



## **Completion of the ConnecteDNA project – conversations and a celebration!**

*28<sup>th</sup> November 2024 - Manchester Museum*

The ConnecteDNA project, funded by the UKRI ESRC, is a collaborative project involving researchers at The University of Manchester, the University of Liverpool, De Montfort University, the University of Warwick and the University of Birmingham. Since March 2021, we have been exploring how people involved in donor conception both use and are impacted by the rise in online DNA testing, also known as direct-to-consumer genetic testing (DTCGT for short).

Our final event, celebrating the work of the team and our many participants, gave us the opportunity to bring together the varied strands of research which have developed over the past three and a half years, and also to hear from those from within and beyond the project team whose expertise and experience has been central in informing the success of this project.

### Session 1

Following an introduction from Lucy Frith (who led the project), the afternoon started with the members of the ConnecteDNA team providing an overview of the project's findings. Leah Gilman presented on the relational implications of commercial DNA testing, exploring the issues of 'early contact' (contact prior to the age at which the donor conceived person gains a right to information through the Human Fertilisation and Embryology Authority (HFEA, the body responsible for regulating fertility treatment in the UK) and of (non-professional) gatekeeping. This kind of gatekeeping refers to the challenging, but not uncommon, situation in which a donor conceived person 'matches' with a genetic relative on a DNA website and is placed in the position of having to decide whether to tell that person that they are donor conceived / related to a gamete donor.

Caroline Redhead then explored the regulatory challenges raised by DTCGT in relation to the management of information about donor conception. In particular, she considered whether there may be a need for retrospective law reform in order to 'level the playing field' in regard to access to information for donor conceived people. She reflected that, because there is no overall consensus on *how* the law should change, the path ahead in terms of law reform is not a simple one. However, there is general consensus that the current legal framework is not working, so change is necessary and urgent. Next, in her talk on 'Relational Dynamite' Petra Nordqvist drew on the data from the ConnecteDNA interviews, bringing it into dialogue with understandings of kinship, to explore the very different approaches that exist when it comes to navigating contact following DNA testing for people impacted by donor conception. Fiona MacCallum spoke from a psychological perspective about the impact that (shock) discovery of donor conception following DNA testing could have upon people's identity. Drawing from the project data, she highlighted that identity is both embodied and relational – and that, for some, a shock DNA discovery can cause significant trauma by disrupting their identity.

These presentations prompted a rich discussion about whether, why, and in what form, legal mechanisms were the correct route for change in relation to donor anonymity – a highly contested issue where different groups within the donor conception community have divergent, and at times competing, interests. The Q&A also prompted reflection on the difference and similarities between donor conception and adoption regarding familial relationships and the journey of information-seeking about genetic relatives.

## Session 2

During the next session, speakers offered three different perspectives on direct-to-consumer genetic testing, and its impact on regulation and on the donor conceived community. Clare Ettinghausen, Director of Strategy and Corporate Affairs at the HFEA, spoke about the need for policy and regulation to keep up with the changing reality brought about by DTCGT, so that the HFEA register does not become just an historical document. Nina Barnsley, the director of the Donor Conception Network (DCN), set out the challenges which the parents of donor conceived children have to navigate when considering what information to share with their children, and when, including whether to carry out a DNA test while their children are still young. She emphasised that DTCGT was significantly shifting the DCN community's conversation and concerns. Laura Bridgens, founder of Donor Conceived UK and herself a late-discovery donor conceived person, provided a moving personal account of the impact of a shock discovery of donor conceived status, and the support needs which follow from this. She advocated for a 'paradigm shift' in the way we conceptualise the experience of being donor conceived in order to ensure that the rights of donor conceived people are adequately protected in the process of modernising the law. She emphasised the fundamental importance of placing the experiences of donor conceived people firmly at the heart of the reform process.

## Session 3

The final session took the form of a 'policy discussion', ably chaired by Sarah Norcross, Director of the Progress Educational Trust. This started with short research presentations from Astrid Indekeu, Research Fellow at KU Leuven in Belgium, and Jackson Kirkman Brown, one of the ConnecteDNA team. Astrid talked about the work she conducted for the government of the Netherlands exploring the age at which donor conceived children should be allowed access to information about their donor. Jackson spoke about the limits in the UK on the number of families to whom a single gamete donor can donate. This was followed by an opportunity for attendees to ask questions on these issues to a panel – comprising Astrid and Jackson, alongside Lucy Frith, Marilyn Crawshaw (University of York and British Association of Social Workers' Project Group on Assisted Reproduction), Angela Pericleous-Smith (the British Infertility Counsellors Association), Laura Bridgens (Donor Conceived UK) and Nicky Hudson, one of the ConnecteDNA team. This generated interesting discussions about the need for international standard setting regarding donation limits in an increasingly globalised fertility marketplace, the appropriate role for the state in defining the age at which donor conceived people ought to be able to access information about their donor, and the potential role that birth certificates might play in activating a donor conceived person's right to know about their genetic origins.

## Thank You & Next Steps

We would like to extend a massive thank you to all who spoke at, and attended this event. While this was technically our 'end of project' event - watch this space for future outputs and project activity, as we are delighted to have been granted a project extension until May 2025!