

*Accessing Origins Information
The Implications of Direct-to-Consumer Genetic
Testing for Donor-Conceived People and Formal
Regulation in the United Kingdom*

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1.1 Introduction

Recent years have seen a growing number of jurisdictions move to prospectively mandate the release of identifying donor information, usually at the age of majority (Allan, 2016; Blyth and Frith, 2015). The only jurisdiction that has currently legislated for this retrospectively is the State of Victoria, Australia (in 2016) though South Australia may follow with the proposed Assisted Reproductive Treatment (Donor Conception Register) Amendment Bill 2021.

Crucially, donor-conceived people (DCP) can only request identifying information through officially regulated systems such as the UK's Human Fertilisation and Embryology Authority (HFEA) Register if they are aware of their donor-conceived origins. The decision about whether to inform a DCP of their origins typically rests with parents, as most governments have been reluctant to mandate disclosure (Ishii and de Miguel Beriain, 2022; Adams, 2021). The HFEA Register is required by law to record, among other information, details of all donor-conception treatments that have taken place in UK licensed treatment centres since 1991 and information about donors and recipients.

There are two parallel developments that have resulted in a growing role for information systems outside of the formal regulation of donor conception. First, more people – including DCP – are using direct-to-consumer genetic testing (DTCGT) to find out about, and connect with, relatives or are being found by such relatives. Second, the use of 'informal' donation is increasing. People can find sperm donors on the Internet and make their own arrangements for insemination rather than using fertility clinics or gamete banks. Such donors are consequently known to the parent(s).

However, it is not yet clear how far this translates into DCP being aware of their donor-conceived origins, or able to access information about their parent's donor.

These expanded possibilities for finding genetic relatives and extended family regardless of legislative measures are producing new landscapes where different systems of information provision collide and interact. In turn these create new spaces of sociality, new possibilities for interacting with donor relatives, and consequently new ways for self-determination and identity construction.

In this chapter, our focus is on the impact of DTCTGT on DCP, the group arguably most affected by existing donor conception policy and regulatory frameworks but whose influence has, until recently, been limited. We will discuss the implications for DCP of information about their genetic relations being located predominantly within two very different systems: publicly funded information-release systems (using examples from the UK, the HFEA Register and UK Donor Conceived Register, as case studies); and digital online systems, such as DTCTGT, ancestry sites and internet groups. We will consider how pre-existing informal and formal power structures, relationships and cultural norms are being affected by DTCTGT, focusing on DCP's rights to access information about their conception. We will argue that the prevalence of DTCTGT is enabling the circumvention of existing policies and practices regarding donor conception. Consequently, the control of information by parents, legislators and fertility treatment providers has not only been eroded but is increasingly shifting to DCP themselves.

1.2 The Official Route to Accessing Information: Publicly Funded Donor Conception Registers

There are donor conception registers in a number of jurisdictions, including Ireland, Finland, the Netherlands, New Zealand, Norway, Croatia and the Australian states of Victoria, New South Wales and Western Australia.

1.2.1 The Human Fertilisation and Embryology Authority (HFEA) Register

In the UK, the HFEA regulates all licensed fertility treatments and is responsible for any associated information release systems. Anyone conceived with donated gametes in a licensed clinic after 1 August 1991 has a legal right to approach the HFEA for non-identifying information about their donor from the age of sixteen, or to ask if anyone to whom they

are married, or with whom they have a civil partnership, or an actual or intended intimate relationship was conceived with the same donor. Those conceived after 1 April 2005 have the right to identifying information from the age of eighteen. They can also receive identifying information about donor-related siblings but only if both parties have registered their agreement. Donors who donated prior to the law change lifting donor anonymity in 2005¹ have the right to re-register as an identifiable donor. There is no charge for these services and a limited amount of free counselling is available to DCP aged sixteen and over and donors approaching the HFEA.

DCP conceived between 1991 and 2005 whose donor has not re-registered can only access non-identifying information as the law change was not retrospective. Recipient parents can request non-identifying information about their donor and their child(ren)'s donor-related siblings until their child's eighteenth birthday. Donors can request information at any stage about the number, gender and year of birth of anyone born as a result of their donation. In the UK, for surrogacy arrangements through licensed centres the rules relating to any gamete donor (where one is used) remain as above.

