of alternative donors, if given any choice was given at all. The finding that donor selection occurred at the clinic with face-to-face discussions with clinic staff was echoed by other respondents: 'It was a face-to-face meeting with the head of the lab telling them we've got one or two available, or this is the best match' (Embryologist D: 4163).

Others explained that subsequent discussions would sometimes then be conducted by telephone or email, including the passing on of donor information:

I've seen emails going to and fro, but they are only like: 'do you like donors A, B and C?', 'I need more time, I need to have a look. B definitely not. Can you give me another one along with C and A', 'OK we'll give you D. And see out of those three', 'Oh no I didn't like D. Is there anything else?' (Embryologist A: 1240)

In this iterative approach to donor selection, the donor choice is arrived at by offering one donor after another. The clinic appears to have direct involvement and oversight of this process. This type of paper-based exercise was often associated with low numbers of donor options, with some respondents explaining that the clinic pre-selects donors for patients. One interviewee spoke of nurses providing 'three or four options' (Embryologist A: 698), others spoke of clinics offering just one donor at a time. This was particularly the case with egg donation, where typically only one donor may be available at any given time. This approach contrasts starkly with the use of a donor catalogue provided to patients or made available online, discussed below.

For egg donation, the recipient would often discuss their requirements with someone at the clinic who, if they were seeking an anonymous donor rather than using a donor known to them, would place them on a waiting list:

We do have an egg donor coordinator who sees the couple. We then go through the options available and [explain] that might involve egg donation in the UK with a known donor, if the couple have a known donor. It might involve egg donation with a donor in the UK, where they will wait on our waiting list or they may decide to go overseas. If they decide that they want one from the UK and go to our waiting list, they will then have a donor matching appointment with our coordinator. (Clinician B: 6657)

Egg donation is more commonly conducted in-house, with very low numbers of available donors. While the number of cycles that use donor eggs is roughly comparable to the use of donated sperm (slightly more cycles are with donor sperm than eggs) and there are more people donating eggs than sperm (HFEA, 2019b), donated sperm can be frozen and used at a later date. Cryopreservation techniques are less successful for eggs than for sperm and success rates are low (in four in five cases the treatment is not successful (HFEA, 2018)). Egg donor conception therefore most commonly uses fresh eggs, which must be transferred to the recipient within a certain limited period of time, usually simultaneously. There are thus fewer donated eggs available to a particular patient. Due to the low numbers of available egg donors, some respondents explained that they would offer sometimes just one egg donor at a time:

If I have an egg donor become available, I would offer it to number one, number two, three and, depending on the characteristics, it might be person number six who accepts the donor because the other five say no.
(Nurse A: 4286)

This comment indicates that where a patient does not use an external bank, the clinic will only offer what is available to them (it also exemplifies how particular some patients can be when searching for the right donor). In some cases, this could be just one donor offered at a time. However, the use of donor catalogues tended to be associated with a greater range of options being presented to patients. These catalogues either featured in-house or were provided for externally.

i) The use of donor catalogues

One of the most notable practices in in donor selection is the use of donor catalogues – both in-house and externally. As outlined in Chapter Two, donor catalogues present lists of various lengths of gamete donors, with patients able to choose to buy and obtain their gametes from the bank or clinic, for use in their treating clinic. They typically allow the patient to choose a donor in their own time. Donor catalogues are now mostly online, although as some respondents indicated, in some cases they were – and still could be – simply a hard-copy folder.

These catalogues presented patients with (sometimes) a large number of donor options from which the patient could then select their preferred gamete donor. As one respondent noted:

When – if you are a heterosexual couple using donor sperm, you used to fill out a little piece of paper with your male partner’s details on – if you were using donor eggs you would put your female characteristics on – and literally you’d get a phone call and someone would say we have a donor who is a bit taller, but he’s got the right eye colour. Slightly off hair colour, but it’s still a good match. Whereas now you can see everybody that is available.

(Counsellor A: 81)

The increased ability to choose donors offered by catalogues was seen by some respondents as empowering the patient: ‘When we put the sperm bank catalogue online it dramatically changed things because it empowered patients with the ability to choose UK donors’ (Counsellor A: 75). This quotation reflects the view that increased donor choice promotes reproductive decision making, which is in turn seen as an exercise of autonomy. Choice and autonomy are dominant themes across medical law and ethics (see, for example, Robertson, 1994; Harris, 2003; Savulescu, 2002) and it is not surprising to see fertility professions make associations with the principles in donor selection. What was less expected was the language of consumerism that was sometimes used to describe donor selection practices. The ability to choose donors online drew analogies with other forms of ‘online shopping’:

Our own catalogues are based on Amazon, so they want it to be a familiar shopping environment so that people feel comfortable and relaxed ordering their eggs or sperm from our unit. (Counsellor A: 101)

This quotation portrays the donor selection process in a consumerist light whereby the relationship between the patient and gamete provider is akin to one involved in ordering goods. However, this analogy does not serve to fully capture the real-life significance of donor decisions and the different ways in which people navigate this. As one respondent explained:

[The patient / recipient] can be sitting in your home in London and a clinic in Washington DC [...] will send you up ten profiles of what they think would work for you with you – similar skin colour, whatever. You are sitting in your home with your glass of wine looking at ten profiles. Well, what are you looking for? I don't ask patients that in the counselling. But sometimes people will talk to me about, 'I really wanted my partner in the room. It is something I didn't want to do separate.' And then there are people who are mirroring the complete opposite. 'You know, I felt I had to do this. When my partner came in from work, I just showed him the two or three I really wanted.' (Counsellor D: 11642)

This quotation shows how donor conception relates in complex ways to people's personal relationships and how their understanding of them. The 'glass of wine' further reinforces that notion that such decisions are contemplated in the patient's private sphere and dilemmas, such as whether and how to involve the partner, are mediated by the patient alone, away from the clinic. It is nonetheless interesting that even where decision-making occurs away from the clinic, some patients would bring their decision into discussion with the treating clinic. References to consumerist methods of donor selection therefore does not diminish the complexity and importance of the choice being made. Indeed, there was little

indication that respondents saw catalogues as trivialising the donor selection process. In fact, such was the importance of choosing a gamete donor that many respondents saw the need to place this catalogue quite literally in the patients' hands. One respondent said catalogues gave patients the ability to choose their donor:

When this was launched, they loved it. We can do this on our own? Especially the people who have had to go through the old version, having somebody else picking for you, you never trust anybody to pick anything for you, I don't think you trust somebody go out to pick a piece of clothing for you, let alone your future children. I am trivialising here but it's the same concept. If you want to buy something, you want to go and see it yourself. Not having others pick it for you. And this is big. This is huge. [You can't just say,] Oh I don't like this baby I'll just return it. You can't. It's huge. (Embryologist A: 954)

Handing over control to the patient was a theme that was echoed by other respondents:

[A catalogue] makes life easier for this stuff. You know, the patients are given their time and they just choose whatever they want. That's the sperm catalogue. This is the egg donor catalogue. These are known donors and there's new arrivals, for example, that means new donors. I think it works. It's all very transparent. The patients are given the option of doing their own selection, and not relying on a third party to do the selection for you. (Embryologist A: 954)

The utility of catalogues was not only seen as presenting a greater number of donors, but also operated in some cases to give patients almost real-time information about which donors, particularly egg donors in short supply, are available:

I think that kind of empowers everybody; it lets recipients know these are the eggs available for you today – if somebody has reserved them, they're not on the catalogue. It kind of works in real time. We all lead busy lives now and just because you want a child the world doesn't stop. (Counsellor A: 406)

Sometimes the interviewees spoke of the use of donor catalogues as even benefitting the clinics themselves. Some respondents saw certain benefits for the clinic in handing over the selection process to the patients, especially the 'tricky' ones:

The patients ... they pick on a word, they just become so obsessed with just one word and they report you for saying one word out of line. So, you really have to be careful. The least said, the better. And I think this is why this works wonders for this stuff. Because you are not putting the stuff on the front line, to be kind of criticised for choosing the wrong donor.

You've chosen it, you pay for it. (Embryologist A: 912)

Donor catalogues were provided either in-house, by the clinic themselves, or were housed externally elsewhere in the UK or overseas.

ii) In-house donor lists

The use of in-house sperm banks was not common across all clinics in my study. The size of the clinic appeared to indicate whether sperm was externally sourced, as well as its history and the clinic's original set up. Also, the clinics with in-house banks tended to discuss matching directly and in person with the patients, rather than facilitated by a catalogue, and presented options by email or telephone, as described above.

Of the three I've worked at, two had in-house donor banks. My previous NHS unit was not-for-profit, the donor bank was purely set up to supply patients. (Counsellor, Embryologist B: 1578)

This respondent indicated their clinic had a relatively small donor bank, yet this was mostly sufficient for their needs.

iii) The use of external gamete banks

The interviews made clear that external gamete banks were used quite extensively by some clinics, reflecting the discussion outlined in Chapter Two, regarding the changing landscape of gamete donation in the UK and the use of commercial third-party banks. Not all UK fertility clinics have their own in-house sperm or egg donors, with those that do not requiring patients to source gametes elsewhere – sometimes for use in that clinic. While a patient may undergo donor conception treatment at a specific UK clinic, gametes used can be sourced from elsewhere in the UK or even imported from overseas.

Respondents spoke about using banks in the US or Europe (discussed above), with a large European bank deemed ‘popular at the moment’ by one respondent (Clinician E: 8900).

A lot of sperm donation in this clinic happens where the patients actually choose – they go to [the US or Europe] and they themselves choose the donors and import a number of vials for their own use themselves.

(Clinician B: 5133)

The use of European or sperm banks in the US was a practice evident in a number of clinics (Embryologist C: 1874):

We tend to buy our sperm from other banks. We buy a lot from [two large European gamete banks]. We do recruit, we do have individuals that come through to share sperm sometimes. It’s not something we do much of.

(Clinician A: 2974)

The use of external gamete banks would also typically entail the use of catalogues and the information provided by external gamete banks can be significantly more extensive than that available for UK donors, particularly in the US. As one respondent put it:

The American banks give you their inside leg measurements (laughs), if you want to know it they’ll tell you it, they’ll give you pen sketches, they can give you a hand-written letter, baby photos – you can delve as deep as you want to go. There are forums set up for women who want to find each

other and have babies with the same donor to have half siblings. It's quite scary. In the UK, no – they tend to be much more about HFEA documentation and they will follow those guidelines. The European sperm banks are a bit more reserved. But the Americans, you could probably find [the donors]. You don't need a home address. (Nurse C: 5282)

The use of overseas donor banks brings its own legal complexities, however. Fertility clinics in the UK who import gametes from overseas must comply with all the regulations that would apply to donation in the UK, including ID-release and the ten-family limit. Some respondents discussed the legal requirements of using an overseas bank and indicated the compliance issues would be a factor for the clinic working with that particular donor bank.

Anyone in the UK we will receive sperm from because they adhere to all guidelines. The only ones we do abroad are [names removed] ... they adhere to all the guidelines. A lot of the banks in the US do not have a ten-pregnancy rule to be about to ship to the UK or the non-anonymity clause. (Nurse C: 5282)

Overall, the interviews demonstrate the way in which patients choose their gamete donors has changed, with the growing emergence and use of donor catalogues and external gamete banks. The emergence of online donor catalogues and banks can be situated within a broader landscape which promotes patient autonomy when it comes to fertility decisions and healthcare more generally (Pennings, 2000:510). It also serves to illustrate the increased commercialisation of fertility services in the UK. Nevertheless, there often remains a level of treating-clinic involvement in

selection decisions. The nature of involvement sparks the potential for discussions around donor selection to occur between patient and staff, which directly engages the clinic with the donor selection process and allows for interpersonal relationships between staff and patient to arise out of the donor selection process. The significance and extent of this involvement is discussed below.

4. The involvement of fertility clinics in donor selection

All respondents were asked to describe the nature and extent of their own and their clinic's involvement in donor selection. What transpired was a picture of a highly variable level of involvement on the part of clinics that does not necessarily correlate with the methods of donor selection employed (although it was an important factor). The extent of clinic's involvement in donor selection, and why this varied, is explored next.

i) Are donor selection decisions discussed in clinics?

The preceding discussion about the methods of donor selection suggests that, on occasions, the use of external gamete banks puts the discussion of donor selection firmly into the patient's domain and that clinics may sometimes have very little involvement in this process. Some respondents did not describe themselves or their clinic as being actively involved in donor selection. (I: 'Are you involved in the selection process itself?' R: 'Not really, no.' (Embryologist A: 552)). One respondent (who also said that staff would not discuss donor selection in the clinic (Clinician B: 6822)) suggested that donor selection was something that occurred elsewhere, sometimes even before the consultation with the treating clinic:

We don't specifically sit down and talk to them about their choice of donor. They have bought this sperm and they bring the sperm in and it's stored in the unit. (Clinician B: 7027)

In fact, some respondents said that they would have little involvement in the discussion of the patient's donor selection:

It's a very private thing. I've never asked 'why do you choose?' It's very unethical to do [that], it's something very private. (Embryologist A: 893)

Others also reflected that it was a 'personal choice that is up to each patient' (Nurse A: 4386) or that they would 'leave them to make the decision' (Clinician A: 2993). Those who indicated that donor selection discussions would not be discussed sometimes referred to nature of the decision:

I think it's a really big thing for a couple to choose a donor and they should be allowed that freedom to almost choose who they want [...] I think it's such a big deal to choose another person's DNA to join your family, as it were, and it's a very personal choice and they should be able to have that freedom. (Embryologist E: 9572)

Some respondents expressly referred to empowerment by choice, referencing the privacy associated with fertility decisions and patient autonomy in the healthcare context:

It's not any of your business to ask [about donor selection]. It's very private. This is what the [gamete] catalogue is giving, it's giving privacy, it's giving autonomy, it's giving freedom to choose whatever you want. (Embryologist A: 899)

Alternatively, donor selection was sometimes discussed in conjunction with the commercial goals of the clinics – as one respondent put it: '[w]hen you are paying for a commodity, you call the shots' (Counsellor D: 11819) – or with an eye to potential legal liability. One respondent spoke about the advantages this would have for the clinic in the context of race selection:

I think the catalogue stays away from the issue of what is most important. It puts race first I think because that is very important, I think that is the fundamental, first thing that you really need to consider is race, because it's where most law problems arise – if you are given the wrong racial sample. (Embryologist A: 861)

Whether because of privacy, commercial reasons, or to avoid future liability, the protection of reproductive decision-making reflects the influence of the principle of autonomy in areas of medical law and healthcare practice. Patient autonomy – or self-governance, manifesting as the right to make decisions about one's healthcare in the medical context (see, for example, Nelson, 2014) – is a complex and contested concept (see, for example, Foster, 2009) but arguably remains at the forefront of medical ethics and healthcare more generally. In the reproductive context, advocates of autonomy tend to emphasise the importance of procreative choice (see, for example, Robertson, 1994; Harris, 2003; Savulescu, 2002) and the

privacy of one's decision to have children, and with whom to have them.²⁶ The interviews indicate that fertility professionals often equated choice with empowerment and control, with some respondents emphasising the importance of a more hands-off approach to allow patients the space and time to navigate of such gravity and complexity (Counsellor D: 11642, above).

Alternatively, a number of respondents claimed they or their clinic were quite actively involved in these processes, although the extent of their involvement did vary considerably across clinics. Commentators have observed elsewhere that most fertility clinics, to varying extents, do discuss donor selection with patients (see, for example, Becker et al, 2005:1303), and this phenomenon was also observed in this study. Some clinics were particularly active in discussion donor selection ('I: Do you discuss donor selection? R: Absolutely, yes.' (Counsellor A: 24)) and made it clear that the donor selection – or 'matching' – would occur at the clinic:

Once they have seen the counselling team [...] we then get them to contact the embryology and the nursing team and that's when the matching tends to take place. (Clinician C: 7191)

Overall, in sixteen interviews where the respondent directly answered if they were involved in donor selection, ten said that they were – two of whom said it was

²⁶ The promotion of autonomy has been critiqued by a number of commentators (see, for example, Foster, 2010), some of whom have called into question the excessively individualistic nature of the concept (Stirrat and Gill, 2005:130; see also, O'Neill, 2002). The promotion of choice and empowerment has in turn been critiqued for voiding issues of their moral content and providing procedural justifications for otherwise potentially ethically contestable practices (see Montgomery, 2006; also Beyleveld and Brownsword, 2007).

someone else in the clinic who conducted the discussion. Fifteen respondents said their clinic (including other staff members) was involved in donor selection. Of two respondents who positively indicated that there was no involvement by the clinic (Clinician C: 7337 and Nurse D: 8364), one did go on to say that the patient may still initiate that discussion (Nurse D: 8428). Some clinics would give patients guidance in choosing their donor:

It starts right at the beginning [...] we [advise patients] to pick a donor who is not outstanding – pick a donor who you feel comfortable with (because we ultimately want your child to feel comfortable). (Counsellor A: 127)

Behind these observations lies a wide range of advice regarding donor selection. In some cases, the advice went beyond the practicalities of donor information and into the science of heritability. Given that the kind of information supplied about donors might imply a strong belief in ideas of genetic heritability, respondents were asked specifically whether the basic science of genetics and heritability would be discussed with patients. Some respondents explained why they felt that an explanation of genetic heritability was needed:

We would talk about how genes work and the unreliability of that being a criteria, what it would be like, how they would feel if their child actually couldn't quite match up to those expectations and what impact it would have on their feelings towards the child. (Counsellor B: 10828)

Some respondents suggested that they might engage in a discussion about genetics with patients concerning their donor choice, such as where the patient had a particular view on heritability:

I: ... would the clinic ever correct a patient's perception of what they are looking for in a donor?

R: Yes, yes. Absolutely. Correct or maybe question and advise. [Laughs.] Sometimes it is, it boils down to correction, yeah. I mean, if a couple have said, we really want a blue-eyed baby and we say well, you know, the chances are – they could talk about recessive and dominant traits and hair types and the height and so we do go through, we have discussions with the couple to try and inform them as much as possible that you are picking these physical characteristics, but the baby that you, fingers crossed, end up with may not look like that, because of these reasons. So, we try and make sure that they are aware as possible when they are picking certain physical characteristics. Unfortunately, people have a certain mindset or a certain figure in their mind. (Clinician E: 9544)

The answers to this question were not uniform, with some respondents showing a reluctance to inform patients further about their selection:

I am not a qualified genetics counsellor. I wouldn't go out of my remit. Actually, if you've got questions about genetics, go back to the doctors and ask for a referral to somebody who can talk to you about it, which sounds quite harsh, but I don't have enough awareness. (Counsellor A: 6392)

Additionally, the interviews show that the implications of using a donor featured in discussions about donor selection – although this occurred largely only where the discussions were with counsellors. Discussions with counsellors tended to be more wide-ranging, covering the use of gamete donation as part of a discussion of the implications of fertility treatment:

What's important to me initially is to find out how things are for them. So yes, there's going to be an awful lot I want to be sure they are aware of and understand, but that comes very secondary. So the initial part of the session, like most counselling sessions, is encouraging [them] to be themselves and their experience and how it's been for them. And how it was when they first began to realise that donation was on the cards. What that process was like [...] It's a really important thing to do because there are people for whom they've been not recognising how traumatised they still are. And maybe aren't at all ready to go ahead with reaching a family this way [...] they need more time. (Counsellor B: 10292)

The discussion with the counsellor also in some cases appeared to go beyond the relaying of donor characteristics but involved an in-depth discussion of their relative importance:

[Patients are] much more aware that the background information is important. They are less likely [than before] to say that they don't want background information. And there are all sorts of things ... they often [say] oh well, it's just a matter of choosing a donor, matching

characteristics ... and then by the time they've had their hour and a half with me they are realising that they are going to need time to do this and think about it. (Counsellor B: 10346)

Counsellors, in particular, said they tend to talk about future situations. One reason for this was to explore how the patient would inform the child that they are donor-conceived:

It's not just about implications ... it's sort of how to tell the child that they are from donated gametes as well as what the implications are and using a known donor, for example, a relative [...] Your relative may think that they have a right to [be involved in] the upbringing of the child and that kind of thing. (Nurse D: 8735)

The discussion of donor information was sometimes also placed in the wider psychological context of parent-child familial relationships:

There is quite a lot of evidence out there about like the family dynamics and how these patients do and the quality of the parent/child relationships. So many patients are very interested in that aspect and that we try and give them as much information as possible. That would occur during the counselling sessions. (Clinician C: 7480)

In summary, the interviews show that donor selection, to a varying extent, involves discussion of the practicalities of donor conception, including where the source gametes, the donor's information (physical and non-physical

characteristics) and also wider issues such as genetic heritability, as well as the consequence of using gamete donors for the individual and family. This wide range of information may in turn have considerable consequences for the examination of what information is or should be relevant to donor selection and the role and expertise of fertility professionals in these discussions.

ii) **Factors relevant to the extent of clinics' involvement in donor selection discussions**

Two factors emerged as being relevant to the extent of clinics' involvement in donor selection: the clinic's methods of selection and the availability of gametes. First, for some respondents, involvement was indicated through the clinic having its own donor matching criteria or policy (e.g. Clinician D: 7668), or by its interaction with patients using external gamete banks. The extent to which clinics were involved therefore varied according to the style of donor selection they employed. The paper-based or email iterative processes (to and fro between patient and clinic) as described above represents quite active participation (Embryologist B: 1360; Embryologist C: 1875; Nurse D: 8542). For example, one respondent said:

We would offer key characteristics and we'd always make it clear that our own in-house donors had specific characteristics we are able to give out – height, weight or build, eye colour and hair colour. Skin colour and ethnicity would be the first thing we talk about then. And then more qualitative characteristics – job, education, hobbies. (Embryologist B: 1335)

The use of external donor banks shows a certain distancing of the selection decision away from the clinic:

With [a European sperm bank], quite often they would have already been in discussion beforehand and they come to us and say: 'We've already found a donor'. (Clinician E: 8972)

However, the use of external gamete banks did not always align with less of an involvement by clinics. Even where the donor selection decision occurred 'outside' the clinic, though a donor catalogue, for example, the selection decision itself could often be discussed before or after with various members of staff, for example with their counsellor (Counsellor D: 11642, above). Some respondents said that patients would be told about, or recommended to use, specific donor banks either in the UK or abroad:

The ones that we tell people about are [a US and European] sperm bank, I'm not sure if we say anymore. We also tell them to go on the internet. We know that these two are very familiar with the HFEA regulations, then we tend to advise those two. (Clinician B: 5220)

Patients might be given email addresses, telephone numbers and website of places where they could source their gametes:

We give [patients] email and telephone contact details of [five sperm banks and] a step-by-step guide of exactly how their databases work ... With egg donation, we've got arrangements with two organisations that

help find donors, egg donors. There are a lot of telephone contacts over that. (Counsellor B: 10794)

Another respondent said:

We would advise them and give them a few choices to go to. And then they would select their own through an agency or another clinic and then have them transported here – so we don't help them with that. (Nurse D: 8251)

Such advice could include donor sources and the types of donation available:

And sometimes they ask about getting treatment abroad, and I explain to them the differences between access to donor information and what they would and wouldn't get, and then they decide if they want to be added to the waiting list. (Nurse A: 4276)

However, some respondents pointed out that patients would often find donor banks and locate gametes of their own accord, even if the clinic itself might recommend a range of options:

As part of the [matching] process, we usually don't tell patients they have got to use this particular sperm bank. We usually recommend them actually having a look at three or four different banks. And then the patient themselves gets a feel for what level of information they want and which donor they feel is most suitable. In our hands, although we are doing a sort

of a bit of a donor matching profile, it's really the patient that does most of the leg work that ultimately makes the final choice. (Clinician C: 7207)

One counsellor said that patients might come and see them to discuss their donor selection and say, for example: "This is my donor and what do you think of [them] and do you think it's okay.' I've had people come in with a profile printed of three donors and said, which one do you think I should choose?' (Counsellor A: 6411). Such responses indicate that, in some cases, donor selection discussions are initiated by patients.

A second factor that appeared to impact on the extent of a clinic's involvement was the availability of gametes. In cases of very low stock of available gametes, the selection 'discussion', if it takes place, was sometimes limited to presenting simply what is available to recipients on a first-come, first-served basis. Some recipients might end up waiting for months or end up not proceeding with donation – although the provision of counselling may be considered in these situations.

The generally greater number of sperm donors available meant that sperm donor selection was often more commonly and extensively discussed in clinics.

Although some respondents also spoke of low numbers of sperm donor options:

We had a very small in-house donor bank where I was – around 15 donors. So, it was easy to email and put in a format. You didn't need a 300-page document. (Embryologist B: 1355)

Additionally, the ethnicity of the patient also appeared to impact on the donor choice and the extent of clinics' involvement. As one respondent noted:

Sometimes it's very difficult, because you've got certain races which it's very difficult to find donors for. And, therefore, and this is particularly pertinent as far as egg donation is concerned, it could be quite difficult to find your right donor. And then the couple are asked whether or not they would accept a donor from a different race. (Clinician B: 6755)

According to figures discussed above (Chapter Two, section 4.iii), over 70% of gamete donors in the UK identified as White British, with only 2% identifying as Black African, by comparison (HFEA, 2019). The shortage of available eggs and sperm from Asian or Black donors was commented on specifically too: 'It depends on the race. For example, it's very difficult to find an adequate ... Asian donors' (Clinician B: 6769); 'I think if we had mixed-race or black donors, we'd be the leading clinic in Europe, probably' (Counsellor A: 6472).

These comments support concerns over the lack of adequate ethnic representation in gamete donation, which has received both critical commentary and media attention (see Chapter Two, section 4.iii), and adds weight to calls for greater ethnic representation in gamete donation (see Packham, 2018).

A third factor that appeared to influence the extent of a clinic's involvement in donor selection the clinic staff's perspective of their legal responsibilities to ensure the informed consent of patients to treatment, plus their obligations to consider the need for supportive parenting under s13(5) HFE Act 1990. In many

cases the clinics went beyond the minimum legal requirements in the provision of treatment. This finding is particularly pertinent given that there is no legal obligation for clinics to discuss donor selection. That said, as discussed elsewhere (see Chapter Two, section 2.ii.b), there is an interpretation of the statutory obligation on clinics to consider the welfare of any child born before offering any treatment, and also to provide an opportunity for counselling, and this could extend to donor selection (sections 13(5) and 13(6) HFE 1990, as amended). At the same time, while the involvement of clinics in donor selection is in many ways unsurprising given the regulatory context, the choice of gamete donor is not a medical decision. Instead, donor selection arguably falls within each patient's sphere of reproductive autonomy and privacy. A patient's receipt of medical treatment for infertility does not necessarily extend such jurisdiction to matters concerning their social and private decision-making.

The mechanics of donor selection, including the method of selection adopted and the availability of gametes, as well as the broader regulatory framework, therefore impact on how donor selection is discussed. Of note, is the relatively high level of involvement as clinics were often involved in these discussions even when the gametes were sourced externally. This finding implicates clinics in the donor selection process, raising questions over the extent and nature of involvement. It also points to the broader ethical question of whether clinics should be involved at all in the donor selection decision (or whether clinics should consider selection made elsewhere as separated from their involvement with the patient).

Furthermore, the interviews indicated that a greater selection of gamete donors associated with the use of external banks in fact often served to increase the potential for deliberation about donor selection.

The mode of information-giving also gives rise to various questions. The ways in which this information is provided varies considerably from the mere imparting of information for patients to evaluate for themselves to a more involved attempt at supporting the patients in evaluating the information received about donors and where to source them. Clearly, donor information is not merely imparted by the clinics but is provided as part of a dialogue with the patient. The variability of importance accorded to donor characteristics and the presence of discussion of them between staff and patients can sometimes be mediated through complex, interpersonal relations. As one respondent said:

I talk to them about their requirements as well. About what they find is important to them. Most of them haven't gone that far so they don't really understand. And so, when I say we will give you height, hair colour, eye colour, weight, build and limited information also that [the donor] may have written or not. And they say oh, how do you decide? And I say you need to have a think about what is important to you, weighting of characteristics. And I normally give them a couple of examples. (Nurse A: 4276)

The mode and nature of information provision and discussion is therefore a very important aspect to donor selection procedures. Fertility professionals engaged in discussion of use of donated gametes must cover a complex, diverse range of practical and legal issues. The interviews indicated that – in some clinics and with some professionals interviewed – a lot was discussed with patients which went

beyond the medical and practical matters regarding their treatment. This fact will be picked up in the following two chapters.

