Submission to Inquiry into Matters Relating to Donor Conception Information (Queensland)

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Expertise

I am a Professor of Family Law and Health Law and the Dean of La Trobe University Law School. I hold a BA/LLB(Hons) from the University of Melbourne and an LLM and PhD from the University of British Columbia, Canada. My research expertise is in the legal regulation of assisted reproduction, with a particular focus on "donor linking", whereby donor conceived people, donors, and recipient parents identify and typically make contact with each other. I have published extensively in the field and contributed to ART law reform debates in both Australia and Canada.

I am also a Board member of the Victorian Assisted Reproductive Treatment Authority (VARTA). However, my submission is made in my private capacity as a legal academic.

The need for reform

A growing number of adult donor conceived people (DCP) are speaking out about the negative impact donor anonymity has on their psychological wellbeing and sense of identity. A 2012 systematic review of 13 empirical studies of donor-conceived children and adults regarding their experiences and perceptions of donor conception concluded that a significant number of "donor-conceived people have an interest in securing information about their genetic and biographical heritage – more information than most of them have been able to obtain."[1] Knowledge of their genetic origins is thus considered integral to the identity formation of some, though not all, DCPs.

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[1] Eric Blyth, Marilyn Crawshaw, Lucy Frith and Caroline Jones, "Donor-conceived people's views and experiences of their genetic origins: a critical analysis of the research evidence" (2012) 19(4) *Journal of Law and Medicine* 769.

A growing number of jurisdictions are providing DCPs with access to their donor's identifying information. While Australia arguably leads the field, many comparable jurisdictions, including the UK, the Netherlands, and New Zealand, have introduced prospective laws, which include the creation of donor registers, to enable DCPs to access their donor's identity.

At present, Queensland is one of a small number of Australian states that does not have a legislative framework that enables DCPs to access their donor's identity via a government-run register. Qualitative research I recently conducted with staff at fertility clinics across Australia found that while some Queensland clinics are open to sharing information with DCPs or recipient parents (RPs),[2] the lack of a legislative directive meant that information disclosure was inconsistent and haphazard, creating feelings of inequity and frustration among RPs and DCPs. A state government administered donor register is needed to ensure equitable and uniform access to information, and to bring Queensland in line with other states.

While there is some dispute in legal circles as to whether DCPs have a legally enforceable right to know their genetic origins, as well as whether such a right should always trump a donor's right to privacy, I believe the state has a *moral* obligation to provide identifying information to DCPs. In Australia, the state financially subsidises donor conception via Medicare, playing a role in the creation of children who do not currently have complete access to information about their genetic origins. It is my view that the state of Queensland, in its stewardship role and in accordance with the principle of the best interests of the child, has a duty to ensure that this information is available to DCPs.

If Queensland does not introduce legislation enabling prospective and retrospective access to donor information, DCPs and RPs will locate their donor through other means, including direct-to-consumer DNA testing, internet searches, and social media "stalking". Research demonstrates that when the state does not support donor linking, parties take matters into their own hands.[3] It is not possible to prevent DCPs from identifying their donors, even when donation occurred as far back as

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[2] Fiona Kelly, Charlotte Frew, Deborah Dempsey, "The Donor Linking Practices of Australian Fertility Clinics" (2019) 27(2) *Journal of Law & Medicine* 355-368.

[3] Joyce Harper, Debbie Kennett & Dan Reisel, "The end of donor anonymity: how genetic testing is likely to drive anonymous gamete donation out of business" (2016) 31(6) *Human Reproduction* 1135-40; Fiona Kelly, "Recipient parents using do-it-yourself methods to make early contact with donor relatives: is there still a place for law?" in Deborah Dempsey & Fiona Kelly, *Donor Linked Families in the Digital Age* (Cambridge University Press, 2023) (forthcoming; chapter available upon request).

the 1970s. However, in the absence of a donor register they will do so without the support services of the state, increasing the risk of poor outcomes.

I make **three recommendations** to the Inquiry.

1. **First, legislation should be introduced that gives DCPs access to their donor's identifying information when they reach a specified age.** This is most effectively achieved by introducing a central Donor Register akin to that found in Victoria, which operates prospectively so that children conceived after the commencement of the legislation are able to access their donor's identity when they turn 18 (or younger with parental support). At present, clinics in Queensland have responsibility for providing this information to DCPs and RPs. Research has shown that clinics do not want this responsibility.[4] RPs and DCPs have also expressed concern about the appropriateness of clinics doing this work.[5]

   A growing number of Australian women are conceiving with sperm donors outside of the clinical environment. These donors are sometimes friends of the women or are met online. While it is difficult to determine the scale of private sperm donation in Australia, anecdotal evidence suggests it is on the rise.[6] To avoid a shadow generation of children who do not have the same rights as those conceived in fertility clinics, it is recommended that the Queensland Central Register be open to RPs and private donors to self-register.

