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When Sperm Cannot Travel: Experiences of UK Fertility Patients Seeking Treatment Abroad

Ilke Turkmendag*

A. Introduction

Assisted reproduction technology (ART) is a term referring to any technique or medical intervention that enables individuals to procreate, where such procreation would be unlikely to occur otherwise.1 ART has become an object of legal intervention in many countries. National restrictions on the availability of ART, and the globalization of health care services, have expanded the growth of an international market for fertility services. The practice of travelling abroad to seek access to ART is often referred as ‘reproductive tourism’. Seeking treatment across borders is a form of medical tourism that enables patients to take advantage of differences in reproductive consumer cultures reflected in variations in the cost and availability of treatments, success rates, and waiting lists. The label ‘tourism’, however, trivializes and obscures the serious issues that underlie cross-border travel in search of treatment. It may also be seen as a ‘reproductive exile’ where patients who are denied access to treatment at home try to find a legal regime under which the treatment they need will be available.2 In the remainder of the chapter, a more neutral language will be used, and the phenomenon will be referred to as ‘cross-border reproductive care’ (CBRC) movement, a term suggested by Pennings.3

Although the United Kingdom has some of the most liberal ART regulations in Europe, increasing numbers of patients seek treatment using donor gametes across the borders of the European Union (EU). The main reason that drives UK patients abroad is the donor shortage. The most comprehensive study on CBRC to date was carried out by European Society of Human Reproduction and Embryology (ESHRE) Task Force on Cross-Border Reproductive Care, with data from forty six clinics across Europe. Thirty four per cent of UK resident patients—more than any other nationality within

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1 ART is often used for infertility treatment. In vitro fertilization (IVF) is the most common ART treatment and it involves removal of sperm and eggs (gametes) from the couple to produce embryos in the laboratory. One or more embryos are then transferred to the female partner’s uterus to achieve pregnancy.


Europe—cited ‘difficulties accessing treatment’ as their reason for travelling abroad.4 Findings from a recent qualitative study of United Kingdom residents provide further insights about the access difficulties at home. Overall, ‘a desire for timely and affordable treatment with donor gametes’ was evident in 71 per cent of cases, making donor conception the most sought-after treatment amongst these CBRC travellers.5 Most patients sought treatment within European borders, the most popular destinations being Spain and the Czech Republic.6

There is now growing concern in the United Kingdom about such CBRC movement, but as yet there seems to be little understanding of the extent to which the regulatory regime may be playing a contributory role. The study presented in this chapter draws on empirical evidence to encourage more engagement with that question. Drawing on semi-structured interviews with a group of patients who sought donor conception treatment across borders, the study discusses the reasons behind CBRC movement. The accounts of the patients presented here provide insights about rights and markets, in particular. The promotion and protection of children’s right to know their genetic identity, a human rights assumption encouraged by the European Convention on Human Rights (ECHR)7 and now embedded in the United Kingdom’s regulation of donor conception, has aggravated the donor shortage. And, as we shall see, the implementation of the EU Tissues and Cells Directive’s (EUTCD)8 voluntary and unpaid donations policy for tissues and cells has made access to treatment even more difficult.

In what follows, I begin with a brief background to the donor conception regulations in the United Kingdom. I will then present the views of the UK patients who received fertility treatment abroad using donated gametes or embryos.

B. Donor Conception and the Law in the United Kingdom

Prior to the 1980s, donor conception was performed without central record-keeping or regulation.9 In 1982, the UK Government commissioned the Committee of Inquiry into Human Fertilization and Embryology to report on the ethical and legal issues associated with assisted conception and related technologies, which led to the Human Fertilisation and Embryology Act 1990 (HFE Act). Section 31(3) of the HFE Act allowed children born following anonymous gamete donation to apply for information about the donor upon reaching the age of 18. The Act did not specify the content of the information but, in practice, donors were asked to provide some non-identifying information, which could be passed to potential recipients. The Code of Practice issued by the relevant regulatory body, the Human Fertilisation and Embryology Authority (HFEA), directed that ‘the Act generally permits donors to preserve their anonymity’.10

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6 Culley (n 5).
Towards the end of the 1990s, there was an alarming decrease in the number of people coming forward as sperm donors in the United Kingdom. Interestingly, although donor shortage was therefore a growing concern, in 2001, the government chose to launch a consultation to review the legislation governing access to information for those conceived through gamete donation.

1. The Child’s Right-to-Know Movement: Rose and Another v Secretary of State for Health

The Children’s Society (a national charity involved in campaigning and social policy work to support children) was the first organization that attempted to transform the anonymity of donors into a public concern. In November 1998, the Society called for a change in the law so that people who were born by sperm or egg donation could access the same information about their donors that adopted children could access about their natural parents. The Society’s call for legal change brought a response from government agencies: in 1999 the Department of Health confirmed that it was looking at the issue and would publish a consultation paper. And, although it took a further two years to start that consultation, the Children’s Society had successfully initiated a controversy.

A few years later another intervention had an impact: this time it was an application for judicial review by two donor-conceived individuals, Rose and EM. Liberty, a human rights NGO, announced the case in a press release with the headline ‘Donor insemination case: children can claim right to personal identity’. Rose, an adult woman and EM, a six-year-old, had both been conceived using donor insemination. They had sought access to information about their anonymous sperm donors and also the introduction of a contact register, but the Secretary of State for Health had rejected their requests on the ground that a consultation exercise on the issue of anonymity was already underway. They sought judicial review of this decision, relying on Articles 8 and 14 ECHR. Article 8 provides for a right to respect for private and family life, and the European Court of Human Rights has held that this right incorporates the concept of personal identity, including the right to obtain information about a biological parent. The claimants also invoked Article 14 in conjunction with Article 8, arguing that there should not be discrimination between donor offspring and adoptees or between donor offspring (like Rose) born before the coming into force of the HFE Act and those (like EM) born thereafter.