In order to better understand the nature of clinics' involvement in donor selection, and to set the groundwork for exploring the role of race, respondents were asked about whether patients, themselves and/or the clinic sought a matching donor. The answers are detailed in the next section.

5. Do clinics match patients to gamete donors?

Having established that donor selection decisions are sometimes discussed quite extensively in fertility clinics, the analysis moves on to the question of whether the interviews evidenced donor matching. Despite the absence of direction on patient–donor selection, the interviews in this study did show that matching occurred in many clinics – but that practices were not uniform. Some respondents described their clinic as having a more or less explicit (albeit unwritten) policy of seeking to match patients to donors ('There is an [informal] protocol that says that ideally you would match ... as close as possible – physical characteristics, however, after discussion with patients. It's very informal' (Counsellor C: 12822)), while for others matching happened in a way that was assumed with no discussion (one respondent acknowledged this practice but then asked whether it should continue to occur). On the other hand, some respondents expressly rejected any attempt to match patients to donors, painting a picture of highly variable practices.

Some respondents indicated that patients themselves sought a donor match:

Yes, they do look for a donor match. What they often will do is that they'll give us the characteristics of the person having the treatment and then the characteristics of the partner and they will ask to match something.

(Embryologist F: 10114)

Some respondents indicated that patients would often match the sperm donor to their male partner: 'The majority of the time, they want something that matches the male partner' (Embryologist F: 9920).

For same-sex couples, some respondents also said a match was sought between the donor and the non-birth partner, reflecting observations made elsewhere (Nordqvist, 2012): 'So, quite often, it's my impression that the people are looking to match the physical characteristics of the non-birth partner' (Embryologist D: 3044).

A number of respondents revealed that clinics and fertility staff themselves might actively seek a donor match to the patient, with this sometimes going well beyond an attempt to match physical characteristics: 'You try to narrow the gap as much as possible. If you have two intellectuals like we had [...] you try and match them with a donor who is on that par' (Embryologist A: 690).

The use of the word 'you' here is interesting and suggests the clinic staff member, in this case an embryologist, inferred that either they themselves or the clinic generally would seek an appropriate match. This respondent went on to say: 'You try to match the best you can but then you have to work with what you've got' (Embryologist A: 697).

The practice of matching was evident in other interviews as well:

Every patient we'd try and match. (Embryologist B: 1476)

We'd try to match them best we can with the list of donors that we have.
(Embryologist F: 9866).

Some clinics appeared to have a great detail of involvement in matching:

'Basically, we have six basic matching criteria, which is body build, weight, height, colour of skin, colour of eyes, colour of hair, ethnic background'
(Clinician D: 7669).

This practice was sometimes identified as a former, now-lapsed practice:

What we used to do is give a form to the woman, put down your characteristics – brown haired, brown eye, 5.9 tall, my hobbies are [...] and you hand that over and a group of nurses who are in the egg sharing or donation group would say OK well this donor fits very much like this lady
(Embryologist A: 661)

Some clinics would often take note of the patient's own physical characteristics.

This practice was also commented on in situations where a donor coordinator was involved:

They see the counsellor and they, once it's completed for the counselling, they then see the donor coordinator for sperm who will then do specific donor matching for them, taking down their physical characteristics and their race and their blood group. And then, we will try and find them a donor. (Clinician B: 6628)

Clinical staff tasked with taking down characteristics of patients would then tend to try and match them to donors available – if the clinic would manage this selection process. However, the emphasis on matching was also often balanced with what the actual patient wanted:

Generally, we would donor match a patient depending on their characteristic. We would have information about the patient's characteristic. If they were Caucasian blonde hair blue eyes, I would match – if we had a donor who was Caucasian blonde hair blue eyes we would say that's a great match, but here are the other donors. So, we would *naturally point them in the direction of a donor that matched their physical characteristics* but allow them to see all of them and pick who they wanted. (Embryologist B: 1333; my emphasis)

Some clinics would thus assume that patients would seek a donor who matched their characteristics as a matter of course. Other respondents suggested that their clinic assumed matching would occur from the outset – by implication:

I assume in the first instance patients are interested in core obvious characteristics, hair colour, skin colour and races. (Embryologist C: 1909)

The finding that donor matching was, in general, common in practice, adds weight to some of the existing literature (Nordqvist, 2010, 2012). A number of respondents did speak about matching to physical characteristics as ‘standard practice’: ‘I think it’s a pretty standard practice. What we try to do is to find a donor in their likeness’ (Clinician B: 6743).

Not all respondents said they would match patients to donors. As with the quotation above, which assumes that matching would accord with the patient’s (albeit unexpressed) wishes, concerns about respecting patient decisions led some respondents to deny any involvement with the selection process:

Basically, it’s not really matching. The patient or the couples are shown what is available. And they we leave it up to them to match – sorry, to choose a donor. (Clinician E: 8918)

We are not involved to or influence in any way the couple either in what they should do, we just cater for what they want or what they need.

Selection, no we’re not involved. I’m not involved in selection. At the clinic now the couple do the selection themselves anyway. (Embryologist A: 577)

These findings appear in line with the discussion of clinic involvement in donor selection discussions above, with respondent Embryologist A explaining (above) an unwillingness to get involved (Embryologist A: 899), while others indicated active participation and also matching. This suggests, on the fact of it, that the

greater involvement a clinic has in donor selection discussions, the more active they might be to facilitate a match.

The interviews indicate that some clinics even encouraged patients seeking a donor match to re-consider whether this was indeed important:

It doesn't matter what you do [in terms of selecting a donor match]. The traditional family used to be, you know, 2.4 children, Mr and Mrs... I ask [patients] to talk about their siblings – how similar they are, you know? Because within some families, children come out like peas in a pod, others are incredibly different, and you can open them up again get them thinking about ... why is it so important that everyone looks the same. (Counsellor C: 12525)

Whether clinics expressly or impliedly sought a donor match, refuted engagement in donor selection all together, or pushed back on donor matching, all deemed motivated by respect to patient autonomy in donor selection and to facilitating the patient's desires. Furthermore, even those clinics who claimed not to be involved in donor selection were nevertheless involved in the process of offering choices that serve to recognise certain characteristics, such as race, eye colour and so on, as important, while other variables are not (see also Deomampo, 2019:629).

6. Do clinics 'racially match' their patients to donors?

While the matching of physical characteristics of donors to patients has been observed in the literature examining donor conception (Zadeh et al, 2016b; Nordqvist, 2012), comparatively little attention has been given to racial matching

(with notable exceptions: see, for example, Davda, 2018; Hudson, 2015; Nordqvist, 2012; Thompson, 2009; Wade, 2015), despite it once being considered good clinical practice (Wade, 2015:122). However, the interviews in this study show evidence of *racial* matching, specifically:

On the whole, there is almost a belief that race *is a given* in matching.

(Counsellor B: 10479; my emphasis)

Obviously if they are British couple they are not going for an Asian donor.

(Embryologist A: 844; my emphasis)

It's because if I am White and married to a White partner, I want White children. (Embryologist A: 868)

The use of the words above 'is a given' and 'obviously' indicate that racial matching is largely assumed by some clinics. Indeed, some respondents themselves believed race to be an important donor characteristic:

I think the race, ethnicity is core information along with your physical characteristics. I think that should be available to everybody right at the beginning. (Counsellor A: 6494)

The clinic itself might seek a match, notwithstanding a request for this from the patient. The donor's race or ethnicity was specifically matched in some cases to the patient:

It was quite obvious that one of the two looked very Mediterranean and so we said, well, we will see whether we have a Mediterranean donor. (Embryologist D: 3956)

[The donors] would be fair skinned yes, and we would find [Asian recipients] an olive-skinned donor. Not someone that has got blue eyes blonde hair, but somebody that has brown. (Nurse B: 5267)

We normally choose the ethnicity to match them. (Clinician B: 5754)

Most respondents identified attempts to match the donor's race to the patient – suggesting that the clinic sometimes assumed or initiated the match. The assumption of racial matching may reflect observations made by Cross that racialised assumptions can lie within ordinary or 'unremarkable' practices (Cross, 2010:416).

Indeed, when respondents were asked about if patients had raised any 'unusual' requests, a number identified requesting donors of a different race to them as being unusual.

I think as I mentioned in the Black patient who requested a White donor. She said that she didn't mind, but she requested a White donor. That was something new to us. (Clinician D: 8096)

A number of respondents spoke about flagging patient requests for non-ethnic matching donors – the appropriateness of which was sometimes questioned:

If someone has picked a donor after they have met me and it's a different ethnicity especially a different colour of skin then it's questioned.

(Counsellor A: 379)

I know we have had a Black lady requesting White donor sperm and certainly there was a discussion about that. And afterwards we thought should we have had that discussion? (Nurse A: 4662)

This is an unusual one I suppose: it is considered a good thing in some Asian families to be lighter skinned and some of the Asian families [we have seen in the clinic] have chosen to have a dark brown hair, brown eyes, olive skinned, Caucasian donor, rather than an Asian donor.

(Counsellor C: 12689)

Other respondents said there might be a case conference where a patient requested a donor of a different ethnicity (Nurse B: 5903; Embryologist B: 1397 – but in this case the request was agreed), or a multidisciplinary ethics team meeting (Embryologist C: 2072). The observation that clinics would push back at non-matching requests, may affirm a certain assumption that remains in clinical practice that patients would be racially matched to donors. However, the interviewees also show that mismatching requests may suggest that the patient had not come to terms with gamete donation (see also Chapter Five, section 4). It might also evidence an incomplete appreciation of genetic heritability (discussed in Chapter Five, section 1.ii). As one respondent explained in the context of egg donation:

If [an Asian patient] want[s] a White one, [they] get a White one. But you take a risk because you're just looking at [the donor] and his background. What if he's got ginger parents? We don't know the long-term genetics and then, you know, we've seen blue eyed Asian babies. We have to have that discussion with them, just to make them aware. (Counsellor C: 12711)

Clinics' concerns over a patient's request to use a donor of a 'different race' have been documented elsewhere. Price discusses a French case where a sperm bank was unable to provide a match on skin colour to a Vietnamese couple, who had requested the bank disregard the mismatch and continue (Price, 1997:226). Only after a 'lively discussion' was the couple accepted for insemination. In another study, Thompson discusses a clinic in the US which refused a patient's choice of egg donor because it found the phenotype mismatch unacceptable (Thompson, 2009:143). The couple, who were White German and Buddhist, expressed an interest in having a child that 'looked Indian', choosing an egg donor of South Asian descent. Similarly, the interviews in this study demonstrate concerns about donor requests considered mismatches. The observation that these requests attracted such attention might reflect the routinisation or normalisation of matching for race, particularly Whiteness (Tyler, 2009:41; see also Bergmann, 2011), which is assumed and made invisible until disrupted by this kind of request.

Given an evidenced indication of racial matching on the clinic's part, it is important to note that some respondents said that they would have no concerns with matching (or non-matching) requests (Embryologist A: 899) and not all

respondents agreed with the notion that selection decisions would be discussed at a team level, with one respondent explaining that they could not recall a situation where donor selection was raised and discussed at a clinic level (Clinician C: 7331). Discussing a recent sperm mix-up case, another respondent pointed out that – hypothetically – there would be no issue with a ‘Caucasian’ patient requesting ‘Jamaican sperm’ (Embryologist A: 774) – although they did highlight that providing sperm from a donor of a different ‘race’ would lead to dissimilarities: ‘obviously we have to be careful if the patient is White [and has chosen Caucasian sperm] then they don’t get Jamaican sperm because definitely that baby is going to become dark, unless there was a request’ (Embryologist A: 768). Other respondents spoke about offering patients donors of a different ethnicity where donor availability was low (Embryologist C: 2074). There seemed to be great variation on this between clinics:

I’ve worked in the clinics where they have refused Asian couples the use of Caucasian donors, egg donors, and I’ve worked in clinics where Asians have been accepted to use Caucasian egg donors. (Embryologist C: 2093)

Therefore, the described practices regarding racial matching were by no means consistent across the clinics or respondents interviewed and there was a significant variation in practice. However, although the interviews present a mixed picture, it is clear that racial matching still occurs in clinics, including in situations where such requests are not initiated by the patient themselves but would be assumed by the clinicians treating them. Indeed, some respondents said that the interviews had caused them to question their approaches to donor selection, revealing perhaps how pervasive matching has become in clinical

practice. This discussion now moves on to explore whether these observed practices may be embedded within more express policies.

7. Standard practices and policies on donor matching

While there are many legal requirements and guidelines for clinics and agencies concerning the recruitment of sperm donors, there is no or very little published guidance that details how clinics should manage the selection process between patient and donor. As discussed in Chapter Two, the previous versions of the HFEA's Code of Practice (HFEA, 1991; 2001; 2003) and also, at one time, the RCOG (Price, 1997:222), advised clinics to seek an ethnic match between donor and recipient and/or their partner. These recommendations are no longer applicable following recommendations in the SEED report (2005). Clinics now have the freedom to decide how their patients select donors and how they manage this process.

This study's finding that the matching of donors is routine in practice is important, because it shows that these practices have survived the removal of specific guidance mandating the matching *by clinics* of patients to donors. Alternatively, evidence of matching may indicate a wider embracement of patient autonomy through the respect for (indeed, the facilitation of) perceived or actual patient preferences in regard to donor selection.

The next section discusses the extent to which the matching practices described above can be subsumed within a broader framework of express policies, notwithstanding the changes to the HFEA's Code of Practice. The first part of this analysis is to ascertain with whom donor selection tended to be discussed.

i) With whom is donor selection discussed?

The interviews in this study confirmed that a range of fertility professionals was involved with donor selection discussions at some stage in the treatment including counsellors, nurses, embryologists and consultant clinicians (see also Moll, 2019:589) – but, again, the extent and order of their involvement did vary. Sometimes the counsellor would initiate the discussion of donor selection, followed by the embryologist or nurse (Clinician C: 7183). In other cases, the patient might see a donor coordinator who would discuss donor selection:

Once that diagnosis is reached, and it is concluded that treatment [using the patient's own gametes] is not possible, then we will refer the couple for counselling. They see the counsellor and once they've completed counselling, they then see the donor coordinator for sperm who will then do specific donor matching for them – taking down their physical characteristics and their race and their blood group. And then we will try and find them a donor. (Clinician B: 6622)

Several respondents in this study indicated that the clinic had staff dedicated to running and coordinating donation programmes (Embryologist B: 1311; Clinician A: 3038; Clinician B: 6612). This was not a uniform practice across all clinics interviewed, with some clinics explaining that their nurses, embryologists or clinicians would discuss donor selection. However, the larger clinics interviewed did tend to allocate specific roles people to manage the donor selection process, who were often nurses (Embryologist C: 1884; Clinician B: 6622). This practice served to place the donor selection decision away from discussions of a more

clinical nature, such as regarding the provision of treatment itself, supporting a view that donor selection was perceived as part of the preparatory work involved in getting patients ready for treatment.

The finding that the selection process often involved a series of discussions with a range of staff, reflects the multi-disciplinary models employed in fertility clinics identified elsewhere. Lee et al have documented a multi-disciplinary, team-based approach to providing fertility treatment in their study examining the welfare provisions under the HFE Act 1990 (Lee et al, 2015:76; see also Moll, 2019).²⁷

The data in this study suggests that this observation has carried through to donor selection practices.

However, the interviews did also show that certain staff were more likely to engage in actual donor matching – helping the patient choose a donor – while others were more likely to discuss the selection more generally. The comments of the respondent (Clinician B), above, shows that it was the donor coordinator (or in some cases the nurse) who did the ‘specific donor matching’, which was reflected by other respondents (Clinician C: 7191; Embryologist C: 1885). Still, it was clear that other staff members and clinicians were also involved along the way or afterwards.

One embryologist interviewed described the lead-in to the selection decision with the donor coordinator:

²⁷ Lee et al, (2015:76) note that feedback from their advisory group for an empirical study on welfare of the child assessments indicated that although each clinic has a person responsible who is responsible for ensuring regulatory compliance, in practice a variety of clinic staff would have input into discussions and decision-making. This is highlighted in this study also in that team discussions take place in regard to ‘unusual’ donor selection decisions.

You and your wife come to my clinic – sorry, you need a sperm donor. The conversation would be more in depth and caring than that. Use of donor, and she'll go through the process and different forms, parenthood you'll need to fill. When you're ready, call ... the donor coordinator. By this point I already know the characteristics referred to me, so you have a donor in mind for them. (Embryologist B: 1819)

Another embryologist explained that the nurse or coordinator were in fact better placed to advise on selection through their more extensive dealings with the patient:

A nurse or a coordinator [...] follows a couple through their journey and builds up quite a close relationship – [they] get a bit more of a feel for the inner thoughts of a couple or an individual. (Embryologist C: 1965)

A difference in the scope of donor selection discussions between treating clinicians and counsellors was noted by another respondent:

When [the patient] sees a consultant, if they just want a consultant plan, they'll just pick a donor based on pure physical match. If they want slightly more information, through to the whole thing [including non-physical traits], they need to do that with me. (Counsellor C: 12382).

Some clinicians saw their role in the treatment of a patient as distinct from donor selection. One clinician explained:

You do not play the role of coordinator in terms of matching. That is not a clinical role. It's not a consultant clinician's role. This is something which is usually performed by a donor coordinator who is often the nurse, but not always and exclusively so. (Clinician B: 6581)

The interviews therefore revealed some variation in the extent to which clinical or scientific roles, such as embryologists and clinicians, were involved in the selection process, but the data shows that a range of staff was involved at various times in donor selection. Counsellors were almost invariably used at some point in the selection process, provision of which (beyond providing an opportunity to receive counselling) is not mandated as part of the clinic's legal obligations.

Many counsellors, and other interviewees who spoke about the use of counselling, said that the discussion with the counsellor would cover donor selection specifically: 'So it is generally a doctor or a nurse, or a counsellor, who does donor selection' (Embryologist E: 9286). As one counsellor observed: 'We work together on these things. I am the one who talks them through all the donor selection' (Counsellor B: 10516). That said, some respondent counsellors said they would only discuss selection if the patient raised it first (Counsellor A: 6017).

Under section 13(6) of HFE 1990 (as amended) every fertility clinic in the UK has a legal obligation to provide a 'suitable opportunity' for counselling as part of its licensing conditions with the HFEA. While the provision of counselling is not mandatory in every case, previous studies have identified a tendency by clinics to

view the provision of counselling as mandatory (Sheldon et al, 2015b:38), especially for those considering donor conception. This finding was echoed in this study. As one clinician said:

Counselling is a must and you shouldn't rush it [...] Give it a few months and a few months and then — once they think about it again and again, they might change their minds or might become more focused on the idea and they have no problem with that. (Clinician D: 7928)

Others said the provision of counselling was a matter of routine practice:

The counselling is an integral part of a patient's journey around donation. And all clinics are required ... from the HFEA to be making sure they offer implication's counselling for people having treatment with the donor. And most clinics, in my experience now, aren't just offering it. They are saying in the politest way possible that the policy in our clinic is that you must have the counselling. (Counsellor D: 11268)

Importantly, not all respondents shared this view. One embryologist respondent said:

The counsellor is only involved if there are genetic problems, not if it's a normal heterosexual couple, young, no issues with welfare of the child that we might see ... In my career, I have only raised one issue about welfare of the child (if this couple go ahead and have a child, whether this child would be in the right place to be). But not all couples will have genetic

counselling or counselling, not all couples. So, most of them will have their consultation with the doctor, the doctors agree, 'yes this what we are going to do', now you go to the fertility nurse and she will guide you through that. (Embryologist A: 534)

Many respondents indicated early discussions with counsellors were becoming routine, especially in recent practice:

But counselling is not mandatory for recipients so if somebody has chosen not to have counselling then they might not actually meet me until during treatment or after treatment when they are pregnant. It's much more routine now that I would see them right at the beginning. (Counsellor A: 54)

The first step in the process is, we get them to see our counselling team. (Clinician C: 7191)

Of the 12 clinics where I conducted interviews in this study, all provided counselling to patients considering the use of gamete donor, with only one suggesting this was not routine (Embryologist A: 539). All the respondents who were not counsellors themselves explained that counsellors would see patients regarding gamete donation in their clinic. These discussions would cover aspects beyond donor selection. An explanation for the provision of counselling for patients using donated gametes provided by one respondent was that it was helpful for patients to understand the donation process before they proceed with treatment:

If you send the patient to see a counsellor before they understand what it is, they feel that you are doubting their judgement. You have to make sure that they understand the process first. And then, they discuss with the nurses and they might have some questions and then they see the counsellor. So, the counselling is a way to help them to understand particularly the non-medical side of it and help them to probably find the right decision. Most of the people before they see the counsellor probably have made their decision already or nearly there. (Clinician D: 7748)

As outlined in Chapter Two, BICA – the only professional association for infertility counsellors in the UK – explains that counselling offers patients a way of understanding the meaning and implications of any choice of action they may take (BICA, n.d). Counselling is also a way of clinics ensuring that patients are appropriately informed when giving consent to treatment or storage. The HFEA says it is supportive of therapeutic counselling, which involve working through feelings at various stages of treatment and also dealing with depression or anxiety that can be triggered by infertility (HFEA, n.d.c).

The use of counselling along with the clear emphasis on patients needing to understand the implications of donor conception and, in turn, their selection of gamete donors, is indicative of the inherent involvement that clinics take from the outset in these processes. The interviews support the finding of other studies that fertility clinics in the UK take their legal and ethical duties in providing fertility treatment seriously (Lee et al, 2015:50), offering patients a range of support services and opportunities to discuss and explore their selection of donors, along

with time to consider the implications of using a donor. In their study of the welfare of the child assessment, Lee et al observe from interviews with fertility professionals that the effect of section 13(5) HFE Act 1990 (as amended) is to turn clinic staff – including counsellors – into ‘gatekeepers’ to treatment (2015:73; see also Davda, 2018:190). From their data, the authors identify a theme of ‘responsibility’ concerning the obligation to consider the welfare of the child under section 13(5) associated with the fact that a future child may be born following their intervention. Of course, while it likely that any professional interviewee would claim that they considered their ethical and legal responsibilities carefully, the way in which donor selection was spoken about – explored in more detail in Chapter Six, section 5 – and the clinic process described themselves indicated a high level of concern and involvement. For example, one counsellor said welfare concerns might be flagged for discussion in a team meeting:

[The best interests of the future child is] a part of ethical decision making. It’s always in our minds. We are involved in assisting the creation of a new generation of people what they use. Babies grow into people and so it’s there as a background. If something alerts us as a worry, then we look at it and discuss it. We don’t assume problems, but we respond to what looks like a problem. (Counsellor B: 10549)

The welfare of the future child seemed to be very much considered part of the counselling role, among other matters:

The welfare of the child very much is on a case-by-case basis. So if the counsellors don't do welfare as a child assessment but like every member of the team we have to safeguard. If we thought there was a risk of harm to a potential child or a lack of understanding, a lack of an inability to embrace and understand the implications, then they're not able to give informed consent. But they have to be comfortable and fully understand.

(Counsellor A: 6286)

The importance placed on welfare considerations was further highlighted when respondents spoke about how clinics dealt with 'unusual requests', discussed below. The provision of counselling for donor selection therefore confirms the observation above that the issue presents psychological complexities for some patients, explaining how in some cases it can delay treatment. It also invites consideration of how the clinics themselves may be including donor selection discussions as falling under their responsibilities to consider the welfare of the child in the provision of treatment. While this presents a critique of the wording in the legislation, it is also an indication of a culture of taking welfare considerations seriously that may be expressed within some fertility clinics. Lee et al observe that where clinics are left with discretion over the provision of treatment at a clinical level (2015:76, citing Jackson, 2001), then it is not surprising that this discretion will be exercised and will result in variation of practice across the sector.

Other than helping patients come to terms with donor selection, there is arguably little reason why clinics should consider such decisions as warranting in-depth discussion with counsellors. On the other hand, many of the counsellors I spoke to

emphasised that the content of discussion with them would largely be determined by the patients and what the patient wanted to raise at counselling.

ii) Does the clinic have a policy on matching?

Notwithstanding the finding above that many clinics would appear to actively seek a donor match to the patient, many respondents said they were unaware of any express requirements, if any, to manage donor-selection in any particular manner. Two respondents knew of the previous requirement under the HFEA's Code of Practice (HFEA, 2003) and only discovered during the interview that the provision on matching had now been removed. Others were aware of the change:

There was a time, I am sure, when the Code of Practice required clinics not to stray from ethnic group matching. They have shifted that now. We had to simply, you know, keep a record of the reason why we hadn't really, you know, said no. (Counsellor B: 10490)

The practice of keeping a record of the reason is, however, of interest and is discussed further in Chapter Six. One respondent explained that an increasing culture of openness meant that matching donors to patients had become less important:

I don't think it's a massive step to realise that 25 years ago when the [HFE Act 1990] was first put together and the Code of Practice was first generated, there was probably an expectation that parents would [not] tell their children. You can see then that matching to the physical characteristics of a potential parent is something that would be more

commonplace. I think the HFEA certainly aspired to parents being much more open and transparent with their children. (Clinician A: 2816)

Most of the respondents were clearly aware that matching was not a current legal requirement or mandated by the HFEA. Some also spoke about a previous written matching policy existing at their clinic but, again, this was spoken about in the context of past practice:

But I do remember, quite clearly, in a number of clinics that I've worked in there was a written statement where we will try and match the donor to the characteristics as closely as possible. (Embryologist C: 2101)

No respondents interviewed identified a current written policy on donor gamete matching. Some respondents observed that it would have to be informal because every patient was different (Embryologist B: 1472):

We kind of discuss it with your counsellor because it is so individual [...] So, a policy one-size wouldn't fit all and it's not about saying you can't do this, but maybe pause things and go explore things about. (Counsellor A: 154)

Some respondents did not recall even every having such a policy:

As far as I am aware and as far as I can think of, none of those clinics have actually had a written policy regarding race and donor allocation. (Embryologist C: 2067)

The absence of any reference to an express matching policy accords with the lack of HFEA direction and professional guidelines in this area but is notable given the published information from some clinics, explaining how they go about matching, discussed in Chapter Two. Of course, differences may exist between material published online and clinical practice, or between current and past practices. It would be useful for further research to clarify these points.

The impression that some clinics continue to operate a matching policy after the matching provision in the HFEA Code of Practice was removed could, at least in one approach, be explained by the idea of ‘regulatory heritage’ developed by Stokes (2012, 2013). Stokes observes that the approach to the regulation of novel nanotechnologies appeared to have ‘inherited’ a regulatory environment consisting of European legislation (2013: 34) and underpinning policies and assumptions (2012:111). The inheritance is not one simply of regulatory rules but also ‘regulatory dispositions’ (2012:94), which could explain the norms in behaviour identified in the interviews in this study.

Of course, it may simply be that the principles behind the Code of Practice’s matching clause still remains pertinent to clinical practices around donor selection for the simple reason that it continues to reflect patient preferences (either expressed or assumed). Given that the finding of standard matching processes did not hold true across every clinic, or for every patient, it is more likely there are a range of reasons that might influence clinical practice in this regard. More wide scale research of fertility clinics across the UK would be needed in order to fully evaluate the sector’s practices.

iii) Dealing with problematic requests

Respondents' descriptions of clinical management of 'unusual' donor requests further indicated levels of involvement in the selection process. All interviewees were asked if patients had made any unusual requests in donor selection and how their clinic might deal with such requests. The kinds of request raised by respondents included the matching of non-physical traits or the request of a donor of a different race from the parents – examples of which are given in the next chapter, which explores the substantive reasons why such requests are considered 'unusual'. Notably, almost all respondents who said patients had raised unusual requests described typical procedure by an interdepartmental or multidisciplinary discussion.

So, we would have monthly meetings to discuss any unusual cases and it's the first time we had a donor who was requesting a different ethnicity to themselves. We discussed it as a clinical team and there wasn't an issue with that [...] It doesn't happen that often. I was at the previous clinic for five and a half years and that's the only time I remember it happening.
(Embryologist B: 1436)

I do remember situations where certain ethnic groups have asked for a donor of another ethnic group and it being discussed in a multidisciplinary team meeting like an ethics committee team meeting to consider.
(Embryologist C: 2067)

If there were any concerns, we'd take them to our clinical review meeting.

