

Information sharing in donor conception: comparing regulations, ethics and cultural practices in the UK and Belgium

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Abstract

Within the context of donor conception, the significance of knowing about one's genetic origins and the moral and legal status of this information has been the subject of on-going and vociferous debate in a number of Western countries. Ten years on from the removal of donor anonymity in the UK, this paper considers the significance of donor identification law and its relationship to social practices in the UK and Belgium. Despite a similar liberal attitude towards medically assisted reproduction, the UK and Belgium have adopted significantly divergent measures on the issue of donor anonymity. In this paper we describe these regulatory differences and consider the perceptions and experiences of donor identification in each country by contrasting the findings of studies relating to donor conception. We conclude by arguing that greater attention should be given to the complex interplay between legal frameworks and social practices relating to gamete donation and highlight the need for more detailed future research to inform policy-making in assisted reproduction.

Introduction¹

Within the context of donor conception,² the significance of knowing about one's genetic origins and the moral and legal status of this information has been the subject of on-going and vociferous debate in a number of Western countries. For a number of reasons, the importance granted to having information regarding identity, family history, and susceptibility to certain illnesses has burgeoned in recent years, with the associated implication that the anonymity of donors and the issue of access to information about donors has been a major ethical, political and legal challenge. Arguments for

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¹ We would like to thank Prof. Guido Pennings and Dr Lucy Frith for their insightful comments on an earlier draft of this paper.

² A means of achieving pregnancy via the use of a third party donor who provides eggs, sperm or embryos for use by intended parents but who has no legal parental responsibility for the resulting offspring.

a move towards more 'openness' in donation systems have also led on occasion to legislative changes, with a number of nations deciding to remove or ban anonymity in favour of identity-release systems³ or those within which both anonymous and non-anonymous donations are possible.⁴

Debate and commentary on this issue in a range of social contexts have tended to conflate a legal position of anonymity for gamete donors with a wider cultural practice of non-disclosure or 'secrecy' within families and, correspondingly, have conflated a legal position of identification with a culture of disclosure between parents and donor offspring. As well as creating possible terminological confusion, the suggested alignment of social practices with the law obscures the complexity and diversity of attitudes regarding the possible disclosure of the use of donor conception within families and communities. Ten years on from the removal of donor anonymity in the UK, this paper considers the significance of donor identification law and its relationship to social practices in two European countries.

As two countries that share a common position regarding the political legitimisation of assisted reproduction as a means of family building, and share features of technological innovation and expertise, the UK and Belgium are of particular interest in relation to the articulation between legal policies and social practices in gamete donation. They have similar reputations for pioneering research and facilitating the application of new reproductive technologies and share a similar liberal approach towards medically assisted reproduction by giving access to a wide range of technologies for diverse patient groups.⁵ In particular, they have played a key role in donor conception, permitting and practising sperm donation widely for more than five decades and egg donation for more than two decades.

However, on the issue of donor anonymity, their legislative positions diverge significantly. While anonymity was removed from the UK in 2005 in favour of an 'identity-release' system of donation, the Belgian comprehensive law on medically assisted reproduction, adopted in 2007, reaffirmed the obligation for gamete and embryo donation to be anonymous, except in 'known' gamete donation where donation results from an agreement between donor and recip-

³ In an identity release system, the donor-conceived child has the right to access to identifying information about their donor at the age of majority. This is for instance the case in Sweden, Norway, Austria, Switzerland, Netherlands and several Australian states (Eric Blyth & Lucy Frith, 'Access to Genetic and Biographical History in Donor Conception: An Analysis of Recent Trends and Future Possibilities', in: Kirsty Horsey (ed.), *Revisiting the Regulation of Human Fertilisation and Embryology* (Routledge 2015), 136-52).

⁴ For instance, in Denmark. For more detail on the different systems, see Tabitha Freeman, John B. Appleby & Vasanti Jadv, 'Identifiable Donors and Siblings: Implications for the Future', in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 250-52.

⁵ For example, many clinics in the UK and in Belgium have a long-standing tradition of treating lesbian couples or single individuals.

ient. Researchers in these countries have also been among the first to collect data on social attitudes to the issue of donor identification and disclosure to donor offspring. The availability of these recent empirical studies offers the opportunity to gain an improved understanding about the interplay between legal changes and social attitudes and practices regarding disclosure amongst British and Belgian donor families. A comparison between these countries therefore allows consideration of the ways in which donor identification has been legislated for and experienced in two socio-legal contexts.

The paper begins with an overview of the recent broader trends surrounding donor identification and information sharing within the context of shifting conceptualisations of personhood, genetics and identity. We then describe the recent regulatory changes relative to gamete donation, first in the UK and then in Belgium. This is followed by a consideration of the perceptions and experiences of donor identification in each country by contrasting the findings of studies relating to donor conception. The penultimate section focuses on the current debates and challenges in relation to donor identification. We conclude by arguing that greater attention should be given to the complex interplay between legal frameworks and social practices relating to gamete donation and highlight the need for more detailed future research to inform policy-making in assisted reproduction.

Shifting mores in relation to disclosure and donor identification

During the 1980s, a discourse in favour of access to information about one's genetic origins emerged in various Western countries. This discourse, which asserted the child's right to personal identity, first developed in relation to adoption in the US and Canada where adoptees and birth parents were pushing for the removal of confidentiality in the adoption registry.⁶ Not only did this movement lead to the creation of 'open adoptions' in the US and the UK where biological and adoptive parents know their respective identity and can (under certain conditions) contact one another, but also to the adoption of international and national laws, similar to the adoption law in the UK, giving adopted children the right to access information about their origins. Overall, this movement contributed to an increasing political and discursive shift in the significance given to knowing one's family origins.

