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ARTICLE

Direct-to-consumer genetic testing and the changing landscape of gamete donor conception: key issues for practitioners and stakeholders

BIOGRAPHY

Lucy Frith is Reader in Bioethics and Social Science at the Centre for Social Ethics and Policy, University of Manchester. Her research focuses on the social and ethical aspects of healthcare practice and policy, with a long-standing interest in the social and ethical aspects of reproductive technologies.

Q1 Leah Gilman[a], Caroline Redhead[b], Nicky Hudson[c], Marie Fox[d], Petra Nordqvist[e], Fiona MacCallum[f], Jackson Kirkman-Brown[g], Lucy Frith[b,*]

KEY MESSAGE

Direct-to-consumer genetic-testing is shifting how knowledge about donor conception is accessed and managed, increasing flexibility regarding age of access to information, creating new gate-keeping roles and accentuating the effect of donor conception on wider extended family. Support and information are needed for all those affected by these changes.

ABSTRACT

Research question: What effect does direct-to-consumer genetic testing (DTCGT) have on information finding and sharing in relation to gamete donor conception?

Design: This study used in-depth qualitative interviews with parents through donor conception, donors, the relatives of donors and donor-conceived people who have used, or considered using, DTCGT. Interviews were conducted between September 2021 and February 2023. Sixty people defined themselves as having been affected by donor conception and DTCGT. Fifty-seven of these were resident in the UK at the time of interview. The final sample included 19 (spermatozoa, egg or embryo) donors, 25 donor-conceived people, 20 parents through donor conception and two relatives of donors. Five participants occupied more than one of these roles.

Results: The rise of DTCGT is affecting how information about donor conception is managed: it shifts patterns of knowledge about donor conception; increases flexibility regarding the age of access to information about donor relatives; can lead to a growing role for non-professionals, including wider family members, in gatekeeping information about donor conception; accentuates the effect of donor conception for donors' and the relatives of donor-conceived people; and shapes, and is shaped, by the formal regulatory donor information management systems.

Conclusion: Fertility professionals should inform people using, or considering, donor conception, or (potential) donors, about the different ways DTCGT can affect sharing information about donor conception. Support is needed for those affected by these changes.

[a] Department of Sociological Studies, University of Sheffield, UK.
[b] Centre for Social Ethics and Policy, University of Manchester, UK.
[c] Centre for Reproduction Research - De Montfort, University, UK.
[d] Law School, University of Liverpool, UK.
[e] Department of Sociology, University of Manchester, UK.
[f] Department of Psychology, University of Warwick, UK.
[g] Institute of Metabolism and Systems Research, University of Birmingham, UK.

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*Corresponding author. E-mail address: Lucy.frith@manchester.ac.uk (L. Frith). https://doi.org/10.1016/j.rbmo.2023.103421
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INTRODUCTION

It has been argued that the increasing popularity of direct-to-consumer genetic testing (DTCGT), and its use as a tool to connect genetic relatives, will lead to the end of gamete donor anonymity (*Harper et al., 2016*; *Darroch and Smith, 2021*). Although this is certainly the case for some individuals, in this paper we argue that the implications of DTCGT in relation to donor conception are more varied and multi-faceted than such rhetoric might imply. Drawing on data collected as part of the UK-based ConnecteDNA study, which included interviews with donor-conceived people, parents through donor conception, donors and the relatives of donors, we highlight five key ways in which DTCGT use is changing the landscape in which donor conception is experienced and, specifically, how it affects the management of information about donor conception. Finally, we discuss the implications of these changes for fertility professionals and other stakeholders.

Direct-to-consumer genetic testing is changing the way information about donor conception is accessed and managed by parents, dojnors and donor-conceived people, as well as their relatives and extended family. It has the potential to circumvent regulatory structures and has important implications for professional practice in terms of what information is provided during pre-treatment and pre-donation counselling and the longer-term repercussions of forming families using gamete donation. The recent Human Fertilisation and Embryology Authority (HFEA) consultation in 2023 highlighted DTCGT as a significant development with the potential to have substantial implications for donor conception:

'The issue of accessing donor information and identifying donors has become more urgent with the growing popularity of easily accessible, relatively affordable direct-to-consumer DNA testing and matching services which have revolutionised our ability to find our genetic relatives. . .. Our proposals seek to provide patients and donors with options that recognise this changed situation.' (*HFEA, 2023*)

The European Society of Human Reproduction and Embryology (ESHRE) guidelines 'Good practice recommendations for information provision for those involved in reproductive donation' point to the important implications of DTCGT for donor conception (*Kirkman-Brown et al., 2022*). The study presented here is the first to investigate DTCGT use with donors, donor-conceived people, parents through donor conception and other relatives, and provides new insights that can be used to inform regulatory responses and practice in fertility clinics.

The rise of direct-to-consumer genetic testing

Direct-to-consumer genetic testing is a rapidly expanding industry. The global market was estimated at US$1.1 billion in 2022 and is projected to grow to US$3.2 billion by 2030. (*Global Industry Analysts, 2023*). The US dominates the global market (*Global Industry Analysts, 2023*); however, the DTCGT market is also growing rapidly in European and East Asian countries, particularly China (*Zhu, 2022*) and Japan (*Nagai et al., 2023*). *AncestryDNA* launched first in the USA in 2012, expanding to the UK and Ireland in 2015. According to their website, they now have a database of 30 million people with over 4 million people estimated to have taken a DTCGT in the UK (*PRNewswire, 2019*; *Ancestry, 2023*). Another popular DNA testing site is *23andMe*, which offers health and relative finding services.

The DTCGT services are often marketed as self-discovery products, enabling customers to find out more about their ancestry, family history or health risks. Many DTCGT platforms also enable their customers to match with genetic relatives also registered on their database. On some sites, such as *Ancestry.com*, these are cross referenced with 'traditional' ancestry data, such as parish records and census data, to find both historic and current relatives. Most companies use autosomal DNA testing that can identify matches up to second cousins and beyond, with decreasing degrees of certainty.

