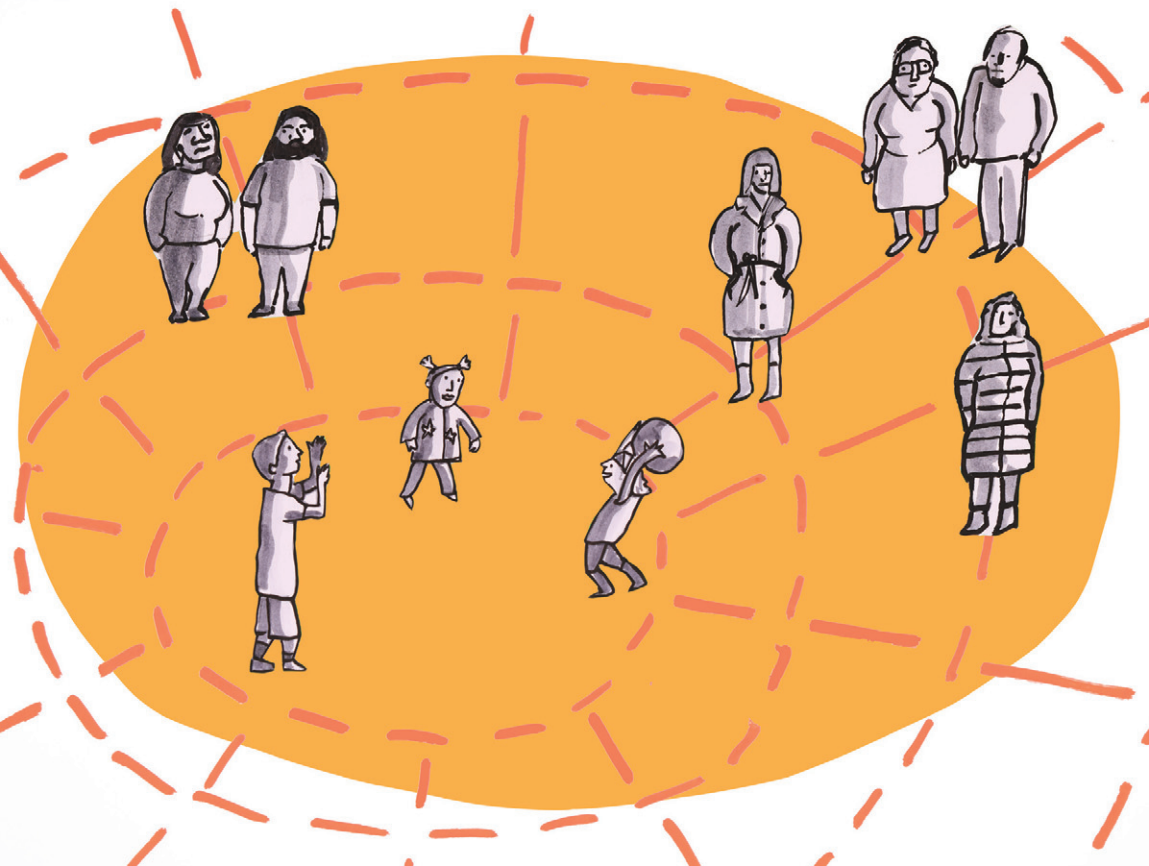


Emerald Studies in Reproduction, Culture and Society

Donors

Curious Connections
in Donor Conception

Petra Nordquist and Leah Gilman



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DONORS

Curious Connections in Donor Conception

BY

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INVESTOR IN PEOPLE

For all touched by donor conception.

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Petra Nordqvist is Senior Lecturer in Sociology and Co-Director of the Morgan Centre for Research into Everyday Lives, University of Manchester. She has published widely on donor conception and how it impacts people's lives and relationships. This book about egg and sperm donors is a sister study to her earlier research into the experiences of parents and grandparents of donor-conceived children, published in *Relative Strangers: Family Life, Genes and Donor Conception* (Palgrave Macmillan 2014, with Carol Smart).