This trend towards 'openness' progressively extended to the field of gamete donation on a number of grounds including the need for knowledge about one's 'genetic' identity as well as a desire not to withhold information about a person's

⁶ Wayne E. Carp, *Family Matters: Secrecy and Disclosure in the History of Adoption* (Cambridge, Massachusett: Harvard University Press 1998).

life story.⁷ Yet a number of authors have highlighted the substantial differences between adoption and gamete donation.⁸ Donor-conceived children have been planned by intending parents well before conception, whilst adopted children have, in contrast, been relinquished by their birth parents and as a result have been raised by another individual.⁹ In addition, adoptees often report feeling aware of the fact that they are not biologically related to adoptive parents due to physical differences within the family. They may also have to deal with the stigma associated with this lack of physical resemblance, unlike donor-conceived children who may have been conceived with the genetic material of one of the intending parents and may have increased resemblance to their parents due to any 'matching' done at the fertility clinic. While both adopted children and donor-conceived children may desire more information about genetic origins, their conception circumstances are quite different and concerns may be distinct, especially in terms of disclosure and identity. It is well documented that some adoptees search for their birth parents in order to understand the context of and reasons for the adoption.¹⁰ Notwithstanding these differences in context, a parallel has been drawn between practices of information sharing in adoption in order to implore the need for more openness in gamete donation.¹¹

This shift towards identification and greater information sharing in gamete donation has also been reinforced by the increasing attention given in recent times to genetics, especially in terms of medical history and family knowledge.¹² With regard to medical progress on genetic disorders, the need to have access to or knowledge about one's own genetic and genealogical history is increasingly significant.¹³ This is also apparent in the proliferation of related phenomena such as 'popular genealogy', involving a search for one's ancestors and mapping of family trees.¹⁴ This shift in thinking about origins as ultimately determinable

7 Richards et al., 'Introduction', in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 1-12.

8 Françoise Shenfield, 'Truth or Dare? Anonymity: The Case For', *Progress in Reproduction* 3:8 (1999); Lucy Blake et al., "'I Was Quite Amazed": Donor Conception and Parent-Child Relationships from the Child's Perspective', *Children & Society* 28:6 (November 2014), 425-37.

9 Jesús Palacios & David Brodzinsky, 'Review: Adoption Research: Trends, Topics, Outcomes', *International Journal of Behavioral Development* 34:3 (1 May 2010), 270-84.

10 Janet Carsten, "'Knowing Where You've Come From": Ruptures and Continuities of Time and Kinship in Narratives of Adoption Reunions', *The Journal of the Royal Anthropological Institute* 6:4 (2000), 687-703.

11 Julia Feast, 'Using and Not Losing the Messages from the Adoption Experience for Donor-Assisted Conception', *Human Fertility* 6:1 (February 2003), 41-45.

12 Dorothy Nelkin & Susan M. Lindee, *The DNA Mystique. The Gene as a Cultural Icon* (New York: Freeman and Company 1995).

13 Kaja Finkler, *Experiencing the New Genetics: Family and Kinship on the Medical Frontier* (Philadelphia: University of Pennsylvania Press 2000).

14 Fenella Cannell, 'English Ancestors: The Moral Possibilities of Popular Genealogy', *Journal of the Royal Anthropological Institute* 17:3 (September 2011), 462-80.

has inflected public and policy discourses related to family relations, kinship and gamete donation.

The emergence of demand for non-anonymous donors amongst certain social groups has also added to the shifting landscape of donor anonymity. An increasing number of lesbian and single women have accessed reproductive technologies over the last two decades, creating family situations where the biological (donor) father is not an active presence. For some of these women, having medical information about the donor as well as information about his interests and personality traits to provide to the future child was of significance.¹⁵

Changes in the uptake of egg donation may also have contributed to changes in practices around donor anonymity. As demand has grown and freezing technologies have advanced, egg donation has become more widely used and, in many contexts, the number of donated eggs is not sufficient to meet the increasing demand. This means that waiting times can be considerable, something which in turn has contributed to a rise in the number of women asking a close relative or friend to become their donor¹⁶ and indirectly, has facilitated known donation and donor identification.

Within this wider context, the culture of anonymity and non-disclosure that had once prevailed appears to have been subject to notable change, as disclosure and identification have increasingly been debated and encouraged in gamete donation.¹⁷

The legal perspective: anonymity vs. identifiability

As countries at the heart of technological developments and ethical debates regarding assisted reproductive technologies, both the UK and Belgium have been exposed to shifting values and trends regarding information about genetic inheritance. Legal decisions regarding the identification of donors in these countries have, however, taken somewhat differing paths. These divergent regulatory positions offer a fruitful opportunity to examine the ways in which laws and social practices may, or importantly, may not be, co-constitutive.

¹⁵ P. Baetens & A. Brewaeys, 'Lesbian Couples Requesting Donor Insemination: An Update of the Knowledge with Regard to Lesbian Mother Families', *Human Reproduction Update* 7:5 (October 2001), 512-19.

¹⁶ P. Baetens et al., 'Counselling Couples and Donors for Oocyte Donation: The Decision to Use Either Known or Anonymous Oocytes', *Human Reproduction (Oxford, England)* 15:2 (February 2000), 476-84.