The judge, Scott Baker J, said that he found it ‘entirely understandable that A.I.D. children should wish to know about their origins’. It was in his view quite clear that Article 8 ECHR and the existing jurisprudence of the European Court of Human Rights supported the idea that ‘everyone should be able to establish details of his identity as a human being’, and that this clearly included the ‘right to obtain information about a biological parent who will inevitably have contributed to the identity of his child’. Scott Baker J’s judgment says nothing, however, about whether there

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11 Rose and Another v Secretary of State for Health [2002] EWHC 1593 (Admin).
14 Rose (n 11).
16 Rose (n 11) [18].
17 Rose (n 11) [47]–[48].
had been a breach of Article 8 in this case: it focuses only on the fact that Article 8 is engaged. The reason for this is that, at a case management conference prior to the hearing, the judge had decided that the issue of breach should be ‘stood over’:

Once the consultation exercise was under way, and it was clear that the government was giving serious consideration to how to tackle this extremely difficult problem, it was obviously sensible that many of the issues in this litigation should be stood over pending ministerial decisions on what if any government action was appropriate.¹⁸

Ultimately, although Rose and EM’s application for judicial review was successful at the first stage, the later hearing to determine whether there had in fact been a breach of Article 8 was delayed and then, in January 2004, the government announced that donor anonymity was to be lifted. With the implementation of the HFEA (Disclosure of Donor Information) Regulations 2004, from 1 April 2005, UK law was changed to allow children born through gamete donation to access identifying details of the donor.¹⁹

Baroness Andrews, speaking in the House of Lords, explained the reasons that made this change in the law seem so necessary.²⁰ She emphasized that the secrecy and even stigma surrounding assisted conception had faded; that public attitudes towards information and rights to information had changed dramatically (referring to the Rose case); and that such openness had worked successfully in recent years in relation to adoption. She argued:

Information now is much more readily accessible than it was in 1991…In a century where access to information is regarded as a personal and political right, this [donor anonymity] does not seem any longer to be appropriate. It has already proved to be a bone of contention—the Government are very likely to be challenged about the provision of information to donor-conceived people, as the Department of Health has already been in an application brought by Liberty.²¹

Rose’s case thus played a significant role in removal of donor anonymity. Although in English law, disputes about parenthood should be resolved according to the best interest or welfare principle stated in the Children Act 1989, the Human Rights Act 1998 which incorporated the ECHR into domestic law is also influential.²² Under the terms of the Human Rights Act, section 3(1), judges must interpret domestic law in a way which is compatible with Convention rights. As we have seen, Scott Baker J said that respect for private and family life had been interpreted by the European Court of Human Rights to incorporate the concept of personal identity; that the concept of personal identity ‘plainly includes the right to obtain information about a biological parent who will inevitably have contributed to the identity of his child’; and that in his judgment there was no great leap in construing Article 8 in this way.²³ Following Rose, then, rejecting right-to-know claims from children who had been born following gamete donation could have left the UK Government exposed to increasing numbers of similar cases, backed perhaps by human rights NGOs.

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¹⁸ *Rose* (n 11) [16].
²⁰ HL Deb, 662 cols 344–8 (2003–4) col 344.
²¹ HL Deb, 662 cols 344–8 (2003–4) col 344.
²³ *Rose* (n 11) [48].
During the debate in Parliament, some peers stated their concerns about the potential shortage of eggs and sperm. In other jurisdictions, the removal of anonymity has generally had a negative impact on both the demand for, and the recruitment of, gamete donors. However, Baroness Andrews said that the government was planning a campaign, costing up to £200,000, to reach out to donors. Moreover, the campaign would be conducted with the support of three organizations: the National Gamete Donation Trust, the British Fertility Society, and the Donor Conception Network.

2. Implementation of the EUTCD into UK Law

After the disclosure regulations passed, the Department of Health undertook a public consultation exercise over the summer and autumn of 2005 on possible changes to update the HFE Act. The exercise culminated in the Human Fertilisation and Embryology Act 2008, an amending statute. Prior to that, however, the HFE Act was amended with effect from 5 July 2007 in order to bring the EUTCD into UK law.

Following the implementation of the EUTCD, the procurement, testing, processing, or distribution of any embryo or sperm and eggs intended for human use must be licensed by the HFEA or be subject to an agreement with a licensed service. If patients are considering obtaining sperm, eggs, or embryos from within the EU, a licensed UK clinic can organize for a transfer to be made from that country. However, the sperm, eggs, or embryos transferred must meet UK requirements. All medical fertility and non-medical fertility services such as internet sperm providers have to abide by UK standards, which include all donors being identifiable. There are other requirements too: donors must have consented to the transfer of their gametes/embryos to the United Kingdom; they must be made aware of the legal position in the United Kingdom on identifying donors and the implications of this for donors; and they must have received no more than reasonable expenses or reimbursement of loss of earnings (that is, ‘inconvenience’ payments are not permitted).

One effect of the introduction of the EUTCD into UK law is that, although patients can exercise their rights to travel within the EU to receive gametes or embryos from a clinic that does not comply with UK standards, the position is different for gametes and embryos: they cannot travel if they do not meet UK requirements on screening. In other words, UK patients cannot get anonymous gametes imported, even if the gametes were lawfully donated in another Member State of the EU.

Whilst the EU aims to promote a market model, the EUTCD seeks to promote an altruistic approach to gamete donation: as stated in Article 12, ‘Member States shall endeavour to ensure that the procurement of tissues and cells as such is carried out on a non-profit basis.’ Having endorsed this principle, and also lifted donor anonymity, UK

25 EUTCD (n 8). There are also two supplementary Technical Directives: 2006/17/EC; 2006/86/EC.
law now offers neither financial incentives nor anonymity to potential donors. And as we shall see later, this policy of non-anonymous and non-remunerated donation seems to be part of the reason that would-be parents are heading abroad.

3. The Impact on Access to Treatment

There was a gamete shortage in the United Kingdom prior to the removal of donor anonymity. Lifting anonymity appears, however, to have exacerbated that shortage. There were 417 sperm donors in 1996, whereas in 2004, the donor supply had fallen to 228 and it had only recovered slightly by 2008 when it was 284. Around this time, acute donor shortages and long waiting lists for would-be parents were regularly reported in the media. According to a BBC investigation in 2006, fifty of the seventy-four clinics in the United Kingdom reported that they had insufficient sperm or none at all. The British Fertility Society claimed that one effect of the change in legislation was that the cost of donor insemination (DI) had risen enormously in many centres, and the programme had effectively been removed from the National Health Service (NHS) as standard practice in most areas.