Leah Gilman is a Research Fellow in the Centre for Social Ethics and Policy at The University of Manchester. Her research interests include the sociology of reproduction, childhood, morality and family relationships, as well as the intersection of fiction and research methods. She holds a PhD in Science and Technology Studies, awarded by The University of Edinburgh for her work on the views and experiences of UK identity-release sperm and egg donors. Leah's research has been published in a number of peer-reviewed journals, including *Sociology*, *Sociology of Health and Illness* and the *International Journal of Law, Policy and the Family*.

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GLOSSARY

AI:	Acronym referring to ‘Artificial Insemination’. Insertion of sperm/ semen into the vagina, cervix or uterus using some form of a syringe. Widely used in clinical and non-clinical donation communities.
CMS:	The Child Maintenance Service, previously referred to as the Child Support Agency (CSA). A UK service for parents who, usually after separation, have not been able to make a private arrangement about how their child’s living costs will be paid.
DCN:	Acronym referring to the Donor Conception Network. Supports those considering using donor conception or have donor-conceived children, and donor-conceived people.
Donation (egg, sperm or embryo):	The transfer of egg, sperm and embryos from one body to another for the purpose of helping someone other than self or a partner conceive.
Donor:	Person who agrees to give away their gametes (egg, sperm or embryo) to another for the purpose of helping someone other than self or a partner conceive a child. See donation.
Donor-conceived person/people:	Person or people born from donated egg, sperm or embryos.
Donor offspring:	Refers to the person conceived from a specific donor’s donated egg, sperm or embryo. We use it as a relational term only, that is, to highlight the specific connection between a donor and the person/people conceived from their gametes. See also donor-conceived person/people.
DSL:	Acronym referring to the Donor Sibling Link; a service provided by the HFEA to enable donor-conceived adults, conceived after 1 August 1991, to exchange contact details with people who share the same donor.
Egg-share donor:	A person (or couple) undergoing IVF who opts to donate half of their eggs which are produced in a given cycle in return for free or (more commonly) discounted treatment.
FET:	Acronym referring to ‘Frozen Embryo Transfer’. Refers to the process whereby a patient uses embryos frozen from a previous IVF cycle in a new embryo transfer.

Gestational surrogacy (also called host surrogacy):	An arrangement whereby a person carries a baby for another person or couple and where the surrogate does not have a genetic connection to the child. Gestational surrogacy arrangements require egg or embryo donation.
HFEA:	The Human Fertilisation and Embryology Authority. The UK independent regulator of fertility treatment and research using human embryos. The HFEA licenses, monitors and inspects UK-based fertility clinics and provides impartial information about treatments and donation.
HFE Act, 2008:	Act of the Parliament of the United Kingdom. It constituted a major review and update of the Human Fertilisation and Embryology Act, 1990.
Host surrogacy:	See Gestational surrogacy.
ICI:	Acronym referring to ‘Intracervical Insemination’. Same as IUI but the sperm is deposited onto the cervix rather than into the uterus.
ICSI:	Acronym referring to ‘Intracytoplasmic Sperm Injection’. Procedure which may be done as part of IVF which involves the sperm being injected directly into the egg.
Identity-release donation:	A regulated form of donation pertaining to UK clinic-based donation practices (and some other jurisdictions) where donors are initially anonymous to recipients but must consent to identifying information about themselves being released to people conceived from their donation (often only after they have reached a given age. In the UK, age 18)
Intended parent/s:	A person or couple who conceives (or tries to conceive) using third-party reproduction (donated gametes or surrogacy) in order to have a child. See also Recipient parent/s.
IUI:	Acronym referring to ‘Intrauterine Insemination’. A fertility treatment performed in medical contexts that involves directly inserting sperm into the uterus.
IVF:	An acronym for ‘In Vitro Fertilisation’, literally meaning ‘in glass’ fertilisation. During IVF, egg and sperm are fertilised outside of the human body, in a laboratory. If fertilisation is successful, the resulting embryo is then transferred to the uterus with the aim of producing a pregnancy.
Known donation:	A donation arrangement where the donor and recipient parent/s have some level of personal knowledge of each other.
NI:	Acronym referring to ‘Natural Insemination’. Term used in online donation communities to refer to sperm being donated through the donor and recipient woman engaging in heterosexual intercourse.
Open donation:	A term used variably to refer either to identity-release donation or donation to a known recipient(s). See also known donation.
Recipient (parent/s):	A person or couple who use donated sperm, egg or embryo with the aim of conceiving a child which they will parent. See also intended parent.