¹⁷ John B. Appleby, Lucy Blake & Tabitha Freeman, 'Is Disclosure in the Best Interests of the Children Conceived by Donation?', in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 231-49; Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013).

In the following section, we present some of the key features of the debates in each country in order to highlight the differing ways information sharing in gamete donation have evolved in each context.

The UK regulation

In 1990, the UK pioneered the legal regulation of assisted reproduction by adopting the Human Fertilisation and Embryology Act. This Act made anonymity mandatory for donor conception¹⁸ but fertility clinics were required to collect some non-identifying information about the donor which could be released upon request by the donor offspring at the age of 18. There was, however, no state mandated possibility to identify the donor at this time. Moreover, parents were usually advised not to tell the children about the circumstances of their conception.

Fifteen years later, the Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulation 2004 abolished donor anonymity in the UK. This change meant that from 2005, offspring conceived through gamete donation were given the right to access identifying information about their donor and thus to make it potentially possible for them to contact their donor at the age of 18 (if their details are up to date). This 'identity-release' donation system was henceforth mandatory for everyone who wished to use gamete or embryo donation in a clinical setting. This also meant that people who wanted to donate gametes must also agree to be identifiable and to accept the possibility of being contacted by the offspring at some point in the future.¹⁹

In the policy debates which led to the removal of donor anonymity in the UK, a number of claims were made regarding the need for donor offspring to be able to access identifying information about their donor. As described above, those lobbying for the rights of adoptees also advocated for the rights of donor-conceived people to have equivalent information about their origins. Progar (the British Association of Social Workers' Project Group on Assisted Conception) and the national charity, the Children's Society, advocated for legal changes with regard to the removal of donor anonymity in the interests and rights of donor-conceived individuals and succeeded in raising public and political attention on this issue.²⁰ The public awareness actions started by the Children's

¹⁸ Previously the Family Law Reform Act adopted in 1987 had allowed the intended parents to be the legal parents of the resulting child, while preventing the donor from making claim to or assuming any rights or responsibilities towards any resulting children.

¹⁹ It is also possible in the UK for 'known' donors to be used, whereby the identity of the donor (often a family member) is known to the recipients at the point of treatment, unlike the identity release system in which intending parents are only given non-identifying information at the point of donation.

²⁰ Ilke Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *Journal of Law and Society* 39:1 (2012), 58-75.

Society occurred almost simultaneously as two donor-conceived individuals (Joanna Rose and 'EM') went to court in order to claim access to information about their donor under the Human Rights Act 1998.²¹ These two factors led the UK government to launch a public consultation in 2002, followed by consultation exercises by the HFEA with clinics and donors, designed to consider the amount of information that should be made available to donor-conceived people and their parents.²² Though responses to the consultation were mixed, following this exercise, the UK government revised the law in order to make anonymous gamete donation illegal. As Frith has suggested, these legal changes were therefore based on a parallel being drawn between gamete donation and adoption, as well as the principle that the ability to identify one's donor was in the 'best interests of the child'.²³ Donor anonymity therefore emerged in the UK as a social problem and saw legal change on the basis of these conceptualisations.²⁴

According to advocates of the removal of donor anonymity, granting donor-conceived individuals access to information about their conception would allow them access to their medical history, information about family relatedness, and would ensure fulfilment of identity.²⁵ These arguments were also in line with the concern about the risks of genetically related sexual partners and the desire to avoid unwitting incest at a time when the number of offspring conceived with gamete donations was increasing.²⁶

Overall, the government emphasised the priority granted to the child's interests in its decision to change the law in 2004 'rather than the best interests of the medical profession or the best interests of those going for treatment'.²⁷ It has been argued that the debates were 'conducted with very limited empirical

²¹ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013), 22.

²² 'Donor Information Consultation: providing information about Gamete or Embryo Donors', UK Department of Health, 20 December 2001. Available at: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4005810.

²³ Lucy Frith, 'The Limits of Evidence: Evidence Based Policy and the Removal of Gamete Donor Anonymity in the UK', *Monash Bioethics Review* 33:1 (March 2015), 29-44.

²⁴ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate, on Donor Anonymity in the United Kingdom', *op. cit.*

²⁵ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013); Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.*

²⁶ Jeanette Edwards, 'Incorporating Incest: Gamete, Body and Relation in Assisted Conception', *Journal of the Royal Anthropological Institute* 10:4 (2004), 755-74; Enric Porqueres i Gené & Jérôme Wilgaux, 'Incest, Embodiment, Genes and Kinship', in: Jeanette Edwards & Charles Salazar (eds.), *European Kinship in the Age of Biotechnology* (New York & Oxford: Berghahn Books 2009), 112-27.

²⁷ Lucy Frith, 'The Limits of Evidence', *op. cit.*, 39.

evidence about the implications of open-identity donation for those involved²⁸ and, some have suggested, without effective consultation processes.²⁹

The direct outcomes of the legal change regarding identifiable donation will remain unknown at least until 2023, when the first donor-conceived individuals will have the opportunity to access identifying information on their donor. Whilst it is currently mandatory for pre-treatment counselling in the UK to include a recommendation that children should be told about their donor-conceived origins,³⁰ there is no legal obligation to do so and therefore children may not be given this information. Open-identity donation can therefore encourage or facilitate the parents' disclosure but it doesn't prevent non-disclosure.³¹ In other words, whether or not parents use an identifiable donor, they will still have to decide to tell the child or not about his or her donor conception.

