

HFEA'S PROPOSALS FOR CHANGE AND RECOMMENDATIONS DEVELOPED FROM CONNECTEDNA FINDINGS

This response is offered on behalf of the ConnecteDNA research team. The ongoing [ConnecteDNA research](#) project is examining the use of direct-to-consumer genetic testing (DTCGT) by, and its impact on, gamete donor (egg, sperm and embryo) conceived adults, donors and parents (and relatives) of donor conceived people. There has (until recently) been very limited empirical research with people affected by donor conception to examine how they understand and experience the implications of this technological development. The project seeks to address this gap in our knowledge.

Our responses and recommendations below draw on our preliminary analysis of our qualitative data (see additional information provided at the end of this detailed response).

Question 21

PROPOSAL: *Clinics should be required by law to inform donors and recipients of the potential for donor identity to be discovered through DNA testing websites [Q21]*

RESPONSE: we support the aim of this proposal to ensure that donors and recipients **are properly informed about the potential for donors' identity to be discovered as a result of the operation of emerging technologies such as DTCGT**. However, in our view, making specific reference to this exact technology in primary legislation would not 'future-proof' the Act. Rather, legal loopholes might quickly be created in the event that DTCGT were the only such technology in respect of which donors would legally be required to be informed. There are other emerging technologies, such as facial recognition technologies to identify genetic relatives, which are likely to have similar impacts (and that may have further implications which are as yet unclear). Thus, reference to specific technologies might best be contained in Guidance/the HFEA Code of Practice, rather than in primary legislation.

RECOMMENDATIONS:

1. **Clinics should be subject to a legal obligation to inform donors and recipients about the possibility that, as a result of developing technologies, such as (but not limited to) DTCGT, any children born from donation could discover their donor's identity before they are 18.** Specific technologies, and related concerns, should be described in Guidance/CoP, updated with sufficient regularity to ensure that clinics' legal obligations to provide proper information can be supported.

Further:

- i) reasonable steps should be taken to inform past donors and parents through donor conception (including pre-2005) of the implications for them of DTCG. This should include the options available to them, including (for example) to re-register as identifiable. Our empirical data suggest that donors, even those who are open to contact or engaged in donor conception issues, are often unaware that re-registration is possible. Thus the benefits of a public information campaign, aimed at past donors and parents by donor conception, are potentially significant. As well as engaging national media platforms, such a campaign might deliver information to past donors and parents

- by donor conception through HFEA contact mechanisms, e.g. where a donor contacts the HFEA or a clinic to find out how many people have been born from their donation(s)).
- ii) the ConnecteDNA preliminary findings show that the potential identifiability of donors is just one of a number of significant implications of DTCGT, about which donors and parents by donor conception should also be informed. These include:
 - a. the possibility that donor conceived individuals will inadvertently discover they are donor conceived;
 - b. the possibility that donor siblings will inadvertently be identified (including a donor's own children);
 - c. the fact that DTCGT enables genetic connections to be identified without explanation, meaning that connections may be misinterpreted as e.g. evidence of secret and possibly extra-marital sexual relationships;
 - d. the challenges often encountered by people affected by donor conception as a result of DTCGT, such as, for example, becoming responsible for gatekeeping knowledge of others' donor conception;
 - e. the fact that a revelation about someone's donor conception via DTCGT, or using DTCGT to facilitate contact, can have both negative and positive outcomes for donor conceived individuals and communities, and that outcomes will vary according to personal circumstances and experiences; and
 - f. the fact that DTCGT does not enable everyone affected by donor conception to identify genetic relatives, causing distress in some cases where connections are *not* able to be found via DTCGT sites.
 - iii) DTCGT is not (and must not be presented as) a substitute for accurate and accessible official systems for information and connection.
2. The consent process for prospective donors should ensure their full understanding of the potential challenges to anonymity from technologies such as (but not limited to) DNA testing and matching services. **It is also important for past donors to be fully informed about the potential challenges to anonymity.** We would support a public information campaign (including via national media) to inform past donors about potential challenges to anonymity and to highlight the possibility of re-registering as identifiable. Our research has suggested that donors may not know about this possibility, or how to re-register, even where they are curious about people born from their donations or broadly supportive of donor conceived people's rights to know their donor's identity. Existing communication channels (e.g. consent processes and implications counselling in fertility clinics) and organisations which support those affected by donor conception (e.g. the Donor Conception Network (DCN), the British Infertility Counselling Association (BICA), the Donor Conceived Register (DCR)) could support and amplify a public information campaign. Full information (explained in accessible language) should be clearly visible in consent processes.