Initially the HFEA showed no inclination to review the change in the law. Instead, in order to try to curb the numbers going abroad, it emphasized ‘risk’. For example, in April 2006, the then chair of the HFEA, Suzi Leather issued a public statement warning people against the poorly regulated treatment in overseas clinics. In the statement Leather referred to those who travel abroad to get treatment as ‘a relatively small number of people’, and she associated CBRC movement with holiday packages:

We know that a relatively small number of people choose to travel abroad to undergo fertility treatment and that sometimes the treatment is packaged as a ‘holiday’ where the patient can convalesce in the sun. However, we are concerned about [sic] people who choose to have their treatment abroad should know about the potential risks. We have heard of some clinics which offer treatment to patients that is so dangerous that it has been banned in the UK. . . . It is very sad when we receive complaints from patients about their treatment abroad and we are not able to help or reassure them. We would urge patients to think twice and consider the risks and implications before going abroad for treatment.

Many would-be parents shared their reactions to this statement on discussion forums for fertility patients on the internet. Would-be parents are generally well informed about the success rates, the treatment costs, the methods, and the consultation and follow-up processes provided by clinics in the United Kingdom and abroad. Not surprisingly, then, on the discussion forums of the Infertility Network UK there were patients who expressed the view that the HFEA’s statement was infantilizing.

One year later the HFEA issued a further warning; this one cautioned patients against buying sperm online. In response to a news report about women purchasing sperm through the internet, the new chair of the HFEA, Professor Lisa Jardine, began

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by emphasizing that it was a criminal offence to ‘procure, test, process or distribute’ any gametes (sperm and eggs) intended for human application without a licence from the Authority. She went on to say that would-be parents seeking donated gametes ‘should only use licensed centres’:

That way, they can be assured that the gametes have been subject to screening checks and that the centre complies with the standards set out in the HFEA code of practice. A further difficulty with using unlicensed centres is that the HFEA is unable to hold, in its statutory registers, information relating to donors or children conceived from gametes obtained from such centres.  

She then returned to the question of criminality:

Responsibility for prosecuting criminal offences rests with the police, and it is the practice of the HFEA to refer concerns about internet procurement to them. We strongly advise any person who becomes aware that a person or organization may be procuring, testing, processing or distributing gametes without a licence to contact the police. The women whose stories you tell are entitled to make such fundamental choices about their personal lives within a safe, clinically sound framework. It is the HFEA’s responsibility to provide that framework, and to be vigilant for the safety of those who undergo fertility treatment. The internet sperm providers referred to in one of your examples are not licensed by the HFEA. The service they offer is unlawful and unsafe.

Two years later, in 2010, two men were convicted of running a fertility website, without a licence, selling sperm from anonymous donors to women trying to conceive. They each received a nine-month custodial sentence, suspended for two years, a £15,000 fine, and 200 hours of unpaid work, and were banned from future work in the industry. Nearly 800 women, however, had signed up to use the online service provided by the men’s company, which had operated under various names including Sperm Direct Limited and First4Fertility.

Fertility travel, internet sperm providers, and the grey market in gametes are phenomena addressed as ‘unsafe’, ‘illegal’, and unethical’, respectively, by policymakers. And, as we have seen, would-be parents have been warned against the consequences of considering any solution to their infertility, other than treatment in a licensed UK clinic. Far less, however, has been said about the reasons would-be parents seek out ‘coping’ or ‘avoidance’ strategies or how solutions might be found to the problems that lead such parents to use ‘illegitimate’ ways of obtaining gametes.

C. CBRC Movement From the Patients’ Perspective

The interviews and the data analysis presented here draw on my PhD work which explored the reactions of patients to the removal of donor anonymity in the United Kingdom. The people whose views are presented are a sub-group of patients who received/or considered receiving fertility treatment abroad: for the most part I refer to them as ‘would-be parents’. The data was collected by thirteen semi-structured qualitative interviews.  


34 Of the thirteen individuals interviewed, five were egg recipients, two were embryo recipients, one was a sperm recipient, one contracted a surrogate mother as well as donating eggs, one was an egg donor, and one was a sperm donor.
experience: first, the decision-making process; secondly, disclosure; and, thirdly, claims-making (both for and against policy change). Ethical concerns relating to informed consent, the right to privacy, and protection from harm were carefully considered both before and after the interviews.

In what follows, the themes that emerged from the interviews will be presented in five main sections: disclosure; donor shortage; rights; markets; and policymaking.

1. Disclosure: ‘Being Forced to Tell’

During the donor anonymity debate in the public sphere, the view that donor-conceived children have a right to have access to identifiable information was legitimized by two principal claims. First, the position of donor-conceived people should be aligned more closely with that of adopted people, with access to identifying information about their donor.\(^{35}\) Secondly, as studies on adopted children had shown, genealogical knowledge is necessary for the development of identity; by denying access to their donor’s identity, the government infringes the human rights of donor-conceived children.\(^{36}\) During the donor anonymity debate that led to the 2004 regulations, these claims were part of broader emphasis on openness and transparency—an emphasis that was not just strong but almost intimidating. For example, any inclination towards secrecy on the part of donor-conception families was portrayed as a potential threat to the resultant child’s welfare; indeed, parents who intended not to disclose were accused of deception and violation of moral standards.\(^{37}\) Similarly the HFEA advised would-be parents that ‘[i]t is certainly best to be open with your child/children about the circumstances of their conception. Secrecy on this subject isn’t in their interests and they will have a right to find out about their origins from our register when they reach 18’.\(^{38}\) Such imposition of disclosure presupposes that there is one way of organizing family life and that transparency will and should work for every family.\(^{39}\) In the next section, I use interview data to show the reactions of would-be parents to this disclosure discourse that asserts openness.

a. ‘The information, once it is out, you can’t get it back’

Parents who choose not to disclose may justify their non-disclosure on the ground that it protects the best interests of the child. In the first extract, Lindsay reflects on her views about the disclosure. Lindsay, who had a daughter, Sandy, as a result of embryo donation, told her ‘you came in a different way, you are special’. Sandy is now four years old. Lindsay still struggles about how to manage the information about Sandy’s origins:

I am struggling . . . that is, you know I have told people information that is basically Sandy’s information and that is where I have the dilemma. Because she is not old enough to know who she would like to tell, and who she would not like to tell. And I am doing it on her behalf . . . And

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\(^{35}\) Turkmen-dag (n 12).
\(^{36}\) Turkmen-dag (n 12).
\(^{37}\) Turkmen-dag (n 12).
the information, once it is out you can’t get it back. That is the reason that I keep cautious, not anything to do with me but because she might not want anyone to know.