In the ten years since the removal of donor anonymity in the UK, there has been a shift in the way donor services are organised and a demonstrable will to improve the experience of donors, donor parents and donor-conceived individuals under the new system. Recent initiatives such as the HFEA's Donor Strategy Group³² and the launch of the National Sperm Bank³³ are being implemented in order to further embed the current system and to address donor shortages. Moreover, in 2012, and following public consultation, donor compensation levels were also increased in the UK, in part, to address this shortage.³⁴

The Belgian regulation

While medically assisted reproduction has been widely practiced in Belgium since the 1960s, its regulation has been largely confined to that of professional oversight and guidance. As a result clinicians and researchers were granted a considerable degree of scientific autonomy and any bioethical and religious orientations were respected.³⁵ It was as recently as July 2007 that

²⁸ Freeman, Appleby & Jadva, 'Identifiable Donors and Siblings: Implications for the Future'.

²⁹ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.*

³⁰ A 2008 amendment to the 1990 Act provides legislative endorsement for early parental disclosure (Section 13(6C)).

³¹ Freeman, Appleby & Jadva, 'Identifiable Donors and Siblings: Implications for the Future'; Jennifer Readings et al., 'Secrecy, Disclosure and Everything in-between: Decisions of Parents of Children Conceived by Donor Insemination, Egg Donation and Surrogacy', *Reproductive Biomedicine Online* 22:5 (May 2011), 485-95.

³² See: www.hfea.gov.uk/7138.html.

³³ See: www.veryspecialman.co.uk/.

³⁴ HFEA, CH(12)01 (Implementation of the outcomes of the Donation Review), January 2012. Available at: www.hfea.gov.uk/6966.html.

³⁵ Nathalie Schiffino, Céline Ramjoué & Frédéric Varone, 'Biomedical Policies in Belgium and Italy: From Regulatory Reluctance to Policy Changes', *West European Politics* 32:3 (2009), 559-85.

a comprehensive law on medically assisted reproduction and the disposition of supernumerary embryos and gametes was adopted in Belgium.³⁶ This law primarily aimed at formalising existing clinical practices and limiting possible excesses. The law permits a broad range of reproductive techniques, such as post-mortem insemination or preimplantation genetic diagnosis, and allows these techniques to be offered to any couple and single woman under the age of 48.³⁷ This liberal law is therefore in line with existing clinical practices and attitudes within some Belgian clinics.

The 2007 law also reinforced the obligation for embryo and gamete donation to remain anonymous, after an intense debate on this issue in Belgium. An exception was made for certain cases of gamete donation where donors do not have to remain anonymous provided they result from an agreement between the donor and the recipient. The aim of this exception was, it seems, in reality to facilitate the supply of egg donors, which constitutes a scarce resource, by allowing egg donation from a family member or a friend.³⁸ Indeed, prior to this, most women in Belgium preferred to receive or donate eggs in circumstances where the donors and recipient knew one other.³⁹ This means that in the case of Belgian egg donation, as in 'known donation' in the UK, some intending parents will know who the donor is from the start. This possibility of known donation is regarded and presented as an exception to the prevailing rule in Belgium where clinics are obliged to guarantee the anonymity of donors in rendering inaccessible all information both identifying (e.g. names) and non-identifying (e.g. physical characteristics) relating to donors. The anonymous model generally followed in Belgium contrasts with UK practices where not only do clinics collect and make available medical and physical information about the donors, but also encourage them to provide a personal and biographical description of themselves which will be accessible to donation families at the point of donation.⁴⁰

A crucial argument used to justify the maintenance of donor anonymity in Belgium was the priority given to the autonomy of parents.⁴¹ According to this principle, parents should be able to decide whether or not and how they wish

³⁶ A first law on in-vitro embryos was nevertheless adopted in May 2003. It authorises the procuring of stem cells from residual embryos, therapeutic cloning and the creation of embryos for research purposes. Only reproductive cloning is forbidden.

³⁷ For more details on the content of the new law, see Guido Pennings, 'Belgian Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes', *European Journal of Health Law* 14 (2007), 251-60.

³⁸ Nicole Gallus, *Le Droit de La Filiation. Rôle de La Vérité Socio-Affective et de La Volonté En Droit Belge* (Bruxelles: Larcier 2009); Pennings, 'Belgian Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes', *op. cit.*

³⁹ Baetens et al., 'Counselling Couples and Donors for Oocyte Donation', *op. cit.*

⁴⁰ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013).

⁴¹ Gallus, *Le Droit de La Filiation. Rôle de La Vérité Socio-Affective et de La Volonté En Droit Belge*.

to tell the child about the nature of their conception. In this model anonymity goes hand in hand with the legislative will to privilege family ties based on parental commitment and daily involvement.

In line with this argument was also the will to respect parents' rights to a private life and to protect their intimacy. The intention of Belgian policymakers was to help donor-conceived children integrate directly into their family without revealing the medical intervention needed for its conception and without the parents fearing the intrusion of the donor in their family. It also intended to prevent the possible disruption to the child and its parents caused by information about and contact with an additional parental figure. Likewise, another aim was to guarantee discretion towards the donor who acted as a genitor and not as a parent. The law was therefore intended to protect the donor against the risk of parental obligations and intrusion in his or her private life at a later stage.