If we felt that we had concerns, or the counsellor had concerns about the choices being made. (Embryologist F: 9956)

As discussed above, Lee et al identified team decision-making involving a range of staff as a feature of clinic's welfare of the child assessments (2015:76). One respondent in this study explained that discussing matters at a team meeting was an express policy of the clinic:

Our clinic has a policy that if there is a concern, for example, about a [potential] ethical concern [... over] a treatment that is being sought, then we would have what we call a multidisciplinary team meeting, we call it an ethics meeting, where we would bring a case and ask all those at the clinics (from our admin staff to our most senior clinical staff) and everyone [...] offer[s] their opinions on whether it was ethical or reasonable to provide a treatment. (Clinician A: 2606)

Attendance at these meetings involved a very wide range of staff:

You have someone from each team taking part in the discussions – clinicians, embryologists and a counsellor and a member of the admin team. Anyone who is welcome to join. (Embryologist B: 1533)

Administrative and other staff are sometimes involved in these meetings, a phenomenon also been observed by Lee et al, whose study demonstrates that receptionists or administrative staff, who may deal with patients over the phone or

at the clinic, were sometimes seen as able to feed into welfare of the child discussions (2014:508). Administrative staff are in a position to witness behaviour that was not observed by other staff. The notion of responsibility towards the future child was a theme expressed by a number of respondents.

If I express a concern that had come up during the counselling session, one of the other counsellors would meet them as well but it'd also be input from the doctors, input from the nursing team, if a receptionist had a fear about somebody, then it's documented and recorded as part of our safeguarding plan. We're a healthcare provider, you have to show evidence of safeguarding. You have to have no ambivalence. We recognise that fertility treatment is stressful, but there's limits. (Counsellor A: 302)

These team meetings must be considered in the context of a fertility clinic's statutory obligation as part of the licensing conditions to take into account the welfare of any child that may be born following the provision of fertility treatment (section 13(5) HFE Act 1990 (as amended)). Coupled with the requirement that clinics must give patients a 'suitable opportunity' to receive counselling (section 13(6) HFE Act 1990 (as amended)), fertility clinics arguably possess a certain culture of oversight over patients' decision-making through their role as treatment providers, a finding also observed by Lee et al (2014:504; 2015:85; see also Davda, 2018: 307). These broader themes were echoed in respondents' reasons for taking donor selection requests to a team meeting, which are explored in Chapter Two.

In almost all cases, clinics proceeded with the ‘unusual’ request described by the interviewee. The review process outlined above was mostly seen as part of the clinic’s safeguarding duties, which was often presented as a reason for possibly not proceeding with treatment. This resonates with the findings of Lee et al, who found that clinics would actively work with patients to resolve potential barriers to treatment (2014: 507).

Because in order to effectively safeguard it means making sure people are capable of making informed decisions, so if there is any ambivalence or naivety, we have to have a clinical discussion to decide whether everybody is happy whether to treat them. And if somebody isn’t then sadly the decision is made not to proceed with treatment. (Embryologist A: 303)

The quotation also reveals that these discussions are about managing staff feelings about treatment, an observation that was made by Lee et al in their study (2015b:48). The reasons why donor selection engage safeguarding concerns in the clinic are explored in the next chapter, but it is rare that treatment would be refused on these grounds (Lee et al, 2014:507).

Quite often respondents would indicate that unusual requests could be resolved by further counselling.

The counsellor discussed that with her in a lot of depth as to why she wanted a different race and I think it was to do with family history, I can’t be certain. But she just had an idea in her mind – I think she might have been a single lady – that she always wanted a partner of that race and

would really like a child of that race. I think it did go ahead, because for us it's not a problem if someone wants a donor of a different race. It's just making sure that the couple or the individual is happy with that choice.

(Embryologist E: 9342)

If there were any concerns about them having treatment I think, rather than the treatment, then yes they might need more counselling. But they may then be offered counselling once the child is born, if they felt they need that, or at the time that they want to tell the child about its origins.

(Embryologist F: 10066)

While respondents pointed out that their welfare considerations could lead to treatment being denied to the patient, none of the respondents believed this had actually happened. However, a clinic may be legally justified to bar treatment if it believed that treatment contrary to the future child's interests. Clinics evidently take their role in this matter seriously. Ultimately, in most cases the clinics appear to go along with their patients' requests, even where the donor selection is perceived as a potential 'mismatch' to the couple.

8. Conclusions

In summary, certain findings were evident from the interviews. First, the data shows that donor selection was discussed between patients and clinics but there was a varying extent of involvement of clinics, with some taking an active approach, others being more passive or reactive to patient requests, and some clinics rejecting any involvement all together. Crucially, the interviews show that clinics do often assume that patients would seek a donor matching, including a

racial match, and might actively facilitate such discussions. While it is not possible within this study to discern how widespread donor matching practices are, most respondents described donor matching in their clinics – although respondents varied in how strongly they felt it was, or should be, important to patients. Racial matching was also often assumed to be the norm, with questions raised over mismatching requests by patients. Clinics also unsurprisingly adopted differing practices and policies in this area, where there is no direct, express legal or policy instruction. The differences observed across the interviews may also reflect the size of the clinic and the realities of donor availability, in addition to the extent to which they may have ‘inherited’ the regulation of donor matching previously expressed by the HFEA.

Second, the early provision of donor information and selection discussions evidence the complex practical and psychological issues raised by donor conception which may present obstacles for patients undergoing treatment. These range from donor availability, various options from where gametes can be sourced, the process of obtaining gametes, and the distress caused to some by the need to use gamete donation. Sometimes the need for further consultations could delay the start of treatment, but such discussions are generally considered positive by clinics as they seek to meet their obligations in offering the provision of counselling and ensuring informed decision-making.

Third, there appears to be a trend towards the increased use of donor catalogues and gamete banks, which is associated with less involvement by the treating clinic in the selection process (yet many clinics still discuss donor selection to varying extents). Meanwhile, some clinics retain more iterative approaches and used small

donor lists, or in some cases even provide one donor option at a time to patients, especially for egg donation. Practices appear to correlate with the size of clinics and type of operation (e.g. whether or not they use an in-house bank).

Fourth, we can discern differences between egg and sperm selection practices, with more choice and selection being associated with sperm donation. More systematic and wide-ranging studies are needed to properly investigate this, however. Relatedly, gamete availability impacts significantly on selection practices. The comparative lack of available eggs has a significant impact on the matching process by limiting choice. The lack of gametes from donors from ethnic minorities also has an impact on the selection process by limiting the range of donors available, and thereby reducing the chances of obtaining a physical or racial match.²⁸

Fifth, the fertility counsellor will often, but not always, discuss donor selection, with some counsellors more involved than others. Furthermore, the findings support the view that clinics invariably require patients using donor gametes to see a fertility counsellor at some point in their treatment. This observation reflects findings from previous studies which identify that many clinics consider the use of counselling as mandatory, when in fact it is not. This ties in with the perception of responsibility that comes with helping people have children discussed above.

Sixth, the content of donor selection discussions includes donor information, but also practical aspects about sourcing gametes from the UK and overseas, as well

²⁸ For a discussion of the difficulties experienced by patients trying to find an egg donor from ethnic minorities see BBC Radio 4, 'Natasha: Trying to find a black egg donor', *My Name Is...*, 6th December 2020, available online <<https://www.bbc.co.uk/programmes/m000d7pg>>

as the wider implications of using gamete donors. The range of content discussed reveals varying levels of involvement by clinics, with some taking a more proactive advisory role, while others are content to allow their patients to make up their own mind away from the clinic's influence. This finding raises questions over what sort of advisory role the clinics should adopt, a question which is raised in the final chapter. It also highlights the scope of selection discussions, and whether matters not relevant to the medical aspects of treatment should be discussed in clinics at all.

It may also represent a certain overreach into the private lives of patients and can be portrayed as an interference with reproductive autonomy. The scope and wide-ranging content of discussion during donor selection also supports a view that in their determination of the welfare of the child, fertility clinics have been observed to discuss the future child in such a way that can be linked to critiques of parenting (Lee et al, 2015:85). However, the provision of fertility treatment is so integrated with legal and ethical issues (for example the removal of donor anonymity and policy moves to encouraging disclosure to donor-conceived people) that it would be unrealistic and unwarranted to ignore such non-medical dimensions.

Seventh, procedures that deal with 'unusual requests' confirm the finding that clinics take seriously their role with regard to the welfare of a future child and that, in some instances, this will extend to scrutinising the choices made about the donor used. This finding complements existing studies that have identified team-decision making as being a particular feature of fertility clinics in discharging their statutory obligations concerning the welfare of the child. Relatedly, the level

of clinic involvement indicated by what is discussed, with whom and when in the course of treatment, is consistent with existing literature that emphasises how seriously fertility clinics take their statutory and broader obligations in assisting their clients to have children – inviting critical examination also.

In summary, the findings set out in this chapter support, complement and develop existing literature by showing that donor matching, including racial matching, occurs in clinics; counselling is often considered to be mandatory; that decisions about treatment are made on a multidisciplinary team basis; that donor selection intersects with wider concerns about the welfare of the child; and that fertility practices display ‘regulatory inheritance’ in the ongoing salience of provisions that have been removed from the legal framework.

This chapter also presents findings that will be taken forward and examined in more detail in the following chapter. These include a more detailed interrogation of why donor matching features as an assumed and routine practice in so many cases; why racial ‘mismatching’ is seen as potentially raising welfare considerations; and what the implications are of donor selection being facilitated by third party and commercial banks.

Chapter Five: The uses of ‘race’ in donor selection

1. Introduction

The previous chapter described the processes by which donor selection takes place in UK fertility clinics, identifying the significant role that clinic staff play in such decisions. This chapter moves on to examine in more detail the key substantive content of discussions presented in the last chapter. As well as describing their own practice and, sometimes, that of other clinic staff, the fertility professionals interviewed were also able to offer insight into the thought processes of patients with whom they discussed donor selection. Although this study did not aim to interview patients, due to restrictions in its scope, the perspectives reported by fertility professionals proved invaluable in generating insight, albeit second-hand, into a wide range of patient experiences than would have otherwise been possible in a study of this size.

The first section of this chapter develops some themes so far identified and considers the donor characteristics that are discussed in donor selection decisions, and which of those characteristics are considered by fertility professionals to be important to patients. It discusses the weight given to physical and non-physical traits and observes the reported level of variation between patients in terms of importance given to donor information, and which information matters to them. The chapter turns to address whether the interviews evidence considerations around genetic determinism or a perceived level of heritability that goes beyond biological science – in that patients may expect their child to look or behave in a certain way based on the donor’s information. The chapter then addresses race specifically – whether race appears to matter to patients and the ways in which

race is discussed. The interviews show that a variety of concepts and phrases were used to discuss race, adding to the complexity of this particular construct.

2. Donor characteristics that are reported as being important to patients in donor selection.

The previous chapter observed that clinics have sometimes quite extensive involvement, both direct and indirect, in the selection of gamete donors by patients, and that a range of staff will be involved in the process. In the section below, the content of those discussions is examined more closely, specifically the range of information reported by fertility professionals as being important to patients, of which – it will be seen – race is just one aspect. This discussion will start by identifying what donor information is considered important and whether this varies across clinics, before turning to whether race, specifically, is considered important in donor selection discussions. In particular, Chapter Four has shown that physical characteristics, including race, are indeed discussed in donor selection through an observation of matching processes; this study now asks what are the perspectives and understandings of fertility professionals in respect to the importance placed on these characteristics by their patients.

i) Physical and non-physical donor characteristics

All interviewees were asked what patients looked for in gamete donors. The data produced a diverse and rich range of responses, largely confirming findings from the existing literature in this area. Several studies have explored what users of donor conception have identified as important to them in donor selection (see Chapter One). Although their conclusions have located donor choice within

broader sociological or anthropological observations regarding kinship building and maintaining resemblance, the more specific question of precisely *which* characteristics patients generally look for in donors and what information provided in the donor information is perceived to be most important – has received comparatively little attention (see Zeifman and Ma, 2012:2; for a notable exception on egg donation, see Rubin et al, 2013). Some empirical studies have compared and contrasted data on what fertility patients look for in gamete donors against those in mate selection more generally (Zeifman and Ma, 2012; Scheib, 1994). These studies point to a high level of complexity involved in trying to pinpoint what patients look for in donors (or partners). In this study, the notion that ‘each patient is different’ was a common theme across the interviews, as well as highlighting that each patient may be given different levels of donor information depending on the mode of donor selection (in clinic or using overseas banks).

We know from Chapter Two that patients generally are given a wide range of health-related, physical and non-physical information about gamete donors. The interviews confirm that the content of donor selection discussions does include the typical range of donor information provided by the HFEA’s donor information form: ‘There are specific rules about what we can give. The [patient] can get characteristics of the donor – height, weight, build, hair colour, eye colour’ (Embryologist E: 9492).

The majority of respondents indicated that the donor’s physical characteristics appeared to be very important to patients:

I think the first thing they go for are the characteristics – the physical characteristics. I think that is most important for the couple. (Embryologist A: 827)

I feel the physical characteristics would be the driver for the selection of the donor. (Embryologist C: 2039)

The finding that physical characteristics are considered particularly important to people undergoing donor conception is also reflected in existing literature (Zadeh et al, 2016b; Hudson, 2015:3; Rubin et al, 2013:313; Nordqvist, 2012:652; Becker et al, 2005). When expressly asked what patients considered particularly important among the donor's physical characteristics, respondents identified a multiplicity of traits. Hair colour and skin tone were frequently identified, and sometimes in ways that associated them explicitly as identifying characteristics of race/ethnicity (e.g. 'complexion' (Embryologist A: 676); see Hudson and Culley, 2014)). Indeed, race – explored in greater detail below – was included by some respondents in the 'core' characteristics that patients look for: 'I assume in the first instance patients are interested in core obvious characteristics, hair colour, skin colour and race' (Embryologist C: 1909).

While respondents indicated that the importance placed on donor information tended to vary according to the patient, race or ethnicity were often said to be of particular importance and references above to hair colour and skin tone may indirectly support such a view. In addition, height (Embryologist D: 3864) and weight (Nurse A: 4358) were also singled out as important features.

Beyond physical information, non-physical information from the donor information form (listed under ‘optional additional information’), was said to be important to some patients. Again, the importance of non-physical information in donor/mate selection has been observed in previous studies. Schieb et al found that ‘character’ was an important attribute mentioned by women selecting a sperm donor (1994). A further study (Zeifman and Ma, 2012), showed a relative preference by those interviewed for sperm donors to be a ‘good parent’ (although both character traits were placed behind indicators of good genes and physical attractiveness). Furthermore, in interviews with men seeking to donate online, Whyte and Torgler identify that income and health were positively correlated with being selected (2016:593), as was describing oneself as being ‘intellectual’.

These same characteristics were also reflected as important in the current study. For example, in this study, occupation was regularly referred to in selection discussions. Education was also said to be particularly important to certain patients (see also Zadeh et al, 2016b):

They go for physical characteristics first, then I think religion. Education is really important [...] they always want a PhD. (Embryologist A: 1214)

Most of our women looking for sperm donors don’t care as much about the physical looks as they do about the education background. They are obsessed with them having been to university. (Nurse C: 5507)

Beyond information on occupation and education, the use of the pen portrait has promoted an even more personalised description of the donor and their

characteristics that extends to other non-physical attributes like hobbies and interests listed under the ‘personal description’ section of the donor information form. The interviews show that such descriptions also featured in donor selection discussions, with some respondents saying that donors’ talents and skills were among the things that patients were looking for:

Certainly, in donor requests that we’ve had in the past, we’ve had people wanting someone who is particularly sporty or who is particularly musical or who likes ballet. (Clinician B: 7032)

Religion was also a factor that was identified as being important by many respondents: ‘One of the biggest things that we find is religion actually – where patients want to have a specific religion’ (Embryologist F: 9972). Another respondent stated: ‘Lots of Hindus and Sikhs don’t want Muslim sperm. We’ve always said, we’re just not going there’ (Counsellor C: 12610).

Religion has been observed as significant in the context of the acceptability of using donor sperm in British South Asian communities (Culley and Hudson 2009:257; see also Argarwal, 2019). Its manifestation in donor selection discussions may represent a complex set of considerations and social structures – religion may also be linked to notions of ‘racial essence’ (Hudson 2015:4, citing Kahn, 2000). In this study, there was some indication from respondents that religion was particularly significant within some ethnic communities, connecting the concept of race to not just physical traits but also cultural matters.

I don't think there is a concern we have as a clinic, but it's often that patients stipulate that they want a particular religion. Particularly in the Asian communities. (Embryologist F: 9978)

Some Asians will not accept different religions and that's been my experience in the past, they specifically said that we don't want to have a donor of a particular religion. (Clinician B: 6914)

The influence of religious and cultural norms on perceptions of donor conception has been explored by Culley and Hudson (2009), who observed particular challenges faced by South Asian women from community pressures to have a child and thus conform to associated cultural norms (2009:262). The authors explain that the intervention of the fertility clinic in reproduction was seen as highly problematic and that the use of donated gametes was considered a last resort (2009:261). This observation was also reflected in this study: 'Muslims aren't supposed to have donation at all. But you've got spectrum – some will have it, so long as nobody knows about it. But some people are just not able to have donation at all' (Counsellor C: 12606). Furthermore, the observed level of specification (in some patients), above, when choosing a donor of the same religion may be indicative of similar cultural norms and social pressures identified by Culley and Hudson (2009). It would be of interest to study the reasons that may underpin such requests in greater detail in further studies.

Other patients were more concerned with health information, revealing a concern for the health of the future child (see also Rubin et al, 2014:313). The interviews evidenced the provision of non-identifying information from the HFEA's donor

information during donor selection discussions as permitted in the Code of Practice. There was also evidence that the donor's CMV status (a common viral infection that causes flu-like symptoms that can be transmitted through bodily fluids, including semen (University Hospitals Coventry and Warwickshire, 2018), for which disclosure and provision is optional but not mandated) was provided to patients and discussed. One respondent said CMV status was, in their view, one of the most important pieces of information for patients.

Despite evident emergent trends in the interview data, many respondents explained that patients varied considerably in what they were looking for in donors:

There's such a level of misunderstanding and poor understanding. And everyone wanted something different. (Embryologist B: 1481)

I think people have their own weighting, their own importance. (Nurse A: 4363)

Some patients are reportedly not so concerned about choosing a particular donor ('Some people are just really not prescriptive at all about it' (Nurse A: 4576)). One respondent acknowledged that some patients just wanted a healthy donor, or simply to get a gamete: 'The vast majority of patients essentially want to know that the donor is healthy and that the donor looks like them. So that is the kind of nub' (Clinician C: 7287). This is especially the case for egg donation, where gametes are less available:

I'd be really honest, most times they are not bothered at all about the characteristics. Most of them are just happy for an egg. So, lots of couples when I say is there anything you are particularly looking for – they just say no. They are happy, even if they were blonde, they would be happy to take an egg from a donor with brown hair or brown eyes. They are really not specific at all. (Nurse E: 11026)

[Patients requiring an egg donor] are far less concerned – just give us an egg, who cares... They know about the availability issues but also they are carrying the pregnancy themselves... Women see other women as being much more generous than other men – there's still that macho crap with sperm count. You know, for women it's a massive act of generosity – for men there's a competition edge to it. (Counsellor C: 12795)

The themes that emerge from the interviews that may underpin selection decisions are explored in Chapter Six, but the empirical observations above raise some immediate (albeit tentative) considerations regarding the weight given to donor characteristics. It is important to highlight that the above findings represent the perspectives and accounts of the fertility professionals interviewed on what in their experience patients found important in donor information.

ii) Genetic determinism and the priority given to physical characteristics

While it is unsurprising to see a wide range of donor information, including physical and non-physical traits, forming the basis of donor selection discussions, the way these traits are reportedly spoken about in donor selection discussion and

their expressed importance indicates a deterministic understanding of genetic heritability. Respondents were asked what they considered to be *important* to patients. The emphasis placed on physical attributes, on the face of it, reflects assumptions about their heritability. This is to some extent supported by biology. Although a person's phenotype (which determines physical appearance) is a complex product of genetics and environment, certain physical characteristics, including height, are more strongly correlated with genetic heritability than others, but even then environmental factors would play a considerable part (Fletcher and Hickey, 2012:149). For example, height is strongly correlated to diet and nutrition, and weight even more so. Although some instances of genetic inheritance are highly predictable – such as Mendelian traits (identified by Gregor Mendel's study of plants (Miko, 2008)), and which are controlled by the inheritance of a single gene – these are most commonly associated with SNP (single nucleotide polymorphism) genetic disorders and are rare (Chial, 2008). Traits included in the donor information form are said to be non-Mendelian, or polygenetic – this is, located across many different genes. Even eye colour, previously believed to be a Mendelian trait, is now thought to be determined by multiple genes (GB HealthWatch, 2019). Coupled with the fact that the child's genes are also mixed with those from the other parent, there is no guarantee that a child would look like their donor. Indeed, as was outlined above, some (but not all) respondents indicated that they would highlight this in consultation with the patients, although some respondents felt informing patients about genetics fell outside of their specific expertise.

The weight given to physical characteristics suggests that some patients could be making an assumption of inheritance, possibly informed by commonplace

understandings of genetic heritability or at least that assumptions about heritability have entered the discourse around donor selection. (Of course, this thesis does not seek to ascertain the views and understandings of patients directly and so any findings relating to this are qualified by their contingency on how discussions generally are reported by fertility professionals). The notion of genetic heritability is further reinforced by the importance placed on non-physical characteristics, such as occupation, religion and education, which are much less heritable than physical traits, if at all. However, while the rationale behind the heritability of physical traits may seep into discussions of non-physical traits, the interviews also demonstrate that more may be at play here.

The reported importance of a wide range of physical and non-physical donor attributes supports the view that the ‘whole package’ presented by the donor is important to patients. One respondent sought to explain the complexity of what patients look for in gamete donors:

I think it goes beyond physical characteristics. It’s all part of feeling comfortable with the donor. They will often look for employment and education. For some people, it’s hobbies or skills. Something that says we are both scientific or they are very artistic. It’s rather like how we choose our partners, on the whole. We are attracted to something that is like. I think there is that that is going on. The physical characteristics is in there, but it’s part of the package. (Counsellor B: 10452)

The importance placed on religion by some patients suggests that not only do the traits and abilities of the donor form in the mind of patients, it is also the donor’s

belief-set, offering a broader and holistic impression of the donor. In that sense, the interviews illustrate that fertility professionals report similar observations to those made in earlier studies that patients are selecting *the donor*, rather than their gametes, in donor conception (Wheatley, 2018). Wheatley points out that patients who purchase sperm are not simply buying donor sperm but are buying sperm from a specific donor (2018). In this way, the transaction can be characterised as an ‘interpersonal’ one between the donor and recipient (the sperm is merely the medium through which the donor’s attributes are delivered), rather than the acquisition and provision of reproductive material (Pennings, 2000). This relationship is unique in healthcare, where other forms of donation such as organ donation – on the NHS – is presented as a healthcare product delivered by the provider rather than a transaction between recipient and donor itself. Fertility clinics are therefore tasked with mediating a relational transaction between patients and gamete donors.

The apparent value-neutrality of sperm has been questioned by several commentators (see, for example, Almeling, 2007) and as Wheatley has argued, is often sold ‘not simply as sperm’ but ‘tied closely to the details of the men who provided it’ (2018:228). According to Wheatley, sperm is considered to be ‘imbued with the specific qualities’ based on an idealised version of the donor (2018:228). That some couples searched for the ‘ideal’ donor – and the difficulties associated with such an approach – was reflected in the interviews, with a number of respondents fully aware of the limitations of such patient expectations: ‘You have no idea what the child is going to come out like. Trying to find that ideal person who does all the ideal things just doesn’t exist’ (Embryologist E: 9739).

However, one respondent indicated that they thought patients on the whole were, in fact, increasingly less interested in wider donor information: ('I think people are asking for less now than they used to. Certainly, five years ago, it was quite common for us to end up printing out the whole [donor information form]' (Counsellor C: 12420)). When asked for their view on the reason for this, the respondent suggested that the clinic might encourage patients to carefully consider if they are indeed choosing the donor rather than the gamete:

I think people are doing actually a bit of reading about it and doing a bit of thinking about it. You are having donor sperm. Are you making this sperm into a person? Think about that, go away, talk to each other. Come back next week, tell me what you want. (Counsellor C: 12428)

While some patients might look for the right donor *for themselves*, the interview respondents reported that some patients may choose donors based on *who they would like their child to meet* – or that this was at least an important consideration in decision-making. The removal of donor anonymity in 2005 has allowed donor-conceived children to access identifying information about their donor at the age of majority, giving rise to the possibility of meeting in future, and which might explain the emphasis placed on the donor's character seen in the interviews.

Donors are encouraged to write pen-portraits of themselves and are made aware that their future child may read them. Furthermore, from the provider perspective, donors themselves have been observed as acting altruistically by exposing themselves to the possibility of being contacted in the future. Therefore, ideas about being the 'right kind of person' is a social construction, and in turn might influence this sort of thinking adopted by patients. Conversely, the removal of

anonymity was also given by some respondents as a reason for believing that people might be less concerned with the inheritance of donor traits as a desire to keep the use of donor gametes a secret diminishes.

Relatedly, not only are donor selection requests unique in many ways, donor information itself is interpreted on a highly individualised level. Adopting Cussins' idea of 'naturalisation', when a patient expresses a preference for certain donor traits, their understanding of heritability may be different from others' (1998). The interviews suggest that patients may be using knowledge about genetics and assisted reproduction processes in reinterpreted ways. According to Cussins, naturalisation involves 'the rendering of states of affairs and facts in a scientific or biological idiom' and demonstrates how uncertainties are reinterpreted to be natural or self-evident (Cussins, 1998:67). These configurations of the 'bedrock' – the 'the moral, epistemic and technical taken-for-granted essential to the practice of infertility medicine' (Cussins, 1998:67) – is revealed in the interview data by the ways in which patients were reported to talk about heritability of non-physical traits in particular. This finding may reflect Nash's assertion, discussed in Chapter One, that discussions of genealogy can slip into genetic essentialism and biological determinism (2002:31), whereby conventional social structures and practices are naturalised by the language of genetics (Nash, 2004:31). Indeed, according to Strathern, natural facts are themselves social constructs (1992:17).

The process capitalises on hope and despite a high failure rate, the discussion of donor information operates in line with the expectation of what *will* happen (having a child), rather than what might happen (a 70% chance of failure). The

variability of genetic inheritance therefore might serve to underscore the uncertainty associated with biological reproduction and assisted conception (Marre and Bestard, 2009:77). Relatedly, by drawing on biological notions of heritability, patients may be attempting to reduce their own sense of uncertainty as part of their efforts to reduce the anxiety associated with infertility and using donated gametes and to instil a sense of certainty around kinship.

Furthermore, the clinical context helps this reconstruction process along. Cussins argues that fertility clinics draw on ‘culturally specific meanings of reproduction and change those meanings in their version of the reproduction of reproduction’ (1998:68). In this study, we can see how the presentation and discussion of donor information portrays notions of heritability. A necessary mutuality in the reproduction of norms of heritability comes into view, which further implicates clinics in the construction of the meaning of donor information. By presenting donor information to patients in the context of helping them conceive, clinics indirectly support a view of heritability that could contribute to inflated ideas of certainty. Indeed, fertility professionals may themselves be involved in the creation of ‘certainty’ in response to the uncertainty of assisted conception, described above.

The emphasis given to physical donor traits and the implication of heritability also raises wider issues. The way that the phenotypic expression of donor information is infused with impressions of genetic heritability in respondents’ accounts of donor discussions raises questions over the way discredited views of heritability and mate selection continue to be expressed in reproductive decision-making (see Davda, 2018:66). Inaccurate references to genetic inheritance evoke deterministic

views of heritability and may reify the categorisation of the human species into physical (and non-physical) characteristics, drawing on the CRT analysis in Chapter One (Quiroga, 2007; Roberts, 1997). It further promotes the expectation of ‘inheritance’, reinforcing the perceived importance of the ‘bloodline’ and genetic connections, while implicating clinics in the classification of donor information in ways that may be charged with the ‘biologisation’ of phenotypic traits, including race (Thompson, 2009:147, cited in Davda, 2018:66).

