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# The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business

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**ABSTRACT:** Thousands of people worldwide have been conceived using donor gametes, but not all parents tell their children of their origin. Several countries now allow donor-conceived offspring to potentially know their genetic parent if they are informed of their donor-conceived status. At the same time, personal genetic testing is a rapidly expanding field. Over 3 million people have already used direct-to-consumer genetic testing to find information about their ancestry, and many are participating in international genetic genealogy databases that will match them with relatives. The increased prevalence of these technologies poses numerous challenges to the current practice of gamete donation. (i) Whether they are donating in a country that practices anonymous donation or not, donors should be informed that their anonymity is not guaranteed, as they may be traced if their DNA, or that of a relative, is added to a database. (ii) Donor-conceived adults who have not been informed of their status may find out that they are donor-conceived. (iii) Parents using donor conception need to be fully informed that their children's DNA will identify that they are not the biological parents and they should be encouraged to disclose the use of donor gametes to their children. Together, these concerns make urgent a wide-ranging societal conversation about how to best safeguard and promote the interests of donor-conceived offspring and protect the rights of donors. Specifically, there is a need to ensure that new genetic information is communicated in a way that promotes both the safety and the privacy rights of offspring and donors alike. All parties concerned must be aware that, in 2016, donor anonymity does not exist.

**Key words:** gamete donation / donor conception / anonymity / genetic testing / disclosure

## Introduction

A significant proportion of fertility treatment is third-party reproduction, involving the use of donor gametes or embryos. Up until now, the use of anonymous donation has prevented thousands of children discovering the identity of their genetic parent. In many cases, children might not have been told how they were conceived, and in some circumstances, this information is exposed by accident in later life (Indekeu *et al.*, 2013). With the progress in direct-to-consumer (DTC) genetic testing and the formation of large international genetic genealogy databases, genetic data can be shared and has the potential to allow donor-conceived individuals to find out identifying information about their genetic parents, half siblings and other genetic relatives.

## Gamete donation

The first recorded sperm donor insemination was performed at the Jefferson Medical Centre, Philadelphia, in 1884 (Brewaeys *et al.*, 2005), and the first oocyte donation took place almost 100 years later in 1983 at Monash IVF Centre, Australia. Since then, many thousands of people throughout the world have been born as a result of donor conception, although it is impossible to quantify the exact number. In the UK alone, 31 000 donor-conceived children were born between 1992 and 2009 (Human Fertilisation Embryology Authority, 2016a).

In most countries, gamete donation is regulated through licensed clinics. In such circumstances, the donor is not the legal parent, has no legal obligation to the child, will not be named on the birth certificate, will not have any rights over how the child is brought up and will not be required to support the child financially (Human Fertilisation Embryology Authority, 2016b). However, many other models exist and meeting a sperm donor or buying sperm directly on the Internet is a growing business. In many cases, this is done as a single transaction, although it can also be part of a co-parenting agreement, where parents who are not in a relationship work together to have a child (Jadva *et al.*, 2015).

## Donor recruitment

Regulation of oocyte and sperm donor recruitment varies greatly depending on the country; donors may be known or anonymous, paid or not paid. In the majority of countries, there is a limit to the number of families or offspring to whom the donor can contribute, which reduces the risk of consanguineous relationships. However, in countries such as the USA, where there are fewer legal restrictions, there are several recorded cases of sperm donors fathering large numbers of children (Matchan, 2011; Mroz, 2011; Harris, 2015). Sperm bought from sperm banks can be used in many countries. Although the bank must adhere to national guidelines restricting the number of offspring in one country, this can accumulate over several countries.

The move towards identifiable donors in many countries led to a change in the donor demographics. Historically, the majority of sperm donors were young students, especially medical students, who needed pocket money to help them through university, but the demographics have now shifted to older men in countries where anonymity has been removed (Van Den Broeck *et al.*, 2012). All donors should be adequately counselled about the implications of their donation.