ROPA method:	Acronym referring to 'Reception of Oocytes from the Partner'. Refers to when a lesbian couple conceive using IVF where one partner contributes eggs for the other partner to carry and gestate. Also referred to as 'intra-partner sharing', or 'reciprocal' or 'partner' IVF.
Self-arranged insemination:	Insemination which is organised by the donor and recipient(s) themselves, and which takes place outside of a clinical environment. Also referred to as 'home insemination'.
Sperm-share donor:	A person who donates sperm in exchange for free, or (more commonly), discounted, IVF treatment for them and their partner.
Surrogacy:	An arrangement whereby a person agrees to gestate a child for another person or couple, but does not intend to be the child's parent.
Surrogate:	A person who agrees to bear and birth a child for another person or persons; see surrogacy.
Traditional surrogacy:	An arrangement whereby a woman carries a baby for another person or couple, using their own eggs and so has a genetic link to the baby.

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INTRODUCTION

Zak is a single gay man in his late forties with an engaging manner. Working in multiple jobs, and with a busy social life, he is always on the go. His life might seem fairly typical for a single man of his age, but there is one aspect of Zak's life that is, by many people's standards, unusual. He is a sperm donor, and when we met him, 14 children had been born as a result of his donations.¹ He explained that he had first become a sperm donor to help his friends (a lesbian couple) have a baby. Realising he was happy to help others too, he later signed up with a clinic to donate to unknown recipients. Although his first attempt to help his friends ultimately proved unsuccessful, it made him think carefully about what it meant to be a donor, and who he was in relation to the recipient parents and the hoped-for child. It also made him think about who else might be affected by his decision to donate, and whether a child born through *his* donations would be *someone* to people in his family. He said:

When I went into the sperm donor process, I never thought of myself in any way as being the child's parent, I've always kind of felt that I'm the donor. [...] [W]ith language I was very careful, even when I was helping [my] two friends, the lesbian couple, I was very... careful in how I talked about it, I talked about 'when you have your child'. [...] But in saying that I always felt that they would be my parents' grandchild, or my niece's cousin, because if you had a

¹The word 'donor' and 'donation' have come under scrutiny in recent years, with a series of international studies showing how donation can play out in ways that are financially exploitative of women, deepening social inequalities. This raises questions about the appropriateness of the word 'donor' because it implies altruistic motivations, governed by voluntary behaviour (e.g. Hudson et al. 2020). Whilst we do not see the word 'donor' as unproblematic, we use it because it remains the dominant term used in the UK: it is used in law and policy, by the HFEA, in clinics, and on matching sites. It applies across both sperm and egg donation, and is widely used among donors themselves, wider communities in the field, and is well established amongst the general public.

long-lost cousin that turned up it would just be your cousin you know.

(Zak, sperm donor, known non-clinic and altruistic identity-release donation)

Zak is clear that any baby conceived from his donated sperm would not be *his* baby. In his view, this is fundamental to the role of a *donor*. However, interestingly, Zak sees the act of donation as creating links beyond the people immediately involved, between his parents, his niece and the donor-conceived child.

These is something both very ordinary and completely extraordinary about Zak's account, how he feels and thinks about his donation and what goes into making a 'parent', a 'grandparent' and a 'cousin'. Being a donor raises new and challenging questions about what it means to be family or relate as kin, and it requires people to think through how it puts people into relation, and how to 'do' relating in this context. As with Zak, the answers people arrive at can be unexpected, even seemingly contradictory, sometimes curious, and yet on some level, they make sense; Zak's comparison with a long-lost cousin 'turning up' offers social legitimacy for his conclusion. Not all donors will arrive at the same answers, but all donors (and families and societies for that matter) will be required to think about what it means to make a baby through reproductive donation.