Furthermore, references to non-inheritable traits such as occupation and education in the reports of patient discussions could indicate the operation of social hierarchies and populist market ‘eugenics’ (Daniels and Golden 2004:6). In their research on sperm banks in the US, Daniels and Golden conclude that both the banks and their customers ‘perpetuate the myth that desirable human traits are transmitted genetically, not socially, and that the traits most characteristic of certain races and social classes are the most desirable universal human traits’ (2004:20). In purchasing such sperm, Daniels and Golden claim that the banks and their customers engaging in the ‘commodification of social ideals’ and are, in effect, hoping to produce (or at least make money from the promise of) a more ‘superior’ child than nature might otherwise grant them (2004:20). Accounts of patient discussions where certain donor information has been understood as being desirable to patients may therefore reflect such observations.

The extent to which this practice applies to fertility clinics in the UK is unclear, but the above discussion makes clear the range of donor information allows patients to express very specific requests and preferences. One such example of a possible ‘commodified’ decision is a patient’s selection of a donor based on a

particular characteristic that does not conform to their own. For example, some respondents spoke of Asian patients sometimes wanting to use pale or Caucasian donors: ‘The most common is wanting pale-skinned Asian donors’ (Nurse D: 8778).²⁹ How such requests are understood by fertility professionals and operationalised by clinics is discussed in Chapters Four and Six.

Overall, the interviews demonstrate that fertility professionals report that patients appear to look for a collection of physical and non-physical characteristics in donors, with a preference shown for physical characteristics. This finding raises tentative observations around genetic heritability, wider concerns of essentialism and commodified decision-making in the donor selection discourse, but also evidences the reconstruction of knowledge at the level of the individual decision maker. Other factors may be at play, including the possibility of the child meeting the donor in the future. However, a high level of variation remains on how much (and which) donor characteristics matter to patients; some respondents say that patients are not bothered at all, but others report that many are. Among those patients that do reportedly find donor characteristics matter, further variation exists between which of those characteristics are important. Whether the patient is seeking an egg or sperm donor is also reported as being significant. The interviews show a greater concern for certain traits when choosing a sperm donor, as well as a stronger preference for matching. This may partly be explained by the lack of available egg donors, but some interviewees did expressly discuss how patients needing egg donors are sometimes ‘not bothered’ about the donor’s characteristics are ‘just happy for an egg’ (Nurse E: 11026). This set of observations paints a complex landscape. However, certain apparent trends do

²⁹ The reference to ‘Asian’ here is more closely associated with ethnicity rather than race, since within the Asian population there are many ‘races’.

emerge, including towards matching (established in Chapter Four) and a priority given to physical characteristics, with indication of genetic determinism operating at least on the face of donor selection decisions. Race is also considered important in these decisions, which is discussed in more detail in the next section.

3. The importance of race in donor selection

All respondents in this study were asked if ‘race’, specifically, was discussed in donor selection meetings and the majority said that it was. Two points emerge from the interviews – first, the interviews show that race plays an important role in donor selection. Second, race was discussed in different ways – sometimes in terms of skin tone, and other times in terms of ethnicity, reflecting findings made elsewhere that race remains highly relevant as a social and discursive construct (Hudson and Culley, 2014). The construct of race was explored in Chapter One and described as primarily being a social (or on some accounts, political) construct, the basis for which is a contested biological version of race as referring to distinct populations separated by certain characteristics but whose meaning has been manipulated and used across societies and eras for a range of purposes.

i) Race matters

A majority of respondents identified that race is discussed during donor selection decisions: ‘[Race] is discussed. Still people want to have [donors] of their own race, the majority’ (Clinician D: 8038).

Many of these respondents also reported that race mattered to patients, although without speaking to patients directly the interviews on provided a partial and second-hand account of patient perspectives:

For some patients, race is a very important issue. I don't think I have ever met a patient where it was a non-issue. I think there are different levels that people would put on it. (Clinician C: 7316)

Just two respondents said that 'race' was not discussed:

No, we've never mentioned race or ethnicity. I don't think I've ever muttered those words when somebody asks me. (Embryologist A: 912)

They talk about their background. I really haven't heard the word race. (Embryologist D: 4067)

This observation is important as it suggests that discussion of race may not be a consistent feature of donor selection discussions (although the data is not sufficiently representative to make wider claims about the frequency of the use of race). However, the observation that in some cases 'race' is not expressly discussed, does not discount the unconscious role that it may play (discussed in Chapter One). It is notable that the respondent Embryologist D claimed to have little involvement in donor selection, instead largely leaving it up to patients to decide through external databases – but also that a discussion of 'background' does not necessarily preclude notions of race.

The normalisation of race such that it may not be consciously discussed, but might otherwise feature implicitly in decision making, was apparent in some interviews. For example, the respondent Embryologist A (above) who said race was not discussed, proceeded to emphasise the importance of race:

[Hypothetically speaking] I am White and married to a White partner, I want White children. I don't want to be too conspicuous and have Black children. ... I think race is the most crucial thing. (Embryologist A: 869)

While this respondent had noted that there was no express discussion of 'race', this comment demonstrates how race can feature unconsciously in decision-making, with racial matching normalised and largely invisible. Having switched from saying race played no part in discussions to acknowledging its role in the process, the interviewee went one further by saying it was '*the most crucial thing*' (my emphasis). According to a CRT framework, it may nonetheless be possible thematise what is otherwise invisible (Cross, 2010:416). In this study, the interviews where race was unconsciously downplayed or not expressed, or where assumptions were made around matching preferences, therefore offer points of analysis for the conception of race and racialised practices.

It is not simply the range of information provided, but the forum in which decisions are made that appears to facilitate patient-donor preferences. As identified in Chapter Four, patients often reportedly use donor catalogues or overseas banks in their selection of gamete donors, which list donors searchable by their characteristics, including race, nationality, hair and eye colour, and so on. Where pictures are involved, the donors are also sometimes presented in a

visually attractive manner. The wider selection of donor information is sometimes presented to patients in a way that can be sorted and prioritised, allowing patients to express their donor selection decision according to their preferences (although not all patients have access to this degree of choice). Furthermore, the expression of patient–donor preferences in the clinical setting raises questions over the extent of the clinic’s involvement in managing patient expectations (discussed in Chapter Four).

There is therefore an evident tension in the analysis of what is perceived to be important to patients. On the one hand, the interviews reveal that fertility professionals perceive a localised and individualised creation of meaning that operates within the patient’s own private and immediate sphere. On the other, such discussions, associations and the perceived level of importance placed by patients on donor information raise wider implications. Crucially, this tension is further mediated by professional involvement, implicating the clinic in these social processes (explored in Chapter Seven). Race clearly matters in many cases, but before exploring why this may be so, the various ways in which race was discussed also presents a number of important findings on the nuances and constructions around race.

ii) Ways of discussing race

References to the word ‘race’ may be surprising given that the donor information form provided by the HFEA does not refer to ‘race’ but instead asks donors to state their ‘ethnicity’. However, some clinics’ own donor profiles did include the word ‘race’, which tended to relate to the same ethnic groups as those associated with the HFEA’s donor information form. The word ‘race’ therefore remains in

the discourse around donor information. The word race is also often used in common parlance about heritability and people's appearance, of which discussion is triggered in part by the donor information that lists a donor's physical traits. Alternatively, the interview questions and interviewer introduced the word 'race' into the conversation. Indeed, despite its scepticism of the concept, the title of this thesis itself adopts the word.

As seen in the quotations above, the word 'race' itself featured prominently in some discussions in this study. While the use of the word 'race' may therefore reflect seemingly ordinary references to the concept in contemporary discourse and conversation, it is important to note that in the interviews, respondents spoke about race in different ways – and these different constructions may reflect more complex and nuanced understandings of race.

Some respondents clarified that ethnicity, rather than race specifically, featured in the discussion. As distinct from the word race, ethnicity is often interpreted to refer to persons from distinct national or cultural communities.

For some people [ethnicity] would be very important and for others it would be less important. I do think people would consider it an extremely important part of their decision making. (Nurse A: 4738)

The dictionary definitions of race and ethnicity are discussed above, and according to these definitions, race and ethnicity can be contrasted as referring to physical and cultural dimensions respectively. However, as seen in the discussion in Chapter One, the construct of race is much more than about physical

characteristics but is more accurately about the *construction* of both physical and non-physical characteristics within certain social and political spheres. It is therefore on some accounts a wider construct than ethnicity – a component of the race construct.

As such, ethnicity can be said to be a ‘race-like’ category (Wade, 2014:588). For analytical purposes, therefore, references to race and/or ethnicity may engage the same or similar set of considerations. As Wade explains, ethnicity can be deployed in a racialised way and the tracing of race-associated categories, such as ethnicity, can reveal underlying continuities that allow us to construct race as an analytical term (2014:588).

Indeed, the interviews in this study show that there was a certain slippage in terminology between ‘race’ and ‘ethnicity’, with some referring to broad categories of ethnicity when discussing ‘race’. For example, in discussing ‘race’, respondents might refer to ‘Asian’, ‘Caucasian’ or ‘Black’ donors (Counsellor A: 151, 289), without further specifying, for example, ‘White British’ or ‘White Irish’. Furthermore, while the word ethnicity tends to have more cultural associations, it was often also used to refer to physical characteristics that others might associated with race, revealing confused, contested or varying definitions of race. As one respondent said:

For [the patients] I feel it is the way the child looks so the colour of their skin is as important as the colour of their hair, but it just so happens the colour of their skin is called ethnicity. We don’t have such questions over

blonde hair or blue eyes like you do over white versus black skin.

(Embryologist B: 1662)

In fact, no respondents spoke about ethnicity, specifically, as related to national or cultural traditions. Conversely, those respondents who spoke about ‘culture’ or ‘heritage’ referred to them in the context of race discussions. One respondent equated race (rather than ethnicity) with cultural heritage raising questions around cross-race donation regarding the child’s ‘different cultural heritage’ (Clinician D: 7918). Despite evidence of the ethnic categories used by the HFEA on the donor information form in discussions of both race and ethnicity, it is also clear that for a number of patients, ‘race’ appeared to denote a certain set of physical characteristics.

Other respondents also spoke about race indirectly where they associated it with a set of physical characteristics, such as skin tone, on which patients were observed to place importance. The reference to a set of physical characteristics in the discussion of race was common. As one respondent said:

I assume in the first instance patients are interested in core obvious characteristics, hair colour, skin colour and races – it feels like [race] is a contributing feature, patients are usually focused on for complexion matches and their complexions. (Embryologist C: 1910)

The respondent went on to clarify that complexion in some cases may be used as a shortcut to race, without using the word itself (patients and respondents may, of course, be consciously wary of using the word ‘race’ so as not to appear ‘racist’):

Maybe [patients] mask the urge to comply or to maintain a similar race in the donor by using complexity of skin complexion as a way of not being able to be so overt and say, look, I want to make sure I've got a donor from this country or a donor from that country or a donor of this race and that race. (Embryologist C: 1940)

One respondent who identified race as being particularly relevant to patients, proceeded to discuss the importance of features such as 'dark-skinned' or 'red-haired' (Embryologist A: 882) – which could explain the respondent's later comment that the clinic never discusses 'race' (Embryologist A: 912). For this respondent, race appeared to represent a set of certain physical characteristics that formed part of the donor selection discussion (although they did also explain the deliberate avoidance of the word 'race' to avoid upsetting patients (Embryologist A: 946)). There was a clear separation here between race and ethnicity:

Race is very clear where you stand – it's either Asian, Black, Caucasian, mixed-race. Ethnic origin you are really more specific. You can be Caucasian, English or French. It's being very specific here. I don't think [ethnicity] is very important, [race] is very important. Race rather than the ethnicity. (Embryologist A: 981)

One respondent also appeared to separate considerations of culture (which may be associated more with ethnicity) from race, which raised issues of physical characteristics:

Many [patients] will want to know the fertile status of the donor and so has she donated or he donated before and other pregnancies. Sometimes culture. Race normally falls into looks, I suppose, does the donor look like me. (Clinician C: 7293)

The physical variations between persons within a single ethnic group were also commented on by other respondents:

Kenyans, Nigerians and Ghanaians will not use each other, just because they have all got black skin [...] they have very, very different facial characteristics. Kenyans are quite small, Ghanaians quite broad, Nigerians very tall and Kenyans have quite pointy noses – it's just completely different characteristics. I've had a French couple come in and say they won't use anything but a French donor, and it's like... I don't know where they are from, they are Caucasian, and that's an ethnic group but they want it to be from France (Nurse C: 5646).

The equation of skin tone and ethnicity suggests how the term 'ethnicity' manifests as particular physical characteristics rather than as a reference to cultural traditions, at least on the face of it (Hudson and Culley observe that race is rarely absent from discussions of ethnicity as biological markers to indicate social and cultural differences between groups (2014:232)). Hair and eye colour could also be associated with race, but as the earlier quotation pointed out (Embryologist B: 1661), European White ethnicity itself encompasses significant variation between skin tone, hair and eye colour, which is considered relevant to certain patients. This observation may reflect what Kroløkke terms, 'affective

assemblages', where an imagined Western European hybridity acts as a stand in for racialised understandings (2014:68). Therefore, in discussion of race, aspects emerge of both physical traits and non-physical characteristics, such as culture or nationality, which are sometimes distinguished and are other times used to signify overlapping constructs. The 'messy' use of language is characteristic of social discourse and serves merely to promote the analytical value of the interviews in this study and add various perspectives to the complex constructions at play.

The interviews in part reveal that how race is discussed in donor selection with reference to physical characteristics and the use of the word 'race' as a category, in itself, might reify an essentialist view of race that has been used to categorise populations according to certain physical features such as hair or skin tone (the implications of this observation are explored in Chapter Seven). Historically, the use of the word 'race' as a noun can be traced back to the sixteenth century where the word was used to signify different groups of people separable by certain physical characteristics (Richards, 1997). In this way, references to physical characteristics associated with race in the interviews may evidence the invocation of discredited notions of race as something reducible to a visually detectable set of characteristics (Bender, 2003; Roberts, 2011:29). The connection between donor features such as 'skin complexion' and 'pointy noses' and race, observed above, echoes Swedish physician Carl Linnaeus' use of physical characteristics to subdivide the human species into four regions of the world: Europeans were described physically as 'muscular' and 'blond', Americans as having 'black hair', 'wide nostrils' and as 'beardless', Asians as having 'black hair, dark eyes' and Africans as having 'black kinky hair', 'silky skin', 'flat nose', 'fat lips' (Roberts, 2011:29; see Chapter One). It is also notable because this information is not

typically provided on the donor's information form (hair colour is), revealing that in some cases that a donor's physical attributes are imagined from a projected view of their race (or ethnicity) – possibly locating such references to race in wider social discourse beyond the immediate material relied on during donor selection. Yet it is clear from the discussion above that donor information including ethnicity and physical characteristics are packaged up by patients and associated with the word 'race' – if not expressly referred to as such.

Such an assessment of race fails to recognise the complex construction processes that operate around its usage. The use of the word 'race' in many ways transcends donor information and implies something that cannot itself be captured by the categorised information – more akin to the ethereal concepts of ethnicity (Mason, 2008:37); something more fluid and contextual in its meaning. The fluidity of concepts is clearly described in the extracts above. Phrases such as 'it just so happens the colour of their skin is called ethnicity' (Embryologist B: 1662) reveal the merging of concepts. Many patients' donor preferences would also be more specific than categories of race and ethnicity – for example, the French couple who would only use a French donor within the broad ethnic category of Caucasian (Nurse C: 5646) – showing that race for many patients was merely part of a much larger set of considerations ('ethnicity is core information *along with* your physical characteristics' Counsellor A: 6494). Race, for many patients discussed in the interviews, meant much more than, say, skin tone – and skin tone, conversely, represents more than 'race' (see Thompson, 2009).³⁰ Such layers of complexity have also been observed by Thompson who, in discussions of skin

³⁰ It is important to note that the views of patients here are expressed through the words of fertility clinic staff and their observations may at times be mixed in with their own opinions of the role of race.

tone in the selection of egg donors, identified connections not only to physical resemblance but also geopolitical and religious bases of identities (2009:147).

This makes the use of 'race' and its meaning particularly difficult to pin down. We saw above that donor information is interpreted in different and unique ways by patients and the interviews suggest that similar construction processes rotate around race, specifically. Indeed, outdated essentialist views of race as representing fixed and rigid biological definitions have given way to constructivist models of race that assume no objectively verifiable definition of race. For many theorists, race should instead be interpreted through various social and political processes and cultures (Roberts, 1995). The deconstruction of race is furthered by scientific developments in genetics that improved biological understandings of variation (Hartigan, 2008:168). The view of race as being a problematic concept was reflected by a number of respondents in this study:

There is no race. They are different characteristics. I don't know where it comes from. I can't remember people talking about race. (Embryologist D: 4066)

The social and political processes that underpin discussions of race in the donor conception context may be different from those associated with oppression and subjection, as argued by many critical race theorists. Retaining the view that there is no fixed definition of race, overall the interviews demonstrate that race signified a range of physical and non-physical information in the 'imaginings' of patients which took on a different meaning through the lens of kinship and the construction of relatedness, discussed below. The variability between references

to the word 'race', its avoidance, and its replacement with the word ethnicity, demonstrates the contested and problematic concept of race itself. As such, race is not rendered unimportant and its contested social and political dimensions remain relevant, but the interviews show that the concept of race is retranslated through a subjective and individualised construction processes that operates very much on the patient's level.

Overall, it is important to highlight that the uses of race identified in the interviews as part of this study correlate in part to critical assessments of how ARTs and donor conception perpetuate the notion of a biological basis for race and social categorisation, race preferences, monoracial coupling, and patriarchal family models. However, the interviews also reveal that much more is going on and that requests for racial matching are not necessarily restricted to certain groups or ethnicities, nor is it consistently requested. The way race is reportedly spoken about reveals a more complex set of construction processes in which the concept of race is recast through the lens of the patient's own perspective. As Thompson argues, a more 'dynamic' aspect of biological racialisation is needed (2009:132) that captures how understanding of human biology entwine with social categories of populations. She suggests that the question to be asked is – 'How and by whom and for what purposes is race biologised and biology racialised?' (2009:132).

The combining of insights derived from both CRT and NKS allows for a more nuanced discussion of the importance of race and resemblance in ARTs, allowing us to interpret the deployment of race through concepts of relatedness and kinship in such a way that emphasises its fluidity and underpinning processes of

construction, as well as its conceptual depth to indicate meaning beyond physical information and tied in with personal/interpersonal identity (Thompson, 2009). This approach challenges the interpretation of essentialism and reinvigoration of outdated biological definitions of race discussed above as a singular phenomenon around the use of race and paints a much more complex, nuanced picture of its usage. Building on notions of reconstruction of knowledge, the manner in which sociologists and anthropologists have observed the creation of kinship in assisted conception supports such processes around donor information and meanings within assisted conception more widely

4. Conclusions

On the question of how race is deployed in donor matching practices, a number of key findings emerge from these interviews. First, it is clear that respondents consider that a wide range of both physical and non-physical donor characteristics is deemed important by patients, with a particular emphasis placed on physical characteristics. What emerged clearly from the interviews was that patients may hold beliefs that display a level of genetic determinism that goes far beyond that which is supported by the science. Consequently, some respondents reported that the ‘whole package’ represented by the donor information is used by patients in their selection decisions, indicating that patients often (but not always) select donors based on their impression of them as a whole – and as a person.

Second, respondents observed that some patients expressed a preference for particular phenotypic traits as more desirable (for example, lighter skin tone), which raises questions over the extent to which patient preferences may be racialised, as observed by some critical race theorists who have examined

reproductive decision making, discussed in Chapter One. However, there may well be additional considerations that make up the bigger picture. The discussion of donor information also reveals highly individualised approaches by patients, who were seen to interpret donor information from their own understanding of genetics and heritability and according to their own perception of what would fit in with their lifestyle and social sphere.

Taken together, the emphasis given to physical characteristics and the ordering of such characteristics according to preference reveals how this language of biological and level of genetic determinism, while contestable, lends new ‘truth’ to what may otherwise be perceived to be largely unfounded beliefs of heritability. For example, the interviews indicated that many patients showed considerable interest in donors’ personal skills and attributes *as if* such traits are heritable to bring them closer to accepting donor conception and helping create a more stable narrative of the likely outcome. Patients were seen to select donors based on characteristics that fitted in with their own understandings of reproduction, genetic heritability and their experience of infertility/donor conception, although without interviewing patients directly these observations are only tentative.

Finally, it was evident that respondents felt that many patients considered ‘race’ important in donor selection. Relatedly, the interviews show that race was directly and indirectly discussed in gamete donor selection. References to race and ethnicity, as well as physical characteristics that may be associated with race, therefore raise important considerations for fertility clinics and donor banks alike. Race is clearly a term heavily imbued with social meaning and was deployed to

mean different things by different respondents. This chapter demonstrates how race was discussed in various ways: sometimes the word ‘race’ was used expressly, sometimes ethnicity was used in its place; sometimes race was differentiated from ethnicity and in other cases there was no express reference to race or ethnicity but associated physical traits of the donor were discussed instead. The interchangeability between race and ethnicity is significant due to their differentiated meanings, as outlined above: ethnicity refers to a group of persons distinguishable by culture.

While certain references to ‘race’ alongside physical information may evoke essentialist views of race as having a biological basis, showing how race may be ‘reinstated’ as a biological category (Deomampo, 2019:629), such interpretations do not necessarily capture the entire picture. The importance placed on race may be more accurately explained by the complex social constructions that operate in this arena. Discussions of race are evidently part of a series of complex processes of construction, as well as the product of immediate and wider social, cultural and economic influences across a range of diverse and different situations, times and places (see also Bender, 2003). The interviews reveal a highly nuanced notion of race in the donor selection context that borrows from and reinterprets pre-existing racialised norms. The interviews show that ‘race’ – as conceived by patients – resists categorical definition, instead representing a more fluid and changeable concept that represents a much wider range of interests and issues. Overall, it was observed that respondents felt that patients often expressed a desire to achieve resemblance as part of the construction of relatedness. The factors that underpin this decision-making are discussed next.

Finally, the findings described in this chapter, coupled with the observations in Chapter Four, highlight the role that fertility professionals play in the construction of race in the donor selection or matching context. This emphasises how the donor matching processes is a relational one managed by fertility professionals who play an important role in the construction of race and donor characteristics (Moll, 2019: 598).

Chapter Six: Why is race deemed important in donor selection?

1. Introduction

This thesis has so far demonstrated a range of important observations in its exploration of race and donor matching. Chapter Four outlined a range of processes that operated around donor matching, showing that racial matching occurs in many instances. Chapter Five then identified that patients were observed to place importance on race and racialised characteristics, as part of a concentration on physical characteristics, but also in some cases as part of an extended understanding of character (and misunderstanding of the heritability of character). Furthermore, both chapters evidence a wide variation in practice and a high level of complexity both around the processes employed but also the constructs used when discussing donor selection. This chapter turns to the underpinning reasons for these observations regarding race specifically: within the context of donor selection, why is race considered important? Why do clinics and patients seek a racial match when choosing a donor? Given the range of normative implications in the usage of race discussed in Chapter One, any answer to these questions adds vital perspectives that could help inform the analysis of race and also even, it is hoped, future policy.

This chapter starts by identifying the perceived reasons why race was deemed important in donor selection, before turning to why this matters. It is important to highlight that the data discussed in this chapter rests upon a constructivist logic, whereby the meanings given to race are displayed through the reports of interactions and behaviours of patients and conveyed through the interview model

of data gathering (James and Busher, 2009). As discussed in Chapter Three, interviews can only provide a partial account of the phenomena studied and so therefore the findings in this chapter are not a factual account of practice but fertility professionals' interpretation of donor selection. Nevertheless, it is clear from the discussion above that race was deemed an important consideration to many, if not all, donor recipients. Interview respondents were also asked for their views on why this was the case and why patients made the selection decisions that they did. A central theme emerged from the interviews: patients sought physical matches to their donor primarily in order to achieve a resemblance between themselves (or their partner) and their future child. The importance of resemblance was underscored by a range of factors. First, some respondents explained that patients expressed particular concerns about privacy, with physical resemblance not an end itself but a means to allow them to keep their use of donor conception from being obvious to others. Second, the importance of resemblance was also explained in terms of its role in the construction of kinship and relatedness. Third, resemblance appeared to play an important role in the narrative building or storytelling engaged in by fertility patients. Finally, respondents also noted that some patients were concerned about the social and psychological effects physical dissimilarity would have on their child and family unit.

These themes are not distinct but were observed to interweave in complex ways. For example, considerations around the welfare of the future child may overlap with notions of resemblance and fitting in, or with attempting to maintain privacy around donor conception, or even the importance of narrative building. Tensions also clearly exist between the importance (and respect for) patient autonomy on

the part of patients on the one hand, and welfare considerations on the part of clinics (and also patients) on the other.

2. Achieving resemblance

When asked why patients looked for certain characteristics in a donor, many respondents indicated that donor selection was planned in order to achieve resemblance between the patient (and/or their partner, if any) and their child, reflecting the importance placed on resemblance identified in the existing literature (see Nordqvist and Smart, 2014; Pennings, 2000). Primarily, the interviews show that some patients would seek a donor that matched their own or their partner's physical characteristics:

Couples are, I'd say the majority of the times couples just want to match characteristics similar to themselves. (Embryologist C: 2237)

Other respondents said that resemblance extended to the wider family also (see Nordqvist, 2014; Becker et al, 2005):

It is not necessarily resembling themselves but resembling their family. It is not necessarily then as individuals... I think people see it as more of a familial thing, not everybody, I think lots of people do, some people talk about extended family. (Nurse A: 4754)

The implication of selecting donors based on similar characteristics is that the resulting child will more closely resemble the parents undergoing donor conception and/or their family. References to race were also seen by many

respondents as implicated in the notion of achieving resemblance between the patient and child:

Still people want to have them of their own race, the majority, the majority. Asian people like to have a child that *looks* Asian. (Clinician D: 8037)

I think that certain individuals are very keen on having somebody who is a very clear match to them, both from their physical appearance. Therefore, this specific race, for example, you may find that an Asian patient would accept a Turkish donor, because they are a similar colour ... on the whole it's because they want the person to *look like them*. (Clinician B: 6910)

Achieving resemblance, on the face of it, appears to denote a need for physical similarity. Some respondents said this was particularly important when donor sperm was used by heterosexual couples (see also Pennings, 2000):

It's a concern when it comes to us with the man being the partner [of the recipient] ... [the female patient is] very very worried that the child would not resemble the father and they spend a long time looking for sperm donors. (Nurse C:5486)

Relatedly, respondents said that the desire to achieve resemblance was less important for same-sex couples, an observation that has also been suggested by Pennings (2000:509):

The majority of women using sperm donors are single or in a lesbian relationship so they are not looking for that resemblance. (Nurse C: 5493)

Although it is important to note that the interviews also demonstrate matching preferences for same-sex couples, discussed in Chapter Four. Once again, this shows that donor preferences vary considerably across patients.

The importance of resemblance was also seen to underpin non-physical matching. As the quotation above demonstrates, patients are sometimes matching on their ‘intellectual’ basis (Embryologist A: 690). Chapter Five also identifies importance placed on non-physical characteristics (see also Clinician B: 7032, above: ‘we’ve had people wanting [a donor]... who likes ballet’):

Our patients, over the years have said, ‘Look we are very musical. Do you have any donors who have a musical gift or tendency?’ (Clinician C: 7432)

Respondents were asked to explain why this was important to patients and provided a range of reasons including the need to maintain privacy around the use of donor conception, the construction of kinship and relatedness and also narrative building.

3. Privacy

One reason given by respondents for patients seeking to achieve resemblance is to maintain the privacy around the use of gamete donation:

The more typical a family look, the less questions there are about the origins of those children. (Embryologist E: 9438)

But more often than not people would like a donor who matches either their partner or their characteristics. In my personal opinion, it's generally so that it's not too obvious that they are using a donor. (Embryologist E: 9329)

The removal of donor anonymity in the UK was described in Chapter Two. Parents are now encouraged to inform children early on about their donor conception origins (HFEA, n.d.j). The reference to maintaining secrecy above therefore appears to be at odds with current thinking and trends around disclosure, but this does also depend on whether patients are seeking secrecy (in not informing their children of their donor-conceived origins) or maintaining privacy (in not informing others, or not making donor conception obvious). However, the above reference to secrecy in the community echoes concerns about a child being stigmatised if it became known that they were donor conceived (Daniels and Taylor, 1993:157). This concern has particular salience when one considers the different cultural values of different communities within the UK. Culley and Hudson identify that the meanings associated with infertility and the need to use gamete donors may be different for those from some ethnic minority backgrounds than White British (2009:251). As one respondent confirmed:

It is a very sensitive topic. Particularly, with some groups, not only ethnically different, but religiously different. I've had a few Muslim couples. It was obvious that it would be a secret ... Donor is absolutely not

acceptable ... absolutely I am never going to talk about it to anyone.