The growth in the use of DTCGT is having a significant effect on practices and relationships in sperm and egg and embryo donation. This has prompted a flurry of articles pointing out the implications of DNA testing sites for donor conception (*Borry et al., 2014*; *Harper et al., 2016*). The DTCGT 'relative finder' service means that it is now easier to search for, and often to find, previously unknown genetic relatives. In using these services, donor-conceived people, recipients of donor gametes and donors open themselves up, sometimes unintentionally, to connections that hitherto might not have been possible. The growing use of these sites, and the resulting increase in their size and international reach, mean that a donor or donor-conceived person might not need to do a test themselves to be identified by people to whom they are genetically related through donor conception (donor relatives), if others in their family network sign up to these DNA testing sites (*Darroch and Smith, 2021*). Some donor-conceived people have found large numbers of donor-siblings, and donors have been traced by their donor offspring conceived many years ago, using 'relative finder' features offered by these sites.

Direct-to-consumer genetic testing can also reveal unexpected origins, and the number of people finding out they are donor-conceived through DTCGT is rapidly increasing (*Crawshaw, 2018*). This may happen in different ways. For example, someone may discover she was donor-conceived after taking a *23and me* test to see if she had the *BRCA 1&2* gene for breast cancer. Or DTGCT results may lead to recipient parents informing their child(ren) of their donor-conceived origins, having previously kept this information secret. These discoveries often come at a cost, disrupting family life and relationships, and exposing family secrets. This can lead to reassessments of family history and individual identity (*Frith et al., 2018a*; *2018b*).

Studies on donor conception and direct-to-consumer genetic testing

To date, relatively few studies have been published on how DTCGT has been used by those involved in donor conception. Guerrini et al. (2023) surveyed people who had used the genetic relative finder function of *FamilyTreeDNA* DTCGT site (approximately 1.0 million registered users) to find out about their experiences of unexpected discoveries about their family relationships. Of the 23,196 responses, 131 were donor-conceived people. One-half of these (n = 59) had found out they were donor-conceived via DTCGT and, compared with most of the participants who were not donor-conceived, they reported 'the highest decisional regret (in relation to using DTCGT) and represented the largest proportion reporting net-negative consequences for themselves.' (p 486)

Wodoslawsky et al. (2023) surveyed sperm donors from two large US sperm banks

about their attitudes to taking a DTCGT, and whether it would influence their decision to donate again. They found that most donors would be prepared to donate again despite DTCGT, and that, perhaps unsurprisingly, open identity donors were more comfortable with genetic information being shared than those who had donated as non-identifiable donors.

Bauer and Meier-Credner (2023) surveyed 59 German donor-conceived adults. Seven had discovered they were donor-conceived via a DTCGT and had also discovered donor siblings. Taking a test was seen as a 'trigger' for confronting parents about their potential donor conception. They concluded that the relationship between donor-conceived adults with family members other than their parents, in particular donor siblings discovered through DTCGT, warrants further research. Finally, a survey of 481 donor-conceived people carried out in 2020 by We Are Donor Conceived (a US-based support group for donor-conceived people), found that one-third of respondents (34%) had discovered they were donor-conceived via a DTCGT (*We Are Donor Conceived, 2022*).

These studies need to be contextualised within the large body of work on how donor-conceived people construct their identity and how people search for donor relatives, donors and donor siblings (*Freeman et al., 2014*; Frith, et al., 2018; *Hertz, 2023*; *Indekeu and Maas 2023*). Existing qualitative studies in this area go some way to achieving this. *Newton's (2022)* important study involved a survey and semi-structured interviews in Australia about the use of DTCGT by donor-conceived people. Her work demonstrates how users' trust in DTCGT as a valid source of identity information is developed in the context of mistrust of medical records and familial narratives, as well as through the validation of DTCGT by online donor-conceived communities. An earlier study by *Klotz (2016)* shows how searching for genetic relatives via DTCGT can be understood by adult donor-conceived people as a way of reclaiming agency over the meaning of genetic connections and kinship relationships in the context of late and often shock discoveries of donor conception. These findings are further supported by *Crawshaw's (2018)* work, which brings together accounts of experiences of DTCGT by those involved in donor conception, focusing on the psychological effect of unexpected DNA results.

To date, few studies have been published on the views of groups other than donor-conceived people and donors, and there is little knowledge about the effect on parents, wider family networks or other affected groups. Further, the existing studies (bar *Klotz, 2016*; *Newton, 2022*) often do not fully address the full complexity of the implications of DTCGT.

Information provision: the legal context

If donation takes place in a licensed clinic, access to information about donor conception is highly regulated in the UK. Significant reform has taken place over the past 2 decades. Sperm donation was shrouded in secrecy historically, as were oocyte and embryo donation once these became available in the 1980s (Frith et al., 2018). Before the 1990s, donor records were routinely destroyed, and medical professionals accepted (if not actively encouraged) non-disclosure of their donor conception to donor-conceived people (*Haimes and Daniels, 1998*). Practices of secrecy and donor anonymity were maintained in the UK with the passing of the Human Fertilisation and Embryology Act 1990 (the 1990 Act). The 1990 Act was later amended in 2004, and from 2005 all gamete donors had to agree to donate under conditions of non-anonymity. Currently, people conceived from their donation can access information about their donors on request, after the age of 18 years (*Blyth and Frith, 2015*). People who donated egg or spermatozoa anonymously between August 1991 and March 2005 have the option to re-register as identifiable. A voluntary register, the Donor Conceived Register (DCR) uses DNA testing via their own arrangement with a laboratory, to match donors and donor-conceived people conceived before August 1991. Of course, both the HFEA and DCR systems depend on donor-conceived people knowing they are donor conceived to access this information. Rates of disclosure have increased significantly in recent decades (*Lampic et al., 2021*); however, longitudinal research suggests that, in the UK, a significant minority of parents of young donor conceived children do not intend to tell their children about their conception (*Lysons et al., 2023*).