Alice has a similar dilemma about revealing the information about her twins’ origins. Alice got pregnant using her late husband’s frozen sperm and donor eggs. She notes that her twins might have trouble with the fact that their father passed away before they were born. Therefore, she wants to wait for the right time before telling the children about their means of origin. She expresses concern that if the egg donation is known, she cannot avoid her children being bullied at school by other kids. Hence, she has shared her treatment only with immediate family and close friends.

Lindsay and Alice regard the information about the donor-conceived child’s origins as the child’s own information. They are therefore reluctant to pass this information to other people on their child’s behalf. They also express concern about a child’s competence in managing the information. Young children may be eager to share the details of their origins at a young age. But once they start to realize the content of the information that they have been sharing with everyone, they might feel that they have made a mistake. These parents are concerned not to give the child greater autonomy ‘at any cost’.

b. ‘Being dictated what you have to tell the child, it doesn’t seem right to me.’

Some participants considered that the disclosure policy discriminates against donor-conception families by comparison with those with naturally conceived children who do not necessarily know their origins. People who conceive naturally (but, for example, as a result of an affair or a one-night stand) are not told what to tell to their children.

Fiona points out that the government does not intervene in other areas of family life and does not tell people how to bring up their children. She stresses that she is doubly discriminated against: nature has discriminated against her, and now it is the policymakers who remind her that she is different.

The government don’t intervene in other areas of family life. They don’t tell people what they must tell their children or how they must bring them up. So when you are already had such a battle, by the time we get another donor now and if we go through a cycle of successful we will be trying for a child for nine years. Now, that itself is hard enough and put an enormous strain on a relationship, as well. Being dictated what you have to tell the child, it doesn’t seem right to me . . . Nature already discriminated against me and it feels like the law was written that way as well.40

Fiona and her husband have been foster parents to nine children; none of these children knew who their genetic father was. Thus, for Fiona, the disclosure policy is not only discriminatory against those who use donor conception, but also against the resultant children. Her foster children do not know who their fathers are, because their mothers were not encouraged to be open about their means of conception:

We had nine foster children and in every single case none of them have known their genetic father. They have all been a result of one-night stands or short relationships and the government isn’t there, telling these mums that they have to provide their children with genetic background so . . . I can’t help feeling a bit discriminated against. The young girls that we’ve got fostering at the moment they have no dads, there is six children in their family from the same mum with six different dad. Not one of them knows their dad and you know, their mum isn’t forced to reveal anything to them, or even tell them the names of their dads or anything. And they know nothing.

40 Emphasis added.
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about their background on their paternal side. So I do feel a bit sort of preached to be told that I have to tell any resultant children . . . At least mine are wanted children and they are gonna be brought up in a stable mother and father relationship unlike the foster children we have.41

In the following extract, Tina talks about family-building practices before the arrival of ARTs. She says that in the past, if one wanted a child, one could have an affair, and this would be unspoken. She points out that the removal of anonymity does not apply to people like her husband’s ex-wife, who got pregnant as a result of an affair:

in 1960s or something . . . It was an unspoken thing, if you found out that the man had a problem, then the woman turned to see . . . She went off, had a little fling. Cause in those days you would expect a baby in a year. You would wonder how many women just go out . . . and men knew it . . . sort of . . . didn’t say anything.

Some of participants suggested that the new disclosure policy may be increasing subterfuge rather than openness. For example, Fiona argued that the disclosure policy makes her ‘rebellious’ against openness. She would be more positive about disclosure if she were not ‘forced’. Although under the current legislation she is not compelled to tell her donor-conceived child about its origins, Fiona feels that she is ‘dictated’, ‘forced’, and ‘preached to’ about disclosure:

I am not against it [disclosure]. I do think it is child’s best interest to tell, I really do but that’s an intellectual decision not an emotional decision as regards actually telling the child. If we are lucky enough to have one in the future, I hope I will, but I know that I would be really worried about telling, and I certainly don’t like being forced to tell. I also think that we would come around to that conclusion a lot quicker if we weren’t forced to tell. We would estimate that decision as good sensible parents. I think we would come to the right answer but being forced to tell sort of makes me back away, you know, makes me want to do the opposite, makes me feel a bit rebellious as well.42

Alice proposes that, instead of lifting anonymity, the HFEA could provide a detailed profile of the donor without giving identifying information. She claims that donor-conceived children will be satisfied with knowing about the characteristics of the donor; they do not necessarily need to know the identity of the donor:

Again going back to the whole child’s right to know thing, I think there are ways of disclosing information without necessarily giving away the donors identity because I really wonder whether . . . it would make any difference to children who were born with donor egg or sperm to know who their donor is as oppose to the characteristics of about their donor.

The interview accounts show that these participants are not convinced that disclosing the means of conception is in the best interests of the child. These parents feel that maintaining secrecy, or limiting information, about the child’s conception is the safest way to protect the child, themselves, and the extended family. The accounts also suggest that the disclosure policy in the United Kingdom creates a socio-legal environment that requires donor-conception families to display their differences from other families.