(Embryologist D: 3565)

Culley and Hudson's study of British Indian, Bangladeshi and Pakistani communities in three cities in England revealed that the use of donated gametes from a third party was considered highly problematic (2009:261). A decision to keep donor conception a secret is therefore a very personal one to the patient and is influenced by the society, culture and time in which they live. Not only is harm in this context impacted by the social-cultural context, it is highly subjective and involves contested definitions of the child's best interests. Turkmendag et al challenge the 'autonomy based' moral reasoning that justifies disclosure of donor-conceived origins, pointing out that most parents routinely decide what is best for their children (2008:302). A dominant theme across the interviews was that patients largely spoke about the donor selection decision in terms of its fit with their own views of family and their future child's welfare.

Finally, the removal of donor anonymity does not provide a consistent explanation for the way concerns around privacy are expressed by patients. The interviews also indicate that the removal of anonymity has meant that more people are open with their children about donor conception, with implications for donor matching:

Because more people become open then matching becomes less important

... It's not as strict as before, because they are more open about it.

(Clinician D: 7995)

For some of them, when they are starting to be so completely open, the physical characteristics don't have the same importance. (Counsellor B: 10386)

However, for others, it made resemblance even more important (again, linking to cultural obstacles over the acceptability of donor conception):

I am convinced from clinical impression that since [the removal of donor anonymity] there are more secrets now than before, because people who are of ethnic groups where the family are more both important and intrusive. (Embryologist D: 4019)

The expressed wish to maintain the use of donor conception a secret has also been observed by Nordqvist and Smart (2014). Despite the removal of anonymity, non-disclosure was still seen by some respondents as quite widespread:

I think [many] patients go overseas for egg donation because they want to remain anonymous and they may not have an intention to tell the child. They want to retain that possibility. They want the child to look like them as much as possible. (Clinician B: 6885)

Significantly, even for patients who have decided to be open about their use of donor conception, respondents still indicated a preference for a match:

I think the matching criteria started when nobody wanted to make it public. The closer the matching criteria the better. Now, some people are

open and so they don't necessarily stick exactly to the matching criteria.

But I think, generally, people still want to have the donor that match with them. (Clinician D: 8070)

This reveals that preferences for donor matching to physical characteristics are not entirely explained by the need to maintain privacy or secrecy for all patients. The concept of privacy is not absolute, of course: while some people may be comfortable with not keeping their use of donor conception a secret, they may not necessarily wish to advertise it to others. This sentiment could also be detected in the interviews presented here:

From the whole—and in part, because there is a privacy issue for them and the child, because even if you are open, you don't want to go around with a large label on your front. If you look very different then it's going to raise questions ... amongst people you might not choose to be. You can be open without shouting it from the rooftops. (Counsellor B: 10419)

As seen in the Northern Ireland case discussed in Chapter One (at 2.iii; 3.ii), the family involved express significant distress at having to explain why their children appeared to look different to casual acquaintances (Sheldon, 2011; Starza-Allen, 2010; Duggan and McCandless, 2015). The perceived difference in resemblance between parent and child gave rise to concerns about infidelity on the part of the parent – a concern that was particularly felt by the family in Northern Ireland, who lived in a predominantly 'White' community. The interviews demonstrate also that a desire for resemblance was in some cases underpinning by

attempts to keep the use of donor conception a secret, so to avoid raising questions about the legitimacy of their children.

I also think it's just fundamentally that people don't want questions being asked about their child. Some people don't think it's necessary for them to know about their use of a donor, and I think some communities can be very secretive about using a donor, and it is very frowned upon to use a donor. The more typical a family look, the less questions there are about the origins of those children. (Embryologist E: 9416)

This quotation emphasises how it may not only be necessarily the notion of legitimacy or the 'bloodline' that families are seeking to present as a phenomenon important in itself, but the invasiveness of people asking questions. The underscores the idea that what is at stake in many of these cases is a question of privacy, rather than maintaining secrets – indeed, many parents may opt to disclose the donor-conceived origins to their child and to close family or friends, while not wishing others to know (or to ask questions about a private matter).

'Privacy' is thus a complex and multi-faceted concept, that is expressed in different ways in this context and is profoundly influenced by different cultural values. While discussion of its salience to donor selection intersects in important ways with the debate regarding the removal of donor anonymity and the child's 'right to know' his or her genetic origins, there are also important differences to be born in mind.

4. Kinship and relatedness

Whether or not a patient intended to disclose their use of donor conception, the interviews indicate a certain preference for resemblance. Beyond privacy, a common explanation for this was that patients wanted donors to resemble other people in their family so that the future child would ‘fit in’ to that unit – whether or not it was known they were donor conceived (see also Rubin et al, 2013:313). As one respondent explained:

It’s not about being deceitful or conning a child who is donor conceived, it’s about actually just being easier to fit in when we’re similar.

(Counsellor A: 188)

Physical and non-physical resemblance is therefore associated with ‘fitting in’ more generally on a familial and a wider social level. Commentators have observed that the selection of a donor match in order to achieve resemblance allows patients to construct relatedness in the absence of a genetic connection to their children (Nordqvist and Smart, 2014:132; Hargreaves, 2006:269). The interviews in this study support this interpretation, revealing that some patients clearly sought a resemblance between the future child and the wider family.

It is not necessarily resembling themselves, but resembling their family ...

I think people see it as more of a familial thing, but not everybody. Some people talk about extended family. There was a lady with red hair, and all she wanted was a child with red hair because all the cousins and all the siblings, all the brothers’ children, they all had red hair. That was the

important thing, she didn't care about anything else so long as the donor had red hair. (Nurse A: 4753)

The reference to 'red hair' shows that the patient here may be seeking to avoid departing from a particular feature that ties the family together (as well as a misunderstanding of heritable traits, discussed above). Physical similarities (such as hair colour) between family members have been observed to confer a sense of relatedness and shared identity (Marre and Bestard, 2009; Nordqvist, 2014:47). The process of identification of shared physical similarities, attributing them to familial identity and exercising a preference for such features in donor selection may be illustrative of the 'cultural imagination' observed around family bonds that allows patients, in the context of donor conception, to reclaim the genetic connectedness lost through the use of donor conception (Nordqvist and Smart, 2014:134; Strathern, 1995). The use of the identifier of 'red hair' to signify relatedness ties in with popular cultural impressions of how particular features unite and identify families, much like phrases such as 'he's got the family nose'.

As discussed above, the concept of race is associated with a discussion of physical characteristics in a number of ways. For example, some respondents grouped race along with hair colour and skin tone together to indicate complexion, according to which some patients were said to seek matches. It was also seen that some respondents who claimed race was not discussed, did indeed discuss racialised characteristics. 'Red hair', as well as 'dark skinned', were examples of characteristics through which race was implicitly discussed. Therefore, race can be implicated in this broader notion of 'fitting in' through the implicit and express references to race in discussions about the family context.

Underpinning the perceived desire for resemblance to achieve relatedness is the notion of ‘legitimacy’, both in the ‘strong’ sense of the phrase, which in the context of reproduction is borrowed from family law to refer to a child that is genetically related to the parents, but also more commonly weaker versions that refer more broadly to genetic relatedness discussed above. The notion of legitimacy gives a good measure of the importance of resemblance to patients. For example, some respondents spoke of the need for resemblance, or specifically the risk of dissimilarity, as causing great concern for certain patients:

It’s often my experience that patients really want to try and have a child in their likeness and they are very worried about having a child in their likeness. Indeed, one of my patients, recently, who made a particular choice of donor, because she was quite a fair skinned lady, but she wanted somebody with, believe it or not, a big nose, because she’s got a big nose. So we went for a particular donor of an ethnicity who is Greek and she was very concerned that the Greek donor would be too dark and that she’d have a dark baby. (Clinician B: 6854)

The concern expressed by the patient here echoes the words of a parent involved in a sperm mix-up that resulted in their children being of a different skin tone to their parents, discussed above. It also supports Becker’s finding that patients harboured fears that errors could result in a child of a different racial or ethnic group (Becker et al, 2005). Indeed, even the possibility that a child’s skin tone could be *interpreted* as a marker of racial difference from the parent caused concern. Physical resemblance between the child and parents suggests (from the

outside) a biological linkage and in this way, the importance of resemblance reflects the wishes to maintain the use of donor conception a secret. In this way, race – as a signifier of physical resemblance – plays a role in displaying relatedness. A lack of resemblance, as Davda explains, is seen by recipients as a ‘kinship risk’ (2018:256).

The discussion above of ‘fitting in’ to the family unit is underpinned by the idea that resemblance legitimises the child to the outside world regardless of the knowledge of its donor conception origins (Becker et al, 2005). Nordqvist observes that perceived physical resemblance can confirm family connectedness and this can establish such families as socially ‘legitimate’ (Nordqvist, 2010: 1132).³¹ In this way, resemblance can help ‘legitimise’ the child into the family both from an internal and external perspective and is linked, potentially, to the manifest well-being and functioning of family life. The interviews in this study indicate that patients may evoke conventional family and kinship discourses as they ‘rehearse hetero-normative ideas of family recognition’ (Marre and Bestard, 2009) even in situations where the families themselves are visibly ‘unconventional’. As discussed in Chapter One, race (as an inheritable concept) has been observed to play a role in the construction of genetic relatedness, albeit – according to Quiroga – in such a way that preserves a White, patriarchal family model (2007:144). Through the prism of resemblance, it can be said that race is sometimes used to underscore a genetic connection between family members, offering a particular sense of legitimacy grounded in shared physical

³¹ On the other hand, this study also showed that contrary to such findings, one respondent indicated that it was different for same-sex couples: ‘I think same-sex couples can be more open to the different options and they are not as concerned with how the family unit will look’ (Embryologist E: 9482).

characteristics, or similarity. An emphasis on race as a shared physical characteristic may represent models of kinship whereby relatives are bounded by the bloodline, which is seen as a defining feature of the family (Strathern, 1992; McLaughlin, 2004). In the donor conception context, where there is no genetic connection or blood line between the donor and the child's family, the construction of kinship based on shared biogenetic substance was still present – in part for reasons around privacy, discussed above, but possibly also out of a perceived intrinsic value or desire to present a certain model of kinship. On this point, interviews in this study echoed findings made previously that families who do not have a genetic connection to their children have been observed to use physical resemblance to construct notions of relatedness (Nordqvist and Smart, 2014:132; Hargreaves, 2006:269).

The interviews also substantiated a view that some patients seek to achieve resemblance between the donor, the patient and/or the wider family where it was visibly clear that none was present – such as same-sex couples or single parents. In these cases, the interviews still show a similar concern to achieve resemblance, revealing a more nuanced understanding of the word 'legitimacy'. It is worth highlighting again Nordqvist's finding above that same-sex parents may seek physical resemblance because they may feel pressure to conform to 'normal' family structures or that they may feel different enough already. Considering the role of race in establishing kinship, we can therefore conclude that references to racial matching and resemblance in the interviews represent indirect or unconscious pressures to conform to a kinship model of racial sameness or similarity. These ideological pressures and confining social structures (Quiroga, 2007:148) may result in donor conception being used to reinforce the status quo –

more ‘conforming than liberating’ (Roberts, 1996:935). Further, the importance given to the genetic connection, as represented by the construction of kinship based on share visible physical characteristics, can be said to preserve ‘Whiteness’ through maintaining racial purity (Roberts, 1996:943).

However, the interviews also show that decisions to choose donors based on race and racialised characteristics, across a range of physical traits, in order to achieve a degree of resemblance are very personal. Respondents provided a range of highly individualised and varied examples of decision making – red hair, big noses, blue eyes, complexion and so on – demonstrating that while such decision making may possibly be influenced by ideology and social structures, the kinship construction occurred very much in the minds of the individual patient according to their specific circumstances. Respondents spoke about a very personal set of decisions. Therefore, notwithstanding ideas of family form that operate across society, users of donor conception may well prefer or seek personal reassurance that *their family* is the way *they envisage*. This reveals the importance of personal narrative of patients in their ideas of relatedness, legitimacy and kinship that is difficult to reduce into generalised conclusions and is linked to various notions of reproductive autonomy and identity. Race clearly plays an important role in these constructions.

Furthermore, while this discussion so far supports a ‘fixed’ or rigid concept of race, reminiscent of essentialist or biological versions of race as something that is visually detectable and shared through genetic connections (Bender, 2003:56), it was also clear from the interviews that relatedness was not conceived in a rigid or static way. Such was the variety of ways in which race was discussed, and which

characteristics were (or could be) associated with race, that a static definition of race did not emerge from the interviews.

Discussion of non-physical traits in this study illustrate the cultural imagining of familial traits, described by Mason as ‘active creation’ (Mason, 2008; Nordqvist, 2014: 269). For example, in many cases it was clear that patients had particular preferences for donors that were highlighted as being unusual by respondents – for example the couple who sought a donor of musical abilities similar to themselves, or the request for a vegan donor. These features are less heritable than physical characteristics but the discussion of such characteristics alongside physical ones suggests either a lack of understanding regarding genetic heritability, or – more likely – that something more complex than that is going on in the minds of those attempting to construct resemblance during donor selection. The connection between non-physical traits and resemblance has been made already in existing literature – for example, Almeling asserts that resemblance also extends to aptitudes and personality (2007) and matching to non-physical traits such as being ‘sporty’ or ‘musical’ has also been observed by Nordqvist (2014:274).

The discussion of non-physical matching illustrates how the notion of resemblance is not restricted to physical characteristics but also extends to the future child’s non-physical traits, bringing the donor’s non-physical characteristics into relevance. For example, discussion of veganism, sporting and musical ability above might suggest a desire for the child not simply to fit in visibly, but also as fitting in with the values of the family in which they will be raised. This notion builds on Strathern’s idea of ‘interpersonal kinship’ (2005),

upon which the child's everyday interactions with their family helps build or identify kin connections. The selection of the donor as a person, and how information represents the 'whole package' described above, is therefore also associated with discussions of resemblance and relatedness.

The reconstruction of knowledge (and race) discussed above resonates strongly with the way patients seek resemblance in a way that builds on notions of biology, moulding kinship into various shapes and forms (Nordqvist, 2014:280). The discussions between clinic staff and patients demonstrate such complex and fluid understandings of donor information. Such constructions are not rendered incoherent or meaningless but operate in a very meaningful way in the creation of or imagining of kin connections. Collectively, references in the interviews to 'red hair', 'big noses', 'veganism', and 'musical abilities', to take a few examples, are representative of Mason's 'tangible affinities' – fixed, negotiated, ethereal and sensory – that represent different ways of imagining and practising relatedness (Mason, 2008). This mirrors Nordqvist's account of a 'flexible and almost playful' approach to genetics (Nordqvist, 2014:274).

5. Storytelling and narrative building

The interview findings in this thesis do not only illustrate that donor information is construed according to ideas of resemblance, which in turn maps back to questions of relatedness and kinship building but indicate that the *exercise* of seeking resemblance through donor selection is itself an observable phenomenon. The ability and the process of a patient choosing a donor based on characteristics that are constructed in such a way to achieve resemblance can allow the patient to maintain a certain level of control over their reproduction (see Marre and Bestard,

2009) and give life to their reproductive narrative. This may be important to patients, not least as a means to ameliorate the anxiety caused by infertility and the uncertainty of using donor gametes.

Patients' concerns about loss of fertility and the psychological impact of using donor conception was raised by a number of respondents in this study. These observations were associated with concerns that patients may not have come to terms with the use of donor conception and there was an evident need for patients to be seen to be 'comfortable' with their decisions about treatment in their own way, and on their own terms. Speaking about a couple they had seen for treatment, one respondent recounted their story, taking on the voice of the couple:

[The recipient and their partner said] 'We went to a clinic and the doctor said we think you need egg donation to have the best chance of a healthy baby ... we were so pleased when we got embryos, you were this when you were popped into mummy's tummy.' So there's no ambiguity or uncertainty that the donor's donated to enable mummy and daddy to be mummy and daddy. The questions of skin colour are often not present because everybody looks so comfy with each other. So now the questions start, there can just be an assumption that [name deleted] conceived with somebody sooner, with a previous relationship and what an amazing stepdad [name deleted] is. Because people *create a fantasy based on what they see and kind of what we do*. The children know their story and are open to questioning and do talk about it all the time. So it's that level of comfiness that promotes a sense of comfiness for the child, the ability to explore.

(Counsellor A: 6092; my emphasis)

The reference to the word ‘fantasy’ suggests that donor information plays an important part of the patient’s narrative of their need for donor conception and reproductive choices, an observation also made by Hertz (2002), which can have manifest implications for the family once the child is born. In fact, being very prescriptive about what patients wanted in a donor indicated to some respondents that the patient had not yet fully come to terms with donation.

I think just being very, very specific about each criteria of the donor it tells me that the recipient may not be very comfortable with the whole process. I want to see a picture and I want to make sure that she looks like me. That makes you sure that she’s not settled to the process yet. Maybe she feels a little bit vulnerable or insecure. And that’s why some patients feel they shouldn’t have rushed into the treatment. (Clinician D: 8164)

The way that donor information is used is therefore highly variable, with the processes around constructing a narrative around reproduction revealing the complexities of the psychological aspects of donor conception. Race itself is discussed in highly varied ways, which fits in with the idea of fantasy and storytelling.

The use of donor conception and IVF highlights the uncertainty around reproduction that contrasts with the ‘certainty of kinship’ (Marre and Bestard, 2009). Most obviously, the break in genetic connection represented by the use of donor gametes and the provision of assisted conception challenges people’s ordinary feelings of certainty around kinship. While natural conception involves

the random shuffling of genes to the same degree that would occur during donor conception, the range of donors available and the break in expectation of genes from one's partner presents a level of uncertainty and variance that people attempting to conceive naturally would not face. The *process* of 'story-telling' regarding the donor's information can therefore be said to facilitate the projection of a view of what a child will inherit and also the success of treatment. The anxiety of the uncertainty of reproduction was reported in the interviews:

People do have worries. I hear stories over the years. I had a lovely young couple many years ago. They were very blonde, very young, and they needed donor sperm and she had this thing about this baby might come out Black. All throughout her pregnancy I kept in touch with her. When she was pushing, the midwife said: 'I think this baby has red hair', at which point she freaked and didn't want to push. Little did that midwife know that was such a huge thing that was so important to the patient, to choose a fair skinned blond sperm donor. So some things are very important to people. It turned out fine, and they ended up having two lovely very blond children actually. (Nurse A: 4614)

Yes, they do look for a donor match. What they often will do is that they'll give us the characteristics of the person having the treatment and then the characteristics of the partner and they will ask to match something. I think it gives them more ownership and if you match with the partners – I know one particular couple who has said that it makes them feel more party to the treatment, so it brings normality – normality isn't really the right word

– but it makes them feel more comfortable with it. (Embryologist F:
10115)

Respondents are receptive to the notion that there is something deeply personal about how patients use donor information and the construction of meaning that is tied in with their own sense of individual or familial identity. The process of construction – the ability to do so, doing so and the forum in which this can be done – is also of importance. Rather than a response to negative feelings associated with donor conception, the exercise of choice in this context can positively support notions of reproductive autonomy and identity. The emphasis placed on resemblance and the ability of patients to construct relatedness reflects studies that demonstrate how patients create a ‘life trajectory’ for the child that maps the parent’s own (Howell, 2003; Nordqvist, 2014; see also Nordqvist, 2012). Exploring transnational adoption in Norway, Howell has found that ‘kinning’ involves a ‘transubstantiation of the child’s essence’ and that adoptive parents enrol their adopted children into a kinned trajectory that overlaps their own (Howell, 2003:446). This thesis shows how such considerations are also understood by the fertility professionals involved in donor selection. Given that patients are interpreted as actively creating kinship bonds in donor selection – ‘choices are made about whether biogenetic kin connectedness is rendered meaningful or not’ (Strathern, 1992) – the interviews show that patients are considered to place value on the freedom to choose their donor and that in many cases the clinic respects this.

The concept of race intersects with the importance of storytelling, or narrative building, in several ways. First, race or racialised characteristics within donor

information appears to play a role in the construction processes described above and, as such, serves to provide patients with a tool or information through which they are observed to discuss, construct and make sense of relatedness in a way that fits in with their understanding of kinship and ideas of their life trajectory – both on an individual and relational level. If race is considered a feature of a patient’s own genealogy then, as Kramer points out above, such information can be caught up in how the patient construes their genealogical past and – by implication – a projection of their genealogical future (2011). Upon such a view, the discussion of red hair, for example, above captures not only the patient’s construction of kinship at the time but – arguably – also as it has been in the past and how they wish for it to be constructed in the future. References to race therefore facilitate the ‘creative imaginings’ of the patient of the future family – how the child will fit in and be raised. Crucially, the fertility professionals involved in donor selection are sensitive to the application of race to these kinship processes, contributing to the ‘creative imaginings’ through the information, space and discourse provided.

Second, race is observed to play an important role in the formation of the patient’s identity in terms of the way they think about themselves and also what they perceive themselves to look like (Ung et al, 2012:79-80). One respondent commented when discussing the importance of race and ethnicity:

I think this is the most important [race]. And when you ask them, when they choose – they choose closer to them. How they perceive themselves... I perceive myself in a way you might think is totally wrong. I think it’s perception. *It’s how I perceive myself to look like.* Not how other people think

I look like. And I think this gives the opportunity for people to choose how people perceive themselves rather than how other people look at you. I think it's perception. (Embryologist A: 993; my emphasis)

This quotation gives a different perspective to the discussion of resemblance and fitting in above in that the perception of race is from the perspective of the patient, rather than others. This links discussions of race in this study to the concept of 'visual race identity' proposed by Ung et al (2012:80) – such as how people perceive their own skin tone. This self-referential construction of race demonstrates that narrative building involves the placing of oneself in a life narrative, as well how this is perceived by others and the position of oneself and the future child in a certain social context. The invocation of race in storytelling therefore supports individualistic and relational versions of autonomy and self-identity, while also potentially serving to ameliorate distress and promote a sense of control over the outcome of the treatment. The fertility professionals interviewed were also very mindful and sensitive to the individualities and subjectivities of how race was invoked during donor selection – indeed many respondents emphasised that it was difficult to make generalised statements since each patient was different. However, actual or potential disruptions to the process of storytelling give rise to cause for concern, in such a way that disruptions to notions of relatedness and the expectation of privacy do also. These disruptions are investigated next under the term welfare concerns.

6. Welfare concerns

Respondents identified a broad range of welfare considerations in their reasons for seeking or preferring a donor-patient match, including a racial match. As a broad

assessment, references to welfare ranged from identification of ‘damage’ or ‘harm’ to the future child following mismatching to assessments of family functioning, to the preparedness of patients to become parents. Some professionals considered donor matching generally as part of their obligations towards the future child:

It’s connected to our accountability to a child and also wanting to be accountable ourselves to show how we thought about this and we were not cavalier, and we didn’t treat this lightly. We wanted to be sure we weren’t acting in a way that, as far as we knew that almost inevitably would be damaging. (Counsellor B: 10504).

The reference to ‘accountability’ above may allude to legal obligations imposed by section 13(5) HFE 1990 (as amended) on clinics to consider the welfare of the child in providing treatment. This respondent also explained that it was seen more as an ‘ethical practice’ more generally:

It’s a part of ethical decision-making. It’s always in our minds. We are involved in assisting the creation of a new generation of people. Babies grow into people and so it’s there as a background. If something alerts us as a worry then we look at it and discuss it. We don’t assume problems, but we respond to what looks like a problem. (Counsellor B: 10548)

The concern that a child might be ‘damaged’ by donor selection was extended specifically to racial matching also – although this was evidenced in negative terms through concerns about requested donors that did not match the patient:

R: We don't do designer babies. So where people have requested – especially if you are a heterosexual couple and you are thinking donor conception just to produce a lighter skinned baby – it'll be turned down. Because of safeguarding concerns.

I: And this has happened before?

R: Yes. Other concerns as well. Because in order to effectively safeguard it means making sure people are capable of making informed decisions, so if there is any ambivalence or naivety, we have to have a clinical discussion to decide whether everybody is happy whether to treat them. And if somebody isn't then sadly the decision is made not to proceed with treatment. (Counsellor A: 288)

Under the HFE Act 1990, a clinic is entitled to turn patients down because of safeguarding concerns against perceived risk factors but it is unusual for clinics to do so (Lee et al, 2014:507) – therefore the reference above to refusing to proceed is significant. There have been reports in the US of cases involving attempts to positively select an embryo using PGD in order to have a child who is deaf (although the parents – who were deaf – believed they were acting in the best interests since the child would be raised in a deaf community) (see Mand et al, 2009). The case raised a great deal of ethical debate (see BBC News, 2008; Savulescu, 2002) and it is important to note that such a request would most likely not be permitted under section 13(5) HFE Act 1990 (as amended) and also provisions against positively selecting an affected embryo under section 13(4) of

the same statute (see also Porter and Smith, 2013).³² However, the conception of harm – while debatable – is arguably quite different from the sort of social disruption and distress seen in the sperm mix-up cases where the resulting child is otherwise ‘healthy’. Still, such cases demonstrate the basis for harms in these cases is often about how they are perceived. Nevertheless, to claim a patient would be rejected on welfare grounds for choosing a certain donor remains a surprising finding in this context.

Rejecting donor choice was also commented on by another respondent:

R: For example, we’ve just had a couple who is Asian and Indian, they are on the Caucasian list and the Indian list, they were happy with a Caucasian donor (for a donor egg) so we offered them a donor egg, only for then to find out that the sperm that they had purchased was Caucasian – blonde, blue eyed – so we couldn’t then offer them the Caucasian eggs.

I: Why?

R: Because they are Indian, you know, it’s welfare of the child...

.... R: Only because of the welfare. I wonder if they know how that would impact on the child once the child is a lot older. The child going to school you know. People say to the child, why have you got... (Nurse B: 5918)

³² Introduced through section 14(4) HFE Act 2008.

Overall, respondents rarely said treatment would be rejected altogether; more likely such decisions would be flagged up for team discussions. Ultimately, even the respondent above who indicated that the clinic sometimes did not proceed with treatment said that generally the clinic would do so: 'It's not like we wouldn't do it' (Nurse B: 5942).

The above quotation also reveals the clinic's reason for refusing the chosen donor, referring to the ability of the child to fit in at school and with their family. Other respondents reflected similarly:

I think we are very aware that we mustn't ever discriminate. I think that's something we have to be aware of, but at the same time, we do have to consider the welfare of a child that might be brought into the world where, for example, with any child they might be subject to bullying or be singled out or identified as different in the community in which they are growing up. (Clinician A: 2699)

If you throw into that story picking the right donor and we pick one of a different ethnicity because it felt that they were the best match for our family then it's just another bit in there. But it might be questioned more later on. Especially if a child is born into a Caucasian family and does experience racism, there can be different ages and stages where life can be more difficult for a non-Caucasian child growing up today. (Counsellor A: 364)

Some respondents also indicated that some patients feared that disclosure would cause their child harm, particularly in relation to their immediate community, a finding that has been observed elsewhere on the part of clinicians expressing concern for the child's 'social welfare' (Davda, 2018:307).