This book is about how being an egg or sperm donor impacts, and is impacted by, donors' own personal lives and relationships. It is about the men and women who donate, their relatives and people who work to emotionally support and guide donors in clinics, and how they understand and navigate the connections that egg and sperm donation are felt to bring about.²

Being a donor introduces a range of questions into people's everyday lives. For instance: How do donors understand what it means to be a 'good' donor, and how might that shape their thoughts and actions? Do donors see themselves as connected to the recipient family in some way? If not a parent

²This book focuses in particular on egg and sperm donation, largely to the exclusion of embryo donation (bar one participant, see her case Chapter 2). This is because the process, spread, circumstance and trajectory of embryo donation differs considerably from egg and sperm donation, not least in the way it creates 'full siblings' in other families. As such, it warrants attention in its own right.

to donor offspring, as Zak states, then who are they, and what is their role? In terms of the recipient parents, is there a sense of connection with them too? Do donors tell their own family members about being a donor, and if so, who do they tell? How do family respond? Might they have different attitudes about these connections and what they mean? How might this change over time as donors, their families, and recipient families get on with their own lives?

THE EXPANSION OF ASSISTED DONOR CONCEPTION, AND EXISTING RESEARCH INTO DONORS' EXPERIENCES

Since the birth of the first baby through In Vitro Fertilisation (IVF) Louise Brown, in 1978, reproductive medicine and reproductive donation have become truly global phenomena. A recent estimate of the number of assisted reproductive treatment cycles worldwide shows that between 2008 and 2010, over 4 million cycles were initiated, with over 1 million babies born as a result (Dyer et al. 2016).³ Looking at the UK specifically, the Human Fertilisation Embryology Authority (HFEA), the UK fertility regulator, estimates that over 1.3 million IVF cycles have been performed since 1991 (when the HFEA was formed and records began). Their data also show that the number of IVF cycles performed per year has gone up dramatically since, and that demand continues to rise. This includes treatment (IVF but also other options) that involve donated gametes (HFEA 2021b). For instance, in 1991, 134 egg donation IVF cycles were performed; by 2019, this had increased 22-fold to 3,058 (HFEA 2019a). The rise in IVF cycles involving the use of donor sperm tells a similar story: In 2006, 1,171 cycles were performed compared to 5,368 in 2019 (HFEA 2019a). Between 1992 and 2016, clinic-based treatment using donated gametes in the UK resulted in the births of just under 58,000 children (HFEA 2018). Looking at donor numbers a total of 17,000 women registered as egg donors in the UK between 2004 and 2016 (HFEA 2019b).

³Defined in Dyer et al. (2016) as IVF, Intracytoplasmic Sperm Injection (ICSI), egg donation, frozen embryo transfer (FET), Preimplantation Genetic Diagnosis (PGD) and Intrauterine Insemination (IUI).

Meanwhile, just under 8,000 men became sperm donors (HFEA 2019b).⁴ These figures do not include UK sperm donors who donate outside of the clinic context (an issue we discuss further below), nor the men or women who became clinic donors prior to or after this time; omissions that only serve to underline how egg and sperm donation now affects a vast and growing number of families in the UK, and worldwide.

Despite this, there is currently limited research into the experiences of egg and sperm donors. With some important exceptions, research to date has tended to focus on the *recipients* of donated gametes. Initially the expansion of reproductive donation was seen to raise important questions about new family forms, indeed a ‘new kinship’, that challenged or even reshaped heteronormative and genetically defined Euro-American notions of kinship (e.g. Carsten 2004; Mamo, 2007; Strathern 1992b; Thompson 2005); in particular, the focus was on recipient parents’ experiences of infertility and treatment (e.g. Becker, 2000; Franklin 1997; Throsby 2004). A body of, largely social-psychological, work has also explored the longer term impact of donor conception with recipient families and for donor-conceived people. These studies have examined child development and family relationships in recipient families (see e.g. Golombok 2015) and the experiences of donor-conceived people (see e.g. Blyth et al. 2012).

In comparison, we know relatively little about the donors. In the 1990s and 2000s, research that did include donors tended to be based on questionnaires surface-mapping donors’ motivations, their attitudes to being a donor and their donor-conceived offspring and potential future contact. The focus was then on sperm donation, which at the time was much more common than egg donation (see below). In 2013, Van den Broeck et al. (2013) undertook a systematic review of research with sperm donors 1985–2011, and found that research exploring sperm donors’ *experiences* was largely missing. Notable exceptions were Dempsey’s (2010, 2012), Riggs’ (2008) and Riggs and Scholz (2011) explorations of gay men donating to lesbian friends to form families together. Early studies into egg donation were rare, but did focus more on donors’ experiences. Konrad (2005), for

⁴ A large proportion of donor sperm in the UK is imported, particularly from the US and Denmark, meaning that a large proportion of these sperm donors were registered abroad (HFEA, 2019b).

example, explored the experiences of anonymous egg donors and recipients in the UK; Shaw (2007) investigated how New Zealand egg donors understood gifting their eggs to unknown recipients; and Almeling's (2011) US-based study explored how gendered perceptions shaped clinics' recruitment and donors' accounts of their motives.

