M ANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Submission to Inquiry into Managing Information Related to Donor Conception

Thank you for the opportunity to provide this submission.

My expertise

I am a Professor of Law at the University of Technology Sydney and an expert in family and relationship law, with a particular focus on non-traditional/non-genetic families and reproductive technologies.

My publication of most relevance to this inquiry is:


I enclose a copy of the report. For the convenience of the committee I have also summarised relevant findings in this submission.

The report arises from an ARC funded empirical research on decision-making in regard to frozen embryos with my colleagues Isabel Karpin and Anita Stuhmcke at UTS. This has involved survey and interviews to explore the experiences of people who have undertaken IVF around Australia. Part of the research focused on decisions regarding gamete and embryo donation, and around one third of our respondents were recipients of donor gametes. This research revealed significant information about the use and impact of donor identity disclosure regimes. This submission relies heavily upon our findings and consultations with counsellors, clinicians and legal and health experts through the life of that research project.

A major emphasis of our recommendations is a radical rethinking of the role of government in regulating ART. We propose a shift away from a focus on prohibition of certain practices and regulation of the activities of providers, in favour of developing more facilitative functions directed towards users.

Research examining the experiences of open donation, including donor gamete recipients seeking contact with other recipient families and also with donors themselves is very recent (and much is from the very different US context).1 It is clear that many

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1 See, eg, Vasanti Jadva, Tabitha Freeman, Wendy Kramer and Susan Golombok, ‘Experiences of Offspring Searching for and Contacting their Donor Siblings and Donor’
Donor offspring are curious about the donor, and virtually all of them believe that they are entitled to have identifying information about him. 2 Many offspring are curious about other offspring families from the same donor, and it appears that single mother and lesbian couple recipient parents are more likely to pursue early contact with other recipient families. 3 However, it is also clear that for those with an interest in having access to information, this does not always translate into a desire for contact, and not all contact gives rise to a meeting, 4 much less to an on-going social relationship. Genetic links are not family relationships. Some, but not all, donor offspring will desire contact with genetic relatives. 5 All are entitled to the information to enable this.

Disclosure Regimes

As you are aware, there is no overarching federal regime of donor identity records in Australia. 6 Although all clinics must only use donors who consent to being identifiable once offspring reach 18, the source and content of the disclosure requirements, and the location of identity records, vary considerably across the states and territories.

The NHMRC Ethical Guidelines required from 2004/2005 that all clinics use only donors who consent to being identifiable. Those records and their release remain under the management of individual clinics. Some states also have their own laws about identity disclosure which are more prescriptive and broad ranging. The state laws are as follows:


4 Note that in Jadva above n 1Error! Bookmark not defined., of the 22 ‘meetings’ only eight were in person; in another study of the 14 families in contact only two had met in person: Joanna Scheib and Alice Ruby, ‘Contact Among Families Who Share the Same Sperm Donor’ (2008) 90 Fertility and Sterility 33.

5 Moreover, there are benefits to having multiple offspring families which are frequently overlooked. One recent study found that when offspring families made contact and didn’t ‘click’, they went on to find other offspring families with whom they felt a better sense of connection: Scheib, above n 4Error! Bookmark not defined.. In the proverbial sense, other offspring families appear to be more like friends than family: you can choose them.

In Victoria, a central government register covers treatment from 1988, with voluntary disclosure for donors between 1988 and 1998, and mandatory identification of donors since 1998;

In Western Australia, there have been central government records since 1993 with a voluntary government register introduced in 2002 and mandatory identification of donors since 2004;

In New South Wales, there is a central government register and mandatory donor identification in operation since 2010, with an additional voluntary register to cover earlier treatment;

In South Australia, legislation passed in 2009 to enable a voluntary government register — however, this had not yet been established at the time of writing (December 2012).

In the states and territories with no legislated donor identity disclosure regimes (Queensland, South Australia, Tasmania, the Australia Capital Territory and Northern Territory) record keeping and disclosure remains in the hands of clinics. Thus there is a complex mix of government and clinic held records, which differ according to the period of treatment, and result in varied practices of information disclosure.

Mandatory registers and the NHMRC Ethical Guidelines all set an age at which offspring may request identifying information about their donor. In Western Australia this is set at 16, while elsewhere it is 18.

The issue of how contact can be made between parties who had not anticipated and consented to it at the time of their donation or treatment is a very complex one. This issue has been largely been addressed by reference to those who undertook treatment in the pre-disclosure era. In the modern era, voluntary registers have been posed to fill the gaps left by mandatory registers – covering those who were treated earlier. We note that there is also a gap left by setting disclosure at the age of majority; as some recipient families and offspring desire earlier contact with donors and other recipients families. I submit that there is a role for voluntary registers in this circumstance also.