It is a criminal offence for the HFEA or a licensed clinic to release identifiable information unless it falls within the parameters described above. This means that any such information provided by the donor must be redacted by the clinic or the HFEA until the DCP reaches the age of eighteen, regardless of the donor's wishes. There are concerns that this requirement can inhibit donors in what they write for their pen portraits. These pen portraits are meant to provide non-identifying information about the donor, such as their interests, hobbies and so on. However, if the clinic staff advising them on the drafting of these are driven more by fear of reprisals than by understanding the potential later significance of such information for DCP, these pen portraits may provide little information or the space on the form left blank. There have also been reports of inconsistencies in the amounts and types of information collected, linked to limited understanding of its significance for DCP and/or varied views about the responsibilities of clinics to collect it (Crawshaw and Dally, 2012). Although UK donors can update their information at any time, it is not known how many donors are made aware of this at the time of donation nor how many actually do so. Further, the Register is not open

¹ Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004.

to non-DC offspring of donors, nor to descendants of the donor or of the DCP. The threat of criminal sanction has also meant the use of strict restrictions on what information, for example on heritable conditions, can be passed between the parties.

1.2.2 UK Donor Conceived Register (DCR)

Anyone conceived prior to August 1991 (i.e. prior to UK legislation) can join the voluntary Donor Conceived Register (DCR) (previously the government-funded UK DonorLink Register and now funded by the HFEA) for DCP, donors and their non-DC offspring. The register uses a DNA database of its registrants as its main source of 'matching' DCP, donors and donor-related siblings. There is no registration charge, and a limited amount of free counselling is available, but the DNA tests incur a charge. While the type of paternity and maternity testing using this DNA database can produce definitive results, it is less reliable than DTCGT companies for determining sibling-ship and can produce false positives and false negatives (Adams and Lorbach, 2012). The authors are aware of growing numbers of DCR registrants who are also using DTCGT to search for donor relatives.

1.3 The Unofficial Route to Accessing Information: Direct-to-Consumer Genetic Testing (DTCGT)

DTCGT companies are marketed as ways for people to find information about their ancestors or their health. In 2017, they were among the fastest growing businesses in the world and more people tested that year than in all preceding years combined. Extensive advertising and a drop in costs make them easily accessible. The prevalence of DTCGT, in addition to other resources such as social media, means that DCP may discover the identity of the donor or donor relatives and could also unexpectedly learn of their origins as a result of them or genetic relatives previously unknown to them undertaking DTCGT (Ishii and de Miguel Beriain, 2022; Crawshaw 2018). This can happen even if the donor has not had their DNA tested themselves, as if one of the donor's genetic relatives is on the database this can produce a match. This will likely become more prevalent as greater numbers continue to join these databases. While numbers stood at 3 million in total in 2016, by 2021 the international databases of 23andMe had over 12 million; Ancestry had over 20 million; FamilyTreeDNA had over 1.7 million; and MyHeritage had over 5 million (O'Brien, 2021). Subsequently,

this led to McGovern and Schlaff (2018) concluding that a donor's anonymity and privacy can no longer be guaranteed, a conclusion with which we agree (Darroch & Smith, 2021).

The growth of commercial DNA testing has been accompanied by an increased use of internet-based forums to help interpret results, undertake genealogy tracing and/or come to terms with unexpected results (Moore, 2016). The International Society of Genetic Genealogists has set up dedicated webpages (see ISOGG, 2021) with guides for DCP and donors (developed with their input) on what to consider ahead of searching and/or making contact. Groups have also been set up to help with tracing relatives and one of the largest, DNA Detectives (Facebook), has a membership of over 178,000 and its offshoot, DNA for the Donor-Conceived (DNA Detectives), has over 2,800 members.

In response to the increased use of DTCGT, in 2018 the HFEA alerted all UK licensed treatment clinics to the need to provide information routinely to actual and prospective donors and parents about the likelihood of being traced. In 2019, it incorporated this into its Code of Practice and reported some progress in their attempts to ensure DTCGT companies make potential customers aware of possible unintended consequences of testing and where to seek support (HFEA, 2019).

1.4 The Right to Know and the Right to Choose

In this section, we will examine the cultural norms and arguments which underpin the shifting policy landscape in donor conception, particularly the move to identity-release donation in the UK and internationally. We will discuss rights-based arguments, which have been influential, concerning DCP's 'right to know' the identity of their genetic parents (the donor/s) and DCP' agency over accessing (or not) this information.