I also think it's just fundamentally that people don't want questions being asked about their child. Some people don't think it's necessary for them to know about their use of a donor, and I think some communities can be very secretive about using a donor, and it is very frowned upon to use a donor. The more typical a family look, the less questions there are about the origins of those children. (Embryologist E: 9416)

The 'harm' or 'damage' caused to a child by visible dissimilarities is a contested and much debated issue, as seen in the sperm mix-up case in Northern Ireland discussed above (see Chapter One, section 2.iii; 3.ii). In this case, the family spoke about the children being bullied at school, but the High Court and Court of Appeal did not consider the child being of a different skin tone to their parents to constitute actionable damage for the purposes of their claim in tort. In this case, Girvan LJ held that 'Having a different skin colour from the majority of the surrounding population and their parents cannot sensibly be regarded as damage or disability' (*A and B (by C, their mother and next friend) v A (Health and Social Services Trust)* [2011] NICA 28 at para 9). However, the conception of damage in this case can be said to be limited and fails to appreciate what Chico explains in the broader context of reproductive harms as the 'individual's perception of her circumstances, rather than a universal perception of what is harmful' (2011: 26). Assessment of notions of harm and damage, including the potential to pursue a

broader recognition of damage in law to achieve goals of social justice (Duggan and McCandless, 2015; Priaulx, 2017; Scott, 2009), are outside the scope of this discussion, but clinics may be drawing on wider discourses of damage (the judiciary may also be taking a conservative approach in order to avoid engaging with contentious concepts such as race). As was discussed above, the psychological associations with fitting in and resemblance were seen as particularly important to patients (Chapter Six, section 3), so clinics may themselves be adopting this mode of thinking, especially given their experience of talking to patients and the sperm mix-up cases highly publicised in the media (see Blackburn-Starza, 2015). The Northern Ireland case discussed above has received a great deal of media and academic attention. Likewise, a previous case in 2002 involving a woman's eggs being fertilised with the wrong donor's sperm during IVF, which resulted in a mixed-race children being born to a White couple, attracted much attention (*Leeds Teaching Hospitals NHS Trust v A and Others* [2003] EWHC 259). Further cases in the United States (Everett, 2009), and also a successful claim for damages in Singapore (*ACB v Thomson Medical Pte Ltd and Others* [2017] SGCA 20), are likely to create a degree of consciousness about race and arguments around race-based disruption in the fertility sector.

The observation of the relevance of welfare in donor selection identified in this study points to a broader assessment of welfare that engages in assessments about family function of the particular patient. As the interviews show, some respondents understand that notions of 'harm' following donor selection are largely determined by the social environment in which the child is raised:

I think that if you have a young person who living in a community which is... predominantly White ... White family, Caucasian family, socialising amongst Caucasian people ... it's a breach of that child's privacy if [they are] obviously a different race. It's not necessarily a problem, but you have to think about it. You have to say well, what impact does that have? The child always will know; always be subject to unspoken questions or spoken questions. It's like, you are wearing it as a badge ... the question would always be is that child adopted? ... It's suddenly that it is exposed to public scrutiny. Is that really something that you think you would want for your child, really? (Counsellor B: 10561)

The above quotation indicates that race, specifically, or a racial match was considered in some cases as being relevant to the welfare of the future child by reference to the community in which they are likely to grow up in. This notion of welfare was evident in the Northern Ireland sperm mix-up case, as well as the more recent US case involving Cramblett (a 'White' woman in a same-sex relationship whose claim for damages following a sperm mix up leading to a mixed-race child (see Starza-Allen, 2014)) and also been documented in adoption literature on racial matching (see Wade, 2015).

The 'harm' seen in the Northern Ireland case was on some accounts seen to be not only the bullying that the children endured at school, but the distress associated with the physical dissimilarity and the calling into question his wife's fidelity (Sheldon, 2011:5). The notion of harm in this case involves consideration of the environment in which the child will be brought up in (Duggan and McCandless, 2015:18). Indeed, much like the 'predominantly White community' in which the

children in the Northern Ireland were raised, in Cramblett the gist of the complaint was that the family held certain views on race and its role in upbringing. The ‘harm’ in these cases is relationally and socially determined – whether by the community or immediate family – thereby highlighting the role of parenting and family functioning in the experience of that child and those concerned.

The link between race and welfare is, of course, highly problematic for several reasons. First, it is not clear that the use of donor conception generally causes adverse consequences for children. As already discussed, recent studies have shown that knowledge of donor conception has not been found to have a negative impact on families generally (Golombok, 2015). Conversely, it has been suggested that secrecy and not informing children early on may be harmful to the children concerned (Frith, 2001, Blyth et al, 2004) and disclosure in adolescence has been highlighted as potentially disruptive to families (Golombok, 2015). Blyth et al point out that a child’s identity is in part built on openness and trust, and that keeping secrets in a family can potentially be destructive (Blyth et al, 2004). Racial matching (as opposed to racial mismatching) may therefore give rise to welfare considerations associated with using the practice to maintain non-disclosure. Furthermore, while disruption caused by racial mismatching has been observed in adoption literature (Barn and Kirton, 2012; Wade, 2012), discussed in Chapter One, section 4.iv.a, care must be taken when drawing parallels between adoption and assisted conception because of the differences between the two processes (Frith, 2001:821). It is not clear that racial mismatching per se causes any discernible harm – although the findings above do appear to make such a claim, instead situating the welfare discussion amid a broad set of relational and social considerations.

Second, envisaging a link between race and welfare engages with a number of issues identified in CRT literature. Commenting on the Cramblett case, Patricia Williams said: ‘Cramblett seems engulfed by the same race panic that has put the bodies of other children at risk. Little Payton [Cramblett’s child] dispossesses her mother by being born, taking the space of a more qualified, more desired White candidate, erupting into the world as damaged goods—a neighborhood defiled as well as a family disappointed’ (Williams, 2014). On a broader level, such assertions carry great weight but the quotations above do also point to an individualised perspective of fitting in, heavily determined by the social environment in which the patient and future child are situated. Furthermore, the welfare discussion in this context overlaps with and is informed by notions of privacy and relatedness, which present a more functional and multi-faceted conception of welfare than does the notion of ‘damaged goods’. It is also important to highlight that the weight given to such welfare considerations above is variable – while damaged goods are not wanted, the respondents above (indeed as did the families in the Northern Ireland and Cramblett cases) did not speak about welfare in terms of it being reason for rejecting treatment (or the child!) but as an important aspect to be respected when delivering treatment. Such potential infringements are discussed in terms of individual, familial and social disruption, albeit causing harm.

Shedding light on the factors that fed into welfare concerns, the interviews reveal that respondents sometimes centered on the preparedness of patients for donor conception when discussing donor selection requests. Hypothesising about the future child’s likely home environment was linked by some respondents to the

notion that patients might not be ready for treatment, as discussed in Chapter Four (section 7.3). Clinics expected patients to consider a range of factors carefully before proceeding, rather than seeing particular issues as raising welfare concerns per se. In this sense, some respondents explained that their welfare concerns were underpinned by the idea that mismatching could indicate that the patient might not have grasped the implications of their donor choice:

We could be sure that both partners understood and have thought through the implications of having a child who may appear ethnically different from themselves and then, that was my experience of one of the ethical dilemmas, if you like that we faced. (Clinician A: 2613)

Yes, just because of the implications it might have on the family. And it has a more direct impact on what the child could look like ... So they just have to consider them. Whether they go with it or not, I don't think is right or wrong, because every family is different. (Embryologist E: 9750)

A number of respondents referred to the need for patients to understand donation. Mismatching requests were seen as an indication that the patient had not fully thought through the implications, raising concerns for the future welfare of the child:

I think for any couple to go for cross-race for cultural donation they have to have proper counselling. The last thing you want to do and that's when I said the couple, you don't want to have like a White child in an Asian family and *the child will struggle*. All the *family will struggle* to explain

and they have to – you don't want that situation to be sort of a sticking point in their life. If they are happy and they have thought about it and they can accommodate it and then they are open about it and there are no issues to worry about, that's not a problem. (Clinician D: 7898; my emphasis)

The use of the phrase 'will struggle' (twice) may reveal the perception that dissimilarity within families is seen as being detrimental to family functioning and child welfare. This further supports the functional and relational version of welfare discussed above.

The outcome of the medical procedure is just one consideration important to respondents, who stressed the need to consider the implications of donor conception. The interviews show that such concerns were not necessarily restricted to mismatching, but also arose where patients were intent on seeking a match:

Being very, very specific about each criteria of the donor tells me that the recipient may not be very comfortable with the whole process. I want to see a picture and I want to make sure that she looks like me. That makes you sure that she's not settled to the process yet. Maybe she feels a little bit vulnerable or insecure. And that's why I say, some patient they feel shouldn't have rushed into the treatment. They should really take their time and give the patient more time to digest the process. To think about the future. To think about everything that will happen and if you have a child by gamete donation. (Clinician D: 8159)

This quotation shows clinics' keen awareness of their statutory obligations to consider the welfare of the child in the provision of treatment. Consideration of the family's future functioning was a common theme:

We wouldn't say that interracial donation is not permitted. What we would want is to be assured that a couple who were embarking on interracial donation, cycle with gametes that they had, that we were assured that they have understood the implications of that and that they had some strategy, if you like, for helping that child understand, for example, why they may appear ethnically different from their parents. (Clinician A: 2674)

Overall, the interviews did not suggest that many respondents held particular views on racial matching within families, or that they believed the matching of characteristics – including race – to be an independent good, or that they saw some kind of 'wrong' or harm in mismatching. However, many reported that issues around donor selection might sometimes indicate that patients were ill prepared and that further discussion was needed:

For me, I don't think it's a problem for a family to have a child that is mixed race – but from an outsider's point of view, if someone wants to keep the fact that they are using donor sperm secret, because some people do decide that, then it would be more difficult and more questions would be raised if you do have a family of mixed race... has [the patient] considered that and how they would tackle that situation and ... would [the patient] be comfortable with that? There is no problem with it, it's just

whether they have thought about those situations that could arise and how they would feel in that situation. (Embryologist E: 9389)

Respondents spoke about the need for parents to be comfortable with their choice of gamete donor, and that the readiness of patients was an important consideration for clinics under their welfare and informed consent obligations:

Ultimately, it really is about being comfy. If parents are comfy and donors are comfy it models comfy to everybody else. And that's what the clinic needs to see. The clinic needs to feel comfortable and have no safeguarding or welfare of the child concerned and be comfortable that you have provided informed consent. (Counsellor A: 6533)

This respondent elaborated further on the clinic's approach to such cases:

On one occasion ... we had ... a family where neither the male or female partner had English as a first language and were from an Asian ethnic background and ... because of the shortage of egg donors from an Asian background this couple were considering having eggs donated from a Caucasian woman. But because of language barriers our clinical team were concerned that there could be welfare of the child issues, because obviously the child might appear ethnically different from their parents. We wanted to explore whether or not the patients fully understood or have full mechanisms within their family to explain a child with different appearance for example, and so we discussed that at some Ethics Committee meetings and in fact, we, as you would expect, we wanted to

have further discussions with them before agreeing to proceed with treatment and recommend counselling. But we wanted to make sure that that counselling was supported by an independent interpreter so we could be sure that both partners understood and have thought through the implications of having a child who may appear ethnically different from themselves. (Clinician A: 2613)

The quotation reveals that there is considerable overlap between patient consent and welfare of the future child in discussions of patient understanding in this context. Reference to the patients' understanding of the implications of their donor choice also appeared to denote a softer version of welfare of the child considerations that could be tempered with notions of patient autonomy:

I think it's a patient's personal decision. I think we do respect their autonomy. Sometimes, you know, I think that it is a difficult decision. For example, we had a Black couple who wanted to have a White child and then one raises a question as to why they want to do that. They are given very specific counselling. We would perhaps make sure that they have looked into every aspect of the donation process and understand the full implications. (Clinician B: 6807)

In fact, in situations where the patient provided an adequate explanation for the donor choice the clinic would appear to be less concerned:

In fact, this particular lady, I recall, had given the clinic a very good explanation that she, herself, her siblings were involved, had interracial

marriages and ... she lived in a community where there was a lot of interracial marriage and a lot of children were of mixed race. And she felt that a child, her child, would be more able to identify and integrate with their cousins and their community if they were of mixed race. That seemed to me a perfectly reasonable explanation of why the lady was making a particular choice. (Clinician A: 2713)

In fact, some respondents were quite sceptical about passing judgment on donor choices for certain patients:

My personal view is that you are allowed to adopt a child of any ethnicity or race, it doesn't bother me at all. So long as it's a safe and secure environment for that child. I think some of the issues that may have been raised may be about social acceptance and acceptance in the wider family, or depending on the type of community they live in whether they would be accepted naturally – I don't like that word – easily as a child of their own ethnicity. But who's to say what is ethnicity, what is race? (Embryologist B: 1459)

The quotation also emphasises how discussions of race are not done in terms of acceptability (or non-acceptability) but instead present a set of relational considerations around resemblance, fitting in and so on.

The discussions of welfare and race seen in this study portray a complex picture. Racial matching and donor selection based on race, or racialised characteristics, demonstrate a problematic link between race and damage – invoking an array of

critical race remonstrations. Yet the interviews also show that a complex and nuanced set of considerations operated around donor selection. Discussions of race are observed to form part of the facilitation of informed consent on the part of patients, as well as their own projection of what is best for their future child and the welfare of the child obligations on the part of the clinic. Importantly, these considerations are not discussed in stark terms of not proceeding with treatment, or not wanting (or wanting) a child of a particular race based on welfare. Instead, these discussions were highly varied and individualised to the patient and their environment, linking back to the discussion of narrative, and the construction of kinship and privacy above (sections 2, 3 and 4). Moreover, race is used as a language or set of concepts through which welfare considerations are articulated and characterised, rather than as a goal to be sought in its own right. Clinics were conscious of allowing patients the space and time to think through donor selection decisions, of which race formed just a part.

7. Conclusions

The interviews as highlighted in this chapter indicate that race in many cases played an important role in donor selection for several reasons. This role, however, is complex and operates in subtle ways. Race feeds into certain broader themes that appear to guide decision-making in donor selection. One of those dominant themes is a desire to achieve resemblance between child and parent. The interviews indicate that patients would often choose a donor to achieve resemblance either to themselves, their partners or their wider family. While again this might appear to echo the practices condemned by CRT scholars as perpetuating racial hegemony, a discussion of kinship processes captures a more nuanced and complex picture of how donor information is used by patients,

supporting the constructivist model of race but also revealing that those processes of construction operate around notions of resemblance. While discussing the notion of resemblance, clinic staff reported that patients spoke about maintaining privacy and constructing kin relations while referring to identity and personal autonomy – all of which represent the range of themes that underpin donor selection. Respondents also spoke about the importance of narrative building. Fertility professionals were sensitive to these accounts of race and the donor selection discussions provided the forum and opportunity for patients to embark on creative kinship work based on and around concepts of race. These themes overlapped and interacted with conceptions of welfare, both from the perspective of prospective parents and the clinic. In turn, ideas of welfare were discussed in terms of privacy, relatedness and narrative building.

The chapter supports the notion that race is a construct, rather than an identifiable, objective biological fact. It builds on the findings in Chapter Five that biological notions of race, as represented through discussion of race and racialised characteristics, are reconstructed in donor selection discussions and given new meaning. The meanings associated with race are found in the complex themes and processes that underpin the importance of resemblance, which serve to influence the way in which race is discussed (or not discussed), the way it is understood and its significance (or insignificance) in donor selection. Race, therefore, is best understood as a concept that can be moulded into different shapes, much like the clay metaphor Nordqvist uses to explain the workings of kinship (2014:28). Race clearly plays an important role in the construction processes around kinship and resemblance, but that does not mean that race as a biological fact is important – the interviews show that it often was not, or at least not in any obvious ways.

Race is a building tool and its importance lies in its construction and the processes that surround it. The overriding explanation emerging from the interviews is very much focussed on kinship and its creation, manipulation and importance in donor selection and race clearly plays a vital role in these processes.

Chapter Seven: Conclusions

The aim of this thesis has been to make a significant original contribution to the knowledge and understanding of racial matching of gamete donors in UK fertility clinics. Using empirical data specifically gathered for the study, the thesis has attempted to both describe and analyse the current position in this largely underexplored field and provides a range of conclusions that may serve as impetus for further research as issues of race, genetics and concepts of kinship continue to evolve. Overall, this study identifies significant findings in response to the primary and secondary research questions: First, does race play a role in donor selection and, if so, how and why? Second, how are patients and gamete donors racially matched and what is the involvement of fertility professionals in this process? The interviews demonstrate that race plays an important role in donor selection, but it does so in complex ways and for a multitude of reasons. The fertility professionals interviewed described complex and sometimes conflicting conceptions of race. Race was often implicated in discussions about resemblance, in which racialised characteristics, such as skin tone, eye and hair colour, were infused with considerations of kinship, privacy, patient autonomy and the welfare of the future child. Fertility professionals were also often extensively involved in the actual process of donor selection, showing how they play a role in the construction processes around race. These findings present important policy considerations that are pertinent to the provision of fertility treatment in the UK. These include normative questions over how patients should choose donors, in addition to considering the role of clinics in the presentation and discussion of donor information, including race.

1. What role does race play in donor selection and why?

The interviews indicate that race was commonly discussed in donor selection and it was given significant weight in this process. More importantly, the way in which race was spoken about by respondents supports a very complex, nuanced and multi-dimensional construct (see Ung et al, 2012). Sometimes the word ‘race’ was used expressly, but other times not. Sometimes the word ethnicity was used instead of race, or characteristics associated with race, such as skin tone, were spoken about. Other times race was seemingly absent, separate or at least quite distant from other considerations – such as the donor’s occupation, education or personality. Race is perceived as an extremely fluid concept: it moves (sometimes within respondents’ accounts) from ‘fixed’ or rigid definitions to more ‘sensory’ definitions (Mason, 2008), at times reflecting Mason’s ‘ethereal’ affinity – beyond rational explanation (2008:37). For example, common references to race that borrow from biological definitions and notions of heritability were often seen to be reinterpreted in ways that matched patients’ own life view and reproductive expectations.

The fertility professionals interviewed were shown to play integral roles in the construction of race in the donor selection context. Fertility clinics provide the space, information and language that shapes donor selection discussion.

Significantly, this finding implicates fertility professionals in processes and constructs that reify biological or essentialist notions of race as heritable (Quiroga, 2007; Roberts, 1997). This is a theme explored in further detail in this chapter.

The role of race was also demonstrated through reports of racial matching. This study further illustrates Davda’s observations that the concept of race is shown to

be 'reified and reproduced' through the various stages and interactions in the matching process (2018:333; see also Deomampo, 2019). This is particularly so given the importance attached to donor matching practices and how these are handled by clinics. Furthermore, the interviews demonstrate how racialised assumptions are arguably made by fertility professionals through the operation of otherwise considered ordinary or mundane practices – for example, racial matching was sometimes said to be a 'given' or race 'not discussed' (Cross, 2010). In particular, the connections made between race and welfare revealed certain assumptions around the norms of family functioning and wellbeing.

However, while the reproduction of race from its contested biological purported basis raises important normative considerations (discussed below), the interviews also illustrate in detail the complex operation of the social construction processes described in kinship studies (Thompson, 2009; Hargreaves, 2006; Nash, 2014; Cussins, 1998; Strathern, 1992). On this level, we can observe a very wide range of meanings given to race and the deployment of the concept within the application of broad themes of privacy, identity and autonomy. While the critical examination provided by the CRT framework exposes assumptions around normative application of race, the account of race in this data also highlights its application as an integral concept to enunciate matters of kinship and personal autonomy in a highly situational, individualistic and deeply important way. Clinics must therefore attempt to navigate this difficult tension between the facilitation of patient decision making and the mitigation of the normative implications concerned with doing so. This thesis provides tentative solutions for how this may be achieved.

i) A fluid and multi-dimensional concept of race

Crucial to an understanding of the role that race plays in donor selection demonstrated by this thesis is the characterisation of the unique versions of race that were deployed in donor selection decisions and shaped by those processes and fertility professionals involved. The thesis supports Lopez's view of race as an ongoing, contradictory, self-reinforcing process' (1994:7). The fluid and interchanging concept of race is evidenced by patients' reported understandings of race and heritability as relayed in the interviews. While some patients may carry strong expectations regarding the heritability of donor characteristics, including race, others were said by interviewees to discuss such features in an almost playful manner, providing a perspective on heritability that does not necessarily conform to scientific norms. For example, one respondent reported how a patient had requested a donor with musical abilities because they were musical and wanted their child to be musical also. However, the interviews show how the construction model shifts the focus from the form of language used to the process whereby it is deployed. On this account, the patient above may well know that musical ability is not heritable, but nonetheless imagines that it is – perhaps since it feeds back into their own sense of identity and feeling of control over reproductive decision-making (Thompson, 2009; Marre and Bestard, 2009). Race was similarly observed to have been spoken about in a more rigid and fixed manner as denoting something that the child would 'inherit', while at other times it was used to signify the less tangible aspects of patients' sense of identity, autonomy and imaginings around reproductive decision making. Pertinent to the research questions in this thesis, fertility professionals were clearly mindful of such apparent contradictions in their patient accounts yet continued to describe a

forum in which these understandings played out in a free manner, rather than to be corrected or refined.

The construction of race is also clearly influenced by the wider context of donor information and environmental factors. Race appears to play a role in a much wider picture of patient understanding and the fantasisation of donor information (Hertz, 2002). The concept was often associated with a range of donor information that was used, or sometimes reinterpreted, through complex processes of construction around kinship and what is important to each family undergoing treatment. However, non-racialised donor characteristics – both physical and non-physical – were also said to be important to patients, including certain aptitudes such as musical ability. Race is therefore discussed by fertility professionals as one item within an array of donor information that constitutes the ‘whole package’ as represented by donor gametes.

The wider social context is also highly influential: the meaning of race is constructed within a complex interpersonal context between the patient/s, the clinic, and the wider family or community, whereby social interactions and norms often influence donor selection requests. It is at this intersection that the race construct becomes susceptible to what Lopez describes as the ‘macro forces of social and political struggle’ (1994:7), discussed below. However, it also shows that the construction of race is often relational in nature, with the immediate and wider family frequently named as important considerations to many patients.

The focus of this thesis was not on the views of patients themselves and so the accounts provided above can only provide incomplete and second-hand accounts

of how race is constructed by patients and only tentative conclusions on this matter can be drawn. What is significant, however, is how such a concept of race was *reported by* fertility professionals and their involvement in race construction processes. The data provides a counter narrative to the reproduction of race as a biological category by showing recognition of race as a complex social construction; an appreciation of (and contribution to) a phenomenon that has the necessary conceptual potential to be shaped by kinship processes and redeployed in meaningful ways. It is important to note, however, the clinic's role in managing or feeding into these construction processes is varied, with some clinics adopting a more hands-off approach and others discussing donor selection decisions with patients at great length and in great depth.

ii) Racial matching

The role and importance of race is most clearly evidenced by the racial matching practices that this study identifies. It was established in Chapter Four, section 6, that most respondents reported attempts to match the donor's race to that of the patient. This was sometimes done at the request of the patient but it was also at times initiated by the clinic, where it was often assumed that a racial match would be sought in a donor. Furthermore, donor information and certain physical traits were observed to be racialised, suggesting a far-ranging operation of racial matching. Conversely, the concerns expressed about requests that were made by patients for donors perceived to not be a racial match also illustrate the role and importance of race. The normative implications of racial matching are considered below, but first it is necessary to highlight the conclusions this thesis has made about why race is important in this matching context.

Turning to the reasons why race was considered important, the interviews show that ideas of race strongly operate around notions of resemblance (Price, 1997; Becker et al, 2005; Quiroga, 2007; Hudson, 2015), which in turn engages elements of privacy (Smart, 2010; Nordqvist and Smart, 2014; Hargreaves and Daniels, 2007), kinship building (Nordqvist, 2012) and narrative building (Kramer, 2011; Mohr, 2015; Hertz, 2002; Howell, 2003). Race was also connected with broader welfare considerations, offering (albeit limited) parallels to adoption studies (Wainwright and Ridley, 2012). These findings illustrate the application of the existing literature on kinship building in ARTs to donor selection and also demonstrate the intricate interaction and overlapping of these concepts. Furthermore, the data reveals the motivations of fertility professionals that lay behind assuming, initiating, facilitating or seeking a racial match. This thesis makes a contribution by specifically demonstrating how racial matching is connected to these themes, the implications of which are discussed next.

iii) Maintaining privacy through resemblance

The interviews demonstrate that considerations of privacy have developed from attitudes around secrecy, observed historically in the development of ARTs (see Richards, 2016) and more recently in the debates around donor anonymity (see Blyth et al, 2004), to a greater concern for non-invasive questioning of family form and connection (discussed in Chapter Six). Patients may not necessarily want to keep their use of donor conception a secret, but equally this does not mean they wish to advertise it to the world at large. It is significant that notwithstanding efforts by the HFEA and others (HFEA, n.d.e; see DCN, 2018) to promote disclosure of the use of IVF to children that fertility professionals appeared to account for maintaining privacy in donor selection discussions.

Indeed, some respondents highlighted that the removal of donor anonymity has made maintaining privacy even more important. The findings on privacy outlined in Chapter Six illustrate an extensive engagement by fertility professionals with the socio-cultural contexts of keeping the use of gamete donation private (Frith et al, 2018), in addition to the more personal reasons for keeping the use of donor conception secret, for example to guard the infertility of the partner or patient (Daniels and Taylor, 1993).

The thesis therefore indicates a prioritisation of the patient's autonomous decision making relative to their familial and social situation, as well as deference to patients knowing what is best for their future children (Turkmenbag et al, 2008). This interpretation accords with other references made by respondents that support the promotion of patient autonomy. It also further indicates an engagement with, sensitivity to or recognition of matters perceived to be important from the patient's perspective that places emphasis on subjective and individualised understandings of race. However, the respect afforded by fertility professionals to the expression of privacy appears at odds with the importance placed on welfare considerations in Chapter Six, section 6, if one accepts arguments that non-disclosure can have an adverse impact on donor-conceived children (Blyth et al, 2004). Nor did respondents view requests for matching to achieve resemblance on the basis of privacy as indicating a patient's lack of preparedness for treatment; on the contrary, perceived mismatching requests were seen to indicate a lack of preparedness (discussed further below). The potential downplaying of these factors may reveal assumptions that traditional family forms (and origins) based on shared genetic bloodline are the norm (Davda, 2018:256-7; see also Strathern, 1992). The model of kinship achieved through requests to

match donors based on maintaining privacy therefore accords with socially legitimate family forms (Nordqvist, 2010) and pass unquestioned by fertility professionals. On this account, requests for resemblance on privacy considerations do not raise the same questions as requests for non-matching donors. The references to privacy by fertility professionals therefore foreground the tension between promotion of autonomy or deference to patient requests and, in doing so, the reproduction of perceived social norms. Interestingly, the discourse about children's rights to know their origins features less strongly in the interviews presented here.

iv) Constructing kinship and relatedness

The interviews also show a clear relationship between race and kinship building, with race operating as a medium through which concepts of relatedness can be constructed. Chapter Six showed that race appeared to play a role in highly individualised constructions of relatedness, legitimacy and kinship, in which the malleability of the concept was observed by fertility professionals to enable patients to make connections. Concepts of relatedness underpinned many of the kinship processes described by fertility professionals, which were understood to be constructed through a display of resemblance (reflecting other studies on this issue, for example Nordqvist and Smart, 2014; Marre and Bestard, 2009; Hargreaves, 2006). Crucially, as with the fluid model of race described above, these processes were also shaped by the involvement of fertility professionals. The interviews provided a detailed account of a high level of involvement in kinship creation through the medium of race.

This set of conclusions raises important considerations for clinics. On the one hand, the evocation of race in kinship-building via the construction of relatedness through resemblance exhibits the reproduction of conventional family and kinship discourses (Marre and Bestard, 2009). In particular, constructing genetic relatedness through race may be said to preserve a White, patriarchal family model (Quiroga, 2007:144). The normative implications of these connections are considered further below. However, the potential of the race construct to represent something other must also be considered. Some respondents who indicated that race was not important, then went on to describe racialised practices (discussed in Chapter Five) that unconsciously downplayed race or rendered it invisible (Cross, 2014). A possible alternative explanation is that the concept of race is decoupled from the use of the word to such an extent that the concept becomes ‘denucleated’, devoid of its original albeit constructed meaning. The shell of the concept is then reinterpreted or reproduced along different lines of meaning. Of course, such an interpretation may in turn be explained in the context of donor selection discussions involving ‘White’ recipients and/or donors as an attempt to code ‘Whiteness’ as something other – a discussion of race and ‘Whiteness’ through what it is not (see Tyler, 2009; Cross, 2001).