7 Note, across jurisdictions with identity disclosure registers there are some provisions enabling earlier access — for example, in Victoria, donor offspring may have access to donors’ identifying information before the set age providing their parent or guardian has consented to this or a counsellor has provided advice to the Registrar that the person is sufficiently mature to understand the consequences of disclosure: see Assisted Reproductive Treatment Act 2008 (Vic) s 59(a)(ii). However, there is no ability for recipient parents to initiate access. In Western Australia, a person with parental responsibility for a child may, after completing approved counselling, consent on their child’s behalf at a younger age following amendments in 2004: Human Reproductive Technology Act 1991 (WA) s 49(2c).

8 See Human Reproductive Technology Act 1991 (WA) s 49(2b).

9 See NHMRC, Ethical Guidelines (2007) para 6.11; Assisted Reproductive Technology Act 2007 (NSW) ss 37(1), 4(1); Assisted Reproductive Treatment Act 2008 (Vic) s 59(a)(i).

The Enhancing Reproductive Opportunity Study

Just over one third of participants in our study (34%, n=138) were recipients of donated gametes or embryos in some or all of their in vitro fertilisation (IVF) treatment. Of study participants who were donation recipients, 84% (n=116) had received donor sperm; 17% (n=23) received donor eggs and 6% (n=8) had received donor embryos. (These percentages add up to more than 100% because a small number of people had received more than one form of donation.)

Among 54 interviewees, 20 were recipients of donor sperm, comprising seven single women, four members of heterosexual couples (two women as sole interviewees and a man and woman interviewed together as a couple) and nine members of lesbian couples (seven women as sole interviewees and two women interviewed together as a couple). Eighteen of the interviewees had children as a result of the donation, ranging in age from newborns to 20 years, and the other two were pregnant at the time of the interview.

Findings

Lack of Donor Gametes

Interviewee experiences indicate a shortage of donor sperm in Australia. This had a major impact upon family formation decisions and options, including: choice of donor, duration of waiting times for treatment and the kind of treatment offered.

These trends are likely to impact upon the long term effectiveness of identity disclosure regimes and associated support services. As a result we see the need for the establishment of a non-profit body to facilitate reproductive donation including donor recruitment that is undertaken outside of individual clinics. Our report endorses the position of the European Society for Human Reproduction and Embryology Ethics and Law Taskforce that:

Advertising in order to recruit donors is best performed by an independent, non-profit-making body whose duty it is to promote donation at the national level, based on the principle of solidarity and excluding financial incentives.12

We propose consideration of a non-profit body performing a recruitment function for donor gametes in Australia in a similar manner as for other biological donations. This function could be undertaken by an independent authority also managing a donor register and other support services.

IDENTITY DISCLOSURE

For most interviewees open disclosure was established as an expectation and those with children old enough to understand had already told them about the circumstances of their conception. Most interviewees reflected that information about the donor’s

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11 Note that the UK regulator, the Human Fertilisation and Embryology Authority (HFEA), has just established a ‘National Donation Strategy Group’ to address barriers to donation: <http://www.hfea.gov.uk/7138.html>. As in Australia, donor recruitment is conducted in the UK by individual clinics, with the result that there is huge divergence in the waiting times for donors per clinic and per location. The UK differs in that it has a specialist government funded charity which represents the views of donors and conducts research into their needs. See National Gamete Donation Trust, <http://www.ngdt.co.uk>.

identity was an important resource for their child, regardless of their own views or feelings and remarked that they wanted to keep all possible opportunities for access to information open until their child could make a decision.

Several interviewees expressed concern that open disclosure regimes may not be able to live up to their promise, given all that may occur in the intervening years.

*It did worry me when I thought if [the donor] dies, do they tell us? It would be just horrible to have gone through 18 years [waiting] … or telling the child when they're old enough to know, you can definitely — then how would we turn around at 18 and say we're really sorry, we've just found out he died when you were 10 … because you could be constructing this future which you can't deliver on.*

Jacqui (Interview 16)

No recipients had children able to access information under mandatory identification regimes in their state (of which only the Victorian register has been in effect for long enough that this was possible). Concerns about communication and identification raised in interviews were therefore much more focused on ‘early contact’. As with contact between recipient families, the issue of early contact with the donor has remained largely unaddressed by government registers and has been the subject of shifting responses from clinics.