Donations that are performed through a clinic ensure that the necessary medical checks are done; usually basic blood typing, rhesus status (positive or negative), screening for blood-borne viruses, sexually transmitted infections and common genetic disorders, such as cystic fibrosis (Dondorp *et al.*, 2014). Clinics also take a note of the donor's medical history, including their wider family. Donors should be followed up regularly to determine if there have been any changes in their medical information, but this practice is sadly not widespread.

There is a growing market for donor sperm, oocytes and embryos to be imported into different countries for use and, if this happens, the donation must comply with the laws and regulations of the country where they are imported. As well as gametes and embryos moving across borders, many individuals also travel to different countries for fertility treatments that may not be available in their country for legal or financial reasons or because there is a waiting list; this is termed Cross Border Reproduction Care (Shenfield *et al.*, 2011).

In the UK, approximately one-third of licensed sperm donation uses donor sperm imported from abroad, principally from Denmark and the USA (Human Fertilisation and Embryology Authority, 2014). These donors have to comply with UK legislation and will be identifiable to the donor-conceived offspring at 18 years of age. However, UK legislation only covers fertility clinics, and does not cover sperm sold DTC for self-insemination at home. There are no data on how prevalent this is, but Cryos International, the largest sperm bank in the world, recently stated that they receive daily requests from UK couples for anonymous sperm donations (Elmhurst, 2014).

## Donor anonymity

Prior to the introduction of government regulation of gamete donation, donor-conceived children had no way of finding out any information about their donor. Many countries now have regulatory bodies that store information about the donor and any resulting children, and oversee the provision of fertility services in both the private and public sector. However, globally there is much variability, both with regard to local regulations and the cultural values and expectations in which these legal frameworks are embedded. Overall, gamete donation is still mostly carried out using anonymous donors (for example, in countries such as the USA, Canada, Spain, France, Japan and China).

In 1984, Sweden was the first country to make donors non-anonymous. Several countries have since removed donor anonymity: Austria, Finland, Iceland, the Netherlands, Switzerland, UK, New Zealand and the Australian states of New South Wales, Victoria and Western Australia (Frith, 2001; Clark, 2012; Carr, 2015). Some countries, such as Denmark, allow both anonymous and non-anonymous donation. This was also the recommendation of the European Society for Human Reproduction and Embryology (ESHRE Task Force on Ethics and Law, 2002).

Whether a donor is anonymous or non-anonymous, in all situations, we have to rely on the parents telling their children that they were donor-conceived (Indekeu *et al.*, 2013). Although there is a growing trend for parents to disclose, the reported disclosure rates vary considerably. The sample sizes of the published studies are small, but it is clear that many donor-conceived children are not told of their origins (Brewaeys *et al.*, 2002, 2005; Lycett *et al.*, 2004, 2005; Readings *et al.*, 2011; Freeman and Golombok, 2012; Isaksson *et al.*, 2012; Sälevaara *et al.*, 2013; Blake *et al.*, 2014; Van Parys *et al.*, 2014). If told, the majority of children would like to trace their biological parent (Ilioi and Golombok, 2014).

Some of those who hold that anonymous gamete donation may be harmful for the offspring advocate for mandatory disclosure. In line with this, the new Children and Family Relationships Act (2015) in Ireland provides a national register where all donor-conceived children will be able to trace their donors, and will be informed of their donor-conceived status when they apply for a copy of their birth certificate. In effect, this makes disclosure mandatory, enabling all donor-conceived offspring to know their genetic origins, irrespective of whether or not they have been informed of their donor-conceived status by their parents.

## DTC genetic testing

There are a growing number of genetic tests that can be commissioned directly from the Internet without the involvement of a clinician. At the moment, these tests are taken up by people who wish to know about their ancestry and health or who have genetic curiosity, but such tests are increasingly being exploited by the donor-conceived community (Australian Broadcasting Corporation, 2015; Klotz, 2016).