Since around 2010, however, international research giving voice to egg and sperm donors has expanded in the social sciences. One important body of work explores donation from the point of view of potential exploitation/agency (often problematizing this binary). These studies show how the pathway to selling/donating eggs and a person's experience of that process are shaped by social and economic precarity, often linked to migration and/or geographic economic inequalities (e.g. Nahman 2013; Marre et al. 2018), racialised practices of matching (e.g. Kroløkke 2014) linked to 'white desirability' (Pande 2021), and gendered expectations of care and dependencies (Perler and Schurr 2021).

Another related body of work (which includes our own) focuses on the relational consequences of donation, particularly questions around kinship and connection. These studies explore donors' sense of connection with the recipient family – including the donor-conceived child(ren) and (less commonly) the recipient parent(s). For example, Hertz and Nelson (2019), Mohr (2018) and Wheatley (2019) highlight that the meaning of blood, genetics and relatedness are negotiated in this context; Konrad (2005) emphasises the important role that imagination and connection can play in relationships with recipient parents. Further, Mohr (2018), Konrad (2005) and Gilman (2020) show the importance of situating the meaning of donation in donors' own lives and relationships and Almeling (2011) and Mohr (2018) show how gender shapes organisational contexts and operations, and how such structures in turn shape donors' experiences. Moreover, Mohr (2018) and Graham et al. (2016) draw attention to how ideas and understandings of morality play a key role in donors' experiences. Together these insights suggest that donation is a matter of significance in donors' lives, and that it can give rise to important connections and relationships (see also Nordqvist, 2019c).

Returning now to Zak, donating can bring up questions not just for donors, but for their families too. This perspective figures much less prominently in the above-mentioned studies, but there is some pre-existing knowledge. For example, we know from studies into donors' feelings about

future contact with donor offspring that relationships with the donor's own family matter; future contact is likely to entail telling partners, children and wider family (Daniels et al. 2005; Speirs 2012). To our knowledge, Beeson et al.'s (2013) is the only study to date that samples the views of *relatives* of egg and sperm donors (in this case donors' parents); it confirms that family can feel affected. Yet, predominantly (bar Speirs 2012), findings in this area are based on quantitative survey results surface-mapping donors' perceptions, and tell us little about how donors' family members might feel, how donors navigate the *processes* of telling other people, and how disclosure impacts on family relationships.

This means we know little about the issues raised by Zak's account. This is problematic because previous research suggests that family networks are important in shaping experiences of donor conception. Nordqvist's previous study 'Relative Strangers' with Carol Smart (funded by the ESRC, PI: Smart) explored the experiences of parents and grandparents in recipient families (Nordqvist and Smart 2014b). They showed that donor conception could affect whole family networks in ways that would shift over time, sometimes giving rise to secrets and sensitivities. If the decision to *receive* donor egg or sperm and have a child in this way could impact whole families, then crucial questions also emerge about how the decision to *give away* genetic material might impact important relationships.

The study on which this book is based was conceived as a 'sister study' to the 'Relative Strangers' study. This book's unique contribution is its focus on the relational aspects of egg and sperm donation, including connections with the family that their donation helped to create, as well as donors' own families. We do so through the lens of a sociology of personal life (Smart 2007) which is valuable here because it allows us to explore meaningful connectedness in the context of donors' lives, and those of their relatives, without being prescriptive about how this might look like, what it is based on, or who might be feeling it. This broad approach to studying egg and sperm donation was built into the research design by including interviews with donors as well as their kin. The book is also original in its interrogation of the contemporary UK context where identity-release donation and an ethic of openness is now well established (see also Gilman and Nordqvist 2018). With an interest in questions of openness, it is also the first major study to draw together accounts of clinic-based and non-clinic-based donors.

