



Inquiry into access by donor-conceived people to information about donors AMA Victoria Submission

AMA Victoria welcomes the opportunity to provide input to the Law Reform Committee's Inquiry into access by donor-conceived people to information about donors.

The Australian Medical Association (Victoria) is the peak body representing Victorian doctors, and exists to provide services, advice, representation and professional support to members as well as working towards improving health services and the overall health of all Victorians. Member-funded, AMA Victoria is a not-for-profit professional association independent of government.

AMA Victoria does not support allowing access to information that would identify a donor without the express consent of that donor. The nature of the agreements reached at the time of the donation must be respected.

For donors that donated after 31 December 1997, donors agreed to the release of identifying information. Those who donated after 1 July 1988 but prior to 1998 agreed to being contacted in the future to obtain consent for the release of information. If this information was sought by a donor recipient or donor conceived offspring. If consent is not given then this information must not be released.

For donors who donated prior to 1988 the arrangements varied but the underlying presumption was that donations were anonymous. Donors were given explicit and implicit assurances that their donations were entirely anonymous and that no contact would be made in the future. These assurances should be respected and pre-1988 donors should not be approached by individual clinics nor by a central registry.

If donors wish to be contacted they should be invited to place their details on a voluntary register to facilitate information exchange between willing parties.

Consent and access to identifying information

Consent should be the guiding principle for the disclosure of donor information. If a donor does not consent to the release of information it should remain confidential. .

AMA Victoria opposes any move to allow access to information that could identify donors without the donor providing their consent. This extends to contacting donors who were given assurances of anonymity. The act of making contact either through individual clinics or through a central registry undermines this anonymity.

Contractual assurances were given to those who donated prior to 1 July 1988 that their identities would not be revealed to donor recipients nor to donor-conceived people and that they would be able to remain anonymous.

Pre-1988 donors agreed, in good faith, to assist other families to conceive and did so on the proviso that their privacy would be maintained. While the rights and interests of donor-conceived children to information related to their genetic origins do not change depending on their date of conception, the rights and obligations of donors and donor recipients do.



The desire to know more about one's ancestry is legitimate for emotional and medical reasons. However, gaining access to this information may come at a significant personal cost to the donor. Forcing the disclosure of the donor's identity or making contact to request information may place significant emotional strain on donors and /or their families.

For donations between 1 July 1988 and 31 December 1997, both the donor and the donor recipients knew that identifying information about the donor would only be disclosed with the donor's consent. Prior to 1 July 1988 both the donor and donor recipients agreed to anonymity.¹ While the donor conceived child was not party to this agreement, the consent of donors and donor recipients was obtained — it should be noted that the donor-conceived child may not exist but for the agreement in question.

The National Health and Medical Research Council's ethical guidelines strike an appropriate balance between the interests of the donor and donor-conceived person. In particular, AMA Victoria supports guideline 6.13:

Respect the privacy of all persons involved in ART procedures. People have a right to privacy. Clinics must not release identifying information to another person without the consent of the person.²

AMA Victoria believes that this respect for privacy extends to not making uninvited contact to pre-1988 donors as this was not agreed to at the point of donation. Consent was not obtained from pre-1988 donors to be contacted in the future.

Facilitating donor linkage

The voluntary register should continue to facilitate linkages between consenting donors and donor-conceived persons. A renewed and continuing public awareness campaign should occur to inform pre-1988 donors about the existence and nature of the register. Efforts should be made to educate the public at large about the existence of a voluntary register and the ability of donors to provide non-identifying information. Pre-1988 donors should only be contacted once they have added their name to the voluntary register.

Where donor-conceived people want access to information, and pre-1988 donors have placed their names on the voluntary register, donors should be discreetly contacted by specialist counsellors and asked information they are willing to provide to their donor-conceived offspring. Additionally, donors should be able to provide information on once-off basis to the voluntary register.

Once contacted, donors should be given a range of options on the level of information that can be provided. This would allow donors, if agreed, to only provide non-identifying information such as a familial medical history.

Information about donors should be stored through a central register to facilitate linkages when both parties are willing. Given that a number of ART clinics that provided services prior to 1988 are no longer operational,³ and current donor linkage services vary between clinics, a central register of pre-1988 donor information is preferable to the current ad hoc approach.

¹ Inquiry into access by donor-conceived people to information about donors: Interim report, p xv.

² NHMRC, Ethical guidelines on the use of Assisted Reproductive Technology in clinical practice and research 2007, p 29.

³ For example Prince Henry Hospital and Queen Victoria Hospital.



The transfer of management of the Central and Voluntary Registers to the Registry of Births, Deaths and Marriages ('BDM') is incomplete as a number of specialist services are not being provided by BDM. The specialist services previously provided for by the Infertility Treatment Authority should be provided by BDM so that those providing these services have access to all available information about donors and donor-conceived offspring. These services include specialist counselling, the 'Letter Box Drop', and the ability to act as an intermediary between parties (as Melbourne IVF currently does for pre-1998 donors and their offspring).

While some pre-1988 donor records may be incomplete, BDM should still endeavour to collate this information. Even limited access to pre-1988 information may be valuable for facilitating donor linkages.

Future Impacts

Retrospectively changing the rights of donors will negatively impact upon public and donor confidence in the ART scheme in Victoria. There is currently a shortage of donors and ART clinics have ongoing difficulty attracting new donors.⁴ The donor shortage could be exacerbated if donors felt that their rights and obligations could be altered in the future without their consent.

The right to make decisions about gametes

AMA Victoria supports the recommendation of Monash IVF that legislation be amended to make clear that the egg and sperm donors only have rights to make decisions about gametes before they are inseminated.⁵ Only donor recipients should have rights over zygotes. Any change to the legislation must also ensure that donors are adequately informed that their ability to withdraw consent ceases at the point of insemination.⁶

⁴ See for example, Brigid O'Connell, 'Urgent call for sperm donors', *Sunday Herald Sun* (13 March 2011); Julia Medew, 'Call for more sperm donations', *The Age*, (12 April 2010).

⁵ Monash IVF, *Submission 26*, Inquiry into access by donor-conceived people to information about donors, p 7.

⁶ AMA Position Statement on Reproductive Health And Reproductive Technology (2005), p 3. Available at http://ama.com.au/system/files/node/520/Position_Statement_on_Reproductive_Health_And_Reproductive_Technology_-_1998_revised_2005.pdf.