A specific prohibition relating to sharing information about embryo donation was also justified by the need to prevent commercialisation of embryos between donors and recipients. However, as Guido Pennings points out, if this was an important reason for justifying anonymity, this rule should also have been extended to egg and sperm donation.⁴²

The decision to retain anonymity was also made to prohibit access to non-identifiable, non-medical information in order to avoid any genetic determinism, whereby the child's character, for example, might be attributed to the donor's genes.⁴³ This differs from the UK where the significance of genetics has potentially been reinforced through policies which appear to imply determining links between the genetics and personality of the donor: for example, through providing the donor-conceived family with a personal and biographical description of the donor.⁴⁴

Finally, anonymity policies were also justified in Belgium for practical reasons, since they also helped to preserve the number of donations and were therefore suggested as important in avoiding a donor shortage. Although this was also an important concern for medical groups in the UK, this factor was not taken into consideration by the UK government in its consultation.⁴⁵

As in the UK context, practices may not align with laws, meaning that even though Belgian law does not allow access to the donor's identity and may therefore assume a position of non-disclosure within families, this does not

⁴² Pennings, 'Belgian Law on Medically Assisted Reproduction and the Disposition of Supernumerary Embryos and Gametes', *op. cit.*

⁴³ Belgian Chamber, 'Rapport Concernant Le Projet de Loi Relatif à La Procréation Médicalement Assistée et à La Destination Des Embryons Surnuméraires et Des Gamètes', Session 2006/2007, 9 March 2007, 41.

⁴⁴ Though it is also the case that this information is provided in order that donor families can incorporate this information in to coherent 'conception stories'.

⁴⁵ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.*

mean that donor conception parents won't discuss with their children the circumstances of their conception. However, in Belgium, the implication of disclosure is that the child will know about the lack of a biological tie with one of his or her parents, but won't be able to access any information regarding the donor.

Contrasting the UK and Belgian legislative landscapes offer an insight into the differing prioritisation of rights and interests in debates and policy about donor anonymity. We can observe that in the UK precedence was given to the rights and interests of donor-conceived children to know their genetic origins,⁴⁶ whilst in Belgium, the rights of parents and donors superseded the rights of the child on the grounds of the principles of autonomy and a right to privacy.

Disclosure and non-disclosure in practice: research in the UK and Belgium

In this section we consider the practices and attitudes of donor conception parents regarding donor information sharing,⁴⁷ by providing an overview of the studies conducted on this issue in the UK and Belgium. While accurate figures are not available given the difficulties in collecting data about children who have not been told about their donor conception,⁴⁸ the qualitative studies available provide noteworthy insights on perceptions of this issue. There is still a significant gap in the evidence base, but these studies offer a valuable snapshot of the complex negotiations and variability surrounding decisions regarding disclosure and non-disclosure within donor conception families and enable a consideration of the ways these practices articulate with local laws.

In the UK, the on-going longitudinal research conducted with donor-conceived families by Susan Golombok and her team from Cambridge University, shows that at age 7, 28% of sperm donation parents and 41% of egg donation parents, were in the process of disclosing information about their conception to their child.⁴⁹ This trend seems to continue at age 10,⁵⁰ with a majority of

⁴⁶ Lucy Frith, 'Gamete Donation and Anonymity: The Ethical and Legal Debate', *Human Reproduction* 16 (2001), 818, 820-22; Lucy Frith, 'Beneath the Rhetoric: The Role of Rights in the Practice of Non-Anonymous Gamete Donation', *Bioethics* 15 (2001), 473, 477.

⁴⁷ In this paper we do not provide a broader discussion about donor-conceived children (see for example Martin Richards, Guido Pennings & John B. Appleby (ed.), *Reproductive Donation: Practice, Policy and Bioethics*, (Cambridge, UK: Cambridge University Press 2012)) but instead focus specifically on the question of disclosure.

⁴⁸ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', (London, April 2013).

⁴⁹ S. Golombok, J. Readings, L. Blake, P. Casey, L. Mellish, A. Marks & V. Jadva, 'Children Conceived by Gamete Donation: Psychological Adjustment and Mother-child Relationships at Age 7', *Journal of Family Psychology* 25 (2011), 230-239.

⁵⁰ Lucy Blake et al., "'I Was Quite Amazed": Donor Conception and Parent-Child Relationships from the Child's Perspective', *op. cit.*

sperm donor parents in particular choosing not to disclose the conception to the child.⁵¹ This study also highlights the need to distinguish between the initial intention to disclose and the actual process of letting the child know about the use of gamete donation. Indeed, while 37 out of 68 donation parents intended to disclose when the child was aged one, only about half of them had done so six years later.⁵² Moreover, for some of these parents disclosure was only partial. They had told the child about the use of reproductive technologies, but not about the donor.⁵³ Most of these children are therefore not aware that one or both of their legal parents is not his or her genetic parent. Another study conducted by the team at Cambridge on donor-conceived children in several European countries showed that amongst the UK sample, donor-conceived parents who had not disclosed to their children at age 12 tended not to do so later on. At age 18, only about a tenth of the children who had not been told at age 12 knew about the circumstances of their birth.⁵⁴ It is important to note that these trends differ in families formed by single mothers who used sperm donation in which, according to Murray and Golombok's study, 90% of single mothers intended to tell their child.⁵⁵ This proportion is even higher in donor conception families headed by same-sex couples, in which all parents, according to studies conducted in the UK, Belgium and the Netherlands, intended to disclose.⁵⁶

Drawing on interviews with donor conception parents and grandparents, a recent UK sociological study has described how even in family situations where parents are in favour of openness (heterosexual and lesbian couples), telling the child about his or her conception may prove to be much more difficult than

⁵¹ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013), 57.