Particular efforts are required to inform harder to reach groups e.g. historical donors and their families, and parents of adult donor conceived children who have not shared the circumstances of their child's conception with them.

3. **Legislation should guarantee access to funded follow-up and support care for those directly or indirectly affected by unexpected genetic discoveries through DTCGT**, including for the relatives of donors and donor conceived people who are increasingly being impacted by, and

implicated in, the sharing of information about donor conception. Existing policies, information provision and support services should be updated to acknowledge the range of ways in which relatives can be impacted (e.g. there should be information aimed at these groups on the websites of the HFEA, the DCR and the DCN, as well as on the websites of DTCGT providers).

In some cases, specialised resources and services will be required to support those affected by DTGCT/donor conception. Members of the ConnecteDNA team, alongside a wide range of other stakeholders, are currently working on the 'preparing for contact' project which aims to inform and support donors and their families in relation to the possibility/experience of contact from people related through donor conception. We would be happy to work with the HFEA as it develops an appropriate regulatory / guidance framework in this area.

4. **In making its recommendations for change to the Government, the HFEA should bear in mind that further cultural and technological change in this area is likely.** Given the long-term nature of donor conception and gamete / embryo donation, we recommend that legislative change should facilitate regulatory systems in which those involved (particularly donors and parents) can be contacted in the long-term future so that they can remain fully informed about the ongoing implications of their decisions and any options they (and/or their children or wider families) may have in relation to them. To this end, we recommend that an additional power should be granted to the Authority (possibly as part of s31 of the Act) to notify a donor of any changes or implications where it considers such notification appropriate, and that the possibility, and potential scope) of such power be discussed as part of the consent process. The amendments to the Act by Schedule 17 of the Health and Care Act 2022 (permitting fertility patients to store both embryos and gametes for up to 55 years) are an example of how such a power might be exercised.
5. Finally, we also **recommend that regulatory attention should be paid to the obligations of DTCGT service providers in the UK to provide more information to users of their services.** This could be done as part of their online consent process. Whilst, clearly, DTCGT services fall outwith the HFEA's remit, the importance of appropriate consent, a key focus of this current consultation, is (arguably) as important within the context of DTCGT as it is in the context of treatment. Our research findings highlight the psychological distress and disruption to family relationships that have resulted (and are resulting) from people discovering they are donor conceived as a result of using DTCGT services. Further, DTCGT providers (such as Ancestry and 23andMe) use a variety of media, including television advertising, to promote their services. Thus, a review by the Competition and Markets Authority of regulatory oversight in this area should form part of the HFEA's recommendations to the Government for change.

Question 22

PROPOSAL: *The Act should be amended to provide parental and donor choice to opt for anonymity until age 18 (as now) or identifiable information on request after the birth of a child [Q22]*

RESPONSE: Our response below considers two separate issues in relation to this proposal;

- i. The 'dual track' proposal; and
- ii. Issues relating to the information available to donor conceived children.

The 'dual track' proposal.

Attendees at the project's stakeholder workshops (unlike our interview participants) were asked directly about the proposed 'dual track' option. Some attendees liked the choice this option would provide, while others noted that, despite allowing flexibility, having a variety of options might cause confusion. There was a general feeling that, with the availability of DTCGT, a donor's identity can no longer be protected, so the 'dual track' option would not be practical. (However, we emphasise our key finding that DTCGT / social media searching does not always allow identification of the genetic relations sought).

Our interviews with regulators in the Netherlands touched on the 'dual track' system that was in place there until anonymity was abolished in 2004. They told us that some Dutch donors who had agreed to be identifiable under the 'dual track' system had subsequently refused to allow their information to be shared, and that a legal loophole had prevented disclosure of their identity. As a result, legislation is currently being considered in the Netherlands to allow disclosure of a donor's identifying information without consent where that donor had donated as an identity release donor in the pre-2004 'dual track' system.