The legislative approach the UK has taken to the release of information is similar to a number of other jurisdictions, including The Netherlands, Sweden, Germany, Austria, Switzerland, Victoria (Australia) and Western Australia. In enacting legislation with retrospective effect, Victoria, however, has gone further than the UK 2005 reforms — one of the only jurisdictions currently to have done so (at the time of writing the Queensland government has also signalled 'in principle' support for similar proposals (*Queensland Parliament Legal Affairs and Safety Committee 2022*). In terms of the age at which donor-conceived people can request information, however, there are a range of positions. Tthese are usually linked to the age of the donor-conceived person (in the Netherlands, for example, non-identifying information can be requested at the age of 12 years, and identifying information at the age of 16 years); hweopver, this is not always the case. Victoria, for instance, has again taken a different approach, and a donor-conceived person has a right to receive information about their donor at any age. Where the child, having received counselling, is considered by the counsellor to be sufficiently mature to understand the consequences of their decision, the information must be provided to the child even in the absence of parental consent (*Victoria, 2008*). Recent research undertaken for the Dutch government supports implementing a similar approach, recommending that information should be made available to families whenever they request it and, further, that age limits should not restrict access by donor-conceived children to information about their donor (*Bolt et al., 2023*).

In the UK, responsibility for regulating gamete donation within licensed clinics lies with the HFEA, a statutory body that is responsible for maintaining a register containing information about embryo and gamete donors, recipients of donated gametes and embryos, and births of donor conceived people. This formal information system, as well as the DCR, exists alongside informal systems of information: DTCGT sites, often used in conjunction with social media platforms. The information available to donor-conceived people in the UK via 'formal' routes, based on the date on which they were conceived, is presented in TABLE 1. Parents of donor-conceived children can apply to find out any non-identifying information about the donor, and the number age and gender of any donor siblings held on the Register. Donors can also apply to find out the age

TABLE 1 FORMAL INFORMATION PROVISION FOR UK DONOR-CONCEIVED PEOPLE BY DATE OF CONCEPTION

Date of conception	Route to information
Before the HFE Act came into force. Born before 1 August 1991	Voluntary registry (DCR) that uses DNA testing to match donors, offspring and any donor-conceived siblings.
Born after 1 August 1991 to 31 March 2005	Non-identifying information, i.e. physical descriptions about the donor and any personal details the donor recorded on their pen portrait can be accessed. Donors who donated in this period can chose to remove their anonymity, enabling some donor-conceived adults to access their donor's identifying information. Donor-conceived adults can also join the voluntary contact service, Donor Sibling Link, which enables those conceived by the same donor to exchange contact details.
From 1 April 2005	At the age of 16 years, non-identifying information about the donor and any donor siblings can be accessed by donor-conceived people (or parents of donor-conceived children can access this information at any time). At the age of 18 years, donor-conceived people can access the donor's name, date of birth and last known address. The first cohort turned 16 years in 2021 and turn 18 years in 2023. Donor-conceived adults can also join the voluntary contact service, Donor Sibling Link, which enables those conceived by the same donor to exchange contact details.

DCR, Donor Conceived Register; HFE Act, Human Fertilisation and Embryology Act, 1990.

and gender of any children that may have resulted from their donation.

The HFEA is required to provide support for those approaching the Register and offer a 'suitable opportunity to receive proper counselling about the implications of compliance with the request.' (1990 Act s31ZA[3][b]). The HFEA notes that this provision, 'is in recognition of the fact that the information contained on the Register is highly sensitive and has the potential to have a significant impact on the recipient.' (*HFEA, 2012*) The HFEA has developed 'Opening the Register' policies to guide the handling and support of people wishing to access information about their donor conception from the Register. It is important to note that, as we have above, that to access information via these formal channels, individuals must be aware that they are donor conceived; whereas the use of DTCGT can reveal the fact of their donor conception to those who previously did not know.

In this legal context, and focusing particularly on the UK position, the ConnecteDNA study has examined how people affected by donor conception engage with, and experience, the possibilities afforded by informal routes to information provision.

MATERIALS AND METHODS

Overview of the study

Our findings are based on data collected as part of the ConnecteDNA study, funded by the UK Economic and Social Research Council, based at The University of Manchester and led by the corresponding author. The study examines the social, ethical, legal and psychological implications of DTCGT in relation to donor conception, using a variety of methods, with the overall objective of improving outcomes and experiences for all affected. In this paper, we focus on the findings from in-depth interviews with people affected by donor conception and DTCGT.

Interviews

Sixty people who defined themselves as having been affected by both donor conception and DTCGT were interviewed. The final sample included 19 (spermatozoa, egg or embryo) donors, 25 donor-conceived people, 20 individual parents through donor conception and two relatives of donors. Five participants occupied more than one of these roles. Participants were recruited via a range of organizations who support these groups, with a focus on those based in the UK, e.g. Donor Conception Network, Donor Conceived Register Registrants group, The Sperm, Egg and Embryo Donation Trust, sharing adverts in relevant social media networks and groups and via referral from existing participants.

The aim was to maximize the diversity of our sample in relation to categories that (based on previous research) we expected to be of explanatory importance, such as gender, age, family structure, donation type, ethnicity and timing of donation. A short questionnaire for people interested in participating was used to screen potential participants and work towards this aim. Additional inclusion criteria were as follows: participants were aged 18 years or over (16 years for donor-conceived people); were able to take part in an interview in English; and had a connection to the UK (with 57 out of 60 participants being resident in the UK at the time of interview).

Ethical approval was obtained from the Research Ethics Committees of the University of Liverpool (9861, date of approval 13 July 2021) and University of Manchester (date of approval 17 September 2021). All participants gave written or verbal recorded consent, after receiving the participant information sheet, which was recorded separately from the interview.