**Early Contact with Donor**

One interviewee, Olivia, noted that both the child’s interest in information about their donor and their readiness for possible contact cannot be knowable in advance. Given that the driving principle of disclosure regimes is to serve children’s potential need for information, legislating a fixed age for such requests may fail this objective.

The option of early contact with donors was noted a preference by 40 of the survey respondents (of 114 gamete recipients). Several interviewees also stated that the option of early contact with the donor was important to them. It was notable that women consistently reported that this was not because they wished to build a close or on-going relationship with the donor, but was rather to be certain of access to information or contact in the future should their child seek it.

*Prior to having the baby, having contact with the donor wasn’t important to me. But as soon as I had the baby it was like, well yeah, you know. I need to find out more. This child may need to know. The earlier [the] contact the better as far as I was concerned because you know, you don’t know what’s going to happen.*

Scoot (Interview 21)

Several women reported that ‘18 is too long to wait’, however this was not a universal view. To the contrary, some women expressed a fear of making early contact in case the donor wanted to ‘become’ a parent or to intrude on their family relationships.

It is notable that more than one interviewee mistakenly believed that the relevant disclosure regime allowing identification at 18 actually *prohibited* it from occurring on a voluntary basis prior to that age.

**Early Contact with Other Recipient Families**

Among interviewees, five women had joined formal and informal voluntary registers; of them four had done so in order to make contact with other recipient families while their
children were still very young (aged less than three years).\textsuperscript{13} These four women were all single mothers and all reported early contact as a search for information in a similar vein to those who sought early contact with the donor.

So these women, I email maybe every six months or so. But we swap photos, we talk about where our kids are up to and that’s about it. It’s a little bit too, like you know if he’s going to be wondering what he looks like or where he comes from … If he wants to know if, you know, if this sort of characteristic or this aspect of his face comes from his donor, at least he’s got a bunch of other kids that he can look at and say, ‘oh well we look the same in this aspect, so that must be from the donor side of things’. I think it’s just the more information the better really.

Jacqui (Interview 16)

Within this quest was a greater sense of common experience and stronger social dimensions than that expressed in desiring contact with donors, as women sought out similarly situated families as part of a broader quasi-familial network in which the children were ‘like cousins’.

In the ideal world, I think it would be nice to all meet up and go to Disneyland or do something like that. Because they’re scattered all over the US. For all of us to meet up and go somewhere or do something, make a holiday out of it, when [our children are] I don’t know, maybe eight or nine or something. The other good thing is, because there’s someone already older than us, [my child] will get the [identifying donor] information first. So we’ll get it early basically.

Apple (Interview 18)

As when considering early contact with donors, the contrary view was also present: some parents expressed hesitation or considered that the relationship might be intrusive.

Not all parents will want to make contact with other recipient families, nor with donors. For those that do, we support consideration of the ways in which such contact can be made, while still respecting the privacy of all participants.

There was a broad spectrum of views among interviewees about where information should be held and when and how it should be released. Some favoured centralised government registers while others preferred record keeping at a clinic level.

Central Government Registers versus Clinic Held Records

Concerns among some interviewees about clinic control of identity disclosure (in those states where there is not a government register, or where treatment pre-dated it) related to the following areas: accuracy and longevity of record keeping, overlap of roles and unforeseen changes in policy. One interviewee who was a member of the support group Solo Mums By Choice (SMC) noted that this group was publically advocating for a national government held donor register based on their view that:

\textsuperscript{13} One woman conceived her children through donor sperm in the era of anonymity and had joined a formal voluntary register many years later when her children were adults.
We just have case after case after case after case of mismanagement of donor details [reported within SMC] because clinics are clinics. They're scientific clinical establishments. They're not meant to manage data in that way. They're not people institutions.

Danielle (Interview 20)

A few interviewees suggested that it was too much to expect clinics to undertake the range of complex psychological and social services associated with being contact ‘brokers’.

I don't think that the clinic’s the right thing. … there is this complex role, are they medical management, are they there to provide psychological services, are they social brokers? I think the problem is that they’ve been picking up … extra roles that they’re not necessarily trained in.

Laurie (Interview 32)

However, a number of interviewees reported that they were happy with the manner in which their clinic facilitated contact, including the option of passing messages via the clinic to the donor or other recipient families in a non-identifying way (often referred to in the literature as a ‘letter-box’ service), as well as clinic support such as counselling concerning identity disclosure and in preparation for meeting if that was chosen.

One interviewee, who was part of an informal voluntary register, openly opposed government registers:

Well it’s a voluntary register. I don't think it should be mandatory. I think some things are a little too big brothery … [The voluntary register] is available and it’s completely on your own terms. If you don’t want to tell people anything, you don’t have to. But if you do want to be a part of it, you can be as well.