Thinking about the challenges experienced in the Netherlands, we feel that it is important to note, in response to the HFEA's proposal of a 'dual track' system in the UK:

- that, in the context of DTCGT, care should be taken to counsel donors about the implications and limitations of their decisions around identifiability, and
- that donors should not be allowed to withdraw consent to be identifiable once they have donated gametes on the basis of such consent.

In addition, we would like to raise the following concerns about **the potential for inequalities to be created / exacerbated by a 'dual track' system**. We note that:

- donor conceived people will have different 'rights' under any dual track system, depending on the basis on which their donor consented;
- this might mean that different rights are accorded to siblings in same family;
- the proposed dual track system has the potential to exacerbate existing socio-economic inequalities. Fertility clinics are commercial entities. Will they start charging more for donors who have consented to be identifiable from birth?
- the proposed dual track system also has the potential to exacerbate existing racial and ethnic inequalities. Will people who are looking for a donor from a minoritised ethnic background really have the choice the HFEA is suggesting they will? If the proposed 'dual track' approach is considered the best way forward, we suggest that it is made clear to those seeking a donor with a particular genetic heritage how likely it is that such a donor will be found.

While we agree that the 'dual track' approach suggested would be preferable to the current legal position, our data suggest that an agree/disagree response is insufficiently nuanced. **A more flexible system would therefore be preferable to a 'dual track' system**. Our research suggest that donor conceived people's views, experiences and circumstances are varied and change over time. Parents (even when they have had good implications counselling) can only fully understand the implications for *their* children having (or not having) information about

their donor or donor siblings, *once that child exists and starts to express views and develop needs and interests*. Several parents who took part in the ConnecteDNA study told us that their interest in using DTCGT was, at least in part, motivated by feelings of guilt about not having used a known donor to conceive. Others sought to identify donor relatives in response to health concerns (even if only minor e.g. questions about a child's allergies) as well as to respond to their child's growing curiosity. A more flexible system would enable parents with a donor conceived child (of any age) to request **information** about the donor, if and when it was needed, and the donor would be able to consent to (or refuse) **contact** based on their circumstances at the time. It would be helpful if some form of mediated communication were possible for those who did not desire identifying information, as well as enabling the exchange of identifying information (by mutual consent) for others.

Issues relating to the information available to donor conceived children

The HFEA's proposal makes reference only to information about the donor. The ConnecteDNA study has found, however, that *connections with same-donor siblings are often seen as equally important, and sometimes more important, to donor conceived people than contact with the donor*. Indeed, the desire to connect with same-donor families and siblings during a donor conceived person's childhood is a key driver for the use of DTCGT, it being the only option available to facilitate those connections. However, the use of DTCGT in this way carries a number of risks, including that connections are made with people who do not know that they are donor conceived, and that contacts are made with gamete donors who want to remain anonymous. There are also risks arising from the sharing on social media platforms of children's special category personal data (as defined in Article 9(1) of the UK GDPR).

Opening up the Donor Sibling Link (DSL) to parents and donor conceived people at a younger age would avoid them unnecessarily undertaking the various social risks involved in using DTCGT.

RECOMMENDATIONS

6. Given the likely impact of the cultural and technological shifts in this area (discussed above see, in particular, **Recommendation 4, above**), **we recommend that both UK policy and clinic practice/guidance should move away from talking about donors or donor conception as 'anonymous' (even if qualifiers are given)**. This language is no longer helpful or accurate. It would be preferable to talk about people's 'contact preferences' or 'expectations' (for example) and the circumstances in which the HFEA will or will not share their personal (identifying) information. It would be important to make clear, in this context, that other individuals and organisations (such as DTCGT providers) are not bound by the Act or the regulatory framework within which the HFEA operates.
7. Irrespective of whether (or how) the Act is amended to provide for access to information, **we recommend that consideration be given to making the DSL service accessible to donor conceived people under the age of eighteen**. Parental consent might be required up to the point at which a child is considered competent to understand the implications of applying to join the DSL service. We note that changes to the Act would not be required: the Act (at s31ZF(2)) currently gives the HFEA broad powers to manage the DSL service in such manner as it thinks fit.