Demographic data collected about interview participants are presented in TABLE 2, TABLE 3 and TABLE 4. The overall sample is varied in relation to many categories of interest, including gender, age, educational status, donation type, donor's status at donation/conception and location of donation. The two donor relatives who participated were both women discussing the anonymous sperm donation of someone in their family. One was a partner and the other the daughter of a sperm donor. To protect participant anonymity, no further demographic details are given. In most cases, the donor conception(s) that were discussed had taken place in a fertility clinic (mostly in the UK but sometimes abroad). A few participants (three donors and two parents), however, had arranged sperm donor conception outside of a clinic or sperm bank (and thus outside of formal systems for information sharing), sometimes in addition to further donor conceptions within the clinic system.

TABLE 2 DETAILS OF DONOR PARTICIPANTS

Category	Outcomes	*n*
Gender	Male	13
	Female	6
Age at interview[a]	Under 18 years	0
	18–34 years	3
	35–59 years	11
	60+ years	4
	No information provided	1
Ethnicity	White British	17
	White (other)	1
	No information provided	1
Highest educational qualification	GCSE	0
	A-level	6
	Degree	3
	Postgraduate degree	9
	No information provided	1
Material donated	Egg	5
	Spermatozoa	13
	Embryo	1
Donor status at donation[b]	Anonymous	11
	Identity-release	8
	Known	3
Timing of donation[b]	Pre-1991	5
	1991–2004	5
	2005+	12
Location of donation[b]	UK clinic/bank (private)	9
	UK clinic/bank (NHS)	7
	Non-UK clinic/bank	2
	Outside of clinic	3

n =19.

[a] Age at interview calculated by year of birth compared with year of interview.

[b] These numbers do not correlate with the number of donor participants because some participants donated multiple times via different routes.

A-level, advanced level qualification; GCSE, general certificate of secondary education; NHS, National Health Service.

All interviews were one-to-one and conducted remotely by the first author via either video call or telephone (according to the participant's preference). Interviews lasted around 60–120 min and followed a loosely chronological framework, beginning with the journey to donation/donor conception or (in the case of donor-conceived people) their memories of growing up, before going on to discuss knowledge and thoughts about the donor conception, views on DTCGT, its use, or both, and the effect it has had on their lives and relationships. All interviews were recorded and transcribed verbatim (except for one interview in which detailed notes were taken instead).

The transcripts were then anonymized through the removal of identifying details (for instance, but not limited to names and places). Participants were given a pseudonym and quotes are reported using these. The first and second authors used Nvivo 12 software to code the data thematically, with codes and sub-codes derived from our research objectives and questions in conjunction with repeated readings and discussions of the data with the other authors. Examples of codes used include: 'journey to using DTCGT', 'connections with donor relatives' and 'gatekeepers'. In addition, the interview data were analysed more holistically, by reading individual interview transcripts and through the creation of interview summaries.

For this paper, we primarily analysed the participant interview data on a case-by-case basis and reflected on the interview dataset as a whole, looking for cross-cutting themes across the participant groups and considering findings in the context of existing research on donor conception.

RESULTS

The analysis identified five key ways in which DTCGT is affecting management of information about donor conception, according to the experiences of our participants: shifting patterns of knowledge about donor conception; increased flexibility regarding the age of access to information about donor conception; a growing role for non-professional intermediaries in sharing information about donor conception; accentuated effect of donor conception for relatives of donors and donor conceived people; and how DTCGT shapes and is shaped by the formal regulatory donor information management systems.

Shifting patterns of knowledge about donor conception

Our findings show that DTCGT has shifted patterns of knowledge about donor conception. In particular, it has led to donor-conceived people discovering the method of their conception, and it has enabled some people that were unknown to each other, but connected through donor conception, to identify and sometimes contact one another. The use of DTCGT often shifts who knows, who does not know, and how they know particular details of donor conceptions. It is worth emphasizing that, even after use of DTCGT, such knowledge is often partial and unequally shared within families.

Knowledge about donor conception can shift quickly and dramatically with the use of DTCGT. Some donor-conceived participants who had used DTCGT without prior knowledge of their donor conception, were immediately matched with an unexpected genetic relative, e.g. genetic father or genetic half sibling, and subsequently quickly discovered both their donor conception and a donor relative. For others, however, their initial DTCGT results did not indicate anything unexpected. Instead, the donor

TABLE 3 DETAILS OF DONOR-CONCEIVED PARTICIPANTS

Category	Outcomes	*n*
Gender[a]	Male	7
	Female	18
	Non-binary	1
Year of birth	Pre-1992	18
	1992–2005	7
	2006+	0
Ethnicity	White British	22
	White (other)	0
	Multiple	3
Highest educational qualification	GCSE	2
	A-level	4
	Degree	13
	Post-graduate degree	6
Donor conception via	Egg	2
	Spermatozoa	22
	Embryo	1
Donor status at conception	Anonymous	24
	Identity-release	1
	Known to parents	0
Family structure at conception	Solo parent	0
	Heterosexual couple parents	23
	Same-sex couple parents	2

n =25.

[a] One person identified as both a woman and non-binary hence the discrepancy in participant numbers.

A-level, advanced level qualification; GCSE, general certificate of secondary education.

conception was revealed months or years later when a new genetic relative joined the database or when they gradually started to notice anomalous results (such as an absence of any known connections on one side of their family, unexpected ethnicity results, or both). Typically, alternative explanations for anomalous results were considered before donor conception. For example, people wondered if their mother had conceived them via a sexual relationship with someone other than their father. We also spoke to donor-conceived people, donors and parents who had tried unsuccessfully over a period of many years to find 'donor relatives' via DTCGT.

We know from previous research with parents that non-disclosure of donor conception was the intention of most UK parents during the 1990s and 2000s. Despite the rhetorical shift to an ethic of openness in recent decades, a significant minority practice non-disclosure (*Lyons et al., 2023*). Our findings show that the rise in DTCGT does not necessarily mean that parents will be (more) open about donor conception. Several donor-conceived participants in our study, who did not know of their conception before using DTCGT, reported that their parents did not disclose this information even once they shared with them the news that they (the participants) had bought or used a DNA test. In other cases, parents initially questioned the reliability of the DTCGT results when confronted with unexpected results, before eventually providing donor conception as an explanation. For example, Anita, a donor-conceived person, explained that her mother had initially described the DTCGT results as a 'mistake', adding that 'DNA is. . .like magic. . .not real'.