Y chromosome testing has been available direct to the consumer since 2000. In most cultures, the transmission of the Y chromosome corresponds with the path of surnames. Consequently, a male can take a Y chromosome test to find matches with patrilineal relations and search for clues to the surname of his biological father. Information about the surname and geographical location of the match's most distant known ancestor is often provided and sometimes pedigree information is available. By triangulating these data with information gleaned from genealogical databases and other public records, it is sometimes possible to identify the donor. Identification is easier with rare surnames. The success rate is estimated to be low at between 12 and 18% in the USA (Gymrek *et al.*, 2013), but is likely to improve as the genetic genealogy databases grow in size. In 2005, a 15-year-old boy tracked down his father after taking a Y chromosome test with a commercial ancestry company. His father was not in the database but was identified through a match with another man sharing the same rare surname (Motluk, 2005). This is thought to be the first case of a donor-conceived

person tracking a relative through genetic testing. Other cases have since been reported (Lehmann-Haupt, 2010), but the number of success stories is unknown.

Family Tree DNA is now the only commercial company which offers a Y-DNA matching database. They have over 550 000 Y-DNA records in their global database, with representation from nearly 400 000 unique surnames. The company also hosts a Donor-Conceived Project. Family Tree DNA also sponsors Ysearch, a free publicly available Y-DNA database which is estimated to contain around 95 000 Y-DNA haplotypes (Gymrek *et al.*, 2013).

Autosomal DNA tests can be taken by both males and females to find matches with genetic cousins in DNA databases. 23andMe was the first company to launch such a test. They introduced a Relative Finder feature as an add on to their personal genome service in November 2009 (23andMe, 2009). The 23andMe test is now sold in 56 countries. Family Finder, a cousin-finding autosomal DNA test for the genealogy market, was introduced by Family Tree DNA in February 2010 and is sold internationally. AncestryDNA launched an autosomal DNA test for genealogists in the USA in May 2012. The AncestryDNA test became available in the UK, Ireland, Canada, Australia and New Zealand in 2015, and was launched in a further 29 countries in February 2016 (Murray, 2016).

The commercial cousin-finding tests genotype between 500 000 and 700 000 single-nucleotide polymorphisms (SNPs) scattered across the genome. Relationships can be predicted based on the amount of DNA shared, and the size and number of shared DNA segments. Customers are provided with a list of matches with their genetic cousins and a prediction of the relationship. The databases have grown rapidly as the cost of testing has decreased, which in turn adds to their consumer appeal. The Family Finder test and the AncestryDNA test now cost just $99 in the USA. The 23andMe test was sold for several years for $99, but the price was raised to $199 when FDA approval was received for the health reports in 2015. By September 2015, both 23andMe and AncestryDNA had genotyped over 1 million people (Kaiser, 2015). AncestryDNA now has the world's largest consumer DNA database. By February 2016, they had tested 1.5 million people, with 1 million of those tests being sold in 2015 alone (Ancestry.com, 2016; Sullivan, 2016).

Autosomal DNA tests are increasingly being used to solve unknown parentage cases for adoptees, foundlings and donor-conceived persons (Carless, 2014; Swayne, 2014; Williams, 2014). People are finding matches with half-siblings and even biological parents. However, identification is also possible if there is a match with another relative such as a first, second or third cousin. The genealogical information provided by the matches can be used in combination with the non-identifying information given to an adoptee or donor-conceived person to identify suitable candidates, even if the parent has not tested (Petrone, 2015). An individual is expected to have around 38 second cousins, 190 third cousins and 940 fourth cousins (Henn *et al.*, 2012), and relationships up to the second-cousin level can be detected with confidence (Huff *et al.*, 2011).

Borry *et al.* (2014) cautioned that healthcare professionals, potential parents and donors should be informed of the limits of privacy protection with the growth of the DTC market. They also recommended that DTC testing companies should alert their customers to the possibility of finding unexpected first-degree relatives in their databases. However, there seems to be little awareness in the fertility industry of the implications of DTC genetic testing. In the USA, where it is up to the donor to decide whether or not to release his identity, the fertility clinics and sperm banks do not educate their users about the possibility of discovery (Kramer, 2015). The Nuffield Council on Bioethics published a detailed report on donor conception and the ethical aspects of information sharing in 2013, but the possibilities of autosomal DNA testing were not discussed.