2. Second, I recommend the introduction of **retrospective legislation** that gives access to a donor's identity to DCPs conceived before the commencement of the legislation, with the option for a donor to file a "no contact" preference. Data from Victoria, where retrospective legislation was introduced in March 2017, shows that more than half of the pre-1998 donors approached following a DCP central register application have agreed to some form of contact.[7] For those who do not wish to have contact with their donor offspring, or who wish to limit contact to certain types, a contact preference can be lodged. Penalties apply if a no

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[4] Fiona Kelly, Charlotte Frew, Deborah Dempsey, "The Donor Linking Practices of Australian Fertility Clinics" (2019) 27(2) *Journal of Law & Medicine* 355-368.
[5] Fiona Kelly, "Recipient parents using do-it-yourself methods to make early contact with donor relatives: is there still a place for law?" in Deborah Dempsey & Fiona Kelly, *Donor Linked Families in the Digital Age* (Cambridge University Press, 2023) (forthcoming; chapter available upon request).
[6] Cal Volks & Fiona Kelly, "Exploring the expectations of Australian informal online sperm donors who have early contact with their donor conceived children" in Deborah Dempsey & Fiona Kelly, *Donor Linked Families in the Digital Age* (Cambridge University Press, 2023) (forthcoming; chapter available upon request).
[7] Victorian Assisted Reproductive Treatment Authority, Annual Report, 2020/21, p 17.

contact preference is breached. There have been no instances of breach since the Victorian law was introduced.

Victorian data shows that retrospective access has been embraced by adult DCPs, with applications soaring in the months after the law came into force and continuing at a steady pace in subsequent years.

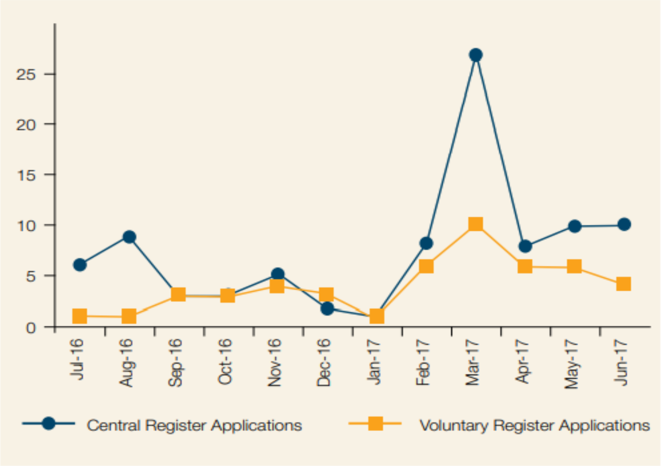

Figure 1: Victorian Central Register DCP applications following introduction of retrospective legislation on 1 March 2017. VARTA Annual Report, 2016/17.

It is recommended that a retrospective law be administered actively. By that I mean the regulatory authority in charge of administering the legislation should have the legal authority to contact previously anonymous donors, inform them of the donor-conceived person's motivations and goals, and counsel them about the implications of participation. DCPs must also have access to counselling. The sensitivity of the request means that a register that simply releases information is inadequate and likely to cause harm.

The success of retrospective legislation turns on the retrieval of historical donor records from fertility clinics and GPs who provided donor conception services. The experience in Victoria has been that most historical donor records are complete and in good condition.[8] However, this may not be the case in Queensland. I recommend that the legislation include a prohibition on the destruction of donor records.

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[8] Fiona Kelly & Deborah Dempsey, *The History of Donor Conception Records in Victoria*, Victorian Assisted Reproductive Treatment Authority, Melbourne, 2018 (available at: The history of donor conception records in Victoria report | VARTA).

3. Third, for a Donor Register to operate effectively and sensitively, it should be accompanied by state-funded **support services** for DCPs, RPs and donors. Given the highly emotional nature of the process of identity release, particularly in cases of retrospective access, DCPs and donors should have access to counsellors who can provide support and facilitate the initial contact. Best practice demands that a statutory authority be created to provide this service. It is recommended that Queensland look closely at the Victoria's Assisted Reproductive Treatment Authority (VARTA), which has been evaluated as providing a positive experience in 98% of cases.[9]

I **do not** recommend:

1. Providing a legislative right to donors to apply for access to information about their offspring, beyond basic information such as sex and year of birth. The purpose of reform is to acknowledge the evidence-based need of DCPs to have access to their donor's identifying information and the state's moral obligation to this population. The same ethical (and legal) arguments cannot be made with regard to donors accessing information about their donor offspring.

Professor Fiona Kelly
29 April 2022

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[9] Victorian Assisted Reproductive Treatment Authority, Annual Report, 2018, p 14.