We also found that the disclosure of donor conception after DTCGT can give rise to new secrets and taboos within families. When parents were compelled to disclose donor conception to their children after use of DTCGT, some donor-conceived participants told us this was a one-off conversation, rather than an ongoing topic for discussion. Lisa, a donor-conceived person, explained how the topic had become a taboo in her relationship with her parents, her father in particular:

'I just feel like mention[ing] anything to do with the sperm donation, you know, half-sisters or whatever, would be [. . .] potentially upsetting to [my Dad]. So, yeah, we've never, me and him have never talked about it since that day [when the donor conception was first disclosed].' (Lisa, donor-conceived person)

Previous research shows that this is not an unusual practice among parents of donor-conceived people (*Nordqvist and Smart, 2014*; *Cosson et al., 2021*).

Some donor-conceived participants told us that their parent(s) asked them not to disclose the donor conception to other family members, such as grandparents or family friends, which echoes relational practices in the world of donation more broadly (*Nordqvist and Smart 2014*; *Nordqvist and Gilman, 2022*). Donor-conceived people could also feel compelled to keep their donor conception a secret if their parents did not voluntarily tell significant others, e.g. siblings or grandparents. We also spoke to one donor-conceived participant (and were told of others) who discovered their donor conception after using DTCGT but chose not to share this with their parents. The participant in this situation believed that his father may have been unaware that he (the participant) had been conceived with donor spermatozoa.

Increased flexibility regarding the age of access to information about donor conception

Age restrictions are often lower, easier to circumvent when using DTCGT, or both, than in formal systems for tracing donor relatives. Under the UK's current identity-release system, donor-conceived people can obtain non-identifying and identifying information at the ages of 16 and 18 years, respectively. The terms and conditions of DTCGT typically state that users should be aged 13–16 years or over to use their general services, but at least 18 years old to purchase or activate a DNA test kit (see, for example, *Ancestry [2022]*, paragraphs 1.2 and 1.4.1). Many DTCGT platforms, however, are designed to allow people to manage the profiles of others easily, including for parents and guardians, to test their children. Parent participants in our

TABLE 4 DETAILS OF PARENTS THROUGH DONOR CONCEPTION

Category	Outcomes	*n*
Gender	Male	2
	Female	18
	Non-binary	0
Ethnicity	White British	14
	White (other)	4
	Multiple	2
Highest educational qualification	GCSE	0
	A-level	0
	Degree	7
	Postgraduate degree	13
Year of birth of donor conceived child(ren)	Pre-1992	3
	1992–2004	7
	2005+	13
Donor conception via	Egg	5
	Spermatozoa	11
	Embryo/double donation	4
Donor status at conception	Anonymous	11
	Identity-release	7
	Known to parents	3
Family structure at conception	Solo parent	4
	Heterosexual couple parents	12
	Same-sex couple parents	4

n = 20.

A-level, advanced level qualification; GCSE, general certificate of secondary education.

study, many of whom were embedded in online donor conception communities, told us that 18 months was widely considered to be the minimum age at which a child could be tested (there were perceived difficulties with collecting an adequate sample before this age). Two parent participants, whose donor-conceived children were infants, stated that they planned to do DTCGT as soon as possible. Four others with pre-school-aged children stated that they were still deciding if, when and how they should use DTCGT to test their children. Three parent participants had already tested their children at ages 7, 14 and 15 years, either at the child's request or after asking them, and managed their children's DTCGT accounts at the time of interview. In addition, as none of the analysed DTCGT sites currently have any effective form of age-verification (other than writing one's date of birth), age restrictions stated in the terms and conditions are easily bypassed by anyone able to navigate the platform and use a credit or debit card. Many of the parents we spoke to were aware that donor-conceived adolescents would probably be able to access DTCGT and, if they chose to do so, could use it without the knowledge or support of their parent(s) or guardian.

Therefore, DTCGT together with (online) communities built around donor conception, create possibilities for parents and their children, at almost any age, to search for (if not necessarily always to identify) relatives through donor conception. As a result, many parents now find themselves with a choice to make, where previously there were few options (at least in the UK), to search for donor relatives. Should they test their child at a young age (perhaps too young to give meaningful consent) so that they might 'grow up with' connections to and knowledge of donor relatives? Should they wait and support their child to use DTCGT only if and when they express an interest in doing so? And, if so, what level of understanding, about, for example, the potential challenges involved or the implications of online data sharing, should the child have before they support this choice? Or should they instead try to enforce the official age restriction of 18 years (at least in the UK)? In the present study, we spoke to parents with varied and often starkly opposing views on these questions. There is insufficient space to explore this fully here (this will be the subject of another paper).

Our findings show that being a parent through donor conception in the age of DTCGT opens up new questions about the appropriate age to disclose and search, which can be experienced as moral dilemmas. Faye, a parent to a toddler conceived through donor conception, who was considering using DTCGT, explained how keenly she felt the 'weight' of this decision:

'And it's just that, still this balance of, does she turn round to me in 10 years, and said, "Oh, you," you know, "You gave away my DNA," versus, "Oh, you could have done a DNA test and I could have found my genetic family earlier." So, I mean I feel the weight of that (Faye, parent).

On the topic of (non)disclosure of donor conception, the dominant view among fertility professionals and within the donor-conceived community in the UK is now firmly established: that it is best to tell children early and often about the circumstances of their conception (*Ilioi et al., 2017*; *Golombok et al., 2023*). However, on the issue of contact with donors, our data suggest that, even among those who are actively engaged in donor conception communities, no consensus has been reached on the value and risks of searching for, connecting with donor relatives, or both, during childhood. The use of DTCGT to search for donor relatives raises further questions about the ethics of sharing genetic data in online contexts, and particularly children's rights and the ability to give or withhold consent for this (as Faye alludes to above). These questions, however, are also challenging because they engage parents and donor-conceived children in grappling with fundamental questions about the meaning of childhood and its relevance to creating family relationships. For example, parents sometimes raised concerns about their ability to maintain the boundaries of their family, if they were to introduce contact with donor relatives during their child's childhood. The same participants often worried that if contact was delayed until adulthood, this might limit the quality of

these potential kinship relationships. The increased use of, and knowledge about, DTCGT in donor-conception communities, therefore, creates new questions and challenges for parents through donor conception in how they manage these kinship networks with and for their children.