As Smart explains, however, nowadays there is an almost unquestionable presumption that it is best for children to know identifiable information about the gamete donor who played a role in their conception, and increasingly this welfare criterion is also linked to a rights-based argument.43 For example, in Re T (A Child) (DNA Tests:

41 Emphasis added. 42 Emphasis added.
Paternity) the judge decided that the child in question had a right to respect for private life under Article 8 ECHR in the sense of having knowledge of his identity which also encompasses his true paternity. Smart is critical of the new enthusiasm about knowing the truth:

The tendency for public policy, with its enthusiasm for DNA testing, to assume that (genetic) truth is better than (relational) fiction means that the addition of more genetic kin through these means is inevitably seen as producing a positive outcome for children (and possibly for adults). Yet children live in webs of relationships that are delicately interconnected and adding more relatives may disrupt and even break some of these links.44

She also gives an example of a recent ruling where the disclosure of paternity meant that the child in question would have lost more kin (a putative paternal grandmother who was his significant carer, a putative half-sibling, and a cousin) than he would have gained (a genetic father who was a stranger to the child).45 In this case, the child did not want to know the truth: not knowing would mean that he could keep his grandmother, his brother, and cousin, and remain living with them rather than living with his genetic father.

Smart’s analysis of the case reminds us that not everyone in family relationships is necessarily going to see genetic truth as an unassailable guiding principle. The interview accounts presented in the following section echo this view.

2. Donor Shortage: ‘Throwing Out the Baby with the Bath Water’

The would-be parents in my study were clear that the shortage of donors could be attributed to the new disclosure law. Rosie claimed that lifting anonymity has had a negative effect on donor recruitment in the United Kingdom. She compared the programme in the United Kingdom to that in Spain, arguing that the latter is successful because the donors are able to preserve their anonymity:

They say it [removal of donor anonymity] doesn’t have any effect but I can’t see how it doesn’t. I mean I—I am sure it will. It is logical and I am sure the programme in Spain would not be so successful, let’s say if the donors were not anonymous. I think that they want to be anonymous. I don’t think they want to be known or want to be contacted.

Alice also took the view that the removal of donor anonymity had caused a reduction in donations. She claimed that the open donation system in the United Kingdom frightens donors, as the resultant child might contact them in the future:

how can you not equate the two? The removal donor anonymity will of course cause a huge deduction in donors who want to come forward, of course that will scare people and they are not going to want to donate. People who donate sperm have done it in past are frightened. People who egg share or donate sperm all have done so in the past are frightened, majority of them are. In 18 years past time this adult can come to the door step, say ‘you are my genetic father and mother’, that’s why.

Alice had travelled to Spain and Poland, countries that allow the treatment she needed (to get pregnant using an embryo created by insemination of her late husband’s frozen sperm using donor eggs). She could have received the treatment in the United Kingdom, but she did not want to wait for eggs. In Alice’s view it is the removal of donor anonymity and the long waiting lists that drive people abroad:

44 (n 43) 409. 45 Re D (paternity) [2007] 2 FLR 26.
It is difficult because you know I can see what they are trying to do but I just wonder, you know, whether, sorry to use this but throwing out the baby with the bath water really, because it is driving people abroad... People are not willing to wait and you know 30s, 40s... they are not going to wait a couple of years. They take the best option... going to Spain, Russia or Poland where there aren’t any waiting lists, cost is not a problem.

For a majority of participants in my study, waiting was not an option. One participant, Tina, who received embryo donation, was in her early forties and had a chance of using her own eggs to conceive. However, after a few failed attempts with IVF, she did not want to try to conceive with her own eggs any longer. She feared that the procedure would be time-consuming, risking her chances of carrying a baby. Another participant, Rosie, felt a need to start her treatment immediately—her age gave her no other choice: ‘I didn’t want to wait any longer I wanted to get on with it.’

Infertility increases by age. The participants in this study who considered donor eggs were between 30 and 40 years old. Because age is a significant determinant of the effectiveness of treatment, they gave up using their own gametes after failed attempts in their early forties, yet they were then faced with long waiting lists in the United Kingdom. Crossing borders was, they believed, the only option available to them if they wanted to become parents.

The United Kingdom’s donor shortage is also an obstacle for couples who want to receive donations from a donor with a physical resemblance to them. Clinics situated in countries where abundant supplies of gametes are available often promise to match the physical characteristics of the donors with those of the would-be parents. A brief review of the postings on message boards on the internet indicates that, by contrast, clinics in the United Kingdom avoid making such promises.66 Accordingly, a would-be parent may need to travel abroad in order to find a donor with a reasonable match to their own physical characteristics, or those of their partner. One of the reasons that motivated Rosie and her partner to get treatment in Spain was the likelihood of finding a donor who resembled their physical appearance.

I am not actually English racially. I am actually Jewish, Polish Jewish and my partner is quite dark skinned... and we are not very tall... so we thought actually Spain is pretty good for us anyway in terms of matching. So I didn’t look anywhere else.

Having a donor with physical similarities provides would-be parents with biological continuity.67 There is a cultural expectation that children resemble their parents; thus, having a child that resembles oneself reduces the level of ‘cognitive dissonance’ that social parents experience.

3. Markets: The Commercial Side of the CBRC Movement

This section deals with payment to donors and helps us to understand how the participants in my study presented the commercial side of CBRC movement. Trade in gametes is driven by two imperatives: the need for infertility treatment, and the need for stem cell research.68 Women are the primary providers of such reproductive material but, at least in the EU context, the economic value of their labour remains

66 Turkmendag, Dingwall, and Murphy (n 24).
largely unacknowledged. Reproductive tissue is constituted as a ‘gift’ from the ‘donor’ to the recipient. For example, Recital 18 of the EUTCD asserts: ‘tissue and cell programmes should be founded on the philosophy of voluntary and unpaid donation, anonymity of both donor and recipient, altruism of the donor and solidarity between donor and recipient.’ According to Article 12(1) of the EUTCD on standards relating to the handling and use of human tissues and cells, ‘[d]onors may receive compensation, which is strictly limited to making good the expenses and inconveniences related to the donation.’

