

ConnecteDNA Research Project : Newsletter #1 May 2022

Hello – and welcome to our first newsletter!

We have now been working as a complete team for just over six months and we set out in this newsletter a summary of our work to date, and our emerging findings.

A message from Dr Lucy Frith, PI

Welcome to our first project newsletter.



Caroline, Leah and I have now moved from the University of Liverpool to the Centre for Social Ethics and Policy (CSEP), part of the School of Law at the University of Manchester. We are settling in well and our work has already been the focus of interest in our new home. We have presented the ConnecteDNA research to Masters students on the Global Health Law and Bioethics course in two lectures (covering Cross border Reproduction and the Bioeconomy, and Regulating Reproductive Technologies) and will be outlining work to date and emerging findings in the May CSEP meeting.

Thanks for all your support with the project and we look forward to continuing our work, with some conference presentations on horizon, notably at the European Society of Human Reproduction and Embryology conference in Milan in July.

Interviews update – Dr Leah Gilman



Interviews completed:

- Donors (11), donor conceived (DC) people (20), parents (15)
- Our aim is to interview 15-20 people in each of these groups.

Recruitment

- Thank you to all the individuals and organisations who have helped to spread the word about our research.
- We are now focussing on recruiting donors and groups who are under-represented amongst donor conceived and parent participants.
- We would especially like to speak to any fathers through donor conception, egg DC people, DC people with same sex parents and people from minority ethnic backgrounds.

One key finding so far:

- People are using DTCGT in very varied ways, not only to trace donor relatives but also to access generalised information about genetic ancestry. Identity-release donors may choose to make themselves available using DTCGT and parents may test their DC children with the aim of building extended kinship networks with their donor siblings and their parents.



Legal environment scan update Dr Caroline Redhead



Work to date:

Review of terms and conditions and privacy policies of DTCGT providers

- Considering compliance: (how) do the terms and conditions meet regulatory requirements?
- Are regulatory requirements fit for purpose? In particular, how do concepts of consent work for DTCGT?
- What new approaches might be relevant in the context of DTCGT?
- How do the existing / possible legal and regulatory approaches seem to fit with what the interview participants are saying?

Doctrinal work

- Considering comparative approaches – looking to societal reasons for removing anonymity
- Engagement with Swedish academics – and offer to present to Nordic PerMed Law: <https://www.nordicpermedlaw.org/>
- Looking in detail at regulatory approaches in the jurisdictions of interest (*ongoing*). Thanks to Claire at VARTA for her help to date.

Looking ahead

- Transcription of interviews will be progressed now transfer of ESRC grant to Manchester is complete
- Stakeholder workshop – Manchester workshop planned for October 2022
- Planning to interview 16-17 year old DCP (ethical approval granted – DBS checks pending)
- Planning to identify and approach employees of official bodies in jurisdictions of interest
- DTCGT providers' website content analysis – pending write-up of the terms and conditions / policies review. To consider in the light of 'dark patterns' concerns
- Funding bid submitted for collaborative work with HFEA / SEED trust. 'Preparing for contact' – support materials and policy work prior to April 2023

Dissemination

The following presentations have been made or accepted:

- *'Theories of relativity'*: Socio-legal Studies Association Conference (April 2022)
- *Direct-to-consumer genetic testing and donor conception: Reconfiguring relatedness in the digital age?* Reproductive Futures conference (June 2022)
- *Donor conception and Commercial Genomics: how are donor conceived people, their parents and donors using direct-to-consumer genetic testing?* ESHRE (July 2022)
- *What are the ethical and legal issues raised by direct to consumer genetic testing for gamete donor conception?* World Congress on Bioethics (July 2022)
- *Individualised vs. relational constructions of origins: Comparing UK policy with lived experiences of donor conception* Late Summer University, Marseille (September, 2022)