A growing role for non-professional gatekeepers

Formal systems primarily rely on professionals (namely those employed by the HFEA and Doner-Conceived Register) to relay information about donor conception (and particularly about genetic relatives through donor conception) to the people directly involved in that conception, i.e. parents, donors and the donor-conceived person. UK law and organizational policies provide rules and protocols regarding if, when and how such information should be relayed and to whom. In contrast, in informal systems, those managing information about donor conception generally have no formal training or guidance for this, and sometimes have no first-hand knowledge of donor conception; for instance they may be the relatives of donors.

In our research, donor-conceived participants who had used DTCGT (with or without prior knowledge of their donor conception) frequently found themselves inadvertently in the position of gatekeeper, having knowledge of another's donor conception when that person may not have it themselves. Typically, this happened when they already knew about their own donor conception and then matched with a genetic half sibling via DTCGT. In such situations, they would know this was likely another donor-conceived person, or perhaps the child of their donor; however, they would not know what (if anything) the person with whom they had matched knew about their genetic heritage or their parent's donation.

Similar situations could also arise for donors who had registered with a DTCGT provider. Donors who had taken this step typically had done so to make themselves more easily contactable by anyone conceived from their donations who might actively want to trace them. Often, such donors had not, at the time of registering, considered the possibility that they might 'match' with a donor-conceived person who did not already know they were donor conceived. This was the case for Bill who, having registered with several DTCGT websites with the aim of making himself contactable by any donor-conceived people who might wish to connect, found that his intentions had, as he put it, 'backfired':

> But the backfiring bit was [. . .] that I hadn't really expected to be telling people they were donor-conceived, that wasn't the role that I was trying to put myself in.' (Bill, sperm donor)

Being a gatekeeper in such situations could be emotionally, morally and socially challenging. Participants in this position were grappling with various questions: should they wait until they are contacted by the other person, specifically asked for information, or both? Should they pursue contact via other social media platforms as well as, or instead of, the messenger services of DTCGT websites (bearing in mind that users of DTCGT platforms do not necessarily log into them on a frequent basis)? Should they make information about their own donor conception instantly available to any matches by including this information in their profile? If new information is obtained, e.g. the identity of the donor or other donor relatives, how, if at all, should this be shared with any other connections or matches? Some participants had to repeatedly revisit these questions if and when new matches were made, or when new information was discovered.

Our findings suggest that participants could find themselves facing moral dilemmas, to pass on information or withhold it, and that these were not 'solved' when a decision has been made but can linger. Participants often wondered if they had made the wrong decision in relation to one of the questions listed above. When information about donor conception was conveyed and then appeared to cause distress for the person told, our research found that people who had passed on such knowledge could feel (partly) responsible and wonder whether they should have acted differently. For example, one donor participant described looking back through all his communications with a donor-conceived person, searching for anything he had said that might have caused the donor-conceived person to cut contact. On the other hand, donor-conceived people who found themselves in a position of withholding information from others sometimes felt guilty or anxious about this.

Accentuating the effect of donor conception for relatives of donor-conceived people and donors

In the UK (and many other jurisdictions that operate formal registers of donor conception), only three roles are discussed in the laws and regulatory guidance relating to information sharing about donor conception: recipient(s) of donated gametes, donors and donor-conceived people. These are the only groups to whom the 1990 Act (at ss 31-31ZE) accords rights to information about donor conception. Others who may have an interest or feel affected by donor conception, such as the relatives or partners of donors, the donor's 'own' children, or the descendants of donor-conceived people, are not included in formal information-sharing systems.

In contrast, our research shows that when information about donor conception is shared via informal systems, such as DTCGT, the relatives of donors often play a key role, and may be significantly affected by such processes. This most often happens when relatives of donors become intermediaries or gatekeepers (see above) in the process of donor-conceived people discovering their donor conception, tracing their donor, or both. Among those donor-conceived participants in our study who had used DTCGT to identify their donor, most had not been matched directly with the donor but had instead found them indirectly via a relative of the donor, e.g. their cousin, sibling, parent, aunt or uncle, who had registered with a DTCGT database.

Formal systems frame the only meaningful connections in donor conception as those between donor-conceived people and donors, and, to a lesser extent, those between same-donor siblings (*Gilman and Nordqvist, 2018*; *Nordqvist and Gilman, 2022*). Use of DTCGT, however, facilitates relatives of donors and donor-conceived people making direct connections, and allows these to be assigned meaning in their own right (as well as, in some cases, as a means to connect with the donor). Several of the donor-conceived people we interviewed who had found donor relatives via DTCGT had formed meaningful connections with donor relatives beyond donor siblings or the donor. Ida, for example, had initially connected with her genetic cousin via DTCGT. Through him she was able to identify her donor and other donor relatives, via a combination of communicating with him and browsing his

social media accounts. She described her connections with the donor's family:

'I think the only two people I suppose [who] found it really hard to take [were] his wife and daughter. And then I think everyone else they've been so welcoming and so have his wife and daughter. . .He said when he first told them, it was almost like he'd had a new baby. [laughs] D'you know, they were all, 'oh, congratulations-' [laughs]. . . They were all very, just so forthcoming and lovely really, yeah, everyone has been. . .I was very lucky to have found a family that had been like that, because obviously not everyone's stories are like that, are they?' (Ida, donor-conceived person)

In two other cases, the donor had died by the time contact had been made, but the donor-conceived person had been welcomed into the donor's extended family. Other participants described how connections with the donor and their family had been built simultaneously, and some noted a closer relationship with the donor's relatives than with the donor him or herself.