Apple (Interview 18)

Numerous community-run informal donor registers, both local and international, have sprung up on the Internet allowing recipient families, offspring and donors to search for matches regardless of legislative disclosure regimes and government held central registers. Such informal registers operate within varied conditions of moderation or mediation of contact, and we suggest that they will continue to grow if government registers fail to adapt to the needs and interests of offspring and recipient families.

Passive Voluntary Registers

The passive operation of both voluntary government registers and clinic matching programs was the source of frustration for several interviewees. The consensual basis of voluntary registers means that regulators will only make contact if both parties have already joined; they will not actually invite someone who is not already on the register

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14 Note that the Australian and New Zealand Infertility Counsellors Association (ANZICA) has developed guidelines for its members in facilitating contact: see, Fertility Society of Australia, Submission No 106 to Senate, Inquiry into Donor Conception in Australia, (October 2010) attachment 3.

to join in order to make a match. One interviewee, Scoot, who was already in contact with her donor, wanted another recipient family alerted to the fact that she was on the register so that they could negotiate the possibility of early contact.

_The Act … says where both parties consent it’s possible to have contact before the child reaches [maturity]. But then you go to the [authority] and they say, yeah, you have to join the registry and then if the donor joins then you can have earlier contact. But it’s like, well that’s not how the Act reads. It says if both parties are willing. Well, how can both parties be willing if you won’t contact the other one and see if they’re willing. You could contact that other party and say, are you willing to have earlier contact. But they won’t do it._

Scoot (Interview 21)

Similarly, a number of interviewees who asked clinics to pass on a communication to the donor and other recipient families, respectively, were offered only ‘passive’ contact: that is, their letter would be placed on file and only offered to the other party if that person were themselves to contact the clinic seeking to initiate communication. Three interviewees were sufficiently discouraged by this that they didn’t in fact follow through with their own letter, such that even if the other party did initiate communication in the future, a connection might still not be made. This is clearly a difficult issue, as clinics sought to avoid intruding upon the privacy of their patients and donors by forwarding a communication which may not be welcomed. While one way of dealing with this issue is to ask for a preference to be expressed at the outset of treatment (or the time of donation) this still does not address the fact that preferences may subsequently change.

Overall we found that clinics were more responsive to a wider range of requests for mediated communication than were voluntary government registers, which were limited by the terms of their governing statutes as well as their more impersonalised mode of operation (for example their lack of counselling and support facilities).

On the negative side, clinic practices were also more diverse, non-transparent and unpredictable. Parents generally had no way of knowing what contact options their clinics supported until they asked, and these practices were also subject to change. Within the study it was apparent that a number of clinics had altered their approach to voluntary disclosure of information and early contact in recent years. In the main, these changes were in response to patient requests and were moves towards more flexible practices around non-identifying communication and voluntary early contact. However, we received reports that two clinics had offered women undertaking treatment the option of early contact (with the donor and with other recipient families, respectively) but then subsequently resiled from this practice. For the mothers who had anticipated the option of early contact, only to find out after their children were born that this was not possible, such changes were distressing and disappointing.

_Before Johnnie was born we were told we would be able to write letters, that Johnnie could write a letter at any age, or whatever. The age was up to us, so if_

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16 See _Springfield v Registrar of Births Deaths and Marriages_ (General) [2011] VCAT 130 (10 February 2011) in which the Registrar held that she did not have the power to even pass a letter on to the clinic to pass on to the donor inviting him to join the voluntary register. The Tribunal subsequently held that it did not have jurisdiction to review the decision.

17 A finding reflected in the recent research by Marilyn Crawshaw into Australian donor registers and donor-linking practices: Marilyn Crawshaw, Submission No 156 to Senate, _Inquiry into Donor Conception in Australia_ (October 2010).
No disclosure regime can accommodate the diverse needs and wishes of all of the participants in donor conception. Moreover, it is apparent even in our small sample that those needs and wishes may change over time, and cannot necessarily be foreseen. However, we conclude that the current regimes in place around Australia are failing for a number of reasons. The patchwork nature of the multiple and ever-changing identity disclosure systems in operation mean that identification options are inconsistent, unduly complex and unpredictable for all concerned. Clear and transparent information about what disclosure options are available, the mandatory or voluntary nature of the system, as well as the organising body behind it was notably lacking. Moreover, the inflexible and non-responsive nature of government held registers means that they may not ultimately serve their intended purpose.