⁵² Readings et al., 'Secrecy, disclosure and everything in-between: decisions of parents of children conceived by donor insemination, egg donation and surrogacy', *op. cit.*

⁵³ *Ibid.*

⁵⁴ L. Owen & Susan Golombok, 'Families Created by Assisted Reproduction: Parent-Child Relationships in Late Adolescence', *Journal of Adolescence* 32:4 (2009), 835-48.

⁵⁵ C. Murray & S. Golombok, 'Going it alone: solo mothers and their infants conceived by donor insemination', *American Journal of Orthopsychiatry* 75:2 (2005), 242-53.

⁵⁶ Fiona MacCallum & Susan Golombok, 'Children Raised in Fatherless Families from Infancy: A Follow-up of Children of Lesbian and Single Heterosexual Mothers at Early Adolescence', *Journal of Child Psychology and Psychiatry, and Allied Disciplines* 45:8 (November 2004), 1407-19; M. Stevens et al., 'Openness in Lesbian-Mother Families Regarding Mother's Sexual Orientation and Child's Conception by Donor Insemination', *Journal of Reproductive and Infant Psychology* 21:4 (1 November 2003), 347-62; K. Vanfraussen, I. Ponjaert-Kristoffersen & A. Brewaeys, 'An Attempt to Reconstruct Children's Donor Concept: A Comparison between Children's and Lesbian Parents' Attitudes towards Donor Anonymity', *Human Reproduction* 16:9 (1 September 2001), 2019-25.

expected in practice, especially given the impact it has on the wider family. Some parents may therefore be hesitant or feel uncomfortable about disclosure.⁵⁷

Overall, it would appear that single women and same sex couples are most likely to disclose, and that whilst the number of heterosexual parents in the UK who are willing to disclose or intend to disclose is increasing, they nevertheless remain a minority of the whole of parents who used gamete donation.⁵⁸ It is also worth noting that the impact of the legal change on disclosure in the families who have used gamete donation after 2005 is still unknown. However, according to the Nuffield Council on Bioethics's report, 'preliminary findings from a study being carried out by Freeman T, Zadeh S, Smith V and Golombok S suggest that the removal of anonymity has not had an immediate impact on disclosure rates'.⁵⁹

In Belgium, an early study by Baetens et al. on egg donation indicated that two thirds of a sample of 144 couples opted for known donation and one third for anonymous donation. One of the main reasons to choose known donation was the fear of using unknown genetic material. Amongst the couples who used egg donation, the proportion of couples intending to disclose later on was similar to those who did not want to disclose (43%).⁶⁰

More recently, another Belgian study on egg donation drawing on interviews with 135 recipient couples and 90 egg donors reported similar rates of disclosure and non-disclosure amongst donor parents, regardless of whether they used an anonymous or identifiable donor.⁶¹ Half of parents using known donation (42 couples) and half of those using an anonymous donor (45 couples) did, indeed, not want to tell the child about his or her conception because of the fear of stigmatisation or rejection within their social circle, as well as to avoid jeopardising the mother-child relationship. Disclosure was also sometimes regarded as a threat to the child's psychological well-being.⁶² The paper also indicates that 'among Europeans (90 couples), 50% were in favour of disclosure compared with only 8.9% of recipients from North or sub-Saharan Africa (45 couples)'.⁶³ In some religious or ethnic communities, using gamete donation was taboo and disclosing this information could be very harmful and stigmatising not

⁵⁷ Petra Nordqvist, 'The Drive for Openness in Donor Conception: Disclosure and The Trouble with Real Life', *International Journal of Law, Policy and the Family* 28:3 (2014), 321-38.

⁵⁸ Appleby, Blake & Freeman, 'Is Disclosure in the Best Interests of the Children Conceived by Donation?', *op. cit.*

⁵⁹ Tabitha Freeman, personal communication, 11 February 2013, indicated in Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing' (London, April 2013), 58.

⁶⁰ Baetens et al., 'Counselling Couples and Donors for Oocyte Donation', *op. cit.*

⁶¹ C. Laruelle et al., 'Anonymity and Secrecy Options of Recipient Couples and Donors, and Ethnic Origin Influence in Three Types of Oocyte Donation', *Human Reproduction* 26:2 (February 2011), 382-90.

⁶² *Ibid.*

⁶³ *Ibid.*

only for the child but also for the social father and the mother.⁶⁴ As a result, it remains unclear whether parents who can choose between an anonymous and a non-anonymous egg donor would prefer to disclose more information or not.⁶⁵ The authors therefore recommend ‘maintaining access to different types of oocyte donation’.⁶⁶

As for sperm donation, a qualitative study drawing on interviews with Belgian couples who had used an anonymous sperm donor has shown that once the child was born, most heterosexual couples ‘avoided talking about the donor because it was perceived as disrupting men’s growing confidence in their position as father’.⁶⁷ This was not dependent on whether or not they had disclosed but rather reflected the couples’ priority to protect the father from possible reminders of the donor. By contrast, attitudes towards the donor amongst lesbian couples who were interviewed in the study were more diverse. While disclosure about donor conception was the norm, there were differences in the ways the donor was constructed, with some couples portraying him as a person, especially as the child grew older, and others only considering the male genetic procreator as a means to the conception and tending to ignore him in discussions about family relationships.⁶⁸