Whilst in previous decades, debates about the ethics of donor-conception practices often centred on questions of harm or welfare, more recent debates on information sharing in donor conception have increasingly used a rights-based logic (Frith, 2001; Johns, 2013; Tobin, 2012). Although some bioethicists have invoked the 'right to privacy' (of both recipient parents and donors) to argue against policies of openness (Ravelingien and Pennings, 2013), the rights of the DCP to know about their conception or the identity of the donor have been argued to be paramount (Ravitsky, 2017; Frith, 2001a). Rights-based approaches to openness typically cite human rights conventions, especially Article Eight of the European Convention on Human Rights, the right to respect for family life and Article Seven of

the United Nations Convention on the Rights of the Child (UNCRC), which describes the right to know one's parents (Blyth and Farrand, 2004; Council of Europe, 2019). This, in turn, is part of the wider cultural shift to give more prominence to children's rights and voices and the UNCRC thus has significant rhetorical value.

Klotz's (2014) work discusses how a recognition of DCP's rights are enacted in the UK, through the policies of the HFEA. Her analysis demonstrates how the HFEA manages the potentially profound implications that knowledge about genetic relatives may have for DCP through a principle of assigning agency to DCP in choosing whether and when to access this information. The HFEA emphasises the importance of supporting informed decision-making for any DCP approaching its Register. They describe it as a 'big decision' with potentially profound emotional consequences, which should be thought about carefully, and ideally with the support of a counsellor (Gilman and Nordqvist, 2018). Such statements convey both the perceived implications of donor information for identity and relationships but also the principle that the choice to access this information should belong to DCP themselves. The attempt to manage the implications of donor information through the model of individual informed choice is also reflected in the UK debates which preceded the introduction of identity-release donation. Melanie Johnson, then Public Health Minister, explained it thus:

The regulations do not force access to information on donor-conceived people. Instead, they give them the option of choosing to obtain access to information about their origins. Some may choose not to use the option at all; others may want only the non-identifying information. For others, however, the identifying information will be very important.²

However, what both rights-based arguments against donor anonymity and the HFEA's emphasis on informed choice fail to address is that DCP have not been given the right to be told that they are donor conceived, a necessary precursor to being able to exercise choice about accessing information (Frith, 2001). Even with improved campaigns to inform parents of the benefits of disclosing to their children such as 'Time to Tell' in the state of Victoria, Australia, only 11 per cent of adult DCP in a small sample from that state were informed of their origins (Bourne et al., 2018). In a recent international online survey, the majority of those conceived prior to the 2000s and 40 per cent of those conceived in the 2000s, had not been told (WADC, 2020). Such findings are reflected in the meta-analysis of

² Human Fertilisation and Embryology Authority (Disclosure of Donor Information) Regulations 2004 Deb 18 May 2004 c.5.

parental intent to tell by Tallandini et al. (2016). Hence, even though there has been an increasing trend to openness and disclosure, there is still a significant proportion of DCP that are not being informed of their origins.

A number of DCP have pointed to the importance of an 'ethic of openness' between recipient parents and DCP. The reasons given by parents for withholding information can be manifold and complex (Crawshaw and Daniels, 2019). Regardless of the reasons, it can be argued that secrecy conflicts with being a virtuous parent (Adams, 2013), defined as a parent who sees the child's welfare as paramount and in this context truthfulness about donor conception from a young age is important for the child's welfare, to prevent or reduce possible trauma and facilitate the flourishing of the child. A participant in a UK study, on registrants of the UK DonorLink, which is now the DCR, whose mother withheld information from her in order to 'protect' her (infertile) husband stated:

When I probed my mum as to why she didn't tell me as a child, she has always been hazy. She claims that if I had known as a child, I may have been mean to my father about it and not respected him. The most painful thing is this ... to think that she wanted to protect him more than me. Had I been in her position I would have put my child first. (Frith et al., 2018, p. 9)

While the earlier decision in the UK to leave the disclosure decision with parents was not unusual across other jurisdictions, it remained in place even after legislative changes in 2008 stating that clinics must provide recipient parents with information about the importance of informing children of their origins at an early age (HFEA, 2019). This is perhaps reflective of wider family policy that views parents as the ones who should decide the best interests of their children except where there are safeguarding concerns. Recently, the UK Birth Registration Reform Group (BRRG) concluded that the approach to disclosure following the lifting of donor anonymity has failed to realise Parliament's intention to enable all DCP to grow up being aware of their origins. David Gollancz, a BRRG member and DCP, argued that there is an urgent need for changes to the birth registration system to provide an 'official' route to enable DCP to be made aware they are donor conceived (Gollancz, 2020).