DONATING IN THE TWENTY-FIRST CENTURY

The question of how donating impacts on donors' own personal lives is particularly relevant given the time and space in which we ask these questions. The social, legal, and technological issues that surround donation have changed in recent years, both internationally and in the UK.

The medico-technical processes of sperm and egg donation have developed along different trajectories. Sperm donation is, or can be, a low-tech procedure which can be performed in a non-medical setting, including at home (e.g. Nordqvist 2011). Technically, all that is needed is for a man to masturbate into a cup for the purpose of artificial insemination, which in turn can be performed using a needleless syringe. Official medical records of the procedure date back to the middle of the eighteenth century (Mohr 2018). However, through the development of medical techniques, such as cryopreservation, sperm donation has become a large-scale, clinic-based, market-driven global practice associated with reproductive medicine (e.g. Mamo 2007). Nevertheless, the basic principle remains technically simple, and self-arranged (non-clinic) donation also occurs. In contrast, egg donation necessarily takes place in clinics. The first birth from egg donation happened in 1984 (Sauer 2018); the procedure was made possible through the development of IVF. A woman who donates eggs undergoes most stages of IVF herself. She usually needs to undertake repeat visits to the clinic and initially takes daily injections (or nasal spray) to suppress her own natural cycle. She then starts a medically controlled cycle through hormone treatment, aimed at boosting egg production. As this progresses, she undergoes medical scans to monitor how her follicles develop. A day or so before the eggs are due to be collected, she is given a hormone injection to help the eggs mature. At the time of egg retrieval, she is sedated, and an ultrasound probe is inserted into the vagina; the eggs are then removed from the follicles using a needle, before being fertilised with the intended parent's (or sometimes another donor's) sperm. Cryopreservation of eggs became possible in the 1980s; however, at the time our participants donated, most clinics preferred to fertilise fresh eggs (Waldby 2019). There is however some suggestion that this is beginning to change (Hudson et al. 2020).

Unlike sperm donation, egg donation carries risks of physical side effects, including reactions to fertility drugs and, in some cases, ovarian hyperstimulation syndrome which can, in rare cases, be life threatening (HFEA 2021b).

Both differ from embryo donation (not the direct focus of this book, but relevant as a comparator), which usually takes place when a person or couple have ‘spare’ embryos following IVF treatment to complete their own family (Hill and Freeman 2011).

These medico-technical differences are embedded in socio-economic structures and practices. Worldwide, fertility is a multi-billion dollar business and donor eggs and sperm circulate, within and across borders, as goods within this global market (Cooper and Waldby 2014; Waldby 2019). This trade in gametes, and the reproductive labour required to transfer them from and between bodies, is profoundly shaped by both global geographic inequalities and racialised matching practices (Pande 2021; Thompson 2009) resulting in various configurations of cross-border reproductive practices (e.g. Gupta 2012; Nahman 2013). Different jurisdictions have attempted to limit the reach of the market into donor conception, for example by offering such treatments via publicly funded health services or by regulating (or sometimes banning) the buying and selling of reproductive labour (including donation). In the UK, treatment is available both to self-funding patients and (if patients meet certain criteria) also for free on the National Health Service, with clinics commonly providing treatment to both groups. In the UK, in both private and NHS-run clinics, payments to UK donors are limited to fixed sums of compensation (currently £750 per cycle for egg donors and £35 per clinic visit for sperm donors).

Alongside these medico-technical and socio-economic issues, donation raises social and cultural anxieties. How this plays out depends on the specific cultural and social context, the so-called ‘local moral worlds’ (Inhorn 2006), in which they take place. Sperm donation remains stigmatised in many Catholic countries where masturbation may be viewed as problematic. For example, it was banned in Italy until 2014 (see Chan 2014), and in Ireland, as far as we have been able to ascertain, there are no sperm donation facilities but clinics import sperm from abroad (e.g. McDonagh 2016). Donation is also perceived to be problematic in many Middle Eastern Muslim countries, particularly Sunni-majority states (Inhorn 2006). Egg donation is seen as controversial in many other societies: it was prohibited until very recently in Sweden, and remains banned in Germany, Switzerland and Turkey.

Donor conception is also controversial in terms of who can access it. Across Europe, 30 countries now permit same-sex marriage or civil partnerships, but of these, only 14 allow same-sex couples access to fertility