The studies conducted to date on gamete donation practices in the UK and in Belgium demonstrate that despite a change of attitudes in professional counselling towards more openness, many heterosexual parents have not disclosed this information to their child or have expressed ambivalence or difficulty in doing so. A currently unknown proportion of donor-conceived children are therefore unaware that one or both of their legal parents is not his or her genetic parent. This proportion seems slightly more significant amongst children conceived using sperm donation than egg donation.⁶⁹ However, studies conducted in several countries also suggest that ‘children who are not informed have positive relationships with their parents and develop normally, which shows that this specific family secret does not always have an impact on the

⁶⁴ Ethnic and cultural differences in public perceptions of disclosure in gamete donation have also been noted in the UK context (see Nicky Hudson & Lorraine Culley, “‘Knock knock, you’re my mummy’: anonymity, identification and gamete donation in British South Asian communities”, in: Hampshire and Simpson (eds.), *Assisted Reproductive Technologies in the Third Phase. Global Encounters and Emerging Moral Worlds* (Oxford: Berghahn Books 2015) 214-229)).

⁶⁵ This is also the conclusion of another study conducted later in the US on disclosure in egg donation (Dorothy A. Greenfeld & Susan Caruso Klock, ‘Disclosure Decisions among Known and Anonymous Oocyte Donation Recipients’, *Fertility and Sterility* 81:6 (June 2004), 1565-71).

⁶⁶ Laruelle et al., ‘Anonymity and Secrecy Options of Recipient Couples and Donors, and Ethnic Origin Influence in Three Types of Oocyte Donation’, 382.

⁶⁷ Elia Wyverkens et al., ‘The Meaning of the Sperm Donor for Heterosexual Couples: Confirming the Position of the Father’, *Family Process* (23 April 2015), 1.

⁶⁸ Elia Wyverkens et al., ‘Beyond Sperm Cells: A Qualitative Study on Constructed Meanings of the Sperm Donor in Lesbian Families’, *Human Reproduction* 29:6 (June 2014), 1248-54.

⁶⁹ Readings et al., ‘Secrecy, Disclosure and Everything in-Between’, *op. cit.* 486.

child's life'.⁷⁰ It is nonetheless worth noting that without more research it is difficult to demonstrate the impact that disclosure might or might not have for those involved and moreover that access to the perceptions of those who do not know they are donor-conceived, is of course impossible.⁷¹

Current debates and challenges

Despite the changes to the legislation of gamete donation in the UK and Belgium described in this paper, debate continues and suggests that there are several issues still at stake in both contexts. First, one effect of the legal shift in favour of open-identity donation is the potential ensuing shortage of gamete donors, which some have argued has been characteristic of the UK context in recent years.⁷² Although evidence suggests that donations are on the increase due to changing donor profiles and improvements in recruitment strategies,⁷³ there is still not sufficient supply to meet increasing demands,⁷⁴ leading some to travel overseas in pursuit of donor treatment.⁷⁵

Moreover, some have proposed that an identity release system has contributed to the genetisation of the family by suggesting that genetic information is crucial for well-being and by giving priority to genetic relationships. Ilke Turkendag notes that 'by marginalizing donor-conceived children, and enforcing a deeply-rooted view that genetic linkage is indeed very important, it is possible that the United Kingdom's disclosure policy compounds stigma and increases subterfuge rather than openness'.⁷⁶

Information sharing and donor identification have continued to be central to regulatory and legal discussions in both countries. In the UK, for example, a call for evidence was launched by the UK Nuffield Council on Bioethics on the ethical aspects of donor information sharing in 2011. It looked at 'issues of

⁷⁰ Inez Raes, An Ravelingien & Guido Pennings, 'Donor Conception Disclosure: Directive or Non-Directive Counselling?', *Journal of Bioethical Inquiry*, in press.

⁷¹ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', *op. cit.*

⁷² Theresa Glennon, 'UK and US Perspectives on the Regulation of Gamete Donation', in: Martin Richards, Guido Pennings & John B. Appleby (eds.), *Reproductive Donation: Practice, Policy and Bioethics* (Cambridge, UK: Cambridge University Press 2012), 90-111.

⁷³ Human Fertilisation Embryology Authority, 'Egg and Sperm Donation in the UK: 2012-2013' (London 2014), www.hfea.gov.uk/docs/Egg_and_sperm_donation_in_the_UK_2012-2013.pdf.

⁷⁴ BBC News, 'UK national sperm bank has just nine donors', 1 September 2015, www.bbc.co.uk/news/health-34113080.

⁷⁵ Lorraine Culley et al., 'Crossing Borders for Fertility Treatment: Motivations, Destinations and Outcomes of UK Fertility Travellers', *Human Reproduction* (June 2011), 2373-2381.

⁷⁶ Turkmendag, 'The Donor-Conceived Child's "Right to Personal Identity": The Public Debate on Donor Anonymity in the United Kingdom', *op. cit.* 75.

privacy, openness, and access to information, and the implications of each of these for the individuals, families and groups affected by donor conception'.⁷⁷ The working group's conclusions were somewhat controversial in that it argued that it is not the role of state authorities to ensure that donor-conceived individuals are told about the nature of their conception, but rather that efforts should be made to encourage an environment where donor conception could be discussed openly and valued as one amongst a number of ways of family-building.⁷⁸

Presently in Belgium, the issue of information sharing in gamete donation remains controversial, against a growing significance of having information about one's genetic origins. This has been influenced most notably by open donation policies in the Netherlands and claims made by donor offspring which, as in the UK, have requested the ban of anonymous donation and access to the identity of the donor. The question of the regulation of donor conception was also reignited amidst recent discussions about possible future regulation of surrogacy which is currently unregulated in Belgium.