1.5 Donor-Conceived People's Voices – The Role of DTCGT

As the Internet and DTCGT break down the potential barriers of formal, regulated access to information about donor relatives and enable the development of virtual communities of DCP, debates about 'geneticisation'

and 'choice' are increasingly informed by the views and experiences of DCP themselves. This includes international activist and support groups such as We are Donor Conceived, Worldwide Donor Conceived People Network, US Donor Conceived Council and Anonymous Us. Although DCP have been written about – and positioned – as the 'subjects' of research, they have recently found a more direct platform for their voices through the 'grey' literature, online and in media outlets. Activism among DCP, parents and advocates has been growing since the 1990s. In the UK it made donor anonymity a matter for public debate and discussion, culminating in the lifting of donor anonymity (Wincott and Crawshaw, 2006). This included a legal challenge to donor anonymity under the Human Rights Act 1998 (Frith, 2015).³ All such actions are in keeping with the principles of Participation, Accountability, Non-discrimination, Empowerment and Legality (PANEL) used in human rights approaches more generally (www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf).

Academic literature was initially geared heavily towards reporting the views and experiences of recipient parents and professionals. As recently as 2012, a review of research directly with donor-conceived children and/or adults, found only thirteen studies, with more than half published since 2008 (Blyth et al., 2012). Interestingly, a common finding was that some DCP considered it their right to have access to information, regardless of whether it carried significance for them at the time. There was also evidence of the frustration and distress of those unable to access the information they wanted and the negative impact on their well-being when disclosure of their origins occurred after childhood and/or in an unplanned way (Frith et al., 2018). DTCGT offers an alternative route to accessing information.

The right to choose and exercise choice based on adequate information have become increasingly important to DCP. Reports from online DCP communities suggest that growing numbers are exercising a 'choice' to use DTCGT to connect with donor relatives, including those for whom this would not be possible through formal routes. The yearly 'We Are Donor Conceived' survey, provides some indication of the extent of the use of DTCGT. Participation in the survey grew from 82 responses in 2017, to 481 responses in 2020, with the percentage of respondents reporting that they had undertaken DTCGT

³ *Rose and Another v. Secretary of State for Health and Human Fertilisation and Embryology Authority*, 2002.

growing from 76 per cent to 95 per cent (WADC, 2017, 2020). In the 2020 survey, 34 per cent had learnt that they were DCP as a result of taking a DTCGT test; 78 per cent had identified their genetic parent through DTCGT and only 4 per cent had done so through an official registry. That said, it is important to acknowledge that some respondents had failed – yet – to identify their donor (22 per cent) or donor siblings (30 per cent). In addition, the findings highlighted that 5 per cent of respondents had identified more than fifty siblings and 79 per cent had between one and ten siblings (WADC, 2020). We return to this below. Perhaps the key feature of DTCGT for DCP is that it provides an avenue of investigation that they can choose themselves and hence control.

1.6 Some Challenges Raised by DTCGT for DCP

Using DTCGT offers new possibilities for finding donor relatives but also throws up complex challenges. Through the use of DTCGT growing numbers of DCP are finding out that they are donor conceived for the first time. These DCP are sometimes described as ‘late discoverees’ and learning of one’s origins in this way has been found to be traumatic for some (Adams, 2013; Dingle 2021). A report in 2019 recounts one woman’s story of receiving an Ancestry testing kit for Christmas. It revealed that her father was not her genetic father. When she talked about this to her parents, they had no idea that a sperm donor had been used during their fertility treatment (Cooke, 2019). In the same year, the story broke of a man and woman dating each other who learnt that they were donor-related siblings after receiving 23andMe kits as Christmas presents (Ojomu, 2019). Such discoveries are not unique to DCP: one recent survey with people using DTCGT reported that 61 per cent found something new about themselves or their relatives, including finding that one parent was not their biological parent or that they had unknown siblings (Guerrini et al., 2022).