While there have been recent calls for a national donor identity register, this was rejected by the federal government.\textsuperscript{18} We are not convinced that one centralised record keeping facility is necessarily the answer to the issues we identify. Legislated regimes are cumbersome and inflexible; when they fail they take many years to fix. Victoria, often regarded as world leader in this area, has notably been through three different incarnations of its register in less than 20 years, held by four different government departments and statutory authorities. The removal of the Victorian register from the previous specialist authority (which also housed a multitude of support services such as counselling, communication brokering, donor matching and DNA testing) and its transfer into the Department of Births, Deaths and Marriages which offered none of these support avenues has been widely criticised.\textsuperscript{19}

Our report concludes that it is not so much who controls the information as how they do so. We support information disclosure regimes that are intended and understood to be something more than a public records office. They must be flexible and responsive, with integrated support services. Both clinic held records and government registers can accomplish this, as could both systems operating in tandem, as long as there was clarity about the respective roles of each.

Among other things, our Report recommends:

\textbf{3.9} Development of protocols concerning clinic approaches to voluntary communication and contact between donors and recipients.

\textbf{3.10} Provision of accessible information in advance about clinic practices concerning early contact.


\textsuperscript{19} See, eg, Parliament of Victoria, above n 10; Victorian Infertility Counsellors Group, Submission No 68 to Senate, \textit{Inquiry into Donor Conception in Australia} (July 2010).
3.11 In each jurisdiction, the establishment of an independent organisation, state run or licensed (such as the Victorian Assisted Reproductive Treatment Authority) to manage a voluntary register and facilitate donor-recipient-offspring contact, including provision of associated counselling and support services.

(a) Access to information identifying donors and donor conceived siblings from treatment prior to 2010

As you are aware, the Parliament of Victoria Law Reform Committee, Inquiry into Access by Donor-Conceived People to Information About Donors – Final Report (2012) recommended retrospective access to identifying information about donors, accompanied by a regime of temporary renewable contact vetos for donors unwilling to be contacted as a result of being identified.

I submit that retrospective access to information should be facilitated but only on a voluntary basis. Retrospective identification of donors without their consent is a breach of faith with donors who understood their donation at the time to be anonymous. Our research found a high degree of confusion among recipients about the rules governing donation and identification – constant changes, and in particular retrospective change, will only worsen such confusion. I suggest that they are also likely to lead to distrust and disengagement from donors and exacerbate donor scarcity.

Some donor conceived people, and their families, desire more information about donors and other offspring from the same donor – this includes but is not limited to identifying information from the pre-disclosure era. We also found an interest in early contact and in non-identifying information.

I propose that a better middle path is to provide far more flexible and supportive voluntary disclosure services, including active registers and associated counselling. This will better serve offspring in the long run by ensuring that more donors come forward and are more willing to receive contact if that is desired.

The experience of the ITA under past Victorian law is instructive – in actively making contact with donors and offering counselling, they were able to explain the motives of offspring and communicate expectations between parties. Donors were far more willing to receive contact as a result. The current Victorian voluntary register is now passive only; BDM will not invite parties to join it and so very few matches are likely to be made. The current Victorian model is a profound failure and appears likely to change again (if so, making it the 5th incarnation of the Victorian disclosure regime).

(b) Which agency should manage donor conception information

A specialised agency should manage this information; whether within the Department of Health or in a semi-independent government Authority. Our report recommends that such a body would be well placed to undertake gamete and embryo donor recruitment; match embryo donors and recipients; provide information and counselling and facilitate direct and indirect contact between donors and recipients.

(c) What counselling and support services are necessary

In addition to counselling and support services listed above, access to DNA matching services (and associated counselling) should be made available to donor offspring who were born pre-disclosure.

Counselling services to assist parents of donor conceived children in the current era, to tell them about the circumstances of their conception would also be helpful.

(d) Any other relevant matter

I reiterate my opposition here to any record of donor conception being marked on birth records as previously recommended by this committee. Parents should be supported but not coerced into telling children about the circumstances of their donor conception. Inadvertent disclosure to adult donor conceived people has been demonstrated to be harmful and this avenue provides a government sanctioned avenue in which this could occur. This is intrusive and unhelpful. It is not supported by most experts in the field and was expressly rejected in the 2008 UK reforms.

To recap, I submit that the best approach is to create a specialist agency such as VARTA with a broad mandate to co-ordinate and support the range of social and legal needs associated with donor conception and ART.

I am willing to give oral testimony to expand or explain any of the above points should you require it.

Yours sincerely,

Jenni Millbank