There are, as Waldby explains, both pros and cons of the gift system: whilst it prevents commodification of human bodily material, it often means that donors are simply treated as open sources of bodily material that can be profitably privatized by biotechnology companies. She argues that although it would contravene the prevailing European ethos opposing the commodification of the human body, it might be worth considering provision of reproductive tissues and cells as a form of labour. As we shall see, the views expressed by the would-be parents in this study are similar; they consider donation (eggs in particular) as a form of labour that deserves incentives, a view that runs contrary to the EUTCD’s non-profit donation system.

a. The United Kingdom’s non-remunerative donation policy: ‘I would get them paid’

There are wide discrepancies in how the gift system is interpreted across EU Member States. The UK policy makes sure that donors do not have financial gain from donating: donors are compensated for expenses and loss of earnings, but not for inconvenience. When the interviews were conducted, the amount an egg donor could claim for loss of earnings was up to a daily maximum of £63.12, with an overall limit of £250 per donation cycle. In many other EU countries there is a blanket fee for loss of earnings, expenses, and inconvenience. For example in Spain, egg donors are compensated by up to €900. In the following extract, Rosie says that such payment is not ‘huge’ enough to encourage people to donate repeatedly:

I think it is good that they pay people [in Spain]. I mean they don’t get a huge amount of money. It is only like seven or 800 Euros or something. Having been through IVF I mean, I don’t think it is a lot of money because it is quite you know, quite a heavy process to go through. I know that they are ok, they get paid but it is not a big amount.

Rosie points out that she is comfortable with the idea of egg donors being paid, because then she can see the process as a ‘business arrangement’. She thinks that for a student, for example, this is ‘not a bad way of earning some money’. Rosie’s account also indicates that the donors deserve to be paid for providing eggs which is a ‘quite heavy process’. Similarly, Tina, too, draws attention to the difficulties of donating eggs. She thinks that egg donors should be paid, because unlike sperm donation, egg donation is not easy:

In Spain you pay woman 600 pounds. It is a cultural thing. It is not nice having been through it. You wouldn’t keep doing it. For men it is easy.

Another participant, Alison, supports the open donation system, yet she expresses concern about the decreasing donor numbers and the long waiting lists. She says that

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49 ibid.  
50 EUTCD (n 8).  
51 Waldby (n 48).  
we expect too much of the donors: they are identifiable, and they only get their travel expenses paid. Like the other participants, Alison states that she would like egg donors to get paid.

I had mixed feelings because I would choose an identifiable donor but obviously it means that the supply is greatly reduced so it is tricky. If it was up to me, I would I’d leave the identified part, but I’d like them get paid.

Unlike sperm, eggs are not a self-renewing, copious, and accessible tissue, and they are never detached from the body in the normal course of events. Donating eggs involves stimulating the ovaries and the multiple follicles, shutting down the donor’s reproductive cycle, several hormone injections, and then a surgical procedure to retrieve the eggs. The participants had an understanding of all of this; they were familiar with the complexity of IVF procedures (and some had been involved in egg sharing). Many of them expressed the view that egg donation was not an easy process and that egg donors should be paid for their efforts. The participants did not think that payment would cause abuse; the amount paid would not be high enough, they said, to encourage people to go through this procedure repeatedly.

b. Standards of the clinics abroad: ‘Why don’t we go, it is in Barcelona, we like Barcelona, it is a nice place you know’

By making both international partnerships and patient bookings much easier, internet communication has facilitated the growth of CBRC. All of the participants in my study had made use of the internet. For example, when Rosie needed egg donation, she started doing research about the procedure and found a website called IVF Connections. She read the postings on message boards and found out that success rates were high in Spain, especially in one clinic in Barcelona:

just reading the stuff from the board at that time. Everyone seemed to be successful, That was really incredible. It was just like very good feeling . . . so many people were getting pregnant and so basically I thought about it. If all these women try that, what’s so special about me that I couldn’t consider it? Why don’t we go, it is in Barcelona, we like Barcelona, it is a nice place you know, go and have a consultation and I heard that they were very quick and the indication of the cost that was a concern but I was lucky. I had enough money to do it . . .

Alice is content with the treatment she received in Spain and Poland. She says that the consultation process is more open and advanced in comparison to the consultation provided in the United Kingdom. Moreover, the cost of the treatment is lower abroad:

What I experienced in Poland and Spain, compared to clinics here, they have more experience. The doctors are out there, [they] are willing to take time to talk to you. . . . In Poland you decide how many embryos can be implanted, they talk to you. This is our recommendation, you can have 2 or 3 . . . Even it is in different country you have their e-mails. I have the mobile number of the doctor . . . In cost of one treatment in this country I can have two treatments.

Some patients expressed ethical concerns around the services provided by United Kingdom clinics. Tina had embryo donation in Spain. She stressed that donor anonymity was the main reason that drove her abroad, but she also commented on her other motives. She started her treatment in the United Kingdom in a private clinic. When they found out that they could not conceive due to male factor infertility, Tina

53 Waldby (n 48). 54 Waldby (n 48).
and her husband decided to receive sperm donation. However, they were advised to get intra-cytoplasmic sperm injection (ICSI) instead, which would enable Tina to get pregnant using her husband’s sperm. Given that ICSI is much more expensive than sperm donation, and more complicated, Tina did not take the clinicians’ advice. When she heard from a friend that the success rate was only 5 per cent for her age group, she decided that the clinic was giving her false hope and her treatment was a waste of time. She thinks that private clinicians have business minds and, when money comes into the equation, their advice is not reliable:

In the beginning when we found out that it was him [my husband] we asked for DI. They said no, you must have ICSI. DI is for 500 pounds, ICSI is 5500. Lord Winston said when money comes to the equation, ethics go out the door. With donor sperm you have a straight insemination, 10% chance, it is not that great but it was... and they said no... your husband has some sperm and you must try to have your husband’s child.

Tina and her husband finally decided to get treatment in Spain using anonymous frozen embryos. The clinic staff in the United Kingdom warned Tina against getting treatment abroad. They thought the clinic in Spain was not ethical:

My clinic here in England took an extremely poor view of me going to Spain... questioned the ethics and the professionalism of the clinic in Spain. They completely, you know, put a down view on the whole thing.

Despite the concerns raised by the clinicians, for Tina the advantages of undergoing treatment in Spain were obvious: the clinics were more advanced, there were donors available, anonymity was preserved, and there were no waiting lists.

In Spain, they are bigger. Their equipment is the latest thing. In England it is all rubbish, you wait for hours and you spend the same money, the same cost....I would have done here, which you can’t. There is no donor egg available....And if you have one, you have to tell the child. Waiting lists are five years. At my age you couldn’t wait. In Spain there is no waiting list.