Some participants who were members of donor conception communities and organizations told us that the gatekeeping processes described above are also now encompassing genetic descendants of donor-conceived people. As more generations of donor-conceived people age, such experiences are likely to increase. Descendants of donor-conceived people bear a particularly heavy burden if they become gatekeepers of the knowledge about their parent's (previously unknown) donor conception and face a decision about sharing this with their (perhaps quite elderly) parents. The issues here may be compounded by the tendency for lower and more flexible age restrictions within informal systems.

As time passes, and generations of donors pass away (potentially not having shared with their relatives the fact that they were gamete donors), it is increasingly likely that DTCGT will match people connected through donor conception where neither party has any knowledge of the donor conception, and there is no longer any living person who can explain the connection. This would be the case where, for example, a donor's relative matches with a donor-conceived person whose parents are deceased and did not disclose the donor conception in their lifetime. The likelihood of donors having passed away also increases with the extension of storage limits for donor gametes, recently enacted in the UK (*HFEA, 2022*).

How direct-to-consumer genetic testing shapes and is shaped by the formal regulatory donor information management systems: interactions between systems

The formal and informal systems (detailed above) through which people can find out about donor conception do not operate in isolation from one another. Instead, they are experienced and understood in relation to one another and may be used in combination. This was evident in several ways through the experiences of those who took part in our research.

Donor-conceived people, and, to a lesser extent, donors and parents, may turn to informal routes in situations where they find themselves excluded from formal routes for accessing the information they desire. In our research, this was most commonly the case for donor-conceived people conceived in the UK before April 2005. This group of participants had often contacted, or read information provided by, the HFEA and, therefore, understood that, if they had been conceived at a later date, they would have rights to identifying information. Those conceived between August 1991 and March 2005 were often acutely aware that the HFEA held identifying information about their donor but could not share it with them unless their donor had re-registered as identifiable. Patricia, for example, explained how dissatisfied her daughter (born in the mid-1990s) had been with the limited information she had been able to obtain from the HFEA:

'So [my daughter] got her HFEA information which she is a bit disappointed with. It was almost like erm, and I'm not speaking for her, but you know there's this, that she said to me, she said, 'it almost felt like they were teasing her'. She said, "I felt like behind that letter those people know more, the HFEA. And how dare they just tell me that my, that the egg donor has a tendency to put on weight.' (Patricia, parent through donor conception)

Those without formal access to information about their donor conception often presented DTCGT as their 'only option' to assert what they saw as an unrealized right to access information about their conception (Adams et al., in press). Several donor-conceived participants raised concerns that this required them to share their genetic data with commercial entities. Beth explained:

'I wouldn't throw my DNA into the world for a giant corporation without thinking about it but it just. . . it was the only way I could have done it [identified donor relatives]. . ..I wouldn't have done it if I didn't need to.' (Beth, donor-conceived person)

For others, DTCGT was used alongside, or instead of, formal routes as it was seen as preferable for a range of reasons. For example, several donor participants explained that they had registered with a DTCGT database as a 'back up' to formal systems for making themselves contactable, i.e. registering with the HFEA or DCR. Although other donors used DTCGT because they were unaware of these formal routes, this group knew about the HFEA, DCR, or both, but imagined that DTCGT would be easier, perhaps cheaper, quicker, more 'personal', or all, than these formal systems, which had often been experienced as slow, bureaucratic and impersonal.

DISCUSSION

This study is, to our knowledge, the first study to investigate DTCGT use with donors, donor-conceived people, parents through donor conception and other relatives. The range of perspectives has produced novel insights into how DTCGT is changing the landscape of contemporary donor conception. In particular, we have demonstrated the multiple and varied ways in which DTCGT (in combination with other sources of information) is affecting the management of information about donor conception. This can happen in ways that undermine formal rules and systems; however, informal routes to information can also be used in tandem with formal routes. Although our research focuses on the UK, our findings will have implications for other contexts and jurisdictions, as DTCGT circumvents policies, regulation and medical practice in relation to record keeping.

Our findings suggest that some of the more negative effects of DTCGT in relation to donor conception, e.g. shock discoveries of donor conception or the challenges of gatekeeping information about donor conception, are connected to

ongoing practices of secrecy in relation to donor conception and donation. We know that non-disclosure of donor conception or donation is connected to a lack of social recognition for parents and families formed this way, shame and anticipated stigma associated with donor conception, for donor-conceived children, or both, and fears of a lack of support from family and friends (*Shehab et al., 2008*; *Indekeu et al., 2013*; *Cosson et al., 2021*). It is important to note that this is likely to be the main experience for parents through donor conception in many parts of the world (*Bharadwaj, 2003*; *Tsui and Cheng, 2021*; *Okafor et al., 2022*).

By analysing the interview data from people implicated by donor conception, we have demonstrated the range of ways in which DTCGT is affecting how information about donor conception is accessed and managed. We make no claims, however, about the relative prevalence of different experiences. Participants in this study were self-selecting and some groups were under-represented in our sample: most participants identified their ethnicity as white; we recruited limited numbers of fathers through donor conception; and most donor-conceived participants were conceived via anonymous sperm donation and had two opposite-sex parents. We also recruited no donors who were actively opposed to contact (one participant was originally resistant but subsequently became amenable), and all the parent participants in this study had disclosed (or planned to disclose) their child's donor conception at a young age. It must also be noted that, in studies such as this, those who participate are often highly engaged in these debates and communities. It is, therefore, possible that the outcomes we have identified are not exhaustive. In addition, most participants in this study were discussing donor conceptions that had been organized via a medical institution. Informal or private sperm donor conception, arranged outside of clinics and often facilitated via digital media, is a growing practice (*Harper et al., 2017*). Although similarities with our findings may exist, differences are also likely in how DTCGT is experienced in this context.

