

ConnecteDNA Research Project : Newsletter #3 December 2023

A message from Dr Lucy Frith, PI

I am delighted to tell you that we have been granted a no-cost extension to the ConnecteDNA project. This means that our funding will continue until the end of December, 2024. While we are sorry that, as most of you know, Leah left the project in May to work on her exciting [Digital Donor Conception study](#) we are pleased that Caroline will now be able to work on ConnecteDNA for another 12 months.

On behalf of the team, I hope you enjoy reading about what we have been working on.

ConnecteDNA website: [here](#)
Twitter/X: [@ConnecteDNA](#)



Human Fertilisation &
Embryology Authority
Modernising fertility law

ConnecteDNA IMPACT ACTIVITIES

Preparing for Contact

From October this year, donor-conceived people turning 18 can access information about their donor by contacting the HFEA. Working with a range of collaborators (with the support of a graphic designer) we led the design and creation of a series of leaflets to help donors and their families prepare for the possibility of contact. You can read our leaflets on the ['Preparing for Contact'](#) page of our website.



We responded to the HFEA's recent consultation, which considered reform of the Human Fertilisation and Embryology Act 1990. **Of particular relevance for our research were the questions about donor anonymity.** The questions and a summary of our responses follow.

Should clinics be required by law to inform donors and recipients of potential donor identification through DTCGT websites? Clinics should have a legal obligation to inform donors and recipients about the possibility that developing technologies, including DTCGT, mean that donor conceived people could discover their donor's identity before they are 18. Specific technologies, and related concerns, should be described in guidance to support clinics to provide proper information. It is also **important for past donors to be fully informed** about the potential challenges to anonymity. **Our research shows that distress and disruptions to families can result from people discovering they are donor-conceived through DTCGT.** Legislation should guarantee funded support care for those affected by unexpected genetic discoveries through DTCGT and, regulators should consider the obligations of DTCGT providers to provide more information to users of their services.

Should the 1990 Act should offer parents and donors a choice between anonymity until age 18 or identifiable information after the birth of a child? Noting that DTCGT means a donor's anonymity can no longer be protected, We raised concerns about the potential for inequalities to be created by a 'dual track' system. Donor conceived people will have different 'rights' depending on the basis on which their donor consented, and the initial choice will be in the hands of donors and parents. Our research suggest that donor conceived people's views, experiences and circumstances are varied and change over time and **a more flexible system would be preferable to a 'dual track' system. We recommended that the Donor Sibling Link be made accessible for under 18s.**

Should the 1990 Act should require all donors and recipients to have implications counselling before starting treatment? Yes, donors and recipients should have at least two (funded) implications counselling sessions, offered by qualified counsellors accredited by BICA.



Engaging with legislators

In June and July 2023, Lucy and Caroline had online meetings with Baroness Finlay and Peter Dowd MP, both members of the Health All-party Parliamentary Group. We discussed reform of the legal framework governing the access by donor-conceived people to information about their donor, and the need for support for donor-conceived people discovering unexpectedly about the circumstances of their conception. We are continuing this impact work [with Policy@Manchester](#).

Donor anonymity - HFEA's recommendations

- Remove donor anonymity from the birth of any child born from donation.
- Require clinics to inform of potential for DTCGT and social media to facilitate discovery of donor identity
- require all donors and recipients to have implications counselling sessions before starting treatment.

ConnecteDNA consultation responses quoted twice in the HFEA's analysis of consultation responses

ConnecteDNA academic outputs and collaborations



We have been presenting our work at conferences in the UK and elsewhere. Here's a selection of our presentations from 2023:

Lucy:

- 'Gamete donor conception and direct-to-consumer genetic testing: How are donor conceived people, their parents and donors using direct-to-consumer genetic testing?' Fertility 2023 Conference
- 'Direct to consumer DNA Testing and Donor Conception' Donor Conception Network Spring Conference

Caroline:

- Datafied DNA and donor-conception. The Datafied Family: Algorithmic Encounters in Care, Intimacies, Routine and Play.
- Donor anonymity and Justice. EACME Conference 2023
- A socio-legal perspective on experiences of donor conception and direct-to-consumer genetic testing: what is the role of law? Association of Reproductive & Clinical Scientists Symposium, 2023 (invited speaker)
- What's the right age to know (about) your donor? Exploring age, agency, best interests and children's decision-making capacity in relation to DNA testing and donor conception. Socio-Legal Studies Association Annual Conference.

Leah:

- 'What's the right age to know your donor? Exploring children's rights, agency and kinship through decisions about DNA testing and donor conception'. British Sociological Association Annual Conference.
- 'Bypassing the Official Record: Exploring the Social and Ethical Issues Raised by Direct-to-Consumer Genetic Databases for Donor Conceived Children and their Parents.' Liverpool University Archive Studies Seminar Series (invited speaker)

Articles in BioNews and The Conversation

Caroline and Leah have written articles for BioNews. Caroline's, *The ConnecteDNA project: thinking about law reform and gamete donor anonymity*. The BioNews article can be accessed [here](#) and you can read Leah's, *Widening the debate about direct-to-consumer genetic testing and donor conception* [here](#).

Caroline, Jackson, Leah and Lucy wrote an article for The Conversation discussing changes to the regulations concerning gamete storage: *Eggs and sperm can now be stored for up to 55 years – here's what that means for donors and people seeking fertility treatment*. You can read the article [here](#)

Engagement with the Donor Conception Network (DCN)

We have benefitted from the support of the DCN in various ways, including

- the 'Preparing for contact' collaboration (see page 1)
- their support for our Stakeholder workshops (see [Newsletter 2](#))
- our ongoing research exchange with the DCN's Research Co-ordinator (ongoing)
- their support for our next event, a regulatory round-table taking place in January 2024.



We have published several journal articles, and are working on several others:

- Direct-to-consumer genetic testing and the changing landscape of gamete donor conception: key issues for practitioners and stakeholders (*RBMO*, September, 2024, led by Leah) Available [here](#)
- Donor conception and Commercial Genomics: how are donor conceived people, their parents and donors using direct-to-consumer genetic testing? (*Human Reproduction*, July 2022, led by Leah) Available [here](#)
- Abstract accepted for, Special edition on 'Reproductive Health, Choice and Justice': Donor conception, *Medical Law Review*: 'Direct-to-consumer genetic testing, choices and procedural justice' (led by Caroline)

Policy work with Policy@Manchester

Caroline and Lucy have published two policy articles via Policy@Manchester. The first, entitled, *ConnecteDNA – the implications of technology on donor conception anonymity*, is available [here](#). The second, *Reforming UK fertility legislation: the effects of online DNA testing* can be read [here](#)



Creating families
with egg and sperm
donor conception
University of Manchester
9th Nov, 2023
5am - 7pm



Lucy, Caroline and Leah presented an event, *Creating families with donor conception – everything you ever wanted to know* as part of the [Manchester Festival of Social Science](#) event. We were very grateful to our presenters, a parent by donor-conception, an egg donor, a donor-conceived person and a fertility counsellor.

DNADialogues Three researchers from the University of Oulu, Finland, visited Manchester in June 2023 for a workshop and to discuss a new research collaboration. [Watch this space](#) for further developments