The accounts quoted here indicate that the participants in the study consider the standards of infertility treatment in other EU countries to be as high, if not better, than those in the United Kingdom. Given that the cost of such services is approximately the same or less than the ones provided in the United Kingdom, and that by going abroad one can avoid the waiting lists at home, it should come as no surprise that growing numbers of patients seek treatment in other EU countries.

4. Policymaking: The HFEA and the Reproductive ‘Tourism’

During the interviews some of the participants referred to the ways in which the HFEA had dealt with CBRC movement. Alice, for example, described the HFEA as being ‘like an ostrich’, burying its head in the ground. She did not think the Authority represented patients’ opinions in its decisions. And she said that, in the absence of statistics revealing the number of people seeking treatment abroad, the HFEA will continue denying the facts.

There is so much opportunity going on at this moment. The way HFEA operates today, their statistics not include anyone who has gone abroad for treatment. So that’s just completely not part of research to them, ‘oh no one is going abroad for treatment, you know because we are not doing the research in that area anyway’.

Alice wondered how the HFEA would respond to statistics revealing a decrease in donor numbers following the removal of donor anonymity. Alice also expressed the
view that the HFEA was responsible for the consequences of the donor anonymity policy, and the donor shortage, and that the Authority was not listening to the voices of would-be parents who were being driven abroad. Alice’s account suggests that going abroad is not the patients’ choice; but ‘their [the HFEA’s] making’. For Alice, CBRC movements are the end-result of policymaking that is not informed by the views of would-be parents:

And I see a couple of programmes where they have interviewed Suzi Leather. She’s just said ‘if people want to go abroad that’s their issue, we don’t look at clinics abroad we look at clinics from UK’. I am thinking yes, but it is actually your making that driving them abroad, you know and there is no recognition of that. No understanding. It is a bit like, the HFEA is like an ostrich, buried in the ground . . . Who represents the patients in these big decisions that they make? Is there anyone? Not that I know of . . . So I have mixed feelings about them.

The would-be parents also reacted to Leather’s remark that fertility treatment was marketed as a holiday. Like many other would-be parents who sent their protests to online support groups, Tina stressed that infertility treatment is not a holiday. You want a baby, the media made out this whole fertility tourism thing ‘yeah, you go on holiday and have your treatment’ and it is like ‘yeah you get to go to a different place and some Spain or whatever’. But it is not a holiday, there are so much going on in your body in your mind, you know.

Alice stated that policymakers should have weighed the cost of lifting anonymity for would-be parents. Alice feels that having access to a donor’s identity and being told about donor conception are different matters, and she is uncertain as to whether knowing the identity of the donor would make a big difference to the donor-conceived child. Disclosure policy, she thinks, is preventing couples from being parents:

Although I can understand, you know, for a child it is important to know what the background is, it is not possible in some families, even in natural families, and you have to weight out what the cost of removal of donor anonymity would be. It may make a difference, it may not. Look how many couples left in the situation, who want to be parents, left in the situation where they have to wait long periods . . . I know we all want to our children best we can, but almost preventing couples to have the opportunity of becoming parents . . . It is a tricky one. For me personally, I am a bit biased, coming from the point that I have donor egg I would say the disclosure policy is not the best policy that HFEA came up with.

The would-be parents in this study saw the donor shortage as a direct consequence of the removal of donor anonymity, and they blamed the HFEA for the circumstances that ‘oblige’ them to seek treatment abroad. The fact that obtaining treatment abroad had been condemned by the HFEA was a cause of further frustration. The parents also expressed the view that their concerns were not taken into consideration by the HFEA. This suggests very strongly that further research examining the communication gap between such stakeholders and the HFEA would contribute to developing strategies that could, and should, inform policymaking.

On a positive note, the HFEA’s approach does seem to be changing. In August 2010, in part because of concern regarding the numbers opting to go to countries such as Spain and Cyprus to receive gametes, the Authority launched a full public consultation into sperm and egg donation policies. In this consultation document, the HFEA noted that the landscape of donation had changed since the Authority looked at these rules in 2005, and it emphasized that it would like to make sure that the rules are up to date. It also expressed concern that some fertility centres overseas may offer substandard treatment, and that increasing numbers of people are purchasing unscreened sperm on the
internet. It asked if gamete supply could be improved by a change in policy, or withdrawal from commitments under the EUTCD.

As a result of the consultation process, the HFEA decided to take a more proactive approach to donor recruitment, and increased the compensation amount that sperm and egg donors should be permitted. Egg donors can now receive £750 per cycle of donation. Sperm donors can receive a £35 fee per individual visit. The donors remain non-anonymous, however.

D. Discussion

The removal of anonymity has had identifiable detrimental effects in the United Kingdom: donors are reluctant to donate; clinics cannot meet the demand for gametes; and there are long waiting lists for patients who wish to get treatment. Why then have would-be parents been reluctant to mobilize against it? It is argued here that this reluctance may reflect the variety of ways in which they can avoid the impact of the change in the law: CBRC, in particular, acts as a safety valve.

It has been argued that CBRC promotes moral pluralism; that it prevents the potential clash between minorities wishing to use ART, and majorities who place restrictions on these practices. Others, however, see CBRC as a poor substitute for moral pluralism. In fact, as Storrow argues, CBRC’s function as a safety valve against organized resistance at home is precisely what enables national legislatures to introduce restrictive regulations limiting access to reproductive care: governments may feel justified in assuming a stricter position than they otherwise might, knowing that CBRC will temper resistance to the law. Arguably, then, diversity between different EU Member States has enabled the United Kingdom to introduce restrictive laws with regard to donor recruitment and the procurement of gametes. However, crossing borders to seek treatment in other jurisdictions is hardly desirable for patients: indeed, the interview accounts presented here suggest that such ‘reproductive exile’ may add to the stigmatization of infertility. In addition, as Robertson notes, CBRC as a solution ‘is grossly unfair because it enables only those with funds to escape the law’s strictures. Those who are able to travel to obtain services must also bear the additional burdens of being away from home for substantial periods, making the already psychologically fraught and stressful situation of infertility all the more difficult.’