Resolution of this apparent tension matters, not least since respondents documented the distress expressed by patients over kinship concerns. The data shows that fertility professionals are mindful of patients’ fears that errors could result in a child resembling a different racial or ethnic group (see Becker et al, 2005, discussed in Chapter Four, section 4 above) – fears which were laid to bare in the Northern Ireland and Cramblett cases discussed above. We must therefore

consider further the findings of this thesis that detail the kinship processes as understood by the fertility professionals involved.

v) Identity, narrative building and patient autonomy

While the focus of this research was not on patient's own perspectives themselves, the interview data provided evidence of fertility professionals' understanding of the role of race in kinship building. Race was seen to be deployed in the exercise of patient autonomy through its use in narrative building and storytelling. Significantly, the interviews demonstrate that donor selection decision making was not viewed as procedural or consumerist, but that such decisions went to the very core of many patients sense of identity and life story (Kramer, 2011). This accords with respondents' views on privacy discussed above. In a negative sense, this concern with race substantiates reported disruptions to patient narratives involving race (as demonstrated in the sperm mix-up cases) in a real-life way (see Blackburn-Starza, 2015). In a positive sense, the concept of race therefore is involved in the formation of individual and familial identity through the exercise of reproductive autonomous decision-making concerning race-selection. This finding again raises implications around the need to examine donor selection decision making to the extent that it might accentuate racial preferences (Fox, 2011) or reproduce traditional family forms (Deomampo, 2019; Davda, 2018) – explored further below. It also adds a perspective to the construction of race that emphasises a deeply personal set of considerations around how one perceives themselves, their family and their life model (see, for example, Carsten, 2000). Beyond racial identity (for example, see Ung et al, 2012), the concept of race provides fertility professionals with the language to allow patients to explore their reproductive decisions in such a way that fits in

best with their own personal narrative and perception of their genealogical history (see Kramer, 2011). Of course, such perspectives themselves may be influenced by ingrained societal attitudes such as pronatalism (Daniels, 1999), hetero-patriarchal (Nordqvist, 2012) and certain racialised family models (Quiroga, 2007).

It is unsurprising to see fertility professionals account for the exercise of patient autonomy and the exercise of reproductive choice in donor selection give the centrality of the principle in medical ethics (see, for example, Robertson, 1994; Harris, 2003; Savulescu, 2002). What is more notable is the relational version of autonomy that fertility professionals facilitate through a discussion of patients' own understanding of their identity, narrative and reproductive options in light of others – their partner, wider family and community. The interviews also highlight the sensitivity expressed by those interviewed to the importance of kinship from an autonomy perspective and how what Davda terms 'kinship risk' (2018:256) resonates with patients on a very real and practical level. While this may not justify the complaints seen in the Northern Ireland and Cramblett cases, it does demonstrate that clinics are mindful of these concerns and provides some further explanation, albeit through the eyes of the fertility professionals, of the possible basis for such complaints.

vi) Race and welfare

Taken together, the conclusions around privacy, kinship and autonomy illustrate a tension between a liberal approach to facilitating patient requests and consideration of the normative implications of doing so. This tension is brought into focus when considering how fertility professionals discuss race and welfare,

which at first glance appear contradictory to the conclusions on the respect for personalised kinship processes premise on a malleable concept of race developed so far.

The findings in this thesis illustrate how certain conceptions of race are reinforced and reproduced by fertility professionals in donor selection decisions through the invocation of welfare considerations in the understanding and application of clinic' statutory duties under the HFE Act 1990. Chapter Four outlines how a range of fertility professionals perform a 'gatekeeper' role in controlling access to fertility services through exercising responsibility to consider the welfare of the future child (see also Lee et al, 2015). This observation raises broad questions around the operation of regulatory frameworks and the limits of professional responsibility in this context, including how the tension between patient autonomy and welfare is negotiated. Furthermore, the tendency of clinics to discuss the implications of donor selection alongside discussions of donor characteristics and donor information raises questions over the appropriateness of these discussions. This practice could, on some views, be questioned as medicalising (or professionalising) what might otherwise be seen to be a private, personal matter whereby patients' requests and preferences are recast amid professional concerns regarding the patient's acceptance of donor conception.

While references to the welfare of the child can be traced back to clinics' understanding of the statutory obligations, the application of the discretion administered to questions of race and racial matching demonstrates an extension of social value judgments described by the medicalisation critique to reveal normative assumptions about race. Indeed, the findings above support

observations made elsewhere that the welfare of the child purview is used by fertility professionals to ‘legitimise’ the casting of social judgments in decision making around donor selection (Davda, 2018:136).

This thesis provides evidence of the implication of race within welfare considerations in this vein, with a particular set of welfare associations with fitting in, the risk of familial disruption, family functioning, the effect of disclosure and the wider community (discussed in Chapter Six). These factors can be grouped together and termed ‘social welfare considerations’ (Davda, 2018:307). The findings discussed in Chapter Six, section 6, raise normative considerations that stem from the problematic connection of race with welfare, while also situating the concept of race in kinship processes of belonging and family functioning. This social construction and interplay of concepts of race and welfare highlight important implications for how the language of kinship in the donor selection context illustrates the problematic tension between giving effect to the family building preferences of individuals and families, and the normative implications for inequality and structural issues for society. The interviews did not demonstrate that respondents considered race or racial matching to be an independent good, or that a racial mismatching would be wrong or cause direct harm (discussed in Chapter Six, section 6 – in fact, respondents expressly disavowed any such conclusions). At times the potential disruption to personal narrative and privacy is considered, while other times donor selection discussions based on race were seen as being indicative of the patients not coming to terms with donor conception. However, the linkage of race and racial matching to welfare through considerations of how the child will fit in with the wider community, their immediate family and the future functioning or current preparedness of patients

seeking donor conception, may expose assumptions about the significance of racial dissimilarity in community and familial cohesion, and the functioning of the family itself.

The finding that some fertility professionals believe that children may ‘struggle’ (Chapter Six, section 6) growing up in an environment of a different race and that this is a factor that patients should contemplate as part of their preparation to become parents reveals an assumption that there is a problem to be addressed. Fertility professionals consider a potential lack of resemblance between the patients and future children as a risk to the welfare of the child, thereby disrupting certain normative ideologies of the family where physical resemblance signifies genetic connectedness (Davda, 2018:201-2). That many (though not all) of the examples of racial mismatching provided by respondents included donors from ethnic minorities furthermore demonstrated a potential unconscious bias against ethnic minority families, where white hegemony is rendered invisible reflecting its status in Britain as a ‘racialised norm’ (Cross, 2001:427) but non-white relatedness is exposed to scrutiny.

The extent to which these responses are explained by the general welfare obligations imposed on clinics (a much wider enquiry) and how far such responses are indicative of assumptions about race is difficult to disentangle and will invariably overlap. However, the observation that fertility professionals, in appearing to discharge their statutory obligations, invoke issues of race among considerations of welfare of the child reflects wider structural inequalities whereby people of ethnic minorities are disadvantaged and perceived to be at

disadvantage in the application of otherwise ‘colour blind’ institutional practices and policies.

In this study, many respondents did positively indicate that a broad range of physical (and also non-physical) characteristics were considered important to establish resemblance. Some of these characteristics, such as hair colour, may be said to be racialised but others more persuasively pointed to a broad concern for resemblance and fitting in that may not be explained on race grounds alone. The conclusion that racialised assumptions are reproduced through social welfare considerations may not reflect the full picture and a more nuanced picture emerges from these interviews.

vii) Conclusions on the use of race in donor selection

What transpires is a high level of complexity and variation across cases of donor selection and selection practices. The themes that underpin resemblance are often overlapping, reflecting the complexity of the race construct identified above, while also highlighting the individuality of each case of donor conception. Every patient brings their own unique set of understandings and viewpoints; every patient is different – and fertility clinics are evidently very conscious and sensitive to this. To say that race is important does not entirely capture this reality – there is no singular, unitary or defining feature of race that makes it important to donor selection. Indeed, in some cases, race may not be important at all. However, race represents a set of vital considerations for many patients and clinics alike. Rather than an objectively discernible empirical fact, race is more accurately described in this context as conductive material – or a linguistic or conceptual tool – through which more deep-rooted concepts of kinship take hold and are played out. This concept of race, in turn, replays ideas of how patients view themselves, their

families and how they wish to construct their future family. This set of findings therefore complicates observations about race and why it is important in donor selection.

2. How are patients and gamete donors (racially) matched and what is the involvement of fertility professionals in this process?

Further to addressing the primary question of the thesis, the interviews present a range of findings that responded to the secondary research question – what happens during donor selection and how extensively are clinics involved? The findings to this question examining clinical processes raise significant implications for institutional, operational and regulatory matters. The conclusions on processes also sheds further light on the use of the race construct described above.

The interviews identified that clinics were often extensively involved in reproductive decision-making in the selection of gamete donors, with this sometimes being the case even where the actual selection occurred outside the clinic, for example using external gamete banks. Selection discussions were conducted with a range of staff, although they mostly involved counsellors who tended to explore the implications of using particular donors in depth. In this way, donor selection can be said to fall within the clinic's responsibilities towards their patients both under the HFE Act 1990 and common law. On the other hand, some clinics expressed no responsibility for (and have little involvement in) the donor selection process, highlighting the variability of approaches in this area.

Significantly, clinics have continued to operate matching practices long after the guidance on matching from the HFEA was removed. This demonstrates how law and policy can impact on informal practices that continue to exist after those rules are removed (although it may equally be possible that the practices predated the HFEA's guidance).

i) Variable levels of clinic discretion

A significant finding outlined in Chapter Four was that the extent and nature of involvement by fertility clinics in donor selection was highly variable, particularly around donor matching. On some accounts, this is surprising given the rigour of the legal framework governing the provision of fertility treatments through the HFE Act 1990 and the HFEA's power under this legislation to direct clinical practice (outlined in Chapter Two, section 2). Clinics are subject to a range of statutory obligations, from providing patients the opportunity to receive counselling to considering the 'need for supportive parenting' (HFE Act 2008, section 14(2)). Furthermore, the HFEA provides detailed guidance to clinics on how to meet these obligations through its Codes of Practice. Indeed, the risk assessment outline in the Codes of Practice can be seen as an attempt to limit discretion in this area (Lee et al, 2014: 504). Yet the respondents in this study documented a wide range of practices and approaches to donor selection. It is therefore apparent that UK fertility clinics retain a certain level of discretion and, within this, there is a broad range of practices. Significantly, this discretion goes beyond clinical discretion, whereby clinicians are granted the freedom to decide the most appropriate treatment for patients, extending to matters of policy and operation. An analogous comparison can be found in the recent review by the Competition and Markets Authority (CMA) into the issue of add-ons offered by

fertility clinics in the UK (Kitcher-Jones, 2020). Concerns have been raised about whether patients are being offered value for money in the treatment options presented to them by clinics (Patel, 2019). The CMA has identified variation in whether add-on treatments were discussed in clinics or not, with some clinics making patients aware but not following up (CMA, 2020:6). Some discussions were initiated by patients and there was variation in how clinics advised them (CMA, 2020:6). The report further highlighted the variation in how treatment costs were provided (2020:7) and how success rates were reported (2020:26). We therefore can observe several areas of operation where fertility clinics have discretion to devise their own approaches and where the HFEA regulatory remit does not reach.

The identification of this area of discretion is problematised by the observations above that fertility professions often include race and racialised assumptions in the exercise of the perceived obligations to consider the welfare of the child and to assess the preparedness of patients for donor conception through the provision of the opportunity to receive counselling. There were several examples of where clinics went beyond these responsibilities, raising wider concerns of medicalisation and paternalism over parenting abilities and exposing people's lives to the scrutiny of medical professionals (Lee et al, 2015:85), as well as raising normative questions around the use of race. While the exercise of discretion and the variability of practices appears to be influenced by a range of factors including the size and location of the clinic (and so therefore the exercise of discretion in part reflects practical differences between clinics and the realities of gamete availability), the discretion also provides a space for clinics to exercise

their own value judgments regarding the normative dimensions of donor selection (see also Davda, 2018:136).

Such an institutional response may be idiosyncratic of the fertility sector which, through its subject matter of reproduction and family building, arguably operates at the forefront of social normative order. Indeed, the availability of discretion is also central to the operation of the HFEA, as transpired in some of the arguments around a period of instability. The McCracken report explains how the HFE 1990 grants discretion to the HFEA to adjust the regulatory environment in line with changes in ART, highlighting the ‘complex and sensitive nature’ of decisions that it takes (McCracken, 2013:15). The investigation into the social normative engagement by fertility professionals may to some extent be explained through a replication of the regulatory context itself. Murdoch observes that discretionary powers afforded to the HFEA under the HFE Act 1990 resulted in a level of involvement in the decision-making process between clinician and patient that was not envisaged by the Warnock Committee (Murdoch, 2013). However, as the conclusions about race demonstrate, such a level of discretion also allows fertility professionals freedom to reproduce their own normative social order in the clinics and its operations – which can be problematic on many levels. The replication of regulatory investigation (or medicalisation) into social aspects of fertility decisions by fertility professionals exercising areas of discretion also links to the next discussion of regulatory heritage.

ii) [Regulatory heritage](#)

It was observed in Chapter Four that some clinics continue to operate a matching policy long after the relevant provision in the HFEA’s Code of Practice on donor-

recipient matching was removed and that this can be explained by the idea of ‘regulatory heritage’, developed by Stokes (2012, 2013). Applying this to the fertility sector, the practices observed in this study are suggestive of a regulatory environment inherited from the Code of Practice where ‘regulatory dispositions’ (Stokes, 2012:94) may explain the practices described. The implications of this are significant for fertility practice around donor selection and more generally, as well as raising important questions for regulation and providing a possible explanation for the findings on the use of race above.

The findings of this thesis illustrate how regulation (both in the form of statute and guidance issued by bodies such as the HFEA) creates a culture and set of linguistic devices that can survive long after the regulation has expired.

Requirements to achieve a physical and racial match between donor and recipient, and to prevent treatment where different physical characteristics to the recipient are sought (see Chapter Four, section 4.iv.a above) were repealed following the SEED Report (2005) and replaced with a provision that states clinics are ‘not expected’ to find a racial match between donor and recipient (HFEA, 2019b:118).

Despite the revision, the requirement for a match has remained in clinical discourse around donor selection. This raises questions about whether the corrective action following the SEED Report was sufficient to bring about a change in discourse and approach, but also illustrates the strength and embeddedness of the cultural appropriation of regulatory norms.

The norm of racial matching may also have been confounded by the social welfare consideration linked to race discussed above, whereby fertility professionals in exercising their understanding of current statutory obligations to

consider the welfare of the child, are both reinforced and influenced by norms around matching generated by expired rules and guidance. In this way, the old continues to influence the interpretation of the new. Another relationship is that the value judgments that lie behind the norms for matching in the previous codes of practice are largely indicative of social norms (or at least in certain fields) at the time. In this way, regulation can be seen to reinforce, even legitimise, social norms in a way that is long lasting.

Considering the analysis of discretion above, the reproduction of inherited regulatory norms may suggest that fertility clinics are acting as quasi-regulators themselves. What the HFEA once did, some clinics are still doing now. Again, in the absence of clear corrective action, the HFEA codes of practice and HFE Act 1990 has turned fertility clinics – the providers of clinical services – into not simply gatekeepers but regulators of the social domain of reproduction. Moreover, the style and nature of approach to regulation adopted by the HFEA may have filtered down into clinical practice. For example, the HFEA has been described as a particularly ‘high-profile’ but ‘ponderous’ decision maker, owing in part to its origins and concern for the regulation of research on embryos (Sethe and Murdoch, 2013). This very involved approach to the provision fertility services was evidenced in the interviews where respondents saw themselves (or the clinics) as responsible for bringing children into the world in the ‘right’ way and placing them in the right environment. The discussion of regulatory heritage therefore provides an explanation for the embedded nature of racialised matching and the conceptualisation of social norms through regulatory behaviours.

iii) Navigating patient autonomy and welfare

The thesis findings on the nature and extent of clinics' involvement in donor selection reveals much about importance placed on patient autonomy in this context and how the concept is conceived and operationalised in clinical practice. What is perhaps more significant, however, is that the interviews highlight an apparent tension between facilitating patient decisions on one hand, and fertility professionals' attempt to deliver on their perceived obligations to consider the welfare of the child (discussed above) on the other. How fertility professionals navigate this tension sheds further light on the problematic social and political implications of how race is conceived and operationalised in this context, while providing a potential counter argument that identifies a distinct role for race in facilitating positive notions of personal and familial identities and narratives.

As outlined in Chapter Four, respondents were observed to view the choice offered to patients in donor selection as promoting reproductive decision-making and the exercise of autonomy. The presentation of choice in donor selection was seen in Chapter Six to promote processes of kinship construction, including personal and familial narrative building. Fertility professionals were shown to place value on these aspects and sought to provide patients with the opportunity through space and time to consider the relative importance of donor information, of which race and race-like characteristics were part of. Indeed, counsellors were seen to encourage such deliberation and sought to ask questions that brought out such considerations for further discussion.

While such references to autonomy reflect wider themes in medical law (see, for example, Robertson, 1994; Harris, 2003; Savulescu, 2002), the perspectives of

fertility professionals described above seemingly contradicts observations on how seriously they take welfare considerations (discussed in section 1.i above). Indeed, some respondents were shown to simultaneously place importance of promoting patient autonomy by taking a non-interventionist approach, while at the same time expressing a concern for the welfare of the child and described potential intervention in the selection process on this ground. Of course, it would be overly simplistic to describe fertility professionals' involvement as adopting a singular approach or presenting multiple approaches as binary tensions – but these findings of this thesis do raise unique perspectives on how clinics navigate the promotion of autonomy with their understanding of their statutory obligations to consider the welfare of the child.

The first set of conclusions on this issue concerns the versions of autonomy evidenced in the respondents' responses. As discussed in Chapter Four, section 4.i, references to choice and online shopping evoke impression of consumerist notions of autonomy. However, as the interviews show, this by no means accounted for the complexity in which the principle of autonomy was deployed. In Chapter Six, sections 4-5, respondents emphasised on the patients' narrative of relatedness, legitimacy and kinship broadly linked to notions of reproductive autonomy and identity. Kinship considerations were, in turn, seen to involve the wider family or community, resulting in perceived importance of both individualistic and relational autonomy. Therefore, the fertility professionals in this study steered attention away from the more consumerist and versions of autonomy, to a thicker and more relational version that entailed the enactment of personal and social identity in addition to the exercise of moral responsibility (see Reis-Dennis, 2020; Blackburn-Starza, 2015).

How did clinics account for such a version of autonomy while maintaining a concern for the welfare of the child? Far from seeing the donor selection decision as being far removed from the clinic, the version of autonomy spoken about by the respondents emphasised the gravity of the donor selection decision. Indeed, it was a decision that was viewed as being the subject for counselling and guidance. By bringing the autonomous patient decision-maker back into the clinic, the clinic not only acted as the safeguard of the outcome but was also able to directly or indirectly influence the construction processes that underpinned the exercise of autonomous decision making. Indeed, the fertility professionals were themselves part of the relational autonomy consideration. Moreover, patients who were seen as being overly commercialistic were viewed as a risk and not prepared for donor conception, thereby revealing concerns over the commodification of children associated with consumerist decision making in the reproductive context. It was therefore important that patients were able to exercise autonomous decision making, but in doing so were encouraged (albeit implicitly in many cases) to do so with responsibility and consideration of how a family might be expected to function. The relevance of resemblance pertains to this question. Patients were free to make their decisions, but there was a sense of the 'right' way of doing so (not necessarily the right outcome) and this often involved dialogue with the fertility professional themselves – who became a key factor in the deployment of the patient's autonomy.

3. Normative considerations for clinics and policymakers

The conclusions above raise important normative considerations regarding the references to race made during donor selection discussions that may inform future policy. The implications of the findings reveal that through their management of donor selection, fertility clinics are heavily involved in processes that, albeit unintentionally, reproduce social normative models of the family. This general finding supports observations made in Deomampo's ethnographic study of egg donation practices that fertility staff (namely, in her study donor coordinators) 'occupy critical positions in shaping racial imaginaries of clients' (2019:625; see also Moll, 2019). Furthermore, the emphasis on racial matching also mirrors Davda's observations that clinicians matching discourses reveal a medicalisation, stratification and racialisation of reproduction according to 'nuanced racialised cleavages' (2018: 307). The normalisation of same-race reproduction and the problematisation of racial mismatching risks perpetuating assumptions around race. Beyond this, the facilitation and assumption of racial matching implicates clinics within notions of race-kinship congruity that are widely challenged (Wade, 2015:122). The CRT analysis has helped elucidate these normative findings that reflect structural issues for wider society. These findings can be grouped together into questions around the biologisation and classification of race, race unconsciousness and the exercise of choice, including to what extent clinics should facilitate or shape patients' donor requests.

i) Biological race and race classification

The thesis demonstrates at various points how through matching practices and the presentation and discussion of donor information, the concept of race is operating

to reify a biological version of race that is reducible to a visually identifiable set of characteristics (see Roberts, 2011:29, Bender, 2003:56). This finding gives further support to existing studies on this issue (see, for example, Deomampo, 2019; Davda, 2018). Chapter Five described how race is ‘biologised’ (Thompson, 2009; Strathern, 1992:19) in reports of donor selection discussions through both express references to the word and implied through emphasis placed on racialised donor characteristics. Furthermore, it was shown that the phenotypic expression of donor information was infused with notions of genetic heritability beyond ways that could be explained by genetics, representing a ‘biologisation’ of phenotypic traits (see Thompson, 2009), extending to racialised donor information. To this extent, the findings illustrate what Cussins called ‘naturalisation’ – the rendering of facts in a scientific idiom (1998:67). The biologisation of race also facilitates classification, as race can be used to sort donor information into different categories based on certain characteristics (Quiroga, 2007). Classification was evidenced in this study by respondents referring to certain donors as being from racialised categories – e.g. a ‘Mediterranean donor’ (discussed below).

The interviews also evidenced the role of professionals in shaping the way race is imagined by patients, through their involvement in dialogue, discussion and the presentation of information. Chapter Four outlines how clinics would often be actively involved in donor selection discussions, presenting donor information to patients and discussing the implications of donor selection during in-depth counselling sessions. Chapter Five showed how fertility professionals were involved in the prioritisation of race and importance placed on racialised physical donor characteristics, such as skin tone, either through active guidance or more passively by allowing patients the space and time to craft meanings around donor

information. References made to ‘race-associated’ characteristics, such as eye colour, implicates clinics in a process whereby race is reinforced as a heritable concept (Deomampo, 2019:629). Deomampo gives the example of the presentation of a donor’s picture to a patient (a practice associated with commercial gamete banks and jurisdictions where donor anonymity is not maintained) where the picture both signifies the visible clues that based donor matching and also references the importance of likeness in single-race families (2009:627). While donor anonymity to the patient is often the case in this jurisdiction and donor profile pictures are not used, this study illustrates how a ‘picture’ of the donor is conveyed through donor information and an image or impression of the donor is often built up during donor selection discussions. Similar to the use of an actual photograph, the imaginary picture of the donor and donor information provides the clues for donor matching and can convey the importance of likeness. The findings in this study echo a term that Moll adopts in the gamete donation context – that race is enacted through ‘curature’ (2019:589). Through their engagement in matching, fertility professionals are involved in the racial classification of donor information; crafting donor information into patient narratives of ‘racialised kinship’ with a notion of biological race (Moll, 2019:589).

The implications of the biologisation of race are significant. Biological race has been used to stratify and segregate certain populations (Quiroga, 2007; Richards, 1997; Roberts, 1995). Essentialist views of race have given ground to and furthered racist practices and beliefs (Roberts, 1995). Racial matching also supports a normative assumption that families should display the same race or share resemblance (Wade, 2015:122). The findings in this study in part support

Davda's observations on egg donation practices that matching constitutes a 'biomedicalisation of kinship' such that normative families are reproduced and familial characteristics are optimised (2018:321). The interviews also provide evidence of what Deomampo describes as the rhetoric of family formation reinforcing the 'biogenetic family norm' (2019:625).

There is, of course, no suggestion that any of those involved in this study consciously harboured any allegiance to such norms. To the contrary, the respondents were highly sensitive to and acutely aware of the pernicious social problems around race and racism. However, one of the primary contributions of CRT has been to acknowledge that racism, inherent bias or normative assumptions are not always consciously or manifested in express ways but can be displayed unconsciously or lie behind otherwise race-neutral statements or practices. Indeed, one of the respondents (Embryologist D) affirmed 'there is no race' (Chapter Five, section 3.ii), but then offered an example where it was 'obvious' that a patient or their partner looked 'very Mediterranean' and so the respondent proffered to search for a 'Mediterranean donor'. The implication in this exchange is that the respondent may be relying on an unexpressed assumption that race is visually detectable and, by further implication, inheritable (otherwise why would a Mediterranean donor be sought?). On the other hand, as explored further below, the exchange can be explained by implicit references to race being used as a proxy for distinct kinship processes – an aspect of donor selection that was strongly articulated by respondents.

Despite the widely accepted view that there is no biological basis to race, it remains troubling to observe the reproduction of a model in contemporary

discourse through indirect and unconscious ways, even when there may be other explanations for such observations. Furthermore, it is particularly surprising to see reproduction of biological race operating seemingly unchecked in donor selection – particularly when improved understanding of genetics and science has been one of the main arguments for abandoning the biological notion of race (Roberts, 2011; Hartigan, 2008).

While the findings give further support to what has already been identified as an important normative question for institutions including fertility clinics, this thesis also illustrates a very complex set of conclusions. As discussed above, the concepts of race described by respondents were extremely fluid and multi-faceted, produced and reproduced within an array of themes and considerations. The meanings generated by race are therefore myriad. The findings suggest a notion that biological race is fact *or* fiction, instead demonstrating that race may both be factual *and* fictional (M'Charek, 2013). Such a view may give weight to what Thompson terms a 'dynamic' aspect of biological racialisation that captures how notions of the biological entwine with the social (2009:132). Thompson asks, 'how and by whom and for what purposes is race biologised and biology racialised?' (2009:132) – a question to which it is hoped that this thesis has begun to provide answers.

ii) Race unconsciousness

The fact that fertility professionals have been shown to be often extensively involved in racial matching raises implications for clinics, which through their discussion and assessment seek to facilitate or initiate such requests. The interviews further indicated that certain family and social norms outlined above

may to a large extent have been assumed or unconsciously reproduced by fertility professionals through standardised matching practices and also the presentation of donor information, including race and racialised characteristics, that were believed to be a match to the patient and/or their family. Chapter Four, section 6, outlined how some respondents thought that race was a 'given' in matching and had assumed from the outset of the consultation with patients that they would seek a donor of the same race or ethnicity, reflecting what Cross observes as racialised assumptions which lay within ordinary or 'unremarkable' practices (Cross, 2010:416). For example, Chapter Four showed that clinics engage in direct and close management of the donor selection process, sometimes presenting patients with one donor at a time. If patients do not make a request for donors of a similar race, clinics would nonetheless present patients with a donor that was perceived as offering a racial match. The comments from Embryologist D in the section above serves as another example of assumptions of race, possibly resulting in the initiating of racial matching while race was at the same time consciously downplayed as a valid concept. The interviews therefore indicate that clinics may to some extent be operationalising (Hudson, 2015:4) or normalising race and racial matching to the extent that it almost becomes invisible or unconscious.

One aspect of racial matching that emerged from the interviews was that respondents' examples of mismatching requests often involved patients of Asian or other ethnic minority backgrounds requesting donors from different ethnic backgrounds. These examples may illustrate the invisibility of Whiteness whereby despite the significantly higher number of White patients accessing donor conception compared to patients from ethnic minorities, Whiteness seem to account for a lower proportion of 'problematic' cases flagged by respondents –

although of course the data was not able to point to a representative observation on this point. This observation may be further supported by the assumptions evident in some interviews that White patients would want a donor match. This points to a possible routinisation or normalisation of racial matching around Whiteness (Tyler, 2009; Thompson, 2009).