Our work, however, demonstrates the importance of empirical research to fully understand the ways in which new technologies affect human social relationships. It is not sufficient to speculate based on technological possibilities alone. By examining the experiences of those affected, our research shows that the implications of using DTCGT for those involved in donor conception go far beyond the reversal of donor anonymity.

Like others (*Crawshaw, 2018*; *Newton et al., 2022*), we have found that using DTCGT can lead to donor-conceived people discovering how they were conceived. It also provides a tool for those with prior knowledge of the circumstances of their conception to actively seek people genetically related through donor conception, i.e. donor siblings, donors or the donors' relatives, where 'formal' options to find this information may be unavailable or ineffective (*Klotz, 2016*; *Darroch and Smith, 2021*). Our research supports previous studies that show that, for some donor-conceived people, access to (and support to use) DTCGT can be experienced as a positive choice, particularly in contexts in which family secrets have been kept (*Klotz, 2016*; *Newton et al., 2022*), or where they have no access to information via 'formal' routes. Our research, however, also shows that the promise of DTCGT is not realised for all; some donor-conceived people continue to lack access to information about their conception despite the rise of DTCGT. Others are negatively affected by the discovery of their donor conception, owing to continued secrecy within families or the emotional burden of becoming a gatekeeper of information about donor conception.

Further, DTCGT opens the possibility of connecting with genetic relatives through donor conception beyond the donor and donor-conceived person dyad. By facilitating the building of theoretically vast webs of relatives, DTCGT supports the sharing of information about donor conception, and the building of connections, beyond the usual triad discussed in policy (donors, donor-conceived people and recipients). In addition, because extended genetic relatives are often more directly involved when donor conception information is shared via DTCGT, they can also become inadvertent gatekeepers of knowledge about donor conception, a role that can be emotionally and socially challenging. It is worth noting, however, that the connections that are facilitated through DTCGT are based on genetic relatedness. Therefore, others who may also feel affected by a donor conception but who have no genetic connection, e.g. partners of donors and non-genetic parents of donor conceived people, are excluded from the relational webs which DTGCT facilitates.

The rise of DTCGT can also mean that parents and donor-conceived people face challenging new decisions, including whether and when to seek information about donor conception. The age at which it is appropriate to test a child is an area of substantial disagreement among our participants. Formal systems for managing information about donor conception have established legal rules and formal protocols for doing so; however, those involved in the informal systems often face difficult questions about when, with whom and how it is right to seek or share this information. Although norms about some aspects of donor conception have been established in the UK, e.g. early disclosure (*Golombok et al., 2023*), there is less agreement about the 'right' way to navigate the possibilities afforded by DTCGT. Therefore, those implicated often find themselves negotiating decisions and situations that are emotionally, socially and morally challenging.

Implications for practice

As per recent ESHRE good practice recommendations (*Kirkman-Brown et al., 2022*), it is important that those who interact with, and counsel, donors and prospective parents by donation inform people of the full range of implications of DTCGT. This includes making it clear to all considering donor conception that anonymity can no longer be guaranteed for any period. In fact, the language of anonymity is perhaps no longer helpful or appropriate in relation to donor conception (see also *Ethics and Practice Committees of the American Society for Reproductive Medicine, 2022*). This is not the only implication of DTCGT, however. As we have shown, other implications include increased flexibility regarding the age at which information can be sought or accessed, the potential for people to become gatekeepers of donor conception information and the increased effect on the relatives of donors and donor-conceived people. This broad range of implications should be shared and discussed by professionals with all involved in, or considering, donation or donor conception. Our results also suggest, though, that a balance needs to be struck between under- and over-stating the current reality. It is not the case, for

example, that all donors can be easily traced. Sufficient attention, however, must be paid to the possibility that DTCGT, social media and potentially other technologies (such as facial kinship verification) may lead to new knowledge of donor conception and, further (whether purposefully or accidentally), finding donors, donor siblings and wider donor relations.

Our research also demonstrates that some of those most significantly affected by the rise in DTCGT are those affected by historic donor conception practices, many of whom will not have any regular contact with fertility professionals. Hence, it is important to provide information to these groups and support them proactively. This includes current and past donors, as well as parents and donor-conceived people, to ensure they are informed of the known implications of DTCGT (and other technologies) for them and their immediate and extended family. This could be done through a public information campaign, making use of national, social media, or both, or it might be achieved by providing information to historic donors or parents who contact regulatory bodies or fertility clinics for other reasons, i.e. when donors request non-identifying information about people conceived from their donation.

Recognition that donor-conceived people need greater support is growing (Best et al., 2023), particularly in the area of DTCGT (*Crawshaw et al., 2016*; *2018*; *Adams et al., 2023*), and our research further supports this need. Counselling and peer support should be offered, as well as signposting to appropriate organizations. Some DTCGT websites do offer information about unexpected genetic 'matches' and how to access support, but, where such information is available, it is not flagged on the home page and is often poorly signposted and difficult to find.

In conclusion, to the best of our knowledge, this is the first study to investigate DTCGT use with donors, donor-conceived people, parents through donor conception and other relatives. It provides new insights that can be used to improve regulatory responses and practice in the fertility clinic. It is important that all those involved in fertility treatment, and those from egg and sperm banks and other intermediary services, inform potential recipients and donors of the multifaceted implications of DTCGT for gamete donor conception, and people are given an opportunity to discuss what this means for them. Further, this information should be provided in a nuanced way. A balance needs to be struck between under- and over-stating the current reality. It is not the case, for example, that all donors can be easily traced and that every donor conceived person will find their donor or donor siblings. Good information provision and implications of counselling are important to ensure that all parties are fully informed about the possible implications of DTCGT, and to help people prepare for donation and parenthood.

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DATA AVAILABILITY

Data will be made available on request.

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AUTHORS' ROLES

All authors contributed to data analysis and reviewed and edited the manuscript.

LW designed the study and contributed to writing and editing the manuscript; LG conducted the interviews, wrote the first draft and edited the manuscript; and CR undertook data collection, contributed to writing and editing the manuscript.

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