In other situations, some DCP have found out that the donor was in fact the treating doctor (Huffman and Smith, 2021). Increasing accounts of doctors using their own sperm to treat their patients has led to the introduction of legislation prohibiting and penalising such practices in the states of Indiana and Texas, for example (Fox et al., 2019).

DTCGT is also increasing the likelihood of connecting to larger numbers of donor-related siblings than has been reported through formal registers and this may be psychologically challenging (Indekeu et al., 2021).

US photographer Eli Baden-Lasar describes the complexity of being part of a large sibling group in a *New York Times* article:

Looking through the camera, I had a feeling I couldn't shake: that these people were all versions of me, just formed in different parts of the country – but were also strangers who might as well have been picked out of a hat. (Peterson, 2019)

Crawshaw (2018) described the experiences of three DCP in their fifties and sixties, all connected as a result of their adult children undertaking DTCGT for health-related reasons. All three learnt the donor's identity and that they had fifteen other donor-related siblings (a number that has now risen to more than fifty). Instead of parents considering whether to be open with their DCP children, DTCGT has turned the question on its head. It is now adult children who can be left with the decision about whether to inform their parents what they have uncovered, decisions that can expose family secrets with all the ensuing emotional and relationship repercussions.

In certain circumstances, DTCGT appears to increase the agency of DCP by giving them the option to choose whether and when to search and/or connect with donor relatives. Research with DCP confirms that using DTCGT can be experienced as empowering, particularly in the context of late or shock discoveries of being donor-conceived. This empowerment is in a context where seeking information in other ways is often unavailable, or limited (i.e. by age restrictions), or dependent on the person's date and place of conception, or involves going through slow and bureaucratic 'official' channels or gatekeepers such as clinics (Klotz, 2016). However, not all DCP who use DTCGT to search will find donor relatives, as reported earlier. Even if they find donor-related siblings, they may well not know if they have identified all their siblings, especially if they have no access to official or clinical records, if the clinic has kept inaccurate records, if the donor's samples were transported to other clinics, if the donor donated at other clinics or if they have offspring through other routes. Of those notified of a potential 'match' through DTCGT some may find that person uncontactable, unwilling to communicate further or even disbelieving of the genetic connection between them. As 'relationship pioneers', DCP are having to investigate and manage connections to relatives they previously did not know existed and navigate what may be very emotionally and psychologically sensitive issues with these new connections (Hertz and Nelson, 2018).

1.7 Donor-Conceived People's Voices – Taking Control

Both recipient parents and fertility health professionals have been found at times to display complex and/or contradictory attitudes towards the significance of genetic relationships and whether genetic knowledge is 'constitutive' of kinship and identity regardless of legislative intent about promoting early disclosure (Crawshaw and Daniels, 2019). These can be enacted within power relations between service providers and recipients in the formative treatment stages, for example with the service provider offering 'reassurance' that the donor's genes will carry little influence on the resulting child while attempting to match donors with the intended parents. Recipient parents may opt for donor conception rather than adoption in order for at least one parent to have a genetic link with the child (Daniels, 2004) and can later highlight perceived physical and trait resemblances to themselves or extended family members rather than acknowledging the possibility of such resemblances to their donor (Isakkson et al., 2019), suggesting the enduring social value of a genetic link. This may also help explain the finding that some recipient parents employ cognitive dissonance, the suspension of prior beliefs about the significance of genetics or views about the nature–nurture debate, as part of entering donor-conception treatment and later when not responding to their child's interest in knowing more about the donor or donor-related siblings (Van den Akker, 2010). Some parents 'choose' to present their family as genetically 'intact' to the outside world, sometimes going to great lengths to do so, seeing genetics as important in one context, yet minimising its importance when seeking to keep donor conception secret from their child (Frith et al., 2018).