In the UK and USA, there are donor registries where donors and donor-conceived people can add their genetic information (and their donor numbers), so it can be linked in the database. The parents of donor-conceived children are also using these databases to search for their child's donor siblings (Freeman *et al.*, 2008). The Donor Sibling Registry in the USA provides a safe space for donors to connect with their offspring and for donor-conceived people to search for their half-siblings and donors. In the UK, results from DNA analysis are shared on the Donor Conceived Register and donors are encouraged to add their DNA to this database. Many people have found half-siblings and their donor using this method (Scheib and Ruby, 2008).

## Uncovering secrets

Genetic testing also has the potential to uncover secrets that were not disclosed either to the parents or the child. One such case has already come to light as a result of a family testing at 23andMe and receiving unexpected DNA results. Pam and John Branum's daughter, Annie, had been conceived by artificial insemination, supposedly using John's sperm, at Reproductive Medical Technologies, a fertility clinic in Salt Lake City, Utah. However, the 23andMe test results showed that Annie was not John's biological daughter. Annie had a match with a first cousin that was not shared with her mother. This led to the discovery that John's semen had been substituted with the semen of Thomas Lippert, an employee at the fertility clinic. It later transpired that Lippert was a regular sperm donor and could potentially be the father of many other children (Bonnici, 2014; Moore, 2014).

Unintended incestuous relationships might also be revealed as a result of DNA testing. There are known historical cases of fertility clinic owners who substituted their own sperm for that of the father, and sometimes fathered hundreds of children (Anonymous, 1992; Rawstorne, 2012). Although commercial DNA testing was not involved, one case has already been reported where a husband and wife, both of whom were the product of sperm donation, discovered that they shared the same father (Yoffe, 2013). We anticipate that in the near future, increased uptake of both commercial and clinical genetic testing will lead to many more instances of people discovering unexpected new information about their genetic background.

## Discussion

Sperm donation has been described as a human experiment carried out without the consent of the unborn offspring. Announcing the end of donor anonymity in regulated clinics in the UK, the Minister for Health, Melanie Johnson MP, said: 'Donor-conceived children do not decide to be born—is it therefore right that access to information about the donation that led to their birth should be denied to them?' (Udoh, 2015). This policy change grew out of an emphasis on the rights of the child, coupled with increased awareness of the harmful effects on children who were unable to trace their donor parent.

Although robust data are lacking, it is likely that a large number, perhaps even the majority, of donor-conceived offspring are not informed by their parents of their donor-conceived status. Parents report a number of different reasons for this, including not wanting to feel estranged from their child, and the prospect of a third party entering into the family unit in some way (Golombok *et al.*, 2013). Concerns have also been raised by parents who worry about the effect on the child of knowing that they are donor-conceived. Whilst there is robust evidence showing that early disclosure often does not lead to detrimental outcomes (Blake *et al.*, 2014), these worries persist, and in many cases lead parents to withhold vital information from their offspring.

It is currently impossible to say what percentage of parents disclose. Despite the good intentions on behalf of politicians and regulators, there is no evidence that the removal of anonymity in the UK in 2005 has led to an increase in parental disclosure. Yet, with the rapid spread of genomic testing, this might change in the near future. The genetic genealogy databases have already reached critical mass in the USA, and can be expected to grow considerably in the next few years in Europe and Australasia.

There has been a significant growth in government-sponsored genomic programmes (Kaiser, 2015). The Harvard-based Personal Genome Project, started in 2005, aims to sequence and publicize the complete genomes and medical records of 100 000 volunteers (Angrist, 2009). It is currently accepting submissions from the USA, Canada and the UK. There are two large UK initiatives: the 100 000 Genomes Project, which will sequence the genomes of NHS patients with cancer and rare diseases (Marx, 2015), and UK Biobank, which is linking genetic data with healthcare records for over half a million people (Sudlow *et al.*, 2015). At the same time, as these large-scale cohort studies are getting under way, there are concerted efforts, both within the scientific community and in society at large, to foster greater openness about genomic data. These developments indicate that, in the near future, many more healthcare clients are going to know information about their genomes. These developments will likely have a profound influence on decision-making around gamete donation, donor anonymity and parental disclosure (Greenfeld, 2008).