In 2014, a law proposal⁷⁹ was submitted to the Belgian Parliament in order to implement five different possibilities in terms of information sharing:

1) known donation; 2) access to non-identifiable information until the child is 18 and then access to the donor's identity; 3) access to non-identifiable information only; 4) no information on the donor until the child is 18 and then access the donor's identity and 5) anonymous donor. The prospective parent could therefore choose which donation option suits them best, while respecting the donors' preferences in terms of involvement. By offering more flexibility for all involved, this proposal also seeks to avoid significant gamete shortages. The primary aim of this recent law proposal is nonetheless to promote openness, which is illustrated by the suggestion that clinical counsellors be obliged to inform parents-to-be about the possible negative consequences of non-disclosure. In February 2015, a range of experts were invited to share their views on these possibilities. The hearing was followed by the submission of two other, more radical, law proposals, which aimed at banning donor anonymity and at creating a specific organisation responsible for centralising and organising the sharing of donor information.⁸⁰ Researchers at the University of Ghent in Belgium also

⁷⁷ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', *op. cit.* 31.

⁷⁸ *Ibid.*, xxvii.

⁷⁹ S. Lahaye-Battheu & I. Somers, 'Proposition de loi du 13 novembre 2014 modifiant la loi du 6 juillet 2007 relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes, en ce qui concerne l'anonymat dans le cadre d'un don de gamètes', Doc 55/0618.

⁸⁰ V. Van Peel, 'Proposition de loi du 11 mars 2015 créant un Institut pour la conservation et la gestion des données relatives aux donneurs', Doc 54/0952; E. Van Hoof & S. Beck, 'Proposition de loi du 6 mai 2015 modifiant la loi du 6 juillet 2007 relative à la procréation médicalement assistée et à la destination des embryons surnuméraires et des gamètes, réglant le don anonyme de gamètes et instaurant un droit à l'identité pour les enfants issus d'un don', Doc 55/1066.

recently held an international symposium on gamete donation,⁸¹ in which most presentations and discussions focused on the relative challenges and dilemmas associated with anonymous and non-anonymous donation. These political and academic debates reflect the increasing attention granted to this issue in Belgium.

Conclusion

In the UK and Belgium the legal approach to donor identification has evolved in divergent ways, despite the fact that both countries share a common liberal framework regarding assisted reproduction. In Belgium, autonomy and freedom for intending parents have been maintained and prioritised: paradoxically the implication of this being that those who want to use gamete donation to form a family have little choice with respect to donor characteristics and there is no possibility for donor-conceived individuals to access information about the donor, either at the time of donation or in the future. In contrast, in the UK, donation policies place importance on allowing children conceived through gamete donation access to information about their origins. However, by allowing parents autonomy regarding the decision to disclose, this right is not guaranteed. This creates significant disparities, therefore, between donor-conceived children who have been told about their conception and will be able to access information about their donor's identity and those who have not been told.

In the ten years since the removal of donor anonymity in the UK, relative political approaches to donor identification and practices related to information sharing have evolved and are continually challenged by the diversity and complexity of family situations. In attempting to overcome these challenges, some commentators have argued for a 'double track' approach to donation, in which the autonomy of parents and donors could be respected. It is argued that in this model, both parties would have the possibility to choose what suits them best and clinics would match donors and recipients according to their preferences.⁸² One of its main disadvantages however, is the difference between the rights of offspring who have access to their donor's identity and those who don't have this possibility, since the choice about with which method to engage still lies with the recipients and donors. This double-track system was temporarily adopted in the Netherlands and is now on-going in Denmark. In both cases, it

⁸¹ 'Donor conception: An unfamiliar path to a normal family?' Symposium organised by the research group on social and genetic parenthood from Ghent University, 27-28 August 2015.

⁸² Pennings, 'The "Double Track" Policy for Donor Anonymity', *Human Reproduction* 12:12 (1997), 2839-44.

has not been implemented for a long enough period to enable conclusions on the implications to be drawn.

With respect to social practices, research about experiences and perceptions of donor identification and information disclosure remains limited. Almost all of what is known about those who are donor-conceived comes from small-scale studies, even though the UK or Belgium were pioneers in this respect.⁸³ Given this, it is difficult to draw firm conclusions about the implications of donor identification, particularly with regards to the articulation of the law with social practices. Current studies however do appear to illustrate more diversity regarding disclosure practices amongst families than has been suggested by various stakeholders in public debates. Despite this, the findings of such research has not, to date, played a significant role in shaping policy making,⁸⁴ demonstrating a potential lack of effective and systematic dialogue between social scientists and law-making in this field. This is striking given the vibrancy of the political and legislative debate and change in these countries in recent years. If legislative changes are to be made which are reflective of and consistent with social practices and lived experiences, further detailed, longitudinal research is needed to better understand the social perceptions of those engaged with donor conception and the meanings that people give to disclosure.

⁸³ Nuffield Council on Bioethics, 'Donor Conception: Ethical Aspects of Information Sharing', *op. cit.*

⁸⁴ Frith, 'The Limits of Evidence', *op. cit.*