Irish abortion policy is another example of an approach to the regulation of reproduction ‘where a government “chooses” to facilitate these services through “delegation and doubt”’. In Ireland abortion is only permissible when there is a risk to the

58 Pennings (n 3).
59 Pennings (n 3).
62 Robertson (n 61) 1696.
pregnant woman’s life. According to the Irish Family Planning Association, between January 1980 and December 2010, at least 147,912 women travelled from the Republic of Ireland for safe abortion services abroad.

Having been through reproductive ‘exile’ in order to terminate their pregnancies, in 2005, three Irish women challenged Ireland’s abortion law at the European Court of Human Rights. The applicants felt that their rights under Articles 2, 3, 8, and 14 of the ECHR had been breached. The Court ruled that the Article 8 rights of all three applicants were engaged. However, it distinguished the situation of A and B (who sought abortion for health and/or well-being reasons) from C (who sought abortion as she felt that the pregnancy posed a risk to her life) and ruled that Ireland’s abortion law violated applicant C’s rights under Article 8 ECHR. The Court also decided that the Irish Government needed to implement an infrastructure to facilitate legal abortions within the jurisdiction, that is, where the woman’s life is at risk. Ultimately, however, the decision did not lead to any liberalization of Irish law on abortion: as McGuinness notes, the Court facilitated Ireland’s restrictive abortion laws through its application of the ‘margin of appreciation’ doctrine. The Court considered, first, that abortion could not be disentangled from the question of when life begins; an issue on which there is no consensus in Europe.

Secondly, the judgment did not try to widen the category of cases when abortion would be legal in Ireland as it considered this to be a highly sensitive and controversial issue for the Irish public. The Court’s decision also suggests that it does not see the risks created by the Irish abortion ban as a human rights issue. The ban risks women’s health by causing abortions to be performed later than is necessary, and creates emotional upset for women at an already stressful time. Moreover, as noted earlier, crossing borders to receive medical help is not an option for everyone. In Ireland, both illegal abortions, and the use of illegal abortion pills have become a necessity for women who cannot travel abroad to end their pregnancies. McGuinness argues: ‘[W]ould the Irish Government’s “choice” to deal with abortion through allowing the provision of information and travel when travel is not possible still fail to breach Article 8 rights?’

The Court’s reluctance to engage deeply with Irish abortion law suggests that European human rights law does not place limits on the power of strongly held moral views in Member States of the Council of Europe. This is problematic because, in a democratic society, because of the fundamental nature of the rights at stake in issues related to human reproduction, majoritarian sentiments should not override the interests of major stakeholders of the problem, even though they are in a minority.

Besides, it is questionable whether the Irish abortion ban reflects the Irish public’s view on the matter. According to McGuinness, in A, B and C the judgment was influenced by the Irish Government’s insertion of ‘anti-abortion’ clauses in the Maastricht and Lisbon Treaties, which in fact, indicate a fear that ‘Europeanization’ could lead to abortion being forced on the Irish people, rather than reflecting a majoritarian attitude on abortion. Similarly, the removal of donor anonymity had little to do with public attitudes on donor conception in the United Kingdom: prior to the removal of

65 A, B and C v Ireland (n 64).
67 McGuinness (n 66).
68 McGuinness (n 66). On NHTs and the margin of appreciation, see also Chapters 3 and 13 in this collection.
69 McGuinness (n 66).
70 McGuinness (n 66) 491.
71 Storrow (n 66).
72 Storrow (n 66) 485.
donor anonymity, the Department of Health’s own consultation indicated widespread agreement that more ‘non-identifying’ information about donors should be made available to donor offspring.\textsuperscript{73}

True, the promotion of the right to know may have shielded the UK Government from further cases akin to \textit{Rose} but it has also exacerbated the donor shortage. The latter risk, moreover, was foreseen: the government knew the potential consequences of removing anonymity from donors, yet it decided that the child’s right to know should be championed at any cost, rather than weighed against the competing interests of would-be parents and donors. Writing in a different context, Murphy and Whitty have argued that the assessment and management of risk has become a pre-eminent concern for governments and organizations alike, and that today managing risk involves managing the ‘risk of rights’.\textsuperscript{74} Moreover, as they also point out, ‘risks exist in both engaging with, and rejecting, human rights’.\textsuperscript{75} In the United Kingdom, promotion of children’s right-to-know their gamete donor meant rejection of potential ‘right to treatment’ and perhaps ‘right to respect for private and family life’ claims that could be raised by would-be parents. For example, on what basis does the state strongly encourage disclosure? On what grounds does the HFEA advise that it is ‘certainly best’ to be open with children about the circumstances of their conception? Disclosure should be a matter for each family to decide for itself. But, due to the confidentiality concerns of those who were considering treatment, such claims were not raised: many would-be parents remained silent during the policy change. Their voices, therefore, went unheard by public bodies, like the HFEA, which can only deal with issues through formal and transparent modes of communication.\textsuperscript{76} This silence gave the UK Government a great advantage in managing the ‘conflicting’ interests of would-be parents and donor offspring.

To date the United Kingdom’s non-anonymous donor conception policy does not seem to have increased openness in families. In spite of the greater encouragement in recent years for parents to disclose their children’s donor origins, a recent study shows that less than 8 per cent of egg-donation parents, and less than 5 per cent of those who used donor insemination, disclosed to their children.\textsuperscript{77} In the near future, management of donor registers may become another problem. The Coalition Government is planning to abolish the HFEA and transfer its functions to the Care Quality Commission. There are concerns as to how effectively the Commission can maintain registers with donors’ information.\textsuperscript{78}

In conclusion, then, the current policy seems to undermine the sustainability of gamete donation while failing to promote communication within families. It is also questionable whether the new donor compensation policy will encourage more donors to come forward. The United Kingdom needs to work towards an inclusive, fully informed, debate on balancing the right to know one’s genetic identity against a range of other rights and interests. Without such a debate, and a comprehensive policy review, more would-be parents will be obliged to seek treatment in jurisdictions where they forfeit any benefits or protections that the HFE Act would otherwise confer.

\textsuperscript{73} Ilke Turkmendag, Dingwall, and Murphy (n 24).
\textsuperscript{75} Murphy and Whitty (n 74) 244.
\textsuperscript{76} Turkmendag, Dingwall, and Murphy (n 24).