Non-invasive prenatal testing has the potential of being applied to all pregnant women. A blood sample is taken from the mother at 10 weeks of pregnancy and next-generation sequencing is used to detect aneuploidy (Chitty and Bianchi, 2015). As technology advances, it is probable that all children will be born knowing their genetic code.

Parents using donor conception need to be fully informed that their children's DNA will identify that they are not the biological parents. Furthermore, they should be encouraged to disclose the use of donor gametes to their children. If this is done early on in the child's life, there is every likelihood that this will not be perceived as traumatic for the child (Blake *et al.*, 2014).

The same is also true for the donors themselves. Whether they are donating in a country that uses anonymous donation or not, donors should be informed that their anonymity is not guaranteed. They may be traced if their DNA, or that of a relative, is added to a database. There will also need to be consideration of any children that a donor might have, as they might find out their parent was a donor from such publicly available information.

Together, these concerns highlight the importance of a wide-ranging societal conversation about how to best safeguard and promote the interests of donor-conceived offspring and protect the rights of donors. Specifically, there is a need to ensure that new genetic information is communicated in a way that promotes both the safety and privacy needs of offspring and donors.

Finally, fertility clinics will need to develop robust guidelines and procedures that enable them to integrate subsequent genomic data into their existing consent agreements. At present, it is not clear whether and how information would be passed on to any offspring at risk, if a historical donor found out they carried a risk mutation and contacted the clinic to inform them. The child in this case has a right to know they are at risk, but if the parents have not disclosed to the child that they are donor-conceived, the information is unlikely to be made available to them. As the current legislation is set up with the paramount importance of the welfare of the child, this is an untenable situation.

In conclusion, the spread of genomic testing is likely to make anonymous gamete donation and parental non-disclosure highly problematic. The likelihood is that such testing will change the way fertility clinics, as well as the general public, perceive the acceptability of non-disclosure.

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All authors have contributed equally to the conception and writing of the manuscript.

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None declared.

## Appendix: useful websites and resources

### Websites

www.donorchildren.com (22 March 2016, date last accessed), Donor Children community.

www.donorconceivedregister.org.uk (22 March 2016, date last accessed), The UK Donor Conceived Register.

www.donorkinderen.com (22 March 2016, date last accessed), Belgian support group.

www.donorsiblingregistry.com (22 March 2016, date last accessed), Donor Sibling Registry.

www.facebook.com/donorchildren (22 March 2016, date last accessed), Donor Children Facebook group.

www.facebook.com/groups/DNADetectives (22 March 2016, date last accessed), DNA Detectives Facebook group.

www.familytreedna.com/groups/donor-conceived (22 March 2016, date last accessed), The Donor-Conceived Project at Family Tree DNA.

www.idoalliance.org (22 March 2016, date last accessed), International Donor Offspring alliance.

www.isogg.org (22 March 2016, date last accessed), International Society for Genetic Genealogy. A volunteer-run organization which provides advice and information on DNA testing.

www.searchingformyspermdonorfather.org (22 March 2016, date last accessed), An international website for people searching for their sperm donor father.

www.spenderkinder.de (22 March 2016, date last accessed), A support group for donor children in Germany.

### Blogs

http://cryokidconfessions.blogspot.com (22 March 2016, date last accessed), Lindsay Greenawait. Confessions of a Cryokid.

http://lippertschildren.blogspot.co.uk (22 March 2016, date last accessed), Was your child fathered by Thomas Lippert? An informational site for the 'victims' of sperm donor Thomas Lippert.

https://oliviasview.wordpress.com (22 March 2016, date last accessed), Olivia's view. A blog from one of the co-founders of the Donor Conception Network.

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