PROPOSAL: The Act should require all donors and recipients to have access to information about the implications of their decision before starting treatment [Q23]

RESPONSE: We note that question 23 asks whether the Act should require all donors and recipients to have *implications counselling* before starting treatment. We suggest that terminology and language are important here, particularly in the context of a proposal that ‘counselling,’ which is always understood to be offered rather than imposed, be mandated. ‘Counselling’ might not be an appropriate term for mandated meetings where information-sharing is the core purpose.

Subject to our concern about terminology, we support the proposal that *implications counselling* be mandatory.

RECOMMENDATIONS

8. People (historically and currently) involved in, or considering, donor conception need to be better informed about the ubiquity and the *full* implications of DTCGT (and other technologies) for them and their relatives (as detailed in our **key findings** below). As our preliminary findings and the above recommendations clearly demonstrate, there are complex and multi-faceted implications of a decision to donate and to use donor gametes to build a family. Thus **we recommend that the Act require donors and recipients to have a minimum of two (funded) implications counselling sessions, with some reflection time in between.** The Act should also require that such counselling be offered by qualified counsellors (ideally accredited by the British Infertility Counselling Association).

Further, we note the importance of implications counselling being attentive to the potential impact on the relatives of donors and donor conceived people by the sharing of information about donor conception through DTCGT. See **key findings 4 and 5**, below).

9. **Patients should continue to be encouraged by clinics to be open with their children about how they were conceived.** Although we feel it is important to acknowledge that openness is preferable, we agree that parents should continue to have the power decide when or if to tell their child about their donor-conceived status.

Additional information

Our responses to the proposals about access to donor information, and our associated recommendations, draw on our preliminary analysis of data gathered from qualitative interviews and stakeholder workshops (n= 101 participants). We are also carrying out interviews with regulators. To date we have spoken to regulators in the Netherlands and Victoria, Australia (n=3). We set out our initial findings below. Our research is ongoing.

Relevant key findings to date

1. The rise of DTCGT has led to growing numbers of people discovering they are donor conceived via late and/or shock discoveries. Such events are described as sometimes being associated with psychological distress and disruption to family relationships.
2. The ease with which DTCGT can be accessed, its relative affordability and the way in which it is subject only to regulation as an online product/service means that it can easily circumvent the Human Fertilisation and Embryology regime.

3. Ease of access to DTCGT also creates greater flexibility with regard to the age at which information about (initially unknown) donor relatives can be accessed. This is a significant difference from the UK's 'official' system for sharing such information, which dictates that donor conceived people can only access identifying information about their donor or donor siblings after the age of eighteen.
4. DTCGT accentuates the potential impact of donor conception for persons outside of the usual triad (donor, parent, and donor conceived persons) typically referenced in UK policy and practice. Whilst UK regulations only permit the sharing of donor conception information between these three groups, 'unofficial' systems (combining DTCGT and personal data shared on social media platforms) often more directly affect and involve donors' genetic family members (and, theoretically, also the descendants of donor conceived people) who may find themselves in the position of being 'information intermediaries' (see further below) and/or may develop their own relationships with people related through donor conception.
5. The rise of DTCGT creates 'information intermediaries'. These people find themselves having to manage information about donor conception and the connections it creates. Often, users of DTCGT find themselves unexpectedly in a situation where they hold knowledge of others' genetic relatives, or someone's status in relation to donor conception, which is sometimes knowledge that person may not have about themselves. This happens when, for example, a donor 'matches' with a donor conceived person via a DTCGT database, but the donor conceived person was previously unaware of the circumstances of their conception. In such situations, the information intermediary might be faced with challenging ethical decisions about whether, with whom and how they should share this information.
6. The rise of DTCGT, and the discussions around its implications for donor anonymity, have created an assumption that the 'official' systems for protecting donor anonymity are always surmountable. However, although it is often the case that a genetic relative is identifiable through a combination of DTCGT and social media searching, this is not always possible. In addition, connection-making through DTCGT and social media is an ongoing process rather than a one-off event – in that there is a continuing potential for new 'matches' with new registrants and searchers. Where no 'matches' are made, this can lead to cycles of disappointment (sometimes distress).
7. A common thread linking all the above findings about DTCGT and donor anonymity is a need for emotional support for those impacted in the ways we have described above.