Better understanding is needed about how DCP themselves perceive the significance of genetics, including the extent to which they see genetic knowledge as 'constitutive' (Strathern, 1999) of kinship and identity and how much this drives their desire for information/contact with the donor and donor-related siblings. DCP have identified the importance of the donor's biography, including their interests, lifestyle, education history and reasons for donating, rather than physical and medical information alone (Blyth et al., 2012). Some wish to know the identity of, and meet, donor-related siblings as well as the donor (Jadva et al., 2010). The donor and donor-related siblings are seen as carrying potentially different genetic significance for the DCP's identity given that donor-related siblings are affected by their non-donor parent and upbringing as well as by their sharing of genes with the donor (Indekeu and Hens, 2019). Some DCP report

feeling an immediate connection on meeting donor-related siblings, but others do not. Some find it difficult to adjust to the realisation that they are genetically disconnected from people whom they thought were genetic relatives (i.e. the non-genetic parent and their extended family), following late or accidental disclosure (for narrative accounts see Shapiro, 2019 and Dingle, 2021). That said, although many DCP embrace the ethic of openness and their right to information, DCP may also be wary of seeking out their donor or donor-related siblings due to concerns that this might disrupt existing kinship relationships (Adams and Lorbach, 2012).

DCP's growing public voices make it clear that they are deciding for themselves the significance of their origins and its repercussions rather than having it ascribed to them by others. In November 2019, DCP and surrogate-born people presented at a United Nations event to mark the 30th anniversary of the UN Convention on the Rights of the Child. They concluded: 'We are the products of this industry, and we have not been heard ... We are now grown, and our voices are stronger. We know what is in our best interests and what is not, and we hope you are listening.' Their recommendations for national and international measures, based on consultation with a broad representation of DC and surrogacy-born persons, stressed the importance of access to information about their donor-conceived relatives (www.donorkinderen.com/united-nations-2019; <https://youtu.be/GEP3ZGPFdeQ>).

1.8 Conclusion

Increasing use and accessibility of DTCTGT is undermining existing policies and practices in donor conception, thereby removing the ability of parents, legislators and fertility treatment providers to dictate what information DCP are able to access about their genetic donor relatives and when and how they are able to access this information. DCP are using DTCTGT to take control over accessing information about donor relatives, deciding for themselves if, and when, such knowledge is important to them. Thus, there is a need for more research into the needs and experiences of DCP and their networks on the impact of DTCTGT.⁴ However, while the regulatory frameworks may be increasingly unfit for purpose as they currently stand, they are not completely redundant as central registers, such as the HFEA Register provide – for some DCP if born in the right place at the

⁴ Frith and Gilman are undertaking research in this area; see: <https://sites.manchester.ac.uk/connecte-d-n-a/>

right time – a way of having guaranteed access to certain types of information. Such registers may also provide services such as specialist counselling or other support, although this is not always guaranteed.

While DTCGT potentially offers DCP a route to realising ‘the right to know’ and ‘the right to choose’ in relation to locating information about and/or contact with finding donor relatives when ‘official’ options are limited or non-existent, choice needs to be seen in its socially constituted context. In the context of wider policies and practices around donor conception, the concept of ‘informed choice’ in relation to DTCGT as well as to any ‘official’ options rings hollow. DCP’s choices are limited by gatekeeping by parents and/or fertility providers, national laws, family and social obligations and perceptions of how this will affect existing relationships. Choices can also be affected by available levels of support be that from peers, family or professional counselling. Neither fertility clinics, commercial DNA companies nor state bodies see this as their ethical or social responsibility to provide funding for professional support to help DCP navigate the potentially challenging and complex process of searching and connecting. DCP and donors have made it clear that they should not have to foot the bill, and funded professional support, such as counselling, should be more generally available (Crawshaw et al., 2016).

Reform of present-day practices in the fertility industry, regulatory bodies and legislative structures to ensure meaningful choice for DCPs could include: requiring central record-keeping; collecting good quality biographical donor information and having robust updating processes; greater flexibility about age limits on information access – a measure that has been mentioned by Peter Thompson, the chief executive of the HFEA, in a newspaper article (*The Guardian*, 2022); and the provision of ongoing professional support to families and to DCP; and the provision of educational campaigns and support services to assist recipient parents in being open with their children about their origins. Options such as birth registration reform have also been proposed by the BRRG, which could go some way to operationalising the original intent of the UK’s Parliament to enable all DCP to grow up aware of their donor-conceived origins.

If parents are not made aware of the power of DTCGT to unravel their secrets, their ability to control the manner in which this information is made available to their child is removed (Kirkham-Brown et al., 2022). In sum, DTCGT testing can be both a benefit and burden to DCP and their families and it is important that all parties are well informed about

these new technologies and the implications they can have for all involved in donor conception both directly (i.e. donors, DCP, recipient parents) and indirectly (i.e. their extended families and networks and subsequent generations).

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