The unconscious reproduction of biological race and classification of race through ordinary or mundane practices and its application through assumptions of racial matching are inherently problematic in the social norms that are indirectly reproduced, albeit unintentionally (see Deomampo, 2019; Davda, 2018; Cross; 2010).

iii) Choice and consumerism in donor selection

The trend towards the use of donor catalogues and external sperm banks also raises normative questions regarding matching practices within a commercialised setting. The use of donor catalogues to present donor information has undergone significant critique from academics who have questioned its promotion of racial hegemony (Fox, 2011; Almeling, 2007; Quiroga, 2007) and also the potential patriarchal portrayal of women or endorsement of pronatalism (Quiroga, 2007; Daniels, 1999), as well as showing a preference for achieving apparent genetic connectedness (Roberts, 1996). Fogg-Davis asserts that race-based gamete donation services cause harm by racially stereotyping individuals and by promoting the view of racial stereotyping as an accepted feature of a largely unregulated market (Fogg-Davis, 2002). The gamete donor market (as represented in this study by the use of external gamete banks) accentuates the normative implications outlined above in a number of ways. First, the provision and

presentation of donor information furthers the biologisation and classification of race. Respondents outlined how patients might access donor catalogues that adopt race-conscious designs critiqued by Fox (2011), for example by positioning race as a searchable characteristic or filter. While the focus of this study is not on gamete donor banks themselves, the prioritisation of race in such a way may then feed into subsequent donor selection discussions once the patient airs or mulls their choice with fertility clinics in the treating clinic. Relatedly, the commercial context places emphasis on the perception of ‘what patients want’, which can serve to condition patients thinking of donor information and their requests.

Second, the commercialised model foregrounds choice as the justification and driving force for design and through the emphasis of choice, the normative implications outline above may be accentuated. Choosing a donor based on their racial characteristic may, upon such a view, involve a presumption of racial stereotyping. The choices made in this context may not merely reflect but also reinforce the routine use of racial discrimination in partner choices for procreative sexual intercourse (Fogg-Davis, 2002); the gamete donation setting makes explicit what is otherwise left unsaid in coital reproduction. As such, practices in the context of ARTs may have the potential to uncover racial bias that permeates society (Fogg-Davis, 2002) and the finding of racial matching in this thesis, as well as the prioritisation and significance given to race as a donor characteristic, adds weight to Fox’s assertion that reproductive decision making should be closely examined for the extent to which it might accentuate racial preferences (2011:11).

4. Recommendations for clinics and policymakers

The normative considerations around the use of race amid the practices described in this thesis must also be considered in light of the complexities and nuances around the construction of race and discussion of donor information that the interviews convey. The interviews illustrate variable yet often extensive involvement of fertility professionals in problematic and contested constructions of race and how it is operationalised in fertility clinics. However, the interviews also demonstrate a significant involvement in processes that are highly individualised and potentially meaningful to patients in respect to kinship practices.

While the normative implications of the use of race in this context appear to be in tension with the attached significance it carries for individual and personal kinship building, it is suggested that this tension can be mediated through an application of responsibility and awareness. The CRT analysis of the interview data has revealed significant implications for inequality, discrimination and racism in the modes and manner of donor selection in UK fertility clinics. Decisions made in this context both reflect and perpetuate problematic structural issues around race that continue to plague current social and political realities. Those engaged in the management and coordination donor selection decisions must therefore be mindful to these realities and take steps to avoid the unintentional reproduction of social problems of stratification and classification according to race. However, the necessary policy considerations and recommendations that may follow must also be mindful of the idiosyncratic, also sometimes irrational and inconsistent understandings of race in donor selection which operate in the space provided by clinics to contemplate donor selection. Race is of course recognised by CRT as a

powerful social phenomenon (Lopez, 1994:19) and a source of identification for many individuals (Fogg-Davis, 2002). The space, time and language discourse presented to patients by clinics, at least in part, contributes to both the rationalisation of personal ideologies but also implicate wider social and political ones. This is a forum that requires careful navigation.

Given the findings of the thesis, and with due consideration to the normative implications, a number of questions emerge from this thesis that could be pursued further and fed into discussions about best practice and the regulation of fertility clinics in the UK. Building on Fogg-Davis' call for 'racial navigation' that urges individuals to avoid absorbing the social and political norms of race into their self-concepts (2002:14), this thesis advocates for the adoption of sensitivity, awareness and responsibility around references to and the use of race in donor selection. The first area of application of these principles relates to racial matching. As discussed, the interview data confirms assertions that racial matching continues in practice. This raises important questions about whether clinics should consciously avoid (or discourage) racial matching, and whether clinics should comply with patient requests based on race? Indeed, possibly also whether patients should be permitted to choose their own gametes at all (see Pennings, 2000:508).

Clinics and fertility professionals alike may consider the implementation of race conscious policies and a role for unconscious bias training to help challenge or explore assumptions held by patients and fertility professionals. This could be achieved through implications counselling but may also form part of donor selection discussions elsewhere. As part of this, it is important to appreciate that

fertility professionals' own views may misalign with what patients want (Deomampo, 2019:626). Policies and practices that assume matching as a starting point should be re-examined. Such interventions could minimise the harmful implications of matching practices by reducing their unconscious replication and opening up assumptions to constructive scrutiny, while retaining a forum and process through which patients can engage in creative kinship work.

Second, the positioning applied to race in donor catalogues and the importance given to it in discussing donor selection could be reconsidered. Should race be retained as a searchable characteristic? Should race feature ahead of other donor information? Should the word race be used at all? The findings of this thesis could serve as impetus for fertility clinics to observe their application of the concept of race and its positioning in their own literature. Likewise, gamete banks may take into account the findings of this thesis in considering how race is presented and searched for through databases. Considerations may include reframing race using different terminology; avoiding race as a presented or searchable characteristic and deprioritising its location in donor information. Steps could also be taken to avoid essentialising race through racialised characteristics by framing discussions and the presentation of donor information in such a way that downplays what is expected to be inherited, or provide further explanations to patients about what they can and cannot expect their child to inherit. Measures to address the references to race in the broader informational framework recognise that the normative questions above cannot solely be attributed to the views of the actors involved in donor selection (see Fox, 2011:6). In many ways the overarching landscape is a more significantly influencing factor (and therefore a target for reform).

Third, more broadly, clinics may need to consider the level of information support provided to patients – and also the appropriate forum for this, as well as the method for presenting such information. It is significant, given the existence of professional advice agencies and organisations that seek to guide and inform patients about legal complexities associated with their use of assisted reproduction, that clinics sometimes recommend where to source gametes. This shows that there are many players in patient support and raises the question of whether there is a need for authoritative information sources for patients considering gamete donation? This consideration also invites questions about whether the treating clinic is the most suitable place or body for providing such specialist advice. Fertility professionals engaged in discussion regarding the use of donated gametes must cover a complex, diverse range of practical and legal issues, raising the question of whether these are matters that should be discussed in the clinic at all. This raises questions over the extent to which clinics should promote neutrality or be actively involved in stripping any the normative connotations and complex narratives in donor selection.

5. Avenues for further research

Overall, the findings of this thesis provide considerable material for further thought, unearthing important questions that deserve future attention. First, the normative implications identified above should be explored further. The findings of this thesis clearly implicate clinics in discussions of race in donor selection, and these discussions do reflect, illustrate and further some of the concerns expressed in the critical race literature in Chapter One. Such is the significance of these implications for individuals and society, there is scope for further detailed

ethical discussion of the ways in which clinics' practices serve to reify biological notions of race that may perpetuate certain family models and notions of genetic relatedness. There is also room to explore further how notions of Whiteness and aspects of nationhood (as associated with the UK) may be deployed in the donor selection context. Such investigations may require additional in-depth interviews with patients themselves about their selection of gamete donor.

Second, the views of patients more generally should be studied in further academic work. For the reasons explained in Chapter Three, this thesis did not rely on interviews conducted with patients. However, the findings indicate a great deal of complexity in donor selection decisions and patient preferences that deserve further consideration both in relation to CRT and NKS. Furthermore, a representative study of patients would cast light on the ways their donor preferences are impacted by donor availability, the nature of the selection process, and whether the patients are in a heterosexual or same-sex relationship or are single, as well as how religion and culture impact on donor selection.

Third, considering again the perspectives of patients, the findings of this thesis point towards a construction of race and resemblance that provides a unique perspective on the understanding of harm in the context of gamete selection, particularly in cases of sperm mix-ups. The manner in which the current findings map onto existing sociological/anthropological literature that examine how ARTs 'reconfigure' notions of kinship (for example, Smart, 2011) signifies the importance of resemblance, the social construction process, the fluidity and paradoxical generation of meaning and the importance of real-life experiences. Such perspectives can shed new light on discussions of harm and actionable

damage in the sperm mix-up cases discussed above, opening up for discussion the substantiation of mental distress, the re-conceptualisation of personal injury, supporting findings of assumption of responsibility or helping establish new categories of actionable damage, such as loss of autonomy (Blackburn-Starza, 2015; Bender, 2003).

Many other areas of potential research can also be identified, including: how gamete availability impacts on the choices people make about their selection of donor; whether the characteristics sought in donors are changing; whether the fertility sector has been materially affected by an increasing outsourcing of certain functions and commercialisation; and why fertility practices vary so considerably between clinics. There is also scope to conduct larger studies on the same issues that seek to achieve a greater representation of clinics across the UK, staff positions and patient demographics, all of which may influence consideration of the above questions.

This thesis demonstrates that race is important – arriving at and providing illustration in the donor selection context of the themes identified in the previous literature on kinship more generally and how these themes are understood by fertility professionals involved in donor matching. Crucially, the findings offer new and unique insight into the complex ways in which race is deemed important and how race has been operationalised in clinical practice, raising important normative considerations for clinics and policymakers alike.

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Workshops and conferences

BSA, 2016. *Human Reproduction Study Group Annual Conference 2016*, De Montfort University, Leicester, 10th June 2016.

Appendices

Appendix A: Interview schedule

1. Can you explain your role in the clinic?

- Do you have opportunities to meet patients? If so, do you discuss donor selection?
- Do you have an involvement in with the selection of gamete donors by recipients?

2. How do patients select a sperm or egg donor?

- Do patients come into the clinic to choose or discuss their selection?
- What information or advice does the clinic / provider give to patients in the selection of donors?
- Are patients given any guidance in selecting a donor? If so, can you explain what it entails?
- What is the level of involvement of the clinic, if any?
- How much of a choice are patients given to select donors?
- Does the availability of sperm/eggs have an impact on selection?
- What are a donor's searchable characteristics? Is race one of them?

3. Does the clinic have a policy or usual practice on sperm/egg donor matching? (For example, is the matching of physical characteristics the norm?) If not, should it?

- Do you have any sense of how donor selection in this clinic compares to other clinics nationally?
- Do you consider there to be a norm or standard practice for donor matching?
- Does the clinic have a policy on 'racial matching'? To your knowledge, has it ever had one?

4. Once a selection is made, what happens next?

- Are donors 'put aside' for patients?
- What happens if the patient's selection is unavailable?
- Do some patients change their mind?

4. What do patients look for in a sperm and egg donor?

- What is the most common characteristic selected? How is this done?
- If discussed in person, how do patients express their preferences?
- Does this differ for egg and sperm donations?
- Does this differ for heterosexual and homosexual couples?
- Are some patient's expectations unrealistic? If so, how you do manage this?
- Would you correct a patient's scientific understanding of the heritability of donor characteristics?

[If race is raised early on, move on to the next set of Qs and return to general questioning on donor preferences]

5. What role does race or ethnicity play in the donor matching process?

- Is race important for patients? Why?
- Is this raised frequently? Is it raised by you or the recipient?
- How does it come up, why does it matter?
- In your view, what does race mean to patients?
- Does the availability of donors from BME backgrounds affect donor requests?
- Do you think race should be a searchable characteristic?
- Is racial matching something that is consciously thought about? What are your views on this? How important is it?

6 Have patients raised any unusual requests?

- Would you question a donor's choice? Why?
- Have patients ever been denied treatment on the basis of their donor request? Why so?

7. What is your opinion of the donor selection process?

- Why do patients choose certain donors?
- What do you think it says about the way patients think about donor conception?
- What is the role of the clinic in all this?

8. Is there anything else you would like to add?

Appendix B: Consent Forms

CONSENT FORM

Title of Project: Race and ethnicity in donor gamete selection

Name of Researcher: Antony Blackburn-Starza

Please tick all
boxes

1. I confirm that I have received the relevant information sheet outlining the research project. I have had the opportunity to consider the information, ask questions and, if so, have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw within three weeks after the interview was conducted without giving any reason. (You also have the right to request that the information be destroyed).

3. I agree to the public dissemination of the interview's content in an anonymised format.

4. I agree to the interview being recorded and a transcript of the recording to be stored securely.

5. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of person
taking consent.

Date

Signature

CONSENT FORM (HRA)

Title of Project: **Race and ethnicity in donor gamete selection**

Name of Researcher: **Antony Blackburn-Starza, PhD candidate, Kent Law School, University of Kent**

Please initial box

1. I confirm that I have received the relevant information sheet outlining the research project. I have had the opportunity to consider the information, ask questions and, if so, have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw within three weeks after the interview was conducted without giving any reason. (You also have the right to request that the information be destroyed).

3. I agree to the public dissemination of the interview's content in an pseudonymised format and the storage of interview material content for such use. This means the names of participants and clinic will not be disclosed and interview content will be given artificial identifiers in publication and analysis. Job positions may be included.

4. I agree to the possible use of interview data in future research in an pseudonymised format and the storage of interview content for such use.

5. I agree to the interview being recorded and a transcript of the recording to be stored securely.

6. I agree to take part in the above study.

A transcript of the interview is available upon request until three weeks after the date of interview. A summary of the study findings can be provided upon request once complete and will be available from the University of Kent library.

<hr/>	<hr/>	<hr/>
Name of participant	Date	Signature
<hr/>	<hr/>	<hr/>
Name of person taking consent	Date	Signature

Appendix C: Information sheets

Information sheet re PhD thesis: 'Donor gamete matching in fertility clinics' *Antony Blackburn-Starza, University of Kent*

About me

I am in the final year of a full-time PhD (Law) at Kent Law School. [...] ³³

About my research

My thesis explores the role that race or ethnicity may play in the donor gamete selection in the provision of fertility treatment in the UK. It will evaluate the meanings generated around notions of race that are played out in UK fertility clinics, specifically what race or ethnicity means to clinical staff and how race may be operationalised in 'routine' clinical practice and 'problem' cases where patients raise a query or challenge norms, or where things go wrong.

I hope to gather empirical evidence of how donor selection and matching is carried out at UK fertility clinics and what clinic staff's views are on the process. Interviews will provide a unique opportunity to gather crucial insight about donor selection that will help inform a theoretical discussion of the topic and also contribute to related literature.

Possible dissemination of research

Preliminary and subsequent observations from the thesis study may be published and once completed the thesis may be freely available in the University of Kent's Library.

Data protection and confidentiality

Data will be stored securely and kept confidential. Participants and institutions will have anonymity. However there may remain a possibility of identification using external information. Staff positions may be required for data analysis and subsequent data presentation. All participants have a right to withdraw within three weeks of the interview.

Contact

If you have any questions about the interview questions or research project you can contact me at [...] or call me on [...].

³³ Personal information has been removed for the purposes of inclusion in the Appendices.

Participant information sheet

For doctoral research at the University of Kent, project title: Race and donor gamete matching in fertility clinics

Study title

An investigation into the role of race and ethnicity in the selection of gamete donors by patients in fertility clinics

About my research

I am conducting a socio-legal thesis supported by empirical data collection that explores the role that race or ethnicity may play in the donor gamete selection in the provision of fertility treatment in the UK. It will evaluate the meanings generated around notions of race that are played out in UK fertility clinics, specifically what race or ethnicity means to clinical staff and how race may be operationalised in 'routine' clinical practice and 'problem' cases where patients raise a query or challenge norms, or where things go wrong.

I hope to gather empirical evidence of how donor selection and matching is carried out at UK fertility clinics and what clinic staff's views are on the process. Interviews will provide a unique opportunity to gather crucial insight about donor selection that will help inform a theoretical discussion of the topic and also contribute to related literature. An examination of the donor matching processes and the role of race and ethnicity has not to date been something that has been covered in relevant academic literature.

Participation

I am asking fertility professionals with views on or experience of donor matching to discuss how this has been / is conducted and what, if any, is the role of race and ethnicity in this process. The interviews will take no longer than an hour, give or take, depending on the availability of each participant.

The participant will be asked to sign a consent form. They will be provided with information about the thesis prior to the interview but there is no preparation necessary.

I am asking to record the interviews, which will be transcribed at a later date. The participant has the right to withdraw up to three weeks after the date of interview, upon which if requested all interview data will be disposed of.

Possible dissemination of research

Preliminary and subsequent observations from the thesis study may be published and once completed the thesis may be freely available in the University of Kent's Library.

Data protection and confidentiality

Data will be stored securely and kept confidential. Participants and institutions will have anonymity. However there may remain a possibility of participant or institution identification using external information held by the clinic by the HFEA, for example, such as location and the name of the licence holder or person responsible. However while generic staff positions may be required for data analysis and subsequent data presentation, the location of the clinic will not so to minimise any risk of identification.

Any personal details about any patients discussed, if mentioned during the interview, will not be disclosed in the presentation of the thesis findings or used in data analysis. It is possible the interviewee will be asked about patients' donor choices in general terms but any confidential information disclosed will be treated as confidential.

All participants have a right to withdraw within three weeks of the interview.

Transcription

I will transcribe the interviews myself and the transcription files will be password protected and stored on a password-protected computer. The audio files will also be stored on a password-protected computer.

About me

I am in the final year of a full-time PhD (Law) at Kent Law School.

Contact

If you have any questions about the interview questions or research project you can contact me at [...] or call me on [...].

Ver1. IRAS ID 215911

Appendix D: Ethics approval

KLS Research Ethics Application Form

For Students: Please complete this application for research ethics clearance with the assistance and approval of your supervisor. Please submit both an electronic form and a paper form signed off by your supervisor via [...] to the Research Ethics Advisory Group.

For Staff: Please complete, and submit electronically via [...] to the Research Ethics Advisory Group.

1) Researcher(s) and project organiser(s)

Name of principal researcher: Antony Blackburn-Starza

E-mail address: [...]

Name of others involved and role (e.g. supervisor) including affiliation if not KLS:
[...]

For Students:

This Project is for (please tick as appropriate)

PhD

Have you discussed this application with your supervisor?

Yes

For supervisors:

Please confirm that you have discussed the contents of this form with your student and that in your view, the research is sufficiently well focussed, any ethical implications of the research have been adequately addressed and the form has been fully and accurately completed.

Yes

2) Project details

a) Title of Project: Donor gamete matching in fertility clinics

b) Funding Institution (for awarded research grant applications only): n/a

c) Proposed Duration of Research: From September 2014 **To** September 2018

d) Purpose of Project/Aims and Objectives

This should include a brief outline (i.e. one or two paragraphs) of the project written in **lay-person's language** and assuming that the reader is **not familiar** with the area of the project.

My thesis explores the role that race and ethnicity may play in the donor selection or matching process in the provision of fertility treatment in the UK. It will evaluate the meanings generated around notions of race are played out in UK fertility clinics. I wish to also explore what race and ethnicity mean to clinical staff and how a concern for race may be operationalised in 'routine' clinical practice and 'problem' cases where patients raise a query or challenges norms, or where things go wrong.

Such an investigation may lend itself to open up broader discussions about patient's interaction with reproductive technologies and how law, policy and practice can respond to the meanings generated in this unique sphere of interaction between patient, donor and clinic.

Through semi-structured interviews, I hope to gain an insight into how donor selection and matching is carried out at UK clinics and clinic staff's views of this process. Interviews will provide a unique opportunity to gather crucial empirical evidence of donor selection practices that will help support a theoretical discussion of donor selection and review of existing study findings.

e) Location of research

The pilot will be conducted at [...] ³⁴, the subsequent full study at 3-4 other private and NHS clinics, chosen on the basis of discussions with my contacts in the [...] and my supervisor'

f) Please describe briefly the methodology/technique used when dealing with human participants in your research (e.g. examples of any questionnaires, etc).

Semi structured interviews – around an hour in length - around but not limited to central open ended questions. I plan to make recordings and later transcribe for analysis.
(Questions attached)

g) Please provide some details on the selection of participants and numbers.

The proposed full study in 2014 may include a range of clinical staff at private and NHS clinics, but the pilot will be conducted at [...] in December or January 2014. I anticipate it may involve between at least two and perhaps up to ten members of clinical staff. I will not interview any patients.

³⁴ The names of individuals, clinics and organisations have been removed for the purposes of inclusion in the Appendices.

h) Please give details on how results of your research will be disseminated to participants.

Findings of the study may be published in a relevant publication, BioNews, which is read by fertility professionals and is freely available. My PhD will be freely available in Kent's Library (and, possibly, on KAR) and I hope to publish other academic papers from it. All participants will be able to request a transcript of their interview upon request.

3) Ethical Considerations

a) Knowledge of professional guidelines and codes of conduct

Have you read and made yourself thoroughly aware of the appropriate conventions and guidelines related to ethical research within your discipline (e.g. *Socio Legal Studies Association's* [Statement of Principles of Ethical Research Practice](#), *Social Research Association's* [Ethical Guidelines](#), *ESRC's* [Research Ethics Framework](#))

Yes (Please state which specific guidelines you consulted): both

b) Does the research involve

- Children/legal minors?
No
- Groups that may be vulnerable or at risk?
No
- Groups that may be involved in illegal activities?
No
- Participants in a dependent relationship with any of the investigators?
No
- Coming into contact with informants as patients of the NHS or clients of the Social Services or residents of care homes?
No
- Prisoners or prison staff?
No
- Payment of participants?
No

If you have answered Yes to any of these questions, please provide more information, including details of measures which you will undertake to protect the participants.

c) Please discuss whether there are any risks to the participants: this might include all forms of harm, e.g. physical or psychological/emotional. Particular attention should be paid to the potential to cause distress and embarrassment. What measures are to be taken to ensure the welfare and safety of participants?

None. Risk of harm to participants is minimal, given the nature of the study.

I will be asking participants to talk about potentially sensitive issues around race and ethnicity, but all participants are professionals and their anonymity and confidentiality will be ensured.

d) How will you deal with issues relating to confidentiality during the project and in subsequent data analysis, presentation and publication?

- Adequate consent will be obtained prior to interviews, with the option to withdraw provided.
- Clinical institutions and individuals will be guaranteed anonymity. A clinic or staff member's name will not be required for research analysis and will not be shared or published. The identity of interviewees will not be used in analysis and identifiers used in research preparation and for necessary consents will be stored securely (below).
- All data published, presented or otherwise disseminated, will be pseudonymised. Data in its original form will not be shared with other members of staff, institutions or other third parties. However, staff positions and a clinic's locations (regions) may be required for data analysis and subsequent presentation. Participants will also be informed of the risks of identification from anonymised / pseudonymised data using other information having regard to the potential low numbers of clinics interviewed and staff titles used e.g. donor coordinator, private clinic, Greater London.
- Interviews will be recorded and stored on a password protected computer to which I will have sole access.
- The interviews will be transcribed by myself and an external transcription service [...]. The transcription word files will be password protected and the audio files transferred securely.

e) Does the research raise any cultural issues (for example, how will the need to provide appropriate interpreters, the impact of different religious backgrounds etc be taken care of)?

No. All participants will be professionals who use English to communicate with patients.

g) It is essential that all those who participate in research should do so voluntarily. Please explain how the consent of participants (and, where the participant is a minor or otherwise lacking legal capacity, his/her guardian) will be sought. Copies of any relevant documentation should be included.

All participants will be provided with an information summary about the project and a consent form to sign (attached). They may also be provided with a sample question list. No participants without capacity will be enrolled in the study.

h) If the research raises any ethical issues other than those which you have outlined above, please give information about them here.

Signature(s) of Investigator(s) (Both supervisor and student in the case of student projects)

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Date.....
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Approval of Research Advisory Group

Comments

Signature of Chair of Research Ethics Advisory Group

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Date.....
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Appendix E: Coding themes

Revised coding (2) 14 Sept 2017

Group 1	Description of donor selection / matching procedures:
A	<u>How do patients select a donor?</u>
A1	Timing of when donor selection takes place
A2	Selection made by clinic staff (no patient involvement)
A3	Use of in-house donors (sperm donation)
A4	Use of in-house donors (egg donation)
A5	Use of a catalogue
A6	Use of external UK sperm banks / Import of gametes
A7	Use of overseas sperm banks
A8	Use of a donor coordinator
A9	Discussion with a different member of staff at clinic
A10	Previous procedures (add to categories below)
A11	Comparison between NHS / Private procedures
A12	Discussion of regulations
A13	Discussion with a counsellor
B	<u>Does the clinic give patients any information or guidance about choosing a donor?</u>
B1	No - No information
B2	Yes - Some discussion
B3	Yes - Documents provided
C	<u>Does the clinic have a policy or standard practice on donor selection?</u>
C1	No - No policy
C2	Yes - Standard practices
C3	A written policy
D	<u>What is the extent of the clinic's involvement in choosing a donor?</u>
D1	A little involvement eg. Health screening, reassurance – needs expansion
D2	Detailed discussion with in-house staff
D3	No involvement
E	<u>Explanatory responses (in response to the extent of clinic's involvement)</u>
E1	Reference made to welfare of the child issues
E2	Reference made to patient autonomy / empowerment / patient's own choice
E3	Reference to the distress associated with infertility
E4	Reference made to the individuality of patients
E5	Concern over potential liability / covering their backs
E6	
E7	
E8	

E9	Patient / customer selling tactics Eugenics The clinic explains genetic heritability to patients Keep the clinic separate from selection process
Group 2	Donor matching including racial matching
F	<u>What do patients look for in gamete donors?</u>
F1	Physical characteristics (e.g. height, hair and eye colour)
F2	“Race” mentioned expressly
F3	Race referred to by association – e.g. skin tone
F4	Less heritable traits (e.g. education, occupation)
F5	Other donor information patients are after / interested in
F6	Depends on the patient
F7	Not bothered – just want an egg / sperm (new code)
G	<u>Are patients ‘matched’ to donors? (old code B)</u>
G1	Yes - A matching is assumed
G2	Yes - Patients actively seek a match
G3	Yes - Clinic tries to ensure a match
G4	No attempt to match
G5	Depends on the patient
G6	Matching expressly discussed
H	<u>Explanatory responses (in response to matching generally)</u>
H1	Reference made to comfortable parenting / patient welfare / coming to terms with donation
H2	Maintaining secrecy
H3	Reference made to the availability of gametes
H4	Patient / child identity
H5	Achieving resemblance
H6	Reference made to the removal of donor anonymity
H7	Reference to eugenics
H8	Reference to welfare of the child
H9	Reference made to social inclusion / fitting in
H10	Legal issues / liability / covering their back
H11	Autonomy / patient’s decision
H12	Just about having a healthy child
J	<u>Is race discussed in donor selection?</u>
J1	Yes
J2	No
J3	Race said to be unspoken / assumption that matching will happen
J4	Reference made to racial matching
J5	Reference made to racial matching
New code J6	Depends on the patient Race said to be “important” (will cover some J1 codes)
K	

K1	Explanatory responses (why is race important?)
K2	Reference made to comfortable parenting / patient welfare
K3	Maintaining secrecy
K4	Reference made to the availability of gametes
K5	Patient / child identity
K6	Achieving resemblance
K7	Reference made to the removal of donor anonymity
K8	Reference to eugenics or undesirable social effects
K9	Reference to welfare of the child
K10	Reference made to social inclusion / fitting in Legal issues / liability / covering their back
L	<u>Discussion of “unusual” requests / occurrences involving</u>
L1	<u>mismatching</u>
L2	Dealt with by interdepartmental / multidisciplinary discussion
L3	Not dealt with by the clinic
L4	Race specifically at issue No formalised process or policy
M	
M1	Explanatory responses (why was this considered an issue?) Reference made to comfortable parenting / patient welfare /
M2	understanding implications
M3	Maintaining secrecy
M4	Reference made to the availability of gametes
M5	Patient / child identity
M6	Achieving resemblance
M7	Reference made to the removal of donor anonymity
M8	Reference to eugenics
M9	Reference to welfare of the child
M10	Reference made to social inclusion / fitting in
M11	Autonomy / clinic not involved / seen as a transaction Each case is different
Group 3	Open ended discussion of reform
N	Suggestions of ways to donor selection process can be
N1	improved
N2	Too much information
N3	Just enough information
N4	Not enough information
N5	Reference to consumerism
N6	Reference to patient autonomy
N7	Discussion of TP donor banks
N8	The clinic’s activities should be separated from donor selection There is a need for validating donor information
O	Other / misc.

End page